SN: 393

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GENERAL SECTION

A: LIFE BEFORE DEATH

B: HEALTH VISITORS AND DISTRICT NURSES (A)

C: HEALTH VISITORS AND DISTRICT NURSES (B)

D: DOCTORS

E: SYMPTOMS

F: HELP

G· HELPERS

H· OFFICIALS

J· COMPLETION RECORD

GENERAL SECTION

ESRC DATA ARCHIVE CODEBOOK

CARD NO.	PAGE	VAR. NO.
SN:393A Life before death		
01	1	1
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02	11	75
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02	19/20	113-123
03	21/22	135-144
04	27	217
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06	42	423/424
07	45	438-448
08	51	512-517
09	58	585
09	62	623-629
09	62	630-631
10	66	659-665
11	73	733
12	80	807-813
12	82	829

PUNCHED CARD DATA - ORIGINAL '69 LAYOUT

CARD	COLUMN NO.	QUESTION NO.
Home care survey: Questionnaire 2		
Y38	5	1
	39	17(f)
	40	17(g)
Y39	5	18
	39	41(b)
Y45	5	42
	8	42
	20/21	43
	30	44
	38	45
	46	48(c)
Y46	5	51
	12	49
	26	58
	37	66
	50	68
Y47	5	69
	17	77
	37	92(c)
	55	—
	60/61	—

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. ESRC DATA ARCHIVE CODEBOOK

CARD NO	PAGE	VAR. NO.
SN: 393J Completion Record		
01	1	2
01	9	50
SN: 393H Officials		
01	1	1
01	4	31
SN: 393G Helpers		
01	1	1
01	4	22
SN: 393F Help		
01	2	2
SN: 393E Symptoms		
01	1	2
01	2/3	16

PUNCHED CARD LAYOUT - ORIGINAL '69 DATA

CARD	COLUMN NO.	QUESTION NO
Y36	5	—
	34	—
Home care survey - Questionnaire 2		
Y57	4	—
	14	—
Home care survey - Questionnaire 2		
Y56	4	—
	80	—
Home care survey Questionnaire 2		
Y49	6/7	—
Home care survey Questionnaire 2		
Y48	5/6	—
	10	—

ESRC DATA ARCHIVE CODEBOOK			PUNCHED CARD LAYOUT - ORIGINAL '69 DATA		
CARD NO	PAGE	VAR. NO.	CARD	COLUMN NO.	QUESTION NO
SN: 393D Doctors			Problems of domiciliary care in terminal illness		
01	1	2	Y35	5	—
01/02	11/12	65-71/72-75		42	22
02	20	134 - 139		61	—
03	21	145		66	—
03	24	155		79	—
SN: 393C Health Visitors + District nurses (B)					
01	1	2	Y34	5	2
01/02	12	65-70		29	16
02	13	72-80		30	17
02	17	103		44	28
SN: 393B Health Visitors + District nurses (A)					
01	1	1	Y37	9	1
01	9	59-66		32	20
02	10	67-77		33	20
02	15/16	133-140		41	21
04/05	29	288/289-293		67	41

(Home care for the dying)

The study is based on the last year of 785 adults, based on interviews with relatives, G.P's and health visitors.

Main questionnaire

There are three similar questionnaires, the main one being questionnare 2. Questionnaires 1 and 3 seem mainly to have been used if no questionnaire 2 was completed or as additional interviews. We have copies of the two questionnaires (1and 3) but no data or codebook; perhaps the information was consolidated with the data from questionnaire 2, which contains the same questions with more detail.

We have a copy of questionnaire 2 and complete codebooks and cards. The codebook has marginals for 786. The questionnaire has been split into five sections as follows:

A pages 1-3 Cdbk for cols 5-40 Card id y38 punched in 1-34, 41-80
(some cards punched 1-80)

*B pages 4-7 Cdbk for cols 5-39 Card ID y39 mainly punched 1-3, 26-80 and 1-15, 26-80

*C pages 8-10 Cdbk for cols 5-46 Card ID y45 mainly punched 1-80

*D page 11-16 CDbk for cols 5-50 Card ID y46 mainly punched 1-80
(some cards punched 1,2,29-80)

E pages 17-21 Cdbk for cols 5-61 Card ID y47 mainly punched 1-80.

*We have two sets of cards (approx 800 in each) for these three packs. Possibly duplicates or have been recoded?

A and E each have another pack but these have been labelled as discarded. We have no card layouts which would appear necessary to match the cards to the codebooks.

July 78

Health Visitors and District Nurses

We have two questionnaires, A and B, each complete with interviewers notes.

Questionnaire A is directed at the H.V. or DN of the particular people in the sample. We have a codebook, with marginals of 198, referring to columns 1-68. The cards (198) have card identification y37 in col 80 and are punched in columns 1-68, 80.

Questionnaire B is a general questionnaire for all health visitors or district nurses involved in the care of terminal illnesses etc. ∴ one person could have completed two questionnaires. We have a codebook for columns 1-50, 79, 80 which matches the pack of approx 550 cards (card identification y34).

General Practitioners

Again we have two questionnaires, one postal (sample 258) and one for interviews (sample 67). These are supposed to be identical in content, but the interview questionnaire has a couple of extra questions.

Also have a codebook (marginals 325) for columns 1-75, 79, 80 and a card layout for columns 1-68,80. There are approximately 800 cards (presumably one per patient in the main sample). Some are punched in columns 1-4, 66-75, 79,80 - probably failures; the remainder are columns 1-75,79,80. Card identification in column 80 is y35.

Completion Record

This is a record of the success/failure of the main interviews, plus details from the death certificate. We have the questionnaire and a codebook (with some marginals - 784) for columns 1-34, 78-80. Also have card design sheet for columns 1-34,80.

Have approximately 800 cards, punched in columns 1-34, 78-80, with card identification y36 in column 80.

Symptoms Card

Questions from questionnaire 2. Have codebook for cols 1-11,80. There are approximately 3,500 cards, punched in columns 1-11, 15-78,80 (card identification y48)

Help Cards

Questions from questionnaire 2. Have codebook for columns 1-12. There are approximately 7,000 cards, punched in columns 1-12, 15-68,80. (card identification y49).

Helpers

Questions from questionnaire 2. Have codebook for columns 1-13,80. There are approximately 2,500 cards punched in columns 1-13, 15-68,80. (card identification y56).

Officials

Questions from questionnaire 2. Have codebook for columns 1-14,80. There are about 700 cards, punched in columns 1-68,80 (card identification y57).

Additional cards & documentation

Have an extra four sets of cards with incomplete documentation.

i) "Nurse-patient card" y58 (card id in col 80)

Approximately 300 cards some punched in cols 1-3, 13-80; some 1-38,80 and some 1-80. No documentation.

ii) "New card for transferring to sub cards & GP card" y59

Approximately 800 cards some punched through 1-80, others punched in cols 1-17, 25,38, 55-75, 80. Have codes for cols 78-79 only.

iii) "GP patient card" y67 (card id in col80)

Approximately 750 cards, some punched 1-80, some punched in cols 1-3, 36-80. No documentation.

iv) "New-new card with 4 new codes" y68 (card id in col 80)

Approximately 750 cards, some punched in cols 1-30, 46-51, 80, others in cols 1-51, 80. Have codes for cols 4-7.

Also have copies of letters sent out during the survey, and interviewers notes.

Also have sheets for transferring col 27 on card y39 to new codes.

SUMMARY OF FILES USED FOR LIFE BEFORE DEATH

Card identification & description		1st name	2nd name
y34	Health Visitors & District Nurses	393C BIN ✓	
y35	Doctors Q	393D BIN ✓	
y36	Completion record	393 J BIN	
y37	DN & HV Q.A.	393B BIN ✓	
y38	Q2A p1-3	393A BIN	
y39	Q2B p4-7	393A BIN	
y45	Q2C p8-10	393A BIN	
y46	Q2D p11-16	393A BIN	
y47	Q2E p17-21	393A BIN	
y48	Q2 P8 Symptoms (G)	393E BIN	
y49	P9 Help (H)	393 F BIN	
y56	P11 Helpers (J)	393 G · BIN	
y57	P12 Officials (K)	393 H · BIN	
y58	Nurse patient card	393P BIN	
y59	New card for transferring to sub cards & GP card	393Q BIN	
y67	GP patient card	393R BIN	
y68	New-new card with 4 new codes.	393S BIN	
y69			
y78			
y79			
y80			

Life before death - Coding procedures.

(1) Code & check completion record.

(2) " " " death certificate

(3) Check coded completion record against questionnaires.

(4) Sort questionnaires into four groups:-

1) Questionnaire 2. Transferring relevant data from questionnaire 1

Questionnaire 1	→	Questionnaire 2	
1		1	If information same on both
1a		1a	
1b		1b	

Marital status	After question 1	Code as given adding X if inadequate
2	31	
3	32	
4	33	

2) Questionnaire 3 adding code given X to indicate

Only 1 completed		1
First out of 2 completed		2
Second " "	2	6
First	3	3
Second	3	4
Third	3	5

N.B. The first / second are arbitrary but will enable us to distinguish questionnaires.

3) Questionnaire 1 when there is no questionnaire 2.

4) Other questionnaire 1's

(5) Extract test packs. (for first three groups above)

Serial numbers from all 12 areas.

A	11	66	25
B	22	77	65
C	33	88	45
D	44	99	85

Survey of Care before Death Classification of cause of death

Code		ICD 1966 no.
00	Infective and parasitic	000–136
	Neoplasms	
10	Malignant neoplasm, stomach	151
11	" " bronchus and lung	162.1
12	" " breast	174
13	" " uterus	180–182
14	" " prostate	185
15	Leukaemia and aleukaemia	204–207
16	Other neoplasm of specified site	Rest 140–238 excluding 199 & 228
17	Neoplasm of unspecified site	199, 228, 239
01	Endocrine, Nutritional and Metabolic	240–279
02	Blood and blood forming organs	280–289
03	Mental disorders	290–315
04	Nervous system and sense organs	320–389
	Circulatory	
20	Hypertensive	400–404
21	Ischaemic heart disease	410–414
22	Rheumatic fever and other heart disease	390–398, 420–429
23	Cerebrovascular disease, stroke	430–438
24	Diseases of the arteries	440–448
25	Other	450–458
26	Bad heart, heart failure, coronary, heart attack	
	Respiratory	
30	Pneumonia	480–486
31	Bronchitis	490–493
32	Other	460–474, 500–519
60	Digestive	520–577
06	Genito urinary	580–629
07	Complications of pregnancy etc.	630–678
08	Skin	680–709
09	Musculoskeletal and Connective	710–738
0Y	Congenital and perinatal	740–779
40	Symptoms exc. heart failure, senility	780–796
70	senility, old age	
	Accidents	
50	Transport	E800–E845
51	Suicide or self inflicted injury	E950–E959
52	Other	E850–E949, E960–E999
XX	Inadequate don't know	
80	loneliness, will to live	

Home Care Survey

Area

List of health visitors and district nurses ever involved in care of dying

Serial no of worker	Name	Attached / Not attached	District N / Health Vis / Combined	Address to Contact	Serial number of any sample deaths gave care to
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		
		4 5	1 2 3		

Area Code

Superintendent

1 Area responsible for -

2 Services responsible for -

District nursing 1
Health visiting. ... 2
Midwifery ... 3
Home helps ... 4
Other SPECIFY ... 5

3 Present staff

	F T	P.T.	F T equiv
District nurses			
Health visitors			
D N/Mid			
D.N /Mid/H V			
Auxiliaries			
Home helps			
Voluntary aides			
Others SPECIFY			

4 Establishment Are you a) fully staffed b) below establishment c) over established d) under established for -

	a) fully	b) below	c) over	d) under
District nursing	1	2	3	4
Health visiting	1	2	3	4
Midwifery	1	2	3	4
Home help	1	2	3	4
Others	1	2	3	4

5 Attachment

	District nurses	Health visitors
None	0	0
All fully	1	1
All partially	2	2
Some fully	3	3
Some partially	4	4

6 Services a) Which are available in your area? b) Which ones would you like extended or introduced?

	a) Available	b) Like extended or introduced
Meals on wheels	1	1
Special laundry service	2	2
Free supply of incontinence pads	3	3
Service for disposing of incontinence pads	4	4
Bathing service	5	5
Supply of sickroom equipment	6	6
Night nursing service	7	7
Night sitting service	8	8
Geriatric social worker	9	9

NIGHT NURSING OR NIGHT SITTING SERVICE AVAILABLE
Who runs this?

	Night nursing	Night sitting
Local authority	1	4
Marie Curie	2	5
Other SPECIFY	3	6

7. Is there any other home service for the terminally ill in your area? Yes... 7
No... 8

IF YES (7) What?

Notes for Interviewers

CARE OF THE DYING

Medical Care Research Unit
Institute of Community Studies

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Documents

Table 1 Study Areas.

Interviewers agreement.

Background and Aims

Background

In 1966 the proportion of deaths which occurred in the home was just under two-fifths, that is 209,410 deaths. Some people are discharged from hospital to die at home, and others are admitted to hospital in the last stages of their illness, after varying periods of care in their homes. Changes in the patterns of disease and the increasing emphasis on community rather than institutional care are likely to increase both relatively and absolutely the numbers of people with terminal illness who are looked after in their homes. At the same time the trend towards earlier marriage, smaller families and the increasing proportion of single person households mean that there will be a greater need for supportive services.

We decided we would like to study the care given to people who had died recently and the Department of Health and Social Security has given us a grant to do this.

Aims

Although the main emphasis of the study is on the implications of terminal home care we hope to build up a complete picture of peoples' last year of life - their health and work, contact with general practitioners, hospitals and local authority services, and the care given by relatives and friends. We will be looking at what could be described as the social epidemiology of death.

The specific aims of the study are to discover whether the care of these patients presented special problems for their families and friends to find out how, by whom and at what social financial and emotional cost needs had been met and to describe the nature and extent of any unmet needs. We also hope to get some information about the adjustment of bereaved relatives.

As with a number of other studies carried out by the Medical Care Research Unit we want to look at problems from the point of view of the professional people who give care as well as trying to see them from the viewpoint of the people who received care. In this study our view of the receivers of care will inevitably be rather restricted as we will be finding out the attitudes and opinions of relatives and friends of people who died and asking them for facts about the person's death and last year of life. To get the views of people who gave help we will be asking the general practitions of the people who died and the district nurses who looked after any people in the sample to co-operate.

in the study. The general practitioners will not be asked for information about specific patients but only about home care in general terms.

Study areas and Timetable

Selection of areas

The areas that have been chosen for this study are registration districts. To select the 12 areas all the registration districts in England and Wales were first divided into two groups: County and London Boroughs in the first group other registration districts (combinations of municipal boroughs, urban districts and rural districts) in the second. Both groups were then listed in regional order and their populations summed cumulatively. We divided the total population by 12 to give us our 'sampling interval' and took a number under this from a book of random numbers for our starting point. The district which contained this number was our first area and the second area was obtained by adding our sampling interval to the starting point. This method gives us what is known as a stratified sample of areas chosen with probability proportional to population.

Details of the areas are in Table 1 - at hand

The Timetable

The interviewing timetable is set out in Table 2.

Table 2
Interviewing Plan.

Month of Interview	Study Areas	Months of Death
July 1969	Barking Teeside	)October 1968)and April 1969
August 1969	Hillingdon North East Cheshire	)November 1968)and May 1969
September 1969	Brentwood Bridgend	)December 1968)and June 1969
October 1969	Northumberland North Second* Eastbourne	)January 1969)and July 1969
November 1969	Birmingham Thanet	)February 1969)and August 1969
December 1969	St. Helens Isle of Wight	)March 1969)and September 1969

* Northumberland North Second is such a small area that more months of death will have to be covered in order to obtain a large enough sample.

Outline of Methods

The Sample

In each of the twelve study areas the General Register Office has selected at random samples of 80 deaths of people aged 15 and ever. This means that the study covers all types of adult deaths: young people killed in accidents, people who have been in institutions for many years, both young and old people who have been chronically ill for sometime, people who've had a first, second or third heart attack, people who've died of 'old age' (although the G.R.O. does not recognise this as a cause of death) etc. Half the deaths will have occurred three months before the month of interview, the other half nine months. This means that in the six months of interviewing we will be covering deaths from all twelve calender months.

The special sample

One in ten of the sample has been selected at random from deaths occurring at home for special study. You will be able to tell which these are because the fourth, last digit, of their serial numbers end in an X. For these deaths we want to carry out more interviews - with other people involved in looking after them.

3 months
9 months

Information on address list

The things you will know about each death which will be recorded on your address list are:-

1) The name, sex and marital status of the deceased
2) The approximate age at time of death
3) The place where he died
4) The month of death
5) The name, address and relationship to the deceased of the person who registered the death.

Who to contact

The person you should normally attempt to contact first is the person who registered the death (or more correctly the person who informed the registrar of the death) If that person:

1) Does not live in the study area
2) Cannot be contacted after several attempts
3) Is too ill, old, or deaf - or has died
4) Refuses to help

Then you should get in touch with people living at the deceased's address - if that is different from the address of the person who registered the death - or, if it is the same, talk to someone else in the same household.

Whoever is interviewed first you start initially with questionnaire 1 The introduction and phrasing of the first question are slightly different if the person registered the death or if they are another sort of first contact.

The three questionnaires for interviewing bereaved

Questionnaire 1 is always used for the first contact: it has two parts - the first part (question 1-7) determines the most suitable person for interview. The next contains basic questions taken from the main questionnaire. These are asked if the informant on questionnaire 1 is not in the same household as the main respondent to make quite sure we get some basic information about the death in case we don't manage to interview the main respondent. + 32 etc

Questionnaire 2 is for the main respondent. It may be used as a separate interview or in conjunction with questionnaire 1 if the initial informant turns out to be the most suitable main respondent.

Questionnaire 3 is only used for the special sample and after Questionnaire 1 and 2 have been completed. It contains questions about the help given by that particular person and his views on some of the opinion questions about the deceased's case. It is used for up to three people who helped with the care of the deceased in the special sample - but if the first contact is interviewed on the whole of questionnaire 1 then only up to two others will be interviewed on questionnaire 3.

So the maximum number of interviews is two for deaths in the ordinary sample and four for those in the special sample. When the first contact is the main respondent there will be one interview in the ordinary sample and up to three in the special sample.

Ordinary

$1 + 2$

Special

$1 + 2 \quad 2 + 2 \times 3$

$= (1+2) + 3 \times 3$

The Questionnaires - General Points

Contents. The questionnaires contain four things:-

1) The questions to be asked. These are in ordinary type. Ask the questions in the order given and as worded on the questionnaire.

2) Instructions to the interviewers These are in capitals and underlined. They mostly relate to which questions to ask and which to omit for certain groups of people.

On this survey which relates to deaths in all different sorts of circumstances, we obviously need and want to ask different questions according to these circumstances. There are a number of occasions on which whole series of questions will have to be skipped and we have, we hope, identified these for;-

a) People who died in a hospital or institution after being there for a year or more.

b) People under 65 who died unexpectedly when they had not been restricted at all in relation to their health during the last 12 months of their life.

c) Informants who were not related to the deceased nor close friends. On occasion the matron or other official of an institution may be the most appropriate person to interview.

d) Informants who did not help in anyway with the care of the deceased.

But other situations may arise when a question does not apply for some other reason. If you are uncertain try to apply this criterion: ask the question if it makes sense, don't if it does not

3) Arrangements for recording the answers These fall mainly into three categories;

(a) Pre-coded questions e.g. questions 4 & 5*
Here you should ring the code number apposite the appropriate answer. Take care not to obliterate the number with your circle. The codes show you how much probing you need to do e.g. an answer 'seven months' is coded '5' without further prompting but if the subject says 'about 3 months' you should probe to find out whether it is a bit more than 3 months or a bit less.

* all examples are taken from questionnaire 2 - the main questionnaire

(ii) Open-ended questions e.g. Question 11 (first part) Here four possible answers are pre-coded, any others are coded '5' but the contents have to be 'specified', written down word for word.

(iii) Open questions e.g.question 8. 'Could you describe how he was restricted?' The answer must be written out in as much detail as possible and always in the subject's own words.

(4) Arrangements for classifying the information and transferring it to punched cards. This is done from the 'pre-codes' and by putting ringed codes at the end of each question. A check is made by coding the answers independently in the coding boxes. in sheets opposite. Interviewers must leave all coding boxes clear, except for serial number, date and interviewer code.

Extra Space When people give more information than will go in the space by the question record it on the almost blank sheet opposite. Put an asterisk * at the question and put the question number beside the answer on the blank sheet. When in any doubt whether an answer fits in the pre-code or not record their answer and qualifications in full. We can then make a decision about this afterwards in the office when we have all the answers together - but of course we cannot go back to do any extra probing that may be needed. Record all relevant comments, anecdotes and stories in as much detail as possible and in the words used. Watch out particularly for vivid phrases and descriptions and get them down.

Layout Many of the questions are dependent on the answers to other questions. Sometimes a group of questions is omitted for some people, e.g. at question 4 or 5 if the answer was a year or more you skip to question 9. Instructions about skipping are given at the point when you should start skipping e.g. at the end of question 4. On other occasions parts of questions are included or omitted according to their answers e.g. at question 6 if the answer to the first part is 'no' you omit the question under IF YES (5)and go on to ask if he was restricted in what he could do outside. Again what you do next depends on their answer to this question.

The questions dependent on the first answer, i.e. IF YES (5) and IF NO (6) are indented slightly and are in line with one another. Questions dependent on the answers to the question about restriction outside are indented still further, and can be ignored if the first answer was 'yes'.

See also Q15

Less than signs 2 years < 5 years means between 2 years and 5 years, precisely 2 years being included, but precisely 5 years goes in the next group 5 years < 10 years.

The deceased has been treated as masculine to avoid cumbersome him/her, s(he) notations. Of course you will need to change this when it was a woman. We've also put a line_____ when we feel it might be appropriate to refer to him by name. But it may be easier to say 'your father' 'your wife' or whatever is appropriate.

Informant/Respondent We have a convention of referring to the person being interviewed as the informant on Questionnaire 1 and the respondent or main respondent on Questionnaire 2

Recording Blue or black biros should be used to record information at the interview. When you check over the questionnnaires afterwards writing in things that are unclear or expanding your personal abbreviations or translating your shorthand do this in pencil. If you ask any additional questions or probes other than standard ones you should record what you said and underline it - to distinguish it from what the person said. Again do it in the actual words used. Never use red, this is what we use in the office for coding or green which will be used by the supervisors for checking.

Questionnaire 1

The Introduction Varies slightly according to whether the person seen is the one who registered the death or some one else. You will need to put this introduction into your own words and not read it. You will also need to be ready to expand parts of the introduction and to give additional explanations. Points you should always make are 1) the sort of organisation you represent. 2) how you came to be knocking on their door and 3) any information they give us will be treated confidentially in that no names will be mentioned in the report.

Question 1 Again the wording varies slightly and depending on whether the person registered the death or not.

Question 2 Record all the people who lived in the same household as the deceased at the time he died or went into hospital (or other institution) last. Make a note both on the questionnaire and mentally, if the informant tells you for example that any of them have since died or moved out of the area. Household includes all the people living under the same roof who share the same housekepping arrangements So a lodger who cooks in his bed-sitting room is not included but a boarder who eats with the family is. Sometimes an old person who starts off as a lodger may, because of ill health or infirmity, gradually change to a boarder. If in doubt in this sort of situation, count them in rather than out.

Question 3 Be sure to record any qualifications, for instance a woman may be the housewife as far as cooking and preparing meals but as she becomes old and infirm the husband may do more and more of the shopping. He then should count as a part-housewife (e.g. at Q.43 on the main questionnaire)

When you have identified the informant's relationship to the deceased (Q1) the composition of the deceased's household (Q2). The housewife (Q3) and whether the informant lived in the same household as the deceased you may be able to identify the most appropriate main respondent.

This is determined on four criterions:-

1) The amount of contact with deceased This means that people in the same household usually take precedence over people living elsewhere.

2) Their relationship with the deceased Here, other things being equal, the order of priority would be:-

Spouse
Son or daughter
Parent
Brother or sister
Son in law / daughter in law
Brother in law / sister in law
Other relatives
Friends
Neighbours
Others

3)The amount of care the person gave - This means that female relatives are usually preferred to male relatives of the same degree!

4) Their availability willingness and suitablity for interview People not living in the study area, who are ill (or have died) or deaf or unwilling are inevitably excluded - but should be thought of as appropriate when making the assessment at (x) on the main questionnaire.

The decision is based on an assessment as far as possible of all these four points. But the only hard and fast rule is that, if there is such a person available, the housewife in the deceased's household should be the main respondent if they are related to the deceased. On many occasions the decision will be clear on others you will have to use your judgement - sometimes on rather inadequate information. But when you have completed questionnaire 2 you should be in a better position to assess that decision - which you do at (x).

Question 5 If it is reasonably clear that the informant is the most appropriate respondent for the main questionnaire you record this and ask them if they are willing to help. If they are, you go straight ahead with the main questionnaire (2) starting at question 2. If they are unwilling you try to establish if there is someone else suitable who might be willing to help.

If it seems clear that someone else other than the informant is the most appropriate person, you check this with them. If they are in the same household as the informant try and either see them straight away or make a definite appointment. If there seems to be any doubt or difficulty about this try and find out if someone else might be suitable and willing. If the person who seems most suitable is not in the same household ask for their name and address. If the informant is unwilling to give you this, try to establish the next most appropriate person and proceed accordingly.

If it is unclear who would be the most appropriate person you should ask the informant who they think it would be and carry on from there.

You don't ofcourse need to record the address of the main respondent if it is the same as the informant.

Question 6 is for recording the 'next most appropriate person' but don't bother to do this if the informant is the most appropriate person and agrees to help or if someone else in the household has been identified and has agreed.

Question 7 is a check question. When this has been completed there are five possibilities.

1) The informant on Questionnaire 1 is found to be the most suitable main respondent and is willing to help. In this case you jump from the ~~first~~ second page of Questionnaire 1 to question 2 on Questionnaire 2 and proceed with that.

2) The informant on Questionnaire 1 is found to be the most suitable respondent but is unwilling to help further. In this case try to identify someone else who might be able and willing to help.

3) The person most suitable is someone else in the same household as the informant on Questionnaire 1. In this case try and interview the other person straight away or make a definite appointment to do so. Do not proceed with Questionnaire 1.

4) The person most suitable is identified as someone in another household and you are given their name and address which is in the area. In this case ask the person who registered the death if they are willing to give us some information and proceed with the rest of Questionnaire 1.

5) The person most suitable is identified as someone in another household but the informant on Questionnaire 1 is unwilling to give you their name and address. In this case try and find if someone else might be suitable and proceed accordingly.

In all cases don't forget afterwards to complete the section about 'details of interview' on the last page of Questionnaire 1. And if you are concluding the interview don't forget to thank the respondent and leave a card. Try also to complete the classification section.

If the death is in the special sample you may want subsequently to interview the same informant on questionnaire 3. (Obviously you won't want to do this if you are also interviewing them on questionnaire 2 or the whole of questionnaire 1) The difficulty is that you cannot know if you want to do this until you have done an interview with the main respondent. However this situation will usually only arise when the main respondent is in the same household (as if he isn't you'll be asking the informant the rest of questionnare 1). In this case (i.e. when the death is in the special sample and the potential main respondent is in the same household as the informant on questionnaire 1 but cannot be interviewed on that same occasion) you should explain to the informant that you might like to ask him some more questions after you've seen the other person, and try and arrange that you'llbe able to do this on the same occasion as you call to see the main respondent.

The rest of the questions on questionnaire 1 are taken in whole apart from the main questionnaire. But of course the skips are different.

Question 8 coressponds to Question 3 on the main questionnaire.

Questions 9-13 corresponds to questions 4-8 on the main questionnaire.

Question 14 is a shortened version of questions 9 & 10

Question 15 corresponds to question 11

Question 16 corresponds to the first part of question 12

Question 17 corresponds to question 19

Question 18 corresponds to question 21

Question 19 is a modified version of questions 25 & 26

Questions 20,22,23, 25 are modified parts of question 43

Question 21 is a modified part of question 49

Question 24 corresponds to Question 48c

Questions 26-30 corresponds to questions 55-59 (58 being shortened)

Question 31 is based on parts of questions 52 and 53 but the unitial wording is rather different because on Questionnaire 1 we haven't ascertained who all the different people who helped at Question 20 (question 43 main) were.

Question 32 corresponds to part of question 75

Question 33 corresponds to part of question 80

Question 34 corresponds to question 15 except that it relates only to the deceased's last hospitalisation.

Question 35 corresponds to question 71

Question 36 corresponds to question 93

Question 37 corresponds to question 51,

Question 38 corresponds to question 98a.

The classification is the same as on the main questionnaire 2.

The details of interview are the same except for the type of interview which is self explanatory.

Questionnaire 2 (The Main Questionnaire)

Question 1 is the same as on Questionnaire 1 and is of course omitted when the main respondent was also the first contact.

Question 2 is intended to help establish rapport with the respondent by showing an interest in his problems. It is omitted if the respondent is not a relative or close friend.

Question 3 helps to establish the circumstances of death. The second part should establish whether for instance the person had had a previous heart attack. The condition from which they died will probably emerge during the course of the question, but you will need to take care to distinguish a preceding illness unrelated to the cause of death. This means you should always use the check at the end. We want to know what the respondent thinks the person died of - which may be different from the cause on the death certificate. - If [illegible]

Questions 4-8 are to determine the extent of any restriction in the deceased's activities during the last 12 months of his life. We are not concerned here about whether or not they were related to the condition of which he died. If he was completely bedridden for some time - but not for the whole year at Question 5 you ask 'before that was he confined mainly to bed' and if the answer to that is no question 6 should be 'Before he was bedridden was he at all restricted' The skip at the end of question 6 applies to those not restricted at all.

Question 7 & 8 are related to the restriction - either inside or outside the house - recorded at Question 6.

Questions 9 & 10 are included because although the person's age is recorded on the death certificate this will be their age as reported by the person who registered the death. This may not always be accurate if the person was up-set at the time or did not know the person very well. We want to know how often discrepancies arise.

Question 11 If the nature of the place where the person died is clear from the address list use the first form of words; If not the second. If it was hospital or institution or such as old person's home we will assume the deceased was a patient there unless you make a note otherwise. Be sure to record the respondent's precise description of the institution, don't 'translate' it at all. If the person was transferred from one hospital or institution to another make a note of this but record at the second part the total length of time they were in a hospital or institution. (If they came home between that of course is different and you'd only record the length of time they were in the last hospital or institution)

Question 12 The first part of this 'question' is a check for you: you record the 'long term institutional deaths' - people who'd been in a hospital or institution for a year or more before they died - and unexpected deaths of people under 65 who were not restricted in any way (from Questions 4-8) as certain sections are omitted for these two groups. For the long term institution deaths you then ask if the person had ever worked, checking if they died in a home for mentally or physically handicapped, whether they worked outside the institution. Find out how recently before he died he had worked and then skip to Question 14.

Question 13 is about any other spells the person may have had in hospital during the last twelve months of his life. Be sure at a) & b) to include the last spell in hospital if he died there. If he did not die in hospital and was not in hospital as an inpatient during the last 12 months of his life skip to Question 17.

Question 14 is to find out about operations and other specific treatment - particularly deep X-ray. If in doubt whether to count a procedure as an operation ask whether they had a general or local anaesthetic and include it if they had either.

Question 15 The first part and a) relate to all the deceased's spells in hospital during the last 12 months of his life. If he had been in more than one hospital make a note of this and ask b) about the hospital he was in for the longest time and c) and d) about the hospital he was in last.

Question 16 We just want to know about how many people visited him at all apart from the respondent, and if more than one including the respondent, who visited most often. Make it clear if it was the respondent and record the relationship to the deceased if it was someone else.

Question 17 is about any visits to outpatients the deceased had had during the last 12 months of his life. If he had only been once omit the 'usually' at c) d) and e). Of course e) includes time spent waiting at the hospital - either before he was seen or afterwards waiting for someone to take him home. Be sure to record any comments made about this. At g) we are again particularly interested in people who had deep X-ray treatment.

Question 18 General practitioners can ask hospital consultants to visit patients in their own homes. So this question goes to everybody, (except long term institutional deaths), We'd like to know if the respondent can tell us, whether he came to assess whether the person should

be admitted, to carry out particular procedures or what.

Question 19 We want to know the address of the deceased's general practitioner so that we can write to him and ask for his views about looking after the terminally ill. We will not be asking the doctor any questions about the particular patient. If the deceased had a doctor in a partnership and the respondent is uncertain whose name to give, ask for the one he saw most of. Be sure to get initials or christian names as some doctors work in partnership with relations.

Question 20 If the respondent is uncertain initially, prompt 'well could you say if it was more or less than five times?' Don't ask b) if the answer to a) was '0' or c) if the answer to b) was '0'.

Question 21 is asked whether the deceased had seen a general practitioner in the last 12 months or not.

Question 23 and 24 are asked if the respondent knows, or has had any contact with the deceased's doctor, or any of the doctors in the same partnership. We want to know why they feel that (Q.23) and to have an example (Q.24) whatever their answers are.

Questions 25 - 30 are about the deceased's work. If he had worked in the last twelve months record 'yes' at the first part of Q.25 and then go straight to Q.26. If they had not worked we want to find out why and you can ask additional questions here. For instance if the deceased was a housewife ask if she had worked at all, for money in the last ten years and if not skip straight to Q.31 or Q.34. If he retired early because of ill health, but with some sort of retirement pension count as retired, but if he gave up work because of ill health without a retirement pension count as ill health. If the deceased had not worked in the last 12 months because of ill health or because he had retired ask appropriate sections then go to Q.29. If they have not worked for some reason other than ill health or retirement you will need to use your judgement about what questions to ask. If for instance he stopped work because he came into some money it would be most appropriate to adapt the questions under the IF RETIRED section and ask a) How old was he when he gave up? Did he give up because of any ill health? and Q.29) What was his main job?

Questions 26-28 are just asked if the deceased had worked at all in the last 12 months of his life. Question 26 determines how recently he worked and the second part whether he had formally given up work or not.

Questions 27 & 28 relate to his most recent work.

Question 29 This is an important question and you should get as much information and detail as you can. Probes to use are "What is the job called?" "What does the firm do?" Descriptions which are quite inadequate are general terms like 'engineer' or 'civil servant'. For a civil servant we need to know the actual grade.

Question 30 relates of course to the respondent's opinion about this.

Question 31-33 are not asked if the main respondent was interviewed on Questionnaire 1 or if someone else in the same household as the main respondent was interviewed on Questionnaire 1 If the interview with the main respondent is done on a separate occasion to the person in the same household interviewed on Questionnaire 1 then you should fill in the replies to questions 31-33 before the interview. So you've got the information there for reference and don't need to ask it again.

You may need a short introduction to Question 31 or 34 'Now can we talk about _____'s household arrangements?'

For unexpected deaths of people under 65 who were unrestricted in the last 12 months Q.34 - Q.77 are omitted. For a number of these questions you will need to vary the wording depending on whether the person was ill or not before he died.

Question 34 If the respondent seems uncertain what sort of thing you mean at the first part of the question and the deceased did not live alone you can go straight on and ask a) and b) but at the end you should check whether there were any other changes and code the answer to the first part. Changes that occurred not because of his illness or old age but which affected his ability to look after himself for example the death of a spouse should be recorded here.

Question 36 The wording for this depends on whether the deceased lived alone -'For how long had he been living alone?' or with one other person - 'For how long had he been living with just that person' - or with more than one person - 'For how long had he been living with just the same people?'

At both question 34 and 36 we want to know the reasons for any changes and we are particularly interested in the death of relatives who had been living with them.

Question 41 Only record the number of steps if it is less than a half flight, 'A flight' being the distance between two floors. If there was a lift be sure to make a note of this.

Because Vo ask Pa long Verm medical

Question 42 First go through the list of 13 possible symptoms finding out whether the deceased had them or not. Then ask all the questions across about each one reported in turn - saying for example 'Now can we talk about _____'s sleeplessness. Do you think he found it very distressing.....' As they have already told you how long the deceased was in hospital you should be able to remember this and check if they had been in hospital at all - whether they had it before they went into hospital or not. Part d) is asked if they died at home or if they had it before they went into hospital. If they did not then you finish at c) and go back to ask about the next symptom.

Loss of bowel or bladder control These are asked about separately initially but the dependant questions across the table are only asked once if they had both. In this case record the time of the longest if they started at different times. If they only had one you still of course ask the dependent questions about that one. In either case whether they had both or one of these two symptoms - don't forget the questions at the bottom. It may not be the deceased who coped with the dirty linen. If the respondent lived with him and looked after him ask how s/he coped. In other cases reward appropriately.

Question 43 Again you should go all through the list of possible things with which the person might have needed help first recording whether or not they did. Ask the questions about shopping etc. if the deceased or respondent was the housewife and ask the last question if for example the deceased was a person with young children. Then go back and start with the first one reported and ask the questions between the two lots of double lines about that. When you've asked these questions about the relevant things in a group go on to ask the rest of the questions as appropriate about the group as a whole. There is a space between each of the groups so you can see which things are taken together as a group for this purpose.

When the table has been completed check with the respondent the summary question at the end. If any discrepancy should arise go back and sort it out Don't forget the additional questions about night care if they apply.

Question 44 Again ask about all the different possible bits of equipment first and don't forget to ask everybody about 'anything else' - before asking the other questions about each one mentioned.

Question 45 When you have established which if any of these four things they had, ask whether each one they had was useful for helping with the care of _____. Then ask whether the others would have been useful.

Question 47 Is only asked if the deceased had or needed some piece of equipment.

Question 48 If the respondent lived in the same household as the deceased you don't need to ask who had the additional expenditure. But still be sure to ask about fares or petrol as the respondent may have visited the deceased in hospital or the deceased may have gone to visit other relatives.

Question 49 All the friends and relatives who helped in any of the ways listed at Q.43 and any who helped after the person died in the ways listed on the card should be recorded in the top half of this table Start with the respondent. If he/she helped at all, then with any other people in the same household as the deceased, any other friends and relatives. When you've got them all listed in the table with their relationship to the deceased ask the questions across the table between the vertical double lines. You'll only need to ask how near they live, if they did not live in the same household as the deceased - otherwise code 0. Ask if they helped regularly or occasionally and if the former how often. If they helped irregularly but frequently make a note of this. List all the different ways they helped by using the code number for all the things listed on the card.

Question 50 Any people mentioned at a) b) or c) are entered in the bottom half of the table. All we want to know about them is their relationship to the subject, where they lived in relation to the deceased and an estimate of the number of times they saw him during the last year of his life. The closeness of the relatives you record at Q. 50c depends to some extent on how many other relatives have been identified. If a number of closely related people who helped or saw him recently have been identified you don't need to push this but if no close relatives who helped or saw him have been identified you do.

Question 51 Here we want to find out who the respondent felt bore the brunt of looking after the deceased. If they didn't personally we want to know how they think it affected that person. For the special sample we want to rank all the people who helped in order of who the respondent felt did most, next most etc. Record the rank on the last column of the table. Indicate tied ranks with ½'s - so if the respondent reckons two people shared the main brunt they will each be ranked 1½, if one person bore the brunt but two other people helped

equally next they will both be ranked 2½ - because they shared 2nd and 3rd places.

Special Sample When you've completed the table up to the double line and asked all the questions down to 51 and filled in the bottom half of the table then ask the names and addresses of the people in the top half of the table. Of course you don't need to record the addresses of people in the same household as the deceased if you've got that already.

Question 52 The first part just checks on and records all the official people who helped the deceased while he was at home in the last 12 months of his life. These will probably have been reported at Question 49, but it may be that someone will be mentioned for the first time here. Other people mentioned may be both attendents. people who visit for company, and so on. If no help was given from any of these sort of people skip to question 53. Ask question a) - h) for each of the people mentioned in turn, so if the district nurse came in at all ask questions a) - h) about her before going on to the next person who helped. Do <u>not</u> prompt the listed responses to a) but always be sure to ask the question - sometimes for example district nurses arrange for a clergyman to visit. If the person only came once record when that was in relation to the deceased's death at b). Also don't think that (f) if not relevant - it may be that the person would have liked the clergyman to read to him or the chiropodist to cut his toenails on the other foot, beside the one he was treating, or the laundry service to wash other things besides bed linen. If the clergyman was reported as a friend who helped at question 49, you should include him at both places but be sure to 'bring forward' any factual information so that you don't ask the same question twice. Similarly with any friends who are nurses, but in this case make a note about this and indicate clearly that the two are the same person. The space under comments is intended for such notes as this and for any other relevant information such as who 'another nurse' was.

Question 53 Is just asked about the types of help that the deceased had not received. If they had had help from all the listed ones - a nurse, a home help, laundry service, chiropodist and bath attendant - you still ask about any other service they could have done with some help from.

Question 55-59 are about the changes in the respondents work and life that looking after the deceased made. So if the respondent did not

help with this at all you skip to question 60. If they were not working at the time they started to look after the deceased you record this at question 55 and skip to question 59. If the respondent was working at the time he/she first started to look after the deceased (and this may have been several years ago) but has since retired but the retirement was not associated with looking after the deceased you make a note of this at question 56 and if there were no other changes related to looking after the deceased skip to question 59.

Question 58 The second parts a) and b) are only asked if the respondent reported that changes in work had made some financial difference to them. Even if they say they don't know where people can get help you still ask if they had applied for any as they may say they don't know where people can get help because they applied to somebody and were not given any.

Question 60 is to find out whether the respondent was able to get the information they wanted about the deceased's illness and prognosis. If they were satisfied with all those aspects you skip to question 63.

Question 61 wording is varied slightly depending on their response to question 60.

Question 63. You should read out the list here. Be sure any relatives mentioned are clearly specified - that makes it clear whether the relationship is to deceased or respondent.

Question 66 is worded rather differently if the person for example had had a heart attack and therefore might have expected another. It is of course the respondent's view of whether the deceased knew or not. If they are uncertain you should probe 'Well do you think they probably knew or probably not' before accepting 'Unable to say'. The wording of b) and c) vary slightly according to whether the deceased knew probably or definitely. So if the respondent says the deceased had definitely known you ask at b) 'Do you think that was best?' c) 'Do you think it would have been better if he had not known?'. If he had probably known ask 'Do you think that was best?' or 'Do you think it would have been better if he had not known or had definitely known?'. Similarly if the person definitely didn't know you ask just 'Do you think that was best or would it have been better for him to know?' And if he probably did not know you ask 'Do you think that was best or would it have been better for him to know or definitely not to know?'
In other words if there is no doubt in the respondent's mind whether

the deceased knew or did not know you omit the part in brackets - when there is a doubt you go on and include it.

Question 68 Bring forward their answer from question 3 to check the first part of this and then ask the appropriate sections.

Question 70 This is to find out whether there were occasions when the deceased was conscious but did not recognise the people he knew well - and if so whether there was a period when he never recognised people or if he sometimes did. Either way we want to know how long he had been like that.

Question 76 Self means the respondent - not the deceased!

Question 78 a) You don't need here to prompt all the answers before accepting one. If they say it was his own doctor code this and don't go on to ask about another doctor who had seen him before etc.

Question 80 This is from any point of view the respondent feels relevant. If for instance there was a spouse who would have liked to have the deceased at home then we hope the respondent will consider this - but of course just ask the question as it is, and only if they ask what you mean explain that it is from any point of view. Record all qualifications or comments, about how easy or difficult it would have been to look after him at home.

Question 82 & 83 people may feel both relieved or distressed in which case record both and their comments.

Question 85 The wording varies slightly if the respondent was at all responsible for the funeral arrangements.

Question 87 - 89 The two questions about religious faith are independent in the sense that an agnostic might feel his belief helpful but the 'C' does not belong to any formal faith or denomination.

Question's 90 & 91 Read out the list asking whether any of the people have visited the respondent first, then just ask if they would have liked any (others) of them to visit. Don't read out the list a second time.

Question 92 If they have seen more than one person code them both (or all) and if it was about more than one thing list them all under b). At. c) just find out whether they think any of them were related to the bereavement and at d) whether either a doctor or chemist gave or sold them any tablets or medicine. We are particularly interested in sleeping pills and tranquillisers.

Question 93 If the respondent lived with the deceased be sure to record any changes in their living arrangements here making it clear whether the respondent has gone to live with someone else or someone has come to live with them. Details of the relationships of people they now live with are recorded at (v).

Classification It is usually helpful to use some sort of introduction to this.

Marital Status You will almost certainly know this by now. If not you will need to ask appropriate questions. 'Have you ever been married?' Are you still married?'

Occupation of self or husband This is omitted if the respondent is the widow of the deceased because it has been asked earlier but not if he is the widower.

Present Household If the respondent lived with deceased you should know who they live with now - but not otherwise. In either case record the number and relationship of the people they live with, and don't forget to ask the additional information - if they live alone.

Questionnaire 3

This is used only when the death is in the special sample for other people beside the main respondent and person interviewed on questionnaire 1 who helped with the care of the deceased. Up to three people, if the main respondent was the first contact, or two people, if someone other than the main respondent was interviewed on questionnaire 1 may be interviewed on questionnaire 3. Of course sometimes more people will have helped in which case try to interview the ones estimated by the main respondent at question 51, to have been most involved. Sometimes fewer than three, or two other people will have been involved in which case you do not do so many interviews. Sometimes no-one will have helped - for instance if the person died unexpectedly and was under 65 with no previous restrictions. There should not be any long term institutional deaths in the special sample as we are only including home deaths in it.

Never attempt to interview people not regarded by the main respondent as being the three (apart from the main respondant) most involved in care. If you are interviewing more than one person in the same household on any of the questionnaires you must be particularly careful both not to repeat unnecessary factual questions and not to break any confidences.

The questions on questionnaire 3 are taken in whole ~~or part~~. from the main questionnarre (2).

Question 1 corresponds to question 1 on the Main Questionnaire
Question 2 " " part of question 32 & 33 on the Main Questionnaire.
Question 3 " " question 3 on the Main Questionnaire
Question 4,5 are taken from question 43. on the main Questionnaire
Question 6,7, & 9, are taken from question 49 on the Main Questionnaire.
Question 8 Corresponds to question 48c. on the Main Questionnaire.
Question 10-14 corresponds to question 55-59 on the Main Questionnaire.
Question 15 is made up of part of questions 52 and 53 on the Main Questionnaire.
Question 16 is a modified version of question 11 on the Main Questionnaire.
Question 17 is a modified version of question 75 on the Main Questionnaire.

Question 18 is a modified version of question 80 in the Main Questionnaire.

Question 19 " " " " " " 15 " " " " "

Question 20 " " " " " " 71 " " " " "

Question 21 " " " " " " 93 " " " " "

Question 22 " "" " " " " v " " " " "

Question 23 " " " " " " 51 " " " " "

Question 24 " " " " " " 98a " " " " "

The questions are basically of two sorts first opinions about the care the deceased had and needed and secondly both facts and opinions about the particular informant and the effect of the deceased's illness and death on him.

As far as possible we have tried to avoid repeating factual questions which have been asked on questionnaires 1 or 2 because the informant may have discussed the interview already with the main respondent and might feel we were 'checking up'. But occasionally we need to establish facts before we can ask opinions and this means some repetition on the two questionnarres - e.g. at questions 2, 15, and 16.

The question which is probably most tricky from this point of view is question 4 and you will have to use some discretion and tact here. Stress that we want the informant's view and of course don't forget that the information you were given by the first contact and main respondent must be treated confidentially.

Completion Record

One of these is completed for each death on your address list.

First part of questionnaire 1- i.e. questions 1 -7. If this was a failure we want as much information as possible, both under the reasons for failure, who was contacted, the deceased's household arrangements and if possible Question 6 - Question 10 on back. Under who contacted record such things as Married Son who registered death - moved out of area. Daughter who lived with deceased refused - now living alone.

Main Questionnaire This may not have been completed by the most appropriate person but that is recorded on the details of interview on that questionnaire. On the completion record we want to know whether it was completed or not, and if not the reason or reasons for failure and who you attempted to interview on this. If you failed with one person you should try any one else who might help.

Questionnaire 3 This only applies if the death is in the special sample and of course if the main questionnaire was not completed you won't know how many people it would have been appropriate to try and see or who they are, so in that case leave this section blank.

Record of calls Keep a note of dates and times, and record both your intention and the outcome.

Section 6-10 This is basic data we would like to have if neither the main questionnaire or the second part of questionnaire 1 were completed. This might be given by neighbours if people have moved away and there is no-one closely involved enough to be interviewed.

Data from death certificate Leave this section blank. We will complete it in the office.

After the Interview

Answering questions

At the end of an interview you should always ask if the person has any questions they want to ask you - either about the study or the Institute. You must be prepared to spend time on this - after all they have given up their time to answer our questions. Leave them some Notes about the Medical Care Research Unit if you think they would be interested.

Leave them as happy as possible

The interview may have been rather traumatic for them if it has revived memories and recalled an unhappy - or happier - time. They may want to talk more about this or to talk about other things while you are still there. You should not rush away the minute you have got what you want if you feel they would like you to stay for a while. But don't try to do any more than a little therapeutic listening.

Reassurance

At the end you should often repeat - in different words - some of the explanations you gave at the beginning particularly who you are, the aims of the study, how we got their name and particularly about the confidentiality. This needs careful explanation and wording and if they have given you the name and address of anyone you want or may want to interview make quite sure they understand this and will not regard it as a breach of your assurance of confidentiality.

The Card

Always leave a card behind so they've got something to show anybody they want to talk about the interview. When you give them the card refer to the statement about confidentiality and make sure they understand what we mean by this - and the limitations - in terms of going to see other people whose names and addresses they have given you.

The Letter

You should post a letter to them the same day or the next day - or drop it in the letter box if you are passing later on. Put the date on the letter and write the person's name after the 'Dear', and your name at the bottom.

Checking questionnaires

All questionnaires should be checked through carefully in pencil the same day or the next day at latest. If you find you've omitted something never attempt to infer it. Write in 'sorry forget this' or if it is something important go back to ask them about it. Write above any illegible writing and translate any shorthand. Fill in appropriate sections of your completion records.

Sending on questionnaires

Send on questionnaires every other day by recorded delivery and be sure to seal the envelopes very carefully. Completed questionnaires are extremely confidential and valuable documents. As soon as you've completed all the interviews related to a death send in the completion record - but you should send in the questionnaires completed earlier before you send in the completion record. Don't keep back the completion records of failures any longer than you need to It is disappointing for us to receive a batch of these at the end.

Pay claims

Send these in each week, to reach the office not later than Tuesday morning. Two pounds ten shillings is paid for every night away from home The mileage allowance is ninepence a mile if you have a car; travelling expenses should be claimed if you use public transport. At week-ends, if you are not working we will pay either two nights subsistance allowance i.e. five pounds, or the return rail fare, whichever is smallest.

Postage and other expenses for example, envelopes and sellotape, should be claimed on the same form.

Table I

Study areas for 'Home Care for the Dying'

Registration District No.	Area	County	Region	Population
33A	Teesside South	Yorkshire, North Riding	I	272,340
	Middlesbrough C.B.			154,580
	Eston U.D.			40,120
	Guisborough U.D. (pt)			1,340
	Redcar M.B.			35,960
	Saltburn & Marske-by-the-Sea U.D. (pt)			10
	Thornaby-on-Tees M.B.			23,450
	Stokesley R.D. (pt)			16,880
218	Barking L.B.	G.L.C.	V	170,100
236	Hillingdon L.B.	G.L.C.	V	234,470
267	Eastbourne C.B.	East Sussex	V	66,800
460	Birmingham C.B.	Warwickshire	IX	1,101,990
534	St Helens C.B.	Lancashire	X	103,320
25	Northumberland North Second	Northumberland	I	30,040
	Amble U.D.			4,980
	Alnwick U.D.			7,500
	Alnwick R.D.			12,320
	Rothbury R.D.			5,240
152	Brentwood	Essex	IV	171,600
	Brentwood U.D.			57,000
	Basildon U.C.			114,600
216	Thanet	Kent	V	136,550
	Margate M.B.			49,060
	Ramsgate M.B.			38,810
	Sandwich M.B.			4,590
	Broadstairs & St Peter's U.D.			20,300
	Eastry R.D.			23,890
312	Isle of Wight	Isle of Wight	VI	98,040
	Newport M.B.			19,690
	Ryde M.B.			21,200
	Sandown-Shanklin U.D.			12,930
	Cowes U.D.			17,820
	Ventnor U.D.			6,260
	Isle of Wight R.D.			19,140
402	Bridgend	Glamorgan	VIII	171,290
	Cowbridge M.B.			1,150
	Maesteg U.D.			21,350
	Ogmore & Garw U.D.			20,490
	Bridgend U.D.			15,110
	Porthcawl U.D.			12,810
	Penybont R.D.			47,560
	Cowbridge R.D.			21,900
	Llantrisant & Llantwit Fardre R.D.			30,920
489	North East Cheshire	Cheshire	X	144,470
	Bredbury & Romiley U.D.			27,620
	Hazel Grove & Bramhall U.D.			34,800
	Marple U.D.			23,300
	Cheadle & Gatley U.D.			54,920
	Disley R.D.			3,830

The sample was drawn on mid-1967 figures.

Mid 1969 figures have since been published and show a general increase of up to 3% in all areas except Birmingham where a decrease of nearly 2½% is recorded.

Institute of Community Studies,
18 Victoria Park Square,
London, E.2.

Interviewer's agreement

I understand that the work I do for the Institute of Community Studies is CONFIDENTIAL and I agree, as a condition of my employment by the Institute, to treat all information which comes into my possession during the course of, and as a result of, this work WITH THE STRICTEST CONFIDENCE, not to be disclosed to anyone outside the Institute. I will treat all survey papers (address lists, completed interview schedules, etc) with great care, and I will not discuss interviews with other members of the interviewing team or with staff members of the Institute in places where the conversation might be overheard.

Date Signature

District Nurse/Health Visitor enquiry.

Interviewer's Notes

Lisbeth Hockey

District Nurse/Health Visitor enquiry.

Interviewer's Notes

Purpose and objectives The purpose of this part of the enquiry is three-fold.

1. We hope to find out the extent of district nursing/health visiting involvement in the care of the deceased in our sample and their bereaved relatives.

2. We want to see how professional workers assess the needs of patients and their families and whether their perception of problems corresponds with that of the bereaved or not.

3. We hope to discover whether terminal home care presents special problems for the local authority nursing service and if so, of what nature these are.

Method The enquiry is in two parts and each part has its own questionnaire.

Questionnaire A is about the specific person in our sample of deceased and their bereaved families. It is designed to get information relating to (1) and (2) above.

Questionnaire B deals with general points and is designed to get information relating to (3) above.

Respondents. Questionnaire A is administered to those local authority workers who were involved in the care of the deceased in the sample or their families. The superintendents of the district nursing and health visiting services will be sent a confidential advance notice of the names and addresses of the deceased in the sample. From these they will in many cases be able to identify those members of staff who were involved in the care. Where nurses do not work in geographical areas but are attached to general medical practices they will not be identifiable as respondents on questionnaire A until all the general practitioners names and addresses have been established.

Questionnaire B is administered to all the local authority nursing staff working in the sample areas, whether they have been involved in the care of the particular deceased persons or not. The only condition is that they must have had a part in the care of terminal illness or bereavement in the last 12 months. This is determined after the first question on questionnaire B.

Place of interview. In most cases it will be possible to interview the nurses/health visitors at a central office or clinic, but sometimes, especially in scattered rural areas it will be necessary to interview in the nurse's own home, an individual appointment having been made.

Confidentiality Of course information given by relatives or others must never be passed on to district nurses, health visitors or any one else. If you interviewed relatives of patients for whom you are completing a questionnaire A with a nurse you should not say that you have done so. In general if it is at all possible try not to interview nurses involved in the care of deceased in your sample as this could lead to embarrassment - or a bias if you were expecting certain answers. If they question you about the interviews with patients explain that we give patients the same assurance of confidentiality as we have given them.

The questions - Reference in these notes to 'nurse' applies also to 'health visitor'.

Questionnaire A

The introduction is very important and it is most necessary to assure the nurse of confidentiality.

q.1. This is a check to make sure that this is the appropriate respondent for questionnaire A. If they had no part in the care of the deceased the whole section on terminal home care is skipped. If they had no part in the care of the family after death either, they are not appropriate respondents on questionnaire A.

q.3. Normally all visits are recorded and the individual nurse should hold the records. It is possible that she does not have them for a variety of reasons, e.g. she could be a relief nurse, the records could have been sent to the office etc. The superintendents will be asked to inform the staff that their record books will be required.

q.4.) should be easily answerable from the records. If he went
q.5.) on and off the books more than once during the last 12
q.6.) months of his life please record details.

q.7. The nurse should have some knowledge about this but she may not know definitely. Fill in the appropriate dates for easy reference.

q.9. If a straight count of visits from the record book, refer to the tables at q.7.

q.10. It may not be easy for the nurse to be certain about the number of her own visits to the patient as apposed to the number of visits the patient has had. If the nurse states a number but is not sure, say so.

q.11. The problem here is similar. Night visits may not be specially recorded. If the nurse answers from memory, say so.

q.12. Can be answered from records.

q.17. The G.P.'s receptionist should be coded (5) and specified

q.18. The information could have been inadequate in content or form, e.g. a telephone message about a complicated treatment which could have been misunderstood.

q.20. Adopt the same principle as on the bereaved questionnaire. Ask first for all the items of care whether the respondent or another district nurse did them or not. If the district nurse did them herself or knows that another district nurse did them you code Yes. If she did not do them herself and is uncertain whether another district nurse did them or not code 'don't know'. For those they did you ask the dependent question a) b) and c). Note that (c) refers to help the nurse could have done with. If she always got all the help she needed code No but make a note, but if she sometimes got help and could have done with it always, or if she always got rather inadequate help code 'Yes' again making a note.

Then ask for all items of care whether any one (else) helped and if the deceased could have done with (more) help. Obviously the 'else' is included if a district nurse had done the things and the (more) is included if the deceased had had some help.
Note that this second section (ii) is omitted for the technical procedures as it does not apply.

q.21. Ask for each item:

a. whether the deceased needed help
b. whether they received all the help they needed on some help or no help at all.

q.22 Include the headings 'usually' 'at most', 'at least' in the question, but ask each one separately:-

How long did your visits take usually? -
at most? -
at least? -

q.23b You can use the code numbers from question 20 to indicate the type of help if that makes it easier or quicker for you.

q.24. Use the same convention as before Ask first for each service whether the deceased or the family had help from it.
Then ask for those they had the dependent question 'IF YES'.
Then ask for those they did not have the dependent question 'would it have been helpful' and if the answer is 'YES' ask the dependent question straight away for each service.

q.25. This gives the respondent the opportunity to mention anything. It could be e.g. more co-operative relatives or a different sort of administrative set-up.

q.27. This to any medical information they had about treatment or medical history whether it was adequate or not.

q.33. Assure the nurse that she is not expected to remember these details but we are just asking them in case she happens to recall the case especially clearly. Explain that we realize she may have looked after many people in rather similar circumstances and we don't want to record information that is incorrect if she is at all uncertain about whether she can remember it or not.

q.34. If they visited in a non professional capacity record any information they give you about this.

q.36a or 36 Ask Q.36a if you have skipped to it from questions 34 or 2 otherwise ask Q.36

More than one member of the family could have had care. Ask who first and then ask q.37.

It is possible that the nurse is not sure of the relationship to deceased.

q.40. 'At [illegible]' means looking after the general medical practice patients and not those living in a circumscribed geographical area.

Questionnaire B

Obviously the introduction and the first question are omitted for respondents ss who have already been asked questionnaire A.

Q. 2. introduces the subject of the study. You will probably get a lot of comment.

Q. 3. Although it is difficult for nurses to generalize try to get an answer and record qualifications under comments.

Q. 4. Ask for each item whether they think it has any effect in preventing more people being looked after in the community. Code all that apply, then ask for those that apply, which contributes most - one answer only and then which contributes next most - one answer only.

Q. 6-11. are omitted for respondents who had no part in the care of terminal illness in the last 12 months although they had been involved with bereaved people. (3 AT Q.1)

Q. 6. First ask for each service whether available or not. If a nurse works in more than one local authority area and a service is available in one but not in the other, ask questions for each area separately on opposite page: Then ask for the available services which ones they have made use of (b) and then (c) for all services with the appropriate wording 'extended' or 'introducted', depending on whether the services were listed under (a) or not.
Don't forget the table on night services where appropriate; more than one answer may apply. Again if there are different night services in the different areas in which the nurse works give details for each with names of areas.

Q. 8. Add (other) if the nurse mentioned any services under (c) at Q.6.

Q. 9. It may be that the nurse has no official name for the service that would be helpful. If this is so ask for a description of it.

Q. 10. Many district nurses feel that they could be more helpful if they were asked to visit earlier in the case of a progressive illness or helplessness. Others feel that relatives could often manage longer without help. Try to get the example. It is an important point.

Q. 11. This is a crucial question in relation to discovering unmet needs. Get as much information as possible.

Q. 12. Many families feel they ought to cope with nursing problems and many patients are independent. The nurse may feel the reasons given for reluctance were not the true ones. If she volunteers this record it, but don't of course suggest that this might be so.

Q. 13. The health visitor's role is mainly in the preventive field and not in nursing care. As many patients in terminal illness need advice and support rather than actual nursing it is thought by some that a health visitor would be the appropriate person to give this.

Q. 14.) Apply same rule as at Q.6. if there are differences in the areas
Q. 15) covered by the nurse.

Q. 16. Some district nurses in the pilot study have expressed concern about the problem of dying patients asking questions about their prognosis.

Q. 18.)
Q. 19.) Omit for those not involved in terminal care <u>(3 AT Q.1.)</u>
Q. 20.)

Q. 19.) We want to know as much as possible about communication problems.
Q. 20.) Get comments please.

Q. 21. It is possible for (4) <u>and</u> (5) to apply

Q. 26. If there is any doubt as to which alternative of night duty applies, ask the nurse for details of hours worked and hours on night call and record the answers fully.

Care of the Dying

Additional Notes for Interviewers

Questionnaire 1

As marital status is not always recorded on the death certificate an additional question has been added to establish at the time of death whether the deceased was married, single, widowed, or divorced or separated. If this is clear from the death certificate or from question 1 you should code this straight away without asking it, otherwise you will need to ask it.

Questionnaire 2

Institution - The definition of an institution is that it involves being looked after in some way by people whose job it is to do this.

Question 34 The final instruction 'IF ANYONE NOT NOW LIVING IN SAME HOUSEHOLD FIND OUT WHAT HAPPENED TO THEM' should be deleted.

Question 43 The instructions about skipping for long term institutional deaths should read: 'SKIP TO BOTTOM OF PAGE 13' - so that you skip to Q.60 if the respondent is a relative or close friend and to Q.65, if he/she is not.

The help needed here refers to the last 12 months of the deceased's life. 'IF APPROPRIATE' over item 71 should be deleted and this item should always be asked - explaining if necessary that some people looked after grandchildren or other children. If the deceased was under 65 at item 44 ask about pension or other benefit.

Question 49d Should read 'Other friends or neighbours' not 'other friends or relatives'

Questions 60-68 Have presented some problems when people have had a chronic illness or condition but have died from something else. In this situation the questions (with the possible exception of Q.67) should be asked as they stand but you should make clear to us - and probe to find out for yourself if you are in doubt - which the respondent is referring to when they answer the question, and you should explain to the respondent if they ask, or if the question would otherwise appear ridiculous that:

a) questions 60,61,62,and 65 - refer to the chronic, underlying condition
b) question 63 refers to both the chronic condition and possible death but should be restricted to discussions in the last 12 months of the deceased's life
c) questions 66 and 68 refer to the possible death.

Question 67 Refers to the diagnosis of the condition from which the person died. This should be explained if necessary and omitted for people who had a chronic illness or restriction but who died suddenly from something else. (It is omitted automatically for those under 65 with no restrictions who died expectedly).

Questions 74, 75, 79, 80, 81, and 83, Should be omitted if the respondent is not a relative or close friend.

Question 90 A health visitor should be included under 'other nurse'. By an oversight there is nothing to record when the respondent did not have a visit from anyone. You could either write in 'NONE' or add an 0 and circle it in the first column, or put dashes beside the code as you go along if the person did not have a visit.

Names Be sure to record on your address list the names of all the

Interviewers Notes

General Practitioners Enquiry

Lisbeth Hockey

Interviewers Notes

General Practitioners Enquiry

From the information on questionnaires 1 and 2 we are making up a list of the general practitioners of the deceased patients in our sample. These will be the sample of doctors for this study. We want to collect information from them about the problems of domiciliary care in terminal illness as they see it. We are not asking for any information about individual patients.

Four/fifths of these doctors will receive a postal questionnaire with a letter asking for their help. A copy of the letter is enclosed.

One-in-five of the doctors will be sent a letter asking them to agree to a personal interview. A copy of this letter is also enclosed. As you see from this letter it needs to be followed by a telephone call asking for an appointment within two weeks from the date of the letter which will be given you with the General Practitioners address list. The postal and interview questionnaires are identical in content.

Appointments. These should be well spaced as it is impossible to predict the length of waiting time at all; the length of interview is also difficult to predict as some general practitioners are extremely talkative whilst others try to rush the questions through as quickly as possible. Punctuality for appointments is essential, so it is a good idea to find out beforehand exactly where the place of appointment is. Some doctors will arrange for the interview in the surgery, others in their own home, some perhaps at a clinic or health centre. Make sure you get the right address when you make the appointment. Also get the telephone number so you can ring up in case of an emergency.

Introduction. It is particularly important to stress the confidentiality of the enquiry. It is also important not to discuss individual patients by name. The doctor may ask for the name of his patient who came up in the sample and whether you have visited the family. (Be completely non-commital and), explain that :-

) the families have been assured of the same confidentiality as the doctors and this must be observed

b) we have a team of interviewers visiting the bereaved

c) we work by serial numbers and not names

Partners in practice. Be sure that you interview the doctor on your list and not another in the practice. It sometimes happens that the senior partners offers to deal with enquiries of this nature and feels he can answer for his partners. Explain that we must see the doctor in the sample.

The questions

q.1. provides an introduction the subject of the enquiry. Get as much information as possible

q.2. This gives five examples of circumstances where doctors may have difficulties in obtaining suitable National Health Service accommodation. If the doctor feels unable to generalise emphasise the word usually and record any qualifications under comments.

q.3. Prompt all categories first and find out if 'more' of each are needed.
Then at:-

q.4. if more than one were said to be needed ask for the one most needed. Note we want one only here. Any qualifications should be noted under comments.

q.5. We want to know here to what extent the G.P. can consult with hospital doctors about

a) getting the patient into a hospital or institution
b) a patient being discharged home under his care

You will probably get a lot of comment here.

q.6. General practitioners are able to ask for a visit by a consultant to the patient's home. This is a domiciliary consultation.

q.7. refers to the number of domiciliary consultations asked for (not necessarily obtained) and we want to know this for terminal illness only.

q.8. Some doctors may be on call regularly but less than once a week. Note this please.

q.9. In some areas there are independent organisations who employ doctors to take night calls and pay night visits. General practitioners using the service pay for it; they are informed early in the morning about any calls to their patients made by the night service.

q.11. We mean here the local authority district nursing service. If the doctor covers more than one local authority area and his answers to questions 11 - 18 indicate that the services in the two or more areas are different, say adequate in one and very inadequate in another, ask for details and record answers for each area separately.

q.14. This question needs to be read slowly with the emphasis on are able and prepared to give. We want to know whether doctors use the district nursing service to support family care or only to replace it, or to do only those things which relatives can't or won't do.

q.15. Sometimes, especially in country areas the district nurse and health visitor is the same person often she is also the midwife. Where this is so, the doctor cannot assess the helpfulness of the health visiting service alone.

q.16. Try to get a lot of comment here-if inadequate in what way etc. but also if adequate why he feels it is so. Add would you give an example please.

q.17. Ask (a) (b) and (c) separately. Obviously b) only applies to the ones available in the area but c) applies to all whether they are available or not

q.18. (a) Services vary a lot between areas, if the doctor can't name the service under What? ask him to describe what it does.
(b) We are interested in any sort of change e.g. differently organized, differently staffed, different methods of communication etc.

q.20. If the doctor indicates that he can't generalize emphasize '<u>on the whole</u>'; try to get an answer and record qualifications under comments.

q.24. Probe all categories first, asking the question. Code all that apply. Then ask 'Which contributes most?' - one answer only and 'Which next most?' - one answer only.

q.25. This question poses three situations where a doctor might be confronted with the problem of whether to tell or not to tell a patient that he is dying. These are hypothetical situations and, of course, not easy to answer definitely. Emphasize probably in the question.

q.26. We want to know the general attitude of the doctor here. Some doctors like the district nurse to act independently in things like this, others prefer to have all queries referred to them. Also, some doctors believe in telling patients the truth about their prognosis, others believe it is best to always give them hope.

q.27. It is possible for more than one answer to apply.

q.28. Some doctors prescribe sedatives as a routine in these circumstances, others only if necessary.

q.29. Be sure to get the correct name of the drug. Ask for spelling if necessary.

q.30. 4 and 5 may both apply

q.31. IF YES (1) should read. . .for patients in terminal illness

q.36. If the doctor does not have his own list of patients in the practice ask him to estimate how many patients he looks after or what proportion of the practice work he does. If he gives the latter you'll obviously also need to know the total number ofpatients in the practice.

q.37. }
q.38. } code all that apply

Leave Notes about the Unit if requested.

INSTITUTE
OF COMMUNITY
STUDIES

Medical Care Research Unit

18 Victoria Park Square Bethnal Green London E2
Telephone 01-980 6263

Dear Dr

As one of the general practitioners on the Advisory Committee of the Medical Care Research Unit, which is part of the Institute of Community Studies, I am writing to ask for your help

The Unit is undertaking a study of domiciliary care in terminal illness, which is financed by the Department of Health and Social Security

The aims of the study are basically to find out what problems terminal home care presents for the family, the general practitioner, the domiciliary nursing and other supportive services

The study is based on 80 deaths in each of twelve registration districts, which form a national random sample Carefully selected and trained mature interviewers will visit the person who has registered the death and other bereaved to ask about their experience and any problems they may have had

Although the general practitioners whose co-operation is invited are those whose deceased patients are in the sample, it is not intended to seek information about these specific patients but only about the problems of home care in general terms

The names of general practitioners have been obtained from the family One of the interviewers will telephone in the next week or two to ask for an appointment with you and I hope very much that you will agree to give this interview If you would like further information about the study please do not hesitate to contact the Unit Miss Lisbeth Hockey, S R N , S C M who is in charge of the study will be pleased to answer any questions (You may know of her studies about district nurses 'Feeling the Pulse' and 'Care in the Balance')

An outline of the study has been sent to the B M A and to the Medical Officers of Health in whose areas the study is being undertaken

I would like to thank you in anticipation of your help with this inquiry which I think should help more effective planning of health services and encourage co-operation between the different branches of the services

Yours sincerely,

John Horder

JOHN HORDER, M A , B M , B Ch , M R C P

Medical Care Research Unit

INSTITUTE
OF COMMUNITY
STUDIES

18 Victoria Park Square Bethnal Green London E2
Telephone 01-980 6263

Dear Dr.

About two weeks ago Dr. Horder wrote to you asking for your help with a study that we are doing of domiciliary care in terminal illness.

I realise that you have many demands on your time, but your personal views are very important to us, as we want to find out about the problems of home care in terminal illness from the point of view of general practitioners. I hope that you can find time to complete our questionnaire, and send it back as soon as possible.

All the information given to us will be treated with the strictest confidence, it will not be passed to anyone outside the Unit. We plane to write a book about the study, but it will not be possible to identify the people taking part; no names will be mentioned in it.

Thank you for your help.

Yours sincerely,

Lisbeth Hockey, S.R.N.,S.C.M.

Institute of Community Studies
Directors Michael Young MA PhD Peter Willmott BSc (Soc)
Treasurer Howard Dickinson FCA

Medical Care Research Unit
Research Director Ann Cartwright BSc PhD

INSTITUTE
OF COMMUNITY
STUDIES

Medical Care Research Unit

18 Victoria Park Square Bethnal Green London E2
Telephone 01-980 6263

8th. July, 1969

Dear

Two slight changes in policy:-

1) Notes about the Unit The notes we gave you to give to anyone who is particularly interested either personally or professionally are slightly out of date and imply that we are asking general practitioners about individual patients. We have revised the notes and are sending you copies. Please be sure to use the new ones - dated July 1969 at the end - and destroy the old ones

2) Thank you letters We are anxious that people should have these as soon as possible so please will you either put them through the letter box yourself when you have completed and addressed them or post them the same day with a 5d. stamp

Both these points are important in maintaining good relationships with people, but of course it is your contact with them and the explanation that you give which are of primary importance. We have had one phone call from a relative who had not understood how we knew about her mother's death. Please be sure to explain this carefully - we had a random sample from the registerof deaths - and of course don't forget to stress that all the information is treated as confidential: it is not passed on to anyone else and no names are mentioned in reports.

With best wishes,

Yours sincerely,

Institute of Community Studies
Directors Michael Young MA PhD Peter Willmott BSc (Soc)
Treasurer Howard Dickinson FCA

Medical Care Research Unit
Research Director Ann Cartwright BSc PhD

Medical Care Research Unit

INSTITUTE OF COMMUNITY STUDIES

18 Victoria Park Square Bethnal Green London E2
Telephone 01-980 6263

About six weeks ago Dr. Horder wrote to you asking for your help with a study that we are doing of domiciliary care in terminal illness.

I realise that you have many demands on your time, but your personal views are very important to us, as we want to find out about the problems of home care in terminal illness from the point of view of general practitioners. I hope that you can find time to complete our questionnaire, and send it back as soon as possible.

All the information given to us will be treated with the strictest confidence, it will not be passed to anyone outside the Unit. We plan to write a book about the study, but it will not be possible to identify the people taking part; no names will be mentioned in it.

Thank you for your help.

Yours sincerely,

Ann Cartwright

Institute of Community Studies
Directors Michael Young MA PhD Peter Willmott BSc (Soc)
Treasurer Howard Dickinson FCA

Medical Care Research Unit
Research Director Ann Cartwright BSc PhD

Medical Care Research Unit

INSTITUTE
OF COMMUNITY
STUDIES

18 Victoria Park Square Bethnal Green London E2
Telephone 01-980 6263

2nd November

I am writing to you again about the study we are doing on domiciliary care in terminal illness, and sending you some notes about our unit and its work.

We are very conscious that general practitioners are busy people and have many requests for help. We would not be asking for your valuable time if we could get the information we need from other sources. But only general practitioners can tell about the problems they encounter in looking after patients at home and we are anxious to present the viewpoint of general practitioners in our analysis of the problems of domiciliary care in terminal illness. If you can find time to complete our questionnaire we would very much appreciate it.

Yours sincerely,

Lisbeth Hockey, S.R.N.,S.C.M.

Institute of Community Studies
Directors Michael Young MA PhD Peter Willmott BSc (Soc)
Treasurer Howard Dickinson FCA

Medical Care Research Unit
Research Director Ann Cartwright BSc PhD

INSTITUTE
OF COMMUNITY
STUDIES

Medical Care Research Unit

18 Victoria Park Square Bethnal Green London E2
Telephone 01-980 6263

Third reminder

Towards the end of last year Dr. Horder sent you a letter telling you about the study we are doing of domiciliary care in terminal illness, and asking for your help.

I realise that over the past few months you have been very busy with your patients and might not have had time to fill in the questionnaire and return it. I hope that you now have more time to complete it but should you not wish to do so it would be a great help to us if you could indicate this on the questionnaire and return it to us in the envelope we have provided for this purpose.

If you would like to receive results of the study, whether or not you have completed the questionnaire, please put a tick in the last box and I shall be pleased to send you the results when available.

Please accept our apologies if this has caused you any inconvenience.

Thank you for your help.

Yours sincerely,

Ann Cartwright

Institute of Community Studies
Directors Michael Young MA PhD Peter Willmott BSc (Soc)
Treasurer Howard Dickinson FCA

Medical Care Research Unit
Research Director Ann Cartwright BSc PhD

Medical Care Research Unit

INSTITUTE OF COMMUNITY STUDIES

18 Victoria Park Square Bethnal Green London E2
Telephone 01-980 6263

Thank you for your help in our study of domiciliary care in terminal illness.

The aims of this study are to describe the care given by relatives, doctors, district nurses and health visitors to terminally ill patients in their own homes; to discover any special problems they may have, and the extent and nature of any unmet need.

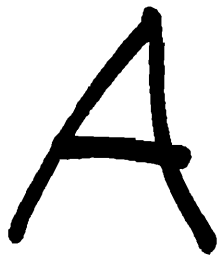
The study is based on a sample of deaths in twelve randomly selected areas (registration districts). We hope to interview the district nurses and health visitors in these districts who have given care to the dying or bereaved. I would like to stress that all the information given to us will be treated with the strictest confidence and not be passed on to anyone outside the Unit. We plan to write a book about the study, but it will not be possible to identify the people taking part; no names will be mentioned in it.

You may like to know that the Institute of Community Studies is a non-profit research organisation which has published a number of books about family life, and medical services. Several doctors and other experts have helped in planning this study and deciding what questions to ask.

Lisbeth Hockey, S.R.N.,S.C.M.,H.V.Tutor,
Queens Nurse

Institute of Community Studies
Director Michael Young MA PhD Peter Willmott BSc (Soc)
Treasurer Howard Dickinson FCA

Medical Care Research Unit
Research Director Ann Cartwright BSc PhD



LIFE BEFORE DEATH

Y38
Y39
Y45
Y46
Y47

)/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case Number	4 digit code	
1/5-6		CARD NUMBER	CARD 01	759
1/7-10		Serial Number	4 digit code (see attached list)	
1/11	1	Relationship of Informant to person who died		
			1 Husband/wife	292
			2 Father/mother	4
			3 Father-in-law/mother-in-law	-
			4 Son/daughter	229
			5 Son-in-law/daughter-in-law	49
			6 Grandchild	7
			7 Brother/sister	46
			8 Brother-in-law/sister-in-law	16
			9 Neighbour	20
			& Friend	32
			0 Official of institution	27
			- Other relative	37
		IF NOT A RELATIVE		
1/12	2	How long have you known him		
			1 Less than a year	4
			2 1 year - 2 years	8
			3 2 years - 5 years	13
			4 5 years - 10 years	9
			5 10 years - 15 years	1
			6 15 years - 20 years	3
			7 20 years or more	27
			8 Inadequate	14
			9 D.N.A.	680
		IF FRIEND OR NEIGHBOUR		
1/13	3	Would you say he was a close friend of yours or not		
			1 Yes, close friend	31
			2 No	14
			3 Inadequate	7
			4 D.N.A.	707
1/14	4	Marital status of deceased at time of death		
			1 Married	385
			2 Single	90
			3 Widowed	260
			4 Divorced/separated	12
			5 Inadequate	12

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/15	5	Death expected or not	1 Death expected 2 Death not expected - no previous illness or warning at all - e.g. unexpected heart attack or accident from which died within 24 hours 3 Intermediate/uncertain/ same illness or warning 4 Inadequate information	420 78 260 1
1/16-17	6	Cause of death	2 digit code (see Appendix 1) -- Inadequate/don't know	 28
1/18-28	7-17	Additional causes of death:-		
1/18	7	Neoplasms	1 Yes 0 Not mentioned	17 742
1/19	8	Circulatory and bad heart etc.	1 Yes 0 Not mentioned	66 693
1/20	9	Respiratory	1 Yes 0 Not mentioned	64 695
1/21	10	Symptoms except senility	1 Yes 0 Not mentioned	23 736
1/22	11	Accidents	1 Yes 0 Not mentioned	20 739
1/23	12	Digestive	1 Yes 0 Not mentioned	17 742
1/24	13	Senility old age	1 Yes 0 Not mentioned	30 729
1/25	14	Loneliness, lost the will to live	1 Yes 0 Not mentioned	8 751
1/26	15	Others	1 Yes 0 Not mentioned	80 679
1/27	16	No additional cause	1 Yes 0 Not mentioned	457 302
1/28	17	Don't know/uncertain	1 Yes 0 Not mentioned	37 722

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/29	18	Before he died was ..... ever completely bedridden IF YES how long was that for		
			0 Never	358
			1 Less than a week	84
			2 1 week < a month	151
			3 1 month < 3 months	89
			4 3 months < 6 months	35
			5 6 months < 1 year	14
			6 1 year or more	26
			7 Inadequate if ever bedridden	-
			8 Inadequate how long bedridden for	2
1/30	19	Before that: Was he confined mainly to bed IF YES how long was that for		
			0 No	540
			1 Less than a week	21
			2 1 week < a month	36
			3 1 month < 3 months	34
			4 3 months < 6 months	35
			5 6 months < 1 year	14
			6 1 year or more	42
			7 Inadequate if ever confined mainly to bed	9
			8 Inadequate how long confined to bed	2
			9 D.N.A.	26
1/31	20	Before that: Was he at all restricted in what he could do inside house		
			1 Yes - severely restricted	175
			2 Moderately	139
			3 A little	89
			4 Inadequate how much	10
			5 No - restricted outside	48
			6 Not restricted outside	200
			7 Inadequate if restricted outside	24
			8 Inadequate	6
			9 D.N.A. (bedridden or confined mainly to bed for a year or more)	68
1/32	21	Would you describe his health in the last 12 months as:-		
			1 Good	87
			2 Fair	48
			3 Poor	19
			4 Very poor	6
			5 Inadequate	40
			6 D.N.A.	559

RD/COLUMN	VAR No	TITLE	CODES		MARGINALS
1/33	22	For how long was he restricted in that way	1	Less than a week	1
			2	1 week < a month	9
			3	1 month < 3 months	29
			4	3 months < 6 months	46
			5	6 months < 1 year	67
			6	1 year or more	279
			7	Inadequate answer	20
			8	D.N.A.	308
1/34	23	Summary code on restriction (VARS. 18-22)	1	Bedridden 1 year or more	26
			2	Bedridden 3 months < 1 year	49
			3	Confined mainly to bed 3 months or more	77
			4	Severely restricted 3 months or more	125
			5	Moderately restricted 3 months or more	108
			6	A little restricted 3 months or more	65
			7	Other restriction 3 months or more	44
			8	Bedridden or confined mainly to bed for less than 3 months	108
			9	Severely or moderately restricted for less than 3 months	7
			&	Other, a little, or restricted outside less than 3 months	10
			0	None	121
			-	Inadequate information	19
1/35	24	How old was he when he died	1	Under 25	4
			2	25 - 34	3
			3	35 - 44	25
			4	45 - 54	57
			5	55 - 64	142
			6	65 - 69	118
			7	70 - 74	109
			8	75 - 79	109
			9	80 - 84	101
			0	85+	89
			-	Inadequate	2
1/36	25	Where died	1	Hospital	354
			2	Other institution	37
			3	Deceased own home	317
			4	Other person's home	22
			5	Other - e.g. street, work, ambulance, etc.	29
			6	Inadequate	-

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
		IF IN HOSPITAL OR OTHER INSTITUTION		
1/37	26	How long was he in hospital before he died	9 24 hours	45
			0 1 day < 3 days	39
			1 3 days < 1 week	46
			2 1 week < 1 month	94
			3 1 month < 3 months	66
			4 3 months < 6 months	28
			5 6 months < 1 year	4
			6 1 year < 2 years	18
			7 2 years < 5 years	28
			8 5 years+	23
			- Inadequate	-
			& D.N.A.	368
1/38	27	Classification of death	1 Long term institutional death	69
			2 Unexpected death of person under 65 with no previous restrictions	38
			3 Other death	634
			4 Other death - treated by interviewer as unspecified	18
			5 Inadequate	-
		IF LONG TERM INSTITUTIONAL DEATH		
1/39	28	Ever worked (outside of institution) how recently before died	1 Never	23
			2 1 year < 2 years	-
			3 2 years < 5 years	2
			4 5 years < 10 years	6
			5 10 years or more before death	28
			6 Inadequate how long, or if ever	10
			7 D.N.A.	690
		Had ..... been in hospital or other institution as an in-patient (on any other occasion) in the 12 months before he died		
1/40	29	IF YES how many times altogether in the last 12 months INCLUDE OCCASION ON WHICH DIED	0 Not at all	228
			1 One	281
			2 Two	117

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/40	29	continued...	3 Three 4 Four 5 Five+ 6 Inadequate if at all 7 Inadequate how many 8 D.N.A.	30 7 8 4 15 69
1/41	30	How long was he in hospital or institution altogether in the last twelve months including the time he died	1 Less than a week 2 1 week < 1 month 3 1 month < 3 months 4 3 months < 6 months 5 6 months < 9 months 6 9 months < 1 year 7 Inadequate - how long or if at all 8 D.N.A.	90 153 142 52 10 3 12 297
		IF DID NOT DIE IN HOSPITAL OR INSTITUTION		
1/42	31	How long before ..... died did he leave hospital (for the last time)	1 Less than a week 2 1 week < 1 month 3 1 month < 3 months 4 3 months < 6 months 5 6 months < 9 months 6 9 months < 1 year 7 Inadequate 8 D.N.A.	4 16 28 28 21 17 26 619
1/43-48	32-37	Did ..... have an operation or any other particular treatment while he was in hospital in the last 12 months:-		
1/43	32	Operation	1 Yes 0 Not mentioned	126 633
1/44	33	Radiotherapy, deep x-ray	1 Yes 0 Not mentioned	31 728
1/45	34	Not known (investigations)	1 Yes 0 Not mentioned	225 534
1/46	35	Other treatment	1 Yes 0 Not mentioned	136 623
1/47	36	Inadequate or don't know (whether deep x-ray or not)	1 Yes 0 Not mentioned	91 668

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/48	37	D.N.A.	1 Yes 0 Not mentioned	232 527
		Did you visit ..... while he was in hospital/institution		
1/49	38	IF YES about how many times during the last 12 months of his life	1 1-4 2 5-9 3 10-19 4 20-49 5 50+ 6 Not at all (visited person who had been in hospital more than a year ago but not in last 12 months 7 Inadequate how many times 8 Inadequate if visited 9 D.N.A. if respondent official in hospital/institution 0 BLANK	75 45 71 133 110 37 11 18 27 232
1/50	39	How long did it take you to get there	1 Less than 15 minutes 2 15 minutes-30 minutes 3 30 minutes-45 minutes 4 45 minutes-1 hour 5 1-2 hours 6 2 hours+ 7 Inadequate 8 D.N.A. 0 BLANK	79 160 80 49 40 20 17 82 232
1/51	40	What were the arrangements for visiting (when ..... was in hospital last)	1 Set times 2 Free visiting 3 Other 4 Inadequate 5 D.N.A. 0 BLANK	215 114 100 16 82 232
1/52	41	Did you feel the arrangements were satisfactory or not satisfactory	1 Satisfactory 2 Not satisfactory 3 Qualified, doubtful or uncertain 4 Inadequate 5 D.N.A. 0 BLANK	369 21 30 25 82 232

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/53	42	Did anyone (else) visit ..... while he was in hospital during the last 12 months of his life IF YES could you say about how many people	0 No	34
			1 One	23
			2 Two - four	170
			3 Five - nine	154
			4 Ten or more	99
			5 Inadequate how many	7
			6 Inadequate if anyone	40
			7 BLANK	232
1/54-64	43-53	Who visited ..... most often (you or someone else, who):-		
1/54	43	Respondent	1 Yes	353
			0 Not mentioned	406
		OTHER PERSONS		
1/55	44	Spouse of deceased	1 Yes	30
			0 Not mentioned	729
1/56	45	Parent or parent-in-law of deceased	1 Yes	4
			0 Not mentioned	755
1/57	46	Child or child-in-law of deceased	1 Yes	85
			0 Not mentioned	674
1/58	47	Grandchild of deceased	1 Yes	3
			0 Not mentioned	756
1/59	48	Sibling or sibling-in-law of deceased	1 Yes	22
			0 Not mentioned	737
1/60	49	Other relative of deceased	1 Yes	15
			0 Not mentioned	744
1/61	50	Friend or neighbour of deceased	1 Yes	11
			0 Not mentioned	748
1/62	51	Other person	1 Yes	3
			0 Not mentioned	756
1/63	52	Inadequate	1 Yes	24
			0 Not mentioned	735

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/64	53	D.N.A.	1 Yes 0 Not mentioned	74 685
1/65	54	Had ..... been to hospital as an outpatient during the last 12 months of his life. How many times	0 Not at all 1 Once 2 2-4 3 5-9 4 10-19 5 20+ 6 Inadequate how many times 7 Inadequate if went 8 D.N.A. Long term institutional death 9 BLANK	430 39 110 36 22 32 19 2 69 -
1/66	55	When was the most recent time before he died	1 Less than a week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 Inadequate 0 BLANK	14 49 77 61 31 26 501
1/67	56	How did he usually get there	1 Ambulance 2 Walk all way 3 Public transport 4 Private transport 5 Other 6 Inadequate 0 BLANK	82 11 59 93 6 7 501
1/68	57	Did anyone usually go with him	1 No 0 BLANK	96 663
1/69-79	58-68	IF YES Who:-		
1/69	58	Respondent	1 Yes 0 Not mentioned	106 653
1/70	59	Spouse	1 Yes 0 Not mentioned	79 680
1/71	60	Parent or parent-in-law	1 Yes 0 Not mentioned	1 758
1/72	61	Child or child-in-law	1 Yes 0 Not mentioned	48 711

RD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/73	62	Grandchild	1 Yes 0 Not mentioned	- 759
1/74	63	Sibling or sibling-in-law	1 Yes 0 Not mentioned	12 747
1/75	64	Other relatives	1 Yes 0 Not mentioned	4 755
1/76	65	Friend or neighbour	1 Yes 0 Not mentioned	13 746
1/77	66	Other person	1 Yes 0 Not mentioned	- 759
1/78	67	Inadequate who	1 Yes 0 Not mentioned	11 748
1/79	68	Inadequate if any	1 Yes 0 Not mentioned	5 754
1/80	69	How long did ..... (usually) have to spend at the hospital	1 Less than 30 minutes 2 30 mins - 1 hour 3 1 hour - 2 hours 4 2 hours - 3 hours 5 3 hours - 4 hours 6 4 hours - 5 hours 7 5 hours - 6 hours 8 6 hours or more 9 Inadequate 0 BLANK	24 74 60 45 15 7 3 5 25 501
2/1-4		Case Number	4 digit code	
2/5-6		CARD NUMBER	CARD 02	759
2/7	70	Were there any problems or difficulties about ..... going to out-patients. What	0 No problems 1 Something mentioned 2 Inadequate, don't know 3 BLANK	157 91 10 501
2/8-11	71-74	Did he go just for checks and advice or for particular treatment:-		
2/8	71	Checks and advice only (including investigation)	1 Yes 0 Not mentioned	153 606

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/9	72	Radio-therapy, deep x-ray	1 Yes 0 Not mentioned	27 732
2/10	73	Other treatment	1 Yes 0 Not mentioned	50 709
2/11	74	Inadequate or do not know whether deep x-ray or not	1 Yes 0 Not mentioned	34 725
2/12	75	Did anyone from a hospital come to visit ..... at home during the twelve months before he died IF YES did the general practitioner come at the same time	1 No 2 Yes 3 No 4 Inadequate if the G.P. came at the same time 5 Inadequate if had domiciliary visit 0 BLANK	560 40 49 5 35 70
2/13	76	.....'s general practitioner	1 N.H.S. 2 Private 3 Inadequate or no G.P. 0 BLANK	650 16 23 70
2/14	77	In the last 12 months before ..... died how often did his doctor - or a locum, partner, assistant or another general practitioner - see him at all either at home or in the surgery	0 Not at all 1 Once 2 2-4 3 5-9 4 10-19 5 20 or more 6 Inadequate how often 7 Inadequate if at all 8 BLANK	28 31 102 127 158 181 43 19 70

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/15	78	How many times did the G.P. (locum etc.) come to see him at home	0 Not at all 1 Once 2 2-4 3 5-9 4 10-19 5 20+ 6 Inadequate how often 7 Inadequate if at all 8 D.N.A. 9 BLANK	47 58 133 106 110 142 25 40 28 70
2/16	79	How many times did the G.P. (locum etc.) come and see him at night between 8p.m. and 8a.m.	0 Not at all 1 Once 2 2-4 3 5-9 4 10-19 5 20+ 6 Inadequate how often 7 Inadequate if at all 8 D.N.A. 9 BLANK	372 100 41 11 6 3 11 70 75 70
2/17	80	When was the last time ..... saw a general practitioner before he died	0 Within 24 hours 1 1 day - 1 week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year - 2 years 7 2 years - 5 years 8 5 years or more 9 Inadequate - BLANK	221 157 123 68 30 15 12 6 7 50 70
2/18	81	Did you personally have the same doctor as ..... then IF DIFFERENT DOCTOR Do you know .....'s doctor (or any of the doctors in that group) at all	1 Same doctor 2 Another doctor in same partnership 3 Yes 4 No 5 Different doctor, inadequate if knew him or partners 6 Inadequate if same doctor	447 30 131 67 2 12

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/18	81	continued...	0 BLANK	70
2/19	82	Overcode at above question	0 Used to have that doctor but has changed	12
			1 BLANK	747
2/20	83	Do you think ....'s doctor is an easy person to talk to or not	1 Easy	432
			2 Not easy	82
			3 Qualified, uncertain, sometimes (comments but no clear code)	61
			4 Inadequate	10
			5 D.N.A.	104
			0 BLANK	70
2/21	84	Do you think he has time to discuss things or not	1 Has time	386
			2 Not	93
			3 Qualified, uncertain, sometimes (comments but no clear code)	81
			4 Inadequate	25
			5 D.N.A.	104
			0 BLANK	70
2/22	85	Did ..... do any paid work in the 12 months before he died IF NO why was that	1 Yes	176
			2 Housewife and not worked 10+ years	202
			3 Retired	237
			4 Ill-health	62
			5 Other	8
			6 Inadequate if worked	1
			7 Inadequate why not	3
			0 BLANK	70
2/23	86	How old was he when he retired from his main job	1 Under 60	21
			2 60-64	54
			3 65-69	123
			4 70+	29
			5 Inadequate	10
			6 D.N.A.	62
			0 BLANK	460
2/24	87	IF UNDER 65 Did he retire early because of ill health or not	1 Yes	28
			2 No	42
			3 Inadequate	5
			4 D.N.A.	62
			0 BLANK	622

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/25	88	Did anyone advise him to give up work. Who	1 No-one	6
			2 G.P.	13
			3 Other medical practitioner	2
			4 Other	1
			5 Inadequate if anyone	4
			6 Inadequate who	2
			7 D.N.A.	62
			0 BLANK	669
2/26	89	IF ILL HEALTH When did he stop working because of ill health	1 1-2 years before death	22
			2 2-5 years	11
			3 5-10 years	11
			4 10 years or longer	15
			5 Never worked because of ill health	-
			6 Inadequate	3
			7 D.N.A.	-
			0 BLANK	697
2/27	90	IF ILL HEALTH How old was he then	1 Under 35	1
			2 35-44	8
			3 45-54	16
			4 55-59	16
			5 60-64	13
			6 65-69	5
			7 70+	1
			8 Inadequate	2
			9 D.N.A.	-
			0 BLANK	697
2/28	91	Did anyone advise him to give up work. Who	1 No-one	12
			2 G.P.	28
			3 Other medical practitioner	2
			4 Other	8
			5 Inadequate who	2
			6 Inadequate if advised	10
			7 D.N.A.	-
			0 BLANK	697
2/29	92	How recently before his death did he work	1 Within last week	55
			2 1 week - 1 month	24
			3 1 month - 3 months	33
			4 3 months - 6 months	37
			5 6 months+	24
			6 Inadequate	-
			7 D.N.A.	3
			0 BLANK	583

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/30	93	Had he actually given up his work or not	1 Given up 2 Not given up 3 Inadequate if given up 4 D.N.A. 0 BLANK	37 65 19 55 583
2/31	94	Was he working part-time or full-time then IF PART-TIME Why was that	1 Full-time 2 Housewife 3 Retired (semi) 4 Ill-health 5 Other 6 Inadequate if full or part-time 7 Inadequate why part-time 0 BLANK	122 12 17 18 1 3 3 583
2/32	95	Was that his main job or not IF NOT MAIN JOB Why did he give up his main job	1 Main job 2 Retired 3 Ill-health 4 Other 5 Inadequate if main job 6 Inadequate why given up 0 BLANK	129 15 18 4 10 - 583
2/33	96	How old was he when he gave up his main job	1 Under 60 2 60-64 3 65-69 4 70+ 5 Inadequate 6 D.N.A. 0 BLANK	16 5 14 - 2 139 583
2/34	97	Do you think ......'s work was ever a physical or mental strain or affected his health in any way	0 No 1 Yes, physical strain 2 Yes, mental strain 3 Yes, other 4 Yes, both mental and physical 5 Inadequate 6 D.N.A. 7 BLANK	291 89 42 10 28 24 274 1

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/35	98	Household Composition	1 On own	114
			2 With spouse only	220
			3 With spouse and child(ren) but no children-in-law	124
			4 With spouse and child(ren) and child (ren)-in-law with or without grandchild(ren)	12
			5 With child(ren) but no child(ren)-in-law	52
			6 With child(ren) and child(ren)-in-law with or without grand-children	93
			7 With other relatives of same generation only	43
			8 With unrelated people only (e.g. friend/landlady)	19
			9 Other three generation households	12
			& In guest house/old people's home/boarding house (no or inadequate information about where living before)	29
			0 Others	38
			- Inadequate	2
			BLANK	1
2/36	99	Who normally did the cooking and other housework	1 Deceased	95
			2 Respondent	332
			3 Deceased and respondent	77
			4 Other(s)	103
			5 Inadequate	6
			6 D.N.A. (lived alone or inadequate who lived with)	145
			0 BLANK	1
2/37	100	Main respondent in household	1 Yes	512
			2 No	132
			3 Inadequate	-
			4 D.N.A. (deceased lived alone)	114
			0 BLANK	1

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/38	101	Were there any changes in ....'s household arrangements after he became ill/as he got older	1 No	377
			2 Yes, someone came to live with him	36
			3 Yes, he went to live with someone else	54
			4 Others	227
			5 Inadequate if any change	8
			6 Inadequate what change	-
			0 BLANK	57
2/39	102	IF YES Before that did he live alone or with someone else	1 Alone	23
			2 Lived with spouse who died	11
			3 Lived with others	16
			4 Inadequate	5
			5 D.N.A.	647
			0 BLANK	57
2/40	103	How long had ..... been living in the same house/ flat before he died/went into hospital	1 Less than a year	42
			2 1 year - 2 years	28
			3 2 years - 5 years	99
			4 5 years - 10 years	93
			5 10 years - 20 years	144
			6 20 years - 50 years	235
			7 50 years+	43
			8 Inadequate	18
			0 BLANK	57
2/41	104	And for how long had he been living alone/with just the same person/ people	1 Less than a year	68
			2 1-2 years	43
			3 2-5 years	116
			4 5-10 years	128
			5 10 years+	326
			6 Inadequate	21
			0 BLANK	57

RD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/42	105	Would you say that .....'s house/flat was very convenient, fairly convenient, or rather inconvenient for him after he became ill/old	1 Very convenient 2 Fairly convenient 3 Rather inconvenient 4 Inadequate 0 BLANK	412 144 113 33 57
2/43	106	Were the rooms or furniture moved around at all because of .....'s illness/old age IF YES Did it affect other people at all	1 No 2 Yes 3 No 4 Inadequate if it affected other people 5 Inadequate if anything moved 0 BLANK	459 79 124 9 31 57
2/44	107	Did .....'s house/flat have its own bathroom or was it shared with other people not in the same household	1 None 2 Own with running hot and cold water 3 Own without running hot and cold water 4 Shared with running hot and cold water 5 Shared without hot and cold water 6 Own, don't know whether running hot and cold water 7 Shared, don't know whether running hot and cold water 8 Inadequate 0 BLANK	102 536 11 15 1 13 - 24 57
2/45	108	And did it have its own indoor lavatory or was that shared or outside	1 Own indoor 2 Shared indoor 3 Outside 4 Inadequate 0 BLANK	528 15 133 26 57

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/46	109	How many steps or floors were there between:- ground level and ....'s bedroom		
			0 No steps or floors	269
			1 1 floor	373
			2 2 floors	6
			3 3 floors	4
			4 4 floors	2
			5 5+ floors	2
			6 Steps but less than 1 floor	17
			7 Inadequate	29
			8 BLANK	57
2/47	110	Overcode at above question		
			1 Lift is recorded	5
			0 BLANK	754
2/48	111	How many steps or floors were there between ....'s bedroom and lavatory		
			0 No steps or floors	458
			1 1 floor	171
			2 2 floors	3
			3 3 floors	-
			4 4 floors	-
			5 5+ floors	-
			6 Steps but less than 1 floor	41
			7 Inadequate	27
			9 More than one answer recorded	1
			8 BLANK	58
2/49	112	Overcode at above question		
			1 Change in arrangements	138
			0 BLANK	621
2/50-60	113-123	Did have to put up with any of these in the last 12 months of his life:-		
		1ST GROUP		
2/50	113	Pain	1 Yes	494
			0 Not mentioned	265
2/51	114	Sleeplessness	1 Yes	367
			0 Not mentioned	392
2/52	115	Loss of bladder control	1 Yes	238
			0 Not mentioned	521
2/53	116	Loss of bowel control	1 Yes	209
			0 Not mentioned	550

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/54	117	Smell	1 Yes 0 Not mentioned	115 644
2/55	118	Vomiting	1 Yes 0 Not mentioned	224 535
2/56	119	Loss of appetite	1 Yes 0 Not mentioned	356 403
2/57	120	Constipation	1 Yes 0 Not mentioned	211 548
2/58	121	Some inadequate	1 Yes 0 Not mentioned	55 704
2/59	122	None	1 Yes 0 Not mentioned	62 697
2/60	123	Inadequate if any	1 Yes 0 Not mentioned	8 751
2/61-70	124-133	Did ..... have to put up with any of these in the last 12 months of his life:- 2ND GROUP		
2/61	124	Bedsores	1 Yes 0 Not mentioned	121 638
2/62	125	Mental confusion	1 Yes 0 Not mentioned	273 486
2/63	126	Trouble breathing	1 Yes 0 Not mentioned	335 424
2/64	127	Depression	1 Yes 0 Not mentioned	269 490
2/65	128	Other 1	1 Yes 0 Not mentioned	182 577
2/66	129	Other 2	1 Yes 0 Not mentioned	13 746
2/67	130	Other 3	1 Yes 0 Not mentioned	3 756
2/68	131	Some inadequate	1 Yes 0 Not mentioned	35 724
2/69	132	None	1 Yes 0 Not mentioned	107 652

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/70	133	Inadequate if any	1 Yes 0 Not mentioned	7 752
2/71	134	Total number of symptoms	0 None 1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Eight 9 Nine & 10+ - Inadequate BLANK	26 55 87 78 103 95 77 64 59 27 25 5 58
2/72-80 to 3/7	135-144	Can you tell me how ..... coped with any soiled bed linen:-		
2/72	135	Special laundry service	1 Yes 0 Not mentioned	14 745
2/73	136	Ordinary laundry	1 Yes 0 Not mentioned	15 744
2/74	137	Launderette	1 Yes 0 Not mentioned	12 747
2/75	138	Washed in home by hand	1 Yes 0 Not mentioned	59 700
2/76	139	Washed in home by machine	1 Yes 0 Not mentioned	88 671
2/77	140	Disposable pads	1 Yes 0 Not mentioned	79 680
2/78	141	Disposable sheets	1 Yes 0 Not mentioned	34 725
2/79	142	Other	1 Yes 0 Not mentioned	42 717
2/80	143	Inadequate	1 Yes 0 Not mentioned	19 740
3/1-4		Case Number	4 digit code	
3/5-6		CARD NUMBER	CARD 03	759

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
		Continued from CARD 02		
3/7	144	D.N.A. (Loss of bowel/ bladder control in hospital but not at home)	1 Yes 0 Not mentioned	471 288
3/8-16	145-153	Disposable, how did ..... get rid of them:-		
3/8	145	Burning indoors in fire place	1 Yes 0 Not mentioned	26 733
3/9	146	Burning indoors in a stove	1 Yes 0 Not mentioned	11 748
3/10	147	Burning outdoors on open fire	1 Yes 0 Not mentioned	19 740
3/11	148	Burning outdoors in incinerator	1 Yes 0 Not mentioned	29 730
3/12	149	Dustbin	1 Yes 0 Not mentioned	19 740
3/13	150	Special collections	1 Yes 0 Not mentioned	- 759
3/14	151	Other	1 Yes 0 Not mentioned	6 753
3/15	152	Inadequate	1 Yes 0 Not mentioned	7 752
3/16	153	D.N.A.	1 Yes 0 Not mentioned	593 166
3/17	154	Was this a problem at all	1 Yes 2 No 3 Inadequate 4 D.N.A. 0 BLANK	17 75 16 593 58
3/18	155	Summary of distress	1 Symptoms very distressing 2 Symptoms fairly distressing 3 Symptoms not very distressing 4 Inadequate how distressing 5 D.N.A. (no symptoms at all) 0 BLANK	504 92 54 20 31 58

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/19	156	Summary of length of time of symptoms experience	1 Any symptoms for 1 year+	469
			2 Any symptoms for 6 months < 1 year	67
			3 Any symptoms for 3 months < 6 months	57
			4 Any symptoms for 1 month < 3 months	35
			5 Any symptoms for 1 week 1 month	18
			6 Less than a week	16
			7 Inadequate how long	8
			8 D.N.A. (no symptoms at all)	31
			0 BLANK	58
3/20-31	157-168	Needing helpers whether got it or not with:-		
3/20	157	To be lifted at all	1 Yes	330
			0 Not mentioned	429
3/21	158	Help with washing or shaving	1 Yes	369
			0 Not mentioned	390
3/22	159	Getting in or out of bath	1 Yes	207
			0 Not mentioned	552
3/23	160	Dressing or undressing	1 Yes	284
			0 Not mentioned	475
3/24	161	Getting in or out of bed	1 Yes	300
			0 Not mentioned	459
3/25	162	Getting hair washed at home	1 Yes	250
			0 Not mentioned	509
3/26	163	Cutting toenails	1 Yes	332
			0 Not mentioned	427
3/27	164	Giving bedpan or bottle	1 Yes	169
			0 Not mentioned	590
3/28	165	Getting to lavatory or commode	1 Yes	296
			0 Not mentioned	463
3/29	166	None of these	1 Yes	146
			0 Not mentioned	613
3/30	167	Inadequate to whole group	1 Yes	11
			0 Not mentioned	748

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/31	168	Inadequate to certain ones	1 Yes 0 Not mentioned	18 741
3/32-41	169-178	Needing helpers whether got it or not with:-		
3/32	169	Giving medicines or tablets	1 Yes 0 Not mentioned	308 451
3/33	170	Injections	1 Yes 0 Not mentioned	136 623
3/34	171	Bandaging or other dressing	1 Yes 0 Not mentioned	99 660
3/35	172	Regular temperature taking	1 Yes 0 Not mentioned	30 729
3/36	173	Massaging/exercises	1 Yes 0 Not mentioned	84 675
3/37	174	Enema	1 Yes 0 Not mentioned	38 721
3/38	175	Any other nursing procedure	1 Yes 0 Not mentioned	67 692
3/39	176	None of these	1 Yes 0 Not mentioned	223 536
3/40	177	Inadequate to all	1 Yes 0 Not mentioned	11 748
3/41	178	Inadequate to some	1 Yes 0 Not mentioned	9 750
3/42-51	179-188	Help needed at night with:-		
3/42	179	Help to get to the toilet	1 Yes 0 Not mentioned	113 646
3/43	180	Bedpan	1 Yes 0 Not mentioned	68 691
3/44	181	Medicines that had to be taken then	1 Yes 0 Not mentioned	94 665

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/45	182	Injections or other treatment	1 Yes 0 Not mentioned	12 747
3/46	183	Drinks	1 Yes 0 Not mentioned	181 578
3/47	184	Company	1 Yes 0 Not mentioned	187 572
3/48	185	Other	1 Yes 0 Not mentioned	62 697
3/49	186	No help needed at night	1 Yes 0 Not mentioned	298 461
3/50	187	Inadequate if any help needed at night	1 Yes 0 Not mentioned	17 742
3/51	188	Inadequate what sort of help needed at night	1 Yes 0 Not mentioned	36 723
3/52-59	189-196	Help needed with:-		
3/52	189	Someone to take him out	1 Yes 0 Not mentioned	207 552
3/53	190	Someone to read to him	1 Yes 0 Not mentioned	50 709
3/54	191	Someone to write letters for him	1 Yes 0 Not mentioned	131 628
3/55	192	Someone to collect his pension	1 Yes 0 Not mentioned	335 424
3/56	193	Someone to change his library books	1 Yes 0 Not mentioned	85 674
3/57	194	None of these	1 Yes 0 Not mentioned	206 553
3/58	195	Inadequate to all	1 Yes 0 Not mentioned	12 747
3/59	196	Inadequate to some	1 Yes 0 Not mentioned	4 755

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/60	197	Needed financial help	1 Yes 2 No 3 Don't know 0 BLANK	145 466 21 127
3/61-69	198-206	IF DECEASED OR RESPONDENT HOUSEWIFE. Did you or he need help with:-		
3/61	198	Shopping	1 Yes 0 Not mentioned	304 455
3/62	199	Preparing/cooking food	1 Yes 0 Not mentioned	235 524
3/63	200	Cleaning house	1 Yes 0 Not mentioned	289 470
3/64	201	Washing clothes	1 Yes 0 Not mentioned	270 489
3/65	202	Looking after other members of the family, children, anyone	1 Yes 0 Not mentioned	46 713
3/66	203	None of these	1 Yes 0 Not mentioned	222 537
3/67	204	Inadequate to all	1 Yes 0 Not mentioned	10 749
3/68	205	Inadequate to some	1 Yes 0 Not mentioned	2 757
3/69	206	D.N.A. (Neither deceased nor respondent housewife)	1 Yes 0 Not mentioned	36 723
3/70-79	207-216	Groups of help needed:-		
3/70	207	Personal	1 Yes 0 Not mentioned	474 285
3/71	208	Nursing	1 Yes 0 Not mentioned	397 362
3/72	209	Night	1 Yes 0 Not mentioned	316 443
3/73	210	Social	1 Yes 0 Not mentioned	412 347
3/74	211	Financial	1 Yes 0 Not mentioned	145 614

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/75	212	Housework	1 Yes 0 Not mentioned	358 401
3/76	213	Family	1 Yes 0 Not mentioned	46 713
3/77	214	None	1 Yes 0 Not mentioned	62 697
3/78	215	Inadequate to all	1 Yes 0 Not mentioned	9 750
3/79	216	Inadequate to some	1 Yes 0 Not mentioned	12 747
3/80		U N U S E D	U N U S E D	-
4/1-4		Case Number	4 digit code	
4/5-6		CARD NUMBER	CARD 04	759
4/7-8	217	Number of different types of help needed	2 digit code -- Inadequate BLANK	 9 127
4/9-19	218-228	Help needed which did not get:-		
4/9	218	Personal	1 Yes 0 Not mentioned	127 632
4/10	219	Nursing	1 Yes 0 Not mentioned	41 718
4/11	220	Night	1 Yes 0 Not mentioned	56 703
4/12	221	Social	1 Yes 0 Not mentioned	35 724
4/13	222	Financial	1 Yes 0 Not mentioned	46 713
4/14	223	Housework	1 Yes 0 Not mentioned	116 643
4/15	224	Family	1 Yes 0 Not mentioned	8 751
4/16	225	Inadequate if got any help	1 Yes 0 Not mentioned	9 750
4/17	226	Inadequate if got some if help needed	1 Yes 0 Not mentioned	222 537

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/18	227	Had enough help with all things needed it for	1 Yes 0 Not mentioned	321 438
4/19	228	D.N.A. did not need any help	1 Yes 0 Not mentioned	70 689
4/20-29	229-238	Who asked for help:-		
4/20	229	No one at all	1 Yes 0 Not mentioned	118 641
4/21	230	Asked for some not others	1 Yes 0 Not mentioned	40 719
4/22	231	Asked G.P.	1 Yes 0 Not mentioned	32 727
4/23	232	Friends or relatives	1 Yes 0 Not mentioned	5 754
4/24	233	Hospital	1 Yes 0 Not mentioned	4 755
4/25	234	L.H.A. Home Help organisations/Supervisors Welfare Department	1 Yes 0 Not mentioned	23 736
4/26	235	Social Security	1 Yes 0 Not mentioned	11 748
4/27	236	Other professional or voluntary sources	1 Yes 0 Not mentioned	18 741
4/28	237	Inadequate if asked for help	1 Yes 0 Not mentioned	48 711
4/29	238	D.N.A.	1 Yes 0 Not mentioned	401 358
4/30	239	The longest period over which the deceased had/ needed personal help of any kind	1 Less than a week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year+ 7 Inadequate to all 8 D.N.A. (no personal help needed) 0 BLANK	51 63 70 40 25 187 39 157 127

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/31	240	Overcode at above question	1 Don't know to some 0 BLANK	27 732
4/32	241	The longest period over which the deceased had/ needed help at night of any kind	1 Less than a week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year+ 7 Inadequate to all 8 D.N.A. (no night help needed) 0 BLANK	77 68 45 22 14 33 58 315 127
4/33	242	Overcode at above question	1 Don't know to some 0 BLANK	2 757
4/34-45	243-254	Equipment needed		
		1ST ANSWER		
4/34	243	Back rest	1 Yes 0 Not mentioned	115 644
4/35	244	Hoist	1 Yes 0 Not mentioned	17 742
4/36	245	Special bed	1 Yes 0 Not mentioned	23 736
4/37	246	Wheel chair	1 Yes 0 Not mentioned	67 692
4/38	247	Crutches/stick/walking aid	1 Yes 0 Not mentioned	124 635
4/39	248	Commode	1 Yes 0 Not mentioned	206 553
4/40	249	Hearing aid	1 Yes 0 Not mentioned	48 711
4/41	250	Bedpan or bottle	1 Yes 0 Not mentioned	192 567
4/42	251	Other	1 Yes 0 Not mentioned	88 671
4/43	252	None of these	1 Yes 0 Not mentioned	13 746

RD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/44	253	Inadequate to all question	1 Yes 0 Not mentioned	15 744
4/45	254	Inadequate to part	1 Yes 0 Not mentioned	30 729
4/46-50	255-259	Equipment needed		
		2ND ANSWER		
4/46	255	Mackintosh sheet	1 Yes 0 Not mentioned	178 581
4/47	256	Pads to protect bed	1 Yes 0 Not mentioned	116 643
4/48	257	Extra linen	1 Yes 0 Not mentioned	71 688
4/49	258	None of these (including D.N.A. because no loss of bowel/bladder control	1 Yes 0 Not mentioned	210 549
4/50	259	Inadequate if needed these or inadequate if had loss of bladder or bowel control	1 Yes 0 Not mentioned	16 743
4/51-58	260-267	Whether got back rest, hoist or special bed or other furniture:-		
4/51	260	Not got	1 Yes 0 Not mentioned	42 717
4/52	261	Bought	1 Yes 0 Not mentioned	48 711
4/53	262	Borrowed	1 Yes 0 Not mentioned	38 721
4/54	263	Given or supplied	1 Yes 0 Not mentioned	59 700
4/55	264	Already had them	1 Yes 0 Not mentioned	21 738
4/56	265	Other (hired, made)	1 Yes 0 Not mentioned	7 752

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/57	266	Inadequate	1 Yes 0 Not mentioned	8 751
4/58	267	D.N.A. not needed or inadequate if needed	1 Yes 0 Not mentioned	221 538
4/59-62	268-271	How did they get them:-		
4/59	268	By relative	1 Yes 0 Not mentioned	7 752
4/60	269	By friend/neighbours	1 Yes 0 Not mentioned	14 745
4/61	270	Chemist, voluntary or official sources	1 Yes 0 Not mentioned	82 677
4/62	271	Inadequate	1 Yes 0 Not mentioned	4 755
4/63-70	272-279	Whether got invalid car, wheel chair:-		
4/63	272	Not got	1 Yes 0 Not mentioned	14 745
4/64	273	Bought	1 Yes 0 Not mentioned	9 750
4/65	274	Borrowed	1 Yes 0 Not mentioned	14 745
4/66	275	Given or supplied	1 Yes 0 Not mentioned	26 733
4/67	276	Already had them	1 Yes 0 Not mentioned	1 758
4/68	277	Other, hired, made	1 Yes 0 Not mentioned	- 759
4/69	278	Inadequate	1 Yes 0 Not mentioned	3 756
4/70	279	D.N.A. not needed or inadequate if needed	1 Yes 0 Not mentioned	341 418
4/71-74	280-283	How did they get them		
4/71	280	By relatives	1 Yes 0 Not mentioned	- 759

ARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/72	281	By friends/neighbours	1 Yes 0 Not mentioned	2 757
4/73	282	Chemist, voluntary or official sources	1 Yes 0 Not mentioned	37 722
4/74	283	Inadequate	1 Yes 0 Not mentioned	3 756
4/75-80 to 5/7-8	284-291	Whether got crutches or stick or walking aid:-		
4/75	284	Not got	1 Yes 0 Not mentioned	1 758
4/76	285	Bought	1 Yes 0 Not mentioned	23 736
4/77	286	Borrowed	1 Yes 0 Not mentioned	9 750
4/78	287	Given or supplied	1 Yes 0 Not mentioned	37 722
4/79	288	Already had them	1 Yes 0 Not mentioned	46 713
4/80	289	Other, hired, made	1 Yes 0 Not mentioned	3 756
5/1-4		Case Number	4 digit code	
5/5-6		CARD NUMBER	CARD 05	759
		Continued from CARD 04		
5/7	290	Inadequate	1 Yes 0 Not mentioned	6 753
5/8	291	D.N.A. Not needed - or inadequate if needed	1 Yes 0 Not mentioned	284 475
5/9-12	292-295	How did they get them:-		
5/9	292	By relative	1 Yes 0 Not mentioned	3 756
5/10	293	By friends/neighbours	1 Yes 0 Not mentioned	5 754

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
5/11	294	Chemist, voluntary or official sources	1 Yes 0 Not mentioned	41 718
5/12	295	Inadequate	1 Yes 0 Not mentioned	3 756
5/13-20	296-303	Whether got commode:-		
5/13	296	Not got	1 Yes 0 Not mentioned	15 744
5/14	297	Bought	1 Yes 0 Not mentioned	43 716
5/15	298	Borrowed	1 Yes 0 Not mentioned	45 714
5/16	299	Given or supplied	1 Yes 0 Not mentioned	27 732
5/17	300	Already had one	1 Yes 0 Not mentioned	68 691
5/18	301	Other, hired, made	1 Yes 0 Not mentioned	6 753
5/19	302	Inadequate	1 Yes 0 Not mentioned	6 753
5/20	303	D.N.A. Not needed or inadequate if needed	1 Yes 0 Not mentioned	200 559
5/21-24	304-307	How did they get it:-		
5/21	304	By relatives	1 Yes 0 Not mentioned	9 750
5/22	305	By friends/neighbours	1 Yes 0 Not mentioned	26 733
5/23	306	Chemist, voluntary or unofficial source	1 Yes 0 Not mentioned	38 721
5/24	307	Inadequate	1 Yes 0 Not mentioned	6 753
5/25-32	308-315	Whether they got hearing aid:-		
5/25	308	Not got	1 Yes 0 Not mentioned	5 754

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
5/26	309	Bought	1 Yes 0 Not mentioned	12 747
5/27	310	Borrowed	1 Yes 0 Not mentioned	- 759
5/28	311	Given or supplied	1 Yes 0 Not mentioned	24 735
5/29	312	Already had one	1 Yes 0 Not mentioned	4 755
5/30	313	Other, hired, made	1 Yes 0 Not mentioned	- 759
5/31	314	Inadequate	1 Yes 0 Not mentioned	5 754
5/32	315	D.N.A. Not needed or inadequate if needed	1 Yes 0 Not mentioned	359 400
5/33-36	316-319	How did they get it:-		
5/33	316	By relative	1 Yes 0 Not mentioned	- 759
5/34	317	By friends/neighbours	1 Yes 0 Not mentioned	- 759
5/35	318	Chemist, voluntary or official sources	1 Yes 0 Not mentioned	26 733
5/36	319	Inadequate	1 Yes 0 Not mentioned	1 758
5/37-44	320-327	Whether got bedpan or bottle:-		
5/37	320	Not got	1 Yes 0 Not mentioned	11 748
5/38	321	Bought	1 Yes 0 Not mentioned	65 694
5/39	322	Borrowed	1 Yes 0 Not mentioned	41 718
5/40	323	Given or supplied	1 Yes 0 Not mentioned	39 720
5/41	324	Already had them	1 Yes 0 Not mentioned	31 728

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
5/42	325	Other, hired, made	1 Yes 0 Not mentioned	2 757
5/43	326	Inadequate	1 Yes 0 Not mentioned	7 752
5/44	327	D.N.A. Not needed or inadequate if needed	1 Yes 0 Not mentioned	215 544
5/45-48	328-331	How did they get them:-		
5/45	328	By relative	1 Yes 0 Not mentioned	3 756
5/46	329	By friends/neighbours	1 Yes 0 Not mentioned	12 747
5/47	330	Chemist, voluntary or official sources	1 Yes 0 Not mentioned	61 698
5/48	331	Inadequate	1 Yes 0 Not mentioned	8 751
5/49-56	332-339	Whether got mackintosh sheet, pads, extra linen:-		
5/49	332	Not got	1 Yes 0 Not mentioned	16 743
5/50	333	Bought	1 Yes 0 Not mentioned	71 688
5/51	334	Borrowed	1 Yes 0 Not mentioned	22 737
5/52	335	Given or supplied	1 Yes 0 Not mentioned	90 669
5/53	336	Already had them	1 Yes 0 Not mentioned	67 692
5/54	337	Other, hired, made	1 Yes 0 Not mentioned	- 759
5/55	338	Inadequate	1 Yes 0 Not mentioned	11 748
5/56	339	D.N.A. Not needed or inadequate if needed	1 Yes 0 Not mentioned	209 550
5/57-60	340-343	How did they get them:-		

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
5/57	340	By relative	1 Yes 0 Not mentioned	11 748
5/58	341	By friends/neighbours	1 Yes 0 Not mentioned	9 750
5/59	342	Chemist, voluntary or official sources	1 Yes 0 Not mentioned	93 666
5/60	343	Inadequate	1 Yes 0 Not mentioned	9 750
5/61-65	344-348	Summary who helped with equipment include help with other equipment:-		
5/61	344	By relatives	1 Yes 0 Not mentioned	32 727
5/62	345	By friends/neighbours	1 Yes 0 Not mentioned	55 704
5/63	346	Voluntary or official source	1 Yes 0 Not mentioned	221 538
5/64	347	Inadequate	1 Yes 0 Not mentioned	25 734
5/65	348	D.N.A. No equipment borrowed, given or supplied	1 Yes 0 Not mentioned	136 623
5/66	349	IF HAD A WHEELCHAIR Did he use it:-	1 Indoors only 2 Outdoors only 3 Both 4 Inadequate 5 D.N.A. (did not use, did not have, or unknown)if had wheelchair) 0 BLANK	8 17 15 10 582 127
5/67-70	350-353	Was it:-		
5/67	350	Motorised	1 Yes 0 Not mentioned	- 759
5/68	351	Self-propelled	1 Yes 0 Not mentioned	9 750

RD/COLUMN	VAR No	TITLE	CODES	MARGINALS
5/69	352	Pushed by other person	1 Yes 0 Not mentioned	34 725
5/70	353	Inadequate	1 Yes 0 Not mentioned	8 751
5/71-77	354-360	Equipment had:-		
5/71	354	Washing machine	1 Yes 0 Not mentioned	332 427
5/72	355	Spin dryer	1 Yes 0 Not mentioned	263 496
5/73	356	Car	1 Yes 0 Not mentioned	212 547
5/74	357	Telephone	1 Yes 0 Not mentioned	205 554
5/75	358	None of these	1 Yes 0 Not mentioned	177 582
5/76	359	Inadequate to all	1 Yes 0 Not mentioned	50 709
5/77	360	Inadequate to part	1 Yes 0 Not mentioned	3 756
5/78-80 to 6/7-11	361-368	Equipment it would have been useful to have:-		
5/78	361	Washing machine	1 Yes 0 Not mentioned	76 683
5/79	362	Spin dryer	1 Yes 0 Not mentioned	111 648
5/80	363	Car	1 Yes 0 Not mentioned	91 668
6/1-4		Case Number	4 digit code	
6/5-6		CARD NUMBER	CARD 06	759
		Continued from CARD 05		
6/7	364	Telephone	1 Yes 0 Not mentioned	182 577
6/8	365	None	1 Yes 0 Not mentioned	212 547

ARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/9	366	Inadequate to all	1 Yes 0 Not mentioned	65 694
6/10	367	Inadequate to part	1 Yes 0 Not mentioned	4 755
6/11	368	D.N.A. has (VARS. 354-357)	1 Yes 0 Not mentioned	100 659
6/12-19	369-376	Equipment it was useful to have:-		
6/12	369	Washing machine	1 Yes 0 Not mentioned	285 474
6/13	370	Spin dryer	1 Yes 0 Not mentioned	231 528
6/14	371	Car	1 Yes 0 Not mentioned	187 572
6/15	372	Telephone	1 Yes 0 Not mentioned	189 570
6/16	373	None	1 Yes 0 Not mentioned	29 730
6/17	374	Inadequate to all	1 Yes 0 Not mentioned	60 699
6/18	375	Inadequate to part	1 Yes 0 Not mentioned	7 752
6/19	376	D.N.A. (VAR. 358)	1 Yes 0 Not mentioned	176 583
6/20	377	Was there any (other) piece of equipment it would have been helpful for ..... to have	1 Yes 2 No 3 Inadequate 0 BLANK	111 437 84 127
6/21	378	Do you know of any organisation or people who help with getting equipment for invalids	1 No 2 Inadequate if knows of any 3 D.N.A. no equipment used or needed 0 BLANK	87 39 224 409

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/22-30	379-387	IF YES who:-		
6/22	379	Red Cross, St. John's Ambulance	1 Yes 0 Not mentioned	78 681
6/23	380	W&V.S. and other known Voluntary Association, Cancer Research	1 Yes 0 Not mentioned	35 724
6/24	381	Local authority health and welfare department	1 Yes 0 Not mentioned	73 686
6/25	382	District Nursing Centre, District nurses	1 Yes 0 Not mentioned	86 673
6/26	383	Hospital - Almoner, Medical Social Worker (Hospital)	1 Yes 0 Not mentioned	47 712
6/27	384	National Assistance, Social Security, N.A.B.	1 Yes 0 Not mentioned	11 748
6/28	385	N.H.S. Ministry of Health - vague general comments	1 Yes 0 Not mentioned	29 730
6/29	386	Other (Chemist, doctor, vicar, priest, laundry service, church, etc., Co-op Guild)	1 Yes 0 Not mentioned	47 712
6/30	387	Inadequate what organisation	1 Yes 0 Not mentioned	6 753
6/31-41	388-398	Additional expenditure incurred:- by deceased (or subject if subject in same household)		
6/31	388	Heating	1 Yes 0 Not mentioned	235 524
6/32	389	Laundry	1 Yes 0 Not mentioned	119 640
6/33	390	Special food	1 Yes 0 Not mentioned	140 619

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/34	391	Extra help	1 Yes 0 Not mentioned	66 693
6/35	392	Prescription charges	1 Yes 0 Not mentioned	102 657
6/36	393	Other medicines	1 Yes 0 Not mentioned	75 684
6/37	394	Fares, petrol	1 Yes 0 Not mentioned	224 535
6/38	395	Equipment	1 Yes 0 Not mentioned	162 597
6/39	396	Anything else	1 Yes 0 Not mentioned	57 702
6/40	397	None of these	1 Yes 0 Not mentioned	164 595
6/41	398	Inadequate	1 Yes 0 Not mentioned	67 692
6/42-53	399-410	Additional expenditure incurred:- by subject if subject in different household		
6/42	399	Heating	1 Yes 0 Not mentioned	7 752
6/43	400	Laundry	1 Yes 0 Not mentioned	9 750
6/44	401	Special food	1 Yes 0 Not mentioned	11 748
6/45	402	Extra help	1 Yes 0 Not mentioned	3 756
6/46	403	Prescription charges	1 Yes 0 Not mentioned	1 758
6/47	404	Other medicines	1 Yes 0 Not mentioned	2 757
6/48	405	Fares, petrol	1 Yes 0 Not mentioned	59 700
6/49	406	Equipment	1 Yes 0 Not mentioned	5 754
6/50	407	Anything else	1 Yes 0 Not mentioned	11 748

ARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/51	408	None of these	1 Yes 0 Not mentioned	82 677
6/52	409	Inadequate	1 Yes 0 Not mentioned	35 724
6/53	410	D.N.A. subject in same household as deceased	1 Yes 0 Not mentioned	443 316
6/54	411	Easy to find extra money. Deceased	1 D.N.A. 2 Easy for deceased (or subject if in same household) 3 Not easy for deceased (or subject if in same household) 4 Inadequate 5 More than one answer recorded 0 BLANK	186 250 138 33 1 151
6/55	412	Easy to find extra money. Subject	1 Easy for subject in different household 2 Not easy for subject in different household 3 Inadequate if easy or not 0 BLANK	64 20 8 667
6/56-60	413-417	If not easy for deceased (or subject if in same household) or not easy for subject in different household, or inadequate. Why:		
6/56	413	Didn't ask anyone	1 Yes 0 Not mentioned	102 657
6/57	414	Asked N.A.B. Social Security	1 Yes 0 Not mentioned	37 722
6/58	415	Asked other officials	1 Yes 0 Not mentioned	12 747
6/59	416	Asked friends or relatives	1 Yes 0 Not mentioned	5 754

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/60	417	Inadequate who or if asked	1 Yes 0 Not mentioned	6 753
6/61	418	Do you know where people can sometimes get help with extra money and other things they need to look after invalids	1 No 2 Inadequate if knows 3 D.N.A. No extra expenditure or inadequate if any extra expenditure 0 BLANK	158 57 186 358
6/62-64	419-421	IF YES Where:-		
6/62	419	N.A.B. Social Security. Public assistance	1 Yes 0 Not mentioned	192 567
6/63	420	Other	1 Yes 0 Not mentioned	41 718
6/64	421	Inadequate where	1 Yes 0 Not mentioned	4 755
6/65	422	How much did it cost you to visit ..... there and back	1 Less than 2/- 2 2/- less than 5/- 3 5/- less than 10/- 4 10/- + 5 Inadequate 6 D.N.A. No or inadequate if extra expenditure on fares or petrol 0 BLANK	41 104 47 43 40 357 127
		PERSON WHO BORE BRUNT		
6/66	423	or did most looking after deceased	1 Respondent 2 Lives in same household 3 Respondent/lives in same household 4 Female 5 Respondent/female 6 Female/lives in same household 7 Female/respondent/ lives in same household	13 10 93 9 55 60 280

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/66	423	continued...	8 Other person (not respondent, female or in same household)	6
			9 None	98
			- Inadequate	7
			0 BLANK	128
6/67	424	Overcode at above question	1 More than one person said to share brunt	31
			0 BLANK	728
6/68	425	Relationship	1 Husband/wife	248
			2 Father/mother	4
			3 Son/daughter	157
			4 Son-in-law/daughter-in-law	20
			5 Grandchild	3
			6 Brother/sister	36
			7 Brother-in-law/sister-in-law	7
			8 Niece/nephew	8
			9 Other relative	6
			& Friend/neighbour	29
			0 Other person	7
			- Inadequate	106
			BLANK	128
6/69	426	Number of different friends and relatives involved in care <u>before death</u> - not just visiting	0 None	65
			1 One	101
			2 Two	157
			3 Three	131
			4 Four	74
			5 Five	44
			6 Six	24
			7 Seven	11
			8 Eight	9
			9 Nine +	9
			- Inadequate if any	6
			& BLANK	128
6/70	427	Overcode at above question	1 Inadequate to some	5
			0 BLANK	754
6/71	428	Number of friends and relatives who helped before or after death - not just visiting	0 None	20
			1 One	54
			2 Two	177
			3 Three	147
			4 Four	105
			5 Five	52

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/71	428	continued...	6 Six	36
			7 Seven	17
			8 Eight	14
			9 Nine	2
			- Ten	2
			& Eleven or more	5
			BLANK	128
6/72	429	Other children and close relatives who visited in year before death but were not involved in care before death	0 None	112
			1 One	109
			2 Two	129
			3 Three	90
			4 Four	61
			5 Five +	99
			6 Inadequate	30
			7 BLANK	129
6/73	430	Overcode at above question	1 Includes children	124
			2 Includes brother/sister	150
			3 Includes both children and siblings	114
			0 BLANK	371
6/74	431	Other close relatives	1 Unknown if visited	22
			0 BLANK	737
6/75	432	Children or siblings living in E and W who did not visit 1st answer	0 No children in E and W	144
			1 All children in E and W visited or lived with deceased	420
			2 1 didn't	26
			3 2 didn't	1
			4 3+ didn't	-
			5 BLANK	166
			6 More than one answer recorded	2
6/76	433	Children or siblings living in E and W who did not visit 2nd answer	1 No siblings in E and W	211
			2 All siblings in E and W visited	241

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
6/76	433	continued...	3 One didn't 4 2 didn't 5 3+ didn't 6 Inadequate 0 BLANK	85 28 24 37 133
6/77	434	Overcode at above questions (VARS. 432, 433)	1 Any other relative recorded in E and W who didn't visit 0 BLANK	27 732
6/78	435	MOST FREQUENT HELPER OR VISITOR FROM OUTSIDE HOUSEHOLD. How often came in the last 12 months	0 No-one 1 1-2 2 3-5 3 6-11 4 12-19 5 20-49 6 50-299 7 300+ 8 Inadequate 9 BLANK	32 15 19 18 21 53 250 149 37 165
6/79	436	Overcode at above question	1 50+ but inadequate if more or less than 300 0 BLANK	60 699
6/80 to 7/7-17	437-448	Relationship:-		
6/80	437	Only females involved	1 Yes 0 Not mentioned	138 621
7/1-4		Case Number	4 digit code	
7/5-6		CARD NUMBER	CARD 07	759
		Continued from CARD 06		
7/7	438	Father/mother	1 Yes 0 Not mentioned	11 748
7/8	439	Son/daughter	1 Yes 0 Not mentioned	289 470
7/9	440	Son-in-law/daughter-in-law	1 Yes 0 Not mentioned	78 681

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
7/10	441	Grandchild	1 Yes 0 Not mentioned	40 719
7/11	442	Brother/sister	1 Yes 0 Not mentioned	92 667
7/12	443	Brother-in-law/sister-in-law	1 Yes 0 Not mentioned	54 705
7/13	444	Niece/nephew	1 Yes 0 Not mentioned	34 725
7/14	445	Other relatives	1 Yes 0 Not mentioned	41 718
7/15	446	Friend/neighbour	1 Yes 0 Not mentioned	170 589
7/16	447	Other person	1 Yes 0 Not mentioned	6 753
7/17	448	Inadequate or no-one	1 Yes 0 Not mentioned	60 699
7/18	449	Was respondent involved in care of deceased (i.e. help before death)	1 Before 2 After 3 Both 4 Neither 5 Inadequate to both parts 0 BLANK	302 54 241 24 10 128
7/19	450	Overcode at above question	1 Inadequate if before or after 0 BLANK	6 753
7/20-30	451-461	Various sorts of official people who helped during the last 12 months of his life (while he was at home):-		
7/20	451	No-one	1 Yes 0 Not mentioned	220 539
7/21	452	District Nurse	1 Yes 0 Not mentioned	227 532
7/22	453	Health Visitor	1 Yes 0 Not mentioned	52 707

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
7/23	454	Other Nurse	1 Yes 0 Not mentioned	35 724
7/24	455	Home Help	1 Yes 0 Not mentioned	69 690
7/25	456	Special laundry service	1 Yes 0 Not mentioned	8 751
7/26	457	Chiropodist	1 Yes 0 Not mentioned	75 684
7/27	458	Vicar, Priest or Minister and other church people	1 Yes 0 Not mentioned	198 561
7/28	459	Any other official or voluntary service night sitter	1 Yes 0 Not mentioned	76 683
7/29	460	Inadequate which official, or part inadequate	1 Yes 0 Not mentioned	3 756
7/30	461	Inadequate to all	1 Yes 0 Not mentioned	10 749
7/31	462	Number of different sorts of official people who helped	1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Eight + 0 None or inadequate to all BLANK	193 117 56 25 9 1 - - 230 128
7/32	463	Longest period for which had any sort of help	1 Less than a week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year or more 7 Inadequate 0 BLANK	40 55 52 25 28 179 22 358

RD/COLUMN	VAR No	TITLE	CODES	MARGINALS
7/33	464	Most often he had any sort of help at its most frequent	1 Daily or more often 2 More than weekly less than daily 3 Weekly 4 More than monthly less than weekly 5 Monthly 6 Less often 7 Inadequate 0 BLANK	147 58 45 26 27 76 22 358
7/34-44	465-475	Would have preferred more help from:-		
7/34	465	Had all help as often as necessary	1 Yes 0 Not mentioned	273 486
7/35	466	Prefer more help from District Nurse	1 Yes 0 Not mentioned	59 700
7/36	467	Health Visitor	1 Yes 0 Not mentioned	9 750
7/37	468	Other Nurse	1 Yes 0 Not mentioned	9 750
7/38	469	Home Help	1 Yes 0 Not mentioned	29 730
7/39	470	Special laundry service	1 Yes 0 Not mentioned	- 759
7/40	471	Chiropodist	1 Yes 0 Not mentioned	6 753
7/41	472	Vicar, Priest, Minister, etc.	1 Yes 0 Not mentioned	14 745
7/42	473	Other	1 Yes 0 Not mentioned	8 751
7/43	474	Inadequate to part	1 Yes 0 Not mentioned	162 597
7/44	475	Inadequate to all	1 Yes 0 Not mentioned	20 739
7/45-56	476-487	Various things helped with:-		
7/45	476	Personal	1 Yes 0 Not mentioned	217 542

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
7/46	477	Nursing	1 Yes 0 Not mentioned	171 588
7/47	478	Night	1 Yes 0 Not mentioned	24 735
7/48	479	Social	1 Yes 0 Not mentioned	12 747
7/49	480	Financial	1 Yes 0 Not mentioned	3 756
7/50	481	Housework	1 Yes 0 Not mentioned	101 658
7/51	482	Family	1 Yes 0 Not mentioned	2 757
7/52	483	After death	1 Yes 0 Not mentioned	11 748
7/53	484	Other types of help (not including visiting)	1 Yes 0 Not mentioned	36 723
7/54	485	Visiting (and praying) in contact with clergy, etc.	1 Yes 0 Not mentioned	222 537
7/55	486	Inadequate to part	1 Yes 0 Not mentioned	15 744
7/56	487	Inadequate	1 Yes 0 Not mentioned	7 752
7/57-65	488-496	Do you think ..... could have done with any help from:-		
7/57	488	A Nurse at home	1 Yes 0 Not mentioned	40 719
7/58	489	Home Help	1 Yes 0 Not mentioned	86 673
7/59	490	Laundry service	1 Yes 0 Not mentioned	44 715
7/60	491	Chiropodist	1 Yes 0 Not mentioned	37 722
7/61	492	Bath attendant	1 Yes 0 Not mentioned	48 711

ARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
7/62	493	Any other type of service	1 Yes 0 Not mentioned	28 731
7/63	494	None	1 Yes 0 Not mentioned	445 314
7/64	495	Inadequate to part	1 Yes 0 Not mentioned	2 757
7/65	496	Inadequate	1 Yes 0 Not mentioned	30 729
7/66	497	Do you think he would have liked a vicar, priest or minister to visit him	1 Yes 2 No 3 D.N.A. (vicar, etc. visited) 4 Inadequate, uncertain, don't know 0 BLANK	60 291 198 82 128
7/67	498	Were you working at the time you started to look after	1 No 2 Yes, full-time 3 Yes, part-time 4 Yes, inadequate if full or part-time 5 Inadequate if working or not 0 BLANK	282 148 65 21 27 216
7/68-78	499-509	Did you have to make any changes in your work because of looking after ....., such as:-		
7/68	499	Changing to different hours	1 Yes 0 Not mentioned	15 744
7/69	500	Changing to less hours	1 Yes 0 Not mentioned	24 735
7/70	501	Changing to different work	1 Yes 0 Not mentioned	8 751
7/71	502	Taking time off	1 Yes 0 Not mentioned	83 676
7/72	503	Retiring early	1 Yes 0 Not mentioned	4 755

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
7/73	504	Giving up work altogether	1 Yes 0 Not mentioned	47 712
7/74	505	Any other changes	1 Yes 0 Not mentioned	16 743
7/75	506	Unspecified, inadequate to part	1 Yes 0 Not mentioned	6 753
7/76	507	No changes in work	1 Yes 0 Not mentioned	66 693
7/77	508	Inadequate to all	1 Yes 0 Not mentioned	5 754
7/78	509	D.N.A.	1 Yes 0 Not mentioned	309 450
7/79	510	For how long was your work affected	1 Less than 2 weeks 2 2 weeks - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year + 7 Inadequate how long 8 D.N.A. 0 BLANK	15 18 25 21 25 46 13 380 216
7/80	511	Did this make a lot, a little, or no difference to you financially	1 A lot 2 A little 3 No difference 4 Inadequate how much difference 5 Inadequate if any difference 6 D.N.A. 0 BLANK	64 31 58 3 7 380 216
8/1-4		Case Number	4 digit code	
8/5-6		CARD NUMBER	CARD 08	759
8/7-12	512-517	Do you know where some people can get financial help over this in some circumstances:-		
8/7	512	Yes N.A.B. Social Security, Assistance	1 Yes 0 Not mentioned	49 710

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
8/8	513	Yes - other	1 Yes 0 Not mentioned	2 757
8/9	514	Yes - inadequate where	1 Yes 0 Not mentioned	- 759
8/10	515	No	1 Yes 0 Not mentioned	42 717
8/11	516	Inadequate if knows	1 Yes 0 Not mentioned	6 753
8/12	517	D.N.A.	1 Yes 0 Not mentioned	445 314
8/13-21	518-526	Did you yourself apply for financial help:-		
8/13	518	No	1 Yes 0 Not mentioned	33 726
8/14	519	Applied to Social Security, given help	1 Yes 0 Not mentioned	14 745
8/15	520	Applied to Social Security, not given help	1 Yes 0 Not mentioned	2 757
8/16	521	Applied to Social Security, inadequate if given help	1 Yes 0 Not mentioned	1 758
8/17	522	Applied to other, given help	1 Yes 0 Not mentioned	1 758
8/18	523	Applied to other, not given help	1 Yes 0 Not mentioned	- 759
8/19	524	Applied to other, inadequate if given help	1 Yes 0 Not mentioned	- 759
8/20	525	Inadequate if applied	1 Yes 0 Not mentioned	- 759
8/21	526	D.N.A.	1 Yes 0 Not mentioned	493 266

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
8/22-31	527-536	Could you describe any (other) difference looking after ..... made to your life:-		
8/22	527	None at all, none mentioned	1 Yes 0 Not mentioned	80 679
8/23	528	Very little, some difference, not great	1 Yes 0 Not mentioned	60 699
8/24	529	Found it a strain, mental anguish, etc.	1 Yes 0 Not mentioned	107 652
8/25	530	Affected health, 'felt tired'	1 Yes 0 Not mentioned	60 699
8/26	531	Took up time	1 Yes 0 Not mentioned	39 720
8/27	532	Restricted or interfered with social, domestic life	1 Yes 0 Not mentioned	187 572
8/28	533	Financial difficulties	1 Yes 0 Not mentioned	6 753
8/29	534	'Glad to do it', not clear if much difference	1 Yes 0 Not mentioned	81 678
8/30	535	Other (more work etc.)	1 Yes 0 Not mentioned	47 712
8/31	536	Inadequate if any other difference	1 Yes 0 Not mentioned	55 704
8/32	537	During .....'s illness or incapacity, were you able to find out all you wanted to know about his illness and how it was likely to affect him	1 No 2 Inadequate if yes or no 0 BLANK	144 39 576

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
8/33	538	IF YES Was there anything else you would have liked to have explained to you in more detail	1 Yes 2 Inadequate if there was anything else 0 BLANK	31 4 724
8/34	539	IF NO Were you able to find out about things as soon as you wanted to	1 Yes 2 No 3 Inadequate if able to find out as soon as wanted 4 D.N.A. (neither involved in care before death, nor relative or close friend) 0 BLANK	404 22 17 39 277
8/35	540	What would you have liked to know about/in more detail/earlier. Anything else	0 Nothing, don't mind 1 Would have liked to know some more specific thing earlier 2 Inadequate 3 D.N.A. (Code 2 VAR.538, or codes 1 or 3 or 4 VAR.539) 4 BLANK	10 168 19 503 59
8/36	541	Did you ask anyone about this	1 No 0 BLANK	66 693
8/37-45	542-550	IF YES Who did you ask:-		
8/37	542	G.P.	1 Yes 0 Not mentioned	57 702
8/38	543	Hospital doctor	1 Yes 0 Not mentioned	29 730
8/39	544	Hospital sister/nurse	1 Yes 0 Not mentioned	25 734
8/40	545	District Nurse	1 Yes 0 Not mentioned	1 758
8/41	546	Asked someone and was told more	1 Yes 0 Not mentioned	36 723

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
8/42	547	Other specified	1 Yes 0 Not mentioned	12 747
8/43	548	Other unspecified Inadequate who asked	1 Yes 0 Not mentioned	- 759
8/44	549	Inadequate if asked	1 Yes 0 Not mentioned	17 742
8/45	550	D.N.A. (Code 0,3 VAR.540)	1 Yes 0 Not mentioned	513 246
8/46-57	551-562	Who did you talk to about ....'s illness and what was likely to happen:-		
8/46	551	....'s G.P.	1 Yes 0 Not mentioned	408 351
8/47	552	Other G.P.	1 Yes 0 Not mentioned	66 693
8/48	553	Hospital doctor	1 Yes 0 Not mentioned	235 524
8/49	554	Hospital Sister/Nurse	1 Yes 0 Not mentioned	203 556
8/50	555	District Nurse	1 Yes 0 Not mentioned	75 684
8/51	556	Home Help	1 Yes 0 Not mentioned	6 753
8/52	557	Vicar, Priest, Minister	1 Yes 0 Not mentioned	58 701
8/53	558	Any other nurse, doctor or professional person	1 Yes 0 Not mentioned	53 706
8/54	559	Unspecified or inadequate which professional person	1 Yes 0 Not mentioned	3 756
8/55	560	No professional person	1 Yes 0 Not mentioned	54 705
8/56	561	Inadequate if any	1 Yes 0 Not mentioned	50 709

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
8/57	562	D.N.A. (Respondent not relative or close friend and not involved in care of deceased)	1 Yes 0 Not mentioned	39 720
8/58-69	563-574	Relationship to informant:-		
8/58	563	Spouse	1 Yes 0 Not mentioned	97 662
8/59	564	Father/Mother	1 Yes 0 Not mentioned	35 724
8/60	565	Son/Daughter	1 Yes 0 Not mentioned	91 668
8/61	566	Son-in-law/Daughter-in-law	1 Yes 0 Not mentioned	12 747
8/62	567	Grandchild	1 Yes 0 Not mentioned	2 757
8/63	568	Brother/sister/brother-in-law/sister-in-law	1 Yes 0 Not mentioned	131 628
8/64	569	Other relative unspecified relative	1 Yes 0 Not mentioned	70 689
8/65	570	Friend/neighbour	1 Yes 0 Not mentioned	83 676
8/66	571	Other person	1 Yes 0 Not mentioned	10 749
8/67	572	No non-professional persons	1 Yes 0 Not mentioned	284 475
8/68	573	Inadequate if any non-professional person	1 Yes 0 Not mentioned	59 700
8/69	574	D.N.A.	1 Yes 0 Not mentioned	39 720
8/70-71	575	Who gave you most information	01 ....'s G.P. 02 Other G.P. 03 Hospital doctor 04 Hospital sister/nurse 05 District nurse 06 Home help	260 26 119 59 14 -

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
8/70-71	575	continued...	07 Vicar, priest, minister	-
			08 Other specified professional person	19
			09 Unspecified professional person	-
			10 Spouse	4
			20 Father/mother	6
			30 Son/daughter	6
			40 Son-in-law/daughter-in-law	2
			50 Grandchild	-
			60 Brother/sister	3
			70 Brother-in-law/siter-in-law	1
			80 Other relative	3
			90 Friend/neighbour	2
			00 Other person	-
			-- Inadequate who or more than one, won't tell who	59
			&& D.N.A.	117
			BLANK	59
8/72	576	Did..... know what was wrong with him	1 No	224
			2 Uncertain	117
			3 Inadequate if knew	43
			4 Knew part not all	32
			0 BLANK	343
8/73-80	577-584	IF YES who told him:-		
8/73	577	No-one	1 Yes	65
			0 Not mentioned	694
8/74	578	G.P.	1 Yes	167
			0 Not mentioned	592
8/75	579	Hospital doctor	1 Yes	59
			0 Not mentioned	700
8/76	580	Hospital sister/nurse	1 Yes	3
			0 Not mentioned	756
8/77	581	District nurse	1 Yes	-
			0 Not mentioned	759
8/78	582	Other specified person	1 Yes	10
			0 Not mentioned	749
8/79	583	Other unspecified person	1 Yes	3
			0 Not mentioned	756
8/80	584	Inadequate who told him	1 Yes	22
			0 Not mentioned	737

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/1-4		CASE NUMBER	4 digit code	
9/5-6		CARD NUMBER	CARD 09	759
9/7	585	Did ... know he was not likely to recover or did ... know this was likely to happen	1 Yes certain 2 Yes probably 3 Probably not 4 Not definitely 5 Unable to say 6 Inadequate 0 BLANK	117 131 60 227 130 35 59
9/8-16	586-594	Had anyone told him - who:-		
9/8	586	No-one	1 Yes 0 Not mentioned	184 575
9/9	587	G.P.	1 Yes 0 Not mentioned	21 738
9/10	588	Hospital doctor	1 Yes 0 Not mentioned	14 745
9/11	589	Hospital sister/nurse	1 Yes 0 Not mentioned	- 759
9/12	590	District nurse	1 Yes 0 Not mentioned	- 759
9/13	591	Other specified person	1 Yes 0 Not mentioned	6 753
9/14	592	Inadequate who told	1 Yes 0 Not mentioned	- 759
9/15	593	Inadequate if told	1 Yes 0 Not mentioned	25 734
9/16	594	D.N.A.	1 Yes 0 Not mentioned	452 307
9/17	595	Do you think that was best or do you think it would have been better if he had not known (or had known definitely)	1 Better not to have known 2 Better to have known definitely 3 Best as it was 4 Uncertain 5 Inadequate 6 D.N.A. 0 BLANK	40 16 132 49 11 452 59

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/18	596	How long before he died had he (or might he have) known	0 Less than 24 hours	10
			1 24 hours - 1 week	25
			2 1 week - 1 month	42
			3 1 month - 3 months	31
			4 3 months - 6 months	20
			5 6 months - 1 year	8
			6 1 year or more	58
			7 Inadequate how long	54
			8 D.N.A.	452
			9 BLANK	59
9/19	597	Do you think that was best or would it have been better for him to know (or definitely not to know)	1 Better to have known	6
			2 Better not to know definitely	24
			3 Best as it was	227
			4 Uncertain	19
			5 Inadequate	11
			6 D.N.A.	413
			0 BLANK	59
9/20	598	Who do you think would have been the best person to tell him	1 G.P.	2
			2 Hospital doctor	1
			3 Hospital sister/nurse	-
			4 District nurse	-
			5 Respondent - self	-
			6 Other specified	-
			7 Inadequate who	3
			8 D.N.A.	694
			0 BLANK	59
9/21	599	What about from your point of view. Did you know what was wrong with ...	1 No	62
			2 Half knew, knew something not all	45
			3 Inadequate if knew	58
			0 BLANK	594
9/22-29	600-607	IF YES who told you:-		
9/22	600	No-one	1 Yes	38
			0 Not mentioned	721

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/23	601	G.P.	1 Yes 0 Not mentioned	299 460
9/24	602	Hospital doctor	1 Yes 0 Not mentioned	144 615
9/25	603	Hospital sister/nurse	1 Yes 0 Not mentioned	33 726
9/26	604	District nurse	1 Yes 0 Not mentioned	2 757
9/27	605	Told by deceased	1 Yes 0 Not mentioned	18 741
9/28	606	Other specified person	1 Yes 0 Not mentioned	39 720
9/29	607	Inadequate who	1 Yes 0 Not mentioned	8 751
9/30	608	I think you said you knew/didn't know/half knew that ... was unlikely to recover	1 Inadequate if knew/didn't know/half knew 2 Knew 0 BLANK	35 458 266
9/31	609	IF DIDN'T KNOW	1 Like to have known 2 Glad didn't 3 Qualified uncertain 4 Inadequate 0 BLANK	47 50 10 7 645
9/32	610	IF HALF KNEW	1 Like to have known definitely 2 Liked not to have known at all 3 Best as it was 4 Qualified uncertain 5 Inadequate 6 D.N.A. (respondent not relative or close friend) 0 BLANK	10 4 31 5 3 40 666
9/33-40	611-618	Knew, told by:-		
9/33	611	No-one	1 Yes 0 Not mentioned	55 704
9/34	612	G.P.	1 Yes 0 Not mentioned	221 538

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/35	613	Hospital doctor	1 Yes 0 Not mentioned	135 624
9/36	614	Hospital sister/nurse	1 Yes 0 Not mentioned	43 716
9/37	615	District nurse	1 Yes 0 Not mentioned	7 752
9/38	616	Other specified person	1 Yes 0 Not mentioned	30 729
9/39	617	Inadequate who, other unspecified person	1 Yes 0 Not mentioned	11 748
9/40	618	D.N.A.	1 Yes 0 Not mentioned	242 517
9/41	619	How long had you known before he died	0 Less than 24 hours 1 1 day - 1 week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year or more 7 Couldn't say 8 Inadequate how long 9 D.N.A. - BLANK	17 54 70 78 52 39 122 3 23 242 59
9/42	620	Would you have preferred not to know or do you think it was better that you did	1 Preferred not 2 Better that knew 3 Uncertain 4 Inadequate 5 D.N.A. 0 BLANK	16 380 45 17 242 59
9/43	621	Would you have liked to have known earlier or later or when you did	1 Earlier 2 Later 3 Right time/no difference 4 Couldn't say uncertain 5 Inadequate 6 D.N.A. 0 BLANK	40 4 309 11 61 275 59

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/44	622	Did you expect ... to die earlier, later or when he did	1 Earlier 2 Later 3 When he did 4 Couldn't say, uncertain 5 Inadequate 6 D.N.A. 0 BLANK	78 127 109 84 60 242 59
9/45-51	623-629	IF like to have known (code 1 - VARS. 609,610) who would have been the best person to tell you:-		
9/45	623	G.P.	1 Yes 0 Not mentioned	23 736
9/46	624	Hospital doctor	1 Yes 0 Not mentioned	8 751
9/47	625	Hospital sister/nurse	1 Yes 0 Not mentioned	4 755
9/48	626	District nurse	1 Yes 0 Not mentioned	- 759
9/49	627	Other specified person	1 Yes 0 Not mentioned	3 756
9/50	628	Inadequate who, other unspecified person	1 Yes 0 Not mentioned	11 748
9/51	629	D.N.A.	1 Yes 0 Not mentioned	653 106
9/52	630	Was ... unconscious before he died	1 No 2 Inadequate 0 BLANK	272 96 391
9/53	631	IF YES for how long	0 Less than 3 hours 1 3 - 24 hours 2 1 day - 1 week 3 1 week or more 4 Inadequate how long 5 BLANK	97 147 112 22 12 369

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/54	632	Could he recognise his relatives up until the time he died - when he was conscious	1 Yes, always	582
			2 Sometimes	88
			3 No	39
			4 Uncertain	8
			5 Inadequate	41
			0 BLANK	1
9/55	633	How long before	0 Less than 24 hours	15
			1 1 day - 1 week	56
			2 1 week - 1 month	27
			3 1 month - 3 months	6
			4 3 months - 1 year	8
			5 1 year+	5
			6 Inadequate	10
			7 D.N.A.	631
			8 BLANK	1
9/56	634	Were you with ... when he died	1 Yes at bedside (at deceased side)	246
			2 Elsewhere in house	83
			3 Inadequate if with deceased	10
			0 BLANK	420
9/57	635	IF NO when was the last time you saw him	0 Within 24 hours	261
			1 1 day - 1 week	65
			2 1 week - 1 month	23
			3 1 month - 3 months	6
			4 3 months or more before death	4
			5 Inadequate how long	60
			6 BLANK	340
9/58	636	Were any (other) relatives or friends with him	1 Yes	224
			2 No	508
			3 Don't know, uncertain	3
			4 Inadequate	23
			0 BLANK	1
9/59	637	Roughly how often did you see him in the last week	0 Not at all	20
			1 Once	32
			2 2-4	77
			3 5-9	148
			4 10-19	24
			5 20+	46
			6 Inadequate how often D.N.A. (died at home in same household as respondent)	95

CARD/COLUMN	VAR No	TITLE	CODES		MARGINALS
9/59	637	continued...	7	Not seen in last 3 months	316
			8	BLANK	1
9/60	638	Roughly how often did you see him in last month			
			0	Not at all	6
			1	Once	10
			2	2-4	23
			3	5-9	30
			4	10-19	46
			5	20+	221
			6	Inadequate how often, D.N.A. (died at home in same household as respondent)	105
			7	Not seen in last 3 months	316
			9	More than one answer recorded	1
			8	BLANK	1
9/61	639	Roughly how often did you see him in last 3 months			
			0	Not at all	-
			1	Once	7
			2	2-4	6
			3	5-9	6
			4	10-19	33
			5	20+	278
			6	Inadequate how often, D.N.A. (died at home in same household as respondent)	111
			7	Not seen in last 3 months	316
			9	More than one answer recorded	1
			8	BLANK	1
9/62	640	How do you feel about ..... dying at home rather than in hospital			
			1	Rather have him die at home	187
			2	Rather have him die in hospital (or institution)	22
			3	Don't mind, don't care, uncertain no clear code above	45
			4	Inadequate	44
			5	D.N.A.	460
			0	BLANK	1

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/63	641	Did you at any stage feel it would have been better for ..... to be in hospital (again)	1 No 2 Inadequate 0 BLANK	189 36 534
9/64-68	642-646	IF YES from whose point of view:-		
9/64	642	From .....'s point of view	1 Yes 0 Not mentioned	25 734
9/65	643	Your point of view	1 Yes 0 Not mentioned	51 708
9/66	644	Point of view of others looking after him	1 Yes 0 Not mentioned	27 732
9/67	645	Inadequate whose point of view	1 Yes 0 Not mentioned	1 758
9/68	646	D.N.A.	1 Yes 0 Not mentioned	460 299
9/69	647	Did you discuss this with .....'s G.P.	1 Yes something happened 2 Yes nothing happened 3 Inadequate if anything happened 4 No, talked to someone else about it 5 No, didn't talk to anyone else about it 6 No, inadequate if talked to anyone else about it 7 Inadequate if discussed with .....'s G.P. 8 D.N.A. 0 BLANK	9 34 4 5 14 4 3 685 1
9/70-80	648-658	Who washed and prepared .....'s body:-		
9/70	648	Self	1 Yes 0 Not mentioned	39 720
9/71	649	Relative in same household	1 Yes 0 Not mentioned	14 745

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
9/72	650	Relative in other household	1 Yes 0 Not mentioned	30 729
9/73	651	Relative inadequate if in same household	1 Yes 0 Not mentioned	- 759
9/74	652	Neighbour/friends	1 Yes 0 Not mentioned	55 704
9/75	653	Nurse	1 Yes 0 Not mentioned	30 729
9/76	654	Undertaker	1 Yes 0 Not mentioned	183 576
9/77	655	Post mortem/coroner etc.	1 Yes 0 Not mentioned	13 746
9/78	656	Other specified person (taken to hospital)	1 Yes 0 Not mentioned	15 744
9/79	657	Inadequate who	1 Yes 0 Not mentioned	10 749
9/80	658	D.N.A.	1 Yes 0 Not mentioned	419 340
10/1-4		Case Number	4 digit code	
10/5-6		CARD NUMBER	CARD 10	759
10/7	659	Looking back on it do you think it would have been helpful if you had known more about what to do when someone died or do you feel you knew enough	1 Like to have known more 2 Inadequate whether knew enough 3 Knew enough, knew from experience 4 Didn't have to do anything, not involved etc. 5 Knew enough, inadequate how 6 D.N.A. (died in institution, street, office, etc.) 0 BLANK	53 17 166 42 15 419 47

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
10/8-13	660-665	IF KNEW ENOUGH who told you:-		
10/8	660	District nurse	1 Yes 0 Not mentioned	4 755
10/9	661	G.P.	1 Yes 0 Not mentioned	12 747
10/10	662	Relative	1 Yes 0 Not mentioned	14 745
10/11	663	Friend/neighbour	1 Yes 0 Not mentioned	9 750
10/12	664	Other (specified)	1 Yes 0 Not mentioned	10 749
10/13	665	Other (unspecified) inadequate who	1 Yes 0 Not mentioned	2 757
10/14	666	Did a general practitioner come to see ..... after he died	1 No 2 Inadequate 0 BLANK	25 7 727
10/15-20	667-672	IF YES (incl. present at death) who:-		
10/15	667	His own doctor	1 Yes 0 Not mentioned	217 542
10/16	668	Another doctor, who'd seen him before	1 Yes 0 Not mentioned	68 691
10/17	669	Another doctor	1 Yes 0 Not mentioned	48 711
10/18	670	Inadequate what doctor	1 Yes 0 Not mentioned	3 756
10/19	671	No: taken to hospital	1 Yes 0 Not mentioned	4 755
10/20	672	D.N.A.	1 Yes 0 Not mentioned	419 340
10/21	673	Was he the doctor who signed the death certificate	1 Yes 2 No 3 Uncertain, inadequate 4 D.N.A. 0 BLANK	244 43 19 452 1

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
10/22	674	How soon did he come after he died	0 Present when died	15
			1 Within hour	163
			2 1-3 hours	56
			3 3-6 hours	35
			4 6-24 hours	27
			5 1 day-2 days	4
			6 2-3 days	-
			7 3 days or longer	-
			8 Inadequate	6
			9 D.N.A.	452
			- BLANK	1
10/23	675	Would you have liked a doctor to come	1 Yes	8
			2 No	12
			3 Inadequate	1
			4 D.N.A.	737
			0 BLANK	1
10/24	676	How did you feel about ..... dying in hospital	1 Rather have him die in hospital	235
			2 Rather have him die at home	44
			3 Indeterminate, uncertain	73
			4 Inadequate	11
			5 D.N.A. (home death, or in street, office etc./resp. official in institution)	395
			0 BLANK	1
10/25	677	Did you at any stage feel it would have been better for ..... to be at home	1 No	292
			2 Yes, discussed it with someone	21
			3 Didn't discuss it with anyone	29
			4 Inadequate whether discussed it with anyone	-
			5 Inadequate	21
			6 D.N.A. (died at home, in street, etc.)	395
			0 BLANK	1
10/26-37	678-689	Did you discuss this with anyone, who:-		
10/26	678	G.P.	1 Yes	3
			0 Not mentioned	756

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
10/27	679	Hospital doctor	1 Yes 0 Not mentioned	6 753
10/28	680	Hospital nurse	1 Yes 0 Not mentioned	6 753
10/29	681	Other specified	1 Yes 0 Not mentioned	1 758
10/30	682	Other unspecified inadequate who	1 Yes 0 Not mentioned	- 759
10/31	683	Something happened	1 Yes 0 Not mentioned	1 758
10/32	684	Inadequate if something happened	1 Yes 0 Not mentioned	- 759
10/33-37	685-689	Didn't talk to above but talked to:-		
10/33	685	Relative	1 Yes 0 Not mentioned	4 755
10/34	686	Friend/neighbour	1 Yes 0 Not mentioned	4 755
10/35	687	Other unspecified, inadequate who	1 Yes 0 Not mentioned	- 759
10/36	688	Inadequate	1 Yes 0 Not mentioned	- 759
10/37	689	D.N.A.	1 Yes 0 Not mentioned	737 22
10/38-45	690-697	When ..... went into hospital (the last time) who first suggested it:-		
10/38	690	Deceased	1 Yes 0 Not mentioned	9 750
10/39	691	Respondent	1 Yes 0 Not mentioned	35 724
10/40	692	Other relative	1 Yes 0 Not mentioned	13 746
10/41	693	G.P.	1 Yes 0 Not mentioned	231 528

ARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
10/42	694	Hospital doctor	1 Yes 0 Not mentioned	38 721
10/43	695	Other specified	1 Yes 0 Not mentioned	30 729
10/44	696	Other unspecified, inadequate who	1 Yes 0 Not mentioned	14 745
10/45	697	D.N.A.	1 Yes 0 Not mentioned	395 364
10/46	698	How about ..... do you think he was relieved, distressed or how did he feel	1 Relieved 2 Distressed 3 Both relieved and distressed 4 Other too ill to care 5 Unconscious, didn't know 6 Inadequate 7 D.N.A. 0 BLANK	122 70 17 62 72 20 395 1
10/47	699	And what about you - did you feel relieved or distressed or what	1 Relieved 2 Distressed 3 Both (including mixed feelings) 4 Other 5 Inadequate 6 D.N.A. (home death, or in street, office etc./respondent official in institution 0 BLANK	218 59 46 22 18 395 1
10/48	700	Who was mainly responsible for the arrangements with the undertakers and all the other formalities	1 Self alone 2 Self with others 3 Others only 4 Inadequate 0 BLANK	209 273 266 10 1

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
10/49	701	Would you have liked any (more) help with (that or) anything after ..... died	1 Yes 2 No 3 Inadequate 0 BLANK	47 642 28 42
10/50	702	Have you a religious faith or belief which you feel helped you at the time of .....'s death	1 Yes 2 No 3 Qualified/uncertain 4 Inadequate 0 BLANK	425 242 29 21 42
10/51	703	What about ..... do you think he had a religious faith or belief which was helpful to him	1 Yes 2 No 3 Qualified/uncertain 4 Inadequate 0 BLANK	412 216 67 22 42
10/52	704	To which faith or denomination do you belong	1 Roman Catholic 2 Church of England 3 Other Protestant 4 Jewish 5 None 6 Other specified 7 Unspecified, inadequate which 8 Inadequate 0 BLANK	81 437 113 1 54 10 1 20 42
10/53	705	What about .....what did he belong to	1 Roman Catholic 2 Church of England 3 Other Protestant 4 Jewish 5 None 6 Other specified 7 Unspecified, inadequate which 8 Inadequate 0 BLANK	72 423 116 2 60 14 3 27 42
10/54-63	706-715	Have any of these people visited you at home since ..... died:-		
10/54	706	Your own doctor	1 Yes 0 Not mentioned	147 612

ARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
10/55	707	Other general practitioner	1 Yes 0 Not mentioned	21 738
10/56	708	District nurse	1 Yes 0 Not mentioned	36 723
10/57	709	Other nurse	1 Yes 0 Not mentioned	5 754
10/58	710	Welfare or Social Worker	1 Yes 0 Not mentioned	40 719
10/59	711	Vicar, priest or minister	1 Yes 0 Not mentioned	226 533
10/60	712	Any other professional person specified	1 Yes 0 Not mentioned	18 741
10/61	713	Unspecified or inadequate to past	1 Yes 0 Not mentioned	343 416
10/62	714	Inadequate	1 Yes 0 Not mentioned	3 756
10/63	715	None of these	1 Yes 0 Not mentioned	25 734
10/64-73	716-725	Would you have liked any of these to visit:-		
10/64	716	Your own doctor	1 Yes 0 Not mentioned	30 729
10/65	717	Other general practitioner	1 Yes 0 Not mentioned	2 757
10/66	718	District nurse	1 Yes 0 Not mentioned	6 753
10/67	719	Other nurse	1 Yes 0 Not mentioned	- 759
10/68	720	Welfare or Social Worker	1 Yes 0 Not mentioned	10 749
10/69	721	Vicar, priest or minister	1 Yes 0 Not mentioned	24 735
10/70	722	Any other professional person specified	1 Yes 0 Not mentioned	- 759

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
10/71	723	Unspecified or inadequate whether wanted anyone	1 Yes 0 Not mentioned	595 164
10/72	724	Inadequate who wanted	1 Yes 0 Not mentioned	10 749
10/73	725	None of these	1 Yes 0 Not mentioned	48 711
10/74	726	Have you consulted a doctor, nurse or chemist professionally for yourself since ..... died	1 No 2 Inadequate 0 BLANK	336 21 402
10/75-80	727-732	IF YES who:-		
10/75	727	G.P.	1 Yes 0 Not mentioned	327 432
10/76	728	Other doctor	1 Yes 0 Not mentioned	23 736
10/77	729	District nurse	1 Yes 0 Not mentioned	3 756
10/78	730	Other nurse	1 Yes 0 Not mentioned	- 759
10/79	731	Chemist	1 Yes 0 Not mentioned	1 758
10/80	732	Inadequate which	1 Yes 0 Not mentioned	23 736
11/1-4		Case Number	4 digit code	
11/5-6		CARD NUMBER	CARD 11	759
11/7	733	Do you think it had anything to do with your bereavement or not	1 Yes 2 No 3 Uncertain 4 Inadequate 5 D.N.A. 0 BLANK	226 106 23 5 357 42

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
11/8	734	If doctor or chemist, did he give/sell you any tablets or medicine	1 Yes 2 No 3 Inadequate 4 D.N.A. 0 BLANK	286 35 39 357 42
11/9	735	Overcode at above question	1 Symptoms mentioned, shock, nerves, anxiety, sleeplessness 0 BLANK	137 622
11/10	736	Have you made any changes in your way of living since ..... died	1 No 0 BLANK	496 263
11/11-16	737-742	IF YES what:-		
11/11	737	Change in household arrangements	1 Yes 0 Not mentioned	24 735
11/12	738	Change in household (going to live with others etc.)	1 Yes 0 Not mentioned	50 709
11/13	739	Change in work	1 Yes 0 Not mentioned	56 703
11/14	740	Other changes (specified)	1 Yes 0 Not mentioned	72 687
11/15	741	Inadequate what changes	1 Yes 0 Not mentioned	9 750
11/16	742	Inadequate if any changes	1 Yes 0 Not mentioned	22 737
11/17	743	Are you planning any (other) changes	1 No 2 Inadequate if 0 BLANK	549 37 173
11/18-23	744-749	IF YES what changes:-		
11/18	744	Change in household arrangement	1 Yes 0 Not mentioned	13 746
11/19	745	Change in household (including going to live with others)	1 Yes 0 Not mentioned	86 673

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
11/20	746	Change in work	1 Yes 0 Not mentioned	20 739
11/21	747	Other specified changes	1 Yes 0 Not mentioned	15 744
11/22	748	Inadequate what changes	1 Yes 0 Not mentioned	7 752
11/23	749	D.N.A. (respondent not relative or close friend)	1 Yes 0 Not mentioned	41 718
11/24-31	750-757	Since ..... died have you had any particular worries or anxieties such as:-		
11/24	750	Financial worries	1 Yes 0 Not mentioned	97 662
11/25	751	Legal ones - to do with the will	1 Yes 0 Not mentioned	63 696
11/26	752	Problems with house or tenancy	1 Yes 0 Not mentioned	45 714
11/27	753	Anything else	1 Yes 0 Not mentioned	52 707
11/28	754	Inadequate what	1 Yes 0 Not mentioned	- 759
11/29	755	Nothing	1 Yes 0 Not mentioned	501 258
11/30	756	Inadequate if any	1 Yes 0 Not mentioned	19 740
11/31	757	D.N.A.	1 Yes 0 Not mentioned	41 718
11/32	758	IF ANY WORRIES: Did you consult anyone about these	1 No 2 Inadequate 0 BLANK	61 16 682
11/33-39	759-765	IF YES who:-		
11/33	759	A relative	1 Yes 0 Not mentioned	12 747

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
11/34	760	A friend/neighbour	1 Yes 0 Not mentioned	3 756
11/35	761	A professional person	1 Yes 0 Not mentioned	98 661
11/36	762	An outsider	1 Yes 0 Not mentioned	- 759
11/37	763	Other specified person	1 Yes 0 Not mentioned	10 749
11/38	764	Inadequate who	1 Yes 0 Not mentioned	4 755
11/39	765	D.N.A.	1 Yes 0 Not mentioned	561 198
11/40	766	Were you able to help	1 Yes 2 No 3 Helped with some not all 4 Inadequate 5 D.N.A. 0 BLANK	71 28 8 13 638 1
11/41-49	767-775	When someone close to you dies who do you feel it is best to talk to about how you feel:-		
11/41	767	A relative	1 Yes 0 Not mentioned	425 334
11/42	768	A close friend	1 Yes 0 Not mentioned	145 614
11/43	769	A professional person	1 Yes 0 Not mentioned	68 691
11/44	770	An outsider	1 Yes 0 Not mentioned	33 726
11/45	771	Or who (specify)	1 Yes 0 Not mentioned	10 749
11/46	772	Inadequate who/unspecified	1 Yes 0 Not mentioned	12 747
11/47	773	No-one	1 Yes 0 Not mentioned	61 698
11/48	774	Inadequate	1 Yes 0 Not mentioned	45 714

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
11/49	775	D.N.A.	1 Yes 0 Not mentioned	41 718
11/50-56	776-782	IF PROFESSIONAL: What sort of person had you in mind:-		
11/50	776	A doctor	1 Yes 0 Not mentioned	35 724
11/51	777	A nurse	1 Yes 0 Not mentioned	7 752
11/52	778	A lawyer	1 Yes 0 Not mentioned	- 759
11/53	779	A clergyman	1 Yes 0 Not mentioned	24 735
11/54	780	Other specified	1 Yes 0 Not mentioned	4 755
11/55	781	Inadequate who/ unspecified/inadequate	1 Yes 0 Not mentioned	4 755
11/56	782	D.N.A.	1 Yes 0 Not mentioned	690 69
11/57	783	Who did you find most helpful	1 Relative 2 Close friend 3 Outsider 4 Doctor 5 Nurse 6 Lawyer 7 Clergyman 8 Other specified (including interviewer) 9 Inadequate who 0 No-one - Inadequate if anyone & D.N.A. BLANK	376 78 18 17 5 - 9 17 14 78 105 41 1
11/58-61	784-787	Is there anything else you would like to say about:-		
11/58	784	....'s care before he died	1 Yes 0 Not mentioned	310 449
11/59	785	His death	1 Yes 0 Not mentioned	148 611

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
11/60	786	The time since he died	1 Yes 0 Not mentioned	222 537
11/61	787	Nothing mentioned	1 Yes 0 Not mentioned	306 453
11/62	788	Do you mind telling me your age	1 21-24 2 25-34 3 35-44 4 45-54 5 55-64 6 65-69 7 70-74 8 75-79 9 80-84 0 85 and over - Inadequate BLANK	15 55 118 165 189 69 74 40 17 4 12 1
11/63	789	Sex	1 Male 2 Female 3 Inadequate 0 BLANK	199 599 - 1
11/64	790	Marital status	1 Single, never married 2 Married now 3 Widow(er) of deceased 4 Other widow/divorced etc. 5 Inadequate 0 BLANK	91 321 298 43 5 1
11/65	791	Household composition	1 On own 2 With spouse only 3 With spouse and child(ren) no children in-law 4 With child(ren) and children-in-law, with or without grand-children 5 With child(ren) no children-in-law 6 With child(ren) and children-in-law, with or without grand-children 7 With other relatives of same generation only 8 With unrelated people only (friend, landlady) 9 Other three generation household & In guest house/old	224 110 169 4 113 16 20 10 10 22

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
11/65	791	continued...	people's home/boarding house, including staff of institutions	
			0 Others	57
			- Inadequate	3
			BLANK	1
11/66-77	792-803	Who is the relative you see most of:-		
11/66	792	Father/mother	1 Yes	4
			0 Not mentioned	755
11/67	793	Son/daughter	1 Yes	90
			0 Not mentioned	669
11/68	794	Son-in-law/daughter-in-law	1 Yes	10
			0 Not mentioned	749
11/69	795	Grandchild	1 Yes	5
			0 Not mentioned	754
11/70	796	Brother/sister	1 Yes	60
			0 Not mentioned	699
11/71	797	Brother-in-law/sister-in-law	1 Yes	12
			0 Not mentioned	747
11/72	798	Other relative of same generation	1 Yes	5
			0 Not mentioned	754
11/73	799	Other relative	1 Yes	23
			0 Not mentioned	736
11/74	800	Inadequate who	1 Yes	8
			0 Not mentioned	751
11/75	801	No relatives/no relatives seen	1 Yes	16
			0 Not mentioned	743
11/76	802	Inadequate if sees any relative	1 Yes	9
			0 Not mentioned	750
11/77	803	D.N.A.	1 Yes	534
			0 Not mentioned	225

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
11/78	804	Where do they live	1 Within 10 minutes walk	54
			2 Within ½ hour journey	70
			3 ½-1 hour	31
			4 1 hour - 2 hours	13
			5 2 hours or more	29
			6 Inadequate	2
			7 D.N.A.	559
			0 BLANK	1
11/79	805	Length of interview	1 Less than 30 mins	11
			2 30-45 mins	37
			3 45 mins - 1 hour	91
			4 1-1½ hours	224
			5 1½-2 hours	227
			6 2 hours or more	154
			7 Inadequate	14
			0 BLANK	1
11/80	806	Overcode at above question	1 Completed on more than one occasion	40
			0 BLANK	719
12/1-4		Case Number	4 digit code	
12/5-6		CARD NUMBER	CARD 12	759
12/7	807	Anyone else present	1 No	508
			0 BLANK	251
12/8-13	808-813	IF YES: who		
12/8	808	Relative	1 Yes	215
			0 Not mentioned	544
12/9	809	Friend/neighbour	1 Yes	21
			0 Not mentioned	738
12/10	810	Other	1 Yes	8
			0 Not mentioned	751
12/11	811	Inadequate who	1 Yes	6
			0 Not mentioned	753
12/12	812	Inadequate if	1 Yes	8
			0 Not mentioned	751
12/13	813	D.N.A. (none mentioned)	1 Yes	1
			0 Not mentioned	758
12/14	814	Main informant was	1 Only appropriate person	563
			2 One of two or more appropriate	157

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
12/14	814	continued...	3 Not the most appropriate person	30
			4 Inadequate	8
			0 BLANK	1
12/15-26	815-826	Who (else) was appropriate:-		
12/15	815	Spouse	1 Yes	50
			0 Not mentioned	709
12/16	816	Father/mother	1 Yes	4
			0 Not mentioned	755
12/17	817	Son/daughter	1 Yes	72
			0 Not mentioned	687
12/18	818	Son-in-law/daughter-in-law	1 Yes	14
			0 Not mentioned	745
12/19	819	Grandchild	1 Yes	3
			0 Not mentioned	756
12/20	820	Brother/sister	1 Yes	18
			0 Not mentioned	741
12/21	821	Brother-in-law/sister-in-law	1 Yes	9
			0 Not mentioned	750
12/22	822	Other relative	1 Yes	7
			0 Not mentioned	752
12/23	823	Friend/neighbour	1 Yes	9
			0 Not mentioned	750
12/24	824	Other person	1 Yes	7
			0 Not mentioned	752
12/25	825	Inadequate who	1 Yes	15
			0 Not mentioned	744
12/26	826	D.N.A.	1 Yes	571
			0 Not mentioned	188
12/27	827	Type of interview	1 Main questionnaire only	121
			2 Main + questionnaire 1 respondent registered death	378
			3 Respondent first contact	229
			4 Main questionnaire after questionnaire 1	28

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
12/27	827	continued...	completed by other household member	
			5 Inadequate	2
			0 BLANK	1
12/28	828	Month	1 January	3
			2 February	-
			3 March	-
			4 April	-
			5 May	-
			6 June	-
			7 July	141
			8 August	140
			9 September	123
			0 October	164
			- November	113
			& December	74
			BLANK	1
12/29-30	829	Interviewer	00 Lisbeth Hockey	2
			01 Beryl Davies	25
			02 Joan Ellis	8
			03 Kathleen Field	26
			04 Mary Whitting	102
			05 Janet Baker	86
			06 Paula Garden	70
			08 Ruth Harris	97
			09 Connie Frost	10
			10 Angela Savage	27
			11 Pat Tizzard	70
			12 Kay Young	82
			13 Millicent Bathgate	17
			14 Stella Brown	34
			15 Anne Long	32
			16 Ellen Latham	16
			17 Muriel Toney	7
			18 Mollie Richards	19
			19 Wyn Tucker	1
			20 John Bond	-
			25 Jill Cove	26
			-- Inadequate	1
			BLANK	1
12/31-80		U N U S E D	U N U S E D	

A P P E N D I X 1

Code		ICD 1966 no.
00	Infective and parasitic	000-136
	Neoplasms	
10	Malignant neoplasm, stomach	151
11	" " bronchus and lung	162.1
12	" " breast	174
13	" " uterus	180-182
14	" " prostate	185
15	Leukaemia and aleuhaemia	204-207
16	Other neoplasm of specified site	Rest 140-238
17	Neoplasm of unspecified site	excluding 199 & 228 199,228,239
01	Endocrine, Nutritional and Metabolic	240-279
02	Blood and blood forming organs	280-289
03	Mental disorders	290-315
04	Nervous system and sense organs	320-389
	Circulatory	
20	Hypertensive	400-404
21	Ischaomic heart disease	410-414
22	Rheumatic fever and other heart disease	390-398,420-429
23	Corobrovascular diease, stroke	430-438
24	Diseases of the arteries	440-448
25	Other	450-458
26	Bad heart, heart failure, coronery, heart attack	
	Respiratory	
30	Pneumonia	480-486
31	Bronchitis	490-493
32	Other	460-474,500-519
60	Digestive	520-577
06	Genito urinary	580-629
07	Complications of pregnancy etc.	630-678
08	Skin	680-709
09	Musculoakelotal and Connective	710-738

.../...

A P P E N D I X 1

Code		ICD 1966 no.
0Y	Congenital and perinatal	740-779
40	Symptoms inc. heart failure, senility	780-796
70	Senility, old age	
	Accidents	
50	Transport	E800-E845
51	Suicide or self-inflicted injury	E950-E959
52	Other	E850-E949,E960-E999
XX	Inadequate, don't know	
80	Loneliness, will to live	

Medical Care Research Unit
Institute of Community Studies
18 Victoria Park Square,
London, E,2

HOME CARE SURVEY

Questionnaire 2

INTRODUCTION I am from a social research organisation the Medical Care Research Unit of the Institute of Community Studies. We are doing a study about how people cope with illness or death, which we hope will eventually help other people in a similar position. We have already seen _____ and he suggested that you would be the best person to help us. We would like to ask you some questions Anything you tell us will be treated as confidential, and no names will be mentioned in the book we are planning to write.

1. I believe you were _____'s :-

Husband/wife 1
Father/mother..... 2
Father-in-law/mother-in-law..... 3
Son/daughter..... 4
Son-in-law/daughter-in-law..... 5
Grandchild..... 6
Brother/sister..... 7
Brother-in-law/sister-in-law..... 8
Neighbour..... 9
Friend..... Y
Other SPECIFY..... 0

IF NOT A RELATIVE a) How long had you known him?

Less than a year..... 1
1 year < 2 years..... 2
2 years < 5 years..... 3
5 years < 10 years..... 4
10 years < 15 years..... 5
15 years < 20 years..... 6
20 years or more..... 7

b) IF FRIEND OR NEIGHBOUR
Would you say he was a close friend of yours or not?

Yes, close friend..... 1
No..... 2

2. OMIT IF NOT RELATIVE OR CLOSE FRIEND
How have you been yourself since _____ died?

3. As far as you were concerned was _____'s death expected or not?

Expected..... 1
Not expected..... 2
Uncertain..... 3

IF EXPECTED (1) What was the matter?

IF NOT EXPECTED OR UNCERTAIN (2 or 3)
a) Was it completely unexpected with no previous illness or warning at all?

Yes..... 4
No..... 5

b) What happened?

CHECK: So the condition _____ died of was:-

4. So before he died was _____ ever completely bedridden?

Yes..... 1
No..... 2

IF YES (1) How long was that for?

Less than a week..... 1
1 week < a month..... 2
1 month < 3 months..... 3
3 months < 6 months..... 4
6 months < 1 year..... 5
1 year or more..... 6

IF A YEAR OR MORE SKIP TO Q 9.

5. (Before that) Was he confined mainly to bed?

Yes..... 3
No..... 4

IF YES (3) How long was that for?

Less than a week..... 1
1 week < a month..... 2
1 month < 3 months..... 3
3 months < 6 months..... 4
6 months < 1 year..... 5
1 year or more..... 6

IF A YEAR OR MORE SKIP TO Q 9

6. (Before that) Was he at all restricted in what he could do inside the house?

Yes..... 5
No..... 6

IF YES (5) Would you say he was:-

Severely restricted..... 1
Moderately restricted..... 2
A little restricted..... 3

IF NO (6) Was he restricted in what he could do outside?

Yes..... 7
No..... 8

IF NO (8) Would you describe his health in the last 12 months as.-

Good..... 1
Fair..... 2
PROMPT Poor..... 3
Very poor..... 4

In what way?

IF NO (8) SKIP TO Q.9

7n For how long was he restricted in that way?

Less than a week.....1
1 week < a month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year.....5
1 year or more.....6

8 Could you describe how he was restricted?

9. How old was he when he died?

Under 25.....1
25 - 34.....2
35 - 44.....3
45 - 54.....4
55 - 64.....5
65 - 69.....6
70 - 74.....7
75 - 79.....8
80 - 84.....9
85 +.....0

10. Could you tell me his exact date of birth?

IF NOT TRY AND GET PRECISE AGE IN YEARS WHEN HE DIED.

11. I believe _____ died in: or Where did _____ die?

Hospital.....1
Other institution SPECIFY BELOW....2
Deceased's own home.....3
Other person's home SPECIFY BELOW..4
Other SPECIFY.....5

IF IN HOSPITAL OR OTHER INSTITUTION How long was he in hospital before he died?

< 24 hours.....Y
1 day < 3 days.....0
3 days < 1 week.....1
1 week < 1 month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year.....5
1 year < 2 years.....6
2 years < 5 years.....7
5 years + SPECIFY.....8

12. CHECK

Long term institutional death (6,7 or 8 at Q11).....1
Unexpected death of person under 65 with no previous restrictions.....2
Other death.....3

IF LONG TERM INSTITUTIONAL Had he ever worked? (outside an institution)

Yes.....3
No.....4

IF YES (3) How recently before he died?

1 year < 2 years.....6
2 years < 5 years.....7
5 years < 10 years.....8
10 years or more before death.....9

SKIP TO Q.14.

13. Had _____ been in hospital or other institution as an inpatient (on any other occasion) in the 12 months before he died?

Yes.....1
No.....2

IF YES (1) a) How many times altogether in the last 12 months?
INCLUDE OCCASION ON WHICH DIED

_____

b) How long was he in hospital altogether in the last twelve months (including the time he died)?

Less than a week.....1
1 week < 1 month.....2
1 months < 3 months.....3
3 months < 6 months.....4
6 months < 9 months.....5
9 months < 1 year.....6

a) IF DID NOT DIE IN HOSPITAL
How long before _____ died did he leave hospital (for the last time)?

Less than a week.....1
1 week < 1 month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 9 months.....5
9 months < 1 year.....6

IF NO (2) AND DID NOT DIE IN HOSPITAL SKIP TO Q.17

14. Did _____ have an operation or any other particular treatment while he was in hospital in the last 12 months?

Operation.....1
Particular treatment.....2
Neither.....3

IF PARTICULAR TREATMENT (2) What was it?

15. Did you visit _____ while he was in hospital/ institution?

Yes.....7
No. 8

IF YES (7) a) About how many times during the last 12 months of his life?

1 - 4..... ...1
5 - 9..... 2
10 - 19.... 3
20 - 49.. 4
50 + ...5

b) How long did it take you to get there?
IF _____ HAD BEEN IN MORE THAN ONE HOSPITAL ASK ABOUT THE ONE HE WAS IN LONGEST DURING THE LAST 12 MONTHS.

Less than 15 mins.... 1
15 mins < 30 mins..... .2
30 mins < 45 mins.... 3
45 mins < 1 hour 4
1 hour < 2 hours.... 5
2 hours + ...6

c) What were the arrangements for visiting (when _____ was in hospital last)?

Set times.....1
Free visiting.....2
Other SPECIFY 3

d) Did you feel the arrangements were satisfactory or not satisfactory?

Satisfactory.....3
Not satisfactory...4

In what way?

16. Did anyone (else) visit _____ while he was in hospital during the last 12 months of his life?

Yes.....8
No.....0

IF YES (5) a) Could you say about how many people?

One.....1
Two - four....2
Five - nine.. 3
Ten or more...4

b) Who visited _____ most often? (You or someone else? Who?) STATE RELATIONSHIP TO DECEASED.

IF LONG TERM INSTITUTIONAL DEATH SKIP TO Q.31 OR Q.34.

17. Had _____ been to hospital as an outpatient during the last 12 months of his life?

Yes..... . . .1
No..... 2

IF YES (1) a) How many times?

Once.....1
2 - 4..... .2
5 - 9..... ...3
10 - 19.. 4
20 + ...5

b) When was the last most recent time before he died?

Less than 1 week... 1
1 week < 1 month.... 2
1 month < 3 months... .. 3
3 months < 6 months..... .4
6 months < 1 year... 5

c) How did he (usually) get there?

Ambulance..... 1
Walk all way..... . ..2
Public transport. 3
Private transport 4
Other SPECIFY.. 5

d) Did anyone (usually) go with him?

Yes. 7
No 8

IF YES (7) Who? GIVE RELATIONSHIP TO DECEASED

e) How long did _____ (usually) have to spend at the hospital?

Less than 30 mins 1
30 mins < 1 hour. . .2
1 hour < 2 hours. . .3
2 hours < 3 hours. 4
3 hours < 4 hours.....5
4 hours < 5 hours. 6
5 hours < 6 hours..... ...7
6 hours or more..... ..8

f) Were there any problems or difficulties about _____ going to outpatients? What?

g) Did he go just for checks and advice or for particular treatment?

Checks and advice only....1
Particular treatment.....2

IF PARTICULAR TREATMENT (2)
What was it?

18. Did a doctor from a hospital come to visit _____ at home during the 12 months before he died?

Yes..... 1
No..... 2

IF YES (1) a) Could you tell me about that?

b) Did the general practitioner come at the same time?

Yes..... 3
No..... 4

19. Could you tell me the name and address of _____'s general practitioner?

NAME AND INITIALS

ADDRESS

a) Was that under the National Health Service or privately?

N.H.S..... 1
Privately.....2

20 In the last 12 months before _____ died how often did his doctor - or a partner, locum, assistant or another general practitioner -

	a) see him at all either at home or in the surgery	OMIT IF 0 to a) b) Come to see him at home?	OMIT IF 0 to b) c) Come and see him at night between 8pm and 8am?
Not at all	0	0	0
Once	1	1	1
2 - 4	2	2	2
5 - 9	3	3	3
10 - 19	4	4	4
20 or more	5	5	5

21. When was the last time _____ saw a general practitioner before he died?

Within 24 hours..... 0
1 day < 1 week.....1
1 week < 1 month..... 2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year..... .5
1 year < 2 years.....6
2 years < 5 years.....7
5 years or more..... 8

22. Did you personally have the same doctor as _____ then?

Same doctor... 1
Another doctor in same partnership. 2
Different doctor altogether...3

IF DIFFERENT DOCTOR (3) Do you know _____'s doctor(or any of the doctors in that group) at all?

Yes.....4
No.....5

IF NO (5) SKIP TO Q.23

SKIP TO Q.25 IF NO G.P. CONSULTED IN LAST TWELVE MONTHS '0' AT Q.20a)

23. Do you think _____'s doctor is an easy person to talk to or not?

Easy..... ..1
Not easy..... . .2

Why do you feel that?

24. Do you think he has time to discuss things or not?

Has time..... 3
Not.....4

Could you give me an example?

I'd like to ask you some questions about _____'s work

25. Did _____ do any paid work in the 12 months before he died?

Yes.....1
No.....2

IF NO (2) Why was that?

housewife and not worked 10+ yrs.....3
Retired.....4
Ill - health.....5
Other SPECIFY.....6

IF (3) SKIP TO Q.31.

IF RETIRED a) How old was he when he retired from his main job?

Under 60.....1
60 - 64.....2
65 - 69.....3
70 +.....4

IF UNDER 65

Did he retire early because of ill health or not?

Yes.....5
No.....6

IF YES (5)(i)What was the matter?

(ii)Did anyone advise him to give up work? Who?

No-one.....1
G.P.....2
Other SPECIFY...3

SKIP TO Q.29

IF ILL HEALTH

a) When did he stop working because of ill-health?

1 yr < 2 yrs before death....1
2 yrs < 5 yrs.....2
5 yrs < 10 yrs.....3
10 yrs or longer.....4
Never worked - ill health....5

b) How old was he then?

Under 35.....1
35 - 44.....2
45 - 54.....3
55 - 59.....4
60 - 64.....5
65 - 69.....6
70 +.....7

c) What was the matter?

d) Did anyone advise him to give up work? Who?

No-one.....1
G.P.....2
Other SPECIFY..3

SKIP TO Q.29.

26 How recently before his death did he work?

Within last week.....1
1 week < 1 month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months +.....5

IF ONE WEEK OR LONGER Had he actually given up his work or not?

Given up.....6
Not given up.....7

27. Was he working part-time or full time then?

Full-time.....6
Part-time.....7

IF PART TIME (7) Why was that?

Housewife.....3
Retired (semi).....4
Ill-health.....5
Other SPECIFY.....6

28. Was that his main job or not?

Main job.....6
Other.....7

IF NOT MAIN JOB a) Why did he give up his main job?

Retired 4
Ill health 5
Other SPECIFY 6

b) How old was he when he gave up his main job?

Under 60.....1
60 - 64.....2
65 - 69.....3
70 +.....4

29. What was his main job?

Self employed with employees.....1
Self employed without employees....2
Manager.....3
Foreman.....4
Other employee.....5

30. Do you think _____'s work was ever a physical or mental strain or effected his health in any way?

No. 0
Yes, physical strain. . . 1
Yes, mental strain 2
Yes - other SPECIFY . . . 3

IF 1, 2 or 3 a) How did it affect him?

b) CHECK Was that his:

Main job 4
Other job. 5

Q.31, Q32 & Q.33 ARE OMITTED IF MAIN RESPONDENT WAS INTERVIEWED ON QUESTIONNAIRE 1 THEY ARE FILLED IN BEFORE INTERVIEW IF MAIN RESPONDENT LIVES IN THE SAME HOUSEHOLD AS THE PERSON INTERVIEWED ON QUESTIONNAIRE 1

31. Can you tell me who lived in the same household as _____ at the time he died/last went into hospital?

RELATIONSHIP TO DECEASED	SEX M	SEX F	AGE GROUP - OMIT FOR RESPONDENT: Under 15	15-34	35-54	55-64	65-74	75-84	85 +
A Deceased	1	2							
B	1	2	3	4	5	6	7	8	9
C	1	2	3	4	5	6	7	8	9
D	1	2	3	4	5	6	7	8	9
E	1	2	3	4	5	6	7	8	9
F	1	2	3	4	5	6	7	8	9

CHECK So there were normally _____ (ENTER NO.) people living in _____'s household?

IF DECEASED LIVED ALONE SKIP TO Q.34 OR Q.59

32. Who normally did the cooking and other housework?
RECORD LETTER _____

RECORD ANY QUALIFICATIONS OR COMPLICATIONS

33. IS MAIN RESPONDENT IN HOUSEHOLD?

Yes. 1
No. 2

IF YES (1) RECORD LETTER _____

FOR UNEXPECTED DEATH OF PERSON UNDER 65 WHO WAS UNRESTRICTED SKIP TO Q.69

34. Were there any changes in _____'s household arrangements after he became ill/as he got older?

Yes. 1
No. 2

IF YES (1) What were they?

CHECK - OMIT IF LIVED ALONE a) Did anyone come to live with him?

Yes. 3
No. 4

IF YES (3) Who?

b) Did he go to live with anyone else?

Yes. 5
No. 6

IF YES (5) Before that did he live alone or with someone else?

Alone. 7
With other(s). . 8

IF WITH OTHERS (8) Who?

IF ANYONE NOT NOW LIVING IN SAME HOUSEHOLD FIND OUT WHAT HAPPENED TO THEM.

35. How long had _____ been living in the same house/flat before he died/went into hospital?

Less than a year.....1
1 year < 2.....2
2 years < 5 years.....3
5 years < 10 years.....4
10 years < 20 years.....5
20 years < 50 years.....6
50 years +.....7

36. And for how long had he been living alone/with just the same person/people?

Less than 1 year.....1
1 year < 2 years.....2
2 years < 5 years.....3
5 years < 10 years.....4
10 years +.....5

IF LESS THAN 5 YEARS FIND OUT REASON FOR AND NATURE OF CHANGE IF NOT ALREADY KNOWN.

Already known.....1
Other SPECIFY.....2

37. Would you say that _____'s house/flat was very convenient, fairly convenient, or rather inconvenient for him after he became ill/old?

Very convenient.....1
Fairly convenient.....2
Rather inconvenient.....3

IF 2 OR 3 In what way?

38. Were the rooms or furniture moved around at all because of _____'s illness/old age?

Yes.....1
No.....2

IF YES (1) a) Could you describe what was done?

b) Did it effect other people at all?

Yes.....5
No.....6

IF YES (5) (i) Whom?

(ii) How did it effect them?

39. Did _____'s house/flat have its own bathroom or was it shared with other people not in his household?

Own.....1
Shared.....2
None.....3

IF 1 OR 2 Had it running hot and cold water?

Yes.....4
No.....5

40. And did it have its own indoor lavatory or was that shared or outside?

Own indoor.....1
Shared indoor.....2
Outside.....3

41. How many steps or floors were there between-

	No. of steps	No. of floors
a) Ground level and _____'s bedroom	_____	_____
b) _____'s bedroom and lavatory	_____	_____

42. I'd like to ask about various symptoms and problems people sometimes have to put up with when they get ill and old. Did _____ have to put up with any of these in the last 12 months of his life-	D.K.	Yes	No	a) Do you think he found it- Very distressing	Fairly distressing	Not very distressing	b) How long had he had it? Less than a week	1 week < 1 month	1 month < 3 months	3 months < 6 months	6 months < 1 year	1 year +	Don't know	c) IF HE DIED IN HOSPITAL CHECK, So old he have it before he went into hospital? Yes	No	d) IF HAD IT AT HOME Did he or you ask any-ones advice about it? Yes	No	e) IF ASKED ADVICE (d) i) Whom did you or he ask? General practitioner	Hospital doctor	Hospital sister/ nurse	District nurse	ii) Were they able to help in any way? How? No	f) IF DID NOT ASK ADVICE(d) Why didn't you or he ask for advice?
1. Pain	9	1	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
2 Sleeplessness	9	2	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
3. Loss of bladder control	9	3	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
4. Loss of bowel control	9	4	0																				
5. Unpleasant smell	9	5	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
6. Vomiting or feeling sick	9	6	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
7. Loss of appetite	9	7	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
8. Constipation	9	8	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
9. Bedsores	9	9	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
10. Mental confusion	9	2	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
11. Trouble with breathing	9	3	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
12. Depression	9	4	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
13. Any other symptoms you or he found distressing SPECIFY	9	5	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	

IF LOSS OF BOWEL OR BLADDER CONTROL AT HOME

Can you tell me how _____ coped with any soiled bed linen?

- Special laundry service....1
- Ordinary laundry....2
- Laundrette....3
- Washed in hose by hand....4
- Washed in home by machine....5
- Disposable pads....6
- Disposable sheets....7
- Other SPECIFY....8

IF DISPOSABLE (6 or 7) a) How did _____ get rid of them?

- Burning in doors in fire place....1
- Burning indoors in a stove....2
- Burning outdoors on open fire....3
- Burning outdoors in incinerator....4
- Dustbin....5
- Special collections....6
- Other SPECIFY....7

b) Was this a problem at all?

- Yes....1
- No....2

IF YES (6) In what way?

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43 LONG TERM INSTITUTIONAL DEATHS SKIP TO Q 50

Here is a list of ways in which people may need help when they are ill or old. Could you tell me if _____ could have done with help of this sort at all (while he was at home) – whether he got it or not? Did he need –

	DK	Yes	No	a) Over what period did _____ need that sort of help? Less than week	< 1 wk	< 1 mth	< 3 mths	< 6 mths	< 1 year	1 year +	Don't know	b) Did anyone help with this? Who help mainly? RELATIONSHIP TO DECEASED OR TYPE OF PERSON No one
11 To be lifted at all	9	1	0	1	2	3	4	5	6	9		0
12 Help with washing (or shaving)	9	2	0	1	2	3	4	5	6	9		0
13 Getting in or out of bath	9	3	0	1	2	3	4	5	6	9		0
14. Dressing or undressing	9	4	0	1	2	3	4	5	6	9		0
15. Getting in or out of bed	9	5	0	1	2	3	4	5	6	9		0
16. Getting hair washed at home	9	6	0	1	2	3	4	5	6	9		0
17. Cutting toenails	9	7	0	1	2	3	4	5	6	9		0
18. Giving bedpan or bottle	9	8	0	1	2	3	4	5	6	9		0
19. Getting to lavatory or commode	9	Y	0	1	2	3	4	5	6	9		0
21. Giving medicines or tablets	9	1	0	1	2	3	4	5	6	9		0
22. Injections	9	2	0	1	2	3	4	5	6	9		0
23. Bandaging or other dressing	9	3	0	1	2	3	4	5	6	9		0
24. Regular temperature taking	9	4	0	1	2	3	4	5	6	9		0
25. Massaging/exercises	9	5	0	1	2	3	4	5	6	9		0
26. Enema	9	6	0	1	2	3	4	5	6	9		0
27. Any (other) nursing procedure SPECIFY	9	7	0	1	2	3	4	5	6	9		0
31. Sitting up with at night ASK Q's AT FOOT OF NEXT PAGE	9	1	0	1	2	3	4	5	6	9		0
32. Other help at night	9	2	0	1	2	3	4	5	6	9		0
41. Someone to take him out	9	3	0	1	2	3	4	5	6	9		0
42 Someone to read to him	9	4	0	1	2	3	4	5	6	9		0
43. Someone to write letters for him	9	5	0	1	2	3	4	5	6	9		0
44 Someone to collect his pension	9	6	0	1	2	3	4	5	6	9		0
45. Someone to change his library books	9	7	0	1	2	3	4	5	6	9		0
51 Financial help	9	8	0	1	2	3	4	5	6	9		0
IF DECEASED OR RESPONDENT HOUSEWIFE Did you or he need help with–												
61. Shopping	9	1	0	1	2	3	4	5	6	9		0
62. Preparing/cooking food	9	2	0	1	2	3	4	5	6	9		0
63. Cleaning house	9	3	0	1	2	3	4	5	6	9		0
64. Washing clothes	9	4	0	1	2	3	4	5	6	9		0
IF APPROPRIATE 71. Did he need help looking after other members of the family, children or anyone else? SPECIFY	9	5	0	1	2	3	4	5	6	9		0

WHEN TABLE COMPLETED CHECK

So _____ didn't need help with any of these things 1

So _____ had some help with all the different things he needed it for 2

So the things _____ could have done with some help with but didn't get any for were :–

RECORD NOS.

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IF HAD SOME HELP Did anyone else help at all? Who? No	(1) Could he have done with any more help with this? Yes / No	IF YES OR IF NEEDED HELP AND DID NOT GET IT Did you or he ask anyone about the possibility of arranging for help with this? Yes / No	IF YES (3) a) Where did you/ they ask? G.P. / Other SPECIFY	b) Were they able to help in any way? How? No	IF NO (4) DID YOU ASK ADVICE Why didn't you ask anyone about this?
0	1 0	3 4	1	0	
0	2 0				
0	3 0				
0	4 0				
0	5 0				
0	6 0				
0	7 0				
0	8 0				
0	Y 0				
0	1 0	3 4	1	0	
0	2 0				
0	3 0				
0	4 0				
0	5 0				
0	6 0				
0	7 0				
0	1 0	3 4	1	0	
0	2 0				
0	3 0	3 4	1	0	
0	4 0				
0	5 0				
0	6 0				
0	7 0				
0	8 0	3 4	1	0	
0	1 0	3 4	1	0	
0	2 0				
0	3 0				
0	4 0				
0	5 0	3 4	1	0	

IF ANY NIGHT CARE NEEDED Can we talk a bit more about the care he needed at night. Was it:-

Comments

PROMPT CODE ALL THAT APPLY

Help to get to the toilet.....1
Bedpan.....2
Medicines that had to be taken then.....3
Injections or other treatment.....4
Drinks.....5
Company.....6
Other SPECIFY.....7

44. Did _____ need any equipment like:	Yes	No	IF YES How did you/he get them? Not got	Bought	Borrowed	Given or supplied	Already had	Other SPECIFY	IF BORROWED, GIVEN OR SUPPLIED Who by/from?
Back rest	1	0	1	2	3	4	5		
Hoist	2	0	1	2	3	4	5		
Special bed SPECIFY	3	0	1	2	3	4	5		
Wheel chair	4	0	1	2	3	4	5		
Crutches/stick	5	0	1	2	3	4	5		
Commode	6	0	1	2	3	4	5		
Hearing aid	7	0	1	2	3	4	5		
IF CONFINED TO BED									
Bedpan/bottle	8	0	1	2	3	4	5		
IF LOSS OF BOWEL/BLADDER CONTROL									
Mackintosh sheet	1	0	1	2	3	4	5		
Pads to protect bed	2	0	1	2	3	4	5		
Extra linen	3	0	1	2	3	4	5		
or anything else SPECIFY	4	0	1	2	3	4	5		

IF HAD WHEEL CHAIR a) Did he use it—

Indoors only.....1
Outdoors only.....2
Both.....3

b) Was it

Motorised.....4
Self propelled.....5
Pushed by other person6

45. There are other sorts of household equipment which may be useful when people are ill or old. Were there any of these in _____'s household —

	Yes	No
Washing machine	1	0
Spin dryer	2	0
Car	3	0
Telephone	4	0

IF YES was it useful / IF NO would it have been useful for helping in the care of _____?

	Yes	No
Washing machine	5	0
Spin dryer	6	0
Car	7	0
Telephone	8	0

46. Was there any (other) piece of equipment it would have been helpful for _____ to have?

Yes.....1
No.....2

IF YES (1) What?

47. OMIT IF NO EQUIPMENT USED OR NEEDED
Do you know of any organisations or people who help with getting equipment for invalids?

Yes.....3
No.....4

IF YES (3) Who does this?

IF RESPONDENT IN SAME HOUSEHOLD AS DECEASED ASK Q.48. ABOUT 'you and he' together - CODING UNDER 'YOU' IF IN SEPARATE HOUSEHOLD ASK ABOUT 'you' and 'he' seperately.

48. Did you and/or he have any additional expenditure during the last 12 months of his life because of his illness/disability/old age on such things as —

	Yes	No	IF YES You	IF YES He
Heating	1	0	1	1
Laundry	2	0	2	2
Special food	3	0	3	3
Extra help (SPECIFY)	4	0	4	4
Prescription charges	5	0	5	5
Other medicines (SPECIFY)	6	0	6	6
Fares, petrol	7	0	7	7
IF EQUIPMENT BOUGHT Q.44 RECORD HERE	8	0	8	8
Anything else SPECIFY	9	0	9	9

IF ANY EXTRA EXPENDITURE a) Would you say it was quite easy for you/him to find that extra money or not?

	You	He
Easy	1	3
Not easy	2	4

IF NOT EASY Did you or he ask anyone for help?

Yes.....5
No.....6

IF YES (5) i) Whom did you ask?

ii) What happened?

IF NO (6) Why not?

b) Do you know where people can sometimes get help with extra money and other things they need to look after invalids?

Yes.....5
No.....6

IF YES (5) Where?

a) IF EXPENDITURE ON FARES OR PETROL How much did it cost you to visit _____ - there and back?

Less than 2/-.....1
2/- < 5/-.....2
5/- < 10/-.....3
10/- < £1.....4

48. Can I check that I've got a note of all the different friends and relations who helped _____ or who helped after he died in any of the ways shown on the card

CHECK

a) Respondent Yes..1 No...2

b) OMIT IF LIVED ALONE OR JUST WITH RESPONDENT
Others in the same household Yes..3 No. .4

c) Other relatives Yes..5 No...6

d) Other friends or relatives Yes .7 No...8

ENTER ALL WHO HELPED ABOVE DOUBLE LINE

50. a) Did _____ have any (other) living brothers or sisters? Yes. 1 No...2

IF YES ENTER BELOW LINE

b) OMIT IF _____ NEVER MARRIED
Did _____ have any (other) living children? Yes. 3 No...4

IF YES ENTER BELOW LINE

c) Did _____ have any (other) close relatives? Yes .8 No ..6

446 IF YES ENTER BELOW LINE

51. Who would you say bore the brunt of looking after _____ you, or someone else?

Respondent.. 7
Other LETTER____

IF NOT RESPONDENT How would you say it affected _____ (person who bore brunt)?

SPECIAL SAMPLE ONLY
j) Who did next most?
k) Who after that? etc
RANK ALL PEOPLE IN TOP HALF OF TABLE ENTERING RANK IN LAST COLUMN.
1 = MOST 2 = NEXT etc.

RELATIONSHIP TO DECEASED	CODE	How near did they live to deceased? Same household	Within 10 mins walk	Within ½hrs journey	½hr < 1hr	1hr < 2hrs	2hrs or more	Did they help - Regularly	Occasionally?	IF REGULARLY How often? Daily	More than weekly < daily	Weekly	Less often
A		0	1	2	3	4	5	6	7	1	2	3	4
B		0	1	2	3	4	5	6	7	1	2	3	4
C		0	1	2	3	4	5	6	7	1	2	3	4
D		0	1	2	3	4	5	6	7	1	2	3	4
E		0	1	2	3	4	5	6	7	1	2	3	4
F		0	1	2	3	4	5	6	7	1	2	3	4
G		0	1	2	3	4	5	6	7	1	2	3	4
H		0	1	2	3	4	5	6	7	1	2	3	4

RELATIONSHIP TO DECEASED	CODE	How near did they live to deceased? Within ½hr	½hr < 1hr	1hr < 2hrs	Engl or Wales	Ireland or Scotland	Abroad	Don't know	Comments.
J		4	5	6	7	8	9		
K		4	5	6	7	8	9		
L		4	5	6	7	8	9		
M		4	5	6	7	8	9		
N		4	5	6	7	8	9		
O		4	5	6	7	8	9		

What things did they help with? Anything else? LIST CODE NOS.	FOR PEOPLE NOT IN SAME HOUSEHOLD Could you say about how many times they saw _____ in the last 12 months? 1 - 2 / 3 - 5 / 6 - 11 / 12 - 19 / 20 - 49 / 50 - 299 / 300 +	SPECIAL PEOPLE ONLY (4th digit of serial no an X) If possible I'd like to see all the different people who helped to look after _____. Could you tell me their names and addresses.		Rnds 9.51.
		NAME	ADDRESS	
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			

	Could you say how many times they saw _____ in last 12 months? Not at all / 1 - 2 / 3 - 5 / 6 - 11 / 12 - 19 / 20 - 49 / 50 / D.K.
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9

52. Can I check the various sorts of official people who helped _____ during the last 12 months of his life (while he was at home). During that time did he have any help from, or was he ever visited by:

IF YES (a) Who arranged for him to have that sort of help?

b) For how long did he have that sort of help?

c) How often did he have that sort of help - at its most frequent?

d) So about how many times did _____ have that sort of help in the last 12 months of his life?

Comments.

	Yes	No	General practitioner	Hospital doctor	Hosp. sister/nurse	District nurse	Health or welfare visitor	Relative or friend	Deceased himself	Other SPECIFY	Less than a week	1 week < 1 month	1 month < 3 months	3 months < 6 months	6 months < 1 year	1 year or more	Daily or more often	More than weekly < daily	Weekly	More than weekly < monthly	Monthly	Less often	1 - 2	3 - 5	6 - 11	12 - 19	20 - 49	50 - 299	300+
A district nurse	1	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7
Health visitor	2	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7
Other nurse	3	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7
Home help	4	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7
Special laundry service	5	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7
Chiropodist	6	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7
Vicar priest or minister	7	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7
Any other official or voluntary service	8	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7

SPECIFY

a) Do you feel he had that help as often as necessary or would it have been better if he'd had it more or less often?

IF MORE OR LESS OFTEN Can you tell me why?

f) Would you have liked (her) to do any other things beside what she did do?

IF YES (4) What things?

IF WOULD HAVE LIKED MORE HELP (2 or 4)

Did you or he ask for more help?

IF YES (6) a) Whom did you ask?

b) What happened?

IF NO (7) Why didn't you or he ask?

g) Can I check the various things _____ he'pad with? HAND CARD LIST CODE NOS.

h) Did she do any thing else? What?

	As often as necessary	Prefer more often	Prefer less often	Yes	No	Yes	No
A district nurse	1	2	3	4	5	6	7
Health Visitor	1	2	3	4	5	6	7
Other nurse	1	2	3	4	5	5	7
Home help	1	2	3	4	5	6	7
Special laundry service	1	2	3	4	5	6	7
Chiropodist	1	2	3	4	5	6	7
Vicar priest or minister	1	2	3	4	5	6	7
Other	1	2	3	4	5	6	7

ASK ONLY ABOUT TYPES OF HELP NOT RECEIVED.

Do you think _____ could have done with any help from -

		Yes
PROMPT ONES NOT RECEIVED	A nurse at home	1
	Home help	4
	Laundry service	5
	Chiropodist	6
	Bath attendant	8
	or any other sort of service	Y
	None	0

IF YES TO ANY CHECK THAT DETAILS OF TYPE HELP NEEDED ARE RECORDED AT Q.43.

54. OMIT IF VICAR etc. HAD VISITED Do you think he would have liked a vicar, priest or minister to visit him?

Yes.....5
No.....6

Comments.

IF RESPONDENT NOT INVOLVED IN CARE OF DECEASED SKIP TO Q.58 - OR Q.59 IF NOT RELATIVE OR CLOSE FRIEND

55. Were you working at the time you started to look after _____?

Yes.....1
No.....2

IF NO (2) SKIP TO Q.59

IF YES (1) Was it full time or part time?

Full time. 3
Part time 4

56. Did you have to make any changes in your work because of looking after _____ such as:-

	Yes	No
Changing to different hours	1	0
Changing to less hours	2	0
Changing to different work	3	0
Taking time off	4	0
Retiring early	5	0
Give up work altogether	6	0
Any other changes? SPECIFY	7	0

IF NO CHANGES SKIP TO Q.59

57. For how long was your work affected?

Less than 2 weeks.....1
2 weeks < 1 month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year.....5
1 year + SPECIFY.....6

58. Did this make a lot, a little or no difference to you financially?

A lot.....5
A little.....6
No difference.....7

IF A LOT OR A LITTLE (5 or 6) a) Do you know where some people can get financial help over this in some circumstances?

Yes.....1
No.....2

IF YES (1) Where?

b) Did you yourself apply for financial help?

Yes.....3
No.....8

IF YES (3) (i) Where did you apply?

(ii) What happened?

IF NO (4) Why was that?

59. Could you describe any (other) differences looking after _____ made to your life?

IF RESPONDENT NOT RELATED TO DECEASED AND NOT A CLOSE FRIEND SKIP TO Q.65.

Can we move onto another subject now?

60. During _____'s illness or incapacity were you able to find out all you wanted to know about his illness and how it was likely to affect him?

Yes.....1
No.....2

IF YES (1) Was there anything else you would have liked to have explained to you in more detail?

Yes.....3
No.....4

IF NO (4) Were you able to find out about things as soon as you wanted to ~~or was there anything you'd have liked to know about earlier~~?

Yes.....5
No.....6

YES(5)

IF NO (6) SKIP TO Q.63

61. What would you have liked to know about/in more detail/earlier? Anything else?

62. Did you ask anyone about this?

Yes.....1
No.....2

IF YES (1) a) Whom did you ask?

General practitioner.....5
Hospital doctor.....6
Hospital sister/nurse.....7
District nurse.....8
Other SPECIFY.....9

b) What happened?

IF NO (2) Why not?

63. Who did you talk to about _____'s illness and what was likely to happen? What about:

		Discussion Yes	No	Most inf.
	_____'s G.P.....	1	0	1
	Other general practitioner..	2	0	2
OMIT IF NOT APPROPRIATE	Hospital doctor.....	3	0	3
	Hospital sister/nurse.....	4	0	4
	District nurse.....	5	0	5
	Home help.....	6	0	6
	Vicar priest, minister.....	7	0	7
	Any other nurse, doctor or professional person SPECIFY.	8	0	8
		Y	0	Y
	Your relatives SPECIFY.....			
		1	0	1
		2	0	2
		3	0	3
	Friends/neighbours.....	4	0	4
	Anyone else-SPECIFY.....	5	0	5
		6	0	6

64.a) Who gave you most information? CODE ABOVE ONE ONLY

b) What sort of thing did they tell you?

65. Did _____ know what was wrong with him?

Yes.....1
No.....2
Uncertain.....3

IF YES (1) Had anyone told him? Who?

No-one.....0
General practitioner....5
Hospital doctor.....6
Hospital sister/nurse...7
District nurse.....8
Other SPECIFY.....9

c) Did _____ know he was not likely to recover?
or Did _____ know this was likely to happen?

Yes, certain.....1
Yes, probably.....2
Probably not.....3
No definitely.....4
Unable to say.....5

IF UNABLE TO S/Y SKIP TO Q.67

IF PROBABLY OR CERTAINLY KNEW (1 or 2)

a) Had anyone told him? Who?

No-one.....0
General practitioner...5
Hospital doctor.....6
Hospital sister/nurse..7
District nurse.....8
Other SPECIFY.....9

b) Do you think that was best or do you think it would have been better if he had not known
(or had known definitely)

Better not to have known 1
Better to have known definitely.... 2
Best as it was.....3
Uncertain.....4

Why do you feel that?

c) How long before he died had he (or might he have) known?

Less than 24hrs. 0
24hrs < 1 week. 1
1 week < 1 month.....2
1 month < 3 months 3
3 months < 6 months.....4
6 months < 1 year. 5
1 year or more 6

IF PROBABLY OR CERTAINLY DID NOT KNOW

Do you think that was best or would it have been better for him to know (or definitely not to know)

Better to have known.....5
Better not to know definitely.....6
Best as it was.....7
Uncertain.....8

Why do you feel that?

IF BETTER TO HAVE KNOWN (5) Who do you think would have been the best person to tell him?

General practitioner.....5
Hospital doctor.....6
Hospital sister/nurse.....7
District nurse.....8
Respondent - self.....1
Other SPECIFY.....0

67. What about from your point of view. Did you know what was wrong with _____?

Yes.....1
No.....2
Half know.....3

IF YES (1) Did anyone tell you? Who?

No-one.....0
General practitioner.....1
Hospital doctor.....2
Hospital sister/nurse.....3
District nurse.....4
Other SPECIFY.....5

IF RESPONDENT NOT RELATED TO DECEASED AND NOT A CLOSE FRIEND SKIP TO Q.69

58. CHECK: I think you said your- knew/ didn't know/half knew that - was unlikely to recover.

Knew..... 4
Didn't know.....5
Half knew.....6

IF KNEW (4) a) Had anyone told you? Who?

No-one.....0
General practitioner.....5
Hospital doctor.....6
Hospital sister/nurse.....7
District nurse.....8
Other SPECIFY.....9

b) How long had you known before he died?

Less than 24 hours..... ..0
1 day < 1 week.....1
1 week < 1 month, ...2
1 month < 3 months.....3
3 months < 6 months..... ..4
6 months < 1 year..... ..5
1 year or more.....6

c) Would you have preferred not to know or do you think it was better that you did?

Preferred not.....1
Better that knew.....2
Uncertain..... 3

Why do you feel that?

IF 2 or 3 Would you have liked to have known earlier or later or when you did?

Earlier..... 5
Later.....6
Right time.....7

d) Did you expect _____ to die earlier, later or when he did?

Earlier.....1
Later..... 2
When he did.....3
Couldn't say.....4

GO ON TO Q 69

IF DIDN'T KNOW (5) Would you have liked to have known or do you think it was better that you didn't?

Like to have known.....5
Glad didn't..... ...6

Why do you feel that?

IF LIKE TO HAVE KNOWN (5) Who would have been the best person to tell you?

General practitioner.....5
Hospital doctor.....6
Hospital sister/nurse..... 7
District nurse .....))
Other SPECIFY.....9

IF HALF KNEW (6) Would you have preferred to know definitely or not to have known at all or do you think it was best as it was?

Liked to have known definitely 1
Liked not to have known at all.. 2
Best as it was..... 3

Why do you feel that?

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69. Was _____ unconscious before he died?

Yes.... 4
No.... 5

IF YES (4) How long before?

Less than 3 hours	0
3 hrs < 24hrs	1
1 day < 1 week	2
1 week or more	3

70. Could he recognise his relatives up until the time he died - when he was conscious?

Yes, always.... 6
Sometimes.... 7
No.... 8

IF NOT ALWAYS (7 or 8) How long before?

Less than 24 hours.... 0
1 day < 1 week.... 1
1 week < 1 month.... 2
1 month < 3 months.... 3
3 months < 1 year.... 4
1 year +.... 5

71. Were you with _____ when he died?

Yes, at bedside.... 1
Elsewhere in house.... 2
No.... 3

IF NO (3) When was the last time you saw _____?

Within 24 hours.... 0
1 day < 1 week.... 1
1 week < 1 month.... 2
1 month < 3 months.... 3
3 months or more before death.... 4

72. Were any (other) relatives or friends with him?

Yes.... 1
No.... 2

73. OMIT IF _____ DIED AT HOME AND INFORMANT IN SAME HOUSEHOLD OR IF NOT SEEN IN LAST 3 MONTHS.

Roughly how often did you see him in.

	Last week	Last Month	Last 3 Months
Not at all	0	0	0
Once	1	1	1
2 - 4	2	2	2
5 - 9	3	3	3
10 - 19	4	4	4
20 +	5	5	5

IF DIED IN HOSPITAL OR INSTITUTION SKIP TO Q.79

IF DIED IN STREET/OFFICE ETC. SKIP TO Q 84

FOR QUITE UNEXPECTED HOME DEATHS SKIP TO Q.76.

74. How did you feel about _____ dying at home rather than in hospital?

75. Did you at any stage feel it would have been better for _____ to be in a hospital (again) either from his point of view or from the point of view of the people looking after him?

Yes.... 1
No.... 2

Could you say why?

IF YES (1) a) So was that from:

CODE ALL THAT APPLY

_____'s point of view.... 3
Your point of view.... 4
Point of view of others looking after him.... 5

b) Did you discuss this with _____'s general practitioner?

Yes.... 6
No.... 7

IF YES (6) What happened?

IF NO (7) a) Why not?

b) Did you talk to anyone else about it?

Yes.... 8
No.... 0

IF YES (8) Who?

76. Who washed and prepared _____'s body?

Self.... 1
Relative SPECIFY.... 2

Neighbour/friends.... 3
Nurse SPECIFY.... 4

Undertaker.... 5
Other person SPECIFY.... 6

77. Looking back on it do you think it would have been helpful if you had known more about what to do when someone died or do you feel you knew enough?

Knew enough 1
Like to have known more 2

IF KNEW ENOUGH (1) Had someone told you about it - or did you know from previous experience?

Someone told. 3
Knew from experience....4

IF TOLD (3) Who told you?

District nurse.. 1
General practitioner....2
Relative... 3
Friend/neighbour.... 4
Other SPECIFY.. 5

78. Did a general practitioner come to see _____ after he had died?

CODE YES IF PRESENT WHEN DIED

Yes.... 5
No.... 6

IF YES (5) a) Was this:

His own doctor.... 1
Another doctor who'd seen him before. 2
or Another doctor....3

b) And was he the doctor who signed the death certificate or not?

Yes....4
No....5

c) How soon did he come - after he died?

Present when died....0
Within hour 1
1 hour < 3 hours....2
3 hours < 6 hours....3
6 hours < 24 hours.... 4
1 day < 2 days.... 5
2 days < 3 days.... 6
3 days or longer. 7

Comments

IF NO (6) Would you have liked a doctor to come or not?

Liked doctor to come....1
Not....2

Comments

HOME DEATHS SKIP TO Q.84

79. How did you feel about _____ dying in hospital (an institution) rather than at home?

80. Did you at any stage feel it would have been better for _____ to be at home?

Yes.... 3
No. 6

Could you say why?

IF YES (3) Did you discuss it with _____ a general practitioner or with anyone at the hospital?

Yes....5
No. 6

IF YES (5) a) Who?

General practitioner.... 1
Hospital doctor.... 2
Hospital nurse.... 3
Other SPECIFY.... 4

b) What happened?

IF NO (6) (7) Why not?

(7:) Did you talk to anyone else about it?

Yes.... 5
No....6

IF YES (5) Who?

81. When _____ went into hospital (the last time) who first suggested it?

Deceased.. 1
Respondent 2
Other relative SPECIFY.3

General practitioner...4
Hospital doctor....5
Other SPECIFY.... 6

82. How about _____ do you think he was relieved, distressed or how did he feel?

Relieved.... 1
Distressed.... 2
Other SPECIFY.... ..3

83. And what about you - did you feel relieved or distressed or what?

Relieved.....4
Distressed.....5
Other SPECIFY.....6

TO ALL

84. Who was mainly responsible for the arrangements with the undertaker and all the other formalities?

Self alone.....1
Self with others.....2
Others only.....3

IF RESPONDENT NOT A RELATIVE OR CLOSE FRIEND SKIP TO Q.98

85. Would you have liked any (more) help with (that or) anything after _____ died?

Yes.....1
No.....2

IF YES (1) What with?

86. Have you a religious faith or belief which you feel helped you at the time of _____'s death?

Yes.....1
No.....2

87. What about _____ do you think he had a religious faith or belief which was helpful to him?

Yes.....3
No.....4

88. To which faith or denomination do you belong?

	Respondent	Deceased
Roman Catholic	1	1
Church of England	2	2
Other protestant	3	3
Jewish	4	4
None	5	5
Other SPECIFY	6	6

89. What about _____ what did he belong to?

90. Have any of these people visited you at home since _____ died?

		Visited	Liked visit
	Your own doctor	Y	Y
PROMPT	Other general practitioner	1	1
	District nurse	2	2
	Other nurse	3	3
	Welfare or social worker	4	4
	Vicar, priest or minister	5	5
	Any other professional person SPECIFY	6	6

91. Would you have liked any (other) of them to visit?

Yes.....7
No.....0

IF YES (7) Who? RECORD ABOVE

Comments:

92. Have you consulted a doctor, nurse or chemist professionally for yourself since _____ died?

Yes.....1
No.....2

IF YES (1)a) Who?

CODE ALL THAT APPLY

General practitioner.....3
Other doctor.....4
District nurse.....5
Other nurse.....6
Chemist.....7

b) What was the trouble?

c) Do you think it had anything to do with your bereavement or not?

Yes.....1
No.....2
Uncertain.....3

d) IF DOCTOR OR CHEMIST Did he give/sell you any tablets or medicine?

Yes.....4
No.....5

IF YES (4) What were they for?

93. Have you made any changes in your way of living - your accomodation, work or anything else - since _____ died?

Yes.....1
No.....2

IF YES (1) What changes?

447

Are you planning any (other) changes?

Yes. 3
No 4

IF YES (3) What?

95. Since _____ died have you had any particular worries or anxieties such as:

PROMPT

Financial worries.....1
Legal ones - to do with the will.....2
Problems with house or tenancy.....3
Anything else SPECIFY.....4

Nothing.....0

IF ANY WORRIES. Did you consult anyone about those?

Yes.....5
No.....6

IF YES (5) (i) Who?

(ii) Were they able to help?

Yes.....7
No.....8

IF NO (6) Why not?

96. When some one close to you dies who do you feel it is best to talk to about how you feel -

PROMPT

A relative.....3
A close friend.....4
A professional person.....5
An outsider.....6
or who? SPECIFY.....7

Why do you say that?

IF PROFESSIONAL What sort of person had you in mind -

PROMPT

A doctor.....1
A nurse.....2
A lawyer.....3
A clergyman.....4
or who.....5

97. Who did you find most helpful?

98. Is there anything else you would like to say about

a) _____'s care before he died?

b) His death?

c) The time since he died?

CLASSIFICATION As I've explained we don't use any names in our study but we do like to know one or two things though about the people who help us.

(i) Do you mind telling me your age?

21 - 24.....1
25 - 34.....2
35 - 44.....3
45 - 54.....4
55 - 64.....5
65 - 69.....6
70 - 74.....7
75 - 79.....8
80 - 84.....9
85 and over.....0

(ii) CHECK. SEX.

Male.....1
Female.....2

(iii) CHECK. Marital status.

Single, never married.....3
Married now.....4
Widow(er) of deceased.....5
Other widow/divorced etc.....6

IF WIDOW OF DECEASED SKIP TO Q.(v)

(iv) IF MAN UNDER 65 or SINGLE WOMAN UNDER 60.
What is your occupation ? RECORD BELOW.

IF MAN 65+ OR SINGLE WOMAN 60+
What was your main occupation? RECORD BELOW.

IF WOMAN & EVER MARRIED BUT NOT TO DECEASED
What is/was your husband's main occupation?

Self-employed with employees.....1
Self-employed without employees.....2
Manager.....3
Foreman.....4
Other employee.....5

v) PRESENT HOUSEHOLD

Respondent now lives alone. 1
Respondent lives with others.. 2

IF WITH OTHERS (2) a) How many are there in the household altogether?

_____

b) Relationship(s) to respondent

A_____
B_____
C_____
D_____
E_____

IF ALONE (1) a) Who is the relative you see most of?

b) Where do they live?

Within 10 mins walk. . ..1
Within ½hr journey.....2
½hr < 1hr 3
1hr < 2hrs 4
2hrs or more..... 5

vi) Is there anything you would like to say or ask about this study - or the Institute of Community Studies?

THANK RESPONDENT LEAVE CARD.

DETAILS OF INTERVIEW

vii) Length of interview

Less than 30 mins.....1
30 mins < 45 2
45 mins < 1 hour.....3
1 hour < 1½hours.....4
1½ hours < 2 hours.....5
2 hours or more.....6

viii) Completed on-

single occasion.....1
more than one occasion.2

ix) Anyone else present

Yes.....3
No.....4

IF YES (3) Who?
RELATIONSHIP TO RESPONDENT

x) Main informant was:

Only appropriate person.....1
One of two or more appropriate people.....2
Not the most appropriate person.3

IF (2 or 3) a) Who (else) was appropriate?
RELATIONSHIP TO DECEASED

WHERE LIVING

xi) Type of interview:

Main questionnaire only.....4
Main + questionnaire 1 respondent registered death.....5
Respondent other first contact....6
Main questionnaire after questionnaire 1 completed by other household member.....7

xii) Date of interview | | | |

xiii) Interviewer. | | |

EXTRA QUESTIONNAIRE FOR SN 393A.

Medical Care Research Unit,
Institute of Community Studies,
18 Victoria Park Square,
London, E.2.

HOME CARE SURVEY

Questionnaire I

INTRODUCTION: FOR PERSON WHO REGISTERED DEATH.....1

I am from a social research organisation the Medical Care Research Unit of the Institute of Community Studies. We are doing a study about how people cope with illness and death which we hope will eventually help other people in a similar position. We feel that the best way to do this is to ask the people concerned. We believe you registered the death of _____, and I hope you will help us by answering some questions. Anything you tell us will be treated as confidential and no names will be mentioned in the book we are planning to write

INTRODUCTION: OTHER FIRST CONTACT.....2

I am from a social research organisation the Medical Care Research Unit of the Institute of Community Studies. We are doing a study about how people cope with illness and death which we hope will eventually help other people in a similar position. We believe that _____ died recently, and we would like to talk to someone who knew him. Would you (be able to) help us? Anything you tell us will be treated as confidential, and no names will be mentioned in the book we are planning to write.

1. IF INFORMANT We know from the register of deaths that _____ died in _____(month). I believe you were his

IF OTHER FIRST CONTACT We know from the register of deaths that _____ died in _____ (month). Were you a relative of his? What?

Husband/wife.....1
Father/mother.....2
Father-in-law/mother-in-law.....3
Son/daughter.....4
Son-in-law/daughter-in-law.....5
Grandchild.....6
Brother/sister.....7
Brother-in-law/sister-in-law.....8
Neighbour.....9
Friend.....Y
Other SPECIFY.....0

IF NOT A RELATIVE a) How long had you known him?

Less then a year.....1
1 year < 2 years.....2
2 years < 5 years.....3
5 years < 10 years.....4
10 years < 15 years.....5
15 years < 20 years.....6
20 years or more.....7

b) IF FRIEND OR NEIGHBOUR
Would you say he was a close friend of yours or not?

Yes, close friend.....1
No.....2

1a At the time - died was he:-

Married.....1
Single.....2
Widowed.....3
Divorced/Separated.....4

2. Can you tell me who lived in the same household as _____ at the time he died/last went into hospital?

RELATIONSHIP TO DECEASED	SEX M	SEX F	AGE GROUP - OMIT FOR INFORMANT Under 15	15-34	35-54	55-64	65-74	75-84	85+
A DECEASED	1	2							
B	1	2	3	4	5	6	7	8	9
C	1	2	3	4	4	6	7	8	9
D	1	2	3	4	5	6	7	8	9
E.	1	2	3	4	5	6	7	8	9
F	1	2	3	4	5	6	7	8	9

CHECK. So there were normally _____ (ENTER NO.) people living in _____'s household?

IF DECEASED LIVED ALONE SKIP TO Q.5.

3. Who normally did the cooking and other housework?
RECORD LETTER _____

RECORD ANY QUALIFICATIONS OR COMPLICATIONS

4. IS INFORMANT IN HOUSEHOLD?

Yes.....1
No.....2

IF YES (1) RECORD LETTER. _____

5. We would like to know about _____'s health and about any help he had to look after him during the last 12 months of his life.

Informant most appropriate person.....1
Other person in household most appropriate.....2
No appropriate person identified.....3

IF (1) Would you be willing to help?

Yes.....4
No.....5

IF YES (4) Thank you GO TO QUESTIONNAIRE 2 Q 2

IF NO (5) Who do you think might help us? RECORD a), b), and c) BELOW

IF (2) It looks as if _____ would be the most suitable person to help. Could you give me his/her name and address? RECORD BELOW

IF (3) Who do you think would be the most suitable person to help?

a) RECORD RELATIONSHIP TO DECEASED

b) Could you say why you think that person would be the most suitable?

c) Could you give me his/her name and address.

NAME

ADDRESS

6. Is there anyone else who would be as suitable or almost as suitable to ask?

Yes.....1
No.....2

IF YES (1) a) RELATIONSHIP

b) NAME

c) ADDRESS

7. CHECK Suggested main respondent lives in:

Same household as informant.....3
Other household.....4

IF (3) MAKE ARRANGEMENTS TO INTERVIEW MAIN RESPONDENT, IF POSSIBLE COMPLETE CLASSIFICATION.

I hope you will help us by giving us some information.

8. As far as you were concerned was _____'s death expected or not?

Expected.....1
Not expected.....2
Uncertain.....3

IF EXPECTED (1) What was the matter?

IF NOT EXPECTED OR UNCERTAIN (2 or 3)

a) Was it completely unexpected with no previous ill ness or warning at all?

Yes.....6
No.....5

b) What happened?

CHECK: So the condition _____ died of was:-

9. So before he died was _____ ever completely bedridden?

Yes.....1
No.....2

IF YES (1) How long was that for?

Less than a week.....1
1 week < a month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year.....5
1 year or more.....6

IF A YEAR OR MORE SKIP TO Q.14

10. (Before that) Was he confined mainly to bed?

Yes.....3
No.....4

IF YES (3) How long was that for?

Less than a week.....1
1 week < a month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year.....5
1 year or more.....6

IF A YEAR OR MORE SKIP TO Q.14.

11. (Before that) Was he at all restricted in what he could do inside the house?

Yes.....5
No.....6

IF YES (5) Would you say he was:-

Severely restricted.....1
Moderately restricted.....2
A little restricted.....3

IF NO (6) Was he restricted in what he could do outside?

Yes.....7
No.....8

IF NO (8) Would you describe his health in the last 12 months as -

Good.....1
Fair.....2
PROMPT Poor.....3
Very poor.....4

In what way?

IF NO (8) SKIP TO Q.14.

12. For how long was he restricted in that way?

Less than a week.....1
1 week < a month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year.....5
1 year or more.....6

13 Could you describe how he was restricted?

14. And was he under 65 or not when he died?

Yes, under 65.....1
65 or more.....2

15. I believe _____ died in: or Where did _____ die?

Hospital.....1
Other Institution SPECIFY BELOW.....2
Deceased's own home.....3
Other person's home SPECIFY BELOW.....4
Other SPECIFY.....5

IF IN HOSPITAL OR OTHER INSTITUTION How long was he in hospital before he died?

< 24 hours.....X
1 day < 3 days.....0
3 days < 1 week.....1
1 week < 1 month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months < 1 year.....5
1 year < 2 years.....6
2 years < 5 years.....7
5 years + SPECIFY.....8

5

16. CHECK

Long term institutional death (6,7 or 8 at Q15).....1
Unexpected death of person under 65 with no previous restrictions. 2
Other death.. 3

IF LONG TERM INSTITUTIONAL SKIP TO CLASSIFICATIONS or Q 33 IF IN SPECIAL SAMPLE

17. Could you tell me the name and address of _____'s general practitioner?
NAME AND INITIALS

ADDRESS

18 When was the last time _____ saw a general practitioner before he died?

Within 24 hours..... 0
1 day < 1 week..... 1
1 week < 1 month.....2
1 month < 3 months..... ...3
3 months < 6 months... 4
6 months < 1 year. 5
1 year < 2 years.....6
2 years < 5 years.. 7
5 years or more..... 8

19 Did _____ do any paid work in the 12 months before he died?

Yes. 1
No 2

IF YES (1) How recently before his death?

Within last week.....1
1 week < 1 month.....2
1 month < 3 months.....3
3 months < 6 months.....4
6 months + ...5

IF NO (2) Why was that?

Housewife and not worked 10+ yrs...3
Retired.....4
Ill - health..... 5
Other SPECIFY... 6

IF UNEXPECTED DEATH OF PERSON UNDER 35 WITH NO PREVIOUS RESTRICTIONS SKIP TO CLASSIFICATIONS

20. Here is a list of ways in which people may need help when they are ill or old. Could you tell me if _____ could have done with help of this sort at all (while he was at home) - whether he got it or not?

Did he need:- IF YES a) Did you help at all with this?
b) Did anyone else help?

	Needed			Inf helped		Other person helped	
	DK	Yes	No	Yes	No	Yes	No
11. To be lifted at all	9	1	0	1	0	1	0
12. Help with washing (or shaving)	9	2	0	2	0	2	0
13. Getting in or out of bath	9	3	0	3	0	3	0
14. Dressing or undressing	9	4	0	4	0	4	0
15. Getting in or out of bed	9	5	0	5	0	5	0
16. Getting hair washed at home	9	6	0	6	0	6	0
17. Cutting toenails	9	7	0	7	0	7	0
18. Giving bedpan or bottle	9	8	0	8	0	8	0
19. Getting to lavatory or commode	9	Y	0	Y	0	Y	0
21. Giving medicines or tablets	9	1	0	1	0	1	0
22. Injections	9	2	0	2	0	2	0
23. Bandaging or other dressing	9	3	0	3	0	3	0
24. Regular temperature taking	9	4	0	4	0	4	0
25. Massaging/exercises	9	5	0	5	0	5	0
26. Enema	9	6	0	6	0	6	0
27. Any (other) nursing procedure SPECIFY	9	7	0	7	0	7	0
31. Sitting up with at night	9	1	0	1	0	1	0
32. Other help at night	9	2	0	2	0	2	0
41. Someone to take him out	9	3	0	3	0	3	0
42. Someone to read to him	9	4	0	4	0	4	0
43. Someone to write letters for him	9	5	0	5	0	5	0
44. Someone to collect his pension	9	6	0	6	0	6	0
45. Someone to change his library books	9	7	0	7	0	7	0
51. Financial help	9	8	0	8	0	8	0
IF DECEASED OR INFORMANT HOUSEWIFE							
Did you or he need help with:-							
61. Shopping	9	1	0	1	0	1	0
62. Preparing/cooking food	9	2	0	2	0	2	0
63. Cleaning house	9,	3	0	3	0	3	0
64. Washing clothes	9	4	0	4	0	4	0
			-		-		
IF APPROPRIATE							
71. Did he need help looking after other members of the family, children or anyone else? SPECIFY	9	5	0	5	0		0

21. During the last 12 months of his life did you help in any (other) of the ways shown on the card - or after he died at all?

Yes 1
No. 2

IF YES (1) How?

IF INFORMANT DID NOT HELP AT ALL SKIP TO CLASSIFICATION OR IF IN SPECIAL SAMPLE TO Q 33 or Q 35

22. Did you help

Regularly	6
Occasionally	7

IF REGULARLY (6) How often?

Daily	1
More than weekly < daily	2
Weekly	3
Less often	4

IF INFORMANT LIVED IN SAME HOUSEHOLD AS DECEASED SKIP TO Q 26

23. How near did you live to _____?

Within 10 mins walk	1
Within ½hr journey	2
½hr < 1hr journey	3
1hr < 2hrs journey	4
2hrs or more	5

24. How much did it cost you to get there and back?

Less than 2/-	1
2/- < 5/-	2
5/- < 10/-	3
10/- < £1	4
£1 or more	5

25. Could you say about how many times you saw _____ in the last 12 months of his life?

1 - 2	1
3 - 5	2
6 - 11	3
12 - 19	4
20 - 49	5
50 - 299	6
300 +	7

26. Were you working at the time you started to look after _____?

Yes	1
No	2

IF NO (2) SKIP TO Q 30

IF YES (1) Was it full time or part time?

Full time	3
Part time	4

27. Did you have to make any changes in your work because of looking after _____ such as:-

	Yes	No
Changing to different hours	1	0
Changing to less hours	2	0
Changing to different work	3	0
Taking time off	4	0
Retiring early	5	0
Give up work altogether	6	0
Any other changes? SPECIFY	7	0

IF NO CHANGES SKIP TO Q 30

28 For how long was your work affected?

Less than 2 weeks	1
2 weeks < 1 month	2
1 month < 3 months	3
3 months < 6 months	4
6 months < 1 year	5
1 year + SPECIFY	6

29, Did this make a lot, a little or no difference to you financially?

A lot	5
A little	6
No difference	7

30 Could you describe any (other) differences looking after _____ made to your life?

31 I'd like to know about any help given by official sort of people during the last 12 months of his life (while he was at home)

During that time did he have any help from or was he ever visited at home by -

	Yes	No	IF NO Do you think he could have done with any help from: Yes	No
A district nurse	1	0	1	0
Health visitor	2	0		
Other nurse	3	0		
Home help service	4	0	4	0
Special laundry service	5	0	5	0
Chiropodist	6	0	6	0
Vicar, priest or minister	7	0	7	0
Any other official or voluntary service SPECIFY	8	0	8	0

IF NOT IN SPECIAL SAMPLE SKIP TO CLASSIFICATION

OMIT IF DID NOT DIE AT HOME

32. Did you at any stage feel it would have been better for _____ to be in a hospital (again) either from his point of view or from the point of view of the people looking after him?

Yes.. 1
No..... 2

Could you say why?

IF YES (1) a) So was that from:

CODE ALL THAT APPLY

_____'s point of view.3
Your point of view.....4
Point of view of others looking after him.... ...5

IF DID NOT DIE IN HOSPITAL OR INSTITUTION SKIP TO Q 35

33. Did you at any stage feel it would have been better for _____ to be at home?

Yes.... 3
No..... . 4

Could you say why?

34. Did you visit _____ while he was in hospital/ institution?

Yes..... .7
No. 8

IF YES (7) a) About how many times (during the last 12 months of his life)?

1 - 4.. 1
5 - 9..... . 2
10 - 19. 3
20 - 49.. 4
50 + ...5

b) How long did it take you to get there?

Less than 15 mins.... 1
15 mins < 30 mins..... .2
30 mins < 45 mins.... 3
45 mins < 1 hour.....4
1 hour < 2 hours.... 5
2 hours + ...6

c) What were the arrangements for visiting?

Set times.....1
Free visiting.....2
Other SPECIFY.....3

d) Did you feel the arrangements were satisfactory or not satisfactory?

Satisfactory.....3
Not satisfactory...4

In what way?

35. Were you with _____ when he died?

Yes, at bedside.....1
Elsewhere in house.....2
No..... 3

IF NO (3) When was the last time you saw _____?

Within 24 hours.. 0
1 day < 1 week..... 1
1 week < 1 month. 2
1 month < 3 months. 3
3 months or more before death....4

36. Have you made any changes in your way of living - your accomodation, work or anything else - since _____ died?

Yes.... 1
No.... 2

IF YES (1) What changes?

37. PRESENT HOUSEHOLD

Respondent now lives alone...1
Respondent lives with others.2

IF WITH OTHERS (2) a) How many are there in the household altogether? _____

b) Relationship(s) to respondent

A _____
B _____
C _____
D _____
E _____

IF ALONE (1) a) Who is the relative you see most of?

b) Where do they live?

Within 10 mins walk . .1
Within ½hr journey.....2
½hr < 1hr.. 3
1hr < 2hrs.....4
2hrs or more.....5

38. Who would you say bore the brunt of looking after _____ you or someone else?

Informant.....7
Other person.....8

IF OTHER a) Who? - RELATIONSHIP TO DECEASED

b) How would you say it effected _____ (person who bore brunt)

39. Is there anything else you would like to say about _____'s care before he died?

CLASSIFICATION As I've explained we don't use any names on our study but we do like to know one or two things though about the people who help us/

(i) Do you mind telling me your age?

21 - 24.....1
25 - 34.....2
35 - 44.....3
45 - 54.....4
55 - 64.....5
65 - 69.....6
70 - 74.....7
75 - 79.....8
80 - 84.....9
85 and over.....0

(ii) CHECK. SEX. Male.....1
Female.....2

(iii) CHECK. Marital status

Single, never married.....3
Married now.....4
Widow(er) of deceased.....5
Other widow/divorced etc.....6

IF WIDOW OF DECEASED SKIP TO Q.(v)

(iv) IF MAN UNDER 65 or SINGLE WOMAN UNDER 60
What is your occupation ? RECORD BELOW.

IF MAN 65+ OR SINGLE WOMAN 60+
What was your main occupation? RECORD BELOW.

IF WOMAN & EVER MARRIED BUT NOT TO DECEASED
What is/was your husband's main occupation?

Self-employed with employees.....1
Self-employed without employees.....2
Manager.....3
Foreman.....4
Other employee.....5

(v) Is there anything you would like to say or ask about this study - or the Institute of Community Studies?

THANK RESPONDENT LEAVE CARD.

DETAILS OF INTERVIEW

vi) Length of interview

Less than 30 mins.....1
30 mins < 45.....2
45 mins < 1 hour.....3
1 hour < 1½hours.....4
1½ hours < 2 hours.....5
2 hours or more.....6

vii) Completed on-

single occasion.....1
more than one occasion.2

viii) Anyone else present

Yes.....3
No.....4

IF YES (3) Who?
RELATIONSHIP TO RESPONDENT

ix) Type of interview

Part I only because other person in household main respondent 1
Part I only because further interview refused 2
Part I and Part 2 of questionnaire 1 3
Part I and questionnaire 2. 4

Other SPECIFY

x) Date of interview

xi) Interviewer.

EXTRA QUESTIONNAIRE FOR SN: 393A

Medical Care Research Unit,
Institute of Community Studies,
18 Victoria Park Square,
London, E 2.

HOME CARE SURVEY
Questionnaire 3

INTRODUCTION I am from the Medical Care Research Unit at the Institute of Community Studies We are doing a study about how people cope with illness and death, which we hope will eventually help other people in a similar position We feel that the best way to do this is to ask the people concerned We know that _____ died fairly recently and we have already seen _____ who suggested that you may also be able to help us I would like to ask you some questions Everything you tell us will be treated as confidential and no names will be mentioned in the book we are planning to write

1. I believe you were _____'s -

Husband/wife	1
Father/mother	2
Father-in-law/mother-in-law	3
Son/daughter	4
Son-in-law/daughter-in-law	5
Grandchild	6
Brother/sister	7
Brother-in-law/sister-in-law	8
Neighbour	9
Friend	Y
Other SPECIFY	0

IF NOT RELATIVE a) How long had you known him?

Less than a year	1
1 year < 2 years	2
2 years < 5 years	3
5 years < 10 years	4
10 years < 15 years	5
15 years < 20 years	6
20 years or more	7

b) IF FRIEND OR NEIGHBOUR
Would you say he was a close friend of yours or not?

Yes, close friend	1
No	2

2. CHECK Did you live in the same household as _____?

Yes	1
No	2

IF YES (1) Who normally did the cooking and other housework before _____ died?

Self	3
Deceased	4
Other person	5

3. As far as you were concerned was _____'s death expected or not?

Expected	1
Not expected	2
Uncertain	3

IF EXPECTED (1) What was the matter?

IF NOT EXPECTED OR UNCERTAIN (2 or 3)

a) Was it completely unexpected with no previous illness or warning at all?

Yes	4
No	5

b) What happended?

CHECK So the condition _____ died of was -

4 Here is a list of ways in which people may need help when they are ill or old Could you tell me if in your view _____ could have done with help of this sort at all (while he was at home) - whether he got it or not?

Did he need - IF YES a) Did you help at all with this?

b) Did anyone else help?

		Needed			Informant helped		Other person helped	
		DK	Yes	No	Yes	No	Yes	No
11.	To be lifted at all	9	1	0	1	0	1	0
12	Help with washing (or shaving)	9	2	0	2	0	2	0
13	Getting in or out of bath	9	3	0	3	0	3	0
14	Dressing or undressing	9	4	0	4	0	4	0
15	Getting in or out of bed	9	5	0	5	0	5	0
16	Getting hair washed at home	9	6	0	6	0	6	0
17	Cutting toenails	9	7	0	7	0	7	0
18	Giving bedpan or bottle	9	8	0	8	0	8	0
19.	Getting to lavatory or commode	9	Y	0	Y	0	Y	0
21	Giving medicines or tablets	9	1	0	1	0	1	0
22	Injections	9	2	0	2	0	2	0
23	Ba daging or other dressing	9	3	0	3	0	3	0
24	Regular temperature taking	9	4	0	4	0	4	0
25	Massaging/exercises	9	5	0	5	0	5	0
26	Enema	9	6	0	6	0	6	0
27	Any (other) nursing procedure SPECIFY	9	7	0	7	0	7	0
31	Sitting up with at night	9	1	0	1	0	1	0
32	Other help at night	9	2	0	2	0	2	0
41.	Someone to take him out	9	3	0	3	0	3	0
42	Someone to read to him	9	4	0	4	0	4	0
43	Someone to write letters for him	9	5	0	5	0	5	0
44	Someone to collect his pension	9	6	0	6	0	6	0
45.	Someone to change his library books	9	7	0	7	0	7	0
51	Financial help	9	8	0	8	0	8	0
	IF DECEASED OR INFORMANT HOUSEWIFE Did you or he need help with -							
61	Shopping	9	1	0	1	0	1	0
62	Preparing/cooking food	9	2	0	2	0	2	0
63.	Cleaning house	9	3	0	3	0	3	0
64	Washing clothes	9	4	0	4	0	4	0
	IF APPROPRIATE							
71.	Did he need help looking after other members of the family, children or anyone else? SPECIFY	9	5	0	5	0	5	0

5 During the last 12 months of his life did you help in any (other) of the ways shown on the card - or after he died at all?

Yes.	1
No	2

IF YES (1) How?

6 Did you help

Regularly	6
Occasionally	7

IF REGULARLY How often?

Daily	1
More than once a week < daily	2
Weekly	3
Less often	4

IF INFORMANT LIVED IN S ME HOUSEHOLD /S DECEASED SKIP TO Q 10

7 How near did you live to _____?

Within 10 mins walk	1
Within ½ hour journey	2
½ hour < 1 hour "	3
1 hour < 2 hours "	4
2 hours or more	5

8 How much did it cost you to get there and back?

Less than 2/-	1
2/- < 5/-.	2
5/- < 10/-	3
10/- < £1	4
£1 or more	5

9 Could you say about how many times you saw _____ in the last 12 months of his life?

1-2	1
3-5,.	2
6-11	3
12-19	4
20-49	5
50-299	6
300 +..	7

10 Were you working at the time you started to look after _____?

Yes	1
No.	2

IF NO (2) SKIP TO Q.14.

IF YES (1) Was it full time or part time?

Full time..	3
Part time.	4

11 Did you have to make any changes in your work because of looking after _____ such as -

	Yes	No
Changing to different hours	1	0
Changing to less hours	2	0
Changing to different work	3	0
Taking time off	4	0
Retiring early	5	0
Give up work altogether	6	0
Any other changes? SPECIFY	7	0

IF NO CHANGES SKIP TO Q 14

12 For how long was your work affected?

Less than 2 weeks	1
2 weeks < 1 month	2
1 month < 3 months	3
3 months < 6 months.	4
6 months < 1 year	5
1 year + SPECIFY	6

13 Did this make a lot, a little or no difference to you financially?

A lot.	5
A little	6
No difference	7

14 Could you describe any (other) differences looking after _____ made to your life?

15 I'd like to know about any help given by official sort of people during the last 12 months of his life (while he was at home)

During that time did he have any help from or was he ever visited at home by -

	Yes	No	IF NO Do you think he could have done with any help from Yes	No
A district nurse	1	0	1	0
Health visitor	2	0		
Other nurse	3	0		
Home help service	4	0	4	0
Special laundry service	5	0	5	0
Chiropodist	6	0	6	0
Vicar, priest, minister	7	0	7	0
Any other official or voluntary service SPECIFY	8	0	8	0

16 CHECK Now I believe _____ died at

At home.	1
In hospital or institution	2
Other	3

17 OMIT IF DID NOT DIE AT HOME Did you at any stage feel it would have been better for _____ to be in hospital (again) either from his point of view or from the point of view of the people looking after him?

Yes... . . 1
No 2

Could you say why?

IF YES (1) a) So was that from

_____'s point of view 3
Your point of view 4
CODE ALL THAT APPLY Point of view of others looking after him 5

IF DID NOT DIE IN HOSPITAL OR INSTITUTION SKIP TO Q 20

18. Did you at any stage feel it would have been better for ____ to be at home?

Yes 3
No 4

Could you say why?

19. Did you visit _____ while he was in hospital/ institution ?

Yes 7
No 8

IF YES (7) a) About how many times during the last 12 months of his life?

1 - 4 . 1
5 - 9 2
10 - 19 . 3
20 - 49 . 4
50 + 5

b) How long did it take you to get there?

IF _____ HAD BEEN IN MORE THAN ONE HOSPITAL ASK ABOUT THE ONE HE WAS IN LAST

Less than 15 mins 1
15 mins < 30 mins 2
30 mins < 45 mins. . 3
45 mins < 1 hour 4
1 hour < 2 hours 5
2 hours + ... 6

c) What were the arrangements for visitors (when _____ was in hospital last)?

Set time 1
Free visiting. .. 2
Other SPECIFY 3

d) Did you feel the arrangements were satisfactory or not satisfactory?

Satisfactory . 3
Not satisfactory. 4

In what way?

20. Were you with _____ when he died?

Yes at bedside 1
Elsewhere in house. 2
No . 3

IF NO (3) When was the last time you saw ____?

Within 24 hours 0
1 day < 1 week 1
1 week < 1 month ... 2
1 month < 3 months . 3
3 months or more before death . 4

21 Have you made any changes in your way of living - your accomodation, work or anything else - since _____ died?

Yes . . 1
No 2

IF YES (1) What changes?

22 PRESENT HOUSEHOLD

Respondent now lives alone 1
Respondent lives with others 2

IF WITH OTHERS (2)

a) How many are there in the household altogether?_____

b) Relationship(to respondent

A_____
B_____
C_____
D_____
E_____

IF ALONE (1) a) Who is the relative you see most of?

b) Where do they live?

Within 10 mins walk 1
Within ½ hr journey . . .2
½ hr < 1 hr 3
1 hr < 2 hrs 4
2 hrs or more 5

23. Who would you say bore the brunt of looking after _____ you or someone else?

Informant 7
Other person 8

IF OTHER a) Who? - RELATIONSHIP TO DECEASED

b) How would you say it effected _____ (person who bore brunt)?

24. Is there anything else you would like to say about _____'s care before he died?

CLASSIFICATION As I've explained we don't use any names on our study but we do like to know one or two things though about the people who help us

(i) Do you mind telling me your age?

21 - 24	1
25 - 34	2
35 - 44	3
45 - 54	4
55 - 64	5
65 - 69	6
70 - 74	7
75 - 79	8
80 - 84	9
85 and over	0

(ii) CHECK. SEX

Male.	1
Female.	2

(iii) CHECK Marital status

Single, never married	3
Married now	4
Widow(er) of deceased	5
Other widow/divorced etc	6

IF WIDOW OF DECEASED SKIP TO Q (v)

(iv) IF MAN UNDER 65 or SINGLE WOMAN UNDER 60
What is your occupation? RECORD BELOW

IF MAN 65+ OR SINGLE WOMAN 60+
What was your main occupation? RECORD BELOW
IF WOMAN & EVER MARRIED BUT NOT TO DECEASED
What is/was your husband's main occupation?

Self-employed with employees	1
Self-employed without employees	2
Manager	3
Foreman	4
Other employee	5

(v) Is there anything you would like to say or ask about this study - or the Institute of Community Studies?

THANK RESPONDENT LEAVE CARD

DETAILS OF INTERVIEW

vi) Length of interview

Less than 30 mins	1
30 mins < 45	2
45 mins < 1 hour	3
1 hour < 1½ hours	4
1½ hour < 2 hours	5
2 hours or more	6

vii) Completed on -

single occasion	1
more than one occasion	2

viii) Anyone else present

Yes	3
No	4

IF YES (3) Who?
RELATIONSHIP TO RESPONDENT

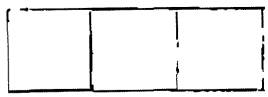
ix) Is this the -

First interview on questionnaire.	1
Second " " "	2
Third " " "	3

x) Of the people recorded at question 51 on the main questionnaire as involved in the care of the deceased and eligible for interview on questionnaire 3 was this person

The most eligible	1
The next most	2
The one after that	3

xi) Date of interview



xii) Interviewer

COL 1 AREA		
Barking	1	72
Teeside	2	70
Hillingdon	3	58
Cheshire NE	4	66
Brentwood	5	67
Bridgend	6	65
Northumberland	7	70
Eastbourne	8	63
Birmingham	9	68
Thanet	0	59
St Helens	x	66
Isle of Wight	y	62

Question 1 First code — Col 5 — Box 1

Relationship of informant to person who died.

Husband/wife	1	303
Father/mother	2	4
Father-in-law/mother-in-law	3	—
Son/daughter	4	237
Son-in-law/daughter-in-law	5	~~51~~ 50
Grandchild	6	8
Brother/sister	7	48
Brother-in-law/sister-in-law	8	17
Neighbour	9	22
Friend	Y	32
Official of institution	0	27
Other relative	X	37

Single coded

Question 1 Second code — Col 6 — Box 2

IF NOT A RELATIVE a) How long have you known him ?

Less than a year	1	4
1 year - 2 years	2	8
2 years - 5 years	3	13
5 years -10 years	4	10
10 years -15 years	5	1
15 years -20 years	6	3
20 years or more	7	27
Inadequate	X	15
D.N.A. (code 1,2,3,4,5,6,7,8X on col.5)	y	705

Single coded

Question 1 Third code — Col 7 — Box 3

b) IF FRIEND OR NEIGHBOUR
Would you say he was a close friend of yours or not ?

Yes, close friend	1	32
No	2	15
Inadequate	X	17
D.N.A. (All except codes 9 or y on Col.5)	y	732

Single coded

Marital status of deceased at time of death — Col 8 — Box 4

Married	1	400
Single	2	93
Widowed	3	267
Divorced/Separated	4	13
Inadequate	X	13

Single coded

Question 3 First code — Col 9 — Box 5

Death expected	1	436
Death not expected - no previous illness or warning at all - e g. unexpected heart attack or accident from which died within 24 hours	4	82
Intermediate/uncertain/some illness or warning	3	267
Inadequate information	X	1

Single coded

Question 3 / Cause of death / Boxes 6 a-f

If more than one condition mentioned, take the main cause of death the one mentioned first

after the CHECK: So the condition died of was:-

		ICD 1966 no.		
00	Infective and parasitic	000–136	0	
	Neoplasms			
10	Malignant neoplasm, stomach	151		(1) 203
11	" " bronchus and lung	162.1		(2) 351
12	" " breast	174		(3) 84
13	" " uterus	180–182		(4) 6
14	" " prostate	185		(5) 24
15	Leukaemia and aleukaemia	204–207		(6) 16
16	Other neoplasm of specified site	Rest 140–239 excluding 199 & 228		(7) 36
17	Neoplasm of unspecified site	199, 228, 239		(8) 37
01	Endocrine, Nutritional and Metabolic	240–279	0	(X) 29
02	Blood and blood forming organs	280–289		
03	Mental disorders	290–315		
04	Nervous system and sense organs	320–389		
	Circulatory			(1) 24
20	Hypertensive	400–404		(2) 46
21	Ischaemic heart disease	410–414		(3) 125
22	Rheumatic fever and other heart disease	390–398, 420–429	2	(4) 33
23	Cerebrovascular disease, Stroke	430–438		
24	Diseases of the arteries	440–448		
25	Other	450–458		
26	Bad heart, heart failure, coronary, heart attack			
	Respiratory			(5) 28
30	Pneumonia	480–486	3	(6) 194
31	Bronchitis	490–493		
32	Other	460–474, 500–519		
60	Digestive	520–577	6	(7) 62
06	Genito urinary	580–629		(8) 1
07	Complications of pregnancy etc.	630–670		(1) 3
08	Skin	680–709	0	
09	Musculoskeletal and Connective	710–738		(0) 14-3
0Y	Congenital and perinatal	740–779		(X) 27
40	Symptoms exc. heart failure, senility	780–796	4	
+60	Senility, old age			
	Accidents			
50	Transport	E800–E845		
51	Suicide or self inflicted injury	E950–E959	5	
52	Other	E850–E949, E960–E999		
XX	Inadequate. Don't know.			
80	Unspecified. Will to live.			
	Non-human			

Col 12
Box 8

Additional causes of death

		I.C.D. no. 1966	Box 9	
1.	Neoplasms	140 – 239		18
2.	Circulatory + bad heart etc.	390 – 458		67
3.	Respiratory	460 – 519		65
4.	Symptoms, except senility	780 – 796		23
5.	Accidents	E800 – E999 with ~~N~~.		20
6.	Digestive	520 – 577		17
7	Senility, old age			32
0.	Others	000 – 136, 240 – 389, 580 – 779		81
8	Loneliness, lost will live			8
~~X.~~	~~Inadequate~~			
9.	No additional cause			476

y Don't know uncertain - can be coded with some specific condition as in previous codes if some doubt or uncertainty expressed.

This may be multi-coded but additional causes within the same broad group of the I.C.D. as the main underlying cause and not taken.

This means that this code never contains the same digit as the first digit of the underlying cause except that both can be 0 if the two causes would have different 2nd digits if both were classified according to the 2 digit code for main underlying cause.

Box 16

Question 4. So before he died was ever completely bedridden? /

IF YES How long was that for?

Never 0 370

Less than a week	1	36
1 week < a month	2	156
1 month < 3 months	3	91
3 months < 6 months	4	38
6 months < 1 year	5	14
1 year or more	6	26

Inadequate if ever bedridden X

" how long bedridden for 9 3

Single coded.

Col 14

Question 5. (Before that) was he confined mainly to bed? Box 17

IF YES How long was that for?

No 0 556

Less than a week	1	22
1 week < a month	2	36
1 month < 3 months	3	36
3 months < 6 months	4	36
6 months < 1 year	5	15
1 year or more	6	46

Inadequate if ever confined mainly to bed X 11

" how long " " " " 9 2

D.K.A. 4 26

Single coded.

Col 15

Box 18

Question 6 1st code (Before box) was he at all restricted in what he could do inside home

Yes - severely restricted	1	179
Moderately	2	165
A little	3	71
Inadequate how much	4	11
No - restricted outside	7	51
not restricted outside	8	204
Inadequate if restricted outside	9	25
Inadequate	X	8
N.M.A. Bedridden or confined mainly	4	72

No bed for a year or more 6in Box 16 or 17.

Single coded.

Question 6 2nd code if 8 (Box 18) Col 16 Box 19

Would you describe his health in the last 12 months as.-

Good.....1	87
Fair.....2	50
Poor.....3	20
Very poor.....4	6
N.M.A (all except code 8 in Box 18)	4 582
Inadequate	X 41

Single coded.

Question 7. For how long was he restricted in that way? Col 17 Box

Less than a week	1	1
1 week < a month	2	9
1 month < 3 months	3	29
3 months < 6 months	4	47
6 months < 1 year	5	67
1 year or more	6	223

Inadequate information X 20

D.M.A (all except codes 1, 2, 3 & 4 in Box 15 p.1) 4 320

Single coded.

Summary code on restriction from questions 4, 5, 6 a, b, c Box Col 18

Bedridden 1 year or more		26
" 3 months < 1 yr		5
Confined mainly to bed 3 months or more		3
Severely restricted 3 months or more		2
Moderately restricted 3 months or more		4
Mildly restricted 3 months or more		6
Other restriction 3 months or more		23
(i.e. outside home, or inadequate information type 3 or two periods of restriction 1 month < 3 months)		
Bedridden or confined mainly to bed for less than 3 months		01
Severely or moderately restricted for less than 3 months		4
Often a little or rest outside less than 3 months		01
None - apparently inside home		02
Inadequate information		X 1

Single coded - mainly as above.

Question 9 How old was he when he died? Col 19 Box 5

Under 25	1	4
25 - 34	2	3
35 - 44	3	26
45 - 54	4	58
55 - 64	5	150
65 - 69	6	120
70 - 74	7	113
75 - 79	8	112
80 - 84	9	104
85 +	0	94
Inadequate	X	-2

Single code

Question 11 1st code Where died Col 20 Box 6

Hospital	1	36
Other institution	2	39
Deceased's own home	3	328
Other private home	4	23
Other - e.g. street, work, ambulance etc	5	30
Inadequate	X	—

Single coded

Question 11 2nd code IF IN HOSPITAL OR OTHER INSTITUTION How long was he in hospital before he died? Col 21 Box 7

< 24 hours	9	45
1 day < 3 days	0	41
3 days < 1 week	1	50
1 week < 1 month	2	97
1 month < 3 months	3	27
3 months < 6 months	4	29
6 months < 1 year	5	4
1 year < 2 years	6	12
2 years < 5 years	7	30
5 years + SPECIFY	8	24
Inadequate	X	—

D.H.A. Code 345 ~ X m Box 4 4 321

Single coded.

Question 12. Final code. Col 22 Box 1

CHECK

Long term institutional death (6,7, or 8 at Q11).....1 — 72

Unexpected death of person under 65 with no previous restrictions.....2 — 10

(Check code 1-5 at Q9 and coded 4 at Q2)

Other deaths — 3. — 656

Inadequate — X — —

Other death-treated by interviewer as unexpected. — 4 — 18

Smyle coded.

Question 12. Second coded. Col 23 Box 1

IF LONG TERM INSTITUTIONAL DEATH. Ever worked (outside an institution)? Has recently before died?

Never.....4 — 24

1 year < 2 years.....6 — —

2 years < 5 years.....7 — 2

5 years < 10 years.....8 — 6

10 years or more before death.....9 — 30

Inadequate knowing, wiseven — X — 10

D.M.A. (all except code 1 in box 16.) — 4 — 714

Smyle coded.

Question 13a Had _____ been in hospital or other institution as an inpatient (on any other occasion) in the 12 months before he died?

IF YES How many times altogether in the last 12 months? INCLUDE OCCASION ON WHICH DIED

Col 24 Box 12

		Codes	Totals
		1	290
		2	123
Not at all	0	3	32
1 - 4	Actual nos	4	7
5 +	5	5	8
Inadequate if at all	X	9	15
Inadequate how many	9	0	236
D.N.A. (Code 1 in Box 11)	y	X	4
Single coded		y	72

Question 13b. b) How long was he in hospital altogether in the last twelve months (including the time he died)?

Col 25 Box 1

Less than a week.....1	193
1 week < 1 month.....2	159
1 months < 3 months.....3	145
3 months < 6 months.....4	56
6 months < 9 months.....5	10
9 months < 1 year.....6	3

D.N.A (Only in Box 13) y 308

Inadequate - how long if at all X 12

Single coded

Question 13 — How long before _____ died did he leave hospital (for the last time)?

Less than a week	1	6
1 week < 1 month	2	16
1 month < 3 months	3	28
3 months < 6 months	4	30
6 months < 9 months	5	21
9 months < 1 year	6	17
Inadequate	X	27

D.M.A. (y on Box 19 or 1, 2 or X ~~3, 4, 5 or X~~ on Box 4) — y 641

Single coded.

Question 14. Did _____ have an operation or any other particular treatment while he was in hospital in the last 12 months? — Col 27 Box 21

Operation	1	128
Radiotherapy, deep X-rays	2	32
Other treatment	4	146
Manitoux (investigation) or don't know.	3	230
Inadequate (whether deep X-rays or not)	X	93

D.M.A. (0 or X on Box 18) — y 240

Col 24

Page 3 first column and Boxes 1 - 6 omitted and codes left blank is coded 0 or X at Question 13 1st code.

Col 28

Question 15 first code. Did you visit ----- while he was in hospital/institution? Box 1

IF YES (7) a) About how many times during the last 12 months of his life ?

1 - 4	1	77
5 - 9	2	46
10 -19	3	76
20 -49	4	138
50+	5	115
Not at all (~~include~~ visited person who had been in hospital, more than a year ago but no in last 12 months of life)	0	40
Inadequate how many times	9	11
Inadequate if visited	X	18
D N A. (respondent official in hosp/institution)	Y	25

Single code

Question 15 2nd part. How long did it take you to get there ? (Rank) R 240 Col 29 Box 2

IF ..... HAD BEEN IN MORE THAN ONE HOSPITAL ASK ABOUT THE ONE HE WAS IN LONGEST DURING THE LAST 12 MONTHS

Less than 15 mins	1	82
15 mins - 30 mins	2	171
30 mins - 45 mins	3	81
45 mins - 1 hour	4	51
1 hour - 2 hours	5	41
2 hours+	6	20
Inadequate	X	17
D.N.A. (Code Y, 0 or X in Box 1)	y	83
	R	240

Single code

Question 15 3rd part. What were the arrangements for visiting (when ----- was in hospital last)? Col 30 Box 3

Set times	1	224
Free visiting	2	120
Other	3	103
Inadequate	X	16
D.N.A. (Code Y or 0 or X in Box 1)	y	83
	R	240

Other will include such things as set times in theory but free visiting in practice, but relaxations of set times on particular occasions or in limited ways should not be counted as changing it from 1 to 2. but come into 3

Single code

Question 15 4th part. Did you feel the arrangements were satisfactory or not satisfactory ? Col 31 Box 4

Satisfactory	3	382
Not satisfactory	4	24
Qualified, doubtful or uncertain	5	32
Inadequate	X	25
D.N.A. (Code Y or 0 or X in Box 1)	y	83
	R	240

Single code

Question 16 1st part. Did anyone (else) visit ~~xxxxx~~ while he was in hospital during the last 12 months of his life? Col 32

No	0	34
IF YES (5) a) Could you say about how many people ?		
One	1	24
Two - four	2	177
Five - nine	3	160
Ten or more	4	104
Inadequate how many	9	7
Inadequate if anyone	X	40
	R	240

Question 16 2nd part. b) Who visited ~~xxxxxx~~ most often ? (You or someone else ? Who?) Col 33 Box 6

STATE RELATIONSHIP TO DECEASED.

Respondent	0	~~370~~ 369
Other person - Spouse - of deceased	1	31
Parent or parent in law "	2	4
Child or child in law "	3	92
Grandchild "	4	3
Sibling or sibling in law "	5	23
Other relative "	6	15
Friend or neighbour "	7	12
Other person "	8	3
Inadequate	X	24
D.N.A. (Code 0, X or y in Box 5)	y	74
	R	240

CHECK with question 1 and try to make sure the interviewer has not recorded the relationship of the respondent.

Usually single coded but 3 codes can be taken if cannot distinguish who visited most often. If more than two indicated and cannot distinguish this code inadequate. Always code 0 if respondent included.

Question 17 a) Had ——— been to hospital as an outpatient during the last 12 months of his life? How many times? Col 34 Box 16

Not at all	0	444
Once	1	40
2 - 4	2	116
5 - 9	3	38
10 -19	4	23
20+	5	32
Inadequate how many times	9	19
Inadequate if went	X	2
D.N.A. Long term institutional death	y	72

Single code.
Note if code 0, X or y the rest of the codes on page three are left blank.

Question 17 b) When was the most recent time before he died ? Col 35 Box 17

Less than a week	1	15
1 week - 1 month	2	52
1 month - 3 months	3	78
3 months - 6 months	4	64
6 months - 1 year	5	33
Inadequate	X	26
	R	518

Single code.

Question 17 c) How did he usually get there ? Col 36 Box 18

Ambulance	1	86
Walk all way	2	11
Public transport	3	60
Private transport	4	98
Other SPECIFY	5	6
Inadequate	X	7
Single code	R	518

Question 17 d) Did anyone usually go with him ? Who? Col 37 Box 19

No	8	100
Yes - spouse	1	81
parent or parent in law	2	1
child or child in law	3	51
grandchild	4	—
sibling or sibling in law	5	13
other relative	6	4
friend or neighbour	7	14
other person	y	—
Inadequate who	9	11
Inadequate if any	X	5
Overcode if person respondent	0	110
May be multicoded		
N.B. Ambulance men do not count if went in ambulance	R	518

You may need to check with question 1 to see if person respondent or not

Question 17 e) How long did ------ (usually) have to spend at the hospital? Col 38 Box 20

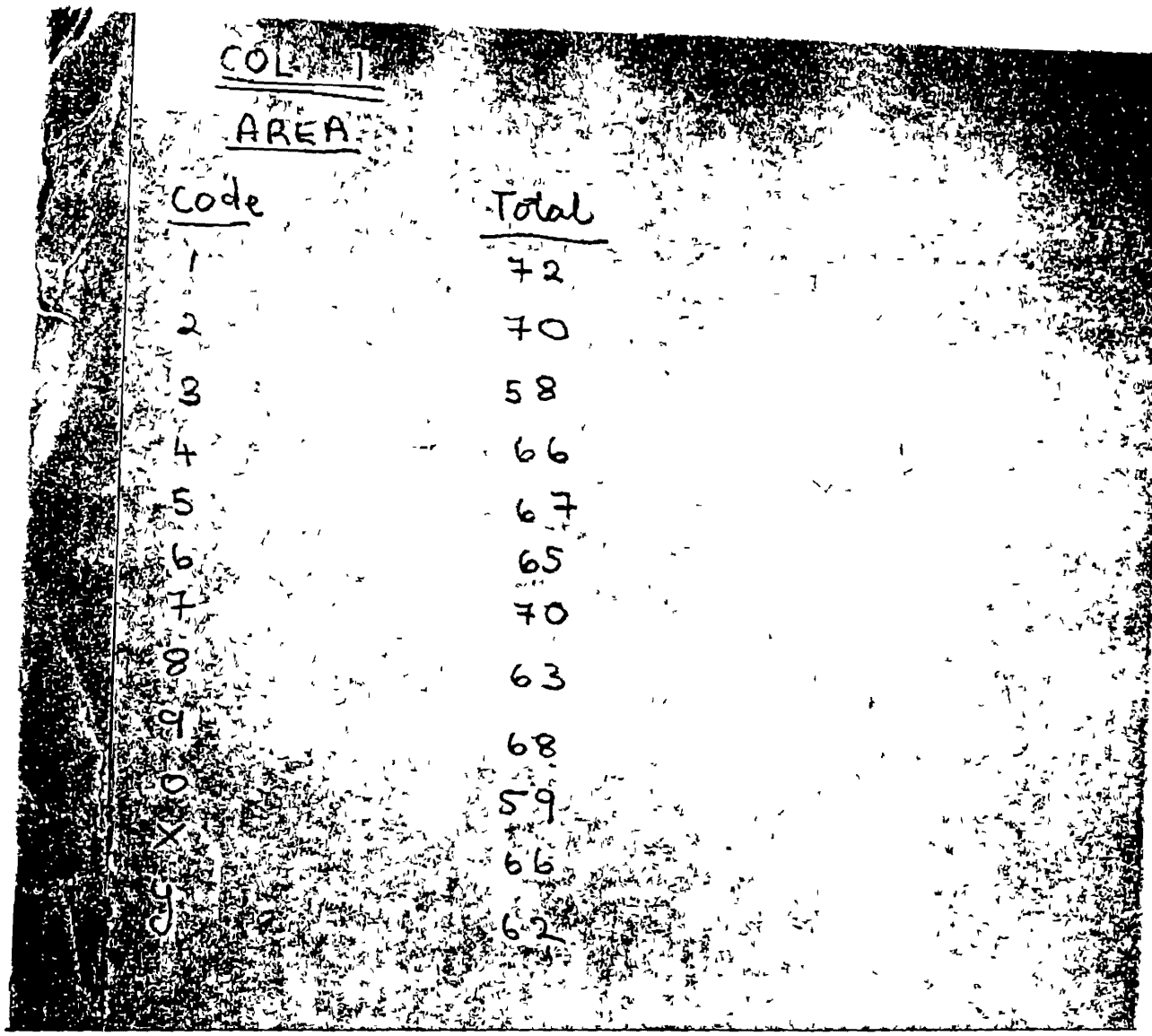
Less than 30 mins	1	24
30 mins - 1 hour	2	76
1 hour - 2 hours	3	63
2 hours - 3 hours	4	47
3 hours - 4 hours	5	17
4 hours - 5 hours	6	7
5 hours - 6 hours	7	3
6 hours or more	8	5
Inadequate	X	26
Single code	R	518

Question 17 f) Were there any problems or difficulties about ------ going to outpatients? What? Col 39 Box 21

No problems	0	163
Something mentioned	1	95
Inadequate. D.K.	X	10
Single code	R	518

Question 17 g) Did he go just for checks and advice or for particular treatment? Box 22 Col 40

Checks and advice only (including investigation)	1	159
Radio-therapy, deep X-ray	2	27
Other treatment	3	54
Inadequate or do not know whether deep X-ray or not	X	34
May be multicoded. except for 1	R	518



COL. 1

AREA

Code	Total
1	72
2	70
3	58
4	66
5	67
6	65
7	70
8	63
9	68
10	59
X	66
Y	62

Page 4 left blank for long term institutional deaths Code 1 Question 12

Question 18 Did anyone from a hospital come to visit ——— at home during the twelve months before he died ? Box 1

No 2

IF YES. Did the general practitioner come at the same time ?

Yes 3

No 4

Inadequate if G.P. came at the same time.....9

Inadequate if had domiciliary visit X

Single coded R

Question 19 a)———'s general practitioner:- Box 2

N.H.S. 1

Private 2

Inadequate - or no G.P. X

Single code R

Question 20 a)In the last 12 months before ——— died how often did his doctor - or a locum, partner, assistant or another general practitioner - see him at all either at home or in the surgery. Box 3

Not at all 0

Once 1

2 - 4 2

5 - 9 3

10 -19 4

20 or more 5

Inadequate how often 9

Inadequate if at all X

Single code R

Question 20 b)How many times did the G.P. (locum etc.) come to see him at home Box 4

D.N.A. (code 0 to Q 20a) .....y

Not at all 0

Once 1

2 - 4 2

5 - 9 3

10 -19 4

20+ 5

Inadequate how often 9

Inadequate if at all X

Single code R

Question 20 c)How many times did the G.P. (locum etc.) come and see him at night between 8 p.m. and 8 a.m. Box 5

D.N.A. (code 0 or y to Q. 20b) .....y

Not at all 0

Once 1

2 - 4 2

5 - 9 3

10 -19 4

20+ 5

Inadequate how often 9

Inadequate if at all X

Single code R

Question 21 When was the last time ——— saw a general practitioner before he died ? Col10 Box

Within 24 hours	0	225
1 day - 1 week	1	164
1 week - 1 month	2	~~127~~
1 month - 3 months	3	69
3 months - 6 months	4	34
6 months - 1 year	5	15
1 year - 2 years	6	12
2 years - 5 years	7	4
5 years or more	8	7
Inadequate	X	52
	R	72

Single code

Question 22 Did you personally have the same doctor as ——— then ? Col11 Box 17

Same doctor	1	464
Another doctor in same partnership	2	31

IF DIFFERENT DOCTOR (3) Do you know ———'s doctor (or any of the doctors in that group) at all ?

Yes	4	134
No	5	70
Different doctor, inadequate if knew him or partners	9	2
Inadequate if same doctor	X	13
Overcode if used to have that doctor but has changed	0	12
	R	72

Question 23 Do you think ———'s doctor is an easy person to talk to or not ? Col12 Box 18

Easy	1	~~442~~ 447
Not easy	2	83
Qualified, uncertain, sometimes (comments but no clear code)	3	63
Inadequate	X	11
D.N.A. (code 5,9,X to ~~Question 22~~ Col11 or 0 or X at ~~Question 20a~~ Col7)	y	109
	R	72

Single code

Question 24 Do you think he has time to discuss things or not ? Col13 Box 19

Has time	3	401 400
Not	4	94
Qualified, uncertain, sometimes (comments but no clear code)	5	24
Inadequate	X	26
D.N.A. (code y at Q23)	y	101
	R	72

Single code

Page 5 Left blank if Long Term Institutional Death - Code 1 Question 12

25. Did ------ do any paid work in the 12 months before he died ? Col 14 Box 1

Yes	1	186
If NO (2) Why was that ?		
Housewife and not worked 10+ years	3	209
Retired	4	145
Ill-health	5	62
Other	6	8
Inadequate if worked	X	1
Inadequate why not	9	3
	R	725

Single coded

If 3, 9 or X leave rest of page blank
If 1 leave col. 1 blank

a) How old was he when he retired from his main job ? Col 15 Box 2

Under 60	1	21
60 - 64	2	58
65 - 69	3	24
70+	4	32
Inadequate	X	10
D.N.A. (all except code 4 Qu.25)	y	62
Single coded (LTI + codes 6, 3, 9, X + 1 on col 14)	R	479

X if coded 3 or 4 or X leave rest of page blank

IF UNDER 65: Did he retire early because of ill health or not ? Col 16 Box 3

Yes	5	30
No	6	44
Inadequate	X	5
D.N.A. (all except code 1 and 2 Box 2)	y	62
Single coded (LTI + codes 6, 1, 9, X + 1 on col 14 + codes 3, 4, X on Col 15)	R	645

If coded 6 or X leave rest of page blank

(11) Did anyone advise him to give up work ? Who ? Col 17 Box 4

No-one	1	6
G.P.	2	14
Other medical practitioner	4	2
Other	3	1
Inadequate if anyone	X	5
Inadequate who	9	2
D.N.A. (all except code 5 Box 3)	y	62
Single coded (LTI + codes 6, 3, 9, X + 1 on col 14 + codes 3, 4, X on Col 15 + codes 6, X on Col 16)	R	694

If this not y leave rest of page blank

IF ILL HEALTH: (5 Box 1) When did he stop working because of ill health ? Col 18 Box 5

1 - 2 years before death	1	22
2 - 5 years	2	11
5 -10 years	3	11
10 years or longer	4	15
Never worked because of ill health	5	—
Inadequate	X	3
~~D.N.A. (all except code 5 Box 1)~~	~~y~~	
Single coded (All except code 5 Box 1)	R	724

IF ILL HEALTH. b. How old was he then ? Col 19 Box 6

Under 35	1	1
35 - 44	2	3
45 - 54	3	10
55 - 59	4	10
60 - 64	5	13
65 - 69	6	5
70+	7	1
Inadequate	X	2
~~D.N.A. (code y Box 5)~~	y	
(all except code 3 Box 1)	R	724

Single coded

d. Did anyone advise him to give up work ? Who ? Col 20 Box 7

No-one	1	12
G.P.	2	28
Other medical practitioner	4	2
Other	3	8
Inadequate who	9	2
Inadequate if advised	X	10
~~D.N.A. (code y Box 6)~~	y	
(All except code 3 Box 1)	R	734

Single coded

Column 2 - Boxes 16-20 left blank unless coded 1 in Box 1

26. How recently before his death did he work ? Col 21 Box 16

Within last week	1	59
1 week - 1 month	2	23
1 month - 3 months	3	35
3 months - 6 months	4	37
6 months +	5	26
Inadequate	X	3
D.N.A. (all except code 1 Box 1)	y	Blank 600

Single coded

Had he actually given up his work or not ? Col 22 Box 17

Given up	6	39
Not given up	7	67
Inadequate if given up	X	21
D.N.A. (code ~~not~~ 1 Box 16)	y	59
(all except code 1 Box 1)	R	600

Single coded

27. Was he working part-time or full-time then ? Col 23 Box 18

Full-time	6	132

if part-time: why was that ?

Housewife	3	12
Retired(semi)	4	17
Ill-health	5	18
Other	0	1
Inadequate if full or part-time	X	3
Inadequate why part-time	9	3
~~D.N.A. (code y Box 17)~~	y	
(all except code 1 Box 1 Col 1)	R	10

Single coded

28. Was that his main job or not ? Col24 Box 19

Main job	6	137
if not main job a) Why did he give up his main job ?		
Retired	4	15
Ill-health	5	33
Other	0	4
Inadequate if main job	X	10
Inadequate why given up	9	—
~~D.N.A. (code y Box 18)~~	~~y~~	
	R	600

Single coded

b) How old was he when he gave up his main job ? Col25 Box 20

Under 60	1	3
60 - 64	2	5
65 - 69	3	14
70+	4	—
Inadequate	X	2
D.N.A. (~~code~~ Code 7 box 17 code 4 or 6 or X Box 19)	y	147
	R	600

Single coded

29. To be coded later

Revised code household composition

	Old.	New	New
On own	1	1	1
With spouse only	2	2	231 F 1
" " & others of younger generation with or without others	3, 4, 9, 0	3	155 F 1
" " & relatives of same or older generation & / or unrelated people,	7, 0	0	
" relatives of younger generation with or without others	5, 6, 9, 0	6	1
" relatives of same generation or older with without others no spouse.	7, 0	7	44 F 1
" unrelated only	8	8	19
In quasi household etc	4	4	29
Inadequate	X	X	

(1) Construct Vols old x new ✓

(2) Take cards A and sort on col. 52 •

(3) Reproduce new card straight from basic code 1 2 3 6 8 4 X on col. 5 leaving col. 41-43 blank.

(4) " " " omitting col 41-43 & 52 for those coded 4 5 7 9 0 on keeping groups separate.

(5) Sort those coded 4 5 7 9 0 on col. 52. by serial no. & regroup into new codes from 1's.

(6) Gang punch new codes on those codes 4 5 7 9 0 on old code.

(7) Sort new pack into serial no. order.

(8) Transfer col. ? from card F to col. 43.

(9) Reproduce new packs with serial no + col. 80. cols 1, 2, 3. (ft. col. 52 on B. col. 27
C 69
D 64
E 70

Sort packs B. C. D. E. into serial no. & transfer omitting relevant cards

Replace old packs with good new ones.

30. Do you think ———'s work was ever a physical or mental strain or affected his health in any way ? Col 26 Box 1

No	0	302
Yes, physical strain	1	91
Yes, mental strain	2	42
Yes - other	3	12
Yes - both mental and physical	4	30
Inadequate	X	25
D.N.A. (code 3 question 25 or if L.T.I.)	y	(also schoolchild + 2 others) 284

Single coded

31. Household composition (see sheet attached) Cols Col 27 Box 2

Inadequate	X
On own	1
With spouse only	2
With spouse and child(ren)(but no children in law)	3
With spouse and child(ren) and child(ren) in law with or without grandchild(ren)	4 - also spouse, children, grandchildren
With child(ren) but no child(ren) in law	5
With child(ren) and child(ren) in law with or without grandchildren	6 + 9/9/children.
With other relatives of same generation only	(7) — also children, mother-in-law, but with grandchildren.
With unrelated people only (e.g.friend/landlady)	8
Other three generation households	9
In guest house/old people's home/boarding house (no or inadequate information about where living before)	y — Long term mental illness may count as household if there for long time and no information about previous household - y
Others	0

Single coded

32. Who normally did the cooking and other housework ? Col 28 Box 3

D.N.A.(lived alone or inadequate who lived with:1 or X or y Box 2)	y
Deceased	1
Respondent	2
Deceased and respondent	3
Other(s)	4
Inadequate	X

Taken as priority. If deceased or respondent did any housework then code as 1, 2 or 3. — (but respondent could be household if not deceased)

If deceased or respondent involved or helped with housework at all these should be included as 1 or 2 or 3 as appropriate

Single coded

Col 27		Col 28	
Code	Total	Code	Total
1	118	1	99
2	291	2	345
3	129	3	80
4	12	4	107
5	55	5	6
6	95	9	149
7	44		
8	9		
9	3		
0	39		
X	2		
y	29		

33. Main respondent in household

Col 29 Box 16

D.N.A. Deceased lived alone .....y
Yes 1
No 2
Inadequate X

Matron, Superintendent, nurse, etc — only when main respond may be coded 1, if L.T.I. coded y box 2

N.B. There should not be any inadequate: do a Sherlock Holmes

Single coded

Sort out separately:
1. Unexpected deaths of person under 65 who was unrestricted (code 2 at Q.12)
2. Those wrongly treated by interviewer as unexpected deaths.

} Do not go boxes 17 & 18

34. Were there any changes in ———'s household arrangements after he became ill/as he got older ?

Col 30 Box 17

No 2
Yes someone came to live with him 3
Yes he went to live with someone else 5
Others 7
Inadequate if any change X
Inadequate what change 9

someone coming for short period only, unless included in household coded 7

going into LTI. = 7
eg when it is ... household

Single coded

IF YES (5) Before that did he live alone or with someone else ?

Col 31 Box 18

D.N.A. (all except code 5) .....y		671
Alone 7		25
Lived with spouse who died 1		11
Lived with others 2		16
Inadequate X		5
	R	~~58~~

58 blanks Col 30 → end

Col 29

Codes	Total
①	531
②	137
ⓧ	—
⑨	118

Col 30

Code	Total
②	392
③	37
⑤	56
⑦	235
⑨	—
ⓧ	8
Ⓡ	58

35. How long had ——— been living in the same house/flat before he died/went into hospital ? Col 32 Box 1

Less than a year	1	43
1 year - 2 years	2	30
2 years - 5 years	3	103
5 years - 10 years	4	93
10 years - 20 years	5	146
20 years - 50 years	6	248
50 years +	7	44
Inadequate	X	19
	R	58

Single coded

36. And for how long had he been living alone/with just the same person/people? Col 33 Box 2

Less than a year	1	70
1 year - 2 years	2	44
2 years - 5 years	3	122
5 years - 10 years	4	131
10 Years +	5	339
Inadequate	X	22
	R	58

Single coded

37. Would you say that ———'s house/flat was very convenient, fairly convenient, or rather inconvenient for him after he became ill/old ? Col 34 Box 3

Very convenient	1	422
Fairly convenient	2	153
Rather inconvenient	3	119
Inadequate	X	34
	R	58

Single coded

---

38. Were the rooms or furniture moved around at all because of ———'s illness/old age ? Col 35 Box 16

No	2	471

if YES, b) Did it affect other people at all ?

Yes	5	92
No	6	124
Inadequate if affected other people	9	10
Inadequate if anything moved	X	31
	R	58

Single coded

39. Did ———'s house/flat have its own bathroom or was it shared with other people not in the same household ? Col 36 Box 17

None	3	105
Own with running hot and cold water	4	556
Own without running hot and cold water	5	11
Shared with running hot and cold water	7	17
Shared without hot and cold water	8	1
Own, D.K. whether running hot and cold water	1	13
Shared, D.K. whether running hot and cold	2	—
Inadequate	X	25
	R	58

Single coded

Col 37
40. And did it have its own indoor lavatory or was that shared or outside? Box 18

Own indoor	1	548
Shared indoor	2	14
Outside	3	136
Inadequate	X	27

Single coded R 58

Col 38
41. How many steps or floors were there between:- Box 19
a) Ground level and ———'s bedroom ?

No steps or floors	0	278
1 floor	1	286
2 floors	2	8
3 floors	3	4
4 floors	4	
5+ floors	5	
Steps but less than 1 floor	6	1
Inadequate	X	30
Overcode if lift is recorded	y	6

Can be double-coded R 58

b) ———'s bedroom and lavatory ? Col 39. Box 20

No steps or floors	0	472
1 floor	1	182
2 floors	2	3
3 floors	3	—
4 floors	4	—
5 + floors	5	—
Steps, but less than 1 floor	6	43
Inadequate	X	28
Overcode if change in arrangements	y	147

May be double-coded (floors) R 58

Card 231

Column 27 old / Column 27 New (2)	1	2	3	4	5	6	7	8	9	0	11	12	R	Total
On Own 1	118													118
With spouse only 2		231												231
With spouse + children, with or without others 3			129	12					7	4				152
With spouse + other relatives of younger generation (+ others) 4										3				3
With spouse and relatives of same generation or older and/or other people 5							6			7				13
With children with or without others 6					55	95			3	4				157
+ relatives of same generation or older (+ others) 7							37			7				44
Unrelated people only 8								19						19
Other relatives (not some of younger generation) + others 9							1		3	14				18
0												-		
I/A 11											2			2
Guesthouse etc 12												29		29
R														
Total	118	231	129	12	55	95	44	19	13	39	2	29		736

With spouse 399

Card 439

Column 27 old code / Column 27 New New code.	1 On own	2 + spouse only	3 + spouse + children	4 + spouse + children + other kin	5 + children	6 + children + other kin	7 Other rel'ns + same generation	8 Unrelated people only	9 Other 3 generation...	0 Others	11 I/A	12 Guest House etc.	R	Total
On Own 1	118													118
With spouse only 2		231												231
With spouse & others of a younger generation with or without others 3			129	12					7	7				155
4														
5														
With relatives of younger generation with or without others 6					55	95	1		6	18				175
With relatives of same generation or older with/without others 7							37			7				44
With unrelated people only 8								19						19
9														
With spouse & relatives of same or older generation 0 +/or unrelated people							6			7				13
Inadequate 11											2			2
Guest house etc 12												29		29
R														
	1	231	129	12	55	95	44	19	13	39	2	29		786

Card 25

	Column 27 old code / Column 27 new code (1)	1 On own	2 With spouse only	3 Spouse + children	4 Spouse + children + children-in-law	5 Children	6 Children + - in-laws	7 Other rel^ns of same gen^n	8 Unrelated people only	9 Other 3 generations	0 Others	11 I/A	12 Guesthouse etc	R	Total
	On Own 1	118													118
X	With spouse only 2		231												231
X	With spouse + children and/or grandchildren (+ others) 3			129	12					7	5				153
X	With other rel^ns (incl some younger) + spouse (+ others)										2				2
	With children +/or grandchildren (+ others) no spouse 5					55	95			5	8				163
	Other rel^ns (incl some younger) no spouse (+ others) 6							1		1	10				12
X	Others of same gen^n or older + spouse 7							6			7				13
	Unrelated people only 8								19						19
	Others of same generation or older (no spouse) 9							37			7				44
	0														
	I/A. 11											2			2
	Guest house etc 12												29		29
	R														
	Total	118	231	129	12	55	95	44	19	13	39	2	29		786

COL 1

AREA		
Barking	1	72
Teeside	2	70
Hillingdon	3	58
Cheshire NE	4	66
Brentwood	5	67
Bridgend	6	65
Northumberland	7	70
Eastbourne	8	63
Birmingham	9	68
Thanet	0	59
St Helens	X	66
I O W	Y	62

Page 8. Question 42 Did — have to put up with any of these in the last 12 months of his life?

Yes 1 - 8	1-8	Col 5 Box 1
Inadequate for any symptom	9	codes + Totals at foot
None	0	of page.
Inadequate if any multi-coded.	X	

Yes 1 - 5 or 6 7 etc	1-5 or 6 7 etc	Box 2
Inadequate for any symptom	9	Col 6
None	0	codes + Totals at foot
Inadequate if any multi-coded.	X	of page

Record total number of symptoms positively identified. Box 3

None	0	Col 7
1 - 9	1 - 9 (Actual No.)	
10 +	9	
Inadequate	X	

Single coded

CHECK TOTALS

	COL 5		COL 6		COL 7
code	Total	code	Total		
1	Pain 513	1	Bedsores 136	(1)	37
2	Sleeplessness 379	2	Mental confusion 279	2	12
3	Loss of bladder control 216	3	Trouble w' breathing 351	3	32
4	Loss of bowel control unpleasant 114	4	Depression 211	4	104
5	Smells 119	5	other 192	5	16
6	Vomiting/feeling sick 232	6	13	6	77
7	Loss of appetite 370	7	" 3	7	66
8	Constipation 222	8	I.A for any symptom 31	8	61
9	I.A for any symptom 589	0	None 112	9	30
0	None 63	X	7	0	27
X	I A		I A	X	5
		R	58	I	26
				R	52

Can you tell me how — coped with any soiled bed linen:

Special laundry service	1	15 Col 8 Box 4
Ordinary laundry	2	15
Launderette	3	14
Washed in home by hand	4	61
" " " machine	5	90
Disposable pads	6	80
Disposable sheets	7	35
Other	8	44
Inadequate	X	9
D.N.A. (all except codes 3 and 4 box 1)	Y	491 490
May be multi-coded hospital but not at home (also loss of bowel/bladder control in	R	58

Y Disposable, How did — get rid of them? Col 9 Box 5.

Burning indoors in fire place	1	27
" " a stove	2	11
" outdoors on open fire	3	20
" in incinerator	4	29
Dustbin	5	20
Special collections	6	—
Other	7	6
Inadequate	X	7

D.N.A. (all except codes 6, 7, or 8 - where disposable, in box 4) Y 618 617

May be multi-coded. Col 10 Box 6

Was this a problem at all? Yes 1 D.N.A. (all except codes 6, 7 or 8 - where disposable, box 4) — Y

No 2

Single coded. Inadequate X

	Col 10	
	Code	Total
	1	19
	2	15
	X	16
	Y	617
	R	58

Summary of distress:	Col 11	Box 7.
If patient has found any symptom very distressing	1	52
" " " " " " fairly "	2	[illegible]
" " " " " not very "	3	56
Inadequate how distressing (ie none recorded at all in col(a).)	X	[illegible]
single coded. D.N.A. (No symptoms at all, code 0 or X box 3)	Y	[illegible]
	R	58

Summary of length of time of symptom experience.	Col 12	Box 8
If patient has had any symptom for 1 year +	6	[illegible]
" " " " " " - 6 months < 1 year	5	42
" " " " " " 3 months < 6 months	4	57
" " " " " " 1 month < 3 months	3	[illegible]
" " " " " " 1 week < 1 month	2	[illegible]
" " " " " " less than a week	1	17
Inadequate how long (i.e. none recorded at all in col. (b).)	X	8
D.N.A. (No symptoms at all. code 0 or X box 3)	Y	32
single coded.	R	59

Page 9 - 1 Long-Term Instructionals left blank.

Box 1. Needing helping, whether get it or not with: Col 13

To be lifted at all	9	1	342
Help with washing (or shaving)	9	2	382
Getting in or out of bath	9	3	214
Dressing or undressing	9	4	296
Getting in or out of bed	9	5	311
Getting hair washed at home	9	6	259
Cutting toenails	9	7	347
Giving bedpan or bottle	9	8	172
Getting to lavatory or commode	9	Y	308
			may be multicoded
None of these		0	155
Inadequate to whole group		X	11
		R	130
Overcode if inadequate to certain ones		9	19

NB. 9 may be overcoded with 0 as well as 1-8 and y, but not X

Box 2:

Giving medicines or tablets	9	1	319 Col 14
Injections	9	2	141
Bandaging or other dressing	9	3	106
Regular temperature taking	9	4	may be multicoded 32
Massaging/exercises	9	5	90
Enema	9	6	40
Any (other) nursing procedure	9	7	73
None of these		0	233
Inadequate to all		X	11
Overcode if inadequate to some		9	10
		R	130

Box 3. Help needed at night with: Col 15

Help to get to the toilet	1	115
Bedpan	2	69
Medicines that had to be taken then	3	96
Injections or other treatment	4	may be multicoded 12
Drinks	5	188
Company	6	190
Other SPECIFY	7	64
No help needed at night	0	310
Inadequate if any help needed at night	X	17
" what sort of help " " "	9	37
	R	130

Box 4. Col 16

Someone to take him out	3	May be multi-coded	216
Someone to read to him	4		55
Someone to write letters for him	5		140
Someone to collect his pension	6		348
Someone to change his library books	7		87
None of these	0		213
Inadequate to all	X		12
Overcode if inadequate to some	9		4
	R		130

Box 5. Col 17

Needed financial help:

Yes	B	151
No	0	484
D.K.	9	21
Single code	R	130

Box 6. Col 18

IF DECEASED OR RESPONDENT HOUSEWIFE

Did you or he need help with-

61. Shopping	1	312
62. Preparing/cooking food	2	242
63. Cleaning house	3	299
64. Washing clothes	4	276

Looking after other members of the family, children & anyone	5	48
None of these	0	235
Inadequate to all	X	10
Overcode if inadequate to some	9	2
D.M.A. Neither deceased or respondent housewife	Y.	37
	R	130

MB If lived alone the deceased was housewife

There has been a build up on Y.

Analyse by [illegible] B28

Box 7. Groups of help needed. Col 19

R 127

11 - 19	Personal	1		489
21 - 27	Nursing	2		412
31 - 32	Night	3		329
41 - 45	Social	4	May be	431
51	Financial	5	multicoded	152
61 - 64	Housework	6		368
71	Family	7		48
None		0		66
Inadequate	No all	X		11
"	" some overcode	9		12

Col 20, 21.

Boxes 8 & 9 Number of different types of help needed (This can be between none and 29 and must agree with the number of help cards punched.

XX = Inadequate (no cards punched)

PID for Totals

Box 10. Help needed which did not get Col 22

D.M.A. Did not need any help [or XX on Box 8 & 9] Y 1 74

Hard (enough) help with all things needed or Pa 00 335

Needed (some) help ~~but did not get~~ with

Personal	1	130
Nursing	2	43
Night	3	57
Social	4	35
Financial	5	48
Housework	6	122
Family	7	8

Inadequate if got any help needed X 19

" " " some part of help needed overcoded 9 238

R 130

col 20

Code	Total
①	289
②	31
⓪	327
ⓧ	9
R	130

col 21

Code	Total
①	60
②	59
③	63
④	70
⑤	68
⑥	68
⑦	52
⑧	54
⑨	42
⓪	111
ⓧ	9
R	130

Box 11. Who asked for help? Col 23

D.M.A. (Code 0 4 or X in Box 10) (with or without 9.) 4

No one at all	0
Asked for some not others	4
Asked G.P.	1
Friends or relatives	2
Hospital	6
L.H.A Home help organisers/supervisors Welfare Dep't.	7
Social Security N.A.B.	8.
Other professional or voluntary sources	9
Inadequate if asked for help.	X

(Overcode X 4 rec 4)

Col 23

code	Total
(1)	35
(2)	5
(4)	43
(6)	4
(7)	23
(8)	12
(9)	18
(0)	120
(X)	49
(4)	418
A	130

ADDITIONAL CODES FOR Q.2

PAGE 9

Box 16 Record the longest period over which the deceased had/needed Personal Help of any kind (categories 11 - 19) Col 24

Less than a week 1	52	
1 week - 1 month 2	65	
1 month - 3 months 3	71	
3 months - 6 months 4	41	
6 months - 1 year 5	26	
1 year + ...6	~~75~~ 193	Single coded
Inad./don't know to some overcode.....9	27	
D.N.A. (No personal help needed, code 0 Box 1).y	106	
Inadequate to all X	39	
R	130	

Box 17 Record the longest period over which the deceased had/needed help at night of any kind (categories 31,32). Col 25.

Less than a week 1	~~79~~ 78	
1 week - 1 month 2	69	
1 month - 3 months 3	49	
3 months - 6 months 4	22	Single coded
6 months - 1 year 5	15	
1 year + ...6	35	
Inad./don't know to some overcode.....9	2	
D.N.A. (No night help needed, code 0 Box 3).y	327	
Inadequate to all X	60	
R	130	

Page 10 Leave blank for long term institutional

Leave Boxes 1-10 blank if No equipment needed at Q 44.
3-10 " X in Boxes 1 and 2

Box 1 Equipment needed :- Col 26

Back rest	1	121
Hoist	2	17
Special bed	3	23
Wheel chair	4	70
Crutches/stick/walking aid	5	129
Commode	6	213
Hearing aid	7	50
Bed pan or bottle	8	194
Other*	y	92
None of these	0	14
Inadequate to all question	X	16
Overcode if inadequate to part	9	31
	R	346

* Excluding those in Box 2

Box 2 Equipment needed : Col 27

Mackintosh sheet	1	183
Pads to protect bed	2	118
Extra linen	3	75
None of these - including D.N.A. because no loss of bowel/bladder control	0	218
Inadequate if needed these - or inadequate if had loss of bladder or bowel control	X	17
	R	346

Whether and how got

Box 3 Rubber ring Cradle / Hoisting Back rest, hoist or special bed or other furniture Col 27

Box 4 Invalid Car Wheel chair Col 29

Box 5 Crutches or stick or walking aid Col 30

Box 6 Bucket made Commode Col 31

Box 7 Hearing aid Col 32

Box 8 " Bed pan or bottle Col 33

Box 9 Mackintosh sheet, pads, extra linen Col 34

D.N.A. Not needed - or I.A. if needed	y
Not got	1
Bought	2
Borrowed	3
Given or supplied	4
Already had them	5
Other Hand Made	6
Inadequate	9

} may be multi coded.

Over code if 3 or 4 or 5 or 6

By relatives	6
By friends/neighbours	7
Chemist → Voluntary or Official ═══ sources	8
Inadequate	9

Box 10 Summary who helped with equipment include help with other equipment. Col 35

D.N.A. no equipment be roved given or supplied	y
By relatives	6
By friends / neighbours	7
Voluntary or official sources	8
Inadequate	9

} } } } May be multi-coded

Col 28		Col 29		Col 30		Col 31	
1	44	1	14	1	1	1	15
2	50	2	9	2	23	2	47
3	40	3	14	3	10	3	45
4	62	4	29	4	41	4	29
5	20	5	1	5	46	5	68
6	7	6	—	6	4	6	9
7	14	7	2	7	5	7	26
8	87	8	40	8	44	8	40
9	5	9	3	9	4	9	6
0	9	0	—	0	3	0	6
x	8	x	3	x	6	x	6
y	225	y	352	y	293	y	208
R	364	R	364	R	364	R	364

col 32		col 33		col 34		col 35	
1	6	1	11	1	17	6	33
2	12	2	65	2	74	7	55
3	—	3	42	3	44	8	228
4	24	4	40	4	91	9	26
5	4	5	31	5	09	y	142
6	—	6	3	6	11	R	364
7	—	7	12	7	7		
8	26	8	63	8	96		
9	1	9	8	9	9		
0	—	0	2	0	—		
x	6	x	7	x	12		
y	371	y	227	y	217		
R	364	R	364	R	364		

Col 36

Box 16 IF HAD WHEEL CHAIR a) Did not use it indoors only 1 8
Outdoors only 2 18
Both 3 16
Inadequate.....9 11
DIDN'T USE IT

b) Was it Motorised 4 1
Self propelled 5 9
Pushed by other person 6 35
Inadequate 8

DID NOT USE
D.N.A. Did not have - or unknown if had - wheel chair Y 603
R 130

Double coded except Y single coded.

Box 17 Equipment had :- Col 37

Washing machine	1	May be multi-coded	~~341~~ 340
Spin dryer	2		269
Car	3		220
Telephone	4		212
None of these	0		186
Inadequate to all	X		51
Inadequate to part (over code)	9		3
	R		130

Box 18 Equipment it would have been useful to have Col 38

Washing machine	5	82
Spin dryer	6	120
Car	7	96
Telephone	8	193
None	0	215
D.N.A. has (1-4)	Y	102
Inadequate to all	X	62
Inadequate to part overcode	9	4
	R	130

Box 19 Equipment it was useful to have Col 39

Washing machine	5	293
Spin dryer	6	236
Car	7	194
Telephone	8	195
None	0	30
D.N.A. (code 0 Box 17)	Y	184
Inadequate to all	X	62
Inadequate to part overcode	9	7
	R	130

13

15

31

35

Box 20 Was there any (other) piece of equipment it would have been helpful for _____ to have? Col 40

Yes	1	118
No	2	454
Inadequate	X	84
	R	130

? Other equipment at Q.44.

Single code

Code (1) if there was any equipment at Q 44 which it would have been useful to have, but was not got.

Box 21 Do you know of any organisations or people who help with getting equipment for invalids? Col 41

Yes.. No equipment (at Q.44) used or needed	Y		234
No	4		91
Inadequate if know of any	X		40
Red Cross St John's Ambul ance	1		79
W.V.S. and other known Voluntary organisations (Cancer Research.	2		35
Local authority health or welfare dept.	3		77
District Nursing Centre. District nurses	5	may be	89
Hospital – almoner. Medical social worker (Hospital)	6	multi.	50
National Assistance. Social worker NAB	7	coded	11
Local Ministry of Health – [illegible]	9		29
Other (Chemist. Doctor Vicar Priest Laundry Service Church Co-op Guild	0		49
Informal help (neighbours, relatives)	2		7
If got equipment from any of these sources as indicated at Q 44	R		130

(Health Centre Help.)

If got equipment from any of these sources as indicated at Q 44 it should also be coded here. Equipt noted at box 1-10 from these sources, but Q 47 not answered – code these sources here, not inadequate.

Additional expenditure incurred ...

Box 31 By deceased (or subject if subject in same household) Col 42
Box — By subject if subject in different household Col 43

On:		Col 42	Col 43
Heating,	1	249	1 7
Laundry	2	125	2 9
Special food	3	148	3 12
Extra help (specify)	4	68	4 3
Prescription charges	5	109	5 1
Other medicines (specify)	6	77	6 3
Fares, petrol	7	234	7 62
*Equipment	8	167	8 7
Anything else	9	61	9 11
None of these	0	167	0 84
Inadequate answers	X	70	X 38
	Y		Y 460
	R	130	R 131

Equipment coded (2) at 3-9, must be recorded as additional nature*

Box 32 D.N.A. – subject in same household as deceased Y

If uncertain whether expenditure is incurred by deceased or respondent (in different households) tick Box 31 and overcode (X). Also code Box 32 (X)

Should be deducted / at foot of 29, Page B

Col 44

Box 33 Easy to find extra money

D.N.A. (Codes 0 or X or Y in Boxes 31 & 32) y - single coded

Easy for deceased (or subject if in same household)	1	single coded
Not easy for deceased (or subject if in same household)	2	single coded
Inadequate	X	may be double coded
Easy for subject in different household	3	single coded
Not easy for subject in different household	4	single coded
Inadequate if easy or not	0	single coded

They say it was easy but had untrained persons code instead of where get assistance on

IF 2 or 4 or X overcode

Didn't ask anyone	6	Totals at
Asked NAB Social Security	7	
Asked other officials	8	foot of
Asked friends or relatives	9	
Inadequate who. or if asked		page

N.B. Count as 'NOT easy' any comment or suggestion that there was a problem unless 'easy' has been ~~wrong~~

Col 45

Box 34 Q.48b Do you know where people can sometimes get help with extra money and other things they need to look after invalids?

No	6	160
Inadequate or unsure	X	60
D.N.A. No extra expenditure incurred. if any other reason	Y	189
N.A.B. Social Security, Public Assistance	1	200
Other	2	43
Inadequate where	9	4
	R	130

Box 35 How much did it cost you to visit _____ there and back? Col 46

Less than 2/-	1	44
2/- less than 5/-	2	148
5/- less than 10/-	3	48
10/- +	4	44
Inadequate or unsure	X	42

D.N.A. No extra expenditure on fares/petrol y 368

R 130

Single code.

Col 44

Codes	Totals
1	261
2	148
3	66
4	21
5	5
6	108
7	41
8	13
9	6
0	9
X	35
Y	189
R	130

Breakdown of y 45 Col 7 Code y

Card

Column / Column	1	2	3	4	5	6	7	8	9	0	11	12	R	Total
10 1														17
11 2														9
3														
4														
5														
6														
7														
8														
9														
0														
11														
12														
R														
Total														

AREA

Code	Total
1	72
2	70
3	58
4	66
5	67
6	65
7	70
8	63
9	68
0	59
X	66
Y	62
Total	786

[redacted]

Third digit - Relationship to Deceased [redacted] Col 6.

Husband/wife	1
Father/mother	2
Son/daughter	3
Son in law/daughter in law	4
Grandchild	5
Brother/sister	6
Brother in law/ sister in law	7
Niece/nephew	8
Other relative	9
Friend/neighbour	Y
Other person	0
Inadequate	X

[redacted]

Page 11 left blank for Long Term Institutional Deaths.

Box 1 and 2 Person who bore brunt (Q. 51) Q. died most in looking after D before de

Box 1 Respondent/same household/sex — Col 5

Respondent 1
Lives in same household 2
Female 4
— additive 1 – 7

Noone 0
Other person (- not respondent, female or in same household) 8
Inadequate X

~~Pull out all ones with shared responsibility for later decision~~

If this is not filled in by interviewer but it is possible to make an intelligent guess on basis of information on p. 9 do this.

If more than one person bore the brunt allocate it on this basis:-

First: person in household takes priority over others

Second: closeness of relationship:-
1) Spouse
2) Children then children in law
3) Siblings then siblings in law
4) Other relatives
5) Friends/neighbours

Single coded (but can overcode?)

Third: respondent takes priority over others

Overcode if more than one person said to share brunt ..9

Only count one person as bearing brunt in 1st digit of 'helper' codes.

N.B. If only type of care given was after death (group 8) code (0) no-one as bearing brunt but code as helpers people involved in the care after de

Box 2 Relationship as 3rd digit of helper but — Col 6

Noone and inadequate X

Box 3 Number of different friends and relatives involved in care before death - not just visiting.

None 0
1 - 8 .....1 - 8
9+ 9
Inadequate if any X
Inadequate to some - overcode .....y

Col 7

Code	Total
1	108
2	160
3	135
4	76
5	48
6	24
7	13
8	8
9	11
0	67
X	6
y	5
B	130

N.B. Totals for Cols 5 & 6 over page

Col 5

Code	Total
1	15
2	12
3	98
4	10
5	56
6	~~62~~ 61
7	289
8	6
9	31
0	101
x	7
R	130

Col 6

Code	Total
1	258
2	4
3	164
4	20
5	4
6	38
7	7
8	8
9	7
0	8
x	109
y	29
R	130

Box 4 Number of friends and relatives who helped before or after death - not just visiting. This must agree with the total number of relatives/friends cards to be punched and should also be recorded at top LHS of page.

Col 8

Totals at foot of page

None	0
1 - 9	1 - 9
Ten	X
Eleven or more	y

If the whole page is inadequate this will be 0

If part is inadequate just code the number known about

Col 9

Box 5 Other children and close relatives who visited in year before death but were not involved in care before death

(This will normally cover people below line who are not coded as '0' did not see, and any above line who did not help before death)

Not including those in same household who didn't help before death

Number		
0	0	146 1/2
1	1	114
2	2	133
3	3	94
4	4	63
5+	5	~~106~~ 105
Inadequate	X	80 33
	R	130
Overcodes		
Includes children	6	132
Includes brother/sister	7	155
Includes both children and siblings	8	119
Overcode if father close relative unknown if visited	9	23 15

Box 6 Children or siblings living in E and W who did not visit. Col 10

No children in E and W	0	150
All " in E and W visited or lived with dec.	y	439
1 didn't	1	28
2 didn't	2	2
3+didn't	3	—
No siblings in E and W	8	220
All " in E and W visited	7	250
One didn't	4	88
2 didn't	5	30
3+ didn't	6	26
Overcode any other relative recorded in E and W who didn't visit	9	27
Inadequate	X	38
	R	130

Normally double-coded but X single-coded and if 9 applies there will be 3 coc

Col 8

Code	Total
1	54
2	183
3	155
4	109
5	55
6	36
7	19
8	14
9	2
X	20
Y	4
0	5
R	130

Most frequent helper or visitor from outside household

Box 7 a) How often came in last 12 months — Col 11

No one	0	32
1 - 2	1	16
3 - 5	2	20
6 - 11	3	18
12 - 19	4	22
20 - 49	5	55
*50 - 299	6	264
300+	7	151
*50+ but inad. nf more or less than 300	8	65
Inadequate	X	40
	R	130

*may be coded together Code 7 priority over 8

Box 8 b) Relationship — Col 12

Father/mother	2	11
Son/daughter	3	303
son in law/daughter in law	4	82
Grandchild	5	42
Brother/sister	6	97
Brother in law/sister in law	7	56
Niece/nephew	8	34
Other relative	9	43
Friend/neighbour	y	174
Other person	0	8
Inadequate ~~or No one~~	X	60
	R	130

May be multi-coded

Overcode if only females involved — 1 — 143
Do not use overcode if multicoded

PAGE 11

Box 9 Was Respondent involved in care of deceased (i.e. help before death) — Col 13

Before	1	315
After	2	56
Both	3	250
Neither	0	25
Overcode to 1 or 2 if inad. to other part	9	6
Inad. to both parts	X	10
	R	130

Page 12 Left blank for L.T.I.

Box 1 Various sorts of official people who helped during last 12 months of his life (while he was at home) Col 14

No-one	0	230
District nurse	1	234
Health visitor	2	53
Other nurse	3	35
Home help	4	71
Special laundry service	5	9
Chiropodist	6	77
Vicar, priest or minister and other church people	7	203
Any other official or voluntary service might suit	8	81
Inadequate which official, or part inadequate	9	3
Inadequate to all	X	10
(8) includes maid, paid help of other sorts	R	130

May be multi-coded

Check with pages 9 and 11. If district nurse, for example, helped on P.9 or P.11 it should be recorded here. Include in category 1 nurses of indeterminate origin. Doctors and social security not included here.

Box 2 Number of different sorts of official people who helped. Col 15

1 - 7	1 - 7	Totals over page of
8+	8	
None or inadequate to all	0	(Leave rest of page blank)

Note: this number should correspond to the total number of 'officials' recorded in the corner of the page.

Box 3 Longest period for which had any sort of help Col 16

Less than a week	1	42
1 week - 1 month	2	57
1 month - 3 months	3	55
3 months - 6 months	4	25
6 months - 1 year	5	29
1 year or more	6	185
Inadequate	X	23
	R	370

Take longest known period - ignore inadequate categories

Box 4 Most often he had any sort of help - at its most frequent Col 17

Daily or more often	1	150
More than weekly less than daily	2	61
Weekly	3	48
More than monthly less than weekly	4	26
Monthly	5	28
Less often	6	80
Inadequate	X	23
	R	370

Box 16 Had all help as often as necessary .....0 280 Col 18

Prefer more help from district nurse 1 62
Health visitor 2 10
Other nurse 3 9
Home help 4 29
Special laundry service 5 1
Chiropodist 6 6
Vicar, priest minister etc 7 17
Other 8 9

Code 2 at 6th digit = 4 at 7th digit

4 at 6th digit and X at 7th digit Box 16 will be part inadequate not nec wholly inad.

Inadequate to part, overcode 9 170
Inadequate to all .....X 21
R 370

Box 17 Various things helped with Col 19

Personal (11 - 19) 1 223
Nursing (21 - 27) 2 176
Night (31, 32) 3 24
Social (41 - 45) 4 12
Financial(51) 5 3
Housework(61 - 64) 6 104
Family (71) 7 2
After death (81 - 84) 8 11
Other types of help (not including visiting) 0 39
Visiting (and praying), in contact with clergy, etc 9 230
Inadequate to part .....y 15
Inadequate .....X 7
R 370

Page 13 left blank for L.T.I.

Box 1 58. Do you think —— could have done with any help from:- Col 20

A nurse at home	1	may be multi-coded	41
Home help	4		92
Laundry service	5		47
Chiropodist	6		38
Bath attendant	8		49
Any other type of service	y		28
None	0		461
Inadequate to part	9	(- overcode)	2
Inadequate	X		30

Box 2 54. Do you think he would have liked a vicar, priest or minister to visit him ? Col 21

Yes	5	62
No	6	307
D.N.A. (vicar etc. visited)	y	203
Inadequate, uncertain, don't know	X	84
	R	130

If respondent was not involved in care of deceased, leave rest of page blank
(i.e. Answer 'No' to Q 49(a) or 'Yes' but help only after death.
If this has not been answered but the rest of P.13 is answered, then carry on through P.13.)

Box 3 55. Were you working at the time you started to look after —— ? Col 22

No	2	293
Yes, full time	3	155
Yes, part time	4	66
Yes, inadequate if full or part time	9	22
Inadequate if working or not	X	29
	R	221

Box 4 56. Did you have to make any changed in your work because of looking after ——, such as:- Col 23

Changing to different hours	1	may be multi-coded	16
Changing to less hours	2		24
Changing to different work	3		8
Taking time off	4		88
Retiring early	5		4
Giving up work all together	6		49
Any other changes, specified	7		17
~~Any other changes~~, unspecified ~~overcode~~	9		6
No changes in work	0		67
Inadequate to part, overcode	9		5
Inadequate to all	X		322
D.N.A. (code 2 or X Box 3)	y		
	R		221

Box 5 57. For how long was your work affected ? Col 24

Less than 2 weeks	1	18
2 weeks - 1 month	2	18
1 month - 3 months	3	28
3 months - 6 months	4	22
6 months - 1 year	5	25
1 year +	6	46
Inadequate how long	X	14
D.N.A. (code OXor y Box 4)	y	394
	R	221

Box 16 58. Did this make a lot, a little, or no difference to you financially ? Col 25

A lot	5	68
A little	6	31
No difference	7	62
Inadequate how much difference	9	3
Inadequate if any difference	X	7
D.N.A. (No change in work, or not working)	y	
(Code 2 or X Box 3)	y	394
	R	221

Box 17 If 5 or 6: Do you know where some people can get financial help over this in some circumstances ? Col 26

Yes - N.A.B., Social Security, Assistance	1	50
Yes - Other	0	2
Yes - Inadequate where	9	—
No	2	44
Inadequate if knows	X	7
D.N.A. (All except codes 5 or 6 Box 16)	y	463
or 9	R	221

Box 18 b) Did you yourself apply for financial help ? Col 27

No	4	33
Applied to Social Security ,given help	1	14
Applied to Social Security,not given help	2	3
Applied to Social Security, inad.if help	3	1
Applied to other,given help	5	1
Applied to other, not given help	6	—
Applied to other, inad.if help	7	—
Inad if applied	X	—
D.N.A. (all except codes 1,0,9 Box 17)	y	514
	R	221

Box 19 59. Could you describe any (other) difference looking after —— made to your life ? (col 28)

None at all, none mentioned	0		83
Very little, some difference, not great	1	may be multi-coded	62
Found it a strain, mental anguish etc.	2		110
Affected health, incl. 'felt tired'	3		63
Took up time ~~interfered with~~	4		41
Restricted social life ~~domestic~~	5		197
Financial difficulties	8		6
'Glad to do it', not clear ~~much~~ difference	9		88
Inadequate if any (other) difference	X		57
Other (more work, etc)	7		47

N.B. Take only the things respondent mentions here. No need to look at other questions for information.

R 221

Col 29

Box 1 60. During ——'s illness or incapacity were you able to find out all you wanted to know about his illness and how it was likely to affect him ?

No 2	~~153~~ 152
Inadequate if yes or no X	39
Yes: Was there anything else you would have liked to have explained to you in more detail ?	
Yes 3	32
Inadequate if there was anything else.....9	4
No : Were you able to find out about things as soon as you wanted to ?	
Yes 5	421
No 6	22
Inadequate if able to find out as soon as wanted 8	17
D.N.A. (neither involved in care before death, nor relative or close friend) includes friends & L T I.'s .....y	40
R	58

Box 2 61. What would you have liked to know about/in more detail/earlier? Anything else ?

Col 30

Nothing, don't mind 0	10
Would have liked to know some more specific thing earlier.....1	178
Inadequate X	19
D.N.A. (code 5 or y or X or 8 in Box 1) .....y or 9	521
R	58

Box 3 62. Did you ask anyone about this ?

Col 31

No 2	71
Yes asked: G.P. 5	21
Hospital doctor 6	30
Hospital sister/nurse 7	27
District nurse 8	1
Other specified 9	12
Other unspecified / Inadequate who asked 0	-
Inadequate if asked X	17
D.N.A.(code 0 or y at Box 2) .....y	531
Overcode if asked someone and was told more ...1	37
R	58

may be multi coded

Box 16 63. Who did you talk to about ——'s illness and what was likely to happen ?

Col 32

——'s G.P.	1	may be multi coded	427
Other G.P.	2		69
Hospital doctor	3		247
Hospital sister/nurse	4		211
District nurse	5		77
Home help	6		6
Vicar, priest, minister	7		62
Any other nurse, doctor or professional person, specified	8		56
Unspecified or inadequate which professional person	9		3
No professional persons	0		54
Inadequate if any	X		61
D.N.A. (respondent not relative or close friend and not involved in care of dec.)	y		40
	R		58

Relationship to informant
Box 17

Col 33

Spouse	1	may be multi coded	101
Father/mother	2		36
Son/daughter	3		95
Son in law/daughter in law	4		13
Grandchild	5		2
Brother/sister	6		133
Brother in law/sister in law			
Other relative ~~unspecified relative~~	7		~~76~~ 75
Friend/neighbour	8		92
Other person	9		10
No non-professional persons	0		286
Inadequate if any non-professional person	X		71
D.N.A. (as Box 16)	y		40
	R		58

Col 34 Col 35

Box 18 and 19 Box 18 . Box 19

64. Who gave you most information ?

——'s G.P.	0	269	1
Other G.P.	0	26	2
Hospital doctor	0	123	3
Hospital sister/nurse	0	~~64~~ 65	4
District nurse	0	15	5
Home help	0	—	6
Vicar, priest, minister	0	—	7
Other specified professional person	0	21	8
Unspecified professional person	0	—	9
Spouse	1	4	0
Father/mother	2	6	0
Son/daughter	3	6	0
Son in law/daughter in law	4	2	0
Grandchild	5	—	0
Brother/sister	6	3	0
Brother in law/sister in law	7	1	0
Other relative	8	3	0
Friend/neighbour	9	2	0
Other person	0	—	0
Inadequate who, ormmore than one, won't tell who	X	63	X
D.N.A. (y at Box 16, and 17 or 0 or X at Box 16) and ■ Box 17)	y	119	y

Single coded at each box R. 58

Box 20 65. Did —— know what was wrong with him ?

Col 36

No	2	230
Uncertain	3	119
Yes: told by no-one	0	69
G.P.	5	177
Hospital doctor	6	61
Hospital sister/nurse	7	3
District nurse	8	1
Other specified person	9	13
Other unspecified person	1	3
Inadequate who told him	4	23
Inadequate if knew	X	45
Overcode if knew part not all	8	33
	R	58

68

may be multi coded

Box 1 66. Did —— know he was not likely to recover ? or Did —— know this was likely to happen ? Col 37

Yes certain 1		121
Yes probably 2		~~138~~ 137
Probably not 3		66
No definitely 4		232
Unable to say 5		135
Inadequate X		36
Single coded	R	58
		785

Box 2 a) Had anyone told him ? Who ? Col 38

No-one.....0		193
G.P. 5	may be multi-coded	22
Hospital doctor 6		14
Hospital sister/nurse..7		—
District nurse 8		—
Other specified person.9		7
Inadequate who told ...1		—
Inadequate if told X		25
D.N.A.(all except 1 or 2 Box 1)...y		469
	R	58

Box 3 b) Do you think that was best or do you think it would have been better if he had not known (or had known definitely) ? Col 39

Better not to have known 1		~~42~~ 41
Better to have known definitely....2		19
Best as it was 3		138
Uncertain 4		49
Inadequate X		11
D.N.A. (all except codes 1,2 at Box 1) .....y		469
Single coded	R	58

N.B. If coded 1 in Box 1, code 3 rather than 2 in this box

Box 4 c) How long before he died had he (or might he have) known ? Col 40

Less than 24 hours.....0		10
24 hrs - 1 week 1		~~37~~
1 week-1 month 2		45
1 month - 3 months 3		32
3 months - 6 months 4		20
6 months - 1 year 5		8
1 year or more 6		62
Inadequate how long X		~~56~~ 54
D.N.A.(all except codes 1 or 2 Box 1).....y		469
Single coded	R	58

Box 5 Do you think that was best or would it have been better for him to know (or definitely not to know) Col 41

Better to have known	5	6
Better not to know definitely	6	25
Best as it was	7	236
Uncertain	8	20
Inadequate	X	11
D.N.A.(all except codes 3 or 4 at Box 1)	y	~~430~~ 429
	R	58

Single coded

N.B. If coded 4 at Box 1, code 7 rather than 6 in this box

Box 6 Who do think would have been the best person to tell him ? Col 42

G.P.	5	2
Hospital doctor	6	1
Hospital sister/nurse	7	–
District nurse	8	–
Respondent - self	1	–
Other specified	0	–
Inadequate who	X	3
D.N.A.(all except code 5 Box 5)	y	722
	R	58

Normally single coded but may be multi-coded

Box 16 67. What about from your point of view. Did you know what was wrong with ——? Col 43

No	6	65
Half knew, knew something, not all	7	47
Yes told by No-one	0	39
G.P.	1)	310
Hospital doctor	2)	
Hospital sister/nurse	3)	~~62~~ 151
District nurse	4)	
Other specified person	5)	
Inadequate who	9	34
Inadequate if knew	X	2
Yes told by deceased	8	42
Don't remember	- 4	8
		60
		18
	R	58

may be multi coded

Col 44

Box 1 68. I think you said you knew/didn't know/half knew that —— was unlikely to recover.

Inadequate if knew/didn't know/half knew....X		37
Knew 4		474 473
Didn't know, like to have known 5		48
(Glad didn't 6		53
(Qualified, uncertain 7		10
(Inadequate 9		7
Half knew, like to have known definitely....1		12
(Liked not to have known at all 2		4
(Best as it was 3		34
(Qualified, uncertain 0		5
(Inadequate 8		3
D.N.A. (respondent not relative or close friend:(i.e. code 0 in Box 1) or 2 in Box 3 Page1))....y		41
Single coded	R	58

Box 2 a) Knew: told by

Col 45

No-one.....0		56
G.P.....5		228
Hospital doctor.....6		~~140~~ 139
Hospital sister/nurse 7		may be multi-coded 45
District nurse.....8		7
Other specified person.....9		31
Inadequate who, other unspecified person....X		12
D.N.A. (all except code 4 in Box 1) .....y		254
	R	58

Box 3 b) How long had you known before he died ?

Col 46

Less than 24 hours.....0		18
1 day - 1 week 1		~~59~~ 58
1 week - 1 month 2		72
1 month - 3 months.....3		80
3 months - 6 months.....4		53
6 months - 1 year.....5		41
1 year or more 6		124
Couldn't say 9		3
Inddequate how long X		24
D.N.A. (all except code 4 in Box 1)...y		254
Single coded	R	58

Box 4 c) Would you have preferred not to know or do you think it was better that you did

Col 47

Preferred not.....1		16
Better that know.....2		~~393~~ 392
Uncertain 3		47
Inadequate X		18
D.N.A. (all except code 4 in Box 1)...y		254
Single coded	R	58

Box 5 Would you have liked to have known earlier or later or when you did Col 48

Earlier	5	42
Later	6	4
Right time, didn't...	7	320
Uncertain, couldn't say	9	11
Inadequate	X	63
D.N.A. (all except codes 2 or 3 in Box 4)	y	288
Single coded	R	58

Box 6 d) Did you expect —— to die earlier, later or when he did Col 49

Earlier	1	79
Later	2	132
When he did	3	~~114~~ 113
Couldn't say, uncertain	4	85
Inadequate	X	64
D.N.A. (all except code 4 in Box 1)	y	254
Single coded	R	58

Box 16 If like to have known. Who would have been the best person to tell you Col 50

G.P.	5	)	24
Hospital doctor	6	)	8
Hospital sister/nurse	7	)	4
District nurse	8	) may be multi-coded	—
Other specified person	9	)	3
Inadequate who, other unspecified person	X		11
D.N.A. (all except code 5 in Box 1)	y		680
Don't care who.	4		—
	R		58

Page 11 left blank for Long Term Institutional Deaths.

Box 1 and 2 Person who bore brunt (Q. 51) Or did most in looking after D. before de

Box 1 Respondent/same household/sex — Col 5

Respondent 1
Lives in same household 2
Female 4
— additive 1–7

Noone 0

Other person (- not respondent, female or in same household) 8

Inadequate X

~~Pull out all ones with shared responsibility for later decision~~

If this is not filled in by interviewer but it is possible to make an intelligent guess on basis of information on p. 9 do this.

If more than one person bore the brunt allocate it on this basis:-

First: person in household takes priority over others

Second: closeness of relationship:-
1) Spouse
2) Children then children in law
3) Siblings then siblings in law
4) Other relatives
5) Friends/neighbours

Single coded (but can overcode?)

Third: respondent takes priority over others

Overcode if more than one person said to share brunt ..9

Only count one person as bearing brunt in 1st digit of 'helper' codes.

N.B. If only type of care given was after death (group 8) code no-one (0) as bearing brunt but code as helpers people involved in the care after de

Box 2 Relationship as 3rd digit of helper but — Col 6

Noone and inadequate X

Box 3 Number of different friends and relatives involved in care before death - not just visiting.

None 0
1 - 8 .....1 - 8
9+ 9
Inadequate if any X
Inadequate to some - overcode .....y

Col 7

Code	Total
1	108
2	160
3	135
4	76
5	48
6	24
7	13
8	8
9	11
0	67
X	6
Y	5
R	150

N.B. Totals for Cols 5 + 6 over page

Col 5

Code	Total
1	15
2	12
3	98
4	10
5	56
6	~~62~~ 61
7	289
8	6
9	31
0	101
x	7
R	130

Col 6

Code	Total
1	258
2	4
3	164
4	20
5	4
6	38
7	7
8	8
9	7
0	8
x	109
y	29
R	130

Box 4 Number of friends and relatives who helped before or after death - not just visiting. This must agree with the total number of relatives/friends cards to be punched and should also be recorded at top LHS of page.

Col 8

Totals at foot of page

None	0
1 - 9	1 - 9
Ten	X
Eleven or more	y

If the whole page is inadequate this will be 0

If part is inadequate just code the number known about

Col 9

Box 5 Other children and close relatives who visited in your before death but were not involved in care before death

(This will normally cover people below line who are not coded as '0' did not see, and any above line who did not help before death)

Not including those in same household who didn't help before death

Number		
0	0	116 112
1	1	114
2	2	133
3	3	94
4	4	63
5+	5	106 105
Inadequate	X	30
	R	130
Overcodes		
Includes children	6	132
Includes brother/sister	7	155
Includes both children and siblings	8	119
Overcode if other close relative unknown if married	9	23

Box 6 Children or siblings living in E and W who did not visit. Col 10

No children in E and W	0	150
All " in E and W visited or lived with dec:	y	437
1 didn't	1	28
2 didn't	2	2
3+didn't	3	—
No siblings in E and W	8	220
All " in E and W visited	7	250
One didn't	4	28
2 didn't	5	3
3+ didn't	6	2
Overcode any other relative recorded in E and W who didn't visit	9	24
Inadequate	X	32
	R	130

Normally double-coded but X single-coded and if 9 applies there will be 3 coc

Col 8

Code	Total
1	54
2	183
3	155
4	109
5	55
6	36
7	19
8	14
9	2
X	20
Y	4
Z	5
R	130

Page 17 - 1: Includes unexpected deaths and L.T.I.

69. Was ---- unconscious before he died ? Col 5 Box 1

No	5	280
Inadequate	X	103
Yes: Less than 3 hours	0	98
3 - 24 Hours	1	151
1 day - 1 week	2	120
1 week or more	3	22
Inadequate how long	9	12

If under anaesthetic and inadequate if conscious or not code X.
Single code

70. Could he recognise his relatives up until the time he dies - when he was conscious ? Box 2 Col 6

Yes always	6	598
Sometimes	7	91
No	8	43
Uncertain	9	8
Inadequate	X	46

Single coded

Col 7 Box 3

How long before ?

Less than 24 hours	0	16
1 day - 1 week	1	58
1 week - 1 month	2	29
1 month - 3 months	3	6
3 months - 1 year	4	10
1 year+	5	5
Inadequate	X	10
D.N.A. (all except codes 7 or 8 in Box 2)	y	652

Single coded

71. Were you with ---- when he died ? Col 8 Box 4

Yes at bedside (at deceased's side)	5	258
Elsewhere in house	6	87
No last time seen within 24 hrs	0	269
1 day - 1 week	1	68
1 week - 1 month	2	23
1 month - 3 months	3	6
3 months or more before death	4	4
Inadequate how long	9	61
Inadequate if with deceased	X	10

431

341

Single coded

72. Were any(other) relatives or friends with him ? Col9 Box 5

	Yes.....1	234
	No 2	526
	Don't know,uncertain.....3	3
	Inadequate X	23

Single coded

73. Roughly how often did you see him in the last week ? Col10 Box 6

20	Not at all.....0	
34	Once 1	
78	2 - 4 2	
155	5 - 9 3	
25	10 - 19 4	
46	20+ 5	
103	Inadequate how often X	
325	D.N.A. (died at home in same household as resp. or if not seen in last 3 mths) .....y	

y respondent in official/etc of institution involved deceased died, thus box is y.
or y died in street, office etc, and in same household.

Roughly how often did you see him in last month ? Col11 Box 7

Codes as in Box 6

Roughly how often did you see him in last 3 months ? Col12 Box 8

Codes as in Box 6

	cd 7 II	cd. 8 IV
0	6	-
1	11	7
2	23	7
3	32	6
4	47	35
5	229	287
x	114	120
y	325	325

74. How did you feel about ---- dying at home rather than in hospital ? Box 16 Col13

Rather have him die at home	1	192
Rather have him die in hospital(or institution)	2	23
Don't mind, don't care, uncertain, no clear code above	3	46
		261
Inadequate	X	46
D.N.A. (not home death;unexpected home death)	y	

Single coded
N.B. Deaths treated as unexpected by interviewer, but which were not coded thus will be X not y

75. Did you at any stage feel it would have been better for ---- to be in hospital (again) ? Col14 Box 17

No	2	192
Inadequate	X	38
Yes from ----'s point of view	3	29
your " " "	4	54
" " " of others looking after him	5	28
		may be multi-coded
Inadequate whose point of view	1	1
D.N.A. (y in Box 16)	y	479

186 317 269

Did you discuss this with ----'s G.P. ? 1 Col15 Box 18

Yes, something happened	1	9
" nothing "	2	36
" inad. if anyhting happened	3	4
No, talked to someone else about it	4	6
" didn't talk to anyone else about it	5	15
" inad. if talked to " " " "	6	4
Inad. if discussed with ----'s G.P.	X	3
D.N.A. (y in Box 16 or 2 or X in Box 17)	y	709

Single coded

76. Who washed and prepared ----'s body ? Col16 Box 19

Self	1	40
Relative in same household	2	15
" " other "	7	31
" inad. if in same household	8	-
Neighbour/friends	3	56
Nurse	4	31
Undertaker	5	187
Other specified person (taken to hospital)	6	15
Inadequate who	9	11
D.N.A. (y in Box 16)	y	435 - except unexpected home death.
Post-mortem / coroners etc.	0	15

May be multi-coded

Col 17 Box 1

77. Looking back on it do you think it would have been helpful if you had known more about what to do when someone died or do you feel you knew enough

Like to have known more.... 6	55
Inad. whether knew enough X	18
Knew enough, knew from experience.....7	172
" " , inad. how 9	16
" " , someone told:.....	
District nurse 1	4
G.P. 2	12
Relative 3	14
Friend, neighbour 4	may be multi-coded 10
Other (specified):.....5	10
Other (unspecified).....0	2
Didn't have to do anything; Not involved, etc. - inad. who 0	8 43
D.N.A. (died in institution, street office etc.) .....y	435

Col 18 Box 2

78a Did a general practitioner come to see —— after he died

No 6	27
Yes (incl. present at death):	
His own doctor 1	224
Another dr. who'd seen him before2	69
Another dr. 3	may be multi-coded 49
Inad. what dr 9	3
Inadequate X	8
DNA (y in box 1)	y 435
No Taken to hospital — overcode	0 4

Col 19 Box 3

78b Was he the doctor who signed the death certificate

Yes 4	250
No 5	47
Uncertain, inad. X	19
D.N.A. (y in Box 1 or 6 in Box 2) .....y	470

Col 20 Box 4

78c How soon did he come after he died

Present when died.....0	15	310
Within hour 1	171	
1 hour - 3 hrs 2	57	
3 hrs - 6 hrs 3	35	
6 hrs - 24 hrs 4	27	
1 day - 2 days 5	4	
2 days - 3 days 6	1	
3 days or longer 7	—	
Inad. X	6	
D.N.A. (y in Box 1,2 X in Box 2).....y	470	

Single coded

Would you have liked a doctor to come — Col 21 Box 5

D.N.A.(all except 6 in Box2)..y	763	
Yes 1	8	
No 2	14	
Inadequate X	1	
Single coded		

79. How did you feel about —— dying in hospital — Col 22 Box 16

Rather have him die in hosp...1	242	366
" " " " at home...2	46	
Indeterminate,uncertain 3	78	
Inadequate X	12	
D.N.A.(home death, or in street,office etc./resp. official in institution) .....y		
Single coded		

80. Did you at any stage feel it would have been better for —— to be at home — Col 23 Box 17

No 4	306
Yes discussed it with someone.....5	21
didn't discuss it with anyone..6	29
inad. whether discussed it with anyone 9	1
Inad. X	22
D.N.A. (died ~~in hospital~~ at home, street etc) and y in 16)	408

Q. 80 contd. — Col 24 Box 18

D.N.A. (all except code 5,Box 17)..y	765
Talked to:	
G.P. 1	3
Hospital doctor 2	6
Hospital nurse 3	6
Other specified 4	1
Other unspec.,inad. who 9	1
Something happened,overcode....5	1
Inad. if " ", overcode....6	-
Didn't talk to above, but talked to:	
Relative 7	4
Friend,neighbour 8	4
Other unspec. inad. who 0	1
Inadequate X	1

81. When —— went into hospital (the last time) who first suggested it Col25 Box 19

Deceased	1	9
Respondent	2	35
Other relative	3	13
G.P.	4	240
Hospital doctor	5	41
Other specified	6	32
Other unspec;inad who	X	15
D.N.A. (y in Box 16)	y	408

may be multi-coded

82. How about —— do you think he was relieved, distressed or how did he feel - Col26 Box 20

Relieved	1	127	45
Distressed	2	73	26
Other ~~Pa all to come~~	3	63	22
Unconscious, didn't know	4	14	
D.N.A.(y in Box 16)	y	408	
Inadequate	X	22	7
Both relieved+distressed	5	19	
			282

Taken to hosp when dead - PIMWC-P

Page 19. - 1.

Col 27

83 And what about you - did you feel relieved or distressed or what? Box 1

Relieved	4	224		62
Distressed	5	64		18
Both (mixed feelings)	9	48	Single	13
Other	6	23	coded	6
Inadequate	X	19		3289
D.N.A. (Home death or in street, office etc / resp. official in institution)	Y	408		

Col 28

84 Who was mainly responsible for the arrangements with the undertaker and all the other formalities? Box 2

Self alone	209	1	
Self with others	289	2	Single
Others only	278	3	Coded
Inadequate	10	X	

Sarah - Please include that bit in here

Col 29

85 Would you have liked any (more) help with (that or) anything after ____ died? Box 3

Yes	481	
No	666	2
Inadequate	30	X
	42	

(NB Y Respondent not a relative or close friend leave rest of page blank)

qe 19-21

Col 30

86 Have you a religious faith or belief which you feel helped you Box 4
at the time of ——'s death?

Yes	445	1	
No	249	2	Single coded
Qualified/uncertain	29	3	
Inadequate	21	X	
	42		

Col 31

87 What about —— do you think he had a religious faith or Box 5
belief which was helpful to him

Yes	430	3	
No	221	4	Single coded
Qualified/Uncertain	70	5	
Inadequate	23	X	
	42		

88 To which faith or denomination do you belong? (32) Col 32 Box 6 (33)

Roman Catholic	82	1	72
Church of England	454	2	44
Other Protestant	20	3	23
Jewish	1	4	Single 2
None	55	5	coded 6
Other specified	10	6	14
Unspecified, inadequate which	1	9	3
Inadequate	21	X	28
	42		42

89 What about —— what did he belong to? Col 33 Box 7

Codes as in Box 6

Page 19-3

Col 34

Q.90 Have any of these people visited you at home since ___ died? Box 16

	R	42	
Your own doctor	153	Y	32
Other general practitioner	22	1	2
District nurse	36	2	6
Other nurse	61	3	
Welfare or social worker	42	4	
Vicar priest or minister	234	5	25
Any other professional person, specified.	18	6	
Unspecified or inadequate to part	3	9	
Inadequate.	26	X	49
None of these	356	0	616

(may be multi coded.)

Col 35

Q.91 Would you have liked any (other) of them to visit? Box 17

Codes as in Box 16.

Inadequate		
"	Who wanted any	X
	who wanted	9

Q.92 Have you consulted a doctor, nurse or chemist professionally for yourself since ___ died? Box 18

Col 36

No	344	2
Yes G.P.	346	3
Other doctor	23	4
District nurse	3	5
Other nurse	—	6
Chemist	2	7
Inadequate which	23	9
Inadequate	21	X
	42	

(may be multi coded.)

qe 19-4

92 (c) Do you think it had anything to do with your bereavement or not? Col 37 Box 19

Yes	236	1	
No	112	2	
Uncertain	25	3	Single coded
Inadequate or X	6	X	
D N A: (code 2 in Box 18)	365	4	
	42		

92(d) Y doctor or chemist, did he give/sell you any tablets or medicine? Box 20 Col 38

Yes	301	4	
No	39	5	Single coded
Inadequate	39	X	(double coded with overcode)
D N A (all except codes 3, 4 or 7 at Box 18)	365	4	
Overcode if symptoms mentioned here include, shock, nerves, anxiety, sleeplessness	1	145	

93: Have you made any changes in your way of living, since R died? Box 21 Col 39 42

No	512	2	
Yes Change in household arrangements	25	3	may be multi coded
Change in household (going to live with others etc)	55	4	
Change in work	62	5	
Other changes (specified)	75	6	
Inadequate what changes	9	9	
Inadequate if any changes	22	X	
	42		

Q. 94 Are you planning any(other) changes ? Col 40 Box 1

No	4		572
Inadequate if	X		37
Yes:Change in household arrange....	5	)	13
" " " (inclu: going to live with others)...	6	)	89
Change in work	7	)	may be multi-coded 21
Other specified changes	8	)	16
Inad. whar changes	9	)	1
D.N.A. (resp. not relative or close friend)	y		42

Q. 95 Since —— died have you had any particular worries or anxieties such as:- Col 41 Box 2

Financial worries	1	)	103
Legal ones - to do with the will	2	)	68
Problems with house or tenancy	3	)	may be multi coded 50
Anything else SPECIFY	4	)	56
Inadequate what	9	)	—
Nothing	0		516
Inadequate if any	X		19
D.N.A. (as in Box 1)	y		42

IF ANY WORRIES: Did you consult anyone about these ? Col 42 Box 3

No	6		61
Inadequate	X		18
Yes: a relative	1	)	16
a friend/neighbour	2	)	3
a professional person	3	)	106
an outsider	4	)	may be multi coded
other specified person	5	)	10
inadequate who	9	)	4
D.N.A. (0,X,y in Box 2)	y		577

Were they able to help ? Col 43 Box 4

Yes	7	77
No	8	30
Inadequate	X	14
D.N.A. (code 6,Y,X in Box 3)	y	656
Helped with some not all	9	9

single coded

Q. 96 When someone close to you dies who do you feel it is best to talk to about how you feel:- Box 5 Col 44

A relative	3	)	440
A close friend	4	)	152
A professional person	5	)	71
An outsider	6	)	may be multi coded 34
or who ? SPECIFY	7	)	10
Inad. who/ unspecified	9	)	12
No-one	0		64
Inadequate	X		46
D.N.A. (as in Box 1)	y		42

IF PROFESSIONAL: What sort of person had you in mind ? Col45 Box 6

A doctor	36. 11	may be multi ooded
A nurse	7. 2	
A lawyer	- 3	
A clergyman	26. 4	
Other specified	4. 5	
Inad. who/ unspec.	5. X	
Inadequate		
D.N.A. (all except code 5 in Box 5)	715 y	

Q. 97 Who did you find most useful ? Col46 Box 7

Relative	1	392
Close friend	2	81
Outsider	3	20
Doctor	4	18
Nurse	5	5
Lawyer	6	-
Clergyman	7	10
Other specified (rel. interests)	8	17
Inadequate who	9	14
No-one	0	80
Inadequate if anyone	X	107
D N A (as in Box 1)	y	42

Q. 98 Is there anything else you would like to say about: Col47 Box 16

a) ——'s care before he died	1	may be multi ooded
b) His death ?	2	
c) The time since he died	3	
Nothing mentioned	0	

(1) Do you mind telling me your age ? Col48 Box 17

21 - 24	17 1	single ooded
25 - 34	57 2	
35 - 44	49 3	
45 - 54	174 4	
55 - 64	195 5	
65 - 69	73 6	
70 - 74	74 7	
75 - 79	44 8	
80 - 84	17 9	
85 and over	4 0	
Inadequate	12 X	

(11) Sex Col49 Box 18

Male	206 1	single ooded
Female	580 2	
Inadequate	X	

(111) Marital status Col50 Box 19

Single, never married	98 3	single ooded
Married now	331 4	
Widow(er) of deceased	309 5	
Other widow/divorced etc	643	
Inadequate	X 5	

Household composition — Col51 — Box 1

Inadequate	X	3
On own	1	237
With spouse only	2	114
With spouse and child(ren), no c. in law	3	175
" " " " and " with or without grandchildren	4	4
With child(ren), no c. in law	5	115
" " and " " , with or without grandchildren	6	16
With other relatives of same generation only	7	20
With unrelated people only (friend, landlady)	8	11
Other three generation household	9	10
In guest house/old people's home/ boarding house	y	22
Others (incl. staff of institutions)	0	59

Single coded

Who is the relative you see most of ? — Col52 — Box 2

Father/mother	1	4
Son/daughter	2	96
Son in law/daughter in law	3	12
Grandchild	4	6
Brother/sister	5	64
Brother in law/sister in law	6	13
Other relative of same generation	7	5
Other relative	8	27
Inadequate who	9	8
No relatives/no relatives seen	0	16
Inadequate if sees any relative	X	9
D.N.A. (all except Code 1 in Box 1)	y	549

M/coded if more than one

Where do they live ? — Box 3 — Col53

closest taken if more than one.

Within 10 mins walk	1	55
Within ½ hr journey	2	79
½ hr - 1 hr	3	33
1 hr - 2 hrs	4	14
2 hrs or more	5	29
Inadequate	X	2
D.N.A (all except Code 1, Box 1) 0, X, Box 2	y	574

Single coded

Length of interview — Col54 — Box 4

Less than 30 mins	1	11
30 - 45 mins	2	37
45 mins - 1 hr	3	93
1 - 1½ hrs	4	233
1½ hrs - 2 hrs	5	232
2 hours or more	6	165
Inadequate	X	15
Overcode if completed on more than one occasion	y	41

Single coded

Anyone else present — Col55 — Box 5

No	4	527	Yes:other	7	9
Yes:relative	5	221	inad. who	9	6
Yes:friend/neighbour	6	24	Inadequate if	X	9

Main informant was — Col 56 — Box 16

Only appropriate person	1	584
One of two or more appropriate	2	162
Not the most appropriate person	3	32
Inadequate	X	8

Who (else) was appropriate ? — Col 57 — Box 17

Spouse	1	52
Father/mother	2	4
Son/daughter	3	74
Son in law/daughter in law	4	14
Grandchild	5	5
Brother/sister	6	20
Brother in law/sister in law	7	9
Other relative	8	7
Friend/neighbour	9	9
Other person	0	7
Inadequate who	X	15
D.N.A. (code 1, Box 16)	y	592

Type of interview — Col 58 — Box 18

Main questionnaire only	4	128
Main + quest. 1. Resp registered death	5	388
Respondent other first contact	6	237
Main quest. after quest. 1 completed by other household member	7	31
Inadequate	X	2

Month — Col 59 — Box 19

1 - 9	1 - 9
10	0
11	X
12	y

1	3
7	141
8	140
9	123
0	174
x	131
y	74

col 60 col 61
Boxes 20 and 21

Interviewer

Lisbeth Hookey	2	0 0	
Beryl Davies	25	0 1	- D ✓
Joan Ellis	8	0 2	
Kathleen Field	26	0 3	- F ✓
Mary Whitting	102	0 4	- W
Janet Baker	86	0 5	- B ✓
Paula Garden	70	0 6	- G ✓
Ruth Harris	107	0 8	- H ✓
Connie Frost	10	0 9	C ✓
Anglea Savage	27	1 0	- S ✓ ✓
Pat Tizzard	70	1 1	- T
Kay Young	87	1 2	- Y
Millicent Bathgate	17	1 3	- B ✓
Stella Brown	34	1 4	- B ✓
Anne Long	32	1 5	- L ✓
Ellen Latham	18	1 6	- L ✓
Muriel Toney	18	1 7	- T ✓
Mollie Richards	19	1 8	- R ✓
Wyn Tucker	1	1 9	
John Bond	-	2 0	
Jill Cove	26	2 5	- C ✓
Inadequate	1	X X	

B

HEALTH VISITORS AND DISTRICT NURSES (A)

Y37

SN 393B Life Before Death: Health Visitors and District Nurses (A)

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case number	4 digit code	
1/5-6		Card number	Card 01	198
1/7-10		Deceased Serial Number	4 digit code (see attached sheet)	
1/11-14		Worker's serial number (note in area 9 these will be 4 digit numbers, in all other areas they are 3 digit numbers, the fourth digit in these cases will be &)	4 digit code	
1/15	1	Care of patient or family	1 Had a part in .....'s care during the last 12 months of his life	197
			2 Had part in care of .....'s family after his death	1
			3 Inadequate	-
1/16-23	2-9	Where care given		
1/16	2	Care given in deceased's home only	1 Yes	178
			0 Not mentioned	20
1/17	3	Care given in deceased's own home	1 Yes	17
			0 Not mentioned	181
1/18	4	Doctors surgery	1 Yes	1
			0 Not mentioned	197
1/19	5	Local Authority Clinic	1 Yes	1
			0 Not mentioned	197
1/20	6	Health Centre	1 Yes	-
			0 Not mentioned	198
1/21	7	Your own home	1 Yes	-
			0 Not mentioned	198
1/22	8	Other	1 Yes	6
			0 Not mentioned	192
1/23	9	Inadequate where	1 Yes	-
			0 Not mentioned	198

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/24	10	Records of visits	1 Records referred to	127
			2 No records referred to	58
			3 Inadequate	10
			0 Blank	3
1/25	11	How long had - been on the books (for the last period)	1 Less than a week	28
			2 1 week - 1 month	45
			3 1 month - 3 months	36
			4 3 months - 6 months	22
			5 6 months - 1 year	18
			6 1 year - 2 years	14
			7 2 years - 3 years	9
			8 3 years - 5 years	12
			0 5 years or more	4
			9 Don't know	1
			- Inadequate	6
			Blank	3
1/26	12	What was the reason for his discharge from the books (the last time)	1 Died	126
			2 Transferred to hospital or other institution	60
			3 Prescribed treatment completed	3
			4 Able to manage	1
			5 Care rejected	1
			6 Moved	2
			7 Other	2
			8 Uncertain	-
			9 Inadequate	-
			0 Blank	3
1/27	13	How many D.N./H.V.S. visited ..... at home during last 12 months of his life	1 One	46
			2 Two	80
			3 Three or four	42
			4 Five - nine	21
			5 Ten or more	4
			6 Don't know	1
			7 Inadequate	1
			0 Blank	3

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/28	14	Were you the D.N./H.V. who made the last visit		
			1 Yes	115
			2 No	39
			3 Don't know	3
			4 Inadequate	-
			5 D.N.A.	38
			0 Blank	3
1/29	15	Is it possible for you to say whether you made more visits than any other individual D.N./H.V.		
			1 Don't know	5
			2 Subject made most	115
			3 Other nurse visited more often	9
			4 About equal	5
			5 Inadequate	15
			6 D.N.A.	46
			0 Blank	3
1/30-33	16-19	How many visits did ..... have		
1/30	16	In the last 12 months of his life		
			0 None	-
			1 1 - 4	20
			2 5 - 9	24
			3 10-19	31
			4 20-29	20
			5 30-49	21
			6 50+	71
			7 Don't know	2
			8 Inadequate	6
			9 D.N.A. (In hospital or institution during this period)	-
			- Blank	3
1/31	17	In the last 6 months of his life		
			0 None	-
			1 1 - 4	22
			2 5 - 9	24
			3 10-19	34
			4 20-29	29
			5 30-49	19
			6 50+	56
			7 Don't know	2
			8 Inadequate	8
			9 D.N.A. (In hospital or institution during this period)	1
			- Blank	3

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/32	18	In the last 3 months of his life	0 None	4
			1 1 - 4	24
			2 5 - 9	27
			3 10-19	42
			4 20-29	27
			5 30-49	17
			6 50+	40
			7 Don't know	3
			8 Inadequate	8
			9 D.N.A. (In hospital or institution during this period)	3
			- Blank	3
1/33	19	The last month of his life	0 None	6
			1 1 - 4	34
			2 5 - 9	33
			3 10-19	44
			4 20-29	26
			5 30-49	21
			6 50+	15
			7 Don't know	5
			8 Inadequate	8
			9 D.N.A. (In hospital or institution during this period)	3
			- Blank	3
1/34	20	How many visits did he have in the last week	0 None	18
			1 One	11
			2 Two	16
			3 Three - four	20
			4 Five - six	20
			5 Seven or more	98
			6 Don't know	3
			7 Inadequate	5
			8 D.N.A. (as column 30-33)	4
			9 Blank	3
1/35	21	How many visits did you make yourself in the last 12 months of .....'s life	1 1 - 4	35
			2 5 - 9	21
			3 10-19	41
			4 20-29	18
			5 30-49	26
			6 50+	48
			7 Don't know	1
			8 Inadequate	5
			0 Blank	3

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/36	22	Did ..... have any visits between 8 p.m. and 8 a.m. in the last year of his life	0 No 1 Don't know 2 Blank	145 6 47
1/37	23	IF YES how many	1 One 2 Two 3 Three - four 4 Five - nine 5 Ten or more 6 Inadequate how many 0 Blank	9 4 9 7 15 - 154
1/38	24	Did you do any of the night visits	1 Yes 2 No 3 Inadequate 0 Blank	37 7 - 154
1/39	25	Is it possible to say from the records what was the maximum number of visits ..... had during any one week - I mean visits at any one time of the day now	1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 8 - 10 0 11- 13 & 14+ 9 Can't say - Inadequate Blank	19 12 18 5 10 7 32 27 7 49 4 5 3
1/40	26	Who requested that ..... should be visited when ..... came on the books for the last time	1 General practitioner 2 Hospital doctor 3 Hospital sister/nurse 4 District nurse 5 Health visitor 6 Welfare/Social Worker 7 Relative/friend 8 Patient himself 0 Other	158 4 1 1 3 1 11 - 8

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/40	26	Continued	9 Don't know/unspecified person	2
			- Inadequate	3
			& No one (D.N. requested)	3
			Blank	3
1/41-49	27-35	What was the reason for the request then Type of care needed		
1/41	27	General nursing care (including weekly baths, help with washing, chiropody, coping with incontinence, senility	1 Yes	83
			0 Not mentioned	115
1/42	28	Treatment, dressings, enemas, rectal washouts	1 Yes	25
			0 Not mentioned	173
1/43	29	Injections	1 Yes	23
			0 Not mentioned	175
1/44	30	Supervision, checking, keeping an eye on, moral and physical support for family	1 Yes	33
			0 Not mentioned	165
1/45	31	Emergency visit	1 Yes	4
			0 Not mentioned	194
1/46	32	Other or vague reason	1 Yes	74
			0 Not mentioned	124
1/47	33	Don't know	1 Yes	-
			0 Not mentioned	198
1/48	34	Inadequate	1 Yes	6
			0 Not mentioned	192
1/49	35	D.N.A. (& at VAR 26)	1 Yes	3
			0 Not mentioned	195
1/50	36	Were you the first person to make a visit in answer to that request	1 Yes (including only one D.N. visited)	143
			2 No	45
			3 Can't remember, uncertain	-

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/50	36	Continued	4 Inadequate (question not asked/answered)	7
			0 Blank	3
1/51-58	37-44	How did the request reach you		
1/51	37	Personal contact with person making request	1 Yes	60
			0 Not mentioned	138
1/52	38	Telephone call from person making request	1 Yes	49
			0 Not mentioned	149
1/53	39	Letter from person making request	1 Yes	5
			0 Not mentioned	193
1/54	40	Message from office	1 Yes	17
			0 Not mentioned	181
1/55	41	Message from other person	1 Yes	5
			0 Not mentioned	193
1/56	42	Other	1 Yes	4
			0 Not mentioned	194
1/57	43	D.N.A. (2 or 4 at VAR 36)	1 Yes	54
			0 Not mentioned	144
1/58	44	Inadequate	1 Yes	2
			0 Not mentioned	196
1/59	45	Do you feel the information you were given on that occasion was:	1 Adequate	114
			2 Rather inadequate	16
			3 Very inadequate	5
			4 Qualified, uncertain, no code rung	2
			5 Inadequate	4
			6 D.N.A. (2 or 4 at VAR 36)	54
			0 Blank	3

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/60	46	Do you feel the service was asked for at the right time or that it would have been appropriate to ask for it earlier or later	1 Right time 2 Earlier 3 Later 4 Inadequate 5 D.N.A. (2 or 4 at VAR 36) 0 Blank	111 22 3 5 54 3
1/61-80 to 2/7-22	47-66 to 67-82	Here is a list of ways people may need help. Could you tell me whether you or any other district nurse (health visitor) did any of these for ..... during the last 12 months of his life		
1/61-72	47-58	Categories 11 - 1X		
1/61	47	11. To be lifted	1 Yes 0 Not mentioned	125 73
1/62	48	12. Help with washing (or shaving)	1 Yes 0 Not mentioned	144 54
1/63	49	13. Getting in or out of bath	1 Yes 0 Not mentioned	29 169
1/64	50	14. Dressing or undressing	1 Yes 0 Not mentioned	59 139
1/65	51	15. Getting in or out of bed	1 Yes 0 Not mentioned	103 95
1/66	52	16. Getting hair washed at home	1 Yes 0 Not mentioned	39 159
1/67	53	17. Cutting toe nails	1 Yes 0 Not mentioned	100 98

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/68	54	18. Giving bedpan or bottle	1 Yes 0 Not mentioned	83 115
1/69	55	19. Getting to lavatory or commode	1 Yes 0 Not mentioned	74 124
1/70	56	1X. Bedmaking	1 Yes 0 Not mentioned	140 58
1/71	57	No help in categories 11 - 1X	1 Yes 0 Not mentioned	22 176
1/72	58	Inadequate	1 Yes 0 Not mentioned	9 189
1/73-80	59-66	Categories 21-26		
1/73	59	21. Giving medicines or tablets	1 Yes 0 Not mentioned	56 142
1/74	60	22. Injections	1 Yes 0 Not mentioned	62 136
1/75	61	23. Bandaging or other dressings	1 Yes 0 Not mentioned	51 147
1/76	62	24. Regular temperature taking (for hypothermia prevention)	1 Yes 0 Not mentioned	25 173
1/77	63	25. Massaging/exercises	1 Yes 0 Not mentioned	43 155
1/78	64	26. Enema	1 Yes 0 Not mentioned	37 161
1/79	65	No help in categories 21-26	1 Yes 0 Not mentioned	49 149
1/80	66	Inadequate	1 Yes 0 Not mentioned	8 190

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/1-4		Case number	4 digit code	
2/5-6		Card number	Card 02	198
		Continued from card 1		
2/7-17	67-77	Categories 91-99		
2/7	67	91. Lavage/douche/ pessary	1 Yes 0 Not mentioned	19 179
2/8	68	92. Catterization	1 Yes 0 Not mentioned	6 192
2/9	69	93. Blood pressure	1 Yes 0 Not mentioned	4 194
2/10	70	94. Eye/ear drops	1 Yes 0 Not mentioned	4 194
2/11	71	95. Care for pressure areas	1 Yes 0 Not mentioned	138 60
2/12	72	96. Electrocardiogram	1 Yes 0 Not mentioned	1 197
2/13	73	97. Dialysis	1 Yes 0 Not mentioned	- 198
2/14	74	98. Taking temperature, pulse, respiration	1 Yes 0 Not mentioned	128 70
2/15	75	99. Any other nursing procedure	1 Yes 0 Not mentioned	23 175
2/16	76	No help in categories 91-99	1 Yes 0 Not mentioned	35 163
2/17	77	Inadequate	1 Yes 0 Not mentioned	9 189
2/18-22	78-82	Categories X1 - X3		
2/18	78	X1. Teaching patient self-care	1 Yes 0 Not mentioned	45 153

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/19	79	X2. Teaching relatives	1 Yes 0 Not mentioned	93 105
2/20	80	X3. Supervision only	1 Yes 0 Not mentioned	47 151
2/21	81	No help in categories X1 - X3	1 Yes 0 Not mentioned	57 141
2/22	82	Inadequate	1 Yes 0 Not mentioned	9 189
2/23-33	83-93	Summary of care given		
2/23	83	None	1 Yes 0 Not mentioned	1 197
2/24	84	Categories 11 - X1	1 Yes 0 Not mentioned	10 188
2/25	85	Categories 21 - 26	1 Yes 0 Not mentioned	7 191
2/26	86	Categories 11 - 1X, 21 - 26	1 Yes 0 Not mentioned	6 192
2/27	87	Categories 91 - 99	1 Yes 0 Not mentioned	1 197
2/28	88	Categories 11 - 1X, 91 - 99	1 Yes 0 Not mentioned	25 173
2/29	89	Categories 21 - 26, 91 - 99	1 Yes 0 Not mentioned	3 195
2/30	90	Categories 11 - 1X, 21 - 26, 91 - 99	1 Yes 0 Not mentioned	124 74
2/31	91	Categories X1 - X3 overcode	1 Yes 0 Not mentioned	128 70
2/32	92	Don't know/Inadequate to some	1 Yes 0 Not mentioned	3 195

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/33	93	Inadequate	1 Yes 0 Not mentioned	5 193
2/34	94	Most regular help	0 None 1 Some help regularly and daily 2 Some help regularly more than weekly less than daily 3 Some help regularly weekly 4 Some help regularly less often 5 Some help regularly inadequate how often 6 Some help occasionally but not regularly 7 Once only 8 Don't know 9 Inadequate - Blank	1 127 26 12 5 1 9 6 - 8 3
2/35-46	95-106	Could you have done with anyone's help with any of these		
2/35	95	No	1 Yes 0 Not mentioned	135 63
2/36	96	More help needed Categories 11 - 1X	1 Yes 0 Not mentioned	29 169
2/37	97	Categories 21 - 26	1 Yes 0 Not mentioned	3 195
2/38	98	Categories 11 - 1X, 21 - 26	1 Yes 0 Not mentioned	4 194
2/39	99	Categories 91 - 99	1 Yes 0 Not mentioned	- 198
2/40	100	Categories 11 - 1X, 91 - 99	1 Yes 0 Not mentioned	4 194
2/41	101	Categories 21 - 26, 91 - 99	1 Yes 0 Not mentioned	- 198

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/42	102	Categories 11 - 1X, 21 - 26, 91 - 99	1 Yes 0 Not mentioned	2 196
2/43	103	More help needed but inadequate what	1 Yes 0 Not mentioned	1 197
2/44	104	Don't know/inadequate to part	1 Yes 0 Not mentioned	9 189
2/45	105	Categories X1 - X3 overcode	1 Yes 0 Not mentioned	17 181
2/46	106	Inadequate	1 Yes 0 Not mentioned	2 196
2/47	107	Did anyone (else) help with this/these	0 No 1 Blank	34 164
2/48-58	108-118	IF YES who		
2/48	108	Spouse	1 Yes 0 Not mentioned	62 136
2/49	109	Father/Mother	1 Yes 0 Not mentioned	1 197
2/50	110	Son/Daughter	1 Yes 0 Not mentioned	61 137
2/51	111	Son in law/daughter in law	1 Yes 0 Not mentioned	16 182
2/52	112	Grandchild	1 Yes 0 Not mentioned	1 197
2/53	113	Brother/sister(in law)	1 Yes 0 Not mentioned	16 182
2/54	114	Other relative	1 Yes 0 Not mentioned	10 188
2/55	115	Friend, neighbour	1 Yes 0 Not mentioned	8 190

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/56	116	Other person	1 Yes 0 Not mentioned	26 172
2/57	117	Don't know, inadequate who helped	1 Yes 0 Not mentioned	- 198
2/58	118	Inadequate	1 Yes 0 Not mentioned	18 180
2/59-70	119-130	Types of help given by others		
2/59	119	D.N.A. no help given by others	1 Yes 0 Not mentioned	48 150
2/60	120	Categories 11 - 1X	1 Yes 0 Not mentioned	53 145
2/61	121	Categories 21 - 26	1 Yes 0 Not mentioned	1 197
2/62	122	Categories 11 - 1X, 21 - 26	1 Yes 0 Not mentioned	15 183
2/63	123	Categories 91 - 99	1 Yes 0 Not mentioned	- 198
2/64	124	Categories 11 - 1X, 91 - 99	1 Yes 0 Not mentioned	11 187
2/65	125	Categories 21 - 26, 91 - 99	1 Yes 0 Not mentioned	1 197
2/66	126	Categories 11 - 1X, 21 - 26, 91 - 99	1 Yes 0 Not mentioned	10 188
2/67	127	General help with everything	1 Yes 0 Not mentioned	33 165
2/68	128	Don't know/inadequate to part, overcode	1 Yes 0 Not mentioned	6 192

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/69	129	Inadequate	1 Yes 0 Not mentioned	21 177
2/70	130	Categories X1 - X3 overcode	1 Yes 0 Not mentioned	7 191
2/71	131	Could the deceased have done with any more help of this sort	0 No 1 Blank	133 65
2/72	132	IF YES what sort of help	1 Help needed with categories 11 - 1X 2 Help need with categories 21 - 26 3 Help needed with both categories 4 Some help needed, inadequate what or unspecified 5 Don't know, inadequate to part 6 Inadequate 7 'Wild code' more than one answer recorded 0 Blank	21 1 2 5 8 29 2 130
2/73-80	133-140	Could you say whether ..... needed help with these sort of things		
2/73	133	Help at night (31 - 32)	1 Yes 0 Not mentioned	110 88
2/74	134	Social needs (41 - 45)	1 Yes 0 Not mentioned	135 63
2/75	135	Financial help (51)	1 Yes 0 Not mentioned	19 179
2/76	136	Domestic help (61 - 64)	1 Yes 0 Not mentioned	129 69
2/77	137	Help needed, inadequate what	1 Yes 0 Not mentioned	- 198
2/78	138	Don't know, overcode	1 Yes 0 Not mentioned	35 163

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/79	139	No help needed	1 Yes 0 Not mentioned	21 177
2/80	140	Inadequate	1 Yes 0 Not mentioned	7 191
3/1-4		Case number	4 digit code	
3/5-6		Card number	Card 03	198
3/7-13	141-147	Could you say whether he had all the help he needed or could have done with some more help		
3/7	141	D.N.A. no more help needed. Received all help needed	1 Yes 0 Not mentioned	129 69
3/8	142	Help at night (31 - 32)	1 Yes 0 Not mentioned	40 158
3/9	143	Social needs (41 - 45)	1 Yes 0 Not mentioned	23 175
3/10	144	Financial help (51)	1 Yes 0 Not mentioned	3 195
3/11	145	Domestic help (61 - 64)	1 Yes 0 Not mentioned	22 176
3/12	146	Inadequate to part/don't know	1 Yes 0 Not mentioned	8 190
3/13	147	Inadequate	1 Yes 0 Not mentioned	4 194
3/14	148	How long did your visits to ..... take, usually	1 Less than 10 minutes 2 10 - 20 minutes 3 20 - 30 minutes 4 30 - 45 minutes 5 45 - 1 hour 6 1 hour - 1½ hours 7 1½ - 2 hours 8 2 hours or longer 9 Uncertain - Inadequate 0 Blank	3 27 42 64 29 15 1 - - 14 3

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/15	149	How long did your visits to ..... take, at most	1 Less than 10 minutes 2 10 - 20 minutes 3 20 - 30 minutes 4 30 - 45 minutes 5 45 - 1 hour 6 1 hour - 1½ hours 7 1½ hours - 2 hours 8 2 hours or longer 9 Uncertain - Inadequate 0 Blank	2 15 18 42 49 46 5 3 - 15 3
3/16	150	How long did your visits to ..... take, at least	1 Less than 10 minutes 2 10 - 20 minutes 3 20 - 30 minutes 4 30 - 45 minutes 5 45 - 1 hour 6 1 hour - 1½ hours 7 1½ hours - 2 hours 8 2 hours or longer 9 Uncertain - Inadequate 0 Blank	16 52 60 31 10 9 - - - 17 3
3/17	151	On the whole do you feel you were able to give enough time to ..... or would you have liked to have been able to give more time to him	1 Gave enough time 2 Inadequate if gave enough time 0 Blank	135 20 43
3/18	152	Liked more time	1 To visit more often 2 To spend longer at visit 3 Both 4 Inadequate what for 0 Blank	9 16 13 2 158
3/19-28	153-162	Do you know if ..... or his family had any help from other services such as:-		

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/19	153	District nursing	1 Yes 0 Not mentioned	10 188
3/20	154	Health visiting	1 Yes 0 Not mentioned	34 164
3/21	155	Private nurse	1 Yes 0 Not mentioned	8 190
3/22	156	Home help	1 Yes 0 Not mentioned	28 170
3/23	157	Special laundry service	1 Yes 0 Not mentioned	10 188
3/24	158	Chiropody	1 Yes 0 Not mentioned	36 162
3/25	159	Vicar, priest, minister	1 Yes 0 Not mentioned	68 130
3/26	160	Inadequate to some (overcode)	1 Yes 0 Not mentioned	73 125
3/27	161	None of these	1 Yes 0 not mentioned	64 134
3/28	162	Inadequate	1 Yes 0 Not mentioned	8 190
3/29-40	163-174	Do you know if ..... or his family had any help from any other services such as :-		
3/29	163	Meals on wheels	1 Yes 0 Not mentioned	8 190
3/30	164	Free supply of incontinence pads	1 Yes 0 Not mentioned	112 86
3/31	165	Service for disposal of incontinence pads	1 Yes 0 Not mentioned	7 191
3/32	166	Bathing service	1 Yes 0 Not mentioned	6 192

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/33	167	Supply of sickroom equipment	1 Yes 0 Not mentioned	111 87
3/34	168	Night nursing service	1 Yes 0 Not mentioned	6 192
3/35	169	Night sitting service	1 Yes 0 Not mentioned	14 184
3/36	170	Geriatric social worker	1 Yes 0 Not mentioned	10 188
3/37	171	Other specified official or voluntary service	1 Yes 0 Not mentioned	7 191
3/38	172	Inadequate to some (overcode)	1 Yes 0 Not mentioned	17 181
3/39	173	None of these	1 Yes 0 Not mentioned	46 152
3/40	174	Inadequate	1 Yes 0 Not mentioned	9 189
3/41-51	175-185	Type of help arranged by informant - 1		
3/41	175	District nursing	1 Yes 0 Not mentioned	3 195
3/42	176	Health visiting	1 Yes 0 Not mentioned	5 193
3/43	177	Private nurse	1 Yes 0 Not mentioned	- 198
3/44	178	Home help	1 Yes 0 Not mentioned	13 185
3/45	179	Special laundry service	1 Yes 0 Not mentioned	9 189
3/46	180	Chiropody	1 Yes 0 Not mentioned	17 181

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/47	181	Vicar, priest, minister	1 Yes 0 Not mentioned	8 190
3/48	182	Inadequate to some (overcode)	1 Yes 0 Not mentioned	2 196
3/49	183	None of these	1 Yes 0 Not mentioned	71 127
3/50	184	Inadequate	1 Yes 0 Not mentioned	7 191
3/51	185	D.N.A. (VAR 161, 162)	1 Yes 0 Not mentioned	72 126
3/52-63	186-197	Type of help arranged by informant - 11		
3/52	186	Meals on wheels	1 Yes 0 Not mentioned	3 195
3/53	187	Free supply of incontinence pads	1 Yes 0 Not mentioned	108 90
3/54	188	Service for disposal incontinence pads	1 Yes 0 Not mentioned	7 191
3/55	189	Bathing service	1 Yes 0 Not mentioned	4 194
3/56	190	Supply of sickroom equipment	1 Yes 0 Not mentioned	94 104
3/57	191	Night nursing service	1 Yes 0 Not mentioned	4 194
3/58	192	Night sitting service	1 Yes 0 Not mentioned	10 188
3/59	193	Geriatric social worker	1 Yes 0 Not mentioned	2 196
3/60	194	Other specified official or voluntary service	1 Yes 0 Not mentioned	4 194
3/61	195	Inadequate to some/ don't know	1 Yes 0 Not mentioned	4 194

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/62	196	None of these (including D.N.A. VAR 183)	1 Yes 0 Not mentioned	64 134
3/63	197	Inadequate	1 Yes 0 Not mentioned	3 195
3/64-73	198-207	Type of help that would have been helpful - 1		
3/64	198	District nursing	1 Yes 0 Not mentioned	- 198
3/65	199	Health visiting	1 Yes 0 Not mentioned	4 194
3/66	200	Private nurse	1 Yes 0 Not mentioned	10 188
3/67	201	Home help	1 Yes 0 Not mentioned	27 171
3/68	202	Special laundry service	1 Yes 0 Not mentioned	21 177
3/69	203	Chiropody	1 Yes 0 Not mentioned	4 194
3/70	204	Vicar, priest, minister	1 Yes 0 Not mentioned	8 190
3/71	205	Inadequate to some	1 Yes 0 Not mentioned	18 180
3/72	206	None of these	1 Yes 0 Not mentioned	106 92
3/73	207	Inadequate	1 Yes 0 Not mentioned	37 161
3/74-80 to 4/7-11	208-214 to 215-219	Type of help that would of been helpful - 11		
3/74	208	Meals on wheels	1 Yes 0 Not mentioned	10 188

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/75	209	Free incontinence pads	1 Yes 0 Not mentioned	1 197
3/76	210	Service for disposal of pads	1 Yes 0 Not mentioned	10 188
3/77	211	Bathing services	1 Yes 0 Not mentioned	17 181
3/78	212	Supply of sickroom equipment	1 Yes 0 Not mentioned	1 197
3/79	213	Night nursing service	1 Yes 0 Not mentioned	14 184
3/80	214	Night sitting service	1 Yes 0 Not mentioned	32 166
4/1-4		Case number	4 digit code	
4/5-6		Card number	Card 04	198
4/7-11	215-219	Continued from card 3		
4/7	215	Geriatric social worker	1 Yes 0 Not mentioned	10 188
4/8	216	Other specified official or voluntary service	1 Yes 0 Not mentioned	1 197
4/9	217	Inadequate to some	1 Yes 0 Not mentioned	5 193
4/10	218	None of these	1 Yes 0 Not mentioned	101 97
4/11	219	Inadequate	1 Yes 0 Not mentioned	34 164
4/12-22	220-230	Type of help respondent tried to arrange - 1		
4/12	220	District nursing	1 Yes 0 Not mentioned	- 198

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/13	221	Health visiting	1 Yes 0 Not mentioned	- 198
4/14	222	Private nurse	1 Yes 0 Not mentioned	1 197
4/15	223	Home help	1 Yes 0 Not mentioned	6 192
4/16	224	Special laundry service	1 Yes 0 Not mentioned	- 198
4/17	225	Chiropody	1 Yes 0 Not mentioned	2 196
4/18	226	Vicar, priest, minister	1 Yes 0 Not mentioned	1 197
4/19	227	Inadequate to some	1 Yes 0 Not mentioned	- 198
4/20	228	None of these	1 Yes 0 Not mentioned	39 159
4/21	229	Inadequate	1 Yes 0 Not mentioned	4 194
4/22	230	D.N.A. (VAR 206, 207)	1 Yes 0 Not mentioned	143 55
4/23-34	231-242	Type of help respondent tried to arrange - 11		
4/23	231	Meals on wheels	1 Yes 0 Not mentioned	3 195
4/24	232	Free supply of incontinence pads	1 Yes 0 Not mentioned	- 198
4/25	233	Service for disposal of incontinence pads	1 Yes 0 Not mentioned	1 197
4/26	234	Bathing service	1 Yes 0 Not mentioned	1 197
4/27	235	Supply of sickroom equipment	1 Yes 0 Not mentioned	- 198

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/28	236	Night nursing service	1 Yes 0 Not mentioned	1 197
4/29	237	Night sitting service	1 Yes 0 Not mentioned	2 196
4/30	238	Geriatric social worker	1 Yes 0 Not mentioned	- 198
4/31	239	Other specified official or voluntary service	1 Yes 0 Not mentioned	- 198
4/32	240	Inadequate to some	1 Yes 0 Not mentioned	1 197
4/33	241	None of these (including D.N.A. VARS 218, 219)	1 Yes 0 Not mentioned	184 14
4/34	242	Inadequate	1 Yes 0 Not mentioned	5 193
4/35	243	Is there anything would have made .....'s care easier for you	1 Yes 2 No 3 Don't know 4 Inadequate 0 Blank	51 133 - 11 3
4/36	244	Would you say that .....'s home was very convenient etc. for him after he became ill/old	1 Very convenient 2 Fairly 3 Rather inconvenient 4 Inadequate 0 Blank	114 48 28 5 3
4/37-41	245-249	Where did you get the medical information you had about ..... and his treatment		
4/37	245	G.P.	1 Yes 0 Not mentioned	165 33
4/38	246	Hospital	1 Yes 0 Not mentioned	9 189

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/39	247	Other	1 Yes 0 Not mentioned	16 182
4/40	248	Inadequate	1 Yes 0 Not mentioned	7 191
4/41	249	None	1 Yes 0 Not mentioned	9 189
4/42	250	Did you feel you had adequate medical information about ..... or would it have been helpful if you had had more information about ..... and his treatment	1 Adequate information 2 Uncertain qualified 3 Inadequate 0 Blank	158 1 9 30
4/43-46	251-254	Helpful to have had more from:		
4/43	251	G.P.	1 Yes 0 Not mentioned	24 174
4/44	252	Hospital	1 Yes 0 Not mentioned	7 191
4/45	253	Other specified	1 Yes 0 Not mentioned	- 198
4/46	254	Inadequate where	1 Yes 0 Not mentioned	- 198
4/47	255	Did you try to get any more medical information about	1 No 2 Yes, but didn't get any more 3 Yes, got more 4 Yes, inadequate if got more 5 Inadequate if tried or not 6 D.N.A. (VAR 250) 0 Blank	12 3 6 6 - 168 3

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/48	256	Household composition	1 Lived alone	20
			2 With spouse only	64
			3 With spouse and children only	22
			4 With spouse and children and children in law, without or with grandchildren	4
			5 With children only	21
			6 With children and children in law with or without grand-children	20
			7 With other relatives of same generation only	18
			8 With other unrelated people	5
			9 Other 3 generation household	5
			& Guest house (O.P. home or no or inadequate information about where living	3
			0 Other	12
			- Don't know	1
			Blank	3
4/49-55	257-263	Who normally did the cooking and other house-work		
4/49	257	D.N.A. (lived alone or inadequate who lived with)	1 Yes	24
			0 Not mentioned	174
4/50.	258	Deceased	1 Yes	8
			0 Not mentioned	190
4/51	259	Other person in same household	1 Yes	142
			0 Not mentioned	56
4/52	260	Deceased and other person in same household	1 Yes	5
			0 Not mentioned	193
4/53	261	Others	1 Yes	18
			0 Not mentioned	180

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/54	262	Inadequate	1 Yes 0 Not mentioned	8 190
4/55	263	Home help/paid help	1 Yes 0 Not mentioned	27 171
4/56	264	Did you visit .....'s home often after the death at all	1 No 2 Inadequate 3 Yes, in a professional capacity 4 Yes, not in a professional capacity 5 Yes, inadequate if in a professional capacity 0 Blank	105 2 75 6 8 2
4/57-66	265-274	Why did you visit them		
4/57	265	Did not know of death	1 Yes 0 Not mentioned	15 183
4/58	266	To collect records	1 Yes 0 Not mentioned	9 189
4/59	267	To collect equipment	1 Yes 0 Not mentioned	32 166
4/60	268	To lay out body	1 Yes 0 Not mentioned	3 195
4/61	269	To support bereaved	1 Yes 0 Not mentioned	37 161
4/62	270	To give care to other member of the family/ household	1 Yes 0 Not mentioned	10 188
4/63	271	Other	1 Yes 0 Not mentioned	6 192
4/64	272	Inadequate	1 Yes 0 Not mentioned	- 198
4/65	273	D.N.A.	1 Yes 0 Not mentioned	113 85

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/66	274	If (VAR 270), care to other member of family: overcode if care started before ..... died	1 Yes 0 Not mentioned	5 193
4/67	275	Did you have any professional contact with bereaved	0 No 1 Inadequate 2 Blank	149 22 27
4/68-76	276-284	Yes, relationship to deceased		
4/68	276	Spouse	1 Yes 0 Not mentioned	14 184
4/69	277	Father/Mother	1 Yes 0 Not mentioned	- 198
4/70	278	Son/daughter	1 Yes 0 Not mentioned	5 193
4/71	279	Son in law/daughter in law	1 Yes 0 Not mentioned	1 197
4/72	280	Grandchild	1 Yes 0 Not mentioned	- 198
4/73	281	Brother/sister (in law)	1 Yes 0 Not mentioned	7 191
4/74	282	Other relative	1 Yes 0 Not mentioned	2 196
4/75	283	Friend, neighbour	1 Yes 0 Not mentioned	- 198
4/76	284	Other person	1 Yes 0 Not mentioned	- 198

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
4/77	285	Over what period	1 D.N.A. 2 Inadequate 3 Less than a week 4 1 week - 1 month 5 1 month - 3 months 6 3 months or more 0 Blank	171 12 2 5 4 4 -
4/78	286	Overcode (at VAR 285)	0 Currently attending 1 Blank	3 195
4/79	287	Were you attached to the deceased's G.P. while you were looking after him	1 Yes 2 No 3 Partial attachment 4 Inadequate 0 Blank	76 116 5 1 -
4/80 to 5/7-11	288 to 289-293	In what capacity did you visit ..... and/or the bereaved		
4/80	288	District nurse	1 Yes 0 Not mentioned	181 17
5/1-4		Case number	4 digit code	
5/5-6		Card number	Card 05	198
5/7-11	289-293	Continued from card 4		
5/7	289	Health visitor	1 Yes 0 Not mentioned	17 181
5/8	290	Midwife	1 Yes 0 Not mentioned	1 197
5/9	291	Combined worker	1 Yes 0 Not mentioned	1 197
5/10	292	Other	1 Yes 0 Not mentioned	- 198
5/11	293	Inadequate	1 Yes 0 Not mentioned	- 198

SN 393B

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
5/12	294	Each subject is given a serial number within H.V./D.N.	1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Eight 9 Nine 0 Ten	126 40 15 9 3 1 1 1 1 1
5/13-80		UNUSED	UNUSED	

A

Medical Care Research Unit,
Institute of Community Studies,
18 Victoria Park Square,
London, E 2

Deceased | | | | |
Worker | | | | |

ROLE OF HOME NURSES IN THE CARE OF THE DYING

QUESTIONNAIRE A - INDIVIDUAL PATIENTS

INTRODUCTION You may have heard about the study we are doing from the Medical Care Research Unit of the Institute of Community Studies We are doing it in twelve randomly chosen areas in England and Wales to find out about the care given in people's homes to those who are dying We plan to write a book about it but no names will be mentioned and it will not be possible to identify anyone nor, of course, will anything you tell us be passed on to anyone outside our Unit which is a small independent research unit, interested in the social aspects of medical care There are two questionnaires The first one is about specific people in our sample of deaths the second briefer one asks for general comments and your views about home care and bereavement. We would be grateful for your help with both of these

These questions are about _____ of who died in _____ (date)

1. First can I check that you had a part in _____'s care during the last twelve months of his life?

Had part . . 1
Had no part 2

IF HAD NO PART (2) Did you have any part in the care of _____'s family after his death?

Yes 3
No. . . . 4

IF YES (3) SKIP TO Q 34

IF NO (4) GO TO QUESTIONNAIRE B

2 Did your part in the care of _____ entail visiting him at home?

Yes . 1
No .. 2

IF YES (1) Did you ever give him care any where else? Where? CODE BELOW

IF NO (2) Where did you give his care?

His home only. . . . 0
Doctor's surgery.. .. . 3
Local authority clinic . 4
Health centre 5
Your own home. 6
Other SPECIFY. 7

IF NEVER VISITED PATIENTS HOME SKIP TO Q 36 a.

3 Have you any records of your visits to _____?

Yes. 1
No . 2

IF YES (1) Would it be possible to refer to them for the next few questions?

Yes . 3
No 4

IF NO(4) STATE REASONS

4. How long had _____ been on the books (for the last period)?
IGNORE BREAKS OR LESS THAN A MONTH

Less than a year . 1
1 year < 2 years 2
2 years < 3 years . 3
3 years < 5 years . 4
5 years or more SPECIFY 5

IF LESS THAN A YEAR (1) a) When did he come on the books (for the last time)?

DATE | | | |

b) Was he on the books at any other time during the last twelve months of his life?

Yes.. . 6
No 7

IF YES (6)
DATE ON | | | |
DATE OFF | | | |

5 When did he come off the books finally?

DATE | | | |

IF LAST ON FOR LESS THAN A YEAR CHECK

So during the last 12 months of his life he was actually on the books for

Less than 1 week 1
1 week < 1 month 2
1 month < 3 months 3
3 months < 6months 4
6 months < 1 year 5

A/

6. What was the reason for his discharge from the books (the last time)?

Died	1
Transferred to hospital or other institution	2
Prescribed treatment completed.	3
Able to manage.	4
Care rejected	5
Moved	6
Other SPECIFY	7
Uncertain,	9

7. Could you say about how many of you (district nurses/health visitors) visited _____ at home during the last 12 months of his life?
I e between and 7

One	1
Two	2
Three or four	3
Five - nine	4
Ten or more	5
Don't know.	

8. Were you the nurse/health visitor who made the last visit?

Yes	6
No	7
Don't know.	9

IF MORE THAN ONE Is it possible for you to say whether you made more visits than any other individual district nurse/health visitor?
(2+ at Q 7.)

Don't know	9
Subject made most	1
Other nurse visited more often	2

IF OTHER NURSE MADE MORE FIND OUT NAME IF POSSIBLE AND IF AVAILABLE

9. How many home visits did _____ have

a) In the last 12 months of his life - that is from _____

b) how many in the last 6 months

c) n the last 3 months

d) the last month

	a) last 12 months	b) last 6 months	c) last 3 months	d) last month
None	0	0	0	0
1 - 4	1	1	1	1
5 - 9	2	2	2	2
10 - 19	3	3	3	3
20 - 29	4	4	4	4
30 - 49	5	5	5	5
50 or more	6	6	6	6
Don't know	9	9	9	9

e) What about the last week - how many visits did he have then?

None.	0
One.	1
Two.	2
Three - four.	3
Five- six	4
seven or more.	5
Don't know	9

10. How many visits did you make yourself in the last 12 months of _____'s life?

1 - 4.	1
5 - 9 .	2
10 - 19 .	3
20 - 29	4
30 - 49	5
50 + . . .	6
Don't know	9

11. Did _____ have any visits at night between 8 p.m and 8 a.m In the last year of his life?

Yes .	8
No	0
Don't know..	9

IF YES (1) a) How many?

One...	1
Two....	2
Three - four.	3
Five - nine.	4
Ten or more	5

b) Did you do any of th. night visits?

Yes.....	6
No,...	7

12 Is it possible to say from the records what was the maximum number of visits _____ had during any one week - I mean visits at any time of the day now

1. . .	..1
2 .	2
3.	3
4	4
5 .	5
6 .	6
7 .	7
8 - 10	8
11 - 13	0
14	Y
5 + SPECIFY	.X
Can't say	.9

We've been talking about _____'s visiting pattern can we now discuss his referral and your part in his care in more detail

13. Who requested that _____ should be visited - when _____ came on the books for the last time?

General practitioner .	1
Hospital doctor..	.2
Hospital sister/nurse. .	.3
District nurse . . .	4
Health visitor . ..	..5
Welfare/Social worker	6
Relative/friend. . . .	..7
Patient himself . .	8
Other SPECIFY	0
Don't know . .	9

14. What was the reason for the request then?

15. Were you the first person to make a visit in answer to that request?

Yes. 1
No 2

IF NO (2) SKIP TO QUESTION 20

17. How did the request reach you?

Personal contact with person making request .	1
Telephone call from " " "	2
Letter from person making request.	3
Message from office 4	
" " other person SPECIFY .	.5
Other.	0

18. Do you feel the information you were given on that occasion was -

	Adequate 1
PROMPT	Rather inadequate. .2
	Very inadequate . . 3

Could you say a bit more about that?

19. Do you feel the service was asked for at the right time or that it would have been appropriate to ask for it earlier or later?

Right time .	4
Earlier. ...	5
Later	6

IF EARLIER OR LATER(5 or 6)

a) Why do you feel that?

b) Do you know why it wasn't asked for earlier/later? Why?

20 Here is a list of ways people may need help. Could you tell me whether you or any other district nurse (health visitor) did any of these things for ____ during the last 12 months of his life?

IF YES a) Was this done -

IF REGULARLY How often?

b) Over what period

c) Could you have done with anyones help with this?

ASK WHETHER SUBJECT HELPED OR NOT

(i) Did anyone (else) help with this? Who?

(ii) Could the deceased have done with any (more) help of this sort?

	Yes	No	Don't Know	Regularly	Occasionally	Once only	Daily	More than weekly < daily	Weekly	Less often	Less than 1 week	1 week < 1 month	1 month < 3 months	3 months < 6 months	6 months < 1 yr	1 yr +	Yes	No	Comments	No	Don't Know	RELATIONSHIP TO DECEASED OR TYPE OF PERSON	Yes	No	Don't Know	Comments
11 To be lifted	1	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	1	0		0	9		1	0	9	
12 Help with washing (or shaving)	2	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	2	0		0	9		2	0	9	
13 Getting in or out of bath	3	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	3	0		0	9		3	0	9	
14 Dressing or undressing	4	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	4	0		0	9		4	0	9	
15 Getting in or out of bed	5	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	5	0		0	9		5	0	9	
16 Getting hair washed at home	6	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	6	0		0	9		6	0	9	
17 Cutting toenails	7	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	7	0		0	9		7	0	9	
18 Giving bedpan or bottle	8	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	8	0		0	9		8	0	9	
19 Getting to lavatory or commode	Y	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	Y	0		0	9		Y	0	9	
1X Bedmaking	X	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	X	0		0	9		X	0	9	
21 Giving medicines or tablets	1	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	1	0		0	9		1	0	9	
22 Injections	2	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	2	0		0	9		2	0	9	
23 Bandaging or other dressing	3	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	3	0		0	9		3	0	9	
24 Regular temperature taking for hypothermia prevention	4	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	4	0		0	9		4	0	9	
25. Massaging/exercises	5	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	5	0		0	9		5	0	9	
26 Enema	6	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	6	0		0	9		6	0	9	
91 Lavage/douche/pessary	1	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	1	0		0	9					
92. Catheterization	2	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	2	0		0	9					
93 Blood pressure	3	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	3	0		0	9					
94 Eye/ear drops	4	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	4	0		0	9					
95 Care of pressure areas	5	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	5	0		0	9					
96 Electrocardiogram	6	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	6	0		0	9					
97 Dialysis	7	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	7	0		0	9					
98 Taking temperature pulse, respiration	8	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	8	0		0	9					
99. Any other nursing procedure SPECIFY	Y	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	Y	0		0	9					
X1 Teaching patient self-care	1	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	1	0		0	9					
X2 " relatives	2	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	2	0		0	9					
X3 Supervision only	3	0	9	6	7	8	1	2	3	4	1	2	3	4	5	6	3	0		0	9					

A1

A1

21 Could you say whether _____ needed any help with those sort of things and if so whether he had all the help he needed or could have done with some more help -

	Help needed			Help received		
	Yes	No	D K	All	Some	None
31 Sitting up with at night	1	0	9	1	2	0
32 Other help at night	2	0	9	1	2	0
41 Someone to take him out	3	0	9	1	2	0
42. Someone to read to him	4	0	9	1	2	0
43 Someone to write letters for him	5	0	9	1	2	0
44 Someone to collect his pension	6	0	9	1	2	0
45 Someone to change his library books	7	0	9	1	2	0
51 Financial help	8	0	9	1	2	0
61 Shopping	1	0	9	1	2	0
62 Preparing/cooking food	2	0	9	1	2	0
63 Cleaning house	3	0	9	1	2	0
64 Washing clothes	4	0	9	1	2	0

22 How long did your visits to _____ take -

	a) usually	b) at most	c) at least
Less than 10 mins	1	1	1
10 < 20	2	2	2
20 < 30	3	3	3
30 < 45	4	4	4
45 < 1 hr	5	5	5
1 hr < 1½ hr	6	6	6
1½ hrs < 2 hrs	7	7	7
2 hrs or longer	8	8	8
Uncertain	9	9	9

23 On the whole do you feel you were able to give enough time to _____ or would you have liked to have been able to give more time to him?

Gave enough time . 1
Liked more time . 2

IF LIKED MORE TIME a) Would you have liked to

PROMPT
Visit more often . 3
Spend longer at visit 4
Both . 5

b) What sort of things would you have liked to do - or liked to do more often for _____?

24. Do you know if _____ or his family had any help from any other services such as	Yes	No	D K	IF YES Did you personally arrange this? Yes	No	D K	IF NO Would this have been helpful Yes	No	D K	IF WOULD HAVE BEEN HELPFUL a) Did you try to arrange it Yes	No	IF YES What happened?	IF NO Why not?
(District nursing)	1	0	9	4	5	9	6	7	9	1	0		
(Health visiting)	2	0	9	4	5	9	6	7	9	1	0		
Private nurse	3	0	9	4	5	9	6	7	9	1	0		
Home help	4	0	9	4	5	9	6	7	9	1	0		
Special laundry service	5	0	9	4	5	9	6	7	9	1	0		
Chiropody	6	0	9	4	5	9	6	7	9	1	0		
Vicar, priest or minister	7	0	9	4	5	9	6	7	9	1	0		
Meals on wheels	1	0	9	4	5	9	6	7	9	1	0		
Free supply of incontinence pads	3	0	9	4	5	9	6	7	9	1	0		
Service for disposal of " "	4	0	9	4	5	9	6	7	9	1	0		
Bathing service	5	0	9	4	5	9	6	7	9	1	0		
Supply of sickroom equipment*	6	0	9	4	5	9	6	7	9	1	0		
Night nursing service	7	0	9	4	5	9	6	7	9	1	0		
Night sitting service	8	0	9	4	5	9	6	7	9	1	0		
Geriatric social worker	9	0	9	4	5	9	6	7	9	1	0		
Any other official or voluntary service SPECIFY	9	0	9	4	5	9	6	7	9	1	0		

*RECORD DETAILS OF ANY EQUIPMENT IT WOULD HAVE BEEN HELPFUL TO HAVE OPPOSITE

25 Is there anything that would have made _____'s care easier for you? BRING FORWARD ANY NEED PREVIOUSLY MENTIONED AND CHECK FOR ANY FURTHER NEED

Yes . . . 1
No . . . 2

IF YES (1) What?

26. Would you say that _____'s home was very convenient, fairly convenient or rather inconvenient for him after he became ill/o d?

Very convenient 1
Fairly convenient 2
Rather inconvenient .3

IF 2 or 3 In what way?

27. Where did you get the medical information you had about _____ and his treatment?

CODE ALL THAT APPLY

General practitioner 1
Hospital 2
Other SPECIFY 3

None 0

28 Did you feel you had adequate medical information about _____ or would it have been helpful if you had had more information about _____ and his treatment?

Adequate information . .5
Helpful to have had more . . .6

IF ADEQUATE (5) SKIP TO Q 33

29 What other sort of information would you have liked?

30. How would it have helped you?

31 Who do you think could have given you this information?

General practitioner . . 1
Hospital 2
Other SPECIFY 3

32 Did you try to get any more medical information about _____?

Yes . . 1
No 2

IF YES (1) What happened?

IF NO (2) Why not?

33 Is it possible for you to remember whether _____ lived alone or not at the time he died (came off your books)?

Can't remember 1
Lived alone 2
Lived with others . 3

IF LIVED WITH OTHERS Do you recall

a) How many there were altogether in the household including deceased _____?

Can't remember. . 9

b) Their relationships if any to deceased

A

B

C

D

E

c) Who normally did the cooking and other housework?

34 Did you visit _____'s home after the death at all?

Yes . . 3
No . 4

IF YES (3) Was that in a professional capacity?

Yes . 5
No . . 6

IF NOT EITHER PART (4 OR 6) SKIP TO Q 36a

35 Why did you visit them?

Did not know of death . . . 1
To collect records . . . 2
To collect equipment . 3
To lay out body . . . 4
To support bereaved 5
To give care to other member of the family . 6
Other SPECIFY 7

IF 6) Had this care started before _____ died?

Yes 1
No 2

IF 1, 2, 3 or 4) ONLY SKIP TO Q 40

36 a) Did you have any professional contact with bereaved?

Yes 1
No 2

IF YES G TO 35 IF NO G T O 39

36 Whom did you support or give care to?

RELATIONSHIPS TO DECEASED

A	1	2	3
B	1	2	3
C	1	2	3

37. What did you do for them? Was it nursing treatment, or just supervision or advice or what? CODE ABOVE

38 IF MORE THAN ONCE Over what period?

Less than a week. 1
1 week < 1 month 2
1 month < 3 months. 3
3 months or more. 4

39 Is there anything else you would like to say about the care of _____ or the members of his family since he died?

40 a) Were you attached to the deceased's general practitioner while you were looking after him?

Yes. . . 3
No 4

41 In what capacity did you visit _____ and/or the bereaved?

District nurse. . . 1
Health visitor 2
Midwife 3
Combined worker 4
Other SPECIFY . .

That's all the questions about _____

Thank you for helping us IF NOT INVOLVED IN CARE OF OTHERS IN SAMPLE I'd like now to ask you a few general questions - GO TO QUESTIONNAIRE B

H.V. and D.N. Questionnaire A – Specific Patients

1
2 } Serial Numbers of Deceased.
3
4
5
6 } Serial Numbers of H.V./D.N.
7
8 } Birmingham H.V./D.N.'s.

9 Had part in care of patient or family.
10 Where care was given.
11 Records of visits – referred to
12 How long X had been on books.
13 Reason for discharge from books
14 How many H.V./D.N's visited
15 Did subject make last visit.
16 Who made most visits.
17 How many home visits did X have in last 12 months
18 " in last 6 months
19 " in last 3 months
20 " in last month
21 " in last week
22 How many visits did S. make in last 12 months
23 Did X have any night visits
24 Max. No. of visits in one week.
25 Who requested X should be visited.
26 Reason for request – type of care given
27 Was S. first person to visit.
28 How request reached S.
29 Adequacy of information then
30 Service asked for at right time or not.
31 Personal Help given by H.V./D.N.
32 Nursing Help " " "
33 Further Nursing Help " " "
34 Supervision/Teaching self care by D.N./H.V.
35 Summary of care given.
36 Most regular help given.
37 Could S have done with more help with these.
38 Who else helped

39 What others helped with.
40 Could X have done with any more of this help
41 Night/Social/Financial/Domestic Help needed

42 Any more needed.
43 How long visits took usually.
44 " " " " at most.
45 " " " " at least
46 Did X give S enough time, or like more.
47 Other services helping X — I
48 " " " " — II
49 Services arranged by S — I
50 " " " " — II
51 Services not got that would have been useful — I
52 " " " " " " " " — II
53 " " " " Stated to arrange — I
54 " " " " " " " " — II
55 Anything that would have made X's care easier.
56 Convenience of time
57 Where S got medical information about X
58 Adequacy of information / who could have given more.
59 Did S try to get more medical information
60 Household composition
61 Who did housework

62 Did S visit home after death.
63 Why did S visit them.
64 Did S have any professional contact with bereaved
65 Over what period.
66 Was S attached to X's G.P. while looking after him.
67 In what capacity did S visit X or bereaved.
68 No. of patients.
69
70
71
72
73
74
75
76
77
78
79
80 Card identification — y 37

T.I. and T.V. Questionnaire A

Deceased's serial number — Cols. 1 - 4

Workers serial number — Cols. 5 - 8
(note in Area 9 these will be 4 digit numbers, in all other areas they are 3 digit numbers, the fourth digit in these cases will be y)

Question 1 Care of patient or family — Col. 9

Had a part in ——'s care during the last 12 months of his life	1	197
Had part in care of ——'s family after his death	3	1
Inadequate	X	–

Single coded
N.B. if code 3 here leave rest blank until Q. 34

Q. 2 Where care given — Col. 10

Care given in deceased's own home only	0	178
" " " " " "	1	17
Doctor's surgery	3	1
Local authority clinic	4	1
Health centre	5	– may be multi coded
Your own home	6	–
Other	7	6
Inadequate where	X	–
	R	1

N.B. leave blank until Q. 36(a) if not code 0 or 1 here.

Q. 3 Records of visits — Col. 11

Records referred to	3	127
No records referred to	2	58
Inadequate	X	10
Single coded	R	3

y① is ringed but 2nd part not answered, check to see if dates are fully recorded. Assume that this gives clue that records were referred to.

Q. 4/5 How long had —— been on the books (for the last period) — Col. 12

Less than a week	1	28
1 week - 1 month	2	45
1 month - 3 months	3	36
3 months - 6 months	4	22
6 months - 1 year	5	18
1 year - 2 years	6	14
2 years - 3 years	7	9
3 years - 5 years	8	12
5 years or more	0	4
Don't know	9	1
Inadequate	X	6
	R	3

Single coded

	Col 5	Col 6	Col 7	Col 8
1	6	63	20	–
2	19	38	16	2
3	11	17	14	1
4	29	5	20	2
5	21	6	15	2
6	18	5	17	4
7	34	1	19	3
8	16	1	26	–
9	14	–	22	–
0	11	61	29	–
x	4	1	–	–
y	15	–	–	–

Q. 6 What was the reason for his discharge from the books (the last time) Col.13

Died	1	126
Transferred to hospital or other institution	2	60
Prescribed treatment completed	3	3
Able to manage	4	1
Care rejected	5	1
Moved	6	2
Other	7	2
Uncertain	9	-
Inadequate	X	-
Single coded	R	3

Q. 7 How many D.N/H.V.s visited —— at home during last 12 months of his life Col.14

One	1	46
Two	2	80
Three or four	3	42
Five - nine	4	21
Ten or more	5	4
Don't know	9	1
Inadequate	X	1
Single coded	R	3

Q. 8 Were you the D.N./H.V. who made the last visit Col. 15

Yes	6	107
No	7	39
Don't know	9	3
Inadequate	X	-
D.N.A. (code 1 at col.14)	y	46
Single coded	R	3

Is it possible for you to say whether you made more visits than any other individual D.N./H.V. Col.16

Don't know	9	5
Subject made most	1	115
Other nurse visited more often	2	9
About equal	3	5
Inadequate	X	15
D.N.A. (code 1 col14)	y	46
Single coded	R	3.

D.V./d.V. 3

Q. 9 How many home visits did —— have — Col.17

a) In the last 12 months of his life

		Col 17	Col 18	Col 19	Col
None 0		—	—	4	6
1 - 4 1		20	22	24	34
5 - 9 2		24	24	27	33
10 - 19 3		31	34	42	41
20 - 29 4		20	29	27	2
30 - 49 5		21	19	17	2
50 + ...6		71	56	40	1
Don't know 9		2	2	3	5
Inadequate X		6	8	8	8
D.N.A (in hosp. or institution during this period)	Y	—	1	3	3
Single coded	R	3	3	3	3

b) In the last 6 months - codes as for col 17 — Col.18

c) In the last 3 months - codes as for col 17 — Col.19

d) The last month — Col.20

Q. 9e) How many visits did he have in the last week — Col.21

None.....0		18
One 1		11
Two 2		16
Three - Four 3		20
Five - six 4		20
Seven or more 5		98
Don't know 9		3
Inadequate X		5
D.N.A. (as col 17)	Y	4
Single coded	R	3

Q. 10 How many visits did you make yourself in the last 12 months of ——'s life — Col.22

None 0		
1 - 4 1		35
5 - 9 2		21
10 - 19 3		41
20 - 29 4		18
30 - 49 5		26
50 + ...6		48
Don't know 9		1
Inadequate X		5
Single coded	R	3

Q. 11 Did —— have any visits between 8 p.m. and 8 a.m. in the last year of his life — Col.23

No 0		145
Don't know /Inadequate X		6
Yes One 1	single coded	9
Two 2		4
Three - four 3		9
Five - nine 4		7
Ten or more 5		15
Inadequate how many 9		—

Normally double coded unless 0 or X

b) Did you do any of the night visits

Yes 6	single coded	37
No 7		7
Inadequate 8		—
R.		3

Q. 12 Is it possible to say from the records what was the maximum number of visits —— had during any one week - I mean visits at any one time of the day now — Col.24

1 1	19
2 2	12
3 3	18
4 4	5
5 5	10
6 6	7
7 7	32
8 - 10 8	27
11 - 13 0	7
14 + ...y	49
Can't say 9	4
Inadequate X	5
Single coded R.	3

Q. 13 Who requested that —— should be visited - when —— came on the books for the last time — Col.25

General practitioner.....1	158
Hospital doctor 2	4
Hospital sister/nurse 3	1
District nurse 4	1
Health visitor 5	3
Welfare/social worker 6	1
Relative/friend 7	11
Patient himself 8	—
Other - specify 0	8
Don't know/unspecified person....9	2
Inadequate X	3
No one (D.N. requested) Y	3
Single ..	—
R	3.

Q. 14 What was the reason for the request then — Col.26

Type of care needed

General nursing care (including weekly baths, help with washing, chiropody, coping with incontinence, senility)	1	83
Treatment, dressings, enemas, rectal washouts	2	25
Injections	3	23
Supervision, checking, keeping an eye on, moral and physical support for family	4	33
Emergency visit	5	4
Other or vague reason	6	74
Don't know	9	–
Inadequate	X	6
D.N.A. (y at 25)	y	3
All except X may be multi-coded	R	3

Q. 15 Were you the first person to make a visit in answer to that request — Col.27

Yes (incl. only one D.N. visited)	1	143
No	2	45
Can't remember, uncertain	3	–
Inadequate (question not asked/answered)	X	7
Single coded	R	3.

Q. 17 How did the request reach you — Col.28

Personal contact with person making request.	1	60
Telephone call from " " "	2	49
Letter from person making request	3	5
Message from office	4	17
Message from other person - specify	5	5
Other	0	4
D.N.A. (code 2 or X at Q.15 col 27)	y	54
Inadequate	X	2
	R	3

Q. 18 Do you feel the information you were given on that occasion was: — Col.29

Adequate	1	114
Rather inadequate	2	16
Very inadequate	3	5
Qualified, uncertain, no code rung	4	2
Inadequate	X	4
D.N.A. (code 2 or X at Q.15 col 27)	y	54
Single coded	R	3

Q. 19 Do you feel the service was asked for at the right time or that it would have been appropriate to ask for it earlier or later — Col.30

Right time	4	111
Earlier	5	22
Later	6	3
Inadequate	X	5
D.N.A. (code 2 or X at Q.15 col 27)	y	54
Single coded	R	3

Q. 20 Here is a list of ways people may need help. Could you tell me whether you or any other district nurse (health visitor) did any of these for —— during the last 12 months of his life ?

~~Col.31~~

Categories 11 - 1X — Col.31

11. To be lifted	1	125
12. Help with washing (or shaving)	2	144
13. Getting in or out of bath	3	29
14. Dressing or undressing	4	59
15. Getting in or out of bed	5	103
16. Getting hair washed at home	6	39
17. Cutting toenails	7	100
18. Giving bedpan or bottle	8	83
19. Getting to lavatory or commode	y	74
1X. Bedmaking	X	140
No help in categories 11 - 1X	0	22
Inadequate	9	9
May be multi-coded	R	3

Categories 21 - 26 — Col.32

21. Giving medicines or tablets	1	56
22. Injections	2	62
23. Bandaging or other dressings	3	51
24. Regular temperature taking (for hypothermia prevention)	4	25
25. Massaging/exercises	5	43
26. Enema	6	37
No help in categories 21 - 26	0	49
Inadequate	9	8
May be multi-coded	R	3

Categories 91 - 99 — Col.33

91. Lavage/douche/pessary	1	19
92. Catherization	2	6
93. Blood pressure	3	4
94. Eye/ear drops	4	4
95. Care of pressure areas	5	138
96. Electrocardiogram	6	1
97. Dialysis	7	—
98. Taking temperature, pulse respiration	8	128
99. Any other nursing procedure (specify)	y	23
No help in categories 91 - 99	0	35
Inadequate	9	9
May be multi-coded	R	3

Categories X1 - X3 — Col.34

X1. Teaching patient self-care	1	45
X2. " relatives	2	93
X3. Supervision only	3	47
No help in categories X1 - X3	0	57
Inadequate	9	9
May be multi-coded	R	3

D.N./H.V. 7

Summary of care given — Col.35

None.....0
Categories 11 - 1X.....1)
Categories 21 - 26 .....2) Additive
Categories 91 - 99 .....4)
Categories X1 - X3, overcode...y
Don't know /.....9
Inadequate X

0	1
1	10
2	7
3	6
4	1
5	25
6	3
7	124
8	–
9	3
X	5
Y	128
R	3.

Most regular help — Col.36

Take most often, i.e. priority as below:

None .....(d.o.c.35).....0	1
Some help regularly and daily.....1	127
" " " more than weekly, less than daily 2	26
" help regularly weekly 3	12
" " " less often 4	5
" " " inadequate how often..5	1
" " occasionally, but not reg. 7	9
Once only 8	6
Don't know 9	–
Inadequate X	8
Single coded R	3.

Q. 20(c) Could you have done with anyone's help with any of these — Col.37

No, or 0 at col 35 0
More help needed
Categories 11 - 1X ....1)
21 - 26 ....2) Additive
91 - 99 ....4)
X1 - X3, overcode ....y
More help needed, but inadequate what....8
Don't know /.....9
Inadequate X

} may be multi-coded.

0	135
1	29
2	3
3	1
4	1
5	1
6	1
7	1
8	1
9	1
X	1
Y	1
R	1

Q. 20(i) Did anyone (else) help with this/these — Col.38

No, or 0 at col 35.....0
Yes spouse 1
father/mother 2
son/daughter 3
son in law/daughter in law 4
grandchild 5
brother/sister (in law) 6
other relative 7
friend, neighbour 8
other person 9
don't know, inadequate who helped ...y
inadequate X

} may be multi-coded.

34	
62	
1	
61	
16	
1	
16	
10	
8	
26	
–	
18	

May be multi-coded

R 3

A1

D.N./H.V. 8

Types of help given by others — Col.39

D.N.A. No help given by others'(code 0 at col.38)...0

Categories 11 - 1X...1 } Additive
" 21 - 26...2 } Additive
" 91 - 99...4 } Additive

Overcode " X1 - X3...y

General help with everything 8
Don't know ./inad..to part..overcode.....9
Inadequate X

0	52
1	53
2	1
3	15
4	–
5	11
6	1
7	10
8	33
9	6
x	20
y	4
R.	3

Q. 20(ii) Could the deceased have done with any more help of this sort — Col.40

No.....0	133
Help needed with categories 11 - 1X 1	23
" " " " 21 - 26 2	1
" " " both categories 3	2
Some help needed, inad what or unspec. ...8	5
Don't know ..inad..to part.....9	10
Inadequate X	29
R	3

Q. 21 Could you say whether —— needed help with these sorts of things — Col.41

may be multi-coded

Help at night (31-31).....3	110
Social needs (41-45).....4	135
Financial help (51).....5	19
Domestic help (61 - 64) 6	129
Help needed, inad. what 8	–
Don't know ..overcode... 9	35
No help needed 0	21
Inadequate X	7
R	3

Could you say whether he had all the help he needed or could have done with some more help — Col.42

D.N.A. no more help needed(code 0,9,X in col. 41) ...)	
Received all help needed (all 1's to this part Q.21)..) y	129
Help at night (31 - 32) 3	40
Social needs (41 - 45) 4	23
Financial help (51) 5	3
Domestic help (61 - 64) 6	22
Inadequate to part /don't know.....9	8
Inadequate X	4
(code when help needed and 2 or 0 rung in second part of Q. 21)	
R	3

may be multi-coded

A1

D.N./H.V. 9

Q. 22(a) How long did your visits to —— take, usually — Col.43

		GS43	GS44	GS45
Less than 10 mins	1	3	2	16
10 - 20	2	27	15	52
20 - 30	3	42	18	60
30 - 45	4	64	40	31
45 - 1 hr	5	29	49	10
1 hr - 1½ hrs	6	15	46	9
1½ hrs - 2 hrs	7	1	5	–
2 hrs or longer	8	–	3	–
Uncertain	9	–	–	–
Inadequate	X	14	15	17
Single coded	R	3	3	3

(b) How long did your visits to —— take, at most — Col.44

Codes as for Col.43

(c) How long did your visits to —— take, at least — Col.45

Codes as for Col.43

Q. 23 On the whole do you feel you were able to give enough time to —— or would you have liked to have been able to give more time to him — Col.46

Gave enough time	1	135
Inad. if gave enough time	X	20
Liked more time		
to visit more often	3	9
to spend longer at visit	4	16
both	5	13
inadequate what for	9	2
Single coded	R	3

Q. 24 Do you know if —— or his family had any help from any other services such as: — Col.47

District nursing	1	may be multi-coded	10
Health visiting	2		34
Private nurse	3		8
Home help	4		28
Special laundry service	5		10
Chiropody	6		36
Vicar, priest, minister	7		68
Inad. to some (covered)	9		73
None of these	0		64
Inadequate	X		8
	R		3

Q. 24 Do you know if —— or his family had any help from any other services such as: — Col.48

Meals on wheels	1
Free supply of incontinence pads	3
Services for disposal of "	4
Bathing service	5
Supply of sickroom equipment	6
Night nursing service	7

D.K./H.V. 10

Q. 24 Do you know if —— or his family had any help from any other services such as: Col.48

Meals on wheels 1	may be multi-coded	8
Free supply of incontinence pads 3		112
Service for disposal of " " 4		7
Bathing service 5		6
Supply of sickroom equipment 6		111
Night nursing service 7		6
" sitting " 8		14
Geriatric social worker 9		10
Other specified official or voluntary service 2		7
Inadequate to some (overlap).....y		17
None of these 0		46
Inadequate X		9
R		3

Type of help arranged by informant - 1 Col.49

District nursing 1	may be multi-coded	3
Health visiting 2		5
Private nurse 3		-
Home help 4		13
Special laundry service 5		9
Chiropody 6		17
Vicar,priest,minister 7		8
Inadequate to some (overlap).....9		2
None of these 0		71
Inadequate X		7
D.N.A. (code 0 at col.47) .....y		72
R		3

Type of help arranged by informant - 11 Col.50

Meals on wheels 1	may be multi-coded	3
Free supply of incontinence pads 3		108
Service for disposal of " " 4		7
Bathing service 5		4
Supply of sickroom equipment 6		94
Night nursing service 7		4
" sitting " 8		10
Geriatric social worker 9		2
Other specified official or voluntary service 2		4
Inadequate to some (overlap).....y		4
None of these (incl. D.N.A code 0 at col. 48).....0		55
Inadequate X		3
R		3

A1

/H.V. 11

ı of help that would have been helpful - 1			Col.51
istriot nursing 1			—
alth visiting 2			4
ivate nurse 3			10
me help 4	may be multi-coded		27
ecial laundry service.....5			21
iropody 6			4
icar,priest,minister.....7			8
nadequate to some 9			18
one of these 0			106
nadequate X			37
R			3.
/pe of help that would have been helpful - 11			Col.52
Meals on wheels 1			10
Free incontinence pads 3			1
Service for disposal of pads....4			10
Bathi:g service 5			17
Supply of sickroom equipment....6	may be multi-coded		1
Night nursing service 7			14
" sitting " 8			32
Geriatric social worker 9			10.
Other specified official or voluntary service 2			1
Inadequate to some .....y			5
None of these 0			101
Inadequate X			34
R			3
Type of help respondent tried to arrange - 1			Col.53
District nursing 1			—
Health visiting 2			—
Private nurse 3			1
Home help 4	may be multi-coded		6
Special laundry service 5			—
Chiropody 6			2
Vicar,priest,minister 7			1
Inadequate to some 9			—
None of these 0			39
Inadequate X			4
D.N.A. (code 0 at col51).....y			143
R			3

C D.N./H.V. 12

Type of help respondent tried to arrange - 11 Col.54

Meals on wheels 1		3
Free supply of incontinence pads....3		—
Service for disposal of " " 4		1
Bathing service 5		1
Supply of sickroom equipment.....6	may be multi-coded	—
Night nursing service 7		1
" sitting " 8		2
Geriatric social worker 9		—
Other specified official or voluntary service 2		—
Inadequate to some .....y		1
None of these(incl. D.N.A. code 0 at col.52).....0		184
Inadequate X		5
R		3

Q. 25 Is there anything that would have made ——'s care easier for you Col.55

Yes.....1	51
No.....2	133
Don't know 3	—
Inadequate X	11
R	3

(check with Q.24 and bring forward any further need)

Single coded

Q. 26 Would you say that ——'s home was very convenient etc. for him after he became ill/old Col.56

Very convenient.....1	114
Fairly " 2	48
Rather inconvenient 3	28
Inadequate X	5
R	3

Single coded

Q. 27 Where did you get the medical information you had about —— and his treatment Col.57

G.P. 1		165
Hospital 2	may be multi-coded	9
Other 3		16
Inadequate X		7
None 0		9
R		3

Q. 28 & 31 Did you feel you had adequate medical information about —— or would it have been helpful if you had had more information about —— and his treatment. Col.58

Adequate information 5		158
Uncertain, qualified 0		1
Inadequate X		9
Helpful to have had more from:		
G.P. 1	may be multi-coded	24
Hospital 2		7
Other specified 3		—
Inadequate where 4		—
R		3.

Q. 32 Did you try to get any more medical information about —— Col.59

No 2	12
Yes, but didn't get any more.....3	3
" got more 4	6
" inad. if got more 5	6
Inad. if tried or not X	—
D.N.A. (codes 5,0,X at col.58)...y	168
Single coded R	3

Q. 33 Household composition Col.60

Lived alone 1	20
With spouse only 2	64
" " and children only.....3	22
" " " " and children in law, without or with grandchildren 4	4
With children only 5	21
" " and children inlaw, with or without grandchildren..6	20
With other relatives of same generation only 7	18
With other unrelated people 8	5
Other 3 generation household.....9	5
Guest house (O.P. home or no or inad. information about where living) .....y	3
Others 0	12
Don't know X	1
Single coded R	3

c) Who normally did the cooking and other housework Col.61

D.N.A. (lived alone or inad. who lived with 1 or X or y at Col.60)...y	24
Deceased 1	8
Other person in same household...2	142
Deceased and other person in same household 3	5
Other(s).....4	18
Inadequate X	8
~~Multi-~~ coded 5	27.
R except y & X.	3

A1

D.N./H.V. 14

Q. 34 Did you visit ——'s home after the death at all — Col.62

No	4	105
Inadequate	X	2
Yes, in a professional capacity	5	75
Yes, not in " "	6	6
Yes, inad. if in " "	9	8
	R	2.

Q. 35 Why did you visit them — Col.63

Did not know of death	1		15
To collect records	2		9
To collect equipment	3		32
To lay out body	4		3
To support bereaved	5	maybe multicoded.	37
To give care to other member of the family/household	6		10
Other	0		6
Inadequate	X		-
D.N.A. (codes 4,6,X, or 9 at col.62)	y		113
If code (6), care to other member of family:			
Overcode if care started before —— died	9		5
	R		2.

Q. 36 Did you have any professional contact with bereaved — Col.64

No (incl. D.N.A. code 1,2,3, or 4 only at col.63)	0	149
Inadequate	X	22
Yes, relationship to deceased:		
C spouse	1	14
father/mother	2	-
son/daughter	3	5
son in law/daughter in law	4	1
grandchild	5	-
brother/sister (in law)	6	7
other relative	7	2
friend,neighbour	8	-
other person	9	-
don		

Q. 38 Over what period — Col.65

D.N.A. (code 0 or X at col.64)	y	171
Inadequate	X	12
Less than a week	1	2
1 week - 1 month	2	5
1 month - 3 months	3	4
3 months or more	4	4
Overcode if currently attending Single coded	0	3

A1

D.N./H.V. 15

Q. 40 Were you attached to the deceased's G.P. while you were looking after him — Col.66

Yes.....3	76	Partial attachment ... 5 .	5
No 4	116		
Inadequate X	1		

Single coded

Q. 41 In what capacity did you visit —— and/or the bereaved — Col.67

D.N. 1		181
H.V. 2		17
Midwife 3	may be multi-coded	1
Combined worker 4		1
Other 5		—
Inadequate X		—

Col 12
Box 8

Additional causes of death

		I.C.D. no. 1966 Box 9
1.	Neoplasms	140 - 239
2.	Circulatory + bad heart dis.	390 - 458
3.	Respiratory dis.	460 - 519
4.	Symptoms except senility	780 - 796
5.	Accidents	E800 - E999 as N's
6.	Digestive	520 - 577
7	Senility, old age	
0.	Others	000 - 136, 240 - 389, 580 - 779
8	Loneliness, lost will live	
~~X.~~	~~Inadequate~~	
9.	No additional cause	
4	Don't know uncertain - can be coded with some specific condition as in previous codes if some doubt as uncertainty expressed.	

This may be multi-coded but additional causes within the same broad group of the I.C.D. as the main underlying cause ~~and~~ one not taken.

This means that this code never contains the same digit as the first digit of the underlying cause except that both can be 0 if the two causes would have different 2nd digits if both were classified according to the 2 digit code for main underlying cause.

Home Care for Dying H.U./D.N. Qu.A.

Serial number - 1st digit - Area Col. 1

Barking	1	6
Teeside	2	19
Hillingdon	3	11
Cheshire (NE)	4	29
Brentwood	5	21
Bridgend	6	18
Northumberland	7	34
Eastbourne	8	16
Birmingham	9	14
Thanet	0	11
St. Helens	X	4
Isle of Wight	Y	15

2nd digit - Interval between month of death and interview month Col. 2

3 months	1 -
9 months	6 -

3rd digit Col. 3

4th digit Col. 4

Qr. 2 Completed	0	167
Qr. 1 Part II Completed	1	4
Qr. 1 Part I Completed	2	4
Failure to Qr. 1 Part I	3	23

	Col 2	Col 3
1	29	26
2	26	21
3	31	13
4	22	15
5	—	24
6	21	21
7	18	15
8	21	20
9	30	25
0	—	18

H.U./D.N. 4th DIGIT OF SERIAL NUMBER

BIRMINGHAM SUB-DISTRICTS:-

1	ASTON
2	BARDESLEY
3	CENTRAL
4	HALL GREEN
5	KINGSTANDING
6	SELLY OAK
7	WASHWOOD HEATH
8	YARDLY
X	HEALTH VISITOR

[redacted]

Y D.N.A. - ALL AREAS OTHER THAN BIRMINGHAM (Qr. A's)

Qr. A. Col. 8

[redacted]

H.V./D.N. Qr. A

Col. 68

Each subject is given a serial number within H.V./D.N.

1 - 9		1 - 9
1 0		0
1	126	
2	40	
3	15	
4	9	
5	3	
6	1	
7	1	
8	1	
9	1	
0	1	

D.N. and H.V. Questionnaire A

Deceased's serial number — Cols. 1 - 4

Workers serial number — Cols. 5 - 8
(note in Area 9 these will be 4 digit numbers, in allcother areas they are 3 digit numbers, the fourth digit in these cases will be y)

Question 1 Care of patient or family — Col. 9

Had a part in ——'s care during the last 12 months of his life...	1	197
Had part in care of ——'s family after his death	3	1
Inadequate	X	–

Single coded
N.B. if code 3 here leave rest blank until Q. 34

Q. 2 Where care given — Col.10

Care given in deceased's own home only	0	178
" " " " " "	1	17
Doctor's surgery	3	1
Local authority clinic	4	1
Health centre	5	-may be multi coded
Your own home	6	-
Other	7	6
Inadequate where	X	–
	R	1

N.B. leave blank until Q. 36(a) if not code 0 or 1 here.

Q. 3 Records of visits — Col.11

Records referred to.....	3	127
No records referred to.....	2	58
Inadequate	X	10
Single coded	R	3

y① is ringed but 2nd patnat answered, check to see if dates are fully recorded. Assume that this gives clue that records were referred to.

Q. 4/5 How long had —— been on the books (for the last period) — Col.12

Less than a week	1	28
1 week - 1 month	2	45
1 month - 3 months	3	36
3 months - 6 months	4	22
6 months - 1 year	5	18
1 year - 2 years	6	14
2 years - 3 years	7	9
3 years - 5 years	8	12
5 years or more	0	4
Don't know	9	1
Inadequate	X	6
	R	3

Single coded

	Col 5	Col 6	Col 7	Col 8
1	6	63	20	–
2	19	38	16	2
3	11	17	14	1
4	29	5	20	2
5	21	6	15	2
6	18	5	17	4
7	34	1	19	3
8	16	1	26	–
9	14	–	22	–
0	11	61	29	–
x	4	1	–	–
y	15	–	–	184

Q. 6 What was the reason for his discharge from the books (the last time) **Col.13**

Died	1	126
Transferred to hospital or other institution	2	60
Prescribed treatment completed	3	3
Able to manage	4	1
Care rejected	5	1
Moved	6	2
Other	7	2
Uncertain	9	-
Inadequate	X	-
Single coded	R	3

Q. 7 How many D.N/H.V.s visited —— at home during last 12 months of his life **Col.14**

One	1	46
Two	2	80
Three or four	3	42
Five - nine	4	21
Ten or more	5	4
Don't know	9	1
Inadequate	X	1
Single coded	R	3

Q. 8 Were you the D.N./H.V. who made the last visit **Col. 15**

Yes	6	107
No	7	39
Don't know	9	3
Inadequate	X	-
D.N.A. (code 1 at col.14)	y	46
Single coded	R	3

Is it possible for you to say whether you made more visits than any other individual D.N./H.V. **Col.16**

Don't know	9	5
Subject made most	1	115
Other nurse visited more often	2	9
About equal	3	5
Inadequate	X	15
D.N.A. (code 1 col 14)	y	46
Single coded	R	3.

Q. 9 How many home visits did —— have **Col.17**

a) In the last 12 months of his life

	Col 17	Col 18	Col 19	Col 20
None 0	–	–	4	6
1 - 4 1	20	22	24	34
5 - 9 2	24	24	27	33
10 - 19 3	31	34	42	44
20 - 29 4	20	29	27	26
30 - 49 5	21	19	17	21
50 + ...6	71	56	40	15
Don't know 9	2	2	3	5
Inadequate X	6	8	8	8
D.N.A (in hosp. or institution during this period)	–	1	3	3
Single coded R	3	3	3	3

b) In the last 6 months - codes as for col 17 **Col.18**

c) In the last 3 months - codes as for col 17 **Col.19**

d) The last month **Col.20**

Q. 9e) How many visits did he have in the last week **Col.21**

None.....0	18
One 1	11
Two 2	16
Three - Four 3	20
Five - six 4	20
Seven or more 5	98
Don't know 9	3
Inadequate X	5
D.N.A. (as col 17)	4
Single coded R	3

Q. 10 How many visits did you make yourself in the last 12 months of ——'s life **Col.22**

1 - 4 1	35
5 - 9 2	21
10 - 19 3	41
20 - 29 4	18
30 - 49 5	26
50 + ...6	48
Don't know 9	1
Inadequate X	5
Single coded R	3

Q. 11 Did —— have any visits between 8 p.m. and 8 a.m. in the last year of his life — Col.23

No	0		145
Don't know / Inadequate	X		6
Yes One	1	single coded	9
Two	2		4
Three - four	3		9
Five - nine	4		7
Ten or more	5		15
Inadequate how many	9		—

Normally double coded unless 0 or X

b) Did you do any of the night visits

Yes	6	single coded	37
No	7		7
Inadequate	8		—
	R		3

Q. 12 Is it possible to say from the records what was the maximum number of visits —— had during any one week - I mean visits at any one time of the day now — Col.24

1	1	19
2	2	12
3	3	18
4	4	5
5	5	10
6	6	7
7	7	32
8 - 10	8	27
11 - 13	0	7
14 +	y	49
Can't say	9	4
Inadequate	X	5
Single coded	R	3

Q. 13 Who requested that —— should be visited - when —— came on the books for the last time — Col.25

General practitioner	1	158
Hospital doctor	2	4
Hospital sister/nurse	3	1
District nurse	4	1
Health visitor	5	3
Welfare/social worker	6	1
Relative/friend	7	11
Patient himself	8	—
Other - specify	0	8
Don't know/unspecified person	9	2
Inadequate	X	3
No one (D.N. requested) Single coded	4	3
	R	3

Q. 14 What was the reason for the request then — Col.26

Type of care needed

General nursing care (including weekly baths, help with washing, chiropody, coping with incontinence, senility)	1	83
Treatment, dressings, enemas, rectal washouts	2	25
Injections	3	23
Supervision, checking, keeping an eye on, moral and physical support for family	4	33
Emergency visit	5	4
Other or vague reason	6	74
Don't know	9	–
Inadequate	X	6
D.N.A. (y at 25)	y	3
All except X may be multi-coded	R	3

Q. 15 Were you the first person to make a visit in answer to that request — Col.27

Yes (incl. only one D.N. visited)	1	143
No	2	45
Can't remember, uncertain	3	–
Inadequate (question not asked/answered)	X	7
Single coded	R	3

Q. 17 How did the request reach you — Col.28

Personal contact with person making request	1	60
Telephone call from " " "	2	49
Letter from person making request	3	5
Message from office	4	17
Message from other person – specify	5	5
Other	0	4
D.N.A. (code 2 or X at Q.15 col 27)	y	54
Inadequate	X	2
	R	3

Q. 18 Do you feel the information you were given on that occasion was: — Col.29

Adequate	1	114
Rather inadequate	2	16
Very inadequate	3	5
Qualified, uncertain, no code rung	4	2
Inadequate	X	4
D.N.A. (code 2 or X at Q.15 col 27)	y	54
Single coded	R	3

Q. 19 Do you feel the service was asked for at the right time or that it would have been appropriate to ask for it earlier or later — Col.30

Right time	4	111
Earlier	5	22
Later	6	3
Inadequate	X	5
D.N.A. (code 2 or X at Q.15 col 27)	y	54
Single coded	R	3

Q. 20 Here is a list of ways people may need help. Could you tell me whether you or any other district nurse (health visitor) did any of these for —— during the last 12 months of his life ? ~~Col.31~~

Categories 11 - 1X — **Col.31**

11. To be lifted	1	125
12. Help with washing (or shaving)	2	144
13. Getting in or out of bath	3	29
14. Dressing or undressing	4	59
15. Getting in or out of bed	5	103
16. Getting hair washed at home	6	39
17. Cutting toenails	7	100
18. Giving bedpan or bottle	8	83
19. Getting to lavatory or commode	y	74
1X. Bedmaking	X	140
No help in categories 11 - 1X	0	22
Inadequate	9	9
May be multi-coded	R	3

Categories 21 - 26 — **Col.32**

21. Giving medicines or tablets	1	56
22. Injections	2	62
23. Bandaging or other dressings	3	51
24. Regular temperature taking (for hypothermia prevention)	4	25
25. Massaging/exercises	5	43
26. Enema	6	37
No help in categories 21 - 26	0	49
Inadequate	9	8
May be multi-coded	R	3

Categories 91 - 99 — **Col.33**

91. Lavage/douche/pessary	1	19
92. Catherisation	2	6
93. Blood pressure	3	4
94. Eye/ear drops	4	4
95. Care of pressure areas	5	138
96. Electrocardiogram	6	1
97. Dialysis	7	—
98. Taking temperature, pulse, respiration	8	128
99. Any other nursing procedure (specify)	y	23
No help in categories 91 - 99	0	35
Inadequate	9	9
May be multi-coded	R	3

Categories X1 - X3 — **Col.34**

X1. Teaching patient self-care	1	45
X2. " relatives	2	93
X3. Supervision only	3	47
No help in categories X1 - X3	0	57
Inadequate	9	9
May be multi-coded	R	3

Summary of care given — **Col.35**

None.....0
Categories 11 - 1X.....1)
Categories 21 - 26 .....2) Additive
Categories 91 - 99 .....4)
Categories X1 - X3,overcode...y
Don't know /need to see.....9
Inadequate X

0	1
1	10
2	7
3	6
4	1
5	25
6	3
7	124
8	–
9	3
X	5
Y	128
R	3.

Most regular help — **Col.36**

Take most often, i.e. priority as below:

None .....(d.o.c.t.35).....0
Some help regularly and daily.....1
" " " more than weekly, less than daily 2
" help regularly weekly 3
" " " less often 4
" " " inadequate how often..5
" " occasionally, but not reg. 7
Once only 8
Don't know 9
Inadequate X

Single coded R

	1
	127
	26
	12
	5
	1
	9
	6
	–
	8
R	3.

Q. 20(c) Could you have done with anyone's help with any of these — **Col.37**

No, or 0 at col 35 0
More help needed Categories 11 - 1X ....1)
21 - 26 ....2) Additive
91 - 99 ....4)
X1 - X3,overcode ....y
More help needed, but inadequate what....8
Don't know ./.need to see.....9
Inadequate X

} may be multi-coded.

0	135
1	29
2	3
3	4
4	1
5	4
6	1
7	2
8	1
9	9
X	18
Y	2
R	3

Q. 20(i) Did anyone (else) help with this/these — **Col.38**

No, or 0 at col 35.....0
Yes spouse 1
father/mother 2
son/daughter 3
son in law/daughter in law 4
grandchild 5
brother/sister (in law) 6
other relative 7
friend, neighbour 8
other person 9
don't know, inadequate who helped ...y
inadequate X

May be multi-coded

} may be multi-coded.

	34
	62
	1
	61
	16
	1
	16
	10
	8
	26
	–
	18

R 3

Types of help given by others — Col.39

D.N.A. No help given by others'(code 0 at col.38)...0

Categories 11 - 1X...1)
" 21 - 26...2) Additive
" 91 - 99...4)

Overcode " X1 - X3...y

General help with everything 8
Don't know ./inad..to part..overcode.....9
Inadequate X

0	52
1	53
2	1
3	15
4	—
5	11
6	1
7	10
8	33
9	6
X	20
y	4
R	3

Q. 20(ii) Could the deceased have done with any more help of this sort — Col.40

No.....0	133
Help needed with categories 11 - 1X 1	23
" " " " 21 - 26 2	1
" " " both categories 3	2
Some help needed, inad what or unspec. ...8	5
Don't know ..inad..t..part.....9	10
Inadequate X	29
R	3

Q. 21 Could you say whether —— needed help with these sorts of things — Col.41

Help at night (31-31).....3)	may be multi-coded	110
Social needs (41-45).....4)		135
Financial help (51).....5)		19
Domestic help (61 - 64) .....6)		129
Help needed, inad. what 8		—
Don't know ..overcode... 9		35
No help needed 0		21
Inadequate X		7
R		3

Could you say whether he had all the help he needed or could have done with some more help — Col.42

D.N.A. no more help needed(code 0,9,X in col. 41) ...)
Received all help needed (all 1's to this part Q.21)..) y — 129

Help at night (31 - 32) .....3)	may be multi-coded	40
Social needs (41 - 45) .....4)		23
Financial help (51) .....5)		3
Domestic help (61 - 64) .....6)		22
Inadequate to part /don't know.....9)		8
Inadequate X		4

(code when help needed and 2 or 0 rung in second part of Q. 21)

R 3

Q. 22(a) How long did your visits to —— take, usually **Col.43**

		Col 43	Col 44	Col 45
Less than 10 mins	1	3	2	16
10 - 20	2	27	15	52
20 - 30	3	42	18	60
30 - 45	4	64	42	31
45 - 1 hr	5	29	49	10
1 hr - 1½ hrs	6	15	46	9
1½ hrs - 2 hrs	7	1	5	–
2 hrs or longer	8	–	3	–
Uncertain	9	–	–	–
Inadequate	X	14	15	17
Single coded	R	3	3	3

(b) How long did your visits to —— take, at most **Col.44**

Codes as for Col.43

(c) How long did your visits to —— take, at least **Col.45**

Codes as for Col.43

Q. 23 On the whole do you feel you were able to give enough time to —— or would you have liked to have been able to give more time to him **Col.46**

Gave enough time	1	135
Inad. if gave enough time	X	20
Liked more time		
to visit more often	3	9
to spend longer at visit	4	16
both	5	13
inadequate what for	9	2
Single coded	R	3

Q. 24 Do you know if —— or his family had any help from any other services such as: **Col.47**

District nursing	1		10
Health visiting	2		34
Private nurse	3		8
Home help	4	may be multi-coded	28
Special laundry service	5		10
Chiropody	6		36
Vicar, priest, minister	7		68
Inad. to some (covered)	9		73
None of these	0		64
Inadequate	X		8
	R		3

Q. 24 Do you know if —— or his family had any help from any other services such as: **Col.48**

Meals on wheels	1
Free supply of incontinence pads	3
Services for disposal of "	4
Bathing service	5
Supply of sickroom equipment	6
Night nursing service	7

Q. 24 Do you know if —— or his family had any help from any other services such as: Col.48

Meals on wheels 1		8
Free supply of incontinence pads 3		112
Service for disposal of " " 4		7
Bathing service 5		6
Supply of sickroom equipment 6	may be multi-coded	111
Night nursing service 7		6
" siting " 8		14
Geriatric social worker 9		10
Other specified official or voluntary service 2		7
Inadequate to some (overcode).....y		17
None of these 0		46
Inadequate X		9
R		3

Type of help arranged by informant - 1 Col.49

District nursing 1		3
Health visiting 2		5
Private nurse 3		—
Home help 4	may be multi-coded	13
Special laundry service 5		9
Chiropody 6		17
Vicar,priest,minister 7		8
Inadequate to some (overcode).....9		2
None of these 0		71
Inadequate X		7
D.N.A. (code 0 at col.47) .....y or X		72
R		3

Type of help arranged by informant - 11 Col.50

Meals on wheels 1		3
Free supply of incontinence pads 3		108
Service for disposal of " " 4		7
Bathing service 5		4
Supply of sickroom equipment 6	may be multi-coded	94
Night nursing service 7		4
" sitting " 8		10
Geriatric social worker 9		2
Other specified official or voluntary service 2		4
Inadequate to some (overcode).....y		4
None of these (incl. D.N.A code 0 at col. 48).....0		55
Inadequate X		3
R		3

: of help that would have been helpful - 1			Col.51
istriot nursing 1			—
alth visiting 2			4
ivate nurse 3			10
me help 4	may be multi-coded		27
ecial laundry service.....5			21
iropody 6			4
icar,priest,minister.....7			8
nadequate to some 9			18
one of these 0			106
nadequate X			37
	R		3
rpe of help that would have been helpful - 11			Col.52
deals on wheels 1			10
Free incontinence pads 3			1
Service for disposal of pads....4			10
Bathing service 5			17
Supply of sickroom equipment....6	may be multi-coded		1
Night nursing service 7			14
" sitting " 8			32
Geriatric social worker 9			10
Other specified official or voluntary service 2			1
Inadequate to some .....y			5
None of these 0			101
Inadequate X			34
	R		3
Type of help respondent tried to arrange - 1			Col.53
District nursing 1			—
Health visiting 2			—
Private nurse 3			1
Home help 4	may be multi-coded		6
Special laundry service 5			—
Chiropody 6			2
Vicar,priest,minister 7			1
Inadequate to some 9			—
None of these 0			39
Inadequate X			4
D.N.A. (code 0 at col51).....y			143
	R		3

Type of help respondent tried to arrange - 11 **Col.54**

Meals on wheels 1		3
Free supply of incontinence pads....3		—
Service for disposal of " " 4		1
Bathing service 5		1
Supply of sickroom equipment.....6	may be multi-coded	—
Night nursing service 7		1
" sitting " 8		2
Geriatric social worker 9		—
Other specified official or voluntary service 2		—
Inadequate to some .....y		1
None of these(incl. D.N.A. code 0 at col.52).....0		184
Inadequate X		5
R		3

Q. 25 Is there anything that would have made ——'s care easier for you **Col.55**

Yes.....1	51
No.....2	133
Don't know 3	—
Inadequate X	11
R	3

(check with Q.24 and bring forward any further need)

Single coded

Q. 26 Would you say that ——'s home was very convenient etc. for him after he became ill/old **Col.56**

Very convenient.....1	114
Fairly " 2	48
Rather inconvenient 3	28
Inadequate X	5
R	3

Single coded

Q. 27 Where did you get the medical information you had about —— and his treatment **Col.57**

G.P. 1		165
Hospital 2	may be multi-coded	9
Other 3		16
Inadequate X		7
None 0		9
R		3

Q. 28 & 31 Did you feel you had adequate medical information about —— or would it have been helpful if you had had more information about —— and his treatment. **Col.58**

Adequate information 5		158
Uncertain, qualified 0		1
Inadequate X		9
Helpful to have had more from:		
G.P. 1		24
Hospital 2	may be multi-coded	7
Other specified 3		—
Inadequate where 4		—
R		3.

Q. 32 Did you try to get any more medical information about —— **Col.59**

No 2	12
Yes, but didn't get any more.....3	3
" got more 4	6
" inad. if got more 5	6
Inad. if tried or not X	—
D.N.A. (codes 5,0,X at col.58)...y	168
Single coded R	3

Q. 33 Household composition **Col.60**

Lived alone 1	20
With spouse only 2	64
" " and children only.....3	22
" " " " and children in law, without or with grandchildren 4	4
With children only 5	21
" " and children in law, with or without grandchildren..6	20
With other relatives of same generation only 7	18
With other unrelated people 8	5
Other 3 generation household.....9	5
Guest house (O.P. home or no or inad. information about where living) .....y	3
Others 0	12
Don't know X	1
Single coded R	3.

c) Who normally did the cooking and other housework **Col.61**

D.N.A. (lived alone or inad. who lived with 1 or X or y at Col.60)...y	24
Deceased 1	8
Other person in same household...2	142
Deceased and other person in same household 3	5
Other(s).....4	18
Inadequate X	8
Home help | Paid help 5	27
~~Single coded~~ multi- accept y + X.	
R	3

Q. 34 Did you visit ——'s home after the death at all — Col.62

No	4	105
Inadequate	X	2
Yes, in a professional capacity	5	75
Yes, not in " "	6	6
Yes, inad. if in " "	9	8
	R	2

Q. 35 Why did you visit them — Col.63

Did not know of death	1	15
To collect records	2	9
To collect equipment	3	32
To lay out body	4	3
To support bereaved	5	37
To give care to other member of the family/household	6	10
Other	0	6
Inadequate	X	–
D.N.A. (codes 4,6,X, or 9 at col.62)	y	113
If code (6), care to other member of family: Overcode if care started before —— died	9	5
	R	2

may be multi coded.

Q. 36 Did you have any professional contact with bereaved — Col.64

No (incl. D.N.A. code 1,2,3, or 4 only at col.63)	0	149
Inadequate	X	22
Yes, relationship to deceased:		
C spouse	1	14
father/mother	2	–
son/daughter	3	5
son in law/daughter in law	4	1
grandchild	5	–
brother/sister (in law)	6	7
other relative	7	2
friend, neighbour	8	–
other person	9	–
don		

Q. 38 Over what period — Col.65

D.N.A. (code 0 or X at col.64)	y	171
Inadequate	X	12
Less than a week	1	2
1 week - 1 month	2	5
1 month - 3 months	3	4
3 months or more	4	4
Overcode if currently attending	0	3
Single coded		

Q. 40 Were you attached to the deceased's G.P. while you were looking after him — Col.66

Yes.....3	76	Partial attachment ... 5 . 5
No 4	116	
Inadequate X	1	

Single coded

Q. 41 In what capacity did you visit —— and/or the bereaved — Col.67

D.N. 1		181
H.V. 2		17
Midwife 3	may be multi-coded	1
Combined worker 4		1
Other 5		—
Inadequate X		—

C

HEALTH VISITORS AND DISTRICT NURSES (B)

Y34

SN 3930 Life Before Death: Health Visitors + District Nurses (B)

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case number	4 digit code	
1/5-6		Card number	01 Card 1	583
1/7-10		Serial number	4 digit code (See attached list)	
1/11	1	Did you have any part in the care of patients with terminal illness in the past 12 months. IF NO Did you have any part in the care of bereaved in the last 12 months	1 Yes to 1st part 2 No to 1st part Yes to 2nd part 3 No to 1st part Inadequate answer to 2nd part 4 Inadequate answer	553 29 1 -
1/12	2	A general practitioner in our pilot study said that: 'No anticipated deaths should be allowed to happen at home'. Do you agree or disagree with this	1 Agree 2 Disagree 3 Inadequate answer	25 557 1
1/13	3	On the whole do you find in this area that most relatives accept the reasonable responsibilities for home care or do they seek admission to hospital or institution or could you say this was equally balanced	1 Most accept responsibility 2 Most seek admission 3 Equally balanced 4 Inadequate answer	186 58 326 13

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/14-23	4-13	Which if any of these things do you think prevent more people being looked after in the community rather than in hospital		
1/14	4	Unsuitable housing	1 Yes 0 Not mentioned	354 229
1/15	5	Unwillingness of relatives to look after them	1 Yes 0 Not mentioned	498 85
1/16	6	Absence of suitable relatives	1 Yes 0 Not mentioned	545 38
1/17	7	Inadequate home nursing service	1 Yes 0 Not mentioned	134 449
1/18	8	Inadequate other supporting services	1 Yes 0 Not mentioned	266 317
1/19	9	Tendancy of hospital to admit unnecessarily	1 Yes 0 Not mentioned	42 541
1/20	10	Tendancy not to discharge people when reasonable	1 Yes 0 Not mentioned	87 496
1/21	11	Overwork of general practitioner	1 Yes 0 Not mentioned	163 420
1/22	12	None of these	1 Yes 0 Not mentioned	3 580
1/23	13	Inadequate answer	1 Yes 0 Not mentioned	1 582
1/24-33	14-23	Which contributes most		
1/24	14	Unsuitable housing	1 Yes 0 Not mentioned	68 515

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/25	15	Unwillingness of relatives to look after them	1 Yes 0 Not mentioned	186 397
1/26	16	Absence of suitable relatives	1 Yes 0 Not mentioned	255 328
1/27	17	Inadequate home nursing service	1 Yes 0 Not mentioned	18 565
1/28	18	Inadequate other supporting services	1 Yes 0 Not mentioned	41 542
1/29	19	Tendancy of hospital to admit unnecessarily	1 Yes 0 Not mentioned	1 582
1/30	20	Tendancy not to discharge people when reasonable	1 Yes 0 Not mentioned	4 579
1/31	21	Overwork of general practitioner	1 Yes 0 Not mentioned	12 571
1/32	22	None of these	1 Yes 0 Not mentioned	- 583
1/33	23	Inadequate answer	1 Yes 0 Not mentioned	8 575
1/34-43	24-33	Which next most		
1/34	24	Unsuitable housing	1 Yes 0 Not mentioned	102 481
1/35	25	Unwillingness of relatives to look after them	1 Yes 0 Not mentioned	173 410
1/36	26	Absence of suitable relatives	1 Yes 0 Not mentioned	168 415

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/37	27	Inadequate home nursing service	1 Yes 0 Not mentioned	18 565
1/38	28	Inadequate other supporting services	1 Yes 0 Not mentioned	69 514
1/39	29	Tendancy of hospital to admit unnecessarily	1 Yes 0 Not mentioned	3 580
1/40	30	Tendancy not to discharge people when reasonable	1 Yes 0 Not mentioned	10 573
1/41	31	Overwork of general practitioner	1 Yes 0 Not mentioned	18 565
1/42	32	None of these	1 Yes 0 Not mentioned	- 583
1/43	33	Inadequate answer	1 Yes 0 Not mentioned	11 572
1/44-53	34-43	(a) Here is a list of services which are available through the local authority or voluntary organisations in some areas. (b) Which ones you have made use of (c) Which ones you would like extended or introduced		
1/44	34	Meals on wheels	1 Yes available, yes used, yes, like extended/introduced 2 Yes available, yes used, No extended/introduced 3 Yes available, No used, yes like extended/introduced 4 Yes available, No used, No like extended/introduced	336 168 13 13

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/44	34	Continued	5 No available, yes like extended/ introduced	12
			6 No available, No like extended/ introduced	3
			7 Inadequate	9
			8 D.N.A.	29
1/45	35	Special laundry service	1 Yes available, yes used, yes like extended/introduced	57
			2 Yes available, yes used, No like extended/introduced	242
			3 Yes available, No used, Yes like extended/introduced	5
			4 Yes available, No used, No like extended/introduced	12
			5 No available, yes like extended/ introduced	172
			6 No available, no like extended/ introduced	54
			7 Inadequate	12
			8 D.N.A.	29
1/46	36	Free supply of incontinence pads	1 Yes available, yes used, yes like extended/introduced	71
			2 Yes available, yes used, No like extended/introduced	394
			3 Yes available, No used, yes like extended/introduced	1
			4 Yes available, No used, No extended/ introduced	13
			5 No available, yes, like extended/ introduced	4
			6 No available, No like extended/ introduced	-
			7 Inadequate	10
			8 D.N.A.	29
			0 Blank	61

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/47	37	Incontinence pads (Birmingham) service not free, or not entirely free	1 Yes used, yes like extended/introduced	10
			2 Yes used, No like extended/introduced	39
			3 No used, Yes like extended/introduced	10
			4 No used, no like extended/introduced	2
			0 Blank	522
1/48	38	Service for disposing of incontinence pads	1 Yes available, yes used, yes like extended/introduced	27
			2 Yes available, yes used, No like extended/introduced	237
			3 Yes available, No used, yes like extended/introduced	9
			4 Yes available, No used, No like extended/introduced	34
			5 No available, yes like extended/ introduced	116
			6 No available, No like extended/ introduced	111
			7 Inadequate	20
			8 D.N.A.	29
1/49	39	Bathing service	1 Yes available, yes used, yes like extended/introduced	171
			2 Yes available, yes used, No like extended/introduced	133
			3 Yes available, No used, yes like extended/introduced	6
			4 Yes available, No used, No extended/ introduced	12
			5 No available, yes like extended/ introduced	168
			6 No available, No like extended/ introduced	53

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/49	39	Continued	7 Inadequate	11
			8 D.N.A.	29
1/50	40	Supply of sick room equipment	1 Yes available, yes used, yes like extended/introduced	80
			2 Yes available, yes used, No like extended/introduced	447
			3 Yes available, No used, yes like extended/introduced	7
			4 Yes available, No used, No like extended/introduced	10
			5 No available, yes like extended/introduced	-
			6 No available, No like extended/introduced	1
			7 Inadequate	9
			8 D.N.A.	29
1/51	41	Night nursing service	1 Yes available, yes used, yes like extended/introduced	125
			2 Yes available, yes used, No like extended/introduced	158
			3 Yes available, No used, yes like extended/introduced	33
			4 Yes available, No used, No like extended/introduced	35
			5 No available, yes like extended/introduced	137
			6 No available, no like extended/introduced	54
			7 Inadequate	12
			8 D.N.A.	29

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/52	42	Night sitting service	1 Yes available, yes used, yes like extended/introduced	183
			2 Yes available, yes used, No like extended/introduced	123
			3 Yes available, No used, yes like extended/introduced	31
			4 Yes available, No used, No like extended/introduced	33
			5 No available, yes like extended/introduced	128
			6 No available, No like extended/introduced	41
			7 Inadequate	15
			8 D.N.A.	29
1/53	43	Geriatric social worker	1 Yes available, yes used, yes like extended/introduced	53
			2 Yes available, yes used, No like extended/introduced	273

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/53	43	Continued	3 Yes available, No used, yes like extended/introduced	17
			4 Yes available, No used, No like extended/introduced	70
			5 No available, yes like extended/introduced	66
			6 No available, No like extended/introduced	50
			7 Inadequate	25
			8 D.N.A.	29
1/54-64	44-54	Who runs night nursing and/or night sitting service		
		NIGHT NURSING		
1/54	44	Local authority	1 Yes	236
			0 Not mentioned	347
1/55	45	Marie Curie	1 Yes	261
			0 Not mentioned	322
1/56	46	Other	1 Yes	13
			0 Not mentioned	570
1/57	47	Inadequate	1 Yes	6
			0 Not mentioned	577
1/58	48	Don't know	1 Yes	6
			0 Not mentioned	577
		NIGHT SITTING		
1/59	49	Local authority	1 Yes	289
			0 Not mentioned	294
1/60	50	Marie Curie	1 Yes	179
			0 Not mentioned	404
1/61	51	Other	1 Yes	21
			0 Not mentioned	562
1/62	52	Inadequate	1 Yes	3
			0 Not mentioned	580

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/63	53	Don't know	1 Yes 0 Not mentioned	12 571
1/64	54	D.N.A.	1 Yes 0 Not mentioned	152 431
1/65	55	Is there any other home service for the terminally ill in your area. IF YES Have you used it	1 No other service 2 Yes other service(s) used 3 Yes other service(s) not used 4 Yes other service(s) inadequate if used 5 Yes other services - some used some not 6 Inadequate if other service 7 D.N.A.	354 146 38 4 - 12 29
1/66	56	Are there any (other) changes you would like to see in any of the services we have mentioned	1 Yes 2 No 3 Inadequate 4 D.N.A.	172 361 21 29
1/67	57	Is there any other service you feel would be helpful in the care of terminally ill patients	1 Yes 2 No 3 Inadequate 4 D.N.A.	220 320 14 29
1/68	58	On the whole do you find that for patients with terminal illness general practitioners ask for district nursing help earlier than necessary, not early enough or about the right time	1 Earlier than necessary 2 Not early enough 3 About the right time 4 Inadequate 5 Qualified answer 6 D.N.A.	19 84 379 23 49 29

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/69	59	On the whole do you feel you are able to give enough time to patients in terminal illness, or would you like to be able to give more time to them	1 Give enough time 2 Like more time 3 Inadequate 4 Qualified answer 5 D.N.A.	194 342 12 6 29
1/70	60	IF LIKE MORE TIME (2)	1 Just to chat - or less rush 2 Additional nursing care 3 Both (1 and 2) 4 Inadequate which 0 Blank	164 72 74 32 241
1/71	61	Have you had any patients or families who have been reluctant or unwilling to accept district nursing care in the last six months	1 Yes 2 No 3 Inadequate	114 466 3
1/72	62	Do you think that health visitors have a part to play in terminal home care	1 Yes 2 No 3 Qualified answer 4 Inadequate	339 212 15 17
1/73	63	For patients in terminal illness would you describe the district nursing service in your area as:-	1 Adequate 2 Rather inadequate 3 Very inadequate 4 Qualified answer 5 Inadequate answer	451 107 11 8 6

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/74	64	Would you describe the home help service in your area as:-	1 Adequate 2 Rather inadequate 3 Very inadequate 4 Qualified answer 5 Inadequate answer	119 322 133 5 4
1/75-80 to 2/7	65-70 to 71	As a general rule if a dying patient asked you about his prognosis which of the following would you do:-		
1/75	65	Change subject	1 Yes 0 Not mentioned	50 533
1/76	66	Tell him to ask the doctor	1 Yes 0 Not mentioned	179 404
1/77	67	Tell him the truth gently	1 Yes 0 Not mentioned	37 546
1/78	68	Give him hope	1 Yes 0 Not mentioned	323 260
1/79	69	If two answers code both and overcode	1 Yes 0 Not mentioned	75 508
1/80	70	Qualified answer no code rung or more than two rung	1 Yes 0 Not mentioned	67 516
2/1-4		Case number	4 digit code	
2/5-6		Card number	02 Card 2	583
2/7	71	Continued from card 1		
2/7	71	Inadequate answer	1 Yes 0 Not mentioned	2 581

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/8-16	72-80	If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell them:-		
2/8	72	His own doctor	1 Yes 0 Not mentioned	455 128
2/9	73	Another doctor	1 Yes 0 Not mentioned	12 571
2/10	74	A vicar, priest, minister	1 Yes 0 Not mentioned	86 497
2/11	75	Spouse	1 Yes 0 Not mentioned	70 513
2/12	76	Other close relative	1 Yes 0 Not mentioned	22 561
2/13	77	A nurse	1 Yes 0 Not mentioned	13 570
2/14	78	Other	1 Yes 0 Not mentioned	5 578
2/15	79	Qualified answer	1 Yes 0 Not mentioned	97 486
2/16	80	Inadequate answer	1 Yes 0 Not mentioned	6 577
2/17	81	On referral of patients for district nursing care would you, in general, describe the information you get as:-	1 Adequate 2 Rather inadequate 3 Very inadequate 4 Inadequate answer 5 Qualified answer 6 D.N.A.	213 195 75 10 32 58
2/18	82	In caring for patients in terminal illness do you feel contact with the general pratitioner is generally:-	1 Adequate 2 Rather inadequate 3 Very inadequate 4 Inadequate answer 5 D.N.A. 6 Qualified answer	430 78 11 16 29 19

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CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/19	83	In caring for patients in terminal illness do you feel contact with the hospital is generally:-	1 Adequate	172
			2 Rather inadequate	180
			3 Very inadequate	121
			4 Inadequate answer	23
			5 No contact	57
			6 D.N.A.	29
			7 Qualified answer	1
2/20	84	Do you think that close bereaved should be given some medical or nursing supervision for a while	1 Yes, medical supervision	207
			2 Yes, nursing supervision	134
			3 No	73
			4 Both medical and nursing	103
			5 Qualified answer	59
			6 Inadequate	7
2/21	85	In our pilot study opinions of health visitors and district nurses were divided about who should provide nursing supervision or support for the bereaved. Do you think the most appropriate person is the health visitor or the district nurse	1 Health visitor	207
			2 District nurse	252
			3 Inadequate	4
			4 Qualified answer joint responsibility	120
2/22-26	86-90	Are you working as		
2/22	86	District nurse	1 Yes	508
			0 Not mentioned	75
2/23	87	Health visitor	1 Yes	76
			0 Not mentioned	507
2/24	88	Midwife	1 Yes	40
			0 Not mentioned	543

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/25	89	Combined worker	1 Yes 0 Not mentioned	41 542
2/26	90	Inadequate	1 Yes 0 Not mentioned	- 583
2/27	91	Are you attached to a general medical practice	1 Yes 2 No 3 Inadequate	314 269 -
2/28	92	Do you work:-	1 Full-time 2 Part-time 3 Inadequate	518 65 -
2/29-34	93-98	Do you do any night duties i.e. duties between 8 p.m. and 8 a.m.		
2/29	93	No	1 Yes 0 Not mentioned	200 383
2/30	94	Late duty shift	1 Yes 0 Not mentioned	230 353
2/31	95	Night call	1 Yes 0 Not mentioned	149 434
2/32	96	Full night duty	1 Yes 0 Not mentioned	8 575
2/33	97	Inadequate which	1 Yes 0 Not mentioned	6 577
2/34	98	Inadequate whether any	1 Yes 0 Not mentioned	2 581
2/35	99	Number of nights a week does late night duty	0 None (but does some of that call or duty) 1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Inadequate how often but does some	90 121 7 1 1 2 - - 8

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/35	99	Continued	9 D.N.A. does not do that type of duty or unknown if does that type of duty	353
2/36	100	Number of nights a week does night call	0 None (but does some of that call or duty)	78
			1 One	32
			2 Two	7
			3 Three	-
			4 Four	-
			5 Five	4
			6 Six	1
			7 Seven	-
			8 Inadequate how often, but does some	27
			9 D.N.A. does not do that type of duty or unknown if does that type of duty	434
2/37	101	Number of nights a week does full night duty	0 None (but does some of that call or duty)	5
			1 One	1
			2 Two	-
			3 Three	-
			4 Four	-
			5 Five	1
			6 Six	-
			7 Seven	-
			8 Inadequate how often, but does some	1
			9 D.N.A. does not do that type of duty or unknown if does that type of duty	575
2/38	102	Age	1 Under 25	25
			2 25-34	143
			3 35-44	168
			4 45-54	170
			5 55-64	74
			6 65 or more	2
			7 Inadequate	1

SN 3930

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/39	103	Marital status	1 Married 2 Single 3 Divorced/separated/ widowed 4 Inadequate	384 152 46 1
2/40	104	Sex	1 Male 2 Female 3 Inadequate	31 550 2
2/41	105	Would you like to be informed of the results of this study	1 Yes 2 No 0 Blank (undefined code on original data)	579 3 1
2/42	106	Length of interview	1 Less than 15 mins 2 15-30 mins 3 30-45 mins 4 45-60 mins 5 60+ 6 Inadequate	14 304 160 56 47 2
2/43	107	Month of interview	7 July) 8 August) 9 September) 0 October) 1969 - November) & December) 1 January) 2 February) 1970 3 Undefined code	30 121 63 67 154 144 - - 4
2/44	108	Interviewer	0 Lisbeth 1 Wyn 2 John 3 Kathleen 4 Stella 5 Angela 6 Ann Griffiths 7 Margo 8 Beryl	132 105 108 17 30 22 80 82 7
2/45	109	Interview	0 Questionnaire B only 1 One questionnaire A 2 Two questionnaires A 3 Three or more questionnaires A 4 Blank (undefined codes on original data)	459 84 26 5 9

SN 3930

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/46-80		Unused		

SN: 393C

H.U./D.N. 4th DIGIT OF SERIAL NUMBER

BIRMINGHAM SUB-DISTRICTS:-

1	ASTON
2	BARDESLEY
3	CENTRAL
4	HALL GREEN
5	KINGSTANDING
6	SELLY OAK
7	WASHWOOD HEATH
8	YARDLY
X	HEALTH VISITOR
0	D.N.A. - ALL AREAS OTHER THAN BIRMINGHAM (Qr. B's)

SN: 3930

Survey of Care before Death: Classification of causes of death

Code		ICD 1966 no.
00	Infective and parasitic	000-136
	Neoplasms	
10	Malignant neoplasm, stomach	151
11	" " bronchus and lung	162.1
12	" " breast	174
13	" " uterus	180-182
14	" " prostate	185
15	Leukaemia and alcuhaemia	204-207
16	Other neoplasm of specified site	Rest 140-238 excluding 199 & 228
17	Neoplasm of unspecified site	199, 228, 239
01	Endocrine, Nutritional and Metabolic	240-279
02	Blood and blood forming organs	280-289
03	Mental disorders	290-315
04	Nervous system and sense organs	320-389
	Circulatory	
20	Hypertensive	400-404
21	Ischaemic heart disease	410-414
22	Rheumatic fever and other heart disease	390-398, 420-429
23	Cerebrovascular disease	430-438
24	Diseases of the arteries	440-448
25	Other	450-458
	Respiratory	
30	Pneumonia	480-486
31	Bronchitis	490-493
32	Other	460-474, 500-519
60	Digestive	520-577
06	Genito urinary	580-629
07	Complications of pregnancy etc.	630-678
08	Skin	680-709
09	Musculoskeletal and Connective	710-738
0Y	Congenital and perinatal	740-779
40	Symptoms	780-796
	Accidents	
50	Transport	E800-E845
51	Suicide or self inflicted injury	E950-E959
52	Other	E850-E949, E960-E999
XX	Inadequate	

SN: 393C

Home Care for Dying H.V./D.N. Qu. B

Serial number - 1st digit - Area Col. 7

Barking	1
Teeside	2
Hillingdon	3
Cheshire (NE)	4
Brentwood	5
Bridgend	6
Northumberland	7
Eastbourne	8
Birmingham	9
Thanet	0
St. Helens	X
Isle of Wight	Y

2nd digit Col. 8

3rd digit Col. 9

393C

Y34

Medical Care Research Unit,
Institute of Community Studies,
18 Victoria Park Square,
London, E.2.

WORKER

PROBLEMS OF DOMICILIARY CARE IN TERMINAL ILLNESS

QUESTIONNAIRE B. - GENERAL

INTRODUCTION: You may have heard about the study we are doing from the Medical Care Research Unit of the Institute of Community Studies. We are doing it in twelve randomly chosen areas in England and Wales to find out about the care given in people's homes to those who are dying. We plan to write a book about it but no names will be mentioned and it will not be possible to identify anyone, nor of course, will anything you tell us be passed on to anyone outside our Unit, which is a small independent research unit, interested in the social aspects of medical care. There are two questionnaires. The first one is about specific people in our sample of deaths : the second briefer one asks for general comments and your views about home care and bereavement. We would be grateful for your help with both of these. As it happens none of the people in our sample seem to have been looked after by you but we would be grateful for your help by giving us your general comment and views.

1. Did you have any part in the care of patients with terminal illness in the last 12 months?

Yes.....1
No.....2

IF NO (2) Did you have any part in the care of bereaved in the last 12 months?

Yes.....3
No.....4

IF YES (3) CONTINUE OMITTING QUESTION MARKED X

IF NO (4) We have to restrict our study to workers who have been involved in terminal care or care of the bereaved in the last 12 months. So, I am very sorry we have troubled you.
THANK RESPONDENT FOR HELP AND LEAVE LEAFLET

2. A general practitioner in our pilot study said that: 'no anticipated deaths should be allowed to happen at home'. Do you agree or disagree with this?

Agree.....1
Disagree.....2

Why do you think that?

3. On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution or could you say this was equally balanced?

Most accept responsibility.....5
Most seek admission.....6
Equally balanced.....7

COMMENTS

4. Which if any of these things do you think prevent more people being looked after in the community rather than in hospital:

PROMPT	Any effect Yes	Any effect No	Most	Next most
Unsuitable housing	1	0	1	1
Unwillingness of relatives to look after them	2	0	2	2
Absence of suitable relatives	3	0	3	3
Inadequate home nursing services	4	0	4	4
Inadequate other supporting services	5	0	5	5
Tendency of hospital doctors to admit unnecessarily	6	0	6	6
Tendency not to discharge people when reasonable	7	0	7	7
Overwork of general practitioners.	8	0	8	8

5. Which contributes most? Which next most? } CODE ABOVE

X

6. Here is a list of services which are available through the Local Authority or voluntary organisations in some areas.
Can you tell me first a) Which are available in your areas:-
b) Which ones you have made use of
c) Which ones you would like extended or introduced

	a)Available	b)Used	c)Like extended or introduced
Meals on wheels	1	1	1
Special laundry service	2	2	2
Free supply of incontinence pads	3	3	3
Service for disposing of incontinence pads	4	4	4
Bathing service	5	5	5
Supply of sickroom equipment	6	6	6
Night nursing service	7	7	7
Night sitting service	8	8	8
Geriatric social worker	9	9	9

IF NIGHT NURSING OR NIGHT SITTING SERVICE AVAILABLE
Who runs this?

	Night nursing	Night sitting
Local Authority	1	4
Marie Curie	2	5
Other (SPECIFY)	3	6

X

7. Is there any other home service for the terminally ill in your area?

Yes.....5
No.....6

IF YES (5) (i) What?

(ii) Have you used it?

Yes.....7
No.....8

X.

8. Are there any (other) changes you would like to see in any of the services we have mentioned?

Yes.....1
No.....2

IF YES (1) What are they?

X.

9. Is there any other service you feel would be helpful in the care of terminally ill patients?

Yes.....3
No.....4

IF YES (3) What are they?

X

10. On the whole do you find that for patients with terminal illness general practitioners ask for district nursing help earlier than necessary, not early enough or about the right time?

Earlier than necessary.....5
Not early enough.....6
About the right time.....7

Could you give an example?

IF EARLIER THAN NECESSARY (5) OR NOT EARLY ENOUGH (6)
Why do you think they do that?

X

11. On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them?

Give enough time.....1
Like more time.....2

IF LIKE MORE TIME(2) What sorts of things would you like more time for?

12. Have you had any patients or families who have been reluctant or unwilling to accept district nursing care in the last six months?

Yes.....1
No.....2

IF YES (1) What were the reasons?

13. Do you think that health visitors have a part to play in terminal home care?

Yes.....3
No.....4

Why do you say that?

14. For patients in terminal illness would you describe the district nursing service in you area as:-

Adequate.....1
PROMPT Rather inadequate....2
Very inadequate.....3

COMMENTS

15. Would you describe the home help service in you area as:-

Adequate.....6
PROMPT Rather inadequate...7
Very inadequate.....8

COMMENTS

16. As a general rule if a dying patient asked you about his prognosis which of the following would you do:-

Change subject.....1
Tell him to ask the doctor.....2
PROMPT Tell him the truth gently.....3
Give him hope.....4

17. If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him:-

His own doctor.....1
Another doctor.....2
A vicar, priest, minister.....3
Spouse.....4
Other close relative.....5
A nurse.....6
Or who? SPECIFY

X

18. On referral of patients for district nursing care would you, in general, describe the information you get as:-

Adequate.....1
Rather inadequate...2
Very inadequate.....3

IF 2 OR 3 What sort of things would you generally like to have more information about?

X

19. In caring for patients in terminal illness do you feel contact with the general practitioner is generally:-

Adequate.....4
Rather inadequate...5
Very inadequate.....6

COMMENTS

X.

20. In caring for patient in terminal illness do you feel contact with the hospital is generally:-

Adequate.....1
Rather inadequate...2
Very inadequate.....3

COMMENTS

21. Do you think that close bereaved should be given some medical or nursing supervision for a while?

Yes, medical supervision.....4
Yes, nursing supervision.....5
No.....6

IF YES (4 or 5) For how long?

COMMENTS

22. In our pilot study opinions of health visitors and district nurses were divided about who should provide nursing supervision or support for the bereaved. Do you think the most appropriate person is the health visitor or the district nurse?

Health visitor.....1
District nurse.....2

COMMENTS

23. Are you working as:-

District nurse.....1
Health visitor.....2
Midwife.....3
Combined worker.....4

IF COMBINED WORKER (4) CODE ALL THAT APPLY AS WELL AS (4)

24. Are you attached to a general medical practice?

Yes.....5
No.....6

25. Do you work:-

Full time.....7
or Part time.....8

26. Do you do any night duties, i.e. duties between 8 p.m. and 8 a.m ?

Yes.....3
No.....4

IF YES (3) (i) Is this a:-

Late duty shift.....5
PROMPT Night call.....6
Full night duty.....7

(ii) How many nights a week do you do this?

IF LESS THAN ONCE A WEEK CODE 0

Late duty shift	0	1	2	3	4	5	6	7
Night call	0	1	2	3	4	5	6	7
Full night duty	0	1	2	3	4	5	6	7

IF 0 SPECIFY

COMMENTS OR COMPLICATIONS

27. We don't mention any names in our report but we like to know the age structure and marital state of the workers who provide the services. So we need to ask them individually.

Do you mind telling me you age?

Under 25.....1
25 - 34.....2
35 - 44.....3
45 - 54.....4
55 - 64.....5
65 or more.....6

28. Are you:-

Married.....1
Single.....2
Divorced/separated.....3

29. CHECK SEX

Male.....4
Female.....5

30. Are there any questions you would like to ask me about the Institute of Community Studies or the survey?

31. Would you like to be informed of the results of this study?

Yes.....1
No.....2

THANK RESPONDENT AND LEAVE NOTE

(i) Length of interview

Less than 15 mins...1
15 < 30.....2
30 < 45..... 3
45 < 60.....4
60 + ...5

(ii) Date of interview:

(iii) Interviewer.

(iv) Interview on:

Questionnaire B only.....0
One questionnaire A.....1
Two " A.....2
Three or more " A.....3

H.V. and D.N. Questionnaire B - General.

1, 2, 3 } Serial Numbers.

4 Care of terminal patients / bereaved.
5 Anticipated deaths allowed at home.
6 Responsibility for care - relatives or institutions
7 What prevents care in community
8 Most important factor.
9 Next most important.
10 Meals on wheels
11 Special laundry service
12 Free supply of incontinence pads
13 Service for disposal of " "
14 Bathing service
15 Supply of sickroom equipment
16 Night nursing service
17 Night sitting service
18 Geriatric social worker

} Available / used / like extended.

19 Who runs night nursing / sitting service.
20 Any other home services available / used in area.
21 Changes in any of above services
22 Any other service which would be helpful
23 Do G.P.'s ask for D.N. help for patients at night time
24 Enough / like more time to give to terminal patients
25 Reluctant or unwilling patients
26 D. H.V. have part to play in
27 D.N. service adequate for terminal patients
28 Adequacy of Home Help service
29 Answer to question about Pregnancies
30 Best person to tell patient he's unlikely to recover.
31 Adequacy of information on referral of patient.
32 Adequacy of contact with G.P
33 " " " Hospital
34 Medical or nursing supervision for close bereaved.
35 Most appropriate person to provide support for bereaved.
36 Working as: D.N., H.V., M.W., Combined.
37 Attachment to General Medical Practice.
38 Work Full or Part-time.
39 Night duties (between 8 PM & 8 am).

40 No. of nights on Late Night Duty
41 " " " " Night Call.
42 " " " " Full Night Duty
43 Age
44 Marital Status
45 Sex
46 Wants Results
47 Length of Interview
48 Month
49 Interviewer
50 Type of Interview
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77
78
79 Birmingham H.V./D.N.
80 Card Identification — y 34

Question 1: Did you have any part in the care of patients with terminal illness in the last 12 months? Col.4.

IF NO Did you have any part in the care of bereaved in the last 12 months?

Yes to 1st. part.....1
No " " " Yes to 2nd part.....3
No " " " No to 2nd part.....2
Inadequate answer.....X

Single coded. N.B. If answer is no to both first and 2nd parts then person should be omitted and no transfer sheet made out.

Question 2: A general practitioner in our pilot study said that: 'no anticipated deaths should be allowed to happen at home'. Do you agree or disagree with this? Col.5

Agree.....1
Disagree.....2
Inadequate answer.....X

Single coded. . . . If person says 'it depends' this should normally be counted as disagreement.

Question 3: On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution or could you say this was equally balanced? Col.6

Most accept responsibility....5
Most seek admission.....6
Equally balanced.....7
Inadequate answer.....X

Single coded.

Question 4: Which if any of these things do you think prevent more people being looked after in the community rather than in hospital: Col.7.

Unsuitable housing.....1
Unwillingness of relatives to look after them.....2
Absence of suitable relatives.....3
Inadequate home nursing services.....4
Inadequate other supporting services.....5
Tendency of hospital to admit unnecessarily...6
Tendency not to discharge people when reasonable.....7
Overwork of general practitioners.....8

None of these.....0

Inadequate answer.....X

May be multi-coded - except for 0 and X.

Question 5 (i) Which contributes most? Col.8.

(ii) Which next most? Col.9.

Codes 1 - 8 as above

P.N.A. None of these (or one only)..... 9
Inadequate answer (or more than two indicated.....X

Single coded but if two tied equally code both and overcode Y N.B. If two tied for most or next most the codes will be the same in cols. 8 & 9.

Question 6: Here is a list of services which are available through the Local Authority or voluntary organisations in some areas.
Can you tell me first a) which are available in your areas:-
b) which ones you have made use of
c) which ones you would like extended or introduced

Meals on wheels Col.10
Special laundry service..... 11
Free supply of incontinence pads..... 12
Service for disposing of " " 13
Bathing service..... 14
Supply of sickroom equipment..... 15
Night nursing service..... 16
Night sitting service..... 17
Geriatric social worker..... 18

Available	Used	Like extended/introduced	
Yes	Yes	Yes	1
Yes	Yes	No	2
Yes	No	Yes	3
Yes	No	No	4
No	-	Yes	5
No	-	No	6
Inadequate			X
Blank code 3. col. 4			9

Can be coded		Used	Like extended/introduced	
Incontinence pads (Bham)	Service not free	Yes	Yes	7
	and extends free	Yes	No	8
		No	Yes	9
		No	No	0

Question 6 Who runs night nursing and/or night sitting service? Col.19

Night nursing

Local authority.....1
Marie Curie.....2
Other.....3
Inadequate.....X
Don't know.....7

Night sitting

Local authority.....4
Marie Curie.....5
Other.....6
Inadequate.....Y
Don't know.....8

D.N.A. (5,6,X or Y in both cols 16 & 17)....9

Single or double coded if multi-coded if more than one org. runs service

Question 7 Is there any other home service for the terminally ill in your area? IF YES Have you used it? Col.20

No other service.....6
Yes other service(s) used.....7
" " " not used 8
" " " inad.if us.....1
" " services - some used some not..2
Inadequate if other service.....X
D.N.A. code 3 col. 4.....9

Single coded

Question 8 Are there any (other) changes you would like to see in any of the services we have mentioned? Col.21.

Yes.....1
No.....2
Inadequate.....X
D.N.A. code 3 col.4.....9

Single coded

Question9 Is there any other service you feel would be helpful in the care of terminally ill patients? Col.22.

Yes.....3
No.....4
Inadequate.....X
D.N.A. code 3 col.4.....9

Single coded

Question 10 On ther whole do you find that for patients with terminal illness general practitioners ask for district nursing help earlier than necessary, not early enough or about the right time? Col.23.

Earlier than necessary.....5
Not early enough.....6
About the right time.....7
Inadequate.....X
Qualified answer.....Y
D.N.A. code 3 col.4.....9

Single coded

uestion 11 On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them? Col.24.

Give enough time.....1
Like more time.....2
Inadequate.....X
Qualified answer.....Y
D.N.A. code 3 col.4.....9

IF Like MORE TIME (2) Overcode

Just to chat - or less rush.....3 Time for talking
Additional nursing care.....4 getting to know
Both (3 & 4).....5 the family (3)
Inadequate which.....6

Double coded if 2 coded in first part
Otherwise single coded.

Question 12 — Have you had any patients or families who have been reluctant or unwilling to accept district nursing care in the last six months? — Col.25

Yes.....1
No.....2
Inadequate.....X

Single coded..

Question 13 — Do you think that health visitors have a part to play in terminal home care? — Col.26.

Yes.....3
No.....4
Qualified answer.....Y
Inadequate.....X

Single coded
N.B. Use Y normally only if no code rung

Question 14 — For patients in terminal illness would you described the district nursing service in your area as:- — Col.27.

Adequate.....1
Rather inadequate.....2
Very inadequate.....3
Qualified answer.....Y
Inadequate answer.....X

Singlde coded
N.B. use Y normally only if no code rung or more than one code rung

Question 15 — Would you describe the home hol, service in your area as:- — Col.28

Adequate 6
Rather inadequate.....7
Very inadequate.....8
Qualified answer.....Y
Inadequate answer.....X

Single coded

Question 16 — As a general rule if a dying patient asked you about his prognosis which of the following would you do:- — Col.29.

Change subject.....1
Tell him to ask the doctor..2
Tell him the truth gently...3
Give him hope.....4
If two answers code both answer code.....Y

Qualified answer - no code rung or more than two rung.....8
Inadequate answer.....X

May be multi-coded

Question 17 — If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him:- — Col.30

His own doctor.....1
Another doctor.....2
A vicar, priest, minister...3
Spouse.....4
Other close relative.....5
A nurse.....6
Other.....0
Qualified answer.....Y
Inadequate answer.....X

May be multi-coded
Can be multi-code qualified answer.

Question 18 — On referral of patients for district nursing care would you, in general, describe the information you get as:- — Col.31

Adequate.....1
Rather inadequate.....2
Very inadequate.....3
Inadequate answer.....X
Qualified answer.....Y
D.K.A. code 3 col.4.....9
also if a HV

single coded

Question 19 — In caring for patients in terminal illness do you feel contact with the general practitioner is generally:- — Col. 32

Adequate.....4
Rather inadequate.....5
Very inadequate.....6
Inadequate answer.....X
D.K.A. code 3 col.4.....9
Qualified answer. Y

single coded

Question 20 — In caring for patients in terminal illness do you feel contact with the hospital is generally:- — Col.33

Adequate.....1
Rather inadequate.....2
Very inadequate.....3
Inadequate answer.....X
No contact.....0
D.K.A. code 3 col 4.....9

(only code this if they do not indicate whether they feel this is inadequate or not)

only use no contact code when no other code has been rung.

single coded

Question 21 — Do you think that close bereaved should be given some medical or nursing supervision for a while? — Col.34

Yes, medical supervision.....4
Yes, nursing supervision.....5
No.....6
Both medical and nursing.....7
Qualified answer.....Y
Inadequate.....X

single coded
Only use qualified answer when no other code rung.

Question 22 — In our pilot study opinions of health visitors and district nurses were ~~divided about who should provide nursing supervision or support for the~~ bereaved. Do you think the most ~~appropriate~~ person is the health visitor ~~or the district nurse~~? * — Col.35

Health visitor.....1
District nurse.....2
Inadequate.....i

single coded — {Qualified answer / Joint responsibility} y

Question 23 — Are you working as:- — Col.36

District nurse.....1
Health visitor.....2
Midwife.....3
combined worker.....4

Is combined work? Code all that apply as usual (4)

Inadequate.....X
may be multi-coded.....

Question 24 — Are you attached to a general ~~medical~~ practice? — Col.37

Yes.....5
No.....6
Inadequate.....X

single coded

Question 25 — Do you work:- — Col.38

Full time.....7
or Part time.....8
Inadequate.....i

single coded

* If 'district nurse because visits most often' code 2
If 'whoever knows family best' code y.

Question 26 Do you do any night duties, i.e. duties between 8 p.m. and 8 a.m.? Col.39

No 4
Late duty shift.....5
Night call.....6
Full night duty.....7
Inadequate which.....8
Inadequate whether any.....X

5.6.7. may be multi-coded

No. of nights a week does:-

Late night duty Col.40
Night call Col.41
Full night duty Col.42

None (but does some of that call or duty)...0
One.....1
Two.....2
Three.....3
Four.....4
Five.....5
Six.....6
Seven.....7
Inadequate how often but does some.....X
D.N.A. does not do that type of duty or unknown if does that type of duty.....9

single coded

Question 27	Age	Under 25.....1 25 - 34.....2 35 - 44.....3 45 - 54.....4 55 - 64.....5 65 or more.....6 Inadequate.....X	Col.43
Question 28	Marital Status	Married.....1 Single.....2 Divorced/separated/Widowed.....3 Inadequate.....X	Col.44
Question 29	Sex	Male.....4 Female.....5	Col.45
Question 31	Would you like to be informed of the results of this study?	Yes.....1 No.....2	Col.46
Length of interview		Less than 15 mins.....1 15 30.....2 30 45.....3 45 60.....4 60 +.....5	Col.47

Month of interview

July		7	Col.48
Aug		8	
Sep	1969	9	
Oct		0	
Nov		X	
Dec		Y	
Jan		1	
Feb	1970	2	

Interviewer

Records

Lisbeth	00	0	Col.49
Wyn	19	1	
John	20	2	
Stella	14	4	
Angela	10	5	
Kathleen	03	3	
Mrs Griffiths		6	
Margo		7	
Beryl	01	8	

Interview

Questionnaire B only	0	Col.50
One questionnaire A	1	
Two " A	2	
Three or more " A	3	

Last digit of serial number / in B'ham (Col. 79.)

Health Centre

1	Aston	6	Selly Oak
2	Bordesley	7	Washwood Heath
3	Central	8	Yardley
4	Hall Green		
5	Kings Norton	X	Health Visitor (B'ham)

H.V./D.N. Qr. B

Col. 50

Number of Qr. A's completed and included in main study.
None - i.e. Qr. B only 0

1 - 9	1 - 9
1 0	Y

583 CARDS

Home Care for Dying H.V./D.N. Qu. β

Serial number - 1st digit - Area Col. 1

Barking	1	31
Teeside	2	59
Hillingdon	3	36
Cheshire (NE)	4	39
Brentwood	5	35
Bridgend	6	36
Northumberland	7	20
Eastbourne	8	27
Birmingham	9	219
Thanet	D	24
St. Helens	X	21
Isle of Wight	Y	36

2nd digit Col. 2

3rd digit Col. 3

(4th digit is on col. 79 - Birmingham H.V./D.N. only)

Question 1: Did you have any part in the care of patients with terminal illness in the last 12 months? Col.4.

IF NO Did you have any part in the care of bereaved in the last 12 months?

Yes to 1st. part.....1
No " " " Yes to 2nd part.....3
No " " " I.A. to 2nd part.....2
Inadequate answer.....X

Single coded. N.B. If answer is no to both first and 2nd parts then person should be omitted and no transfer sheet made out.

Question 2: A general practitioner in our pilot study said that: 'no anticipated deaths should be allowed to happen at home'. Do you agree or disagree with this? Col.5

Agree.....1	25
Disagree.....2	557
Inadequate answer.....X	1

Single coded. N.B. If person says 'it depends' this should normally be counted as disagreement.

Col 6

Question 3: On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution or could you say this was equally balanced?

Most accept responsibility....5	186
Most seek admission.....6	58
Equally balanced.....7	326
Inadequate answer.....X	13

Single coded.

Question 4: Which if any of these things do you think prevent more people being looked after in the community rather than in hospital: Col.7

Unsuitable housing	1	354
Unwillingness of relatives to look after them	2	498
Absence of suitable relatives	3	545
Inadequate home nursing services	4	134
Inadequate other supporting services	5	266
Tendency of hospital to admit unnecessarily	6	42
Tendency not to discharge people when reasonable	7	87
Overwork of general practitioners	8	164
None of these	0	3
Inadequate answer	X	1

May be multi-coded - except for 0 and X.

Question 5 (i) Which contributes most? Col.8

(ii) Which next most? Col.9

Codes 1 - 8 as above

D.N.A. None of these (or one only)..... 9
Inadequate answer (or more than two indicated.....X

Single coded but if two tied equally code both and overcode Y
N.B. If two tied for most or next most the codes will be the same in cols. 8 & 9.

	Col 8	Col 9
1	68	102
2	186	173
3	255	168
4	18	18
5	41	69
6	1	3
7	4	10
8	12	18
9	3	26
X	8	11
Y	13	15

	Col 10	Col 11	Col 12	Col 13	Col 14
1	336	57	71	27	171
2	168	242	394	237	133
3	13	5	1	9	6
4	13	12	13	34	12
5	12	172	4	116	168
6	3	54	—	111	53
7	—	—	10	—	—
8	—	—	39	—	—
9	29	29	29	29	29
0	—	—	2	—	—
x	9	12	10	20	11
y	—	—	10	—	—

	Col 15	Col 16	Col 17	Col 18
1	80	125	183	53
2	447	158	123	273
3	7	33	31	17
4	10	35	33	70
5	—	137	128	66
6	1	54	41	50
9	29	29	29	29
x	9	12	15	25

page 2.

Question 6: Here is a list of services which are available through the Local Authority or voluntary organisations in some areas.
Can you tell me first a) Which are available in your areas:-
b) Which ones you have made use of
c) Which ones you would like extended or introduced

Meals on wheels	Col.10
Special laundry service	11
Free supply of incontinence pads	12
Service for disposing of " "	13
Bathing service	14
Supply of sickroom equipment	15
Night nursing service	16
Night sitting service	17
Geriatric social worker	18

Available	Used	Like extended/introduced	
Yes	Yes	Yes	1
Yes	Yes	No	2
Yes	No	Yes	3
Yes	No	No	4
No	-	Yes	5
No	-	No	6
Inadequate			X
D.N.A. code 3. col. 4			9

single coded

Incontinence pads (B'ham) (9)

Yes avail. Service not free consistently free

Used	Like extended/introduced	
Yes	Yes	7
Yes	No	8
No	Yes	9
No	No	0

Question 6 Who runs night nursing and/or night sitting service? Col.1

Night nursing

Local authority	1	236
Marie Curie	2	261
Other	3	13
Inadequate	X	6
Don't know	7	6

Night sitting

Local authority	4	289
Marie Curie	5	179
Other	6	21
Inadequate	Y	3
Don't know	8	12
D.N.A. (5,6,X or 9 in both cols 16 & 17)	9	152

Single or double coded or multi-code if more than one organization runs service.

Question 7 Is there any other home service for the terminally ill in your area? IF YES Have you used it? Col.2

No other service	6	354
Yes other service(s) used	7	146
" " " not used	8	38
" " " inad.if used	1	4
" " services - some used some not	2	—
Inadequate if other service	X	12
D.N.A. code 3 col. 4	9	29

Single coded

Question 8 Are there any (other) changes you would like to see in any of the services we have mentioned? Col.21.

Yes	1	172
No	2	361
Inadequate	X	21
D.N.A. code 3 col.4	9	29

Single coded

Question9 Is there any other service you feel would be helpful in the care of terminally ill patients? Col.22.

Yes	3	220
No	4	320
Inadequate	X	14
D.N.A. code 3 col.4	9	29

Single coded

Question 10 On the whole do you find that for patients with terminal illness general practitioners ask for district nursing help earlier than necessary, not early enough or about the right time? Col.23.

Earlier than necessary	5	19
Not early enough	6	84
About the right time	7	379
Inadequate	X	23
Qualified answer	Y	49
D.N.A. code 3 col.4	9	29

Single coded

Question 11 On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them? Col.24.

Give enough time	1	194
Like more time	2	342
Inadequate	X	12
Qualified answer	Y	6
D.N.A. code 3 col.4	9	29

IF LIKE MORE TIME (2) Overcode

164	Just to chat - or less rush	3
72	Additional nursing care (not telling of them what to do.)	4
74	Both (3 & 4)	5
32	Inadequate which	6

Time for talking getting to know the family (3)

Double coded if 2 coded in first part
Otherwise single coded.

Question 12 — Have you had any patients or families who have been reluctant or unwilling to accept district nursing care in the last six months? — Col.25

Yes	1	114
No	2	466
Inadequate	X	3

Single coded..

Question 13 — Do you think that health visitors have a part to play in terminal home care? — Col.26.

Yes	3	339
No	4	212
Qualified answer	Y	15
Inadequate	X	17

Single coded
N.B. Use Y normally only if no code rung

Question 14 — For patients in terminal illness would you described the district nursing service in your area as:- — Col.27.

Adequate	1	451
Rather inadequate	2	107
Very inadequate	3	11
Qualified answer	Y	8
Inadequate answer	X	6

Single coded
N.B. use Y normally only if no code rung or more than one code rung

Question 15 — Would you describe the home help service in your area as:- — Col.28

Adequate	6	119
Rather inadequate	7	322
Very inadequate	8	133
Qualified answer	Y	5
Inadequate answer	X	4

Single coded

Question 16 — As a general rule if a dying patient asked you about his prognosis which of the following would you do:- — Col.29.

Change subject	1	50
Tell him to ask the doctor	2	179
Tell him the truth gently	3	37
Give him hope	4	323
If two answers code both and over code	Y	75
Qualified answer - no code rung or more than two rung	8	67
Inadequate answer	X	2

May be multi-coded

Question 17 — If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him:- — Col.3

His own doctor	1	455
Another doctor	2	12
A vicar, priest, minister	3	86
Spouse	4	70
Other close relative	5	22
A nurse	6	13
Other	0	5
Qualified answer	Y	97
Inadequate answer	X	6

May be multi-coded

Can multi-code qualified answer

Question 18 — On referral of patients for district nursing care would you, in general, describe the information you get as:- — Col.3

Adequate	1	206
Rather inadequate	2	193
Very inadequate	3	72
Inadequate answer	X	3
Qualified answer	Y	32
D.N.A. code 3 col.4	9	77

also if anH.V. (Q 23 code 2)

single coded

Question 19 — In caring for patients in terminal illness do you feel contact with the general practitioner is generally:- — Col.32

Adequate	4	430
Rather inadequate	5	78
Very inadequate	6	11
Inadequate answer	X	16
D.N.A. code 3 col.4	9	29
Qualified answer	Y	19

single coded

Question 20 — In caring for patient in terminal illness do you feel contact with the hospital is generally:- — Col.33

Adequate	1	172
Rather inadequate	2	180
Very inadequate	3	121
Inadequate answer	X	23
No contact	0	57
D.N.A. code 3 col 4	9	29
	Y	1

(only code this if they do not indicate whether they feel this is inadequate or not)

Only use no contact code when nothing has been wrong.

single coded

Question 21 Do you think that close bereaved should be given some medical or nursing supervision for a while? Col.34.

Yes, medical supervision	4	207
Yes, nursing supervision	5	134
No	6	73
Both medical and nursing	7	103
Qualified answer	Y	59
Inadequate	X	also. 7

single coded Only use qualified answer when no code rang.

Question 22 In our pilot study opinions of health visitors and district nurses were divided about who should provide nursing supervision or support for the bereaved. Do you think the most appropriate person is the health visitor or the district nurse? * Col.35.

Health visitor	1	207
District nurse	2	252
Inadequate	X	4
Qualified answer joint responsibility	Y	120

single coded

Question 23 Are you working as:- Col.36.

District nurse	1	~~467~~ 505
Health visitor	2	~~75~~ 76
Midwife + D.N.	3	40
(4) Combined worker	4	D.N. + H.V. 1.

IF COMBINED WORKER (4) CODE ALL THAT APPLY AS WELL AS (4)

Inadequate	X
May be multi-coded	

Question 24 Are you attached to a general medical practice? Col.37

Yes	5	314
No	6	269
Inadequate	X	—

single coded

Question 25 Do you work:- Col.38

Full time	7	518
or Part time	8	65
Inadequate	X	—

single coded

* If 'district nurse because visits more often' code 2
If 'whoever knows family best' code Y

Question 26 Do you do any night duties, i.e. duties between 8 p.m. and 8 a.m.? Col.39

No	4	200
Late duty shift	5	230
Night call	6	149
Full night duty	7	8
Inadequate which	8	6
Inadequate whether any	X	2

5.6.7. may be multi-coded

No. of nights a week does:- Col.40 Col.41 Col.42

Late night duty	
Night call	
Full night duty	
None (but does some of that call OR duty)	0
One	1
Two	2
Three	3
Four	4
Five	5
Six	6
Seven	7
Inadequate how often but does some	X
D.N.A. does not do that type of duty or unknown if does that type of duty	9

single coded

	Col 40	Col 41	Col 42
1	121	32	1
2	7	7	–
3	1	–	–
4	1	–	–
5	2	4	1
6	–	1	–
7	–	–	–
9	353	434	575
0	90	78	5
X	8	27	1

Question 27 Age

Under 25.....1 Col.43
25 - 34.....2
35 - 44.....3
45 - 54.....4
55 - 64.....5
65 or more.....6
Inadequate.....X

Question 28 Marital Status

Married.....1 384 Col.44
Single.....2 152
Divorced/separated.....3 46
/Widowed
Inadequate.....X 1

Question 29 Sex

Male.....4 Col.45
Female.....5

Question 31 Would you like to be informed of the results of this study?

Yes.....1 Col.46
No.....2

Length of interview

Less than 15 mins.....1 Col.47
15 30.....2
30 45.....3
45 60.....4
60 +.....5

Month of interview

July		7	Col.48
Aug			
Sep	1969	9	
Oct		0	
Nov		X	
Dec		Y	
Jan		1	
Feb	1970	2	

Interviewer

Col.49

Lisbeth	00	0	~~16 = 6~~
Wyn	19	1	17 = 7.
John	20	2	Margo — 7
Sheila	14	4	Beryl, 01 = 8
Angela	10	5	
Karen	03	3	
Ann Griffin	16	6	

H.V./D.M. Qr. B

Col 50

Number of Qr. A's completed and included in main study.
None - i.e Qr B only 0

1 - 9	1 - 9
10	Y

H.U./D.N. 4th DIGIT OF SERIAL NUMBER

BIRMINGHAM SUB-DISTRICTS:-

1	ASTON
2	BARDESLEY
3	CENTRAL
4	HALL GREEN
5	KINGSTANDING
6	SELLY OAK
7	WASHWOOD HEATH
8	YARDLY
X	HEALTH VISITOR
0	D.N.A. - ALL AREAS OTHER THAN BIRMINGHAM (Qr. B's)

[redacted]

Qr. B. Col. 79

G.P. CODES y35

393

N.B. There were 325 individual G.P.'s last 2 of these have now been removed of the 818 patients doctors 3 cards should be blank most of the way and have to be included in the R category

Problems of domiciliary care in terminal illness

Total N= of cards = 818

Life before death. G.P. Codes.

N.B.

Serial number - 1st digit - Area

Col 1

'select if' 1 on 66, 79

Barking	1	72	27
Teeside	2	73	30
Hillingdon	3	65	39
Cheshire (WL)	4	68 (WL)	34
Brentwood	5	71	29
Bridgend	6	67	27
Northumberland	7	73	13
Eastbourne	8	64	17
Birmingham	9	68	43
Thanet	0	63	26
St. Helens	X	69	25
Isle of Wight	Y	65	25
			325

2nd digit - Interval between month of death and interview month Col 2

3 months	1 -	1	43
6 months	6 -	2	42
		3	42
		4	36
		6	53
		7	39
		8	39
		'1	31
			325

Col.4.

0 = Main questionnaire completed
1 = Questionnaire 1 second part completed (but no main questionnaire)

check totals for col 4

1 8

0 317

325

Col 6.

Totals for transferred cards y67.

1	33
2	494
X	7
R	251

0= Main questionnaire completed Col 4

1= Questionnaire 1 2nd part completed but no questionnaire 2.

Postal/Interview Col.5

Postal (should have been and was).....1 437 434 ~~253~~ 251.

Interview " " " " " 2 109 67

Should have been postal, was interview...3 — —

" " " interview was postal...4 7 5

Single coded R 265

~~325~~ 323

Question 1 col.6.

A general practitioner on our pilot study said that: 'no anticipated deaths should be allowed to happen at home' Do you agree or disagree with this?

Blank.....R 268

Agree.....1 ~~433~~ ~~20~~ 19

Disagree .....2 ~~510~~ ~~303~~ 302

Inadequate answer.....X 7 2

Single coded, N.B. If doctor says 'it depends' this should normally be counted as disagreement

Question2

Do you find it usually easy, rather difficult, or very difficult to get admission into suitable N.H.S. Institution for:-

a) Young patient with a short term terminal illness Col.7.

b) An old patient with a short term terminal illness Col.8.

c) An old patient likely to need long term nursing care Col.9.

d) A young patient with a progressive degenerative condition likely to need long term nursing care Col.10.

e) An old patient with an acute infection Col.11.

Easy.....0

Rather difficult.....1

Very difficult.....2

Sometimes 0, sometimes 1....3

Sometimes 1, sometimes 2,....4

Inadequate.....X

PTO for check totals cols 7–11

~~Overcode X if part inadequate~~

Single coded Blank — — — R

code	col 7	col 8	col 9	col 10	col 11
1	119	~~248~~ 247	~~197~~ 198	233 ~~234~~	175 ~~176~~
2	31	~~24~~ 133	27+	132	31
3	6	8	3	5	11
4	–	2	2	1	3
0	374 ~~377~~	154 ~~155~~	60	153 ~~155~~	314 ~~316~~
x	20	6	1	26	5
R	365	365	365	362	365

1 on col 79 (325 cards)

	col 4	col 6	col 9	col 10	col 11
1	70	148	~~122~~ 120	~~147~~ 146	99
2	20	~~76~~ 75	114	71	23
3	3	5	4	2	11
4	----	1	3	1	2
0	224 ~~226~~	91 90	31	~~89~~ 88	~~187~~ 185
x	6	4	1	15	3
R					

Question 2 Summary of difficulty Add scores for 5 parts of question 2 when codes 0,1 or 2 Count code 3 as $\frac{1}{2}$ and code 4 as $1\frac{1}{2}$

Col.12

Total Score	Code		
0	0	12	8
1 or $1\frac{1}{2}$	1	46	26
2 or $2\frac{1}{2}$	2	87	4645
3 or $3\frac{1}{2}$	3	80	5352
4 or $4\frac{1}{2}$	4	101	60
5 or $5\frac{1}{2}$	5	108	60
6 or $6\frac{1}{2}$	6	50	30
7 or $7\frac{1}{2}$	7	34	24
8 or $8\frac{1}{2}$	8	25	10
9 or $9\frac{1}{2}$	9	5	4
10	y	4	3
Inadequate	x	49	23
Overcode if part inadequate	X		
Single coded Blank	R	265	
			325

Transferred totals y67

1	45
2	84
3	78
4	96
5	107
6	49
7	31
8	24
9	5
0	12
X	47
y	4
R	249

Question 3 In your area which if any of these do you think you need more of:- Col.13.

transferred

Short term general hospital beds 1	265		149
Chronic hospital beds.....2	484		273
Geriatric beds.....3	509		268
Mental hospital places.....4	202		107
District nurse services.....5	121		78
Home help services.....6	300		176
None.....0	2		1
Inadequate answer.....X	7		4
Blank R	259		

May be multi-coded - except 0 or X single coded

N.B. If on the postal questionnaire they have ticked any of these in the 'most needed' but not in the 'need more' include them here.

Question 4 Which one do you feel is needed most? Col.14.

Codes as for question 3

If two coded, code both and overcodes.....y
If three " " three " " 9
If more than three coded count as inadequate.....
If only one coded at question 3 repeat that code/ herd
If none coded at question 3 code 0 here too.

N.B. If they have ticked more things under 'most needed', than under 'needed more' assume they reversed the headings 'in error'.

COL 14	
Code	Totals
1	54
2	178
3	333
4	20
5	12
6	45
9	18
0	2
x	27
y	82
R	255

col 14 transferred y67

29	1	52
111	2	169
185	3	325
11	4	20
9	5	12
29	6	43
13	9	17
1	0	2
20	X	27
46	Y	81
	R	249

Question 5 Do you feel there is adequate consultation between you and hospital medical staff about: Col.15.

a) Admission of patients

Yes.....1	178	~~275~~ 273
No.....2	72	47
Qualified answer.....y	–	—
Inadequate answer.....X	3	3
	R 265	—

Single coded

b) Discharge of patients Col.16.

Yes.....3	214	~~124~~ 123
No.....4	319	~~190~~ 189
Qualified answer.....y	4	3
Inadequate answer.....X	16	8
	R 265	—

Single coded

Question 6 Do you consider the arrangements for domiciliary consultations are:- Col.17.

PROMPT	Satisfactory..... 5	525	305
or	Not satisfactory.....6	21	15
	Qualified answer.....y	6	4
	Inadequate answer.....X	1	1
		R 265	—

Single coded

Question 7 Could you estimate how many domiciliary consultations you have asked for in the last twelve months for patients with terminal illness Col.18.

None.....0	164	~~98~~ 96
One.....1	51	37
Two - Four.....2	182	104
Five or more.....3	118	68
Inadequate X	38	18
	R 265	—

N.B. Count one ~~and~~ or two as 2-4. Code 2

Single coded

Question 8 How many nights a week are you on call on average for cases other than obstetrics? Col.19.

transferred

Every night.....1	54	29
5 or 6.....2	51	29
3 or 4.....3	160	87
1 or 2.....4	241	146
None.....5	14	11
Less often than once a week.....6	7	5
Inadequate.....X	17	10
	9	8
	R 265	

1 52
2 49
3 155
4 236
5 14
6 7
7 16
X 9
R 437

Single coded

Question 9 Do you ever use an emergency service for night calls? Col.20

transferred

Yes.....6	124	90
No 7	428	234
Inadequate.....X	1	1
	R 265	

6 122
7 413
X 1
R 249

Single coded

Question 10 Do you think an emergency service for night calls is a good idea or not? Col.21.

Good idea.....1	325	207
Not a good idea..2	177	87
Qualified answer.....y	45	27
Inadequate.....X	6	4
	R 265	

Single coded

Question 11 For patients at home with terminal illness do you find the district nursing service:- Col.22

Very helpful.....1	466	273
Moderately helpful.....2	80	46
Not helpful.....3	1	1
Qualified answer.....y	1	1
Inadequate.....X	5	4
	R 265	

single coded

Question 12 Would you like to see any changes in the service or in the way it is organised? Col.23.

Yes.....4	204	120
No.....5	334	195
Qualified answer.....y	7	3
Inadequate.....X	8	7
	R 265	

single coded

Question 13 Is there any sort of help or care which you feel district nurses could give that they are not giving at the moment? Col.24.

Yes.....6	73	46
No.....7	461	266
Qualified answer.....y	5	4
Inadequate.....X	14	9
	R 265	

single coded

Question 14 If a patient needs just nursing care that relatives are able and prepared to give do you tend to ask the district nurse to visit or not. Col.25.

Ask district nurse to visit.....1	224	136
Not.....2	307	179
Qualified answer.....y	17	6
Inadequate.....X	5	4
	R 265	

single coded

Question 15 Are the health visiting and district nursing services in this area separate or combined? Col.26.

Combined.....2	98	62

IF SEPARATE For patients at home with terminal illness do you find the health visitor services:-

Very helpful.....3	126	67
Moderately helpful.....4	111	60
Not helpful.....5	136	113
Inadequate answer 2nd part.....X	17	12
Inadequate answer 1st part.....9	8	7
Qualified answer 2nd part.....y	7	4
R	265	

single coded

Question 16 Would you described the home help service transferred your area as: Col.27

6 146	Adequate.....6	151	78
7 232	Rather inadequate.....7	238	153
8 148	Very inadequate.....8	154	86
X 7	Qualified answer.....y	3	3
Y 3	Inadequate answer X	7	6
R 249	Blank . . R	265	

single coded

1 on col 79

col 28

1 75
2 ~~[illegible]~~ 188
3 3
4 ~~[illegible]~~ 35
5 7
6 4
7 3
8 2
X 6

col 29

3
~~85~~ 84
2
~~24~~ 23
105
70
9
16
11

col 30

14
190
4
~~37~~ 33
38
~~20~~ 19
6
13
6

col 31

1
55
1
~~16~~ 15
97
~~107~~ 100
11
37
6

col 32

1 10
2 ~~11~~ 110
3 3
4 ~~27~~ 26
5 83
6 77
7 1
8 6
X 7

col 33

32
~~187~~ 180
7
~~38~~ 37
27
29
2
3
6

col 34

24
~~31~~ 30
10
18
159
~~62~~ 61
4
10
7

col 35

40
36
10
22
155
~~45~~ 43
5
6
6

col 36

1 14
2 86
3 13
4 29
5 105

→ cont.

6 ~~54~~ 52
7 4
8 12
X 8

Check totals Cols 28 - 36

overpage

Question 17

Here is a list of services which are available through Local Authority and Voluntary organisations in some areas. Can you tell me first which are available in your area.-
b) which ones have you made use of?
c) which ones would you like extented or introduced?

Meals on wheels	Col.28
Special laundry service	Col.29
Free supply of incontinence pads	Col.30
Service for disposing of incontinence pads	Col.31.
Bathing service	Col.32.
Supply of sickroom equipment	Col.33.
Night nursing service	Col.34.
Night sitting service	Col.35.
Geriatric social worker	Col.36.

Available	Used	Like extended/introduced	Code
Yes	Yes	Yes/	1
Yes	Yes	No	2
Yes	No	Yes	3
Yes	No	No	4
No	-	Yes	5
No	-	No	6
DK		Yes	7
DK		no	8
Inadequate			X
single coded			R

N.B. On postal assume blanks are 'NO' unless whole question blank or other indication that not answered.

Code	col 28	col 29	col 30	col 31	col 32	col 33	col 34	col 35	col 36
1	113	3	19	1	12	59	49	68	24
2	307	130	232	80	179	309	42	61	131
3	8	2	7	1	4	12	17	14	20
4	45	24	60	23	40	66	27	29	50
5	22	180	74	170	159	43	282	285	174
6	31	130	26	192	137	47	105	69	113
7	3	13	8	14	1	3	8	9	5
8	2	24	17	55	9	4	11	7	20
x	7	37	11	11	12	11	12	11	16
R	265	205	205	205	203	212	265	240	225

Question 18 Interview Last part Q.17 (postal) Col.37

Is there any other home service for the terminally ill in your area? IF Y S Have you used it?

No other service 6			282
Yes " service(s) used.....7			11
" " " not used.....8			4
" " " inad. if used.....1	22		9
" " services some used some not.....2			2
Inadequate if other service.....X			17

single coded

Question 18(b)

Are there any changes you would like to see in any of these services? Col.38

Yes.....1	192	112
No.....2	304	180
Inadequate.....X	57	33
	R 265	

single coded

Question 19

Is there any other service you feel would be helpful in the care of terminally ill patients? Col.39

Yes.....3	83	52
No.....4	388	230
Inadequate.....X	82	43
	R 265	

single coded

Question 20 On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution or would you say this was equally balanced: Col.40

transferred 175 131 218 12 249 single coded

Most accept reponsibility.....5	181	~~106~~ 105
Most seek admission.....6	134	79
Equally balanced.....7	226	~~134~~ 133
Inadequate answer.....X	12	6
	R 265	

Question 21 Which if any of these things do you think prevent more people being looked after in the community rather than in hospital: Col.41.

Unsuitable housing.....1	310	~~177~~ 175
Unwillingness of relatives to look after them.....2	489	~~281~~ 280
Absence of suitable relatives.....3	494	291
Inadequate home nursing services.....4	117	73
Inadequate other supporting services.....5	163	98
Tendency of hospital drs. to admit unnecessarily..6	20	14
Tendency not to discharge people when reasonable..7	27	20
Overwork of general practitioners.....8	139	78
None of these.....0	—	
Inadequate answer.....X	14	9
	Y 57	32 31
Multi-coded - except for 0 and X	R 265	

N.B. Include any ticked in the columns headed two with most effect. If they have only given one or two with most effect code both here and overcode Y.

Question 22 Which contributes most? Col.42.
Which next most? Col.43.

(Codes 1 - 8 as above) D.N.A. None of these or one only.....9
Inadequate answer.....X

single coded but if two tied equally code both and overcode ~~Y~~.
N.B. If two tie for most and next most the codes will be the same in cols. 42 and 43.

PTO for Totals for Cols 42 43

col 42	
code	Total
1	140
2	255
3	209
4	10
5	30
6	2
7	—
8	16
9	2
X	54
Y	84
R	250

27
48
129
14
2
8
1
38
49

785 cards
Check totals

col 42

1	39
2	255
3	209
4	10
5	30
6	2
7	—
8	16
9	2
0	—
X	54
Y	84
R	249

col 43	
code	Total
1	77
2	166
3	218
4	23
5	54
6	1
7	1
8	25
9	15
X	59
Y	86
R	250

48
89
124
15
32
1
1
14
13
40
52

col 43

1	75
2	159
3	213
4	22
5	51
6	1
7	1
8	25
9	15
0	—
X	57
Y	83
R	249

Question 23

On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them

Col.44

Give enough time.....1	~~317~~ 314	~~192~~ 190
Like more time. 2	219	125
Qualified answer.....y	4	1
Inadequate.....X	13	7
	R 265	

single coded

Question 24

If you had more time do you think it would be appropriate for you to look after more patients who were terminally ill at home?

Col.45.

Yes.....3	222	142
No.....4	~~273~~ 270	~~152~~ 150
Inadequate.....X	45	26
Qualified answer....Y	13	5
	P 265	

SINGLE CODED

Question 25 — Whether a person should be told that they are dying probably depends on a number of different things. Could you say what you would probably do in those situations - all related to people with cancer who will almost certainly die within six weeks

Col.4

a) A businessman of 55 who asks directly 'Is this going to kill me doctor?'
Would you:-

Say yes probably.....1	148	201	203
Say you don't know.....2	54		32
Say no.....3	62	col.6	38
Change subject.....4	18		12
Qualified answer.....y	53		26
Inadequate.....X	18		14
	R 265		

single coded

b) A young mother of 35 with young children who does not raise the subject and seems unaware of the prognosis.
Would you :-

Tell her.....1	2		2
Tell her husband.....2	536	310	311
Tell them both.....3	6		3 4
Tell neither.....4	1	col.47.	1
Qualified answer.....y	3		3
Inadequate.....X	5		4
	R 265		

single coded

c) An elderly widower who asked: 'This won't kill me doctor will it?'
Would you:-

Agree.....1	189		122
Pass it off as joke.....2	176		107
Tell him truth.....3	85		40 4
Qualified answer.....y	81	col.48.	42
Inadequate.....X	22		12 13
	R 265		

single coded

Question 26 As a general rule if a dying patient asked his district nurse about his prognosis which of the following would you like her to do:-

Col.49

Change subject	1	22	13
Tell him to ask the doctor	2	288	~~155~~ 157
Tell him truth gently	3	51	26
Give him hope	4	297	~~114~~ 183
If two answer code both and overcode	/	119	67
Qualified answer - no code number for this			4
8 only	8	8	4
Inadequate	X	6	5
may be multi-coded		R 265	

Question 27 If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him.-

Col.50

His own doctor	1	494	~~253~~ 281
Another doctor	2	20	15
A visiting priest, minister	3	57	35
Spouse	4	37	23
Other close relative	5	19	11
A nurse	6	1	1
Other	0	—	—
Qualified answer	y	19	12
Inadequate	X	8	7
May be multi-coded No one	9	6	4
		R 265	

Question 29. Cd. 52

Intention

Sedative & tranquilliser	1	Addictive
Hypnotic	2	Addictive
Antidepressant	4	Addictive
Other	8	
Inadequate	X	

Context

Contains barbiturate, phenobarb, Amylobarb etc.

Yes	y
No	0
Inad	9

Manually double coded but may have more codes of 8 as well as one of 1-7.

	Local
1	187 11
2	39 2
3	208 120
4	2
5	5
6	2 1
7	6
8	79 5
9	98 64
0	182 111
x	99 53
y	272 147
A	265

Fantazine 10
Kensedal, Nealbarbitone 3y
Diazepam 180
Concordin 5-10 40
Amytal 1y
meprobamate 10
mep 400 10
Meparon 10
Miltown 10
Mellaril 10
Sparine 10
Doriden 20
Emitriptyline, Zoxyl, Sardon, Tryptizol 40

Post. Bromide (Bromdia etc) 13 or
Sodium Amytal 31y
Librium (Chlordiazepoxide) 10
Barbiturates 3y
Valium (diazepam) 180
Mogadon 20
Nembutal 3y
Phenobarb 38y
Welldorm 30
Largactil (Chlorpromazine) 10
Equanil (meprobamate) 10
Amylobarbitone (Sodium) 3y

Pentobarbitone 3y
Nembrex 20
Stelazine 180
Tuinal - 1y
Second Sodium 3y
Soneryl 3y
Oblivon 10
Serenid-D 10
Beplate 18y
Doriden 20
Atarax 10

Question 28

transferred

1 ~~117~~ 116
2 ~~255~~ 254
3 ~~137~~ 140
X 7
R 20
~~249~~ 252

single coded

Do you think that close bereaved should:-

always be offered a sedative.....1	123		71 ~~72~~
Generall be offered a sedative....2	260		155
Only exceptionally be offered a sedative.....3	142	Col.51.	~~79~~ 80
Qualified answer.....y	21		12
Inadequate answer.....X	7		6
	R 265		

Question 29

What do you prescribe in such circumstances Col.52.

Barbiturates.....1
Narcotics.....2
Both or either barbiturates or Narcotics.....3
Others.....0
D.N.A. Don't give anything.....9
Inadequate X

single coded except 0 may be coded with 1,2, or 3.

Question 30

Do you think that close bereaved should be given some medical or nursing supervision for a while? Col.53.

(467) transferred totals

4 160
5 20
6 282
7 18
X 4
Y 52
R 249

single coded

Yes, medical supervision.....4	162		90
Yes nursing supervision.....5	22		15
No.....6	293		172 ~~174~~
Both nursing and medical.....7	20		9
Qualified answer.....y	52		34
Inadequate.....X	4		3
	R 265		

Question 31

Apart from any obstetric beds do you as a general practitioner have direct access to any N.H.S. beds where you retain full responsibility for treatment of your patients while in hospital

Col.54.

No.....2 390 237

IF YES Can you use any of them for patients in terminal care?

Yes.....3 129 64

No.....4 26 19

Inadequate answer to 1st part.....X 4 3

" " to 2nd part.....1 4 2

R 265

single coded

Question 32

Would you like any such beds, or more beds, that you could use for patients who are terminally ill?

col 55
1 on col 79 (325 cards)

Yes.....5 389

No.....6 132 Col.55

Inadequate answer.....X 32

R 265

5 229
6 83
X 13

single coded

Question 33 (Interview only)

Can you think of any particular patient with a terminal illness in your own practice during the last six months, who had to be looked after at home, although some other arrangement would have been better.

Col.56.

D.N.A. (postal).....9 444 258

Yes.....7 40 22

No.....8 67 43

Inadequate.....X 2 2

R 265

single coded

Question 34 (Interview only) Col.57

Have you had any patients or families who have been unwilling to accept district nursing care in the last six months?

⅔D.N.A. (Postal)	9	444	258
Yes	1	19	11
No	2	89	55
Inadequate	X	1	1
Single coded		R 265	

Number of doctors

In col 79

Single handed	1	67	Col.58.
In partnership of 2 - or two doctors	2	68	
" " " 3 - three	3	93	
" " " 4 - four	4	53	
" " " 5 or more or five or more	5	41	
Inadequate	X	3	
⊙ Barcode for assistants (do not count as partner)		8	

single coded

Number of patients

Could you tell me the approximate number of N.H.S. patients you (yourself) look after? Col.59.

transferred

1 39
2 103
3 172
4 148
5 67
X 7
R 249

single coded

None	0	1	1
Under 2000	1	40	25
2000 - 2499	2	03	59
2500 - 2999	3	75	99
3000 - 3499	4	54	91
3500 or more	5	68	44
Inadequate	X	7	6
Blank	R	265	

Attached staff — Have you any local authority staff attached to your practice, such as:- — Col.60

A district nurse	1	275	162
A health visitor	2	257	135
A social worker	3	41	24
None	0	230	136
Inadequate	X	4	3
	R	265	

May be multi-coded

Marsh Midwives are disregarded

Ancillary help — Do you have any ancillary help such as:- — Col.61.

Secretary	5	441	246
Receptionist	6	476	276
Nurse	7	144	92
Other	8	40	29
None	0	26	19
Inadequate	X	4	3
	R	265	

May be multi-coded. N.B. Numbers of staff are disregarded. a person who works as a secretary and receptionist is coded 5 & 6.

Like to know about stddy — ~~Col.62~~ Ion col 79

Yes	1	302
No	2	20
Inadequate if would like to know	X	3

Overcode If postal and wanted interview too. — 8

Interviewed Yes 3

No 4

Length of interview Col.63

D.N.A. (postal).....	9	258
Less than 30 mins.....	1	16
30 < 45 mins.....	2	35
45 mins < 1 hr.....	3	10
1 hr. < 1½hr.....	4	5
1½ hrs < 2hrs.....	5	
2 hrs. or more.....	6	
Inadequate.....	X	1

Single coded

Month in which interview done or questionnaire completed Col.64.

Col 65					Col.64.
1	9	July	1969	7	1 2
2	13	August		8	2 5
3	1	Sept		9	3 2
4	9	October		0	4 1
5	5	November		X	5 5
6	6	December		Y	6 1
7	3				7 17
8	9	January	1970	1	8 59
9	258	February		2	9 52
0	3	March		3	0 62
X	3	April		4	X 58
Y	6	Interviewer May		5	Y 51
		D.N.A. (postal)		9	Col.65.

Item col 79

	col 66	col 67	col 68
1	200	199	
2	72	72	
3	29	34	
4	8	5	
5	6	6	
6	3	3	
7			
8	1	2	
9	2		
10	4	1	
11			
12			R 325
R			

Col.66 No. of patients with main questionnaire completed.

0 - 9	Straight.
X	10
Y	11 or more.

← check totals

Col.67 No. of patients with main questionnaire or questionnaire 1 second part completed.
As col. 66.

Col.68 No doctor recorded (L.T.I.) 0
Dr. refused / no reply / Temp. away / ill. 1.
Dr. moved / died 2
Dr. Not traced. 3
Refused name of Dr 4

transferred

Sex. Col 69 100

MALE	1	667 / 670	306 304
FEMALE	2	28	15
INADEQUATE	X	11	4
	R	109	

m col 79 (a) Age codes at 1 October 1969 Col 70

	R	Blanks		
4	1	Under 30	-	born October 1939 or later
22	2	30-34	-	born between October 1934 and September 1939
42	3	35-39	-	born between October 1929 and September 1934
52	4	40-44	-	born between October 1924 and September 1929
60	5	45-49	-	born between October 1919 and September 1924
51	6	50-54	-	born between October 1914 and September 1919
46	7	55-59	-	born between October 1909 and September 1914
30	8	60-64	-	born between October 1904 and September 1909
6	9	65-69	-	born between October 1899 and September 1904
4	0	70 and over	-	born before October 1899
4	X	Inadequate.		

Col 66		Col 67		Col 68	
Code	Total	Code	Total	Code	Total
1	282	1	274	1	36
2	211	2	200	2	20
3	112	3	129	3	28
4	51	4	56	4	4
5	45	5	50	5	3
6	51	6	44	6	3
7	9	7	7	7	1
8	28	8	1	8	1
9	18	9	27	9	1
0	21	0	1	0	1
X	11	X	20	X	1

No. of Principals.		Col 71
0	0	
1-9	1-9	
10+	4	
INADEQUATE	X	

No. of Assistants.		Col 72
0	0	
1-9	1-9	
10+	4	
INADEQUATE	X	

2	163	78
3	221	89
4	100	46
5	49	27
6	6	3
7	1	1
8	—	—
9	—	—
0	—	—
X	28	14
R	109	—
	COL 72	325

Rural Practice Payments Code (RPPC) Col 73

Code		Total	Col 79
ELIGIBLE	1	84	31
	2	—	—
	5	12	5
INELIGIBLE	0	577	279
	3	11	2
	4	5	1
INADEQUATE	X	20	7
	R	109	—
			325

(b) Medical Practice Committee Area codes Col 74

1	Designated area	290	151
2	Intermediate area	126	44
3	Restricted area	52	17
4	Open area	221	106
X	Inadequate.	20	7
R	Blank	109	—

Group Practice Payments Code. Col 75

ELIGIBLE	1	383	172
INELIGIBLE.	0	306	146
INADEQUATE	X	20	7
BLANK	R	109	—

Col 71	Col. 79	
325		
—	1	499
—	2	160
—	3	63
—	4	24
—	5	15
—	6	9
—	7	3
—	8	3
—	9	3
—	0	1
—	X	
	R	109
325		

Patients numbered within Dr., by sequence 1,2, etc.

D.N.A. - i.e. No. Dr. (0 on Col.68) or Dr. not traced (3 on Col 68) or refused name of Dr (4 on Col 68) } Y

Use before Death.
G.P.Survey.Col.52

Drug	Intention	Content	Drug	Intention	Content.
Amylozine	1	Y	Mepavlan	1	0
Amytal	1	Y	Mep -/.2	1	0
Amylobarbitone (Sodium)	3	Y	Meprobomate	1	0
Atarax	1	0	Mylomide	1	Y
Amitriptylene	4	0			
			Nembutal	3	Y
			Nux vomica	3	0
Bromide	1	0	Nealbarbitone	3	Y
Beplete	18	Y			
Barbiturates	X	Y	Oblivon	1	0
Censadal	3	Y	Phenergan	3	0
Cancordin	4	0	Potassium Bromide	1	0
Chlorpromazine	1	0	Phenobarb	38	Y
Chlordiazepoxide	1	0	Pentobarbitone	3	Y
			Serenid - D	1	0
Doridin	2	0	Soreryl	3	Y
Diazepam	18	0	Seconal Sodium	3	Y
Equanil	1	0	Stelazine	18	0
Eu Valerol	1	Y	Sodium Amytal	3	Y
Fentazin	1	0	Saroten	4	0
			Sparine	1	0
Gentian Alk.	8	0	Tofranil	4	0
Librium	1	0	Tofranil w.Promazine	4	0
Largactil	1	0	Triptizol	4	0
Largoxyl	4	0	Tuinal	2	Y
Mandrax	2	0	Valium	18	0
Mogadon	2	0			
Melleril	1	0	Weldorm	3	0
Miltown	1	0			

D

Doctors

Y35

SN 393D Life before Death: Doctors

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case number	4 digit code	
1/5-6		Card number	Card 01	806
1/7-9		Serial number	3 digit code (see attached list)	
1/10	1	Questionnaire completed	0 Main questionnaire completed	774
			1 Questionnaire 1 second part completed (but no main questionnaire)	32
1/11	2	Postal/Interview	1 Postal (should have been and was)	434
			2 Interview	109
			3 Should have been postal, was interview	-
			4 Should have been interview, was postal	7
			Blank	256
1/12	3	A general practitioner on our pilot study said that 'no anticipated deaths should be allowed to happen at home'. Do you agree or disagree with this	1 Agree	33
			2 Disagree	510
			3 Inadequate answer	7
			0 Blank	256
1/13-17	4-8	Do you find it usually easy, rather difficult, or very difficult to get admission into suitable N.H.S. Institution for:-		
1/13	4	Young patient with a short term terminal illness	0 Easy	374
			1 Rather difficult	119
			2 Very difficult	31
			3 Sometimes 0, sometimes 1	6
			4 Sometimes 1, sometimes 2	-
			5 Inadequate answer	20
			6 Blank	256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/14	5	An old patient with a short term terminal illness	0 Easy	154
			1 Rather difficult	247
			2 Very difficult	133
			3 Sometimes 0, sometimes 1	8
			4 Sometimes 1, sometimes 2	2
			5 Inadequate answer	6
			6 Blank	256
1/15	6	An old patient likely to need long term nursing care	0 Easy	62
			1 Rather difficult	194
			2 Very difficult	277
			3 Sometimes 0, sometimes 1	8
			4 Sometimes 1, sometimes 2	8
			5 Inadequate answer	1
			6 Blank	256
1/16	7	A young patient likely to need long term nursing care	0 Easy	153
			1 Rather difficult	233
			2 Very difficult	132
			3 Sometimes 0, sometimes 1	5
			4 Sometimes 1, sometimes 2	1
			5 Inadequate answer	26
			6 Blank	256
1/17	8	An old patient with an acute infection	0 Easy	314
			1 Rather difficult	175
			2 Very difficult	34
			3 Sometimes 0, sometimes 2	19
			4 Sometimes 1, sometimes 2	3
			5 Inadequate answer	5
			6 Blank	256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/18	9	Summary of difficulty add scores for (Cols 13-17 VARS 4-8) when code 0, 1, or 2 count code 3 as ½ and code 4 as 1½	0 0 1 1 or 1½ 2 2 or 2½ 3 3 or 3½ 4 4 or 4½ 5 5 or 5½ 6 6 or 6½ 7 7 or 7½ 8 8 or 8½ 9 9 or 9½ - 10 or more & Blank	12 46 86 78 101 108 50 34 25 5 4 257
1/19-26	10-17	In your area which if any of these do you think you need more of:-		
1/19	10	Short term general hospital beds	1 Yes 0 Not mentioned	254 552
1/20	11	Chronic hospital beds	1 Yes 0 Not mentioned	465 341
1/21	12	Geriatric beds	1 Yes 0 Not mentioned	489 317
1/22	13	Mental hospital places	1 Yes 0 Not mentioned	190 616
1/23	14	District nurse services	1 Yes 0 Not mentioned	115 691
1/24	15	Home help services	1 Yes 0 Not mentioned	289 517
1/25	16	None	1 Yes 0 Not mentioned	2 804
1/26	17	Inadequate answer	1 Yes 0 Not mentioned	7 799
1/27-36	18-27	Which one do you feel is needed most		
1/27	18	Short term general hospital beds	1 Yes 0 Not mentioned	53 753

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/28	19	Chronic hospital beds	1 Yes 0 Not mentioned	177 629
1/29	20	Geriatric beds	1 Yes 0 Not mentioned	332 474
1/30	21	Mental hospital places	1 Yes 0 Not mentioned	20 786
1/31	22	District nurse services	1 Yes 0 Not mentioned	12 794
1/32	23	Home help services	1 Yes 0 Not mentioned	45 761
1/33	24	None	1 Yes 0 Not mentioned	2 804
1/34	25	If more than three coded count as inadequate	1 Yes 0 Not mentioned	27 779
1/35	26	If two coded code both and overcode	1 Yes 0 Not mentioned	82 724
1/36	27	If three coded code three and overcode	1 Yes 0 Not mentioned	18 788
1/37-38	28-29	Do you feel there is adequate consultation between you and hospital medical staff about:		
1/37	28	Admission of patients	1 Yes 2 No 3 Qualified answer 4 Inadequate answer 0 Blank	475 72 - 3 256
1/38	29	Discharge of patients	1 Yes 2 No 3 Qualified answer 4 Inadequate answer 0 Blank	212 318 4 16 256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/39	30	Do you consider the arrangements for domiciliary consultations are:-	1 Satisfactory 2 Not satisfactory 3 Qualified answer 4 Inadequate answer 0 Blank	522 21 6 1 256
1/40	31	Could you estimate how many domiciliary consultations you have asked for in the last twelve months for patients with terminal illness	0 None 1 One 2 Two - four 3 Five or more 4 Inadequate answer 5 Blank	162 51 181 118 38 256
1/41	32	How many nights a week are you on call on average for cases other than obstetrics	1 Every night 2 5 or 6 3 3 or 4 4 2 or 3 5 1 or 2 6 None 7 Less often than once a week 8 Inadequate answer 0 Blank	54 51 159 17 240 13 7 9 256
1/42	33	Do you ever use an emergency service for night calls	1 Yes 2 No 3 Inadequate answer 0 Blank	123 426 1 256
1/43	34	Do you think an emergency service for night calls is a good idea or not	1 Good idea 2 Not a good idea 3 Qualified answer 4 Inadequate answer 0 Blank	323 176 45 6 256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/44	35	For patients at home with terminal illness do you find the district nursing service:-	1 Very helpful 2 Moderately helpful 3 Not helpful 4 Qualified answer 5 Inadequate answer 0 Blank	463 80 1 1 5 256
1/45	36	Would you like to see any changes in the service or in the way it is organised	1 Yes 2 No 3 Qualified answer 4 Inadequate answer 0 Blank	203 332 7 8 256
1/46	37	Is there any sort of help or care which you feel district nurses could give that they are not giving at the moment	1 Yes 2 No 3 Qualified answer 4 Inadequate answer 0 Blank	73 458 5 14 256
1/47	38	If a patient needs just nursing care that relatives are able and prepared to give do you tend to ask the district nurse to visit or not	1 Ask district nurse to visit 2 Not 3 Qualified answer 4 Inadequate answer 0 Blank	222 306 17 5 256
		1st Part		
1/48	39	Are the health visiting and district nursing services in this area separate or combined	1 Combined	96

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
		2nd Part IF SEPARATE for patients at home with terminal illness do you find the health visitor services:-	2 Very helpful 3 Moderately helpful 4 Not helpful 5 Inadequate answer to second part 6 Inadequate answer to first part 7 Qualified answer to second part 0 Blank	126 110 186 17 8 7 256
1/49	40	Would you describe the home help services in your area as:-	1 Adequate 2 Rather inadequate 3 Very inadequate 4 Qualified answer 5 Inadequate answer 0 Blank	149 238 153 3 7 256
1/50-58	41-49	Here is a list of services which are available through Local Authority and Voluntary organisations in some areas. Can you tell me first which are available in your area, which ones have you made use of, which ones would you like extended or introduced		
			AVAILABLE / USED / LIKE EXTENDED/INTRODUCED	
1/50	41	Meals on Wheels	1 Yes / Yes / Yes 2 Yes / Yes / No 3 Yes / No / Yes 4 Yes / No / No 5 No / - / Yes 6 No / - / No 7 Don't know / - / Yes 8 Don't know / - / No 9 Inadequate answer 0 Blank	113 306 8 62 21 21 3 2 14 256

CARD/COLUMN	VAR No	TITLE	CODES			MARGINALS
				AVAILABLE	USED	LIKE EXTENDED/ INTRODUCED	
1/51	42	Special laundry service	1	Yes	Yes	Yes	3
			2	Yes	Yes	No	129
			3	Yes	No	Yes	2
			4	Yes	No	No	33
			5	No	-	Yes	180
			6	No	-	No	129
			7	Don't know	-	Yes	13
			8	Don't know	-	No	24
			9	Inadequate answer			37
			0	Blank			256
1/52	43	Free supply of incontinence pads	1	Yes	Yes	Yes	18
			2	Yes	Yes	No	331
			3	Yes	No	Yes	7
			4	Yes	No	No	59
			5	No	-	Yes	74
			6	No	-	No	25
			7	Don't know	-	Yes	8
			8	Don't know	-	No	17
			9	Inadequate answer			11
			0	Blank			256
1/53	44	Service for disposing of incontinence pads	1	Yes	Yes	Yes	1
			2	Yes	Yes	No	86
			3	Yes	No	Yes	1
			4	Yes	No	No	22
			5	No	-	Yes	170
			6	No	-	No	190
			7	Don't know	-	Yes	14
			8	Don't know	-	No	55
			9	Inadequate answer			11
			0	Blank			
1/54	45	Bathing service	1	Yes	Yes	Yes	12
			2	Yes	Yes	No	178
			3	Yes	No	Yes	4
			4	Yes	No	No	39
			5	No	-	Yes	158
			6	No	-	No	137
			7	Don't know	-	Yes	1
			8	Don't know	-	No	9
			9	Inadequate answer			12
			0	Blank			256

CARD/COLUMN	VAR No	TITLE	CODES			MARGINALS
				AVAILABLE	USED	LIKE EXTENDED/ INTRODUCED	
1/55	46	Supply sickroom equipment	1	Yes	Yes	Yes	58
			2	Yes	Yes	No	307
			3	Yes	No	Yes	12
			4	Yes	No	No	65
			5	No	-	Yes	43
			6	No	-	No	47
			7	Don't know	-	Yes	3
			8	Don't know	-	No	4
			9	Inadequate answer			11
			0	Blank			256
1/56	47	Night nursing service	1	Yes	Yes	Yes	48
			2	Yes	Yes	No	41
			3	Yes	No	Yes	17
			4	Yes	No	No	27
			5	No	-	Yes	282
			6	No	-	No	104
			7	Don't know	-	Yes	8
			8	Don't know	-	No	11
			9	Inadequate answer			12
			0	Blank			256
1/57	48	Night sitting service	1	Yes	Yes	Yes	68
			2	Yes	Yes	No	60
			3	Yes	No	Yes	14
			4	Yes	No	No	29
			5	No	-	Yes	285
			6	No	-	No	67
			7	Don't know	-	Yes	9
			8	Don't know	-	No	7
			9	Inadequate answer			11
			0	Blank			256
1/58	49	Geriatric Social Worker	1	Yes	Yes	Yes	24
			2	Yes	Yes	No	131
			3	Yes	No	Yes	20
			4	Yes	No	No	50
			5	No	-	Yes	174
			6	No	-	No	111
			7	Don't know	-	Yes	5
			8	Don't know	-	No	19
			9	Inadequate answer			16
			0	Blank			256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
		INTERVIEW (POSTAL)		
1/59	50	Is there any other home service for the terminally ill in your area. IF YES have you used it	1 No other service 2 Yes, other service(s) used 3 Yes, other service(s) not used 4 Yes, other service(s) inadequate if used 5 Yes, other services some used some not 6 Inadequate if other service 0 Blank	453 29 7 22 4 35 256
1/60	51	Are there any changes you would like to see in any of these services	1 Yes 2 No 3 Inadequate answer 0 Blank	191 303 56 256
1/61	52	Is there any other service you feel would be helpful in the care of terminally ill patients	1 Yes 2 No 3 Inadequate answer 0 Blank	83 387 80 256
1/62	53	On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution or would you say this was equally balanced	1 Most accept responsibility 2 Most seek admission 3 Equally balanced 4 Inadequate answer 0 Blank	179 134 225 12 256
1/63-73	54-64	Which if any of these things do you think prevent more people being looked after in the community rather than in hospital:		

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/63	54	Unsuitable housing	1 Yes 0 Not mentioned	308 498
1/64	55	Unwillingness of relatives to look after them	1 Yes 0 Not mentioned	486 320
1/65	56	Absence of suitable relatives	1 Yes 0 Not mentioned	493 313
1/66	57	Inadequate home nursing services	1 Yes 0 Not mentioned	116 690
1/67	58	Inadequate other supporting services	1 Yes 0 Not mentioned	162 644
1/68	59	Tendency of hospital doctors to admit unnecessarily	1 Yes 0 Not mentioned	20 786
1/69	60	Tendency not to discharge people when reasonable	1 Yes 0 Not mentioned	27 779
1/70	61	Overwork of general practitioners	1 Yes 0 Not mentioned	138 668
1/71	62	None of these	1 Yes 0 Not mentioned	- 806
1/72	63	Overcode one or two with most effect	1 Yes 0 Not mentioned	56 750
1/73	64	Inadequate answer	1 Yes 0 Not mentioned	14 792
1/74-80 to 2/7-10	65-71 to 72-75	Which contributes most		
1/74	65	Unsuitable housing	1 Yes 0 Not mentioned	39 767
1/75	66	Unwillingness of relatives to look after them	1 Yes 0 Not mentioned	263 543

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/76	67	Absence of suitable relatives	1 Yes 0 Not mentioned	216 590
1/77	68	Inadequate home nursing services	1 Yes 0 Not mentioned	10 796
1/78	69	Inadequate other supporting services	1 Yes 0 Not mentioned	31 775
1/79	70	Tendency of hospital doctors to admit unnecessarily	1 Yes 0 Not mentioned	2 804
1/80	71	Tendency not to discharge people when reasonable	1 Yes 0 Not mentioned	- 806
2/1-4		Case number	4 digit code	
2/5-6		Card number	Card 02	806
2/7-10	72-75	Continued from card 1		
2/7	72	Overwork of general practitioners	1 Yes 0 Not mentioned	16 790
2/8	73	D.N.A. none of these or one only	1 Yes 0 Not mentioned	2 804
2/9	74	Inadequate answer	1 Yes 0 Not mentioned	56 750
2/10	75	If two tied equally code both and overcode	1 Yes 0 Not mentioned	85 721
2/11-21	76-86	Which next most		
2/11	76	Unsuitable housing	1 Yes 0 Not mentioned	75 731
2/12	77	Unwillingness of relatives to look after them	1 Yes 0 Not mentioned	165 641

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/13	78	Absence of suitable relatives	1 Yes 0 Not mentioned	218 588
2/14	79	Inadequate home nursing services	1 Yes 0 Not mentioned	23 783
2/15	80	Inadequate other supporting services	1 Yes 0 Not mentioned	54 752
2/16	81	Tendency of hospital doctors to admit unnecessarily	1 Yes 0 Not mentioned	1 805
2/17	82	Tendency not to discharge people when reasonable	1 Yes 0 Not mentioned	1 805
2/18	83	Overwork of general practitioners	1 Yes 0 Not mentioned	25 781
2/19	84	D.N.A. none of these or one only	1 Yes 0 Not mentioned	14 792
2/20	85	Inadequate answer	1 Yes 0 Not mentioned	59 747
2/21	86	If two tied equally code both and overcode	1 Yes 0 Not mentioned	85 721
2/22	87	On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them	1 Give enough time 2 Like more time 3 Qualified answer 4 Inadequate answer 0 Blank	314 219 4 13 256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/23	88	If you had more time do you think it would be appropriate for you to look after more patients who were terminally ill at home	1 Yes 2 No 3 Inadequate answer 4 Qualified answer 0 Blank	222 270 45 13 256
2/24-26	89-91	Whether a person should be told that they are dying probably depends on a number of different things. Could you say what you would probably do in these situations - all related to people with cancer who will almost certainly die within six weeks		
2/24	89	A businessman of 55 who asks directly 'Is this going to kill me doctor' would you:-	1 Say yes probably 2 Say you don't know 3 Say no 4 Change subject 5 Qualified answer 6 Inadequate answer 0 Blank	345 54 62 18 53 18 256
2/25	90	A young mother of 35 with young children who does not raise the subject and seems unaware of the prognosis would you:-	1 Tell her 2 Tell her husband 3 Tell them both 4 Tell neither 5 Qualified answer 6 Inadequate answer 0 Blank	2 534 5 1 3 5 256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/26	91	An elderly widower who asked 'This won't kill me doctor will it' would you:-	1 Agree 2 Pass it off as joke 3 Tell him truth 4 Qualified answer 5 Inadequate answer 0 Blank	189 176 83 81 21 256
2/27-33	92-98	As a general rule, if a dying patient asked his district nurse about his prognosis which of the following would you like her to do:-		
2/27	92	Change subject	1 Yes 0 Not mentioned	22 784
2/28	93	Tell him to ask the doctor	1 Yes 0 Not mentioned	286 520
2/29	94	Tell him the truth gently	1 Yes 0 Not mentioned	51 755
2/30	95	Give him hope	1 Yes 0 Not mentioned	296 510
2/31	96	If two answer code both and overcode	1 Yes 0 Not mentioned	119 687
2/32	97	Qualified answer - no code rung or more than two rung	1 Yes 0 Not mentioned	8 798
2/33	98	Inadequate answer	1 Yes 0 Not mentioned	6 800
2/34-43	99-108	If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him:-		

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/34	99	His own doctor	1 Yes 0 Not mentioned	491 315
2/35	100	Another doctor	1 Yes 0 Not mentioned	20 786
2/36	101	A vicar, priest, minister	1 Yes 0 Not mentioned	57 749
2/37	102	Spouse	1 Yes 0 Not mentioned	37 769
2/38	103	Other close relative	1 Yes 0 Not mentioned	19 787
2/39	104	A nurse	1 Yes 0 Not mentioned	1 805
2/40	105	Other	1 Yes 0 Not mentioned	- 806
2/41	106	Qualified answer	1 Yes 0 Not mentioned	19 787
2/42	107	Inadequate answer	1 Yes 0 Not mentioned	8 798
2/43	108	No one	1 Yes 0 Not mentioned	6 800
2/44	109	Do you think that close bereaved should:-	1 Always be offered a sedative 2 Generally be offered a sedative 3 Only exceptionally be offered a sedative 4 Qualified answer 5 Inadequate answer 0 Blank	122 259 141 21 7 256
2/45-53	110-118	What do you prescribe on such circumstances		
2/45	110	Sedative and tranquilliser	1 Yes 0 Not mentioned	187 619

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/46	111	Hypnotic	1 Yes 0 Not mentioned	39 767
2/47	112	Sedative, tranquilliser and hypnotic	1 Yes 0 Not mentioned	206 600
2/48	113	Antidepressant	1 Yes 0 Not mentioned	2 804
2/49	114	Sedative, tranquilliser and antidepressant	1 Yes 0 Not mentioned	5 801
2/50	115	Hypnotic, and antidepressant	1 Yes 0 Not mentioned	2 804
2/51	116	Sedative, tranquilliser, hypnotic, and antidepressant	1 Yes 0 Not mentioned	6 800
2/52	117	Other	1 Yes 0 Not mentioned	78 728
2/53	118	Inadequate answer	1 Yes 0 Not mentioned	98 708
2/54	119	Content contains barbiturate, phenobarbs, amylobarbs etc	1 Yes 2 No 3 Inadequate answer 0 Blank	269 182 98 257
2/55	120	Do you think that close bereaved should be given some medical or nursing supervision for a while	1 Yes, medical supervision 2 Yes, nursing supervision 3 No 4 Both nursing and medical 5 Qualified answer 6 Inadequate answer 0 Blank	162 22 291 19 52 4 256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/56	121	Apart from any obstetric beds do you as a general practioner have direct access to any N.H.S. beds where you retain full responsibility for treatment of your patients while in hospital	1 No 2 Inadequate answer 0 Blank	387 4 415
2/57	122	IF YES can you use any of them for patients in terminal care	1 Yes 2 No 3 Inadequate answer 0 Blank	129 26 4 647
2/58	123	Would you like any such beds, or more beds, that you could use for patients who are terminally ill	1 Yes 2 No 3 Inadequate answer 0 Blank	387 131 32 256
		Interview only		
2/59	124	Can you think of any particular patient with a terminal illness in your own practice during the last six months, who had to be looked after - at home, although some other arrangement would have been better	1 D.N.A. (Postal) 2 Yes 3 No 4 Inadequate answer 0 Blank	441 40 67 2 256
		Interview only		
2/60	125	Have you had any patients or families who have been unwilling to accept district nursing care in the last six months	1 D.N.A. (Postal)	441

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/60	125	Continued	2 Yes 3 No 4 Inadequate answer 0 Blank	19 89 1 256
2/61	126	Number of doctors	1 Single handed 2 In partnership of 2 - or two doctors 3 In partnership of 3 - or three doctors 4 In partnership of 4 - or four doctors 5 In partnership of 5 or more, or five or more 6 Inadequate answer 0 Blank	106 121 178 80 61 4 256
2/62	127	Overcode at above question	1 Assistants (not counted as partner) 0 Blank	12 794
		NUMBER OF PATIENTS		
2/63	128	Could you tell me the approximate number of N.H.S. patients you (yourself) look after	0 None 1 Under 2000 2 2000 - 2499 3 2500 - 2999 4 3000 - 3499 5 3500 or more 6 Inadequate answer 7 Blank	1 40 106 175 153 68 7 256
		ATTACHED STAFF		
2/64	129-133	Have you any local authority staff attached to your practice such as:-		
2/64	129	A district nurse	1 Yes 0 Not mentioned	272 534
2/65	130	A health visitor	1 Yes 0 Not mentioned	256 550

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/66	131	A social worker	1 Yes 0 Not mentioned	41 765
2/67	132	None	1 Yes 0 Not mentioned	230 576
2/68	133	Inadequate answer	1 Yes 0 Not mentioned	4 802
2/69-74	134-139	ANCILLARY HELP Do you have any ancillary help such as:-		
2/69	134	Secretary	1 Yes 0 Not mentioned	439 367
2/70	135	Receptionist	1 Yes 0 Not mentioned	473 333
2/71	136	Nurse	1 Yes 0 Not mentioned	143 663
2/72	137	Other	1 Yes 0 Not mentioned	40 766
2/73	138	None	1 Yes 0 Not mentioned	26 780
2/74	139	Inadequate answer	1 Yes 0 Not mentioned	4 802
2/75	140	Would you like to be informed about the results of this study	1 Yes 2 No 3 Inadequate if would like to know 0 Blank	515 31 4 256
2/76	141	If postal and wanted interview too	1 Yes 2 No 0 Blank	16 - 790
2/77	142	Length of interview	1 D.N.A. (postal) 2 Less than 30 minutes 3 30 - 45 minutes 4 45 minutes - 1 hour 5 1 hour - 1½ hours 6 1½ hours - 2 hours 7 2 hours or more 8 Inadequate answer 0 Blank	441 24 60 14 6 - - 5 256

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
2/78-79	143	Month in which interview was done or questionnaire completed	1969	
			7 July	31
			8 August	100
			9 September	79
			0 October	126
			11 November	89
			12 December	87
			1970	
			1 January	21
			2 February	7
			3)	2
			4) Undefined codes	1
			5)	6
			6)	1
			Blank	256
2/80		Unused	Unused	
3/1-4		Case number	4 digit code	
3/5-6		Card number	Card 03	806
3/7	144	Interviewer	9 D.N.A. (postal)	441
			0 Lisbeth Hockey	10
			1 Wyn Tucker	12
			2 John Bond	22
			3 Kathleen Field	1
			4 Stella Brown	21
			5 Angela Savage	8
			6 Ann Griffiths	7
			7 Margo ?	5
			8 Beryl Davies	12
			- Mollie Richards	5
			+ ?	6
			Blank	256
3/8	145	Number of patients with main questionnaire completed		
			0 None	8
			1 One	274
			2 Two	207
			3 Three	114
			4 Four	48
			5 Five	50
			6 Six	44
			7 Seven	-
			8 Eight	9
			9 Nine	28

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/8	145	Continued	- 10	21
			+ 11 or more	-
			Blank	3
3/9	146	Number of patients with main questionnaire or questionnaire 1 second part completed		
			0 None	-
			1 One	266
			2 Two	197
			3 Three	131
			4 Four	52
			5 Five	55
			6 Six	37
			7 Seven	7
			8 Eight	-
			9 Nine	27
			- Ten	20
			+ 11 or more	11
			Blank	3
3/10	147	Doctors response	0 No doctor recorded	81
			1 Dr. refused/no reply temporary away/ill	125
			2 Dr. moved/died/ returned	19
			3 Dr. not traced or name not known	29
			4 Dr. name refused	2
			Blank	550
3/11	148	Sex	1 Male	656
			2 Female	27
			3 Inadequate answer	11
			0 Blank	112
3/12	149	Age codes at 1st October 1969	1 Under 30 - born October 39 or later	7
			2 30 - 34 - born between October 1934 and September 1939	48
			3 35 - 39 - born between October 1929 and September 1934	76
			4 40 - 44 - born between October 1924 and September 1929	105
			5 45 - 49 - born between October 1919 and September 1924	120

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/12	149	Continued	6 50 - 54 - born between October 1914 and September 1919	133
			7 50 - 59 - born between October 1909 and September 1914	101
			8 60 - 64 - born between October 1904 and September 1909	65
			9 65 - 69 - born between October 1899 and September 1904	22
			0 70 and over - born before October 1899	6
			- Born before October 1899	11
			Blank	112
3/13	150	Number of Principals	0 None	-
			1 One	136
			2 Two	160
			3 Three	216
			4 Four	99
			5 Five	49
			6 Six	6
			7 Seven	1
			8 Eight	-
			9 Nine	-
			+ Ten or more	-
			- Inadequate answer	27
			Blank	112
3/14	151	Number of Assistants	0 None	618
			1 One	57
			2 Two	-
			3 Three	-
			4 Four	-
			5 Five	-
			6 Six	-
			7 Seven	-
			8 Eight	-
			9 Nine	-
			+ Ten or more	-
			- Inadequate answer	19
			Blank	112

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
3/15	152	Rural practice payments code (RPPC)	1 Eligible	83
			2 Eligible	-
			3 Eligible	12
			4 Ineligible	565
			5 Ineligible	11
			6 Ineligible	4
			7 Inadequate answer	19
			0 Blank	112
3/16	153	Medical practice committee area codes	1 Designated area	284
			2 Intermediate area	126
			3 Restricted area	49
			4 Open area	216
			5 Inadequate answer	19
			0 Blank	112
3/17	154	Group practice payments code	1 Eligible	376
			2 Ineligible	299
			3 Inadequate answer	19
			0 Blank	112
3/18	155	Patients numbered within doctor by sequence	1 One	416
			2 Two	160
			3 Three	63
			4 Four	23
			5 Five	15
			6 Six	7
			7 Seven	3
			8 Eight	3
			9 Nine	3
			+ D.N.A. (no doctor, or doctor untraced, or name refused)	112
			- Undefined code	1
3/19-80		Unused	Unused	

Y35

Medical Care Research Unit,
Institute of Community Studies,
18 Victoria Park Square,
London, E.2.

PROBLEMS OF DOMICILIARY CARE IN TERMINAL ILLNESS

INTRODUCTION: I'd first like to stress that anything you tell us will be treated confidentially. In any report we write on this study it will not be possible to identify any individuals.

1. A general practitioner on our pilot study said that: 'no anticipated deaths should be allowed to happen at home' Do you agree or disagree with this?

Agree.....1
Disagree.....2

Why do you think that?

2. Do you find it usually easy, rather difficult, or very difficult to get admission into a suitable N.H.S. Institution for:-

a) A young patient with a short term terminal illness

Easy.....0
Rather difficult.....1
Very difficult.....2

b) An old patient with a short term terminal illness

Easy.....0
Rather difficult.....1
Very difficult.....2

c) An old patient likely to need long term nursing care

Easy.....0
Rather difficult.....1
Very difficult.....2

d) A young patient with a progressive degenerative condition

Easy.....0
Rather difficult.....1
Very difficult.....2

e) An old patient with an acute infection.

Easy.....0
Rather difficult.....1
Very difficult.....2

Comments

3. In your area which if any of these do you think you need more of:-

PROMPT	Need More Yes	No	Most Needed
Short term general hospital beds	1	0	1
Chronic hospital beds	2	0	2
Geriatric beds	3	0	3
Mental hospital places	4	0	4
District nurse services	5	0	5
Home help services	6	0	6

4. IF MORE THAN ONE NEEDED Which one do you think is needed most? CODE ABOVE

Comments

5. Do you feel there is adequate consultation between you and hospital medical staff about:

a) Admission of patients
Yes.....1
No.....2

b) Discharge of patients
Yes.....3
No.....4

Comments

6. Do you consider the arrangements for domiciliary consultations are:-

PROMPT Satisfactory.....5
Or Not satisfactory.....6

Comments

7. Could you estimate how many domiciliary consultations you have asked for in the last twelve months for patients with terminal illness.

Number.....

8. How many nights a week are you on call on average for cases other than obstetrics?

Every night...1
5 or 6.....2
3 or 4.....3
1 or 2.....4
None.....5

9. Do you ever use an emergency service for night calls?

Yes.....6
No.....7

10. Do you think an emergency service for night calls is a good idea or not?

Good idea.....1
Not a good idea.....2

Comments

11. For patients at home with terminal illness do you find the district nursing service:-

PROMPT
Very helpful.....1
Moderately helpful....2
Not helpful.....3

12. Would you like to see any changes in the service or in the way it is organised?

Yes.....4
No.....5

IF YES (4) What changes?

13. Is there any sort of help or care which you feel district nurses could give that they are not giving at the moment?

Yes.....6
No.....7

IF YES (6) What sort of help?

14. If a patient needs just nursing care that relatives are able and prepared to give do you tend to ask the district nurse to visit or not.

Ask district nurse to visit...1
Not.....2

Comments

15. Are the health visiting and district nursing services in this area separate or combined?

Separate.....1
Combined.....2

IF SEPARATE (1) For patients at home with terminal illness do you find the health visitor service:-

Very helpful.....3
PROMPT
Moderately helpful.....4
Not helpful.....5

Comments

16. Would you describe the home help service in your area as:

Adequate.....6
PROMPT
Rather inadequate.....7
Very inadequate.....8

Comments

17. Here is a list of services which are available through Local Authority and Voluntary organisations in some areas. Can you tell me first which are available in your area:- CODE a)
b) Which ones have you made use of?
c) Which ones would you like extended or introduced?

	a)Available	b)Used	c)Like extended or introduced
Meals on wheels	1	1	1
Special laundry service	2	2	2
Free supply of incontinence pads	3	3	3
Service for disposing of incontinence pads	4	4	4
Bathing service	5	5	5
Supply of sickroom equipment	6	6	6
Night nursing service	7	7	7
Night sitting service	8	8	8
Geriatric social worker	9	9	9

18 a) Is there any other home service for the terminally ill in your area?
Yes.....5
No.....6

IF YES (5) (i) What?

(ii) Have you used it?
Yes.....7
No.....8

18 b) Are there any changes you would like to see in any of those services?
Yes.....1
No.....2

IF YES (1) What are they?

19. Is there any other service you feel would be helpful in the care of terminally ill patients?
Yes 3
No.....4

IF YES (3) What are they?

20. On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution or would you say this was equally balanced:
Most accept reponsibility.....5
Most seek admission.....6
Equally balanced.....7

Comments

21. Which if any of these things do you think prevent more people being looked after in the community rather than in hospital:

PROMPT	Any effect Yes	Any effect No	Most	Next Most
Unsuitable housing	1	0	1	1
Unwillingness of relatives to look after them	2	0	2	2
Absence of suitable relatives	3	0	3	3
Inadequate home nursing services	4	0	4	4
Inadequate other supporting services	5	0	5	5
Tendency of hospital drs. to admit unnecessarily	6	0	6	6
Tendency not to discharge people when reasonable	7	0	7	7
Overwork of general pratitioners	8	0	8	8

22. Which contributes most? } CODE ABOVE
Which next most? }

23. On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them.
Give enough time.....1
Like more time.....2

24. If you had more time do you think it would be appropriate for you to look after more patients who were terminally ill at home?
Yes.....3
No.....4

Comments

25. Whether a person should be told that they are dying probably depends on a number of different things. Could you say what you would probably do in these situations - all related to people with cancer who will almost certainly die within six weeks.

a) A businessman of 55 who asks directly 'Is this going to kill me doctor?'
Would you:-

Say yes probably.....1
Say you don't know 2
PROMPT Say no.....3
Change subject.....4

b) A young mother of 35 with young children who does not raise the subject and seems unaware of the prognosis.
Would you:-

Tell her.....1
Tell her husband.....2
PROMPT Tell them both.....3
Tell neither.....4

c) An elderly widower who asks: 'This won't kill me doctor will it?'
Would you:-

Agree.....1
PROMPT Pass it off as joke.....2
Tell him truth.....3

Comments

26. As a general rule, if a dying patient asked his district nurse about his prognosis which of the following would you like her to do:-

Change subject.....1
Tell him to ask the doctor....2
PROMPT Tell him truth gently.....3
Give him hope.....4

27. If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him:-

His own doctor.....1
Another doctor.....2
A vicar, priest, minister.....3
PROMPT Spouse.....4
Other close relative.....5
A nurse.....6
Or who?.....
SPECIFY

28. Do you think that close bereaved should:-

Always be offered a sedative.....1
PROMPT Generally be offered a sedative..2
Only exceptionally be offered a sedative.....3

29. What do you prescribe in such circumstances?

30. Do you think that close bereaved should be given some medical or nursing supervision for a while?

Yes, medical supervision.....4
Yes, nursing supervision.....5
No.....6

IF YES (4 or 5) For how long?

Comments

31. Apart from any obstetric beds do you as a general practitioner have direct access to any N.H.S. beds where you retain full responsibility for treatment of your patients while in hospital.

Yes.....1
No.....2

IF YES (1) Can you use any of them for patients in terminal care?

Yes.....3
No.....4

32. Would you like any such beds, or more beds, that you could use for patients who are terminally ill?

Yes.....5
No. 6

33. Can you think of any particular patient with a terminal illness in your own practice during the last six months, who had to be looked after at home, although some other arrangement would have been better.

Yes.....7
No.....8

IF YES (7) Can you tell me about them
PROBE TO FIND OUT ABOUT PERSON, ILLNESS, FAMILY CIRCUMSTANCES, ATTEMPTS TO MAKE OTHER ARRANGEMENTS, REASONS FOR FAILURE.

34. Have you had any patients or families who have been unwilling to accept district nursing care in the last six months?

Yes.....1
No.....2

IF YES (1) What were the reasons?

Finally a few details about your practice.

35. Do you work single handed or with others?

Single handed.....1
With others.....0

IF WITH OTHERS (0) How many doctors work here then, including yourself?

Two.....2
Three.....3
Four.....4
Five or more.....5

36. Could you tell me the approximate number of N.H.S. patients you (yourself) look after?

Under 2000.....1
2000 - 2499.....2
2500 - 2999.....3
3000 - 3499.....4
3500 or more.....5

37. Have you any local authority staff attached to your practice, such as:-

A distric nurse.....1
A health visitor....2
A social worker.....3
None.....0

38. Do you have any ancillary help such as:-

Secretary.....5
Receptionist.....6
Nurse.....7
Other.....8
None.....0

39. Would you like to be informed about the results of this study?

Yes.....1
No.....2

40. Have you any other comments or suggestions about the general practitioners role and domiciliary care in terminal illness?

41. Are there any questions you would like to ask me about the Institute or the survey?

THANK DOCTOR FOR HELP

(i) Length of interview:-

Less than 30 mins.....1
30 < 45 mins.....2
45 mins < 1 hr.....3
1 hr. < 1½ hr.....4
1½ hrs. < 2 hrs.....5
2 hrs or more.....6

(ii) Date of interview

(iii) Interviewer

Medical Care Research Unit
Institute of Community Studies
18 Victoria Park Square,
London, E.2.

PROBLEMS OF DOMICILIARY CARE IN TERMINAL ILLNESS

Most questions can be answered by putting a tick beside the appropriate answer but please write in any comments or qualifications you want to make.

1 A general practitioner on our pilot study said that 'no anticipated deaths should be allowed to happen at home' Do you agree or disagree with this?

Agree . . . .
Disagree . . . . . .

2 Do you find it usually easy, rather difficult, or very difficult to get admission into a suitable N.H.S. institution for

a) A young patient with a short term terminal illness

Easy . . . . . .
Rather difficult. . . . .
Very difficult .

b) An old patient with a short term terminal illness

Easy . . . . . .
Rather difficult.....
Very difficult.....

c) An old patient likely to need long term nursing care

Easy . . . . . .
Rather difficult . . . . . .
Very difficult. . . . . .

d) A young patient with a progressive degenerative condition

Easy..... . . . . .
Rather difficult . . . . . .
Very difficult.. . . . . .

e) An old patient with an acute infection

Easy . . . . . .
Rather difficult.....
Very difficult.....

3. In your area which if any of these do you think you need more of?

4. Which one do you feel is needed most?

	Need More	Most Needed
Short term general hospital beds		
Chronic hospital beds		
Geriatric beds		
Mental hospital places		
District nurse services		
Home help services		
None		

Comments

5. Do you feel there is adequate consultation between you and hospital medical staff about.

a) Admission of patients Yes.. ..
No. . . . .

b) Discharge of patients
Yes.....
No..... ...

Comments

6. Do you consider the arrangements for domiciliary consultations are:-
Satisfactory.....
Not satisfactory.....

Comments

7. Could you estimate how many domiciliary consultations you have asked for in the last twelve months for patients with terminal illness
Number.....

8. How many nights a week are you on call on average for cases other than obstetrics?
Every Night.....
5 or 6. .....
3 or 4..... ....
1 or 2.....
None.....

9. Do you ever use an emergency service for night calls?
Yes.....
No.....

10. Do you think an emergency service for night calls is a good idea or not?
Good idea.....
Not a good idea. ...

Comments

11. For patients at home with terminal illness do you find the district nursing service -

Very helpful... ... .
Moderately helpful. .....
Not helpful... . ...

12. Would you like to see any changes in the service or in the way it is organised?

Yes. ....
No.. ... .

If yes, what changes?

13. Is there any sort of help or care which you feel district nurses could give that they are not giving at the moment?

Yes... .. .. .
No .

If yes, what sort of help?

14. If a patient needs just nursing care that relatives are able and prepared to give do you tend to ask the district nurse to visit or not.

Ask district nurse to visit .
Not... ....

Comment

15. (Please skip this question if health visitors and district nurses are combined in your area)

For patients at home with terminal illness do you find the health visitor service

Very helpful..... .....
Moderately helpful.....
Not helpful. ....

16. Would you describe the home help service in your area as:

Adequate.... .. ..
Rather inadequate.....
Very inadequate.... . ....

Comments

17. Here is a list of services which are available through Local Authority and Voluntary organisations in some areas but not everywhere Please would you indicate:-

a) Which are available in your area
b) Which ones you have made use of.
c) Which ones you would like to see extended or introduced.

	a) Available	b) Used	c) Like extended or introduced
Meals on wheels			
Special laundry service.			
Free supply of incontinence pads			
Service for disposing of incontinence pads			
Bathing service			
Supply of sickroom equipment			
Night nursing service			
Night sitting service			
Geriatric social worker			
Any other service please indicate what			

18. Are there any changes you would like to see in any of these services?

Yes..... .
No.. . .. .. .

If yes, what are they?

19. Is there any other service you feel would be helpful in the care of terminally ill patients?

Yes.....
No.....

If yes, what?

20 On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution.

Most accept responsibility.. .....
Most seek admission..... ....
Equally balanced.... . ...

Comments

21. Which if any of these things do you think prevent more people being looked after in the community rather than in hospital.

22. Which contributes most? - Please put a '1' beside it in the right hand column below

Which next most?- Please mark with 2.

	Any effect	Two with most effect
Unsuitable housing		
Unwillingness of relatives to look after them		
Absence of suitable relatives		
Inadequate home nursing services		
Inadequate other supporting services		
Tendency of hospitals to admit unnecessarily		
Tendency not to discharge people when reasonable		
Overwork of general practitioners		

23. On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them

Give enough time. . .. ...
Like more time.. . ...

24. If you had more time do you think it would be appropriate for you to look after more patients who were terminally ill at home?

Yes.. . .. .
No.. . . ..

Comments

25. Whether a person should be told that they are dying probably depends on a number of different things But could you say what you would probably do in these situations - all related to people with cancer who will almost certainly die within six weeks.

a) A businessman of 55 who asks directly 'Is this going to kill me doctor?'

Say yes probably..... .... ..
Say you don't know. .
Say no. . .. .
Change subject.. ... .

b) A young mother of 35 with young children who does not raise the subject and seems unaware of the prognosis

Tell her . ...
Tell her husband. ... .
Tell them both . . ..
Tell neither. . . ..

c) An elderly widower who asks: 'This won't kill me doctor will it?'

Agree..... .....
Pass it off as joke.. .....
Tell him truth. .....

Comments

26. As a general rule, if a dying patient asked his district nurse about his prognosis which of the following would you like her to do -

Change subject .
Tell him to ask the doctor,...
Tell him truth gently .
Give him hope.. ....

27. If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him

His own doctor. ...
Another doctor . ..
A vicar, priest, minister.. ..
Spouse. . ...
Other close relative. .....
A nurse. .. . .
Or who?. .. . .

28. Do you think that close bereaved should:-

Always be offered a sedative.....
Generally be offered a sedative ..
Only exceptionally be offered a sedative.. ..

29. What do you prescribe on such circumstances?

30. Do you think that close bereaved should be given some medical or nursing supervision for a while?

Yes medical supervision... .
Yes nursing supervision.. . . ...
No ....

Comments.

31. Apart from any obstetric beds do you as a general practitioner have direct access to any N.H.S. beds where you retain full responsibility for treatment of your patients while in hospital.

Yes..... ...
No. .. ..

If yes can you use any of these for patients in terminal care?

Yes... .....
No . .....

32. Would you like any such beds, or more beds, that you could use for patients who are terminally ill?

Yes... .....
No. .....

Finally a few details about your practice.

33. Do you work:

Single handed.....
In partnership of two.....
In partnership of three . ..
In partnership of four.....
In partnership of five or more... ... .

34. Approximate number of N.H.S. patients If in partnership please estimate the number you yourself look after.

Under 2000. . .. .
2000 - 2499 . . ..
2500 - 2999. .....
3000 - 3499..... . .....
3500 or more.. ... .

35. Have you any local authority staff attached to your practice, such as.

A district nurse..... .. ...
A health visitor.. .. ..
A social worker. .....
None..... ... .

36. Do you have any ancillary help such as.

Secretary..... ..... .
Receptionist. ... .
Nurse. .. ..
Other. ....
None . . ..

Would you like to be informed about the results of this study?

Yes.....
No . ...

If you would like to discuss any points raised by this study personally please put a tick in this box and we will make an appointment to come and see you.

WE ARE VERY GRATEFUL FOR YOUR HELP - If you have any points you would like to make please record them here, or on the blank sheet enclosed.

G.P.

1 Area

2 } Serial no.
3 }

4 Main Q / Q1 2nd part

5 Interview / Postal

6 Agrees no anticipated deaths at home

7 Young - short } Admission
8 Old - short } easy / difficult
9 Old - long }
10 Young - long }
11 Old - acute }

12 Summary of difficulty

13 Need more beds etc.

14 Need more

15 Admission } Adequate
16 Discharge } consultation

17 Dom. consultation satisfactory

18 " " - numbers

19 Night's on call

20 Night emergency service used

21 " " good idea

22 Helpful } District
23 Changes } nursing
24 Other help } service
25 Asked to visit }

26 D.H & H.V combined / H.V. helpful

27 H.H adequate

28 Meals on wheels } Available /
29 Laundry } Used /
30 Supply } Incontinence } Idea
31 Disposal of pads }
32 Bathing }
33 Equipment }
34 Night nursing }
35 Night sitting }
36 Geriatric social worker }

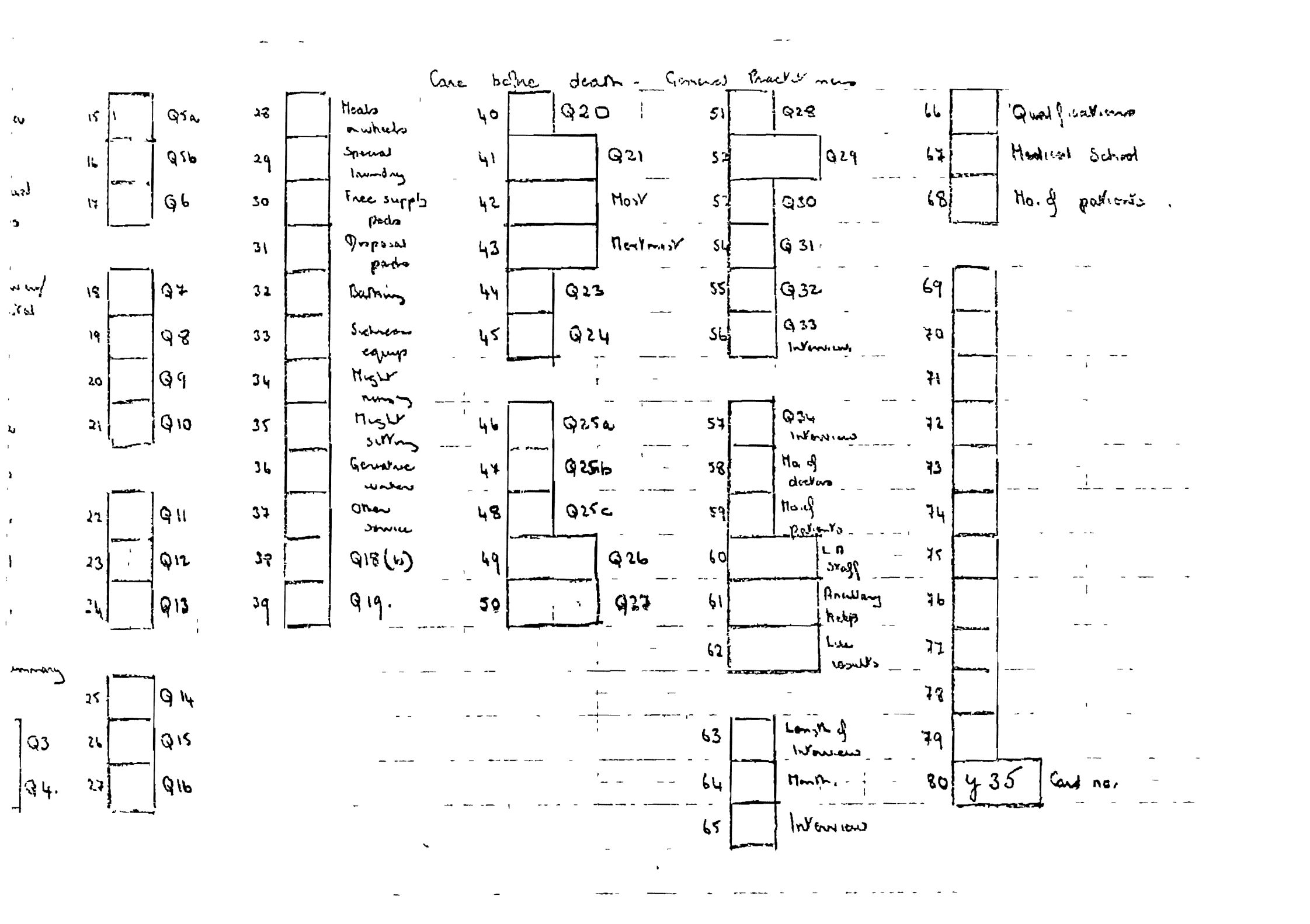
37 Other service - exists

38 Changes

39 Other service helpful

40 Relatives accept response.

41 All reasons } Preventive care
42 How } in community
43 Howmuch }
44 Enough time
45 If more time appropriate use
46 Business man } Tell
47 Mother with young children }
48 Elderly widows }
49 What should district nurse do
50 Best person to tell
51 Offered secretaries
52 What pressures
53 Supervision for bereaved
54 Access to beds
55 Like beds for terminal patient.
56 Any patients at home when required
57 Family unwilling to accept DN
58 No of doctors
59 No. of patients
60 LA staff attached
61 Ancillary help
62 Know about study / want interview
63 Length of interview
64 Month of interview
65 Interviewer
66 No of patients with main questionnaire
67 " " with Q 1 or 2.
68 Reason for failure to interview G.P.
69 Sex } D.H 55
70 Age group
71 No of principals
72 " " assistants
73 Rural practice payments
74 Type of area
75 Group practice payments
76
77
78
79 Patients no. with same G.P.
80 y 35


Care before death - General Practice
15 Q5a
16 Q5b
17 Q6
18 Q7
19 Q8
20 Q9
21 Q10
22 Q11
23 Q12
24 Q13
25 Q14
26 Q15
27 Q16
Q3
Q4.
28 Meals on wheels
29 Special laundry
30 Free supply pads
31 Disposal pads
32 Bathing
33 Sickroom equip
34 Night nursing
35 Night sitting
36 Genitive waters
37 Other service
38 Q18(b)
39 Q19.
40 Q20
41 Q21
42 Mor
43 Next mor
44 Q23
45 Q24
46 Q25a
47 Q25b
48 Q25c
49 Q26
50 Q27
51 Q28
52 Q29
53 Q30
54 Q31
55 Q32
56 Q33 Interviews
57 Q34 Interviews
58 No of doctors
59 No of Patients
60 LA staff
61 Ancillary Help
62 Liaison visits
63 Length of Interview
64 Month.
65 Interviewer
66 Qual of relatives
67 Medical School
68 No. of patients
69
70
71
72
73
74
75
76
77
78
79
80 y 35 Card no.

Life Before Death. G.P. Survey Card # 35

For each subject a G.P. card is punched. The subjects' serial numbers are recorded in the top left corner of the transfer sheet.

Cols 1-4 contain the serial number of the first subject for whom a G.P. card has to be punched. The Serial Numbers of the other subjects appear in the corner, thus:-

2490
2320

1	2	Area
2	7	
3	6	Serial No.
4	0	
5	1	Interview/ Postal

Here 2760 is the 1st serial number, and 2490, 2320, the 2nd and 3rd.

The total number of cards punched should correspond to the number recorded at col. 67., in this case 3.

Cols 5 - 65 Contain the information from the questionnaire and nine of these should be blank for completed questionnaires.

Col 68 records reasons for failure and is only filled in when Cols 5-65 are blank, ie when no information was obtained. When Cols 5-65 are filled, col 68 is blank.

Cols 69 - 75 contain data from the Dr. Ministry and should only be blank when col 68 is 0, 3 or 4, ie. when the doctor was not traced etc.

Cols 76 - 78 should be blank.

Cols 79 should record the number of the patients within D. by sequence. ie. in the above example, 2760 will be (1) at 79, 2490 will be (2) and 2320 will be (3). Where there was no Doctor traced/recorded etc, code 0, 3 or 4 at col 68, col 79 will be (4).

Col 80 is for the card identification number, 435.

B. When Col 5 is (1) or (4), cols 56/57/63/65 will be (9)

Life before death. G.P. Codes.

Serial number - 1st digit - Area — Col 1

Barking	1	43	27
Tooside	2	45	30
Hillingdon	3	47	29
Cheshire (NE)	4	41	34
Brentwood	5	33	29
Bridgend	6	133	27
Northumberland	7	15	13
Eastbourne	8	24	17
Birmingham	9	55	43
Thanet	0	32	26
St. Helens	X	33	25
Isle of Wight	Y	28	25
			325

2nd digit - Interval between month of death and interview month — Col 2

3 months	1 -	1	43
9 months	6 -	2	42
		3	42
		4	36
		5	—
		6	53
		7	39
		8	39
		9	31
			325

Col.4.

0 = Main questionnaire completed
1 = Questionnaire 1 second part completed (but no main questionnaire)

check totals for col 4

1 8

0 317

0 = Ill or refused [illegible] completed

1 = Questionnaire #1 2nd part completed
(but no questionnaire 2)

Col.4.

Postal/Interview Col.5

Postal (should have been and was).....1	253
Interview " " " " " 2	67
Should have been postal, was interview...3	—
" " " interview was postal...4	5
	325

Single coded

Question 1 col.6.

A general practitioner on our pilot study said that: 'no anticipated deaths should be allowed to happen at home' Do you agree or disagree with this?

Agree.....1	34	20
Disagree 2	512	303
Inadequate answer.....X	7 /812	2

Single coded, N.B. If doctor says 'it depends' this should normally be counted as disagreement

Question2

Do you find it usually easy, rather difficult, or very difficult to get admission into suitable N.H.S. Institution for:-

a) Young patient with a short term terminal illness Col.7.

b) An old patient with a short term terminal illness Col.8.

c) An old patient likely to need long term nursing care Col.9.

d) A young patient likely to need long term nursing care Col.10.

e) An old patient with an acute infection Col.11.

Easy.....0

Rather difficult.....1

Very difficult.....2

Sometimes 0, sometimes 1....3

Sometimes 1, sometimes 2,....4

Inadequate.....X

Single coded

PTO for check lists
Cols. 7-11

Question 2 Summary of difficulty Add scores for 5 parts of question 2 when codes 0,1 or 2 Count code 3 as $\frac{1}{2}$ and code 4 as $1\frac{1}{2}$

Col.12

Total Score	Code	
0	0	8
1 or $1\frac{1}{2}$	1	26
2 or $2\frac{1}{2}$	2	46
3 or $3\frac{1}{2}$	3	53
4 or $4\frac{1}{2}$	4	60
5 or $5\frac{1}{2}$	5	60
6 or $6\frac{1}{2}$	6	30
7 or $7\frac{1}{2}$	7	24
8 or $8\frac{1}{2}$	8	10
9 or $9\frac{1}{2}$	9	4
10	y	3
Inadequate	X	23
		325.

Single coded

C

Question 3 In your area which if any of these do you think you need more of:- Col.13.

Short term general hospital beds 1	150
Chronic hospital beds.....2	274
Geriatric beds.....3	286
Mental hospital places.....4	107
District nurse services.....5	78
Home help services.....6	176
None.....0	1
Inadequate answer.....X	4

May be multi-coded - except 0 or X single coded

N.B. If on the postal questionnaire they have ticked any of these in the 'most needed' but not in the 'need more' include them here.

Question 4 Which one do you feel is needed most? Col.14.

Codes as for question 3

If two coded, code both and overcodes.....y
If three " " three " " 9
If more than three coded count as inadequate.....X
If only one coded at question 3 repeat that code here
If none coded at question 3 code 0 here too.

N.B. If they have ticked more things under 'most needed', than under 'needed more' assume they reversed the headings 'in error'.

	Col 14
1	30
2	112
3	185
4	11
5	9
6	29
9	13
0	1
X	20
Y	116

Question 5 Do you feel there is adequate consultation between you and hospital medical staff about: Col.15.

a) Admission of patients

Yes.....1	275
No.....2	47
Qualified answer.....y	3
Inadequate answer.....X	

Single coded

b) Discharge of patients Col.16.

Yes.....3	124
No.....4	190
Qualified answer.....y	3
Inadequate answer.....X	8

Single coded

Question 6 Do you consider the arrangements for domiciliary consultations are:- Col.17.

PROMPT	Satisfactory..... 5	305
or	Not satisfactory.....6	15
	Qualified answer.....y	4
	Inadequate answer.....X	1

Single coded

Question 7 Could you estimate how many domiciliary consultations you have asked for in the last twelve months for patients with terminal illness Col.18.

None.....0	98
One.....1	37
Two - four.....2	104
Five or more.....3	68 N.B. Count one as two as 2-4. Code 2
Inadequate X	18

Single coded

Question 8 How many nights a week are you on call on average for cases other than obstetrics? Col.19.

Every night.....1	29
5 or 6.....2	29
3 or 4.....3	87
1 or 2.....4	146
None.....5	11
Less often than once a week.....6	5
Inadequate.....X	10
Doc 3 7	8

Single coded

Question 9 Do you ever use an emergency service for night calls? Col.20

Yes.....6	90
No 7	234
Inadequate.....X	1

Single coded

Question 10 Do you think an emergency service for night calls is a good idea or not? Col.21.

Good idea.....1	207
Not a good idea..2	87
Qualified answer.....y	27
Inadequate.....X	4

Single coded

Question 11 For patients at home with terminal illness do you find the district nursing service:- Col.22

Very helpful.....1	273
Moderately helpful.....2	46
Not helpful.....3	1
Qualified answer.....y	1
Inadequate.....X	4

single coded

Question 12 Would you like to see any changes in the service or in the way it is organised? Col.23.

Yes.....4	120
No.....5	195
Qualified answer.....y	3
Inadequate.....X	7

single coded

Question 13 Is there any sort of help or care which you feel district nurses could give that they are not giving at the moment? Col.24.

Yes.....6	46
No.....7	266
Qualified answer.....y	4
Inadequate.....X	9

single coded

Question 14 If a patient needs just nursing care that relatives are able and prepared to give do you tend to ask the district nurse to visit or not. Col.25.

Ask district nurse to visit.....1	136	
Not.....2	179	
Qualified answer.....y	6	
Inadequate.....X	4	

single coded

Question 15 Are the health visiting and district nursing services in this area separate or combined? Col.26.

Combined.....2	62	
IF SEPARATE For patients at home with terminal illness do you find the health visitor services:-		%
Very helpful.....3	67	28
Moderately helpful.....4	60	25
Not helpful.....5	113	46
Inadequate answer 2nd part.....X	12	
Inadequate answer 1st part.....9	7	
Qualified answer 2nd part.....y	4	

single-coded

/244

Question 16 Would you described the home help service in your area as: Col.27

Adequate.....6	78
Rather inadequate...../	153
Very inadequate.....8	86
Qualified answer.....y	3
Inadequate answer X	6

single coded

	col 28	col 29	col 30	col 31	col 32
1	75	3	14	1	10
2	189	85	190	55	111
3	3	2	4	1	3
4	36	24	34	16	27
5	7	105	38	97	83
6	4	70	20	101	77
7	3	9	6	11	1
8	2	16	13	37	6
x	6	11	6	6	7

Question 17

Here is a list of services which are available through Local Authority and Voluntary organisations in some areas. Can you tell me first which are available in your area:-
b) which ones have you made use of?
c) which ones would you like extended or introduced?

Meals on wheels	Col.28
Special laundry service	Col.29
Free supply of incontinence pads	Col.30
Service for disposing of incontinence pads	Col.31.
Bathing service	Col.32.
Supply of sickroom equipment	Col.33.
Night nursing service	Col.34.
Night sitting service	Col.35.
Geriatric social worker	Col.36.

Available	Used	Like extended/introduced	Code
Yes	Yes	Yes/	1
Yes	Yes	No	2
Yes	No	Yes	3
Yes	No	No	4
No	-	Yes	5
No	-	No	6
DK		Yes	7
DK		No	8
Inadequate			X

single coded

N.B. On postal assume blanks are 'NO' unless whole question blank or other indication that not answered.

	Col 33	Col 34	Col 35	Col 36
1	32	2	40	14
2	181	3	36	70
3	4	0	10	13
4	12	1	22	29
5	34	1	155	105
6	1		45	54
7		1	5	4
8	2	1	6	12
X	0	7	6	7

325 cards

Question 18 Interview Last part Q.17 (postal) Col.37

Is there any other home service for the terminally ill in your area? IF YES Have you used it?

No other service 6	282
Yes " service(s) used.....7	11
" " " not used.....8	4
" " " inad. if used.....1	9
" " services some used some not.....2	2
Inadequate if other service.....X	17

single coded

Question 18(b)

Are there any changes you would like to see in any of these services? Col.38

Yes.....1	112
No.....2	180
Inadequate.....X	33

single coded

Question 19

Is there any other service you feel would be helpful in the care of terminally ill patients? Col.39

Yes.....3	52
No.....4	230
Inadequate.....X	43

single coded

Question 20 On the whole do you find in this area that most relatives accept reasonable responsibility for home care or do they seek admission to hospital or institution or would you say this was equally balanced: Col.40

Most accept reponsibility	5	106	33
Most seek admission	6	79	25
Equally balanced	7	134	42
Inadequate answer	X	6	

single coded

Question 21 Which if any of these things do you think prevent more people being looked after in the community rather than in hospital: Col.41.

Unsuitable housing	1	177	60
Unwillingness of relatives to look after them	2	281	96
Absence of suitable relatives	3	291	99
Inadequate home nursing services	4	73	25
Inadequate other supporting services	5	98	33
Tendency of hospital drs. to admit unnecessarily	6	14	5
Tendency not to discharge people when reasonable	7	20	7
Overwork of general practitioners	8	78	27
None of these	0	9	
Inadequate answer	X	32	

325 125 32 29%

Multi-coded - except for 0 and X

N.B. Include any ticked in the columns headed two with most effect. If they have only given one or two with most effect code both here and overcode Y.

Question 22 Which contributes most? Col.42.

Which next most? Col.43.

(Codes 1 - 8 as above) D.N.A. None of these or one only..... 9

Inadequate answer.....X

single coded but if two tied equally code both and overcode Y. N.B. If two tie for most and next most the codes will be the same in cols. 42 and 43.

	Col 42	Col.43.
1	27	48 17
2	148 51	29 31
3	129 45	24 44
4	7 2	5
5	14 5	32
6	2 1	1
7	-	1
8	8 3	4
9	1 -	3
X	38	-

Question 23

On the whole do you feel you are able to give enough time to patients in terminal illness or would you like to be able to give more time to them

Col.44

Give enough time.....1 192
Like more time. 2 125
Qualified answer.....y 1
Inadequate.....X 7

single coded

Question 24

If you had more time do you think it would be appropriate for you to look after more patients who were terminally ill at home?

Col.45.

Yes.....3 142
No.....4 152
Inadequate.....X 26
Qualified answer....Y 5

SINGLE CODED

Question 25 — Whether a person should be told that they are dying probably depends on a number of different things. Could you say what you would probably do in these situations - all related to people with cancer who will almost certainly die within six weeks

Col.46.

a) A businessman of 55 who asks directly 'Is this going to kill me doctor?'
Would you:-

Say yes probably	1	203
Say you don't know	2	32
Say no	3	38 ~~Col. 5~~
Change subject	4	12
Qualified answer	y	26
Inadequate	X	14

single coded

b) A young mother of 35 with young children who does not raise the subject and seems unaware of the prognosis.
Would you :-

Tell her	1	2
Tell her husband	2	311
Tell them both	3	4
Tell neither	4	1 col.47.
Qualified answer	y	3
Inadequate	X	4

single coded

c) An elderly widower who asked. 'This won't kill me doctor will it?'
Would you?

Agree	1	122
Pass it off as joke	2	107
Tell him truth	3	41
Qualified answer	y	42 col.4 .
Inadequate	X	13

single coded

Question 26 As a general rule, if a dying patient asked his district nurse about his prognosis which of the following would you like her to do:- Col.49

Change subject	1	13
Tell him to ask the doctor	2	158
Tell him truth gently	3	28
Give him hope	4	184
If two answer code both and overcode	7	67
Qualified answer - no code rung or more than two rung 8 only		4
Inadequate	X	5

399

may be multi-coded

Question 27 If a patient is to be told that he is unlikely to recover who do you think is usually the best person to tell him:- Col.50

His own doctor	1	283
Another doctor	2	15
A vicar priest, minister	3	35
Spouse	4	23
Other close relative	5	11
A nurse	6	1
Other	0	—
Qualified answer	y	12
Inadequate	X	7
No one	9	4

May be multi-coded

Question 29. Col. 52

Intervion

Sedative or Tranquilliser	1	Addicts
Hypnotic	2	
Antidepressant	4	
Other	8	
Inadequate	X	

Convent

Contains barbiturate, phenobarb, Amylobarb etc.

Yes	4
No	0
Inad	9

Manually double coded but may have more codes of 8 as well as one of 1-7. ~~Buff~~

1	113
2	22
3	121
4	2
5	4
6	1
7	4
8	54
9	64
0	111
X	54
-	149

C

Question 28 — Do you think that close bereaved should:-

always be offered a sedative.....1 72
Generall be offered a sedative....2 155
Only exceptionally be offered a sedative.....3 80 Col.51.
Qualified answer.....y 12
Inadequate answer.....X 6

single coded

Question 29 — What do you prescribe in such circumstances Col.52.

Barbiturates.....1
Narcotics.....2
Both or either barbiturates or Narcotics.....3
Others.....0
D.N.A. Don't give anything.....9
Inadequate X

single coded except 0 may be coded with 1,2, or 3.

Question 30 — Do you think that close bereaved should be given some medical or nursing supervision for a while? Col 53.

Yes. medical supervision.....4 90
Yes nursing supervision.....5 15
No.....6 174
Both nursing and medical.....7 9
Qualified answer.. .....y 34
Inadequate.....X 3

single coded

Question 31 — Apart from any obstetric beds do you as a general practitioner have direct access to any N.H.S. beds where you retain full responsibility for treatment of your patients whilein hospital — Col.54.

No.....2 237

IF YES Can you use any of them for patients in terminal care?

Yes.....3 64

No.....4 19

Inadequate answer to 1st part.....X 3

" " to 2nd part.....1 2

single coded

Question 32 — Would you like any such beds, or more beds, that you could use for patients who are terminally ill?

Yes.....5 229

No.....6 Col.55 83

Inadequate answer.....X 13

single coded

Question 33 (Interview only)

Can you think of any particular patient with a terminal illness in your own practice during the last six months, who had to be looked after at home, although some other arrangement would have been better. — Col.56.

D.N.A. (postal).....9 258

Yes.....7 22 } 34 4/34

No.....8 43 }

Inadequate.....X 2

single coded

C

Question 34 (Interview only) Col.57

Have you had any patients or families who have been unwilling to accept district nursing care in the last six months?

D.N.A. (Postal)	9	258
Yes.....	1	11
No.....	2	65
Inadequate.....	X	1

Single coded

Number of doctors

Single handed.....	1	67
In partnership of 2 - or two doctors...	2	68
" " " 3 - three ...	3	93
" " " 4 - four ...	4	53
" " " 5 or more or five or more.....	5	41
Inadequate.....	X	3
Override for answers (do not count as partner)	y	8

Col.56.

single coded

Number of patients

Could you tell me the approximate number of N.H.S. patients you (yourself) look after? Col.59.

None	0	1
Under 2000.....	1	25
2000 - 2499.....	2	59
2500 - 2999.....	3	99
3000 - 3499.....	4	91
3500 or more.....	5	44
Inadequate.....	X	6

single coded

-

Attached staff — Have you any local authority staff attached to your practice, such as:- — Col.60

A district nurse.....1	162
A health visitor.....2	135
A social worker.....3	24
None.....0	136
Inadequate.....X	3

May be multi-coded

Marked Midwives are disregarded

Ancillary help — Do you have any ancillary help such as:- — Col.61.

Secretary..... 5	246
Receptionist.....6	276
Nurse..... 7	92
Other.....8	29
None.....0	19
Inadequate.....X	3

May be multi-coded. N.B. Numbers of staff are disregarded. a person who works as a secretary and receptionist is coded 5 & 6.

Like to know about study — Col.62

Yes.....1	302
No.....2	20
Inadequate it would like to know. X	3

Overcode if postal and wanted interview too.

Interviewed Yes.....3	8
No.....4	—

Length of interview Col.63

D.N.A. (postal).....9	258
Less than 30 mins.....1	16
30 < 45 mins.....2	35
45 mins < 1 hr.....3	10
1 hr. < 1½hr.....4	5
1½ hrs < 2hrs.....5	
2 hrs. or more.....6	
Inadequate.....X	1

Single coded

Month in which interview done or questionnaire completed Col.64.

July	1969	7
August		8
Sept		9
October		0
November		X
December		Y
January	1970	1
February		2

Interviewer

D.N.A. (postal) 9 Col.65.

col 64	
1	12
2	5
3	2
4	1
5	5
6	1
7	17
8	59
9	52
0	22
X	58
Y	51

col 65	
1	9
2	13
3	1
4	9
5	5
6	6
7	3
8	9
9	258
X	3
Y	3

G.P. CODES

LIFE BEFORE DEATH

Interviewer		Col. 65
Lisbeth Hockey	00	0
Wyn Tucker	19	1
John Bond	20	2
Stella Brown	14	4
Angela Savage	10	5
Kathleen Field	03	3
Ann Griffiths	16	6
Margo _____	-	7
Beryl Davies	01	8
Mollie Richards	18	X
_____ _____	17	Y
		9

D N A (Postal)

1 on col 74

	col. 66	col. 67	col 68.
1	200	199	—
2	72	72	—
3	29	34	—
4	8	8	—
5	6	6	—
6	3	3	—
7	—	—	—
8	1	—	—
9	2	2	—
0	4	—	—
X	—	1	—
Y	—	—	—
R	—	—	325

col 79.

1 325.

Life before death. G.P. Codes.

Col.4.

0 = Main questionnaire completed
1 = Questionnaire 1 second part completed
(but no main questionnaire)

Col.66 No. of patients with main questionnaire completed.

0 - 9	Straight.
X	10
Y	11 or more.

Col.67 No. of patients with main questionnaire or questionnaire 1 second part completed.
As col. 66.

Col.68

No doctor recorded	0
Dr.refused / no reply	1 temp away/ill
Dr.moved / dead /retired	2
Qn. not traced a name not known.	3
Qn. name refused	4

Col.79 Patients numbered with in/~~=~~ doctor by sequence 1, 2 etc

D.N.A. - ie. no doctor 0 in col 68 y -
a doctor untraced 3 in col 68
or name refused 4 in col 68

Life before death. G.P. Codes.

Col.4.

0 = Main questionnaire completed
1 = Questionnaire 1 second part completed
(but no main questionnaire)

Col.66 No. of patients with main questionnaire completed.

0 - 9	Straight.
X	10
Y	11 or more.

Col.67 No. of patients with main questionnaire or questionnaire 1 second part completed.
As col. 66.

Col.68 No doctor recorded (L.T.I.) 0
Dr. refused / no reply / Temp. away/ill. 1.
Dr. moved / died 2

Dr. Not traced. 3
Refused name of Dr 4

Col.79 Patients numbered within Dr., by sequence 1,2, etc.

D.N.A. - i.e. No. Dr. (0 on Col.68) } Y
or Dr. not traced (3 on Col.68) }
or Refused name (4 on Col. 68)

	Col 71	Col 72
1	67	28
2	78	
3	89	
4	46	
5	27	
6	3	
7	1	
8		
9		
0		290
x	14	7
y		

SEX.

MALE	1	306	Col. 69.
FEMALE	2	15	
INADEQUATE	X	4	

Col. 70.

Ion Col 79 (a) Age codes at 1 October 1969

4	1	Under 30	-	born October 1939 or later
22	2	30-34	-	born between October 1934 and September 1939
42	3	35-39	-	born between October 1929 and September 1934
52	4	40-44	-	born between October 1924 and September 1929
60	5	45-49	-	born between October 1919 and September 1924
51	6	50-54	-	born between October 1914 and September 1919
48	7	55-59	-	born between October 1909 and September 1914
30	8	60-64	-	born between October 1904 and September 1909
8	9	65-69	-	born between October 1899 and September 1904
4	0	70 and over	-	born before October 1899
4	X	Inadequate		

Nº OF PRINCIPALS. Col 71

0	0
1-9	1-9
10+	X
INADEQUATE	X.

Nº OF ASSISTANTS. Col. 72

0	0
1-9	1-9
10+	X
INADEQUATE	X

Check totals for cols 71 & 72 ←

RURAL PRACTICE PAYMENTS CODE (RPPC)

Col. 73

ELIGIBLE	1	31	
	2		
	5	5	
INELIGIBLE	0	279	
	3	2	
	4	1	
INADEQUATE	X	7	

(b) Medical Practice Committee Area codes

Col. 74

1	Designated area	151
2	Intermediate area	44
3	Restricted area	17
4	Open area	106
X	Inadequate.	7

GROUP PRACTICE PAYMENTS CODE

Col 75

ELIGIBLE	1	172
INELIGIBLE	0	146
INADEQUATE	X	7

E

SYMPTOMS

Y48

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case Number	4 digit code	
1/5-6		Card Number	Card 01	3352
1/7-9		Serial Number	3 digit code (See attached list)	
1/10	1	Total number of symptoms		
			0 None	-
			1 One	57
			2 Two	184
			3 Three	246
			4 Four	424
			5 Five	490
			6 Six	462
			7 Seven	462
			8 Eight	488
			9 Nine	270
			& 10 +	269
1/11-12	2	Type of symptoms	01 Pain	514
			02 Sleeplessness	379
			03 Loss of bladder control	63
			04 Loss of bowel control	32
			0- Loss of bladder control, loss of bowel control	185
			05 Unpleasant smell	118
			06 Vomiting or feeling sick	232
			07 Loss of appetite	372
			08 Constipation	222
			09 Bedsores	126
			10 Mental confusion	279
			11 Trouble with breathing	347
			12 Depression	275
			13 Any other symptoms	194
			14 Undefined code	12
			15 Undefined code	2
1/13	3	How distressing	1 Very distressing	1366
			2 Fairly distressing	682
			3 Not very distressing	875
			4 Distressing to some extent mentioned by respondent but not falling into 1,2,3 above	29
			5 Inadequate how distressing	400
1/14	4	How long had he had it	1 Less than a week	288
			2 1 week - 1 month	433
			3 1 month - 3 months	435

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/14	4	continued	4 3 months - 6 months 5 6 months - 1 year 6 1 year + 7 Don't know, inadequate 0 Blank	357 306 1356 149 28
1/15	5	Overcode - at above question (VAR 4)	1 Period not that of greatest distress 0 Blank	18 3334
		WHOSE ADVICE WAS SOUGHT		
1/16	6	If he died in hospital did he have it before he went into hospital	1 No 0 Blank	235 3117
1/17	7	Yes: Did you or he ask anyone's advice about it	1 No 0 Blank	709 2643
1/18-25	8-15	IF YES Whom did you or he ask		
1/18	8	G.P.	1 Yes 0 Not mentioned	1833 1519
1/19	9	Hospital doctor	1 Yes 0 Not mentioned	180 3172
1/20	10	Hospital sister/nurse	1 Yes 0 Not mentioned	10 3342
1/21	11	District Nurse	1 Yes 0 Not mentioned	94 3258
1/22	12	Other	1 Yes 0 Not mentioned	10 3342
1/23	13	Inadequate if had it at home	1 Yes 0 Not mentioned	58 3294
1/24	14	Inadequate if asked for advice	1 Yes 0 Not mentioned	271 3081
1/25	15	Inadequate whom asked	1 Yes 0 Not mentioned	71 3281
1/26	16	Were they able to help in any way	0 No 1 Yes: something mentioned	1366 91

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/26	16	continued	2 Inadequate 3 D.N.A. 4 Blank	1273 622 -
1/27	17	Symptom Number	1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Eight 9 Nine & 10 +	695 638 546 464 358 260 183 117 56 35
1/28-80		U N U S E D	U N U S E D	

G 448

Symptoms Card p 8

Serial no.

Total number of symptoms

Symptom type

Duration

How long

Who asked for help

Able to help.

Serial number of symptom

3358 cards

Life Before Death

Symptoms Card. Qu.2 P.8. Y48 (G)

Area	Col. 1.	Serial Number
Interval	Col. 2.	
3rd Digit of Serial Number	Col. 3.	
Total Number of Symptoms	Col. 4.	

0 - 9 0 - 9
10+ y

Type of Symptom	Cols. 5-6	
Pain	01	515
Sleeplessness	02	381
Loss of bladder control	03	63
Loss of bowel control	04	both..OX — 185
Unpleasant smell	05	32
Vomiting or feeling sick	06	118
Loss of appetite	07	233
Constipation	08	372
Bedsores	09	223
Mental Confusion	10	126
Trouble with breathing	11	280
Depression	12	347
Any other symptoms	13	275
	14	195
	15	12
		2

2247

1111

42(a) How Distressing	Col. 7	
Very distressing	1	1369
Fairly distressing	2	683
Not very distressing	3	877
Distressing to some other extent mentioned by respondent but not falling into 1,2,3, above	4	29
Inadequate how distressing	X	400

42(b) How long had he had it?	Col. 8	
Less than a week	1	288
1 week - 1 month	2	433
1 month - 3 months	3	436
3 months - 6 months	4	357
6 months - 1 year	5	308
1 year+	6	1359
Don't know, inadequate	9+X	177
Overcode if period not that of greatest distress (if two periods, take longest)	8	18

Col 1	Col 4
281	51
341	184
288	246
307	424
275	490
252	468
294	462
259	438
345	270
209	-
279	-
228	269

Whose advice was sought — Col. 9

42(c) If he died in hospital, did he have it before he went into hospital?

No — 5 — 235

(d) Yes. Did you or he ask anyone's advice about it?

No — 7 — 710

(e) Yes: Whom did you or he ask?

G.P.	1	may be multi-ooded.	1838
Hospital doctor	2		180
Hospital Sister/Nurse	3		10
District Nurse	4		94
Other	0		10
Inadequate if had it at home	8		58
Inadequate if asked for advice	9		271
Inadequate whom asked	X		71

(11) Were they able to help in any way? — Col. 10

No	0	622
Yes. something mentioned	1	1371
Inadequate	X	91
D.N.A. (codes 5,7,8 or 9 at Col. 9)	Y	1274

Symptom Number — Col. 11

1 - 9	1 - 9
10+	y

Card Number (Y48) — Col. 80

	col 1	col 2	col 3	col 4	col 5
1	446	874	672	4078	530
2	636	703	596	640	458
3	549	790	606	———	538
4	648	655	656	———	720
5	403	———	550	———	780
6	504	709	603	———	678
7	603	715	536	———	614
8	358	820	527	———	652
9	590	813	715	———	488
0	390	———	622	1362	620
x	551	———	———	———	———
y	402	———	———	———	———

	col 6	col 7	col 7
11	342	24	31
12	382	25	91
13	215	26	42
14	298	27	73
15	309	31	220
16	260	32	213
17	342	41	217
18	173	42	5½
19	311	43	137
21	320	44	350
22	142	45	87
23	107	51	151
		61	311
		62	243
		63	300
		64	277
		71	49

Life Before Death

Symptoms Card. Qu.2 P.8. Y48 (G)

Area	Col. 1.	Serial Number
Interval	Col. 2.	
3rd Digit of Serial Number	Col. 3.	
Total Number of Symptoms	Col. 4.	

0 - 9 0 - 9
10+ y

Type of Symptom	Cols. 5-6	
Pain	0 1	
Sleeplessness	0 2	
Loss of bladder control	0 3	both..OX
Loss of bowel control	0 4	
Unpleasant smell	0 5	
Vomiting or feeling sick	0 6	
Loss of appetite	0 7	
Constipation	0 8	
Bedsores	0 9	
Mental Confusion	1 0	
Trouble with breathing	1 1	
Depression	1 2	
Any other symptoms	1 3	

42(a) How Distressing	Col. 7
Very distressing	1
Fairly distressing	2
Not very distressing	3
Distressing to some other extent mentioned by respondent but not falling into 1,2,3, above	4
Inadequate how distressing	X

42(b) How long had he had it?	Col. 8
Less than a week	1
1 week - 1 month	2
1 month - 3 months	3
3 months - 6 months	4
6 months - 1 year	5
1 year+	6
Don't know, inadequate	9
Overcode if period not that of greatest distress (if two periods, take longest)	8

Whose advice was sought — Col. 9

42(c) If he died in hospital, did he have it before he went into hospital?

No — 5

(d) Yes. Did you or he ask anyone's advice about it?

No — 7

(e) Yes: Whom did you or he ask?

G.P.	1	may be multi-coded.
Hospital doctor	2	
Hospital Sister/Nurse	3	
District Nurse	4	
Other	0	
Inadequate if had it at home	8	
Inadequate if asked for advice	9	
Inadequate whom asked	X	

(ii) Were they able to help in any way? — Col. 10

No	0
Yes: something mentioned	1
Inadequate	X
D.N.A. (codes 5,7,8 or 9 at Col. 9)	Y

Symptom Number — Col. 11

1 - 9 — 1 - 9
10+ — y

Card Number (Y48) — Col. 80

Symptoms Card. Q°.2 P.8. 4 48

Col 1-3 First three digits of Serial Number.

Col 4. Total Number of symptoms.
This should correspond to the figure in Box 3 on page 8, and the number of the last symptom card punched.

Col 5+6. Symptom Type Number, 01...09, 10...14 etc

Col 7. Extent of distress of Symptom

Col 8 How long the symptom was experienced. (may have overcode.)

Col 9 Whose advice was sought. (may be multi-coded.

Col 10. Were they (above) able to help.

Col 11. Symptom Number (1, 2, ... etc)

All columns except 8 & 9 are single punched.

NB Col 4 is not 4th digit of serial number from Q°.2, but is Total N° of Symptoms (recorded in corner of page)

42. I'd like to ask about various symptoms and problems people sometimes have to put up with when they get ill and old. Did _____ have to put up with any of these in the last 12 months of his life?

	D.K.	Yes	No	a) Do you think he found it: distressing? Very distressing	Fairly distressing	Not very distressing	b) How long had he had it? Less than a week	1 week < 1 month	1 month < 3 months	3 months < 6 months	6 months < 1 year	1 year +	Don't know	c) IF HE DIED IN HOSPITAL CHECK, So did he have it before he went into hospital? Yes	No	d) IF HAD IT AT HOME Did he or you ask any advice about it? Yes	No	e) IF ASKED ADVICE (d) i) When did you or he ask? General practitioner	Hospital doctor	Hospital sister/nurse	District nurse	ii) Were they able to help in any way? How? No	f) IF DID NOT ASK ADVICE (d) Why didn't you or he ask for advice?
1. Pain	9	1	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
2 Sleeplessness	9	2	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
3. Loss of bladder control	9	3	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
4. Lose of bowel control	9	4	0																				
5. Unpleasant smell	9	5	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
6. Vomiting or feeling sick	9	6	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
7. Loss of appetite	9	7	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
8. Constipation	9	8	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
9. Bedsores	9	9	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
10. Mental confusion	9	2	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
11. Trouble with breathing	9	3	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
12. Depression	9	4	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	
13. Any other symptoms you or he found distressing SPECIFY	9	5	0	1	2	3	1	2	3	4	5	6	9	4	5	6	7	1	2	3	4	0	

IF LOSS OF BOWEL OR BLADDER CONTROL AT HOME

Can you tell me how _____ coped with any soiled bed linen?

- Special laundry service....1
- Ordinary laundry..... 2
- Laundrette. 3
- Washed in home by hand.....4
- Washed in home by machine. 5
- Disposable pads.... 6
- Disposable sheets..... 7
- Other SPECIFY. 8

IF DISPOSABLE (6 or 7) a) How did _____ get rid of them?

- Burning in doors in fire place. 1
- Burning indoors in a stove. 2
- Burning outdoors on open fire.. 3
- Burning outdoors in incinerator. 4
- Dustbin. 5
- Special collections.. 6
- Other SPECIFY 7

b) Was this a problem at all?

- Yes.....1
- No.....2

IF YES (1) In what way?

F

HELP

Y49

SN 393F Life Before Death: Help

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case number	4 digit code	
1/5-6		Card number	Card 01	6067
1/7-9		Serial number	3 digit code (See attached list)	
1/10-11	1	Total number of types of help needed	2 digit code (01-29)	
1/12-13	2	Type of help	11 Lifting	342
			12 Washing (or shaving)	382
			13 Getting in or out of bath	215
			14 Dressing or undressing	298
			15 Getting in or out of bed	308
			16 Getting hair washed at home	260
			17 Cutting toenails	341
			18 Giving bed pan or bottle	173
			19 Getting to lavatory or commode	311
			21 Giving medicines or tablets	320
			22 Infections	142
			23 Bandaging or other dressings	97
			24 Regular temperature taking	31
			25 Massaging/exercise	91
			26 Enema	42
			27 Any (other nursing procedure)	73
			31 Sitting up with at night	220
			32 Other help at night	243
			41 Taking out	217
			42 Reading to	56
			43 Writing letters for	137
			44 Collecting pension	350
			45 Changing library books	87
			51 Financial help	151
			61 Shopping	311
			62 Preparing/cooking food	242
			63 Cleaning house	299

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/12-13	2	Continued	64 Washing clothes 71 Looking after other members of the family, children or anyone else 1? Undefined code	278 49 1
1/14	3	Period over which help was needed	1 Less than a week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year + 7 Don't know/inadequate	542 845 859 489 371 1752 1209
1/15-26	4-15	Who helped		
1/15	4	No-one	1 Yes 0 Not mentioned	180 5887
1/16	5	Spouse	1 Yes 0 Not mentioned	2217 3850
1/17	6	Daughter	1 Yes 0 Not mentioned	1784 4283
1/18	7	Son	1 Yes 0 Not mentioned	665 5402
1/19	8	Brother/Sister	1 Yes 0 Not mentioned	348 5719
1/20	9	Other relative	1 Yes 0 Not mentioned	1154 4913
1/21	10	Friend/neighbour	1 Yes 0 Not mentioned	576 5491
1/22	11	District nurse	1 Yes 0 Not mentioned	783 5284
1/23	12	Home help/hairdresser/ N.A.B./social security/ chiropodist	1 Yes 0 Not mentioned	350 5717
1/24	13	Other professional or voluntary help	1 Yes 0 Not mentioned	358 5709

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/25	14	Inadequate who helped	1 Yes 0 Not mentioned	25 6042
1/26	15	Inadequate if anyone helped	1 Yes 0 Not mentioned	60 6007
1/27	16	Could he have done with more help	1 Yes - No-one helped 2 Yes - but had some help 3 No 4 Inadequate, but had some help 5 Inadequate if anyone helped 4 Wild code	189 807 3996 1019 55 1
1/28-29	17	Serial number of help	2 digit code (01-29)	
1/30-80		Unused	Unused	

Life before Death

Help card P. 9 445

Serial no.

Total no of types of help needed

Type of help

Over what period

Who helped

Enough help

Serial number of helps.

LONG TERM INSTITUTIONAL DEATH SKIP TO Q 60				a) Over what period did ____ need that sort of help?							b) Did anyone help with this? Who helps mainly?
Here is a list of ways in which people may need help when they are ill or old. Could you tell me if ____ could have done with help of this sort at all (while he was at home) - whether he got it or not? Did he need -	DK	Yes	No	Less than week	1 wk < 1 mth	1 mth < 3 mths	3 mths < 6 mths	6 mths < 1 year	1 year +	Don't know	RELATIONSHIP TO DECEASED OR TYPE OF PERSON No one
11 To be lifted at all	9	1	0	1	2	3	4	5	6	9	0
12 Help with washing (or shaving)	9	2	0	1	2	3	4	5	6	9	0
13 Getting in or out of bath	9	3	0	1	2	3	4	5	6	9	0
14. Dressing or undressing	9	4	0	1	2	3	4	5	6	9	0
15. Getting in or out of bed	9	5	0	1	2	3	4	5	6	9	0
16. Getting hair washed at home	9	6	0	1	2	3	4	5	6	9	0
17. Cutting toenails	9	7	0	1	2	3	4	5	6	9	0
18. Giving bedpan or bottle	9	8	0	1	2	3	4	5	6	9	0
19. Getting to lavatory or commode	9	Y	0	1	2	3	4	5	6	9	0
21. Giving medicines or tablets	9	1	0	1	2	3	4	5	6	9	0
22. Injections	9	2	0	1	2	3	4	5	6	9	0
23. Bandaging or other dressing	9	3	0	1	2	3	4	5	6	9	0
24. Regular temperature taking	9	4	0	1	2	3	4	5	6	9	0
25. Massaging/exercises	9	5	0	1	2	3	4	5	6	9	0
26. Enema	9	6	0	1	2	3	4	5	6	9	0
27. Any (other) nursing procedure SPECIFY	9	7	0	1	2	3	4	5	6	9	0
31. Sitting up with at night ASK Q's AT FOOT OF NEXT PAGE	9	1	0	1	2	3	4	5	6	9	0
32. Other help at night	9	2	0	1	2	3	4	5	6	9	0
41. Someone to take him out	9	3	0	1	2	3	4	5	6	9	0
42 Someone to read to him	9	4	0	1	2	3	4	5	6	9	0
43 Someone to write letters for him	9	5	0	1	2	3	4	5	6	9	0
44 Someone to collect his pension	9	6	0	1	2	3	4	5	6	9	0
45. Someone to change his library books	9	7	0	1	2	3	4	5	6	9	0
51. Financial help	9	8	0	1	2	3	4	5	6	9	0
IF DECEASED OR RESPONDENT HOUSEWIFE Did you or he need help with-											
61. Shopping	9	1	0	1	2	3	4	5	6	9	0
62. Preparing/cooking food	9	2	0	1	2	3	4	5	6	9	0
63. Cleaning house	9	3	0	1	2	3	4	5	6	9	0
64. Washing clothes	9	4	0	1	2	3	4	5	6	9	0
IF APPROPRIATE 71. Did he need help looking after other members of the family, children or anyone else? SPECIFY	9	5	0	1	2	3	4	5	6	9	0

WHEN TABLE COMPLETED CHECK

So _____ didn't need help with any of these things 1

So _____ had some help with all the different things he needed it for 2

So the things _____ could have done with some help with but didn't get any for were -

RECORD NOS.

IF HAD SOME HELP Did anyone else help at all? Who? No	(1) Could he have done with any more help with this? Yes	No	IF YES OR IF NEEDED HELP AND DID NOT GET IT Did you or he ask anyone about the possibility of arranging for help with this? Yes No	IF YES (3) a) Where did you/ they ask? G P.	Other SPECIFY	b) Were they able to help in any way? How? No	IF NO (4) DID TO ASK ADVICE Why didn't you ask anyone about this?
0	1	0					
0	2	0					
0	3	0					
0	4	0					
0	5	0	3 4	1		0	
0	6	0					
0	7	0					
0	8	0					
0	Y	0					
0	1	0					
0	2	0					
0	3	0					
0	4	0	3 4	1		0	
0	5	0					
0	6	0					
0	7	0					
0	1	0					
0	2	0	3 4	1		0	
0	3	0					
0	4	0					
0	5	0	3 4	1		0	
0	6	0					
0	7	0					
0	8	0	3 4	1		0	
0	1	0					
0	2	0					
0	3	0	3 4	1		0	
0	4	0					
0	3	0	3 4	1		0	

IF ANY NIGHT CARE NEEDED Can we talk a bit more about the care he needed at night. Was it:-

Comments

PROMPT CODE ALL THAT APPLY

Help to get to the toilet.....1
Bedpan.....2
Medicines that had to be taken then.....3
Injections or other treatment.....4
D-Inks.....5
Company.....6
Other SPECIFY.....7

LIFE BEFORE DEATH

Help Card Qu.2. P.9. Y49 (H)

Area	Col. 1)
Interval	Col. 2) Serial Number
3rd Digit of Serial Number	Col. 3)
Total Number of types of help needed 01, 02, ... 29	Cols. 4-5

Type of Help — Cols. 6-7

11. Lifting
12. Washing (or shaving)
13. Getting in or out of bath
14. Dressing or undressing
15. Getting in or out of bed
16. Getting hair washed at home
17. Cutting toenails
18. Giving bedpan or bottle
19. Getting to lavatory or commode

21. Giving medicines or tablets
22. Injections
23. Bandaging or other dressings
24. Regular temperature taking
25. Massaging/exercises
26. Enema
27. Any (other) nursing procedure

31. Sitting up with at night
32. Other help at night

41. Taking out
42. Reading to
43. Writing letters for
44. Collecting pension
45. Changing library books

51. Financial help

61. Shopping
62. Preparing/cooking food
63. Cleaning house
64. Washing clothes

71. Looking after other members of the family, children or anyone else

Period Over Which the Help was Needed — Col. 8

Less than a week	1
1 week - 1 month	2
1 month - 3 months	3
3 months - 6 months	4
6 months - 1 year	5
1 year +	6
Don't Know/inadequate	9

Who helped — Col. 9

No-one	0
Spouse	1
Daughter	2
Son	3
Brother/sister	4
Other relative	5
Friend/neighbour	6
District nurse	7
Home help/hairdresser/N.A.B./Social Security / Chiropodist	8
Other professional or voluntary help	Y
Inadequate who helped	9
Inadequate if anyone helped	X

(All except 0, X, 9 may be multi-coded)

Could he have done with more help	Col. 10
Yes - No-one helped	1
Yes - but had some help	2
No	0
Inadequate, but had some help	9
Inadequate if anyone helped	X

Serial Number of Help	Cols. 11-12
01, 02, ... 29	

6,079 ind.

LIFE BEFORE DEATH

Help Card Qu.2. P.9. Y49 (H)

Area	Col. 1
Interval	Col. 2 } Serial Number
3rd Digit of Serial Number	Col. 3
Total Number of types of help needed 01, 02, ... 29	Cols. 4-5

Type of Help — Cols. 6-7

Col 6

11. Lifting
12. Washing (or shaving)
13. Getting in or out of bath
14. Dressing or undressing
15. Getting in or out of bed — 2632
16. Getting hair washed at home
17. Cutting toenails
18. Giving bedpan or bottle
19. Getting to lavatory or commode

21. Giving medicines or tablets
22. Injections
23. Bandaging or other dressings
24. Regular temperature taking
25. Massaging/exercises — 805
26. Enema
27. Any (other) nursing procedure

31. Sitting up with at night — 463
32. Other help at night

Col 6

41. Taking out
42. Reading to
43. Writing letters for — 847
44. Collecting pension
45. Changing library books

51. Financial help — 151

61. Shopping
62. Preparing/cooking food
63. Cleaning house — 1131
64. Washing clothes

71. Looking after other members of the family, children or anyone else — 49

Period Over Which the Help was Needed — Col. 8

Less than a week	1	542
1 week - 1 month	2	850
1 month - 3 months	3	863
3 months - 6 months	4	493
6 months - 1 year	5	371
1 year +	6	1752
Don't Know/inadequate	9	1208

Who helped — Col. 9

No-one	0	181	181
Spouse	1	1342	2211
Daughter	2	1096	1711
Son	3	352	646
Brother/sister	4	240	316
Other relative	5	957	1195
Friend/neighbour	6	577	771
District nurse	7	505	607
Home help/hairdresser/N.A.B./Social Security	8	350	350
Other professional or voluntary help	Y	199	358
Inadequate who helped	9	25	45
Inadequate if anyone helped	X	60	60

(All except 0, X, 9 may be multi-coded)

Could he have done with more help — Col. 10

Yes - No-one helped	1	45
Yes - but had some help	2	410
No	0	1840
Inadequate, but had some help	9	352
Inadequate if anyone helped	X	15

Serial Number of Help — Cols. 11-12

01, 02, ... 29

col. 11

1
2
3
4
5
6
7
8
9
10

Help with:

11. Lifting
12 Washing (or shaving)
13. Getting in or out of bath
14. Dressing or undressing
15. Getting in or out of bed
16. Getting hair washed at home
17. Cutting toenails
18 Giving bedpan or bottle
19. Getting to lavatory or commode

21. Giving medicines or tablets
22. Injections
23. Bandaging or other dressings
24. Regular temperature taking
25 Massaging/exercises
26. Enema
27. Any (other) nursing procedure

31 Sitting up with at night
32. Other help at night

41 Taking out
42. Reading to
43 Writing letters for
44 Collecting pension
45. Changing library books

51. Financial help

61. Shopping
62. Preparing/cooking food
63 Cleaning house
64 Washing clothes

71. Looking after other members of the family, children or anyone else

81. Washing and preparing the body
82. Making arrangements with the undertaker
83. Breaking the news to other relatives
84 Sorting out legal questions or problems with the house or tenancy

G

HELPERS

Y56.

SN 393G Life Before Death: Helpers

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case number	4 digit code	
1/5-6		Card number	Card 01	2193
1/7-9		Serial number	3 digit code (See attached list)	
1/10	1	Total number of helpers	1 One	54
			2 Two	366
			3 Three	465
			4 Four	435
			5 Five	275
			6 Six	216
			7 Seven	132
			8 Eight	112
			9 Nine	18
			- Ten	40
			& Eleven +	80
1/11	2	Identification	1 Respondent	99
			2 Lives in same household	291
			3 Respondent, and lives in same household	60
			4 Bore brunt	14
			5 Respondent, and bore brunt	73
			6 Lives in same household, and bore brunt	75
			7 Respondent, lives in same household, and bore brunt	380
			8 None of these but helped	1201
1/12	3	Sex	1 Male	789
			2 Female	1133
			3 Inadequate	271
1/13	4	Relationship to deceased	1 Husband/Wife	318
			2 Father/Mother	16
			3 Son/Daughter	694
			4 Son-in-Law/Daughter-in-Law	210
			5 Grandchild	74
			6 Brother/Sister	152

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/13	4	Continued	7 Brother-in-Law/Sister-in-Law	89
			8 Niece/Nephew	72
			9 Other relative	104
			& Friend/Neighbour	424
			0 Other person	40
			- Inadequate	-
1/14	5	How near did they live	0 Same household	816
			1 Within 10 minutes walk	547
			2 Within ½ hour journey	440
			3 ½ hour - 1 hour	131
			4 1 hour - 2 hours	84
			5 2 hours or more	88
			6 Inadequate	87
1/15	6	How frequently did they help		
			1 Occasionally	668
			2 Daily	889
			3 More than weekly less than daily	262
			4 Weekly	157
			5 Less often	43
			6 Inadequate	58
			7 Other	3
			8 Inadequate if regularly or occasionally	113
1/16-27	7-18	Type of help given		
1/16	7	Personal	1 Yes	940
			0 Not mentioned	1253
1/17	8	Nursing	1 Yes	482
			0 Not mentioned	1711
1/18	9	Night	1 Yes	566
			0 Not mentioned	1627
1/19	10	Social	1 Yes	729
			0 Not mentioned	1464
1/20	11	Financial	1 Yes	73
			0 Not mentioned	2120
1/21	12	Housework	1 Yes	655
			0 Not mentioned	1538
1/22	13	Family	1 Yes	94
			0 Not mentioned	2099

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/23	14	After death	1 Yes 0 Not mentioned	899 1294
1/24	15	Other types of help - but not just visiting (including intermediate brunt borne by spouse)	1 Yes 0 Not mentioned	232 1961
1/25	16	Inadequate to part	1 Yes 0 Not mentioned	6 2187
1/26	17	Inadequate to all	1 Yes 0 Not mentioned	4 2189
1/27	18	D.N.A. no help	1 Yes 0 Not mentioned	- 2193
1/28	19	Number of different things helped with <u>before</u> death	0 None 1 One 2 Two 3 Three 4 Four 5 Five - nine 6 Ten - fourteen 7 Fifteen + 8 Inadequate	372 632 261 123 112 356 257 67 13
1/29	20	<u>Overcode</u> at above question	1 If not clear but can guess 0 Blank	25 2168
1/30	21	How many times saw deceased in last months	& D.N.A. lived in same household 0 Not at all 1 1 - 2 2 3 - 5 3 6 - 11 4 12 - 19 5 20 - 49 6 50 - 299 7 300+ 9 Respondent did not know - Inadequate	816 12 38 47 49 62 176 572 234 9 178

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/31	22	Serial number of helper	1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Eight 9 Nine - Ten & Eleven +	636 581 399 243 135 80 44 25 11 9 30
1/32-80		Unused	Unused	

Table - cont' Cs18 (D) 2195

LIFE BEFORE DEATH

Helpers Card Qu.2. P.11. Y56 (J)

Area	Col. 1	Serial Number
Interval	Col. 2	
3rd Digit of Serial Number	Col. 3	
Total Number of Helpers	Col. 4	
1 - 9	1 - 9	
10	X	
11+	Y	

Identification First digit — Col. 5

Respondent	1	Additive
Lives in same household	2	
Bore brunt	4	
None of these but helped	0	

Second digit - Sex — Col. 6

Male	1	789
Female	2	1134
Inadequate	X	272

Third digit - Relationship to Deceased — Col. 7

Husband/wife	1	318
Father/mother	2	16
Son/daughter	3	695
Son in law/daughter in law	4	210
Grandchild	5	74
Brother/sister	6	152
Brother in law/ sister in law	7	89
Niece/nephew	8	72
Other relative	9	105
Friend/neighbour	Y	424
Other person	0	40
Inadequate	X	—

How near did they live? — Col. 8

Same household	0	816
Within 10 minutes walk	1	547
Within ½ hour journey	2	441
½ hour - 1 hour	3	131
1 hour - 2 hours	4	84
2 hours or more	5	88
Inadequate	X	88

	Cs11	Cs12	Cs13	Cs14	Cs15
1	170	281	246	54	99
2	246	250	224	366	292
3	142	260	208	465	60
4	254	250	202	436	14
5	171	—	236	275	73
6	195	316	205	216	75
7	229	257	213	133	380
8	138	305	188	112	—
9	225	276	250	18	—
0	123	—	223	—	1202
X	182	—	—	40	—
Y	120	—	—	80	—

How frequently did they help? — Col. 9

Occasionally	7	670
Regularly.		
Daily	1	889
More than weekly less than daily	2	262
Weekly	3	157
Less often	4	43
Inadequate	9	58
Other	0	3
Inadequate if regularly or occasionally	X	113

Type of help given — Col. 10

Personal	1	942
Nursing	2	484
Night	3	567
Social	4	730
Financial	5	73
Housework	6	656
Family	7	94
After Death	8	900
Other types of help - but not just visiting (incl. indeterminate brunt borne by spouse)	0	232
Inadequate to part, overcode	9	6
Inadequate to all	X	4
D.N.A. No help	Y	—

(All except X & Y may be multi-coded)

Number of different things helped with before death — Col. 11

None (i.e. 8 only)	0	373
One	1	632
Two	2	261
Three	3	123
Four	4	112
5 - 9	5	356
10 - 14	6	258
15 +	7	67
Inadequate	X	13
If not clear but can guess - overcode	9	25

How many times saw deceased in last month — Col. 12

D.N.A. lived in same household	Y	816
Not at all	0	12
1 - 2	1	38
3 - 5	2	47
6 - 11	3	49
12 - 19	4	62
20 - 49	5	176
50 - 299	6	572
300 +	7	235
Respondent did not know	9	9
Inadequate	X	179

Serial Number of Helper — Col. 13

1 - 9	1 - 9	1	636
10	X	2	582
11 +	Y	3	399
		4	244
		5	135
		6	80
		7	44
		8	25
		9	11
		X	9
		Y	30

Card Identification (Y56) — Col. 80

	Col 1	Col 2	Col 3	Col 4
1	41	109	77	203
2	85	91	66	240
3	38	92	73	171
4	78	77	66	104
5	65	–	77	45
6	62	86	88	6
7	97	90	75	–
8	69	110	69	–
9	68	114	98	–
0	37	–	80	–
x	75	–	–	
y	54	–	–	–

H

OFFICIALS

Y57

SN 393H Life Before Death: Officials

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case number	4 digit code	
1/5-6		Card number	Card 01	768
1/7-9		Serial number	3 digit code (See attached list)	
1/10	1	Total number of Official Helpers	1 One	202
			2 Two	240
			3 Three	171
			4 Four	104
			5 Five	45
			6 Six	6
			7 Seven	-
			8 Eight +	-
1/11	2	Type of Official	1 District Nurse	234
			2 Health Visitor	53
			3 Other Nurse	35
			4 Home Help	71
			5 Special Laundry Service	9
			6 Chiropodist	76
			7 Vicar, Priest, or Minister	203
			8 Any other Official or voluntary service	87
1/12-20	3-11	Who arranged for him to have that sort of help		
1/12	3	G.P.	1 Yes	316
			0 Not mentioned	452
1/13	4	Hospital Doctor	1 Yes	12
			0 Not mentioned	756
1/14	5	Hospital Sister/Nurse	1 Yes	8
			0 Not mentioned	760
1/15	6	District Nurse	1 Yes	23
			0 Not mentioned	745
1/16	7	Health or Welfare Visitor	1 Yes	17
			0 Not mentioned	751
1/17	8	Relative or friend	1 Yes	100
			0 Not mentioned	668

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/18	9	Deceased himself	1 Yes 0 Not mentioned	53 715
1/19	10	Other (including V./P./M always visited, etc)	1 Yes 0 Not mentioned	124 644
1/20	11	Inadequate, don't know	1 Yes 0 Not mentioned	119 649
1/21	12	For how long did he have that sort of help	1 Less than a week 2 1 week - 1 month 3 1 month - 3 months 4 3 months - 6 months 5 6 months - 1 year 6 1 year or more 7 Inadequate	104 110 97 48 56 266 87
1/22	13	How often did he have that sort of help - at its most frequent	1 Daily or more often 2 More than weekly less than daily 3 Weekly 4 More than monthly less than weekly 5 Monthly 6 Less often 7 Inadequate	167 101 91 56 58 198 97
1/23	14	About how often did .... have that sort of help in the last 12 months of his life	1 1 - 2 times 2 3 - 5 times 3 6 - 11 times 4 12 - 19 times 5 20 - 49 times 6 50 - 299 times 7 300+ 8 Inadequate	145 95 100 83 100 109 22 114
1/24	15	Do you think he had that help as often as necessary or would it have been better if he had had it more or less often	1 As often as necessary 2 Prefer more often 3 Prefer less often 4 Inadequate	561 129 2 76

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/25	16	Would you have liked (her) to do any other things besides what she did do	1 Yes 2 No 3 Inadequate	68 376 324
1/26	17	Did you or he ask for more help	1 No 2 D.N.A. 0 Blank	80 616 72
		IF YES		
1/27	18	Asked Officials	1 Some change in arrangements 2 No change in arrangements 3 Inadequate if any change in arrangements 0 Blank	9 27 1 731
		IF YES		
1/28	19	Asked others	1 Some change in arrangements 2 No change in arrangements 3 Inadequate if any change in arrangements 4 Inadequate if asked anyone 5 Overcode if double coded 6 Wild code 0 Blank	2 - 1 32 - 1 732
1/29-39	20-30	Various things helped with		
1/29	20	Personal	1 Yes 0 Not mentioned	268 500
1/30	21	Nursing	1 Yes 0 Not mentioned	191 577
1/31	22	Night	1 Yes 0 Not mentioned	26 742

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/32	23	Social	1 Yes 0 Not mentioned	12 756
1/33	24	Financial	1 Yes 0 Not mentioned	3 765
1/34	25	Housework	1 Yes 0 Not mentioned	113 655
1/35	26	Family	1 Yes 0 Not mentioned	2 766
1/36	27	After death	1 Yes 0 Not mentioned	13 755
1/37	28	Other types of help - not including visiting	1 Yes 0 Not mentioned	44 724
1/38	29	Visiting (and praying), in contact with clergy, etc	1 Yes 0 Not mentioned	257 511
1/39	30	Inadequate	1 Yes 0 Not mentioned	25 743
1/40	31	Serial number of Official	1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Eight +	415 213 93 36 10 1 - -
1/41-80		Unused	Unused	

K

Officials Card p 13

Serial no

Total N° of official helpers
Type of official helpers
Who arranged for official
How long had
How often
How many times
Preferred more/less often
Help with other things
Who asked for more
Things helped with
Serial number of official.

LIFE BEFORE DEATH

Officials Card Qu.2. P.12 Y57 (K)

Area	Col. 1	Serial Number
Interval	Col. 2	
3rd Digit of Serial Number	Col. 3	

Total number of Official Helpers Col. 4

1 - 7 1 - 7
8 + 8

Type of Official Col. 5

District Nurse	1
Health Visitor	2
Other Nurse	3
Home Help	4
Special Laundry Service	5
Chiropodist	6
Vicar, Priest or Minister	7
Any other official or voluntary service	8

Who arranged for him to have that sort of help? Col. 6

G.P.	1
Hospital Doctor	2
Hospital Sister/Nurse	3
District Nurse	4
Health or Welfare Visitor	5
Relative or Friend	6
Deceased himself	7
Other (including U./P./M. always visited, etc.)	0
Inadequate, don't know	X

For how long did he have that sort of help? Col. 7

Less than a week	1
1 week - 1 month	2
1 month - 3 months	3
3 months - 6 months	4
6 months - 1 year	5
1 year or more	6
Inadequate	X

How often did he have that sort of help - at its most frequent? Col. 8

Daily or more often	1
More than weekly less than daily	2
Weekly	3
More than monthly less than weekly	4
Monthly	5
Less often	6
Inadequate	X

About how often did X have that sort of help in the last 12 months of his life? — Col. 9

1 - 2 times	1
3 - 5 times	2
6 - 11 times	3
12 - 19 times	4
20 - 49 times	5
50 - 299 times	6
300 +	7
Inadequate	X

Do you think he had that help as often as necessary or would it have been better if he had had it more or less often? — Col. 10

As often as necessary	1
Prefer more often	2
Prefer less often	3
Inadequate	X

Would you have liked (her) to do any other things beside what she did do? — Col. 11

Yes	4
No	5
Inadequate	X

Did you or he ask for more help? — Col. 12

No	7
D.N.A. (all except code 2 at col. 10, or 4 at 11)	Y

Yes - asked officials

some change in arrangements	1
no change in arrangements	2
inadequate if any change in arrangements	3

Yes - asked others

some change in arrangements	4
no change in arrangements	5
inadequate if any change in arrangements	6
inadequate if asked anyone	X
overcode if double coded	9

May be double cod

Various things helped with — Col. 13

Personal	1
Nursing	2
Night	3
Social	4
Financial	5
Housework	6
Family	7
After death	8
Other types of help - not including visiting	0
Visiting, (and praying), in contact with clergy, etc.	9
Inadequate	X

Serial Number of Official — Col. 14

1 - 7	1 - 7
8 +	8

Card Identification (Y57) — Col. 80

52. Can I check the various sorts of official people who helped _____ during the last 12 months of his life (while he was at home). During that time did he have any help from, or was he ever visited by:

IF YES (a) Who arranged for him to have that sort of help?

	Yes	No	General practitioner	Hospital doctor	Hosp. sister/nurse	District nurse	Health or welfare visitor	Relative or friend	Deceased himself	Other SPECIFY	b) For how long did he have that sort of help? Less than a week	1 week < 1 month	1 month < 3 months	3 months < 6 months	6 months < 1 year	1 year or more	c) How often did he have that sort of help – at its most frequent? Daily or more often	More than weekly < daily	Weekly	More than monthly < weekly	Monthly	Less often	d) So about how many times did _____ have that sort of help in the last 12 months of his life? 1 - 2	3 - 5	6 - 11	12 - 19	20 - 49	50 - 299	300+	Comments.
A district nurse	1	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	
Health visitor	2	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	
Other nurse	3	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	
Home help	4	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	
Special laundry service	5	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	
Chiropodist	6	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	
Vicar priest or minister	7	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	
Any other official or voluntary service	8	0	1	2	3	4	5	6	7	0	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6	7	

SPECIFY

	e) Do you feel he had that help as often as necessary or would it have been better if he'd had it more or less often? As often as necessary	Prefer more often	Prefer less often	IF MORE OR LESS OFTEN Can you tell me why?	f) Would you have liked (her) to do any other things beside what she did do? Yes	No	IF YES (4) What things?	IF WOULD HAVE LIKED MORE HELP (2 or 4) Did you or he ask for more help? Yes	No	IF YES (6) a) Whom did you ask?	b) What happened?	IF NO (7) Why didn't you or he ask?	g) Can I check the various things _____ he's paid with? HAND CARD LIST CODE NOS.	h) Did she do any thing else? What?
A district nurse	1	2	3		4	5		6	7					
Health visitor	1	2	3		4	5		6	7					
Other nurse	1	2	3		4	5		5	7					
Home help	1	2	3		4	5		6	7					
Special laundry service	1	2	3		4	5		6	7					
Chiropodist	1	2	3		4	5		6	7					
Vicar priest or minister	1	2	3		4	5		6	7					
Other	1	2	3		4	5		6	7					

769 Cards

LIFE BEFORE DEATH

Officials Card Qu.2. P.12 Y57 (K)

Area	Col. 1	Serial Number
Interval	Col. 2	
3rd Digit of Serial Number	Col. 3	

Total number of Official Helpers — Col. 4

1 - 7
8 +

769

Type of Official — Col. 5

District Nurse	1	234
Health Visitor	2	53
Other Nurse	3	35
Home Help	4	71
Special Laundry Service	5	9
Chiropodist	6	77
Vicar, Priest or Minister	7	203
Any other official or voluntary service	8	87

Who arranged for him to have that sort of help? — Col. 6

G.P.	1	316
Hospital Doctor	2	12
Hospital Sister/Nurse	3	8
District Nurse	4	23
Health or Welfare Visitor	5	17
Relative or Friend	6	100
Deceased himself	7	54
Other (including U./P./M. always visited, etc.)	0	124
Inadequate, don't know	X	119

For how long did he have that sort of help? — Col. 7

Less than a week	1	104
1 week - 1 month	2	110
1 month - 3 months	3	97
3 months - 6 months	4	48
6 months - 1 year	5	56
1 year or more	6	267
Inadequate	X	87

How often did he have that sort of help - at its most frequent? — Col. 8

Daily or more often	1	167
More than weekly less than daily	2	101
Weekly	3	91
More than monthly less than weekly	4	56
Monthly	5	59
Less often	6	198
Inadequate	X	97

About how often did X have that sort of help in the last 12 months of his life? — Col. 9

1 - 2 times	1	145
3 - 5 times	2	95
6 - 11 times	3	100
12 - 19 times	4	84
20 - 49 times	5	100
50 - 299 times	6	109
300 +	7	22
Inadequate	X	114

Do you think he had that help as often as necessary or would it have been better if he had had it more or less often? — Col. 10

As often as necessary	1	562
Prefer more often	2	129
Prefer less often	3	2
Inadequate	X	76

Would you have liked (her) to do any other things beside what she did do? — Col. 11

Yes	4	68
No	5	376
Inadequate	X	325

Did you or he ask for more help? — Col. 12

No	7	80
D.N.A. (all except code 2 at col. 10, or 4 at 11)	Y	617

Yes - asked officials

some change in arrangements	1	9
no change in arrangements	2	27
inadequate if any change in arrangements	3	1

May be double coded

Yes - asked others

some change in arrangements	4	3
no change in arrangements	5	-
inadequate if any change in arrangements	6	1
inadequate if asked anyone	X	32
overcode if double coded	9	1

Various things helped with — Col. 13

Personal	1	269
Nursing	2	191
Night	3	26
Social	4	12
Financial	5	3
Housework	6	113
Family	7	2
After death	8	13
Other types of help - not including visiting	0	44
Visiting, (and praying), in contact with clergy, etc.	9	257
Inadequate	X	25

Serial Number of Official — Col. 14

1 - 7	1 - 7	1 416
8 +	8	2 213
		3 93
		4 36
		5 10
		6 1

Card Identification (Y57) — Col. 80

J

COMPLETION RECORD

Y36

SN 393J Life before Death: Completion Record

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/1-4		Case number	4 digit code	
1/5-6		Card number	Card 01	959
1/7-9		Serial number	3 digit code (See attached list)	
1/10	1	Special sample	1 In a special sample 2 Not in a special sample	96 863
1/11	2	Failure/success (Questionnaire 1 part 1)	1 Failure 2 Completed by person who registered death 3 Completed by other person	121 481 357
1/12	3	Reason for failure	1 D.N.A. (code 2 or 3 on col 11 VAR 2) 2 Refusal - by relevant person (direct) 3 Other refusal 4 No one living in area could help because relevant people moved or died 5 No one living in area who could help because no relevant people 6 Temporary away (holiday) 7 Other reason	838 60 8 23 18 4 8
		N.B. A relevant person is a relative, neighbour, or official in institution who knew enough about deceased to give them basic information		
1/13	4	People contacted for failures	1 D.N.A. (Code 2 or 3 at VAR 2) 2 Spouse of deceased 3 Son/daughter 4 Other relative 5 Neighbour	838 28 18 19 30

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/13	4	Continued	6 People now living at address of informant or deceased	15
			7 Official in institution where deceased died	1
			8 No contact	7
			9 Inadequate	3
1/14	5	Deceased's household composition (for failures)		
			1 D.N.A. (code 2 or 3 at VAR 2)	838
			2 Alone	11
			3 With spouse only	30
			4 With spouse and others	6
			5 With spouse unknown if with others	6
			6 With other relatives	22
			7 With unrelated person(s)	1
			8 In long term institution	-
			9 Other	1
			- Inadequate	44
1/15	6	Questionnaire 1 - second part		
			1 D.N.A. (Code 1 at VAR 2)	121
			2 Completed	84
			3 Not completed because informant main respondant	641
			4 Not completed because informant in same household as main respondent	45
			5 Not completed - refused 2nd part	53
			6 Not completed for other unknown reasons	15
1/16	7	Questionnaire 2 - main	1 D.N.A. failure to 1st part questionnaire 1	121
			2 Completed by informant on questionnaire 1	641

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/16	7	Continued	3 Completed by person in same household as informant on questionnaire 1	45
			4 Completed by person in other household	99
			5 Not completed	53
1/17	8	Reason for failure to complete main	1 D.N.A. - main completed (Codes 2, 3,4, and 5 at VAR 7)	785
			2 Failure to questionnaire 1 first part	121
			3 Refused name and address of relevant person	1
			4 Refusal by relevant person	28
			5 Name and address of relevant person not known	5
			6 No relevant person living in area	12
			7 Temporary away (on holiday) other reason	7
1/18-26	9-17	People contacted for main failure		
1/18	9	D.N.A. (main completed or failure to questionnaire 1)	1 Yes	906
			0 Not mentioned	53
1/19	10	Spouse	1 Yes	9
			0 Not mentioned	950
1/20	11	Son/daughter	1 Yes	7
			0 Not mentioned	952
1/21	12	Other relative	1 Yes	14
			0 Not mentioned	945

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/22	13	Neighbour landlady	1 Yes 0 Not mentioned	13 946
1/23	14	People now living at deceased or informant's house	1 Yes 0 Not mentioned	3 956
1/24	15	Official of institution	1 Yes 0 Not mentioned	2 957
1/25	16	No contact	1 Yes 0 Not mentioned	9 950
1/26	17	If more than one coded overcode	1 Yes 0 Not mentioned	4 955
1/27	18	Questionnaire 3 No. appropriate and completed	& D.N.A. Not in special sample - People not identified (questionnaire 2 not completed)	862 13

CODE NUMBER	APPROPRIATE	NO. COMPLETED	
1	1	1	14
2	2	2	6
3	3	3	6
4	1	0	9
5	2	0	3
6	2	1	8
7	3	0	3
8	3	1	-
9	3	2	6
0	0	0	29

1/28	19	Number of discrepencies	1 D.N.A. (& on col 27 VAR 18)	862
			2 Unknown (- on Col 27 Var 18)	13
			3 None (0,1,2,3, on Col 27 VAR 18)	55
			4 One (4,6,9,on Col 27 VAR 18)	23
			5 Two (5, 8 on Col 27 VAR 18)	3
			6 Three (7 on Col 27 VAR 18)	3

CARD/COLUMN	VAR No	TITLE	CODES		MARGINALS
1/29	20	Failures on questionnaire 2 or questionnaire 1 2nd part	1	D.N.A. Did not die in hospital or institution	4
			2	Unknown if died in hospital or institution	117
			0	Blank D.N.A. (Questionnaire 2 or 2nd questionnaire 1 completed)	838
1/30	21	IF DIED IN HOSPITAL OR INSTITUTION How long was he there before he died	1	Less than a week	8
			2	1 week < 1 month	5
			3	1 month < 3 months	4
			4	3 months < 6 months	1
			5	6 months < 1 year	1
			6	1 year+	-
			7	Unknown how long in	3
			0	Blank	937
1/31	22	Failure on questionnaire 2 or questionnaire 1 2nd part - was death expected	1	Expected	18
			2	Not expected	12
			3	Uncertain	3
			4	Inadequate information	110
			0	Blank (D.N.A. Blank (0) on col 29 VAR 20)	816
1/32	23	Any restrictions in what he could do in last 12 months	0	No restrictions	2
			1	Some	15
			2	Qualified - i.e. some illness but no 'restriction'	4
			3	Inadequate if any restrictions	122
			4	Blank (D.N.A. Blank (0) on Col 29 VAR 20)	816

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/33-37	24-28	Help in last twelve months		
1/33	24	District nurse	1 Yes 0 Not mentioned	9 950
1/34	25	Health visitor	1 Yes 0 Not mentioned	- 959
1/35	26	Home help	1 Yes 0 Not mentioned	3 956
1/36	27	None of these	1 Yes 0 Not mentioned	20 939
1/37	28	Unknown if any help	1 Yes 0 Not mentioned	112 847
1/38	29	Who bore the brunt of looking after deceased	1 Inadequate information 2 Spouse 3 Son/daughter 4 Other relative 5 Neighbour 6 Other 7 No one 0 Blank (D.N.A. Blank on Col 29 VAR 20)	107 14 10 6 1 - 5 816
1/39	30	Marital status of deceased	1 Married at time of death spouse since died 2 Spouse alive 3 Unknown if spouse alive 4 Widowed 5 Single 6 Separated/Divorced 7 Unknown 0 Blank (D.N.A. Blank on Col 29 VAR 20)	2 54 9 24 14 - 40 816
1/40	31	Number of calls	1 One 2 Two 3 Three 4 Four 5 Five 6 Six 7 Seven 8 Eight 9 Nine	295 277 161 101 55 23 17 9 5

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/40	31	Continued	& Ten or more - Inadequate	5 11
1/41	32	Sex of deceased	1 Male 2 Female	504 455
1/42-43	33	Age of deceased	2 digit code (actual age) -- Inadequate 00 100+	
1/44	34	Age group of deceased	1 Under 25 2 25 - 34 3 35 - 44 4 45 - 54 5 55 - 64 6 65 - 69 7 70 - 74 8 75 - 79 9 80 - 84 & 85+ - Inadequate	7 5 33 68 168 155 141 140 119 122 1
1/45	35	Where died	1 Teaching hospital 2 Other general hospital 3 Psychiatric institution 4 Private nursing home 5 Permanent residence of institutional nature 6 Own home 7 Elsewhere 0 Blank	21 398 31 40 29 380 59 1
1/46	36	Overcode (at above question)	1 In institution 6 months + 0 Blank	48 911
1/47	37	Type of hospital	1 Mental illness or subnormality (M.S.) 2 Chest T.B. 3 Chronic, long stay, geriatric 4 Acute	31 8 68 238

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/47	37	Continued	5 Mainly or partly acute and some acute included	94
			6 Cancer and radio therapy	2
			7 Dying, terminal care and advanced cases	3
			8 Other (including combination of above)	24
			9 Inadequate	2
			- D.N.A.	489
1/48≤49	38	Underlying cause of death	2 digit code (See attached lists)	
1/50-57	39-46	Additional causes of death		
1/50	39	Neoplasms	1 Yes	19
			0 Not mentioned	940
1/51	40	Circulatory	1 Yes	91
			0 Not mentioned	868
1/52	41	Respiratory	1 Yes	120
			0 Not mentioned	839
1/53	42	Symptoms	1 Yes	91
			0 Not mentioned	868
1/54	43	Accidents	1 Yes	3
			0 Not mentioned	956
1/55	44	Digestive	1 Yes	24
			0 Not mentioned	935
1/56	45	Others	1 Yes	86
			0 Not mentioned	873
1/57	46	No additional cause	1 Yes	592
			0 Not mentioned	367
1/58	47	The person registering death is	1 Husband/wife	214
			2 Father/mother	6
			3 Father-in-Law/Mother-in-Law	1
			4 Son/daughter	378
			5 Son-in-Law/Daughter-in- Law	53
			6 Grandchild	12

CARD/COLUMN	VAR No	TITLE	CODES	MARGINALS
1/58	47	Continued	7 Brother/sister	68
			8 Brother-in-law/Sister-in-law	29
			9 Other relatives	72
			& Coroner	33
			0 Other	90
			- Inadequate	3
1/59	48	Sex of person registering	1 D.N.A. (if & at Col 58 VAR 47)	33
			2 Male	551
			3 Female	373
			4 Inadequate	2
1/60	49	Person who registered death lives at:-	1 Same address as deceased lived	418
			2 Same address as deceased died (but deceased did not live there)	21
			3 Same road as deceased lived	21
			4 Other	462
			5 Inadequate	4
			6 D.N.A. (if 8 at Col 58 VAR 47)	33
1/61	50	Social class of deceased classified by occupation of deceased or spouse from the death certificate according to classification of occupations 1966	1 Social class 1	30
			2 Social class 11	152
			3 Social class 111 non-manual	115
			4 Social class 111 manual	309
			5 Social class IV	203
			6 Social class V	98
			7 Student or armed forces	11
			& Inadequate	41
1/62-80		Unused	Unused	

Underlying cause of death

ICD no	Code
000 - 136	00
140 - 150	16
151	10
152 - 1620	16
1621	11
163 - 173	16
174	12
180 - 182	13
183 - 184	16
185	14
186 - 198	16
199	17
200 - 227	16
228	17
230 - 238	16
239	17
240 - 279	01
280 - 289	02
290 - 315	03
320 - 389	04
390 - 398	22
400 - 404	20
410 - 414	21
420 - 429	22
430 - 438	23
440 - 448	24
450 - 458	25
460 - 474	32

Underlying cause of death (cont.)

ICD no	Code
480 - 486	30
490 - 493	31
500 - 519	32
520 - 577	60
580 - 629	06
630 - 678	07
680 - 709	08
710 - 738	09
740 - 779	0Y
780 - 796	40
E800 - E845	50
E850 - E949	52
E950 - E959	51
E960 - E999	52

SN: 393J

Home Care for Dying

Col. 7

Serial number - 1st digit - Area

Barking	1
Teeside	2
Hillingdon	3
Cheshire (NE)	4
Brentwood	5
Bridgend	6
Northumberland	7
Eastbourne	8
Birmingham	9
Thanet	0
St. Helens	X
Isle of Wight	Y

2nd digit - Interval between month of death and interview month Col. 8

3 months	12345
9 months	67890

3rd digit - Sequential number Col. 9

CARE OF DYING
COMPLETION RECORD

All deaths

1 Questionnaire 1 part 1

Failure 1
Completed by person who registered death 2
Completed by other person 3

If 1 or 3 Reason for failure or for not interviewing person who registered the death

	Informant	Other
Not living in area	1	1
Dead	2	2
Too ill, old, deaf	3	3
Refusal	4	4
No other person identified	-	0
Other SPECIFY		

IF FAILURE (1) a) Details of people contacted

b) Deceased's household composition before died/went into hospital

Alone 1
With spouse only 2
With others SPECIFY 3

2 Questionnaire 1 - second part

D.N.A. - Failure to 1st part y
Completed 3
Not completed because informant main respondent . . . 4
Not completed because informant in same household as main respondent . 5
Refused 2nd part 6

3 Questionnaire 2 - Main

D.N.A. Failure to 1st part questionnaire 1 y
Completed by informant on questionnaire 1 . . 1
Completed by person in same household as informant on questionnaire 1 2
Completed by person in other household 3
Not completed 4

IF NOT COMPLETED (4) a) Reason

Refused name and address	1	1
Personal refusal	2	2
Other	3	3

b) Details of people contacted

Special sample only

4 Questionnaire 3

(i) Number it would have been appropriate to complete _____

(ii) Number completed _____

IF ANY DISCREPANCY a) Reason(s)

	(i)	(ii)	(iii)
Not living in area	1	1	1
Dead	2	2	2
Too ill, old, deaf	3	3	3
Refused name/address	4	4	4
Refusal	5	5	5
Other SPECIFY			

b) Relationship to deceased

Husband/wife	1	1	1
Father/mother	2	2	2
Father-in-law/mother-in-law	3	3	3
Son/daughter	4	4	4
Son-in-law/daughter-in-law	5	5	5
Grandchild	6	6	6
Brother/sister	7	7	7
Brother-in-law/sister-in-law	8	8	8
Neighbour	9	9	9
Friend	y	y	y
Other SPECIFY	o	o	o

c) Sex

Male	1	1	1
Female	2	2	2

d) Seen personally

Yes	3	3	3
No	4	4	4

P T.O.

5 Record of all calls

Date	Time	Intention: Person who registered death	Intention: Other 1st contact	Intention: Main Questionnaire 3	Outcome: Interview: 1 – 1st part	Outcome: Interview: 1 – 1st and 2nd	Outcome: Interview: 1 and 2	Outcome: Interview: 2	Outcome: Interview: 3	Outcome: Interview: No contact	Outcome: Other	Notes
1.		1	2	3 4	1	2	3	4	5	0		
2.		1	2	3 4	1	2	3	4	5	0		
3.		1	2	3 4	1	2	3	4	5	0		
4.		1	2	3 4	1	2	3	4	5	0		
5.		1	2	3 4	1	2	3	4	5	0		
6.		1	2	3 4	1	2	3	4	5	0		
7.		1	2	3 4	1	2	3	4	5	0		
8.		1	2	3 4	1	2	3	4	5	0		
9.		1	2	3 4	1	2	3	4	5	0		

IF NEITHER QUESTIONNAIRE 2 OR SECOND PART OF QUESTIONNAIRE 1 COMPLETED

6. IF DIED IN HOSPITAL OR INSTITUTION How long was he there before he died?

Less than a week..... 1
1 week < 1 month 2
1 month < 3 months 3
3 months < 6 months..... 4
6 months < 1 year 5
1 year + ...6

7. Was death

Expected 1
Not expected. 2
Uncertain.....3

8. Any restrictions in what he could do in last 12 months?

9. Any help at home in last 12 months from

District nurse. 1
Health visitor..... 2
Home help.....3
None of these.....0

10. Who bore brunt of looking after

Total calls

Data from death certificate

Sex

Age at death

Age group

Marital status

Where died

Cause of death

Occupation

Person registering death
a) Relationship

b) Sex

c) Same household

Person who signed death certificate

Care of Dying

Date sent: ☐☐☐☐☐☐

Doctors' Completion Record ☐☐☐

Name:	
Address:	
Telephone:	

Interviewer: ☐☐

Outcome:

Completed	1
Dead	2
Moved out of area	3
Refused	4
Not completed	5
Other	6

Comments:

J 456

Helper Card p II

} Serial no.

Total N° of helpers
Respondent / same house / Basement
Sex
Relationship
How near lived
Frequency of help
Categories helped with
N°. of categories helped with
How many times same deceased
Serial number of helper.

LIFE BEFORE DEATH

Helpers Card Qu.2. P.11. Y56 (J)

Area		Col. 1	Serial Number
Interval		Col. 2	
3rd Digit of Serial Number		Col. 3	
Total Number of Helpers		Col. 4	
1 - 9	1 - 9		
10	X		
11+	Y		

Identification First digit — Col. 5

Respondent	1	Additive
Lives in same household	2	
Bore brunt	4	
None of these but helped	0	

Second digit - Sex — Col. 6

Male	1
Female	2
Inadequate	X

Third digit - Relationship to Deceased — Col. 7

Husband/wife	1
Father/mother	2
Son/daughter	3
Son in law/daughter in law	4
Grandchild	5
Brother/sister	6
Brother in law/ sister in law	7
Niece/nephew	8
Other relative	9
Friend/neighbour	Y
Other person	0
Inadequate	X

How near did they live? — Col. 8

Same household	0
Within 10 minutes walk	1
Within ½ hour journey	2
½ hour - 1 hour	3
1 hour - 2 hours	4
2 hours or more	5
Inadequate	X

How frequently did they help? — Col. 9

Occasionally	7
Regularly:	
Daily	1
More than weekly less than daily	2
Weekly	3
Less often	4
Inadequate	9
Other	0
Inadequate if regularly or occasionally	X

Type of help given — Col. 10

Personal	1
Nursing	2
Night	3
Social	4
Financial	5
Housework	6
Family	7
After Death	8
Other types of help - but not just visiting (incl. indeterminate brunt borne by spouse)	0
Inadequate to part, overcode	9
Inadequate to all	X
D.N.A. No help	Y

(All except X & Y may be multi-coded)

Number of different things helped with before death — Col. 11

None (i.e. 8 only)	0
One	1
Two	2
Three	3
Four	4
5 - 9	5
10 - 14	6
15 +	7
Inadequate	X
If not clear but can guess - overcode	9

How many times saw deceased in last month — Col. 12

D.N.A. lived in same household	Y
Not at all	0
1 - 2	1
3 - 5	2
6 - 11	3
12 - 19	4
20 - 49	5
50 - 299	6
300 +	7
Respondent did not know	9
Inadequate	X

Serial Number of Helper — Col. 13

1 - 9	1 - 9
10	X
11 +	Y

Card Identification (Y56) .. — Col. 80

49. Can I check that I've got a note of all the different friends and relations who helped _____ or who helped after he died in any of the ways shown on the card.

CHECK

a) Respondent Yes..1 No...2

b) OMIT IF LIVED ALONE OR JUST WITH RESPONDENT
Others in the same household Yes..3 No. .4

c) Other relatives Yes..5 No...6

d) Other friends or relatives Yes..7 No...8

ENTER ALL WHO HELPED ABOVE DOUBLE LINE

50. a) Did _____ have any (other) living brothers or sisters? Yes. 1 No...2

IF YES ENTER BELOW LINE

b) OMIT IF _____ NEVER MARRIED
Did _____ have any (other) living children? Yes 3 No...4

IF YES ENTER BELOW LINE

c) Did _____ have any (other) close relatives? Yes .5 No ..6

IF YES ENTER BELOW LINE

51. Who would you say bore the brunt of looking after _____ you, or someone else?

Respondent . 7
Other LETTER____

IF NOT RESPONDENT How would you say it affected _____ (person who bore brunt)?

SPECIAL SAMPLE ONLY
j) Who did next most?
k) Who after that? etc
RANK ALL PEOPLE IN TOP HALF OF TABLE ENTERING RANK IN LAST COLUMN.
1 = MOST 2 = NEXT etc.

	RELATIONSHIP TO DECEASED	CODE	How near did they live to deceased? Same household	Within 10 mins walk	Within thrs journey	½hr < 1hr	1hr < 2hrs	2hrs or more	Did they help - Regularly or	Occasionally?	IF REGULARLY How often? Daily	More than weekly < daily	Weekly	Less often
A			0	1	2	3	4	5	6	7	1	2	3	4
B			0	1	2	3	4	5	6	7	1	2	3	4
C			0	1	2	3	4	5	6	7	1	2	3	4
D			0	1	2	3	4	5	6	7	1	2	3	4
E			0	1	2	3	4	5	6	7	1	2	3	4
F			0	1	2	3	4	5	6	7	1	2	3	4
G			0	1	2	3	4	5	6	7	1	2	3	4
H			0	1	2	3	4	5	6	7	1	2	3	4

	RELATIONSHIP TO DECEASED	CODE	How near did they live to deceased? Within ½hr	½hr < 1hr	1hr < 2hrs out in England & Wales	England or Scotland	Abroad	Don't know	Comments.
J			4	5	6	7	8	9	
K			4	5	6	7	8	9	
L			4	5	6	7	8	9	
M			4	5	6	7	8	9	
N			4	5	6	7	8	9	
O			4	5	6	7	8	9	

456

What things did they help with? Anything else? LIST CODE NOS.	FOR PEOPLE NOT IN SAMPLE HOUSEHOLD Could you say about how many times they saw _____ in the last 12 months? 1 - 2 / 3 - 5 / 6 - 11 / 12 - 19 / 20 - 49 / 50 - 299 / 300 +	SELECT 1 PEOPLE ONLY (4th digit of serial to an X) If possible I'd like to see all the different people who helped to look after _____. Could you tell me their names and addresses.		
		NAME	ADDRESS	Refer Q.51.
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			
	1 2 3 4 5 6 7			

	Could you say how many times they saw _____ in last 12 months? Not at all / 1 - 2 / 3 - 5 / 6 - 11 / 12 - 19 / 20 - 49 / 50 / D.K.
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9
	0 1 2 3 4 5 6 9

F 436

Completion / Death cert.

1 Area
2 Interval
3
4 Special sample
5 Q 1 Part 1 Success / Failure
6 Reason for failure
7 People contacted
8 Household comp
9 Part 2 Success / Failure
10 Q 2 Success / Failure
11 Reasons for failure
12 People contacted
13 Q 3 No. appropriate & completed
14 Discrepancies
15 Hawking in interview
16 Death expected
17 Any restrictions
18 Help in last 12 months
19 Who bore brunt
20 Marital status
21 No. of calls.
22 Sex
23, 24 } Age at death
25 Age group
26 Where died
27 Type of hospital
28, 29 } Cause of death

Death cert.

30 Additional causes
31 Relationship
32 Sex
33 Same address
34 Social class

Reason registering death

Case before [illegible] - Col [illegible]

1. Area
2. }
3. }
4. Special sample
5. Questionnaire 1 Part 1 Success/Failure
6. " " Reason for failure
7. " People contacted
8. " Household composition
9. " 1 Part 2 Success/Failure
10. " 2 Success/Fail
11. " 2 Reasons for failure
12. " 2 People contacted
13. " 3 No. appropriate and completed
14. " 3 Discrepencies
15. How long in hospital or institution
16. Death expected
17. Any restrictions
18. Help in last 12 months
19. Who bore brunt
20. Marital status
21. Number of calls

When neither questionnare 2 or second part of questionnaire 1 completed

22. Sex
23. }
24. } Age at death
25. Age group
26. Where died
27. Type of hospital
28. } Cause of death
29. }
30. Additional causes
31. Relationship
32. Sex
33. Same address

Person registering death

34. Social class

From death certificate

COLUMN 80 CARD NO 936

Questionnaire 1 part 1. Failure/Success. Col.5.

Failure 1
Completed by person who registered death....2
Compl ted by other person.....3

Questionnaire 1 partl. Reason for failure Col.6.

839 D.N.A. (code 2 or 3 on col.5.).....Y
60 Refusal - by relevant person (direct).....1
8 Other refusal.....2
No on e living in area who could help
23 Because relevant people moved or died....3 } Assume 4 unless know to be 3
18 Because no relevant people.....4 }
8 Other reason.....0
4 Temporary away (holiday) 5

Single coded N. B. A relevant person is a relative neighbour or official in institution who knew deceased enough about them to give basic information.

People contacted for failure Col./.

D.N.A. (code 2 or 3 col.5.).....Y		839
Spouse of deceased.....1		28
Son/daughter.....2		18
Other relative.....3		19
Neighbour.....4		130
People now living at address of informant or deceased 5		15
Official in institution where deceased died 6		1

Single coded - priority as above except 6 takes precedence over 5 and 4.

No contact 0 7

Inadequate x 3

Deceased's household composition (for failures) Col.8.

D.N.A. (code 2 or 3 col.5.) .....Y
Alone.....1
With spouse only.....2
" " and other(s).....4
" " unknown if with others.....8
" other relatives.....5
" unrelated person(s).....6
In long term institution.....7
Other.....0
Inadequate.....X

Single coded

Questionnaire 1 - second part Col.9.

D.N.A. (1 on col.5) .....Y 121
Completed.....3 84
Not completed because Informant main respondent.....4 642
Not completed because Informant in same household as main respondent.....5 45
Not completed : refused 2nd part.....6 53
Not complete for other or unknown reason...X 15

N.B. Codes 4 or 5 should only be coded if a main questionnaire is completed

Single coded

Questionnaire 2 - main Col.10

D.N.A. Failure to 1st. part questionnaire 1.....Y 120 121
Completed by informant on questionnaire 1...1 640 642
Completed by person in same household as informant on questionnaire 1.....2 45 45
Completed by person in other household.....3 99 99
Not completed.....4 56 55
53

784

786

Reason for failure to complete main — Col.11.

D.N.A. - main corpleted (codes 1,2,3 4, col 10)....Y
Failure to questionnaire 1. first part 9
Refused name and address of relevant person.....1
Refused by relevant person.....2
Name and address of relevant person not known...4
No relevant person living in area.....0

Single coded Codes 1,2,4. additive

Temporary away (on holiday) other reason 8

People contacted for main failure — Col.12.

D.N.A. (main completed or failure to questionnaire 1) .....Y 907
Spouse.....1
Son/daughter.....2
Other relative 3
Neighbour.....4
People now living at deceased or informant's house.....5
Official of institution.....6
no callback 0

May be multi-coded. If more than one coded overcode.....9

Home Care for Dying

Col. 7.

Serial number - 1st digit - Area

Barking	1		72
Teeside	2		70
Hillingdon	3		57
Cheshire (NE)	4		64
Brentwood	5	80	67
Bridgend	6		65
Northumberland	7		70
Eastbourne	8		63
Birmingham	9		68
Thanet	0		59
St. Helens	X		66
Isle of Wight	Y		63
			784

Col 8

2nd digit - Interval between month of death and interview month

3 months	1 2 3 4 5	489	389
9 months	6 7 8 9 0	488	395
			784

Col. 14

4th digit - Special sample

In special sample X
Not in special sample 0

Underlying cause of death

ICD no	Code
000 - 136	00
140 - 150	16
151	10
152 - 1620	16
1621	11
163 - 173	16
174	12
180 - 182	13
183 - 184	16
185	14
186 - 198	16
199	17
200 - 227	16
228	17
230 - 238	16
239	17
240 - 279	01
280 - 289	02
290 - 315	03
320 - 389	04
390 - 398	22
400 - 404	20
410 - 414	21
420 - 429	22
430 -438	23
440 - 448	24
450 - 458	25
460 - 474	32
480 - 486	30
490 - 493	31
500 - 519	32
520 - 577	60
580 - 629	06
630 - 678	07
680 - 709	08
710 - 738	09
740 - 779	OY
780 - 796	40
E800 - E845	50
E 850 - E949	52
E950 - E 959	51
E960 - E999	52

~~Boxes 7 & 8~~

Questionnaire 3 Col.13.

D.N.A. Not in special sample	Y
People not identified (Questionnaire 2 not completed)	X

Number appropriate	No. completed	
1	1	1
2	2	2
3	3	3
1	0	4
2	0	5
2	1	6
3	0	7
3	1	8
3	2	9
0	0	0

Number of discrepencies Col.14

D.N.A. (y on col. 13).....y
Unknown (X on col.13)..... X
None (0,1,2,3, on col.13). 0
One (4.6.9. on col.13)..... 1
Two (5,8, on col.13).....2
Three (7 on col. 13).....3

Failure on questionnaire 2 or questionnaire 1 2nd part (re born) col.15.

121

D N.A. (Questionnaire 2 or 2nd part questionnaire1 completed)) Blank (2)

D.N.A. Did not die in hospital or institution 2 y 2

Unknown if died in hospital or institution 106 X 10

IF DIED IN HOSPITAL OR INSTITUTION How long was he there before he died?

Less than a week 1	3	5
1 week < 1 month 2	3	2
1 month < 3 months 3	2	2
3 months < 6 months 4	1	–
6 months < 1 year 5	1	–
1 year + ... 6	–	
Unknown how long 9	3	

Single coded N.B. This is data from attempted interviews-not death certificate

Failure on questionnaire 2 or questionnaire 1 2nd part Col.16.

D .N.A. Blanks on col.15. 820 Blank

Was death

Expected.....1	19
Not expected.....2	12
Uncertain.....3	3
Inadequate information.....X	106

Any restrictions in what he could do in last 12 months? Col.17.

D.N.A. Blank on col.15..... Blank

No restrictions..... 0

Some..... 1

Qualified - i.e. some illness but no 'restriction'..... 2

Inadequate if any restrictions..... X

Help in last twelve months — Col.18.

D.N.A. Blank on col.15.....Blank
District nurse.....1
Health visitor.....2
Home help.....3
None of these.....0
Unknown if any help.....X

May be multi-coded

Who bore brunt of looking after deceased — Co.19.

D.N.A. Blank on col.15.....Blank
Inadequate information.....X
Spouse.....1
Son/daughter.....2
Other relative.....3
Neighbour.....4
Other 5
No one.....0

Single coded

Marital status of deceased — Col.20

D.N.A. Blank on col.15.....Blank
Married at time of death spouse since died..... .1
spouse alive.....2
unknown if spouse alive...3
Widowed.....4
Single.....5
Separated/divorced.....6
Unknown.....X

N.B. Use information from death certificate if necessary

Number of calls — Col.21

One.....1
Two - Nine.....2-9
Y..... .....10 or more
Inadequate.....X

Single coded
N.B. Calls to establish appropriate address - Telephone calls Should be included not included

Col 22

Sex of Deceased

505	Male.....1	418+1	~~Box 1~~
455	Female.....2	366+1	

Age of deceased (2 digits as given) Col. 23 & 24

Inadequate.....XX ~~Boxes 2 and 3~~

100 + Col. Y Col 25

Age groups of Deceased ~~Box 4~~

✓ 7	Under 25.....1	4	
✓ 5	25 - 34.....2	3	
✓ 33	35 - 44.....3	28	
✓ 68	45 - 54.....4	55	
✓ 168	55 - 64.....5	145	
✓ 155	65 - 69.....6	128	
✓ 142	70 - 74.....7	111	
✓ 140	75 - 79.....8	111	
✓ 119	80 - 84.....9	100	
✓ 122	85+.....Y	98	
1	Inadequate.....X	1	
960		784	

Where died (1st Code)

Col 78

		No.	
Teaching hospital	2	21	16
Other general hospital	1	399	318
Psychiatric institution	3	31	25
Private nursing home	4	40	31
Permanent residence & institutional nature	5	29	24
Own home	6	381	323
Elsewhere	7	59	49
Overseas or institution 6 months +	X	61	40
		960	786

Cd 27

Type of hospital

Box 6

Mental illness or subnormality(.M.S.).....1
Chest T.B.....2
Chronic, long stay, geriatric.....3
Acute.....4
Mainly or partly acute.....5
Cancer and radio therapy.....6
Dying, Terminal Care and Advanced Cases.....7
Other (including combination of above).....0
Inadequate. X
D.N.A. (All codes except 1 & 2 in Box 5).....9

Single coded

Cd. 30

Additional causes of death

		L.C.D. no.1966 Box 9
1.	Neoplasms	140 - 239
2.	Circulatory	390 - 458
3.	Respiratory	460 - 519
4.	Symptoms	780 - 796
5.	Accidents	E800 - E999
6.	Digestive	520 - 577
0.	Others	000 - 136, 240 - 389, 580 - 779
X.	Inadequate	
9.	No additional cause	

This may be multi-coded but additional causes within the same broad group of the IC.D. as the underlying cause ~~and~~ one not taken.

This means that this code never contains the same digit as the first digit of the underlying cause except that both can be 0 if the two causes would have different 2nd digits if both were classified according to the 2 digit code for underlying cause.

Col. 31

The person registering death is ~~Box 10~~

Husband/wife.....1
Father/mother.....2
Father-in-law/mother-in-law.....3
Son/daughter.....4
Son-in-law/daughter-in-law.....5
Grandchild.....6
Brother/sister.....7
Brother-in-law/sister-in-law....8
Other relative.....9
Coroner.....Y
Other.....0
Inadequate.....X

Col 32

Sex of person registering Death ~~Box 11~~

D.N.A. if y in box 10.....9
Male.....1
Female.....2
Inadequate.....X

Col. 33

Person who registered death lives at.- ~~Box 12~~

Same address as deceased lived.....1
" " " " died (but deceased did not live there.....2
Same road as deceased lived.....3
Other.....0
Inadequate.....X

D.N.A. if y in box 10.....9

C

Cd. 34.

Social class of deceased ~~Box 13~~

Classified by occupation of deceased or spouse from the death certificate according to classification of occupations 1966.

Social class I	1	30	27
II	2	152	117
III non manual	3	115	87
III manual	4	309	259
IV	5	204	177
V	6	98	83
Student or armed forces	7	11	8
Inadequate	X	41	26

NB Look at G & H

G. seems to give industry

H. employment status.

1 = Employee

2 = Self employed with employees

3 = Self employed without employees.

Death Certificate Code on Place of death.

1. General hospitals. — NHS
2. Mental institutions psychiatric hospitals — NHS + other
3. Private nursing homes. — Private not in NHS hosp.
4. Permanent places of residence of an institutional nature
5. Deceased's own home.
6. Elsewhere.
7. Overpunch In institution over 6 months.

This does not distinguish -
Teaching hospitals.
Voluntary hospitals
Other addresses.

The simplest thing seems to me to add this code to card F. (y 36) say on col. 79. Then cross analyse by col. 26 and col. 27, and decide where to go from there. The first step is to sort card F into Serial no. order.

See col. 26
Previous on col 73.

CARE OF DYING
COMPLETION RECORD

All deaths

1 Questionnaire 1 part 1

Failure	1
Completed by person who registered death	2
Completed by other person	3

If 1 or 3 Reason for failure or for not interviewing person who registered the death

	Informant	Other
Not living in area	1	1
Dead	2	2
Too ill, old, deaf	3	3
Refusal	4	4
No other person identified	-	0
Other SPECIFY		

IF FAILURE (1) a) Details of people contacted

b) Deceased's household composition before died/went into hospital

Alone	1
With spouse only	2
With others SPECIFY	3

2 Questionnaire 1 - second part

D.N.A. - Failure to 1st part	y
Completed	3
Not completed because informant main respondent	4
Not completed because informant in same household as main respondent	5
Refused 2nd part	6

3 Questionnaire 2 - Main

D.N.A. Failure to 1st part questionnaire 1.	y
Completed by informant on questionnaire 1	1
Completed by person in same household as informant on questionnaire 1	2
Completed by person in other household	3
Not completed.	4

IF NOT COMPLETED (4) a) Reason

Refused name and address	1	1
Personal refusal	2	2
Other	3	3

b) Details of people contacted

Special sample only

4 Questionnaire 3

(i) Number it would have been appropriate to complete _____

(ii) Number completed _____

IF ANY DISCREPANCY a) Reason(s)

	(i)	(ii)	(iii)
Not living in area	1	1	1
Dead	2	2	2
Too ill, old, deaf	3	3	3
Refused name/address	4	4	4
Refusal	5	5	5
Other SPECIFY			

b) Relationship to deceased

Husband/wife	1	1	1
Father/mother	2	2	2
Father-in-law/mother-in-law	3	3	3
Son/daughter	4	4	4
Son-in-law/daughter-in-law	5	5	5
Grandchild	6	6	6
Brother/sister	7	7	7
Brother-in-law/sister-in-law	8	8	8
Neighbour	9	9	9
Friend	y	y	y
Other SPECIFY	o	o	o

c) Sex

Male	1	1	1
Female	2	2	2

d) Seen personally

Yes	3	3	3
No	4	4	4

P T O.

5 Record of all calls

Date	Time	Intention: Person who registered death	Intention: Other 1st contact	Intention: Main	Intention: Questionnaire 3	Outcome: Interview: 1 - 1st part	Outcome: Interview: 1 - 1st and 2nd	Outcome: Interview: 1 and 2	Outcome: Interview: 2	Outcome: Interview: 3	Outcome: No contact	Outcome: Other	Notes
1.		1	2	3	4	1	2	3	4	5	0		
2.		1	2	3	4	1	2	3	4	5	0		
3.		1	2	3	4	1	2	3	4	5	0		
4.		1	2	3	4	1	2	3	4	5	0		
5.		1	2	3	4	1	2	3	4	5	0		
6.		1	2	3	4	1	2	3	4	5	0		
7.		1	2	3	4	1	2	3	4	5	0		
8.		1	2	3	4	1	2	3	4	5	0		
9.		1	2	3	4	1	2	3	4	5	0		

IF NEITHER QUESTIONNAIRE 2 OR SECOND PART OF QUESTIONNAIRE 1 COMPLETED-

6. IF DIED IN HOSPITAL OR INSTITUTION How long was he there before he died?

Less than a week..... 1
1 week < 1 month..... 2
1 month < 3 months..... 3
3 months < 6 months..... 4
6 months < 1 year..... 5
1 year + ... 6

7. Was death

Expected 1
Not expected..... 2
Uncertain..... 3

8 Any restrictions in what he could do in last 12 months?

9. Any help at home in last 12 months from

District nurse 1
Health visitor..... 2
Home help..... 3
None of these..... 0

10. Who bore brunt of looking after

Total calls

Data from death certificate

Sex

Age at death

Age group

~~Marital status~~ Where died (1)

Where died Typed here

Cause of death

~~Occupation~~ Other causes of death

Person registering death

a) Relationship

b) Sex

c) Same household

~~Person who signed death certificate~~

Occupn.

Care before death - Completion record - Card design

1. Area
2.)
3.)
4. Special sample
5. Questionnaire 1 Part 1 Success/Failure
6. " " Reason for failure
7. " People contacted
8. " Household composition
9. " 1 Part 2 Success/Failure
10. " 2 Success, Fail
11. " 2 Reasons for failure
12. " 2 People contacted
13. " 3 No. appropriate and completed
14. " 3 Discrepancies
15. How long in hospital or institution
16. Death expected
17. Any restrictions
18. Help in last 12 months
19. Who bore brunt

} When neither questionnaire 2 or second part of questionnaire 1 completed

20. Marital status
21. Number of calls
22. Sex
23.) A
24.) Age at death
25. Age group
26. Where died
27. Type of hospital
28.) Cause of death
29.)
30. Additional causes
31.) Relationship
32.) Sex

} Person registering death

33. Same address
34. Social class

} From death certificate

79 Place of death

COLUMN 80 CARD NO 98

Home Care for Dying

Col 1.

Serial number - 1st digit - Area

Barking	1	80
Teeside	2	80
Hillingdon	3	80
Cheshire (N?)	4	80
Brentwood	5	80
Bridgend	6	80
Northumberland	7	80
Eastbourne	8	80
Birmingham	9	80
Thanet	0	80
St. Helens	X	80
Isle of Wight	Y	80

Col 2

2nd digit - Interval between month of death and interview month

3 months	1 -	480	1	119
			2	120
			3	120
			4	120
			5	120
9 & months	6 -	480	6	1
			7	120
			8	120
			9	120
			0	120

Col 4

4th digit - Special sample

In special sample X

Not in special sample O

Questionnaire 1 part 1. Failure/Success. Col.5.

(1)

Failure	1	121
Completed by person who registered death	2	481
Completed by other person	3	358

1 or 3 Questionnaire 1 part1. Reason for failure Col.6.

D.N.A. (code 2 or 3 on col.5.)	Y	839
Refusal - by relevant person (direct)	1	60
Other refusal	2	8
No one living in area who could help Because relevant people moved or died	3	23
Because no relevant people	4	18
Other reason	0	8

Single coded N. B. A relevant person is a relative neighbour or official in institution who knew deceased enough about them to give basic information.

IF FAILURE(1)

People contacted for failures Col.7.

2)

D.N.A. (code 2 or 3 col.5.)	Y	839
Spouse of deceased.	1	28
Son/daughter	2	18
Other relative	3	19
Neighbour	4	30
People now living at address of informant or deceased	5	15
Official in institution where deceased died	6	1

Single coded - priority as above except 6 takes precedence over 5 and 4.

No contact. 0 · 7

Inadequate × 3

Deceased's household composition (for failures) Col.8

D.N.A. (code 2 or 3 col.5.)	Y	839
Alone	1	11
With spouse only	2	30
" " and other(s)	4	6
" " unknown if with others	8	6
" other relatives	5	20
" unrelated person(s)	6	1
In long term institution	7	0
Other	0	1
Inadequate	X	44

Single coded

(2) Questionnaire 1 - second part Col.9

D.N.A. (1 on col.3)	Y	~~120~~ 121
Completed	3	~~86~~ 85
Not completed because Informant main respon ent	4	~~643~~ 639
Not completed because Informant in same household as main respondent	5	45
Not completed : refused 2nd part	6	~~51~~ 54
Not complete for other or unknown reason	X	~~15~~ 16

N.B. Codes 4 or 5 should only be coded if a main questionnaire was com leted

Single coded

(3) Questionnaire ~~3~~ 2 - main Col.10

~~D~~.N.A. Failure to 1st. part questionnaire 1	Y	~~120~~ 121
Completed by informant on questionnaire 1	1	~~640~~ 639 642
Completed by person in same household as informant on questionnaire 1	2	45
Completed by person in other household	3	99
Not completed	4	~~56~~ 53

not completed 41 a) 52304

all thumbs if applicable

Reason for failure to complete main — Col.1

D.N.A. - main completed (codes 1,2,3 in col 10)	Y	786
Failure to questionnaire 1. first part	9	121
Refused name and address of relevant person	1	1
Refusal by relevant person	2	28
Name and address of relevant person not known	4	5
No relevant person living in area	0	12

Single coded Codes 1,2,4, additive

Relevant person on holiday or temporarily away 8 — or other 7 reasons

b) Details of people contacted

People contacted for main failure — Col.12.

D.N.A. (main completed or failure to questionnaire 1)	Y	907
Spouse	1	9
Son/daughter	2	7
Other relative	3	14
Neighbour	4	13
People now livign at deceased or informant's house	5	3
Official of institution	6	2
No Contact	⊗	9
May be multi-coded. If more than one coded overcode	9	4

(4)

Questionnaire 3 Col.13.

D.N.A. Not in special sample Y

People not identified (Questionnaire 2 not completed) X

Number appropriate	No. completed	
1	1	1
2	2	2
3	3	3
1	0	4
2	0	5
2	1	6
3	0	7
3	1	8
3	2	9
0	0	0

Number of discrepencies Col.14

D.N.A. (y on col. 13).....y

Unknown (X on col.13).....X

None (0,1,2,3, on col.13).....0

One (4.6.9. on col.13).....1

Two (5,8, on col.13).....2

Three (7 on col. 13).....3

6

Failures on questionnaire 2 or questionnaire 1 2nd part — col.15.

D.N.A. (Questionnaire 2 or 2nd part questionnaire1 completed) — Blank 816

D.N.A. Did not die in hospital or institution — y 4

Unknown if died in hospital or institution — X 118

IF DIED IN HOSPITAL OR INSTITUTION How long was he there before he died?

Less than a week	1.	8
1 week < 1 month	2	5
1 month < 3 months	3	4
3 months < 6 months	4	1
6 months < 1 year	5	1
1 year +	6	—
Unknown how long it was	9	3

7

Single coded N.B. This is data from attempted interviews-not death certificate

Failure on questionnare 2 or questionnaire 1 2nd part — Col.16.

D .N.A. Blanks on col.15. 820 — Blanks

Was death

Expected	1	19
Not expected	2	12
Uncertain	3	3
Inadequate information	X	106

8

Any restrictions in what he could do in last 12 months? — Col.17.

D.N.A. Blank on col.15		Blank 816
No restrictions	0	2
Some	1	15
Qualified - i.e. some illness but no 'restriction'	2	4
Inadequate if any restrictions	X	123

These can include only those recently ill and restricted

(9)

Help in last twelve months — Col.18.

D.N.A. Blank on col.15	Blank	816
District nurse	1	9
Health visitor	2	0
Home help	3	3
None of these	0	20
Unknown if any help	X	113

May be multi-coded

Who bore brunt of looking after deceased — Co.19.

D.N.A. Blank on col.15	Blank	816
Inadequate information	X	108
Spouse	1	14
Son/daughter	2	10
Other relative	3	6
Neighbour	4	1
other	5	—
No one	0	5

Single coded

Marital status of deceased — Col.20

D.N.A. Blank on col.15	Blank	817
Married at time of death spouse since died	1	2
spouse alive	2	54
unknown if spouse alive	3	9
Widowed	4	24
Single	5	14
Separated/divorced	6	—
Unknown	X	40

N.B. Use information from death certificate if necessary

Number of calls — Col.21

One	1
Two - Nine	2-9
Y	10 or more
Inadequate	X

Telephone calls not included

Single coded

N.B. Calls to establish appropriate addresses Should be included

1	295
2	277
3	161
4	101
5	55
6	24
7	17
8	9
9	5
—	
x	11
y	5

	Col 23	Col 24
1	6	83
2	2	100
3	14	87
4	48	101
5	119	92
6	248	99
7	281	94
8	206	112
9	54	107
0	1	84
x	1	1

Death Certificate

Totals for transferred cols

Col 22

Sex of Deceased

418 ~~+ 19~~ Male.....1 505 ~~Box 1~~

367 Female.....2 455

Age of deceased (2 digits as given)

Inadequate.....XX

'00 + 0 digits

Col 23-24 ~~Boxes 2 & 3~~

Age groups of Deceased

Col 25 ~~Box 4~~

CHECK TOTALS FOR TRANSFERRED Code	Total	COLS		
1	4		Under 25.....1	7
2	3		25 - 34.....2	6
3	28		35 - 44.....3	33
4	55		45 - 54.....4	68
5	145	~~46~~ 145	55 - 64.....5	~~168~~ 169
6	128		65 - 69.....6	155
7	~~111~~	110	70 - 74.....7	~~148~~ 141
8	112		75 - 79.....8	140
9	101		80 - 84.....9	119
x	1		85+.....Y	122
y	98		Inadequate.....X	1

Where died (1st Code) (Delete Marital Status on Completion Record)

Col 26 ~~Box 5~~

	Transferred	Totals		
	~~967~~	16	21	Teaching hospital (Section 5*).....1
1	318	340	426	Other N.H.S. hospital (Section 4*).....2
2	16	14	17	Voluntary hospital (Section 12*).....3
3	25			Private nursing home (so specified on death cert. and not listed in section 12).....4
4	31	13	17	
5	24	2	3	Other institution.....5
6	321	341	403	Deceased's own home**.....6
7	49	36	41	Other address.....7
0	(39)	23	30	Other (i.e. in road, dead on arrival at hospital etc.....0
X	1	1	2	Inadequate.....X

* Hospitals Year Book 1969

** Assume own home if no additional address given to place where died and this is not a hospital or institution.

Type of hospital (delete where died)

Col 27

Mental illness or subnormality(.M.S.).....1	27
Chest T.B.....2	8
Chronic, long stay, geriatric.....3	68
Acute.....4	238
Mainly or partly acute..[arrow acute included 5	94
Cancer and radio therapy.....6	2
Dying, Terminal Care and Advanced Cases.....7	3
Other (including combination of above).....0	24
Inadequate.....X	23
D.N.A. (All codes except 1 & 2 in Box 5).....9	493
	494

Single coded

Check totals for transferred cols

1	25
2	7
3	56
4	184
5	74
6	2
7	3
8	
9	412
0	23
x	
y	
	786

Survey of Care before Death. Classification of cause of death

Code		ICD 1965 no.		
00	Infective and parasitic	000–136	5	
	Neoplasms			
10	Malignant neoplasm, stomach	151	26	
11	" " bronchus and lung	162.1	57	
12	" " breast	174	25	
13	" " uterus	180–182	8	
14	" " prostate	185	9	
15	Leukaemia and aleuhaemia	204–207	—	
16	Other neoplasm of specified site	Rest 140–238 excluding 199 & 228		124
17	Neoplasm of unspecified site	199,228,239	9	
01	Endocrine, Nutritional and Metabolic	240–279	10	
02	Blood and blood forming organs	280–289	—	
03	Mental disorders	290–315	—	
04	Nervous system and sense organs	320–389	12	
	Circulatory			
20	Hypertensive	400–404	13	13
21	Ischaemic heart disease	410–414	231	187
22	Rheumatic fever and other heasrt disease	390–398,420–429	65	48
23	Cerebrovascular disease	430–438	162	133
24	Diseases of the arteries	440–448	21	17
25	Other	450–458	1	1
	Respiratory			
30	Pneumonia	480–486	55	
31	Bronchitis	490–493	52	
32	Other	460–474,500–519	10	
60	Digestive	520–577	15	
06	Genito urinary	580–629	17	
07	Complications of pregnancy etc.	630–678	—	
08	Skin	680–709	—	
09	Musculoskelotal and Connective	710–738	1	
0Y	Congenital and perinatal	740–779	1	
40	Symptoms	780–796	4	
	Accidents			
50	Transport	E800–E845	7	
51	Suicide or self inflicted injury	E950–E959	8	
52	Other	E850–E949,E960–E999	12	
XX	Inadequate		—	

Col 28 = 29

Totals of Col 13 transferred

Code	Total
1	215
2	399
3	~~417~~
4	3
5	21
6	12
0	38
X	—
Gr.	~~786~~

Col 30

Additional causes of death (delete occupation on completion record).

I.C.D. no.1966 ~~Box 9~~

1.	Neoplasms	19	140 - 239
2.	Circulatory	91	390 - 458
3.	Respiratory	120	460 - 519
4.	Symptoms	91	780 - 796
5.	Accidents	3	E800 - E999 as N's.
6.	Digestive	24	520 - 577
0.	Others	86	000 - 136, 240 - 389, 580 - 779
X.	Inadequate	0	
9.	No additional cause	593	

This may be multi-coded but additional causes within the same broad group of the ICD. as the underlying cause ~~and~~ are not taken.

This means that this code never contains the same digit as the first digit of the underlying cause except that both can be 0 if the two causes would have different 2nd digits if both were classified according to the 2 digit code for underlying cause.

Col 31

The person registering death is — ~~Box 10~~

Husband/wife.....1	215
Father/mother.....2	6
Father-in-law/mother-in-law.....3	1
Son/daughter.....4	378
Son-in-law/daughter-in-law.....5	53
Grandchild.....6	12
Brother/sister.....7	68
Brother-in-law/sister-in-law....8	29
Other relative.....9	72
Coroner.....Y	33
Other.....0	90
Inadequate.....X	3

Col 32

Sex of person registering Death — ~~Box 11~~

D.N.A. if y in box 10.....9	33
Male.....1	551
Female.....2	374
Inadequate.....X	2

Col 33

Person who registered death lives at.- — ~~Box 12~~

Same address as deceased lived.....1	419
" " " " died (but deceased did not live there.).....2	21
Same road as deceased lived.....3	21
Other.....0	462
Inadequate.....X	4
D.N.A. if y in box 10.....9	33

Social class of deceased (delete person who secured death certificate on ~~Box 13~~ completion record)

Col 34

Classified by occupation of deceased or spouse from the death certificate according to classification of occupations 1960.

		Totals for Transferred Cols
Social class I.....1	30	27
II.....2	152	117
III non manual.....3	115	83
III manual.....4	309	259 176
IV.....5	204	~~177~~
V.....6	98	34
Student or armed forces.....7	11	8
Inadequate.....X	41	26

MB Look at G & H.

G. seems to give industry

H. employment status.

1 = Employee

2 = Self employed with employees

3 = Self employed without employees.

Col 78

Where died

		No.	
Teaching Hospital	2	21	16
Other General Hospital	1	399	318
Psychiatric Inst.	3	31	25
P.N.H	4	40	31
Perm residence	5	29	24
Own Home	6	351	323
Elsewhere	7	59	49
C C Inst 6 M +	X	61	40
		960	7861

(62)

Card 246

(2)

Column / Column 15 Nº of Officials	1	2	3	4	5	6	7	8	9	0	11	12	R	Total
1														204
2														118
3														57
4														26
5														9
6														1
7														—
Eight or more. 8														—
9														
None or inadequate to all 0														240
11														
12														
R														71
Total														726

| | | |

Place of death

Col 79

		TOTALS
1	General hospital	420
2	Mental institution	1
3	Mental institution	30
4	Private nursing home	40
5	Permanent place of residence - institution	29
6	Own home	381
7	Elsewhere	59
X	In hospital or institution 6 months +	51 (overcode
V	Ignore.	

960 cards.

Place of death

Col 79

		TOTALS
1	General hospital	420
2	Mental institution	1
3		30
4	Private nursing home	40
5	Permanent place of residence. institution	29
6	Own home	381
7	Elsewhere	59
X	In hospital or institution 6 months +	51 (overcode
V	Ignore.	

960 cards.