

Paper 4: Carers Survey – paper for SSUSG

Background

A Carers module was commissioned by the Department of Health as a trailer in the General Household Survey (GHS) every five years between 1985 and 2000, with the module ceasing to run in 2005 due to operational changes at ONS. As the survey function of the DH has now transferred to the IC, the Survey Team were approached in 2006 to look at repeating the survey and continuing the time series.

As the GHS can no longer run a trailer module, it has been proposed that a similar module could run the ONS Omnibus Survey, with minimal impact on the time trend data.

Geographical Coverage

The ONS Omnibus would cover around 16,000 respondents in Great Britain, consisting of one face-to-face computer assisted interview of one randomly selected adult (aged 16 and over) per household. Given that around 16% of the general population are informal carers, this will provide a sample size of around 2,560, which is roughly equivalent to the sample size in 2000.

While this survey will not be able to provide breakdowns to a regional level or below it is planned that the IC will provide assistance to any Local Authorities (or similar) who may wish to commission a local boost. The IC will make the questionnaire available for use and provide support in sample selection methods, advice for interviewing, survey management and analysis to the same standard as the national level data. Please note this is not the same as the questionnaire provided by the Beacon Scheme, as it is population based (not just service users), more detailed and designed to be used in a face-to-face interview.

Topic coverage

The survey questionnaire is expected to be a modified version of that used in the 2000 survey with some modifications. The main areas to be covered are

- General demographic characteristics (age, gender, ethnicity, income etc)
- Prevalence of caring in the general population (proxy questions for other carers in household to account for move to Omnibus format)
- Characteristics of cared for person (reason they need care, relationship)
- Type of care provided (main cared for person)
- Hours of care (main cared for person)
- Benefits received
- Social care/professional care received (including carers assessment)
- Support in providing care (respite, breaks etc)

- Impact on health and wellbeing of carer

Timing

Although it is not yet known when fieldwork will commence (see below), it is expected that fieldwork will take 12 months, and 9 months for data cleaning and reporting. It is hoped that fieldwork will begin in 2008/09.

Progress with commissioning the survey

The business case for this survey has been discussed by both the Survey Programme Review Board and the Executive Directors Group at the IC, who agreed that this survey would provide important data that cannot be collected by any other means. However, in light of funding constraints at the IC, we are currently pursuing alternative sources of funding within DH. Until these issues have been solved it is not known when the survey will commence fieldwork.

Questions for SSUSG

1. How useful is the national level data for local commissioning? Have you used the GHS survey data and/or the Census level data to determine the level of need in your area?
2. Would you be likely to take up the local boost in your area? Please bear in mind that the cost of the face-to-face interviews would have to be borne by the LA, although the IC can provide a framework and analysis to allow for direct comparison to national level data. Is this a helpful option? (Any comments very useful!)

IC Survey Team 2008

The questions

INFORMAL CARERS

1. INTRO Ask all fully co-operating adults

I'd like to talk now about caring informally for others. Some people have extra responsibilities because they look after someone who has long-term physical or mental ill health or disability, or problems related to old age. [These questions are about caring long-term and do not apply if you or another person are caring for someone on a temporary basis, such as someone with flu or a broken leg.](#)

2. DepLivIn [*] Ask if there is more than one person in the household (NPersn >1), others Q3

May I check, is there anyone **living with you** who is sick, disabled or elderly whom you look after or give special help to, other than in a professional capacity (for example, a sick or disabled (or elderly) relative/husband/wife/child/friend/parent, etc)?

CODE 'NO' IF GIVES FINANCIAL HELP ONLY

Yes..... 1_Q3
 No 2_Q4
 Not sure 3

3. DlivNo Ask if respondent is caring for someone in household (DepLivIn = 1 or DlivOut = 1)

Do you look after or help one sick, disabled or elderly person living with you, or is it more than one?

IF MORE THAN 6 CODE AS 6

1 .. 6_Q6

4. DlivOut [*] Ask all co-operating adults

Is there anyone, **not living with you** who is sick, disabled or elderly whom you look after or give special help to, other than in a professional capacity, (for example, a sick or disabled (or elderly) relative/husband/wife/child/friend/parent, etc)?

CODE 'NO' IF GIVES FINANCIAL HELP ONLY
 CODE ALL THAT APPLY

Yes; in another household 1_Q5
 No 2_Family
 Not sure 3 Information

5. DOutNo Ask if respondent is caring for someone in another household (DlivOut = 2)

Do you look after or help one sick, disabled or elderly person living elsewhere, or is it more than one?

IF MORE THAN 6 CODE AS 6

1..6 _ Q6

6. TotDep1 Computed in Blaise if respondent is caring for someone (*DepLivIn = 1 or DlivOut = 1-2*)

TOTAL NUMBER of PEOPLE HELPED (DLIVNO+DOUTNO) (computed in Blaise)_ Q7

7. OthercarerHH Ask if there is more than one person in the household

Does anyone else in your household look after a sick, disabled or elderly person, either living with you or living somewhere else? They can be providing care to you, or the same people you care for.

RECORD WHO IN HOUSEHOLD IS PROVIDING CARE(NAME OF PERSON)

8. OthercarerNum Ask if other person in household provides care. Repeat for all named people in household who provide care

Does {name of person} look after or help one sick, disabled or elderly person, or is it more than one?

IF MORE THAN 6 CODE AS 6

1..6 _ Q6

If respondent is caring for someone (in this or another household) ask the following block of questions until question after Dillness, for each person cared for in turn, starting with people living in the household

9. DrellInf (*DepLivIn = 1 or DlivOut = 1*)

Who is it (in your household/ not living with you) that you look after or help?

- Spouse/partner 1_ Q8
- Own/adopted/step child 2_ Q8
- Foster child 3_ Q8
- Parent 4_ Q8
- Parent-in-law 5_ Q8
- Other relative 6_ Q8
- Friend or neighbour 7_ Q8
- Client of voluntary organisation 8_ next dependent
- Other 9_ Q8

10. DepName Ask about all people being cared for, except clients of voluntary organisation

(*DRelInf ≈ 8*)

RECORD name or relationship by which person(s) cared for will be referred to in following questions _ Q9

11. DAge ASK OR RECORD

Age of (NAME OF PERSON CARED FOR) ESTIMATE IF NECESSARY IF ESTIMATE CODE 997, AND ENTER ESTIMATED AGE IN THE NEXT QUESTION _ Q10

12. XDAge Ask if estimating age (*DAge = 997*)

Enter estimated age range 0..120 _ Q11

13. Dsex Ask about all people cared for, except clients of voluntary organisation (*DRelInf ≠ 8*)

ASK OR RECORD

Sex of person cared for _ Q12

Male 1 _ See Q12

Female 2

14. Dillness Ask about all clients

ASK (or RECORD if already mentioned by respondent)

May I check, why does (NAME OF PERSON CARED FOR) need care?

DO NOT PROBE Q17

RECORD ILLNESS/CONDITION _

15. Affected You mentioned what was the matter with (NAME OF PERSON CARED FOR) Could I just check, how is he/she affected?

READ OUT OR SHOW CARD M or RUNNING PROMPT

Is it ...

physically 1

mentally 2

both physically and mentally? 3

SPONTANEOUSLY ONLY –

old age 4

Other 5

16. Dhelp Ask

What kinds of things do you usually do for (NAME OF PERSON CARED FOR) IF IS IN HOUSEHOLD (over and above what you would normally do for someone living with you/a child of his/her age?)

SHOW CARD N

PROMPT FIRST ITEM AS EXAMPLE

CODE ALL THAT APPLY

Do you usually help with

Personal care ?

(eg. dressing, bathing, washing, shaving, cutting nails, feeding,

using the toilet)	1
Physical help?	
(eg. with walking, getting up and down stairs, getting into and out of bed)	2
Helping him/her deal with services (eg helping with applications for benefits, arranging visits or services with social services, dealing with schools etc)	3
Helping with paperwork or financial matters? (eg. writing letters, sending cards, filling in forms, dealing with bills, banking)	4
Other practical help?	
(eg. preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital)	5
Keeping him/her company?	
(eg. visiting, sitting with, reading to, talking to, playing cards or games)	6
Taking him/her out?	
(eg. taking out for a walk or drive, taking to see friends or relatives)	7
Giving medicines?	
(eg. making sure he/she takes pills giving injections, changing dressings)	8
Keeping an eye on him/her to see he/she is all right?	9
Other help?	10

17. HelpHrs

About how long do you spend each week looking after or helping (NAME OF PERSON CARED FOR) - that is doing the things you've mentioned and including time when you just need to be there (apart from when you are asleep/ including time travelling to and from his/her home)?
PROMPT AS NECESSARY or SHOW CARD O

0-19 hours per week	1
10-19 hours per week	2
20-34 hours per week	3
35-49 hours per week	4
50-99 hours per week	5
100 or more hours per week	6
Varies - Under 20 hours	7
Varies - 20 hours or more	8
Other	9

CHOOSING THE MAIN PERSON CARED FOR

a. If the Carer assists more than one person, select the one that the respondent spends most time helping. b. If the same amount of time is spent assisting two people, select the one that lives in the respondent's household. c. If the same amount of time is spent assisting two people, both of whom live in the respondent's household, ask MdepNo (see below). Select the person on whom more time is spent. If the respondent is unable to say for which person she/he spends most time caring, select the first one listed. d. If

there is more than one person cared for and they all live outside the household, select the one with the highest number of hours helped. e. If the same amount of assistance is given to more than one person, all of whom live outside the household, choose the first one listed

18. **MdepNo** SELECT THE PERSON CARED FOR WHO THE RESPONDENT SPENDS MOST TIME WITH IF SPENDS THE SAME AMOUNT OF TIME WITH MORE THAN ONE PERSON THAT THEY CARE FOR, THEN SELECT THE PERSON WHO IS 'AT HOME'

Otherwise ASK:

You mentioned earlier that you spend a similar amount of time per week looking after or helping (NAME ALL 'EQUAL' PERSONS CARED FOR)
Can you say which one you spend most time helping on average, or is there no difference?

IF RESPONDENT SAYS NO DIFFERENCE SELECT THE FIRST ELIGIBLE PERSON CARED FOR

Enter person number of person cared for
1..7 _ Q19

19. **IntChk** INTERVIEWER: HAVE DETAILS ALREADY BEEN COLLECTED FOR (NAME OF PERSON CARED FOR)?

Ask the following questions about the MAIN PERSON CARED FOR

20. **HelpYrs** About how long have you been looking after or helping (NAME OF PERSON CARED FOR) IF PERSON CARED FOR IS IN HOUSEHOLD (that is doing things for him/her over and above what you would normally do for someone living with you/a child of that age)?

PROMPT AS NECESSARY

- Less than 6 months 1
- 6 months, less than 1 year 2
- 1 year, less than 3 years 3
- 3 years, less than 5 years 4 _ Q18
- 5 years, less than 10 years 5
- 10 years, less than 15 years 6
- 15 years, less than 20 years 7
- 20 years or more 8

21. **WherElse**

Where does (NAME OF PERSON CARED FOR) live. If they sometimes live in more than one place, tell us where they live most often. PROBE FULLY

- Same household..... 1_Q13
- In another private household 2_Q13
- Boarding school/
residential college 3_Q13
- Hospital or Nursing home 4_Q14
- Residential home 5_Q14
- Other institution 6_Q13
- Other 7_Q13

22. Benefits Do you receive carers allowance or other state benefits to allow you continue to provide care

- Carers allowance.....1
- Direct payments for carers.....2
- Pension – cannot receive carers allowance3
- Other benefit4
- Not eligible/don't receive benefits.....5

23. CareAssess

Have you had a carer's assessment of your own needs by your local social services or health authority?

- Yes..... 1_Q24
- No..... 2
- SPONTANEOUS
- Offered but declined..... 3

24. CareServ Ask if carer had an assessment (CareAssess = 1)

Did you receive any services or help as a result of the assessment? Please specify

- No Services..... 1
- Information about cared for person's condition..... 2
- Information about other organisation providing services..... 3
- Break in own home..... 4
- Break away from home.....5
- Carers support.....6
- Carers centre.....7
- Training.....8

25. CareWorkAsk if carer had an assessment (CareAssess = 1)

When you had your assessment, did social services take into account your wish to work or take-up educational or leisure opportunities as well as care for someone?

Yes..... 1
No 2

I'm now going to ask some questions about how much help the main person you care for gets.

26. **OthHelp** Apart from any **professional** people, such as nurses or home carers, who may regularly visit (NAME OF MAIN PERSON CARED FOR), is there anyone else who helps to look after him/her - for example, another member of your household, another member of the family, a relative or friend or some kind of paid helper?

Yes..... 1 _ Q27
No 2
Don't know 4

27. MoreTime Ask if there is someone else who helps look after the person cared for (*OthHelp = 1*)

)
Can I just check, do any of these people (including anyone in your household) spend more time looking after (NAME OF PERSON CARED FOR) than you do?

Yes..... 1
No 2
Other person(s) spend equal time 3
Don't know 4

28. Dvis Ask if main person being cared for is a relative, or living in the household (*DrelInf = 1-6 or DPersn < 15*), others *Q49*

I am now going to ask a few questions about (MAIN PERSON CARED FOR)

Does (NAME OF PERSON CARED FOR) receive regular visits at least once a month from any of these people?

SHOW CARD P

CODE ALL THAT APPLY

Doctor 1 _ Q28
Community/district nurse 2 _ Q28
Health visitor 3 _ Q28
Social worker/care manager 4 _ Q28
Home help/care worker 5 _ Q28
Meals on wheels 6 _ Q28
Voluntary worker 7 _ Q28
Other professional visitor 8 _ Q24
No, none 9 _ Q29
Don't know 10 _ Q24

29. Dnurs Ask if main person cared for does not receive regular visits from any of the people listed above (Dvis = 9)

What are the reasons for (NAME OF PERSON CARED FOR) not receiving regular visits at least once a month from any of the above? Please choose your answers from the card.

SHOW CARD Q

CODE ALL THAT APPLY

- Not available/not offered 1
- Not needed 2
- Tried, but not helpful 3
- Not wanted by you 4
- Not wanted by the person
you care for 5
- Not at a convenient time 6
- Too expensive 7
- Other 8

30. 24. DGo Ask if main person cared for is a relative, or living in the household (DRelInf = 1-6 or WhereEls = 1)

Does (NAME OF PERSON CARED FOR) regularly go to any of the places or activities listed on this card?

SHOW CARD R

- Work 1
- Day centre 2
- School or college 3
- Day hospital 4
- Social club, support group or other club 5
- None of these 6

31. 25. DgoHrs Ask if person cared for goes to at least one place/activity (DGo = 1-5)

About how many hours a week in total does he/she usually spend without you and outside the home?

IF VARIES ASK FOR AVERAGE NUMBER OF HOURS PER MONTH AND CALCULATE AVERAGE NUMBER PER WEEK IF HOURS VARY AND CANNOT GIVE AVERAGE, CODE 97

1..97

32. 26. Resp2Hrs Ask if respondent spends 20 or more hours a week caring for this person (THelpHrs = 2-5 or 7), others see Q49

You've told me about the things you do for (NAME OF PERSON CARED FOR).

If you wanted a break for a few hours (during the time when you usually look after him/her) would someone else have to look after him/her?

Yes, someone else needed 1 _ Q25

No 2 _ Q28

33. 27. Hlp2Hrs Ask if someone else would have to look after the person being cared for (*Resp2Hrs = 1*)

Is there anyone whom you could rely on to look after him/her either at home or elsewhere?

Yes..... 1 _ Q26

No 2 _ Q28

34. 28. Xhelp2H Ask if someone else could be relied on to look after him/her (*Hlp2Hrs = 1*)

Who could you rely on to look after him/her?

Relative 1

Friend or neighbour 2

Paid helper 3

Other

35. 29. RspType Ask if respondent spends 20 or more hours a week caring (*HelpHrs = 2-5 or 7*)

The card shows various types of temporary care or holidays which may be available. Are any of these services available if you wanted a break?

SHOW CARD U

CODE ALL THAT APPLY

Help provided in the home

(eg sitting/befriending service) 1 _ Q28

Help provided in a residential setting

(volunteer family, residential/nursing home

or hospital) 2 _ 28

Holiday together 3

SPONTANEOUS – None of _ Q29

these available/possible 4

SPONTANEOUS – Don't know 5

36. 30. RspHrs Ask if help is provided in the home (*RspType = 1*)

You mentioned that help provided in the home is available if you wanted a break. How many hours of temporary care would be available?

0-8 hours

(eg sitting/befriending service) 1

9-24 hours 2 _ Q30

25 hours or more 3

SPONTANEOUS – Don't know 4

37. **31. RspSit** In the last year, have you made use of a sitting service for (NAME OF PERSON CARED FOR) in order to go out for a couple of hours?

- Yes..... 1
- No 2
- Not available /Don't know _ Q31
about service 3

38. **32. RspBef** Ask if respondent spends 20 or more hours a week caring
(*HelpHrs = 2-5 or 7*)

In the last year, have you made use of a befriending service for (NAME OF PERSON CARED FOR) (that's where a volunteer takes him/her out for the day?)

- Yes..... 1
- No 2
- Not available /Don't know
about service 3

39. **33. Break** Ask if no-one else would have to look after the person being cared for (*Resp2Hrs = 2*)

Have you had a break of more than a few hours since you started to look after (NAME OF PERSON CARED FOR)?

- Yes..... 1 _ Q33
- No 2 _ Q35

40. **34. Brk1Ago** Ask if has a break for more than a few hours (*Break = 1*)

About how long is it since you last had such a break. Was it less than or more than 1 year ago?

- Less than 1 year ago 1
- 1 year or more ago 2

41. **35. Brk1Typ** Ask if has a break for more than a few hours (*Break = 1*)

What sort of arrangements did you use for (NAME OF PERSON CARED FOR) when you last had a break for 2 days or more?

- Nursing or residential home 1
- NHS hospital 2
- Local Authority hostel 3
- Arranged holiday (PERSON cared for only) 4
- Arranged holiday (PERSON and carer) 5
- Stay with a volunteer family 6
- Stay with relatives or friends 7
- Friend or relative staying with
PERSON CARED FOR 8
- Other 9

42. 36. Carehlth Ask if caring for someone (in this or another household)
(DepLivIn =1 or DlivOut = 1 or 2)

Has your own health been affected by the assistance you give to (NAME OF PERSON CARED FOR) in any of the ways on this card?

CODE ALL THAT APPLY

SHOW CARD V

- Feeling tired 1
- Feeling depressed 2
- Loss of appetite 3
- Disturbed sleep 4
- General feeling of stress 5
- Physical strain (eg back) 6
- Short tempered/irritable 7
- Had to see own GP 8
- Other 9
- No, none of these 10