

four-level interview schedule (INT4) for carers

Interviewer Notes

1. Definition of Support and Services

The interview is flexible so that the definition of support and services can be tailored to the needs of your particular research study. Where the schedule reads <<EXAMPLE>>, the interviewer should either:

- a. Insert the name of the specific service that is being investigated: for example, home care, personal budget, carer support group; or
- b. (If asking about the full social care package) give some examples of the support and services that the carer and/or cared-for person are receiving.

The interview is designed to measure the impact of social care services¹ on the social care-related quality of life (SCRQoL) of family/friend (unpaid) carers² aged 18 years or older. We found that a clear definition of what is, or is not, included helps the respondent to answer the questions. It is suggested (although this may be adapted to your particular needs) that:

- a. If there are any specific services you would like to exclude (for example, NHS support and services) then the interviewer should use the prompts to exclude NHS support and services when answering the filter (for example, question 2) and expected situation questions (for example, question 3). You may wish to ask respondents to include some NHS services, for example if they are caring for someone with a mental health problem who has support from a Community Mental Health Team (CMHT) that is joint-funded by Adult Social Care Services and the NHS.

¹ The services may be received by both the carer and the person they care for or by either of them.

² Carer(s) – an adult (18 years of age or older) who cares for an adult who has a long-term health condition, illness, disability, frailty, or other support needs. Sometimes called an informal, family/friend or unpaid carer or caregiver, this person is often (but not always) a spouse or relative of the person being cared for.

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In this case, we would strongly recommend that the interviewer makes this clear in the definition of support and services at the start of the interview, as well as in the prompts throughout the interview schedule.

- b. There may be situations where social care services are funded by streams outside of social care. It is recommended that you ask carers to include all social care services, regardless of the funding source, when answering the filter and expected questions.

2. Using the Interviewer Prompts

- a. When asking the interviewee about their social-care related quality of life in the absence of services (expected situation questions, for example question 3):
 - i. Emphasise that the respondent does *not base his/her answers on the assumption that any other help steps in*.
 - ii. Reassure them that the question is about a *purely imaginary situation and does not affect the services they receive in any way*.
- b. Make sure that the interviewer prompts are used frequently to define 'support and services', as cognitive interviewing has shown that this helps respondents in answering the questions.
- c. We have found that carers tend to answer the current social care-related quality of life (SCRQoL) questions with reference to an 'average day' based on recent experience over the preceding weeks or month, without a more precise definition of the timeframe. Although some current situation questions (for example, question 7, 16 and 19) include a timeframe reference ('*your present situation*') in the question, the use of timeframe reference prompts ('*think about your situation at the moment*') may aid comprehension and guide the respondent to answer the current SCRQoL questions based on their current, rather than expected, situation.

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3. Notes on the Filter Questions (for example, question 2)

We have found that carers find it difficult to separate the services they receive from those of the person they care for; therefore, the filter questions (for example, question 2) and questions about what their life would be like in the absence of services (for example, question 3), are worded to include both. However, this interview is designed to be flexible and you can focus on the impact of specific services if you want to, as long as you make it very clear for the person you are interviewing and when you analyse and report your findings.

When asking the filter questions:

- a. Be very clear about which services you are interested in and use examples to help you.
- b. Emphasise that the question is asking whether the support and services affect a particular aspect of the carer's life (for example, 'do support and services affect how you spend your time?'). If needed, explain to the respondent that we are not asking whether support and services make a difference generally, but whether they make a difference (either positive or negative) to that particular aspect of their life.
- c. Emphasise that the question is asking whether the support and services affect the carer's life, not the cared-for person's or other family member's life (for example, 'do support and services affect how you spend your time?').

4. Notes on Sensitive Questions

It should be noted that the set of questions asks respondents to think about their lives and experiences. This may be upsetting to some respondents, particularly if they are currently experiencing difficulties. We would recommend that the interviewer clearly explains the nature of the questions before obtaining informed consent, and emphasises the

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respondent's right to terminate the interview or to refuse to answer specific questions without further explanation.

The 'expected situation' questions may be particularly sensitive in situations where the respondent, or the person they help or look after, has recently experienced cuts to their social care support or services. In this case, we would recommend that the interviewer be especially aware of the potential sensitivity of the questions and be prepared to terminate or pause the interview, if needed.

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Introduction

To help us to measure the impact of services and support, we are talking to people who actually use them. We think people themselves are best able to judge how services and support affect their lives.

When we talk about 'services and support' in the next set of questions, we mean for you to think about:

Interviewer note: Insert here a phrase that makes sense both in local context and in the context of the service that you are investigating; for example, home care, personal budget, carer support group.

Example wording (if asking about the full social care package): "services provided by different organisations, such as voluntary organisations, private agencies or your local authority / council. For example, <<Give specific examples based on service receipt questions³>>. This may be support you receive directly from your local authority or voluntary organisations, or which you pay for yourself, or with a personal/individual budget or direct payment. We do **not** mean any other help you may get from friends, neighbours or family, or support from health professionals, such as doctors/GPs, nurses or physiotherapists".

*I'll ask you some questions about different aspects of your life at the moment. Then I'll ask you whether support and services make a difference to that aspect of your life. Finally, I'll ask you to imagine a situation where you do not have the support and services that you do now. This is a purely imaginary situation and the answer you give will not affect the services that you or the person you look after receives. The purpose of these questions is to measure how the services and support affect **your** life.*

³ If the interview is being conducted to measure the impact of the full social care package, the carer should be asked detailed questions about the support and services that they (and/or the care recipient) are receiving before administering the ASCOT Carer INT4.

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Occupation

1. Which of the following statements best describes how you spend your time?

Interviewer prompt: When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others.

If needed, please prompt: When answering the question, think about your situation at the moment.

Please tick (☑) one box

- | | |
|---|--------------------------|
| I'm able to spend my time as I want, doing things I value or enjoy | <input type="checkbox"/> |
| I'm able to do enough of the things I value or enjoy with my time | <input type="checkbox"/> |
| I do some of the things I value or enjoy with my time, but not enough | <input type="checkbox"/> |
| I don't do anything I value or enjoy with my time | <input type="checkbox"/> |

2. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect how you spend your time?

Interviewer prompt: By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. Please do not include help from health professionals, such as GPs and nurses, or from friends and family.

Please tick (☑) one box

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

If 2 = yes or don't know, then go to question 3

If 2 = no, then go to question 4

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3. **Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now and no other help stepped in. In that situation, which of the following would best describe how you would spend your time?**

Interviewer note: It is important that respondents do not base their answers on the assumption that any other help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

I would be able to spend my time as I want, doing things I value or enjoy ☐

I would be able to do enough of the things I value or enjoy with my time ☐

I would do some of the things I value or enjoy with my time, but not enough ☐

I wouldn't do anything I value or enjoy with my time ☐

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Control over daily life

4. Which of the following statements best describes how much control you have over your daily life?

Interviewer prompt: If needed, please prompt: *When answering the question, think about your situation at the moment.*

Please tick (☑) one box

- | | |
|--|--------------------------|
| I have as much control over my daily life as I want | <input type="checkbox"/> |
| I have adequate control over my daily life | <input type="checkbox"/> |
| I have some control over my daily life, but not enough | <input type="checkbox"/> |
| I have no control over my daily life | <input type="checkbox"/> |

5. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect how much control you have over your daily life?

Interviewer prompt: By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. Please do not include help from health professionals, such as GPs and nurses, or from friends and family.

Please tick (☑) one box

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

If 5 = yes or don't know, then go to question 6
If 5 = no, then go to question 7

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6. **Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now and no other help stepped in. In that situation, which of the following would best describe the amount of control you would have over your daily life?**

Interviewer note: It is important that respondents do not base their answers on the assumption that any help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

- | | |
|--|--------------------------|
| I would have as much control over my daily life as I want | <input type="checkbox"/> |
| I would have adequate control over my daily life | <input type="checkbox"/> |
| I would have some control over my daily life, but not enough | <input type="checkbox"/> |
| I would have no control over my daily life | <input type="checkbox"/> |

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Looking after yourself

- 7. Thinking about how well you look after yourself – such as, getting enough sleep or eating well – which statement best describes your present situation?**

Interviewer prompt: If needed, please prompt: *When answering the question, think about your situation at the moment.*

Please tick (☑) one box

I look after myself as well as I want ☐

I look after myself well enough ☐

Sometimes I can't look after myself well enough ☐

I feel I am neglecting myself ☐

- 8. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect how well you look after yourself?**

Interviewer prompt: By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. Please do not include help from health professionals, such as GPs and nurses, or from friends and family.

Please tick (☑) one box

Yes ☐

No ☐

Don't know ☐

If 8 = yes or don't know, then go to question 9

If 8 = no, then go to question 10

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9. **Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now, and no other help stepped in. In that situation, which of the following would best describe how well you would look after yourself, such as getting enough sleep or eating well?**

Interviewer note: It is important that respondents do not base their answers on the assumption that any other help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

- | | |
|--|--------------------------|
| I would look after myself as well as I want | <input type="checkbox"/> |
| I would look after myself well enough | <input type="checkbox"/> |
| Sometimes I wouldn't look after myself well enough | <input type="checkbox"/> |
| I would feel that I am neglecting myself | <input type="checkbox"/> |

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Personal safety

10. Which of the following statements best describes how safe you feel?

Interviewer prompt: By 'feeling safe' we mean feeling safe from fear of abuse, being attacked or other physical harm, such as accidents, which are a result of your caring role.

If needed, please prompt: When answering the question, think about your situation at the moment.

Please tick (☑) one box

- | | |
|---|--------------------------|
| I feel as safe as I want | <input type="checkbox"/> |
| Generally I feel adequately safe, but not as safe as I would like | <input type="checkbox"/> |
| I feel less than adequately safe | <input type="checkbox"/> |
| I don't feel at all safe | <input type="checkbox"/> |

11. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect how safe you feel?

Interviewer prompt: By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. Please do not include help from health professionals, such as GPs and nurses, or from friends and family.

Please tick (☑) one box

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

If 11 = yes or don't know, then go to question 12

If 11 = no, then go to question 13

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12. Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now, and no other help stepped in. In that situation, which of the following would best describe how safe you would feel?

Interviewer note: It is important that respondents do not base their answers on the assumption that any other help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

- | | |
|---|--------------------------|
| I would feel as safe as I want | <input type="checkbox"/> |
| Generally I would feel adequately safe, but not as safe as I would like | <input type="checkbox"/> |
| I would feel less than adequately safe | <input type="checkbox"/> |
| I wouldn't feel at all safe | <input type="checkbox"/> |

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Social participation and involvement

13. Thinking about how much contact you have with people you like, which of the following statements best describes your social situation?

Interviewer prompt: If needed, please prompt: *When answering the question, think about your situation at the moment.*

Please tick (☑) one box

- | | |
|---|--------------------------|
| I have as much social contact as I want with people I like | <input type="checkbox"/> |
| I have adequate social contact with people | <input type="checkbox"/> |
| I have some social contact with people, but not enough | <input type="checkbox"/> |
| I have little social contact with people and feel socially isolated | <input type="checkbox"/> |

14. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect how much contact you have with people you like?

Interviewer prompt: By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. *Please do not include help from health professionals, such as GPs and nurses, or from friends and family.*

Please tick (☑) one box

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

If 14 = yes or don't know, then go to question 15

If 14 = no, then go to question 16

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15. Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now, and no other help stepped in. In that situation, which of the following would best describe how much contact you would have with people you like?

Interviewer note: It is important that respondents do not base their answers on the assumption that any other help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

- | | |
|---|--------------------------|
| I would have as much social contact as I want with people I like | <input type="checkbox"/> |
| I would have adequate social contact with people | <input type="checkbox"/> |
| I would have some social contact with people, but not enough | <input type="checkbox"/> |
| I would have little social contact with people and would feel socially isolated | <input type="checkbox"/> |

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Space and time to be yourself

16. Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?

Interviewer prompt: If needed, please prompt: *When answering the question, think about your situation at the moment.*

Please tick (☑) one box

- | | |
|---|--------------------------|
| I have all the space and time I need to be myself | <input type="checkbox"/> |
| I have adequate space and time to be myself | <input type="checkbox"/> |
| I have some of the space and time I need to be myself, but not enough | <input type="checkbox"/> |
| I don't have any space or time to be myself | <input type="checkbox"/> |

17. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect the space and time you have to be yourself in your daily life?

Interviewer prompt: By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. *Please do not include help from health professionals, such as GPs and nurses, or from friends and family.*

Please tick (☑) one box

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

If 17 = yes or don't know, then go to question 18

If 17 = no, then go to question 19

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18. Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now, and no other help stepped in. In that situation, which of the following would best describe how much space and time you would have to be yourself?

Interviewer note: It is important that respondents do not base their answers on the assumption that any other help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

- | | |
|---|--------------------------|
| I would have all the space and time I need to be myself | <input type="checkbox"/> |
| I would have adequate space and time to be myself | <input type="checkbox"/> |
| I would have some of the space and time I need to be myself, but not enough | <input type="checkbox"/> |
| I wouldn't have any space or time to be myself | <input type="checkbox"/> |

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Feeling supported and encouraged

19. Thinking about feeling supported and encouraged in your caring role, which of the following statements best describes your present situation?

Interviewer prompt: If needed, please prompt: *This question is asking about feeling supported and encouraged, rather than how you are supported and encouraged by particular people or organisations.*

If needed, please prompt: *When answering the question, think about your situation at the moment.*

Please tick (☑) one box

- | | |
|--|--------------------------|
| I feel I have the encouragement and support I want | <input type="checkbox"/> |
| I feel I have adequate encouragement and support | <input type="checkbox"/> |
| I feel I have some encouragement and support, but not enough | <input type="checkbox"/> |
| I feel I have no encouragement and support | <input type="checkbox"/> |

20. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect how supported and encouraged you feel in your caring role?

Interviewer prompt: By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. Please do not include help from health professionals, such as GPs and nurses, or from friends and family.

Please tick (☑) one box

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

If 20 = yes or don't know, then go to question 21

If 20 = no, then end

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21. Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now, and no other help stepped in. In that situation, which of the following would best describe how you would feel?

Interviewer note: It is important that respondents do not base their answers on the assumption that any other help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

- | | |
|--|--------------------------|
| I would feel I have the encouragement and support I want | <input type="checkbox"/> |
| I would feel I have adequate encouragement and support | <input type="checkbox"/> |
| I would feel I would have some encouragement and support, but not enough | <input type="checkbox"/> |
| I would feel that I have no encouragement and support | <input type="checkbox"/> |

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