

Additional file 1: Caregiver network analysis questionnaire – patient

1. Which caregivers do you have contact with to receive daily care, advice about your disease, medical treatment, psychological support, finances, etc.?

Family/informal caregiver	<input type="checkbox"/> Yes	<input type="checkbox"/> No
GP	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Home care worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Nurse	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Medical specialist	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Allied Health Professional	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Social Worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Faith leader	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Psychological support worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Hospice worker	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Other, ...	<input type="checkbox"/> Yes	<input type="checkbox"/> No

2. For those with whom you have contact, how often and how do you have contact?

Family/informal caregiver	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
GP	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Home care worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Nurse	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Medical specialist	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Physiotherapist	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Social Worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Faith leader	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Psychological support worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Hospice worker	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail
Other, ...	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Less Often	<input type="checkbox"/> Face-To-Face <input type="checkbox"/> Telephone <input type="checkbox"/> E-Mail

3. For those with whom you have contact, how would you rate your relationship with this caregiver?

Family/informal caregiver	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
GP	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Home care worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Nurse	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Medical specialist	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Physiotherapist	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Social Worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Faith leader	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Psychological support worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Hospice worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Other, ...	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor

4. For those with whom you have contact, how would you rate care that you receive from these caregiver?

Family/informal caregiver	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
GP	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Home care worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Nurse	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Medical specialist	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Physiotherapist	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Social Worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Faith leader	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Psychological support worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Hospice worker	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor
Other, ...	<input type="checkbox"/> Excellent	<input type="checkbox"/> Very Good	<input type="checkbox"/> Good	<input type="checkbox"/> Reasonable	<input type="checkbox"/> Poor

Statements and questions about collaboration between caregivers from whom you receive care:

5. These caregivers appear to work together very well.

Strongly Agree Agree Neutral Disagree Strongly Disagree

6. The care given by these caregivers appears to be well-connected.

Strongly Agree Agree Neutral Disagree Strongly Disagree

7. These caregivers pass on information to each other well.

Strongly Agree Agree Neutral Disagree Strongly Disagree

8. These caregivers always know very well what the other caregivers have done.

Strongly Agree Agree Neutral Disagree Strongly Disagree

9. Sometimes I perceive friction between caregivers.

Strongly Agree Agree Neutral Disagree Strongly Disagree

10. Who, do you think, is the main responsible caregiver of all caregivers you receive care from? (i.e. the person(s) who decide(s) how your care is being organised)

11. Is there anything missing from the care you receive and who do you think should be providing it? (Which persons/organisations do you miss and why?)

12. In your opinion, might there be too many caregivers from whom you receive care? (Which persons/organisations may be redundant and why?)