

Supplementary file 2: Questionnaire Quality of Care - PCP

	General	Ref.nr. <input type="text"/> <input type="text"/> <input type="text"/>
1	Date of birth of your loved one? <input type="text"/> <input type="text"/> day <input type="text"/> <input type="text"/> month <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> year	
2	When did your loved one die? <input type="text"/> <input type="text"/> day <input type="text"/> <input type="text"/> month <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> year	
3	What was his/her nationality? <input type="checkbox"/> Dutch <input type="checkbox"/> other, namely	<input type="text"/>
4	What was his/ her marital status? <input type="checkbox"/> married or living together <input type="checkbox"/> widow <input type="checkbox"/> divorced <input type="checkbox"/> single <input type="checkbox"/> other, namely	<input type="text"/>
5	Did your loved one had children? <input type="checkbox"/> yes <input type="checkbox"/> no	
6	What age is this child or these children? <i>(you can tick multiple boxes)</i> <input type="checkbox"/> 0-12 year number of children in this age: <input type="checkbox"/> 13-18 year number of children in this age: <input type="checkbox"/> 19 years and older number of children in this age:	<input type="text"/> <input type="text"/> <input type="text"/>
7	How was your loved one's living situation? <input type="checkbox"/> single-housing <input type="checkbox"/> with partner <input type="checkbox"/> with partner and child / children	<input type="checkbox"/> without partner, with child / children <input type="checkbox"/> with parent(s) <input type="checkbox"/> other
8	What was his/her highest completed level of education? <input type="checkbox"/> primary education <input type="checkbox"/> lower secondary education <input type="checkbox"/> upper secondary education <input type="checkbox"/> post-secondary non-tertiary education	<input type="checkbox"/> short-cycle tertiary education <input type="checkbox"/> bachelor or equivalent <input type="checkbox"/> other

9	<p>Was your loved one religious or did he/she have a certain philosophy/religion of life?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don't know</p>
10	<p>Which philosophy/religion?</p> <p><input type="checkbox"/> Catholic</p> <p><input type="checkbox"/> Protestant</p> <p><input type="checkbox"/> Islamic</p> <p><input type="checkbox"/> Buddhist</p> <p><input type="checkbox"/> Hindu</p> <p><input type="checkbox"/> don't know</p> <p><input type="checkbox"/> other</p> <div style="border: 1px solid black; width: 350px; height: 20px; margin-left: 400px;"></div>
11	<p>What kind of relation did you have with your loved one?</p> <p><input type="checkbox"/> partner</p> <p><input type="checkbox"/> mother</p> <p><input type="checkbox"/> father</p> <p><input type="checkbox"/> child</p> <p><input type="checkbox"/> other</p> <div style="border: 1px solid black; width: 350px; height: 20px; margin-left: 400px;"></div>
12	<p>What is your age?</p> <p><input type="text"/> <input type="text"/> year</p>
13	<p>Are you a woman or a man?</p> <p><input type="checkbox"/> man</p> <p><input type="checkbox"/> woman</p>
14	<p>How is your health in general?</p> <p><input type="checkbox"/> very good</p> <p><input type="checkbox"/> good</p> <p><input type="checkbox"/> average</p> <p><input type="checkbox"/> good days / bad days</p> <p><input type="checkbox"/> bad</p>

	<p>The following questions are concerned with information that the health professionals may have given you and..... about his/ her illness, and about any anxiety or depression he/she may have had</p>
15	<p>During his/her last three months, did..... suffer from anxiety and/or nerves or get depressed? Please tick one box</p> <p><input type="checkbox"/> yes, most of the time</p> <p><input type="checkbox"/> yes, often</p>

	<input type="checkbox"/> yes, sometimes <input type="checkbox"/> rarely <input type="checkbox"/> never <hr/> <p>b) If Yes: Did he/she get any help to cope with these problems?</p> <input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> help was not necessary <hr/> <p>c) If yes, did they help relieve the anxiety, nerves or depression?</p> <input type="checkbox"/> yes, most of the time <input type="checkbox"/> yes, often <input type="checkbox"/> yes, sometimes <input type="checkbox"/> rarely <input type="checkbox"/> never <p>Please comment if you would like to: <input type="text"/></p>
16	<p>a) During’s illness or incapacity were you able to find out all you wanted to know about his or her illness and how it was likely to affect him / her?</p> <input type="checkbox"/> yes <input type="checkbox"/> no <hr/> <p>b) Was there anything else you would like to have been explained to you in more detail?</p> <input type="checkbox"/> yes <input type="checkbox"/> no <p>If yes, please say which things you would liked to have known more about:</p> <input type="text"/>
17	<p>How involved were you with the decisions made about..... ’s care?</p> <input type="checkbox"/> very involved <input type="checkbox"/> fairly involved <input type="checkbox"/> not involved <input type="checkbox"/> don’t know
18	<p>Were you satisfied with your involvement?</p> <input type="checkbox"/> no, I wished to be more involved <input type="checkbox"/> no, I wished to be less involved <input type="checkbox"/> yes <input type="checkbox"/> don’t know
19	<p>Were you told he/she was likely to die?</p> <input type="checkbox"/> yes <input type="checkbox"/> no <p>If yes, were you satisfied with the way you were told?</p> <input type="checkbox"/> yes <input type="checkbox"/> no

	<p>Please comment if you would like to:</p> <div style="border: 1px solid black; height: 25px; width: 100%;"></div> <p>If no, would you have liked to have been told?</p> <p><input type="checkbox"/> yes <input type="checkbox"/> no</p> <p>Please comment if you would like to:</p> <div style="border: 1px solid black; height: 25px; width: 100%;"></div>
--	---

	<p>The following questions are about the circumstances surrounding’s death, and your feelings about the way in which the health and social services treated you and..... at that time.</p>
20	<p>Where did..... die?</p> <p><input type="checkbox"/> his/her own home</p> <p><input type="checkbox"/> your homes</p> <p><input type="checkbox"/> hospital</p> <p><input type="checkbox"/> hospice</p> <p><input type="checkbox"/> old people’s home / nursing home</p> <p><input type="checkbox"/> on the way to hospital</p> <p><input type="checkbox"/> on the way to hospice</p> <p><input type="checkbox"/> other (please explain) </p>
21	<p>a) Did..... ever say that there was a place where he/she would like to die?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don’t know</p> <p>_____</p> <p>b) If yes, where was the place?</p> <p><input type="checkbox"/> at home</p> <p><input type="checkbox"/> In an old people’s home / nursing home</p> <p><input type="checkbox"/> In a hospice</p> <p><input type="checkbox"/> In a hospital</p> <p><input type="checkbox"/> other (please explain) </p>

22	<p>Did he/she died in the place he/she wanted to die in?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don't know</p> <p>If no, what was the reason for that? Please tick one box only</p> <p><input type="checkbox"/> he/she changed his mind</p> <p><input type="checkbox"/> there was insufficient help for him/her to stay at home</p> <p><input type="checkbox"/> the family/carers were too tired to continue looking after him/her at home</p> <p><input type="checkbox"/> the staff at the old peoples/nursing home were no longer able to look after him/her</p> <p><input type="checkbox"/> he/she could no longer afford to stay there</p> <p><input type="checkbox"/> he / she deteriorated and dies so quickly that there wasn't time for him/her to be moved</p> <p><input type="checkbox"/> there were no beds available</p> <p><input type="checkbox"/> other (please explain) <input style="width: 150px; height: 15px;" type="text"/></p>
23	<p>On balance. Do you feel that where he dies was the right place for him or not?</p> <p><input type="checkbox"/> Yes, it was the right place</p> <p><input type="checkbox"/> No, it wasn't the right place</p> <p><input type="checkbox"/> Not sure</p> <p>If no, was it because</p> <p><input type="checkbox"/> It wasn't where he/ she wanted to die</p> <p><input type="checkbox"/> The care he / she received there was poor</p> <p><input type="checkbox"/> It was too far away from family and friends</p> <p><input type="checkbox"/> Other (please explain) <input style="width: 150px; height: 15px;" type="text"/></p>
24	<p>Is there any other help or support you would have liked from the health and/or social services since his/her death?</p> <p><input type="checkbox"/> yes <input type="checkbox"/> no</p> <p>If yes, please comment on what you feel would have helped</p> <p><input style="width: 150px; height: 20px;" type="text"/></p>

Shared decision-making End-of-life	
25	<p>Was your loved one told he/she had an incurable illness?</p> <p><input type="checkbox"/> Yes, by a medical specialist</p> <p><input type="checkbox"/> Yes by a ward physician</p> <p><input type="checkbox"/> Yes, by a family doctor or physician in a nursing home</p> <p><input type="checkbox"/> Yes, all above mentioned</p> <p><input type="checkbox"/> no</p>
26	<p>Were you present during this message/discussion?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> other <input style="width: 150px; height: 15px;" type="text"/></p>

27	<p>How long before death of your loved one's death was told about this incurable illness?</p> <p><input type="checkbox"/> More than 12 months before death</p> <p><input type="checkbox"/> 3-12 months before death</p> <p><input type="checkbox"/> 1 week – 3 months before death</p> <p><input type="checkbox"/> Less than a week before death</p>
28	<p>When this message was told to your loved one and/or you, were you given the opportunity to talk about it?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don't know</p> <p>Please comment if you would like to: <input type="text"/></p>
29	<p>Before his/her death, did your loved one discuss with someone his/her preferences for end-of-life medical treatment? (You can tick multiple boxes)</p> <p><input type="checkbox"/> yes, with:</p> <p style="padding-left: 40px;"><input type="checkbox"/> partner</p> <p style="padding-left: 40px;"><input type="checkbox"/> children</p> <p style="padding-left: 40px;"><input type="checkbox"/> other family members</p> <p style="padding-left: 40px;"><input type="checkbox"/> friends</p> <p style="padding-left: 40px;"><input type="checkbox"/> family doctor</p> <p style="padding-left: 40px;"><input type="checkbox"/> medical specialist</p> <p style="padding-left: 40px;"><input type="checkbox"/> physician in a nursing home</p> <p style="padding-left: 40px;"><input type="checkbox"/> nurse</p> <p style="padding-left: 40px;"><input type="checkbox"/> somebody else</p> <p><input type="checkbox"/> no</p> <p><input type="text"/></p>
30	<p>If yes, do you know which preferences were discussed?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p>If yes, such as: <input type="text"/></p>
31	<p>Did they fulfill these preferences?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p>If no, please explain: <input type="text"/></p>
32	<p>Do you think if your loved one had needed more discussions regarding his or her preferences for end-of-life medical treatment?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don't know</p>
33	<p>If yes, do you know about which preferences your loved one wanted to discuss?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="text"/></p>

	If yes, such as:
34	<p>Do you think your loved one was sufficiently involved in his or her medical treatment?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> sometimes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don't know</p> <p>Please explain</p>
35	<p>Was your loved one able to handle and complete issues with related to his or her imminent death? <i>It includes other issues than medical discussions, e.g. doing things from their bucket list, recovering lost contacts, arranging funeral and/or legacy, saying goodbye, etc.</i></p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p>Please explain</p>

Satisfaction with care in the Maastad Hospital (out- and / or inpatient)							
How would you rate doctors, in terms of:		Poor	Fair	Good	Very good	Excellent	
36	Their knowledge and experience of your illness?	1	2	3	4	5	
37	The treatment and medical follow-up they provided?	1	2	3	4	5	
38	The attention they paid to your physical problems?	1	2	3	4	5	
39	Their willingness to listen to all of your concerns?	1	2	3	4	5	
40	The interest they showed in you personally?	1	2	3	4	5	
41	The comfort and support they gave you?	1	2	3	4	5	
42	The information they gave you about your illness?	1	2	3	4	5	
43	The information they gave you about your medical tests?	1	2	3	4	5	
44	The information they gave you about your treatment?	1	2	3	4	5	
45	The frequency of their visits/consultations?	1	2	3	4	5	
46	The time they devoted to you during visits/consultations?	1	2	3	4	5	
How would you rate nursus (if applicable), in terms of:		Poor	Fair	Good	Very good	Excellent	N.a.

47	The way they carried out your physical examination (took your temperature, felt your pulse,...)?	1	2	3	4	5	N.a
48	The way they handled your care (gave your medicines, performed intravenous injections,...)?	1	2	3	4	5	N.a
49	The attention they paid to your physical comfort?	1	2	3	4	5	N.a
50	The interest they showed in you personally?	1	2	3	4	5	N.a
51	The comfort and support they gave you?	1	2	3	4	5	N.a
52	Their human qualities (politeness, respect, sensitivity, kindness, patience,...)?	1	2	3	4	5	N.a
53	The information they gave you about your medical tests	1	2	3	4	5	N.a
54	The information they gave you about your care?	1	2	3	4	5	N.a
55	The information they gave you about your treatment?	1	2	3	4	5	N.a
56	Their promptness in answering your buzzer calls?	1	2	3	4	5	N.a
57	The time they devoted to you?	1	2	3	4	5	N.a
How would you rate services and care organisation of the hospital in general?							
		Poor	Fair	Good	Very good	Excellent	N.a.
58	The exchange of information between caregivers?	1	2	3	4	5	N.a
59	The kindness and helpfulness of the technical, reception, laboratory personnel,...?	1	2	3	4	5	N.a
60	The information provided on your admission to the hospital?	1	2	3	4	5	N.a
61	The information provided on your discharge from the hospital?	1	2	3	4	5	N.a
62	The waiting time for obtaining results of medical tests?	1	2	3	4	5	N.a
63	The speed of implementing medical tests and/or treatments?	1	2	3	4	5	N.a
64	The ease of access (parking, means of transport,...)?	1	2	3	4	5	N.a
65	The ease of finding ones way to the different departments?	1	2	3	4	5	N.a.
66	The environment of the building (cleanness, spaciousness, calmness,...)?	1	2	3	4	5	N.a.
67	Overall, how would you rate the care received during your hospital stay?	1	2	3	4	5	N.a.

Post-bereavement needs	
68	<p>After the death of your loved one, have you spoken with a hospital healthcare professional regarding his/her illness or death? (You can tick multiple boxes)</p> <p><input type="checkbox"/> yes, directly after his / her death</p> <p><input type="checkbox"/> yes, after a few weeks</p> <p><input type="checkbox"/> no</p>
69	<p>If yes, have these discussion(s) helped you?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don't know</p> <p>Please explain</p> <div style="border: 1px solid black; height: 20px; width: 50%; margin-left: 100px;"></div>
70	<p>If no, would you have appreciated talking to someone?</p> <p><input type="checkbox"/> yes</p> <p><input type="checkbox"/> no</p> <p><input type="checkbox"/> don't know</p>
71	<p>How much effort did it take to detach yourself from thoughts of, or grief over your loved ones and focus on other possible new obligations, activities or contacts?</p> <p><input type="checkbox"/> great difficulty</p> <p><input type="checkbox"/> some difficulty</p> <p><input type="checkbox"/> no difficulty</p>
72	<p>Have you received sufficient support from family and friends to cope with the grief and loss of your loved one?</p> <p><input type="checkbox"/> yes, amply sufficient</p> <p><input type="checkbox"/> yes, sufficient</p> <p><input type="checkbox"/> no, insufficient</p>
73	<p>If you might have a final remark concerning coping with the loss of your loved one, please explain it below:</p> <div style="border: 1px solid black; height: 50px; width: 60%; margin-left: 100px;"></div>