

## EPCOG study

## Palliative care manual

## PC intervention reporting form

Patient ID:

Caregiver ID (if applicable):

Date:

  -   
  -   
  -   -        
D D M M Y Y Y Y

number of study visit	1*	2	3	4b	6	7	8b	10	11	12b	14	15	16b
please tick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\*First informal contact, which only serves the purpose that the EIPC team introduces itself to the patient (if applicable to the caregiver), so that study participants know who will contact them by telephone in one month; no further documentation is necessary, except for the fact that this contact has taken place, since no palliative medical consultation has yet taken place.

## 1. Arrangement of visit

☐ face to face☐ telephone☐ with patient alone☐ with caregiver alone☐ with both patient and caregiver<sup>1</sup>

<sup>1</sup>This caregiver can either be the caregiver who also participates in the study or another (formal or informal) caregiver who attends this visit without being a study participant.

## 2. Documentation

profession	<input type="radio"/> palliative care social worker
	<input type="radio"/> palliative care physician

## 3. Total expenditure of time

Palliative care physician

<input type="radio"/> up to 10 min	<input type="radio"/> 11-20 min	<input type="radio"/> 21-30 min	<input type="radio"/> 31-45 min	<input type="radio"/> 46-60 min	<input type="radio"/> 61-75 min	<input type="radio"/> 76-90 min	<input type="radio"/> 91-105 min
<input type="radio"/> 106-120 min	<input type="radio"/> 121-150 min	<input type="radio"/> 151-180 min	<input type="radio"/> 181-210 min	<input type="radio"/> 211-240 min	<input type="radio"/> 241-300 min	<input type="radio"/> more than 300 minutes, please specify: <input type="text"/> <input type="text"/> <input type="text"/>	

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**Palliative care social worker**

<input type="radio"/> up to 10 min	<input type="radio"/> 11-20 min	<input type="radio"/> 21-30 min	<input type="radio"/> 31-45 min	<input type="radio"/> 46-60 min	<input type="radio"/> 61-75 min	<input type="radio"/> 76-90 min	<input type="radio"/> 91-105 min
<input type="radio"/> 106-120 min	<input type="radio"/> 121-150 min	<input type="radio"/> 151-180 min	<input type="radio"/> 181-210 min	<input type="radio"/> 211-240 min	<input type="radio"/> 241-300 min	<input type="radio"/> more than 300 minutes, please specify: <div style="display: flex; justify-content: space-between; width: 100%;"> <div style="border-bottom: 1px solid black; width: 20px;"></div> <div style="border-bottom: 1px solid black; width: 20px;"></div> <div style="border-bottom: 1px solid black; width: 20px;"></div> <div style="border-bottom: 1px solid black; width: 20px;"></div> </div>	

**4. Time division**

Please indicate here how the total time necessary for the intervention (see 3.) can be subdivided (anamnesis and activities carried out, by phone or face to face).

**Palliative care physician**

person / activity	time expenditure
patient alone	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="margin-left: 5px;">min</div> </div>
caregiver alone	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="margin-left: 5px;">min</div> </div>
together with both patient and caregiver	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="margin-left: 5px;">Min</div> </div>
(healthcare) professionals	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="margin-left: 5px;">min</div> </div>
"systemic" <sup>2</sup>	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="margin-left: 5px;">min</div> </div>

<sup>1</sup>e.g. physicians, nurses, therapists, hospice coordination, employees of offices or insurance companies

<sup>2</sup>e.g. filling out forms, documentation, reading doctor's letters, documents, internet research

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**Palliative care social worker**

person / activity	time expenditure
patient alone	<input type="text"/> <input type="text"/> <input type="text"/> min
(caregiver alone	<input type="text"/> <input type="text"/> <input type="text"/> min
together with both patient and caregiver	<input type="text"/> <input type="text"/> <input type="text"/> Min
(healthcare) professionals	<input type="text"/> <input type="text"/> <input type="text"/> min
"systemic" <sup>2</sup>	<input type="text"/> <input type="text"/> <input type="text"/> min

**5. Anamnesis; collection of individual complaints, symptoms, problems**

Please indicate in the following list which contents were addressed during the visit with the patient and / or the caregiver and which symptoms, complaints and / or problems became apparent during this contact.

<b>Pain and other physical symptoms/concerns</b>	<input type="radio"/> no <input type="radio"/> yes  if <u>yes</u> , please specify:	
	<input type="checkbox"/>	pain other than headache
	<input type="checkbox"/>	headache
	<input type="checkbox"/>	nausea
	<input type="checkbox"/>	vomiting
	<input type="checkbox"/>	constipation
	<input type="checkbox"/>	shortness of breath
	<input type="checkbox"/>	poor appetite
	<input type="checkbox"/>	increase of appetite
	<input type="checkbox"/>	sore or dry mouth
	<input type="checkbox"/>	drowsiness
	<input type="checkbox"/>	weakness or lack of energy
	<input type="checkbox"/>	poor mobility
	<input type="checkbox"/>	wounds
	<input type="checkbox"/>	assistance with activities of daily living (ADLs)
	<input type="checkbox"/>	epileptic seizures
	<input type="checkbox"/>	singultus
	<input type="checkbox"/>	pareses
<input type="checkbox"/>	spasticity	

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	<input type="checkbox"/>	sensation deficit (skin)
	<input type="checkbox"/>	sensory disturbances (sensory organs)
	<input type="checkbox"/>	deficits in coordination
	<input type="checkbox"/>	neuropsychological disorders
	<input type="checkbox"/>	quantitative disturbance of consciousness
	<input type="checkbox"/>	change in personality
	<input type="checkbox"/>	symptoms of delirium
	other, please specify:	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
<b>Questions about treatment decisions</b>	<input type="radio"/> no <input type="radio"/> yes  if <u>yes</u> , please specify:	
	<input type="checkbox"/>	questions about the disease and the expected course of the disease
	<input type="checkbox"/>	questions about treatment and treatment goals
	<input type="checkbox"/>	questions about palliative and hospice care possibilities
	<input type="checkbox"/>	questions about advanced care planning
	other, please specify:	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
<b>Psychological problems</b>	<input type="radio"/> no <input type="radio"/> yes  if <u>yes</u> , please specify:	
	<input type="checkbox"/>	anxiety
	<input type="checkbox"/>	depression
	<input type="checkbox"/>	psychological adjustment disorders
	<input type="checkbox"/>	grief
	<input type="checkbox"/>	wish for death
	<input type="checkbox"/>	social isolation
	<input type="checkbox"/>	fears of the future
	<input type="checkbox"/>	loss of autonomy

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	<input type="checkbox"/>	worry about caregivers
	<input type="checkbox"/>	no one there to talk about my feelings and problems
	other, please specify:	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
<b>Spiritual issues</b>	<input type="radio"/> no <input type="radio"/> yes  if <u>yes</u> , please specify:	
	<input type="checkbox"/>	question of a higher might/higher mights
	<input type="checkbox"/>	questions of meaning
	<input type="checkbox"/>	questions of guilt
	<input type="checkbox"/>	question of life balance
	<input type="checkbox"/>	question in dealing with existential distress
	<input type="checkbox"/>	religious needs
	<input type="checkbox"/>	question of unity/community with other people
	<input type="checkbox"/>	questions about farewell and grieving process
	other, please specify:	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
<b>Problems with organization and social law issues</b>	<input type="radio"/> no <input type="radio"/> yes  if <u>yes</u> , please specify:	
	<input type="checkbox"/>	problems with organization of further medical / nursing / home care
	<input type="checkbox"/>	problems with solving social law issues
	<input type="checkbox"/>	problems with solving economic problems
	<input type="checkbox"/>	problems with organising (re)participation in working life
	<input type="checkbox"/>	problems with organizing of personal affairs
	other, please specify:	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	

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	<input type="checkbox"/>	
<b>Hospice care issues</b>	<input type="radio"/> no <input type="radio"/> yes  <u>if yes</u> , please specify:	
	<input type="checkbox"/>	question of support by hospice volunteers
	<input type="checkbox"/>	questions about fulfilment of a special/individual wishes ("I'd like to have/do one last time ...")
	<input type="checkbox"/>	questions about advanced care planning, apart from addressing with physician/social worker
	<input type="checkbox"/>	questions about grief counselling (possibly even during your lifetime)
	other, please specify:	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
<b>Caregiver burden</b>	<input type="radio"/> no <input type="radio"/> yes  <u>if yes</u> , please specify:	
	<input type="checkbox"/>	physical problems
	<input type="checkbox"/>	psychological problems
	<input type="checkbox"/>	social law issues
	<input type="checkbox"/>	economic problems
	<input type="checkbox"/>	hospice care issues
	<input type="checkbox"/>	spiritual questions
	other, please specify:	
	<input type="checkbox"/>	
	<input type="checkbox"/>	
<input type="checkbox"/>		

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**6. Activities carried out according to the individual concerns, complaints, symptom**

In the next step, please document what you have done to address / minimize the concerns, complaints and symptoms identified above. Your activities may have taken place during the palliative care visit itself (e.g. discussion with the patient to develop a palliative care medical treatment plan) or following the visit in order to work on the resulting action plan (e.g. discussion with outpatient physiotherapy to ensure outpatient care; discussion with funding agencies to ensure economic security).

The documentation is done according to the coding of table I and II. Please, proceed as follows for the documentation:

Table I: Choose the overall type of activity ("how?", option A-C).

Table II: Choose - in the case of a conversation/telephone call - with whom you have conducted it ("with whom?", option 1-44)

Table III: Enter the abbreviations (e.g. A19; B8 or C) after the respective action performed in the sense of the individual action plan of the patient (and, if applicable, the caregiver). There can be several abbreviations behind an action if, for example, an action was carried out in different ways (conversation (directly opposite), (telephone call)) with different persons.

**Table I: How? (type of activity)**

A	conversation face-to-face
B	telephone call
C	documentation

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**Table II: With whom?** (conversation face-to-face or telephone call with:)

1	patient alone
2	caregiver alone
3	together with both patient and caregiver
4	clinic physician
5	clinic nurse
6	palliative care consulting service (clinic)
7	case Management (clinic)
8	social service (clinic)
9	occupational therapy (clinic)
10	physiotherapy (clinic)
11	logopedics (clinic)
12	psychological / psychosomatic / psycho-oncological service (clinic)
13	spiritual/pastoral care (clinic)
14	hospice care service (clinic)
15	administrative employee (clinic)
16	family doctor
17	outpatient specialist
18	general palliative care physician (representing general outpatient palliative care (AAPV))
19	nursing home
20	general nursing service
21	nursing service with expertise in general palliative care
22	specialized outpatient palliative care service (SAPV)
23	palliative care ward
24	hospice
25	outpatient hospice service
26	rehabilitation institution (outpatient / inpatient)
27	hospital (except for palliative care ward and rehabilitation institution)
28	occupational therapy (outpatient)
29	physiotherapy outpatient
30	logopedics (outpatient)
31	psychological / psychosomatic / psycho-oncological service (outpatient)
32	spiritual/pastoral care (outpatient)
33	pharmacy
34	healthcare supply store
35	social advisory center
36	legal guardian
37	funding agencies
38	administrative agencies
39	advice center
40	lawyer
41	notary
42	court
43	funeral service
44	others, please specify:  <hr/>



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Table III: Actions carried out

<b><u>Palliative care physician</u> - Actions carried out</b>	<b>How? (A, B or C; see table I)</b>	<b>With whom? (1-44; see table II)</b>
developing of a palliative care medical treatment plan		
reevaluation of a palliative care medical treatment plan		
developing of a palliative care (medical) emergency plan		
advice / recommendation / explanation of palliative care symptom-relieving measures		
advice / recommendation / explanation of palliative and hospice care structures / services		
crisis talk		
relieving conversation		
discussion of disease situation and disease processing/coping		
discussion of the treatment and treatment measures		
reevaluation of a treatment measure taken		
discussion of aim of therapy		
reevaluation of aim of therapy		
discussion of changes in therapy and of restriction of treatment measures		
suggestion of a (ethical) case discussion		
give advice on advanced care planning (patient decree, healthcare proxy, legal guardian)		
creating a patient decree, healthcare proxy		
discussion of present caring situation		
discussion of care options (outpatient / inpatient)		
discussion of the family situation / relationship situation		
conversation to strengthen resources		
discussion of economic situation		
discussion of housing situation		
discussion of working situation		
discussion of insurance situation		
application for legal guardian		
notes on draw up a will		
organization of a contact		
organization of a treatment appointment		
obtaining information		
organization of further outpatient care		
organization of further inpatient care		
intervention for problems in the social setting		
interventions for economic security		
clarification of cost absorption		
documentation of conversation contents		
search for information and documentation of results		
written summary of information		
assistance in filling out application forms		
filling out forms		
drafting of texts / wording proposals		

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exchange of information with healthcare professionals (e.g. primary carers/practitioners and following carers/practitioners), which serves the further optimal treatment / care		
others, please specify:  <hr/> <hr/>		

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<b><u>Palliative care social worker</u> - Actions carried out</b>	<b>How? (A, B or C; see table I)</b>	<b>With whom? (1-44; see table II)</b>
developing of a palliative care medical treatment plan		
reevaluation of a palliative care medical treatment plan		
developing of a palliative care (medical) emergency plan		
advice / recommendation / explanation of palliative care symptom-relieving measures		
advice / recommendation / explanation of palliative and hospice care structures / services		
crisis talk		
relieving conversation		
discussion of disease situation and disease processing/coping		
discussion of the treatment and treatment measures		
reevaluation of a treatment measure taken		
discussion of aim of therapy		
reevaluation of aim of therapy		
discussion of changes in therapy and of restriction of treatment measures		
suggestion of a (ethical) case discussion		
give advice on advanced care planning (patient decree, healthcare proxy, legal guardian)		
creating a patient decree, healthcare proxy		
discussion of present caring situation		
discussion of care options (outpatient / inpatient)		
discussion of the family situation / relationship situation		
conversation to strengthen resources		
discussion of economic situation		
discussion of housing situation		
discussion of working situation		
discussion of insurance situation		
application for legal guardian		
notes on draw up a will		
organization of a contact		
organization of a treatment appointment		
obtaining information		
organization of further outpatient care		
organization of further inpatient care		
intervention for problems in the social setting		
interventions for economic security		
clarification of cost absorption		
documentation of conversation contents		
search for information and documentation of results		
written summary of information		
assistance in filling out application forms		
filling out forms		
drafting of texts / wording proposals		

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others, please specify:  <hr/> <hr/>		