

Note: this is an English translation of a Dutch validated questionnaire to inform the reader. The English version has not been validated.

Patient involvement in medical decision-making. Inclusion form.

Please answer the questions below together with the patient (Some things are probably mentioned in the medical file, but thank you for covering these questions with the patient anyway). Unless indicated otherwise, there is only one answer possible to every question.

1. Identification patient:

Name _____

Street, no _____

Zip code, city _____

Phone number _____

2. Identification of next of kin:

2.1. Who is involved the most in your care and can be contacted in case you cannot be reached?

Name _____

Street, no _____

Zip code, city _____

Phone number _____

2.2. What is your relationship to this person?

- Spouse
- Partner
- Child
- Son or daughter in law
- Parent
- Brother/sister
- Friend
- Other, namely: _____

3. Identification general practitioner

3.1. Do you have a general practitioner?

- Yes
- No ⇒ go to question 4

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3.2. Who is your general practitioner?

Name _____

Street, no _____

Zip code, city _____

Phone number _____

3.3. How often have you seen him/her in the last three months?

- More than once a week
- Once a week
- Once every two weeks
- Once a month
- Less, namely: _____

4. Comorbidity (use the legend on page 4):

(More than one answer is possible)

- Myocardial infarct
- Congestive heart failure
- Peripheral vascular disease
- Cerebrovascular disease (except hemiplegia)
- Dementia
- Chronic pulmonary disease
- Connective tissue disease
- Ulcerative disease
- Mild liver disease
- Diabetes (without complications)
- Diabetes with end organ damage
- Hemiplegia
- Moderate or severe renal disease
- 2nd solid tumor (non metastatic)
- Leukemia
- Lymphoma, MM
- Moderate or severe liver disease
- 2nd metastatic solid tumor
- AIDS

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5. Socio-demographic data of the patient:

5.1. Age _____ year

5.2. Sex M
 F

5.3. Partner Yes
 No

5.4. Educational level patient (highest completed education or degree)

Primary school

Lower secondary

Higher secondary

Higher education, university, if so, medical or paramedical training? Yes, namely: _____
 No

Legend: Rules for Completing the Charlson Comorbidity Index (CCI)

Myocardial infarct	Hx of medically documented myocardial infarction
Congestive heart failure	Symptomatic CHF w/ response to specific treatment
Peripheral vascular disease	Intermittent claudication, periph. arterial bypass for insufficiency, gangrene, acute arterial insufficiency, untreated aneurysm (>=6cm)
Cerebrovascular disease (except hemiplegia)	Hx of TIA, or CVA with no or minor sequelae
Dementia	chronic cognitive deficit
Chronic pulmonary disease	symptomatic dyspnea due to chronic respiratory conditions (including asthma)
Connective tissue disease	SLE, polymyositis, mixed CTD, polymyalgia rheumatica, moderate to
Ulcer disease	Patients who have required treatment for PUD
Mild liver disease	cirrhosis without PHT, chronic hepatitis
Diabetes (without complications)	diabetes with medication
Diabetes with end organ damage	retinopathy, neuropathy, nephropathy
Hemiplegia (or paraplegia)	hemiplegia or paraplegia
Moderate or severe renal disease	Creatinine >3mg% (265 umol/l), dialysis, transplantation, uremic
2nd Solid tumor (non metastatic)	Initially treated in the last 5 years exclude non-melanomatous skin cancers and in situ cervical carcinoma
Leukemia	CML, CLL, AML, ALL, PV
Lymphoma, MM...	NHL, Hodgkin's, Waldenström, multiple myeloma
Moderate or severe liver disease	cirrhosis with PHT +/- variceal bleeding
2nd Metastatic solid tumor	self-explaining
AIDS	AIDS and AIDS-related complex Suggested: as defined in latest definition

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Thank you for filling in this part yourself (without help of the patient).

6.Type of therapy and intention:

6.1. Goal of treatment?

- Cure Yes No
- Life prolongation Yes No
- Palliation Yes No
- Other, namely: _____

6.2. Which treatments does the patient receive at this moment to your knowledge? **(More than one answer is possible)**

- Chemotherapy
- Radiotherapy
- Experimental therapy
- Chirurgy
- Medication
- Administration of artificial food and/or fluid
- Thoracentesis
- Non-conventional treatment (homeopathy)
- Other, namely: _____

7.Estimated life expectancy:

7.1. Would you be surprised if the patient would die within 3 months?

- Yes
- No

7.2. How long do you think will this patient still live? You can express this in days, weeks, months or years.

- ... days
- ... weeks
- ... months
- ... years

Date:.....