EPCOG study Health care use reporting form

Patient ID: **Caregiver ID** (if applicable)**:** **Date:**

__ __ - __ __ __ __ __ __ __ __ T T - M M - J J J J

number of study visit	1 (Baseline)	5	9	13	17	19	21	23	25
please tick	❑	❑	❑	❑	❑	❑	❑	❑	❑

The case reporting form is completed by the assessment researcher who carries out the data collection as part of the regular outcome measurement every three months.

To keep the burden on patients / caregivers as low as possible the assessment researcher is held to primarily access the following data as far as possible from patient' s University Hospital file or affiliated University Medical Care Centre file.

To gain information on further treatment except for that done in the University Hospital the assessment researcher is held to ask patient / caregiver whether during the last three months patients had further treatments except for those done in the University Hospital. The assessment researcher should stick to the questionnaire and fill in respective answers.

To be kept blinded the assessment researcher should inform patients / caregivers not to tell whether they are in the intervention group or not. (Please note: palliative care tasks of the palliative care physician and the palliative care social worker as part of the palliative care intervention will be raised and documented separately.)

Golla H, *et al. BMJ Open* 2020; 10:e034378. doi: 10.1136/bmjopen-2019-034378

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Patient's current medication list

Extraction from patient's University Hospital file or possibly affiliated University Medical Care Centre file and comparison with patient's medication plan at home and supplement if necessary

	medication (active ingredient)	total daily dose (mg)	route* 1;2;3;4;5	start of medication			end of medication	
				before study	start date during study (DD/MM/YYYY)	see previous assessment**	date (DD/MM/YYYY)	or ongoing
1				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
2				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
3				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
4				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
5				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
6				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
7				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
8				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑
9				❑	__ __/__ __/__ __ __ __	❑	__ __/__ __/__ __ __ __	❑

*1= p.o. 2= s.c. 3= i.v. 4= i.m. 5=other **if date already acquired

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The following **first part** of the questionnaire is to be answered with the help of the available university patient files (University Hospital and / or affiliated University Medical Care Centre).

Part 1	
Participation in hospital trials	In the last three months: Did the patient participate in additional hospital trials (other than EPCOG)? ❍ no ❍ yes if yes, please specify 1. - kind of trial? _____ - from when to when? start D D - M M - Y Y Y Y end D D - M M - Y Y Y Y or: ❍ ongoing 2. - kind of trial? _____ - from when to when? start D D - M M - Y Y Y Y end

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	D D - M M - Y Y Y Y or: ❍ ongoing	
Tumorspecific therapies, University Hospital	In the last three months: Did the patient receive tumorspecific therapies?	
	surgery	❍ no ❍ yes if yes, which kind? ❍ resection date D D - M M - Y Y Y Y ❍ open biopsy date D D - M M - Y Y Y Y ❍ stereotactic biopsy date D D - M M - Y Y Y Y
	radiation therapy	❍ no ❍ yes if yes, which kind? ❍ conventional from (date) D D - M M - Y Y Y Y to D D - M M - Y Y Y Y gray ☐☐ (total dose) or: ❍ ongoing

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		❍ stereotactic date __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y gray __ __ (total dose)
	chemotherapy	❍ no ❍ yes <u>if yes</u>, which kind? ❍ temozolomide (Temodal®) from (date) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing number of cycles completed: __ __ ❍ temozolomide (Temodal®) and lomustine (CECENU®) from (date) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing number of cycles completed: __ __

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		❍ PV(C) (procarbazine (Natulan®), vincristine, lomustine (CECENU®)) from (date) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing number of cycles completed: __ __ ❍ others, please specify: _____ from (date) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing number of cycles completed: __ __
	other tumorspecific therapies	❍ no ❍ yes if yes, which kind? ❍ bevacizumab (Avastin®) from (date) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y

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		to D D - M M - Y Y Y Y or: ❍ ongoing number of drug administrations completed: ___ ❍ tumor treating fields (TTF) from (date) D D - M M - Y Y Y Y to D D - M M - Y Y Y Y or: ❍ ongoing ❍ others, please specify: _____ from (date) D D - M M - Y Y Y Y to D D - M M - Y Y Y Y or: ❍ ongoing if applicable number of cycles / drug administrations completed: ___

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Diagnostic tests, University Hospital	In the last three months: Did the patient receive following diagnostic tests?	
	Magnetic resonance imaging (MRI)	❍ no ❍ yes if yes, how often? ___
	Computer tomography (CT)	❍ no ❍ yes if yes, how often? ___
	Diagnostic X-rays	❍ no ❍ yes if yes, how often? ___
	Ultrasound scan	❍ no ❍ yes if yes, how often? ___
	Positron emission tomography (PET)	❍ no ❍ yes if yes, how often? ___
	Electroencephalogram (EEG)	❍ no ❍ yes if yes, how often? ___
	Electrocardiogram (ECG)	❍ no ❍ yes if yes, how often? ___
	Blood tests	❍ no ❍ yes if yes, how often? ___

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	Histology	❍ no ❍ yes if yes, how often? ⌊__⌋⌊__⌋
	Microbiology	❍ no ❍ yes if yes, how often? ⌊__⌋⌊__⌋
	other diagnostic tests	❍ no ❍ yes if yes, please specify: _____ _____ how often? ⌊__⌋⌊__⌋
Hospital stays in University Hospital	In the last three months: Was the patient inpatient at the University Hospital (including day hospital)? ❍ no ❍ yes if yes, please specify: number of hospital admissions at the University Hospital / three months ⌊__⌋⌊__⌋ specifically in days ❍ intensive care unit ⌊__⌋⌊__⌋ ❍ neurosurgery ward ⌊__⌋⌊__⌋ ❍ stereotactic ward ⌊__⌋⌊__⌋ ❍ neurology ward ⌊__⌋⌊__⌋	

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	❍ psychiatric ward └┘└┘ ❍ rehabilitation ward └┘└┘ ❍ internal medicine ward └┘└┘ ❍ palliative care unit └┘└┘ ❍ emergency department └┘└┘ ❍ other ward, please specify: which specialization? _____ _____ how long (days / three months)? └┘└┘ ❍ day hospital (e.g. rehabilitation, psychiatry), please specify: which specialization? _____ _____ how long (days / three months)? └┘└┘ Please specify whether the hospital stay(s) during the last three months were planned or unscheduled: numbers of planned hospital stays at University Hospital: └┘└┘ numbers of unscheduled hospital stays at University Hospital:

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	⌊__⌋⌊__⌋
Consultant services in University Hospital	In the last three months: Did the patient receive consultant services during hospital stay at University Hospital? ❍ no ❍ yes if yes, please specify number of attendances / three months: ❍ neurosurgery ⌊__⌋⌊__⌋ ❍ stereotaxis ⌊__⌋⌊__⌋ ❍ neurology ⌊__⌋⌊__⌋ ❍ psychiatry ⌊__⌋⌊__⌋ ❍ internal medicine ⌊__⌋⌊__⌋ ❍ radiation therapy ⌊__⌋⌊__⌋ ❍ palliative medicine ⌊__⌋⌊__⌋ ❍ other specialty, please specify: which specialization? _____ _____ how often in the last three months? ⌊__⌋⌊__⌋
University outpatient specialists	In the last three months: Did the patient have outpatient appointments with University Hospital specialists? ❍ no ❍ yes

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	if yes, please specify number of attendances / three months: ❍ neurosurgery ⌊__⌋⌊__⌋ ❍ stereotaxis ⌊__⌋⌊__⌋ ❍ neurology ⌊__⌋⌊__⌋ ❍ psychiatry ⌊__⌋⌊__⌋ ❍ internal medicine ⌊__⌋⌊__⌋ ❍ radiation therapy ⌊__⌋⌊__⌋ ❍ palliative medicine ⌊__⌋⌊__⌋ ❍ ambulance of other specialty, please specify: which specialty? _____ _____ how often, number / three months? ⌊__⌋⌊__⌋
Use of university hospital therapists	In the last three months: Did the patient have outpatient appointments with therapists of the University Hospital (in-/outpatient)? ❍ no ❍ yes if yes, please specify number of attendances / three months: ❍ physiotherapist ⌊__⌋⌊__⌋ ❍ occupational therapist

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	❑❑ ❍ speech therapist ❑❑ ❍ psychotherapist / psychooncologist ❑❑ ❍ other therapist, please specify: which specialty? _____ _____ how often, number / three months? ❑❑

The following **second part** of the questionnaire should be answered with the **help of the patient or** - if the patient himself / herself is not able to do so - with the help of another **third person** present who is informed on this subject. This third person should usually be the caregiver who is also participating in the study (if there is any). However, also another formal or informal caregiver might be asked as far as he / she is informed on this subject.

Part 2		
Tumorspecific therapies	In the last three months: Did the patient receive tumorspecific therapies?	
	Surgery	❍ no ❍ no statement possible ❍ yes if yes, which kind? ❍ resection date (if known) ❑❑-❑❑-❑❑❑❑ D S M M Y Y Y Y ❍ open biopsy date (if known) ❑❑-❑❑-❑❑❑❑ D S M M Y Y Y Y

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		❍ stereotactic biopsy date (if known) __ __ - __ __ - __ __ __ __ D S M M Y Y Y Y
	Radiation therapy	❍ no ❍ no statement possible ❍ yes <u>if yes</u>, which kind? ❍ conventional from (date, if known) __ __ - __ __ - __ __ __ __ D S M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D S M M Y Y Y Y or: ❍ ongoing Gray __ ❍ stereotactic date (if known) __ __ - __ __ - __ __ __ __ D S M M Y Y Y Y Gray __
	Chemotherapy	❍ no ❍ no statement possible ❍ yes <u>if yes</u>, which kind? ❍ temozolomide (Temodal®) from (date, if known) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to

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		D D - M M - Y Y Y Y or: ❍ ongoing number of cycles completed: _ _ ❍ temozolomide (Temodal®) and lomustine (CECENU®) from (date, if known) D D - M M - Y Y Y Y to D D - M M - Y Y Y Y or: ❍ ongoing number of cycles completed: _ _ ❍ PV(C) (procarbazine (Natulan®), vincristine, lomustine (CECENU®)) from (date, if known) D D - M M - Y Y Y Y to D D - M M - Y Y Y Y or: ❍ ongoing number of cycles completed: _ _ ❍ others, please specify:

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		_____ from (date, if known) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing number of cycles completed: __ __
	Other tumorspecific therapies	❍ no ❍ no statement possible ❍ yes if yes, which kind? ❍ bevacizumab (Avastin®) from (date, if known) __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing number of drug administrations completed: __ __ ❍ tumor treating fields (TTF) from (date, if known)

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		__-__-____ (D D - M M - Y Y Y Y) to __-__-____ (D D - M M - Y Y Y Y) or: ❍ ongoing ❍ others, please specify: _____ from (date, if known) __-__-____ (D D - M M - Y Y Y Y) to __-__-____ (D D - M M - Y Y Y Y) or: ❍ ongoing if applicable number of cycles / drug administrations completed: __
Diagnostic tests	<u>In the last three months</u>: Did the patient receive diagnostic tests?	
	Magnetic resonance imaging (MRI)	❍ no ❍ no statement possible ❍ yes <u>if yes</u>, how often? __
	Computer tomography (CT)	❍ no ❍ no statement possible ❍ yes <u>if yes</u>, how often? __
	Diagnostic X-rays	❍ no ❍ no statement possible

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		❍ yes if yes, how often? ___
	Ultrasound scan	❍ no ❍ no statement possible ❍ yes if yes, how often? ___
	Positron emission tomography (PET)	❍ no ❍ no statement possible ❍ yes if yes, how often? ___
	Electroencephalogram (EEG)	❍ no ❍ no statement possible ❍ yes if yes, how often? ___
	Electrocardiogram (ECG)	❍ no ❍ no statement possible ❍ yes if yes, how often? ___
	Blood tests	❍ no ❍ no statement possible ❍ yes if yes, how often? ___
	other diagnostic tests	❍ no ❍ no statement possible ❍ yes if yes, please specify: _____ _____

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		how often? ⌊_⌊_⌋
Hospital stays	In the last three months: Was the patient inpatient at hospitals apart from University Hospital (including day hospital)? ❍ no ❍ no statement possible ❍ yes if yes, please specify: number of hospital admissions / three months (apart from University Hospital) ⌊_⌊_⌋ specifically in days: ❍ intensive care unit ⌊_⌊_⌋ ❍ neurosurgery ward ⌊_⌊_⌋ ❍ stereotactic ward ⌊_⌊_⌋ ❍ neurology ward ⌊_⌊_⌋ ❍ psychiatric ward ⌊_⌊_⌋ ❍ rehabilitation ward ⌊_⌊_⌋ ❍ internal medicine ward ⌊_⌊_⌋ ❍ palliative care unit ⌊_⌊_⌋ ❍ emergency department ⌊_⌊_⌋ ❍ other ward, please specify	

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	which specialization? _____ how long? (days / three months) ⌊__⌋⌊__⌋ ❍ day hospital (e.g. rehabilitation, psychiatry), please specify: which specialization? _____ how long? (days / three months) ⌊__⌋⌊__⌋ Please specify whether the hospital stay(s) during the last three months were planned or unscheduled (other than those at University Hospital): Numbers of planned hospital stays (other than those at University Hospital): ⌊__⌋⌊__⌋ Numbers of unscheduled hospital stays (other than those at University Hospital): ⌊__⌋⌊__⌋
Emergency services	<u>In the last three months:</u> Did the patient use emergency services apart from emergency department in University Hospital or other hospitals? ❍ no ❍ no statement possible ❍ yes <u>If yes,</u> please specify number of attendances / three month: ❍ primary care emergency service (coming to patient´s home) ⌊__⌋⌊__⌋ ❍ ambulance (coming to patient´s home) ⌊__⌋⌊__⌋

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	❍ emergency doctor service (coming to patient´s home) ⌊_⌊_⌋ ❍ other emergency services, please specify: _____ _____ how often? (number / three months) ⌊_⌊_⌋
Use of services general practitioners and outpatient specialists	In the last three months: Did the patient have outpatient appointments with general practitioners and outpatient specialists (home visits or visits at practice; (excluding University Hospital specialists)? ❍ no ❍ no statement possible ❍ yes if yes, please specify number of attendances / three month: ❍ primary care physician ⌊_⌊_⌋ at practice ⌊_⌊_⌋ home visits ❍ neurologist ⌊_⌊_⌋ at practice ⌊_⌊_⌋ home visits ❍ psychiatrist ⌊_⌊_⌋ at practice ⌊_⌊_⌋ home visits ❍ internal medical doctor) ⌊_⌊_⌋ at practice

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	⌊_⌊_⌋ home visits ❍ doctor of other specialty, please specify which specialty? _____ _____ how often? (number / three months) ⌊_⌊_⌋ at practice ⌊_⌊_⌋ home visits
Use of therapists	In the last three months: Did the patient have appointments with outpatient therapist (excluding University Hospital therapists)? ❍ no ❍ no statement possible ❍ yes if yes, please specify number of attendances / three month: ❍ physiotherapist ⌊_⌊_⌋ ❍ occupational therapist ⌊_⌊_⌋ ❍ speech therapist ⌊_⌊_⌋ ❍ psychotherapist / psychooncologist ⌊_⌊_⌋ ❍ other therapist, please specify: which specialty? _____ _____

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	how often? (number / three months) ⌊_⌊_⌋
Use of nursing services and / or housekeeping services financed by the health insurance fund	In the last three months: Did the patient receive nursing care and / or housekeeping services (financed by health insurance)? ❍ no ❍ no statement possible ❍ yes if yes, please specify: ❍ outpatient nursing service since ⌊_⌊_⌋-⌊_⌊_⌋-⌊_⌊_⌊_⌊_⌋ (D D - M M - Y Y Y Y) to ⌊_⌊_⌋-⌊_⌊_⌋-⌊_⌊_⌊_⌊_⌋ (D D - M M - Y Y Y Y) or: ❍ ongoing number of contacts / day ⌊_⌊_⌋ ❍ outpatient 24-hours nursing service since ⌊_⌊_⌋-⌊_⌊_⌋-⌊_⌊_⌊_⌊_⌋ (D D - M M - Y Y Y Y) to ⌊_⌊_⌋-⌊_⌊_⌋-⌊_⌊_⌊_⌊_⌋ (D D - M M - Y Y Y Y) or: ❍ ongoing ❍ meals on wheels since ⌊_⌊_⌋-⌊_⌊_⌋-⌊_⌊_⌊_⌊_⌋ (D D - M M - Y Y Y Y) to ⌊_⌊_⌋-⌊_⌊_⌋-⌊_⌊_⌊_⌊_⌋ (D D - M M - Y Y Y Y) or: ❍ ongoing

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	❍ short-term nursing since __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing ❍ nursing home since __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing ❍ housekeeping service, financed by health insurance since __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing
Utilization of specialized outpatient palliative care (SAPV) and hospice services (inpatient / outpatient)	In the last three months: Did the patient receive specialized outpatient palliative care (SAPV) and/or hospice services (inpatient/outpatient)? ❍ no ❍ no statement possible ❍ yes if yes, please specify: ❍ specialized palliative care outpatient service since __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y

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	or: ❍ ongoing ❍ hospice (inpatient) since __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing ❍ outpatient hospice service __ __ visits / three months ❍ others, please specify: _____ _____ since __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y to __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y or: ❍ ongoing
Use of aids	In the last three months: Did the patient receive new aids because of GBM disease? ❍ no ❍ no statement possible ❍ yes if yes, please specify: ❍ walking stick ❍ rollator ❍ wheelchair ❍ healthcare bed

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	❍ shower stool ❍ bathtub lift ❍ others, please specify: _____ _____ _____
Patient´s nursing care level	Does the patient have a nursing care level? ❍ no ❍ no statement possible ❍ yes if yes, please specify: ❍ level 1 ❍ level 2 ❍ level 3 ❍ level 4 ❍ level 5
Disabled person´s pass	Does the patient have a disabled person´s pass? ❍ no ❍ no statement possible ❍ yes if yes, please specify: since when? __ __ - __ __ - __ __ __ __ D D M M Y Y Y Y how severe is the disability in per cent? __ __ __ please specify the disease for which a severe disability is present: _____

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Working situation of patient	Is the patient <u>currently</u> working? ❍ no statement possible ❍ <u>no</u>, please specify: ❍ unemployed since when? D D - M M - Y Y Y Y ❍ retired since when? D D - M M - Y Y Y Y ❍ incapacitated for work since when? D D - M M - Y Y Y Y What was the patient´s professional activity? _____ ❍ employed ❍ self-employed ❍ never been employed ❍ in education, e.g. student, trainee ❍ <u>yes,</u> please specify: What is the patient´s professional activity? _____ Is the patient employed or self-employed? ❍ employed ❍ self-employed

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	Has the patient reduced the professional activity due to the GBM disease? ❍ no ❍ yes, please specify: patient's current working hours per week ____ by how many hours per week did the patient reduce the professional activity? ____ since when? ____-____-____ D D M M Y Y Y Y
Working situation of the caregiver (if applicable)	Does the caregiver <u>currently</u> have a job? ❍ no statement possible ❍ <u>no</u>, please specify: ❍ unemployed since when? ____-____-____ D D M M Y Y Y Y ❍ retired since when? ____-____-____ D D M M Y Y Y Y ❍ incapacitated for work since when? ____-____-____ D D M M Y Y Y Y

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	What was the caregiver´s professional activity? _____ ❍ employed ❍ self-employed ❍ never been employed ❍ in education, e.g. student, trainee ❍ yes, please specify: What is the caregiver´s professional activity? _____ Is the caregiver employed or self-employed? ❍ employed ❍ self-employed Has the caregiver reduced the professional activity due to the GBM disease of the patient? ❍ no ❍ yes, please specify: caregiver's current working hours per week ____ By how many hours per week did the caregiver reduce the professional activity? ____ since when? ____-____-____ D D M M Y Y Y Y
Caring for the patient by caregiver	How many hours per week does the caregiver actually spend caring for the patient? ____

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	since when? __ __ - __ __ - __ __ __ __ T T M M J J J J ❍ no statement possible

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