Please send the completed CRFs to the Data Center:

PD Dr. med. Carsten Friedrich, Universitätsklinik für Kinder- und Jugendmedizin, Klinik für Allgemeine Kinderheilkunde, Hämatologie/Onkologie, Klinikum Oldenburg AöR, Rahel-Straus-Str. 10, 26133 Oldenburg, Tel.: +49 (0)441 403707082013, Fax: +49 (0)441 4032789278

## **KRANIOPHARYNGEOM Registry 2019 Data at Diagnosis Recording Form**

Llagnital		City		Country	
Hospital		City		Country	
Date of diagnosis (Imaging)		Date of diag	nosis (Histo	ogy)	
Anthropometric data Examination Date:		Measured	body height	: (cm):	
Measured		Measured	body weigh	t (kg <b>)</b> :	······
waist circumference (cm):	,	Measured	head circun	nference (cm):	,
Birth weight (g):	,		al age (wk)		
Pubertal (PH) stage (Tanner):			B/G) stage (		
	,	-	ght father (kg		
Body hight mother (cm):	,	Body weig	ght mother (k	(g):	,
Symptoms before diagnos	is: CTC-grade:	hospita	lization	duration i	n month
Growth decline:	O yes	_	O no		mo
Weight gain:	O yes	_	O no	_	mo
Polyuria / Polydypsia /DI:	O yes	_	O no		mo
Neurological findings:	O yes	•	O no		mo
Headaches: Visual disorders:	O yes	_	O no		mo
Cognitive disturbance:	O yes O yes	· · · · · · · · · · · · · · · · · · ·	O no O no		mo mo
Alopecia:	• yes	-	O no	_	mo
Skin disorder:	O yes		O no		mo
(Hypo-/Hyperpigmentation, Ulceration	on, Teleangiectasia	a, Induration)			
Fatigue:	O yes	O yes	O no	duration: _	mo
Incidental finding	O yes O	no			
Preoperative endocrine fin	dings:		Pube	erty:	
Diabetes insipidus:	<i>J</i> I			rtas tarda:	O
Hypothyroidism: C Growth hormone deficiency: C		sm: O	Pube Norm	rtas praecox:	O O
Behavioural abnormalities	O yes	O no	140111	ui.	
Hypothalamic syndrome (food-seeking behaviour/morb	O yes id obesity, som	O no nolence/sleep o	disturbance,	temperature insta	ability)
Remarks:					
Address/Fax to Data Centr	e within 3 mor	nths			
Date	Stamn		Sia	nature	

#### KRANIOPHARYNGEOM Registry 2019 Neurosurgery Recording Form Date of Birth Date of Diagnosis = Surgery Centre ID Malig-ID

Bate of Birtin	Date of Di	agnosis cargory centre in	Wang ib
	ا للنا		шшш
		Male □ Female □	Initials 🔲
Hospital	Cit	y Country	
Date of 1 <sup>st</sup> surgery:		Number of previous surge	eries:
Hospital			
Surgeon:			
Planned OP Procedures		Realized OP Procedures	
Radical resection	•	Radical resection	<b>O</b>
Limited resection	•	Limited resection	O
Biopsy	•	Biopsy	O
Cyst drainage, subtotal tumor	•	Cyst drainage, subtotal tumor	O
resection, relief of hydrocephalus		resection, relief of hydrocephalus	
Installation of sclerosing	•	Installation of sclerosing	•
substances		substances	Tissue
or radioisotopes into the cyst	$\mathbf{O}$	or radioisotopes into the cyst	o sample
Shunt (e.g. relief of hydrocephalus	<b>O</b> (a	Shunt (e.g. relief of hydrocephalus)	o preserved:
yes O no O	,	( 3 ) , , ,	preserveu.
•	On a n /Trans	Transhamaidal O	
Surgical approach to tumor	Open/Trans	scranial O Transphenoidal O	Endoscopic O
Pituitary stalk (intraoperativ):		cut O obtained O	not identified O
Hypothalamic infiltration (intraopera	ıtiv):	yes O no O	not evaluated O
Second surgery intervention			
Date of 2 <sup>nd</sup> surgery:		Number of previous surge	eries:
Planned OP Procedures		Realized OP Procedures	
Radical resection	$\mathbf{O}$	Radical resection	•
Limited resection	$\mathbf{O}$	Limited resection	•
Cyst drainage, subtotal tumor	O	Cyst drainage, subtotal tumor	O
resection, relief of hydrocephalus		resection, relief of hydrocephalus	
Installation of sclerosing	O	Installation of sclerosing	O
substances		substances	
or radioisotopes into the cyst	$\mathbf{O}$	or radioisotopes into the cyst	O
Shunt (e.g. relief of hydrocephalus	<b>C</b> (a	Shunt (e.g. relief of hydrocephalus)	O Surgical
<b>tumor</b> Ope	en/Transcran	nial O Transphenoidal O Endosc	approach to opic O
Pituitary stalk (intraoperativ):		cut O obtained O	not identified O
Hypothalamic infiltration (intraopera	ıtiv):	yes O no O r	not evaluated O
Histology: yes O no	<b>O</b>		
Perioperative complications (with	nin 30 days o	of surgery):	_
Blood transfusion requirement O	New visua	al disturbance O Subdu	ral effusion O
CSF infection (meningitis)	Severe sal	t and flood balance review O	
Strokes O	Paresis	O	
Remarks:			
Address/Fax to Data Centre withi	in 3 months		
D. (		<b>2</b> 1	
Date Sta	mp	Signature	

# KRANIOPHARYNGEOM Registry 2019 Radiotherapy Recording Form 1.0 – General Information Date of Birth Date of Diagnosis-Surgery Centre ID

C	R	F	3
•		•	v

Date of Birth	Date of Diagnosis	s=Surgery Centre ID	Malig-ID
	шш		
		Male □ Female □	Initials
ospital	City	Country	
ame of responsible Radiation O	ncologist	Department of Rac	diotherapy (stamp)
Date start of RT:		ate end of RT:	
	of operations before		
	rative radiotherapy rapy after progress		
		<u> </u>	
adiotherapy treatment terruption	O no O yes Number of Breaks		_
	Total number of da	ays/missed RT sessions	_
Break 1	_	Break 2	_
dose achieved before break dose compensation O no O yes	Gy s with Gv	dose achieved before break dose compensation O no O	ves with Gv
causes of treatment interruption	<del></del>	causes of treatment interrupt	
O Toxicity Adverse Event (AE, CTCA	λΕ v5.0)	O Toxicity Adverse Event (AE, C	TCAE v5.0)
AE: AE:	grade:	AE: AE:	grade:
AE:	grade:	AE:	grade:
O Disease progression		O Disease progression	
O Bank holidays		O Bank holidays	
O Other:		O Other:	
Early termination of RT		Hospitalization during rad	iotherapy
O no O yes		O no O yes total number of unplanned h	oenitalization dave:
causes of treatment interruption		•	lospitalization days
O Toxicity Adverse Event (AE, CTCA	∆E V5.0)	causes of hospitalization:  O Toxicity Adverse Event (AE, 0	CTCAE v5.0)
AE:	grade:	-	
AE:	grade:		
AE:			
emarks			

Signature

Stamp

Date

## **KRANIOPHARYNGEOM Registry 2019 Radiotherapy Recording Form 1.1 – Treatment Technique**

CRF	3
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Date of Birth	Date of Diagnosis=Surgery Centre ID Malig-ID
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	Male □ Female □ Initials □□
Image fusion (MRI/CT) for treatment planning	O no O yes
3-D treatment planning	O no O yes
RT mode	O Photons O Protons O Other
RT technique	<ul> <li>Conventional simulation-based XRT</li> <li>3D conformal XRT without intensity modulation</li> <li>Intensity-modulated XRT with fixed gantry agles (IMRT)</li> <li>Volumetric modulated arc therapy (VMAT)</li> <li>Tomography</li> <li>Active scanning/ pencil beam scanning (protons)</li> <li>Passive scattering/ uniform scanning (protons)</li> <li>Fractionated stereotactic radiotherapy</li> <li>Radiotheraphy</li> <li>Brachytherapy</li> <li>Daily imaging for set-up</li> <li>Other</li> </ul>
Target of radiotherapy	<ul> <li>Residual tumor, recurrent/progressive tumor only</li> <li>Residual tumor + high risk area</li> <li>Total area with initial tumor contact (tumor bed, primary tumor/recurrent/progressive tumor + residual tumor)</li> <li>Volume GTV (residual tumor/ recurrent tumor) (cm³):</li> <li>not applicable</li> <li>Volume GTV (residual tumor + tumor bed) (cm³):</li> <li>not applicable</li> <li>Volume CTV (cm³):</li> <li>Margin GTV-CTV (mm):</li> <li>Volume PTV (cm³):</li> </ul>
Dose of prescription	Total dose: Gy Number of fractions: Single dose: Gy

Target volume/ risk organs	Uniform name	May (D2%) in Gy	Mean dose in Gy
GTV	GTV_res/rel		
(residual/progressive tumor)	_		
GTV (residual tumor +	GTV_res+tb		
tumor bed)			
CTV	CTV_XXXX		
	(prescribed dose in cGy)		
PTV	PTV_XXXX		
	(prescribed dose in cGy)		
Brainstem	Brainstem		
Brainstem centre	Brainstem_Cent		
( ø 2-3 mm)			
Spinal cord (below C1)	SpinalCord		
Cochlea (left)	Cochlea_L		
Cochlea (right)	Cochlea_R		
Eye lense (left)	Lens_L		
Eye lense (right)	Lens_R		
Hippocampus (left)	Hippocampus_L		
Hippocampus (right)	Hippocampus_R		
Hypothalamus	Hypothalamus		
Infratentorial brain	Brain^Înfratent		
(posterior fossa)			
Chiasma	OpticChiasm		
Nervus opticus (left)	OpticNrv_L		
Nervus opticus (right)	OpticNrv_R		
Pituitary gland	Pituitary		
Supratentorial brain	Brain^Supratent		
Temporal lobe (left)	Lobe_Temporal_L		
Temporal lobe (right)	Lobe_Temporal_R		
Thyroid gland	Glnd_Thyroid		

#### Remarks:

As part of quality assurance, the RT data set must be sent to Reference Radiation Therapy after the end of irradiation. The dataset should contain the following data: 1. diagnostic imaging (initial and postoperative MR), 2. planning CT, 3. RT structure set, 4. RT image, 5. RT plan for target volumes and contoured risk organs, 6. MR sequences used for contouring, 7. registration matrix of MR fusion.

Please contact the Reference Center Radiation Therapy Essen for submission of the radiation plan in DICOM format:

Westdeutsches Protonentherapiezentrum Essen (WPE) Referenzzentrum Strahlentherapie Essen Am Mühlenbach 1 45147 Essen

Tel.: +49 201 723-8156 FAX: 49 201 723-5978

Mail: wpe\_referenzzentrum\_strahlentherapie@uk-essen.de

Radiation plan sent to the Reference Center Radiation Therapy Essen?

O yes O no

Date Stamp Signature

# KRANIOPHARYNGEOM Registry 2019 CRF 4 Consignment bill for sending the radiological imaging to the Radiological Reference Center Augsburg

Date of Birth	Date of Diagnosis=Surgery	Centre I	D Malig-ID
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		Male □	Female □ Initials □□
Hospital	City		Country

### Only enclose this form when sending CDs by postal mail!

We prefer sending the images to the neurological reference center via **MDPE-Server** (<a href="https://www.mdpe-hit.de/">https://www.mdpe-hit.de/</a>)! If sending by postal mail, send the CD with Dicom data without viewer to the following address:

### Dr. Brigitte Bison,

Diagnostische und interventionelle Radiologie und Neuroradiologie Universitätsklinikum Augsburg, Stenglinstr. 2, 86156 Augsburg, Tel.: +49 (0)821 4002954; Fax: +49 (0)821 4003312 E-Mail: hit-nrad@uk-augsburg.de

Original images are returned to the centers as soon as possible after scanning/documentation. The reference assessment of the neuroradical findings is sent to the centers within few working days.

				Multiple answers possible
Diagnosis:			Date of surgery:	
Examination:		O at first diagnosis	Date of MRI:	
		O during the course	Date of CT:	11111111
lmaging:	СТ	O yes O no	O without contrast medium (CM)	with contrast medium (CM)
	MRI	O yes O no	O T1-weighted	O with CM
			O T2-weighted	O without CM
Date of shipm	ent:			
Date of medic	al report:			
lmages return	ed:			

Date	Stamp	Signature
		3

Date

Stamp

## KRANIOPHARYNGEOM Registry 2019 Follow-Up Recording Form

**CRF 5** 

- Onow-op Necording	9 1 01111				
Date of Birth	Date of Dia	gnosis=Surge	ery Co	entre ID	Malig-ID
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			Male □	Female □	Initials □□
Hospital	Ci	ty	Co	ountry	
Anthropometric data					
Examination Date:	шшц	ш	Measured both	ody	ш, ц
Measured body height (cm)	ш, ப		Measured bo weight (kg)	ody	ш, п
Measured head circumference (cm)	ш, ப				
Pubertal (PH) stage (Tanner)	Л		Pubertal (B/0 (Tanner)	G) stage	Ш
Symptoms in the course:	CTC-grade:	hospitaliza	ation	duration	in month
Growth decline:	<b>O</b> yes	O yes	O no		mo
Weight gain:	O yes	,	O no		mo
Neurological findings:	O yes	,	<b>O</b> no		mo
Headaches:	O yes	,	<b>O</b> no		mo
Visual disorders:	O yes	,	<b>O</b> no		mo
Cognitive disturbance:	O yes	,	O no		mo
Alopecia:	O yes	,	) no		mo
Skin disorder: (Hypo-/Hyperpigmentation, Ulceration	O yes , Teleangiectasia, Ind		<b>O</b> no	duration:	mo
Fatigue:	O yes	O yes	O no	duration:	mo
Endocrine findings:			Puberty:		
Diabetes insipidus	O Hypocorti		Pubertas p		O
Hypothyroidism Growth Hormone deficiency	O Hypogona	adism O	Pubertas t	arda	O O
	_	_	Horman		
Behavioural abnormalities	O yes	O no			
Hypothalamic syndrome (food-seeking behaviour/morbid	O yes obesity, somnoler	O no nce,/sleep dis	turbance, temp	perature ins	stability)
Medication:					
Minirin/DDAVP: Q yes	O no	Sex steroids		yes On	
L-Thyroxine:	O no O no	Psychopharr Sleep modify	naceuticals: O	yes On yes On	
Glucocorticoids: O yes	O no	others:	mig drugs O		<del></del>
Remarks:					
Address/Fax to Data Centre	within 3 months				
Addieson as to Data Celiffe	w.u 5 1110111115				

Signature

O annually, O at relapse a	nd/or death	
Date of Birth	Date of Diagnosis=Surgery	Centre ID Malig-ID
		Male □ Female □ Initials □□
Hospital	City	Country
Status at follow up		
Date of Examination		
Status of patient	<ul> <li>Alive - free from tumor</li> <li>Alive with post op residence</li> <li>Relapse after complete</li> <li>Progression of residual</li> <li>Dead</li> </ul>	dual tumor re resection
comments:		
	-	unt
Death:	Date o	of death:
Cause:  O Primary tumor disease O Relapse/ progression O Treatment related mort O Addison's crisis O 2 <sup>nd</sup> malignancy	O Hypopit ality Cardiov	differentiate if tumor or treatment tuitarism vascular cause (eg. strokes) cause
Remarks:		
Address/Fax to Study Ce	entre within 3 month	
Date: Stam	o: Si	ignature:

## **KRANIOPHARYNGEOM Registry 2019**Radiological Reference Evaluation Recording Form

Radiological Reference Evaluation Recording Form									
Date of Birth	Date of Diagnosis=Su		rgery Centre ID		Malig	Malig-ID			
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			Male	e□ Fe	emale □	Initials			
Hospital	italCountry								
Date of surgery:	ا سا سا	ш	١						
Examination:	○ at first diagno	t diagnosis		MRI date:		ш ш шш			
	O during the co	g the course		CT date:		سس س			
Imaging: CT	O yes O no		O without comedium (			n contrast dium (CM)			
MRI	O yes O no		O T1-weigh O T2-weigh		O with CM O without CM				
Tumor localization	O intrasellar		O intra-extra	asellar	O ext	rasellar			
Tumor structure:	O solid O cy	stic (	O mixed						
Displacement/Compression of:  O Pituitary stalk O III. Ventricle O Ant. Hypothalamus O Post. Hypothalamus O Opt. chiasm									
Hydrocephalus	O yes		O no O L	ateral ve	entricles	O III. Ventricle			
max. Tumor-Diameter (solid and cystic) (mm) based on: MRI-Finding O CT-Findings O									
Total tumor (mm):	Cystic	part	(mm):						
Cranio-caudal []	Cranio	o-caudal	Ш		-	rt > 50 %:			
Ant-posterior LIL	Ant-po	osterior	Ш		O yes O no				
right-left LILI	right-left		Ш						
max. midline height									
•	cifications cifications	,	O no O no						
MRI evaluation (slices <= 3 mm):  Signal T1  O hypointense  O isointense  O hyperintense  Signal T2  O hypointense  O isointense  O hyperintense									
Overall: Pro	gression: O yes	O no	Recu	ırrence:	O yes	O no			
Remarks:									
Address/Fax to Data Centre within 3 months									
Date Stamp			Signature						

Please send the completed CRFs to the Data Center:

PD Dr. med. Carsten Friedrich, Universitätsklinik für Kinder- und Jugendmedizin, Klinik für Allgemeine Kinderheilkunde, Hämatologie/Onkologie, Klinikum Oldenburg AöR, Rahel-Straus-Str. 10, 26133 Oldenburg, Tel.: +49 (0)441 403<u>70708</u>2013, Fax: +49 (0)441 4032789278

## **KRANIOPHARYNGEOM Registry 2019**

Report of serious adverse events Recording Form									
Date of Birth	Date of Diagr	nosis=Surgery	Centre I	D Malig-	-ID				
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			Male □	Female □	Initials 🔲				
Hospital		City		Country					
Reporting party / contact pe	rson / name:								
Contact phone number / fax	number:								
Hospital: Date/Signature (Sta	amp):								
ascertainable), symptoms of il accidents occurring during the ol study treatment. Expected AEs AEs will be documented on this Serious adverse events occurring within 24 hours, to the study ce	oservation peri related to radio form. ng during thera	od, irrespective otherapy (toxiciti	of a possiblees) will be i	e causal relati recorded on C	ionship with the CRF 3; all other				
AEs classification is based on	severity:								
<ul><li>Mild (symptoms that</li></ul>	•		-	_	,				
<ul> <li>Moderate (symptoms require medical intervenience)</li> </ul>		ere enough to I	imit the pat	ient's ability t	o perform and				
<ul> <li>Severe (symptoms the cannot perform his/here)</li> </ul>									
Serious adverse events includ	le:								
<ul><li>Any death, regardless</li></ul>	of cause of d	eath.							
<ul><li>Life-threatening/life-th</li></ul>	reatening med	lical conditions.							
<ul><li>Events that result in p</li></ul>	ermanent seve	ere disability.							
<ul> <li>Overdose events that</li> </ul>	result in symp	toms							
Date of Event:	-								
Exact description of event:	tion/ooverity		. talcam if an						
Type, onset, duration, manifesta Related signs, symptoms, and la					lition.				