

Craniopharyngioma - Prospective observational study

DATA AT DIAGNOSIS

Form 1

Date of Birth

□□ □□ □□□□
D D M M Y Y Y Y

Date of Diagnosis=Surgery

□□ □□ □□□□
D D M M Y Y Y Y

Centre ID

□□□

Patient ID

□□□□□□□□

Male Female Initials

Hospital.....

City.....

Country.....

Anthropometric data

Examination Date

□□ □□ □□□□

Measured body height (cm) □□□□ , □

Measured body weight (kg) □□□□ , □

Birth weight (g) □□□□

Gestational age (wk) □□

Pubertal (PH) stage (Tanner) □

Pubertal (B) stage (Tanner) □

Body height father (cm) □□□

Body weight father (kg) □□□

Body height mother (cm) □□□

Body weight mother (kg) □□□

Symptoms before diagnosis

Growth decline:	<input type="radio"/> yes	<input type="radio"/> no	duration: _____ months
Weight gain:	<input type="radio"/> yes	<input type="radio"/> no	duration: _____ months
Polyuria / Polydypsia /DI:	<input type="radio"/> yes	<input type="radio"/> no	duration: _____ months
Incidental finding:	<input type="radio"/> yes	<input type="radio"/> no	duration: _____ months
Neurological findings:	<input type="radio"/> yes	<input type="radio"/> no	duration: _____ months
Headaches:	<input type="radio"/> yes	<input type="radio"/> no	duration: _____ months
Visual disorders:	<input type="radio"/> yes	<input type="radio"/> no	duration: _____ months
fields	<input type="radio"/> yes <input type="radio"/> no		
optic atrophy	<input type="radio"/> yes <input type="radio"/> no		
acuity	<input type="radio"/> yes <input type="radio"/> no		
squint	<input type="radio"/> yes <input type="radio"/> no		

Preoperative endocrine findings

Diabetes insipidus

Hypothyroidism

Growth hormone deficiency

Hypocortisolism

Hypogonadism

Puberty:

Pubertas tarda

Pubertas praecox

Behavioural abnormalities yes no

Hypothalamic syndrome yes no
(food-seeking behaviour/morbid obesity, somnolence/sleep disturbance, temperature instability)

Remarks:

Address/Fax to Data Centre within 3 months

Date

stamp

signature

Craniopharyngioma - Prospective observational study

RADIOLOGICAL RECORDING FORM

Form 2

Date of Birth

□□	□□	□□□□
D D	M M	Y Y Y Y

Date of Diagnosis=Surgery

□□	□□	□□□□
D D	M M	Y Y Y Y

Centre ID

□□□

Patient ID

□□□□□□□□

Male Female Initials

Hospital.....

City.....

Country.....

Date of surgery: □□ □□ □□□□

Examination: at first diagnosis
 during the course

MRI date: □□ □□ □□□□

CT date: □□ □□ □□□□

Imaging:

CT	<input type="radio"/> yes <input type="radio"/> no	<input type="radio"/> without contrast medium (CM)	<input type="radio"/> with contrast medium (CM)
MRI	<input type="radio"/> yes <input type="radio"/> no	<input type="radio"/> T1-weighted <input type="radio"/> T2-weighted	<input type="radio"/> with CM <input type="radio"/> without CM

Tumour localization intrasellar intra-extrasellar extrasellar

Tumour structure: solid cystic mixed

Displacement/Compression of:

- pituitary stalk
- III. Ventricle
- Ant. Hypothalamus
- Post. Hypothalamus
- Opt. chiasm

Hydrocephalus yes no Lateral ventricles III. Ventricle

max. Tumour-Diameter (solid and cystic) (mm) based on:

MRT-Findings <input type="radio"/>	CT-Findings <input type="radio"/>
Cranio-caudal	□□□
Ant-posterior	□□□
right-left	□□□
max. midline height	□□□

CT evaluation:

preoperative:	calcifications	<input type="radio"/> yes <input type="radio"/> no
during the course	calcifications	<input type="radio"/> yes <input type="radio"/> no

MRI evaluation (slices <= 3 mm):

Signal T1	<input type="radio"/> hypointense	<input type="radio"/> isointense	<input type="radio"/> hyperintense
Signal T2	<input type="radio"/> hypointense	<input type="radio"/> isointense	<input type="radio"/> hyperintense

Remarks:

Address/Fax to Data Centre within 3 months

Date

stamp

signature

Craniopharyngioma - Prospective observational study

NEUROSURGERY RECORDING FORM

Form 3

Date of Birth

D D M M Y Y Y Y

Date of Diagnosis=Surgery

D D M M Y Y Y Y

Centre ID

Patient ID

Male Female Initials

Hospital.....

City.....

Country.....

date of first surgery:

D D M M Y Y Y Y

Hospital _____

Surgeon: _____

Planned OP Procedures

Radical resection
 Limited resection
 (Cyst drainage,
 subtotal tumour resection
 Relief of hydrocephalus

Realized OP Procedures

Radical resection
 Limited resection
 Cyst drainage,
 subtotal tumour resection
 Relief of hydrocephalus

Surgical approach to tumour Open/Transcranial Transphenoidal Endoscopic

Pituitary stalk (intraoperativ): cut obtained not identified
 Hypothalamic infiltration (intraoperativ): yes no not evaluated

Second surgery intervention

date of 2. surgery:

D D M M Y Y Y Y

Planned OP Procedures

Radical resection
 Limited resection
 (Cyst drainage,
 subtotal tumour resection
 Relief of hydrocephalus

Realized OP Procedures

Radical resection
 Limited resection
 Cyst drainage,
 subtotal tumour resection
 Relief of hydrocephalus

Surgical approach to tumour Open/Transcranial Transphenoidal Endoscopic

Pituitary stalk (intraoperativ): cut obtained not identified
 Hypothalamic infiltration (intraoperativ): yes no not evaluated

Histology: yes no

Peri-operative complications (within 30 days of surgery):

subdural effusion strokes new visual disturbance
 blood transfusion requirement CSF infection severe salt and flood balance review

Remarks:

Address/Fax to Data Centre within 3 months

Date

stamp

signature

Craniopharyngioma - Prospective observational study

RADIOTHERAPY RECORDING FORM

Form 4

Date of Birth

D D M M Y Y Y Y

Date of Diagnosis=Surgery

D D M M Y Y Y Y

Centre ID

Patient ID

Male Female Initials

Hospital.....

City.....

Country.....

Radiation strategy:

1. After subtotal resection immediate radiation therapy (within 3 months after surgery) initially waiting (XRT if signs of progression)
2. At relapse after total resection yes no

External radiation

yes no

Start of therapy

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End of therapy

D D M M Y Y Y Y

Total dose:

Gy

Energy:

Single fractions:

Gy

Field size (cm):

Length

Width

Volume (90%-Isodose) (ccm):

ccm

Radiation technique:

3D-Planning

yes

no

Seed-Implantation

yes no

Date:

Day Mo Year

Emitter:

Instillation of radio-isotope:

Phosphorus

Date

Radium

Date

Yttrium

Date

D D M M Y Y Y Y

Complications during RT

- Surgical intervention during RT
 Interrupted or delayed treatment programme
 planning change during treatment
 Acute or delayed radiation oedema/ toxicity
 no complications

Address/Fax to Data Centre within 3 months

Date

stamp

signature

Craniopharyngioma - Prospective observational study FOLLOW UP

Form 5

Date of Birth

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D D M M Y Y Y Y

Date of Diagnosis=Surgery

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D D M M Y Y Y Y

Centre ID

□□□

Patient ID

□□□□□□□□

Male Female Initials

Hospital.....

City.....

Country.....

Anthropometric data

Examination Date

□□ □□ □□□□

Measured body height (cm) □□□□ , □

Measured body weight (kg) □□□□ , □

Pubertal (PH) stage (Tanner) □

Pubertal (B) stage (Tanner) □

Symptoms in the course

- Growth decline: yes no
Weight gain: yes no
Polyuria / Polydypsia / DI: yes no
Neurological findings: yes no
Headaches: yes no
Visual disorders: yes no
 fields yes no
 optic atrophy yes no
 acuity yes no
 squint yes no

Endocrine findings:

- Diabetes insipidus
Hypothyroidism
Growth Hormone deficiency
Hypogonadism/Hypocortisolism

Puberty:

- Pubertas praecox
Pubertas tarda

Behavioural abnormalities yes no

Hypothalamic syndrome yes no
(food-seeking behaviour/morbid obesity, somnolence,/sleep disturbance, temperature instability)

Medication:

- Growth hormone: yes no Sex steroids: yes no
L-Thyroxine: yes no Psychopharmaceuticals: yes no
Minirin/DDAVP: yes no Sleep modifying drugs yes no
Glucocorticoids: yes no others: _____

Remarks:

Address/Fax to Data Centre within 3 months

Date

stamp

signature

Craniopharyngioma – Prospective observational study

STATUS, RELAPSE AND DEATH

Form 6

annually, at relapse and/or death

Form 6

Date of Birth

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D D M M Y Y Y Y

Date of Diagnosis=Surgery

□□ □□ □□□□
D D M M Y Y Y Y

Centre ID

□□□

Patient ID

□□□□□□□□

Male

Female

Initials □□

Hospital.....

City.....

Country.....

Status at follow up

Examination Date:

□□ □□ □□□□
D D M M Y Y Y Y

Status of patient

- Alive - free from tumour
- Alive with post op residual tumour
- relapse after complete resection
- progression of residual tumour
- Dead

comments:

Relapse/ progression treatment

Date:

□□ □□ □□□□
D D M M Y Y Y Y

- no treatment
- surgery
 - complete
 - subtotal
- radiotherapy
- cyst drainage
- ventriculo-pert.Shunt
- instillation of radioisotopes
 - phosphorus
 - yttrium
 - radium
- instillation of e.g.Bleomycin
- other _____

Death

Date:

□□ □□ □□□□
D D M M Y Y Y Y

Cause :

- primary tumour disease
- relapse/ progression
- treatment related mortality
- hypopituitarism
- cardiovascular cause (eg strokes)
- cannot differentiate if tumour or treatment
- second malignancy
- other cause.....

Remarks:

Address/Fax to Study Centre within 3 month

Date:

Name:

Signature: