

# ENSAT Registry Data Dictionary

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This document lists the data fields that are present in all sections of the current ENSAT registry. It is divided into the four tumor types (ACC, Pheo, NAPACA, APA), and sub-divided into the relevant tables within those sections.

Each data point has the following descriptors:

- Name
  - o The name as rendered on the registry website
- Type
  - o The four main types are date, number, text and menu. However there are some dynamically generated text and menu options as well.
- Selection options
  - o If the item is a menu
- Parent parameter relation
  - o If the parameter can only be viewed by making a selection on another item, this other item is referenced in this column
- Optional status
  - o false = mandatory, true = optional
- Additional comments
  - o Any other relevant information, including the prescribed range for number items

The identification and studies tables are common to all sections so are detailed first.

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## Identification

Name	Type	Menu options	Parent parameter	Optional	Comments
Year of birth	Number			False	Specified as year for de-identification
Sex	Menu	- Male - Female		False	
Center ID	Menu	- All national center codes		False	Generated from database
Referral doctor	Text			False	
Email	Text			False	
Date of ENSAT registration	Date			False	
Level of consent for clinical research	Menu	- Local - National - ENSAT consortium - International		False	Specifies the level of consent for sharing of information
Associated studies	Menu	- All studies associated with this tumor type		True	Generated from database

## Studies

The following list outlines the studies that are currently supported by the ENSAT registry:

- EURINE-ACT
- Ki-67
- Stage III/IV ACC
- PMT
- TMA
- Long-term PHPGL
- AVIS-2
- PMT3
- ADIUVO
- ADIUVO Observational
- HairCo-2
- FIRST-MAPPP
- CHIRACIC
- German Cushing Registry
- German Conn Registry
- ACC Molecular Marker
- UK Pheo Audit
- Lysosafe
- FIRMACT
- MAPP-Prono
- MIBG Impact
- Predict Ancillary FIRM-ACT

Details of these studies can be found by title in the SOPs and Study Information section of the registry.

## Adrenocortical Carcinoma (ACC)

### Diagnostic Procedures

Table is filled out once per patient

Name / Units	Type	Menu options	Parent parameter	Optional	Comments / Range
Date of diagnosis	Date			True	
Disease status (at time of ENSAT registration)	Menu	- Free of disease - Not free of disease		True	
Modality of diagnosis	Menu	- Pathology - Hormonal + Imaging Work-Up		True	
Height	Number			True	10 – 200
Weight	Number			True	30 – 250
Symptoms related to tumor mass	Menu	- Yes - No		True	
Incidentally detected	Menu	- Yes - No		True	
Related to unspecific paraneoplastic symptoms	Menu	- Yes - No		True	
Symptoms related to hormonal secretion	Menu	- Yes - No		True	
Cushing's syndrome	Menu	- Yes - No - Unknown	Symptoms related to hormonal secretion	True	
Virilisation	Menu	- Yes - No - Unknown	Symptoms related to hormonal secretion	True	
Feminization	Menu	- Yes - No - Unknown	Symptoms related to hormonal secretion	True	

Mineralocorticoid excess	Menu	- Yes - No - Unknown	Symptoms related to hormonal secretion	True	
Hypertension	Menu	- Yes - No - Unknown		True	
Hypokalemia	Menu	- Yes - No - Unknown		True	
Diabetes	Menu	- Yes - No - Unknown		True	
Hormonal hypersecretion	Menu	- Yes - No		True	
Glucocorticoids	Menu	- Yes - No - Unknown	Hormonal hypersecretion	True	
Androgens	Menu	- Yes - No - Unknown	Hormonal hypersecretion	True	
Estrogens	Menu	- Yes - No - Unknown	Hormonal hypersecretion	True	
Mineralocorticoids	Menu	- Yes - No - Unknown	Hormonal hypersecretion	True	
Precursor secretion	Menu	- Yes - No - Unknown	Hormonal hypersecretion	True	
ACC during pregnancy	Menu	- Yes - No - Unknown		True	
Associated malignancy	Menu	- Yes		True	

		- No			
Specific malignancies	Text		Associated malignancy	True	
Cortisol after dexamethasone 1 mg overnight	Number		Glucocorticoids	True	0 – 100
Cortisol units	Menu	- mcg/dl - nmol/l	Glucocorticoids	True	
Date of FIRM-ACT enrolment	Date			True	
Hemoglobin (g/l)	Number			True	0 – 100
Performance status to ECOG	Menu	- - Asymptomatic - 1 - Symptomatic but completely ambulatory - 2 - Symptomatic, lt 5% in bed during the day - 3 - Symptomatic, gt 5% in bed, but not bedbound - 4 - Bedbound - 5 - Death		True	
Platelet (1 <sup>9</sup> per liter)	Number			True	0 – 100
Bilirubin (mg/dl)	Number			True	0 – 100
Creatinine (umol/L)	Number			True	0 – 100
LDH (UI/L)	Number			True	0 – 100



## Tumor Staging

Table is filled out once per patient

Name / Units	Type	Menu options	Parent parameter	Optional	Comments / Range
Site of adrenal tumor	Menu	- Right - Left - Both		True	
Information based on	Menu	- Pathology - Imaging - Both (Pathology and Radiology)		True	
Size of adrenal tumor (mm)	Number			True	0 – 400
Regional lymph nodes positive	Menu	- Yes - No - Not Determined		True	
Extracapsular local invasion to adipose tissues	Menu	- Yes - No - Not Determined		True	
Extracapsular local invasion to adjacent organs	Menu	- Yes - No - Not Determined		True	
Tumor in vena cava or vena renalis	Menu	- Yes - No - Not Determined		True	
Distant metastases	Menu	- Yes - No		True	
Bone	Menu	- Yes - No - Not Determined - Determined By Other Means	Distant metastases	True	

Liver	Menu	- Yes - No - Not Determined - Determined By Other Means	Distant metastases	True	
Lung	Menu	- Yes - No - Not Determined - Determined By Other Means	Distant metastases	True	
Abdomen lymph nodes	Menu	- Yes - No - Not Determined - Determined By Other Means	Distant metastases	True	
Other metastases	Text			True	
Imaging	Menu	- CT - MRI - PET		True	
Hounsfield units on CT (required for EURINE- ACT)	Number		Imaging	True	-100 – 100
Date of metastases (stage IV) diagnosis	Date			True	

## Biomaterial

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Biomaterial Date	Date			False	
Associated Study	Menu	<ul style="list-style-type: none"> <li>- ENS@T Biobank</li> <li>- PMT</li> <li>- ADIUVO</li> <li>- EURINE-ACT</li> <li>- CHIRACIC</li> <li>- German Conn Registry</li> <li>- German Cushing Registry</li> <li>- No biomaterial available</li> </ul>		True	
Associated Study (Phase/Visit)	Menu (dynamic)	[Menu options dependent on selection – the options outline the phase/visit number depending on what the study requirements are]	Associated Study	True	
Tumor Tissue (Frozen)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Following ENSAT SOP	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> <li>- Unknown</li> </ul>	Tumor Tissue (Frozen)	True	
Tumor Tissue (Paraffin)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Tumor Tissue (DNA)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	

Leukocyte DNA	Menu	- Yes - No		True	
EDTA Plasma	Menu	- Yes - No		True	
Heparin Plasma	Menu	- Yes - No		True	
Serum	Menu	- Yes - No		True	
24h Urine	Menu	- Yes - No		True	
24h Urine Volume (ml)	Text		24h Urine	True	
Spot Urine	Menu	- Yes - No		True	
Normal Tissue (Frozen)	Menu	- Yes - No		True	
Specific Tissue (Frozen)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (Frozen)	True	
Normal Tissue (Paraffin)	Menu	- Yes - No		True	
Specific Tissue (Paraffin)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat	Normal Tissue (Paraffin)	True	

		(Subcutaneous) - Others			
Normal Tissue (DNA)	Menu	- Yes - No		True	
Specific Tissue (DNA)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (DNA)	True	
Whole blood	Menu	- Yes - No		True	
Freezer information	Text			True	
Blood clot	Menu	- Yes - No		True	

## Chemoembolisation

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Chemoembolisation Date	Date			False	
Type	Menu	- First - Repeated		True	
Best objective evaluation	Menu	- Progressive - Stable - Objective Response - Unknown		True	

Evaluation Date	Date			True	
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## Chemotherapy

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Chemotherapy Date	Date			False	
Chemotherapy initiation	Date			True	
Chemotherapy end	Date			True	
Indication	Menu	- Adjuvant - Palliative		True	
Best objective evaluation	Menu	- Progressive - Stable - Objective Response - Unknown		True	
Evaluation Date	Date			True	
Regimen	Menu	- EDP - Cisplatin (P) - Carboplatin - Doxorubicin - Etoposide - Streptozotocin - Docetaxel - Paclitaxel - Gemcitabine - Others		True	

## Follow-Up

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Follow-up Date	Date			False	
Patient status	Menu	<ul style="list-style-type: none"> <li>- Alive with disease</li> <li>- Alive without evidence of disease</li> <li>- Death related to ACC or treatment toxicity</li> <li>- Death not related to ACC</li> <li>- Other</li> </ul>		True	
Lost to follow-up	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Alive with disease	Menu	<ul style="list-style-type: none"> <li>- Local Recurrence</li> <li>- Thoracal Lymph Nodes</li> <li>- Remaining Adrenal Tumor</li> <li>- Lung</li> <li>- Liver</li> <li>- Bone</li> <li>- Abdomen/Lymph Nodes</li> <li>- Others</li> </ul>	Patient status	True	
Comment	Text			True	
Most recent imaging Date	Date			True	
Imaging method	Menu	<ul style="list-style-type: none"> <li>- CT</li> <li>- MRI</li> <li>- PET</li> </ul>		True	

		- Other			
Currently on mitotane	Menu	- Yes - No		True	
Mitotane ongoing	Menu	- Yes - No	Currently on mitotane	True	
Mitotane end Date	Date		Mitotane ongoing	True	
Reason for mitotane discontinuation	Menu	- Adjuvant mitotane was stopped after the planned time interval - Unacceptable toxicity - No success - Compliance problems	Mitotane ongoing	True	
Recent level (mg/L)	Number		Currently on mitotane	True	
Recent dose (mg/daily)	Number		Currently on mitotane	True	
Current glucocorticoid replacement	Menu	- Hydrocortisone - Prednisolone - Dexamethasone - Cortisone acetate - None		True	
Current glucocorticoid dose (mg/daily)	Number			True	
Current fludrocortisone replacement	Menu	- Yes - No		True	
Testosterone replacement	Menu	- Yes - No		True	
Replacement choice	Menu	- Testogel - Testosterone IM - Other	Testosterone replacement	True	



## Metabolomics

Table can be filled out multiple times per patient

Table is specific to the EURINE-ACT study

Name	Type	Menu options	Parent parameter	Optional	Comments
Comment	Text			True	
Metabolomics Date	Date			False	

## Mitotane

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Mitotane initiation	Date			True	
Mitotane end	Date			True	
Indication	Menu	- Adjuvant - Palliative		True	
Best objective evaluation (palliative)	Menu	- Progressive - Stable - Objective Response - Unknown	Indication	True	
Evaluation Date	Date			True	
Maximum dosage (g/d)	Number			True	0 – 100
Maximum level (mg/l)	Number			True	0 – 100
Best objective evaluation (adjuvant)	Menu	- Free of disease - Recurrence - Unknown	Indication	True	
Recurrence	Menu	- Local - Distant - Both	Best objective evaluation (adjuvant)	True	

## Pathology

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Pathology derived from	Menu (dynamic)	[Surgery form numbers available for this patient]		True	
Surgery biopsy Date	Date		Pathology derived from	True	
Local pathologist	Text			True	
Central pathology review	Menu	- Yes - No		True	
Central review pathologist	Text		Central pathology review	True	
Number of mitoses (Exact count per 5 HPF)	Number			True	0 – 10000
Ki67 (in %/5 HPF)	Number			True	0 – 100
17p13 loss of heterozygosity	Menu	- Yes - No - Not Available		True	
IGF overexpression	Menu	- Yes - No - Not Available		True	
Weiss score	Text (generated)			True	Automatically calculated from the following 9 fields
Nuclear atypia	Menu	- Yes - No - Not Available		True	
Atypical mitosis	Menu	- Yes - No - Not Available		True	
Spongicytic tumor cells	Menu	- Yes		True	

		- No - Not Available			
Diffuse architecture	Menu	- Yes - No - Not Available		True	
Venous invasion	Menu	- Yes - No - Not Available		True	
Sinus invasion	Menu	- Yes - No - Not Available		True	
Capsular invasion	Menu	- Yes - No - Not Available		True	
Necrosis	Menu	- Yes - No - Not Available		True	
Number of mitoses (>5/5 HPF)	Menu	- Yes - No - Not Available		True	
Specify Number of cells (5 - 2)	Number		Ki67 (in %/5 HPF)	True	0 – 100

## Radiofrequency

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Radiofrequency Date	Date			False	
Type	Menu	- First - Repeated		True	
Best objective evaluation	Menu	- Progressive - Stable - Objective Response - Unknown		True	
Evaluation Date	Date			True	
Locations	Menu	- Liver - Lung - Lymph Node - Others		True	

## Radiotherapy

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Radiotherapy Date	Date			False	
Radiotherapy initiation	Date			True	
Radiotherapy end	Date			True	
Radiotherapy type	Menu	- First - Repeated		True	
Indication	Menu	- Adjuvant - Palliative		True	
Best objective evaluation	Menu	- Progressive - Stable - Objective Response - Unknown		True	
Evaluation Date	Date			True	
Locations	Menu	- Tumor Bed - Bone - Others		True	

## Surgery

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Surgery Date	Date			False	
Type	Menu	- First - Repeated		True	
Method	Menu	- Open - Laparoscopic - Laparoscopic and Open		True	
Overall resection status	Menu	- R - R1 - R2 - RX - Not known		True	
Extended	Menu	- Loco-Regional Relapse - Metastases - Liver - Metastases - Lymph Node - Metastases - Lung - Metastases - Others - Others		True	
First	Menu	- Adrenalectomy - Nephrectomy - Other Adjacent Organs - Lymphadenectomy		True	

		<ul style="list-style-type: none"><li>- Vena Cave</li><li>Surgery</li><li>- Metastases</li><li>- Others</li><li>- Loco-Regional</li><li>Relapse</li></ul>			
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## Pheochromocytoma and Paraganglioma (Pheo)

### Patient History

Table is filled out once per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
History of hypertension	Menu	- Yes - No		True	
Year of diagnosis of hypertension	Text		History of hypertension	True	
Height at the time of consent (cm)	Number			True	100 – 200
Weight at the time of consent (kg)	Number			True	30 – 250
Systolic BP at the time of consent (mmHg)	Number			True	60 – 200
Diastolic BP at the time of consent (mmHg)	Number			True	40 – 150
PHPGL operation before Date of consent	Menu	- Yes - No		True	
Residual disease	Menu	- Yes - No	PHPGL operation before date of consent	True	
Disease metastatic	Menu	- Yes - No	PHPGL operation before date of consent	True	
Multiple primary tumors	Menu	- Yes - No	PHPGL operation before date of consent	True	
Number of first degree relatives with tumors	Number			True	0 – 10
Documented genetic disease	Menu	- Yes - No		True	
Phenotypic diagnosis	Menu	- MEN2 - VHL	Documented genetic disease	True	



		<ul style="list-style-type: none"> <li>- NF1</li> <li>- SDHA</li> <li>- SDHAF2</li> <li>- SDHB</li> <li>- SDHC</li> <li>- SDHD</li> <li>- TMEM127</li> <li>- MAX</li> </ul>			
History of non-PHPGL tumors	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
System or organ	Menu	<ul style="list-style-type: none"> <li>- Bone and connective tissue</li> <li>- Breast</li> <li>- CNS</li> <li>- GI track</li> <li>-</li> <li>Leukemia/Lymphoma</li> <li>- Lung</li> <li>- Pancreas</li> <li>- Skin</li> <li>- Thyroid</li> <li>- Urogenital</li> <li>- Other</li> </ul>	History of non-PHPGL tumors	True	
Comment	Text			True	
Presentation at diagnosis of first tumor	Menu	<ul style="list-style-type: none"> <li>- Suggestive hormone and/or tumor-related symptoms</li> <li>- Therapy resistant hypertension</li> <li>- Incidentaloma</li> <li>- Presymptomatic screening</li> <li>- Other</li> </ul>		True	

Index case	Menu	- Yes - No		True	
Other syndromal tumor	Menu	- Yes - No		True	
Other syndromal tumor (specific)	Menu	- Renal cell carcinoma - Gastrointestinal stromal tumour (GIST) - Parathyroid hyperplasia/adenoma - Medullary thyroid carcinoma - Cerebellar haemangioblastoma - Retinal haemangioblastoma - Endolymphatic sac tumor - Pancreatic neuroendocrine tumor - Papillary cystadenoma of epididymis/broad ligament - Other	Other syndromal tumor	True	
Other non-syndromal tumor	Menu	- Yes - No		True	
Other non-syndromal tumor (specific)	Text		Other non-syndromal tumor	True	
Family history suggestive of syndromal disease	Menu	- Yes - No		True	
Date of first pathological	Date			True	

diagnosis					
Date of malignancy diagnosis at imaging	Date			True	
Date of malignancy diagnosis at pathology	Date			True	
Hormone-related symptoms at malignancy diagnosis	Menu	- Yes - No		True	
Specific symptoms	Menu	- Diabetes related - Constipation - Sweat / flushes - Palpitations - Headaches - Others - Arterial hypertension - Arterial hypotension	Hormone-related symptoms at malignancy diagnosis	True	
Tumor-related symptoms at malignancy diagnosis	Menu	- Yes - No		True	
Specific symptoms	Menu	- Bone pain - Other pain - Compression / blockade - Others	Tumor-related symptoms at malignancy diagnosis	True	
Stage of first diagnosis (TNM)	Menu	- Primary (size <= 5) - Primary (size > 5) - Locoregional extension (fat tissue) - Proximal lymph nodes - Adjacent organ extension		True	

		<ul style="list-style-type: none"> <li>- Venous thrombosis (renal / vena cava)</li> <li>- Distant lymph nodes</li> <li>- Distant metastasis without bone met</li> <li>- Distant metastasis including bone met</li> </ul>			
Stage of malignancy diagnosis (TNM)	Menu	<ul style="list-style-type: none"> <li>- Primary (size &lt;= 5)</li> <li>- Primary (size &gt; 5)</li> <li>- Locoregional extension (fat tissue)</li> <li>- Proximal lymph nodes</li> <li>- Adjacent organ extension</li> <li>- Venous thrombosis (renal / vena cava)</li> <li>- Distant lymph nodes</li> <li>- Distant metastasis without bone met</li> <li>- Distant metastasis including bone met</li> </ul>		True	
Date of malignancy diagnosis at biochemical assessment	Date			True	
Date of malignancy diagnosis at biological assessment	Date			True	

## Biochemical Assessment

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Plasma epinephrine concentration	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Plasma norepinephrine concentration	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Plasma measurement Date	Date			True	
Plasma-free metanephrine concentration	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100		True	

		N			
Plasma-free normetanephrine concentration	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Plasma-free methoxytyramine concentration	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Plasma-free measurement Date	Date			True	
Plasma-free methodology	Text			True	
Serum chromogranin A concentration	Number			True	0 - 30000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100		True	

		N			
Serum chromogranin A measurement Date	Date			True	
Serum chromogranin A methodology	Text			True	
Urinary-free epinephrine excretion	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Urinary-free norepinephrine excretion	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Urinary-free measurement Date	Date			True	
Urinary metanephrine excretion	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100		True	

		N			
Urinary normetanephrine excretion	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Urinary methoxytyramine excretion	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Urinary creatinine	Number			True	0 - 10000000
Value above normal upper limit	Menu	- less than 2 N - 2-5 N - 5-10 N - greater than 10 N - greater than 50 N - greater than 100 N		True	
Urinary methodology	Text			True	
Value indexed to urinary creatinine	Text			True	
Urinary measurement	Date			True	



Date					
Plasma dopamine concentration	Number			True	0 - 10000000
Value above normal upper limit	Menu	<ul style="list-style-type: none"> <li>- less than 2 N</li> <li>- 2-5 N</li> <li>- 5-10 N</li> <li>- greater than 10 N</li> <li>- greater than 50 N</li> <li>- greater than 100 N</li> </ul>		True	
Plasma dopamine measurement Date	Date			True	

## Biological Assessment

Table can be filled out multiple times per patient

Table is specific to the MAPP-Prono study

Name	Type	Menu options	Parent parameter	Optional	Comments
Assessment Date	Date			False	
<b>Hemoglobin [Hgb] (g/dl)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Platelets (10<sup>9</sup> / L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	

<b>Leukocytes [total WBC] (10<sup>9</sup> / L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Neutrophils/Granulocytes [ANC/AGC] (10<sup>9</sup>/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Creatinine (μmol/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the		True	

		lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit			
<b>SGPT [ALT] (IU/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>SGOT [AST] (IU/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper		True	

		normal limit			
<b>Alkaline phosphatase (IU/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Total bilirubin (µmol/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Total protein (g/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	

Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Albuminemia (g/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Glycemia (mmol/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times		True	

		above the upper normal limit			
<b>LDH (IU/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	
<b>Calcium (mmol/L)</b>					
Results	Number			True	0 – 10000
Complete	Menu	- Yes - No		True	
Status	Menu	- Low - under the lower normal limit - Normal - High - 2 to 5 times above the upper limit - HH - 5 times above the upper normal limit		True	

## Biomaterial

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Biomaterial Date	Date			False	
Associated Study	Menu	<ul style="list-style-type: none"> <li>- ENS@T Biobank</li> <li>- PMT</li> <li>- ADIUVO</li> <li>- EURINE-ACT</li> <li>- CHIRACIC</li> <li>- German Conn Registry</li> <li>- German Cushing Registry</li> <li>- No biomaterial available</li> </ul>		True	
Associated Study (Phase/Visit)	Menu (dynamic)	[Menu options dependent on selection – the options outline the phase/visit number depending on what the study requirements are]	Associated Study	True	
Tumor Tissue (Frozen)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Following ENSAT SOP	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> <li>- Unknown</li> </ul>	Tumor Tissue (Frozen)	True	
Tumor Tissue (Paraffin)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Tumor Tissue (DNA)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	



Leukocyte DNA	Menu	- Yes - No		True	
EDTA Plasma	Menu	- Yes - No		True	
Heparin Plasma	Menu	- Yes - No		True	
Serum	Menu	- Yes - No		True	
24h Urine	Menu	- Yes - No		True	
24h Urine Volume (ml)	Text		24h Urine	True	
Spot Urine	Menu	- Yes - No		True	
Normal Tissue (Frozen)	Menu	- Yes - No		True	
Specific Tissue (Frozen)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (Frozen)	True	
Normal Tissue (Paraffin)	Menu	- Yes - No		True	
Specific Tissue (Paraffin)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat	Normal Tissue (Paraffin)	True	

		(Subcutaneous) - Others			
Normal Tissue (DNA)	Menu	- Yes - No		True	
Specific Tissue (DNA)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (DNA)	True	
Whole Blood	Menu	- Yes - No		True	
Freezer information	Text			True	
Blood clot	Menu	- Yes - No		True	

## Clinical Assessment

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Assessment Date	Date			False	
Height	Number			True	100 – 200
Weight	Number			True	30 – 250
Systolic blood pressure	Number			True	40 – 250
Diastolic blood pressure	Number			True	40 – 150

## Follow-Up

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Follow-up Date	Date			False	
Alive	Menu	- Yes - No		True	
PHPGL free	Menu	- Yes - No	Alive	True	
Disease state	Menu	- Stable disease - Progressive disease - Partial remission - Not applicable - Recurrence	PHPGL free	True	
Date of death	Date			True	
Cause of death	Menu	- PHPGL-related - Non-PHPGL-related - Unknown		True	
Comment	Text			True	

## Genetics

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Date	Date			False	
<b>VHL</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>SDHD</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>SDHB</b>					
Testing performed	Menu	- Yes - No		True	

Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>RET</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>NF1</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	

<b>TMEM127</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>MAX</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>SDHC</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	

Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>SDHA</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	
<b>SDHAF2</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented		True	
Mutation detected	Menu	- Yes - No		True	
Nomenclature	Text			True	

## Imaging Tests

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
CT	Menu	- Positive - Negative - Not done		True	
CT Date	Date		CT	True	
CT Location	Menu	- Neck - Thorax - Abdomen - Hepatic - Rachis - Pelvis	CT	True	
Primary (Number)	Number		CT	True	0 – 20
Metastases - liver/lung/bone (Number)	Number		CT	True	0 – 20
NMR	Menu	- Positive - Negative - Not done		True	
NMR Location	Menu	- Neck - Thorax - Abdomen - Hepatic - Rachis - Pelvis	NMR	True	
NMR Date	Date		NMR	True	
Primary (Number)	Number		NMR	True	0 – 20
Metastases - liver/lung/bone (Number)	Number		NMR	True	0 – 20



MIBG	Menu	- Positive - Negative - Not done		True	
MIBG Date	Date		MIBG	True	
Primary (Number)	Number		MIBG	True	0 – 20
Metastases - liver/lung/bone (Number)	Number		MIBG	True	0 – 20
Octreoscan	Menu	- Positive - Negative - Not done		True	
Octreoscan Date	Date		Octreoscan	True	
Primary (Number)	Number		Octreoscan	True	0 – 20
Metastases - liver/lung/bone (Number)	Number		Octreoscan	True	0 – 20
FDG-PET	Menu	- Positive - Negative - Not done		True	
FDG-PET Date	Date		FDG-PET	True	
Primary (Number)	Number		FDG-PET	True	0 – 20
Metastases - liver/lung/bone (Number)	Number		FDG-PET	True	0 – 20
F-DOPA PET	Menu	- Positive - Negative - Not done		True	
F-DOPA PET Date	Date		F-DOPA PET	True	
Primary (Number)	Number		F-DOPA PET	True	0 – 20
Metastases - liver/lung/bone (Number)	Number		F-DOPA PET	True	0 – 20

Synthesis of imaging work-up	Date			True	
Primary PHPGL (Number)	Number			True	0 – 20
Metastases - liver/lung/bone (Number)	Number			True	0 – 20
Comment/other imaging name	Text			True	
Other imaging tool	Menu	- Positive - Negative - Not done		True	
Other Date	Date		Other imaging tool	True	
Primary (Number)	Number		Other imaging tool	True	0 – 20
Metastases - liver/lung/bone (Number)	Number		Other imaging tool	True	0 – 20
Somatostatine receptor scintigraphy (SRS) status	Menu	- Positive - Negative - Not done		True	
Somatostatine receptor scintigraphy (SRS) Date	Date		Somatostatine receptor scintigraphy (SRS) status	True	
Best nuclear imaging scan to follow patient	Menu			True	

## Morphological Progression

Table can be filled out multiple times per patient

Table is specific to the MAPP-Prono study

Name	Type	Menu options	Parent parameter	Optional	Comments
Date of baseline imaging for RECIST progression assessment	Date			False	
Date of second RECIST imaging	Date			True	
Rate of normalized progression (in % per 3 months)	Number			True	0 – 100
Date of baseline CGA assessment	Date			True	
Rate of normalized progression (in % per 3 months)	Number			True	0 – 100
Date of baseline O-methylated catecholamine metabolites assessment	Date			True	
Date of second O-methylated catecholamine metabolites assessment	Date			True	
Rate of normalized progression (in % per 3 months)	Number			True	0 – 100
Liver met	Menu	- Yes - No		True	
Number of liver met > 1	Number		Liver met	True	0 – 20

cm at CT or MRI					
Lung met	Menu	- Yes - No		True	
Number of lung met > 1 cm at CT or MRI	Number		Lung met	True	0 – 20
Bone met	Menu	- Yes - No		True	
Number of bone met > 1 cm at CT or MRI	Number		Bone met	True	0 – 20
Lymph node with short axis above 1.5cm at CT or MRI	Menu	- Yes - No		True	
Locoregional	Menu	- Yes - No	Lymph node with short axis above 1.5cm at CT or MRI	True	
Distant lymph nodes	Menu	- Yes - No	Lymph node with short axis above 1.5cm at CT or MRI	True	
Size of the primary or recurrent locoregional tumors (cm)	Number			True	0 – 200

## Non-Surgical Interventions

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
MIBG therapy	Menu	- Yes - No		True	
Therapy Date	Date		MIBG therapy	True	
Comment	Text		MIBG therapy	True	
Other targeted radiotherapy	Menu	- Yes - No		True	
Therapy Date	Date		Other targeted radiotherapy	True	
Comment	Text		Other targeted radiotherapy	True	
Chemotherapy	Menu	- Yes - No		True	
Therapy Date	Date		Chemotherapy	True	
Therapy end Date	Date		Chemotherapy	True	
Comment	Text		Chemotherapy	True	
Radiofrequency ablation (lungs/liver/bones)	Menu	- Yes - No		True	
Therapy Date	Date		Radiofrequency ablation (lungs/liver/bones)	True	
Comment	Text		Radiofrequency ablation (lungs/liver/bones)	True	
External radiotherapy	Menu	- Yes - No		True	
Therapy Date	Date		External radiotherapy	True	
Comment	Text		External radiotherapy	True	
Targeted molecular therapy	Menu	- Yes - No		True	
Therapy Date	Date		Targeted molecular therapy	True	
Therapy end Date	Date		Targeted molecular therapy	True	

Comment	Text		Targeted molecular therapy	True	
Chemoembolisation	Menu	- Yes - No		True	
Therapy Date	Date		Chemoembolisation	True	
Comment	Text		Chemoembolisation	True	
Therapy end Date	Date		External radiotherapy	True	
Cryoablation	Menu	- Yes - No		True	
Cryoablation Date	Date		Cryoablation	True	
Somatostatine	Menu	- Yes - No		True	
Somatostatine Date	Date		Somatostatine	True	
Interferon	Menu	- Yes - No		True	
Interferon Date	Date		Interferon	True	
Radiolabelled octreotide	Menu	- Yes - No		True	
Radiolabelled octreotide Date	Date		Radiolabelled octreotide	True	
Others	Menu	- Yes - No		True	
Others Date	Date		Others	True	

## Surgery

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Surgery Date	Date			False	
Procedure	Menu	- Biopsy - Open - Laparoscopic		True	
Evidence of malignancy	Menu	- Yes - No - Unknown		True	
Evidence of loco-regional spread	Menu	- Yes - No - Unknown		True	
Comment	Text			True	
Proliferative index	Number			True	0 – 100
ki67 (%)	Text			True	
Mitotic Number per 1 HPF	Number			True	0 – 10000
Number of cells counted	Number			True	0 – 10000
Necrosis	Menu	- Yes - No - Unknown		True	
Capsular/adipose tissue invasion	Menu	- Yes - No - Unknown		True	
Extra-tumors vascular invasion	Menu	- Yes - No - Unknown		True	
In-growth in adjacent organs	Menu	- Yes - No		True	

		- Unknown			
Agents used for pre-operative blockade	Menu	- Phenoxybenzamine - Doxazocin - Propranolol - No agents - Other		True	
Agents used for intra-operatively for hypertensive BP control	Menu	- Phentolamine - Sodium nitroprusside - Esmolol - Magnesium - Other		True	
Highest systolic BP intra-operatively	Number			True	60 – 200
Highest diastolic BP intra-operatively	Number			True	40 – 150
Local institutional review	Menu	- Yes - No		True	
In-growth invasion in surrounding fat/tissue	Menu	- Yes - No		True	
Venous invasion within the tumor	Menu	- Yes - No		True	



## Tumor Details

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Tumor Date	Date			False	
Size of largest tumor - x dim (mm)	Number			True	0 – 400
Size of largest tumor - y dim (mm)	Number			True	0 – 400
Size of largest tumor - z dim (mm)	Number			True	0 – 400
Tumor resected	Menu	- R0 - R1 - R2 - RX - No resection		True	
Adrenal or extra-adrenal	Menu	- Adrenal - Extra-adrenal		True	
Tumor site	Menu	- Right adrenal - Left adrenal - Both adrenals - Abdominal PGL - Thoracic PGL - Cervical PGL - HN-PGL		True	
Multiple primary tumors	Menu	- Yes - No		True	
Distant metastases	Menu	- Yes - No		True	

Location	Menu	- Lung - Liver - Bone - Others	Distant metastases	True	
Source of information	Menu	- Imaging - Pathology - PatientHistory		True	

## Non-Aldosterone Producing Adenomas (NAPACA)

### Diagnostic Procedures

Table is filled out once per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Height (cm)	Number			True	100 – 200
Weight (kg)	Number			True	30 – 250
Year of diagnosis of NAPACA (yyyy)	Number			True	1900 onwards
Month of diagnosis of NAPACA	Menu	- Jan - Feb - Mar - Apr - May - Jun - Jul - Aug - Sep - Oct - Nov - Dec		True	
Tumor found incidentally	Menu	- Yes - No - Unknown		True	
Symptoms related to hormonal secretion	Menu	- Yes - No - Unknown		True	
Cushing's syndrome	Menu	- Yes - No - Not Determined	Symptoms related to hormonal secretion	True	
Virilisation	Menu	- Yes	Symptoms related to hormonal	True	

		- No - Not Determined	secretion		
Feminization	Menu	- Yes - No - Not Determined	Symptoms related to hormonal secretion	True	
Mineralocorticoid excess	Menu	- Yes - No - Not Determined	Symptoms related to hormonal secretion	True	
Hypertension at presentation	Menu	- Yes - No - Unknown		True	
Year of diagnosis (yyyy)	Number		Hypertension at presentation	True	
Diabetes type-2 at presentation	Menu	- Yes - No - Unknown		True	
Year of diagnosis (yyyy)	Number		Diabetes type-2 at presentation	True	1900 onwards
Dyslipidaemia at presentation	Menu	- Yes - No - Unknown		True	
Year of diagnosis (yyyy)	Number		Dyslipidaemia at presentation	True	1900 onwards
Osteoporosis at presentation	Menu	- Yes - No - Unknown		True	
Year of diagnosis (yyyy)	Number		Osteoporosis at presentation	True	1900 onwards
Proximal myopathy at presentation	Menu	- Yes - No - Unknown		True	
Skin fragility (easy bruising, striae) at	Menu	- Yes - No		True	

presentation		- Unknown			
Previous cardiovascular events	Menu	- Yes - No - Unknown		True	
Year of event 1 (yyyy)	Number		Previous cardiovascular events	True	1900 onwards
Year of event 2 (yyyy)	Number		Previous cardiovascular events	True	1900 onwards
Currently receiving anti-diabetic drugs	Menu	- Yes - No - Unknown		True	
Currently receiving lipid-lowering drugs	Menu	- Yes - No - Unknown		True	
Currently receiving osteoporosis drugs	Menu	- Yes - No - Unknown		True	
Currently receiving anti-hypertensive drugs	Menu	- Yes - No - Unknown		True	
Serum cortisol after 1mg Dex overnight	Menu	- Suppressed - Not Suppressed - Not Done		True	
Specific value	Number		Serum cortisol after 1mg Dex overnight	True	0 – 10000
Units	Menu	- mcg/dl - nmol/l	Serum cortisol after 1mg Dex overnight	True	
Baseline plasma ACTH	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Baseline plasma ACTH	True	0 – 10000
Units	Menu	- pg/mL - pmol/L	Baseline plasma ACTH	True	

Urinary free cortisol	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Urinary free cortisol	True	0 – 10000
Units	Menu	- nmol/24h - mcg/24h	Urinary free cortisol	True	
Urinary free method	Menu	- Immunoassay - Mass spec assay		True	
Midnight salivary cortisol	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Midnight salivary cortisol	True	0 – 10000
Units	Menu	- ng/ml - mcg/l - nmol/L	Midnight salivary cortisol	True	
Midnight serum cortisol	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Midnight serum cortisol	True	0 – 10000
Units	Menu	- mcg/dl - nmol/l	Midnight serum cortisol	True	
Random plasma renin activity	Menu	- Suppressed - Increased - Normal - Not Done		True	
Random plasma renin concentration	Menu	- Suppressed - Increased - Normal - Not Done		True	
Random serum	Menu	- Suppressed		True	

aldosterone		- Increased - Normal - Not Done			
Serum 17-Hydroxyprogesterone	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Serum 17-Hydroxyprogesterone	True	0 – 10000
Units	Menu	- ng/ml - nmol/L	Serum 17-Hydroxyprogesterone	True	
Serum DHEAS	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Serum DHEAS	True	0 – 10000
Units	Menu	- mcg/ml - umol/L	Serum DHEAS	True	
Urinary free catecholamine excretion	Menu	- Suppressed - Increased - Normal - Not Done		True	
Urinary metanephrine excretion	Menu	- Suppressed - Increased - Normal - Not Done		True	
Plasma metanephrines	Menu	- Suppressed - Increased - Normal - Not Done		True	
Associated malignancy	Menu	- Yes - No - Unknown		True	
Specific	Text		Associated malignancy	True	

malignancies					
Year of diagnosis (yyyy)	Number		Associated malignancy	True	1900 onwards
Tumor Size (mm)	Number			True	3 – 250



## Biomaterial

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Biomaterial Date	Date			False	
Associated Study	Menu	<ul style="list-style-type: none"> <li>- ENS@T Biobank</li> <li>- PMT</li> <li>- ADIUVO</li> <li>- EURINE-ACT</li> <li>- CHIRACIC</li> <li>- German Conn Registry</li> <li>- German Cushing Registry</li> <li>- No biomaterial available</li> </ul>		True	
Associated Study (Phase/Visit)	Menu (dynamic)	[Menu options dependent on selection – the options outline the phase/visit number depending on what the study requirements are]	Associated Study	True	
Tumor Tissue (Frozen)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Following ENSAT SOP	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> <li>- Unknown</li> </ul>	Tumor Tissue (Frozen)	True	
Tumor Tissue (Paraffin)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Tumor Tissue (DNA)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	

Leukocyte DNA	Menu	- Yes - No		True	
EDTA Plasma	Menu	- Yes - No		True	
Heparin Plasma	Menu	- Yes - No		True	
Serum	Menu	- Yes - No		True	
24h Urine	Menu	- Yes - No		True	
24h Urine Volume (ml)	Text		24h Urine	True	
Spot Urine	Menu	- Yes - No		True	
Normal Tissue (Frozen)	Menu	- Yes - No		True	
Specific Tissue (Frozen)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (Frozen)	True	
Normal Tissue (Paraffin)	Menu	- Yes - No		True	
Specific Tissue (Paraffin)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal)	Normal Tissue (Paraffin)	True	

		- Fat (Subcutaneous) - Others			
Normal Tissue (DNA)	Menu	- Yes - No		True	
Specific Tissue (DNA)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (DNA)	True	
Freezer information	Text			True	
Whole blood	Menu	- Yes - No		True	
Blood clot	Menu	- Yes - No		True	

## Follow-Up

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Follow-Up Date	Date			False	
Alive	Menu	- Yes - No		True	
Death related to adrenal tumor	Menu	- Yes - No - Unknown	Alive	True	
Date of death	Date		Alive	True	
Imaging	Menu	- Yes - No		True	
Imaging type	Menu	- CT - MRI - Ultrasound - FDG-PET	Imaging	True	
Max. tumor (mm)	Number		Imaging	True	0 – 10000
Changes in hormone secretion	Menu	- Yes - No		True	
Serum cortisol after 1mg Dex overnight	Menu	- Suppressed - Not Suppressed - Not Done		True	
Cortisol value	Number		Serum cortisol after 1mg Dex overnight	True	0 – 10000
Cortisol units	Menu	- mcg/dl - nmol/l	Serum cortisol after 1mg Dex overnight	True	
Baseline plasma ACTH	Menu	- Suppressed - Increased - Normal - Not Done		True	
Urinary free cortisol	Menu	- Suppressed - Increased		True	

		- Normal - Not Done			
Random plasma renin activity	Menu	- Suppressed - Increased - Normal - Not Done		True	
Random plasma renin concentration	Menu	- Suppressed - Increased - Normal - Not Done		True	
Random serum aldosterone	Menu	- Suppressed - Increased - Normal - Not Done		True	
Serum 17-Hydroxyprogesterone	Menu	- Suppressed - Increased - Normal - Not Done		True	
Serum DHEAS	Menu	- Suppressed - Increased - Normal - Not Done		True	
Urinary free catecholamine excretion	Menu	- Suppressed - Increased - Normal - Not Done		True	
Urinary metanephrine excretion	Menu	- Suppressed - Increased - Normal - Not Done		True	
Plasma metanephrines	Menu	- Suppressed - Increased - Normal		True	

		- Not Done			
Further plans for follow-up	Menu	- Discharged - Surgery - Further Monitoring		True	
Midnight salivary cortisol	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Midnight salivary cortisol	True	0 – 10000
Units	Menu	- ng/ml - mcg/l - nmol/L	Midnight salivary cortisol	True	
Midnight serum cortisol	Menu	- Suppressed - Increased - Normal - Not Done		True	
Specific value	Number		Midnight serum cortisol	True	0 – 10000
Units	Menu	- mcg/dl - nmol/l	Midnight serum cortisol	True	

## Imaging

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Imaging Date	Date			False	
Tumor sides	Menu	- Right Adrenal - Left Adrenal - Both Adrenals		True	
Right adrenal - max tumor diameter (mm)	Number		Tumor sides	True	0 – 400
Left adrenal - max tumor diameter (mm)	Number		Tumor sides	True	0 – 400
CT data available	Menu	- Yes - No		True	
CT: pre-contrast tumor density	Menu	- < 10 - 10-20 - > 20 - Not done	CT data available	True	
Exact HU value	Number		CT: pre-contrast tumor density	True	-100 – 100
Delayed contrast washout determined	Menu	- Yes - No	CT data available	True	
Absolute contrast washout % value at 1-15 min (please type -1%)	Number		Delayed contrast washout determined	True	0 – 100
Relative contrast washout % value at 1-15 min (please type -1%)	Number		Delayed contrast washout determined	True	0 – 100

Imaging suggestive of extra-adrenal malignancy	Menu	- Yes - No		True	
Studies other than CT performed	Menu	- Yes - No		True	
MRI chemical shift analysis performed	Menu	- Yes - No	Studies other than CT performed	True	
Drop of intensity signal between in- and out-of-phase imaging by more than 3%	Menu	- Yes - No	MRI chemical shift analysis performed	True	
FDG-PET: significant uptake in adrenal tumor	Menu	- Yes - No	Studies other than CT performed	True	
Comments	Text			True	

## Metabolomics

Table can be filled out multiple times per patient

Table is specific to the EURINE-ACT study

Name	Type	Menu options	Parent parameter	Optional	Comments
Comment	Text			True	
Metabolomics Date	Date			False	



## Pathology

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Pathologist Name	Text			True	
Pathologist Location	Text			True	
Pathology Diagnosis	Menu	<ul style="list-style-type: none"> <li>- Adrenocortical Adenoma</li> <li>- Adrenomyelolipoma</li> <li>- Adrenal Ganglioneuroma</li> <li>- Adrenal Haemangioma</li> <li>- Adrenal Cyst</li> <li>- Adrenocortical Oncocytoma</li> <li>- Indeterminate</li> <li>- Metastasis</li> <li>- Lymphoma</li> <li>- Pheochromocytoma</li> <li>- Adrenocortical Carcinoma</li> <li>- Other</li> <li>- Adrenal Hyperplasia</li> </ul>		True	
Number of mitoses (exact count per 5 HPF)	Number			True	0 – 10000
ki67 (in %/5 HPF)	Number			True	0 – 100
Weiss Score	Text			True	

	(generated)				
Nuclear Atypia	Menu	- Yes - No - Not Available		True	
Atypical Mitosis	Menu	- Yes - No - Not Available		True	
Spongicytic Tumor Cells	Menu	- Yes - No - Not Available		True	
Diffuse Architecture	Menu	- Yes - No - Not Available		True	
Venous Invasion	Menu	- Yes - No - Not Available		True	
Sinus Invasion	Menu	- Yes - No - Not Available		True	
Capsular Invasion	Menu	- Yes - No - Not Available		True	
Necrosis	Menu	- Yes - No - Not Available		True	
Number of Mitoses (> 5/5 HPF)	Menu	- Yes - No - Not Available		True	

## Surgery

Table can be filled out multiple times per patient

<b>Name</b>	<b>Type</b>	<b>Menu options</b>	<b>Parent parameter</b>	<b>Optional</b>	<b>Comments</b>
Surgery Date	Date			False	
Surgical Approach	Menu	- Open Surgery - Minimal Invasive		True	

## Aldosterone-Producing Adenomas (APA)

### Patient History

Table is filled out once per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Year of diagnosis of PAL	Text			True	
Hypertension at presentation	Menu	- Yes - No		True	
Year of diagnosis of hypertension	Text		Hypertension at presentation	True	
Number of first degree relatives with hypertension	Number			True	0 – 20
Number of first degree relatives with PAL	Number			True	0 – 20
Documented genetic disease	Menu	- None - FH1 - FH2 - FH3		True	
Lowest kalemia (mmol/l)	Number			True	0 – 10000
Comment	Text			True	

## Biochemical Assessment

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Assessment Date	Date			False	
Spironolactone or eplerenone in last 4 wks	Menu	- Yes - No - Unknown		True	
Other diuretic in the last week	Menu	- Yes - No - Unknown		True	
Beta-blocker in the last week	Menu	- Yes - No - Unknown		True	
ACE inhibitor in the last week	Menu	- Yes - No - Unknown		True	
Ang II receptor antagonist in the last week	Menu	- Yes - No - Unknown		True	
Centrally acting anti-HT in the last week	Menu	- Yes - No - Unknown		True	
Calcium channel antagonist in the last week	Menu	- Yes - No - Unknown		True	
Alpha blocker in the last week	Menu	- Yes - No - Unknown		True	
Potassium supplementation in the last week	Menu	- Yes - No - Unknown		True	

Serum potassium (mmol/l)	Number			True	0 – 10000
Serum sodium (mmol/l)	Number			True	0 – 10000
Plasma creatinine (Åµmol/l)	Number			True	0 – 10000
Supine plasma renin activity (PRA) (ng/ml.h)	Number			True	0 – 10000
Sitting or standing PRA (ng/ml.h)	Number			True	0 – 10000
Supine active renin concentration (ARC) (ng/l)	Number			True	0 – 10000
Sitting or standing ARC (ng/l)	Number			True	0 – 10000
Standing aldosterone concentration (ng/L)	Number			True	0 – 10000
Sitting or supine aldosterone concentration (ng/L)	Number			True	0 – 10000
Urinary aldosterone (Åµg/day)	Number			True	0 – 10000
Urinary tetrahydroaldosterone (Åµg/day)	Number			True	0 – 10000
Post captopril aldosterone	Number			True	0 – 10000

concentration (ng/L)					
Post oral sodium load aldosterone concentration (ng/L)	Number			True	0 – 10000
Post saline infusion aldosterone concentration (ng/L)	Number			True	0 – 10000
Post fludrocorticone aldosterone concentration (ng/L)	Number			True	0 – 10000
Post furosemide aldosterone concentration (ng/L)	Number			True	0 – 10000
Aldosterone concentration, right side (ng/L)	Number			True	0 – 10000
Cortisol concentration, right side (Âµg/L)	Number			True	0 – 10000
Aldosterone concentration, left side (ng/L)	Number			True	0 – 10000
Cortisol concentration, left side (Âµg/L)	Number			True	0 – 10000
Aldosterone	Number			True	0 – 10000

concentration, inferior vena cava (ng/L)					
Cortisol concentration, inferior vena cava (Åµg/L)	Number			True	0 – 10000
Successful bilateral adrenal vein sampling	Menu			True	
Stimulation during AVS	Menu			True	
Comment	Text			True	



## Biomaterial

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Biomaterial Date	Date			False	
Associated Study	Menu	<ul style="list-style-type: none"> <li>- ENS@T Biobank</li> <li>- PMT</li> <li>- ADIUVO</li> <li>- EURINE-ACT</li> <li>- CHIRACIC</li> <li>- German Conn Registry</li> <li>- German Cushing Registry</li> <li>- No biomaterial available</li> </ul>		True	
Associated Study (Phase/Visit)	Menu	[Menu options dependent on selection – the options outline the phase/visit number depending on what the study requirements are]	Associated Study	True	
Tumor Tissue (Frozen)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Following ENSAT SOP	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> <li>- Unknown</li> </ul>	Tumor Tissue (Frozen)	True	
Tumor Tissue (Paraffin)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	
Tumor Tissue (DNA)	Menu	<ul style="list-style-type: none"> <li>- Yes</li> <li>- No</li> </ul>		True	

Leukocyte DNA	Menu	- Yes - No		True	
EDTA Plasma	Menu	- Yes - No		True	
Heparin Plasma	Menu	- Yes - No		True	
Serum	Menu	- Yes - No		True	
24h Urine	Menu	- Yes - No		True	
24h Urine Volume (ml)	Text		24h Urine	True	
Spot Urine	Menu	- Yes - No		True	
Normal Tissue (Frozen)	Menu	- Yes - No		True	
Specific Tissue (Frozen)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (Frozen)	True	
Normal Tissue (Paraffin)	Menu	- Yes - No		True	
Specific Tissue (Paraffin)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal)	Normal Tissue (Paraffin)	True	

		- Fat (Subcutaneous) - Others			
Normal Tissue (DNA)	Menu	- Yes - No		True	
Specific Tissue (DNA)	Menu	- Adjacent Adrenal - Kidney - Liver - Lung - Lymph Node - Fat (Periadrenal) - Fat (Subcutaneous) - Others	Normal Tissue (DNA)	True	
Freezer information	Text			True	
Whole blood	Menu	- Yes - No		True	
Blood clot	Menu	- Yes - No		True	

## Cardio

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Event Date	Date			False	
Echocardiography	Menu	- Yes - No		True	
Echocardiography (specific)	Menu	- Normal - Left ventricular hypertrophy	Echocardiography	True	
Electrocardiogram	Menu	- Yes - No		True	
Electrocardiogram (specific)	Menu	- Atrial fibrillation - Left ventricular hypertrophy - Normal - Other	Electrocardiogram	True	
Electrocardiogram (other)	Text		Electrocardiogram	True	

## Clinical Assessment

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Assessment Date	Date			False	
Height (cm)	Number			True	100 – 200
Weight (kg)	Number			True	30 – 250
Systolic blood pressure (mmHg)	Number			True	90 – 200
Diastolic blood pressure (mmHg)	Number			True	40 – 150

Heart rate (bpm)	Number			True	40 – 200
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## Complication

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Event Date	Date			False	
Complication	Menu	<ul style="list-style-type: none"> <li>- Stroke</li> <li>- Cerebrovascular stenosis</li> <li>- Angina pectoris</li> <li>- Myocardial infarction</li> <li>- Chronic heart failure</li> <li>- Atrial fibrillation</li> <li>- Coronary angioplasty</li> <li>- Hypertensive emergency</li> <li>- Other atrial dysrhythmia</li> <li>- Other ventricular dysrhythmia</li> <li>- Coronary artery bypass</li> <li>- Retinopathy</li> <li>- Peripheral arterial occlusive disease</li> <li>- Diabetic foot</li> </ul>		True	

		syndrome - Chronic renal failure - Deep vein thrombosis - Osteoporosis - Neoplasma - Sleep apnea - Hypokalemia - Hyperkalemia - Spine fracture - Radial fracture - Hip fracture			
Diabetes	Menu	- Yes - No		True	
Hypercholesteremia	Menu	- Yes - No		True	
Smoking status	Menu	- Yes - No - Former smoker		True	
Comment	Text			True	

## Follow-Up

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Follow-up Date	Date			False	
Alive	Menu	- Yes - No - Unknown		True	
Cause of death	Text		Alive	True	
Weight	Number			True	30 – 250
Systolic BP	Number			True	90 – 200
Diastolic BP	Number			True	40 – 150
Spironolactone or eplerenone in last 4 weeks	Menu	- Yes - No - Unknown		True	
Other diuretic in the last week	Menu	- Yes - No - Unknown		True	
Beta-blocker in the last week	Menu	- Yes - No - Unknown		True	
ACE inhibitor in the last week	Menu	- Yes - No - Unknown		True	
Ang II receptor antagonist in the last week	Menu	- Yes - No - Unknown		True	
Centrally acting anti-HT in the last week	Menu	- Yes - No - Unknown		True	
Calcium channel antagonist in the	Menu	- Yes - No		True	

last week		- Unknown			
Alpha blocker in the last week	Menu	- Yes - No - Unknown		True	
Potassium supplementation in the last week	Menu	- Yes - No - Unknown		True	
Evaluation of BP outcomes	Menu	- Yes - No - Unknown		True	
Serum potassium (mmol/l)	Number			True	0 – 10000
Serum sodium (mmol/l)	Number			True	0 – 10000
Plasma creatinine (Åµmol/l)	Number			True	0 – 10000
Standing plasma renin activity (PRA) (ng/ml.h)	Number			True	0 – 10000
Sitting or supine PRA (ng/ml.h)	Number			True	0 – 10000
Standing active renin concentration (ARC) (ng/l)	Number			True	0 – 10000
Sitting or supine ARC (ng/l)	Number			True	0 – 10000
Standing aldosterone concentration (ng/L)	Number			True	0 – 10000
Sitting or supine aldosterone	Number			True	0 – 10000



concentration (ng/L)					
Urinary aldosterone (Åµg/day)	Number			True	0 – 10000
Urinary tetrahydroaldosterone (Åµg/day)	Number			True	0 – 10000
Comment	Text			True	
Complications	Menu	<ul style="list-style-type: none"> <li>- Stroke</li> <li>- Cerebrovascular stenosis</li> <li>- Angina pectoris</li> <li>- Myocardial infarction</li> <li>- Chronic heart failure</li> <li>- Atrial fibrillation</li> <li>- Coronary angioplasty</li> <li>- Hypertensive emergency</li> <li>- Other atrial dysrhythmia</li> <li>- Other ventricular dysrhythmia</li> <li>- Coronary artery bypass</li> <li>- Retinopathy</li> <li>- Peripheral arterial occlusive disease</li> <li>- Diabetic foot syndrome</li> </ul>		True	

		<ul style="list-style-type: none"><li>- Chronic renal failure</li><li>- Deep vein thrombosis</li><li>- Osteoporosis</li><li>- Neoplasma</li><li>- Sleep apnea</li><li>- Hypokalemia</li><li>- Hyperkalemia</li><li>- Spine fracture</li><li>- Radial fracture</li><li>- Hip fracture</li></ul>			
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## Genetics

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Genetics Date	Date			True	
Nodules	Menu	- One - Multiple - None - Unknown		True	
APA cell type analyzed	Menu	- Yes - No - Unknown		True	
Zona fasciculata like cells	Menu	- Yes - No - Unknown	APA cell type analysed	True	
Zona glomerulosa like cells	Menu	- Yes - No - Unknown	APA cell type analysed	True	
Mixed phenotype	Menu	- Yes - No - Unknown	APA cell type analyzed	True	
CYP11B2 IHC or ISH performed	Menu	- Yes - No		True	
Number of nodules with positive staining	Number		CYP11B2 IHC or ISH performed	True	0 – 20
<b>KCNJ5</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing	Testing performed	True	

		and search for large deletions - Not documented			
Mutation detected	Menu	- Yes - No	Testing performed	True	
Nomenclature	Text		Mutation detected	True	
<b>ATP1A1</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented	Testing performed	True	
Mutation detected	Menu	- Yes - No	Testing performed	True	
Nomenclature	Text		Mutation detected	True	
<b>ATP2B3</b>					
Testing performed	Menu	- Yes - No		True	
Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented	Testing performed	True	
Mutation detected	Menu	- Yes - No	Testing performed	True	
Nomenclature	Text		Mutation detected	True	
<b>CACNA1D</b>					
Testing performed	Menu	- Yes - No		True	

Method	Menu	- Direct sequencing only - Direct sequencing and search for large deletions - Not documented	Testing performed	True	
Mutation detected	Menu	- Yes - No	Testing performed	True	
Nomenclature	Text		Mutation detected	True	

## Imaging

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Imaging Date	Date			False	
Adrenal morphology	Menu	- Normal - Hyperplasia - Tumor		True	
Tumor sites	Menu	- Right adrenal - Left adrenal - Both adrenals - No tumor		True	
Max tumor diameter by CT - right (mm)	Number		Tumor sites	True	0 – 400
Max tumor diameter by MR - right (mm)	Number		Tumor sites	True	0 – 400
Max tumor diameter by CT - left (mm)	Number		Tumor sites	True	0 – 400
Max tumor diameter by MR - left (mm)	Number		Tumor sites	True	0 – 400
Scintigraphy	Menu	- Not available - Tumor seen - Tumor not seen		True	

## Surgery

Table can be filled out multiple times per patient

Name	Type	Menu options	Parent parameter	Optional	Comments
Intervention Date	Date			False	
Operated tumor sites	Menu	- Right Adrenal - Left Adrenal - Both Adrenals		True	
Procedure	Menu	- Open Surgery - Minimal Invasive		True	
Adrenal sparing	Menu	- Yes - No - Unknown		True	
Max tumor diameter - right (mm)	Number		Adrenal sparing	True	0 – 400
Max tumor diameter - left (mm)	Number		Adrenal sparing	True	0 – 400
Tumor weight (g)	Number			True	0 – 10000
Comment	Text			True	

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30<sup>th</sup> August 2015*