ERN eUROGEN registry
Report on Expertise Area 3.3

INTRODUCTION

This report entails the first ERN eUROGEN registry retrospective analysis of the Expertise Area 3.3: Adrenal tumors. This report aims to give insight in the current clinical practices using the Clinical Practice Snapshot data about the patients entered.

The Clinical Practice Snapshots should only contain data about the first year of treatment. However, sometimes information outside the 1-year window was added, and at other times, the dates are unknown. If this occurs, we interpreted this variable for this patient as 'No', 'Not performed', or 'Unknown'. An example: A patient had the first visit to the hospital (start treatment) at 23-01-2021, and the adrenal tumor surgery took place at 08-02-2022 (more than a year after the start of treatment). This surgery should not be entered in the Clinical Practice Snapshot of the ERN eUROGEN registry. If this information was there, we interpreted it as 'No surgery'. If it was indicated that the surgery took place but the date is unknown, we interpreted the variable as 'Unknown', because we don't know if this surgery took place within a year from the start of treatment.

Furthermore, as retrospective data entry is still ongoing for the majority of HCPs, not all HCPs have reached the minimum of 30 retrospective patients per Expertise Area, yet. Therefore, the results cannot be equally compared between HCPs, but the analyses give an indication of trends.

Please keep in mind these reports are meant to inform you about some general treatment characteristics using the Clinical Practice Snapshot data, not to perform in-depth statistical analysis. If you have any suggestions about information to add to these reports, or to delete because the information is not relevant, please let us know and it will be taken into account for the next report.
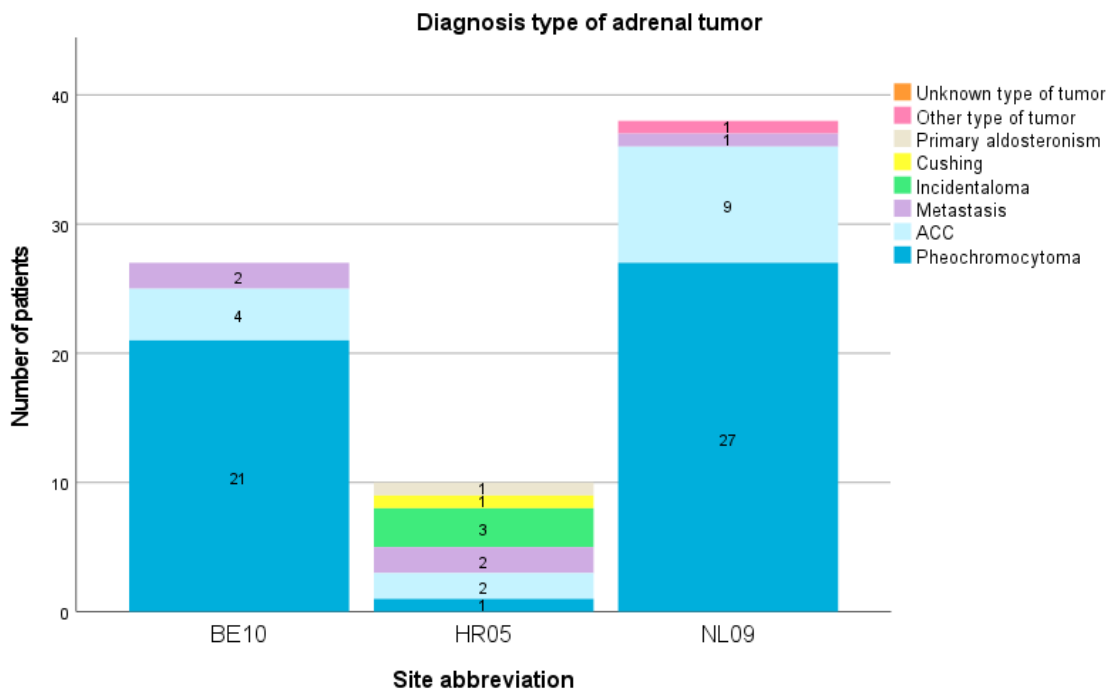
Descriptive statistics

The table below provides an overview of the descriptive statistics for patients from Expertise Area 3.3, adrenal tumors. Corresponding figures were made of the variables, and they are displayed on the next pages.

	Total N=75	Netherlands NL09 (N=38)	Belgium BE10 (N=27)	Croatia HR05 (N=10)
Diagnosis				
Primary aldosteronism; N (%)	1 (1.3%)	-	-	1 (10.0%)
Cushing; N (%)	1 (1.3%)	-	-	1 (10.0%)
ACC; N (%)	15 (20.0%)	9 (23.7%)	4 (14.8%)	2 (20.0%)
Metastasis; N (%)	5 (6.7%)	1 (2.6%)	2 (7.4%)	2 (20.0%)
Pheochromocytoma; N (%)	49 (65.3%)	27 (71.1%)	21 (77.8%)	1 (10.0%)
Incidentaloma; N (%)	3 (4%)	-	-	3 (30.0%)
Other; N (%)	1 (1.3%)	1 (2.6%)	-	-
Unknown, N (%)	-	-	-	-
Preoperative care				
Discussed in MDT, N (%)	45 (60.0%)	35 (92.1%)	2 (7.4%)	8 (80.0%)
Preoperative imaging				
MRI; N (%)	25 (33.3%)	11 (28.9%)	13 (48.1%)	1 (10.0%)
CT; N (%)	68 (90.7%)	35 (92.1%)	25 (92.6%)	8 (80.0%)
PET-CT; N (%)	38 (50.7%)	27 (71.1%)	11 (40.7%)	-
Other; N (%)	30 (40.0%)	15 (39.5%)	15 (55.6%0	-
Unknown; N (%	1 (1.3%)	-	-	1 (10.0%)
No imaging; N (%)	-	-	-	-
Surgery				
Surgery performed; N (%)	71 (94.7%)	37 (97.4%)	27 (100%)	7 (70.0%)
No surgery; N (%)	2 (2.7%)	-	-	2 (20.0%)
Unknown; N (%)	2 (2.7%)	1 (2.6%)	-	1 (10.0%)
Type of surgery				
Laparoscopy; N (%)	28 (39.4%)	9 (23.7%)	15 (55.5%)	4 (57.1%)
Retrop. scopy; N (%)	13 (18.3%)	12 (31.6%)	1 (3.7%)	-
Robot-assisted; N (%)	1 (1.4%)	1 (2.6%)	-	-
Open; N (%)	24 (33.8%)	14 (37.8%)	9 (33.3%)	1 (14.3%)
Other; N (%)	3 (4.2%)	1 (2.6%)	2 (7.4%)	-
Unknown; N (%)	2 (2.8%)	-	-	2 (28.6%)
Lymph node dissection				
Yes, N (%)	5 (7.0%)	2 (5.4%)	3 (11.1%)	-
No, N (%)	64 (90.1)	34 (91.9%)	24 (88.9%)	6 (85.7%)
Unknown, N (%)	2 (2.8%)	1 (2.7%)	-	1 (14.3%)
Not malignant, N (%)	-	-	-	-
Status after surgery				
Horm. cured: N (%)	8 (11.3%)	6 (15.8%)	-	2 (28.6%)
Neg. margins; N (%)	53 (74.6%)	27 (73.0%)	26 (96.3%)	-
Not cured; N (%)	3 (4.2%)	2 (5.3%)	-	1 (14.3%)
Other; N (%)	4 (5.6%)	1 (2.6%)	1 (3.7%)	2 (28.6%)
Unknown; N (%)	3 (4.2%)	1 (2.6%)	-	2 (28.6%)
Complications after surgery				
Yes; N (%)	16 (22.5%)	9 (24.3%)%	7 (25.9%)	-
No; N (%)	55 (77.5%)	28 (75.7%)	20 (74.1%)	7 (100%)
Unknown; N (%)	-	-	-	-

MDT: Multidisciplinary Team, Surgery bef. first contact: surgery before first contact, Retrop. scopy: retroperitoneoscopy, Horm. cured: hormonally cured, Neg. margins: negative resection margins.
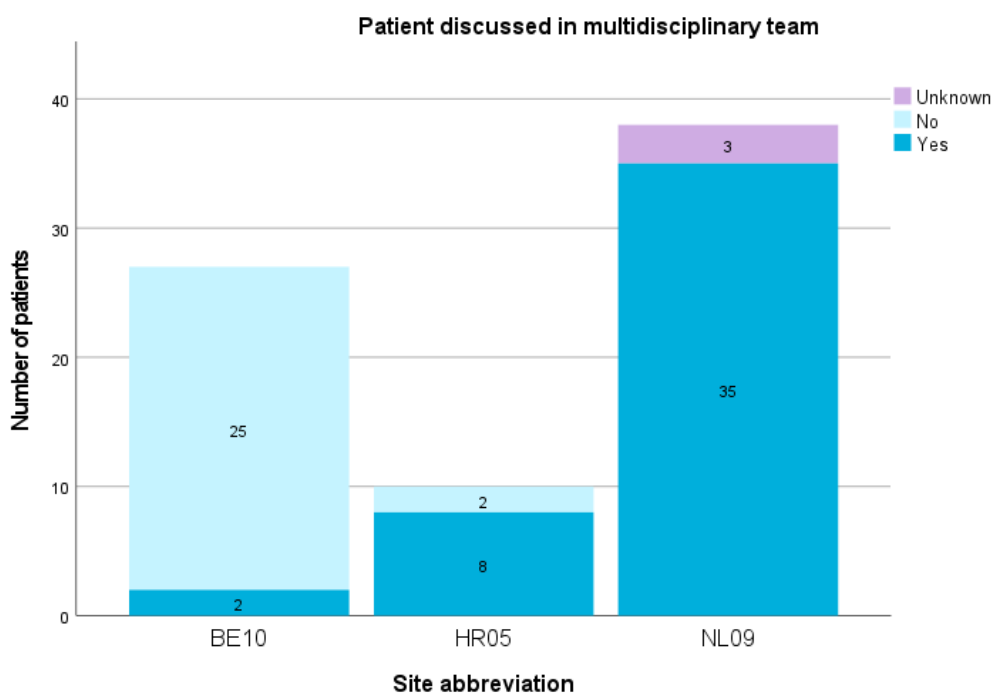
Diagnosis

The majority of patients was diagnosed with pheochromocytoma, followed by Adrenal Cell Carcinoma (ACC).

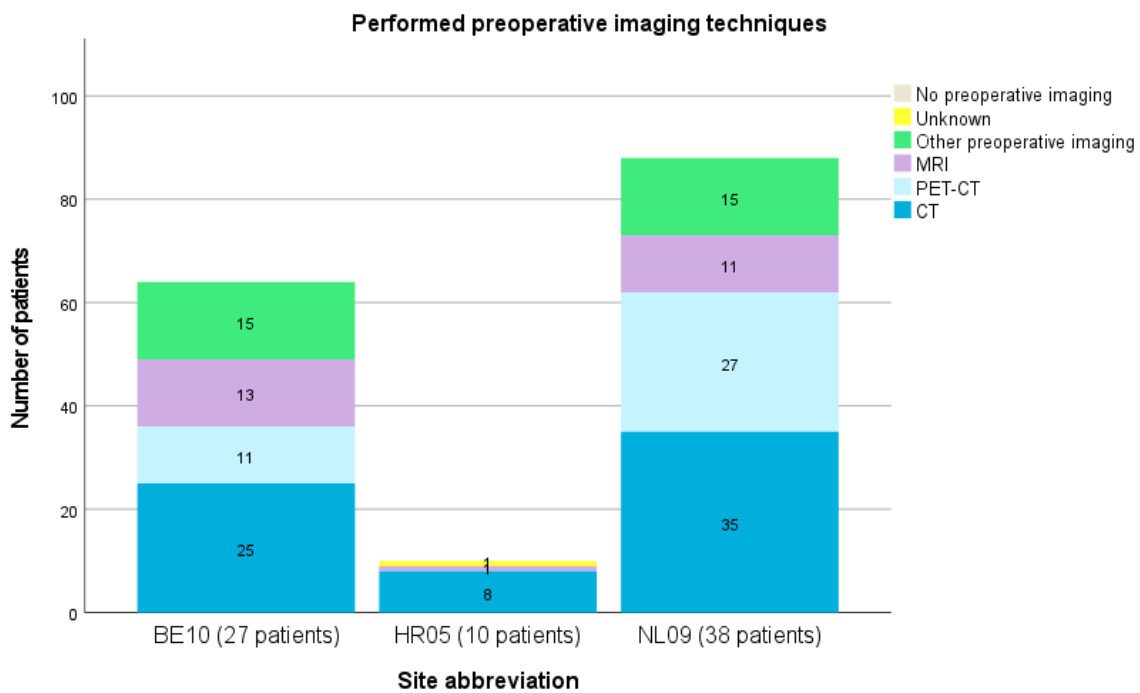Diagnosis type of adrenal tumor

Preoperative care

Multidisciplinary team (MDT)

Most patients for NL09 and HR05 were discussed in an MDT. On the other hand, most patients from BE10 were not discussed in an MDT.
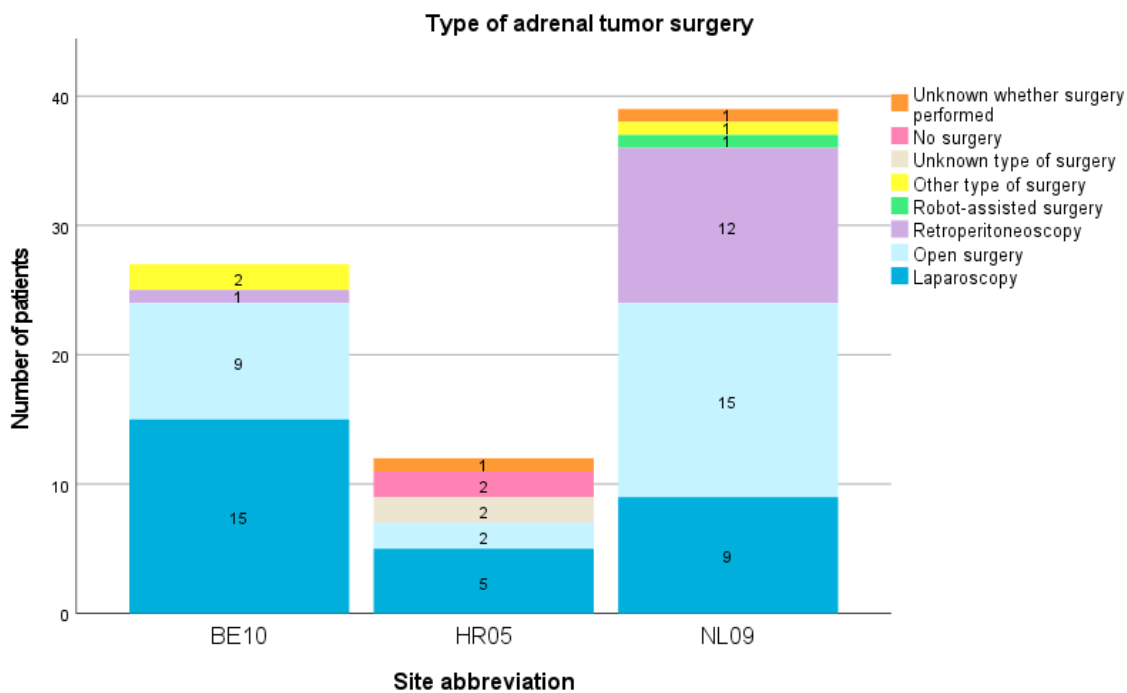

Patient discussed in multidisciplinary team

Preoperative imaging techniques

For the BE10 and NL09 patients, multiple preoperative imaging techniques were performed. The most performed technique was the CT scan.
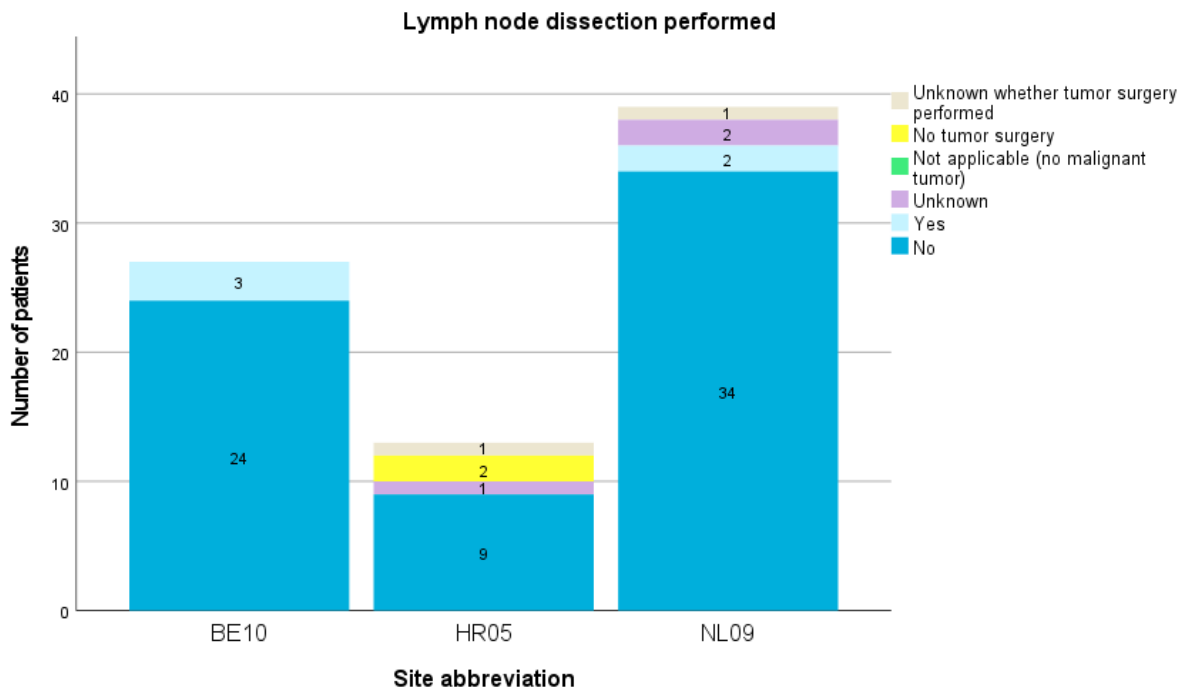

Performed preoperative imaging techniques

Surgery

Type of adrenal tumor surgery

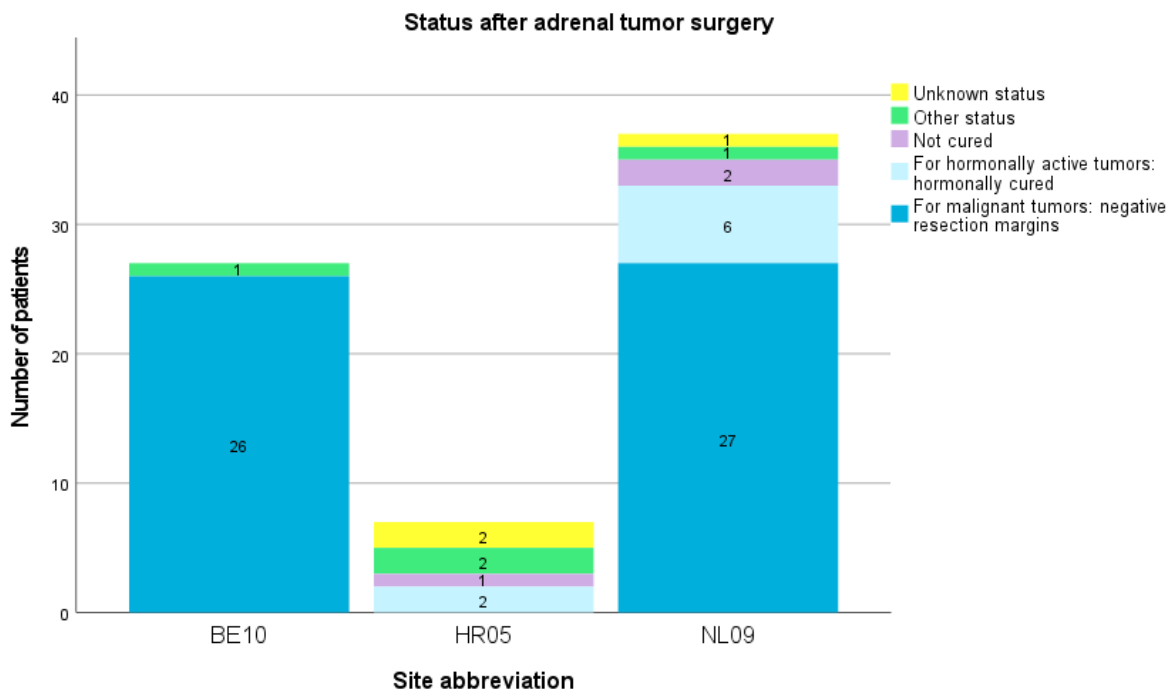Most patients of BE10 and HR05 had laparoscopy, where NL09 patients mostly had open surgery.

Type of adrenal tumor surgery

Lymph node dissection

Overall, lymph node dissection only took place for a few patients.
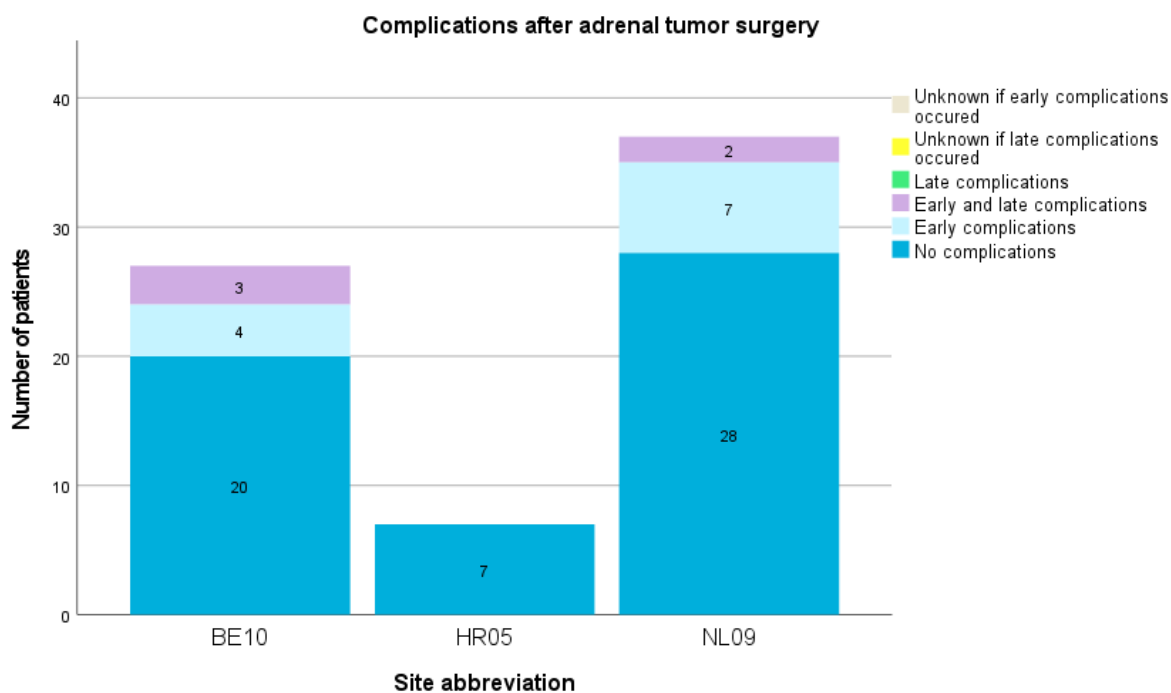
Lymph node dissection performed

Status after adrenal tumor surgery

After the surgery, most patients were hormonally cured or the resection margins were negative. Few tumors were not cured.

Status after adrenal tumor surgery

Complications after surgery

Most patients had no complications. If any complications occurred, it concerned early complications.

Complications after adrenal tumor surgery

ERN eUROGEN is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are co-funded by the European Commission. For more information about the ERNs and the EU health strategy, please visit http://ec.europa.eu/health/ern