

ERN eUROGEN registry

Report on Expertise Area 3.3

INTRODUCTION

This report entails the 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. 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. Only HCPs which entered more than 5 patients for 3.3 Adrenal tumor were included in these analyses. As patient numbers are not similar, the results cannot be equally compared between HCPs, but the analyses give an indication of trends.

The Clinical Practice Snapshots should only contain data about the first year of treatment, which starts from the date the patients first visits the ERN eUROGEN HCP for the adrenal tumor. 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 'Not performed'. An example: A patient had the first visit to the hospital (start treatment) at 23-01-2021, and the adrenal surgery took place at 08-02-2022 (more than a year after the start of treatment). This surgery should not have been entered in the Clinical Practice Snapshot of the ERN eUROGEN registry. If this information was there, we interpreted it as 'No adrenal tumor surgery'.

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.

EA 3.3; ADRENAL TUMORS

Descriptive statistics

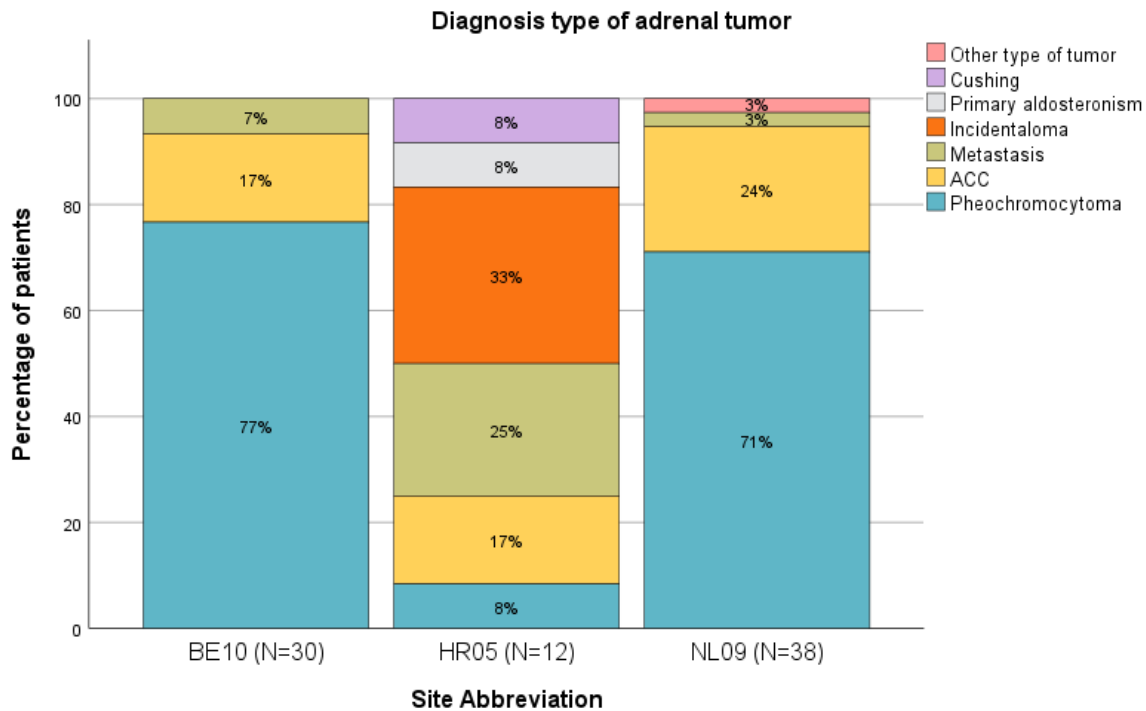
The table below provides an overview of the descriptive statistics for patients from Expertise Area 3.3, adrenal tumors. Corresponding figures were made of the variables, and they are displayed on the next pages.

	Total N=80	Belgium BE10 (N=30)	Croatia HR05 (N=12)	Netherlands NL09 (N=38)
Diagnosis (filled out for all patients)				
Primary aldosteronism; N (%)	1 (1.3%)	-	1 (8.3%)	-
Cushing; N (%)	1 (1.3%)	-	1 (8.3%)	-
ACC; N (%)	16 (20.0%)	5 (16.7%)	2 (16.7%)	9 (23.7%)
Metastasis; N (%)	6 (7.5%)	2 (6.7%)	3 (25.0%)	1 (2.6%)
Pheochromocytoma; N (%)	51 (63.8%)	23 (76.7%)	1 (8.3%)	27 (71.1%)
Incidentaloma; N (%)	4 (5%)	-	4 (33.3%)	-
Other; N (%)	1 (1.3%)	-	-	1 (2.6%)
Preoperative care				
Discussed in MDT, N (%) (filled out for all patients)	46 (57.5%)	2 (6.7%)	9 (75.0%)	35 (92.1%)
Surgery performed in first year of treatment; N (%)	74 (92.5%)	30 (100%)	7 (58.3%)	37 (97.4%)
No surgery; N (%)	5 (6.3%)	-	4 (33.3%)	1 (2.6%)
Unknown if surgery performed; N (%)	1 (1.3%)	-	1 (8.3%)	-
Surgery characteristics (filled out for N=74 (92.5%))				
Preoperative imaging				
MRI; N (%)	25 (33.8%)	15 (50.0%)	-	10 (27.0%)
CT; N (%)	68 (91.9%)	28 (93.3%)	6 (85.7%)	34 (91.9%)
PET-CT; N (%)	38 (51.4%)	11 (36.7%)	-	27 (73.0%)
Other; N (%)	31 (41.9%)	16 (53.3%)	-	15 (40.5%)
Unknown	1 (1.4%)	-	1 (14.3%)	-
Type of surgery				
Laparoscopy; N (%)	29 (39.2%)	16 (53.3%)	4 (57.1%)	9 (24.3%)
Retrop. scopy; N (%)	14 (18.9%)	2 (6.7%)	-	12 (32.4%)
Robot-assisted; N (%)	1 (1.4%)	-	-	1 (2.7%)
Open; N (%)	25 (33.8%)	10 (33.3%)	1 (14.3%)	14 (37.8%)
Other; N (%)	3 (4.1%)	2 (6.7%)	-	1 (2.7%)
Unknown; N (%)	2 (2.7%)	-	2 (28.6%)	-
Lymph node dissection				
Yes, N (%)	5 (6.8%)	3 (10.0%)	-	2 (5.4%)
No, N (%)	67 (90.5%)	27 (90.0%)	6 (85.7%)	34 (91.9%)
Unknown, N (%)	2 (2.7%)	-	1 (14.3%)	1 (2.7%)
Status after surgery				
Horm. cured; N (%)	8 (10.8%)	-	2 (28.6%)	6 (16.2%)
Neg. margins; N (%)	56 (75.7%)	29 (96.7%)	-	27 (73.0%)
Not cured; N (%)	3 (4.1%)	-	1 (14.3%)	2 (5.4%)
Other; N (%)	4 (5.4%)	1 (3.3%)	2 (28.6%)	1 (2.7%)
Unknown; N (%)	3 (4.1%)	-	2 (28.6%)	1 (2.7%)
Complications after surgery				
Yes; N (%)	16 (21.7%)	7 (23.3%)	-	9 (24.3%)
No; N (%)	58 (78.4%)	23 (76.7%)	7 (100%)	28 (75.7%)

MDT: Multidisciplinary Team, Retrop. scopy: retroperitoneoscopy, Horm. cured: hormonally cured, Neg. margins: negative resection margins.

Diagnosis

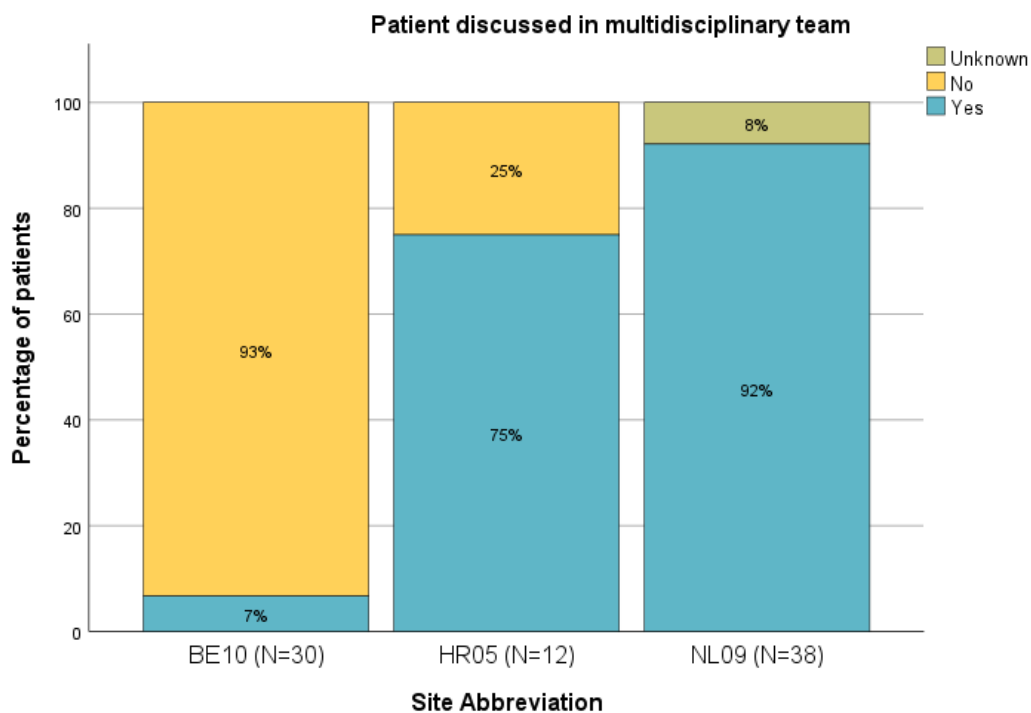
The majority of patients was diagnosed with pheochromocytoma, followed by Adrenal Cell Carcinoma (ACC).



Preoperative care

Multidisciplinary team (MDT)

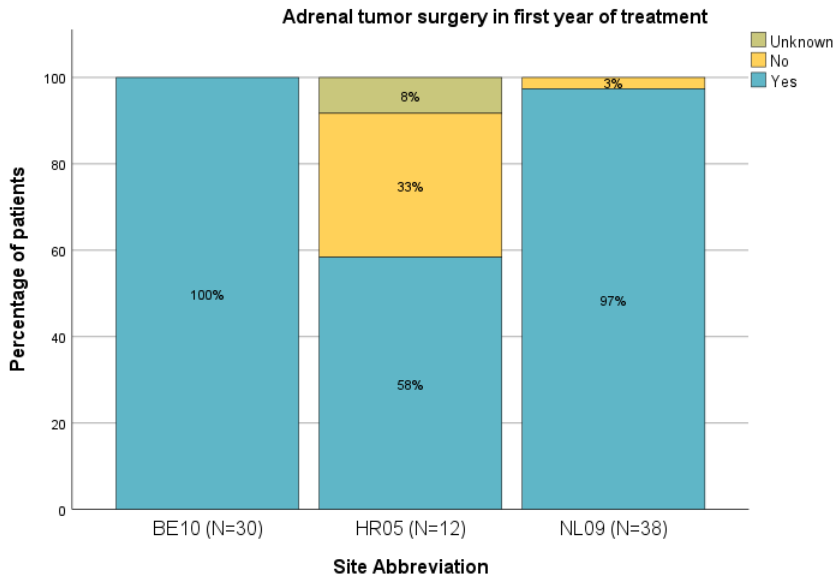
Most patients for NL09 and HR05 were discussed in an MDT. On the other hand, most patients from BE10 were not discussed in an MDT.



Surgery

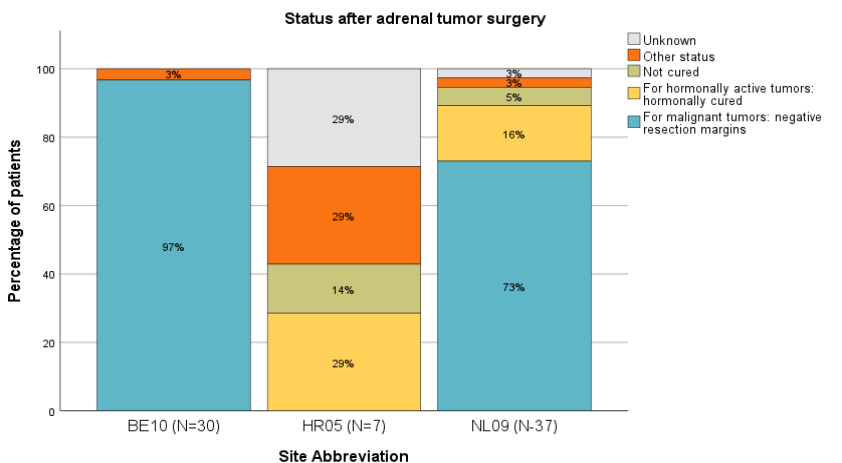
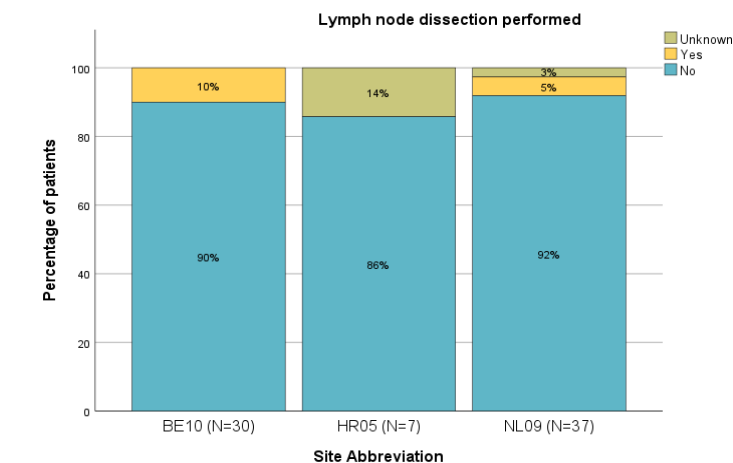
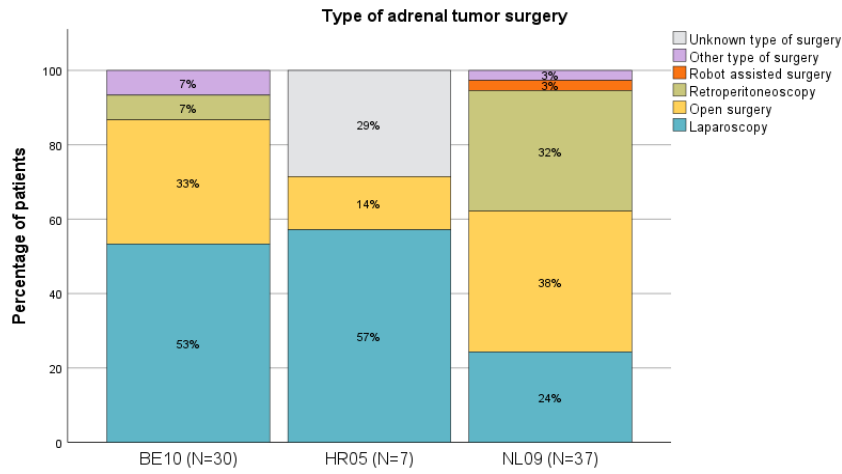
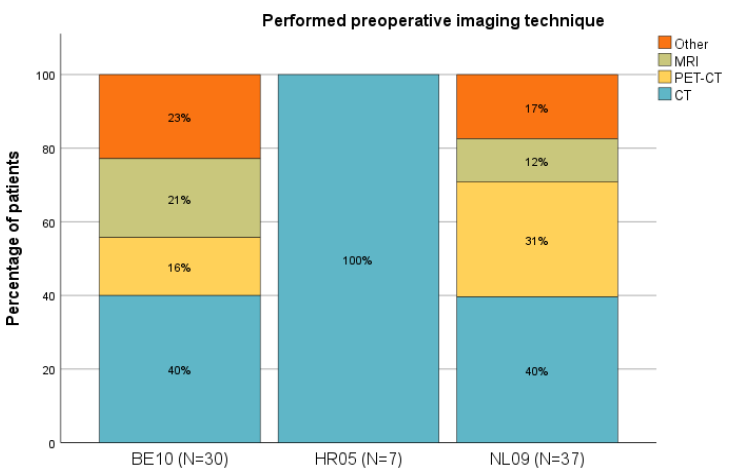
Surgery performed in HCP in the first year of treatment (the year after they first visited the HCP)

Most patients had surgery in their first year of treatment. Some patients had surgery before they visited the HCP, or the surgery took place after the first year of treatment ('No'). 'Unknown' indicates that either the date of the first visit to the HCP or the surgery date was unknown.



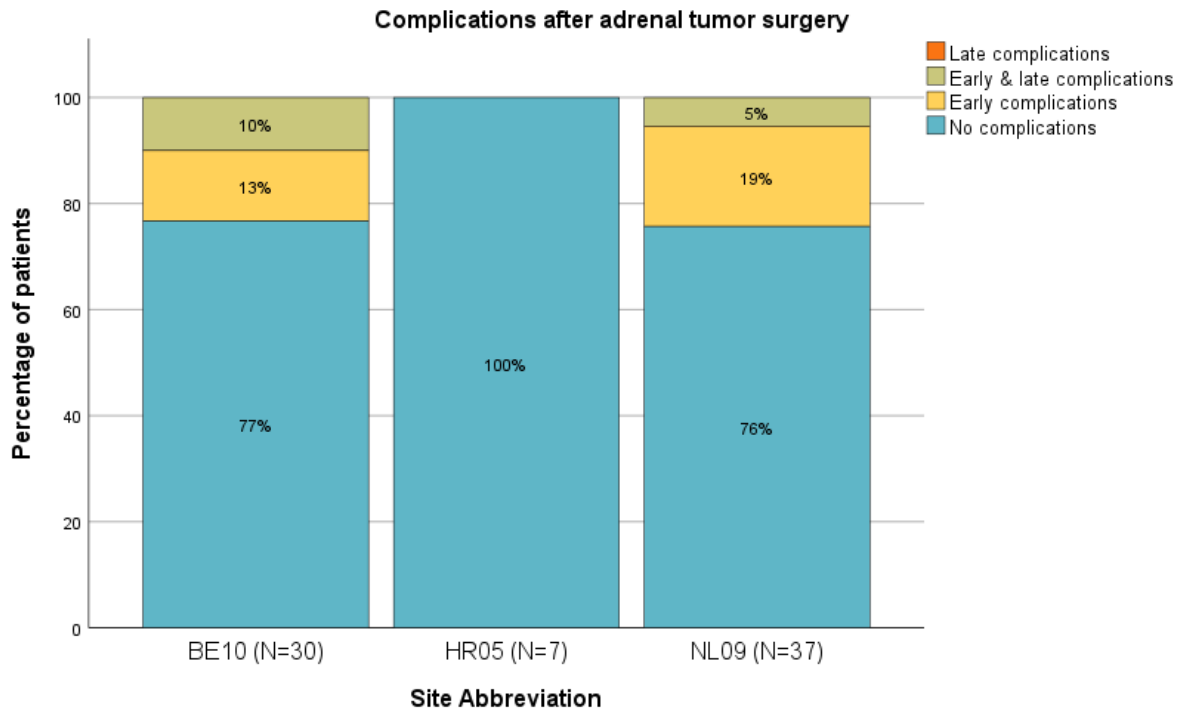
Surgery characteristics

For the BE10 and NL09 patients, multiple preoperative imaging techniques were performed. The most performed technique was the CT scan. The most occurring type of surgery was laparoscopy, followed by open surgery. Overall, lymph node dissection was only performed for a few patients. The surgery resulted in either negative resection margins or a cured status for most patients.



Complications after surgery

Most patients had no complications. If any complications occurred, it concerned early complications for most patients. Some patients experienced both early and late complications.



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