

ERN eUROGEN registry

Report on Expertise Area 3.3

INTRODUCTION

This report entails an analysis of the data on Expertise Area 3.3: Adrenal tumours in the ERN eUROGEN registry. This report aims to give insight in the current clinical practices using the Clinical Practice Snapshot data about the patients entered. Only HCPs that entered more than 5 patients for 3.3 Adrenal tumour 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 tumour. 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, and we interpreted it as 'No adrenal tumour surgery within the first year'.

Please keep in mind that 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 considered for the next report.

EA 3.3; ADRENAL TUMOURS

Descriptive statistics

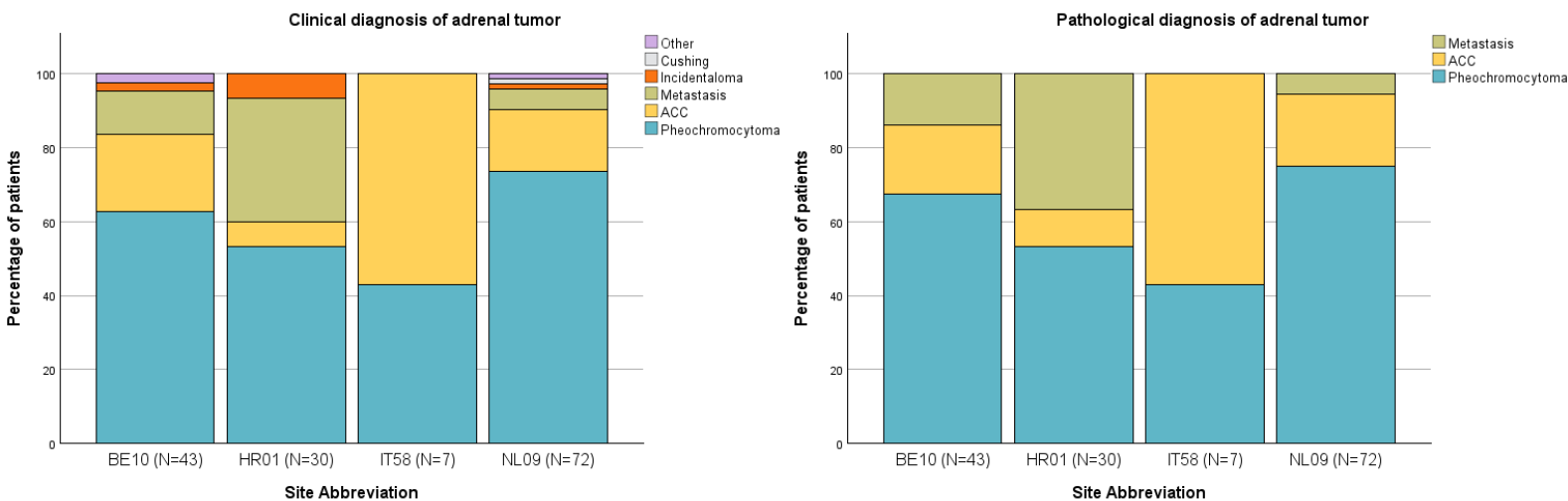
The table below provides an overview of the descriptive statistics for patients from Expertise Area 3.3, adrenal tumours. Corresponding figures were made of the variables, and they are displayed on the next pages.

	Total N=152	Belgium BE10 (N=43)	Croatia HR01 (N=30)	Italy IT58 (N=7)	Netherlands NL09 (N=72)
Diagnosis					
Pathologic diagnosis					
ACC; N (%)	29 (19.1%)	8 (18.6%)	3 (10.0%)	4 (57.1%)	14 (19.4%)
Metastasis; N (%)	21 (13.8%)	6 (14.0%)	11 (36.7%)	-	4 (5.6%)
Pheochromocytoma; N (%)	102 (67.1%)	29 (67.4%)	16 (53.3%)	3 (42.9%)	54 (75.0%)
Primary tumour metastasis					
Melanoma; N (%)	1 (4.8%)	-	1 (9.1%)	-	-
Lung cancer; N (%)	4 (19.0%)	3 (50.0%)	1 (9.1%)	-	-
Renal cancer; N (%)	9 (42.9%)	-	5 (45.5%)	-	4 (100%)
Other; N (%)	6 (28.6%)	3 (50.0%)	3 (27.3%)	-	-
Unknown; N (%)	1 (4.8%)	-	1 (9.1%)	-	-
Preoperative care					
Discussed in Multidisciplinary Team; N (%)	104 (68.4%)	5 (11.6%)	24 (80.0%)	6 (85.7%)	69 (95.8%)
Biopsy performed; N (%)	4 (2.6%)	1 (2.3%)	-	-	3 (4.2%)
Primary surgery					
Surgery performed in first year of treatment; N (%)	150 (98.7%)	43 (100%)	28 (93.3%)	7 (100%)	72 (100%)
No surgery; N (%)	2 (1.3%)	-	2 (6.7%)	-	-
Days between first contact and surgery; (median, range)	56 days (0;352)	37 days (4;259)	65 days (0;309)	20 days (0;88)	84 days (9;352)
Surgery characteristics					
Preoperative imaging					
MRI; N (%)	41 (27.3%)	24 (55.8%)	-	3 (42.9%)	14 (19.4%)
CT; N (%)	135 (90.0%)	35 (81.4%)	28 (100%)	6 (85.7%)	66 (91.7%)
PET-CT; N (%)	74 (49.3%)	18 (41.9%)	1 (3.6%)	2 (28.6%)	53 (73.6%)
Other; N (%)	37 (24.7%)	20 (46.5%)	-	2 (28.6%)	15 (20.8%)
Type of surgery					
Laparoscopy; N (%)	81 (54.0%)	20 (46.5%)	26 (92.9%)	1 (14.3%)	34 (47.2%)
Retroperitoneoscopy; N (%)	24 (16.0%)	8 (18.6%)	-	-	16 (22.2%)
Robot-assisted; N (%)	2 (1.3%)	-	-	-	2 (2.8%)
Open; N (%)	39 (26.0%)	13 (30.2%)	2 (7.1%)	6 (85.7%)	18 (25.0%)
Other; N (%)	4 (2.7%)	2 (4.7%)	-	-	2 (2.8%)
Lymph node dissection					
Yes; N (%)	20 (13.3%)	2 (4.7%)	10 (35.7%)	2 (28.6%)	6 (8.3%)
No; N (%)	126 (84.0%)	41 (95.3%)	18 (64.3%)	3 (42.9%)	64 (88.9%)
Unknown; N (%)	4 (2.7%)	-	-	2 (28.6%)	2 (2.8%)
Status after surgery malignant tumours					
Negative resection margins; N (%)	122 (81.3%)	36 (83.7%)	26 (92.9%)	4 (57.1%)	56 (77.8%)
Positive resection margins; N (%)	-	-	-	-	-
Unclear resection margins; N (%)	7 (4.7%)	4 (9.3%)	-	2 (28.6%)	1 (1.4%)
Not applicable; N (%)	11 (7.3%)	-	2 (7.1%)	1 (14.3%)	8 (11.1%)
Unknown; N (%)	10 (6.7%)	3 (7.0%)	-	-	7 (9.7%)
Status after surgery hormonally active tumours					
Cured; N (%)	95 (63.3%)	28 (65.1%)	14 (50.0%)	5 (71.4%)	48 (66.7%)
Not cured; N (%)	5 (3.3%)	3 (7.0%)	-	1 (14.3%)	1 (1.4%)
Not applicable; N (%)	31 (20.7%)	8 (18.6%)	12 (42.9%)	1 (14.3%)	10 (13.9%)
Unknown; N (%)	19 (12.7%)	4 (9.3%)	2 (7.1%)	-	13 (18.1%)
Complications after surgery					
Yes; N (%)	31 (20.7%)	14 (32.6%)	-	1 (14.3%)	16 (22.2%)
No; N (%)	117 (78.0%)	29 (67.4%)	28 (100%)	6 (85.6%)	54 (75.0%)
Unknown; N (%)	2 (1.3%)	-	-	-	2 (2.8%)

Diagnosis

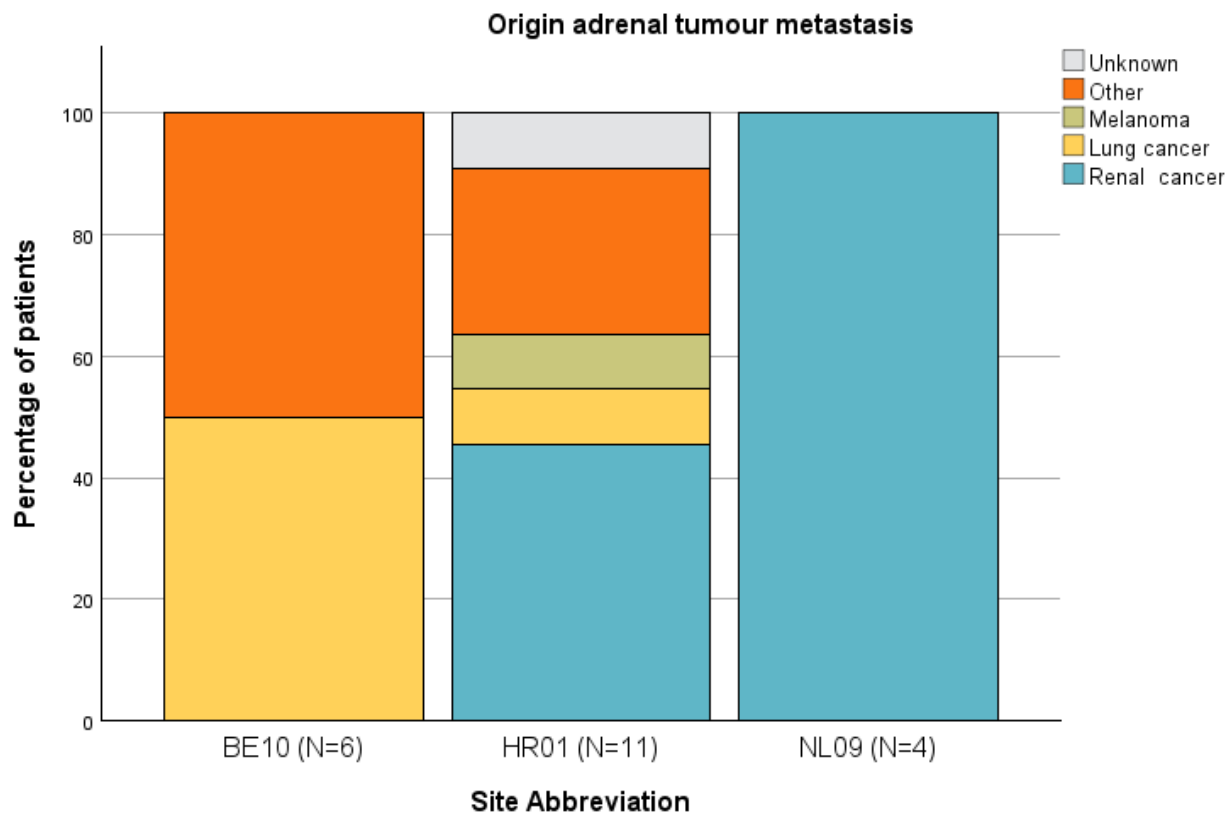
Clinical and pathologic diagnosis

The clinical and pathological diagnosis overlapped for the majority of patients. The majority of patients was diagnosed with pheochromocytoma, followed by Adrenal Cell Carcinoma (ACC).



Origin metastasis

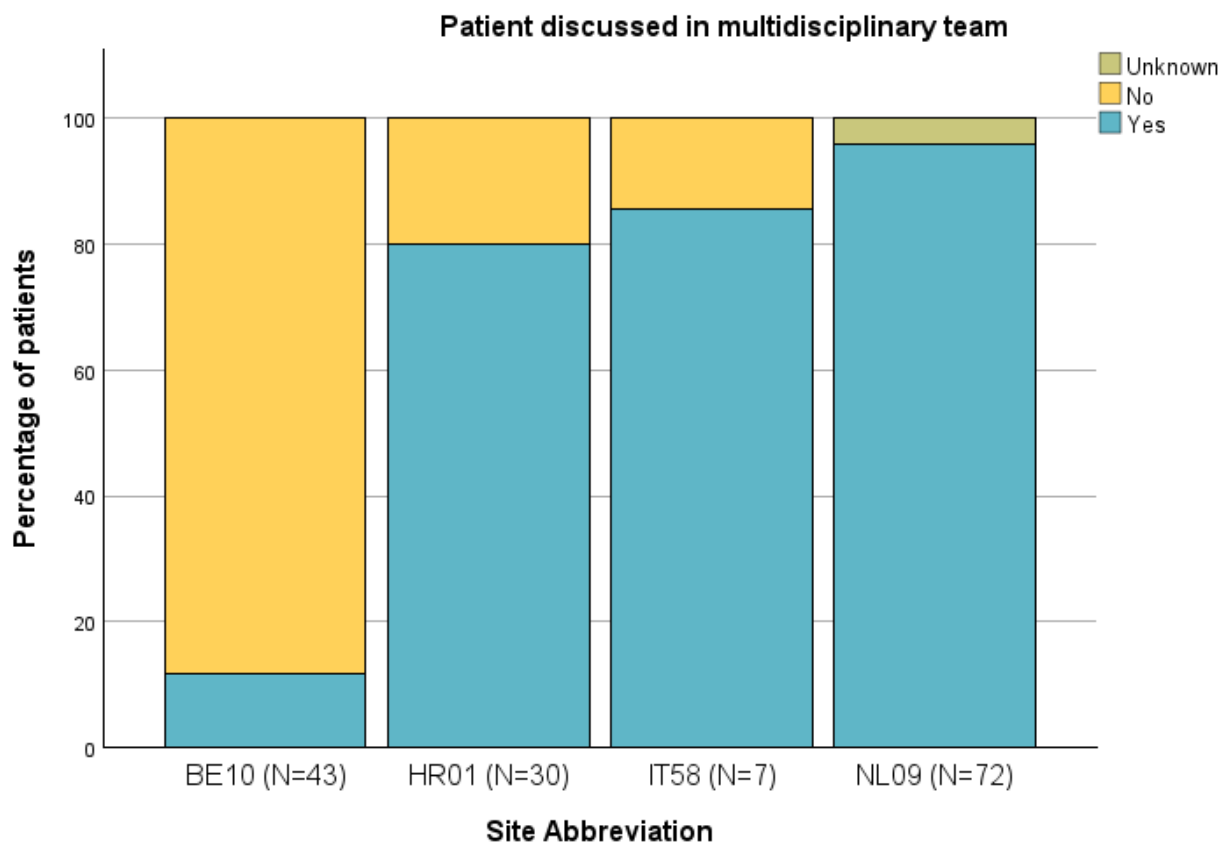
Few patients had an adrenal tumour that originated from elsewhere, most occurring were renal tumour metastasis.



Preoperative care

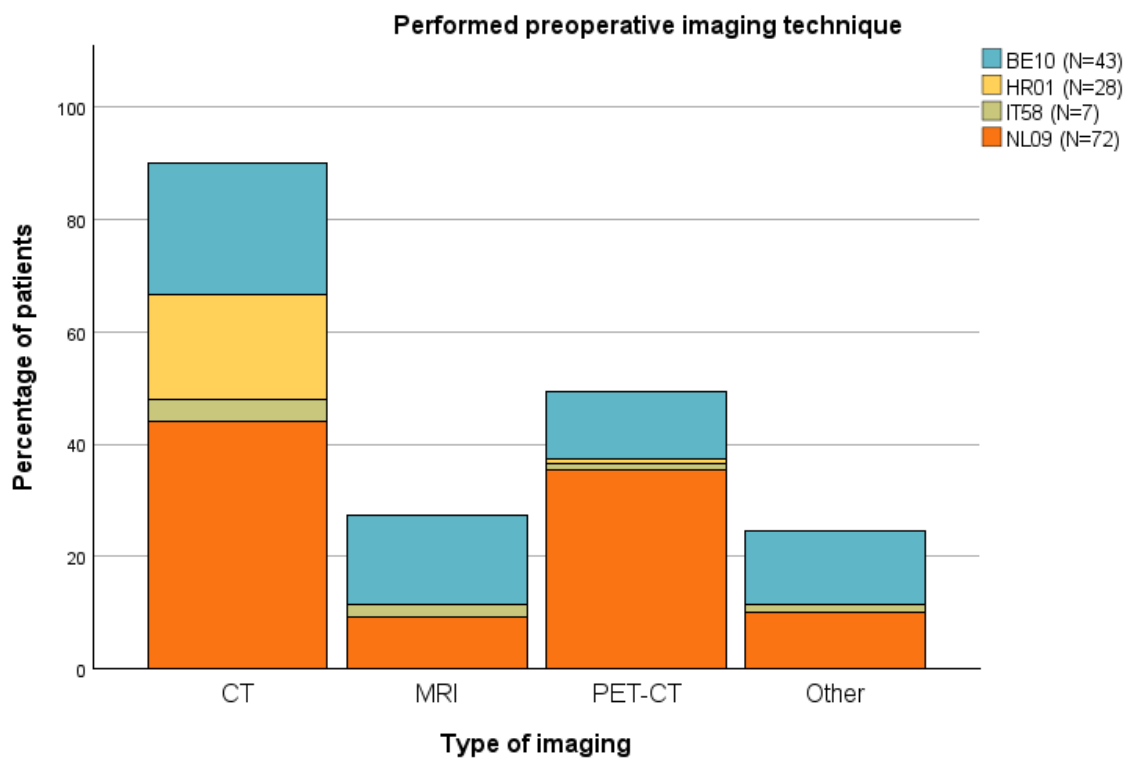
Multidisciplinary team (MDT)

Most patients for HR01, IT58 and NL09 were discussed in a MDT. On the other hand, most patients from BE10 were not discussed in a MDT.



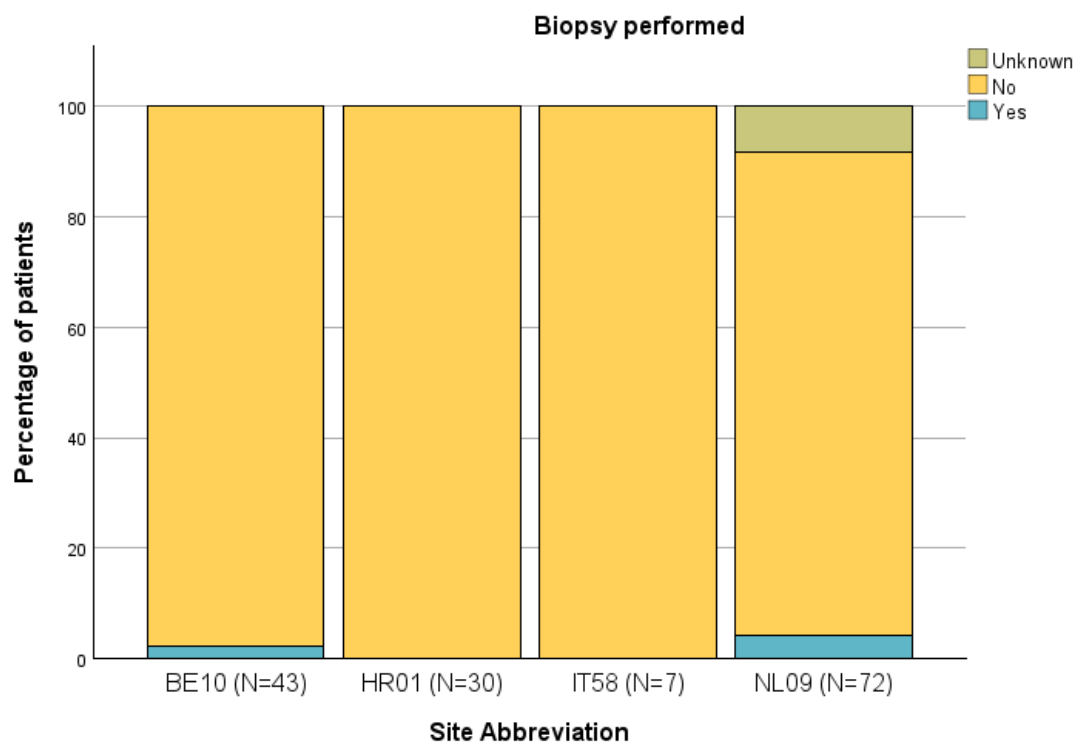
Pre-operative imaging

Almost all patients received a CT scan before their surgery. MRI and other scans were also performed, but only for a minority of the patients. PET-CT scans were performed in approximately half of the patients.



Biopsy performed

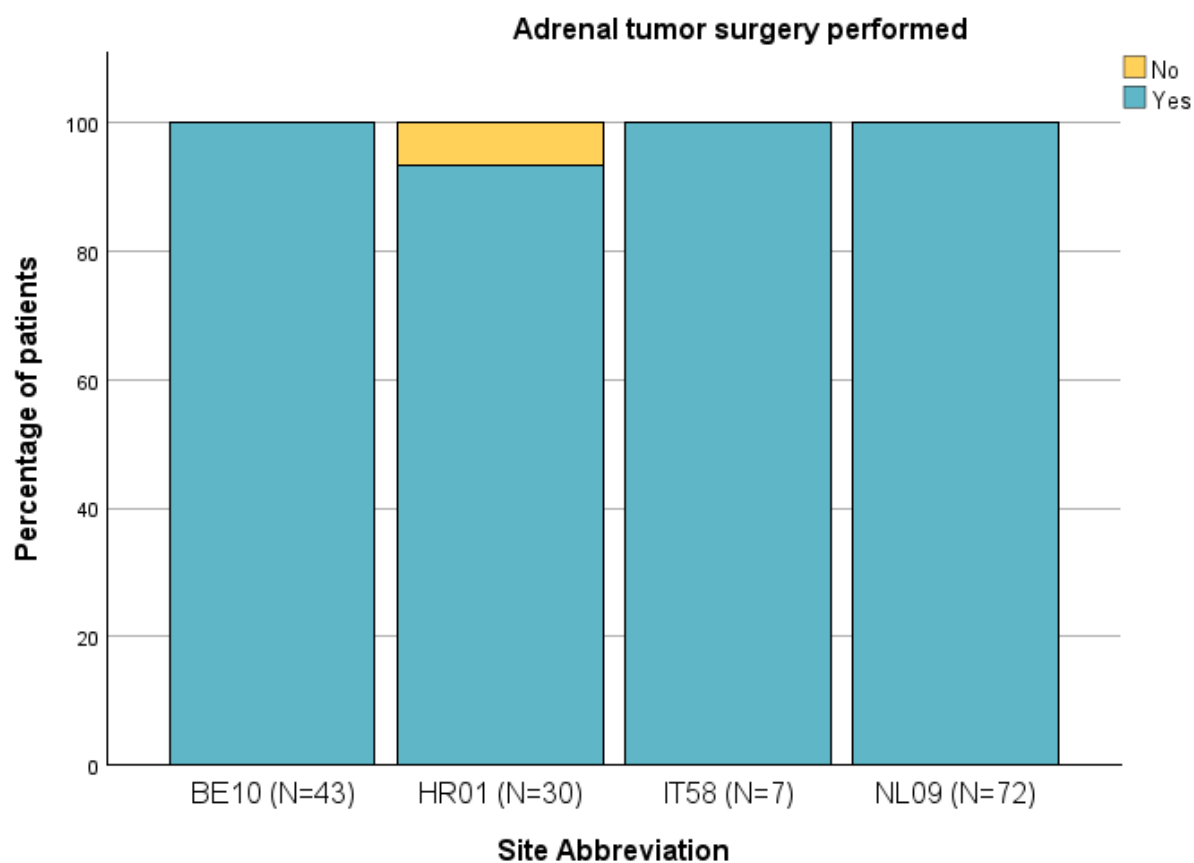
Most patients did not receive a biopsy.



Surgery

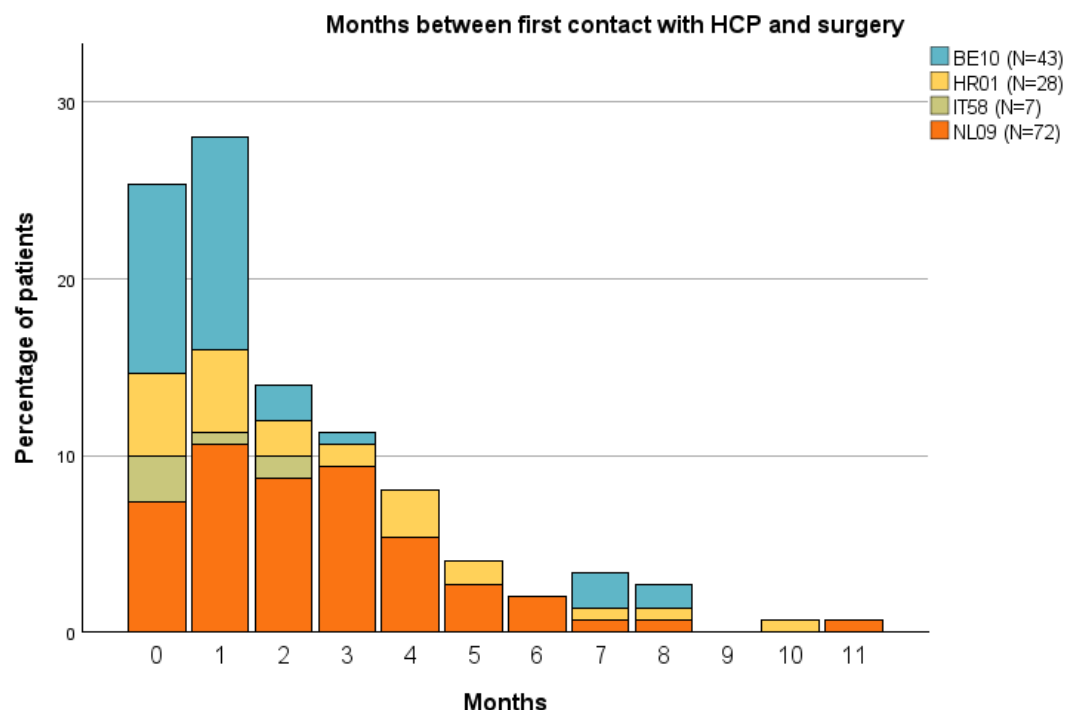
Surgery performed in HCP during the first year of treatment

Only two patients did not have surgery during the first year of treatment.



Time between first contact with Health Care Provider and adrenal surgery

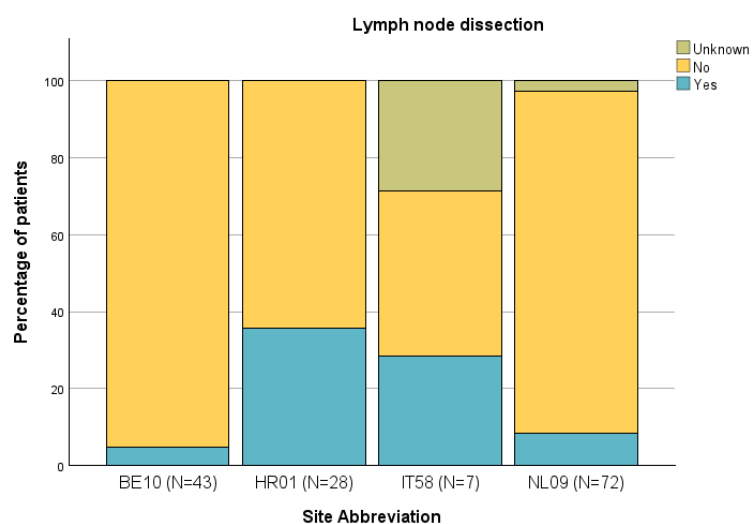
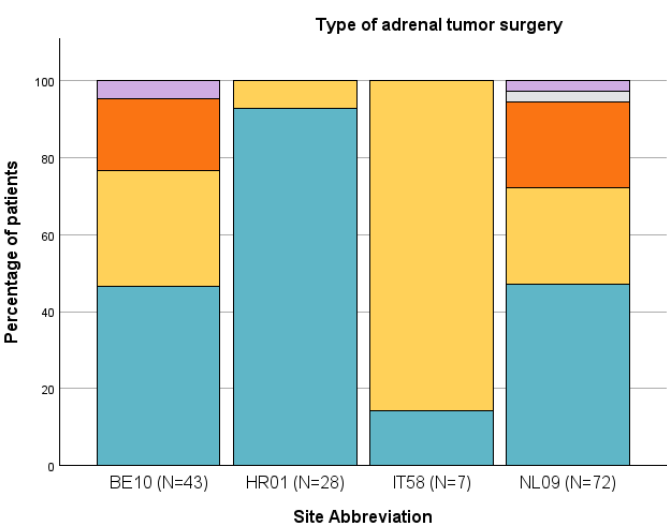
Most patients had the adrenal surgery within 4 months after the first visit to the HCP.



Surgery characteristics

Among the HCPs, there's a great variety of used surgery techniques. Where in HR01 almost all patients receive a laparoscopy, in IT58 all patients received an open surgery. For BE10 and NL09, there was a mix of surgery types used.

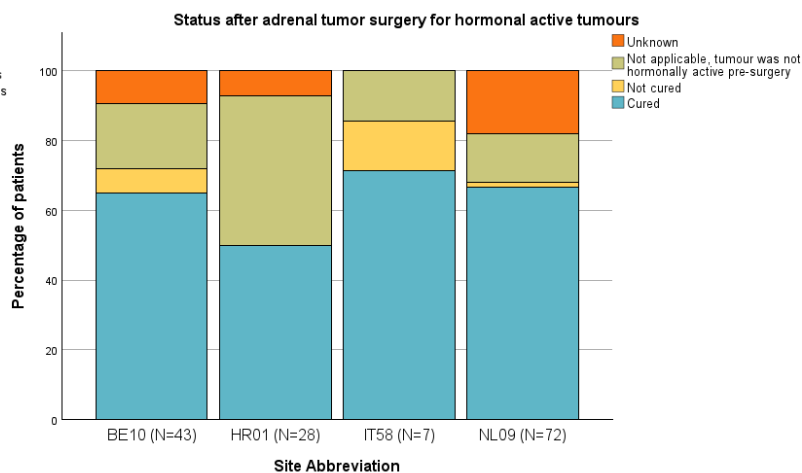
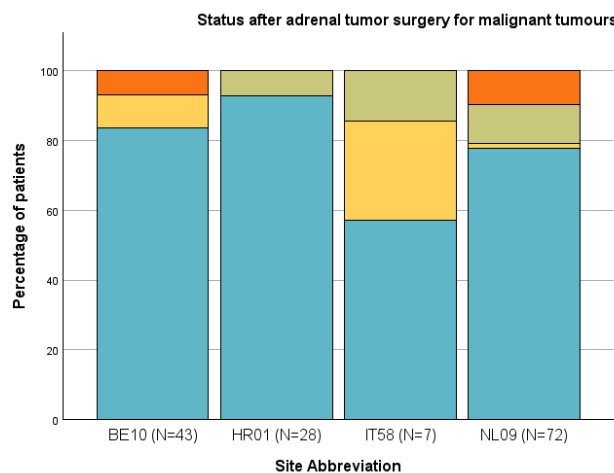
Lymph node dissection was performed by all HCPs, but only for a minority of patients.



Status after surgery

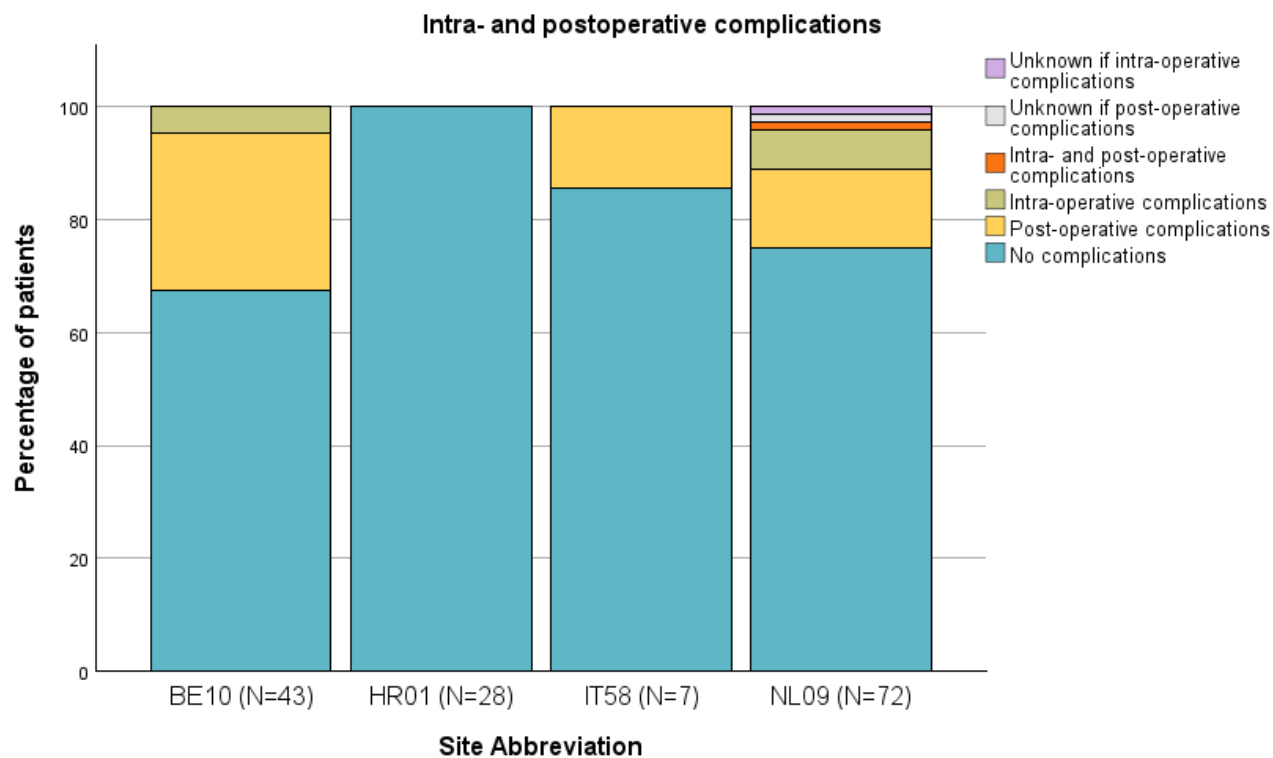
Status after surgery for malignant and hormonally active tumours

For patients with a malignant tumour, no patients had positive resection margins after the surgery. For patients with a hormonally active tumour before surgery, most patients were cured within 1 year of treatment.



Complications after surgery

Most patients had no complications. If any complications occurred, it concerned post-operative complications for most patients. Almost no patients experienced both intra- and postoperative complications.





⚙ Network
Urogenital Diseases
(ERN eUROGEN)

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