

ERN eUROGEN registry

Report on Expertise Area 1.5

INTRODUCTION

This report entails the first ERN eUROGEN registry retrospective analysis of the Expertise Area 1.5: Posterior urethral valves. 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 valve resection took place at 08-02-2022 (more than a year after the start of treatment). This valve resection should not be entered in the Clinical Practice Snapshot of the ERN eUROGEN registry. If this information was there, we interpreted it as 'No valve resection'. If it was indicated that the valve resection took place but the date is unknown, we interpreted the variable as 'Unknown', because we don't know if this valve resection 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 1.5, posterior urethral valves. Corresponding figures were made of the variables, and they are displayed on the next pages.

	Total (N=65)	Netherlands NL09 (N=34)	Belgium BE10 (N=30)	Spain ES15 (N=1)
1st surgical procedure				
Valve resection; N (%)	64 (97.0%)	34 (100%)	29 (96.7%)	1 (100%)
Age at 1 st valve resection; Median (range)	173 days (8;6597)	20 days (8;2858)	432 days (10;6597)	395 days(-)
Type of procedure 1 st surgery				
Hot knife; N (%)	29 (45.3%)	-	29 (100%)	-
Cold knife; N (%)	35 (54.7%)	34 (100%)	-	1 (100%)
Other; N (%)	-	-	-	-
Unknown; N (%)	-	-	-	-
2nd surgical procedure				
Performed control cystoscopies; N (%)	22 (33.9%)	21 (61.7%)	1 (3.3%)	-
Days after valve resection; Mean (range)	95 days (49;145)	93 days (49;145)	101 days (-)	-
Control scopy with valve resection; N (%)	15 (68.2%)	15 (71.4%)	1 (100%)	-
Additional intervention with anesthesia; N(%)	10 (15.4%)	4 (11.8%)	6 (20.0%)	-
Renography and MCG				
MAG-3/DMSA performed N (%)*	39 (60.0%)	26 (76.5%)	12 (40.0%)	1 (100%)
MAG-3 first performed; N (%)	26 (66.7%)	24 (92.3%)	2 (16.7%)	-
DMSA first performed; N (%)	13 (33.3%)	2 (7.7%)	10 (83.3%)	1 (100%)
Unknown if renography performed; N (%)	2 (3.1%)	2 (5.9%)	-	-
MCG performed, N (%)	50 (76.9%)	30 (88.2%)	19 (63.3%)	1 (100%)
VUR left; N (%)	7 (14.0%)	4 (13.3%)	3 (15.8%)	-
VUR right; N (%)	5 (10.0%)	2 (6.7%)	3 (15.8%)	-
VUR both; N (%)	11 (22.0%)	7 (23.3%)	4 (21.1%)	-
No VUR; N (%)	27 (54.0%)	17 (56.7%)	9 (47.4%)	1 (100%)
Unknown if MCG performed; N (%)	2 (3.1%)	2 (5.9%)	-	-
Creatinine values				
Creatinine available before surgery; N (%)**	40 (61.5%)	26 (76.5%)	13 (43.3%)	1 (100%)
Lowest value; Median (range)	34.0 (0.29;208)	40.0 (18;208)	29.5 (17;192)	0.29 (-)
Creatinine available at 1 year of age; N (%)	21 (36.2%)	15 (44.1%)	6 (20.0%)	-
Value at age 1; Median (range)	31 (17;368)	33.0 (19;368)	25.0 (17;39)	-
Creatinine available 1 year after surgery; N(%)	7 (10.8%)	-	7 (23.3%)	-
Value 1 yr post-surg; Median (range)	28.0 (19;80)	-	28.0 (19;80)	-

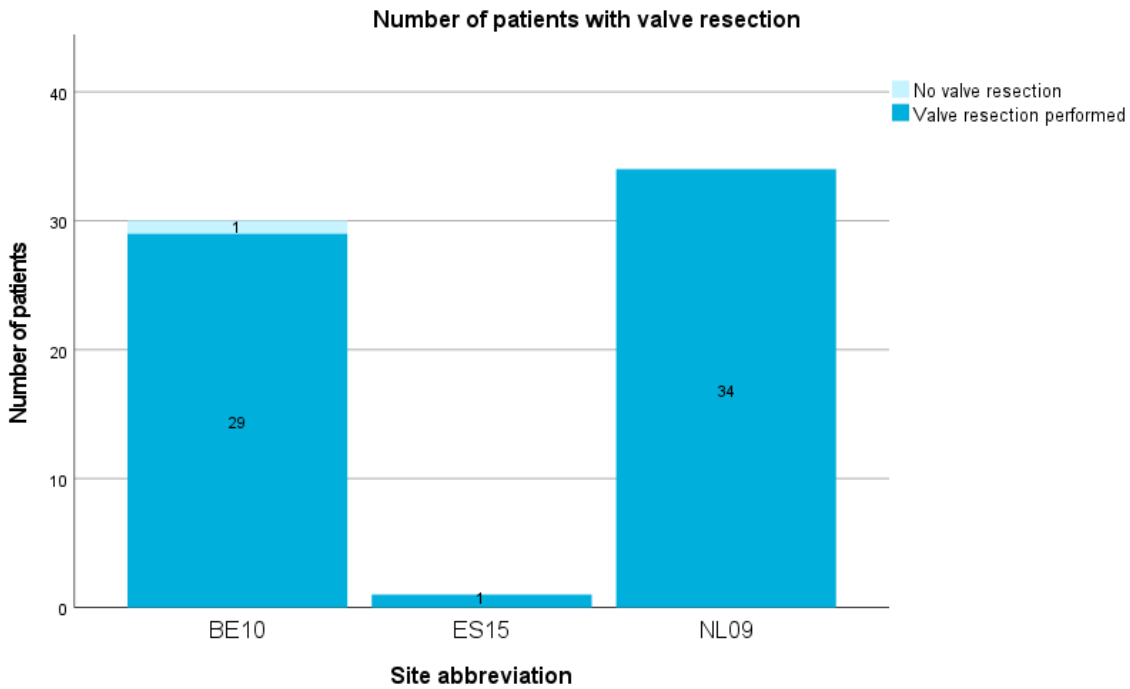
* Including procedures that were performed before the first contact with the HCP.

** Creatinine values measured until 60 days before the valve resection surgery were included.

1st surgical procedure

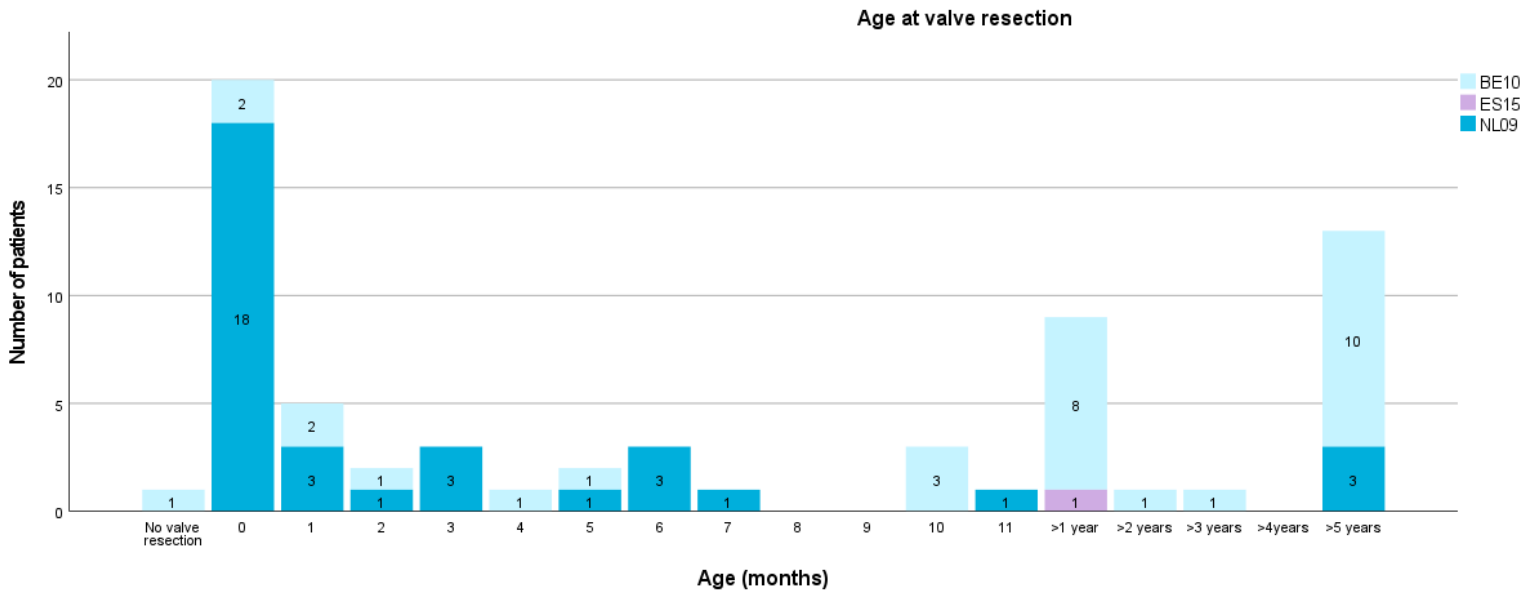
Number of patients with valve resection

Except for one, all patients received a valve resection in the first year of treatment.



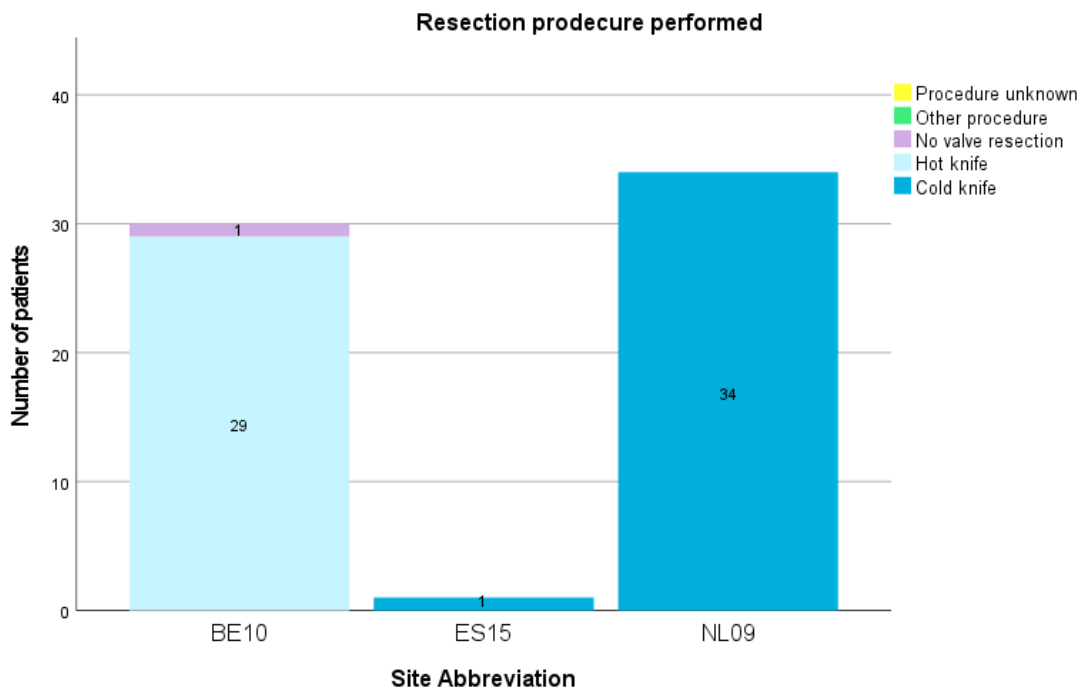
Age at valve resection

Most patients from NL09 received their valve resection in their first year of life, while a substantial group from BE10 received their valve resection when they were five years of age or older.



Resection procedures

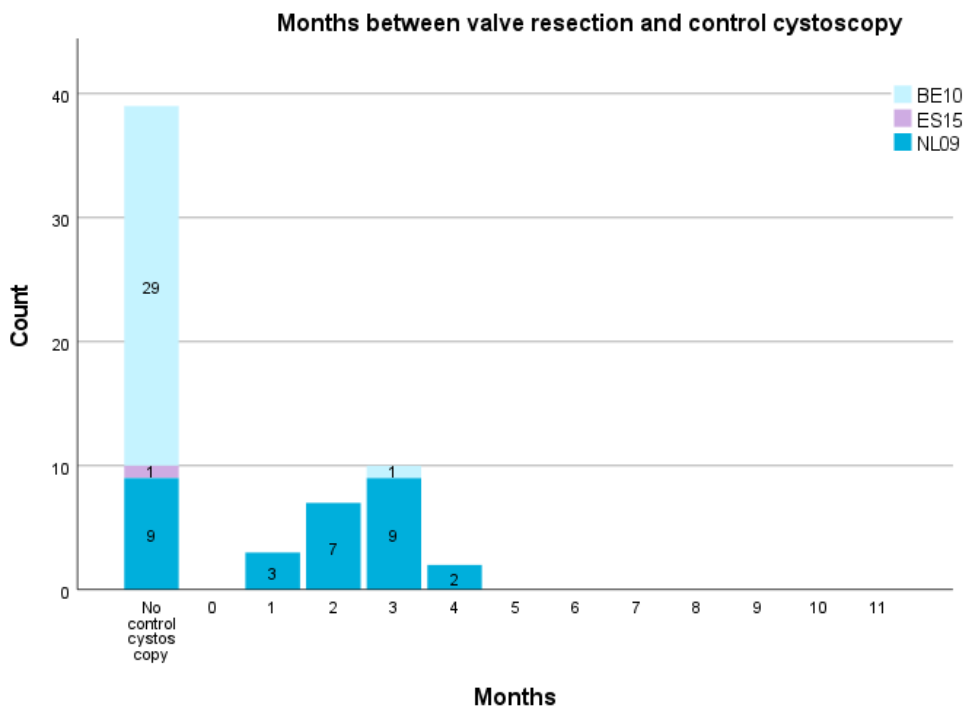
There is a clear difference in preferred resection procedure; NL09 (and ES15) use the cold knife procedure, whereas BE10 uses the hot knife procedure.



2nd surgical procedure

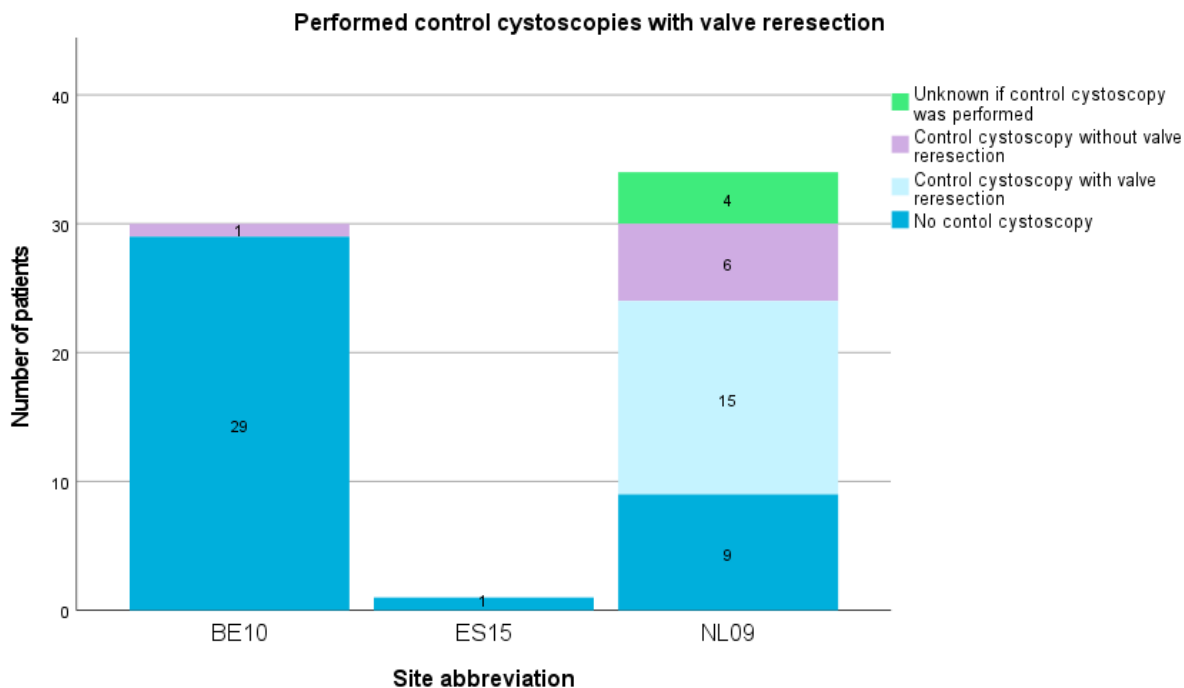
Months between resection and control cystoscopy

Control cystoscopies were not performed in BE10, while they were performed in most cases in NL09. They were always performed within five months after the first valve resection.



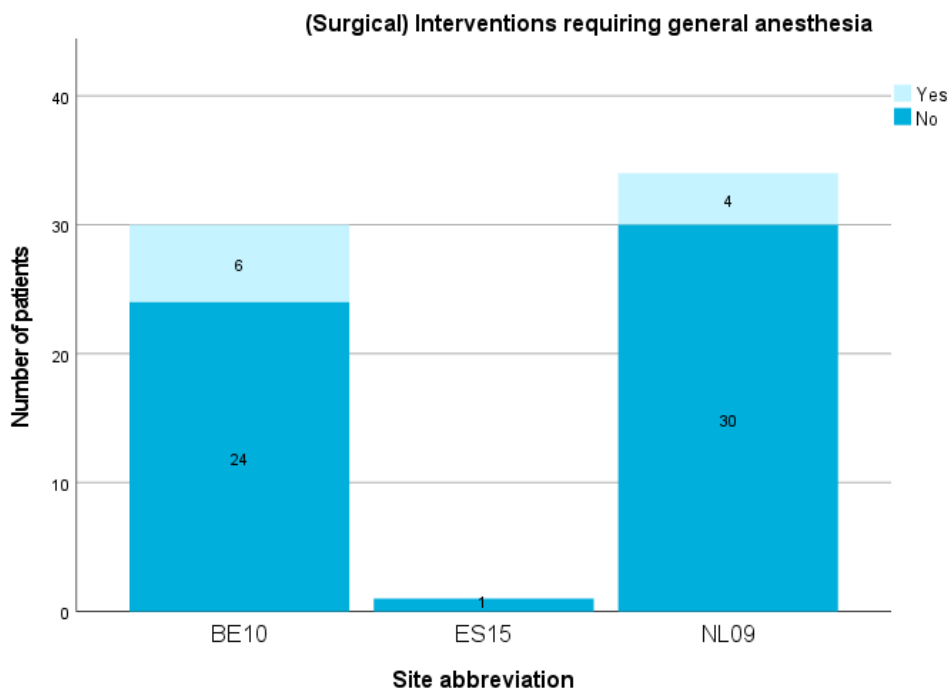
Control cystoscopies and valve resection

Control cystoscopies were not performed in BE10, while they were performed in most cases in NL09. In most cases, a valve resection was needed.

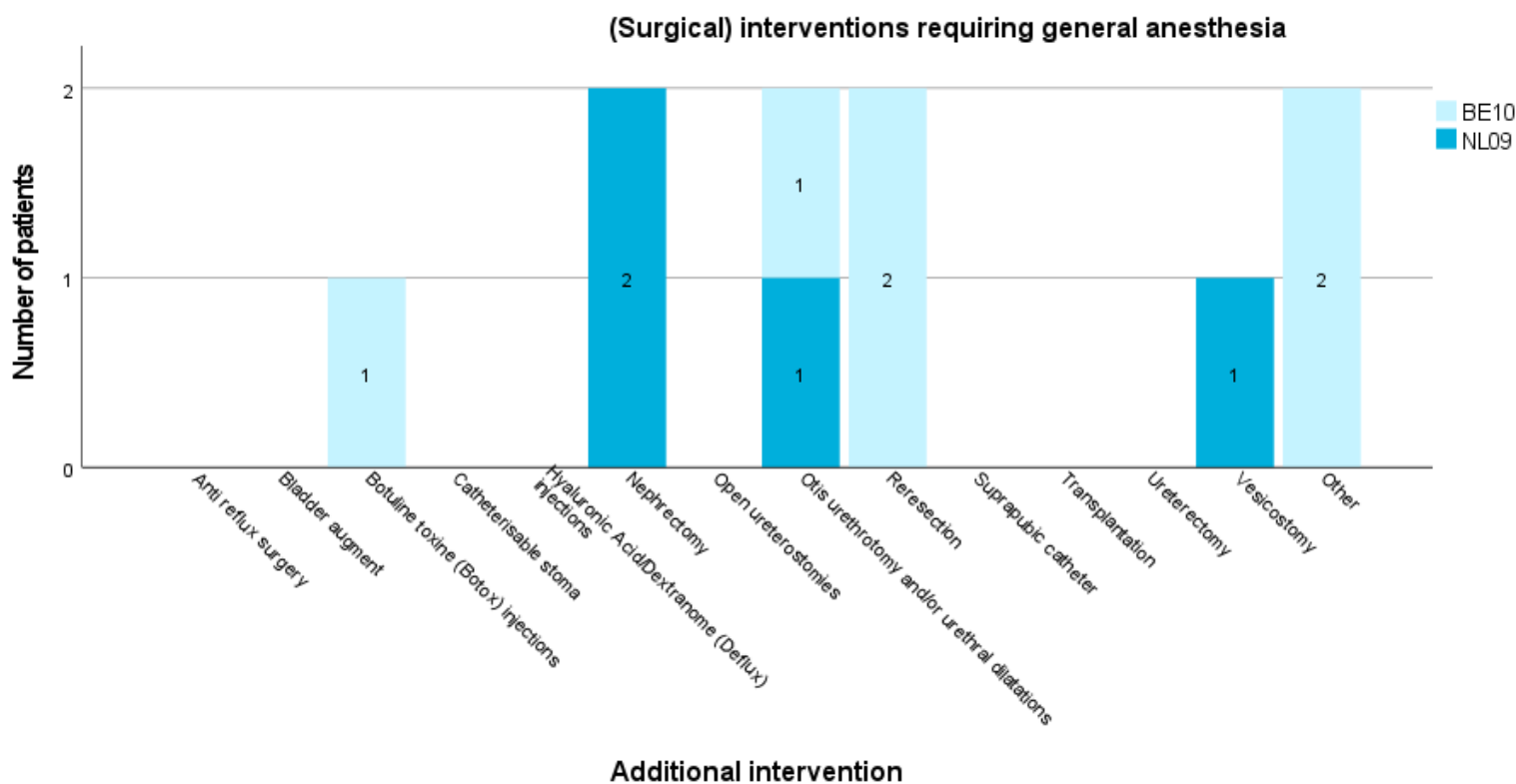


(Surgical) interventions requiring general anesthesia

Most patients did not need any additional interventions.



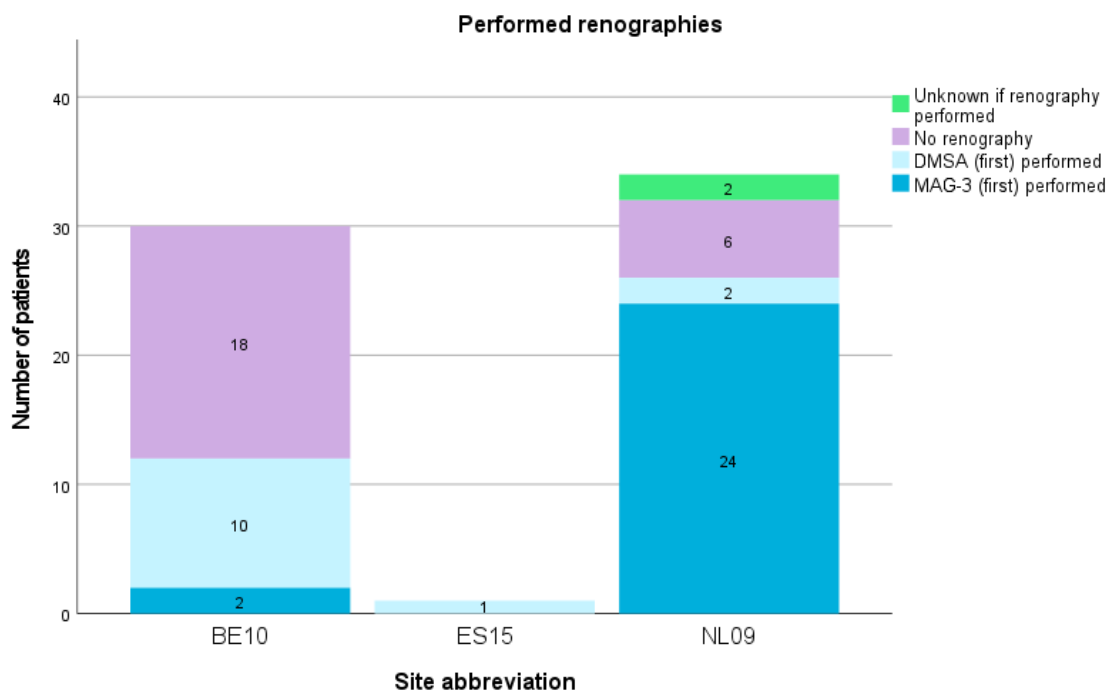
In the patients who did need an additional intervention, a variety of additional interventions was performed.



Renography and MCG

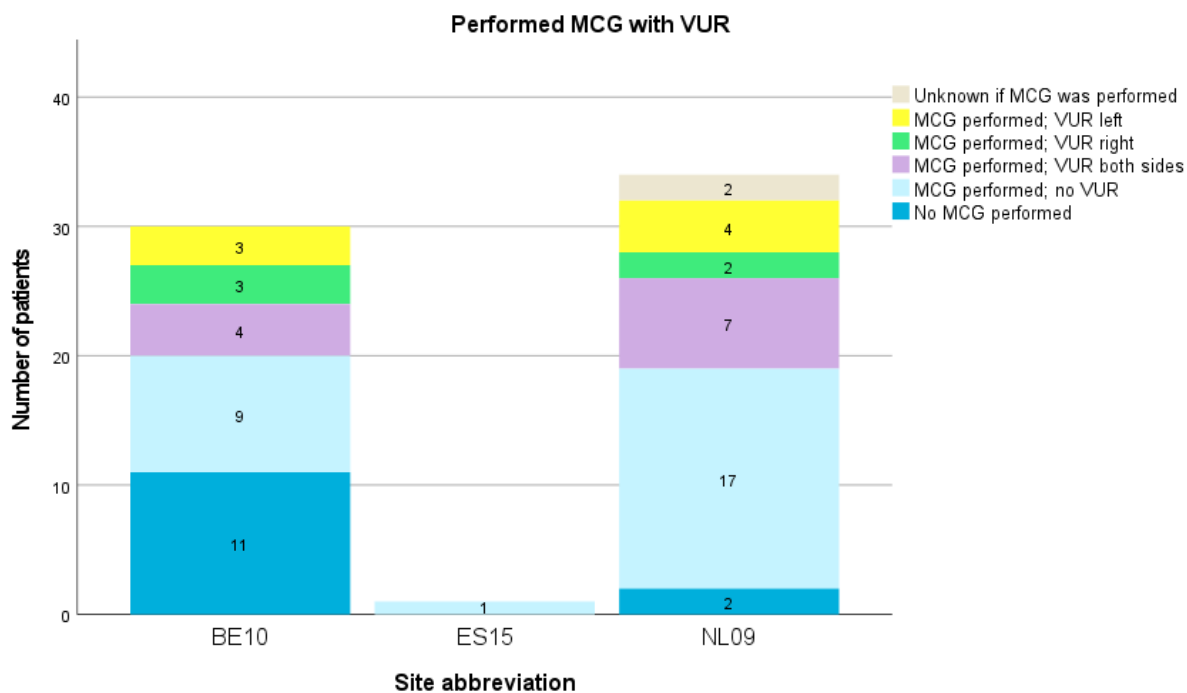
Renographies

A renography was performed for most patients, but it differs per HCP which type of renography was used most.



MCG and VUR

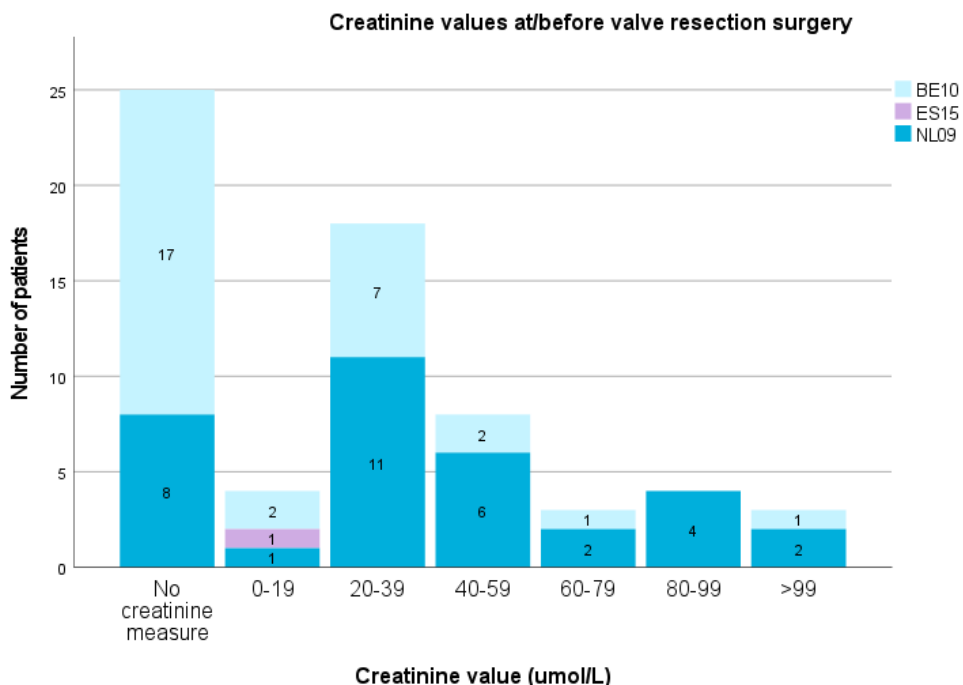
For most patients, an MCG was performed with no diagnosed VUR. If VUR was diagnosed, it was mostly present on both sides.



Creatinine values

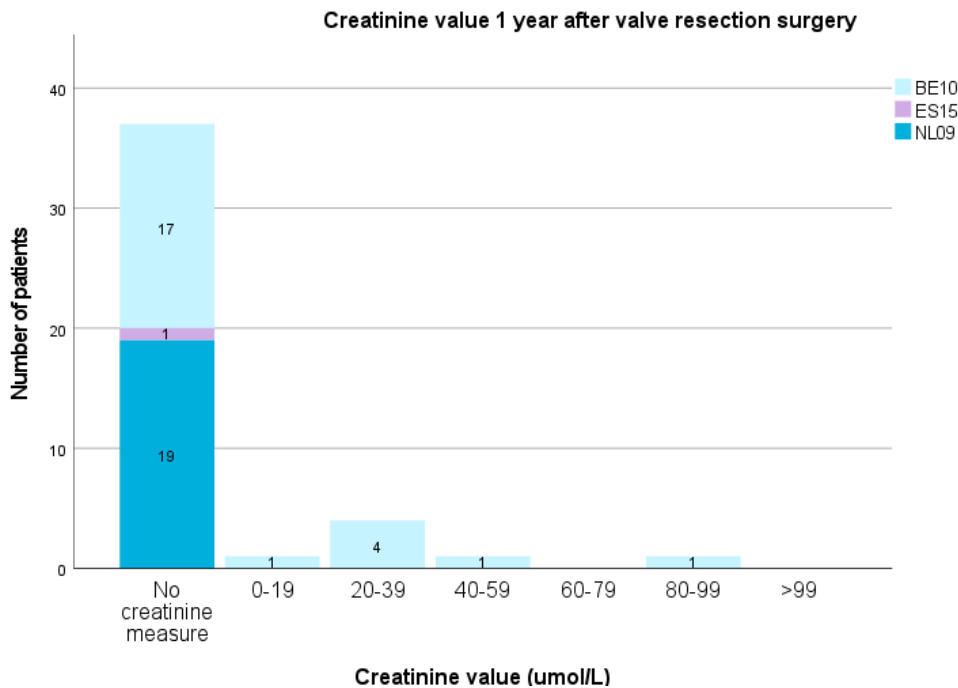
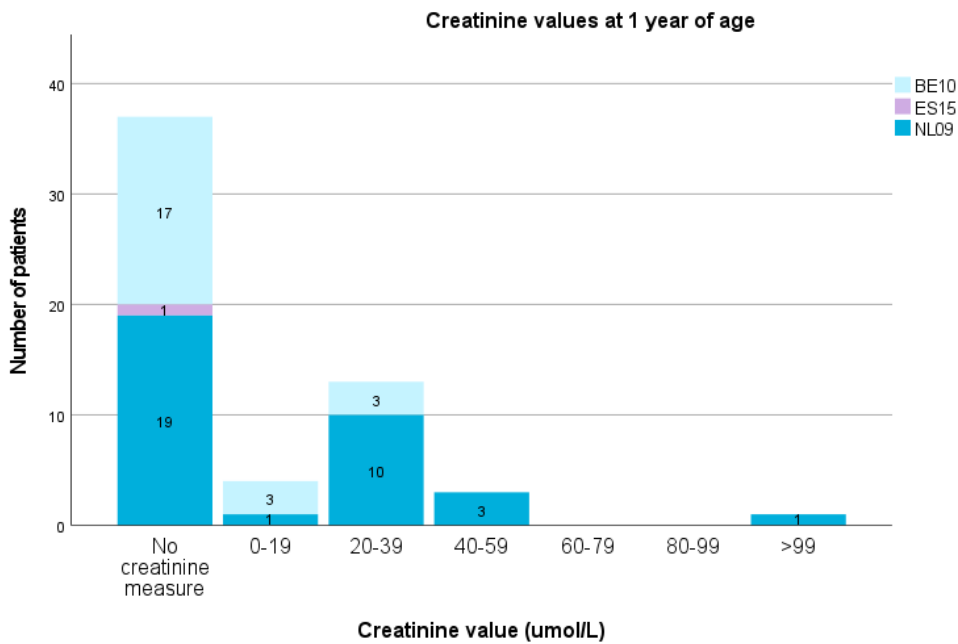
Creatinine values at/before valve resection surgery

For patients who had their creatinine measured at/before surgery, most had a value between 20 and 39 $\mu\text{mol/L}$.



Follow-up: creatinine values at 1 year of age or 1 year after valve resection

For most patients, no follow-up creatinine values were present. If they were present, we made 2 groups; 1 with a value measured around the age of 1, and the other with a value measured approximately 1 year after surgery. This latter group was used for patient who had their valve resection after the age of 1. In both groups, most patients had a value between 20 and 30 $\mu\text{mol/L}$.





Network
Urogenital Diseases
(ERN eUROGEN)

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Co-funded by the European Union



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>