

ERN eUROGEN registry

Report on Expertise Area 1.5

INTRODUCTION

This report entails an analysis of the data on Expertise Area 1.5 Posterior urethral valves 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 1.5 Posterior Urethral Valves were included individually in these analyses. HCPs that entered less than 5 patients, were grouped in an 'Other' HCP group. This 'Other' HCP group consists of: DK02 (N=2), ES15 (N=1), SE01 (N=3). 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 posterior urethral valves. 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 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, and we interpreted it as 'No valve resection'.

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 analyses. 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 1.5; POSTERIOR URETHRAL VALVES

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=141)	Austria AT08 (N=11)	Belgium BE10 (N=32)	Czech Republic CZ02 (N=13)	Germany DE19 (N=8)	Spain ES17 (N=8)	Italy		Netherlands NL09 (N=37)	Sweden SE03 (N=15)	Others OTH (N=6)
							IT05 (N=6)	IT58 (N=5)			
1st surgical procedure											
Valve resection											
Valve resection in first year of treatment; N (%)	136 (96.5%)	10 (90.9%)	31 (96.9%)	13 (100%)	7 (87.5%)	6 (75.0%)	6 (100%)	5 (100%)	37 (100%)	15 (100%)	6 (100%)
No valve resection in first year of treatment; N (%)	5 (3.5%)	1 (9.1%)	1 (3.1%)	-	1 (12.5%)	2 (25.0%)	-	-	-	-	-
Age at 1 st valve resection; Median (range, days)	182 (6;6795)	382 (71;4362)	643 (10;6795)	111 (6;1023)	422 (44;2977)	368 (53;1512)	92 (10;185)	132 (77;475)	20 (8;2858)	71 (6;3183)	128 (14;395)
Type of procedure											
Hot knife; N (%)	37 (27.2%)	-	31 (100%)	-	-	5 (83.3%)	1 (16.7%)	-	-	-	-
Cold knife; N (%)	93 (68.4%)	10 (100%)	-	12 (92.3%)	7 (100%)	1 (16.7%)	5 (83.3%)	-	37 (100%)	15 (100%)	6 (100%)
Laser; N (%)	4 (2.9%)	-	-	-	-	-	-	4 (80.0%)	-	-	-
Other; N (%)	1 (0.7%)	-	-	1 (7.7%)	-	-	-	-	-	-	-
Unknown; N (%)	1 (0.7%)	-	-	-	-	-	-	1 (20.0%)	-	-	-
2nd surgical procedure											
Performed control cystoscopies;	61 (44.9%)	3 (30.0%)	1 (3.2%)	9 (69.2%)	2 (28.6%)	4 (66.7%)	3 (50.0%)	4 (80.0%)	23 (62.2%)	8 (53.3%)	4 (66.7%)
Control cystoscopy with valve resection; N (%)	44 (72.1%)	3 (100%)	-	8 (88.9%)	2 (100%)	-	1 (33.3%)	3 (75.0%)	17 (73.9%)	7 (87.5%)	3 (75.0%)
Days after valve resection; Median (range)	98 (12;317)	218 (111;317)	101 (-)	122 (13;288)	123 (108;137)	174 (135;266)	95 (70;151)	144 (91;201)	93 (49;145)	68 (12;169)	66 (31;106)
Additional interventions											
Additional intervention with anesthesia; N (%)	45 (31.9%)	4 (36.4%)	6 (18.8%)	11 (84.6%)	6 (75.0%)	1 (12.5%)	1 (16.7%)	4 (80.0%)	4 (10.8%)	6 (40.0%)	2 (33.3%)
No additional interventions; N (%)	96 (68.1%)	7 (63.6%)	26 (81.2%)	2 (15.4%)	2 (25.0%)	7 (87.5%)	5 (83.3%)	1 (20.0%)	33 (89.2%)	9 (60.0%)	4 (66.7%)
Renography and MCG											
MAG-3/DMSA performed N (%)	78 (55.3%)	8 (72.7%)	13 (40.7%)	8 (61.6%)	3 (37.5%)	1 (12.5%)	2 (33.3%)	2 (40.0%)	29 (78.4%)	8 (53.4%)	4 (66.7%)
MAG-3 (first) performed; N (%)	43 (55.1%)	-	2 (15.4%)	5 (62.5%)	2 (66.7%)	-	2 (100%)	1 (50.0%)	27 (93.1%)	1 (12.5%)	1 (20.0%)
DMSA (first) performed; N (%)	35 (44.9%)	8 (100%)	11 (84.6%)	3 (37.5%)	1 (33.3%)	1 (100%)	-	1 (50.0%)	2 (6.9%)	7 (87.5%)	3 (80.0%)
Unknown if renography performed; N (%)	5 (3.5%)	-	-	-	-	-	-	-	2 (5.4%)	3 (20.0%)	-
MCG performed, N (%)	78 (55.3%)	5 (45.5%)	13 (40.7%)	10 (76.9%)	4 (50.0%)	3 (37.5%)	3 (50.0%)	4 (80.0%)	26 (67.6%)	5 (33.3%)	5 (83.3%)
VUR left; N (%)	11 (14.1%)	-	2 (15.4%)	-	-	-	2 (66.7%)	1 (25.0%)	4 (15.4%)	1 (20.0%)	1 (20.0%)
VUR right; N (%)	7 (9.0%)	-	1 (7.7%)	3 (30.0%)	-	-	-	-	2 (7.7%)	1 (20.0%)	-
VUR both; N (%)	24 (30.8%)	2 (40.0%)	4 (30.8%)	1 (10.0%)	2 (50.0%)	3 (75.0%)	-	2 (50.0%)	8 (30.8%)	1 (20.0%)	1 (20.0%)
No VUR; N (%)	36 (46.2%)	3 (60.0%)	6 (46.2%)	6 (60.0%)	2 (50.0%)	-	1 (33.3%)	1 (25.0%)	12 (46.2%)	2 (40.0%)	3 (60.0%)
Unknown if MCG performed; N (%)	3 (2.1%)	-	-	1 (7.7%)	-	1 (12.5%)	-	-	1 (2.7%)	-	-
Creatinine values											
Creatinine available before surgery; N (%)*	77 (54.6%)	3 (27.3%)	12 (37.5%)	7 (53.8%)	5 (62.5%)	-	4 (66.7%)	4 (80.0%)	29 (78.4%)	8 (53.3%)	5 (83.3%)
Lowest value; Median (range)	34.0 (0.3;342)	19.0 (17;30)	29.5 (19;192)	45.0 (20;134)	24.8 (17.6;30.8)	-	34.3 (24.6;200)	37.9 (34.3;48.4)	41 (18;208)	28.0 (15;204)	23 (0.3;342)
Creatinine available at ~ 1 year of age; N (%)	52 (36.9%)	-	4 (12.5%)	11 (84.6%)	2 (25.0%)	-	4 (66.7%)	5 (100%)	17 (45.9%)	4 (26.7%)	5 (83.3%)
Value at age 1; Median (range)	31 (0.3;635)	-	25.0 (17;39)	38 (21;132)	22 (17.6;26.4)	-	30.0 (24.6;41.4)	35.2 (29;48.4)	33.0 (1.4;368)	28.5 (21;33)	26.0 (0.3;635)
Creatinine available ~1 year after surgery**; N(%)	14 (10.7%)	-	9 (28.1%)	1 (7.7%)	2 (25.0%)	-	-	-	-	2 (13.3%)	-
Value 1 yr post-surg; Median (range)	28.0 (18;80)	-	28.0 (18;80)	30.0 (-)	26.3 (18.4;34.3)	-	-	-	-	31 (18;44)	-

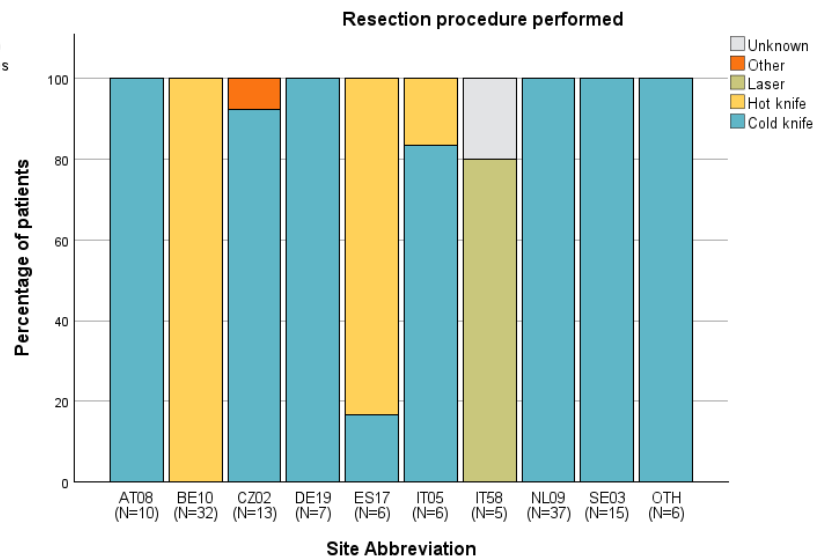
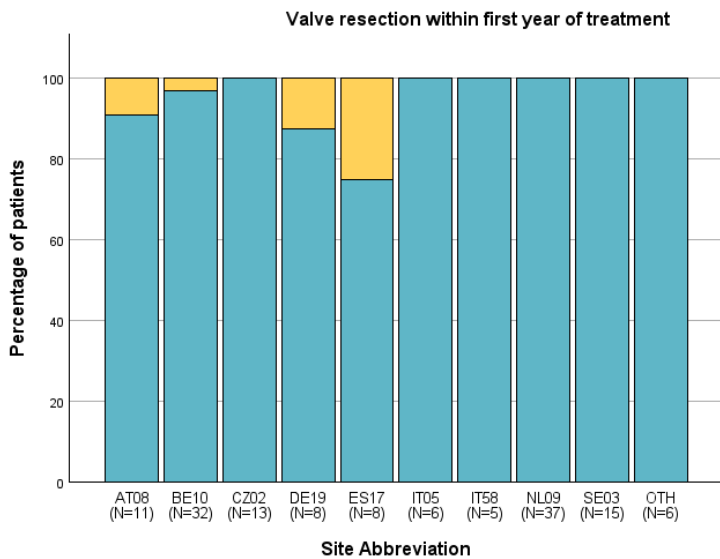
* Creatinine values measured at or just before surgery, with a maximum until 60 days before the surgery, were included.

** Creatinine values only taken into account if surgery took place after 1 year of age and a creatinine measurement was available within 1.5 years after the surgery.

1st surgical procedure

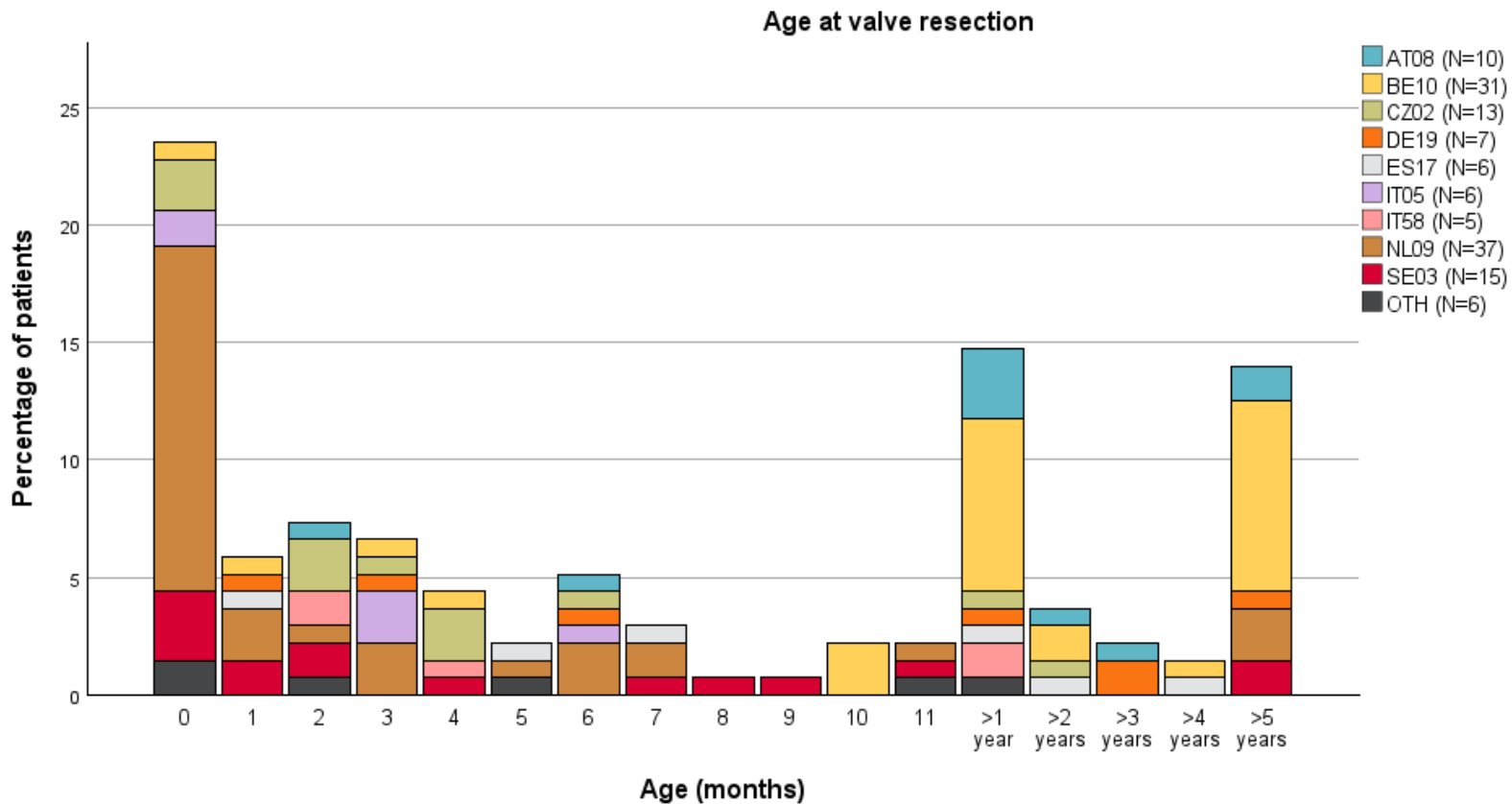
Number of patients with valve resection in the first year after first visiting the HCP and resection procedure

Most patients received a valve resection in their first year of treatment. There is a clear difference in preferred resection procedure; Most HCPs use the cold knife procedure, whereas BE10 exclusively uses the hot knife procedure. ES17 and IT05 use a mix of both resection procedures and IT58 is the only HCP to use laser.



Age at valve resection

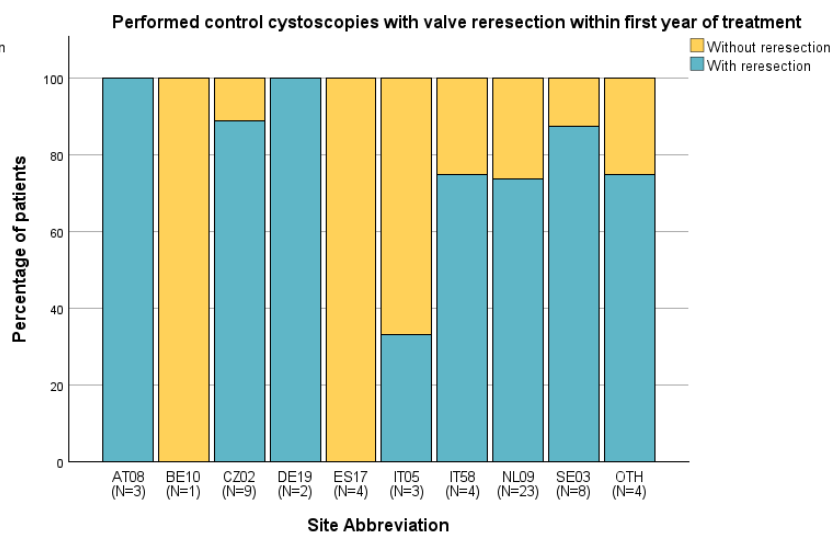
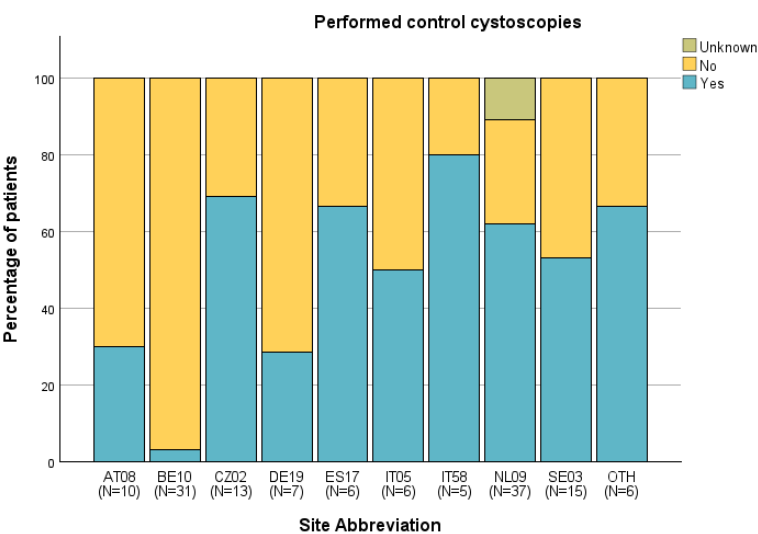
Most patients from NL09 received their valve resection in their first year of life, while a substantial group from BE10 received their valve resection when they were one year of age or five years of age or older. The age at valve resection varied for the other HCPs.



2nd surgical procedure

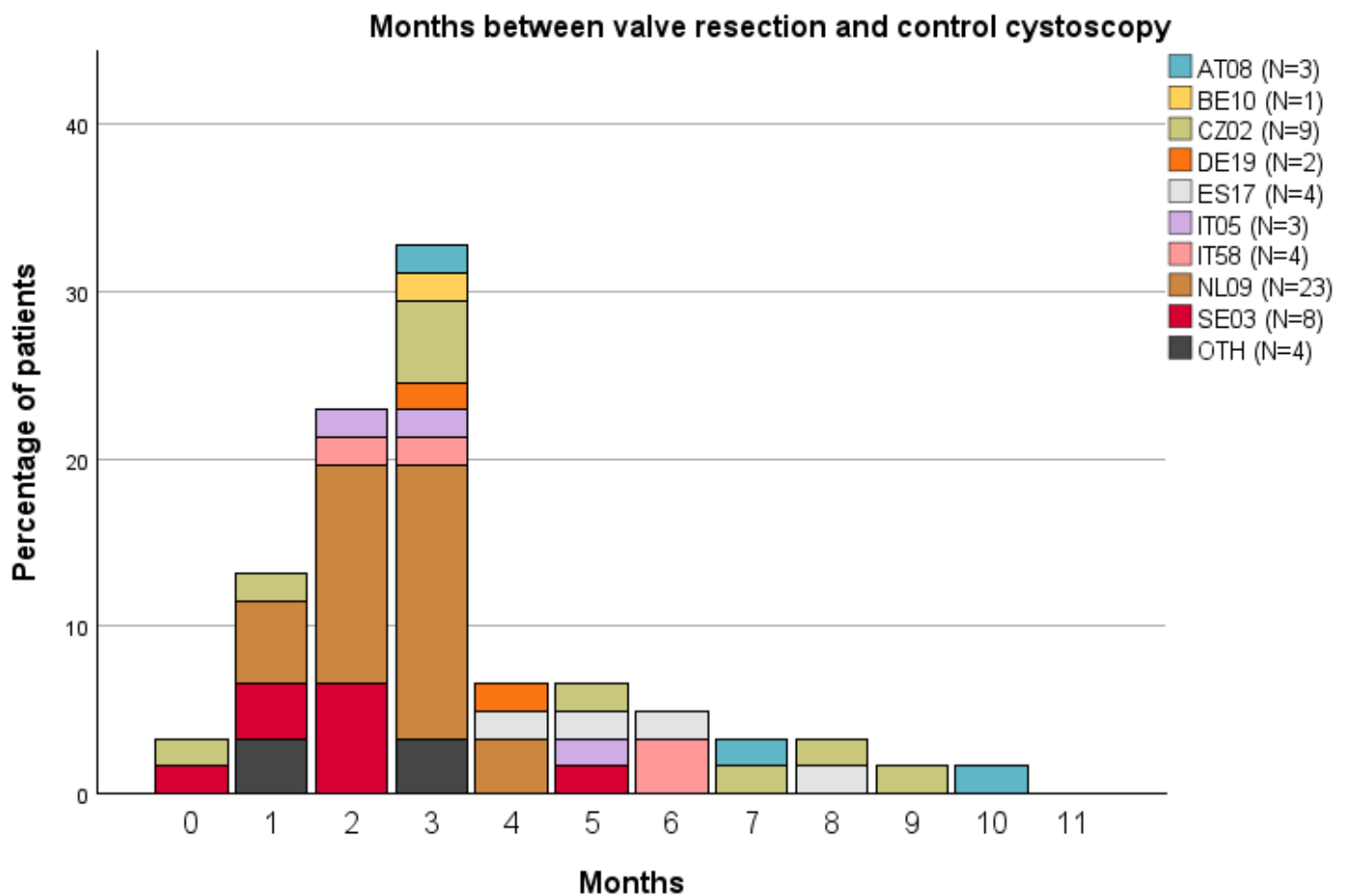
Control cystoscopies and valve resection in the first year of treatment

Control cystoscopies were overall performed in approximately 50% of patients. Control cystoscopies mostly result in resection of the valves.



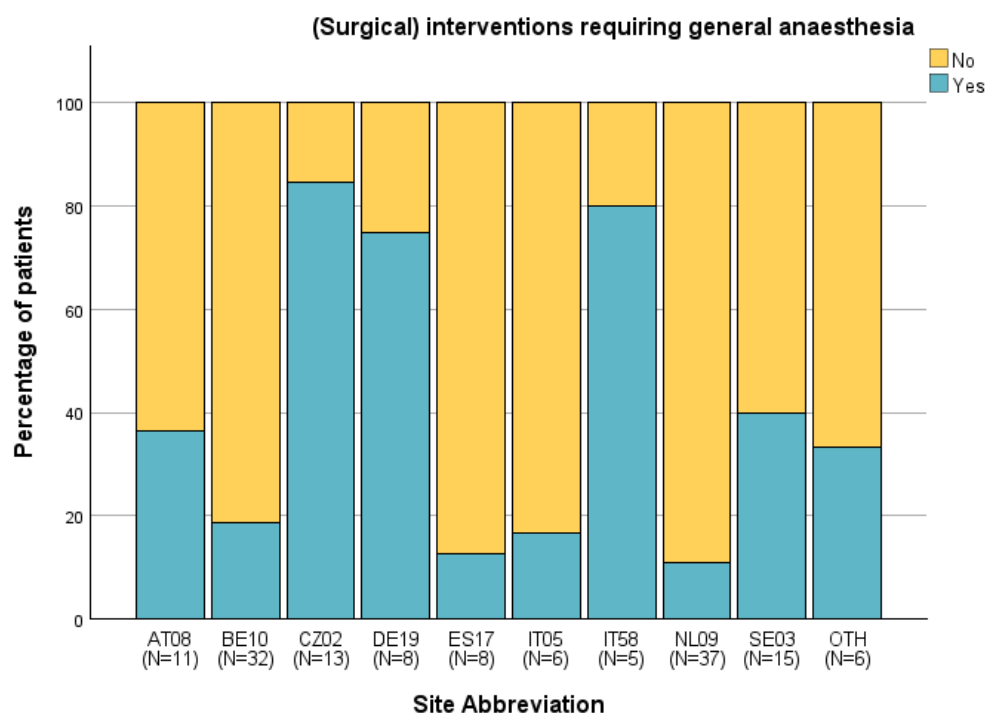
Months between resection and control cystoscopy

If a control cystoscopy was performed, it took place within 3 months after the valve resection in most cases.

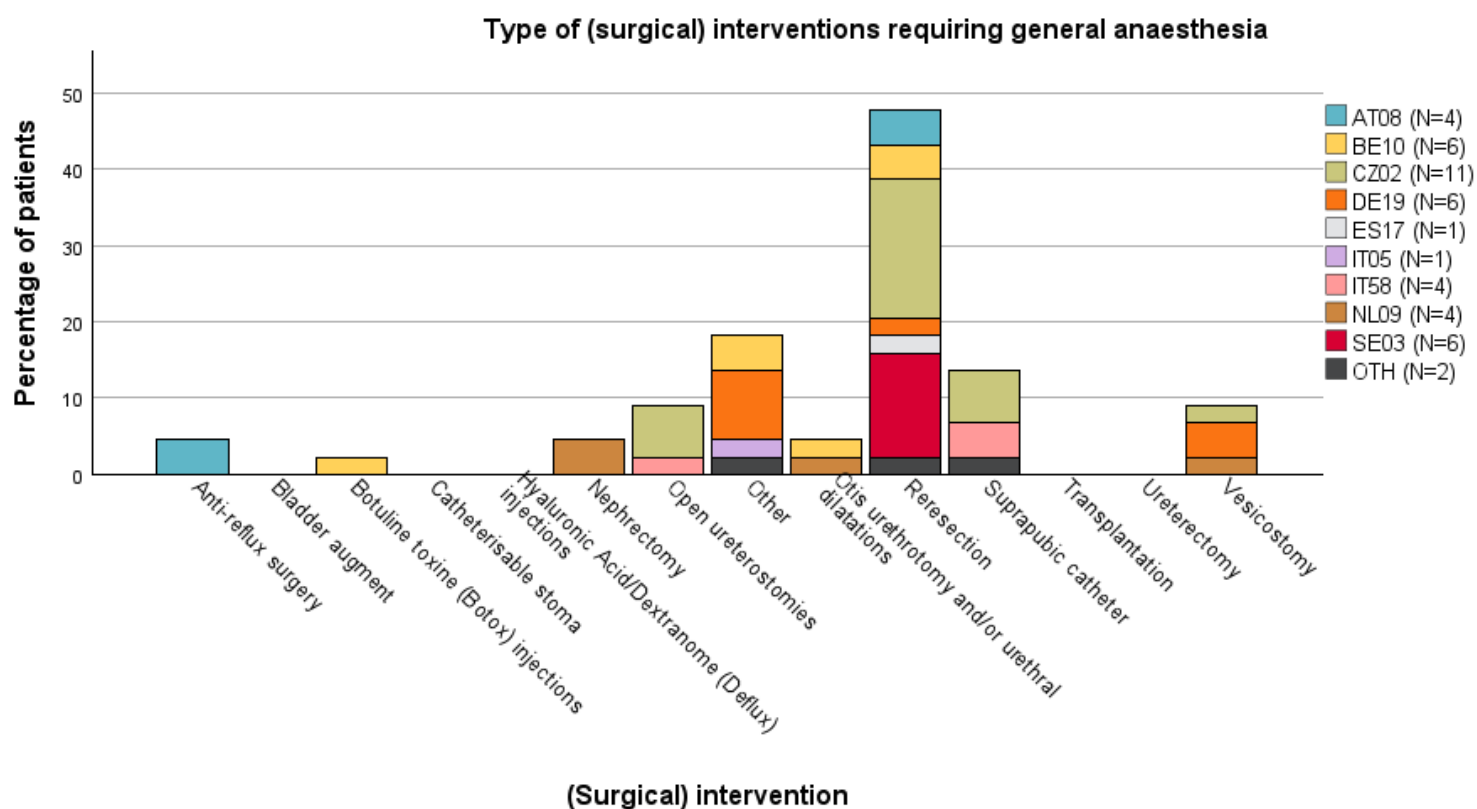


Additional (surgical) interventions requiring general anesthesia

Most patients did not need any additional interventions.



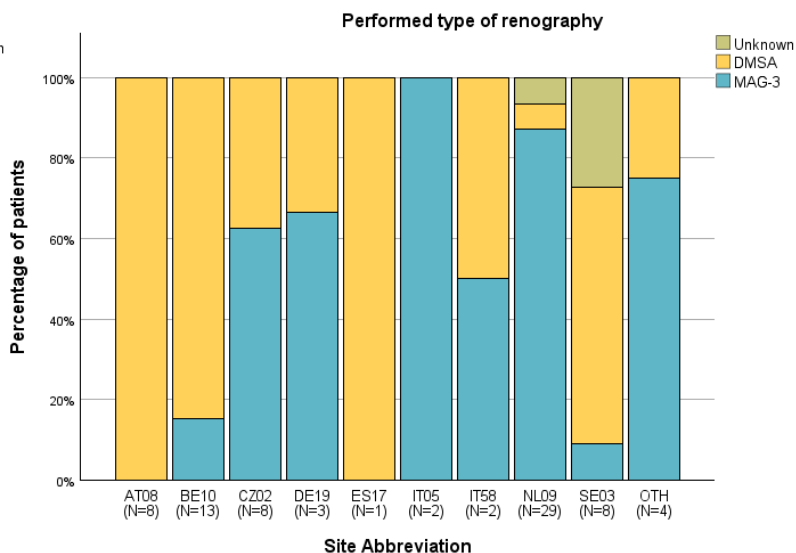
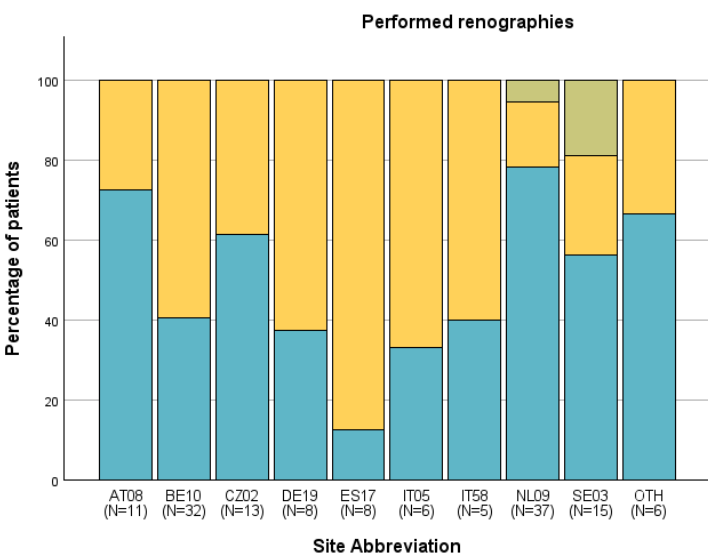
The patients who did need an additional intervention, underwent a variety of additional interventions, with reresection being the most common one.



Renography and MCG

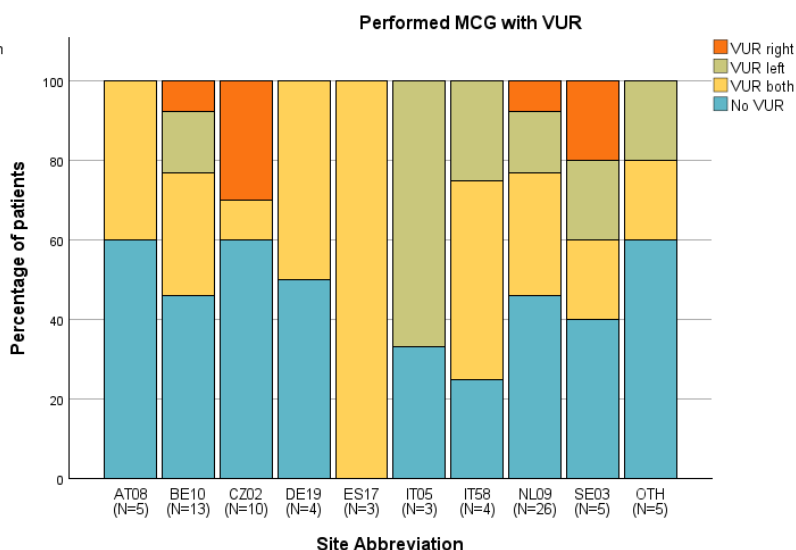
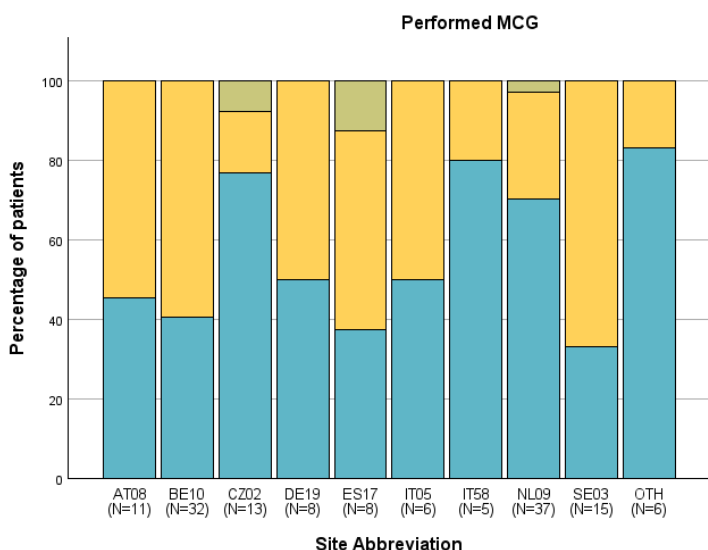
Renographies

A renography was performed for just over half of the patients, with differences in the number of performed renographies between the HCPs. If a renography was performed, it differs per HCP which renography type (DMSA or MAG-3) was performed or performed first.



MCG and VUR

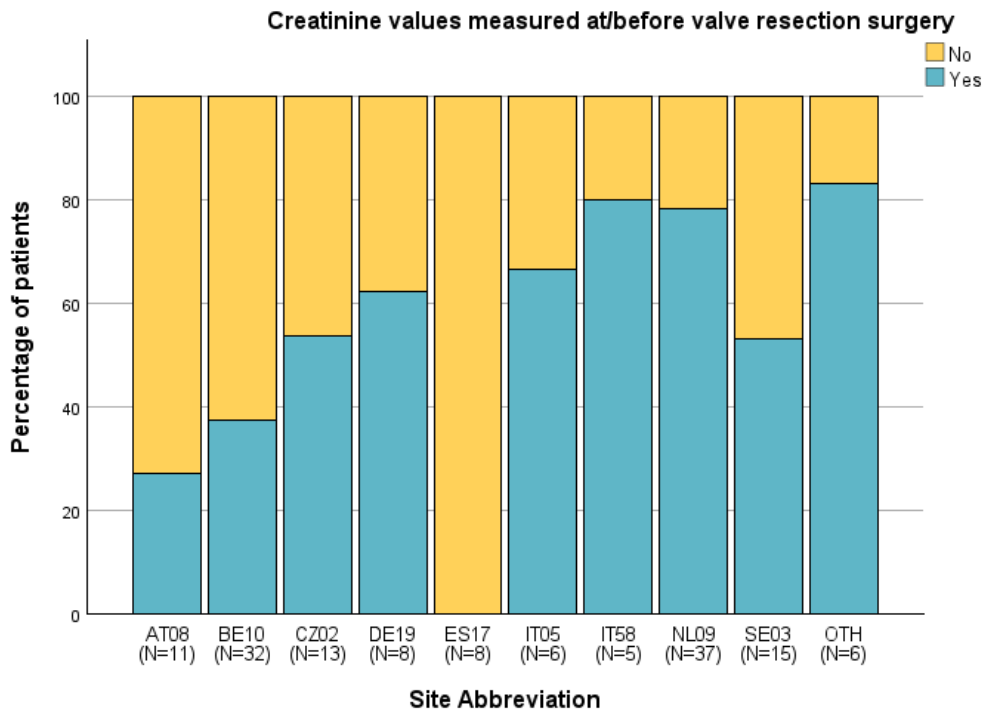
In approximately half of the patients, an MCG was performed. If an MCG was performed, no VUR was diagnosed in half of the patients. If VUR was diagnosed, it was mostly present on both sides.



Creatinine values

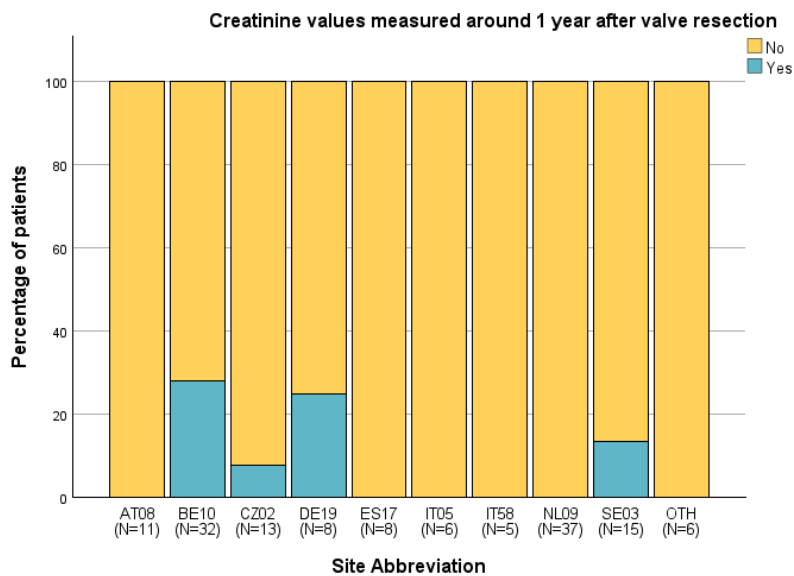
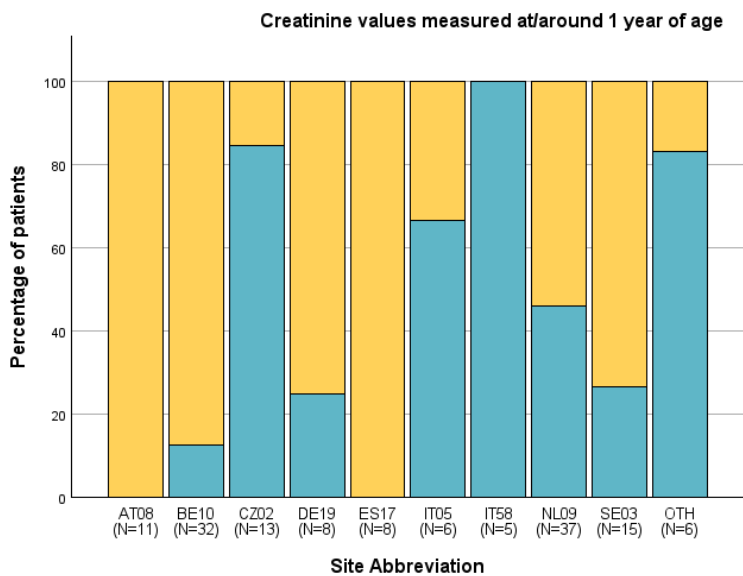
Creatinine values at or just before valve resection surgery

It varies per HCP if patients had creatinine measurements at or just before (maximum of two months before) their surgery.



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

For most patients, no follow-up creatinine values were present. If they were present, we made 2 groups; one group holds patients who had their first valve resection before the age of 1 and had a creatinine value around the age of 1. The other group contains the patients who had surgery after the age of 1 and had a creatinine value measured approximately 1 year after surgery (with a maximum of 1.5 years after surgery).





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