

# ERN eUROGEN registry

## Report on Expertise Area 1.5

### INTRODUCTION

This report entails the 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. 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 1.5 Posterior Urethral Valves 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 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. If this information was there, we interpreted it as 'No valve resection'.

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 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 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=74)	Belgium BE10 (N=32)	Spain ES17 (N=8)	Netherlands NL09 (N=34)
<b>1<sup>st</sup> surgical procedure</b>				
Valve resection (filled in for all patients)				
Valve resection in first year of treatment; N (%)	71 (95.9%)	31 (96.9%)	6 (75.0%)	34 (100%)
No valve resection in first year of treatment; N (%)	3 (4.1%)	1 (3.1%)	2 (25.0%)	-
Age at 1 <sup>st</sup> valve resection; Median (range) (N=71 (95.9%))	217 days (8;6795)	643 days (10;6795)	368 days (53;1512)	20 days (8;2858)
Type of procedure (N=71 (95.9%))				
Hot knife; N (%)	36 (49.3%)	31 (100%)	1 (16.7%)	-
Cold knife; N (%)	35 (50.7%)	-	5 (83.3%)	34 (100%)
<b>2<sup>nd</sup> surgical procedure</b>				
Performed control cystoscopies; N (%) (N=71 (95.9%))	26 (36.6%)	1 (3.2%)	4 (66.7%)	21 (61.8%)
Control cystoscopy with valve resection; N (%) (N=26 (35.1%))	16 (68.2%)	1 (100%)	0 (-)	15 (71.4%)
Days after valve resection; Median (range) (N=26 (35.1%))	98 days (49;266)	101 days (-)	174 days (135;266)	93 days (49;145)
<b>Additional interventions</b> (filled in for all patients)				
Additional intervention with anesthesia; N (%)	13 (17.6%)	6 (18.8%)	3 (37.5%)	4 (11.8%)
No additional interventions; N (%)	61 (82.4%)	26 (81.2%)	5 (62.5%)	30 (88.2%)
<b>Renography and MCG</b> (filled in for all patients)				
MAG-3/DMSA performed N (%)				
MAG-3 performed; N (%)	40 (54.0%)	13 (40.7%)	1 (12.5%)	26 (76.5%)
MAG-3 (first) performed; N (%)	26 (65.0%)	2 (15.4%)	-	24 (92.3%)
DMSA (first) performed; N (%)	14 (35.0%)	11 (84.6%)	1 (100%)	2 (7.7%)
Unknown if renography performed; N (%)	2 (2.7%)	-	-	2 (5.9%)
MCG performed, N (%)				
VUR left; N (%)	39 (52.7%)	13 (40.7%)	3 (37.5%)	23 (67.6%)
VUR right; N (%)	5 (12.8%)	2 (15.4%)	3 (100%)	3 (13.0%)
VUR both; N (%)	3 (7.7%)	1 (7.7%)	-	2 (8.7%)
No VUR; N (%)	13 (33.3%)	4 (30.8%)	-	6 (26.1%)
Unknown if MCG performed; N (%)	18 (46.2%)	6 (46.2%)	1 (100%)	12 (52.2%)
Unknown if MCG performed; N (%)	2 (3.1%)	-	-	2 (5.9%)
<b>Creatinine values</b> (filled in for all patients)				
Creatinine available before surgery; N (%)*				
Lowest value; Median (range)	38 (51.2%) 35.5 (18;208)	12 (37.5%) 29.5 (19;192)	-	26 (76.5%) 40.5 (18;208)
Creatinine available at ~ 1 year of age; N (%)				
Value at age 1; Median (range)	19 (25.7%) 31 (17;368)	4 (12.5%) 25.0 (17;39)	-	15 (44.1%) 33.0 (19;368)
Creatinine available ~1 year after surgery**; N(%)				
Value 1 yr post-surg; Median (range)	9 (10.8%) 28.0 (18;80)	9 (28.1%) 28.0 (18;80)	-	-

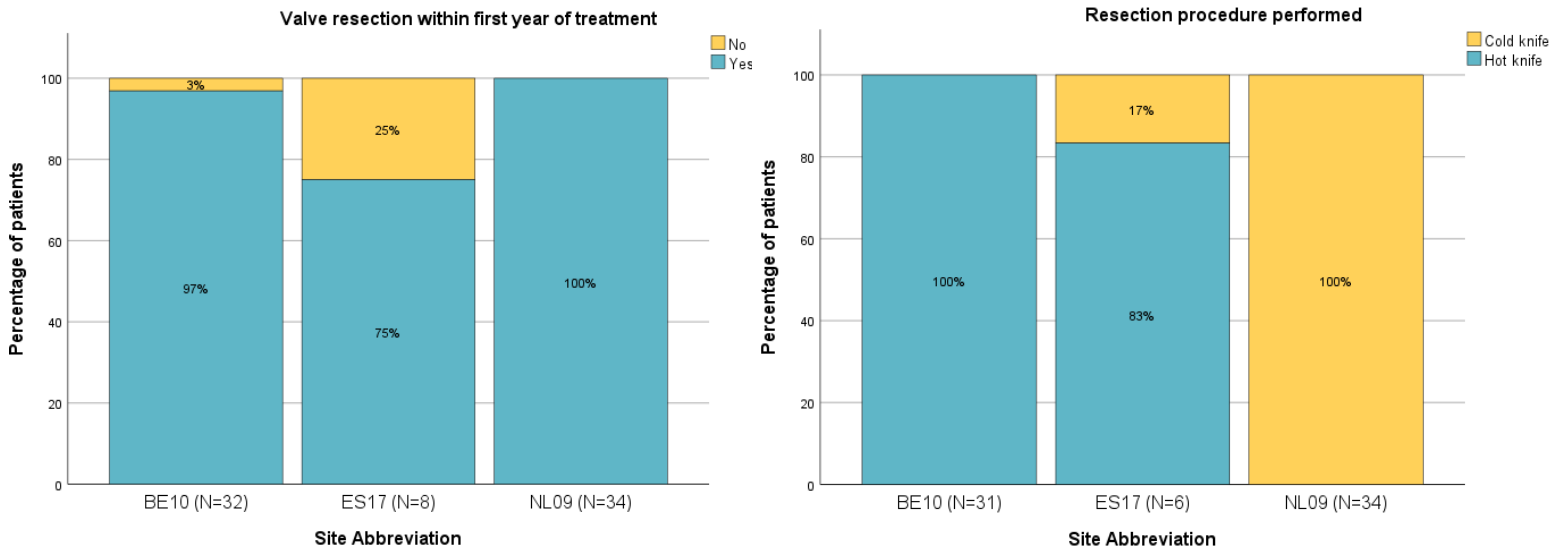
\* Creatinine values measured at or just before surgery, with a maximum until 60 days before the surgery, were included.

\*\* 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.

## 1<sup>st</sup> surgical procedure

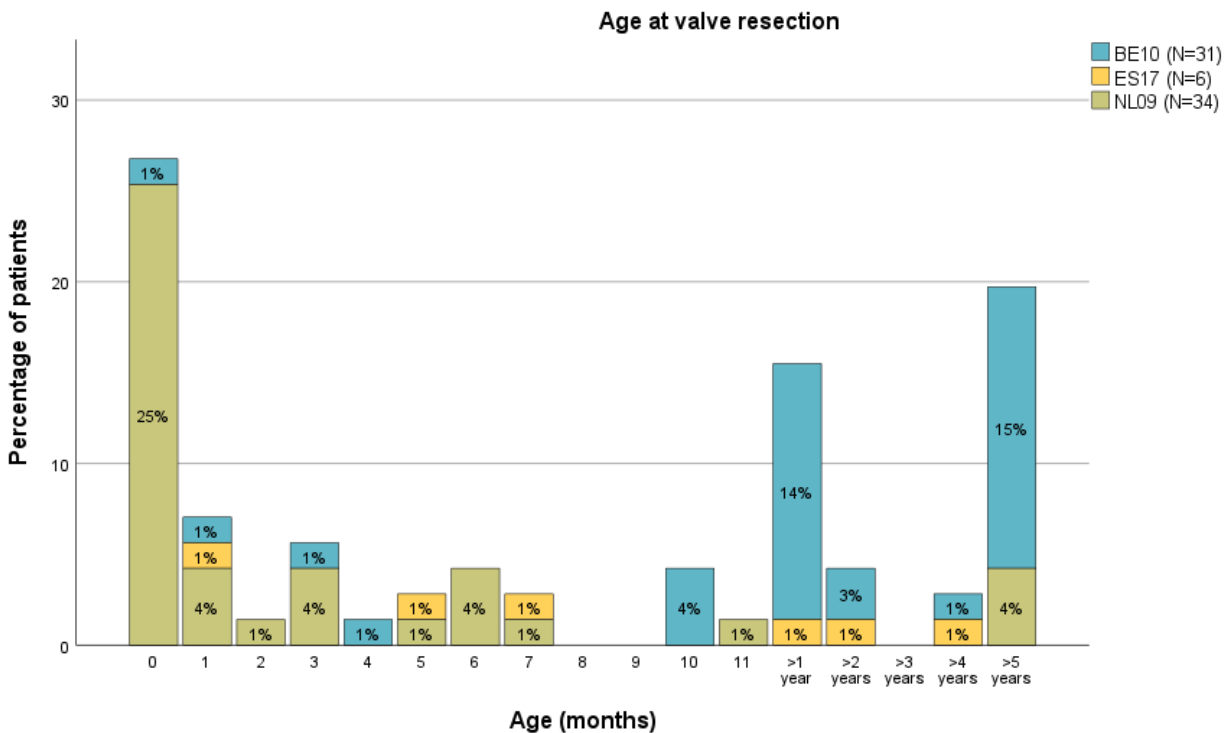
### Number of patients with valve resection in the first year after first visiting the HCP and resection procedure

Most patients received a valve resection in their first year of treatment. There is a clear difference in preferred resection procedure; NL09 uses the cold knife procedure, whereas BE10 uses the hot knife procedure. ES17 uses a mix of both resection procedures.



### Age at valve resection

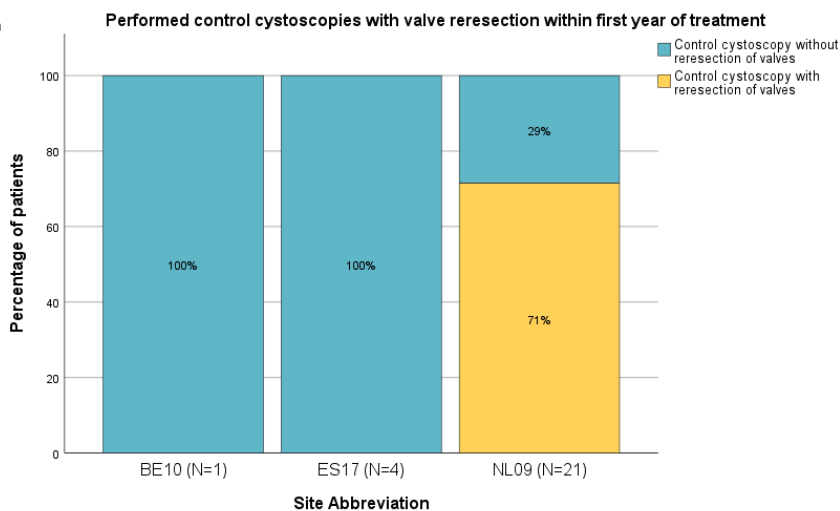
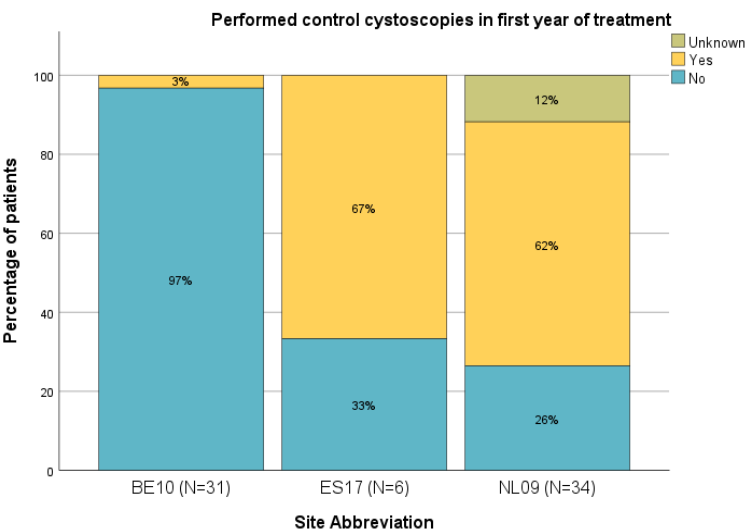
Most patients from NL09 received their valve resection in their first year of life, while a substantial group from BE10 received their valve resection when they were five years of age or older. The age at valve resection varied for the ES17 patients.



## 2nd surgical procedure

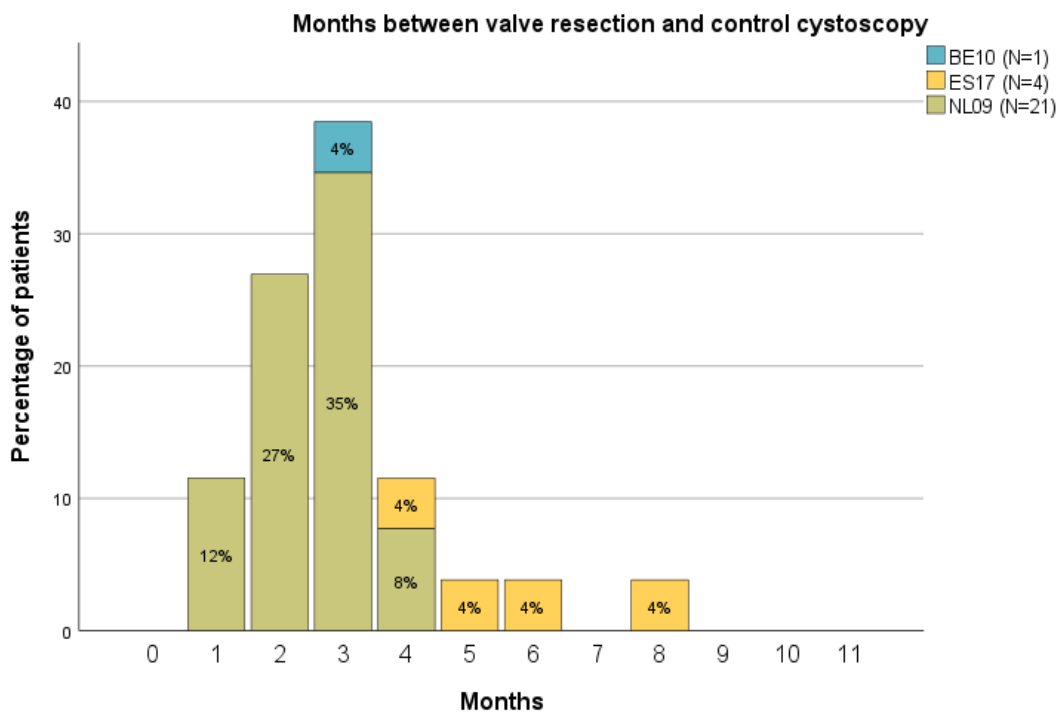
### Control cystoscopies and valve resection in the first year of treatment

Control cystoscopies were overall not performed in BE10, while they were performed in most cases in NL09 and in half of the cases in ES17. Control cystoscopies in BE10 and ES17 did not lead to resection of valves, where most control cystoscopies in NL09 did result in resection of valves.



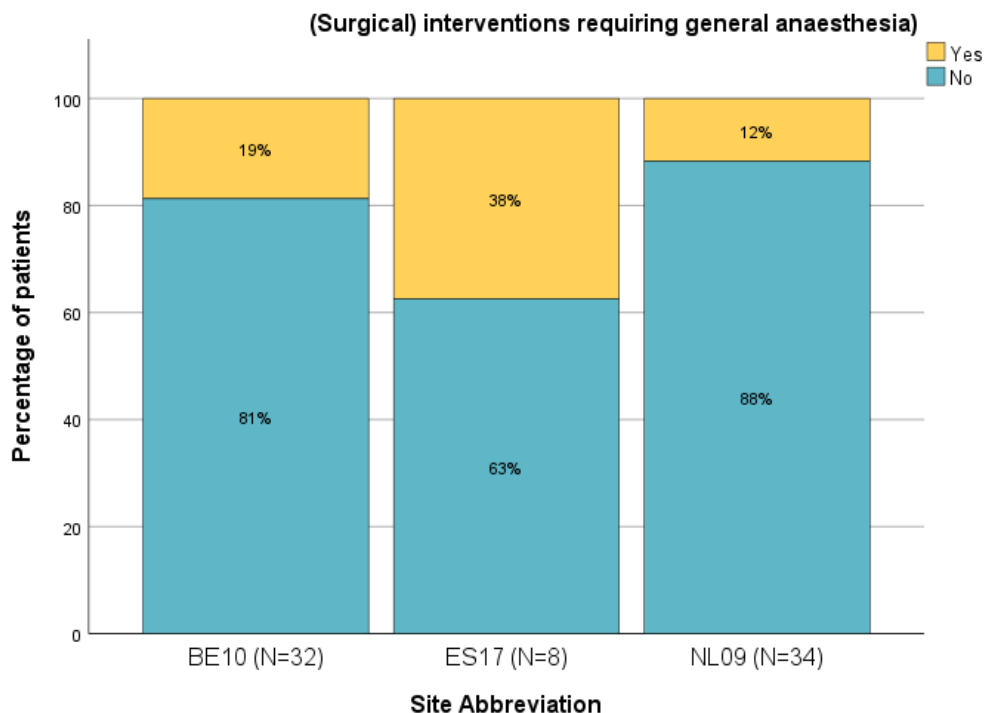
### Months between resection and control cystoscopy

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

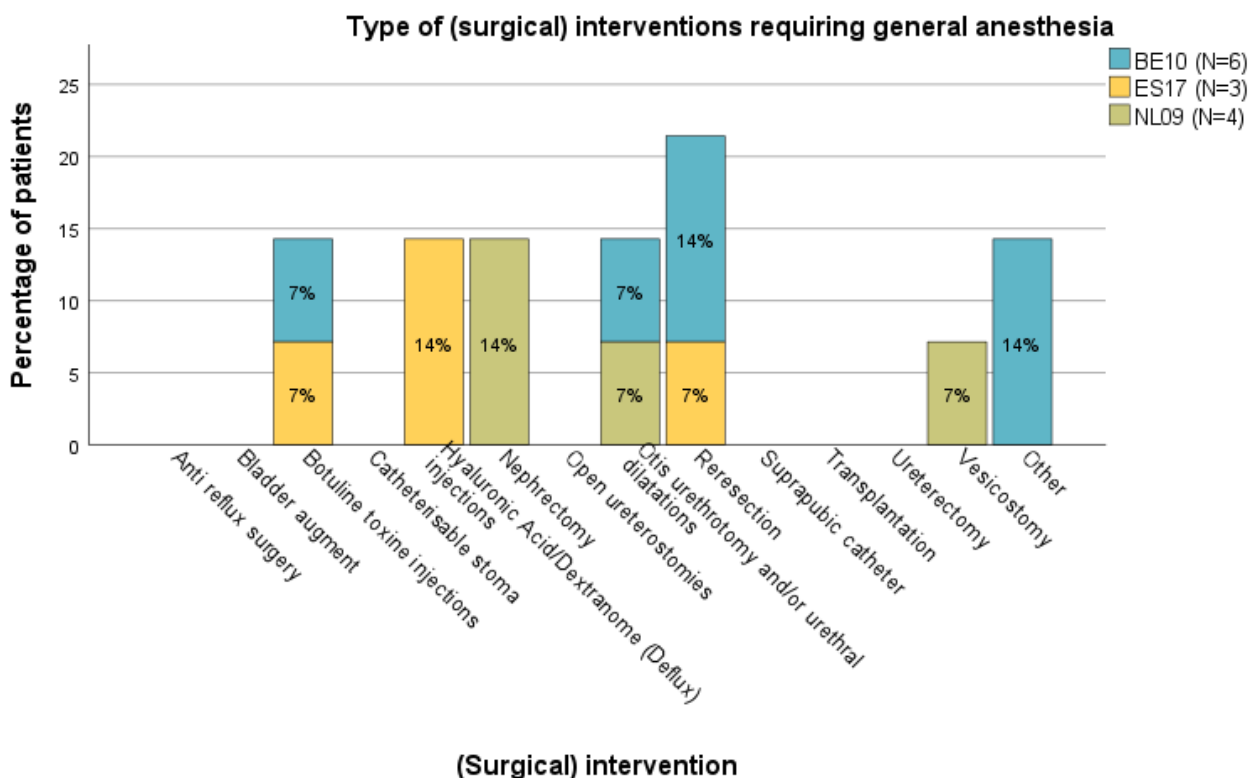


## (Surgical) interventions requiring general anaesthesia

Most patients did not need any additional interventions.



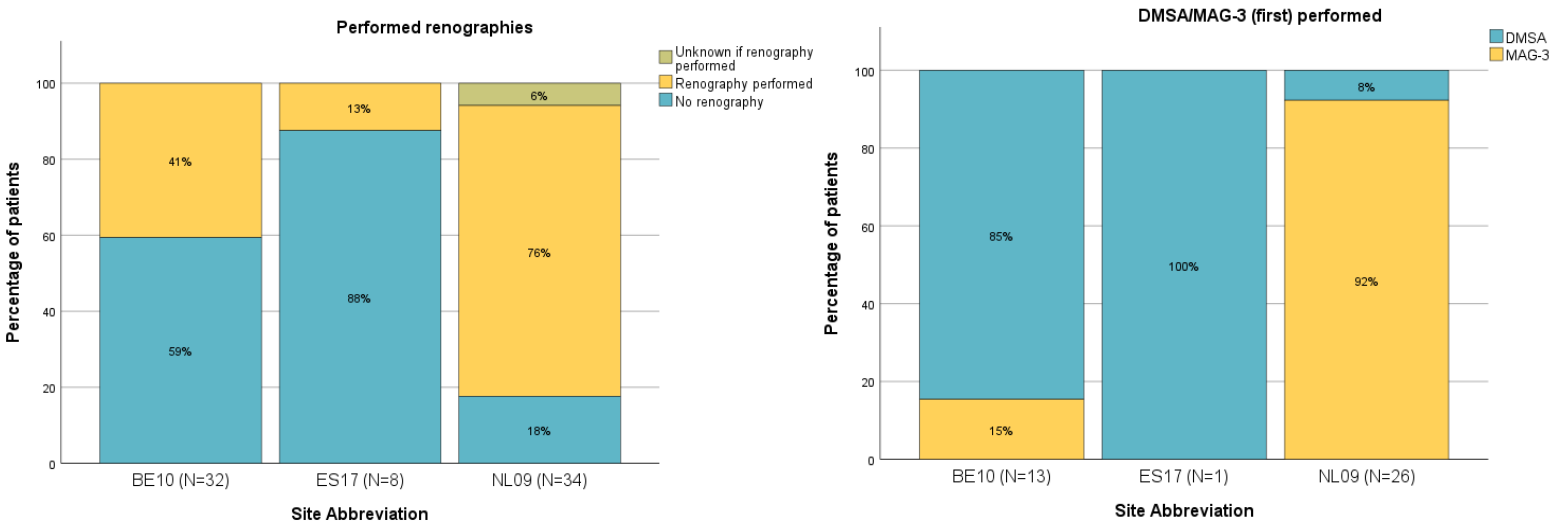
The patients who did need an additional intervention, underwent a variety of additional interventions.



# Renography and MCG

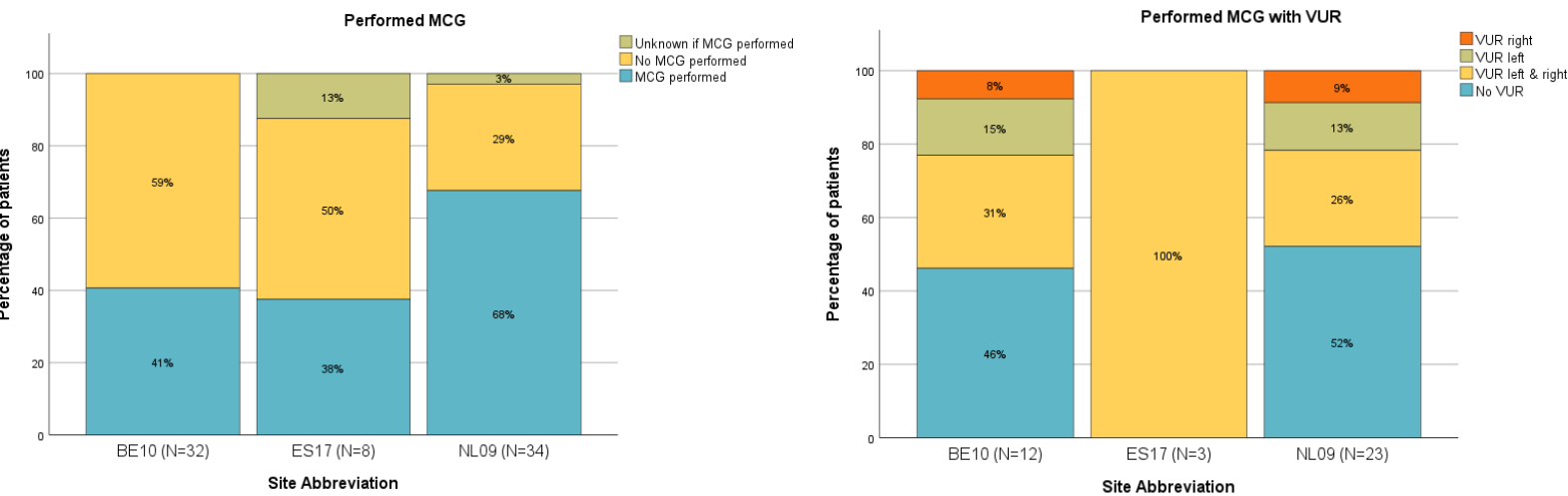
## Renographies

A renography was performed for most patients of NL09, in the other HCPs renographies were performed for a minority of the patients. If a renography was performed, it differs per HCP which renography type (DMSA or MAG-3) was performed or performed first.



## MCG and VUR

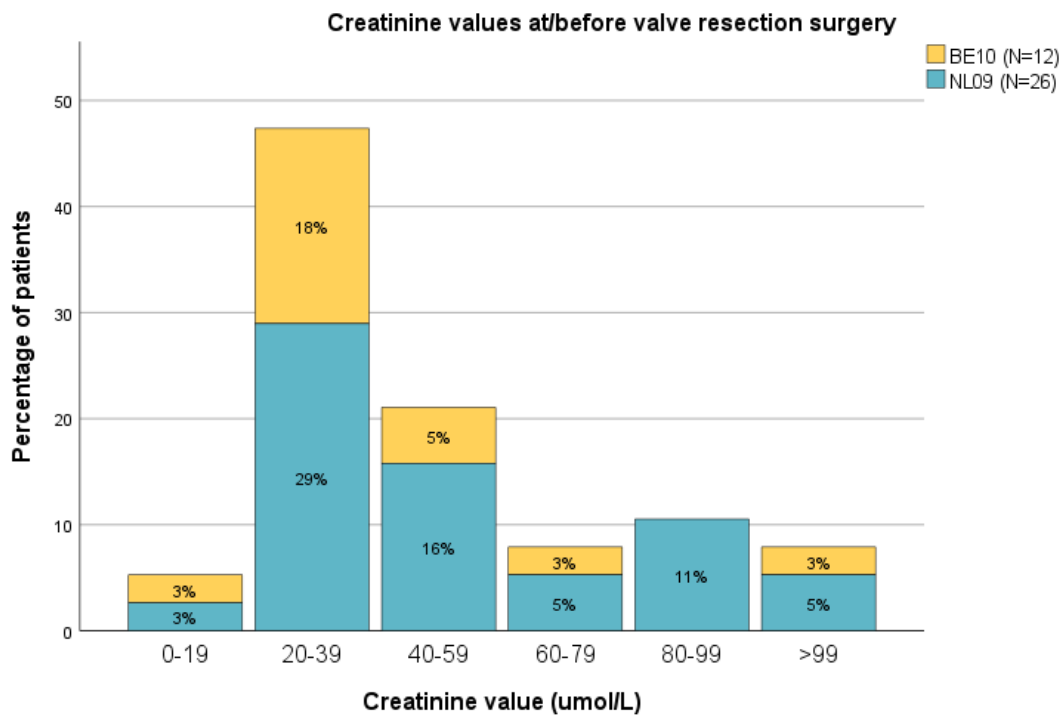
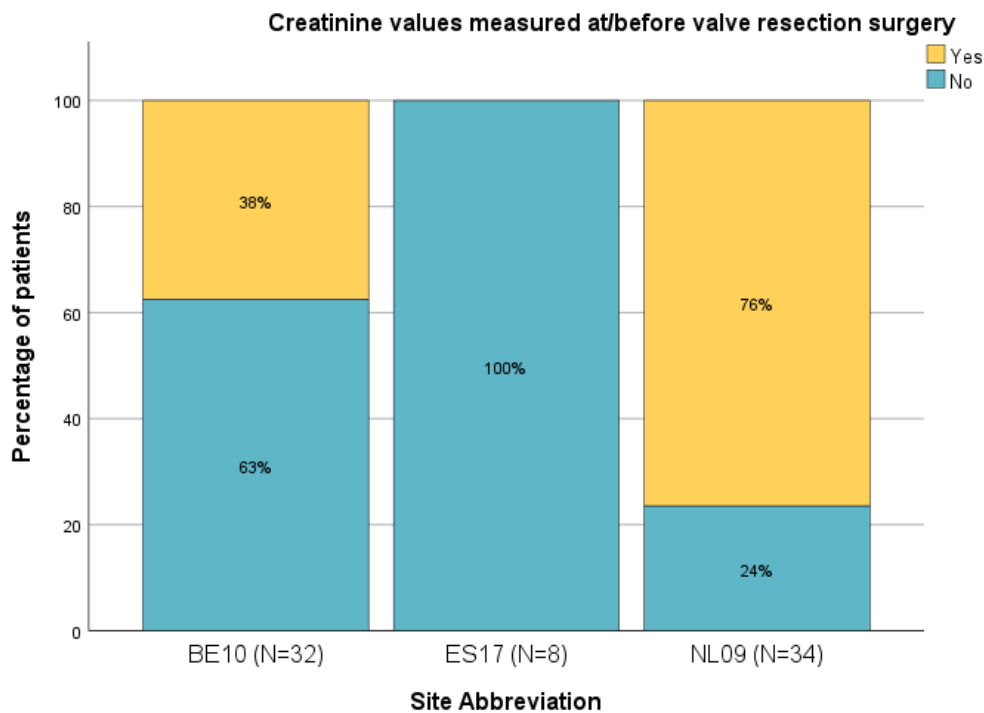
In NL09, most patients had an MCG, where in the other HCPs a minority of the patients had an MCG. If an MCG was performed, no VUR was diagnosed in half of the patients of NL09 and BE10. If VUR was diagnosed, it was mostly present on both sides.



## Creatinine values

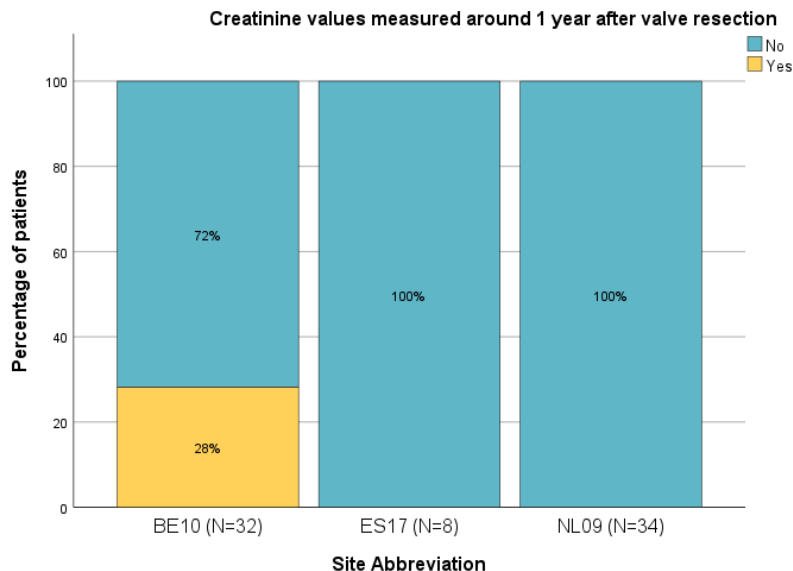
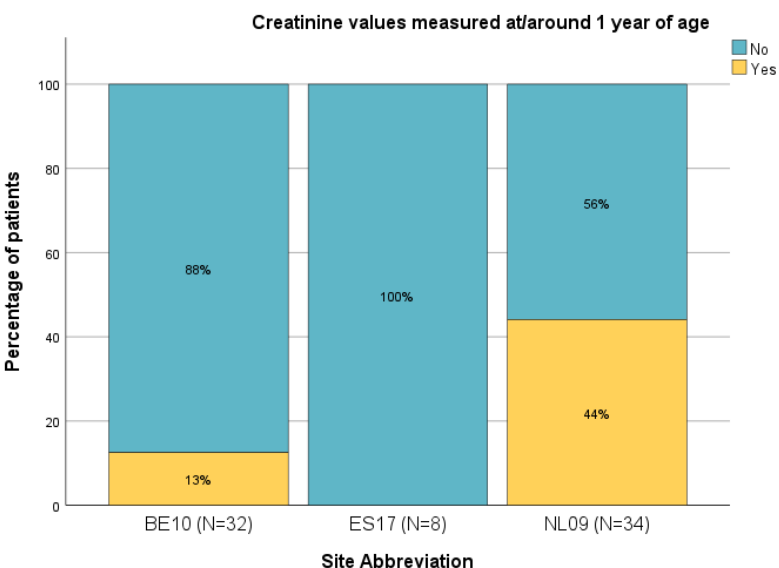
### *Creatinine values at or just before valve resection surgery*

It varies per HCP if patients had creatinine measurements at or just before (maximum of two months before) their surgery. Patients who had their creatinine measured at or just before surgery, most had a value between 20 and 39  $\mu\text{mol/L}$ .



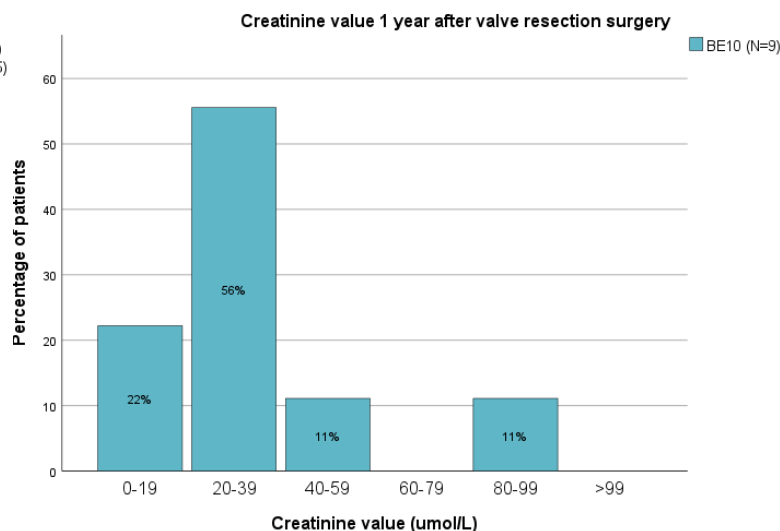
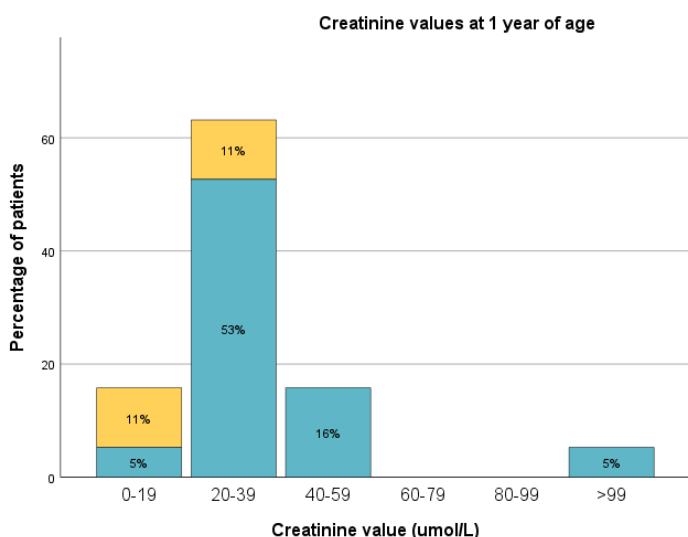
*Follow-up: measurements of creatinine values at 1 year of age and or 1 year after valve resection*

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). In both groups, most patients had a value between 20 and 30  $\mu\text{mol/L}$ .



*Creatinine values at 1 year of age or one year after resection*

If creatinine values were present, most patients had a value between 20 and 30  $\mu\text{mol/L}$ .







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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>