

# ERN eUROGEN registry FAQ 1.5 Posterior Urethral Valves

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# 1. QUESTIONS

## Common Data Elements

### 2.6 ITEM: Moment of onset (at which symptoms/signs (medical/pathological/clinical) first appeared)

**Question:** Is a dilated pyelum seen on ultrasound antenatally a symptom of PUV?

**Answer:** Yes.

**Question:** Are recurrent urinary tract infections symptoms of PUV?

**Answer:** Yes.

## 1st surgical procedure performed to resect the valves

### 5.3 ITEM: Date

**Question:** The first valve resection has been done in another hospital, the patient was then referred to my hospital for another resection, what date should I select?

**Answer:** Patients that have not had their first resection in your hospital can be included in the registry and their data should be collected for the Common Data Elements, but not for the Clinical Practice Snapshot.

### 5.4 ITEM: Procedure

**Question:** What is a cold knife and what is a hot knife?

**Answer:** A cold knife is just the cutting procedure by a scalpel (knife), whereas a hot knife is when diathermy is used.

## 2nd surgical procedure performed to check for and, if applicable, resect valve remnants

### 5.5 ITEM: Was there a control cystoscopy performed?

**Question:** What is meant with control cystoscopy?

**Answer:** A control cystoscopy is a standard planned cystoscopy after the first resection, regardless of the outcome of the surgery.

### 5.5/5.6 ITEM: Reresection of valves

**Question:** The patient had a reresection of the valves. Do I enter this reresection under control cystoscopy or additional interventions?

**Answer:** If the reresection took place during a control cystoscopy, you only have to add the reresection under the control cystoscopy item. It might be that in your HCP, a control cystoscopy after surgery is not standard practice. If the cystoscopy for reresection was only planned because e.g. persistent complaints, the reresection must be entered under (surgical) interventions requiring general anesthesia.

### 5.6/5.7 ITEM: ((non-)Surgical) interventions requiring general anesthesia

**Question:** I'm not sure if the patient had a surgical procedure or whether the patient needed general anaesthesia for the additional intervention, what do I select?

**Answer:** You can simply select the intervention you are looking for in either list.

**Question:** When during a nephrectomy, part of the ureter is also removed, should this be registered separately as nephrectomy and ureterectomy?

**Answer:** Only if the complete ureter is also removed, then yes.

**Question:** A patient has undergone an additional intervention (e.g., Botox injections), more than once, how do I register this?

**Answer:** Once you have selected intervention, you should get a question asking you whether the intervention has been done more than once. You can select “Yes” and then enter how many times the patient has undergone this intervention, and then add the date per session.

**Question:** After revision of the vesicostomy, the patient received a suprapubic catheter, should this be registered separately?

**Answer:** Yes.

**Question:** The patient received medication to treat e.g. UTIs/kidney insufficiency, should I enter this under (non-surgical) interventions requiring no general anaesthesia?

**Answer:** No. This question only concerns performed procedures.

**Question:** The patient received dialysis, how do I register this?

**Answer:** Select 'Other' under (non-surgical) interventions requiring no general anaesthesia. Then a text box appears where you can type 'Dialysis' and enter the start date of the dialysis.

#### 5.6.7 ITEM: **Was the vesicostomy performed more than 1 time?**

**Question:** Is revision and/or closure of the vesicostomy considered ‘vesicostomy performed more than one time’?

**Answer:** No, only placement(s) of vesicostomy.

## 5.8 Renal function renography MAG-3 / DMSA

**Question:** Multiple renography’s have been performed, which one should I chose?

**Answer:** You should choose the very first renography that has been performed.

## 5.9. Micturition cystourethrography (MCG) vesico-ureteric reflux (VUR)

**Question:** Multiple MCG VURs have been performed, which one should I chose?

**Answer:** You should choose the very first MCG that has been performed.

## 5.10 Lowest creatinine

#### 5.10.2 ITEM: **Date lowest creatinine was measured at or before surgery**

**Question:** The date of the lowest creatinine measure was the date of birth, is this okay?

**Answer:** Yes, the date of the lowest creatinine measure can be anywhere from birth to the day of surgery.

#### 5.10.4 ITEM: **Date creatinine was measured at one year of age or if patient is older, at approximately one year after surgery**

**Question:** The patient underwent surgery at a later age, what date and value should I enter for creatinine measurement?

**Answer:** Choose the date and value closest to approximately one year after surgery.

**Question:** The closest date of creatinine measurement is two years after surgery, is this okay?

**Answer:** Yes, this is fine.



# European Reference Networks

[https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)



## European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Urogenital Diseases  
(ERN eUROGEN)

<http://eurogen-ern.eu/>



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