



Network
 Urogenital Diseases (ERN eUROGEN)

ERN eUROGEN registry Report on Common Data Elements

INTRODUCTION

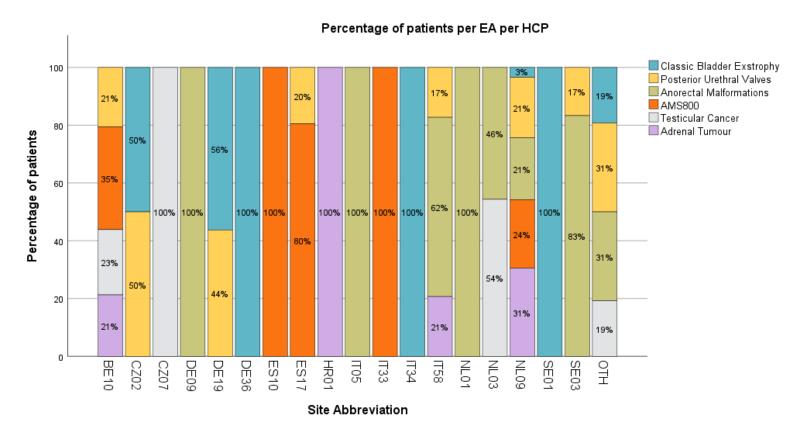
This report shows the number of patients for which a Clinical Practice Snapshot was filled out in the ERN eUROGEN registry. The included Expertise Areas are 1.2 Classic Bladder Exstrophy, 1.5 Posterior Urethral Valves, 1.7 Anorectal Malformations, 2.1 Complicated and complex pelvic floor disorders: AMS800 device, 3.2 Testicular Cancer and 3.3 Adrenal Tumours. Currently, the ERN eUROGEN registry includes almost 1500 patients, but only 738 patients are included in the current analysis. For the remaining patients, only the Common Data Elements were filled out. Only the HCPs who completely entered the Clinical Practice Snapshot of an Expertise Area for at least 5 patients are included individually in this report. The remaining HCPs, with less than 5 included patients per Expertise Area, are aggregated and included under 'Others'.

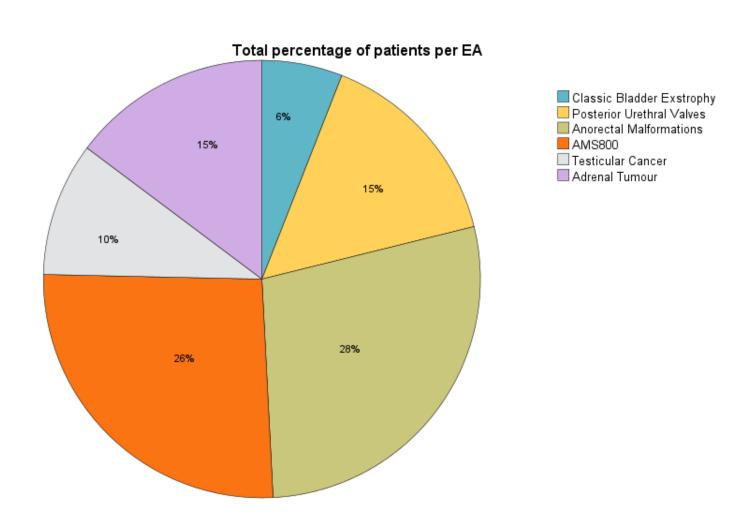
COMMON DATA ELEMENTS

Patient numbers

Overview of retrospective patients entered in the ERN eUROGEN registry per HCP and per Expertise Area (EA).

HCP EA	1.2 - CBE	1.5 - PUV	1.7 - ARM	2.1 - AMS800	3.2 - TEC	3.3 - ADT	TOTAL
BE10 - Leuven UZ		32		55	35	33	155
CZ02 - Prague VFN	8	8					16
CZ07 - Prague Thomayer					8		8
DE09 - Bremen-Mitte Klinik			51				51
DE19 - Regensburg UK	9	7					16
DE36 - Ulm UK	6						6
ES10 - Madrid 12 de Octubre				44			44
ES17 - Barcelona Fundacio Puigvert		8		33			41
HR01 - Zagreb KBC						16	16
IT05 - Bergamo Papa Giovanni XXIII			8				8
IT33 - Rome Gemelli				19			19
IT34 - Milan Policlinico	5						5
IT58 - Rome Bambino Gesu		5	18			6	29
NL01 - Amsterdam AMC			28				28
NL03 - Rotterdam Erasmus			21		25		46
NL09 - Nijmegen Radboudumc	6	37	38	42		54	177
SE01 - Stockholm Karolinska	5						5
SE03 - Lund SUS		7	35				42
OTH - Others	5	8	8		5		26
TOTAL	44	112	207	193	73	109	738









for rare or low prevalence complex diseases

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http://eurogen-ern.eu/



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