ERKReg

ERKNet

The European Rare Kidney Disease Registry

Disclosure

I have no actual or potential conflict of interest in relation to this presentation

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On behalf of Prof. Franz Schaefer

ERKReg
The European Rare Kidney Disease Registry

ERKNet

Network-wide single core registry for all rare kidney disease in pediatric and adult patients

Objectives:

➢ Continous and comprehensive collection of relevant patient information

➢ Identify currently patient cohorts for clinical research

➢ Performance assessment, benchmarking: Disease-specific key quality and outcome indicators

Open to all European nephrology centers interested in rare diseases

Registry Concept

- Core registry to obtain basic information (and disease specific performance information) from all RD patients in all ERN centers

- External links to existing disease specific registries

- Integration of new disease specific registries (first use case: ESPN distal RTA Registry)

ERN-wide Data Collection
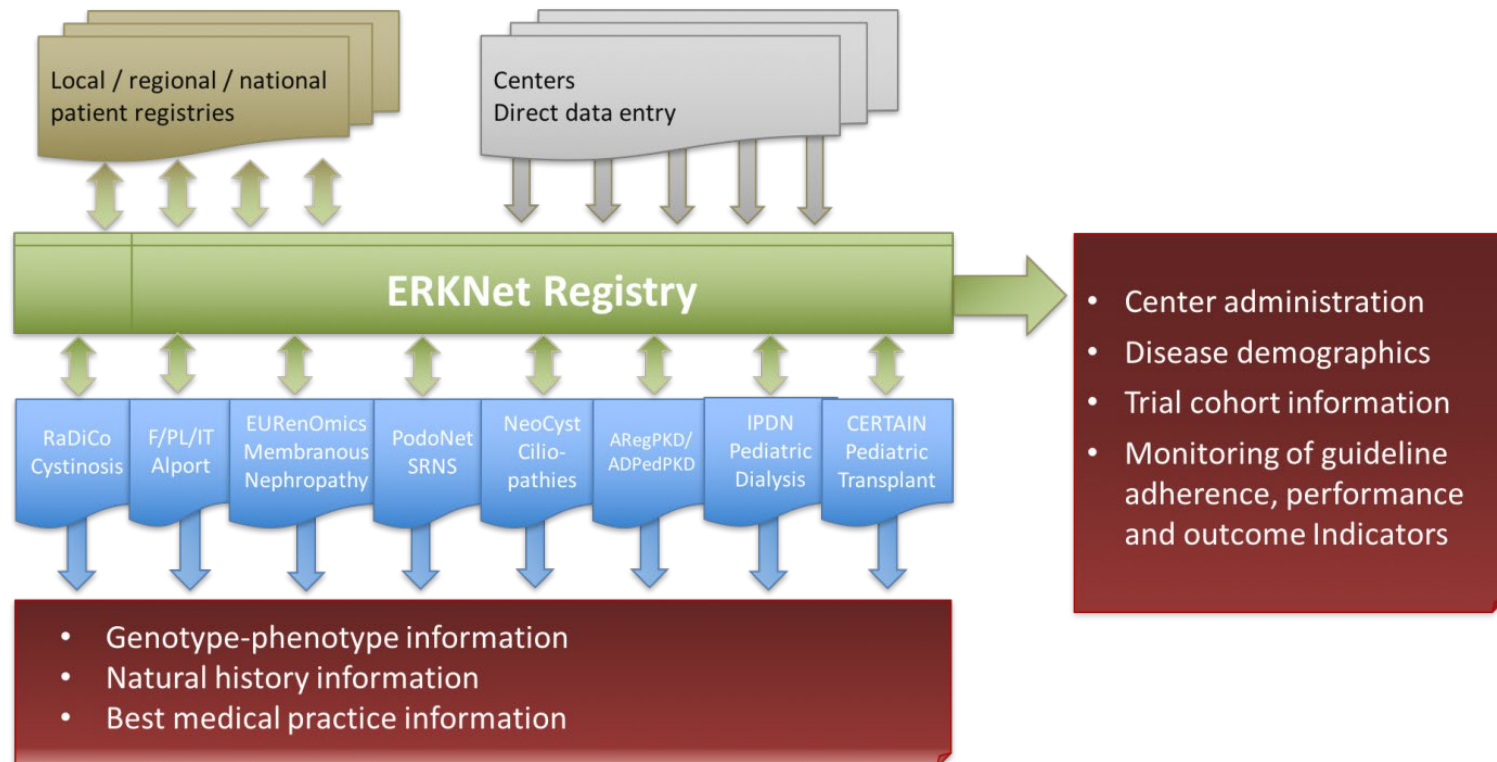
ERKReg collects **two datasets:**

(1) A **common data set (CDS)** including
- the JRC minimum data set, ensuring full inter-operability with other RD registries
- essential information relevant to all patients with rare kidney diseases.

(2) **A Disease-specific data set.** 40 key performance and outcome indicators **(KPI)** were defined by the thematic workgroups in a Delphi consensus-building process following structured review of existing clinical guidelines

Performance and Outcome Monitoring

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Incentive for ERN centers:

Efficient Quality Monitoring and Outcomes Benchmarking

You are logged in as
admin_schaefer

Logout

Registry start page

Data entry

Statistics & Benchmarking
General
Glomerulopathies
Tubulopathies & metabolic nephropathies
Thrombotic microangiopathies
Structural kidney disorders
CAKUT, Ciliopathies & OUP
Pediatric CKD
Pediatric Dialysis
Pediatric Transplantation

Enrolment by center

Downloads

Administration Area

ERKNet Home Page

Statistics & Benchmarking: Tubulopathies & metabolic nephropathies

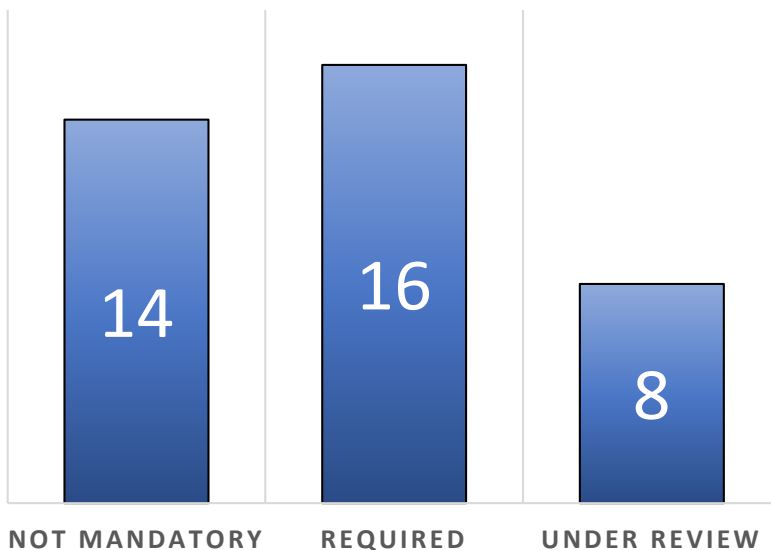|	Pediatric patients		Adult patients	
	Your center	All ERKNet centers	Your center	All ERKNet centers
% children (<16y) with normal length/height SDS	66.7 % (2/3)	66.7 % (2/3)	---	---
% patients with hereditary nephropathy with genetic confirmation	50.0 % (2/4)	50.0 % (2/4)	---	0.0 % (0/0)
% patients with renal tubular acidosis maintaining normal serum bicarbonate	50.0 % (1/2)	50.0 % (1/2)	---	0.0 % (0/0)
% cystinosis patients with documented cystein level in therapeutic range	50.0 % (1/2)	50.0 % (1/2)	---	0.0 % (0/0)
% cystinuria patients free of new stones in past 12 months	0.0 % (0/0)	0.0 % (0/0)	---	0.0 % (0/0)

HCP Local Ethics Approval

September 2018:

All ERKNet centers were asked to clarify whether formal ethics approval is required to use ERN IC forms for use in clinical registry

STATUS NOV 2018

NOT MANDATORY	REQUIRED	UNDER REVIEW
14	16	8

GDPR-conforming informed consent forms designed by the EU Commission for ERN patients

Operational Support Team

ERKReg
The European Rare Kidney Disease Registry

➢ Regional contact for different European regions

➢ Provides technical, administrative and practical help
for both CPMS and ERKNet Registry

➢ Regular on-site visits (1 to 2/year) by a tutor to help updating patient entries

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Nijmegen

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Gdansk

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ERKNet Helpdesk Team