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EDITORIAL

A snapshot of European registries on chronic kidney disease patients not on kidney replacement therapy

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BACKGROUND

Traditionally, renal registries collect and report population-based epidemiological data on patients with kidney failure who are treated by kidney replacement therapy (KRT), i.e. dialysis or transplantation. Over the past decade, a number of these registries have started to widen the inclusion of patients to those with kidney failure treated with comprehensive conservative management and in some cases to earlier stages of chronic kidney disease (CKD), leading to, for example, CKD Stages 4–5 registries. As a result, they are increasing their value by not only providing numbers on those receiving or refraining from extremely expensive therapies, but also to stages of CKD in which kidney failure may still be prevented.

The European Renal Association (ERA) Registry currently collects data on patients treated by KRT and uses them for comparison and collaborative research. In this article we report the current status of CKD registries in Europe in relation to their data collection on patients not on KRT so that in the future we may investigate to what extent their data may be used for similar purposes, such as collaborative research on CKD trajectories and patient outcomes.

CKD REGISTRIES IN EUROPE

Information was collected from six existing CKD registries and one in preparation. Most had been started by the boards of the national KRT registry with which they formed one registry, but in Romania the CKD registry was separate from that on KRT (Table 1). The Czech registry was fully funded by non-governmental sources, whereas five others—those in French-speaking Belgium, France, Norway, Romania and Sweden—managed to secure at least partial funding from their ministries of health or other healthcare system authorities, mostly for the set-up or maintenance of their web-based data collection platforms. In the majority of cases, data collection was voluntary.

RESEARCH OBJECTIVES AND PATIENT POPULATIONS COVERED

While most registries aimed to conduct epidemiological and clinical research now or in the future, health economics research was also among their objectives. Four registries—those from French-speaking Belgium, Czech Republic, Norway and

Table 1. CKD registry characteristics, as of March 2021

Characteristics	French-speaking Belgium	Czech Republic	Finland	France	Norway	Romania	Sweden
Initiator	Board of French-speaking registry (GNFB)	Czech Society of Nephrology (CSN)	Board of Finnish Registry for Kidney Diseases	Board of French KRT Registry (REIN)	Ministry of Health	Romanian Association of Nephrology, Dialysis and Vascular Access	Board of Swedish Renal Registry (SRR)
Financial and other support in addition to any support received from the hosting departments	Federal Ministry of Health (data collection system)	Czech Society of Nephrology	To be specified	French KRT Registry (REIN; data collection system); and hospitals (labour force for data entry)	Ministry of Health	Romanian Association of Nephrology, Dialysis and Vascular Access and Ministry of Health (set-up and maintenance of data collection system) and hospitals (labour force for data entry)	Swedish Association of Local Authorities and Regions and clinic fees
Objectives							
Epidemiological research	+	+	+	In the future	+	+	+
Clinical research	+	+	+	−	+	In the future	+
Health economics research	−	+	−	In the future	+	In the future	−
Quality improvement (QI) through benchmarking	+	+	+	−	+	−	+[a]
Understand access to KRT and conservative care	−	−	−	+	+	−	−
Forecast future care needs	−	−	+	+	+	In the future	+
Providing data for bundle payment	−	−	−	+	−	−	−
Year of start	2015	2009	In preparation	2019	2016	2018	2008
Obligatory data collection	No	No	No	Only for those collecting data for bundle payment	Yes	Yes	No
CKD stages included	1–5	Serum creatinine >300 µmol/L in men and 250 µmol/L in women[b]	4–5 (eGFR dropping below 20 mL/min/1.73 m^2)	4–5 (since 2020 and 2019, respectively)	5	1–5	4–5 (all centres include patients with eGFR dropping below 30 mL/min/1.73 m^2; some centres include from 45 mL/min/1.73 m^2)
CKD patients included							
Age range	Adults only	Adults only	None	All ages	All ages	All ages	Adults only
N	2348	5816	None	>2500	1615	15 601	47 804
Per cent coverage of CKD patients treated by nephrologists	Unknown	40	NA	Unknown	65–85	Unknown	75%
Participating centres (*n*/*N*)	10/34	73/115	None	59/1233	26/26	80/unknown	47/48
Publication of annual reports	In the future	Yes	In the future	In the future	Yes	Yes	Yes

[a]QI benchmarks: blood pressure (percentage <140/90 mm/Hg), phosphate (percentage <1.6 mmol/L), haemoglobin 10–12 g/dL if on erythropoiesis-stimulating agent, percentage diagnosed with PRD, percentage on angiotensin-converting enzyme inhibitor/angiotensin II recpetor blocker if diabetic kidney disease.
[b]eGFR determined by the Chronic Kidney Diease Epidemiology Collaboration equation available for further distribution of CKD stages.

Table 2. Data collection besides laboratory test results

Characterisitcs	French-speaking Belgium	Czech Republic[a]	Finland	France	Norway	Romania[a]	Sweden[a]
Methods	Manual data entry in web platform	Electronic automated data extraction	Manual data entry in web platform	Manual data entry in web platform	Paper forms	Manual data entry in web platform	Manual data entry in web platform (but patient-reported outcomes are entered by patients online)
Patient identifier	French-Belgian ESRD Registry identification number	National identification number and Registry identification number	National insurance number	REIN identification number	National identification number	National identification number	National insurance number
Follow-up scheme	Every year or at change of CKD stage	Every year	TBD	At 3 months after inclusion; thereafter every year. For bundle payment every 6 months	Every year	At each patient visit	Every year; <20 mL/min/1.73 m^2 every 6 months
Patient characteristics at inclusion							
Demographics	+	+	+	+	+	+	+
Education level	−	−	TBD	+	−	−	−
Living conditions	−	−	TBD	+	−	−	−
PRD	+	+	+	+	+	+	+
Date first visit to nephrologist	+	+	TBD	+	−	−	+
Date first eGFR <15 mL/min/1.73 m^2	−	−	TBD	+	+	−	+
Comorbidities	+	+	TBD	+	+	+	+
Height	+	+	TBD	+	+	+	+
Weight	+	+	TBD	+	+	+	+
Blood pressure	−	+	TBD	−	+	−	+
Planned care (KRT versus non-KRT versus not fixed/discussed)	−	−	TBD	+	+	−	−
Patient characteristics during follow-up							
Living conditions	−	−	TBD	+	−	−	−
Comorbidities	−	+	TBD	+[b]	+	+	+
Height	−	+	TBD	−	−	+	+
Weight	−	+	TBD	−	+	+	+
Blood pressure	−	+	TBD	−	+	−	+

Continued

Table 2. Continued

Characterisitcs	French-speaking Belgium	Czech Republic[a]	Finland	France	Norway	Romania[a]	Sweden[a]
Planned care (KRT versus non-KRT versus not fixed/ discussed)	−	−	TBD	+	−	−	+
Treatment at inclusion							
Antihypertensives	−	+	TBD	−	+	+	+
Antidiabetics	−	−	TBD	−	+	+	−
Diuretics	−	+	TBD	−	−	+	+
ESA	−	+	TBD	−	+	+	+
Iron	−	−	TBD	−	−	+	+
Ketoanalogues	−	+	TBD	−	−	+	−
Phosphate binders	−	+	TBD	−	+	+	+
Protein intake recommendation	−	−	TBD	−	−	+	−
Statins	−	+	TBD	−	+	+	+
Vitamin D analogues	−	+	TBD	−	+	+	+
Vit D supplements	−	+	TBD	−	−	+	+
Treatment during follow-up							
Antihypertensives	−	+	TBD	−	+	+	+
Antidiabetics	−	−	TBD	−	+	+	−
Diuretics	−	−	TBD	−	−	+	+
ESA	−	+	TBD	−	+	+	+
Iron	−	−	TBD	−	−	+	+
Ketoanalogues	−	+	TBD	−	−	+	−
Phosphate binders	−	+	TBD	−	+	+	+
Protein intake recommendation	−	−	TBD	−	−	+	−
Statins	−	−	TBD	−	+	+	+
Vitamin D analogues	−	+	TBD	−	+	+	+
Vitamin D supplements	−	+	TBD	−	−	+	+
Outcomes							
CKD progression	+	+	+	+	+	+	+
Acute kidney injury	−	−	TBD	−	−	+	−
Dialysis	+	+	TBD	+	+	+	+
Transplant waiting list	−	+	TBD	+	+	−	−
Transplantation	+	+	TBD	+	+	+	+
Patient-reported outcomes	−	−	TBD	−	−	−	+
Death	+	+	TBD	+	+	+	+
Cause of death	+	+	TBD	+	+	−	+

[a]Collection of medications data through Anatomical Therapeutic Chemical or similar codes.
[b]For bundle payment.+, positive; −, negative; TBD, to be determizned.

Table 3. Data collection with respect to laboratory test results

Characteristics	French-speaking Belgium	Czech Republic	Finland	France	Norway	Romania	Sweden
Laboratory test results at inclusion							
ACR	−	−	TBD	−	+	+	+[a]
eGFR	−	+	TBD	+	+	+	+[a]
Serum/plasma							
Sodium	−	−	TBD	−	−	+	−
Potassium	−	+	TBD	−	−	+	+
Bicarbonate	−	−	TBD	−	+	+	+
Calcium	+	+	TBD	−	+	+	+[a]
Phosphate	+	+	TBD	−	+	+	+[a]
Uric acid	−	+	TBD	−	−	+	+
Urea	−	−	TBD	−	+	+	+
Creatinine	−	+	TBD	−	+	+	+
Cholesterol	−	+	TBD	−	−	+	+
Triglycerides	−	+	TBD	−	−	+	+
Haemoglobin	+	+	TBD	−	+	+	+[a]
Iron	+	−	TBD	−	−	+	−
TSAT	−	−	TBD	−	−	−	+
Ferritin	−	+	TBD	−	−	+	+
Albumin	−	+	TBD	−	+	+	+[a]
CRP	−	+	TBD	−	−	+	+[a]
HbA1c	−	−	TBD	−	−	+	+
PTH	−	+	TBD	−	+	+	+[a]
Urine							
Albumin (spot urine)	−	−	TBD	−	−	+	+[a]
Creatinine (spot urine)	−	−	TBD	−	−	+	+[a]
Proteinuria (24 h)	−	+	TBD	+[b]	−	+	−
Laboratory test results during follow-up							
ACR	−	−	TBD	−	+	+	+[a]
eGFR	−	+	TBD	+	+	+	+[a]
Serum/plasma							
Sodium	−	−	TBD	−	−	+	−
Potassium	−	+	TBD	−	−	+	+
Bicarbonate	−	−	TBD	−	+	+	+
Calcium	+	+	TBD	−	+	+	+[a]
Phosphate	+	+	TBD	−	+	+	+[a]
Uric acid	−	+	TBD	−	−	+	+
Urea	−	−	TBD	−	+	+	+
Creatinine	−	+	TBD	−	+	+	+[a]
Cholesterol	−	+	TBD	−	−	+	+
Triglycerides	−	+	TBD	−	−	+	+
Haemoglobin	+	+	TBD	−	+	+	+[a]
Iron	+	−	TBD	−	−	+	−
TSAT	−	−	TBD	−	−	−	+
Ferritin	−	+	TBD	−	−	+	+
Albumin	−	+	TBD	−	+	+	+[a]
CRP	−	+	TBD	−	−	+	+[a]
HbA1c	−	−	TBD	−	+	+	+
PTH	−	+	TBD	−	+	+	+[a]
Urine							
Albumin (spot urine)	−	−	TBD	−	−	+	−
Creatinine (spot urine)	−	−	TBD	−	−	+	+[a]
Proteinuria (24 h)	−	+	TBD	+[b]	−	+	−

[a]Mandatory.
[b]For bundle payment.+, positive; −, negative; ACR, albumin:creatinine ratio; CRP, C-reactive protein; HbA1c, haemoglobin A1c; PTH, parathyroid hormone; TBD, to be determined; TSAT, transferrin saturation.

Sweden—specifically aimed for quality improvement making use of benchmarking.

Patient inclusion was mostly restricted to CKD Stages 4 and 5 patients from nephrology departments. In Norway, however, the inclusion was limited to CKD Stage 5 patients, whereas in French-speaking Belgium and Romania the registry was set up to include all stages of CKD. With an estimated 75%, the coverage of the CKD patients treated by nephrologists was highest in Sweden, followed by Norway, which also included more than half of the patients. Undoubtedly the difficulty in reaching full coverage is caused by the relatively high number of patients suffering from this

condition and by the fact that a substantial number of them may be followed by non-nephrologists or in whom the condition may go unrecognized. This may result in a risk of selection bias, e.g. in epidemiological research.

DATA COLLECTION

All registries collected demographic data, primary renal disease (PRD), comorbidities and height and weight at baseline, but in France and Norway this was extended to information on care plans (Table 2). Most collected medications, often accompanied by their Anatomical Therapeutic Chemical codes. Additionally, all registries gathered baseline and follow-up data on estimated glomerular filtration rate (eGFR). In contrast, only three registries collected data on urinary albumin:creatinine ratio. All countries with functioning registries collected at least some laboratory test results (Table 3), frequently by linkage to national or regional laboratory databases.

The outcomes studied included CKD progression, dialysis and transplantation (including pre-emptive transplantation), date and cause of death, sometimes supplemented with data on (pre-emptive) transplant waitlisting, hospitalization and complications. The Swedish registry also collected patient-reported outcomes in the form of RAND-36 data.

CONCLUSION

Given the importance of obtaining knowledge on patients with advanced CKD, it is not unexpected but still disappointing that the results of this inventory show that in Europe only six countries or large regions have engaged in routine data collection on patients with CKD Stages 4–5 who are under the care of nephrologists and Finland is making preparations to do so. Most are collecting data on a growing number of patients while facing challenging issues in registry management, such as the efforts needed for data collection. As a next step, we will explore whether the data quality and potential differences in methods and definitions used by the countries will allow collaboration in a European CKD registry under the umbrella of the ERA Registry with the purpose of joint scientific analyses to advance our knowledge of treatments and outcomes in advanced CKD.

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AUTHORS' CONTRIBUTIONS

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CONFLICT OF INTEREST STATEMENT

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