



CKJ REVIEW

Step-by-step guide to setting up a kidney replacement therapy registry: the challenge of a national kidney replacement therapy registry

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ABSTRACT

Chronic kidney disease (CKD) has become one of the most important public health problems worldwide. Analysis, and understanding, of this global/national/regional reality would benefit from renal registry databases. The implementation of a CKD registry (including all categories) is difficult to achieve, given its high cost. On the other hand, patients with end-stage kidney disease (ESKD) are easily accessible and constitute the most severe subgroup in terms of comorbidities and healthcare costs. A kidney replacement therapy registry (KRTR) is defined as the systematic and continuous collection of a population-based data set from ESKD patients treated by dialysis/kidney transplant. The lack of available data, particularly in emerging economies, leaves information gaps on healthcare and outcomes in these patients. The heterogeneity/absence of a KRTR in some countries is consistent with the inequities in access to KRT worldwide. In 2014, the Pan American Health Organization (PAHO) proposed to determine the prevalence of patients on dialysis for at least 700 patients per million inhabitants by 2019 in every Latin American (LA) country. Since then, PAHO and the Sociedad Latinoamericana de Nefrología e Hipertensión have provided training courses and certification of KRTR in LA. The purpose of this manuscript is to provide guidance on how to set up a new KRTR in countries or regions that still lack one. Advice is provided on the sequential steps in the process of setting up a KRTR, personnel requirements, data set content and minimum quality indicators required.

Keywords: chronic kidney disease, epidemiology, hemodialysis, kidney transplantation, peritoneal dialysis

INTRODUCTION

Chronic kidney disease (CKD) has become today one of the most important public health problems worldwide [1–3]. The Global Burden of Disease Study shows that CKD moved up from the

25th position as a cause of death in 1990 to the 17th position in 2015 [3]. Also, CKD contributes 1.35% to the disability-adjusted life year (DALY), increasing 1% per year [3]. Diabetes and hypertension remain as leading etiologies of CKD worldwide. From

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1990 to 2016, diabetes followed by hypertension were the leading drivers of increased CKD DALYs globally (50.62 and 23.26%, respectively) [1–4]. In addition, there is a clear need for improved knowledge, as well as control, of a kidney disease epidemic, known as CKD of unknown etiology (CKDu), in Central America, Sri Lanka, India and north western African countries. CKDu is not related to diabetes or hypertension and mainly affects young working class men. A renal registry would enable data collection and analysis to help understand this regional reality [5, 6].

A patient registry is an organized system that applies methodology derived from observational studies to collect standardized data (clinical records and others) to evaluate specific results. Collected information is used to achieve predetermined scientific, clinical or health policy purposes, such as describing the natural history and rising awareness of the disease, estimating the clinical and cost-effectiveness relationship of the products of healthcare services, and measuring or monitoring the risk profile and patient safety, as well as evaluating the quality of healthcare [7–10].

The implementation of a registry of patients with CKD (including all stages in the progression of disease) is difficult to achieve, given the high costs involved. On the other hand, patients with end-stage kidney disease (ESKD) are easily accessible and constitute the most severe subgroup in terms of comorbidities and healthcare costs [11] (Figure 1).

A kidney replacement therapy registry (KRTR) involves the systematic and continuous collection of a population-based data set of patients with ESKD who are treated with dialysis or kidney transplant (KT). In this way, the KRTR represents a useful tool for epidemiological research and planning and improvement in quality of care, as well as enabling countries to monitor and evaluate progress made. Moreover, it allows estimation of the impact of interventions on patients in their previous stages of CKD, and accordingly, planning of healthcare policies to prevent disease progression. To that end, having good-quality records makes it possible to set up the databases required to carry out such analyses. From this perspective, the capacity of a KRTR to achieve these objectives is based on the quality of its data and on the control procedures used to obtain quality information [10–13].

The lack of available data, particularly in emerging economies, leaves information gaps in healthcare and outcomes in patients with renal disease [13]. The heterogeneity, or even the absence, of KRTRs in some countries is consistent with the inequities in access to kidney replacement therapy (KRT) for

patients with ESKD worldwide [13, 14]. Renal registries have been collecting data on ESKD treatment rates in Australia/New Zealand, Europe and North America for up to 50 years. There are also remarkably successful renal registries in Latin America (LA), Africa and Malaysia. However, many low- and middle-income countries (and also some high-income countries) do not have renal registries yet, and if they do, the registries collect data on an incomplete and voluntary basis and at an aggregate level. In response to this inequality, various actions have been carried out at regional, as well as global, levels. In 2014, the Pan American Health Organization (PAHO) proposed to determine the prevalence of patients on dialysis for at least 700 patients per million inhabitants by 2019 in every LA country. Since then, PAHO and the Sociedad Latinoamericana de Nefrología e Hipertensión (SLANH) have been providing training courses and certification of KRT registries for LA countries affiliated to SLANH [11]. However, despite these efforts, although the situation of KRTRs has improved in LA, the heterogeneity and inequities in their development still remain (Table 1).

Some worldwide actions, such as those of the International Society of Nephrology and the SHARing Expertise to support the set-up of Renal Registries initiative, are implementing resources that kidney healthcare advocates can use to establish or develop a renal registry in their countries. These resources include, but are not limited to, open access to a global inventory of renal registries, including key facts on how the registries operate, a list of experts willing to provide advice and workshops covering a range of topics [15].

Our purpose is to provide recommendations for setting up, maintenance and improvement of a KRTR, with guidance on database content and minimum quality indicator requirements (Figure 2).

FIRST STEP: WHAT IS THE TARGET POPULATION AND WHAT IS THE CASE DEFINITION?

In a KRTR, a case is defined as any patient with ESKD treated with peritoneal dialysis (PD), hemodialysis (HD) or KT in a defined region. Thus, a KRTR may include all types of renal replacement (the most recommended) or only one or two of the replacement modalities. The KRTR can be regional (representing a region of a country), such as the Registry of Castilla-La Mancha [16], national (representing a country) such as the United States Renal Data System (USRDS) [17] or the Argentinian Dialysis Registry [18], or international (representing a set of countries), e.g. the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) registry [19], the Australia and New Zealand Dialysis and Transplant (ANZDATA) [20] and the LA Dialysis and Renal Transplantation Registry [21]. In the case of regional registries, they should share similar variables and tools to collect data, so they can be aggregated and analyzed easily at a national level.

A topic of interest and controversy is defining the chronic character of treatment. In general terms, a patient is considered to be in chronic treatment when they have been on KRT for >90 consecutive days. Nevertheless, to use this definition would underestimate the real incidence of patients on KRT, especially given the high mortality rate in the first 3 months. Thus, patients should be registered on day 1 of their chronic treatment, but if patients are registered with a stay exceeding 90 days, their data should be specified and analyzed separately.

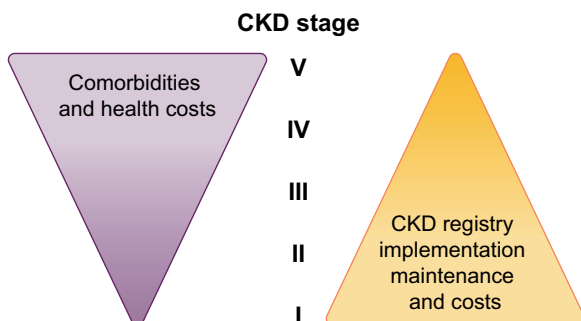


FIGURE 1: Figure showing the difficulty in implementing a CKD registry (including all stages), given the costs involved. In contrast, patients with ESKD (Stage V) are easily accessible and constitute the most serious subgroup in terms of comorbidities and healthcare costs.

Table 1. Situation of KRTR in LA countries affiliated to SLANH

Country	Character	Type of registration	Completeness (%)	Digitalized	Category ^a
Argentina	Mandatory	By patients	>90	Yes	5
Bolivia	Mandatory	By patients	32 (only SS ^b)	No	2
Brazil	Voluntary	By centers	≤50	Yes	3
Chile	Voluntary	Hemodialysis: by centers Peritoneal dialysis and kidney transplantation: by patients	>90	No	3
Colombia	Mandatory	By patients	>90	Yes	5
Costa Rica	Mandatory (starting)	By patients	>90	Yes	1
Cuba	Mandatory	By patients	>90	No	4
Dominican Republic	Mandatory	By patients	>90	Yes	2
Ecuador	Mandatory	By patients	>90	Yes	1
El Salvador	Mandatory (starting)	By patients	<90	Yes	1
Guatemala	Mandatory	By patients	>70 (only SS ^b)	Yes	1
Honduras	Mandatory (starting)	By patients	<90	Yes	1
Mexico (Jalisco)	Mandatory	By patients	>90	Yes	3
Mexico (the rest)	No registry	No registry	No registry	No registry	No registry
Nicaragua	No registry	No registry	No registry	No registry	No registry
Panama	Mandatory	By patients	84 (only SS ^b)	Yes	1
Paraguay	Mandatory	By patients	>90	Yes	3
Peru	Mandatory	By patients	77 (only SS)	Yes	1
Puerto Rico	Mandatory	By patients	>90	Yes	3
Uruguay	Mandatory	By patients	>90	Yes	4
Venezuela	Voluntary	By patients	<90	No	1

^aThe categories of registries are defined by their complexity and data quality (see Table 4).

^bOnly patients with coverage by Social Security System (SS).

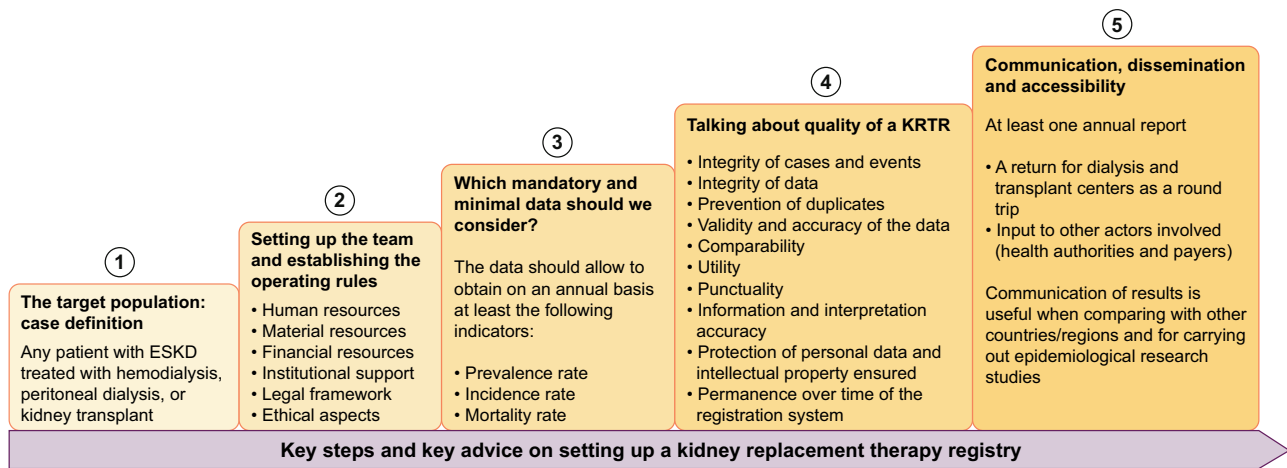


FIGURE 2: Summary of the key steps in, as well as key advice on, setting up a KRTR.

On the other hand, patients with acute kidney injury should be excluded.

SECOND STEP: SETTING UP THE TEAM AND ESTABLISHING THE OPERATING RULES

This can be considered to be the most difficult step. It is recommended to bring together the key players involved in the KRT process (dialysis and KT teams), so there is commitment to their participation in the setting up of, as well as their continued contribution to, a KRTR.

The success of a KRTR depends on several factors, including human, material and financial resources, as well as institutional support. A registry team should be composed of technical

staff and a registry committee. The technical staff are in charge of data management and should include at least a data set assistant (full-time), an administrative team, an epidemiologist and a consultant biostatistician (all three on a part-time basis). If the registry development group has no formal links with experts skilled in this area, it is worth checking with universities or other registry groups that might help. It is useful to list in table format the key roles or duties expected from individual registry personnel, as well as the necessary work times expressed as full-time position equivalents. The registry committee should include nephrologists who are members of national or regional societies, delegates of Nephrology Chairs and representatives from healthcare providers and the Ministry of Health. Their contribution would help ensure the best-quality

Table 2. Minimum indicators that a KRTR should include and their definitions

Indicator	Definition	Formula
Prevalence rate	Ratio of the total number of patients with ESKD on KRT to the general population in the coverage area, expressed per million population. Point prevalence includes all the patients alive on 31 December of the current year: <ul style="list-style-type: none"> • Crude • Stratified by age, sex or nephropathy 	Number of patients alive on 31 December/population of the country (expressed in millions)
Incidence rate	Ratio of the number of patients starting KRT for the first time in a given year to the general population in the coverage area, expressed per million population: <ul style="list-style-type: none"> • Crude • Stratified by age, sex or nephropathy 	Number of new cases/population of the country (expressed in millions)
Mortality rate	Ratio of the number of deceased patients with ESKD on KRT to the number of patients exposed to risk during the same year: <ul style="list-style-type: none"> • Crude • Adjusted—age, sex, nephropathy (diabetic/non-diabetic) 	$(100 \times \text{number of deaths})/\text{number of patients} (\Sigma \text{ of years of exposure to patient risk})$

Table 3. Minimum set of variables that should be recorded for individual or aggregated data registries

General data	KRT modality	Patient status by 31 December
Identifier	HD	• Alive
Gender	PD	• Event type:
Ethnicity	KT	• Change of modality (between HD, PD and KT)
Date of birth		• Recovery of renal function
Place of birth		• Death
Current residency		• Lost to follow-up
Patient occupation		• Cause of death (codification system)
Health coverage (public, private and none)		• Date of event
KRT starting date		
Etiology of ESKD (codification system)		

database, as well as the achievement of the objectives and goals of the registry. The governing body must be reviewed periodically, including election and renewal of committee members. In countries with a large population or territorial area, it may be helpful to establish a regional system where each region reports to a national office that centralizes and manages data.

Furthermore, collaboration of financial institutions in data collection is essential. In most countries, dialysis and KT are financed by non-state-funded institutions, the department of Social Security or the Ministry of Public Health. In this sense, there is no single funding model that can be applied across all countries, so each country must consider their own best suited model based on their local circumstances and available resources.

But beyond the model to be applied, there is a common and exclusive denominator—that is, the continuity of registration must be assured. For this reason, it is important that in the case of a national registry, the constitution of the registry, as well as its operation, should be regulated by a decree, norm or law.

To ensure the smooth development of a national KRTR, data processing must be carried out in accordance with the national legal and ethical principles of conducting research in humans, ensuring periodical updates of the database and publishing an annual report of processed data. It should be noted that, in

addition to their useful contribution in healthcare planning, annual reports must be considered as a fair return to data providers (namely dialysis or transplantation centers) by offering them useful information in return.

THIRD STEP: WHICH MANDATORY AND MINIMAL DATA SHOULD WE CONSIDER?

A KRTR should provide data, on an annual basis, on the following indicators: prevalence, incidence and crude and adjusted mortality rates in the dialysis and transplant populations [10–12]. Prevalence is defined as the number of patients alive on treatment (dialysis or transplantation) up to 31 December of the current year, and incidence is defined as the number of patients who were commenced on KRT for the first time (dialysis or transplantation) during the study year. Both prevalence and incidence should be presented as crude or adjusted for age, sex and nephropathy. Mortality rates should be presented as crude, as well as adjusted at least for age, sex and nephropathy (diabetic or non-diabetic), according to reference tables set up either by the registry itself or by other national or regional registries [10–12]. Table 2 shows the minimum indicators that a KRTR must include, and their definitions.

Data collection can be performed according to: modality of treatment (HD, PD and transplantation separately or globally); type of registration (registration of each patient or global data recorded by the dialysis/transplant center); and nature of the information (voluntary or mandatory reporting). In considering CKD and ESKD as a single disease in the context of KRT and by taking into account that patients can receive different modalities of treatment throughout their disease evolution or they can change dialysis and transplant center for treatment, data collection should be carried out as part of a global registry (including all treatment modalities), on an individual patient basis (with collection of individual data) and on a mandatory basis [10–12]. Table 3 shows the minimum set of variables that must be recorded for each patient.

In addition, all patients with CKD who receive KRT must be included with utmost caution to avoid generating duplicate cases. It is important to bear in mind that patients' treatment modality can change (for instance, patients who receive a functioning KT should not be included as 'on dialysis', or patients who change from HD to PD, or vice versa, should not be recorded in both modalities). It is crucial to follow up patients during their KRT journey in a reliable way, by making use of their unique identification number (preferably their social security numbers or national identification document numbers if allowed). Considering the minimum data requirements suggested (Table 3), patients should enter the database only upon admission and all types of event should be recorded, while performing annual evaluation of the patient population as of 31 December of each year. Prevalence should be reported in terms of patients receiving the KRT modality at the time point defined by the registry. On the other hand, incidence is reported by including all patients receiving KRT only once in their lifetime, regardless of the treatment modality received at that particular moment. In calculating the incidence for each separate treatment modality, patients should be classified as either newly initiated on KRT or transferred from another modality.

Other important data that may be included on admission include the type of vascular access (transient or definitive) and the immunization status for hepatitis B, since this would allow the registry team to infer the quality of previous care before starting patients on KRT. Comorbidities and patients' socioeconomic status, as well as other data that are considered relevant when analyzing the characteristics of patients on KRT, can also be included.

It is important to note that maximum efforts should be made to record the causes of ESKD (nephropathy) and death, adjusted according to previously established consensus codification systems (ICD, SNOMED, ERA-EDTA PRD coding system, locally predefined, etc.). This will allow comparison of differences in epidemiology within and between regions, as well as changes in epidemiology over time.

In case it is necessary to use the registry to evaluate the quality of KRT, more extensive data will be required, as well as a higher frequency (monthly) of data loading for all patients, e.g. hemoglobin levels, Kt/V urea, patients with and without erythropoietin treatment and doses of erythropoietin used. It is recommended to start with a registry that provides data on the incidence, prevalence and mortality rates, as well as allowing determination of the reasons for entry into dialysis treatment, and then to consider, in the second stage, its use in the evaluation of treatment quality.

It is important that the working group defines the population of patients 'lost to follow-up'; this is a problem particularly with transplanted patients as they visit their physicians at a

lower frequency. Most registries consider transplanted patients as 'lost to follow-up' 1 year after the 'date last seen' by their nephrologist.

With respect to technical support for data collection, electronic reporting is recommended, which can be either online or deferred (initially uploading the electronic data sheet and subsequently sending), while avoiding the use of paper forms. In the first stage with the minimum data required, setting up an electronic online register by means of cell phone use is a valid option if computers are not available.

Finally, patient registration can be either voluntary or mandatory; without doubt, the latter option ensures collection of maximum data on patients receiving KRT. Mandatory registration may be associated with economic recognition of the benefit (in the form of reimbursement) or a norm or legislation (as is the case of the statutory duty to notify certain infectious diseases, for example). As in most countries, KRT is funded by non-state institutions or by the department of Social Security, and the responsibility of the Ministry of Public Health is to centralize registry activities, which should be key in achieving completeness of data collection. As mentioned earlier, there is no standard method of registration that is applicable to all countries and each country must consider what is best suited according to their local factors and available resources.

FOURTH STEP: DETERMINING THE QUALITY OF A KRTR

It is essential for a quality control system to be in place to ensure proper registry operation and data processing, according to established procedures. Additionally, it must guarantee personal data protection in order to attain the quality levels necessary for the purposes and usage of the data. The quality assurance requirements of a registry should be established when setting up the registry, as well as before, during and after data collection.

The essential data quality indicators for a KRTR are [11, 12, 21–24]:

- i. integrity of cases and events: considered as the proportion of patients and the total events that are included in the registry database. A high degree of integrity allows for more accurate estimations (i.e. values of incidence or prevalence);
- ii. integrity of data: refers to the proportion of missing data of a certain variable;
- iii. prevention of duplicates: as patients can be transferred from one dialysis center to another, the same patients can therefore be registered several times. Duplication cases can be avoided by using a single identifier for each patient;
- iv. validity and accuracy of the data: validity refers to the proportion of cases with a given characteristic that are confirmed to have this attribute. Accuracy is the extent to which the data element measures what is really intended to be measured;
- v. comparability: the degree to which the data collected can be analyzed and compared with other records or over time. This is a major aspect in the analysis of geographical and temporary variations. International comparisons can be made as standardized definitions and coding procedures exist;
- vi. utility: refers to the condition of having practical value and applicability (for the medical community, healthcare administrators, etc.);

Table 4. Categories of registries by complexity and data quality

1. There is no basic type of dialysis and/or kidney transplant systematic registry.
2. There are only partial (institutional/regional) systematic records of dialysis and/or kidney transplantation, not subject to quality control and not mandatory.
3. There is a systematic population-based national registry of dialysis and/or kidney transplantation, which collects basic data (incidence, prevalence and mortality), based on efforts of non-governmental organizations or healthcare providers (scientific societies and healthcare institutions). 3A: with <90% of the patients registered; 3B: with >90% of the patients registered.
4. The registration of dialysis and transplantation is national in scope, with >90% of the patients registered, is multi-institutional, covers the entire population and all techniques of renal replacement and performs an annual report of basic data.
5. The registration of dialysis and transplantation is national in scope, with >90% of the patients registered, is regulated by legislation, norms or ministerial decrees, and is multi-institutional. It collects basic, evolutionary data and includes quality control of the provision. It produces an annual report in which the results of the treatment, the quality of the service and the performance of the providers are detailed.

- vii. punctuality: refers to the balance between the opportunity of data recording and their completeness and security. Fast accessibility to information has clear benefits for nephrologists, healthcare providers and researchers;
- viii. information and interpretation accuracy: the closeness between the results and the actual values. As data records are usually in the form of complex data sets, the participation of multiple members in data processing should be avoided as this can lead to confused, or even wrong, interpretations;
- ix. ensuring protection of personal data and intellectual property: refers to the guarantee of correct enforcement of national and international law; and
- x. long-term operation of the registry: the institution or society responsible for the registry must ensure its maintenance over time and provide the necessary resources to achieve this.

The minimum variables required, the data flow from recording to processing and returning information to the data providers (dialysis or transplant centers) have to be taken as a single process for which quality control is mandatory. All these requirements must be considered when planning to set up or improve a national registry.

FIFTH STEP: COMMUNICATION, DISSEMINATION AND ACCESSIBILITY

At least one annual report should be considered, which is a return for all those who participate in data loading (dialysis and transplant centers), as well as for other players involved (healthcare authorities and funding sources). Communication of results is useful when comparing data with other countries/regions, as well as when carrying out epidemiological research studies. Knowing the prevalence, incidence and mortality rates of patients with CKD on KRT should be accessible and made public. That is why data accessibility can be considered another aspect that defines the quality of a KRTR [13].

Actions to improve on the first step

Many countries, regions and renal healthcare facilities own or share ESKD registries of different complexity and data quality. The first step in initiating the process of improving registry quality is to perform a diagnosis of the actual situation. This may be done by classifying the registry according to five steps of continuing growth in terms of quality and complexity. A structured and planned analysis of the determinants of the actual situation should be the basis for future planning, thus allowing decision-makers to implement actions directed to fill

the gaps in order to achieve a high-quality five-step registry (Table 4).

Summary and conclusion

Renal registry databases can be used to improve awareness of the burden of CKD and ESKD among healthcare policymakers and funding sources through initiatives such as the Global Burden of Disease Study [1, 3]. Such databases can also provide crucial information to support the planning, delivery and evaluation of renal services, highlighting discrepancies in service provision within and between countries and informing the allocation of resources and planning of services. Registry databases can also help to identify the most important causes of kidney disease in different countries and thereby guide efforts to prevent, detect and treat the early stages of CKD. An overall national registry may contain hotspots showing higher CKD incidence rates that are not evident from a countrywide analysis. CKD hotspots are defined as countries, region, communities or ethnic groups with higher-than-average incidence rates of CKD, when compared with worldwide, national or regional rates. Using current residency databases of KRT patients and assessing whether they cluster in particular cities or regions could help identify CKD hotspots [25].

A national KRTR must have the minimum data sets recommended to be able to report, on an annual basis, the prevalence, incidence and mortality rates of all patients receiving KRT in their country.

It is recommended that data collection should be carried out globally, using individual data and on a mandatory basis. A successful KRTR includes the setting up of a multidisciplinary group composed of representatives from relevant scientific societies, the Ministry of Health and financial funding institutions.

Worldwide actions are developing resources that kidney healthcare advocates can use to assist in the establishment or development of a renal registry in their countries. These resources include, but are not limited to, an open-access global inventory of renal registries, including key facts on how they operate, a list of experts willing to provide advice and workshops covering a range of topics [26].

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AUTHORS' CONTRIBUTIONS

All authors contributed in data acquisition and design and drafting of the manuscript. All authors had full access to the data and had final responsibility for the decision to submit for publication.

CONFLICT OF INTEREST STATEMENT

None declared.

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