

National and international kidney failure registries: characteristics, commonalities, and contrasts



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Registries are essential for health infrastructure planning, benchmarking, continuous quality improvement, hypothesis generation, and real-world trials. To date, data from these registries have predominantly been analyzed in isolated “silos,” hampering efforts to analyze “big data” at the international level, an approach that provides wide-ranging benefits, including enhanced statistical power, an ability to conduct international comparisons, and greater capacity to study rare diseases. This review serves as a valuable resource to clinicians, researchers, and policymakers, by comprehensively describing kidney failure registries active in 2021, before proposing approaches for inter-registry research under current conditions, as well as solutions to enhance global capacity for data collaboration. We identified 79 kidney-failure registries spanning 77 countries worldwide. International Society of Nephrology exemplar initiatives, including the Global Kidney Health Atlas and Sharing Expertise to support the set-up of Renal Registries (SharE-RR), continue to raise awareness regarding international healthcare disparities and support the development of universal kidney-disease registries. Current barriers to inter-registry collaboration include underrepresentation of lower-income countries, poor syntactic and semantic interoperability, absence of clear consensus guidelines for healthcare data sharing, and limited researcher incentives. This review represents a call to action for international stakeholders to enact systemic change that will harmonize the current fragmented approaches to kidney-failure registry data collection and research.

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Kidney-failure registries play key roles in health infrastructure planning, benchmarking, continuous quality improvement, hypothesis generation, and the conduct of real-world trials (Figure 1). From a public health perspective, kidney-failure registries serve to quantify disease burden, thus informing preventative strategy development and health infrastructure planning.¹ Additionally, kidney-failure registries enable clinicians and healthcare management organizations to audit practice patterns and evaluate service quality, supporting benchmarking across jurisdictions and regulatory oversight.^{1–3} Kidney-failure registries also are utilized increasingly to support epidemiologic,^{4–6} health-outcomes,^{7–10} and health-economics¹¹ research (Figure 2). Such findings predominantly can be described as either (i) hypothesis generating, thus supporting the future design of interventional trials,¹² or (ii) prognostic, thus guiding patient counselling and clinical decision making, as well as public health interventions.^{7–10,13–17} The strength of registry-based research is that it provides the ability to study population-based cohorts under real-world conditions, with longitudinal follow-up, overcoming some of the limitations of single-center reports (uncertain generalizability) and randomized controlled trials (highly selected patient cohorts, shorter follow-up). Registries also enable the study of rare diseases, such as Fabry disease¹⁸ and Alport Syndrome.¹⁹

Benefits of registry research can be amplified by utilizing data from multiple registries, thus improving statistical power and generalizability, while enabling comparisons among jurisdictions. However, the majority of studies have been restricted to single registries (Nadeau-Fredette A-C, Sukul N, Lambie M, et al. Risk factors for early mortality after switch from peritoneal dialysis to hemodialysis: a multinational registry study [abstract]. *J Am Soc Nephrol*.

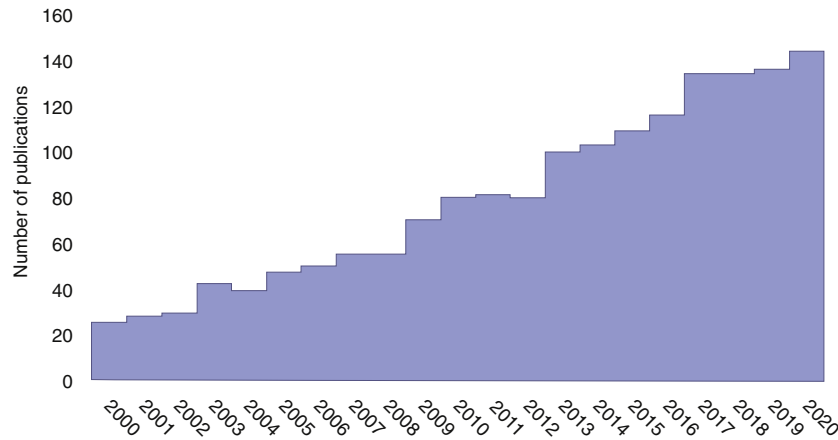


Figure 1 | Graph of the number of kidney-failure registry studies published and indexed on PubMed between January 2000 and December 2020, showing a steady increase in the annual number of reports.

2019;30(suppl):579. Abstract FR-PO536).^{4-6,20-31} The few inter-registry studies that have been performed have described predominantly the basic epidemiology of kidney failure^{5,20,21,23,24,26,29-31} (Supplementary Table S1). Other studies have investigated risk factors for mortality after transition from peritoneal dialysis (PD) to hemodialysis (HD), (Nadeau-Fredette A-C, Sukul N, Lambie M, et al. Risk factors for early mortality after switch from peritoneal dialysis to hemodialysis: a multinational registry study [abstract]. *J Am Soc Nephrol.* 2019;30(suppl):579. Abstract FR-PO536) or compared post-transplant mortality²² and daily HD practices²⁸ between jurisdictions. Ivory *et al.* used data from the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA), to develop a point tool for predicting patient mortality in early stages of dialysis, and from the United Kingdom Renal Registry (UKRR), for external validation.²⁵

Barriers to inter-registry research are multidimensional and complex, involving ethico-legal, technical, financial, political, motivational, and sociocultural arenas.³² As a result,

international calls to improve access to registry information and collaborative research³³ have been difficult to answer, as these require a coordinated, multifaceted approach across oftentimes resource-limited settings. This review aims to address these barriers to inter-registry research by first characterizing the status quo of kidney-failure registries and then proposing strategies to overcome these barriers, citing examples and lessons relating to research on other conditions that can be applied to kidney-failure registries.

Identification and characterization of existing kidney-failure registries

In preparing this review, we searched PubMed for publications describing kidney-failure registries, using the following search string: “(registry) AND ((kidney failure) OR (end stage kidney disease) OR (ESKD) OR (end stage renal disease) OR (ESRD) or (renal replacement therapy) or (RRT) or (kidney replacement therapy) OR (KRT)) Filters: humans, from 1 January, 2000 to 7 June, 2021.” A list of kidney-failure registries was then compiled from publications describing registry designs, registry-based studies, and registry reports. Registry staff contact details were garnered from registry websites and corresponding authors on registry studies and/or reports. Registry staff members were contacted electronically, with questions regarding founding year, population coverage, funding body, patient enrollment criteria, data-collection methods, and data availability for research. Copies of registry data-collection sheets were also requested from registry staff. The above information was sought from registry reports, publications, and studies, in cases in which registry staff were not available. Figure 3 indicates the main sources of information used to gather information regarding each registry when preparing this review. Registries were classified as being active if they had an up-to-date website, had at least one publication within the past 5 years, or had contributed data to a secondary registry within the past 5 years. Registries were defined as being developing if they were initiated within the past 5 years and had not yet published any

Advocacy + infrastructure planning	Outcome reporting + benchmarking
<ul style="list-style-type: none"> • Advocate for infrastructure development in under-resourced areas • Quantify disease burden for preventative strategy + health infrastructure planning 	<ul style="list-style-type: none"> • Audit practice patterns • Quality assurance • Benchmarking across jurisdictions • Regulatory oversight
Registry value	
Hypothesis-generating	Real-world trials
<ul style="list-style-type: none"> • Provide hypothesis-generating data to support randomized controlled trials • Big data for creation of prognostication tools or scoring systems 	<ul style="list-style-type: none"> • Reflects actual medical practice • Includes populations not represented in clinical trials • Longitudinal follow-up

Figure 2 | Key roles of kidney-failure registries.

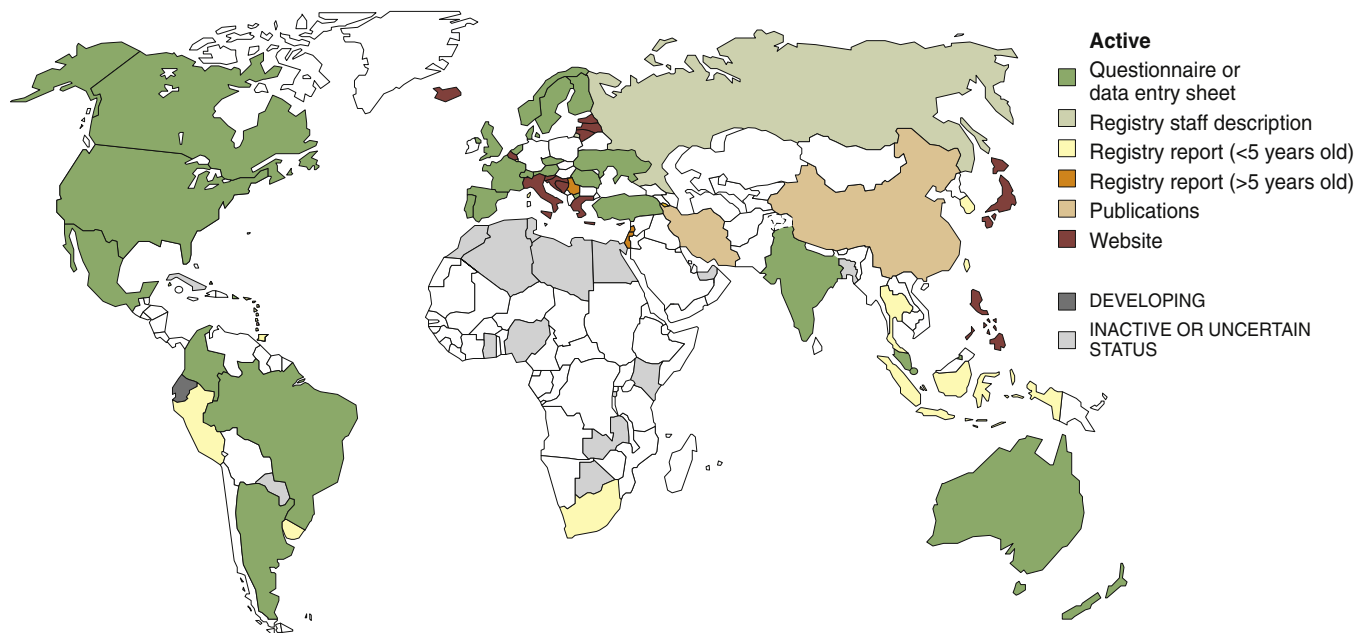


Figure 3 | A world map identifying countries with a kidney-failure registry and the method by which information regarding this registry was obtained. Color coding depicts the primary data source used to extract registry information for this review; registries for which limited data were publically available were designated as having developing, inactive, or uncertain status.

reports. Registries were defined as being inactive or unknown if the registry was reported to have ceased functioning, registry staff were uncontactable, the most recent report was published >10 years ago, or the registry was only mentioned in passing in a literature review. When summarizing the characteristics of individual registries (e.g., percentage collecting data on a particular variable), only active registries were included in the denominator population.

The status quo of kidney-failure registries

In total, we identified 61 active, national kidney-failure registries (Supplementary Table S2), 3 active, international registries consisting of amalgamated information (Supplementary Table S3), 15 registries with inactive or uncertain status (Supplementary Table S4), and 2 developing registries. Together, these registries enrolled patients from 77 countries across 6 continents (Supplementary Table S5). Notably, 1 of the registries covers 6 countries, and some countries had multiple kidney-failure registries. These numbers are higher than those reported in the Global Kidney Health Atlas (75 dialysis registries, 68 transplant registries), a cross-sectional survey of kidney-failure registries conducted in 2019,³⁴ a difference likely explained by the fact that, in preparing this current review, contact of registry staff was used to support data obtained from publications.

We identified 3 major types of kidney failure registry, as follows: (i) registries aiming for complete capture of the target population within a defined country or region (Supplementary Table S2); (ii) multinational databases that source primary data from existing national registries ($n = 3$; Supplementary Table S3); and (iii) research registries that include data from multiple geographic regions but have

incomplete capture of contributing country populations, typically owing to inclusion of data from only a sample of centers or dialysis units (e.g., the Dialysis Outcomes and Practice Patterns Study, the North American Pediatric Renal Trials and Collaborative Studies). This review focuses predominantly on the former 2 types (i and ii) of registries.

Funding sources. We identified 9 categories of registry funding, as follows: government (43%), national society (38%), kidney medicine department (3%), industry (3%), academic institution (2%), charity (2%), other (2%), and unfunded (13%; Supplementary Table S2). These percentages are similar to results from a global survey of kidney health surveillance systems completed by Hole *et al.*³⁵

Inclusion criteria. We identified variability with respect to inclusion criteria for kidney-failure registry enrollment (Table 1). People could be enrolled at the time of dialysis initiation^{36–39} or up to 90 days after dialysis initiation.^{40–42} Some registries include kidney-failure patients on conservative care pathways who are not receiving dialysis or a kidney transplant.^{38,40,43–47} However, enrollment is typically incomplete for patients on conservative care pathways (e.g., 58% in the Norwegian Renal Registry,⁴⁴ 60% in the Svenskt Njurregister [SNR]⁴⁵), as these patients may have reduced interaction with kidney-disease services and may be primarily treated by non-kidney-disease specialists (e.g., those in general practice, internal medicine, or palliative care). The Renal Registry of Hong Kong and the Brunei Dialysis and Transplant Registry record data only from patients treated in the public healthcare systems. This does not alter inclusivity in the latter case, as the public healthcare system covers 100% of kidney replacement therapy (KRT) costs.⁴⁸

Table 1 | Variability in patient population enrolled in kidney-failure registries

Inclusion criteria	Kidney-failure registries
Timing of enrollment	
At time of KRT start	ANZDATA, Cyprus, Russia, Serbia, Ukraine, UKRR, Indonesia
≥45 d after KRT start	REIN
≥60 d after KRT start	USRDS
≥90 d after KRT start	CORR, Norwegian Renal Registry, DNSL
Includes conservative care	Singapore Renal Registry, Norwegian Renal Registry, REIN, UKRR, SNR, Caribbean Renal Registry, ISPN CKD registry
Includes public patients only	Renal registry of Hong Kong, Brunei Dialysis and Transplant Registry

ANZDATA, Australia and New Zealand Dialysis and Transplant Registry; CORR, Canadian Organ Replacement Registry; DNSL, Danish Nephrological Society National Register; ISPN CKD, Indian Society of Pediatric Nephrology Chronic Kidney Disease Registry; KRT, kidney replacement therapy; REIN, Le Réseau Epidemiologie et Information en Nephrologie; SNR, Svenskt Njurrregister; UKRR, United Kingdom Renal Registry; USRDS, US Renal Data System.

Data collection. All registries collect data at least annually (Supplementary Table S2). Comorbidities may be recorded at patient enrollment only (e.g., United States Renal Data System [USRDS]⁴¹) or updated regularly (e.g., ANZDATA⁴⁹). Event notifications, such as those for change in dialysis modality, kidney transplantation, peritoneal dialysis (PD) peritonitis, acute rejection, graft failure, and death, may be made in real time (e.g., ANZDATA,⁴⁹ Singapore Renal Registry, Korean Renal Data System,⁵⁰ and USRDS⁴¹) or at prespecified time intervals (e.g., the Japanese Society for Dialysis Therapy Renal Data Registry [JRDR]⁵¹ and the Colombia Renal Registry⁵²).

Data collected by registries can be broadly divided into demographic, comorbidity, dialysis, transplant, and outcome categories (Figure 4). Variables reported in greater than 50% of registries include the following: current treating center (70%), age (95%), gender (93%), cause of kidney failure (95%), hepatitis status (54%), date of KRT initiation (80%), KRT modality (93%), hemodialysis (HD) access type (66%), hemoglobin (56%), erythropoiesis-stimulating agent use (52%), date of kidney transplant (82%), donor type (56%), mortality rate (86%), and cause of death (89%).

Disease definitions vary significantly among registries (Table 2). For example, coronary artery disease is recorded as coronary artery disease, ischemic heart disease, myocardial infarction, and angina pectoris (Table 2). Le Registre de Dialyse Peritoneale de Langue Francaise (RDPLF) and the Danish Nephrological Society National Registry (DNSL) both record comorbidities using the Charlson comorbidity score—an index that can be used to predict 10-year survival in people with multiple comorbidities. Some registries do not collect comorbidity data, including the Renal Registry of Bosnia and Herzegovina, the Croatian Registry of Renal Replacement Therapy (CRRRT), and the Dutch Renal Function Replacement Registry (RENINE).

The cause of kidney failure is occasionally recorded in a free-text format, but it is more typically based on disease-classification systems, such as that in the International Statistical Classification of Diseases and Related Health Problems 10th Revision [ICD-10], the European Renal Association – European Dialysis and Transplant Association Registry (ERA-EDTA) disease codes, or internally bespoke coding systems (Table 2). Only 30% of registries record whether kidney disease diagnoses are biopsy-proven, either as part of the disease classification or via an extra question (Figure 4).

The registries show tremendous variability in data granularity and format. The comprehensiveness of KRT modality data varies, with some registries using only 3 categories (HD, PD, transplant), whereas others have additional categories for home HD, in-center HD, self HD, hemodiafiltration, continuous ambulatory PD, and automated PD. The 26% of registries that report a reason for changing KRT modality specify reasons only for changing from PD to HD.^{43,53,54} PD peritonitis is documented variably, with 4 different measures of incidence utilized; reporting of clinical findings, causative organism, drug treatment, PD solution at time of infection, hospitalization requirements, and response to treatment is more limited (Figure 5). Similar variability is observed across all data categories (Supplementary Table S2).

Approach to inter-registry research under current conditions

Planning of any research using registries involves key steps, including study question conception, registry selection, and methods development. Registry selection, in turn, will depend on the study question, registry protocol, and data availability. Data availability is governed by various ethico-legal, political, and financial motivational factors.³² Key ethico-legal considerations include privacy, respect for autonomy, and data protection regulations.^{32,55} These issues can be addressed via official/legal approval of the study, ethical approval by a research ethics committee/institutional review board, legislation permitting data collection and sharing, health data anonymization, and confidentiality measures via data security audits. The majority of registries (70%) allow data requests for research, pending ethical and registry committee approvals (Supplementary Table S2). Several registries, such as the Austrian Dialysis and Transplant Registry (OEDTR), the Croatian Registry for Renal Replacement Therapy, and the Czech Republic Registry of Dialysis Patients require the applicant to be residing in the country or a member of the affiliated nephrology professional society. Even in the absence of such data-access restrictions, the authors of this review recommend collaborating with local investigators when considering inter-registry research, as their input is critical to navigating the local ethico-legal environment, as well as contextualizing study development and data interpretation in the setting of local practice patterns and resource availability.

Navigating data protection regulations becomes more complex when datasets are transmitted across national boundaries—particularly because regulations vary considerably across countries.^{32,56} The General Data Protection

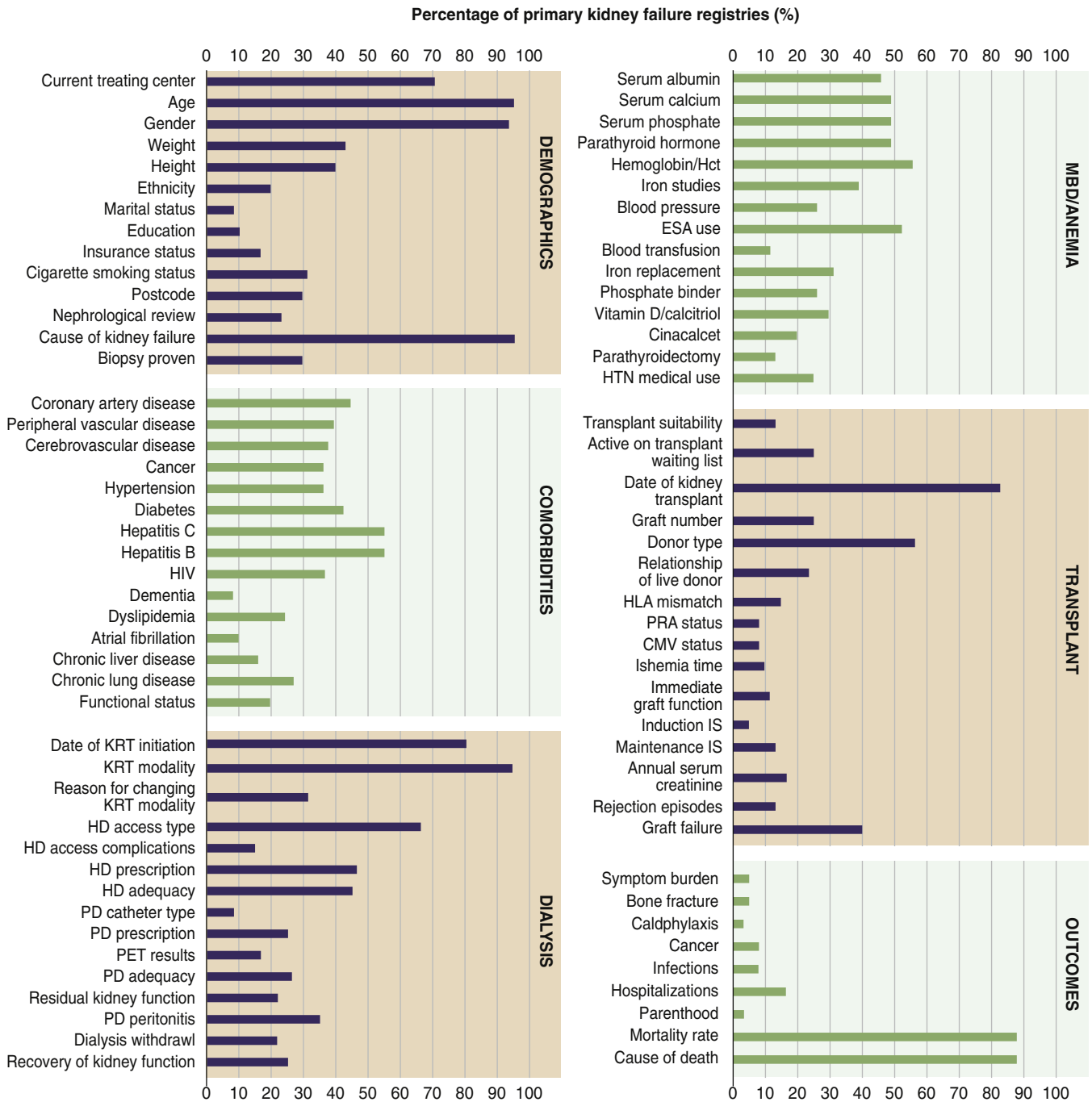


Figure 4 | Summary of variables reported with the highest frequency by kidney-failure registries. Percentages are calculated by dividing the number of registries that record each variable by the number of primary kidney-failure registries with active status multiplied by 100. CMV, cytomegalovirus; ESA, erythropoiesis-stimulating agent; HD, hemodialysis; HLA, human leukocyte antigen; HTN, hypertension; IS, immunosuppression; KRT, kidney replacement therapy; PD, peritoneal dialysis; PET, positron emission tomography; PRA, panel-reactive antibody.

Regulation (GDPR) attempts to harmonize fragmented policies across the European Union with provisions to facilitate research “designed to serve mankind” (Recital 4).^{57,58} However, legal uncertainty resulting from variable interpretation of the GDPR and various cantonal requirements continues to discourage researchers from sharing data in Europe.⁵⁹ Parallel analyses of single-registry data, followed by comparison of

aggregated results (without sharing of individual-level data), may offer a temporary solution until a clear legal framework to support data sharing across jurisdictions has been developed.

Ethical issues can arise when managing data from vulnerable populations (e.g., minorities, Indigenous peoples, those residing in developing countries) and need to be

Table 2 | Examples of challenges to semantic interoperability

Disease term	Kidney-failure registries
Coronary artery disease	
Coronary artery disease	ANZDATA, SNR, Singapore Renal Registry, Finnish Registry for Kidney Diseases, REIN, Swiss Renal Registry
Ischemic heart disease	JRDR, RDPLF, MDR, Singapore Renal Registry, TWRDS, RIDT/SIN, SNR, Norwegian Renal Registry, USRDS, UKRR, Uruguayan Dialysis Registry
Myocardial infarction	Finnish Registry for Kidney Diseases, REIN, Swiss Renal Registry, Argentina Renal Registry, CORR, RDPLF, UKRR, Swiss Renal Registry
Angina pectoris	Finnish Registry for Kidney Diseases, UKRR
Peripheral vascular disease	
Peripheral vascular disease	ANZDATA, OEDTR, Belgian Society of Nephrology (Dutch-speaking) Renal Registry, Finnish Registry for Kidney Diseases, RIDT/SIN, SNR, Norwegian Renal Registry, Swiss Renal Registry, UKRR, Brazilian Dialysis Registry, Uruguayan Dialysis Registry, Argentina Renal Registry, Puerto Rico Renal Registry, Lebanon National Kidney Registry, USRDS, CORR
Limb amputation	OEDTR, Belgian Society of Nephrology (Dutch-speaking) Renal Registry, Finnish Registry for Kidney Diseases, Swiss Renal Registry, UKRR, Brazilian Dialysis Registry, Argentina Renal Registry, Puerto Rico Renal Registry, USRDS, CORR
Limb claudication	UKRR
Symptomatic peripheral vascular disease	USRDS, RDPLF
Kidney disease coding	
Free text	Singapore Renal Registry
ICD-10	ANZDATA, Czech Republic Registry of Dialysis Patients, Finnish Registry for Kidney Diseases, Ukrainian National Renal Registry, Brazilian Dialysis Registry, Puerto Rico Renal Registry, USRDS
ERA-EDTA	OEDTR, Croatian Registry for Renal Replacement Therapy, DNSL, RENINE, Finnish Registry for Kidney Diseases, Greek Renal Registry, RIDT/SIN, SNR, Norwegian Renal Registry, Spanish Renal Disease Registry, Swiss Renal Registry, UKRR, South African Renal Registry
Bespoke	MDTR, Renal Registry of Hong Kong, Korean Renal Data System, Brunei Dialysis and Transplant Registry, Indian Society of Paediatric Nephrology Chronic Kidney Disease Registry, Indonesia Renal Registry, REIN, North Macedonia Renal Registry, Portuguese Society of Nephrology Renal Registry, Caribbean Renal Registry, Uruguayan Dialysis Registry, Argentina Renal Registry, TRDS
Unknown	JRDR, Chinese Scientific Registry of Kidney Transplantation, Chinese Renal Data System, TRT, TWRDS, Iceland Renal Registry, Latvia Renal Patient Registry, Lithuania Renal Registry, RRR, SRR, Serbia Renal Registry, Slovenia RRT Registry, Chilean Society of Nephrology Dialysis Register, Colombia Renal Registry, Israel National Registry of Renal Replacement Therapy, Iran Renal Registry, Lebanon National Kidney Registry, CORR, RDPLF, Belgian Society of Nephrology (Dutch-Speaking) Renal Registry, Renal Registry of Bosnia and Herzegovina, Cyprus Renal Registry, Estonia Renal Registry

ANZDATA, Australia and New Zealand Dialysis and Transplant Registry; CORR, Canadian Organ Replacement Registry; DNSL, Danish Nephrological Society National Register; ERA-EDTA, European Renal Association–European Dialysis and Transplant Association Registry; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; JRDR, Japanese Society for Dialysis Therapy Renal Data Registry; MDR, Malaysian Dialysis and Transplant Registry; OEDTR, Austrian Dialysis and Transplantation Register; RDPLF, Le Registre de Dialyse Peritoneale de Langue; REIN, Le Reseau Epidemiologie et Information en Nephrologie; RENINE, Dutch Renal Function Replacement Registration; RIDT/SIN, Italian Registry of Dialysis and Transplantation; RRR, Romania Renal Registry; RRT, renal replacement therapy; SNR, Svenskt Njurregister; SRR, Scottish Renal Registry; TRDS, Turkish Renal Data System; TRT, Thailand Renal Replacement Therapy Registry; TWRDS, Taiwan Renal Data System; UKRR, United Kingdom Renal Registry; USRDS, US Renal Data System.

considered carefully throughout the research process. Data sovereignty and community engagement in all research processes are paramount to respect sociocultural practices and ensure that generated results translate into tangible benefits that align with each group’s priorities and interest.^{60,61} Several guidelines are available regarding research approaches involving Indigenous peoples in Australia,^{62,63} New Zealand,⁶⁴ Canada,^{65,66} and the US.⁶⁷ The consolidated criteria for strengthening reporting of health research involving Indigenous peoples (CONSIDER) statement provides information for reporting of health research involving Indigenous peoples.⁶⁸ Medical research in developing countries is broadly guided by the Declaration of Helsinki, the Council for International Organisations of Medical Sciences guidelines, and the Guidance on Good Clinical Practice document.⁶⁹ The European Union and the Nuffield Council on Bioethics provide specific commentary pertaining to healthcare research in developing countries.^{70,71} Research regarding vulnerable people should be community-driven, and researchers should actively seek input from all stakeholders. Inclusion of local and Indigenous peoples is key to creating

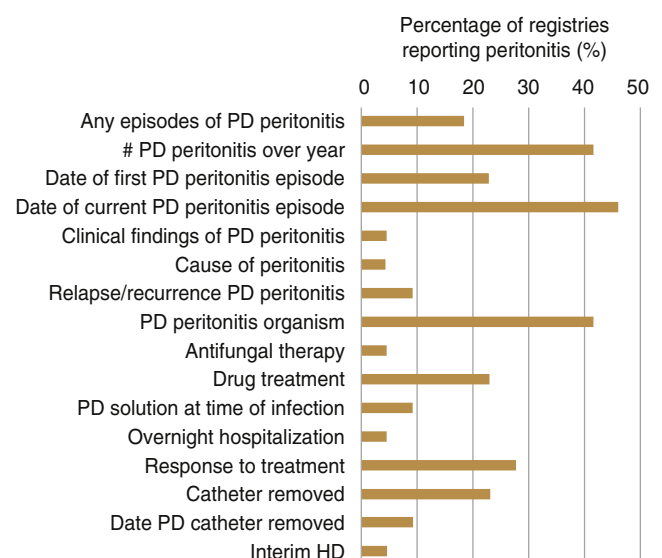


Figure 5 | Variability in the reporting of peritoneal dialysis (PD) peritonitis episodes across kidney-failure registries. Percentages are calculated by dividing the number of registries that record each variable by the number of primary active registries reporting on PD peritonitis.

equal partnerships, ensuring cultural competence, and developing local expertise.^{60,72} Building capacity for registry research and maintaining local access to data should be critical components of any research project to level the playing field and provide lasting benefits to local communities.

Data-sharing agreements can be used to address mistrust among stakeholders, data ownership issues, and institutional requirements. Lack of funding and research incentives have been cited as major barriers to conducting inter-registry studies, as data extraction, preparation, and annotation require extensive human and technical resources.⁵⁵ This obstacle is particularly relevant for low-resource settings in which registry activities are unfunded and research is completed on top of full-time workloads. Incorporation of data from resource-limited countries into existing registries bears consideration, as exemplified by the intermittent contributions of North African countries to the ERA-EDTA and USRDS registries.⁷³ Although some registries, such as the UKRR, charge fees for data requests in some circumstances,⁷⁴ in-kind remuneration (e.g., coauthorship, data-processing skill sharing, equipment, software, researcher time) could be considered when monetary payment is not possible due to resource constraints. The investigators of the Explaining the Variation in Epidemiology of RRT through Expert opinion, Secondary data sources and Trends over time (EVEREST) study reported that official study endorsements by the ERA-EDTA and the International Society of Nephrology (ISN) also improved study response rates.²¹

Technical aspects of data sharing include data transfer, security, storage, and maintenance. The internet is the default standard for secure data transfer.⁷⁵ Various available methods for combining health data can be used, depending on whether data are collected prospectively or retrospectively. Prospective data collection from multiple registries can be facilitated using system integration software (e.g., the PINNACLE Registry),⁷⁵ creation of new registry interfaces (e.g., ERA-EDTA, Database of Databases),^{75,76} and health information exchanges (e.g., Oakland Southfield Physicians Quality Registry).^{56,77} These methods ultimately reduce the data-entry burden by allowing data from diverse registries to be periodically extracted from primary registries and mapped to a centralized registry. These tremendous undertakings require strong support from government and participating registries to provide the organizational, technical, and financial resources during the start-up, launch, and maintenance phases.^{75,77} For one-off projects, anonymized retrospective data can be manually combined into an encrypted file for statistical analysis.^{20,22,28} Although this method is labour-intensive, it remains the most common approach utilized in inter-registry studies.

Another challenge to inter-research research is the need for data harmonization—that is, the process of bringing together data with varying formats, naming conventions, and variable definitions into 1 cohesive dataset. Evaluation of harmonization potential starts with an assessment of all variables in each dataset and the extent to which each is present across

datasets. Up-to-date and historical information regarding variable definitions and availability should be sought from each registry, as these factors are dynamic and change over time. For example, data on comorbidity, smoking status, and body mass index have been consistently collected in ANZDATA only since the mid-1990s.⁷⁸ The JRDR recorded dialyzer membrane material and surface area in 2000, 2002, 2009, 2010, and 2017 only.⁷⁹ The Le Réseau Epidemiologie et Information en Nephrologie (REIN) is considering changing from using its bespoke disease classification system to using ERA-EDTA disease codes for cause of kidney failure (personal communication, C. Couchoud, November 5, 2020).

In some cases, variable categories may need to be collapsed into less-detailed categories or via a single binary (yes/no) variable. For example, peripheral vascular disease has been recorded in various registries as defined by each of the following: (i) peripheral vascular disease only; (ii) amputation only; (iii) peripheral vascular disease and amputation; and (iv) peripheral vascular disease, amputation, and claudication (Table 2). In a harmonized dataset, these data may be converted via a binary classification of peripheral vascular disease (yes/no), to maximize dataset inclusion. Desired information also can be inferred from collected variables. For example, dialyzer features have been recorded as (i) model and brand in ANZDATA and the Malaysian Dialysis and Transplant Registry and (ii) surface area and material in the JRDR and the Czech Republic Registry of Dialysis Patients. The latter 2 dialyzer features (ii) can be inferred from data from (i). Program extraction codes are then required to extract data from each individual dataset into the harmonized dataset. Care must be taken at each step to ensure consistent, adequate harmonization. Issues and questions should be discussed regularly amongst the harmonization team, local registry staff, and other stakeholders to ensure appropriate harmonization.

The ISN strategic plan for integrated care of patients with kidney failure advocates for agreement on standardized minimum and progressive datasets, a scoping review of ethical issues for registries, development of an ISN “registry standards” document and “registry checklist” for publications, and appointment of local champions for recognition and networking.⁸⁰ Moreover, data capture could potentially be improved and/or simplified by employing innovative approaches, such as mobile phone platforms or use of machine learning to automate data extraction from electronic health records or registries.⁷³ In addition to supporting the local development and maintenance of regional registries, the hope is that these recommended approaches streamline data harmonization approaches and facilitate inter-registry research.

Statistical analysis should be defined a priori to increase the transparency and validity of findings.⁸¹ Data reporting should conform to the Strengthening The Reporting of Observational studies in Epidemiology (STROBE) statement,⁸² the Meta-analysis Of Observational Studies in Epidemiology (MOOSE) guidelines,⁸³ or the Transparent Reporting of a multivariable prediction model for Individual

Prognosis Or Diagnosis (TRIPOD)⁸⁴ guidelines, depending on study design. Data from different registries can be analyzed as a single dataset or separately in parallel. Caskey *et al.* combined data from 46 countries to examine associations among KRT incidence, national gross domestic product, and healthcare spending²⁰ (Supplementary Table S1). This approach enhanced power by using a large study population and allowed head-to-head comparisons between countries. Nadeau-Fredette *et al.* analyzed data from ANZDATA, USRDS, the Canadian Organ Replacement Register (CORR), and ERA-EDTA separately and compared summary statistics to identify risk factors for mortality after PD-to-HD transition (Nadeau-Fredette A-C, Sukul N, Lambie M, et al. Risk factors for early mortality after switch from peritoneal dialysis to hemodialysis: a multinational registry study [abstract]. *J Am Soc Nephrol.* 2019;30(suppl):579. Abstract FR-PO536). This method allows the raw dataset to remain with each local investigator, overcoming ethico-legal barriers related to data transfer across national boundaries. The granularity of each dataset is also maintained, as the categorizations within each discrete variable do not need to be “harmonized” among registries. However, this method does not enable direct quantitative comparisons among datasets.

The limitations of registry-based research, as compared to randomized controlled trials or prospective cohort studies, include the following: (i) exposures and treatments are not randomly assigned; (ii) data for some variables of interest might not be available; and (iii) data may be missing. As is the case with other retrospective cohort studies, registry-based studies are susceptible to bias and confounding, as exposures and treatments are not randomly assigned. Registry data collection also tends to focus on breadth rather than depth of knowledge, to reduce the administrative workload, particularly in the setting of stretched healthcare resources.⁸⁵ As a result, some potentially confounding variables of interest might not be included in multivariable analyses. This impact of this effect can be ameliorated by requesting additional data from companion (e.g., transplant) registries or by performing data linkage with independent data sources.^{86–88} Incomplete data can introduce susceptibility to selection and information bias.⁸⁹ In South Korea, 70% of the overall kidney-failure population is included in registry data, and individual-level data contribution was only 46% overall—49.2% from private clinics, 38.2% from general hospitals, and 66.7% from university hospitals.⁹⁰ In 2018, mean center participation per province in the Indonesian Renal Registry (IRR) was 76.4% (95% confidence interval 67.2%–85.7%).³⁹ In both cases, people who were “missing” from the registry may differ from included people, thereby limiting the generalizability of findings to the national population. Specific data components can also be underreported, despite complete population capture. For example, the Shanghai Dialysis Registry reported 100% population capture between 1999 and 2006.⁹¹ However, dialysis adequacy was only reported in 57% of people on PD in 2006. Approaches to address missing data in research studies include complete case analysis, single imputation, and

multiple imputation—all of which are susceptible to bias and confounding.⁹² Sensitivity analyses are required to explore the potential effect of missing not-at-random data on estimated results.⁹³

However, despite these limitations, inter-registry studies have the major advantage of including large, nationally representative patient populations, which enhances the generalizability of study findings. However, populations not covered by registries, in particular those in lower-income countries, remain marginalized. People living in these countries might differ fundamentally from people living in countries with established kidney-failure registries, with respect to disease susceptibility, healthcare systems, and socioeconomic factors. However, not all the countries lacking a national registry have a low gross domestic product and limited healthcare services. For example, Germany and Luxembourg lack kidney-failure registries yet their gross domestic product per capita is among the highest in Europe and among universal healthcare systems.^{94–96} Lack of a registry can be overcome by supplementing registry-derived data with data requested from countries without a registry. The EVEREST study was an international collaboration that examined associations between patient factors and kidney-failure outcomes across 46 countries.^{20,21} Countries with no known kidney-failure registries (e.g., Germany) were approached for data to ensure coverage, thereby enhancing the generalizability of study findings.

Proposed solutions to build capacity for registry research

Key goals in building capacity for registry-based research should include the following: (i) the construction and maintenance of kidney-failure registries worldwide; (ii) enhancement of the sustainability, quality, and comprehensiveness of registry data; (iii) harmonization of data elements among registries; and (iv) development of international consensus, guidelines, and incentives for health registry collaboration (Figure 6).

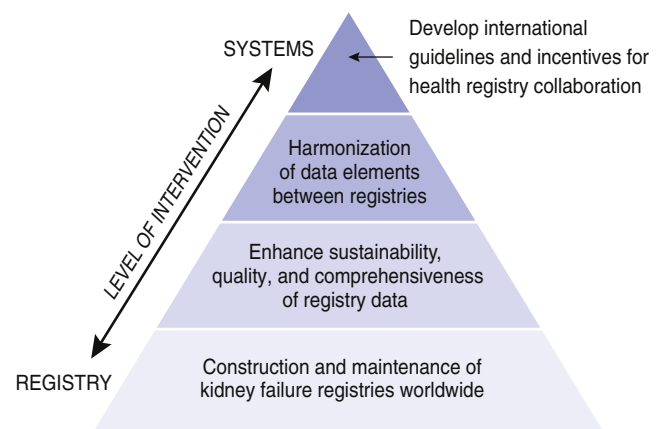


Figure 6 | Proposed solutions to build capacity for inter-registry research.

Table 3 | Final proposed ERA-EDTA registry dataset developed by the NephroQUEST project

Domain	Variable
Demographic	Age
	Gender
	Dry weight
	Smoking status
	Primary renal disease
Comorbidity	Amputation
	Comorbidities at start of kidney replacement therapy
Kidney replacement therapy	Treatment modality Duration of kidney replacement therapy
Dialysis	Dialysis duration + frequency
	Vascular access type
	Treatment with erythropoietin-stimulating agents
	Urea clearance
	Creatinine clearance
Vital signs	Blood pressure
Biochemistry	Serum albumin
	C-reactive protein
	Total cholesterol
	High-density lipid cholesterol
	Triglycerides
	Hemoglobin
	Ferritin
	Serum calcium
	Serum phosphorus
	Serum parathyroid hormone
Transplant	Source of kidney donor
	Graft survival
Outcomes	Survival on kidney replacement therapy

ERA-EDTA, European Renal Association–European Dialysis and Transplant Association Registry; NephroQUEST, Nephrology QUality European Studies.

According to the Global Kidney Health Atlas, less than 1 in 4 low-income countries can estimate their incidence or prevalence of chronic kidney disease, owing to deficiencies in health information systems (HIS).⁹⁷ In Africa and South America, kidney-failure registries are often established by local nephrologists with little funding and poor participation from local centers, resulting in limited sustainability.^{98,99} As a result, supporting the development and maintenance of kidney-failure registries in low-income countries is a key goal to improving information for advocacy, health infrastructure development, quality assurance monitoring, and research. To this end, Sharing Expertise to support the set-up of Renal Registries (SharE-RR) is an ISN initiative encouraging shared learning among countries with kidney-disease registries.³⁵ The initial objectives involved a global survey of kidney-disease registries and a workshop for registry conception.³⁵ Although this initiative can foster individual knowledge and skills, it does not address systemic barriers to HIS development in low- and middle-income countries.

Establishing sustained and comprehensive HIS is an expensive, long-term endeavor that holds little appeal for decision-makers with short-term horizons.¹⁰⁰ Decision-makers need to be shown return on investment, which may be achieved via increased emphasis by global aid providers on results-based

management and performance-based funding—both of which require sound data generated through reliable and transparent systems. The shift toward “payment by results” programs by global aid providers represents the vanguard of this movement.^{101,102} Resource allocation guided by real-world data improves spending efficacy and efficiency, thereby allowing countries to maximize net income. A learning healthcare system driven by sound data delivers additional returns with each successive correction.¹⁰³ The next step involves harmonizing fragmented and overlapping HIS funding by global organizations. Active between 2005 and 2013, the Health Metrics Network was a global partnership hosted by the World Health Organization that sought to provide coordinated support to strengthen HIS.¹⁰⁴ The network is credited with HIS-driven improvements in mortality rates and cost effectiveness.¹⁰⁵ The Partnership in Statistics for Development in the 21st Century (PARIS21) initiative continues the effort to build statistical capacity for data production, maintenance, and analysis in developing countries.¹⁰⁴

Enhancing sustainability, quality, and comprehensiveness of registry data is key for effective inter-registry collaboration. Efforts to maintain data sustainability need to be driven locally, and tailored to available infrastructure, technological, and financial capacities.¹⁰⁵ For example, paper-based HIS may be more appropriate than electronic HIS in countries with unreliable electricity supply, limited internet access, and low computer literacy. Databases that can be understood and used by policymakers are more likely to be continuously funded. Sustained funding and center engagement require policymakers to recognize the value of evidence-driven healthcare and incentivize service providers. As a result, the majority of longstanding kidney-failure registries are funded by government subsidy or kidney health societies (Supplementary Table S2).

The collection and curation of high-quality data should be the *modus operandi* of all registries. In practice, many kidney-failure registries lack systematic internal data-quality audits, owing to resource limitations.⁸⁵ Data errors can arise at various stages in the registry process.¹⁰⁶ Examples include incompleteness regarding data source, nonadherence to data definitions, calculation errors, programming errors in extraction software, transcription error, incomplete transcription, and typing errors. Methods to address these issues include extensive training and selection of motivated data collectors, routine completeness checks and site visits, clear data definitions, use of closed questions, and regular feedback on results and recommendations to resolve data errors.¹⁰⁷

Data comprehensiveness is beneficial to maximizing capacity to control for confounders and maximizing data potential for secondary use. Endeavors to increase data comprehensiveness need to be balanced against feasibility in the setting of finite healthcare resources. Direct upload from electronic health records may ameliorate data-entry burden, although this solution is only available to jurisdictions with electronic health records. Furthermore, large-scale developments to create syntactic and semantic interoperability are required across fragmented and diverse electronic health records before this aspiration can be realized.

Harmonization of data elements would reduce the amount of data synthesis required for inter-registry research. Initially, we propose that this would involve a universal shift toward collecting individual-level data. Ultimately, a carefully defined core set of variables should be collected in a standardized way by all registries, allowing datasets to be merged seamlessly (e.g., unit of measure for PD peritonitis = number of PD peritonitis episodes per year at risk). Core variables should be established through partnership with all stakeholders, including patients, caregivers, health professionals, database managers, biostatisticians, and policymakers. The Standardised Outcomes in Nephrology (SONG) initiative exemplifies optimal processes for establishing core outcome domains in clinical research and engaging consumers as partners. This method utilizes multimodal approaches, such as nominal group techniques, Delphi surveys, and consensus workshops, to ensure that selected variables are relevant and important to all stakeholders, and feasible to implement.¹⁰⁸

In 1997, the International Federation of Renal Registries (IFRR) was organized to standardize kidney-disease registries with respect to terminology, data collection, and data analysis protocols.¹⁰⁹ The outcomes of this initiative are unknown, as no further reports have been generated since 1997 after their first meeting. More recently, the Nephrology Quality European Studies (NephroQUEST) project was initiated by the ERA-EDTA to provide a consensus on quality performance indicators (Table 3) to be included in European kidney-disease registries.^{110,111} Selected variables are skewed significantly toward hemodialysis populations with limited variables relevant to peritoneal dialysis and kidney transplant cohorts. Additionally, this initiative had no patient or caregiver input and was limited to the European continent. Other initiatives to improve semantic interoperability include the Kidney Health Initiative—data harmonization in kidney transplantation,¹¹² the Kidney Disease: Improving Global Outcomes (KDIGO) consensus on kidney-failure reporting in clinical trial outcomes,¹¹³ and the Clinical Data Interchange Standards Consortium (CDISC) guidelines for reporting in diabetic kidney disease, kidney transplant, and polycystic kidney disease.¹¹⁴ Ironically, work designed to harmonize data has been fragmented across disease subtypes and/or locations, highlighting the need for coordinated consensus approaches.

International consensus, guidelines, and incentives are required to facilitate health registry collaboration. In a qualitative study, researchers identified legal uncertainty and lack of fair attribution mechanisms as major barriers to data sharing.⁵⁹ Dialogue and consensus-building among stakeholders, including funders, researchers, institutions, journal editors, ethics committees, multinational agencies, and governments are essential to developing unified guidelines on global health data collaboration.¹¹⁵ Such discussion could be facilitated by a nonpartisan third party, such as the World Health Organization or the Organisation for Economic Cooperation and Development. Furthermore, reliable citation of datasets is required to incentivize researchers to share datasets in the hypercompetitive research environment.^{33,116}

Other requisite reforms involve the development of searchable databases for metadata (e.g., DataCite), procedures for quality control of datasets, and standards governing data use, as seen in the fields of genomics and proteomics.^{33,56}

Conclusion

Kidney-failure registries fulfill an important role in collecting data regarding disease burden, service provision, and patient characteristics and outcomes. This information drives advocacy efforts, health infrastructure development, preventative health policies, and service benchmarking. Increasingly, kidney-failure registries are used for epidemiologic and hypothesis-generating research. This review serves as an important resource that comprehensively describes the structure, funding, and content of kidney-failure registries globally in 2021, as well as suggested approaches to support inter-registry research. We are hopeful that this review, in conjunction with initiatives such as the Global Kidney Health Atlas, SharE-RR, and NephroQUEST, will provide a roadmap to guide and encourage future collaborative inter-registry research.

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SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

Table S1. Summary of multiregistry studies.

Table S2. Summary characteristics of national databases.

Table S3. Summary characteristics of secondary multiregional databases.

Table S4. Renal registries of inactive or unknown current status.

Table S5. Data collected by kidney-failure registries.

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