International collaborative efforts to establish kidney health surveillance systems

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Data on disease rates, treatment rates, and resources are needed to advocate for change that will reduce the burden of kidney disease on individuals and populations.[1–4] Although most high-income countries have some form of kidney health surveillance system, such as a renal registry, this is not the case for middle-income and, particularly, low-income countries,[2] where the human and economic impacts of end-stage kidney disease can be catastrophic.[5] At present, most kidney health surveillance systems are in the form of kidney replacement therapy registries, but new definitions of chronic kidney disease[6] and acute kidney injury[7] create the opportunity to capture earlier stages of kidney disease and shift efforts to prevention. The management of kidney failure without replacement therapy, whether as a result of patient choice or limited resources, must also be prioritized for counting cases and quality assurance; this is a particularly vulnerable, high-risk group of patients.[5]

Recognizing this, in 2017 the International Society of Nephrology (ISN) supported a proposal for a pilot project—SHARing Expertise to support the set-up of Renal Registries (SharE-RR).[8] The overarching aim, at that stage, was to establish an infrastructure to support data capture for advocacy, quality assurance, and research. The focus was primarily on supporting countries without surveillance systems, while recognizing that there is great opportunity for shared learning among countries with established systems. If international agreement can be achieved on key definitions, data sharing for global kidney health advocacy and research will be facilitated without the need to establish and maintain a global renal registry.

After a successful pilot, SharE-RR became a formal ISN project in 2019. It sits under the advocacy theme, with close links to the education and research themes. This report describes the work undertaken during the 2-year SharE-RR pilot and sets out SharE-RR's plans. Although most current registries focus on dialysis and transplantation, the goal of the ISN, ultimately, is to promote surveillance systems that extend beyond this, that is, create those that would also monitor chronic kidney disease and even acute kidney injury.

Oversight and setting strategy

A steering committee was established comprised of a chairperson and representative members from 5 large kidney health surveillance systems: the African Association of Nephrology (AFRAN) Registry, the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, the European Renal Association–European Dialysis and Transplant Association (ERA-EDTA) Registry, the Sociedad Latinoamericana de Nefrología e Hipertensión (SLANH) Registry (LADRTR), and the United States Renal Data System (USRDS).

The steering committee met by videoconference each month, and in person at international conferences, overseeing all aspects of SharE-RR strategy, delivery, and progress monitoring. Objectives were agreed on (Supplementary Table S1), and a website[8] was created to publicize the initiative, host resources as they became available, and provide access to the team. The initial objectives later were focused on 2 activities: the undertaking of a global survey of kidney health surveillance systems and the convening of a workshop for people in countries aspiring to create a kidney health surveillance system.

Global survey of kidney health surveillance systems

The purpose of the SharE-RR survey was to capture the approaches currently in operation to collect, manage, and report data on people with kidney disease. The resulting inventory could be used to signpost individuals developing systems to harness the expertise, experiences, and approaches being used around the world that are most relevant to their own settings. The survey was targeted at organizations collecting data on adults receiving maintenance dialysis; organizations collecting only kidney transplant and pediatric data were not approached directly. As the Global Kidney

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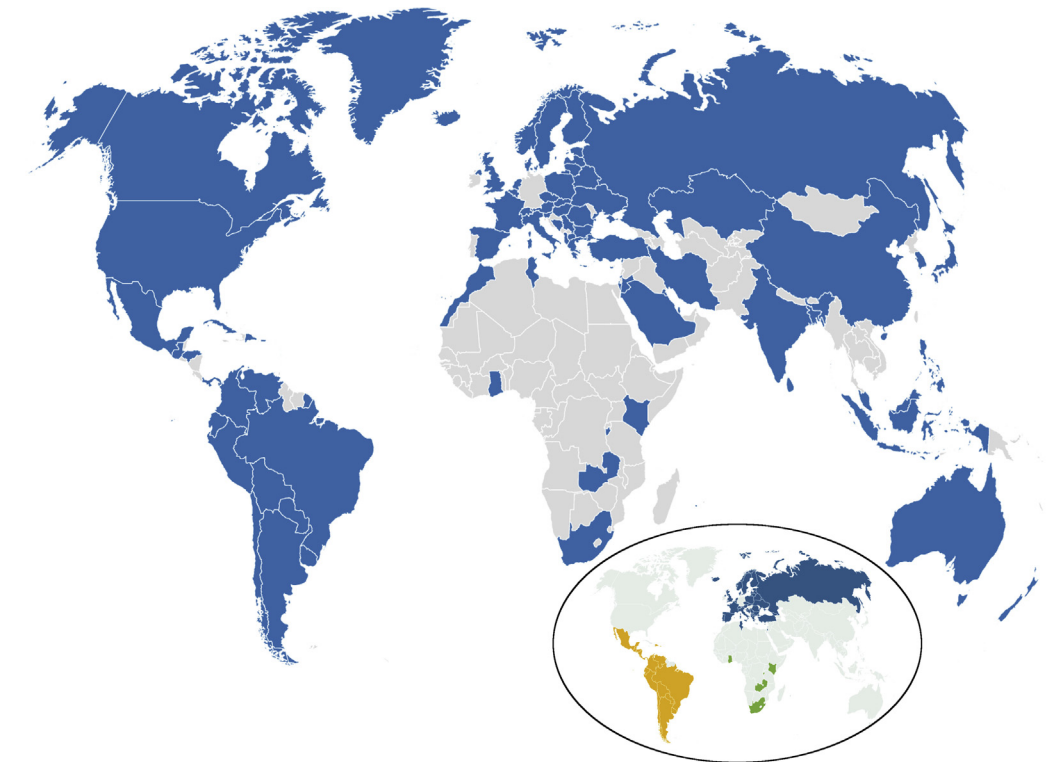
Figure 1 | Countries reporting international, national, and regional renal registries in the SHARing Expertise to support the set-up of Renal Registries (SharE-RR) survey. Dark blue = kidney health surveillance system; gray = no registry. Inset shows coverage of the Sociedad Latinoamericana de Nefrología e Hipertensión (SLANH; yellow), European Renal Association–European Dialysis and Transplant Association (ERA-EDTA; blue), and African Association of Nephrology (AFRAN; green) Renal Registries.

Health Atlas already collects and reports data on which countries have registries, the SharE-RR survey focused on more technical aspects, with the ultimate aim of producing a resource that could be a signpost to relevant registry experience and expertise.

Questionnaire development began in late 2017, with compilation, internal piloting, and iterative revision. The questions were related to geographic and kidney replacement therapy coverage, clinical and demographic data items collected, information governance and administrative factors, and challenges. The final survey included between 40 and 49 questions, depending upon answers to stem questions. The survey was provided in English and administered via SurveyMonkey (SurveyMonkey Inc., San Mateo, CA) between June 1, 2018 and September 30, 2018 (Supplementary Table S2). Appropriate contacts were provided by the steering committee. Non-responding organizations were recontacted, and when an operational registry was known to exist, direct communication was reattempted by a steering committee member until all available contacts had been exhausted. If more than one response was received from a country or region, clarification and consensus were sought from sources.

Responses were received from 85 of the 126 kidney health surveillance systems contacted (Figure 1; Supplementary Table S3). Data were highly incomplete for 5, and 2 did not describe themselves as registries. The earliest surveillance system reported establishment in 1964, and 3 had been established as recently as 2018. Eighty-four of the 85 responding organizations (99%) collected adult hemodialysis data, 78 (92%) collected adult peritoneal dialysis data, and 63 (74%) collected adult transplant data. Pediatric hemodialysis, peritoneal dialysis, and transplant data were collected by 64 (75%), 56 (66%), and 51 (60%) responding organizations, respectively. Eight (9%) responding organizations reported also collecting acute kidney injury data, and 19 (22%) reported collecting non-dialysis-dependent chronic kidney disease data. Table 1 presents a summary of the infrastructural, funding, and information governance findings from the responding organizations.

Table 1 | Infrastructural, financial, and information governance results from the 85 adult dialysis registries that responded to the SHARing Expertise to support the set-up of Renal Registries (SharE-RR) Survey

Adult dialysis registries only (n = 85)	n (%)
Modality	
Hemodialysis	84 (99)
Peritoneal dialysis	78 (92)
Granularity of data[a]	
Incident patients	
Individual patient data	58 (69)
Aggregate patient data	15 (18)
Mixed individual/aggregate	9 (11)
Prevalent patients	
Individual patient data	54 (60)
Aggregate patient data	19 (23)
Mixed individual/aggregate	11 (13)
Funding	
Government	45 (53)
National society	27 (32)
Renal centers	12 (14)
Industry	11 (13)
Academic institution	8 (9)
Charity	4 (5)
Other	9 (11)
Unfunded	9 (11)
Multiple	27 (32)
Consent	
Waiver of individual patient consent	56 (66)[b]
For audit/quality improvement	
Ethical approval	47 (55)
Legal approval	32 (38)
None of the above	17 (20)
For research	
Ethical approval	68 (80)
Legal approval	36 (43)
None of the above	7 (8)
Data collection and reporting	
Web-based forms	44 (52)
Paper-based forms	31 (36)
E-mail	24 (28)
Extraction from clinical systems	19 (22)
Secure link	14 (16)
Billing data	4 (5)
Publish annual report	63 (74)
Maintain website	36 (46)
Number of registries employing the following staff	
Nephrologist(s)	27 (32)
Trainee nephrologist(s)	5 (6)
Clinical epidemiologist(s)	12 (14)
Nurse(s)	14 (17)
Nonclinical epidemiologist(s)	9 (11)
Statistician(s)	29 (34)
Programmer(s)	31 (37)
Data manager(s)	34 (40)
Administrator(s)	29 (34)
Other(s)	13 (16)
Voluntary staff	44 (52)
Data sharing	
Within country	
Patient level only	3 (4)
Summary data only	44 (52)
Both	33 (39)

(Continued in next column)

Table 1 | (Continued)

Adult dialysis registries only (n = 85)	n (%)
Outside country	
Patient level only	5 (6)
Summary data only	40 (47)
Both	30 (35)

[a]Adult hemodialysis registries only.
[b]These numbers do not sum to 85 due to differing response rates to certain questions and interpretations of the terms "audit/quality improvement" and "research."
Values are n (%). Percentages are currently based on % of completed responses for that question rather than % of all respondents.

Dominant themes relating to challenges faced included limited resources (human, financial, space, and technological—69 organizations); maintenance of center participation (38 organizations); legal, ethical, and information governance issues (18 organizations); capture of key information in the absence of an agreed-on standard (15 organizations), and governmental buy-in (13 organizations). Individual organizations also reported challenges associated with geography (e.g., establishing a surveillance system in an archipelago) and size (e.g., maintaining full data collection in a country with >100,000 dialysis recipients).

A wide breadth of expertise was volunteered, including technological and systems approaches for the acquisition and management of surveillance data; negotiation of complex information governance, and legal and ethical challenges; statistical analysis; engagement of and influencing stakeholders; and experience of establishing, sustaining, and developing a surveillance system in underfunded settings. Cataloging this expertise will allow the creation of an online resource, hosted by ISN, that directs individuals establishing a surveillance system to individuals with experience in a particular area.

The first SharE-RR workshop
Following the global survey, SharE-RR organized a 1-day pre-congress workshop at the 2019 World Congress of Nephrology in Melbourne, Australia. The aim of the workshop was to give representatives from countries establishing surveillance systems the opportunity to share experiences, goals, and challenges with each other and the SharE-RR steering committee.

The objectives of the workshop were for attendees to:
- form supportive relationships and links with the SharE-RR steering committee and other attendees;

Box 1 | Steps in planning a registry

1. Articulate the purpose of the registry
2. Determine if a registry is an appropriate means to achieve the purpose
3. Identify key stakeholders
4. Assess the feasibility of the registry
5. Build a registry team
6. Establish a governance and oversight plan
7. Define the scope and rigor needed
8. Define the data set, patient outcomes, and target population
9. Develop a study plan or protocol
10. Develop a project plan

Reprinted from Gliklich RE, Dreyer NA, Leavy MB. Planning a registry. In: Registries for Evaluating Patient Outcomes: *A User's Guide [Internet]*. 3rd ed. Rockville MD: Agency for Healthcare Research and Quality; 2014. Available at: www.ncbi.nlm.nih.gov/books/NBK208631/?report=classic. Accessed June 3, 2020.[9]

- share the goals for their surveillance systems and explore ways in which these can be achieved;
- share stories of information technology/governance, financial, and political challenges experienced and how they have been overcome; and
- identify the key stakeholders who influence the establishment/maintenance of a surveillance system in their settings.

Potential attendees for the workshop were identified by the steering committee, responses to the survey, and suggestions from nongovernmental organizations. One to three delegates from 10 countries attended the workshop: Bangladesh, Brazil, Fiji, Ghana, Indonesia, Kenya, Sri Lanka, Tanzania, Zambia, and Zimbabwe.

Delegates began by briefly describing the state of the surveillance systems in their countries. Four then gave presentations covering specific challenges and how they were working with stakeholders to achieve their goals. Presentations from steering SharE-RR committee members covered lower- and higher-income country perspectives on setting up a renal registry, dataset essentials, and the potential scope for registries once developed. Common challenges to setting up and maintaining surveillance systems were identified—funding, staffing, administration of data collection and information governance—and strategies to overcome these were discussed. Robust discussions were had about both the pragmatic and aspirational aspects of data collection. Information governance challenges were a recurring theme, and it was agreed that guidance produced by ISN may help with these.

SharE-RR: future directions

Continuing the pilot work to completion, the central register of kidney health surveillance systems and expertise identified through the survey will now be created and hosted on the SharE-RR website. Learning from the restrictions that the coronavirus disease 2019 pandemic has placed on travel and face-to-face workshops, digital approaches will be developed to provide learning opportunities for individuals setting up registries.

In addition, recognizing the logistical, resource, and political challenges involved, SharE-RR has prioritized 2 further tasks for the coming years:

- Create a network of individuals and organizations interested in supporting the objectives of SharE-RR. These individuals and organizations will often have a degree of their own capacity and resources to support work, especially when based in high- or middle-income countries. They may also access local and national funding opportunities to support such global health work.
- Develop a toolkit for establishing and developing a renal registry. When possible, existing guidance will be adopted and adapted, such as that of the Agency for Healthcare Research and Quality in the United States[9] (Box 1), and World Health Organization principles will be considered, to ensure global relevancy. This work will be undertaken by 3–4 small working groups comprised of volunteers from the SharE-RR Network.

To support the work, capacity will be built leveraging existing ISN opportunities, such as the Sister Renal Center programme ("sister

renal registries"), the ISN Fellowship programme, the Educational Ambassador programme, the Mentorship programme, and the Clinical Research programme.

Although the primary purpose of SharE-RR is to support the establishment of kidney health surveillance systems where they don't currently exist, there is also an opportunity for established systems to learn lessons from this global network and extend their reach into chronic kidney disease and acute kidney injury. This extension of the coverage of kidney health surveillance systems would enable more of a public health, preventive focus and support the global community's ambition of kidney health for everyone everywhere.

Of course, challenges lie ahead. Barriers to system establishment and maintenance have been identified at all stages of the SharE-RR project. Most noteworthy are resource constraints, apparently the main driver of the current paucity of data on kidney replacement therapy in low-income nations, and some higher-income ones. Data protection must be a priority for all organizations that process personal and sensitive data, to guard against misuse for malign purposes, which will be more relevant in some countries than others. Nevertheless, numerous successful systems can be found operating in low-income settings. It is hoped that SharE-RR will facilitate the further sharing of these experiences, resources, and passions across borders to fill in the data black holes and ultimately improve care for people with kidney disease around the world.

DISCLOSURE

All the authors declared no competing interests.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)
Table S1. Initial objectives of SharE-RR.
Table S2. SharE-RR survey.
Supplementary File (Excel)
Table S3. Table of all countries and whether a response was received.

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