

The global landscape of kidney registries: immense challenges and unique opportunities

Christopher H. Grant¹, Fergus J. Caskey², M. Razeen Davids³, Manisha Sahay⁴, Aminu K. Bello⁵, Dorothea Nitsch⁶ and Samira Bell¹

¹ *Division of Population Health & Genomics, University of Dundee, Dundee, UK*

² *Population Health Sciences, University of Bristol, Bristol, UK*

³ *Division of Nephrology, Department of Medicine, Stellenbosch University and Tygerberg Hospital, Cape Town, South Africa*

⁴ *Department of Nephrology, Osmania General Hospital & Osmania Medical College, Hyderabad, India*

⁵ *Department of Medicine, University of Alberta, Alberta, Canada*

⁶ *Faculty of Epidemiology & Population Health, London School of Hygiene and Tropical Medicine, London, UK*

E-mail: s.t.bell@dundee.ac.uk

Kidney registries are essential to understand the burden of kidney disease and facilitate the development of sustainable and effective programs for kidney disease prevention and care. Key barriers to implementation of registries at a global scale include funding and data quality. These issues warrant the attention of the global nephrology community.

Introduction

The increasing burden of chronic kidney disease (CKD) is a public health issue worldwide. The provision of kidney replacement therapy (KRT) for kidney failure confers a substantial cost in terms of healthcare resources as well as increased hospitalizations, infections and mortality. Registries are essential to capture these events and facilitate the development of policies for kidney disease care and prevention.¹ Kidney disease registries vary in their geographical coverage and scope, with most capturing treated kidney failure (i.e. KRT) at a national level.² KRT registries (KRTRs) provide invaluable data on the incidence, prevalence and mortality of kidney failure together with indices of quality of care. These data are essential for service provision, planning, auditing, empirical research, identifying at-risk populations and driving high standards of care by creating an informed culture of excellence.

Huge disparities exist in the nature, presence, and quality of kidney registries worldwide.³ The latest estimates from the International Society of Nephrology (ISN) Global Kidney Health Atlas (GKHA) suggest that only a quarter of low-income countries have a KRTR, compared to over 80% of upper-middle and high-income countries.⁴ This disparity poses challenges to the effective capture and monitoring of critical data to inform public health policy, particularly in low-income regions worldwide.

Setting up kidney registries

Identification and engagement of key stakeholders is necessary to establish and maintain KRTRs. Continual centre engagement is challenging, particularly in resource-limited settings where staff must prioritise multiple competing demands to safely deliver patient care. This issue is further complicated by the absence of data management systems, such as electronic health records (EHRs), in primary facilities. Regional and national governments that provide long-term financing often require regular dissemination of key registry outputs through annual reporting, which can be labour intensive in resource-limited settings.³

Inadequate financial resources represent the greatest barrier to the development, implementation and sustainability of KRTRs. The ISN-GHKA data show that just under two-thirds of countries (102/159) provide public funding for KRT and less than half of low income countries provide such funding (11/23).⁵ Governments that are unable to provide funding for KRT rarely support the development of complex health information systems such as KRTRs to monitor a condition for which treatment is perceived to be unaffordable.⁶ Resource needs are not only financial, but also relate to personnel and technology. In addition to nephrologists, registries require a multidisciplinary team of experts including statisticians, data managers, programmers and administrators.⁷ The information technology infrastructure that is necessary to maintain a registry requires a reliable electricity supply, internet capacity, analytical software and, ideally, subject-level EHRs that enable direct imputation of data from source centres.³

Kidney registries must define their target population: KRT, non-dialysis CKD or acute kidney injury. Unsurprisingly, most countries opt to establish KRTRs given the disproportionately high costs of delivering this treatment for a small proportion of the population. Case ascertainment is challenging in resource-limited settings where the requisite diagnostics and resources for data capture may be lacking, leading to under-reporting. The number of patients receiving KRT in low-income countries is a surrogate for treatment availability rather than burden of disease and quantification of the treatment gap (i.e. identifying patients with kidney failure in the absence of KRT provision) is challenging. Identification of patients who receive KRT for a short time owing to insufficient finances or death following late presentation may prove difficult if reliant upon a single data source that may lack granularity.⁶ The common practice of reporting one-year survival only after the first 90 days of KRT misses important information on early mortality and cessation of treatment.

An effective governance framework in the form of organisational oversight with a hierarchy of designated roles and responsibilities is essential to ensure data quality, safety, transparency, and accountability. Registries must have the capacity to manage data in a manner that conforms to national and international data protection obligations. A registry must have a defined purpose, which requires data to be of sufficient rigour and quality to

justify the expense of its collection. Obtaining individual patient consent for data collection is resource intensive and results in incomplete data, thereby undermining evidence-based policy decisions.^{6,8}

Registry data has limitations. Integration of different registries may be challenging owing to different data collection platforms. Furthermore, the nature of 'real-world' data limits direct comparisons due to heterogeneity and potential unmeasured confounders.

Equitable kidney health surveillance

Despite the innate difficulties of delivering healthcare in resource-limited settings, global initiatives to support the creation of renal registries offer reasons for optimism. In 2017, the ISN established the SHARing Expertise to support the set-up of Renal Registries (SharE-RR) initiative. A panel of international experts created a toolkit with freely available resources, including a global inventory of the operational logistics of functioning registries, guidance for advocacy and international best practice.⁹ This work was part of an ISN/WHO Collaboration Plan (2021-2023), and the ShareE-RR toolkit was released in February 2024. The toolkit enables knowledge and skills exchange with the potential for extensive training in relevant data analytics but is unlikely to directly impact the funding of new KRTRs.

Advocates for equitable kidney care must ensure that policymakers and funders realise the value of real-world, evidence-based, decision-making resulting from surveillance to guide health service delivery and planning. Both the economic justification for activities and the interpretability of registry outputs must be emphasized.³ Integration of registries with international collaborations can enhance collective expertise. Well-established systems (such as USRDS, ERA-EDA, ANZDATA, UKRR and CORR) should continue to share expertise and support capacity building in low-income countries and resource-poor settings. In 2015, the African Renal Association Network (AFRAN) established the African Renal Registry, which enables sharing of costs, staffing, governance structures, technological advances, infrastructure and advocacy for financial support.⁶ New registries must seek funding from multiple partners beyond governments, including kidney centres and societies, industry, academic institutions, philanthropists and charities.⁷

In countries where EHRs are not available at individual centres, paper-based health information systems can be implemented despite their inherent difficulties in quality assurance, data linkage and analytics.³ Registries with the legislative authority to mandate centre participation have greatly enhanced prospects of accurate case ascertainment, improving data completeness and quality.⁸ Data collection should be streamlined and limited to a clearly defined set of parameters with an emphasis on quality, reproducibility and temporal trends rather than expansive datasets with the aim of speculative research

pursuits. Implementation of codes for kidney failure and KRT, such as those established by the ERA-EDTA¹⁰, enable a robust process of data capture with clear definitions and closed questions, improving data completeness. The resource-intensive nature of individual patient consent procedures can be circumvented by the granting of waivers from regional or national ethics boards.⁶

The enormity of the challenges in implementing kidney registries worldwide is without question; however, a systematic means of quantifying population-level harm and the impact of treatment is vital to achieve equitable global kidney health. Nephrologists must work together to engage with patients, societies, governments and international advocates to realise this ambition.

Competing interests

FJC leads the ISN’s SharE-RR initiative. AKB received grant funding from the Canadian Institute of Health Research, and Heart and Stroke Foundation of Canada in addition to consultancy fees from Amgen Canada, Bayer and Otsuka unrelated to this manuscript. DN is the Director of Informatics Research at the UK Kidney Association. SB is chair of the Scottish Renal Registry. The other authors declare no competing interests.

Acknowledgements

CHG is funded by a PhD scholarship at the *University of Dundee* as part of the *Multimorbidity PhD Programme for Health Professionals* supported by the *Wellcome Trust*.

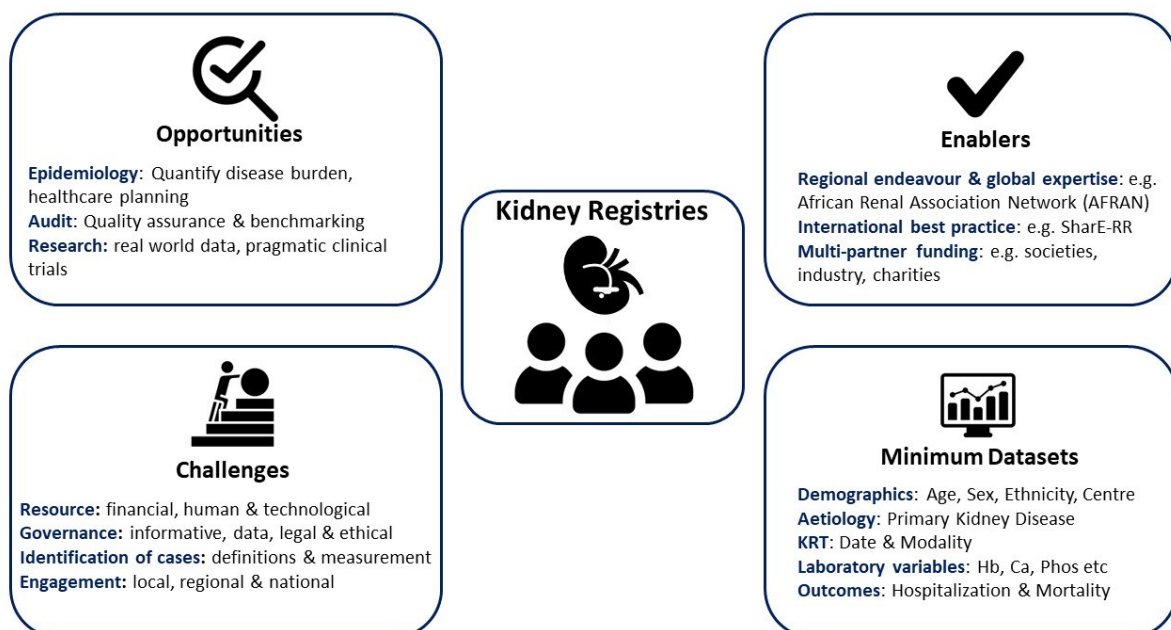


Figure 1 - Challenges, enablers, opportunities & minimum datasets of KRTRs. The implementation of national KRTRs presents unique opportunities including audit, research and health service planning. Substantial challenges to establishing KRTRs include sufficient resource, information governance, case identification and engagement of policymakers. Factors which enable these challenges to be overcome include the use of regional expertise, international best practice and multi-partner funding. KRTRs should define a minimum dataset including demographics, aetiology and onset of kidney failure, KRT modality, laboratory variables and outcomes.

References

1. Solomon, D. J., Henry, R. C., Hogan, J. G., Van Amburg, G. H. & Taylor, J. Evaluation and implementation of public health registries. *Public Health Rep* **106**, 142-150 (1991).
2. See, E. J. *et al.* Availability, coverage, and scope of health information systems for kidney care across world countries and regions. *Nephrol Dial Transplant* **37**, 159-167, doi:10.1093/ndt/gfaa343 (2021).
3. Ng, M. S. Y., Charu, V., Johnson, D. W., O'Shaughnessy, M. M. & Mallett, A. J. National and international kidney failure registries: characteristics, commonalities, and contrasts. *Kidney Int* **101**, 23-35, doi:10.1016/j.kint.2021.09.024 (2022).
4. Bello A. K. *et al.* ISN–Global Kidney Health Atlas: A report by the International Society of Nephrology: An Assessment of Global Kidney Health Care Status focussing on Capacity, Availability, Accessibility, Affordability and Outcomes of Kidney Disease. Brussels, Belgium. Available from: https://www.theisn.org/wp-content/uploads/media/ISN%20Atlas_2023%20Digital.pdf [Accessed 26th November 2023].
5. Bello, A. K. *et al.* Status of care for end stage kidney disease in countries and regions worldwide: international cross sectional survey. *BMJ* **367**, l5873, doi:10.1136/bmj.l5873 (2019).
6. Davids, M. R. *et al.* A renal registry for Africa: first steps. *Clin Kidney J* **9**, 162-167, doi:10.1093/ckj/sfv122 (2016).
7. Hole, B. D. *et al.* International collaborative efforts to establish kidney health surveillance systems. *Kidney International* **98**, 812-816 (2020).
8. Rosa-Diez, G., González-Bedat, M. C., Luxardo, R., Ceretta, M. L. & Ferreiro-Fuentes, A. Step-by-step guide to setting up a kidney replacement therapy registry: the challenge of a national kidney replacement therapy registry. *Clin Kidney J* **14**, 1731-1737, doi:10.1093/ckj/sfab015 (2021).
9. International Society of Nephrology. ISN-Share-RR Toolkit. Available from: <https://www.theisn.org/in-action/advocacy/advocacy-activities/share-rr/isn-share-rr-toolkit/>. [Accessed 12th March 2024].-
10. Venkat-Raman, G. *et al.* New primary renal diagnosis codes for the ERA-EDTA. *Nephrol Dial Transplant* **27**, 4414-4419, doi:10.1093/ndt/gfs461 (2012).