



CKJ REVIEW

A renal registry for Africa: first steps

M. Razeen Davids¹, John B. Eastwood², Neville H. Selwood³, Fatiu A. Arogundade⁴, Gloria Ashuntantang⁵, Mohammed Benghanem Gharbi⁶, Faïçal Jarraya⁷, Iain A.M. MacPhee², Mignon McCulloch⁸, Jacob Plange-Rhule⁹, Charles R. Swanepoel¹⁰ and Dwomoa Adu¹¹ for the African Association of Nephrology and the African Paediatric Nephrology Association

¹Division of Nephrology, Stellenbosch University and Tygerberg Hospital, Cape Town, South Africa, ²Department of Renal Medicine, Institute of Medical and Biomedical Education, St. George's, University of London, London, UK, ³The Oaks, Tower House Drive, Lowbands, Gloucestershire, UK, ⁴Department of Medicine, Obafemi Awolowo University, Ile Ife, Nigeria, ⁵Department of Internal Medicine & Specialties, University of Yaoundé I, Yaounde, Cameroon, ⁶Nephrology Department, Faculty of Medicine, University Hassan II, Casablanca, Morocco, ⁷Research Unit 12ES14 and Nephrology Department, Hedi Chaker University Hospital, Sfax, Tunisia, ⁸Red Cross War Memorial Children's Hospital and University of Cape Town, Cape Town, South Africa, ⁹School of Medical Sciences, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana, ¹⁰Division of Nephrology and Hypertension, University of Cape Town, Cape Town, South Africa, and ¹¹University of Ghana and Korle-Bu Teaching Hospital, Accra, Ghana

Correspondence to: M. Razeen Davids; E-mail: mrd@sun.ac.za

Abstract

There is a dearth of data on end-stage renal disease (ESRD) in Africa. Several national renal registries have been established but have not been sustainable because of resource limitations. The African Association of Nephrology (AFRAN) and the African Paediatric Nephrology Association (AFPNA) recognize the importance of good registry data and plan to establish an African Renal Registry. This article reviews the elements needed for a successful renal registry and gives an overview of renal registries in developed and developing countries, with the emphasis on Africa. It then discusses the proposed African Renal Registry and the first steps towards its implementation. A registry requires a clear purpose, and agreement on inclusion and exclusion criteria, the dataset and the data dictionary. Ethical issues, data ownership and access, the dissemination of findings and funding must all be considered. Well-documented processes should guide data collection and ensure data quality. The ERA-EDTA Registry is the world's oldest renal registry. In Africa, registry data have been published mainly by North African countries, starting with Egypt and Tunisia in 1975. However, in recent years no African country has regularly reported national registry data. A shared renal registry would provide participating countries with a reliable technology platform and a common data dictionary to facilitate joint analyses and comparisons. In March 2015, AFRAN organized a registry workshop for African nephrologists and then took the decision to establish, for the first time, an African Renal Registry. In conclusion, African nephrologists have decided to establish a continental renal registry. This initiative could make a substantial impact on the practice of nephrology and the provision of services for adults and children with ESRD in many African countries.

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Key words: dialysis, transplantation, epidemiology, ESRD, renal replacement therapy

Background

The continent of Africa has a population of 1.1 billion living in 54 countries. Many African countries are facing the dual burdens of infectious and non-communicable diseases (NCDs). The World Health Organization (WHO) estimated that 63% of global deaths in 2008 were due to NCDs [1], with most occurring in low- and middle-income countries. There are few studies on NCDs in Africa and there have been calls for more research to be conducted in this area [2].

While there is widespread concern about the epidemics of diabetes and cardiovascular disease (CVD), it is less well appreciated that this is accompanied by an epidemic of chronic kidney disease (CKD) and end-stage renal disease (ESRD). The disease burden of CKD in Africa is likely to be at least as high as is reported elsewhere [3, 4]. An increase in 'lifestyle' diseases combined with a high burden of infectious diseases may contribute to a high incidence of CKD and ESRD. Congenital renal problems are an important cause of CKD in children, with delays in diagnosis resulting from limited availability of foetal ultrasound screening.

The World Health Assembly recently endorsed the WHO Global Action Plan for the Prevention and Control of NCDs 2013–2020 [5]. The targets for this important initiative include a 25% reduction in premature mortality from NCDs by 2025. While CKD is not explicitly mentioned, the actions that planned have the potential to make a significant impact on the burden of CKD.

There are few published data on CKD in most African countries [6–8]. A recent systematic review reported a population prevalence of CKD in sub-Saharan Africa of 13.9% [7] but highlighted the need for more studies of good quality. Regarding the burden of more advanced stages of CKD, the annual incidence of ESRD in North African countries has been estimated to be around 150 pmp [9, 10]. Anand *et al.* [11] modelled the incidence of ESRD in developing regions and predicted an annual incidence of 239 pmp in people with diabetes and hypertension who live in sub-Saharan Africa. They found that renal replacement therapy (RRT) use correlated with regional income, with most patients unable to access RRT. Liyanage *et al.* [12] estimated that at least 432 000 people in Africa require RRT but are not receiving it. There seem to be no major differences in the incidence of ESRD among developing countries [13]. The extremely wide variations in reported prevalence are therefore mainly a reflection of differing access to dialysis and transplantation [13]. This is strongly associated with gross national income per capita [3]. It must be emphasized that, in developing countries, the number of patients in an RRT programme is an indicator of the provision and accessibility of RRT services and is not a proxy for the burden of disease.

The lack of renal registries means that there are few reliable statistics on RRT from Africa. Indeed, most governments in Africa are probably unaware that many of their citizens are dying of kidney disease. Estimates are based mainly on old registry reports and unpublished data [6, 14], but suggest that the provision of RRT services has been a low priority for most African countries, with few state-funded dialysis or transplantation programmes [6]. In most countries where services are available, patients carry the full cost and few are able to afford dialysis beyond the first 3 months [15].

Most developed countries have renal registries that provide critical information to support the planning, delivery and

evaluation of dialysis and transplantation services. In Africa, where access to treatment is restricted on economic grounds, the publication of registry data can draw attention to the underappreciated problem of CKD and highlight discrepancies in the provision of RRT services within and between countries. This may encourage governments and other funders to increase their support, as has been the case with Tunisia [16]. Furthermore, registry data can aid efforts to prevent, detect and treat the earlier stages of CKD by identifying the most important causes of renal disease in each country.

In several African countries, nephrologists have established renal registries and published data on RRTs. Unfortunately, most have not been sustainable and in recent years no African country has regularly published countrywide data on the provision of RRT. The African Association of Nephrology (AFRAN) and the African Paediatric Nephrology Association (AFPNA) have recognized this serious knowledge gap and, at their 2013 congress in Accra, decided to pursue the establishment of a renal registry for Africa.

Establishing renal registries

A patient registry collects a defined set of health and demographic data from patients with a particular disease or who have had a particular intervention. Such data are held in a central database and may include information on longitudinal follow-up and outcomes [17–19]. Solomon *et al.* [19] have identified several factors required for the successful development of a new registry and these are included in the sections that follow.

Clarifying the purpose and scope

Early discussions are needed to decide on the purpose, scope and minimum outputs. Our proposed registry would include adults and children, in keeping with the adult–paediatric collaboration that was formalized at the 2013 AFRAN/AFPNA meeting. The purpose would be to generate information on the prevalence, incidence and causes of ESRD in patients on RRT and information on treatments and outcomes. The aim should be to collect a small set of well-defined epidemiological data over many years; any suggestions to turn the registry into a hybrid which also caters for various research projects or doubles as a practice management tool should be strenuously resisted. Unnecessary complexity and 'scope creep' will delay implementation dates, drive up costs and dramatically decrease compliance with data submission.

Good documentation

Providing information to patients, the public, registry personnel, colleagues and other registry users is essential and can be done via the registry website and by providing specific documents to the relevant parties as appropriate. There should be clear documentation on the management structure and key personnel of the registry, a description of inclusion or exclusion criteria, a data dictionary, documentation guiding the collection and further processing of data, a data access policy, documentation on confidentiality and ethics issues and copies of all registry publications.

Defining and finding patients to be included

All patients who receive RRT for ESRD should be included. Counting only patients who have been on dialysis for 90 days leads to the loss of important data on patients who start dialysis but cannot continue for financial reasons and those ‘crash landers’ who die soon after commencing RRT. Documenting all patients with ESRD who do not access RRT would be extremely useful in highlighting the treatment gap. This is possible for those patients who are seen at centres offering RRT but it is currently not feasible for all patients, as most are treated conservatively at local health facilities.

The extent to which all patients are captured impacts on the precision and level of bias in registry data [20]. Active case finding and the use of multiple sources of information increases completeness but may substantially increase costs. Sources of information may include the patients’ doctors, treatment centres, funders, and suppliers of medications or consumables. Ideally, reporting should be mandated by law and linked to reimbursement and the licensing of treatment centres.

Determining what data should be recorded

The golden rule is to keep it as simple as possible [21]. This lowers the costs and time requirements and improves compliance. Clearly defining the purpose of the registry helps in keeping the amount of data collected to a minimum. There should be core items that will be collected for the lifetime of the registry and provision for additional items of time-limited interest. Many registries focus their annual data collection on 31 December, often employing a centre questionnaire and a questionnaire for collecting data on individual patients.

The year-end centre questionnaire can produce useful information relatively quickly. This allows the registry to report the numbers of new patients starting RRT in a particular year (incidence), the deaths during that year, the number of patients on RRT at year-end (prevalence) and the numbers on each treatment modality.

The individual questionnaire collects demographic and treatment-related information to identify characteristics that may be related to the development of kidney disease, access to RRT, survival and other outcomes. Core data collected on each patient would include the following:

- Country, region and centre
- Patient unique identification number and name
- Date of birth and gender
- Ethnicity
- Primary renal disease
- Date and modality of first treatment
- Current treatment modality
- Changes of doctor, centre or modality, with dates
- Cessation of treatment or loss to follow-up, with date
- Death date and cause

The capture of additional data would be optional and might include more detail about the RRT, medications and indicators of treatment quality. In children, for example, recording height and weight would be particularly useful.

The data dictionary

The data dictionary describes the elements to be collected by the registry. This includes specifying the name of the element, data type (categorical, ordinal, numerical), precision (number of decimal points), range of acceptable values, etc. These definitions should conform to those used by well-established registries to

facilitate comparisons and to allow the aggregation of data. The coding of the primary renal disease is of particular importance and we would recommend adopting an established system such as the ERA-EDTA Registry coding scheme [22].

Collecting and cleaning data

This consumes most of the resources required to maintain a registry. Written standard operating procedures should guide data collection, entry into the database, and verification. Abstracting data from patient records is time consuming and prone to errors and can be facilitated by using purpose-designed paper or Web-based forms. Where possible, data should be collected directly from health information systems, as this greatly improves the accuracy and completeness of data capture and lowers costs. The UK Renal Registry, for example, extracts data electronically from National Health Service information technology systems.

Ensuring data quality

The value of a registry critically depends on data quality. Quality control processes must focus on data completeness, the prevention of duplicates, validity and accuracy, timeliness, usefulness of items and the accuracy of data interpretation and reporting [23]. A high degree of completeness is required for essential items so that key results such as the incidence and prevalence are close to their true values.

Random and systematic errors must be minimized. Logical rules enforced by the database software can ensure that only plausible values are entered, and internal consistency checks such as examining the sequences of dates can further reduce error rates. For example, the system should not allow the entry of a date for starting RRT that precedes the date of birth or a primary renal disease of ‘nephropathy due to pre-eclampsia/eclampsia’ if the gender has been indicated as male. An example of a systematic error is that black patients are more likely to be assigned a diagnosis of ‘hypertensive kidney disease’ than other patients with similar clinical histories [24].

Quality control should be built into the system with a feedback loop to inform data capturers of errors. It is important to appreciate that costs will increase as the desired level of completeness and accuracy required increases or if the data need to be made available more quickly [19].

Data ownership and data access

Data ownership would reside primarily with the renal societies of participating countries, who would have full access to their own data and be able to report their country-specific findings. Joint analyses and reporting of combined data would be the responsibility of the AFRAN Registry Committee. Making information widely available is a principle common to many registries and requires a data access policy for responding to requests for data while safeguarding patient confidentiality.

Dissemination of registry findings

Routine outputs might include annual reports, presentations at academic meetings, media releases, publications in medical journals and the release of datasets. Guidelines on the authorship of publications involving combined data should be available. In principle, each national registry contributing individual patient data would nominate one author, provided that the criteria for authorship are met.

Ethical considerations

There must be scrupulous attention to ethical aspects and relevant privacy and data protection legislation. Patients are managed in many different treatment centres across each country and obtaining individual consent would be a daunting task. An editorial in the *NEJM* [25] makes the point that public health is threatened more by incomplete data than individual privacy is threatened by disease registries. Registries that require written informed consent achieve only partial enrolment and limit our ability to evaluate and optimize care for patients.

The collection of data involves minimal risk to patients, as identifiable information would be protected from improper use and disclosure. For the South African Renal Registry, a waiver was granted by the Health Research Ethics Committee of Stellenbosch University so that individual consent does not have to be obtained. This is similar to the practice of the UK Renal Registry, the Scottish Renal Registry, and the French Renal Epidemiology and Information Network. Each country participating in the African registry initiative will need approval from its local ethics committee and we would recommend applying for a waiver of individual consent.

Funding

Establishing and operating a renal registry is resource intensive, and securing sustainable funding is critical to its success. AFRAN/AFPNA and the national societies will have to liaise with governments, industry and other funders and this is likely to be challenging in an environment where treatment provision is generally seen as unaffordable. Data collection often consumes most of the budget and few resources are then available for quality control, data analysis and reporting of findings. Considerable resources will be spent on establishing a registry and we should ensure that it does not fail thereafter because of a lack of funding.

Renal registries in developed and developing countries

The European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) Registry and other registries

The ERA-EDTA Registry is the world's oldest renal registry, started in 1964 [26, 27]. Willem Drukker reported on patients treated with chronic dialysis while Frank Parsons first reported on patients who had been transplanted [28]. The registry currently publishes an annual report and a number of scientific papers each year. It also plays an active educational role, offering courses in epidemiology and hosting visiting researchers while providing them with training in data analysis.

Many other registries have followed, including the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA, 1977), the Canadian Organ Replacement Register (CORR, 1981), the Japanese registry (1983) [29], the United States Renal Data System (USRDS, 1988), the Scottish Renal Registry (1991), the Malaysian Renal Registry (1992) and the UK Renal Registry (1995).

The 2014 USRDS report [30] presents data from 54 countries in its chapter on international comparisons. The countries include Indonesia, Thailand, Colombia, Mexico, Uruguay, Argentina and Brazil. Data from African countries have been notably absent, but the inclusion of the South African data in the 2014 USRDS report may herald the start of a new era where reliable data on RRT in Africa are published regularly.

Table 1. Contributions of data to the ERA-EDTA Registry by North African countries. The dates refer to the dates of data collection and not the publication dates of the registry reports

| Country | First/last data submissions | Comments |
|---------|-----------------------------|--------------------------------------------|
| Algeria | 1981/1997 | No data submitted for 1994 |
| Egypt | 1975/1996 | No data for 1978–80, 1994–5 |
| Libya | 1980/1996 | No data for 1993–4 |
| Morocco | 1995/1997 | |
| Tunisia | 1975/2008 | No data for 1978–80, 1994, 1998–2000, 2006 |

Renal registries from countries in Africa

Few renal registries have been established in African countries. Most have been from North Africa, but reports have not been published regularly. The earliest reports are from Egypt and Tunisia in 1975, followed by South Africa in 1977 and thereafter by Libya, Algeria and Morocco.

Nephrologists from North African countries have contributed data to the ERA-EDTA Registry (Table 1), starting with Egypt and Tunisia, whose data from 1975 to 1977 were included in the 1978 report. Libya joined in 1980, followed by Algeria in 1981 and Morocco in 1995. The last contribution from a North African country was in 2008.

The Egyptian Renal Registry's first report described its 1996 data [31] while the last reported data is from 2008 [32]. The Tunisian dialysis registry was established in 1990 and had a major impact on the country's development of RRT [16]. Registry data influenced decisions to increase the number of nephrologists, develop a new transplant programme, start new dialysis units and develop a kidney disease prevention programme. However, the registry stopped functioning after 2011. The Moroccan Registry for End-Stage Renal Disease (Magredial) was started in 2006 by the Ministry of Health in collaboration with the Moroccan Society of Nephrology and the Agence de Biomédecine. Its first report was published in 2008 [33]. Unfortunately, this registry subsequently experienced enormous difficulties related to a lack of resources and poor compliance with data submission and has not produced further reports.

The Nigerian Renal Registry was conceived 20 years ago, with sporadic reports presented at annual congresses. Complex questionnaires significantly limited participation. A simplified version was introduced in 2014 and data from a few participating centres were presented at the 2015 Nigerian Association of Nephrology meeting (F. Arogundade, personal communication).

The South African Dialysis and Transplant Registry was started by Koppel Furman in 1977. The last annual report described the 1994 data and the registry then stopped functioning due to a lack of resources. It has now been re-established as the South African Renal Registry and the first report provides an analysis of the 2012 data on RRT across the country [34].

An African Renal Registry

There are good reasons for establishing an African Renal Registry as a single entity. They include the following:

- Resources would be combined and costs shared by participating national renal societies.
- Improvements to the technology platform would be available to all countries simultaneously.
- Fundraising is likely to be easier with the participation of many different countries.

- Sharing of expertise related to the technology platform, epidemiology, statistical analysis and scientific writing.
- A single data dictionary and the collection of a common set of data to facilitate joint analyses and the comparison of findings between countries.
- More effective patient advocacy.

The role of AFRAN/AFPNA and the national renal associations

The African Renal Registry is a project of AFRAN/AFPNA and its member societies, who will assist in securing funding from governments, industry and international funding agencies. This is essential to support the central registry platform and to support operations within participating countries. We will also draw on expertise available from outside Africa. Experienced colleagues from the ERA-EDTA Registry, UK Renal Registry and USRDS, for example, have indicated their willingness to assist.

First steps toward implementation

The AFRAN General Meeting in March 2015 decided that an African Renal Registry should be developed that allows national societies to maintain control over their own data and the freedom to report their own findings but also allows the aggregation of all data for joint analyses and comparisons. It will utilize the Internet-based platform of the South African Renal Registry. The intention is to pilot the registry in selected African countries and then extend this to all interested countries.

Workshop report: SARS-AFRAN-ERA-EDTA Renal Registry Workshop, 12 March 2015

Another practical step forward has been taken in the form of a workshop for nephrologists from African countries who are involved with their own renal registries or who have been mandated by their national societies to lead the development of a new registry. On behalf of AFRAN, Razeen Davids of the South

African Renal Registry organized the workshop just before the World Congress of Nephrology (WCN) in Cape Town. The aim was to provide training on starting a renal registry and improving the quality of existing registries and to introduce basic principles of epidemiology and data analysis.

The programme included topics such as data quality, databases and software, coding and definitions, data security and statistical analysis. The presentations were delivered by Kitty Jager and her team from the ERA-EDTA Registry, with contributions from Fergus Caskey (UK Renal Registry), Cecile Couchoud (the French registry, REIN) and Razeen Davids. The workshop was attended by 28 delegates from 11 African countries as well as delegates from New Zealand, the UK and Brazil. The list of delegates and speakers is provided as an appendix.

This workshop, and the decisions that were made at the AFRAN General Meeting at the WCN in March 2015, marks the official launching of the African Renal Registry.

Conclusions

African nephrologists have a unique opportunity to establish a continental renal registry. We believe that this is an initiative whose time has come and that it has the potential to make a substantial impact on the practice of nephrology and the provision of services for patients with CKD and ESRD on the African continent.

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Conflict of interest statement

This paper has not been published previously and none of the authors have any conflicts of interest to declare.

Appendix 1

Table A1. List of workshop delegates and speakers

Delegates from African countries

| | |
|--------------|-----------------------------------------------------------------------------------------------------------|
| Cameroon | François Folefack Kaze |
| Ghana | Dwomoa Adu, Vincent Boima, Charlotte Osafo, Elliot Tannor |
| Kenya | Mathew Koech, George Moturi |
| Nigeria | Gbenga Awobusuyi, Felicia Eke, Chris Esezobar, Zumnan Gimba, Ulasi Ifeoma, Ogiator Monday, Daniel Uchendu |
| Senegal | Sidy Seck |
| South Africa | Julian Jacobs, Stefano Mestriner, Adriano Pellizon, Sarala Naicker |
| Sudan | Mohamed Elamin Awad |
| Tanzania | Jacqueliën Shoo, Kessy Shija, Onesmo Kisanga, Frederick Francis |
| Tunisia | Faiçal Jarraya |
| Uganda | Emmanuel Ssekasanvu |
| Zambia | Kenneth Kapembwa, Aggrey Mweemba |

Delegates from other countries

| | |
|----------------|------------------------------|
| Brazil | Jose Divino |
| New Zealand | Gillian Balbir Singh |
| United Kingdom | John Eastwood, Malcolm Lewis |

Speakers

| | |
|-----------------|----------------------------------------------------------------------|
| The Netherlands | Kitty Jager, Anneke Kramer, Marlies Noordzij |
| United Kingdom | Fergus Caskey |
| France | Cecile Couchoud |
| South Africa | Razeen Davids, Jimmy Volmink (Faculty Dean, Stellenbosch University) |

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