

Original Article

CKD.QLD: chronic kidney disease surveillance and research in Queensland, Australia

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Abstract

Background. Chronic kidney disease (CKD) is recognized as a major public health problem in Australia with significant mortality, morbidity and economic burden. However, there is no comprehensive surveillance programme to collect, collate and analyse data on CKD in a systematic way.

Methods. We describe an initiative called CKD Queensland (CKD.QLD), which was established in 2009 to address this deficiency, and outline the processes and progress made to date. The foundation is a CKD Registry of all CKD patients attending public health renal services in Queensland, and patient recruitment and data capture have started.

Results. We have established through early work of CKD.QLD that there are over 11 500 CKD patients attending public renal services in Queensland, and these are the target population for our registry. Progress so far includes conducting two CKD clinic site surveys, consenting over 3000 patients into the registry and initiation of baseline data analysis of the first 600 patients enrolled at the Royal Brisbane and Women's Hospital (RBWH) site. In addition, research studies in dietary intake and CKD outcomes and in models of care in CKD patient management are underway.

Conclusions. Through the CKD Registry, we will define the distribution of CKD patients referred to renal practices in the public system in Queensland by region, remoteness, age, gender, ethnicity and socioeconomic status. We will define the clinical characteristics of those patients, and the CKD associations, stages, co-morbidities and current management. We will follow the course and outcomes in individuals over time, as well as group trends over time. Through our activities and outcomes, we are aiming to provide a nidus for other states in Australia to join in a national CKD registry and network.

Keywords: chronic kidney disease; registry; surveillance

Introduction

Chronic kidney disease (CKD) in Australia is a major public health problem. At least one biomarker of kidney injury has been found in one in seven Australian adults over the age of 25 years [1, 2]. CKD contributed to nearly 10% of deaths in 2006 and over 1.1 million hospitalizations in 2006–07 [3], both of which are underestimates driven by the incompleteness of CKD-related diagnostic coding.

Excellent data of treated end-stage kidney disease (ESKD) patients are available from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) [4]. Based on their reports, the incidence of treated ESKD in Australia is projected to increase by 80% between 2009 and 2020 [5]. In addition, incidence and prevalence of ESKD is more common in the Aboriginal and Torres Strait Islander population, who represent almost 10% of new cases of treated ESKD, despite being only 2.5% of the Australian population [6]. However, people on renal replacement therapy (RRT) represent only a small proportion of the CKD population.

There are no existing systematic mechanisms to estimate the incidence, prevalence and distribution of severity of Stages 1–4 CKD in Australia. The best available source of population-based CKD rates is The Australian Diabetes, Obesity and Lifestyle (AusDiab) study [1, 2]. However, this study is outdated and may have overestimated CKD prevalence, as it did not collect information on two occasions 3 months apart and its estimates may include some cases of spurious or temporary elevations of serum creatinine or of acute kidney injury. Studies like the Bettering the Evaluation And Care of Health (BEACH) Program [7] are continuously gathering excellent data on the burden of CKD in primary practice in the Australian

population through recording of General Practice (GP) consultations. However, this study sacrifices meaningful detail to capture a wide array of summative health indices. A unique study called the '45 and Up Study' [8] is currently recruiting 250 000 men and women aged 45 and over from the general population in the state of New South Wales, Australia. This study is expected to provide a range of health-related information, including risk factors for CKD, through a self-administered questionnaire and capture of additional information through linkage of health-related data sets.

Notwithstanding these important initiatives, major gaps in our knowledge of CKD will remain. To address this deficiency, the Australian Government, through the Australian Institute of Health and Welfare (AIHW), established the National Centre for Monitoring Chronic Kidney Disease (NCM CKD) in 2007 [9]. The NCM CKD is located in the Cardiovascular, Diabetes and Kidney Unit at the AIHW, and the Medical Director of Kidney Health Australia (KHA) is the Chairman of the Advisory Committee. Centre, the AIHW and other organizations using existing data sets to collect, aggregate, link, analyse and estimate future disease burdens. They have produced important documents on ESKD and on CKD including its relationships with other conditions such as diabetes and cardiovascular disease [10–14]. However, the Agency's work is also impeded by the lack of population-based CKD data. The NCM CKD has therefore proposed a conceptual framework for building a surveillance system to monitor CKD with reference to Australia [9].

Consistent with the vision and strategy of the NCM CKD, we have established a programme for surveillance including the generation of an original data set, practice improvement and research for CKD across the entire referred renal practice network in the public health system in Queensland, through an entity called CKD Queensland (CKD.QLD). It is unique within Australia and one of the few comprehensive CKD surveillance entities globally.

Queensland has a current population of 4.6 million, or 20% of the Australian population. The number of retired individuals aged over 65 who are at high risk for CKD is 493 525, and this figure is expected to increase over time [15]. Queensland's multiethnic mix includes large numbers of Chinese, other Asian and Indian people, Pacific Islanders, Maori and more recently, Africans. It also includes 146 400 Indigenous Australians, the second largest number in any state [16]. Queensland had 3511 prevalent RRT patients at the end of 2009 [17], ~20% of the prevalent patients in the ANZDATA Registry, consistent with Queensland's proportion of the total Australian population. Queensland has 80 nephrologists and 20 CKD nurse practitioners spread across 15 Health Service districts [18]. The demographic profile of Queensland is comparable to the rest of Australia (Table 1).

The objectives of CKD.QLD include establishing a Registry and an ongoing surveillance system of all the CKD patients in renal practices in the public health system in the state of Queensland. We will define CKD distribution and characteristics, evaluate longitudinal CKD population trends and outcomes, identify treatment gaps, promote best practice and conduct clinical trials in collaboration with the Australian Kidney Trials Network (AKTN) [19]. We are also exploring models of CKD health service delivery and aim to develop CKD education and training streams. This will provide a platform for continuous practice improvement and research and build knowledge and capacity in the care of CKD patients (Figure 1).

Structure and organization of CKD.QLD

CKD.QLD arose from collaboration between the Centre for Chronic Disease at the University of Queensland (UQ) and Kidney Research in the Department of Renal Medicine at the Royal Brisbane and Women's Hospital

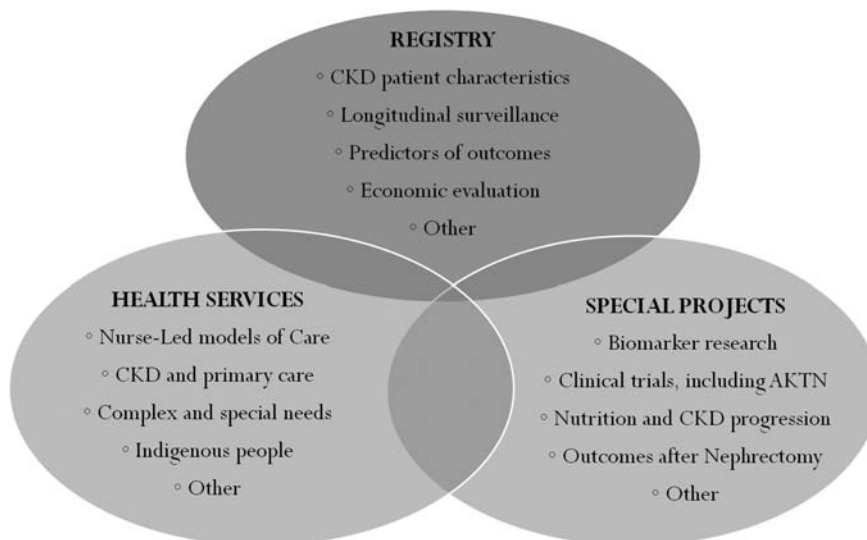


Fig. 1. CKD.QLD research operating platforms.

Table 1. 2006 Australian Census: Queensland versus Australia^a

	Queensland	% of persons	Australia	% of persons
Total persons (residents)	3 904 532	—	19 855 288	—
Males	1 935 381	49.6	9 799 252	49.4
Females	1 969 151	50.4	10 056 036	50.6
Indigenous persons	127 578	3.3	455 031	2.3
Age group				
0–4 years	257 077	6.6	1 260 405	6.3
5–14 years	549 455	14.1	2 676 807	13.5
15–24 years	539 206	13.8	2 704 276	13.6
25–54 years	1 638 354	42.0	8 376 751	42.2
55–64 years	437 550	11.2	2 192 675	11.0
65 years and over	482 891	12.4	2 644 374	13.3
Median age of persons	36	—	37	—
Language spoken at home				
English only	3 371 684	86.4	15 581 333	78.5
Mandarin	24 447	0.6	220 601	1.1
Italian	22 032	0.6	316 890	1.6
Cantonese	19 627	0.5	244 553	1.2
Vietnamese	17 145	0.4	194 855	1.0
German	14 743	0.4	75 636	0.4
Income (persons ≥15 years) \$ weekly				
Median individual income	476	—	466	—
Median household income	1033	—	1027	—
Median family income	1154	—	1171	—

^aAdapted from 2006 Australian Census, Quickstats-Queensland <http://www.censusdata.abs.gov.au/>.

(RBWH) in Brisbane, Queensland, Australia. It has expanded to include all public health renal practices in Queensland. Everyone involved in the care of renal patients in Queensland, encompassing medical, nursing, allied health and scientists, have become partners in the initiative. Participating Queensland Health Renal Services are shown in Figure 2.

Online resources

The CKD.QLD website [20] is a key resource for communicating activities and network outcomes between the participating renal services distributed throughout Queensland, which is Australia's second largest state measuring more than 1.72 million km², 25% of Australia's land mass. It is four times the size of Japan, nearly six times the size of the UK and more than twice the size of Texas in the USA. The website informs and interfaces between CKD.QLD and the rest of the world, with exponential growth in access to the website internationally as well as nationally.

Governance

A Management Committee governs CKD.QLD with specific subcommittees that drive key activities such as specific research projects [20].

Progress to date

Substantial investment of personnel and resources has led to impressive progress as outlined below.

Survey 1 of public health CKD services, Queensland

All public renal services were eligible and agreed to participate in the CKD.QLD collaborative. The initial consultative and foundation work involved a broad clinical audit and profile of CKD in Queensland, through face-to-face meetings with senior providers at each site. It was completed in March 2010 and the results presented at the Australian and New Zealand Society of Nephrology (ANZSN) Annual Scientific Meeting in 2010 [*Nephrology* 2010; 15 (Suppl 4), 29]. This survey gathered information on the structure and functioning of services, including the burden of CKD, available resources and the processes involved in the delivery of clinical care. We established that all sites collected CKD patient data, usually in an Excel spreadsheet. This encouraged us to proceed to the next step of populating a central data repository (CDR). It also involved exploratory snapshot visits to private CKD practices, which revealed large numbers of patients in those settings, but substantial overlap with patients in the public system.

Survey 2 of public health CKD services, Queensland

Public renal services were resurveyed. Site Survey 2 was completed in March 2011 with results shared at the ANZSN 2011 conference [*Nephrology* 2011; 16 (Suppl 1), 37: 52]. This survey aimed to profile CKD management in more detail and employed a web-based questionnaire completed by senior renal medical and nursing staff at each Queensland Health (QH) renal service. The response rate of 100% demonstrated the commitment of Public Renal Service Providers to CKD.QLD. This survey indicated that there are 11 668 CKD patients potentially available for recruitment into the CKD.QLD registry in QH public CKD clinics. The majority of these patients (90%) are seen by nephrologists as the clinics are hospital based. Multidisciplinary CKD clinics are available throughout the state with variable allied health resources. CKD Nurse Practitioner (NP)-run clinics, especially in the community setting, are an increasing trend with five NPs seeing CKD patients independently and another 10 NPs actively taking part in CKD patient management. This survey also provided useful information on the clinical management of CKD including risk factor modification, such as blood pressure (BP) therapy, HbA1c monitoring and management of complications and referral patterns for RRT [*Nephrology* 2011; 16 (Suppl 1), 37: 53]. Angiotensin-converting enzyme inhibitors (ACEI) form the cornerstone of BP control and proteinuria reduction. Dual therapy with angiotensin receptor blockers is utilized in <50% of cases. HbA1c levels are followed in up to 85% of cases to assess the control of diabetes. Lipid-lowering agents, including statins, are increasingly used in the majority of cases (>90%) but not with the intention of slowing CKD progression. These findings from the

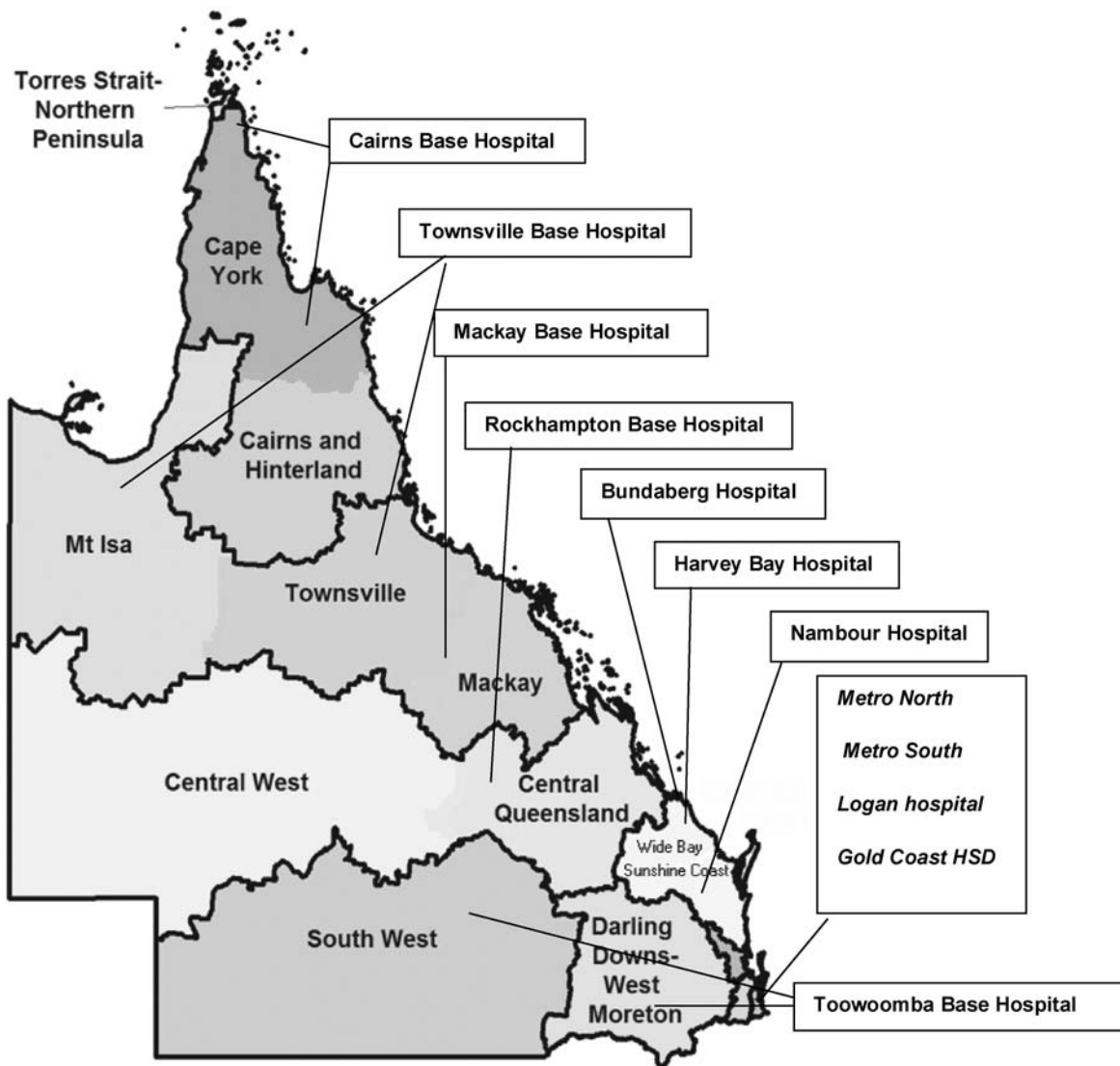


Fig. 2. Participating Queensland Health Renal services.

survey laid the foundation and collaborative approach for the more refined and structured next phase of CKD Registry activity of defining the characteristics of all potentially recruitable patients across Queensland.

Queensland CKD Registry

The establishment of a CKD Registry in Queensland is a key objective of CKD.QLD. It is a major achievement given that no such system is available in Australia and very few exist globally. The structure and logistics for a Registry were developed during a Database Workshop held in mid-2010, which defined ethical issues, governance structure, roles and responsibilities and terms of reference. Queensland state-wide ethical approval of the Registry was obtained in November 2010, allowing applications for Site Specific Governance Approvals for each Renal Service site to proceed. Governance approval has

now been achieved for all 12 primary sites and consenting and centralized data collection has started. Approval at four smaller affiliated hospitals with facilities to care for CKD patients is in process and are expected to begin recruitment soon. The primary objective of the CKD.QLD Registry is to narrow the knowledge gap currently existing in CKD. A database will be populated from the CDR with the flexibility to scale to population level for epidemiological purposes or single patient level for clinical care. The latter will allow the longitudinal assessment of putative parameters or biomarkers recorded at the baseline, including data from additional testing. Such predictors can be incorporated into evaluations of models of CKD care, intensity of surveillance and interventions, and customization of individual therapy. It is envisioned that the Registry will be a valuable resource to cross-link data of CKD patients entering the ANZDATA Registry. The goals of the CKD.QLD Registry are summarized in Table 2.

Table 2. Objectives of CKD.QLD Registry

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- To characterize patients within the CKD.QLD Registry
 - To evaluate longitudinal population trends in CKD
 - To document the course and outcomes of CKD patients
 - To develop predictors of prognosis and responsiveness to interventions
 - To identify treatment gaps and support and promote best CKD practice
 - To evaluate models of CKD health service delivery
 - To support CKD clinical trials
 - To develop a platform to link clinical data to a repository of biological samples for CKD biomarker research
 - To develop educational streams to improve knowledge and management of CKD
 - To establish data linkage of all stages of CKD with existent data sets like ANZDATA Registry
 - To develop a research capability in healthcare workers
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Patient recruitment

Consenting and recruitment of both incident and accrued prevalent patients (the resource-intensive component) has progressed very well across all CKD practices. We are on target with 1450 patients having given consent by the end of March 2012 with a negligible refusal rate. With this positive experience, we will seek ethical approval for an 'opt out' consent protocol rather than 'opt in' recruitment system. The Australian National Health and Medical Research Council (NHMRC) is developing guidelines for opt out consent method, and CKD.QLD is engaged in the development process. The collaborative timeline is to recruit 3000 patients by mid-2012 and 11 000 by the end of the year. Informing and consenting of incident CKD patients as they are referred to clinics will be a less labour intensive process and performed by the Renal Service provider seeing the patient for their first consultation, as a proposed part of standard care. The analysis of the first 600 patients recruited to the registry at the RBWH site has begun and the profile and characteristics of this group will be reported in the near future. Similar analysis of data from other sites will follow.

Data collection

CKD.QLD facilitates initiation and start up of the Registry at each site by providing patient information, assistance with consenting prevalent patients and refining data capture protocols. The CDR has the flexibility to accommodate data feeds from sources ranging from Excel spreadsheets to proprietary software like Audit4 [21]. The CDR is housed at a QH site in the Centre for Chronic Disease, RBWH.

CKD models of care

The combination of increased referrals and earlier referral has put significant strain on resources and required a shift

in focus and strategy of delivering renal care. The previous concentration of hospital-based speciality practices is diffusing towards community CKD clinics and primary care. Practicing CKD NPs are complementing medical renal management across the state of Queensland and these different models of CKD care are the targets for nursing research initiatives of CKD.QLD.

Clinical trials

The CKD patient platform provides excellent opportunities for large-scale clinical trials, and currently, there are several studies in progress. The CKD Nursing Models of Care (CKiDNaP Study) is developing operational definitions for the NP role and expert renal nurse in clinical care of patients with CKD. This study is capturing the multidisciplinary team's acceptance of the NP role in the delivery of CKD care. Potentially modifiable dietary factors in CKD are being characterized in another study. Changes in the dietary factors will be mapped and correlated over time with patient outcomes. This study has a target recruitment of 500 patients across multiple sites. Once completed, this study is expected to provide useful information on dietary intake, body composition and their influence on cardiovascular outcomes in CKD patients. Studies in development will evaluate the introduction of palliative care earlier and during CKD management, focusing on pain management, treatment of depression and symptom control, especially in the elderly. Planned future studies include randomized controlled trials assessing the effects of fish oil and allopurinol in mitigating the course of CKD. Our close collaboration and shared investigators with the AKTN is a major benefit.

Biomarker research

The search for biomarkers that accurately represents the onset, progress and prognosis of kidney disease is a priority of international research. Currently, a multitude of candidate markers are reported in the literature [22], but validation in the clinical setting is problematic [23]. Our registry provides an opportunity to integrate CKD clinical practices with applied biomarker research and post-marketing evaluation. Novel biomarker discovery and validation is based at the Institute for Molecular Bioscience (IMB), University of Queensland, Australia. In addition, a critical link has been established with international biomarker research collaboration and validation, between the Proof Centre of Excellence, Canada, and CKD.QLD. We are aiming at a recruitment target of 2100 patients into a biomarker study across three sites in Queensland to test the transferability of the Canadian Study of Prediction of Risk and Evolution to Dialysis, Death and Interim Cardiovascular Events Over Time study (CanPREDICT study) [24] results to the Australian context. This study protocol includes the development of a biobank to store samples for future studies, an important planned future development of CKD.QLD.

Collaborations

CKD.QLD investigators have established major collaborations with important stakeholders at various levels. In Queensland, CKD.QLD is affiliated with two non-government kidney health advocacy agencies, KHA and Kidney Support Network (KSN). An important relationship is established with the Queensland Aboriginal Islander Health Council (QAIHC), the peak body representing the community controlled indigenous health-care sector. Nationally, CKD.QLD is in discussion with Western Australia, the Northern Territory, Victoria and New South Wales in progressing a National Network in CKD research, a concept that is supported by key renal bodies, including KHA and ANZDATA. Internationally, we are in collaboration with CKD investigators in British Columbia, Canada.

Significance of CKD.QLD

We know of no other comprehensive regional or state/territory-wide longitudinal Registry of CKD patients in renal speciality practices in Australia. There is as yet no comprehensive data source on people with Stages 1–4 CKD and no precedence to cross-link their clinical data to existing data sets of mortality or RRT dependent ESKD. This initiative in Queensland will establish the progress and prognosis of CKD in earlier stages in the sequence of health, risk, unrecognized CKD, recognized and referred CKD and ESKD. The successful development of the CKD Registry has substantial beneficial outcomes for many other groups. Some of the end-users who will benefit from CKD.QLD activities are given in Table 3.

Future directions

The next major task is to aggregate data collected from all CKD.QLD sites, which will be supplied in different data formats. We have now completed recruitment of the first 1450 patients and data audit is being performed and missing information will be sought from the primary sources. Preliminary analysis of already accrued patient information will help us to refine the process, improve the methodology and review uniform data collection parameters.

Future projects will include sampling of CKD patients in Queensland private practices, sampling from other specialities such as cardiology, gerontology and endocrinology, and sampling within primary care and general practice. This collaboration will allow us to develop primary and secondary preventive programmes targeting CKD.

Conclusions

CKD.QLD has evolved as a platform for research and practice improvement in CKD management in Australia. We have successfully established the Registry and are on target to recruit 5000 CKD patients by mid-2012. In the process, we have developed a systematic and

Table 3. End-users who will benefit from the activities and outcomes of CKD.QLD

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- CKD patients, through better outcomes
 - Practitioners, from structured and efficient support systems and models of care
 - Health systems, from more efficient models of care
 - The taxpayer, from cost containment achieved through more efficient services
 - The general population, through better health awareness
 - Commercial interests, through increased identification of CKD and its better management, the clinical trials platform, new diagnostic agents and opportunities for private insurance
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comprehensive surveillance system for referred CKD monitoring in Australia. The Registry will also facilitate and inform data cross-linkage between the initial stages of CKD with that of treated ESKD as reported in ANZDATA. We have initiated major research studies of various aspects of CKD management. It is anticipated that the activities and products of CKD.QLD will be a benchmark for other states in Australia in understanding and managing CKD across the nation. We expect the findings by demographic group generated through the CKD.QLD registry mechanism may be extrapolated to populations groups in other states/territories and their accuracy evaluated. We anticipate that CKD.QLD will coalesce with other states and regions in Australia into a broader National CKD Registry and network. In the longer term CKD.QLD will continue to grow international collaborations and contribute significantly towards a global improvement of CKD management.

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Conflict of interest statement. None declared.

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