



DATA NOTE

The CKD.QLD data linkage framework: chronic kidney disease and health services utilisation in Queensland, Australia

[version 1; peer review: 1 approved]

Jianzhen Zhang ^{1,2}, Zaimin Wang^{1,2}, Anne Cameron^{1,2}, P Marcin Sowa^{2,3}, Vishal Diwan^{1,2}, Sree Krishna Venuthurupalli^{2,4}, Helen G. Healy^{2,5}, Luke B Connelly ^{2,3,6}, Wendy E Hoy^{1,2}

¹Centre for Chronic Disease, The University of Queensland, Brisbane, QLD, 4029, Australia

²CKD.QLD, NHMRC CKD.CRE, Brisbane, QLD, 4034, Australia

³Centre for Business and Economics of Health, The University of Queensland, Brisbane, QLD, 4029, Australia

⁴Kidney Health Service (Toowoomba Hospital), Darling Downs Hospital and Health Service, Brisbane, QLD, 4350, Australia

⁵Kidney Health Service, Royal Brisbane and Women's Hospital, Brisbane, QLD, 4029, Australia

⁶Department of Sociology and Business Law, The University of Bologna, 40126 Bologna, Emilia-Romagna, Italy

V1 First published: 02 Nov 2021, 10:1107
<https://doi.org/10.12688/f1000research.53782.1>

Latest published: 02 Nov 2021, 10:1107
<https://doi.org/10.12688/f1000research.53782.1>

Abstract

Chronic kidney disease (CKD) is one of the most common chronic diseases in the western world. In Australia, around 1.7 million Australians aged 18 years and over (about one in ten) have indicators of CKD, and 1.8 million hospitalisations were associated with CKD in 2017–18. There is currently very little understanding of the impact of CKD on health service utilisation and costs. Understanding the disease pathways of CKD and its effects on service utilisation and patient outcomes is essential to predicting the course of the disease in the future, its effects on health services utilisation and capacity to better manage the burden of premature deaths or the need for dialysis that results from CKD. We describe the establishment of a data linkage framework to study hospital admissions of CKD patients in the public renal services in the Australian state of Queensland, and its potential to advance understanding of their course and outcomes.

Seven years of retrospective data (2011–2018) on hospital-based health services utilisation were provided by Queensland Health for all 7,341 patients who enrolled in the CKD.QLD Registry up to Jan 2019. The data were supplied from three datasets: the Queensland Hospital Admitted Patient Data Collection, the Queensland Registrar General deaths, and the Activity Based Funding Model Output data. In addition, data were supplied from two cohorts of de-identified patients admitted to hospital in the same interval (22,023 patients each), who were not in the CKD.QLD Registry, the first with CKD and the second without CKD as indicated by International Classification of

Open Peer Review

Reviewer Status

Invited Reviewers

1

version 1

02 Nov 2021

report

1. **Son Nghiem** , Griffith University,
Brisbane, Australia

Any reports and responses or comments on the article can be found at the end of the article.

Diseases and Related Health Problems, Tenth Revision, Australian Modification.

The comprehensive and multifaceted data via the data linkage will enable us to identify opportunities for efficiencies in management of patients with CKD and for interventions that improve their outcomes.

Keywords

chronic kidney disease, CKD.QLD Registry, data linkage, framework, health service utilisation, Queensland Health

Corresponding author: Jianzhen Zhang (jenny.zhang@uq.edu.au)

Author roles: **Zhang J:** Conceptualization, Data Curation, Formal Analysis, Investigation, Methodology, Project Administration, Supervision, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Wang Z:** Conceptualization, Data Curation, Formal Analysis, Investigation, Methodology, Project Administration, Supervision, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Cameron A:** Conceptualization, Data Curation, Methodology, Project Administration, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Sowa PM:** Conceptualization, Data Curation, Formal Analysis, Methodology, Project Administration, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Diwan V:** Conceptualization, Data Curation, Methodology, Project Administration, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Venuthurupalli SK:** Conceptualization, Data Curation, Formal Analysis, Methodology, Project Administration, Supervision, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Healy HG:** Conceptualization, Funding Acquisition, Supervision, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Connelly LB:** Conceptualization, Methodology, Supervision, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Hoy WE:** Conceptualization, Funding Acquisition, Investigation, Methodology, Supervision, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: The development of this framework, to this point, has been supported in part by the National Health and Medical Research Council under the Centre of Research Excellence (APP1079502).

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Copyright: © 2021 Zhang J *et al.* This is an open access article distributed under the terms of the [Creative Commons Attribution License](https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

How to cite this article: Zhang J, Wang Z, Cameron A *et al.* **The CKD.QLD data linkage framework: chronic kidney disease and health services utilisation in Queensland, Australia [version 1; peer review: 1 approved]** F1000Research 2021, 10:1107 <https://doi.org/10.12688/f1000research.53782.1>

First published: 02 Nov 2021, 10:1107 <https://doi.org/10.12688/f1000research.53782.1>

Introduction

Chronic kidney disease (CKD) is a condition characterised by a constant loss of kidney function over time. It may eventually lead to kidney failure, which requires dialysis or a kidney transplant to maintain life. Recent findings from the Australian Health Survey 2014–2015 showed that 203,400 Australians, or 0.9% of the population, self-reported that they had kidney disease,¹ and biochemical testing revealed that 10% of adults (approximately 1.7 million people in 2011–12) had markers of CKD (aihw.gov.au). However, nearly 90% of people with CKD (about 1.5 million in Australia) are unaware they have indicators of the disease.² Rates of CKD increase with age, and are higher in Indigenous Australians, in other minority groups and in people who are socioeconomically disadvantaged.³ Around 1.8 million hospitalisations in Australia were associated with CKD (principal and/or other diagnosis) in 2017–18 or 16% of all hospitalisations.⁴ Thirteen percent of all hospitalisations were for scheduled dialysis as a principal diagnosis, performed as a same-day day procedure, which was the most common reason for hospitalisation in Australia. There were 16,800 CKD-related deaths, which contributed to 11% of all deaths in 2018.⁵ In 2019, 26,746 Australians were receiving kidney replacement therapy (KRT) for end-stage kidney failure, including 12,815 who had a functioning kidney transplant and 13,931 who were receiving dialysis.⁶ The number of people receiving KRT continues to climb, increasing from 23,111 in 2015 to 26,746 in 2019.⁶ KRT places a large burden on the Australian health-care system, particularly dialysis, including frequent and regular hospitalisations.⁷

CKD shares many common risk factors with other chronic conditions such as cardiovascular disease and type 2 diabetes, including being overweight and obesity, physical inactivity, poor diet, tobacco smoking and hypertension.⁸ Kidney disease increases the risk of having heart and blood vessel disease, as well as develops complications like high blood pressure, anaemia, weak bones, poor nutritional health and nerve damage. These problems may happen slowly over a long period of time. CKD may be caused by diabetes, high blood pressure and other disorders.⁵ Early detection and treatment can often keep chronic kidney disease from getting worse. The better understanding, prevention, and modification of CKD is the potential to reduce the escalating burden of kidney disease. The techniques and the costs of dialysis for people with terminal kidney failure are well delineated, but the appropriate streams of care and cost for the pre-terminal phase of CKD are not well defined and studied.

There is no system for systematic ambulatory CKD surveillance in Australia. In 2011, we established the CKD Queensland (CKD.QLD) Registry, which is a program for surveillance, practice improvement and research of adult patients with CKD referred to the renal practice network in the public health system within Queensland. This program, which we have described elsewhere,⁹ is unique within Australia. Queensland has the **second-largest land area and is the third-most populous** Australian state, with over 5.1 million people in March 2020.¹⁰ The state's population is multicultural, with 28.9% of inhabitants classified as **immigrants**. Four percent of the population identified as **Indigenous Australians (Aboriginal and/or Torres Strait Islander Australians)** in 2016.¹¹ Public health services in Queensland are provided through **16 Hospital and Health Services (HHSs)**, distributed across different regions in Queensland. These are statutory bodies, each governed by a Hospital and Health Board. Some public health services are also provided by private providers. **Queensland Health** operates and administers the state's **public health** system, and monitors the performance of HHSs.¹²

The key strength of the CKD.QLD Registry is its framework of data linkage. To date, with ethics approvals and an opt-in patient consent process, the registry has developed a core data set of demographic and clinical information of CKD patients, generated from the participating kidney health services at the time of patient consent. Unique patient identifiers were assigned in the Registry and linked with relevant person-specific data derived from a variety of site-specific databases, which have historically included Ferret, Audit4, ERIC, Kidney Health Service-BigR, and from larger multi-site data platforms such as The Viewer, the integrated electronic Medical Record (ieMR) being progressively deployed across the state, and the laboratory information system AUSLab, all operated by Queensland Health, as previously described.⁹

There is currently very little understanding of the impact of CKD on health service utilisation and costs. Understanding the multiple components of the resource bundles consumed in the care pathways of CKD and their interactions in service utilisation and impact on patient outcomes is essential to predicting future need and identifying opportunities to better manage the burden of premature deaths and morbidities. In this manuscript we describe the establishment of a data linkage framework to study hospital admissions of CKD patients in the public renal services in the Australian state of Queensland, and its potential to advance understanding of their course and outcomes.

Methods

Data linkage framework

Seven years of retrospective data for persons with any hospital admissions with a discharge date from 1 May 2011 to 30 June 2018 were sourced from Queensland Health (QH) for two cohorts of patients with CKD and one cohort without

CKD. The specific data sources were the Queensland Hospital Admitted Patient Data Collection (QHAPDC), the Queensland Registrar General (RG) deaths and the Activity Based Funding (ABF) Model Output data for Queensland. The data linkage framework is illustrated in **Figure 1**.

The first cohort of people with CKD (Cohort 1) had consented and enrolled in the CKD.QLD Registry until January 2019. As for all admitted patients, the Data Linkage Team of the Queensland Department of Health assigned each a unique identifier within the QH system.^{13,14}

A second cohort of people with CKD (Cohort 2), but not in the CKD.QLD Registry, were identified by the QH Data Linkage Team through International Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) codes related to their first hospital admission that were compatible with CKD (see **Table 1**). They were matched by HHS with Cohort 1 patients in a ratio of 3 to 1. The second cohort reflects a broader group of people with CKD than those in the CKD.QLD Registry and includes many managed by non-nephrologists.

The third cohort (Cohort 3) consisted of people without an ICD-10-AM diagnosis compatible with CKD in their first hospital admission, as identified by the QH Data Linkage Team, who were matched by age, sex and HHS to Cohort 1 in a ratio of 3 to 1.

Data were generated for the discharge from hospital admission period of 1 May 2011 to 30 June 2018. For all members of Cohort 2, and Cohort 3 the same scope and data items were requested from QHAPDC, Deaths and the ABF Model Output datasets, as for as Cohort 1. In addition, patient details including date of birth, sex, country of birth and Indigenous status were provided.

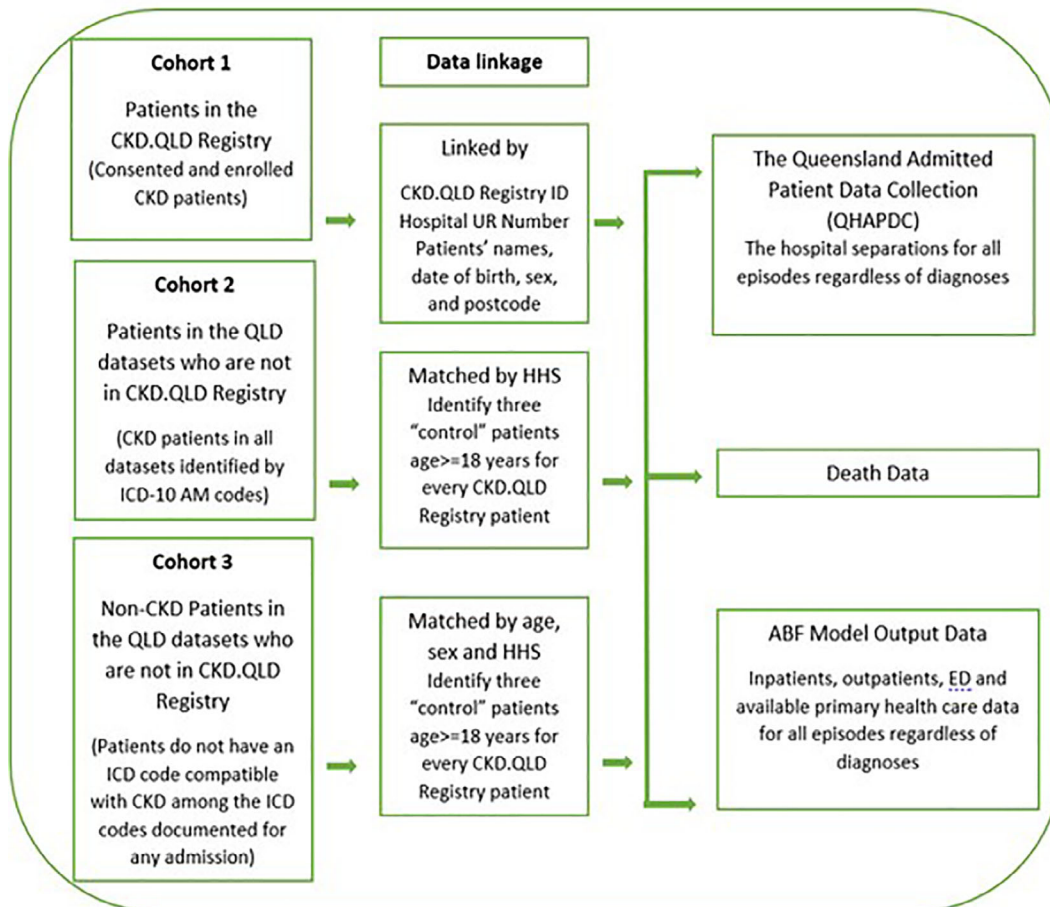


Figure 1. The data linkage framework of the sub-study of CKD.QLD Registry.

Table 1. ICD-10-AM chronic kidney disease (CKD) diagnosis codes for the matched cohort (Cohort 2, with CKD but who were not in the CKD.QLD Registry).

ICD-AM codes for chronic kidney disease (CKD)	
All N18	Chronic kidney disease (CKD)
N18.0	End-stage renal disease
N18.1	Chronic kidney disease, stage 1
N18.2	Chronic kidney disease, stage 2
N18.3	Chronic kidney disease, stage 3
N18.4	Chronic kidney disease, stage 4
N18.5	Chronic kidney disease, stage 5
N18.9	Chronic kidney disease, unspecified
N19	Unspecified kidney failure
U87.1 (where available)	Chronic kidney disease, stage 3-5

Settings and participants

CKD.QLD is an initiative of the University of Queensland's Centre for Chronic Disease, in partnership with Queensland Health and the Queensland University of Technology.

There are 12 adult public renal services across the 16 regional Queensland Health Hospital and Health Services (see [Figure 2](#)). The renal services operate varied models of CKD community and satellite clinics. Participants are pre-dialysis CKD patients who were referred or within these services are eligible for inclusion in the Registry, via informed consent, and with ethics and governance oversight. Patients with CKD from both the Registry and the matched cohorts in Queensland are age 18 years and over.

Data sources for data linkage

QHAPDC and RG deaths

The Queensland Hospital Admitted Patient Data Collection (QHAPDC) receives demographic and clinical information on all admitted patients separated (an inclusive term meaning discharged, died, transferred or statistically separated) from both public and licensed private hospitals and licenced day surgery units in Queensland.¹⁵

The linked data included the following QHAPDC data items and death Registry data from the Queensland RG deaths for participants in the three cohorts (see [Table 2](#)).

Queensland ABF model output data

QH allocate funds to the HHSs on their activity using the ABF Model.¹⁶ The model calculates number of episodes of care and case complexity to derive a weighted unit of activity (WAU). The methodology of deriving WAU standardises resource utilisation across episodes of care that are diverse in resource usage and geography. The ABF model calculates a Queensland Efficient Price using Queensland WAUs (QWAU) and the Queensland base price per WAU, noting the QWAU may differ from the national WAU (NWAU) reflecting State-Government specific costs and priorities.¹⁷ HHSs report their activities through the National Hospital Cost Data Collection (NHCDC) and the data are also used as inputs into the ABF model to derive output data.¹⁸ Person service level costs are determined using the methodology of the NHCDC and are reported in NHCDC summation and format. The data in scope for the NHCDC includes all patient level activity for all public hospital facilities across Australia, and the costs incurred by the hospital with the activity in each financial year. For this data linkage study, we had the following ABF data items (see [Table 3](#)), linked to the cohort file for each CKD.QLD Registry participant and participants in the matched cohorts 2 and 3.

Data linkage process

The data linkage process for this study is illustrated in [Figure 3](#). The process is adapted from the "Overview of Application Process for Access to Confidential Health Information held by Queensland Health for Research Purposes" published by the State of Queensland (Queensland Health), January 2016.¹⁴ We adopted the process, contacting the Statistical Analysis and Linkage Team (SALT), Statistical Services Branch, Queensland Health for initial advice and consulted

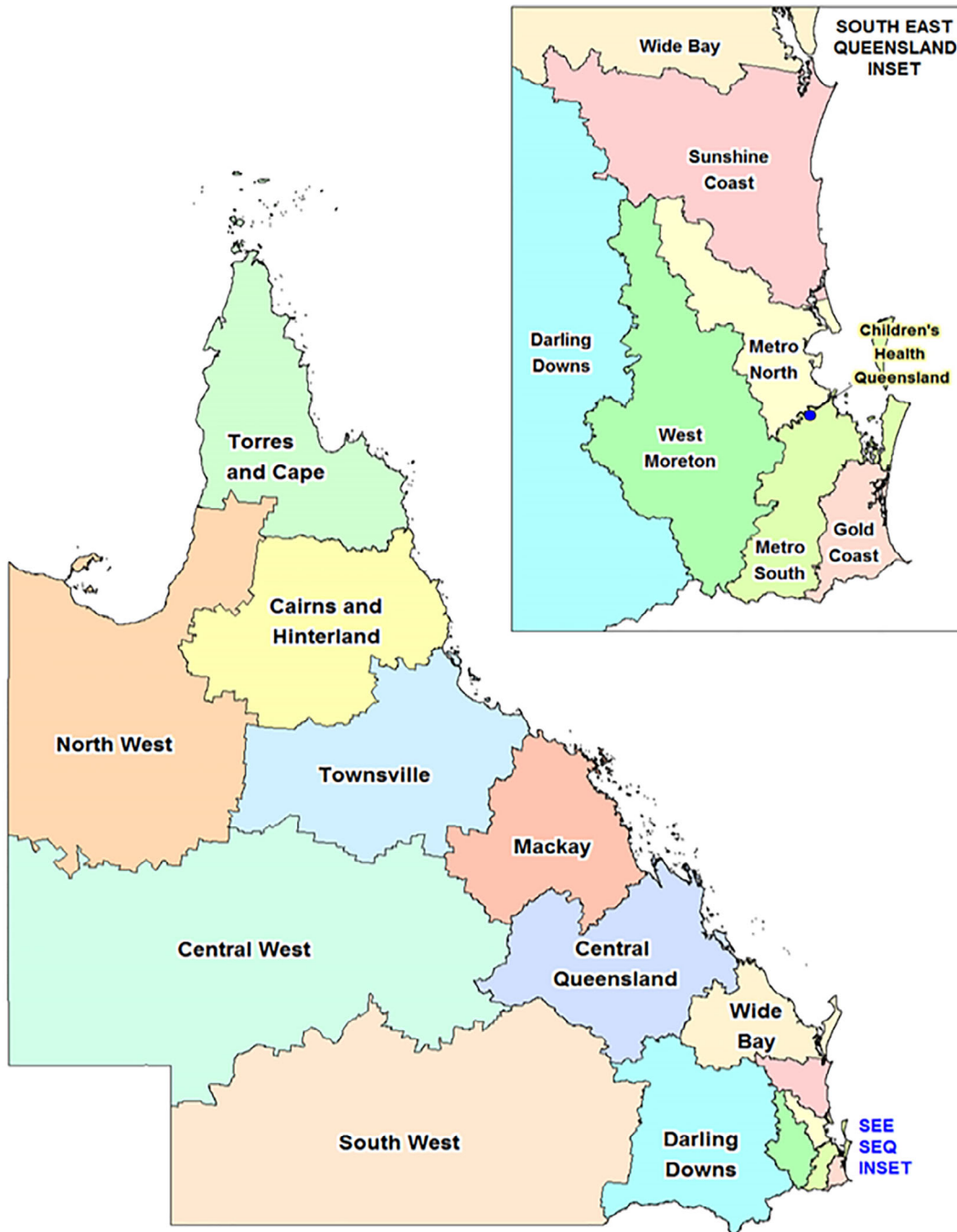


Figure 2. Queensland Health Adult Renal Services by Hospital and Health Service area.

data custodians. The work was conducted with the ethical approval of the QH Health Innovation, Investment and Research Office (HIRO) under the Public Health Act (PHA), a pathway if researchers are requesting identifiable or potentially re-identifiable health information but are unable to obtain participant consent. The Public Health Act 2005¹⁹ establishes the process for accessing health information held by Queensland Health for approved research projects.

After receiving PHA approval, CKD.QLD provided a unique identifier – Registry ID – and associated patient key demographic variables (see Table 4) to the Data Linkage Unit in a password protected file. Using this unique identifier, data outlined in this framework were linked from data custodian sources to the affiliated individual.

Table 2. Domains of linked Queensland Hospital Admitted Patient Data Collection (QHAPDC) data.

Data domains	Data items	Description
QHAPDC data		
Admission details	Admission date (dd/mm/yyyy)	Date on which the admitted patient commences an episode of care
	Admission source	Indicates the referral point of the patient immediately before they are admitted either formally (hospital admission) or statistically (type of episode change)
	Care type	The overall nature of a clinical service provided to an admitted patient during an episode of care (admitted care), or the type of service provided by the hospital for boarders or posthumous organ procurement (care other than admitted care)
	Elective patient status	Whether an admission occurred on an emergency or elective basis for an episode of admitted patient care
	Planned same day	Indicates if it is planned for an admitted patient to be discharged before midnight on the day of admission to hospital
	Admission unit	A code assigned by the admitting hospital indicating the hospital unit to which a patient is admitted or transferred for an episode of admitted patient care
	Hospital type	Classification of type of facility used by the Department of Health for statistical reporting
	Separation date (dd/mm/yyyy)	Date on which an admitted patient completes an episode of care
	Mode of separation	Patient status at separation (discharge/transfer/death) and place to which patient is released
	Transferring to facility	The class of facility (private/public) to which the patient is referred for an episode of admitted care
	Preferred language (public hospital)	The language (including sign language) most preferred by the patient for communication
	Interpreter required (public hospital)	Indicates if an interpreter service is required by or for a person
	Length of stay	Length of a patient's stay in days for an admitted episode of patient care, excluding leave days
	Duration of continuous ventilator support	The total time a patient spent on continuous ventilatory support during a single episode of admitted patient care, expressed as hours and minutes
	Chargeable status	Accommodation chargeable status elected by a patient on admission
	Compensable status	Indicates any entitlement(s) including payment of compensation for damages or other benefits (including payment in settlement of a claim for compensation, damages, or other benefits) due to a patient in respect of injury, illness or disease for which treatment and care is being provided
Morbidity details	ICD code type	A qualifier for each ICD-10-AM/ACHI code indicating if the particular code is for a principal or other diagnosis, procedure, external cause or morphology
	Principal diagnosis (ICD-10-AM)	A code assigned after institutional health care to specify a disease, injury, morphology, procedure, external cause and/or other factor influencing health status that describes the reason for hospital stay
	Date of procedure(s)	Date on which a procedure is performed during an admitted patient episode of care

Table 2. *Continued*

Data domains	Data items	Description
	Australian Refined Diagnosis Related Group (AR-DRG) Code	A code which signifies the patient's classification in the hospital's case mix, derived from the ICD-10-AM diagnostic codes for principal and secondary diagnoses, procedures performed, age, sex, and discharge status
	Major diagnostic category (MDC)	One of 23 mutually exclusive major diagnostic categories (MDCs) that correspond to a single body system or aetiology and derived from the Diagnosis Related Group code. In general, MDCs are associated with a particular medical speciality
	Contract flag	Indicates the procedure was performed by another hospital or private health provider as a contracted service, either as an admitted or non-admitted service.
Palliative care details	First admission for palliative care treatment (dd/mm/yyyy)	Indicates if this admission is the patient's first admission at any hospital for palliative care treatment
	Previous specialised non-admitted palliative care treatment	Indicates if the patient has had previous non-admitted service contact for palliative care treatment
Queensland RG deaths		
	Date of death (dd/mm/yyyy)	The date of decease recorded in the Queensland Death Registry
	Cause of death	The reason(s) for the person's decease recorded on the death certificate
	Place of death	The deceased's recorded place of death categorised as "Hospital" or "Other"

Table 3. Domains of linked Activity Based Funding (ABF) data National Hospital Cost Data Collection (NHDC), NHDC cost centre (NHDCCC).

Data items	Description
Fiscal year	This field is to contain the fiscal year in which the intermediate product was consumed by the patient/client/consumer based on the time date stamp associated with the date of service field.
Facility ID	The facility ID identifies the location where the health service intervention or support was delivered to the patient.
Product type	Type of product (care type) costed.
NHDCCC	A national unique ID for each final cost centre as defined in the Australian Hospital Patient costing standards form NHDC. Each Queensland department is mapped to a single NHDC cost centre (NHDCCC).
NHDC item	A unit of information in a document, record, or statement, shown on a separate line of its own. Line items often refer to a budget element that is separately identified.
Direct cost	The sum of the direct cost for all encounters classified to a final product in that facility.
Overhead cost	This is the sum of the overhead direct costs from indirect departments.
Total cost	This is the sum of the direct costs from direct departments and the overhead costs from indirect departments for the feeder key department combination at Cost Type category level for each intermediate product as calculated by the source costing system.

Data security

The information on CKD.QLD participants to enable data linkage was provided to Queensland Health by the research Chief Investigator (WH) at the University of Queensland. The data were stored electronically with an encrypted and password protected file and sent to the Linkage Team for linkage to the requested cohort and extraction of their data. The data linkages were carried out in compliance with QH data management guidelines, under the governance of the

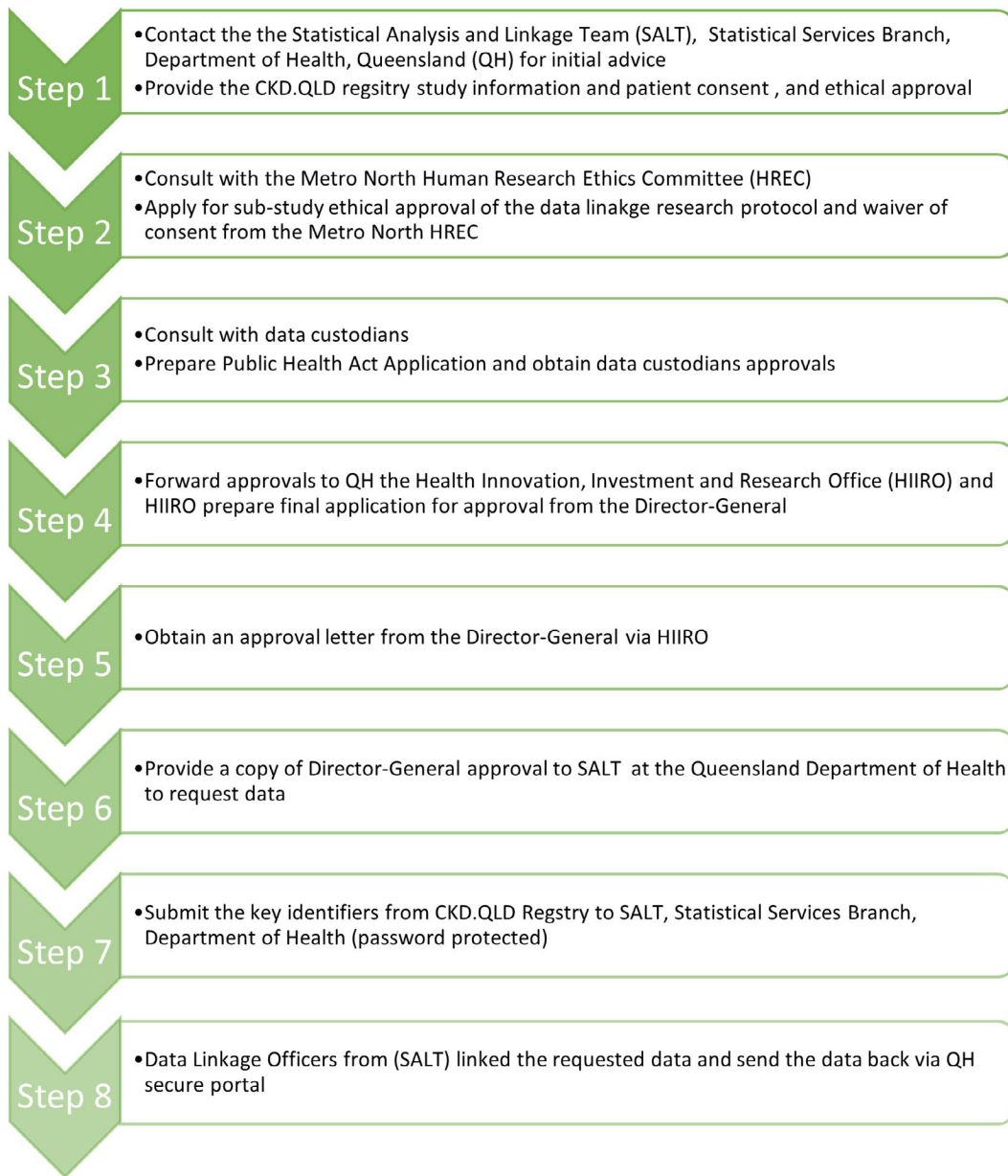


Figure 3. CKD.QLD data linkage process.

Table 4. The identifiers from CKD.QLD Registry supplied for data linkage.

Variables	Notes
CKD.QLD Registry ID	Unique ID for data linkage
Hospital UR Number	As recorded by the Renal Health Service at the consent
Hospital Name	Study Hospital
Patient’s first, second, surname	As recorded at the consent
Date of birth	Patient’s date of birth at consent
Sex	Patient’s sex at consent
Postcode	Patient’s residence postcode at consent

Statistical Services Branch, the Queensland Department of Health.¹⁴ Participant privacy was paramount. Upon the collation of the data via the data linkage protocols, a zipped file was loaded by SALT onto a secure web portal and downloaded by one of the approved investigators in this study (JZ) who stored it in a secure database at the University of Queensland.

Data reporting

The linked data are being analysed by the CKD.QLD research team and by the health economics team using statistical software (Stata Statistical Software: Release 16. StataCorp LLC (RRID:SCR_012763)). (An open-access alternative that can provide an equivalent function is the R stats package (R Project for Statistical Computing, RRID:SCR_001905)). The analysis methods including descriptive statistics, comparisons, and multivariable analysis, e.g., cox regressions are or will be applied. The results will be transformed into reports of de-identified data for user groups and collaborators, which will include, but are not be limited to, Queensland Health, the Australian Institute of Health and Welfare, The University of Queensland, the Australasian and New Zealand Society of Nephrology, the Renal Society of Australasia, and Kidney Health Australia. In addition, outcomes will be published in academic journals and on the CKD.QLD (www.ckdqld.org) and CKD.CRE website (<https://cre-ckd.centre.uq.edu.au>) addresses for professional and patient access and dissemination. Data will be published in a form that does not identify, or allow the re-identification, of any individual participant or health service provider.

Ethical approval and consent to participate

This study under the data linkage framework is considered a sub-study of the CKD.QLD Registry (HREC/15/QRBW/294), which has been approved by Metro North Human Research Ethics Committee and University of Queensland Medical Research Ethics (Number: 2011000029). The study of the QH held datasets of CKD patients, both those in the CKD.QLD Registry and the comparison patient cohort, listed in this study is through an ethically approved waiver of consent according to the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research.²⁰ In addition, a Public Health Act application (RD006802) was approved to access all hospitalisation information of the CKD.QLD Registry patients.

Database utility and applications

The framework linked 7,341 CKD patients from the CKD.QLD Registry (Cohort 1) to health service data including QHAPDC, RG Deaths and Queensland ABF Model Output Data. In addition, a cohort of 22,023 participants with CKD (Cohort 2) and a cohort of 22,023 without CKD (Cohort 3) were matched. This dataset embraces 51,387 persons and 974,700 admissions over seven years of retrospective data, with admitted persons divided into three groups, as follows.

In the CKD.QLD cohort (Cohort 1), 45.9% were female and 54.1% were males, and 8.4 % were Indigenous Australians. The mean age (SD; IQR) on their first admission was 65.2 (21.0; 18.8). They had 221,347 admissions, of which 77,822 admissions (35.2%) were for KRT for people who ultimately required that treatment. Of the 7,341 CKD.QLD patients who had at least one hospitalisation episode, 831 patients (11.3%) started KRT and 1,797 died (23.1%) during the study period. The person years of the study period (from their first admission to death or censor date) was 27,900.8 years.

Of the 22,023 people in the non-CKD.QLD CKD cohort (Cohort 2), 45.9% were female and 54.1% were males, and 4.3 % were Indigenous Australians. The mean age (SD; IQR) on their first admission was 73.8 (13.7; 17.0). They had 626,554 admissions, of which 277,994 admissions (44.4%) were eventually for KRT. Of the 22,023 participants in this cohort, 1,233 (5.6%) started KRT and 9,494 died (43.1%). The person years of the study interval was 128,570.6 years.

Of the 22,023 age and gender matched non-CKD cohort (cohort 3), 45.8% were female and 54.2% were males, and 1.8 % were Indigenous Australians. The mean age (SD; IQR) on their first admission was 63.5 (14.9; 18.6). They had 126,799 total admissions, only three eventually had dialysis, and 2,444 patients died (11.1%). The person years of the study interval was 149,439.3 years.

Linking established large datasets is a powerful approach to identifying patterns and interaction between multiple variables without bias whilst limiting the costs of data acquisition. Our first objective in establishing this framework is to better understand hospital admissions and outcomes among persons with preterminal CKD seen in public renal services across the Australian state of Queensland. The second objective is to compare them with persons from the same regions who had CKD documented in one or more hospital admissions who were not in the CKD.QLD cohort, to understand the characteristics and outcomes of CKD in other community and practice settings. The third objective is to compare these findings with persons admitted to hospital without a diagnosis of CKD, but who are matched age, gender, place of residence and HHSs with the CKD cohort in order to assess the degree which a diagnosis of CKD and its accompaniments might influence hospital usage.

The data on CKD.QLD patients will allow evaluation of health service utilisation for individual patients, covering all admissions, not limited to renal admissions, both public and private, across all disciplines. Many facts can be illuminated, including assessment of the extent to which CKD-related conditions drive admissions vs conditions not clearly related to CKD, characterisation of high cost users of hospital services, potentially avoidable hospital admissions and readmissions, trajectory over time of persons of different baseline characteristics, processes, costs and outcomes with specific interventions, different models of care and changes in policy, for example, strengthening supportive/palliative care pathways for patients with end stage kidney failure, and for persons who ultimately go onto KRT, the changes in resource utilisation and costs. Additionally, patterns of hospital utilisation can be inspected by postcode of residence, by HHS, by ethnic group, and other variables, to identify gaps and opportunities for service modification to improve outcomes.

The data from the comparator CKD group show the broader view of persons with CKD interacting with all hospitals in Queensland. These include patients in private renal practices, in nonrenal public specialty practices, in primary care and general practice, in Indigenous health services, and people in whom CKD was not recognised prior to their hospital admission within the study period.

The data from the non-CKD matched cohort will help clarify to what extent the presence of CKD influences the frequency, causes, costs and outcomes of hospital admissions in persons who are otherwise matched for age, gender, region and hospital services.

There is extensive information on the health and outcomes of patients on KRT in Australia and elsewhere, but hospital usage by preterminal CKD patients is not well defined. This study is the first in Australia aiming to define this issue in preterminal CKD in public renal practices, to compare it with CKD patients in other practice and community settings and to estimate how much CKD amplifies hospital usage over the level of matched persons without CKD. The Queensland population is similar to the aggregate Australian populations in demographics, ethnic mix,²¹ and rates of CKD,¹⁻⁴ so our findings are likely to be generalizable across Australia. In addition, hospital admission data include all (licensed) hospital facilities across the state of Queensland, so that all episodes of care were captured even if patients used both private and public facilities.

There are several limitations to this study. First, whilst most public renal practices participated in CKD.QLD, patient enrolment depended on availability of discretionary time of study coordinators who were busy with other clinical duties, so not all patients were captured. Second, the final CKD.QLD cohort does not include one major renal specialty practice, for which all 998 enrollees were dropped from the database after discrepancies in outcomes data could not be resolved. Third, renal patients who received care exclusively in private specialty practices are not included; patient profiles and service utilisation in private renal services might be somewhat different than described here. Finally, people with CKD who were not admitted to the hospital during the observation interval were not included. For example, 11.6% of CKD.QLD patients did not have hospital admissions after their recruitment to the registry. Finally, the framework does not capture encounters and resource consumption in the outpatient setting. This usage is under study in another framework.²²

We have already used this framework to describe hospital admissions for patients at each individual registry site (ongoing), to define impacts of anaemia in CKD patients,²³ frequency and consequences of acute kidney injury in patients with CKD,²⁴ the characteristics of high-cost users,^{25,26} and to explore factors involved with readmissions by Machine Learning,²⁷ and several other studies are planned. Beyond these, the datasets can inform CKD health practitioners, Queensland Health, the Federal government, the national and international research communities, and local and national advocacy groups like Kidney Health Australia. The outcomes of this linkage study can assist the Australian Institute of Health and Welfare in defining the broader implications of CKD in terms of service consumption and its associated costs.

Conclusion

This study will provide the first detailed overview of the utilisation of health care resources, affiliated activity-based funding, and death of patients with CKD in Australia, who are in the public renal specialty system and those in other streams of care. Analysis of the data will provide opportunities for better understanding of CKD, early diagnosis of renal disease and its attendant cardiovascular risks and interventions to improve the outcomes of patients, whilst improving the value of provided health care. The outcomes from this study will subsequently inform other bodies of work to support best practice throughout the CKD practice network. Finally, we expect our research to identify opportunities for efficiencies of CKD management and for interventions to improve the outcomes of patients.

Data availability

Underlying data

The CKD.QLD Registry is managed according to legislative requirements including the Information and Privacy Act 2009, and as per the National Statement on Ethical Conduct in Human Research.²⁰ This study utilises an established data

linkage methodology to ensure the security and confidentiality of all participants' data, and to minimise any risk to participants, family members and the community.

Researchers (including PhD students) interested in using the data, should contact Jenny Zhang (jenny.zhang@uq.edu.au) and an amendment PHA will be submitted to Queensland Health adding the researcher's name in the application. Researchers must write a letter requesting access to specific data and attach their CV. Once the amendment PHA is approved, a policy agreement regarding data access must be signed by the researchers and then a deidentified dataset will be sent.

Acknowledgements

The study is operated under the NHMRC CKD Centre of Research Excellence and Chronic Kidney Disease (CKD.CRE) in Queensland Research Collaborative (CKD.QLD). We thank the clinical and academic teams that have enabled the linkage study and wholeheartedly thank all the patients who are participating in the CKD.QLD Registry Study. Sincere thanks also to the Queensland Health data custodians for providing the linked data and data linkage officers from the Statistical Analysis and Linkage Team of Queensland Health for conducting the data linkage.

References

1. Australian Bureau of Statistics: *National Health Survey: First Results, 2014-15*. Canberra: Australian Bureau of Statistics; 2015.
2. Australian Bureau of Statistics: *Australian health survey: First results 2011-12*. Canberra: ABS; 2012.
3. Australian Bureau of Statistics: *Australian Health Survey: Biomedical Results for Chronic Diseases, 2011-12*. Canberra: ABS; 2013.
4. Australian Bureau of Statistics: *National Health Survey: First results, 2017-2018*. Australian Bureau of Statistics; 2018.
5. AIHW: *Chronic kidney disease* Canberra: AIHW; 2020; **2021**.
6. ANZDATA Registry: *43rd Annual Report 2020 (Data to 2019)*. Adelaide: Australia and New Zealand Dialysis and Transplant Registry; 2020.
7. Australian Institute of Health and Welfare: *Dialysis and kidney transplantation in Australia: 1991-2010. Cat. no. PHE 162*. Canberra: AIHW; 2012.
8. Australian Institute of Health and Welfare: **Cardiovascular disease, diabetes and chronic kidney disease—Australian facts: Risk factors**. *Cardiovascular, diabetes and chronic kidney disease series no 4 Cat no CDK 4*. Canberra: AIHW; 2015.
9. Venuthurupalli SK, Hoy WE, Healy HG, *et al.*: **CKD.QLD: Establishment of a chronic kidney disease [CKD] registry in Queensland, Australia**. *BMC Nephrol.* 2017; **18**(1): 189. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
10. Australian Bureau of Statistics: *National, state and territory population - June 2020*. Canberra: Australian Bureau of Statistics; 2020.
11. **2016 Census of Population and Housing: General Community Profile**.
12. Queensland Health: *Handbook for Queensland Hospital and Health Boards (second edition)*. Brisbane © State of Queensland (Queensland Health); 2018.
13. Kelman CW, Bass AJ, Holman CDJ: **Research use of linked health data — a best practice protocol**. *Aust. N. Z. J. Public Health.* 2002; **26**(3): 251-255. [PubMed Abstract](#) | [Publisher Full Text](#)
14. Department of Health: *Queensland Data Linkage Framework*. Brisbane The State of Queensland (Queensland Health); 2016.
15. Queensland Health: *The Queensland Hospital Admitted Patient Data Collection (QHAPDC) Manual 2016-2017*. Brisbane, QLD: State of Queensland (Queensland Health); 2017.
16. Queensland Health: *Health funding principles and guidelines 2016-17 financial year*. Brisbane: QLD State of Queensland (Queensland Health); 2015.
17. Queensland Health: *Health funding principles and guidelines 2019-20 financial year*. Brisbane: QLD State of Queensland (Queensland Health); 2019.
18. Independent Hospital Pricing Authority: **National Hospital Cost Data Collection, Public Hospitals Cost Report, Round 19 (Financial year 2014-15)**. *National Hospital Cost Data Collection, Public Hospitals Cost Report*. Sydney: IHPA; 2017.
19. Queensland Health: *Public Health Act 2005*. Queensland Health: Brisbane: Queensland Government; 2017.
20. The Australian Research Council and the Australian Vice-Chancellors' Committee: *National Statement on Ethical Conduct in Human Research (Updated May 2015)*. The National Health and Medical Research Council: Canberra: Commonwealth of Australia; 2007.
21. Australian Bureau of statistics: *Census of Population and Housing: Reflecting Australia - Stories from the Census, 2016*. statistics ABo: Canberra: Australian Bureau of statistics 2017.
22. Byrnes J, Nghiem S, Afoakwah C, *et al.*: **Queensland Cardiovascular Data Linkage (QCard): A population-based cohort study [version 1; peer review: awaiting peer review]**. *F1000Res.* 2020; **9**(282). [Publisher Full Text](#)
23. Zhang J, Diwan V, Wang Z, *et al.*: **The Impact of Anaemia on Outcomes and Costs in Patients with Chronic Kidney Disease in Two Public Nephrology Practices in Queensland: A CKD.QLD Registry Study**. *ANZSN*. Sydney: Australian and New Zealand Society of Nephrology; 2020.
24. Zhang J, Healy HG, Baboolal K, *et al.*: **Frequency and Consequences of Acute Kidney Injury in Patients With CKD: A Registry Study in Queensland Australia**. *Kidney Medicine.* 2019; **1**(4): 180-190. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
25. Sowa PM, Zhang J, Hoy WE, *et al.*: **Intensive Users of Hospital Care in Chronic Kidney Disease**. *ANZSN*. Sydney Australian and New Zealand: Society of Nephrology; 2019.
26. Sowa M, Venuthurupalli S, Hoy W, *et al.*: **Factors associated with high cost use of hospital care in pre-end stage chronic kidney disease**. *The 55th ANZSN ASM: 2020; Online*. Australian and New Zealand: Society of Nephrology; 2020.
27. Im SJ, Xu Y, Watson J, *et al.*: **Hospital Readmission Prediction using Discriminative patterns**. *2020 IEEE Symposium Series on Computational Intelligence (SSCI): 1-4 Dec. 2020*. 2020; 50-57.

Open Peer Review

Current Peer Review Status: 

Version 1

Reviewer Report 15 November 2021

<https://doi.org/10.5256/f1000research.57198.r98786>

© 2021 Nghiem S. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



Son Nghiem 

Centre for Applied Health Economics, Griffith University, Brisbane, Qld, Australia

This article present the description of CKD.QLD data linkage framework. The article is clearly written and almost can be indexed without changes. I have only a couple of minor recommendations:

1. Provide a rationale for the choice of matching ratio of 1:3 for both second and third data cohorts relatively to the first cohort.
2. Was CKD in the second cohort identified using primary or other diagnosis codes?
3. What is the rationale to limit the matching variable to only sex, age and HHS?
4. What method was used to match data across cohort? What criteria was used to identified match records?
5. Adding a table to summarize three cohorts and test for difference based on matching variables would be useful.

Is the rationale for creating the dataset(s) clearly described?

Yes

Are the protocols appropriate and is the work technically sound?

Yes

Are sufficient details of methods and materials provided to allow replication by others?

Partly

Are the datasets clearly presented in a useable and accessible format?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health economics

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

The benefits of publishing with F1000Research:

- Your article is published within days, with no editorial bias
- You can publish traditional articles, null/negative results, case reports, data notes and more
- The peer review process is transparent and collaborative
- Your article is indexed in PubMed after passing peer review
- Dedicated customer support at every stage

For pre-submission enquiries, contact research@f1000.com

F1000Research