Characteristics, health services utilisation, costs and outcomes of patients with chronic kidney disease (CKD): Queensland Health data linkage

Jenny Zhang
PhD; MPH; GradCert Stat; BMed

Marcin Sowa, Zaimin Wang, Anne Cameron,
Luke Connelly, Wendy Hoy

NHMRC CKD.CRE, University of Queensland
Background

- In 2014-15, 203,400 Australians, or 0.9% of the population, reported having kidney disease

- In 2014–15, 1.7 million hospitalisations were associated with CKD in Australia, and 80% of these were for regular dialysis

- 1 in 9 Australian deaths had CKD as the underlying and/or associated cause of death, that is 16,500 in 2014

- CKD closely co-exists with cardiovascular disease and type 2 diabetes, with these three diseases accounting for around a quarter of the entire disease burden in Australia

- While the costs of dialysis are continually in focus, there are no quality studies of health service utilisation or costs of preterminal CKD
Aim

- To comprehensively review health services utilisation, costs and outcomes in CKD patients in Queensland through a collaboration with Queensland Health data custodians

Objectives

- To describe the demographic and clinical characteristics of patients from state-wide health services utilisation data
- To conduct comprehensive economic evaluations of services provided to CKD patients
- To compare characteristics, health services utilisation, and costs of patients enrolled in the CKD.QLD registry with those of CKD patients in other health care environments in the state
- To describe all deaths of patients in both these cohorts
Design and Methods

- This is a sub-study of the CKD.QLD Registry, approved by Metro North Human Research Ethics Committee.

- The Registry patients (Cohort 1) linked to QH data by the Statistical Analysis and Linkage Unit, Queensland Health using a unique ID with other identifiers (names, dob, gender, ur-number).

- A cohort of CKD patients in other health care environments (Cohort 2) matched (3:1) with the registry patients by the Hospital and Health Services (HHSs), where the registry patients had their first admission or their neighbouring HHS’s if they had no admissions.

- Five years of retrospective data (2011-2016) on health service utilisation were provided by Queensland Health.
The data linkage framework of the sub-study of CKD.QLD Registry

**Cohort 1**
CKD patients (age 18 years & over) consented and enrolled in the CKD.QLD Registry (n=7,300)

**Cohort 2**
CKD patients (age 18 years & over) in the QH datasets who are not in CKD.QLD Registry identified by ICD codes (n=21,900)

**Data linkage**
- Linked by CKD.QLD Registry ID
- Hospital UR Number
- Patients’ names, date of birth, sex, and postcode

**The Queensland Admitted Patient Data Collection (QHAPDC)**
The hospital separations for all episodes regardless of diagnoses

**Death Data**

**ABF Model Output Data**
Inpatients, outpatients, ED and available primary health care data for all episodes regardless of diagnoses
Data sources

- **QHAPDC Data:** The Queensland Hospital Admitted Patient Data Collection (QHAPDC): collects demographic data and clinical information (admission details: LOS; morbidity details: principal diagnosis, DRG) on all admitted patients separated from both public and licensed private hospitals and private day surgeries in Queensland.

- **Death Data:** from the Queensland Death Registry, linked to the cohort file including date of death, cause of death, and place of death (hospital or other).

- **Queensland ABF Model Output Data:** capture cost information used the activity based funding (ABF) Model for HHSs (encounter cost, services direct and indirect cost...).
**Data Linkage Process**

1. **Step 1**
   - Contacted the Statistical Analysis and Linkage Unit (SALT), QH for initial advice

2. **Step 2**
   - Consulted with data custodians, QH and obtain their approval

3. **Step 3**
   - Applied for sub-study ethical approval and waiver of consent from HREC

4. **Step 4**
   - Applied for Public Health Act (PHA) and obtain an approval letter from the Director-General, QH

5. **Step 5**
   - Provided a copy of approval to SALT request data

6. **Step 6**
   - Submitted key identifiers from CKD.QLD Registry to SALT in two tranches

7. **Step 7**
   - Link the data by Data Linkage Officers

8. **Step 8**
   - Send the linked data back to CKD.QLD
Data security

- The identifiers from CKD.QLD are stored electronically with an encrypted and password protected file and sent to the linkage team for the requested data linkage.

- The linkage team sends the linked data in a zipped file using a secure web portal to one of the approved investigator (JZ), who downloads and stores the data in the University’s secure database.

- As specified by Queensland Health, “All Queensland Health data provided to CKD.QLD will be kept separately from the CKD.QLD Registry for the purpose of this study only, and stored electronically with an encrypted and password protected file, which can only be accessed by PHA approved researchers.”
Progress

- Of 7,300 patients (CKD.QLD), the first tranche of identifiers of 4,628 patients (6 sites) has been submitted to QH and their linked data have been received. The second tranche of identifiers of 2,672 patients (7 sites) has been submitted and their linked data are in process.

- 21,900 de-identified patients with CKD will be matched with registry patients, and all linked data will be available by the end of August.

Significance

- This platform provides opportunities for better understanding CKD, early diagnosis of renal disease and for interventions to improve the outcomes of patients.

- It permits economic evaluation of health service utilisation for individual patients in both public and private practice environments across all disciplines.

- It allows comparison of CKD patients in public renal practice with the broader population of CKD patients across QH Services.
Limitations

- The data from data linkage so far do not reflect the utilisation of primary health care since the data collection from QH is limited to hospital data collection.
- The data linkage focuses on all patients with CKD, and does not include comparisons between CKD patients and non-CKD patients.

Conclusion

- This is first insight into state-wide utilisation of health care resources, costs, and death of patients with CKD.
- The outcomes will subsequently inform other bodies of work to support best practice in CKD throughout Queensland.
- The study will inform CKD health practitioners, QH, Federal governments, Kidney Health Australia, and national and international research communities.
Acknowledgements

- Funded by the National Health and Medical Research Council under the Centre of Research Excellence (CRE)

- Operated under the Centre for Chronic Disease, UQCCR, faculty of Medicine, The University of Queensland

- Thanks all clinical and academic teams who are participating in this study

- Thanks all of the patients who consented in the CKD.QLD Registry Study

- Sincerely thanks to the QH data custodians and data linkage officers for providing and conducting the linked data from the Statistical Analysis and Linkage Unit of Queensland Health

Thanks very much for your attention!