# The CKD.QLD Registry and Research Platform

Wendy Hoy

Co-Chair, QLD CKD Registry

# Chronic Kidney Disease (CKD) in Queensland and Beyond.
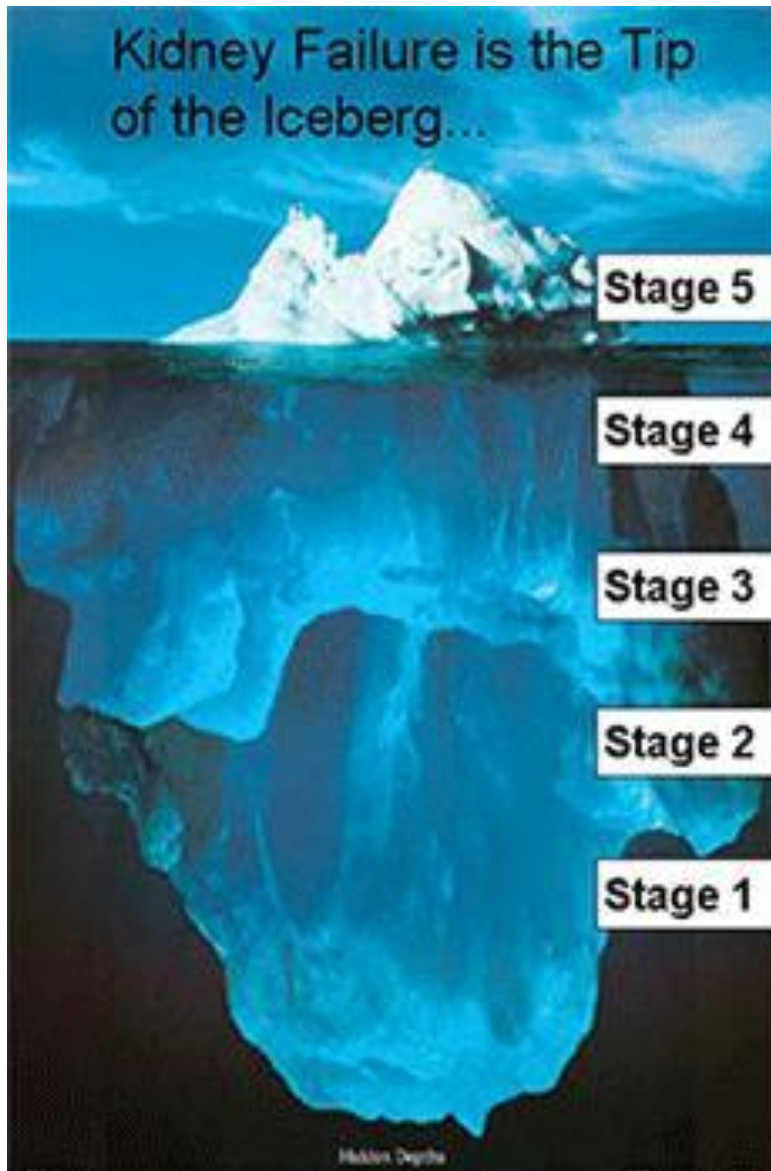
## HREC/15/QRBW/294

March 2017

Kidney Failure is the Tip of the Iceberg...

Stage 5
Stage 4
Stage 3
Stage 2
Stage 1

## Purposes of CKD surveillance

- Define CKD distribution (hot spots, risk factors, high risk groups)

- Define CKD progression and associations

- Define outcomes

- Define resource consumption

- Define CKD management and gaps

- Predict RRT and

- Predict burden of XS renal-related deaths

- Track trends

Number of RRT-treated and non-RRT-treated cases, by age group 2003-07
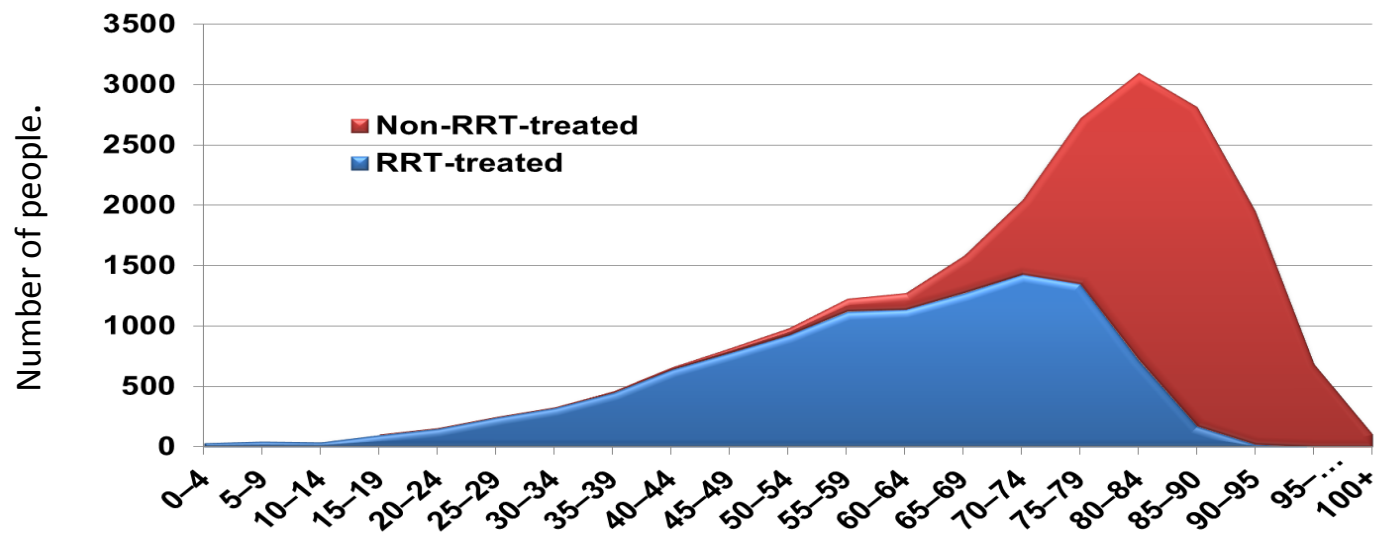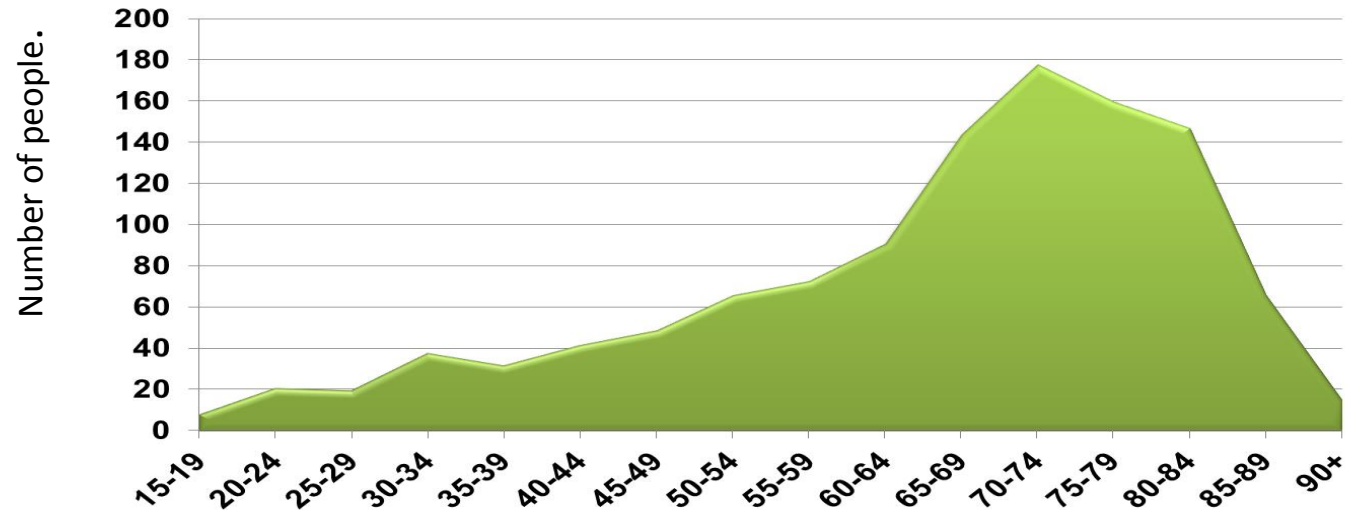
# Number of RRT-treated and non-RRT-treated cases, by age group 2003-07
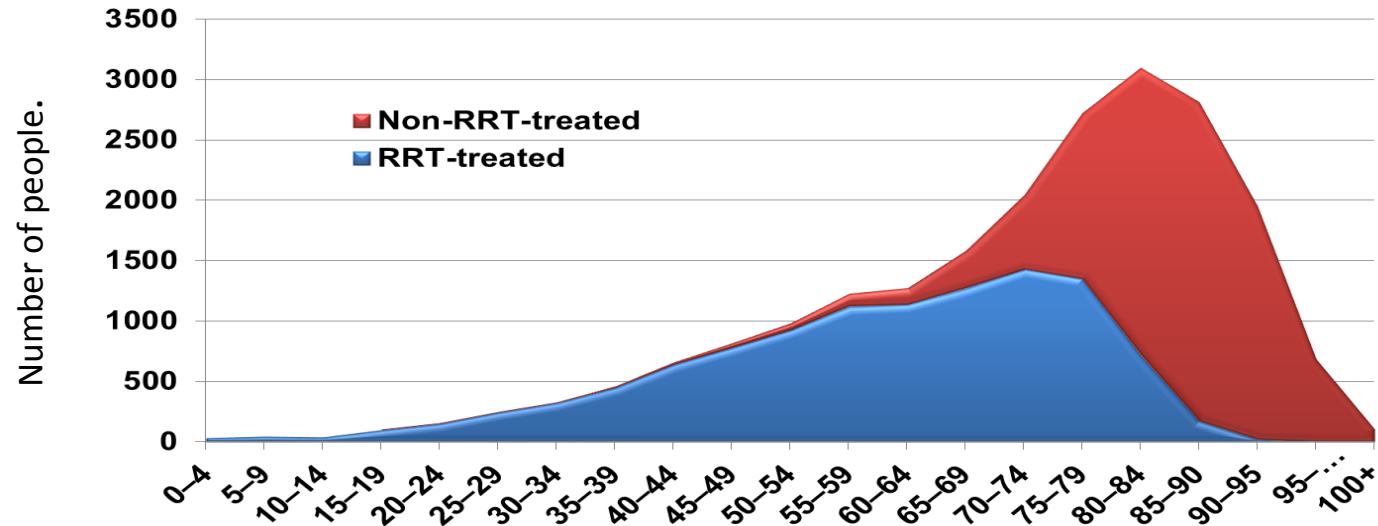
CKD QLD



Age at consent, CKF.QLD patients at RBWH

# CKD.QLD Registry

A multidisciplinary research and practice collaborative network
embracing all renal units in the public health system in Queensland,
under the jurisdiction of Queensland Health.

- concept developed in late 2009
- central ethics approval (Q Health and UQ) 2010
- staggered individual site specific approvals
- patient enrolment is with informed consent
- first enrolment in May 2011

www.ckdqld.org

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UQ Health Science Building
RBWH – Herston Campus
QLD 4029

**www.ckdqld.org**

Ph. 07 3346 4995

**CKD.QLD Management Committee:**
Prof Wendy Hoy   Dr Helen Healy   Prof Ann Bonner
Prof Geoff Mitchell

**Founding co-chair:**
Prof Robert Fassett

**Manager:**
Anne Cameron

**Research Fellows:**
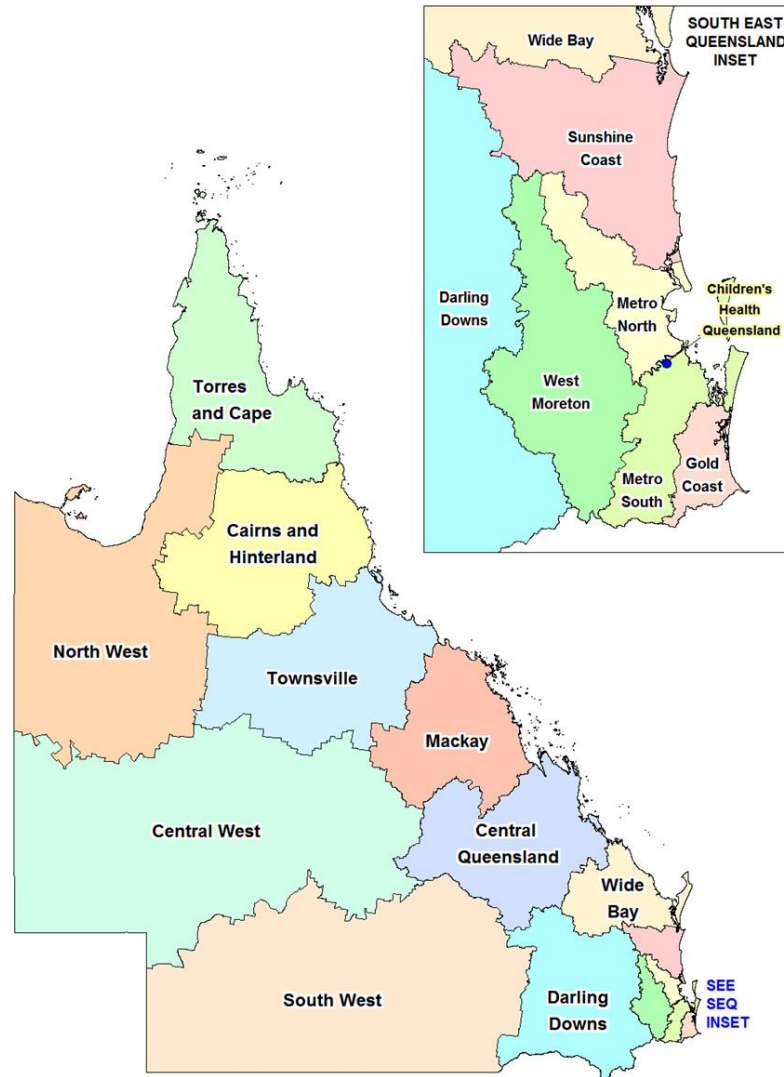Jenny Zhang
Zaimin Wang

# Queensland population: 4.8 million
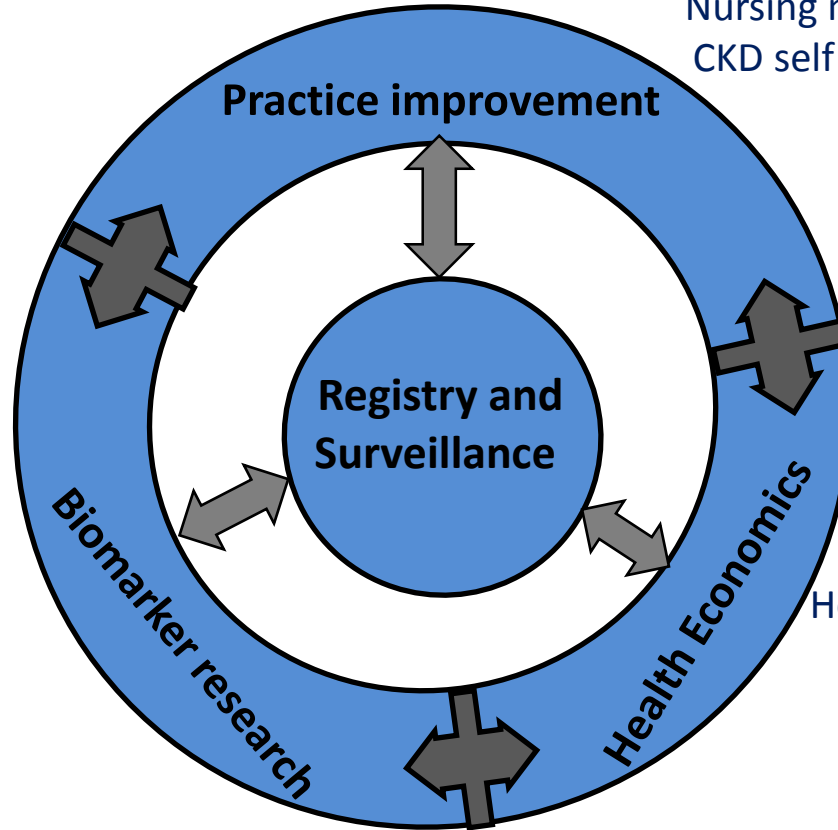## Multi-ethnic; across metropolitan, regional, rural and remote/very remote



- One public health service provider: Queensland Health

- Incorporates 16 HHS's, each with an affiliated kidney health service

- The state has approx. 20% of the national population, with 20% of the RRT population

- **Mirrors nationwide demographic**

**Research and Practice Platforms**

Renal supportive & pall care
Primary health care
Nursing models of care
CKD self management

Practice improvement

Registry and Surveillance

Biomarker research

Health Economics
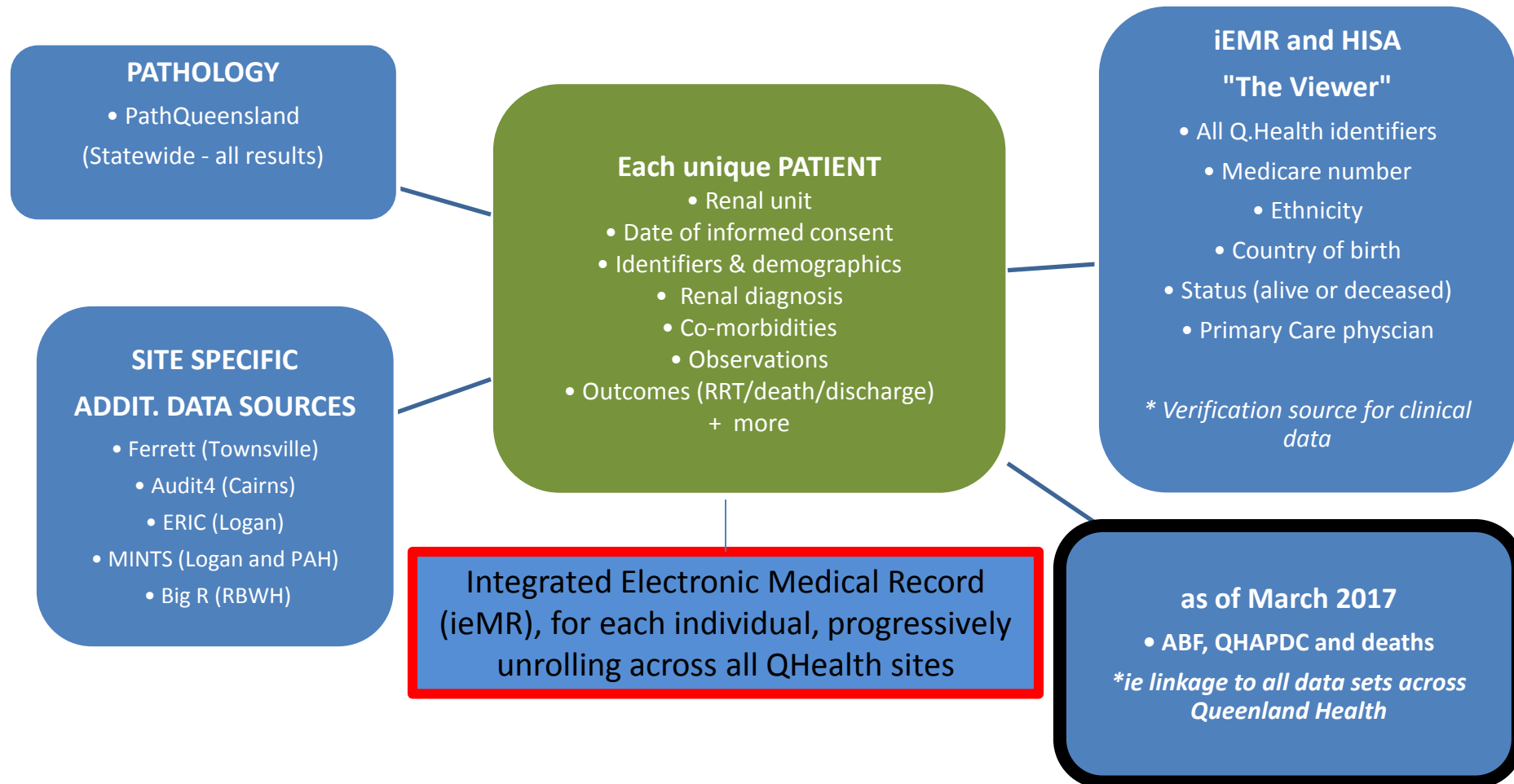
CKD.Biobank
Genetics
Biomarkers
aCQuiRE study

Health service utilisation
Economic evaluations

The platform can support a multitude of Investigator initiated projects
eg Qld Renal Biopsy Registry, clinical trials, intervention studies etc

# CKD.QLD Registry
# Data linkage framework

**SITE SPECIFIC ADDIT. DATA SOURCES**
- Ferrett (Townsville)
- Audit4 (Cairns)
- ERIC (Logan)
- MINTS (Logan and PAH)
- Big R (RBWH)

**PATHOLOGY**
- PathQueensland
(Statewide - all results)

**Each unique PATIENT**
- Renal unit
- Date of informed consent
- Identifiers & demographics
- Renal diagnosis
- Co-morbidities
- Observations
- Outcomes (RRT/death/discharge)
+ more

**iEMR and HISA "The Viewer"**
- All Q.Health identifiers
- Medicare number
- Ethnicity
- Country of birth
- Status (alive or deceased)
- Primary Care physcian

*Verification source for clinical data*

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Integrated Electronic Medical Record (ieMR), for each individual, progressively unrolling across all QHealth sites

**as of March 2017**

• ABF, QHAPDC and deaths

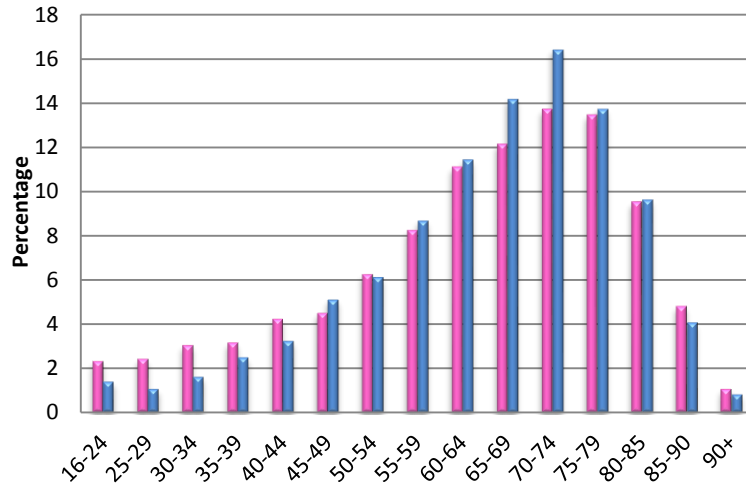*\*ie linkage to all data sets across Queenland Health*

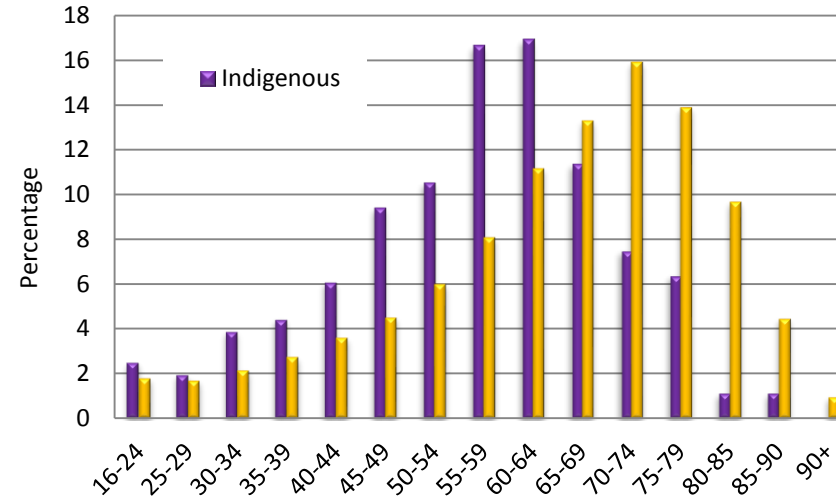Enrolment with consent to CKD.QLD Registry [7,061].
Active and Inactive
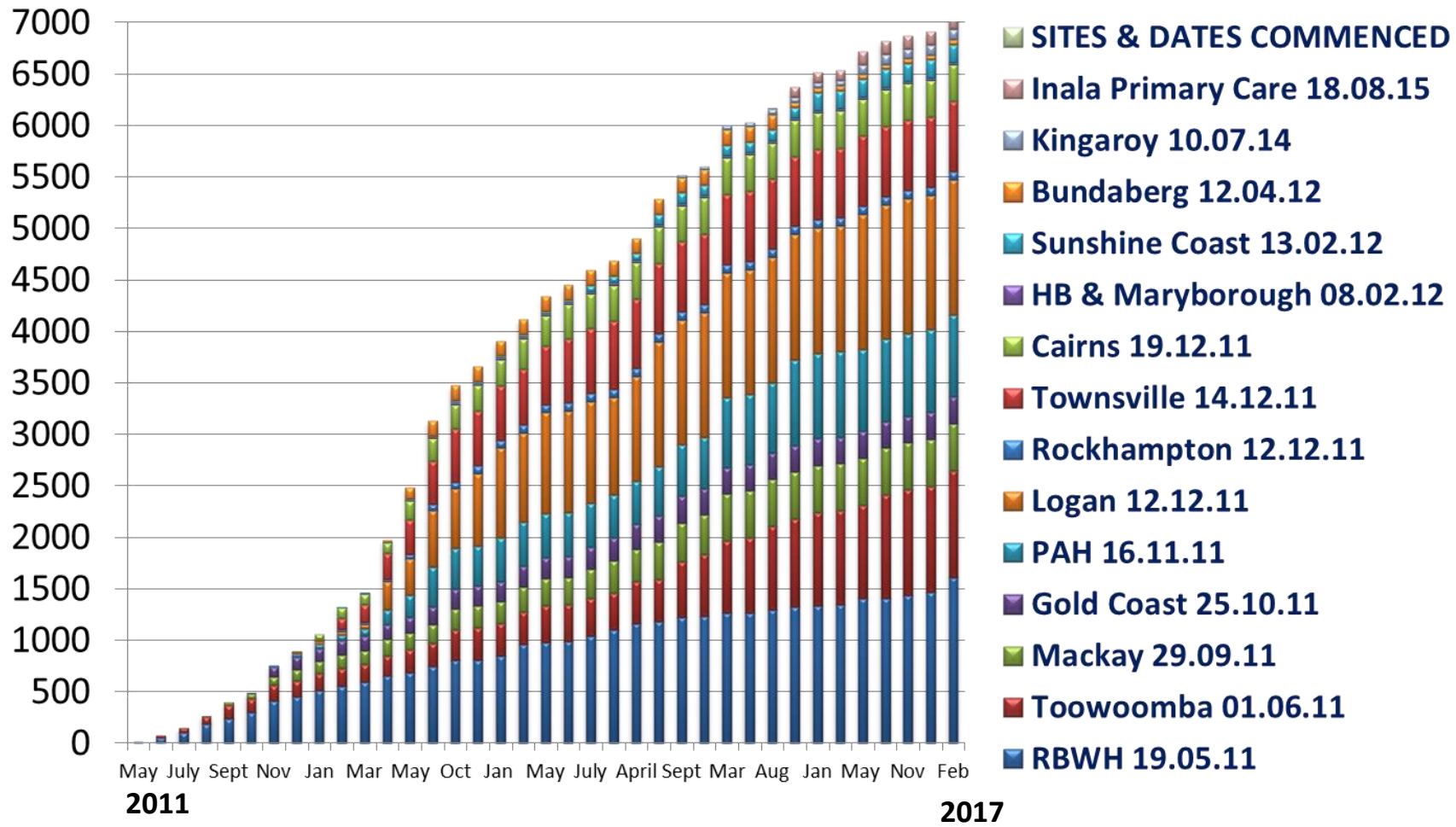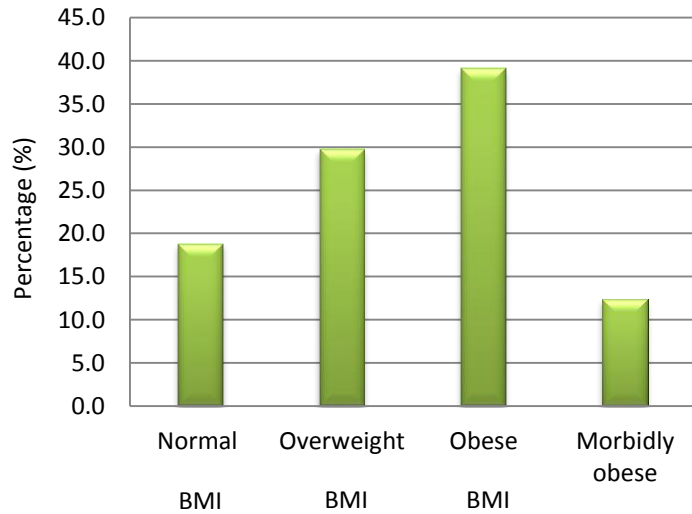
And about 25,000 person years of observation

Age distribution (by gender) at consent.
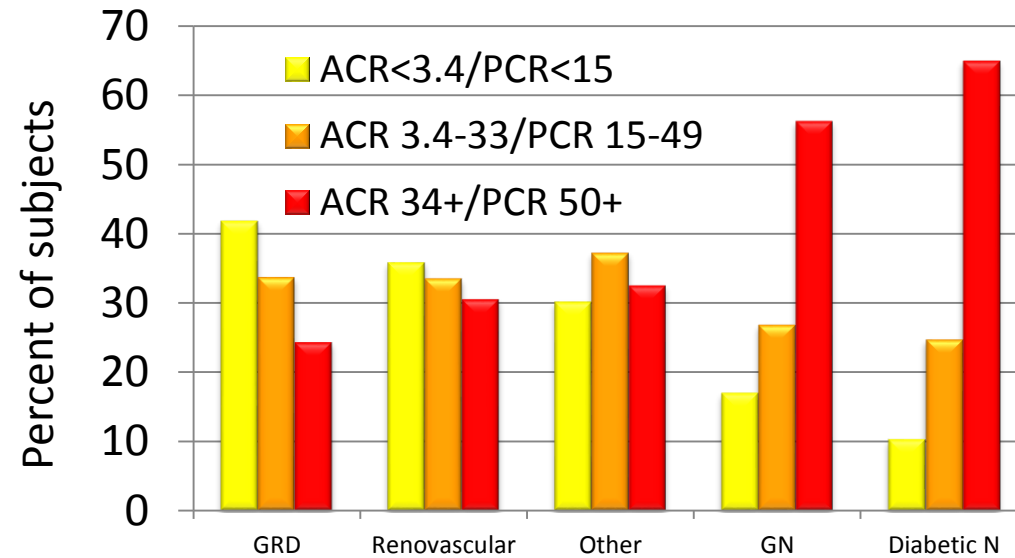[female =2,719, male = 3,216; F:M 46:54]



Age distribution in CKD patients, Indigenous vs nonindigenous in Townsville.
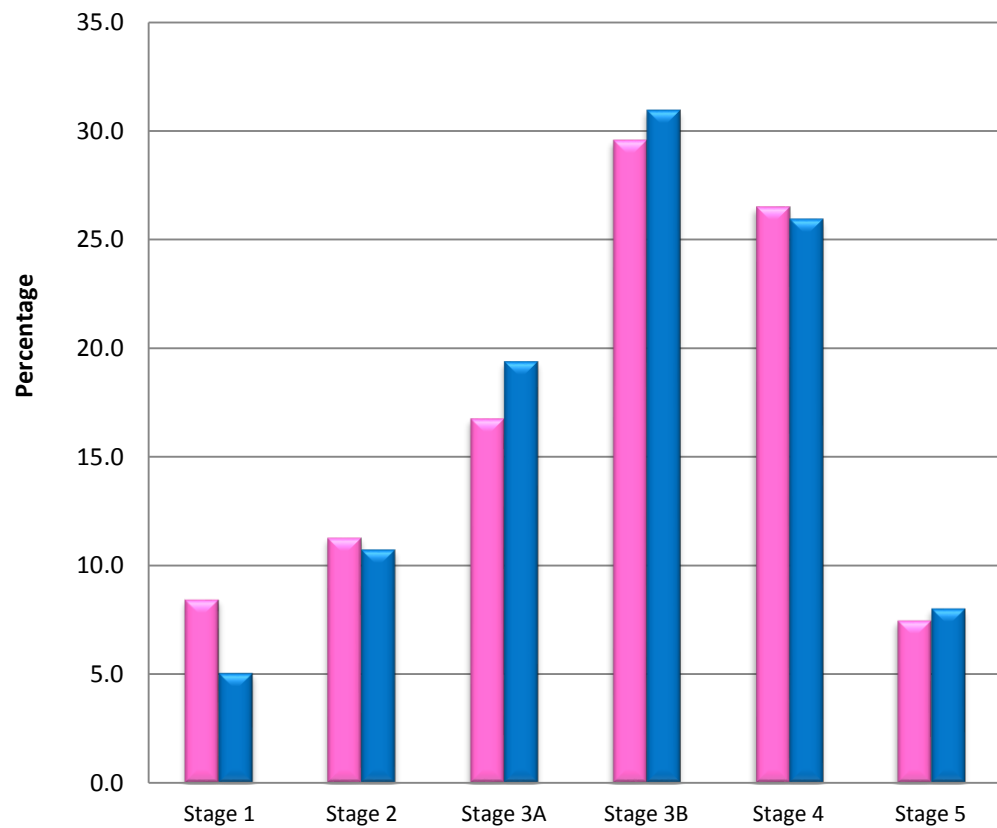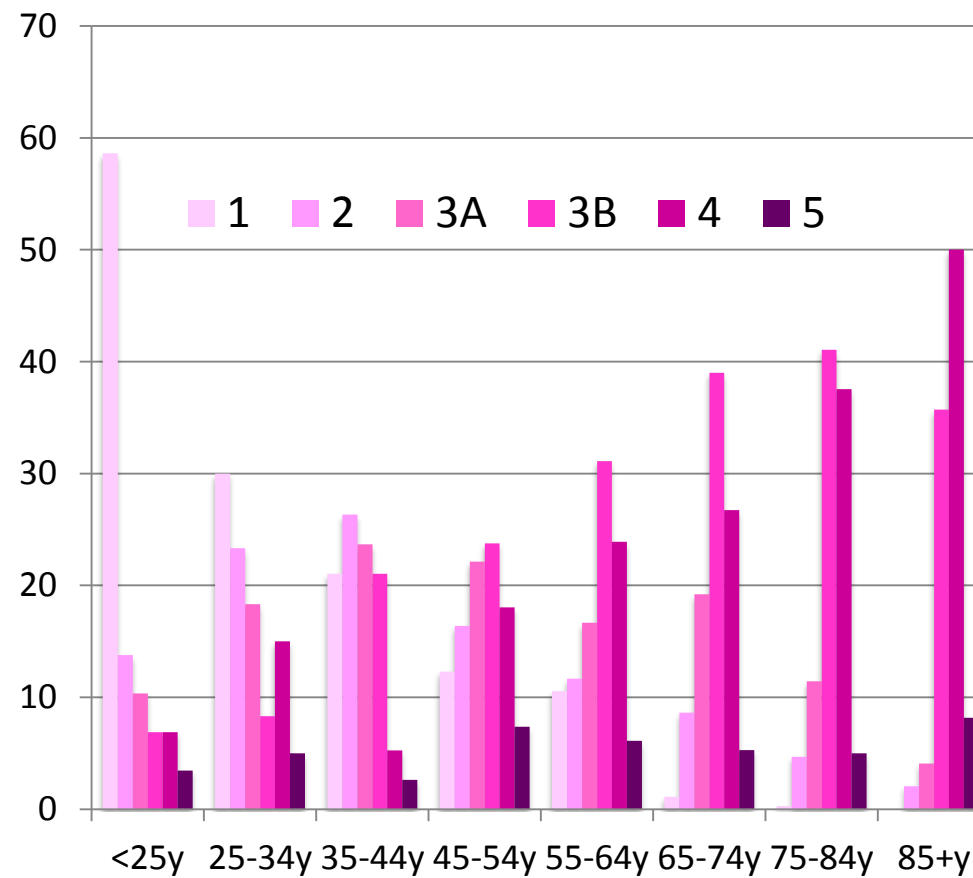


BMI at consent: RBWH, Logan, Toowoomba, n=3,366



Proteinuria /albuminuria by primary renal disease

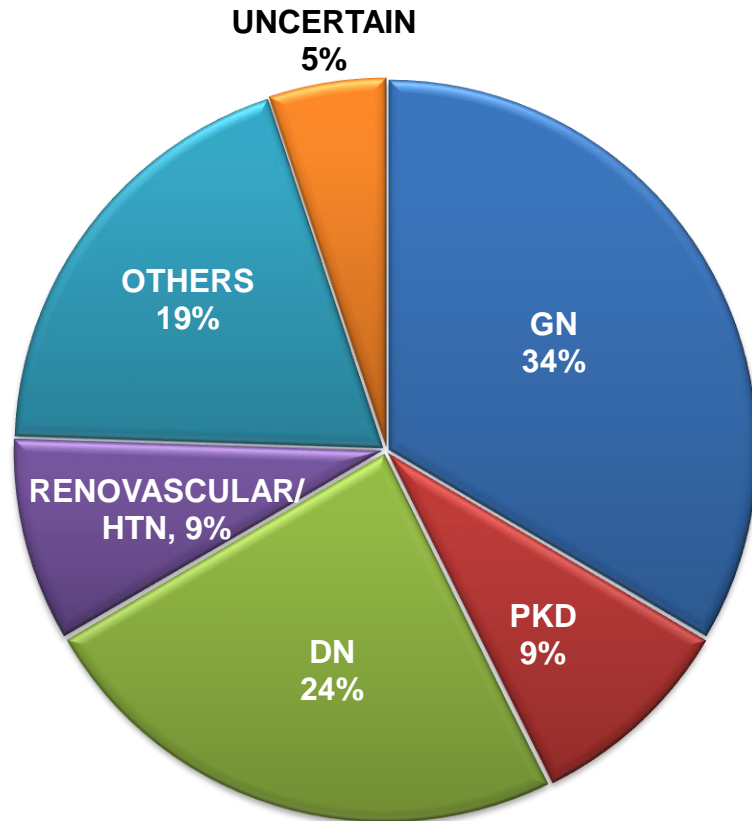CKD Stage by gender at consent, female=2,703, male n=3,200

CKD stage by age group

**ANZDATA 2014:**
**Primary renal disease in**
**Australian RRT population.**
**n=22,234**

UNCERTAIN
5%

OTHERS
19%

GN
34%

RENOVASCULAR/
HTN, 9%

PKD
9%

DN
24%

**CKD.QLD 2016:**
**Primary renal disease in**
**CKD population**
**n=5,773**

UNCERTAIN
7%

GN
12%

OTHERS
21%

GRD
6%

RENOVASCULAR/HTN
29%

DN
25%
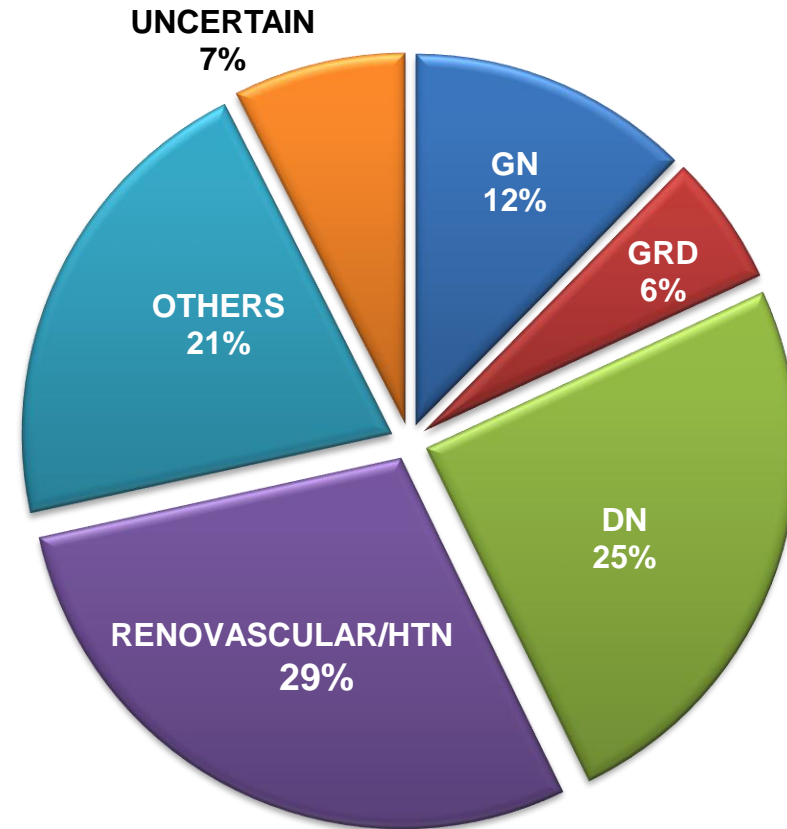
Median age by primary renal diagnosis, n=4,584
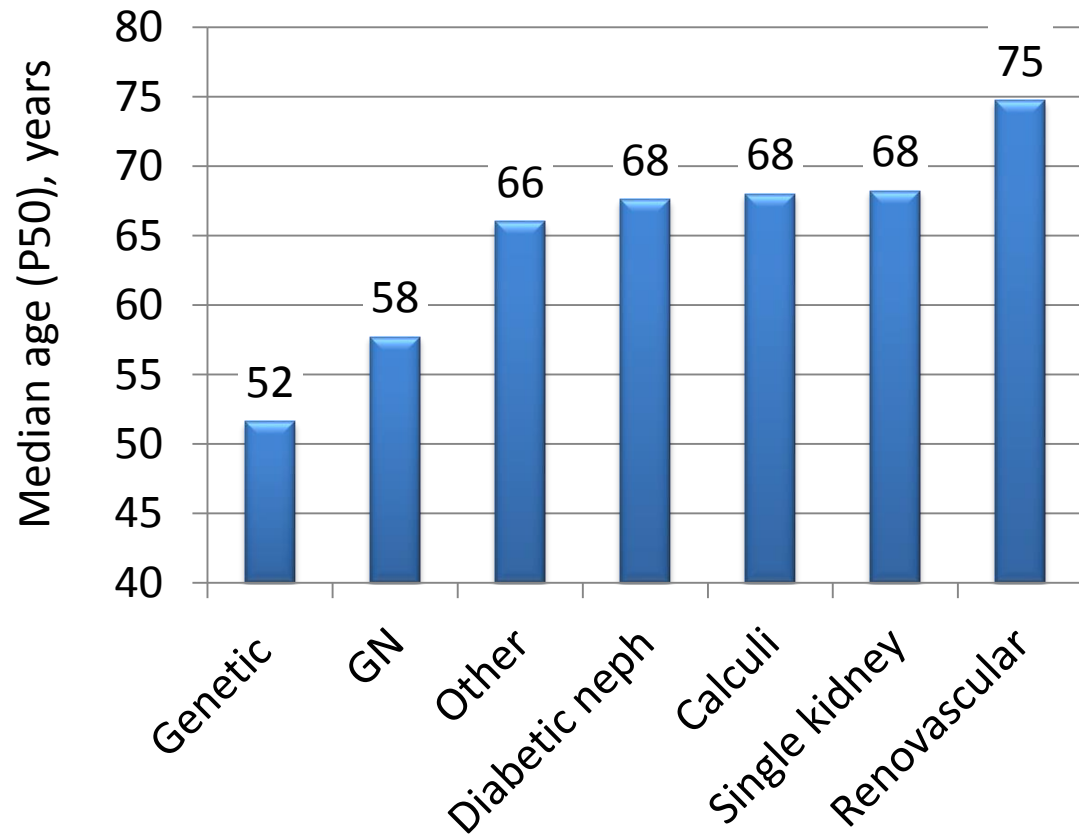
Numbers of primary renal diagnoses
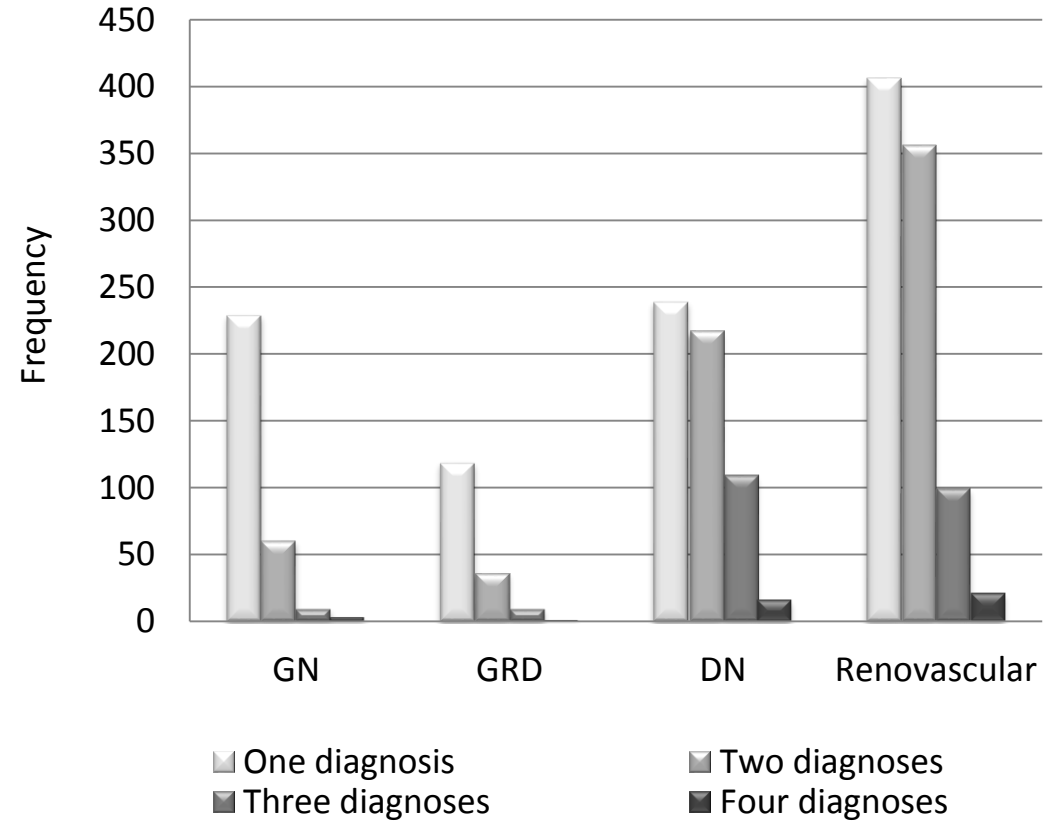
Leading 19 conditions by age group.
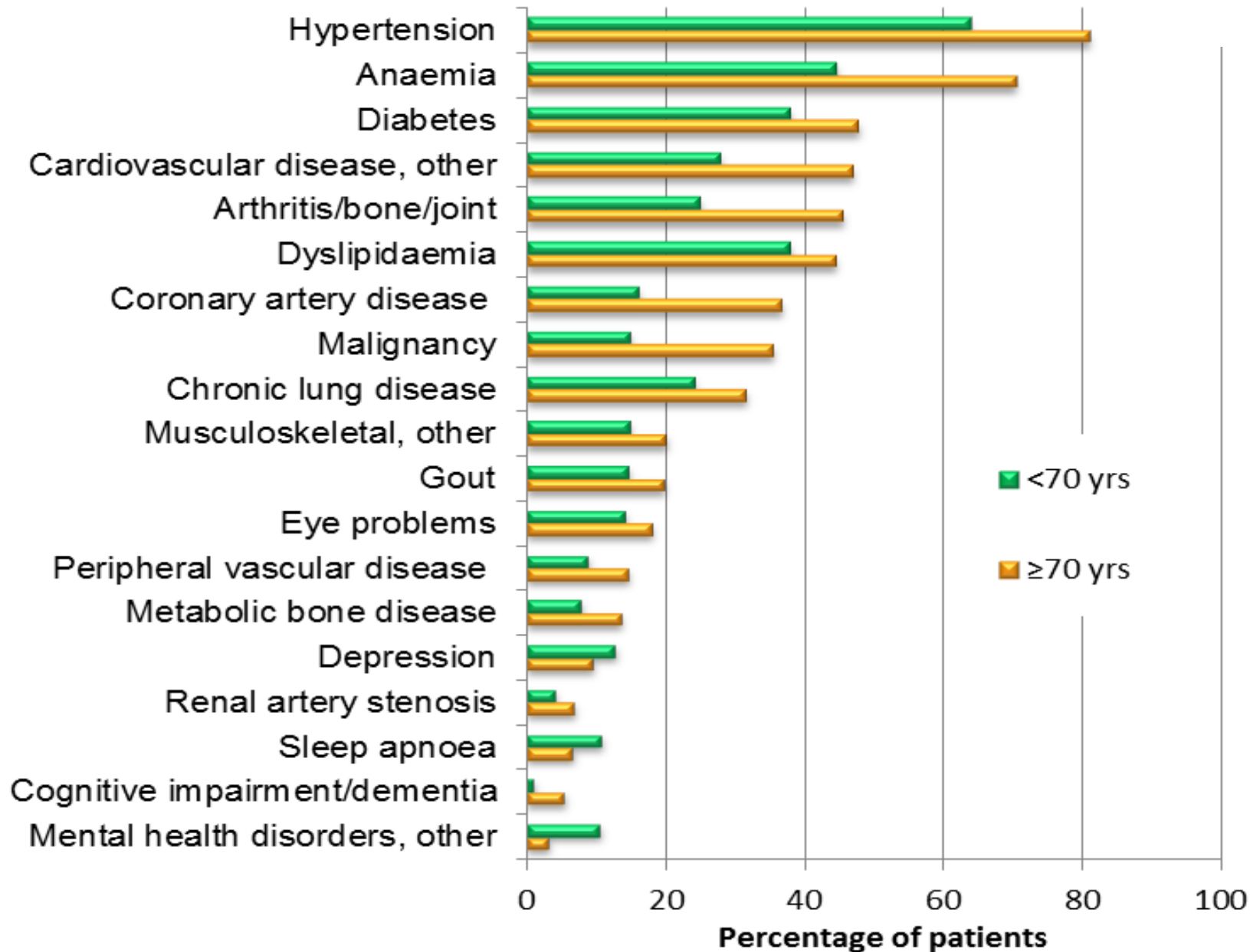
## Annual changes in EGFR per year, n=1,945
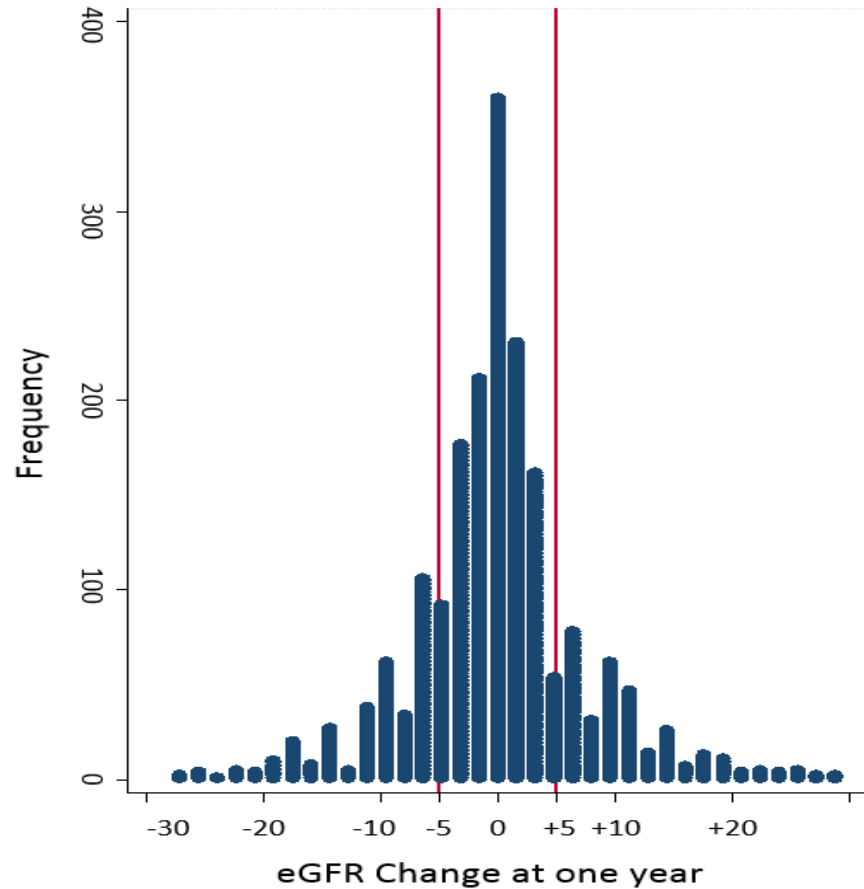


## Progression by primary renal disease
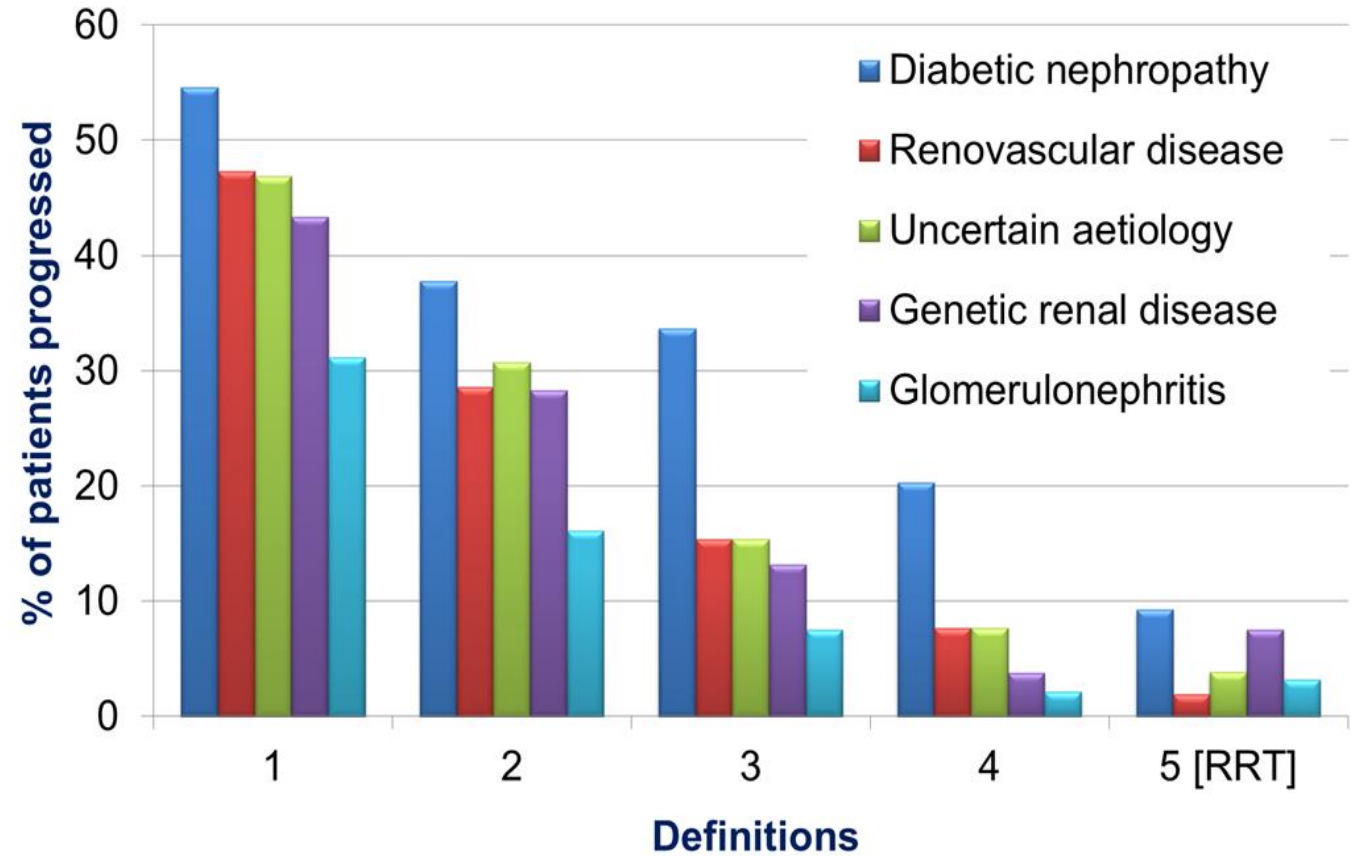


Definition 1: >2ml/min/1.73m2/year eGFR reduction
Definition 2: >5ml/min/1.73m2 /year eGFR reduction
Definition 3: 20% eGFR reduction
Definition 4: Combination of CKD stage change & 25% eGFR reduction [KDIGO definition][2].
Definition 5: commencing renal replacement therapy [RRT]

## Annualised costs of hospitalisations by CKD stage



Bar chart — Total costs, Aus$ (y-axis, 0 to 600000) by stage (x-axis: Stag 1, 2, 3a, 3b, 4, 5)

## Rate of *hospital cost* (AU$) (per 100 person years) by renal disease diagnosis



Bar chart — Rate per 100 person yrs (y-axis, 0 to 450000) by renal disease diagnosis:
- GN: $168,891
- GRD: $180,492
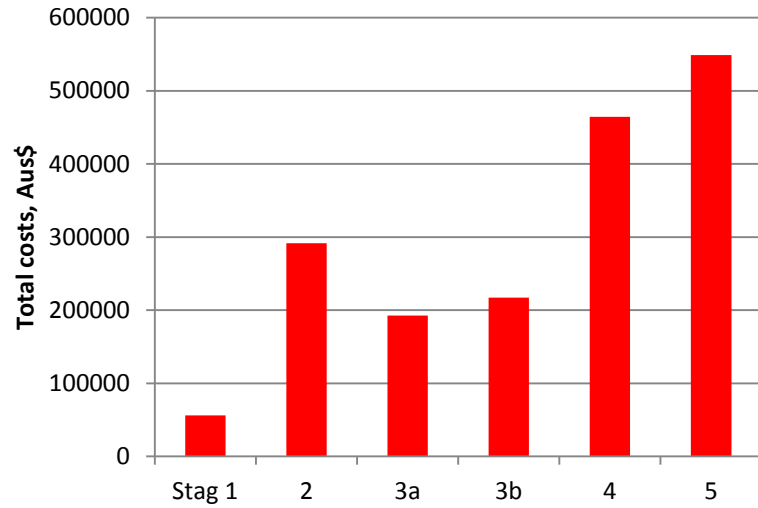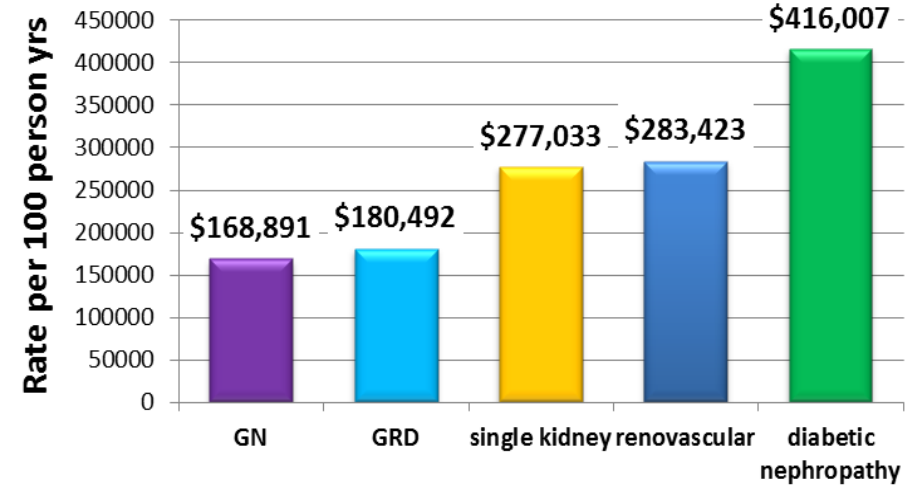- single kidney: $277,033
- renovascular: $283,423
- diabetic nephropathy: $416,007

## Most frequent DGRs for hospsitalisations for Stage 3 CKD patients



Horizontal bar chart — Number of admissions for this DRG (x-axis, 0 to 40):
- BONE DISEASES AND ARTHROP-CSCC
- RENAL FAILURE +SCC
- KDNY & UNRY TR SGNS&SYMPS-CSCC
- OESPHS, GASTR +CSCC
- OTHER SKIN, SUBC TIS & BRST PR
- OTHER RESPIRATRY SYS OR PR+CCC
- RETINAL PROCEDURES
- OTH KIDNY & URNRY TRCT DX-CSCC
- RESPIRATORY NEOPLASMS -CCC
- RESPIRATORY NEOPLASMS -CCC
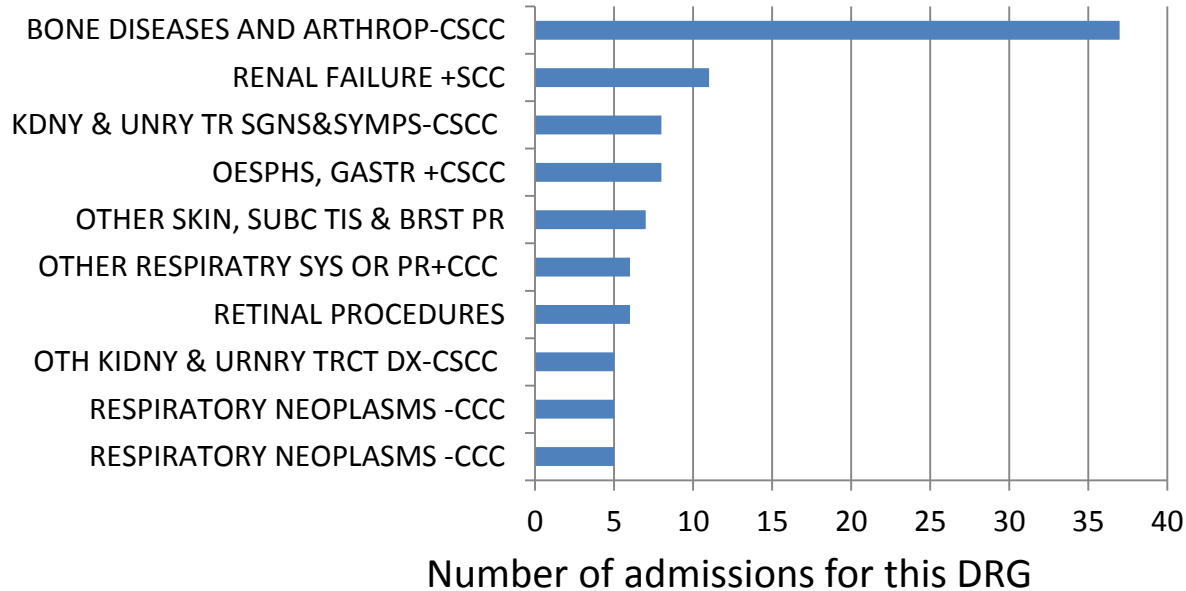
## Most frequent DRGs for hospitalisation of stage 4 and 5 CKD patients, RBWH



Horizontal bar chart — Number of admissions for this DRG (x-axis, 0 to 60):
- RETINAL PROCEDURES
- RED BLOOD CELL DISDERS -CSCC
- RED BLOOD CELL DISDERS +SD
- MISC METABOLIC DISORDERS -CSCC
- KDNY & UNRY TRCT INF -CSCC
- CYSTOURETHROSCOPY
- DIABETES -CSCC
- RESP SYS DX +NON-INVAS VENTILN
- KDNY,URT&MJR BLDR PR NPSM +SCC
- RENAL FAILURE -CSCC
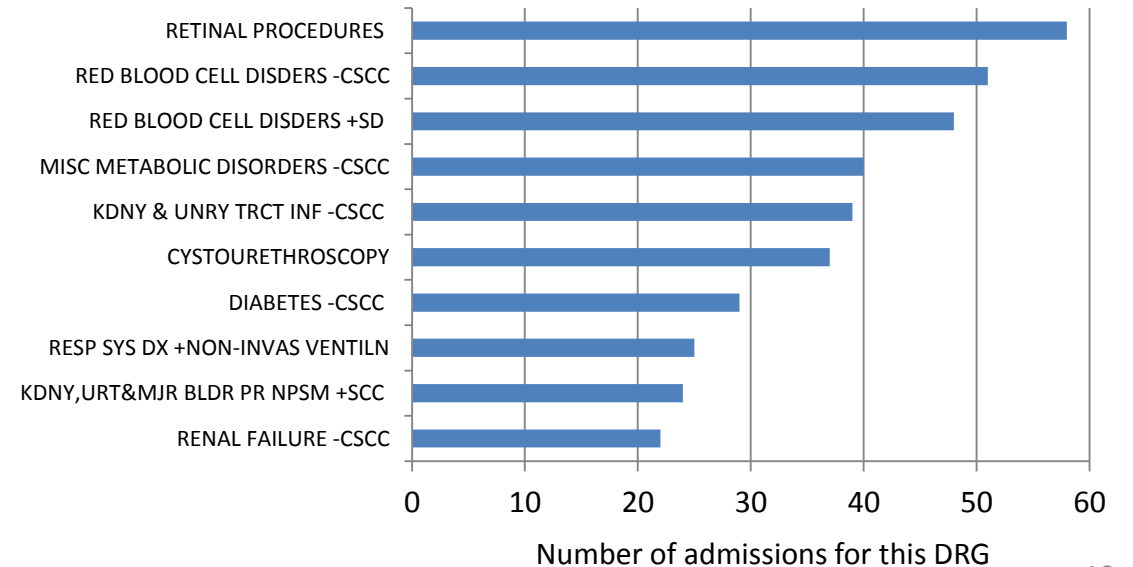
Incidence of RRT per 100 person years by CKD stage at consent, three major sites
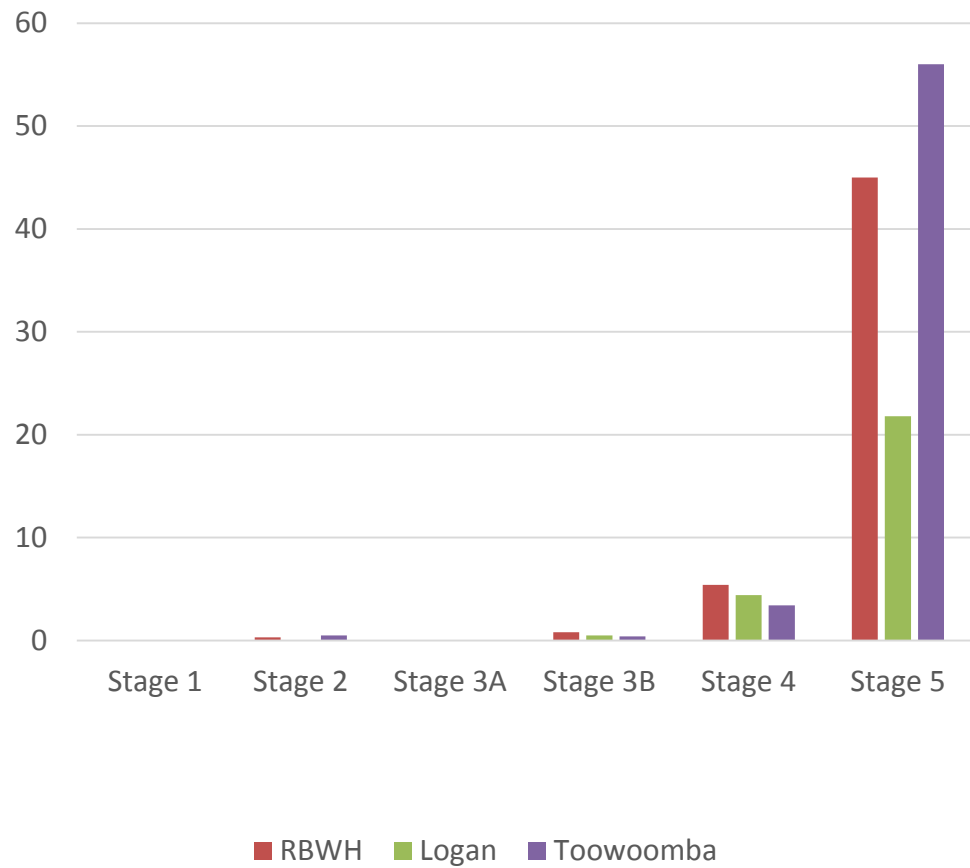
Incidence of death per 100 person years by stage at consent three major sites
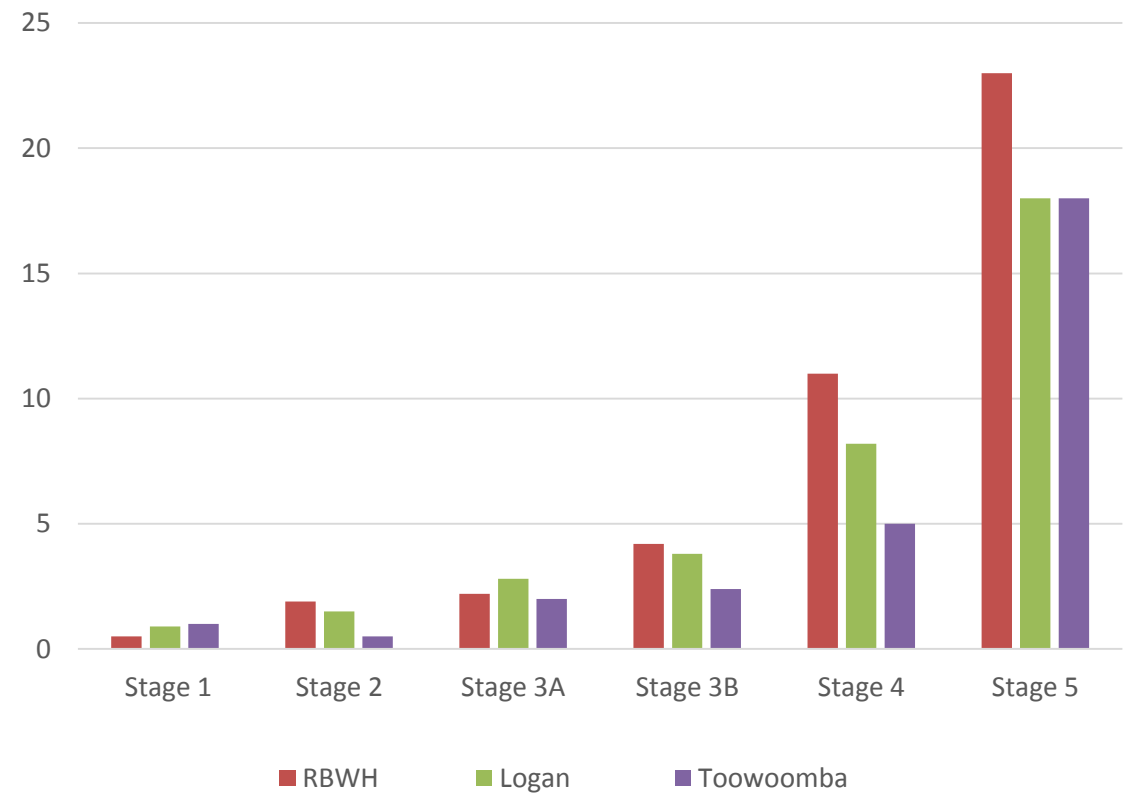
Independent predictors of RRT in CKD patients at time of consent, RBWH, Logan and Toowoomba combined, total patients=2,537, RRT =176

| Predictors | HR (95% CI) |
|---|---|
| Stage 4+5 at baseline | 20.1 (11.8-34.0) |
| ACR≥34 or PCR≥50 | 5.2 (2.5-10.9) |
| Genetic renal disease | 3.0 (1.5-6.0) |
| Diabetic nephropathy | 1.9 (1.1-3.2) |
| Male | 1.5 (1.11-2.1) |
| BMI 40+ | 0.55 (0.32-0.94) |
| Age≥70 yrs | 0.24 (0.16-0.36) |

Hazard Ratio (95% CI) * Log base 2 transformed
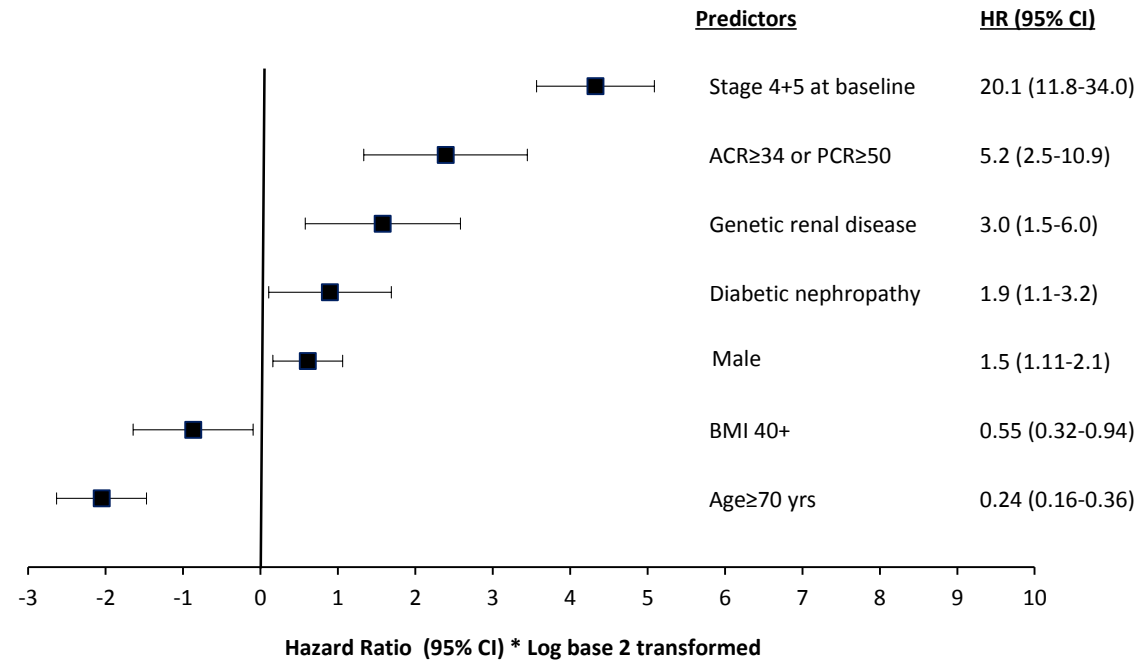
Referent groups: stages 4+5, vs lower; ACR>=34 or PCR>50 vs ACR<3.4, PCR<15; GRD vs GN; diabetic nephropathy vs GN; male vs female: BMI 40+ vs BMI<25; age 70+ vs <70 yr

# Independent predictors of death in CKD patients at time of consent,
## RBWH, Logan and Toowoomba combined, total patients 2,537, deaths=282

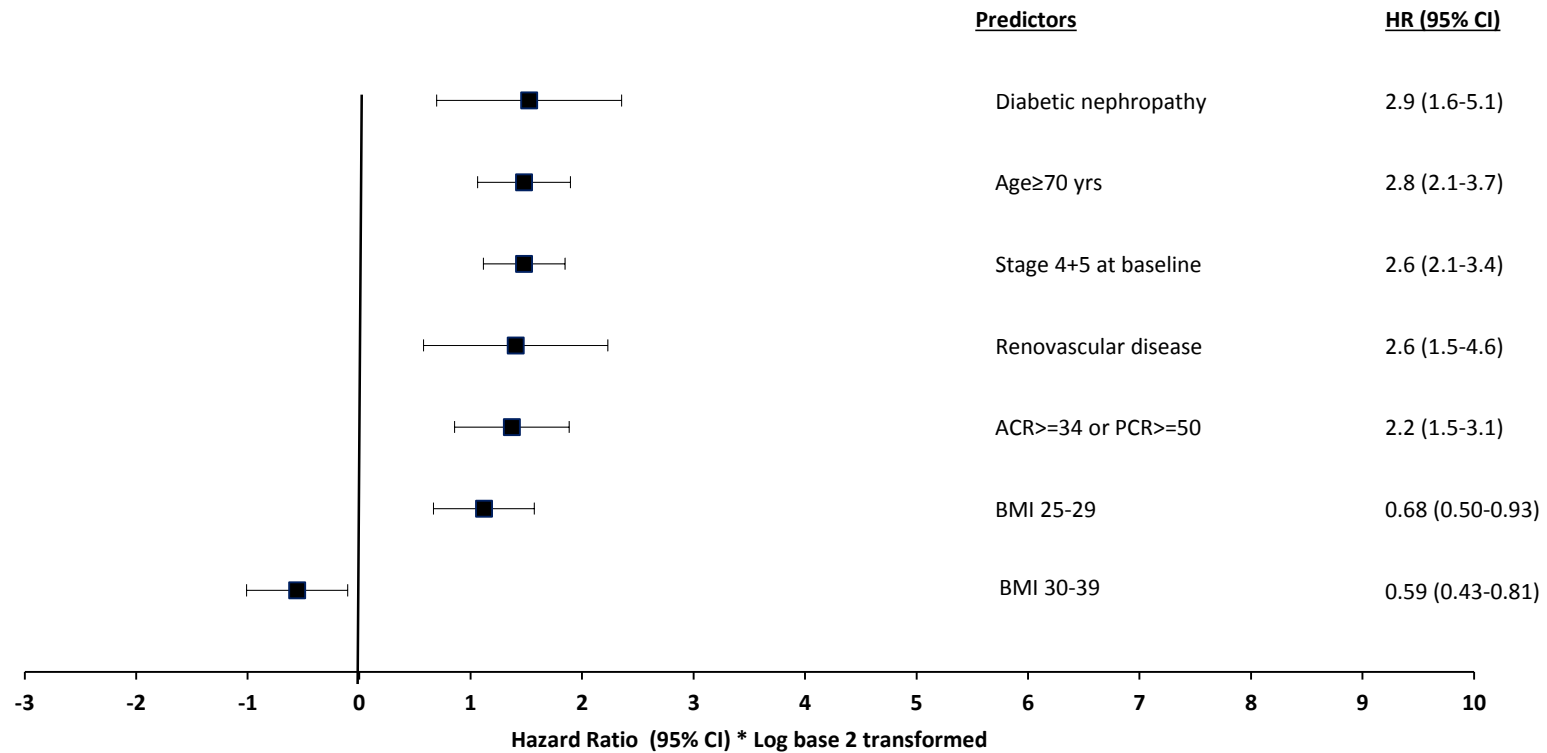| Predictors | HR (95% CI) |
|---|---|
| Diabetic nephropathy | 2.9 (1.6-5.1) |
| Age≥70 yrs | 2.8 (2.1-3.7) |
| Stage 4+5 at baseline | 2.6 (2.1-3.4) |
| Renovascular disease | 2.6 (1.5-4.6) |
| ACR>=34 or PCR>=50 | 2.2 (1.5-3.1) |
| BMI 25-29 | 0.68 (0.50-0.93) |
| BMI 30-39 | 0.59 (0.43-0.81) |

-3  -2  -1  0  1  2  3  4  5  6  7  8  9  10

**Hazard Ratio  (95% CI) * Log base 2 transformed**

Referent groups: diabetic nephropathy vs GN;  age 70+ vs <70 yr;  stages 4+5 vs lower; renovascular disease vs GN; ACR≥34 or PCR≥50 vs ACR<3.4 or PCR<15; BMI 25-29 vs lower; BMI 30-39 vs lower

# Participating studies in iNET-CKD.



EQUAL
(GB, DE, NL, IT, SW, PL)

4C Study
(AT, CZ, FR, DE, IT, LT, PL, PT, RS, CH, TR, GB)

Triple-A
(Scotland)

CanPREDDICT
(Canada)

2,546

412

1,450

PROVALID
(HU, PL, AT, NL GB)

4,067

C-STRIDE
(China)

CKD-REIN
(France)

CKiD
(US, CA)

896

3,200

737

BIS
(Germany)

2,069

3,600

CKD-JAC
(Japan)

2,975

CRIC
(United States)

5,439

GCKD
(Germany)

5,217

NRHP-Uruguay
(Uruguay)

13,300

CKD.QLD
(Australia)

6,700
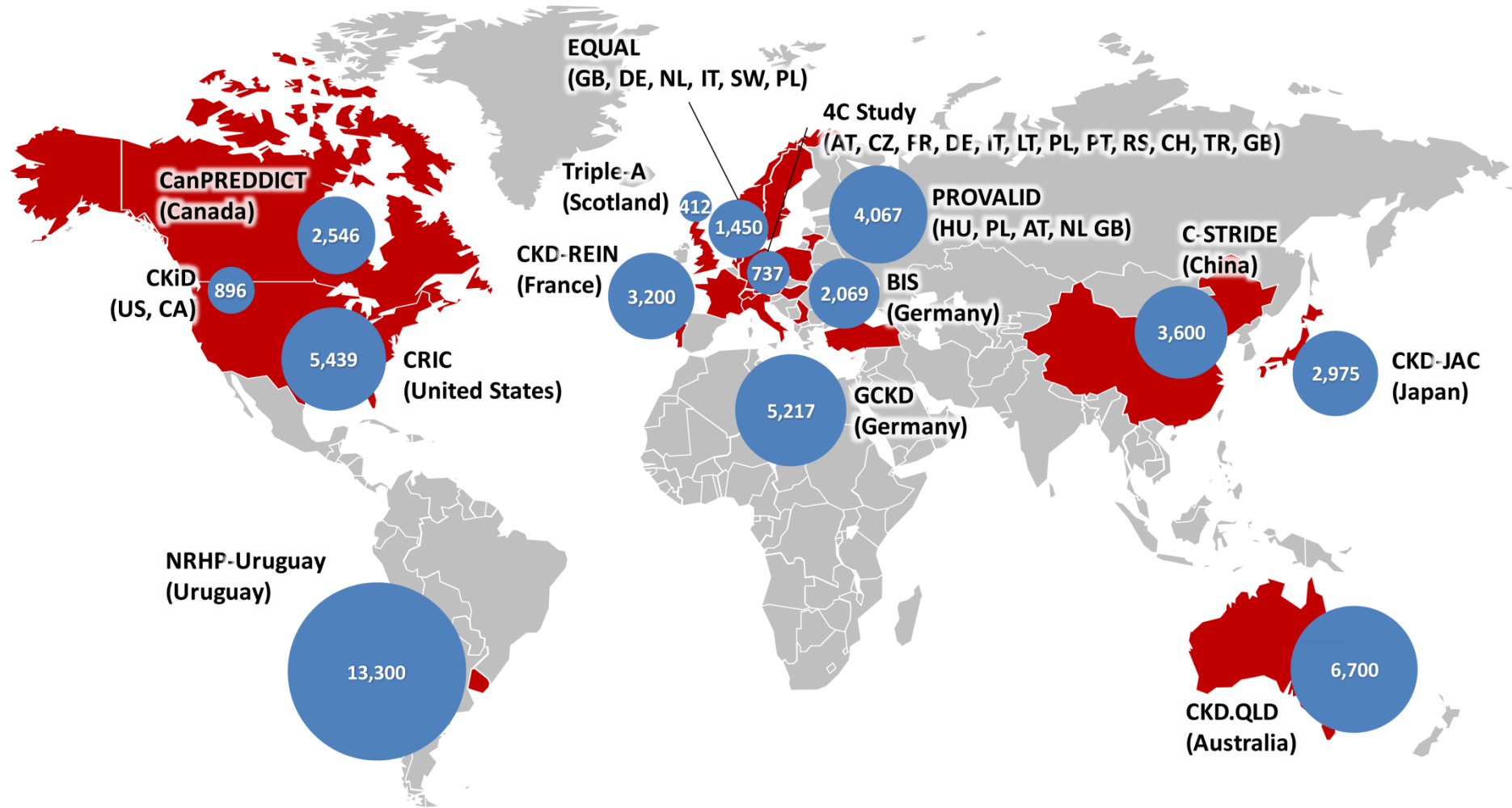
**ABBREVIATIONS:** AT, Austria; CA, Canada; CH, Switzerland; CZ, Czech Republic; DE, Germany; FR, France; GB, United Kingdom; HU, Hungary; IT, Italy; LT, Lithuania; NL, Netherlands; PL, Poland; PT, Portugal; RS, Serbia; SW, Sweden; TR, Turkey; US, United States;
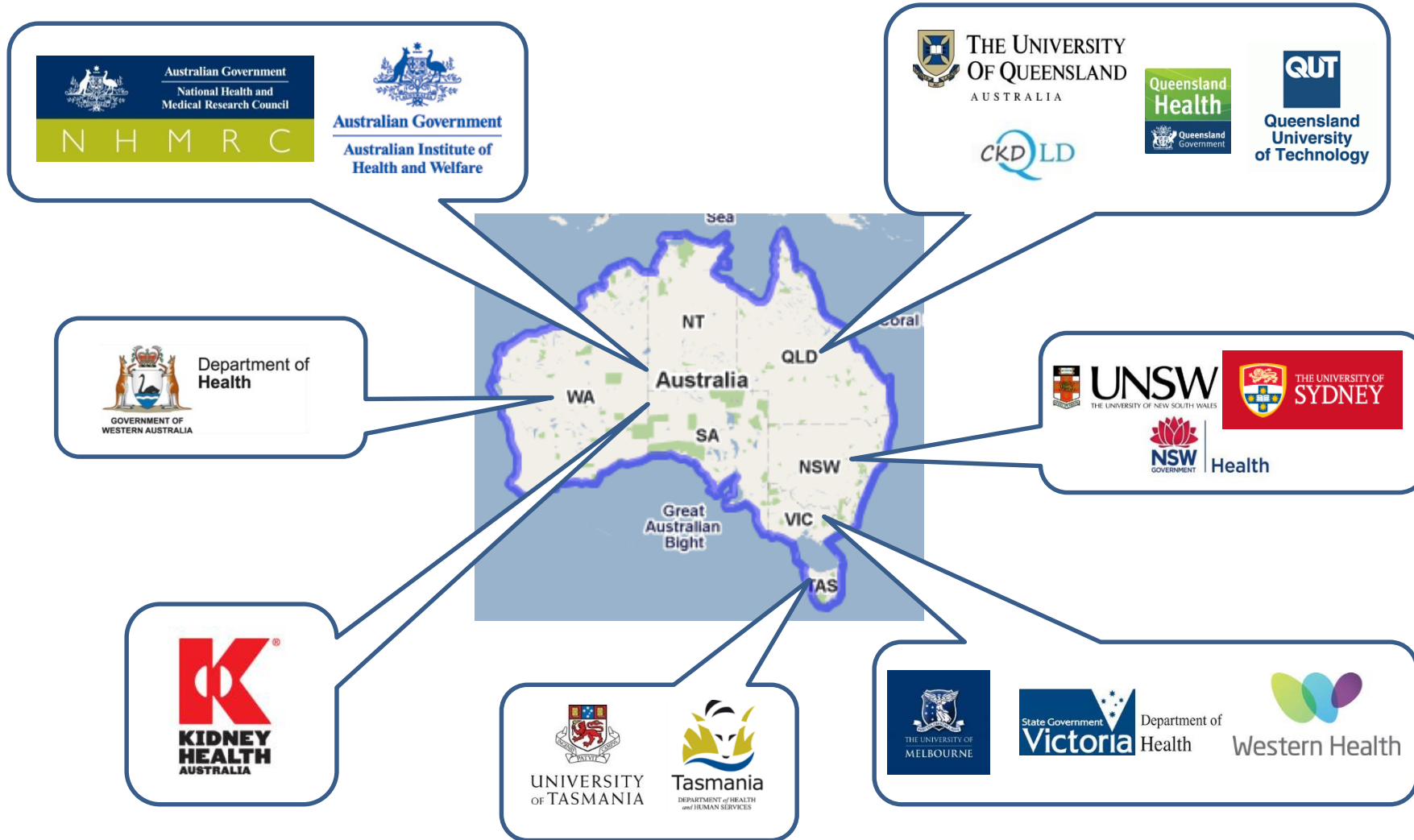
# 2015-2019

*Synopsis; August 2016*
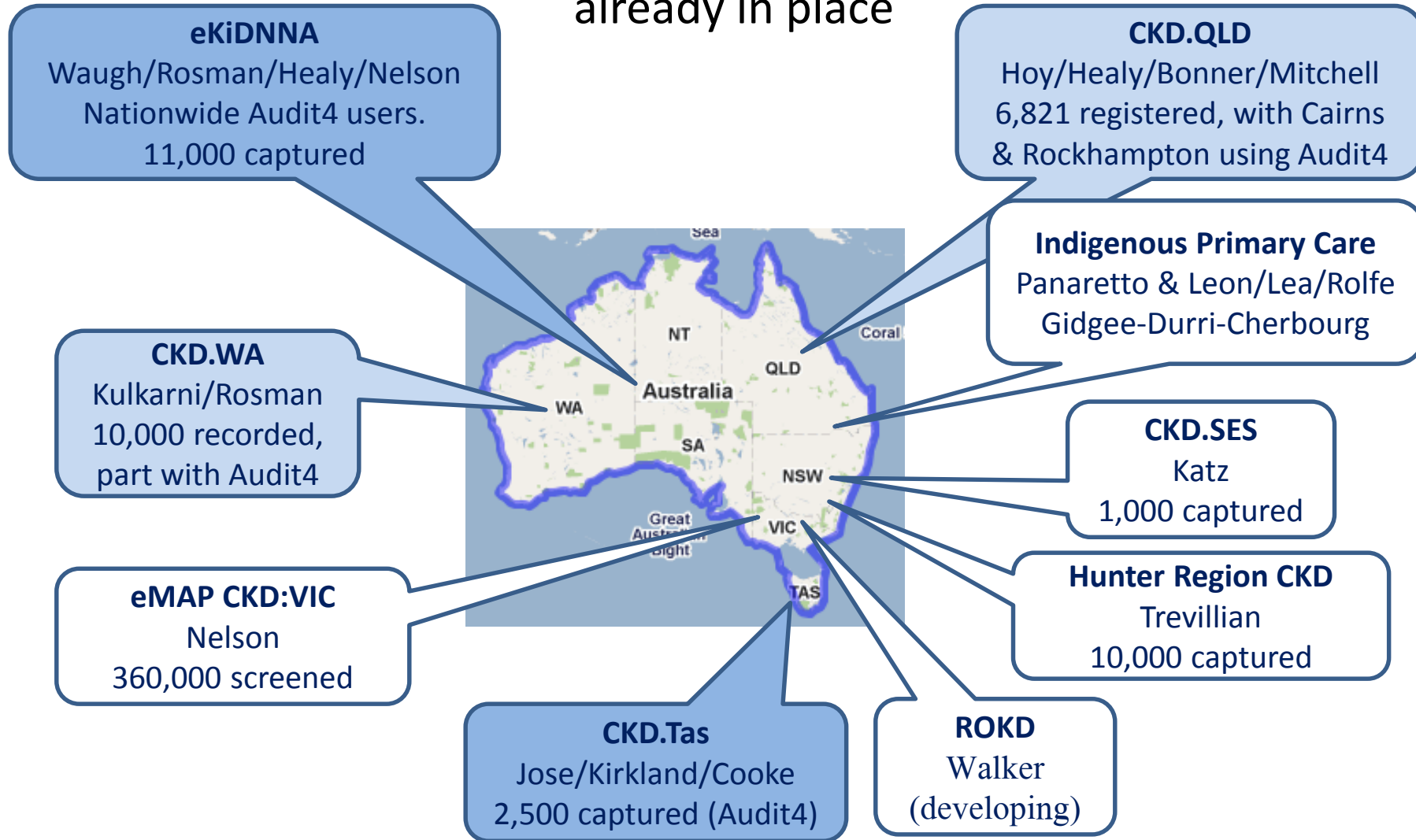
Lead institutional partners

# Chief Investigators



- Prof Wendy Hoy, CCD, University of Qld
- Dr Helen Healy, MNHHS, Queensland Health
- Prof Luke Connelly, HABS, University of Qld
- Prof Geoff Mitchell, DGP, University of Qld
- A/Prof Katie Panaretto, James Cook University
- Prof Zoltan Endre, University of NSW
- Prof Jeff Coombes, HMNS, University of Qld
- A/Prof Glenda Gobe, TRI, University of Qld
- Prof Ann Bonner, SON, Qld University of Technology
- Prof Robert Fassett, HMNS, University of Qld

# National CKD Surveillance Network, using data and systems already in place

**eKiDNNA**
Waugh/Rosman/Healy/Nelson
Nationwide Audit4 users.
11,000 captured

**CKD.QLD**
Hoy/Healy/Bonner/Mitchell
6,821 registered, with Cairns
& Rockhampton using Audit4

**Indigenous Primary Care**
Panaretto & Leon/Lea/Rolfe
Gidgee-Durri-Cherbourg

**CKD.WA**
Kulkarni/Rosman
10,000 recorded,
part with Audit4

**CKD.SES**
Katz
1,000 captured

**eMAP CKD:VIC**
Nelson
360,000 screened

**Hunter Region CKD**
Trevillian
10,000 captured

**CKD.Tas**
Jose/Kirkland/Cooke
2,500 captured (Audit4)

**ROKD**
Walker
(developing)

Call for collaborations.

- With ANZDATA
- With other organisations
- With pharma and biotechnical companies
- With investigator initiated projects

Any queries, please contact the Centre for Chronic Disease:
Chronic Kidney Disease Centre for Research Excellence

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CKD.CRE Manager: Anne Cameron (Salisbury) @ a.salisbury1@uq.edu.au

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