

# Data for equity in transplant access and outcomes

Angela Webster

[angela.webster@sydney.edu.au](mailto:angela.webster@sydney.edu.au)

Collaborative  
Centre for  
Organ   
Donation  
Evidence

ANZSN Christchurch 2023





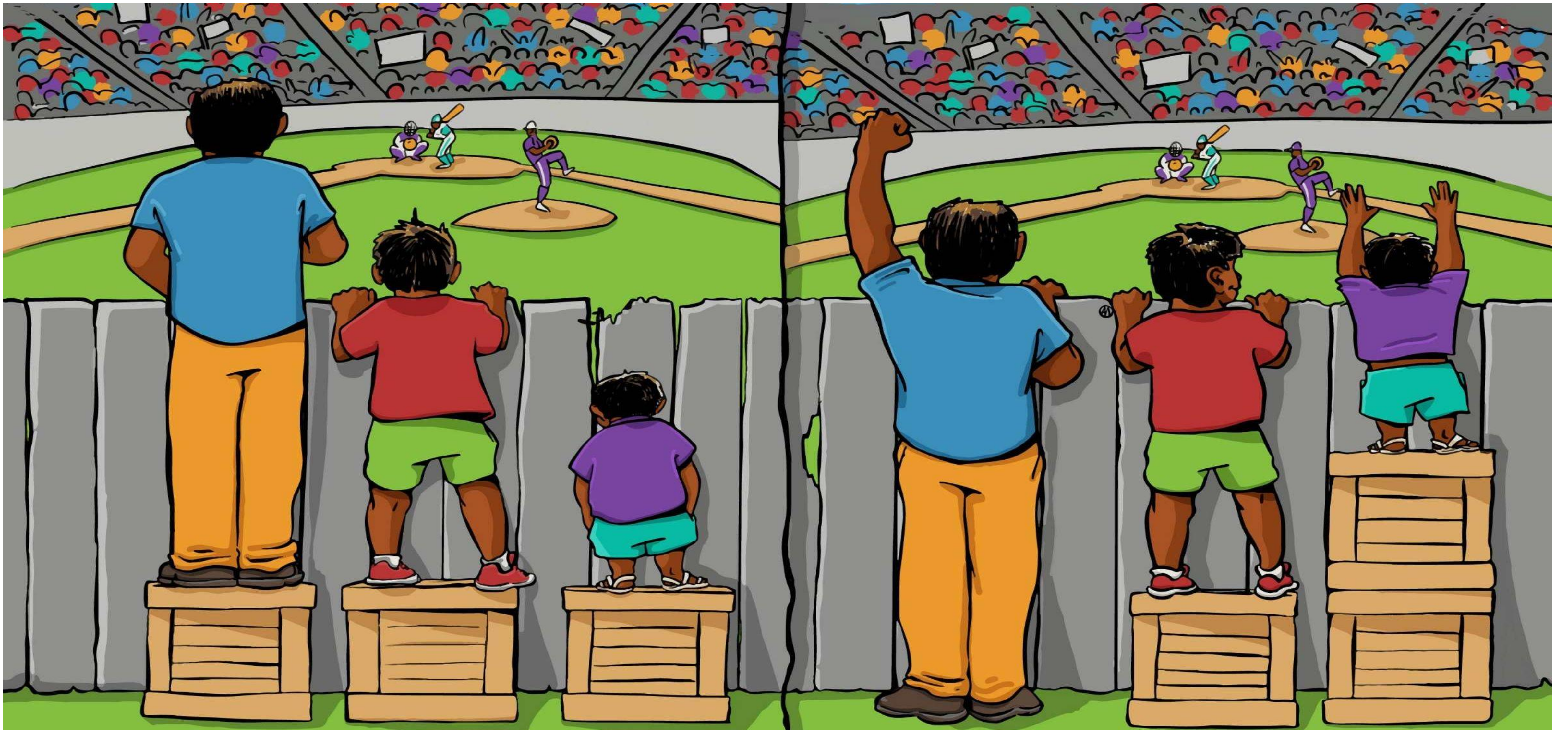
**Tēnā koutou, tēnā koutou,  
tēnā koutou katoa**

Collaborative  
Centre for  
Organ ●  
Donation  
Evidence

# Outline of talk - lots of NZ data

- Equity and dis/advantage
- Data integration as an art
- Aotearoa data to shape service design and delivery
  
- Bias in health care – Australia
  - Data to challenge what we think we know





**EQUALITY**

**EQUITY**



# Care Disparities



INDIVIDUAL RELATED	
Lifestyle	Cultural beliefs
Socioeconomic status	
Race and ethnicity	
Psychological factors	Age
Mobility and geographical factors	
Education	Gender/Sex
Migration	Family support
Physiology and comorbidities	
Familial and genetic factors	

SYSTEM RELATED	
Monitoring and reporting	
Reimbursement	Spatial barriers
Treatment delays	Survivorship
Screening programs	
Clinical trial access	Equipment
Optimal treatment	Staff quality
Palliative and supportive care	
Multidisciplinary working	
Evidence-based medicine	

**Intersection  
Interaction  
Multiple jeopardy**

**Its never one issue, it's  
"stackable" dis/advantage**

# Integrating data to reveal and address disparity in care



# Integrating data to reveal and address disparity in care

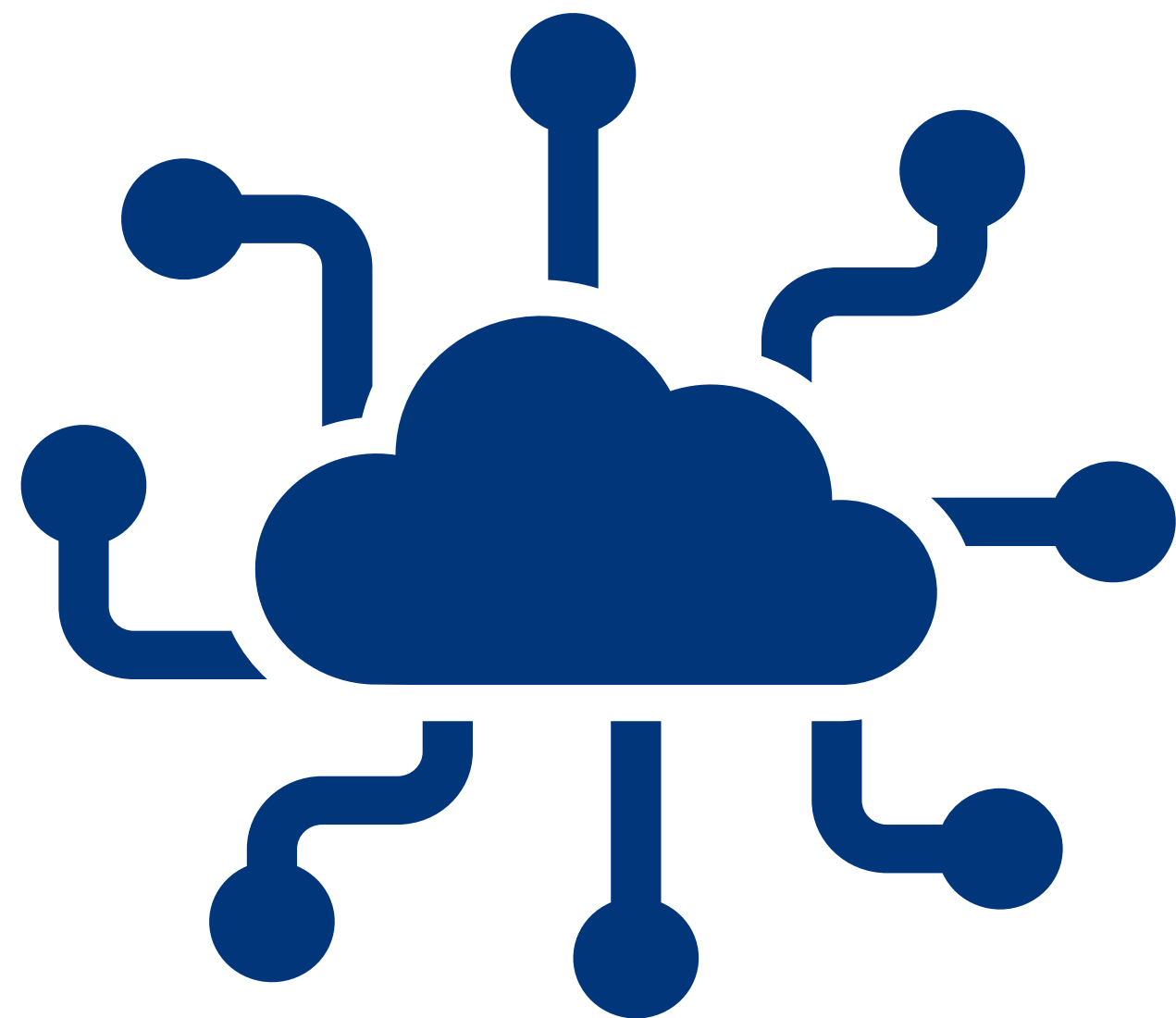
- Caution in an era of “Big Data”
- Spectrum from simple linkage to very complex integration
- Applied methods



# Integrating data to reveal and address disparity in care

- Caution in an era of “Big Data”
- Spectrum from simple linkage to very complex integration
- Applied methods

EXPECTATION



42945 ASSET ANZDATA Calciphylaxis	
42945 ASSET ANZDATA CancerInDonor	
42945 ASSET ANZDATA CancerNonSkinTumours	cas2161
42945 ASSET ANZDATA CancerSkinTumours	dim_form_pack_subsidy
42945 ASSET ANZDATA CentreHistory	ESKD_nhis
42945 ASSET ANZDATA CentreTransfers	LKD_nhis
42945 ASSET ANZDATA Comorbidities	mos4089
42945 ASSET ANZDATA ComorbiditiesOther	nap1022_2006_2007
42945 ASSET ANZDATA CourseOfTreatments	nap1022_2007_2008
42945 ASSET ANZDATA Dialysis	nap1022_2008_2009
42945 ASSET ANZDATA Patients	nap1022_2009_2010
42945 ASSET ANZDATA Transplant	nap1022_2010_2011
42945 ASSET ANZDATA TransplantCYADrug	nap1022_2011_2012
42945 ASSET ANZDATA TransplantRejectionEpisodes	nap1022_2012_2013
42945 ASSET ANZDATA TransplantRejectionTreatments	nap1022_2013_2014
42945 ASSET ANZDATA TransplantSerumCreatinine	nap1022_2014_2015
42945 ASSET ANZDATA TransplantTherapies	nap1022_2015_2016
42945 ASSET ANZDATA TransplantWeight	nap1022_2016_2017
42945 ASSET LKDPatients	nap1022_2017_2018
BloodService_data	nap1022_2018_2019
MoH_cas2161	nap1022_2019_2020
MoH_dim_form_pack_subsidy	nap1022_2020_2021
MoH_ESKD_nhis	phh1030
MoH_LKD_nhis	pus11131
MoH_mos4089	cas2161
MoH_phh1030	
MoH_pus11131	

REALITY



# Integrating data needs care

- Starting point always has to be patient-centric
  - Better service design or delivery
- Design phase of study critical to meet the “So what?” test
  - Regularly re-visiting the nub of the rationale
- Mixed methodology as a starting point
  - Patient and clinician perspectives
  - Behaviour change



# Integrating data can transform care

- Starting point always has to be patient-centric
  - Better service design or delivery
- Design phase of study critical to meet the “So what?” test
  - Regularly re-visiting the nub of the rationale
- Mixed methodology as a starting point
- ***This is the precision medicine of health services research***



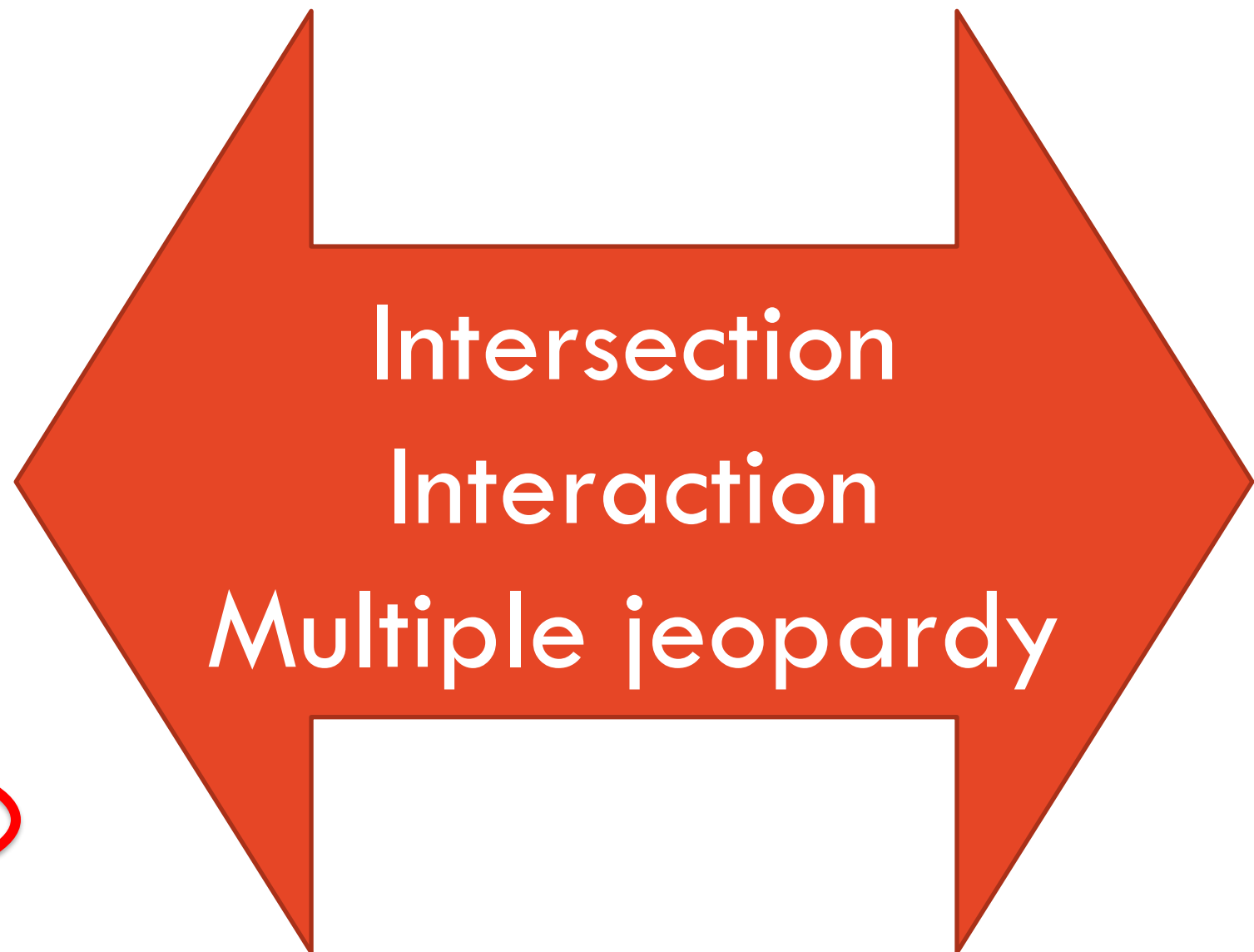


# Care Disparities



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Multidisciplinary working	
Evidence-based medicine	



Its never one issue, it's "stackable" dis/advantage

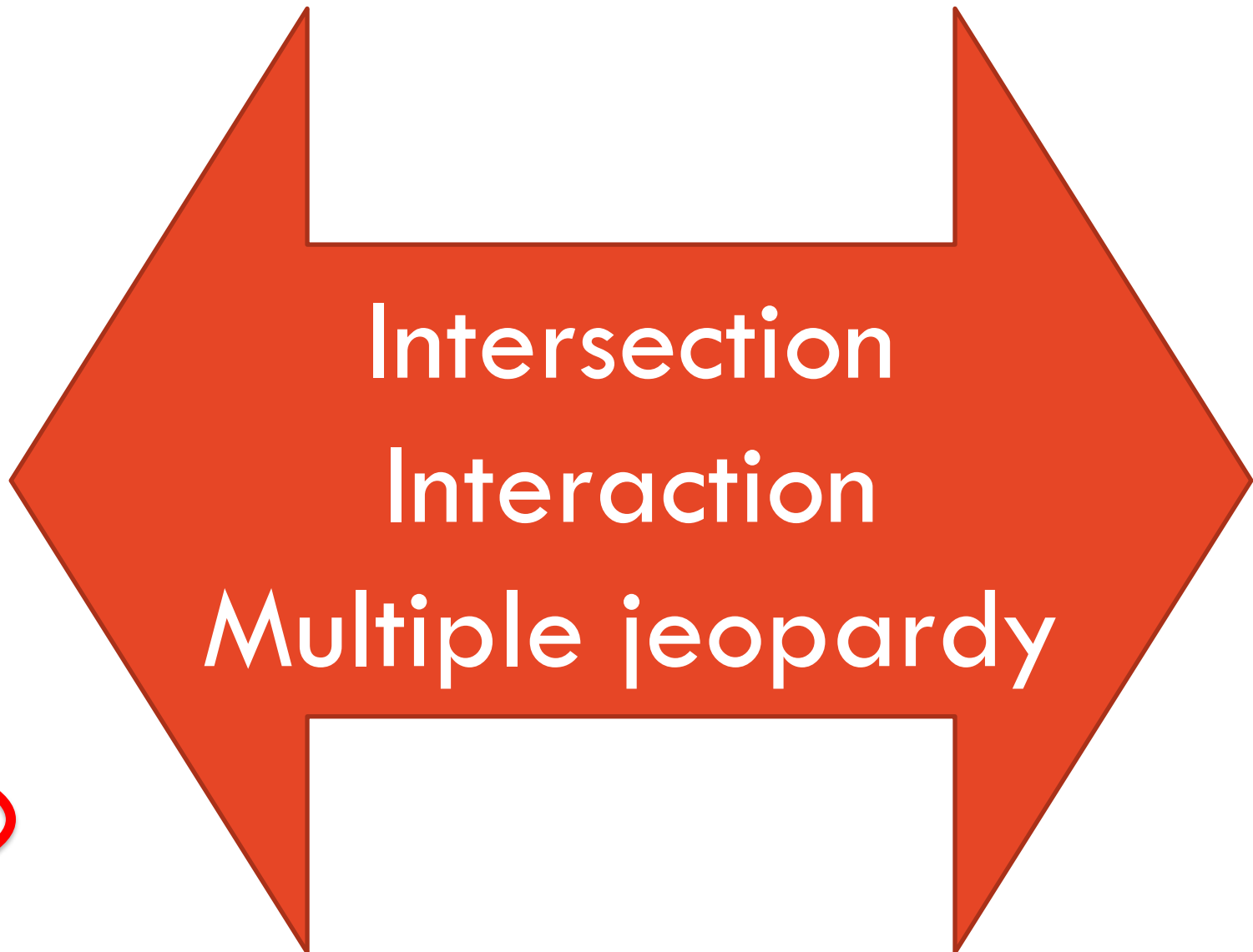


# Care Disparities



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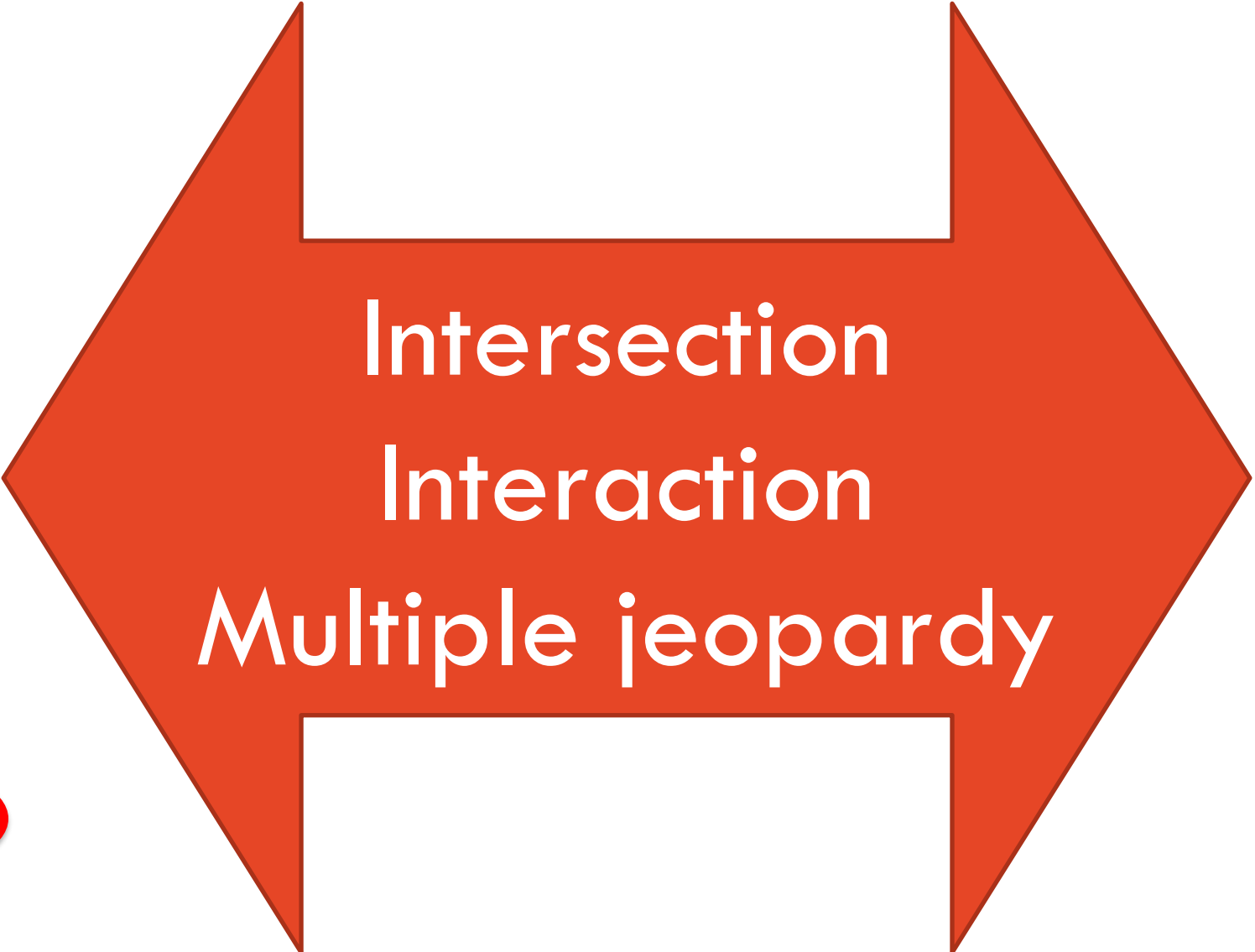


# Care Disparities



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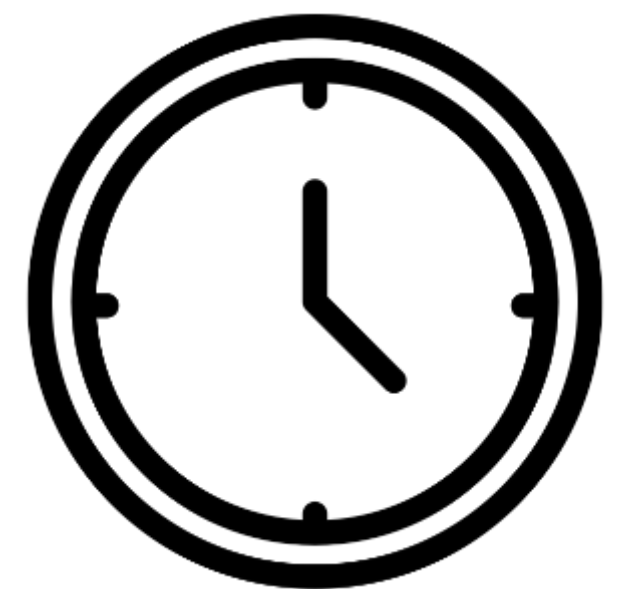
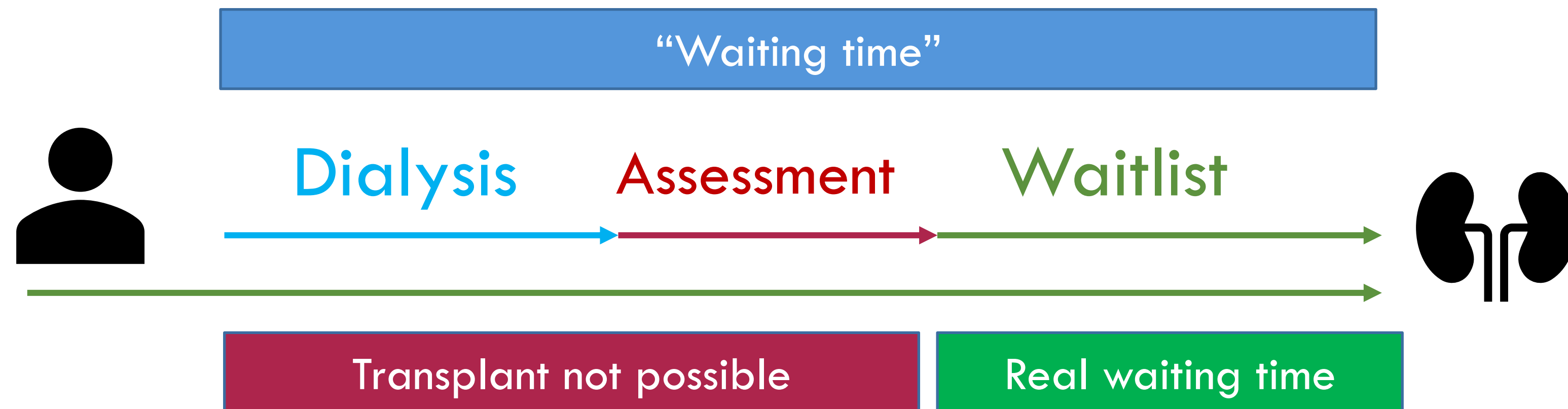
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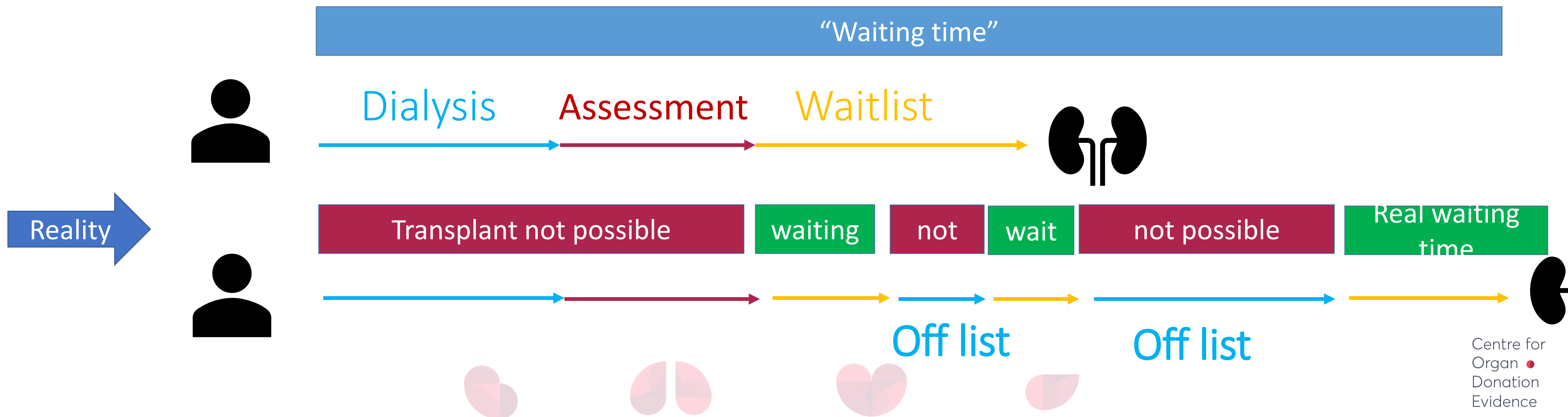
# Conceptualising equity of access

- Access to the waiting list
- Equity while waiting
- Achieving transplantation, post transplant outcomes
- When does waiting time to start? (CKD, dialysis initiation, or listing?)



# What is the real lived experience of waiting?

- Individuals may cycle on- and off-waitlist (once or several times)
  - competing health events
- Individual experience on kidney waitlist not described
  - *No initiatives to ensure fair waiting – immortal time bias*





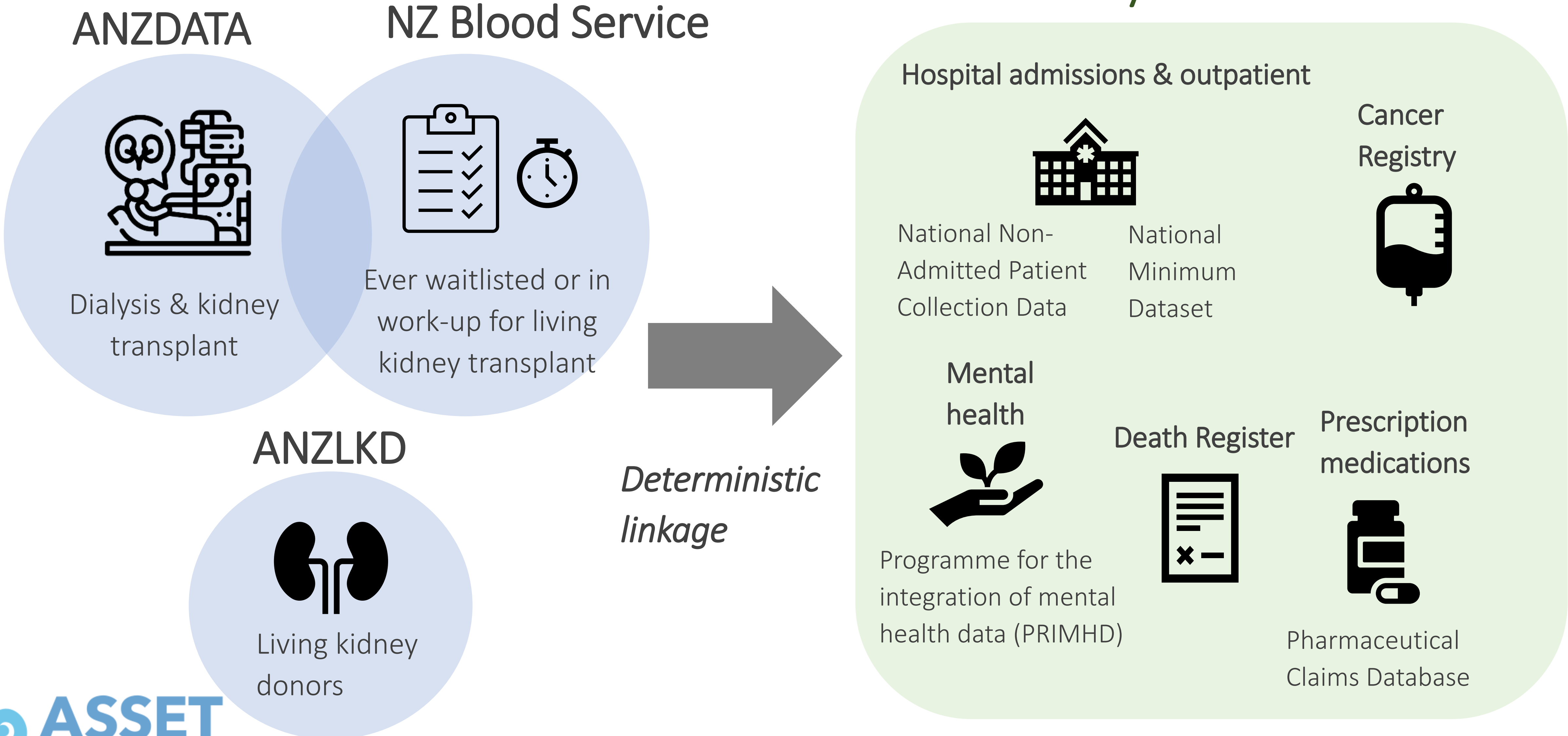
ASSET has brought together data for New Zealanders with kidney disease, to investigate equity in access to best health outcomes, initially with a focus on kidney transplantation. These data include health and administrative data, which is anonymised.



# ASSET linked data platform

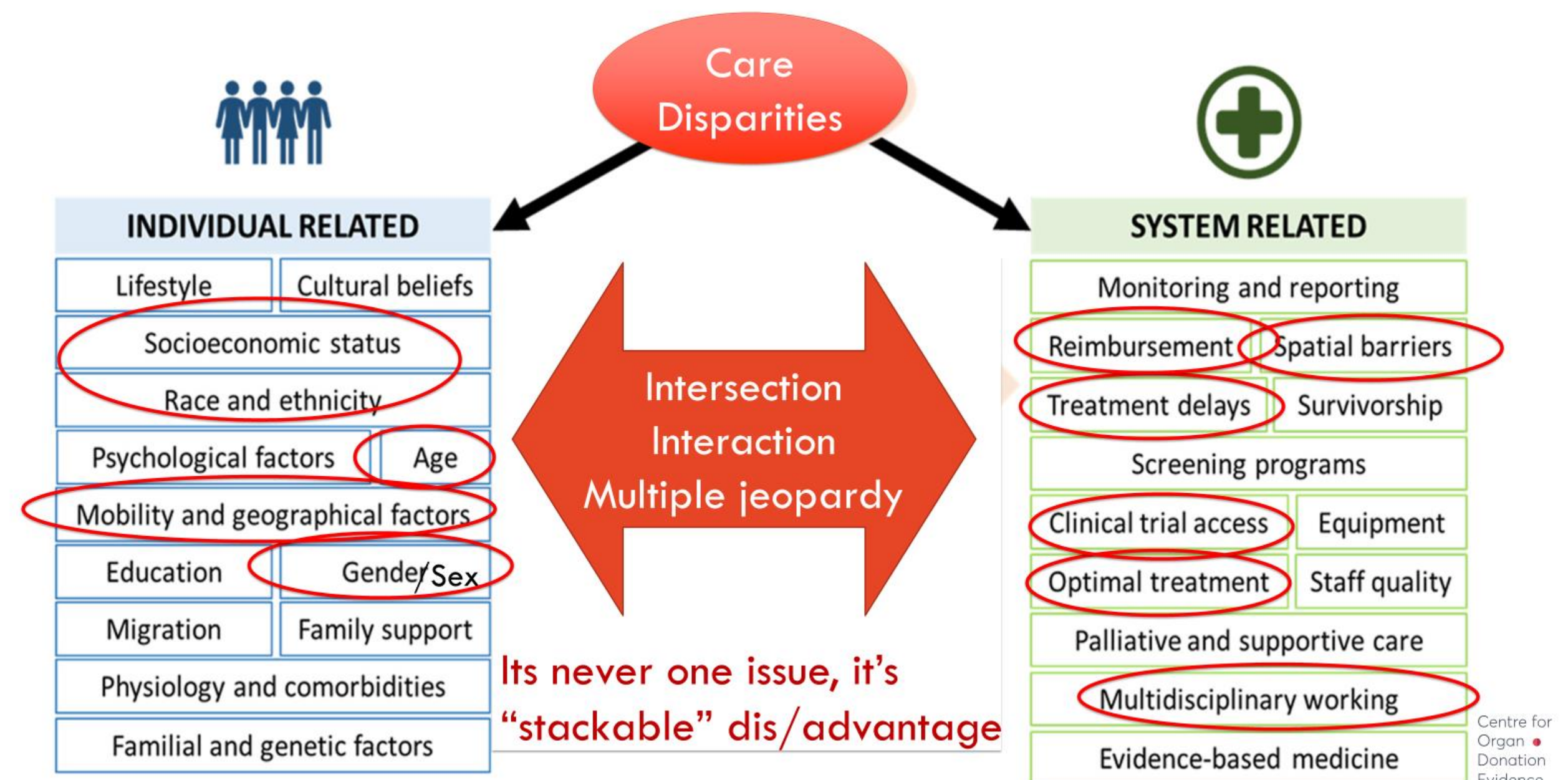
Study cohort

Ministry of Health data



# ANZSN Key Performance Indicator: transplanted or “active” on the wait list within 6 months of ESKD

- Understanding the distribution of people with ESKD in Aotearoa will help service planning
- Health services might need adaptation or intensifying to meet need



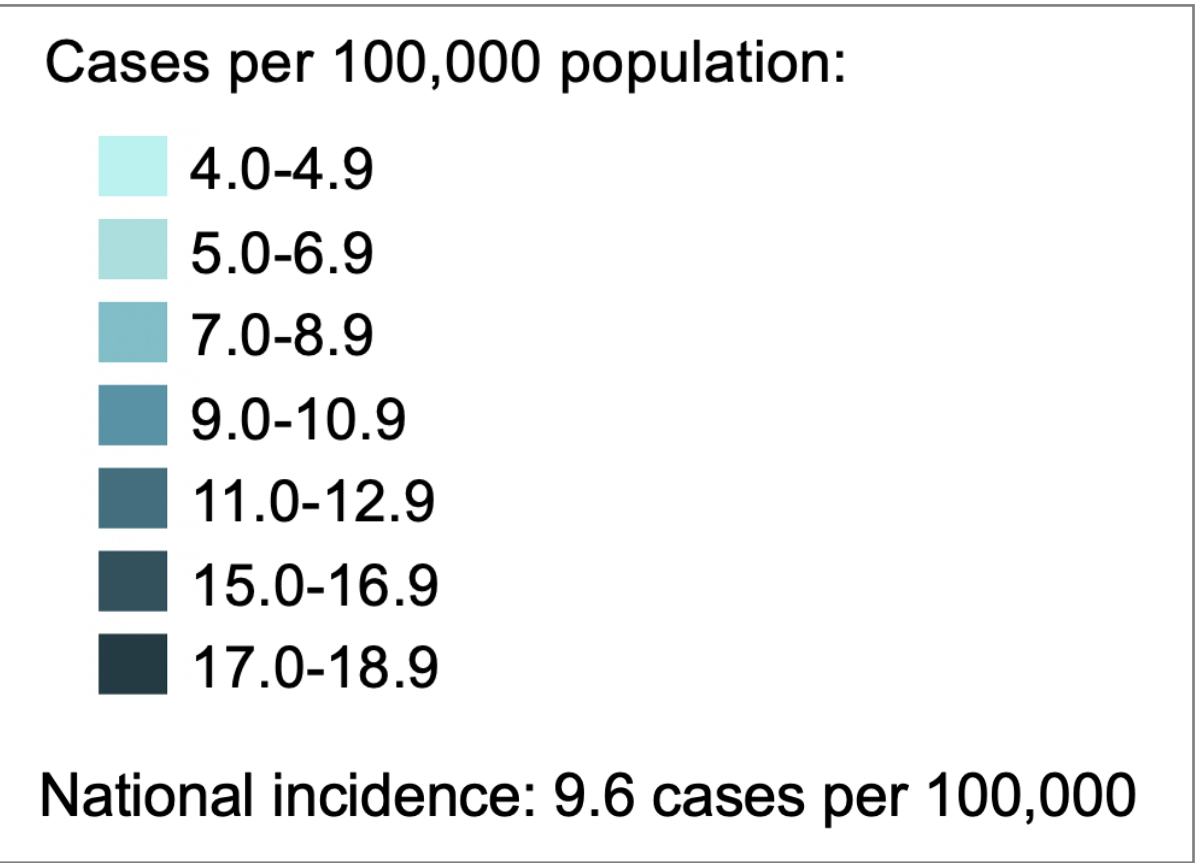
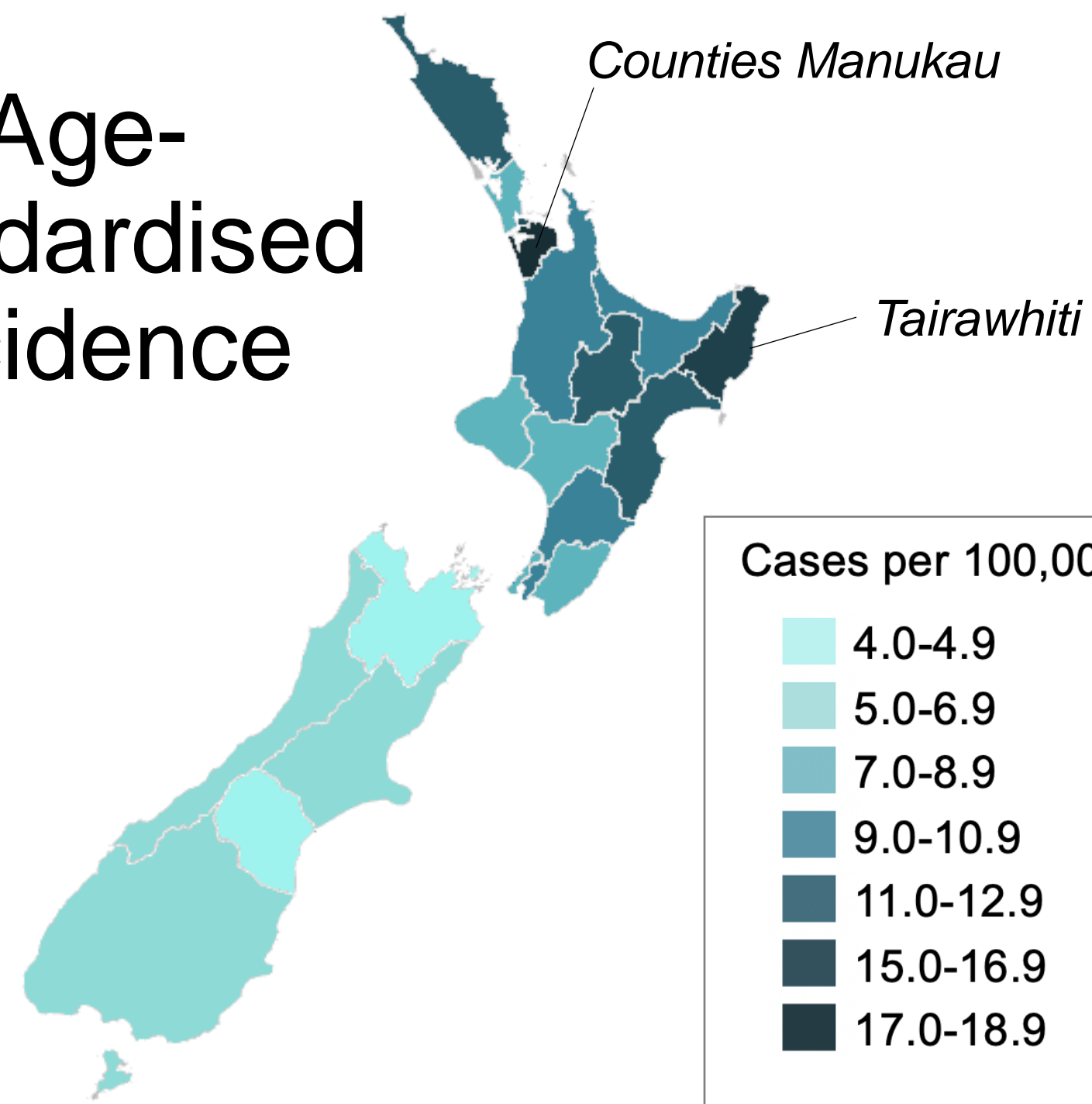
# Geographic variations in the epidemiology of kidney failure in New Zealand, 2006-2019

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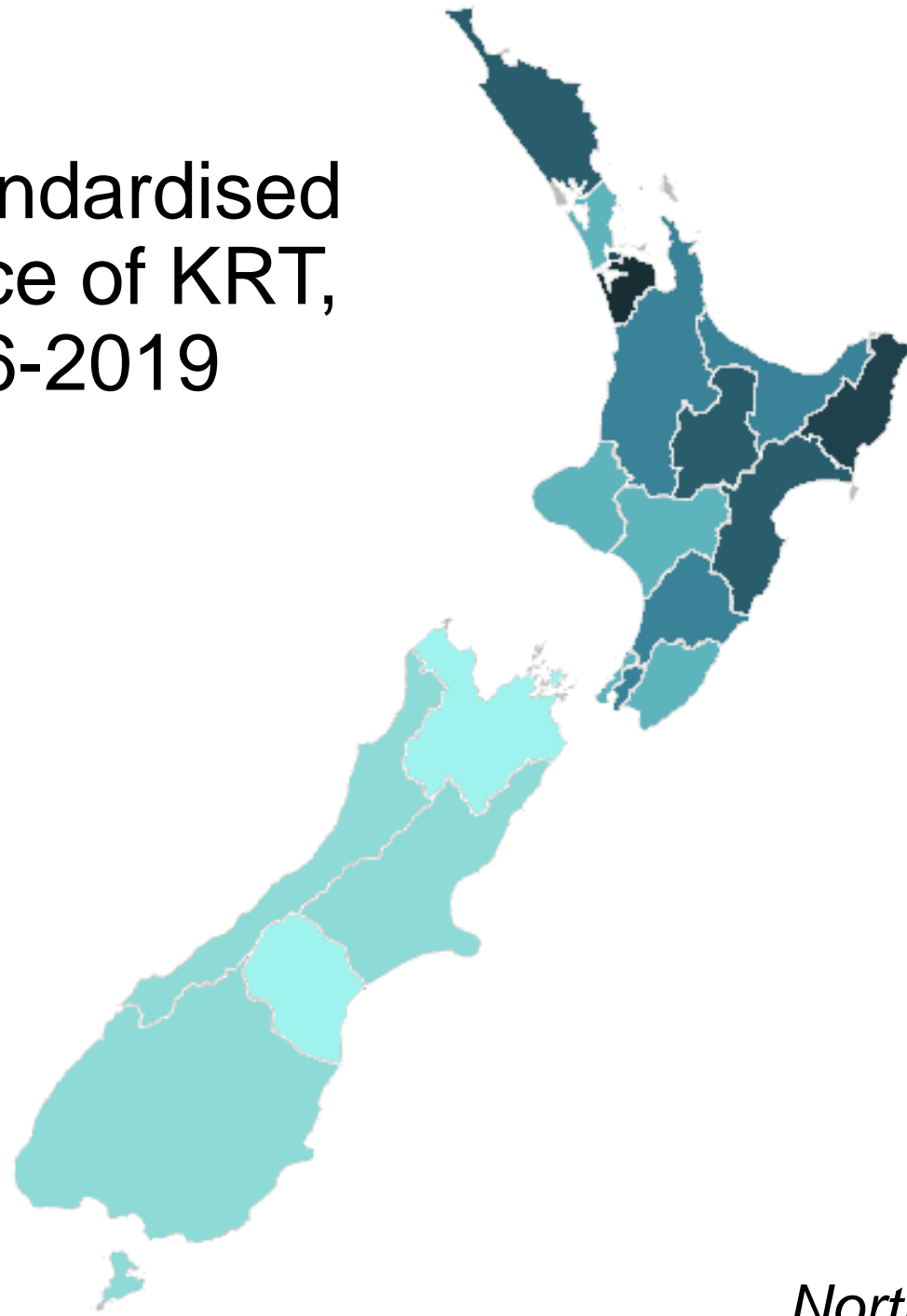
- Johanna Birrell
- ASSET's 1<sup>st</sup> research degree student



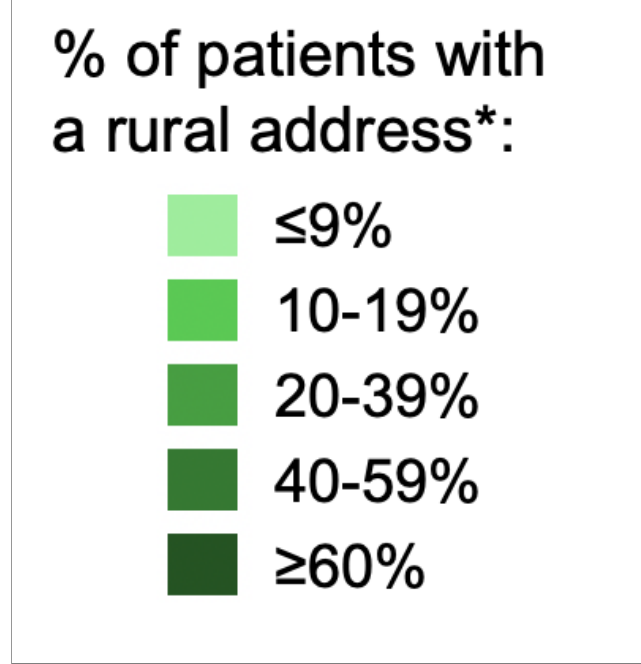
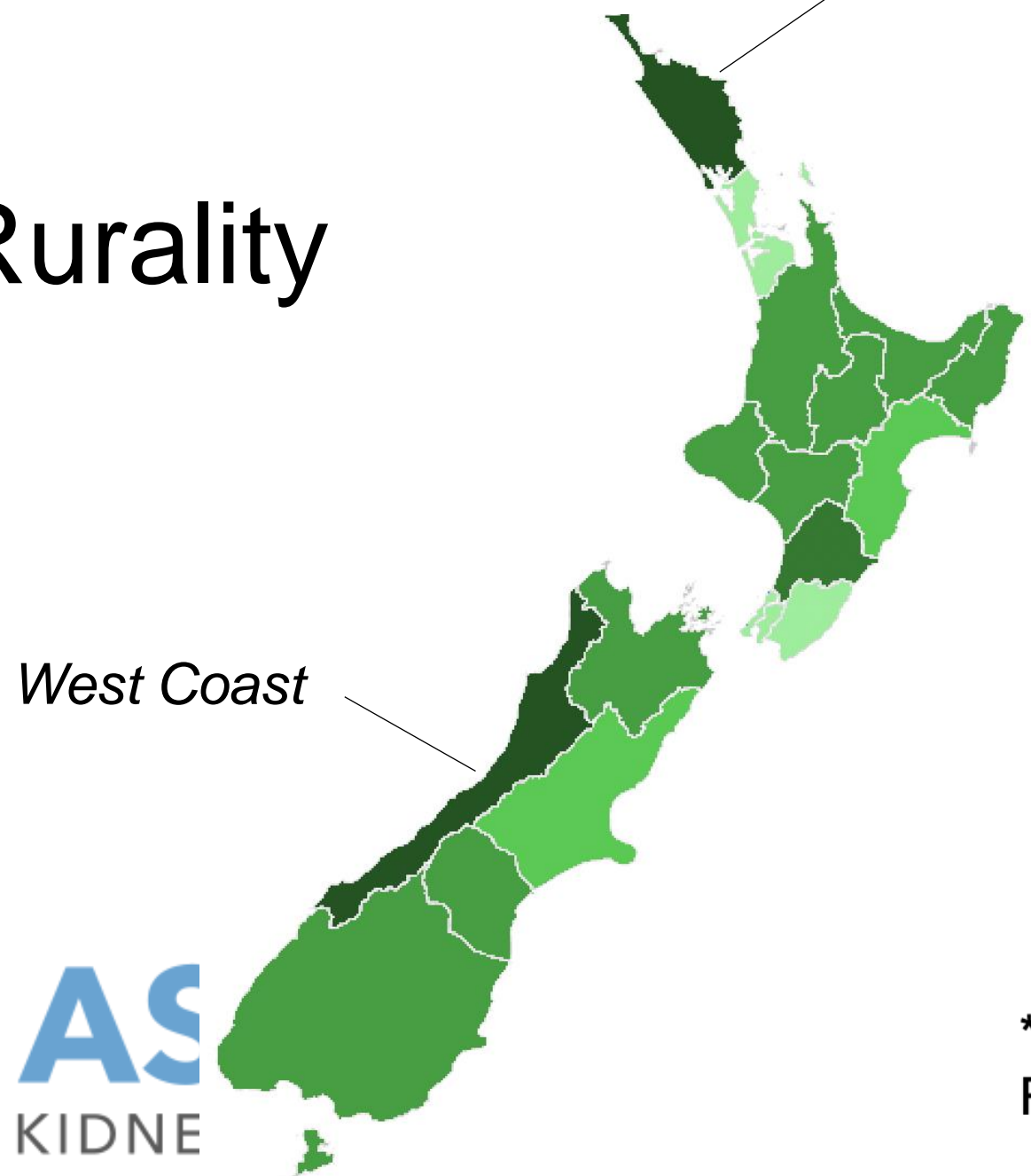
# Age-standardised incidence



Age-standardised  
incidence of KRT,  
2006-2019

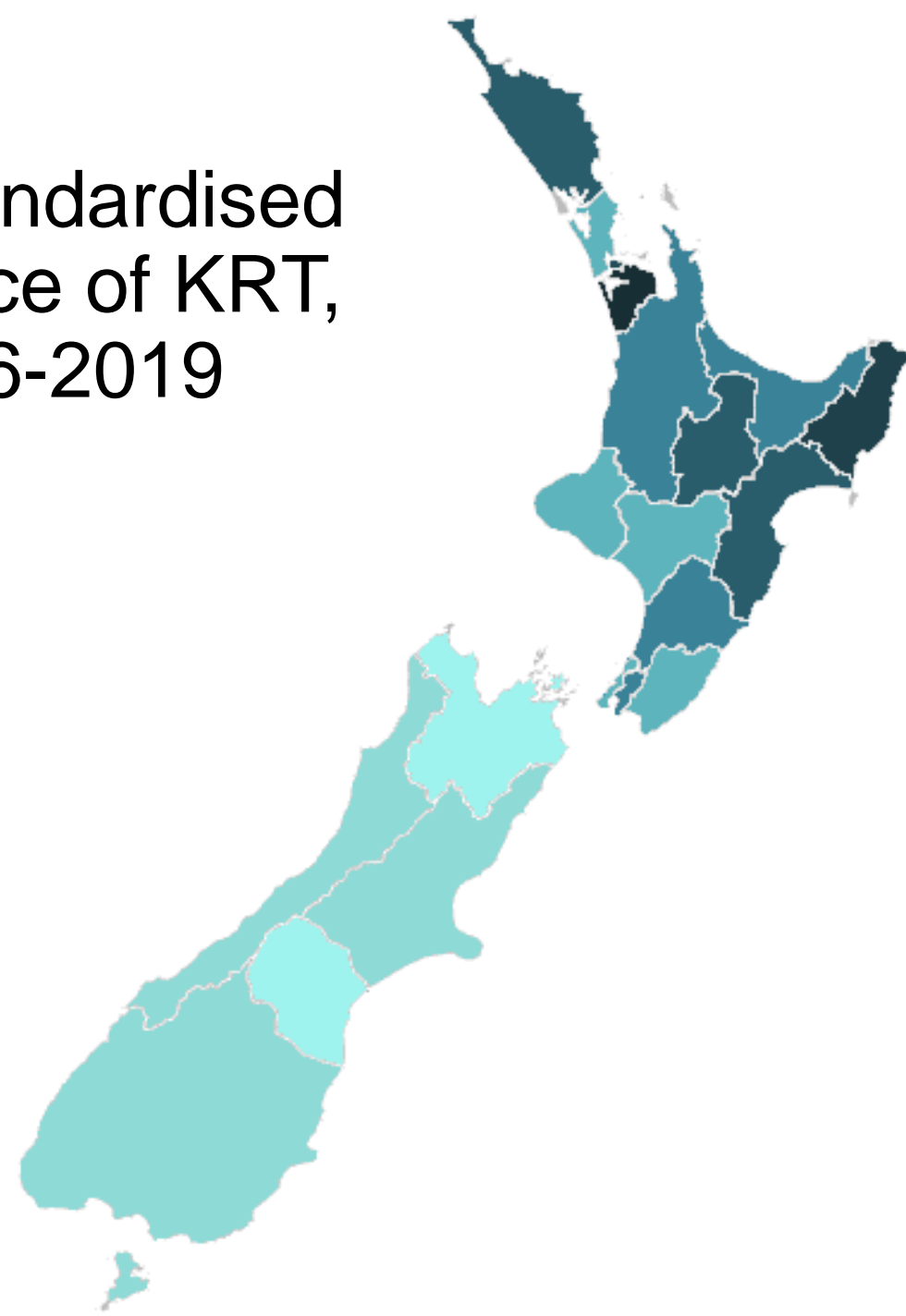


Rurality

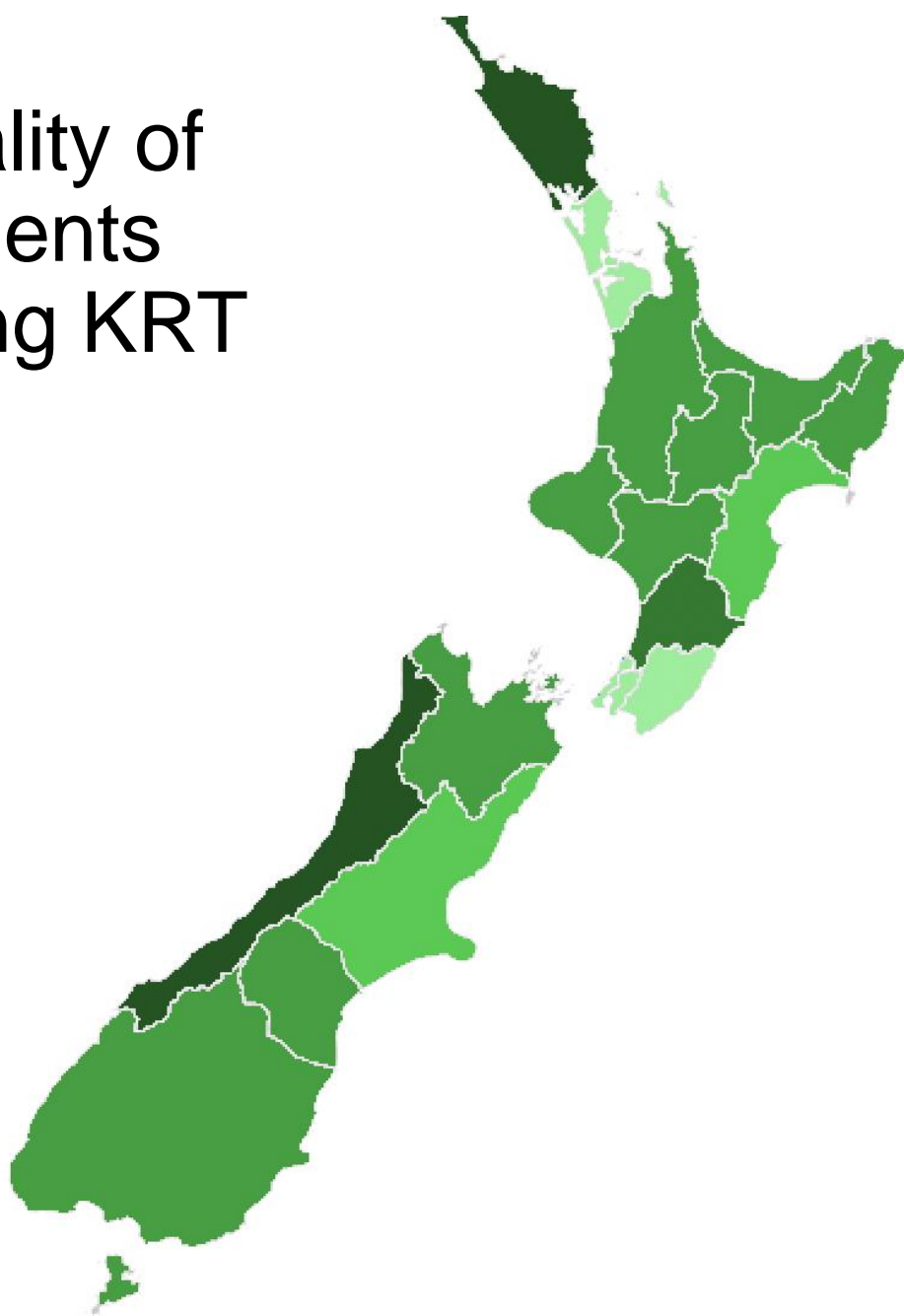


\*Geographic Classification for Health R1-R3 area, based on domicile

Age-standardised incidence of KRT, 2006-2019



Rurality of patients starting KRT

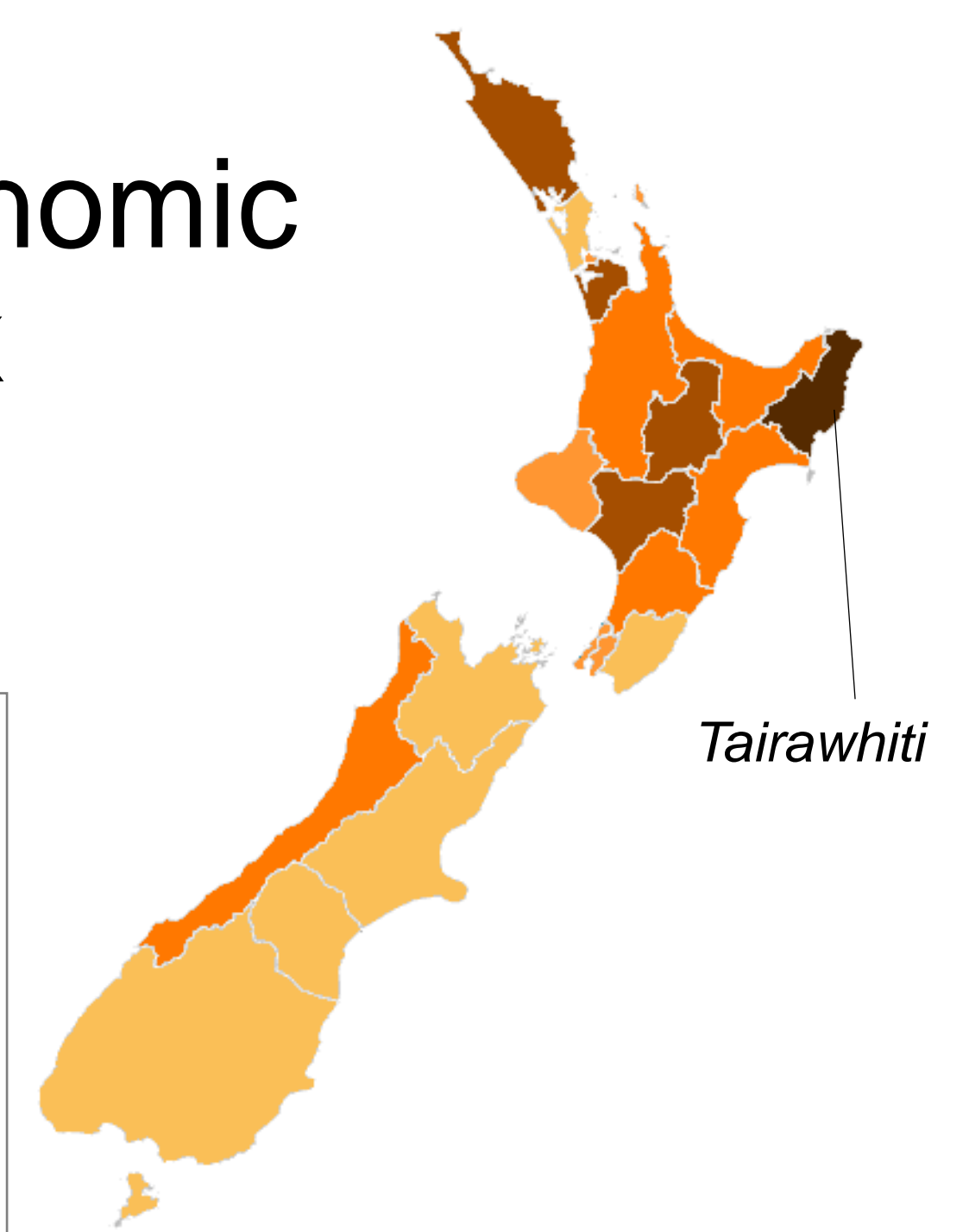


## Socio-economic index

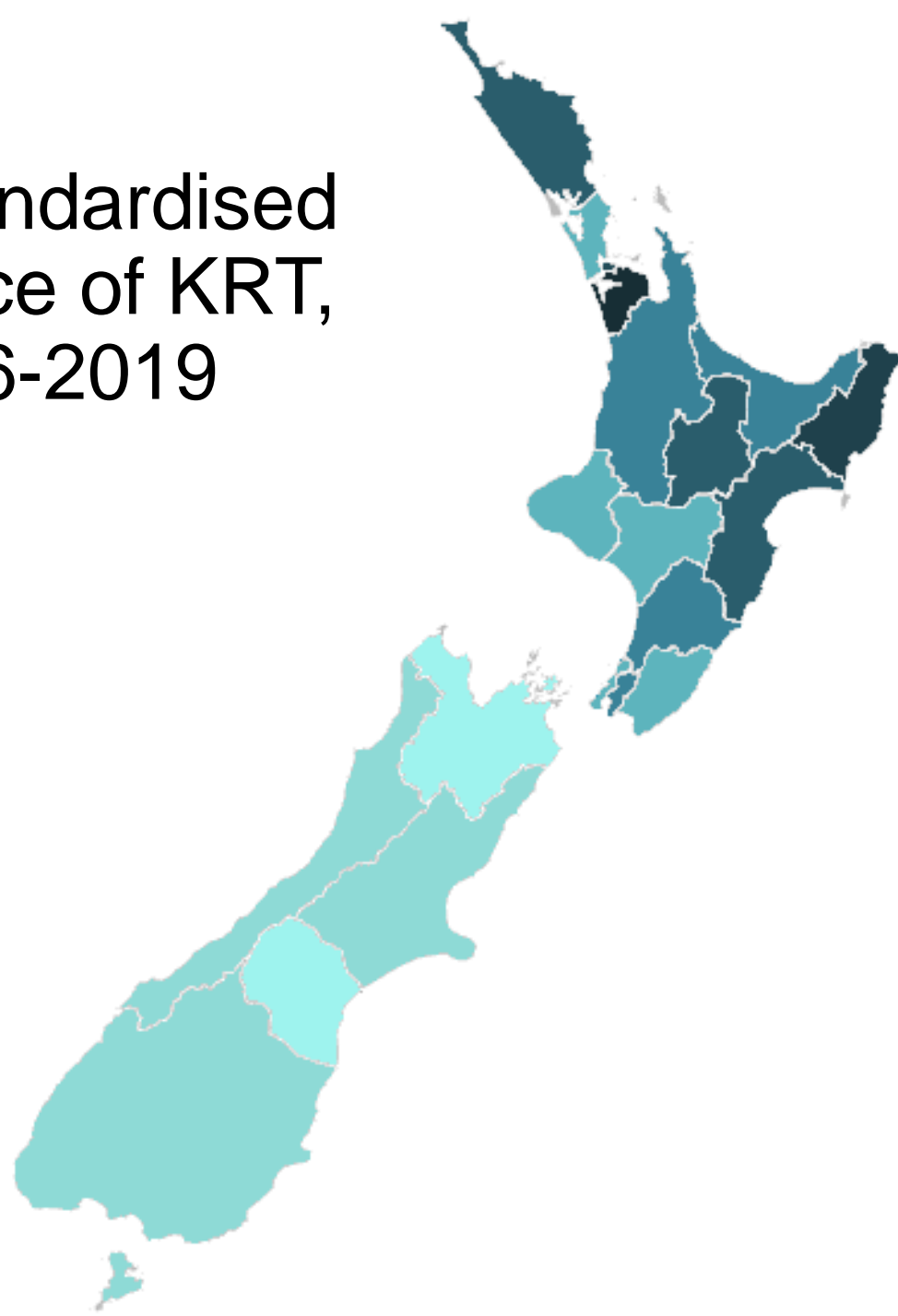
% of patients living in the most disadvantaged socioeconomic quintile\*:

- ≤19%
- 20-39%
- 40-59%
- 60-79%
- ≥80%

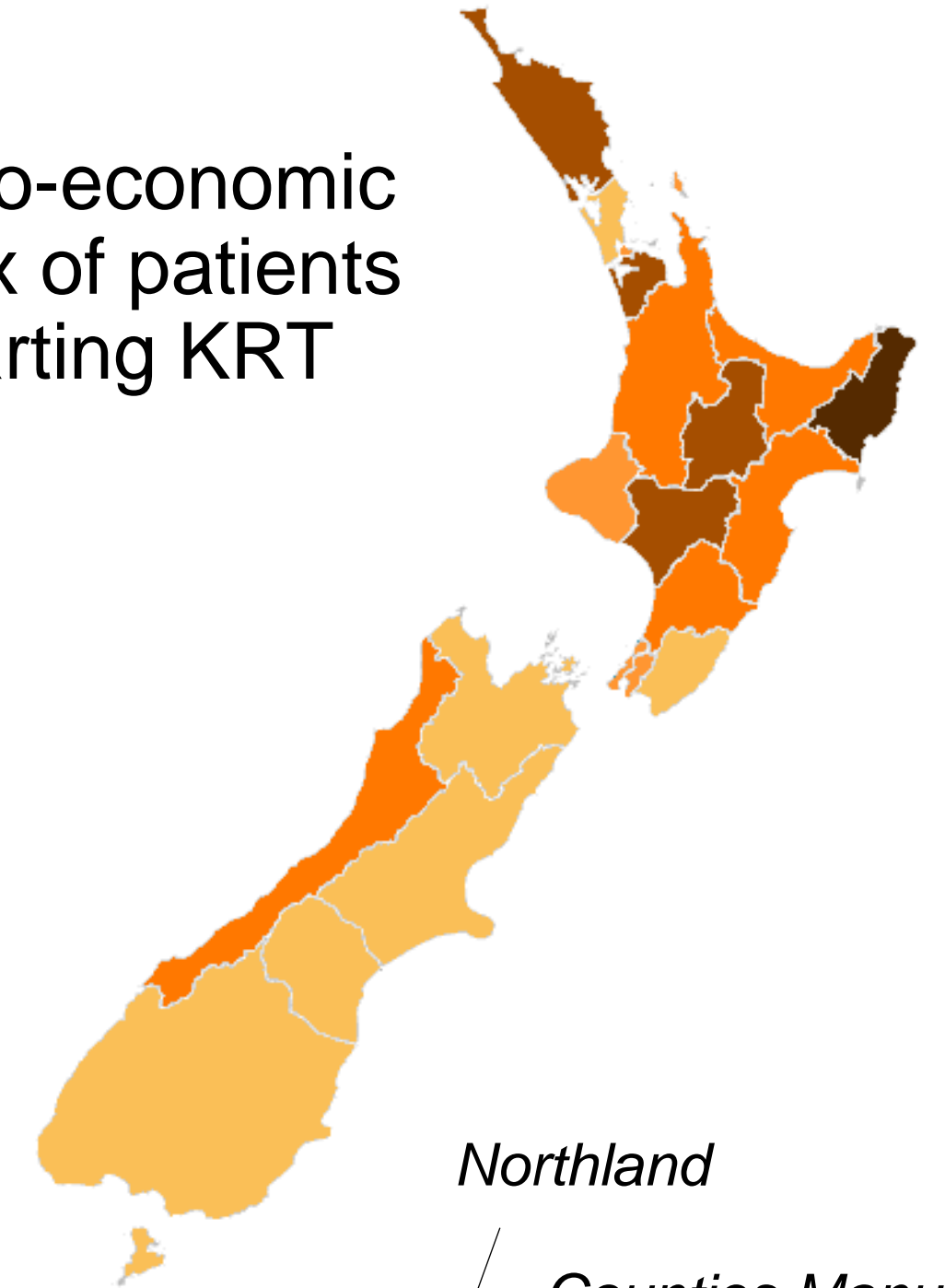
\*NZDep index of 9-10



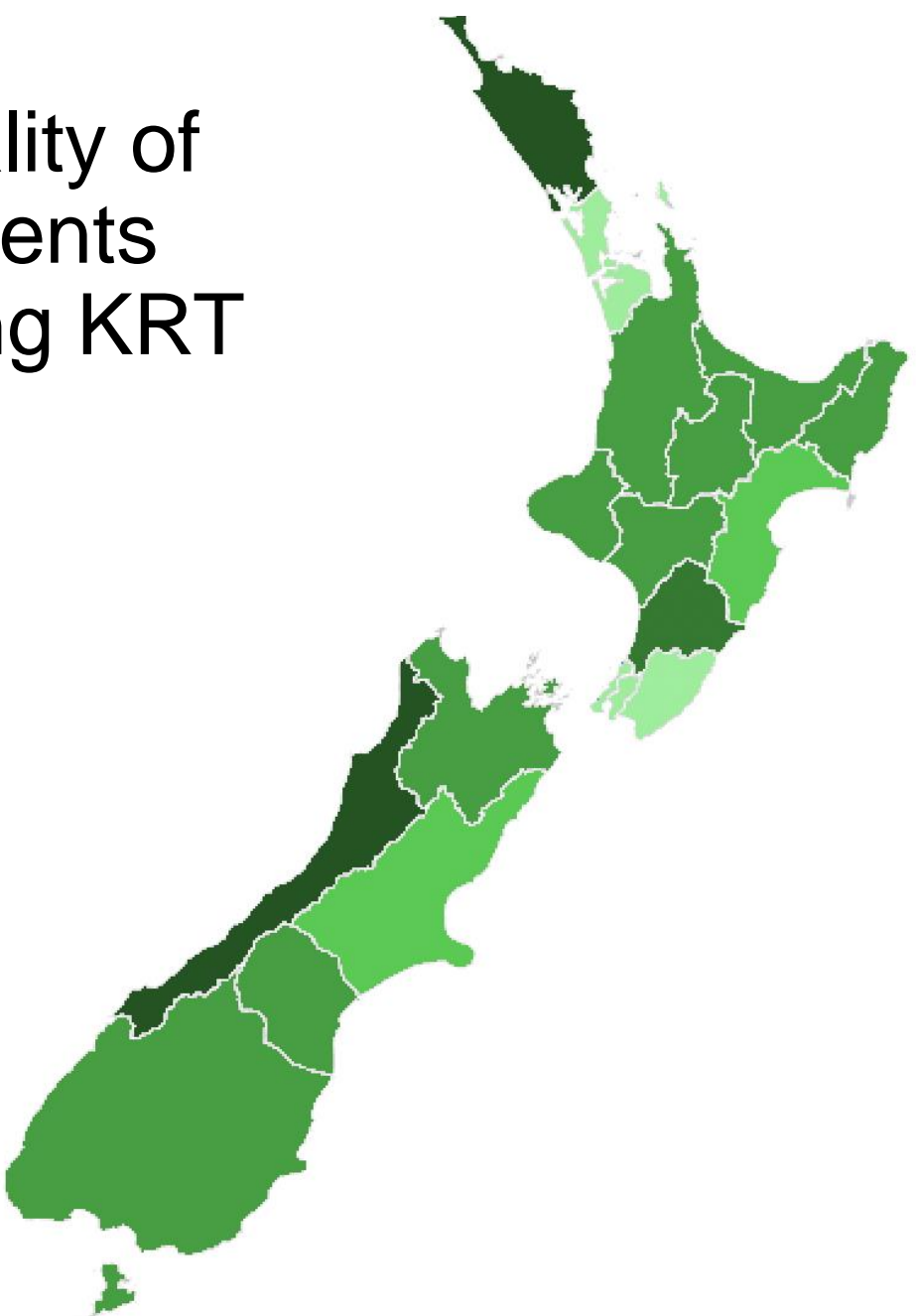
Age-standardised incidence of KRT, 2006-2019



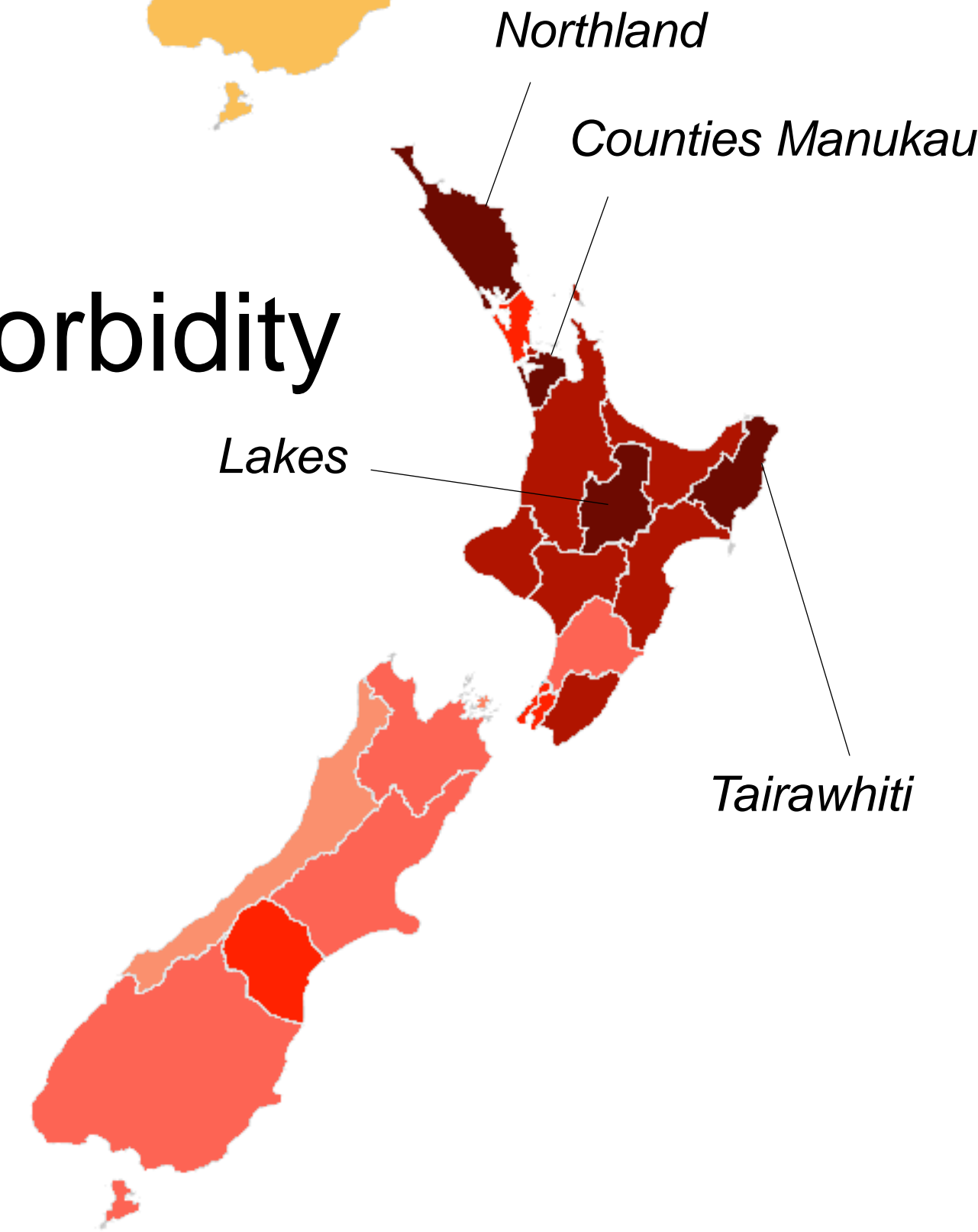
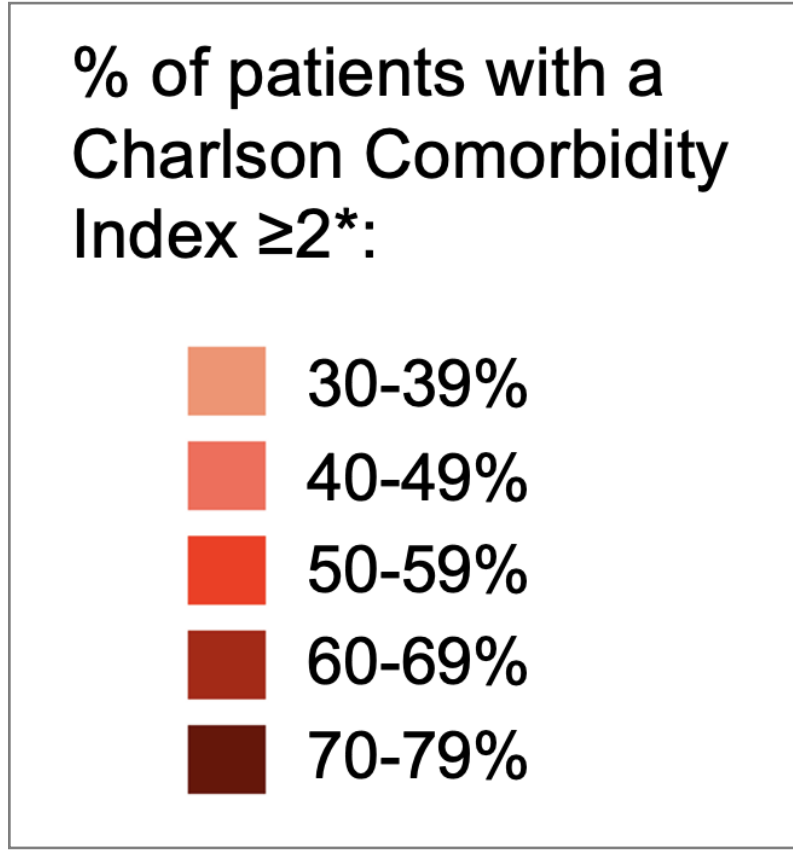
Socio-economic index of patients starting KRT



Rurality of patients starting KRT

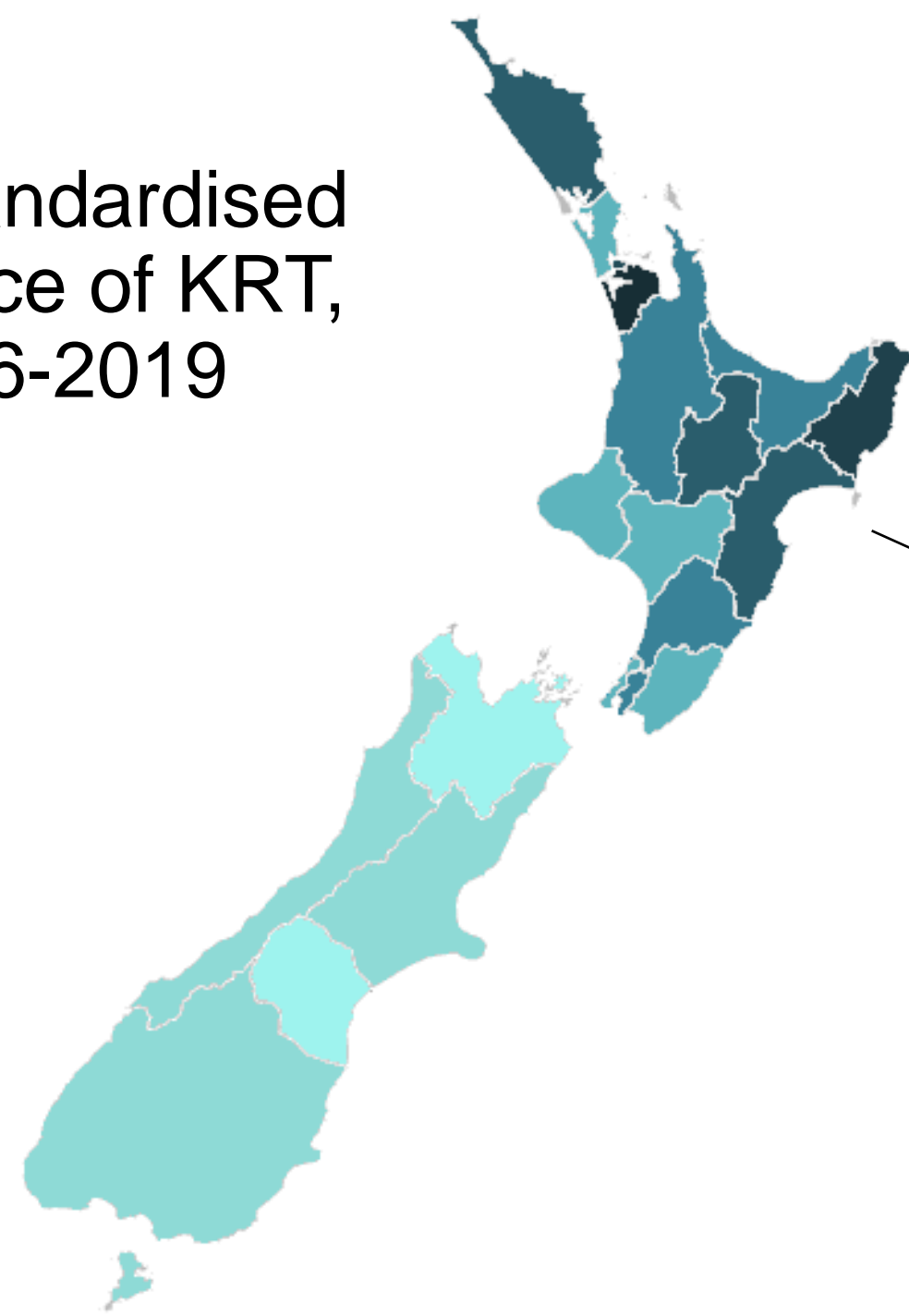


### Multimorbidity

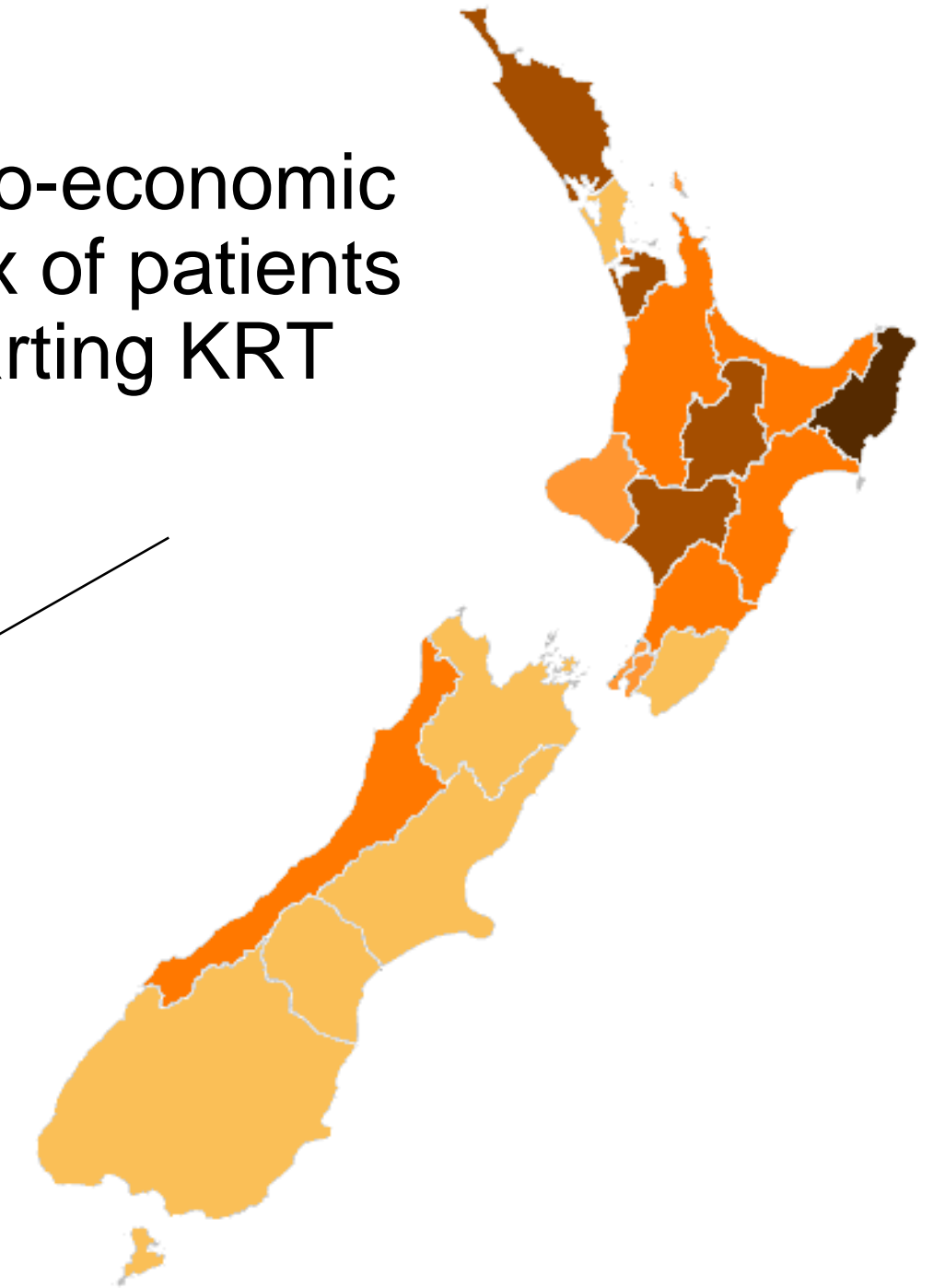


\*Estimated 10-year survival  $\leq 53\%$

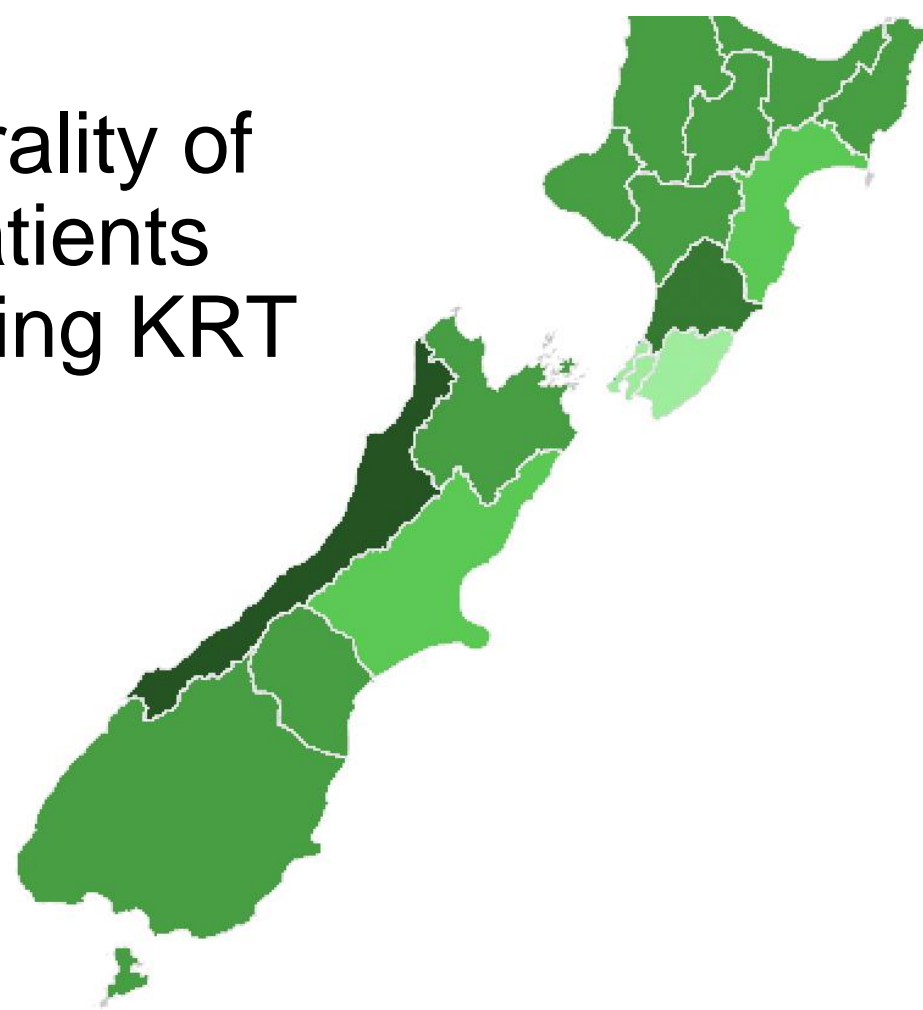
Age-standardised incidence of KRT, 2006-2019



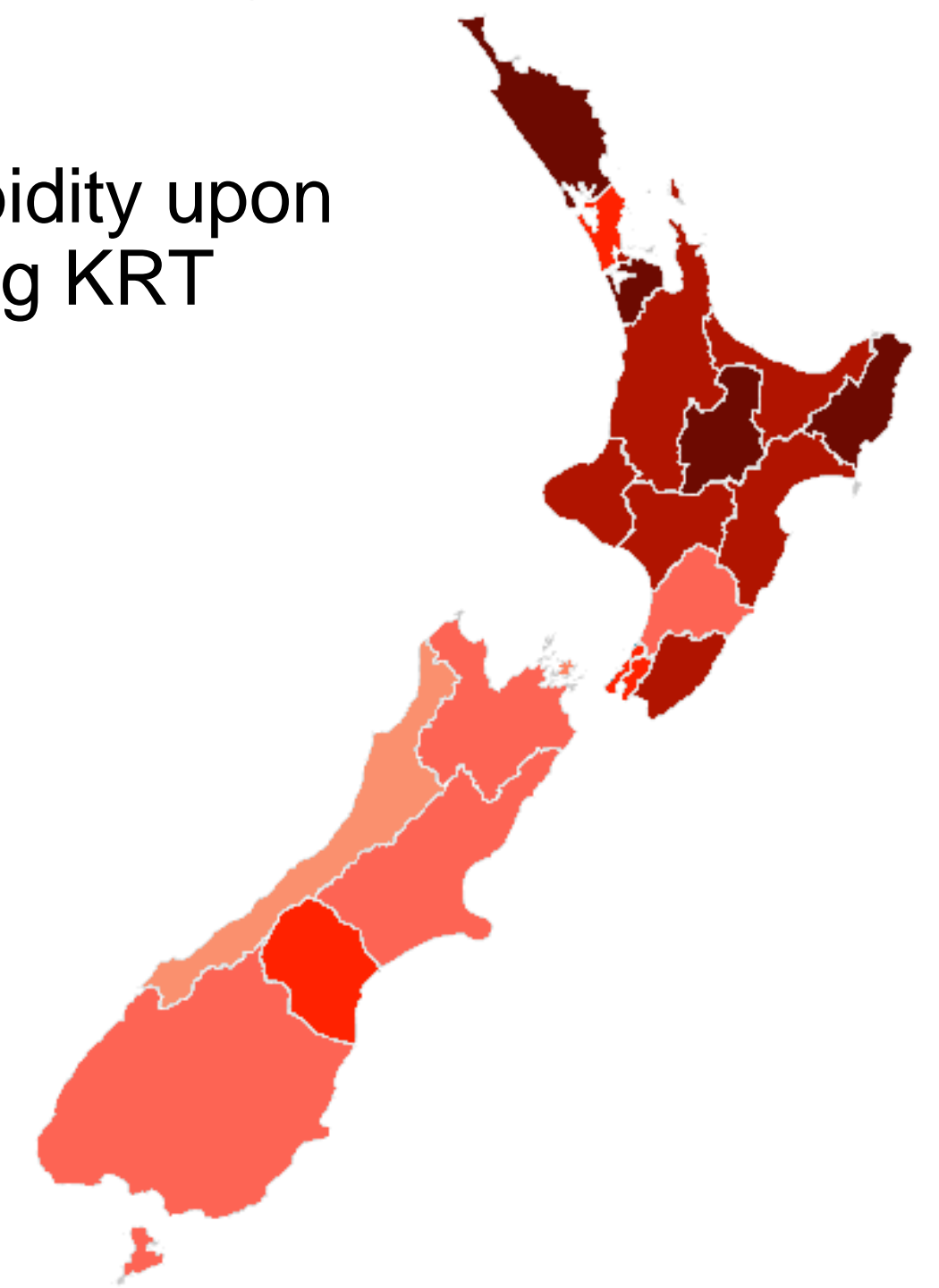
Socio-economic index of patients starting KRT



Rurality of patients starting KRT



Multimorbidity upon starting KRT



Challenges of equitable service provision are not equally distributed across NZ



# Complexity of service provision



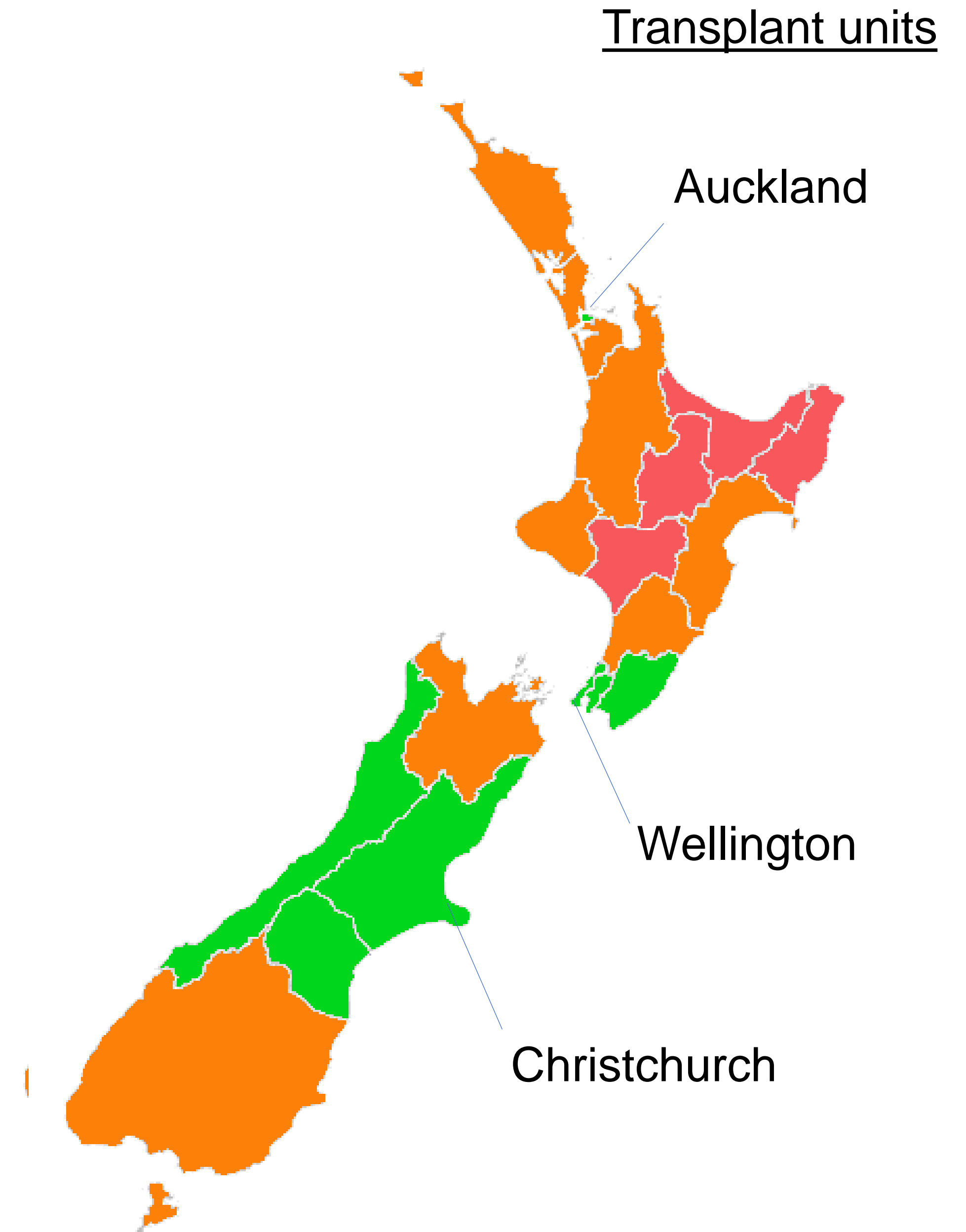
*'Transplanting regions'* District Health Boards with transplant unit, or adjacent



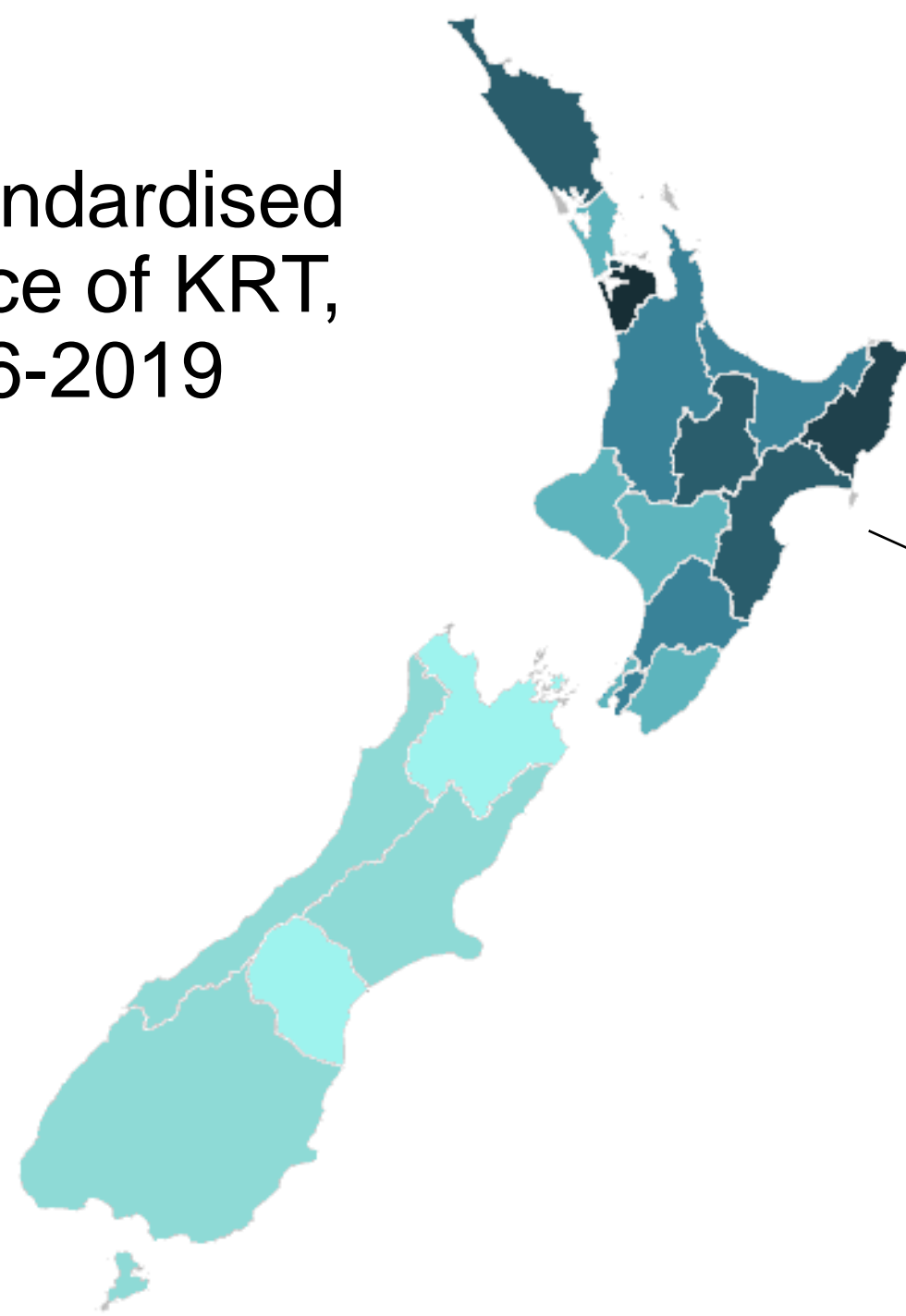
*'Intermediate regions'* = DHBs with nephrologists or visiting transplant staff.



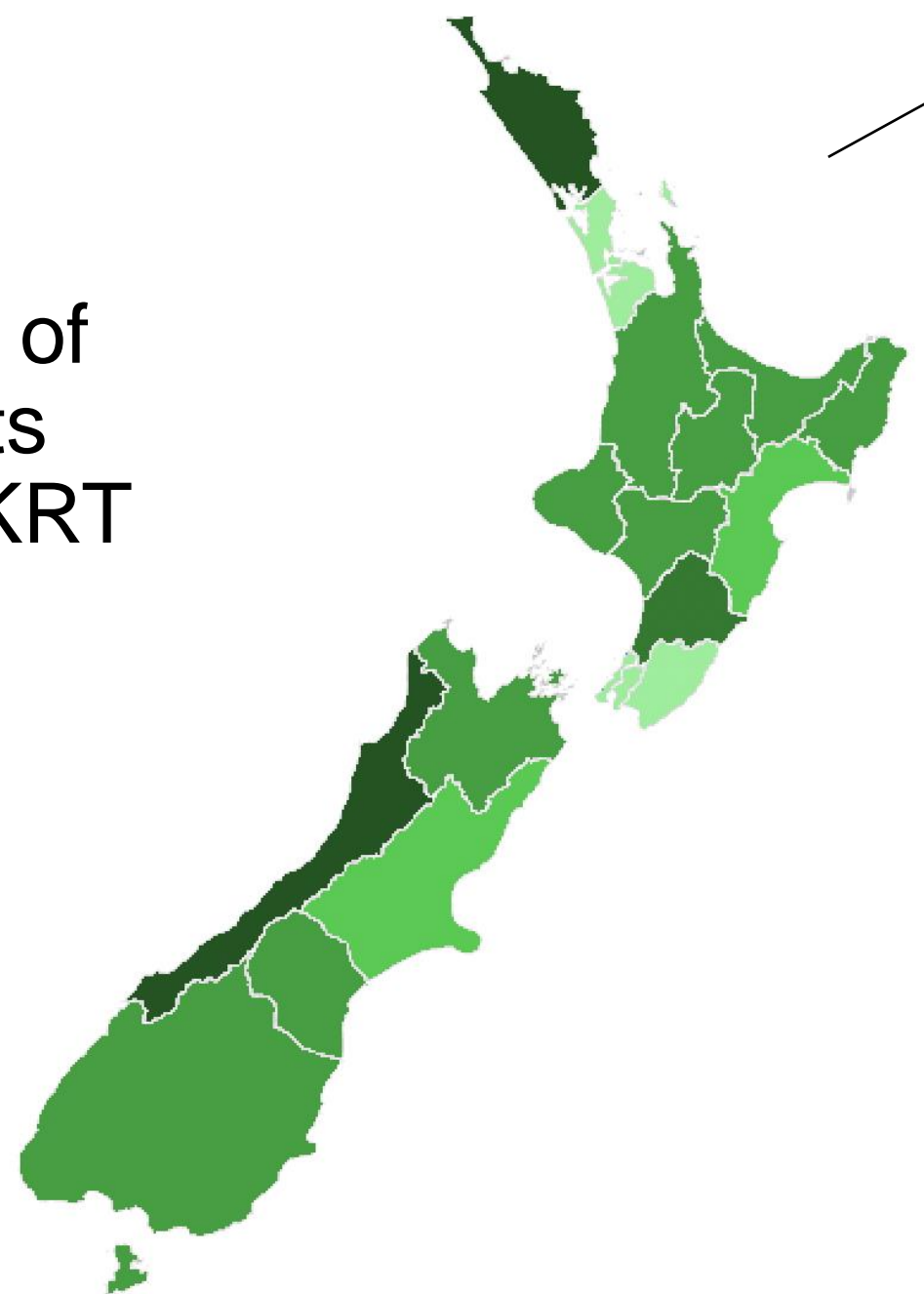
*'Remote regions'* require referral to another DHB for nephrology review, followed by a second referral to a transplant unit.



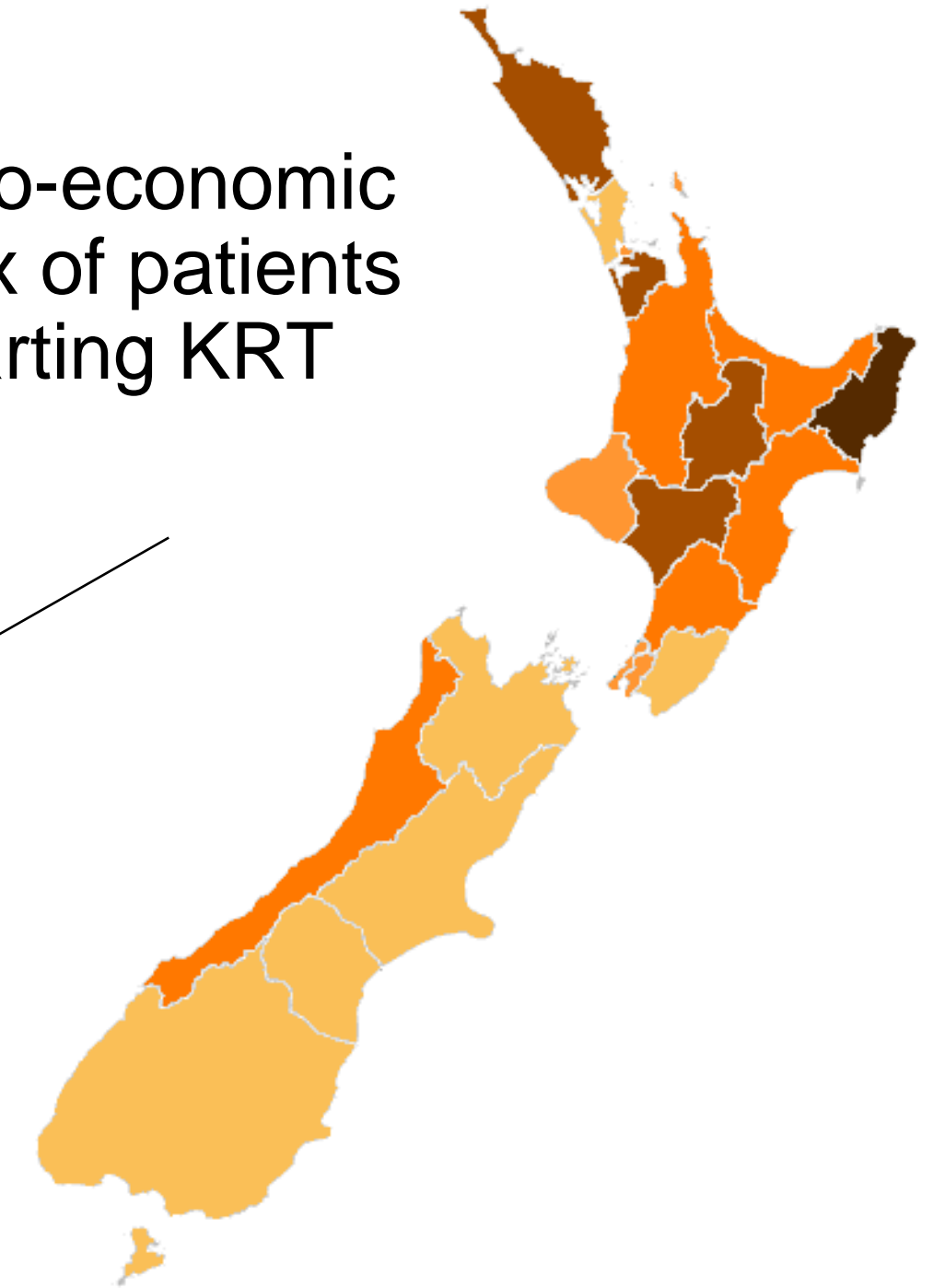
Age-standardised incidence of KRT, 2006-2019



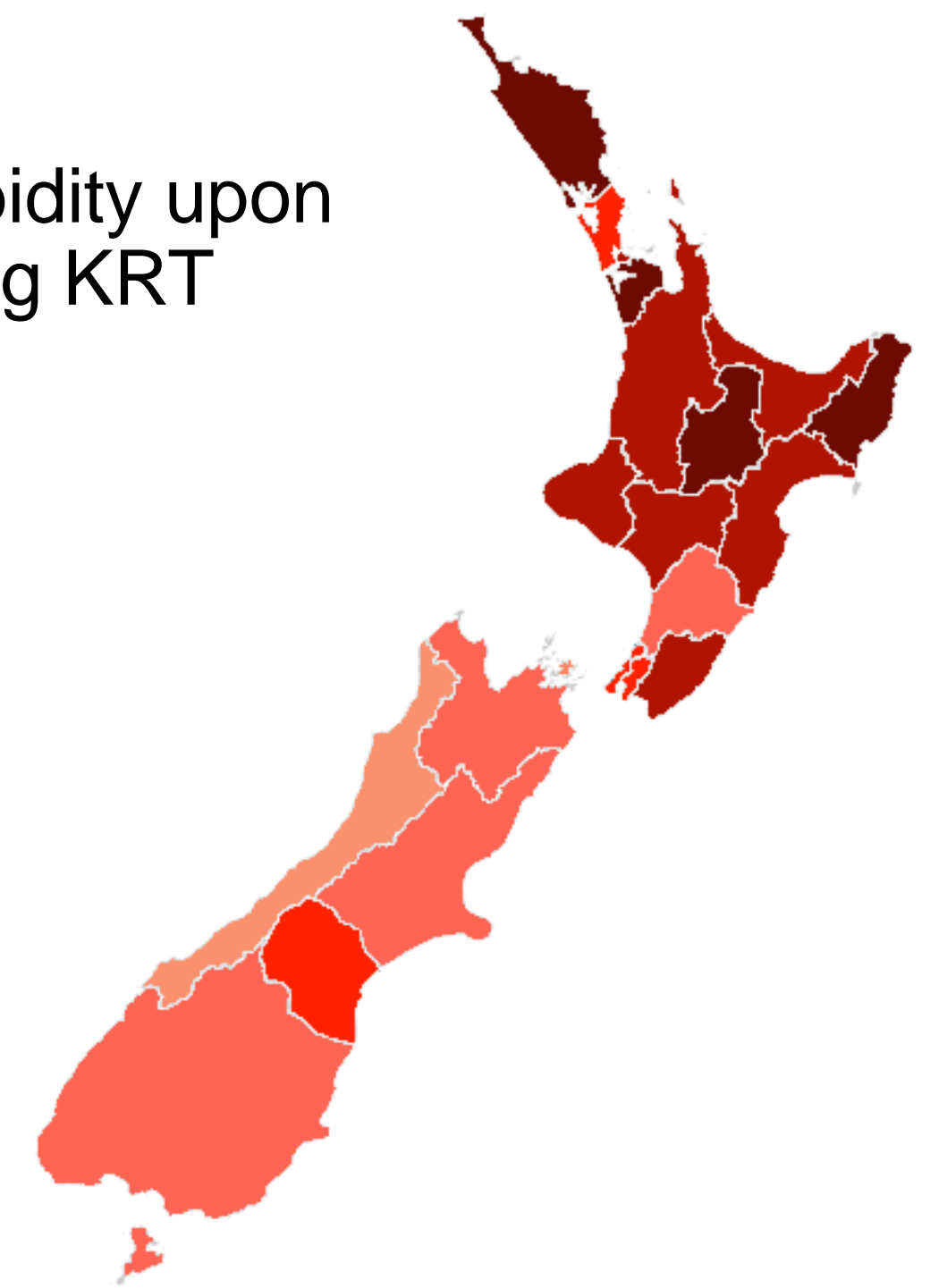
Rurality of patients starting KRT



Socio-economic index of patients starting KRT



Multimorbidity upon starting KRT



Auckland

Wellington

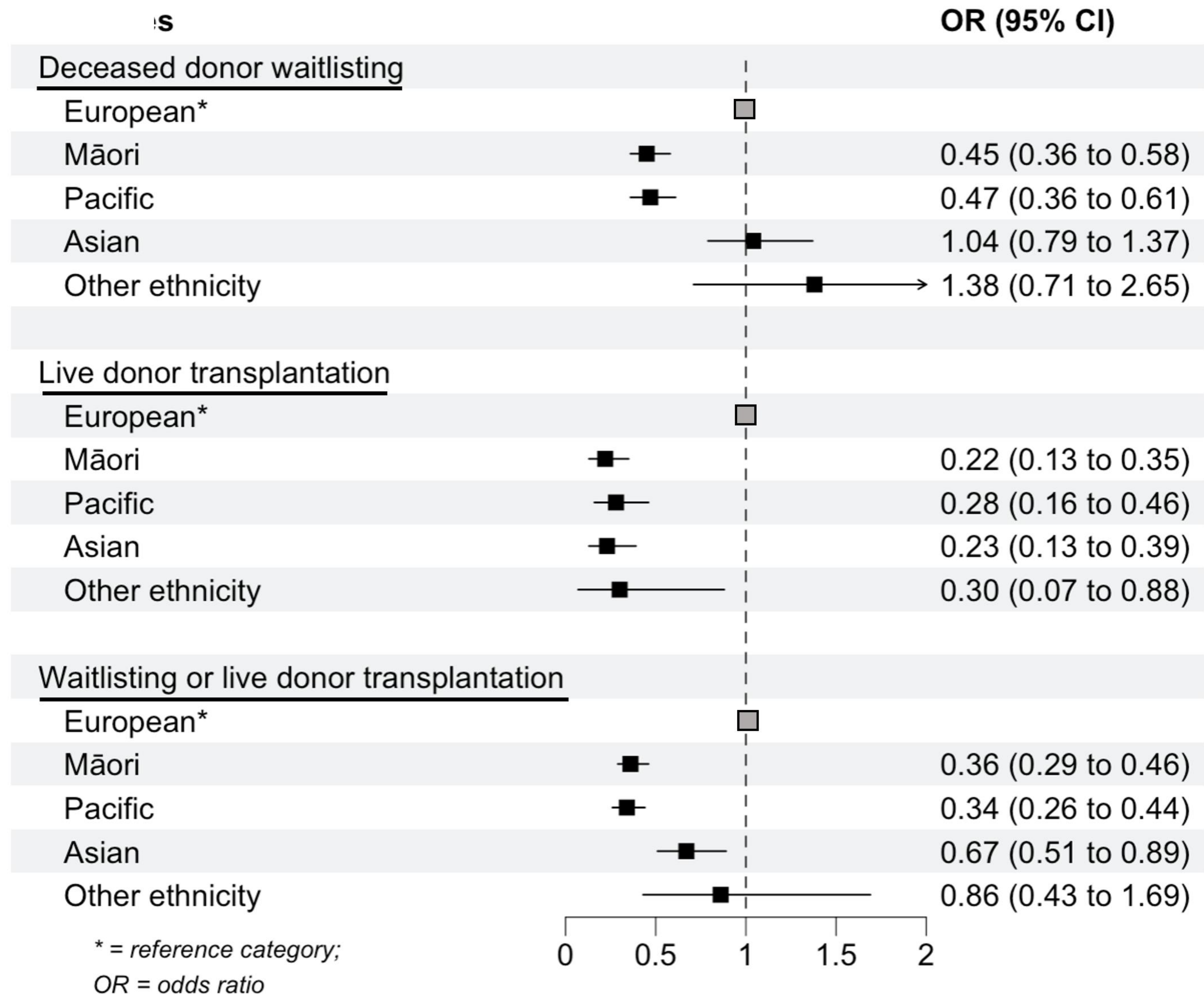
Christchurch

Most complex service design for greatest volume and complexity of patients

# KPI: Waitlisting / live donor transplant in 6 months of ESKD

Adjusted for:

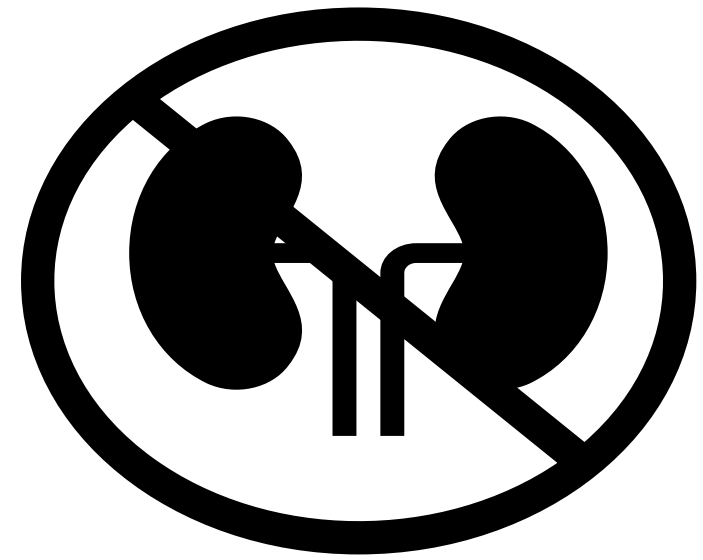
- Region category (transplanting / intermediate / remote)
- Age
- Sex
- Socioeconomic quintile
- Body mass index
- M3 Multimorbidity Score
- Late referral





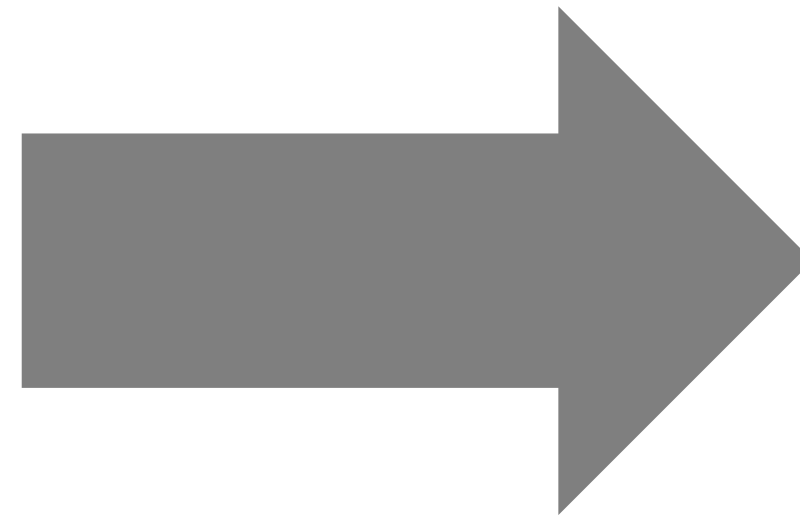
# Characterising mental illness in kidney failure

Kidney failure



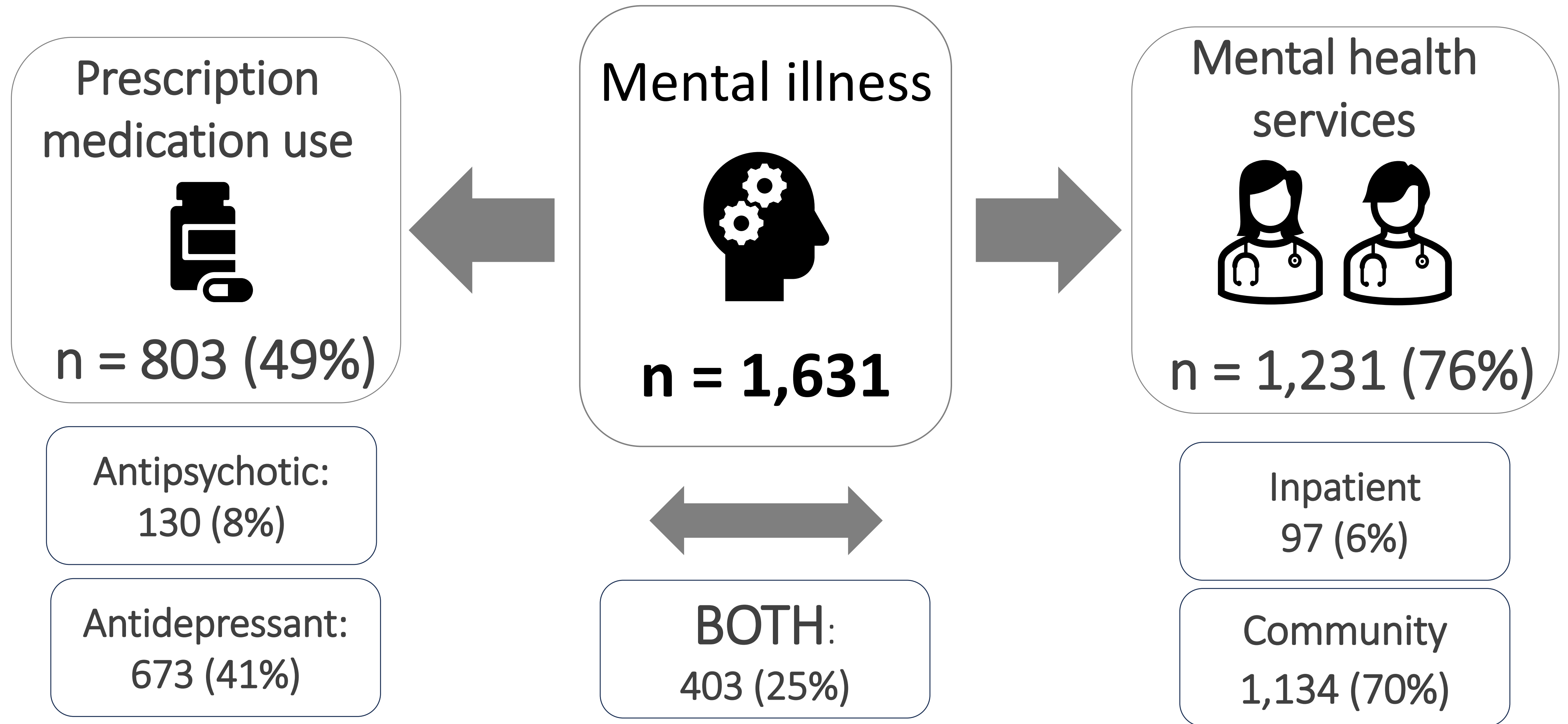
n = 6,392  
2008-2019

- Prasad Ravi
- ASSET's 1<sup>st</sup> nephrology trainee research affiliate



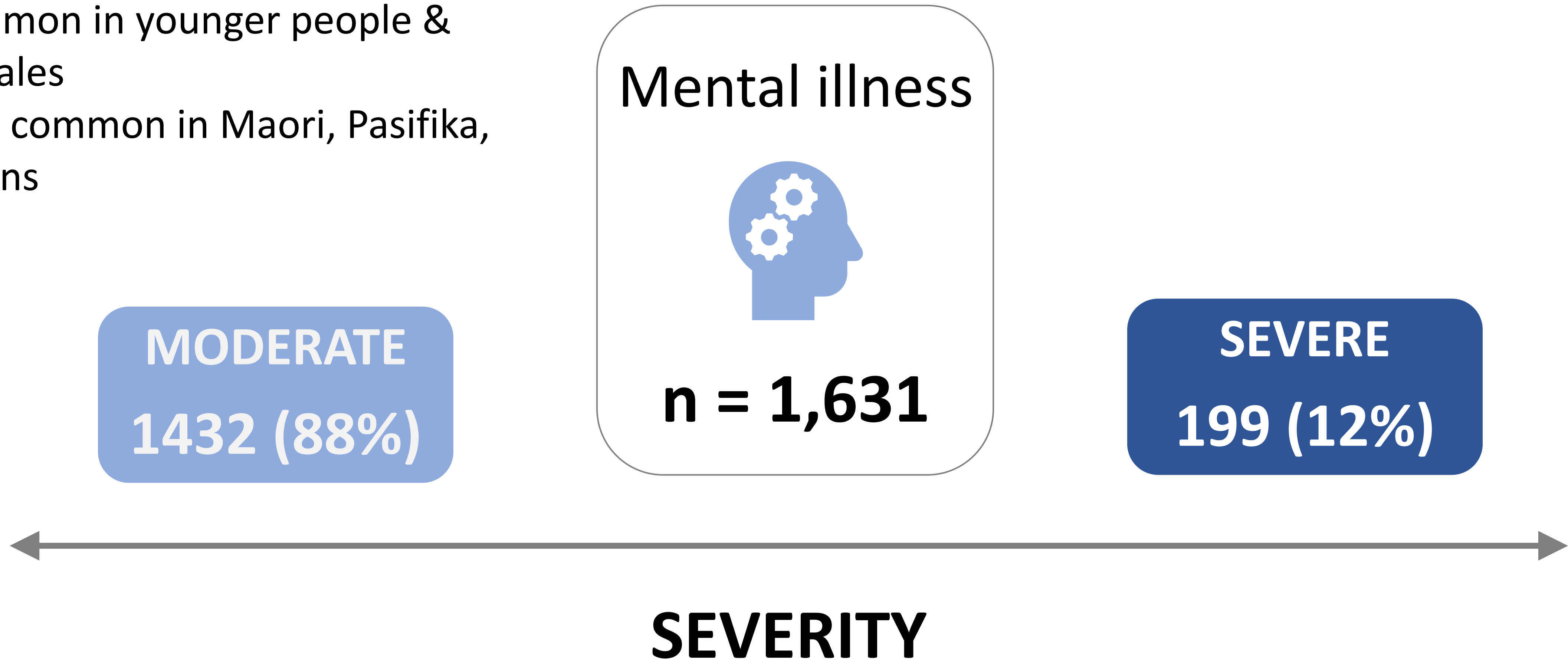
Mental illness  
n = 1,631  
(26%)

# Mental illness in kidney failure



# Mental illness in kidney failure

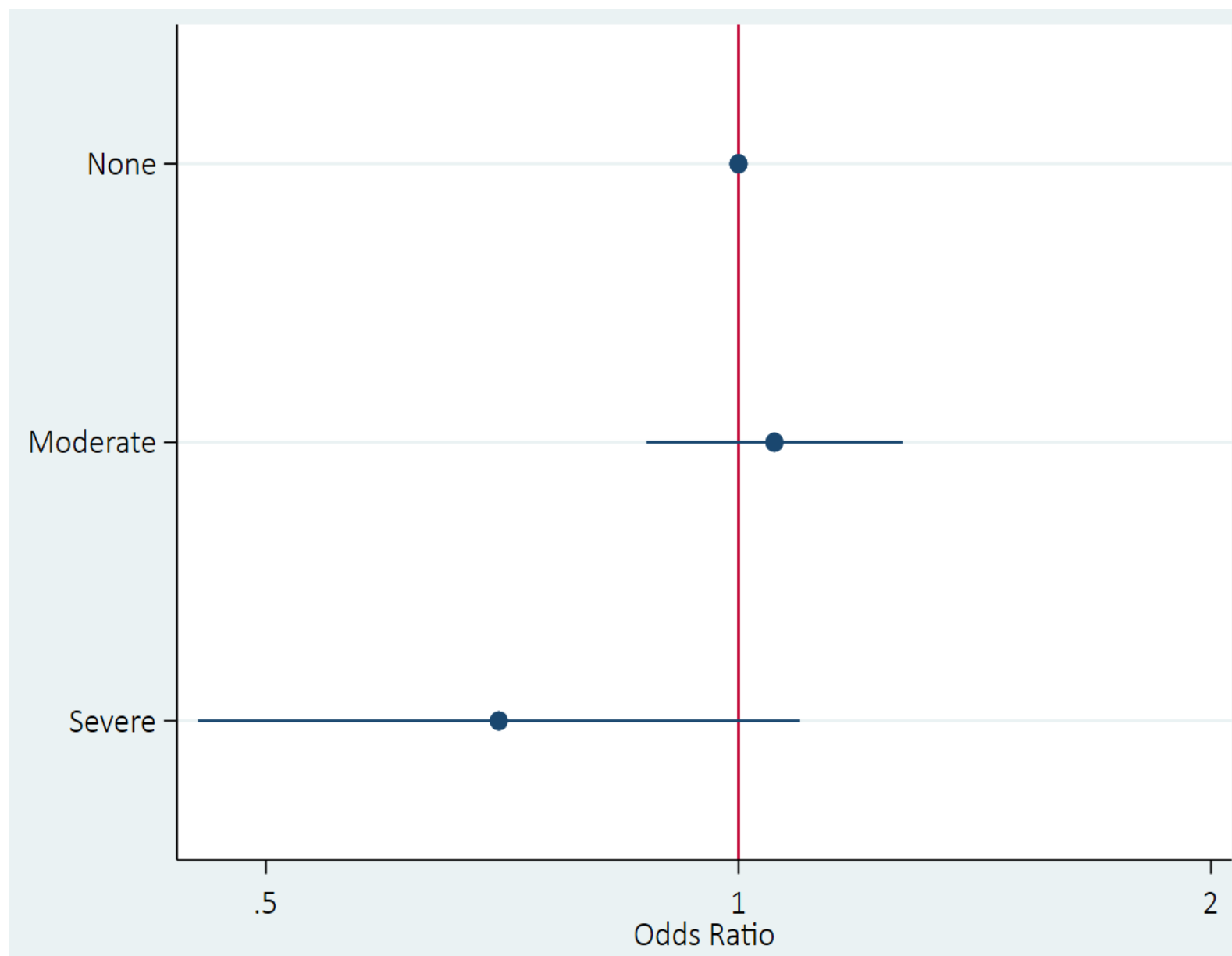
- Treated mental illness more common in younger people & females
- Less common in Maori, Pasifika, Asians



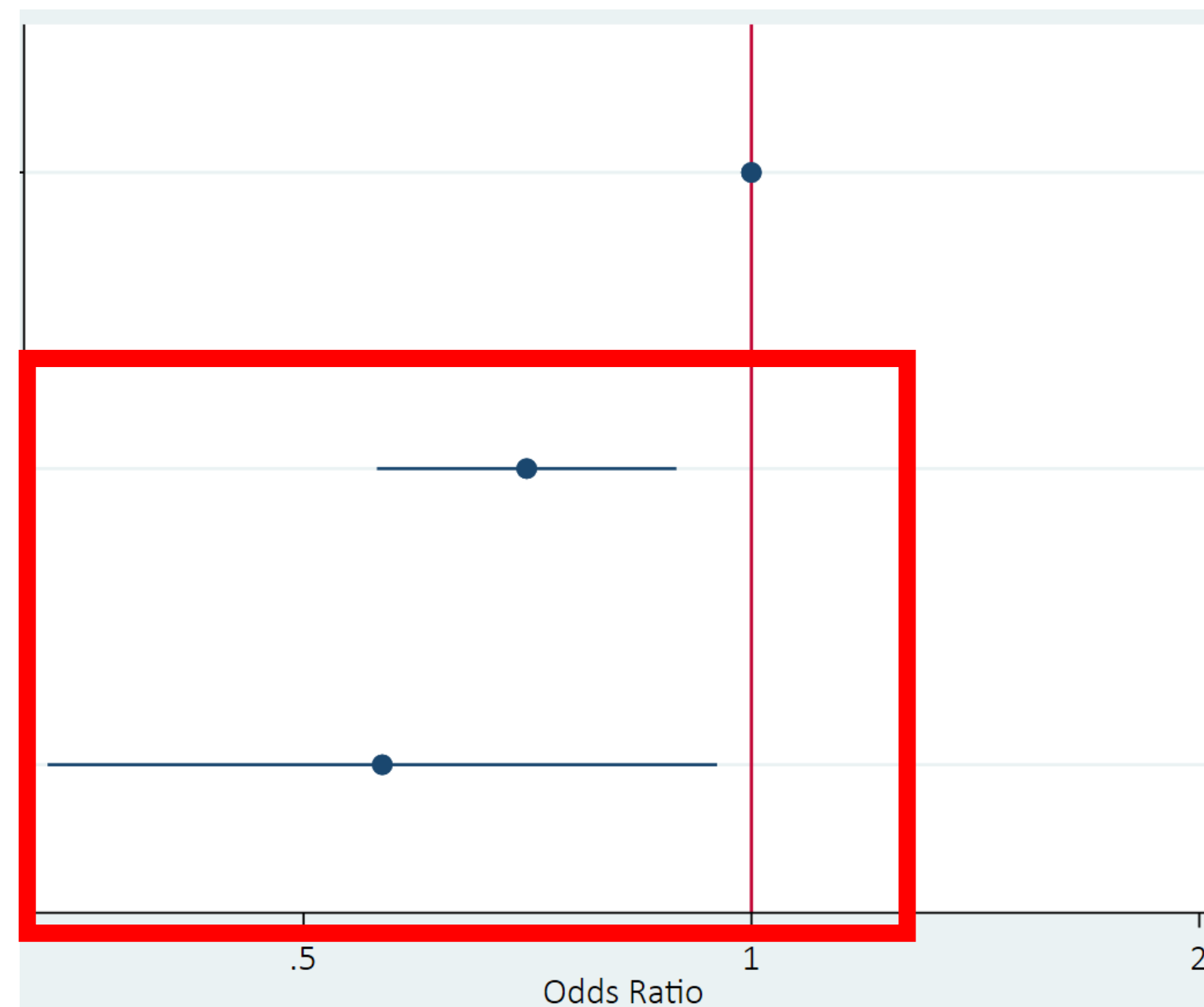
# Impact of mental illness on transplant KPIs

Mental illness **BEFORE** kidney failure

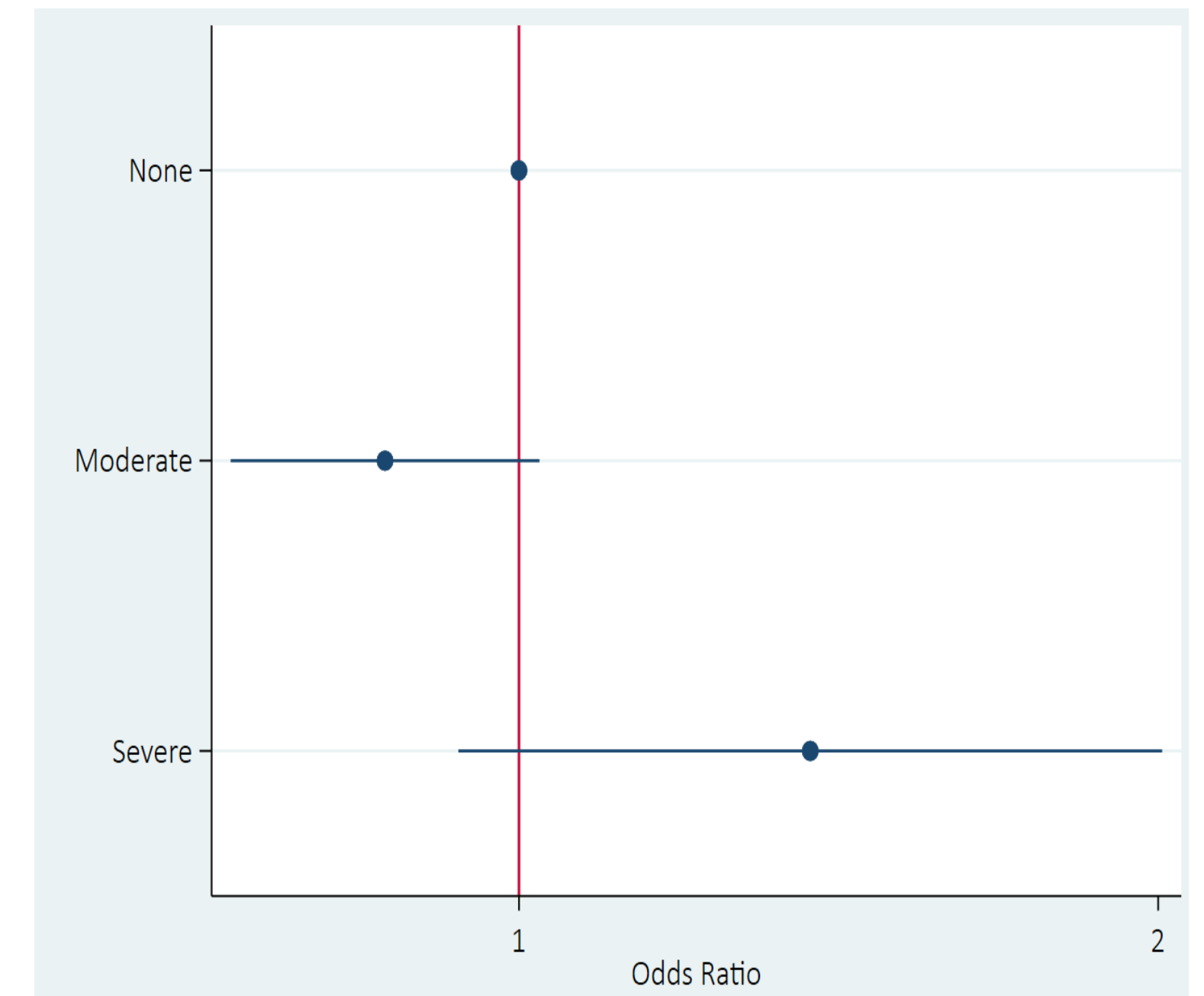
Waitlist



Transplant



Death



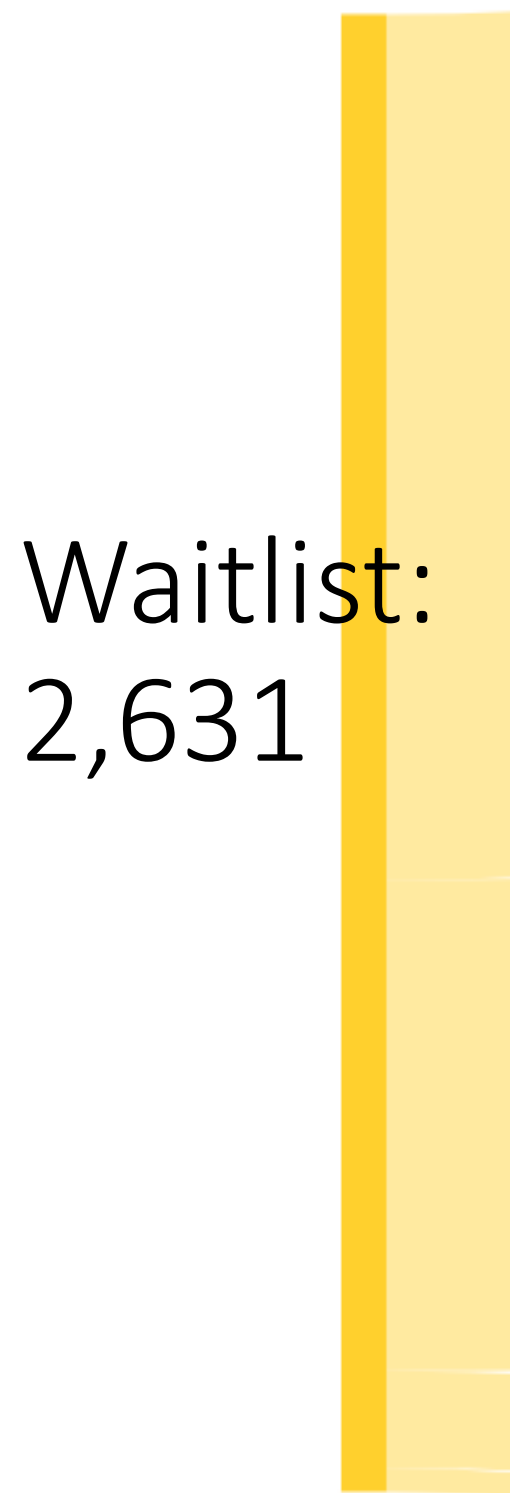
Adjusted for sociodemographic covariates, and comorbidities including BMI & smoking status.

## Data integration has shown

1. Burden of kidney failure highly variable across Aotearoa
2. Service design associated poorer access to transplantation
3. People of Māori or Pacific ethnicity independently disadvantaged in waitlisting and live donor transplantation
4. 1 in 4 people with kidney failure in Aotearoa has moderate-severe mental illness, and this impacts their access to transplantation

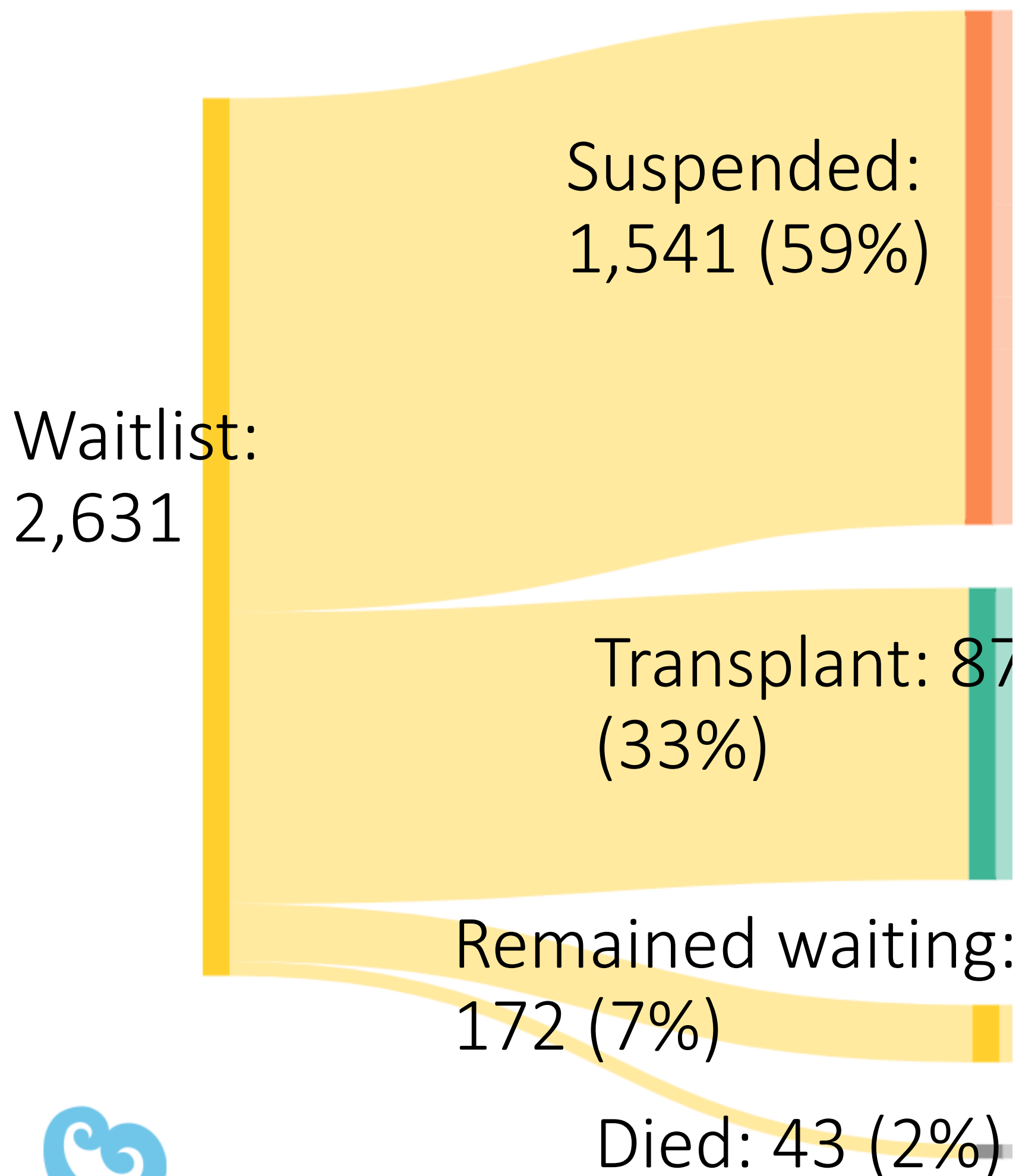


# Equity in waitlist journey: staying on the waitlist

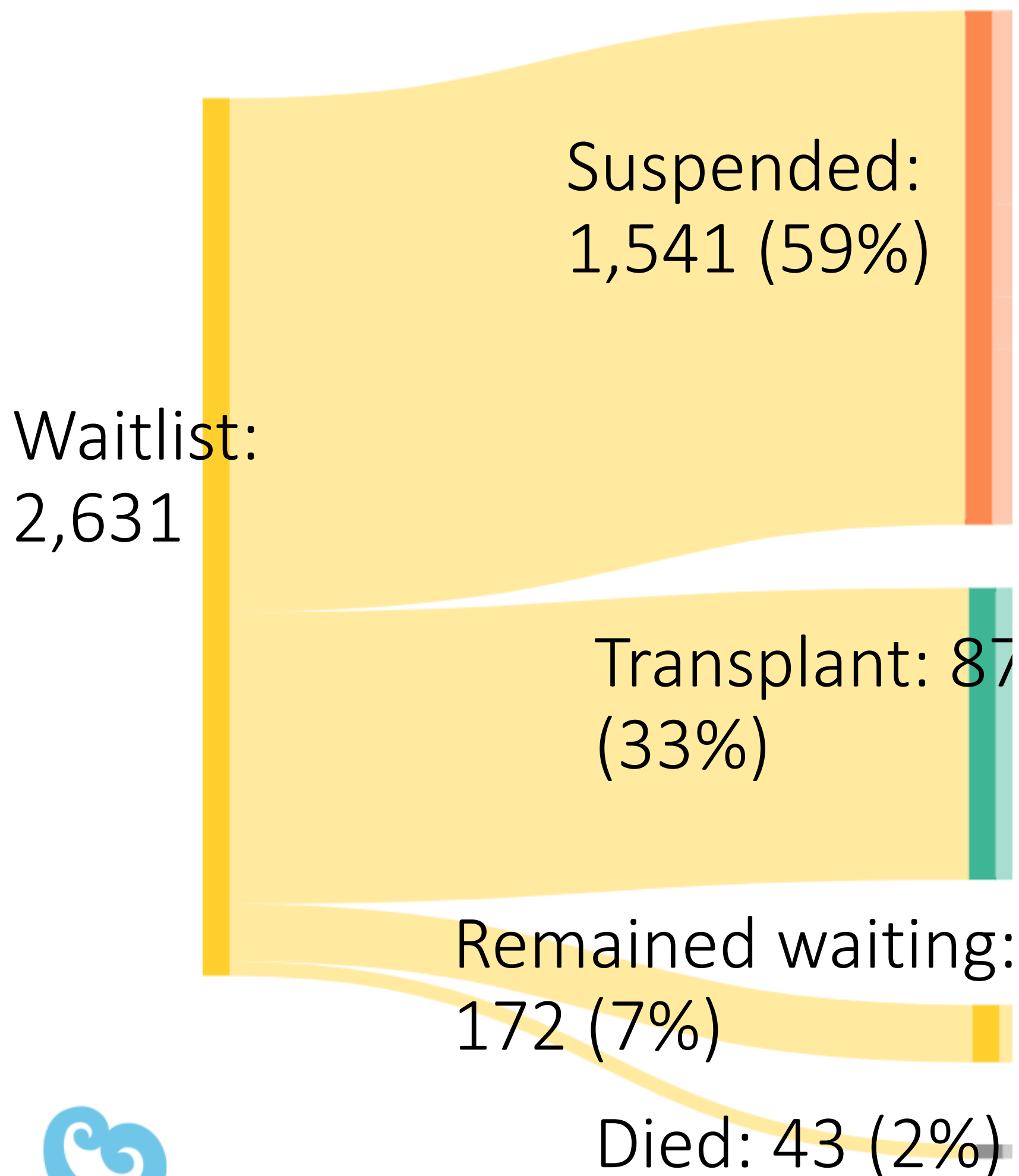


Nicole De La Mata

# Equity in waitlist journey: staying on the waitlist



# Equity in waitlist journey: staying on the waitlist

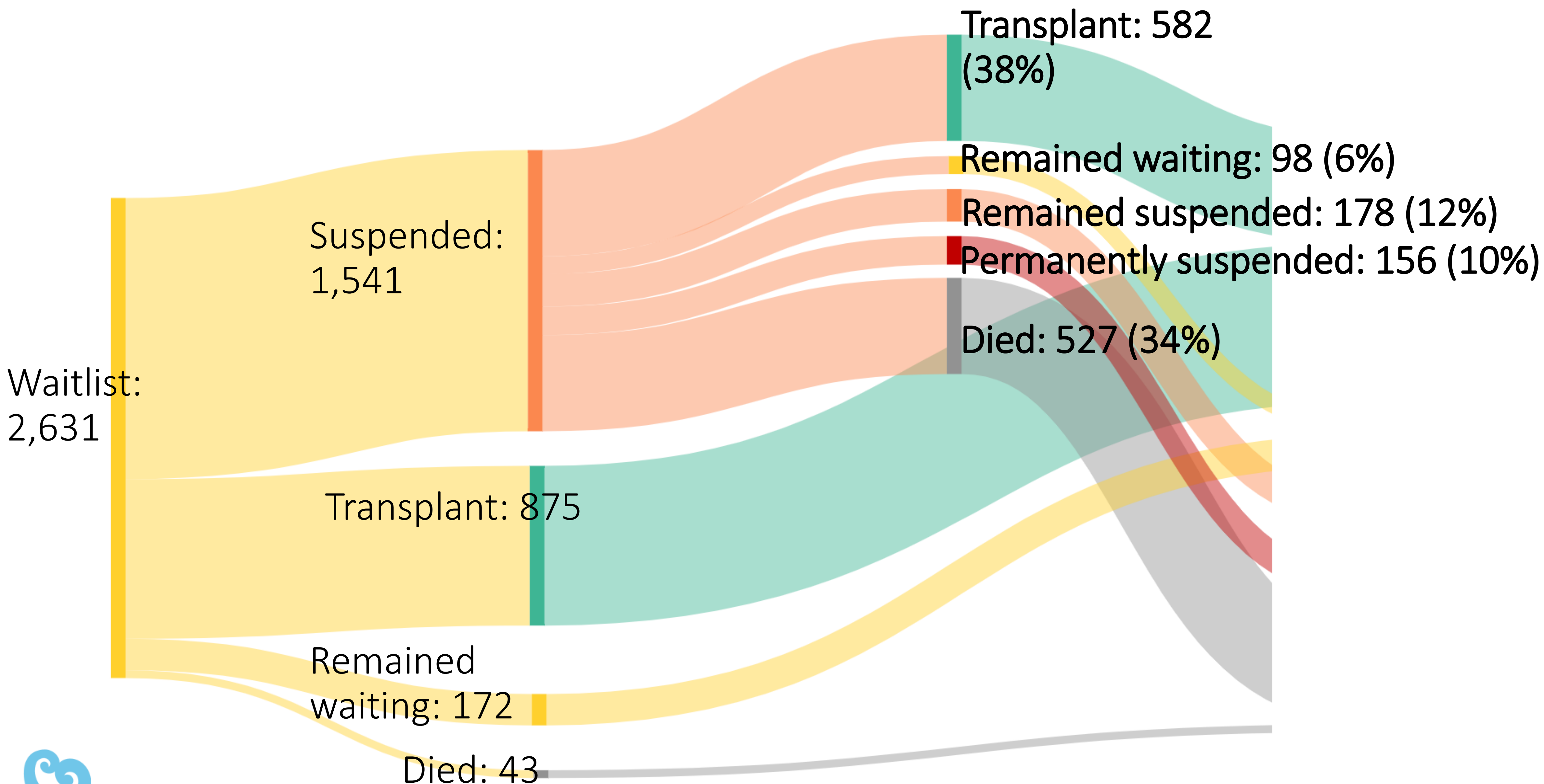


## Time per suspension

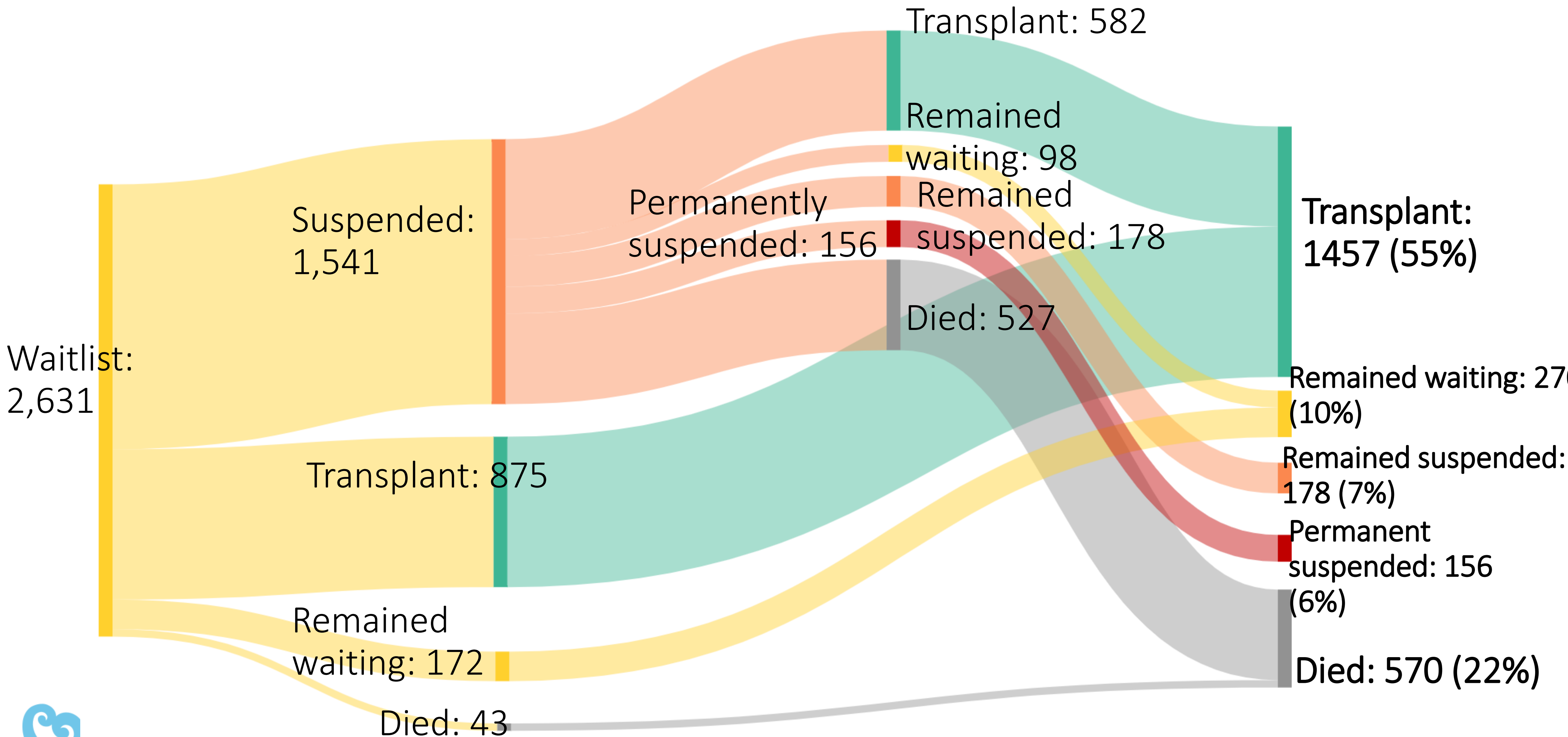
- 30% were <3 months
- 34% were 3-12 months
- 35% were >12 months



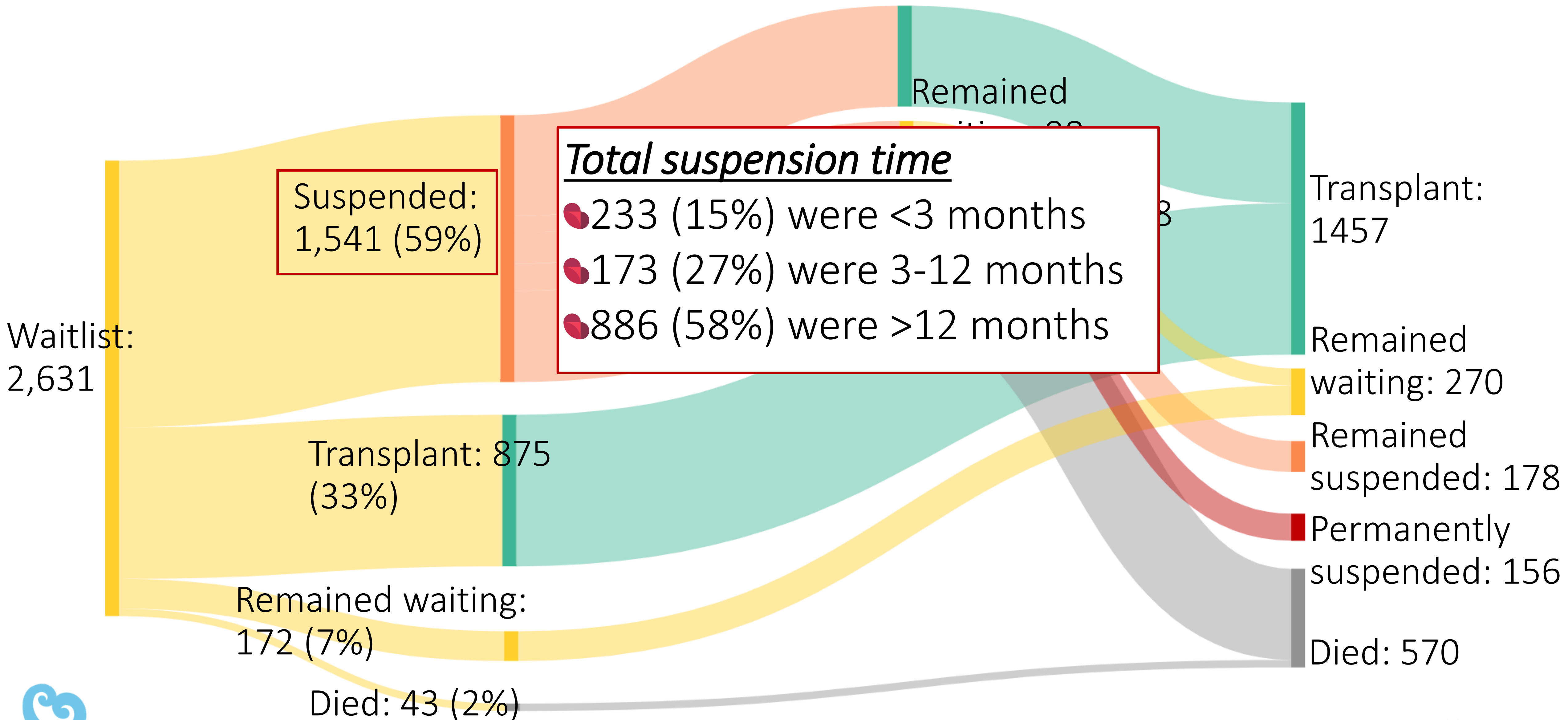
# Equity in waitlist journey: staying on the waitlist



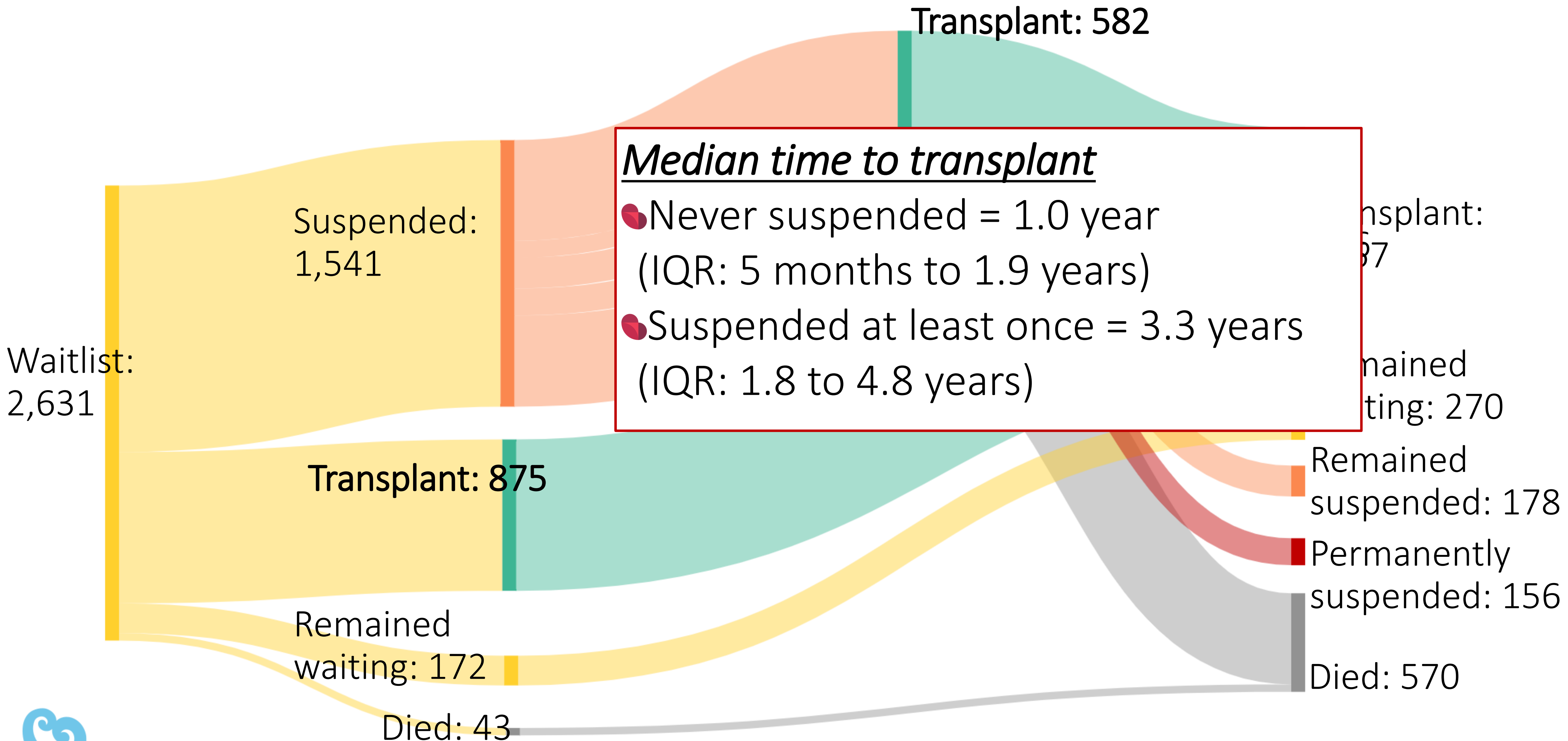
# Equity in waitlist journey: staying on the waitlist



# Equity in waitlist journey: staying on the waitlist



# Equity in waitlist journey: staying on the waitlist



**Median time to transplant**

- Never suspended = 1.0 year (IQR: 5 months to 1.9 years)
- Suspended at least once = 3.3 years (IQR: 1.8 to 4.8 years)



# QUICKLY JUMPING TO AUSTRALIAN DATA TO SHOW VALUE OF EXAMINING INTERSECTIONAL/STACKABLE DISADVANTAGE



# What about equity considerations?

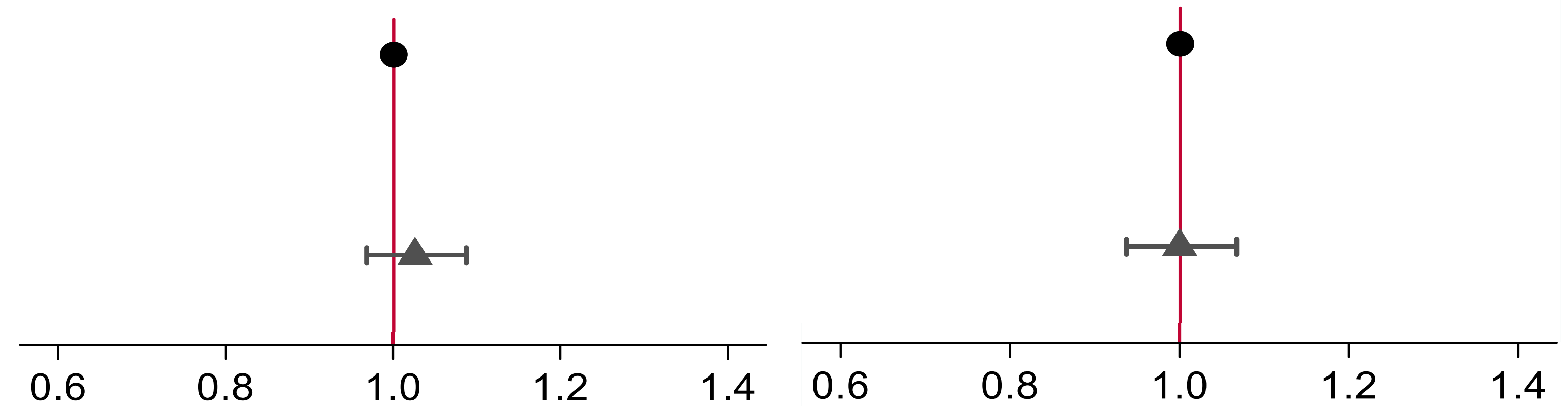
Unadjusted

Waitlist to off-waitlist

Off-waitlist to waitlist

Female

Male



← Less likely

→ More likely

← Less likely

→ More likely

Hazard ratio for transition



# Comparing transitions between sexes

Unadjusted

Waitlist to off-waitlist

Off-waitlist to waitlist

Female

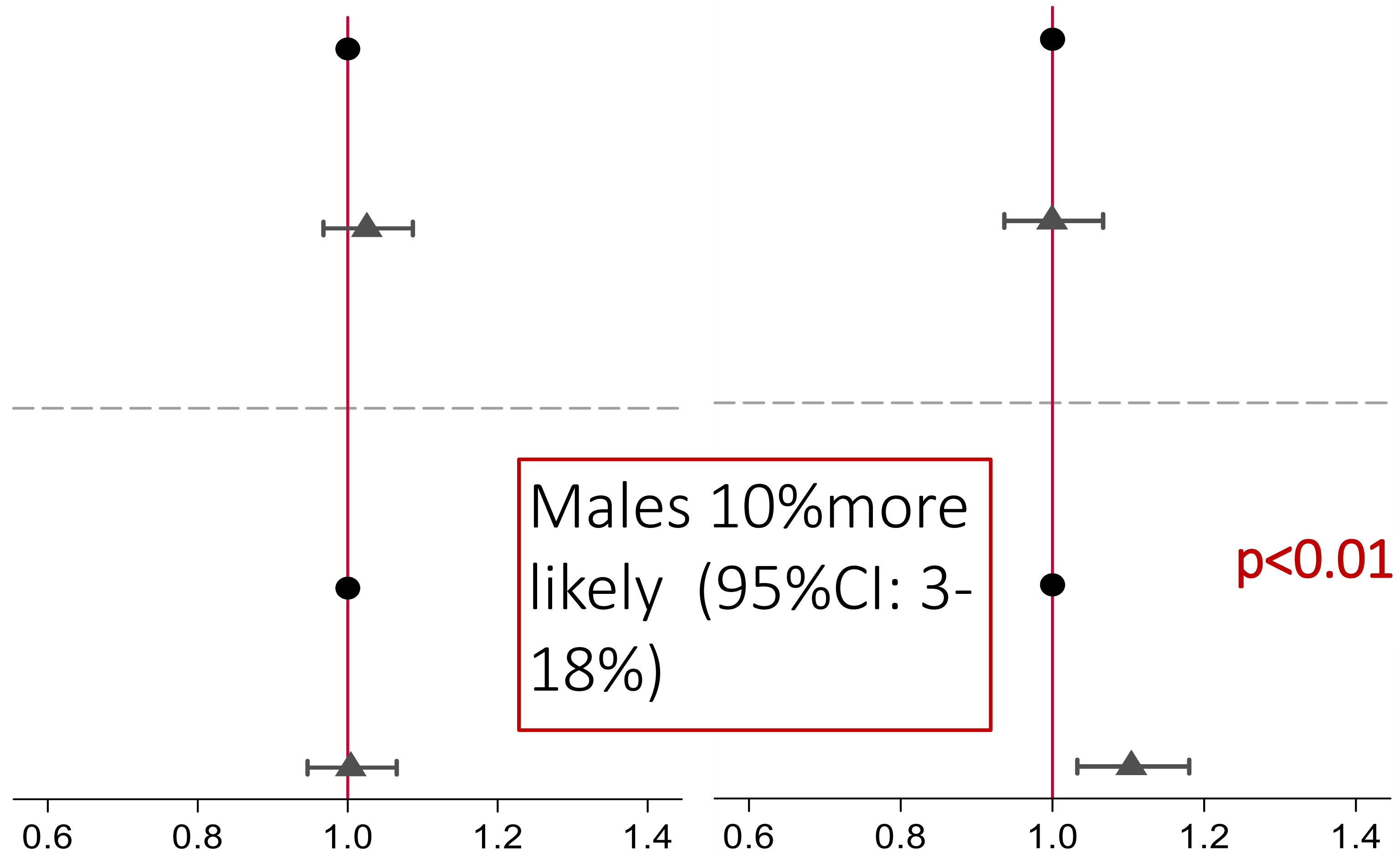
Male

Adjusted

age, calendar year,  
ethnicity, blood group,  
previous delisting  
episodes, comorbidity  
count, cause of kidney  
failure

Female

Male



# Off-waitlist to waitlist: intersectional disadvantage

Non-indigenous Australian  
& not Māori

Female  
Male

$p < 0.01$

Males are 13%  
(95%CI: 4-23%)

Aboriginal & Torres Strait  
Islander

Female  
Male

Māori & Pasifika

Female  
Male

Asian

Female  
Male

$p < 0.01$

Males are 23%  
(95%CI: 6-42%)

0.6 0.8 1.0 1.2 1.4 1.6 1.8

← Less likely

→ More likely

Adjusted hazard ratio for transition

# Comparing endpoints between sexes

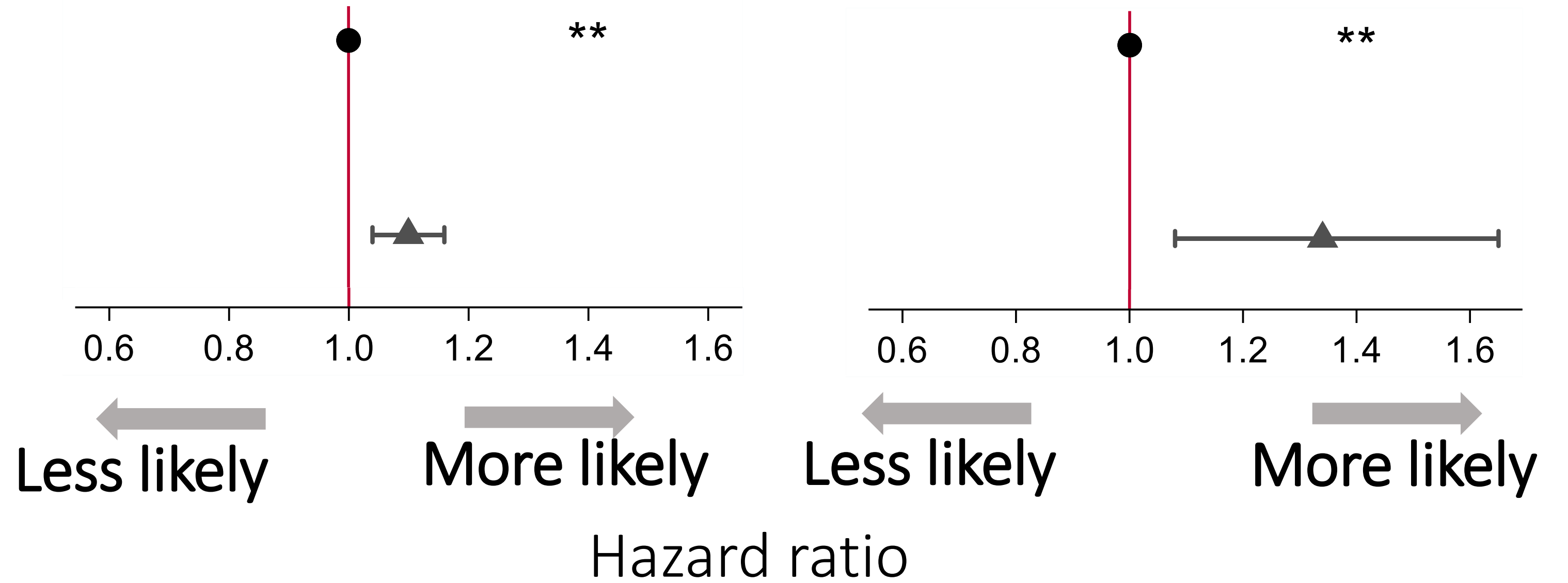
Unadjusted

Female

Male

Waitlist to transplant  
(deceased donor)

Waitlist to death before  
transplant



# Comparing endpoints between sexes

Unadjusted

Female

Male

Waitlist to transplant  
(deceased donor)

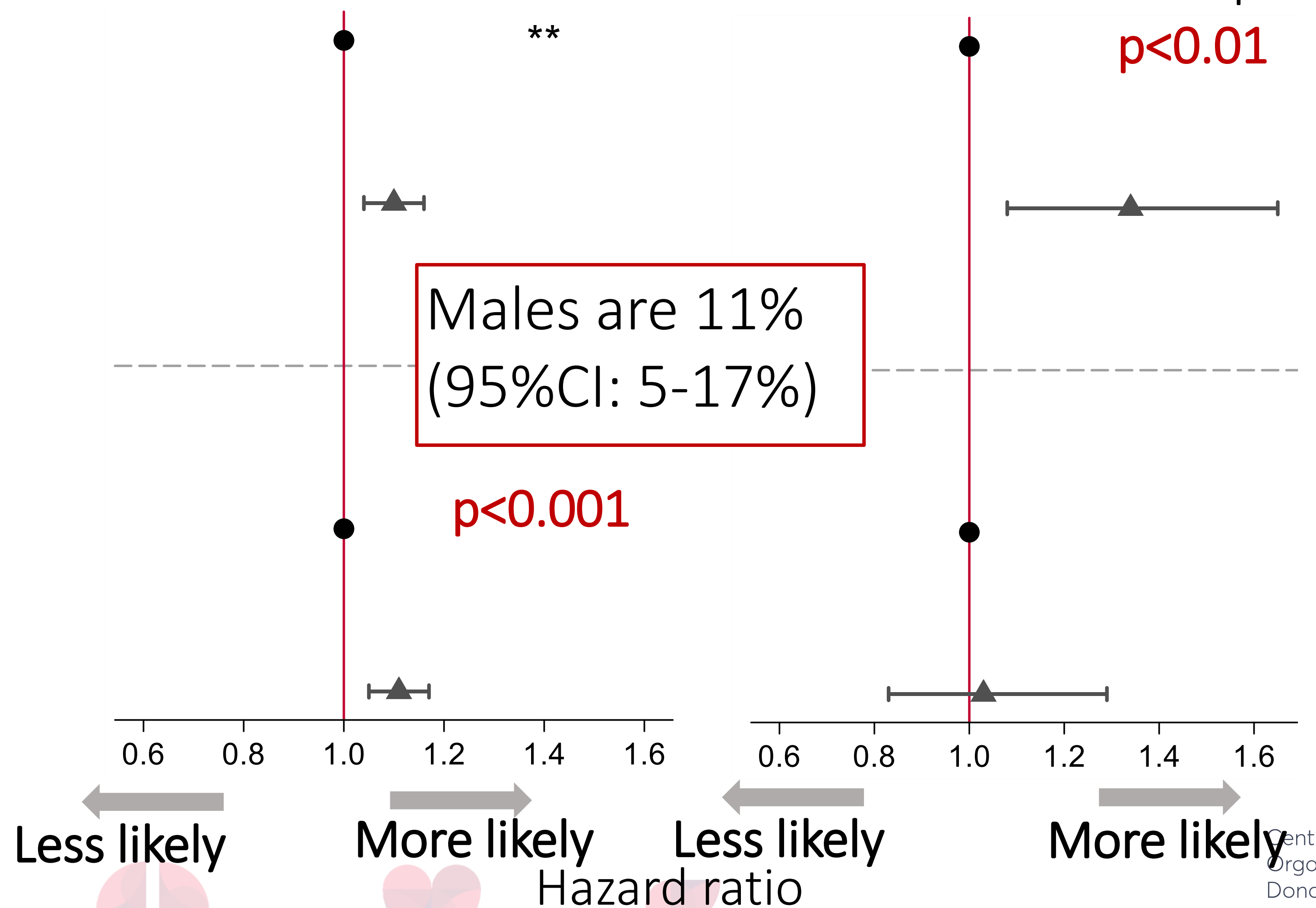
Waitlist to death before  
transplant

Adjusted

Female

Male

age, calendar year,  
ethnicity, blood group,  
previous delisting  
episodes, comorbidity  
count, cause of kidney  
failure



# Kidney waiting list outcomes

This tool calculates expected outcomes after being waitlisted for a kidney transplant, based on patient characteristics

Based on: *De La Mata et al., 2023*

**Age**  
30-49

**Sex**  
Female

**State/territory**  
NSW

**Ethnicity**  
Aboriginal or Torres Strait Islander

**Blood group**  
O

**Prior suspensions**  
0

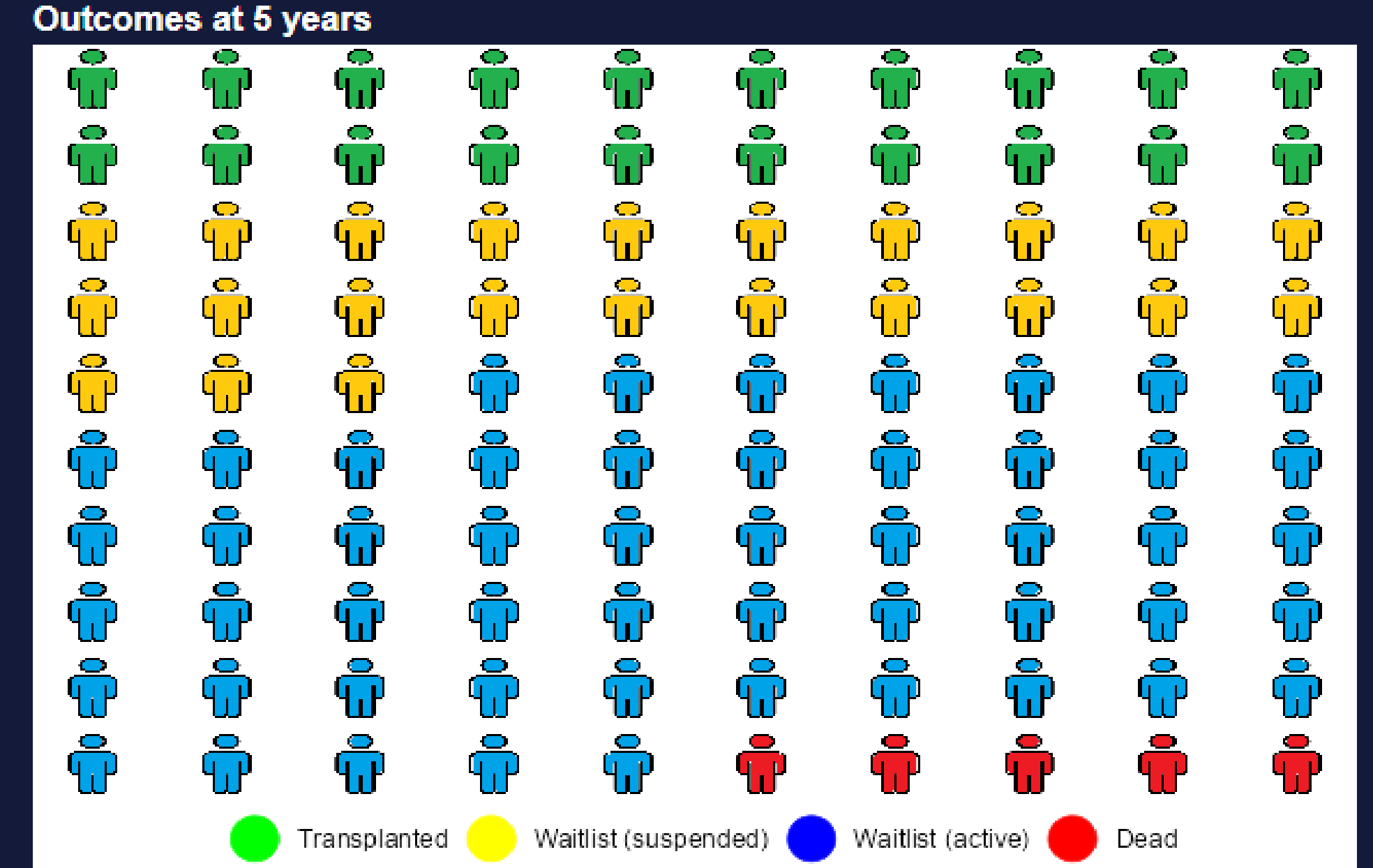
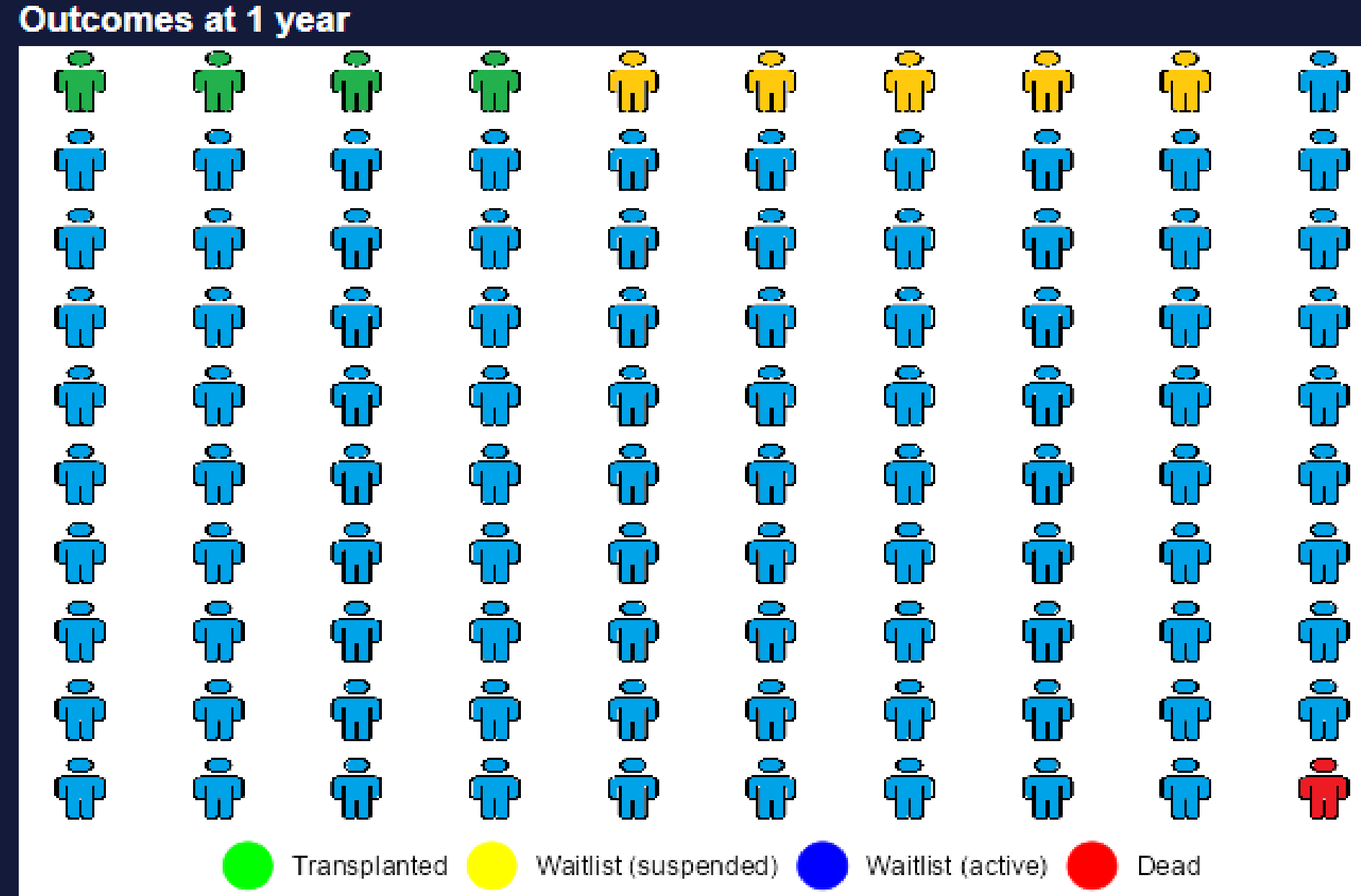
**Cause of kidney failure**  
Diabetes

**Comorbidities**

- Cerebrovascular disease
- Coronary artery disease
- Peripheral artery disease
- Chronic lung disease
- History of cancer

**Time on dialysis**  
0 years 0 months

**Time since kidney failure**  
0 years 0 months



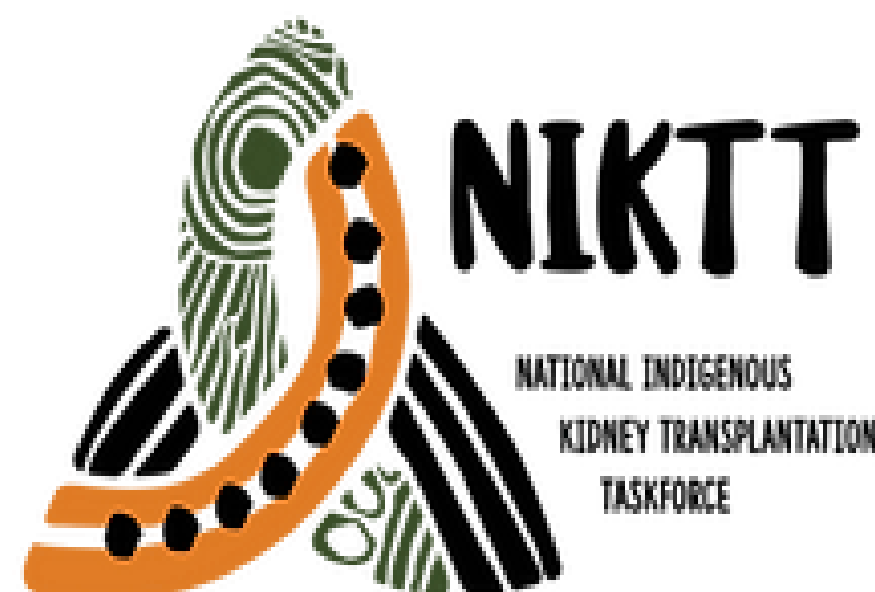
Dashboard design in process to aid clinician-patient discussions personalising likely journey

# Outline of talk - lots of NZ data

- ★ • Equity and dis/advantage
- ★ • Data integration as an art
- ★ • Aotearoa data to shape service design and delivery
  
- Bias in health care – Australia
  - Data to challenge what we think we know



# Data integration to shape approach to closing the gap



## PUBLICATIONS

Eleanor Garrard and Stephen McDonald

**Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia: Performance Report**

Read →

National Indigenous Kidney Transplantation Taskforce

**Performance Report: June 2022**

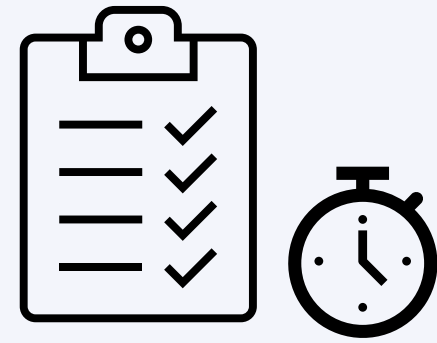
Read →

- Reporting of Aboriginality in ANZDATA has not been validated



# ANZDATA Reporting of Aboriginality

Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)



Ever waitlisted for kidney transplant



Dialysis & kidney transplant

Country of Birth

Ethnicity 1

Ethnicity 2

Codes based on Australian Standard Classification of Cultural and Ethnic Groups (2016) by Australia Bureau of Statistics (ABS)

# ANZDATA Reporting of Aboriginality pre 2014

## 10 Caucasoid

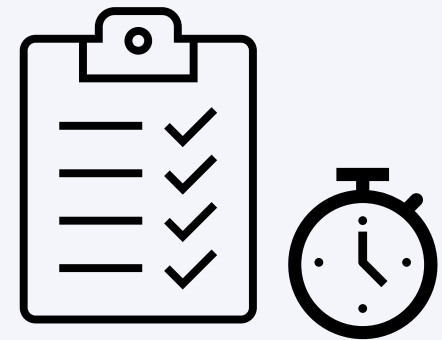
- 1101 Oceanian - Australian
- 1102 Oceanian - Australian Aboriginal
- 1103 Oceanian - Australian South Sea Islander
- 1104 Oceanian - Torres Strait Islander
- 1201 Oceanian - New Zealand Māori
- 1202 Oceanian - New Zealand European
- 1300 Oceanian - Melanesian And Papuan (Specify)
- 1400 Oceanian - Micronesian (Specify)
- 1500 Oceanian - Polynesian (Specify)
- 1501 Cook Islander
- 1502 Fijian
- 1503 Niuean
- 1504 Samoan
- 1505 Tongan
- 1508 Tokelauan
- 1515 Cook Islands Māori
- 2000 North-West European (Specify)

- 3000 Southern and Eastern European (Specify)
- 3103 Southern and Eastern European - Italian
- 3205 Southern and Eastern European - Greek
- 4000 North African and Middle Eastern (Specify)
- 4100 North African and Middle Eastern - Arab (Specify)
- 4907 North African and Middle Eastern - Turkish
- 5000 South-East Asian (Specify)
- 5107 South-East Asian - Vietnamese
- 5201 South-East Asian - Filipino
- 5202 South-East Asian - Indonesian
- 5205 South East Asian - Malay
- 6000 North - East Asian (Specify)
- 6101 North - East Asian - Chinese
- 7000 Southern and Central Asian (Specify)
- 7100 Southern Asian (Specify)
- 7106 Southern and Central Asian - Indian
- 7200 Central Asian (Specify)
- 8100 North American (Specify)
- 8105 Hispanic North American
- 8200 South American (Specify)
- 8300 Central American (Specify)
- 8400 Caribbean Islander (Specify)
- 9000 Sub-Saharan African (Specify)
- 9999 Other (Specify)



# Data sources: ASSET NSW collaboration

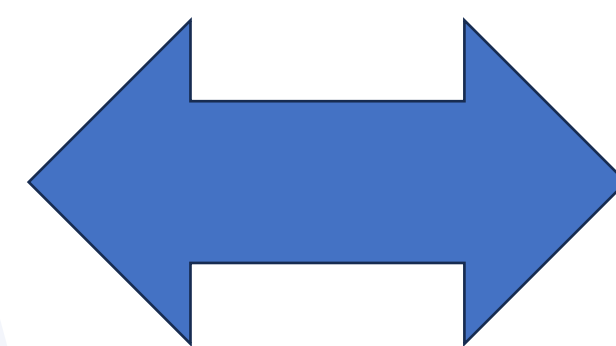
Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)



Ever waitlisted for kidney transplant

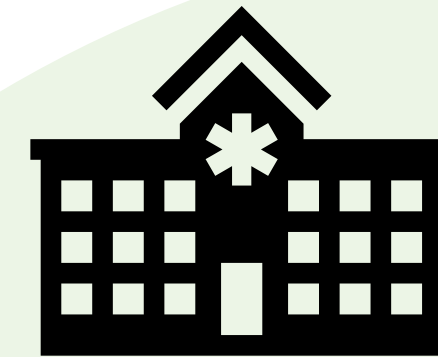


Dialysis & kidney transplant



LINKAGE

Mental Health Living Longer (MHHL)



Hospital admissions

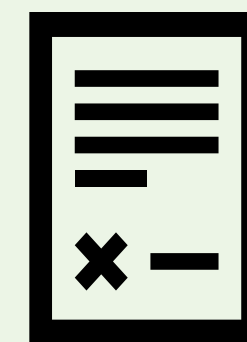
NSW Admitted Patient Data Collection (APDC)

NSW Emergency Department Data Collection (EDDC)

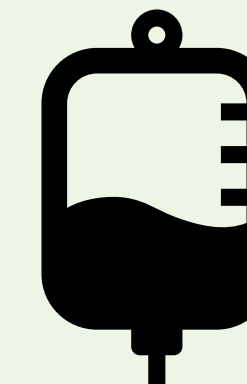


Mental health

Non-admitted mental health (CHAMB)



Death Register



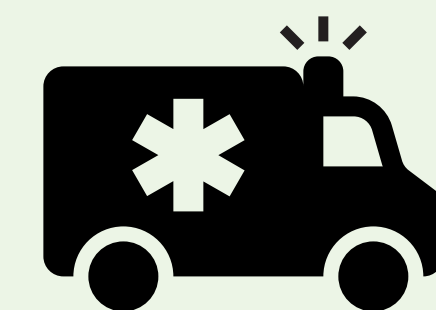
Cancer Registry



Cancer screening

Pap test register

Breast Screen NSW

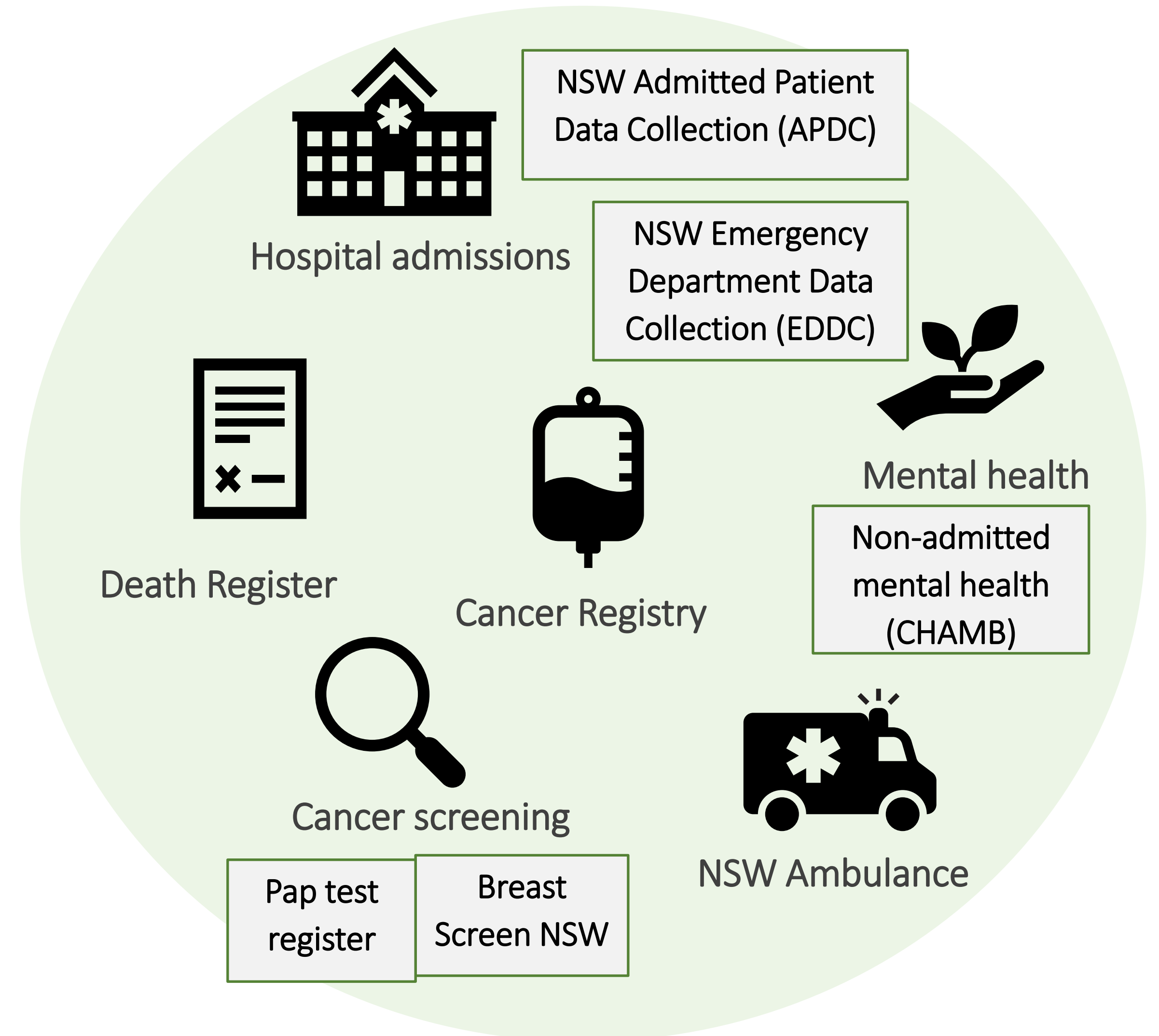


NSW Ambulance

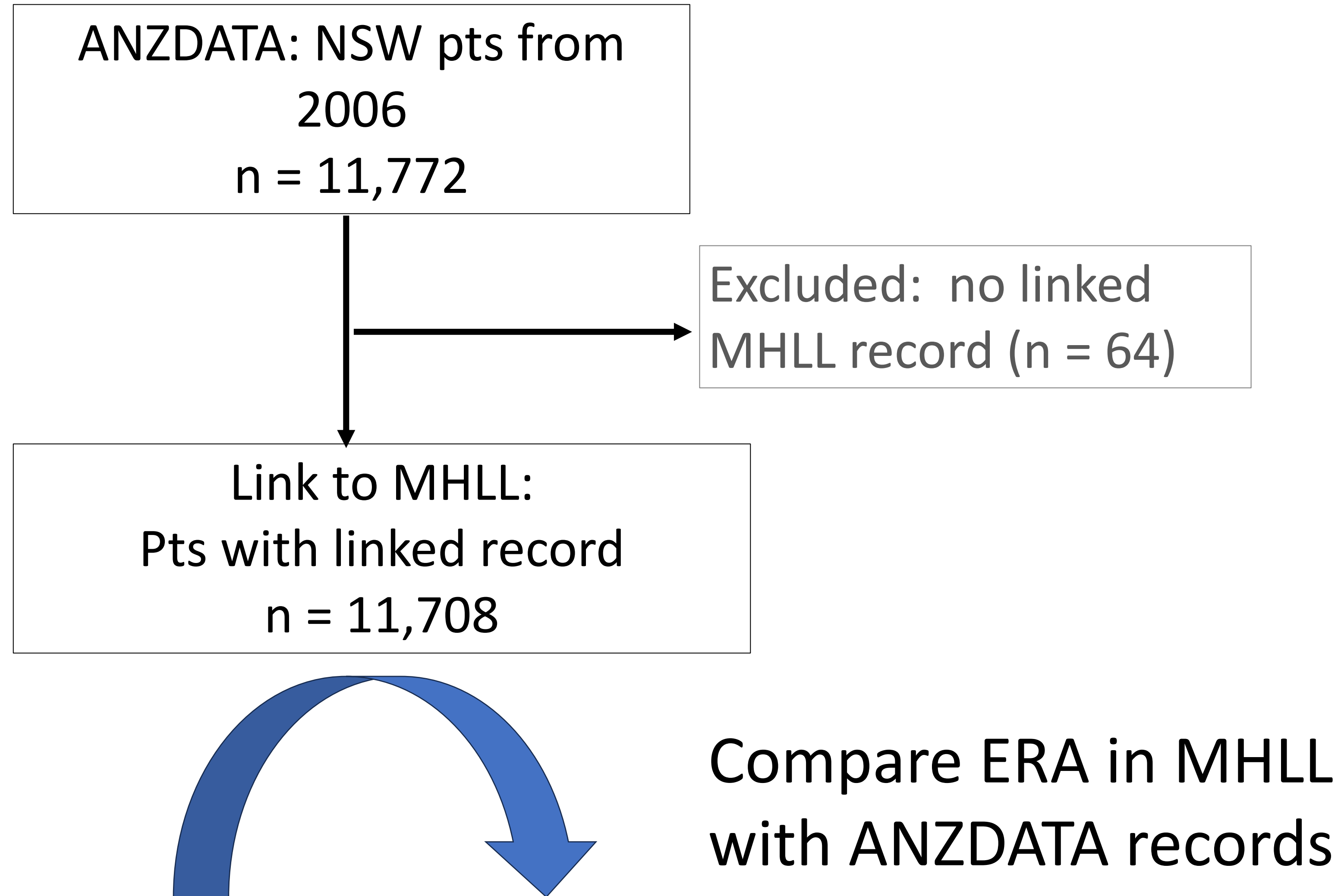
# Enhanced Reporting of Aboriginality (ERA) method

- NSW Health data collections use the national standard indigenous question
- ERA algorithm routinely applied by NSW health to improve reporting of Aboriginality

## Mental Health Living Longer (MHHL)



# Simple validation of ANZDATA Aboriginality



# ANZDATA significantly underestimates Indigenous Australians

- 713 people identified as Aboriginal (6.1% of 11,708)
- ANZDATA: 484 (67.9%) of 713
  - 229 people identified as Aboriginal in NSW health datasets, but not in ANZDATA
- MHLL (ERA): 693 (97.2%)
  - 20 people ANZDATA identified as Aboriginal that NSW health did not

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**Missing were more likely younger, male, more affluent, live in urban area, have less comorbidity**

# Outcomes better for Indigenous Australians unrecognized by ANZDATA

<b>Outcome %</b>	<b>ANZDATA &amp; ERA 464</b>	<b>ERA only 229</b>	<b>P</b>
<b>Waitlisted</b>	17.5	25.3	0.02
<b>Transplanted</b>	11.9	23.1	<0.001
<b>Death</b>	56.5	44.5	0.01



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Data governance critical if we are serious about acting on inequity. We need metrics and we need to maximise value in linkage to elevate our analyses

# ARE YOU OF ABORIGINAL OR TORRES STRAIT ISLANDER ORIGIN?

## Why asking this question is important

The collection of every patient's Indigenous status is necessary for the government and other services to:

- › plan and deliver appropriate health services for all Australians
- › measure the impact of services on particular groups
- › monitor trends and changes in the health and wellbeing of Australians over time.

The most accurate and reliable way to collect Indigenous status is to have patients answer the standard question for themselves.

It is also important to ask because Aboriginal and Torres Strait Islander patients may wish to see an Aboriginal Health Worker, or access specific Medicare services such as a Health Check.

## When to ask the question

The Indigenous status question should be asked at the point of intake, when a patient's other details, such as name, date of birth, and address are being collected.

## How to ask the question

This question should be asked of *all* patients irrespective of appearance, country of birth, or whether you personally know the patient or their family background:



### **'Are you [is the person] of Aboriginal or Torres Strait Islander origin?'**

Patients may be asked the question in person or over the phone, or asked to complete a form.

It is important that the question is asked exactly as it is worded. Changing the question even slightly has the potential to alter the question's meaning, and this may in turn influence the patient's response.

## How to record the answer

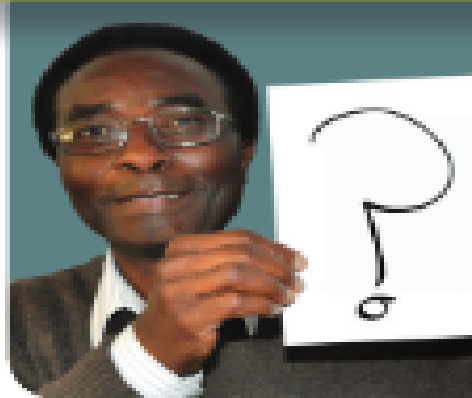
Patients should be provided with at least three response options:

- › No
- › Yes, Aboriginal
- › Yes, Torres Strait Islander

For patients of both Aboriginal and Torres Strait Islander origin, both 'Yes' boxes should be marked.

Alternatively, you may include a fourth response category:

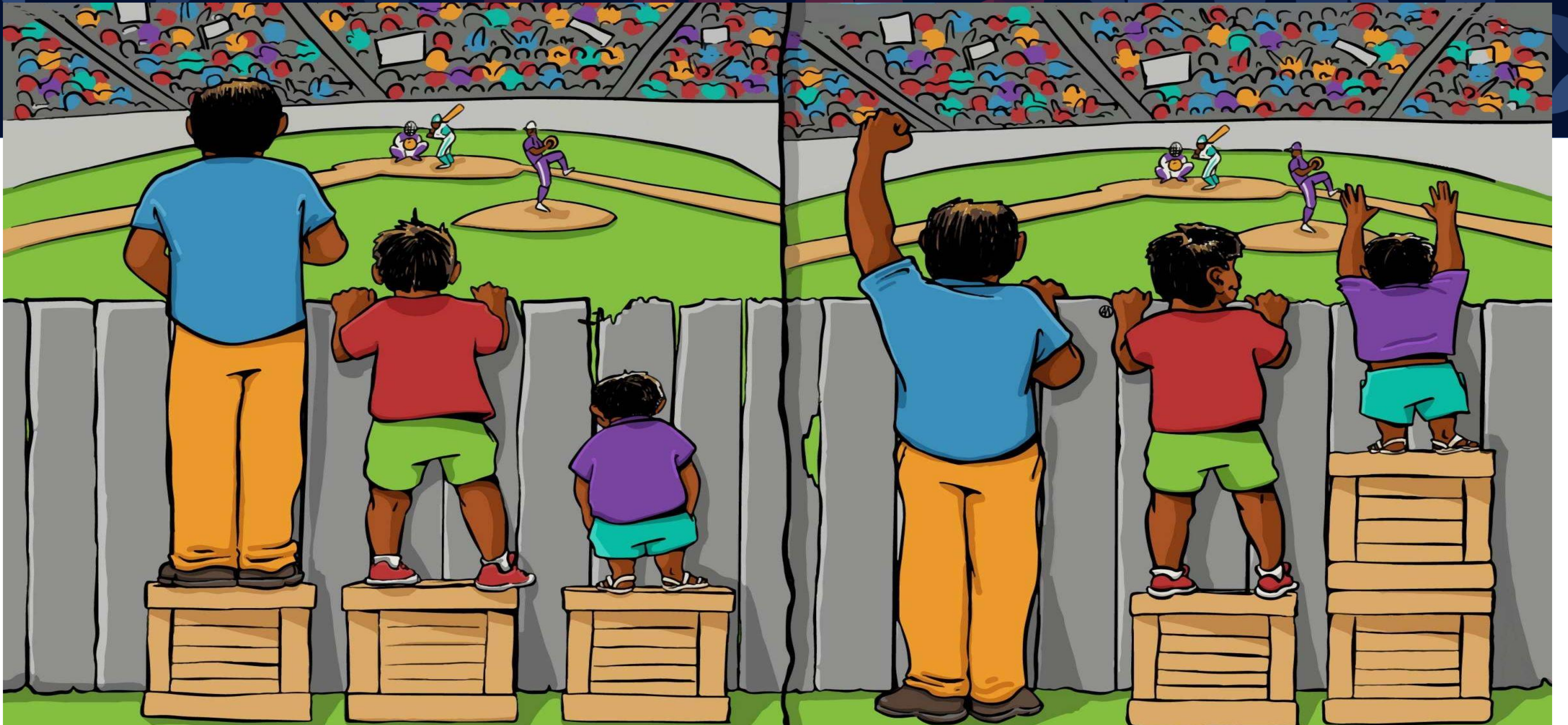
- › Yes, both Aboriginal and Torres Strait Islander



## When a patient is unable to answer

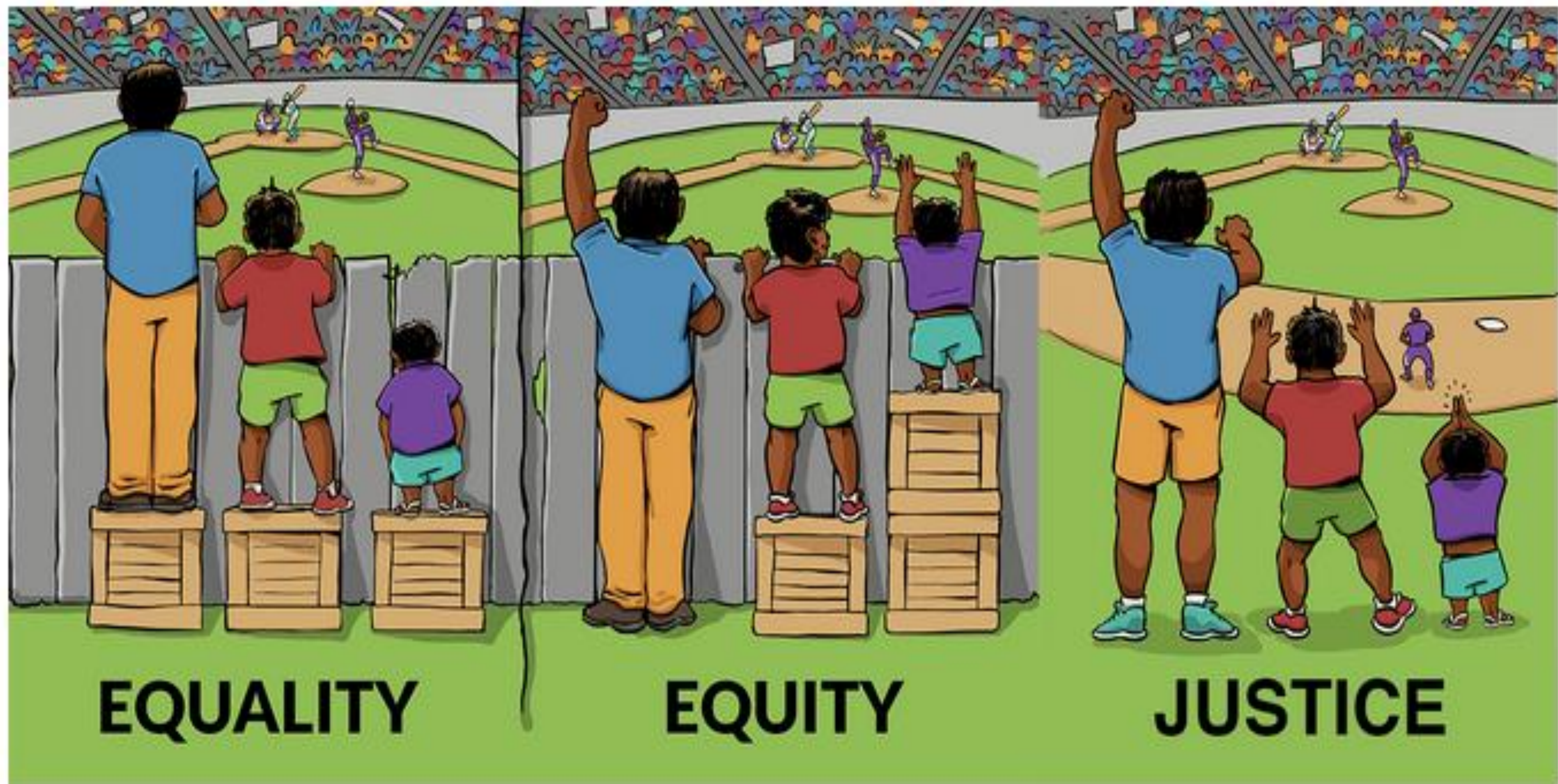
There are some situations when the patient will be unable to answer the question. In these instances it is acceptable for someone else—a close friend, relative or member of the household—to answer on the patient's behalf. You should verify this response with the patient at a later time if possible.





**EQUALITY**

**EQUITY**



(Adaption of work by [Interaction Institute for Social Change](#) | Artist: Angus Maguire)



### New Zealand Investigators

- Dr Nicholas Cross, Te Waipounamu/Waitaha (Canterbury), Te Whatu Ora
- Dr Heather Dunckley, New Zealand Blood Service
- Dr Ben Beaglehole, University of Otago
- Dr Ian Dittmer, Te Toka Tumai (Auckland), Te Whatu Ora
- Dr John Irvine, Te Waipounamu/Waitaha (Canterbury), Te Whatu Ora
- John Kearns
- Dr Curtis Walker, Te Pae Hauora o Ruahine o Tararua (MidCentral), Te Whatu Ora
- Merryn Jones, Kidney Health New Zealand

### Sydney School of Public Health, University of Sydney

- Dr Nicole De La Mata
- Prof Angela Webster
- A/Prof Patrick Kelly
- Prof Kate Wyburn

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Centre for  
Organ •  
Donation  
Evidence



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SYDNEY

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# Questions?



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