CARDIOVASCULAR RESEARCH GROUP
SCHOOL OF POPULATION AND GLOBAL HEALTH

THE UNIVERSITY OF WESTERN AUSTRALIA

End RHD in Australia: Study of Epidemiology (ERASE) Project

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NHMRC

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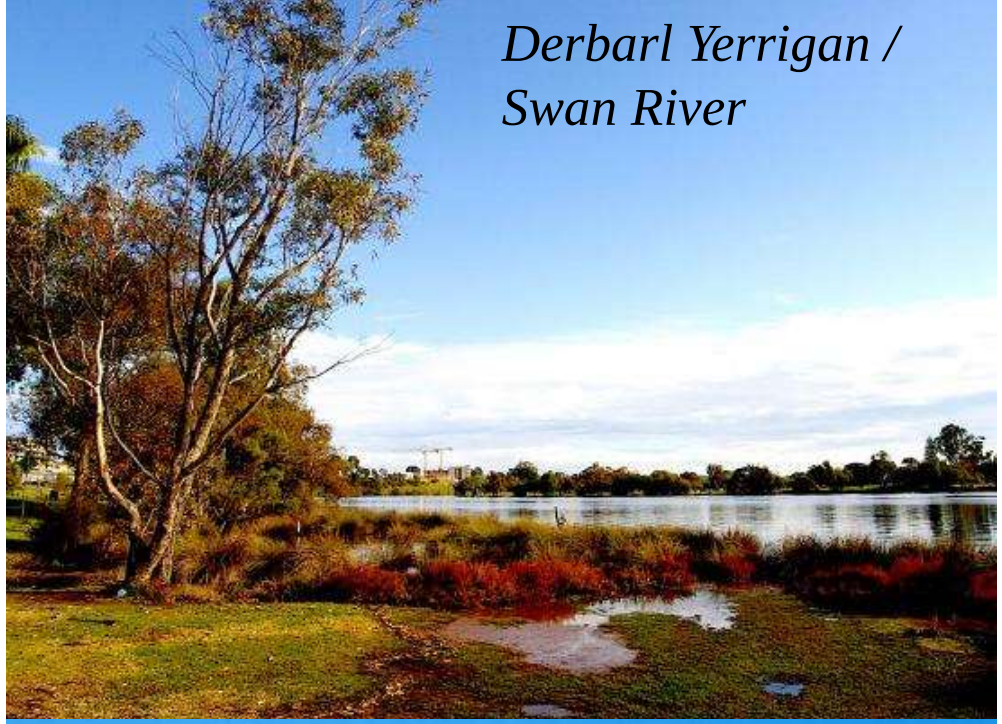
Heart Foundation



I would like to acknowledge the Wadjuk Noongar people - the Traditional Custodians of the land I am today

Outline of presentation

- Background to ERASE study
- Methods
- Key results
- Way forward – End RHD Strategy – Dr Katharine Noonan

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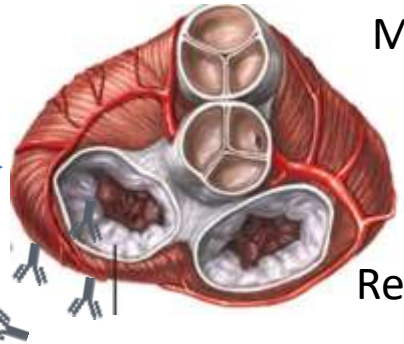
SEEK WISDOM

Natural history of RHD

1-4 days

Strep throat

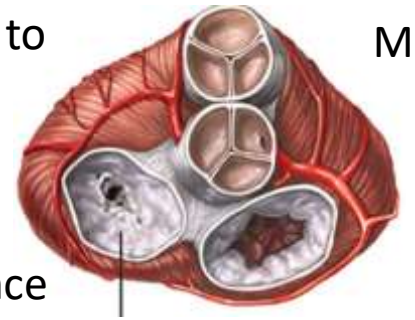
2-6 weeks



Acute Rheumatic fever
joints
heart
skin
brain

Months to years

Recurrence



RHD
Chronic heart valve damage

Months to years

Death

RHD Complications

Primordial

Addressing
- Living conditions
- SE circumstances

Improving
- Access to healthcare
- Hygiene

Primary

- Aggressive treatment against strep throat

Secondary

- RF-RHD registers
- Secondary prophylaxis of antibiotics

Tertiary

- Medical management of RHD symptoms
- Cardiac surgery

Rheumatic fever & rheumatic heart disease in Australia: Evidence of two concurrent patterns

Non-Indigenous

- Previous epidemic before 1960s
- ARF/RHD comprised high % of patients on the wards

Indigenous

- Currently endemic
- RHD mortality rates 18x higher
- ~6,000 people on RHD Registers, >90% Indigenous

END
RHD
CRE

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End RF/RHD in Australia

Research, Advocacy, Action

Produce a roadmap of actions to remove RHD as a PH problem in Australia

Wyber R et al. The Endgame for RHD in Australia – forthcoming 2020.

Need for epidemiological data as a baseline for:

- **Planning**
- **Monitoring**
- **Engaging communities as partners**
- **Advocacy**

End RHD in Australia: Study of Epidemiology (ERASE)

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AIM: To characterise the epidemiology and management of ARF/RHD in selected jurisdictions harnessing linked health data.

NHMRC

RHD linked data analysis (WA, QLD, SA, NT, NSW)

Health Systems Research
What factors impact on implementation of known strategies?

Methodology:
*Case identification using ICD 10
*Adherence index
*ARF episode defs

Burden of ARF/RHD (Stage 1)
- Incidence
- Prevalence
* Mortality/Survival

Outcomes (Stage 2)
- Progression, Complications
- Impact of interventions
- Service utilisation & costs

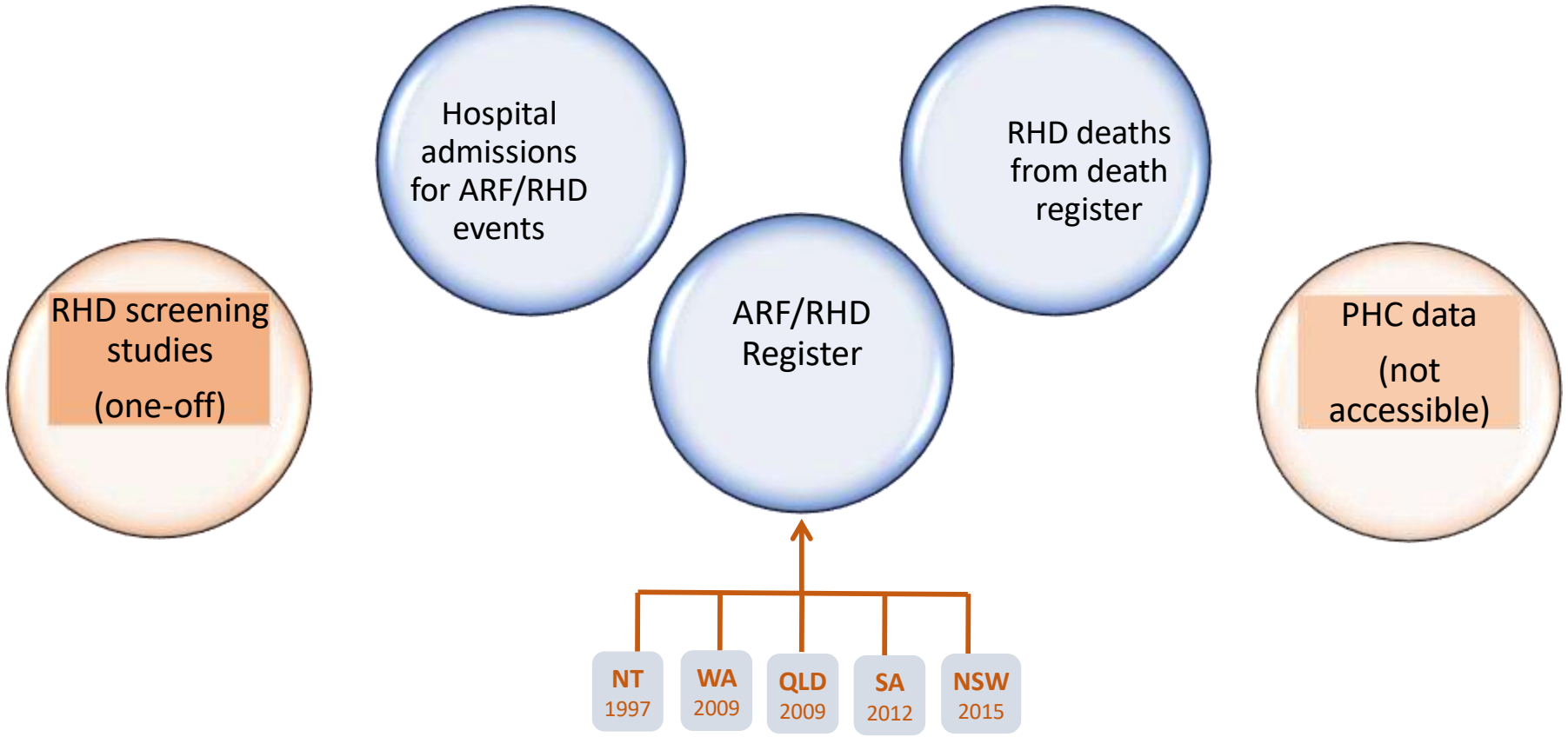
Acknowledgements

- Peak Aboriginal health organisations in each State
- Data linkage units and custodians from each jurisdictions
- Funding: HeartKids and NHMRC

Analytic team	Chief investigators	Assoc Investigators
Daniela Bond-Smith	JM Katzenellenbogen	Alex Brown
Rebecca Cunneen	Anna Ralph	Rosemary Wyber
Jeffrey Cannon	Dawn Bessarab	Vicki Wade
Ingrid Stacey	Lee Nedkoff	Jonathan Carapetis
Melanie Greenland	Frank Sanfilippo	Kalinda Griffiths
Karen Dempsey	Joe Hung	Christopher Reid
Hideo Tohira	Nick de Klerk	Graeme Maguire
Sara Noonan	Elizabeth Geelhoed	Jess de Dassell
Emma Haynes	Daniel Williamson	Fadwa Al-Yaman
Alice Mitchell	Angelita Martini	Anne Russell
Geri Vaughan		Mellise Anderson

DEVELOPING APPROPRIATE METHODS

Potential sources of data for ARF/RHD

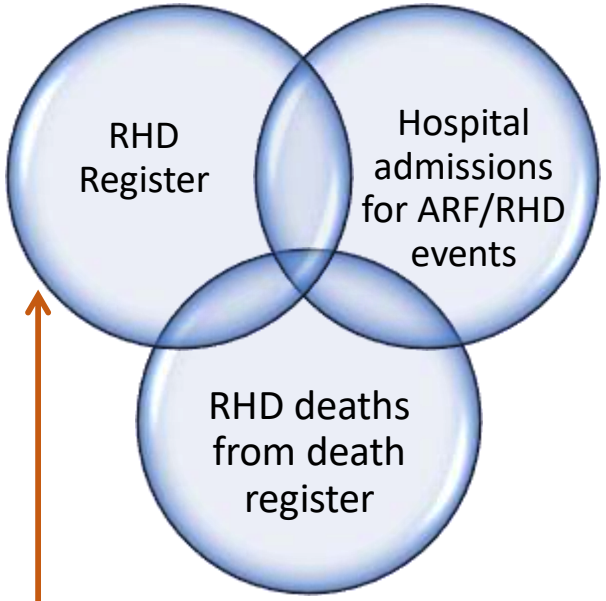


Linked data sources: data generating cohort

WA, SA, NT, QLD, NSW

Challenges – jurisdictional RHD registers

- Disparate data platforms
- Often reliance on manual entry
- Missing data
- Variable coverage



Challenges – hospital data

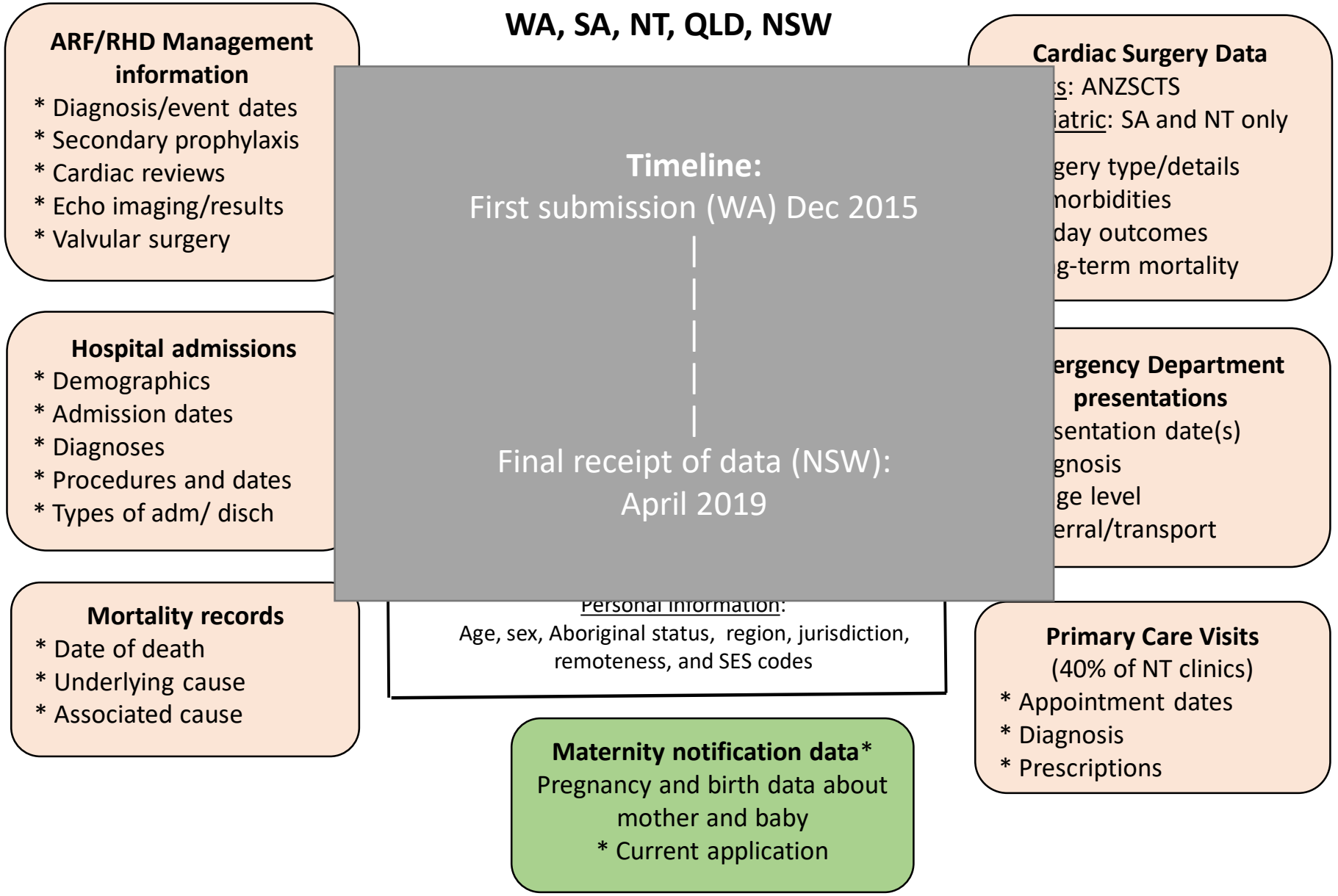
1. Not all diagnosed cases are admitted
2. Systematic problems with ICD codes for RHD= high false +ves

<u>Harmonisation across jurisdictions</u> Identification of initial and episode dates/ episode

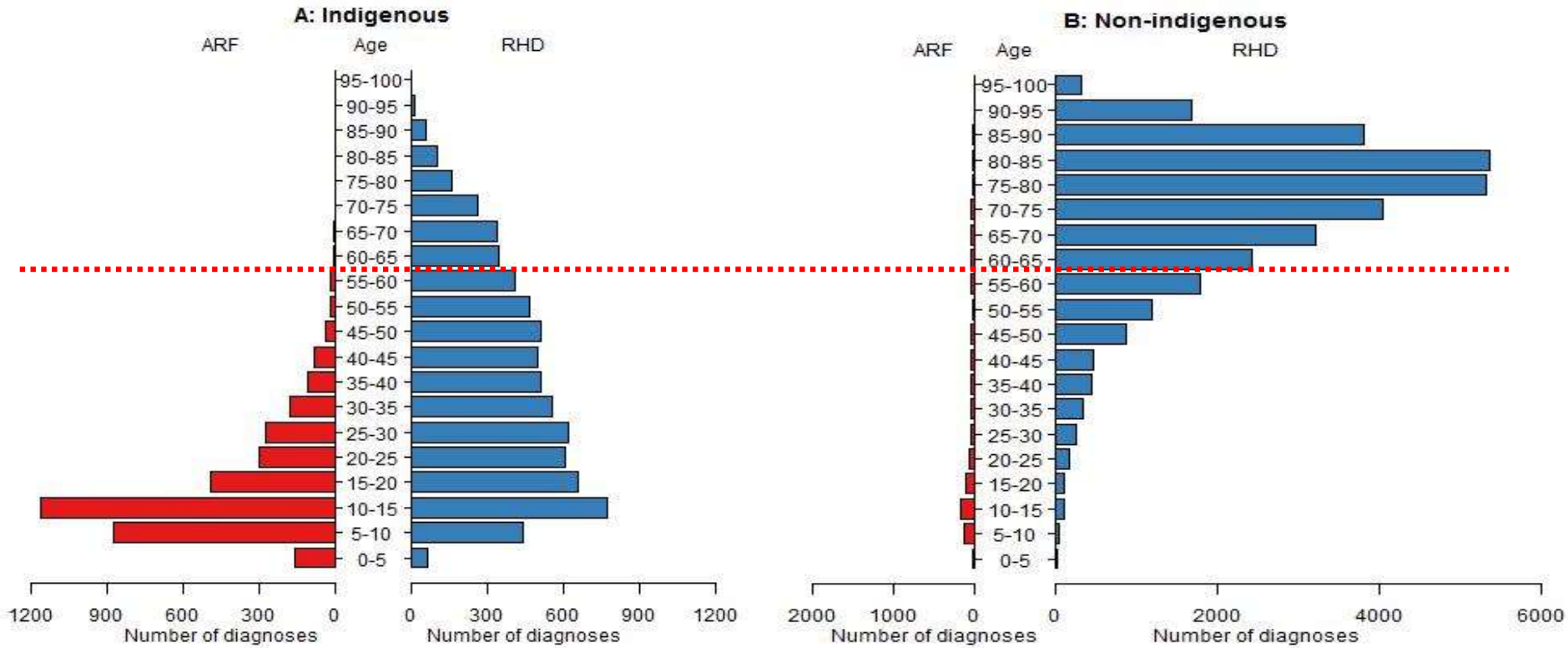
<u>Data-driven Prediction algorithm for RHD</u>: Generalized linear mixed model applied to linked data

Bond-Smith et al: 2020

Data sources: cohort definition & additional information



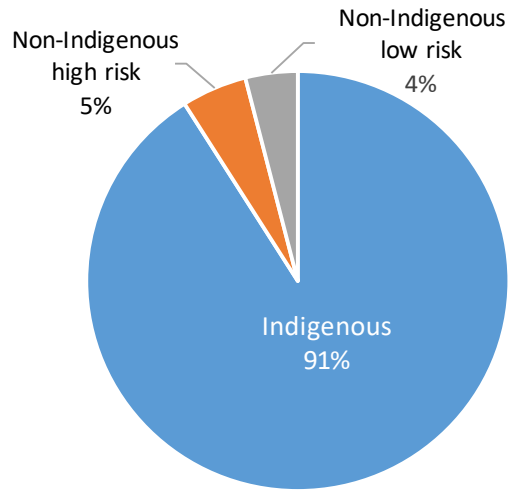
Age-pyramid: ANALYSIS COHORT (0+ years)



Restricted to persons <60 years

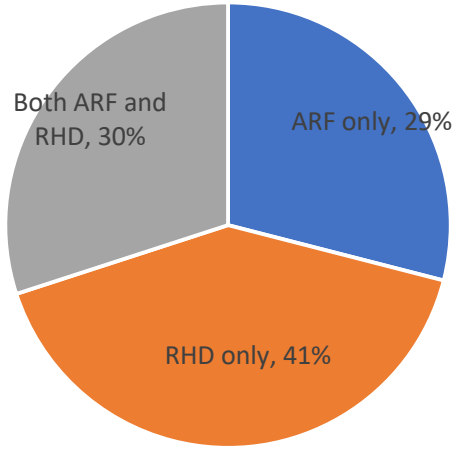
Register cohort

Population category

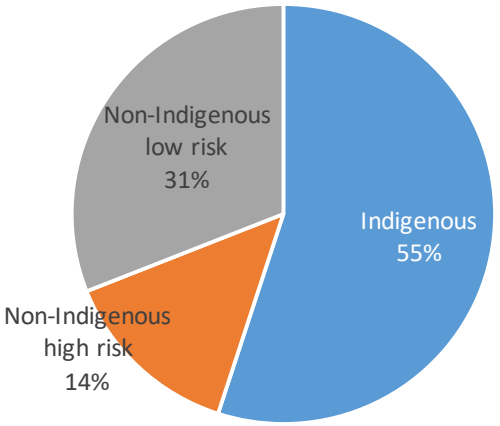


Median age at diagnosis 17 years

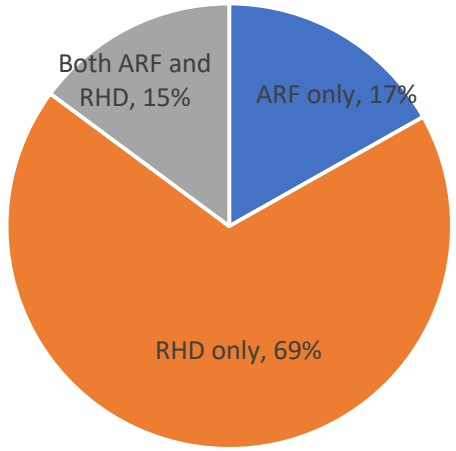
Diagnosis at end of follow-up



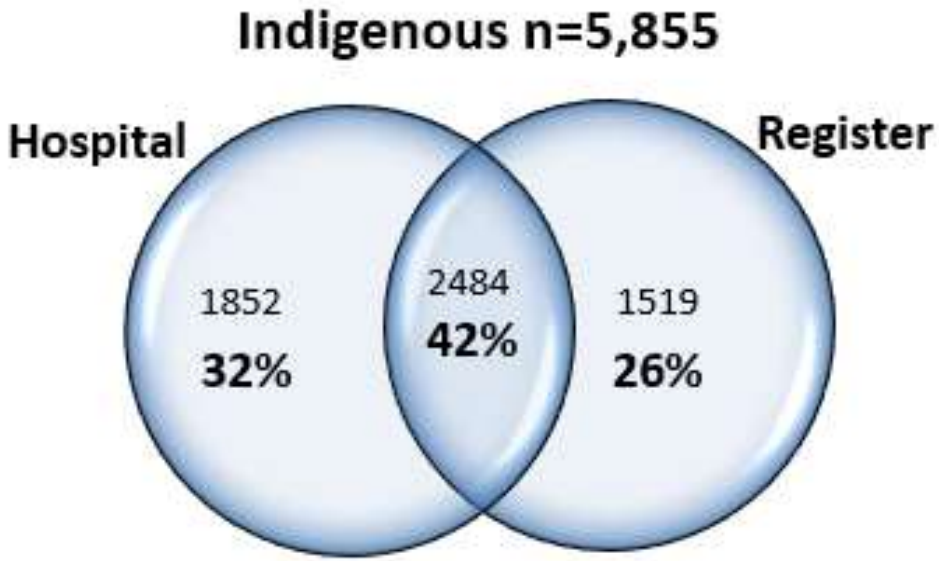
Analysis cohort

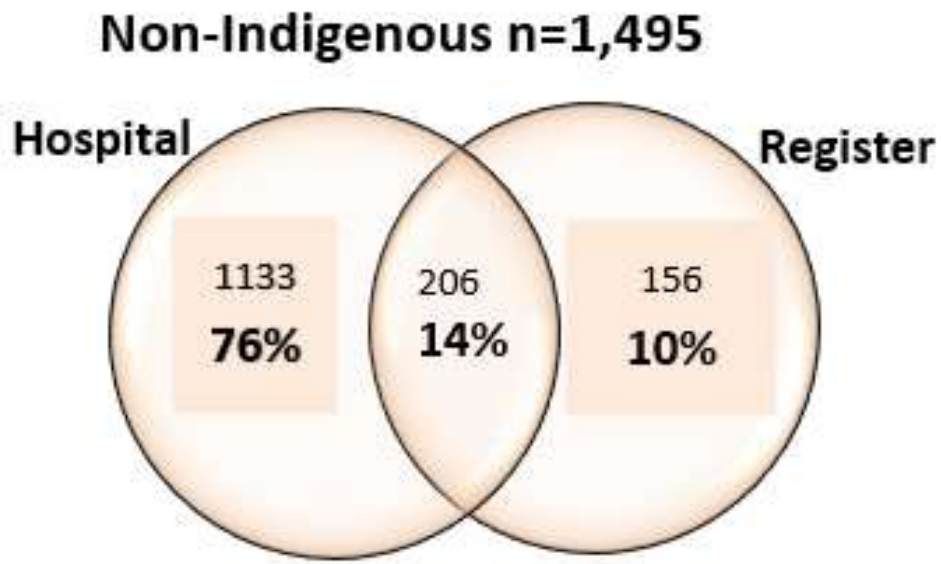


Median age at diagnosis 36 years



Evaluation of case capture: hospital vs registers
(considering only periods in which registers existed)



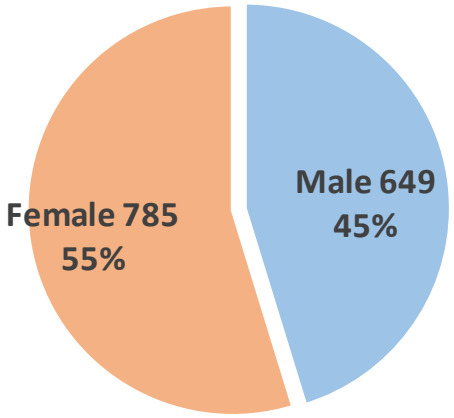


Ages 3-59 years at time of diagnosis
At least one calendar year following register establishment
Excluding NSW

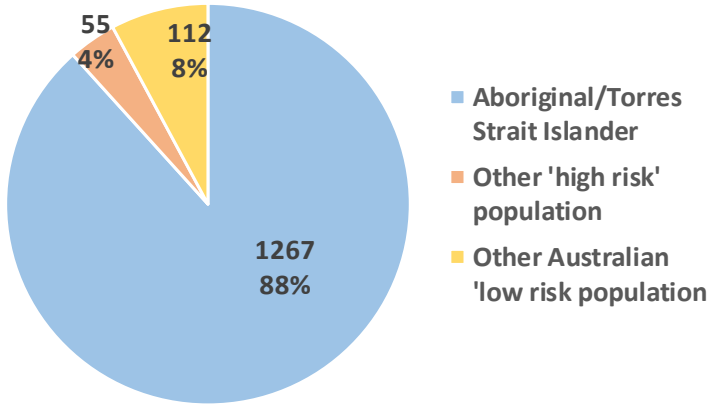
Agenson T et al. Case ascertainment on Australian ARF/RHD registers; Int J Env Research & Pub Hlth (in press)

RESULTS: Burden of Disease

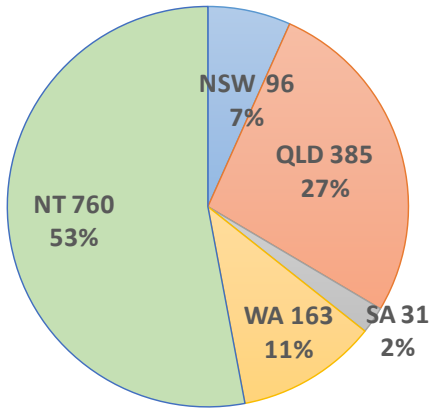
1. Profile of all ARF episodes (2015-2017) (n=1425)



Gender

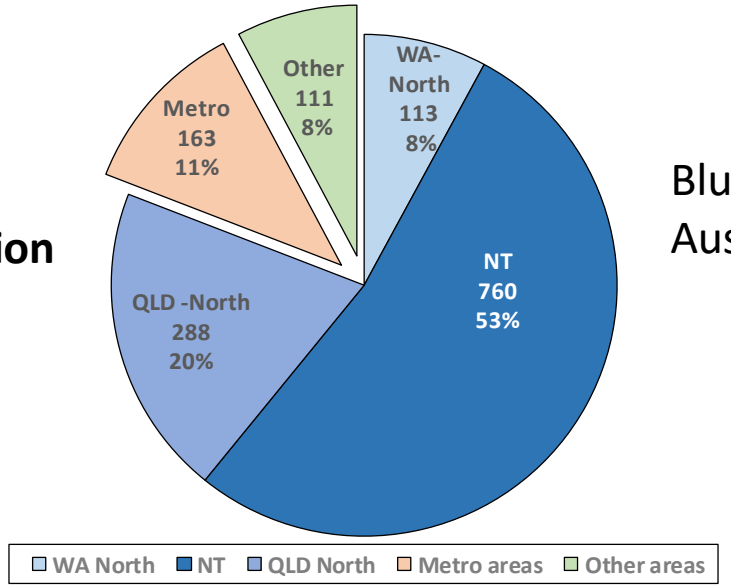


Ethnicity



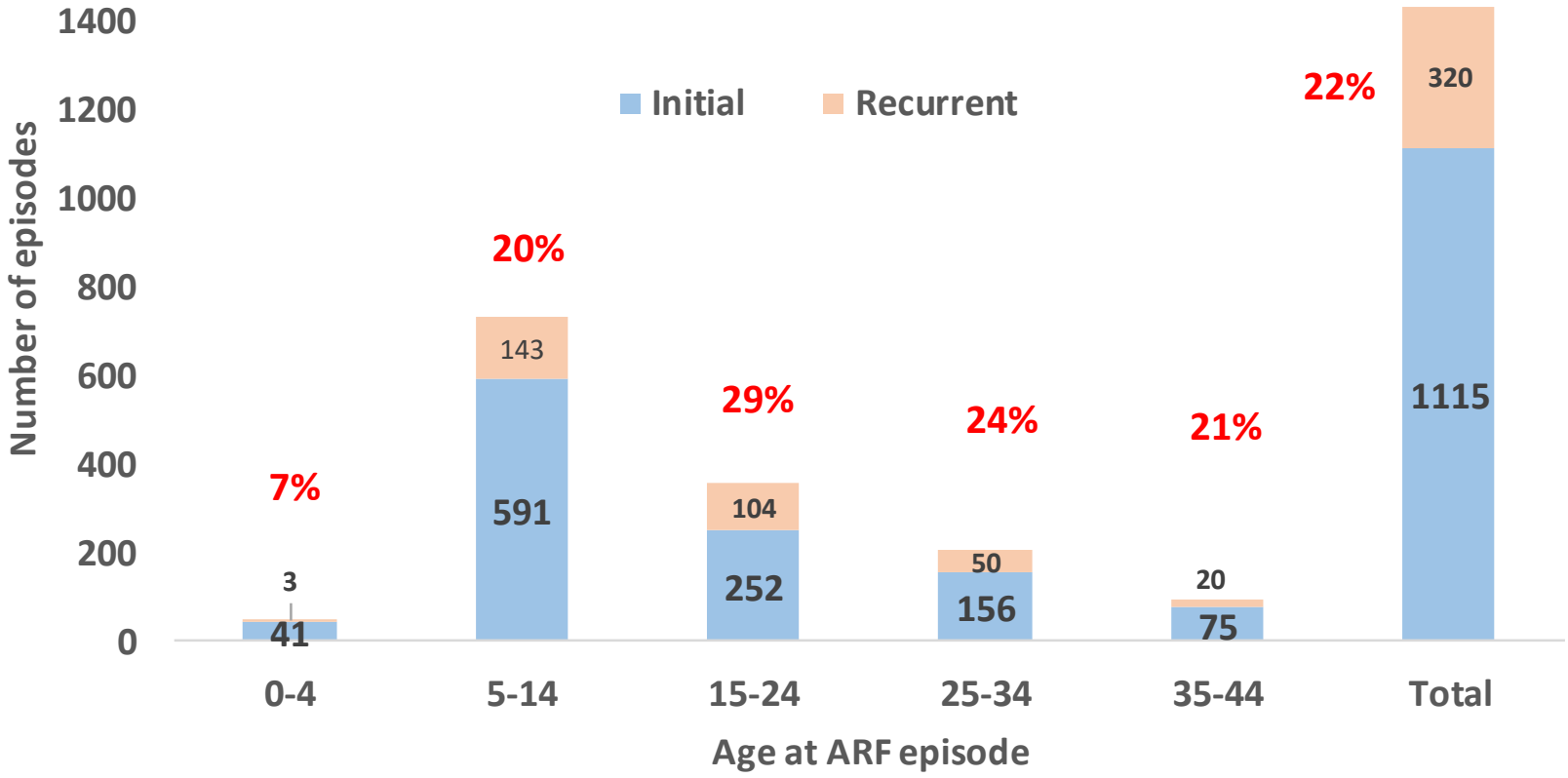
State/Territory

Indigenous Region Category

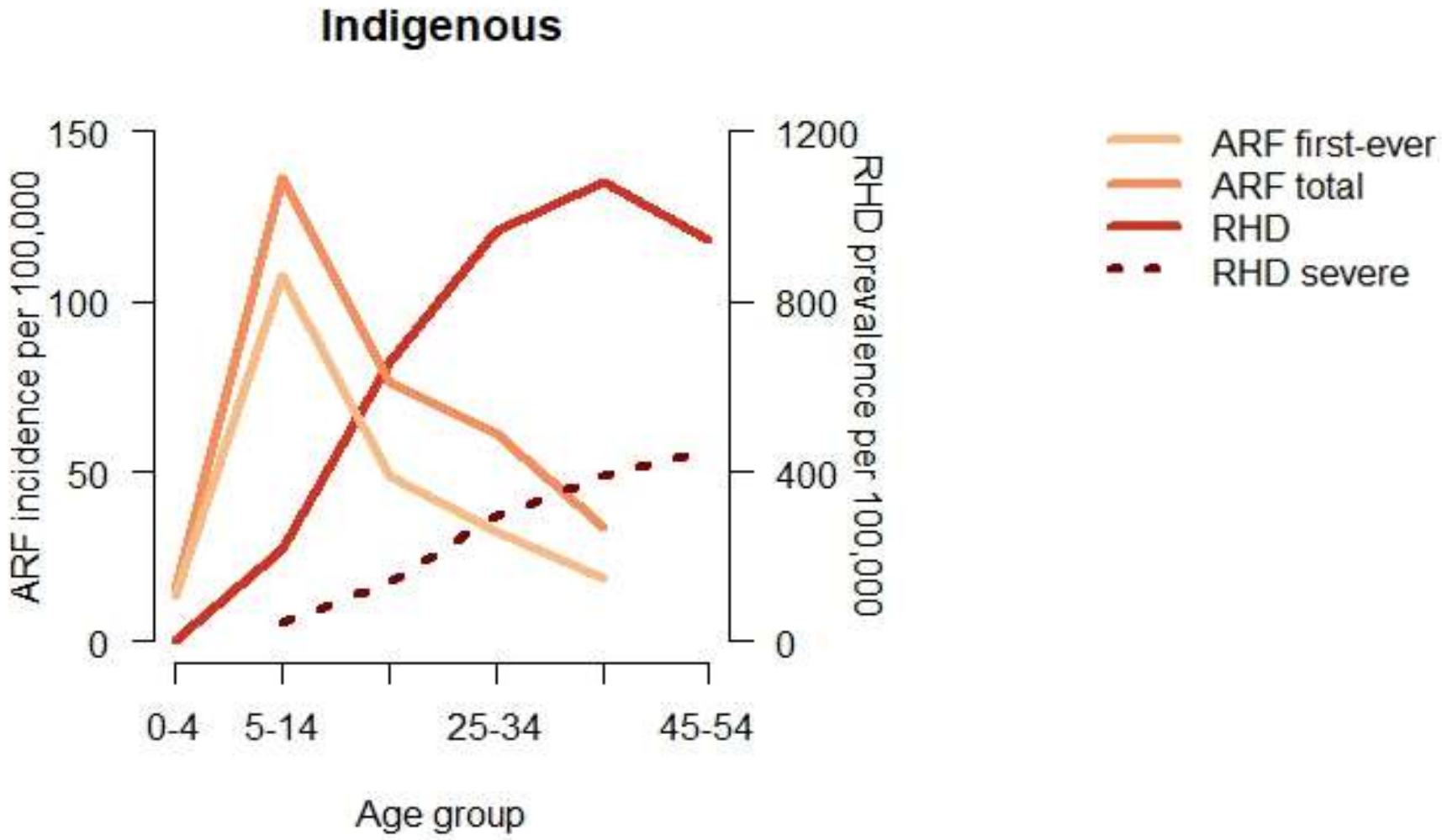


Blue= Northern Australia 81%

ARF episodes by age and type (2015-2017) (n=1435)



Age-specific rates of ARF incidence (first-ever and total) and RHD (severe and total) 2015-2017, by Indigenous status



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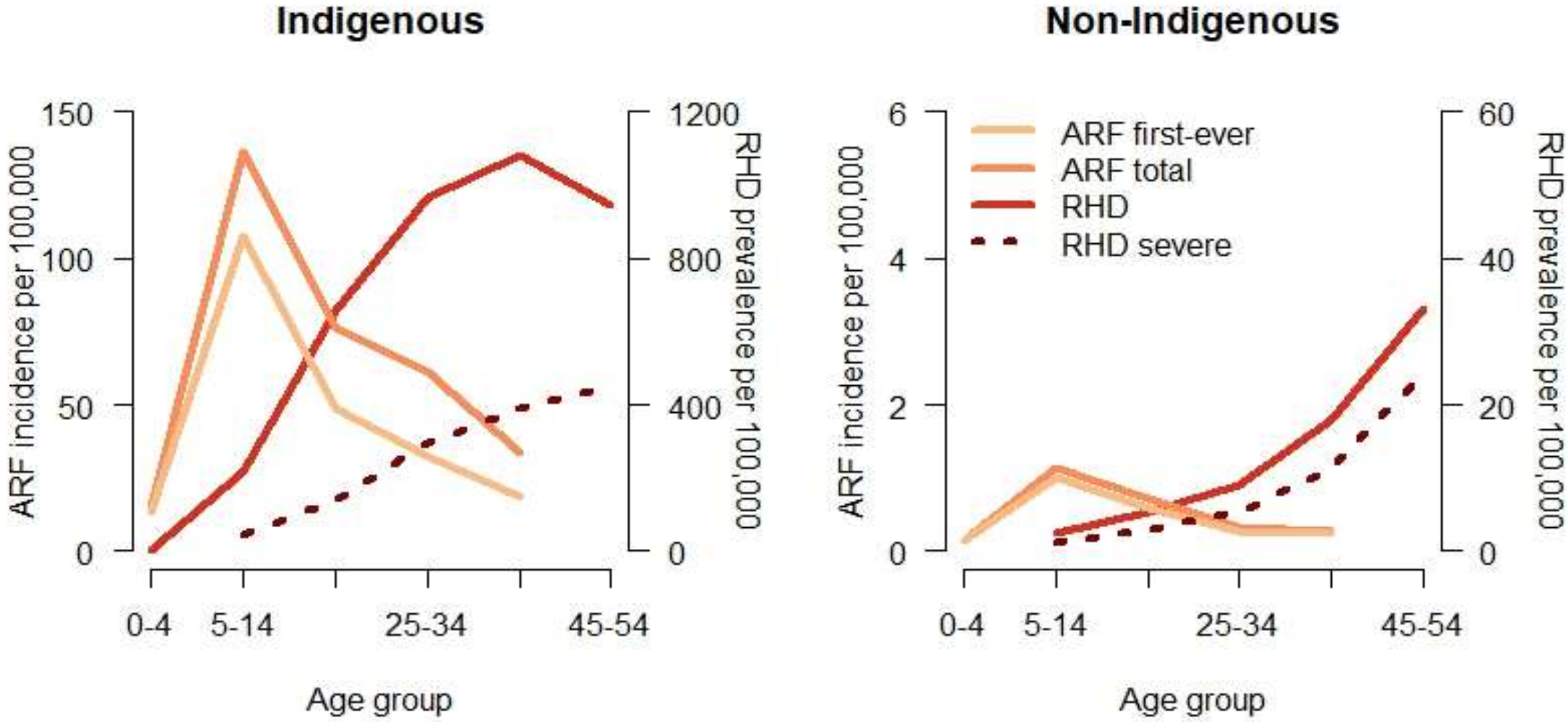
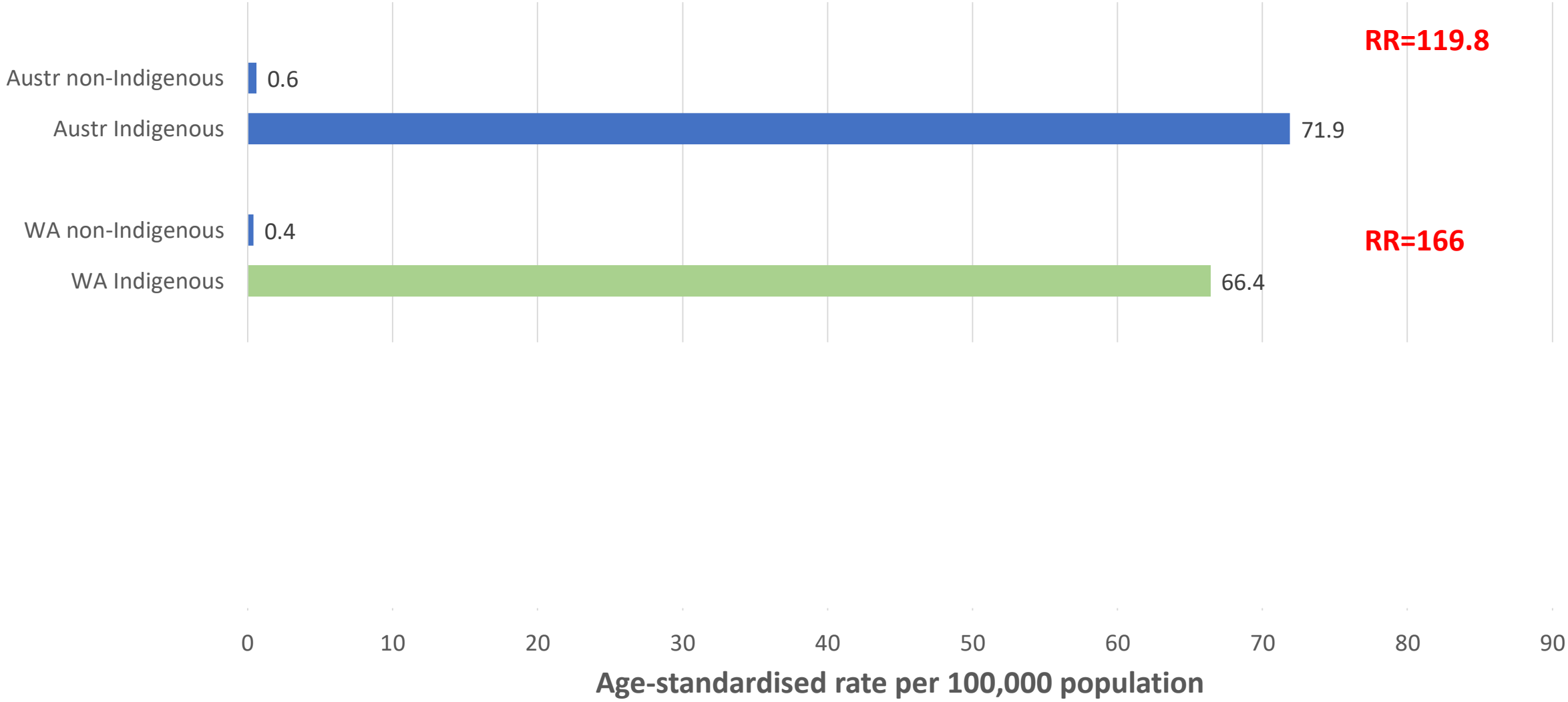


Age-standardised ARF rates (0-44 years): SA, NT, WA, QLD, NSW (2015-2017)



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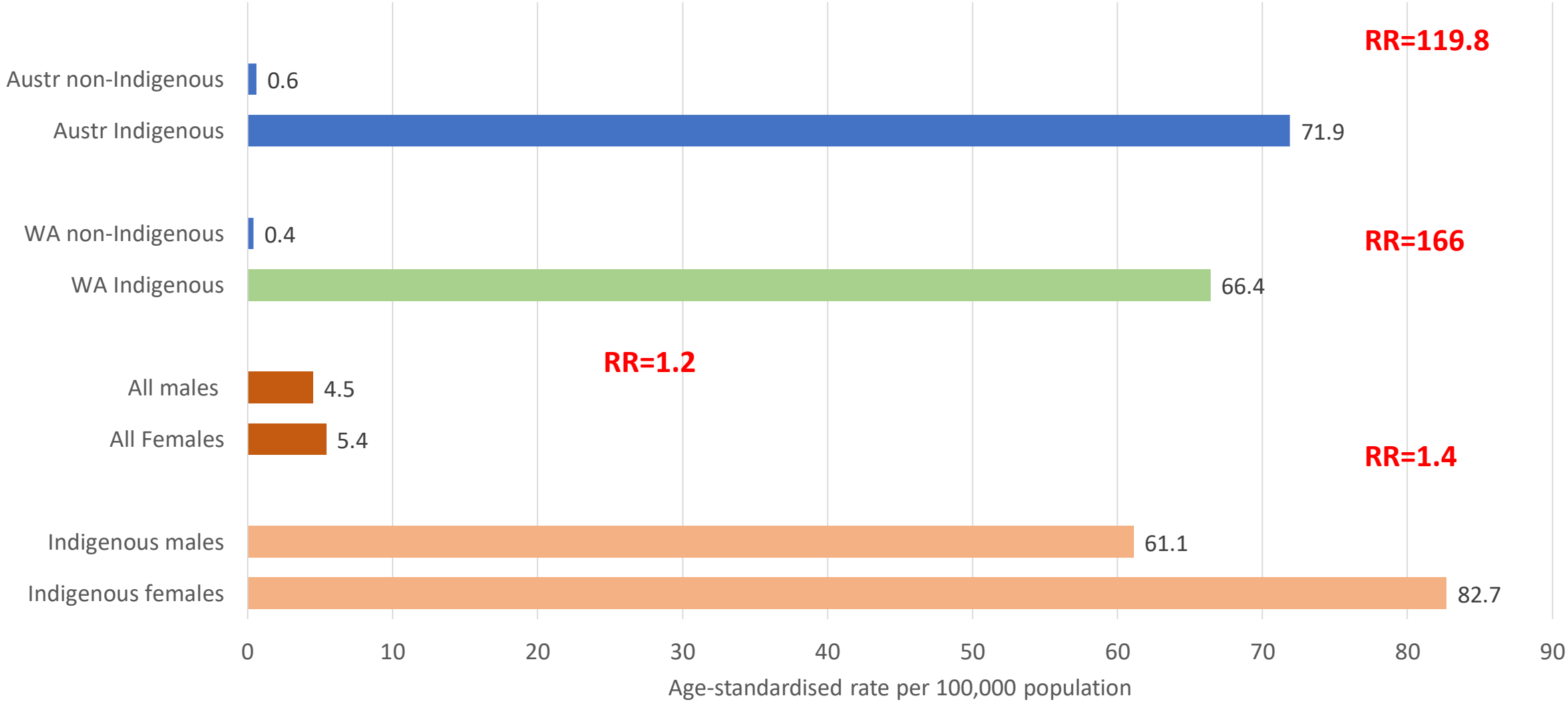
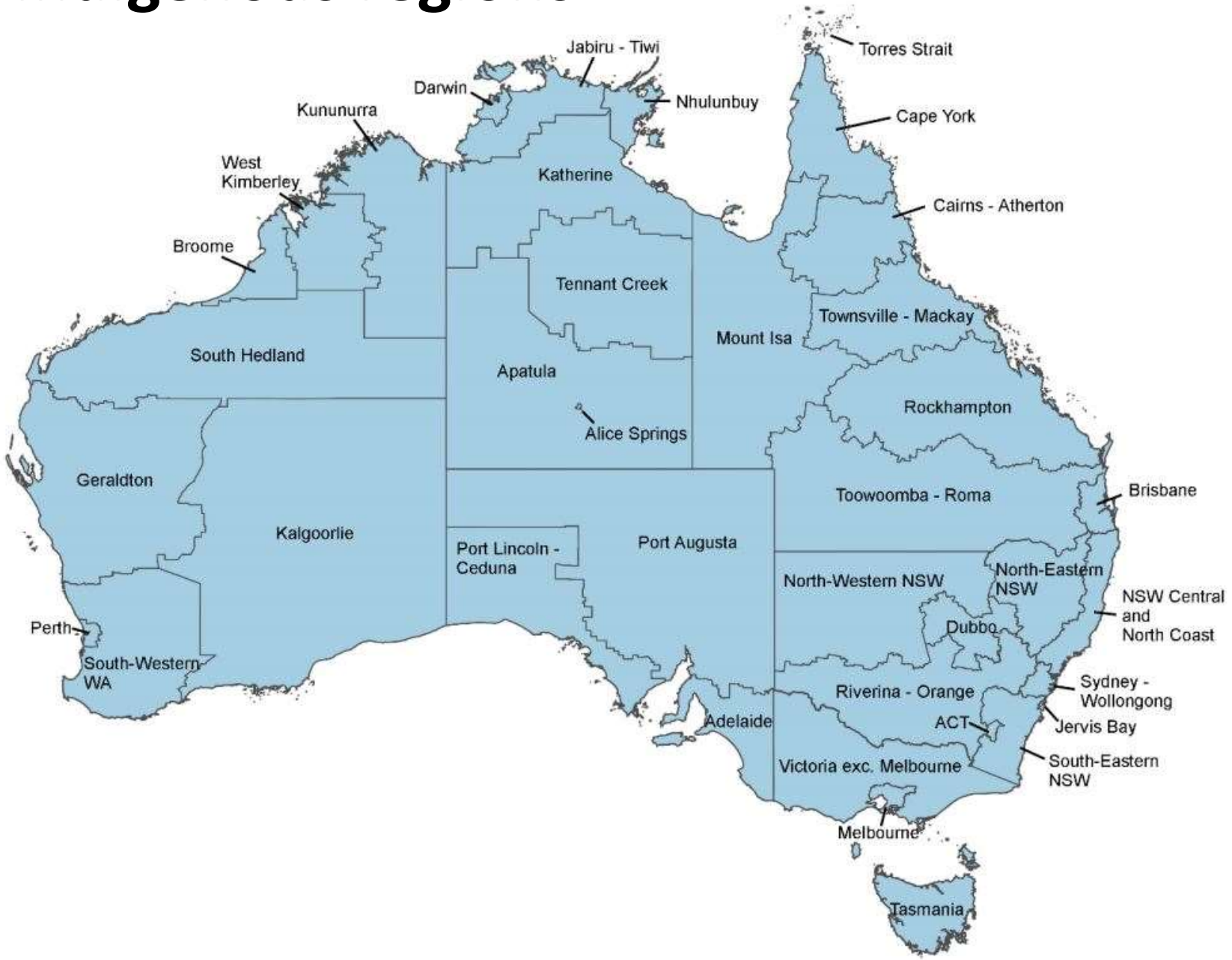


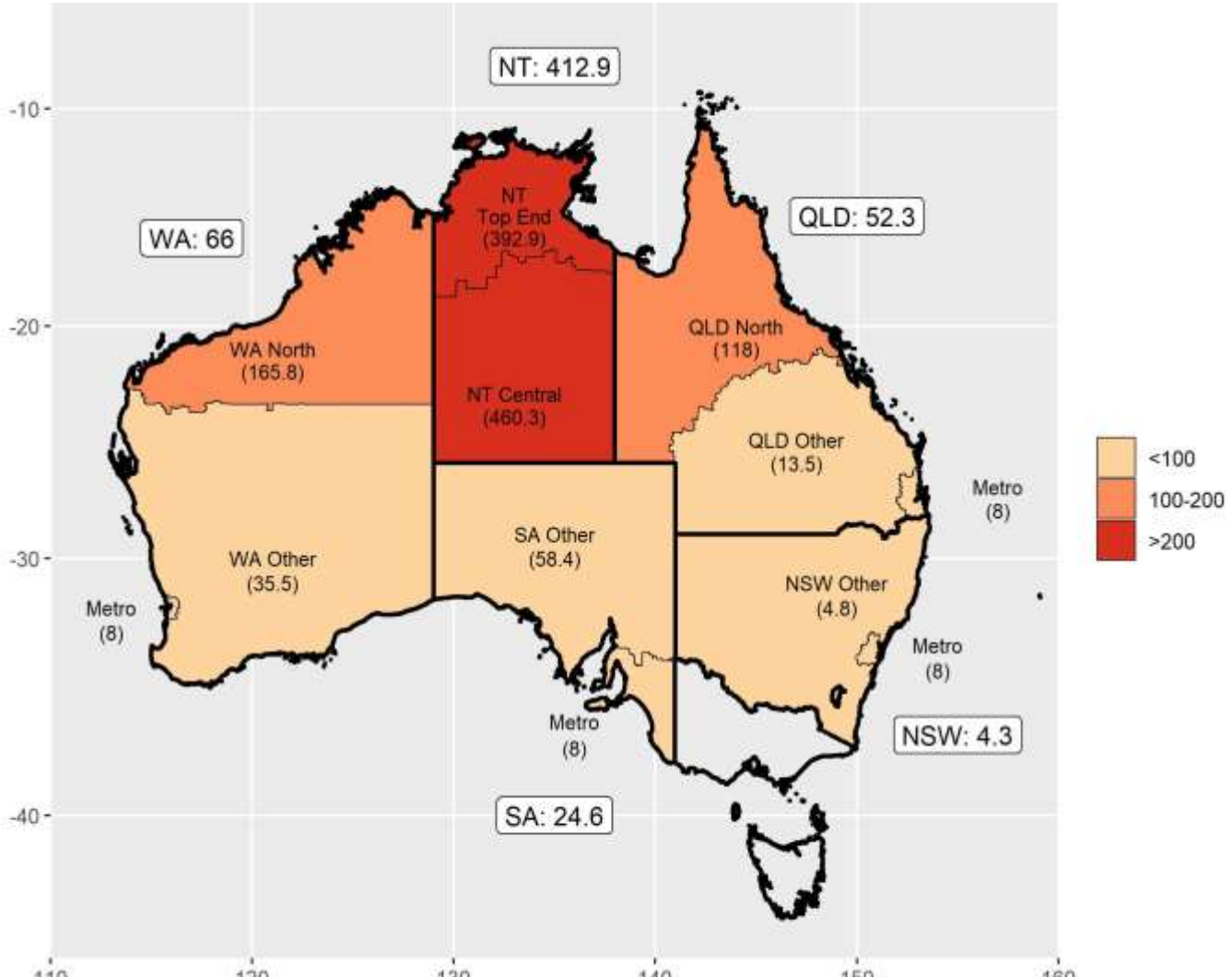
Indigenous regions

Data from 33 of 38 regions

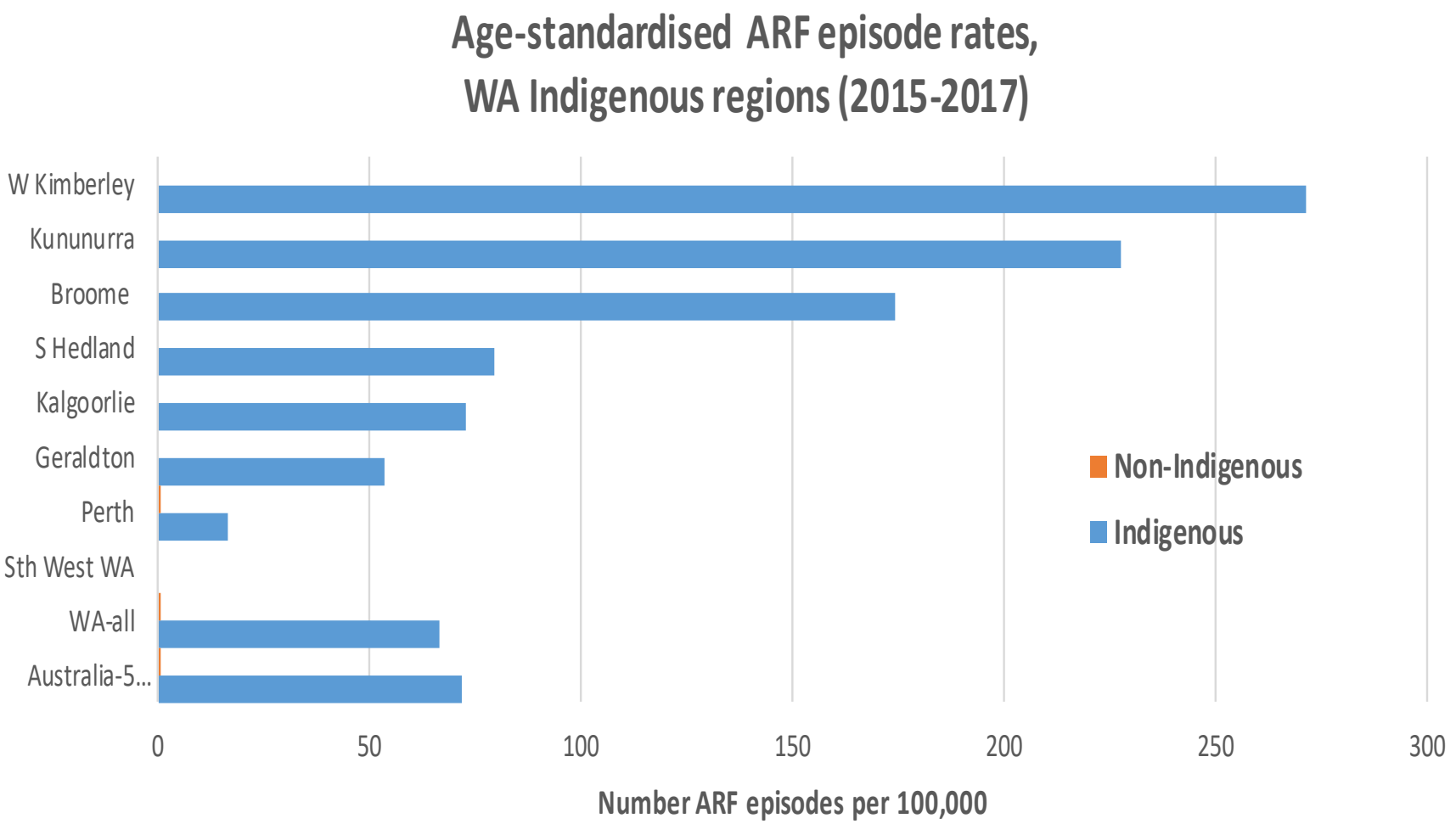


Dubbo, NSW	NSW Other
North-Eastern NSW	NSW Other
North-Western NSW	NSW Other
NSW Central and North Coast	NSW Other
Riverina - Orange	NSW Other
South-Eastern NSW	NSW Other
Sydney - Wollongong	Metro
Brisbane	Metro
Cairns - Atherton	QLD North
Cape York	QLD North
Mount Isa	QLD North
Rockhampton	QLD Other
Toowoomba - Roma	QLD Other
Torres Strait	QLD North
Townsville - Mackay	QLD North
Adelaide	Metro
Port Augusta	SA Other
Port Lincoln - Ceduna	SA Other
Broome	WA North
Geraldton	WA Other
Kalgoorlie	WA Other
Kununurra	WA North
Perth	Metro
South Hedland	WA North
South-Western WA	WA Other
West Kimberley	WA North
Alice Springs	NT Central
Apatula	NT Central
Darwin	NT Top End
Jabiru - Tiwi	NT Top End
Katherine	NT Top End
Nhulunbuy	NT Top End
Tennant Creek	NT Central

Age-standardised rates of acute rheumatic fever in Indigenous people under 45 years, by region & State



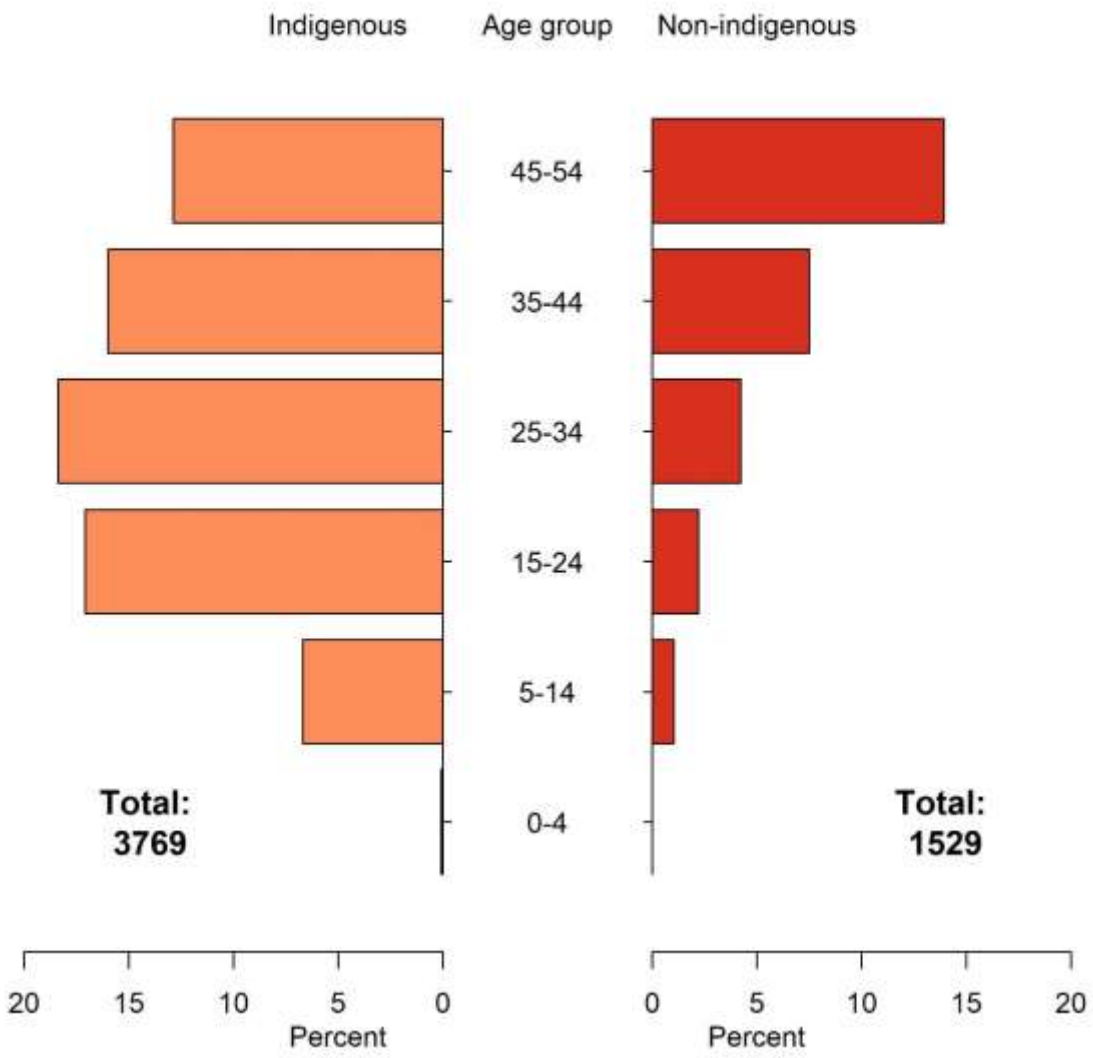
ACUTE RHEUMATIC FEVER IN WA



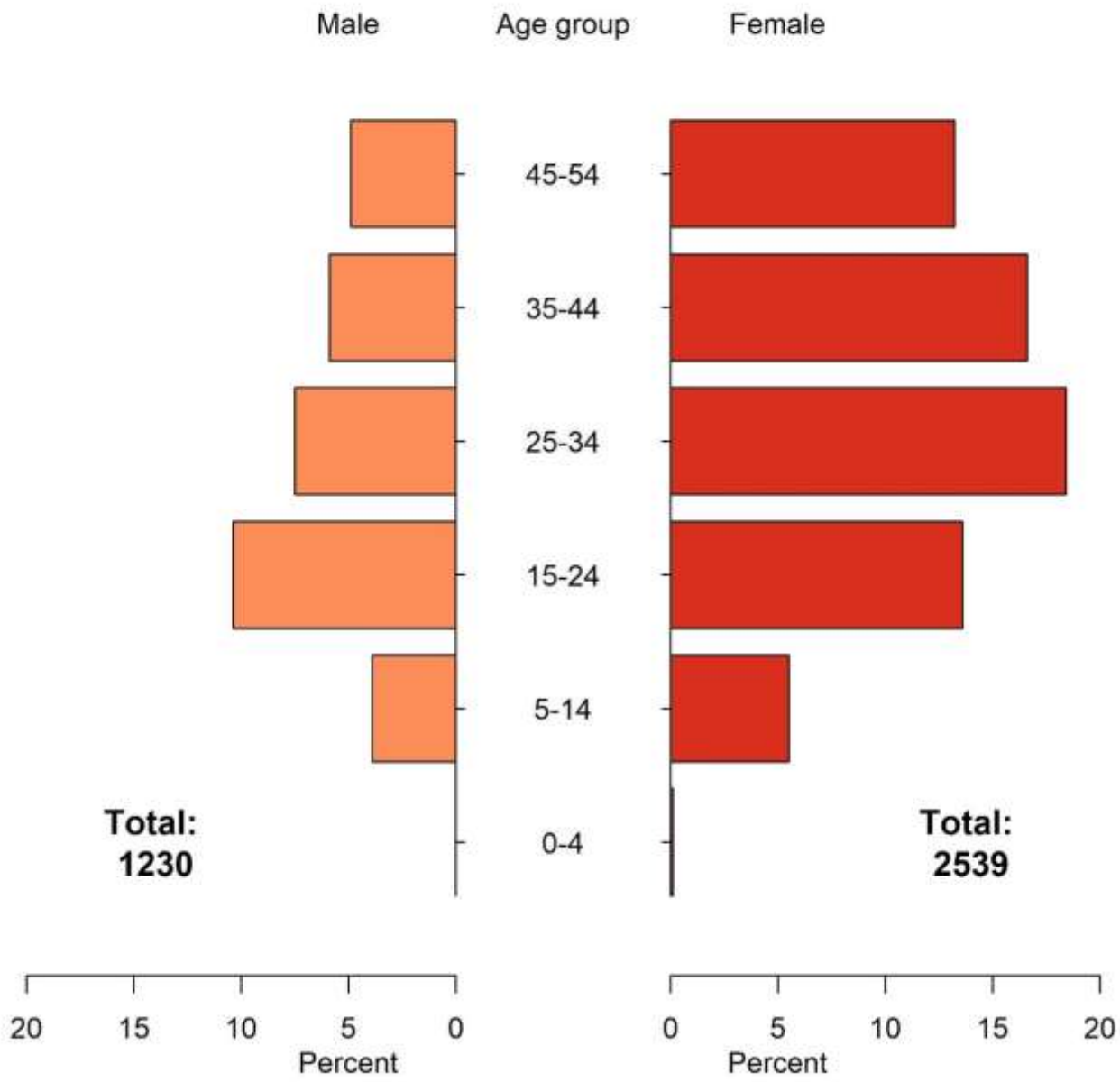
ARF episode counts

	Indigenous	Non-Indigenous	Total
W Kimberley	39	< 5	39
Kununurra	33	< 5	33
Broome	25	< 5	25
S Hedland	22	< 5	22
Kalgoorlie	14	< 5	14
Geraldton	11	< 5	12
Perth	17	5	22
Sth West WA	< 5	< 5	<5
WA-all	165	6	171
Australia-5 States	1265	159	1425

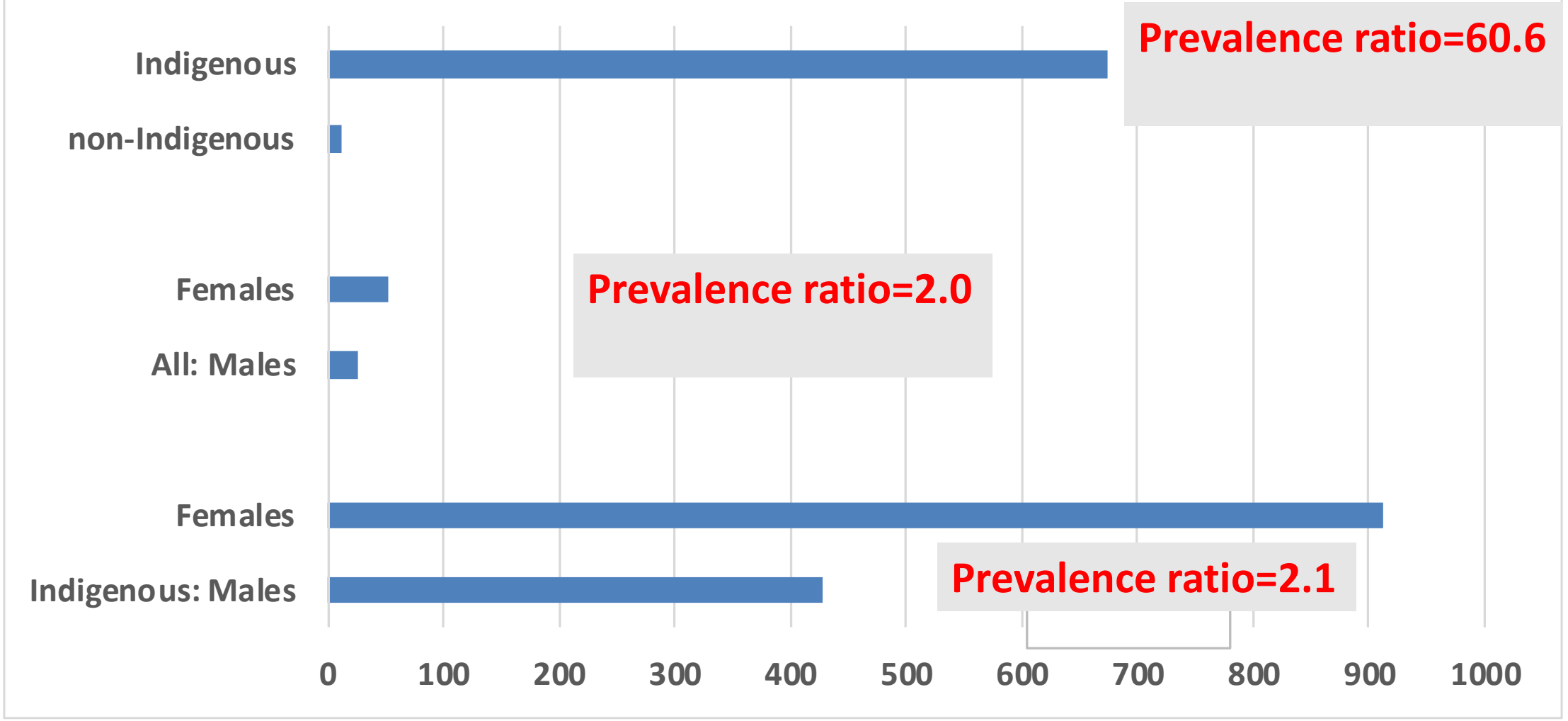
Distribution of prevalent cases of RHD, by age group and Indigenous status (average annual counts 2015-17)



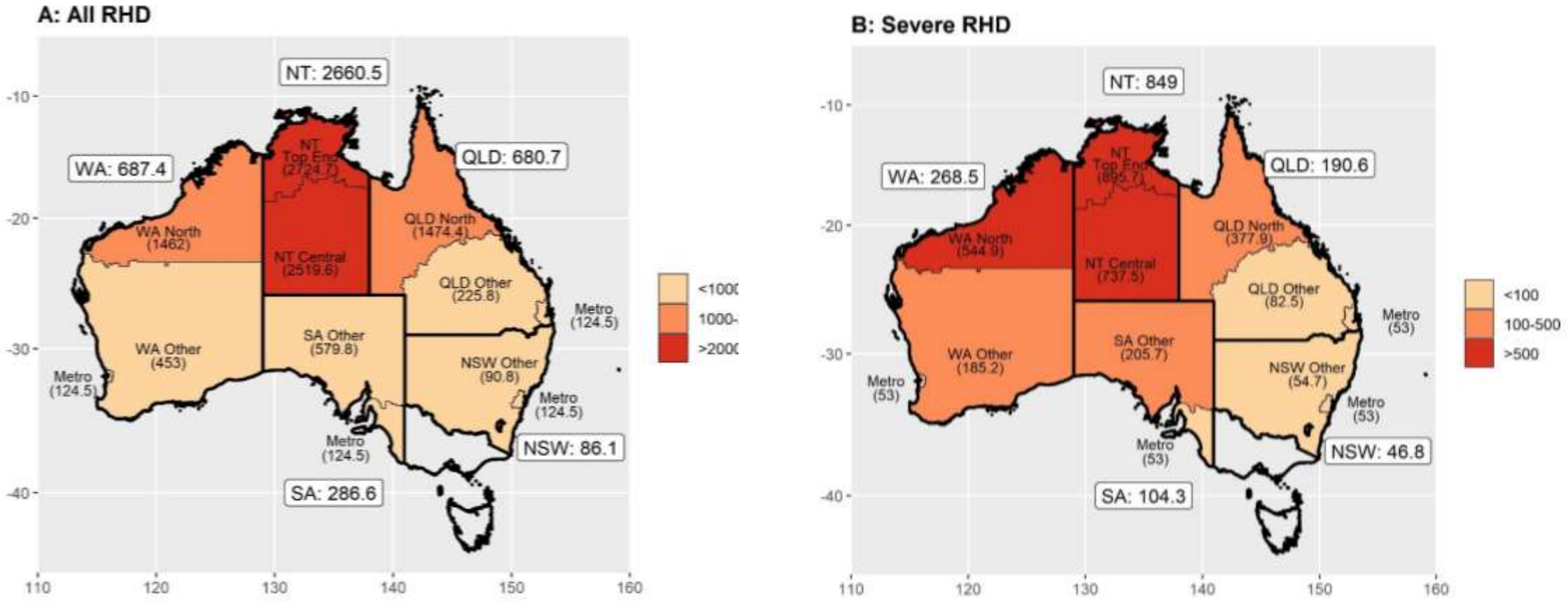
Distribution of prevalent cases of RHD, by age group and sex (Indigenous only) (average annual counts 2015-17)



Age-standardised RHD prevalence (0-54 years), SA, NT, WA, QLD, NSW (2015-2017)

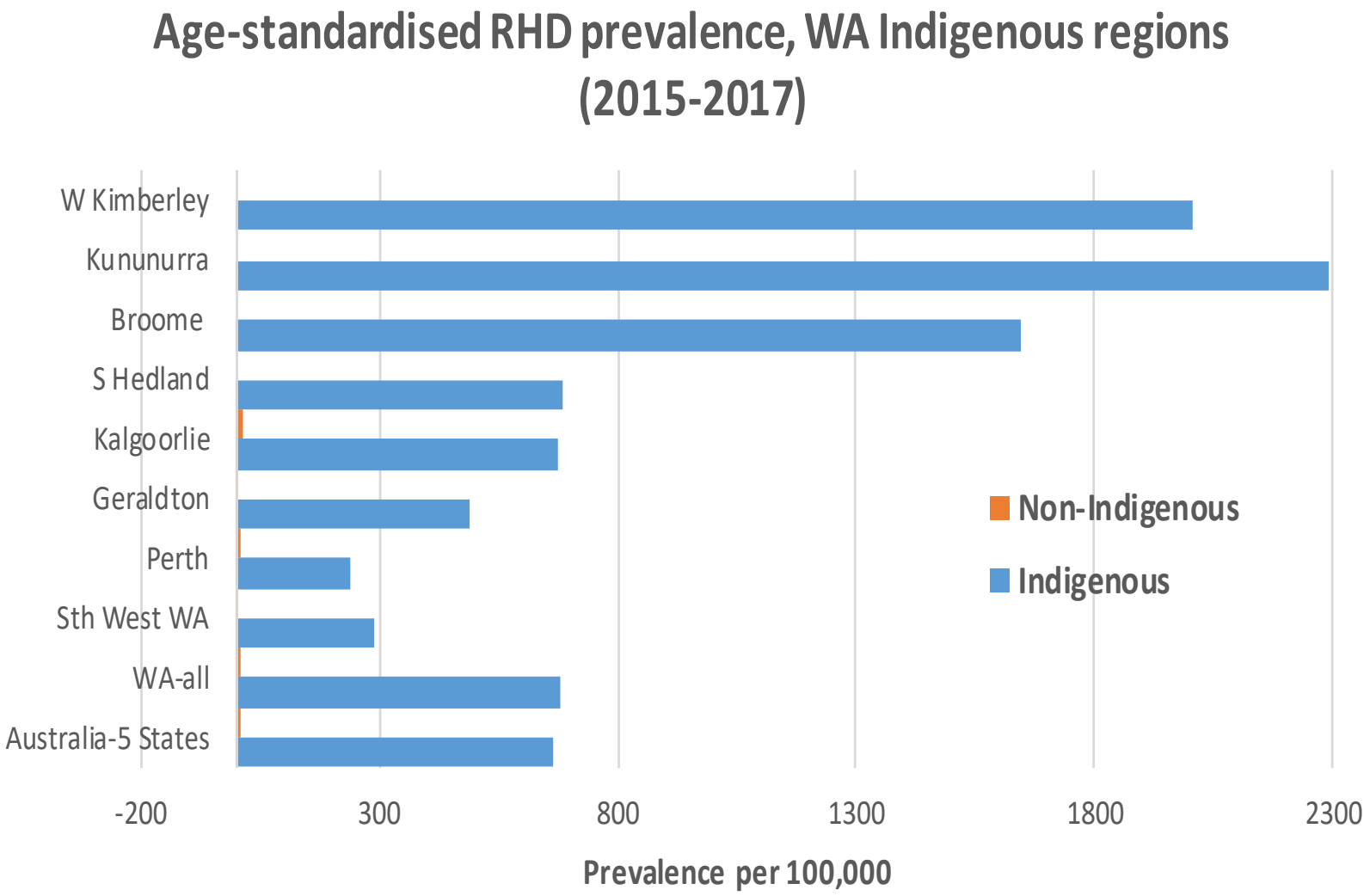


Indigenous age-standardised prevalence of total RHD and severe RHD, by Indigenous region category and jurisdiction (2015-17)



Prevalence per 100,000

RHEUMATIC HEART DISEASE IN WA



	Indigenous	Non-Indigenous	Total
W Kimberley	104	< 5	105
Kununurra	117	< 5	117
Broome	82	< 5	82
S Hedland	72	< 5	73
Kalgoorlie	43	6	49
Geraldton	33	< 5	35
Perth	77	124	201
Sth West WA	32	15	47
WA-all	564	150	714
Australia-5 States	3734	1496	5230

Sub-studies to further harness the power of our data:

- Progression
  - ARF→recurrence;
  - ARF →RHD
  - RHD →death
- Complications
  - RHD →stroke
  - RHD →infective endocarditis
  - RHD→ HF
- Mortality
  - RHD-attributable mortality
  - All-cause mortality in RHD patients

- Adherence measures: development and estimates
- Valvular procedural short and medium-term outcomes
- Determinants of hospitalized RHD being missed by registers and visa versa
- Missed ARF diagnoses
- RHD in pregnancy
  - trends, outcomes, birth spacing

Data are the means: but to what end?

Evidence base for new ARF/RHD guidelines

Example:

Provided data to support decision about which demographic groups should be considered ‘high risk for ARF’

Data are the means: but to what end?

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Evidence to inform Endgame strategies

- Tables and graphics presented in the Endgame Report
- Provide burden data used in costing of interventions
- Baseline for monitoring

Data are the means: but to what end?

Evidence base for new ARF/RHD guidelines

Example:

Provided data to support decision about which demographic groups should be considered ‘high risk for ARF’

Evidence to inform Endgame strategies

- Tables and graphics presented in the Endgame Report
- Provide burden data used in costing of interventions
- Baseline for monitoring

Dissemination to communities & services; facilitate action

- Share data
- Adhere to data sovereignty principals
- Use to build solutions, not focus on deficit
- Use for policy

END RHD

- Broad-based national alliance of health and community organisations
- Advocating for resources to prioritise the end of RHD in Australia.

AHCWA
Aboriginal Health Council of Western Australia

Heart Foundation

AMA

ABORIGINAL MEDICAL SERVICES ALLIANCE NORTHERN TERRITORY
AMSANT

NACCHO
www.naccho.org.au

END
RHD
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Challenges of data in Australia

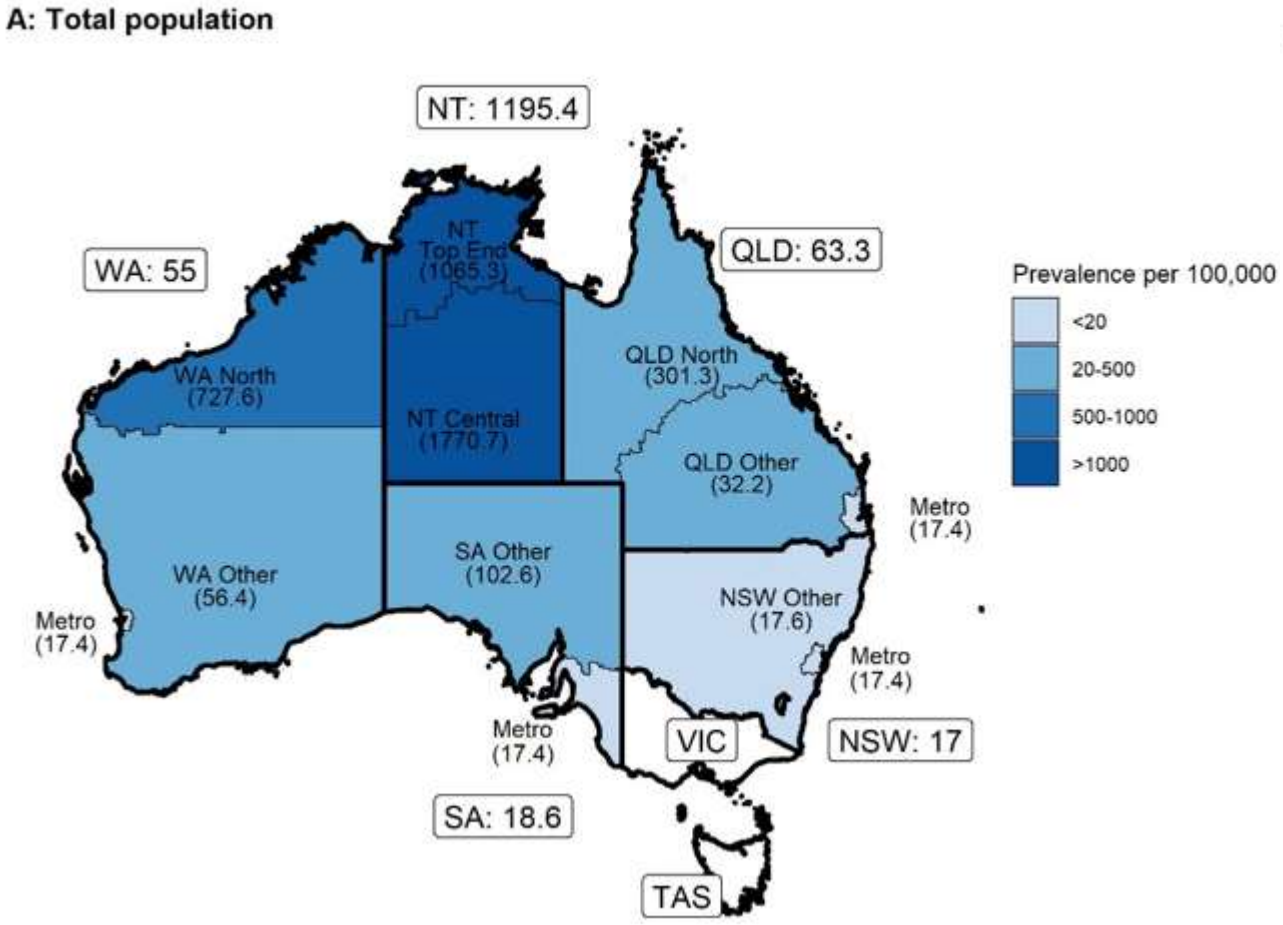
1. Federal structure: each State has its own data
   - Hospitals: variables, formats, withhold different variables
   - Jurisdictional RHD registers have different data base and structure, Start dates

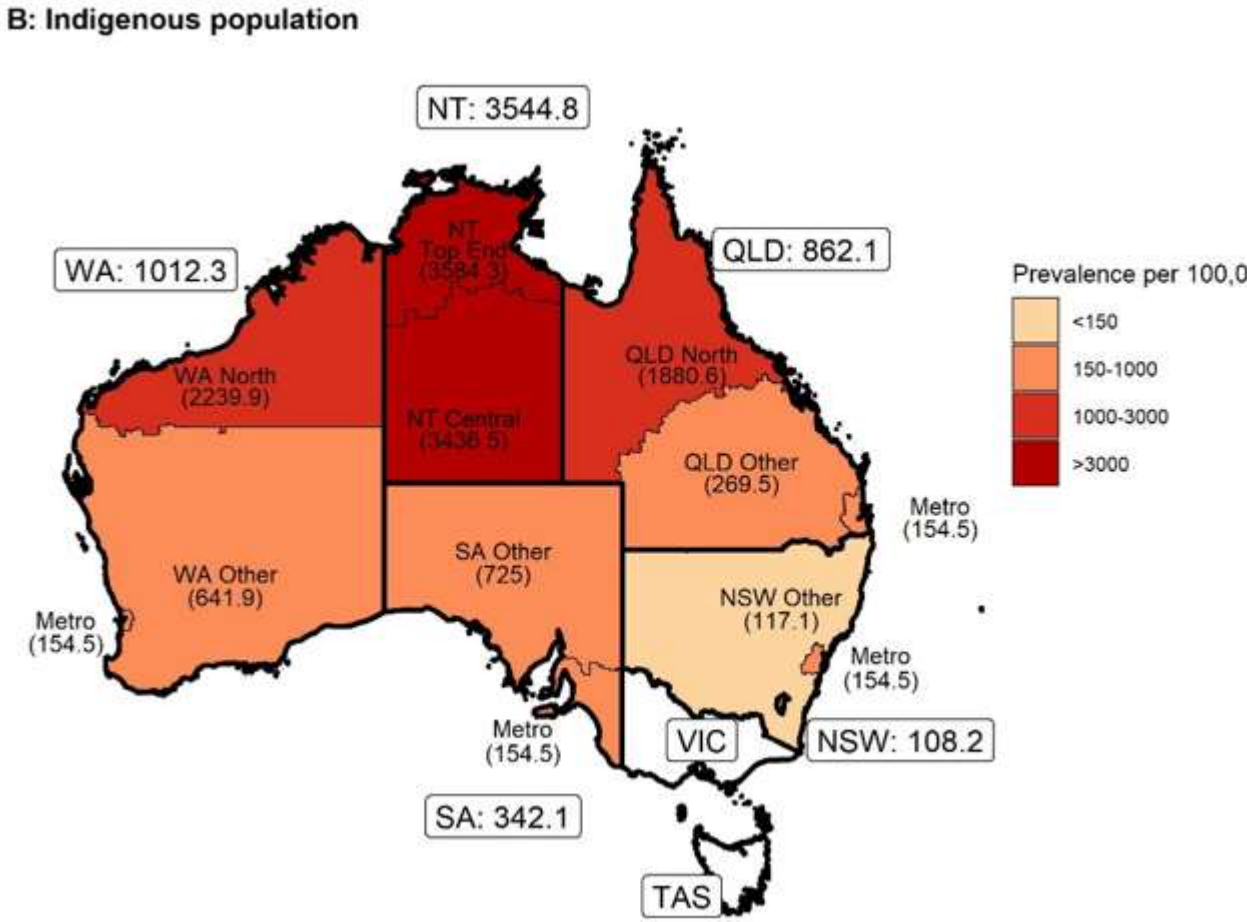
2. Small numbers of Indigenous cases: small cell sizes

3. Indigenous Population estimates: unstable below State level

4. No national linked data in Australia: Multiple data and ethics applications →DELAYS

Age-standardised prevalence (per 100,000) of ARF or RHD, by broad Indigenous Region Categories.





Total population and Indigenous age-standardised prevalence (per 100,000) of acute rheumatic fever or rheumatic heart disease in five Australian jurisdictions, by Indigenous Region Categories.