



What are the big Commonwealth challenges in addressing chronic disease for Aboriginal and Torres Strait Islander people?

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Kanyini Vascular Collaboration Chief Investigator (with Prof Alex Brown)

discovery for a healthy tomorrow





NT News

Tuesday, July 22, 2011

ntnews.com.au

\$1.20 (incl GST)



YES, IT'S RE

NT NEWS photographer Kaitlín Bridgford took this amazing photograph of Boris, a 5.5m saltwater croc, giving a boatload of tourists a moment they'll never forget on the Adelaide River last week.

FULL

NT News

Tuesday, May 6, 2011

ntnews.com.au

\$1.20 (incl GST)



WHY I'VE GOT A PACKER UP MY CLACKER

FIST ON NINE: Media heavyweights and besties James Packer and David Gyngell come to blows in street **SEE OUR EXCLUSIVE PICTURES >>P4**

Photo: Salma/Chris WICKHAM/ABC.COM

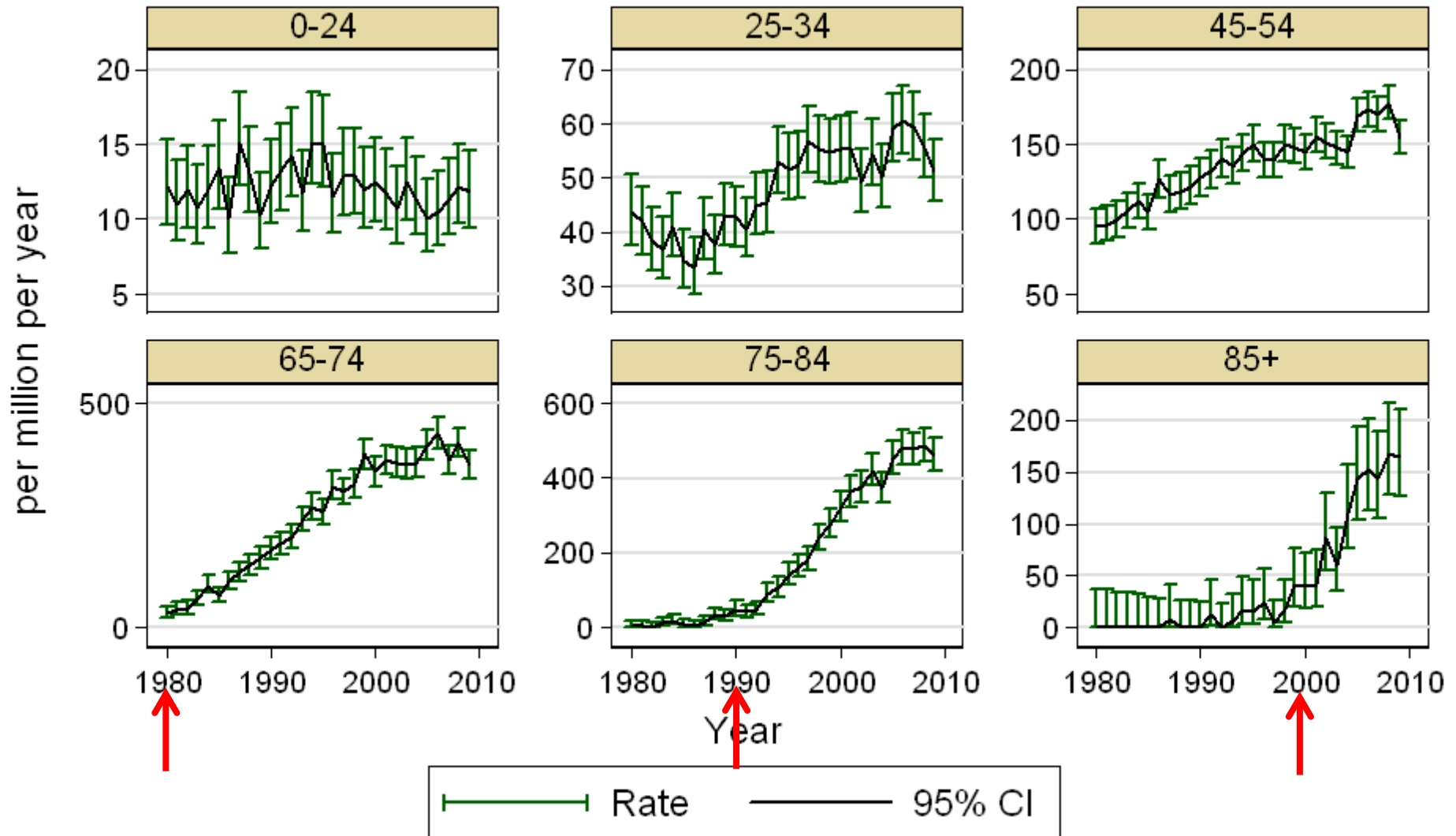
1. Burden of chronic disease

- **Gap in life expectancy estimated by ABS**
 - 12 years for men and 10 years for women
- **80% of the mortality gap amongst people aged 35 to 74 years due to chronic diseases**
- **Disease rates higher – in 2012-13, among Indigenous adults:**
 - CVD 1.3 times higher (27% v 21%)
 - Diabetes 3.5 times higher (18% v 5%)
 - CKD 2.2 times higher (22% v 10%)

AIHW 2011 and 2015

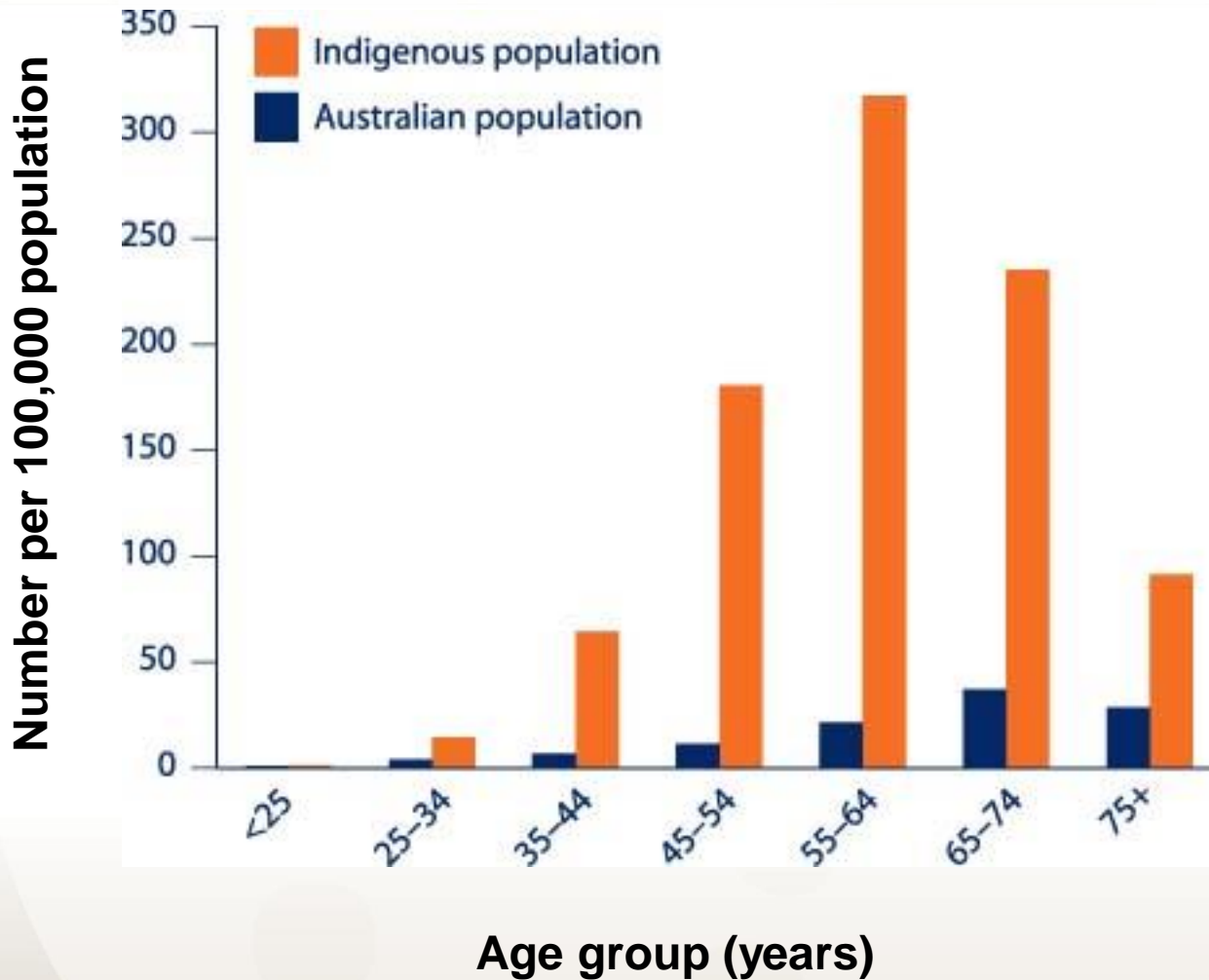
New patients ESKD

Australia



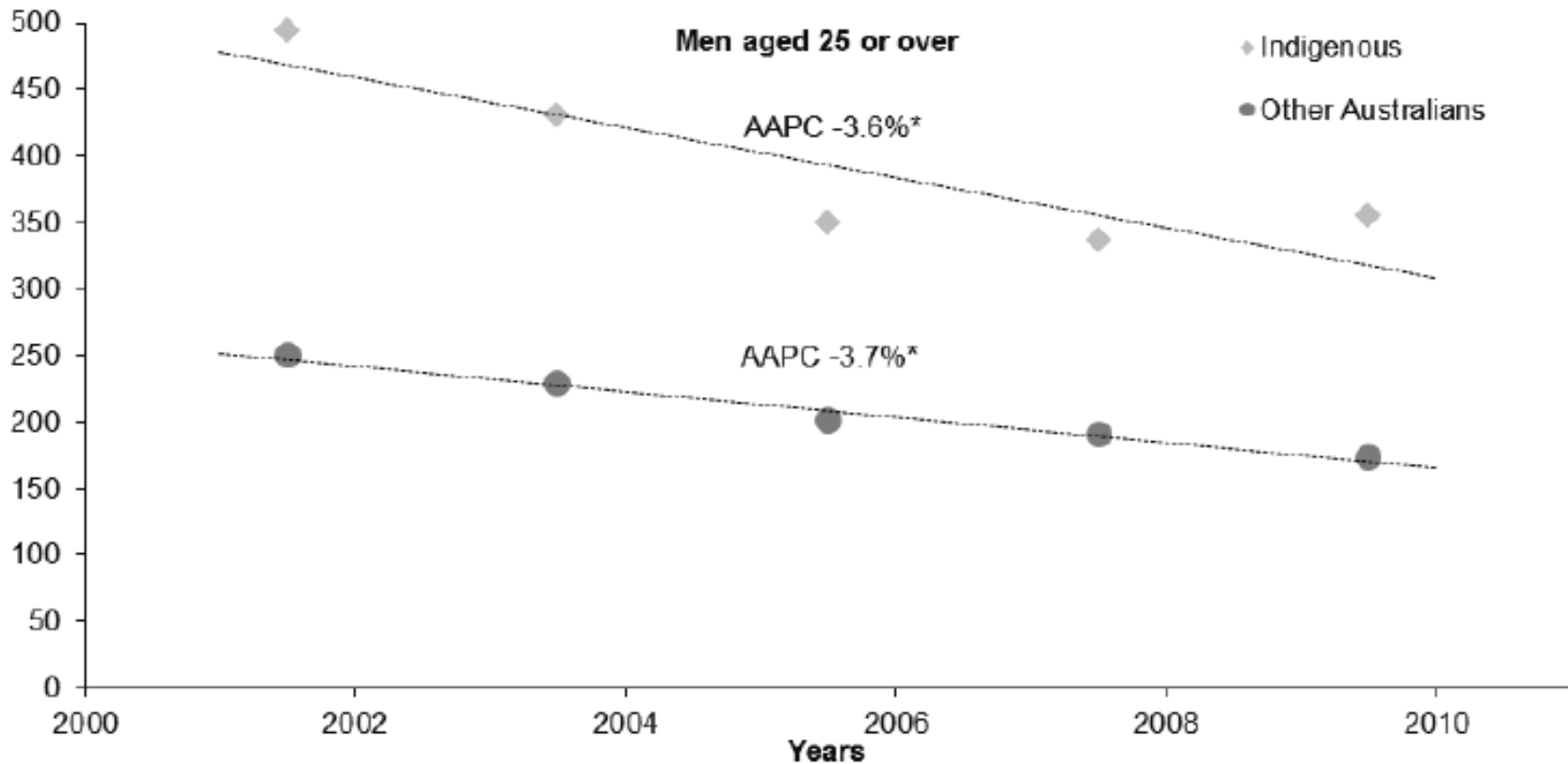
Graphs by age group

New patients ESKD



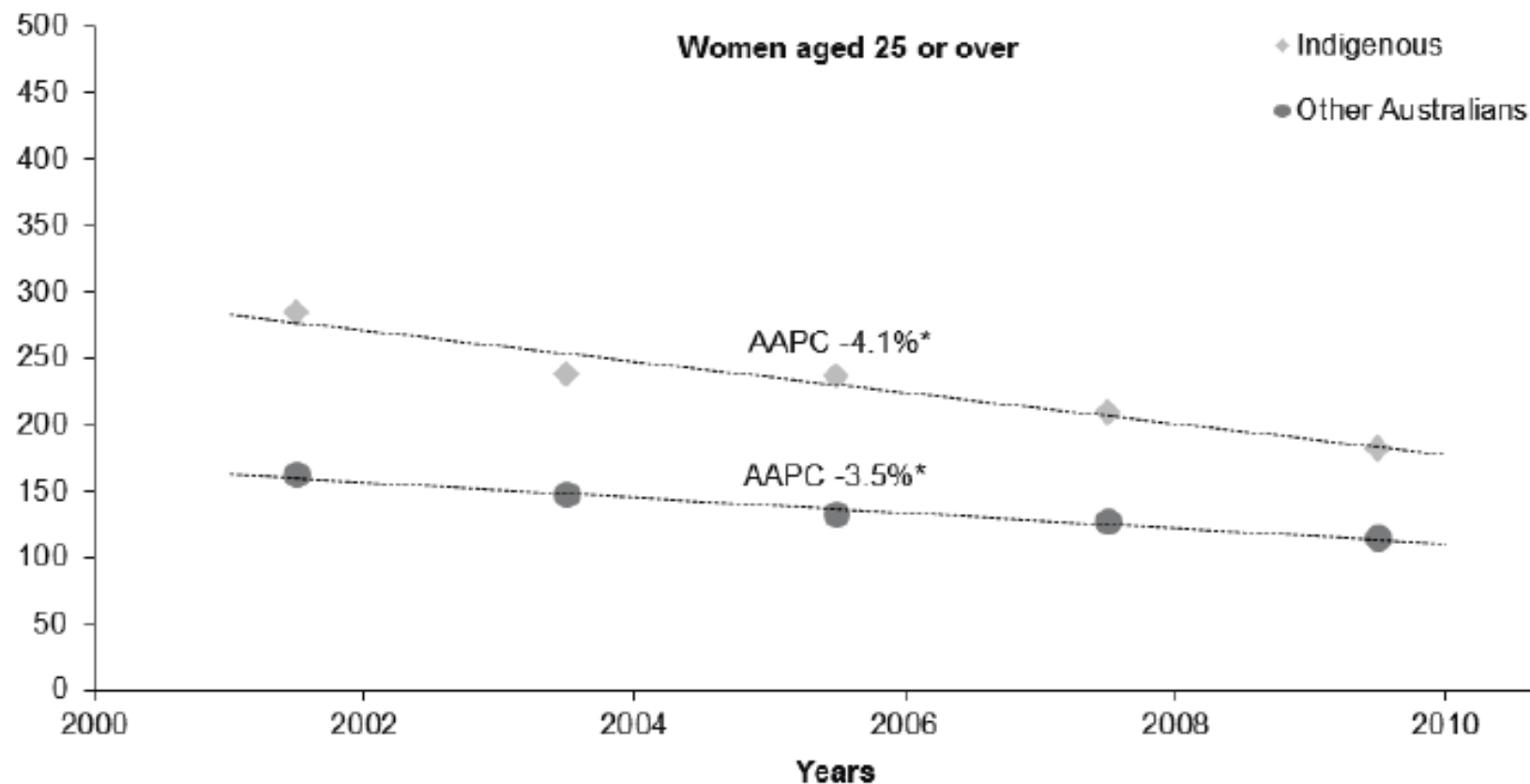
Trends in CVD: Indigenous men

Deaths per 100,000 population



Trends in CVD: Indigenous women

Deaths per 100,000 population



- Recent global increase in prevalence of metabolic syndrome (abdominal obesity, elevated BP, elevated fasting BSL, abnormal lipids) obesity and type 2 diabetes (T2DM)
- Rates disproportionately ↑ amongst disadvantaged and ethnic minority groups
- Ethnicity may play ↑ role in youth than adult-onset T2DM
 - High prevalence in Indigenous (USA, Canada & Australia)

Torres Study: Obesity and Met Syn

- Cross-sectional study
- 158 youth (aged 5-17 yrs), outer Torres Strait Is
- Findings:
 - 31% overweight, 15% obese
 - 38% ↑ waist circumference
 - 27% hypertension
 - 17% met syn
- Of those who were overweight or obese:
 - 33% had metabolic syndrome
 - ↑ levels of circulating insulin, insulin resistance & HbA1c (vs normal weight)

NT data: Obesity and Met Syn

- Aboriginal Birth Cohort Study: Top End, NT, 486 children aged 9 – 14 yrs:
 - 6.4% overweight, 4.9% obese by BMI
 - 26% ↑waist circumference
 - 59% of those with ↑waist were NOT overweight/obese by BMI
 - 14% MetS
- Darwin Region Urban Indigenous Diabetes Study:
 - 1000 participants aged ≥ 15 yrs
 - WHR = index of obesity most closely assoc with T2DM

Sellers, J Ped 2008.

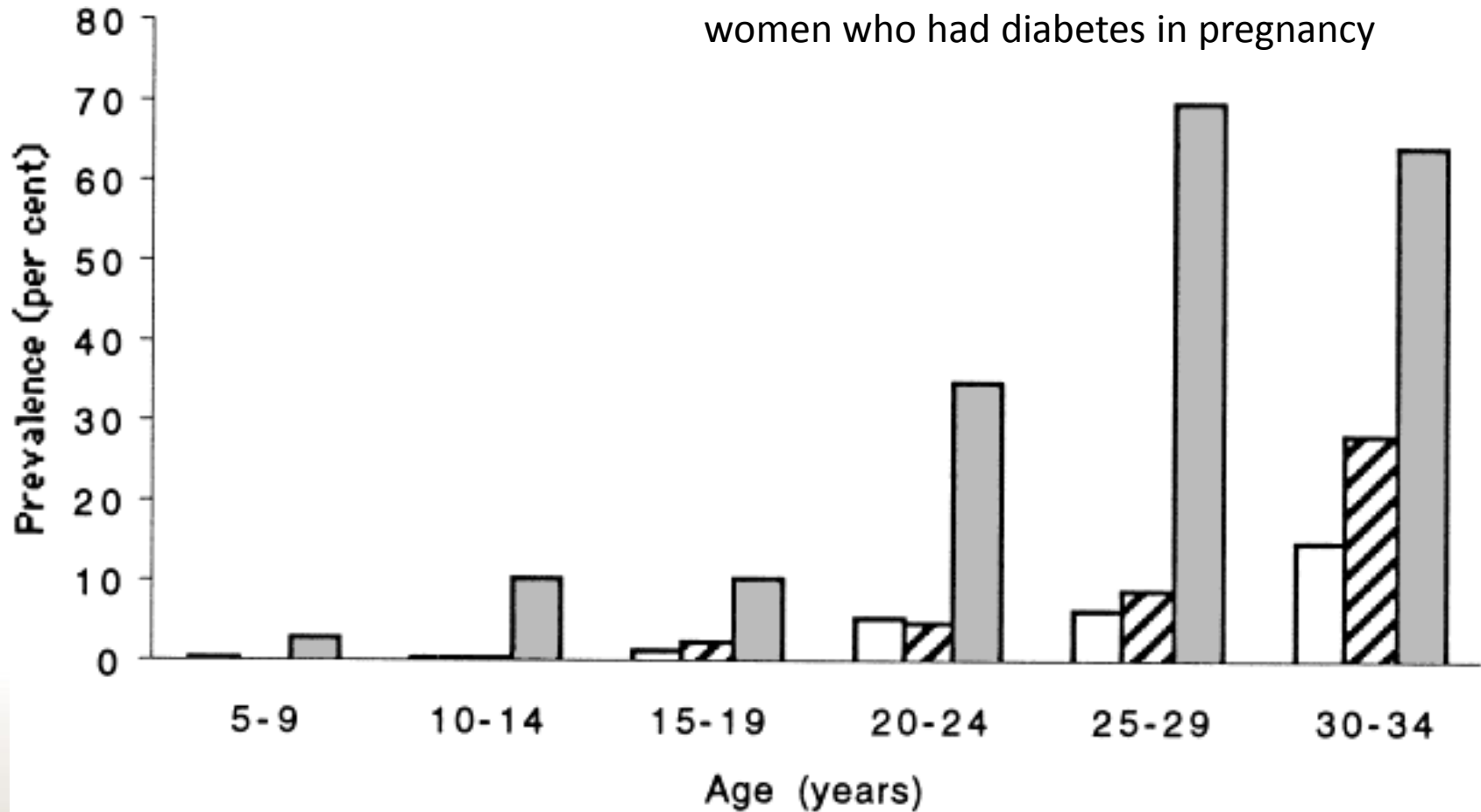
O'Dea, Diab Res Clin Prac, 2008

Escalating risk of early diabetes

- Recent studies indicate high incidence of diabetes among Indigenous women aged 15-34 yr
 - Darwin, NT (DRUID Study): 14% of young women had diabetes or IGT (*O'Dea et al, DRCP 2008*)
 - Remote Northern Territory communities: 10% of young women have diabetes (*Hoy et al, ANZJPH, 2007*)
 - North Queensland: Incidence of diabetes 29 cases/1000 py, weight gain 1.5 kg/year (*McDermott et al, MJA 2010*)
- Overweight/obesity strongest risk factor for diabetes and young women are gaining weight fast

High prevalence of T2DM in offspring

Prevalence much higher in offspring of Pima women who had diabetes in pregnancy



No diabetes
 GDM
 Pre-existing DM

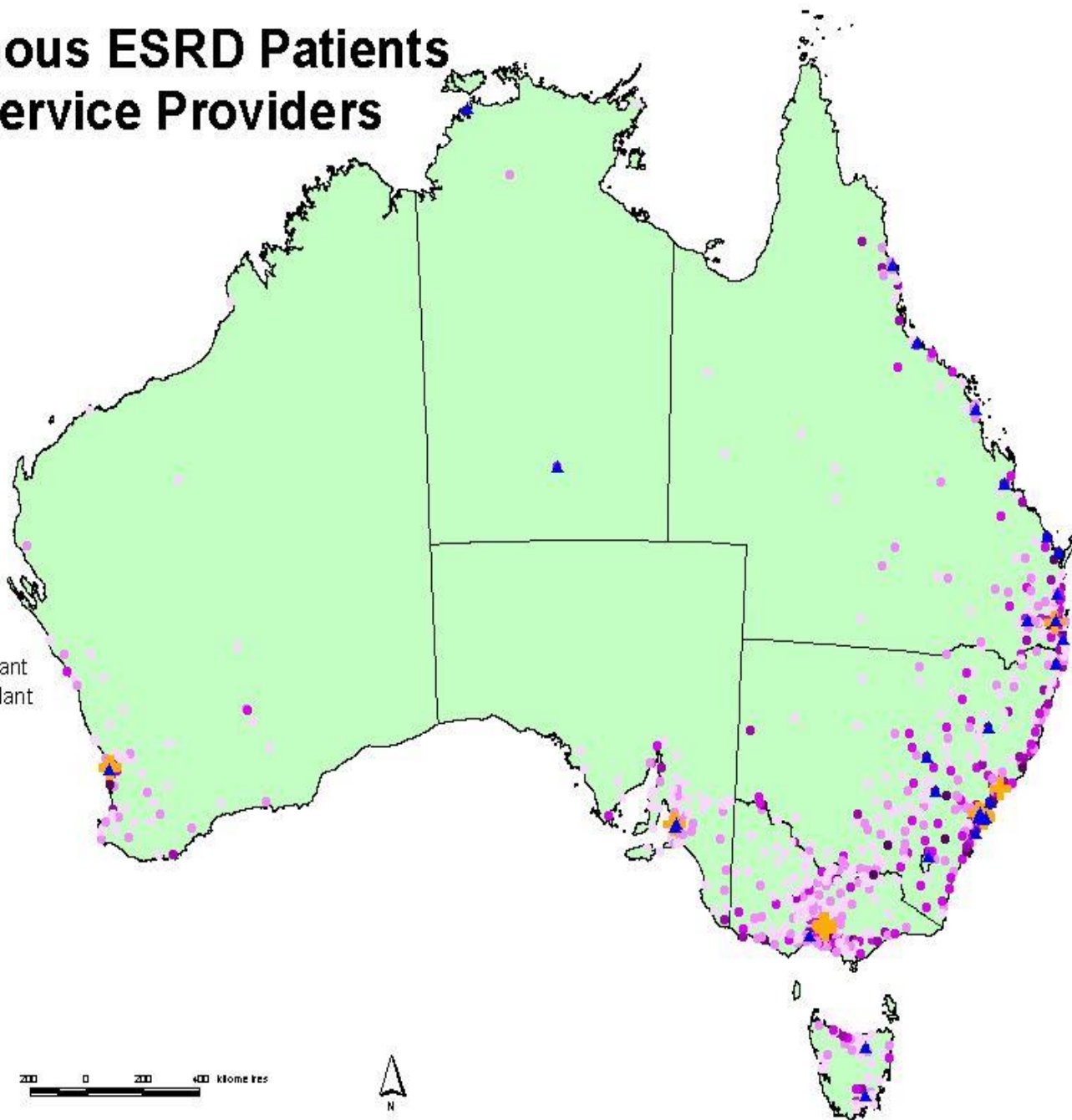
- Pima: 70% of offspring have diabetes age 25-34yr vs <15% in offspring of non-diabetic mothers
- Canadian First Nations: in children of mothers with pre-preg DM (<18yo):
 - at age 10-19 years, 43% DM ¹
- Continuing cycle of diabetes and DIP:
 - Offspring have diabetes at younger age than their parents
 - then diabetes pre-conception in mother and father and during mother's pregnancy

2. Geographical distribution

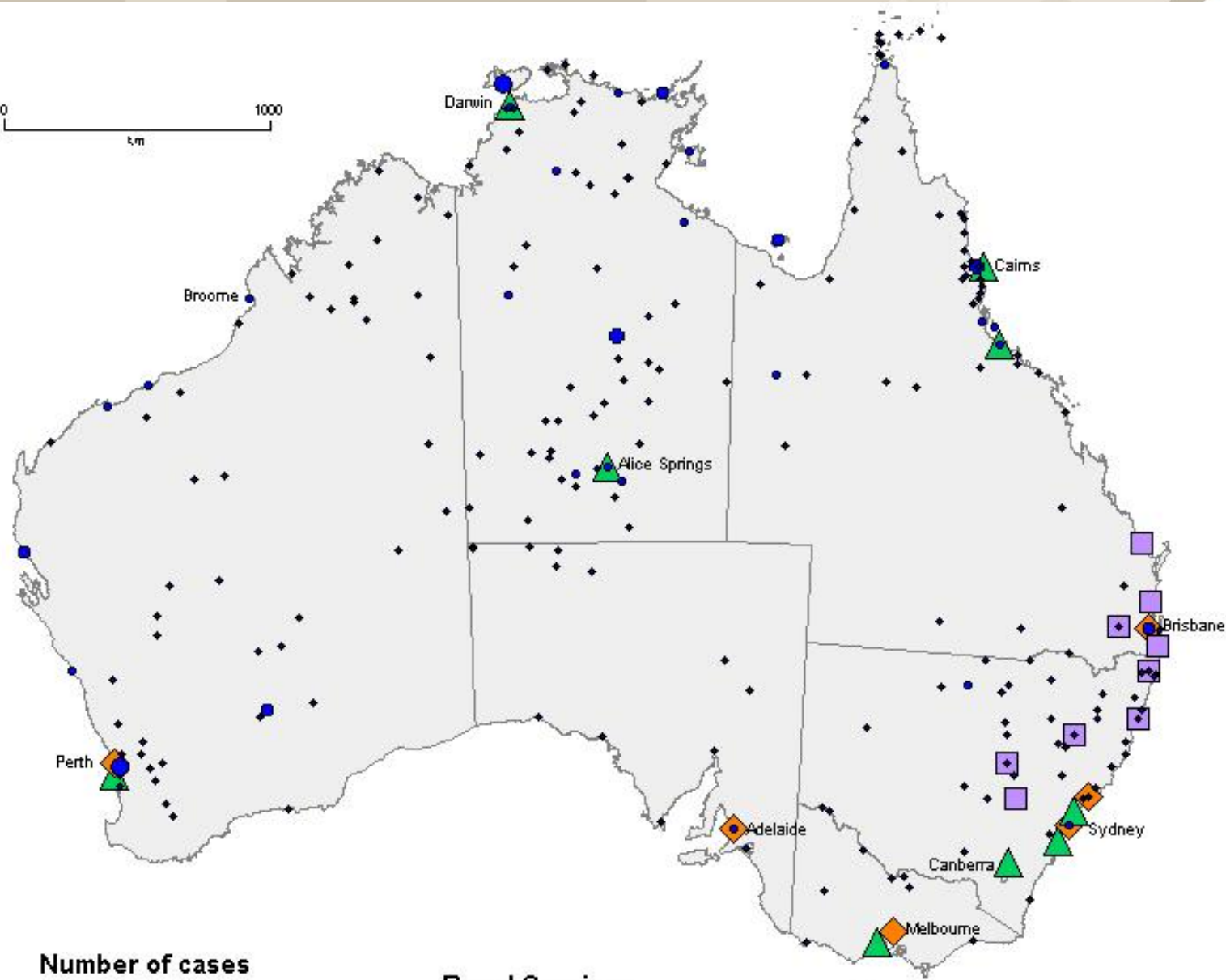
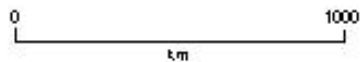
- **Disease rates increase with increasing remoteness**
 - **Less well resourced areas**
 - **High staff turnover**
 - **Most challenging environments in terms of cross-cultural care, health literacy, disadvantage**
 - **Dealing with complex chronic diseases far removed from major centres**
 - **Need for innovative approaches to building, sustaining an appropriately skilled workforce**

Non-Indigenous ESRD Patients and Renal Service Providers

- ▲ dialysis unit w/o transplant
- ⊕ dialysis unit with transplant
- number of patients
 - 1
 - 2 - 3
 - 4 - 6
 - 7 - 11
 - 12 - 50



Map prepared by GISCA
Adelaide University
March 2001



Number of cases

- 21 to 27
- 16 to 20
- ◆ 11 to 15
- 6 to 10
- ◆ 1 to 5

Renal Services

- ◆ Transplant and Tertiary Dialysis
- ▲ Tertiary Dialysis
- Secondary Dialysis



3. Complex comorbidity

- **CVD, diabetes and CKD, Indigenous Australians (AIHW)**
 - More likely have at least 2 of 3
 - At a younger age
 - Proportion of hospitalisations and deaths with all three much higher
- **Driver of integrated chronic disease not condition-specific approach**

Prevalent CVD and depression

VARIABLE	OR	95%CI	P
Age	1.05	1.01-1.1	0.017
Hypertension ($\geq 140/90$)	2.88	1.1 – 7.8	0.038
Major depression §	9.46	1.8– 50.6	0.009
TOTAL CHOLESTEROL	1.16	0.7 – 1.8	0.529
DIABETES	1.52	0.4 – 6.1	0.554
CURRENT SMOKER	0.69	0.2 – 2.2	0.692
EMPLOYMENT (Y/N)	0.87	0.3 – 2.9	0.825
Education ≥ 16 YRS	1.6	0.5 – 4.9	0.406
INCOME (>\$1000 v \$0-399)	0.58	0.1 – 2.5	0.462

§PHQ-9 scoring for DSM-IV Criteria for Major Depressive Disorder

Over the *last 2 weeks*, how often have you been bothered by any of the following problems?
(use "✓" to indicate your answer)

1. Little interest or pleasure in doing things

2. Feeling down, depressed, or hopeless

3. Trouble falling or staying asleep, or sleeping too much

4. Feeling tired or having little energy

5. Poor appetite or overeating

6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down

7. Trouble concentrating on things, such as reading the newspaper or watching television

8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual

9. Thoughts that you would be better off dead.

IN THE LAST TWO WEEKS, HOW OFTEN HAVE YOU BEEN FEELING THE FOLLOWING:

1 HAVE YOU BEEN FEELING SLACK, NOT WANTED TO DO ANYTHING?

2 HAVE YOU BEEN FEELING UNHAPPY, DEPRESSED, REALLY NO GOOD, THAT YOUR SPIRIT WAS SAD?

3 HAVE YOU FOUND IT HARD TO SLEEP AT NIGHT, OR HAD OTHER PROBLEMS WITH SLEEPING?

4 HAVE YOU FELT TIRED OR WEAK, THAT YOU HAVE NO ENERGY?

5a⁵ HAVE YOU NOT FELT LIKE EATING MUCH EVEN WHEN THERE WAS FOOD AROUND?

5b⁵ HAVE YOU BEEN EATING TOO MUCH FOOD?

6 HAVE YOU BEEN FEELING BAD ABOUT YOURSELF, THAT YOU ARE USELESS, NO GOOD, THAT YOU HAVE LET YOUR FAMILY DOWN?

7 HAVE YOU FELT LIKE YOU CAN'T THINK STRAIGHT OR CLEARLY, ITS HARD TO LEARN NEW THINGS OR CONCENTRATE?

8a⁵ HAVE YOU BEEN TALKING SLOWLY OR MOVING AROUND REALLY SLOW?

8b⁵ HAVE YOU FELT THAT YOU CAN'T SIT STILL; YOU KEEP MOVING AROUND TOO MUCH?

9 HAVE YOU BEEN THINKING ABOUT HURTING YOURSELF OR KILLING YOURSELF?

Adapted PHQ-9 wording

TOTAL,

TOTAL:

NHMRC-funded Validation study

- Setting: Aboriginal Medical Services in Australia (aiming for 10 high recruiting centres)
- Design: Cross sectional, validation study
- Participants: Identify as Aboriginal or Torres Strait Islander, ≥ 18 years, attending a primary health care service, can give informed consent
- Baseline assessment: Demographics, history of depression, chronic disease history
- Measure for validation: aPHQ-9 (paper or iPad)
- Gold standard: MINI International Neuropsychiatric Interview (MINI) 6.0.0
- Primary Outcome: Criterion validity of aPHQ-9: sensitivity, specificity, positive and negative predictive values
- Other analyses: Association depression and chronic disease

- Structured mental health intervention using Indigenous specific content and imagery
- Developed in an iPad app format
- Designed to focus on wellbeing
- For use by Aboriginal Health Workers, nurses, GPs, allied health professionals, community workers and others within clinical and community settings



iPad 2:36 PM 86%

Things That Keep Me Strong

next

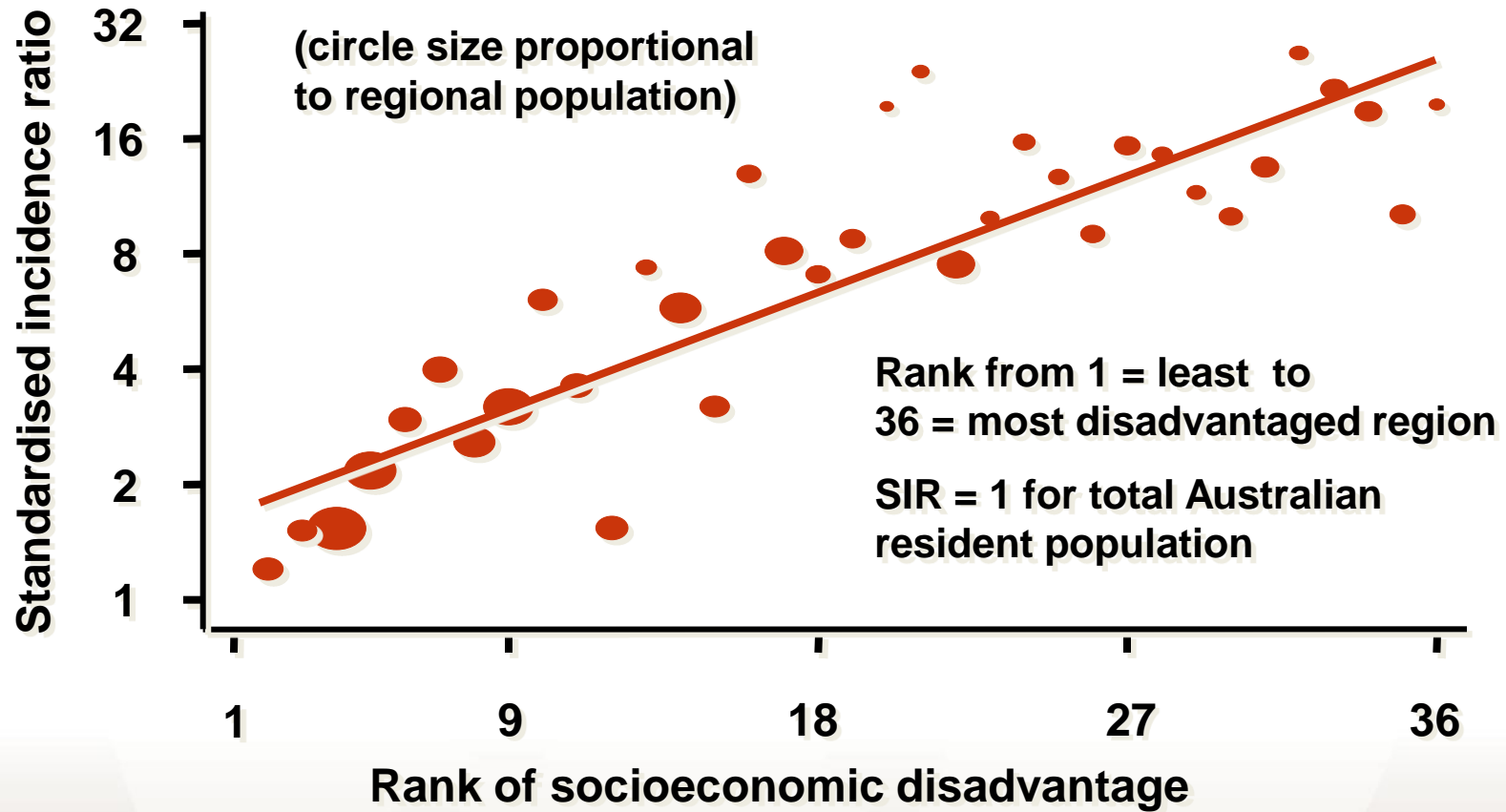
NOT SO STRONG TREE

GROW STRONG TREE

?

NOT SO STRONG TREE	GROW STRONG TREE	PHYSICAL	FAMILY, SOCIAL AND WORK	MENTAL AND EMOTIONAL
Identity	Spirituality	Health Centre	Work or Jobs	Understanding Health
Culture Worry	Music or Dance	Good Tucker	Teach Kids	Goals
Missing Country	Going to Country	Exercise	Family and Friends	Thinking Positive
Missing Culture	Other	Other	Dog	Exercise

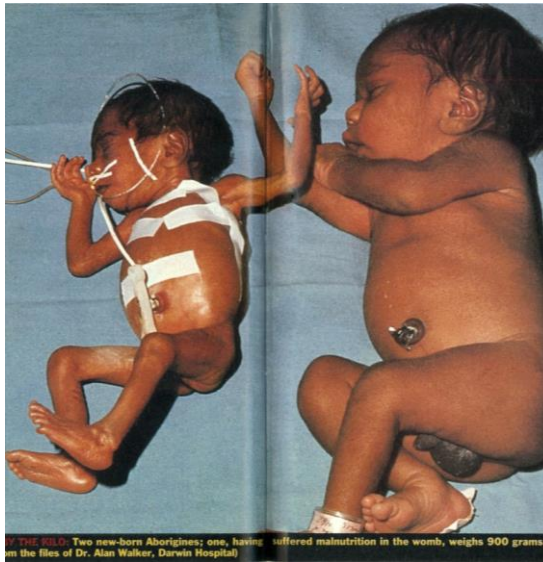
4. Social determinants of CD burden



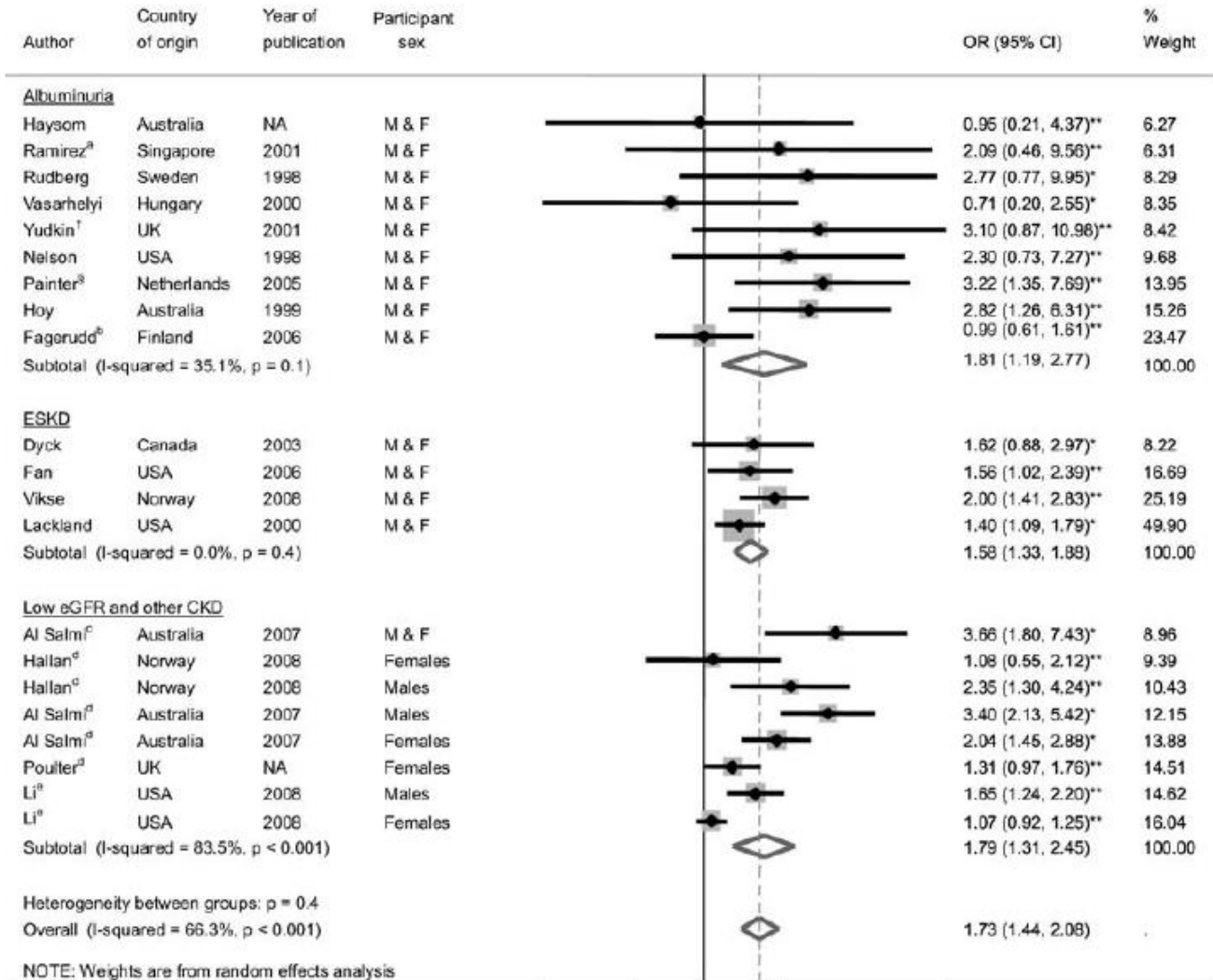
Ethnicity & Disease 2002; 12 (3): 373-8

Early life determinants

(White et al *AJKD* 2009)



THE BILD: Two new-born Aboriginals; one, having suffered malnutrition in the womb, weighs 900 grams on the files of Dr. Alan Walker, Darwin Hospital

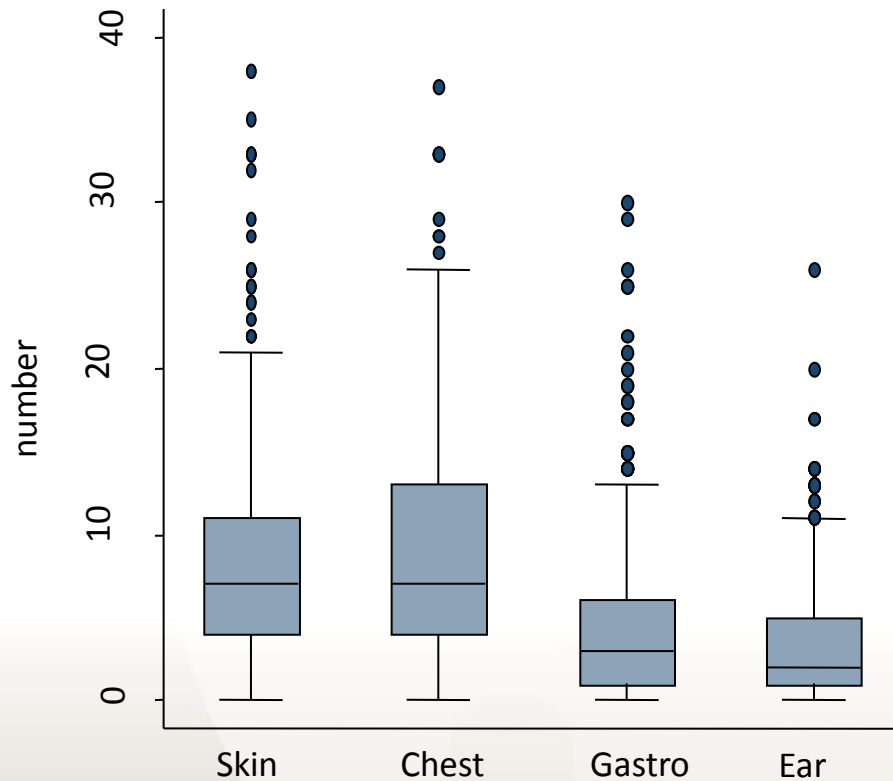


NOTE: Weights are from random effects analysis

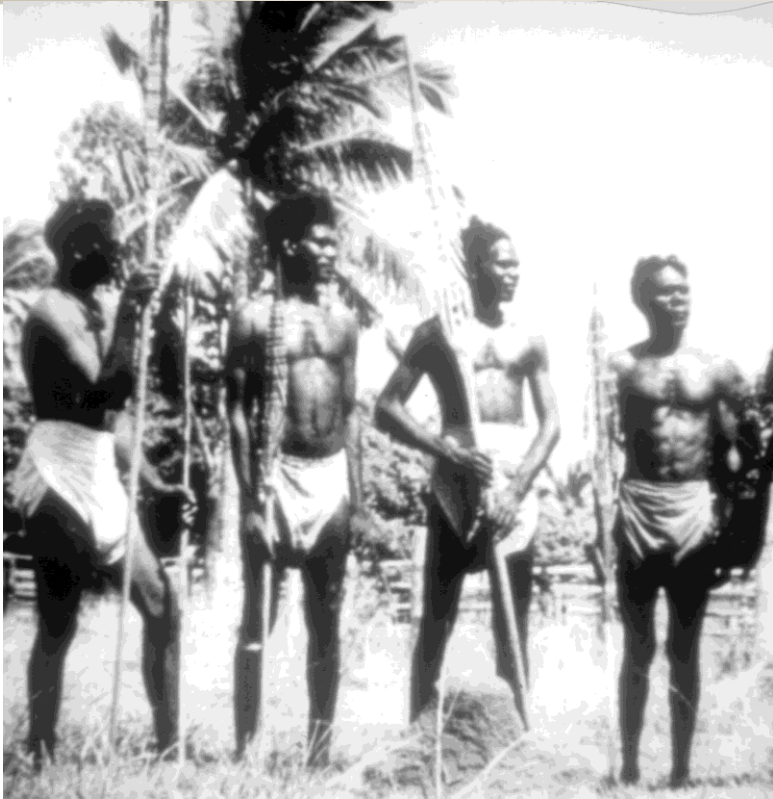
Environmental effects on health



Infectious episodes per child <15 yr



Environmental changes



Welcome to
**KINTORE
STORE**

**STORE
OPENING TIMES:**

MONDAY - FRIDAY

9:00am-12noon

2:00pm-5pm

SATURDAY

9:00am-12noon

SUNDAY

Closed



SALAD PACK 750g

0 200044 1

NET WT kg 0.750kg

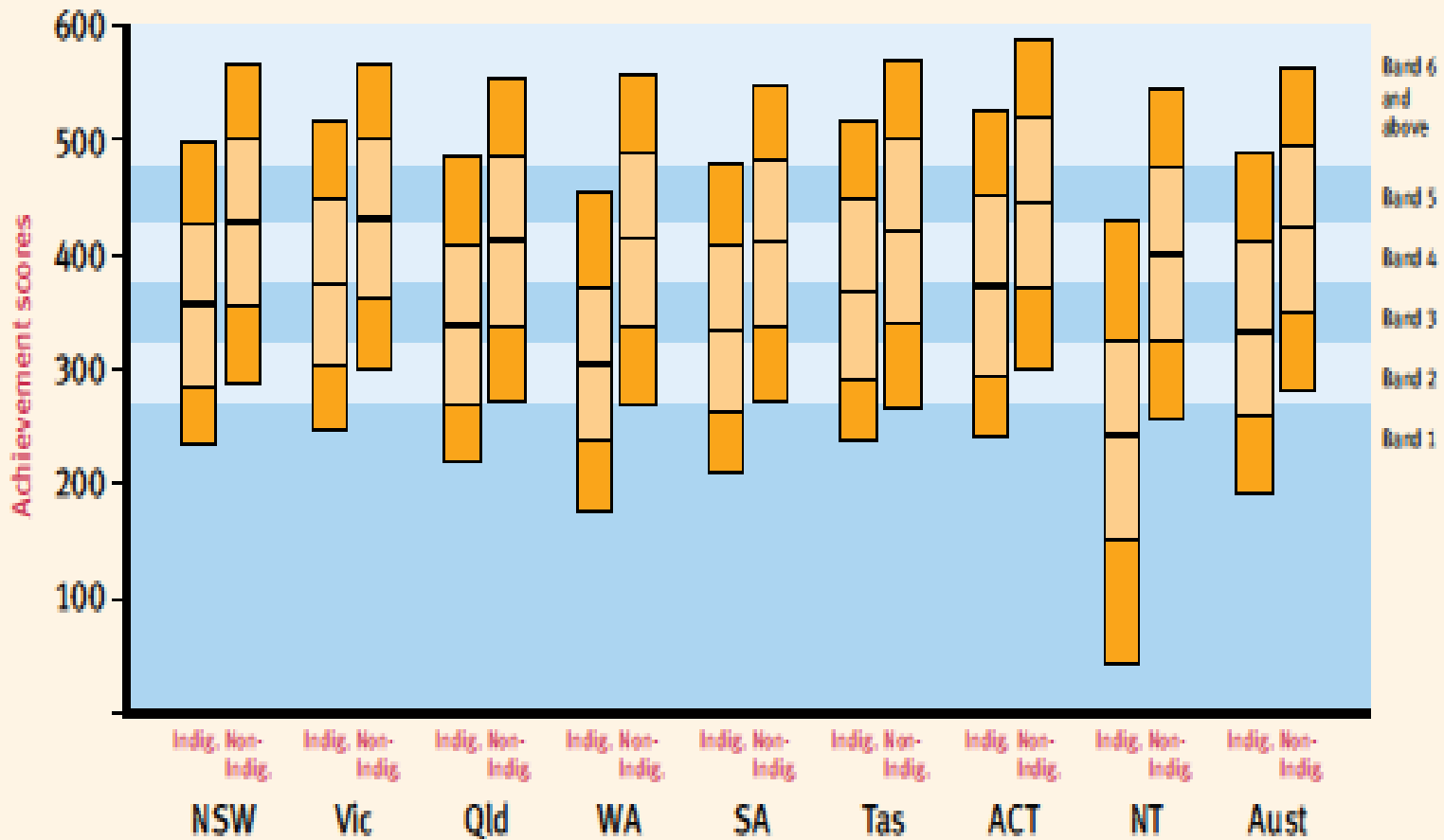
PRICE \$6.50

TOTAL PRICE \$6.50

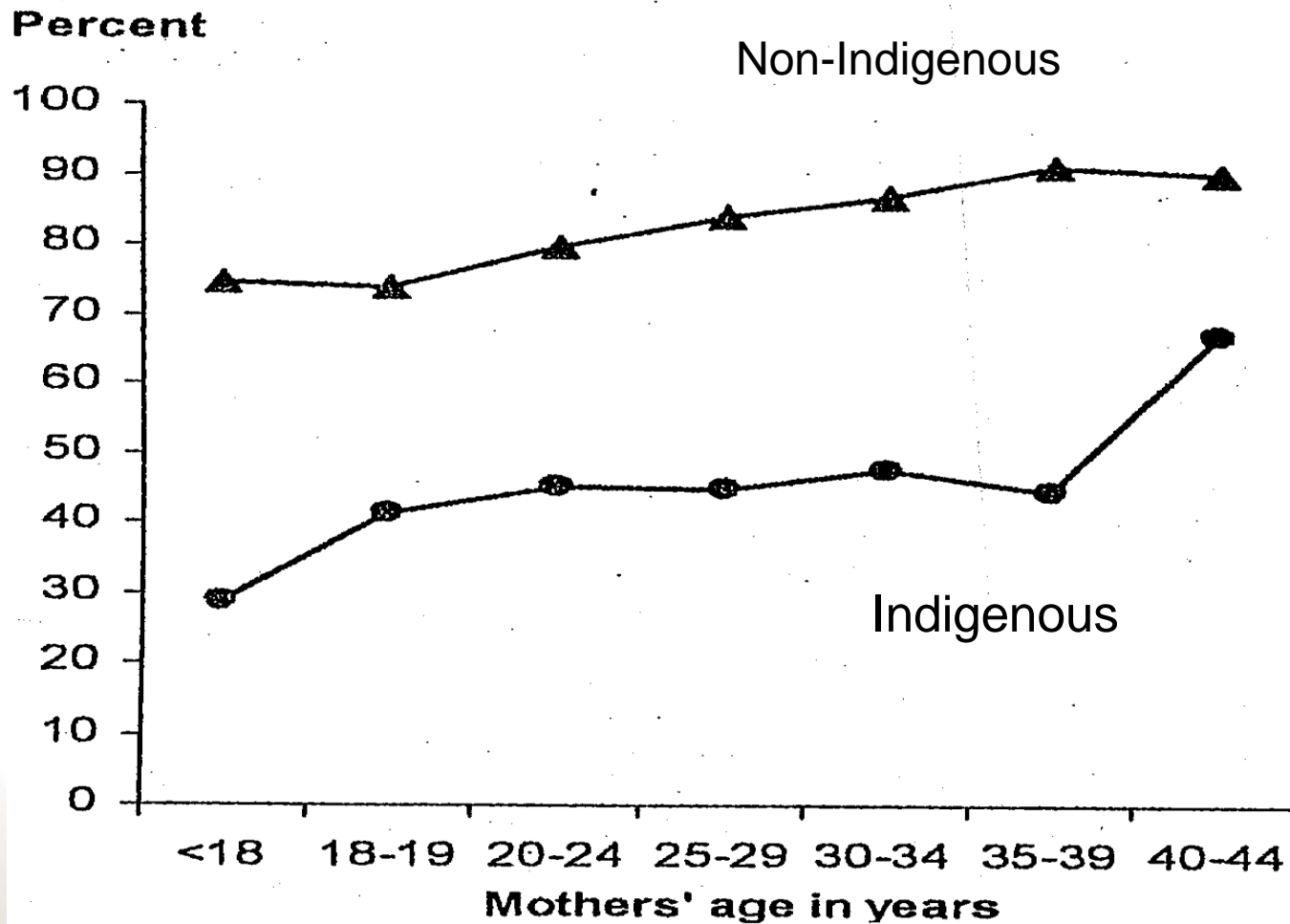
CENTRAL FOODS PTY LTD 25 WILKINSON ST
 H. VIC. 3002



Naplan Yr 3 reading 2012

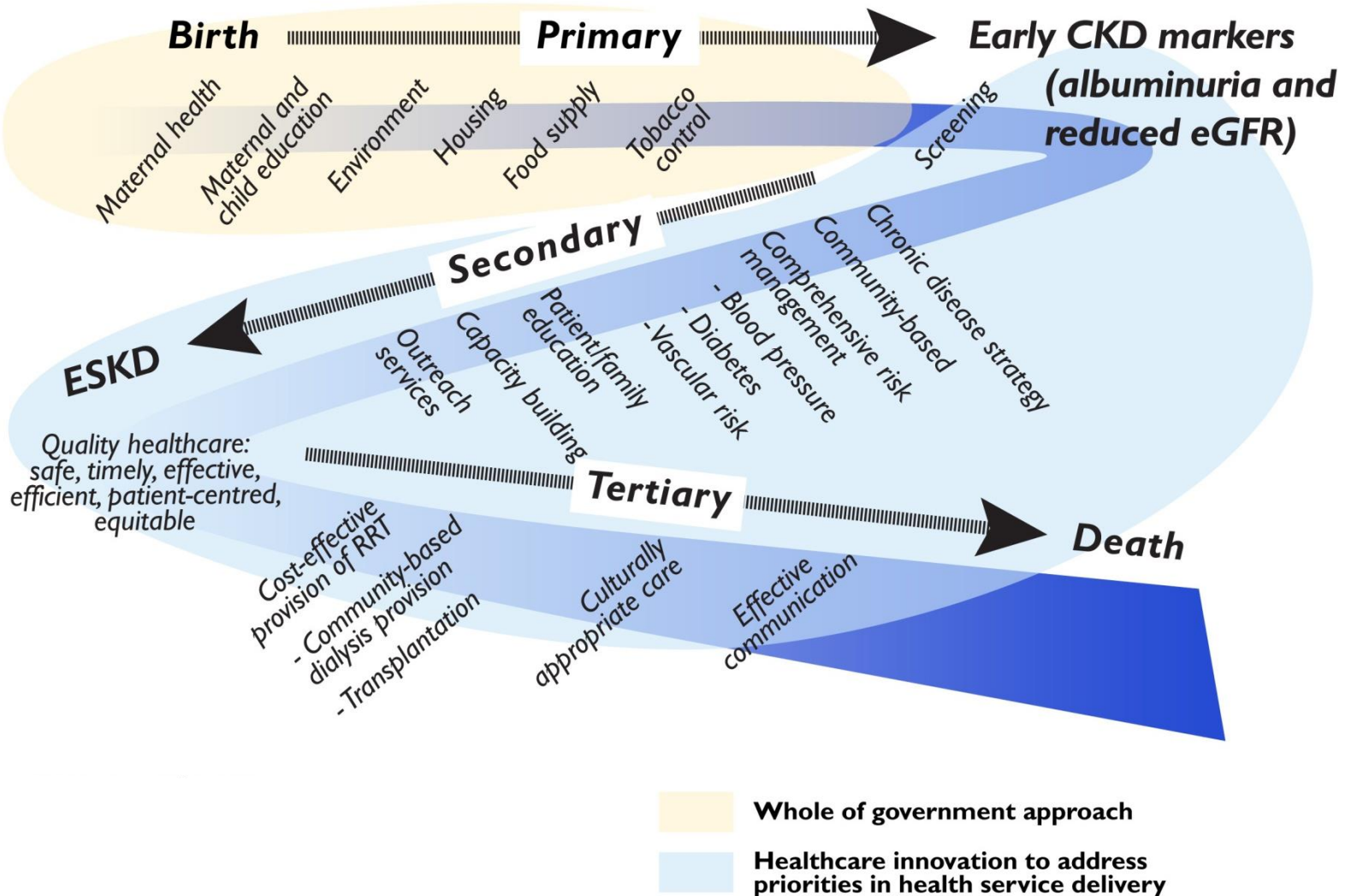


Age at birth and NAPLAN (% above national minimum standard)



SA-NT Datalink preliminary data

5. Life-course approach to address CD burden



6. Whole of government approach: Dialysis MoC

Determining the cost-effectiveness of taking dialysis to people vs. people to dialysis

- Three year NHMRC-funded Partnership Project
- Partners – Menzies, Health, Housing, EY, WDNWPT, AMSANT
- Collaborators – ANZDATA, Dept of Educ, NT BDM, patient/ consumer reps

What are the impacts on patients and families?
What are the impacts on other services?
Can these be quantified?

- Four components
 - Service Mapping
 - Data Linkage
 - Qualitative Analysis
 - Economic Analysis

Service Mapping - Models of Care

M1 - Urban

M2 - Regional

M3 – Remote

M4 – Supported CBHD

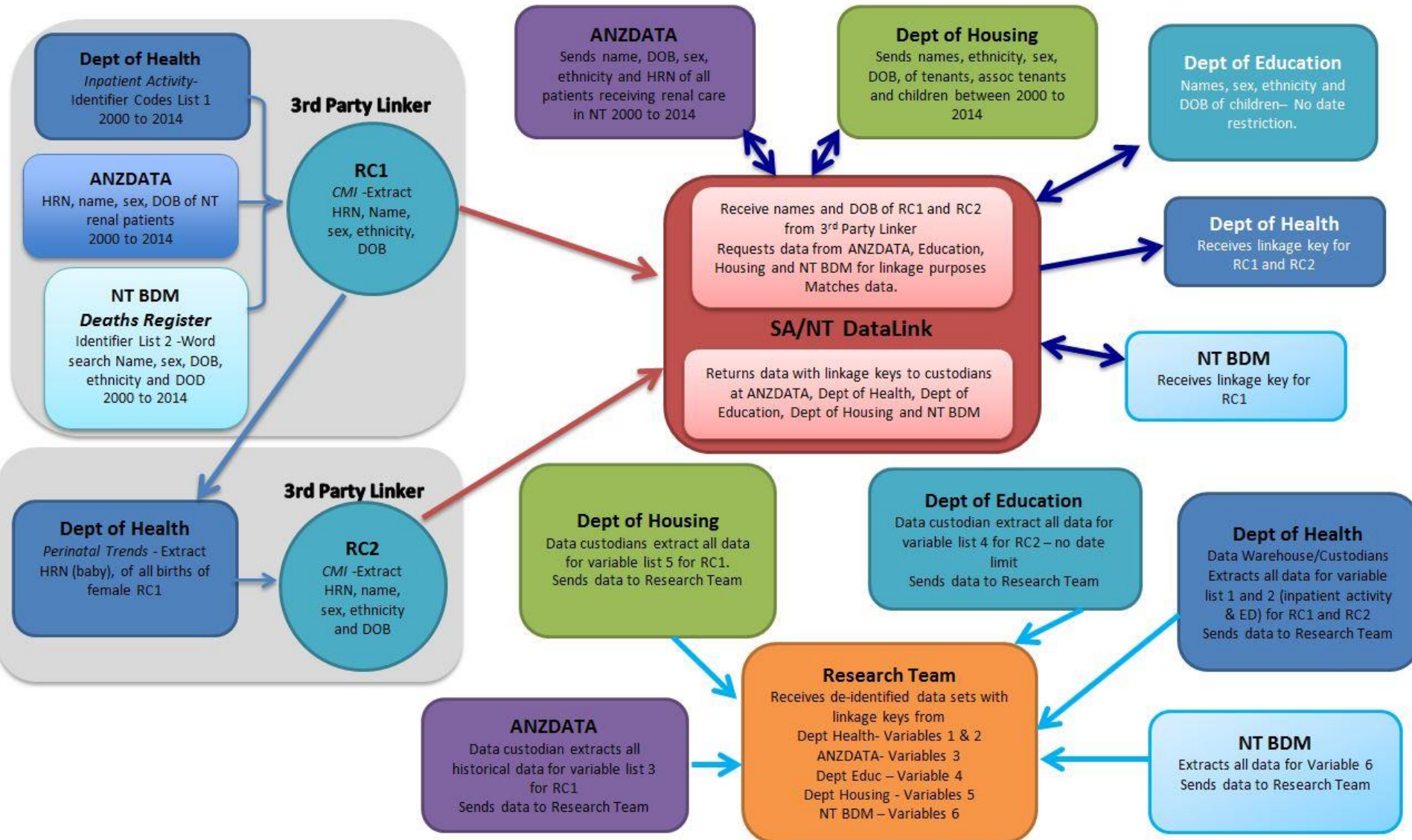
M5 – Self-care Dx (PD and HD)

Understand history – changes in policy, capacity, funding – how did these influence uptake and attendance rates

Data linkage

- Data linkage with ANZDATA, health, housing and education
 - Activity - health service utilisation – inpatient, emergency department and medical evacuation
 - Costs associated with diagnosis, procedures, medications, service provision
- Understand accommodation needs
- Determine impact on educational and health outcomes of children

Data Linkage



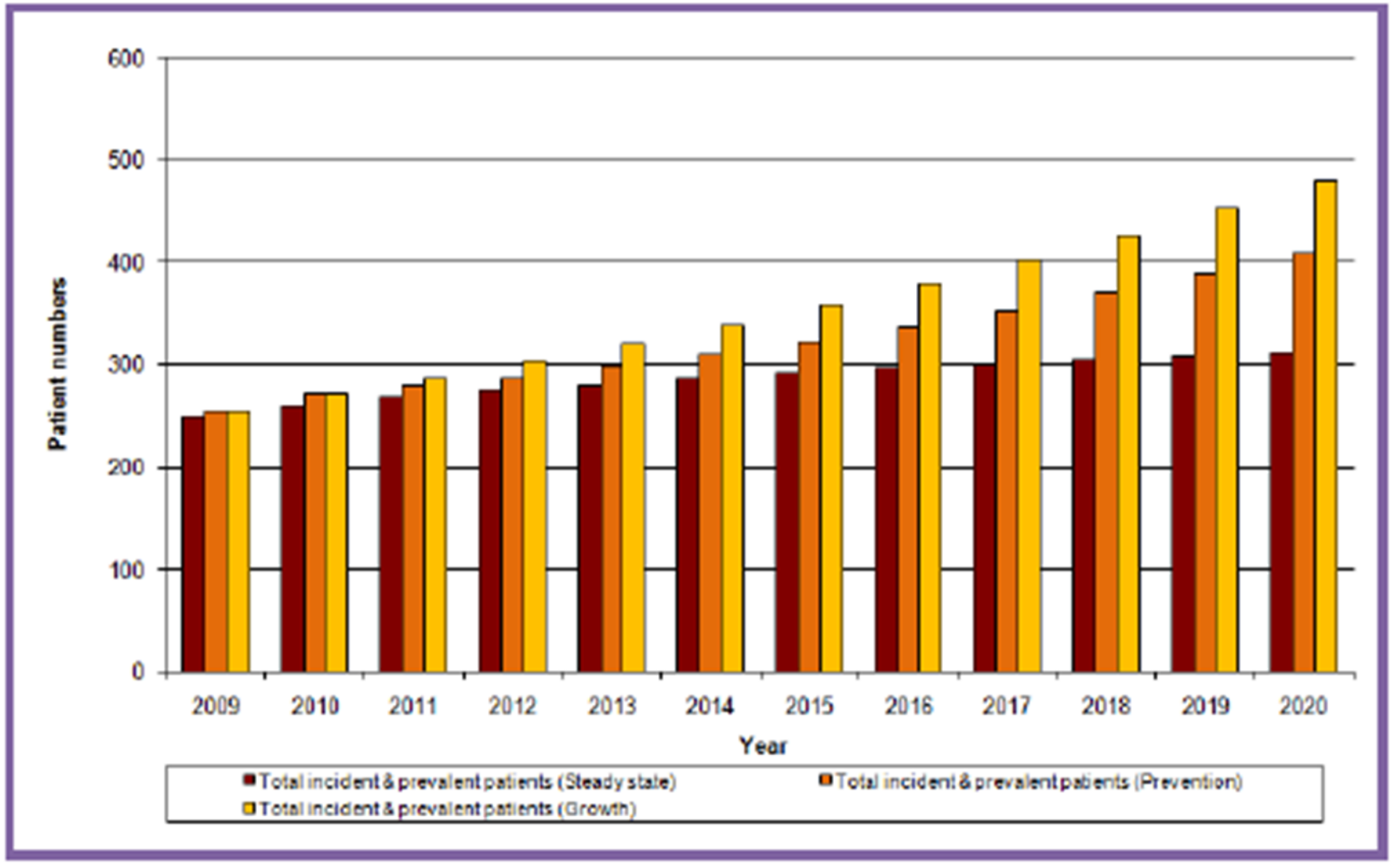
Qualitative

- Interviews – patients, families, clinicians, community stakeholders, service providers
- Patient case studies - longitudinal
- Patient capacity building
- Understanding what impacts quality of life for Aboriginal kidney patients

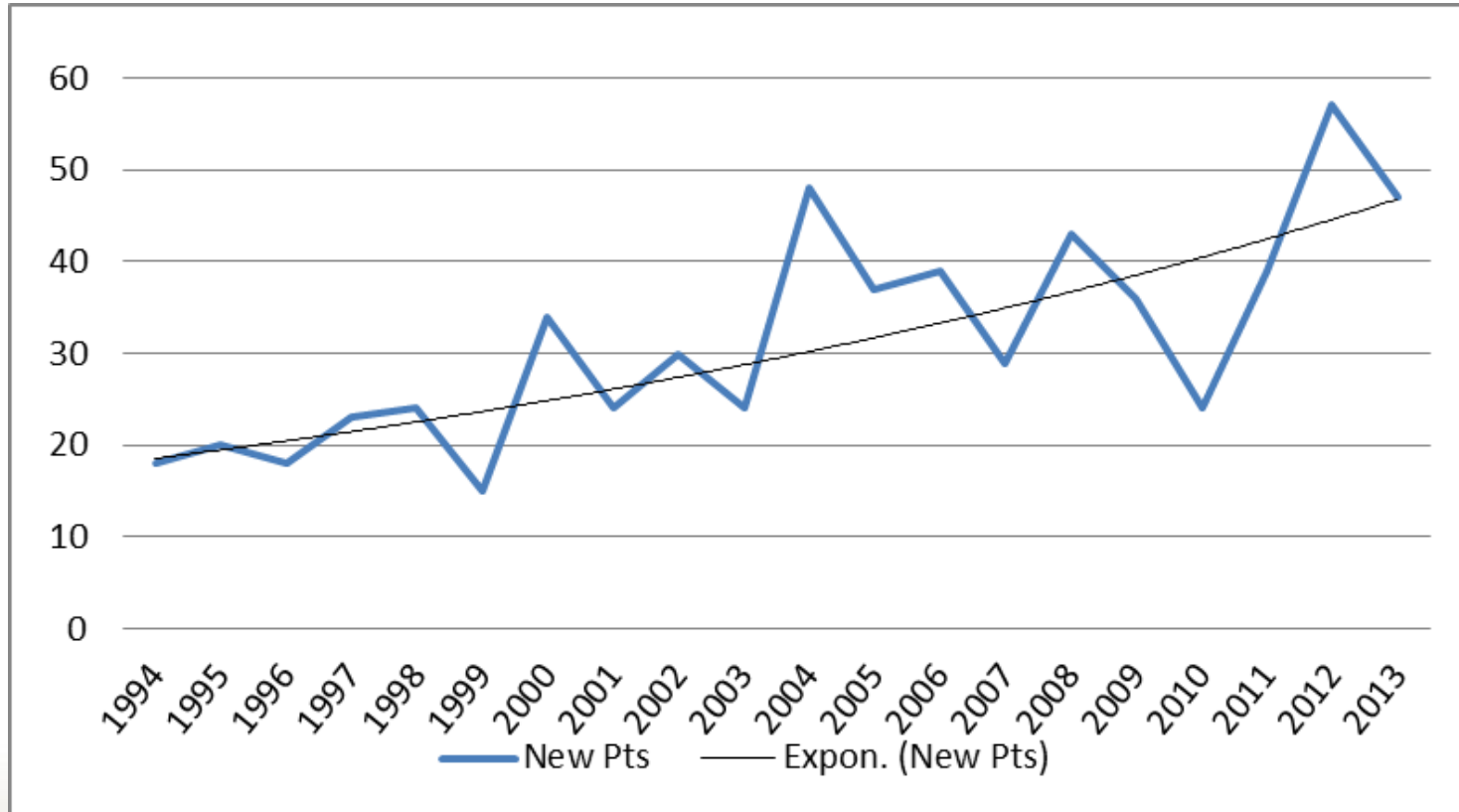
Economic Analysis

- Overall health service utilisation - cost for individuals attributed to each model
- Broader costs associated with model – transport, accommodation and support services
- Impact on children – educational outcomes, health service utilisation – future impacts
- What are best options for QoL tools that can be used in economic modelling for health service planning?

7. Need comprehensive community-based health data



Actual new ESKD cases



Chronic Condition Management Model (CCMM)

Dana Fitzsimmons & Mark Ramjan
Primary Health Care
Identifying and Addressing Cardiovascular Disease,
17 August 2015

CCMM Reports:

The CCMM program produces and distributes to 51 remote health centres plus the Darwin and Alice Springs Prisons (PCIS using sites) 3 different types of chronic condition reports:

- **Monthly Recall Lists**
(Work list)
- **3 Monthly Traffic Light Reports**
(Snapshot)
- **6 Monthly Trend Reports**
(Trends)

3 Month Traffic Light Report (snap shot)

Traffic Light Report

Version 8.2

Community Health Centre

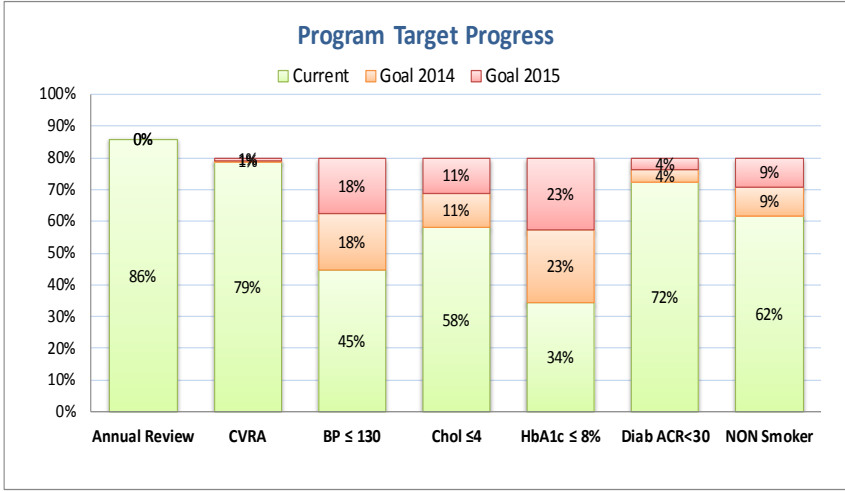
CONFIDENTIAL INFORMATION : Restricted to use in Remote Health Clinics

Total Population : **217**
 ATSI Population : **209**
 Non-ATSI Population : **8**

Data Extract : **Aug-15**

Program Targets

	Current	Program Goal
PCD Annual Review past year :	86.0%	80%
Cardiovascular Risk Assessment :	78.6%	80%
CVRA High and BP ≤ 130 :	44.8%	80%
CVRA High and Total Chol ≤ 4 :	58.1%	80%
Diabetic and HbA1c ≤ 8% :	34.5%	80%
Diabetic and ACR < 30 :	72.4%	80%
NON Smoker :	61.8%	90%



Known Data Issues

- Some Care plans which have "completed" as opposed to being "de-activated" may still appear on list as active.
- A few AHC plans which have been recently de-activated may still appear on list as active. This will be rectified with next Business Objects load

NT AHKPI's

	Current
KPI 1.7 (Diab/IHD GPMP last 2 years)	91.4%
KPI 1.8* (Diabetics & HbA1c past year)	96.7%
KPI 1.9 (Diabetes, ↑ ACR on ACEorARB)	94.1%
KPI 1.10 (AHC 15-55 years age)	59.6%
KPI 1.11 (AHC 55 years and older)	36.4%



≥ 75%	Green
50% - 74%	Yellow
25% - 49%	Red
< 25%	Black

Cardiovascular Risk

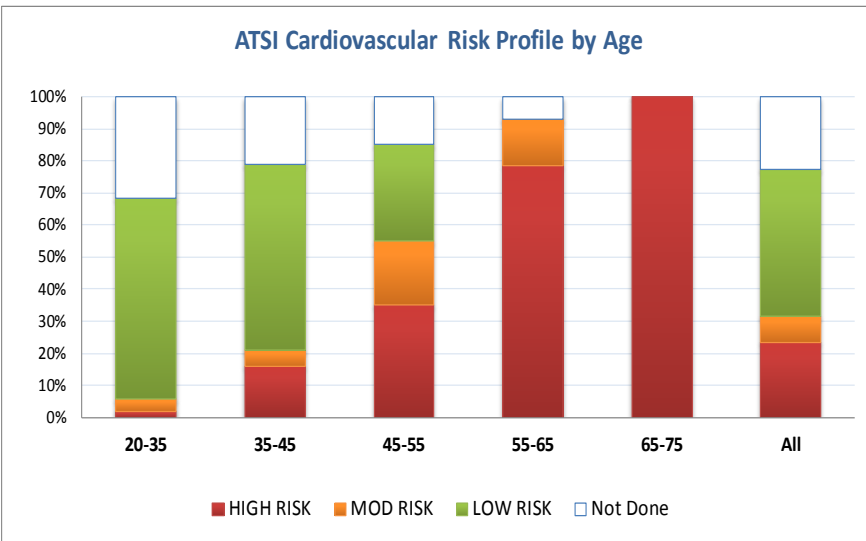
ATSI Clients age 20 and over: 117
 ATSI Clients with CVRA last 2 years : 92

78.6%

Cardiovascular Risk Category	All clients	PCD Clients	Non PCD
HIGH RISK :	31	30	1
MOD RISK :	10	7	3
LOW RISK :	51	7	44
NO CVRA ASSESSMENT :	25	2	23
Total CVRA Assessments :	92	44	48
	78.6%	96%	68%

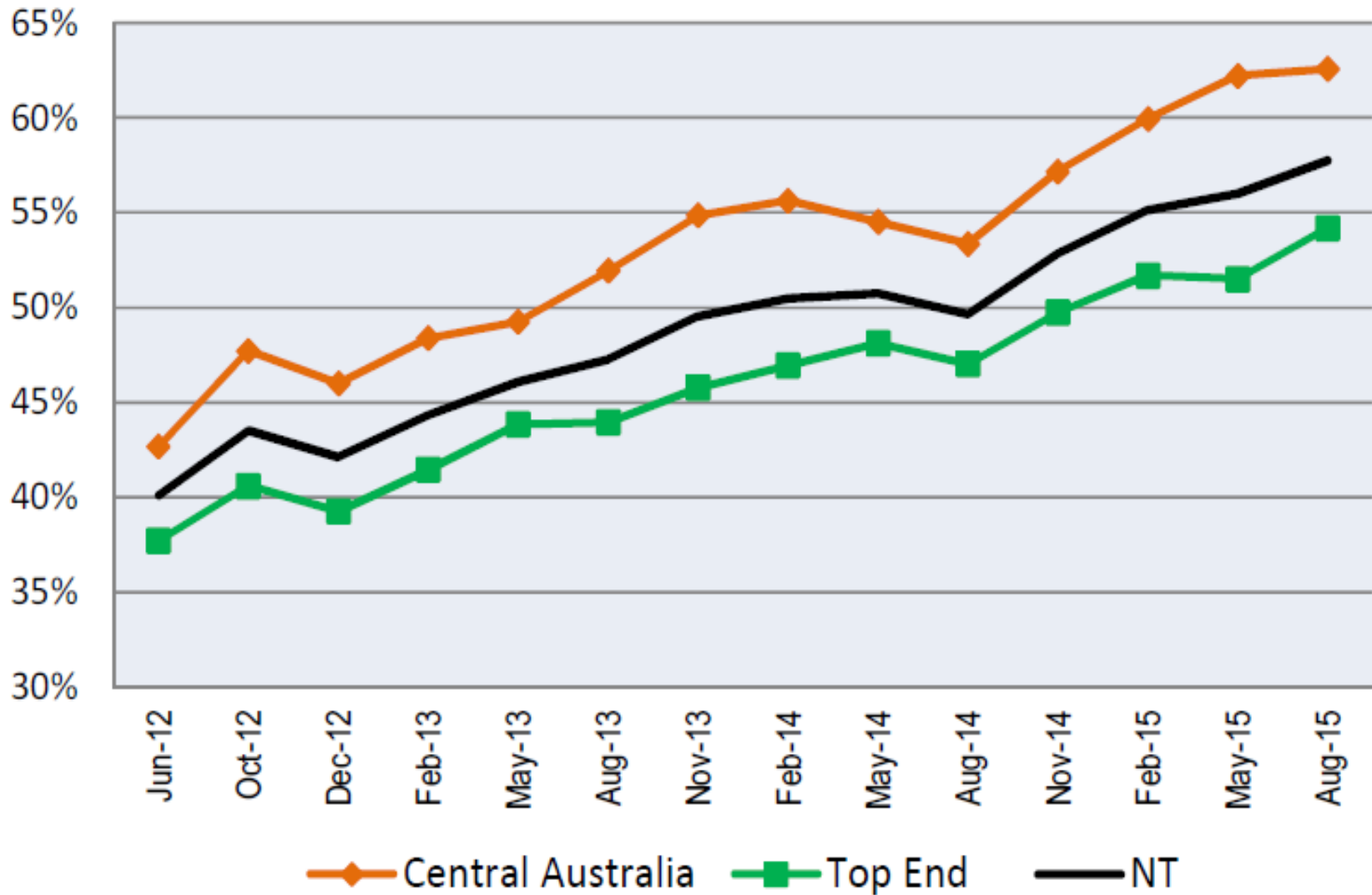
CVR Management Journey

	PROCESS	INTERVENTION	OUTCOME	The GAP	INERTIA
Cardiovascular Risk - HIGH : 31	Measured	On Rx	To target	>target on Rx	> target no Rx
Systolic BP (target ≤ 130) :	29	31 on BP meds	13	16 out of 16	0 out of 16
Total Cholesterol (target ≤ 4.0) :	31	23 on statin	18	9 out of 13	4 out of 13
Smoking Status :	30	-	23	-	-
Diabetes AND Hi CVRA : 20 patients		15 on aspirin	15	-	5

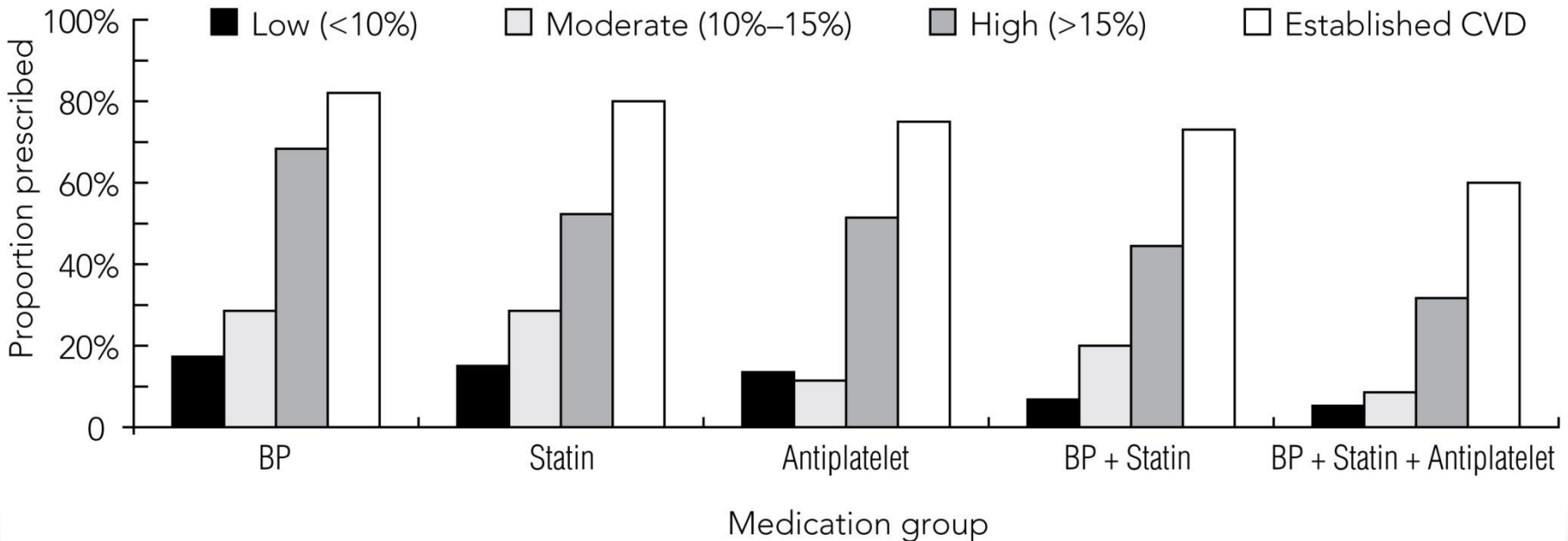


Trend Graph

Proportion PCD Patients with GPMP Past Year



- **Retrospective review of clinical records of a random selection of 1165 regular attendees**



Prescribing of major cardiovascular medication groups by absolute cardiovascular disease risk category

8. Cultural competence mainstream services

Results: A shared understanding of key concepts was rarely achieved. Miscommunication often went unrecognised. Sources of miscommunication included lack of patient control over the language, timing, content and circumstances of interactions; differing modes of discourse; dominance of biomedical knowledge and marginalisation of Yolngu knowledge; absence of opportunities and resources to construct a body of shared understanding; cultural and linguistic distance; lack of staff training in intercultural communication; and lack of involvement of trained interpreters.

Conclusions: Miscommunication is pervasive. Trained interpreters provide only a partial solution. Fundamental change is required for Aboriginal patients to have significant input into the management of their illness. Educational resources are needed to facilitate a shared understanding, not only of renal physiology, disease and treatment, but also of the cultural, social and economic dimensions of the illness experience of Aboriginal people.

Engagement of Indigenous ESKD patients

- Indigenous Australians are confused and feel poorly informed about their illness:
 - *They just say “end-stage” — that’s all I was told.*
 - *There’s a whole lot of us who just don’t understand what’s going on.*
 - *Everyone seems to think it’s all caused solely by alcohol. So they are ignorant. That’s what they say: “All you Indigenous people who have got kidney disease, you’re all alcoholics”.*

Engagement of Indigenous ESKD patients

- Reported feeling excluded from information:
 - *There's a whole lot of us who just don't understand what's going on. They know though, the doctors and the nurses know, but they don't tell us.*
 - *I don't know how to talk to the nurse or doctor. He comes down here and just checks out how we're looking after our body. It's not enough time.*
 - *You don't go knocking on their door, [that's the] "danger one". The door is locked. They sit behind closed doors.*



“I was born and bred on these lands. How on earth could I go all the way to the city, away from my family and country, knowing there was no possibility for them to come down and stay with me, no accommodation, no facilities ... There's no way I could think about being so far away ... I'd just be in total despair all the time.”

(Senior community member, September 2010)

I don't think the community have a lot of faith in mainstream, and I have to admit I've seen it where I've taken a client, or a couple of clients, to the hospital, and they're just treated atrociously. And I don't think it was because of their condition...It was because they identified as being Aboriginal...one of our clients was admitted because he had a heart attack, and she [one of our nurses] went in to visit him, and she could actually hear the nurses in the hallway sneaking about him. And she walked out and she tore strins off them, ...a lot of people didn't want to go there [the local mainstream health service] because they felt the place was unfriendly, the staff were not friendly towards them and there was a lot of attitudes happening, people felt they were discriminated against, and the place was very sterile ... it wasn't like a, it wasn't a comfortable environment ... and people spoke ... didn't speak in the way we speak ... like very abrupt, loud and abrupt, communication wasn't there too, you know? Just that lack of understanding in how you talk, the tone you use for Indigenous people ... so there was that, where there was no probably no cultural knowledge with the staff ... [...]. Yeah, like discrimination, racism, or you know, just ignorance and no sensitivity and no understanding of Indigenous health issues... [Aboriginal_Community_F_Urb]

Big challenges

1. Emerging trends in burden of chronic disease
2. Greatest CD burden in remote areas
3. Complex comorbidities including mental health
4. Social determinants and need for
5. Intervention across life-course
6. Extend from narrow focus on cost of health service to broader assessment of impact and cost
7. Integrated systems of measurement, monitoring and reporting to drive change in clinical care and enable best-informed planning
8. Work to improve cultural competence of mainstream services