

Thesis submitted for the degree of Master of Philosophy in Applied Epidemiology

VOLUME II - APPENDICES

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10 November 2017

Indigenous Health Division

Australian Government Department of Health



Australian Government

Department of Health



**Australian
National
University**

Academic Supervisor: Dr David Harley

Field Supervisor: Nick Pascual

This research is supported by an
Australian Government Research Training Program (RTP) Scholarship

Originality Statement

'I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at the Australian National University or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by others is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation or linguistic expression is acknowledged'.

Signed

Date

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There are no appendices for Chapters 1 and 2 of the thesis

**CHAPTER 3 – DETERMINANTS OF SOCIAL AND EMOTIONAL
WELLBEING IN ABORIGINAL AND TORRES STRAIT ISLANDER
CHILDREN: RESULTS FROM THE FOOTPRINTS IN TIME STUDY**

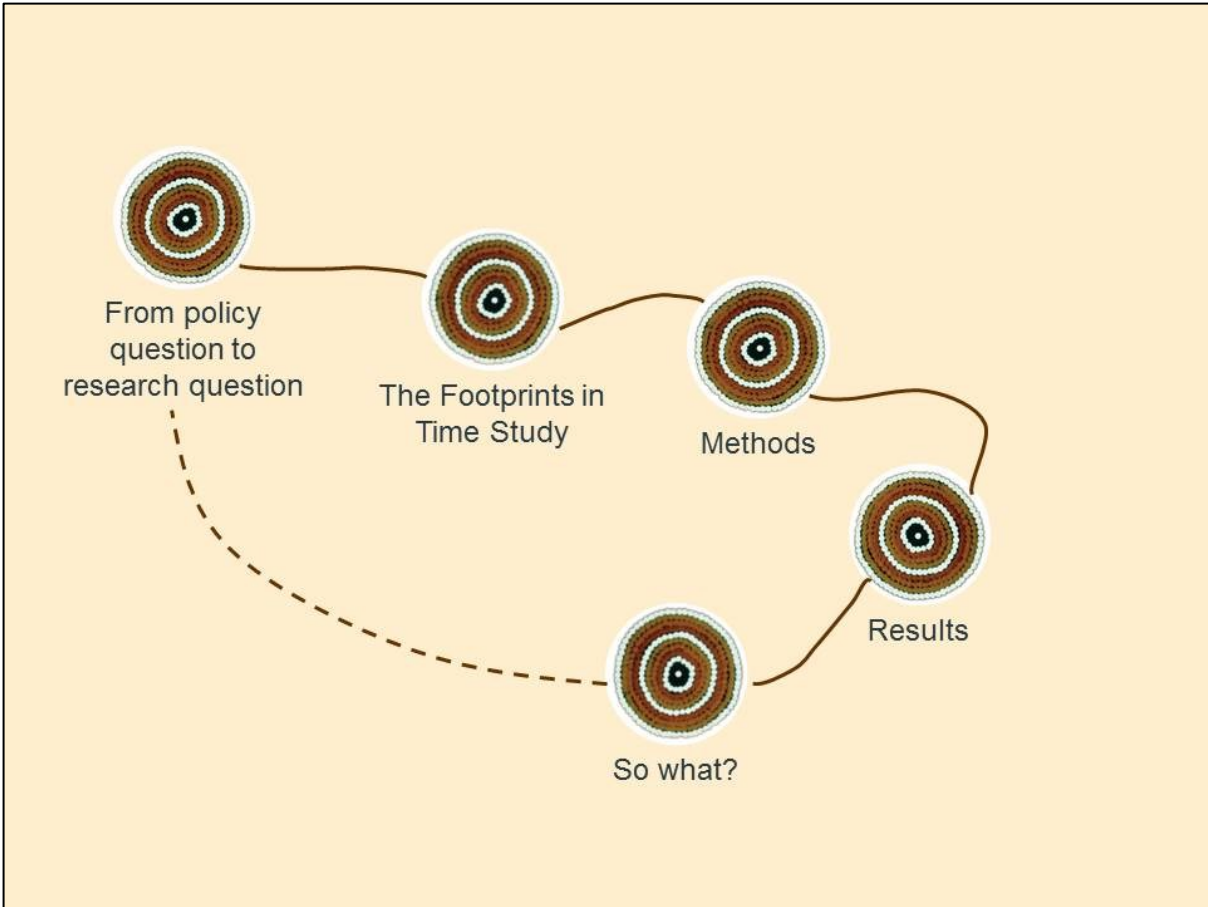
**APPENDIX 3.1 – Presentation to the monthly Forum of the
Indigenous Health Division, Department of Health,
Australian Government, October 2016**




What promotes social and emotional wellbeing for children in the Footprints in Time study?

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Policy question:

What are the determinants of social and emotional wellbeing (SEWB) for Aboriginal and Torres Strait Islander children?



Research question:

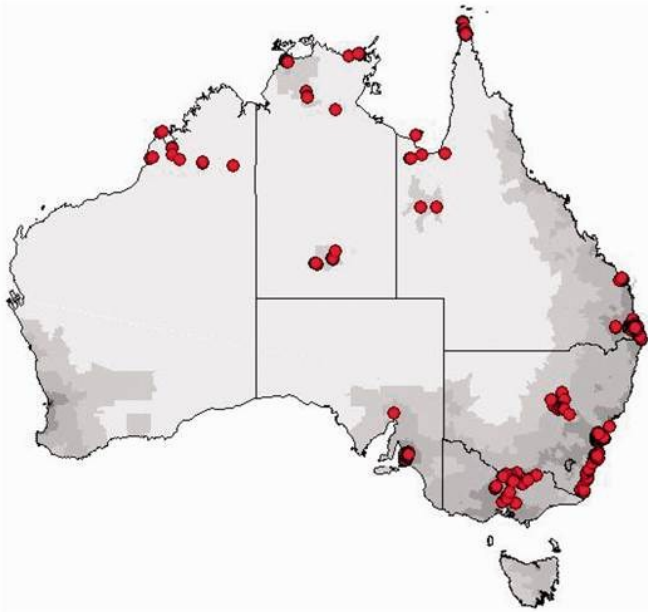
Which factors in the first years of life determine SEWB in Footprints in Time children at the time of starting school?

Footprints in Time

What do Aboriginal and Torres Strait Islander children need to have the best start in life to grow up strong?

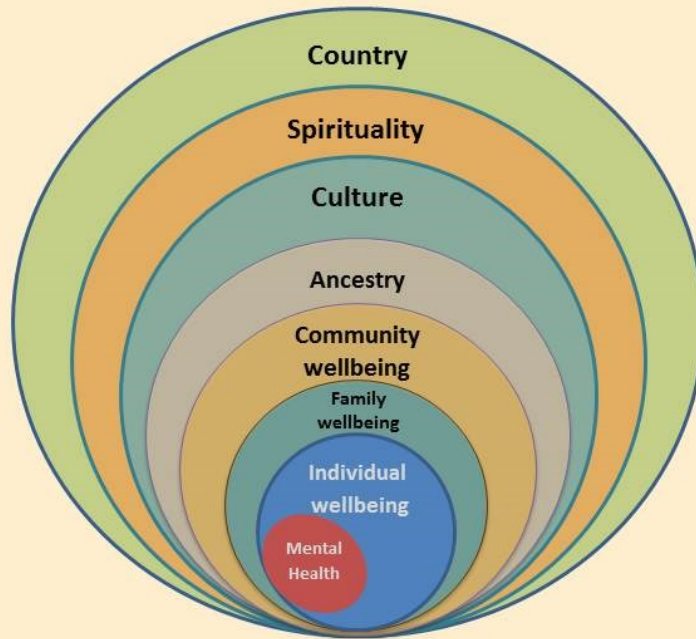


Where do the children live?

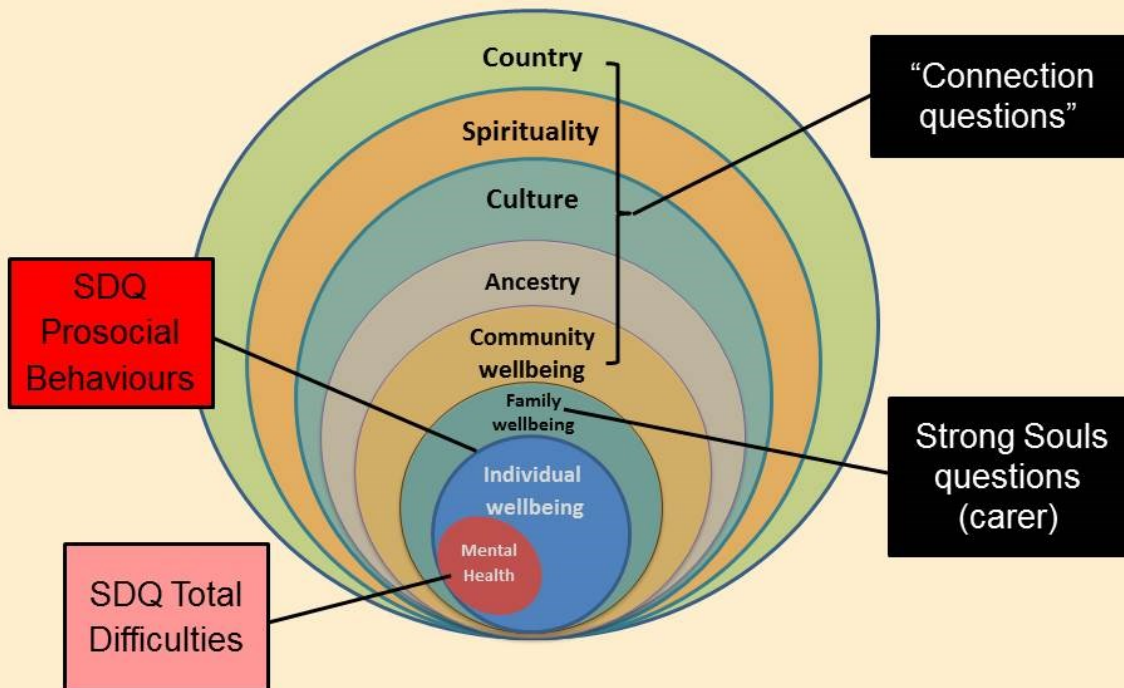


Thurber et al. (2014). *Int. J. Epidemiol*, 44:789-800

Social and Emotional Wellbeing

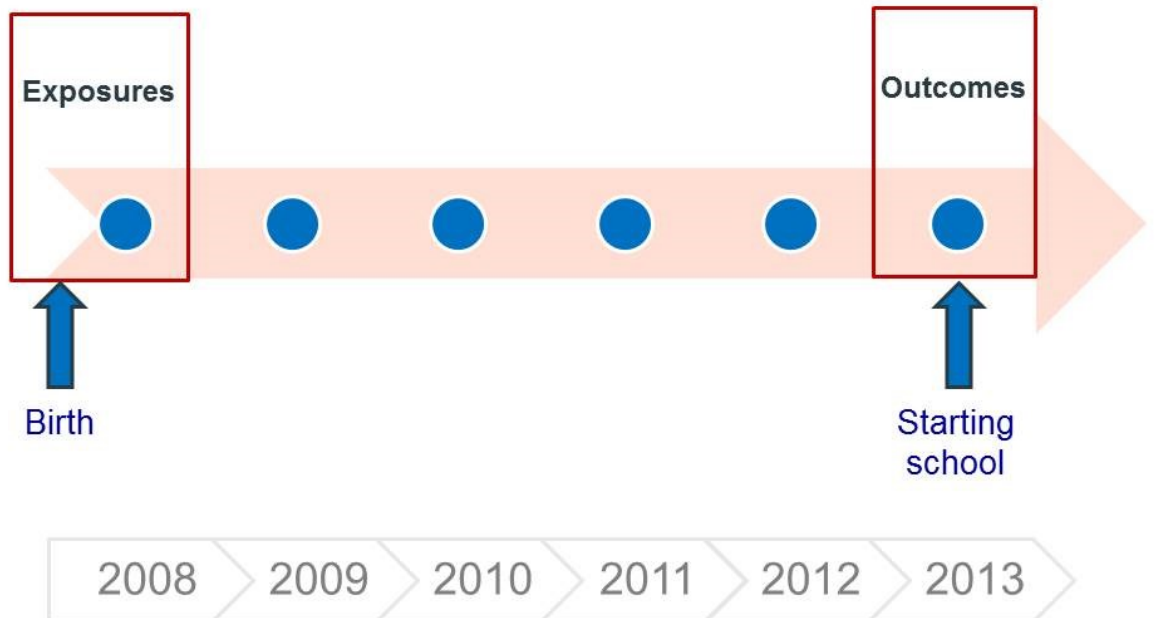


Social and Emotional Wellbeing

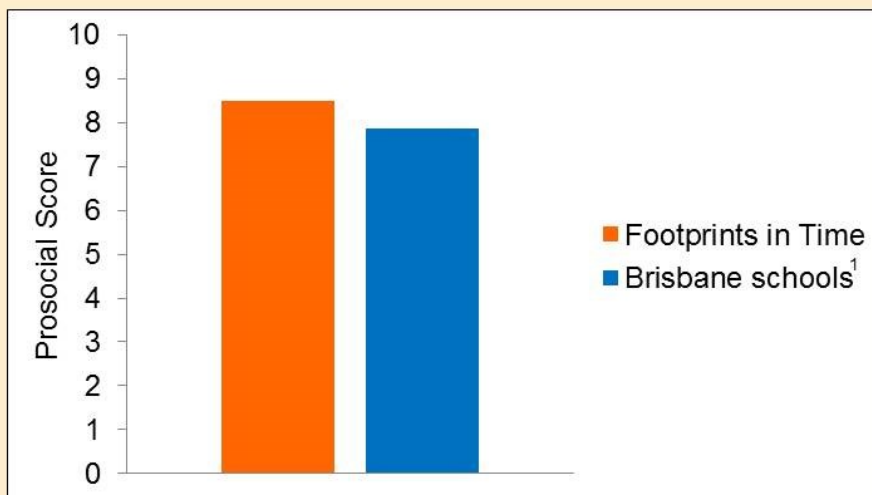


Exposures

- Antenatal factors
- Having a family member removed
- Child physical health
- Home life
- Characteristics of primary carer
- Attending childcare or daycare
- Family experience of racism
- Geographical isolation (LORI)
- Socio-economic measure (IRISEO)



Mean SDQ Prosocial Score, children aged 4-7 years

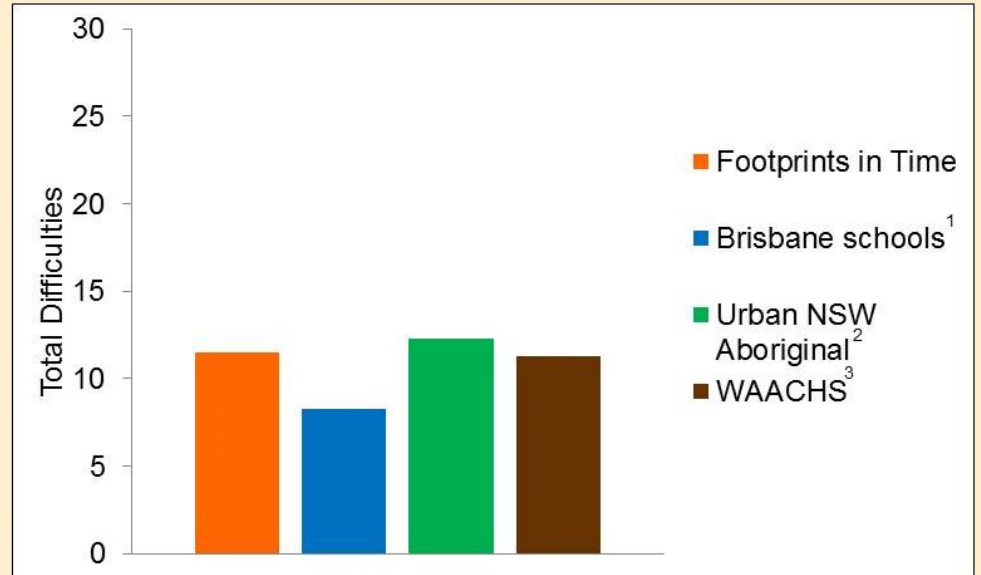


¹Hawes & Dadds, 2004, *ANZJP*, 28:644-651

A higher Prosocial score was associated with...

- Overall health of the child at time of starting school

Mean SDQ Total Difficulties Score, children aged 4-7 years



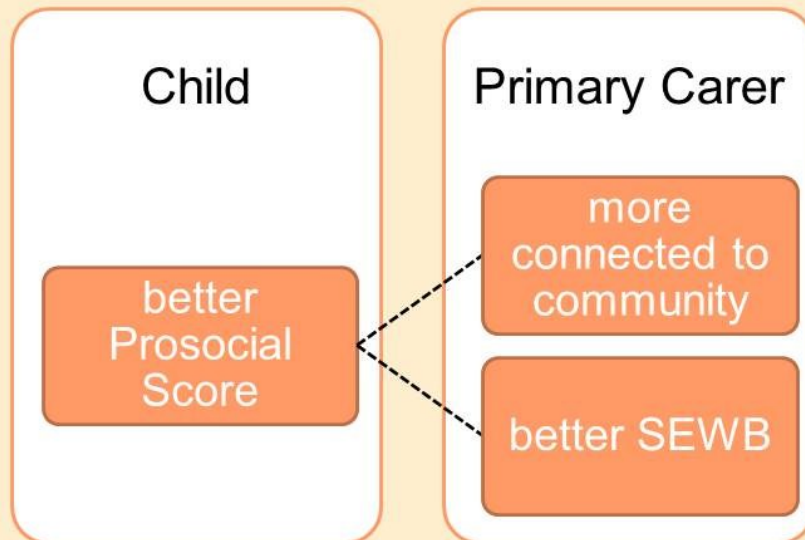
¹Hawes & Dadds, 2004, *ANZJP*, 28:644-651 ²Williamson et al, 2016, *BMJ Open*, 6.

³Zubrick et al, 2005, *Western Australian Aboriginal Child Health Survey*.

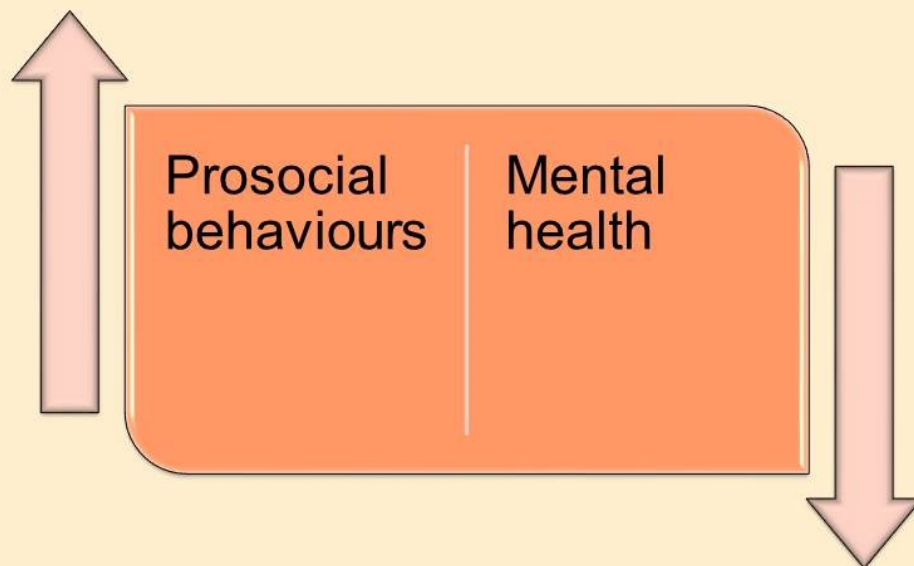
A lower Total Difficulties Score was associated with...

- Better overall health in first 2 years of life
- Fewer major life events
- Better mental health as infant/toddler

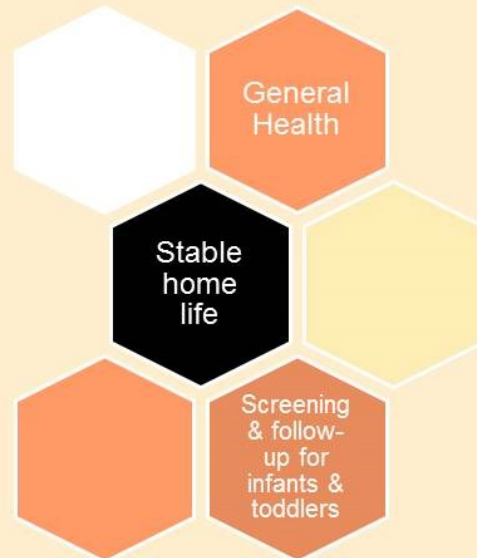
Prosocial Score, Strong Souls & 'Connection Questions'



So what?



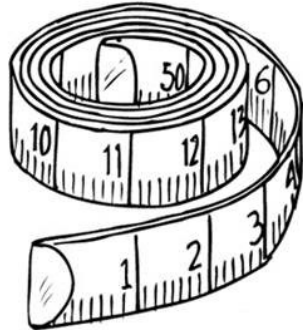
Policy Implications



Policy question:

What are the determinants of social and emotional wellbeing (SEWB) for Aboriginal and Torres Strait Islander children?

How to measure SEWB?



*What we measure affects
what we do; and if our
measures are flawed,
decisions may be distorted¹*

Stiglitz, Sen & Fitoussi (2009). *Report by the Commission on the Measurement of Economic Performance and Social progress.*

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Footprints in Time children and families

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Dr Liana Leach, ANU

Fiona Skelton, DSS

Samantha Siripol, MAE

Dr Amy Burroughs, MAE

Artwork is from *Making Two Worlds Work*
<http://www.whealth.com.au/mtww>

APPENDIX 3.2 – Presentation to the Australian Longitudinal Data Conference, October 2016, Canberra



What promotes social and emotional wellbeing for children in the Footprints in Time study?

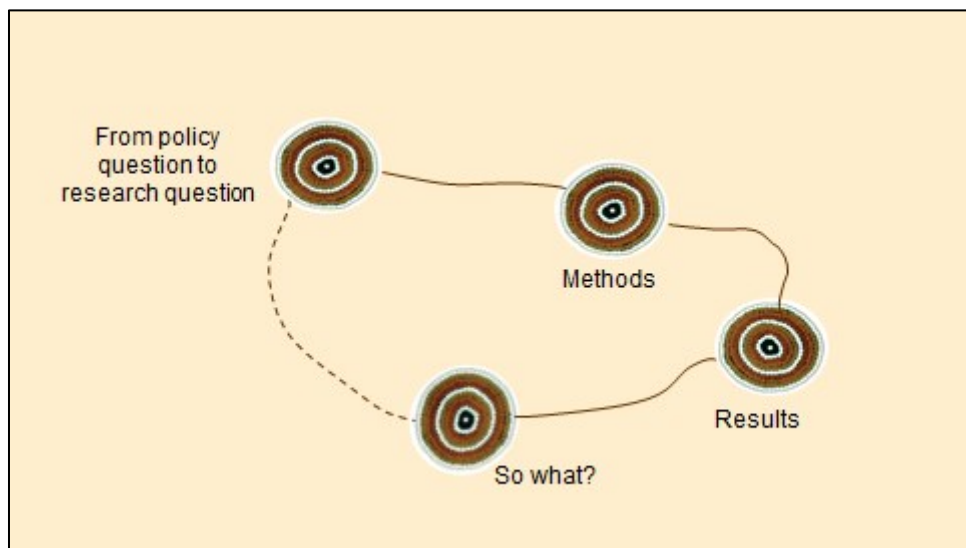
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Associate Professor David Harley
NCEPH, ANU

Indigenous Health Division
Department of Health

Australian Government
Department of Health

Australian National University

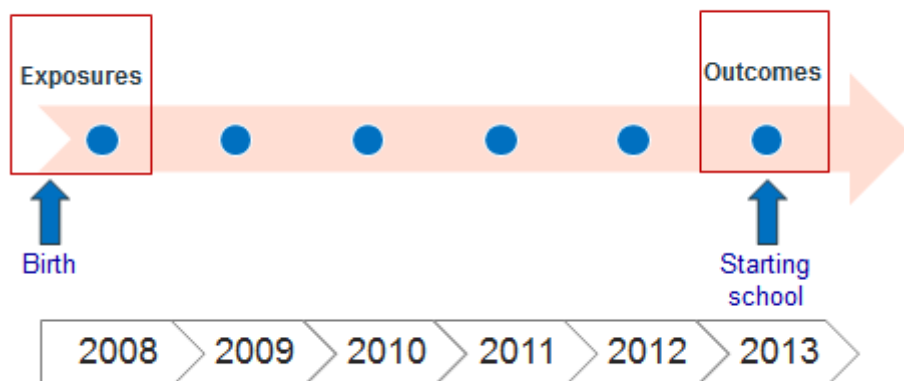


Policy question:

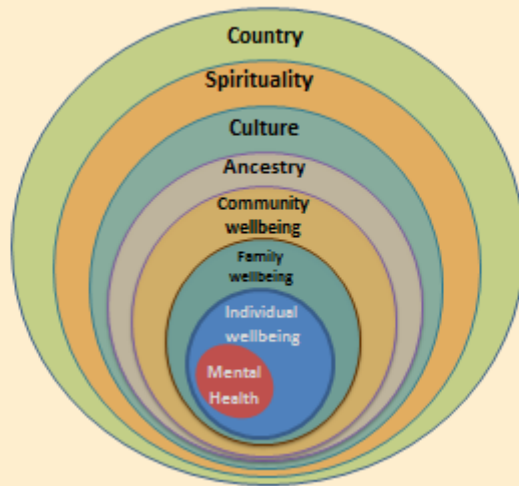
What are the determinants of social and emotional wellbeing (SEWB) for Aboriginal and Torres Strait Islander children?

Research question:

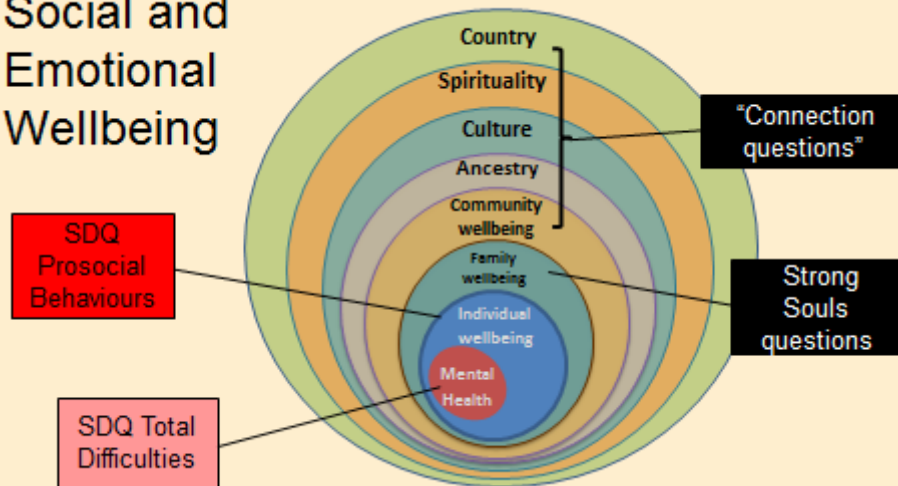
Which factors in the first years of life determine SEWB in Footprints in Time children at the time of starting school?



Social and Emotional Wellbeing

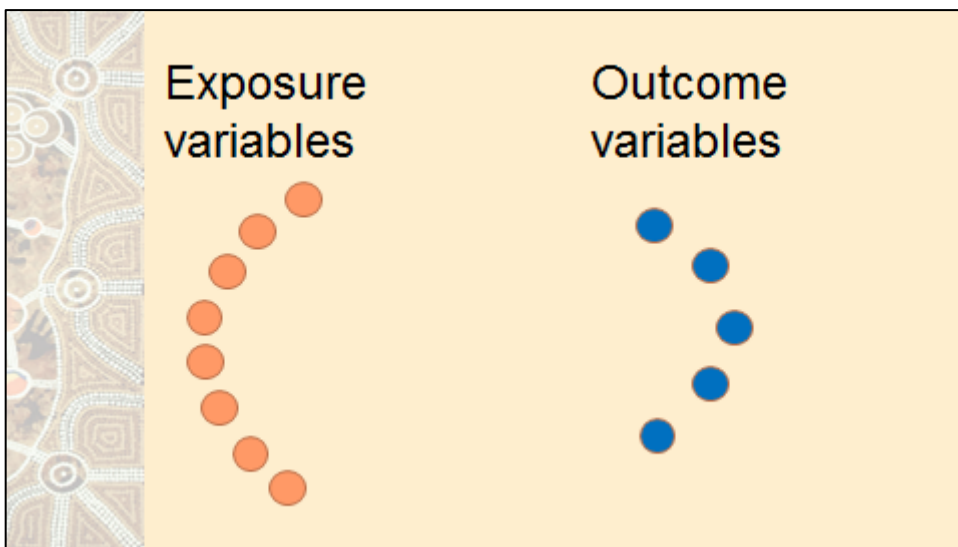
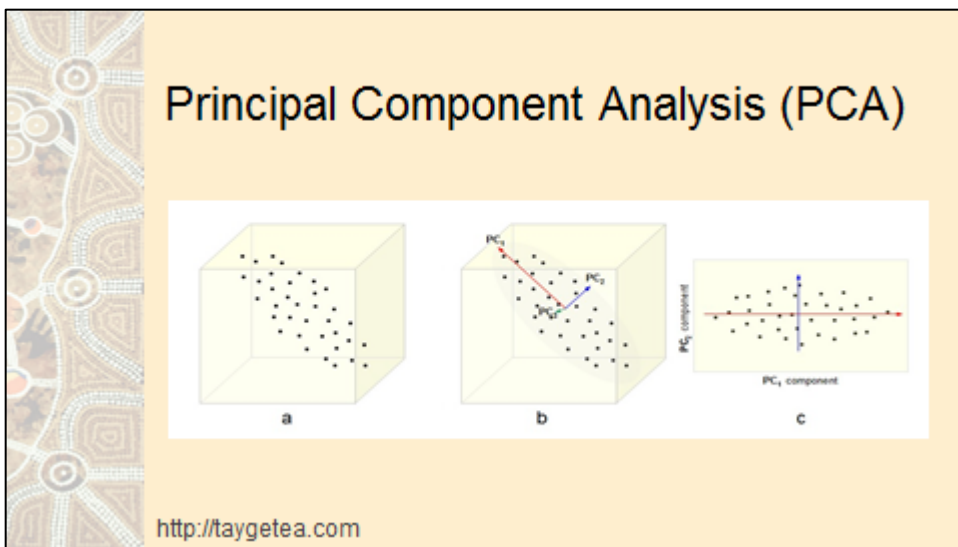
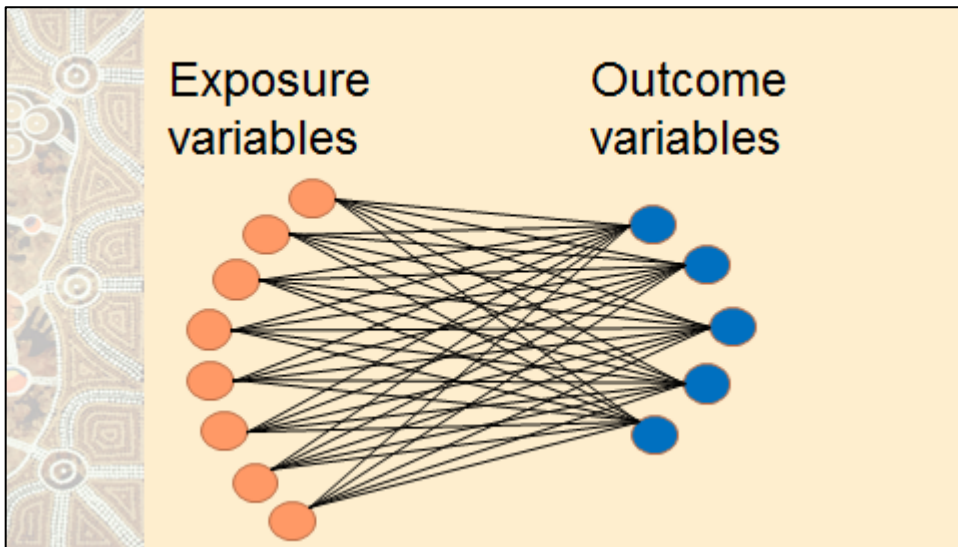


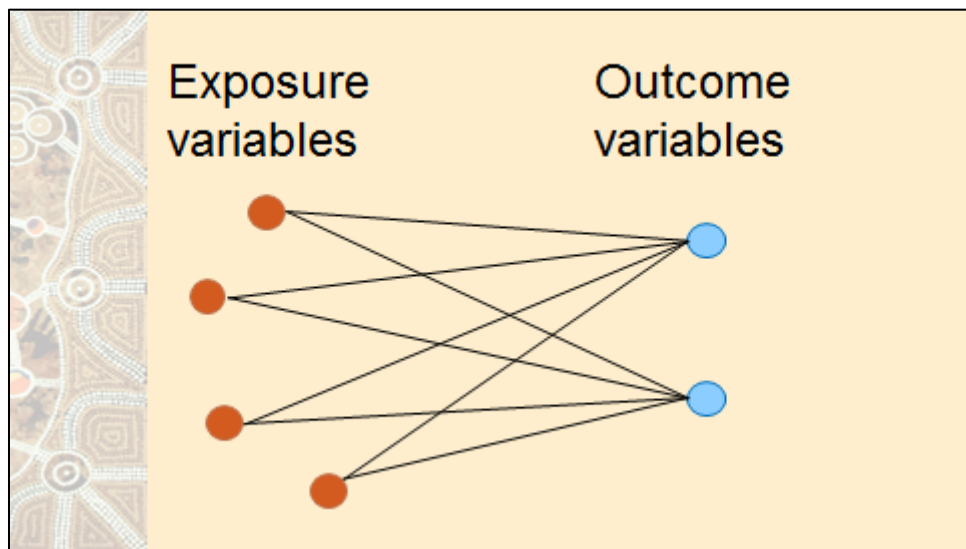
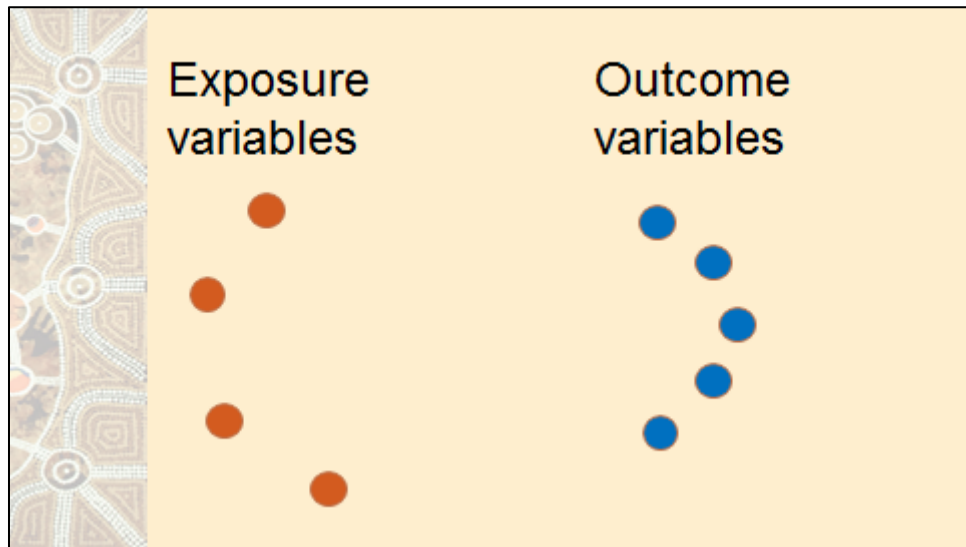
Social and Emotional Wellbeing



Exposures

- Antenatal factors, physical health
- Characteristics of primary carer
- Home life and events
- Intergenerational trauma and racism/discrimination
- Parenting and care
- Macro-level socio-economic indicators





Results – PCA

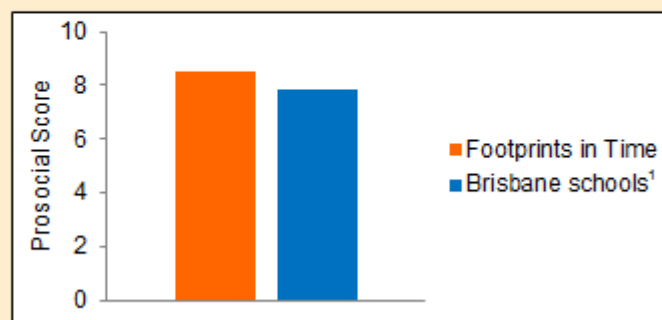
variable	Comp1	Comp2	Comp3	Comp4	Comp5	Comp6
lowbirthw						
ghlth_c						1.0000
earprobnever			1.0000			
hoapno						
antennat20wk				1.0000		
pnprobnot						
alcoholno						
smokingno	1.0000					
plpartn		1.0000				
breaetfed						
playgroup						
geetfullteam						
advice						
acolea_p_b						
ractiamw_c						
employ						
monyeitar						
qual_p_b						
peoplehh					1.0000	
parvarnhtoc						
events						
numhome						

Methods

- SDQ Prosocial Score
 - Ordinal logistic regression
- SDQ Total Difficulties Score
 - Linear regression

Results

Mean SDQ Prosocial Score,
children aged 4-7 years (n=726)

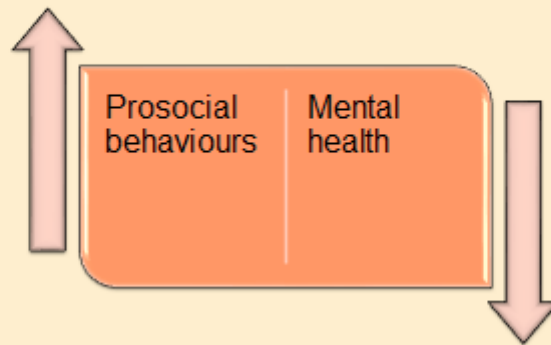


¹Hawes & Dadds, 2004, ANZJP, 28:644-651

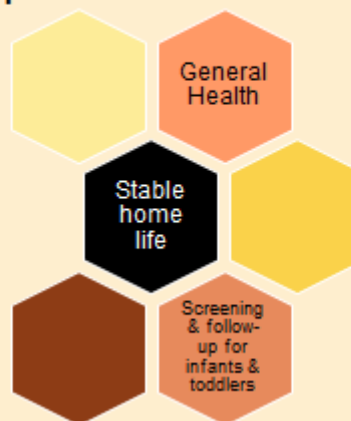
Results – lower Total Difficulties Score

Wave 1	Regression coefficient	95% Confidence Interval	p
Poor general health	-8.91	-11.57 – -6.25	0.000
BITSEA Problem score	-0.29	-0.40 – -0.18	0.000
Major life events	-0.29	-0.55 – -0.02	0.042

So what?



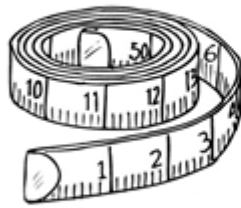
Policy Implications



Policy question:

What are the determinants of SEWB for Aboriginal and Torres Strait Islander children?

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MAE Scholars: Samantha Siripol, Dr Amy Burroughs

Artwork is from *Making Two Worlds Work*

www.whealth.com.au/mtww

APPENDIX 3.3 – Article submitted to *Family Matters* journal

WHAT PROMOTES SOCIAL AND EMOTIONAL WELLBEING IN ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN?—LESSONS IN MEASUREMENT FROM THE LONGITUDINAL STUDY OF INDIGENOUS CHILDREN

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DISCLAIMER

This article uses unit record data from the Longitudinal Study of Indigenous Children (LSIC). LSIC was initiated and is funded and managed by the Australian Government Department of Social Services (DSS). The findings and views reported in this paper, however, are those of the authors and should not be attributed to DSS or the Indigenous people and their communities involved in the study.

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- Dr Alice Richardson, who gave statistical advice
- Dr Liana Leach, who gave advice about the study design
- Fiona Skelton, Laura Bennetts-Kneebone and Debora Kikkawa, DSS, who provided helpful feedback on the data analysis plan.

AM completed this work while she was a Master of Philosophy (Applied Epidemiology) scholar, on placement at the Australian Government Department of Health, and supported by an Australian Government Research Training Scholarship.

ABSTRACT

Promotion of social and emotional wellbeing (SEWB) in Aboriginal and Torres Strait Islander children is an important aim for policy makers in maternal and child health. Mainstream mental health assessment tools do not reflect the positive, holistic concept of SEWB. We analysed data from the Longitudinal Study of Indigenous Children with the primary aim of identifying early life exposures associated with SEWB at the time of starting school. Our secondary aim was to develop a new indicator of SEWB. Large household size and frequent exposure to life events were associated with reduced sharing, helping and mental health in the child, and lower primary carer wellbeing. Our findings are consistent with the social determinants theory of SEWB and supportive of holistic, trans-portfolio approaches. We were unable to create a single index of SEWB. If mainstream measures of mental health are used for planning and evaluation of Aboriginal and Torres Strait Islander programs, their limitations must be acknowledged.

KEYWORDS

Indigenous Australians, Wellbeing, Early childhood policy, Antenatal care, Research, Measures, Longitudinal studies

MEASURING CHILDREN'S SOCIAL AND EMOTIONAL WELLBEING

Social and emotional wellbeing (SEWB) is central to the holistic view of health held by Aboriginal and Torres Strait Islander people (Department of Health and Ageing, 2013). Social and emotional wellbeing is broader concept than Western understandings of mental health and resilience; individual wellbeing is

...intimately associated with collective wellbeing. It involves harmony in social relationships, in spiritual relationships and in the fundamental relationship with the land and other aspects of the physical environment. (Haswell, Blignault, Fitzpatrick, & Jackson Pulver, 2013)

The absence of mental ill health is necessary but not sufficient for social and emotional wellbeing, a positive concept that values relationships (Henderson et al., 2007). A child's wellbeing is dependent upon family and community wellbeing and connection to ancestry, culture, spirituality and country. Mental health is important but not central to the child's SEWB (Figure 1A). Limited quantitative studies indicate that Aboriginal and Torres Strait Islander children have significantly higher rates of social and emotional difficulties, mental health problems and psychological distress than non-Indigenous children (Australian Institute of Health and Welfare, 2009; Priest, Baxter, & Hayes, 2012; Zubrick et al., 2005). This disparity is apparent by three years of age (Baxter, 2014). Identifying interventions and approaches that promote SEWB will guide policy makers and program managers—particularly those working in the area of maternal and child health.

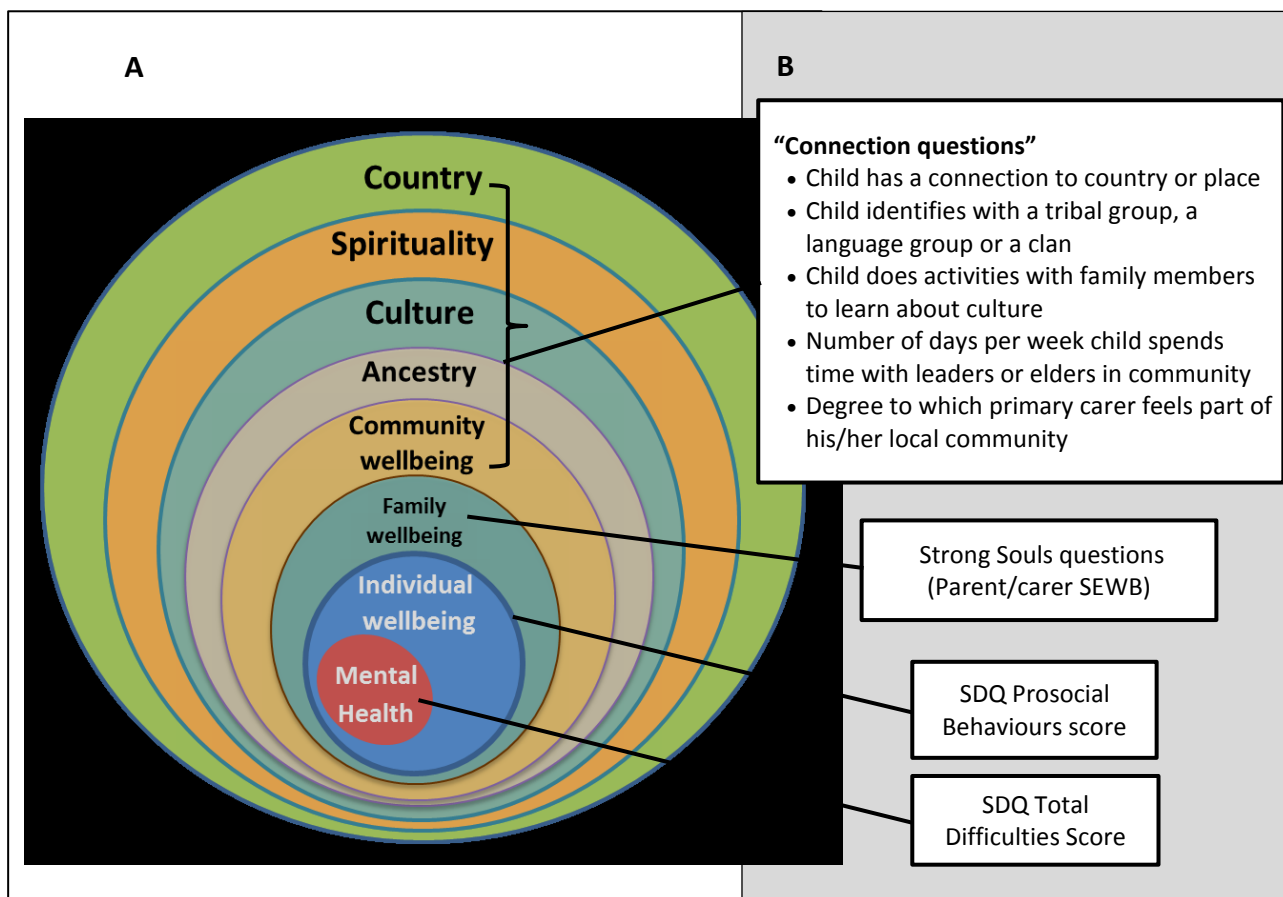


Figure 1: (A) Conceptual framework for social and emotional wellbeing (SEWB) of Aboriginal and Torres Strait Islander children; and (B) variables from the Longitudinal Study of Indigenous Children chosen as outcome measures to operationalise this concept

Mainstream mental health assessment tools do not adequately reflect social and emotional wellbeing (Henderson et al., 2007). Normal behaviour is culturally constructed, and tools may not account for Aboriginal and Torres Strait Islander societal norms or language (Dingwall & Cairney, 2010). Many studies of Aboriginal and Torres Strait Islander children measure SEWB using the Strengths and Difficulties Questionnaire (SDQ). This 25-item questionnaire was designed to assess the “psychological adjustment” of children aged three to 16 years (Goodman, 2001). The SDQ consists of five scales which score emotional symptoms, conduct problems, hyperactivity-inattention, peer problems, and prosocial behaviour. The first four scales are summed to generate a Total Difficulties score, with a higher score indicating more difficulty. The fifth scale is summed to generate a Prosocial Behaviours score, with a higher score indicating better behaviours. The items and their groupings were selected based on their relationship to categories of mental disorders (Goodman, 2001).

Parents, researchers, youth workers and health workers in Aboriginal communities in Sydney indicated that the standard SDQ was acceptable as a measure of mental health, but does not assess “connection to or relationship with extended family, Aboriginal identity, feeling that you are accepted by or belong to an Aboriginal community, and the impact and experience of racism” (Williamson et al., 2010). The Total Difficulties score of the SDQ has been used as a measure of SEWB (Li, Jacklyn, Carson, Guthridge, & Measey, 2006; Priest et al., 2012; Priest, Paradies, Gunthorpe, Cairney, & Sayers, 2011; Skelton, 2015; Zubrick et al., 2005) but includes only the deficit-

focused subscales. The prosocial scale of the SDQ provides information about an Aboriginal child’s relationship with their family that is central to SEWB (Williamson et al., 2010).

We aimed primarily to identify factors, *in utero* to two years of age, associated with SEWB in Aboriginal and Torres Strait Islander children at the time of starting school. A secondary aim was to explore the possibility of developing a new indicator of SEWB.

METHOD

We selected a sample of children from the Longitudinal Study of Indigenous Children (LSIC) who were aged two years or under at Wave 1, or who entered in Wave 2 aged three years or under. We developed a conceptual framework to represent SEWB in Aboriginal and Torres Strait Islander children and guide the selection of outcome measures from Waves 5 and 6, around the time of starting school (shown in Figure 1B). Children’s prosocial behaviour and mental health were measured using the two SDQ subscale scores. We used Principal Component Analysis (PCA) (Navarro Silvera et al., 2011) to reduce these outcome measures to a new index of SEWB. A successful PCA results in a handful of components to which “common sense meanings” can be assigned (Navarro Silvera et al., 2011). Principal components are continuous variables that can be used in analyses in place of the many variables that were used to create them (Navarro Silvera et al., 2011). We selected early life exposure variables from Waves 1 or 2 based upon factors found by previous studies to be associated with SDQ scores, factors that have a biologically or socially plausible link to SDQ scores, and factors that reflect the activities or intended outcomes of maternal and child health services (Table 1). We incorporated exposures and potential confounders with a *p* value of 0.25 or less from univariable analyses into linear regression models. Models were adjusted for the geographic clustering in the LSIC sample. All analyses were conducted using StataSE version 13. This research was approved by the Australian National University Human Research Ethics Committee.

Table 1: Description and coding details for LSIC variables included as exposures in univariable analyses

Variable	LSIC Interview question wording or description
Mother received first antenatal visit < 20 weeks gestation	<i>How far along [in weeks] [were you/was she] in [your/her] pregnancy when [you/she] had [your/her] first check-up?</i>
Mother did not drink alcohol during pregnancy	<i>After finding out you were pregnant with [child’s name] did you drink any alcohol during the pregnancy?</i>
Mother did not smoke during pregnancy	<i>After finding out you were pregnant with [child’s name] did you smoke any cigarettes during the pregnancy?</i>
Mother did not use any substances during pregnancy	<i>We aren’t after any details here, but after finding out you were pregnant with [child’s name] did you use any other substances like smoking marijuana, drinking kava, sniffing petrol, or</i>

Table 1: Description and coding details for LSIC variables included as exposures in univariable analyses

Variable	LSIC Interview question wording or description
	<i>taking any illicit drugs during the pregnancy?</i>
Low birthweight	<i>Can you read out the birthweight from the record book? How much did [child's name] weigh at birth?</i> If primary carer has the baby health book they are asked to read the weight from the book, otherwise they are asked to recall the birthweight.
Global health measure	<i>In general, would you say [child's name]'s health is excellent, very good, good, fair or poor?</i>
Not hospitalised in last 12 months	<i>In the last 12 months, did [child's name] stay in hospital because (he/she) was sick, injured, or required surgery?</i>
Child never had any ear problems	<i>Has [child's name] ever had runny ears/perforated eardrum/hearing loss (total/partial/one ear) /other ear problem?</i>
Attends childcare, daycare or family daycare	<i>Does [child's name] go to childcare, day-care or family day care?</i>
Primary carer is employed	<i>Do you have a job?</i>
Highest qualification of the primary carer	<i>What was the highest qualification that you have completed?</i>
Parental warmth measure (primary carer)	<i>When answering, please say whether you Always, Often, Sometimes, Rarely, or Never do each thing I ask about:</i> <ul style="list-style-type: none"> • <i>hug or hold [child's name] for no particular reason?</i> • <i>enjoy listening to [child's name]?</i> • <i>enjoy doing things together with [child's name]?</i> • <i>feel close to ([child's name] when [he/she] is happy?</i> • <i>feel close to ([child's name] when [he/she] is upset?</i> • <i>go out of your way to say how pleased you are when [child's name] does something really well?</i>
Stolen generations	<i>Were you or any of your (or your partner's) relatives removed from your family by welfare or the government or taken away to a mission?</i>
Frequency with which family experiences racism ^a	<i>How often does your family experience racism, discrimination or prejudice?</i>
Total number of people living in household	Derived from household survey question: <i>What are the first and last names of all the people who live in this household, starting with you?</i>
Number of major life events in previous year	<i>I'd like to ask you about any big things that have happened to you, your family or [child's name] in the last year...[list possible events]</i>
Number of homes child has lived in since birth	<i>How many homes has [child's name] lived in since he/she was born?</i>
Family financial stress	<i>Which words best describe your family's money situation?</i>
Index of Relative Indigenous Socio-economic Outcomes	Based on Indigenous Area of child's residential address. 1=most favourable outcome; 10= favourable outcome
Level of Relative Isolation	Based on geocoding of child's residential address.

Notes: ^a Wave 3 data used.

Source: (Department of Social Services [DSS], 2016)

OUR RESEARCH STANDPOINT

Licensed users of LSIC data are required to openly acknowledge their research standpoint (DSS, 2013). We are non-Indigenous Australians with middle-class backgrounds. Following Pyett, Waples-Crowe and van der Sterren (2008), we have attempted to interpret the data through a strengths-based lens and challenge the deficit model of Aboriginal and Torres Strait Islander health. Also, by recognising and favouring Indigenous understandings of SEWB, we have used a decolonising approach.

RESULTS

CHARACTERISTICS OF CHILDREN IN THE STUDY SAMPLE

A total of 950 children from the LSIC cohort met the age eligibility criteria, but only 726 of these (76%) had a SDQ Prosocial Behaviours score at endpoint and were included in the sample. Excluded children were more likely to be low birthweight, have a younger and unemployed primary carer, to have a mother who smoked while pregnant, and to live in a remote or very remote area (Table 2).

Table 2: Comparison of selected baseline characteristics of children included in and excluded from the study sample

Characteristic at baseline ^a	Included in sample %	Excluded from sample % ^b	<i>p</i> value for differenc e
Female	49.6	49.1	0.90
Low birthweight	8.0	15.1	0.01
Mother did not smoke after discovering she was pregnant	50.9	41.1	0.02
Mother did not drink alcohol after discovering she was pregnant	78.7	74.1	0.17
Very good or excellent general health	79.5	76.2	0.30
Primary carer aged <20 years	7.0	13.0	<0.01
Primary carer completed Year 12	41.0	33.0	0.74
Primary carer employed	30.2	17.9	0.00
Primary carer parental warmth score (mean, 95% CI)	4.8	4.7	0.18
Lived in remote or very remote area	33.4	49.1	0.00

Notes: ^a Characteristics with a statistically significant difference ($p < 0.05$) between groups are shown in bold. ^b Children of eligible age at baseline were excluded if SDQ Prosocial Behaviours score was missing for Waves 5 and 6.

PRINCIPAL COMPONENTS OF SEWB

The PCA of the outcome variables included data for 444 children (Table 3). Three principal components emerged¹. The first, “Child’s connection”, comprised variables representing the child’s connection to community and country. The second, “Child’s helping, sharing and mental health” was constructed from the child’s two SDQ scores; while the third, “Primary carer’s SEWB factors”, was mostly loaded by the primary carer’s SEWB score and connection to community. Higher component scores respectively indicate: a stronger connection; greater helping, sharing and mental health; and greater connection and SEWB of the carer.

Table 3: Rotated components and loadings from Principal Component Analysis of outcome measures, using oblique promax rotation (n=444)

	Component 1	Component 2	Component 3
Assigned Component Name	“Child’s connection”	“Child’s helping, sharing and mental health”	“Primary carer’s SEWB factors”
Eigenvalue	2.62	1.64	1.04
Proportion of variance explained	32%	18%	16%
Variable Loadings^a			
SDQ Prosocial Behaviours score		0.73	
SDQ Total Difficulties score		-0.64	
Child has a connection to country or place	0.55		
Child identifies with a tribal group, a language group or a clan	0.53		
Child does activities with family members to learn about culture	0.46		
Number of days per week child spends time with leaders or elders in community	0.39		
Degree to which primary carer feels part of his/her local community			0.70
SEWB of primary carer			0.65
Component Scores			
Minimum – maximum	-4.0 – 2.2	-13.7 – 11.6	0.6 – 17.9
Mean (standard deviation)	-1.5 (1.1)	2.7 (5.0)	13.3 (3.3)

Note: ^a Only loadings greater than 0.2 or less than -0.2 are shown.

EARLY LIFE EXPOSURES ASSOCIATED WITH SEWB COMPONENTS

“CHILD’S CONNECTION” COMPONENT SCORE

None of the early life exposures were strongly associated with a “Child’s connection” component score (Table 4, Figure 2). The regression model predicted a slightly better score for children:

¹ These were the only components with eigenvalues greater than one.

- living in households with 11 or more people, compared with those in two person households (Figure 2A);
- whose primary carer had less than Year 10 education, compared with a Year 12 education (Figure 2B); and
- of families that never or hardly ever experienced racism, compared with daily experience of racism (Figure 2C).

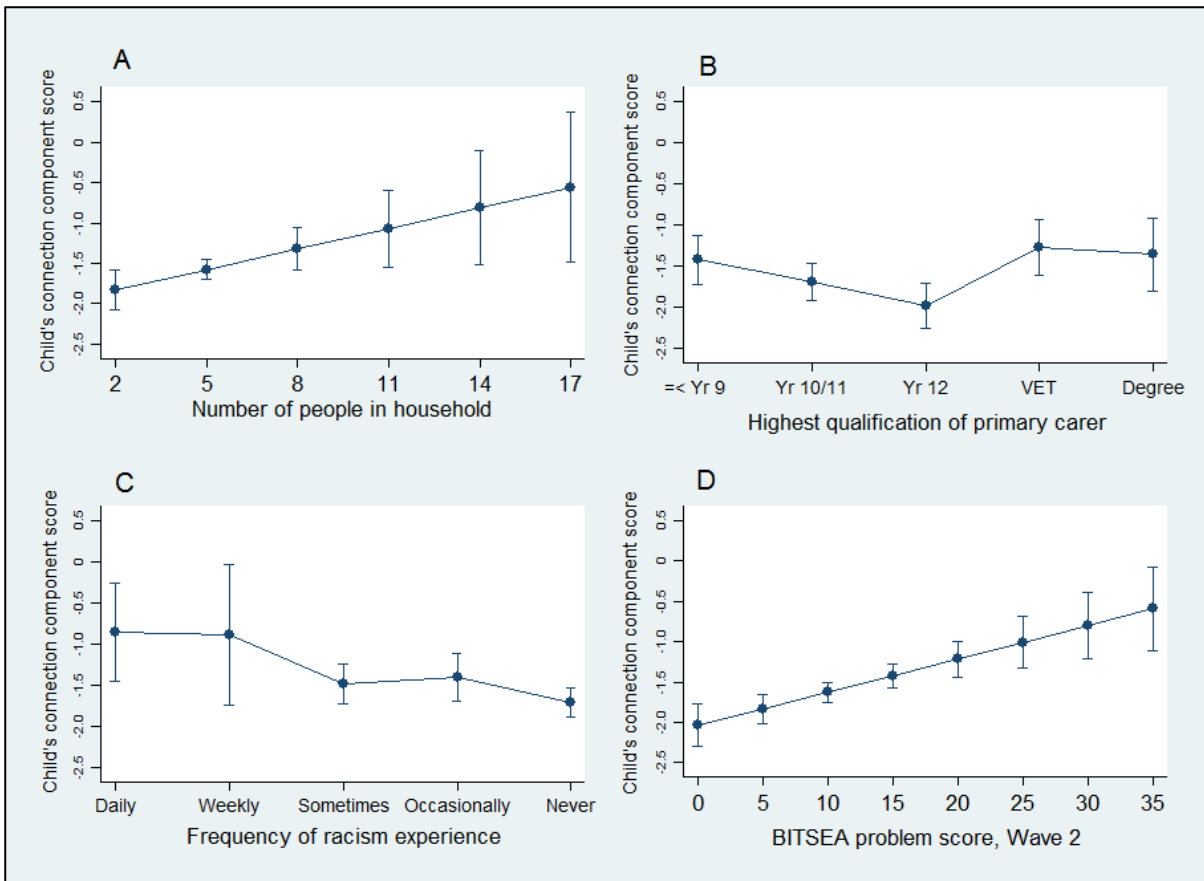
Although experiencing a greater number of major life events was statistically associated with greater connection, the effect was mild. Poorer social and emotional wellbeing at Wave 2 (measured using the Brief Infant-Toddler Social Emotional Assessment [BITSEA] Problem score), which was included in the model as a potential confounder, was also modestly associated with a better score for this component (Figure 2D). A *post hoc* analysis conducted to check the relationship between this component and SDQ Total Difficulties score showed a moderate positive correlation between these two variables (Spearman’s rho=0.55, 95% CI 0.48 to 0.61, $p=0.00$).

Table 4: Results of linear regression of factors in first years of life associated with “Child’s connection” component score at the time of starting school, Footprints in Time cohort 2008-2013

Exposure ^{a, b}		Adjusted effect size (n=230) ^c		p value
		coefficient	95% CI	
Mother did not drink alcohol during pregnancy		-0.22	-0.55 – 0.11	0.19
Mother did not smoke during pregnancy		-0.06	-0.39 – 0.27	0.71
Mother did not use other substances during pregnancy		0.19	-0.35 – 0.72	0.49
Child never had any ear problems		-0.14	-0.44 – 0.15	0.33
Attends childcare, daycare or family daycare		0.08	-0.26 – 0.42	0.66
Primary carer is employed		0.18	-0.19 – 0.55	0.34
Stolen generations		0.09	-0.18 – 0.35	0.51
Highest qualification of the primary carer	Less than Year 10	ref	-	-
	Year 10/11	-0.27	-0.61 – 0.07	0.12
	Year 12	-0.56	-1.02 – -0.10	0.02
	VET qualification	0.16	-0.30 – 0.60	0.50
	Bachelor degree or higher	0.06	-0.53 – 0.66	0.83
Parental warmth measure (primary carer)		-0.05	-0.61 – 0.52	0.87
Number of people in the household		0.09	0.01 – 0.16	0.03
Number of major life events in previous year		0.06	0.00 – 0.12	<0.05
Number of homes child has lived in since birth		0.03	-0.11 – 0.16	0.71
Frequency with which family experiences racism	Every day	ref	-	-
	Every week	-0.03	-0.96 – 0.90	0.95
	Sometimes	-0.62	-1.25 – 0.003	0.05
	Only occasionally	-0.55	-1.29 – 0.20	0.15
	Never or hardly ever	-0.86	-1.53 – -0.18	0.01

Family financial stress	Run out of money before payday	ref	-	-
	Spending more money than we get	0.25	-0.29 – 1.19	0.59
	Have just enough money to get us through to next pay day	0.27	-0.18 – 0.73	0.24
	Some money left over each week but we just spend it	0.10	-0.64 – 0.84	0.79
	Can save a bit every now and then	0.02	-0.55 – 0.57	0.96
	Can save a lot	0.22	-0.60 – 1.03	0.60
IRISEO		-0.04	-0.11 – 0.02	0.19
Level of Relative Isolation	None	ref	-	-
	Low	0.12	-0.18 – 0.43	0.43
	Moderate	0.51	-0.05 – 1.07	0.07
	High/Extreme	0.70	-0.67 – 2.07	0.31
Brief Infant-Toddler Social Emotional Assessment (BITSEA) Competency score ^d		-0.03	-0.11 – 0.05	0.50
BITSEA Problem score ^d		0.04	0.02 – 0.06	0.00
Global health measure at time of SDQ assessment ^d	Poor/Fair	ref	-	-
	Good/ Very good/ Excellent	-0.25	-0.96 – 0.46	0.49

Notes: CI - Confidence interval. ref – Reference group. ^a Variables with $p \leq 0.25$ from univariable analysis were included in the regression model. ^b Results with $p < 0.05$ are shown in bold. ^c Adjusted for 95 clusters. ^d Potential confounding factor.



Note: A higher component score indicates a greater degree of connection.

Figure 2: Predicted "Child's connection" component scores (with 95% CIs) from linear regression for (A) number of people in the household; (B) highest qualification of the primary carer; (C) frequency with which the family experiences racism; and (D) BITSEA problem score at Wave 2

"CHILD'S HELPING, SHARING AND MENTAL HEALTH" COMPONENT SCORE

The regression model predicted better scores for children (Table 5):

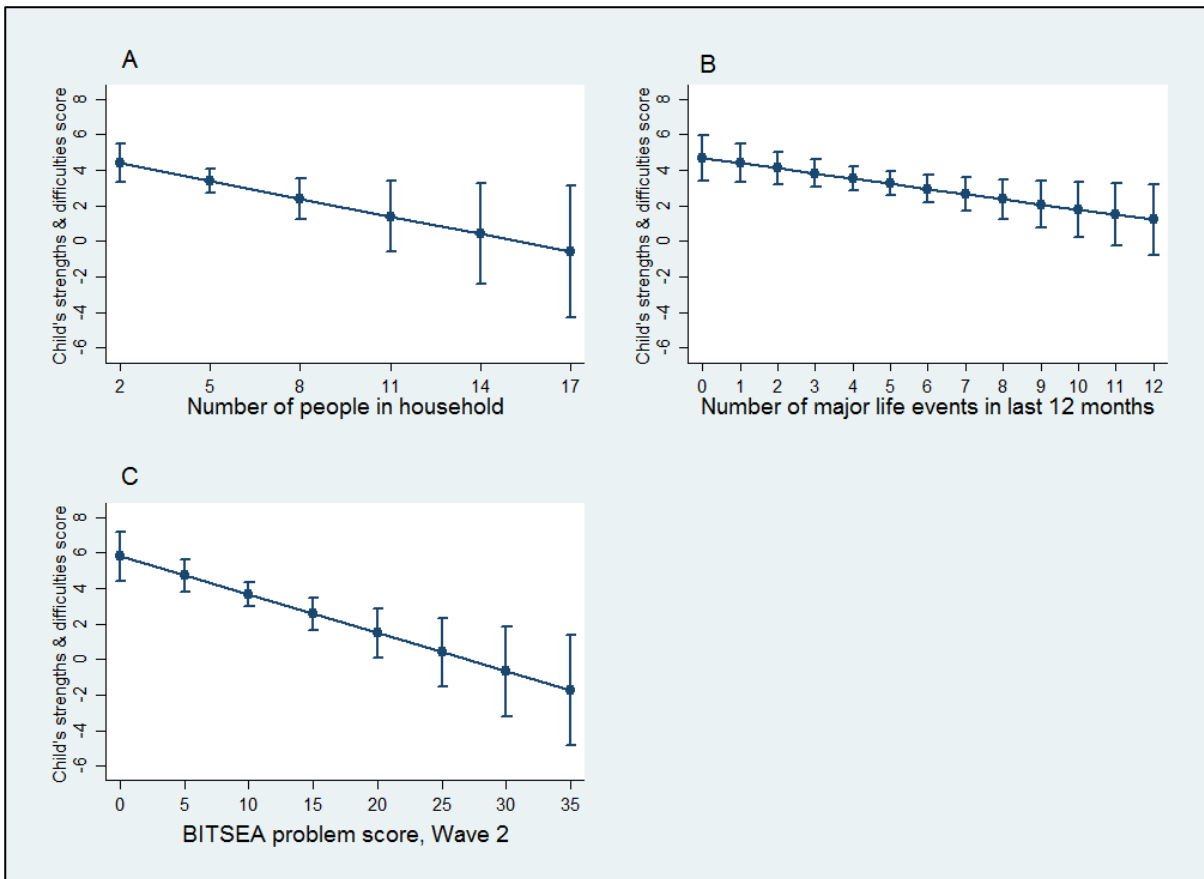
- living in a household of two people, compared with 11 or more people (Figure 3A); and
- who experienced no major life events, compared with 10 or more events (Figure 3B).

Children with better BITSEA Problem score at Wave 2 also had slightly better scores for this component (Figure 3C).

Table 5: Results of linear regression of factors in first years of life associated with “Child’s helping, sharing and mental health” component score at the time of starting school, Footprints in Time cohort 2008-2013

Exposure ^{a, b}		Adjusted effect size (n=230) ^c		p value
		coefficient	95% CI	
Mother did not drink alcohol during pregnancy		0.03	-1.66 – 1.71	0.98
Mother did not smoke during pregnancy		1.20	-0.46 – 2.86	0.15
Mother did not use other substances during pregnancy		-0.59	-0.43 – 1.24	0.52
Low birthweight		-0.90	-3.08 – 1.28	0.41
Child not hospitalised in the past 12 months		-0.20	-1.77 – 1.37	0.80
Attends childcare, daycare or family daycare		-0.15	-1.65 – 1.36	0.85
Excellent, very good or good global health		-1.00	-6.93 – 4.92	0.74
Primary carer is employed		-0.27	-1.87 – 1.33	0.74
Stolen generations		-0.11	-1.56 – 1.34	0.88
Highest qualification of the primary carer	Less than Year 10	ref	-	-
	Year 10/11	1.00	-1.45 – 3.45	0.42
	Year 12	1.81	-0.55 – 4.18	0.13
	VET qualification	0.72	-1.77 – 0.28	0.57
	Bachelor degree or higher	1.02	-2.72 – 4.75	0.59
Parental warmth measure (primary carer)		-0.40	-2.37 – 1.58	0.69
Number of people in household		-0.33	-0.63 – -0.03	0.03
Number of major life events in previous year		-0.29	-0.54 – -0.04	0.02
Number of homes child has lived in since birth		-0.24	-0.87 – 0.35	0.45
IRISEO		-0.16	-0.45 – 0.14	0.29
Level of Relative Isolation	None	ref	-	-
	Low	0.04	-1.48 – 0.56	0.96
	Moderate	-0.53	-2.02 – 1.84	0.66
	High/Extreme	-2.27	-4.71 – 0.17	0.07
BITSEA Competency score ^d		0.12	-0.20 – 0.44	0.47
BITSEA Problem score^d		-0.22	-0.34 – -0.10	<0.01
Female ^d		0.44	-0.94 – 1.81	0.53
Age at time of SDQ assessment ^d		0.03	-0.11 – 0.16	0.81
Global health measure at time of SDQ assessment ^d	Poor/Fair	ref	-	-
	Good/ Very good/ Excellent	6.7	-0.71 – 13.25	0.08

Notes: CI - Confidence interval, ref – Reference group. ^a Variables with $p \leq 0.25$ from univariable analysis were included in the regression model. ^b Results with $p < 0.05$ are shown in bold. ^c Adjusted for 95 clusters. ^d Potential confounding factor.



Note: A higher component score indicates a greater degree of helping, sharing and mental health.

Figure 3: Predicted “Child’s helping, sharing and mental health” component scores from linear regression for (A) number of people in the household; (B) number of major life events in previous year; and (C) BITSEA problem score at Wave 2

“PRIMARY CARER’S SEWB FACTORS” COMPONENT SCORE

Similar results were generated from the regression model for the “Primary carer’s SEWB factors” component (Table 6). The model predicted a better component score for children:

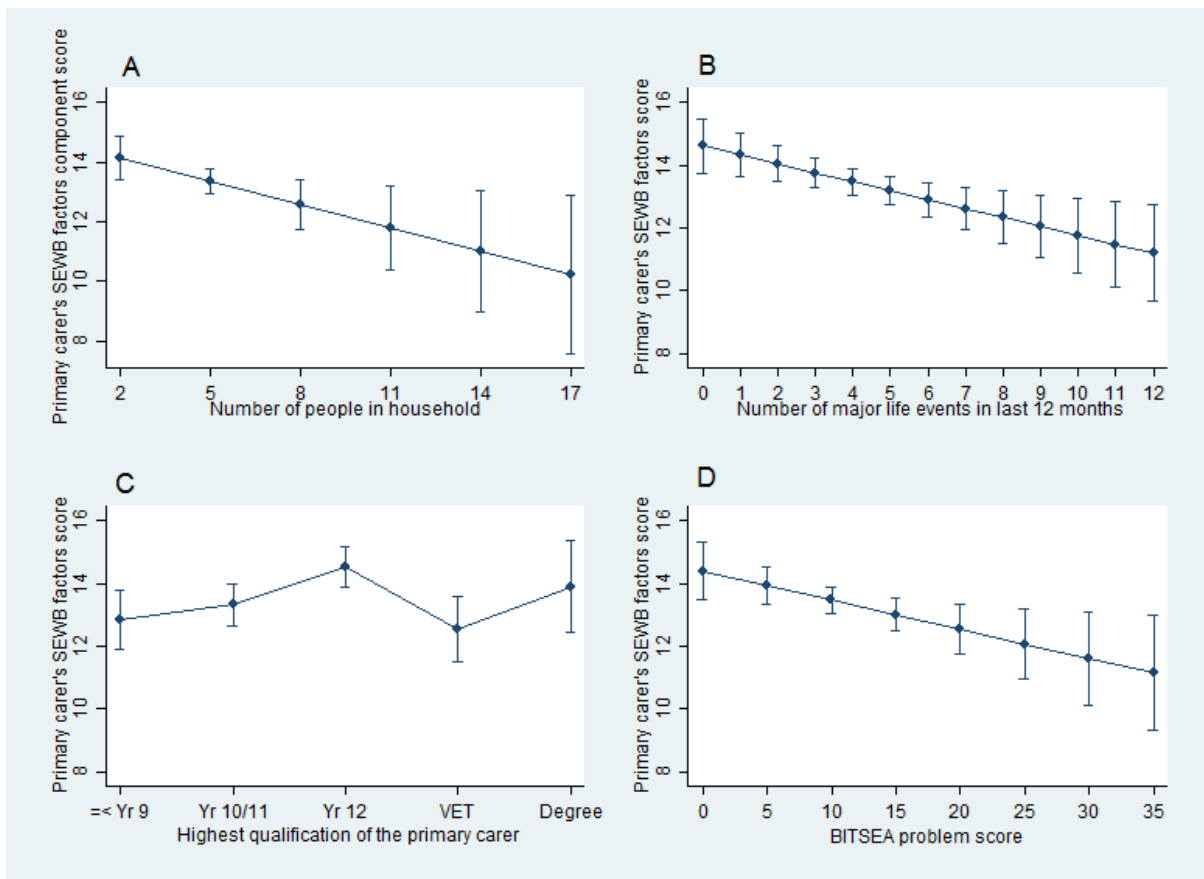
- living in a household of two people, compared with 11 or more people (Figure 4A);
- who experienced no major life events, compared with five or more events (Figure 4B); and
- whose primary carer completed Year 12, compared with carer Year 10 completion (Figure 4C).

Again, the child’s BITSEA Problem score at Wave 2 also had a negligible negative correlation with the score (Figure 4D).

Table 6: Results of linear regression of factors in first years of life associated with “Primary carer’s SEWB factors” component score at the time of starting school, Footprints in Time cohort 2008-2013

Exposure ^{a, b}		Adjusted effect size (n=230) ^c		
		coefficient	95% CI	p value
Mother did not drink alcohol during pregnancy		0.71	-0.41 – 1.81	0.21
Mother did not smoke during pregnancy		0.68	-0.34 – 1.70	0.19
Child not hospitalised in the past 12 months		0.31	-0.77 – 1.39	0.57
Primary carer is employed		-0.50	-1.60 – 0.59	0.36
Stolen generations		-0.29	-1.07 – 0.49	0.46
Highest qualification of the primary carer	Less than Year 10	ref	-	-
	Year 10/11	0.48	-0.53 – 1.49	0.35
	Year 12	1.68	0.39 – 2.97	0.01
	VET qualification	-0.31	-1.59 – 0.98	0.64
	Bachelor degree or higher	1.04	-0.67 – 2.75	0.23
Parental warmth measure (primary carer)		0.31	-1.11 – 1.74	0.66
Frequency with which family experiences racism	Every day	ref	-	-
	Every week	-1.77	-3.71 – 3.35	0.92
	Sometimes	1.40	-1.22 – 4.02	0.29
	Only occasionally	0.41	-2.34 – 3.16	0.77
	Never or hardly ever	0.70	-1.96 – 3.35	0.60
Number of people in household		-0.26	-0.47 – -0.05	0.02
Number of major life events in previous year		-0.28	-0.47 – -0.10	<0.01
Number of homes child has lived in since birth		-0.002	-0.40 – 0.40	0.99
Family financial stress	Run out of money before payday	ref	-	-
	Spending more money than we get	-1.20	-3.71 – 1.31	0.35
	Have just enough money to get us through to next pay day	-0.50	-1.73 – 0.73	0.42
	Some money left over each week but we just spend it	-0.41	-2.38 – 1.55	0.68
	Can save a bit every now and then	-0.23	-1.70 – 1.25	0.76
	Can save a lot	-1.16	-3.58 – 1.25	0.34
IRISEO		0.04	-0.13 – 0.21	0.64
BITSEA Competency score ^d		0.01	-0.23 – 0.25	0.93
BITSEA Problem score^d		-0.09	-0.17 – -0.02	0.01
Age at time of SDQ assessment ^d		-0.05	-0.14 – 0.04	0.24
Global health measure at time of SDQ assessment ^d	Poor/Fair	ref	-	-
	Good/ Very good/ Excellent	2.09	0.03 – 4.15	0.05

Notes: CI - Confidence interval. ref – Reference group. ^a Variables with $p \leq 0.25$ from univariable analysis were included in the regression model. ^b Results with $p < 0.05$ are shown in bold. ^c Adjusted for 95 clusters. ^d Potential confounding factor.



Note: A higher component score indicates a greater degree of the primary carer's SEWB.

Figure 4: Predicted "Primary carer's SEWB factors" component scores from linear regression for (A) number of people in the household; (B) number of major life events in previous 12 months; (C) highest qualification of the primary carer; and (D) BITSEA problem score at Wave 2

All regression models were statistically significant overall and did not violate regression assumptions (data not shown). The models explained 20% of the variability in the "Child's connection" component scores, 12% of the variability in the "Child's helping, sharing and mental health" scores, and 18% of the variability in the "Primary carer's SEWB factors" scores.

DISCUSSION

MAIN FINDINGS

Early life exposures associated with surrogate measures of SEWB at school commencement were household size and number of major life events experienced. Larger household and larger numbers of events were associated with reduced sharing, helping and mental health in the child, and poorer wellbeing in the primary carer. Conversely, more people in the household and exposure to more events were weakly associated with greater connection of the child to community, culture and country.

We were unable to create a single index of SEWB using PCA and, surprisingly, *post hoc* analysis revealed that measures of connectedness and relationship were positively correlated with poorer mental health, as measured by the SDQ Total Difficulties score. Those seeking evidence to support SEWB policy development, program planning and evaluation must be cautious in applying Western biomedical health and wellbeing measures to Indigenous concepts and states.

COMPARISON WITH OTHER STUDIES – WHAT DOES THIS STUDY ADD?

Exposure to a greater number of major life events in the early years appeared to be mildly detrimental to “Child’s helping, sharing and mental health” component scores. In a study of the older LSIC cohort at Wave 4, when the children were aged around seven years, Skelton and Kikkawa (2013) found a similar strength of association between SDQ Total Difficulties score and exposure to major life events in the previous 12 months. In a cross-sectional analysis of data from the Western Australian Aboriginal Child Health Survey for children aged four to 17 years, Zubrick et al. (2005) found that exposure to more than seven major life events in the preceding year increased by over fivefold the likelihood of a child being at high risk of clinically significant difficulties (SDQ Total Difficulties score >17), compared with children who experienced two or fewer events.

In the present study, however, experiencing a greater number of events was also associated with greater connectedness to elders, culture and country. It is important to note that, unlike in the WAACHS, not all of the events reported in LSIC are inherently negative. Two of the four most commonly reported events in this sample were pregnancy or a new baby in the household, and one of the child’s carers returning to work or study. Large, strong family and community networks increase the likelihood of major life events. For example, the larger the network the more likely are friends and relatives to die, the more likely is the child to move between households, and the more likely are friends and family to give birth.

In this study, having more people living in the household had a negligible positive association with better “Child’s connection” component scores. However, an opposite and stronger effect of this exposure was observed for the two other component scores. Similarly, children in the WAACHS living with high household occupancy levels were half as likely to have a high risk SDQ Total Difficulties score, compared with those living with low occupancy. Zubrick et al. (2005) suggest this “may relate to more help being available within the household, greater flexibility in managing stresses, and greater buffering of risk exposures”.

It is not possible to infer household crowding (and related stress) from the number of people reported as living in the household. The LSIC survey question simply asks for the names of “all the people who live in the household” (DSS, 2008), with no clarification about temporary or regular visitors, or people who may sleep elsewhere but use the kitchen and/or bathroom facilities of the home. In contrast to the WAACHS analysis (Zubrick et al., 2005), we did not calculate household occupancy

from the number of bedrooms as well as the number of people who lived in the home. The international standard measure for household utilisation also takes into account the age, sex and relationship status (couples or singles) of occupants (Memmott et al., 2012). However, as Memmott et al. (2012) note, it is important to distinguish between high density of household occupants and household crowding. They argue that crowding is a perception of spatial inadequacy, influenced by a range of factors including the physical setting, an individual's experience and expectations, their relationship to other occupants, and the occupants' activities and behaviour. Crowding is an experience that is culturally defined and, for some families and communities, "[high] density may be an expression of proper intimacy with kin and others, which in fact reduces stress" (Memmott et al., 2012).

Previous cross-sectional studies of Aboriginal and Torres Strait Islander children of similar ages have found associations between lower SDQ Total Difficulties scores and better general health (Armstrong et al., 2012; Skelton & Kikkawa, 2013); ear health (Zubrick et al., 2005); higher qualification of the primary carer; living in an area of less socio-economic disadvantage (Armstrong et al., 2012) or greater geographic isolation (Zubrick et al., 2005); lower household financial stress (Kikkawa, 2015); having a primary carer who was employed; and living in fewer than four (Williamson et al., 2016) or five homes (Zubrick et al., 2005). In the only published examination of the determinants of better SDQ Prosocial Behaviours score in Aboriginal and Torres Strait Islander children, Armstrong et al.'s (2012) study of the older LSIC cohort found negligible positive effects at Wave 3 for the children who lived in an area of less socio-economic disadvantage at Wave 2. However, none of these factors, occurring in early life, were significant at school entry in this longitudinal study.

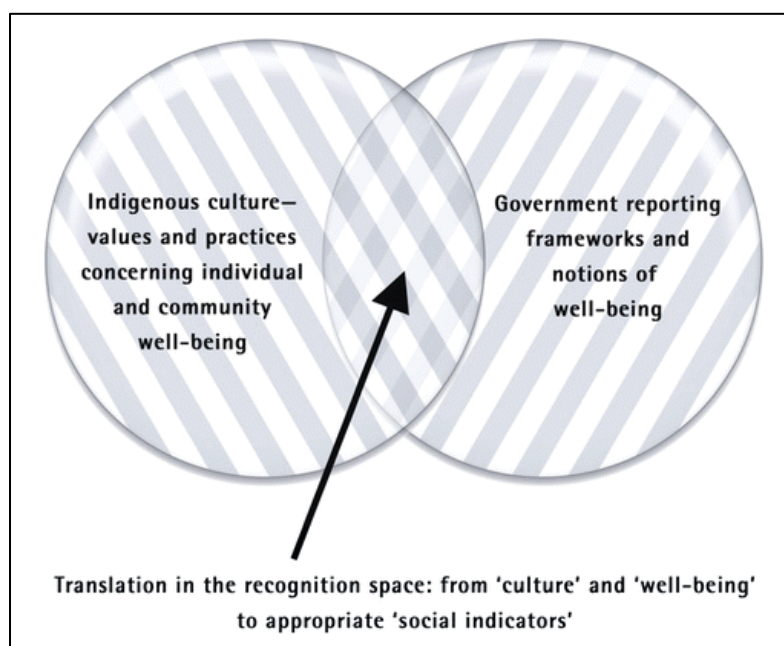
THE CHALLENGE OF MEASURING SOCIAL AND EMOTIONAL WELLBEING

The concept of SEWB cannot be captured using only the SDQ Total Difficulties subscale, the most commonly used measure of Aboriginal and Torres Strait Islander child mental health in large studies. By generating strengths-based outcome measures we have challenged the common assumption that child mental health is the same as the absence of mental illness, as did Goldfeld et al. (2016). These authors argue for a dual continuum model in which mental health is seen as correlated to, but distinct from, mental disorder. However, measuring these two states only will still fail to capture the Indigenous concept of SEWB. For operationalising SEWB, perhaps what is needed is a 'triple continuum model', which includes a domain of relational health of community, culture and country. We could not achieve this by adding the "connection questions" available for this sample of LSIC children, which *prima facie* cannot quantify a concept that encompasses a rich web of relationships between flourishing individuals, families, language, culture, spirituality and land and sea country.

Taylor (2008) names the intersection between Indigenous culture and government reporting frameworks the 'recognition space' (Figure 5). This space is

... where policy makers and Indigenous people can seek to build meaningful engagement and measurement. This is the area that allows for a

necessarily reductionist translation of Indigenous people's own perceptions of their well-being into measurable indices sought by government. What is captured in this space is obviously far from the totality of Indigenous understandings of well-being.



Source: (Taylor, 2008)

Figure 5: The 'recognition space' for indicators of Indigenous wellbeing

We may feel that by choosing standard measures we are ensuring objectivity. However, Prout (2012) warns that reducing Indigenous notions to narrow conventional indicators is a political exercise. In so doing, we “invisibilise many of the positive, enduring and protective factors, associated with Indigenous ways of life which are not amenable to this kind of analysis and reporting” (Prout, 2012). Our own values and worldviews also influence our interpretation of these indicators, and may be in conflict with Indigenous perceptions of wellbeing. Furthermore, Prout argues, by using non-Indigenous populations as the reference group we are assuming that equity based on these flawed indicators is the ambition for Indigenous populations.

An alternative approach is offered by the Indigenous quantitative methodologies described by Walter and Andersen (2013). In these methodologies, power is returned to communities by framing research through lenses of Indigenous values, ways of being and of knowing. A recent relevant example is the project auspiced by the Kimberley Institute to develop culturally relevant measures of wellbeing for the Yawuru people, who live in and around Broome (Yap & Yu, 2016). In this qualitative project, Yawuru men and women described their concept of wellbeing and selected relevant indicators to develop gender-specific and collective wellbeing frameworks. Although this example was developed for adults in a specific community, the indicators for collective wellbeing listed in Table 7 highlight the complexity of the wellbeing concept and contrast with the much narrower constructs measured by the SDQ scales.

Table 7: Examples of valuable functionings for Yawuru men and women that contribute to Yawuru’s experience of wellbeing

Wellbeing themes	Potential indicators
Family, identity and relatedness	<ul style="list-style-type: none"> • Sharing your fish or kill with family and friends • Seeing and spending time with family
Community	<ul style="list-style-type: none"> • Participating in community cultural events • Being able to have a say or have control over what happens in my community
Connection to country	<ul style="list-style-type: none"> • Looking after country • Eating bush tucker, eating fish that was caught in season and meat that was hunted in season
Connection to culture	<ul style="list-style-type: none"> • Speaking and understanding the Yawuru language • Participation in law and ceremonies
Safety and respect	<ul style="list-style-type: none"> • Feel respected and show respect to Indigenous groups in my community • Feel respected and show respect to family and friends
Standard of living	<ul style="list-style-type: none"> • Adequate housing conditions • Having a secure income stream including a diversity of sources of income
Rights and recognition	<ul style="list-style-type: none"> • Environment free from pollutants and hazards • Feel recognised and proud to be Native Title holders
Health	<ul style="list-style-type: none"> • Healthy body to enjoy life • Minimise ill health from too much alcohol or drugs

Source: (Yap & Yu, 2016)

STRENGTHS OF THIS STUDY

While recognising our worldview and social position, we have attempted to use an Indigenous quantitative methodology for this study. Walter and Anderson (2013) define this methodology as one in which “the practices and processes of research are conceived and framed through an Indigenous standpoint”. We were fortunate to have access to the LSIC data—data which were collected using protocols that exemplify this methodology (Walter & Andersen, 2013). We have also taken advantage of the power of the longitudinal LSIC design.

LIMITATIONS OF THIS STUDY

The non-random purposive sampling technique used for LSIC means generalisation of the results of this study to all Aboriginal and Torres Strait Islander children requires caution. The characteristics of the children excluded from the sample suggest that we may have underestimated the effects of low birthweight, primary carer employment, remote living and maternal smoking. Similarly, missing exposure data reduced sample

size for the regression models, possibly lessening the effect of factors significant in univariable analyses.

Only a little of the variation in outcomes is explained by the regression models presented here. This means either there is a great deal of random variation in the outcome measures chosen, or there are other factors that we did not include or consider that determine these outcomes. We were constrained in selection of both outcome and exposure variables by the Waves in which certain questions were asked by the LSIC team. Furthermore, as there are no clinical measures or clinical record review in LSIC data collection, there may be considerable measurement error for questions about the child's health and birthweight, depending upon on the primary carers' recall and health literacy.

IMPLICATIONS

We have been unable to provide strong evidence to guide policy makers on interventions and approaches that will promote SEWB in children about to start school, particularly in the maternal and child health space. However, our findings are consistent with the social determinants theory of SEWB (Henderson et al., 2007) and supportive of holistic, trans-portfolio approaches. The results also provide some evidence for screening and management of infants and toddlers with social and emotional difficulties for prevention of mental health problems later in childhood.

Measuring SEWB of Aboriginal and Torres Strait Islander children for the purposes of policy development, program planning or evaluation is not straightforward. If mainstream measures of mental health are used to plan and evaluate programs, their limitations must be acknowledged. Ideally, communities would be supported to develop their own measures of wellbeing. This presents a challenge: striking a balance between the need to privilege Indigenous ontologies and epistemologies, and the governments' requirement to demonstrate investment accountability using indicators that can be applied throughout jurisdictions cost-effectively.

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APPENDIX 3.4 – Results of tests of regression assumptions

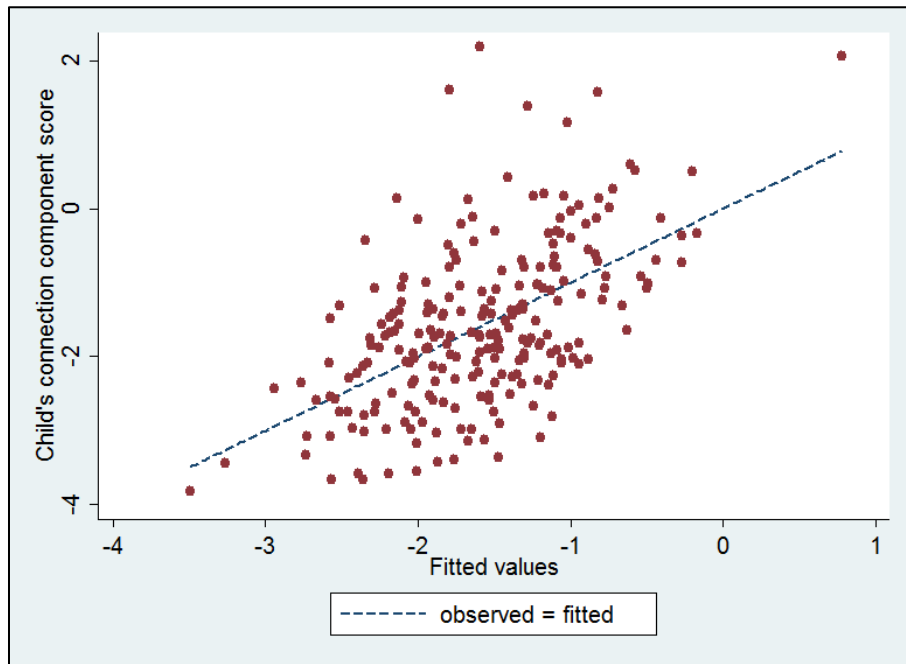


Figure A Goodness of fit of the linear regression model for the “Child’s connection” component (observed versus predicted values, adjusted R-squared=0.20).

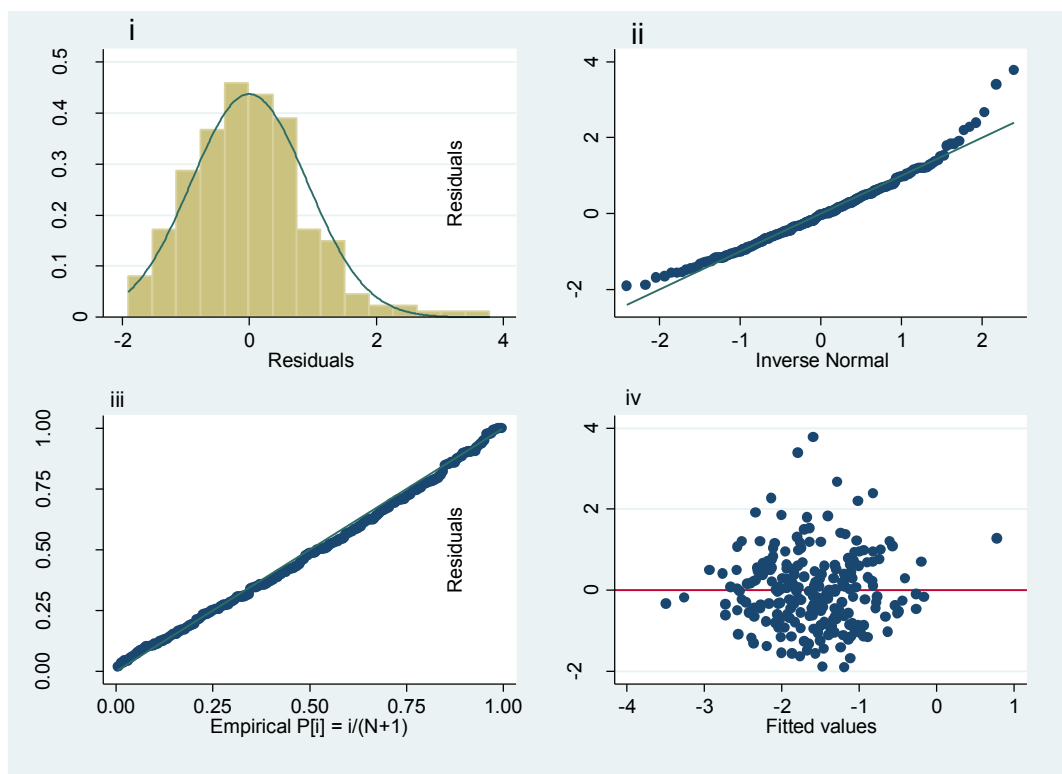


Figure B Assessment of the normality of distribution and homoscedasticity of residuals for the “Child’s connection” component: (i) histogram of the residuals (ii) standardised normal probability plot; (iii) residual quantile plot; and (iv) graph of residuals versus fitted values.

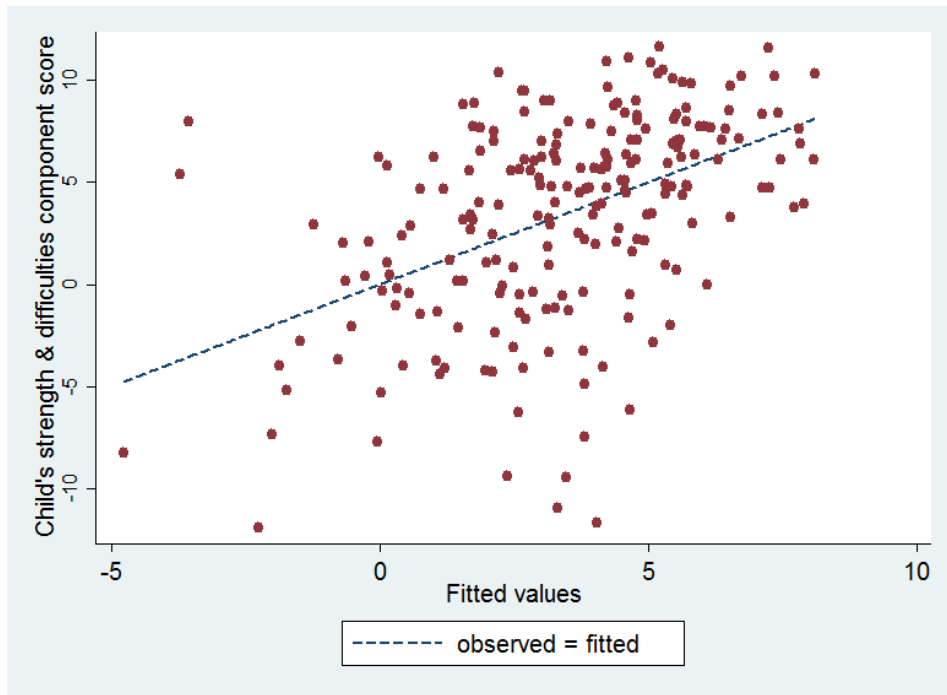


Figure C Goodness of fit of the linear regression model for the “Child’s helping, sharing and mental health” component (observed versus predicted values, adjusted R-squared=0.12).

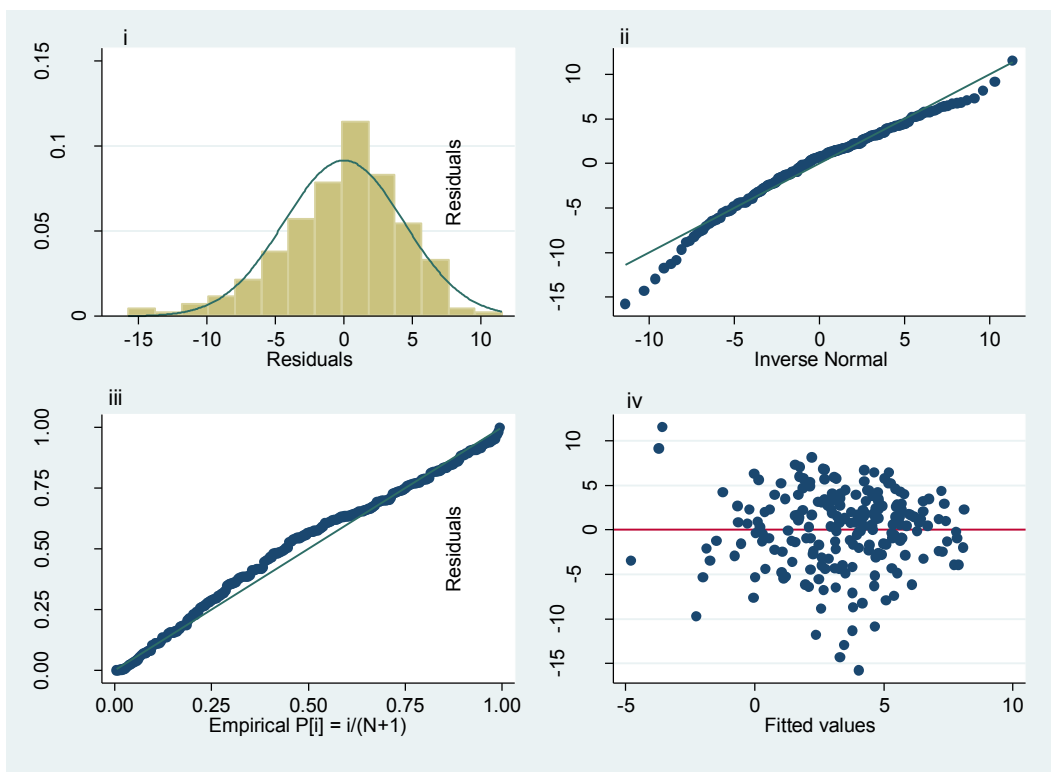


Figure D Assessment of the normality of distribution and homoscedasticity of residuals for the “Child’s helping, sharing and mental health” component: *(i)* histogram of the residuals *(ii)* standardised normal probability plot; *(iii)* residual quantile plot; and *(iv)* graph of residuals versus fitted values.

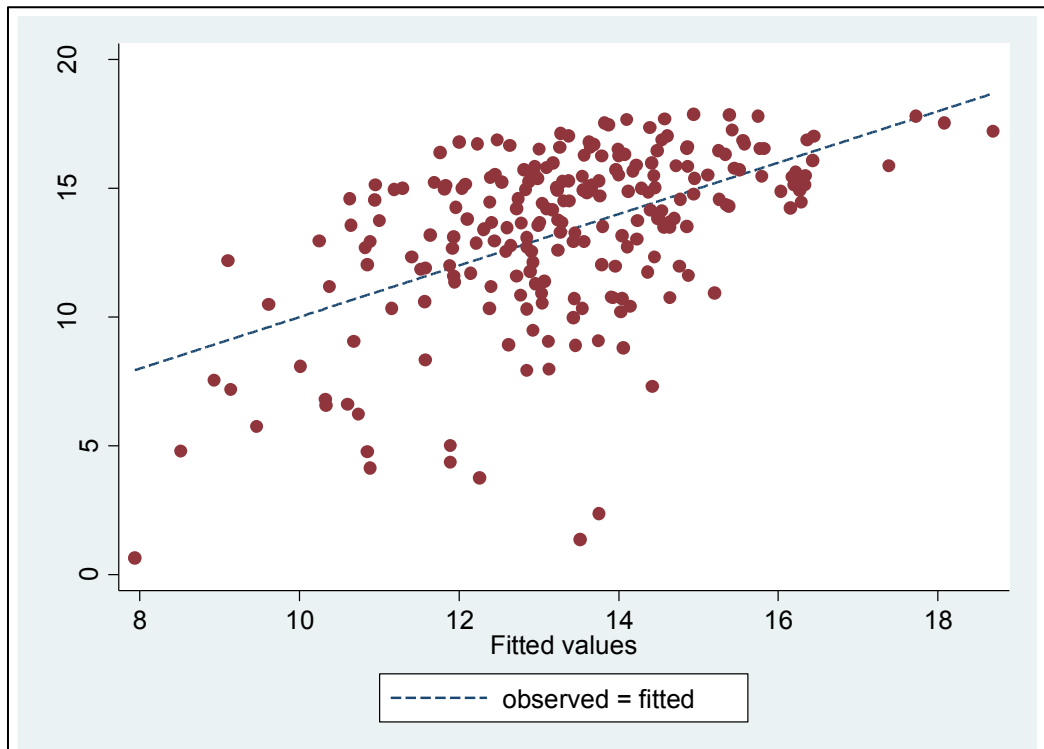


Figure E Goodness of fit of the linear regression model for the “Primary carer’s SEWB factors” component (observed versus predicted values, adjusted R-squared=0.18).

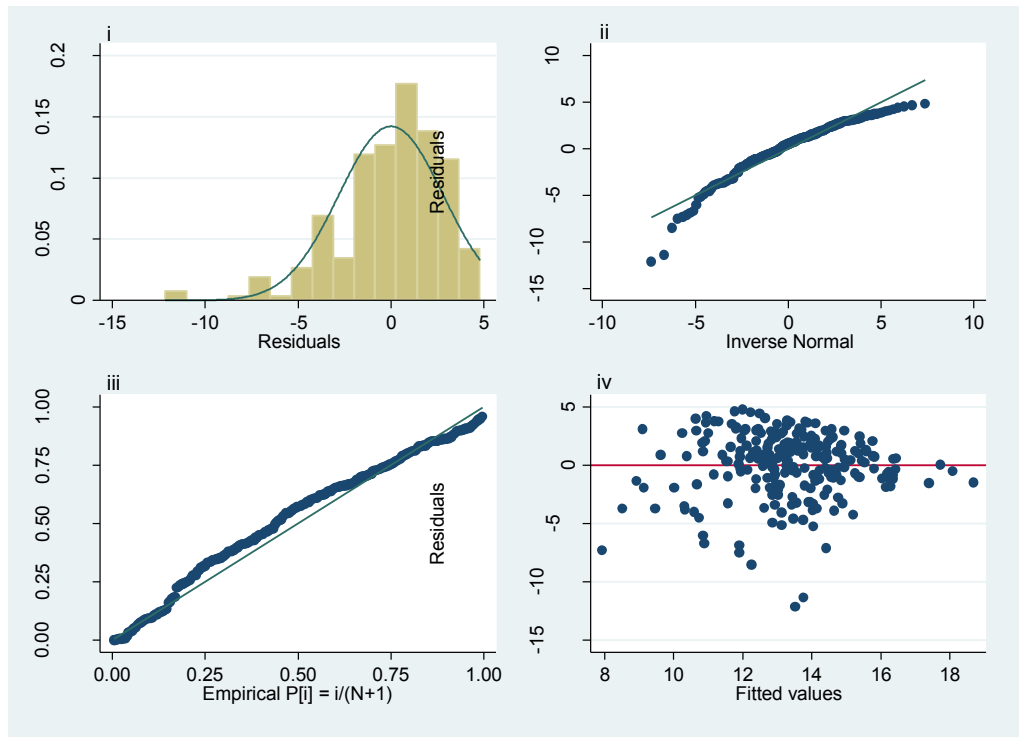


Figure F Assessment of the normality of distribution and homoscedasticity of residuals for the “Primary carer’s SEWB factors” component: *(i)* histogram of the residuals *(ii)* standardized normal probability plot; *(iii)* residual quantile plot; and *(iv)* graph of residuals versus fitted values.

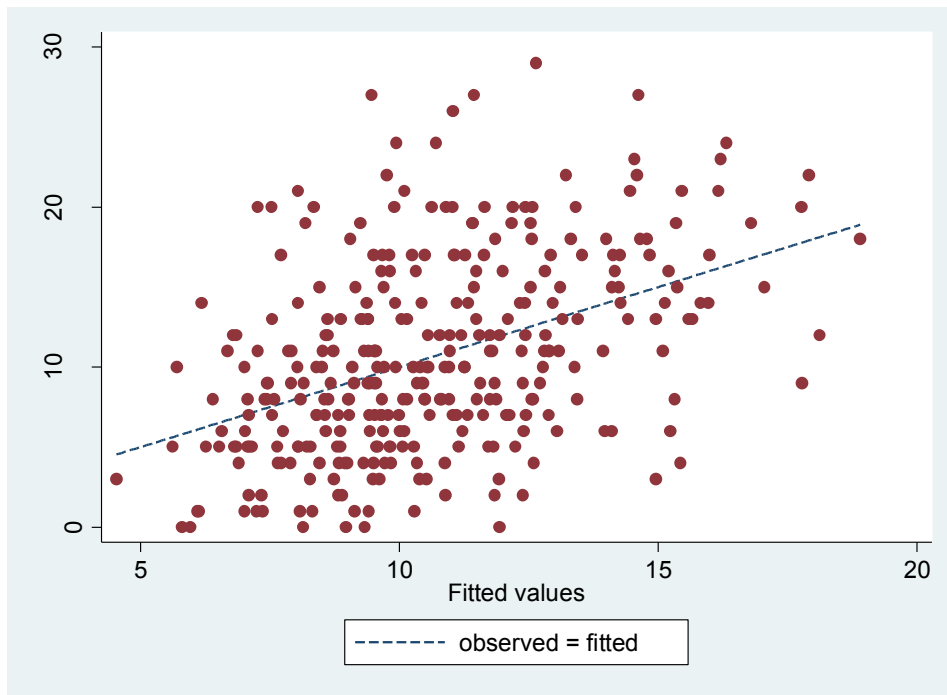


Figure G Observed SDQ Total Difficulties Score versus scores predicted by the linear regression model (adjusted R-squared=0.12).

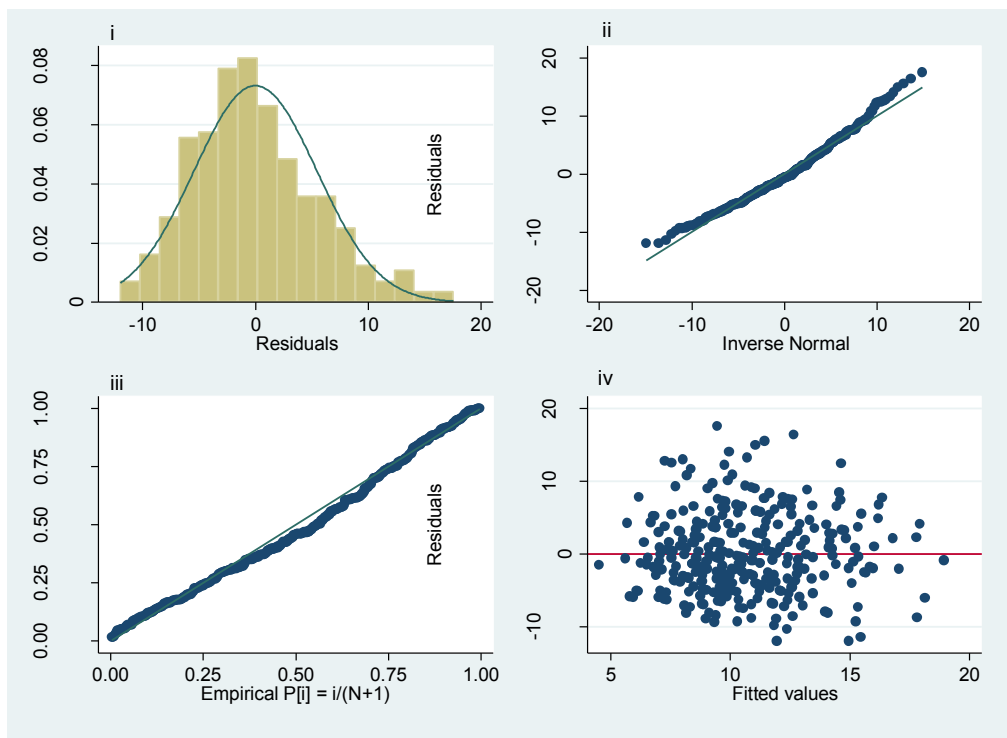


Figure H Assessment of the normality of distribution and homoscedasticity of residuals for the SDQ Total Difficulties score: *(i)* histogram of the residuals *(ii)* standardised normal probability plot; *(iii)* residual quantile plot; and *(iv)* graph of residuals versus fitted values.

CHAPTER 4 – EVALUATION OF AUSTRALIA’S ENHANCED PNEUMOCOCCAL DISEASE SURVEILLANCE PROGRAM

APPENDIX 4.1 – Article submitted to *Communicable Diseases Intelligence*

EVALUATION OF AUSTRALIA’S ENHANCED INVASIVE PNEUMOCOCCAL DISEASE (IPD) SURVEILLANCE PROGRAM

Abstract

Australia’s Enhanced Invasive Pneumococcal Disease Surveillance Program is part of the National Notifiable Diseases Surveillance System, and is coordinated by the Enhanced Invasive Pneumococcal Disease Surveillance Working Group (EIPDSWG). This first evaluation of the surveillance program aimed to evaluate its performance, identify ways in which surveillance may be improved, and make recommendations to the EIPDSWG. We examined the program operation and collected evidence regarding usefulness and performance against a number of attributes. We conducted literature and document reviews; key informant interviews; an online stakeholder survey; and descriptive analyses of a subset of surveillance data. The program is complex, but has proved very useful for monitoring the effectiveness of the national infant vaccination program—informing a change to the recommended vaccine in 2011. The program is less useful for evaluating targeted programs in other high-risk groups, because complete data for cases aged between five and 50 years is not universally collected, and data collection is hampered by the absence of accessible electronic health records. Lack of support for reference laboratories for antimicrobial susceptibility testing, and data entry and transmission problems in some jurisdictions, has reduced the utility of the program for surveillance of antimicrobial resistance. Although complex, the IPD surveillance program is a highly useful, flexible and stable system that is acceptable to users and stakeholders. Priority recommendations to the EIPDSWG focus on collecting complete data for all cases, ensuring stakeholders can easily access surveillance data at the level of detail they require, and improving collection of antimicrobial resistance data.

Keywords: Invasive Pneumococcal Disease; evaluation; disease surveillance

Introduction

Invasive pneumococcal disease (IPD) is caused when the respiratory pathogen *Streptococcus pneumoniae* invades a normally sterile site. (1) This gram-positive bacterium is transmitted person-to-person via respiratory droplets and colonises the nasopharynx of many children within the first year of life. (2) Determinants of colonisation include overcrowding, childcare attendance, and exposure to tobacco smoke. (3) The pathogen can cause non-invasive infections such as otitis media, sinusitis and non-bacteraemic pneumonia (4), but in susceptible people may migrate to the bloodstream and other sterile sites, leading to invasive disease (5). The most common types of IPD are bacteraemic pneumonia, bacteraemia without focus, and meningitis. (6) Over 90 serotypes of *S. pneumoniae* have been identified, although not all serotypes cause disease, and some are more likely than others to be associated with IPD and poorer outcomes following infection. (7) IPD cases tend to be sporadic and epidemics are rare since the advent of antibiotics. (8)

Invasive pneumococcal disease remains a disease of public health importance in Australia. It is relatively uncommon, and incidence rates have reduced by around 20% since 2003, remaining relatively unchanged for the past four years. (9) However, disease can be severe. The case fatality rate for invasive pneumococcal pneumonia is just under 20%; (10, 11) for pneumococcal meningitis up to 37%, (12) and serious disabilities in meningitis survivors are common. (5, 13) Despite the positive impact of targeted vaccination programs, significant disparities in the incidence of IPD persist, with relatively higher rates among those aged under five and over 65 years, and among Aboriginal and Torres Strait Islander people. (9) Costs of IPD treatment and pneumococcal vaccination are substantial. (13-16) Continued enhanced surveillance of IPD is vital to detect changes in serotype and resistance profiles, and to inform and evaluate vaccination and treatment strategies.

Invasive pneumococcal disease has been a notifiable condition nationally since 2001, and enhanced passive surveillance is conducted in all jurisdictions. (17) This surveillance is a part of the National Notifiable Diseases Surveillance System (NNDSS) and is coordinated by the Enhanced Invasive Pneumococcal Disease Surveillance Working Group (EIPDSWG), a subcommittee of the Communicable Diseases Network Australia (CDNA). (18) Although the NNDSS as a whole was

evaluated in 2004, (19) an evaluation focused on the IPD Surveillance Program has not been conducted. The purpose of this evaluation is to:

- assess the performance of the program;
- identify ways in which surveillance may be improved; and
- make recommendations to the EIPDSWG.

Methods

We followed the framework outlined in the Centers for Disease Control and Prevention (CDC) *Updated Guidelines for Evaluating Public Health Surveillance Systems*. (20) We described the program's operation and collected evidence regarding usefulness and performance against a number of attributes (Box 1). We used literature and document reviews; key informant interviews; an online stakeholder survey; and descriptive analyses of surveillance data for cases notified between 1 July 2013 and 30 June 2016. Respondents indicated their informed consent on the online survey. The stakeholder survey and surveillance data analysis were reviewed and approved by the Australian National University Human Research Ethics Committee. An interim summary of the findings and recommendations was presented to the EIPDSWG for correction and comment.

Box 1 Surveillance system attributes defined in the CDC guidelines. (20)

- **Usefulness:** contribution to prevention and control of IPD
- **Simplicity:** simplicity of structure and ease of operation
- **Data Completeness & Quality:** the completeness and validity of the data collected
- **Flexibility:** ability to adapt to changing information needs or operating conditions
- **Acceptability:** willingness of persons and organisations to participate in the surveillance system
- **Sensitivity:** proportion of incident cases detected and the ability of the system to detect outbreaks
- **Positive Predictive Value:** proportion of notified cases that truly have IPD
- **Representativeness:** ability to accurately describe the occurrence of IPD over time and its distribution in the population by place and person
- **Timeliness:** time between steps in the system, production of useful data and timeliness for public health intervention
- **Stability:** ability to collect, manage and provide data properly without failure; and the

ability to be operational when it is needed

Results

Twenty interviews were conducted with EIPDSWG members and data managers from the Australian Government Department of Health. All jurisdictions and reference laboratories were represented. On average, members had over seven years of experience on the Working Group, and six were founder members. There were 28 responses to the stakeholder survey. Most respondents were academic researchers, or from diagnostic laboratories or vaccine companies.

Program Operation

The program is complex, with variation in notification processes, follow-up, data entry and transmission from the jurisdictions to the NNDSS. The case definition for IPD involves laboratory confirmation (Box 2), requiring the participation of a large number of public and private diagnostic laboratories, as well as four public health reference laboratories and the communicable disease branches in each jurisdiction (Figure 6).

Box 2 The case definition for a confirmed case of invasive pneumococcal disease (IPD), Australia, 2017.(21) Only confirmed cases are notified.

- Isolation of *S. pneumoniae* from a normally sterile site by culture
- OR
- Detection of *S. pneumoniae* from a normally sterile site by nucleic acid testing

While data are collected for all notified cases, the two largest jurisdictions do not routinely collect data on Indigenous status, vaccination history or enhanced data (including risk factors) for cases aged between five and 50 years. Data collection in some jurisdictions is hampered by the absence of accessible electronic health records. Summaries of surveillance data are published in regular IPD reports (22) and NNDSS Annual Reports, (23) and selected variables of the IPD dataset from 2009 to 2015 are publically available on the Australian Government Department of Health website.

Nearly 200 jurisdictional and reference laboratory staff are involved in IPD surveillance data collection nationally, but all have other duties. Testing, data entry and reporting of a case by reference laboratories takes an average 30, but up to 60, minutes. Data collection in jurisdictions with electronic access to clinical records takes

90 minutes or less per case, but three to 10 hours per case in jurisdictions without electronic access.

There are five objectives for the surveillance program published on the Department of Health's website. (24) These have not been endorsed by the EIPDSWG. Overall, EIPDSWG members thought that the objectives were appropriate, although not all were currently being met.

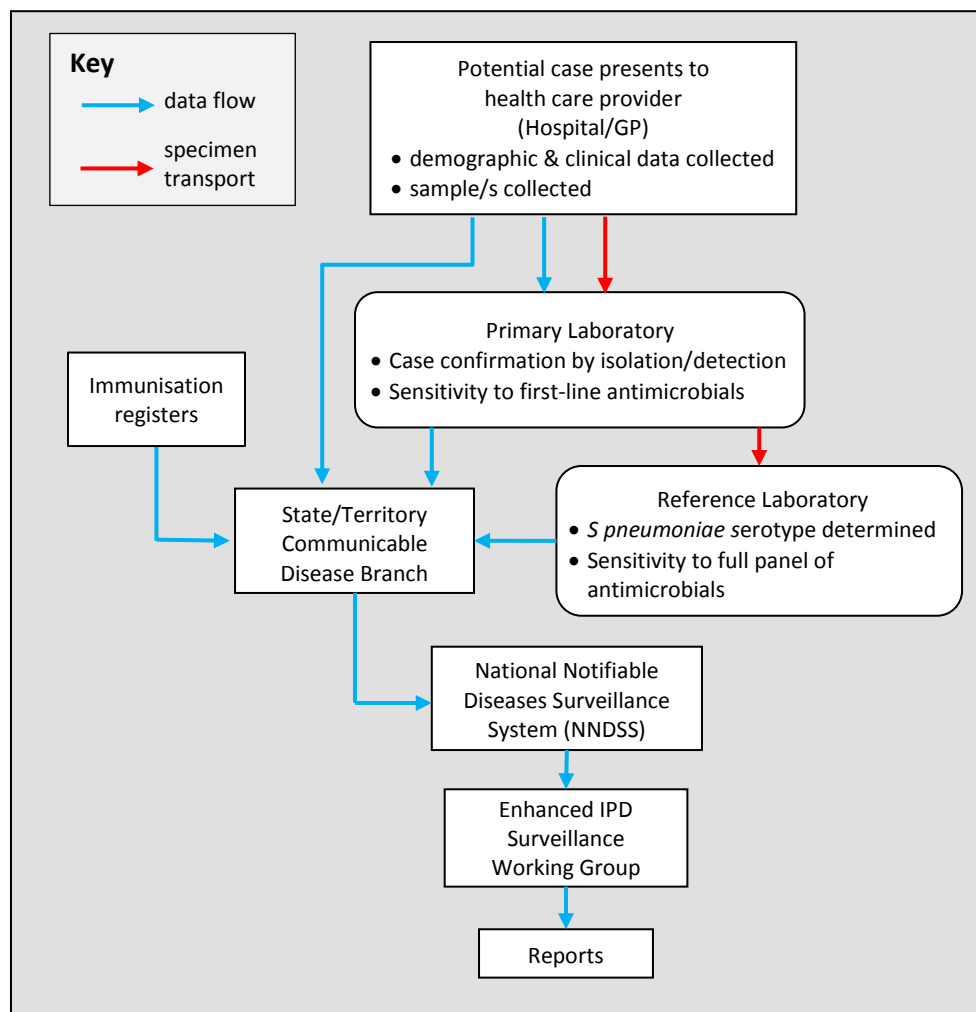


Figure 6 Simple representation of the operation of Australia's Enhanced Invasive Pneumococcal Disease Surveillance Program, 2017.

Usefulness

Over 90% of respondents in EIPDSWG interviews and the stakeholder survey indicated that the program was very or extremely useful. The program has been valuable for monitoring the effectiveness of the national infant pneumococcal

vaccination program from 2005. Surveillance data provided evidence of replacement of vaccine serotypes in this population, which informed a change in the recommended vaccine for infants in 2011. (25) However, the program is less useful for evaluating the effectiveness of targeted vaccination programs in other high-risk groups, due to lower completeness in vaccination and risk factor data fields for cases aged over five years. There are inconsistencies between risk factor categories in jurisdictional data collection forms, the national dataset, and *The Australian Immunisation Handbook 10th Edition*. (26) Antimicrobial resistance (AMR) data collected during IPD surveillance has been requested by the Antimicrobial Use and Resistance in Australia (AURA) project for monitoring *S. pneumoniae* resistance. Currently, the surveillance data have only moderate utility for this purpose, because reference laboratories are not funded to test susceptibility to the full panel of antimicrobials, and because problems with data entry and transmission in some jurisdictions have led to missing data on sensitivity to first-line antimicrobials. Other stakeholders indicated that the public IPD dataset would be more useful if it included more detailed data from 2001 onwards. The EIPDSWG has proved a useful forum for rapid communication between jurisdictions and detection of outbreaks.

Simplicity

Although stakeholders indicated that the notification process was easy, the surveillance program is not a simple system. This is largely due to the collection of enhanced data. The flow of data is complicated, and this is compounded by the fact that data collection systems are not harmonised across jurisdictions.

Data completeness and quality

The quality and completeness of the surveillance data is excellent overall (Figure 7), but some issues were identified (Table 8).

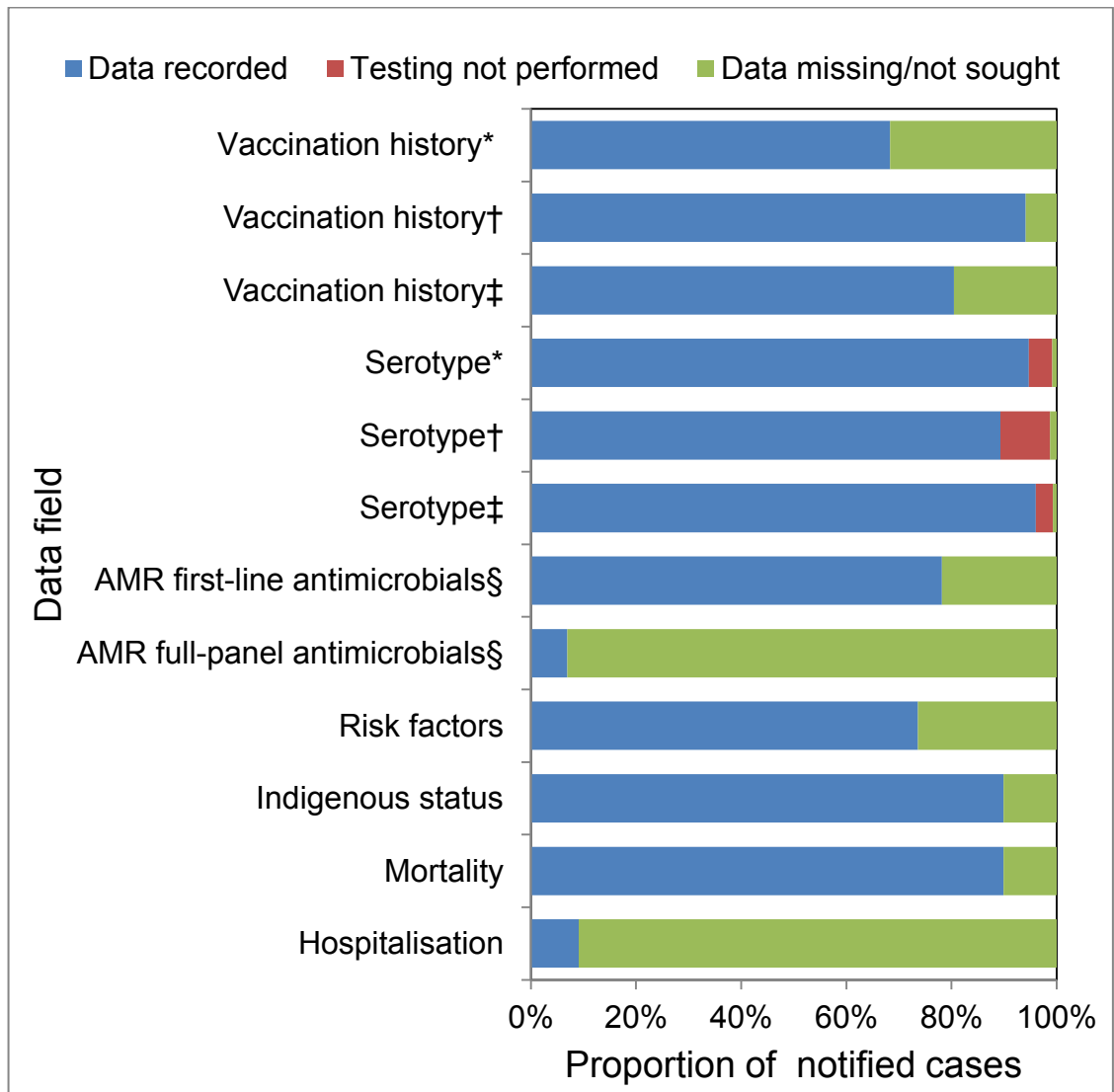


Figure 7 Completeness of data for IPD cases notified between 1 July 2013 and 30 June 2016, Australia.* All cases; †cases aged <5 years only; ‡cases aged >50 years only; § the proportion of cases for which testing is performed is unknown.

Table 8 Issues affecting quality and completeness of data in Australia’s Enhanced Invasive Pneumococcal Disease Surveillance Program, 2017.

Issue	Data fields affected	Jurisdictions affected	
		all	some
Cases aged 5-50 years not routinely followed up	Vaccination history*		✓
	Risk factors		✓
	Clinical category		✓
Difficulty accessing medical records	Vaccination history*		✓
	Mortality		✓
	Risk factors		✓
	Clinical category		✓
Testing not performed	Sensitivity to full panel of antimicrobials	✓	
	Serotype (non-culture specimens only)		✓
Data entry/transmission	Sensitivity to first-line antimicrobials		✓
Data field missing from national data collection form†	Hospitalisation	✓	
Data entry errors/illogical data	Date fields	✓	
	Serotype/ Laboratory method		✓

*For cases aged over seven years prior to October 2016 only. The whole-of-life Australian Immunisation Register was introduced in 2016 to record all vaccinations administered under the NIP and most privately-funded vaccines.

†Hospitalisation was ratified as a NNDSS core data field in March 2016 and to the data collection form in April 2016, therefore it was not routinely collected for the years 2013-2016.

Flexibility

Over 15 years, the program has been flexible enough to accommodate changes in IPD epidemiology and available vaccines. However, the program needs to accommodate trends in laboratory methods. In particular, the increase in the proportion of cases confirmed by polymerase chain reaction (PCR) only will reduce the program’s ability to attain high completeness for serotype and AMR data fields. The move towards whole-genome sequencing (WGS) for diagnosis and surveillance will lead to profound advances in the understanding of communicable disease epidemiology. (27) The speed of change in next-generation sequencing indicates that WGS may soon be comparable to conventional laboratory methods in terms of time and cost. (27, 28) Now is the time for the EIPDWG to initiate work with relevant parties to plan for such a change in Australia, ensuring that standards and formats allow data to be shared and synthesised internationally. The EIPDSWG should also consider initiating or auspicing pilot implementation studies of WGS using Australian IPD surveillance data.

Acceptability

The program is highly acceptable, largely as a result of engagement with diagnostic laboratory networks during the planning and early implementation phases in 2000 and 2001. However, work is required to ensure the ongoing commitment of laboratories to forward isolates to the reference laboratories for serotyping and AMR testing.

Sensitivity

The sensitivity of the program for detecting cases of IPD is unknown, but EIPDSWG members and stakeholders felt that it was acceptable. Occurrences of disease in which a specimen was not sought (e.g. milder illness), or could not be obtained, are not notified.

Positive Predictive Value

As only laboratory-confirmed (not suspected) cases are notified it is rare for non-IPD cases to be notified, so it is likely that the positive predictive value is high. Notified cases that are not IPD are mainly due to notification of isolates from a non-sterile site (eg sputum, bronchial washings, ear swabs), or urinary antigen testing. Rarely, the reference laboratory identifies the isolate as a bacterium other than *S. pneumoniae*, despite a positive culture in the diagnostic laboratory.

Representativeness

As the true sensitivity of the program is unknown, it is difficult to determine if there is any pattern to missed cases. It is clear that, for cases aged between five and 50 years, there is relatively lower completeness of vaccination history, Indigenous status, and enhanced data fields (including risk factors), compared with other cases.

Timeliness

The median time between onset of disease and receipt of notification by the jurisdictions (six days, Figure 8), and between notification and publication of data summaries in Quarterly Reports (three months), was acceptable. However, there is significant delay of enhanced data transmission from the NNDSS to the National

Centre for Immunisation Research and Surveillance (up to 10 months) due to data quality checks.

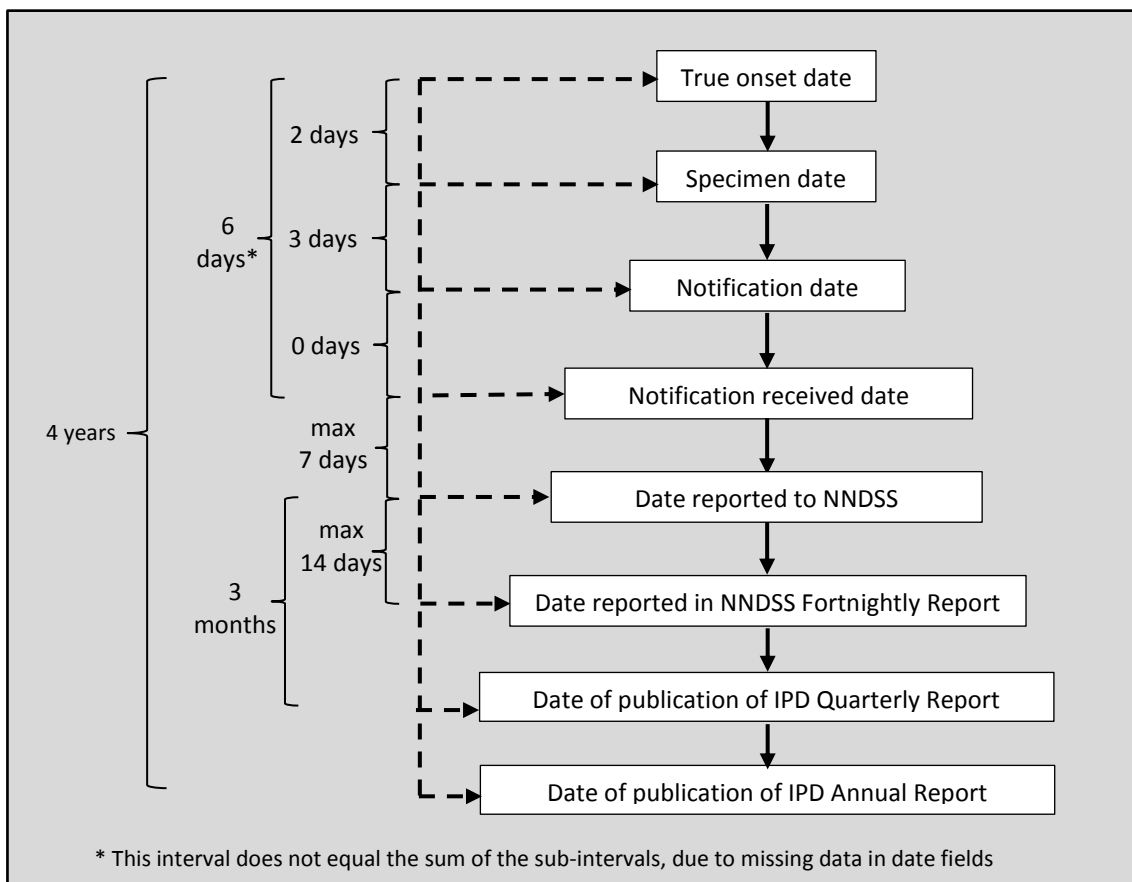


Figure 8 Median intervals between elements of case notification (1 July 2013 to 30 June 2016) and reporting (2001 – 2016) in Australia’s enhanced IPD surveillance program.

Stability

Forty percent of EIPDSWG interviewees rated the stability of the program as ‘excellent’, and half rated it as ‘good’. None indicated that there had been any significant periods during which the program could not function. The exception was one reference laboratory which became overwhelmed during the 2009 H1N1 influenza pandemic, and was unable to type about 20% of IPD isolates. These favourable responses reflect the fact that the program has operated for over 15 years without major problems, and confirm that the NNDSS is a stable system. Steps must be taken to ensure the succession of EIPDSWG members who, through their passion for IPD prevention, have achieved the stability and longevity of the program so far.

Discussion

This evaluation confirms that the enhanced IPD surveillance program is one of Australia's most useful, flexible and stable disease surveillance systems. Nonetheless, the program is not performing to its full potential, particularly in terms of data collection for cases aged between five and 50 years to inform targeted vaccination programs, AMR monitoring, and providing easily accessible and useful surveillance data. The declining number of cases, the increasing availability of vaccination data for all ages on the whole-of-life Australian Immunisation Register, (29) and the continued move towards electronic medical records should put complete data collection for all cases within the reach of all jurisdictions. Ongoing work is required of the EIPDSWG to ensure complete AMR testing; to harmonise notification, data entry and transmission processes; and to plan for the shift to whole genome sequencing. Specific recommendations to the EIPDSWG are listed in Box 3.

This evaluation was limited by the low number of responses to the stakeholder survey, which was unlikely to capture a representative sample of users of the program and its data. We only assessed data quality using logic checks of notification data. It may be useful to conduct a quality audit of a random sample of notified cases using the original data sources. We did not estimate the sensitivity of the program, but this could be approached using a capture-recapture analysis of linked surveillance and hospitalisation data.

Box 3 Recommendations to the EIPDSWG for improving Australia’s enhanced IPD surveillance program, 2017.

Priority Recommendations	
<ul style="list-style-type: none"> ❖ Collect complete surveillance data for all cases in all jurisdictions. If resource constraints preclude this in some jurisdictions, consider prospectively following-up a random sample of cases aged five to 50 years. ❖ Ensure researchers and vaccine developers can access the data at the level of detail they require in the public dataset, while maintaining the privacy of cases. This includes <ul style="list-style-type: none"> • finer stratification of age-groups for cases aged less than five years • data from 2001 onwards • all available serotype data • data on vaccine failures. ❖ Improve the completeness and quality of antimicrobial resistance (AMR) data by <ul style="list-style-type: none"> • addressing issues with data transmission in some jurisdictions • agreeing on the standards for reference laboratory AMR testing • advocating for funding for reference laboratories to undertake this testing for every case. 	
Other Recommendations	
<ul style="list-style-type: none"> ❖ Review the program objectives to ensure they reflect the EIPDSWG’s aspirations for the program. ❖ Harmonise notification processes, data collection forms and data transmission from the jurisdictions to the NNDSS. This should include standardising risk factor data domains to ensure they reflect groups at high risk of IPD, as identified in the <i>Australian Immunisation Handbook 10th Edition</i>. ❖ Advocate for all jurisdictions to implement exclusively electronic laboratory notification systems, ensuring that these collect data consistent with the NNDSS data fields. ❖ Support jurisdictions to modify their databases to prevent entering non-logical data, and to conduct post-entry logic checks, where these are not already in place. 	<ul style="list-style-type: none"> ❖ Working with relevant partners, plan for the shift to whole-genome sequencing by overseeing the development of quality standards for IPD sequencing and bioinformatics, and by auspicing pilot implementation studies. ❖ Work with the Public Health Laboratory Network to enhance engagement and communication with diagnostic laboratories to ensure their full participation. This should include a review and promotion of the guidelines for forwarding samples to reference laboratories. ❖ Implement succession planning interventions to ensure there is depth of capacity within the EIPDSWG, reference laboratories and jurisdictions to maintain the program at the current high standard.

Acknowledgements

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APPENDIX 4.2 – Working Group consultation interview tool



Evaluation of the National Invasive Pneumococcal Disease Surveillance Program

Enhanced IPD Surveillance Working Group Interview Tool

Study ID _____ State/Territory _____ Time as WG member (yrs) _____

Date of interview ____ / ____ / _____

Mode face to face Data entered on ____ / ____ / _____
 phone
 videoconference

Introduction

The purpose of this interview is to gather information about the national IPD surveillance program in order to

- describe the program accurately
- confirm the objectives of the program
- evaluate program performance with respect to usefulness, simplicity, flexibility, sensitivity, data completeness and quality, acceptability, timeliness and stability.

1. Confirm the objectives of the program

I will read out each of the published objectives of the program. Please indicate by answering “yes” or “no” firstly whether the objective is appropriate, and secondly, whether it is being met. Please provide comment if you wish...

Objective	Appropriate?	Objective met?	Comments
a) To record every case of IPD occurring in Australia (NB this implies that sensitivity, completeness and representativeness are 100%)	<input type="checkbox"/> Y <input type="checkbox"/> N	<input type="checkbox"/> Y <input type="checkbox"/> N <input type="checkbox"/> Unsure	
b) To collect detailed information on each case of IPD as set out in the NNDSS IPD Enhanced Surveillance Form	<input type="checkbox"/> Y <input type="checkbox"/> N	<input type="checkbox"/> Y <input type="checkbox"/> N <input type="checkbox"/> Unsure	

Objective	Appropriate?	Objective met?	Comments
c) To collate nationally this information in the NNDSS dataset for enhanced IPD surveillance	<input type="checkbox"/> Y <input type="checkbox"/> N	<input type="checkbox"/> Y <input type="checkbox"/> N <input type="checkbox"/> Unsure	
d) To measure the impact of conjugate pneumococcal vaccination on the rates and types of pneumococcal disease, the prevalence of circulating serotypes and levels of antibiotic resistance	<input type="checkbox"/> Y <input type="checkbox"/> N	<input type="checkbox"/> Y <input type="checkbox"/> N <input type="checkbox"/> Unsure	
e) To assess whether cases or deaths in children under 5 years and adults over 65 years are due to IPD vaccine failure or antibiotic resistance	<input type="checkbox"/> Y <input type="checkbox"/> N	<input type="checkbox"/> Y <input type="checkbox"/> N <input type="checkbox"/> Unsure	

f) *Should further objectives be added?*

Y

N *Go to Section 2*

g) *If yes, please specify and describe the program's performance against the additional objective/s.*

2. Confirm the flow of data in the program

a) Please refer to **Attachment 1 - provisional flow chart for data**

Is IPD data managed in accordance with this flowchart?

Y *Go to Section 3*

N

b) *If not, please give details*

3. Data management

In your jurisdiction, describe what happens for...

a) (for Public Health Units) Case ascertainment (ie how are notifications received, from whom etc)	
b) (for Public Health Units) confirming a case and collecting the enhanced data	

c) Entering the data (including format and data checks)	
d) De-identifying the data	
e) Securely storing and backing up the data	
f) Securely transmitting the data to other elements of the surveillance system	
g) Frequency of data transmission (ie from reference lab to PHU; or from PHU to C'wlth)	

4. Stability

a) *How would you rate the stability of the program?*

- Excellent
- Good
- Average
- Poor
- Terrible

b) *Why have you given this rating?*

c) *Have there been periods during which case notification, confirmation, data entry, transmission of data, data access or reporting have been prevented?*

Y

N *Go to Section 5*

d) *If yes, please describe these periods in terms of cause, impact and response.*

5. Data Completeness and Quality

Please provide suggestions for how data completeness and quality could be improved:

6. Sensitivity

a) *How would you rate the sensitivity of the national surveillance program?*

- Excellent
- Good
- Average
- Poor
- Terrible

b) *Why have you given this rating?*

7. Timeliness and Flexibility

Are national data analysed and reported frequently enough by the Working Group to...

a) inform prevention programs and policy?	<input type="checkbox"/> Y <i>Comment</i> <input type="checkbox"/> N
b) respond to IPD outbreaks?	<input type="checkbox"/> Y <i>Comment</i> <input type="checkbox"/> N

Please comment on the program's ability to respond to changes in...

c) IPD epidemiology	
---------------------	--

d) available vaccines	
e) laboratory testing and typing	

8. Predictive Value Positive (Public Health Units only)

a) *Please estimate the number of times a false positive case is identified each year in your jurisdiction:*

9. Usefulness

a) *How would you rate the usefulness of the national surveillance program (including the national data, published reports and the EIPDSWG network)?*

- Extremely useful
- Very useful
- Moderately useful
- Slightly useful
- Not at all useful

b) *Why have you given this rating?*

c) *Do you use national IPD data or published reports?*

- Y
- N *Go to Question 9g*

d) *Do you use these data or reports for*

- monitoring national trends?
- IPD surveillance reporting in your jurisdiction?
- research?
- policy development?
- informing program management?
- evaluating vaccination interventions?
- other, please specify

_____?

e) *How often do you use these data or reports?*

- Daily
- Weekly
- Fortnightly
- Monthly
- Quarterly
- Yearly

f) *Which data or reports do you access?*

- the IPD public data set
- the IPD quarterly reports
- the IPD annual reports
- data requests to CDNA

Go to Question 10

g) *Why don't you use these data or reports?*

- difficult to access
- the data are insufficient
- national IPD data or reports are not relevant to my work
- other, please specify

10. Resources Required

a) *How many staff are involved in collecting data or managing the program in your jurisdiction?*

_____ staff

b) *Please estimate the average number of hours to takes to deal with each case. (for PHUs: ie receiving notifications, collecting enhanced data, entering and transmitting data; for labs: testing specimens, entering and transmitting data)*

_____ hours

11. General

a) *Shortly I will be surveying the stakeholders and users of the program data. Is there anything in you'd like to glean from this survey?*

Please provide any other comments about the program or the evaluation:

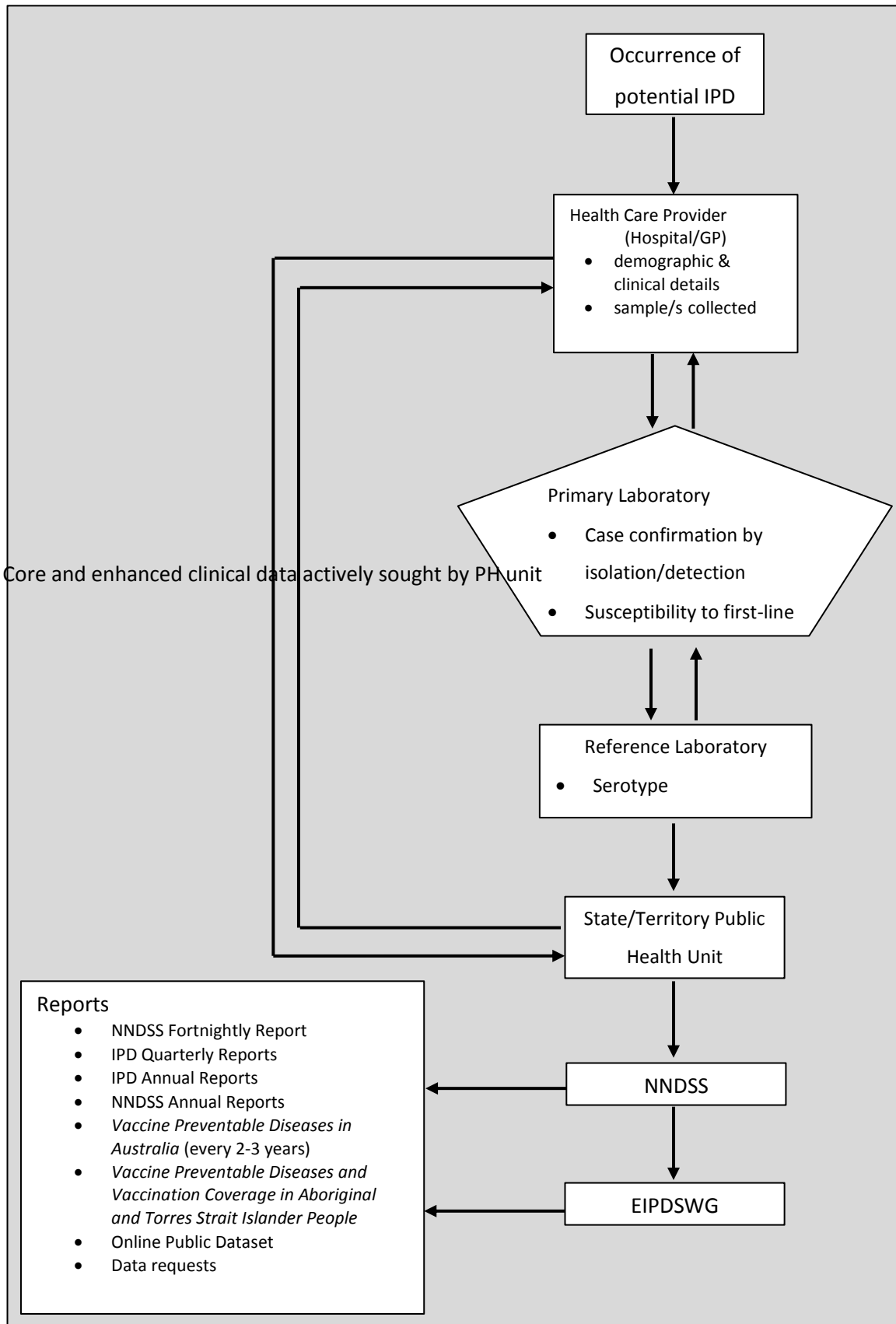
Thank you for your time. I have provided a simple template for reporting the resources required for running the program. Please return it to me by email.

What happens next?

I will collate the responses from all the EIPDSWG members and develop and administer an online survey of the program's stakeholders. I will also conduct simple analyses of the surveillance data to inform the evaluation.

Please contact me at any time if you think of anything to add or if you have concerns or questions about the evaluation.

Attachment 1 - provisional flow chart for IPD data



APPENDIX 4.3 – Stakeholder online survey

Evaluation of Australia's Enhanced Invasive Pneumococcal Disease (IPD) Surveillance Program

Invasive pneumococcal disease (IPD) is caused by the bacterium *Streptococcus pneumoniae* and results in illnesses such as pneumonia, bacteraemia and meningitis. National surveillance of all cases of IPD has been in place since 2001. IPD surveillance is enhanced, which means extra information about risk factors for disease and antibiotic resistance is collected. Surveillance data are used to monitor the effects of the national pneumococcal vaccination program and have provided valuable evidence to inform a change in this program for infants.

This is the first evaluation of the Enhanced IPD Surveillance Program, and it aims to determine to what extent the program is achieving its stated objectives, to identify ways in which surveillance may be improved, and to make recommendations to the IPD surveillance Working Group as appropriate.

Purpose of the survey

This anonymous survey gives users and providers of the IPD surveillance system data the opportunity to provide feedback on the Program's usefulness, flexibility, acceptability and timeliness, as well as the quality and completeness of its data. The survey should take a maximum of 15 minutes to complete.

Consent for Participation

Your participation is voluntary. No personal information (including IP addresses) will be collected. I plan to discuss the results with the Australian Government Department of Health and my supervisor at the Australian National University. In any publication, information will be presented in such a way that you cannot be identified.

Please click [here](#) to read the full Participant Information Sheet.

If you have any questions about the evaluation you may contact me at u3034396@anu.edu.au or 02 6289 8690.

Thank you

Alex Marmor

Master of Philosophy in Applied Epidemiology (MAE) Scholar
Australian National University

I have read and understood the Participant Information Sheet and give permission for my responses to be used in the evaluation:

- Yes
- No

Please indicate your affiliation or stakeholder group: You may select more than one option

- Diagnostic laboratory (private or public)
- Researcher or academic
- NCIRS - National Centre for Immunisation Research and Surveillance
- ATAGI - Australian Technical Advisory Group on Immunisation
- Vaccine manufacturer
- AMR Coordination Unit - Australian Commission for Safety and Quality in Health Care
- Infectious Disease Physician
- Paediatrician
- Other medical officer
- Policy and programs - Australian Government
- Policy and programs - State and Territory government
- Other, please specify _____

Display This Question:

If Please indicate your affiliation or stakeholder group:You may select more than one option Infectious Disease Physician Is Selected

Or Please indicate your affiliation or stakeholder group:You may select more than one option Other medical officer Is Selected

Or Please indicate your affiliation or stakeholder group:You may select more than one option Diagnostic laboratory (private or public) Is Selected

Or Please indicate your affiliation or stakeholder group:You may select more than one option Paediatrician Is Selected

Have you ever notified a case of IPD to the health department in your state or territory?

- Yes
- No

If No Is Selected, Then Skip To Please describe your laboratory's pro...

Display This Question:

If Have you ever notified a case of IPD to the public health unit in your state or territory? Yes Is Selected

How would you describe the ease of use of the notification system, including any follow-up?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Display This Question:

If Acceptability Have you ever notified a case of IPD to the public health unit in your state or terr... Yes Is Selected

Please provide any comments about your experience of notifying cases of IPD.

Display This Question:

If Have you ever notified a case of IPD to the health department in your state or territory? Yes Is Selected

And Please indicate your affiliation or stakeholder group:You may select more than one option Paediatrician Is Selected

Or Please indicate your affiliation or stakeholder group:You may select more than one option Infectious Disease Physician Is Selected

Or Please indicate your affiliation or stakeholder group:You may select more than one option Other medical officer Is Selected

Would receiving case-by-case feedback on serotype and antibiotic resistance be useful/improve clinical management?

- Yes
- No
- Maybe

Display This Question:

If Would receiving case-by-case feedback on serotype and antibiotic resistance be useful/improve clinical management? Yes Is Selected

Or Would receiving case-by-case feedback on serotype and antibiotic resistance be useful/improve clinical management? Maybe Is Selected

Or Would receiving case-by-case feedback on serotype and antibiotic resistance be useful/improve clinical management? No Is Selected

Please comment on the type of feedback you would like to receive about the cases you notify:

Display This Question:

If Please indicate your affiliation or stakeholder group: You may select more than one option Diagnostic laboratory (private or public) Is Selected

Please describe your laboratory's process for forwarding PCR-positive IPD samples to the reference laboratory for typing:

Display This Question:

If Please indicate your affiliation or stakeholder group: You may select more than one option Diagnostic laboratory (private or public) Is Selected

Has your laboratory ever received feedback from the Enhanced IPD Surveillance Working Group about how the notification data is used?

- Yes
- No
- Unsure

Display This Question:

If Please indicate your affiliation or stakeholder group: You may select more than one option Diagnostic laboratory (private or public) Is Selected

What kind of feedback would you like to receive about how the notification data is used?

Q57 How would you rate the usefulness of the IPD surveillance program overall?

- Extremely useful
- Very useful
- Moderately useful
- Slightly useful
- Not at all useful

Why have you selected this rating?

Have you used data from the IPD Public Dataset? This dataset is available from the National Notifiable Disease Surveillance System (NNDSS) web page.

- Yes
- No

If No Is Selected, Then Skip To Have you used the IPD Surveillance Qu...

Display This Question:

If Have you used data from the IPD Public Dataset? This dataset is available from the National Notifiable Disease Surveillance System (NNDSS) web page. Yes Is Selected

What have you used the IPD Public Dataset for? Please select all that apply.

- Monitoring national trends
- IPD surveillance reporting in my jurisdiction
- Research
- Policy development
- Informing program management
- Evaluation of public health interventions
- Education and training
- Other, please specify _____

Display This Question:

If Have you used data from the IPD Public Dataset? This dataset is available from the National Notifiable Disease Surveillance System (NNDSS) web page. Yes Is Selected

Which data fields in the Public Dataset have you found most useful? Please select all that apply

- Vaccination history
- Clinical category
- Serotype
- Indigenous status
- Demographic data (ie age group, sex)

Display This Question:

If Have you used data from the IPD Public Dataset? This dataset is available from the National Notifiable Disease Surveillance System (NNDSS) web page. Yes Is Selected

Please list any other data fields that you would find useful and why:

Display This Question:

If Have you used data from the IPD Public Dataset; This dataset is available from the National Notifiable Disease Surveillance System (NNDSS) web page.; Yes Is Selected

How useful are the IPD Public Dataset data caveats and interpretation notes for understanding the data fields? These caveats and notes are included as a spreadsheet in the Public Dataset file.

- Extremely useful
- Very useful
- Moderately useful
- Slightly useful
- Not at all useful
- I did not know there were data caveats or interpretation notes

Display This Question:

If Have you used data from the IPD Public Dataset?; This dataset is available from the National Notifiable Disease Surveillance System (NNDSS) web page. ; Yes Is Selected

Please comment on ways in which the IPD Public Dataset and/or data caveats could be improved:

Have you used the IPD Surveillance Quarterly Reports? These reports are published in Communicable Diseases Intelligence and on the National Notifiable Disease Surveillance System web page.

- Yes
- No

If No Is Selected, Then Skip To Have you requested line-listed IPD su...

Display This Question:

If Have you used the IPD Surveillance Quarterly Reports? These reports are published in Communicable Diseases Intelligence and on the National Notifiable Disease Surveillance System web page... Yes Is Selected

What have you used the IPD Quarterly Reports for? Please select all that apply.

- Monitoring national trends
- IPD surveillance reporting in my jurisdiction
- Research
- Policy development
- Informing program management
- Evaluation of public health interventions
- Education and training
- Other, please specify _____

Display This Question:

If Have you used the IPD Surveillance Quarterly Reports? These reports are published in Communicable Diseases Intelligence and on the National Notifiable Disease Surveillance System web page. &n... Yes Is Selected

Please comment on the usefulness of the Quarterly Reports and any suggestions for improvement:

Have you requested line-listed IPD surveillance data from the National Notifiable Diseases Surveillance System (NNDSS) via the Department of Health?

- Yes
- No

If No Is Selected, Then Skip To Why don't you use IPD data or reports...

Display This Question:

If Have you requested line-listed IPD surveillance data from Communicable Diseases Australia? Yes Is Selected

How would you describe the ease of the data request process?

- Extremely easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Extremely difficult

Display This Question:

If Have you requested line-listed IPD surveillance data from Communicable Diseases Australia? Yes Is Selected

Please provide comments on the data request process:

Display This Question:

If Have you requested line-listed IPD surveillance data from Communicable Diseases Australia? Yes Is Selected

For what purpose did you request the IPD surveillance data? Please select all that apply.

- Monitoring national trends
- IPD surveillance reporting in my jurisdiction
- Research
- Policy development
- Informing program management
- Evaluation of public health interventions
- Other, please specify _____

Display This Question:

If Have you requested line-listed IPD surveillance data from Communicable Diseases Australia? Yes Is Selected

Which fields in the data you requested did you find most useful? Please select all that apply

- Vaccination history
- Clinical category
- Serotype
- Antibiotic susceptibility
- Risk Factors
- Hospitalisation
- Mortality
- Indigenous status
- Demographic data (ie age group, sex)
- Other, please specify _____

Is there any data not currently collected during surveillance that you would find helpful?

Display This Question:

If Have you used data from the IPD Public Dataset? This dataset is available from the National Notifiable Disease Surveillance System (NNDSS) web page. No Is Selected

And Have you used the IPD Surveillance Quarterly Reports? These reports are published in Communicable Diseases Intelligence and on the National Notifiable Disease Surveillance System web page. No Is Selected

And Have you requested line-listed IPD surveillance data from Communicable Diseases Australia? No Is Selected

Why don't you use IPD data or reports? Please select all that apply

- National IPD data are not relevant to my work
- The data do not contain the information I need
- The data are not accurate
- There is too much missing data
- The data I need are too difficult to access
- Other, please specify _____

How would you rate the sensitivity of the surveillance program? Sensitivity refers to the proportion of true cases of disease detected by the program.

- Excellent
- Good
- Average
- Poor
- Terrible

Q76 Why have you given this rating?

How well can the surveillance program respond to...

						Comments
	Extremely well	Very well	Moderately well	Slightly well	Not well at all	Please indicate why you have given this answer
...changes in IPD epidemiology?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
...changes in pneumococcal vaccines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
...changes in laboratory testing and typing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Do you think data from the program are analysed and reported frequently enough to...

				Comments
	Yes	No	Unsure	
...inform prevention programs and policy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
...respond to IPD outbreaks?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

In your opinion, are there any features of the program that could be improved? Please provide details:

Please provide any other comments about the program that could be helpful in the evaluation:

**APPENDIX 4.4 – Interim summary report for the Enhanced
Pneumococcal Disease Surveillance Working Group**

**EVALUATION OF AUSTRALIA’S ENHANCED
INVASIVE PNEUMOCOCCAL DISEASE
SURVEILLANCE PROGRAM**

**SUMMARY REPORT
FOR THE
ENHANCED INVASIVE PNEUMOCOCCAL DISEASE
SURVEILLANCE WORKING GROUP**

February 2017

ALEX MARMOR

MASTER OF PHILOSOPHY (APPLIED EPIDEMIOLOGY) SCHOLAR

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**Australian
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Nick Pascual



Australian Government
Department of Health

Introduction

Invasive Pneumococcal Disease (IPD) has been a notifiable condition in Australia since 2001, and enhanced passive² surveillance is conducted in all States and Territories ('the jurisdictions'). Australia's Enhanced Invasive Pneumococcal Disease Surveillance Program is a part of the National Notifiable Diseases Surveillance System, and is coordinated by the Enhanced Invasive Pneumococcal Disease Surveillance Working Group (EIPDSWG). Pneumococcal vaccination is funded under the National Immunisation Program (NIP) for all infants and for other high risk population groups. This is the first evaluation of the surveillance program. The purpose of the evaluation is to:

- confirm the need for continued enhanced surveillance of IPD in Australia;
- determine the appropriateness and extent of achievement of the stated program objectives;
- identify ways in which surveillance may be improved; and
- make recommendations to the EIPDSWG as appropriate.

Methods

For this evaluation, I followed the framework outlined in the Centers for Disease Control and Prevention's *Updated Guidelines for Evaluating Public Health Surveillance Systems* (16). This includes a description of the system, and collection of credible evidence regarding its usefulness, and its performance against the attributes of simplicity, data completeness and quality, flexibility, acceptability, sensitivity, representativeness, predictive value positive, timeliness and stability. To collect this evidence, I conducted

- a literature and document review;
- key informant interviews between 16 June and 11 August 2016;
- an online stakeholder survey between 12 October and 14 November 2016; and
- a descriptive analyses of surveillance data for cases notified between 1 July 2013 and 30 June 2016 ("the study period").

Findings

I conducted twenty interviews with EIPDSWG members and OHP data managers. All jurisdictions and reference laboratories were represented. There were 28 responses to the stakeholder survey. Most respondents were researchers or from diagnostic laboratories, and four were from companies that produce pneumococcal vaccines for the Australian market.

² Passive surveillance consists of regular reporting of disease data by all institutions that see cases or test specimens, and are part of a reporting network. There is no active search for cases.

Public Health Importance

- Approximately 1,500 IPD cases were reported in 2015, representing a notification rate of 6.7 per 100,000.
- Most cases of IPD are hospitalised. Pneumococcal meningitis may have a mortality of up to 37% in developed countries, and serious neurological sequelae are common.
- The incidence of IPD is disproportionately high for those aged under five and over 65 years, and for Aboriginal and Torres Strait Islander people. Incidence of non-invasive pneumococcal disease (which may be affected by vaccination programs) is also high for these groups.
- The introduction of pneumococcal vaccination programs has reduced the incidence of IPD markedly, but has also led to replacement of vaccine serotypes with emerging serotypes.
- Continued enhanced surveillance is vital to detect changes in serotype and resistance profiles, and to inform and evaluate vaccination and treatment strategies.

Program operation

- Reporting of surveillance data involves many public and private organisations (see Figure 1).
- There are 38 fields in the IPD surveillance dataset, and completion of the enhanced data fields requires information about a case that is difficult to obtain without access to electronic medical and vaccination records.
- Processes differ between jurisdictions for notification of cases, follow-up, data entry and data transmission to the NNDSS.
- Core data are collected for all notified cases in all jurisdictions.
- In NSW, Victoria and some Public Health Units in Queensland, enhanced data are not routinely obtained for cases aged between five and 50 years.
- Up to date IPD summaries are publically available through the IPD Quarterly Reports and NNDSS Annual Reports. The IPD Annual Reports and Public dataset provide data up to 2012 and 2014, respectively.
- There are 181 staff involved in IPD surveillance data collection nationally. Serotyping, case follow-up and data entry takes between two and ten hours per case.
- Overall, EIPDSWG members thought that the program's objectives were appropriate, but that some were not being met due to lack of universal collection of enhanced data, and missing vaccination, serotype and antimicrobial resistance (AMR) data. Members suggested changes to the fourth and fifth objectives and suggested objectives that more accurately represent the program aims.

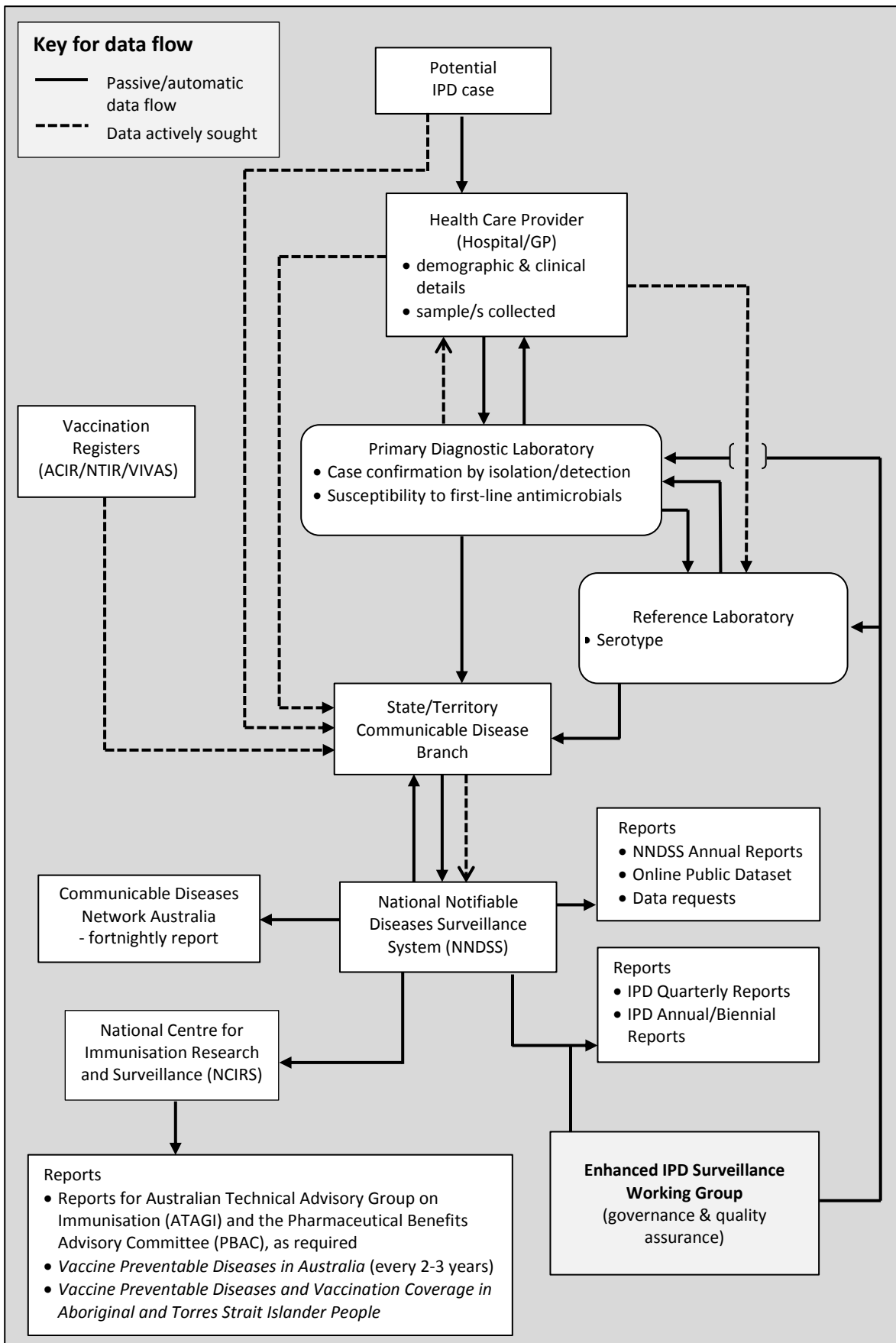


Figure 1 Flow of IPD surveillance data, 2016

Usefulness

- EIPDSWG members and stakeholders rated the usefulness of the program very highly. Most respondents used the data for monitoring national IPD trends and for research purposes, and agreed that the program was vital for monitoring and evaluating the infant pneumococcal conjugate vaccination programs.
- However, the program is less useful for evaluating the effect of vaccination programs on other high risk groups. This is due to poor availability of adult vaccination data and because of inconsistencies between the risk groupings in the *Immunisation Handbook* and those in the surveillance dataset.
- Around half of responding stakeholders had used data from the public data set, including all who were affiliated with pharmaceutical companies. They wished to have access to more detailed data, presented in finer detail, and from a longer time period (pre-2004 to date).
- The utility of the program for monitoring AMR is reduced by the absence of Western Australian data on first-line antimicrobial sensitivity. Some reference laboratories may also be performing AMR tests. However, they are not funded to do so, the panel of antimicrobials tested and methods vary, and most of these data are not being captured by the program. As the Australian Group on Antimicrobial Resistance will not be conducting any further surveys of *Streptococcus pneumoniae* resistance, it is vital that high quality, useful AMR data is collected and reported through IPD surveillance.
- This, together with more accessible data on clinical presentations and serotype, would be useful for informing clinical practice.
- Several members of the Working Group noted the usefulness of this network as a means of rapid communication between jurisdictions.

Simplicity

- Notification was considered easy.
- The collection of enhanced data increases the program's complexity, and this is compounded by the wide range of notification processes, data collection forms, databases, and data transmission process across jurisdictions.

Data quality and completeness

- Over the study period, jurisdictions achieved well over the 80% target for completeness of serotype data for targeted vaccination age groups, as specified in the *Project Agreement for Vaccine Preventable Diseases Surveillance Program*. The exception is South Australia, which reported data for only 64% of cases aged less than five years.
- All jurisdictions but NSW achieved the *Project Agreement* target of 95% completeness of vaccination data for cases aged less than seven years.
- Hospitalisation is poorly recorded, probably due to the absence of a hospitalisation field on the national data collection form. Although mortality is recorded in over 90% of cases, IPD deaths may be misclassified, particularly in jurisdictions that lack access to electronic medical records.

- Nationally, completeness of the Indigenous status field has increased modestly from 80% in 2004 to 90% in the study period, although the quality of data may have improved. I expect this trend to continue with the implementation of national standards for hospital, general practice and laboratories.
- Completeness of clinical category and risk factor data is 86% and 74%, respectively. This is likely due to the fact that not all jurisdictions routinely follow-up all cases, and absence or lack of access to electronic medical records.
- Data quality has improved since the quarterly feedback of NNDSS data to the jurisdictions. I identified consistent errors that would be avoided through the use of field validation and logic checks, preferably at the level of the jurisdiction where it is easiest to verify data.

Flexibility

- Stakeholders and EIPDSWG members agreed that the program was flexible enough to accommodate changes in IPD epidemiology and available vaccines.
- A predicted shift towards culture-independent diagnostic testing, particularly whole-genome sequencing (WGS), poses a challenge for all surveillance programs. The EIPDSWG has a role to play in developing and trialling WGS standards for sample preparation, sequencing, and data analysis.

Acceptability

- A key factor in the success of this program has been the engagement with diagnostic laboratory networks during the planning and implementation phases.
- Ongoing work is required to ensure the commitment of laboratories to forward isolates to the reference laboratories for serotyping and AMR testing, particularly in South Australia. The published guidelines for collecting, storing and transportation of PCR-positive specimens would benefit from a review, and direct engagement with laboratory networks may also be required.

Sensitivity

- Most interviewees and respondents thought that the sensitivity of the program was good to excellent. The true sensitivity is unknown. Failure to collect clinical specimens and failure of laboratories and clinicians to notify reduce sensitivity.
- It would be difficult to detect an increase in some clinical presentations of IPD due to the way these surveillance data are categorised.

Representativeness

- The enhanced data is not representative of all age groups in all jurisdictions; there is missing Indigenous status data; and categorisation in the dataset hinders the identification of cases in groups with some risk factors.

Predictive value positive

- Representatives of the jurisdictions and reference laboratories believe that there are few notified cases that are not true IPD cases.

Timeliness

- Over the study period, the median time between onset of disease and receipt of notification by the jurisdiction was six days, with a range of four to nine days.
- There is a 10 month delay in the transmission of data to the National Centre for Immunisation Surveillance and Research, which reduces the utility of the data. This is mainly due to data quality checks.
- Annual IPD reports are not timely. Quarterly reports are published promptly but do not contain the level of information that some stakeholders are seeking.
- Eighty percent of cases are notified within 14 days of onset. However, delays in receiving serotype data means that early identification of linked cases is unlikely and therefore the capacity for use of the system to identify outbreaks is limited.

Stability

- The majority of EIPDSWG members rated the stability of the program as good to excellent, and there have been no significant disruptions in program operation.
- Passionate EIPDSWG members have driven the program for over 15 years. Continued success will require succession planning.

Recommendations

Priority Recommendations

- ❖ *Undertake enhanced surveillance of all cases in all jurisdictions. If resource constraints preclude this in NSW, Victoria and Queensland, consider following-up of a random sample of cases aged five to 50 years in these jurisdictions.*
- ❖ *Ensure researchers and vaccine developers can access the data and level of detail they require, while ensuring the privacy of cases is maintained. This includes*
 - *finer stratification of age-groups for cases aged less than five years;*
 - *data before 2009;*
 - *all available serotype data; and*
 - *vaccine failures.*
- ❖ *Improve the completeness and quality of AMR data by*
 - *investigating the poor completeness for first-line AMR data from Western Australia;*
 - *agreeing on the standards for reference laboratory AMR testing; and*
 - *advocating for funding for reference laboratories to collect these data for every case*

Other Recommendations

- ❖ *Replace program objectives 4 and 5 with the following (or similar):*
 - “To provide and report high quality enhanced data to allow
 - *monitoring of changes in disease presentations*
 - *monitoring of antimicrobial susceptibility/resistance patterns; and*
 - *assessment of the impact and cost-effectiveness of targeted vaccination programs.”*
- ❖ *Standardise risk factor data domains in notification forms, case report forms and surveillance databases across all jurisdictions, ensuring they reflect groups at high risk of IPD, as identified in the Immunisation Handbook.*
- ❖ *Investigate the feasibility of developing regional-level summaries of clinical presentation, serotype and AMR for the different age groups, presented on a platform that is accessible at the bedside.*
- ❖ *Harmonise notification processes, data collection forms and data transmission from jurisdictions to OHP.*

- ❖ *Investigate the poor completeness for vaccination data in cases aged less than seven years in NSW.*
- ❖ *Include 'hospitalisation' in the National Enhanced Surveillance Data Collection Form and explanatory notes.*
- ❖ *Advocate for all jurisdictions to implement exclusively electronic laboratory notification systems, ensuring that these systems collect data consistent with the IPD surveillance data fields.*
- ❖ *Support jurisdictions to update their databases to prevent entering non-logical data and to conduct post-entry logic checks, where these are not already in place.*
- ❖ *Working with relevant partners, plan for the shift towards whole genome sequencing by overseeing the development of quality standards for IPD sequencing and bioinformatics, and by auspicing pilot implementation studies.*
- ❖ *Work with the Public Health Laboratory Network to enhance engagement and communication with diagnostic laboratories to ensure their full participation in the program. This should include a review and promotion of the guidelines for forwarding samples to the reference laboratories, with a particular focus on South Australia.*
- ❖ *Review the domains and specifications for the clinical category data field to ensure that changes in clinical presentation can be detected.*
- ❖ *Investigate the reason for the relative delay in notifications in NSW.*
- ❖ *Ensure there is depth of capacity within the EIPDSWG, reference laboratories and jurisdictions to maintain the program at the current high standard.*

CHAPTER 5 – NEW DIRECTIONS: MOTHERS AND BABIES SERVICES – EVALUATION OF THE PROGRAM USING AUSTRALIAN EARLY DEVELOPMENT CENSUS DATA 2009 - 2015

APPENDIX 5.1 – List of Indigenous Areas (IAREs) serviced by New Directions: Mothers and Babies Services-funded organisations

<i>IARE code</i>	<i>IARE name</i>	<i>IARE code</i>	<i>IARE name</i>
New South Wales		106003	Shoalhaven
101005	Parkes	107003	Blacktown
102001	Armidale	107006	Camden
102005	Inverell - Gwydir	107007	Campbelltown
102007	Moree	107008	Canterbury - Bankstown
102009	Muswellbrook	107009	Fairfield
102010	Narrabri	107014	Hurstville - Kogarah
104001	Ballina - Bagotville	107015	Kiama - Shellharbour
104002	Byron	107016	Leichhardt
104003	Cessnock	107017	Liverpool
104005	Coffs Harbour - Nambucca	107019	Marrickville
104007	Gosford	107023	Randwick - La Perouse
104008	Great Lakes	107024	Rockdale
104009	Kempsey	107025	Sutherland Shire
104011	Lake Macquarie	107029	Wollondilly
104013	Maitland	107030	Wollongong
104014	Newcastle		
104015	Port Macquarie - Hastings	Victoria	
104016	Port Stephens	201011	Melbourne - North-East
104018	Singleton	202001	Ballarat
104019	Taree	202003	Bendigo
104021	Wyong	202005	Castlemaine - Kerang
105003	Bathurst	202009	Macedon Ranges - Moorabool
105004	Blayney - Cabonne	202010	Mildura
105005	Carrathool - Murrumbidgee	202012	South-West Central Victoria
105009	Cowra	202014	Swan Hill
105011	Forbes	202019	Wodonga
105012	Griffith - Leeton		
105013	Gundagai - Junee - Harden	South Australia	
105017	Narrandera	402003	Eyre
105018	Orange	402005	Port Augusta
105019	Tumut	402006	Whyalla
105021	Wagga Wagga	403001	Ceduna

IARE code IARE name**Queensland**

302001 Atherton
302002 Cairns
302006 Herberton - Ravenshoe
302007 Innisfail - Johnstone
302009 Mareeba
302011 Yarrabah
304004 Mount Isa
306012 Paroo
306015 Toowoomba - Central
307002 Kalakawal - Top Western Islands
307003 Kalalagal - Western Islands
307004 Kulkalgal - Central Islands
307005 Meriam - Eastern Islands
308006 Mackay
308007 Mackay - Surrounds
308015 Tully - Cardwell - Jumbun

Western Australia

502001 Carnarvon - Mungullah
502004 Geraldton
502007 Shark Bay - Coral Bay - Upper
Gascoyne
503002 Kalgoorlie - Dundas - Goldfields
503003 Kalgoorlie - Ningia Mia
503005 Menzies - Leonora
504001 Argyle - Warmun
504003 Halls Creek
504006 Kununurra
504007 North Kimberley
506001 East Pilbara
506002 Exmouth - Ashburton
506004 Port Hedland
506005 Roebourne - Wickham
507002 Avon
507005 Champion
507011 Moora - Chittering
507014 Northam
508004 Outer Derby - West Kimberley

IARE code IARE name**Tasmania**

601001 Central Coast - Devonport
601003 Greater Hobart
601004 Huon Valley
601005 Kingborough
601008 Tasmania - North-East Coast
601010 Tasmania - West Coast
601011 West Tamar - Latrobe

IARE code IARE name**Northern Territory**

701002 Alice Springs Town Camps
702002 Ampilatwatja and Outstations
702007 Hermannsburg
702009 Mutitjulu - Uluru - Imanpa
702013 Walungurru and Outstations
702014 West MacDonnell Ranges
702017 Yuendumu and Outstations
703005 Darwin - Inner Suburbs
704001 Douglas-Daly
704005 Thamarrurr inc. Wadeye
705002 Daguragu - Kalkarindji and
Outstations
705003 Elsey - Roper
705004 Gulf
705005 Katherine Town
705006 Lajamanu
705007 Ngukurr
705008 Victoria River
705009 Walangeri
706003 Laynhapuy - Gumatj Homelands
706004 Marthakal Homelands - Galiwinku
706005 Nhulunbuy - Gunyangara
706008 Yirrkala

IARE code IARE name**Australian Capital Territory**

801001 Canberra - North
801002 Canberra - South
801003 Stromlo-Namadgi

APPENDIX 5.2 – Technical Summary

Study Objective	To evaluate the ecologic effect of New Directions: Mothers and Babies Services (NDMBS) investment between 2007 and 2015 on school readiness.	
Research question	Did indicators derived from the Australian Early Development Census (AEDC) improve between 2009 and 2015 for Aboriginal and Torres Strait Islander children who lived in NDMBS-serviced areas, compared with children who did not live in these areas?	
Study Design	Ecologic time-trend study with two exposure groups	
Population	<p>Aboriginal and Torres Strait Islander children in the first year of school in 2009 and 2015 who:</p> <ul style="list-style-type: none"> • did not have special needs • were aged over three years • had a valid Indigenous area (IARE) code. <p>Children were excluded from analyses of individual developmental domains if they did not have a valid score for the respective domain, and from analyses of summary vulnerability indicators if they did not qualify for the denominator for each calculation.</p>	
Data Sources and variables	<i>Exposure variable</i>	<p>FaHCSIA Online Funding Management System (FOFMS):</p> <ul style="list-style-type: none"> • IAREs serviced by organisations that received grants under the NDMBS program 2007-2015.
	<i>Outcome measures</i>	<p>Unit record data from the 2009 and 2015 Australian Early Development Censuses:</p> <ul style="list-style-type: none"> • on-track, at-risk and vulnerable in each developmental domain • vulnerable in one or more domains • vulnerable in two or more domains • Multiple Strengths Indicator (MSI)

Data Sources and variables (cont)	<i>Covariables</i>	Unit record data from the 2009 and 2015 Australian Early Development Censuses: <ul style="list-style-type: none"> • IARE of usual residence • State/Territory of usual residence • remoteness category of usual residence • SEIFA quintile of usual residence • age • sex • English as a second language (ESL) • language background other than English (LBOTE)³ • child assessed by an Aboriginal and Torres Strait Islander teacher • teacher assisted in assessment by an Indigenous cultural consultant • attended a pre-school program in the year before school
Analysis Packages	Stata Version 13 Microsoft Excel 2010	
Descriptive analysis	Means, frequencies and percentages <ul style="list-style-type: none"> • demographic variables • regional-level socio-economic variables 	

³ Children who speak a language other than English in the home or whose parent(s)/guardian(s) speak a language other than English in the home.

Outcome analysis	<p>Performed in three steps, calculating:</p> <ol style="list-style-type: none"> 1. the proportion of children in the exposure groups in 2009 and 2015 who were <ul style="list-style-type: none"> ○ developmentally “on-track”, “at risk” and “vulnerable” in each domain; ○ vulnerable in one or more or two or more domains; and ○ in each MSI category. 2. the change from 2009 and 2015 in each indicator in terms of a percentage-point change 3. the difference in this change between the exposure groups. <p>This analysis was repeated for the vulnerability indicators and MSI categories for each State and Territory.</p>
Tests for statistical significance – Sampling error	<p>As the AEDC is a census, data for the whole population of Aboriginal and Torres Strait Islander children was analysed and a sample of children was not taken for this study. Therefore, there is no sampling error, and hypothesis tests (calculation of <i>p</i> values) were not performed, nor were confidence intervals calculated.</p>
Tests for statistical significance - Measurement error	<p>Measurement error resulting from teacher and class level variation can be assessed using the ‘critical difference’ margins for each domain score and the vulnerability indicators. The critical differences were calculated in Microsoft Excel using the relevant power functions for each of these outcome measures developed by Gregory and Brinkman (2016)⁴. Power functions are not yet available for the MSI categories. The smaller exposure group sizes (from 2009) were used in the calculations. The power functions and critical differences are shown below for Australia (Table A) and by State and Territory (Table B).</p>
Results	<p>Shown in Tables C-G below.</p>

⁴ Gregory T, Brinkman S. Exploring change in the Australian version of the Early Development Instrument: The estimation of a critical difference for the “vulnerable”, “at risk” and “on track” categories. Adelaide: Telethon Kids Institute, 2016.

Limitations of the study	<ul style="list-style-type: none"> • Causal inference is limited by the ecologic design: <ul style="list-style-type: none"> ○ we have assessed the changes in aggregate data for children in their first year of school in the exposure groups, not the changes in individual children over time. • We have not measured or controlled for child-related confounding factors (eg individual-level measures of disadvantage) • The likelihood of individual children being misclassified is high. This is due to: <ul style="list-style-type: none"> ○ probable mismatch of IAREs and NDMBS-serviced areas ○ possible change in areas serviced by NDMBS-funded organisations over time ○ families accessing non-NDMBS maternal and child health services despite living in an NDMBS-serviced area, and vice-versa ○ migration of families across IARE boundaries. • The AEDC is just one measure of school readiness related to characteristics of the child. It does not measure the ability of schools to engage children in high quality teaching and learning.
Ethical Review	<ul style="list-style-type: none"> • Australian National University Human Research Ethics Committee • Protocol: 2015/371
Funding	<ul style="list-style-type: none"> • Alex Marmor completed this work while she was a Master of Philosophy (Applied Epidemiology) scholar, on placement at the Australian Government Department of Health, and supported by an Australian Government Research Training Scholarship.

Table A Power functions for calculating the critical difference in change in developmental domains and vulnerability indicators in the exposure and comparison groups, Australia, 2009-2015.

Domain/Indicator	NDMBS IAREs			Non-NDMBS IAREs	
		Calculation	Critical difference	Calculation	Critical difference
Physical health & wellbeing	On-track	=65.824*(POWER(5438,-0.494))	±0.94%	=65.824*(POWER(6521,-0.494))	±0.86%
	At risk	=69.543*(POWER(5438,-0.495))	±0.98%	=69.543*(POWER(6521,-0.495))	±0.90%
	Vulnerable	=56.2*(POWER(5438,-0.493))	±0.81%	=56.2*(POWER(6521,-0.493))	±0.74%
Social competence	On-track	=48.218*(POWER(5438,-0.486))	±0.74%	=48.218*(POWER(6508,-0.486))	±0.68%
	At risk	=62.313*(POWER(5438,-0.491))	±0.91%	=62.313*(POWER(6508,-0.491))	±0.84%
	Vulnerable	=37.135*(POWER(5433,-0.487))	±0.56%	=37.135*(POWER(6508,-0.487))	±0.52%
Emotional maturity	On-track	=50.303*(POWER(5438,-0.486))	±0.77%	=50.303*(POWER(6458,-0.486))	±0.71%
	At risk	=69.417*(POWER(5438,-0.501))	±0.93%	=69.417*(POWER(6458,-0.501))	±0.86%
	Vulnerable	=48.062*(POWER(5387,-0.515))	±0.58%	=48.062*(POWER(6458,-0.515))	±0.52%
Language & cognitive skills	On-track	=51.978*(POWER(5438,-0.488))	±0.78%	=51.978*(POWER(6496,-0.488))	±0.72%
	At risk	=67.78*(POWER(5438,-0.498))	±0.94%	=67.78*(POWER(6496,-0.498))	±0.86%
	Vulnerable	=41.927*(POWER(5410,-0.497))	±0.58%	=41.927*(POWER(6496,-0.497))	±0.53%
Communication & general knowledge	On-track	=59.974*(POWER(5438,-0.497))	±0.83%	=59.974*(POWER(6523,-0.497))	±0.76%
	At risk	=73.207*(POWER(5438,-0.499))	±1.00%	=73.207*(POWER(6523,-0.499))	±0.92%
	Vulnerable	=50.933*(POWER(5436,-0.5))	±0.69%	=50.933*(POWER(6523,-0.5))	±0.63%
Vulnerable in 1 or more domains		=67.888*(POWER(5438,-0.502))	±0.90%	=67.888*(POWER(6500,-0.502))	±0.83%
Vulnerable in 2 or more domains		=47.639*(POWER(5438,-0.495))	±0.67%	=47.639*(POWER(6499,-0.495))	±0.62%

Table B Power functions for calculating the critical difference in change in developmental domains and vulnerability indicators in the exposure and comparison groups by State and Territory, 2009-2015.

Jurisdiction		Vulnerable in ≥ 1 domains		Vulnerable in ≥ 2 domains	
		Calculation	Critical difference	Calculation	Critical difference
NSW	NDMBS IAREs	$=67.888*(POWER(2115,-0.502))$	$\pm 1.45\%$	$=47.639*(POWER(2115,-0.495))$	$\pm 1.08\%$
	Non-NDMBS IAREs	$=67.888*(POWER(1596,-0.502))$	$\pm 1.67\%$	$=47.639*(POWER(1596,-0.495))$	$\pm 1.24\%$
VIC	NDMBS IAREs	$=67.888*(POWER(200,-0.502))$	$\pm 4.75\%$	$=47.639*(POWER(200,-0.495))$	$\pm 3.46\%$
	Non-NDMBS IAREs	$=67.888*(POWER(419,-0.502))$	$\pm 3.28\%$	$=47.639*(POWER(419,-0.495))$	$\pm 2.40\%$
QLD	NDMBS IAREs	$=67.888*(POWER(1563,-0.502))$	$\pm 1.69\%$	$=47.639*(POWER(1564,-0.495))$	$\pm 1.25\%$
	Non-NDMBS IAREs	$=67.888*(POWER(1899,-0.502))$	$\pm 1.53\%$	$=47.639*(POWER(1899,-0.495))$	$\pm 1.14\%$
SA	NDMBS IAREs	$=67.888*(POWER(101,-0.502))$	$\pm 6.69\%$	$=47.639*(POWER(101,-0.495))$	$\pm 4.85\%$
	Non-NDMBS IAREs	$=67.888*(POWER(132,-0.502))$	$\pm 5.85\%$	$=47.639*(POWER(132,-0.495))$	$\pm 4.25\%$
WA	NDMBS IAREs	$=67.888*(POWER(604,-0.502))$	$\pm 2.73\%$	$=47.639*(POWER(604,-0.495))$	$\pm 2.00\%$
	Non-NDMBS IAREs	$=67.888*(POWER(1136,-0.502))$	$\pm 1.99\%$	$=47.639*(POWER(1136,-0.495))$	$\pm 1.46\%$
Tas	NDMBS IAREs	$=67.888*(POWER(226,-0.502))$	$\pm 4.47\%$	$=47.639*(POWER(226,-0.495))$	$\pm 3.26\%$
	Non-NDMBS IAREs	$=67.888*(POWER(84,-0.502))$	$\pm 7.34\%$	$=47.639*(POWER(84,-0.495))$	$\pm 5.31\%$
NT	NDMBS IAREs	$=67.888*(POWER(510,-0.502))$	$\pm 2.97\%$	$=47.639*(POWER(504,-0.495))$	$\pm 2.19\%$
	Non-NDMBS IAREs	$=67.888*(POWER(921,-0.502))$	$\pm 2.21\%$	$=47.639*(POWER(921,-0.495))$	$\pm 1.62\%$
ACT	NDMBS IAREs	$=67.888*(POWER(129,-0.502))$	$\pm 5.92\%$	$=47.639*(POWER(101,-0.495))$	$\pm 4.85\%$

Table C Characteristics of Aboriginal and Torres Strait Islander children with AEDC data, 2009, by NDMBS service areas, Australia.

Group	Area received NDMBS (n=5 674)	Area did not receive NDMBS (n=6 785)	All Aboriginal & Torres Strait Islander children (n=12 459)
Mean age (years)	5.5	5.5	5.5
Female	2 889 (51%)	3 369 (50%)	6 258 (50%)
Language background other than English	1 405 (24%)	1 966 (29%)	3 371 (27%)
English as a second language	1 132 (20%)	1 658 (24%)	2 790 (22%)
Lived in SEIFA quintile (1 = most disadvantaged; 5 = least disadvantaged)	1 2 685 (48%)	1 3 106 (46%)	1 5 791 (47%)
	2 1 168 (21%)	2 1 526 (23%)	2 2 694 (22%)
	3 824 (15%)	3 1 034 (15%)	3 1 858 (15%)
	4 600 (11%)	4 722 (11%)	4 1 322 (11%)
	5 364 (7%)	5 335 (5%)	5 699 (6%)
Remote or very remote location	1 345 (24%)	2 058 (30%)	3 403 (27%)
Indigenous teacher	763 (14%)	951 (14%)	1 714 (14%)
Non-Indigenous teacher who was assisted by an Indigenous consultant	1 440 (29%)	2 151 (37%)	3 591 (33%)
Attended a preschool program	3 266 (69%)	4 196 (72%)	7 462 (71%)

Table D Change in percentage of Aboriginal and Torres Strait Islander children in each developmental domain for the exposure and comparison groups, Australia, 2009-2015.

		Physical health & wellbeing			Social competence			Emotional maturity			Language & cognitive skills			Communication & general knowledge		
		On-track	At risk	Vuln	On-track	At risk	Vuln	On-track	At risk	Vuln	On-track	At risk	Vuln	On-track	At risk	Vuln
Area received NDMBS	2009	60.0%	17.5%	22.5%	59.0%	21.4%	19.6%	60.1%	23.5%	16.5%	49.0%	23.6%	27.4%	56.2%	30.1%	21.0%
	2015	62.9%	17.1%	20.0%	60.4%	19.7%	19.9%	64.2%	19.7%	16.1%	65.1%	16.0%	18.9%	60.2%	21.0%	18.8%
	Absolute change (percentage points)	2.9%	-0.4%	-2.5%	1.4%	-1.7%	0.3%	4.1%	-3.8%	-0.3%	16.1%	-7.6%	-8.5%	4.0%	-9.1%	-2.1%
	Critical difference (%)	±0.94	±0.98	±0.81	±0.74	±0.91	±0.56	±0.77	±0.93	±0.58	±0.78	±0.94	±0.58	±0.83	±1.00	±0.69
	Critically different change?*	Y	N	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y
Area did not receive NDMBS	2009	60.1%	17.5%	22.4%	56.9%	21.6%	21.5%	58.9%	23.0%	18.1%	45.6%	23.1%	31.3%	53.8%	31.2%	23.2%
	2015	61.8%	16.3%	22.0%	58.1%	21.0%	21.0%	61.0%	21.5%	17.5%	60.9%	17.9%	21.2%	59.0%	21.3%	19.8%
	Absolute change (percentage points)	1.7%	-1.3%	-0.5%	1.2%	-0.7%	-0.5%	2.1%	-1.5%	-0.6%	15.3%	-5.2%	-10.1%	5.2%	-10.0%	-3.4%
	Critical difference (%)	±0.86	±0.90	±0.74	±0.68	±0.84	±0.52	±0.71	±0.86	±0.52	±0.23	±0.27	±0.53	±0.76	±0.92	±0.63
	Critically different change?*	Y	Y	N	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Difference in absolute change (percentage points)		1.2%	0.8%	-2.0%	0.2%	-1.0%	0.8%	2.0%	-2.3%	0.3%	0.8%	-2.4%	1.6%	-1.3%	0.0%	1.3%
NDMBS performed better?		Y		Y	Y		N	Y		N	Y		N	N		N

* The absolute change exceeds the critical difference (yes/no)?

Table E Change in percentage of Aboriginal and Torres Strait Islander children in each vulnerability indicators and the Multiple Strengths Indicator for the exposure and comparison groups, Australia, 2009-2015.

		Vulnerable in 1 or more domains	Vulnerable in 2 or more domains	Multiple Strengths Indicator		
				Highly-developed strengths	Well-developed strengths	Emerging strengths
Area received NDMBS	2009	46.9%	29.0%	30.6%	24.9%	44.5%
	2015	40.8%	25.2%	38.6%	23.5%	37.9%
	Absolute change (percentage points)	-6.1%	-3.8%	8.0%	-1.4%	-6.6%
	Critical difference (%)	±0.90	±0.67	*	*	*
	Critically different change?*	Y	Y	*	*	*
Area did not receive NDMBS	2009	49.7%	31.8%	27.8%	25.0%	47.2%
	2015	43.2%	27.1%	34.8%	23.7%	41.5%
	Absolute change (percentage points)	-6.5%	-4.7%	7.0%	-1.3%	-5.7%
	Critical difference (%)	±0.83	±0.62	*	*	*
	Critically different change?*	Y	Y	*	*	*
Difference in absolute change (percentage points)		0.4%	0.9%	0.9%	-0.1%	-0.9%
NDMBS areas performed better?		N	N	Y		Y

* The absolute change exceeds the critical difference (yes/no)?

Table F Change in percentage of Aboriginal and Torres Strait Islander children in each vulnerability indicator and the Multiple Strengths Indicator for the exposure and comparison groups, NSW, Victoria, Queensland and South Australia, 2009-2015.

Group	NSW				Victoria				Queensland				South Australia				
	Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths	Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths	Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths	Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths	
Area received NDMBS	2009	37.23%	21.52%	38.73%	35.75%	47.50%	29.50%	46.50%	31.00%	50.10%	31.07%	26.30%	48.88%	54.46%	38.61%	23.76%	54.46%
	2015	32.97%	18.92%	46.54%	30.02%	45.39%	26.37%	39.25%	36.18%	42.62%	25.98%	35.14%	40.11%	55.30%	35.11%	24.24%	50.00%
	Absolute change (percentage points)	-4.30%	-2.60%	7.80%	-5.70%	-2.1%	-3.1%	-7.3%	5.2%	-7.5%	-5.1%	8.8%	-8.8%	0.8%	-3.5%	0.5%	-4.5%
	Critical difference (%)	±1.45	±1.08	N/A	N/A	4.75	3.46	N/A	N/A	1.69	1.25	N/A	N/A	6.69	4.85	N/A	N/A
	Critically different change?*	Y	Y	N/A	N/A	N	N	N/A	N/A	Y	Y	N/A	N/A	N	N	N/A	N/A
Area did not receive NDMBS	2009	41.23%	24%	35.50%	35.50%	39.95%	25%	35%	39.95%	51.29%	32%	22.78%	50.55%	48.20%	31%	31.59%	47.40%
	2015	35.84%	22%	42.71%	33.57%	38.47%	24%	36%	41.38%	44.84%	29%	31.83%	44.94%	45.19%	29%	33.48%	42.79%
	Absolute change (percentage points)	-5.40%	-1.60%	7.20%	-1.90%	-1.5%	-1.5%	1.0%	1.4%	-6.5%	-2.9%	9.1%	-5.6%	-3.0%	-2.0%	1.9%	-4.6%
	Critical difference (%)	±1.67	±1.24	N/A	N/A	3.28	2.40	N/A	N/A	1.53	1.14	N/A	N/A	5.85	4.25	N/A	N/A
	Critically different change?*	Y	Y	N/A	N/A	N	N	N/A	N/A	Y	Y	N/A	N/A	N	N	N/A	N/A
Difference in change (percentage points)	1.10%	-1.00%	0.60%	-3.80%	-0.6%	-1.6%	-8.3%	3.8%	-1.0%	-2.2%	-0.2%	-3.2%	3.9%	-1.5%	-1.4%	0.2%	
NDMBS areas performed better?	N	Y	Y	Y	Y	Y	N	N	Y	Y	N	Y	N	Y	N	N	

* The absolute change exceeds the critical difference (yes/no)?

Table G Change in percentage of Aboriginal and Torres Strait Islander children in each vulnerability indicator and the Multiple Strengths Indicator for the exposure and comparison groups, Western Australia, Tasmania, Northern Territory and Australian Capital Territory, 2009-2015.

Group		Western Australia				Tasmania				Northern Territory				Australian Capital Territory [#]			
		Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths	Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths	Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths	Vulnerable in ≥ 1 domains	Vulnerable in ≥ 2 domains	Highly developed strengths	Emerging strengths
Area received NDMBS	2009	53.31%	30.40%	23.64%	49.92%	34.96%	21.15%	44.05%	29.52%	74.71%	53.77%	11.51%	67.46%	36.30%	25.74%	40.59%	33.66%
	2015	52.26%	34.45%	27.42%	49.00%	30.14%	16.51%	49.04%	27.51%	72.83%	55.20%	12.93%	68.13%	41.86%	28.68%	31.78%	37.21%
	Absolute change (percentage points)	-1.1%	4.1%	3.8%	-0.9%	-4.8%	-4.6%	5.0%	-2.0%	-1.9%	1.4%	1.4%	0.7%	5.6%	2.9%	-8.8%	3.6%
	Critical difference (%)	2.73	2.00	N/A	N/A	4.47	3.26	N/A	N/A	2.97	2.19	N/A	N/A	5.92	4.85	N/A	N/A
	Critically different change?*	N	Y	N/A	N/A	Y	Y	N/A	N/A	N	N	N/A	N/A	N	N	N/A	N/A
Area did not receive NDMBS	2009	52.20%	34%	25.13%	49.56%	33.33%	20%	42.86%	33.33%	74.71%	48%	19.93%	59.26%	N/A			
	2015	45.62%	27%	30.61%	43.27%	28.23%	14%	52.42%	22.58%	57.33%	40%	24.44%	53.37%				
	Absolute change (percentage points)	-6.6%	-7.1%	5.5%	-6.3%	-5.1%	-6.5%	9.6%	-10.8%	-17.4%	-8.6%	4.5%	-5.9%				
	Critical difference (%)	1.99	1.46	*	*	7.34	5.31	*	*	2.21	1.62	*	*				
	Critically different change?*	Y	Y			N	Y			Y	Y						
Difference in change (percentage points)		5.5%	11.1%	-1.7%	5.4%	0.3%	1.9%	-4.6%	8.7%	15.5%	10.0%	-3.1%	6.6%				
NDMBS areas performed better?		N	N	N	N	N	N	N	N	N	N	N	N				

* The absolute change exceeds the critical difference (yes/no)?

[#] All of the IAREs in the ACT were serviced by a NDMBS-funded organisation, so no comparison could be made in this jurisdiction.

CHAPTER 6 – TEACHING EXPERIENCE

APPENDIX 6.1 – First-year teaching: Lesson plan and skit script

Lesson Plan

Topic	What We Want You to Know about Confounding
Date and Time	Friday 4 March 2016 1330-1355 (approx.)
Presenters	Darren Westphal Samantha Siripol Amy Burroughs Alex Marmor
Learning Objectives	<i>By the end of the session, participants will be able to:</i> <ul style="list-style-type: none"> • <i>define the relationship between a confounder and an outcome</i> • <i>differentiate a “red herring” from a confounder</i> • <i>apply this understanding to examples</i>
Ways of assessing if objectives have been achieved	Pre-test (informal): asking students what they know before the lesson Post-test: interactive quiz Teaching evaluation: electronic/paper survey
Materials	<p>Skit</p> <ul style="list-style-type: none"> <input type="checkbox"/> narrator’s script <input type="checkbox"/> corpse <input type="checkbox"/> knife <input type="checkbox"/> fake blood <input type="checkbox"/> police badge <input type="checkbox"/> handcuffs <input type="checkbox"/> notebook <p>Lectures</p> <ul style="list-style-type: none"> <input type="checkbox"/> computer and projector for powerpoint <p>Interactive Quiz</p> <ul style="list-style-type: none"> <input type="checkbox"/> headbands with names for exposures and outcomes (eg “Murder victim”, “secretary”, “co-worker”, “birth defects”, “Zika Virus”, “insecticide”) <input type="checkbox"/> large laminated labels for participants to assign: “outcome”, “confounder”, “true relationship”, “spurious relationship”

Outline

Timing (approx.)	Key Points	Instructional Technique	Presenter
1330-1340	<ul style="list-style-type: none"> Participants drawn outside to the garden by a blood-curdling scream Actors act silently while Narrator describes how a secretary was found red-handed at the scene of her husband's murder 	Attention-grabbing skit	All
1340-1343	Why is confounding so...confounding? <ul style="list-style-type: none"> explain the aims of the session present the learning objectives 	Lecture	Sam
1343-1346	What is confounding? <ul style="list-style-type: none"> A quick recap asking participants to recall what they learnt from the morning's lecture on confounding 	Lecture/group discussion	Amy
1346-1350	Zika example <ul style="list-style-type: none"> confounding explained using the "waterpipes" approach 	Lecture	Darren
1350-1355	Assessment of learning objectives <ul style="list-style-type: none"> Characters from skit return with names on their heads Participants are asked to apply the labels to the characters and their relationships If there's time, participants can apply the labels to the other examples presented Allow time for questions Distribute teaching assessment survey (although this may be integrated with other groups at the end of the afternoon) 	Interactive Quiz	All

Skit Script

Location: Area outside Balmain Crescent cottage

Cast:

Narrator (Darren)

David Smith (Craig)

Mary Brown (Amy)

DCI Shoe-leather (Sam)

Peter Green (Paul)

PART 1 (Pre-lecture)

[David Smith is lying dead on the ground, covered in blood]

[Mary Brown is kneeling next to David, also covered in blood, holding a knife, hysterical]

Narrator (Darren):

[Runs into classroom]

Someone's been killed, there's a dead body on the ground!!!

[Wait for class to get out onto the grass to see David's body and Mary kneeling over with the knife, crying]

Narrator (Darren):

You are all looking at the dead body of NCEPH senior academic, David Smith.

Another NCEPH staff member, Mary Brown, is kneeling over him, covered in blood and with a knife in her hand.

[DCI Shoe-leather enters the scene with clipboard in hand, handcuffs Mary and starts to photograph scene]

[Peter Green enters scene just after DCI Shoe-leather arrives and tries to console Mary]

[Mary too hysterical to talk]

[DCI Shoe-leather interviews Peter instead]

[DCI Shoe-leather and Peter mime a conversation]

Narrator (Darren):

DCI Shoe-leather has arrived quickly on the scene to investigate David's murder.

Also arriving at the scene is David's old friend and NCEPH colleague, Peter Green.

Mary is too hysterical to be questioned at the moment so DCI Shoe-leather instead asks Peter some questions.

Peter reveals to DCI Shoe-leather that David has been involved in a scandalous affair with Mary, Peter's secretary. It's his guess that Mary has only just found out that David has a wife and got her revenge.

On the face of it, the evidence against Mary as David's murderer is very convincing. However, there are more secrets to this case which will be revealed in due course...

PART 2 (Post-lecture, as part of interactive quiz)

Narrator (Darren):

There is strong evidence to suggest that Mary is David's murderer.

However, on closer investigation, DCI Shoe-leather made some startling discoveries.

After Mary had calmed down, she told DCI Shoe-leather that she had never met David before. She only came across David's body because Peter had asked her earlier that day to meet her at that time and location. She was caught with the knife in her hand while trying to revive him.

Mary never knew David, let alone had an affair with him.

With her keen investigative skills, DCI Shoe-leather got to the bottom of the mystery: Peter was jealous of David's recent promotion to a position he had been coveting for years.

Out of frustration he murdered David and framed Mary by making up the story of the affair. Peter was present on campus and could not provide an alibi.

The apparently strong case against Mary is greatly reduced when you remove the malicious influence of Peter.

Peter was confounding the relationship between Mary and David.

The confounder, Peter, was actually the murderer, and Mary was a red herring.

APPENDIX 6.2 – First-year teaching: Presentation

Confounding

Amy, Darren, Sam

Outline

- Why is confounding so.. Confounding?
- What is confounding? (quick recap)
- Zika Virus example – “water pipes” model
- Solving the mystery – interactive approach – “your turn”

What this session is... and isn't

It is:

- to share with you our “a-ha!” moment about what a confounder is
- to present different ways to conceptualise what a confounder is

It isn't:

- a repeat of this morning's lecture

Why is confounding so.... confounding?

(Hopefully it's not as much after we've described it though...)

define confound

Definition | Images | Videos

con·found (kən-found', kŏn-)

- v. To cause to become confused or perplexed. See Synonyms at [puzzle](#).
- v. To fail to distinguish; mix up: *confound fiction and fact*.
- v. To make (something bad) worse: *Do not confound the problem by losing your temper.*

More at Wordnik | from The American Heritage® Dictionary of the English Language, 4th Edition

define confound

Definition | Images | Videos

con·found (kən-found', kŏn-)

- v. To cause to become confused or perplexed. See Synonyms at [puzzle](#).
- v. To fail to distinguish; mix up: *confound fiction and fact*.
- v. To make (something bad) worse: *Do not confound the problem by losing your temper.*

More at Wordnik | from The American Heritage® Dictionary of the English Language, 4th Edition

Learning objectives

- To identify that the confounder is the exposure that has a true relationship with the outcome
- To differentiate exposures that are associated with the outcome only due to the effect of a confounder
- To apply this understanding to examples

What do you know about confounding?

What is confounding?

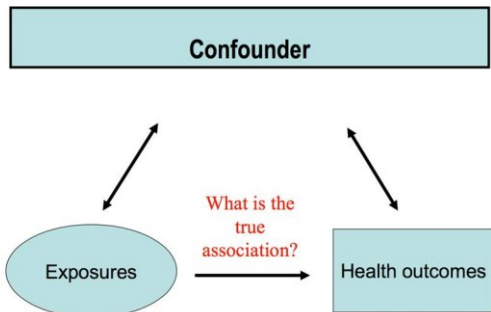
Confounding – some definitions

- Risk factor: Truly influences development of disease (outcome)
- Association:
 - Statistical term
 - Even though a statistical association between an exposure and outcome exists, may not be relevant in 'real life'
 - Ideally the risk factor will be statistically associated with the outcome

Confounding

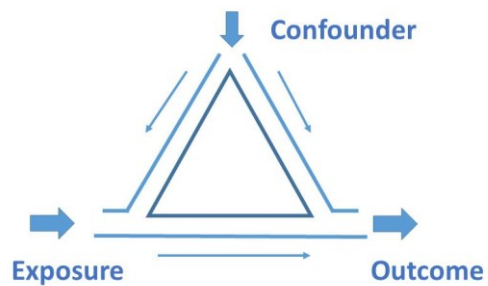
- An effect to consider when searching for the likely risk factor for disease or outcome variable
- Confounding gives the false impression that an exposure is a risk factor for the disease ("guilty by association")
- Give some examples of how confounding creates this false impression...

Explaining confounding: traditional "triangle" model

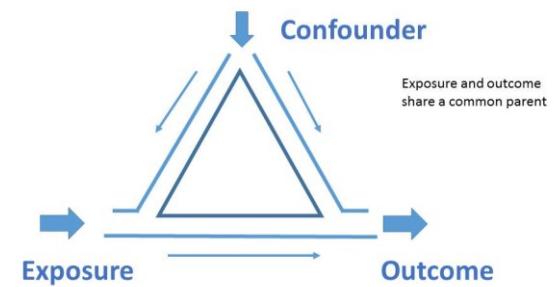


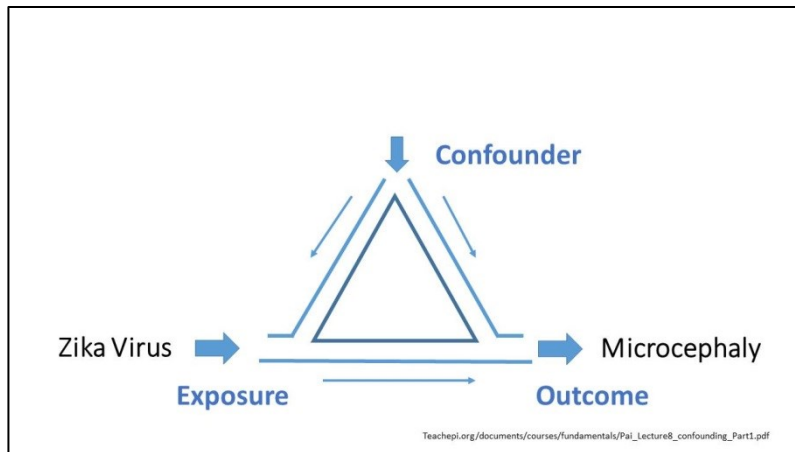
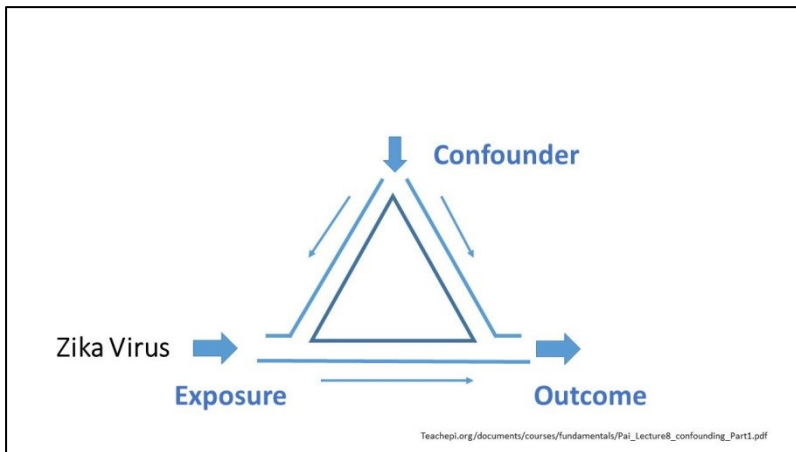
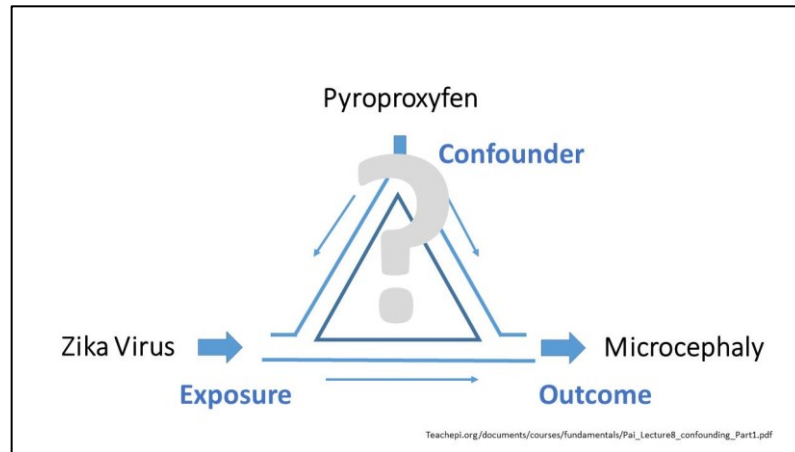
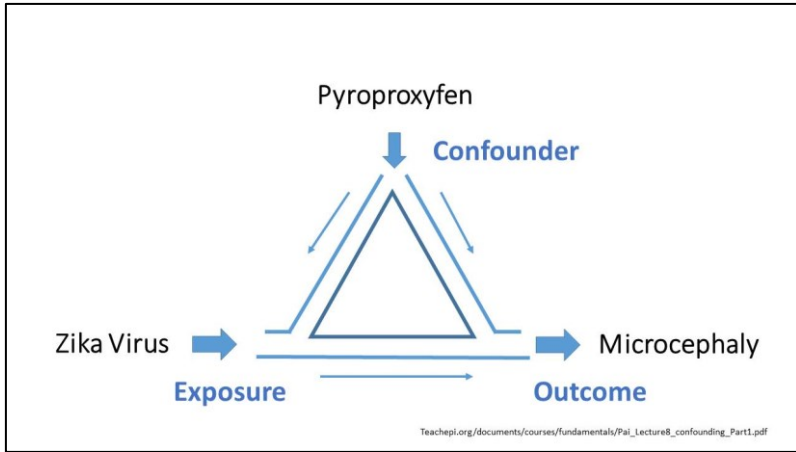
Explaining confounding:
"water pipes" model

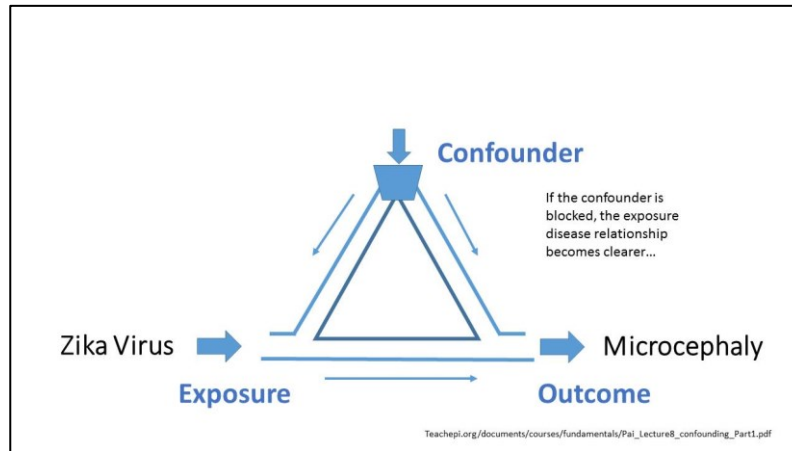
Water pipes model




Water pipes model

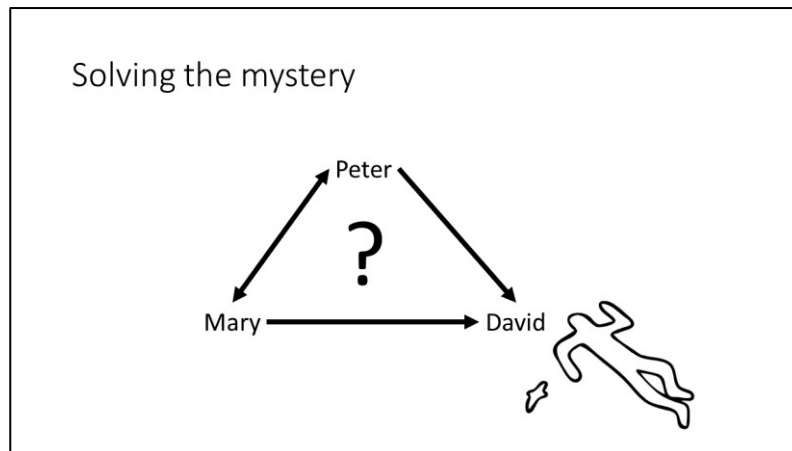






Solving the mystery – your turn!

Confounding:  **guilty by association?**



Solving the mystery

- “There is strong evidence to suggest that Mary is David’s murderer”
- “However, on closer investigation, DCI Shoe-leather made some startling discoveries”
- “After Mary had calmed down, she told DCI Shoe-leather that she had never met David before. She only came across David’s body because Peter had asked her earlier that day to meet her at that time and location. She was caught with the knife in her hand while trying to revive him”
- “Mary never knew David, let alone had an affair with him”
- “With her keen investigative skills, DCI Shoe-leather got to the bottom of the mystery: Peter was jealous of David’s recent promotion to a position he had been coveting for years”
- “Out of frustration he murdered David and framed Mary by making up the story of the affair”
- “Peter was present on campus and could not provide an alibi”

APPENDIX 6.3 – First-year teaching: Student evaluation

First-year scholars were asked to rate the quality of the teaching session on a scale of 0-5, with 5 being excellent. The results are presented here.

Criterion	Scholar	1	2	3	4	5	6	7	8	9	10	11	Cumulative	Average
Content		5	5	5	4	5	4	4	4	4	4	4	48	4.4
Instructor presentation		4	5	5	5	5	5	5	4	5	4	4	51	4.6
Teaching methods		5	5	5	5	5	5	5	4	5	4	4	52	4.7
Learnt something new		5	5	5	4	5	4	4	4	4	5	3	48	4.4
Engagement		5	5	5	-	5	5	5	4	4	4	4	46	4.6
Asking questions		4	5	5	4	5	5	5	4	5	4	5	51	4.6

Additional comments from scholars:

- Enjoyed the balance between interactive and didactic learning
- Thought the session was fun no need to improve
- All sessions very well run - to the point and clear!
- The case study/skit with the murder victim was great! Loved the pipes example as well
- Session was great. Don't be afraid to go out into deeper detail though, I think we would have coped
- No, it was pretty good. Oh, actually we really liked hearing about your projects and more info on these would be super
- Short and sweet
- Explained well, thorough
- Perhaps some more examples, and ones that are a bit trickier to define, in case we come across such things

An Introduction to Principal Component ANALYSIS (PCA) FOR MAE SCHOLARS

Alex Marmor 2016

Please watch the 15 minute video “What is Component or Factor Analysis?” first www.youtube.com/watch?v=k5zpfl-p5cc .

INTRODUCTION

Principal Component Analysis is a method for reducing the complexity of data. It's also called “data reduction” or “dimension reduction”. Its aim is to reduce a larger set of variables into a smaller set of 'artificial' variables, called “principal components”, which account for most of the variance in the original variables.

REASONS TO PERFORM PCA

- **To facilitate description and insight**

When we first open a large dataset with a gazillion variables, it can be a bit daunting. We might want to get a quick idea of how the variables relate to each other. PCA can discover combinations of variables that explain the most variation in the data.

- **Minimising the problem of multiple significance testing**

Often we want to explore the effect of multiple exposures on an outcome. But remember, if we find an association by doing one hypothesis test at significance level of 0.05, there is a one in 20 probability that the association was observed by chance alone. The more hypotheses we test in an analysis, the more likely we are to discover at least one false association (type I error) – and we won't know which one is false. Some statisticians recommend reducing the significance level (say to 0.01 or 0.001, or by dividing 0.05 by the number of tests), but this increases the likelihood of missing a true association (type II error)⁵. PCA can condense variables to a few components, helping to minimise the likelihood of type I error without losing power.

- **Discovering “latent variables” or underlying constructs**

Let's say you have data from a personality test comprising 65 questions. PCA may reveal that these 65 questions represent only five constructs or components of personality (eg extraversion, agreeableness, conscientiousness, neuroticism, and

⁵ See Perneger (1998) *What's wrong with Bonferroni adjustments?* BMJ 316:1236 <http://www.bmj.com/content/316/7139/1236> for an interesting discussion of this.

openness). In this case, a closely related method to PCA called **factor analysis** is often used. These components or factors could then be used to make subscales using only some of the questions. You can also then test for associations between a particular construct and an exposure by using the artificial component variable created by the PCA method.

ASSUMPTIONS

PCA is not an appropriate method for all data. Before applying PCA, you should check that your data meet the following assumptions:

1. For PCA to produce a reliable result you need to have an adequate sample size. Two rules-of-thumb you could use here are: a minimum sample size of 150; or at least 10 times as many observations as you have variables.
2. There needs to be adequate correlation between variables in order to reduce them to a smaller number of components. One rule-of-thumb is that you need pairwise correlations generally greater than 0.3 (or less than -0.3 for negative correlations). You may have a low level of correlation because the variables are truly uncorrelated, or because your sample is too small to detect the correlations in the population. You can test for sampling adequacy in Stata after performing the PCA by using the `-estat kmo-` command (Kaiser-Meyer-Olkin test). An overall result of ≥ 0.5 from this test indicates the dataset is suitable for PCA.
3. There must not be collinearity between variables. That is, you cannot have one variable that is predicted by or derived directly from one or more of the other variables (eg $x = y+4$). Leave these variables out of the PCA.
4. There should be no outliers in your data, as they can disproportionately influence your results.
5. In a standard PCA, all your variables need to be continuous and normally distributed to perform PCA. You should consider transforming skewed variables. However, the method can be adapted to ordinal and binary data, but not to unordered categorical (nominal) variables.

STEPS IN PCA

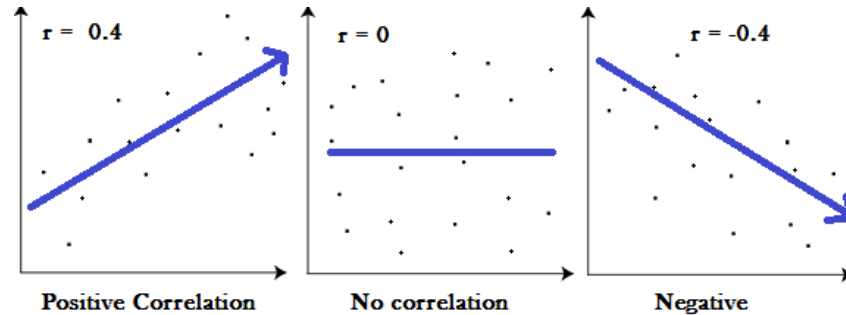
1. SELECT YOUR VARIABLES FOR THE PCA

Choose the variables that you wish to reduce to components. Discard any that are collinear or nominal. If you have the option, choose a continuous variable over an ordinal or binary one (eg choose 'age in years' over 'age group'; 'IQ score' over 'IQ >100 yes/no'). PCA works better with continuous variables.

Often it will make more sense to ensure all your variables measure in the same direction. Say you have a bunch of questions asking about life satisfaction, each on a scale of 0-5. It's easier if 0 = dissatisfaction and 5 = greatest satisfaction for all questions.

2. CAREFULLY CREATE A CORRELATION MATRIX

Create a matrix showing the pairwise correlations between each variable (ie get your stats package to do it!). If all your data are continuous, you are simply creating a matrix of Pearson correlation coefficients (r) for each pair of variables, showing the strength and direction of correlation:



If you have a mixture of data types you will need to construct a matrix of tetrachoric (binary) or polychoric (ordinal) correlations. In these methods, the coefficients are calculated by assuming that the variables were created by categorising a normally-distributed underlying continuous variable.

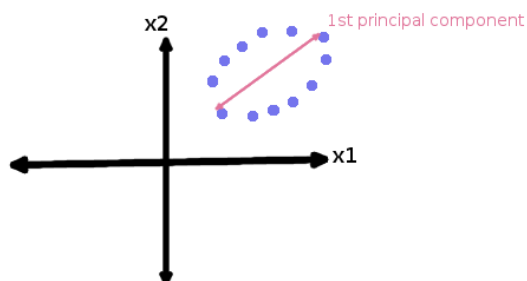
3. CHECK FOR THE LEVEL OF CORRELATION IN THE DATA

Looking at the matrix you have created, is there correlation between the variables? If correlations are small (ie $-0.3 < r < 0.3$), you are unlikely to extract any useful principal components.

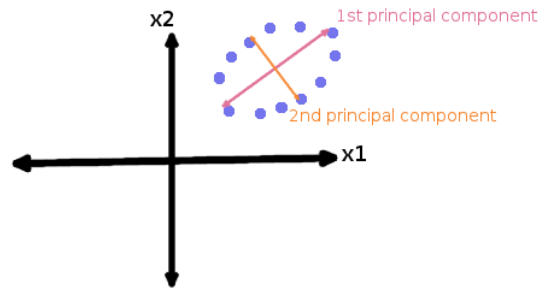
4. CALCULATE THE PRINCIPAL COMPONENTS FROM THE MATRIX

Thankfully packages like Stata will do this for you! The method projects the data into a 3D space, with as many axes as there are variables. Then it draws a line (vector) through the space in a way that captures the most variance in the data. This line is the first principal component.

To look at it simply, imagine we have two variables, x_1 and x_2 , plotted against each other in 2D space. The first principal component is the line that explains highest amount of variance in the data.



The second principal component is always orthogonal (90°) to the first, and explains the variance that is not captured by the first component. This means that the two components are independent of each other.



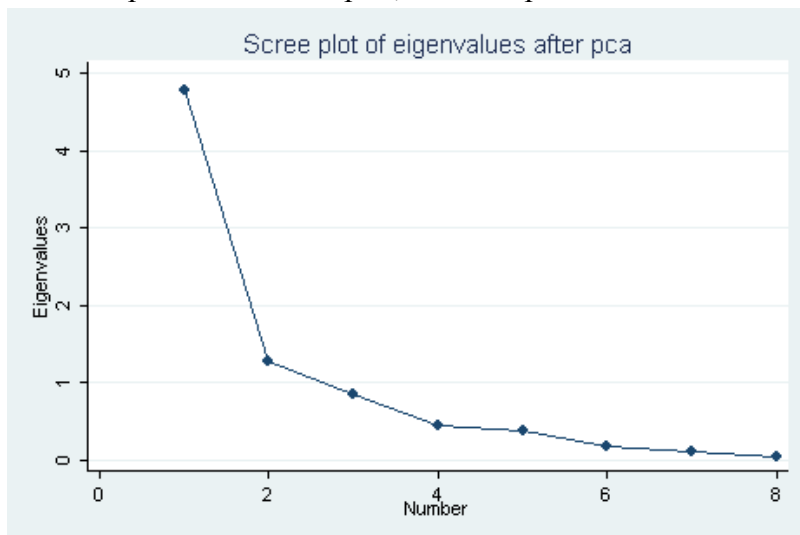
The program continues in this way, identifying orthogonal components that explain the variance in the data.

The line (or direction) for each component is called an **eigenvector**. Each eigenvector has a corresponding **eigenvalue**. This indicates how much variance there is in the data along the eigenvector. A larger eigenvalue means that the principal component explains a large amount of variance. As the eigenvalues for all the components add up to 1, the proportion of variance explained by each component can be calculated by dividing the eigenvalue by the number of components.

5. SELECT PRINCIPAL COMPONENTS

Now we need to look at the output of the PCA and decide which principal components we want to create new variables for.

The simplest way to select components is to use the “eigenvalues greater than one” rule (although there are some problems with this⁶). We can plot the eigenvalues for each component in a screeplot, for example this one for variables to do with cars:



In this example, most of the variance is explained by the first component. The second component has an eigenvalue of more than 1, but not much more. Looking at the corresponding output for these components, we can see that although 100% of the variance is explained by the 8 components, the first two components explain over 75% of it. The other components don't help much and we would probably disregard them.

⁶ Coste, J., et al. (2005), Methodological issues in determining the dimensionality of composite health measures using principal component analysis: Case illustration and suggestions for practice. *Quality of Life Research*, 14(3): p. 641-654.

Principal components/correlation	Number of obs	=	69
	Number of comp.	=	8
	Trace	=	8
Rotation: (unrotated = principal)	Rho	=	1.0000

Component	Eigenvalue	Difference	Proportion	Cumulative
Comp1	4.7823	3.51481	0.5978	0.5978
Comp2	1.2675	.429638	0.1584	0.7562
Comp3	.837857	.398188	0.1047	0.8610
Comp4	.439668	.0670301	0.0550	0.9159
Comp5	.372638	.210794	0.0466	0.9625
Comp6	.161844	.0521133	0.0202	0.9827
Comp7	.109731	.081265	0.0137	0.9964
Comp8	.0284659	.	0.0036	1.0000

6. ROTATE THE COMPONENTS TO GIVE THEM MEANING

Before creating new variables for the components, we need to rotate the components in space. Basically this procedure aims to make clear the patterns of variables that contribute to each component.

There are two main kinds of rotation: varimax and promax. Varimax is the most commonly used and assumes that there is no correlation between the components. Promax allows for correlation between components.

After rotation, we give meaning to the components by checking which variables contribute to, or “load onto”, each component. Continuing our example from above, the variables that load most heavily onto Component 1 are engine weight, length and displacement. So we could say this component is about “engine dimensions”. We might say the idea underlying Component 2 is “expensive foreign & squishy”.

Rotated components

variable	Comp1	Comp2	Comp3	Comp4	Comp5	Comp6
price	0.1324	0.6397	-0.3334	-0.2099	0.4974	-0.2815
mpg	-0.2897	-0.1065	0.0824	0.2568	0.6975	0.5011
rep78	-0.2368	0.2697	0.3960	0.6256	-0.1650	-0.1928
headroom	0.2560	-0.5315	0.8439	-0.3750	0.2560	-0.1184
engweight	0.8435	0.0979	-0.0325	0.1792	-0.0296	0.2657
englength	0.7298	0.0687	0.0864	0.1845	-0.2438	0.4144
displacement	0.6304	0.0851	-0.0445	0.1524	0.1782	0.2907
foreign	-0.2254	0.4820	0.0498	-0.5183	-0.2850	0.5401

7. CREATE NEW VARIABLES FOR YOUR CHOSEN COMPONENTS

Following rotation, we can create new variables that predict scores for each individual in our sample for each of our selected components. These variables are continuous and can be used in later analyses. So in our example, our two new variables will score each of the cars on the “engine dimensions” index and the “expensive foreign & squishy” index.

ANOTHER WAY OF EXPLAINING PCA...⁷

Imagine a big family dinner, where everybody starts asking you about PCA (...fascinating!).

First you explain it to your great-grandmother; then to your grandmother; then to your mother; and finally to your spouse (who is an epidemiologist). Each time the next person is less of a layman. Here is how the conversation might go.

Great-grandmother: *I heard you are studying "Pee-See-Ay". I wonder what that is...*

You: Ah, it's just a method of summarising some data. Look, we have some wine bottles standing here on the table. We can describe each wine by its colour, by how strong it is, by how old it is, and so on. We can compose a whole list of different characteristics of each wine in our cellar. But many of them will measure related properties and so will be redundant. If so, we should be able to summarise each wine with fewer characteristics! This is what PCA does.

Grandmother: *This is interesting! So this PCA thing checks what characteristics are redundant and discards them?*

You: Excellent question, granny! Actually, no, PCA is not selecting some characteristics and discarding the others. Instead, it constructs some *new* characteristics that turn out to summarise our list of wines well. In fact, PCA finds the best possible characteristics, the ones that summarise the list of wines as well as possible. This is why it is so useful.

Mother: *Hmmm, this certainly sounds good, but I am not sure I understand. What do you actually mean when you say that these new PCA characteristics "summarise" the list of wines?*

You: I suppose I can give two different answers to this question. First answer is that you are looking for some wine properties (characteristics) that strongly differ across wines. Indeed, imagine that you come up with a property that is the same for most of the wines. This would not be very useful, would it? Wines are very different, but your new property makes them all look the same! This would certainly be a bad summary. Instead, PCA looks for properties that show as much variation across wines as possible.

The second answer is that you look for the properties that would allow you to predict, or "reconstruct", the original wine characteristics. Again, imagine that you come up with a property that has no relation to the original characteristics; if you use only this

⁷ This has been adapted from explanations posted on an online forum

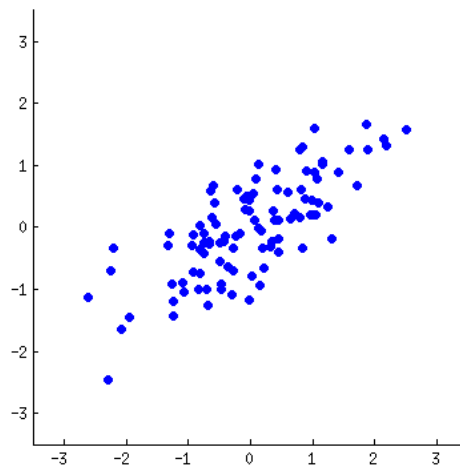
stats.stackexchange.com/questions/2691/making-sense-of-principal-component-analysis-eigenvectors-eigenvalues

new property, there is no way you could reconstruct the original ones! This, again, would be a bad summary. So PCA looks for properties that allow you to reconstruct the original characteristics as well as possible. Surprisingly, it turns out that these two aims are equivalent and so PCA can kill two birds with one stone.

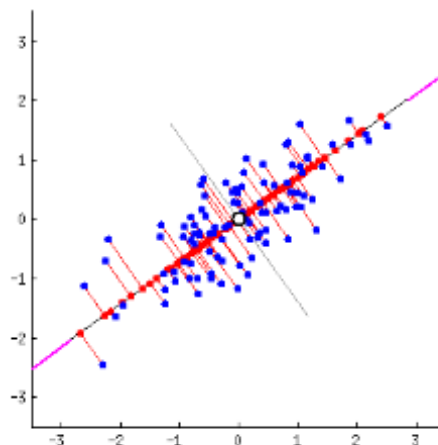
By the way, PCA stands for "principal component analysis" and this new property is called "first principal component". And instead of saying "property" or "characteristic" we usually say "variable".

Spouse: *I'd like to see some graphs, darling... and I heard that PCA is somehow related to eigenvectors and eigenvalues...?*

You: Hmm. Perhaps I *should* make a little drawing (*takes a napkin and starts scribbling*). Let us pick two wine variables, perhaps wine darkness and alcohol content -- I don't know if they are correlated, but let's imagine that they are. Here is how a scatter plot of different wines could look like:



Each dot in this "wine cloud" shows one particular wine. You see that the two variables are correlated. A new variable can be constructed by drawing a line through the centre of this wine cloud and projecting all points onto this line (red dots are projections of the blue dots):



As I said before, PCA will find the "best" line according to two different criteria of what is the "best". First, the variation or spread of values along this line should be maximal. A line in any other direction would have more 'clumping' of the red dots. Second, if we reconstruct the original two variables (position of a blue dot) from the new one (position of a red dot), the reconstruction error will be given by the length of the connecting red line. A PCA "best" line will minimise the total length of the red lines and corresponds to the new wine property.

Eigenvectors are just the linear combinations of the original variables (in the simple or rotated component space); they describe how variables "contribute" to each component axis. Basically, think of PCA as a way to construct new axes that point to the directions of maximal variance (in the original variable space), as expressed by the eigenvalue, and how variables contributions are weighted or linearly transformed in this new space.

EXAMPLES OF STUDIES USING PCA AND FURTHER READING

PDF attached:

Silvera et al (2011). *Principal Component Analysis of dietary and lifestyle patterns in relation to risk of subtypes of esophageal and gastric cancer*. *Annals of Epidemiology*, 21:543–550.

Other examples:

Takano, Nakamura & Watanabe (2002). *Urban residential environments and senior citizens' longevity in megacity areas: the importance of walkable green spaces*. *Journal of Epidemiology & Community Health*, 56:913-918.
<http://jech.bmj.com/content/56/12/913.short>

Karasik et al (2004). *Genome screen for a combined bone phenotype using principal component analysis: the Framingham study*. *Bone*, 34 (3):547–556.
<http://www.sciencedirect.com/science/article/pii/S8756328203004265>

This paper has a nice tutorial on using PCA:

Vyas & Kumaranayake (2006) *Constructing socio-economic status indices: how to use principal components analysis*. *Health Policy & Planning*, 21 (6):459-468.
<http://heapol.oxfordjournals.org/content/21/6/459.full>

A discussion of PCA for genome-wide expression studies

Ringnér (2008). *What is principal component analysis?* *Nature Biotechnology* 26 (3): 303-304.
http://www.montefiore.ulg.ac.be/~kbessonov/present_data/GBIO0002-1_GenAndBioinf2015-16/lectures/L6/Suppl2_Ringner2008.pdf

APPENDIX 6.5 – Lesson from the field: Exercise and model answers

LESSON FROM THE FIELD

Alex Marmor 2016

Principal Component Analysis

LEARNING OBJECTIVES

After completing this LFF you should be able to:

- describe simply how Principal Component Analysis (PCA) works
- perform PCA using Stata
- interpret the output of the analysis
- identify when PCA may be useful, and when it is no good at all.

TO COMPLETE THIS LFF YOU WILL REQUIRE

- *An Introduction to Principal Component Analysis for MAE Scholars*
 - Stata v13 or higher
 - the dataset *sewb.dta*
-

INTRODUCTION

1. *Watch the 15 minute video of Ray Cooksey explaining What is component or factor analysis*
<https://www.youtube.com/watch?v=k5zpfl-p5cc>
2. *Read the document “An Introduction to Principal Component Analysis for MAE Scholars” (attached).*
3. *Have a quick look at the example of how PCA can be used in an epidemiological study (Silvero et al, 2011, attached)*
4. *Answer the following six questions.*

Question 1: *Describe PCA in your own words, using three or fewer sentences.*

It can identify patterns and relationships among individual variables. It summarises the most of the variance in the variables. However, it does not suit all type of data, assumptions need to be checked before applying.

Principal component analysis (PCA) uses maths to collapse a heap of correlated variables into a smaller number of uncorrelated variables (principal components).

Combines variables to help explain the most variance in your dataset i.e. to explain the biggest chunk of data

PCA is a way of reducing the number of variables that you have to analyse in a particular data set. This is done by grouping variable with common variance together, allowing you to analyse each groups of variables as one unit.

PCA uncovers the internal structure of the data and presents it in a way that best describes how individuals in the sample differ. It creates new variables (called components) that express the patterns of correlation between variables and the underlying constructs that they measure. These components can be used instead of the variables that contribute to them, thus reducing the dimensions of the data.

SCENARIO – FACTORS ASSOCIATED WITH SOCIAL AND EMOTIONAL WELLBEING IN CHILDREN

You have started a new job as an epidemiologist in a federal government department of health, in a section that administers maternal and child health (MaCH) programs for a disadvantaged population. Your team is trying to decide which types of MaCH services they should fund in order to have the greatest impact on children's social and emotional wellbeing (SEWB).

You have access to a longitudinal dataset from a study of children from this population. A huge amount of health and social data has been collected from the children and their families over the years.

After reviewing the literature and the dataset, you select a variable that adequately reflect a child's SEWB that you can use as an outcome measure. But what to do about the exposure variables?! There are so many and they all seem so interesting!! Again, you review the literature and narrow down the dataset to 17 variables that have a biologically or socially plausible link to SEWB.

You have read about the perils of conducting multiple significance tests. You stumble across Principal Component Analysis (PCA) and decide to use it to try to reduce your many exposure variables to just a few components that you can then test for association with the outcome.

5. Open Stata and use the file sewb.dta

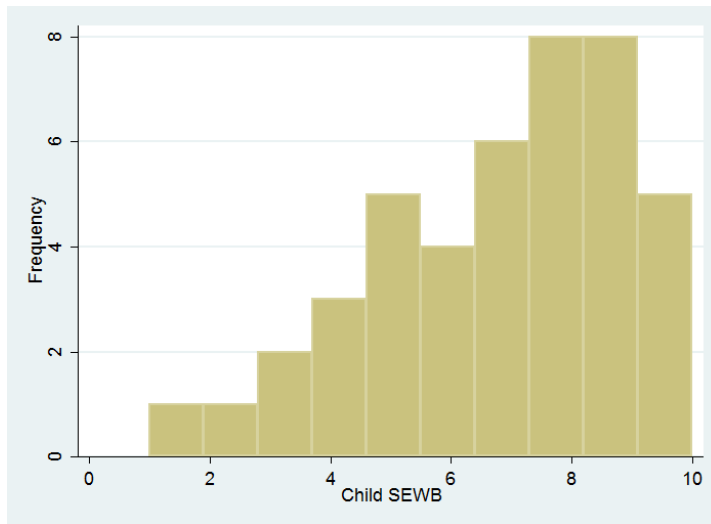
6. Inspect the data

Open the data browser and look at the variable names and the data itself. Note the types of data in the dataset (ie continuous, binary, ordinal etc). Some of the variables have notes that provide metadata.

For example, in the command bar, type

```
notes _dta
codebook, compact

notes sewb_c
summarize sewb_c, detail
hist sewb_c, bin(10) frequency
```

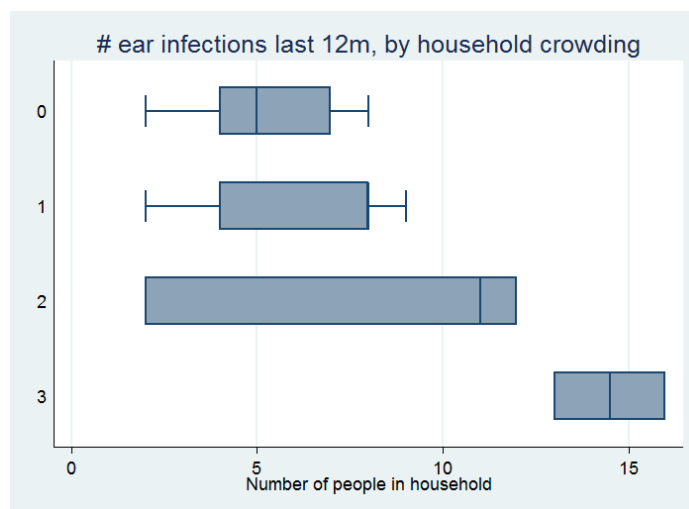


```
tab fin_stress, missing
```

```
notes lowbirthw
```

```
tab smoking lowbirthw
```

```
graph hbox peoplehh, over (ear_inf) ytitle(Number of people in household) title("# ear infections last 12m, by household crowding")
```



7. Construct a correlation matrix of the exposure variables

The first step of PCA is to carefully construct a correlation matrix.

Stata has a command `pca varlist` that will automatically construct a Pearson correlation matrix and identify the principal components, but it only works if all the variables in `varlist` are continuous. As you have a mixture of data types, you need to construct a polychoric matrix and then perform the PCA.

In the command bar, type

```
findit polychoric
```

and download the user-written command `polychoric`

In the command bar, type (*it takes a minute or two to work*)

```

polychoric age_m hhincome smoking alcohol substance
antenatal20w unemploy peoplehh events removed racism lowbirthw
fin_stress childcare ear_inf hosp sewb_m

```

The output is the polychoric correlation matrix of all the exposures you are interested in. You can see the correlation between each of the pairs of variables.

Question 2 – Describe the strength and direction of correlation between low birthweight (lowbirthw) and maternal smoking during pregnancy (smoking).

A strong positive relationship (r=0.8)

8. Perform a PCA on the correlation matrix

To perform the analysis, you need to know how many records (N) were used to create the matrix (“r”), so type in

```
display r(N)
```

Now insert this N into the PCA command:

```
pcamat r(R), n(43) forcepsd
```

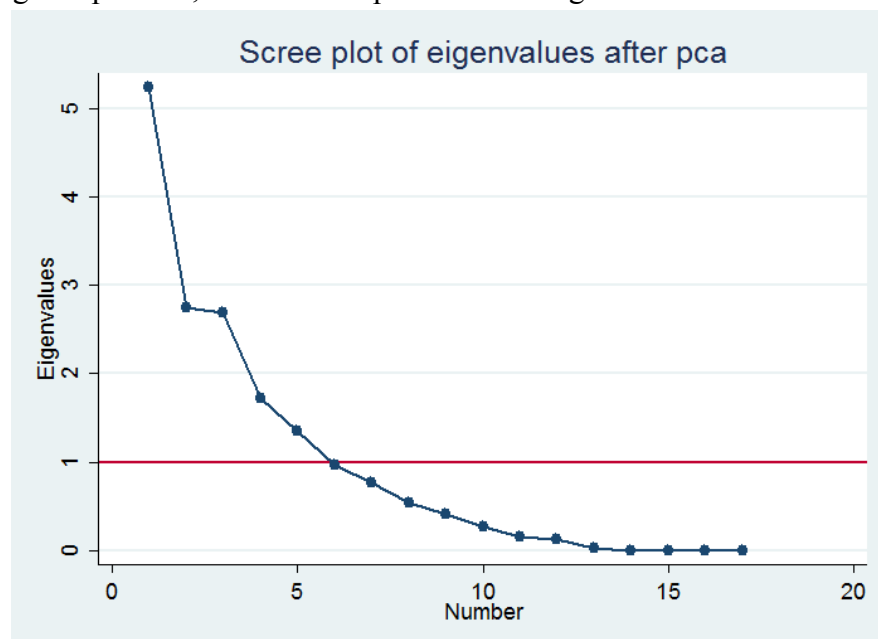
Stata will now perform a PCA on our matrix.

(Note: Here we have used the option [**forcepsd**]. This is a bit complicated, but essentially modifies the matrix by setting negative eigenvalues to 0 and reconstructing it to be positive semidefinite (psd) and so to be a proper covariance matrix. Yikes!!! You do not need to use [**forcepsd**] every time. Try **-pcamat-** without it first. If you get the error "r(R) not positive (semi)definite" then you need to reconstruct the matrix and then use the [**forcepsd**] option)

Now graph a screeplot to visualise which components are contributing the most to the variance:

```
screepLOT, yline(1)
```

This plots the eigenvalues for each component. Following the simplest rule for selecting components, look for components with eigenvalues > 1.



Question 3 – How many components have eigenvalues >1? Looking at the “Principal components/correlation” table in the Stata output, what proportion of the variance in the dataset is explained by these components altogether?

5 components with eigenvalues > 1

Together they explain 81% of the variance in these 17 variables.

(NB we have not yet done any tests for association with the outcome)

You will apply the most commonly used rotation, varimax, which rotates the components orthogonally:

```
rotate, varimax(5) blanks(.2)
```

The option [`blanks (.2)`] suppresses any negligible eigenvectors in the output. It just makes it easier to see which variables load most heavily onto the components. You now need to look at what each of these components actually means. Look at the “Rotated components” table in the output and see which variables load most heavily onto each component.

Question 4 – Describe the construct or idea that underlies each of the top five components:

Component 1	Component 2	Component 3	Component 4	Component 5
<i>Alcohol, smoking and substance use in pregnancy</i>	<i>Household crowding and stress</i>	<i>Hospitalisation and substance use in pregnancy</i>	<i>Experience of racism and intergenerational trauma</i>	<i>Childcare attendance, stable life experiences</i>
<i>(Loadings: alcohol 0.8 smoking 0.4 substance 0.4)</i>	<i>(Loadings: No. people in household 0.8; No. major life events last 12m 0.5)</i>	<i>(Loadings: Hospitalised 0.9 Substance use 0.5)</i>	<i>(Loadings: Family exp of racism 0.9 Family member removed 0.3)</i>	<i>(Loadings: Childcare 0.8 No. major life events -0.3 Family member removed -0.4)</i>

9. Predict scores for each child based on the principal rotated components

Let’s say you decide to use the first five principal components for our later analyses.

You can ask Stata to create new variables based on these components:

```
predict pc1 pc2 pc3 pc4 pc5, score
```

The output shows the loadings of each variable on the component. It is the same as the output from `- rotate, varimax blanks(.2) -`, but without any suppression.

Now open the data viewer. You can see that each observation has a score for the five principal components named pc1 pc2 pc3 pc4 and pc5. These are all continuous variables.

In practice, now would be a good time to rename and label the new component variables and add metadata.

10. Use the Principal Components in a univariate analysis

Now you can see if these components are associated with the outcome, ie
For the effect size:

```
ci2 sewb_c pc1, spearman
```

For the hypothesis test:

```
spearman sewb_c pc1
```

Repeat these tests for the other components.

If you had been able to explain 100% of the dataset variance with these five components, then you could discard the other 17 variables as redundant.

However, there is still nearly 20% of the variance unexplained, and there are eight of your original exposure variables that barely contribute anything to the top five components (ie their scoring coefficients are very small). This just means that these eight variables are not strongly correlated with other variables in the dataset. It does not mean that they are not associated with the outcome. By doing PCA, you have reduced the dimensions of your data from 17 to 13 variables (ie 5 components + 8 uncorrelated variables).

The variables not reflected in the principal components would need to be included in your univariate analysis, ie

```
spearman sewb_c age_m  
spearman sewb_c sewb_m
```

```
ranksum sewb_c, by(lowbirthw)porder  
ranksum sewb_c, by(antenatal20w) porder  
ranksum sewb_c, by(unemploy) porder
```

```
kwallis sewb_c, by(fin_stress)  
kwallis sewb_c, by(hhincome)  
kwallis sewb_c, by(ear_inf)
```

[Please see the do. file for better commands that provide confidence intervals for the effect sizes]

Question 5– Based on your univariate analysis, what recommendations would you make about targeting maternal and child health services for maximum impact on children’s SEWB?

There is a statistically significant difference in SEWB between financial stress categories ($p=0.01$) and household income categories ($p= 0.02$). Our programs could focus on screening and follow-up support for children in lower income, high financial stress households. We could also consider advocating for social welfare reforms that reduce financial stress for families.

There is a reasonably strong positive correlation between Principal Component 1 (alcohol, smoking and substance use in pregnancy) and SEWB ($r=0.46$ $p=0.002$). This means this combination of exposures is protective. Similarly the probability of those with normal birthweight having a higher SEWB is 0.2 ($p= 0.0009$). The converse of this is there is an 80% probability that those with low birthweight will have a higher SEWB score. These are surprising findings that warrant further investigation.

11. Recognising the limitations of the PCA method

You now think you are all over this PCA thing! You decide to apply it to another dataset you are working on. After rotation, you get the following output:

Variable	Comp1	Comp2	Comp3	Comp4	Comp5	Comp6	Comp7	Comp8
q1		1.0000						
q2							1.0000	
q3	1.0000							
q4					1.0000			
q5			1.0000					
q6				1.0000				
q7						1.0000		
q8								1.0000

Question 6– Describe the results of this PCA. Why do you think this has happened?

We have created 8 components, each entirely loaded by only one variable (ie Component 2 contains the same information as “q1”). So we have not reduced the data at all.

The most likely cause of this is a lack of correlation between the eight variables.

There is simply no ‘pattern’ in the sample for PCA to detect. This could be because there is really no pattern in the population of interest, or your sample is too small to detect the correlations. Or, perhaps the variables are nominal (unordered categorical).

This problem could have been anticipated by looking at the correlation matrix: most of the pairwise correlation coefficients would have been very small. PCA was not an appropriate method for this data.

Thanks for your participation!

I hope this helps you to interpret studies that use the PCA method, and perhaps apply it yourself.