Program

International Group for Indigenous health Measurement Meeting (IGIHM) 2013

6-7 August, 2013, Montreal Canada

Day 1: 6 August 2013

Morning session:	**Infant Mortality**
8:30 – 8:45	Introduction of participants
8:45 – 9:45	Presentation by each country:
	Australia: Dr Fadwa Al-Yaman, Australian Institute of Health and Welfare
	Canada: Stacey Bushnik, Statistics Canada
	New Zealand: Dr John Waldon, University of New South Wales
	United States of America: Dr Sam Notzon, National Centre for Health Statistics/Michele Connolly
9:45-10:15	Coffee/Tea
10:15-10:45	Overview presentation on linkage methodology and data uses: Sam Notzon, National Centre for Health Statistics
10:45-12:00	Facilitated discussion and recommendations: Discussant – Assc Prof Janet Smylie, University of Toronto
12:00-12:30	Summary and conclusions – Assc Prof Janet Smylie, University of Toronto
12:30-1:30	Lunch

Afternoon session: Life Expectancy/Child Mortality – identification, linkage, and data uses

1:30 – 3:00	Country presentations on identification, linkage, and data uses:

Australia: Prof Ngiare Brown, National Aboriginal Community Controlled Health Organisation; Prof Richard Madden, University of Sydney; Mr Bjorn Jarvis, Australian Bureau of Statistics; Assc Prof Len Smith

Canada: Dr Mike Tjepkema, Statistics Canada

New Zealand: Kim Dunstan, Statistics New Zealand

United States of America: Sujata Joshi/Jenine Dankovchik, Improving Data & Enchancing Access, Northwest Portland Area Indian Health Board

3:00 – 3:30	Coffee/Tea
3:30 – 4:15	Presentation on ASA linkage and related material for use at the workshop: Dr Fritz Scheuren, NORC
4:15 – 5:00	Facilitated discussion and recommendations regarding identifiers: Discussant – Dr John Waldon, University of New South Wales /Prof Lisa Jackson-Pulver, University of Sydney

Evening session: Workshop Reception

6:30 – 10.00pm	Discussion, (over dinner and drinks) of topics for 2014 meeting

Day 2: 7 August 2013

Morning session: Life Expectancy/Child Mortality – identification, linkage, and data uses (cont from Day 1)

9:00 – 10:00	Summarize country presentations and first day's discussion – Prof Ian Ring, University of Wollongong
10:00-10:30	Coffee/Tea
10:30-12:00	Facilitated discussion and recommendations: Discussant – Prof Ian Ring, University of Wollongong
12:00-12:30	Summary and conclusions – Prof Ian Ring, University of Wollongong
12:30-1:30	Lunch

Afternoon session: Broader Indigenous Issues

1:30 – 2:00	Dr. Malcolm King, Canadian Institutes of Health Research - Institute of Aboriginal Peoples' Health and others to outline issues
2:00 – 3:00	Using estimates/indicators to improve health and health services:
	Country Presentations:
	Australia: Prof Ngiare Brown, National Aboriginal Community Controlled Health Organisation
	Canada: Kathy Langlois, Health Canada
	New Zealand: Dr John Waldon, University of New South Wales
	United States of America: Michele Connolly
	Sweden: Per Axelsson; Centre for Sami Research, Umeå University
3:00 – 3:30	Coffee/Tea
3:30 – 4:30	Topics to consider for 2014 meeting
4:30 – 5:00	Summary and conclusions

STAGING

AIHW Authoritative information and statistics
to promote better health and wellbeing

shopping cart 🛒 | change text size

| Home | About ▼ | | Subjects ▼ | Publications ▼ | Data ▼ | Committees ▼ | Education ▼ | Jobs ▼ |

Media ▼ Help ▼

You are here: home ❯ subjects ❯ indigenous australians ❯ international group for indigenous health measurement (igihm) ❯

print | share

Presentations - IGIHM 2013

Presentations from the International Group for Indigneous Health
Measurement meeting held in Montreal, Canada, 6-7 August 2013.

Day 1: 6 August 2013

Morning session: Infant Mortality

Presentation by each country:

- **Australia:** Dr Fadwa Al-Yaman, Australian Institute of Health and Welfare -
  Dr Fadwa Al-Yaman presentation (826KB PDF)
- **Canada:** Stacey Bushnik, Statistics Canada
- **New Zealand:** Dr John Waldon, University of New South Wales
- **United States of America**: Dr Sam Notzon, National Centre for Health
  Statistics/Michele Connolly

**Afternoon session: Life Expectancy/Child Mortality - identification,
linkage, and data uses**

Country presentations on identification, linkage, and data uses:

- **Australia**: Prof Ngiare Brown, National Aboriginal Community Controlled
  Health Organisation; Prof Richard Madden, University of Sydney; Mr Bjorn
  Jarvis, Australian Bureau of Statistics; Assc Prof Len Smith
- **Canada:** Dr Mike Tjepkema, Statistics Canada
- **New Zealand:** Kim Dunstan, Statistics New Zealand
- **United States of America**: Sujata Joshi/Jenine Dankovchik, Improving
  Data & Enchancing Access, Northwest Portland Area Indian Health Board

Presentation on ASA linkage and related material for use at the workshop: Dr
Fritz Scheuren, NORC

Day 2: 7 August 2013

**Morning session: Life Expectancy/Child Mortality - identification,
linkage, and data uses (cont from Day 1)**

Summary and conclusions - Prof Ian Ring, University of Wollongong

Afternoon session: Broader Indigenous Issues

In this section

International Group for Indigenous
Health Measurement (IGIHM) ⬟

Presentations - IGIHM 2013 ⬟

Related publications and AIHW
websites

Speakers - IGIHM 2012

Presentations - IGIHM 2012

Speakers - IGIHM 2006

Presentations - IGIHM 2006

Country presentations - **Using estimates/indicators to improve health and health services**:

- **Australia**: Prof Ngiare Brown, National Aboriginal Community Controlled Health Organisation
- **Canada**: Kathy Langlois, Health Canada
- **New Zealand:** Dr John Waldon, University of New South Wales
- **United States of America:** Michele Connolly
- **Sweden:** Per Axelsson; Centre for Sami Research, Umeå University

Summary and conclusions

Authoritative information and statistics
to promote better health and wellbeing

Infant Mortality Rate

Dr Fadwa Al- Yaman

International Group for Indigenous Health Measurements

6 August 2013-Montreal Canada

Infant mortality rates

Infant mortality rates are worse for Aboriginal and Torres Strait Islander people than they are for non-Indigenous Australians.

Several potential risk factors have been found for this disparity:

- *Poorer health of Indigenous women of childbearing age*

- *Poorer socioeconomic status*

- *Higher rates of smoking during pregnancy*

- *Poorer nutrition*

- *Lack of access to culturally appropriate maternal and child health services*

- *Younger maternal ages*

- *Higher parities*

- *Higher rates of obesity*

Child and infant deaths (2006-2010)
most child mortality (83%) is infant mortality
most infant mortality happens during the neonatal period (63%)

Fetal Deaths (>20wks/400g to birth) - 472

Neontal Deaths (Birth to 27 days) - 338

Perinatal Deaths (>20wks/400g to 27 days) - 810

Infant Deaths (Birth - <1 yr) - 533

Child Deaths (Birth - 4 yrs) - 645

Infant mortality rate is variable by jurisdiction and published for only 5 jurisdictions

State	Number	Rate	Number	Rate	Rate Ratio	Rate difference
NSW	129	6.5	1835	4.2	1.5	2.3
Qld	182	8.0	1340	4.7	1.7	3.2
WA	94	8.3	416	3.0	2.8	5.3
SA	26	6.0	321	3.4	1.8	2.6
NT	102	13.1	43	3.8	3.4	9.3
Sub-total	**533**	**8.1**	**3955**	**4.1**	**2.0**	**4.0**

Source: http://www.aihw.gov.au/publication-detail/?id=60129543988

Infant mortality rates are declining

	Deaths per 1,000 live births			% contribution to fall in infant mortality rate
Causes of infant mortality	2001-05	2006-10	Reduction in rate	
Certain conditions originating in the perinatal period	4.9	4.1	0.8	25.0%
Signs, symptoms & ill-defined conditions	2.6	1.2	1.4	45.1%
SUDI (R95, R96, R98, R99)	2.6	1.2	1.4	44.4%
Diseases of the respiratory system	0.7	0.3	0.4	13.1%
Congenital malformations	1.5	1.3	0.2	7.1%
Injury & poisoning	0.5	0.4	0.2	5.8%
Infectious and parasitic diseases	0.4	0.2	0.1	4.6%
Diseases of the circulatory system	0.1	0.2	-0.1	-3.4%
Other conditions[m]	0.5	0.4	0.1	2.7%
Total decline in Indigenous rate 2001-2005 to 2006-2010	**11.3**	**8.1**	**3.2**	**100%**

Why do we need a linkage study to estimate IMR?

- To estimate IMR accurately, need **accurate estimates of the total numbers of births and deaths**

- Different sources of birth and deaths data **give different numbers of births and deaths**

- Different data sets capture **Indigenous status information on different clients**

- IMR current estimates are **vary by state an territories and by remoteness**

- In some admin data (e.g. hospital)- there is a link between **increasing remoteness and better identification**

  - **Compare admission records with bed-side interviews (gold standard)**

  - **20,099 interviews**

  - **88% agreement between the two records nationally**

  - **Varied by remoteness -77% major cities to 99% in very remote areas**

We don't know if this association hold for births and deaths data

7

Indigenous status by data collection

Data set	Mother	Child/client	Father
Birth registration (births)	**Y**	**N**	**Y**
Perinatal (births)	Y	Yes – from 2012	N
Hospital (births)	N	Y	N
Death registration (deaths)	**N**	**Y**	**N**
Death Cause of death Certificates (deaths)	N	Y	N
Total	**2/5 (40%)**	**3 or 4/5 (60-80%)**	**1/5 (20%)**

Aboriginal and Torres Strait births by data sets, Vic 2006/07

Data Set	Number of births
Aboriginal Hospital Liaison Officer	550 - all three
Perinatal data collection- births to Aboriginal mothers	569- mother
Vic Admitted Episodes dataset- births to Aboriginal mothers	589- child
Total Aboriginal Births	782- mother and father

Prior to 2009 : 13% of births in Vic were births to Aboriginal mothers and Aboriginal fathers , 44.8% were to Aboriginal mothers only and 40.3% to aboriginal fathers only

Source: http://www.vacms.net.au/files/vacms/VACMS%20Report.pdf

Quality of data for IMR data linkage project

Births registration data

- no assessment of quality of births registration

- late registration especially for Indigenous Australians but what is the differential by remoteness

- level of unregistered births- both in urban and remote areas unkown (police data, NAGATSIHID concern)

Quality of data for IMR data linkage project

Mortality data

some national assessment (AIHW and ABS)

under identification by state /territory

no assessment of data quality by remoteness

no adjustments made where the level is estimated

Published data are underestimates

No national reporting – data quality concerns for three jurisdictions

What could affect data quality

- When the Indigenous status was introduced in the data
- Efforts to improve the quality of the data
- Proportion of Indigenous people living in a remote area within jurisdictions- depends on the data set
- The number of Indigenous people in an area both absolute and relative (issues for some jurisdictions)
- Which data sets are used for the linkage and the quality of the underlying data

Completeness (%) of Indigenous identification in hospital data and Indigenous status in hospital data by year of commencement

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Completeness	**80**	78	87	96	91	**64**	**58**	98
Hospitalisation	**1997**	1986	1993	1981	1984	**1997**	**1981**	1976

Aims of IMR data linkage project

- Link birth records in Perinatal Data Collection, the Registry of Births, Deaths and Marriages to produce an accurate account of births to Aboriginal (and non-Aboriginal) parent/s

- Link National Death Index to mortality data

- Create a complete birth-death linked record for each infant

- Review of disparities in maternal characteristics (maternal age and marital status) and birth outcomes (birth weight and gestational age), between Aboriginal and non-Aboriginal births.

Estimate of total births

- **Perinatal data**
  midwives notifications data held by the AIHW National Perinatal Epidemiology and Statistics Unit (NPESU)

- **Birth registrations**
  from state/territory Registries of Births, Deaths and Marriages

Estimate of total deaths

- **Death notification and cause of death data**
  from state/territory Registries of Births, Deaths and Marriages

- **National Death Index**
  Held at AIHW – monthly supply of deaths notification data

Variables that could be used for linkage

National Perinatal Data Collection	State perinatal data collections	Birth registrations	National Death Index	National Mortality Database
Parental demographics • **Mother's date of birth** • Area of residence • Usual Address • Mother: Unit Record No. • Hospital code **Labour and Birth** • Date of admission **Postnatal** • Separation date **Neonatal** • Baby date of birth • Sex • Baby separation date • Baby date of death	**Parental demographics** • **Mother Name*** • Mother's date of birth • Area of residence • Usual address* • Mother: Unit Record No. • Hospital code* **Postnatal** • Separation date* **Neonatal** • Baby unit record number* • Baby date of birth • Sex • Baby date of death	**Parental demographics** • Mother Name • Mother's maiden name* • Mother's date of birth • Usual Address • Father's name • Father's address* • Father's date of birth • Date of marriage **Labour and Birth** • Actual place of birth **Neonatal** • Baby name • Baby date of birth • Sex	Mortality ID unique record identifier (Linkage key composed of components of: • Year of registration • State of registration • Death registration number) **Deceased demographics** • first name • middle name • surname • sex • date of birth • date of death • Year of registration • State of registration • SLA of usual residence	Mortality ID unique record identifier (Linkage key composed of components of: • Year of registration • State of registration • Death registration number) **Deceased demographics** • sex • date of birth • date of death • place of usual residence • cause of death

Linked PBD Project: Linkage Process

- NDI and NMD linked using Mortality ID to attach **names** (NDI) to cause of death data (NMD)

- National Perinatal & Birth registrations linked using DOB, DOD, sex and address components to attach **names** (Births) to Perinatal variables.

- NDI-NMD & Perinatal-Births linked using **name components**, along with DOB, DOD, sex and address components.

  - With names now attached to perinatal & deaths data, it is possible to combined analysis variables from both data sets into a single unit record for each person.

- National Perinatal identifiers (mothers & babies) could be used to link to additional analysis variables in state perinatal data collections that are not currently stored in National Perinatal Data Collection

Benefits of a national linked Perinatal-Births-Deaths data set

- Investigation of the relationship between infant/child deaths and large numbers of antenatal and perinatal factors and maternal factors

- Accurate estimate of IMR at different levels of disaggregation, national, S/T and remoteness and changes over time

- Increase the statistical power of numbers of infant and child deaths

- Useful for evaluating programs and policies which aim to reduce the disparity in infant/child mortality especially at states level

- Allow for comparison with similar linked data from other countries

The AIHW is uniquely placed to bring about this National Linked Data Set

| PHRN node	• Is a node of the Population Health Research Network (PHRN)
Data Integrating Authority	• Australia's first accredited Data Integrating Authority, accredited to link Commonwealth data
Other Perinatal data linkage projects	• Simultaneously pursuing other data linkage projects using perinatal data, notably the **Early Childhood Development Researchable Data Set (ECD RDS)**
Experience	• Experience with linking perinatal, births and/or deaths data to create national linked data sets e.g. the **Enhanced Mortality Database**
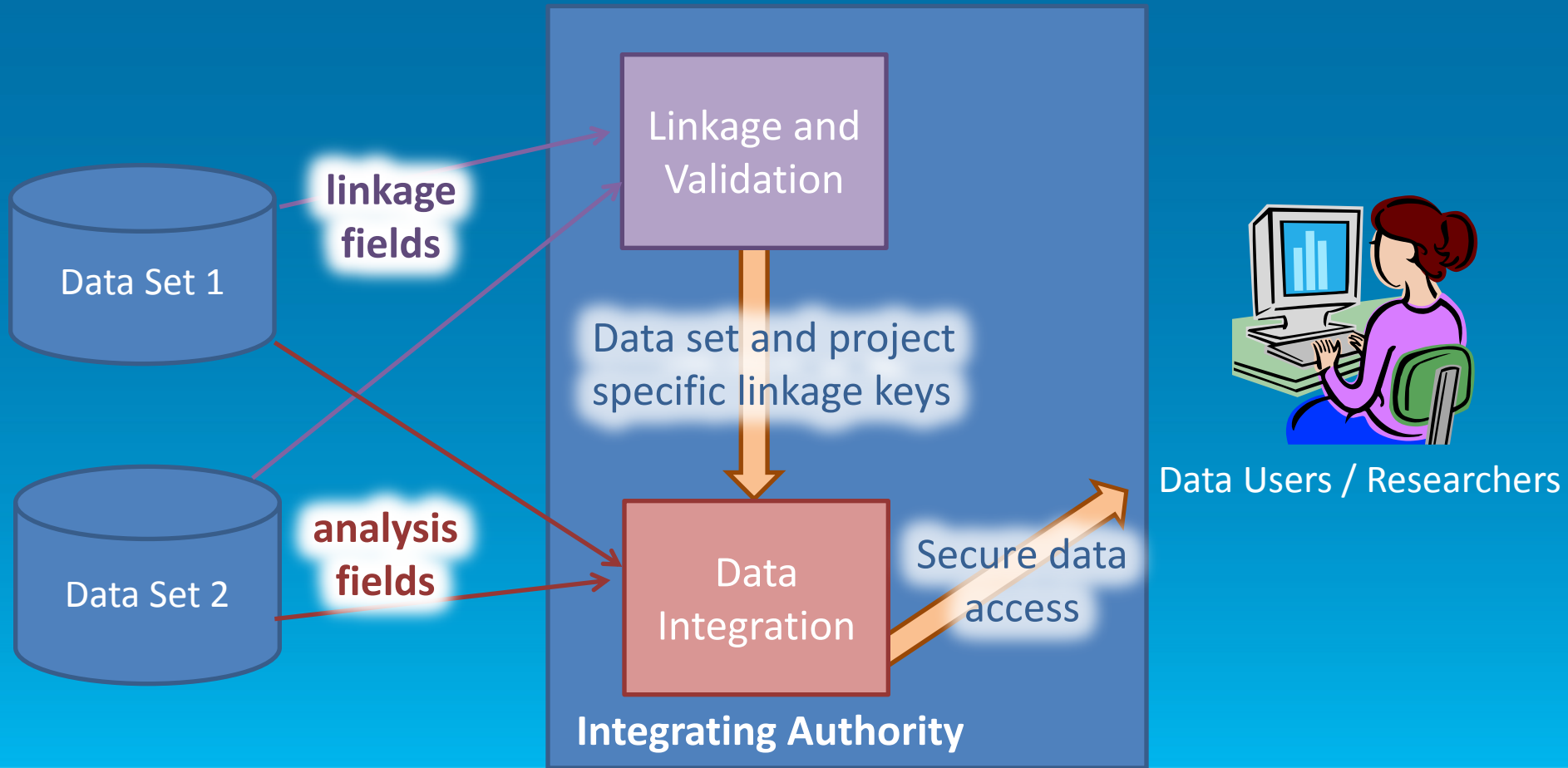
Learning from other AIHW data linkage project
enhance mortality data set

Each data set was progressively linked to each other using multiple pass strategies

| National Death Index and National Mortality Data extracts linked deterministically using unique identifier (Mortality ID) | Aged Care data (included names) linked probabilistically | Hospital data (no names) linked deterministically | Perinatal data (no names) linked last |

Lessons from the Enhanced Mortality Data project-Project processes

Approval takes time	Multiple data custodians	Data use approval can change mid-stream	Approval time and multiple re-application	AIHW Ethics not enough-multiple ethics submissions

Progress to date for the IMR data linkage project and timelines

- Ethics approval by AIHW ethics committee obtained

- Letters being sent to various data custodian for data approval use and access

- Made contacts with Victoria to collaborate with and learn from the Victorian linkage study experience

- Work on this project with our International collaborators within the IGIHM

Relevant AIHW Reports

http://www.aihw.gov.au/international-group-for-health-measurement/

Improving Indigenous identification in health data sets

National best practice guidelines for collecting Indigenous status in health data sets

Evaluation of the national best practice guidelines for collecting Indigenous status in health data sets (report on Stage 1) -Towards better Indigenous health data

Taking the next steps: Identification of Aboriginal and Torres Strait Islander status in general practice

Principles on the use of direct age-standardisation in administrative data collections: for measuring the gap between Indigenous and non-Indigenous Australians

Relevant AIHW Reports

Guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people

National Best Practice Guidelines for Data Linkage Activities Relating to Aboriginal and Torres Strait Islander People

Report on the use of linked data relating to Aboriginal and Torres Strait Islander people

Thematic list of projects using linked data relating to Aboriginal and Torres Strait Islander people

Improving estimates of Indigenous under-identification in key data sets

The Indigenous identification in hospital separations data quality report

An Enhanced Mortality Database for Estimating Indigenous Life Expectancy: a feasibility study

A comparative analysis of indirect methodologies for estimating Indigenous life expectancy

Comparing life expectancy of indigenous people in Australia, New Zealand, Canada and the United States: conceptual, methodological and data issues

Thank You

www.aihw.gov.au