



DISCOVER-TT
Centre of Research Excellence

STREP-CaCIndA
A Strategic Research Partnership

National Indigenous Cervical Screening Project: a data linkage study.

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Overview

- Background on cervical cancer & cervical screening in Australia
- Issues of Indigenous Identification in datasets
- Can data linkage solve issues of Indigenous identification?
- Queensland data linkage process
- Share insights about linkage in other states/territories

National Cervical Screening Program

Recommends: screening with Pap smears every two years for women between the 20-69 years

Pap Test Registers:

- collect screening histories of individual women;
- provide a safety net if women have not had follow-up of an abnormal smear;
- send reminders to women overdue for routine screening; &
- provide Australia-wide data on the epidemiology and natural history of pre-cancerous lesions.

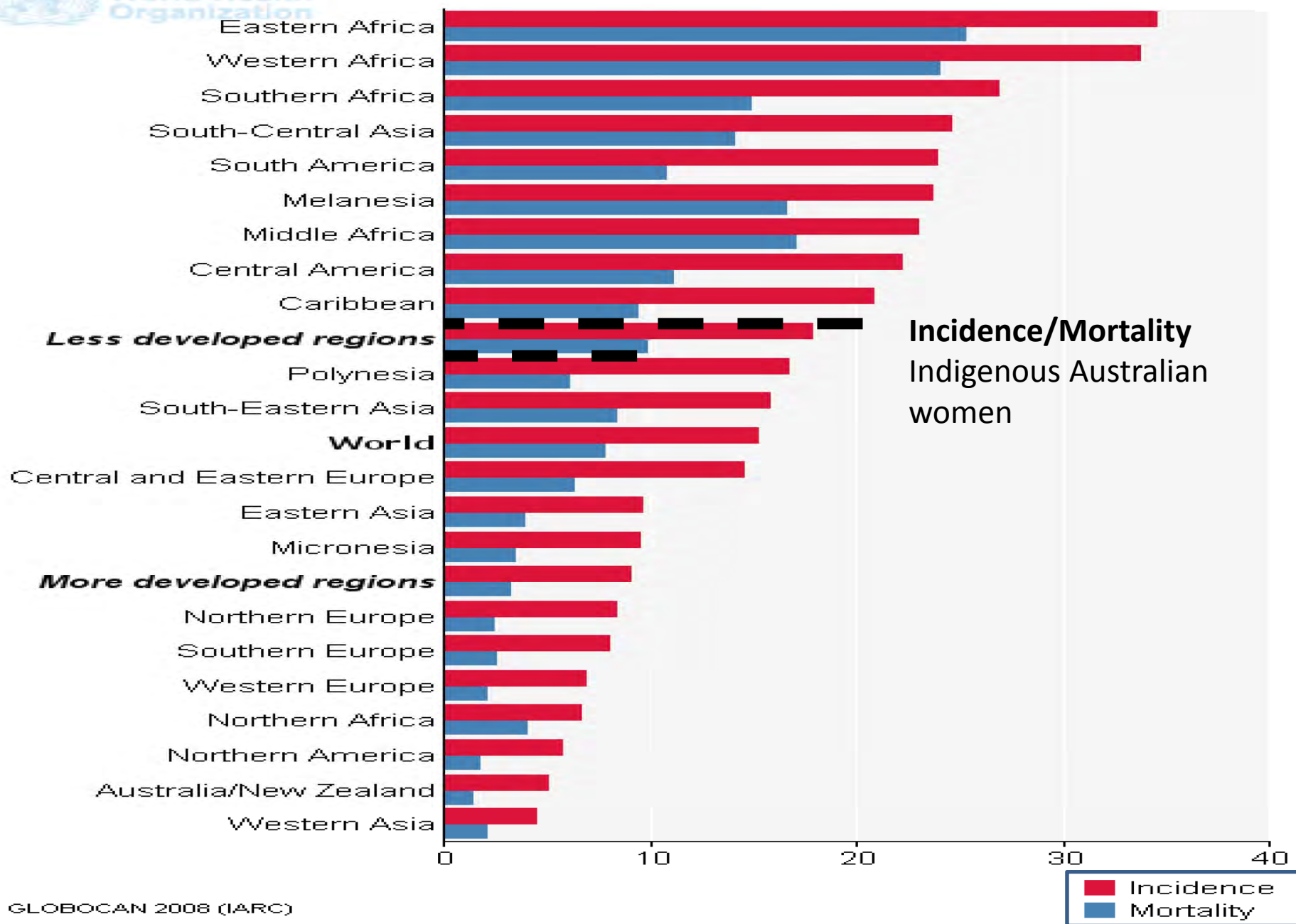
50% reduction in incidence and mortality since introduction of national program

Cervical Cancer Indigenous Australians



- **2.8 times** as likely to **develop** cervical cancer
- **3.9 times** as likely to **die** from cervical cancer
- **3 times** as likely to be **hospitalised** for cervical cancer
- **Lower 5 year survival** following diagnosis of cervical cancer

AIHW & Cancer Australia 2013



Pathology forms inform Pap Test Registers

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graph TD; A[Pathology forms inform Pap Test Registers] --> B[Pathology forms do not record Indigenous status]; B --> C[Most Pap Test Registers do not record the Indigenous status of screened women]; C --> D[No data is available to monitor the overall performance of the National Cervical Screening Program for Indigenous women.];
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Pathology forms do not record Indigenous status

Most Pap Test Registers do not record the Indigenous status of screened women

No data is available to monitor the overall performance of the National Cervical Screening Program for Indigenous women.



Can data linkage solve issues of Indigenous identification?



National Indigenous Cervical Screening Project



Aim

identify Indigenous women within the Queensland Pap Smear Register to **measure** their **screening participation** and **outcomes**.

How?

Linking the Pap Smear Register to a data source which collects Indigenous status with a known high level of accuracy such as the hospital separations data (QLD: 87%, 95% CI 84-91 complete 2011-2012*)

Approval Process



- Ethics:
 - Queensland Health Office of Health and Medical Research (HREC/11/QH/49)
 - Northern Territory Department of Health and Menzies School of Health Research Human Research Ethics Committee (HOMER-2012-1737)
- Data Linkage Branch
- 3 data custodians
- Chief Health Officer
- Director General of QLD Health

Queensland linkage approach



[Diagram removed please contact author]

Linkage Results

[Results removed please contact author]

We can now report on:

- Key Performance indicators of the National Cervical Screening Program:
 - Participation of Indigenous women in cervical screening
 - Prevalence of cervical abnormalities
 - Time to follow-up of high grade abnormalities
- The role of comorbidities in screening and cancer outcomes.
- Survival differences for women with screening history

Queensland summary



- Linkage can overcome the lack of Indigenous status on the Pap Test Registers.
- Sample size far larger than that of a usual research project
- Lengthy approval process (19 months)
- Resource intensive (5 months, 30,000 clerical reviews).
- 6 months for our data manager to build database
- One-off project!

Insights from a National project



- Process of obtaining linked data different in each jurisdiction
- Approval from the Data Linkage Branch within each state/territory (excluding ACT/TAS = 6)
- Data custodian approval for each dataset (~26)
- Ethics approval for the state (often more than one =11)
- Cost of linking the data (range 0 – 64K)
- Linked datasets (outputs of linkage metrics etc.)
- Some states have included Pap Test Reg in routine linkage as a result of this study (eg WA).

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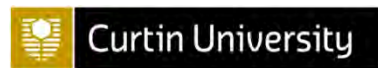
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