



Record Linkage - Public Good or Invasion of Privacy?

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Overview

1. The power of population data and linkage for public good
2. Privacy & Consent issues
3. Future Challenges



1

The Power of Population Data & Record Linkage for Public Good



What is Record Linkage?

- Brings together records from different sources, relating to the same individual
- Used for:
 - administration or case management
eg taxation, criminal investigation
 - population based research and policy
- Focus today: on public good i.e. to improve the outcomes for children & youth



An Example of Record Linkage of Population Data for the Public Good

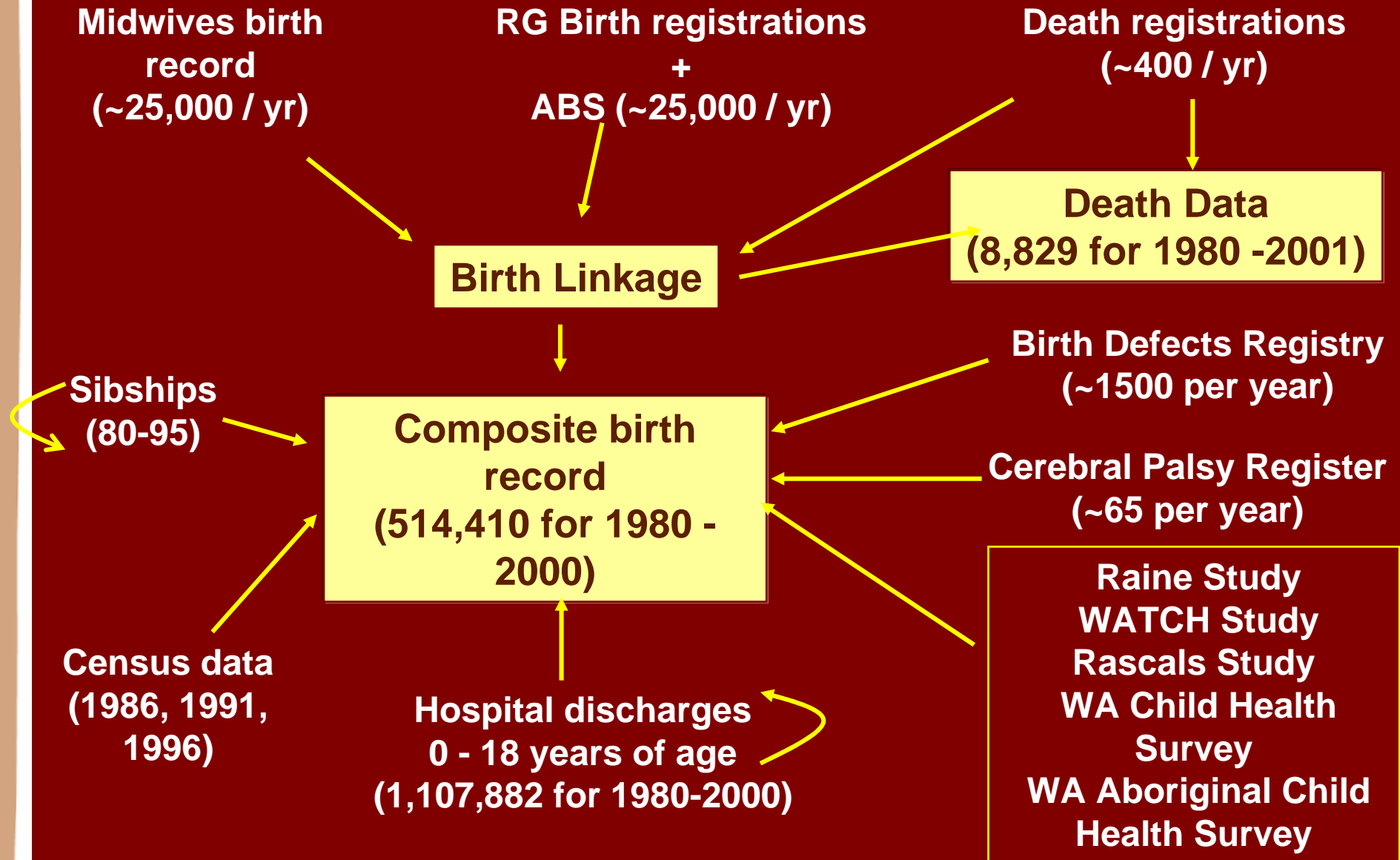
The Western Australian Maternal & Child Health Research Data Base

Data on all birth cohorts from 1980 onwards to:

- Describe total burden of problems in children & youth
- Describe the risk & protective factors for these problems
- Sample unbiased groups for epidemiological studies (cohorts, cases & controls)
- Evaluate the impact of interventions (public health or clinical programs)



Maternal and Child Health Research Database



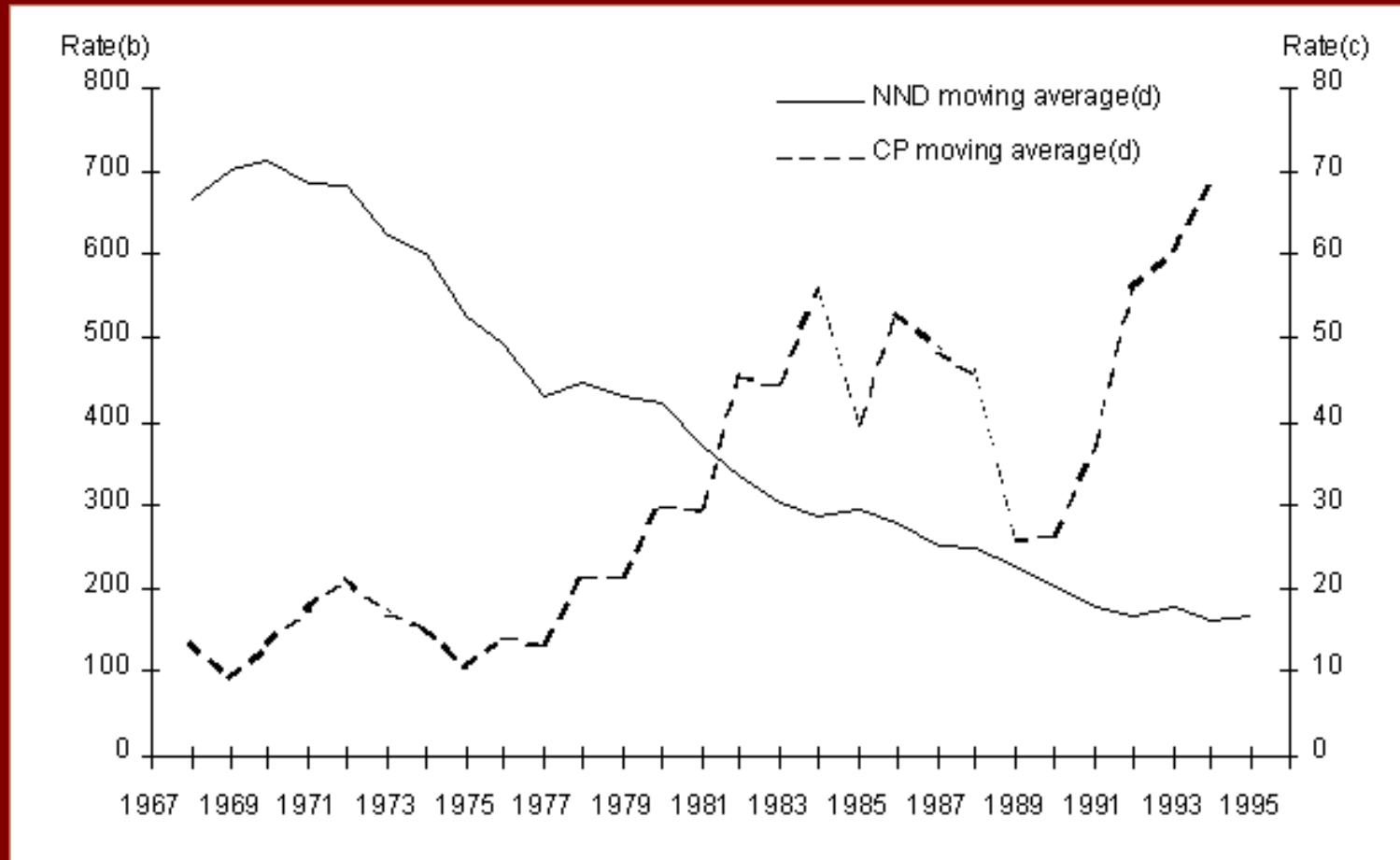


Advantages of Population Record Linkage

1. Complete ascertainment and thus not biased, no one excluded
2. Results apply and are useful for the whole population & complete subsets (eg: rural, Indigenous, teenage mothers).
3. Cheap compared with any studies where contact and consent from participants needs to be sought.
4. Valid & reliable data on issues often difficult to obtain in direct ways (eg psychiatric illness, abortion, drug use etc)



Very low birth weight (a), neonatal death and cerebral palsy rates in Western Australia 1967 to 1996



(a) Birthweight less than 1,500g. (b) Neonatal death rates per 1,000 live births less than 1,500g. © Cerebral palsy rates per 1,000 live births less than 1,500g. (d) 3-year moving averages, note that CP moving average rate for 1994 is derived from 2 years' data only.

Source: Cerebral Palsy Register, Institute for Child Health Research, Perth. Unpublished data



Drug Use & Suicidal Behaviour

Linkage between Suicide data, mental health data & drug blood levels provided new & important information on the risk of Cannabis use.

- Suicide strongly related to cannabis use
- Adolescent suicidal attempts:

Cannabis users	41%
Not users	17%
- Similar results linking road traffic accidents to drug exposure data



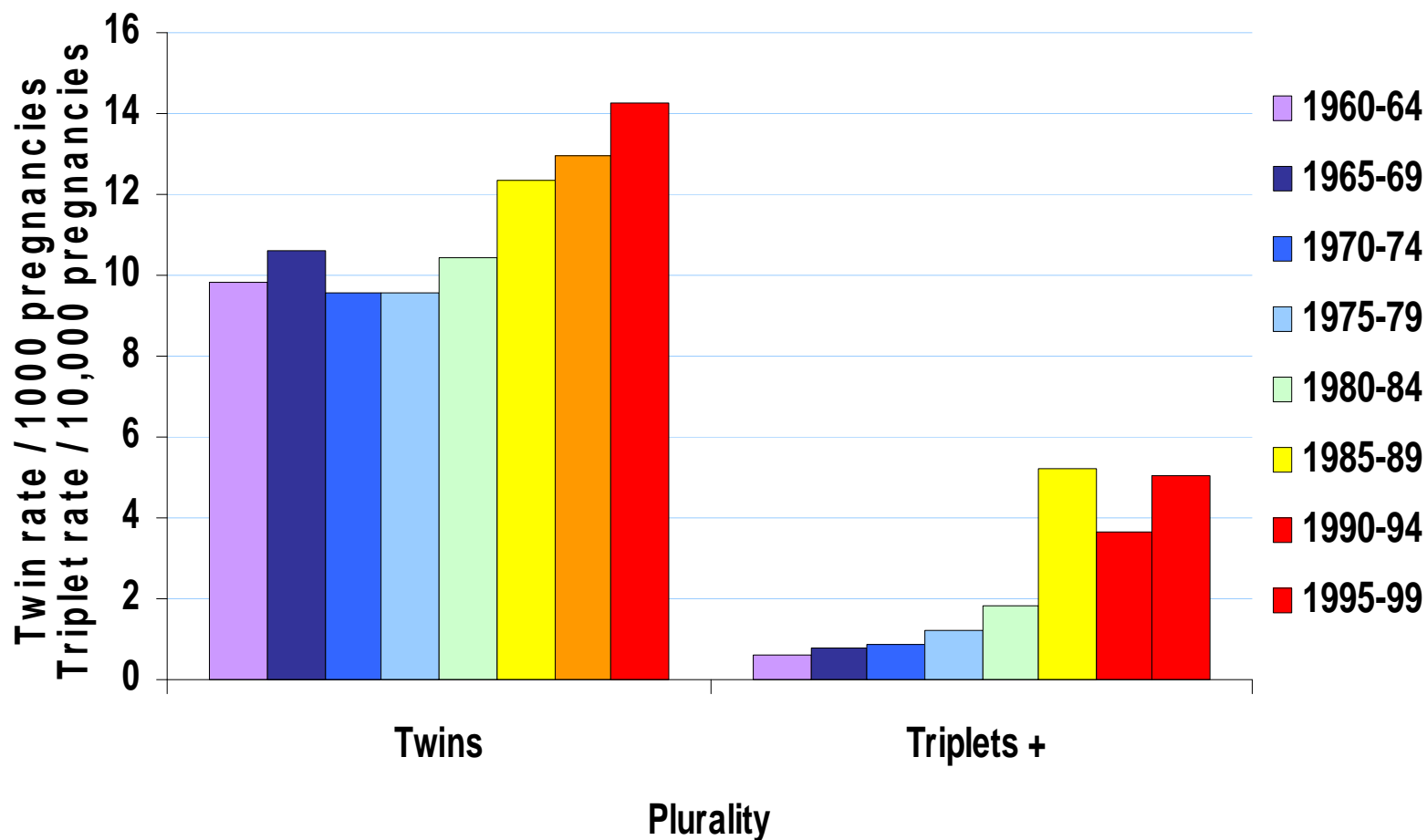
Relation between centile birth weight, single parenthood and mental health outcomes in teenagers (WA Child health Survey linked to the MCHRDB)

Characteristic	Adjusted odds ratio	95% Confidence interval
Percentage expected		
Birth weight		
< 2%	2.90	(1.2 – 7.1)
2 - < 6%	1.75	(0.9 – 3.6)
6 - <10%	1.35	(0.6 – 2.9)
10 - <90%	1.23	(0.8 – 1.9)
> 90%	1	
Marital status at delivery		
Married	1	
Single	2.32	(1.6 – 3.4)



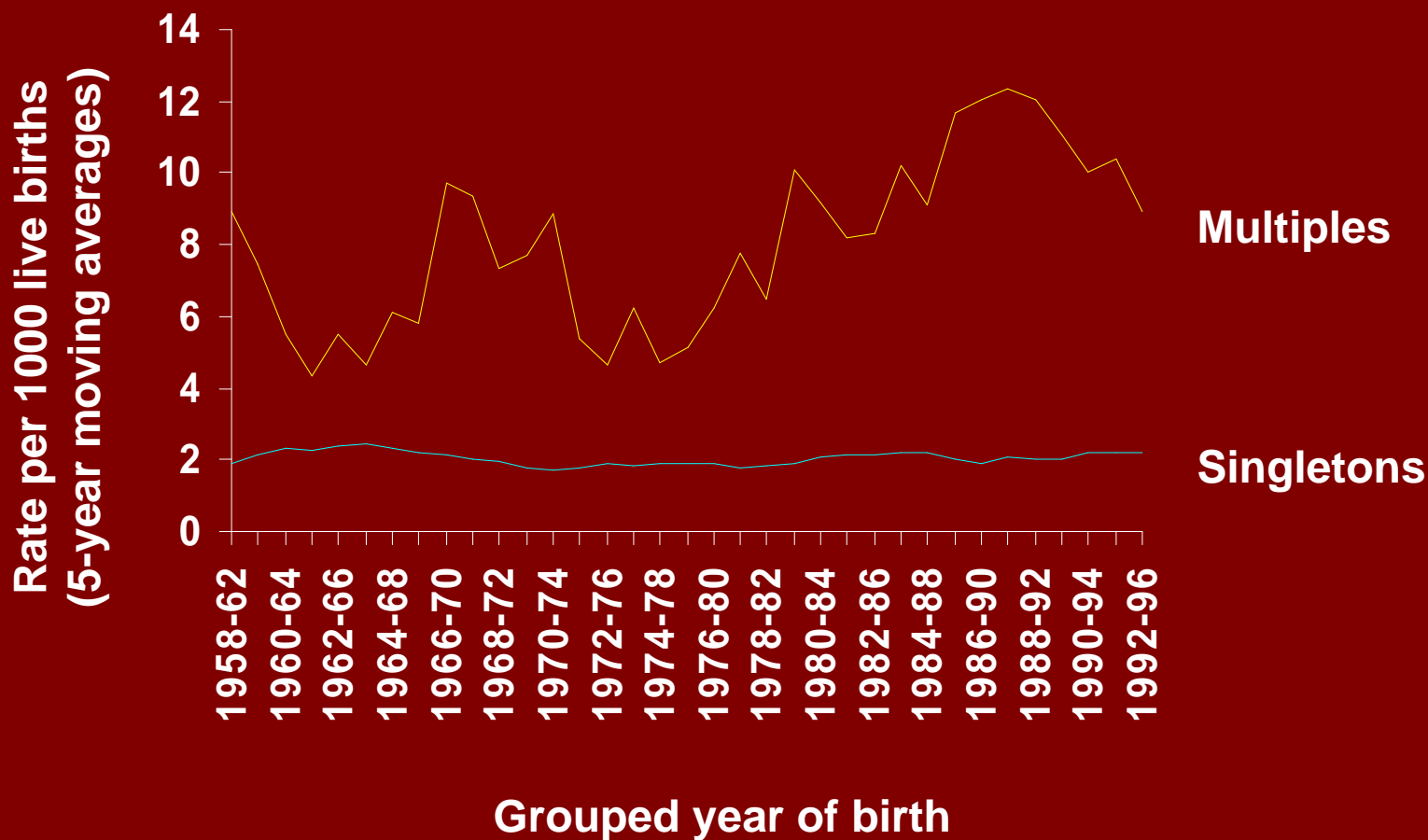
Twin and Triplet Rates, Western Australia 1960-1999

Twin and triplet rates, Western Australia 1960-1999





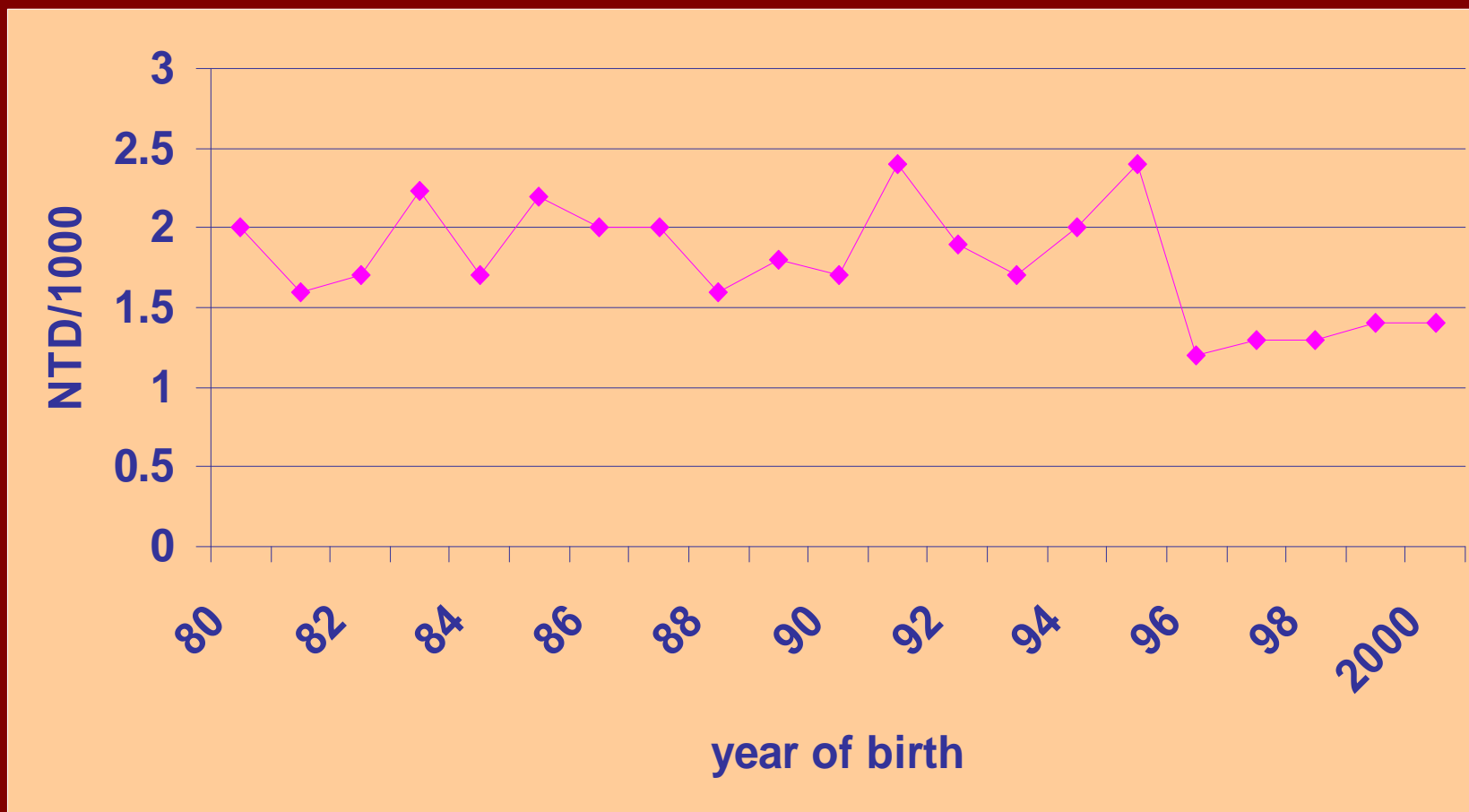
Cerebral palsy¹ rates in singleton and multiple births, Western Australia, 1960-1996



1 Excludes cerebral palsy due to postneonatal causes

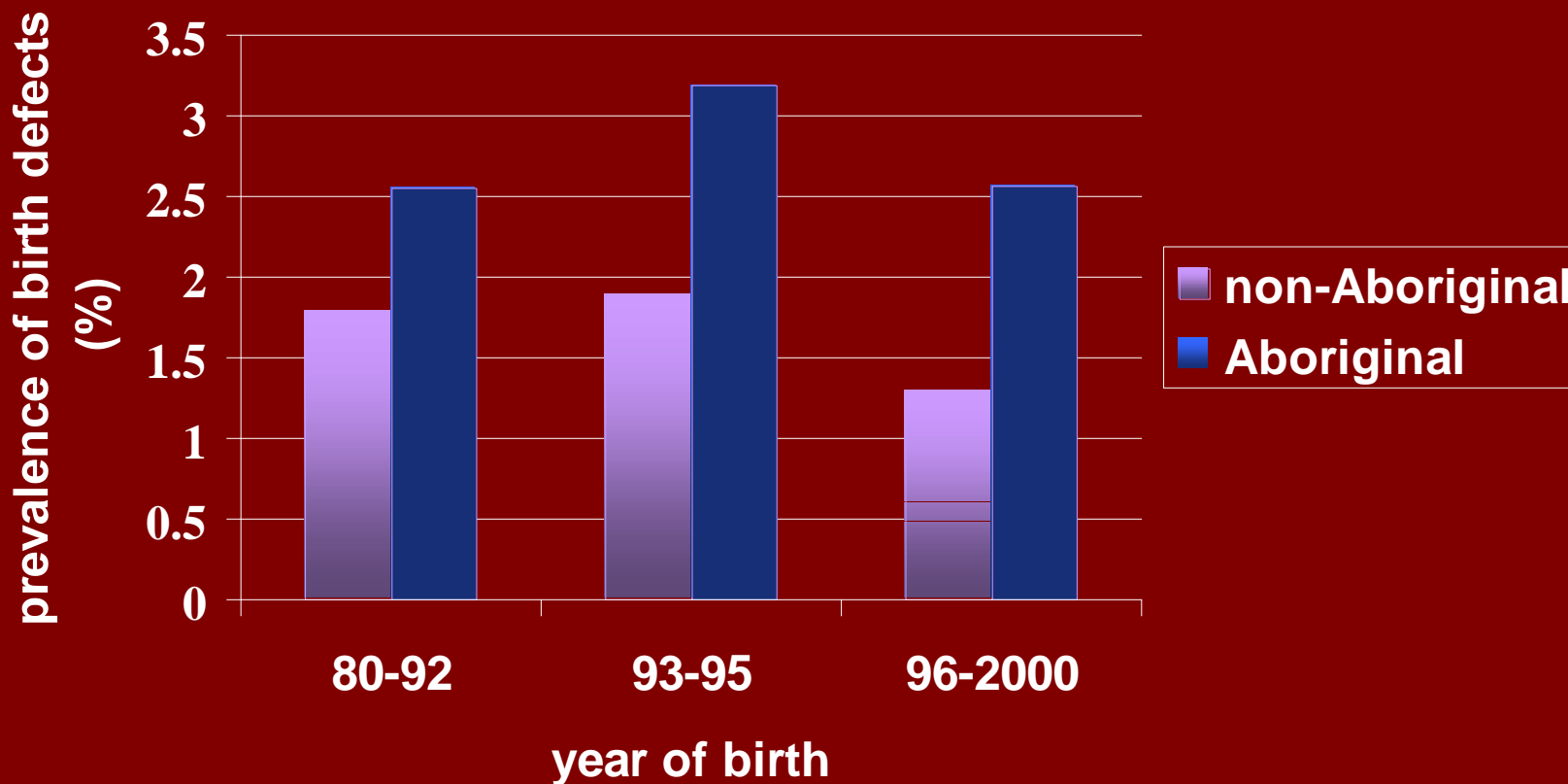


Neural tube defects WA 1980-2000





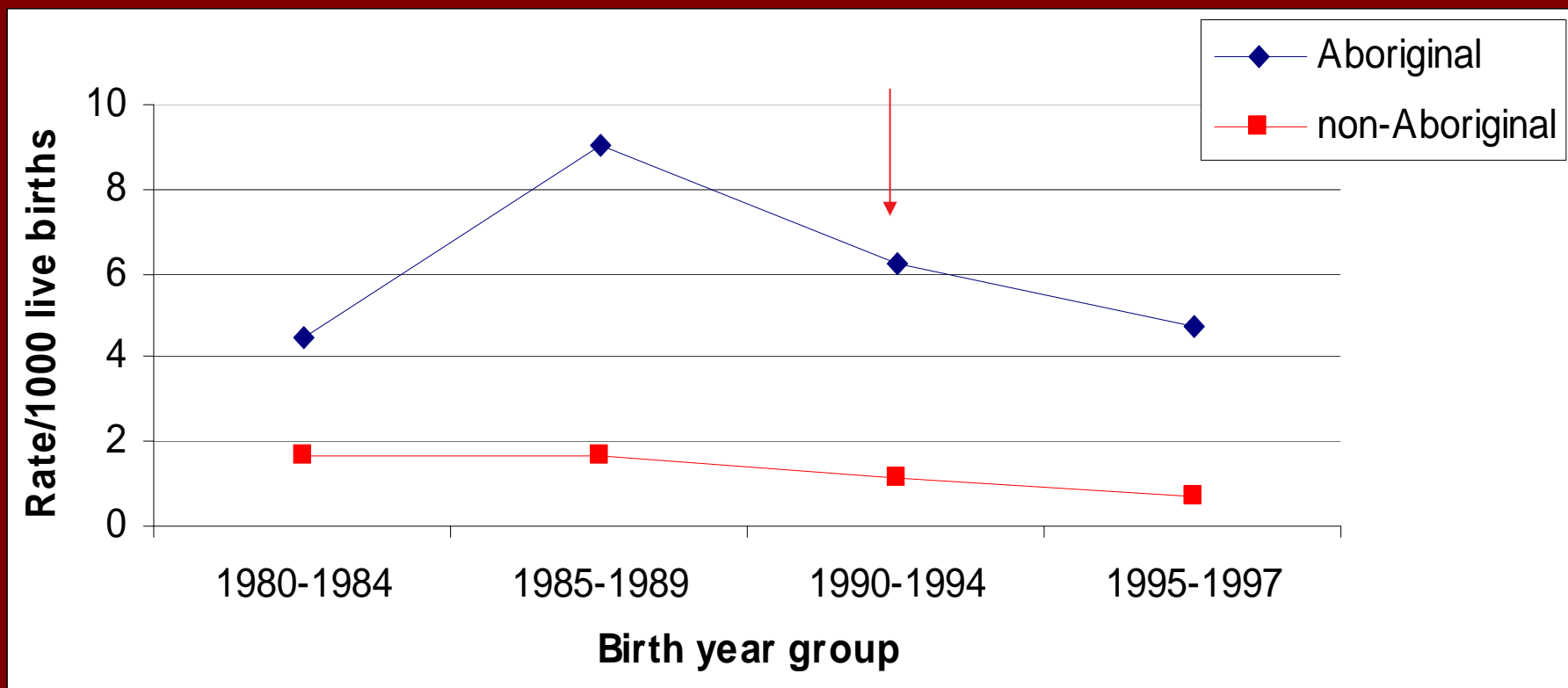
Neural tube defects in infants born to Aboriginal and non-Aboriginal mothers in Western Australia 1980-2000



Source: Carol Bower et al, ICHR



Infant mortality rate attributable to SIDS for Indigenous and non-Indigenous infants, 1980-1998



Source: Jane Freemantle, ICHR



Other Examples of Public Good Research from WA Linked Data

- Preventable morbidity & mortality amongst psychiatric patients
- Risks of cancers in environmental contamination
- Prescription drug exposures & birth outcomes
- Evaluation of effectiveness of immunisations



Advantages of Record Linkage Summary

- Inclusive, representative, accurate
- Best use of existing data
- Cost effective compared to contact & consent
- Avoids biased response rates, poor recall etc.
- Maybe particularly advantageous regarding sensitive research questions
- Information limited to that available in data sets



2

PRIVACY & CONSENT ISSUES



Is Record Linkage of Individual Data without Consent an Invasion of Privacy?

National Health & Medical Research Council (NHMRC) guidelines for epidemiological research .

- Role of ethics committees
- Protection of identified data
 - linkage procedures
 - computerised methods
 - safe storage
 - de-identification & anonymous analysis
- Evidence that 90% of those contacted, consent to linkage (eg Aboriginal child health survey sensitive data : 99% consent to linkage)



National Statement on Ethical Conduct in Research Involving Humans : NHMRC Guidelines

- A Human Research Ethics Committee (HREC) may approve access to identified or potentially identifiable data without consent of those the data identifies where the HREC is satisfied that:
 - (a) either
 - the procedures required to obtain consent are likely either to cause unnecessary anxiety for those whose consent would be sought or to prejudice the scientific value of the research and there will be no disadvantage to the participants or their relatives or to any collectivity involved
 - or
 - it is impossible in practice, due to the quantity, age or accessibility of the records to be studied, to obtain consent;
AND
 - (b) the public interest in the research outweighs to a substantial degree the public interest in privacy.



Guidelines on Privacy in the Private Health Sector

(Office of the Federal Privacy Commissioner, 2001)

- Use and disclosure necessary for research and statistics relevant to public health or public safety
NPP 2.1(d)
- In limited circumstances, this provision allows uses or disclosures of health information for research purposes, or for the compilation or analysis of statistics without consent, where these activities are relevant to public health or public safety. That is, the research must be about, or the statistics related to, public health or safety.



Federal Privacy Laws 2001 cont.

- Health information may be used or disclosed without consent for these purposes, only if:
- health and safety;
- seeking consent is impracticable;
- the activities are carried out in accordance with guidelines that are developed by the National Health and Medical Research Council (or a prescribed authority) and are approved by the Privacy Commissioner; and
- for disclosure - the health service provider reasonably believes that the organisation to which they disclose will not further disclose the health information or any personal information derived from it.



Federal Privacy Laws 2001 cont.

- Whether it is impracticable to seek consent will depend on the particular circumstances of the case. Simply incurring some expense, or having to exercise some effort to seek the consent of individuals whose information is to be used or disclosed, would not ordinarily make it 'impracticable' to seek consent. Circumstances where it may be impracticable to seek consent could include where there are no current contact details for the individuals in question and where there is insufficient information to get up-to-date contact details. This might occur in longitudinal studies of old records.



3

FUTURE CHALLENGES



Trends in Problems Affecting Children & Youth in Today's World

- Many are increasing in incidence
- Rise in complex problems (eg mental health, obesity)
- Demand complex information to monitor, study & prevent them
- Costly to treat & manage
- Crisis in child & youth services (health, mental health, education & crime)

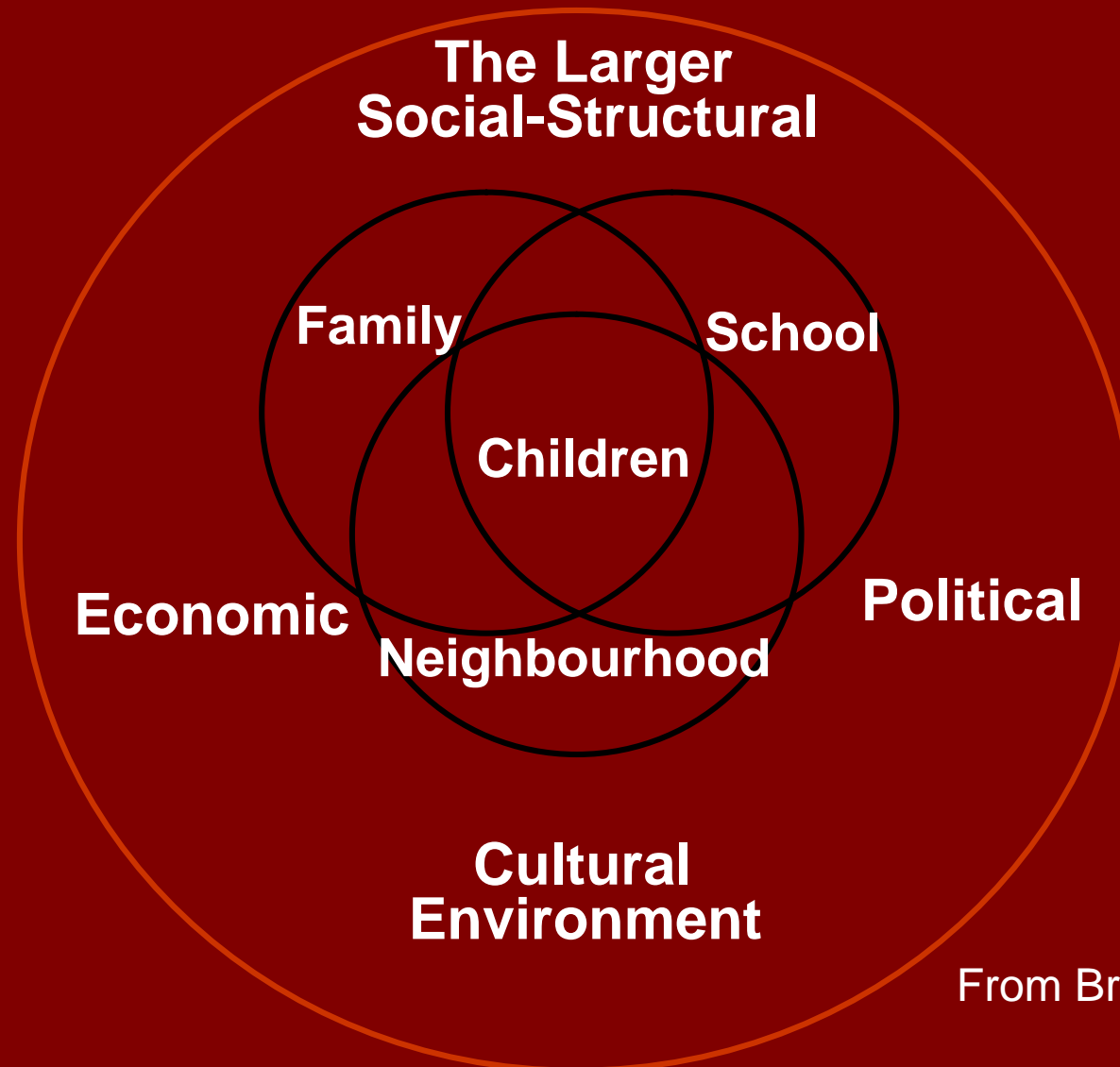


Most Causal Pathways

- Complex
- Start early in life (some intergenerational)
- Arise in social, environmental adversity
- Inadequately researched
- Research is fragmented, done in separate silos and does not inform solutions



Ecological Contexts Shaping Child Development



From Bronfenbrenner



Are Current Social & Economic Policies Cost Effective?

- Developed in silos
- Focus on the end of pathways
- Not evidence based (informed by research)
- Not properly evaluated
- Dollar costs more easily measured than benefits



*For every complex problem
there is a simple solution
and it is usually wrong.*



Summary of Rationale for Improved Collaboration

- Increases in many childhood diseases, disabilities and problems
- Causal pathways many and varied but often have common antecedents
- Multiple outcomes from single pathways and multiple pathways to single outcomes
- Research in silos
- Policy not evidence based
- Fragmented databases



Purpose of Alliance

A national collaboration established to facilitate, coordinate and support the development of knowledge and its effective use to enhance the well-being and life chances of children and young people.



Australian Research Alliance for Children and Youth

- National data network
- Maximise national research infrastructure
- Collaboration: ABS, CSIRO, AIHW etc
- Enhance public good by making full use of existing data.
- Maximise national research effort



*“There can be no keener
revelation of a society’s soul
than the way it treats
it’s children”*

Nelson Mandela 1997