



Data for a Civil Society

How we can harmonise privacy and use
population data for public good

Predictive Health Ethics Research (PredictER)

Indianapolis

15 June 2007

Professor Fiona Stanley AC

Director: Telethon Institute for Child Health Research

Executive Director: Australian Research Alliance for Children and Youth

Population of Western Australia:
2 Million

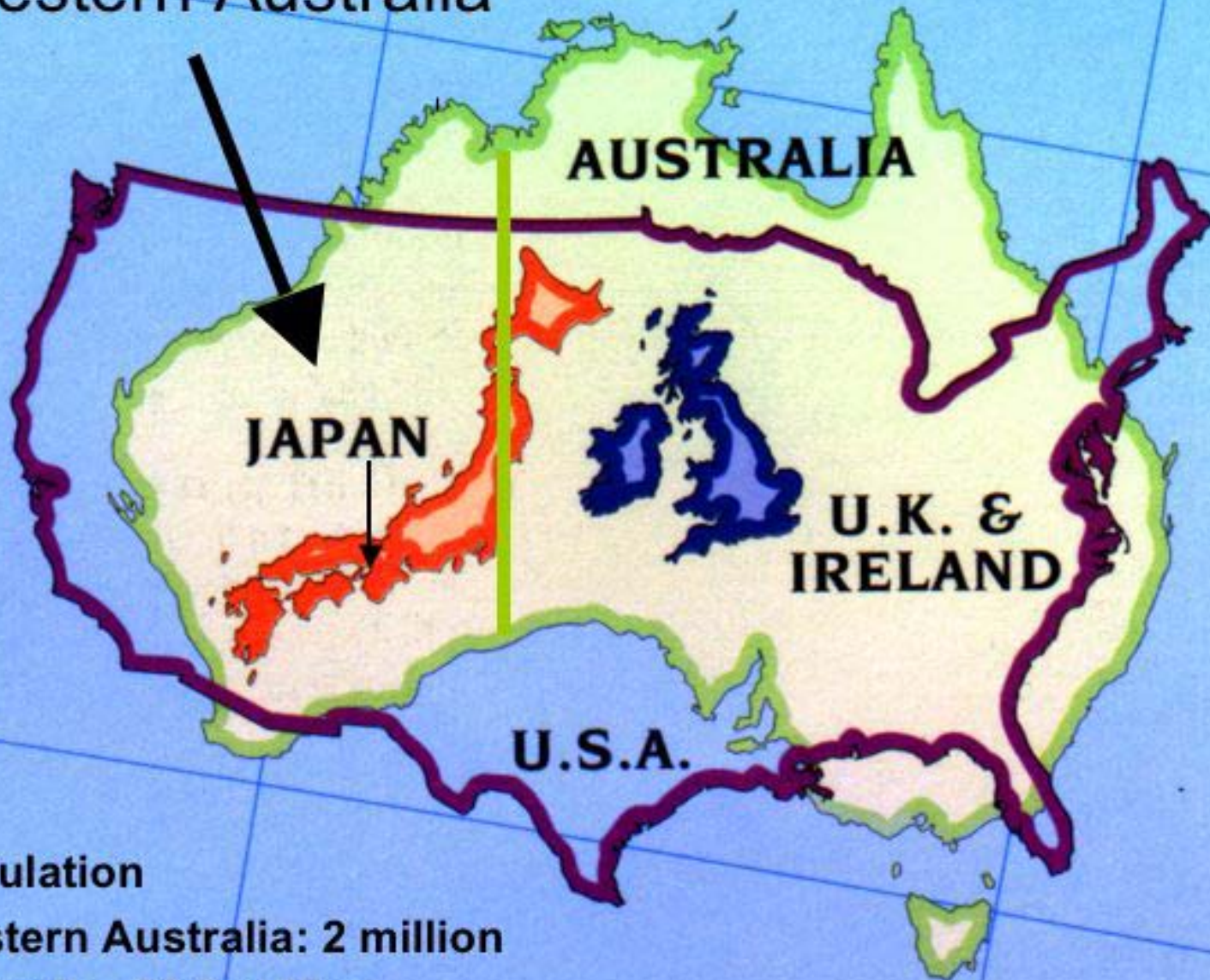
Population of Australia:
20.2 Million



Western
Australia

Largely
Unexplored

Western Australia



Population

Western Australia: 2 million

Australia: 20.2 million

TELETHON INSTITUTE FOR CHILD HEALTH RESEARCH



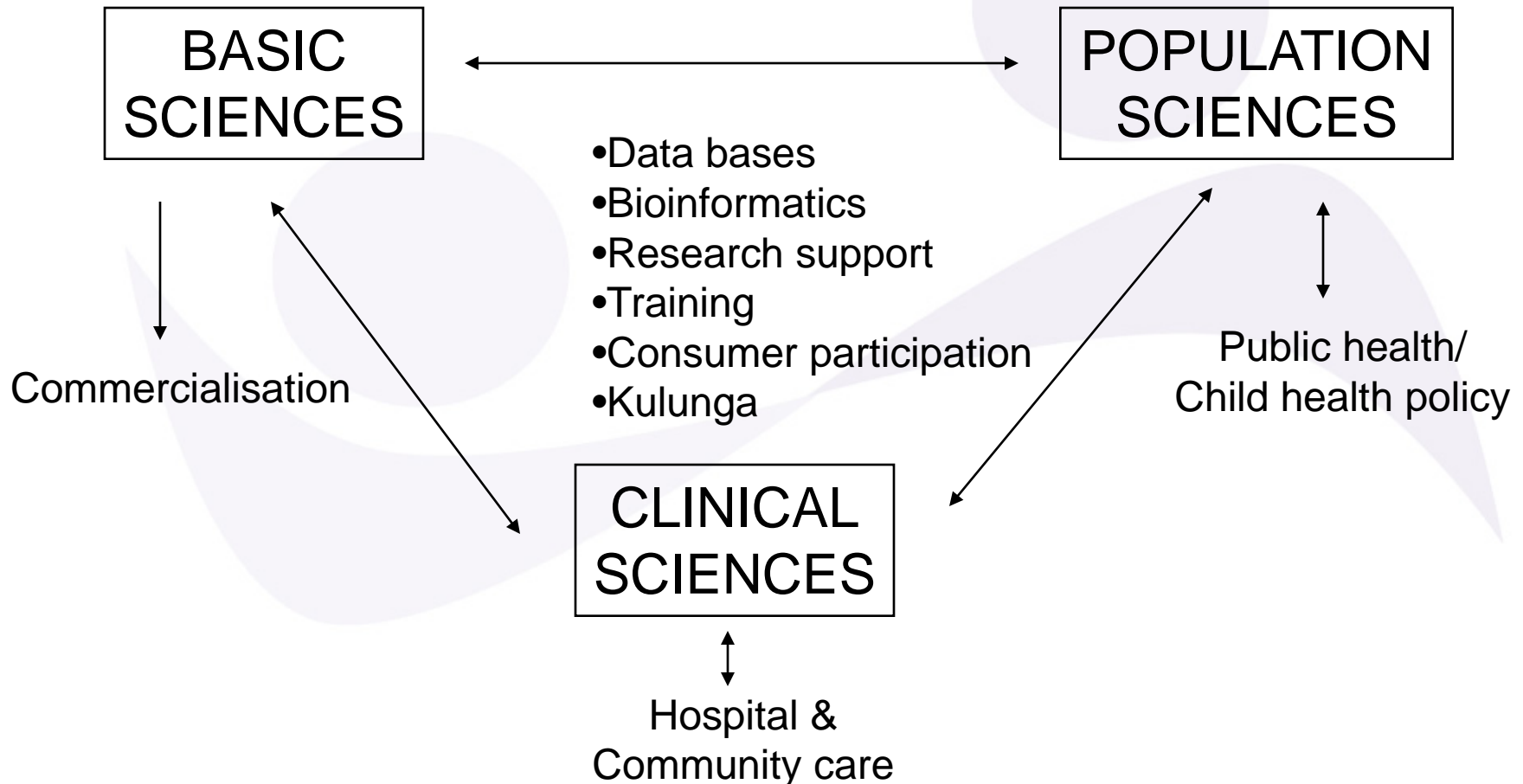
Our Mission

'To improve and promote the health and well being of all children through the unique application of multi disciplinary research'

Aims:

- To conduct high quality research
- To apply research findings to improve the health of children, adolescents and families
- To teach the next generation of health researchers.
- To be an advocate for research and for children

ICHR Philosophy



LOCAL, NATIONAL & INTERNATIONAL COLLABORATIONS

Research Themes



- Aboriginal child health
- Asthma, allergies & respiratory diseases
- Cancer & leukaemia
- Developmental disorders (BD, CP, ID)
- Infectious diseases
- Mental health
- Developmental origins of health & disease

Law and Population Health

“Law and ethics in population health are having a renaissance. Once fashionable during the Industrial and Progressive eras, the ideals of population health began to wither with the rise of liberalism in the late 20th century. In its place came a sharpened focus on personal and economic freedom. Political attention shifted from population health to individual health and from public health to private medicine.”

HIPPOCRATES OFF THE RECORD



"First, treat no lawyers."

Outline

1. Modernity's paradox - an uncivil society
2. Population data and record linkage
3. Understanding bias
4. Harmonising individual privacy and public good

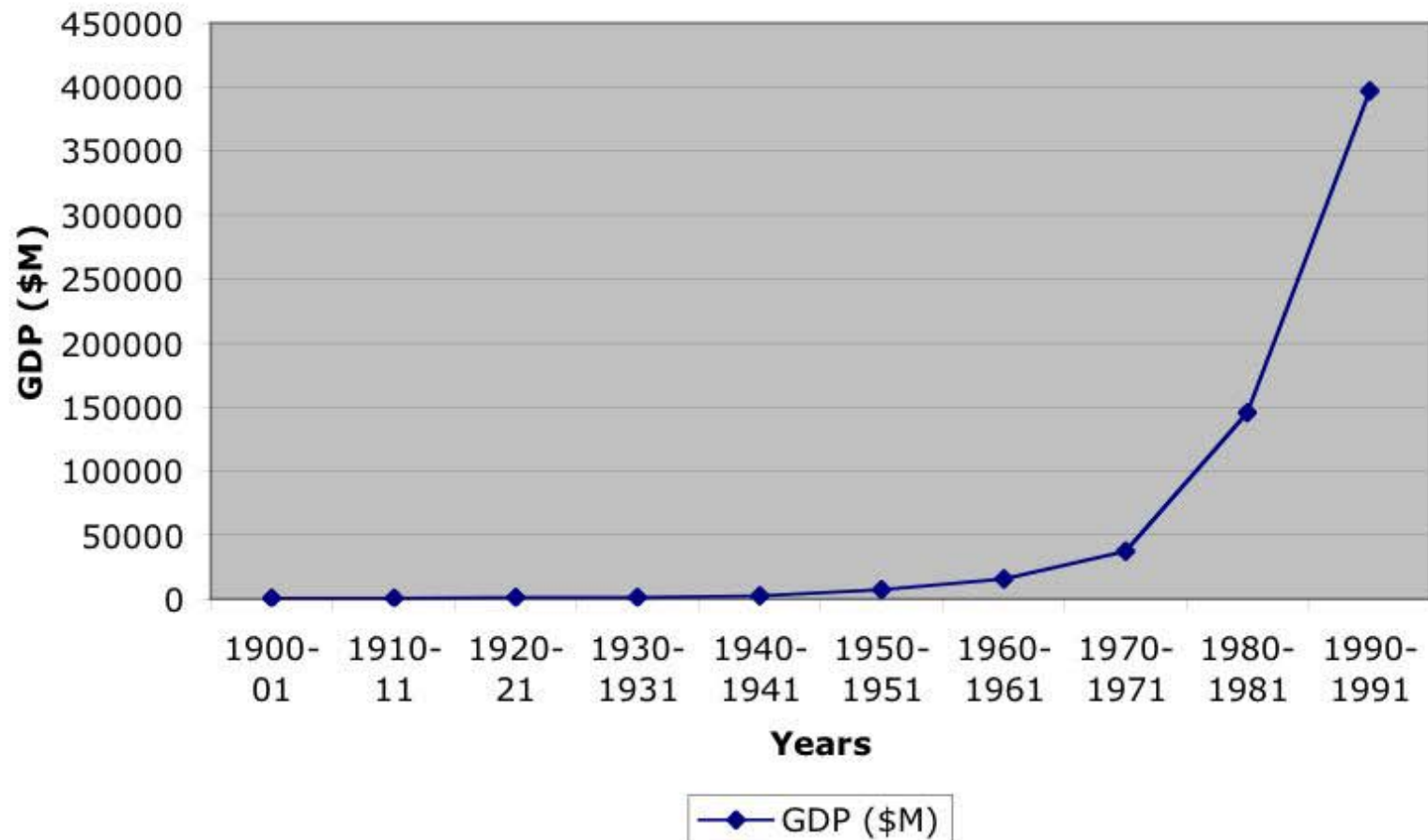


1. Modernity's Paradox: An uncivil society

Modernity's Paradox

- Increasing prosperity
- Increasing problems for children & youth
- Increasing inequalities in outcomes & opportunities

Australia's GDP at Current Prices





Indicators of Poor Developmental Health which are Increasing in Australian Children and Youth

Health Outcomes

- Low birth weight
- Complex diseases (asthma, diabetes, obesity)
- Mental Health problems, suicide

Lifestyle risk factors

- Child abuse/neglect/domestic violence
- Behavioural problems, substance abuse

Others

- Juvenile crime
- Learning disorders
- Disabilities (intellectual, physical)

Characteristics of Child & Youth Problems

- Younger ages and Girls = Boys
- Associated with disadvantage
- Social gradients increasing however most affected children & youth in middle income groups
- Costly or unable to treat/manage
- Creating crisis in health, mental health, education, family services and justice
- No indication of improvements
- Complex causes but share common antecedents

Child Wellbeing in 21 Wealthy Countries (OECD Data)

<u>DIMENSIONS</u>	<u>RANKINGS (out of 21)</u>		
	USA	UK	AUS
Material wellbeing	17	18	13
Health & safety	21	12	14
Educational wellbeing	12	17	7
Family & peer relationships	20	21	NA
Behaviours & risks	20	21	NA
Subjective wellbeing	NA	20	NA

Changes in Australian Society

Families, Children, Neighbourhoods

- Divorce, single parents, blended families
- Conflict, violence, isolation, homelessness
- Smaller families, contraction of the extended family
- Mothers working, childcare
- Hours of work, work stress, work mobility
- Children needing fostering
- Child abuse and neglect
- Insecure neighbourhoods, decreased connections
- Decreased social capital (trust, cooperation, civic engagements & reciprocity)



"Before we discuss destroying the competition, screwing our customers, and laughing all the way to the bank, let's begin this meeting with a prayer."

Bad Parenting....



CIVIL SOCIETY

Focus on:

Equality/diversity

Trust, care

Collective good

Valuing parents

Valuing
childhoods

Prevention more
than cures

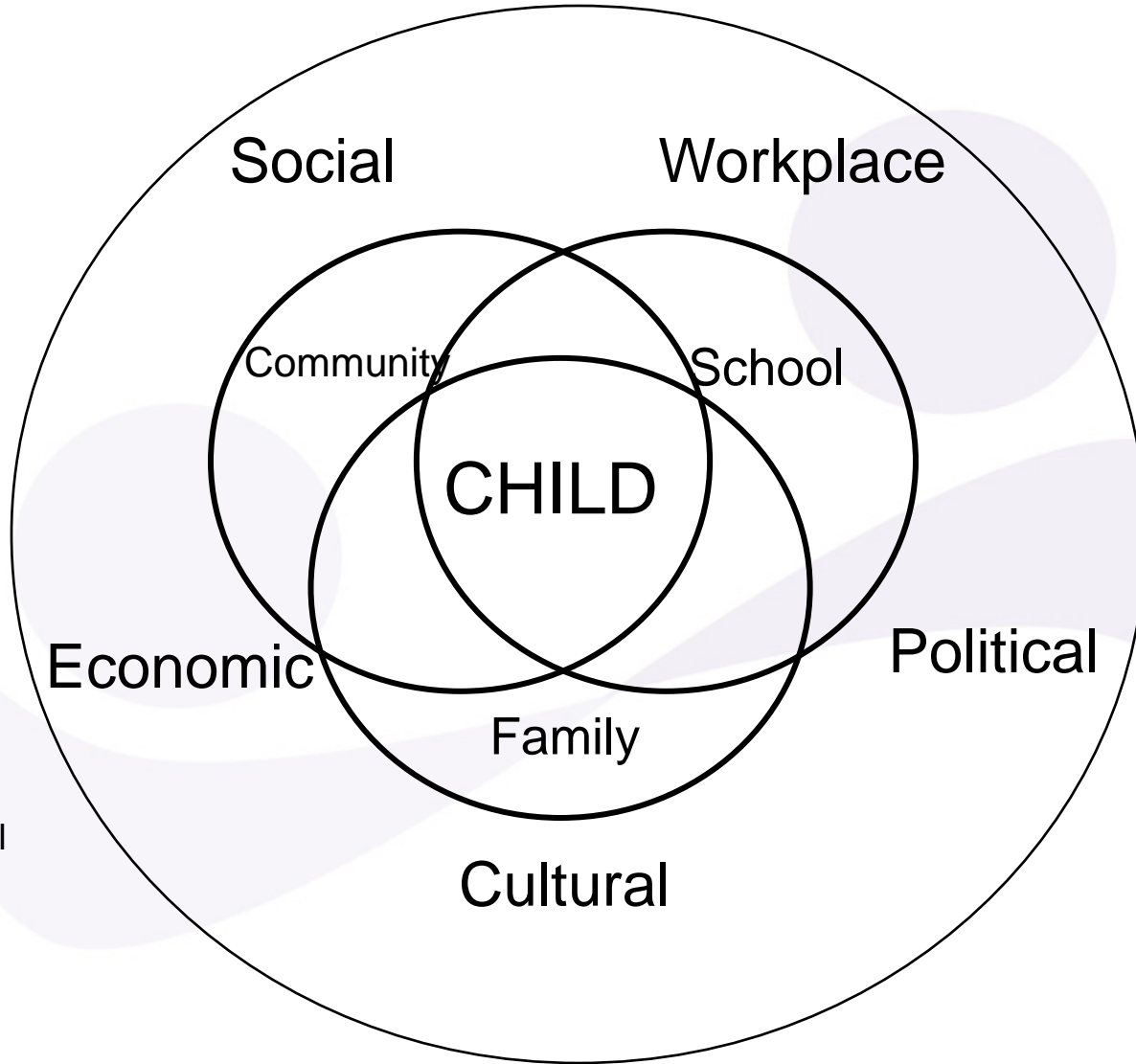
Protected
environments

Safe places for all

Effective use of
helpful
technologies

Child needs as well
as adults

Ecological contexts shaping child development



UNCIVIL SOCIETY

Accepting of:

Inequalities

Fear, violence

Priority for material
wealth

Parents not valued

Fast tracking
childhoods

Cures more than
prevention

Environmental
degradation

Safe places for the
few

Excessive use of
damaging
technologies

Adults needs more
than children's



"I'm afraid you have humans."



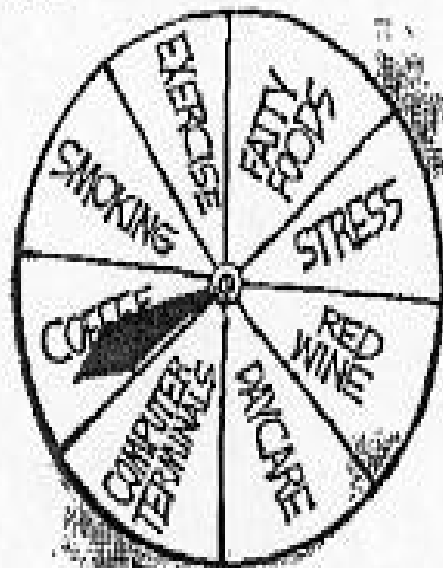
Trends in Problems Affecting Children & Youth in Today's World

- Many are increasing in incidence
- 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)
- Research in silos
- Services in silos

Today's Random Medical News

from the New England
Journal of
Panic-Inducing
Gobbledygook

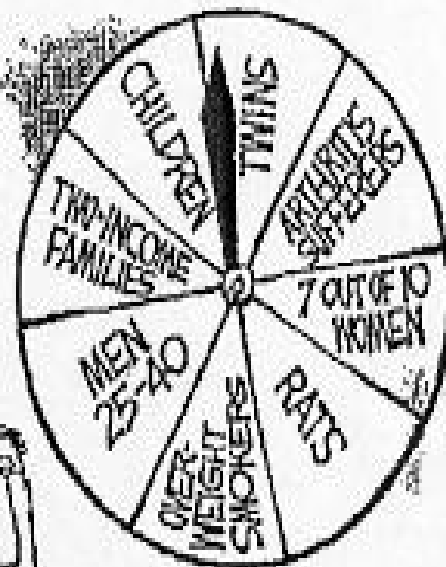
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© 1998 BY WILSON



CAN CAUSE



IN



ACCORDING TO A
REPORT RELEASED
TODAY...



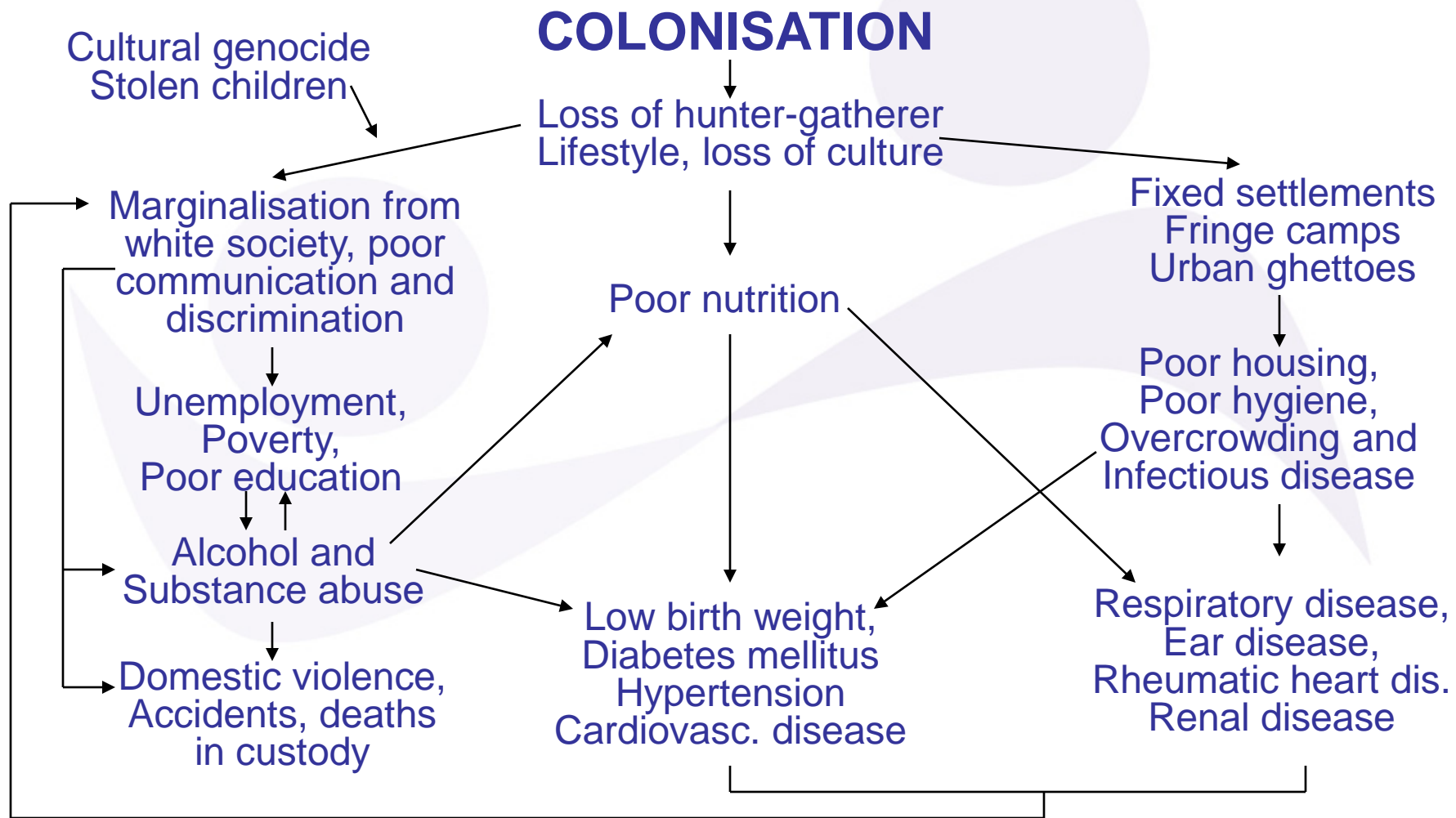
PRICE \$3.95

MAY 12 2003

THE NEW YORKER



Impact of white colonisation on Aboriginal health today





2. Population data and record linkage



What is Record Linkage?

- Brings together records from different sources, relating to the same individual
- Used for:
 - administration or case management
 - population based research and policy
- Focus today: on public good i.e. monitoring, research & evaluation to improve the health & wellbeing of the population

WA Maternal and Child Health Research Data Base 1977-2004

1970's

- Public concerns re thalidomide and adverse effects of perinatal care

1980/81

- Establish 1st Australian linkage of births, deaths and midwives (perinatal) records (total population)
- Establish registers of cerebral palsies and birth defects to link to data base

1982/83

- Link computerised hospitalisations

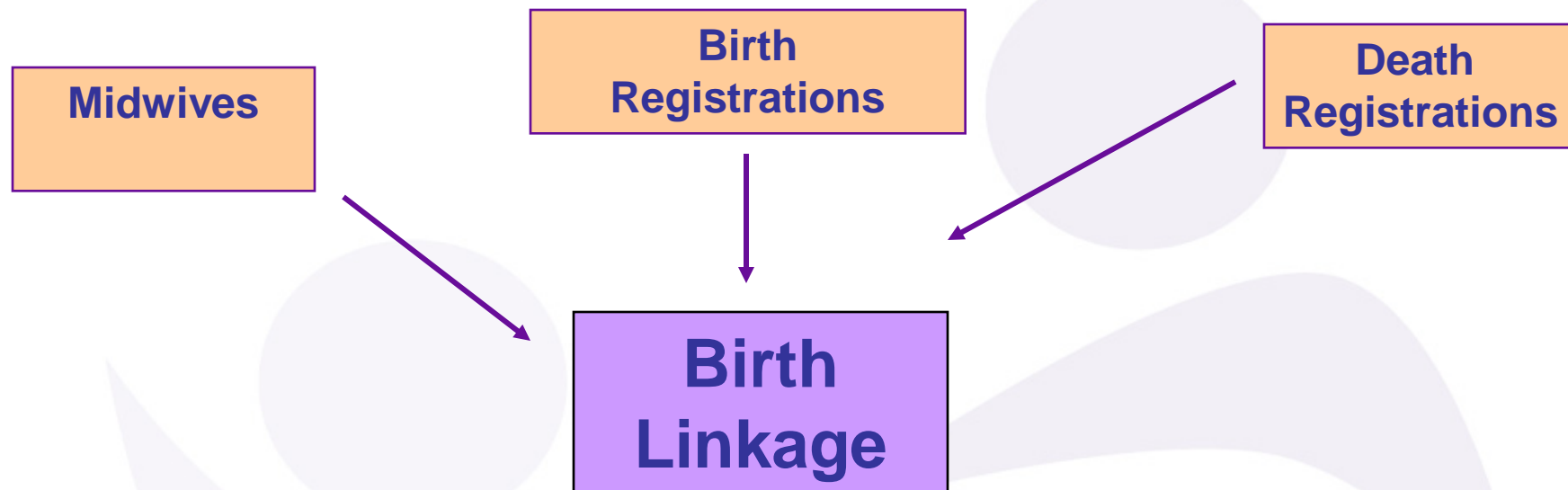
1990 onwards

- Ongoing MCHRDB

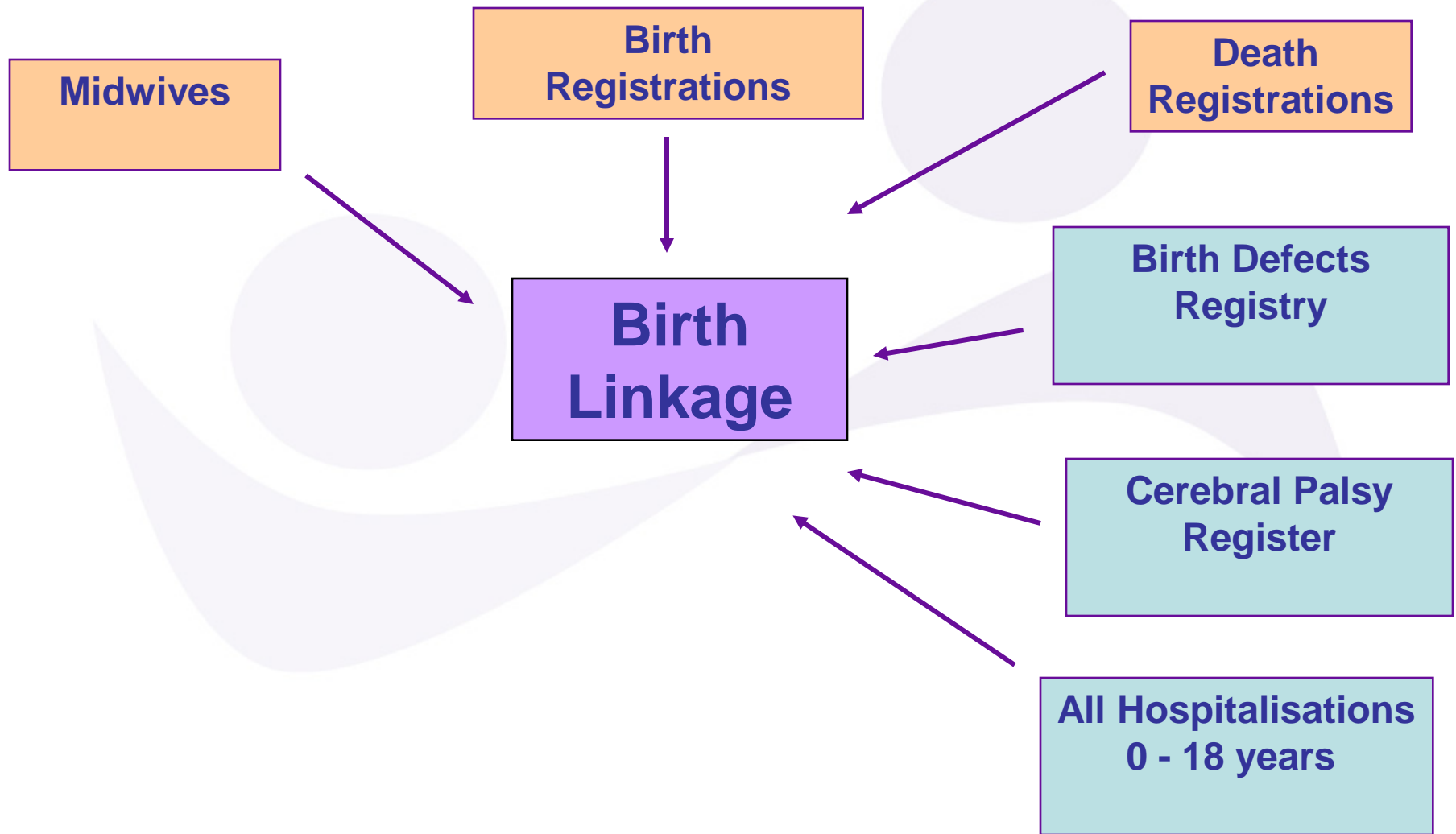
2004

- WA data linkage system

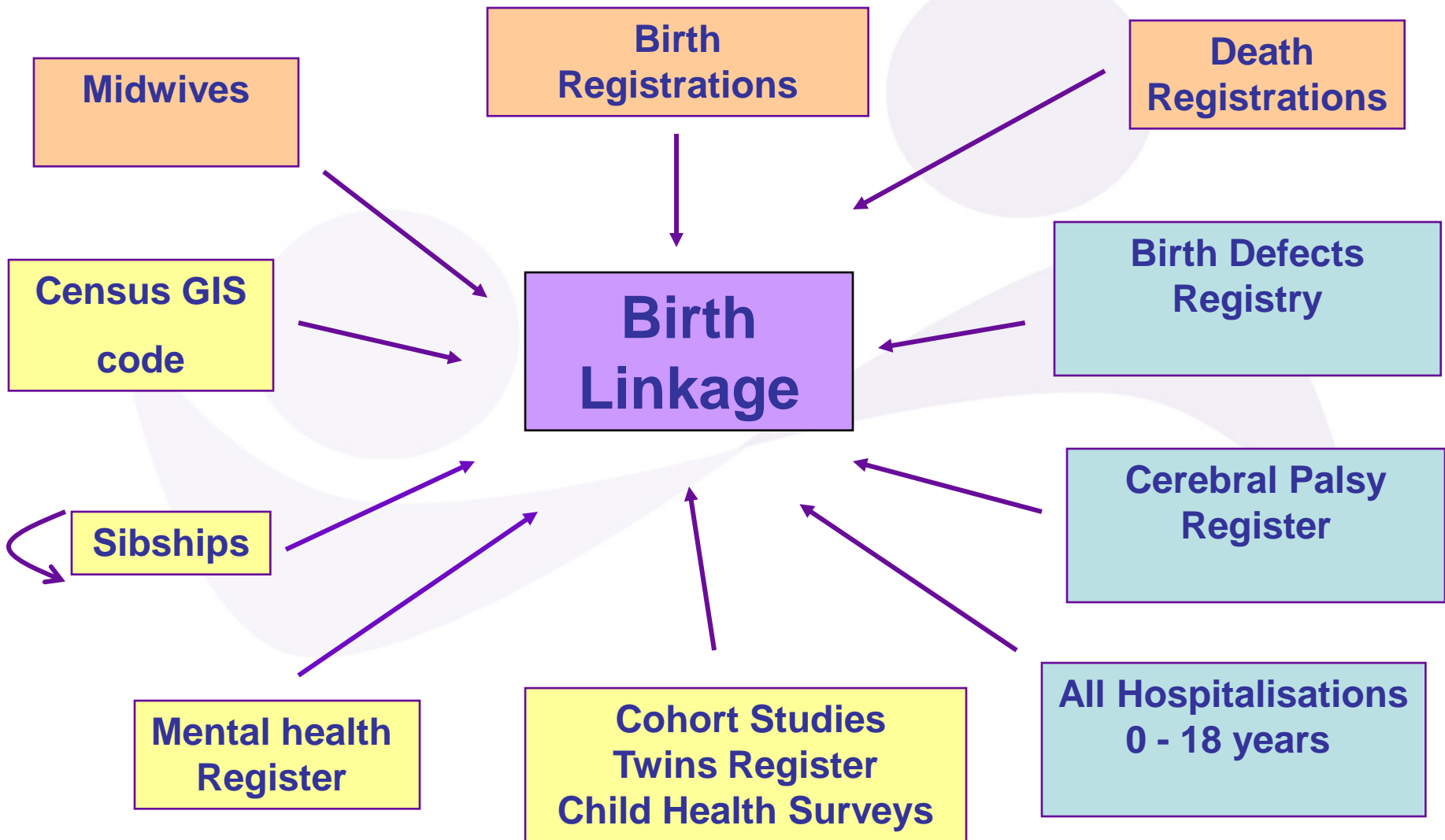
Maternal and Child Health Research Database 1980-2003



Maternal and Child Health Research Database 1980-2003

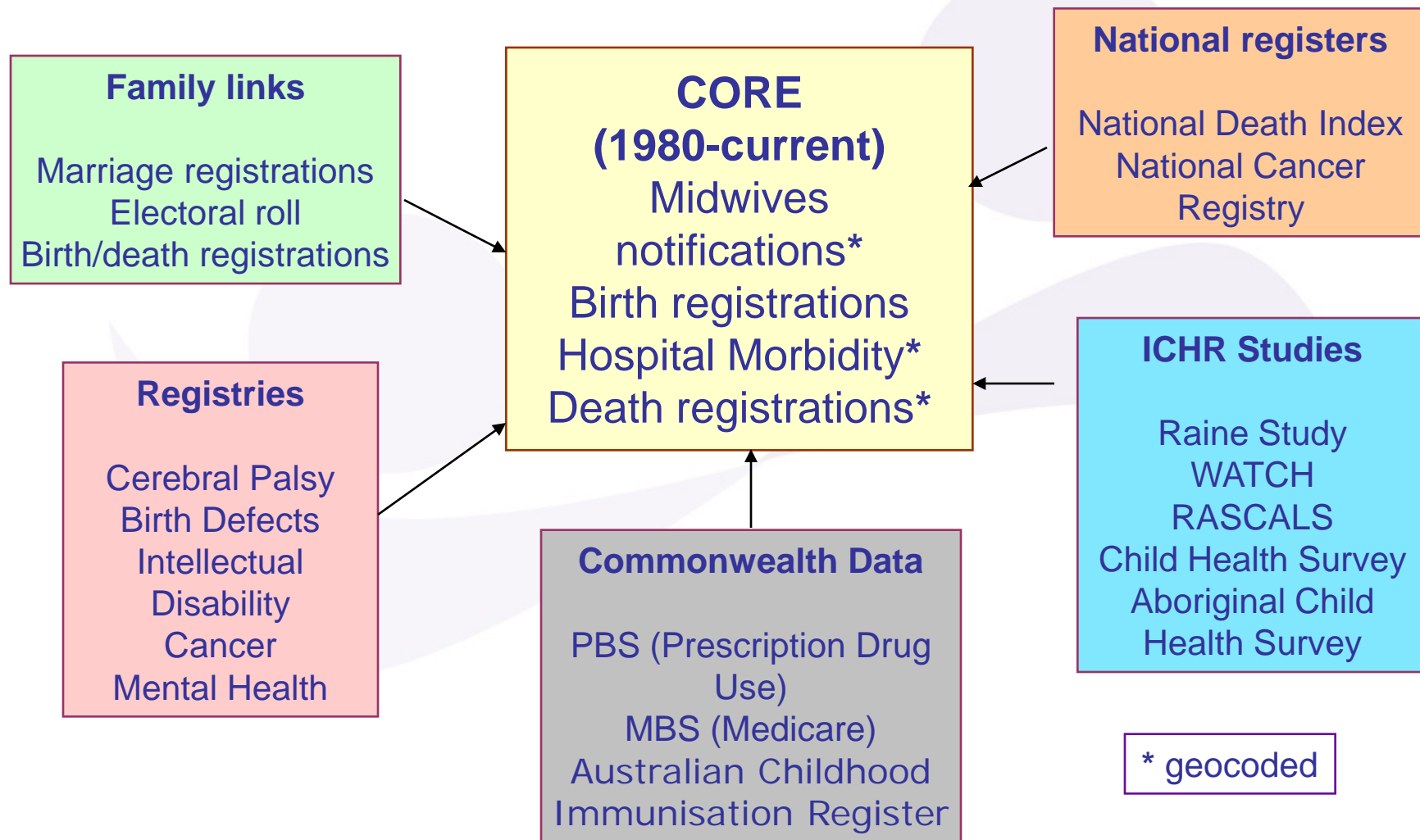


Maternal and Child Health Research Database 1980-2003



WA Data Linkage Unit

MCHRDB 2004 Onwards



Advantages of WA Population Data & Record Linkage

eg MCHRDB

- 100% sample: unbiased, no one excluded
- Cheap cf. seeking consent/ surveys
- Valid & reliable data on sensitive issues
- Reduces survey burden on populations
- Fast, effective linkage technology
- Privacy protected
- Better data for policy, planning, evaluation
- Improve administrative data

Limitations of WA Population Data & Record Linkage

- Information only available on items and outcomes recorded in data bases (breadth > depth)
- Privacy issues still need to be addressed eg ethics committees, understanding of public good by the community
- Need better, complete denominators
- Changes in diagnostic classifications present challenges for temporal analyses
- (In)accuracy of recorded information
- Incomplete ascertainment
- Sample size for rare disorders (APSU)

Antenatal factors in later disease/ disability

- Trends in diseases & disability (complete)
- Environmental exposures & later diseases
- Birth outcomes in psychiatric patients
- Intra-uterine growth & teenage mental illness
- Pregnancy problems & later childhood diseases

Evaluation of medical care

- Increased very preterm survival - problems in survivors
- IVF & cerebral palsy
- IVF & birth defects
- Reasons for and impact of, increasing caesarean sections
- Effects of increased obstetric intervention
- Adverse drug effects

Evaluation of health promotion

- Prevention of cot deaths
- Folate campaign for spina bifida
- Childhood vaccination coverage
- Anti-smoking programs

The background features a stylized graphic of two human figures in shades of purple. The figure on the left is smaller and positioned lower, while the figure on the right is larger and positioned higher, suggesting a sense of growth or progression. Both figures are composed of simple shapes: a circular head and a curved, open-bottom body. The overall aesthetic is clean and modern.

3. Understanding bias

Consent



- Consent is essential for all research involving participation of individuals
 - Questionnaires, interviews
 - Donate blood, tissues
 - Drug trials etc
- Not all research requires consent

Bias

- Bias is the distortion of the true relationship between exposure and outcome due to flaws in either study design or analysis
- Can give wrong answers




Bias from Non-Participation

- Inability to trace/ contact (most common)
- Refusal (rare)

Both of these groups very different from participants

- Magnitude and direction not predictable
- Not quantifiable
- Explain differences in risks between studies
- Poor information for health services and epidemiological research



4. Harmonising privacy
concerns & access
Can we have a win:win?



Privacy Concerns

- Abuse, particularly genetic risk data, by insurers or employers
- Sensitive information on individuals given out without their knowledge
- Government control of personal data
- Prefer consent for record linkage
- However, in focus groups:(McCallum et al 1993, Kelman 2005)
 - Strong support for public good research
 - Trusted research in universities
 - Acknowledged low risk



Privacy Concerns

- Can't address if not known
- Public understanding of
 - Research
 - Trade offs (protecting privacy/ allowing access)
 - Contexts and current legislation and processes

Record linkage without consent is allowed:

- We are guided by the National Health & Medical Research Council (NHMRC) Australian Health Ethics Committee
 - Guidelines for researchers and for Human Research Ethics Committees (HREC)
 - Balance public right to privacy against public right/interest in proposed research/activity
 - Influenced Privacy Act of 2001

NHMRC Guidelines for Epidemiological Research

- Role of Ethics Committees (composition, information, guidelines)
- Reasons for data collection
- Reasons why impracticable to seek consent
- Protection of identifiable data- security standards etc
- Nominated custodians, etc
- De-identified & anonymous analysis
- Conform to National Privacy Principles

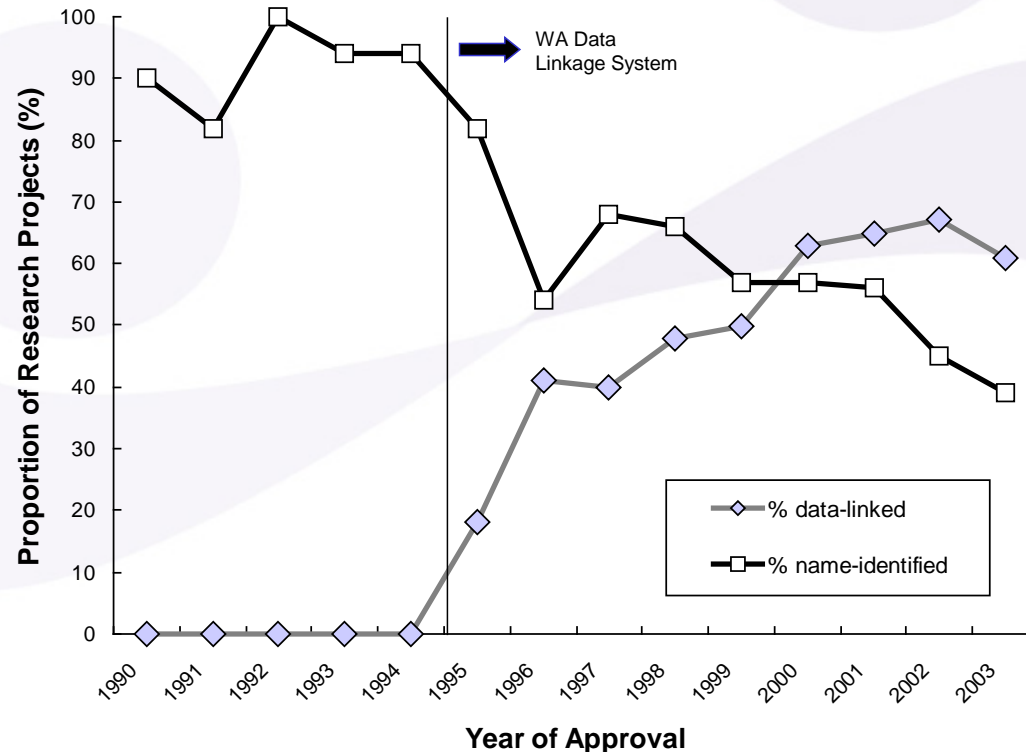
WA Data Linkage Unit

Best Practice for Cross Jurisdictional Linkage (harmonising privacy & encouraging access)

1. Obtain files of identified individual's records from Custodians (eg. Births, prescriptions, birth defects registries)
2. Link identifiers, but no access to clinical/sensitive data
3. Strip off identifying information
4. Return to each Data Custodian with a project ID
5. Researchers apply to:
 1. Institutional NHMRC Ethics Committee
 2. DLU Confidentiality Committee
 3. DLU Advisory Committee
6. Researchers go to Data Custodians to obtain de identified linked data set.
No individual data available or used
(eg. analyse drugs in pregnancy - effects on birth outcomes & birth defects)

Proportion of Ethics Approved Research Projects using Name Identified & Data Linked Administrative Health Information WA 1990-2003

Figure Proportions of ethics-approved research projects (N=408) using name-identified and data-linked administrative health information in Western Australia 1990-2003



PRIVACY & RELATED LEGISLATION IN AUSTRALIA

Commonwealth:

- [Privacy Act 1998](#)
 - ❑ handling of personal info by Cth & ACT public sector agencies;
 - ❑ handling of personal info by some private sector organisations
 - ❑ Part IIIA: credit worthiness info held by credit reporters & providers;
 - ❑ tax file number use by individuals & organisations;
- [Taxation Administration Act 1953](#) (handling of tax file numbers)
- [National Health Act 1953](#) (handling of Medicare and pharmaceutical benefits info)
- [Data-matching Program \(Assistance and Tax\) Act 1996](#) (matching b/t ATO & other assistance agencies)
- [Freedom of Information Act 1982](#)
- [Archives Act 1983](#)
- [Crimes Act 1914](#), Pt VIII (spent convictions)
- [Surveillance Devices Act 2004](#)
- [Telecommunications Act 1997](#) (personal info disclosed by telco providers)
- [Telecommunications \(Interception\) Act 1979](#)

Northern Territory:

- [Information Act 2002](#) (privacy, FOI and public records)
- [Criminal Records \(Spent Convictions\) Act 1992](#)
- [Surveillance Devices Act 2000](#)
- [Telecommunications \(Interception\) Northern Territory Act 2001](#) (not yet in force)

Western Australia:

- No privacy law nor administrative privacy regime, but see discussion paper ([released 20 May 2003](#))
- [Freedom of Information Act 1992](#)
- [State Records Act 2000](#)
- [Spent Convictions Act 1988](#)
- [Surveillance Devices Act 1998](#)
- [Telecommunications \(Interception\) Western Australia Act 1998](#)

South Australia:

- No privacy law, but see [Cabinet Administrative instruction to comply with Information Privacy Principles](#) (originally issued in 1988, re-issued in 1992)
- [Freedom of Information Act 1991](#)
- [State Records Act 1997](#)
- [Listening and Surveillance Devices Act 1972](#)
- [Telecommunications \(Interception\) Act 1988](#)
- No spent convictions law, but see discussion paper ([released 5 May 2004](#))

Victoria:

- [Information Privacy Act 2000](#)
- [Health Records Act 2001](#)
- [Freedom of Information Act 1982](#)
- [Public Records Act 1973](#)
- No spent convictions law, but see [Victoria Police policy on release of criminal history information](#)
- [Surveillance Devices Act 1999](#)
- [Telecommunications \(Interception\) \(State Provisions\) Act 1988](#)

Queensland:

- No privacy law, but see [State Government Standards Nos. 42 \(Information Privacy, Sep 2001\) & 43A \(Information Privacy for the Qld Dept of Health, Sep 2001\)](#) (administrative standards); also see Parliamentary report ([tabled April 1998](#))
- [Freedom of Information Act 1992](#)
- [Public Records Act 2002](#)
- [Criminal Law \(Rehabilitation of Offenders\) Act 1986](#) (spent convictions)
- [Invasion of Privacy Act 1971](#) (credit reporting, listening devices, invasion of privacy of the home)
- [Police Powers and Responsibilities Act 2000](#), Chap 4 (covert evidence gathering)
- No state telecommunications interception power, but see Parliamentary report ([tabled December 1999](#))

New South Wales:

- [Privacy and Personal Information Protection Act 1998](#)
- [Health Records and Information Privacy Act 2002](#)
- [Freedom of Information Act 1989](#)
- [State Records Act 1998](#)
- [Criminal Records Act 1991](#) (spent convictions)
- [Listening Devices Act 1984](#)
- [Workplace Video Surveillance Act 1998](#)
- [Telecommunications \(Interception\) \(New South Wales\) Act 1987](#)
- [Workplace Surveillance Bill 2004](#) (exposure draft)

Australian Capital Territory:

- [Privacy Act 1988 \(Cth\)](#)
- [Health Records \(Privacy and Access\) Act 1997](#)
- [Freedom of Information Act 1989](#)
- [Territory Records Act 2002](#) (public records)
- [Human Rights Act 2004](#) (right to privacy)
- [Spent Convictions Act 2000](#)
- [Listening Devices Act 1992](#)

Tasmania:

- [Personal Information Protection Act 2004](#) (not yet in force)
- [Freedom of Information Act 1991](#)
- [Archives Act 1983](#)
- [Annulled Convictions Act 2002](#) (spent convictions)
- [Listening Devices Act 1991](#)
- [Telecommunications \(Interception\) Tasmania Act 1999](#)



Office of the
Victorian Privacy
Commissioner

www.privacy.vic.gov.au
enquiries@privacy.vic.gov.au
Local call 1300 666 444

Canadian privacy activities 2004-2006

- 4 workshops on harmonising privacy
- Privacy toolkit
- Privacy audits
- Privacy officers

UK Privacy & Medical Research

Personal data for public good: using health information in medical research

- Increased complex laws/regulations
- Variable interpretation
- Many projects blocked/delayed
- Increase in costs
- Poor public awareness of value and methods of research

Commentary Lancet, 2006

Our health system needs effective evaluation

- Spiraling costs of care
- Increase complex diseases
- New technologies, drugs - harmful side effects
- Patient expectations
- Concerns over safety
- Poor data for service planning

Are patients morally obliged to participate in research projects as a “mandatory contribution to public good”, particularly for those aimed at preventing serious harms and providing important benefits?

John Harris
Prof of Bioethics
University of Manchester

“We are optimistic that a win:win is possible: where privacy is protected, where important health research can proceed. There is evidence that a shift in thinking is possible on behalf of ethics review committees, regulators, researchers and the public.”

Dr E Meslin 2006
Director Indiana University
Centre for Bioethics

Towards a win:win

1. HRECs understand and accept current guidelines which allow identifiable data for research without consent if privacy issues addressed and rationale acceptable
2. Develop Australian privacy and research best practice for the researchers using personal data
3. Public aware of how personal records are used and how research is done
4. e.Health: ensure records can be used to evaluate health system

CIVIL SOCIETY

Focus on:

Equality/diversity

Trust, care

Collective good

Valuing parents

Valuing
childhoods

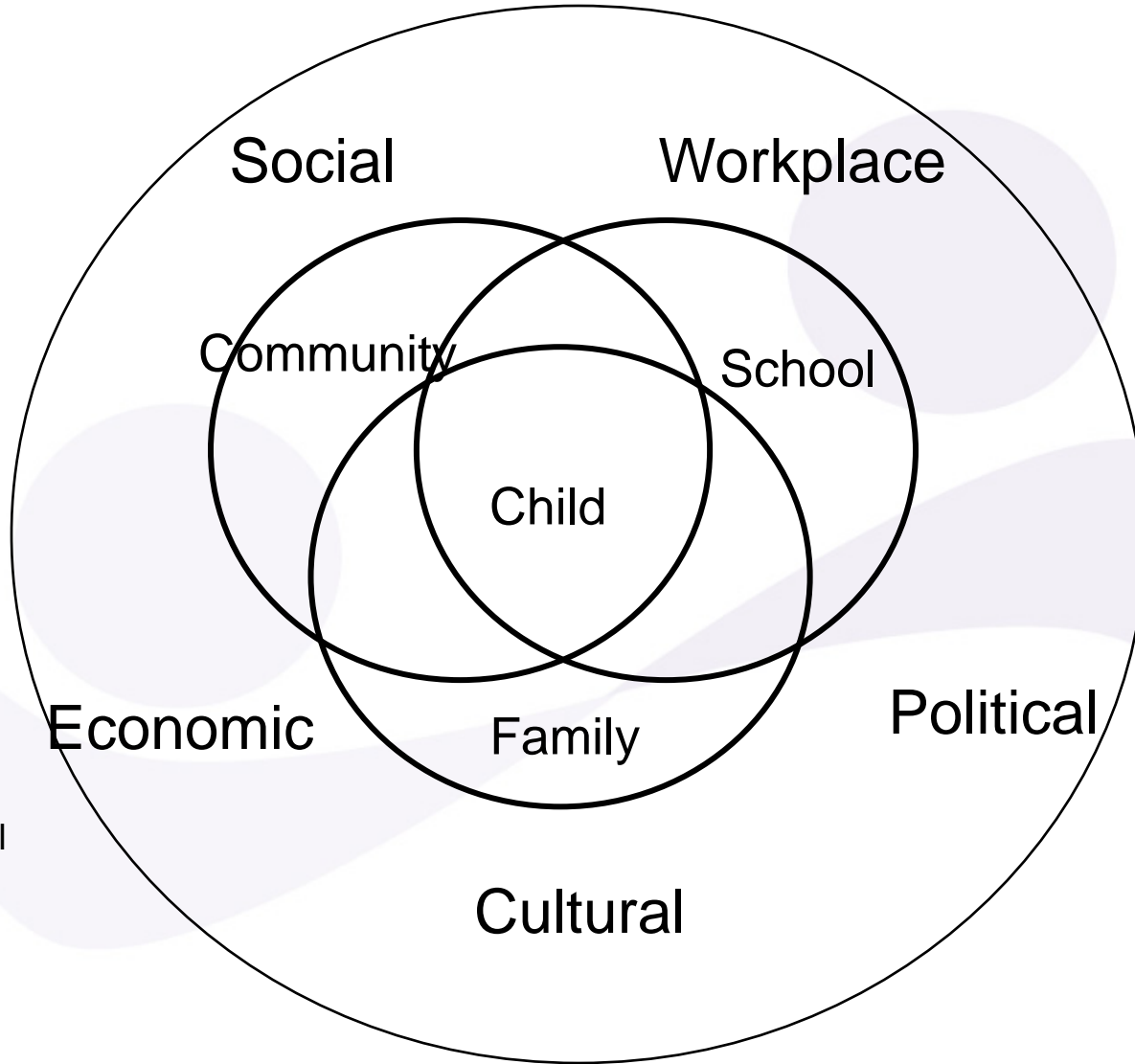
Prevention more
than cures

Protected
environments

Safe places for all

Effective use of
helpful
technologies

Children's needs as
well as adults



UNCIVIL SOCIETY

Focus on:

Inequalities/
intolerance

Fear, violence

Individual greed &
wealth

Parents not valued

Fast tracking
childhoods

Cures more than
prevention

Environment
exploited

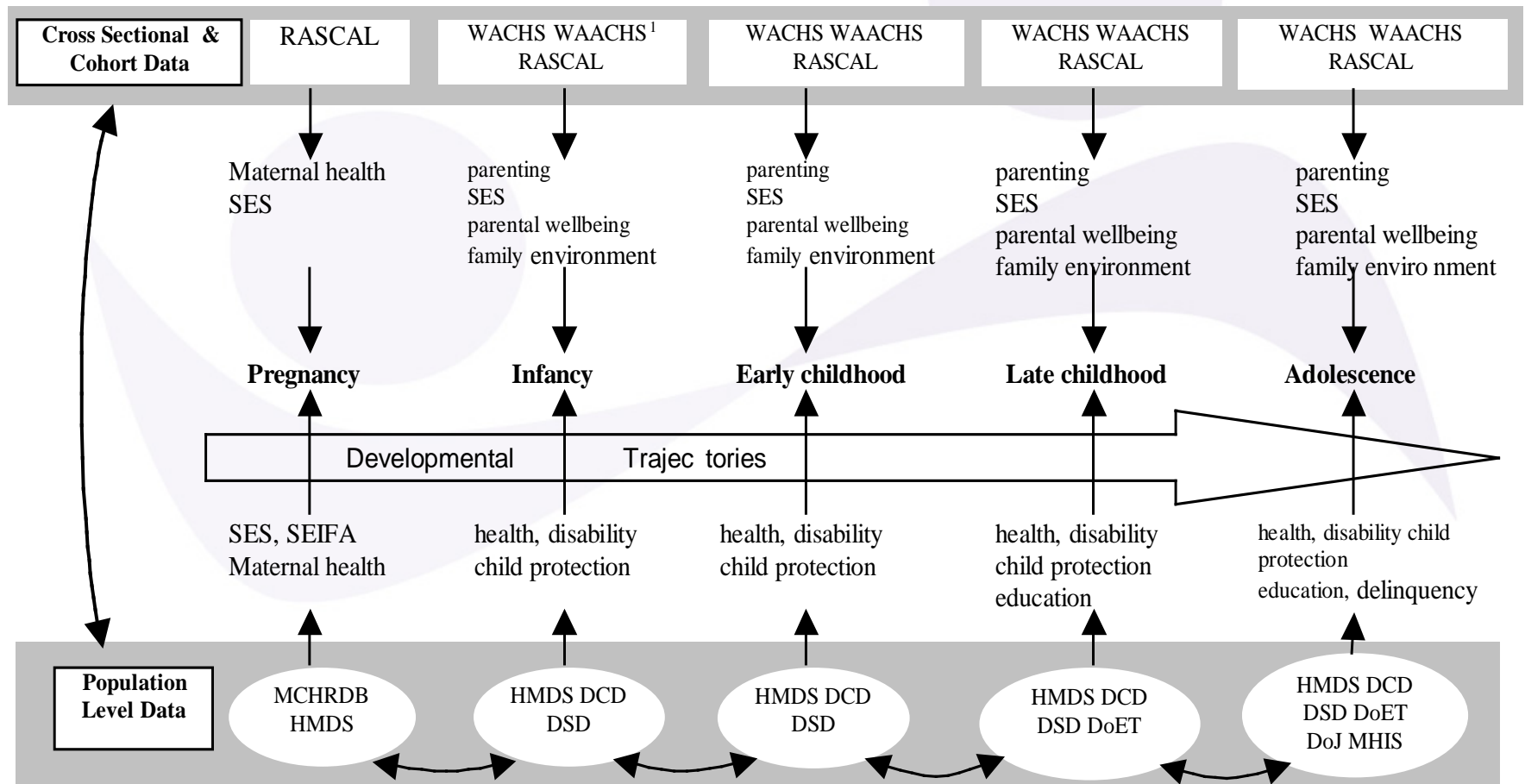
Safe places for few


Excessive use of
damaging
technologies

Adult's needs more
than children's

MCHRDB & ARC Linkage Grant

Overview of databases and trajectories





“ In the late 20th century, scholars and politicians posed a key question ‘What desires and needs do you have as an autonomous rights bearing person to privacy, liberty and free enterprise?’ Now it is important to ask another kind of question ‘What kind of community do you want and deserve to live in, and what personal interests are you willing to forgo to achieve a good and healthy society?’ “

*Prof Lawrence O Gostin 2004
University of Georgetown*