

# POLICY, PRACTICE AND HEALTH SERVICES RESEARCH

## RELATING TO NSW CHILDREN AND FAMILIES

AIHI Research Symposium, Macquarie University

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## **Overview**

### Joanna Holt, Chief Executive NSW Kids and Families

- + About NSW Kids and Families
- + Evidence-driven policy development
- + Making it happen...

### Les White, NSW Chief Paediatrician

- + Research Portfolio
- + Philosophy of partnership
- + An example: Caretrack Kids



# ABOUT NSW KIDS AND FAMILIES



## The Formation of NSW Kids and Families



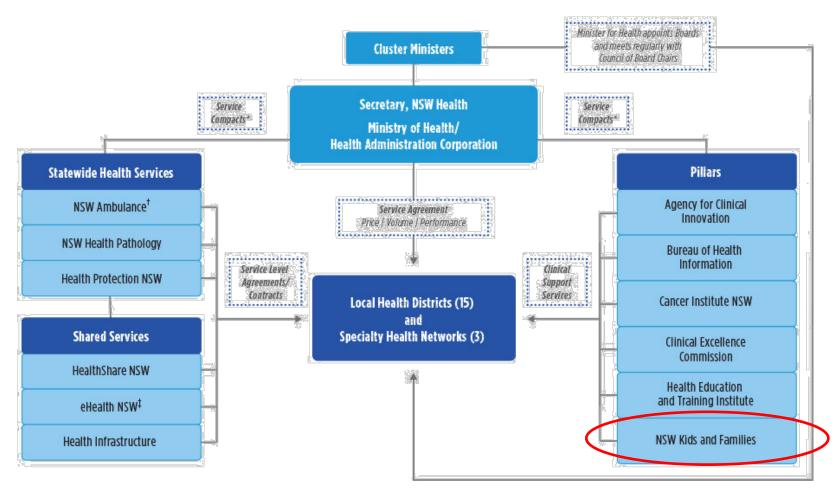
Emerging evidence about fetal origins of disease; neural development; cumulative adverse events

### **NSW Kids and Families**

- + commenced operations November 2012
- + a broader scope than envisioned by Justice Garling but no role in direct service delivery



## **NSW Kids and Families in context**



<sup>\*</sup>Service Compact — Instrument of engagement detailing service responsibilities and accountabilities

<sup>&</sup>lt;sup>†</sup>No Service Compact between Ministry of Health and Ambulance Service of NSW

<sup>&</sup>lt;sup>‡</sup>To be formally established in 2014

As at 30 September 2013



## **NSW Kids and Families Vision**



That kids and families in NSW will be healthy, safe and well

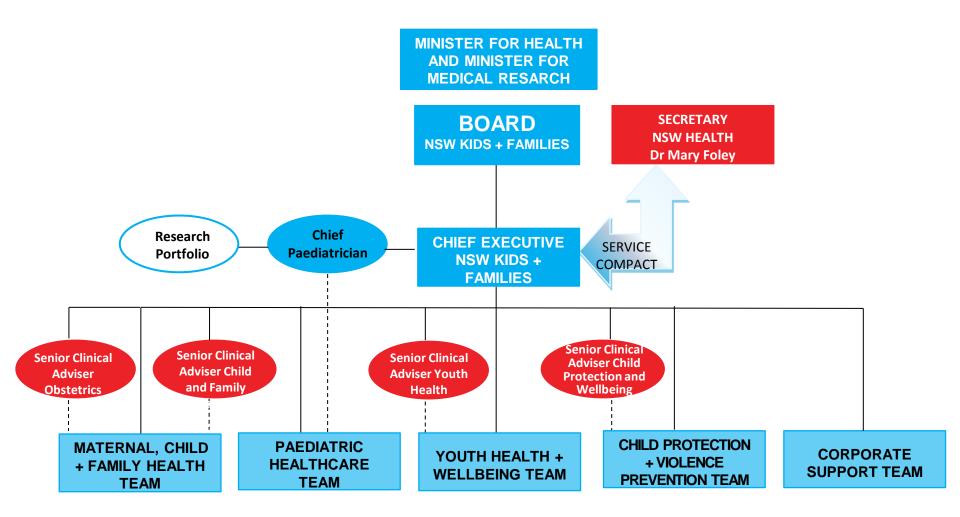


## **Purpose of NSW Kids and Families**

- Provide leadership to the NSW health system and partner with our stakeholders to champion outstanding health, wellbeing and healthcare for all children, young people and families
- + Reduce the health impact of sexual, domestic and family violence, child abuse and neglect



## Organisational structure



healthy, safe and well

Home Members

Careers

Contact Us

GO

Aboriginal Acknowledgement

#### **ABOUT US**



- What we do
- Our board
- Our people
- Corporate Governance and Organisational Structure
- + Strategic health plan 2014-2024
- Research

#### **CURRENT WORK**



- + Maternal, child and family health
- Paediatric healthcare
- Child protection and violence prevention
- Youth health and wellbeing
- Programs

#### **PUBLICATIONS**



- Media releases
- Newsletters
- + Policy directives/ guidelines
- + Fact sheets/ brochures
- Reports
- Multimedia

#### TRAINING/EDUCATION



- Events
- Maternity and newborn training
- Paediatric training
- Child protection and violence prevention training
- Youth health and wellbeing training

#### WHAT'S NEW

 Keep Them Safe - a shared approach to child wellbeing

#### Online Mandatory Reporter Guide

 Healthy, Safe and Well: A Strategic Health Plan for Children, Young People and Families launched

#### **NEW PUBLICATIONS**

- NEW ISSUE! Read latest corporate newsletter News + Views
- NSW Kids and Families first Year in Review 2013/14: First Steps now available

#### **UPCOMING EVENTS**

 100 Years of Child and Family Health Centres



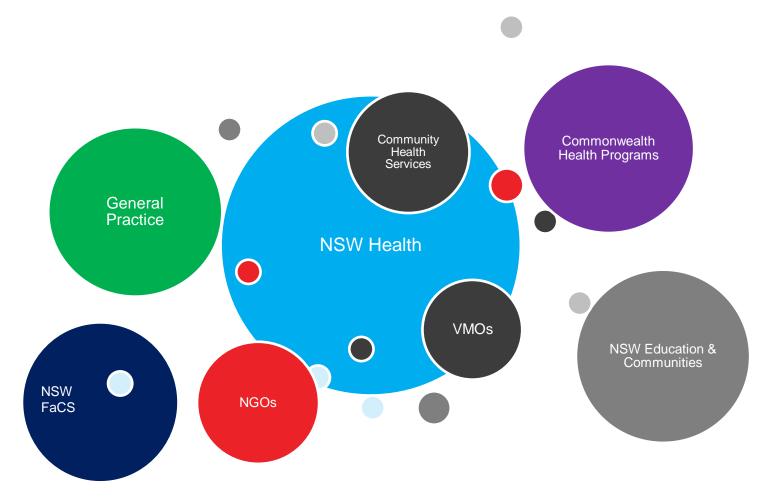
### FOR PARENTS, CARERS + YOUNG PEOPLE

- + Having a baby book
- The Blue Book' child personal health record
- + Youth issues

#### Networks outside NSW Health \_ **NSWKIDS +FAMILIES** NSW Health system **Child Protection & Violence Prevention** - Women, children, young people and families Networks - Interagency; NGOs Youth Health **Paediatric** Healthcare and Wellbeing NSW - Youth 12-25 - Support hospital system/clinicians vears Kids and Networks - youth Children to 16 workers in Health vears **Families** - Networks and outside; CHN, MP4: government RP4; NETs; agencies; and allied health **NGOs** Maternal, Child and **Family Health** Other government agencies GPs and private practices of healthy, safe and well 10



## The Health System for Children, Young People and Families

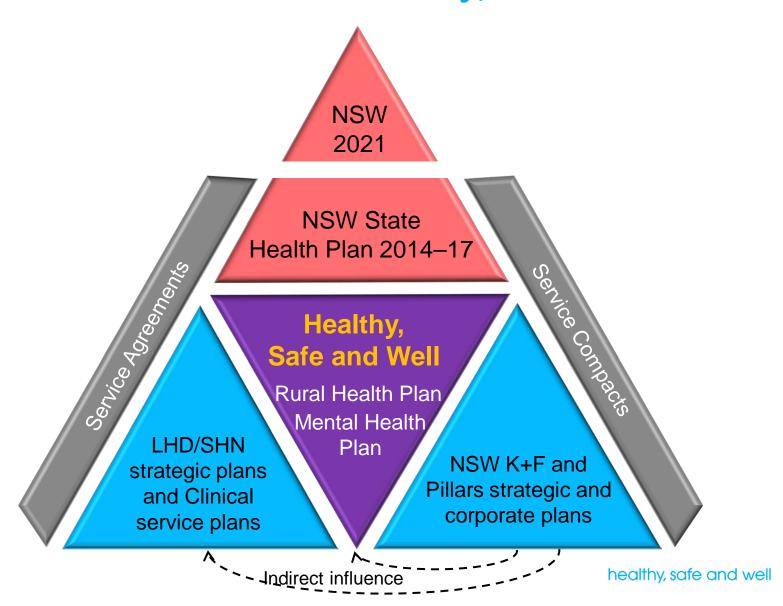








## Context of Healthy, Safe and Well





## The Purpose of this Plan

This 10 year Plan sets out an ambitious agenda to guide our collective efforts to:

- Prevent harm and ill health (avoidable)
- Intervene early to mitigate morbidity and mortality
- Provide the best healthcare possible to mothers, babies, children and young people who need hospital care.



## The Strategy Map

Children, young people and families in NSW are healthy, safe and well **WELL** SAFE 1. Caring for women and 2. Keeping children and 3. Addressing risk and 4. Early intervention 5. Right care, right place, **Strategic Directions** young people healthy right time 1.1 Help parents prepare for 2.1 Boost community 3.1 Increase awareness of 4.1 Identify children who 5.1 Deliver best-practice need extra support capacity to pursue good health violence, abuse and neglect on health over time care as close to home as possible pregnancy and improve Objectives 4.2 Intervene early to prevent 3.2 Improve identification and 5.2 Provide safe, high-quality, 1.2 Improve access to 2.2 Improve screening, health poor health, growth and development for children at high-quality, womanchecks and immunisation rates triage care for those at risk of harm and effective healthcare centred care from early pregnancy 2.3 Improve health 3.3 Build capacity to 5.3 Deliver integrated, connected healthcare 4.3 Act early to help children literacy 1.3 Strengthen provision of safe, appropriately respond to victims of violence, abuse with chronic health conditions evidence-based birth Prime responsibility of options and neglect NSW Health 2.4 Reduce risk taking and 5.4 Provide inclusive, family-4.4 Engage with young people minimise harm 1.4 Support transition 3.4 Reduce the incidence and centred, culturally respectful at risk of poor health or Responsibility of NSW from postnatal care to and age-appropriate care health impact of parenthood absence from school Health in collaboration accidents, injuries and with partners self-harm Influencing role for NSW Health **MAKING IT HAPPEN MAKING IT HAPPEN** Workforce **Evidence** eHealth Leadership Metrics **Partnerships** 



# EVIDENCE-DRIVEN POLICY DEVELOPMENT



## **Building evidence**

## The Strategic Health Plan identified Evidence and Measurement as key enablers:

### Workforce

We will ensure health professionals have the skills to deliver quality health care

### Evidence

We will promote translation of evidence-based research to support delivery of quality health care

### eHealth

Use of technology will improve information sharing and delivery of quality health care

### Leadership

NSW Kids and Families and a guiding Council will coordinate strategies in relation to this Plan

### Measurement

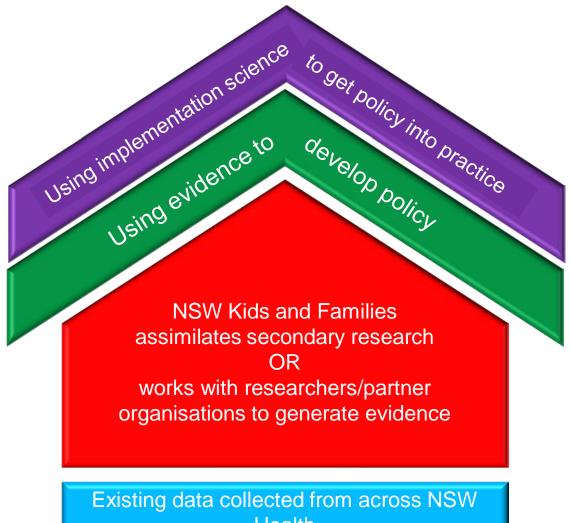
We will monitor implementation, evaluate cost-effectiveness, measure and report on the outcomes

### Partnership

We will work collaboratively with partners, build services within communities, and partner with Aboriginal and other communities



### From Evidence to Practice



Health



## **MAKING IT HAPPEN...**



## **Examples of evidence assimilation**

Child Protection & Violence Prevention

 Forensic and medical photography, video recording and video transmission for cases of suspected sexual abuse in children and young people

 Adolescents and young adults' use of emergency departments

Youth Health and Wellbeing

NSW
Kids and
Families

Paediatric Healthcare

- Clinical variation in paediatric care
- Paediatric services capability

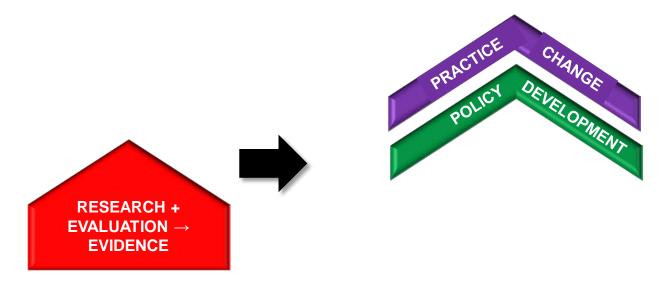
 Models for screening and surveillance of hearing in early childhood

- Screening and surveillance in early childhood health
- Tests and models for screening to prevent blindness in infants and children

Maternal, Child and Family Health



## Using Evidence to Develop Policy





EXISTING DATA /
KNOWLEDGE BASE



## **Example 1:**

## Youth Health Competency Framework

**FRAMEWORK** 



RESEARCH + EVALUATION → EVIDENCE



EXISTING DATA / KNOWLEDGE BASE



- Current youth health training programs and other resources
- Consultation with health agencies, young people, health professionals and training providers

Youth Health Policy 2010-16 - annual data collection



## Example 2:

## Sustaining NSW Families (Keep the Safe)

PROGRAM MODIFICATION



RESEARCH + EVALUATION → EVIDENCE



EXISTING DATA / KNOWLEDGE BASE



- Implementation fidelity ?
- Outcomes achieved?
- Needs of families met?
- Cost-effectiveness?

Data/information from services at 5 sites



## Example 3:

### Standards for Paediatric IV Fluids

#### PRACTICE CHANGE





RESEARCH + EVALUATION → EVIDENCE



Standards for Paediatric IV Fluids

## RISKS ASSOCIATED WITH USE OF LOW SODIUM CONTENT FLUIDS

- Reports in medical literature
- Warnings issued in other countries

#### RISKS ASSOCIATED WITH HIGH CHLORIDE

- Emerging evidence

Existing practice in NSW Health hospitals / facilities



## RESEARCH PORTFOLIO

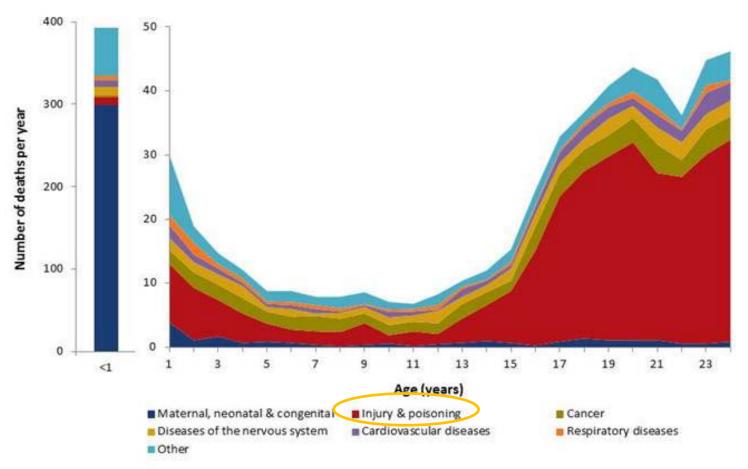


## Research portfolio

- + Coordinator position established in January 2014
- + Research Alliance for Children's Health
- + Systems to support and monitor research
- + Guidance: Research Leadership Group
- + Engagement: monthly Research & Evaluation Seminars
- + Networks; Partnerships; Participation
- + Joint venture with Sydney Children's Hospitals Network to co-host a forum on Paediatric Injury Research



### Leading causes of mortality, NSW, 2002-2011



Source: NSW Ministry of Health. The Health of Children and Young People in NSW - Report of the Chief Health Officer 2014 (in press).

## PAEDIATRIC INJURY PREVENTION + MANAGEMENT RESEARCH FORUM



### A Research Forum Coordinated by







## Leadership / Partnership in Injury Research

- + Forum Report: setting direction
- + Reference Group; broad network
- + Surveillance: Advocate; NSW Kids and Families; Ombudsman
- + NGO relationships and coordination
- + Research funding: NHMRC, NSW K+F, industry



# PHILOSOPHY OF PARTNERSHIP



## Current projects - research focussed

Child Protection & Violence Prevention

- 45 and Up Study longitudinal study of healthy ageing -Sponsorship of questions
- National burden of disease study examining the impact of violence

t women

Paediatric Healthcare

ooriginal and Antenatal ng Impact Study ic Violence research

ncy services study

- Access Phase 3 work in the area of access to youth health
- Appropriateness of h delivered to Australia CareTrack Kids
- Seeding success: A sechild health and development.

  Aboriginal children

Youth Health

and Wellbeing

- Get healthy in pregnancy trial
- 'Watch Me Grow' universal surveillance and early identification of developmental disorders
- Longitudinal outcomes of children with hearing impairment
- Kids in communities study (KiCS)

Maternal, Child and Family Health

NSW

Kids and

**Families** 

safe and effective care to children in with eHealth systems

ted concussion in youth

- major injury
- Paediatric injury prevention projects

healthy, safe and well



## **Partnering on Research**

- NSW Kids and Families criteria for partnering
  - Alignment with our overall strategic priorities
  - Alignment with identified team workplan / priorities
  - Team capacity for involvement within the timeframe
  - Assessment of the project quality, feasibility, credibility, and importance
  - What involvement is requested over what time?
  - Are there risks in not being involved?



## **Levels of Participation**

No participation

Link and facilitate

Contribute support/ approval

Contribute support/approval & support in kind

Contribute support/ approval, support in kind & contribute funding

Contribute directly to work

Initiate and undertake the research



## **Example 1: Improving outcomes for severely injured children**

- + NHMRC Partnership Grant which started in 2015
- + Led by Chief Investigators: Associate Professor Kate Curtis, Professor Andrew Holland, Dr Rebecca Mitchell, Professor Deborah Black
- In partnership with: NSW Agency for Clinical Innovation (ACI), NSW Institute of Trauma and Injury Management (ITIM), Day of Difference Foundation, Ambulance Service of NSW and NSW Aeromedical and Medical Retrieval Service (AMRS), NSW Kids and Families, Australian Trauma Quality Improvement Program (AusTQIP)
- + Aim: To evaluate existing paediatric care pathways from time of injury to definitive care and their impact on health outcomes. Specifically:
  - patient health-related quality of life at 6 and 12 months
  - + appropriateness of the processes and delivery of care
  - + Treatment costs including different modes of transport





## **Example 2: The Seeding Success Study**

- + Study population: All children who started school in NSW in 2009 and 2012, followed from birth to school age
- + <u>Data:</u> linked, administrative health, community services, welfare and education data

### + Aims:

- To determine factors that predict positive early childhood health and development in Aboriginal children
- 2) To investigate geographic variation in positive early childhood development in Aboriginal children and identify area-level characteristics that seed success
- 3) To test the impact of two early childhood services (Aboriginal Maternal and Infant Health Service and Brighter Futures program) on early childhood health and development in Aboriginal children

Chief Investigators: Prof Louisa Jorm (UNSW), Dr Kathleen Falster (ANU, Sax Institute, UNSW), Prof Sandra Eades (Baker IDI), Prof John Lynch (University of Adelaide), Prof Emily Banks (ANU), A/Prof Marni Brownell (University of Manitoba, Canada), Prof Rhonda Craven (UWS), Dr Kristjana Einarsdottir (Telethon Kids Institute, Perth), Deborah Randall (UNSW). Associate Investigators: Prof Alastair Leyland (University of Glasgow, Scotland), Elizabeth Best (NSW Kids and Families), Marilyn Chilvers (NSW Family and Community Services) and A/Prof Sharon Goldfeld (The Royal Children's Hospital & Murdoch Children's Research Institute, Melbourne).



## **CARETRACK KIDS**



## **Background**

 Mangione-Smith et al showed that children received 'recommended care' only 46% of the time in the years 1999-2000



- No Australian paediatric study published
- NSW Health audit of CPG's
  - uptake: variables, challenges
  - messages: access, decision support
- NSW K+F: standardisation of care; studies

Mangione-Smith et al., NEJM 2006









### Who is involved

### Project Team

- 5 Chief Investigators, 9 Associate Investigators, 5 International Advisory Group, 5 operational team
- Expertise: Paediatrics, General Practitioners, health services research methods, patient safety, project management

### Funding

- NHMRC Partnership Grant
- BUPA Health Foundation
- Sydney Children's Hospitals Network, NSW Kids and Families, Children's Health Queensland, the South Australian Department of Health, NSW Clinical Excellence Commission.
- Managed by Macquarie University and UniSA











- Obtain national agreement on sets of indicators for the management of 16 common paediatric conditions (i.e. wiki).
- Measure the appropriateness of health care delivered to children in Australia in acute, primary and community health care settings.
- 3. Measure the frequencies and types of *adverse events* encountered in Australian paediatric care.









## Methodology

- Modified Delphi panel to develop clinical indicators (internal / wiki review)
- Medical record review for appropriateness and adverse events (2012-2013)
- Appropriateness (as per the adult study): care in line with evidenceor consensus-based guidelines
- Children aged <16 years with one of the proposed conditions</li>
- De-identified list (MRN, DOB) requested from hospitals of inpatient and ED presentations meeting the requirements above.
- Sample then randomised to provide a final list of 100 medical records to be reviewed
- Surveyors (RNs) employed to collect the data









## **Conditions**

### Importance

- High prevalence of presentations
- Burden of disease (BOD) data
- National Health Priority Area (NHPA)
- Impact in terms of cost and health outcomes

## Feasibility, accessibility

- Multiple healthcare providers per condition
- High frequency of encounters
- Likely to be documented in medical record









## **Candidate conditions**

Condition	
Acute abdominal pain	Fever
ADHD	Gastro – Oesophageal Reflux Disease (GORD)
Acute Bronchiolitis	Head injury
Acute Gastroenteritis	Obesity
Anxiety/Depression	Otitis media
Asthma	Preventive care
Autism	Seizures
Croup	Tonsillitis
Diabetes	Upper Respiratory Tract Infection
Eczema	Urinary Tract Infection









## External wiki-based review of indicators

- Indicators have been derived from clinical practice guidelines
- Conditions ready for review available via the wiki website
- Recruitment of clinical experts
   https://www.caretrackaustralia.org.au/











## **Adverse Events**

- Aim: to measure the frequency and type of adverse events (AEs) associated with healthcare encounters in Australian paediatric care
- Using a modified version of the IHI Global Trigger
   Tool a 2 stage process
- Collect AEs from all types of healthcare providers pending feasibility results from pilot study
- Undertaken simultaneously to the collection of appropriateness data









## **Further information**

- Professor Jeffrey Braithwaite Chief Investigator, jeffrey.braithwaite@mq.edu.au
- Professor Les White Chief Investigator, <u>lwhit@doh.health.nsw.gov.au</u>
- Ms Tamara Hooper Project Manager, tamara.hooper@unisa.edu.au, 08 8302 1004
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