POLICY, PRACTICE AND HEALTH SERVICES RESEARCH
RELATING TO NSW CHILDREN AND FAMILIES

AiHI Research Symposium, Macquarie University
Joanna Holt, Chief Executive NSW Kids and Families
Les White, NSW Chief Paediatrician

31 March 2015
### 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

2008
+ Garling Report
+ Wood Report

2009
Keep Them Safe

2011
+ State/national health reforms
  + SCHN
  + Expert Group

2012
NSW Kids and Families established

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

Cluster Ministers

Secretary, NSW Health
Ministry of Health/Health Administration Corporation

Statewide Health Services
- NSW Ambulance
- NSW Health Pathology
- Health Protection NSW

Shared Services
- HealthShare NSW
- eHealth NSW
- Health Infrastructure

Service Compacts

Service Agreement
Price / Volume / Performance

Local Health Districts (15) and Specialty Health Networks (3)

Pillars
- Agency for Clinical Innovation
- Bureau of Health Information
- Cancer Institute NSW
- Clinical Excellence Commission
- Health Education and Training Institute
- NSW Kids and Families

Minister for Health appoints Boards and meets regularly with Council of Board Chairs

Service Compacts

*Service Compact – Instrument of engagement detailing service responsibilities and accountabilities
No Service Compact between Ministry of Health and Ambulance Service of NSW
To be formally established in 2014
As at 30 September 2015
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
Youth Health and Wellbeing
- Youth 12-25 years
- Networks – youth workers in Health and outside; government agencies; and NGOs

Child Protection & Violence Prevention
- Women, children, young people and families
- Networks – Interagency; NGOs

Maternal, Child and Family Health
- Pregnant women, mothers, babies, children 0-12 years, families
- Networks – PSN; other

Paediatric Healthcare
- Support hospital system/clinicians
- Children to 16 years
- Networks – CHN, MP4; RP4; NETs; allied health

Networks outside NSW Health –
- Networks – youth workers in Health and outside; government agencies; and NGOs
- Networks – Interagency; NGOs
- Networks – PSN; other
- CHN, MP4; RP4; NETs; allied health

healthy, safe and well
The Health System for Children, Young People and Families

General Practice

Community Health Services

Commonwealth Health Programs

VMOs

NSW Health

NSW FaCS

NSW Education & Communities

NGOs
HEALTHY, SAFE AND WELL

A STRATEGIC HEALTH PLAN FOR CHILDREN, YOUNG PEOPLE AND FAMILIES

2014-2024
Context of Healthy, Safe and Well

NSW 2021

NSW State Health Plan 2014–17

Healthy, Safe and Well

Rural Health Plan

Mental Health Plan

LHD/SHN strategic plans and Clinical service plans

NSW K+F and Pillars strategic and corporate plans

Indirect influence
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 Strategic Health Plan identified Evidence and Measurement as key enablers:

<table>
<thead>
<tr>
<th>Workforce</th>
<th>Evidence</th>
<th>eHealth</th>
<th>Leadership</th>
<th>Measurement</th>
<th>Partnership</th>
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</thead>
<tbody>
<tr>
<td>We will ensure health professionals have the skills to deliver quality health care</td>
<td>We will promote translation of evidence-based research to support delivery of quality health care</td>
<td>Use of technology will improve information sharing and delivery of quality health care</td>
<td>NSW Kids and Families and a guiding Council will coordinate strategies in relation to this Plan</td>
<td>We will monitor implementation, evaluate cost-effectiveness, measure and report on the outcomes</td>
<td>We will work collaboratively with partners, build services within communities, and partner with Aboriginal and other communities</td>
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Existing data collected from across NSW Health

NSW Kids and Families assimilates secondary research or works with researchers/partner organisations to generate evidence.

Using evidence to develop policy

Using implementation science to get policy into practice

From Evidence to Practice
Examples of evidence assimilation

- 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
- Adolescents and young adults’ use of emergency departments
- Forensic and medical photography, video recording and video transmission for cases of suspected sexual abuse in children and young people
- Clinical variation in paediatric care
- Paediatric services capability
Using Evidence to Develop Policy

EXISTING DATA / KNOWLEDGE BASE

RESEARCH + EVALUATION → EVIDENCE
Example 1: Youth Health Competency Framework

Youth Health Policy 2010–16 - annual data collection

2014
Independent scoping study on:
- Literature on workforce development
- Current youth health training programs and other resources
- Consultation with health agencies, young people, health professionals and training providers

EXISTING DATA / KNOWLEDGE BASE

RESEARCH + EVALUATION → EVIDENCE

FRAMEWORK

YOUTH HEALTH

COMPETENCY FRAMEWORK

Youth Health Policy 2010–16 - annual data collection

healthy, safe and well
Example 2:
Sustaining NSW Families (Keep the Safe)

Evaluation of Sustaining NSW Families (Keep Them Safe) to investigate:
- 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

POLICY CHANGE

RESEARCH + EVALUATION → EVIDENCE

EXISTING DATA / KNOWLEDGE BASE

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

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
Current projects – research focussed

- Access Phase 3 - work in the area of access to youth health
- Appropriateness of healthcare delivered to Australian children: CareTrack Kids
- Seeding success: A study of early child health and development in Aboriginal children
- 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)
- 45 and Up Study - longitudinal study of healthy ageing - Sponsorship of questions
- National burden of disease study examining the impact of violence against women
- Aboriginal and Antenatal Screening Impact Study - Domestic Violence research
- Delivering safe and effective care to children in hospitals with eHealth systems
- Improving health outcomes in children suffering major injury
- Paediatric injury prevention projects
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

0. No participation
1. Link and facilitate
2. Contribute support/approval
3. Contribute support/approval & support in kind
4. Contribute support/approval, support in kind & contribute funding
5. Contribute directly to work
6. 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
The Seeding Success Study

- **Study population:** All children who started school in NSW in 2009 and 2012, followed from birth to school age

- **Data:** linked, administrative health, community services, welfare and education data

- **Aims:**
  1) 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
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
**Aims**

1. Obtain *national agreement* on sets of indicators for the management of 16 common paediatric conditions (i.e. wiki).

2. 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 evidence- or consensus-based guidelines
- Children aged <16 years with one of the proposed conditions
- 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
<table>
<thead>
<tr>
<th>Condition</th>
<th>Candidate conditions</th>
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<tr>
<td>Acute abdominal pain</td>
<td>Fever</td>
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<tr>
<td>ADHD</td>
<td>Gastro – Oesophageal Reflux Disease (GORD)</td>
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<tr>
<td>Acute Bronchiolitis</td>
<td>Head injury</td>
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<tr>
<td>Acute Gastroenteritis</td>
<td>Obesity</td>
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<tr>
<td>Anxiety/Depression</td>
<td>Otitis media</td>
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<tr>
<td>Asthma</td>
<td>Preventive care</td>
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<tr>
<td>Autism</td>
<td>Seizures</td>
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<tr>
<td>Croup</td>
<td>Tonsillitis</td>
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<tr>
<td>Diabetes</td>
<td>Upper Respiratory Tract Infection</td>
</tr>
<tr>
<td>Eczema</td>
<td>Urinary Tract Infection</td>
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</table>
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/

SEEKING CLINICIANS
with paediatric expertise to edit condition indicators in a national online survey for the CareTrack Kids project

Register online at:
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, lwhit@doh.health.nsw.gov.au

• Ms Tamara Hooper – Project Manager, tamara.hooper@unisa.edu.au, 08 8302 1004

• Mr Peter Hibbert – Program Manager, peter.hibbert@mq.edu.au