Growing deadly families
a healthy start for young children

4 August 2017
Brisbane Convention and Exhibition Centre

Partnering to improve the health of Aboriginal and Torres Strait Islander peoples
Please be aware that this report may contain images of Aboriginal and Torres Strait Islander people who have passed away.

Queensland Clinical Senate, Meeting Report
Published by the State of Queensland (Queensland Health), October 2017.

This document is licensed under a Creative Commons Attribution 3.0 Australia licence. To view a copy of this licence, visit creativecommons.org/licenses/by/3.0/au
© State of Queensland (Queensland Health) 2017

You are free to copy, communicate and adapt the work, as long as you attribute the State of Queensland (Queensland Health).

For more information contact:
The Queensland Clinical Senate, email qldclinicalsenate@health.qld.gov.au phone 3328 9188. An electronic version of this document is available health.qld.gov.au/clinical-practice/engagement/clinical-senate/default.asp

Disclaimer:
The content presented in this publication is distributed by the Queensland Government as an information source only. The State of Queensland makes no statements, representations or warranties about the accuracy, completeness or reliability of any information contained in this publication. The State of Queensland disclaims all responsibility and all liability (including without limitation for liability in negligence) for all expenses, losses, damages and costs you might incur as a result of the information being inaccurate or incomplete in any way, and for any reason reliance was placed on such information.
## Contents

**WELCOME** ....................................................................................................................................................... 4

**OUTCOMES AND RECOMMENDATIONS** ............................................................................................................ 6

**VISION** ............................................................................................................................................................. 7

**APPROACH** ........................................................................................................................................................ 7

**WHY FOCUS ON IMPROVING THE HEALTH OF ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN?** ....................... 7

**KEY STATISTICS** .................................................................................................................................................... 8

**WELCOME AND BLESSING** ................................................................................................................................ 8

**PRESENTERS AND PANELLISTS** .......................................................................................................................... 8

**DELEGATES** ...................................................................................................................................................... 8

**PRESENTER HIGHLIGHTS** .................................................................................................................................. 9

**THE COMMONWEALTH PERSPECTIVE** .................................................................................................................. 9

**THE CONSUMER EXPERIENCE** .......................................................................................................................... 10

**SYSTEM CHANGES** .............................................................................................................................................. 11

**DISCUSSION: WHAT SYSTEM REDESIGN COULD MAKE INTEGRATION BETWEEN PRIMARY, COMMUNITY AND TERTIARY SERVICES HAPPEN?** .......................................................... 12

**PANEL DISCUSSION – CARING FOR ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN AND FAMILIES** ...... 14

**PANEL MEMBERS** .............................................................................................................................................. 14

**KEY POINTS** ...................................................................................................................................................... 14

**APPENDIX 1:** .................................................................................................................................................. 16

---

Growing deadly families meeting report • 4 August 2017
Welcome

Health and well-being is a basic standard by which we can identify and measure inequality and fairness. For far too long Aboriginal and Torres Strait Islander people have tolerated and accepted their poor health status. Neither Queensland Health, nor the Queensland Aboriginal and Torres Strait Islander Community Controlled Health Sector, can shrink from the challenges ahead to improve Aboriginal and Torres Strait Islander health in Queensland.

The Queensland Clinical Senate provided a forum for discussion and knowledge sharing on Aboriginal and Torres Strait Islander health and wellbeing of children and families. Attended by more than 150 delegates, it provided a calm and sobering assessment of how much work must occur before we will see better health outcomes. Others will debate the complex reasons why Aboriginal and Torres Strait Islander health isn’t improving. It is not a time to dramatise this shameful condition, however no one should overlook the urgency of the moment.

The meeting took place at a time when grave issues face our state. While the government debates health funding priorities, and Hospital and Health Services move to tackle institutional racism, Queensland clinicians and health service leaders must continue to be engaged in one of the most important challenges of modern time – improving Aboriginal and Torres Strait Islander health and wellbeing.

No person at the meeting could fail to be deeply moved by the stories they heard from Aboriginal and Torres Strait Islander consumers, presenters and the many dedicated clinicians and health service leaders who are trying hard to make a difference. It was refreshing to see Queensland Health staff be brave enough to talk about their challenges and not substituting words for their failure to understand, address and improve the health of Aboriginal and Torres Strait Islander Queenslanders.

Queensland Health knows why it is important to improve Aboriginal and Torres Strait Islander health. In a series of measured steps, Queensland Health have seen some progress - but more must be done. The old rhetoric of ‘treating everyone the same’ that plagues the health system in Australia has shown no signs of accomplishing a dramatic improvement. For decades, this approach has failed and we need to disrupt this thinking.

The Queensland Aboriginal and Islander Health Council understands and knows the challenges that are needed to improve Aboriginal and Torres Strait Islander health. Together with the Queensland Aboriginal and Torres Strait Islander Community Controlled Health Sector, we have worked hard to identify solutions. Our minds and hearts continue to be focused on a seamless culturally competent health system that improves lives, and Aboriginal and Torres Strait Islander health and wellbeing. QAIHC has demonstrated that it is a leader in change. We extend our hand to Queensland Health so that together we can work, side by side, not in competition, but as collaborators to improve the health system so we have deadly families.

A number of participants at the Queensland Clinical Senate have had success in improving the lives of Aboriginal and Torres Strait Islander people, some of whom are veterans in the Aboriginal and Torres Strait Islander health space. I encourage you to stay committed and to share your wisdom with colleagues and peers, just as QAIHC will share its evidence based solutions with Queensland Health leaders.

Older generations – both Aboriginal and Torres Strait Islander advocates, clinicians and health service leaders, have made sacrifices in their efforts to see improvements in Aboriginal and Torres Strait Islander health.
health. Today, it falls on us to bear the same responsibility and to not stop trying. We need to reassert our commitment with greater determination so that Aboriginal and Torres Strait Islander Queenslanders can have the same quality of life as non-Indigenous Queenslanders. You can achieve this.

I wish all the participants at Queensland Clinical Senate the best in your efforts to improve the health of Aboriginal and Torres Strait Islander Queenslanders.

Neil Willmett
Chief Executive Officer
Queensland Aboriginal and Islander Health Council

Consumer input is vital for effective health care. Without the ideas, stories and experiences of those who actually use the services, designing and redesigning health services that meet the needs of the community is pointless. This is even more so for Aboriginal and Torres Strait Islander healthcare.

We were very fortunate to have had the invaluable input of Aboriginal and Torres Strait Islander elders, mothers and healthcare providers at our Growing Deadly Families meeting. Their honesty and thoughtful feedback was critical in helping clinicians and health system administrators to really appreciate the issues and develop a set of recommendations that have the potential to make a genuine difference to the health of Aboriginal and Torres Strait Islander children and families. We thank each of you for your time, efforts and involvement.

One of the messages that was loud and clear from our guests was that these partnerships with consumers and other key organisations, such as Aboriginal Community Controlled Health Services, must continue or be established if we are serious about better access to care for Aboriginal and Torres Strait Islander people.

We need to work in partnership to identify goals, co-design, implement and evaluate services to ensure they are working. There are many collaborative approaches and models of care that have been implemented locally and are meeting community needs. We need share those successes with others. And if it isn’t working, stop doing it! Step back and look at the service from the point of view of those using it – listen to their ideas, stories and experiences. If a service meets the needs of the people, they will use it.

It was also very apparent from our consumer feedback that one size doesn’t fit all. We cannot expect a service that is successful in Brisbane, for example, to have the same success in a remote Aboriginal and Torres Strait Island community without modifications that consider the culture and needs of the people.

We have to build a comfort and confidence in providing care to our Aboriginal and Torres Strait Islander patients and their families and I believe this will go a long way in breaking down the barriers to care.

David Rosengren
Chair
Queensland Clinical Senate
Outcomes and recommendations

Aboriginal and Torres Strait Islander people have a holistic view of health and wellbeing that is inseparably linked to their cultural, spiritual, emotional and physical connection with the land and sea.

While improving Aboriginal and Torres Strait Islander peoples’ health and wellbeing is everyone’s business, enabling local communities to take charge of their healthcare is key to closing the gap.

Aboriginal Community Controlled Health Services (ACCHSs) are strong and effective advocates and play a critical role in delivering holistic and culturally appropriate health care to their communities.

Working differently together, local communities, ACCHSs, Primary Health Networks, Hospital and Health Services (HHSs), the Department of Health and other key local stakeholders can improve the health and wellbeing of Aboriginal and Torres Strait Islander people by:

1. Partnering to identify goals, co-design, implement and evaluate an integrated health system that empowers Aboriginal and Torres Strait Islander people so that their journey through the health system is coordinated, culturally safe and maximises their wellbeing.

2. Leaders working together to improve experiences and health outcomes through:
   - Committing to a shared vision, goals and strategies that meet community priorities, starting at a strategic level with the Boards with a memorandum of understanding between leader groups
   - Agreed, coordinated and joint funding (government, philanthropic and non-government sectors) to address priority targets
   - Establishing governance structures with clearly defined roles, strengthened responsibilities and reportable accountability at ACCHS and HHS Board level
   - Implementing mechanisms to shift and direct resources to enable the most appropriate organisation/s to deliver care, including transferring resources from tertiary to primary care and where best placed, to ACCHSs
   - Maximising opportunities for ACCHSs to improve the continuity of care for patients during their hospital stay.

3. Leaders resolving to be innovative and active in developing and implementing strategies to embed cultural competence and cultural safety within organisational culture, governance, policies and practices through:
   - Rethinking ‘safety’ by placing equal importance on cultural safety as clinical safety
   - Inviting local community members to provide the workforce with experiences that nurture an attitude and desire to better understand Aboriginal and Torres Strait Islander peoples’ culture
   - Identifying and empowering cultural mentors in work units to support staff to learn and deliver services in a culturally respectful and appropriate way, and
   - Sharing models and approaches that have proven to be successful and having the courage to stop doing what does not work
   - Acknowledging and strategically addressing the ongoing impact on families and their relationship with service providers, of historical policies including those of Aboriginal and Torres Strait Islander child removals

4. Changing the workforce to reflect the community and its needs.
   - Developing a specific leadership program to nurture, grow and support our Aboriginal and Torres Strait Islander workforce, and
   - Increasing the number of Aboriginal and Torres Strait Islander people trained and employed in health services across all professional streams.
Vision
The aim of the Growing Deadly Families forum was for communities, clinicians and health systems leaders to work together to improve the health of Aboriginal and Torres Strait Islander children.

Approach
Five of the state’s peak health bodies partnered to deliver the Growing Deadly Families forum:
- The Queensland Clinical Senate
- Queensland Health
- Health Consumers Queensland
- The Institute for Urban Indigenous Health
- Queensland Aboriginal and Islander Health Council

The forum took a unique approach to addressing the poorer health outcomes of Queensland’s Aboriginal and Torres Strait Islander people. Senate members, clinicians and health system leaders were invited to listen to the stories of Aboriginal and Torres Strait Islander people and healthcare providers about their experience of the health system. Presentations about successful programs gave guests insights into what is working and why.

Clinicians and health service leaders then worked in partnership with the forum’s Aboriginal and Torres Strait Islander guests to highlight the key problem areas and how improvements could be made.

The meeting followed a forum on Aboriginal and Torres Strait Islander maternal health and maternity care. The Department of Health and colleagues will consider strategies to address the issues raised and develop an action plan to improve services. For more information please contact PSQIS_Maternity@health.qld.gov.au

Why focus on improving the health of Aboriginal and Torres Strait Islander children?
While most Queenslanders enjoy a healthy start to life, there is still a gap to close on birthing and early childhood outcomes for Aboriginal and Torres Strait Islander children. Investing in the health of our little ones and their mum is proven to be one of the best ways to address disadvantage throughout life.
Key statistics

- The difference in life expectancy between Aboriginal and Torres Strait Islander people and non-Indigenous people in Queensland is: 10.8 years for males and 8.6 years for females.
- Mortality rates for children under five are 1.7 times higher than non-Aboriginal and Torres Strait Islander children.
- Mortality rates for children under one are 1.6 times higher than non-Aboriginal and Torres Strait Islander children.
- Mortality rates for neonates are 1.5 times higher than non-Aboriginal and Torres Strait Islander children.
- The top four reasons for Aboriginal and Torres Strait Islander children hospitalisations are: respiratory system; conditions originating in the perinatal period; injury poisoning and other external causes; and infectious and parasitic diseases.

Welcome and blessing
Aunty Carol Currie – Welcome to Country
Annai Ghee, Blessing

Presenters and panellists
Dr Raymond Blackman, general practitioner, Palm Island Community Company
Chelsea Bond, health consumer and University of Queensland academic
Adrian Carson, Chief Executive Officer, The Institute for Urban Indigenous Health (IUIH)
Elder Aunty Lillian Gray, Doula Program, Cherbourg
Dr Carmel Nelson, Clinical Director, IUIH
Chelsea Rolfe, health consumer
Trudi Sebasio, Regional Indigenous Operations Manager, Mackay Hospital and Health Service
Professor Cindy Shannon, forum facilitator
Kristie Watego-Ivory, Health consumer and Manager, Birthing in Our Community, IUIH
The Hon. Ken Wyatt AM, MP, Commonwealth Minister for Indigenous Health and Minister for Aged Care

Delegates
More than 150 delegates including Aboriginal and Torres Strait Islander people and elders, healthcare providers, clinicians and health system leaders attended the full-day forum.

The involvement of Aboriginal and Torres Strait Islander consumers and healthcare providers from around Queensland was vital for this meeting. Listening to their experiences, stories and ideas, gave clinicians and healthcare administrators a real perspective of what is working and where we can do better. Thank you to everyone who shared stories, ideas, thoughts and perspectives. Feedback from consumers about various aspects of the meeting has been collated and is available to inform future meetings involving Aboriginal and Torres Strait Islander people.
Presenter highlights

The Commonwealth Perspective

The Hon. Ken Wyatt AM, MP, Commonwealth Minister for Indigenous Health, Minister for Aged Care

- While there has been progress in advancing sustainable improvements in Indigenous healthcare, it remains the nation’s most confronting health challenge.
- But we have to celebrate the jewels in the crown. We have to talk about the gains we are making over the gaps that exist. If you keep giving a negative message to a child, or an adult or to a profession then they become imbued with the view that nothing will ever succeed.
- The hue of language is an important element in the engagement with Aboriginal and Torres Strait Islander people. We make assumptions as professionals and as people who hold positions of leadership that everybody within the context of our discussions understands every word that we speak. Part of what we have to learn to do when we engage with our communities is about the notion of understanding each other clearly if we are to make the changes over the next 25 years that bring the outcomes that we need.
- We are not going to change Aboriginal and Torres Strait Islander people health unless we start to engage at a very different level.
- We also have to engage as equals both in shaping and designing what is required at the community level.
- We have to remember that one size does not fit all. Without local consumer and community partnerships health services can’t understand the problems, design the right aims, measure the effect of care and change ideas. Systems of care need to be tailored/flexible to meet local needs of the community, individual and family.
- Aboriginal and Torres Strait Islander people and community partnerships with healthcare service organisations in the design, delivery, evaluation and monitoring of services benefits all – an improved experience of cultural safety for Indigenous people; improved quality and efficiencies in healthcare service delivery; encourages people to be more aware of and have a better understanding of their health needs and ‘Partnering with Aboriginal and Torres Strait Islander people and communities is a key driver and mechanism to improve the quality of care provided - partnerships result in safer care, better health outcomes and more efficient services.’
take more responsibility and responsiveness in their own healthcare. Ultimately, partnering delivers a system that people:

- Trust – that it will meet and respond to their needs.
- Have a voice in.

- Where something isn’t delivering the results you want and need, redesign it with those who will use the system and consider what additional options you might want to reform instead of doing it the same way you always have.

- Examples of excellent services in Queensland that have been co-designed with co-accountability and that are delivering improved outcomes:
  - The Institute of Urban Indigenous Health (IUIH)
  - Birthing in our Community is a partnership between IUIH, Mater Mothers’ Hospital and Aboriginal & Torres Strait Islander Community Health Service (ATSICHS) to provide clinically and culturally safe antenatal care to Aboriginal and Torres Strait Islander women living in urban areas.
  - Apunipima Baby One Program
  - West Moreton Hospital and Health Service partnership with local community controlled health organisations to co-design service delivery models.

The consumer experience

Kristie Watego-Ivory, mother of two boys

‘I need to feel safe in an environment where I can ask silly questions and not feel judged for what I don’t know. I have always been taught to trust and follow what authority tells you but I have learnt to find the courage to question that and trust myself if I feel like something is wrong and also seek out those familiar faces that I feel comfortable with to ask the silly questions.’

- Both of my experiences (birthing) were wonderful but very different.
- My first experience was through the public system (The Murri Clinic) – it was beautiful but daunting because it was at a hospital where we had recently lost some family members but it was beautiful to go into a space that was familiar and with familiar faces. I felt very comfortable asking silly questions to some familiar faces.
- Having those ladies walk with me on that journey was wonderful.
- I elected to go with an obstetrician through the private system with my second child because my pregnancy was high risk – I found the experience to be extremely clinical and scary because I felt like I couldn’t ask the silly questions that I really needed to ask.
- I felt shameful because I was worried I had disadvantaged my unborn child as a result of gestational diabetes and that the clinicians who I see as authority figures would judge me for asking ‘silly questions’.
- I would have been able to talk to someone I felt could understand my journey or talk ‘on my level’. Someone who was in tune with how I was feeling and would have supported me with the information I needed rather than me having to find the courage to ask the questions.
Chelsea Rolfe, mother of four

- Living in Brisbane exposes me to many more choices than women living in rural and remote areas.
- I was linked with Ngarama for my last two pregnancies and I felt that whenever I needed them they were there - as a result I was empowered with choice.
- The challenge for me was in the post-partum period. The six weeks of home visits from Ngarama was vital for checking in on my health and the baby’s health – it’s a very proactive model.
- I felt like I had built real relationships with those women and they would have picked up if anything was wrong. They were so encouraging, so I felt like I was doing a deadly job.

Health system changes

Trudi Sebasio, Regional Indigenous Operations Manager, Mackay Hospital and Health Service

- The hospital liaison service started as one person and has grown into a full service – a liaison service doesn’t work with just one person.
- Started by looking at our community – Aboriginal and Torres Strait Islander people make up 5.4% of overall population, with hospital admission rates at 8.7%, mental health unit 12-14% and paediatrics 12-15%.
- Cultural considerations in developing the service included gender and background (Aboriginal, Torres Strait Islander, Australian South Sea Islanders) of hospital liaison officers.
- Healthcare providers in hospital and community settings/services.
- Liaison officers in hospital are non-clinical and they provide support to patients throughout their hospital journey. IT systems are used to identify when an Aboriginal and Torres Strait Islander person has been admitted and to generate reports flagging future outpatient appointments and fail to attend outpatient appointments.
- A day in the life of a hospital liaison officer includes ward rounds, organising family meetings when needed for complex admissions, linking patients to appropriate GPs / Aboriginal Islander Medical Service if they aren’t already connected and other social services.
- We work on the principle of ‘Nothing about me without me’.
- All antenatal clinics are outreach clinics into the suburbs with higher population of Aboriginal and Torres Strait Islander people.
- Key performance indicators - potentially preventable admissions and addressing discharge against medical advice.
Dr Carmel Nelson, Clinical Director
The Institute for Urban Indigenous Health (IUIH)

- CareConnect was established in 2012 to provide a connector service between tertiary and primary care for people with chronic kidney disease.
- It was recognised that the service wasn’t working as initially intended – harder to reach out to community from hospital than reaching into the hospital from community.
- Redesign solution was to transfer resources to IUIH to establish IUIH Connect.
- The service includes nurse care coordinators and Indigenous outreach workers whose brief is to connect Aboriginal and Torres Strait Islander people – as they make the journey from home to hospital and back home – with ACCHS, mainstream GP, social and other support services.
- Technology, people and relationships are required to create the link.
- To build on this we need to strengthen partnerships and trust to allow Aboriginal Community Controlled Health Organisations reaching into hospital to do the work they need to do.
- Need to be seen as ‘inside system’ not outside of the system.
- To do this and make it work better: regional model (hub and spoke) that works well in urban areas and would work well in regional areas. May need resourcing in some areas, but primarily it is a redesign effort that needs commitment to the solution by all. Partners with resources and expertise coming together to share the resources – a leadership investment.

Discussion: What system redesign could make integration between primary, community and tertiary services happen?

- Start at a strategic level with the Boards with a memorandum of understanding between leader groups
- Put governance in place and support people on the ground to work with the community to design, implement and evaluate it.
- Need to have incentives in place (state and commonwealth) to support organisations to integrate.
- Through incentives, policy and putting the necessary infrastructure in place, the system can ‘expect’ integration to be a part of how organisations do business into the future.
- Hospital and Health Services should be working closely with the Primary Health Networks.
- When the nurse navigator services were introduced in Torres Strait it became apparent that healthcare provider navigators are essential to work alongside the nurse navigators. Healthcare providers have an intimate knowledge of the community, the people and the barriers.
• Health is about everybody so we need to enable the leadership and communities (Indigenous and non-Indigenous) to have a voice in what their health services look like and we need to listen. But how do we change the system – we need to enable the leadership and give them permission to work differently and work with the community to get an answer that works.

• Western Queensland Primary Health Network has an agreement with the three hospital and health services in the region and the ACCHS – a strategic level agreement to ensure decisions around systems and initiatives are made together and that resources can be shifted toward achieving a common goal.

How do we make the system culturally competent?

• It’s about sitting down and talking to people and trying to get an understanding and learning more about their culture. You have to have a desire to learn about someone else’s culture.

• Cultural competence really means going beyond tolerating other cultures to reflect on yourself and your own attitudes and genuinely valuing the different perspectives that people bring to a situation.

• You’re a novice until you become an expert – apply this framework to cultural capability. You might be the deadliest clinician but culturally you’re a novice. It’s a lifelong learning experience and you’re not going to be an expert if you don’t put any energy in.
Panel discussion – caring for Aboriginal and Torres Strait Islander children and families

Panel members
- Adrian Carson, Chief Executive Officer, The Institute for Urban Indigenous Health
- Elder Aunty Lillian Gray, Doula Program, Cherbourg
- Chelsea Rolfe, Health consumer
- Kristie Watego-Ivory, Health consumer and Manager, Birthing in Our Community, The Institute for Urban Indigenous Health
- Dr Raymond Blackman, general practitioner, Palm Island Community Company

Key points
- Care happens within a cultural, social and family context. Issues that impact on care include:
  - Child safety – fearful that child will be taken from them if they go to hospital.
  - Greater social issues within the family and community. They must be considered with every interaction and how they will impact health and treatment.
- Access to medicines under the S100 Remote Area Aboriginal Health Service Program and the Close the Gap Pharmaceutical Benefit Scheme Co-payment measure has created a number of challenges in ensuring a consistent level of care to patients. These issues, and the current inability of a Aboriginal Health Services to operate a community pharmacy, have been acknowledged in the Review of Pharmacy Remuneration and Regulation Interim Report (June 2017).

‘I use both the Hospital and CRAICCHS [Cherbourg Regional Aboriginal and Islander Community Controlled Health Services]. CRAICCHS give me my medications for free but I have to pay for it if I get it from the hospital.’
Elder Aunty Lillian Gray
• Meeting participants supported the recommendations made in the review that access to medicines programs for Aboriginal and Torres Strait Islander people under programs and co-payment measures should be reformed so that the benefits to the individual follow that individual, regardless of where the prescription is written or dispensed.
• On Palm Island patients are treated and respected as ‘family’ - medicine is practiced as a family.
• Opportunities to integrate models of care so that patients can access care more easily rather than trying to navigate the various disparate systems.
• Role for ACCHSs to ensure Indigenous people can access the full range of health services they might require through one door.
• System needs to empower Aboriginal and Torres Strait Islander people to take control of their health and to create a system that enables people to access the care they require in a way that supports people (not punishes them).
• Health is much bigger than just health service delivery.
• Key lessons from services that are working and not working:
  o There are good examples of success – they need to be promoted and resourced so that they can be sustained.
  o Hospital services are important but the biggest gains that need to be made to improve the gap in Indigenous health sit outside the acute hospital care system (i.e. primary care and child health services). Queensland Health and Hospital and Health Services need to rethink their roles ‘outside of hospitals’ and how they support primary care.
  o Clinicians need to have greater awareness on how Aboriginal and Torres Strait Islander people can be supported within the existing system (e.g. access to free medicines).
• What needs to change: working together to create the change; stronger genuine relationships; connecting and respecting Aboriginal and Torres Strait Islander people to create a trusting relationship; needs to be a big change (not incremental little changes) to close the gap.

Photo (L to R): Health consumers Stephanie and Evie-Rose (9 months) from Mount Isa, Chantelle and Ruby (5 months) from Dalby, Ashleigh and Harper (9 weeks) from Hervey Bay, and Che and Dhaluwan (9 months) from Badu Island.

Photo: ‘The worry about accessing the services that our families require is our worry not theirs.’ Adrian Carson (pictured left), Chief Executive Officer, The Institute for Urban Indigenous Health with Cindy Shannon, meeting facilitator.
Appendix 1:

Attendees, working in groups, provided responses to a number of questions about the following case study. A summary of the responses to each of the questions is provided in the table below.

Background Information (note: this is a hypothetical case) Jordan is three years old. His mother (Ruthie) was born and raised in a remote Cape York community. She was 19 when he was born and this was her third pregnancy. Her first child, Adam, born prematurely when Ruthie was sixteen died [while in the care of Ruthie's mother, Jenny] aged nine months. The second child, Spencer, aged 15 months, was also premature and born in Cairns. The father of both Spencer and Jordan is Peter, a Torres Strait Islander. Jordan was also born premature (at 32 weeks) in Cairns Base Hospital and his mother returned home to her community in Cape York three days after delivering him, while he remained in hospital for several weeks. The family moved to Brisbane a year ago but maintains strong connections with their communities in North Queensland.

Case Study - Jordan is three years old and is brought into the ED of a major Brisbane hospital by his grandmother. He has extensive skin sores over his body, which have become crusted and itchy.

His record shows he was seen by a colleague six months ago and treated with antibiotics for impetigo. His grandmother was unaware of this and unable to give a full medical history. She did however, express concerns about Jordan's behaviour of late and thought his development was a “bit slow”. Jenny suggested the local clinic would be able to help with his medical history. Immunisations are up-to-date, however were delayed during first 12 months. Jordan's parents are currently unemployed and living with extended family in overcrowded rented accommodation in Caboolture. His cousins regularly visit from out of town, most recently two months ago during school holidays. Jordan attends a local Indigenous playgroup once a week.

**SUMMARY – First session – Family, cultural and social context**

<table>
<thead>
<tr>
<th>Critical Context</th>
<th>Issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social</td>
<td>- Housing (overcrowding, temporary, poorly equipped, hygiene)</td>
</tr>
<tr>
<td></td>
<td>- Economic disadvantage (unemployment, financial stress, increased demand on limited resources, nutrition)</td>
</tr>
<tr>
<td></td>
<td>- Limited transport options</td>
</tr>
<tr>
<td></td>
<td>- Away from home (Cairns) – why, isolated, how connected now?</td>
</tr>
<tr>
<td></td>
<td>- Children attending indigenous playgroup</td>
</tr>
<tr>
<td></td>
<td>- Ashamed to bring child in for checkup, upset re: waiting with itchy child</td>
</tr>
<tr>
<td></td>
<td>- Presentation – why now? Why emergency department (ED) and not general practitioner (GP)?</td>
</tr>
<tr>
<td></td>
<td>- Communication: effective, two-way</td>
</tr>
<tr>
<td></td>
<td>- Clinicians need to understand child’s life including fragmentation of care</td>
</tr>
<tr>
<td></td>
<td>- Repetition of questions annoying</td>
</tr>
<tr>
<td></td>
<td>- Existing infrastructure unable to deliver healthcare locally</td>
</tr>
</tbody>
</table>

| Emotional         | - Family/mother’s trauma: grief and loss influences own psychological wellbeing and perception/trust of healthcare facility  |

| Cultural          | - Separation from country, community and family supports  |
|                  | - Family expectations, child not born on country  |
|                  | - Healthcare provider involvement within system  |
|                  | - Racism  |
|                  | - Fear of health service and judgment  |
|                  | - Appropriateness of health service (staff diversity, consistency, understanding, safety, training and experience)  |
|                  | - Understanding of Western healthcare  |
### Family
- Role of extended family (esp. grandmother) in caring for children – consent issues?
- Provides context of presentation, including concerns about cognitive functioning
- Young parents, where is the mother, who is the primary carer?
- Missed opportunity for mother and extended family to bond with baby in initial weeks
- Consideration of other children
- Infected contacts and family members

### The view from within the health system
- Preconceived notions about Aboriginal and Torres Strait Islander people
- Lack of information leads to judgment re: what’s the involvement of the young parents, are they coping, lack of hygiene?
- Carer role falls to grandmother who isn’t legal guardian – consent and language issues?
- Risk aversion: child safety concerns, neglect?
- Some EDs link patient with hospital liaison officer
- Were the patient’s needs (medical, cultural and communication) met on previous presentation/s?
- Focuses on acute illness and risk rather than wellness and strengths, disregard concerns re: development
- Low urgency, low triage, long wait, grandmother may walk out (due to wait time and trust issues)
- Lack of resources impedes ability to provide thorough care

### Implications of the treatment of such cases?
- Family won’t engage in future if feel unsafe. Psycho-social impact on mother
- Lack of continuity of care, limited focus in ED
- Lack of suitable staff with understanding and skills to manage the critical context issues and/or failure to consider the cultural, social and environmental barriers
- No time, no connection, no trust
- Cost of medication
- Providing the required services locally
- Legal v cultural, cascading crisis if child safety involved

### How to ensure the health system deals with these issues appropriately?
- Provide access to indigenous healthcare provider/navigator/liaison officer at ED (make available outside of hours) – develop a family genealogy diagram
- Undertake opportunistic assessment (of child development)
- Partnering with primary healthcare providers, including Aboriginal Community Controlled Health Services (ACCHSs), awareness of referral pathways including introducing patients to local Aboriginal Medical Service (AMS)
- Improve information flow through partnerships with other health organisations/healthcare providers and utilising technology (access to the Viewer, My Health Record)
- Ensure cultural capability throughout the care continuum, including appropriate communication and engagement
- Provide a ‘one-stop-shop’ with ease of access, holistic assessment without bias or prejudice
- Follow-up through home visiting (or at childcare), including for developmental issues ideally with same healthcare provider
- Build connections, communication and relationships, provide medical and social support
- Consider likelihood of medication being administered as prescribed and provide the administration type (frequency, route, etc.) that is most likely to have the desired effect
- Consider other family who may be infected
- Better education, justice, child safety, health, community
### SUMMARY – Second session – Part Three (integration and co-ordination)

| How might Jordan’s care be addressed to ensure optimal co-ordination and integration with other services? | - Key Performance Indicators (KPIs) for each Hospital and Health Service (HHS):  
  Number of Indigenous Healthcare Providers (IHP), their training levels and access to training – fund, measure, evaluate  
- Designated hospital-based positions to coordinate information gathering  
- Implement guidelines  
- More time, better training/skills, communication, integrated care  
- Stronger partnerships and linkages (ACCHSs / AMS / Community organisations / Social support / non-government organisations), publicise details and make available  
- Information sharing, respecting everyone’s knowledge  
- Coordination of integration  
- Be responsive to patients’ current needs and supportive of follow-up choices  
- Put ‘Health’ back into ‘Hospital and Health Service’ |
| | |
| What role does the health system have in leading this response? | - Listen and provide more time in ED, gather and provide information, improve wait times  
- IHW pathways  
- Technology: Shared electronic patient records, shared across system (with consent):  
  - Identify/note Aboriginal and Torres Strait Islander status  
  - Active follow-up (self-discharge, did not attends, etc.) by health workers, pre- and post-presentation, referral initiation  
  - Regular reporting of outcomes  
  - Mobile device accessibility  
- Healthcare provider navigators, follow up with AMS  
- Embedding cultural capability  
- Leadership that commits to local holistic wellness care (physical, social, psychological and spiritual)  
- Family meeting with Hospital liaison Officers (HLOs) and treating team  
- Look into health needs of other family members  
- Development screening at immunisation / child health clinic / childcare |
| What are the key workforce implications of an integrated/coordinated response? | - Appropriate support in ED (e.g. Indigenous Liaison Officers / IHP / Support Worker), available 24/7 (on-call), first point of contact, assist with other issues (e.g. housing)  
- Scholarships for health professionals  
- Indigenous Certificate 4 – respected, empowered, engaged, leading clinical skills autonomy, Australian Health Practitioner Regulation Agency (AHPRA) registered, accessible in Queensland  
- Appropriate environment (culturally sensitive with local indigenous workers  
- Practical cultural capability / competence / leadership, novice to expert  
- More Aboriginal and Torres Strait Islander clinicians, champions in all areas  
- Aboriginal and Torres Strait Islander healthcare provider role in ED, train for clinical skills, navigators, case management – empowered  
- Consistency of role and educational, training, professional development, with career planning  
- Role clarity |