There was movement at the (out)station...

Developmental Screening of High Risk Remote Infants in the Top End

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Royal Darwin Hospital
Outline

• About the NT
  – NT geography and demographics, NT babies, NT services
  – Where we’ve come from, where we’re going

• The first project
  – The RDH Watch Me Grow clinic

• The second project
  – The General Movement Assessment
    • What is it?
    • How’s it going so far?
  – Plans from here

• Summary, References, Contact details...
1% Australian Population

10% of Australia’s indigenous Population

30% of NT residents identify as Indigenous

58% total NT population live in Darwin

6% of NT’s Indigenous people live in Darwin
Top End Health Service (TEHS)
NT Infants at a glance

- NT 4000 births/year
- NT Indigenous Mothers*: 31-38%
  - 62% remote
  - Av age indigenous mother 25y (vs 30y national average)
- NT Indigenous Mothers 5x more likely to be smoking during first 20 weeks
  - 50% vs 10% nationally

(Hall et al 2015, AIHW 2016, Li et al 2011)
All babies born NT (2013)

Mother's usual residence

Adapted from Hall et al 2015
NT Infants at a glance

• NT lowest national BW
  – Highest incidence of LBW (<2500g) and VLBW (<1500g)

• NT ~10.3% preterm (8.6% nationally)
  – Highest rate in Australia
  – 16% of indigenous babies are born preterm

(Hall et al 2015, AIHW 2016, Li et al 2011)
Significance of Preterm

• Well established evidence:
  – Preterm (born <37 weeks) infants are at increased risk of
    • Motor,
    • Cognitive,
    • Language, and
    • Behavioural issues
  – Marlow 2004; Prins et al 2010; Wang et al 2006;

• 5-15% children born preterm will be diagnosed with CP

• Nationally and Internationally best practice to provide developmental screening of preterm infants using valid and reliable assessment tools.
  – Anderson et al 2010, Wang et al 2006 and others

• Early Intervention programs (EI) can positively impact outcomes at infancy and preschool age
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Where are we coming from?

![Infant mortality per 1000 births graph](chart)
AMAZING PICTURE
HUGE CROC vs SHARK
IN BATTLE TO DEATH
JUST FOOTY: AFL & NRL FINALS PREVIEWS
TEHS EI Services

• Hospitals
  – RDH
  – KDH
  – GDH

• Urban Darwin
  – Children’s Development Team
  – Carpentaria Disability Service (NGO)
TEHS EI Services

• Remote Top End Disability Service
  – Key workers, Trans-disciplinary role
  – 4-6 weekly visits
  – One contact supports:
    • Aged Care
    • Disability case management
    • Developmental Delay
    • Equipment
  – Criteria:
    • Disability, Developmental Delay or Frail aged ONLY
  – Have support available from Paeds Physio - consult
  – Well known “on the ground” with good rapport and respect with and of local people
Lack of routine, standardised developmental screening
RDH should lead screening clinic for their NICU/SCN graduates
  – Intended MDT service including neonatology/paeds
    • Didn’t eventuate
  – Allied Health “Watch Me Grow Clinic” commenced Jan 2014
    • Criteria: <33 weeks gestation
      – (also <2kg BW; HIE, IVH>2, any other neurological concerns)
    • Physiotherapy, Speech Pathology and Dietician initially
    • Now Physio, Speech and OT clinic
    • 3 Assessments in first year only +/- referral
    • ONLY LOCAL FAMILIES (no patient travel funding)
WMG Data

Gestation <33 weeks admitted to Royal Darwin Hospital

<table>
<thead>
<tr>
<th>Year</th>
<th>Remote</th>
<th>Local</th>
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<tbody>
<tr>
<td>2013</td>
<td>33</td>
<td>42</td>
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<tr>
<td>2014</td>
<td>36</td>
<td>52</td>
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<td>2015</td>
<td>44</td>
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<td>2016</td>
<td>54</td>
<td>35</td>
</tr>
<tr>
<td>2017</td>
<td>13</td>
<td>9</td>
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An obvious gap...

- Vulnerable patient group
- Negligible access to developmental screening in remote community
- Limited access to Allied Health services including Early Intervention in community
- Unable to come to us at RDH
- What can we do???
General Movements project

• General Movements Assessment (GMA)
  – Low cost, highly evidenced developmental screening tool
  – Non-invasive
  – Can be introduced prior to discharge
  – Remote Disability Service (& NDIS) accept GMA outcome as basis for referral
  – Enables access to Early Intervention

• Opportunity to trial Telehealth follow up
What is the General Movements Assessment?

• The General Movements Assessment (GMA) is used to identify abnormal or absent general movements (GMs), which can be used to predict future neurological impairments particularly Cerebral Palsy (CP)
• Also known as “Prechtl’s” after Heinz Prechtl
• Infants have typical and identifiable spontaneous ‘general movement’ patterns from preterm age up to 20 weeks corrected age.
• GMA involves recording an infant who is supine, settled and awake for a period of up to 10mins.
• Very high sensitivity and specificity
• Reliably predicts Cerebral Palsy in high risk populations
What are General Movements?

- Preterm and Term age: “Writhing Period”
  - Large amplitude movements
  - Variable/complex sequence and speed
  - Gradual beginning and end
  - Involve fluent rotations

- Good prognostic indicator, but best predictive value if repeated assessment at ~12 weeks during the “Fidgety Period”
What are General Movements?

• Post term phase: “Fidgety Period”
  – Continuous movement
  – Moderate speed
  – All directions
  – Small amplitude

  – Strong prognostic indicator – if fidgety movements are present at 12 weeks, anticipate normal gross motor development
Voluntary and Antigravity M.

Fidgety M.

Writhing M.

Postmenstrual Age (weeks)

5 10 15 20 25 30 35 40 45 50 55 60 65 70

Term 5 10 15 20 25 30

General Movements Trust Training Documents, 2014
GMA Evidence

- Valid, reliable, sensitive and specific
- As sensitive and specific as MRI for predicting motor outcomes
  - Combined with MRI improves further
- Predictor of CP (GMFCS level)
  - Markers for Hemiplegia
  - Markers for dyskinetic CP
- Trajectory of GMA is best assessment protocol
- Should be combined with MRI
GMA Evidence

http://general-movements-trust.info/51/papers
Eligible infant (born <33 weeks, remote family) identified in weekly ward Allied Health meeting

Provide parent education and seek consent once medically stable
  • Including consent for Telehealth if required

Videos taken at 1 or more occasions prior to DC
  • Target ages 32 weeks CA, 36wCA, Term CA

12 week assessments via Allied Health Telehealth Clinic

GM assessors meet monthly* to review and report
RDH GMA Project

• Attempted start 1\textsuperscript{st} Jan 2017
• 13 remote dwelling infants have met the criteria so far
  – 6 were missed as inpatients
  – 3 have had 1\textsuperscript{st} GMA
  – 1 declined
  – 3 remain inpatients progressing toward DC
RDH GMA Project

• Disappointed that we missed some...
  – Competing priorities of Acute inpatient Physiotherapy team and GM Assessors
  – Availability of families/carers to consent
• Allied Health Assistant support became available in mid March to support recruitment, consent and filming
  • No babies missed since then!
• RDH OT GMA training completed in March
  – Assisting with GMA project as able
• Those missed in Writhing period will still be offered Fidgety period assessment (12w CA)
Barriers/Lessons Learned

• Equipment
  – User vs technology
• Privacy
  – Recordings & Storage
• Consent
  – Access to families
  – Interpreter
• Timing
  – Age of infant
  – Access to infant
Barriers/Lessons (to be) Learned

• Majority of published GMs research in academic settings

• Even in well funded, large centres barriers for performing GMs in clinical settings:
  – found 33% appointments were too late for GMs for both Writhing and Fidgety periods
  – Also had labelling and transferring issues with videos
  – 15% recordings inadequate (behavioural state)
  – Lessons learned

• CPA (NSW) recent publication GMs in clinical use
  – De Bock et al 2017
Where to from here?

- 12 week CA Assessments are currently booked in!
- Need to run some trials of connecting and logistics...
- Development of 'Policy Guideline Centre' policy after trial period
- Allow for adjustments and further lessons learned
- Sharing of processes and protocols within TEHS and DoH (NT)...
- Stop. Collaborate. And listen.
- Thank you Twitter user!

To “Down South”
Where to from here?

• Developmental Outcomes and Trajectories of Indigenous infants?
• Validating existing tools in Remote Aboriginal Populations?
• Baby Moves – Alicia Spittle & colleagues MCRI (Victoria)
  – May make ‘live’ Telehealth unnecessary...
  – May need ‘live’ Telehealth for support...
Summary

• Service and access gap remains wide for remote at-risk infants born in the Top End
• RDH Allied Health Team are attempting to narrow the gap by offering developmental screening with the GMA
• Telehealth may be an effective way to screen and refer for early intervention...
Thank You

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References

- http://general-movements-trust.info/51/papers accessed 21/04/2017
- Google maps