HEALTH PROFESSIONALS RESEARCH EDUCATION PROGRAM –

Session 3: IMPROVING THE APPROPRIATENESS AND BENEFIT OF RESEARCH WITH ABORIGINAL PEOPLE

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

NSW GOVERNMENT Health
Hunter New England Local Health District

12.15 – 2.00pm Friday 31 August 2018
John Hunter Hospital – Large Lecture Theatre [6065]

RESEARCH ADVANTAGE
connecting and empowering

PROFESSOR JODIE SIMPSON

Acting Assistant Dean Research
Faculty of Health and Medicine

INTRODUCTION

WELCOME TO COUNTRY

AUNTY JUNE ROSE

ACKNOWLEDGEMENT OF COUNTRY

**We acknowledge and pay respect to the Awabakal people,
traditional custodians of the land
on which the John Hunter Hospital is situated
and also acknowledge and pay respect to other Aboriginal and
Torres Strait Islander nations from which our students,
staff and community are drawn**

SCENE SETTING

JOHN WIGGERS

Director
Clinical Research and Translation
HNELHD

SHARYN TYTER

Senior Program Manager Aboriginal Chronic Care
Aboriginal Health Unit
HNELHD

Aboriginal and Torres Strait Islander health: Improving appropriateness and benefit of research

Sharyn Tyter
Snr Program Manager
Aboriginal Chronic Care
Aboriginal Health Unit HNELHD

Healthy Aboriginal People - Now and into the future

Acknowledgement of Country

Overview of Session

- Improving benefit of general research
  - Context in the HNE area (Sharyn Tyter)
  - Opportunities re research processes (John Wiggers)
  - Service delivery strategies (Hannah Briggs and Matt Crawford)
  - Research project strategies (Belinda Tully and Mel Kingsland)

HNE Aboriginal and Torres Strait Islander population

- 24 % NSW Aboriginal and/or Torres Strait Islander population
- 5.9 % (52,726) HNE population
- Numerous Aboriginal Nations
- Aboriginal and Torres Strait Islander people residing in our District from many other Nations
- Metro, regional, rural and remote locations

Healthy Aboriginal People - Now and into the future

NSW GOVERNMENT Health
Hunter New England Local Health District

Why does this matter?

- Respect and recognition for Australia's First Peoples
  - Facilitate inclusion
  - Provide space for Aboriginal and Torres Strait Islander peoples to have a voice about what is meaningful and important
  - Value diversity and strengths in Aboriginal and Torres Strait Islander communities
- Contribute to closing the gap
  - Review data
  - Avoid risk of increasing the gap
  - Consider research setting/s and design to facilitate equitable access
  - Design research to positively inform culturally appropriate, safe and beneficial practice
  - Provide employment opportunities and build research capacity
  - Ensure research practices don't cause harm

New Resources

- NHMRC, Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (2018), Commonwealth of Australia: Canberra
- NHMRC, Keeping research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (2018), Commonwealth of Australia: Canberra

Health
Hunter New England
Local Health District

Health Professionals Research Education Program - #03

Enhancing the appropriateness and benefit of research and improvement initiatives with Aboriginal peoples

Professor John Wiggers
Director, Health Research and Translation
Hunter New England Local Health District
August 2018

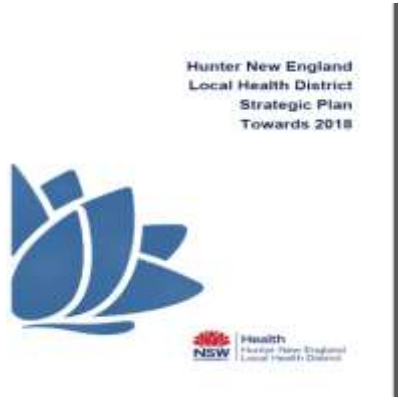
Overview

- Strategic context

- Ensuring appropriateness and benefit
  - Design of research and improvement initiatives
  - Conduct of research and improvement initiatives

HNE Strategic Context

- **Strategy 1.4**:
  Close the gap between Aboriginal and Non Aboriginal Health



- **Strategy 3.3**: Facilitate innovation and translational research to improve patient centred care

- **Goal 4**: Enhance Aboriginal Health Research and the cultural safety and appropriateness of all HNE research

Broader Context

- Medical Research Futures Fund
- NSW Translational Research Grant Scheme

Ensuring appropriateness and benefit

1. **Design of Research and Improvement Initiatives**
   - Burden of illness (problem to be addressed)
     - Describe extent (prevalence) for Aboriginal peoples
   - Describe evidence of likely benefit of proposed solution for Aboriginal peoples
     - Will the impact of the initiative Close, maintain or increase the Gap?
   - Ensure access to, and acceptability of proposed solution for Aboriginal peoples
   - Ensure proposed evaluation design, participant recruitment and measurement methods, materials, and reporting approaches are acceptable for Aboriginal peoples

Ensuring appropriateness and benefit

2. Conduct of research and improvement initiatives

- Engagement/involvement of Aboriginal peoples/organisations
  - As Investigators
  - In project governance
  - As team members (including employment)
- Engagement/involvement to occur through all stages of the initiative
  - Problem/solution identification, initiative design, conduct, analysis, reporting, dissemination
- Partnership

Patient Stories

When it works and when it doesn't

Hannah Briggs
Aboriginal Health Worker (Peel Sector)
Integrated Chronic Care for Aboriginal People Program
Hunter New England LHD

Matt Crawford
Clinical Nurse Consultant (Peel Sector)
Integrated Chronic Care for Aboriginal People Program
Hunter New England LHD

Acknowledgement to country

Integrated Chronic Care for Aboriginal People Program

Improve access to health services for Aboriginal & Torres Strait Islander people aged 15 years and over who have or are at risk of *diabetes*, *cardiac*, *respiratory* or *renal* disease across Hunter New England Local Health District.

Peel Sector

Matt & Hannah

Mehi Sector

Nat & Alwyn

Lower Hunter,GNC & MNC

Donna, Troy, Tammy

Tablelands Sector

Peter & Brad

Staff Specialist

Pat

Program Coordinator

Sharyn

Project Officer

Sarah

Discharge F/U for Aboriginal People

Anna & Tammy

ICCAPP Model of Care

Donna

Background Hx

- 70 year old Gamilaroi woman
- Large family & extended family
- Lives with husband who has major health issues
- IHD, CCF, AF, Type 2 DM, COPD, Stage 3 CKD
- Smoker
- BMI 37kg/m2

Issues

1. Regular hospital admissions related to CCF or chest pain
2. Difficulties adhering to daily fluid restriction
3. Poorly controlled Type 2 DM
4. No regular GP
5. Medication problems
6. Social isolation & family stress
7. Not sleeping relating to dyspnoea, coughing + fear
8. Leg weakness (decrease mobility)
9. Smoking
10. Diet

Hospital presentations 2015-2017

Date	Diagnosis	Admitted days	ICU
15/05/15	CCF	10	-
07/10/15	Resp Infec	3	-
31/08/16	CCF	15	4
01/01/17	Chest pain	4	-
19/01/17	CCF	6	-
Total		38	4

We have a plan

Steps forward

Building Relationship

Home visits

Options

Set of scales for home

Finding regular GP

Pathology home visits

Exercise group

ICCAPP Physician input via telehealth + F2F

Webster pack + insulin

Diet education

Social & emotional support

ICCAPP Contacts 2015-2018

Year	F2F	Phone/Text
2015	-	-
2016	-	3
2017	21	13
2018	10	15
Total	30	29

Hospital presentations
Feb 2017 - present

Kelly

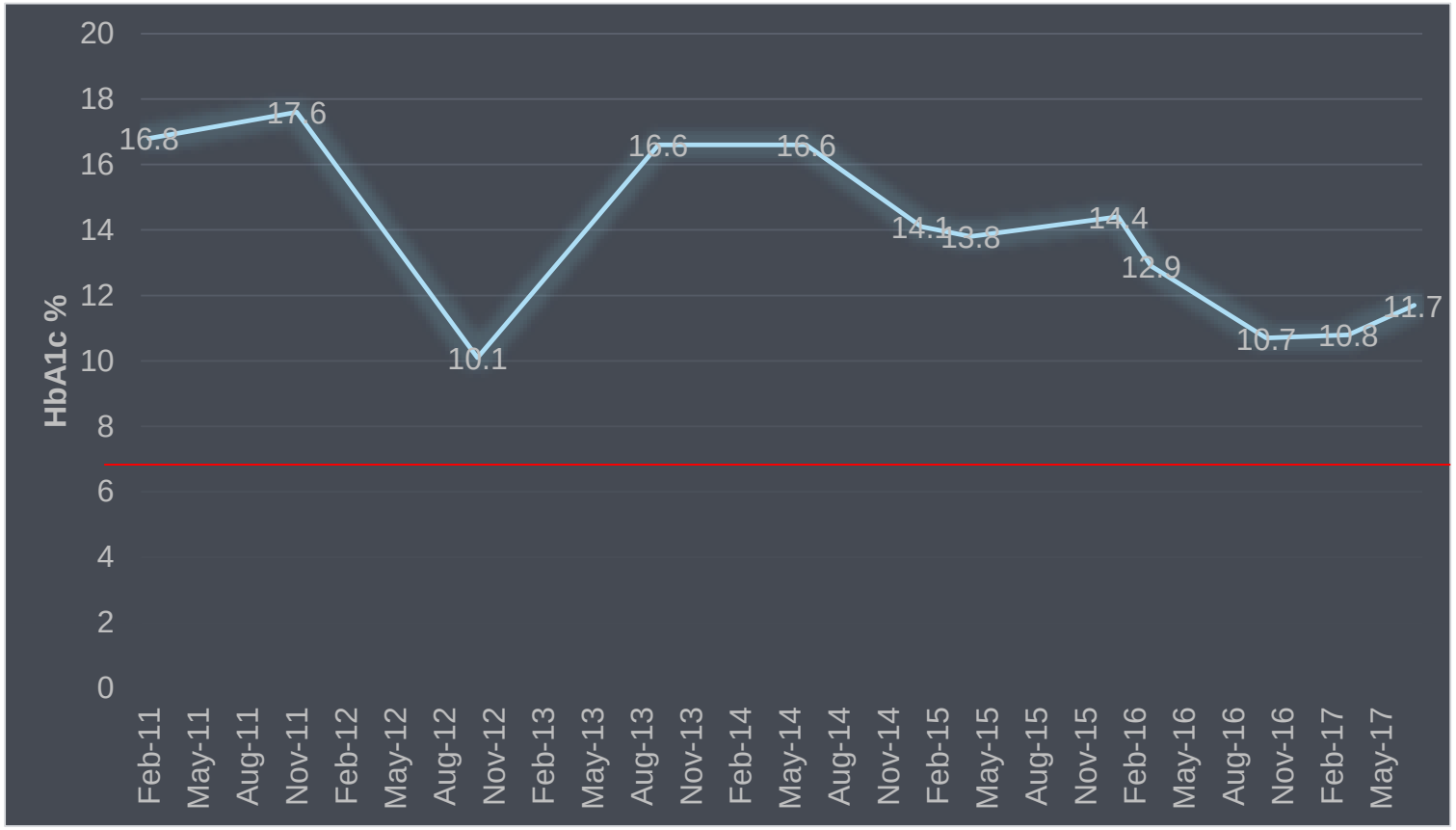
Background Hx

- 48 yr old Aboriginal woman
- Has 3 children, 20yr daughter, 23yr son and 27yr son
- No current partner
- Diagnosed with Type 1 DM in 2006
- Significant Peripheral Neuropathy, Gastroparesis, CVA, Depression, T11 crush #, chronic pain, opioid dependence & Stage 2 CKD.
- Smoker
- Long term unemployment

Issues

1. Ongoing hospital admissions related to DKA
2. Depression/suicidality
3. Very poorly controlled Type 1 DM
4. Associated complications from Type 1 DM
5. Documented allergies to Glargine & Detemir insulin
6. Chronic pain
7. Social isolation
8. Labelled as “frequent flyer”, “attention seeking” etc
9. Diet
10. Smoking

Average Blood Glucose – HbA1c %



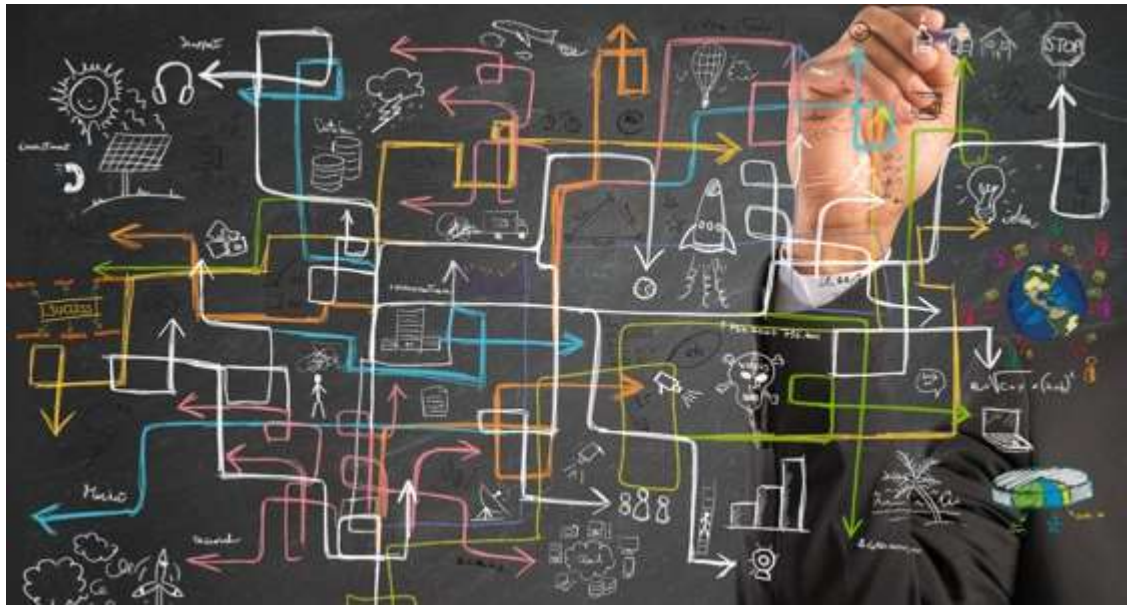
Hospital presentations 2014-2017

Date	Diagnosis	Admitted days	ICU
29/01/14	DKA	47	7
17/09/14	? O/D	3	2
18/03/15	DKA	15	3
12/09/15	DKA/Sepsis	14	1
04/03/16	DKA/HG	18	-
24/03/16	DKA	57	2
24/05/16	DKA	3	3
15/09/16	DKA	4	3
05/10/16	DKA	1	-
06/11/16	DKA	2	1

Hospital presentations 2014-2017 (cont'd)

Date	Diagnosis	Admitted days	ICU
19/03/17	DKA	12	3
11/07/17	DKA	15	-
26/07/17	Comp of DM	64	3
Total		255	28

Another plan



Steps forward

Building Relationship

Home visits

IPT commencement

Options

Finding regular GP

ICCAPP Physician input

TIPS input

Applying for own IPT device

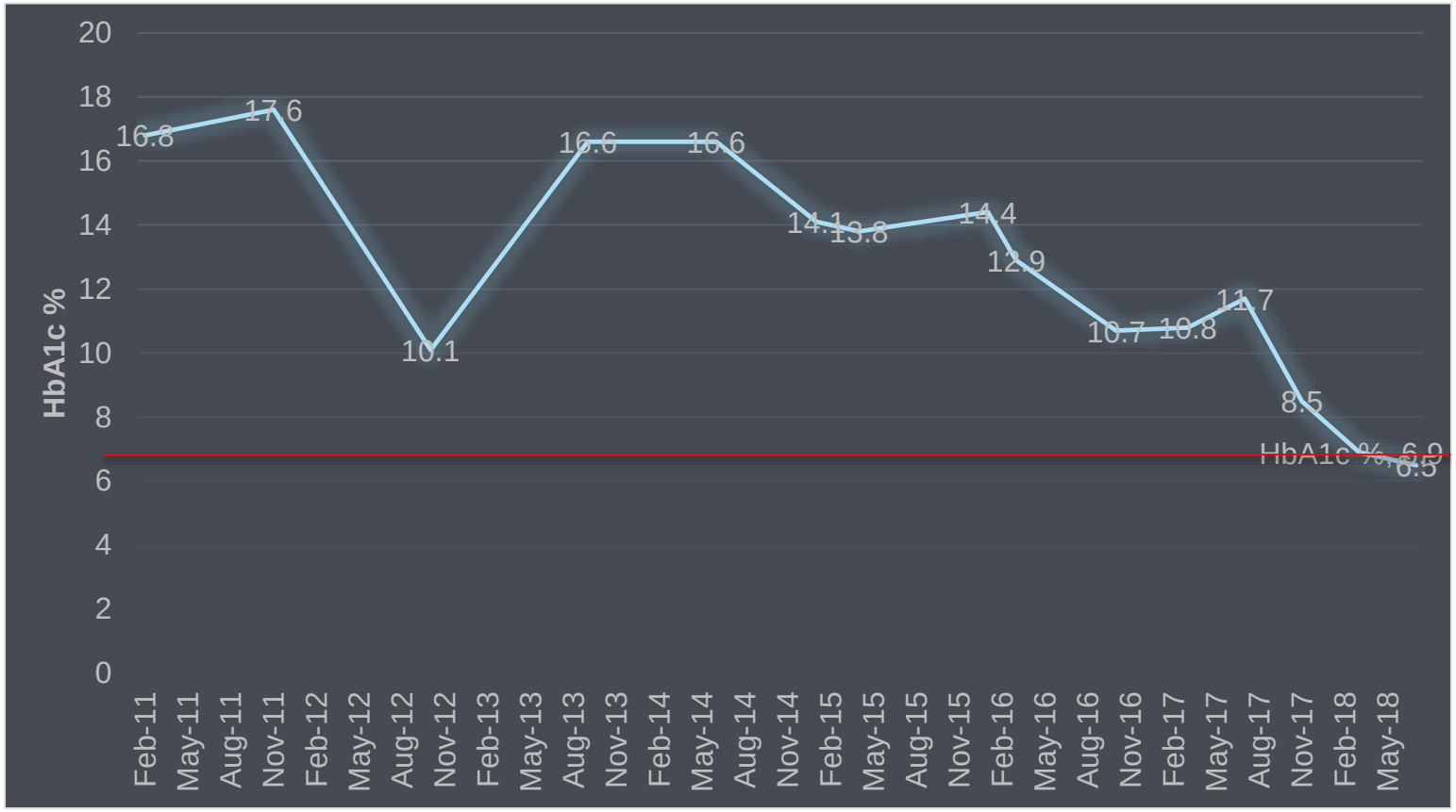
No judgements

Social & emotional support

ICCAPP Contacts 2014-2018

Year	F2F	Phone/Text	Est Cost
2014	-	-	
2015	-	-	
2016	-	-	
2017	34	29	
2018	14	25	
Total	48	54	

Average Blood Glucose – HbA1c %



Hospital presentations
October 2017 - present

What works

- Persistence, consistency & continuity
- Building therapeutic relationships
- Empathy
- Options
- The value of case management /care coordination (time needed) vs cost of hospital/ICU stay
- Partnership in health
- Flexibility in own role and system processes
- Health literacy
- Empowerment
- Flexible access to good medical/allied health advice when needed eg telehealth, ‘mindful’ referrals, collaboration

PATIENT STORIES

MELANIE KINGSLAND
Program Manager/Postdoctoral Researcher, HNE Population Health/UON

BELINDA TULLY
Aboriginal Population Health Trainee |HNE Population Health

NSW GOVERNMENT Health
Hunter New England Local Health District

THE UNIVERSITY OF NEWCASTLE AUSTRALIA

A trial of an initiative to improve antenatal screening and care for alcohol consumption during pregnancy

Empowering Aboriginal women and babies by mobilizing Indigenist research methods and governance models

Belinda Tully & Melanie Kingsland
Hunter New England Population Health

31 August 2018

Acknowledgment of Country

Today's presentation

1. A practice change initiative to improve antenatal screening and care for alcohol consumption during pregnancy
   - **Why we are undertaking the trial and what it involves**
2. Ensuring appropriateness to empower Aboriginal women and babies
   - **Consultation and engagement process**
   - **Cultural advice embedded into the trial**

A practice change initiative to improve antenatal screening and care for alcohol consumption during pregnancy

NSW GOVERNMENT Health
Hunter New England
Local Health District

Alcohol consumption during pregnancy

- NHMRC Guidelines recommended **no alcohol** is consumed at any stage **during pregnancy** based on potential risks to the pregnancy and baby[1]
- 25% of Australian women report consuming alcohol after knowing they are pregnant[2]

NSW GOVERNMENT Health
Hunter New England Local Health District

1. National Health and Medical Research Council. Australian guidelines to reduce health risks from drinking alcohol. Canberra: Commonwealth of Australia; 2009.
2. Australian Institute of Health and Welfare. National Drug Strategy Household Survey detailed report 2016. Drug statistics series no 31. Cat. No. PHE 214. Canberra: AIHW; 2017

Recommended antenatal care

Recommended that antenatal health professionals:

- ✓ **Assess** alcohol consumption of all pregnant women
- ✓ **Advise** women not to consume alcohol during pregnancy and of risks of doing so
- ✓ **Refer** to appropriate support services

At booking in antenatal visit and multiple times during pregnancy

This level of care is not routinely provided

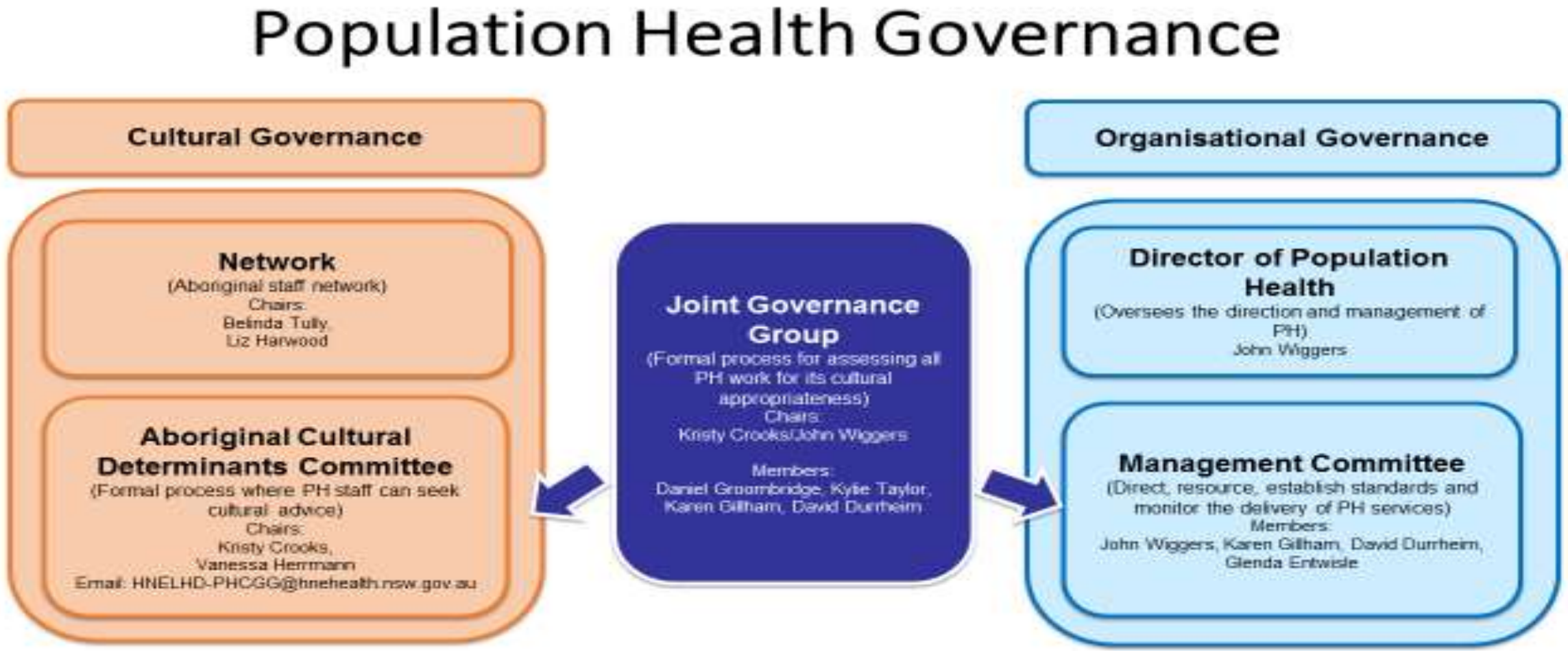
Implementation trial across 3 HNE sites

- **Aim:** to test effectiveness of implementation strategies (reminders, training, etc.) in improve screening and management of alcohol consumption during pregnancy
- **Stepped-wedge trial:** antenatal services in Greater Newcastle, Peel and Lower Mid North Coast sectors
- **Partnership project**:
  - HNELHD Maternity, Population Health and Drug and Alcohol
  - Foundation for Alcohol Research and Education
  - NSW Health, Office of Preventive Health

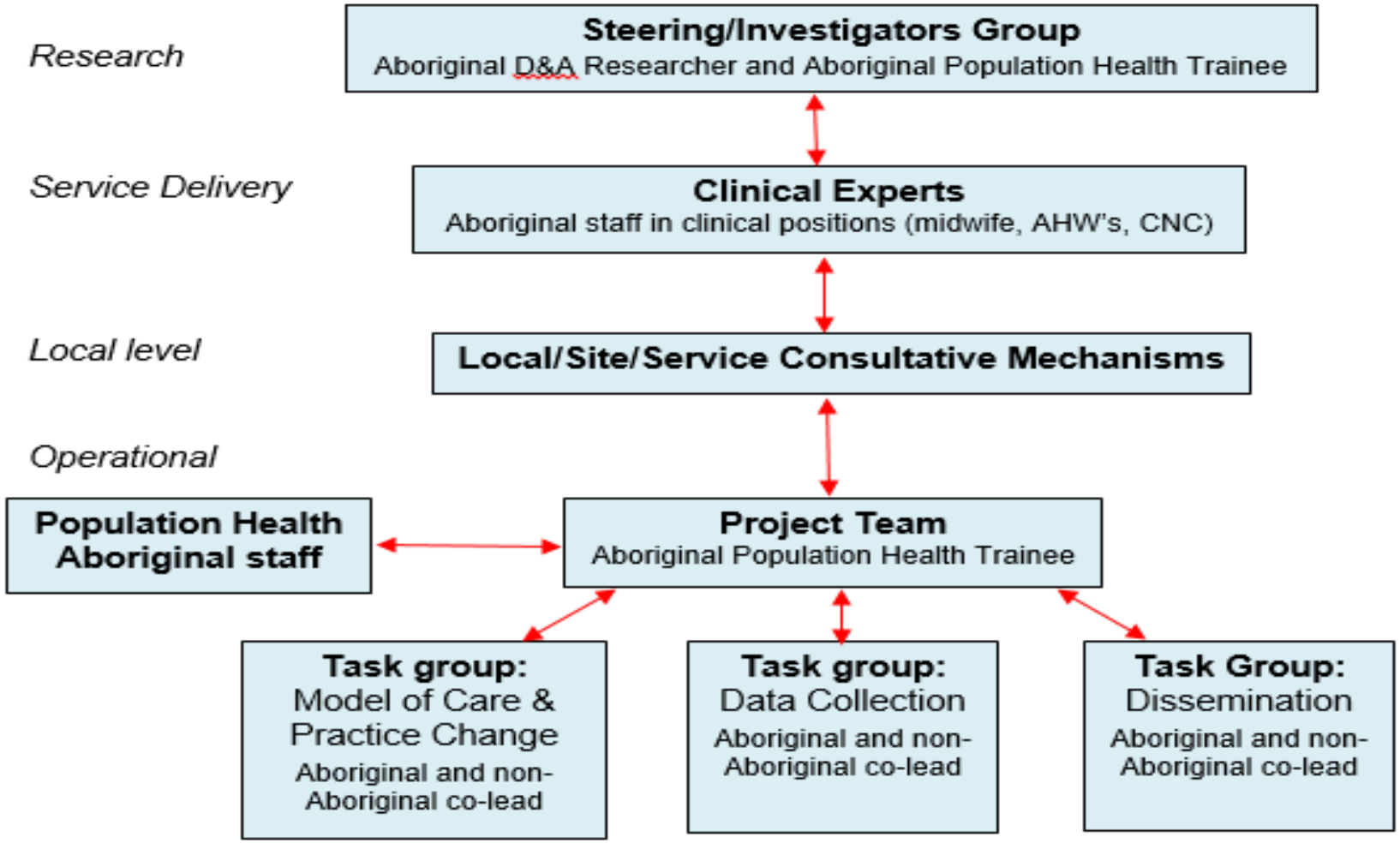
Ensuring appropriateness to empower Aboriginal women and babies

CULTURAL GOVERNANCE & CONSULTATION AND ENGAGEMENT PROCESS

HNE Population Health: Joint Governance



Cultural governance for the trial



Cultural consultation and engagement process

We sought advice from:

- Aboriginal mums
- Aboriginal Community Controlled Health Services
- Aboriginal Maternal and Infant Health Services
- HNE Aboriginal Health staff – including submission of Aboriginal Health Impact Statement
- HNE Close the Gap Collaboratives
- HNE Aboriginal Drug and Alcohol
- Population Health Aboriginal Cultural Determinants Committee
- Task groups developed specifically for the initiative - co-led by an Aboriginal staff member
- Aboriginal Health and Medical Research Council (trial approval)

Cultural consultation with Aboriginal mums

Focus Groups with Aboriginal mums

- 2 Aboriginal Population Health staff members led 6 focus groups with 4-6 women in each group-Newcastle and Peel sectors
- Aboriginal women who attended a HNE maternity services in the past 18 months invited to participate through existing Mums and Bub groups or similar.

Cultural consultation with Aboriginal mums

Focus Groups with Aboriginal mums (cont.)

- Sought to hear women's experiences and seek advice on what culturally safe antenatal care for alcohol consumption in pregnancy would look like to the women.
- Key preliminary findings include:
  - importance of understanding women's experiences
  - providing safe and consistent care / building trust
  - adopting strength-based approaches
  - issues around stereotypes, stigma, perception and judgement

Cultural advice embedding into the trial

Through the consultations **3 key components** of the trial were identified as requiring adaptations to empower Aboriginal women in an attempt to increase cultural safety of care

1. **Data collection processes** which involve pregnant women reporting on care received for alcohol consumption in pregnancy
2. **Content of the care** provided to women for alcohol consumption in pregnancy
3. **Content of the implementation support** strategies strategies for antenatal services

1. Data collection processes

ADVICE RECEIVED: participation by Aboriginal women would be enhanced by providing an alternative to participating in the data collection through a telephone survey

WHAT WE DID: For Aboriginal women and/or women attending an Aboriginal Maternal and Infant Health Service for antenatal care:

- Choice of participating in data collection via online or telephone survey
- Choice of undertaking telephone survey with an Aboriginal interviewer
- Interviewers are all women

2. Content of care for alcohol consumption in pregnancy

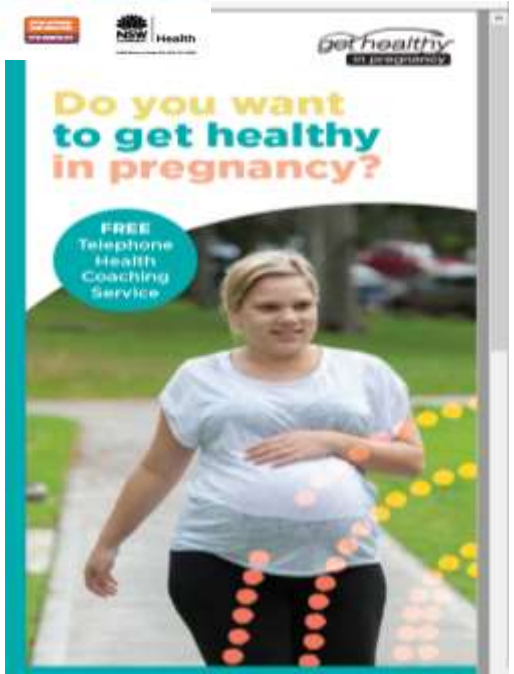
ADVICE RECEIVED:

- Culturally appropriate resources
- Appropriate referral services for Aboriginal women, beyond telephone services
- Alternative D&A options

2. Content of care for alcohol consumption in pregnancy

WHAT WE DID: with advice from Aboriginal women and Aboriginal partners

- **Stay Strong and Healthy Resources**
- Women with 'Medium risk of harm' due to alcohol use in pregnancy:
  - **Aboriginal Medical Service referral** or
  - Get Healthy in Pregnancy telephone service (female **Aboriginal Liaison Officer** for support)
- Women with 'High risk of harm' due to alcohol use during pregnancy:
  - Drug and Alcohol clinical services (supported by workers, transports, etc. from **Aboriginal Maternal and Infant Health Services or Aboriginal Medical Services**



3. Implementation support strategies for antenatal staff

ADVICE RECEIVED:

- Continuity of care
- Explain what is going to be asked and how often
- Open and transparent communication
- Dispel myths and stereotypes about alcohol and Aboriginal women

3. Implementation support strategies for antenatal staff

HNELHD Local Guideline and Procedure

- Developed and includes the different referral pathways for Aboriginal women and links to Aboriginal specific resources

No alcohol during pregnancy is the safest choice.

3. Implementation support strategies for antenatal staff

Staff Training: Online and face-to-face training

Includes:

- Dispelling myths with facts
- Translating what it means to be open and transparent
- Scenario for providing an Aboriginal woman with care that was expanded on in face-to-face training

3. Implementation support strategies for antenatal staff

Accountability and Monitoring

- Performance measures developed for maternity services and antenatal outpatients
- 3 measures relating to antenatal care for Aboriginal women across all services:
  - % Aboriginal women with alcohol assessment conducted at 28 weeks gestation
  - % Aboriginal women with alcohol assessment conducted at 36 weeks gestation
  - % Aboriginal women for whom appropriate referral for alcohol use in pregnancy offered/followed-up

Ongoing monitoring & review of cultural considerations

- **Monitoring and review of participation in data collection**
  - by Aboriginal women and non-Aboriginal women
  - to further improve participation in future trials

- **Monitoring and review of primary outcome** (care provision for alcohol consumption):
  - for Aboriginal women compared to non-Aboriginal women
  - to ensure there is no gap in care delivery and modifying support strategies (e.g. clinician training) as needed

Thank you

NHMRC Guidance

- ***Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*** provides a set of principles to ensure research is safe, respectful, responsible, high quality and of benefit to Aboriginal and Torres Strait Islander people and communities.

- ***Keeping research on track II*** was developed to provide advice on how these values and principles can be put into practice in research.

Both of these guidelines support the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* and can be accessed via the Research Ethics Governance website under “Policies and Guidelines

Questions?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WRAP UP

WHAT'S NEXT in 2018

Health Professionals Research Education Program:
Session 4: **Research Support Services**
12noon – 1:30pm 9 November 2018 [John Hunter Hospital]

Save the Date!

2019:
Friday 15 March
Friday 14 June
Friday 30 August
Friday 8 November

http://www.newcastle.edu.au/research-and-innovation/resources/research-advantage