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AUSTRALIA

Evidence-Practice Policy Gap


NHMRC

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Contents

Evidence-practice policy gap (EPPG)

An evidence-practice/policy gap is the difference between what is known from the best available research evidence and what is practised in reality (through delivery of medical care or drafting of policies or guidelines).

The identification and reporting of evidence-practice/policy gaps is consistent with the overarching aims of the National Health and Medical Research Council (NHMRC), as defined in the National Health and Medical Research Council Act 1992:

- To raise the standard of individual and public health throughout Australia,
- To foster the development of consistent health standards between the various states and territories,
- To foster medical research and training and public health research and training throughout Australia, and
- To foster consideration of ethical issues relating to health.

Identifying and exploring evidence-practice/policy gaps will facilitate more effective allocation of funding to areas of greatest need and raise awareness of the extent of these gaps to encourage the development of more effective health services, guidelines and policies.

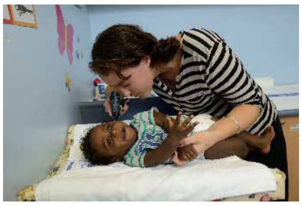
The evidence-practice/policy gaps project began in 2015 as a means of showcasing the impact to date (and identifying areas for improvement) of NHMRC funding of Aboriginal and Torres Strait Islander research.

Aboriginal and Torres Strait Islander health

Influenza vaccination of Aboriginal and Torres Strait Islander adults

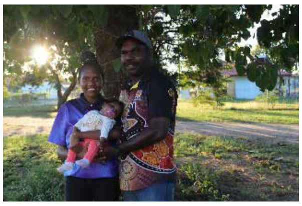
Current influenza vaccination coverage in Indigenous Australian adults is 34 per cent. Increasing the coverage to 90 per cent would prevent 1,200 hospitalisations and 250 deaths in Indigenous adults each year. Although free annual influenza vaccinations are available, the uptake is low. Better community consultations and engagement are required to ensure higher vaccination rates.

Evidence-based management of otitis media in high risk populations



Ear infections have a significant impact on Aboriginal and Torres Strait Islander children, frequently leading to hearing loss and putting them at an educational disadvantage. Clinical guidelines highlight the need for regular ear checks at doctor appointments, and better training for health professionals to recognise and treat ear disease. Better ear health means better hearing and improved learning, behaviour and school attendance, leading to better educational opportunities and social outcomes for future generations.

Delivering family-centred care for Aboriginal and Torres Strait Islander children under 5 years



Family-centred care is not being fully delivered across primary healthcare services particularly in child health. While the delivery of services has improved, follow-up health assessment still remains poor. Family oriented care could improve the health and wellbeing of Aboriginal and/or Torres Strait Islander children and their families by empowering families to make informed decisions, supporting a holistic concept of care for young children and their families.

Culturally safe advice on alcohol cessation in pregnancy

Health professionals are well-positioned to prevent Fetal Alcohol Spectrum Disorder (FASD) through providing accurate and timely advice about risks, complications and referral services. However, gaps exist in their knowledge, skills and confidence, particularly within Aboriginal and Torres Strait Islander Australian communities. Properly trained health professionals will better ensure women are informed that *no* alcohol is the safest option when pregnant. This will also ensure women who are alcohol addicted have increased access to support and treatment services.

Early diagnosis of Fetal Alcohol Spectrum Disorder in Indigenous children

Guidance and training for health professionals to recognise the signs of Fetal Alcohol Spectrum Disorder (FASD) and treatment options for Indigenous children will mean earlier diagnosis and treatment. Early diagnosis can reduce rates of intellectual disabilities, behavioural and developmental disorders. These improvements will reduce the burden to health care, education and justice systems.

The aims of these reports are to:

- Take advantage of NHMRC’s legislated role to provide advice to governments and the community,
- Demonstrate how adopting the findings of research could lead to improved health outcomes,
- Demonstrate the impact of NHMRC funding,
- Raise awareness, celebrate success, acknowledge where there is room for improvement (such as care delivered in a manner that is not consistent with the best available evidence), and identify research that will address the gap, and
- Direct funding of Aboriginal and Torres Strait Islander research to areas of greatest need.

Background

In 2002, the National Health and Medical Research Council (NHMRC) pledged to allocate a minimum of 5% of the total Medical Research Endowment Account each year to fund research in Aboriginal and Torres Strait Islander health, which has been achieved since 2008. The Principal Committee Indigenous Caucus (PCIC) identified research translation in Indigenous health as a priority in 2012. To demonstrate the impact of the 5% pledge, as well as highlight areas for further improvement, the NHMRC proposed a body of work in 2015 relating to research translation in Indigenous health.

The NHMRC Translating Research into Policy and Practice (TRIPP) Forum held in May 2016 identified the most significant current evidence-practice/policy gaps, and sorted these according to the Life Course stages (obtained from the National Aboriginal and Torres Strait Islander Health Plan 2013–2023). Additional gaps were identified from financial data from

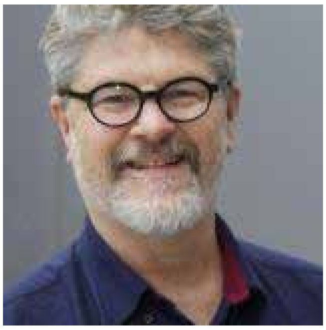
NHMRC and input from PCIC. The NHMRC identified authors for evidence-practice/policy gap synopses for the report from relevant national Centres of Research Excellence (CREs). Synopses were peer reviewed by a member of PCIC and external referees.

Achievements to date include:

- An overview of systematic reviews of research into the health of Aboriginal and Torres Strait Islander people
- A Special Collection of the Cochrane Library: Health of Indigenous Peoples
- A forum to identify current evidence-practice/policy gaps, held in 2016: Translating Research Into Policy and Practice (TRIPP) forum

NHMRC acknowledges the time and effort, and express our genuine gratitude for the contributions and support of the peer reviewers.

Influenza vaccination of Aboriginal and Torres Strait Islander adults



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Despite improvements in vaccine uptake in Aboriginal and Torres Strait Islander people, adults experience greater rates of influenza hospitalisation than non-Indigenous adults of the same age.

What is the gap and why is it important?

Influenza, and other vaccine preventable diseases, still cause a higher disease burden in Indigenous adults compared to non-Indigenous adults.[1,2] The death rate due to pandemic influenza in 2009 was 5.8 times higher in Indigenous people compared to non-Indigenous people.[3] In 2015 respiratory disease caused 5.4% of hospitalisations and 7.6% of deaths in Indigenous people, constituting 12% of the mortality gap between Indigenous and non-Indigenous people.[4]

A national policy is in place to address this — free influenza vaccine for all Indigenous people 6 months and older — under the National Immunisation Program.[5] However, while coverage in elderly Indigenous (≥65 years) is adequate at >70%, uptake of less than 30% 18–49 year-olds is inadequate.[6, 7]

What does the best available evidence tell us?

Influenza vaccine is recognised internationally as the most effective method of preventing influenza-related morbidity and mortality.[8] It is effective in preventing influenza infection and influenza-related serious morbidity and mortality in healthy young adults, adults with chronic disease or immunosuppression, the elderly, and in preventing influenza-related respiratory and cardiac disease.[9] Effectiveness varies from year to year depending on the match between circulating and vaccine strains, and between individuals depending on their age and the presence of medical conditions that affect the immune response. At time of publication, the current influenza vaccine has been estimated to be 45% effective overall against the 2019–2020 seasonal influenza A and B viruses.[10]

However, the successful implementation of vaccination policies requires a strong national system, including national leadership, strategies and plans to identify and target the under-vaccinated, as well as a skilled workforce, an accurate health information system and community support.[11] Further, systematic reviews have identified strategies that are effective in increasing vaccination coverage in targeted or hard-to-reach groups. These include measures to increase provider recommendations to clients such as reminders, incentives and feedback to providers, supportive immunisation information systems, provisions to enable vaccination by non-medical personnel, and incentives, reminders and recalls for clients.[12] While information specific to implementing vaccination programs targeted at Indigenous people is lacking, effective implementation of Indigenous Australian healthcare in general has been found to be supported by clearly defined management systems, employment of Indigenous health workers as leaders, community control, partnerships, tailoring for diverse places and settings and active facilitation methods.[11]

What is current practice or policy?

Current national policy is for broader recommendations and eligibility for free annual influenza vaccine for Indigenous people (ie. all aged 6 months and older) compared to non-Indigenous adults (6 months to less than 5 years; aged 6 months and over with medical at-risk conditions; pregnant women at any time and those aged 65 years or older), due to higher rates of serious outcomes in Indigenous adults.[9] This policy appears to be appropriate, based on available evidence, however current practice remains inadequate to achieve satisfactory implementation.

Areas where current practice at the national level is not consistent with the best evidence outlined above are: inadequate national leadership, inability to identify and target the under-vaccinated and inadequate health information systems. For strategies targeting hard-to-reach groups, there are no incentives for vaccination and strategies such as recall and reminders are at the discretion of individual providers. There are also limitations on the use of strategies that are effective in Indigenous healthcare delivery in general, including the use of Indigenous health workers and community control. More specifically, vaccination coverage data are available only once every eight years from the National Aboriginal and Torres Strait Islander Health Survey, down to the state/territory level but not smaller areas.[1]

An expansion of the Australian Childhood Immunisation Register to include all ages[13] has occurred but adult vaccinations are substantially under-reported[14] and substantial obstacles exist to its ability to adequately identify Indigenous people in the future. There are no performance indicators related to Indigenous adult vaccination at the national, state/territory or local levels.[15] The accreditation of Aboriginal Health Workers to vaccinate occurs in only a minority of jurisdictions.[16] Indigenous community engagement and the involvement of Aboriginal Health Workers (AHW) are determined at the local level and the extent of these practices at a broader level is not known.[17] Given the limited distribution of Aboriginal Community Controlled Health Services, substantial reliance is placed on General Practice to implement this policy, with no requirements for community engagement or employment of AHWs and low levels of identification of the Indigenous status of clients.[18]

What would the impact be if the proposed action was implemented?

The implementation of strategies to correct the deficiencies in current practice mentioned above are likely to result in a substantial increase in vaccination coverage and have flow-on impacts on other areas of health care delivery through strengthening systems. However, community consultation and engagement, as well as rigorous evaluation will be required to ensure the potential benefits are realised.

We estimate that increasing influenza vaccination coverage in Indigenous adults from 34% to 90% would prevent 1,200 hospitalisations and 250 deaths in Indigenous adults each year.[19]

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Evidence-based management of otitis media in high risk populations

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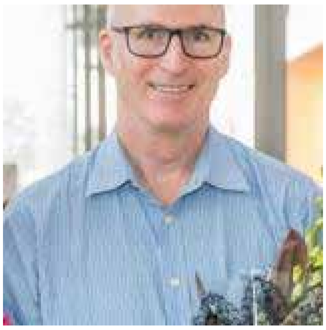

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Otitis media (OM) is a common and complex disease of childhood and refers to inflammation and/or infection of the middle ear. Aboriginal and Torres Strait Islander children have an increased risk of developing OM compared to their non-Aboriginal or Torres Strait Islander counterparts. [1,2,3]

What is the gap and why is it important?

Otitis media and associated hearing impairment in Aboriginal and Torres Strait Islander children living in remote communities has been extensively studied.[1-11] Otitis media (middle ear infection) can be classified as acute OM (with or without perforation of the tympanic membrane), OM with effusion (accumulation of fluid) or chronic suppurative (discharge of puss) OM.[12,13] Aboriginal children are at greater risk of early onset of bacterial otopathogen colonisation of the nasopharynx [1,3] which leads to persistent otitis media with effusion (OME), recurrent (or persistent) episodes of acute otitis media (AOM), progression to acute otitis media with tympanic membrane perforation (AOMwiP), and chronic suppurative otitis media (CSOM).1 Progressive and chronic OM is also possibly due to the asymptomatic presentation of acute OM.[10] In the absence of pain, fever or irritability parents or clinicians may not suspected AOM, therefore infections are not diagnosed or treated and result in prolonged and progressive disease and associated disabling hearing impairment. Best practice requires that appropriate bilateral ear examinations should be made at all scheduled child health checks as well as opportunistically.[13,14] These examinations need to include both otoscopy and testing of tympanic membrane mobility in both ears. Otoscopy with a view of both tympanic membranes allows the detection of the bulging which distinguishes OME from AOM. Tympanometry or pneumatic otoscopy allows the detection of middle ear fluid. Whilst these examinations are recommended, in practice examinations are rarely undertaken and/or poorly documented, with consequent impact on disease management and follow-up.[15]

The population prevalence of OM across jurisdictions, and in urban, rural and remote regions, is not currently known. Limited available data from small population surveillance[10] or clinical audits suggest an ongoing crisis.[11]

The prevalence of severe OM or “runny ears” (AOMwiP or CSOM) among young children has declined in remote communities, from around 24% in 20014 to approximately 15% in 2010.[10] This was partially due to pneumococcal conjugate vaccines. However few children have bilaterally healthy ears; in 2013, surveillance of 140 one-year-old children in 15 remote NT communities found that 50% had OME, 20% AOM, 15% CSOM, and 10% had normal ears.[10] A clinical audit of 2300 records from 46 primary healthcare and community clinics in Queensland (2009 to 2013) found, on average, 70% of children attending a clinic received an ear examination, of whom 45% had chronic OM.[16] This is likely to be an underestimation. Ongoing care comprised follow-up examination (average of 93%), advice (85%), antibiotics prescription (89%), action plan (68%), referral to audiology (62%) and referral to an Ear, Nose and Throat specialist (ENT) (59%).[16]

Why is it important?

Failure to detect and treat early ear disease leads to chronic OME or CSOM.[7] Both of these conditions are associated with long term disabling hearing loss. This has a negative impact on communication,[17] learning, behaviour, school attendance,[18] education outcomes, employment and can even be associated with incarceration.[19] Gaps in Indigenous education, employment and incarceration are well described. Failure to improve clinical management of ear disease will perpetuate the long-term disadvantage associated with hearing loss.

What does the best available evidence tell us?

Without targeted clinical training and community awareness campaigns, the high prevalence of OM and hearing loss in Aboriginal and Torres Strait Islander children will likely continue unabated.

The 2010 OM Guideline[13] (revised 202014) sets out recommendations for clinical care including diagnosis, prognosis, treatment, audiological and surgical options for each form of OM. The 2020 update includes a full revision of the evidence (to March 2017) using the GRADE (Grading of Recommendations, Assessment, Development and Evaluation) approach. "Summary of Findings" tables with effect sizes and a "what happens" explanation are accessible to 2020 OM Guideline users on line and freely downloadable OMapps.[14]

The best evidence from international studies (and Australian research) has been incorporated into the 2020 OM Guidelines[14] from the most recent Cochrane systematic reviews.[5, 20-30] There are modest benefits from antibiotic treatments for OME (Relative Risk 0.57)[14,23] and acute otitis media without perforation (AOMwoP) (RR 0.7).[14,22] The benefits for the prevention of AOMwiP and CSOM are substantial (RR 0.37 and RR 0.45).[14,5] The case management described in the OM Guidelines will mean that the risk of AOMwiP progression is reduced, and that new cases of CSOM can be avoided.

The 2020 Guideline will form the evidence base for clinical training and practice evaluation.[14] An evaluation of the 2010 OM Guideline identified multi-system failures in uptake, and recommended a dual approach to training and service delivery.[15] This model will be actioned for the 2020 OM Guideline and OM-app.[14]

What is the current practice and study?

Most jurisdictions in Australia have formulated ear health policies based on the 2010 Guideline. The focus has been on priority areas such as early detection and appropriate management of young children at risk of CSOM.

Current practice suggests substantial confusion among practitioners about how to diagnose and manage OM in high-risk Aboriginal and Torres Strait Islander children compared to low-risk or non-Aboriginal children.[31] Our analysis of data on appropriate management of OM from a birth cohort to three years of age[32,33] in four large remote communities shows that scheduled ear examinations with recommended follow-up are rarely conducted, findings are poorly documented and there is a mismatch between recommended management and practice.[unpublished data] This includes under-prescribing of antibiotics, and over-(inappropriate) referral to infrequent specialist outreach services for services that should be delivered in primary healthcare.

At the same time, there is increasing concern in Australia about over-prescribing antibiotics, and childhood OM has been identified as a key contributor to over-prescribing.[34]

It is important that practitioners in Aboriginal Medical Services and other services with Aboriginal clients, particularly in regions with a high prevalence of bacterial OM and CSOM and relatively low incidence of self-resolving episodic OM, prescribe antibiotics for persistent OME in high-risk children, and for AOM with or without perforation, and that antibiotic treatment, particularly for AOMwiP and CSOM, is continued until resolution is achieved.[14]

What would the impact be if the proposed action was implemented?

The proposal is to promote and evaluate the evidence based management of OM in Aboriginal and Torres Strait Islander children, through dissemination, education and training of the 2020 OM Guideline and OM-app.

The short-term impact would be increased health care provider (General Practitioner, Aboriginal Health Practitioner, Nurse Practitioner) diagnostic skills and confidence, early detection of OM, reduced progression of AOM to AOM with perforation, and reduced progression to CSOM. This in turn will lead to fewer hearing impaired children, fewer audiology and speech pathology referrals for children with persistent hearing loss and language delay, and fewer ENT referrals for tympanoplasty (tympanic membrane repair).

Longer term benefits of a successful primary healthcare ear health program will be improved learning, improved behaviour and school attendance, increased education and better social outcomes for future generations of Australian Aboriginal and Torres Strait Islander children.

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Delivering family-centred care for Aboriginal and Torres Strait Islander children aged < 5 years

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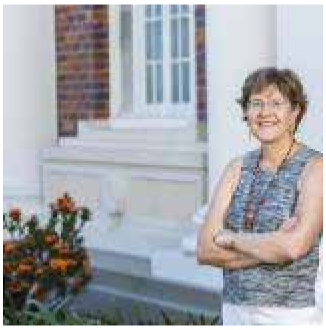

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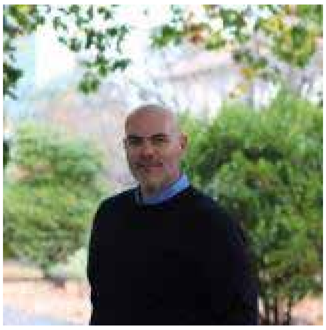

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The first five years of a child's life are a critical time period for influencing growth, development and learning.[1]

What is the gap and why is it important?

Growth, development and learning are largely influenced by sociocultural factors, poverty, psychosocial and biological risk factors, and central nervous system development and function.[2] Primary health care services are uniquely placed to deliver a wide variety of interventions to improve health and wellbeing outcomes for Aboriginal and/or Torres Strait Islander children. Data suggests that while the delivery of services, particularly child health checks, has improved over time, actions and follow-up after a health assessment still remain poor.[3, 4] Improving the quality of care delivered to Aboriginal and/or Torres Strait Islander children remains a challenging issue for primary health care services.

Family-centred care is a way of caring for children and their families within primary health care services that ensures care is planned around the whole family, not just the individual child/person, and that all family members are recognised as care recipients.[5] Family-centred care can be achieved through a variety of interventions. These include environmental interventions (collaborative partnerships with the family and/or child resulting in the design or redevelopment of the home or primary health care environment to maximise parental involvement and enhance child-health and well-being), communication interventions (promoting parental participation in health education to plan antenatal or postnatal care), educational interventions with structured support for families and continuing education for staff, counselling interventions such as brief interventions, and family support interventions such as referral to community services. These interventions are flexible in their approach and can involve, but are not limited to, collaborative care pathways, health promotion, brief interventions, home visiting and referrals to community services for children and their families.

Family-centred care is an approach which could improve the health and well-being outcomes of children and their families. It is seen by families to have great potential, particularly during the antenatal period, as long as services are responsive and flexible to families' needs, provide adequate, timely information and support, and provide opportunities to share ideas and suggestions.[6, 7] Although family-centred interventions are implemented in some primary health care services, they are not being delivered to their fullest extent within and across primary health care services, and many health care services are not meeting the needs of children and their families.[8] Due to the historical disempowerment of Aboriginal and/or Torres Strait Islander families, the provision of culturally proficient and empowering health care services that enable family satisfaction and ownership over decision making in the health of their children are very much needed.

What does the best available evidence tell us?

Family-centred care may improve the quality of care provided to children and their families, and provide broader advocacy by primary health care services to impact the social determinants of health, improving the way in which health care services are provided. There is limited evidence on the effectiveness of family centred care within primary health care services. Reviews completed on this topic are out of date or not specific to child health within primary health care services.[9, 10]

A recent scoping review found eighteen studies for family-centred interventions by primary health care services for Indigenous children aged up to 5 years in Australia, Canada, New Zealand and the USA.[11] Three randomised controlled trials plus 15 qualitative or exploratory studies were identified, describing six key strategies for improving the health of families: supporting family behaviours and self-care, increasing maternal knowledge and skills, linking families to clinical services, building the Indigenous workforce, promoting cultural and community connectedness and advocating for social determinants of health. These strategies are enabled by conditions such as competent and compassionate staff, flexibility in access, continuity and integration of care and culturally supportive care. These were implemented to a varying degree across the studies. To provide additional evidence to support the delivery of family centred care, a systematic review was completed to determine the effectiveness of family-centred interventions for Indigenous children by primary health care services.[12]

What is current practice or policy?

Primary health care services are delivered through a variety of private, state-based and Aboriginal Community Controlled Health Organisations (ACCHOs) for Aboriginal and/or Torres Strait Islander children and their families. As a result it is difficult to know the variants of the family-centred model of care being implemented or the extent of implementation. While there is evidence to suggest that models of family-centred care are being implemented in primary care health services in Australia,[11] it is unclear the extent to which these services have achieved improved family satisfaction with healthcare, empowerment of families in the healthcare of their children, or health and well-being outcomes as a result of this model. One model of care, the Baby One Program, that is delivered throughout Cape York by Apunipima Cape York Council, is aimed at early and frequent attendance at antenatal clinics and regular postnatal check-ups through empowering their families.[13] An evaluation of the program found uptake by 161 eligible families, with the key to effective implementation being the relationships formed between health practitioners, especially Indigenous Health workers, and families.[6]

The 'National Framework for Health Services for Aboriginal and Torres Strait Islander Children and Families' policy supports the implementation of child and family health service systems that include the delivery of family-centred care as a key approach to providing culturally safe and appropriate care for children and their families.[14] Although this framework, in combination with other national policies, sets the national context of health service delivery for Aboriginal and/or Torres Strait Islander children, there still remains a substantive gap between policy and the realities of providing family-centred care.[15-17]

What would the impact be if the proposed action was implemented?

- Family-centred primary health care models that respect cultural context and empower families to make informed decisions concerning the health and wellbeing of their children.
- Primary health care-delivered family-centred care could significantly improve the health and wellbeing of Aboriginal and/or Torres Strait Islander children and their families.[18] This could also increase satisfaction with, and utilisation of, healthcare services.
- At the core, family-centred care encompasses the importance of both immediate and extended family, and the home environment. It also reflects the decision making process of families. In its essence, family-centred care supports the holistic concept of care for young children and their families.
- Strategies such as supporting family behaviours and self-care, increasing maternal knowledge and skills, linking families to clinical services, building the Aboriginal and/or Torres Strait Islander workforce, promoting cultural and community connectedness and advocating for social determinants of health are a good basis for delivering family-centred care.
- Long-term vision, support, resourcing and change within primary health care organisations is needed.
- Evaluation of the effectiveness of this model of care is needed.

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Culturally safe advice on alcohol cessation in pregnancy

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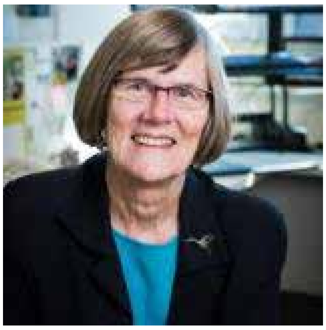

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Drinking alcohol in pregnancy can harm the unborn child and may cause a range of neurodevelopmental disorders including Fetal Alcohol Spectrum Disorder (FASD).[1]

What is the gap and why is it important?

FASD is a diagnosis that can result from prenatal alcohol exposure. According to the 2016 Australian Guide to the Diagnosis of FASD, it is categorised as either FASD with three sentinel facial features (previously referred to as Fetal alcohol syndrome [FAS]) or FASD with fewer than three sentinel facial features.[2] FASD is characterised by lifelong intellectual disability, behavioural and developmental impairment, and is also potentially preventable. It is estimated that approximately 60% of Australian pregnancies are alcohol-exposed.[3, 4] Although a smaller percentage of Indigenous Australian women drink alcohol compared with non-Indigenous Australian women, they tend to drink at high-risk levels.[5] In 2014–2015 the National Aboriginal and Torres Strait Islander Social Survey 2014-15 found that approximately 10% of Indigenous Australian children aged 0–3 years-old had prenatal alcohol exposure, which is about half the rate found in 2008. Most of this difference was due to decreases in non-remote areas. In 2010/2011 in the remote Fitzroy Valley, Western Australia (WA), 55% of women who participated in a population based study reported alcohol use during pregnancy (for children born in 2002/2003), and 95% of these women drank at risky to high-risk levels.[6] Their children had among the highest rates (19%) of FASD worldwide.[7] To maximise opportunities for prevention and identification of children at risk for FASD, all women should be educated about the potential harms of alcohol use in pregnancy. The World Health Organisation recommends that all women who are pregnant or planning a pregnancy should be asked and advised about alcohol consumption at every antenatal visit, and be referred to treatment and support services as necessary.[8]

Health professionals are well-positioned to prevent FASD through providing accurate and timely advice about risks, complications and referral services, however gaps exist in their knowledge, skills and confidence. Although 98% of health professionals in Western Australia provide advice consistent with NHMRC guidelines on alcohol use during pregnancy (see NHMRC's alcohol guidelines),[9] some pregnant women receive inaccurate advice,[10] and opportunities for prevention and diagnosis are missed. For example, only 46% of health professionals routinely ask pregnant women about alcohol use and 32% inform them about the consequences.[11] In addition 70% of mothers of children with FAS do not have an alcohol-related diagnosis recorded during pregnancy, and 51% of children with FAS already have an affected sibling.[12, 13] Most health professionals are unaware of the availability of high-quality, culturally appropriate FASD prevention resources.

What does the best available evidence tell us?

Abstinence from alcohol during pregnancy prevents FASD,[2] however evidence on effective prevention approaches for FASD is of poor quality, so it is not possible to recommend one particular approach for sustained and effective behaviour change in pregnant women.[14, 15] Nevertheless, 97–99% of Australian women expect health professionals to ask, advise, and readily provide information to them about potential harms from alcohol use in pregnancy.[11] Specifically, advice was sought from antenatal services by 54% of Indigenous mothers who reported alcohol use during pregnancy (see Aboriginal and Torres Strait Islander Health Performance Framework). Prenatal screening followed by empathetic interventions by health professionals has been shown to be effective in reducing prenatal alcohol exposure in USA. Research in 2015 with American Indian/Alaska Native women, showed that assessment of maternal alcohol use alone, even without intervention, reduced vulnerability to prenatal alcohol exposure.[16] Asking and advising women about alcohol use is a logical first step to enabling the identification of women with alcohol use and misuse and children at risk for FASD.[2] Starting the conversation with all pregnant women provides the health professionals an opportunity to offer advice on alcohol use, brief intervention, referral, and monitoring. Contraception is an important component of prevention for women of child-bearing age who regularly drink alcohol.

The reasons for harmful alcohol consumption by Aboriginal people are complex and must be understood in the context of whole-of-life experience including historical trauma, cultural, and economic circumstances.[17] Health professionals should provide a culturally safe service, informed by Aboriginal Health Workers, and preferably delivered with Indigenous practitioners (see UNSW).

What is the current practice or policy?

National guidelines recommend that health professionals : i) ask all pregnant women about alcohol consumption using a standardised tool (the Alcohol Use Disorders Identification Test-Consumption [AUDIT-C]);[2] ii) advise that not drinking is the safest option; iii) provide brief intervention to women who drink during pregnancy; and iv) refer to specialist medical services if necessary.[8, 18, 19] Only 64% of midwives provide pregnant women with information about harms of prenatal alcohol exposure, and 70% provide brief interventions when indicated.[20] Only 22% of paediatricians ask about alcohol use and 10% provide information about prenatal alcohol exposure.[21] In Hunter New England Health, 64% of women surveyed were not asked about alcohol use and only 35% received appropriate advice and referral.[22] The AUDIT-C, treatment advice and referral pathways have now been embedded in their e-maternity system (NHMRC Partnership grant #1113032). Additional Australian Government-funded initiatives include the National FASD Action Plan (2014) and the National FASD Strategic Action Plan (2018–2028).

What would the impact be if the proposed action was implemented?

If all women who were pregnant or planning a pregnancy were asked about alcohol use by their health professionals, advised that no alcohol is the safest option and provided with support to abstain from alcohol throughout pregnancy or obtain treatment for alcohol misuse or dependency, the expected impact would be:

- A reduction in the numbers of alcohol-related adverse pregnancy, neonatal and child health outcomes
- Increased awareness and a systematic approach to supporting women who consume alcohol
- Early follow-up of children prenatally exposed to alcohol and earlier identification of FASD
- Harm prevention through education of patients, and earlier support for mothers at risk of drinking alcohol in subsequent pregnancies
- A reduction in the numbers of FASD cases, and
- Acquisition of more accurate prevalence data on alcohol use in pregnancy to inform future services and interventions and monitor progress with prevention.

Prevention of alcohol use in pregnancy remains a challenge and will require legislative and societal attitudinal change and education to underpin behavioural change.[23] The responsibility to prevent prenatal alcohol exposure and FASD should be shared amongst women, their partners, families/communities, health professionals and social services, society (with social norms not promoting risky drinking), and government.[24]

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Early diagnosis of Fetal Alcohol Spectrum Disorder in Indigenous children

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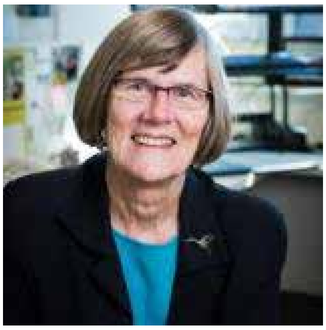

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Fetal Alcohol Spectrum Disorder (FASD) is caused by prenatal alcohol exposure and is characterised by severe neurodevelopmental impairment, that may include intellectual disability, behavioural and other developmental problems.[1,2] FASD causes a significant burden to individuals, the health care, education, and justice systems and society.[1,2]

What is the gap and why is it important?

In Australia, the diagnosis of FASD is divided into two sub-categories: FASD with three sentinel facial features (replacing the diagnosis of Fetal Alcohol Syndrome [FAS]); and FASD with less than three facial features.[3] Indigenous Australian women, although less likely to drink alcohol during pregnancy, drink at riskier levels than non-Indigenous women.[4] Research showed FAS prevalence in Indigenous Australian children born in the Top End of the Northern Territory between 1990 and 2000 to range between 1.87 and 4.7 per thousand live births, significantly higher than rates in non-Indigenous children.[5] In 2010, a survey of 7 to 8 year old children in the Fitzroy Valley, Western Australia (WA), showed 19% had FASD, which is among the highest rate observed worldwide.[6] Many of these children had learning and behaviour difficulties which warrant early intervention.[7] In a juvenile justice setting in WA, 36% of children/adolescents assessed had a diagnosis of FASD, of whom 74% were Indigenous.[8] Early diagnosis enables early intervention, which decreases the risk of adverse adolescent/adult outcomes including disrupted schooling, trouble with the law, incarceration, repeated inappropriate sexual behaviours, social disorders, and alcohol/drug problems by 2–4 fold.[9,10] Interventions focused on self-regulation and attentional control can improve outcomes.[11] Primary healthcare providers are positioned to enable early diagnosis and management of FASD.[6] However, gaps in health professionals' knowledge, skills and confidence and their attitudes; as well as the lack of local diagnostic guidelines prevent optimal management of FASD. In 2007, only 16% of health professionals in WA could identify the essential diagnostic criteria for FAS.[12] In the past, the adoption of international FASD diagnostic guidelines by health professionals in Australia has been hampered by perceptions of limited applicability to the Australian population; the poor evidence base for treatment and prevention of FASD;[13] and the lack of interdisciplinary and interagency models to support service delivery in Australia.[14] Health professional and service shortages compound this problem for families in rural and remote areas.[15,16]

What does the best available evidence tell us?

Early recognition and treatment of FASD (before the age of 6 years) improves health outcomes.[9,10,11] To diagnose FASD, a multidisciplinary team of health professionals including paediatricians, psychologists, occupational therapists, physiotherapists, and speech therapists is optimal.[3] Early diagnosis will reduce risks of adverse outcomes in adolescence and adulthood through provision of family support services, specialised schools, programs and interventions; improved preparation of families when the affected child transitions into young adulthood; effective treatment of the mother if necessary; and family access to appropriate supports and benefits.[9,10,17]

Guidelines that provide clear diagnostic criteria, assessment methods, and provide guidance for developing management plans, and include an implementation tool are more likely to be adhered to.[18,19] Guidelines are more likely to be adopted by health professionals if they are developed in consultation with health professionals and are locally relevant. This requires consideration of the cultural context and available services and input from Indigenous Australian peoples.[20,21]

When implementing practice change in Indigenous Australian communities, community consultation is essential to avoid imposing a "one size fits all" solution, which may be exclusionary and detrimental to the communities.[20] Implementation should involve partnerships between health professionals, Indigenous Australian community groups, and where applicable, Government.[21]

What is current practice or policy?

Education alone contributes minimally to increased diagnosis and reporting[17,18] with small increases in the number of health professionals who; knew the features of FAS (from 12% to 16%); had diagnosed FAS (from 5% to 7%) and had referred children to confirm a FAS diagnosis (13% to 18%).[12,22] Despite education, 47% of health professionals feel unprepared to deal with FAS; with only 3% being "very prepared".[22] Only 22% of paediatricians routinely asked pregnant women about prenatal alcohol exposure and only 18% knew the FAS diagnostic features.[22]

The evidence-based Australian Guide to the Diagnosis of FASD (2016) was developed with input from Indigenous Australians, to provide a standardised approach to FASD diagnosis which was consistent with international guidelines.[3] Since 2016, the Australian Guide to the Diagnosis of FASD has been widely disseminated and training in its use has been provided nationally. The Australian Guide is the most frequently accessed page on the FASD Hub Australia website. The Australian Guide to the Diagnosis of FASD is currently undergoing review. Formative evaluation needs to be done to determine the most effective and acceptable framework for active dissemination and use by each health professional group;[24,25] and routine evaluation of its efficacy will be required.[19]

Indigenous Australian families in rural/remote areas have limited access to health professionals with experience or training in the use of the Australian Guide to the Diagnosis of FASD,[3] let alone access to multidisciplinary teams.[15,16] In these communities, most children use the Aboriginal Medical Services and Aboriginal Health workers are often the first contact.[16] Also, children in remote/very remote areas with an Indigenous Australian carer are less likely to see a doctor.[16] This contributes to additional barriers to early detection and treatment of FASD.

In 2017, the Australian Government allocated funding to FASD prevention, education, and referral programs in Northern Territory and New South Wales; and to develop capacity for FASD diagnostic services in Western Australia, Northern Territory, South Australia, Tasmania, Victory, and Queensland. In 2018, they funded further dissemination and evaluation of the Australian Guide to the Diagnosis of FASD and e-Learning Modules. This was followed in late 2018 with a new national action plan and $7 million in new funding which includes review of the Australian Guide to the Diagnosis of FASD.

What would the impact be if the proposed action was implemented?

We propose that health professionals are provided with access to the *Australian Guide to the Diagnosis of FASD* and training in its use for assessment of children. This would result in:

- Earlier diagnosis of FASD
- Increased FASD diagnosis
- Standardisation of diagnosis of FASD
- Opportunity for early optimal management to minimise secondary adverse outcomes
- Increased opportunity for FASD prevention in subsequent pregnancies
- Acquisition of more accurate prevalence and outcome data on FASD to inform future services and interventions.

Remaining challenges include:

- Formative evaluation to identify the extent of dissemination of the Australian Guide to the Diagnosis of FASD, and methods to maximise uptake of the training by health professionals.
- National dissemination of the Guide and effective training of health professionals who may be involved in the FASD diagnostic process to build capacity nationally.

- Equitable access for Indigenous Australians to resources and services including:
  - Multidisciplinary assessment for FASD, especially in rural and remote Indigenous Australian communities
  - Improving the evidence-base for treatment of people with FASD
  - Support, education and parenting training for families living with FASD
  - Access to Government support (e.g., National Disability Scheme, carer's allowance)

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