Collective and negotiated design for a clinical trial addressing smoking cessation supports for Aboriginal and Torres Strait Islander mothers in NSW, SA and QLD - developing a pilot study.

The term Aboriginal will be used in this paper to refer to both Aboriginal and Torres Strait Islander peoples but with recognition and respect to the autonomy of the two peoples.

Abstract

Tobacco smoking leads to one in five deaths of Aboriginal Australians and accounts for 17% of the reversible health gap between. One in two Aboriginal women are reported to smoke during pregnancy with no effective strategies currently available for health practitioners to utilize for supporting Aboriginal women. Aboriginal community participation in primary health research is crucial to implementing ethical research with a clear benefit to the people and communities involved. However, currently there is little evidence on how Aboriginal programs and interventions are being developed in partnership with Aboriginal people and communities.

Indigenous Counseling and Nicotine (ICAN) QUIT in Pregnancy aims to address the prevalence of smoking during pregnancy by enhancing health providers' training in offering evidence-based smoking cessation care to Aboriginal mothers during pregnancy. This paper outlines the participatory research approach adopted for the developmental phase of the *ICAN QUIT in Pregnancy* project developed in partnership with two Aboriginal Community Controlled Health Services in NSW, and negotiation processes undertaken to implement a pilot intervention across NSW, SA and QLD.

What is known about this topic?

- Community participation in health research is fundamental to implementing ethical research with clear benefit to Aboriginal people and communities: however there is little evidence how these relationships between researcher and community are functioning.

What does this paper add?

- This paper describes the process undertaken to develop a culturally responsive smoking cessation research project for expectant Aboriginal mothers. Processes outlined inform how Aboriginal people and communities can be integrated in the development of primary health research in a respectful and ethical partnership.

Introduction

Closing the Gap in Indigenous health disparities is a priority focus for Australia. Systematic reviews addressing Indigenous health highlight the relevance of local community settings for health programs and interventions. Health programs should include full participation of Aboriginal individuals in decision-making and implementation (Minichiello et al. 2016), and encompass community control, tailoring for diverse sites and sustaining effective partnerships (McCalman et al. 2016).

Several key publications guide researchers to understand appropriate processes for developing and implementing Aboriginal health research. The *AH&MRC Guidelines for Research into Aboriginal Health* and *Keeping Research on Track* provides an explanation of ethical health research; and the *NHMRC Road Map II* provides the strategic framework and key action areas for Aboriginal health research (AH&MRC Ethics Committee, 2013; NHMRC, 2005, 2010). This literature aids a researcher to understand *when* and *why* Aboriginal health research is appropriate, relevant and ethical, however there is limited knowledge on *how* this is implemented in partnership with Aboriginal people and communities in primary health care settings.

The importance of Aboriginal community involvement is clearly articulated in all documents pertaining to Aboriginal Health Ethics (AH&MRC Ethics Committee, 2013; Council, 2003; (Committee 2013; Dunbar and Scrimgeour 2006; NHMRC, 2005, 2010). The *National Aboriginal & Islander Health Organisation (NAIHO), Report on the National Workshop on Ethics of Research in Aboriginal Health (1987)* states a need for 'consultation/negotiation' to be clearly defined to ensure that Aboriginal communities

are offered ethical research with clearly define benefit and involvement of Aboriginal communities (Mundine, 2001).

Collaborative approaches require consultations, full participation and effective partnerships (Jamieson et al. 2012; O'Donahoo & Ross 2015). Involving Aboriginal communities in a truly collaborative way, when recognizing the diversity among Aboriginal people and communities and their past experiences with research (Kendall & Barnett 2015; Mc Loughlin et al. 2014), will also include negotiation.

This article addresses *how* we have developed a targeted smoking cessation intervention collectively, incorporating Aboriginal partnerships and building capacity of Aboriginal researchers; and with negotiation, developing a pilot study design. This paper aims to present purely the early stages of intervention development, outlining our approach of involving Aboriginal people and communities. This is not a 'how to' guide for Aboriginal research Jamieson (Jamieson et al., 2012) and O'Donahoo (O'Donahoo & Ross, 2015) have already offered these principles. This paper is reporting our process as an example of how Aboriginal people can become involved in intervention development and design.

Context

Tobacco smoking accounts for 17% of the reversible health gap in Indigenous Australians (Vos, et al 2009). Tobacco use during pregnancy remains disproportionately high among Aboriginal women in comparison to their non-Aboriginal counterparts (47% vs 13%) (Australian Institute of Health and Welfare, 2015). Smoking during pregnancy results in higher rates of infant morbidity and mortality and is well established as the most modifiable risk factor for adverse health outcomes for mother and child (Arnold et al 2016; Passey & Sanson-Fisher, 2015).

Reducing the rates of smoking is a national priority in the National Aboriginal and Torres Strait Islander Health Plan 2013-2023, and the National Closing the Gap Health Campaign to assist in closing the gap in life expectancy between Indigenous and non-Indigenous Australians within a generation, which is currently not on track (Commonwealth of Australia, 2015). Leading Indigenous academic Eades, has called

for a *"comprehensive framework that guides and monitors the effectiveness of tobacco control efforts among Aboriginal people at the local, state and national levels"* (Eades et al. 2015). The Smoke Check program in NSW and QLD demonstrated a positive change in Aboriginal Health Worker capacity to deliver smoking cessation advice to a range of Aboriginal communities through training of Aboriginal Health Workers (Hearn et al. 2011).

A systematic review of studies evaluating Aboriginal community development projects reported a *serious underutilization in smoking cessation interventions in antenatal care* (Snijder, J et al 2015). Over the past decade researchers have engaged in a variety of research methods including qualitative, quantitative, program evaluations, and pilot studies addressing Aboriginal maternal smoking, and have reported smoking trends, environmental factors, social and cultural determinants, and some preliminary data on effectiveness (Australian Institute of Health and Welfare & Cancer Australia; Eades et al., 2012; Gilligan et al 2007; Gilligan et al., 2010; Gilligan et al 2009; Gould et al., 2013; Panaretto et al., 2009; Wood et al 2008). Only one randomized controlled trial (RCT) has been implemented to address Aboriginal maternal smoking cessation during 2005-2009 with a non-significant increase in quit rates reported (Eades et al., 2012).

As yet, there are no effective strategies to support Aboriginal women quit smoking during pregnancy in Australia. In order to address the current gap a cohort of researchers began to work collaboratively with Aboriginal people and communities in New South Wales (NSW), South Australia (SA) and Queensland (QLD).

The *Indigenous Counseling and Nicotine (ICAN) QUIT in Pregnancy* project builds on the published *"Pragmatic Guide to culturally competent care for Aboriginal and Torres Strait Islander maternal smokers"* (Gould et al 2015). These guidelines incorporate counseling and the expedited use of NRT following an ABCD framework: A- ask/assess; B- brief advice; C- cessation; D- discuss psychosocial context. The intervention trains health providers to offer evidence-based smoking cessation care to Aboriginal mothers during pregnancy. The project was designed as a 3 phase study: 1) formative research, 2) pilot study and 3) a cluster RCT.

Review of Literature of Similar Cases

A Medline search on “Aboriginal Health” revealed that there is an emerging trend in published literature reporting; community consultations, community participation, community governance, collaborative approaches to study design and implementation of Aboriginal Health research (Adams & Tongs, 2011; Durey et al., 2016; Eades & Read, 1999; Fletcher et al. 2011; Fredericks et al., 2011; Holmes et al 2002; Lin et al 2016; Massey et al., 2011; Rae et al., 2013; Reeve et al., 2015). Jamieson published the *Ten principles relevant to health research among Indigenous Australians* (Jamieson et al., 2012) with a cohort of experts in Aboriginal Health which was extended by O’Donahoo in 2015 (O’Donahoo & Ross, 2015) and has since functioned as a reporting tool for studies publishing research practice (Gwynn et al., 2015; Singer et al 2015).

In 2014 and 2015 two other smoking cessation research projects described *how* they have conducted community engagement and development (Couzos et al., 2015; Marley et al., 2014). “Talking About the Smokes”, a national epidemiological project, reports their community-based participatory research methodology in accordance with the World Health Organisation guiding principles (Couzos et al., 2015). BOABS Study reflects on qualitative data to report challenges and successes of implementing a randomized smoking cessation intervention in two Aboriginal communities (Marley et al., 2014).

Resources such as this are invaluable to any academic working in Aboriginal Primary Health Research. Knowing *how* research can be developed, implemented and evaluated in partnership with Aboriginal people and communities. For Aboriginal people and communities this offers an avenue for transparency of practice and accountability of researchers to communities participating in research. Clear articulation on *how* research is being conducted ethically in Aboriginal communities, *how* Aboriginal ownership is developed and upheld and *how* research within Aboriginal communities is being conducted to address clear benefit to Aboriginal people and communities is crucial to report on given the prevalence of non-Aboriginal academics working in this space.

The Case Study

The developmental phase of *ICAN QUIT in Pregnancy* is discussed using three keys areas of development relevant to equitable Aboriginal health research: establishing a community need for the research and partnerships, building capacity, and developing a pilot study design (AH&MRC Ethics Committee, 2013).

Establishing a community need for research and partnerships

Conceptualization of the project began in early 2015. Progressively, over an 18 month period, the project team developed a partnership framework engaging: funding bodies, 16 academic researchers including six Aboriginal Researchers (AR), Aboriginal leaders and peak bodies such as the National Coordinator Tackling Indigenous Smoking, AH&MRC, AIDA, NSW Ministry of Health, and Aboriginal Community Controlled Health Services (ACCHS).

Investigations to address local priorities began when ACCHS' were contacted across NSW, QLD, SA and NT. Consultations revealed a joint concern about the consistent smoking rates in their communities during pregnancy. In some cases, funding and partnership changes had resulted in specialist smoking cessation support being reduced or cut (Carson, 2014). Services reported that while they believed smoking cessation supports they generally offered their community were positive, there was limited access to interventions during pregnancy, and limited referrals into mainstream smoking cessation support.

Through these community-based investigations, two NSW based ACCHS' agreed to work collaboratively with the research team and project staff to co-develop an appropriate intervention. Both CEOs of these ACCHS' are Associate Investigators on this project.

Engagement with ACCHS' commenced early to ensure adequate time for relationship building, consultations with internal and external services, boards and communities. The strategy was to commence with two local ACCHS' to co-develop the research design and resources while seeking appropriate funding and additional services to pilot

the intervention in NSW, SA and QLD. The close locality of the two ACCHS' allowed for a reduction in travel expenses and time, ability to engage in increased face-to-face meetings, building strong relationships with Associate Investigators and increased opportunities for community engagement. Four further ACCHS' have been engaged in NSW, SA and QLD for the pilot intervention: three of these will also pre-test the resources via focus groups during Phase 1 of the study (Gould et al 2016).

Individual ACCHS' in SA and QLD were targeted for the pilot study using pre-existing networks to provide comparative data on the feasibility of the study across Aboriginal community's interstate. Using pre-existing networks that had knowledge and experiences in research previously lead by the Principal Investigator, aided in a time-effective and more trustful engagement process interstate. For NSW, an information package on the research was developed and distributed to all ACCHS' to seek further expressions of interest from communities. We initially received three services' expressions of interest, and a further seven services subsequently expressed interest through community networks and conference presentations. All ACCHS' partnering in the project required several consultations. These included contact by telephone, face-to-face meetings, presentations to their CEO and Community Board, and sometimes Research Board, before support and engagement in the project could be obtained, and relevant ethics applications commenced. Transparent processes for consultations included sharing all formal research documents i.e. the research protocol and approved ethics applications, in addition to specifically developed 1-2 page briefs; service brochures introducing the study, an overview of cost versus benefit of participating in the study, project overviews, consultations to date, and newsletters with up to date information about researchers, implementation developments, funding, research outputs, and ethics progress.

A Stakeholder and Consumer Aboriginal Advisory Panel (SCAAP) was formed in 2015. This included CEOs, Aboriginal Maternal Health staff, Aboriginal Health Workers and Female Aboriginal community members of the two co-developing ACCHS'. The SCAAP oversaw the development of ethics applications, the pilot study design, and methods of implementation and evaluation. The SCAAP established a Terms of Reference to set out the expectations the community had of the research team, and the roles and responsibilities the research team was seeking from the community. The

Terms of Reference is a living document, tabled during all meetings, to accommodate changes in roles and responsibilities, and for new services to have ownership over the process. SCAAP met bi-monthly over 8 months and was coordinated by an Aboriginal PhD student (MB) with a smaller working group (WG) meeting every 2-3 weeks. The WG comprising: Maternal Health Team and Aboriginal Health Workers, two PhD students one Aboriginal and one non-Aboriginal. The WG guided the co-development of appropriate intervention resources.

Innovative ways of collaborative partnerships are being explored for the pilot intervention, allowing ACCHS' across NSW, SA and QLD to engage in an expanded SCAAP via video link ups. Creating transparency is a key focus for collaborative partnerships: a secure, password protected web-based platform will be offered to all ACCHS sites to ensure they have access to all relevant documentation relevant to the project implementation, in consultation with their community and/or partnering agencies.

Building capacity

The research team developed several capacity building areas to ensure the research has clear benefit to Aboriginal people and communities including: employment of Aboriginal research staff and students, Aboriginal community education in research implementation and reporting, and webinar training of health providers as part of up skilling staff for the pilot intervention. Webinar will also be used to train and support ACCHS-based Research Facilitators (RF), funded by the project.

From the early stages of development, the project employed an Aboriginal Research Assistant (ARA) to guide community consultation and engagement in the study design and development. An additional ARA was engaged to continue the high level of communication and consultation needed across Aboriginal communities as the project was implemented. One ARA (MB) enrolled in a PhD in Aboriginal Health, with a scholarship from the Faculty of Medicine and Public Health at University of Newcastle (UON). Ongoing part time employment was offered to MB while undertaking her PhD on the project, which is co-supervised by a senior Aboriginal academic.

The research capacity-building strategy enables opportunities to collaboratively deliver conference presentations and develop journal papers. For example, the WG co-convener (an ACCHS Continuous Quality Improvement Officer) and the Aboriginal PhD student (MB) co-presented the project development at the 2016 AH&MRC Tackling Tobacco and Chronic Conditions Conference (Bovill, 2016).

The developmental phase included plans for capacity-building elements for further phases of the study. These include site-based RFs to support the pilot intervention. RFs will receive training on how to gain informed consent, data collection, and ethical guidelines for conducting research. All health professionals at ACCHS' piloting the project will receive a series of webinar training sessions, and culturally safe resources to support Aboriginal women to quit smoking during pregnancy. The training will be flexible to accommodate service delivery, including catch up training via online webinars to allow for staff turnover, and refresher training for individuals when needed.

Developing a pilot study design

ICAN QUIT in Pregnancy was developed based on literature reviews (Gilligan et al., 2007; Ivers, 2004; Minichiello et al., 2016; Passey et al 2013), prior research (Gould et al., 2013; Gould, et al 2013; Gould et al., 2014), with planned design and outcome measures. Previous implementation challenges with RCT studies in Indigenous smoking were also addressed (Eades et al., 2012; Marley et al., 2014; Patten, 2012). These implementation challenges include: low participation rates, cross contamination of intervention and control groups, high rate of staff and loss to follow-up. These challenges have been addressed and new approaches discussed with SCAAP and WG to implement our project; engaging ACCHS' training their current staff to be RFs to recruit women into the study and coordinate follow up appointments. The developed study design (using a cluster approach) mitigates the opportunity for cross contamination. Resources co-developed and tested across Aboriginal communities make the research more culturally responsive and engaging for Aboriginal women. Our intervention also negotiates with Aboriginal people and communities in the implementation of study design to ensure appropriateness across communities.

Formative research

Community participation in resource development was essential to respectfully acknowledge cultural diversity among Aboriginal people, in the multiple States where the intervention will be piloted (Gould et al., 2016). The WG guided the resource development for the project over a series of workshops. During the first workshop, the WG examined a range of existing smoking cessation resources and considered which would be the most appropriate for Aboriginal pregnant women; what resources would be best suited to this type of intervention; and key considerations when designing them. The WG preferred positive images of real Aboriginal and Torres Strait Islander community members, rather than cartoon imagery of people, for resources. Acknowledging limitations of literacy skills of some communities, project staff and the WG considered the use of inbuilt videos for the print resources (Commonwealth of Australia, 2015). Videos have potential to enable greater engagement with resources, as well as a deeper level of understanding of the content. The WG advised that utilizing smart phone technology would assist Aboriginal women to engage in the information sharing process. The WG advised brochures on “quitting in pregnancy”, “how to make your home smoke-free” and “smoking triggers” were most needed. A flip chart was approved to support the Health Worker to engage in conversation with Aboriginal women on smoking in pregnancy in a non- confrontational way. WG all agreed that the messages for the project needed to make Aboriginal women feel supported, non-judgmental and non-confrontational approaches were crucial to engagement in addressing smoking cessation during pregnancy for their Aboriginal women.

MB worked collaboratively with a local Aboriginal photographer/filmmaker to develop a library of images and short film clips for resources. Using local networks, Aboriginal women residing in Hunter New England area were engaged. Women were purposively approached from a range of communities including: NT, QLD, VIC and both inland and coastal NSW communities. The short videos to be embedded in printed brochures included: Aboriginal Obstetrician explaining how tobacco smoke reaches a baby while in utero, and addressing myths of smoking in pregnancy; Aboriginal women speaking about their smoking triggers during pregnancy; and a Torres Strait Islander general practitioner explaining how to use each form of nicotine replacement therapy (NRT).

Planned Implementation of the study

A need for flexibility in project implementation was identified early in the consultation stage. We commenced our engagement as a negotiated process. The most rigorous design and outcome measures were planned with consideration as to how they could be implemented in an ACCHS', the services' capacity to conduct such research, and the acceptability by Aboriginal women recruited to the study. The research team consulted Aboriginal researchers and ACCHS' on the acceptability of scientific measures by Aboriginal women, and optional study elements were identified. For example, when consulting with one ACCHS, who presented interest in the pilot intervention, it was evident that the planned audio-recording of consultations may not be acceptable in their community. Thus we amended the research protocol so that audio-recordings could be *optional* for both the ACCHS' and Aboriginal women participating in the study. This approach enabled a pragmatic yet robust design. As the study moves into the next phase, further consultations and negotiations will be required to maintain acceptability of the research in a broader range of communities.

Collective and negotiated design

Collective and negotiated design moves beyond a collaborative model of working with Aboriginal communities to articulate the specific ways in which researchers are implementing ethical health research with Aboriginal communities. There will always be a level of negotiation involved in any research conducted in Aboriginal health to ensure that Aboriginal people and communities are respected and their values upheld. The development of the *ICAN QUIT in Pregnancy* project built on community need and interest. Through establishing partnerships and relationships with Aboriginal people and communities and engaged in models of collaboration such as: formal engagement of Aboriginal researchers in the study and developing a SCAAP. By building systems for capacity building, innovative ways to collaborate and negotiate arise. Negotiation of the finer details of study design across Aboriginal communities with an ongoing commitment allowed for changes to protocol and implementation. It is essential to recognize that individual Aboriginal communities require individual negotiation processes for ethical participation in research.

Aboriginal community participation in primary health care research is recommended by NHMRC and AH&MRC and is evident in the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 (Australian Government, 2013; NHMRC, 2005, 2010). Collective and negotiated methods are important for the development of culturally responsive research design, creating new knowledge to address health disparities in partnership with Aboriginal people and communities (Cochran et al., 2008; Eades & Stanley, 2013). This research in ACCHS' acknowledges them as being best positioned to influence key maternal and child health outcomes (Jongen et al 2014).

Conclusion

This article outlined the developmental and consultative processes for *ICAN QUIT in Pregnancy* project contributing to the practice and learning of appropriate and ethical research development with Aboriginal communities.

There remains limited knowledge on *how* community participation can be woven into the research design, delivery and evaluation, and *how* Aboriginal ownership can be upheld. By reporting on these aspects other primary health research projects may engage in more equitable and ethical Aboriginal health research, reflecting a commitment to this, and a transparency to Aboriginal people and communities involved.

Conflicts of interest

The authors declare that they have no conflicts interests.

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