

## Our journey preparing a protocol to collect Aboriginal people's stories of diabetes care

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Research has an important role to play in ensuring that health services meet the needs of people living in rural and remote places. Practice based research can facilitate collaborative approaches enabling governments, organisations and individuals to work collaboratively to close the gap between Aboriginal and non-Aboriginal Australians. Our paper acknowledges that differences exist between Aboriginal and non-Aboriginal ways of knowing (1) and strives to bring respectful practice(2) and understanding to research. We have chosen to write in a narrative style to share our story of developing a research protocol.

The organisations we work for (the Dubbo Aboriginal Medical Service, Western NSW Medicare Local and Western NSW Local Health District) decided that providing integrated care for Aboriginal people with diabetes was a priority health issue. The organisations believe it is possible to learn how health services can improve by understanding the patient experience of receiving care for their diabetes more fully. An experienced researcher was approached and each organisation nominated at least one Aboriginal Health Worker to become part of the research team. Together, our research team has over 60 years experience in health and has qualifications in Aboriginal health, nursing, diabetes education and research.

The Dubbo Aboriginal Research Team was formed in the following way. We all knew at least one other person in the team, but had not worked together as a group previously. At our first meeting we got to know each other, we discussed what research was and what each of our organisations hoped it would achieve. We also discussed what our personal hopes were in undertaking the research. We agreed that we wanted to work collaboratively and value the varying skills and experiences brought to the research team by each individual. We agreed it was important for all members to be open to learning, changing our personal view and to look for ways to change how our health system works as a result of undertaking the research.

These discussions highlighted that some of the standard approaches to research practice needed to be considered in relation to their appropriateness for our study. Specifically we identified approach to participants and coercion, data collection and reciprocity as key elements that required us to consider undertaking the research in a different way.

One of the first issues raised was about coercion and approach to participants. If we tried to invite participants individually by sending a letter or having an independent person phone this would be seen by participants as potentially frightening, as it would be someone they did not know or trust making the approach. We felt this was more likely to be seen as being coercive as people would feel they had to agree to participate. A less coercive approach was thought to be one where potential participants were given the opportunity to get to know the researchers and establish a relationship with them in a group situation. In this way potential participants would be in a situation where they felt culturally safe, could decide whether they thought our study was important, and were willing to trust our research team with their stories.

To achieve our goal of recruiting participants without coercion, we thought we could attend a variety of pre-existing group activities popular with Aboriginal adults. This would give potential participants a chance to get to know us, learn about the research and decide whether they wanted to join our study. It was not known whether members of the groups would meet the criteria for our study, but the very high prevalence of diabetes in the Aboriginal community meant that it was likely to be the case.

We discussed the best way to collect data and have participants feel comfortable with sharing their stories. The venue was one consideration, so we decided to approach a local sports association who have a clubhouse on the banks of the river. This would provide a venue that was central and quiet

during the day, and that many Aboriginal people would already be familiar with but would also be perceived to be neutral.

Another consideration was the way we collected data. We decided on a 'yarning style' focus group using the visual aid of a Conversation Map (3) and conversation cards. The Conversation Map was designed as a diabetes education tool. It gives a visual representation of different aspects of diabetes such as knowing your numbers, exercise, feelings, medications and diet. We thought these would act as visual prompts to discuss things that might be important for some participants that had not yet been raised by others.

To encourage each participant to have a turn and to share their story, we developed conversation cards to complement the Conversation Map. We planned to use eight questions with the focus group and each question was placed on an individual conversation card. Each card was distributed randomly to participants. We wrote our questions in a way that we hoped would promote the participants as the experts and the research team as the learners. An example of the questions include "How did you first find out that you had diabetes?" (Question 1) "Who were the people who helped you understand your diabetes?" (Question 2), "What goals do you have around your diabetes at the moment?" (Question 4) and "What would you do to improve diabetes care for Aboriginal people in Dubbo?" (Question 8). For each question extra prompts help participants expand on their story. For example with Question 2 our prompts are "Had you heard of diabetes before you were diagnosed? What did you know already about diabetes? Who did you talk to about diabetes? How long before you felt you understood about diabetes? Are there things about your diabetes you still want to know? Who do you go to now if you have these questions?"

We planned to create a friendly, social feel of the focus group so a barbeque lunch was proposed to follow the focus group. The barbeque menu was approved by a diabetes educator from within the research team and one of the research team members offered to make Johnny cakes where time permitted.

Reciprocity was another important consideration for the research team. As a research team we would be benefiting from knowing people's stories so we also wanted to make sure participants could receive something they valued. We wanted to make sure that we could respond to any questions people might have about diabetes when they were there at the focus group. By having a barbeque lunch after the focus group, we anticipated participants could discuss any questions with the diabetes educators in the research team. It was proposed that during the focus group any questions that were raised about diabetes would be taken down by the note taker. These questions could then be covered in an education session conducted based on Feltman(4) over lunch. Any questions that could not be followed up in a group (for example someone mentioning symptoms that might relate to a complication of diabetes) could be followed up after the focus group with the permission of the participant. Finally participants received a small gift bag which included written information about diabetes and the Close the Gap initiative and a \$10 gift voucher to a local fruit and vegetable shop.

The study design process took us just under seven weeks from our first team meeting to submitting our research proposal for ethical review. During this period we met four times, emailed regularly and reviewed and commented on documents such as the research protocol, participant information form, research flyer and consent form. Throughout the study design process we regularly asked each other "who else should we be talking to?" This led to discussions with the Aboriginal Lands Councils, the Aboriginal Community Working Group and Koori Interagency Network. Various members of the research team went along to these groups to talk about our research proposal. An example of the types of questions asked of the research team included:

"Will these questions (on the focus group/interview schedule) give you the answer to your research question?"

"How will you ensure your research improves health care, because we have been part of research before but have not seen improvements?"

"What if participants raise racism as an issue, are you prepared to hear about that?"

These questions were sometimes difficult to answer, but the thing we valued was that we thought they were the 'right' questions to be asked and agreed we needed to be able to both answer these questions and defend our research design. Talking to many different people about our study and being asked these questions in the design phase, meant we had a strong proposal to submit to the ethics committee. We have continued many of these conversations throughout the research including providing written and verbal updates on progress of our research to these committees.

In hindsight seven weeks is a very short time to design a study of this nature. This was only possible because of the strong community connections that existed within the research team. This assisted with knowing who the right people were to talk to, getting an audience with them and receiving their feedback. Having experienced Aboriginal Health Workers on the research team was another great advantage as they understood and could convey what would work for the community and their experience meant they were confident in putting forward suggestions and giving their opinion. Having an experienced researcher was also valuable to assist with all the documentation and to explain the type of details ethics committees were after. Finally the full endorsement of the organisations to collaborate on the study meant that staff felt they could include research into their already busy clinical role.

In summary, our approach shows the value of having a diverse range of skills in our research team and fostering a team who have strong links with the community. As a result of this, we were able to identify quickly a suitable manner to approach potential participants, a suitable way to collect people's stories and a way to help participants in order to demonstrate our appreciation for them helping us.

Our policy recommendation would be to support practice based research by Aboriginal Health Workers in rural and remote health services as we believe this will lead to more culturally suitable research being undertaken.

In telling our story of preparing our research protocol, we would like to inspire others to challenge research practices in order to give Aboriginal people an authentic voice and value an Aboriginal way of knowing. If we had imposed empirical research designs in our study proposal, Aboriginal people may not have felt comfortable to participate. We felt failing to foster Aboriginal participation, could lead to further harm and disempowerment if Aboriginal people are blamed for not caring about their health because of a lack of engagement in research. In sharing how we have approached our research, we encourage others to challenge methodological norms. Coming up with new research methods with their communities allows the unique voice of their community to be heard, and listened to. The possibility of more powerful research is exciting and will bring better understanding of the factors that impact on the health and wellbeing of people in rural and remote places.

**Note:** Since the research commenced July 2014 the Dubbo Aboriginal Medical Service has changed its name to the Dubbo Regional Aboriginal Health Service and Emma Webster now works for the University of Sydney - School of Rural Health.

## References

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## Presenter

The **Dubbo Aboriginal Research Team** is a group of five researchers working together to study Aboriginal people's stories of diabetes care in Dubbo as part of a larger Integrated Care trial. The team bring experience and qualifications in Aboriginal health, nursing, social services, diabetes education and research. Between them they have over 60 years' experience in health. They represent Dubbo Regional Aboriginal Health Service, Western NSW Medicare Local and Western NSW Local Health District. Val Smith is a Wiradjuri woman. Dubbo is on Wiradjuri country in western NSW. Bernie Kemp was born in Wilcannia and is a part of the Barkindji people, he has spent most of his life working in Aboriginal health in far western NSW providing health checks, preventing and treating chronic disease. Bernie recently relocated to Dubbo. Craig Johnson and Monica Johnson are from the Ngiyampaa tribe in western NSW. The Ngiyampaa were located at Carowa Tank in 1926, and later moved to Menindee Court station in 1933. In 1949 the inhabitants of the Menindee Court station were moved once again by train and truck to Murrin Bridge near Lake Cargelligo. Emma Webster is a non-Aboriginal woman who has lived in Dubbo for the past 22 years.