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Ethical genetic research in Indigenous communities: challenges and successful approaches☆

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Indigenous populations, in common with all populations, stand to benefit from the potential of genetic research to lead to improvements in diagnostic and therapeutic tools for a wide range of complex diseases. However, many Indigenous communities, especially ones that are isolated, are not included in genetic research efforts. This situation is largely a consequence of the challenges of ethically conducting genetic research in Indigenous communities and compounded by Indigenous peoples' negative past experiences with genetic issues. To examine ways of addressing these challenges, we review one investigation of a cancer cluster in remote Aboriginal communities in Arnhem Land, Australia. Our experiences demonstrate that genetic research can be both ethically and successfully conducted with Indigenous communities by respecting the authority of the community, involving community members, and including regular community review throughout the research process.

Genetic research into Indigenous health

Genetic epidemiology can help elucidate the etiological roles of genes in complex diseases, identify potential diagnostic and therapeutic targets, facilitate personalized medicine through pharmacogenomic analysis, and assist in clarifying the roles of environmental factors in disease [1–3]. Yet, in Indigenous populations research efforts are complicated by a controversial history and the potential benefits are counterbalanced by significant potential harms, such as racial stereotyping, cultural undermining, genetic theft, and the potential for genetics to be used to define Aboriginality [4–6]. The result is that these populations are often excluded from projects focused on genetic research.

Much of the literature relating to genetic research in Indigenous populations focuses on population genetics rather than complex disease etiology. Although many of the potential risks identified during the process of studying population genetics may be relevant to the study of disease etiology, this type of research raises issues of its own, including the potential for the disproportionate disease burden experienced by Aboriginal populations to be attributed to genetics, detracting from more important health influences [6]. Nevertheless, some evidence exists that negative experiences with anthropological genetic research has resulted in a generalized distrust of genetic research by Indigenous communities and that this feeling is exacerbated by experiences with colonization [7–10].

Relatively little genetic research has been conducted in Australian Indigenous populations compared with Indigenous populations in Canada, New Zealand, and the United States, and scholarship surrounding the ethical conduct of such research in Australia is correspondingly limited. No guidelines in Australia specifically deal with this issue, although the *National Statement on Ethical Conduct in Human Research* [11] contains a section relating to human genetic research and the *Values and Ethics: Guidelines for Conduct of Aboriginal and Torres Strait Health Research* [12] provides guidance on how to conduct health research in Indigenous populations. However, recent round table discussions have provided a much-needed fillip to this discussion and have raised questions of whether specific guidelines are necessary and what they might cover [6].

In the absence of formal guidelines, the SISTERS in GEANS project undertook a genetic study in Arnhem Land (Northern Territory, Australia), guided both by the organizational culture and experience of the Menzies School of Health Research (which specializes in Indigenous health research [13,14]) and by literature produced through comparable international endeavors [15–17]. Our experiences in undertaking this extremely sensitive project are of interest to other researchers, both locally (regarding the current debates surrounding guidelines) and to the wider genetic research community who conduct work in socially identifiable groups across the globe. This paper offers an exploration of our methodology and experiences, combined with commentary from two senior Yolngu women who have been involved throughout the project (Box 1).

SISTERS in GEANS

Vulvar cancer is usually a rare gynecological malignancy that predominantly affects older women. There is, however, an extraordinarily high incidence of vulvar intraepithelial

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☆ Aboriginal and Torres Strait Islander people are warned that this article may contain images of deceased people.

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Box 1. Yolngu researchers

Figure I. Djapirri Mununggirritj.

Figure II. Dipililnga Marika.

Djapirri Mununggirritj (Figure I) and Dipililnga Marika (Figure II) are senior Yolngu women in one of the remote communities of East Arnhem, and both are leaders in efforts to bridge the gap between Indigenous and non-Indigenous people. Mununggirritj, the manager of the community Women's Center, helped to establish the local Night Patrol, and sits on the National Reconciliation Australia and Yothu Yindi Foundation boards. Marika is a Community Worker involved with the Strong Women, Strong Culture, Strong Babies Program, and the community Health Center. Both women have been involved in a range of health research projects run by Menzies School of Health Research and acted as consultants for the present study.

Box 2. Arnhem Land

The Northern Territory (NT) is a large, sparsely populated region of northern Australia, populated by approximately 230 000 people, of whom 30% are Indigenous (mainly Aboriginal). The East Arnhem district (Figure I) is the most remote part of the NT, with approximately 11 000 Indigenous people living in small communities and 5000 non-Indigenous people living mostly in two mining towns; most communities are accessible only by air or sea. The Aboriginal population of this region comprise mainly Yolngu and Warnindilyakwa people.

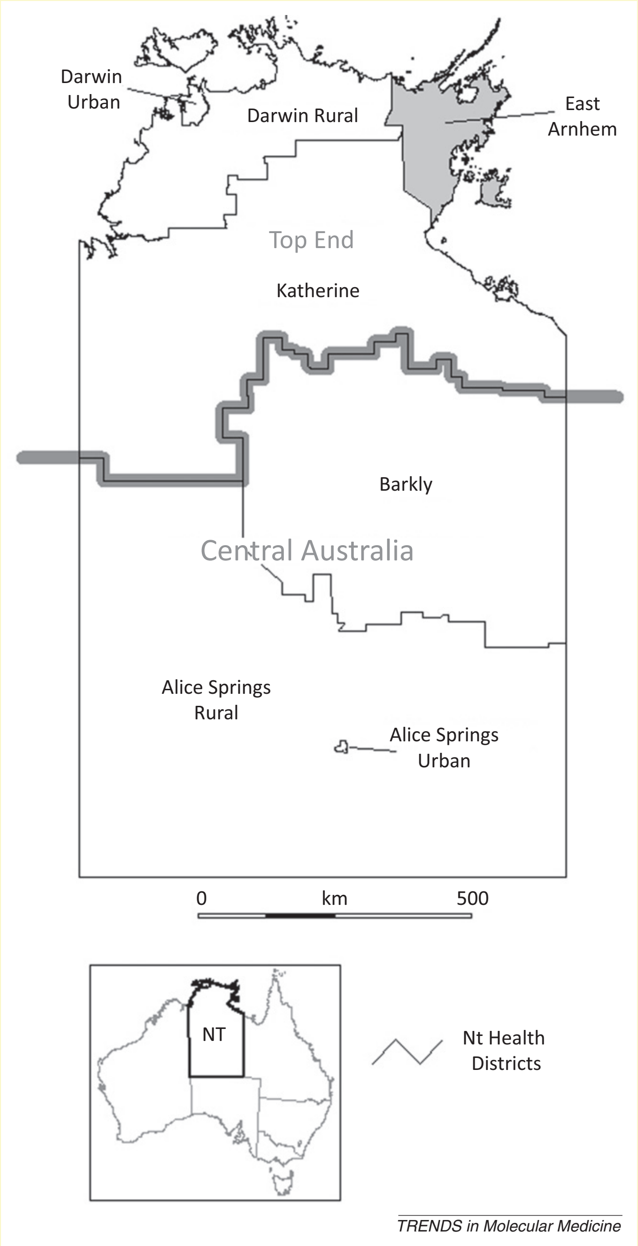


Figure I. The Northern Territory (NT), showing NT Government administration districts.

neoplasia (VIN) and vulvar cancer in young Australian Aboriginal women resident in Arnhem Land in the Northern Territory (NT) (Box 2). In collaboration with the NT Department of Health, the Menzies School of Health Research led the investigation of this cancer cluster and helped institute a public health response based on early identification, treatment, follow-up of cases of cancer, and vaccination of adolescent girls. Stage one of the investigation confirmed the existence of the cluster previously reported by clinicians: in this region, the incidence of vulvar cancer in women aged less than 50 years is more than 50 times higher than in Australia as a whole [18]. The subsequent stage, known as the SISTER study, provided evidence that the cluster is not principally caused by excessive prevalence or unusually virulent strains of human papillomavirus (HPV).

The current stage of this project is a GEnetic and ANthropological (GEAN) Study that builds upon the SISTER project by exploring local knowledge and beliefs about the disease and its impact, examining the role of possible environmental agents, and investigating the possibility of genetic risk factors. Encompassing nine remote Indigenous communities across the East Arnhem region, this study has involved numerous ethical sensitivities relating to both the nature of the cancer under study and the genetic methodology.

International discussions of genetic research in Indigenous communities consistently emphasize two main points: the ethical implications of decisions need to be considered at all stages of the research process, and the most effective means of ensuring ethical research conduct is to include the community in the research process, especially during the study design phase [2,10,15,19,20]. This, of course, reflects wider discussions of ethical research conduct in Indigenous communities [21–23], and these precepts are included in the current Australian health research guidelines. The fact that the recommendations for addressing the challenges of genetic research in Indigenous communities are largely the same as those experienced for other disciplines reveals these challenges as not so much a novel issue but rather a new context in which to discuss long-running tensions and debates.

Current literature suggests that most of the ethical problems that arise while conducting genetic research in Indigenous communities can be addressed by Indigenous participation in the research process. However, as Kowal and colleagues argue [21], precisely what is meant by 'Indigenous participation' in research is often unclear. To facilitate our analysis and discussion, the research process will be considered in stages, given that each stage has its own set of ethical considerations.

Consultation

Many Indigenous communities in the NT complain of over-research and the lack of tangible benefits resulting from this work, echoing the experiences of Indigenous communities around the world [24]. One way in which this problem can be addressed is through extensive consultation before any new study commences. The following is a primary set of considerations to ascertain: whether the proposed research topic is considered a community priority, whether the proposed methodology is appropriate, and what would be done as a consequence of the research.

In the process of consulting the community, our study team found that women were very concerned by the remarkably high rates of vulvar cancer and VIN in these communities, and there was general support for our proposed method of investigating the underlying cause(s). There was also significant demand for education regarding this problem and women's cancers more generally, prompting us to revise our methods of communicating medical and genetic information into a coherent vulvar cancer story that was meaningful to the women we were trying to engage in our research.

Conducting adequately extensive consultation can be challenging, and researchers must be prepared to be flexible and to respond to the individual circumstances of each community. Before visiting any of our affected communities, we first consulted with our Indigenous Reference Group (IRG) comprising female representatives from each community, most of whom had been involved with previous stages of our study. This group's purpose was to advise us on each stage of the research process and to help us to develop culturally appropriate and effective means of communicating genetic concepts. Over the course of the three main stages of the study, we met with the IRG on four occasions, each time chartering planes to transport the representatives to and from Nhulunbuy, the largest township in the region, and paying them for their time.

Within communities, we began by approaching local Health Boards and clinics, after which it was possible to work with these bodies to construct a formal community participation agreement. Restricting consultation to these bodies, however, would usually be insufficient, although they can provide recommendations of people or groups in the community to consult and guidance for approaching them in an appropriate manner.

Our study involved women's business; we could only consult with women on the details of the project, although it was possible to discuss generalities with men, where necessary. Depending on the community, we consulted with women associated with Women's Centers, Night Patrol, Aged Care, Art Centers, crèches, cleaning crews, and schools. Furthermore, an IRG member, female Aboriginal Health Worker, or Community Worker from the community health center (or, less commonly, a local woman recommended by clinic staff) would work with us to consult with other female members of the community. It was important to allow adequate time for this process, as it takes time to develop relationships of trust that are crucial to effective working partnerships, relationships based upon honesty and respect.

The cost of consultation was built into the grant application. Although incorporating this level of consultation into the project appears to effectively double the number of community visits, the time and effort invested into building relationships with the communities and designing the study in collaboration with the women of the communities meant that the implementation phase of the study proceeded more efficiently than it would have otherwise.

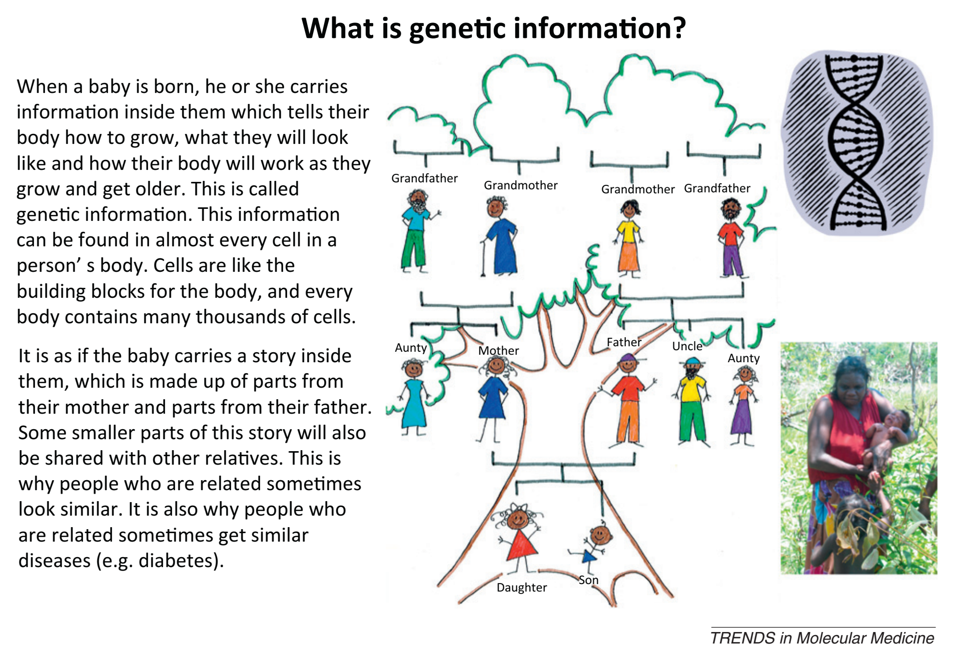
Consent

Informed consent is one of the fundamental principles of conducting ethical health research. It is a principle that is complicated in this context by two salient factors: researchers and potential participants are often separated by cultural and language barriers that can complicate the process of ensuring that participants are making a truly informed decision; and genetic studies can result in findings that have implications for people other than the participant who has given consent, namely their relatives with whom they share genetic information. These two issues have caused much of the controversy surrounding previous genetic research in Indigenous communities and continue to be the subject of much current debate.

The Human Genome Diversity Project is a high-profile example of how these challenges can lead to ethically controversial research conduct and, indeed, was so poorly received by Indigenous communities in the Northern Territory that it has been referred to as the 'Vampire project' [5,7] (see http://www.hreoc.gov.au/legal/submissions/genetic_information.html). Dodson and Williamson [7] reported instances of researchers claiming that 'informed consent was not obtained because the tribal peoples involved would not understand DNA research, so there was no use providing explanations, although they then claimed that consent was obtained "in as much as they could".' This was not our experience. Although understanding of (Western) scientific concepts was limited, the peoples of Arnhem Land possessed a reasonable level of genetic literacy through exposure to work regarding Machado–Joseph disease (an autosomal dominant neurodegenerative disease found in families in this region) and were thoroughly comfortable with the idea that some traits could be passed down through generations and that relatives could share inherited characteristics. We worked closely with representatives of the affected communities to develop information materials that utilized analogies that resonated with the target audience. This resulted in the creation of a book that illustrated each concept and was accompanied by a recording in a dialect that was widely understood across the region (Box 3).

Box 3. Explaining genetic research

This page from our audio information book illustrates the analogies we developed in collaboration with the women of the IRG to explain the concept of genetic information (Figure I). The family tree pictured is simplified, especially given the complex kinship rules of the Yolngu people, but it was satisfactory for discussion purposes. This explanation worked for our study population, and although it may be useful for other populations the explanation we arrived at is not the point. Rather, the process of developing the study protocols and research materials with the communities, resulting in an explanation that was meaningful for our study population, is the reason behind its success.



What is genetic information?

When a baby is born, he or she carries information inside them which tells their body how to grow, what they will look like and how their body will work as they grow and get older. This is called genetic information. This information can be found in almost every cell in a person' s body. Cells are like the building blocks for the body, and every body contains many thousands of cells.

It is as if the baby carries a story inside them, which is made up of parts from their mother and parts from their father. Some smaller parts of this story will also be shared with other relatives. This is why people who are related sometimes look similar. It is also why people who are related sometimes get similar diseases (e.g. diabetes).

TRENDS in Molecular Medicine

Figure I. Single page excerpt of the audio book devised to explain scientific and research concepts.

This book was used in conjunction with local interpreters, who would facilitate question and answer sessions until everyone was satisfied that they understood. Although the English spoken by many of our participants was very good, many of the words and concepts necessary for consent procedures were new, and presenting the information in multiple formats (visually, aurally, and through discussion) facilitated understanding.

The fact that genetic studies can have implications for all members of a community, and not only the participants, has given rise to the concept of group consent in which authority is vested at the community level to approve or reject research involving members of that community [25,26]. Consent is necessary from the appropriate Land Councils and Health Boards before a research team may enter an Indigenous community. In this sense, it is easier to obtain group consent from remote Indigenous communities than from less localized and culturally homogeneous populations, such as the Ashkenazi Jews, although some practical and moral objections to this approach remain and are discussed thoroughly in the extant literature [27,28]. Sharp and Foster [15], however, argue that this narrow focus on group consent rather misses the point, and that it is more useful to frame the discussion in terms of the broader concept of community review. They outline a framework for describing different types of community review, in order of increasing levels of structure: community dialogue, community consultation, formal community approval (or disapproval), and community partnership, although they note that these forms are not mutually exclusive and that different strategies may be utilized at different points during the research process.

Our experiences support Sharp and Foster's argument, in that the formal process of obtaining group consent (in our case, gaining approval to proceed from Land Councils and Health Boards) was overly narrow and insufficient, on its own, to minimize the group risks. These approvals are a once-off event and cannot entirely account for developments that occur post-approval. Rather, by involving various forms of community review in every stage of the research process the research team can effectively and sensitively respond to concerns and changes as they arise.

Of course, even in communities where an entity exists with the authority to grant group consent, the process is not necessarily straightforward, as is clearly evident in our negotiations with one of the community Health Boards. This Board, like many in similar positions, suffered under a deluge of research applications and struggled to keep up with submissions. By the time the Board got to our application, the sole female member of the Board had left the community for an undefined period of time, leaving only men to discuss our application, a situation that was culturally unacceptable. As this Board was recognized as the representative group with the authority to approve health research projects, and had an agreement with the community health center that no study was to go ahead without their approval, we could not continue before surmounting this obstacle. We worked closely with the CEO over a number of months to develop a culturally appropriate solution. Although the Board members were uncomfortable dealing with a topic that was clearly women's business, they were also concerned that the women of their community were disproportionately affected by a serious disease and might miss out on health care, education, and potentially beneficial research that were available to other communities. The evidence of support we had collected during the consultation phase in that community, comprising signatures from a large number of women – including, fortuitously, the one woman on the Board – was imperative in allowing the Board to feel comfortable in approving our research application. This incident suggests that group consent from a recognized body representing the community provides a useful mechanism for regulating research activity, but is no substitute for wide-ranging and thorough community consultation or development of community partnerships.

Within the cultures of the peoples of Arnhem Land it can sometimes be necessary to include family members or important community members such as *djunggaya* – analogous to lawyers of the *Ngarra rom* (law of Arnhem Land) – in processes consenting to medical procedures, as some procedures or body parts intersect with cultural practices and traditions [29,30]. This is less relevant to genetic research, as blood and saliva taken for medical or research purposes can be disposed of in the normal way without transgressing the cultural traditions of the peoples of Arnhem Land (although it should be noted that there are some cultural practices that relate to blood). Amputated limbs or umbilical cords, by contrast, need to be returned to the community for ceremonial burial. Researchers wishing to utilize tissues other than blood or saliva would need to discover whether this was an appropriate methodology, and whether extra processes needed to be established to sensitively handle specimen collection and disposal.

Conducting research

During the participant recruitment, data, and specimen collection phases of the study, researchers have a good opportunity to provide immediate and tangible benefits to the community. Working from the premise that this study was a collaborative effort, local women were employed to work with the team in their home community as research officers and interpreters. In some communities, we worked with existing programs, such as the Community Development Employment Projects, to provide training and practical experience in research methods to young women interested in careers in health research. This approach transferred knowledge and skills in both directions: the local researchers provided translation skills and ensured that the study team adhered to cultural protocols, and project-related employment and training opportunities for local women provided immediate benefits and facilitated a situation where they possessed the skills and experience to take greater responsibility and leadership in future research projects.

Employing local researchers was also crucial for ensuring that participant consent was truly voluntary. The peoples of Arnhem Land will often feel uncomfortable saying no to a stranger, but will feel able to refuse the request of a fellow community member. Relatives of local researchers may feel obliged to participate as a way of helping their family member, which is why consent procedures need to emphasize that participation is entirely voluntary and that they can say no at any time.

The consultation process highlighted the demand for more information about women's cancers in these communities, which the research team responded to by organizing women's health education sessions that covered the signs, symptoms, and implications of breast, cervical, and vulvar cancers. These were interactive and flexible sessions, often run in conjunction with other health professionals visiting the community at that time, and involved a mix of DVDs, activities, food, props, and discussions. These sessions often created increased demand for Well Women's Screening, and by working closely with community health services, endeavored to ensure that women had access to these services. These activities also resulted in increased awareness of vulvar cancer and its diagnosis among health professionals, both permanent and visiting, and are indicative of the broader social responsibilities of researchers in these communities.

During this period, we emphasized that the research aim was to identify the cause of the high rates of vulvar cancer among young Indigenous women in this region so that new diagnostic or therapeutic tools could be developed; it was also noted that research takes a long time and might not be successful in these aims. Although the potential long-term benefits are ultimately the justification for conducting research, the delayed and uncertain nature of their gratification reinforces the ethical necessity for short-term, tangible benefits for the communities participating in genetic research.

Data and samples

Saliva samples are better suited than blood samples to studies of the Indigenous communities of NT, both in terms of acceptability to participants as well as the ability to withstand high temperatures and transport vagaries. It is important at the collection stage to explain exactly what will happen to the samples, what they will be used for, and for how long they will be stored. Although explaining these details can be challenging, it is achievable with sufficient preparation and the inclusion of community review processes. The trust that has often been missing between genetic researchers and Indigenous communities can only be rebuilt if researchers make the effort to explain the entire story with all its implications.

Participants particularly need to be informed if these implications may involve the potential for commercialization, as well as how they and their community will benefit from this. Recommendations from both Canada and Australia highlight the importance of viewing DNA as being 'on loan' from participants, to prevent exploitation of vulnerable populations [31]. The issue of sample ownership, however, continues to be a contested and unclear legal area [32]. Participants can nevertheless retain substantial control over the fate of their samples and be included in benefit-sharing discussions. Part of this obviously includes obtaining voluntary and informed consent, but it also extends to ensuring that participants can withdraw and have their samples destroyed and know that their samples cannot be used for anything that they have not explicitly agreed to. For example, in our study participants had the option of agreeing to their samples being used only for other studies relating to vulvar cancer, and participating communities are partners in interventions resulting from this work.

As part of efforts to tell a true and complete story, researchers also need to make clear what feedback participants can expect to receive and within what time frame.

Disseminating results

Disseminating study findings takes two major forms: (i) feedback to participants and participating communities, and (ii) communication to academia through journal articles and conferences. The guidelines for Aboriginal and Torres Strait Islander health research explicitly state that 'researchers should not make the publication of research findings a greater priority than feedback of findings to the community in an appropriate and understandable way' [12], and they note that the principle of mutual respect, upon which effective research partnerships with communities are founded, means that researchers need to consider the implications of the research for the members of the participating communities. The logical way to handle this is to discuss the findings with the communities before publication in any format. This is a multi-stage process that ensures the results are communicated to both participants and the academic community in a culturally sensitive and effective manner.

For our team, discussion with the IRG is the first step in this process. There are many similarities with earlier stages in that these discussions will help identify potential problems and solutions and assist in developing appropriate methods of communicating study findings. This can have some surprising outcomes; current discussions indicate that our study findings will be best fed back to participants in DVD format, drawing on cultural reference points and traditional stories as the framework for the health message. This has the multiple benefits of couching the message in terms that makes the relevance to participants' lives clear and links it to generations past and future, provides the legacy of a permanent, reusable source of information, contributes to a strengthening of traditional culture through integration of health messages into traditional stories, and provides employment and experience for local women who will be involved all aspects of the DVD production.

Throughout the process of providing feedback to communities, there will be ongoing opportunity for community members to provide input into how results are communicated to academia and in the media, as part of efforts to ensure that study findings do not contribute to undermining of culture or racial stereotyping – two of the major risks of genetic research in populations [4].

Concluding remarks

Although this paper provides information about our experiences that may be useful to other researchers interested in conducting genetic research in the remote Indigenous communities of Arnhem Land, its relevance extends to the conduct of genetic studies in a broad range of socially identifiable communities. Our experiences highlight the necessity of working with communities to ensure that studies are conducted appropriately and tailored to the individual needs of that community. By situating these experiences within the context of international experiences and discourse regarding genetic research in comparable populations, it highlights both the particularities of the situation in this region and the broad similarities in effective approaches to ethical conduct of research across the world. In doing so, it contributes to the current conversation regarding the potential need for guidelines addressing genetic research in Australian Indigenous communities and emphasizes the need for continual open and frank discussion of issues in novel situations and as circumstances, such as health outcomes and genetic literacy, evolve over time. It is this continued discussion, perhaps more so than formal guidelines, that will contribute to a culture of ethical research not just for genetic methodologies but also for all health research, leading to improved outcomes for all involved.

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