

PRACTICES OF INFORMING AND CONSENTING IN INDIGENOUS COMMUNITIES: THE CASE OF THE MARSHALL ISLANDS

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Abstract

The 1979 Belmont Report established the guiding principles of informed consent. The 2007 United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) pointed out several problems in the meaning of these principles, and in how they were operationalised in small, indigenous communities. The Belmont Report originated in a developed economy, and was taken forward by researchers in individualist societies more than collectivist societies. But in the 21st century, with cross-cultural work a routine element of academic research, these issues have greater salience. UNDRIP focuses on the local meanings of concepts such as respect, informed, consent and privacy. It privileges local cultural norms, meanings and practices in the processes of gaining consent, and foregrounds the need for selecting culturally appropriate processes of consulting, comprehending, and withdrawing. This paper uses examples from the Republic of the Marshall Islands (RMI) to explore these issues, and make recommendations for social science researchers in navigating cross-cultural dimensions of informing, respect, privacy and consent.

Keywords: Informed Consent, Belmont Report, UNDRIP, Respect for Persons,
Information Comprehension, Privacy, Anonymity, Republic of the Marshall Islands.

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Introduction

In 1978, the Belmont Report established informed consent as a guiding principle of research with human subjects (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Thirty years later, the United Nations (UN) defined free, prior and informed consent (FPIC) as a right due to indigenous peoples under UNDRIP (UN General Assembly, 2007). FPIC responded to issues arising in the thirty years between the two reports. Research projects undertaken in small indigenous communities highlighted significant disparities between researchers and participants in the understanding of what concepts like informed consent and respect for persons meant in practice, in specific contexts (Millum, 2020). Ways of learning, beliefs about what local knowledge is and how it is acquired, expectations for social interactions, obligations and ethical responsibility, and how people go about deciding to participate in a group activity – all of these are instantiated in local practices and understood in local terms. UNDRIP privileged the local understanding and normative assumptions of indigenous groups, which impact the meaning of the constituent terms of informed consent for the social science researcher. This makes sense: in a communicative act, if the intended receiver does not receive the message, communication has not occurred (Mortensen, 2017).

This issue is a matter of increasing importance, as indigenous ways of life have become a matter of greater scholarly interest. Indigenous groups highlight the inadequacy of first-world practices and insights for building a complex and fine-grained understanding of diverse global realities, experiences and opportunities. The divergence of indigenous knowledge from the norms of the global knowledge economy means they hold the potential for substantive contributions to scholarship and the record of knowledge, in areas such as ethnomedicine, linguistic diversity, conservation and sustainable living (Whyte, 2014). However, as their social practices are aboriginal, and given a

global history of injustices including forcible relocation, discrimination and deracination, recent declarations by the United Nations have foregrounded their role in the global order, and highlighted their right to self-determination, in following their pre-colonial cultural practices. This reflects a history of mistreatment in scientific research studies (Datta, 2018). For these reasons, the new treaties give indigenous people protective control over their heritage, traditional knowledge, and cultural heritage, and over any associated scientific knowledge or benefits (Lynch, 2017). Respect is a crucial dimension of interaction between members of the global community, and indigenous peoples, including in research studies. This methodological review explores the principles of informed consent, as these are instantiated in research of indigenous communities.

Greater concern with how people understand informed consent has been a trend in medical research for some time. Here, the concept of being informed increasingly locates the meanings of the constituent elements of informed consent within the understanding of the human subjects, not the investigator. This trend poses a challenge for researchers from developed economies who are working in developing contexts, and who have been used to getting their signed consent form quickly and easily. Recent media attention has been drawn to small Pacific Island nations, due to their geopolitical role in China-US relations, and the unique challenges they face due to climate change. This paper is a methodological review, exploring contemporary understandings of the issues faced by researchers working with indigenous communities, in particular in the area of informed consent. Developments in global understanding of research practices with human subjects are relevant to small Pacific Island nations, particularly those with indigenous cultures, as well as modalities of informing, information competence and comprehension, risk-benefit analysis, and privacy. Examples are used from the culture and history of the Republic of the Marshall Islands (RMI), to illustrate the complexities of social science research in small indigenous communities.

The Marshall Islands as a Research Context

The Republic of the Marshall Islands is a set of 1100+ coral atolls and volcanic seamounts spread across 1.9 million km², in the Micronesia island group, in the South Pacific Ocean. It has a per capita GDP of USD 4,171, ranking 140th of 190 world economies (World Bank, 2022). The Marshallese have inhabited their islands for about four millennia. They were colonised first by the Spanish in the 1500s, then the Germans in the 1800s, and finally the Americans in the twentieth century (Hezel, 2001). The Marshallese suffer a diversity of health problems due to extensive US nuclear testing in the 1940s and 1950s (Yamada & Akiyama, 2013). While they received financial compensation under the 1966 Compact of Free Association (COFA), rapid dollarization of the economy replaced traditional subsistence farming and fishing, leading to high alcohol and drug use, and high suicide rates (Okamoto, 2008; Howard & Hammad, 2014). RMI has also lost about one-quarter of its total land mass to ocean-level rise, with the nation likely to disappear entirely in the coming decades due to climate change (Ford & Kench, 2015). Given these circumstances, documenting Marshallese culture is a matter of urgency. Yet, Marshallese culture is thousands of years old. The conventional Marshallese sense of relationships means that talk progresses differently among Marshallese as compared to talking with outsiders. Talk among Marshallese reflects the age, gender, status, clan links and past relationships that exist between interlocutors (Ayers, et al., 2018; Schwartz, 2016). Silence, including when asked a question, is culturally acceptable, particularly when a younger person is spoken to by an older person (United States of America, 1983). For researchers wanting to document Marshallese culture, and who must rely on Marshallese people informing them, the need to gain replies to their questions means they must first adjust their informed consent procedures to Marshallese norms of interaction.

The differences between the conventional assumptions underlying informed consent as they emerged in a wealthy Western context, and social

realities in small indigenous communities such as RMI, highlight the need for cultural knowledge, local guidance, social awareness, and community involvement in going about getting informed consent. Contemporary geopolitical issues, including climate change and the rise of Chinese power, have thrust Pacific Island nations into the spotlight, with the result that interest in these regions and their communities has increased. This paper reviews six issues in the evolving methodological understanding of effective ways to manage issues of informing and consenting, in these contexts.

1. Cultural Contexts and Mutual Reception

Western researchers' project proposals tend to frame participants in standardised terms. Sample homogeneity, as conceived within social science research methods, is based on participants' similar demographic traits (Robinson, 2014). But the character of that homogeneity varies across cultures. To begin with, the specific practices that constitute and are recognised as respect for persons are local (Friesen, Kearns, Redman & Caplan, 2017). With a population of only 60,000 on the islands, Marshallese distinguish among themselves according to island domicile, clan membership, land and fishing rights, and family pedigree. While the Marshallese are skilled navigators, the costs and challenges of inter-island travel across such distances mean that it is undertaken only when necessary (Genz, 2014, 2016). Almost all of those on a given island are related to almost all others on that island (McElfish, et al., 2019). Connections among people from the same island are multiple and reflect the complexities of a complex hierarchy differentiating people based on social status, particularly relationships with the current clan chief, as well as family, and gender (Berman, 2014). These connections are fundamental constituents of individual Marshallese identity and underlie daily social interactions. Respect, in the Marshall Islands, begins with a long exchange of questions and answers, which can take 30 minutes or more, in which interlocutors recall and establish the many details of their mutual identities and connections,

according to island, clan, fishing and farming activities, family, status, gender, and past interactions, often going back several generations (Blocker et al., 2020). Without this rehearsal of identities and connections, Marshallese participation in conversation, for example with a researcher who is not from the islands, is unlikely. The challenge for the researcher, then, is to find a way to establish a place for him/her in the social order. The best basis for this is the researcher's work relationships with Marshallese people at the cooperating NGO or other organisation through which the research has been arranged.

Developed-economy researchers and developing-economy participants come from very different contexts. These differences create diverse perceptions each of other. Developed economy researchers may be seen by locals as aligned with global economic or political powers, including those with a history of resource exploitation or colonial abuses (Halkoaho et al., 2016). History attests to multiple instances of corporations using consent, gained with little community understanding but written and thus legal, to justify actions which indigenous people felt were destructive of their lands and communities (Hanna, & Vanclay, 2013). For the Marshallese, the COFA provided minimal financial recompense for decades of US nuclear testing, but also guaranteed the US the right to use Kwajalein Atoll as a military base. Feeling themselves caught between two superpowers, China and the US, Marshallese renewals of the COFA reflect a local sense of the adage, better the devil you know (Baker, 2012). These long-standing issues are present as part of the Marshallese reception of every non-Marshallese who arrives on their islands.

The Belmont Report was written in the USA. The research norms for informed consent, as framed in Belmont, reflect an individualist society which assumes the autonomy of the adult human subject in making decisions for themselves, rather than elaborating their connections and obligations to various members of their social groups. Belmont conceives of participation in a research project as a matter of personal choice, with socially

independent individuals tending to think for themselves when making their individual decisions. Marshallese are highly collectivist. A decision to participate in discussing Marshallese culture, or to participate in any new project, will involve discussion with the community. Particularly if an activity is initiated by an outsider, Marshallese are unlikely to participate in novel activities without listening to the views of their family and clan. This social cohesion also reflects past experiences of painful social embarrassment when their society has been represented by Western outsiders to other Western outsiders. Some instances of social shame remain salient in the everyday Marshallese reception of outsiders today, particularly the nineteenth- and twentieth-century criticism of Marshallese women by Christian missionaries over their custom of wearing no clothing on the top half of their bodies, and general Western denigration of Marshallese traditional clothing, tattoos, dancing, chanting and story-telling (Besnier, 2011). Having been Christianised over centuries of colonisation, the Marshallese have adopted Christian habits of dress and modesty, and compartmentalise the wearing of traditional looks in island festivals (Kuchler & Were, 2014). Still, there is a distinctive island look which incorporates traditional elements with contemporary dress (DeCoursey & Krawczyk, 2020). It is understandable, then, that the Marshallese are reluctant to discuss their culture with outsiders, given the history of negative endonormative depictions and reception (Stevenson, 2011). Researchers need to anticipate collectivist social practices, inform themselves about issues on which their potential participants might feel anxieties, and accommodate locals discussing their participation within their network before making a decision to participate (Morris, 2018). In these cases, more time must be allowed for decision-making, prior to asking for informed consent.

2. Modalities of Informing

About 14 per cent of the world is currently illiterate, with higher illiteracy rates in developing than developed economies (Behrens, 2018). In low

-literacy contexts, presenting information in written format is unlikely to effectively convey what a project aims for, and its benefits and risks (Conway III et al., 2022). RMI's first school buildings were constructed in the 1960s (Ministry of Education, 2012–2013). While school attendance is compulsory, RMI truancy rates exceed 20 per cent, and college entrants' math and English proficiency levels are at a Grade 4 level (Ministry of Education, 2015–2016; Hickman, 2017). This does not mean the Marshallese lack knowledge. Their literacies reflect local realities. In Pacific Island nations, traditional educational practices are situated in real contexts, and learning means moving towards practical expertise while sharing responsibility for real outcomes. In Pacific Island communities, rather than written communication oral is the norm; ethics are integrated with knowledge and the individual shares responsibility for outcomes with the community. By contrast, classroom-based Western education seems to limit authentic knowledge and entrench the loss of language, identity, ethical engagement, and practical skill (Curnow, 2022). In RMI, the modalities of fishing, farming and extracting copra (coconut meat) are well known, though they take time to master. They have remained the same for four millennia. Novel activities originate with outsiders, and have an ambivalent character. For the researcher, this highlights the need to spend time talking with locals about the intended real-world, pragmatic outcomes of the project and how they can benefit people in the community, and to carefully identify roles, obligations, and ethics.

In such communities, the processes of informing take time. Inviting community members to read and sign a piece of paper will elicit little cooperation - they are unlikely to act, as they normally rely on what they learn in discussion with family, elders, and clan chiefs in deciding how to act. In many indigenous settings, community leaders are seen as those responsible for interacting with outsiders, speaking in public to outsiders, asking questions in consultation sessions, and then informing the community of their views, which many will accept. Researchers should spend time discussing the project with community

leaders, to build a foundation for moving towards gaining consent from individuals. Community consultations should be called and run by locals, with the researcher in the role of go-to person, answering questions leaders and elders cannot. Researchers should engage in several of these sessions before asking for consent.

In high-context cultures, and indigenous communities with a history of colonial and corporate abuses, questions of ethics and responsibility are particularly significant. Researchers should expect community leaders to have different perceptions about roles and responsibilities in collecting, storing and using data, as compared to themselves. Elders and chiefs may repeatedly raise concerns, in consultation sessions and afterwards, about the potential impacts of a research project on their community, reflecting previous experiences with developed-economy organisations. They may object to the collection of some data types, for example, video interactions. Time is required, to allow these concerns to be brought forward, and for the community to discuss their various perspectives. Researchers should come to an agreement with community leaders about roles, obligations, and limitations, to address concerns and allay fears (Afolabi et al., 2014). In some cultures, respect for elders and clan hierarchies may also involve personal meetings with these members of the community, to gain their support prior to community consultation (Hanna & Vanclay, 2013). Once consent has been gained, it is wise for researchers to continue offering community consultations as the project goes forward, to hear and respond to community concerns as they arise.

3. Information Competence and Comprehension

Pacific Island nations are often referred to as "paradise," an epithet that reflects their pristine natural surroundings, the absence of industrial zones and urban sprawl. In developed nations, the economy facilitates a relatively higher presence of healthcare, engineering, computing, and other scientific and technological infrastructure in the built landscape, which in turn, shapes public awareness

of scientific work, the place of researchers in society, their style of reasoning and habitual activities, and so on (Plankey-Videla, 2012). The entertainment and news media also create public familiarity with science and technology, with roles such as astronomers, physicists and neuroscientists, and practices such as climate science, epidemics and genetic engineering central to many fictional and news stories (Frequency Check Country Reports, 2022). In these contexts, the public has a casual familiarity with the theories, processes, jargon, skills, procedures and applications of science and technology. While this understanding is often inaccurate and lacking in detail, still it underwrites a sense of recognition and ease when a researcher asks for their participation in a study. Developed-economy researchers benefit from the basic scientific comprehension these participants gain from living in a developed economy, where the information environment supports them feeling they can decide on participation.

In contexts where scientific and technological infrastructure and information are minimal, this kind of casual awareness is absent. A few short sentences describing the project and its objectives will not connect with the same kind of background awareness, in the minds of participants. Majuro, RMI's capital city and the most developed area in the country, has a few dozen multi-story buildings. Schools and colleges do not provide computer access. With a population of about 28,000, it has only about 2,200 internet subscribers, and 700 mobile phone users of whom most have an inexpensive package which permits calls but not internet access. On six smaller islands beyond the capital region, a 2G system operates through a single computer connected to a satellite dish, providing limited connectivity for the entire island. The majority of islands have no phone and no connection. RMI has four radio broadcasting stations, but no TV broadcasting station (Fontana & Grugel, 2016). In such contexts, achieving comprehension of a research project requires additional effort from the researcher, to build the conceptual model of the project in locals' understanding. Researchers can start by helping

local leaders become familiar with the project, and they then can act as proxies in explaining it to the community (Bucchi, 2012). Visual aids, narratives, and role plays are useful ways of getting across what a project is about and why it is important. Effective ways of presenting the project involve show rather than tell modalities, such as PPTs, multimedia or theatre presentations (Kadam, 2017).

4. *Perceptions, Realities, Benefits and Risks*

In a low-literacy content, it can be difficult for researchers to manage expectations about study outcomes, and what benefits might flow from it (Guillaumont, 2011). Given the power asymmetries between the researcher's home country and the community where the research is taking place, researchers may be perceived as a source of financial benefit, though this is rarely the case. Community self-esteem is a common area of anxiety: locals worry about how they will be represented by researchers to the wider world. For example, RMI is geographically isolated. Yet locals fear this kind of phrase, conventionally used in research reports, may lead readers to view them negatively, for example as poor or genetically inbred. Similarly, the benefits of connecting to communities facing similar issues worldwide are not always desired, as locals may view such connections as bringing risks more than benefits. When asked about their views of changes in daily life, one Marshallese participant responded: "I will only describe the most important challenges in our culture. Due to migration, there are lots of outsiders such as Chinese, Kiribati, and many others. As you can see nowadays, the population of the RMI has been increasing because many people from other countries want to explore new things and most importantly they want to build up their business and company to make money. Another cultural challenge could be time management, and ways of dressing are much different than before."

One may appreciate the Marshallese perspective on their isolation, considering that RMI contracted its first case of COVID-19 only in August 2022 (World Health Organisation, 2022).

The answers to questions have the power to disrupt everyday life. In documenting a culture, social science researchers ask questions about people's views and opinions, past experiences, and habitual activities. Such questions, even when framed carefully, are fraught with potential problems and unintended consequences, when shared in a small community (Leach et al., 2012). For example, intimate partner violence and corporal punishment are endemic in RMI (Berman, 2018; Paterseon et al., 2007). Asking questions about home and school may inadvertently raise disturbing memories, revictimising the study participant. They may raise issues of sensitive topics such as drug and alcohol use, causing the participant embarrassment (Kruger, Ndebele, & Horn, 2014). In Marshallese culture, schools are not permitted to teach sex education. While HIV and STD infections are not uncommon, discussing issues of gender and sexuality is socially unacceptable (Besnier Alexeyeff, 2014; Saunkeah et al., 2021). Unwanted disclosures and differences of opinion may be revealed between participants as a result of answering study questions, resulting in family or local discord. Ethics as they have developed from the time of the Belmont Report have been modelled on medical research, and assume homogeneity among human subjects. But in situ, ethics vary from culture to culture, and so research procedures must adjust to, and respect their context. Ongoing information sessions and dynamic consent, with participants repeatedly engaging with researchers about detailed aspects of the research as it progresses, are advisable (Saunkeah, Beans, Peercy, Hiratsuka & Spicer, 2021).

5. When Participation Goes Wrong

Privacy is a complex issue in many indigenous cultures (Barelli, 2012). All Marshallese are multiply connected by clan, fishing rights, land rights, family and marriage, and these connections are widely known by others. Social science researchers are used to making the claim that participants may be quoted in research articles, but their identities will never be revealed. Yet in small communities, anonymity is hardly possible (Novak, 2014). In RMI, conversation is an important social pastime and

entertainment. An individual's opinions on a particular topic, and the phrases they use in expressing themselves, may be well known. In this case, the identities of those quoted might be guessed at, with discord arising whether guesses were accurate or not. If the topic is sensitive, this could be quite painful for individuals and the community. Thus, it is essential to make it clear to potential participants that they may be quoted and that others may perceive their identity despite the research project observing every technicality of human subject anonymity. In this case, it is essential for researchers to present anonymity as limited, and to specify what they can guarantee.

The dilemma for the researcher is that such warnings are likely to create reticence among participants in expressing their views, reducing the value of the dataset. It is also the case that the youth, many of whom use PELL grants to attend college, are among the most likely potential informants to cooperate with social science research projects. But Marshallese culture is matrilineal, with female elders holding great authority, which is recognised by Marshallese youth (Kattil-deBrum, 2022). Again, it is clear that to persuade the individual, the researcher must have the community on side. In this case, the ethical problem cannot be sidestepped. Privacy issues and limitations must be made clear, despite potential impacts on the dataset. The right to withdraw from participation is also part of informed consent. Yet it is difficult to ensure that anonymised data is destroyed, if it has already been entered into a software, coded, analysed, added to existing databases, or shared. This is another reason to use ongoing or dynamic consent, and to ensure that a limited form of anonymity is clearly delineated. In some developing-economy contexts, the right to withdraw is also moot at a practical level. In RMI, most people do not have phones, emails, or postal addresses: they cannot let a researcher know if they decide to withdraw, and it is equally impossible for the researcher to let them know that their data has been deleted. The use of clan chiefs would be effective, but this option itself may represent a borderline privacy violation.

Conclusion

The trend, in the contemporary understanding of informed consent, is to privilege the interiority of the human subject, focusing on their feelings and understandings, rather than simply gaining their signature on the basis of scant information that is technically compliant with institutional requirements. Other trends involve ongoing or dynamic consultation and consent, gained repeatedly as projects go forward (Prentice, Appelbaum, Conley & Carpenter, 2007). Indigenous knowledge remains uniquely valuable to the global scientific community, as it holds on to ancient practices and insights which have not yet come to the attention of the contemporary research community. Research conducted among indigenous groups, and within indigenous lands may yield insights in areas such as the social determinants of health, and as-yet-undiscovered therapeutic properties of novel botanicals. Aboriginal groups also offer potential insights for reorganising industrial societies, in a world facing crises in areas such as ecological sustainability and biological diversity (Mistry & Berardi, 2018).

The insights of UNDRIP and the examples from RMI show that social science researchers face greater complexity in the processes of informing potential participants, and gaining their consent when working in developing economies and indigenous communities. For these projects, cultural knowledge is essential, from the planning phase and then, particularly in the data collection phase. Even with detailed cultural knowledge, researchers are unlikely to gain access and cooperation without involving community leaders in presenting the project, and allowing extensive time for community discussion. In developing economies, audio-visual modalities are effective means of informing communities which do not have the infrastructure found in developed economies. Modified forms of consent such as audio recording of verbal assent are also advisable. Concerns about privacy and anonymity make it clear that ongoing communication between researchers and community members are key factors in participant retention.

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