Research ethics committees in the Pacific Islands: gaps and opportunities for health sector strengthening

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<http://dx.doi.org/10.5588/pha.16.0076>

There has been a range of developments in recent years to stimulate increasing public health research activity throughout the Pacific. Development of local capacity for ethics committee review and oversight is, however, frequently underdeveloped. This is reflected in the number of Pacific Island nations where ethics committees have not been established or where only informal processes exist for ethics review and oversight. This is problematic for the optimal development of relevant and culturally appropriate research, and building up local ethics committees should be part of continued research development in the Pacific. Three areas in which local ethics committees may add value are 1) offering better capacity to reflect local priorities, 2) providing broader benefits for research capacity building, and 3) assisting to strengthen systems beyond research ethics. This article considers benefits and challenges for ethics committees in the Pacific, and suggests directions for regional development to further strengthen public health research activity.

In recent years there has been a range of developments for stimulating the increase of public health research activity throughout the Pacific region. This has included two programmes particularly focused on increasing the amount and quality of programmatic and operational research in public health programmes in these countries. Data for Decision Making–Strengthening Health Interventions in the Pacific (DDM–SHIP), a capacity-building programme focused on public health surveillance and epidemiology, was introduced in response to requests made by the Pacific Island Ministers of Health. A total of 24 DDM modules have been conducted since August 2013, with over 220 health workers in attendance. In parallel, the Structured Operational Research and Training Initiative (SORT IT) programme, led by the Centre for Operational Research of the International Union Against Tuberculosis and Lung Disease (The Union), has concentrated on capacity building and mentoring health-care workers for health programme strengthening through the conduct and application of operational research. There were four SORT IT courses in the Pacific region between 2010 and 2016, two for Fiji and two for the Pacific Islands region. In these four courses, 46 participants successfully completed all milestones and a total of 48 scientific papers were submitted to peer review journals—of which 33 have been published at the time of writing this review.¹ Although developed independently, programmes of this

nature are in line with global recognition for the need to increase the extent and quality of research to effectively achieve important public health goals such as those reflected within the End TB strategy and the Sustainable Development Goals.^{2,3} These initiatives have encouraged a greater number of research projects conducted in the region, and it is pleasing to see the results reflected both in the published literature and in important changes in public health policy and practice across the region.^{4–6}

As researchers involved in several of these initiatives, we have, however, observed that the development of local capacity for ethics committee, Human Research Ethics Committee (HREC) or Institutional Review Board (IRB) review and oversight is frequently under-developed or unavailable. This is reflected in the number of Pacific Island nations where ethics committees have either not been established or exist only as an informal process for ethics review and oversight. While Fiji and Vanuatu have established national research ethics committees, no committee exists for Kiribati or the Federated States of Micronesia, for example, and the conduct of monitoring and evaluation policy and processes is highly variable between countries.⁹ This article therefore considers the benefits and challenges for ethics committees in the Pacific region, and suggests directions for regional development to further strengthen public health research activity.

Using the example of the SORT IT courses, each project is reviewed by the Ethics Advisory Group (EAG) of The Union.⁷ In keeping with international best practices, it is also required that local ethics committees review projects at individual sites where research is conducted; it is frequently observed, however, that no local committee with appropriate jurisdiction is available.⁸ While this may on occasion relate to a researcher's lack of familiarity with existing local processes for ethics review, predominantly it reflects an absence of established human research ethics committees in many countries in the region. Beyond the simple availability of processes for research ethics review, there is a wide range of infrastructure for research ethics and oversight in the Pacific, with many countries not currently equipped with sufficient capacity for research oversight and support.⁹

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KEY WORDS

research ethics; Pacific Islands; operational research; public health; ethics

WHY DOES THIS MATTER?

A system for the ethical consideration of proposed research projects and their conduct is recognised as es-

Received 6 September 2016
Accepted 12 November 2016

PHA 2017; 7(1): 6–9
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sential for modern research, particularly that which is intended for wider distribution through the published literature. Some may wonder, however, whether the development of local ethics committees needs to be seen as a priority for action in the Pacific region. Alternative structures, such as the EAG, have arguably been effective in providing a process for ethics review to occur.⁸ There are a variety of reasons, however, why we would argue that building up local ethics committees should represent a critical element of continued research development in the Pacific. Three particular areas in which local ethics committees may add value are 1) offering better capacity to reflect local priorities, 2) providing broader benefits for research capacity building, and 3) impact and assistance to strengthen systems beyond research ethics.

Better capacity to reflect local priorities and cultural considerations

International ethics committees may be predominantly or wholly comprised of members not representative of the countries and communities where the research is being conducted, and may therefore lack critical insights into issues of ethical importance in the local context.¹⁰ This may include sensitivity to issues not commonly encountered by international ethics bodies, such as concerns about taboos, dissemination of 'secret' or 'sacred' information to outside audiences, or the appropriateness of collective decision making for participation.^{11,12} Local ethics committees may provide better and more appropriate review, leading to improved research conduct in these settings.¹³ With this consideration in mind, ownership of and interest in research findings may be greater if a local ethics committee has approved a study, provided that communities perceive that the ethics committees appreciate local issues in their appropriate context. International committees may be unaware of other research and programme activities already planned, and local ethics committee review also allows an opportunity to ensure that 'duplicate' research is limited and genuine partnerships are fostered.¹⁴

International ethics committees may only provide a service for particular types of diseases or projects (such as tuberculosis) or collaborative research projects involving particular groups, such as studies funded by a particular organisation or including researchers from certain institutions. Local ethics committees help to ensure that the research priorities of local communities are supported, and they can be available to engage with locally initiated research regardless of focus.¹⁵

Broader benefits for research capacity building and impact

Research is a holistic enterprise, and developing local capacity for good quality research should include consideration of how the entire process can be supported. Local ethics committees are an important part of modern research infrastructure, and thus deserve to be included in these efforts at local capacity building. Beyond simple consideration and approval of research protocols, local policy makers may be able to be held more accountable for uptake of study recommenda-

tions if the research is approved locally. Ethics committees that review all or a large proportion of research in a particular country may also be in a good position to advise institutions and governments on the type of research being conducted, for example through publishing regular activity reports. One of the roles of an ethics committee is to ensure that researchers demonstrate the intention to disseminate results and promote appropriate consideration of the results. International ethics committees are not in a position to follow up on whether this occurs; it may, however, be appropriate for a local committee to do so, and to make recommendations about the specific groups to which dissemination should be prioritised. Finally, local ethics committees should be able to keep more accurate records regarding whether approved studies are completed and published, as such follow-up is less likely to be conducted for remotely approved projects.

Strengthening systems beyond research ethics

Developing research ethics committees involves supporting and developing the expertise of members, which in turn can equip a group of people with the capability for engagement in a range of health service strengthening activities. Representatives of local ethics committees may develop and deliver health-care ethics curricula for academic and professional development courses as well as encouraging the development of this subject in medical and nursing school curricula. While structures for ethics, governance and oversight structures will vary between countries, local ethics committees can also contribute to providing useful and helpful oversight for programmatic activities, such as infectious diseases surveillance, pandemic preparedness, or contact tracing for patients lost to follow-up from tuberculosis or human immunodeficiency virus/acquired immune-deficiency syndrome programmes to their homes, and allow for culturally appropriate debate about good and ethical practice.^{16,17}

More widely, the process of establishing and maintaining an ethics committee in a country or institution requires much discussion between local stakeholders about the meaning of ethical principles for their context. The preparation and dissemination of ethics committee documents may have additional 'spin-off' benefits for other institutional policies that would benefit from the inclusion of the principles of research ethics or the updating/harmonisation of existing statements. The process may therefore stimulate the revision of policies or guidelines, for example in universities, hospitals or penitentiary institutions.

WHAT CAN BE DONE ABOUT IT?

As outlined above, there are a variety of reasons why the establishment of local ethics committees should be a priority for the Pacific region. While the formation of an increased number of committees would be a valuable contribution, a broader capacity-building effort is required to ensure that such processes for ethics review and oversight are robust, sustainable and well-equipped for their functions.

ACKNOWLEDGEMENTS

Funding for this paper was provided by the International Union Against Tuberculosis and Lung Disease, Paris, France, and the Secretariat of the Pacific Community, Noumea, New Caledonia. Costs for open access publication were funded by La Fondation Veuve Emile Metz-Tesch, Luxembourg. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. Conflicts of interest: none declared.

New committees should not need to develop in isolation, and it is of critical importance that appropriate support be provided from the range of ethics review bodies and organisations already in existence. It is helpful for new committees to look for existing networks and form partnerships with existing groups, to allow experience and practical support to be shared.

Existing ethics committees in the region can also provide valuable support for fledgling groups in practical ways. Several members with experience in committee management and project review could be persuaded to join a new committee for a pre-defined establishment period, for example, before withdrawing to allow local governance to continue. Established ethics committees can also provide practical support through sharing of standard operating procedures, guidelines and protocols, which can then be modified for local applicability rather than being created from scratch for each new setting.

The ministries of health and other local government also play an important role. Pacific health ministries should be aware of the fundamental role of research in tackling many of the region's major health issues and the need for an improved research ethics infrastructure to accomplish important objectives. They should encourage research ethics infrastructure development, in particular by ensuring that appropriate administrative support is provided and that the activities of committee members are considered in work-related performance indicators. Where research training is planned, ethics should form part of the core curriculum, while cross-training of ethics committee members and researchers is to be promoted.

Organisations that are frequently engaged in research in the Pacific region, such as Australia's National Health and Medical Research Council or the US National Institutes of Health, can continue to assist by providing guidelines for establishing and maintaining human research ethics committees.^{18,19} They may also provide opportunities for education and training, including on-line or remotely accessible platforms, given the geographical barriers to access in the region. They should also ensure that the grants provided include available allocations for research ethics review, as well as contributions toward developing and strengthening research ethics infrastructure where it does not exist or is underdeveloped.

While the establishment of local human research ethics committees is only one model for strengthening public health and research activity in the Pacific, we would argue that it is a useful approach, consistent with established international standards. The Council for International Organizations of Medical Sciences Guidelines for Biomedical Research Involving Human Subjects, for example, is currently under review, and it explicitly emphasises the need for community engagement and local perspectives on the fair allocation of research burdens and benefits, particularly in low resource settings.²⁰ Such judgements require specific cultural expertise, and human research ethics committees provide an important means of providing local engagement and oversight. Ideally, local and international committees should work together in dialogue to ensure resolution of ethical tensions relating to research. Local human research ethics committees must, however, be in a position to provide ultimate approval for locally conducted re-

search, ensuring that such resolution is governed by community priorities and perspectives.

In conclusion, there is a significant need for greater development of human research ethics capacity in the Pacific Island region. Meeting this need will involve prioritisation of ethics committee development and overcoming a variety of logistical challenges. It will also, however, bring a wide range of benefits for the research enterprise in the Pacific region, including the implementation of policies and programmes that are better supported with context-specific, evidence-based research. Addressing these challenges will require the work of a variety of partners, which we hope will lead to greater engagement and better outcomes in this critical aspect of public health delivery.

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Il y a eu toute une gamme de développements au cours des dernières années visant à stimuler un accroissement des activités de recherche en santé publique à travers la région Pacifique. Cependant, le renforcement des capacités locales de révision et de surveillance par les comités d'éthique est fréquemment sous-développé. Ceci est reflété par le nombre de nations insulaires du Pacifique où aucun comité d'éthique n'a été mis en place ou seules des procédures informelles de revue et de surveillance existent. Ceci pose un problème pour le bon développement d'une recherche pertinente et culturellement appropriée ; la mise en place de comités d'éthique

locaux devrait faire partie du développement continu de la recherche dans le Pacifique. Trois domaines dans lesquels les comités d'éthique locaux pourraient avoir une valeur ajoutée sont 1) offrir une meilleure capacité de refléter les priorités locales, 2) apporter des bénéfices plus grands pour le renforcement des capacités de recherche, et 3) contribuer à renforcer les systèmes au-delà de l'éthique de la recherche. Cet article envisage les bénéfices et les défis des comités d'éthique dans le Pacifique et suggère des orientations pour le développement régional afin de développer davantage les activités de recherche en santé publique.

En los últimos años se ha observado una diversidad de progresos que estimulan las actividades de investigación en salud pública en toda la región del Pacífico. Sin embargo, la creación de competencias locales en materia de comités de ética y supervisión suele ser deficiente. Esta situación se refleja en el número de estados insulares del Pacífico que aun no cuentan con comités de ética o donde se practica solo un proceso informal de examen de los aspectos éticos y de supervisión de los estudios clínicos. Estas circunstancias representan un obstáculo al desarrollo óptimo de una investigación pertinente y culturalmente apropiada; la creación de comités de ética debe formar parte del

desarrollo continuo de la investigación en el Pacífico. Estos comités aportarían ventajas en tres esferas principales, a saber: 1) una mayor capacidad de responder a las prioridades locales; 2) la ampliación de las ventajas que ofrece el fortalecimiento de la capacidad de realizar investigaciones; y 3) el mejoramiento de los sistemas de salud, más allá del terreno de la ética de la investigación. En el presente artículo se examinan las ventajas y las dificultades que presentan los comités de ética en la región del Pacífico y se proponen orientaciones para el desarrollo regional que promuevan la actividad de investigación en salud pública.