



**Global Forum on
Bioethics in Research**

Satellite meeting booklet:

*Ethics of research with refugee and migrant
populations*

Bangkok, Thailand

30 November – 1 December 2017

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Introduction

Meeting Rationale

The protection of refugee and migrant health requires evidence-informed national, regional and global migration health policies and practices. The ethical imperative for conducting this research in these populations is clear, given the scale of migration across the globe and the associated health risks faced by migrants and refugees.

In the context of growing recognition of the importance of health research that is sensitive to the needs of migrant and refugee populations, there is a need to consider the ethics of, and ethical approaches to, conducting research with migrant and refugee populations. There are significant ethical challenges given the diverse forms of vulnerability that may be experienced by refugee and migrant populations (issues of stigma and discrimination, safety, access to services, exclusion and compromised relationships with authority), and cultural and language barriers. While the ethical concerns may be similar across typologies of research and migration groups, they may be experienced in very different ways, which points to the need for exploration of different strategies. Standard ethics guidance and approval processes may not be optimised for research involving migrant and refugee populations or may unjustly exclude participation (for example of unaccompanied minors who may not be considered competent to provide consent).

There is an urgent need for policymakers, researchers, ethics review committee members and other stakeholders to meet and compare experiences of ethical challenges in research implementation in this context and to consider how best to address these. With the majority of globally displaced people being hosted in low- and middle-income countries (LMICs), it is relevant that this meeting is being organised by the Global Forum on Bioethics in Research, in collaboration with the National University of Singapore and the Mahidol Oxford Tropical Medicine Research Unit (MORU), Thailand. The GFBR exists to provide a global platform for the exchange and sharing of experience and expertise on research ethics with a focus on LMIC settings and real life case studies.

Meeting Objectives

The aim of this meeting is to identify and discuss the ethics of, and ethical approaches to, conducting research with migrant and refugee populations. By identifying what is needed to advance ethical research in this field, the meeting aims to stimulate an agenda to improve research practice and health outcomes for migrant and refugee populations.

The meeting will address the following questions:

1. What are the main ethical challenges for research with the various migrant subpopulations (e.g., refugee, asylum-seeking, labour migrant, minors) who are particularly vulnerable, marginalised or at risk of harm? Is the way research is done fit for purpose and “ethical” with these populations (e.g. the design of research). What is it that makes research with these populations different?
2. What is needed to improve research ethics in these populations and how best can the need be addressed (including the development of appropriate and targeted ethical guidance)?
3. How can we rethink some of the current processes related to research ethics (e.g. IRB review, training of field workers and community participation) to ensure that research with mobile populations is carried out in an ethical manner and promotes rigorous research and robust findings?

Meeting Organisers

Global Forum on Bioethics in Research

The Global Forum on Bioethics in Research (GFBR) was created in the late 1990s by a group of global health research funders with a shared interest in the ethics of conducting research involving people in low- and middle-income countries. The GFBR aims to provide a global platform to bring together key stakeholders from different geographical, cultural and scientific communities to debate the ethics, legal and public policy issues relating to international health research. The Forum meets annually, with an emphasis on discussion and the development of networks and runs a fellowship scheme. Current funders are Wellcome, the Bill & Melinda Gates Foundation, the National Institutes of Health and the UK Medical Research Council.

Website: www.gfbr.global

National University of Singapore

The Centre for Biomedical Ethics (CBME) was established in September 2006 at the National University of Singapore (NUS), Yong Loo Lin School of Medicine, through a generous gift by the Chen Su Lan Trust. Forging interdisciplinary collaborations with other faculties at NUS, including Law, Science, Arts and Social Science, as well as key stakeholders in Singapore's healthcare sector and the research community, CBME has initiated a wide range of research projects in both clinical ethics and the ethics of the biomedical sciences. Over the past decade, it has become a major centre for teaching and research in South East Asia with its main focus on global ethical values in an Asian context.

Website: <http://cbme.nus.edu.sg>

Mahidol Oxford Tropical Medicine Research Unit

The Mahidol Oxford Tropical Medicine Research Unit (MORU) develops effective and practical means of diagnosing and treating malaria and other neglected diseases such as melioidosis, typhus, TB and leptospirosis. MORU was established in 1979 as a research collaboration between Mahidol University (Thailand), Oxford University (UK) and the UK's Wellcome Trust. MORU's main office and laboratories are located within the Faculty of Tropical Medicine at Mahidol University in Bangkok, Thailand, with MORU study sites and collaborations across Thailand, Asia and Africa. MORU is generously supported with significant funding from the Wellcome Trust, our major funding partner. We also receive funding from other trusts and foundations, governments, and multi-lateral donors.

Website: <http://www.tropmedres.ac/home>

Members of the Planning Committee for this meeting:

Teck Chuan Voo, Singapore

Sharon Kaur, Malaysia

Phaik Yeong Cheah, Thailand

Katherine Littler, UK

Adrienne Hunt, UK

Agenda

Thursday 30 November 2017

08:15	<i>Registration</i>
08:45	Welcome and introduction Phaik Yeong Cheah (Mahidol Oxford Tropical Medicine Research Unit) and Katherine Littler (Wellcome) on behalf of the Planning Committee
09:00	Keynote presentation Kolitha Wickramage, International Organisation for Migration (IOM), Philippines
Session 1 09:30	Questions relating to the ethics of research with labour migrants and trafficked persons Introduction to the theme Chair : Mike Parker, Oxford University, UK
09:40	Case study 1: Overview of the ethics in trafficking research: Study on Trafficking, Exploitation & Abuse in the Mekong (STEAM) Nicola Pocock, United Nations University, Malaysia
09:55	Case study 2: Ethics of qualitative research: Labour exploitation, trafficking and migrant health: Multi-country findings on the health risks and consequences of migrant and trafficked workers Vanessa Vaca, IOM South America, Argentina
10:10	General discussion
10:30	Breakout group discussion
11:00	<i>Tea/coffee break</i>
Session 2 11:30	Questions relating to the ethics of research with refugees and undocumented migrants Introduction to the theme Chairs: Anne Harmer, Research for Health in Humanitarian Crises Programme, UK and Dónal P. O'Mathúna, Dublin City University, Ireland
11:40	Case study 3: Beyond do no harm – A journey towards ethical research practice with refugee women and communities Linda Bartolomei, University of New South Wales, Australia
11:55	Case study 4: 'Hidden spaces' and health for all: Ethical challenges in researching migration and urban health in Johannesburg, South Africa Jo Vearey, University of the Witwatersrand, South Africa
12:10	Case study 5: Health research on refugee populations in Lebanon: Whose agenda and the role of national institutions Iman Nuwayhid, American University of Beirut, Lebanon
12:25	General Discussion
12:45	Breakout group discussion
13:20	<i>Lunch</i>

Session 3	Questions relating to the ethics of research with migrants facing multiple vulnerabilities
14:30	Introduction to the theme Chair: Susheela Balasundaram, United Nations High Commissioner For Refugees (UNHCR), Malaysia
14:40	Case study 6: Child labour among Syrian refugees in Lebanon: Research challenges and ethics concerning a “triplely vulnerable” community Rima Habib, American University of Beirut, Lebanon
14:55	Case study 7: Ethical issues associated with research in humanitarian settings – The case of an integrated intervention to improve mental health and reduce intimate partner violence among Congolese women in Nyarugusu Camp, Tanzania Samuel Likindikoki, Muhimbili University, Tanzania
15:10	General discussion
15:30	Breakout group discussion
16:00	<i>Tea/coffee break</i>
Session 4	Breakout group feedback
16:30	Chair : Katherine Littler, Wellcome, UK
16:35	Panel session Involving breakout group chairs on key issues and needs identified by their group
16:55	General discussion
17:30	<i>Close of day 1</i>
18:30	Meet in the foyer for departure to dinner at Osha

Friday 1 December 2017

Session 5	IRB issues and supporting researchers
09:00	Introduction to the theme Chair: Anant Bhan, Yenepoya Medical College, India
09:10	Case study 8: Tak Province Community Advisory Board (T-CAB), a community engagement initiative on Thai-Myanmar border Napat Khirikkoekong, Mahidol Oxford Tropical Medicine Research Unit, Thailand
09:25	Case study 9: Community advisory boards as local IRBs: Prioritising community protection in research on displacement and migration Court Robinson, Johns Hopkins, USA
09:40	Case study 10: The case for an independent Institutional Review Board for vulnerable populations: A proposed model for independent cross-institutional ethics review in the Malaysian context Veena Pillai, Dhi Consulting & Training, Malaysia
09:55	Case study 11: Beyond ethics approval: Learning lessons and supporting researchers Dónal P. O'Mathúna, Dublin City University, Ireland
10:10	General discussion
10:45	<i>Tea/coffee break</i>
Session 6	Concluding panel
11:15	Chair: Kolitha Wickramage, IOM, Philippines
11:20	Panel discussion Involving session chairs discussing the three questions from the meeting objectives drawing on discussion from both days
11:45	General discussion
12:15	Concluding comments and thanks Teck Chuan Voo, National University of Singapore, Singapore Sharon Kaur, University of Malaya, Malaysia
12:30	<i>Close of meeting and lunch</i>

Case Studies

Case study 1: Overview of the ethics in trafficking research: Study on Trafficking, exploitation & abuse in Mekong (STEAM)

Nicola Pocock, United Nations University, Malaysia and Cathy Zimmerman, London School of Hygiene and Tropical Medicine, UK

Background

In studies with trafficked persons about their health, studies have been conducted in different settings: directly interviewing participants in post-trafficking services^{1, 2} interviewing participants by phone whilst they are calling a migrant helpline³ and obtaining ethical and institutional approval to review medical case files in hospital settings⁴.

Besides health studies, studies with trafficked persons about reintegration have been conducted in their home communities after a trafficking experience; usually via NGO referrals or sometimes by snowball sampling in home communities^{5,6}. Some studies are conducted with labour migrants who are currently working, who may disclose exploitation and trafficking like conditions during interviews^{7,8}.

In general, experiences and needs of trafficked persons are becoming more widely researched as awareness grows about the scale of the problem. Supply chains research is another strand of work, where suppliers and workers are interviewed, often as part of corporate audits, in face of consumer pressure or legislative changes to do so (e.g. California supply chains act).

Brief description

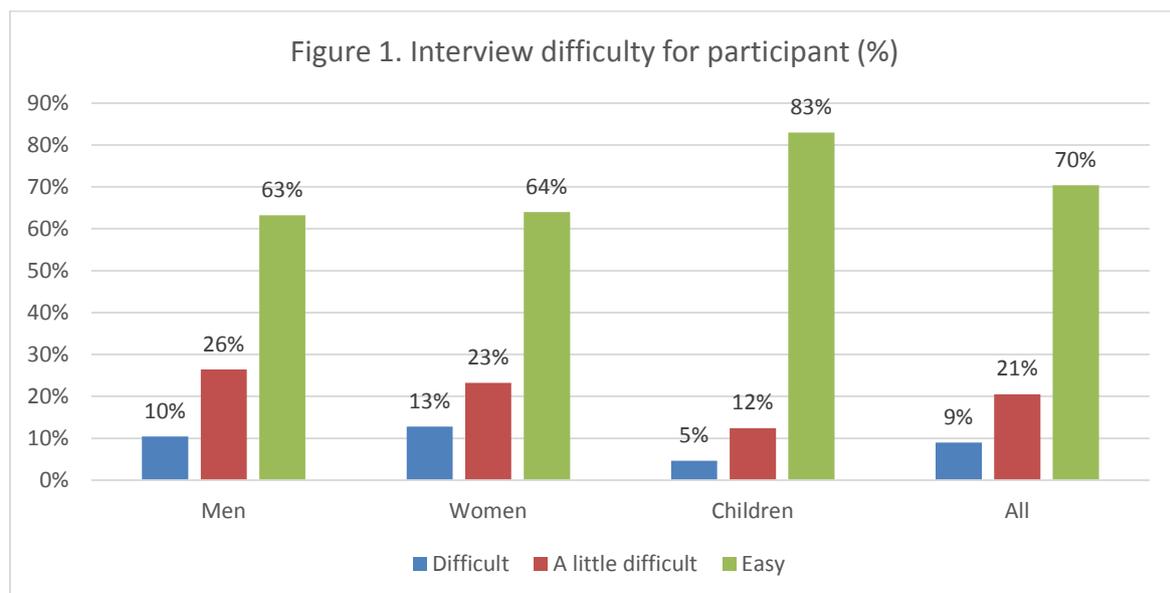
STEAM was a collaboration between the LSHTM and the International Organization for Migration (IOM). The aim of STEAM was to estimate the prevalence of health outcomes, and explore risk factors and consequences of migrant labour exploitation among post-trafficking service users in Mekong countries. A multi-site, longitudinal survey was carried out with men, women and children who received assistance after a trafficking experience between October 2011 and May 2013. The sample was selected in two stages. First, 15 post-trafficking service providers were purposively selected in Thailand, Cambodia and Vietnam. Second, a consecutive sample of individuals aged 10 or older were invited to participate within 0-14 days of admission to one of the service providers. Follow up interviews were conducted with individuals who remained in contact with services between 30-90 days after the first interview. To participate, individuals had to meet the following criteria: 1. Entering service 10 or fewer days before the interview; 2. Aged 10 or above; 3. Be mentally and physically able (as assessed by trained support or case workers). A total of n=1102 participants took part in the first interview and n=354 in the follow-up interview (those still in shelters or in contact with services).

Comment on the ethical issues from STEAM

Ethical approval for STEAM was granted by the LSHTM Ethics Committee, the Hanoi School of Public Health Institutional Ethics Review Board in Vietnam, the National Ethics Committee for Health Research in Cambodia and the Ministry of Social Development and Human Security in Thailand.

Data collection for STEAM adhered to the ethical and safety protocol outlined in the WHO recommendations for interviewing trafficked women⁹. The protocol specifies the need for clarity about the optional nature of participation, privacy during interviews, anonymity of data and wording of questions to minimize the risk of re-traumatizing participants. In addition, interviewers were trained to detect and respond to signs of distress and reactions to trauma recounted, and referral options for treatment were available at interview sites. Interviews were conducted by shelter staff (social workers, counsellors) who received one week intensive training from the PI (Ligia Kiss). The questionnaire was translated to Khmer, Thai, Burmese, Vietnamese and Lao via discussions with professional translators and IOM counter-trafficking teams in each country. Translations were reviewed during the training and pilot-tests. Finally, the revised versions were back-translated to English and final adjustments were made¹⁰.

Participants were asked at the end of the interview whether they found it difficult, a little difficult or easy (see Figure 1). Higher proportions of adult men and women (36%) found the interview difficult/a little difficult compared to children (17%) >> does this tell us anything?>> overall 30% found it difficult/a little difficult >> indicates that interview was not *too traumatizing?



Children were included as they represent a substantial group accessing services, and service providers were interested to learn more about children's needs to improve services offered. Following consultation with an expert on children in domestic labour, it was decided that inclusion of children aged 10 to 12 years old posed little to no additional risk, as they were already using services that provided support by professionally trained social workers. Participation invitation and consent procedures were adapted for children participating in the STEAM study¹¹.

Some limitations/concerns:

- There was an > 99% response rate. Participants were assured that declining to be interviewed (or being interviewed) would not affect services received and that participation was voluntary, but we must acknowledge the power dynamic (these groups are used to saying yes to people in authority positions).
- Among the 10% of participants who had questions following the interview, most questions were about whether the service provider could find a job for the participant or provide vocational training. We do not know whether service providers were able to fulfil these needs.

Comment on the ethical issues with trafficking research overall

Despite the selection biases in sampling shelter populations (e.g. those who accept assistance may be more disadvantaged than those who do not, not all trafficked persons are identified), researchers acknowledge that they are however the most suitable population with which to conduct primary research^{12,13}. In shelters and post-trafficking services, individuals can be safely and ethically identified and recruited for interviews. Should individuals need assistance during or after the interview, service staff are on hand to provide support¹³. In contrast, attempting to access current trafficked individuals may be dangerous for both the individual and the researcher. Finding former trafficked persons poses other problems, such as the risk of stigmatization in the community if the individual concerned does not want their experience to be known¹³. Even the most careful and well-intentioned researcher may put the individual at risk of harm if he is currently in a trafficking situation⁹. In most settings, it is not a good idea to do research with persons who may still be in trafficking situation - if you do, there MUST be a referral channel to an agency/organisation who can get them out safely.

Conclusions

1. Local partnerships from the outset are a must. Research must be co-designed around what information is most needed/a priority for service providers. Dissemination and advocacy strategies should be a built-in component to projects (researchers in some ways have an ethical duty to ensure results get to the right places/are used to inform practice).
2. Referral pathways must always be in place and be made very clear to participants at the start of an interview. Researchers must have a plan for emergency response if participant indicates they want to leave, or are in imminent danger. Be aware when approaching participants for interviews and potential stigma, e.g. calling participants “trafficked” (try to avoid this) stigma associated with sex work. Shame/guilt associated with being a “failed” migrant is very commonly experienced (41% in STEAM) and we should be mindful of how the interview is framed.
3. International Agencies who contract out trafficking studies – we need better research and ethical literacy among staff who oversee these outsourced studies. IRB is not often obtained and/or reporting on ethical procedures is insufficient or unclear. We need these agencies to insist on better reporting standards, e.g. akin to Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria for observational studies¹⁴ and to make obtaining ethical approval mandatory before data are collected.
4. Ethical review should be conducted, at minimum, in the country where trafficked persons are interviewed. LSHTM mandates that both home institution and local country ethics approval is obtained – this is recommended for researchers working in third countries.

References

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Case study 2: Ethics of qualitative research: Labour exploitation, trafficking and migrant health: Multi-country findings on the health risks and consequences of migrant and trafficked workers ¹

Buller AM, Vaca V, Stoklosa H, Borland R and C Zimmerman

Brief description

The aim of this study was to qualitatively explore the experiences of exploitation and exposures to occupational risk (both physical and psychological), and how these impacted the health of trafficked persons and exploited migrant workers in Argentina, Peru and Kazakhstan working, respectively, in textiles, artisanal gold mining and construction.

From a total of 71 interviews (men and women aged 18 to 55), of these, 18 were formally identified as victims of trafficking and 53 were migrant workers. The research team explored experiences and perceptions of exploitation, occupational risk exposures and health impacts among identified trafficked persons and exploited migrant workers in selected labour sectors. The research explored the differences and similarities between the health needs of those who have been identified as trafficked compared to other migrants working in the same labour sector who have not.

Ethical issues taken into consideration during the study:

Ethical approval for the study was granted by the London School of Hygiene & Tropical Medicine (lead partner of the study) and by local ethics boards in all the countries where fieldwork was conducted.

The study adhered to the guidance in the World Health Organization Ethical and Safety Recommendations for Interviewing Trafficked Women as well as the IOM Data Protection Principles². Among many ethical considerations, the following were prioritised:

- Local risk assessment of the field sites through trusted local partners: fieldwork staff followed strict procedures for checking in and checking out before and after interviews to ensure their safety in the field. If possible, interviews were conducted at IOM offices, at local support organisations (such as shelters in Kazakhstan) or health services providers' locations.
- Consent that was truly *informed* and in language that could be easily comprehended by participants: potential participants were offered clear information in their own language, verbally and in writing, when possible, about the purpose, subject and nature of the study and what would be required of them if they consented to participate. It was emphasised that participation was voluntary and that the study was separate from any support they might receive from local providers, including IOM, and was not in any way related to government, immigration or policing matters. During the formal consent procedures, each participant was informed that their responses were anonymous and confidential. Participants were advised that they did not have to answer any questions if they did not wish to, and that they could take a break or terminate the interview at any time. All participants were interviewed in private by experienced researchers.
- Anonymity and confidentiality were ensured through coding and secure data storage and publication. All participants were assigned a unique ID number and referred to only by this number during management of the research data.
- Referral options to problems reported by interviewees: In cases where an interviewer observed distress in the participant, they had a list of available services to which they could be referred.

Main challenges and recommendations based on case study:

Lack of immediate services offered to the migrant worker

The study showed similarities in labour and exploitation conditions among victims of trafficking (VoT) and migrants. While identified VoTs were receiving assistance (psychological support, shelter, and other support), and migrant workers were not eligible to receive such assistance, it was challenging to manage their needs and expectations, and the research team had to be aware of the limitations of support they could provide. The team was able to provide referral information in case it was needed, but their lack of basic needs in their living conditions was a limiting factor as the migrants were not able to receive the same assistance that an identified VoT would receive through a victim assistance program.

Risk to the research participants

Identified victims of trafficking were under assistance in safe environments out of the trafficking situation, whereas migrant workers were still working in unregulated and unsafe or hostile working conditions. The teams could not conduct interviews in their workplace, given the irregular or illegal working conditions and activities, such as clandestine textile workshops in unsafe areas or clandestine mining camps located deep in the jungle. Not only were the activities in dangerous areas, but being seen talking to members of the research team could have put migrant workers in physical danger, or could have caused them to lose their jobs.

Psychological distress

Discussing the experiences of migrant workers and victims of trafficking about their exploitation brought emotional stress on both the interviewers and participants. This was particularly challenging for the migrant workers who were still operating in the hostile working environment. The research team also experienced distress due to the limited ability to assist the migrant workers learning of their experiences and conditions.

To improve research ethics in these populations, guidelines on how to address security issues, for both for the research team and the participants, should be provided to the team members. In addition to security issues, guidelines should include how to manage migrant expectations, personal stress

To improve ethical research and conduct in the field, it is important to prepare your research team. It is important to provide a document with guidelines and recommendations on situations they may encounter. Topics to be addressed in the document should include:

- Guidelines on how to manage participant expectations,
- Limitations of ability of research team to assist,
- Referral resources to assist a participant when possible,
- Recommendations on security issues in hostile or risk-prone settings, for both the team member and the participant,
- Guidelines on how to manage difficult situations with participants,
- Guidelines on self-care and team support.

Reference

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Case study 3: Beyond do no harm – A journey towards ethical research practice with refugee women and communities

Dr Linda Bartolomei, Forced Migration Research Network, UNSW, informed by collaborative research with Adjunct Professor Eileen Pittaway and Professor Richard Hugman and with many extraordinary women and men in refugee communities across the world who have shared their ideas, knowledges and experiences

Brief description

We are really fed up with people just coming and stealing our stories, taking our photos and we never get anything back, not even a copy of the report. Nothing ever changes¹.

This case study is informed by a body of research undertaken with Eileen Pittaway, which has spanned numerous projects with refugee women and communities, in camps and urban settings in over 15 different countries. Much of this research has explored the risks and challenges experienced by refugee women and girls, in particular the endemic levels of sexual and gender-based violence in refugee camps and urban displacement settings across the globe. The key ethical issues and challenges that will be discussed were raised by women and men in refugee communities with whom we have worked over the last 20 years. They challenged us to consider both our own ethical research practice and the value of the organisational ethical arrangements which informed our work. Most importantly, they challenged us to examine if we applied the principles of human rights and community participation, which we so proudly espouse in theory, as social work and social policy academics to our work on the ground. Drawing from this background my presentation will reflect on some of the strategies to support research that moves beyond the very valid concern of ‘doing no harm’ to an approach which explicitly seeks to add value to the lives of the refugees involved in research, rather than regard them simply as sources of data. In particular this includes research informed policy advocacy designed to positively influence refugee policy and practice as well as the active involvement of diverse refugee community members and in particular refugee women, as research participants in all stages of the research process, from problem identification to advocacy for change.

Background

I will discuss some of the particular challenges that have arisen in the context of working with refugee communities living in protracted situations with few legal rights. In these contexts, as researchers we needed to be aware, not only of the vulnerabilities of refugees associated with previous experiences of violent displacement including the endemic levels of sexual and gender related violence, but also of the physical, psychosocial and political risks exacerbated by their lack of legal rights to residency and citizenship. In this regard while members of refugee communities may share risks of vulnerability with other groups such as the survivors of sexual violence, persons with an intellectual disability or children, all of whom indicate a particular duty of care, refugees lack of legal and citizenship rights highlights the need for an additional layer of care. For a lack of legal rights can exacerbate both the risks to refugee communities from poorly conducted research and limit their capacity to seek redress. This requires a particular understanding of the specific social and political contexts in which the research is conducted and an awareness of the power imbalance between researchers and refugee communities. While on the one hand this highlights the imperative for research to meet the highest ethical standards, it also raises significant questions in relation to the researchers’ obligations to undertake research which can positively contribute to ending or reducing the often multi-layered forms of human rights abuses faced by refugee communities.

Among the communities with whom we have worked, the strongest message of all was the desire to be valued as active participants in the research process, to retain some control over their personal stories and to be involved with researchers in the process of designing solutions and making recommendations.

It was a lesson learnt because the organisations kept doing pilot projects, which always failed and ended up very badly. Those organisations tried their best but they never came to the conclusion of asking people what they want²

This led us to develop the participatory action research approach which we named “Reciprocal Research³”. Informed by many of the refugee communities with whom we have worked, it is specifically designed for working with communities and individuals experiencing multiple oppressions and persecution to fulfil the aim of undertaking ethical advocacy-focused research grounded in participatory human rights principles.

Commentary on the ethical issues

I will discuss some of the tensions that arise in relation to balancing concerns about potential harm and vulnerability with the rights of autonomy and self-determination. This will include: thinking about informed consent as an iterative process; the power issues related to giving informed consent in a dangerous camp or city in the hope that engagement might lead to tangible outcomes; the importance of research approaches which actively value the skills, capacities, diversities and knowledges of refugee communities and in particular refugee women and girls; and the importance of building relationships of trust and of negotiating reciprocal benefit for refugee communities. This will include discussion of the need to openly negotiate potential reciprocal benefits.

I will also discuss the importance of researchers being attuned to issues of gender inequality and the different experiences of women and men and girls and boys. This will include highlighting the risks to methodological and research integrity of not considering potential barriers to hearing women and girls’ voices and therefore the risks they face. I will highlight the importance of creating safe and inclusive research environments to both reduce risk to individuals and but to also ensure a gendered understanding of the issues being researched and the research recommendations developed for policy and practice.

Conclusions

- The importance of building sound relationships with refugee communities and community organisations early and over time, including through multiple short visits rather than only one longer one. In new or emergency situations establishing rapport and establishing credibility quickly. Strategies might include: accessing the community using trusted and gender sensitive advisers, including where possible participants from earlier projects with a shared background with the refugee communities or sharing film or visual outcomes of earlier similar projects with the new community and working with the community for many days to genuinely build rapport.
- Approach informed consent as an iterative process in order to ensure that refugee community members fully understand the project in which they are consenting to participate and what the right to ‘withdraw at any time’ means in practice.
- Negotiate what a reciprocal community benefit might be in both the short and long term. For example, this might include anything from providing community training or workshops, sharing an abbreviated version of the research report to support the community’s own advocacy work, providing certificates of participation, access to information or other resources.

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Case study 4: ‘Hidden spaces’¹ and health for all: Ethical challenges in researching migration and urban health in Johannesburg, South Africa

Jo Vearey, PhD, African Centre for Migration & Society, University of the Witwatersrand, Johannesburg

Brief description

This case study draws on a body of research work undertaken in Johannesburg, South Africa. Driven by a social justice agenda, this research aims to contribute to the development of evidence-based responses to improve and maintain the health and wellbeing of people on the move in southern Africa. Involving both internal (South African) and cross-border migrants with various documentation statuses, this research initiative explores the linkages between migration and (urban) health, with a focus on urban poor migrants who reside on the periphery of social welfare provision in Johannesburg. The case study highlights the ethical tensions inherent in undertaking research with marginalised migrant groups who live and work in what I term ‘hidden spaces’ in the city. ‘Being hidden’ is something that can be both a deliberate tactic employed by particular urban migrant groups in order to evade the state, and the result of marginalisation where the state bypasses groups in need of intervention. Specifically, this case study raises questions and concerns about the ethics associated with research that ‘makes visible’ these hidden spaces and the (potentially) vulnerable urban poor migrant groups who live and work within them.

Background

Cities in southern Africa are associated with interlinked health challenges, including limited access to positive social determinants of urban health; a high prevalence of communicable diseases; an increasing non-communicable disease burden; and a growing population of urban poor migrant groups – those who enter the city through its periphery, remaining on the edge of urban life, both physically and socially. The diverse population movements into, within and between cities - including both internal (within South Africa) and cross-border migration – present challenges to the development and implementation of migration-aware health interventions that are required to improve health for all. The city of Johannesburg provides a lens through which to explore some of the ethical dilemmas associated with researching migration, mobility and urban health in southern Africa.

In Johannesburg, research shows that many marginalised urban poor migrant groups live and work in ‘hidden spaces’: (informal) spaces that are physically, socially, politically and in some ways economically, hidden from the functioning of the rest of the (formal) city. Municipal services are limited; environmental and social services are sporadic; and health service provision fails to meet the needs of this population. Where services physically exist—and where residents actively attempt to engage with them—discrimination at the point of delivery is common. Urban poor migrant groups struggle daily for survival, and seek livelihood opportunities within insecure, unstable and often violent spaces. Detached from the central-city, these urban poor migrant groups create their own informal – and often illegal – livelihood activities as they battle to survive in complex urban spaces.

These ‘hidden spaces’ result in bureaucratic invisibility and present multiple challenges to local government practitioners who are mandated to provide services to those urban migrant populations who wish to remain hidden – e.g. those with an irregular documentation status, or who work in criminalised livelihood activities, such as sex work - as well as to those urban migrant groups who are hidden yet wish to ‘be seen’ – e.g. South African internal migrants residing in peripheral informal settlements.

Commentary on ethical issues

Researchers must be cautious: exposing and making visible these ‘hidden spaces’ - and the migrant communities residing and working within them - can have negative implications. Whilst well-intended research aims to improve understanding of and responses to the health challenges and needs of urban poor migrant groups, engaging in these spaces without careful and respectful engagement with residents can have unintended consequences, presenting multiple risks to these populations. Mapping, identifying and reporting on the spaces where potentially irregular migrants live and work, and where both internal and cross-border migrants engage in criminalized livelihood activities that are necessary for survival in the city, can guide law enforcement and immigration officers to these spaces.

It is essential that researchers understand and engage with the fact some urban migrant groups deliberately employ a range of tactics for urban living in order to evade state intervention. What then is the responsibility of the public health researcher who is working to improve the health and wellbeing of marginalised urban migrant groups?

Conclusions

This case study has highlighted the potential for causing harm when aiming to generate evidence to support improved responses to migration and urban health in order to improve health for all. The consequences of making hidden populations and places visible must be carefully weighed up with the public health imperatives for undertaking research in these complex urban settings. Suggestions for improving research ethics in this context include:

1. Careful and constructive relationship building with local authorities to navigate the tensions between (1) identifying and responding to the health needs of migrant groups; (2) developing evidence-based interventions to improve health for all; and (3) identifying irregular migrants and those working in illegal livelihood activities.
2. Working with urban migrant communities to identify research agendas and strategies for protecting those residing in ‘hidden spaces’. This should involve exploring alternative research methodologies – as part of larger mixed methods studies - that facilitate direct benefits to the communities being researched. Evidence suggests that arts-based, participatory research approaches that are linked to partnerships with relevant civil society and social justice groups can support this.
3. Developing improved research ethics training for postgraduate students and working with national and local research ethics committees to develop contextually-relevant, evidence-based codes of conduct for research with (potentially) vulnerable urban migrant populations. These guidelines should assist researchers in weighing up the potential for causing harm with the public health imperative of improving health and wellbeing for all.

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Case study 5: Health research on refugee populations in Lebanon: Whose agenda and the role of national institutions

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Brief description

In my capacity as dean of the Faculty of Health Sciences (FHS) at the American University of Beirut (AUB) in Lebanon, I receive multiple requests from UN and humanitarian agencies, international NGOs, and researchers and universities from High Income Countries (HIC) to conduct joint research or provide support, including IRB clearance, to proposed research projects.

This case study will report on a single experience not because it is representative but rather because it is idiosyncratic and summarises the multiple issues surrounding health research on refugees, namely quality and rigour of research, ethical clearance, and partnership. A researcher from a university in a HIC requested my support as dean in securing IRB clearance from AUB for his proposed research project conducted for an international humanitarian organisation providing medical services to Syrian refugees in Lebanon. He also asked for my recommendation for competent faculty and research assistants to help him in conducting the project. We disagreed on all levels and he sought the support of another university.

I will report on this incident, albeit an exception, because it reveals the fault lines that need to be addressed in health research on refugee populations. I will also examine all papers published in peer-reviewed journals on Syrian refugees in Lebanon between 2011 and mid-2017, reporting on the lead researchers and institutions, ethical clearances, and partnerships. Finally, I will share the approach adopted by AUB's IRB on health research in refugee settings.

Background

Lebanon is a small country (10,452 km²/4,036 sq. miles) bordered by Syria (north and east), Israel (south), and the Mediterranean Sea (west).

More than one million Syrians have taken refuge in Lebanon since the start of the Syrian crisis in March 2011. Together with Palestinian and Iraqi refugees who have been in Lebanon since 1948 and 2003, respectively, the total number of refugees in Lebanon is estimated at two million in a country whose population does not exceed 4.5 million rendering it the country with the highest number of refugees per capita globally.

Multiple UN organisations, international NGOs, and foreign government aid agencies responded to the crisis in Lebanon providing humanitarian aid and health services to the refugee and host communities, and direct and indirect support to the Lebanese educational, and health and social care systems. Data on the refugees and host communities and an understanding of the healthcare system and socio-political context in Lebanon were needed to guide programmes and interventions. The dynamic and protracted nature of the crisis, the burden of disease in a refugee population from a middle income country, and the evolving- and occasionally- conflicting needs of the refugees and host communities stimulated the interest of researchers from universities and research institutions in high income countries (HIC). The influx of Syrian and other refugees into Europe presented yet another stimulus, driven by a security concern, for HIC to invest in development, aid, and research programmes for refugees in the neighbouring countries to Syria. At a national level, government agencies, NGOs, and universities were also engaged in similar aid and research activities directed to the refugees and funded by international donors.

Commentary on the ethical issues

UN agencies, international organisations and NGOs, local governmental agencies and NGOs, and academic institutions from within and outside the region are interested in and conducting research on the health of these vulnerable populations. The purpose of these research projects, however, is driven by different needs and interests determining its quality (rigour of research design and methods), ethical clearance (by whom?), level of participation (studied populations, partnerships), use of data (open, limited or no access), uptake (impact on services and health of studied population), and impact on policy (national or international). These realities pose a set of ethical questions and considerations including which body provides the ethical clearance for a research project, who speaks for the vulnerable populations (refugees and host communities), how to balance urgency for research with need for tight ethical control, who owns the data, and how are findings impacting policy and practice.

Conclusions

The experience with health research on refugee and displaced populations in Lebanon spreads over decades but the questions around its ethical implications have been most striking with the influx of Syrian refugees into the country. These implications (or lessons) reflect the dynamic nature of the political crises in the region and the uncertainties that engulf the daily lives and livelihoods of the refugees and their future.

The following suggestions may serve as points of departure to improve research ethics in these contexts:

1. Building local IRB capacities to ethically but efficiently clear proposed health research on these vulnerable populations. How to balance urgency with proper ethical clearance? Are there ethical principles adaptable to crisis situations?
2. Assessing and proposing guidelines for partnerships between local and international academic institutions and between those and local and international NGOs and agencies, while including the voice of refugees and host communities.
3. Developing guidelines or criteria to assess relevance of health research question and clear quality and impact of research designs. Should these criteria include the ability of the research to inform policy and practice? Should these criteria include setting health priorities for research?
4. Integrating research on displaced and refugee populations into academic programs, especially in schools/programs of public health.

Case study 6: Child labour among Syrian refugees in Lebanon: Research challenges and ethics concerning a “triple vulnerable” community

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Brief description

In 2015, a project focusing on child labor among Syrian refugees in select agricultural settings in Bekaa, Lebanon was launched by a multidisciplinary team of researchers from the Faculty of Health Sciences at the American University of Beirut. Employing a mixed methodology, our study-design came to include three parts: a desk review and document analysis, ethnographic qualitative fieldwork, and a quantitative survey developed for the assessment of child labor practices among the displaced children and their families. The quantitative assessment took the form of a household survey, in which specific informal tented settlements (ITS) near agricultural areas were randomly from lists of ITS's in Lebanon provided by UNICEF. All households in each randomly selected ITS where working children resided were included in our household survey. Interviews within selected tents were carried out using two structured questionnaires: a *household and parent* questionnaire and a *child* questionnaire. While our research is still ongoing, the research team will survey around 1500 households, and as of now data has been collected for over 4,000 working children between the ages of 4-18. A final objective of our project is to, based on our findings, formulate and recommend policies and action to protect children from the worst forms of child labor and minimize school dropout.

Background

In Lebanon, Syrian children have increasingly entered the workforce to provide for their families and close the gap of shortage of agricultural labour force in the country. To date, more than 1.2 million Syrians are believed to have sought refuge in Lebanon and are registered with UNHCR. While the majority of displaced Syrians live in urban settings in Lebanon, there is a large number of Syrians—mostly new and former seasonal workers and their families—who continue to live in Informal Tented Settlements (ITS) that are widely spread across agricultural settings in Lebanon.

Prior to the start of our research, it had been suggested that Syrian children as young as six years old were working 5-10 hour shifts and earning less than \$1 per hour. It had also been found that the most common form of employment among children in Lebanon was agricultural work, which is known to be associated with school dropout. A recent study by UNICEF in the Beqaa, Lebanon found that nearly 36% of Syrian children working in agriculture were functionally illiterate—that is with inadequate reading and writing skills to manage daily living and employment tasks. Research and anecdotal evidence also suggest that many of these children are involved in hazardous and exploitative working conditions, including exposure to pesticides, toxic chemicals, heavy loads, and long-work-hours. In response to these reported conditions, multiple UN agencies (ILO, UNICEF, FAO) and the Lebanese Ministry of Labour approached the Faculty of Health Sciences at the American University of Beirut in 2015 to commission the study which is now underway.

Commentary on the ethical issues

The legal and ethical imperatives to assess the conditions and practices of child labour in Beqaa, Lebanon are self-evident. However, conducting the assessment itself also posed ethical questions and dilemmas. The Institutional Review Board (IRB) at the American University of Beirut recognised that our research participants ('working', 'refugee', 'children') experience “triple vulnerability”. Because children were the focus of our study, we were faced with the challenge of constructing an ethical consent process, which was

complicated by factors including Lebanese law, and the absence of fathers in many of the families of displaced Syrians now residing in Lebanon. As workers, our research participants and their families were additionally vulnerable to repercussions from employers and shaweesh (job finding middle men) if privacy and confidentiality were not maintained. As refugees, they were living in precarious conditions, often without basic needs being met, and were already the focus of intense research by NGOs, government agencies, and academic researchers alike, making the families that we interviewed vulnerable to questionnaire fatigue as well to infringements against their dignity. Due to this convergence of many complex ethical challenges, our project protocol required 20 months and several cycles of revision to receive IRB approval. Although, the IRB process was time consuming and demanding, which made it difficult to meet reporting and funding deadlines, the process ultimately resulted in the adoption of many measures that protected both our research participants and fieldworkers. To help protect the confidentiality of our research participants, we decided strictly not to interview children or home-makers in the occupational (agricultural) setting, but rather at home, in private. Additionally, we introduced the use of tablets to collect data for our questionnaires. All responses were uploaded directly to the university's protected central server, so that no documents or digital files were vulnerable to theft during transport from the field to the office.

One ethical challenge that was not resolved, however, was the dilemma of collecting food security/nutritional data from families that simply do not have enough to eat. Illustrating this dilemma clearly is the story of Manal, a pseudonym for one of our fieldworkers, who decided unilaterally to stop data collection regarding food security. Part of our questionnaire included questions about food availability and diversity of caloric sources. Manal, while interviewing a home-maker, saw that the household suffered from scarcity in food supplies. Manal found it personally unjustifiable, in that case, to ask questions that would be painful, embarrassing, and insensitive to vulnerable research subjects. She decided, unilaterally, to skip that section of the questionnaire regarding food security and nutritional data. Anecdotes like the story of Manal raise the serious question: How can we document the conditions faced by displaced working children in a quantitatively sound manner, and communicate the severity of the crisis to government agencies and the international community, while remaining empathetic and sensitive to particularly vulnerable situation of refugees in rural Lebanon?

Conclusions

First, the ethical guidelines provided in the Belmont Report and National Research Act of 1974, and enforced via the IRB process, must be contextualised vis-à-vis the situation facing refugee and migrant populations.

Second, the use of International scales/questionnaires ought to be adapted to marginalised contexts where the questions need to be sensitive to the setting.

Third, it must be recognised that most research (even action-oriented research, designed to provide evidence for policy changes) takes time to finish. When working with vulnerable populations, time is of the essence, and research ought to be conducted under the charge of advocacy on behalf on marginalised communities.

Fourth, balancing advocacy/need for immediate action and scientific rigour in research: Empirical research often does not include advocacy or immediate interventions to address the needs of study participants. Researchers often face the ethical dilemma of choosing between impartially implementing the research protocol (for example, surveys, observational studies, qualitative ethnographies) or taking action, at the expense of focusing on the research protocol, to alleviate community suffering (for example, medical intervention, and supply of basic necessities). Researchers ought to keep these issues in mind, although there are no straightforward answers to this dilemma.

Case study 7: Ethical issues associated with research in humanitarian settings – The case of an integrated intervention to improve mental health and reduce intimate partner violence among Congolese women in Nyarugusu Camp, Tanzania

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Brief description

There is minimal empirical evidence regarding the effectiveness of programmes addressing gender-based violence (GBV), particularly intimate partner violence (IPV), and associated sequelae. Systematic reviews have focused on two types of interventions to respond to IPV in health-care settings: universal screening and empowerment (advocacy)-focused counselling. Universal screening has shown diagnostic accuracy, but limited effectiveness for reducing IPV rates or improving health outcomes. Given that certain programmes, such as advocacy/empowerment interventions, have shown promise in their potential to reduce IPV-related mental health problems and recurrence of IPV we propose to deliver an adapted advocacy/empowerment intervention integrated into an evidence-based mental health intervention for female survivors of IPV detected using universal screening methods. We piloted research and intervention protocols for a cluster randomised, parallel group, controlled trial with two study conditions. Our trial methods followed the standards described in the updated CONSORT statement, and extension for pragmatic trials. Our main research question concerns whether an additional dedicated mental health component (i.e., group Cognitive Processing Therapy -CPT) will result in stronger improvements in mental health and reduction of IPV compared to a standard IPV protocol. In preparation for a fully powered definitive trial, our objectives were to strengthen evidence for public health interventions in humanitarian settings through (1) Developing an integrated mental health treatment and IPV prevention intervention; (2) Assess relevance, feasibility, and acceptability of the research and intervention protocols; (3) Gain preliminary knowledge on whether the intervention shows promise with regard to reducing IPV and improving psychosocial health as compared to the standard IPV protocol among refugees in a low-income country using a randomised controlled trial design. We were furthermore interested in (4) Increasing knowledge on task shifting, i.e. mental health interventions implemented by non-specialist staff in refugee primary healthcare. (5) Making available contextually adapted and piloted quantitative measures for use with refugees from DRC in Tanzania. These measures can be used by humanitarian agencies to strengthen knowledge on public mental health interventions through their implementation in operational research and monitoring.

Background

This study was conducted in Nyarugusu refugee camp located in northwest Tanzania in the Kasulu district. This camp hosts approximately 134,696 refugees, 69,577 [51.7%] being Congolese and 64,893 [48.2%] being Burundian refugees. Many of the Congolese residents arrived at the camp in 1996 following the war in South Kivu and have thus lived in Nyarugusu for 18 years. As of 2014, several countries including Australia, Canada, the United States and several European countries have stated that they plan to resettle Nyarugusu residents in the upcoming years (Norman & Niehuus, 2015).

SGBV against Congolese women: The conflicts in DRC have been characterised by large-scale human rights violations that have been a product of the ongoing conflict and influx of foreign armed groups, including SGBV (Kelly et al., 2012; Michalopoulos, 2014). The prevalence of SGBV remains high in the DRC. Leaders of Congolese communities have argued that apathy from the international community, despite increased awareness, has slowed progress towards reducing the incidence of SGBV. They further claim that the humanitarian response to the conflict and SGBV was inappropriate and did not focus on

community needs, which resulted in the misappropriation of humanitarian resources and lack of attention towards underlying, precipitating factors (Trenholm et al., 2011).

Mental health among Congolese women: In a population-based survey of Congolese adult females, the prevalence of current substance misuse (21%), past-year major depressive disorder (42%), past-month PTSD (54%), past-year suicidal ideation (27%) and lifetime suicide attempt (17%) was high. Adults with a history of sexual violence (male and female) had a higher prevalence of past-year major depressive disorder (60%), past-month PTSD (70%), past-year suicidal ideation (38%) and lifetime suicide attempt (29%) relative to adults with no history of sexual violence.

Commentary on ethical issues

Being a refugee renders a person to be in a vulnerable position, e.g. depending on external assistance with regard to livelihoods, accommodation, and with limited mobility. Importantly, asking questions related to previous or current personal experiences such different forms of violence, mental health issues can carry serious risks, both to the participants themselves and the community. This poses clear challenges for research in humanitarian setting with large numbers of refugees. Hence it is imperative to ensure that ethical and safety issues addressed ahead of time and given consideration throughout a research project to minimize any potential harm to the participants. Knowing the safety and ethical issues challenges in doing research in humanitarian setting, our study sought ethical review and approval from the International [Johns Hopkins University] and local [Muhimbili University of Health and Allied Science as well as National Institute for Medical Research] Institutional Review Boards. The study team ensured that most of the set safety and ethical considerations were fulfilled during the study including; 1) we carefully selected Congolese refugees women who are incentive workers in gender-based violence programming and well versed with Congolese culture to be the research assistants and intervention facilitators, 2) the research team was vigorously trained to be able to maintain privacy and confidentiality 3) all study participants provided informed consent prior to participation 4) protection of data by assigning ID numbers to participants to maintain anonymity, data files were pass worded and only accessed by the research team. We, (5) only screened women already engaged in existing women's groups to avoid suspicion around activities; (6) conducted a detailed mapping of existing gender-based violence services; and (7) as part of the intervention we conducted danger assessments and safety options. Additionally, at local level, we shared our protocol with: (a) the inter-sectoral coordination group for sexual and gender-based violence in the camp; (b) the camp leadership to ensure safety and security oversight; and (c) a community advisory board. However, we were faced with a number of ethical challenges when implementing the research especially for those women who received the intervention.

1. **Risk and benefits** - we had three women who reported to have experienced severe abuse from their partners, raising questions whether we should report cases to the local agencies, especially when formal protection agencies may not be of higher quality than the offered intervention. In all three cases we had to present the case the Data Safety and Monitoring Board [DSMB] to determine whether or not these experiences were resultant of the intervention, the DSMB determined this not to be the case.
2. **Access to emergency and referral services** - according the WHO ethical and safety recommendations for researching, documenting and monitoring, it is imperative to ensure availability of basic and support for survivors available locally before commencing any activity that may involve individuals disclosing information about their experiences of sexual violence. In our study we found that the camp had standard, emergency basic and support as well as referral services for the study participants who need such care. However, these services were at times not available at the right time and right place. The questions being what should be the role of the researcher in such situations? At time we referred for either mental health issues or experience of violence the available facility/centre. However there were reports of delays and constraints in the

services that were provided in those places. The study needed to continue follow up with these women to ensure their safety and wellbeing.

3. **Confidentiality and Disclosure** - it was critical to ensure the confidentiality of individuals who provided information. However, in a humanitarian setting there are number of agencies and actors to support refugees, most of the time with a critical interest in the survivors' information. We needed to provide assurance about the safety of participants' information and why is it important to include different actors to help with their problems.

Conclusions

There is a need to explore context-specific safety and ethical considerations when conducting formative assessment before a larger definitive randomised controlled trial. This will help to bring up to surface any relevant safety and ethical concerns and identify ways of dealing with those potential issues. Generally, there are available sets of safety and ethical guidelines related to conducting research in humanitarian setting [WHO and UNHCR], hence it is imperative to follow those sets and document any emergent issues for future consideration. We recommend that researchers should work with implementing partners and refugee leadership to identify the gaps in provision of needed services, improve the reliability of the services and ensures presence of clear and practical referral pathways whenever the situation calls for referral services.

Case study 8: Tak Province Community Advisory Board (T-CAB), a community engagement initiative on Thai-Myanmar border

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Brief description

T-CAB, a community ethics advisory board currently has 11 members who are from the Thai-Myanmar border population. T-CAB was set up in 2009 on the Thai-Myanmar border to guide and advise on research activities undertaken by the Shoklo Malaria Research Unit (SMRU)/Mahidol Oxford Tropical Medicine Research Unit. This platform offers direct interaction and exchange between the advisory board members and researchers to improve understanding between researchers and the community where participants of research come from. The board contribute ideas related to ethical issues, assess risks and benefits and provide suggestions on recruitment and informed consent processes, as well as compensation and confidentiality.

Background

The Shoklo Malaria Research Unit (SMRU) is a field research site of a Bangkok based Wellcome Trust funded Mahidol-Oxford Tropical Medicine Research Unit (MORU). SMRU has been providing healthcare and conducting operational research (e.g. in malaria, maternal and child health) with the Thai-Myanmar border population for more than 30 years. All research conducted here has been reviewed and approved by at least two ethics committees (Bangkok and Oxford) and ensuring that they meet the international ethical and scientific standards. However, it remains challenging for these ethics committees to provide recommendations on specific ethical issues to the border populations.

The relationship between SMRU and this community has gradually grown over the course of years and having more than 95% of staff members who are from this community allow this relationship become more profound. To promote community engagement and to formalise the existing engagement with the border community, T-CAB was founded in 2009.

Fourteen members from the community through contacts of SMRU staff joined the board and introduction to SMRU roles and summaries of diseases affected the border community were provided. Of the current eleven members, six joined the board since its inception in 2009. Other members joined the board at later times were through contacts of existing board members and introduction of the roles were shared with newly appointed members by existing members.

A meeting is held approximately every 4-6 weeks where members of the board and SMRU researchers are invited. The meeting usually lasts for approximately three to four hours, depending on the discussions and numbers of presentations presented. This is where the researchers and the board members have direct interaction with one another. All of the board members speak fluent Karen and some also speak Burmese, and the discussion during the meeting is in English and Karen with translation provided.

Commentary on the ethical issues

The main ethical issue is representativeness¹. The T-CAB members are not elected representatives of the community. They serve on the board on a voluntary basis. They are of the opinion that they do not speak on behalf of the community but as individuals who are knowledgeable about the community, and therefore they understand many of the relevant issues. It is acknowledged that there are voices in the community which are not heard. This is because to be a T-CAB member, one has to have the time to attend meetings, be literate in their own language and have a relatively stable life, whilst the many of those living on the border live on a daily wage, are illiterate and have travel restrictions.

T-CAB members are willing and have time to serve and committed to be part of this board and contribute as much as they can with the knowledge they have and additional knowledge gained over the past years of being exposed to different studies². Two of the board members are farmers, two are civil servants, five are working in health sector and the other two are housewives. They understand the hardship and challenges encountered by people living in this community as they experience these themselves on daily basis. The combination of this board appears to be adequate for them to be recognised as a community “representative” to some extent especially at the grassroots level. They may not be able to make medical and scientific recommendations on research but they have been able to recommend on issues that are directly related to them and the research participants which are still relevant to ethics and essential to research.

SMRU facilitates meetings, assist with transport to meetings and compensate members for their time off work. One can argue that they are not truly independent but it is impractical to ask members to be out-of-pocket to travel to attend meetings.

Conclusions

Engaging the community in research is essential and different approaches and methods must be explored. Working with the community especially community with such unique setting needs flexibility and true understanding of the diversity. The T-CAB is a complementary ethical check to our existing formal ethics reviews. The current CAB members are satisfied with the level of involvement they have and committed to their roles as they have already demonstrated in the past eight years.

To improve this board, additional member recruitment is necessary, preferably to include a few members who have some medical/public health/community health/community based participatory research approach background and some youth members. Seeking members with such qualification remains a challenge but having additional lay members from different community along the Thai-Myanmar border would also strengthen the representation of this board.

An annual refresher training should be considered, possibly a two to three days training/workshop, where all members are available to attend. This would allow them to discuss their roles and clarify some of the issues that they may have and reflect their thoughts on their participation as an advisory board. Shorter training sessions focusing on issues that come up as well as on process related issues, such as communication, prioritization, methodological questions can also be considered.

We acknowledge that the T-CAB is only one way of engaging with the community. It is important that many parallel engagement strategies are used in order to maximize our reach including to those whose voices are often not heard. We will continue to conduct other engagement work such as engaging the community through workshops, house-to-house visits, organising fun activities with children to complement the work of the T-CAB. In order to enhance the work of the T-CAB, T-CAB members can be invited to join these engagement activities.

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Case study 9: Community advisory boards as local IRBs: Prioritizing community protection in research on displacement and migration

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Brief Description

Over the past 20 years, I have conducted research among refugee and displaced populations in acute phase emergencies as well as among vulnerable populations in migration, including migrant workers and survivors of human trafficking. These include (a) research on the China-North Korea border to measure the mortality impacts of the 1996-1997 famine by interviewing North Korean refugees and migrants in China, and (b) research on the Thailand-Myanmar (Burma) border in 2012-2013 to measure prevalence of sex and labour trafficking among Myanmar migrant workers and displaced persons in Tak Province, Thailand. In both instances (and a number of other settings as well) we established Community Advisory Boards to serve as local IRBs for the duration of the projects (Johns Hopkins Bloomberg School of Public Health served as the IRB of record). In both instances, it was our view that the research posed potentially not only individual but group risk and that protection of community interests warranted the establishment of Community Advisory Boards with roles and responsibilities akin to that of a local IRB.

Background

Since 1994 or 1995, significant numbers of North Koreans began moving across the Chinese border in search of refuge and asylum and/or survival necessities for themselves and their families. It was estimated that, as of 1998, between 50,000 and 150,000 North Koreans were staying temporarily in China, principally in Yanbian Korean Autonomous Prefecture, which is home to nearly one million Korean-Chinese. Beginning in 1998, the Center for Humanitarian Health (then the Center for Refugee and Disaster Response) began monitoring the health and human rights of the North Korean population within and outside the country's borders.

Thailand is a source, transit, and destination country for trafficking. Main sectors for work for trafficked persons in Thailand include commercial sex work, begging, domestic work, factory work, construction, agriculture, and fishing industries. The majority come to Thailand from Myanmar (Burma). Tak Province is home to over 120,000 migrants, most of whom are undocumented Myanmar migrant workers living in Mae Sot District. Myanmar migrants in Mae Sot end up in a variety of occupations, ranging from domestic help to factory work to commercial sex, and are denied full legal status and rights, increasing their vulnerability to trafficking and labor exploitation, and increasing their risk of adverse physical and mental health outcomes.

For both projects, we established Community Advisory Boards to serve as local IRBs for the research. In China, the five CAB members included a local physician, a local academic (also a clinician), a local NGO director, and two local church leaders (churches were active in providing aid to the North Korean population. The CAB included two females and three males; all were Korean-Chinese. In Thailand, the five CAB members included a local academic, the director of a local NGO, a member of the Burma Medical Association, and two local headmasters. Of the five, two were female; all were born in Myanmar, and had been migrants and displaced persons in Thailand, though one had obtained a Thai ID card. Both CABs were provided training in human subjects research by the JHSPH study team. Both were provided all study documents (research plans, recruitment scripts, consent forms, questionnaires in both English and local languages) and met once at the beginning of the project to review the documents and offer comments and suggestions. One member served as an ongoing contact to the study team, to the JHPSH IRB, and to the community, should they have any concerns or questions about the study. CAB members were also provided regular updates on study progress and were provided summaries of study findings and recommendations.

Commentary on the ethical issues

There are a number of ethical issues that bear discussion. These include the risk that CAB members may have had in serving on these Boards. Our analysis of the local context, and discussed with CAB members, was that the research we were conducting was not in violation of any known laws. That said, the populations that were the focus of our research (and some CAB members were also members of these populations) were largely undocumented and subject to harassment, even arrest and deportation, by local authorities. In the case of the North Korean refugee and migrant research, our CAB members asked that their names and their functions be kept confidential and not be made public in any project documentation or study findings.

As to the findings themselves, and their dissemination, we received guidance from the CAB that extra caution needed to be taken to ensure that, above and beyond the normal protections of confidentiality regarding identification of individuals, the community would not be exposed to possible harm. For the North Korean research, this included delaying release of some publications (or providing only limited release to key stakeholders). In both contexts, it also meant careful review and vetting of study details (including location) with the CAB and other local stakeholders (study partners) to ensure that the dissemination of study findings would not expose the community to unwanted scrutiny and risk.

Conclusions

I feel that where research among migrant and displaced populations poses both individual and community risk, and where other local IRBs may not have sufficient understanding of community concerns and vulnerability, or agency to act on behalf of community interests in the conduct of the study and the dissemination of results, then local CABs can and should be empowered beyond an advisory role to serve, for the duration of a project as a local IRB.

Case study 10: The case for an independent Institutional Review Board for vulnerable populations: A proposed model for independent cross-institutional ethics review in the Malaysian context

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Background

Vulnerable populations in the Malaysian context include the indigenous, the homeless, children, migrants, refugees, people of low socioeconomic status, people with disabilities, survivors of gender based violence, survivors of trafficking, incarcerated persons and persons in shelter. For the context of this presentation, this proposal will focus on migrants and refugees.

In the climate of the current migrant crisis, pioneering research is being conducted in a challenging and quick-changing environment. This presents exciting and important opportunities to learn more about the vulnerable migrant populations, but caution must play a part to ensure that we are not violating any ethical code while doing so. An added challenge includes the fact that refugee research is a new topic and there may be new ethical challenges that pop up, unanticipated and the researchers may not be adequately equipped to address them. Researchers have become jaded with the challenges of the ethical process, beginning to believe that the IRB process are unnecessary hoops to jump through, and simply part of a checklist for publishing academic papers. This project is to ensure we return to the beginning, and remind ourselves of why there is an IRB process in the first place: To protect human subjects.

In Malaysia, research ethics infrastructure is present in the form of IRBs placed at Universities, the Ministry of Health and the major Hospitals. For research conducted in the community, in civil society organisations (CSOs), by international agencies, there is no avenue for ethical review. In addition, most existing IRBs have limited knowledge/capacity to address research on vulnerable populations. Existing IRBs also have known political conflicts of interest that have been reported anecdotally as affecting the review of the project. This is an issue with migrant and refugees, where the government and related bodies do not want attention on this issue. All these factors result in researchers having to affiliate with a local university, not going through ethics review or simply not doing the research.

Brief description

This project proposes an independent cross-institutional Ethics Review Board (ERB-VP) for all research conducted with vulnerable populations, including refugee and migrant populations. The project will outline the rationale for and approach to setting up an independent ERB; including the resources, networks and considerations involved.

Objective of the ERB-VP

To provide ethical and independent review for research for vulnerable populations:

- For individuals and organisations unable to access a traditional University based Institutional Review Board (IRB)
- For individuals and organisations who seek an additional and specialized review due to the inclusion of vulnerable populations

The ERB-VP Model

The ERB-VP will have two committees

- (1) The Research Ethics Steering Committee (RESC)

The RESC will be composed of a mixture of academics, civil society organisation reps, community reps and bioethicists. Responsibilities of the RESC include selection of ERB members, coordination and oversight of training of ERB members, adapting training content to each vulnerable population as necessary.

- (2) Ethic Review Board(s)

The role of the ERB under the ERB-VP model will be similar to a normal Institutional Review Board i.e. to review research protocols involving human participants to ensure that the rights of the participants are protected, that they are not subject to unreasonable harm (physical and emotional), and that information about them is kept confidential. There will be an additional emphasis on vulnerable populations and their

needs, including an enhanced community representation and input. The ERB-VP will seek accreditation from regional IRB accreditation boards, e.g. and subsequently seek accreditation from academic journals to allow projects that undergo this ethical review to be able to publish and disseminate their information effectively.

The ERB-VP will be formed with the input of the following institutional players: A local University, the ministry of welfare and social work, the ministry of health, civil society organisations, international agencies and community based organisations.

Commentary on the ethical issues

There is a plethora of ethical issues that are of increased concern when it comes to refugees and migrants. Firstly, respect for persons is difficult to maintain in respect to informed consent. A simple informed consent may not suffice when one considers the power dynamic and the trust between the population and the researcher. Second, beneficence is of importance in this community, with increasing number of researchers focusing on this community. In this time of transition and crisis, it is increasingly important to ensure research delivers some direct benefit to the individuals participating in the project. Third, non-maleficence must be ensured as the local legal situation and authorities will only be known by local members directly in touch with the communities. Many research projects also involve community members in their project, and it is important to ensure the protection of the research assistants and participants. Lastly, justice in terms of participation selection may also be closely regulated, as key persons are often used repetitively, leading to an oversampling of a portion of the community, which is even more problematic if there is a significant benefit to participants. By selecting community leaders, there is also an opportunity for exploitation that must be kept in mind, and all efforts must be made to prevent it from occurring. These ethical issues are not immediately apparent to ERB investigators who are not provided specialized training on refugees and migrants. This ERB, with its specialised training, focus on protection and community representation will be able to address all these issues.

Conclusions

This ERB will be truly independent which is important in a developing country like Malaysia i.e. where institutions and government bodies are influenced by the political climate. The lack of a need for an academic affiliation will allow more civil society organisations to conduct research ethically, as well as disseminate their findings via publication. Increased community representation and specialized training will get an insight into the specialized needs of refugees and migrants.

Recommendations

- Set up of a cross institutional independent IRB reviewing research concerned with human subjects done by independent parties and NGOs
- A move towards more implementation science and service oriented research approach among vulnerable populations, particularly in times of crisis
- Development of training modules for research with refugees and migrants

Case study 11: Beyond ethics approval: Learning lessons and supporting researchers

Dónal O’Mathúna, Dublin City University, Ireland, & the Ohio State University, USA

Brief description

This presentation will discuss the background to and some preliminary findings from a funded research project examining ethical issues in humanitarian research. The project is entitled “Post-research ethics analysis (PREA): A tool for ethical reflection and sharing lessons learnt from health research in humanitarian crises” (<http://PREAportal.org>). PREA is funded by the UK’s Research for Health in Humanitarian Crises (R2HC), a programme funded equally by the Wellcome Trust and the Department For International Development (DFID), with Enhanced Learning and Research for Humanitarian Assistance (Elrha) overseeing the programme.

The PREA project aims to gather evidence on actual experiences of research ethics issues by researchers, ethics committees and other stakeholders when health research is conducted in humanitarian crises and disasters. The research will conduct in-depth qualitative research interviews in five countries, with some of the interviewees conducting research on refugees and internally displaced persons (IDPs). The findings from the qualitative analysis will be used to inform the development of a new tool to facilitate reflection and analysis of ethical issues experienced during humanitarian research; i.e., post-research ethics analysis (PREA). The proposed tool is anticipated to contribute to the development of ethical decision-making skills among researchers working in humanitarian settings.

Background

The PREA project is currently pursuing ethical approval and other permissions to carry out interviews with researchers and other stakeholders involved in previously conducted research. The plans (subject to revision) are to involve people from the following projects.

Country	Type of Health Research Project	Original Research Setting/Population
Afghanistan	Mental health	Conflict induced internally displaced persons (IDPs)
Ethiopia 1	Refugee health	Refugee camps
Ethiopia 2	Clinical research	Subjects in clinical research
Nepal	Nutrition/Psychosocial support	Communities directly affected by conflict/natural disaster
South Sudan	Health service delivery, mental health, conflict and internal displacement	Communities in many regions directly affected by conflict
Sri Lanka	Conflict and child psychosocial health	Communities directly affected by civil conflict and tsunami

Commentary on the ethical issues

The PREA project itself does not have findings yet. However, background work to PREA has led to some preliminary reflections. Research ethics procedures have tended to focus on approval of research protocols prior to the research starting on the ground. Humanitarian research sometimes has difficulties with these traditional procedures and committees, in part because of uncertainty and instability in the research settings involved. Research involving refugee and migrant participants raises additional ethical challenges for traditional research ethics procedures. This presentation will comment on three issues in the current research ethics situation.

One is that the current focus on pre-approval of research protocols reflects a limited understanding of the purpose of research ethics. Ethical issues arise throughout the research process. Ethical decisions are made while a project is being designed, during its implementation, and in the dissemination phase. Research teams should carry out ethical reflection throughout a project's life. To assist with this, some members of the PREA research team were involved in the development of a Research Ethics Tool commissioned by the R2HC funding programme. This tool will be described during the presentation.

A second issue with research ethics procedures is that the type of lengthy, detailed ethical approval process can raise challenges for some humanitarian projects. The current research ethics approval process (involving IRBs) arises from a healthcare context involving formally defined research. Such research methodologies are appropriate for some questions, but not for all. Some questions that arise from healthcare practice are being addressed by methods of quality improvement, programme evaluation, evidence-based practice, etc. All these methodologies involve ethical issues and require ethical reflection and oversight. However, the IRB approach will not address the ethics of each methodology best. Lessons need to be learned from current debates in healthcare about the ethical issues in developing evidence-based practice and these applied to humanitarian settings.

The third issue is researchers require training and support with the ethical issues in their research and other projects. The presentation will discuss some initiatives in which the speaker is involved. Lessons need to be learned from previous research and best practice with ethical issues disseminated. Another resource is a developing initiative to make real-time ethics consultation available to organisations sponsoring humanitarian research and to researchers in the field.

Conclusions

Careful reflection is needed on the original purpose of 'research ethics.' As a branch of applied ethics, its purpose is about helping researchers do the right thing in the right way. This involves much more than getting 'ethics approval' and informed consent. One aim is to ensure that participants are respected and treated with dignity while they are involved in research. This includes finding ways to ensure research maximises potential benefits and minimises harms (understood very broadly). To bring this about, three suggestions will be proposed. (1) Ethics should be considered throughout the research cycle, from formulating the research question to design, implementation and dissemination. (2) Discussions about ethics should include all stakeholders, especially participants and their communities. (3) Researchers should be offered support and practical tools to help them during all phases of the research cycle.

Website and social media

Website

The GFBR website contains details of all previous GFBR meetings, including meeting reports and presentations where available. Presentations from this meeting will be posted on the site shortly after the event. www.gfbr.global

Social media

At this Forum meeting we encourage the use of social media to engage in conversation and to spread the discussions to those unable to attend the meeting itself.

If you use Twitter, please use the hashtag [#gfbrsat2017](#) to tag your tweets about the meeting.

Social media etiquette

Social media is still relatively new at a lot of academic conferences and meetings, so please follow these guidelines to ensure that it is used in a positive way that benefits the meeting and its participants:

1. Be polite and constructive

If you are going to tweet during a presentation or discussion, make sure you do so on a positive note. Share what you learned from the session or pose an interesting key question that would warrant further discussion. If the presenter has a social media profile, tag them in your post, and use the conference hashtag [#gfbrsat2017](#).

2. Respect presenters' requests for no social media

Some topics discussed may be sensitive or present early findings from research that has not yet been published. The chair should indicate at the beginning of a session if the presenter would prefer their talk not to be tweeted.

3. Engage with others

The meeting is an opportunity to learn from others, to hear about their experiences and perspectives. Social media is a useful tool for these interactions but do take the opportunity to talk to people in person during the breaks as well!