Meeting report:

The ethics of research with refugee and migrant populations

Bangkok, Thailand

30 November – 1 December 2017

Contents

1. Executive Summary

Grounding and justification: The Global Forum on Bioethics in Research convened a satellite meeting in Bangkok, Thailand in November 2017, to explore the "Ethics of research with refugee and migrant populations". Over two days and with the use of case studies, 42 participants from 24 countries discussed their experience of conducting research with migrant and refugee populations and the associated ethical challenges. By identifying what is needed to advance ethical research in this field, the meeting aimed to stimulate an agenda to improve research practice and health outcomes for migrant and refugee populations.

Research with migrant and refugee communities

- It is important to conduct research with migrant and refugee populations. However, this can only be justified if the research provides new information that is useful to the study population. Researchers and funders should assess **the necessity and utility of research proposals** before the work begins. This assessment should be based on the **community's needs and should involve input from the population(s) who will participate in the research**.

- There are significant ethical challenges to conducting research with migrant and refugee populations. **These challenges result from 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.

- Refugees and migrants are often categorised as 'vulnerable' in terms of being unable to consent or to protect oneself. However, many GFBR participants argued that being a migrant or refugee does not make one vulnerable as such by default. **Such vulnerability is linked to the context of the research, living conditions, age, power relations etc.** The framing of migrants and refugees as 'vulnerable' may have implications for the ethics review process and engage specific regulatory protections. These special protections may inhibit rather than promote beneficial or critical research for these populations.

- **As a necessary element of ethical research, consent should be viewed as an iterative process based on maintaining respect for persons and building of trust.** Migrants' and refugees' dependence on humanitarian and non-governmental organisation (NGO) service providers who work with researchers or are conducting research themselves may however raise questions concerning their voluntariness in research participation. There was consensus among GFBR participants that even when the right to refuse participation in research is stressed, people may still participate due to power imbalances. However, the opposite can also be true if negative interactions with authorities lead to suspicion of consent processes and a refusal to participate.

- Research proposals should factor in the time needed to establish a trusted relationship with the research population. This will **help researchers understand the communities' needs and develop an appropriate reciprocal benefit policy**. Funders should provide support for the time required for this relationship to be established. However, in emergency situations it may not be possible to build a relationship over time. In such cases it will be necessary to establish rapport and credibility quickly (e.g. by accessing the community using trusted

advisers, including where possible participants from earlier projects with a shared background with the research 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). **In relation to reciprocity, it is critical to manage expectations around what exactly researchers can provide participants with, for example, what referral pathways for assistance with their needs are available.**

- **Local communities should be involved in the design and conduct of research**. Engaging the community in research is essential and different approaches and methods must be explored. Ideally, researchers should find ways to learn from the migrant and refugee communities' experience and to use this to improve their research practice. **Community advisory boards (CABs) can provide complementary ethical input to the research team's existing formal ethics reviews and can bring an important measure of "cultural competency" to the informed consent process**. There are examples of CABs being empowered to act beyond their traditional advisory role and taking on responsibilities more akin to a traditional Institutional Review Board (IRB).

Researchers' role and relationship with other stakeholders

- **There are challenges for researchers who move beyond the traditional role of a neutral observer to being advocates for the populations they work with**. In order to link and balance these two roles, there is a need for careful planning, working with a wider network of stakeholders and adapting research protocols based on learning throughout the process. Working in partnerships with advocacy organisations, and providing timely, evidence-based recommendations to partners at field level is one potential solution for overcoming some of the challenges. Another possibility could be to **establish an independent oversight mechanism which would support researchers with their work around advocacy and provide guidance**.

- Non-academic organisations (e.g. International-NGOs and NGOs) conduct research through academic partnerships, internally and through contracting private research firms. More needs to be done to enhance ethical literacy among non-academic organisations who oversee outsourced research. **INGOs and NGOs should insist on better research practices and undertake ethical review processes equivalent, if not identical to, traditional IRBs for academics**.

- **Working with national governments is a necessity in many settings and can bring benefits (e.g. improving access to communities and resources as well as promoting the uptake of research)**. It can also be a hinderance, however e.g. researchers being constrained to the services that a given government is prepared to grant access to and therefore creating bias in the process. **There is also a risk of being seen as 'colluding' with the government, particularly in cases where governments are seen as instruments of potential harm**. There is a risk of research forcing visibility on communities that do not wish to be made visible to government authorities (e.g. those living and working in a country without legal documentation).

Ethics oversight and support

- Some researchers lack experience or appropriate training to work directly with migrants and refugees. As a result, the researchers may not be appropriately equipped or able to provide support to the communities they are researching and, in some cases, could cause them inadvertent harm (e.g. by disseminating research results that have a negative impact

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or by making participants who prefer to remain hidden visible to authorities). A survey with researchers conducted by Research for Health in Humanitarian Crises (R2HC) found that the majority felt they were not prepared for the ethical challenges they encountered and the difficulties they came across when trying to get IRB approval. **Certain mandatory skills should be acquired before researchers go into the field (e.g. via online ethics courses and by reviewing relevant literature)**. It is of critical importance that researchers understand how their presence and actions are related to conducting ethical research and doing no harm.

- **Even the highest quality studies may still cause harm and not be fit for purpose.** It is important to remember that ethical practice is about questioning whether the way in which we do research is appropriate in the context in which the research is taking place. This may mean **moving beyond methodological limitations to use different methodological approaches – e.g. arts-based and participatory**.

- **International scales and survey instruments serve a useful purpose but they should be validated or adapted as required to reflect the local context**. Otherwise, researcher may find themselves asking painful and insensitive questions to vulnerable research subjects. A powerful example was given at the meeting of a researcher collecting food security data from families who had very limited access to food. The mother being questioned pretended to cook from an empty pot in order to calm her hungry children in the tent. This raises the question of **how researchers can document the conditions faced by a displaced people in a quantitative and sound manner while being empathetic and sensitive**. Also, **how they can then communicate the severity of the crisis to government and international organisations?**

- There is a lack of appropriate and transferable tools to support research with refugee and migrant populations. The tools that do exist are not always widely available or accessible from a central repository. When there are no standardised tools, methods are not always described by researchers and, therefore, are not replicable. This means researchers are not accountable to the wider scientific community and their participants. **Standardised tools (e.g. questionnaires, protocols and guidance) should be developed for use in this field and be accessible via a central repository**.

- There is a lack of ethical guidance to support research with refugee and migrant populations and where guidelines do exist these are often in silos. **Existing guidelines should be brought together in a single repository or in systematic reviews**. Where guidance does exist[1] it should be followed and researchers should document and share any emergent issues for future consideration. The Migration Health and Development Research Initiative[2] was discussed as an important example of an initiative that aims to advance evidence based global migration health policies and practices through international research. This supports the development of ethical guidance through creating coalitions of researchers that can support each other and build capacity.

- **Resources are required to facilitate ethical reflection and sharing lessons learnt from health research with refugee and migrant populations**. The Post-research ethics analysis (PREA) tool focuses on research in humanitarian crises and is an example of such a resource. It aims to contribute to the development of ethical decision-making skills among

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[1] e.g. Zimmerman C, Watts C. WHO Ethical and Safety Recommendations for Interviewing Trafficked Women. Geneva, Switzerland: World Health Organization (WHO); 2003

[2] https://migrationhealthresearch.iom.int/mhadri

researchers working in humanitarian settings by drawing on the actual experiences of researchers, IRBs and other stakeholders. Case studies could also be a useful resource to facilitate training of researchers and IRBs working in the field of health research with migrant and refugee populations more broadly.

- It is important to have some form of ethical review conducted in the country where the research takes place. IRBs serve an important function in this regard but may not always be available, appropriately trained or able to respond in a crisis. Where possible, **the capacity of IRBs should be developed to ethically and efficiently review proposals for research with migrant and refugee populations and to provide guidance to researchers**. However, there may be other mechanisms for supporting and/or achieving ethics input and oversight, rather than having an over-dependence on a single, local IRB that may not have the time or institutional support to develop the capacity to deal with these applications. For example, **a dedicated IRB could be established at the national level that is trained and responsible for reviewing all applications for research with refugees and migrants. Systems could be set up to allow IRBs from different countries to communicate and share their experience and tools. In particular, funders and others should facilitate coordination between experienced and less experienced IRBs to improve collaboration and learning**.

2. Introduction

The Global Forum on Bioethics in Research (GFBR) convened a satellite meeting in Bangkok, Thailand in November 2017, to explore the "Ethics of research with refugee and migrant populations". The ethical imperative for conducting research in these populations is clear, given the scale of migration across the globe and the associated health risks faced by migrants and refugees. The protection of refugee and migrant health requires evidence-informed national, regional and global migration health policies and practices. However, 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).

With experts in bioethics, trafficking research, migration health, policy, ethics review, public health, clinical research and epidemiology from 24 countries[3], the meeting used a case study approach to delved into the ethical issues associated with research with these populations and what is needed to advance ethical research in this field.

The case studies focused on different geographical areas, contexts and communities yet common ethical challenges and themes were evident across presentations and discussions. Relationships between communities and researchers and resulting expectations was a key cross cutting theme. The role of IRBs, their appropriateness, capacity and ability to respond rapidly were also widely discussed. The report focuses on the meeting's key discussion points.

With the majority of globally displaced people being hosted in low- and middle-income countries (LMICs), it is relevant that this meeting was organised by the Global Forum on Bioethics in Research

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[3] Participants were drawn from a wide range of organisations and disciplines. Speakers were drawn from: International Organisation for Migration; United Nations University, Malaysia; University of New South Wales, Australia; University of the Witwatersrand, South Africa, American University of Beirut, Lebanon; United Nations High Commissioner For Refugees (UNHCR), Malaysia; Muhimbili University, Tanzania; Mahidol Oxford Tropical Medicine Research Unit, Thailand; Johns Hopkins, USA; Dhi Consulting & Training, Malaysia; Dublin City University, Ireland.

(GFBR), 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. By bringing the ethical challenges associated with research with refugee and migrant population to the forefront of global discourse in bioethics and policy-making, the GFBR aimed to stimulate an agenda to improve research practice in this field and health outcomes for migrant and refugee populations.

3. Research with migrant and refugee communities

Necessity of research

Meeting participants agreed on the importance of conducting research with migrant and refugee populations. However, this can only be justified if the research provides new information that is useful to the study population. GFBR participants had witnessed research with migrant and refugee populations that appeared to be linked to convenience of access and lack of governance rather than necessity and reciprocity. Researchers and funders should assess the necessity and utility of a proposal before the research starts. This could be achieved through systematic reviews and/or by establishing local partnerships from the outset allowing research to be co-designed around what information is most needed/a priority for service providers.

This is particularly important from the participants' perspective. Researcher should not raise expectations among communities and participants by undertaking research that will not result in a long-term benefit (e.g. new or improved service provision). Discussions focused on the frequent separation of research and implementation and how these are funded. While there is often funding available for research and/or monitoring there is often no funding provision for the activities which may be recommended as a result. GFBR participants agreed that there is a need for improved alignment between research and implementation funders.

Decisions about research priorities are largely not made in the countries where the research takes place or by the populations who will participate in the research. This can be problematic as there may be differences between the context specific needs and the global research and humanitarian agenda. It is important that the research agenda and priorities are decided and managed within a country rather than by external funders or research communities. Models and processes need to be established that allow migrant and refugee populations as well as community-based organisations (CBOs) to participate in - and even lead - the decision-making process. An example was given from the Committee for Coordination of Services to Displaced Persons in Thailand, which included NGOs and other relevant entities in the decision-making process. Involving communities and in-country stakeholders should also have the advantage of avoiding duplication of research and oversampling of the same population.

Dissemination and advocacy strategies should be a built-in component to projects so the impact of findings is maximised. The strategy could involve the preparation of multiple research outputs such as briefs, policy papers and case studies of lessons learned. Activities related to policy uptake should be timed and budgeted for by the researchers and funders.

Key ethical issues

Perceptions and framing of vulnerability and how it impacts ethical research: Migrant typologies were discussed and it was highlighted that, while typology is often relevant to the research being conducted, it is nonetheless important to look at the migratory process as a whole. Distinctions were made between cases of large crisis-driven acute movement of people as opposed to short or long term migration resulting from disparity for aspirational purposes. As migration is driven by a variety of factors, there is ongoing mapping by the International Organisation for Migration (IOM)[4] to determine whether research priorities match the scale of movement globally[5]. Based on this mapping a much higher proportion of research is conducted with refugees compared to domestic migrant workers.

GFBR participants discussed the categorisation of migrant and refugee populations as 'vulnerable' and how this might affect the way in which ethical approval is sought and how research is conducted. This was particularly raised in relation to seeking ethical approval; some IRBs approach these communities in a manner similar to the way prisoners are approached, giving participants limited autonomy to provide informed consent. Some GFBR participants argued that being a migrant or refugee did not make you vulnerable in terms of being unable to consent or protect oneself by default. Vulnerability, rather, is linked to the context of the research, living conditions, age, power relations etc. Others GFBR participants thought it was better to err on the side of caution in these cases. Using the assumption of vulnerability may create tension between what is ethical and what is legally required. For example, the law may not permit minors to consent to research but there could be strong ethical reasons for allowing a minor to consent (or assent) to certain potentially beneficial research.

Consent: GFBR participants agreed that consent for research is an iterative process based on maintaining respect and building trust taking into account the insecure and unstable environments of migrants and refugees. Researchers should be aware that migrants and refugees are called upon to tell their story many times, often to authorities, and participating in research may add to this burden.

Migration calls into question people's legal status, meaning they do not always have access to government services. Migrants and refugees may therefore depend on humanitarian and NGO service providers who often work with researchers or conduct research themselves. This dependence for services raises questions concerning their voluntariness in research participation. GFBR participants agreed that even when the right to refuse participation in research is stressed, people tend to participate due to power imbalances. However, the opposite can also be true if negative interactions with authorities lead to suspicion of consent processes such as signing consent forms and a refusal to participate.

In **case study 1** participants were assured that declining to be interviewed (or being interviewed) would not affect services received and that participation was voluntary. However, the researchers achieved a >99% response rate and acknowledged the power dynamic at play when the groups being interviewed are used to saying yes to people in authority positions. GFBR participants agreed on the need for more qualitative data on why participants take part in research, as well as why they withdraw. Such data would help researchers assess (potential) participants' expectations and concerns about the research (including what benefits they expect to receive).

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[4] http://migrationhealthresearch.iom.int/projects-search
[5] https://www.ncbi.nlm.nih.gov/pubmed/29925353

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

STEAM was a collaboration between the London School of Hygiene and Tropical Medicine and the International Organization for Migration. 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.

Case study 3 focused on the way in which participants consent to things they may not understand or engage with and on how to better understand the process by which people decide to consent. It proposed conducting in-depth consultations on what real consent means; this might include agreeing that nothing will be published without the participants' approval.

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

This case study drew on numerous projects conducted by the author 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 identified in the case were raised by women and men in refugee communities. They include the importance of building sound relationships early and over time, approaching informed consent as an iterative process and negotiating what a reciprocal community benefit might be in both the short and long term.

Case study 6 focused on consent relating to minors and issues of guardianship. It described how, under Lebanese law, obtaining consent from minors with absent fathers is difficult and that legally the government is responsible for guardianship in such cases. This raises questions about the minor's autonomy. Some GFBR participants felt that there are ethical concerns with imposing an adult to have the role of guardian without the child's agreement. They recommended that research ethics guidelines should make provision for a waiver of the guardian necessity where the unaccompanied minor is clearly emancipated (e.g. is acting as head of the household).

Case study 6: Child labour among Syrian refuges in Lebanon: Research challenges and ethics concerning a "triply vulnerable" community

Rima Habib, American University of Beirut, Lebanon

In 2015, a project focusing on child labour among Syrian refugees in select agricultural settings in Beqaa, 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, the study-design includes three parts: a desk review and document analysis, ethnographic qualitative fieldwork, and a quantitative survey developed for the assessment of child labour practices among the displaced children and their families. The quantitative assessment took the form of a household survey, in which individual tents within informal tented settlements near agricultural areas were selected using cluster random sampling. Interviews within selected tents were carried out using two structured questionnaires: a household and parent questionnaire and a child questionnaire. A final objective of the project is to, based on the findings, formulate and recommend policies and action to protect children from the worst forms of child labour and minimise school dropout.

Benefit sharing, reciprocity and remuneration: Benefit sharing approaches should be informed by an understanding of the research population's needs. Slow and meaningful engagement and research can facilitate a trusted relationship with the research population and help researchers understand their needs. Funders should provide support for the time required for this relationship to be established. However, in emergency situations it may not be possible to build relationships over time. **Case study 3** proposed strategies for establishing rapport and credibility quickly, including: 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.

A benefit can have both social and/or scientific value to the research population, and this may depend on the context. For example, if research participants have the opportunity to contribute to advocacy they may be able to use this participation to understand their own experience.

Reciprocity is often defined in terms of what support research participants will have access to. **Case studies 1 and 2** referred to requests made by participants for follow up services which researchers were not able to refer them to or which were not always accessible. Similarly, researchers in **case study 7** found that although support and referral services (for gender-based violence) were available in the refugee camp, these were sometimes not available at the right time and right place. The presenter recommended 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 ensure presence of clear and practical referral pathways.

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

Vanesa Vaca, IOM South America, Argentina

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.

Case study 3 defined reciprocity more widely, to include the ability to protect and promote behaviours and address human rights violations. The case considered 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.

Reciprocity should be addressed through an aspirational lens; recognising that it may never be achieved entirely, but working towards achieving the maximum benefit for participating in the study. However, it is critical to manage expectations around what exactly researchers can provide participants with and what referral pathways for assisting with their needs are available. Reciprocity needs to be continually negotiated throughout the research as the availability of resources, services and benefits may change over time.

GFBR participants noted that NGOs and other international organisations do not in general offer payment to migrants and refugees who participate in research. This is justified on the basis of not wanting to exacerbate existing power imbalances, thus undermining voluntary participation. However, double standards are at play given that in Europe and America participants may be paid to participate in health-related research. It is unclear why the same is not true for migrant and refugee populations and why different standards are used in these cases.

Community engagement: Meaningful community engagement underpins many of the ethical issues identified above is therefore key to addressing the challenges. Community engagement is not merely about education but should aim to identify the interests of all stakeholders and should include two-way communications.

GFBR participants agreed on the need to involve local communities in the design and conduct of research. Engaging the community in research is essential and different approaches and methods should be explored. Ideally, researchers should find ways to learn from the migrant and refugee communities' experience and to use this to improve their research practice. Case study 7 provided an example of this when Congolese refugees women who are incentive workers in gender-based violence programming and well versed with Congolese culture were trained to be the research assistants and intervention facilitators.

The following were also identified as potential strategies for respect for persons in terms of providing outlets for their voices to be heard or working with them to meet their needs:

- bringing women from refugee camps to speak at UN and government meetings,
- using story circles and human rights-based matrices to provide frameworks for communities to articulate the problems they face,
- story boarding to move from problems to solutions,
- active co-operation between research and communities leading to joint presentations of analysis to key decision makers and stakeholders,
- using film and photography to talk about informed consent and as a way of developing relationships rapidly, accessing communities and linking with local partners.

Case study 8 explored the role of a community advisory board (CAB) based on the Thai-Myanmar border. The CAB provides a complementary ethical check to the research team's existing formal ethics reviews. The CAB members have demonstrated great commitment to their roles over the past eight years. GFBR participants shared experiences of how CABs remain motivated through training to create an understanding about health issues and research. In communities where access to health care is a challenge, contributing to its improvement can be very motivating.

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

T-CAB is a community ethics advisory board comprising 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.

Case study 9 provided further examples of CABs established for research conducted on the China/North Korea and Thai/Myanmar borders. In both border projects, the researchers felt that the protection of community interests among displaced, marginalized border populations warranted the establishment of CABs with roles and responsibilities akin to that of a local IRB. CAB as local IRB meant that they provided a forum and format for community consultation but also a mechanism for community consent (although individual consent of study participants also was sought). All study protocols and study documents were reviewed and approved both by the US University IRB (from where the research was being implemented) and by the local CAB-IRB before research could begin. Both Boards were informed of ongoing implementation procedures and of study results, and efforts were made to empower the CAB-IRB to review and ask questions about the study documents (which they did).

> **Case study 9: Community advisory boards as local IRBs: Prioritising community protection in research on displacement and migration**
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> Court Robinson, Johns Hopkins, USA
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> This case study drew on the author's experience over 20 years of conducting 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) the researchers 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 the researchers' 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.

This model gave rise to questions about the legitimacy of the CAB-IRB and how meaningfully empowered the members were – or felt they were – to question methods and protocols. To ensure legitimacy, a CAB-IRB must meet both training and participation requirements and in many local communities training can be a significant challenge. There were some concerns raised about an IRB being run entirely by community members. However, the majority of GFBR participants agreed that CABs as IRBs can bring an important measure of "cultural competency" to the informed consent process in international health research, especially research involving marginalized and vulnerable communities. While a formal, national IRB will most likely possess no cultural competency over border populations, the CAB can help identify and mitigated risks for both communities and researchers.

GFBR participants also discussed the issue of institutional authority and its importance particularly as the role of traditional IRBs is not limited to approval, but includes continuous oversight, response and the empowerment to take decisions. There was agreement that there is immense value in establishing a locally constituted IRB (which may or may not be a CAB-IRB) with institutional responsibility. However, questions were raised about the meaning of institutional authority among populations for whom institutional authority has failed.

4. Researchers' role and relationship with other stakeholders

Advocacy and its limits

Participants discussed the challenges for researchers who move beyond the traditional role of a neutral observer to being advocates for the populations they work with. In order to link and balance these two roles, there is a need for careful planning, working with a wider network of stakeholders and adapting research protocols based on learning throughout the process. Working in partnerships with advocacy organisations, and providing timely, evidence-based recommendations to partners at field level is one potential solution for overcoming some of the challenges. Another possibility could be to establish an independent oversight mechanism which would support researchers with their work around advocacy and provide guidance.

An example of using research for advocacy was given with reference to the Global Compact on Migration[6]. Academic institutions were engaged in the development process and provided evidence in response to consultations. However, the resulting Compact contains little mention of health and social justice issues. This is a concern as it will impact on the funding of health-related activities, and limit the type of work which can be conducted.

Case study 6 identified a broader issue of balancing advocacy, the need for immediate action and scientific rigour in the conduct of empirical research. Researchers often face the ethical dilemma of choosing between impartially implementing the research protocol (for example, surveys, observational studies, qualitative ethnographies) or taking action to alleviate community suffering (for example, medical intervention, and supply of basic necessities) at the expense of protocol adherence. Researchers ought to keep these issues in mind, although there are no straightforward answers to this dilemma.

Working with non-academic organisations

Collaboration between researchers and international organisations, NGOS, CSOs and advocates was widely discussed. Those who have worked with non-academic organisations in the context of research highlighted some of the benefits of being able to conduct research and maintain the necessary distance from participants while at the same time working alongside organisations who are directly involved with communities and understand the context in a different way. In **case study 1** the interviews were performed by the shelter staff (social workers, counsellors) who received one weeks intensive training. This was an advantage if individuals needed assistance during or after the interview, as the service staff were on hand to provide support. The 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.

Discussion also focused on the way in which INGOs and NGOs conduct research, whether through academic partnerships, internally or through contracting private research firms. **Case study 1** focused on trafficking, exploitation and abuse in the Mekong and the way in which INGOs conduct research. GFBR participants agreed that more needs to be done to enhance ethical literacy among organisations who oversee outsourced research. INGOs and NGOs should insist on better research practices and undertake ethical approval processes equivalent, if not identical to, traditional IRBs for academics. All partners need to be on the same page in terms of their ethical practices and guidelines.

Working alongside governments

Working with national governments is a necessity in many settings and can bring benefits (e.g. ensuring research complies with national legislation and promoting the uptake of research into policy). **Case studies 1 and 2** highlighted the additional benefits of improved access to communities and centres which would otherwise be difficult to access.

It can also be a hinderance, however e.g. researchers being constrained to the services that a given government is prepared to grant access to and therefore creating bias in the process. There is also a risk of being seen as 'colluding' with the government, particularly in cases where governments are seen as instruments of potential harm. There is a risk of research forcing visibility on communities that do not wish to be made visible to government authorities (e.g. those living and working in urban settings without legal documentation or those engaged in illegal activities) (**case study 4**).

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[6] https://www.iom.int/global-compact-migration

Reporting these activities or the participation of these individuals to governments or national authorities would mean a breach of confidentiality and trust with the communities in question.

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

This case study drew on a body of research work undertaken in Johannesburg, South Africa. Driven by a social justice agenda, the 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.

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5. Ethics oversight and support

Capacity, training and safety of researchers

GFBR participants expressed concerns about the lack of experience or appropriate training among the research community working directly with migrants and refugees. A survey conducted by R2HC with researchers found that the majority felt they were not prepared for the ethical challenges they encountered and the difficulties they came across when trying to get IRB approval. Other challenges related to the potential negative impact of result dissemination to the research participants, conflict of interest among research partners and the feeling that researchers are not appropriately equipped or able to provide support to the communities.

The issues of researchers, particularly PhD students, arriving in crisis situations without appropriate knowledge or skills can be a problem. Potential solutions include the acquisition of certain mandatory skills before researchers go into the field. Online short courses on research ethics are readily available as are a number of papers specifically related to ethics of research with refugees and migrants. These materials would allow people to develop their skill sets before conducting research in the field. It is of critical importance that researchers understand how their presence and actions are related to conducting ethical research and doing no harm.

Risk to researchers is not always considered in the ethics review process. However, such risks were identified in a number of the case studies, for example, **case study 2** focused on the danger to researchers interviewing migrant workers who worked in unregulated and unsafe or hostile working conditions. Local risk assessment of the field sites was performed through trusted local partners and fieldwork staff followed strict procedures for checking in and checking out before and after interviews to ensure their safety in the field. **Case study 9** provided a useful example of CABs helping to develop procedures for field travel and contact with local community members. Researchers' safety can also be compromised if they publish potentially critical reports exposing abuses.

There are also potential risks related to the emotional wellbeing of researchers. For example, the research team in **case study 3** experienced distress due to their limited ability to assist the migrant workers having learnt of their experiences and conditions. Strategies for mitigating these risks include team meetings and continuous support throughout the research process. This is particularly

true for researchers who come from the communities participating in the studies. It is important to develop mechanisms which allow and promote professional reflection over time and sharing of experiences.

GFBR participants highlighted that there are issues which are not often discussed (unlike the more openly discussed one of 'parachute researchers') related to ghost partnerships with in-country institutions. Often, institutions from high income countries submit proposals with national partners, whose expertise they do not really use. These 'partnerships' pose significant ethical challenges and put researchers and participants at risk as overseas institutions lack understanding of the local contexts and needs. A mechanism should be put in place to reflect on where such partnerships go wrong or cause harm and ensure honest information gathering about these partnerships.

Appropriateness of data collection methods and tools

International scales and survey instruments serve a useful purpose but researchers should be able to adapt them where required to reflect the local context. **Case study 6** highlighted the dilemmas researchers can face when using standardised data collection methods: A researcher collecting food security data from families who have very limited access to food experienced a mother pretending to cook from an empty pot in order to calm her hungry children in the tent. The researcher found it personally unjustifiable, in that case, to ask questions that would be painful, embarrassing, and insensitive to vulnerable research subjects and so unilaterally stopped data collection regarding food security. This raises the question of how researchers can document the conditions faced by a displaced people in a quantitative and sound manner while being empathetic and sensitive. Also, how they can then communicate the severity of the crisis to government and international organisations?

The American University of Beirut (AUB) is conducting a systematic review looking at survey tools developed in western contexts that have been applied in research with refugee children. They aim to assess the appropriateness of the tools and examine how many were validated in the local setting. An alternative strategy might be to develop new questions and pilot test them in the local context, using participatory approaches so that any tool is more sensitive to the needs of the communities which participated. More research is required on the adaption of standard tool for particular contexts.

According to GFBR participants, there are no tools for measuring violence and abuse in migrant domestic worker settings; appropriate research methods and ethical practice in this area are a priority for the international community. When there are no standardised tools, methods are not always described by researchers and, therefore, are not replicable. This means researchers are not accountable to the wider scientific community and their participants.

Concern was expressed that local translators or field workers may have certain biases towards refugee or migrant people which may be introduced into recording/transcription. On the other hand, external translators may be not trusted by people in the refugee and migrant community. Technologies for translation was suggested to replace or complement local translators' work and mitigate their biases and prejudices.

GFBR participants discussed the need to move past methodological limitations and to understand that even the highest quality studies may cause harm and not be fit for purpose. It is important to remember that ethical practice is about questioning whether the way in which we do research is appropriate for the context in which it will take place. Areas this relates to are:

- respect of confidentiality and recording of responses,

- putting people at risk (e.g. risk of identification by authorities for people who want to remain 'hidden', risk of stigmatising people, risk of re-traumatising people when asking them to relay their stories)
- issues around offering advice to participants which may interfere with the objectivity of or distort the study findings.

Case study 4 recommended the use of 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. But it will require effort to encourage the wider research community that such methods are as legitimate as others and potentially more ethical in practice.

Ethical guidance and tools

There is a lack of appropriate and transferable ethical guidance to support research with refugee and migrant populations. GFBR participants agreed that it is important to try and bring these together in a repository or in systematic reviews. Also, where guidance does exist[7] it should be followed and researchers should document and share any emergent issues for future consideration. A colleague from IOM highlighted the existence of a database where resources can be stored and shared. The Migration Health and Development Research Initiative aims to advance evidence based global migration health policies and practices through international research. This supports the development of ethical guidance through creating coalitions of researchers that can support each other and build capacity.

Case study 11 described a project that aims to create a tool for ethical reflection and sharing lessons learnt from health research in humanitarian crises. It will 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 tool will contribute to the development of ethical decision-making skills among researchers working in humanitarian settings. This project speaks directly to the need to support researchers by providing them with practical tools to help them during all phases of the research cycle.

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

Dónal P. O'Mathúna, Dublin City University, Ireland

This case study focused on a project entitled "Post-research ethics analysis (PREA): A tool for ethical reflection and sharing lessons learnt from health research in humanitarian crises" (http://PREAportal.org). 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. 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.

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[7] e.g. Zimmerman C, Watts C. WHO Ethical and Safety Recommendations for Interviewing Trafficked Women. Geneva, Switzerland: World Health Organization (WHO); 2003.

The author of **case study 2** recommended that research teams should be provided with a document containing guidelines and recommendations on the situations they may encounter. This would be specific to the research project and the context in which the research is taking place. The document could include guidance on:

- how to manage participant expectations,
- the limitations on the ability of the research team to assist participants,
- the available referral resources to assist a participant (if any),
- security issues in hostile or risk-prone settings, for both the team member and the participant,
- how to manage difficult situations with participants,
- self-care and team support.

GFBR participants agreed on the importance of a risk assessment tool. This should be used to consider political situations in the countries and to assess the physical and emotional risks to participants and researchers at an individual and community level. Guidance will be important in these cases to ascertain how multiple and appropriate stakeholders are identified, who is working with the communities already and who is conducting research.

Ethics review and Institutional Review Boards

Institutional Review Boards (IRBs) serve an important function but may not always be available, appropriately trained or able to respond in a crisis. Where possible, the capacity of IRBs should be developed to ethically and efficiently review proposals for research with migrant and refugee populations and to provide guidance to researchers.

GFBR participants agreed on the need to have some form of ethical review conducted in the country where the research takes place. However, there may be other mechanisms for supporting and/or achieving ethics input and oversight, rather than having an over-dependence on a single, local IRB that may not have the time or institutional support to develop its capacity to deal with these applications. For example, a dedicated IRB could be established at the national level that is trained and responsible for reviewing all applications for research with refugees and migrants. Systems could be set up to allow IRBs from different countries to communicate and share their experience and tools.

An example was given from H3Arica where additional ethical governance has been institutionalised given that existing IRBs do not have the capacity to provide continuous support on genomics projects in Africa. A dedicated ethics working group has been set up within the project to monitor the issues coming out of individual studies and at consortium level. This provides a learning opportunity for other types of research which require long term, tailored ethical oversight.

Some GFBR participants described the way in which they work with ethicists - either within their departments or as an integral part of their research teams. The relevant expertise provides the opportunity for critical reflection during the project. This approach could be taken up more widely. For example, funders could require the inclusion of an ethics adviser as part of a research team as a way of providing supervision throughout the research process (design, implementation and dissemination) and ethics training for the researchers.

Sidestepping or manipulating the ethical review process: It is not clear if or how institutions such as non-health academics, NGOs and INGOs, are seeking alternative ethical approval for research or receiving relevant oversight in lieu of IRB approval. Meeting participants who have worked with such organisations on research projects described how delays in receiving ethical approval affected

their collaboration leading their partner to conduct the research independently of academia. **Case study 5** gave another example of a HIC researcher requesting support to secure IRB clearance from AUB for his proposed research project to be conducted for an international humanitarian organisation providing medical services to Syrian refugees in Lebanon. Disagreements on the proposal resulted in the researcher seeking support of another university.

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

The American University of Beirut (AUB) in Lebanon receives multiple requests from UN and humanitarian agencies, international NGOs, and researchers and universities from High Income Countries to conduct joint research or provide support, including IRB clearance, to proposed research projects. This case study focused on one such 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.

To limit the sidestepping of the ethical review process, or 'cherry-picking' collaborators, **case study 10** recommended the establishment of an independent 'alternative' ethics review board for vulnerable populations (including migrants and refugees). The Board would be cross-institutional and provide ethical guidance and approval for organisations who are not able to access traditional IRBs. It would be formed with local university input, including potentially government bodies such as the Ministry of Welfare and Ministry of Health as well as CBOs and CSOS. This alternative mechanism would have a steering committee and an ethics review board and would seek accreditation from regional bodies and from journals to facilitate research dissemination. The Board could provide a rapid review and offer services to organisations that would not normally seek formal IRB approval. This example was in the Malaysian context but the model could usefully be applied more broadly.

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

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. As one solution to this problem, this case study proposed the establishment of an independent cross-institutional Ethics Review Board for all research conducted with vulnerable populations, including refugee and migrant populations.

GFBR participants discussed whether this proposed model could expand and take the form of a multi-institution IRB that covers all studies conducted outside academia and fill the gap in circumstances where NGOs are conducting research. A critical issue is how to get buy-in from research organisations, especially those who would not normally see ethics review. Others

mentioned the potential risks associated with creating a business model out of IRBs (raising potential conflicts of interest) and the issue of IRB liability and the need to ensure that there is a mechanism in place to stop projects which are not being carried out appropriately.

Careful consideration should be given to the benefits and risks associated with including political bodies on any such review board. It could be useful to have government buy-in but it could also pose challenges if government tries to dictate how and where research is conducted and what results are published.

Capacity building for IRBs: The capacity of IRBs was widely discussed, in particular their ability to respond rapidly in humanitarian crises and to work collaboratively, particularly in LMICs. Rapid reviews are necessary in urgent contexts and mechanisms are needed to facilitate shorter applications and response times without compromising the standard of review. The problems associated with capacity and speed however, are not specific to LMICs. It is important to invest in building the capacities of IRBs for them to be able to respond to these types of situations, support broader institutional capacity and knowledge exchange.

GFBR participants have witnessed improvements in recent years regarding cross country support and learning for IRBs. Yet, more needs to be done to support IRBs in LMICs to participate in creative discussions and partnerships. GFBR participants suggested conducting shared approval processes between IRBs in different countries as one solution. Meeting participants mentioned the existence of strong regional and sub-regional IRB networks and stressed the fact that lessons learned from their operation should feed into wider international collaborations. There are attempts by partners and funders to facilitate coordination between experienced and less experienced IRBs to improve collaboration and learning.

6. Acronyms

- AUB- American University of Beirut
- CAB- Community Advisory Boards
- CBO- Community based organisation
- CSO- Civil Society Organisation
- GFBR- Global Forum on Bioethics in Research
- IOM- International Organization for Migration
- INGO- International non-governmental organisations
- IRB- Institutional review board
- LMIC- Low and middle-income countries
- MORU- Mahidol Oxford Tropical Medicine Research Unit
- NGO- Non-governmental organisation
- R2HC- Research for Health in Humanitarian Crises

Full case study write-ups are available on the GFBR website