

**Title:**

From Ethical Dilemmas to Opportunities: Reflections on participatory and collaborative research with refugees in Australia

**Authors:**

**Jaya Dantas\*** is Professor of International Health and Dean International in the Faculty of Health Sciences, Curtin University, Western Australia.

Email: [jaya.dantas@curtin.edu.au](mailto:jaya.dantas@curtin.edu.au)

ORCID: 0000-0002-0625-4330

**Shelley Gower** is a Research Officer, International Health Programme, and Lecturer, School of Nursing, Midwifery and Paramedicine in the Faculty of Health Sciences at Curtin University Western Australia.

Email: [shelley.gower@curtin.edu.au](mailto:shelley.gower@curtin.edu.au)

ORCID: 0000-0001-9663-0207

**Funding:**

The research reported in this article was supported by two projects: the first funded by Healthway (The Health Promotion Foundation of Western Australia – Grant Number 24265 and the second by the Office of Learning and Teaching – Grant Number ID15-4758.

**Disclosure statement:**

There are no conflicts of interest for either author

## *Abstract*

This reflective article draws upon our recent experiences in researching with refugees, especially women and youth, who have resettled in Australia. It is a practice and research-oriented article that presents our experience as a series of ethical challenges and how these were resolved to form opportunities for ongoing collaboration. We discuss the limitations of existing ethical guidelines relating to research with displaced people especially refugees; the difficulties of gaining consent in a manner that balances university requirements with participant self-determination; the issue of tangible benefits and reciprocity for participants; the challenge of accurate representation of refugee voices, using imagery; and finally our ongoing accountability to participants. In trying to address these issues, our projects have used a participatory, collaborative research method, in keeping with recent calls for greater use of this approach. In doing so, we have attempted to redistribute social power, ownership of results and resources from the researchers to the participants. We posit that giving refugee participants the opportunity to actively participate in sharing their stories is empowering and builds strength and resilience.

## *Keywords*

Refugees; resettlement; reflexivity; ethics; youth; women

## *Introduction*

This reflective article draws upon our recent experiences in researching with refugees, especially women and youth, who have resettled in Australia. Undertaking research with vulnerable populations requires skill, sensitivity and empathy with a particular emphasis on ethical issues. As qualitative researchers using participatory and rights based approaches, our focus has been on the complex issues of migration both forced and voluntary, resettlement, resilience and empowerment. Since 2000, the first author has conducted research in complex settings of Rwanda, Timor Leste, and Uganda and in India and Australia. The second author was involved with maternal and women's health in Australia, with a focus on empowerment, during the same period.

As researchers affiliated with the Refugee Research Team in the School of Public Health, Faculty of Health Sciences at XXX University, we have undertaken research studies and participatory intervention projects with refugee and migrant participants especially women and youth in Australia since 2005, exploring re-settlement experiences and educational trajectories. Underpinning the research we conduct, are the concepts of collaboration, building respectful relationships, humility, gender, equity, consent, reciprocity and understanding power between researchers and participants. Our research is also undertaken with community organisations and educational institutions who are our established partners in the research. Our particular focus is on refugee health promotion and psychosocial wellbeing. These foci are socially and ethically important as host governments throughout the world continue to have divisive and exclusionary policies that exclude refugees from much needed health, education and social opportunities (1). This article outlines two of our recent projects and presents our responses to a number of ethical challenges we encountered in undertaking those projects. In reflecting upon those responses we

propose recommendations, and discuss implications, advocacy and ongoing collaborations. This article is set in the context of refugee re-settlement in Australia under the Australian humanitarian program

### *The Australian Humanitarian Program and Impacts*

In order to provide context for the reader, the following description of the Australian Humanitarian Program is provided. Australia is a signatory to the UN Refugee Convention (2) and one of 37 countries that participate in the UNHCR Refugee Resettlement Programme (3). Australia's refugee intake was 18,762 for 2018-19(4) with the major source countries being Iraq, Democratic Republic of Congo, Myanmar, Syria and Afghanistan. The majority of humanitarian visas were allocated to young people up to the age of 17 years, and approximately 60% of humanitarian entrants were resettled in metropolitan areas (4). A total of 58 different religious groups were included in the humanitarian program, but the majority of visas were granted to people of a Christian background (5). Australia also has a specific 'women at risk' visa category (Subclass 204) that resettles women from settings of conflict, personal violence and persecution. In 2018-19 a total of 2947 women were resettled under this visa category (4).

The Australian Government's policy of detaining asylum seekers arriving by boat in detention centres has been in place since 1992 and was abolished as an election promise in 2007. In 2012 the Australian Government re-established offshore processing of asylum seekers and opened processing centres in Nauru and Manus Island, Papua New Guinea. Asylum seekers arriving by boat after 19<sup>th</sup> July 2013 were all processed offshore, and banned from gaining permanent residency in Australia even if found to meet refugee criteria (6). The policy of offshore processing and detention has been widely criticised by international law experts, and the psychological harm suffered by detainees has been well documented (6-8).

In 2019 the Australian Federal Parliament passed a landmark bill to bring sick asylum seekers to Australia from off-shore detention – a moral and ethical issue that was publicly divisive, and has since been overturned (9). Our research seeks to explore the experiences of refugees who have navigated this complex system and re-settled in Australia.

### *Project Descriptions*

We share brief project descriptions of two major intervention projects we undertook and reflect on the ethical challenges we were confronted with.

- 1. (Re)claiming social capital: improving language and cultural pathways for refugee students into Australian Higher Education:** This longitudinal project commenced in 2016 and explored the transitions of refugee students into and through Australian tertiary education. Students with a refugee background were recruited between August and October 2016 from Intensive English Centres (IECs) in high schools in Western Australia. The first author had over a decade long relationship with the IECs and the researchers were welcomed into the IECs. Undergraduate students in their first year at university were recruited between March and October 2017. Data were collected using individual interviews as well as focus group discussions. This project was funded through a nationally competitive Office of Learning and Teaching Grant and the larger study was undertaken with two partner universities in New South Wales.
  
- 2. Empowerment and mental health promotion of refugee women through Photovoice:** Utilising the participatory method of photovoice this project explored 50 refugee women’s perspectives of resettlement, including resilience processes in coping with various life domains. Participants were provided with a camera, which they could

then keep and were asked to take photographs of their resettlement experiences in Western Australia. The women selected a number of their photographs for sharing and exploration through focus group discussions and reflective narratives to identify emergent themes. The project culminated in a travelling exhibition that has been displayed in several settings around the world. This project was funded by the Health Promotion Foundation of Western Australia through a competitive intervention grant.

Applying a participatory action research (PAR) approach, students' and women's voices guided the research projects and their outcomes, including personal and systemic responses for supporting successful education trajectories and resettlement.

In this article we reflect on the international and national ethical frameworks currently in use, and consider the cultural, social and linguistic issues that influence the autonomous and ongoing participation of refugee participants in university and community research. The specific ethical practices presented and discussed in this article include gaining consent in a manner that balances university requirements with participant self-determination; the issue of tangible benefits and reciprocity for participants; the challenge of accurate representation of refugee voices, using imagery; and finally our ongoing accountability to participants. We use the notion of ethical challenges as throughout the research process we grappled with these, discussing the challenges as they arose - from obtaining ethics approval, to consent, to sharing of traumatic experiences, to discussing and presenting results and to continuing relationships. The challenges we encountered were addressed and overcome, always through sharing our responsibility for these with our partners. We have documented our approach in dealing with the challenges in the next sections.

## *The Challenge of Informed Consent*

The Declaration of Helsinki (10) is one of a number of international statement of ethical principles for research involving human subjects developed after the atrocities of the Nazi regime in World War 2 and other social and medical examples of ethical breaches by practitioners (11). This declaration highlights the importance of informed consent, for all research methodologies including the collection of bio-physical data and of personal information and stories. However, current ethical frameworks are limited in how they guide researchers to abide by the Declaration of Helsinki with certain groups, such as refugees. The dimensions of power and trauma are not adequately addressed in the declaration.

Human research in Australia is guided by the National Health and Medical Research Council (NHMRC) national statement and guidelines. The NHMRC statement provides guidelines on researching with vulnerable populations including Aboriginal and Torres Strait Islander Peoples (chapter 4.7) and People in Other Countries (chapter 4.8)(12). However, specific guidelines for researching with refugees in Australia are not included, with no consideration for their vulnerability, emotional or psychological state or the difficulties of undertaking research in a different language and culture. This results in a reliance on the trust, dedication and commitment of the researcher to be reflexive during the research process which includes the need to constantly engage in critical self-reflection; analyse their own biases, assumptions, preconceptions and motivations to ensure participants rights are protected; collect appropriate and authentic data that truly reflect participant experiences; and to ensure accountability is maintained (11). At times, the criteria of these ethical guidelines, designed to minimise harm, are in fact in conflict with the needs of participants, and indeed appear to be potentially detrimental.

## *Balancing University Requirements with Actual Informed Consent – a Moral Challenge*

The ethical principle of ‘*Respect for Persons*’ is based on the concept of the adult and mature autonomous person being capable of making judgements regarding their participation based on the provision of information provided to them about the research. There is an assumption that the participant will take part in the study on a voluntary basis after considering the potential risks and benefits of the research through an Information Sheet and Consent Form (11). Gabriel (13) discusses the potential misunderstanding of purpose and process that may occur when refugee participants are required to interpret lengthy written consent forms. Pittaway et al (14) have noted the potential power imbalances and lack of opportunity for participants to redress concerns in the current methods of gaining informed consent.

The more traditional consent forms and the philosophy underpinning them are taken from positivist interpretations of research, drawn from the biomedical sciences. In this paradigm the researcher is considered to be objectively observing phenomena from a controlled distance, and describing an observable ‘reality’ (11). There is little regard for ownership of data by participants. In contrast, qualitative research is based in a constructivist paradigm, where researchers interact with the world to interpret the realities and lived experiences of participants (15). In the case of vulnerable groups such as refugees, and of participatory action research, different techniques of gaining consent are needed.

For project one, we obtained ethics approval from the university and the Western Australian department of education, and received permission to undertake the study in high schools. However, we encountered a number of challenges during the research that required us to reflect,



modify and adapt our ethical processes as the project progressed. As we were conscious of the age of our participants (refugee youth), we developed information sheets and consent forms that were suitable to the varying levels of English among our participants, as well as the possible variations in the cultural understandings of the research process. In particular, we were committed to ensuring that our participants understood the ethical principles of informed consent, autonomous participation, and the right to refuse and withdraw from the research.

One possibility available to us was having the Information Sheet and Consent Form translated. However, there was a wide range of languages spoken by our participants which would have made this process complex. Further, we chose to include participants who had been part of the education system for at least one year, including in the tertiary system, and they had a level of English sufficient to understand the specifically-created Information Sheet and Consent Forms. We also discussed this issue with our community partners and the IEC principals.

As our participants were 15-18 years old or even older, we considered them '*mature minors*'(12) and initially we did not intend to seek parental consent which was accepted by the University. However, the Western Australian Department of Education guidelines require parents to be fully informed about all research projects and for their consent to be obtained. This resulted in a lengthy, and prescriptive set of documents which then had to be sent home to parents. In reality, this placed a significant burden on the participants, who had the responsibility of explaining the study to their parents and arranging for relevant signatures. As researchers we were unaware if parents understood they were consenting to a longitudinal project, or how they felt about it. In reality, it was likely that parents were actually less informed by the process required by the education department than they would have been under our original approach. Additionally, anecdotally, we were informed that parents were happy for their children to participate in the research, but were reluctant to sign a document due to privacy

concerns and a lack of trust of institutions. Our experience reflected the concerns of Hugman, Bartolomei and Pittaway (16) in that in effect, the consent form was serving purely governance and bureaucratic purposes rather than minimising harm for the participants.

Block et al (17) raise the issue of the difference between *Ethics in Practice* (getting approval from the ethics committee) and *Ethics in Process* (responding to ethical issues throughout the research). Block et al (17) posit that obtaining consent *before* data collection has the potential to enhance power imbalance and this was evident in our projects. In project one, if the parents had questions about the research they needed to contact the researchers or the university ethics committee directly - both representatives of more powerful institutions. Interestingly, this process was considered appropriate by the ethics department at both the university and the education department.

In project two, due to the use of interpreters we were unsure as to how well the participants understood the time commitment of the project although every attempt was made to explain the project in an ongoing process. Informed consent was obtained prior to the start of the project but when attendance at focus group discussions became intermittent over time we became concerned as to the true understandings of the participants of the expected commitment.

Yohani (18) suggests using an alternative contact person that refugee participants can go to with their concerns when taking part in research. This could be a community member with the language and research knowledge required to act as a trusted person with whom participants could speak about their concerns. This cultural brokerage would perhaps reduce power imbalance and enhance understanding. We felt that to some degree this role was filled by the IEC Principals and teachers at the schools in project one. Whilst not ideal, it did ensure a balance

between university and departmental ethical requirements, minimised the burden on students, and maximised participation rates. In project two, the interpreters and bicultural workers at the community organisation fulfilled this role.

In keeping with the need for reflexivity and consistency, the second author conducted all the focus groups and interviews in project one. A separate researcher took responsibility for conducting the focus groups in project two. In this way consistency was assured, positive relationships were maintained with the participants and researchers could keep reflexive notes on how their own philosophies both influenced the project, and changed over time. The entire research team debriefed continuously during both research projects. This allowed us to ‘sustain mindful presence’ (19), reflecting on the moral aspects of the research, the expected and unexpected impacts on participants, and enhancing the power of the participants.

In project one, the lives of the refugee students changed often; including moves to different states of Australia and income fluctuations as parents moved into and out of employment. It was important to reaffirm participants’ understanding and consent throughout the research journey. Previous authors have reported difficulties in obtaining institutional ethical approval where changes in the relationship between researcher and participants requires repeated gaining of consent over time (20, 21). However, we were sensitive to life changes and were able to adjust timelines as needed. We also chose to modify the traditional consent technique. When we first met with participants, we only sought consent for the initial focus group. We did not seek consent for the 12 month follow-up visit in the initial consent form. It was only after the first focus group, when rapport and trust was established, that we asked for permission to visit again in 12 months’ time. Students who had been initially nervous to speak with us were far more amenable and readily agreed.

The two projects presented numerous ethical challenges that were not readily addressed using existing ethical frameworks. Innovative methods, some drawn from the literature, were required to ensure the rights of participants were ensured. The relevance of existing frameworks to researchers working with refugee participants needs further exploration.

### *The Challenge of Tangible Benefits and Reciprocity for Vulnerable Populations*

Literature documents that researchers have a history of considering participants purely as data sources, with no real attempts made at improving conditions for refugees once data is collected (22). Our projects are not conducted in the camp environment and our participants are living, studying and working in the Australian community. As such, some of the issues pertinent to working in the field are not applicable to our context. However, the marginalised nature of refugee lives in Australia renders them vulnerable to exploitation by researchers, and to them viewing the research process with the lens of potential assistance-seeking, contrary to that of the researcher (16, 22).

The principle of beneficence states we should maximise benefits to participants who are part of the research. Following the principles of *ethics in process* (17) we arranged for the students to visit the university campus for a day of engaging activities and tours to expose them to university life, to university students and university courses. This was seen as a reward, and also an educational experience.

Once data collection commenced and the participants built trust, another issue emerged concerning beneficence. During the focus groups refugee students asked for assistance that went beyond the scope of the project. They asked for assistance with their studies, their

assessments, and finding employment. The ethical guidelines available to us were unclear on where our responsibilities lay in this regard. We were faced with a dilemma of wanting to assist but limited in what we could realistically do. We were concerned that student participation in the research was influenced by perceived external benefit.

Molyneux, Peshu and Marsh (23) describe this as *Strategic Trust* – when someone makes themselves available on the basis of an expectation that in the future the entrusted partner will provide assistance in return. Hugman et al (22) also refer to this vulnerability and desperation, which leads to participants having misunderstandings about their perceived continued involvement in a project even after the researcher has left the field. Our response in project one was to gently place limits on our involvement in the lives of the high school students. We were unable to offer much assistance and this remained an ethical challenge.

For our university student participants we did provide academic mentoring initially, which was undertaken by the second author. When this became unsustainable, an external mentor who was a retired academic volunteered to support the refugee students and did so with a small group of refugee university students. This in turn has led to the possibility of a formalised refugee mentoring programme at the university in 2020. Most of the participants at undergraduate level did not take up the offer of academic mentoring, due to time and work constraints or not wanting to be identified as different to locally born students (24). The tangible benefits to participants remain elusive.

Interestingly, in project two we experienced the reciprocal effect, whereby a minority of women were inconsistent in attending the focus groups once they had received their cameras. To encourage participation for the entirety of the project we issued gift vouchers to participants

contingent on participation in a minimum number of focus group sessions. In this way the focus shifted from consent to compensation. Whilst the vouchers were of tangible benefit to the women, they also served to keep participants in the study for longer than the participants truly intended (16). The low socio-economic status of the participants meant the benefits of the shopping voucher outweighed any reluctance to continue participating, and the majority of women continued to the completion of the project. Despite these concerns, the women reported gains in social connectedness, a sense of belonging, and pride in their newly acquired photographic skills (25).

The ability of researchers to provide tangible benefit appears to be limited to this group of participants whose needs are complex. It is perhaps in the area of advocacy that researchers are most able to make a difference to participants' lives. However, policy change takes time and we continue to lobby, advocate and make submissions along with the refugee council, Public Health Association of Australia, refugee advocacy groups and community organisations to not leave refugees and asylum seekers behind and ensure their rights are not denied. We have also provided opportunities for former refugees to share their stories at different events. Changing political will is an ongoing and long process.

### *The Challenge of Accurate Representation – Imagery and our Photovoice Project*

When sharing the stories and voices of refugees, we as researchers have a responsibility to ensure that our own biases and perceptions are distanced and that the narratives and experiences of participants are accurately presented (14, 22). Researchers must ensure they are not influenced by the dominant representation of refugees in the media and political discourse which is that of vulnerability, helplessness and opportunism (24). These images disregard

human agency, resilience and voice and the need to rebuild lives of safety in environments that are politically peaceful.

Furthermore, whilst it is desirable to use images that accurately portray participant experiences, it is also essential to ensure the safety of participants, particularly those who do not want to be identified due to further risk of persecution (22). To address this, at the commencement of the project, a significant amount of time was invested in teaching our participants the basics of photography and explaining the ethical considerations involved in taking photographs of others, especially of children. We ensured that the rights to confidentiality of those photographed, as well as of the photographers were protected and safeguarded.

In project two women shared their photographic images themselves in focus groups. Interpreters were used to help explain the women's perspectives during the focus group discussion. Our community partner assisted in recruiting interpreters who frequently worked at the organisation so our women participants were familiar with them. In this way we tried to ensure accuracy in how women's perspectives were conveyed, some of which were highly personal. (14) However, as none of the researchers spoke the languages of the participants, we could not be completely satisfied that the interpreters were accurately representing the women's perspectives. Unfortunately there is no clear resolution to this dilemma. It also raises questions of confidentiality, something we could not guarantee. Interpreters and participants were asked to sign confidentiality agreements, but anecdotally doubts remained in the minds of the women as to whether their stories would be repeated in the community.

On some occasions, interpreters were unavailable for specific languages rendering us dependent on Google Translate, an inferior and sometimes inaccurate approach. Where possible, we tried

to confirm participant interpretations at subsequent focus groups when interpreters were available.

Another issue encountered by us was the reluctance of the women to speak about their negative experiences in refugee camps or in transit. Where we felt it was necessary to hear those stories to add context to their stories, the women themselves did not freely reveal them. It is possible that we as researchers were using our own assumptions to guide the data collection to obtain what we thought was the true story. Where we made the initial assumption that their refusal to speak of their journey was due to a reluctance to revisit traumatic circumstances, it became clear that it was a symbol of the women's determination to look forward to their life in Australia with positivity and resilience.

Despite these challenges, by using interpreters the participants had direct input into how they wanted to be represented and in the telling of their own stories. After data collection, the women were also involved in a planning session to select photographs that were included in a travelling exhibition. Photographs that were not included in the travelling exhibition were published in a small booklet which was presented to the women upon completion of the project. The women also participated in a scrap booking session that was well attended and enjoyed by the participants and they each created a beautiful booklet for themselves that included the photos they selected. By choosing their own photographs, issues pertaining to unwanted identification of participants were avoided.

The challenges encountered in the area of accurate representation of participant stories occurred throughout all stages of the two projects. However, by including the participants in the choosing



of their own photographs for the travelling exhibition they did have the final say in the overall visual messaging of the project and in the quotes for each of the images.

### *The Challenge of Accountability to our Participants*

Research participants from refugee backgrounds are often asked to share very personal accounts of their displacement and resettlement experiences. It is a responsibility of researchers to guarantee findings and outcomes of the research are shared with participants. Continued engagement with participants beyond the data collection period is a necessary component of research work with refugees and other vulnerable groups (22). This may avoid the undesirable phenomena of refugee participants feeling as though their stories and contributions are used by researchers for academic benefits only (22). In both our projects, launch events were held to share the findings in ways appropriate to our participants. Participants were asked to speak at these events and share their experiences of the research and life in Australia.

The *first event* was held at Ishar Multicultural Women's Health Service - our community-based partner for project two. Our participants were originally recruited from Ishar and it was a safe venue that the refugee women can access, both in terms of transport and cultural acceptability. A meal was provided to enhance comraderie and community spirit. The travelling photographic exhibition was displayed and the major findings of the project were presented to the women. When interviewed about their participation, refugee women reported feeling empowered, socially connected and of having hope for their future.

The *second event* was held at the university and representatives from academia, community,

stakeholders and service providers, refugee communities and the education sector attended. This event not only shared findings, it promoted community discussion and sought solutions to the gaps identified in both projects.

Unfortunately we were not able to share our findings with our refugee students from project one in person. Whilst the report was sent to IEC Principals, teachers and stakeholders, we were not able to contact the students themselves. Most of them had left the school system and did not respond to requests to meet. As such, they remain unaware of how their stories were shared during the launch event and the community interest it generated.

Despite this, by sharing our findings directly with our participants from the photovoice project, and with the broader community, we honoured our participants' stories and sought tangible solutions. Some of the participants have agreed to participate in subsequent projects designed to address the gaps identified in the photovoice project in particular.

### *Discussion*

#### *Our reflections on addressing the ethical challenges*

Throughout the data collection and analysis, as a research team we grappled with the nuances and lenses of appropriate representation for our participant voices. We discussed these issues with our community partner who have worked with refugee women for nearly 30 years (26, 27). We attempted to resolve the ethical challenges as best as we could and were heartened that practical solutions were offered and used.

We found that sharing our concerns honestly had positive results. When we faced delays in ethics approval from the Department of Education, discussions with the ethics officer resulted

in some helpful advice. When women participants shared distress – a protocol for dealing with this was proposed by our community partners. The project officer from our partner organisation was always available and responsive to the shared concerns of researchers and participants.

We shared our findings and have addressed issues of equity, hope and social justice as the women and young students interwove and navigated these within the stories of their everyday lives. We also re-examined our own research position embedded in the constructs of privilege, and how that affected our interpretation of the realities of the lives of our refugee participants. We felt privileged to be allowed to listen to their stories and continue our relationship with the partners (28). Our reflective stance is thus aligned to the concept of continuous researcher reflexivity in our research with refugee participants as suggested by Block et al (17).

Our research used community based participatory research (CBPR) and involved our community partners' right from the stage of grant writing. We had ongoing discussions about the project with them. The ability of CBPR to empower communities, democratise knowledge and create social change is well-recognised and our research results have been used by the community organisation to improve their practice and apply for their own funding.(29, 30) CBPR emphasizes collaboration, and shared decision-making between researchers, community partners and participants during the research and at all times we involved the project officer from the community organisation and the IEC principals (31-33).

### *Recommendations, Implications, Advocacy and ongoing Collaborations*

Our research highlighted that current ethical frameworks do not provide sufficient guidance on the role of the researcher in supporting refugee participants after the research; we recommend guidelines on this vital aspect will assist both the researcher and participants in addressing these

ethical challenges of reciprocity. We propose that institutional ethical requirements also need to be adapted to reduce linguistic and cultural barriers to participation in refugee research by refugee participants.

It is also important that ongoing advocacy and lobbying on behalf of our participants be undertaken by researchers as it is a hallmark of ethical research, as outlined by Block et al (17) and Hugman et al (22). Despite having resettled in Australia, and received the social and economic supports that accompany permanent resettlement, it is well known that refugee groups in Australia continue to experience racism, low socio-economic status and poor employment prospects (34, 35). We undertook a number of advocacy activities to improve the policy and systemic responses to the needs of refugees resettled in Australia.

The Photovoice exhibition has been displayed in libraries across Perth, and at international conferences in Greece, USA and Canada. The exhibition recommends strengths-based approaches to be implemented in policy to support refugee women.

In July 2018, our research results from the 'photovoice' project were quoted in the Labor Party's dissenting report to the Federal government's proposed changes to citizenship legislation following an advocacy letter by the researcher. In 2018, the first author assisted the Public Health Association of Australia in its submission to the National Women's Health Strategy for 2020-2030. Our project undertaken in IECs examined pathways taken by refugee students to enter higher education. The multiple outputs from the project are shared nationally through several open access websites:

<https://www.refugeetransitions.com/>; <https://www.refugeecouncil.org.au/education/sig/>

A further two projects that arose from participant recommendations arising from the

‘Photovoice project’ were submitted for funding, one has been funded – a project delivering a peer mentoring program for refugee and migrant women. Details of the project are available on the website that has been developed: <http://empower-project.com.au/> and another project is under consideration. Some of the women involved in the original ‘Photovoice project’ will participate in the subsequent participatory intervention, this highlights an ongoing commitment to support our participants and design projects based on participant needs. From the launch event and subsequent funding, a proposal for a university student mentoring programme is being developed and preliminary discussions have been undertaken with schools in the Faculty of Health Sciences.

One of the most challenging aspects of advocating on behalf of community organisations that support refugees is the lack of consistent on-going funding to run sustainable support programs. Garnering political will to fund evidence-based support programs requires consistent advocacy and relationship building across the political divide. Our research is aligned to the first two enduring strategies of the recent 2019 Western Australian Sustainable Health Review, where there is collaboration to address public health issues; a need to reduce disparities in health outcomes for Culturally and Linguistically Diverse Communities and to improve mental health outcomes, but the difficulties with advocacy continue. We continue to support and advocate with government bodies for funding, write grants with community partners as collaborators and undertake ongoing advocacy.

### *Conclusion*

Current ethical frameworks and guidelines available to researchers do not provide adequate guidance for research with refugee participants. Some of the institutional requirements regarding the format and content of information sheets and consent forms, whilst designed to

minimise harm, actually create additional confusion and potentially lessen participants' ability to share their experiences. By involving refugees as co-participants we were able to document that while there are social, cultural and systemic barriers needing attention, refugees had strengths, were resilient, and this needs to be harnessed in policy and programs.

This includes continued involvement in programs following completion of the project. In this way the principles of accountability, respect, beneficence and justice are applied in ways more appropriate and meaningful to refugee participants (22). It may also help to address the challenge of providing tangible benefits to participants and enhancing reciprocity. It may reduce the risk of participants being simply a source of data for researchers. As recipients of the stories of refugee participants, we are ethically bound to work to foster positive gains in these areas. Participatory action research helps to overcome power imbalances during the research process, but continued action after the researcher leaves the field is important. It is hoped that research we undertook enabled the conduct of meaningful, practical, impactful and ethical research.

### *References*

1. Blythe R, Clarke J, Connell T, Wallace J, Woods C. 'States of Refuge': Access to Health, Housing and Education for People Seeking Asylum and Refugees in Australia 2018.
2. UNHCR. States Parties to the 1951 Convention relating to the Status of Refugees and the 1967 Protocol. 1951.
3. UNHCR. Resettlement [Internet]. 2019 Available from <https://www.unhcr.org/resettlement.html>.

4. Department of Home Affairs. 2018-19 Humanitarian Program Outcomes [Internet]. 2019 Available from <https://www.homeaffairs.gov.au/research-and-stats/files/australia-offshore-humanitarian-program-2018-19-glance.pdf>.
5. Department of Home Affairs. Australia's offshore Humanitarian Program: 2018–19 [Internet]. 2019 Available from <https://www.homeaffairs.gov.au/research-and-stats/files/australia-offshore-humanitarian-program-2018-19.pdf>.
6. Hedrick K, Armstrong G, Coffey G, Borschmann R. Self-harm in the Australian asylum seeker population: A national records-based study. *SSM - Population Health*. 2019;8.10.1016/j.ssmph.2019.100452
7. Essex R. Healthcare and clinical ethics in Australian offshore immigration detention. *The International Journal of Human Rights*. 2016;20(7):1039-53.10.1080/13642987.2016.1192538
8. von Werthern M, Robjant K, Chui Z, Schon R, Ottisova L, Mason C, et al. The impact of immigration detention on mental health: A systematic review. *BMC Psychiatry*. 2018;18(382).10.1186/s12888-018-1945-y
9. Dehm S. The evidence is clear: the medevac law saves lives. But even this isn't enough to alleviate refugee suffering [Internet]. *The Conversation*; 2019 Available from <https://theconversation.com/the-evidence-is-clear-the-medevac-law-saves-lives-but-even-this-isnt-enough-to-alleviate-refugee-suffering-125308>.
10. World Medical Association. WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects [Internet]. 2018 Available from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
11. Polit DF, Beck CT. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. 9th ed. Philadelphia: Wolters Kluwer; 2018.
12. National Health and Medical Research Council. National Statement on Ethical Conduct in Human Research [Internet]. 2007 Available from <https://nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018#block-views-block-file-attachments-content-block-1>.
13. Gabriel PS. *Practical and ethical issues in conducting health research with refugees*: Simon Fraser University; 2013.
14. Pittaway E, Bartolomei L, Hugman R. 'Stop stealing our stories': The ethics of research with vulnerable groups. *Journal of Human Rights Practice*. 2010;2(2):229-51
15. Richardson-Tench M, Nicholson P, Taylor B, Kermode S, Roberts K. *Research in Nursing, Midwifery and Allied Health: Evidence for Best Practice*. 6 ed: Cengage Learning Australia; 2018.
16. Hugman R, Bartolomei L, Pittaway E. Human agency and the meaning of informed consent: Reflections on research with refugees. *Journal of Refugee Studies*. 2011;24(4):655-71
17. Block K, Warr D, Gibbs L, Riggs E. Addressing ethical and methodological challenges in research with refugee-background young people: Reflections from the field. *Journal of Refugee Studies*. 2013;26(1):69-87. <https://doi.org/10.1093/jrs/fes002>
18. Yohani S. Educational cultural brokers and the school adaptation of refugee children and families: Challenges and opportunities. *Journal of International Migration and Integration* 2013;14(1):61-79.<https://doi.org/10.1007/s12134-011-0229-x>
19. Woodgate RL, Tennent P, Zurba M. Navigating ethical challenges in qualitative research with children and youth through sustaining mindful presence. *International Journal of Qualitative Methods* 2017;16:1-11.<https://doi.org/10.1177/1609406917696743>
20. Redwood S, Todres L. Exploring the ethical imagination: Conversation as practice versus committee as gatekeeper. *qualitative Social Research*. 2006;7(2)
21. Dominelli L, Holloway M. Ethics and governance in social work research in the UK. *British Journal of Social Work*. 2008;38(8):1009-24
22. Hugman R, Pittaway E, Bartolomei L. When 'do no harm' is not enough: The ethics of research with refugees and other vulnerable groups. *British Journal of Social Work*. 2011;41:1271-87.10.1093/bjsw/bcr013

23. Molyneux CS, Peshu N, Marsh K. Trust and informed consent: insights from community members on the Kenyan coast. *Social science & medicine*. 2005;61:1463-73.<https://doi.org/10.1016/j.socscimed.2004.11.073>
24. Fagan S, Baker S, Irwin E, Dantas J, Gower S, Singh S, et al. (Re)Claiming social capital: Improving language and cultural pathways for Students from Refugee Backgrounds into Australian higher education. Newcastle University. Refereed report prepared for the Office for Learning and Teaching, Department of Learning and Teaching. ISBN 978-1-76051-464-8.; 2018.
25. Dantas JA, Lumbus A, Gower S. Empowerment and Health Promotion of Refugee Women: the Photovoice Project <https://espace.curtin.edu.au/handle/20.500.11937/75503>; 2018.
26. Sangtin Writers, Nagar R. *Playing with fire: Feminist thought and activism through seven lives in India*. Minneapolis, MN: University of Minnesota Press.; 2006.
27. Hinton R, Earnest J. Stressors, Coping and Social Support among Women in Papua New Guinea. *Qualitative Health Research*. 2010;20(2):224-38
28. Tomaselli K, Dyll L, Francis M. "Self" and "other:" Autoreflexive and indigenous ethnography. Denzin N, Lincoln Y, editors. Thousand Oaks, CA: Sage.; 2008.
29. Masuda JR, Creighton G, Nixon S, Frankish J. Building capacity for community-based participatory research for health disparities in Canada: The Case of "Partnerships in Community Health Research". *Health Promotion Practice*. 2011;12(1):280-92
30. Themba MN, Minkler M. Influencing policy through community based participatory research. In: MMN W, editor. *Community-based participatory research for health*. San Francisco: Jossey-Bass; 2003. p. 349-70.
31. Hacker K, Taylor JG. Community-engaged research and the institutional review board: Principles, challenges, and opportunities. [Internet]. The Harvard Clinical and Transitional Science Center; 2011 Available from [https://catalyst.harvard.edu/pdf/regulatory/CEnR\\_Webpage\\_101\\_Presentation.pdf](https://catalyst.harvard.edu/pdf/regulatory/CEnR_Webpage_101_Presentation.pdf).
32. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*. 1998;19:173-202.[10.1146/annurev.publhealth.19.1.173](https://doi.org/10.1146/annurev.publhealth.19.1.173)
33. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*. 2010;100(1):S40-S6
34. Earnest J, Mansi R, Bayati S, Earnest JA, Thompson SC. Resettlement experiences and resilience in refugee youth in Perth, Western Australia. *BMC Research Notes*. 2015;8(236):1-10.[10.1186/s13104-015-1208-7](https://doi.org/10.1186/s13104-015-1208-7)
35. Ramsay G, Baker S. Higher education and students from refugee backgrounds: A meta-scoping study. *Refugee Survey Quarterly*. 2019;38:55–82.[10.1093/rsq/hdy018](https://doi.org/10.1093/rsq/hdy018)