



# **Translational Health Research Institute (THRI)**

## **Summer Scholarship Research Program 2020**

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## **Project 111: A place to call home**

**Supervisor(s):** Elizabeth Conroy - [e.conroy@westernsydney.edu.au](mailto:e.conroy@westernsydney.edu.au)  
Principal Supervisor

### **Project description**

Jesuit Refugee Service (JRS) are undertaking participatory action research with people seeking asylum in Western Sydney on their experiences of housing and home/lessness. This research will test some of the housing options scoped in the Foundations Housing Study conducted in partnership with Life Without Barriers and the Asylum Seeker Centre with contributions from House of Welcome, Australian Red cross and St Vincent de Paul Society.

The purpose of the research is to understand the housing experiences and realities of people seeking asylum, as well as structural barriers, in order to develop innovative responses to address needs, at the individual (knowledge & capacity building), organisational (casework), sectoral (asylum seeker and homelessness) and societal levels. The research will prioritise investigations of women's experiences, experiences of families, and people who are at the end of their asylum seeking journey (post-review).

The project will involve telephone or in-person interviews with asylum seekers and online focus groups with sector stakeholders. It is anticipated that the project will include a participatory component, in which JRS will collaborate with participants to present, disseminate and discuss the results of the research. The project will also outline feasible and strategic advocacy tasks to local, state and federal governments and develop a draft advocacy action plan.

### **Project Aims**

1. To explore experiences of housing and home(lessness) among people seeking asylum in Western Sydney, with a focus on women, families, and people at the post-review stage
2. To co-create a housing resource for people seeking asylum in Western Sydney
3. To develop an advocacy action plan on housing for asylum seekers

### **Project Methods**

The project will adopt a participatory action framework and be conducted in 2 stages.

#### *Stage 1:*

- Semi-structured Interviews with people seeking asylum in Western Sydney will be conducted either in-person or by telephone to explore experiences of housing and home(lessness). This will include challenges and facilitators in accessing housing, current housing arrangements and experiences of homelessness while seeking asylum in Australia, and meanings associated with having a home/house in Australia. Interviews will be conducted in the preferred language of participants (Tamil, Hindi, Malayalam, Malay, Farsi). Participants will be recruited via existing networks and facilitated by the project Advisory Committee. Recruitment efforts will focus on women, families, and people in the post-review stage of the asylum process. Interviews will be recorded with the consent of participants and transcribed verbatim and translated to English and de-identified in preparation for data analysis.
- Focus groups will be conducted with professional stakeholders across the refugee/asylum seeker and housing/homelessness sectors to explore facilitators and challenges in supporting asylum seekers to access appropriate housing and experiences of homelessness and insecure housing among the asylum seeker population in Western

Sydney. Stakeholders will be identified via existing networks and facilitated by the project Advisory Committee. Focus groups will be conducted either in-person or by video-conference and will be recorded with participants' consent. The recordings will be transcribed verbatim and de-identified in preparation for data analysis.

#### *Stage 2:*

- Interview and focus group transcripts will be analysed using thematic analysis and a summary of findings will be drafted for presentation to a sub-group of participants from Stage 1
- Feedback sessions and/or co-design workshops will be held with participants to discuss and interpret the findings and identify advocacy and dissemination strategies. The number and format of these sessions/workshops will be guided by the participants themselves and the Project Advisory Group.
- Development of resource for people seeking asylum and draft advocacy action plan for the refugee/asylum seeker and housing/homelessness sectors.

The student could potentially be involved in both stages of the research project. The student will need to have intermediate competence in one of the community languages to conduct the semi-structured interviews or assist with transcription. The student will also be required to participate in all team meetings and attend any scheduled Advisory Group meetings during their scholarship.

### **Opportunity for Skill Development**

The student may have the following experiences and opportunities for skill development:

- Observation of project Advisory Group processes in managing a research project
- Skills in conducting semi-structured interviews and focus groups; this will include skills in obtaining informed consent through a continual consent process and management of potential distress.
- Transcription and analysis of interview and focus group material including the use of qualitative data management software such as NVivo
- Conducting searches of the peer-reviewed and grey literature in preparation for the feedback sessions/co-design workshops and to provide background material to support Advisory Group decisions

### **Students are required to have the following skills/meet the following pre-requisite(s) to apply**

#### *Essential requirements:*

- An interest in understanding the issues faced by people seeking asylum and refugees living in Australia, particularly in relation to health, housing and home/lessness;
- Capacity to work with vulnerable populations, including through building knowledge, communication and building relationships;
- Police Check and Working with Children Check.

#### *Desirable requirements:*

- Intermediate competence in one or more of the following community languages: Tamil, Hindi, Malayalam, Malay, Farsi.

## **Project 112: Can knowledge translation promote maternal, newborn and women's health? A systematic review**

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### **Project description**

In Australia and abroad, maternal, newborn, and women's health is far from ideal<sup>1</sup>. Many women and their newborns experience clinical issues that can have short- and long-term consequences. For women, these issues include (but are not limited to): gestational diabetes; pre-eclampsia; complications following the use of birthing interventions; postpartum haemorrhage; and premature death<sup>2-5</sup>. For newborns, they include (but are not limited to): low-birth weight; infection; birth asphyxia; as well as premature death<sup>6-8</sup>. Despite (emerging) evidence on what works, for who, and when, and relatedly, recent improvements<sup>9-11</sup>, there is considerable opportunity to optimise maternal, newborn, and women's health(care). This is because, as Prolman<sup>12</sup> helpfully summarised:

almost 800 women die because of complications during pregnancy and childbirth... MOST of the maternal deaths that happen CAN be prevented... Many women don't see a skilled health professional enough during pregnancy... [and] The lack of skilled care is the main obstacle to better health for mothers... My biggest takeaway is that all of this suffering is completely unnecessary. And the good news is, this CAN be prevented.

In addition to the personal implications for women and their newborns, poor maternal, newborn, and women's health(care) can have social and economic implications. Consider for instance, the effects on family members – including children and young people: who are required assume greater caring responsibilities; who prematurely end their education to enter the workforce or labour market; or who experience mental health issues associated with trauma and loss<sup>13-16</sup>. Beyond the family budget, economic implications include the increased use of limited public health resources, as well as the government welfare destitute family members might require.

Knowledge translation represents an avenue to address the oft-cited chasm between what should happen and what does happen<sup>17</sup>. Although variously defined, knowledge translation encompasses myriad processes through which different knowledge's coalesce to inform practice. As such, it is more than the mere use of empirical results or clinical guidelines – it involves the amalgam of these with other knowledge's, including (but are not limited to): the experiential wisdom and preferences of a patient and their family members; cultural norms; clinician expertise; the managerial and leadership prowess of their superiors; as well as the knowledge embedded within local networks – be they clinical or familial<sup>18,19</sup>. Despite considerable interest in knowledge translation<sup>20-26</sup>, with few exceptions<sup>27-30</sup>, there is a dearth of research to clarify how it can promote maternal, newborn, and women's health. This project will address this void.

Heeding national and international calls for action<sup>31-34</sup>, the aim of the supervisory team's research program is to promote quality maternal, newborn, and women's healthcare. This aspiration will be addressed via a systematic review of extant literature to clarify:

- How knowledge translation is characterised in maternal, newborn, and women's healthcare
- How knowledge translation has been explored in this context
- Research questions that warrant (further) attention
- The associated implications for policymakers, managers, practitioners (*sensu lato*), and recipients of health services – be they patients or carers

Furthermore, and perhaps more importantly, this project aligns with the Western Sydney University [Research and Innovation Plan \(2018 - 2020\)](#). Specifically, and as per the research plan of the Translational Health Research Institute:

- Following a systematic review of academic databases, this project will culminate with evidence that serves to:
  - 'Develop a cogent research narrative and community profile to define our role in the health and wellbeing industry and to ensure our reputation matches our research quality'
  - Inform ways to helpfully 'transform the health and wellbeing of the people of Western Sydney, Australia and globally through translational research that is holistic, collaborative and targeted'
  - Champion 'person-centered care, evidence-based practice and systemic change'
- Premised on 'collaboration, translation and reputation', this project will:
  - 'Build on and formalise current collaborations... to ensure health challenges are understood, research is relevant and new knowledge is applied where it is needed'
  - Determine opportunities to pursue to optimise knowledge translation
  - Further the standing of this reputable Institute given the international significance of the project focus

### **Project Aims**

The aim of this project is to promote quality maternal, newborn, and women's healthcare. This will be achieved by addressing the following objectives:

1. Develop and pilot-test search strategies to systematically scour relevant academic databases for publications pertaining to knowledge translation in maternal, newborn, and women's healthcare
2. Identify publications that meet inclusion criteria
3. Extract and analyse pertinent content from the identified publications to clarify:
  - a. How knowledge translation is characterised in maternal, newborn, and women's healthcare
  - b. How knowledge translation has been explored in this context
  - c. Research questions that warrant (further) attention
  - d. The associated implications for policymakers, managers, practitioners (*sensu lato*), and recipients of health services - be they patients or carers
4. Report on the findings for the purpose of a manuscript for a refereed academic journal

## **Project Methods**

The supervisory team, including the student, will:

- Develop, pilot-test, and deploy search strategies tailored for relevant academic databases
- Determine the inclusion criteria
- Develop an extraction tool to aid the analysis of pertinent content from the identified publications

The student will:

- Cull the identified publications
- Extract pertinent content from the identified publications
- Contribute to a manuscript for a refereed academic journal

## **Opportunity for Skill Development**

- Superior analytical skills to conduct a systematic review
- Improved writing skills to report on research findings for an academic audience

## **Students are required to have the following skills/meet the following pre-requisite(s) to apply**

- Is in their final-year of an undergraduate degree
- Is studying, has studied, or has an interest in the discipline(s) of: management, nursing, allied healthcare, medicine, health and/or social policy, social science, psychology, sociology, the humanities, and/or health science
- Has excellent communication skills and confidence in their basic writing skills

## **Project 113:      LGBTQI and experiences of cancer survivorship and care**

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Second Supervisor

### **Project description**

Sexual and gender minorities, including those who are lesbian, gay, bisexual, transgender, and intersex (LGBTI), represent an “ignored epidemic” and a “growing and medically underserved population” in cancer care. Findings suggest LGBTI communities experience a disproportionate cancer burden, and face unique psychosocial challenges, such as higher rates of cancer related distress and sexual concerns, lower levels of family support, difficulties in accessing general health care or cancer services, gaps in patient-provider communication and lower satisfaction with cancer care. Recently, the American Society of Clinical Oncology recognised this health disparity and concluded there is “insufficient knowledge about the health care needs, outcomes, lived experiences and effective interventions to improve outcomes” for LGBTI populations. As a result, health care providers and policy makers are ill-equipped to provide culturally-competent advice or assistance to LGBTI cancer survivors and their families, an often marginalised population who experience social equity concerns.

### **Project Aims**

This interdisciplinary ARC Linkage funded project will address this gap in research through investigating the following aims:

1. Identify and understand the complex intersection of gender, sexual identity, age, and other categories of difference, in relation to the cancer survivorship and care experiences of LGBTI individuals, using a mixed methods design including arts based methods.
2. Ascertain barriers and facilitators to the delivery of culturally competent cancer communication and care to LGBTI patients through an audit of guidelines and resources, and via the perspective of service providers.
3. Synthesise and implement these findings into tailored support materials for LGBTI survivors and carers, and Australian LGBTI cancer best practice and policy recommendations

*The summer scholarship student will work on the first aim, working on analysis of data collected through photovoice collected from LGBTQI+ cancer survivors. The data collection is currently underway, and the student can be part of the team coding, analysing and writing up the data.*

### **Project Methods**

**Participants and procedure:** Cancer survivors and carers who are LGBTI identified, gender diverse, or same sex attracted will be invited to opt-in and consent to participate in a survey. We have 407 completed surveys to date.

**Semi-structured interviews:** Interviewee samples will be selected from survey participant volunteers. The interviews will examine subjective experience of survivorship and care, including those aspects outlined above. Interviews will be telephone or face to face, depending on participant preference and location. This facilitates a national sample, found to be effective in our previous research. We have conducted 130 interviews to date.

**Photovoice:** After the interview, participants will be invited to photograph aspects of their life that are relevant to their experience of cancer survivorship. Photovoice is an arts based methodology that enable participants to become active agents in the research process, empowering and encouraging them to collect their own data through photographing lived experience. Arts based methodologies have arisen from interest in new forms of knowledge translation to uncover meanings and questions at individual and societal levels. Such methods enhance health literacy, decrease stigma, and change practice and behaviour when used in research creation and dissemination. Theoretical thematic analysis will be used to analyse the interview and photovoice data. Thematic analysis is ideal for this project as it can be utilised across a variety of data types including visual and textual data. Visual analysis: We draw on Rose's critical visual methodology framework, which focuses specifically on the images themselves, examining meaning-making sites:

- Production of the image,
- the image itself, and
- the site(s) where various audiences view it.

These overlap with three modalities: the technological, compositional, and social. Rose's method compliments the aforementioned thematic analysis as both approaches are underpinned by self-reflexive, context-driven, thematically focused analyses.

The student will work on the collected photo voice data analysis as part of the team, focusing on one specific group of participants (ie adolescents and young adults, transgender people, intersex people).

### **Opportunity for Skill Development**

- Working as part of a research team
- Knowledge and experience of working on research where social equity and belonging is a key component
- Experience in working with a marginalised population – LGBTQI+ cancer survivors
- Opportunity to understand issues of gender and sexuality diversity, and how these issues influence health and wellbeing
- Opportunity to understand how and why arts based methods are used in research
- Experience in doing photovoice analysis and working collaboratively in writing it up

### **Students are required to have the following skills/meet the following pre-requisite(s) to apply**

- Interest in working in the area of gender and sexuality diversity
- Interest in arts based methods