

**Effective consultation: a strategy to
enhance Queensland Health's Patient
Experience data collection from people
of a refugee background**

Findings arising from the Patient
Experience Project (2020)

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Executive Summary

This report outlines the peer research model undertaken by QUT in partnership with Mater Centre for Integrated Care and Innovation (CICI) and reflects on the benefits and difficulties of employing peer researchers from refugee backgrounds to gather information about patient experiences of the health system. The peer research component of this evaluation was part of a broader evaluation of the *Refugee Health and Wellbeing policy and Action Plan (2017-2020)*¹ and is intended to inform the development of the new *Refugee Health and Wellbeing Policy and Action Plan for 2020* by Queensland Health and partners.

This report does not detail the findings from this broader evaluation. The baseline evaluation report can be found [online](#)². This report aims to reflect on the process of employing peer researchers to engage vulnerable communities to gather meaningful patient feedback about the health system. The report also formulates some recommendations for mechanisms for seeking consumer feedback from refugee background communities in the future and ways to plan a sustainable strategy for engagement.

This report acknowledges the limitations of community engagement in collaborative public health research and lists some considerations when working towards including people from refugee backgrounds in meaningful patient satisfaction evaluation processes.

¹ https://www.health.qld.gov.au/_data/assets/pdf_file/0031/646078/refugee-policy.pdf

² <http://www.refugeehealthnetworkqld.org.au/wp-content/uploads/2016/11/Evaluation-QLD-Refugee-Health-Policy-and-Action-Plan-Report-BASELINE-FINAL-MAY-2019.pdf>

Background

There is an increasing recognition of the potential role of consumers in developing appropriate and effective health care systems. World Health Organization conventions such as the *Alma-Ata Declaration* (1978), the *Ottawa Charter* (1986) and the *Jakarta Declaration* (1997) identify the principle of consumer participation in the planning and implementation of health care as critical to the development of systems which promote the health and wellbeing of communities³. In Queensland, Health Consumers Queensland has developed the *Consumer and Community Engagement Framework* (2017)⁴. The Framework provides health organisations with an understanding of what engagement is, when and where it can take place and why they are doing it.

However, despite these guiding documents, the practical application of consulting with and gaining patient feedback about patient experience within the health system from hard to reach patient groups such as those from refugee backgrounds, is sometimes viewed as too resource intensive or complicated. The complexity of language and cultural barriers are typically the reasons cited. As a result, people from refugee backgrounds and in particular those that don't speak English well are generally under-represented in patient evaluation activities.

In a literature review produced by the National Resource Centre for Consumer Participation in Health (2000)⁵ it was found that:

In Australia, a great deal of innovative work is being done to increase consumer participation in the health system. However, policy makers, service providers and consumer organisations often find it difficult to ensure the diversity of consumers and community members is reflected in participation initiatives.

Consumer centred care is integral to health departments and the *National Safety and Quality Health Service (NSQHS)*⁶ *Partnering with Consumers Standard* aims to create health service organisations in which consumers are partners in planning, design, delivery, measurement and evaluation of systems and services. The standards encourage the consideration of diversity when selecting methods of consumer participation.

Queensland Health has acknowledged that consumer and community engagement is the most effective way for health services to understand how to best meet the healthcare needs of their community. Barriers to consumers from culturally diverse background giving feedback include:

- Structural barriers; many mainstream organisations have developed neither the capacity to provide appropriate and accessible health care services to the diverse groups within their communities, nor systematic and appropriate strategies for seeking input from consumers from diverse groups.
- Barriers that relate to consumer sensibility. They may
 - Not want to give negative feedback;
 - May experience, or fear, discrimination as a consequence of providing feedback;
 - Be sceptical about the capacity of service providers to hear the feedback;

³ Feedback, Participation and Consumer Diversity: A Literature Review produced by the National Resource Centre for Consumer Participation in Health (2000) <https://apo.org.au/organisation/83307>

⁴ Health Consumers Queensland, *Consumer and Community Engagement Framework* (2017) <http://www.hcq.org.au/our-work/framework/>

⁵ <https://apo.org.au/organisation/83307>

⁶ The National Safety and Quality Health Service (NSQHS) Standards <https://www.safetyandquality.gov.au/standards/nsqhs-standards>

- Find the measurement scales typically used in evaluation surveys meaningless or incomprehensible.

The Queensland Government has demonstrated its support to improving the health and wellbeing of people from refugee backgrounds living in Queensland through the development and endorsement of the *Refugee Health and Wellbeing: A Policy and Action Plan for Queensland 2017-2020*⁷. By 2020, the impact of the Policy needed to be evaluated in order to inform future policy and practice. Queensland Health noted the imperative that such evaluation be informed by the lived experience of patients, their families and their communities. Mater CICI was engaged to obtain feedback on patient experiences from refugee background individual and families. This requires innovative and community focused strategies acknowledging that mainstream strategies such as patient satisfaction surveys did not capture the experience of this group.

The Queensland Context of Refugee Health

In April 2017, the Hon Cameron Dick, then Minister for Health and Ambulance Services, launched the *Refugee Health and Wellbeing: a policy and action plan for Queensland 2017 – 2020*, which articulates a shared vision and common purpose for refugee health in Queensland and promotes a state-wide approach to improving the health and wellbeing of refugees.

In early 2018, the Mater UQ Centre for Integrated Care and Innovation (CICI) received funding from Queensland Health to conduct a comprehensive evaluation of the effectiveness and impact of the Policy and Action Plan in improving the health and wellbeing of people from refugee backgrounds settling in Queensland. Funding included a peer research component to enable the voices and experience of patients from refugee backgrounds with the health system to be included.

The Mater UQ Centre for Integrated Care and Innovation worked in partnership with Associate Professor Ignacio Correa-Velez, from the School of Public Health and Social Work, Queensland University of Technology, to undertake this Evaluation.

The evaluation was a step towards involving consumers in developing new and innovative models for service provision. The results of the findings from the data will impact on the development of a new Refugee Health and Wellbeing Policy and Action Plan which will impact on service delivery across Queensland.

The Evaluation

Evaluation Methods

A mixed-methods evaluation was used including a pre-post design (baseline – 2018; end of evaluation – 2020). This evaluation involved the collection of data through:

1. Quantitative survey with recently arrived refugee background participants (Patient Experience Survey);
2. Semi-structured qualitative interviews with refugee background families (Patient Experience Qualitative Interview);
3. Survey with services and other stakeholders (Services and stakeholders experience survey); and

⁷ Refugee Health and Wellbeing Policy and Action Plan for Queensland 2017 – 2020
https://www.health.qld.gov.au/_data/assets/pdf_file/0031/646078/refugee-policy.pdf

4. Document audits.

The two components of the evaluation that focused on patients' experience (#1 and #2 above) were undertaken through the employment and training of peer researchers⁸.

Patient participants were adults from refugee backgrounds (18+ y/o) living in the greater Brisbane metropolitan area, Toowoomba, and Cairns.

The patient interviews and surveys were conducted by the Refugee Health Advisory Group based at Mater. This group, known as the G11, are trained peer researchers and are Brisbane based. They were joined by 2 regional peer researchers in Toowoomba and Cairns who were also trained in research methods and skills. The Patient Experience Survey was adapted from the annual ABS Patient Experience Survey⁹. The ABS survey collects data on access and barriers to a range of health care services. For the purpose of this evaluation, only general practitioners, medical specialists, dental professionals, hospital admissions, and emergency department visits were included.

The peer researchers using the *Patient Experience Survey* surveyed recently arrived people from refugee backgrounds to ascertain their experience of the health system in the previous 6 months. Potential survey participants were randomly selected from the Mater Integrated Refugee Health Service (MIRHS) database (Brisbane), and the regional settlement service in Toowoomba and Cairns, controlling for arrival date and language capacity present in the research team. The five most common language groups were included in each case. The peer researchers contacted potential participants to explain the intent of the survey, address concerns, obtain consent, and provide language and cultural support.

The G11 peer researchers plus the two regional peer researchers also conducted in-depth semi structured interviews (Patient Experience Qualitative Interview) with members of their 13 respective communities (their peers) about their experiences of accessing health services in Queensland. Consent was sought to interview these participants at the baseline point and to follow the same participants up in 18 months' time to track longitudinal impacts of the introduction of the policy in the health system.

Evaluation Participants

Patient Experience Survey

Random samples of patients from refugee backgrounds were identified through the Mater Integrated Refugee Health Service (MIRHS) database (Brisbane). In Brisbane, the Patient Experience Survey included participants from the five most common countries of origin. In regional areas (Toowoomba and Cairns), recently arrived refugee background participants were identified through local refugee settlement services.

In the baseline evaluation survey (Patient Experience Survey) 63 individuals from refugee backgrounds (62% males and 38% females) participated in the patient experience survey. They were born in Syria, Afghanistan, Iraq, Bhutan, Eritrea, DRC, Congo, Nepal, Iran and Pakistan.

Patient Experience Qualitative Interviews

Semi-structured face to face qualitative interviews were also conducted with 53 families about their experiences with the healthcare system in Australia. Respondents were born in a variety of

⁸ Ethics approval was obtained from the Mater Misericordiae Human Research Ethics Committee (HREC/17/MHS/143).

⁹ The ABS Patient Experience Survey <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4839.0>

countries including Afghanistan, Bhutan, Burma (Myanmar), Burundi, Eritrea, Iraq, Liberia, Rwanda, Somalia, South Sudan, and Syria.

Each trained refugee peer researcher recruited a sample of 4-5 people from refugee backgrounds through their own ethnic community networks. Where possible and to ensure a diverse range of perspectives regarding health care services use, peer researchers sought at least 50% of participants to be people who had arrived in Australia within the past 2 years. The remaining 50% may have lived in Australia for a longer period of time.

Evaluation Findings

The findings from the Final evaluation will form part of the stepping stones to the development of the new Policy and Action Plan.

The effectiveness of the Evaluation lies in the fact that Peer Researchers were engaged to interview refugee background consumers about their lived experience.

Thus the survey gives one dimension of relevant feedback:

- Only 64% were (always/often) offered an interpreter when visiting a GP;
- Only one respondent was offered an interpreter while seeking service from a pharmacy/chemist;

The qualitative interviews expanded on those issues as evidence by the following examples. :

- *The only issue is that my GP does not use interpreter.*
- *The first doctor that we used to see wasn't good at all. Whatever you ask the doctor he used to answer with "Google it".*
- *The Pharmacist never asks me whether I need interpret or if I understand the medications regime. I gave my script to the Pharmacist... she did not explain anything or even ask me to wait.*
- *I have a sick daughter who requires constant medication and to not speak English and not have an interpreter is very hard, even when I am going to the pharmacy to buy something like Panadol. I use my hands and face to express what I need and this is very difficult.*
- *When she asked me to sign the consent form to let her access my daughter's information I was hesitant and didn't want this to happen. She explained to me what the purpose of the form was, why she needed access to my daughter's information and how safe it is for her to do so.*
- *It was really overwhelming because we did not know what was expected of us in terms of what should we say to the healthcare professionals and what not to say.*
- *The only difficult was that my GP did not address prevention regime such referring to a dietician and health life style especially in Australia*

The richness of information to come from the Baseline Evaluation gave the consumer view of the priorities for health system reform in Queensland with a clear agenda about where to focus its quality improvement strategies. This includes the imperative for

- Promotion of interpreters and addressing the quality of language services accessed in the hospitals, primary care, dental services;
- Developing a strategy to promote engaging interpreters in pharmacies;
- Developing strategies to improve health literacy;

- Developing education for clinicians to build communication skills with patients from refugee backgrounds.

Models to obtain effective feedback for the health system from people of refugee backgrounds

The Patient Experience Project used the Peer Research Model to gain a vivid insight into the real experiences of people from refugee backgrounds as consumers of the health system. This section explores the utility of this model.

Peer Research

Research has shown that who asks the questions in interviews may impact on the quality of the information collected and having skilled interviewers from similar backgrounds to clients and undertaking interviews in people's own environments could improve the quality of the information collected.¹⁰ It has also been shown that utilising bilingual interviewers can assist in improving the quality and meaning of the information collected.¹¹

According to Vaughn *et al* (2018)¹² traditional forms of research models have limited success as they fail to engage the social, cultural and economic needs of the community. There is evidence that involving a community peer is an empowering experience that builds local capacity, trust and rapport with respective communities¹³. Jameson *et al* (1999)¹⁴ identified that descriptive information was received in the data collection process when peer consultants from the respective cultures were engaged.

In the current evaluation the quality of the information coming from the evaluation process was made possible because there is an existing group of people from refugee backgrounds who have the skills and capacity to undertake all aspects of the quantitative and qualitative research methods. Thus it was possible to not only quantify the scope of the issue; it was also possible to understand the implication of the findings such as how the issues affect patients directly. Participants were clear, that while sometimes the health consultation is less than perfect, patients themselves have very clear achievable strategic advice about service improvement.

The Peer Research model is an effective approach to build trust between the community of research participants and the research project itself. Conducting the interview in the consumer's own language ensures consent to engage and clarity of message as well as streamlining the logistics of conducting the interview. Trust and rapport are easily established. However, the model is not without its limitations. Peer researchers in this project reported the tendency for participants to

¹⁰ Bhatti-Sinclair K 1999, Evaluating social work and medical practice with black and ethnic minority groups using the clinical audit model, *British Journal of Social Work* 29, British Association of Social Workers, pp 303–320.

¹¹ Small R, Yelland J, Lumley J and Rice PL 1999, Cross-cultural research: trying to do it better. No 1. Issues in study design, *Australian and New Zealand Journal of Public Health*, vol 23, no 4

¹² Vaughn, M.L., Whetstone, C., Boards, A., Busch, D.M., Magnusson, M., & Maatta, S. (2018). Partnering with insiders: A review of peer models across community-engaged research, education and social care. *Health and Social Care in the Community*, 26 (6), 769-786. doi: 10.1111/hsc.12562

¹³ Guta, Flicker & Roche, 2013; Bartram, Abell & Murphy, 1999

¹⁴ Jameson, A., Sligo, F., & Comrie, M. (1999). Barriers to pacific women's use of cervical screening services. *Australia and New Zealand Journal of Public Health*, 20 (1), 89-92.

“overshare” and to have high expectations that the researcher would be able to effect systemic change promptly.

Other case study examples of best practice in the Queensland Hospital and Health System

The following examples are projects within the health system that demonstrate a commitment to hear stories from those patients who may have not had a voice in the past, by taking the time to really engage with community members and trial innovative ways of gathering patient feedback about the health system.

Metro South Hospital and Health Service, Logan-Beaudesert Health Service

The service is adapting their current model of patient feedback with an aim to overcome barriers faced by patients from CALD backgrounds and increase participation rates.

In 2019 Best Practice Australia (BPA) *Inpatient Surveys*¹⁵ were administered to patients, with a reduction of questions from 72 down to 34, based on feedback from Logan Consumer Partnership Committee, a diverse group of community members, staff and consumers. Ten volunteers were recruited and trained to administer the new survey. Interpreter Booking Reports for In-patients were sent weekly to the volunteers so that volunteers arrived at the appointments where interpreter had been booked. The volunteers were then able to offer patients the opportunity to participate in the survey with an interpreter present.

Metro South Hospital and Health Service, Logan-Beaudesert Health Service have also added an agreement in 2019 to fund interpreters for consumer engagement opportunities and this is outlined in the *Booking and Using Interpreters Procedure*¹⁶. This will ensure that patients who may have previously not been consulted due to limited English abilities can be included in future community consultation and patient feedback.

Logan Hospital Allied Health Team

In 2020, Logan Hospital Allied Health Team will interview 20 Non-English Speaking patients using interpreters to understand their patient journey. This project will be based on the report *Perceptions of the Patient Journey – A Qualitative Review of Patient Perspective* where 20 patients were interviewed about their patient journey into Logan Hospital from Emergency to Ward Admission. This project is not yet complete but aims to:

- Understand CALD Patient Journey
- Understand gaps in service provision
- Develop tools and resources for working with Interpreters for Consumer Engagement

Considerations for collecting patient feedback with patients from refugee backgrounds

The *Consumer and Community Engagement Framework (2017)*, developed by Health Consumers Queensland¹⁷ summarise what consumer and community engagement is not:

- **ONE-WAY** – the health service is only informing the community, not listening or learning from it and involving consumers in meaningful partnerships.
- **TOKENISTIC** – not about seeking agreement to pre-determined decisions.

¹⁵ Best Practice Australia (BPA) <https://bpanz.com/>

¹⁶ Metro South Hospital and Health Service Logan-Beaudesert Health Service 'Booking and using Interpreters'

¹⁷ <http://www.hca.org.au/our-work/framework/>

- **ONLY COMPLETED WITH PEOPLE WHO ARE EASY TO REACH** – health services must deliver services that are appropriate for their entire population. This cannot be done without engaging with the diversity of people in the organisation's community.
- **USING THE SAME FEW VOICES TO REPRESENT THE ENTIRE COMMUNITY** – Queensland communities are diverse and organisations must work to engage with people from a variety of backgrounds with varied opinions and ideas through activities throughout their region.
- **A SINGLE PROCESS** – organising an annual on-line survey to hear from the community or involving a consumer or two on a high level patient safety and quality governance, strategic projects or capital works committee is not enough. Engagement needs to occur in multiple ways and places at multiple times¹⁸.

Recommendations

Queensland Health acknowledges that consumer and community engagement is the most effective way for health services to understand how to best meet the healthcare needs of their community. It is also integral in ensuring quality and safety standards of health care are met for all consumers. The patient experience project demonstrates not only the importance of engagement but also the importance of developing engagement strategies specifically aimed to reach refugee background communities. To sustain engagement it is recommended that:

1. Queensland Health continue to support targeted sustained refugee community engagement strategies such as the G11¹⁹;
2. Queensland Health extends its commitment to training and up-skilling "natural health leaders" across Queensland. In so doing, Queensland Health leverages on the G11 for mentoring and support;
3. Queensland Health ensures the patient voice is heard in clinical education and training events. QH and PHNs could consider engaging up-skilled health leaders from relevant communities so that many clinical education events include a Refugee Health Advisor. This would enable clinicians to hear first-hand issues emerging from the communities and improves clinical practice;
4. Queensland Health commits to a role to champion community engagement with refugee background communities in partnership with existing successful engagement initiatives, refugee communities and the Queensland Refugee Health Network;
5. Queensland Health ensure future strategies to include consumers from refugee backgrounds are informed by the experience of this project and
 - a. Ensure surveys use open ended questions (not simple Yes/No responses)
 - b. Use multi-platform methodologies – e.g. phone, texts, consumer advisory groups
 - c. Ensure matching of consumer with interviewer language and cultural background
6. Queensland Health extends its commitment to cultural competency training for clinicians.

¹⁸ Consumer and Community Engagement Framework 2017 <http://www.hcq.org.au/our-work/framework/>

¹⁹ Peterson, P. Ali, S. Kenney, A. Wakefield, A. *Community engagement with refugee-background communities around health: the experience of the Group of 11*, Australian Journal of Primary Health 25(2) 113-117 <https://doi.org/10.1071/PY18139>

Conclusion

Patient feedback structures and processes in health system are often not appropriate to involving consumers from diverse backgrounds. In general patients are only involved when they are the focus of a specific project or strategy. The development of effective structures and processes to ensure the participation of a diversity of consumers is a considerable and ongoing challenge for Queensland Health.

Although this piece of evaluation work was undertaken as an individual project, it is hoped that the lessons learned about gathering quality information using a peer research model will assist Queensland Health to make patient feedback processes and consequent services more accessible and appropriate to patients from non-English speaking backgrounds by involving individuals who have been previously excluded and that this can then be translated across organisations and systems.

This also leads to the critical question of how to ensure that this feedback is utilised to create the kinds of health care systems that provide services that are appropriate, safe and sensitive to the diversity of the communities in which they are established to provide care.

The *Competency Standards Framework Culturally responsive clinical practice: Working with people from migrant and refugee backgrounds*²⁰ establishes recommended and optimal cultural responsiveness competency standards for clinicians in all healthcare settings. The standards recommend that cultural responsiveness be embedded in clinical education, training, professional development and practice standards. Culturally responsive clinical practice contributes to the equity of health access and outcomes for all Australians, and improves the quality and safety of health care. Integrating patient feedback mechanisms that collect vital information from diverse patient groups is an essential part of creating equity of health access and safe health care for all.

²⁰ Competency Standards Framework Culturally responsive clinical practice: Working with people from migrant and refugee backgrounds (2019) <https://www.culturaldiversityhealth.org.au/wp-content/uploads/2019/02/Culturally-responsive-clinical-practice-Working-with-people-from-migrant-and-refugee-backgrounds-Jan2019.pdf>