No one size fits all: working with communities of refugee and migrant backgrounds in clinical and population health research

Why Know our story?

Welcome to the Know our story initiative.

Our ambition is to inspire, encourage and support clinical and population health researchers to work towards greater social inclusion and equity in research practices. *Know our story* is about working in partnership with communities of refugee and migrant backgrounds. It is also about consultation, collaboration and co-design of research; the sharing of knowledge; and different ways of working that promote social equity and inclusion.

Learn more about *Know our story*, access resources, and watch the animation: **strongerfutures.org.au/know-our-story**

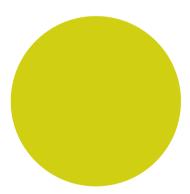


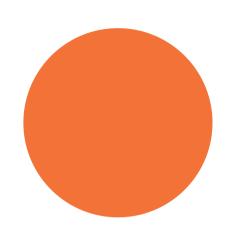
We acknowledge the traditional owners and custodians of the lands on which we live and work. We pay our deepest respects and express our gratitude to their Elders past, present and emerging. We recognise and value the resilience and diversity of Aboriginal and Torres Strait Islander people and their spiritual connections to land, community and culture.

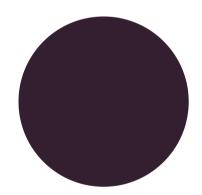
Purpose

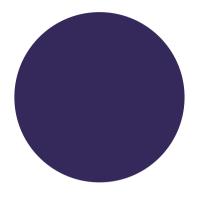
This resource provides a practical guide for how and why you might partner with communities of refugee and migrant backgrounds at different stages of planning and conducting clinical and population health research. The resource is not prescriptive, rather it offers a framework for partnering with communities across a range of research contexts and purposes. We offer insights from our own work, which may help research teams planning research timelines, budgets, and other project resourcing.

If you have not already done so, please read resource *Community researchers* and community advisors before you read on, as it contains important information about the roles that community researchers and community advisors can play in clinical and population health research. This information provides important context for understanding the approaches to community engagement outlined within this resource.









Engaging with communities across the life of a project

There are many different reasons why research teams may wish to engage with communities of refugee and migrant backgrounds across the life of a project. The diagram on the next page illustrates some of these.



Figure 1. Engaging with communities of refugee and migrant backgrounds across the life of a project

1. Strategic planning, developing funding applications

Community advisors can provide powerful insights when teams are undertaking strategic planning and/or planning grant applications, including deciding on the focus of research and establishing research questions.

2. Research design

Engaging community advisors at this stage of the research cycle can help to ensure research approaches are culturally appropriate and reflect community priorities and needs.

3. Approaches to data collection and use

Community advisors may inform approaches to data collection, use of established data sets (e.g. secondary analyses of lifecourse cohort studies) and analyses of routinely collected data, including record linkage studies.

4. Data analysis and interpretation

Insights about important nuanced contexts relevant to data analysis and interpretation, including cultural, linguistic and historical factors relevant to people's lives and the topics being studied, can be generated by engaging community advisors at this stage of the research cycle.

5. Dissemination and knowledge translation

With insights from community advisors, research teams are better able to share research findings with community members, tailor their dissemination of findings to local contexts, and propose steps forward that are informed by the perspectives and voices of community members.

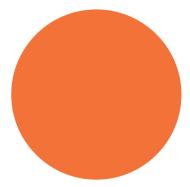
6. Identifying future priorities

Community advisors – especially those embedded within a project or program for a long period of time – will develop a strong understanding of the health issues being studied, and can help to ensure future research and policy priorities align with community priorities and needs.

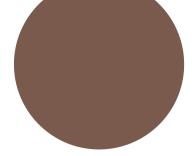
Approaches to community engagement

The reason we have called this resource 'No one size fits all' is because all research projects are different. The timing and nature of community engagement will vary according to the goals of each project, the resources available and the degree to which research teams wish to involve community researchers and community advisors in decision-making.

The spectrum of research engagement outlined below and in Figure 2 is informed by the International Association for Public Participation (IAP2) Spectrum for Public Participation.¹ Importantly, this spectrum recognises that research teams will engage with communities differently depending on several factors, including the needs and stage of the project, study timeframes, resources, availability of community researchers and advisors, and expertise within the research team.







It is possible that a research team may engage with communities in different ways across the life of a study, for example, consulting regarding research questions when first applying for funding and later collaborating when translating and culturally adapting study measures. Even well-established studies, such as longitudinal cohort studies, may identify a need to engage with communities of refugee and migrant backgrounds well into the life of the study. This may be to consult or collaborate on measures to be used in the next wave of data collection, or to seek community input into interpretation and applicability of study findings to specific populations and contexts. The latter may be especially important for research teams planning to build on the findings of epidemiological studies to design and test intervention strategies.

While the term *co-design* now appears frequently in policy documents and public health literature, few studies genuinely achieve true 'co-design' across all stages of the research process. This is partly because of the number of different stakeholders involved, especially in studies that are conducted in health and social care settings. Only a small number of studies conducted by the Refugee and Migrant Health Research Program and Intergenerational Health group have achieved co-design across all stages of the life of a project. These studies involved communities right from the start in identification of research questions and approaches, and embedded community advisory processes from the beginning. There was also a very strong commitment in these projects to empowerment of communities and foregrounding the voices of community members in decision-making.2-5

Figure 2 provides an overview of approaches across this spectrum of engagement. Developing a planned approach to community engagement, at any stage in the life cycle of a research project, takes time. It is important to consider what level of involvement you are seeking, and especially the degree to which community researchers and community advisors will be involved in decision-making. Working collaboratively with community researchers and community advisors will strengthen the integrity of the research findings and outputs.

We recommend that researchers seek to engage community researchers and community advisors as integral members of research teams, and where possible involve them in all major decisions relating to the conduct of research and translation of research findings. If this is not possible, due to time or resource constraints or other factors outside of researchers' control. it is important for this to be clear at the outset. This clarity will help to shape the expectations of community researchers, community advisors and community members regarding the project and what they are being invited to do.

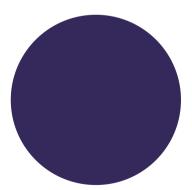
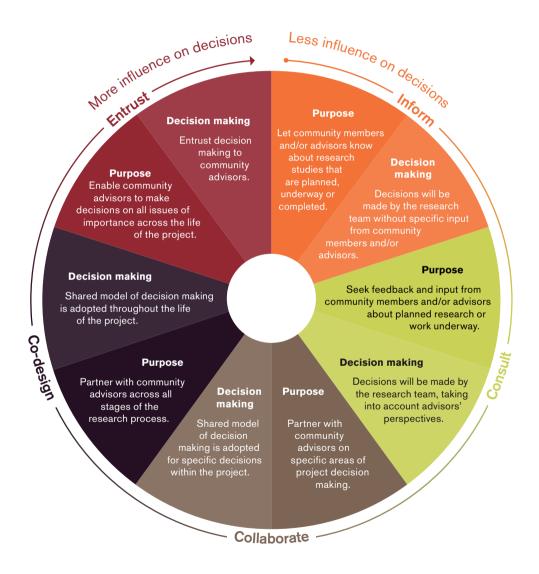


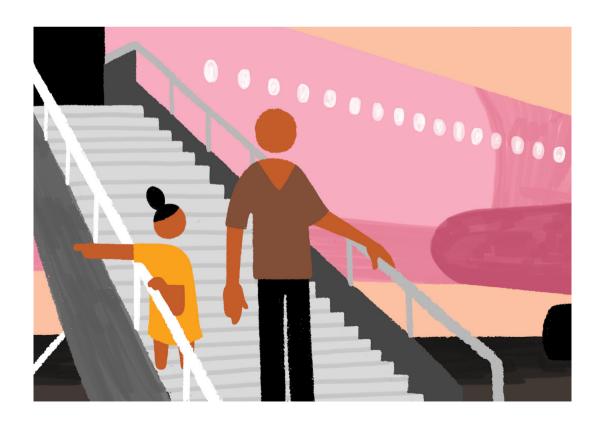
Figure 2.

Different approaches to engagement and decision making in research with communities of refugee and migrant backgrounds



How to get started: practical considerations

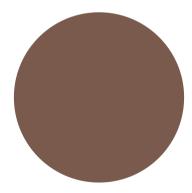
Once you have identified the purpose of community engagement in a specific study, informed by factors like the stage of your project and degree to which you wish to involve communities in decision making, you can begin to plan community engagement activities. This section of the resource aims to provide practical guidance which may be helpful at this stage of planning.



Community researcher

If your team does not already include community researchers, this is likely to be the most important next step to enable you to engage with specific communities. The earlier in the research process you can embed a community researcher or researchers in your team the more impactful their contributions can be. When you are getting started, it may be beneficial to collaborate with a team who already has an established team of community researchers.

Budget tip: If you plan to employ, train, and mentor your own community researchers we recommend allowing 6-10 weeks for interviewing, onboarding and training, based on the researcher working 1-2 days/week.





Community advisors

The community researcher/s you are working with are best positioned to lead the process of recruiting, establishing and maintaining a community advisory group. The group is likely to consist of a combination of community leaders and elders, such as faith leaders, and others with a lived experience relevant to the specific research study.

Budget tip: Our established process, informed by the practices of Foundation House, is to reimburse community advisors \$75 per 2-hour advisory meeting attended.



Community advisory meetings

There are a number of things to consider when establishing and maintaining community advisory groups, including:

- · who will facilitate meetings
- meeting formats
 (virtual, in person, hybrid)
- locations for in person meetings (taking into consideration ease of access using a range of transportation methods, availability of parking and child care)
- what language/s the meeting will be held in
- time required if the meeting is being held in multiple languages.

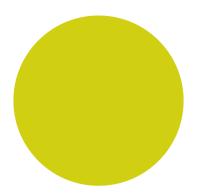
Wherever possible, approaches to advisory meetings should be decided and established by advisors themselves, in collaboration with the community researcher/s. If meetings are to be held across multiple languages it is important to allow enough time for reflections and stories to be shared across all languages so that all participants can follow discussions and contribute to decisions.

Budget tip: The number of meetings required to address your individual engagement goals can vary. As a general rule, for ongoing advisory groups embedded across all project activities and decisions across the life of a project, we budget for five to six meetings per year with five to eight members.



In summary

Research teams will engage communities of refugee and migrant backgrounds differently depending on several factors, including the needs and stage of the research, study timeframes, resources, availability of community researchers and advisors, and expertise within the research team. Well planned and executed community engagement can offer significant reciprocal benefits for communities and research teams alike, helping to ensure high quality inclusive clinical and population health research that reflects and benefits diverse Australian communities.

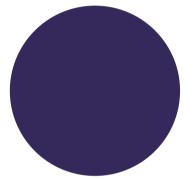




Learn more about *Know our story*, access resources, and watch the animation: strongerfutures.org.au/know-our-story

References

- International Association for Public Participation. IAP2 Public Participation Spectrum. IAP2 Australasia. Published 2019. Accessed August 14, 2023. https://iap2.org.au/resources/spectrum/
- Riggs E, Muyeen S, Brown S, et al. Cultural safety and belonging for refugee background women attending group pregnancy care: an Australian qualitative study. *Birth*. 2017;44(2):145-152. doi:10.1111/birt.12272
- Riggs E, Yelland J, Mensah FK, et al. Group Pregnancy Care for refugee background women: a codesigned, multimethod evaluation protocol applying a community engagement framework and an interrupted time series design. *BMJ Open*. 2021;11(7):e048271. doi:10.1136/ bmjopen-2020-048271
- Riggs E, Yelland J, Szwarc J, et al. Promoting the inclusion of Afghan women and men in research: reflections from research and community partners involved in implementing a "proof of concept" project. Int J Equity Health. 2015;14(13). doi:10.1186/s12939-015-0145-3
- Buckskin M, Ah Kit J, Glover K, et al. Aboriginal Families Study: a population-based study keeping community and policy goals in mind right from the start. Int J Equity Health. 2013;12(1):41. doi:10.1186/1475-9276-12-41









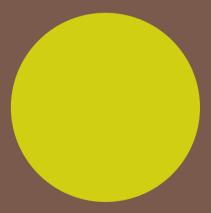
Know our story resources



Know our story:
a toolkit for social equity
and inclusion



No one size fits all: working with communities of refugee and migrant backgrounds in clinical and population health research



Community researchers and community advisors: why they are central to working with communities of refugee and migrant backgrounds



Lost in translation: using standardised self-report measures in cross-cultural research



Best practice in ascertainment: cultural, ethnic, refugee, and migrant backgrounds in clinical and population health research



Intergenerational Health
Murdoch Children's Research Institute

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