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

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

The purpose of this resource is to outline strategies that may be useful for researchers seeking to facilitate engagement of communities of refugee and migrant backgrounds in clinical and population health research. The strategies outlined are based on approaches developed and implemented by the Refugee and Migrant Health Research Program at the Murdoch Children's Research Institute (MCRI).

The Refugee and Migrant Health Research Program was established in 2012. The Program is located in the Intergenerational Health group at the MCRI and works in partnership with the Victorian Foundation for Survivors of Torture (Foundation House).
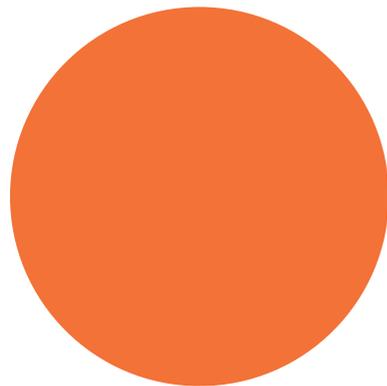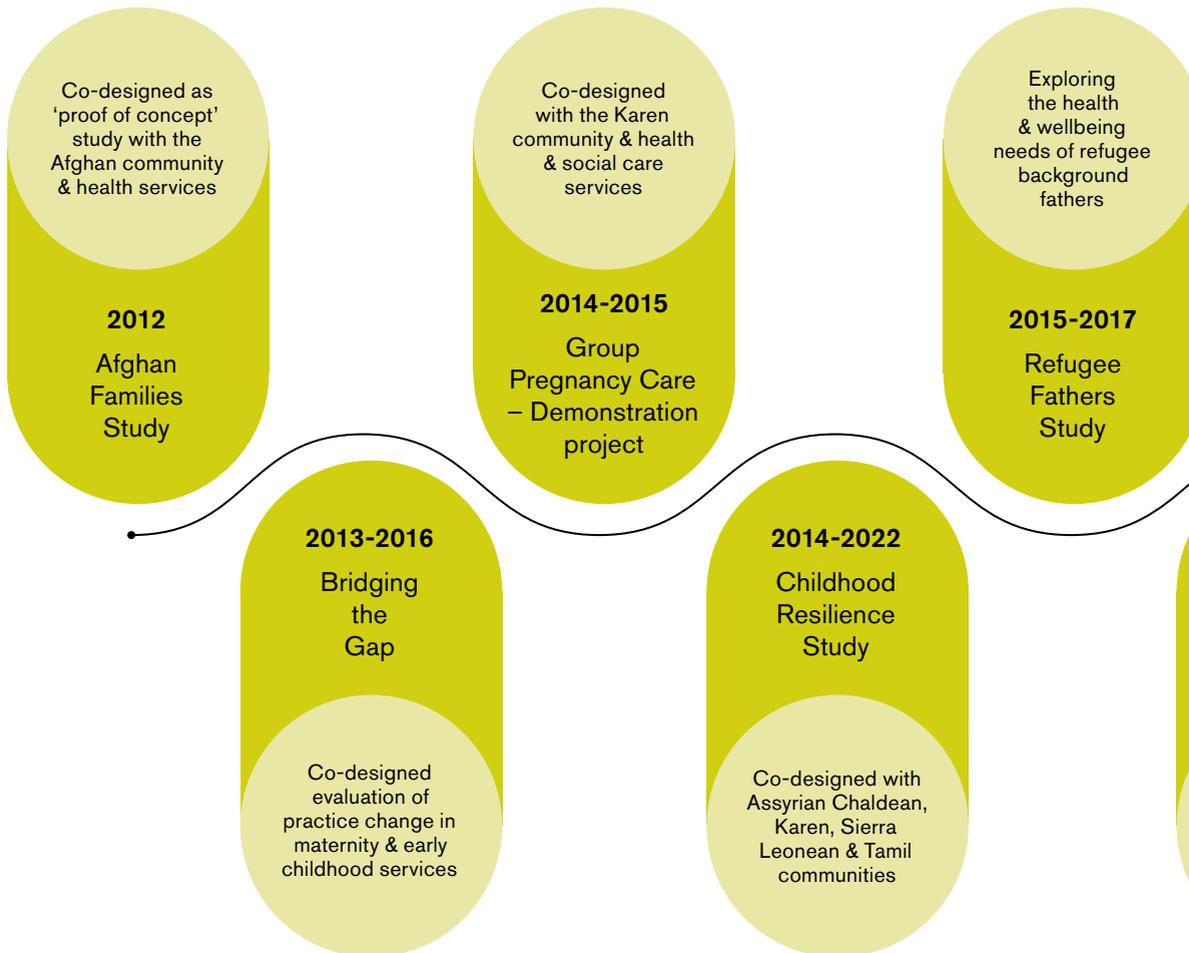
Figure 1. Timeline of projects in our Refugee and Migrant Health Research Program

This resource builds on our experience of working in partnership with communities of refugee and migrant backgrounds over the past decade in a range of studies and using a variety of study methods. These include studies involving surveys, one-on-one interviews, discussion groups, co-design workshops, and analysis of routinely collected perinatal data. We have used these methods in: a study utilising an interrupted time series design to evaluate strategies to improve maternal and child health outcomes;[1,2] a four-year study implementing and evaluating a new model of group pregnancy care for families of refugee backgrounds;[3,4] a quality improvement study that successfully increased

Having a baby
during the COVID-19
pandemic

2020

Listening
to What
Matters

Partnering with
maternity & maternal
& child health services
to support equity-
oriented care

2021-2023

Strong
Families Strong
Babies

2016-2020

Group
Pregnancy
Care Study

Formative
evaluation
in partnership
with services
implementing
model

2020-2024

Talking about
Stillbirth & Working
Together

Co-designing
resources
& professional
development to
support culturally
safe approaches to
stillbirth prevention

access to interpreters for women of refugee and migrant backgrounds during labour and birth;[1,5] and development of culturally adapted health promotion resources to help prevent stillbirth.[6] Each of these studies involved processes of community and key stakeholder consultation and engagement. Most have involved elements of collaboration

and co-design and sustained efforts to engage communities of refugee and migrant backgrounds as partners in research processes.

This resource provides

- an outline of the approach we have taken to employing and embedding **community researchers** – culturally and linguistically matched to communities we are working with – within our research team;

- an outline of the roles that **community advisors** and **community advisory groups** play in our program of work.

Working with community researchers and community advisors culturally and linguistically matched to communities taking part in our research has been critical to our team's success in engaging diverse communities in our research program.[7,8]
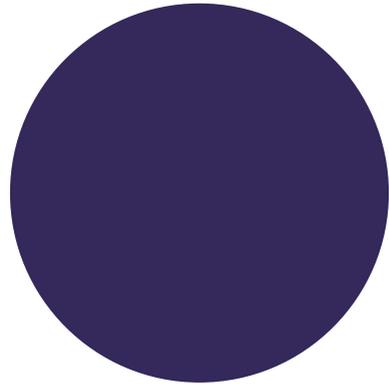
A note on terminology

Community researchers

The term 'community researcher' refers to researchers specifically employed for the purpose of leading and facilitating community engagement in research. The Refugee and Migrant Health Research Program employs community researchers who are culturally and linguistically matched to communities participating in our research program. Community researchers bring expertise, knowledge and social connections that are essential to engaging communities at different stages of research projects and across all levels of community engagement (see resource *No one size fits all*). This includes deep knowledge of their community's perspectives and norms, familiarity with community language/s, and a nuanced understanding of issues of concern in their community. It is important to note that the role of community researchers is different to that of interpreters and translators.

Community advisors

The term 'community advisor' refers to community members who have agreed to provide guidance to a research team at a specific stage or across all stages of a research project. Community advisors also need to be culturally and linguistically matched to the communities participating in research. They may be senior community leaders or elders in their community and/or people with lived experience of the issues that are the topic of the research project. They bring an additional layer of knowledge of their community and issues that may be of concern related to the topic of the research and the way in which the research is conducted.
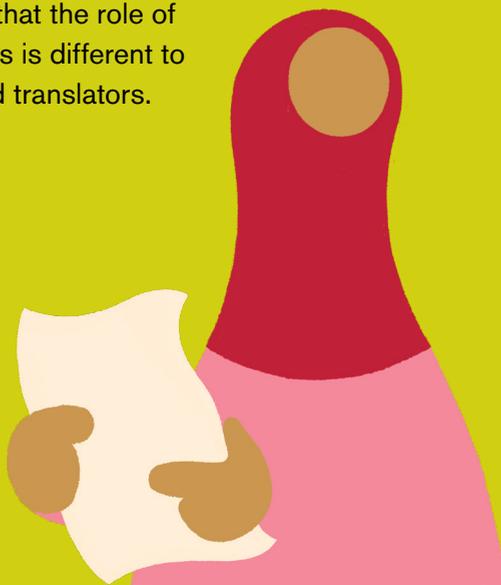
Why work with community researchers?

Many of the standard approaches used in research, such as the use of English language information and consent forms, and English language surveys, systematically exclude people who are not fluent in English from participation. However, language is not the only barrier. Undertaking research with communities of refugee and migrant backgrounds requires research teams to develop the ability to work across languages and cultures and appreciate different values, life experiences and perspectives, as well as levels of education and literacy. It is also important to recognise that people of refugee and migrant backgrounds may be unfamiliar with research processes and have diverse expectations of what participation in research may involve and achieve. For communities that have fled torture, other types of persecution, and war-related trauma to find safety in Australia, there can be additional barriers for researchers to overcome. These include: lack of familiarity with consent processes; fear of authority due to experiences of forced displacement and the potential for past trauma to be triggered by participation in research.[7]

Community researchers are key to overcoming these barriers.[7,8] Currently (mid-2023) there are eight community researchers of refugee and migrant backgrounds employed in the Refugee and Migrant Health Research Program at MCRI. Collectively, they speak multiple languages including Arabic, Chaldean, Dari, Dinka, Hazaragi, Hindi, Matu, S'gaw Karen, Punjabi, and Urdu, and have connections to communities from Afghanistan, Burma, India, Iraq, South Sudan, and Syria.

Community researchers bring essential skills and expertise to guide research processes, including: knowledge of their communities, fluency in community languages, lived experience of migration, and a nuanced understanding of issues of concern in their community.[7-9] Their roles can include: establishing and maintaining community advisory groups, facilitating community consultation and engagement, including in the co-design of study measures and research processes, interpretation of study findings and dissemination of results. Since the knowledge they bring is critical for building relationships with communities, it is preferable that they are involved at the outset of planning and designing research studies. This applies equally to clinical and population health research.

Community researchers also bring cultural knowledge and language skills that may be essential for assessing the cultural acceptability of study processes and the cultural acceptability and validity of planned study measures (see resource *Lost in translation*). They also bring knowledge of their community which may be very important for making sense of study findings, regardless of the data collection method. For example, in studies examining routinely collected perinatal and hospital data, they bring a unique perspective for understanding factors underpinning disparities in health outcomes.
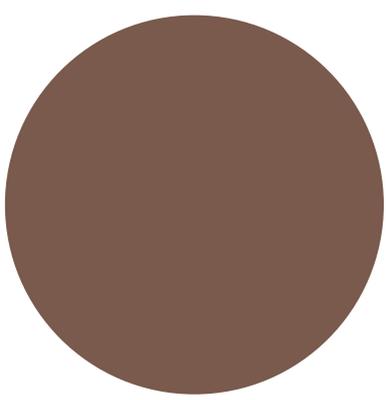
Roles of community researchers

The role of community researchers will vary depending on the nature of the research being undertaken. The following is an overview of some of the many different roles that community researchers may play in a variety of research contexts.

Depending on the context, community researchers may:

- provide guidance and support to the research team in building relationships with specific communities

- identify and engage community leaders, elders, and community members with lived experience relevant to the research topic to act as community advisors to the research team

- work with community advisors to facilitate community consultation and engagement

- advise the research team regarding the cultural acceptability of proposed study measures and procedures

- support and enable pre-testing of study measures and procedures to ensure cultural acceptability and validity

- support the steps involved in co-design of culturally adapted study measures

- facilitate recruitment of study participants in preferred community languages

- facilitate (or co-facilitate) interviews, discussion groups and workshops in community languages

- assist with and check the quality of translations of study materials, including participant information and consent forms and interview schedules

- contribute to the interpretation of research findings, drawing on their knowledge of their communities

- facilitate community feedback and dissemination of research findings.
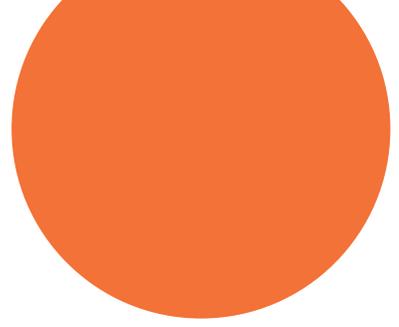
In short, community researchers are pivotal to a range of research processes spanning all stages of the research lifecycle, from conception of a research study through to data analysis and interpretation and dissemination of study findings.

There are many benefits of involving community researchers at the outset of a study. In particular, this facilitates:

- increased understanding of community priorities and concerns, which may be useful to shape research questions and approaches to the design and conduct of research;

- two-way knowledge exchange enabling communities of refugee and migrant backgrounds to learn about research and research processes, and researchers to learn about community priorities.
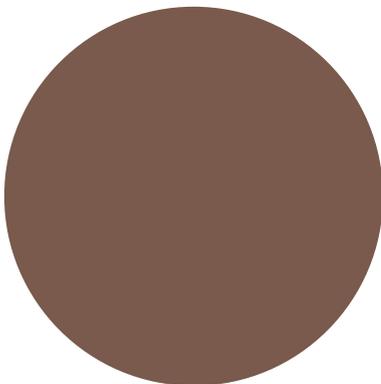
Recruitment, training and mentoring of community researchers

This section includes recommendations for recruiting, training and mentoring community researchers drawing on the experiences of the Refugee and Migrant Health Research Program at MCRI over the past decade.
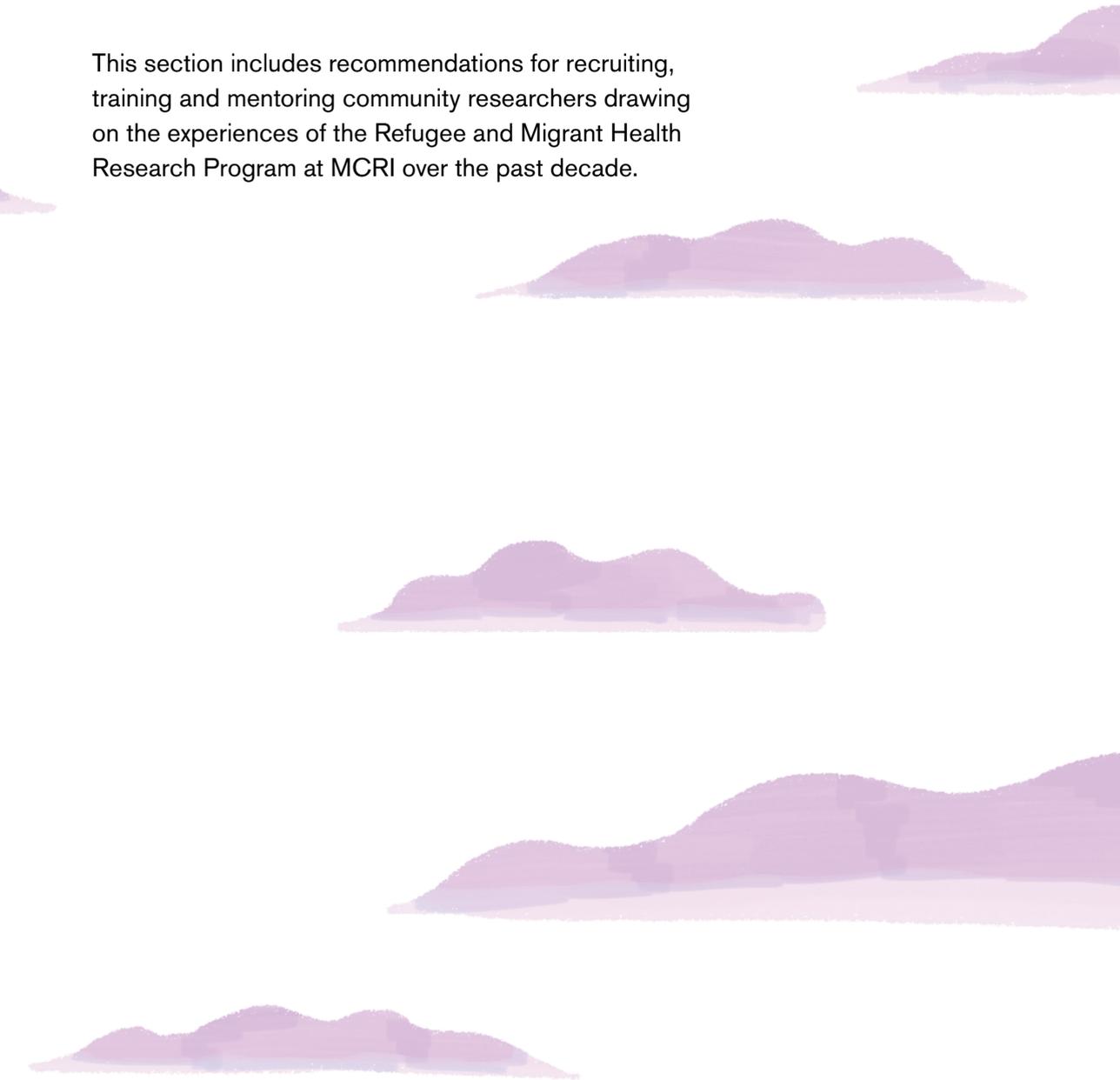
Recommendation #1
Facilitate recruitment via non-traditional pathways

Community researchers are generally employed for their community and cultural knowledge, social networks, and linguistic skills, rather than prior experience and qualifications in research. In addition to standard recruitment practices, we recommend:

- reaching out to community agencies to promote vacancies and encourage people with non-traditional research qualifications and experience to apply

- drafting position descriptions to emphasise the importance of community knowledge and community networks given the centrality of this to the role

- tailoring selection criteria and interview procedures to focus on the relationship building role of community researchers and their familiarity with community concerns that may impact community engagement in the type of research planned

- providing some interview questions ahead of time to enable candidates to develop their responses in advance and enable more fruitful discussion during the sometimes stressful and possibly unfamiliar context of job interviews.

Recommendation #2
Provide on-the-job training and professional development

The need for on-the-job-training and professional development will vary depending on the roles that community researchers are expected to play in specific research contexts. Since it is often the role of community researchers to introduce a research study to a particular community, they need to have a good understanding of why the research is being conducted and what is involved. This can also be an important opportunity to integrate their knowledge and wisdom into your study design and begin mapping out ways to engage communities in your research. For this reason, it can be highly rewarding to conduct training in a workshop format that optimises opportunities for two-way knowledge and capacity exchange between team members.

As a general guide, it is important to consider:

- research and research processes may be unfamiliar to new team members

- the importance of social inclusion in team environments, and the ways in which structural power imbalances can undermine team cohesion

- the way in which power dynamics in academic research settings can operate to undermine cultural safety and teamwork

- the benefits of good facilitation when seeking to establish a sense of belonging and group safety in teams.

**Recommendation #3
Prioritise regular supervision,
mentoring and support**

Given that most community researchers enter research roles via non-traditional pathways, there are many aspects of research that may be unfamiliar to them. Providing regular one-to-one supervision using a strengths-based approach will help to support and mentor community researchers and prevent possible sources of misunderstanding. The opportunity to come together with other community researchers working on the same project for joint or group supervision – in addition to one-to-one supervision – is another approach to supervision and mentoring that our team has found useful, particularly for building a sense of belonging, and supporting skill development and knowledge exchange.

Working with your own community has inherent challenges. Community researchers often reflect that they are always 'on call' for members of their community. This adds to their workload and can impact their ability to manage the responsibilities of their position. Since community researchers are embedded in their communities, they are also impacted by events that impact their community. For example, when the Taliban took power in Afghanistan in 2021, members of the Afghan community living in Australia were significantly affected. Many people had family members living in Afghanistan who were at risk of human rights violations.

Human rights defenders, health and humanitarian workers, women activists, and religious and ethnic minorities were among those targeted by the Taliban. When things like this happen, research processes and timelines may need to be adjusted. Maintaining regular contact with community researchers and building in time to hear about what's happening within their communities is an important consideration to build into supervision.

The Childhood Resilience Study: working in partnership to facilitate community engagement

The *Childhood Resilience Study* – led by the Intergenerational Health group – was a five-year study funded by the NHMRC to develop a socially inclusive, multi-dimensional measure of resilience in middle childhood (5-12 years of age). The study was designed to ensure that the measure was acceptable and appropriate for use with children with socially, culturally and linguistically diverse backgrounds. Community based participatory methods were used to engage children and families of refugee backgrounds.[10]

In the initial stage of the study, discussion groups were conducted with Assyrian Chaldean (from Iraq/Syria), Karen (from Burma), and Sierra Leonean children and their parents/caregivers. In this study, we worked in partnership with Foundation House to recruit families to the study drawing on their established relationships with communities. The groups were co-facilitated by two facilitators, a Community Liaison Officer employed by Foundation House and another member of the research team.

In this project, Community Liaison Officers employed by Foundation House were trained to act as community researchers. A senior researcher in the Refugee and Migrant Health Research Program at MCRI provided training and support for the Community Liaison Officers to familiarise them with the aims of the study and planned research procedures. Two groups were conducted in the community's preferred language, facilitated by Community Liaison Officers. Interpreters were also employed to assist the research team to document discussion points in English. All groups began with a welcome and introduction (i.e. sharing names, country of birth). Participants were invited to develop group agreements to facilitate group safety (i.e. the importance of listening to understand each other, maintaining confidentiality, respecting each other's ideas, and opportunity to stop participating at any time).

Participants were reminded that the focus of the discussion was about what helps children cope during difficult or tough times, rather than on specific situations, events, or experiences. Following this, children and parents/caregivers joined separate groups on opposite sides of the room or using an adjacent room so that each group could engage in their discussion activity.

Both children and parents/caregivers were introduced to the idea of resilience with a story using a tree as a metaphor of resilience. The group was then asked about what a tree needs to grow up big and strong. This was extended by asking, 'What do you think children need to grow up strong when life gets challenging or hard?' The children were given a worksheet with an outline of a tree to write or draw what helps children to grow up strong. The facilitators encouraged the children to share their ideas and discuss them through a shared activity whereby the children drew a large tree on poster paper, and then added their worksheet ideas for all to see.

Similarly, parents were given coloured cardboard shaped as tree leaves and asked to draw or write down the things they thought were important for children to grow up strong. The facilitators encouraged parents to share their ideas and discuss what they had drawn or written with others in the group. All ideas were added to a shared *Childhood Resilience Study* tree poster. In the last part of the discussion group, parents/caregivers and children were brought back together to share their ideas about what children need to grow up strong. The factors identified by children and parents/caregivers informed the development of a draft measure of childhood resilience, that was then tested with children and families in the next stage of the study.[11,12]

Community Liaison Officers (acting in the role of community researchers) were essential to the success of this project, providing valuable support to build trust with communities and engage both children and parents/caregivers from diverse communities of refugee backgrounds in this study.

Working with community advisors

Establishing a community advisory group can be a highly effective way to facilitate community engagement.[7,9,13,14] Depending on the type and context of the study, community advisors may:

- provide expert advice to inform refinement of research questions and study procedures

- support research teams to consult and engage communities in research processes

- provide expert advice to assess the quality of translated study materials, including information and consent forms

- support research teams to assess the cultural acceptability and validity of standardised study measures

- contribute to interpretation and dissemination of research findings.

Other important considerations may include:

- whether to hold meetings in a community venue or online as per community preference

- many community leaders have multiple commitments and responsibilities within their communities and may only be available after hours or on weekends

- provision of interpreting support if needed

- making sure there is sufficient time factored into meetings to enable communication using interpreters

- providing an honorarium to community advisors acknowledging both their contribution and the time they are committing to research processes

- it may be necessary for community researchers to attend community events after hours or on weekends to facilitate community engagement.
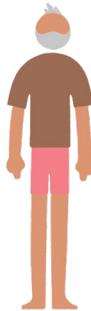
Having a Baby in a New Country: building trust in research processes

The *Having a Baby in a New Country* study – often referred to as the Afghan Families Study – was undertaken by the Refugee and Migrant Health Research Program at MCRI to investigate:

- the experiences of women and men of refugee background accessing public maternity and early childhood services, and

- experiences of health professionals providing their care.[7]

Community advisors were identified and invited to participate by two Afghan community researchers (one female and the other male) and via existing networks of our research partner, Foundation House.[7] The community advisory group included Afghan women and men from three ethnic groups living in the outer south eastern suburbs of Melbourne: Hazara, Pashtun and Tajik. The roles of the community advisory group were to:

- provide community perspectives to ensure the research questions were addressing issues of concern to the community

- provide advice on processes for data collection to ensure that planned approaches were acceptable

- contribute to interpretation and dissemination of findings

- facilitate further consultation and community engagement

- provide a conduit between the research and broader partnership team and the community.

The community advisory group met three times during the project, and members received an honorarium in appreciation of their time.

Ninety-four Afghan women and men participated in the consultations to guide the design and conduct of the study. Twelve discussion groups were held: seven with women, and five with men. There were no mixed gender groups. Most of the women's groups were pre-existing groups such as playgroups, while men were approached and invited to participate in once-off discussion groups. Three community members participated in telephone consultations. Community feedback guided the design of the next stage of the study involving one-to-one interviews with Afghan women and men who had recently had a baby in Australia. All discussion groups and interviews were conducted by community researchers in participants' preferred languages.[7]

One of the community researchers reflected:

The Afghan community is less familiar with the term 'research' and it is often taken as 'investigation'. Therefore, to familiarise members of the community with the research project, informal visits were made prior to formal consultations to meet the women and introduce the project. Participants were highly appreciative of the consultation process and having the opportunity to contribute to the direction of the research. Most of the participants have never been part of a research project or have never heard about the research process.

Community advisors played a critical role in this project, supporting community engagement and assisting the research team to build the trust of Afghan community members in research processes.
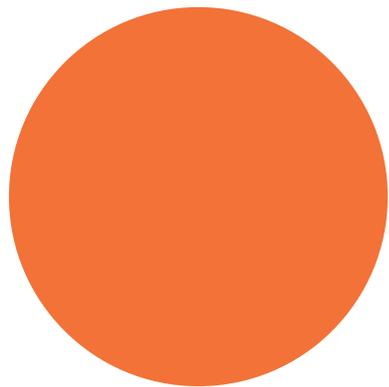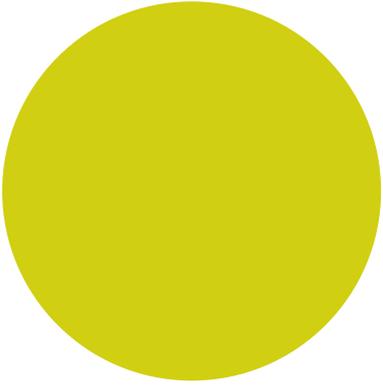
In summary

- working with community advisors and community researchers culturally and linguistically matched to the communities that researchers are seeking to engage can be highly effective strategies for engaging people of refugee and migrant backgrounds in research

- community advisors and community researchers can make significant contributions to research integrity, including expert contributions to pre-testing of study methods and procedures and assessment of cultural acceptability and validity of study measures

- community advisors and community researchers also have an important role to play in community feedback processes and broader dissemination of research findings.
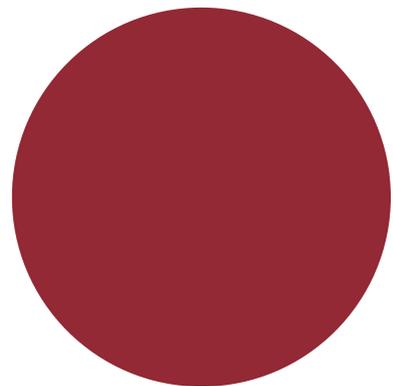
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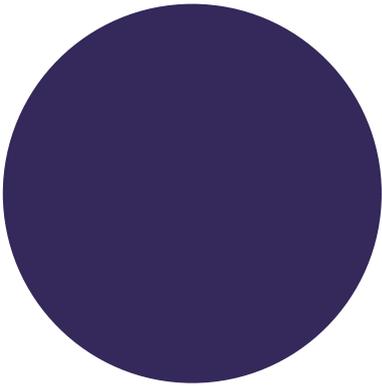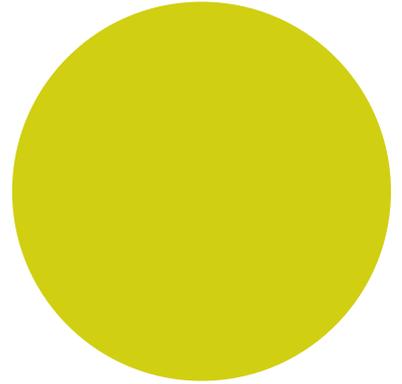
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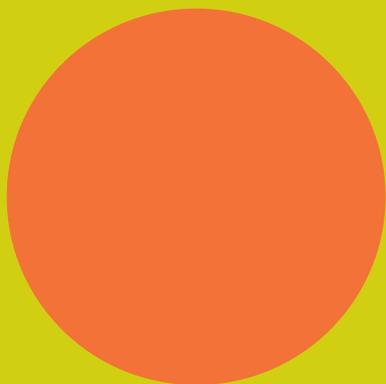
Know our story:
a toolkit for social equity
and inclusion
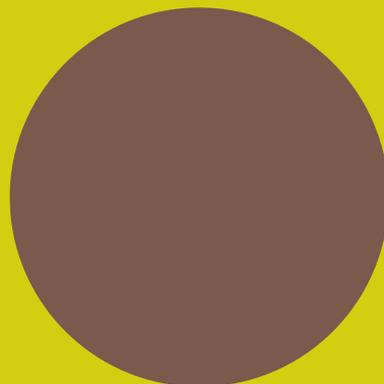
No one size fits all:
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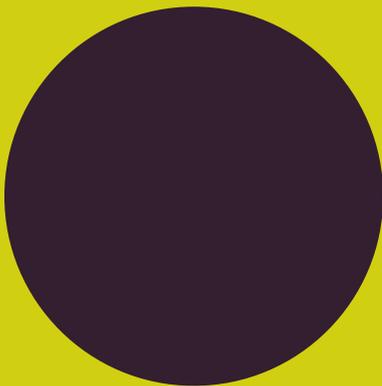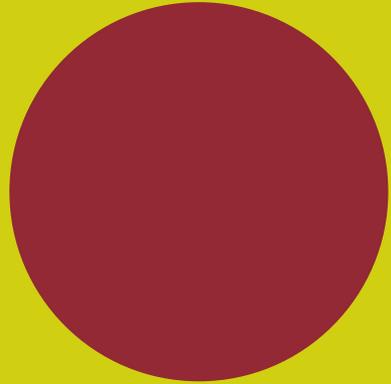
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