Abstract

The G21 Refugee and Asylum Seeker Mental Health Project (RAS MH) aimed to implement a Co Design framework that would assist service providers to gain an understanding of the barriers refugees and asylum seekers face accessing mental health services in the Geelong Region. An Experience Based Co Design (EBCD) approach was identified as the preferred framework for this project. The project revealed that refugees and asylum seekers in the Geelong region face numerous barriers to accessing mental health services. Five of these barriers were prioritized and recommendations developed. It is intended that the recommendations developed with the EBCD framework will inform service provision changes to address these barriers in the Geelong region.
Table of Contents

Project summary 3
Introduction 5
Purpose 10
Approach 11
Findings 20
Recommendations 21
Conclusions 25
Appendices 28
References 38

“The people with big voices need to take this to the people with big ears!”

—RAS participant

Acknowledgments

We would like to thank the Refugee and Asylum Seeker working group and the G21 RAS mental health and wellbeing-working group for their cooperation and participation in the ‘Working With us – For us’ project.
Project Summary

An Experience Based Co-Design Framework (EDCD) was applied to gain insight into the barriers and enablers to accessing mental health services in the Geelong Region and to then develop and present recommendations.

Aim

The aim of this project was to implement a co design framework that would enable the voice of Refugee and Asylum Seeker (RAS) mental health service users to be heard with respect to defining access barriers to mental health services in the Geelong region and developing recommendations to address these issues.

Outcomes Framework

An outcomes framework was adopted to guide this project. The outcomes framework incorporated both population/community level and client level outcomes. The methodology used to design the framework was Outcomes Based Accountability or OBA (Friedman, 2005). An overview of the framework is as follows:
Figure 1: Outcomes Framework

Figure 1 outlines a narrative description of the outcomes framework for this project. The population and client outcomes draw inspiration from the Fifth National Mental Health and Suicide Prevention Plan (2017). The framework recognises that clients are subsets of whole populations; therefore, to achieve population wellbeing we must achieve associated client wellbeing. This project has defined RAS clients, who are part of the broader population and has outlined how the project improves direct client outcomes and its contribution to the bigger picture population wellbeing.

Participants of the project were mental health service users and carers from a refugee and asylum seeker background living in the Geelong region and mental health service providers.
Introduction

A large percentage of people from a refugee background settling in Australia have experienced persecution; they have been forced from their homes, have experienced torture and trauma and now face the stress of settling into a new country and culture. According to the 2017 Building a New Life in Australia (BNLA) longitudinal study, three quarters of respondents surveyed reported having experienced at least one traumatic event before settling in Australia (Department of Social Services, 2017). Research demonstrates that while Culturally and Linguistically Diverse (CALD) communities do often have strong protective factors, such as strong family and community support, together with a connection to culture and faith, the stress resulting from settlement, acculturation, racial discrimination, equity and language barriers can have an enormous impact on the health and wellbeing of individuals, families and communities. Evidence suggests that Humanitarian entrants are also at higher risk of serious mental illness than the broader Australian population (Department of Social Services, 2017). However, despite this evidence, Australian national data indicates low rates of access to mental health services by communities from a refugee background and CALD communities in general (Department of Health, 2017).

There has been both international and Australian research, which has investigated barriers faced by communities from a refugee and asylum seeker background in engaging with services. The findings conclude that when providing psychological support to these clients, services must be coordinated and service providers must be equipped to work with the layers of complex factors including past trauma, language, lack of trust and settlement issues. There are a myriad of cultural understandings to consider and respond to, including perceptions of health and illness, coping mechanisms, gender, treatment seeking patterns, family structures and stigma. Service providers and policy makers must also consider the impact of language and the use of interpreters. Cultural responsiveness and the need to focus on ethno-specific approaches to mental health will enable services to adapt to these differences across cultures.

In 2017 Geelong settled approximately 240 refugees and is home to around 1,600 people from refugee and asylum seeker backgrounds who have been settled in the region for five years or less. An additional 300 people from Iraq and Syria settled over the previous eighteen
months. The mental health system in the Geelong region has been identified by the G21 Health and Wellbeing Pillar as requiring further improvement in order to meet this significant increase in demand for culturally responsive services (Systems thinking workshop, 2016). It is recognised that while working cross culturally raises a number of challenges for mental health service provision, there are also numerous opportunities to work in unique and effective ways towards positive mental health outcomes (Gopalkrishnan & Babacan, 2015).

Working to improve the lives of people within the G21 region through co-ordinated research, consultation and planning, the Geelong Region Alliance (G21) is a formal alliance of Government, business and community organisations. The G21 Health and Wellbeing Pillar is one of eight Pillars and is guided by the priorities outlined in the ‘Health & Wellbeing Pillar’s Strategic Plan for 2017–18’. These priorities include:

- Healthier Eating and Active Living;
- Promoting Gender Equity;
- Improving social connectedness and mental health & wellbeing;
- Capacity building & leadership; and
- Measuring our progress.

Refugee and Asylum Seeker Health & Wellbeing is one of the projects contributing to the Social Connectedness and Mental Health & Wellbeing priority. The G21 Health & Wellbeing Pillar have been working collaboratively with Diversitat, Western Vic PHN, Catholic Care, Barwon Child Youth and Family, and Barwon Health to identify challenges in the Mental Health System regarding access, care and outcomes for Refugees and Asylum Seekers in the G21 Region. The ‘Working With Us — For Us’ project was funded by Give where You Live Foundations’ Capacity Building grants. The project was developed in response to the Refugee and Asylum Seeker Mental Health mapping (RASHMAP) report (Glastonbury Community Services, 2015), and the Refugee and Asylum Seeker ‘Improving Mental Health Care and Outcomes’ mapping workshops recommendations (G21 Geelong Region Alliance, 2016). This is underpinned by the collective action to improve care and outcomes for people from a refugee and asylum seeker background engaged in the mental health system in the Geelong region. Initially, a one-year action plan was developed to enable the collective G21 Refugee and Asylum Seeker (RAS) Governance Group to start to plan and implement this change.
According to the Department of Health (2015), research indicates that effective service user and carer engagement and participation in improving health services, results in higher quality, more cost effective and accountable services, with improved health outcomes for service users and carers. Service user and carer engagement and participation refers to ‘participation by consumers and carers in formal or informal planning, delivery, implementation, and evaluation of all activities associated with mental health services (voluntary or paid), as well as in all processes which affect the lives of consumers and carers, through sharing of information, opinions, and decision making power’ (Department of Health, 2015).

Service users and carers are defined here as people with a lived experience of mental illness. Service users are people who access (or could potentially access) mental health services, while carers are the support people who provide personal care and assistance to a person who has a mental health illness. Many people are both service users and carers, and many carers provide support to more than one person (Department of Health, 2015). The RAS Mental Health Governance Group recognise that service users and carers from a refugee and asylum seeker background are a key cohort who have not been included in participatory consultations regarding mental health services, including access, cultural appropriateness and their experience using these systems in the Geelong Region. According to Multicultural Mental Health Australia (2014), service user and carer participation is a central principle in Australian government, state and territory mental health policies and plans, however very few service users or carers from culturally and linguistically diverse (CALD) backgrounds have participated in mental health consumer and carer participatory research activities in Australia. The Australian Government’s health department consider consumer and carer engagement and participation fundamental to a person-centred mental health system that is designed around the needs of consumers and their carers. It shifts control away from service providers and supports the inclusion and participation of vulnerable and hard to reach groups by recognising diverse cultural and experiential needs (Department of Health, 2015).

The RAS Mental Health Governance Group recognise that collaborative partnerships are vital to consumer and carer engagement and participation. Collaborative partnerships form the basis of co design, which is a participatory method of working collaboratively with consumers to design services, products or processes with the aim of better outcomes for all involved. The Governance group acknowledges that consumers and carers will experience improved
outcomes when their participation and engagement is embedded in collaborative partnerships and co-design processes across the whole of the mental health system. In order to gain a comprehensive understanding of the barriers and enablers to accessing mental health services in Geelong for people from a Refugee and Asylum Seeker background and to work collaboratively to improve services for this group, an Experience Based Co-Design (EBCD) framework was implemented.

The principal goal of the EBCD framework is to engage consumers, carers and service providers to actively work together to co-design features of service delivery, making it very relevant to the RAS MH project (Bate & Robert, 2006a). EBCD uses features of participatory action research, user-centred design, learning theory and narrative-based approaches to change. According to Van Citters (2017), the implementation of an EBCD framework by health services has resulted in the improvement of service user experience and a positive change in health service provider behaviour, culture and values.

EBCD differs from traditional health service research in a number of ways. Traditional research has a focus on quality and health outcomes, and organisational change is often implemented using a top down approach. In comparison, EBCD has a focus on improving the overall experience of service users by identifying key ‘touch points’ from their health service journey and enabling service users, family members and service providers to work collaboratively to improve services by redesigning the experience at these ‘touch points’ (Mulvale et al, 2016). Experience in this context is defined, as, ‘how well people understand it, how they feel about it while they are using it, how well it serves its purpose, and how well it fits into the context in which they are using it’ (Bate & Robert, 2006b).

An EBCD framework addresses the issue of power imbalance when service providers and service users work collaboratively. This is of particular importance when working with service users who are often vulnerable as in the case of those from a refugee and asylum seeker background. Approaches used to achieve this are the establishment of equal status among all participants from the outset of the project; a focus on experiences and perspectives of all participants throughout the project; storytelling and visual media, reimbursement for time service users give to the project; ensuring confidentiality; offering counselling and support as required; and employing skilled facilitators and interviewers (Mulvale et al, 2016).
The Social Care Institute for Excellence in the UK has identified four critical principles of EBCD as Equality, Diversity, Accessibility and Reciprocity. In 2016 a Carer and Consumer led project in NSW expanded on these principles:

- **Equity**—Collaborative and promoting an equitable partnership between all stakeholders;
- **Inclusion**—Supporting the involvement of all stakeholders;
- **Capacity**—Ensures skill development and capacity building for all participants;
- **Co-created**—Participants commit to learning from each other;
- **Purposeful**—Works towards real outcomes that are meaningful to all participants;
- **Innovative**—opportunities to explore and experiment with alternative solutions; and
- **Sustained**—opportunities to build on the Co design process for future initiatives.

These principles together with those identified by SCIE are very relevant to the needs of the RAS MH project.
Purpose

Research has documented the many barriers to participation in accessing mental health services at all levels by CALD communities including lack of service provider cultural responsiveness, racism, language barriers, stigma and shame, models of mental health that differ to that of the Western model and a lack of knowledge of the service system and how to access services. Implementing an Experience based co design framework the ‘Working With us – For us’ project aimed to understand if and how communities from a refugee and asylum seeker background experienced these barriers to accessing mental health services in the Geelong region and to work together to develop recommendations to improve these experiences and reduce barriers. To do this an Experience based Co Design framework was implemented based on the approaches developed by the ACI NSW Agency for Clinical Innovation.

It is acknowledged that procedures need to exist to facilitate the active participation of consumers, carers and family members across a range of levels and in a manner that respects cultural differences and demonstrates understanding of the needs of CALD communities (Multicultural Mental Health Australia, 2014). These processes should ensure participation at the personal level, the service level and the system manager and corporate levels.

Whilst the ‘Working With us – For Us’ project focused specifically on the ‘service level’ and the ‘system manager and corporate level’, it did however, also impact on the ‘personal level’. RAS participants reported increased understanding of mental health services and a decrease in perceived stigma, enabling participants to be more involved and to have a voice in their care. Engagement with the service level gives consumers and carers the opportunity to participate in the planning, development, delivery and evaluation at a service level while participation in the system manager and corporate levels enable them to inform policy development and legislation (Multicultural Mental Health Australia, 2014).
Approach

Eileen Pittaway and Linda Bartolomei for the Centre of Refugee Research at the UNSW developed the participatory action research methodology implemented in this project (University of New South Wales, 2012). This method was implemented in order to gain insight into the experience of the mental health system in the Geelong region by the RAS participants. Reciprocal research is an empowering and safe approach to working with vulnerable often-marginalised communities, such as people from a refugee and asylum seeker background, which has the potential to bring about change (University of New South Wales, 2012). The method enables people to be active participants in research and facilitates community lead outcomes without the need for written language. Participatory action research was incorporated into the EBCD framework. The following key steps were undertaken, with key activities and learning noted below.

‘It’s an empowering project. It uses an active approach’
RAS participant

Engage

The Outcomes Based Accountability framework (OBA) and Project Plan were developed, and a Literature review undertaken to establish the best framework to be used in this co design project. This would be the pilot for the use of EBCD for Mental health services in the Geelong region. An ethics application was submitted to Barwon Health for approval.

Implementing a community engagement approach, and adapting this to reach communities from Refugee and Asylum Seeker backgrounds, the project was explained in detail to community leaders, community members and caseworkers currently working in Settlement programs in the Geelong Region. A flyer translated into all relevant languages was emailed to leaders to distribute to their communities. Due to the stigma attached to mental health in many new arrival communities, the flyer asked that interested community members who
have had experience of mental health services in the Geelong region themselves or are carers to contact the project coordinator directly.

When a client made contact with the project coordinator a meeting time was arranged with an interpreter to ensure the project aims, expectations and the responsibilities of both participants and the program coordinator were understood before the client made a commitment to participate in the working group. This conversation was also an opportunity to start building trust and rapport with the client.

The project was to be made up of two working groups — the service user and carers group and the service provider group. The service provider working group was in place as part of the G21 RAS MH Governance Group and was made up of representatives from Barwon Child Youth and Family, Barwon Health, Catholic care, Western Vic PHN and Diversitat. A meeting was held with the Service Provider working group to explain the EBCD framework and what their role would be.

The project stipulated that approximately 8-9 consumers from an Asylum Seeker or Refugee background, be recruited to the service user and carer working group. Participants were required to come from a range of ages, gender and cultural backgrounds including new arrivals from Afghanistan, Iran, Iraq, Syria, and the Karen and Karenni from Burma. The group also needed to include people from more established communities from a refugee background, for example the Sudanese community.

Ten RAS service users or carers agreed to participate in the project from five different communities. The group was made up of three Afghan women, two Iranian men, one Iraqi woman, one Syrian man, one Karen woman, one Karenni man and one Liberian woman. The length of time settled in Australia ranged from six months to fourteen years and three members of the group spoke English. One participant is on a Temporary Protection Visa (TPV) and nine others arrived in Australia on Humanitarian Visas. The group was a mix of carers, siblings and service users. Once the group was established it was important to check that each person was happy to work with the other members who were from their same language group – trust within the group was vital to the success of the project. It was also important that the group trust the bilingual worker or professional interpreter they would work with
and to have continuity of staff. The Arabic bilingual support worker did change on two occasions however the participant approved the replacement worker on each occasion.

It should be noted that the project coordinator was known in some capacity by most of the participants. While trust and rapport still had to be gained both within the group and with the project coordinator the time taken to do this was reduced due to this prior experience. Some of the group had also met each other at Diversitat facilitated activities or English classes. This was of enormous value and made the short time frame of the project possible. Without prior knowledge and with a longer timeframe the time spent building trust and rapport would ideally be given more time. It should be noted that the whole conversation process with this group was time consuming due to the need for interpretation throughout the process.

Initial training around working cross culturally, EBCD and the Story board technique would have been beneficial for the service provider working group. The RAS working group would also have benefitted from more information about mental health service provision in the Geelong region. While a great deal of learning and understanding took place organically over the course of the project, some initial training may have given both groups a greater understanding of the many aspects of the project and more confidence in working together from the outset.

As well as being an active learning experience, involvement in the project required a big time commitment from participants, as it required a number of after hour meetings and working in a way that was not familiar. All participants were very open to learning from each other, they were committed to what the project was aiming to achieve and took up the challenge of attempting something new with enthusiasm.

---

**Understand**

**Refugee and Asylum Seeker (RAS) working group**

The RAS working group was invited to an introductory meeting. Nine participants and four bilingual workers attended the first meeting with two apologies. The Iraqi woman who was the TPV holder later decided not to participate in the project. A bilingual community development worker was also employed for the first three meetings to assist the project...
coordinator with scribing, evaluation of group dynamics and occasionally interpreting when needed. Week one included the following:

- Introductions.
- Getting to know each other and trust building activities.
- Explanation of the project – this was repeated each week, but real understanding only came as the project progressed and the group could see that they did have experience and knowledge that was valued and how this was going to be presented.
- Reading, explanation and signing of project agreement by participants.
- Information was given regarding access to support and counselling if required at any stage of the project.
- The group was informed that they would be reimbursed for the time they gave to the project.
- The importance of confidentiality while participating in the project and signing of a Confidentiality agreement – members of the group have mentioned the importance of this agreement in enabling them to speak more freely, to share personal stories and to trust the people they were working with.
- Explanation of the Human Rights Framework and how it is incorporated into Australian Law. Discussion of how this fits with the project — specifically in relation to health, disability and mental health.
- Discussion of where and when the group would like to meet — the group decided they would meet at the Diversitat Northern Community Hub in Norlane at 5.30pm once per fortnight.

**Key learning:**

Training for the RAS participants at the commencement of the project would have been of benefit to ensure the participants had an understanding of mental health service provision in the Geelong region, knowledge that there are different cultural understandings and beliefs of mental illness and mental health literacy in the Australian context. While the group did report gaining a great deal of knowledge throughout the life of the project training would have enabled better understanding from the outset. It would have given more time for building trust and rapport within the group and the increased knowledge may have assisted participants to understand the intention and hoped for outcomes of the project at an earlier stage.
Follow up workshops, allowed opportunity for further discussion and clarification of the project, along with explanation of the confidentiality agreement and further discussions of Human Rights. Each member of the working group was asked to tell a story of either a positive or a negative experience of mental health service provision in the Geelong region. At the completion of each story the group discussed the issues and barriers, or positive experience — these were later translated into each language to be distributed to participants the following week. (See appendix 1 for stories).

Many of the group became involved in the project because they had faced particular issues or barriers they wanted to see addressed. While all of these issues raised had a clear impact on their mental health and wellbeing, some related to early settlement issues and were not relevant specifically to mental health services, however the group did want these issues to be addressed.

Issues were discussed in more detail with translated versions and each language group prioritised five issues. Using a voting system the whole group agreed on five priorities to be presented to the Service Provider Working Group.

**Key learning:**

For RAS participants it is not possible / reasonable for them to be able to separate experiences that impact on their mental health. As such, discussion around settlement versus mental health services barriers and enablers occurred, with agreement the project coordinator would meet with the General Manager of Settlement services to discuss how and when Settlement issues could be addressed.

Participants decided they would like to present settlement issues to Diversitat Management and the Humanitarian Settlement Program team. Due to the short time frame for this project it has been agreed with the group that the Diverse Safe Place Project will continue this work from June 2018 with those participants who would like to continue to be involved.

Participatory action research approach requires a shift from a focus on personal experience and stories, to situational analysis and problem solving. The ‘Storyboard’ method was implemented to achieve this in a safe and empowering way (University of New South Wales, 2012). The participants were asked to draw

‘The storyboard gives us self-confidence to talk clearly about our problem’

RAS participant
a series of pictures to enable the discussion of one of the prioritised issues / barriers faced by their communities and the impact of this issue. The use of the Storyboard method was to lessen the impact of the barriers of power imbalance, language, education and literacy levels that can prevent trusting engagement and active participation. Mental health is a very sensitive topic in many communities so it was vital to use an approach that would build trust within the group.

As part of the process of reciprocal research and this EBCD project, the RAS group discussed how they would present the storyboards to the G21 service provider working group.

Presentations were made to the Service provider-working group by the RAS working group. The RAS group had never been given the opportunity to be heard in this way before and they were lacking confidence in their ability to convey the message. The storyboards proved to be an excellent communication tool and enabled the RAS groups to confidently present the issues in a very powerful way.

‘I valued the presenter’s honesty, passion and commitment to advocating for a better mental health system. I appreciated their willingness to share personal stories about their experiences in Geelong and I left feeling very honoured & privileged to have been able to hear first-hand information. I felt it was a very powerful session’ (Service provider).

‘Engaging and moving. Interpreters and participants worked well together to educate the audience. Genuine’ (Service provider).

Improve

Co design process

‘Working With Us — For Us’ 2018
Recognising that trust and rapport is essential and can be further challenging when working cross culturally and with interpreters, ice breaker and trust building exercises were employed during the first two workshops with the combined RAS working group and the service provider working group. Taking the time to plan appropriate exercises was very important to facilitation of the building of trust and rapport, enabling the groups to work together in an open and engaged way.

It was also noted for the RAS participants, that the service providers they were working with were going to be ‘champions’ and were working at a level where they could influence service provision. This process was challenging due to the inherent power imbalance within the working group. The service providers played a critical role throughout the co design process to ensure the RAS participants felt valued and listened to.

In order to consider the collective experiences for each of the issues raised in the presentation, to identify opportunities for improvement and to develop recommendations, the group divided into four language groups with two service providers and a bilingual support worker joining each group. The following priority issues were discussed:

**Issue 1**: Language barriers — the need to rely on interpreters and difficulties understanding telephone interpreters.

**Issue 2**: Timeframes — slow procedures and processes to get referrals can have a further negative impact on mental health.

**Issue 3**: Variety — medication is not enough, people need other strategies and activities to help them get well.

**Issue 4**: New arrivals not given the information they need about mental health services in Australia. Not enough information given to community members/leaders about mental health so that communities have a better understanding and reduce stigma.

**Issue 5**: When an ambulance is called police are sent for to assist someone with a mental health issue instead of a mental health professional/crisis team. There is no consideration of the potential fear Refugee and Asylum Seeker communities often have of people in uniform, in particular police officers — this can often escalate
issues. This priority was discussed by the whole group and recommendations developed as a group.

The storyboard method was implemented again as it enables the acknowledgement of the equal value of each individual’s unique knowledge and experience of the mental health service system in the Geelong region.

While the first storyboard assisted the RAS groups to explore the nature of an issue and its impact on communities, the groups were now asked to extend this thinking to the identification of existing relevant services or service gaps, and to co-design recommendations including individuals or groups who may be able to assist these to be implemented.

‘I enjoyed the storyboard process, even though my own drawing was dreadful. I had no previous experience in this type of pictorial communication, but I felt that it was a great way to build relationships & connections with the participants and was a meaningful way of creating clear messages when use of English language is a challenge’

Service Provider

‘Challenging but really useful; provided an opportunity to participate on a more equal level and really bring the expert into the space (the consumer)’

Key learning:

The storyboard method enabled all participants to have a role in the development and presentation of recommendations and an opportunity to have a voice. The approach assisted in overcoming barriers of language and literacy.

Some enjoy the process of drawing pictures more than others and there were different skill levels across both working groups, therefore using this method in these circumstances can be seen as a ‘leveller’. Drawing skills are not important and one group chose to use magazine pictures to demonstrate the story — what is important is that each participant is involved equally and everyone plays a role in discussion, development and the presentation.

Over a period of four weeks the groups developed the recommendations and decided how they would present their storyboard. Each group presented to the broader group, listened
to feedback then finalised their presentation to be delivered to the G21 Refugee and Asylum Seeker mental Health Governance Group and others who are key to mental health service provision in the Geelong Region.

**Measure**

**Step 1. Communicate achievements and Celebrate success**

The group workshopped the fifth issue together and prioritised recommendations. It was decided that two members of the RAS group who have personal experience and felt strongly about this issue would present. It is hoped that this issue can also be presented to Emergency services.

**Presentation of Recommendations by Co Design Working group**

“The people with big voices need to take this to the people with big ears!” (RAS participant).

The co design-working group presented recommendations to the G21 Refugee and Asylum Seeker Mental Health Governance Group and others who are key to mental health service provision in the Geelong Region.

**Celebration Dinner**

All participants were invited to attend an end of project celebration and thank you dinner. Each participant received a certificate of participation.

**Measure**

**Step 2. Identify key indicators to measure impact**

**Step 3. Measure impact using words and numbers**

**OBA Performance Measures**

The OBA frameworks use performance measures (quantitative data) to measure outputs and outcomes associated with projects, services or systems that defined client’s access.
Findings

Overall, quantitative and qualitative evidence collected for this project suggest that both service users and service providers actively participated in the project and worked together to develop recommendations using an EBCD framework. They report improved skills, knowledge, attitude and behavioural change outcomes. The following quotes from the working group supported this as follows:

- ‘A better understanding between clients and service providers’ (Service User).
- ‘We came up with good ideas and I hope that they support our ideas and bring some into services’ (Service User).
- ‘I feel that this was a big step into moving into this space and the intent of all parties was genuine and we did sit down and talk about issues. I feel what we did was significant, I am not convinced that it was true collaboration in the sense of service design but it is a learning process and a big one from this perspective’ (Service Provider).
- ‘I thought the process was clear, client led & client directed, outcomes focused and driven by the bottom up, which meant that the results were genuine and without unnecessary external bias or influence’ (Service Provider).
- ‘I think each and everyone in each group learnt how to seek help or how to help others when they need. And also know that what are the things that service providers can provide for us. What is their job to do for these kinds of sickness’ (Service User).

Outputs and outcomes data supports qualitative narrative around participation and outcomes:

- 9 RAS clients were involved in the service user working group
- 8 service providers were involved in the provider working group
- 24 recommendations were submitted to the G21 governance group
- 100% (8/8) RAS clients reported they enjoyed preparing the presentation to the G21 governance group
• 100% (8/8) RAS clients reported they felt more valued and listened to. This is an important outcome for RAS people because evidence suggests they are often stigmatised, feel discriminated against and their voice is not valued or heard (BNLA, 2017).

• 100% (14/14) RAS and provider clients reported the co-design process enabled them to work together to develop recommendations. This is an important outcome for RAS service users and service providers because whilst the EBCD process was used to articulate access barriers (which ranged from power imbalances through to language and cultural disconnects); the very same exploratory process was used to overcome barriers to ensure both parties worked collaboratively to identify recommendations.

Recommendations
See complete list of barriers and enablers as noted by the RAS working group – Appendix 2

Priority Issue 1 - Language barrier:

‘A language barrier is a significant structural obstacle that can prevent people from accessing and receiving continuing mental health care, and attaining improved health status and outcomes. There is a strong association between language barriers and stress levels and instances of self-reported poor health. Those with low English language proficiency are more likely to seek assistance for mental health problems from primary care, rather than specialist providers. Language barriers may also limit or confuse communication about emotional and mental health problems, as the majority of the assessment and treatment options for mental illness are based on communication’ (Multicultural Mental Health Australia, 2014). The following key issues were identified in relation to language barriers:

• Sometimes there is a need to rely on interpreters.

• There can be difficulties understanding interpreters, in particular when engaging over telephone.

• The language used by service providers is not always easily understood or translated to other languages.
Priority Issue 2 - Timeframes:

Key issues highlighted by the RAS working group were:

- **Referrals are not made soon enough and the process is too slow.**

Recommendations:

1. Volunteer advocates assisting with language barriers and different cultural understandings.
2. When going through the referral process their stories have to be retold and the retelling can be very traumatising. A person can own their story for example by having a hard copy of their story that can be read by all professionals.
3. Self-referral to mental health services.
4. GP needs to be kept updated with form changes — this lack of knowledge slows process.

Priority Issue 3 — Medication is not enough

Key issues highlighted by the RAS working group were:

- **Medication is not enough — people need other strategies and activities to help them get well.**
- **Medication — Clinical rather than ‘preventative, self-help, peer-supported and health-promotion pathways**
Priority Issue 4 – Lack of information:

Key issues highlighted by the RAS working group were:

- **New arrivals are not given the information they need about mental health services in Australia.**
- **There is not enough information given to community leaders/members about mental health to reduce stigma.**

A lack of understanding of the mental health system in Australia and different cultural understandings by clients are major barriers to successful referrals. While there is some information given regarding the Western model of health and the services available when people initially settle in the Geelong region, there does not appear to be any other information pathway or strategy in place for them to receive a greater knowledge and understanding of this complex area. Due to the stigma around mental health for many communities engaging clients to share knowledge is also extremely challenging.
Key issues highlighted by the RAS working group were:

- Police being called to assist someone with a mental health issue instead of a mental health professional/crisis team.

Recommendations:

1. Youth Mental Health First Aid taught in schools.
2. Mental health crisis team to come to the home and schools instead of police.
3. More specific people in schools trained to manage/support mental health issues.
4. Alert card – information for communication and language spoken.
5. More people from different cultural backgrounds employed in mental health and emergency services in the Geelong Region.
6. Attend meeting of Emergency services to present issues and recommendations.
Conclusions

‘The importance of hearing the consumer’s voices, experiences and stories was very powerful and confronting at times. It clearly demonstrated the importance of co-design and consumer input when planning system and service changes and improvements’ (service provider).

The ‘Working With us – For us’ co design project has achieved a number of outcomes utilising the EBCD framework. A group of nine service users and carers and three bilingual support staff from a Refugee background have been engaged and committed to working in the project, together with eight service providers in senior roles from five organisations across the Geelong region. This group of service providers are the champions who are the links back to senior executives and management processes within their organisations – these links are key to the success of the project. Five barriers were prioritised, twenty-four recommendations were developed to address these issues and a presentation was made to executives and key management in mental health service provision in the Geelong region. Outcomes have also included capacity building for all participants. RAS service users have a much greater understanding of mental health from a Western perspective and a resulting decrease in feelings of stigma and shame. Participants also reported having a greater understanding of the mental health service system in Geelong and have been sharing this knowledge with their families and communities with some reporting they have been encouraging people to seek help if needed.

‘I will tell my friends if they have a mental problem they should mention it without feeling embarrassed and talk with a service provider as soon as possible’ (Service User).

‘During this project we learned how to treat a person with a mental illness in a fair and good way. We learned that these illnesses need care and treatment – like a physical illness. We should treat them well and help them to gain their health’ (Service user).

With the opportunity to share experiences, to problem solve as a group, to feel listened to and valued, individuals have grown in confidence. Having the courage to stand up and present personal stories to a large number of people has been an enormous achievement and demonstrates their commitment to making a difference to improving the mental health service system in Geelong. The knowledge that they were considered to be the experts of
their experience accessing mental health services and that they did have something of great value to add to the co design process was an empowering experience.

‘Good cooperation, better understanding. Shared ideas and express feelings’ (Service User).

The service providers have gained confidence in working cross culturally and with interpreters. They have also gained a much deeper understanding of the barriers and the issues faced by communities from a RAS background and a real commitment to seeing sustainable changes made within their organisations and across the Geelong region.

‘Hearing these experiences crystallised the challenges around the community’s cultural understandings and stigma surrounding the western model of ‘mental health’ and clearly identified that further work within communities is needed’ (Service provider).

The service providers involved in the co design process can see the real benefits of including service users in the process of designing and evaluating services in order to work together to develop sustainable long-term changes.

‘It would have been better to have more time to further develop the recommendations and how these could be actioned: Talk to Action. So that the co-design could also be part of how the recommendations are designed as well as what the recommendations are’ (Service Provider).

When working with CALD and specifically with RAS service users and carers, training and support is required to ensure some understanding of the Western model of mental health, service provision, co design and their role within the process and working cross culturally. Service providers require a clear understanding of the co design process and their role, participatory research models, strategies to mitigate the power imbalance and working cross culturally and with interpreters. Training and support needs to be embedded into all co design procedures and is vital when working with any client group.

‘At the client, service provider partnership level it would be good to have more training for the Service Providers on how to interact and work with clients from a CALD background’ (Service provider).

The next step needs to be the continuation of the co design process to work on experiences of very specific ‘touch points’ within these recommendations. While the RAS working group
have reported that they have been heard, valued and understood they are also waiting to see what happens next.

‘I would like to see the action plan for the recommendation and implementation’ (service user).

It is essential that collaboration and EBCD is encouraged and enabled by all mental health service providers in the Geelong region. The use of the language and ideal of co-design can easily become rhetoric if a co-design framework is not embedded into all service systems and supported with training, procedures, policies, resources, and of critical importance leadership. The G21 Governance Group has a role to play as its purpose is to coordinate and monitor efforts that improve quality of care and outcomes for refugees and asylum seekers engaging within the mental health system in the Barwon Region.

‘What is the continuity plan and commitment from those that will be taking this forward? Consistency of agency representation and for each of those players to raise (and respond to) these issues with their respective organisations is critical so that this can get even more awareness, traction and response’ (Service provider).

Whilst so much has been achieved the EBCD process cannot end with the completion of the project timeframe and a written report. The project brief was very broad; therefore the recommendations at completion of the project are quite broad. While research and the project outcomes support that collaborative mental health practice can positively impact service user and carer wellbeing it is critical that this working group of service users, carers and service providers receive continued support and opportunities to translate these recommendations into meaningful and sustainable practice realities.
Appendices

Appendix 1: Stories

First country — third country — medical reports sent to settlement services but seem to be ignored. Some of the staff at Diversitat do not seem to have knowledge and training about how to work with a person with mental health issues or stressed people. It’s about the way they use their voice, the way they dress and their manner. I am talking about bilingual staff, maybe someone who comes about housing or caseworkers. It doesn’t matter what their role is if they are working with us they should have more training about mental health.

When an ambulance was called when a person had a seizure the ambulance workers insisted the patient walk to the ambulance — despite muscles being seized up — they were dragged to the ambulance saying the patient was faking it — when this was heard the patient had another seizure.

On another occasion when an ambulance was called they came in with the stretcher. They spoke loudly. They didn’t say what they were doing and then they started to strap the patient on to the stretcher — the patient didn’t understand what they were doing or why and got very upset and started to resist until a worker told them you need to explain what you are doing.

Medical file comes with the patient — but here they must start everything again — so many visits to the GP and many appointments — a three-month process — far too long for someone needing medication and treatment. Repeating story too many times with new workers. Appreciate what has been done by some workers but once they leave we have tell the story and all that has happened again.

Crucial time for people is the first few weeks when they need the most help — while they might have arrived on a comfortable plane no one knows what trauma they have been through.

After 4 years in turkey where life was hard to make ends meet and it was a very difficult life — I used to promise my family that soon they would go to another country and everything would be alright. As a father I provided for my family and I must protect them. When we came to Australia we arrived at 2am to a house that was cold and dirty with lots of spiders. The
heating was broken and didn’t work. My family was asking me what did you mean it would be better?? My children were crying in the corner. I felt very responsible. I am still here but I don’t want others to go through this.

When you need assistance from a GP they see you as someone who is trying to get Centrelink. They should never generalise for everyone. I went to a psychologist on a day after no sleep — my eyes were very tired and dry and I was blinking a lot — the psychologist was imitating the blinking – he was mocking me.

Many problems in Pakistan and our own country — big hopes that things will be much better in this country. At first happy to arrive then we had days with no food and did not know where to go. Then my brother’s sickness started. My brother had an appointment at the hospital for a sore arm and he was taken to the hospital by a caseworker because we were moving house on the day and he was 18 so we did not go with him. He was not dropped back to the new house and he did not know where to find us. He had no way of contacting us so he spent from 4.30pm–11.30pm wandering the streets of Geelong lost. He did not know who to ask for help – he had no English. We were very worried when he did not return and we didn’t know what to do. We finally got hold of a community guide who drove all over looking for him. When we finally found him he was crying and shaking – we were all very scared. He was so upset and asking my mother why did you bring us here to this terrible place. He started school but believed that other students were laughing at him. He wanted to go back to Afghanistan: “these people here are not good people”. There was a situation at the school — the principal called the police — he thought he would be taken to prison — he asked his mum to just take him home but the principal wanted him to be taken to hospital by the police. He was very scared and ran away from the school so we lost him again. At home he had finished high school and had started uni — there was no sickness until he was left like that at the hospital. If we take him to the GP — they say go to the hospital I cannot help you – we don’t understand what is happening to him.

Life is very challenging in Australia — a lot of pressure when we first arrive — Centrelink, job search — much more than we are used to — it’s a real mental pressure – not used to doing all these things. They want us to solve the problems we have like Australians but we don’t have the skills — we are from developing countries — for e.g. we do not have computer skills. My son had the start of a mental health issue in Afghanistan but here it has got much worse.
There are so many challenges – he wants to be like everyone else and to fit in. He punched a boy at school who was teasing him and bullying him — the principal called the police — from that day he has not wanted to go to school.

Headspace — everyone askes the same questions and asking his story over and over again but there are never any answers.

Not sleeping, walking around — please give him medication to help — we can’t do that this time we will make another appointment — with medicine he has put on a lot of weight – 110kg. It is always next time we will do something. Blood tests done but we are never told the results.

With medication he sleeps late — his whole life is destroyed. I don’t know what to do — I don’t know the rules of Australia. I’m stuck in one place and I can’t help my son. Sometimes I am thinking I should take him back to Afghanistan to a doctor — we can’t afford private care here. I don’t know what to do....

Story of pregnant woman told her baby was very abnormal and would die. What a shock this is to a new arrival — only here a few weeks. Discussion around how this news was told and that culturally Australians are too direct and blunt in the way we give this information. Other cultures would make sure the person had support or tell a family member who would tell person when the ‘time was right’

I want to tell a positive story first. When we arrived everything going well. We arrived at the airport and given a warm welcome. We felt welcome after being in a remote camp in Thailand where we saw no one friendly and had nothing. But we had to learn from zero. We had never had a phone, computer or car. We felt supported by Diversitat staff and caseworkers at first but then the support got less and less — like a tank of water that starts full and slows to a drip.

My sister is different ability — support for her less and less — I worry about the future. I have been here 3 years.

Phone interpreters make it very difficult — on site much easier. I often can’t understand the phone interpreter. When a decision has to be made I need good information but when I can’t understand I just say yes to anything and then things get worse and more confusing.
It is hard to keep having to repeat the story to people — re traumatising.

Some organisations offer more support but nothing happens.

As was mentioned — not the education- everything you need is on a computer so I don’t get information because I can’t use the computer. Another eg of this is getting information about my sons and what is happening at school — I just don’t know anything because I can’t use a computer. It is very hard.

Before we came to Australia people told us that we would never be allowed come here with a person with a disability. This caused a lot of stress, but finally we came to Australia. I was stressed when I had to report to Centrelink that I had a kid with a disability but they said its ok here we have many people with a disability. So it’s ok.

I feel like the trauma is repeated when organisations come to assess — taking photos, checking everything — just trying to get some help. Everyone asking why she doesn’t talk — when and why all the time. I don’t know the answers. I cannot answer the same thing so many times — sometimes I say my child used to speak with me in the womb but then they stopped when they were born.

We came from developing countries — so many different systems — expecting access to health and education to be easier — better. Refugee is 3 countries — shocked that system here not better – waiting list for so many things — 3 years if not urgent. Need a stable job to get private cover.

Not always the support you need. My daughter is living on her own but she has no idea about money or what she needs to do living on her own. There has been some support but not enough.

Children’s mental health ward was helpful but as older it is harder to get help. I am getting support from friends from Australia. We have been here 12 years. Grateful we are in Australia before she got this problem — in our country they would see things differently – done something wrong and now suffering for it — but we know here that we are just unlucky to get something like this — just like getting cancer or another illness. When she first got sick I didn’t know what was happening I thought she was just playing up and being naughty. I had
no understanding of mental health illness. I didn’t know what to do. It is so hard. It is still so hard.

Now she is older I can’t get information but it is still me who has to care for her even though she is living on her own. She is too sick to do everything and she could not got to school from Year 7. She needs a lot of help. Makes it harder if you are not kept informed just because she is an adult.

Appendix 2: Full list of Barriers and enablers barriers noted by the RAS working group: Repeated trauma from repeating stories.

- Making an apology is not good enough; action is needed.
- Lack of training in mental health for settlement workers.
- Not enough support for people with mental health issues who are new arrivals.
- People accessing medical services do not always feel respected or have confidence and trust in the care/advice they are given by mental health professionals.
- Lack of or the wrong support received by new arrivals in first weeks can have a negative impact on mental health.
- A lack of support for family members who are cares and or siblings, children of person with mental health issues.
- Slow procedures and processes to get referrals can have a further negative impact on mental health.
- Lack of acknowledgment and use of previous medical history by caseworkers and medical services.
- Medication is not enough — people need other strategies and activities to help them get well.
- Lack of cultural sensitivity by medical staff.
- Lack of professionals with mental health training working at schools.
- No consideration of potential fear Refugee and Asylum Seeker communities often have of people in uniform, in particular police officers — often make issues worse when police sent for.
- Police being called to assist someone with a mental health issue instead of a mental health professional/crisis team.
• Service providers make promises but often do not deliver any action.
• Language barriers. The need to rely on interpreters and difficulties understanding telephone interpreters.
• Long waiting lists.
• Ambulance staff need more cultural awareness training and more respect shown to patients.
• Referrals not made soon enough for new arrivals — e.g. NDIS.
• New arrivals not given the information they need about mental health services in Australia.
• Not enough information given to community members/leaders about mental health so that communities have a better understanding and reduce stigma.
• Family, especially main carers are not kept informed and involved.
• Orientation is too intense. It is not possible to remember the information when given day after day.

The following positive experiences were also noted of mental health services:

• Professionals visit clients at their homes. Clients feel more comfortable at their own homes so are more relaxed and more able to express their thoughts.
• Community members stay with the unwell person every day so they are not left alone.
• Centrelink payments for carers is a positive, as enables carers to stay at home and spend time with person.
• The future of people with a mental illness is guaranteed in Australia because they are respected as a human.

Appendix 3: RAS working group Presentation 1 Service provider feedback

1. What was your impression of the presentation?

• The storyboards from each of the individuals were very powerful and provided meaningful examples of their respective issues, as well as an understanding of their own health and well-being in that context and/or as a result of their experience(s).
• Rapport and trust was clearly well established between project manager and RAS working group.
• Responses from RAS working group were clear, honest and raw.

• The breadth of challenges experienced and the complexity of the issues are incredibly complex. Breaking these down into ‘bite size chunks’ that are attainable may be challenging for the Governance group.

• The importance of hearing the consumer’s voices, experiences and stories was very powerful and confronting at times. It clearly demonstrated the importance of co-design and consumer input when planning system and service changes and improvements.

• I valued the presenter’s honesty, passion and commitment to advocating for a better mental health system. I appreciated their willingness to share personal stories about their experiences in Geelong and I left feeling very honoured & privileged to have been able to hear first-hand information. I felt it was a very powerful session.

• Excellent presentation and the use of storyboard is absolutely the most appropriate method. I think we should be able to continue to use it going forward.

• Engaging and moving. Interpreters and participants worked well together to educate the audience. Genuine.

2. What could be improved on?

• It’s important to keep their stories real and authentic – this came across strongly and so I would stick with that. My only concern was whether or not (or how) to comfort or support those individuals that were clearly (and understandably) distressed when telling their stories. At the other end of this is also how to pull back on some, e.g., the last one so that the issue is not lost in a myriad of others.

• It would have been interesting to hear more about their experiences once they entered/ received services, or what the referral process was like.

• In some stories it felt like it was just skimming the surface of their experience.

• I felt sometimes the use of interpreters meant that the key messaging was lost a little in translation. It also seemed that the questions asked from the audience were not fully understood, so therefore the replies were not as comprehensive as they could
have been. Maybe the key messages from each presenter could have been highlighted at the end of each session.

- Not sure about anything that can be improve on as this is life stories from people that we hearing about — v raw and moving.

- The set up of the room, rather than tables open the audience to the presenters with a semi-circle of chairs.

3. **What did you learn?**

- It was more reinforcement for me of the challenges and struggles that this ‘population’ faces and with the added challenge of interpretation and potentially being dismissed by practitioners, to a point that they may themselves retract and not seek the support that they need.

- The storyboards were very effective when helping the RAS working group explain their stories and experiences.

- Experiences with first response services and service providers (Ambulance and police) was a strong part of the RAS working group members presentations and clearly a huge barrier when trying to access appropriate services.

- The examples of the clients being admitted to services and then told to return home because staff weren’t able to communicate with them, even though family members were not able to cope either was very alarming.

- Hearing these experiences crystallised the challenges around the community’s cultural understandings and stigma surrounding the western model of ‘mental health’ and clearly identified that further work within communities is needed.

- Responses regarding the wellbeing/social isolation within communities was not surprising but certainly clearly identified the important and need to address this too.

- Information provided to RAS communities through the settlement process regarding mental health and accessing services was unclear. The stigma surrounding mental health is clearly something that is very challenging for RAS community members due
to the ingrained cultural understanding or lack of information surrounding mental health.

- The general fear about the police that still exists within the communities; the stigma of mental health and feeling of embarrassment that is strongly felt by the families and their community; also the frustration about lack of information from mental health providers.

- Learning a lot — especially about how difficult it is to navigate a system. Too much to recall in an email.

- The challenge of inpatient units to support people for a period of time if the patient speaks a language other than English. Some of the challenges are similar to what existing patients of mental health services experience for example, police turning up when the ambulance is called, medications being the main form of treatment with little support for group activities, not knowing what mental health services to access etc.

4. **What long-term benefits are there from this approach?**

- The approach needs to be sustained and told to more ‘influencers’ in this space. Other CEO’s, such as those from G21 and Barwon Health, including clinical leaders, need to see and hear these stories.

- Learning directly from the RAS group will inform future planning and ongoing collaboration.

- Incredibly powerful source of information that has been missing from work previously undertaken. Raises questions that we may have been focusing our resources and energy on areas that are not as critical. This has been invaluable to understand the barriers and challenges experience from both sides.

- Hopefully we can work together to make sustainable long-term changes and the participants feel heard, valued and understood.
• I believe that there are exceptionally good long-term benefits with this approach and it should be encouraged. A paper should be written, presentations made and dissemination of information be made possible through a number of channels.

• Capacity building for participants, educating and influencing service providers to improve customer experiences, shared problem solving.

5. **Any other comments**

• What is the continuity plan and commitment from those that will be taking this forward? Consistency of agency representation and for each of those players to raise (and respond to) these issues with their respective organisations is critical so that this can get even more awareness, traction and response(s).

• It has been a great privilege and learning experience to hear directly from this group of people.

• Looking forward to seeing the next steps of the co-design process unfold.
References


