A mental health research agenda for people of refugee background in Australia: a consensus study

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ABSTRACT

Background: There is a need to develop a comprehensive and coherent mental health research agenda to guide the development of policy and practice relevant mental health research for children, young people and adult of refugee background.

Aim: To develop a mental health research agenda for a) children/young people and b) adults of refugee background for Australia.

Method: On-line surveys were used to develop consensus on research priorities in refugee mental health. A panel of experts was established, with representation from refugee health and mental health providers, other service providers, researchers and health policy makers. A round table discussion had previously identified broad priority areas in refugee mental health. These themes, together with themes from other research agendas, were used to develop an open-ended survey that was administered to the expert group and additional relevant providers identified by the group. Respondents were asked to provide three research questions relating to nine research domains for children/young people and for adults. These responses were collated, summarised and used to develop a second survey, where respondents were asked to rank the importance of research questions using a 3-point scale. Research questions ranked as essential by 50% or more of the respondents were deemed to be a consensus and high priority items.

Results: 71 participants were invited to complete the first survey; 51 (72%) surveys were returned, with 916 research questions identified. These were analysed and collated into 123 research questions on refugee children/young people and 113 questions on refugee adults for ranking in the second round. In the second round, 39/51 surveys were completed (76%, 55% original sample). Consensus was reached for 61 research questions relating to mental health in refugee children/young people, and for 49 research questions relating to mental health in refugee adults. Key research priorities were similar for both age groups and included the design and delivery and location of mental health services for refugee clients, how existing services can be adapted and extended for refugee clients, the prevalence of mental health problems in refugee clients, and factors promoting resilience and successful transition to life in the new country of settlement.

BACKGROUND

At the end of 2009 there were 36.5 million people of concern to UNHCR, including refugees (8.8 million), internally displaced persons, stateless persons and asylum seekers (UNHCR, 2010a). Women and girls constituted 47% of refugees and asylum-seekers and 41% of refugees and asylum-seekers were children below 18 years of age (UNHCR, 2010b). Developing countries are host to four-fifths of the world's refugees (UNHCR, 2010b). During 2009 only 112,400 refugees were admitted by 19 resettlement countries[1]. Australia accepts 13,500 refugees through its Humanitarian Program annually, including people whose visa applications are processed overseas (offshore applicants) and people arriving as asylum seekers who are subsequently granted Humanitarian visas (onshore applicants).

People of refugee background experience multiple forms of disadvantage, including rates of long-term physical and psychological problems that are higher than for other immigrants (Victorian Refugee Health Network, 2009; Department of Human Services, 2008). Although research in this area is scarce, people of refugee background are also known to be at higher risk of suicide (Baron, 2002; Vijayakumar & Jotheeswaran, 2010).

Reviews of prevalence studies (e.g. Davidson, Murray & Schweitzer, 2008; Fazel, Wheeler & Danesh, 2005; Gerritsen et al., 2004) show a huge range in reported mental health disorders prevalence rates among people of refugee background, due to the heterogeneity (especially sample size) of the study population and the measurement instruments and process (e.g. interviewer non-native to the refugee's ethnic group vs. native). For instance, the prevalence rates for depression range from 2% to 88% and from 3% to 86% for post-traumatic stress disorder (PTSD). Similar percentages are reported for the prevalence of anxiety (2% to 80%). However, the meta-analysis by Fazel, Wheeler and Danesh (2005) suggests that about one in ten adult refugees in Western countries has post-traumatic stress disorder, about one in 20 has major depression and about one in 25 has a generalized anxiety disorder, with the probability that these disorder overlap in many people (i.e. high levels of comorbity). Although research is much more limited on children/youth, studies reported in this meta-analysis suggest even higher prevalence rates (at least for PTSD) in this population.

Following initial health assessment, refugees commonly need referral to specialist

[1] As specified by UNHRC (2004, p. 1), 'resettlement' involves the selection and transfer of refugees from a State in which they have sought protection to a third State, which has agreed to admit them – as refugees - with permanent residence status.

services such as paediatrics, maternity care, and specialist mental health (Department of Human Services, 2008). As will be indicated in the following paragraph, concerns have been raised around issues of underutilization and lack of engagement with mental health services among this population.

Underutilisation and lack of engagement with mental health services

Refugees are identified as having multiple risk factors for mental health problems and suicide, however rates of contact with specialist mental health services appear to be lower than expected (see Colucci, Minas, Szwarc & Guerra, under submission, for a review of the literature). Newly arrived refugees can often experience difficulties in accessing health and community services in a timely and effective way (Department of Human Services, 2008). Factors that constitute impediments to service use, and factors facilitating appropriate access to mental health services, are poorly understood. For those who make use of mental health services, there is little information about the quality of services received or about treatment outcomes. There is a need to understand, and improve, refugees' engagement with mental health services, and to identify what works and what does not work when providing mental health services to this population.

The importance for research, practice and policy to be aligned is indicated, among others, by Beiser, 2009) thus a short overview of relevant Australian policies will now be provided.

The mental health reform agenda and refugee health policy

At the end of 2009, the Australian Health Ministers' Conference launched the "Fourth National Mental Health Plan: an agenda for collaborative government action in mental health 2009-2014″ (Commonwealth of Australia, 2009). The plan prioritises social inclusion and recovery; prevention and early intervention; service access, coordination and continuity of care; quality improvement and innovation; and accountability, measuring and reporting progress. "Vulnerable children and young people with experiences of abuse or trauma" are identified as a priority group. Furthermore, the document indicates that, while education regarding mental heath problems should incorporate those issue and problems, which are common, front line workers also need to be able to recognize and respond appropriately to those who present with more complex problems as well as having an appreciation of issues facing particular groups such as refugees.

Recognising the need to improve the mental health outcomes for refugees and their families, the Victorian refugee health action plan (Department of Human Service, 2008) outlined a number of key actions including supporting the primary health care system to work more effectively with refugees and recognise the signs of poor mental health in refugees at an earlier stage and improving the cultural competency of specialist mental health services. Several research projects addressing these priorities have been supported by the Department of Human Services and listed in the action plan such as a project to explore models of specialist care for refugee patients, a status report on the health and wellbeing of refugee children and young people, and research into patterns of alcohol and drug use among refugee young people. There is no mention, however, in the document of the development of a research agenda to establish these or other research priorities in the sector, and similar agendas do not seem to have been developed neither in the other Australian states and territories. Nevertheless, the need to develop a mental health research agenda was specifically mentioned in the National Mental Health Plan (Commonwealth of Australia, 2009).

The need for a refugee mental health research agenda in Australia

Gaps in knowledge affect the capacity of government and service providers to address the needs of refugee background Australians with mental health problems effectively. Developing a research agenda offers an opportunity to formulate relevant research questions, address need, create partnerships, reduce duplications in research as well as ad hoc or reactive research. A research agenda can also motivate and assist public and private funders into supporting research, and can engage students (and early career researchers) seeking research topics (Kirchner, Gold & Goodrich, 2005).

Although, as mentioned above, the importance of establishing a mental health research agenda was indicated in the National Mental Health Plan (Commonwealth of Australia, 2009), no previous refugee research agenda for Australia was found in the literature. The two closest agendas found were unpublished research questions raised during consultations carried out by the Department of Human Services (2010) for the project: *Connections for "At risk" young refugee people. Making crisis supports work*, the research priorities in mental health (not specific for migrant and/or refugees) by Jorm, Griffiths, Christensen and Medway (2002), and in New Zealand (Te Pou, 2008). These latter was a research agenda for migrant and refugee's mental health and addiction.

This study was conducted as a collaboration between the Centre for International Mental Health (University of Melbourne), the Victorian Foundation for Survivors of Torture (VFST), Foundation House), the Centre for Multicultural Youth (CMY) and the Royal Children's Hospital. The study objectives were to develop a mental health research agenda for a) children/young people[2] and b) adults of refugee background in Australia.

This project is one of three linked projects; the other projects are a qualitative study of practitioners' views about providing effective mental health services to young people of refugee background (see Colucci, Szwarc, Minas, Paxton & Guerra, under submission) and a roundtable discussion including young people of refugee background, service providers, policy makers and academics, to ascertain young refugees' perspectives on mental health services (see CMY, 2011). These three linked project were result of a round table discussion that was held, at the end of 2009, at The University of Melbourne between experts and key stakeholders involved at several levels with young people of refugee background (e.g. policy makers, senior health, mental health and allied health professionals, academics, community workers and representatives from the refugee communities), (VFST, 2009).

METHODS

Traditionally mental health research funding has tended to use a disease-focused approach to determine funding priorities (Jorm et al., 2002), however there is increasing recognition of the need to establish broader research priorities and develop research questions by eliciting the views of relevant stakeholders across a variety of disciplines (Jorm et al, 2002; Jorm & Minas, 2010). Consultations with clinicians, service providers, researchers, research consumers and other stakeholders such as politicians and the general community have been carried out through a variety of methods including individual interviews, focus groups, surveys and consensus methods (see Jorm et al. 2002, for examples).

In this project, on-line surveys were used to develop consensus on research priorities in refugee mental health for children/young people and adults. The procedure for the development of a mental health research agenda for people of refugee background involved the eight steps indicated below:

[2] The term children and young people in this context was used to refer to the age period 0 – 25 years.

1. Roundtable discussion (where the three components of the project were conceived);
2. Construction of an Expert Panel (including criteria for selection);
3. Preparation of the open-ended survey;
4. Open-ended web-based survey of refugee experts to generate information about important areas for research (Round 1);
5. Construction of a list of research questions suggested by the expert panel, in addition to those generated from the literature review;
6. Web-based structured survey to elicit consensus concerning the essential components of a refugee mental health research agenda (Round 2);
7. Construction of the agenda;
8. Dissemination of the agenda.

Ethics: Ethics approval for the study was obtained from the University of Melbourne (ID 0932986) and the VFST Ethics Committee.

Expert panel

Participants at the initial roundtable were invited to be part of the experts' panel to obtain their views about key research questions and priorities. To this initial list were added other stakeholders who were suggested by other participants, well-known individuals who deal on a variety of levels with people of refugee background and individuals identified through web/literature search. Potential participants were invited to take part in the study if they were currently working in Australia and had been identified, by others or in the literature, as having expertise in refugee mental health.

The final sample of participants who were invited to take part in the study was composed of 71 academics, key practitioners and policy makers from Victoria and other Australian states. They received an email invitation to become part of the panel of experts and a link to survey, together with the Plain Language Statement (PLS).

Surveys item development and consensus procedure

The above-mentioned roundtable discussion with the expert group was used to identify broad priority areas in refugee mental health (VFST, 2009). These priority areas, together with priorities highlighted in Te Pou (2008), were used by the research team to identify the main types/domains of refugee mental health research for the first survey (see Box 1).

Box 1. Nine domains identified in refugee mental health research
1. Epidemiology/prevalence of mental health problems 2. Understanding determinants of mental health (e.g. what are the key risk and protective factors) 3. Assessment of mental health problems 4. Conceptualization of “mental health/illness” and help-seeking strategies 5. Mental health service models/systems 6. Mental health services utilization 7. Treatment methods and interventions’ evaluation 8. Mental health promotion 9. Research methodology

In **Round 1** of the research agenda development, panel members were sent an individualized link to an on-line survey that was administered using the SurveyMonkey application. After giving consent to take part in the study, participants were asked to complete the on-line open-ended survey. The survey consisted of the nine broad research domains indicated above.

In relation to each of the nine domains, panel members were asked to identify three key research questions for child and young people of refugee background (i.e. up to 25 years of age) and for adults (over 25). They were also asked to provide any additional research domains and/or questions, describe their own roles in relation to refugee mental health and for any additional comment or feedback. Participants were sent two email reminders where no response or incomplete surveys were received by deadline.

During the first stage of the study, 976 answers were collected. Answers that were unclear or vague, not explicitly linked to mental health or were not a question but a comment, were excluded. The remaining 916 research questions proposed by the panel of experts at Round 1 were collated and summarised. A few additional questions, or an aspect of a question, were added looking at the current international and national literature, in particular at research priorities set in the research agendas mentioned before and from a literature review on children and young refugee’s utilization of mental health services (see Colucci, Szwarc, et al., under submission). Using the questions generated through this process, a questionnaire was prepared for the **Round 2** of the study, which was designed to assess which research questions had strongest support among respondents.

As for Round 1, panel members received an email with an individualized link to a second online survey. They were informed that the research questions in the survey

represented all the significant themes and issues that emerged from the questions suggested in the first round of the survey, as well as a few additional questions from the literature.

Panel members were asked to rate the level of priority of each research question for mental health research with children and young people and with adults, unless the question was not applicable to one or the other. They were then given a list of research questions divided in the nine research domains as for the previous survey and were asked to rank the importance of research questions using a 3-point Likert scale:

- *Essential* (if they agreed that without an answer to the question Australia's ability to contribute to a better mental health of people from refugee background is seriously hampered) or
- *Important* (if they agreed that Australia's ability to contribute to a better mental health of people from refugee background would be assisted by having an answer to the research question).
- The option *Neither/Uncertain* could be selected if the respondent thought the question proposed was neither "Essential" nor "Important", or if they were uncertain of the item's importance.

Participants were made aware that only the questions rated "Essential" would be considered high priority in the final research agenda and that only the participants who took part in the first round of the study had been invited in this final round. Also in this second phase of the study, participants were sent an email invitation and two email reminders where no response or incomplete surveys were received.

As will be further described, the five items that received the highest score across research domains for children/youth and for adults were used to set the top priorities for the research agenda. Furthermore, for each domain, the three items that were rated "Essential" by the greatest number of respondents were indicated. A similar approach was used by the Lancet Global Mental Health Group (2007). However, while they used the leading five research questions for their four domains, the authors decided to limit the selection to the three leading questions (because of the larger number of domains in the current study) that were ranked as essential by 50% or more of respondents.

RESULTS

At Round 1, 51 surveys were completed by individuals or groups. During the data collection, we were informed by some participants that they had developed research questions as a group (e.g. in a group meeting) and a representative of the group had then completed the survey on behalf of the group.

Participants who contributed to the Round 1 of the study were approximately equally distributed across the areas of activity we planned to involve in the project: University/Academia, non-mental health and mental health services and government/policies (see table below).

Table 1: Expert panel – primary areas of activity

Participants' primary area of activity	Percentage
University or other research sector	23%
Mental health service: specific for refugees and immigrants	21%
Other (generalist) mental health service	9%
Other (non-mental health) service for refugees and immigrants	21%
Government	18%
Other	9%

The 916 research questions proposed by these participants were analysed, grouped by themes and collated into 123 questions relating to children/young people and 113 questions relating to adults for rating in the second round survey. This survey was returned by 39 participants (which, as above, represented answers by individuals or groups). Consensus (i.e. item rated "Essential" by 50% or more of the participants) was reached for 61 research questions in refugee children/young people and for 49 research questions in refugee adults. These results are summarized in the figure below whereas percentages for each research question are provided in Appendix A.

ROUND 1

First survey distributed

(open-ended, divided into 9 research domains)

⬇

71 participants invited in the first survey

⬇

51 surveys completed

(916 suggested research questions)

⬇

ROUND 2

Second survey developed

(with 123 research questions divided into 9 domains)

⬇

39 surveys completed

(Consensus reached for 61 research questions for children/young people and for 49 questions for adults)

The five items rated as essential by the highest proportions of participants across the research domains are shown in Table 2.

Table 2: Priorities in refugee mental health research

Rank	Children/young people	Adults
1	How can services be adapted and extended to better meet the needs of children and young people of refugee background?	How can services be adapted and extended to better meet the needs of people of refugee background?
2	What determines/promotes resilience and successful adaptation among children and young people of refugee background?	What is the prevalence of mental health problems, including trauma related disorders, among people of refugee background?
3	What elements of the design and delivery of mental health services are most important for children and young people of refugee background?	What elements of the design and delivery of mental health services are most important for people of refugee background?
4	Where should mental health services targeting children and young people of refugee background be delivered and what form should they take?	Where should mental health services targeting adults of refugee background be delivered and what form should they take?
5	What is the prevalence of mental health problems, including trauma related disorders, among children and young people of refugee background?	* What determines/promotes resilience and successful adaptation among people of refugee background? * What protective factors in people of refugee background are supporting positive mental health and well-being?
		* equal rank

Table 3 shows details on the three highest ranked items for each of the research domains were a consensus was reached (i.e. agreed by 50% or more of the participants). Research questions have been listed in ranking order and, when two or more questions received the same ranking positions, the same number has been used to indicate their rank. The table indicates both the rank and percentage of agreement that the research question is a priority for the refugee's mental health research agenda.

Children/young people		Adults	
DOMAIN 1. EPIDEMIOLOGY/PREVALENCE OF MENTAL HEALTH PROBLEMS			
1. What is the prevalence of mental health problems, including trauma related disorders, among people of refugee background?	77%	1. What is the prevalence of mental health problems, including trauma related disorders, among people of refugee background?	72%
2. In what ways do mental health problems affect the lives of people of refugee background?	69%	2. In what ways do mental health problems affect the lives of people of refugee background	64%
3. How does the prevalence of mental health problems among people of refugee background change during resettlement?	54%		
DOMAIN 2. UNDERSTANDING DETERMINANTS OF MENTAL HEALTH			
1. What determines/promotes resilience and successful adaptation among people of refugee background?	82%	1. What determines/promotes resilience and successful adaptation among people of refugee background?	69%
2. What protective factors in people of refugee background are supporting positive mental health and well-being?	72%	1. What protective factors in people of refugee background are supporting positive mental health and well-being?	69%
3. What are the key mental health determinants (risk and protective factors), pre and post arrival, in people from refugee background?	67%	2. What key risk and protective factors pre- and post-migration influence the mental health of people of refugee background (e.g. experience of trauma and torture, resettlement)	61%
DOMAIN 3. ASSESSMENT OF MENTAL HEALTH PROBLEMS			
1. Which mental health assessment tools and procedures are suitable and culturally appropriate, and validated, for people of refugee background?	65%	1. Which mental health assessment tools and procedures are suitable and culturally appropriate, and validated, for people of refugee background?	68%
1. What support do mental health service professionals require to enable them to perform culturally appropriate assessments of people of refugee background?	65%	2. What support do mental health service professionals require to enable them to perform culturally appropriate assessments of people of refugee background?	65%
2. What mental health assessment and procedures are essential for people of refugee background but currently unavailable?	57%	3. What mental health assessment and procedures are essential for people of refugee background but currently unavailable?	54%
DOMAIN 4. CONCEPTUALIZATION OF MENTAL HEALTH/ILLNESS AND HELP-SEEKING STRATEGIES			
1. What do people of refugee background think are the most effective methods of treatment for mental health problems?	72%	1. What do people of refugee background think are the most effective methods of treatment for mental health problems?	67%
2. What help-seeking strategies do people of refugee background use for mental health problems?	61%	2. What help-seeking strategies do people of refugee background use for mental health problems?	64%
3. How do people from refugee background and their families identify the presence of a mental health problem?	58%	3. How do people from refugee background and their families identify the presence of a mental health problem?	56%
		3. What are the understandings and explanatory models of mental health issues among people of refugee background?	56%
DOMAIN 5. MENTAL HEALTH SERVICE MODELS/SYSTEMS			
1. How can services be adapted and extended to better meet the needs of people of refugee background?	86%	1. How can services be adapted and extended to better meet the needs of people of refugee background?	80%

2. What elements of the design and delivery of mental health services are most important for people of refugee background?	77%	2. What elements of the design and delivery of mental health services are most important for people of refugee background?	71%
2. Where should mental health services targeting children/youth or adults of refugee background be delivered and what form should they take?	77%	2. Where should mental health services targeting children/youth or adults of refugee background be delivered and what form should they take?	71%
DOMAIN 6. MENTAL HEALTH SERVICES UTILIZATION			
1. What are the mental health service utilisation patterns and rates for people of refugee background (e.g. what services are they currently accessing, with what kind of problems)?	62%	1. What are the mental health service utilisation patterns and rates for people of refugee background (e.g. what services are they currently accessing, with what kind of problems)?	59%
1. What are the key barriers within refugee communities to access and engagement with mental health services? And how can these be overcome?	62%	1. What are the key barriers within refugee communities to access and engagement with mental health services? And how can these be overcome?	59%
1. What are the most effective strategies for facilitating utilization and engagement with mental health services by people of refugee background?	62%	1. What are the most effective strategies for facilitating utilization and engagement with mental health services by people of refugee background?	59%
DOMAIN 7. TREATMENT METHODS			
1. Which interventions are effective for which groups at which ages for which problems?	68%	1. Which interventions are effective for which groups at which ages for which problems?	65%
2. How effective are existing interventions/treatments in dealing with mental health problems among people of refugee background?	65%	2. How effective are existing interventions/treatments in dealing with mental health problems among people of refugee background?	62%
2. How can current mental health treatments/therapies be adapted to be culturally appropriate and effective for people of refugee background?	65%	3. How can current mental health treatments/therapies be adapted to be culturally appropriate and effective for people of refugee background?	59%
DOMAIN 8. MENTAL HEALTH PROMOTION			
1. What do people of refugee background see as the most effective means of promoting mental health?	68%	1. What do people of refugee background see as the most effective means of promoting mental health?	65%
2. What are the existing methods/models of mental health promotion designed for people of refugee background in Australia and how effective are they?	56%	2. What are the existing methods/models of mental health promotion designed for people of refugee background in Australia and how effective are they?	53%
3. What are the most important topics for mental health promotion for people of refugee background?	53%	2. What are the most important topics for mental health promotion for people of refugee background?	53%
3. What are effective ways of supporting families, religious bodies (e.g. church/temple/mosque) and schools to promote good mental health for people of refugee background?	53%		
DOMAIN 9. RESEARCH METHODOLOGY			
1. What research approaches best allow the voices of participants of refugee background to be heard?	56%	1. What research approaches best allow the voices of participants of refugee background to be heard?	53%
2. How can the inclusion of people of refugee background in mental health research on the general population be promoted and ensured?	50%	2. How can the inclusion of people of refugee background in mental health research on the general population be promoted and ensured?	50%

The mean scores in each domain for children/young people and adults of refugee background are presented in Table 4. How can be noted, the three domains that on average received the highest scores were “Mental health service models/systems”, “Mental health services utilization” and “Treatment methods”.

Table 4. Mean domain scores

Domain	Children/young people	Adults
Epidemiology/prevalence of mental health problems	44%	44%
Understanding determinants of mental health	46%	43%
Assessment of mental health problems	45%	42%
Conceptualization of “mental health/illness” and help-seeking strategies	42%	40%
Mental health service models/systems	57%	54%
Mental health services utilization	54%	51%
Treatment methods and interventions’ evaluation	51%	47%
Mental health promotion	50%	48%
Research methodology	42%	40%

DISCUSSION

Refugee mental health research priorities

The large amount of potential research questions indicated as high priority (61 for the children/youth refugee mental health agenda and 49 for the adult research agenda) highlights the necessity to increase, overall, Australian mental health research among people of refugee background, in particular among children and young people.

When the specific research questions are taken into considerations, it is clear that according to several Australian experts from University, services and government, a number of gaps are present in our knowledge of issues relevant to refugee’s mental health. For instance, gaps were indicated in relation to our understanding of the key protective factors, what promotes resilience and successful adaption among this particular population, as well as refugees’ conceptualization of what constitutes a mental health problem, and which kind of help they might seek and expect for those problems. Understanding the process by which ethnic minority youth and their families (including refugees) identify problems, seek help and engage in treatment, was indicated as a top priority also by Cauce and collaborators (2002).

More research is also needed to support the development of valid and culturally appropriate mental health assessment tools for people of refugee background. The need for culturally appropriate assessment was observed also in the refugee health action plan (Department of Human Services, 2008). The document indicated that language and cultural differences further increase the complexity of assessment (as well service provision). A variety of barriers can impact on the effectiveness and relevance of commonly used assessment and diagnostic tools and be significant barriers to access and accurate assessment. Even if the assessment tools were adequate, a number of factors could still interfere with the assessment process. For instance, some parts of an assessment may need to be delayed until trust is developed (Department of Human Services, 2008). Furthermore, even if a method of assessment measures what the researcher intends, results may hold a very different meaning for participants (Tempany, 2009).
Research could play an important role in improving mental health assessment and, with it, access to services.

The area of mental health services, from models and settings of delivery to barriers to access and effectiveness of treatments offered, urges research to enable us to offer adequate help to this population. This was evident from the high priority given to these domains and the specific item and reflects the scarcity of research in these areas (see Colucci, Minas, et. al, under submission), which was the reason why we undertook a study on engagement of young people of refugee background with Mental Health services (see Colucci, Szwarc, et al., under submission)
Also the National Mental Health Plan (Commonwealth of Australia, 2009) observes that implementation of new and proven service models and practices needs to be underpinned by a research agenda (including both quantitative and qualitative research led by or involving consumers). In particular, the national plan specifies that research and evaluation should cover relevant areas such as effectiveness of treatment, community support services, service coordination models, prognosis and course of illness; and should cover the life span and service system so to make it possible to develop or expand services based on a solid body of information regarding their effectiveness. Building data collection and research capacity to inform service design and delivery was listed also among the objectives of the action plan (Department of Human Services, 2008).
Watters (2010) observed that research in this area, although has gained recent impetus, is at a relatively early stage. Cauce and collaborators (2002), on the other side, argued that the sparseness of work in the area of mental health treatments for

any ethnic minority is so great that no single direction for future research is more compelling than another direction.

Although, as recently indicated by Watters (2010), a great portion of recent academic research on refugees and mental health has focussed on examining the prevalence of certain mental health problems among refugee populations, the panel of experts who developed the research agenda expressed consensus that research on prevalence and how this changes during the settlement process is still an high priority. This finding might reflect the scarcity of local (national and state-wide) information on prevalence. Furthermore, in spite of a large body of prevalence literature internationally, there is a wide range of prevalence rates reported in the refugee population (as earlier indicated), which might need further investigation. With regards to prevalence studies, it must be noted that approaches that rely primarily on the medical models of refugee health and on assessment methods that characterise adjustment and traumatic stress as mental illness have attracted broad criticism (Davidson, et al, 2008). Therefore, the expert panel's answers could also represent a demand for improvements in the way prevalence rates are assessed (see answers to Domain 3).

Ethical and methodological considerations on refugee mental health research

Research questions addressing what are the existing and most effective means to promote good mental health among people of refugee background were also seen as high priority in the current body of Australian mental health research. Tempany (2009) advocated for more research that goes beyond a focus on psychopathology, to explore other aspects of mental health and wellbeing.

When we start talking about refugee research, as for any research that will inevitably end up dealing with cultural constructs, we must be aware that collection and analysis of any cultural data is inherently problematic. As pointed out by Kleinman and Good (1985, p.38) "Cross-cultural work necessarily involves translation between distinctive systems of meaning, that is, between popular conceptualizations in non-Western societies, on the one hand, and both Western psychiatric theory and broader theories of self and societies in American and European cultures, on the other hand". This kind of consideration dismantles the illusion of the existence of something such as a value-free language also in research.

Davidson and colleagues (2008) have specifically highlighted that existing research with people of refugee background is methodologically problematic, "(it) relies on assessment tools and techniques that are not necessarily sensitive to refugee's cultural and linguistic backgrounds, pathologises refugee's suffering and distress following extreme adversity, and shifts attention and resources away from engagement that promotes individual and community resilience onto engagement that is aimed primarily at symptom relief" (p. 168). The authors thus argue that the alternative position is that research should be "evidence based and should tangibly benefit refugees who are distressed by seeking to relieve them of their distress as soon as possible through services that have been "shown to work" (idem). On this point, MacKenzie, McDowell and Pittaway (2007) expressed the view that research with refugees can only be justified if it is seen to entail an obligation to ensure that the research provides reciprocal benefits for those concerned. These authors have described two main sets of challenges involved in undertaking refugee research: the difficulties of constructing an ethical consent process and obtaining genuinely informed consent, and taking fully into account and responding to refugee participants' capacities for autonomy. The issues and challenges when researching newly-arrived refugee youth, in particular around obtaining a truly *informed* consent were discussed also by Block (in press). Among such issues, trust, as mentioned above, is of paramount importance in refugee research. Gaining authentic ("backstage") access to refugee communities depends to significant extent on the development of relations of trust between researchers and community members (see Miller, 2004). Given the salience of issues related to access and trust in research with refugees, their neglect in the refugee mental health literature, as observed by Miller (2004), is somewhat puzzling.

Methodological and ethical considerations must be part of any research process and were also indicated as essential by the expert panels in this study, who proposed research priorities on refugees' participation and inclusion and research ethics guidelines specific for this population. As far as refugees' participation and voices are concerned, there is no argument that this same research agenda would benefit from consultation with people of refugee background (although a number of research participants in his project were ex-refugees), such as community elders and youth leaders, about what they would like to add to a refugee mental health research agenda. Participation of refugee consumers and carers in research and development projects was encouraged also in the Victorian Mental Health Riform Strategy (Department of Human Services, 2009).

Community participation can only be possible when every effort is made to “engage” communities and to give voice to their voices. For this to happen, as argued by Gifford, Bakopanos, Kaplan and Correa-Velez (2007), we need to think outside the box by engaging with new and innovative approaches to refugee research (such as the use of integrated/multi-method approaches).

“The refugee experience is inherently one of change and resilience, of finding new solutions for life; and refugee research should be equally responsive and courageous”

Gifford, Bakopanos, Kaplan and Correa-Velez, 2007, p. 346

CONCLUSION

At the beginning of this manuscript, some of the benefits of setting a research agenda were highlighted, which included the formulation of relevant research questions while reducing ad hoc/reactive research and assistance to public and private funders into supporting research that reflects an acknowledged need. We hope that this research agenda will achieve these and other aims and that, by addressing the knowledge gaps identified in this research agenda, and promoting (ethically and methodologically adequate) research to answer these high priority research questions, policy makers, service providers and funding agencies will be able to support and enhance health and well-being, and develop and deliver better services for people of refugee background.

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APPENDIX

REFUGEE MENTAL HEALTH RESEARCH AGENDA[3]

DOMAIN 1. EPIDEMIOLOGY/PREVALENCE OF MENTAL HEALTH PROBLEMS	Children/ Youth	Adults
1. What is the prevalence of mental health problems, including trauma related disorders, among people of refugee background?	76.9%	71.8%
2. What is the co-morbidity of mental health problems among people of refugee background?	48.7%	48.7%
3. In what ways do mental health problems of people of refugee background differ across cultural groups, geographical areas, gender, age and time since arrival in Australia?	38.5%	35.9%
4. How does the prevalence of mental health problems in people of refugee background differ from the prevalence of mental health problems in non-refugees?	46.2%	38.5%
5. In what ways do mental health problems affect the lives of people of refugee background?	69.2%	64.1%
6. What are the most common presenting problems when people of refugee background with mental health problems first attend mental health services?	53.8%	48.7%
7. How does the prevalence of mental health problems among people of refugee background change during resettlement?	53.8%	46.2%
8. How does the prevalence of mental health problems in asylum seekers differ from the prevalence of mental health problems in people of refugee background?	33.3%	30.8%
9. What is the cost/burden of disease attributable to mental health problems in people of refugee background?	33.3%	30.8%
10. In what ways does the impact of mental health problems on people of refugee background differ from the impact of mental health problems on non-refugees?	25.6%	23.1%
11. What is the prevalence of mental health problems amongst Australian-born children of parents of refugee background who have mental health problems?	30.8%	N/A
12. What is the prevalence of mental health problems amongst children of parents of refugee background who have experienced significant trauma?	43.6%	N/A
13. What is the long-term impact on the mental health of children of parents of refugee background who have experienced significant trauma?	48.7%	N/A
14. Does the prevalence of mental health problems differ between unaccompanied minors and accompanied minors?	51.3%	N/A
15. What is the prevalence of mental health problems in blended families (i.e. families with children from different parents)?	0.0%	N/A

[3] Research questions rated “essential” by 50% or more of the participants have been highlighted.

DOMAIN 2. UNDERSTANDING DETERMINANTS OF MENTAL HEALTH	Children/ Youth	Adults
16. What are the key mental health determinants (risk and protective factors), pre and post arrival, in people from refugee background?	66.7%	59.0%
17. Do risk and protective factors for mental health differ across age, ethnic group, gender, resettlement location (urban vs. rural) and time since arrival?	51.3%	48.7%
18. What protective factors in people of refugee background are supporting positive mental health and well-being?	71.8%	69.2%
19. What determines/promotes resilience and successful adaptation among people of refugee background?	82.1%	69.2%
20. What are the factors that enable people of refugee background to get through episodes of mental health problems?	56.4%	59.0%
21. Are social factors such as experience of economic disadvantage, prejudice and social exclusion significant determinants of poor mental health among people of refugee background?	41.0%	41.0%
22. What aspects of family relationships constitute significant risk or protective factors for the mental health of people of refugee background?	46.2%	38.5%
23. Are there significant differences among the mental health determinants (risk and protective factors) in people of refugee background and non-refugees?	25.6%	23.1%
24. What key risk and protective factors pre- and post-migration influence the mental health of people of refugee background (e.g. experience of trauma and torture, resettlement)?	64.1%	61.5%
25. What is the relationship between specific cultural factors (such as religion, cultural beliefs and norms) and mental health of people of refugee background?	33.3%	30.8%
26. What is the impact of intergenerational issues on the mental health of people of refugee background?	41.0%	35.9%
27. What is the relationship between availability and quality of settlement support services, including education and mental health, of people of refugee background?	61.5%	56.4%
28. What is the relationships between immigration policies and processes (including detention) and the mental health of people of refugee background?	64.1%	61.5%
29. Does being labelled as 'refugee' when already having a Permanent Residence status impact the personal and community identities and mental health of people of refugee background?	12.8%	10.3%
30. What is the impact of positive and negative media coverage on the mental health of people from newly arrived refugee communities?	23.1%	20.5%
31. Is a sense of control over important decisions protective in the mental health of people of refugee background?	25.6%	23.1%
32. In people of refugee background, are mental health problems more likely to occur at key transition points, such as settling into family, school, employment, and child/adolescent development cycle points?	46.2%	35.9%
33. What are the specific things that host communities can do to promote the mental health of people of refugee background?	48.7%	46.2%

34. What is the impact of domestic violence on the mental health of families of refugee background?	35.9%	30.8%
35. What factors predict a long duration of untreated mental illness in people of refugee background?	38.5%	30.8%
36. Are there significant differences in mental health determinants (risk and protective factors) in unaccompanied and accompanied minors?	41.0%	N/A
37. How and to what extent do community organizations (e.g. religious groups or civil society) promote mental health and well-being in refugee communities?	30.8%	N/A
DOMAIN 3. ASSESSMENT OF MENTAL HEALTH PROBLEMS	Children/ Youth	Adults
38. What are the currently used mental health assessment tools (e.g. inventories, scales) and procedures for people of refugee background?	29.7%	29.7%
39. Which mental health assessment tools and procedures are suitable and culturally appropriate, and validated, for people of refugee background?	64.9%	67.6%
40. What mental health assessment and procedures are essential for people of refugee background but currently unavailable?	56.8%	54.1%
41. Do factors such as limited formal education, culture/ethnicity, gender and age influence assessment outcomes in people of refugee background?	27.0%	21.6%
42. Are assessments conducted outside of clinical settings (e.g. school, home) more acceptable, effective and valid than clinic-based assessments for people of refugee background?	54.1%	40.5%
43. Is the standard assessment of family function in refugee families reliable and valid?	45.9%	37.8%
44. What are the limitations of the main diagnostic classifications (DSM and ICD) when applied to people of refugee background?	51.4%	51.4%
45. How can these main diagnostic classifications be complemented with other assessment and 'diagnostic' approaches?	40.5%	37.8%
46. What are the relationships between the features of mental disorder in people of refugee background and specific cultural factors?	29.7%	24.3%
47. What are the positive and negative experiences with assessment tools and procedures among people of refugee background?	32.4%	27.0%
48. Is screening for mental health problems acceptable to people of refugee background?	40.5%	37.8%
49. What support do mental health service professionals require to enable them to perform culturally appropriate assessments of people of refugee background?	64.9%	64.9%
DOMAIN 4. CONCEPTUALIZATION OF MENTAL HEALTH/ILLNESS AND HELP-SEEKING STRATEGIES	Children/ Youth	Adults
50. What are the understandings and explanatory models of mental health issues among people of refugee background?	55.6%	55.6%
51. How do these compare to those of people from the general community?	16.7%	11.1%
52. How do people from refugee background and their families identify the presence of a mental health problem?	58.3%	55.6%

53. In what ways does the mental health literacy of people of refugee background differ from that of people from the general community?	33.3%	36.1%
54. What role does culture/ethnicity and spirituality/religion play in the understanding of mental illness among people of refugee background?	47.2%	44.4%
55. How do people of refugee background conceptualise well-being and how does culture/ethnicity influence their sense of well-being?	50.0%	52.8%
56. Are there differences in conceptions of mental health and illness and help-seeking among newly arrived people of refugee background and those who have settled in the country (e.g. more than 5 years since arrival)?	36.1%	33.3%
57. What levels of stigma towards people with mental illness exist among people of refugee background, how does this compare with other communities and between cultures?	38.9%	36.1%
58. What help-seeking strategies do people of refugee background use for mental health problems?	61.1%	63.9%
59. What kinds of assistance would people from refugee background seek in their country of origin for the problem?	30.6%	30.6%
60. What alternative/traditional help-seeking strategies are used by people of refugee background and how do they differ across cultures?	38.9%	36.1%
61. How do help-seeking behaviours differ among people of refugee background and the general community?	30.6%	27.8%
62. What are the attitudes of people of refugee background, and their families, towards seeking professional help for mental health problems?	50.0%	52.8%
63. What role does culture/ethnicity and spirituality/religion play in helpseeking behaviours of people of refugee background?	36.1%	30.6%
64. What is the impact of diverse understandings/explanatory models of mental health problems among people of refugee background on helpseeking behaviours?	25.0%	25.0%
65. Do mental health help-seeking strategies in people of refugee background change according to changes in levels of acculturation and/or years since resettlement and, if so, how?	36.1%	33.3%
66. In what ways do the coping strategies of people of refugee background with mental health problems differ from the coping strategies of non-refugees with mental health problems?	30.6%	25.0%
67. What do people of refugee background think are the most effective methods of treatment for mental health problems?	72.2%	66.7%
68. What are the differences in the cultural understandings of mental health/illness held by children and young people of refugee background and their families?	52.8%	N/A
DOMAIN 5. MENTAL HEALTH SERVICE MODELS/SYSTEMS	**Children/ Youth**	**Adults**
69. What mental health service models are currently being used in Australia for people of refugee background?	45.7%	42.9%
70. What elements of the design and delivery of mental health services are most important for people of refugee background?	77.1%	71.4%

71. Where should mental health services targeting children/youth or adults of refugee background be delivered and what form should they take?	77.1%	71.4%
72. Does the location of mental health services in health or non-health settings (e.g. in a mental health centre, in a school, etc.) have an impact on rates of mental health service access by people of refugee background?	68.6%	65.7%
73. In what ways are different models of service differentially accessible and effective for people of refugee background?	68.6%	62.9%
74. How can services be adapted and extended to better meet the needs of people of refugee background?	85.7%	80.0%
75. What is the impact of cultural competency training of professional staff on service experience and outcomes for people of refugee background?	60.0%	54.3%
76. How adequate is the training of mental health service providers to work with people of refugee background?	57.1%	54.3%
77. Which traditional/alternative methods of intervention are effective for which mental health problems among people of refugee background?	51.4%	51.4%
78. What is the capacity of mental health services to accommodate/incorporate alternative models of mental health care for people of refugee background?	60.0%	54.3%
79. What are the structural barriers to good mental health (e.g. poverty, discrimination, etc.) that may undermine the effectiveness of mental health services for people of refugee background?	51.4%	51.4%
80. How can we obtain effective collaboration between disciplines and between sectors (e.g. health, non-health, government) dealing with people of refugee background?	51.4%	51.4%
81. What role can information communication technology play in improving the mental health and well-being of people of refugee background?	17.1%	11.4%
82. How can mental health professionals be supported to minimize their personal stress experienced in supporting people of refugee background?	37.1%	34.3%
83. In what ways should mental health services for refugee children differ from services for adolescent refugees?	48.6%	N/A
84. What roles can schools and other educational settings play in the delivery of mental health services for children and young people of refugee background?	60.0%	N/A
DOMAIN 6. MENTAL HEALTH SERVICES UTILIZATION	Children/ Youth	Adults
85. What are the key referral points and pathways to mental health care for people of refugee background?	52.9%	52.9%
86. What are the mental health service utilisation patterns and rates for people of refugee background (e.g. what services are they currently accessing, with what kind of problems)?	61.8%	58.8%
87. Are there differences between service utilization by people of refugee background compared with that of people in the general community and, if so, what are the likely reasons?	41.2%	35.3%

88. What are the key health system barriers to access and engagement with mental health services among people from refugee backgrounds? And how can these be overcome?	58.8%	55.9%
89. What are the key barriers within refugee communities to access and engagement with mental health services? And how can these be overcome?	61.8%	58.8%
90. Does the fear of authoritative figures (such as Police, mental health services, DIAC, etc) inhibit the use of mental health services by people of refugee background and, if so, how can this be best managed?	38.2%	35.3%
91. What are the most effective strategies for facilitating utilization and engagement with mental health services by people of refugee background?	61.8%	58.8%
92. What are the positive and negative experiences of people of refugee background when attending mental health services?	50.0%	47.1%
93. How do people of refugee background learn about mental health issues and about where to seek help? What are their levels of understanding and how can these be improved?	55.9%	55.9%
DOMAIN 7. TREATMENT METHODS	Children/ Youth	Adults
94. What are the interventions/treatments for people of refugee background currently used in Australia?	41.2%	35.3%
95. How effective are existing interventions/treatments in dealing with mental health problems among people of refugee background?	64.7%	61.8%
96. Which interventions are effective for which groups at which ages for which problems?	67.6%	64.7%
97. What are the determinants of positive treatment outcomes among people of refugee background?	52.9%	50.0%
98. How can the expertise of specialist practitioners be used to strengthen the evidence base for practice standards with people of refugee background?	35.3%	32.4%
99. Are any further treatment methods needed in addition to current treatments and, if so, what is needed for people of refugee background?	50.0%	44.1%
100. How can current mental health treatments/therapies be adapted to be culturally appropriate and effective for people of refugee background?	64.7%	58.8%
101. What are the differences in effectiveness of culturally adapted treatment methods as compared to standard treatment among people of refugee background?	47.1%	44.1%
102. Which, if any, traditional/alternative treatments should be incorporated into standard treatment methods?	55.9%	52.9%
103. What impacts does the presence of a bilingual therapist have on engagement, assessment and effectiveness of treatment among people of refugee background?	29.4%	26.5%
104. What impacts does the presence of an interpreter have on engagement, assessment and effectiveness of treatment among people of refugee background?	58.8%	55.9%
105. How do factors such as age, gender and ethnic group, influence acceptability and effectiveness of intervention among people of refugee background?	32.4%	29.4%

106. Are the outcomes measures that are used for general mental health services appropriate and adequate for people of refugee background?	58.8%	55.9%
107. What are the differences between service providers and people of refugee background in conceptualization of good treatment outcomes?	50.0%	47.1%
DOMAIN 8. MENTAL HEALTH PROMOTION	**Children/ Youth**	**Adults**
108. What are the existing methods/models of mental health promotion designed for people of refugee background in Australia and how effective are they?	55.9%	52.9%
109. How effective are mental health promotion strategies for people of refugee backgrounds in comparison with non-refugee people?	29.4%	26.5%
110. Are mental health promotion strategies aimed at the general population reaching people of refugee background?	50.0%	50.0%
111. How can mental health promotion strategies better target people of refugee background?	50.0%	47.1%
112. What do people of refugee background see as the most effective means of promoting mental health?	67.6%	64.7%
113. What is the significance of factors such as gender, culture and language for the content and delivery of mental health promotion directed at people of refugee background?	38.2%	38.2%
114. What are the most important topics for mental health promotion for people of refugee background?	52.9%	52.9%
115. What are effective ways of supporting families, religious bodies (e.g. church/temple/mosque) and schools to promote good mental health for people of refugee background?	52.9%	50.0%
DOMAIN 9. RESEARCH METHODOLOGY	**Children/ Youth**	**Adults**
116. How can the inclusion of people of refugee background in mental health research on the general population be promoted and ensured?	50.0%	50.0%
117. What are the most successful strategies to recruit participants from the refugee population?	44.1%	44.1%
118. Do certain methodologies such as action research have particular advantages or limitations in studying people of refugee background?	38.2%	35.3%
119. What kinds of research questions can be satisfactorily answered by the different available research methods/strategies?	29.4%	29.4%
120. Do certain methodologies such as action research have particular advantages or limitations in studying people of refugee background?	26.5%	23.5%
121. What research approaches best allow the voices of participants of refugee background to be heard?	55.9%	52.9%
122. How should NH&MRC and other relevant research ethics guidelines be modified for application to research with participants from refugee background?	47.1%	44.1%
123. What are effective ways of disseminating findings to target specific audiences such as communities (including the refugee community) and policy makers?	47.1%	44.1%