



# MONASH University

## **Perinatal Mental Health in Women of Refugee Background**

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Bachelor of Arts in Psychology

Bachelor of Social Sciences (Psychology) Honours

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School of Public Health and Preventive Medicine  
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## Abstract

**Background:** As many as 20% of women are affected by mental health disorders during pregnancy or the first year after birth, making mental health screening crucial during this period of vulnerability. Maternal mental health conditions can impact upon birth outcomes as well as influence the quality of parent-child attachment at a critical time of infant development. Women of refugee background are at even greater risk of developing or re-experiencing mental illness during pregnancy as a result of the conflict, trauma, and displacement associated with refugee experiences. Routine and universal screening for mental health disorders in pregnancy is recommended in the Australian Clinical Practice Guidelines for depression and related disorders. Yet these recommended standards are often integrated to varying degrees into routine pregnancy services. This alarming trend is nowhere more evident and damaging than in at-risk populations such as women of refugee background.

**Methods:** This PhD is embedded within a pilot program of perinatal mental health screening for women of refugee background. The research was conducted across four projects to address current knowledge gaps related to prevalence of mental illness in refugees, assessment of mental health, and implementation of service level screening and management of mental health in pregnancy for refugee women. First, in order to establish the prevalence estimates of mental illness within current global refugee and asylum-seeker populations, two systematic reviews and meta-analyses were conducted: for adults, and children and adolescents. A comprehensive search of electronic databases was undertaken from 1 January 2003 to 4 February 2020. Quantitative studies were included if diagnosis of mental illness involved a clinical interview and used a validated assessment measure. Second, the screening properties of a Dari translation of the recommended perinatal mental health screening measure, the Edinburgh Postnatal Depression Scale (EPDS), were assessed by administering the Dari EPDS to 52 Dari speaking

women. Scores were compared to a diagnostic interview using the depressive and anxiety modules from the Structured Clinical Interview for DSM-5 (SCID-5). These interviews also investigated the prevalence of depression and anxiety diagnoses within this sample of women. Third, in order to determine whether the Harvard Trauma Questionnaire (HTQ) is an adequate screener for post-traumatic stress disorder (PTSD) during pregnancy, this same cohort of women also completed the HTQ. Scores were compared to a diagnostic interview using the trauma module from the SCID-5 and the prevalence of PTSD and its associated symptomatology was also investigated. For projects two and three, interview material was presented to an expert panel to achieve consensus DSM-5 diagnoses. The interviews and diagnostic process were undertaken blind to EPDS and HTQ scores. Finally, a synthesis of the strategies that were devised and delivered in the implementation of a pilot perinatal mental health screening program was generated. Using the behavioural change framework of the COM-B model, which identifies three factors (capability, opportunity, motivation) required for behaviour change, the key barriers, processes, and outcomes were described for a real-world example that was designed to maximise accessibility, feasibility, and acceptability. Throughout the implementation process, ongoing co-design and problem-solving were key features, resulting in the provision of an implementation guide, which can be translated into health services both within Australian and internationally.

**Discussion:** The systematic reviews provide a comprehensive, timely, and much needed update regarding the prevalence of mental illness within the refugee population. The results indicate that adult refugees and asylum seekers have high and persistent rates of PTSD and depression and highlighted the need for ongoing, long-term mental health care beyond the initial period of resettlement. Pregnancy provides an opportune time for this as it is a time when women engage with the health system. Refugee and asylum seeker children and adolescents have high rates of PTSD, depression, and anxiety and require early support and identification in order to promote

improved mental health outcomes and reduce the risk of poor social integration into host communities. For projects two and three, the results address some of the identified barriers to perinatal mental health screening by validating commonly used screening measures in a current refugee language. The results support the use of the EPDS Dari version to screen for symptoms of depression and anxiety as well as the use of a lowered cut-off score. Identifying women at risk of experiencing pregnancy with PTSD is critical in order to achieve the best mental health outcomes for women and their children. Prior to this study, there was a lack of research on the prevalence of PTSD among women of refugee background during the perinatal period. The results indicate that consideration of subthreshold PTSD and its associated symptomatology needs to be included as part of perinatal mental health screening programs for women of refugee backgrounds. The application of optimal cut-off scores allows all women, including those who may fall short of formal diagnosis, to access the appropriate intervention and support they require. Finally, the implementation guide synthesises the learnings from the pilot perinatal mental health screening program. These findings provide an equity-informed and evidence-based approach to assist healthcare organisations in regards to implementing perinatal mental health screening, particularly for women from refugee populations.

**Conclusion:** The findings from this program of research generate new knowledge about common mental health conditions in refugee and asylum seeker populations as well as contribute to potential improvements in health care by addressing some of the identified barriers to the implementation of perinatal mental health screening. The findings and provision of the evidence-based implementation guide will assist health services within Australia and internationally in the planning and implementation of perinatal mental health screening.

## Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes 2 original papers published in peer reviewed journals and 3 submitted publications. The core theme of the thesis is refugee mental health and mental health during the perinatal period for women of refugee background. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Monash Centre for Health Research and Implementation under the supervision of Dr Melanie Gibson-Helm.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of chapters 2 - 6 my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status (published, in press, accepted or returned for revision, submitted)	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
2	<i>The prevalence of mental illness in refugees and asylum seekers: a systematic review and meta-analysis</i>	<i>Published</i>	<i>60%: primary responsibility for study concept and design, screening results, data extraction and analysis and manuscript drafting and revisions.</i>	<i>Co-authors 30% 1) Melanie Gibson-Helm study design and development, screening articles, data extraction, and manuscript drafting 2) Jacqueline Boyle study design and development, risk of bias assessment, and manuscript drafting Co-authors 10%</i>	<i>No</i>

				3) Kylie Gray study design and development and manuscript drafting 4) Sanjeeva Ranasingha statistical analyses 5) Grace Fitzgerald article screening 6) Mina Fazel and Marie Misso study design and manuscript drafting	
3	Systematic review and meta-analysis: The prevalence of mental illness in child and adolescent refugees and asylum seekers.	Published	60%: primary responsibility for study conception and design, data extraction and interpretation and manuscript drafting and revisions.	Co-authors 30% 1) Melanie Gibson-Helm study design and development, screening articles, data extraction, and manuscript drafting 2) Kylie Gray study design and development, risk of bias assessment, and manuscript drafting Co-authors 10% 3) Jacqueline Boyle study design and development and manuscript drafting 4) Sanjeeva Ranasingha statistical analyses 5) Grace Fitzgerald article screening 6) Mina Fazel and Marie Misso study design and manuscript drafting	No
4	Validation of the Dari translation of the Edinburgh Postnatal Depression Scale among women of refugee background at a public antenatal clinic.	Submitted, under consideration	60%: primary responsibility for study conception and design, data analysis and interpretation, and manuscript drafting	Co-authors 30% 1) Kylie Gray and Glenn Melvin study conception and design, data analysis and interpretation, and manuscript drafting. 2) Melanie Gibson Helm study design and development, data analysis and interpretation, and manuscript drafting. Co-authors 10%	No

				5) Jacqueline Boyle study design and manuscript drafting 6) Mina Fazel data interpretation and manuscript drafting	
5	<i>Identifying post-traumatic stress disorder in women of refugee background at a public antenatal clinic</i>	Submitted, under consideration	60%: primary responsibility for study conception and design, data analysis and interpretation, and manuscript drafting	Co-authors 30% 1) Melanie Gibson-Helm study design and development, data analysis and interpretation, and manuscript drafting. 2) Kylie Gray and Glenn Melvin study design and development, data analysis and interpretation, and manuscript drafting. Co-authors 10% 3) Jacqueline Boyle study design and manuscript drafting 4) Louise Newman data interpretation and manuscript drafting	No
6	<i>Introducing perinatal mental health screening: development and implementation toolkit</i>	Submitted, under consideration	50%: primary responsibility for study development, data analysis and interpretation, and manuscript drafting	Co-authors 30% 1) Melanie Gibson-Helm, Jacqueline Boyle, and Kylie Gray study conception, design and development and manuscript drafting Co-authors 20% 2) Suzanne Willey, Nicole Highett study design and development, manuscript drafting	No

I have not renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

**Student name: Rebecca Peace Blackmore**

**Student signature:**

**Date:**

I hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

**Main Supervisor name: Melanie Gibson-Helm**

**Main Supervisor signature:**

**Date:**

## **My PhD journey**

Prior to commencing my PhD, I had gained extensive research and clinical expertise, working as a Psychologist. I have completed a Bachelor of Arts in Psychology followed by a Bachelor of Social Sciences (Psychology) Honours and have since gained full registration as a Psychologist including becoming a member of the Australia Psychological Society (APS). Through my roles as a Psychologist working in both clinical and research settings, I gained experience in conducting interviews and psychological assessments as well as community engagement activities involving the delivery of presentations to a wide variety of audiences. These experiences further developed my research skills as well as igniting the passion and motivation to consider PhD studies.

Throughout my career, I had been involved with working with families from diverse backgrounds including those of refugee backgrounds. I gained a greater understanding of the barriers and inequalities faced by these families. When the opportunity arose to be involved as a PhD student working within a broader program to improve mental health screening processes for women of refugee background, I knew immediately that this was exactly where I wanted to dedicate myself for the next few years.

My time as PhD student has enabled me to develop new skills which complement my previous clinical and research skillset. I completed substantial specialised training required to administer the study measures as well as courses on conducting refugee-appropriate clinical research. I undertook a three-day qualitative research methods short course in order to conduct the thematic analysis as the second researcher for a qualitative assessment on women's

experiences of the pilot perinatal mental health screening program. I have also completed the required courses on good research practice, conducting systematic reviews, and the compulsory unit within the Master of Public Health; *Introduction to Epidemiology*. My PhD program of research sits within a larger implementation project for a perinatal mental health screening program. I have been involved in many aspects of the implementation of this project such as establishing working relationships with the necessary health services teams, establishing and co-chairing the community advisory group meetings, a member of the steering committee including organisation of meetings and taking minutes, providing education and ongoing onsite support for midwives and other staff at the antenatal clinic, providing feedback of screening results to clinic staff, data collection, analysis, liaising with interpreters, and compiling ethics applications and amendments. In addition, I have worked with translators and cultural support staff in order to ensure that all measures used as part of this project are appropriate, sensitive, and able to be clearly understood by women from a range of cultural groups and ethnic backgrounds, many of whom had limited English language skills.

## Thesis by publication

Monash University doctoral students are permitted to submit a thesis by publication, which includes papers that have been published, accepted, or submitted for publication. The papers can be inserted in their published format and may have more than one author. The thesis must reflect a sustained and cohesive theme, and concise framing or linking text is generally required to introduce and link the chapters and manuscripts.

This thesis contains eight chapters and five manuscripts. Two manuscripts have been published and three have been submitted and are under consideration. These manuscripts make up the majority of chapters two to six. A further three published manuscripts, on which I am a co-author, have been completed during candidature but do not form part of my thesis. These manuscripts are listed in the *Publications* section.

### **The prevalence of mental illness in refugees and asylum seekers: a systematic review and meta-analysis**

**Chapter two:** I have conducted a systematic review and meta-analysis which summarises the current body of evidence for the prevalence of mental illness in refugee populations. This systematic review and meta-analysis updates and expands the systematic review by Fazel, Wheeler, and Danesh previously published in *The Lancet* in 2005. It provides a timely and much needed update on the impact of refugee experiences on mental illness. To the best of my knowledge, this systematic review implemented the strictest inclusion criteria regarding the assessment and diagnosis of mental illness in recent refugee and asylum seeker populations. This has allowed a focused analysis of the more rigorous studies in the field. This review expands the current evidence base by not only focusing on PTSD but reporting other mental illnesses such as depression, anxiety, and psychosis. Additionally, this review offers a

comprehensive overview by including studies from countries of permanent resettlements such as Germany, U.K, and Australia and countries of first asylum such as Lebanon, Turkey, Uganda, and Nepal.

At the commencement of this systematic review, I undertook the MCHRI systematic review training and support program (12 days over six months), developed the protocol, and completed registration with PROSPERO. I conducted a comprehensive search of electronic databases, resulting in 21,842 articles. Associate Professor Mina Fazel, an international expert in refugee mental health and lead author of the systematic review published in 2005, was engaged to be a co-author on this systematic review. I completed the screening and selection of articles in conjunction with my primary supervisor, Dr Melanie Gibson-Helm. I completed a formal quality appraisal of all included studies in conjunction with my co-supervisor Associate Professor Jacqueline Boyle. I completed the data extraction and worked closely with the statistician in conducting the data analysis in STATA. I also led the manuscript preparation and submission, and the response to reviewer comments. This systematic review has been published in PLoS Medicine (ranked in the top 5% of general medicine journals, 8/165).

**Systematic review and meta-analysis: the prevalence of mental illness in child and adolescent refugee and asylum seeker populations.**

**Chapter three:** The comprehensive search conducted for the systematic review in chapter two placed no limits on population age in the hope that there would be enough articles meeting the inclusion criteria to prepare a review focussing solely on children and adolescents, in addition to adults. Therefore, this chapter presents the results from a secondary meta-analysis which was conducted for studies which focused on the prevalence of mental illness in current child and adolescent refugee and asylum seeker populations. Despite comprising half of the world's refugee and asylum seeker population, there is a lack of high-quality prevalence estimates of

mental illness for children and adolescents. A comprehensive search of eight electronic databases, grey literature, and Google Scholar was undertaken with strict inclusion criteria regarding the diagnosis of mental illness and no limits were placed on country or origin. To our knowledge, this is the first time mental illness prevalence has been estimated by a comprehensive systematic review and meta-analysis for this population. The results of this review contributed to updating the prevalence estimates for PTSD by conducting the largest analysis of PTSD prevalence for this population, which was based on rigorous methods of mental illness diagnosis. This review also expanded the current evidence base by contributing prevalence estimates for depression, anxiety disorders, attention deficit hyperactivity disorder (ADHD), and oppositional defiant disorder (ODD). I completed the screening and selection of articles in conjunction with my primary supervisor, Dr Melanie Gibson-Helm. I completed a formal quality appraisal of all included studies in conjunction with my co-supervisor Associate Professor Jacqueline Boyle. I completed the data extraction and worked closely with the statistician in conducting the data analysis in STATA. I also led the manuscript preparation and submission, and the response to reviewer comments. This review was published in the Journal of the American Academy of Child and Adolescent Psychiatry (ranked in the top 2% of developmental psychology journals, 2/77).

### **Validation of a Dari translation of the Edinburgh Postnatal Depression Scale among women of refugee background at a public antenatal clinic**

**Chapter four:** Despite Afghanistan being one of the largest source countries for refugees globally, there is no validated measure in Dari to screen for symptoms of depression and anxiety during pregnancy. This chapter presents my work on assessing the screening properties of a Dari translation of one of the most widely used and recommended perinatal mental health screening measures, the Edinburgh Postnatal Depression Scale (EPDS). This study involved administering the Dari EPDS to 52 Dari speaking women of refugee background who were

receiving care at a public antenatal clinic, in Melbourne, Australia, one of the major areas of resettlement for people from Afghanistan. In addition to obtaining ethics approval, I conducted clinical interviews with all of the women using the depressive and anxiety disorders modules from the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders-5 (SCID-5 for DSM-5). Female interpreters were used for the majority of interviews. Prior to the commencement of the diagnostic interviews, I completed a training course in the administration of the SCID-5 (four sessions x four hours) plus additional reading and research. Interview material was presented to an expert panel in order to achieve consensus DSM-5 diagnoses. The interview and diagnostic process was undertaken blind to EPDS screening scores. For this study, I conducted the data extraction and analysis and led the manuscript preparation, submission, and the response to reviewer comments.

### **Identifying post-traumatic stress disorder in women of refugee background at a public antenatal clinic**

**Chapter five:** This chapter presents the work I have conducted in identifying and screening of post-traumatic stress disorder (PTSD) in women of refugee background seeking antenatal care and whether the Harvard Trauma Questionnaire (HTQ) is an adequate screener for trauma and stressor-related disorders during pregnancy. Prior to the commencement of this study, I undertook training in the administration of the SCID-5 as well as a program offered by Foundation House which is designed to enhance knowledge of the refugee experience and the provision of trauma-informed care. For this study, I had primary responsibility for obtaining ethics approval, recruitment of women from the antenatal clinic, conducting face-to-face clinical interviews administering the HTQ and the SCID-5, and using interpreters where necessary. I conducted the data extraction and analysis led the manuscript preparation and submission.

## **Introducing perinatal mental health screening: development and implementation toolkit**

**Chapter six:** My PhD research is embedded within a larger project that involved the implementation of a pilot perinatal mental health screening program. Together, with another PhD student, I shared responsibility for obtaining ethics approval, recruitment of women and data collection, management of the steering committee, co-chairing the community advisory committee, delivering educational workshops to clinic staff, and providing ongoing onsite support for staff to ensure the successful implementation of the screening program. Specifically, the manuscript presented in this chapter is a synthesis of the practical strategies that were co-designed and delivered during the implementation of the program. The strategies were identified (and mapped using the Theoretical Domains Framework (TDF)) as part of formative research that preceded the initial design in order to address the individual and systems-level barriers to implementing perinatal mental health screening. Further strategies were developed iteratively during implementation to address additional barriers as they arose. Post-implementation, I collated and interpreted the strategies in the context of behavioural and organisational change. Using the behavioural change framework of the COM-B model, which identifies three factors (capability, opportunity, motivation) that need to be present for behaviour change to occur, I interpreted the relationship between key inputs and processes and the resulting outcomes with a view to providing an implementation guide to encourage other services to use this framework when planning their implementation. Finally, I led the manuscript preparation and submission.

## **Acknowledgements**

I am truly grateful for the financial support offered throughout my candidature from the following institutions:

- Departmental scholarship from the Monash Centre for Health Research and Implementation
- Australian Rotary Health Ian Scott PhD Scholarship
- Doctoral scholarship from the Windermere Foundation

## **Professional**

I was extremely fortunate to be supported throughout my PhD candidature by three incredible supervisors: Dr Melanie Gibson-Helm, Associate Professor Jacqueline Boyle, and Professor Kylie Gray. I was inspired by your work ethic and have learnt so much from all of you about being dedicated, passionate, and assertive. These three qualities you all had in abundance and I truly believe it is what makes a great researcher. It has been a privilege to work with you all and I am very grateful for the learnings, experiences, and opportunities presented to me along the way. Above all, I appreciate the unwavering support that you have all offered to me which is the greatest gift a supervisor can give to their students.

I thank the Monash Centre for Health Research Implementation for providing such a supportive and inspiring workplace with a great team of senior researchers and fellow PhD students. I was very lucky to be able to share my PhD experience with another student and midwife, Dr. Suzanne Willey. I very much appreciate the support and encouragement you offered and believe that our collaboration and complementing skillset made for a better project.

I would like to acknowledge the members of the project's steering committee for their input into developing an innovative perinatal mental health screening program. I would also like to acknowledge the women of the community advisory committee who shared with us a common goal of improving health care outcomes for all women, no matter their background. In particular, Razia Ali who provided a wealth of experience and knowledge in ensuring this program was meeting the needs of women from different cultural backgrounds.

Finally, to the women who participated in the mental health screening program and in particular the interviews with myself. I truly value and appreciate your honesty. I know it is not always easy to open up to a stranger and divulge stories of loss, trauma, fear, and grief. You inspired me to be braver in my life and I realised how very similar we all are in our desire to lead a life of happiness and freedom and the opportunity to raise our children well. Your stories will remain with me forever.

***To all those seeking refuge and asylum, may you find peace and safety.***

## **Personal**

To my husband Ben, I absolutely could not have done this without you. This PhD journey has not been easy, especially whilst raising three little humans and yet you have always offered nothing but love, humour, and fantastic motivational speeches. To my mother, Kerry, who inspired me when I was young by going to university later in her life and not only completing her Masters in Midwifery but receiving an award for academic excellence. To my three boys, Hugo, Liam, and Jack who will probably not remember much of this journey when they are grown but I do hope it inspires you to reach as far as you can in this life and to give everything a go.

## Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
CME	Continuing Medical Education
COM-B	The Capability, Opportunity, Motivation – Behaviour Model
COPE	Centre of Perinatal Excellence
DSM-5	Diagnostic Statistical Manual of Mental Disorders, 5 <sup>th</sup> Edition
EPDS	Edinburgh Postnatal Depression Scale
HTQ	Harvard Trauma Questionnaire
IF	Impact Factor
MCHRI	Monash Centre for Health Research and Implementation
MHTP	Monash Health Translation Precinct
NGO	Non-Governmental Organisation
NPT	Normalization Process Theory
ODD	Oppositional Defiant Disorder
PTSD	Post-Traumatic Stress Disorder
Q1	1 <sup>st</sup> Quartile
RHNL	Refugee Health Nurse Liaison
TDF	Theoretical Domains Framework
SCID	Structured Clinical Interview for DSM
SPSS	Statistical Package for the Social Sciences
WHO	World Health Organization

## Publications

### Publications included in this thesis

1. **Blackmore R**, Boyle JA, Fazel M, Ranasinha S, Gray KM, Fitzgerald G, Misso M, Gibson-Helm M. The prevalence of mental illness in refugees and asylum seekers: A systematic review and meta-analysis. PLoS Med. 2020;17(9):e1003337. Available from: <https://doi:10.1371/journal.pmed.1003337> (ranked 8/165 general medicine, Q1, IF 9.390) [Chapter 2]
2. **Blackmore R**, Gray KM, Boyle JA, Fazel M, Ranasinha S, Fitzgerald G, Misso M, Gibson-Helm M. Systematic review and meta-analysis: The prevalence of mental illness in child and adolescent refugees and asylum seekers. J Am Acad Child Adolesc Psychiatry. 2020;59(6), 705-14. Available from: <https://doi:10.1016/j.jaac.2019.11.011> (ranked 2/77 psychology, developmental Q1, IF 6.936) [Chapter 3]
3. **Blackmore R**, Gibson-Helm M, Melvin G, Boyle JA, Fazel M, Gray KM. Validation of a Dari translation of the Edinburgh Postnatal Depression Scale among women of refugee background at a public antenatal clinic. Accepted: Australian and New Zealand Journal of Psychiatry 27/05/2021, (ranked 73/545 within psychiatry and mental health, Q1, IF 4.657) [Chapter 4]
4. **Blackmore R**, Gray KM, Melvin G, Boyle JA, Newman L, Gibson-Helm M. Identifying post-traumatic stress disorder in women of refugee background at a public antenatal clinic. Submitted: Archives of Women's Mental Health 01/03/2021, under review (ranked 30/185 within obstetrics and gynaecology, Q1, IF 2.5) [Chapter 5]
5. **Blackmore R**, Boyle JA, Gray KM, Willey S, Highett N, Gibson-Helm M. Introducing and integrating perinatal mental health screening: development of an equity-informed evidence-based approach. Submitted: Bulletin of the World Health Organization 17/03/2021, under consideration (ranked 14/559 within public health, environmental, and organisational health, Q1, IF 6.96) [Chapter 6]

## Additional publications produced during candidature

1. Boyle JA, Willey S, **Blackmore R**, East C, McBride J, Gray K, Melvin G, Fradkin R, Ball N, Highett N, Gibson-Helm M. Improving mental health in pregnancy for refugee women: protocol for the implementation and evaluation of a screening program in Melbourne, Australia. JMIR Res Protoc. 2020;8(8):e13271. Available from: <https://doi.org/10.2196/13271>
2. Willey S, **Blackmore R**, Gibson-Helm M, Ali R, Boyd L, McBride J, Boyle JA. “If you don’t ask...you don’t tell”: Refugee women’s perspectives on perinatal mental health screening. Women Birth. 2020;33 5):e429-37. Available from: <https://doi.org/10.1016/j.wombi.2019.10.003>
3. Cheng IH, Advocat J, Vasi S, Enticott JC, Willey S, Wahidi S, Crock B, Raghavan A, Vandenberg BE, Gunatillaka N, Wong VHL, Girdwood A, Rottler A, **Blackmore R**, Gibson-Helm M, Boyle JA. A rapid review of evidence-based information, best practices and lessons learned in addressing the health needs of refugees and migrants: report to the World Health Organization. Melbourne: World Health Organization; 2018. Available from: [https://www.who.int/migrants/publications/partner-contribution\\_review.pdf](https://www.who.int/migrants/publications/partner-contribution_review.pdf)

## Conference presentations

### Conference presentations regarding research included in this thesis

The presenting author's name is highlighted

### Workshop selected from abstract

1. North American Refugee Health Conference, Portland, Oregon, June 2018

**Boyle JA, Willey S, Blackmore R**, Ali R. Leaving no one behind – implementing evidence-based screening and support for mental health in pregnancy in women of refugee background. North American Refugee Health conference, Portland, Oregon, June 2018 [Chapter six]

### Oral presentations selected from abstract

1. 15<sup>th</sup> World Public Health Congress, Melbourne, April 2017

**Blackmore R**, Boyle JA, Fazel M, Ranasinha S, Gray KM, Fitzgerald G, Misso M, Gibson-Helm M. The prevalence of mental illness in refugees and asylum seekers: preliminary findings of a systematic review and meta-analysis [Chapter two]

2. 15<sup>th</sup> European Congress of Psychology, Amsterdam, The Netherlands, July 2017

**Blackmore R**, Boyle JA, Fazel M, Ranasinha S, Gray KM, Fitzgerald G, Misso M, Gibson-Helm M. The prevalence of mental illness in refugees and asylum seekers: a systematic review and meta-analysis [Chapter two]

### **Oral presentations selected from abstract (cont.)**

3. North American Refugee Health Conference, Portland, Oregon, June 2018

**Blackmore R**, Boyle JA, Fazel M, Ranasinha S, Gray KM, Fitzgerald G, Misso M, Gibson-Helm M. The prevalence of mental illness in refugees and asylum seekers: final results of a systematic review and meta-analysis [Chapter two]

4. International Association for Child and Adolescent Psychiatry, Singapore, December 2020

**Blackmore R**, Gray KM, Boyle JA, Fazel M, Ranasinha S, Fitzgerald G, Misso M, Gibson-Helm M. (2020). Systematic review and meta-analysis: The prevalence of mental illness in child and adolescent refugees and asylum seekers. [Chapter three]

## Scholarships and funding

Year	Scholarship or Award
2016 - 2020	Departmental Scholarship, Monash Centre for Health Research and Implementation
2017 - 2018	Windermere Doctoral Scholarship
2017 - 2021	Ian Scott PhD Scholarship, Australian Rotary Health
2018	School of Public Health and Preventive Medicine, Postgraduate Travel Award

## Coursework and short courses

Year	Course
Semester 1, 2016	Library Focus Series: Literature reviews and critical writing
Semester 1, 2016	Communication skills training for MCHRI researchers
Semester 1, 2016	MCHRI systematic review training
Semester 2, 2016	Research Integrity, Monash University
Semester 2, 2016	Training in administration of the SCID-5-RV
Semester 2, 2016	Refugee and Asylum-Seeker Experience Workshop, Foundation House
Semester 1, 2017	Ethics and Good Research Practice
Semester 1, 2018	MPH5040 Introductory Epidemiology
Semester 1, 2018	MPH6040 Introduction to Biostatistics (Recognition of Prior Learning)
Semester 2, 2018	Ethics and Professional Conduct, Monash University
Semester 1, 2019	Media Skills Training for Researchers, Australian Rotary Health
Semester 2, 2019	Qualitative Research Methods for Public Health, Monash University

## **Statement of aims**

### **Overall Aims**

The overall aims of this research are:

1. to generate new knowledge about the prevalence of common mental health conditions in refugee and asylum seeker populations and
2. to contribute to improved health care by addressing barriers to mental health screening, related to assessment and implementation, during the perinatal period for women of refugee background.

### **Chapter two: A systematic review and meta-analysis of the prevalence of mental illness in adult refugee and asylum seeker populations**

This chapter presents a systematic review and meta-analysis on the prevalence of mental illness in adult refugee and asylum seeker populations. This review aims to:

1. Determine the reported prevalence in the research literature of depression, anxiety, PTSD, and psychosis in current global refugee and asylum seeker populations.

### **Chapter three: A secondary systematic review and meta-analysis of the prevalence of mental illness in child and adolescent refugee and asylum seeker populations**

This chapter presents a secondary systematic review and meta-analysis on the prevalence of mental illness in child and adolescent refugee and asylum seeker populations. This review aims to:

2. Determine the reported prevalence in the research literature of depression, anxiety, PTSD, attention deficit hyperactivity disorder, and oppositional defiant disorder in current child and adolescent refugee and asylum seekers populations.

### **Chapter four: A cross-sectional study identifying anxiety and depression prevalence and symptomatology in a sample of Dari speaking women, and assessing the screening properties of the Dari version of the EPDS**

3. To determine the prevalence and severity of depression and anxiety symptoms in a sample of Dari speaking women of refugee background during pregnancy (using the EPDS).
4. To determine the prevalence of diagnosed clinical depression and anxiety during pregnancy in a sample of Dari speaking women of refugee background (using the SCID-5)
5. To assess the sensitivity and specificity of the Dari version of the EPDS in detecting depression and anxiety during pregnancy in a sample of Dari speaking women.

**Chapter five: A cross-sectional study identifying PTSD prevalence and symptomatology in a sample of Dari speaking women, and assessing the screening properties of the HTQ**

6. To determine the prevalence and severity of PTSD symptomatology and frequency of trauma events in a sample of Dari speaking women of refugee background during pregnancy (using the HTQ).
7. To determine the prevalence of diagnosed PTSD and other trauma related disorders in a sample of Dari speaking women of refugee background (using the SCID-5).
8. To assess whether the HTQ is an adequate screener for symptoms of PTSD during pregnancy.

**Chapter six: A summary and evidence-based guide for the implementation of a perinatal mental health screening program for women of refugee background**

9. To synthesise the learnings and key findings from the implementation of a digital perinatal mental health screening program in a public antenatal clinic.

## **Thesis overview**

This PhD research has generated new knowledge about common mental health conditions such as depression, anxiety, and PTSD in current, global refugee and asylum seeker populations and the need for long-term support after resettlement. This PhD is a part of a larger research program regarding the implementation of perinatal mental health screening. My research contribution can be used to inform and implement universal and routine perinatal mental health screening, for women of refugee background and other populations with complex needs. I assisted with the evaluation and implementation of a mental health screening program for women of refugee background at a dedicated refugee antenatal clinic at Dandenong Hospital, Monash Health, in Melbourne, Victoria, Australia. Within this program I designed and conducted original research projects which were conceived through identifying the gaps in the literature and identified barriers to perinatal mental health screening. The manuscripts resulting from these projects form my thesis (Chapters two - six). Three co-author publications have resulted from this work but do not form part of my thesis

This thesis has eight chapters with five publications. The first two publications update and expand upon the current body of evidence for the prevalence of mental illness in global adult, child, and adolescent refugee and asylum seekers populations. By establishing these updated prevalence estimates of mental illness within this population, this allowed for an understanding of the magnitude of this public health issue. The results from the systematic reviews provided a foundation which informed the remaining manuscripts from my PhD, which now focused on the perinatal period and specifically women of refugee background. The third and fourth publications investigate the prevalence of perinatal depression and anxiety, and PTSD respectively as well as assessing the screening properties of recommended screening measures, the EPDS and HTQ with a sample of Dari speaking women, the largest refugee population attending the antenatal

clinics at Monash Health. The final publication provides a synthesis of strategies that were developed and delivered, informed by formative research and stakeholder consultation, during the implementation of the perinatal mental health screening program. This publication provides an implementation toolkit and guide which can be used by healthcare services in Australia and internationally.

In **chapter one**, an introduction is provided to the global refugee crisis and the ways in which the refugee experience impacts upon mental illness, and describes the aims of this PhD.

**Chapter two** provides the results of a comprehensive systematic review and meta-analysis investigating the prevalence of mental illness in current global adult refugee and asylum seeker populations (Aim 1).

**Chapter three** provides the results of a secondary meta-analysis investigating the prevalence of mental illness in current global child and adolescent refugee and asylum seeker populations (Aim 2).

**Chapter four** presents the manuscript investigating the prevalence of perinatal depression and anxiety in a sample of Dari speaking women as well as reporting the results of an assessment of the screening properties of a Dari translation of the EPDS (Aims 3, 4, and 5).

**Chapter five** reports the results from the manuscript assessing PTSD in Dari speaking women of refugee background at a public antenatal clinic and assessing the screening properties of the HTQ (Aims 6,7, and 8).

**Chapter six** provides a summary manuscript which details a synthesis of strategies used to guide the implementation of a pilot perinatal mental health program (Aim 9).

**Chapter seven** presents the discussion, summary of findings, future directions, and conclusions of this PhD program of research.

**Chapter eight** reports the translational activities associated with this research.

## **Chapter one: Introduction**

### **1.1 The global refugee crisis**

Globally, there has been a dramatic rise in the numbers of individuals forcibly displaced from their homes over the past decade. At the end of 2019, there were 79.5 million people forcibly displaced worldwide as a direct consequence of human rights violations and conflict, which is the largest number recorded in history.(1) Of that figure, 26 million are recognised as refugees and 4.2 million as asylum seekers.(1) More than half of all refugees originate from three countries which have endured devastating ongoing and renewed conflicts; the Syrian Arab Republic, Venezuela, and Afghanistan.(1) These ongoing conflicts have resulted in the movement of large populations which raises challenging social, political, and humanitarian issues for the global community.(2)

According to the 1951 Refugee Convention the term “refugee” is defined as “any person who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable, or owing to such fear, is unwilling to avail himself/herself of the protection of that country”.(3) People seeking asylum are those who have sought protection as a refugee but are awaiting the outcome of their claim for refugee status, which has not yet been assessed.(4) Throughout this thesis, the terms “refugee” and “asylum seeker” will be used. The term “women of refugee background” will be used to describe women who have been granted refugee status, or are seeking asylum, or from refugee source countries but may arrived on other types of visas such as a partner visa.

For many refugees and asylum seekers, the experience of displacement is not a temporary or short-term issue. Those fleeing conflict often experience displacement many times as movement can occur through neighbouring nations which are unstable or also experiencing conflict. Resettlement is a lengthy and complex process with many uncertainties and difficulties to finding permanent resettlement solutions in order to rebuild lives. In recent times, fewer options are available to refugees and asylum seekers in regards to resettlement in a new country and many are unable to return home due to ongoing conflict. Some host nations have experienced population cultural shifts against immigration and increased hostility towards refugee populations resulting in harsh immigration policies including detention, deportation, and delayed processing of refugee and asylum seeker applications which have reduced or limited the numbers accepted for resettlement.(5, 6)

## **1.2 Mental health of refugees and asylum seekers**

Refugees and asylum seekers are likely to have been exposed to a number of potentially traumatic pre-migration stressors such as experiencing conflict, torture, loss or separation from family, and an often-life-threatening journey to safety. Post-migration stressors can involve protracted situations of uncertainty due to delays in visa processing, mandatory detention in some countries, and, once resettled, issues of poverty, isolation, discrimination, and difficulties adjusting to life in their new country. Acculturation difficulties such as learning the language of the host country and acceptance of new cultural practices can impact upon the ability to obtain employment or educational opportunities which are crucial to rebuilding and establishing a new life.(7) The ongoing stressors and challenges associated with the post-migration environment can intensify the traumatic events experienced pre-migration and result in an exacerbation of mental health issues.(8, 9) Prolonged mandatory detention or temporary visa status has also been reported to have adverse effects on the mental health of refugees and asylum seekers.(10)

Previous research has reported high rates of mental illness in refugee and asylum seeker populations with PTSD, depression, and anxiety being the most common.(11, 12) Historically, the prevalence estimates of mental illness within refugee and asylum seeker populations have varied greatly. Two of the most highly cited reviews were published in 2005 and 2009, highlighting the need for an updated review to reflect prevalence in current refugee populations.(11, 12) Much of the literature in this field has focussed on the prevalence of PTSD with other mental illnesses such as depression, anxiety, or psychosis largely under investigated. Prevalence estimates of PTSD have been reported to vary anywhere between 3 – 86%.(11) This variance is mostly attributable to methodological differences across studies such as sampling methods, diagnostic measures, as well as the heterogeneity of refugee populations. For the health systems of host countries, the prevalence of mental illness within these populations has considerable implications for health service planning and provision. However, more precise prevalence estimates are required, rather than a wide range which poses difficulties for planning and provision and understanding the true magnitude of this public health issue. Basing healthcare delivery decision at the lower end of the range could contribute to a neglect of refugee mental health, equally relying on the upper limits of that range may in fact result in the stigmatisation of refugee populations and incorrect expectations about the level of psychiatric morbidity.(11)

### **1.3 Refugees and asylum seekers in Australia**

In Australia, there consists of two main migration programs: the migrant program for skilled workers and family migrants, or the humanitarian program for refugees and those in refugee-like situations.(13) The humanitarian program is comprised of the offshore component which provides resettlement to those subject to persecution, discrimination, or violation of their human rights.(13)

The second component of the humanitarian program is the onshore program which provides for non-citizens residing in Australia who are deemed to be a refugee.(13) During 2018 – 2019, Australia's annual humanitarian program was set at 18,750 places. During that period, the Australian government received 75,656 applications for offshore humanitarian visas with over half of those applications originating from individuals from the Middle East.(13) The vast majority of applicants were under 30 years of age (62%) and 49% were female.(13)

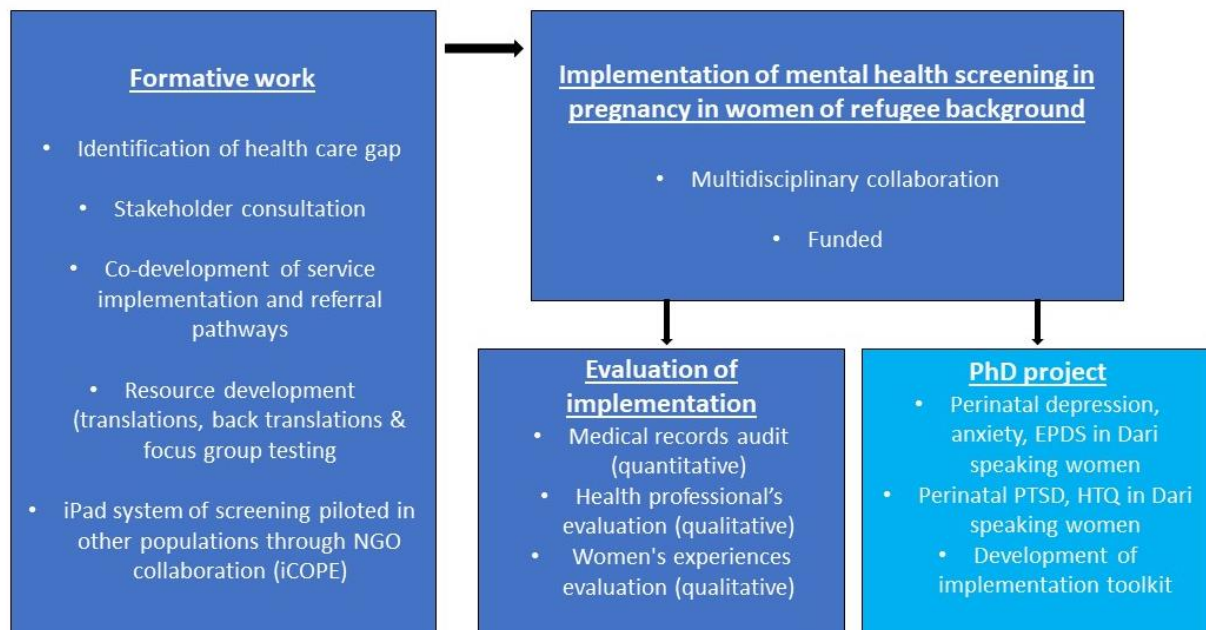
#### **1.4 Women of refugee background**

During times of conflict, women face increased risks of sexual violence, safety, exploitation, and trafficking.(14) Sexual violence is often used as a weapon of war. It is estimated that one in five women refugees experience some form of sexual violence, however that is likely to be an underestimation due to the underreporting and stigma associated with sexual violence.(14) Trauma type has been shown to impact upon the likelihood of developing PTSD and sexual violence is considered a high-risk trauma type.(15) In addition, women refugees and asylum seekers face other risks during both the pre-and-post migration environment including domestic violence, child-rearing pressures, and sexual and reproductive health issues.(16) Experiencing pregnancy as a refugee can bring about a host of vulnerabilities and increased risks for the development of or retriggering of mental illness. As pregnancy represents a period of risk for all women, women of refugee background are therefore faced with a two-fold risk for experiencing or reexperiencing mental illness which is conferred by their perinatal status as well as their experiences of being a refugee. In many cases this population of women faces limited access to health care as a result of refugee situations which can be particularly detrimental during pregnancy.(16) However, pregnancy can also be the first time that women of refugee background have regular contact with the healthcare system in their new host country, making pregnancy an opportune time to assess and address perinatal mental illness.

## **1.5 Perinatal mental health screening for women of refugee background**

As a result of a number of barriers, the extent to which perinatal mental health screening is integrated into routine antenatal care often varies. Women of refugee background experience further barriers to mental health screening due to the lack of availability of translated and validated screening measures in languages of current refugee populations. Prior to the commencement of this PhD project, a solid 24 months of collaboration, research, and developing community support from relevant multidisciplinary clinicians, managers, and service providers was undertaken in order to design and implement a perinatal mental health screening program for women of refugee background (Figure 1). Together with Monash Health, the Centre for Developmental Psychiatry and Psychology, and the Centre of Perinatal Excellence (COPE), a novel perinatal mental health screening program was implemented in the antenatal clinic at the Dandenong Hospital in Melbourne, Australia. My PhD project is embedded within this screening program and will address crucial gaps in current knowledge.

Figure 1. Monash University and Monash Health Refugee Perinatal Mental Health Research Program



The Edinburgh Postnatal Depression Scale (EPDS) is the nationally recommended screening measure to detect depression and anxiety during pregnancy.(17, 18) It has been widely translated and validated but not with Dari speaking women. Not only is Afghanistan one of the largest refugee source countries in the world currently, but Dari speaking women comprise one of the largest cultural groups attending the antenatal clinic at the Dandenong Hospital.(1) This PhD uses an existing Dari translation of the EPDS which has not yet been validated. This study will validate this version and provide results regarding the psychometric performance of the translated measure by administering it with a group of Dari speaking women attending the antenatal clinic at the Dandenong Hospital. There is also no guidance for midwives and obstetricians and very little literature on how to best assess trauma and risk of PTSD in pregnancy, which is a key concern when providing care to refugee populations.(19) Formative research conducted prior to implementation of the screening program, found that health professionals acknowledged that PTSD experienced during the perinatal period is an important consideration when providing

mental health care and assessment during pregnancy, particularly for women of refugee background. (19) However, there is a lack of knowledge and understanding amongst health professionals about the prevalence of perinatal PTSD and appropriate screening measures.(19) One possible measure for consideration would be the Harvard Trauma Questionnaire (HTQ) as it is a cross-cultural screening measure designed to specifically assess trauma events and symptoms with refugee populations.(20) These knowledge gaps are on top of uncertain estimates of the prevalence of depression, anxiety, and PTSD in refugee populations in general and particularly in women, making it very difficult for health services to plan and allocate resources.

## **1.6 Research questions**

The primary research questions of this PhD are:

1. What is the reported prevalence in the research literature of depression, anxiety, PTSD, and psychosis in current global refugee populations?
2. What is the prevalence and severity of depression and anxiety symptoms in Dari speaking women from refugee background during pregnancy?
3. What is the prevalence of diagnosed clinical depression, anxiety, and PTSD in Dari speaking women from refugee backgrounds during pregnancy?
4. What is the sensitivity and specificity of the Edinburgh Postnatal Depression Scale in Dari speaking women in detecting depression and anxiety?
5. Is the Harvard Trauma Questionnaire an adequate screener for symptoms of trauma during the perinatal period?
6. How do we translate the key findings and learnings from the implementation of a digital perinatal mental health screening program to inform the development of an implementation guide for perinatal mental health screening?

## 1.7 Summary of chapter

The annual rates of forced displacement have now reached the highest levels recorded in history and as a result the global community is facing some of the most challenging humanitarian issues.(1) Refugees are exposed to a number of potentially traumatic events as a result of the refugee experience and therefore at greater risk of experiencing mental illness.(2,8) Women of refugee background are at even greater risk due to gender-based violence and experiencing pregnancy as a refugee can bring about a host of vulnerabilities and increased risks for the development of mental illness.(21) This PhD project will address crucial gaps in current knowledge by generating new evidence and synthesising existing evidence about depression, anxiety, and PTSD in Dari speaking women during pregnancy. Firstly, it will contribute new knowledge about the prevalence of mental health conditions in current global refugee and asylum seeker populations. Secondly, by addressing some of the identified barriers to perinatal mental health screening and validating the EPDS in the Dari language and assessing the screening properties of the HTQ. Finally, by providing a synthesis and novel interpretation of the strategies delivered during the implementation of the perinatal mental health screening program and the description of an implementation guide which can be utilised by health services within Australia and internationally.

## **Chapter two: The mental health of adult refugees and asylum seekers**

### **2.1 Introduction**

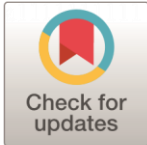
Given the increasing numbers of refugees and asylum seekers, it is imperative that current prevalence estimates of mental illness based on rigorous diagnostic assessment be established in order for host nations to understand the magnitude of this public health issue. These prevalence estimates can be used as a tool for advocacy in order to strengthen and argue for the delivery of essential and critical mental health assessment and intervention for newly resettled refugees and asylum seekers. The systematic review and meta-analyses presented in chapters two and three provide an update and expansion on a systematic review by Fazel, Wheeler, and Danesh previously published in *The Lancet* in 2005.<sup>(12)</sup> This systematic review is one of the most highly cited publications in the field of refugee mental health, however due to the changing nature of forced displacement and the growing numbers of refugees and asylum seekers an update and expansion was much needed. In order to better understand the true extent of the prevalence of mental illness within this ever-growing population, a systematic review which included data from both women and men was considered critical. It was hoped that within the analysis, a subgroup analysis based on sex could be conducted in order to report upon the sex differences in prevalence estimates across all of the mental illnesses. However, the subgroup analysis for sex was only possible for PTSD, due to a lack of sex data for the other mental illness outcomes. This outcome highlighted a potential limitation of the current literature, however this may also reflect the fact that the search strategy omitted specific gender terms. This is discussed further within the manuscript.



**Manuscript one: The prevalence of mental illness in refugees and asylum seekers: a systematic review and meta-analysis**



## PLOS MEDICINE



# The prevalence of mental illness in refugees and asylum seekers: A systematic review and meta-analysis

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**DataAvailabilityStatement:** All relevant data are within the manuscript and its Supporting Information files.

RESEARCH ARTICLE

## Background

Globally, the number of refugees and asylum seekers has reached record highs. Past research in refugee mental health has reported wide variation in mental illness prevalence data, partially attributable to methodological limitations. This systematic review aims to summarise the current body of evidence for the prevalence of mental illness in global refugee populations and overcome methodological limitations of individual studies.

## Methods and findings

A comprehensive search of electronic databases was undertaken from 1 January 2003 to 4 February 2020 (MEDLINE, MEDLINE In-Process, EBM Reviews, Embase, PsycINFO, CINAHL, PILOTS, Web of Science). Quantitative studies were included if diagnosis of mental illness involved a clinical interview and use of a validated assessment measure and reported at least 50 participants. Study quality was assessed using a descriptive approach based on a template according to study design (modified Newcastle-Ottawa Scale). Random-effects models, based on inverse variance weights, were conducted. Subgroup analyses were performed for sex, sample size, displacement duration, visa status, country of origin, current residence, type of interview (interpreter-assisted or native language), and diagnostic measure. The systematic review was registered with PROSPERO (CRD) 42016046349. The search yielded a result of 21,842 records. Twenty-six studies, which included one randomised controlled trial and 25 observational studies, provided results for 5,143 adult refugees and asylum seekers. Studies were undertaken across 15 countries:

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**Competing interests:** The authors have declared that no competing interests exist.

**Abbreviations:** ASA-SI, Adult Separation Anxiety

Semistructured Interview; CAPS, Clinician Administered PTSD Scale; CI, confidence interval;

DSM, Diagnostic and Statistical Manual of Mental Disorders; ICD, International Classification of

Disease; IS, Islamic State; M.I.N.I., the MiniInternational Neuropsychiatric

Interview; NA, not assessed in study; NOS, Newcastle-Ottawa Scale; NR, not reported;

PTSD, posttraumatic stress disorder; RCT, randomised controlled trial; SCID,

Structured Clinical Interview for DSM; SD, standard deviation; WHO, World Health

Organization; WMHCIDI, World Mental Health Composite International Diagnostic Interview.

Australia (652 refugees), Austria (150), China (65), Germany (1,104), Italy (297), Lebanon (646), Nepal (574), Norway (64), South Korea (200), Sweden (86), Switzerland (164), Turkey (238), Uganda (77), United Kingdom (420), and the United States of America (406). The prevalence of posttraumatic stress disorder (PTSD) was 31.46% (95% CI 24.43–38.5), the prevalence of depression was 31.5% (95% CI 22.64–40.38), the prevalence of anxiety disorders was 11% (95% CI 6.75 – 15.43), and the prevalence of psychosis was 1.51% (95% CI 0.63–2.40). A limitation of the study is that substantial heterogeneity was present in the prevalence estimates of PTSD, depression, and anxiety, and limited covariates were reported in the included studies.

## Conclusions

This comprehensive review generates current prevalence estimates for not only PTSD but also depression, anxiety, and psychosis. Refugees and asylum seekers have high and persistent rates of PTSD and depression, and the results of this review highlight the need for ongoing, long-term mental health care beyond the initial period of resettlement.

## Author summary

### Why was this study done?

- Globally, the numbers of refugees and asylum seekers have reached record highs.
- This systematic review aims to estimate how common mental illnesses are in current adult refugee and asylum-seeker populations.

### What did the researchers do and find?

- We performed a comprehensive literature search looking for studies that diagnosed mental illness in refugee and asylum-seeker populations.
- For studies to be included, the diagnosis must have resulted from a clinical interview using a validated diagnostic assessment measure.
- We found adult refugee and asylum seekers have high and persistent rates of posttraumatic stress disorder (PTSD) and depression. The prevalence of anxiety disorders and psychosis are more comparable to findings from general populations.

### What do these findings mean?

- The increased prevalence of PTSD and depression appears to persist for many years after displacement.
- These results highlight the importance of early and ongoing mental health care, extending beyond the period of initial resettlement, to promote the health of refugees and asylum seekers.

### Introduction

Globally, the numbers of refugees and asylum seekers have reached record highs [1]. Ongoing conflicts around the world raise challenging social, political, and humanitarian issues [2]. For host-country health systems, the refugee crisis can have major implications for service planning and provision. Refugees and asylum seekers may have been exposed to traumatic events such as conflict, loss or separation from family, a life-threatening journey to safety, long waiting periods, and complexities with acculturation [3,4]. A sizable proportion are therefore at risk of developing psychological symptoms and major mental illness that can persist for many years after resettlement [5].

Estimates of the prevalence of mental illness in refugees vary greatly, even at the level of systematic reviews. Fazel and colleagues (2005) [6] conducted a systematic review and meta-analysis of refugees resettled in high-income countries, covering the period 1986–2004, and reported a prevalence of 9% for posttraumatic stress disorder (PTSD), 5% for major depressive disorder, and 4% for generalised anxiety disorder, based on studies reporting at least 200 participants. A subsequent systematic review into the association between torture or other traumatic events and PTSD and depression, covering studies between 1987 and 2009 and comprising 81,866 refugees and conflict-affected populations, reported an unadjusted weighted prevalence of 30% for PTSD and 30% for depression [7]. A recent systematic review of 8,176 Syrian refugees resettled in 10 countries reported a prevalence of 43% for PTSD, 40% for depression, and 26% for anxiety [8]. As the literature has focused on either specific cultural groups or specific host nations or has combined internally displaced populations with refugees and asylum seekers, there is a lack of estimates on the prevalence of mental illness in more representative refugee and asylum-seeker populations [9–12]. There is also a lack of research investigating the full breadth of mental illness, as the literature has mainly focused on PTSD and depression, hence the need for a comprehensive, worldwide, systematic review to investigate mental illness in the current refugee populations.

Some of the variation across individual studies may be attributable to methodological differences. For example, self-report measures tend to overestimate symptomatology, yet the literature relies heavily on these data rather than comprehensive psychiatric assessments using validated diagnostic tools [7,13]. There is also no uniform refugee experience: country of origin or resettlement, duration of displacement, or experience of displacement, amongst other important factors.

Given the changing nature of forced displacement and record numbers of refugees and asylum seekers, it is timely to re-examine this topic based on the many studies published since the two previously mentioned major reviews. Current prevalence information could be a powerful tool for advocacy and also assist host countries and humanitarian agencies to strengthen health services to provide the essential components of timely diagnosis and treatment for mental illnesses, in line with the priorities and objectives of the World Health Organization (WHO) Draft Global Action Plan ‘Promoting the health of refugees and migrants’ (2019–2023) [14]. Providing appropriate, early, and ongoing mental health care to refugees and asylum seekers benefits not only the individual but the host nation, as it improves the chances of successful reintegration, which has long-term benefits for the social and economic capital of that country, which will likely impact not only the displaced generation but the second generation as well [15]. Bringing together the global literature on the prevalence of mental illness in refugee and asylum-seeker populations would also enable the research community to move ahead and focus on different components of the mental health needs of this population, for example, on interventions, on less well-understood mental health conditions, or longitudinal mental health trajectories.

This systematic review aims to establish the current overall prevalence of mental illnesses in refugee and asylum-seeker populations by summarising the current global body of evidence and overcoming some methodological limitations of individual studies.

## Methods

### Search strategy and selection criteria

We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement ([S1 Prisma Checklist](#)) [16] and registered the protocol with PROSPERO (record CRD42016046349) ([https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=46349](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=46349)). The search was based on that used in the earlier systematic review by Fazel and colleagues [6] but expanded to increase the range of databases searched, number of search terms, and stricter criteria regarding study inclusion. This review also placed no restrictions on resettlement countries. In total, eight databases were searched: MEDLINE, MEDLINE

In-Process, EBM Reviews, Embase, PsycINFO, CINAHL, PILOTS, Web of Science. The search strategy included terms for refugees and asylum seekers and terms related to mental illness, diagnosis, and trauma. An example of a complete search string is provided in [S1 Table](#). The date limits of the search were 1 January 2003 to 4 February 2020. This start date reflects the end date of the search conducted by Fazel and colleagues [6], in order to provide a contemporary estimate of mental illness within this population. The reference lists of 92 relevant systematic reviews identified during the search were also screened, resulting in an additional 37 articles to review.

Studies were included if (1) the sample solely comprised adult refugees and/or asylum seekers residing outside their country of origin, (2) had a sample size larger than 50, and (3) reported quantitative prevalence estimates of a mental illness as classified by the Diagnostic and Statistical Manual of Mental Disorders (DSM) [17] or the International Classification of Disease (ICD) [18]. This diagnosis must have resulted from a clinical interview using a validated diagnostic assessment measure. The interview needed to be conducted either by a mental health professional (psychiatrist, psychologist, psychiatric nurse) or trained paraprofessional (psychology research assistant, trained researcher). In studies administering the WHO World Mental Health Composite International Diagnostic Interview (WMH-CIDI) [19], non-clinicians who had completed official WHO training were accepted, as this fully structured interview measure is intended for use by trained lay interviewers. If multiple articles reported data from the same study, the article providing data best meeting the selection criteria was included. Randomised controlled trials (RCTs), longitudinal cohort, and cross-sectional studies were considered for inclusion, whereas retrospective registry reviews, medical records audits, and qualitative studies were excluded. Case-control studies were excluded if cases were selected based on the presence of our outcomes of interest. Studies were excluded if they met the following criteria:

- Participants were recruited from psychiatric or mental health clinics (to reduce selection bias). However, those studies that recruited participants from primary healthcare clinics were still included.
- The sample included asylum seekers whose applications had been rejected and the results were not disaggregated or the assessment was not conducted prior to rejection (when the individuals met the definition of asylum seekers).
- Diagnoses were based solely on self-report questionnaires or symptom rating scales.

Two reviewers (RB and MG-H or GF) independently assessed the title, abstract, and keywords of every article retrieved against the selection criteria. Full text was then assessed if the title and abstract suggested the study met the selection criteria. We contacted 31 study authors for further information regarding methodology and data and received 28 responses. Studies in languages other than English were assessed first by a native speaker when possible or via Google translate and then professionally translated if assessed as potentially eligible.

### Data analysis

Using a fixed protocol, two review authors (RB and MG-H) independently extracted statistical data and study characteristics: host country, publication year, sample size, country or region of origin, sampling method, diagnostic tool and criteria, use of interpreter, age, proportion of female participants, visa status, duration of displacement, and prevalence of mental illness (numerator and denominator). Data regarding the sex distribution of samples were extracted separately for males and females, when possible.

Meta-analysis results (Stata software version 14.1 [StataCorp]) were expressed as prevalence estimates of mental illness calculated with 95% confidence intervals (CIs) in the pooled data. Random-effects meta-analyses using a DerSimonian and Laird estimator based on inverse variance weights were employed [20]. Random-effects meta-analysis was chosen, as heterogeneity was anticipated because of between-study variations in clinical factors due to the heterogenous nature of refugees and asylum seekers (e.g., country of origin, language, host nations, etc.). The DerSimonian and Laird method incorporates a measure of the heterogeneity between studies. Heterogeneity was assessed using the  $I^2$  statistic [21]. In the case of five or more studies being available, publication bias was assessed by visual inspection of funnel plots and applying Egger's test set at a threshold of a  $p$ -value less than 0.05 to indicate funnel plot asymmetry [22]. Prevalence rates were for current diagnoses, except studies reporting 1-year prevalence as assessed by the WHO WMH-CIDI [23–25].

Sources of heterogeneity between studies were investigated, when reported data allowed, by subgroup analyses. This included sex, sample size, displacement duration, visa status, country or region of origin, current residence, type of interview (interpreter-assisted or native language), and diagnostic measure. As prevalence of mental illness is related to sample size [6], the subgroup analysis for sample size compared studies with more or less than 200 participants.

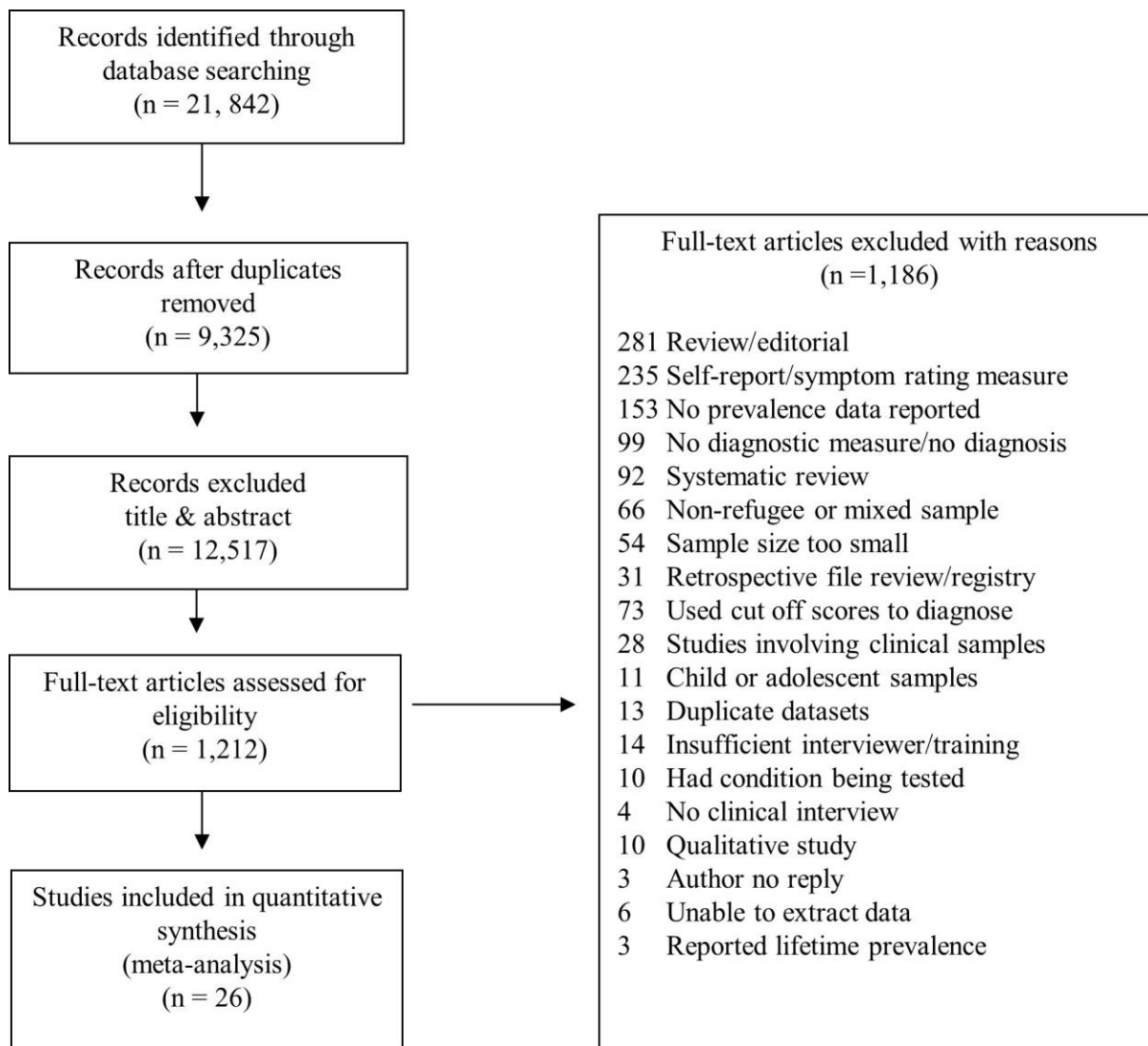
### Risk of bias assessment

Methodological quality was independently assessed by two reviewers (RB and JAB) using an assessment template for risk of bias, developed a priori according to study design, which meant the criteria to assess an RCT were different from the criteria of an observational study ([S1 Risk of Bias](#)) [26]. These templates are based upon the Newcastle-Ottawa Scale (NOS) [27], with the addition of further risk of bias components assessing internal and external validity such as use of appropriate study design, explicit and appropriate use of inclusion criteria, reporting bias, confounding, sufficient power for analyses, and any apparent conflicts of interest, as has been used in international evidence-based guidelines and other systematic reviews [28–30]. Using a descriptive approach, studies were assigned a rating of low, moderate, or high risk of bias. Any disagreement was resolved by discussion with other reviewers (MG-H and MF) to reach a consensus. Such discussions occurred on two occasions, both times regarding papers assigned at high risk of bias [31,32].

### Results

The entire search yielded 21,842 records ([Fig 1](#)). After removing duplicates, 12,517 records were excluded based on title and abstract and a further 1,186 records were selected for full text review. Twenty-six studies met the inclusion criteria, providing data for 5,143 adult refugees and asylum seekers ([Fig 1](#)). Characteristics of the included studies are provided in [Table 1](#). All were observational, except one RCT from which we included baseline prevalence data [24]. Studies were undertaken in 15 countries: Australia (652 refugees) [33–37], Austria (150) [38], China (65) [32], Germany (1,104) [39–44], Italy (297) [39], Lebanon (646) [45,46], Nepal (574) [25], Norway (64) [23], South Korea (200) [47], Sweden (86) [48], Switzerland (164) [49,50], Turkey (238) [51], Uganda (77) [24], UK (420) [39,52], and the US (406) [31,53]. Participants were from four geographic regions: the Middle East (43%), Europe (29%), Asia (20%), and Africa (5%), with two studies reporting refugee samples coming from 18 different countries (3%) [26, 41] (97% of total sample due to unreported countries of origin).

Five diagnostic measures were used ([S1 Table](#)): Structured Clinical Interview for DSM (SCID) [54], Mini-International Neuropsychiatric Interview (M.I.N.I.) [55], Clinician Administered PTSD Scale (CAPS) [56], and WHO WMH-CIDI [18]. None of these instruments were developed specifically for refugee populations but have been widely used in different cultural contexts.



**Fig 1.** Search results and selection of studies reporting prevalence of mental illness among refugees and asylum seekers.

<https://doi.org/10.1371/journal.pmed.1003337.g001>

Table 1.

## Characteristics of included studies.

Study	Country or Region of Origin	Sampling	Instrument and Criteria	Interview in Native Language	N	Age: Years M (SD)	Female: %	PTSD (%)	DEP (%)	ANX (%)	PSY (%)	Risk of Bias
Bogic et al., 2012 [39] (Germany, Italy, and UK)	Former Yugoslavia	In Germany and Italy, refugees contacted via resident registry lists. In UK, refugees contacted via community organizations and snowball techniques.	M.I.N.I. DSM-IV	Yes	854	41.6 (10.8)	51.29	283 (33.14)	292/851 (34.31)	74/854 (7.36)	11 (1.29)	Mod.
Charney and Keane, 2007 [31] (USA)	Former Yugoslavia	Advertised psychological treatment study for Bosnian refugees suffering the effects of the Balkans' civil war.	SCID DSM-IV	Yes	115	46 (13.78)	67	NA	NA	NA	9 (8)	High
Eckart et al., 2011 [40] (Germany)	Albania, Serbia, Romania, and Turkey	Recruited participants from shelters for asylum seekers and Kurdish recreational facilities.	CAPS and M.I.N.I. DSM-IV	No	52	PTSD group: 36.2 (7.7) Trauma controls: 34.1 (9.9) Nontrauma controls: 29 (7.2)	0	20 (38.46)	17 (32.69)	NA	NA	Low
Heeren et al., 2012 [49] (Switzerland)	Europe, Africa, and Asia	Two groups sampled consecutively from lists provided every 2 weeks for 6 months from the national register of adult asylum seekers in Switzerland.	M.I.N.I. DSM-IV	No	86	Group 1: 26.7 (7.2) Group 2: 32.9 (9.6)	30.23	20 (23.25)	27 (31.39)	7 (8.13)	NA	Low
Hocking et al., 2018 [36] (Australia)	Africa and Asia	Consecutive sample populations of 'general access-listed' clients at ASRC and Refugee Health Clinic, Dental Clinic in Victoria, Australia.	M.I.N.I. DSM-IV	No	185	33	30.3	38 (20.7)	56 (30.3)	6 (3.2)	2 (1)	Mod.
Jakobsen et al., 2011 [23] (Norway)	Middle East, North Africa, Somalia, and former Yugoslavia	12 reception centres, all eligible asylum seekers (i.e., stay in Norway 4 months, age > 18 years, and speakers of one of the included languages).	WHO-CIDI DSM-IV	No	64	33 (11.6)	46.88	29 (4.31)	21 (32.81)	17 (26.56)	1 (1.56)	Low
Jeon et al., 2005 [47] (South Korea)	North Korea	All North Korean refugees living in Seoul (July 1998–November 2000) were contacted via telephone and asked to participate.	SCID DSM-III	Yes	200	34.7 (10.3)	41.5	59 (29.50)	NA	NA	NA	Low

Kazour et al., 2017 [46] (Lebanon)	Syria	Household survey on refugees between 18 and 65 years old in six Central Bekaa camps in Lebanon.	M.I.N.I. DSM-IV	Yes	452	35.05 (12.35)	55.75	123 (27.21)	NA	NA	NA	Low
Kizilhan, 2018 [42] (Germany)	Iraq	Participants were part of special quota project in Baden-Wuerttemberg to support women escaped from IS.	SCID DSM-IV	Yes	296	23.72 (2.6)	100	144 (48.6)	158 (53.4)	116 (39.1)	NA	High

(Continued)

Study	Country or Region of Origin	Sampling	Instrument and Criteria	Interview in Native Language	N	Age: Years M (SD)	Female: %	PTSD (%)	DEP (%)	ANX (%)	PSY (%)	Risk of Bias
Llosa et al., 2014 [45] (Lebanon)	Palestine	Selected households chosen from the Burj elBarajneh camp in southern Beirut, Lebanon.	M.I.N.I. DSM-IV	Yes	194	41.5 (15)	71.13	9 (4.64)	31 (15.98)	15 (7.73)	5 (2.58)	Low
Maier et al., 2010 [50] (Switzerland)	18 different countries: Asia, Africa, and Europe	List provided by Swiss Federal Office for Migration, all adult (18 + years old) asylum seekers applying after 1 August 2007 and assigned to the Zurich canton.	M.I.N.I. DSM-IV	No	78	29.9 (8.4)	26.92	19 (24.36)	26 (33.33)	8 (10.26)	NA	Low
Momartin et al., 2004 [33] (Australia)	Former Yugoslavia	The Bosnian Resource Centre provided a list of names. In order to obtain additional participants, a snowball technique was also utilised.	CAPS and SCID DSM-IV	No	126	47 (NR)	61.11	79 (62.70)	58 (46.03)	NA	NA	Mod.
Neuner et al., 2004 [24] (Uganda)	Sudan	Participants randomly chosen from list of respondents who had previously been randomly selected in a hut-to-hut survey at the Imvepi Settlement in Uganda.	WHO-CIDI DSM-IV	No	77	NR (NR)	NR	43 (55.84)	NA	NA	NA	Low
Rees et al., 2019 [37] (Australia)	Middle East, Sri Lanka, and Sudan	The study was conducted at three public antenatal clinics in Sydney and Melbourne, Australia. At first appointment, women were identified by clinic records through requests for interpreters, culturally recognizable surname, and country of birth data.	M.I.N.I. DSM-IV	Yes	289	30 (5.8)	100	NA	94 (32.5)	NA	NA	Low

Renner et al., 2006 [38] (Austria)	Chechnya, West Africa, Afghanistan	All participants had applied for political asylum in Austria.	CAPS DSM-IV	No	150	Chechnya: 32.4 (10.7) West Africa: 32.5 (7.1) Afghanistan: 27.5 (9)	26.67	38 (25.33)	NA	NA	NA	Low
Richter et al., 2018 [43] (Germany)	Middle East, Russia, Azerbaijan	Asylum seekers from an admission centre in southern Germany. Two samples; help seekers, those responding to flyers regarding psychiatric services, and random sample, randomly selected residents of the centre.	M.I.N.I. ICD-10	Yes	283	31.9 (10.6)	44	58 (20.5)	62 (21.9)	11 (3.8)	3 (1)	High

(Continued)

Study	Country or Region of Origin	Sampling	Instrument and Criteria	Interview in Native Language	N	Age: Years M (SD)	Female: %	PTSD (%)	DEP (%)	ANX (%)	PSY (%)	Risk of Bias
Silove et al., 2010 [34] (Australia) Data obtained from same refugee population used by Momartin et al., 2004 [33]	Former Yugoslavia	The Bosnian Resource Centre provided a list of names. In order to obtain additional participants, a snowball technique was also utilised.	ASA-SI DSM-IV	No	126	47 (NR)	61.11	NA	NA	22 (17.46)	NA	Mod.
Sondergaard and Theorell, 2004 [48] (Sweden)	Iraq	Recently resettled refugees from Iraq.	CAPS DSM-IV	No	86	34.7 (7.7)	37.21	32 (37.21)	NA	NA	NA	Low
Tay et al., 2013 [35] (Australia)	Refugees in Australia from 18 different countries covering Middle East, Africa, Asia	Participants selected using cluster probabilistic sampling method. Randomly approached 87 migration agents who had represented asylum seekers during a 12-month period (2001–2002).	SCID DSM-IV	No	52	39 (13.5)	34.61	31 (59.61)	30 (57.69)	NA	NA	Low
Tekin et al., 2016 [51] (Turkey)	Iraq	Yazidi refugees displaced from Shengal region in Iraq and entered Turkey between July and September 2014 and living in camp (February–April 2015) in the Cizre district of Turkey.	SCID DSM-IV	Yes	238	32.7 (11.87)	55.88	102 (42.86)	94 (39.50)	NA	NA	Mod.

Turner et al., 2003 [52] (UK)	Kosovo	Participants recruited from five reception centres in the north of England for refugees from Kosovo (November 1999–January 2000).	CAPS DSM-IV	Yes	118	37.1 (14.7)	53.33	46 (38.98)	NA	NA	NA	Mod.
Van Ommeren et al., 2004 [25] (Nepal)	Bhutan	Participants randomly selected from United Nations camp list of Bhutanese refugees.	WHO-CIDI ICD-10	Yes	574	Shamans: 51.3 (11.7) Non-healers: 43.7 (12.9)	0	154 (26.8)	11 (1.92)	27 (4.70)	NA	Mod.
von Lersner et al., 2008 [41] (Germany)	Bosnia, Serbia, Kosovo, Iraq, Turkey	Participants recruited by advertisements posted in refugee centres, language schools, and doctors' offices. Organizations involved in the return of refugees were contacted.	M.I.N.I. DSM-IV	No	100	43.2 (14.9)	50	NA	42 (42.00)	2 (2.00)	NA	Mod.
Wright et al., 2017 [53] (USA)	Iraq	Adult Iraqi refugees randomly selected from population who arrived in Michigan between October 2011 and August 2012. Recruited with collaboration of three resettlement agencies.	SCID DSM-IV	Yes	291	34.30 (11.37)	45.7	11 (3.78)	8 (2.75)	NA	NA	Low

(Continued)

Study	Country or Region of Origin	Sampling	Instrument and Criteria	Interview in Native Language	N	Age: Years M (SD)	Female: %	PTSD (%)	DEP (%)	ANX (%)	PSY (%)	Risk of Bias
Wulfes et al., 2019 [44] (Germany)	Middle East and Sudan	Asylum seekers living in refugee accommodation (Braunschweig) Residents were asked to participate by staff at centre, social workers, research team, and flyers.	SCID DSM-5	No	118	32.9 (13.1)	35.6	35 (29.7)	39 (33.1)	NA	NA	Mod.
Yu and Jeon, 2008 [32] (China)	North Korea	Refugees over 15 years of age who were in protective facilities in China under the South Korean government protection.	SCID DSM-IV	Yes	65	NR (NR)	70.77	3 (4.61)	NA	NA	NA	High

Abbreviations: ANX, anxiety; ASA-SI, Adult Separation Anxiety Semi-structured Interview; ASRC, Asylum Seeker Resource Centre; CAPS, Clinician Administered PTSD Scale; DEP, depression; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; ICD-10, International Classification of Disease, 10th Edition; IS, Islamic State; M, mean; Mod., moderate; M.I.N.I., the Mini-International Neuropsychiatric Interview; N, number; NA, not assessed in study; NR, not reported PSY, psychosis; PTSD, posttraumatic stress disorder; SCID, Structured Clinical Interview for DSM; SD, standard deviation; WHO-CIDI, World Health Organization–Composite International Diagnostic Interview

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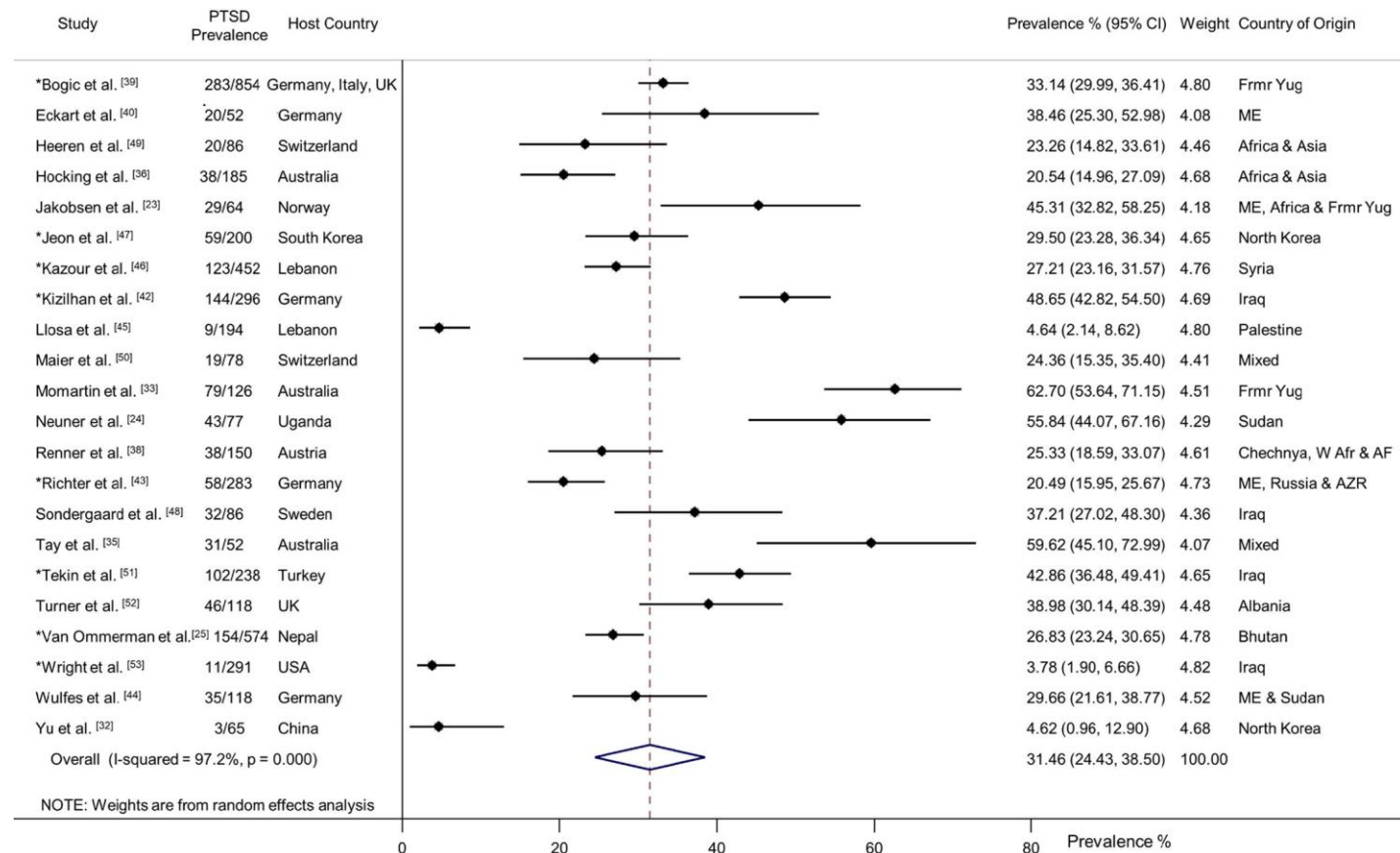
Nine studies mentioned the reliability or validity of the used instruments [23,35,36,39,41,44–46,51]. Thirteen studies conducted the assessment in the refugee's native language [25,31,32,37,39,42,43,45–47,51–53]. Thirteen studies were conducted with assistance from interpreters [23,24,33–36,38,40,41,44,48–50].

Twenty-two studies of PTSD were identified ( $n = 4,639$ ) [23–25,32,33,35,36,38–40,42–53]. Participants had a weighted mean age of 35.2 years and 44% were women. Overall, 31.46% (95% CI 24.43–38.50) were diagnosed with PTSD (1,376/4,639) (Fig 2). There was substantial heterogeneity between studies (Fig 2), and subgroup analyses indicated PTSD prevalence was significantly higher for women (34.02%, 95% CI 31.12–37.01,  $p = 0.02$ ), in the smaller studies ( $n < 200$ ) (37.35%, 95% CI 34.86–39.90,  $p < 0.001$ ), those with refugee status (31.01%, 95% CI 29.52–32.54,  $p < 0.001$ ), and those originating from Africa (48.25%, 95% CI 39.82–56.75,  $p < 0.001$ ) (Fig 3). In the eight largest studies with 200 participants or more, PTSD prevalence was significantly lower (29.30%, 95% CI 27.72–30.91,  $p < 0.001$ ) [25,39,42,43,46,47,51,53]. Duration of displacement had no significant impact on PTSD prevalence ( $p = 0.11$ ). The prevalence of PTSD for those displaced less than 4 years was 30.17% (95% CI 28.24–32.14) compared to 33.14% (95% CI 29.99–36.41) for those displaced longer than 4 years. The PTSD prevalence for interpreter-assisted interviews was 35.75% (95% CI 33.80–39.70) compared to 27.82% (95% CI 26.40–29.30) for interviews conducted in the native language ( $p < 0.001$ ).

There was a statistically significant difference across diagnostic measures ( $p < 0.001$ ) with the CAPS yielding a higher prevalence of PTSD (40.41%, 95% CI 36.20–44.70), followed by the WHO-CIDI (31.6%, 95% CI 28.20–35.20), the SCID (30.55%, 95% CI 28–33.20), and the M.I. N.I. (25.8%, 95% CI 24–27.70).

Seventeen studies of depression were identified ( $n = 3,877$ ) [23,25,33,35–37,39–45,49–51,53]. Participants had a weighted mean age of 35.7 years and 48% were women. Overall, 31.51% (95% CI 22.64–40.38) were diagnosed with depression (1,066/3,877) (Fig 4). Three studies provided separate data for dysthymia ( $n = 1,135$ ) [39,41,45]. The overall prevalence of dysthymia was 6.72% (95% CI 3.63%–9.81%) with moderate heterogeneity between studies



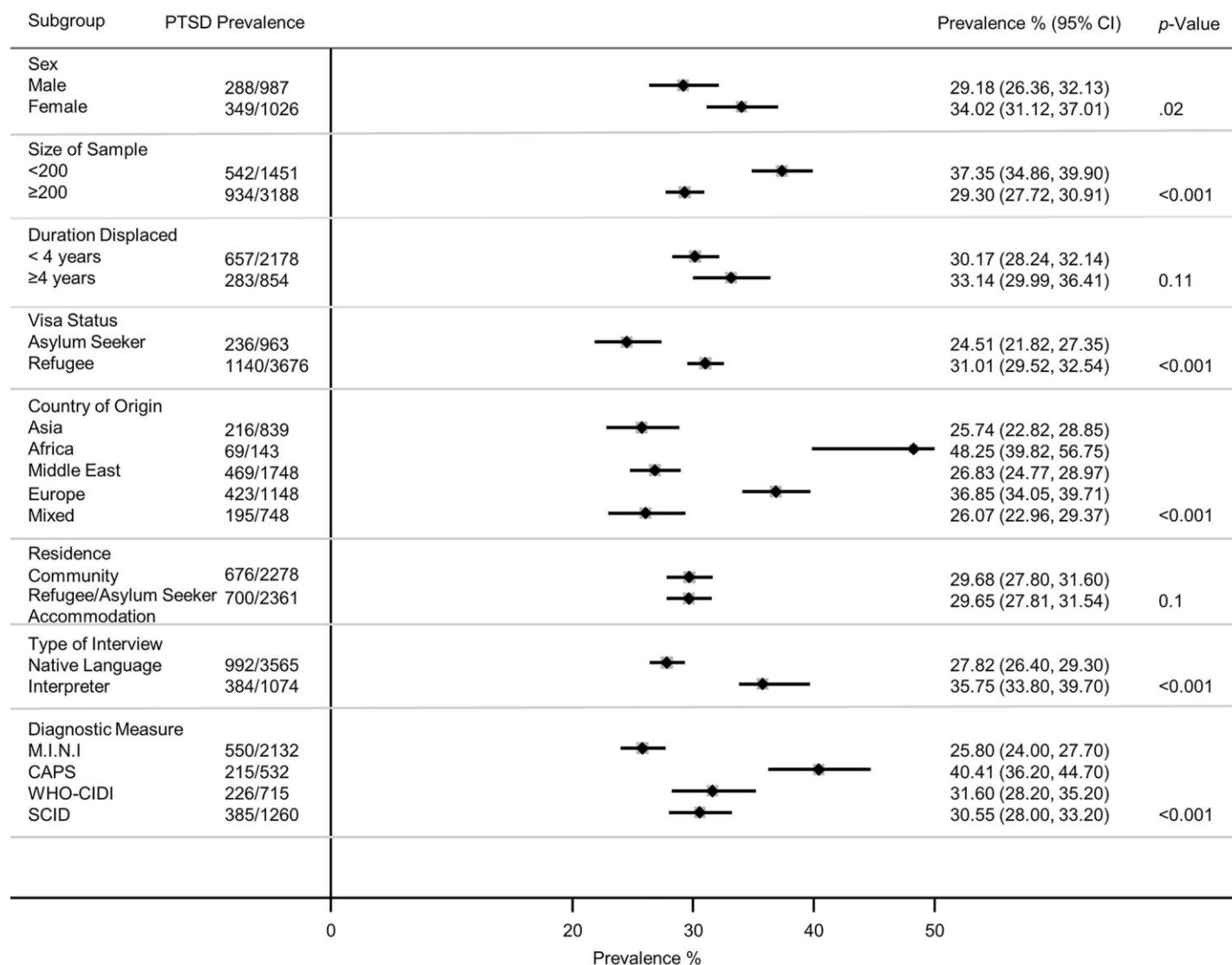


**Fig 2. Prevalence of PTSD in refugees and asylum seekers.** \*Study with sample size of 200. Horizontal lines indicate 95% CIs; horizontal points of the open diamond are the limits of the overall 95% CIs; and the red dashed line shows the position of the overall prevalence. AF, Afghanistan; AZR, Azerbaijan; CI, confidence interval; Fmr Yug, former Yugoslavia; ME, Middle East; PTSD, posttraumatic stress disorder; W Afr, West Africa.

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( $I^2 = 65.6\%$ ,  $p = 0.055$ ). There was considerable heterogeneity between the studies (Fig 4). Subgroup analyses indicated depression prevalence was significantly higher in the smaller studies 32.89% (95% CI 30.06–35.82,  $p < 0.001$ ), for those deemed asylum seekers 30.14% (95% CI 27.10–33.32,  $p = 0.04$ ), those originating from Europe 35.82% (95% CI 32.81–38.92,  $p < 0.0001$ ), and for those living in the community 30.70% (95% CI 28.74–32.72,  $p < 0.0001$ ) (Fig 5). The subgroup analysis for sex could not be conducted, owing to a lack of reported data. In the seven larger studies with 200 or more participants [25,37,39,42,43,51,53], the reported depression prevalence was 20.65% (95% CI 18.88–22.51), which was significantly lower ( $p < 0.001$ ) than in the smaller studies, 32.89% (95% CI 30.06–35.82). Duration of displacement had no significant impact on depression prevalence ( $p = 0.17$ ). The prevalence of depression for those displaced less than 4 years was 32.44% (95% CI 30.00–34.95) and 35.12% (95% CI 32.08–38.25) for those displaced longer than 4 years. The depression prevalence for interpreter-assisted interviews was 35.35% (95% CI 32.05–38.76) compared to 24.87% (95% CI

23.33–26.45) for interviews conducted in the native language ( $p < 0.0001$ ). There was a statistically significant difference across type of diagnostic measures ( $p < 0.0001$ ) with the SCID yielding a higher prevalence of depression (34.52%, 95% CI 31.74–37.39), followed by the M.I. N.I. (30.55%, 95% CI 28.59–32.56) and the WHO-CIDI (5.02%, 95% CI 3.46–7.01). Eleven studies of anxiety disorders were identified ( $n = 2,840$ ) [23,25,34,36,39,41–43,45,49,50]. Participants had a weighted mean age of 36.8 years and 31% were women.

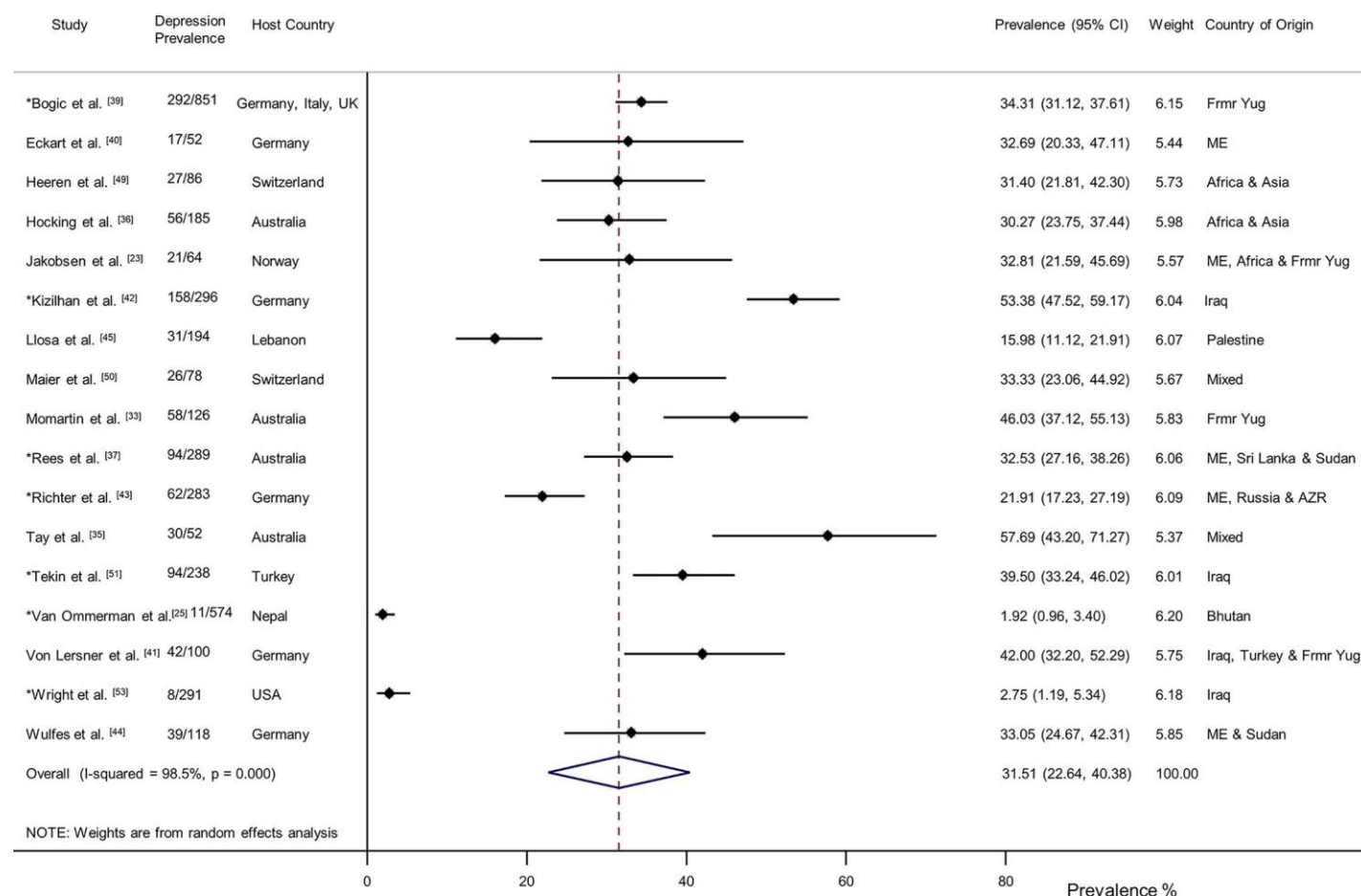


**Fig 3. Prevalence of PTSD by various study characteristics.** *p*-Values derived from random-effects models; horizontal lines indicate 95% CIs. CAPS, Clinician Administered PTSD Scale; CI, confidence interval; M.I.N.I., the Mini-International Neuropsychiatric Interview; PTSD, posttraumatic stress disorder; SCID, Structured Clinical Interview for DSM; WHO-CIDI, World Health Organization–Composite International Diagnostic Interview.

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Four studies reported prevalence for generalised anxiety disorder [25,39,41,45], six reported any anxiety disorder [23,36,42,43,49,50], and one study diagnosed adult separation anxiety disorder [34]. Overall, 11.09%

(95% CI 6.75–15.43) were diagnosed with an anxiety disorder (305/ 2,840) (Fig 6). There was substantial heterogeneity between studies (Fig 6). Subgroup analyses indicated anxiety prevalence was higher for those displaced less than 4 years (21.72%, 95% CI 18.74–24.94,  $p < 0.0001$ ), those granted formal refugee status (11.44%, 95% CI 10.12–12.87,  $p = 0.0009$ ), those originating from the Middle East (26.73%, 95% CI 22.86–30.89,  $p < 0.0001$ ), and those living in temporary refugee accommodation (13.18%, 95% CI 11.46–15.06,  $p < 0.0001$ ) (Fig 7). The subgroup analysis for sex could not be conducted, owing to a lack of reported data. Sample size had no significant impact on anxiety disorder prevalence ( $p = 0.21$ ). The prevalence of anxiety disorders in the smaller studies ( $N < 200$ ) was 9.24% (95% CI 7.36–11.42), and in the larger studies ( $N \geq 200$ ), the prevalence was 10.83% (95% CI 9.50–12.27).



**Fig 4. Prevalence of depression in refugees and asylum seekers.** \*Study with sample size of 200. Horizontal lines indicate 95% CIs; horizontal points of the open diamond are the limits of the overall 95% CIs; and the red dashed line shows the position of the overall prevalence. AZR, Azerbaijan; CI, confidence interval; Fmr Yug, former Yugoslavia; ME, Middle East.

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The use of an interpreter to conduct assessments had no significant impact on the reported prevalence of anxiety disorders ( $p = 0.34$ ). The prevalence of anxiety for interpreter-assisted interviews was 9.70 (95% CI 7.50–12.30) and 11.04% (95% CI 9.76–12.40) for those interviews conducted in the native language. The subgroup analysis for diagnostic measure could not be conducted, owing to insufficient studies for each measure.

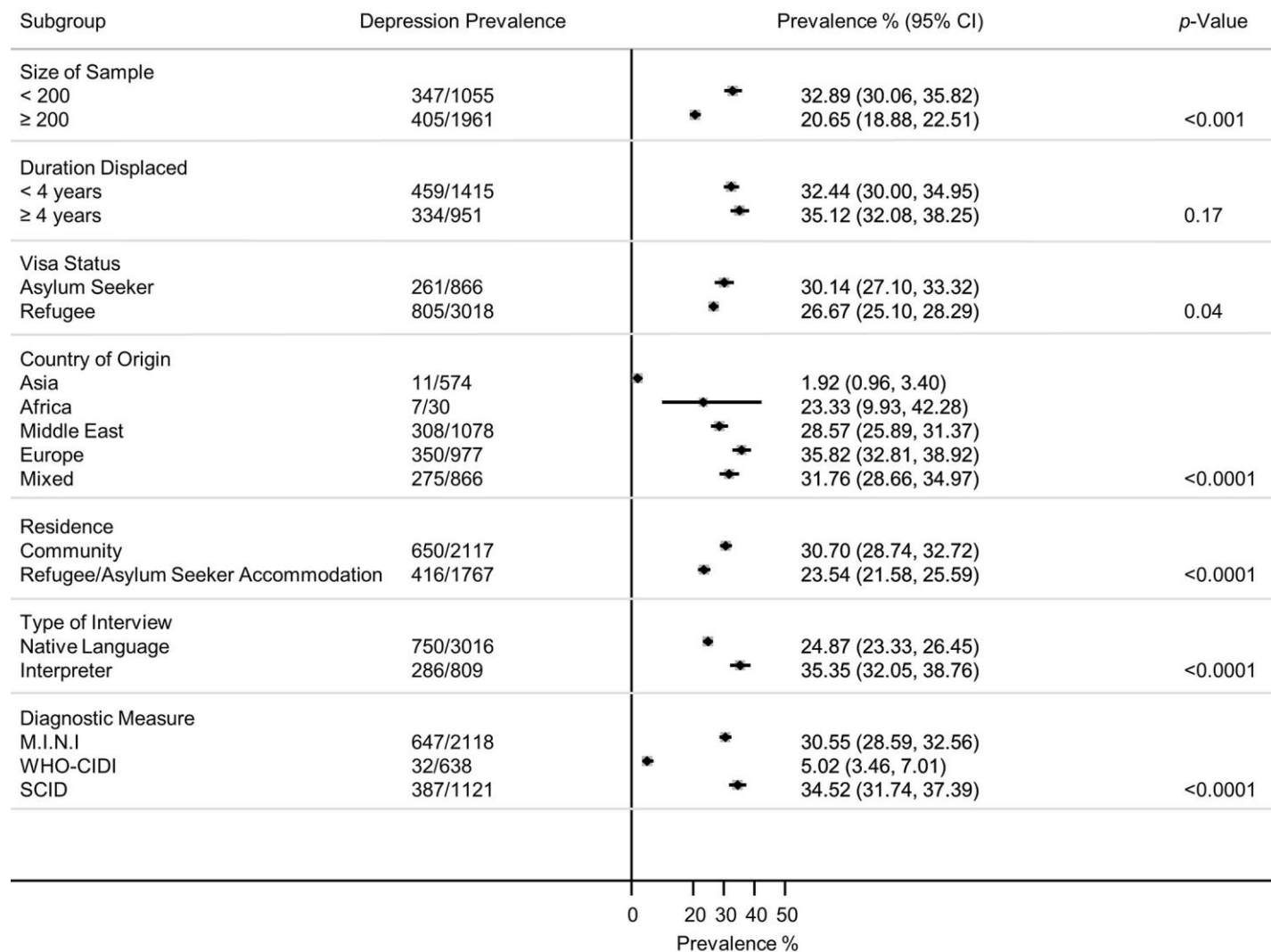
Six studies of psychotic illness were identified ( $n = 1,695$ ) [23,31,36,39,43,45]. Participants had a weighted mean age of 37.6 years and 51% were female. Overall, 1.51% (95% CI 0.63–2.40) were diagnosed with psychosis (31/1,695), with low heterogeneity between studies (Fig 8).

### Publication bias

There was no evidence of publication bias for PTSD, depression, anxiety, or psychosis (S1–S4 Egger's Tests).

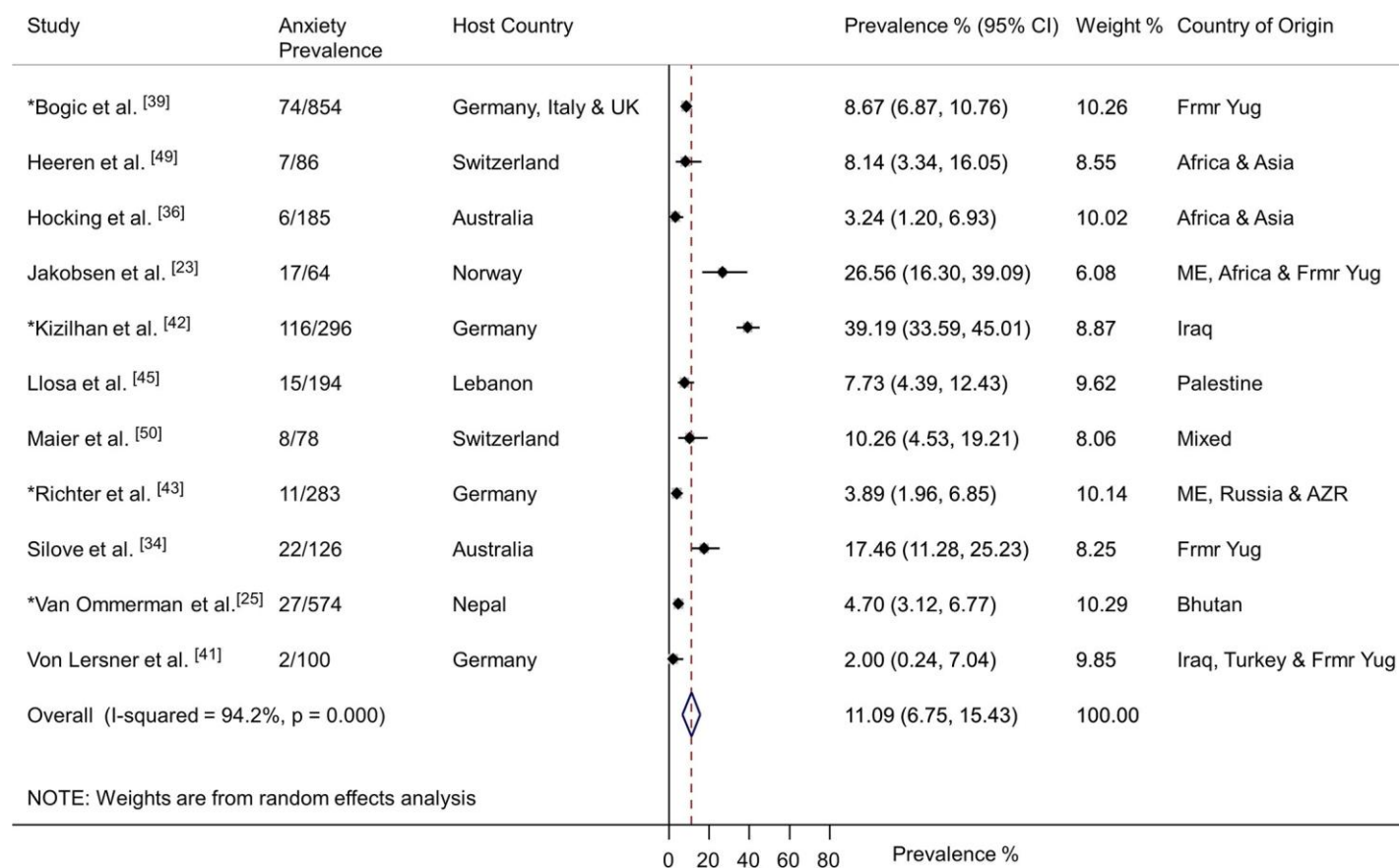
### Risk of bias

Thirteen studies were assigned a low risk of bias and determined to be of high quality [23,24,35,37,38,40,45–50,53]. Nine studies demonstrated moderate risk of bias [25,33,34,36,39,41,44,51,52]. A moderate rating was assigned to studies that had issues with the representativeness of their sample or used non-random sampling techniques. Additionally, in one study, only male psychologists conducted the diagnostic assessments, and this was associated with fewer than expected reports of sexual assault [51]. Four studies were assigned a high risk of bias [31,32,42,43]. One study, providing data for PTSD and depression, assessed the mental health consequences of captivity by the Islamic State (IS) militant group on a sample of Yazidi women. It was reported that some of the women were not yet ready to receive psychotherapy for their symptoms [42]. This may have impacted upon the reported prevalence rates, particularly PTSD, as some women may have been reluctant and not ready to disclose trauma details during the research interviews. Another study, providing PTSD data, conducted diagnostic assessments in non-confidential areas of a detention facility [32]. The reported PTSD prevalence was low but similar to two other studies assigned a low risk of bias. Two studies recruited help-seeking populations through the use of advertisements or flyers offering psychological treatment for those affected by war [31,43]. One of these studies compared their help-seeking population to a randomly recruited sample, and there was a difference in prevalence rates, with higher rates in the help-seeking population [43].



**Fig 5. Prevalence of depression by various study characteristics.** *p*-Values derived from random-effects models; horizontal lines indicate 95% CI. Subgroup analysis for sex could not be conducted, owing to a lack of reported data. CI, confidence interval; M.I.N.I., the Mini-International Neuropsychiatric Interview; SCID, Structured Clinical Interview for DSM; WHO-CIDI, World Health Organization–Composite International Diagnostic Interview.

<https://doi.org/10.1371/journal.pmed.1003337.g005>



**Fig 6. Prevalence of anxiety in refugees and asylum seekers.** \*Study with sample size of 200. Horizontal lines indicate 95% CIs; horizontal points of the open diamond are the limits of the overall 95% CIs; and the red dashed line shows the position of the overall prevalence. AZR, Azerbaijan; CI, confidence interval; Frmr Yug, former Yugoslavia; ME, Middle East.

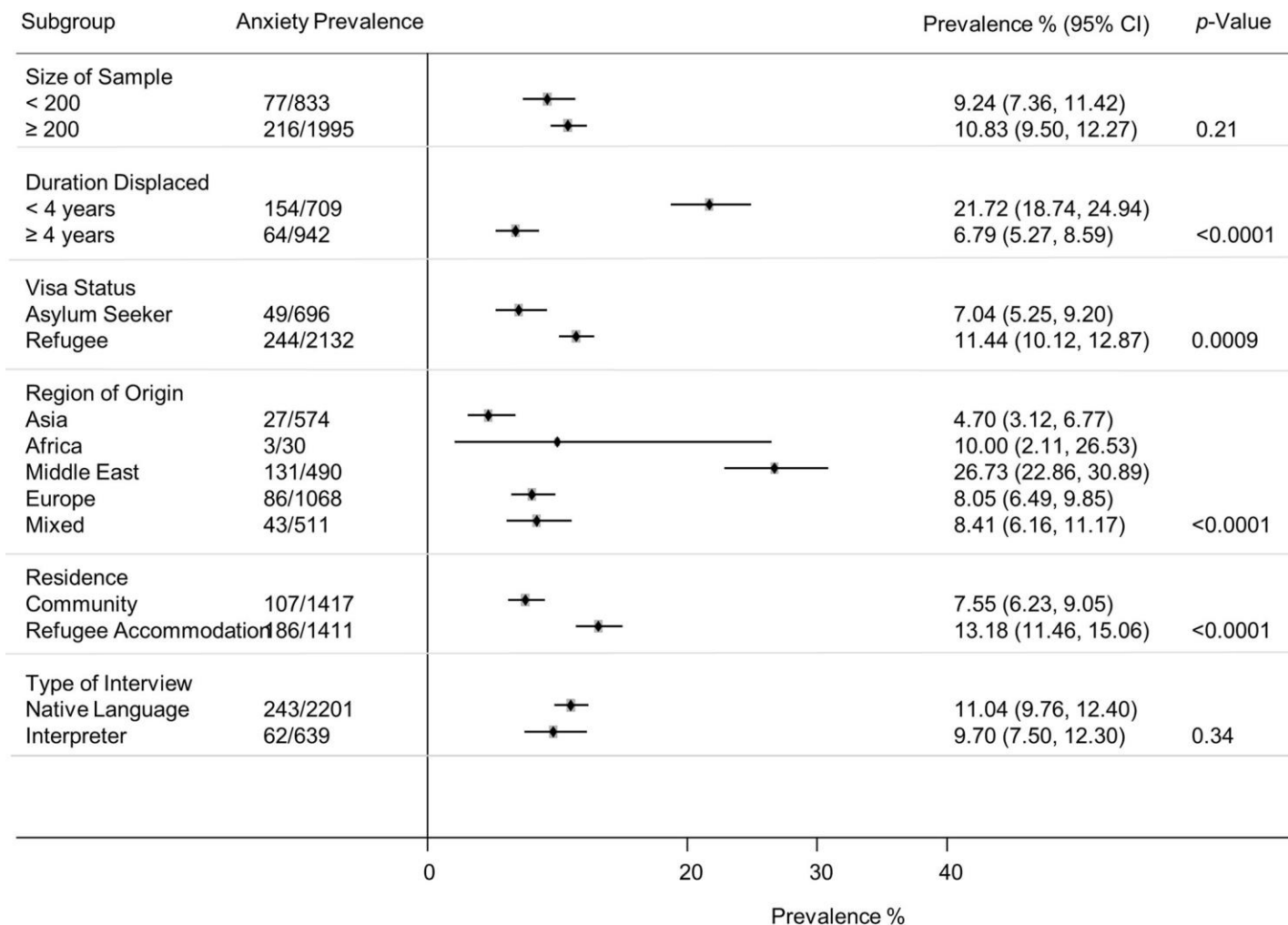
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## Discussion

Our results indicate that refugees and asylum seekers experience high rates of mental illness, in particular PTSD and depression. PTSD and depression appear to persist for many years post displacement, as there was no difference in prevalence between those displaced less than 4 years and those displaced longer. However, this was not the case for the prevalence of anxiety disorders, which we found to be higher among those displaced less than 4 years.

PTSD and depression in refugees and asylum seekers appear to be more prevalent than in the general population. According to data from the World Mental Health Surveys, lifetime prevalence in the general population is 3.9% for PTSD [57] and 12% for any depressive disorder [58], compared to our findings of 31% for PTSD and 31.5% for depression. However, the prevalence of anxiety disorders (11%) and psychosis (1.5%) in refugees and asylum seekers appears to be less than the lifetime prevalence in general

population samples: 16% [58] and 3% [59], respectively. Only 11 studies reporting data on anxiety prevalence met the inclusion criteria for this review, and of those 11, only six assessed the full range of DSM anxiety disorders.

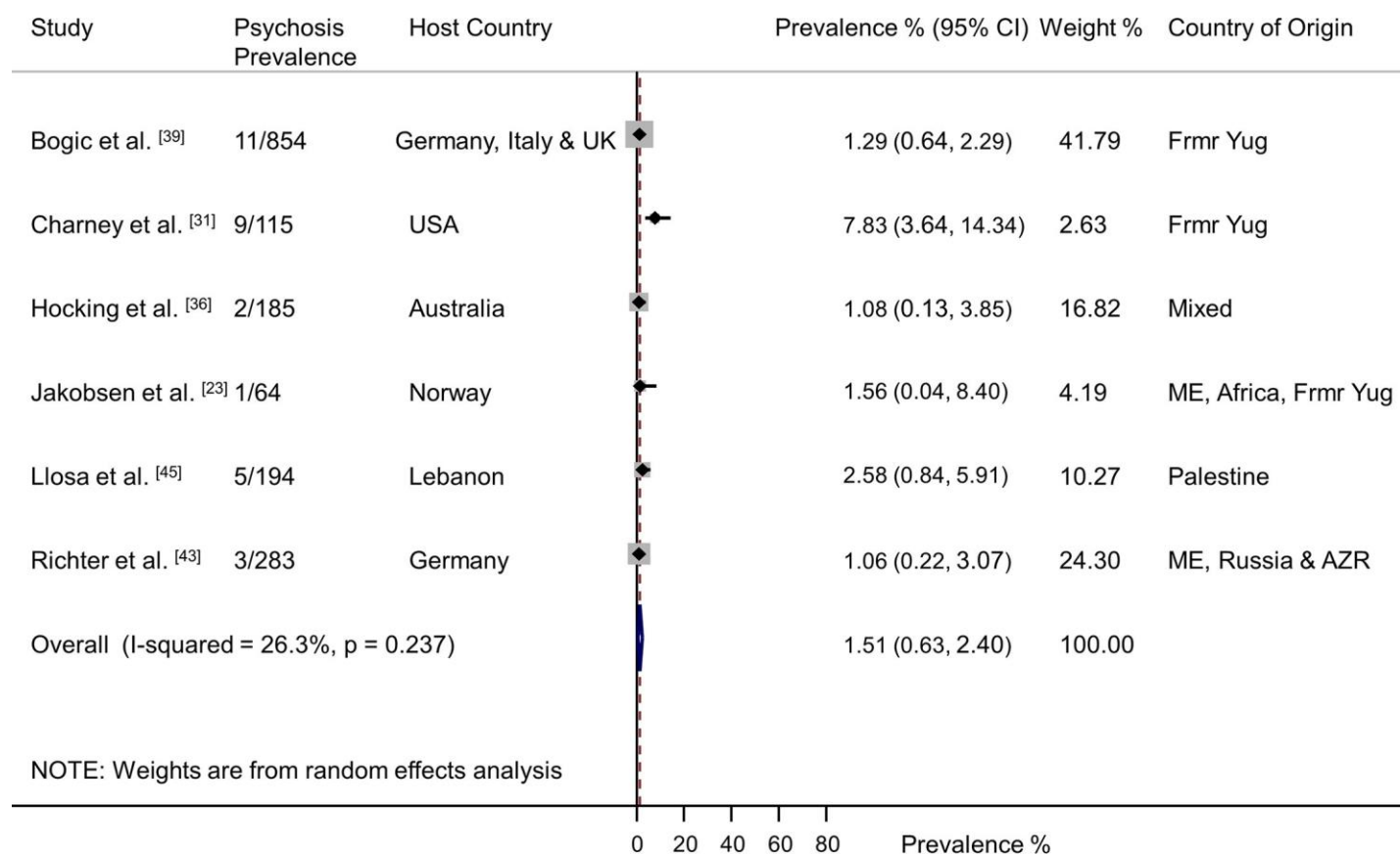


**Fig 7. Prevalence of anxiety by various study characteristics.** *p*-Values are derived from random-effects models; horizontal lines indicate 95% CI. Subgroup analysis for sex could not be conducted, owing to a lack of reported data. Subgroup analysis for diagnostic measure could not be conducted, owing to insufficient studies for each measure. CI, confidence interval.

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With a heavy emphasis on PTSD and depression, the full breadth of anxiety disorders is less frequently examined and reported in the literature. It was only recently, with the release of DSM-5, that PTSD was no longer classified as an anxiety disorder but in a separate category of trauma and stressor-related disorders [60]. Further research on the prevalence of the full range of anxiety disorders and comorbidities is needed.

With the aim of including all possible refugee populations that have been studied, this systematic review placed few restrictions on characteristics of refugee experiences (region of origin or resettlement, duration of displacement, etc.). As a result, the review's criteria could in fact have been a contributing factor to the resulting substantial statistical heterogeneity. Despite this high heterogeneity, which is expected when investigating and analysing prevalence across global refugee populations, knowledge of current prevalence estimates provides a foundation for the field to build on. Researchers can progress with this knowledge and focus their attention on addressing the critical need for immediate, appropriate, and ongoing mental health support and interventions. Without the progression of further high-quality research that explores the different components of mental health needs, culturally appropriate and



**Fig 8. Prevalence of psychosis in refugees and asylum seekers.** Horizontal lines indicate 95% CIs. Horizontal points of the open diamond are the limits of the overall 95% CIs; and the red dashed line shows the position of the overall prevalence. AZR, Azerbaijan; CI, confidence interval; Fmr Yug, former Yugoslavia; ME, Middle East.

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effective interventions, and longitudinal mental illness trajectories, untreated mental illnesses will severely impact upon successful integration into host communities. For host countries and humanitarian agencies, current prevalence estimates of mental illness within this ever-growing population can be used in advocacy and health service planning to strengthen mental health services for refugees and asylum seekers, in line with WHO priorities and objectives [14].

Subgroup analysis for sex was only possible for PTSD, owing to a lack of sex data for the other outcomes, and this is a major limitation of the current literature. The subgroup analysis indicated a higher PTSD prevalence for women, consistent with studies of sex differences and PTSD within general populations [61–63]. During times of conflict, women face not only an increased risk of sexual violence [64–66], which is considered to confer a high risk for developing PTSD, but other risks associated with migration trauma such as safety concerns, childrearing pressures, and exploitation and trafficking [67]. Although trauma type in relation to PTSD diagnosis was not adequately described in the studies, many of the studies included participants from countries such as the former Yugoslavia, Syria, and Iraq, areas with conflicts reported to have perpetrated systematic sexual violence [68]. In line with best-practice research reporting, future research in the field must ensure outcome measures are disaggregated by sex.

The studies with populations from Africa reported the highest prevalence of PTSD. This result likely reflects how countries within Africa are consistently ranked at the highest levels of the Political Terror Scale [69]. This scale is a five-point rating system based on data from Amnesty International and the US State Department and measures the levels of extensive human rights violations and violence within nations. In our review, the refugee populations from Europe, which mostly consisted of individuals from the former Yugoslavia, had the highest prevalence of depression, and the Middle East refugee populations had the highest prevalence of anxiety.

The prevalence of PTSD and depression appeared to be higher in studies that utilised interpreter-assisted diagnostic assessments. However, this was not the case for anxiety disorders, for which we did not find evidence for a difference between the interpreter-assisted interviews and those conducted in the native language. This difference could be due to a number of factors, such as language fluency, which plays an important role in the diagnosis of mental illness because the clinician relies heavily on the self-reported symptoms of the individual [70]. However, further research is required to understand the differences in diagnosis rates between interpreter-assisted interviews and clinicians conducting the assessment in the native language and whether there are cultural and linguistic nuances that can impact on diagnostic rates that might only be accessible to native interviewers. Even though the different diagnostic measures are

considered comparable in performance and diagnosis precision [71], our results suggest some differences, which highlight the importance of careful consideration of the method and instrument used in the mental health assessments of refugee populations. Although beyond the scope of this review, further investigation is required to understand potential differences in case identification between diagnostic measures.

Our findings suggest that the prevalence of PTSD and depression persists for many years post displacement, suggesting ongoing suffering from mental illnesses in the postmigration environment. This environment can include complexities of social and cultural isolation, reconfigured family relationships, difficulties adjusting to life in a foreign country, and often limited opportunities to contribute economically and socially to their new communities. Previous longitudinal studies have demonstrated how these hallmarks of the postmigration environment, alongside poor social support and acculturation difficulties, may contribute to a deterioration in mental health [5,72–74]. In contrast to the findings for PTSD and depression, anxiety prevalence was higher for those individuals recently displaced. Factors contributing to anxiety might be influenced by the uncertainty of the resettlement process and participation in the refugee determination process, which might have a detrimental effect on psychological well-being; however, robust longitudinal research is needed in this field.

We found that the prevalence of PTSD and depression is higher than in the review by Fazel and colleagues [6]. This could reflect the fact that this current systematic review included refugee populations from low- and middle-income countries or that the more recent refugee flows might be exposed to higher numbers of risk factors. In contrast, the results for anxiety disorders and psychosis are comparable with previously reported prevalence rates [6]. The influence of sample size is further supported, with the larger studies reporting lower prevalence rates for PTSD and depression. However, this was not the case for anxiety, for which sample size did not influence prevalence. The results for PTSD and depression are comparable to the findings by Steel and colleagues [7] and slightly lower than other systematic reviews, which have reported PTSD prevalence in the range of 36%–43% and depression 40%–44% [12,75].

Two phenomena currently affecting refugee and asylum-seeker populations should be considered when interpreting the results of this review. First is the increased targeting of civilian populations in areas of mass conflict. Second is the postmigration environment in countries with increasingly harsh immigration policies including detention, deportation, and delayed granting of refugee status—possibly mirroring local population shifts against immigration and heightened hostility towards refugee populations [76,77]. Investigation of these situations and their impact on mental health is warranted.

## Limitations and strengths

Some statistical heterogeneity is to be expected as a result of the review's design, which set no exclusion criteria for host country, country of origin, sex, or duration of displacement. We addressed this by using random-effects models to calculate more conservative 95% CIs. The conventional method to investigate potential sources of heterogeneity is to conduct a meta-regression; however, this was not possible, because of the limited covariates reported in the studies. We conducted subgroup analyses to investigate potential sources heterogeneity, but some subgroup analyses were also not possible, and some studies were excluded from subgroup analyses because of a lack of reported data. There are many challenges to conducting research with refugee populations, one of which is sampling. Ideally, this review would have restricted the inclusion criteria to studies that incorporated multistage representative sampling. However, such a restriction in this field would have yielded so few studies that the prevalence estimates could not have been made. In fact, only two of the included studies in this review would have met this criterion. Other limitations were imposed when studies combined illnesses to form diagnostic groups and/or reported only the number of comorbidities rather than the actual diagnoses. Although many of the diagnostic measures had been widely used in different cultural contexts, none had been specifically developed for refugee populations or cross-cultural use. Although the DSM-5 attempts to enhance cultural validity, all of the included studies used the DSM-IV, DSM-III-R, or ICD-10 criteria, previously criticized for limited recognition of cultural perspectives [78]. In particular, the diagnostic framework for PTSD has largely been investigated using military personnel and single-incident trauma survivors from high-income nations [79]. Somatic symptoms and related disorders were outside the scope of this review but warrant specific investigation and characterization.

As far as we are aware, this is the only systematic review to implement strict inclusion criteria regarding the diagnosis of mental illness in current refugee and asylum-seeker populations. This allowed for the selective analysis of higher-quality studies reporting the prevalence of mental illness based on clinical interviews with trained assessors using validated diagnostic measures. This review also expands the current evidence base by not only focusing on PTSD but also reporting depression, anxiety, and psychosis. To the best of our knowledge, this is the first systematic review to place no restrictions on language or on countries of origin or settlement. The majority of studies in this field are undertaken in high-income countries, which are often not countries of first asylum. Although most studies in this review came from countries such as the UK, Germany, Switzerland, and Australia, it also included studies from key refugee host nations such as Lebanon, Turkey, Uganda, and Nepal.

The ever-growing refugee and asylum-seeker populations pose a major global public health crisis with serious implications for mental health. This review provides current prevalence estimates for PTSD, depression, anxiety, and psychosis and suggests that both short-term and ongoing mental health services, beyond the period of initial resettlement, are required to promote the health of refugees.

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## **Chapter three: The mental health of child and adolescent refugees and asylum seekers**

### **3.1 Introduction**

According to figures reported by the UNHCR, children and adolescents under the age of 18 years currently comprise almost half of the world's refugee population.(1) Children and adolescents who are forcibly displaced from their homes experience significant disruption to their lives including loss and separation from their family, harsh living conditions, and exposure to violence. Exposure to violence is a well-established risk factor for mental illness; combine this exposure with the instability of the refugee experience all occurring at critical time points in a child's development and the result can be a lasting psychological impact.(22, 23) There is a lack of high-quality prevalence estimates of mental illness in refugee children and adolescents. This lack of current estimates combined with the growing number of children and adolescents forcibly displaced motivated the design of a comprehensive search for the systematic review. No limits were placed on age with the hope that there would be enough articles meeting the inclusion criteria to prepare a secondary review focussing solely on children and adolescents, in addition to adults. As new populations of refugee children and adolescents continue to arrive into countries of resettlement, host nations do not have accurate and up-to-date estimates on mental illnesses such as PTSD, depression, and anxiety. Therefore, there is an urgent need to establish current prevalence estimates of mental illness in child and adolescent refugee populations.

**Manuscript two: A systematic review and meta-analysis: The prevalence of mental illness in child and adolescent refugees and asylum seekers**

## REVIEW



# Systematic Review and Meta-analysis: The Prevalence of Mental Illness in Child and Adolescent Refugees and Asylum Seekers

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**Objective:** Over half of the world's refugee population are under the age of 18 years. This systematic review aims to summarize the current body of evidence for the prevalence of mental illness in child and adolescent refugee populations.

**Method:** Eight electronic databases, gray literature, and Google Scholar were searched for articles from 1 January 2003 to 5 February 2018. Strict inclusion criteria regarding the diagnosis of mental illness were imposed. Study quality was assessed using a template according to study design, and study heterogeneity using the  $I^2$  statistic. Random effects meta-analyses results were presented given heterogeneity among studies. The protocol for this systematic review was registered with PROSPERO (CRD42016046349).

**Results:** Eight studies were eligible, involving 779 child and adolescent refugees and asylum seekers, with studies conducted in 5 countries. The overall prevalence of posttraumatic stress disorder (PTSD) was 22.71% (95% CI 12.79-32.64), depression 13.81% (95% CI 5.96-21.67), and anxiety disorders 15.77% (95% CI 8.04-23.50). Attention-deficit/hyperactivity disorder (ADHD) was 8.6% (1.08-16.12) and oppositional defiant disorder (ODD) was 1.69% (95% CI -0.78- 4.16). Because of the high heterogeneity, further subgroup analyses were conducted.

**Conclusion:** Refugee and asylum seeker children have high rates of PTSD, depression, and anxiety. Without the serious commitment by health and resettlement services to provide early support to promote mental health, these findings suggest that a high proportion of refugee children are at risk for educational disadvantage and poor social integration in host communities, potentially affecting their life course.

**Key words:** refugee, systematic review, mental illness



Children and adolescents comprise 51% of the world's refugees and asylum seekers,<sup>1</sup> many of whom have experienced significant social and emotional disruption. Many are exposed to potentially traumatic experiences, harsh living conditions, deprivation of basic health care, separation from or loss of family members, and an interrupted education.<sup>2,3</sup> Unaccompanied refugee minors face even greater risks, including increased vulnerability to traffickers and exploitation without the possibly protective buffer of primary caregivers.<sup>4</sup> Experiencing violence and instability at a young age and at critical points in a child's cognitive and emotional development can have a lasting psychological impact.<sup>5,6</sup> Although many young people demonstrate resilience and an ability to overcome the chaos and challenges of forced displacement, others are at risk for developing serious mental illness.<sup>7-9</sup> Despite comprising half the world's refugee and asylum seeker population, there is a lack of high-quality prevalence estimates of mental illness in refugee children and adolescents. There is therefore a lack of clarity on the extent of the public health problem when new, forcibly displaced populations of children and adolescents arrive in a country of resettlement, potentially hampering efforts to improve awareness among the populations and institutions of host countries, to advocate for services, and to mobilize resources within health systems and resettlement programs.

Previous systematic and narrative reviews examining the prevalence of mental illness in child and adolescent refugee populations have three limitations: (1) a reliance on self-report questionnaires with cut off scores to determine diagnoses that might not be validated for the populations being studied<sup>10-12</sup>; (2) a focus on specific geographical locations of refugee populations<sup>13</sup>; and (3) a focus on posttraumatic stress disorder (PTSD) rather than the breadth of mental illness.<sup>6</sup>

Previous research has largely relied on the use of symptom rating measures and self-report questionnaires. This can explain some of the variability in the reported prevalence of mental illness in this population, as these types of measures tend to overestimate symptomatology.<sup>14-16</sup> Self-report measures, although practical for their ease of administration, particularly in low-resource settings, are prone to response inaccuracy and issues with item interpretation, which can result in false-positive results.<sup>17</sup> Individual clinical interviews using validated assessment measures are viewed as the gold standard in assessing mental illness in children and adolescents.<sup>18</sup> A recent review on the epidemiology of PTSD and depression in refugee minors highlighted the need for more rigorous research involving professionals

trained in clinical mental health assessments, to increase the accuracy of the reported prevalence of these conditions.<sup>19</sup>

The global conflicts forcing increasing numbers of populations to become displaced are changing in nature, with the involvement of more civilian populations and increasing targeting of children.<sup>20</sup> Therefore, establishing more current prevalence estimates to inform public policy, in terms of resettlement support and mental health care, for refugee populations is needed. Furthermore, although the vast majority of refugees live in low- and middle-income countries, these populations have often been omitted from systematic reviews and studies; hence their inclusion here.

Previous systematic reviews have focused on PTSD. A comprehensive 2005 systematic review and meta-analysis of adult, child, and adolescent refugees resettled in western countries identified only 5 studies reporting the prevalence of PTSD in children and none reporting diagnoses of other mental illnesses (from 1996 to 2002).<sup>21</sup> These studies provided data on a total of 260 refugee children, of whom 11% were diagnosed with PTSD. The samples of children were drawn from Bosnia, Central America, Iran, Kurdistan, and Rwanda. It is therefore timely to update and expand that review.

We have therefore conducted a systematic review that aims to overcome some of the methodological limitations of the current body of evidence and to establish a current estimate of mental illness in child and adolescent refugee populations. To our knowledge, this is the first systematic review to use rigorous inclusion criteria regarding the method of diagnosis determination, the first to place no limits on country of origin or resettlement, to place no limits on publication language, and to include a review of gray literature.

## METHOD

### Search Strategy and Selection Criteria

The protocol for this systematic review and meta-analysis was registered with PROSPERO CRD42016046349

([https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=46349](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=46349)). We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).<sup>22</sup> A PRISMA checklist is provided in Table S1 (available online). The protocol was based on that used in the earlier systematic review by Fazel et al.<sup>21</sup> (which included adult, child, and adolescent refugee populations) but expanded the range of databases searched and the number of search terms, imposed stricter criteria for mental illness diagnosis,

and placed no restrictions on resettlement countries or publication language. Studies pertaining to child and adolescent populations were extracted for this specific systematic review and meta-analysis.

We undertook a systematic search, developed using the OVID platform, combining Medical Subject Headings (MeSH terms) with related text-based search words, and translated to other databases. An example of the search strategy used in MEDLINE is provided in Table S2, available online. Studies about refugees or asylum seekers in combination with terms related to mental illness, diagnosis, and trauma were searched across eight databases: MEDLINE; MEDLINE In-Process; EBM Reviews; Embase; PsycINFO; CINAHL; PILOTS, and Web of Science. Any mental illness that met our criteria for diagnostic assessment was accepted. Searching the gray literature using the database Open Grey (<http://www.opengrey.eu/>) as well as Google Scholar allowed for the possible inclusion of reports from refugee, government, and other nongovernment agencies. The date limits were January 1, 2003, to February 5, 2018. This start date reflects the end date of the search conducted by Fazel et al.<sup>21</sup> Therefore, none of the included studies from the earlier systematic review were included in this analysis, to provide a contemporary estimate on mental illness within this population. The reference lists of 67 systematic reviews, 13 of which pertained to child and adolescent samples, were identified through the search and screened for any further relevant articles. This resulted in the manual checking of 17 additional articles, 8 of which were relevant to child and adolescent populations.

Studies were included in this review if the sample included refugee and/or asylum seeker children and/or adolescents; if the study had a sample size larger than 50, to overcome potential sampling bias associated with smaller sample sizes<sup>21</sup>; and if the study reported quantitative prevalence estimates of a mental illness as classified by the DSM<sup>23</sup> or the International Classification of Diseases (ICD).<sup>24</sup> The diagnosis must have been made as a result of a clinical interview using a validated diagnostic assessment measure. Studies that based diagnoses solely on self-report questionnaires or symptomatology rating scales were excluded. The interview needed to have been conducted either by a mental health professional (psychiatrist, psychologist, psychiatric nurse) or other trained paraprofessional (psychology research assistant, trained researcher). In studies that administered the World Health Organization, World Mental Health Composite International Diagnostic Interview (WHO WMH-CIDI),<sup>25</sup> non-clinicians who had completed official WHO-recommended training requirements were accepted. The WHO WMH-CIDI is a fully structured interview for the assessment of mental disorders intended for use by trained lay interviewers. Studies were selected if they had recruited representative samples of refugee children; hence those recruiting participants solely from medical clinics were excluded to reduce selection bias. Studies stating that the sample included

asylum seekers whose applications had been rejected were excluded if the results were not disaggregated, or if the mental health assessment was not conducted prior to rejection (when the individuals met the definition of asylum seekers). Qualitative or case report studies were excluded. When multiple articles used data from the same study, the article providing data that best met the search criteria was included.

Two reviewers (R.B. and M.G.H./G.F.) independently assessed all the titles, abstracts, and key words of every article retrieved against the selection criteria. Full-text articles were then assessed if the title and abstract suggested that the study met the selection criteria or if there was any doubt regarding eligibility of the article. Disagreements were resolved by discussion and, where appropriate, we contacted the study authors for further information. The reviewers contacted eight study authors to obtain further information regarding methodology and data, of whom seven responded.<sup>26-32</sup> Studies in languages other than English were assessed first by a native speaker where possible or via Google translate, and then officially translated by a professional translation service if they potentially met inclusion criteria.

#### Data Extraction and Analysis

Two review authors (R.B. and M.G.H.) independently extracted statistical data from the included studies into Stata software version 14.1 (StataCorp LP, College Station, TX) for the meta-analysis. Study characteristics such as sample size, sampling framework, diagnostic instrument, diagnostic criteria, and use of native interviewer were also extracted. Meta-analysis results were expressed as prevalence estimates of mental illness calculated with 95% CIs in the pooled data. Random effects were presented given heterogeneity among studies. This statistical model is based on the assumption that the samples of the included studies are drawn from different populations.<sup>33</sup> Heterogeneity was assessed using the  $I^2$  statistic.<sup>34</sup> The  $I^2$  value provides a measure of the variation explained by the differences between the included studies rather than chance. In the case of 5 or more studies being available, publication bias was assessed by visual inspection of funnel plots and applying the Egger test<sup>35</sup> set at a threshold of a  $p < .05$  to indicate funnel plot asymmetry. Prevalence rates were for current diagnoses and were combined by direct summation of numerators and denominators across studies, thereby providing a pooled estimate.

Possible sources of heterogeneity between studies were investigated, where reported data allowed, by subgroup analyses. These included the following: sex, duration of displacement (timeframes to be determined by the reported data), visa status, use of native interviewer (whereby the diagnostic interview was conducted in the preferred language of the child or adolescent), and current residence status (residing in the local community versus refugee facility/reception center).

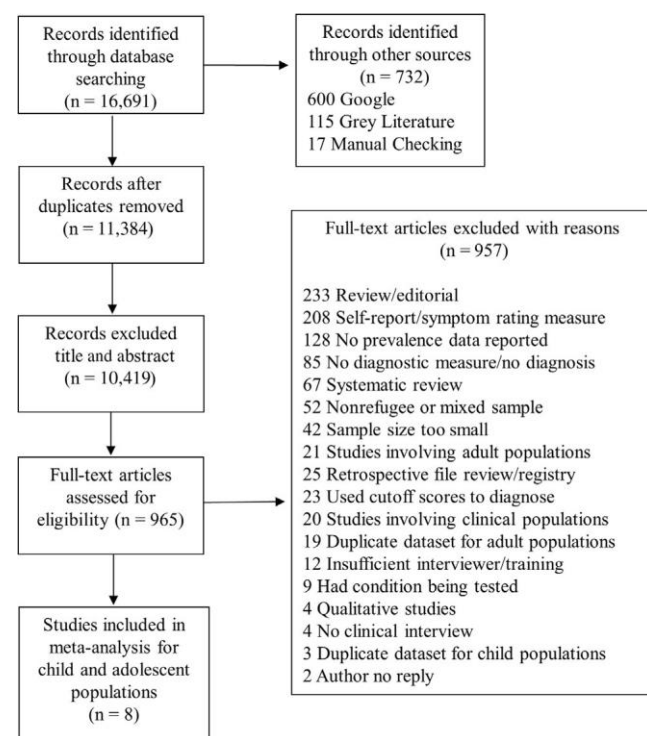
## Risk-of-Bias Appraisal

Methodological quality of the included studies was assessed by two independent reviewers (R.B. and K.M.G.) using a risk-of-bias assessment template (Table S3, available online) according to study design.<sup>36</sup> This template incorporates the Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomized studies in meta-analyses and includes additional risk-of-bias components.<sup>37</sup> It has been used in international evidence-based guidelines and other systematic reviews.<sup>38-40</sup> Individual items related to study quality such as internal and external validity, reporting bias, confounding, and conflict of interest were assessed. Studies were assigned a rating of low, moderate, or high risk of bias. Any disagreement was to be reviewed by a third author, but this was not required.

## RESULTS

The entire search, including electronic databases and other sources, yielded a total of 17,423 documents. A flowchart outlining the search results and selection of studies is provided in Figure 1. After removing duplicates, 10,419 documents were excluded based on title and abstract, and a further 965 documents were screened by full-text retrieval. Eight studies pertaining to child and adolescent populations met the inclusion criteria,<sup>29-32,41-44</sup> after a final exclusion of three papers that reported duplicate datasets.<sup>45-47</sup>

**FIGURE 1** Search Results and Selection of Studies



One study was published in German and professionally translated for inclusion.<sup>30</sup> The 8 eligible studies provided data on 779 child and adolescent refugees and asylum seekers. Six studies included both children and adolescents in their samples<sup>30-32,41,43,44</sup>; however, 2 studies recruited solely adolescents, 10 to 19 years<sup>42</sup> and 15 to 18 years.<sup>29</sup> The included studies provided data on the following range of mental illnesses: PTSD, depression, anxiety disorders, attention-deficit/hyperactivity disorder (ADHD), and oppositional defiant disorder (ODD).

Characteristics of the included studies are provided in Table S3 (available online). The age range for each sample was consistent with the World Health Organization definition of child or adolescent (19 years or younger)<sup>48</sup> except for one sample, from a study specifically recruiting unaccompanied asylum-seeking children,<sup>29</sup> that contained some participants 20 years of age. Considering the focus of the study and that the mean age of participants ( $16.23 \pm 0.83$ ) was within the adolescent range, the authors decided to include it. Studies were undertaken in 5 countries: Germany (197 refugees),<sup>30,32</sup> Malaysia (90),<sup>42</sup> Norway (160),<sup>29</sup> Sweden (191),<sup>31,41</sup> and Turkey (144).<sup>43,44</sup> Refugee samples were drawn from the Middle East (45%), a combination of Middle Eastern and African countries (31%), and Southern Asia and the Middle East (11.5%). One study reported a sample originating from up to 15 different countries (12.5%).<sup>30</sup> In 2 of the studies, a proportion of the participants had been born in the host nation (4.8%,  $n = 5$ ,<sup>30</sup> and 31.4%,  $n = 32$ <sup>31</sup>). Disaggregated data were not reported in these studies.

Seven diagnostic measures were used to assess mental illness (Table S4, available online). One of the measures, the Posttraumatic Stress Symptoms in Children (PTSS-C) was specifically developed as a cross-cultural, semi-structured interview to diagnose PTSD.<sup>31</sup> Six studies made mention of the psychometric properties of the instruments used and/or previous use with child refugee populations.<sup>29-31,41-43</sup> Four studies conducted the diagnostic interview in the native language of the child or adolescent,<sup>31,41,43,44</sup> three with assistance from interpreters<sup>29,30,42</sup> and one with a combination of native interviewers and interpreters.<sup>32</sup>

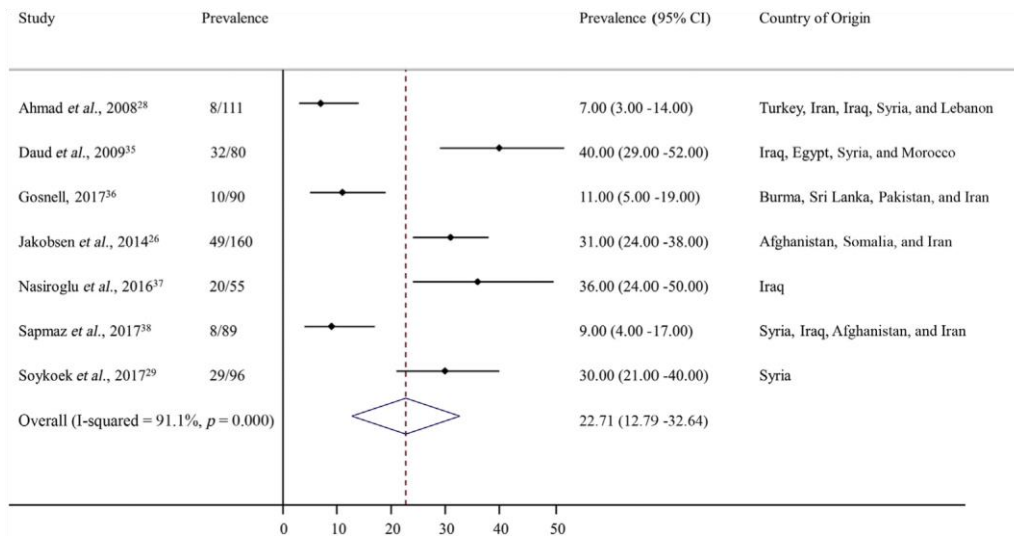
PTSD was investigated in 7 studies, with data for a total of 681 children and adolescents.<sup>29,31,32,41,42,44</sup> Overall, 22.71% (95% CI 12.79-32.64) were diagnosed with PTSD (Figure 2). Participants had a weighted mean age of 12.3 years, and 40% were girls. There was substantial heterogeneity between the studies ( $I^2 = 91.1\%$ ,  $p = .000$ ); therefore, subgroup analyses were conducted for duration of displacement, visa status, use of native interviewer, and current residence (Figure 3). The subgroup analysis for sex could not be conducted because of a lack of reported data. The PTSD prevalence was higher for those displaced less than 2 years and for those with an insecure visa status. Conducting the diagnostic interview in the native

language of the child or adolescent and current community residence resulted in lower reported prevalence of PTSD.

Five studies of depression were identified, providing data for a total of 492 children and adolescents.<sup>29,30,42-</sup>

<sup>44</sup> Overall, 13.81% (95% CI 5.96-21.67) were diagnosed with depression (Figure 4). Participants had a

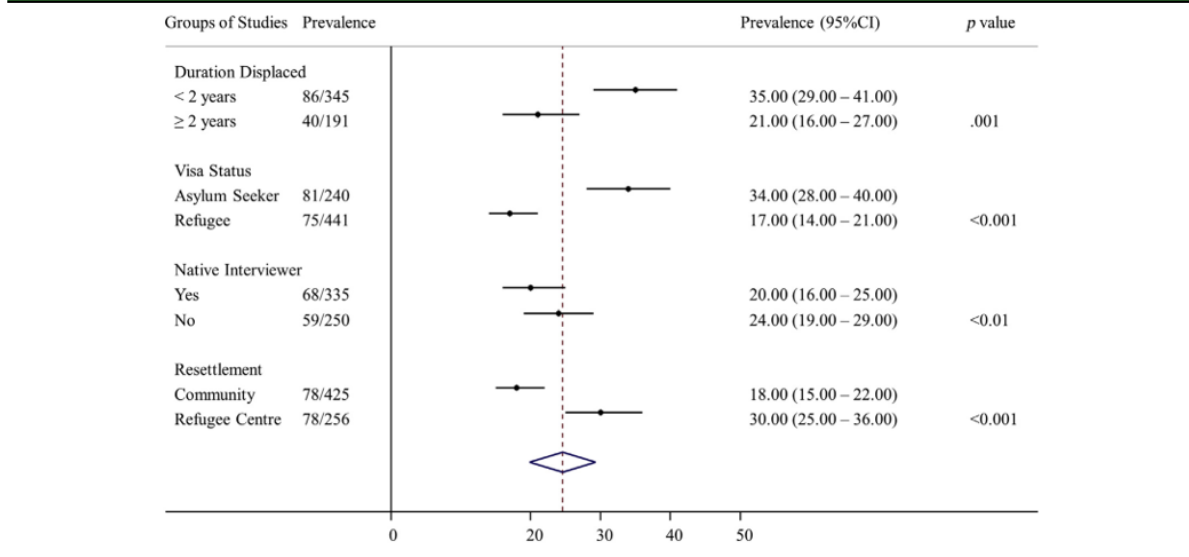
**FIGURE 2 Prevalence of Posttraumatic Stress Disorder in Child and Adolescent Refugees and Asylum Seekers**



Note: Horizontal lines indicate 95% CIs; open diamond denotes subtotals.

weighted mean age of 12.9 years, and 36% of the sample were girls. One study reported sex data for the total sample ( $N = 104$ ); however, only 98 of these individuals completed the full diagnostic assessment.<sup>30</sup> Two studies reported prevalence of major depression,<sup>30,42</sup> two studies reported prevalence of any depressive disorder,<sup>43,44</sup> and one study reported prevalence of major depression and dysthymia, which was combined for the analysis.<sup>29</sup> There was substantial heterogeneity between the studies ( $I^2 = 86.5\%$ ,  $p = .000$ ), so subgroup analyses were conducted for duration of displacement, visa status, use of native interviewer, and current residence (Figure 5). The subgroup analysis for sex could not be conducted because of a lack of reported data. Depression prevalence was higher for those displaced less than 2 years, those with refugee visa status, use of native interviewer for diagnostic assessment, and current community residence.

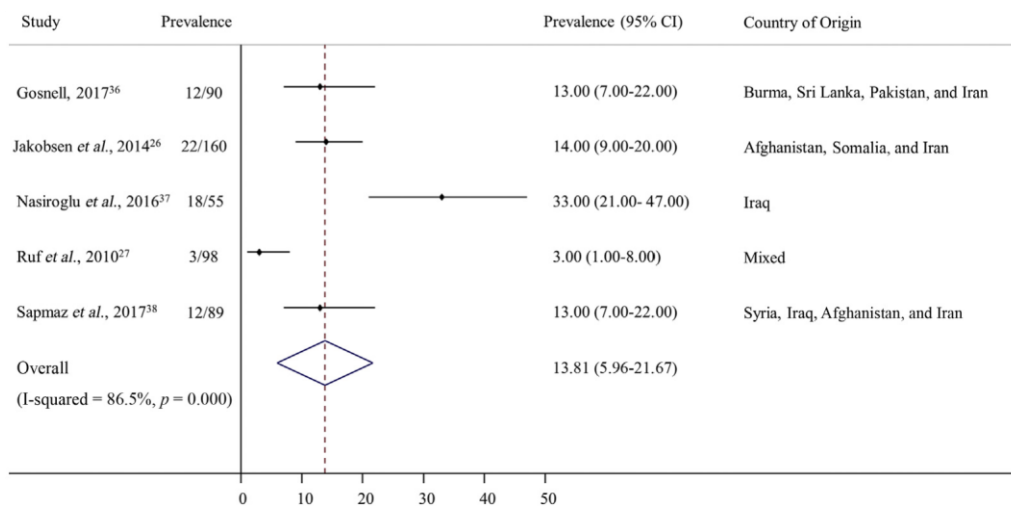
FIGURE 3 Prevalence of Posttraumatic Stress Disorder by Various Study Characteristics



Note: p values are derived from random-effects models. Horizontal lines indicate 95% CIs. One study<sup>29</sup> was not included in this analysis, as both native interviewers and interpreters were used for the assessment, and disaggregated data were not available.

Four studies reporting the prevalence of anxiety disorders were identified, consisting of data for a total of 402 children and adolescents.<sup>29,30,43,44</sup> Overall, 15.77% (95% CI 8.04–23.50) were diagnosed with an anxiety disorder (Figure S1, available online). Two studies reported diagnosis of any anxiety disorder,<sup>43,44</sup> and two studies provided a breakdown of diagnosis across individual anxiety disorders,<sup>29,30</sup> which were combined for analysis. These disorders included: generalized anxiety disorder, separation anxiety disorder, obsessive compulsive disorder, social anxiety disorder, agoraphobia, and specific phobia. Participants had a

FIGURE 4 Prevalence of Depression in Child and Adolescent Refugees and Asylum Seekers



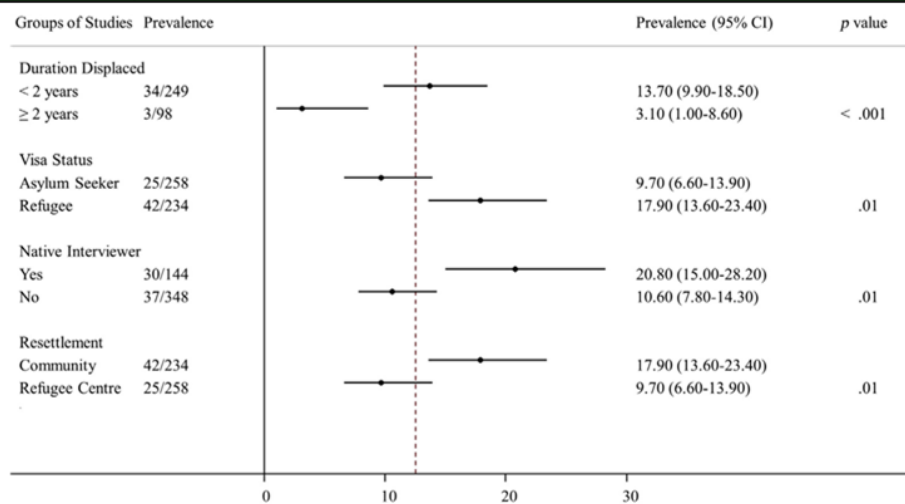
Note: Horizontal lines indicate 95% CIs; open diamond denotes subtotals.

weighted mean age of 12.7 years, and 32% of the sample were girls. There was substantial heterogeneity between the studies ( $I^2 = 76.0\%$ ,  $p = .006$ ), so subgroup analyses were conducted for duration of displacement, visa status, use of native interviewer, and current residence status (Figure S2, available online). Anxiety prevalence was higher for those displaced less than 2 years, with refugee visa status, use of native interviewer for diagnostic assessment, and current community residence.

Four studies reporting the prevalence of ADHD were identified, consisting of data for a total of 322 children and adolescents.<sup>30,41,43,44</sup> Overall, 8.6% (95% CI 1.08–16.12) were diagnosed with ADHD (Figure S3, available online). Participants had a weighted mean age of 11 years, and 52% of the sample were girls. There was substantial heterogeneity among the studies ( $I^2 = 84.9\%$ ,  $p = .000$ ), so subgroup analyses were conducted for duration of displacement, visa status, use of native interviewer, and current residence status. The ADHD prevalence was higher for those displaced longer than 2 years and for those with an insecure visa status (Figure S4, available online).

Two studies reported prevalence of ODD, consisting of data for a total 178 children and adolescents.<sup>30,41</sup> Overall, 1.69% (95% CI 0.78–4.16) were diagnosed with ODD (Figure S5, available online). There was a low level of heterogeneity between the studies ( $I^2 = 9.6\%$ ,  $p = .293$ ). Subgroup analyses were not conducted, as there were only two studies.

**FIGURE 5** Prevalence of Depression by Various Study Characteristics



Note: P values are derived from random-effects models. Horizontal lines indicate 95% CIs.

## Publication Bias

There is some evidence of publication bias for PTSD and depression, based on the results of the Egger test where the  $p$  values were less than .05 (Egger test plots provided in Figures S6 and S7, available online). The funnel plots showed some asymmetry in the scatter of the studies, which can be an indication of publication bias; hence a search of gray literature was conducted. These results, however, should be interpreted with caution, as they may instead be a result of the small number of studies published in the field.

## Risk of Bias

Five of eight studies were assigned a low risk of bias and determined to be of high quality.<sup>29-32,42</sup> Three studies demonstrated moderate risk of bias.<sup>41,43,44</sup> Moderate ratings were assigned because there were potential issues with the representativeness of the samples. In one study, there was a high rate of nonparticipation.<sup>43</sup> Interviews were conducted with a small number of participants compared to the total number screened. In the second study, immigration lists were unable to be used for recruitment because of the high mobility of the population.<sup>44</sup> Therefore, only families who had registered with the obstetrics and gynecology departments of the local hospitals were contacted for recruitment. The third study investigated the comorbidity of PTSD and ADHD and the impact of a parental history of torture.<sup>41</sup> This study recruited a group of children who had at least one parent with a history of torture, and a comparison group of children whose parents had no history of torture. It could therefore be argued that a proportion of the sample had a greater risk of mental illness due to parental experience of torture. No study was assigned a high risk of bias.

## DISCUSSION

This systematic review aimed to overcome some of the methodological limitations of the current body of evidence, and to establish new estimates of mental illness in child and adolescent refugee populations. The review identified a limited number of high-quality studies measuring prevalence estimates of mental illness, despite the substantial number of children and adolescents displaced globally. Overall, the findings have shown that refugee and asylum seeker children have high rates of PTSD (22.71%), anxiety (15.77%), and depression (13.81%).

PTSD, depression, and anxiety disorders were all higher for those displaced less than 2 years, compared to those displaced more than 2 years. However, the prevalence of ADHD was higher among those

displaced more than 2 years. This may be a result of the small number of included studies. Alternatively, this might be partly explained by the phenomena of spontaneous or natural recovery, which can occur in some cases of PTSD and depression,<sup>49,50</sup> whereas ADHD persists in childhood with some change in presentation as individuals become older.<sup>51</sup> PTSD was higher for those with insecure visa status and temporary residence. This was not the case for depression and anxiety disorders, which were higher for those with refugee visa status and community residence. Rigorous longitudinal research is required to truly understand the relationship between refugee experiences, different mental illnesses, visa status and resettlement experiences, and trajectories of recovery.

The results from our systematic review show higher prevalence for PTSD, depression, anxiety, and ADHD in refugee and asylum seeker populations compared to data in the literature for nonrefugee populations. A recent meta-analysis of 3,563 trauma-exposed children and adolescents reports a PTSD prevalence of 15.9%.<sup>52</sup> Our systematic review found an overall PTSD prevalence of 22.71% and even higher for those displaced less than 2 years (35%). However, direct comparisons of PTSD rates are challenging, as prevalence varies according to trauma type and sex.<sup>52</sup> In regard to the other mental illnesses, the reported worldwide pooled prevalence of any depressive disorder in general populations of children and adolescents is 2.6%, any anxiety disorder 6.5%, ADHD 3.4%, and ODD 3.6%.<sup>53</sup> Although our results were higher for depressive disorders (13.81%), anxiety disorders (15.77%), and ADHD (8.6%), the prevalence of ODD (1.69%) was comparable to the general population estimate, and in fact slightly lower in refugee and asylum seeker children. Overall, these comparison data confirm that refugee children and adolescents have substantial need for mental health services.

These findings build on the previous systematic review by Fazel et al.,<sup>21</sup> by providing an updated prevalence estimate for PTSD as well as new estimates for depression and other mental illnesses, based on rigorous diagnostic methods. The prevalence of PTSD reported in this systematic review is higher. The fact that this current review was able to contribute data for the prevalence of depression, anxiety, ADHD, and ODD highlights some growth within the field. More than half of the world's current refugee and asylum seeker population are aged 18 years and less<sup>1</sup>; yet this review was able to pool data for only 779 children and adolescents. This not only limited the precision of our estimates, but demonstrates that this is an underrepresented population in the research literature.

Our subgroup analyses and quality assessments highlight the effect that study design can have on prevalence rates and the importance of considering these factors when interpreting current evidence or designing new studies. Previous research has suggested that the use of native interviewers during mental

health assessments results in lower reported prevalence of mental illness.<sup>21</sup> This was the case for PTSD, whereby lower prevalence was reported when the interviews were conducted in the child's or adolescent's native language. However, for depression and anxiety, the prevalence was higher when the interview was conducted in the native language, and for ADHD the results were not significant.

Although our intention was to determine the current prevalence of mental illnesses, the generalizability of the results was limited by the lack of studies. Few restrictions were placed on characteristics of the refugee experience, in the hope of including all possible studies, and as a result the meta-analysis yielded expectedly high statistical heterogeneity. Taking this heterogeneity into account, random effects models were used in order to calculate conservative confidence intervals. Meta-regression is often used to assess sources of heterogeneity, but was not possible because of limited covariates reported in the included studies. Although subgroup analyses were conducted to investigate the possible sources of heterogeneity, some subgroup analyses were also not possible due to a lack of reported data, such as sex. As PTSD prevalence rates have been shown to vary by sex, future research should include this analysis.<sup>52</sup> Subgroup analysis for country of origin could not be undertaken, as many of the study samples were highly diverse.

Relevant information pertaining to some aspects of the refugee experience were lacking, such as number of relocations, which has been shown to increase risk of developing mental illness.<sup>54</sup> There was limited information reported on the prevalence of comorbid illnesses, with only two studies providing such data.<sup>41,43</sup> Only one study explored the relationship between parent mental health and child mental health outcomes.<sup>41</sup> The role of family, particularly parental psychopathology, is crucial in its ability to mediate or exacerbate child mental health symptoms.<sup>6,55-58</sup> The decision to include the two studies,<sup>30,31</sup> in which a proportion of the sample had been born in the host nations, may affect the generalizability of the results.

The cross-cultural application of a western psychiatric framework must also be acknowledged as a limitation. Efforts to enhance cultural validity have been made in the DSM-5; however, the included studies applied DSM-IV and DSM-III diagnostic criteria, which have been criticized for limited recognition of cultural perspectives.<sup>59</sup> The diagnostic framework for PTSD was largely established using adult military samples and single-incident trauma survivors from high-income nations, which may not adequately capture the posttraumatic symptomatology of refugee youths.<sup>60</sup>

Our quality assessment identified a few limitations of individual studies that are worth noting here. First, one study compared children with and without parents who had a history of torture.<sup>41</sup> Therefore it was not a truly representative community sample, which may explain the high rates of PTSD and ADHD reported in this study. Another study, which reported a high prevalence of depression in comparison to

that in the other included studies, described issues with a low participation rate from the initial screened study sample.<sup>43</sup> It is possible that families with children or adolescents experiencing more severe mental distress had a greater motivation to participate. The reported PTSD prevalence from this study was also high in comparison to other studies.

### Implications for Clinical Practice and Policy

Despite the limitations, the findings have implications for clinical practice and resettlement policy. There are immediate and detrimental effects of pre-migration trauma, forced displacement, and the postmigration environment on the mental health of child and adolescent refugee and asylum seekers. With the exception of ADHD, all of the other mental illnesses showed higher prevalence for individuals recently displaced (2 years or less), emphasizing the need for early support following arrival into a country of refuge. This support may involve adequately resourced refugee centers designed to protect children from further traumatization and to address the many facets of resettlement stressors that can increase risk of poor social integration and educational disadvantage.<sup>55,61</sup> The high prevalence of mental illness within this population leads also to the need to provide youth- and refugee-appropriate, cross-culturally valid screening in refugee centers to streamline allocation to clinical assessment and treatment services.

### Implications for Future Research

To determine more accurate prevalence estimates, there is an urgent need for large studies that incorporate random sampling of populations, use rigorous diagnostic methods, clearly characterize the study sample, report relevant details of the refugee experience, and provide diagnosis data based on sex and age. The limited body of high-quality research in this field is a barrier to the provision of appropriate and informed mental health care for this population.<sup>8</sup> The results have shown that, whereas the limited literature available focuses on PTSD, depression and anxiety disorders also appear to be highly prevalent within this population. This highlights the need for future research to investigate the full range of mental illnesses. The majority of studies in this field are often undertaken in high-income host countries, which may not be countries of first asylum and often differ in terms of post-settlement support. Although the studies of this review included key refugee host nations such as Turkey and Malaysia, future research needs to be conducted in less-resourced host nations such as Pakistan, Lebanon, Libya, and Ethiopia. Further research is also needed to identify appropriate and effective real-world examples of mental health support services for refugee children and adolescents, and their families.

The results of this review contribute not just an updated prevalence estimate for PTSD but the largest analysis of PTSD prevalence for this population, based on rigorous diagnostic methods. It has also expanded the current evidence base by contributing prevalence estimates for depression, anxiety disorders, ADHD, and ODD. Overall, the findings confirm that refugee and asylum seeker children have high rates of PTSD, depression, and anxiety. Without a serious commitment by health and resettlement services to provide early support to promote mental health, these findings suggest that a high proportion of refugee children are at risk for educational disadvantage and poor social integration in host communities, potentially further affecting their life course.

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## **Chapter four: Identifying perinatal depression among women of refugee background**

### **4.1 Introduction**

As women adjust to pregnancy and early parenthood, they experience heightened risk of developing or re-experiencing mental illness including depression and anxiety. Perinatal depression and anxiety are reported to affect up to 13% of women living in high-income countries.(24, 25) However, for women originating from low-and-middle-income countries, the prevalence of perinatal depression is more than double this rate with a pooled prevalence of 31% for any depressive disorder.(26) With so many women affected by mental illness during pregnancy or the first year after birth, which is considered the perinatal period, mental health screening during this period of vulnerability is crucial.(17) Maternal mental health conditions can impact upon family relationships, including the quality of parent-infant attachment at critical times, potentially impacting the child's future behaviour and development.(27) Expectant parents are often motivated to seek and receive help to provide the best outcome for their baby. They usually engage frequently with the healthcare system through pregnancy care and for women of refugee background, pregnancy is often the first time this sustained contact occurs.(28) Routine screening for mental illness in pregnancy is recommended, however due to a number of barriers it is often integrated to varying degrees or not implemented at all.(17, 19)

In Australia, the mental health burden is high and costs of perinatal depression (PND) have been assessed across primary care, psychiatry, allied health services, medications, hospitals, and community services. Total direct healthcare costs in 2019 attributable to maternal depression

were estimated at \$60.1 million Australian dollars per year with an additional \$131.1 million of indirect costs, largely due to productivity losses. (29) There is also significant intergenerational impact to consider with estimates reporting that 72% of the total cost of perinatal mental illness is borne by the child. (30) Women of refugee background are at even higher risk of mental illness due to refugee experiences such as violence, torture, trauma, displacement and post-migration stressors such as poverty and social isolation.(31) Despite this, a major limitation of the current literature is a lack of investigation of sex differences when estimating mental illness prevalence for refugee populations.(32) There is a lack of research on the prevalence of mental illness, specifically anxiety and PTSD among women of refugee background during the perinatal period. (26)

## **4.2 Barriers to perinatal mental health screening**

Screening for mental illness during pregnancy is justified to improve health outcomes for women and their children. Perinatal depression screening programs have been shown to improve referral uptake and engagement with services, which in turn has a positive impact on mental health outcomes.(33) However, although recommended and justified, perinatal screening programs are often not implemented due to significant barriers at both the level of the healthcare service and the individual. This results in a critical gap in best-practice antenatal care with serious consequences for women and their families. Identified barriers to implementation include a perceived lack of time to integrate screening into routine care, inadequate training on the administration of screening measures and interpretation of results, and a lack of knowledge regarding appropriate referral pathways.(19) For women of refugee background, screening may not be offered due to reasons of lack of interpreters, lack of health professional skills and knowledge regarding refugee health, and a lack of validated screening measures in languages other than English. (17, 19)

### **4.3 The Edinburgh Postnatal Depression Scale (EPDS)**

One of the most widely used depression and anxiety screening measures is the Edinburgh Postnatal Depression Scale (EPDS) which has been validated for use during pregnancy and translated into a number of different languages.(18,34-37) It is a ten-item, self-report questionnaire used to detect symptoms of emotional distress over the past seven days. The final item (item 10) on the EPDS assesses the risk of self-harm and suicidal ideation. When administering the English version during pregnancy, the EPDS performs with moderate sensitivity 0.83 (0.76-0.88) and high specificity 0.90 (0.88-0.92).(17) However, the psychometric properties can vary across translations, with the variability in performance attributed to the use of different cut-off scores and varying translation standards.

The EPDS has a number of strengths. As stated above the English version offers strong psychometric performance. It is also the recommended mental health screening measure for use with all women during pregnancy, as stated in the Australian clinical guidelines. (17) In addition, it has been reported as the most suitable perinatal depression screening tool, particularly in low-resource settings, due to its superior level of sensitivity based on a review comparing seven other screening measures.(38) By selecting and applying the EPDS in this study, it provided an opportunity to see whether it would be acceptable and clinically useful for women of refugee background. If antenatal clinics, which provide care for different populations of women, can implement the same measure across their services, it will assist in improving the accessibility of perinatal mental health programs.

There is a lack of validated screening measures to screen for symptoms of depression and anxiety during pregnancy in languages from key humanitarian source countries, which raises concerns regarding equity of healthcare. If the recommended screening measure is unavailable in their

language, it forms another barrier to accessing the same level of healthcare as English-speaking women. Validated screening measures are needed in order to ensure marginalised women at-risk, such as those from refugee backgrounds, can be identified and referred for support. The conflict in Afghanistan has been ongoing, devastating, and recently renewed which has resulted in one of the largest refugee populations globally, second only to the Syrian Arab Republic.<sup>(1)</sup> The antenatal clinic at Dandenong Hospital is not only one of Australia's largest maternity providers but is located in a major area of refugee resettlement, which includes a large Dari speaking population. Currently, there is no validated measure in Dari to screen for symptoms of perinatal depression and anxiety. The findings presented in this chapter will contribute to addressing an important barrier to perinatal mental health screening for one of the largest refugee populations.

**Manuscript three: Validation of a Dari translation of the Edinburgh Postnatal Depression Scale among women of refugee background at a public antenatal clinic**

## **Abstract**

**Objective:** Identifying women at risk of depression and anxiety during pregnancy provides an opportunity to improve health outcomes for women and their children. One barrier to screening is the availability of validated measures in the woman's language. Afghanistan is one of the largest source countries for refugees yet there is no validated measure in Dari to screen for symptoms of perinatal depression and anxiety. The aim of this study was to assess the screening properties of a Dari translation of the Edinburgh Postnatal Depression Scale (EPDS).

**Methods:** This cross-sectional study administered the EPDS Dari version to 52 Dari speaking women at a public pregnancy clinic in Melbourne, Australia. A clinical interview using the depressive and anxiety disorders modules from the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders-5 (SCID-5 for DSM-5) was also conducted. Interview material was presented to an expert panel to achieve consensus diagnoses. The interview and diagnostic process was undertaken blind to EPDS screening results.

**Results:** Cronbach's alpha coefficient for the EPDS Dari version was good ( $\alpha = 0.79$ ). Criterion validity was assessed using the receiver operating characteristics curve and generated excellent classification accuracy for depression diagnosis 0.90 (95% CI 0.82 – 0.99) and 0.94 (95% CI 0.88 – 1.00) for anxiety diagnosis. For depression, a cut-off score of 9, as recommended for culturally and linguistically diverse groups, demonstrated high sensitivity 1.00 (95% CI 0.79 – 1.00) and specificity 0.88 (95% CI 0.73 – 0.97). For anxiety, a cut-off score of  $\geq 5$  provided the best balance of sensitivity 1.00 (95% CI 0.72 – 1.00) and specificity 0.80 (95% CI 0.65 – 0.91).

**Conclusion:** These results support the use of this EPDS Dari version to screen for symptoms of depression and anxiety during pregnancy as well as the use of a lowered cut-off score.

## Introduction

Pregnancy can be a time of increased risk for developing or re-experiencing mental illnesses, most commonly depression and anxiety (Smith et al., 2011). Depression during pregnancy is associated with poor birth outcomes such as premature birth, low birth weight, and low Apgar score which is a measure of newborn health (Marcus, 2009; Räisänen et al., 2014). Maternal mental health conditions can impact family functioning and disrupt crucial mother-child attachment, affecting infant and later child development and behaviour (Austin et al., 2011; Śliwerski et al., 2020). There is also substantial financial burden associated with perinatal depression and anxiety. Long-term costs, which include healthcare expenses, losses to wellbeing, productivity, and intergenerational impact, have been assessed at \$5.2 billion (Pricewaterhouse Coopers Ltd., 2019) in Australia and £8.1 billion in the U.K (Bauer et al., 2014). Given depression during pregnancy has been identified as one of the strongest risk factors for developing postpartum depression (O'Hara and Wisner, 2014) the need for mental health screening during this period is critical, particularly as it has been shown to increase referrals and service usage (Reilly et al., 2020).

The perinatal period can be defined as including the antenatal period (conception through to birth) and the first 12 months following birth (Austin et al., 2011). Prevalence of perinatal depression and anxiety varies across countries, with high co-morbidity between these two disorders (Austin et al., 2010). In high income countries, perinatal depression is reported to affect between 8.5% - 12.9% of women and anxiety 12.3% - 13.0% of women (Gavin et al., 2005; Howard et al., 2014). A systematic review of forty studies assessing perinatal depression in women living in low- and middle-income countries reported a pooled prevalence of 31% for any depressive disorder (Fellmeth et al., 2017), which is more than double the reported rate in high income countries. This systematic review also highlighted a paucity of studies on perinatal anxiety disorders, which are

an important consideration for pregnancy care, particularly with traumatised populations, as it can impact foetal development and neonatal outcomes (Dayan et al., 2002).

Women of refugee background are at even higher risk of perinatal mental health disorders due to refugee experiences such as exposure to violence, trauma, displacement, and post-migration stressors such as poverty and social isolation (Collins et al., 2011). Accessing antenatal care in pregnancy can often be the first regular contact with the host nation's health system, making antenatal services a key opportunity to provide for mental health needs and other social needs (Yelland et al., 2014). It is vital that maternity services acknowledge the impact of refugee experiences on pregnancy and the challenges that women of refugee background face as they adapt to parenthood within the context of a new culture and often without support from family (Rogers et al., 2020). Clinical guidelines recommend mental health screening in pregnancy for all women (NICE, 2018; Austin et al., 2017); however, screening remains a common gap in the implementation of best-practice pregnancy care (Yelland et al., 2009). The gap is likely to be even larger for women of refugee background not only due to issues of low health literacy, availability of interpreters, cross-cultural limitations of Western medical models, and stigma regarding disclosure of mental illness, but also a lack of access to translated and validated screening measures (Nithianandan et al., 2016).

The enduring conflict in Afghanistan has resulted in one of the largest refugee populations globally, second only to the Syrian Arab Republic (UNHCR, 2019). A combination of prolonged exposure to conflict and a lack of mental health care provision within Afghanistan, has seen an increase in the risk of mental illnesses for this population, specifically depression and post-traumatic stress disorder (Alemi et al., 2014). Refugees and asylum seekers from Afghanistan

continue to resettle across many countries including Iran, Pakistan, USA, and Australia (Alemi and Stempel, 2018). To date, the Dari version of the Edinburgh Postnatal Depression Scale (EPDS) (Cox et al., 1987), one of the most widely used depression and anxiety screening measures during pregnancy, has not been validated against clinical diagnosis. There is a clear need for the availability of culturally specific perinatal mental health screening measures.

The EPDS has been validated for use during pregnancy and translated into a number of different languages (Ing et al., 2017; Kheirabadi et al., 2012). The English version of the EPDS, when administered during pregnancy, performs with moderate sensitivity (0.76 – 0.88) and high specificity (0.88-0.92) (Austin et al., 2017). However, its psychometric properties vary across translations and settings, with the variability in performance attributed to the use of different cut-off scores and varying translation standards. A review comparing seven screening measures reported that the EPDS was the most suitable perinatal depression screening tool, particularly in low-resource settings, due to its superior level of sensitivity (Chorwe-Sungani and Chipps, 2017).

Optimal cut-off points for the EPDS, which balance sensitivity and specificity, are required in order to accurately identify women at risk of depression and anxiety across different populations. When administering the English version of the EPDS, the recommended cut-off score for use during the antenatal period is  $\geq 15$  and  $\geq 13$  when administered during the post-partum period (Matthey et al., 2006). When screening women from other cultures and non-English speaking backgrounds, a lower cut-off score of  $\geq 9$  is recommended in order to account for language and cultural differences that may reduce the specificity of the measure (Austin et al., 2011). The EPDS also provides a sub-scale score for symptoms of anxiety. This can be calculated from items 3, 4, and 5. A study by Swalm et al., 2010 reported that a cut off score of 4 or more was optimum in capturing the top quartile of scores in a large sample of Australian pregnant women.

The objective of the present study was to investigate the screening properties of the EPDS with a sample of Dari speaking women seeking antenatal care. This study assesses the ability of the EPDS to detect depressive and anxiety disorders in this population of women of refugee background.

## **Methods**

### **Setting**

This cross-sectional study was conducted at a public antenatal clinic at one of Australia's largest health services. This health service provides healthcare in one of the most culturally diverse localities in Australia (over 100 languages spoken), including a large Dari speaking population (City of Greater Dandenong, 2018). One day per week the clinic operates as a designated refugee antenatal clinic. Women are allocated to this clinic following referral from their general practitioner (GP) for maternity care based on availability and preference. All women attending the service completed the EPDS as part of their standard maternity care.

### **Participants and Recruitment**

Participants were recruited between July 2016 and November 2018. Permission was granted by the health service to approach women identified from clinic appointment lists if Dari was listed as their preferred language. A few days prior to their scheduled appointment, a member of the research team (RB) phoned the women, with the assistance of a female interpreter experienced in healthcare. Women were asked to participate in a one-on-one interview to discuss their emotional health during pregnancy and to talk about their experience of arriving in Australia. The interviews were booked on the same day as their clinic appointment. Women aged 18 years and over, currently pregnant, and arrived to Australia on a humanitarian visa, asylum seeker or spousal visa were invited to attend. Women presenting with an acute psychotic episode, intellectual impairment, or

any serious complications with their pregnancy resulting in termination were excluded from participating in this study.

## **Measures**

### **Edinburgh Postnatal Depression Scale (EPDS)**

The EPDS is a ten-item, self-report questionnaire used to detect symptoms of depression and anxiety. Each item uses a four-point Likert response scale, ranging from zero to three, asking women to rate how they have been feeling over the past seven days. The final item (item 10) on the EPDS assesses the risk of self-harm and suicidal ideation.

### **Structured Clinical Interview for DSM-5 Research Version (SCID-5-RV)**

The Structured Clinical Interview for DSM-5 Research Version (SCID-5-RV) is a semi-structured interview designed to assess and determine current and lifetime mental health diagnoses in line with internationally recognised diagnostic criteria (DSM-5) (First et al., 2015). It has been used in validation studies with refugee populations (Brink et al., 2015; Ing et al., 2017). It is designed to be administered by a clinician or trained mental health professional with experience of the DSM-5 diagnostic criteria. The Research Version is the most comprehensive of the versions as it contains more disorders than the clinical version. To our knowledge, there is currently no literature available on the psychometric properties of the research version of the SCID-5. However, the clinician version of the SCID-5 is reported to have good diagnostic sensitivity ( $>0.70$ ) and specificity ( $>0.80$ ) (Osório et al., 2019). For the purposes of this study, the modules pertaining to depressive and anxiety related disorders were administered in English with the assistance of interpreters where required. The trauma module was also administered; however, this was part of a separate study.

In addition to the researcher who conducted the interviews (RB), two other members of the project team (psychologists; GM and KG) joined with RB to form an expert panel to review all clinical

interview material for each participant, in order to determine consensus DSM-5 diagnoses. All of these researchers were blind to the screening results of the EPDS.

### **Adaption and Translation**

The process used to translate this Dari version was developed and described elsewhere (Shafiei et al., 2015). In summary, Shafiei et al. (2015) reported the English version EPDS was translated into Dari by an accredited professional translator, the translation was then reviewed and discussed by a group of professional translators, bilingual mothers from the community, and members of the research team and then pilot tested. For the purposes of this study, the EPDS Dari version was also back translated.

### **Procedure**

On the day of their appointment, women completed the EPDS in Dari on a tablet device using the digital platform iCOPE, which was developed by the Centre of Perinatal Excellence (COPE) (COPE, 2019). The iCOPE platform calculates the scores and provides instant reports to both the woman and the health professional. The clinical report provides the item responses, total EPDS score, anxiety sub-scale score, and highlights the response to item 10, which assess for risk of self-harm. A member of the research team experienced in risk assessment provided training to all staff as well as the availability of flowcharts in each clinic room detailing the referral process depending on level of risk. Women completed the EPDS screening in the clinic waiting room. Accredited female interpreters employed by the health service were used if required by the woman.

Following completion of their appointment, women attended an interview with the researcher (RB), who was blinded to their EPDS screening scores, in order to complete the Structured Clinical Interview for DSM-5 (SCID-5-RV) (American Psychiatric Association, 2013). The researcher

(RB) is a registered psychologist and had received training in refugee health, trauma, and administering the SCID-5-RV. During the interview the depressive, anxiety, and trauma disorder modules were administered, along with the Harvard Trauma Questionnaire (HTQ) (Mollica et al., 1992). Women who received a diagnosis of a current mental illness were offered a referral to a refugee-focussed counselling service or to their GP according to their preference. This study was approved by the Monash Health Human Research Ethics Committee (14475L). Participants provided written informed consent via consent forms translated into Dari. A witness signature was also collected from the interpreter if required to complete the interview. Women were able to end the interview at any time and withdraw their participation without any effect on their maternity care. Women received a \$20 gift card for their participation and taxi vouchers, if required. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines (Elm et al., 2007).

### **Statistical Analyses**

The total sample was divided into those who received a DSM-5 diagnosis for any current depressive or anxiety disorder and those who did not. The screening efficacy of the EPDS Dari version was then evaluated, using the recommended cut-off score of 9. The effect of increasing the cut-off score to 10 and decreasing to 8 was also investigated, as well as the recommended cut-off score of 13 used in English-speaking populations. For each cut-off, we calculated sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV). Sensitivity is the ability of the EPDS to correctly identify all women with depressive and/or anxiety disorders (Altman and Bland, 1994a). Specificity is the ability of the EPDS to correctly identify all women who do not have depressive or anxiety disorders (Altman and Bland, 1994a). PPV refers to the proportion of women who screen positive on the EPDS and receive a diagnosis of depression or

anxiety (Altman and Bland, 1994b). NPV is the proportion of women who screen negative on the EPDS and do not have a current diagnosis of depression or anxiety (Altman and Bland, 1994b). Cronbach's alpha was calculated to determine the internal consistency of the Dari adaptation of the EPDS. A Receiver Operating Characteristic (ROC) curve was used to assess the accuracy of the EPDS (Metz, 1978; Zweig and Campbell, 1993). Accuracy of the EPDS (proportion of results correctly identified) was estimated by the area under the ROC curve (AUC). Statistical significance was set at  $p < 0.05$  and all analyses were conducted using the DAG\_stat spreadsheet designed specifically for the assessment of diagnostic tests (Mackinnon, 2000).

### **Sample Size Estimation**

A statistical power analysis was performed for sample size estimation based on the expected prevalence of 28% of women of refugee background being diagnosed with a depressive disorder (Collins et al., 2011). With an alpha = 0.5 and power = .80, the projected sample size needed was approximately  $n = 47$ .

### **Results**

Fifty-two women were interviewed. EPDS screening using the iCope digital platform took approximately 6-14 minutes to complete and the interviews lasted between 60 – 90 minutes.

The mean age was 27.56 years (SD 5.196). Forty-four (84.6%) of the interviews were conducted with the assistance of a female interpreter experienced in healthcare. All 52 women were married or in de facto relationships. Women were assessed between 13 – 39 weeks gestation. Further socio-demographic details of the women are provided in Table 1.

Seventy-three women were approached in the clinic and 20 (27%) declined to participate. Most women cited lack of time or caring responsibilities as the reason for non-participation, and for three women their husbands refused their participation. There was no significant difference between mean EPDS scores of the women who participated and those who declined. One woman agreed to participate but was later excluded due to serious medical complications with her pregnancy resulting in termination. There were no dropouts and all interviews were completed.

Table 1. Socio-demographic characteristics of the study population (N=52).

<b>Demographic characteristics</b>	<b>Frequency</b>	<b>%</b>
<b>Age (years)</b>		
18-24	18	34.6%
25-35	31	59.6%
36-45	3	5.8%
46+	0	0%
Overall	27.56 (Mean)	5.196 (SD)
<b>Educational Level</b>		
No formal education	3	5.8%
Grade 6 or less	21	40.4%
Grades 7 to 12 (without graduating secondary school)	23	44.2%
Graduated secondary school	3	5.8%
Completed trade qualification	2	3.8%
Completed university qualification	0	0%
<b>Employment</b>		
Full-time job	1	1.9%
Part-time job	2	3.8%
Full time caregiver	44	84.6%
Studying	5	9.6%
<b>Visa Status Upon Arrival</b>		
Special humanitarian program	15	28.8%

Partner visa	34	65.4%
Asylum Seeker	3	5.8%
<b>Gestation (in weeks)</b>		
1 to 12	0	0%
13 to 25	34	65.4%
27 to 42	18	34.6%
<b>Number of children</b>		
0	16	30.8%
1	15	28.8%
2	16	30.8%
3	4	7.7%
4	1	1.9%
<b>Country of Birth</b>		
Afghanistan	49	94.2%
Iran	3	5.8%
<b>Time in Australia</b>		
Less than 2 years	22	42.3%
2 – 5 years	23	44.2%
6 – 10 years	6	11.5%
More than 10 years	1	1.9%

### Screening Scores and Mental Health Diagnoses

The mean EPDS score of the total sample was 7.04 (SD 5.48). Nine women (17%) responded with either a score of 1 or 2 for item 10 and received a referral for counselling. None of the women responded with a score of 3 for item 10. Eighteen women (34.6%) met criteria for at least one current depressive, anxiety, or trauma-related disorder and twenty-eight (53.8%) met criteria for a historical depressive, anxiety, or trauma-related disorder. Thirteen women (25%) received a diagnosis of a current depressive episode. The mean score of the EPDS for women diagnosed with a current depressive disorder was 12.77 (SD 2.42) and for women without depression 5.13 (SD 4.84). Eleven women (21%) received a diagnosis of a current anxiety disorder. The mean EPDS

anxiety sub-scale score for women diagnosed with an anxiety disorder was 5.82 (SD 0.75) and for women without an anxiety disorder 2.38 (SD 2.17). Eight women received a comorbid diagnosis of depression and anxiety, one woman was diagnosed with Generalised Anxiety Disorder and Panic Disorder, and one woman received a diagnosis of PTSD and depression. Seven women (13.5%) were diagnosed as experiencing episodes of both current and historical mental illness. Table 2 provides a list of current and historical mental illness diagnoses according to the DSM-5 classification.

Table 2. Current and historical mental illness according to DSM-5 classification.

Mental Illness (N=52)	Current	Historical
	n (%)	n (%)
Major Depressive Episode	9 (17.3)	15 (28.8)
Persistent Depressive Disorder	4 (7.7)	--
Generalised Anxiety Disorder	6 (11.5)	--
Panic Disorder	1 (1.9)	2 (3.8)
Panic Attacks	6 (11.5)	--
Social Anxiety	1 (1.9)	--
Agoraphobia	--	1 (1.9)
Posttraumatic Stress Disorder	4 (7.7)	3 (5.8)
Other Specified Trauma-and-Stressor-Related Disorder	1 (1.9)	--

## Internal Consistency

The internal consistency of the translated EPDS was assessed using Cronbach's alpha and the result was  $\alpha = 0.79$ . Item-total scale correlations displayed three items with a correlation below 0.40 (see Table 3); item 2 "I have looked forward with enjoyment to things" (0.33), item 7 "I have been so unhappy that I have had difficulty sleeping" (0.365), and item 10 "the thought of harming myself has occurred to me" (0.233).

Table 3. Internal consistency (Cronbach's Alpha) of the Dari translation of the EPDS

Item	Description	Mean Item Score (SD)	Corrected item-total correlations	Cronbach's alpha if item deleted
1	I have been able to laugh and see the funny side of things	0.42 (0.667)	0.416	0.775
2	I have looked forward with enjoyment to things	0.44 (0.777)	0.330	0.783
3	I have blamed myself unnecessarily when things went wrong	1.60 (0.934)	0.554	0.757
4	I have been anxious or worried for no good reason	1.04 (1.028)	0.573	0.753
5	I have felt scared or panicky for no very good reason	0.94 (0.938)	0.583	0.753
6	Things have been getting on top of me	1.06 (0.958)	0.490	0.765
7	I have been so unhappy that I have had difficulty sleeping	0.88 (1.199)	0.365	0.789
8	I have felt sad or miserable	0.79 (0.936)	0.613	0.749
9	I have been so unhappy that I have been crying	0.52 (0.641)	0.453	0.772

10	The thought of harming myself has occurred to me	0.23 (0.581)	0.233	0.791
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(SD) = standard deviation

A Receiver Operating Characteristic curve (ROC) analysis was used to assess the diagnostic ability of the EPDS for both current depression and current anxiety diagnosis. Accuracy of the EPDS is estimated by the area under the ROC curve (AUC). The AUC for the EPDS and current depression diagnosis was 0.90 (95% CI 0.82 – 0.99) and for current anxiety diagnosis 0.94 (95% CI 0.88 – 1.00). For both depression and anxiety, the AUC was close to 1, indicating high discriminative power of the EPDS. Figure 1 presents the ROC plot for the EPDS and current depression diagnosis and Figure 2 presents the ROC plot for the EPDS and current anxiety diagnosis.

Figure 1. Receiver Operating Characteristic (ROC) plot for the EPDS and current depression diagnosis

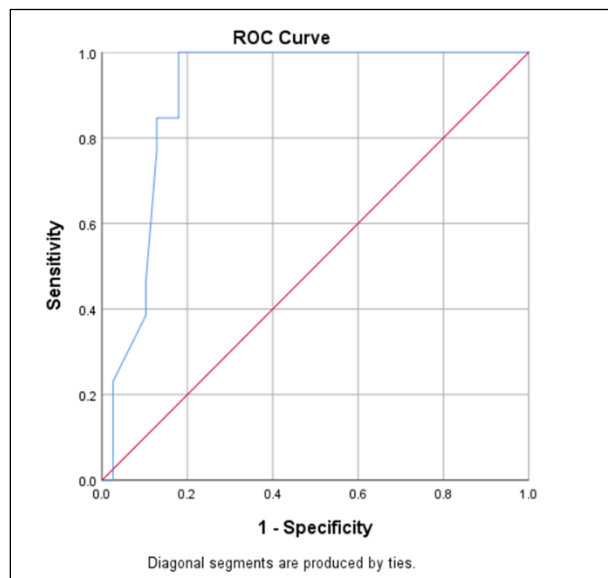
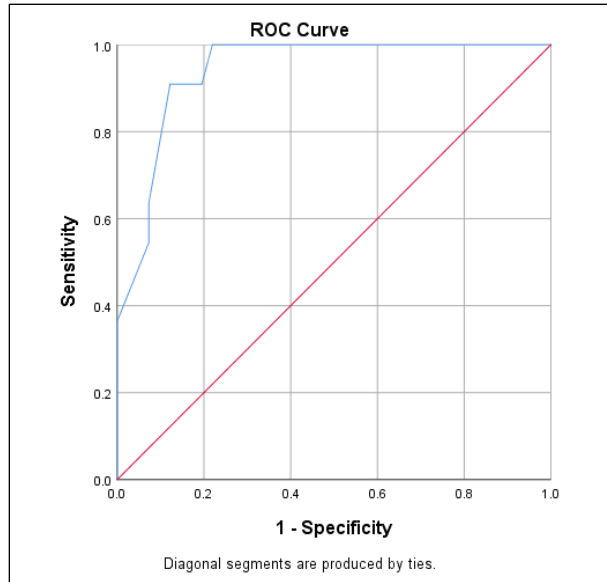


Figure 2. Receiver Operating Characteristic (ROC) plot for the EPDS and current anxiety diagnosis



### Screening Efficacy

The sensitivity, specificity, and predictive values of the EPDS Dari version are presented in Tables 4 and 5. Using the cut-off score of  $\geq 8$ , 24 women screened positive on the EPDS while 28 screened negative. Of those who screened positive, 16 (67%) received a diagnosis of either current depression or anxiety, while eight (33%) did not. This resulted in a sensitivity of 1.00 (95% CI 0.79 – 1.00) and a specificity of 0.78 (95% CI 0.61 – 0.90).

Using the recommended cut-off score of  $\geq 9$ , 20 women screened positive on the EPDS while 32 screened negative. Of those who screened positive, 16 (80%) received a diagnosis of either current depression or anxiety, while four (25%) did not. This resulted in a sensitivity of 1.00 (95% CI 0.79 – 1.00) and specificity of 0.89 (95% CI 0.74 – 0.97). Increasing the cut-off score to  $\geq 10$  resulted in 20 women screened positive on the EPDS while 32 screened negative. Of those who screened

positive, 16 (80%) received a diagnosis of either current depression or anxiety, while four (20%) did not. Of those who screened negative, two (6.25%) women received a diagnosis of current depression. This resulted in a sensitivity of 0.89 (95% CI 0.65 – 0.99) and specificity of 0.88 (95% CI 0.73 – 0.97).

Using the cut-off score of  $\geq 13$ , 10 women screened positive on the EPDS while 42 screened negative. Of those who screened positive, 9 (90%) received a diagnosis of either depression or anxiety, while one (10%) did not. Of those who screened negative, seven (17%) received a diagnosis of depression or anxiety. This resulted in a sensitivity of 0.56 (95% CI 0.30 – 0.80) and a specificity of 0.97 (95% CI 0.85 – 1.00)

Table 4. EPDS cut off scores and screening efficacy for the diagnosis of DSM-5 current depressive illness

EPDS Cut-Off Score	Sensitivity (95% CI)	Specificity (95% CI)	Positive Predictive Value (95% CI)	Negative Predictive Value (95% CI)
$\geq 8$	1.00 (0.79 – 1.00)	0.78 (0.61 - 0.90)	0.67 (0.45 – 0.84)	1.00 (0.88 – 1.00)
$\geq 9$	1.00 (0.79 – 1.00)	0.88 (0.73 – 0.97)	0.80 (0.56 – 0.94)	1.00 (0.88 – 1.00)
$\geq 10$	0.89 (0.65 – 0.99)	0.88 (0.73 – 0.97)	0.80 (0.56 – 0.94)	0.94 (0.79 – 0.99)
$\geq 13$	0.56 (0.30 – 0.80)	0.97 (0.85 – 1.00)	0.90 (0.55 – 1.00)	0.83 (0.69 – 0.93)

EPDS = Edinburgh Postnatal Depression Scale; CI = confidence intervals

The sensitivity, specificity, and the predictive values of the anxiety sub-scale score in accurately detecting those diagnosed with an anxiety disorder are presented in Table 5. The cut-off score of  $\geq 5$  provided the optimum balance of sensitivity and specificity.

Table 5. EPDS cut off scores and screening efficacy for the diagnosis of DSM-5 current anxiety disorders

Anxiety sub-scale Score	Sensitivity (95% CI)	Specificity (95% CI)	Positive Predictive Value (95% CI)	Negative Predictive Value (95% CI)
≥3	1.00 (0.72 – 1.00)	0.61 (0.45 – 0.76)	0.41 (0.22 – 0.61)	1.00 (0.86 – 1.00)
≥4	1.00 (0.72 – 1.00)	0.71 (0.54 – 0.84)	0.48 (0.27 – 0.69)	1.00 (0.88 – 1.00)
≥5	1.00 (0.72 – 1.00)	0.80 (0.65 – 0.91)	0.58 (0.33 – 0.80)	1.00 (0.89 – 1.00)
≥6	0.64 (0.31 – 0.89)	0.93 (0.80 – 0.98)	0.70 (0.35 – 0.93)	0.90 (0.77 – 0.97)

CI = confidence interval

## Discussion

The objective of the present study was to investigate the screening properties of the EPDS with a sample of Dari speaking women and its ability to determine the presence of depression and anxiety in women of refugee background seeking antenatal care. This paper presents the psychometric properties of a commonly used screening measure, the EPDS, with a Dari speaking population of women of refugee background. To the best of our knowledge, this is the first study to investigate the clinical utility of administering the EPDS for screening during pregnancy with Dari speaking women.

Overall, the internal consistency as measured by the Cronbach's alpha coefficient was good ( $\alpha = 0.79$ ). However, the results of this study raised some issues with the performance of a few items on the EPDS; items 2, 7, and 10. Item 2 asks whether respondents “have looked forward with enjoyment to things”, item 7 asks whether the respondent has been ‘so unhappy they have had difficulty sleeping’, and item 10 assesses risk of self-harm and suicide, which is critical in

determining the need for an acute referral. It could be speculated that issues with translating may have resulted in the poor performance of these items. Poorer performing items are an important consideration for health professionals when administering this translated version of the EPDS. Understanding cultural sensitivities and translation difficulties with particular items may require additional clinical judgement and further discussion with the woman during screening. Future research could investigate whether the wording used for these items on the EPDS could be altered in order to improve cross-cultural use.

The Dari translation of the EPDS has shown favourable sensitivity and specificity characteristics in its ability to detect both depression and anxiety. The results from the comparison of cut-off scores support the use of the lowered cut-off score of  $\geq 9$ , which is recommended for culturally and linguistically diverse groups, when using the EPDS to screen for depression. At this cut off, the measure demonstrated high sensitivity 1.00 (95% CI 0.79 – 1.00) and specificity 0.88 (95% CI 0.73 – 0.97). Recommended cut-off scores vary across translations, settings, and timing. The Persian and Arabic versions of the EPDS recommend a cut-off score of 12/13 (Mazhari and Nakhee, 2007; Naja et al., 2019). However, both of these translations were administered postpartum and to non-refugee populations. A validation study of the EPDS in Karen and Burmese with women of refugee background reported recommended cut-off scores of  $\geq 10$  (Ing et al., 2017). When using the EPDS to screen for anxiety, a cut-off score of  $\geq 4$  has been suggested for English-speaking women (Swalm et al., 2010). Based on the results of this study, when using the EPDS to screen for anxiety disorders, a cut-off score of  $\geq 5$  provided the best balance of sensitivity 1.00 (95% CI 0.72 – 1.00) and specificity 0.80 (95% CI 0.65 – 0.91).

A systematic review of the evidence on the validity of the EPDS in detecting perinatal depression reported noticeable variability between the thirty-seven included studies with a range of 0.34 –

1.00 for sensitivity and 0.44 – 1.00 for specificity (Gibson et al., 2009). This variability was mostly attributable to differences in language, populations sampled, diagnostic measures and methods, and study methodology (Gibson et al., 2009). The performance of this Dari version of the EPDS is similar to other translations of the EPDS for languages from refugee source countries. In detecting depression, using the lowered cut-off score of  $\geq 9$ , the Burmese version reports a sensitivity of 1.00 and specificity of 0.95 and the Karen version reports a sensitivity of 1.00 and specificity of 0.98 (Ing et al., 2017).

Applying the best cut-off score during administration is vital in optimally identifying women at risk of depression and anxiety. In our study, the previously recommended cut-off score of  $\geq 9$  produced the best balance of sensitivity, specificity, and predictive values. Applying the cut-off score of  $\geq 13$ , recommended for the general population, resulted in a concerning number of false negatives. This has serious implications for how mental health screening is implemented in clinical practice. Applying one cut-off score across a multicultural service population may limit the efficacy of mental health screening programs during pregnancy, highlighting the importance of the use of culturally specific cut-off scores. Without applying appropriate cut-off scores women who require treatment may not be identified or offered the necessary intervention, which is likely to result in a worsening of prognosis.

The importance of having a validated Dari version of the EPDS is supported by the high proportion of women in this study who met DSM-5 criteria for a current depressive or anxiety disorder. These results are consistent with the current body of literature which suggests that perinatal depression and anxiety are more prevalent in women of refugee background compared to women from general populations (Fellmeth et al., 2017). With the continued increase in global numbers of refugees, combined with the specific vulnerabilities faced by these women during pregnancy, there is a need

to develop and implement perinatal mental health screening programs which can be delivered across a range of healthcare settings and to populations experiencing adversity. Given the impact of perinatal depression and anxiety on pregnancy health, birth outcomes, and mother-infant bonding, it is critical that health-equity in perinatal care is prioritised so that women of refugee background can receive appropriate screening in order to provide early management and treatment of symptoms. Elements of trauma-informed practice should be integrated into models of pregnancy care for those health services in areas of refugee resettlement.

In order to best provide for the specific health needs of resettled women of refugee background, it is vital that health services be able to correctly identify these women. More than half of the women who participated in this study arrived to Australia on a partner visa. At the time of booking clinic appointments, these women were not identified as formal refugees and were selected for the study based on their language preference. Throughout the clinical interviews, it became very apparent that all of these women had experienced exposure to potentially traumatic events, grief, conflict, isolation, and extreme poverty; common hallmarks of refugee experiences. Even in high income host nations, most health services do not have access to immigration data and therefore country of birth is often the only way of identifying those individuals who may have been exposed to the stressors of forced displacement (Gibson-Helm et al., 2014). This highlights the issues surrounding the identification and formal recognition of women of refugee background which is crucial if health services are to adequately manage the increased risks to mental health problems for this population of women, particularly during pregnancy.

This study has several strengths worthy of note. Firstly, a standardised clinical interview was conducted, and consensus diagnosis approach by a panel of experienced psychologists and researchers was used to determine diagnoses. Secondly, this process was conducted blind to the

EPDS scores. The EPDS screening scores were compared to consensus clinical diagnosis according to DSM-5 criteria. We were also able to report the number of women who declined to participate in the study, along with a comparison of their mean EPDS scores. Few validation studies within the EPDS literature have reported participation rates (Smith-Nielsen et al., 2018). Despite these strengths, there are some limitations. Even though the cohort of women came from one of Australia's largest maternity services, which serves a substantial migrant and refugee population, recruitment occurred at one clinic only. This may limit the generalisability to the whole population of Dari speaking women. Finally, although the DSM-5 has made attempts to enhance cultural validity and incorporate cultural aspects of symptom presentation, it is still a framework of mental illness that has been developed within a Western population, resulting in limitations when applied cross-culturally. The EPDS was originally developed with a population of English-speaking women from the UK and although translated into many languages and validated, it was not developed specifically for refugee populations or cross-cultural use.

The EPDS Dari version is a valid and reliable screening instrument for detecting women at-risk of depression and anxiety during pregnancy. It should be noted, however, that there are some poorer performing items; items 2 and 7, which may have implications for clinical practice, and particularly item 10 which assesses risk of self-harm. Importantly, these results further support the use of a lowered overall cut-off score ( $\geq 9$ ) and consideration of an anxiety sub-scale cut-off score of  $\geq 5$  when screening this population of women.

Perinatal health services provide an opportune setting to screen pregnant women who might be at risk of depression or anxiety. If screening can be provided with simple and validated measures, such as the EPDS, then a major barrier to improving access to mental health care will be addressed. Perinatal mental health screening has been shown to be acceptable and supported by women of

refugee background (Willey et al., 2020). Providing appropriate and timely intervention during this period of vulnerability, particularly for women of refugee background, has the potential to not only improve mental health and birth outcomes, but to also have a long-term positive impact across generations.

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The Authors declare that there is no conflict of interest.

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## **Chapter five: Identifying PTSD during pregnancy for women of refugee background**

### **5.1 Introduction**

Identifying mental illness in women of refugee background during pregnancy is crucial in order to provide appropriate intervention with the aim of improving health outcomes for women and their children. Despite a consistent acknowledgement within this field of research, that factors associated with the refugee experiences can contribute to the development of PTSD during pregnancy, there is a lack of literature on the prevalence of PTSD and related trauma symptomatology during the perinatal period amongst refugee populations.(20,21,26) Further research is needed not only to investigate the prevalence of PTSD but to also determine ways to increase the recognition of women at risk of PTSD during pregnancy.(19) There is also lack of brief psychometrically validated screening tools to detect symptoms of trauma for use with women during the antenatal period. Healthcare workers acknowledge that screening for perinatal PTSD, particularly for women of refugee background, is critical, but lack the knowledge and process skills required to undertake screening.(19) These critical gaps identified in the current body of literature were the driving force behind the design of the study presented in chapter five which was in direct response to the needs identified by the clinical workforce. In contrast to the Edinburgh Postnatal Depression Scale (EPDS), the Harvard Trauma Questionnaire (HTQ) is not universally recommended as a trauma screener during the perinatal period, however as previously discussed there is a lack of clinical guidance for healthcare workers on this topic. The HTQ was selected for this study as it is widely used and was developed specifically for refugee populations and cross-cultural use. It is also a readily accessible measure which would allow for greater ease of implementation within healthcare settings. The findings have important implications for health services working with women of refugee background during pregnancy as they will assist in

identifying women who are a risk of PTSD and its associated symptomatology due to their experiences of trauma.

**Manuscript four: Identifying post-traumatic stress disorder in women of refugee background at a public antenatal clinic**

## **Abstract**

**Purpose:** The aim of this study was to investigate symptomatology and diagnoses of PTSD and subthreshold PTSD and the screening properties of the Harvard Trauma Questionnaire (HTQ) within a sample of Dari speaking women of refugee background receiving antenatal care.

**Methods:** This cross-sectional study administered the HTQ to 52 Dari speaking women at a public pregnancy clinic. The trauma module from the Structured Clinical Interview (SCID-5) was administered. Interview material was presented to an expert panel, blinded to the HTQ screening results, in order to achieve consensus diagnoses of PTSD using Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) criteria.

**Results:** Three women (5.8%) met DSM-5 criteria for PTSD. Eleven women (21.15%) met criteria for subthreshold PTSD, defined as meeting two or three of the DSM-5 criteria domains. A comparison of HTQ cut-off scores was conducted and a score of  $\geq 2.25$  on the HTQ demonstrated excellent sensitivity 1.00 (95% CI 0.29 – 1.00) and specificity 0.76 (95% CI 0.61 – 0.87) in detecting PTSD, however a wide confidence interval for sensitivity was found. A cut-off score of  $\geq 2$  provided the best balance of sensitivity 1.00 (95% CI 0.72 – 1.00) and specificity 0.80 (95% CI 0.65 – 0.91) when assessing for subthreshold PTSD.

**Conclusion:** Screening for perinatal PTSD for women of refugee background is recommended, in order to identify those at risk of DSM diagnosis and also those women experiencing distressing PTSD symptomatology.

## Introduction

Post-traumatic stress disorder (PTSD) experienced during the perinatal period, that is, from conception to twelve months following the birth (Austin M-P 2011), is associated with adverse birth outcomes such as preterm birth, low birthweight, and smaller head circumference at birth (Morland et al. 2007; Seng et al. 2011; Zhu et al. 2010; MacGinty et al. 2020). If left untreated, the symptomatology not only impacts the wellbeing of the woman but also the quality of maternal-infant attachment, negatively influencing child development and infant emotional regulation (Bosquet Enlow et al. 2011; Cook et al. 2018). To date, much of the perinatal mental health literature has focused heavily on depression (Howard et al. 2014). However, PTSD is beginning to be recognised as an important mental health concern during pregnancy (Seng et al. 2010).

Perinatal PTSD is reported to affect 3.3% of women (95% CI 2.44 - 4.54) and a higher prevalence of 18.95% (95% CI 10.62 – 31.43) amongst women from at-risk populations (Yildiz et al. 2017). Women of refugee background are more likely to experience PTSD, largely attributable to the increased risk of sexual violence during conflict which is an established risk factor for PTSD (Blackmore et al. 2020; Vu et al. 2014). However, a recent systematic review concluded there were insufficient studies to assess the prevalence of perinatal PTSD within refugee populations (Fellmeth et al. 2017). In addition to trauma associated with refugee experiences, acculturation stress, which includes the loss of family supports and separation from cultural practices during pregnancy and birth, intersect to increase risk of PTSD (Hameed et al. 2018).

Some individuals who experience a traumatic event develop subthreshold PTSD. This is defined as insufficient symptomatology to qualify for diagnosis, however meeting two or three of the DSM-5 criteria across domains B-E (McLaughlin et al. 2015). Subthreshold PTSD is clinically significant as it interferes with a woman's experience of pregnancy, impacting functioning, and increasing the risk for suicidality and comorbidity with disorders such as depression (Cukor et al. 2010; Marshall et al. 2001).

Given its contribution to adverse perinatal and postnatal outcomes (Seng et al. 2011), there is a critical need to address PTSD during the perinatal period. There is consistent acknowledgement that factors associated with refugee experiences can contribute to the development of PTSD during pregnancy; however, there is a lack of research on PTSD and trauma symptomatology during the perinatal period amongst refugee populations (Anderson et al. 2017; Fellmeth et al. 2017). There is also a lack of guidance for healthcare providers about whether PTSD screening is warranted for women of refugee background and the performance of refugee-appropriate PTSD screening measures to ensure these at-risk populations of women can be identified (Nithianandan et al. 2016).

The objective of this study was to investigate the rates of symptomatology and diagnoses of PTSD and subthreshold PTSD as well as the screening properties of the Harvard Trauma Questionnaire (HTQ) with a sample of women from refugee backgrounds receiving antenatal care at a public pregnancy clinic.

## **Materials and Methods**

### **Population and Setting**

This cross-sectional study was conducted at a public hospital antenatal clinic at one of Australia's largest health services. This health service provides healthcare within a large refugee and asylum seeker resettlement area [Greater Dandenong Council 2018]. Dari speaking women, mostly originating from Afghanistan, are one of the largest groups of women with refugee experiences to attend this clinic.

### **Study Design**

Participants were recruited between July 2016 and November 2018. Women aged 18 years and over, currently pregnant, and who arrived in Australia on a humanitarian visa, asylum seeker or spousal visa were invited to participate. Potential participants were identified from the clinic appointment lists. Prior to their scheduled appointment, a member of the research team (RB) phoned women, with the assistance of a

female interpreter to invite them to participate in an interview. Women presenting with overt psychosis, intellectual impairment, or serious pregnancy complications were excluded.

The Harvard Trauma Questionnaire (HTQ) (Mollica et al. 1992) and the trauma module from the Structured Clinical Interview for DSM 5 Research Version (SCID-5 RV) (First et al. 2015) were administered in English and verbally translated into Dari by trained female interpreters. The depressive and anxiety modules from the SCID were also administered; these results are reported elsewhere. The researcher conducting the interviews (RB) is a registered psychologist and received training in refugee health, trauma, and SCID administration. Women diagnosed as having a current mental illness were offered a referral to support services. The administration of the HTQ and the SCID interviews lasted on average 60 minutes.

In addition to the researcher who conducted the interviews (RB), two other members of the project team (psychologists; GAM and KMG) formed an expert panel to review all clinical interview material for each participant in order to determine consensus DSM-5 diagnoses. All researchers were blind to the screening results of the HTQ.

This study was approved by the Monash Health Human Research Ethics Committee (14475L).

Participants provided written informed consent via consent forms translated into Dari. Women received a \$20 gift card for their participation and taxi vouchers, if required.

A pilot phase was conducted, recruiting women from any refugee source countries, and established that Dari-speaking women were going to be the vast majority of participants. It was decided to limit participation to Dari-speaking women to reduce heterogeneity that may be introduced by including small numbers of women from many different backgrounds.

## **Measures**

### **Harvard Trauma Questionnaire (HTQ)**

The HTQ is a cross-cultural screening measure assessing trauma events and symptoms (Mollica et al. 1992). It was originally validated among a refugee population from South East Asia; the results showed robust internal consistency for part one (0.90) and part four (0.96) and inter-rater reliability of 0.93 for trauma events and 0.98 for symptoms (Mollica et al. 1992). Part one is a self-report checklist of 17 items describing a range of traumatic experiences. Part four consists of 30 items assessing symptoms of PTSD according to DSM-IV. The same validation study also showed that the recommended cut off score of 2.5 performed with 78% sensitivity and 65% specificity in determining a PTSD diagnosis (Mollica et al. 1992). For the purposes of this study, parts one and four of the HTQ for DSM-IV (APA 2013) were administered. Individuals with scores (from either the DSM-IV items or the total items) over 2.5 are considered symptomatic for PTSD.

### **Structured Clinical Interview for DSM-5 Research Version**

The Structured Clinical Interview for DSM-5 Research Version (SCID-DSM-5 RV) is a semi-structured interview designed to determine current and lifetime mental health diagnoses in line with DSM-5 diagnostic criteria (First et al. 2015). It has been used in validation studies with refugee populations (Brink et al. 2015; de Fouchier et al. 2012; Ing et al. 2017). The Research Version contains more disorders than the clinical version. To our knowledge, there is currently no literature available on the psychometric properties of the Research Version. However, the clinician version of the SCID DSM-5 is reported to have diagnostic sensitivity and specificity of >0.70 (Osório et al. 2019). For the purposes of this study, the modules pertaining to trauma-related disorders were administered.

## **Statistical Analyses**

The total sample was divided into those who received a DSM-5 diagnosis for current PTSD, subthreshold PTSD (as defined by meeting two or three of the DSM-5 criteria B-E) (McLaughlin et al. 2015), and those who did not. The screening efficacy of the HTQ was evaluated using the recommended cut-off score of 2.5. The effect of decreasing the cut-off score to  $>2.25$  and  $>2.0$  was also investigated, due to evidence suggesting that lowering the cut off score to 2.0 may improve the performance of the measure (Mollica et al. 1998). For each cut-off, we calculated sensitivity, specificity, positive predictive (PPV), and negative predictive values (NPV) (Altman and Bland 1994a; Altman and Bland 1994b). Statistical significance was set at  $p < 0.05$ , and all analyses were conducted using the DAG\_stat designed specifically for the evaluation of diagnostic tests (Mackinnon 2000).

## **Sample Size Estimation**

A power analysis was performed for sample size estimation based on the expected prevalence of 19% of women of refugee background being diagnosed with perinatal PTSD and 3.3% prevalence in general population (Yildiz et al. 2017). With an alpha = 0.5 and power = .80, the projected sample size needed was approximately  $n = 44$ .

## **Results**

Seventy-three women were approached in the clinic and 20 (27%) declined to participate. Most women cited lack of time or caring responsibilities as the reason for not participating and for three women their husbands refused their participation. Fifty-two Dari speaking women were interviewed. The mean age was 27.6 years ( $SD = 5.2$ ). Forty-four (84.6%) of the interviews were conducted with the assistance of an interpreter. Further socio-demographic details of the participating women are provided in Table 1.

Between women who participated and those who declined, there was no statistically significant difference

in mean age and no statistically significant difference in mean score for the Edinburgh Postnatal Depression Scale (completed by all women attending this clinic). One woman agreed to participate but was later excluded due to serious medical complications with her pregnancy. There were no dropouts and all interviews were completed.

Table 1. Socio-demographic characteristics of the study population (N=52).

<b>Demographic characteristics</b>	<b>Frequency</b>	<b>%</b>
<b>Age (years)</b>		
18-24	18	34.6
25-35	31	59.6
36-45	3	5.8
Overall	M = 27.6	SD = 5.2
<b>Educational Level</b>		
Never educated	3	5.8
Grade 6 or less	21	40.4
Grades 7 to 12 (without graduating high school)	23	44.2
Graduated high school	3	5.8
Completed trade qualification	2	3.8
<b>Employment</b>		
Full-time job	1	1.9
Part-time job	2	3.8
Keeping house or care giving full-time	44	84.6
Studying	5	9.6
<b>Visa Status Upon Arrival in Australia</b>		
Special humanitarian program	15	28.8
Partner visa	34	65.4
Asylum seeker	3	5.8
<b>Gestation (in weeks)</b>		
13 - 25	34	65.4
26 – 42	18	34.6
Overall	M = 16	SD = 3.8

<b>Number of children</b>		
0	16	30.8
1	15	28.8
2	16	30.8
3	4	7.7
4	1	1.9
<b>Country of Birth</b>		
Afghanistan	49	94.2
Iran	3	5.8
<b>Time in Australia</b>		
Less than 2 years	22	42.3
2 – 5 years	23	44.2
6 – 10 years	6	11.5
More than 10 years	1	1.9

## Diagnoses

Three women (5.8%) met DSM-5 criteria for current PTSD. Eleven women (21.2%) met criteria for subthreshold PTSD, as defined by meeting two or three of the DSM-5 criteria B-E (McLaughlin et al. 2015) (see table 2). One woman (1.9%) met criteria for current Adjustment Disorder. Thirty-seven women (71.2%) did not meet any criteria for a current trauma or stressor related disorder. Three women (5.8%) met DSM-5 diagnostic criteria for an historical diagnosis of PTSD.

Table 2. PTSD symptom endorsement according to DSM-5 criteria (N = 14 women meeting criteria for current PTSD or subthreshold PTSD).

DSM-5 Criterion	Women diagnosed with PTSD or subthreshold PTSD (n = 14) (%)	Women diagnosed with PTSD (n = 3) (%)	Women diagnosed with subthreshold PTSD (n = 11) (%)

Criterion A: Exposure to event	14 (100)	3 (100)	11 (100)
Criterion B: Re-experiencing	14 (100)	3 (100)	11 (100)
Criterion C: Avoidance	14 (100)	3 (100)	11 (100)
Criterion D: Negative cognitions and mood	7 (50)	3 (100)	4 (36.4)
Criterion E: Arousal	4 (28.6)	3 (100)	1 (9.1)

### Screening Scores

The mean HTQ score of the total sample was 1.73 (SD = 0.53). The mean HTQ score was 2.5 (SD = 0.17) for women diagnosed with PTSD, 2.35 (SD = 0.09) for women with subthreshold PTSD, and 1.45 (SD 0.33) for women without any trauma or stressor related disorder. Table 3 presents the results from part one of the HTQ which assesses experience of trauma events.

Table 3. Prevalence of trauma events (HTQ Part 1, n = 52) experienced by Dari speaking women of refugee background.

Trauma Event		Experienced n (%)	Witnessed n (%)	Heard about it n (%)	No n (%)
1	Lack of food or water	47 (90.38)	21 (40.38)	11 (21.15)	4 (7.69)
2	Ill health without access to medical care	9 (17.30)	21 (40.38)	13 (25.0)	15 (28.84)
3	Lack of shelter	16 (30.76)	18 (34.61)	10 (19.23)	14 (26.92)
4	Imprisonment	2 (3.85)	8 (15.38)	34 (65.38)	15 (28.85)
5	Serious injury	3 (5.77)	11 (21.15)	28 (53.85)	17 (32.7)

6	Combat situation	21 (40.38)	23 (44.23)	12 (23.08)	5 (9.62)
7	Brainwashing	0 (0)	8 (15.38)	19 (36.54)	25 (48.08)
8	Rape or sexual abuse	2 (3.85)	0 (0)	15 (28.85)	35 (67.31)
9	Forced isolation from others	3 (5.77)	16 (30.77)	14 (26.92)	26 (50.0)
10	Being close to death	2 (3.85)	29 (55.77)	21 (40.38)	6 (11.54)
11	Forced separation from family members	25 (48.08)	13 (25.0)	9 (17.3)	11 (21.15)
12	Murder of family or friend	11 (21.15)	2 (3.45)	25 (48.07)	21 (40.38)
13	Unnatural death of family or friend	11 (21.15)	2 (3.45)	25 (48.07)	21 (40.38)
14	Murder of stranger or strangers	1 (1.92)	9 (17.3)	39 (75.0)	9 (17.31)
15	Lost or kidnapped	0 (0)	1 (1.92)	24 (46.15)	34 (65.38)
16	Tortured	0 (0)	1 (1.92)	21 (40.38)	37 (71.15)
17	Any other situation that was very frightening or you felt that your life was in danger	0 (0)	0 (0)	0 (0)	0 (0)

<sup>a</sup> Participants are able to select more than one response to each item

### HTQ Screening Efficacy

Using a cut-off score of  $\geq 2.0$ , 19 women screened positive on the HTQ while 33 screened negative. Of those who screened positive, three women (15.8%) received a diagnosis of PTSD, while 16 (84.2%) did not. Of the 33 that screened negative, none received a diagnosis of PTSD. This resulted in a sensitivity of 1.00 (95% CI 0.3 – 1.00) and a specificity of 0.67 (95% CI 0.52 – 0.80).

Using a cut-off score of  $\geq 2.25$ , 15 women screened positive while 37 screened negative. Of those who screened positive, three women (20%) received a diagnosis of PTSD, while 12 (80%) did not. Of the 37 that screened negative, none received a diagnosis of PTSD. This resulted in a sensitivity of 1.00 (95% CI 0.29 – 1.00) and specificity of 0.76 (95% CI 0.61 – 0.87).

Using the recommended cut-off score of  $\geq 2.5$ , two women screened positive on the HTQ while 50 screened negative. Of those who screened positive, the two women (100%) received a diagnosis of PTSD. One woman screened negative on the HTQ and was diagnosed with PTSD. This resulted in a sensitivity of 0.67 (95% CI 0.09 – 0.99) and specificity of 1.00 (95% CI 0.93 – 1.00).

Table 4. Screening Efficacy of the HTQ for PTSD

HTQ Cut-Off Score	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)
$\geq 2$	1.00 (0.30 – 1.00)	0.67 (0.52 – 0.80)	0.16 (0.03 – 0.4)	1.00 (0.90 – 1.00)
$\geq 2.25$	1.00 (0.30 – 1.00)	0.76 (0.61 – 0.87)	0.20 (0.04 – 0.48)	1.00 (0.90 – 1.00)
$\geq 2.5$	0.67 (0.09 – 0.99)	1.00 (0.93 – 1.00)	1.00 (0.16 – 1.00)	0.98 (0.89 – 1.00)

A comparison of cut-off scores for detecting subthreshold PTSD versus no PTSD was also conducted. Of the 19 women who screened positive using a cut-off score of  $\geq 2.0$ , 11 women (57.9%) received a diagnosis of subthreshold PTSD. Of the 33 that screened negative, none received a diagnosis of subthreshold PTSD. This resulted in a sensitivity of 1.00 (95% CI 0.72 – 1.00) and a specificity of 0.80 (95% CI 0.65 – 0.91).

Of the 15 women who screened positive using a cut-off score of  $\geq 2.25$ , 11 (73%) women received a diagnosis of subthreshold PTSD. Of the 37 that screened negative, one woman (2.7%) received a diagnosis of subthreshold PTSD. This resulted in a sensitivity of 0.92 (95% CI 0.62 – 1.00) and a specificity of 0.90 (95% CI 0.76 – 0.97).

At the cut-off score of  $> 2.5$ , all of the women who met criteria for subthreshold PTSD screened negative on the HTQ. This resulted in a sensitivity of 0.00 (95% CI 0.00 – 0.30) and a specificity of 0.95 (95% CI 0.83 – 0.99).

Table 5. Screening Efficacy of the HTQ for subthreshold PTSD among Dari-speaking women

HTQ Cut-Off Score	Sensitivity (95% CI)	Specificity (95% CI)	PPV (95% CI)	NPV (95% CI)
≥2	1.00 (0.72 – 1.00)	0.80 (0.65 – 0.91)	0.58 (0.33 – 0.80)	1.00 (0.90 – 1.00)
≥2.25	0.92 (0.62 – 1.00)	0.90 (0.76 – 0.97)	0.73 (0.45 – 0.92)	0.97 (0.86 – 1.00)
≥2.5	0.00 (0.00 – 0.30)	0.95 (0.83 – 0.99)	0.00 (0.00 – 0.84)	0.78 (0.64 – 0.88)

## Discussion

This study investigated symptomatology and diagnoses of PTSD and subthreshold PTSD as well as the screening properties of the HTQ with a sample of Dari speaking women of refugee backgrounds seeking pregnancy care. There was a higher prevalence of subthreshold PTSD than PTSD, highlighting the importance of avoiding a reliance or sole focus on PTSD. Screening solely for PTSD risks underestimating the true demand for mental health services with the potential of neglecting a larger proportion of individuals, who although may fall short of the diagnosis, are experiencing distressing symptomatology.

The prevalence of PTSD was lower in our study (5.8%) than estimates provided by a recent systematic review (18.95%) which investigated perinatal PTSD in women of high-risk backgrounds (Yildiz et al. 2017). However, the studies included in the high-risk populations were predominantly focused on experiences of high-risk pregnancies or birth trauma. To our knowledge, this is one of the first studies to investigate perinatal PTSD with women of refugee background. With forcibly displaced populations increasing each year (UNHCR 2019), there is a critical need for accurate prevalence estimates.

The HTQ is considered the most widely-used screening measure of PTSD for refugee populations (Sigvardsson et al. 2016). Its psychometric properties have been well-established, however there is

some debate in regards to the optimal cut-off score. Originally, the recommended cut-off score of  $\geq 2.5$  was established by comparing screen scores to a clinical interview with a sample of 91 male and female refugees from South East Asia (Mollica et al. 1992). Some evidence suggests that a cut-off score of 2.0 may improve the performance in detecting cases (Silove et al. 2007). Our results suggest that a lowered cut-off score of  $\geq 2.25$  provides the best balance of sensitivity 1.00 (95% CI 0.29 – 1.00) and specificity 0.76 (95% CI 0.61 – 0.87) for PTSD diagnosis. However, at this cut-off the PPV is low and the wide confidence interval for sensitivity warrants caution with interpretation and further investigation using larger sample sizes. Our results suggest a cut-off score of  $\geq 2.0$  provides adequate screening for subthreshold PTSD.

Screening for perinatal depression and anxiety is recommended in clinical practice guidelines, yet despite the known risk there has been a lack of guidance on PTSD screening, particularly for women from refugee background (Austin et al. 2011; NICE 2018; Nithianandan et al. 2016). The combined prevalence of PTSD and subthreshold PTSD among women in this study justifies the need for routine perinatal PTSD screening with women of refugee background. The results highlight the importance of consideration of PTSD and the impact of trauma experiences when providing pregnancy care for this population of women, with the HTQ an appropriate starting point and adequate screening measure. Maternity services that provide care in areas of refugee and asylum seeker resettlement would benefit from integrating elements of trauma-informed care into their model of pregnancy care.

This study has several strengths. Firstly, a standardised clinical interview was conducted, and consensus diagnosis approach by a panel of experienced psychologists and researchers was used to determine diagnoses. Secondly, this process was conducted blind to the HTQ screening scores. The HTQ screening scores were compared to consensus clinical diagnosis according to DSM-5 criteria. We were able to include all possible eligible women as we engaged trained and experienced female healthcare translators. We have reported the number of women who declined to participate in the study, along with a comparison

of their screening scores on a common mental health screening measure used during pregnancy, the EPDS.

Despite these strengths, there are some limitations to this study. Even though the cohort of women came from one of Australia's largest maternity services, which serves a substantial migrant and refugee population, recruitment occurred at one clinic. This may limit the generalisability to the whole population of Dari speaking women. These findings contribute further knowledge to the limited literature on the mental health of women of refugee background during pregnancy. However, we acknowledge that the small sample size may have contributed to the wide confidence intervals for the sensitivity analyses of the HTQ, highlighting the need for further studies involving larger sample sizes. The HTQ, although it demonstrated adequate screening properties, is not gender specific and lacks recognition of events related to pregnancy and birth trauma, common for women experiencing forced displacement and transiting in refugee camps.

The HTQ has been revised to incorporate the changes to the diagnostic criteria of PTSD released with DSM-5. It would have been ideal to compare the results from the SCID DSM-5 to the screen scores from the HTQ-5 but the HTQ-5 was not available at the time of conducting this study. The HTQ-5 is undergoing reliability and validity testing in order to establish the optimal cut-off scores (Berthold et al., 2019). We hope the results from this study will help to inform the recommendation of cut-off scores for the HTQ-5 in order to allow for the screening and detection of PTSD and subthreshold PTSD.

## **Conclusion**

Women of refugee background have been exposed to a range of traumatic experiences and the impact of these experiences can disrupt their pregnancy journey and transition to parenthood. Identifying women at risk of PTSD as a result of refugee experiences is crucial in order to prevent ongoing difficulties throughout their pregnancy and to promote the best mental health outcomes for both mother and child. Consideration of subthreshold PTSD and its associated symptomatology needs to be included as part of

integrated maternity and perinatal mental health screening programs for women of refugee backgrounds. The application of optimal cut-off scores allows all women, including those who may fall short of meeting full diagnostic criteria but are experiencing impairment due to their symptoms, to access the appropriate intervention and support they require.

### **Declarations**

### **Funding**

The authors did not receive support from any organization for the submitted work.

### **Conflicts of interest/Competing interests**

The authors have no relevant financial or non-financial interests to disclose.

### **Ethics Approval**

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Monash University and Monash Health (14475L on 03/03/2015).

### **Consent to participate**

Informed consent was obtained from all individual participants included in the study.

### **Code availability**

Not applicable

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## **Chapter six: Implementing perinatal mental health screening**

### **6.1 Introduction**

Routine and universal screening for mental health disorders in pregnancy is recommended in the Australian Clinical Practice Guidelines.<sup>(17)</sup> Yet these recommended standards are often integrated to varying degrees into routine pregnancy services due to a number of systems-level and individual barriers. Some of the organisational barriers include a lack of knowledge from health professionals regarding administration and appropriate screening measures, additional time and organisational support to conduct screening, clear referral pathways, and skills in sensitively discussing mental health.<sup>(19)</sup> For women of refugee background, they face additional barriers to screening such as a lack of validated screening measures in their language, availability of face-to-face interpreters, and cultural stigma surrounding mental health.<sup>(19)</sup> Prior research which identified these key barriers to implementation informed the delivery of a pilot perinatal mental health screening program which was evaluated at a large public maternity service delivering care to a culturally diverse population of women, including women of refugee background.<sup>(19)</sup> In collaboration with the Centre for Perinatal Excellence (COPE), the objective of the manuscript presented in chapter six was to synthesise the strategies that were identified during the stages of implementation. The strategies were mapped to theoretical frameworks of behaviour change to allow for a greater understanding of the results and inform the development of an implementation guide. This guide can be used by health services within Australia and internationally to introduce and implement perinatal mental health screening using the COPE digital mental health screening platform.

**Manuscript five: Introducing and integrating perinatal mental health screening:  
development of an equity-informed evidence-based approach**

## **Abstract**

**Objective:** To develop a theory-informed, evidence-based guide for introducing and integrating perinatal mental health screening across health settings; and to synthesise the learnings from an implementation initiative and multi-sectoral partnership between the Centre of Perinatal Excellence (COPE), and a university-based research centre.

**Methods:** In this case study, barriers to implementation were prospectively identified and strategies to overcome them were developed. A pilot perinatal screening program with a strong health equity focus was implemented and evaluated at a large public maternity service delivering care to a culturally diverse population of women in metropolitan Melbourne, Australia, including women of refugee background. Strategies identified pre-implementation and post-evaluation were mapped to theoretical frameworks. An implementation guide was developed to support future policy, planning and decision-making by healthcare organisations.

**Findings:** Using a behavioural change framework (COM-B), the key barriers, processes, and outcomes are described for a real-world example designed to maximise accessibility, feasibility and acceptability. A program logic model was developed to demonstrate the relationships of the inputs, which included stakeholder consultation, resource development, and a digital screening platform, with the outcomes of the program. A seven-stage implementation guide is presented for use in a range of settings.

**Conclusion:** These findings describe an equity-informed, evidence-based approach that can be used by healthcare organisations to address common systems and individual level barriers to implement perinatal mental health screening guidelines.

## Introduction

Perinatal mental health has been acknowledged by the World Health Organization as a significant public health issue directly impacting maternal morbidity, obstetric outcomes, as well as infant development.<sup>1-4</sup> Associated long-term costs as a result of perinatal mental illness, including costs to healthcare, wellbeing, productivity, and intergenerational impact, have been assessed at \$5.2 billion in Australia<sup>5</sup> and £8.1 billion pounds per year in the UK.<sup>6</sup>

During the perinatal period, defined as conception to twelve months following birth, depression and anxiety are the most commonly experienced mental illnesses.<sup>7, 8</sup> For women from high-income countries, perinatal depression and anxiety is reported to affect up to 13%.<sup>9, 10</sup> For migrant and refugee women from low-and-middle-income countries, the prevalence is more than double this rate, with a pooled prevalence of 31% for any depressive illness.<sup>11</sup> Women of refugee background are at greater risk of mental illness during pregnancy, attributable to the conflict, trauma, and protracted situations of uncertainty which are hallmarks of refugee experiences.<sup>12</sup>

Routine screening in pregnancy for mental illness is recommended in countries such as the United Kingdom,<sup>13</sup> the United States of America<sup>14</sup> and Australia.<sup>2</sup> However, due to a number of barriers, implementation remains a common evidence-practice gap.<sup>15</sup> This represents a missed opportunity in best-practice pregnancy care resulting in the under-recognition of women at risk of mental illness. To improve health-equity, the barriers to screening must be addressed for all women, including those who experience additional barriers such as women of refugee background. Additional challenges when working with refugee populations can include availability of face-to-face interpreters, lack of translated measures, and cultural barriers such as the stigma of mental illness.<sup>15</sup>

The aim of this paper is to provide a synthesis of strategies to address the complex nature of implementation. A perinatal mental health program using a digital screening program implemented at a

public maternity service is presented as the exemplar, with relevance to services with refugee populations. Barriers and enablers to implementation were identified and further strategies were developed iteratively during implementation. An evaluation of the program yielded further refinements for large-scale roll-out. Here, we bring the learnings from each stage and interpret them together for the first time. This novel synthesis uses the Theoretical Domains Framework (TDF),<sup>16</sup> a Program Logic Model,<sup>17</sup> and The Capability, Opportunity, Motivation – Behaviour Model (COM-B).<sup>18</sup> Concurrent with the implementation and evaluation of this program, a perinatal mental health screening implementation guide was developed to further assist health services implement perinatal mental health guidelines in their specific context.

## **Methods**

### **Setting**

We used a case study approach<sup>19</sup> to describe how the perinatal mental health screening program was implemented. The protocol for the evaluation of this program has been published elsewhere.<sup>20</sup> The study was conducted at an antenatal clinic within a public hospital in Melbourne, Australia which is home to a large refugee population.

### **Implementation Strategy Development**

The implementation strategies were informed by formative research. This involved interviews with health professionals (n = 28) and women of refugee background (n = 9).<sup>15</sup> The results identified barriers and enablers using the Theoretical Domains Framework (TDF).<sup>15, 16</sup> A steering committee was then formed to facilitate implementation. The committee comprised of hospital clinicians and managers, refugee health professionals, GP liaison, the Centre of Perinatal Excellence (COPE), and academic experts in psychology, midwifery, obstetrics, and public health. This committee met fortnightly for two years to implement and evaluate the program. A community advisory group was also formed and comprised of women from eight different countries, some of refugee backgrounds, with most having

recently had a baby at the health service. This committee met bi-monthly and was instrumental in facilitating an understanding of cultural complexities.

The acceptability and feasibility of the perinatal mental health screening program was evaluated from the perspective of the health professionals and women of refugee background. A mixed methods approach was undertaken, whereby health professionals completed a survey (n = 38), focus groups (n = 2, 13 participants), and semi-structured interviews (n = 8, 11 participants) (21). The evaluation was guided by the Normalization Process Theory (NPT).<sup>22</sup> The perspectives of women of refugee background was evaluated using focus groups (n = 1; 5 participants) and telephone interviews (n = 17).<sup>23</sup> The evaluation findings led to the development of strategies required for program refinement and scale-up. In the synthesis presented here, these strategies are described and interpreted using implementation theories and behaviour change frameworks for the first time.

## **Synthesis Process**

Three frameworks were used to better understand the relationships between barriers and strategies, inputs and outcomes associated with implementing perinatal mental health screening.

### **1. Theoretical Domains Framework (TDF)**

The TDF is an integrated framework of theoretical constructs that are related to behaviour change.<sup>16</sup> The TDF was used to map the strategies and barriers devised before, during, and after implementation.

### **2. Program Logic Model**

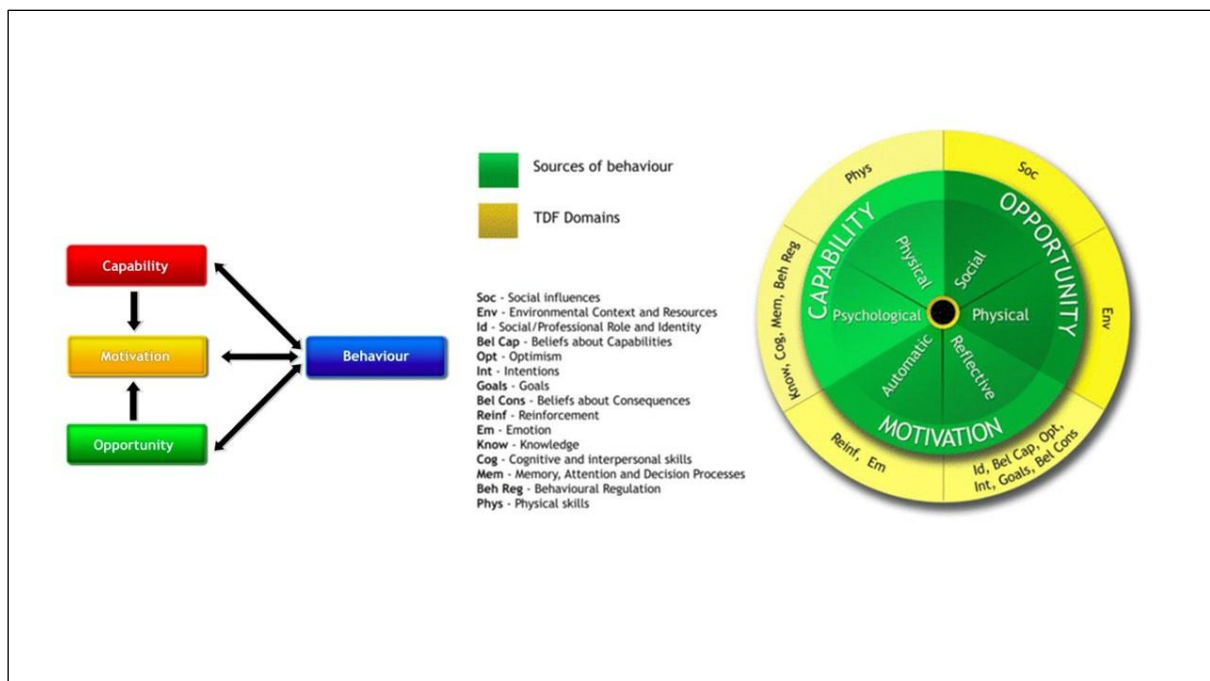
A program logic model was developed to demonstrate the relationships of the inputs, outputs, and outcomes of the program.<sup>17</sup> Logic models are useful in evaluating how outcomes are produced by processes (inputs), however a logic model alone is not sufficient to capture the dynamics of complex

interventions.<sup>24</sup> Therefore, the theoretical framework of the COM-B model was applied to understand the requirements for behaviour change.

### 3. The Capability, Opportunity, Motivation – Behaviour Model (COM-B)

The Capability, Opportunity, Motivation, Behaviour (COM-B) model is part of the Behaviour Change Wheel (BCW).<sup>18</sup> It proposes that for someone to engage in a behaviour, they must be physically and psychologically able (capability), have the social and physical opportunity to do the behaviour (opportunity), and want to do the behaviour more than other competing behaviours (automatic and reflective motivation).<sup>18</sup> As each of the TDF domains relates to a component of the COM-B model (Figure 1 and Table 1), when incorporated together this provides greater understanding of behaviour change to improve implementation.

Figure 1. Map of Theoretical Domains Framework (TDF) to the COM-B model. Figure reproduced from Alexander et al. 2014.<sup>25</sup>



## **Developing an Implementation Guide: Translation of Evidence into Practice**

The Centre of Perinatal Excellence (COPE) was represented on the steering committee from the screening program's inception. COPE is a peak body in perinatal mental health and the Non-Governmental Organization commissioned to update the Australian national perinatal mental health guidelines and rollout innovative digital screening across healthcare settings. Based on the learnings from this pilot screening program, as well as implementation of the digital platform across other healthcare settings, COPE has developed a guide to assist healthcare services in implementing perinatal mental health screening.

## **Results**

Some barriers and enablers to perinatal mental health screening were identified prior to implementation and mapped to the TDF previously.<sup>15</sup> Here we build on the pre-implementation mapping to describe and interpret barriers identified at all three stages and the strategies devised to address said barriers, using the TDF domains: knowledge and skills, social/professional role and identity, beliefs about capabilities and consequences, environmental context and resources, social influences, and behavioural regulation.

## **Identified Barriers and Strategies for Implementation**

### **Knowledge and Skills**

#### **Pre-implementation barriers**

Health professionals acknowledged the importance of routine antenatal mental health screening. However, a lack of knowledge and skills regarding screening measures, administration and scoring, and the specific mental health needs of women of refugee background was identified as a barrier.<sup>15</sup>

### Pre-implementation strategies

Training for all staff in the antenatal clinic was delivered. Members of the research team (a midwife and two psychologists) provided training on perinatal mental health, the Edinburgh Postnatal Depression Scale (EPDS), use of the digital platform iCOPE, referral pathways, and the health needs of women of refugee background. Midwives were also provided access to an online perinatal mental health course delivered by COPE.

### Strategies developed during implementation

Existing weekly staff meetings were used to discuss process issues as they arose, facilitating a collaborative approach and shared decision-making responsibilities for managing issues, challenges, as well as noting successes.

## **Social/professional role and identity**

### Pre-implementation barriers

Health professionals identified the need for a “go-to” person within the service, with perinatal mental health and refugee health expertise, to support staff and women in screening and referral.<sup>15</sup>

### Pre-implementation strategies

Collaborating with the organization’s refugee health service by including the manager as a member of the project steering committee enabled the mobilization of key personnel. A Refugee Health Nurse Liaison (RHNL) supported staff in the clinic and a bi-cultural worker telephoned women prior to their appointment to introduce the research project as well as asking them to attend 15 minutes earlier to complete screening.

## **Beliefs about capabilities**

### Pre-implementation barriers

Health professionals recommended the need for an efficient screening process as there were concerns regarding existing time pressure.<sup>15</sup> These time pressures could potentially contribute to errors when manually calculating EPDS scores.<sup>26</sup>

#### Pre-implementation strategies

The digital screening platform, iCOPE, developed by the Centre of Perinatal Excellence (COPE) was designed to improve efficiency of mental health screening.<sup>27</sup> It takes approximately 6 – 10 minutes to complete, slightly longer if an interpreter is used. On completion, healthcare professionals received a clinical report automatically calculating scores, eliminating scorer error. The report included a clinical management guide to assist discussion of results. The iCOPE program also generated a score based, language appropriate report for women post screening with links to further information.

#### Strategies developed during implementation

During implementation, “organisational champions” were recognized and fulfilled the role of engaging their colleagues and facilitating a supportive practice environment. Senior managers were regularly updated throughout implementation. This included the acknowledgement that added time may be required to complete antenatal appointments during the early implementation phase whilst staff familiarised themselves with the new program.

### **Beliefs about consequences**

#### Pre-implementation barriers

The stigma surrounding the disclosure of mental illness and interpreter confidentiality were both described as barriers to screening.<sup>15</sup>

#### Pre-implementation strategies

All staff received training on how to introduce mental health screening, sensitively presenting options for mental health services, and the use of non-threatening and culturally appropriate terminology. Referral options included a refugee health service which was multidisciplinary and culturally competent. A small and consistent group of interpreters worked within the clinic which contributed to building trust among the women.

#### Strategies developed during implementation

Further targeted training was deemed necessary in order to support midwives in administering item 10 on the EPDS which assesses for self-harm and suicidality. Further training was arranged with flowcharts provided for clear referral pathways to manage positive responses to item 10.

### **Environmental context and resources**

#### Pre-implementation barriers

It was agreed by health professionals that phone interpreters were inappropriate for mental health screening.<sup>15</sup> Health professionals identified the importance of translated screening measures but raised concerns over the quality of translations available.<sup>15</sup> Literal translation of the EPDS can be problematic and best practice translation process involves forward and back translation and testing.<sup>28</sup>

#### Pre-implementation strategies

After identifying the key languages of the women attending the clinic, existing validated EPDS translations were obtained and new translations were conducted using best-practice methods.<sup>28</sup> For one identified language, Dari, the investigation of the reliability and validity of this version formed an additional part of the program. The clinic provided face-to-face interviews with female interpreters, experienced in maternity care and perinatal mental health screening.

#### Barriers arising during implementation

Women with low literacy were not able to complete self-administered screening. The Burmese EPDS version was unable to be loaded on the digital screening platform due to technical issues associated with the script.

#### Strategies planned for scale-up

The provision of translated audio versions of the EPDS will allow women with low literacy and those whose preferred language is Burmese to have the option of self-administration.<sup>21, 23</sup>

### **Social influences**

#### Pre-implementation

Women of refugee background often lack the social supports that most women and families rely on during pregnancy. Therefore, continuity of care was identified as important for building rapport and facilitating disclosure between the women and their healthcare professionals.<sup>15</sup>

#### Barriers arising during implementation

Due to staffing constraints experienced in most public antenatal clinics, continuity of care can be challenging. Regular staff turnover in the clinic meant there was an ongoing need to ensure new staff received training and support to include screening as part of their routine practice.

#### Strategies developed during implementation

The presence of a “go-to” person such as the Refugee Health Nurse Liaison (RHNL) acted to assist staff with screening and women with referrals and follow-up. The RHNL fulfils the role of regular clinic contact for staff and women when there is a need to discuss mental health services and referrals. The “organisational champions” were critical in maintaining enthusiasm for the program and engaging new staff.

## **Behavioural regulation**

### **Pre-implementation**

Health professionals identified a need for immediate follow up for positive responses to the screening questions on self-harm and suicidality.<sup>15</sup> Clear referral guidelines were requested in clinic rooms to ensure appropriate referrals.<sup>15</sup>

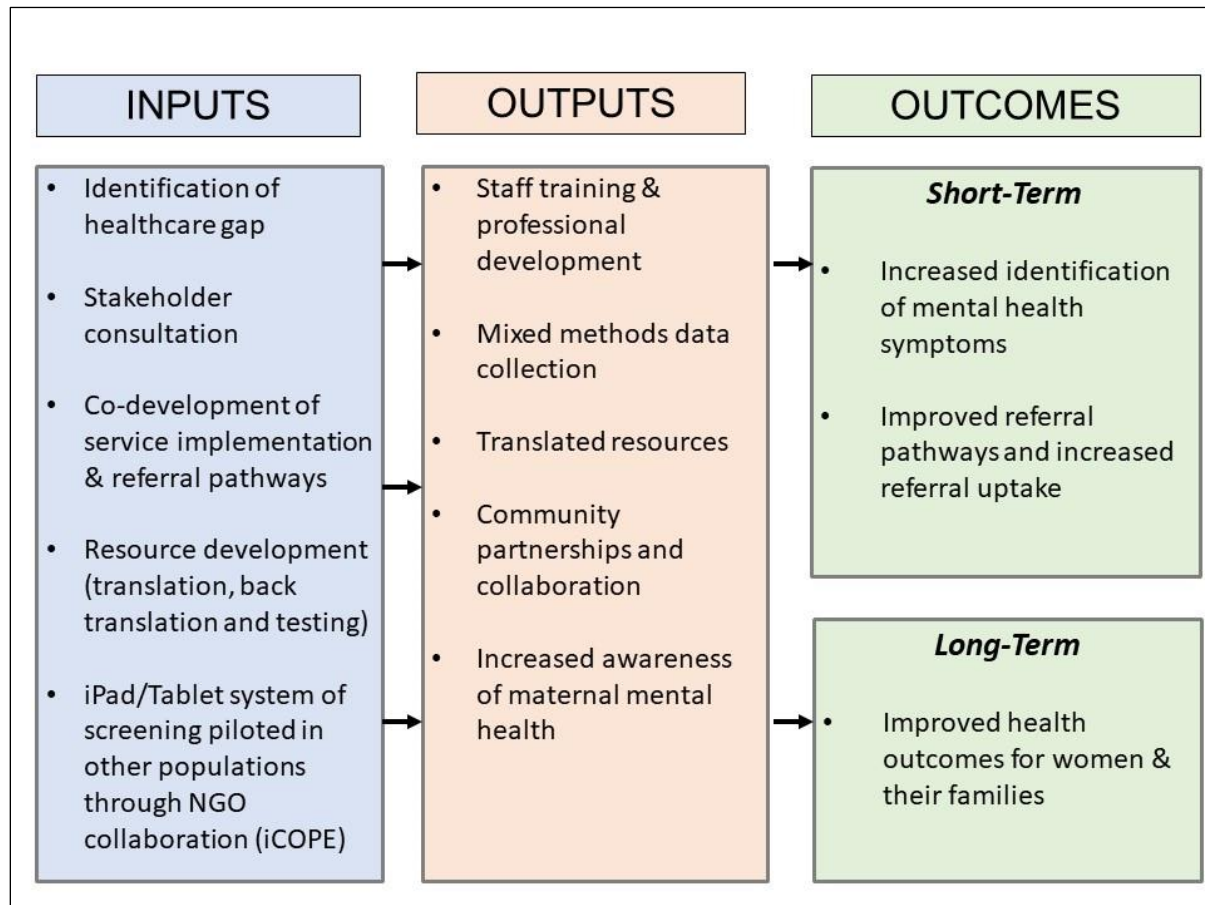
### **Strategies developed during implementation**

Referral pathways were co-designed by the steering committee with options for both women of refugee or non-refugee backgrounds. Stakeholder consultation identified relevant refugee health services within the community. Flowchart diagrams were developed in order to ensure a clear process for referrals including appropriate management of self-harm and suicidality risk.

## **Program Logic Model**

The logic model (Figure 2) describes all of the featured elements (inputs and outputs) that were involved in implementing the perinatal mental health screening program along with the proposed short- and long-term outcomes.

Figure 2. Logic model of the perinatal mental health screening program



### The Capability, Opportunity, Motivation – Behaviour Model (COM-B)

Using the behavioural change framework of the COM-B model, the key barriers, processes, and outcomes are described.<sup>18</sup> The application of this framework highlights the importance of a multi-strategy approach to behaviour change which delivers strategies that address the multiple factors at play.

Table 1. Applying the COM-B model to the creation of a perinatal mental health screening program

<b>Capability</b>	<b>Motivation</b>	<b>Opportunity</b>
An individual's physical (skills, strength, stamina) and psychological (knowledge, psychological skills) capacity to engage in the behaviour.	Processes that affect ability to do the behaviour at the required time  Motivation is reflective (self-conscious planning) and automatic (processes related to wants and needs, desires).	Factors that affect the behaviour in the context of the environment; physically (time, triggers, resources, physical barriers) and socially (interpersonal influences, social cues, cultural norms).
<p><b><u>Psychological Capability</u></b></p> <p><b>Knowledge:</b></p> <ul style="list-style-type: none"> <li>• Knowledge on how to implement best-practice antenatal care (clinical guidelines)</li> <li>• Knowledge and experience of mental health screening measures (e.g. staff training)</li> </ul> <p><b>Behavioural regulation:</b></p> <ul style="list-style-type: none"> <li>• Follow-up of (short and long-term) of women as a result of screening practices</li> <li>• Clear referral guidelines (e.g. referral flowcharts available in clinic rooms)</li> </ul>	<p><b><u>Reflective Motivation</u></b></p> <p><b>Beliefs about consequences:</b></p> <ul style="list-style-type: none"> <li>• Small group of trained and experienced interpreters (e.g. ensuring confidentiality and consistency)</li> <li>• Sensitive approach to screening to reduce stigma surrounding disclosure of mental health symptoms</li> <li>• Screening introduced as part of normal routine antenatal care and for all women</li> </ul> <p><b>Beliefs about capabilities:</b></p> <ul style="list-style-type: none"> <li>• Efficient screening process (e.g. iCope platform)</li> </ul>	<p><b><u>Physical Opportunity</u></b></p> <p><b>Environmental context &amp; resources:</b></p> <ul style="list-style-type: none"> <li>• Availability of face-to-face interpreters</li> <li>• Interpreters experienced and trained in mental health and EPDS</li> <li>• High-quality translated screening measures</li> <li>• Time-efficient screening (e.g. self-administration)</li> <li>• Privacy for screening (e.g. self-administration)</li> </ul>

	<ul style="list-style-type: none"> <li>• Clear referral process (e.g. staff training)</li> <li>• Onsite support staff (e.g. identification of organisational “champions”)</li> </ul>	
<p><b><u>Physical Capability</u></b></p> <p><b>Skills:</b></p> <ul style="list-style-type: none"> <li>• Training in the “How to” of screening, recognition of symptoms, referral pathways</li> <li>• Understanding of refugee experiences and specific health needs</li> </ul>	<p><b><u>Automatic Motivation</u></b></p> <p><b>Social/Professional Role &amp; Identity:</b></p> <ul style="list-style-type: none"> <li>• “Go-to” person for staff and women in supporting access to referrals and follow-up</li> <li>• Bi-cultural worker to assist with the introduction of screening to women and improve cultural appropriateness</li> </ul>	<p><b><u>Social Opportunity</u></b></p> <p><b>Social influences:</b></p> <ul style="list-style-type: none"> <li>• Identifying potential social supports for women of refugee background</li> <li>• Continuity of care in the clinic to facilitate honest discussions and referral uptake (e.g. “go-to” person)</li> </ul>

## Implementation Guide

The iCOPE digital platform, developed by the Centre of Perinatal Excellence (COPE), was designed to facilitate mental health screening in healthcare settings during pregnancy by ensuring accurate interpretation of screening measures in accordance with international clinical guidelines.<sup>27</sup> COPE was involved in all stages of the pilot screening program from design through to delivery, including involvement in the steering committee and evaluation of the program. Based on the experiences of this pilot program as well as implementation of their digital screening platform across other healthcare settings, they have developed an implementation guide to assist healthcare services in implementing perinatal mental health screening (Figure 3).

Figure 3. COPE Implementation Guide for Perinatal Mental Health Screening



## Implementation Guide

The iCOPE Digital Screening Program has been successfully implemented across a range of maternity settings. This brief seven-step guide is designed to help you define WHAT your program may look like and HOW to get people engaged and invested in implementing digital screening within your service.

- 1

**Start with the why**

People need reasons to change behaviour, fund or spend time on improving clinical practice. Take time to define why iCOPE digital screening is important and help people clearly understand what's in it for them and their patients. They will be more excited about helping.
- 2

**Mobilise the right leadership**

Implementation is a social process that relies on people to drive commitment. Enlist support from influential leaders from key disciplines who will guide, make decisions, learn, share, actively problem solve, and stay involved to make the iCOPE happen.
- 3

**Take a collaborative, interdisciplinary approach**

People are more likely to support what they help create. Invite representatives likely to be impacted by iCOPE screening (e.g. midwives, allied health, administrative staff, medical records and IT teams) to be involved. Enlist their ideas and help them to understand how iCOPE screening impacts them and how you can work together.
- 4

**Define your Clinical Program**

Each setting is different. iCOPE can be tailored to support your setting, clinicians and patients. Our team will support as you plan to implement iCOPE into your screening schedules, patient cohorts, record keeping systems, communication channels and and referral pathways.
- 5

**Do the 'techy' Stuff**

While implementing iCOPE is not difficult, optimal outcomes are achieved with IT integration. If this is your goal, our team will work closely with your IT representatives to enable clinical reports to be seamlessly integrated into existing electronic health record systems.
- 6

**Prepare people**

To achieve lasting change in clinical practice, consistency is key. Once you've raised awareness and desire to participate, help teams get ready by equipping them with the knowledge, skills, support tools and mentoring to help them confidently deliver iCOPE screening. We will assist in the provision of learning materials to prepare your people.
- 7

**Monitor, Evaluate & Improve**

Ongoing evaluation is an integral part of any quality care initiative. It helps clearly define your desired outcomes at the outset, and decide how and when you'll measure success. By collecting baseline data of your current practice and then continuing to monitor results, you can assess and adjust your program as needed.

The Prime Minister's commitment to a Perinatal Mental Health Check.  
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Further information regarding each of these steps can be found at:

<https://www.cope.org.au/hospital-to-home/>

## Discussion

In order to identify women at risk of perinatal mental illness, there is a need to develop screening programs, grounded in behaviour change theory, which can be delivered across a range of antenatal care settings and with refugee and multicultural populations. To improve health-equity in perinatal care, the barriers to implementation must be addressed for all women, including those who experience additional barriers such as women of refugee background. This case study provided a valuable opportunity to study how a healthcare organisation, in partnership with research and an NGO, could implement screening that is appropriate for a population with complex health and wellbeing needs.

To date, routine perinatal mental health screening has been inadequately implemented creating a critical gap in maternity health care.<sup>29</sup> The implementation of screening programs within antenatal services is often inconsistent as it requires action from different departments within the health service and across disciplines of health professionals. These findings highlight the importance of a multi-strategy approach and how successful implementation involves delivering strategies that address all of the multiple factors involved. The results from this study aim to reduce the barriers to screening based on the requirements for behaviour change; *capability* (e.g. staff training, onsite support, clear referral pathways), *opportunity* (e.g. time efficient screening, self-administration, high quality translations of screening measures) and *motivation* (e.g. consistent group of interpreters and sensitive approach to screening).<sup>18</sup>

This case study has a number of strengths. The antenatal clinic was chosen due to its location within a large multicultural and refugee population. The learnings from the implementation of the screening program within this setting are generalisable to other health service settings, particularly those with diverse populations. Ongoing stakeholder involvement facilitated co-design and an ability to evolve as challenges arose. The use of a theory informed approach enabled a detailed approach to program design. Despite the many learnings this program can provide for other health services, it remains a case study and further adaption will be required when implementing this approach within other settings.

Pregnancy is a time of increased likelihood of experiencing mental illness. Women of refugee background are at even greater risk of mental illness during this period. Therefore, mental health screening during the perinatal period is critically important in order to achieve the best health outcomes for women. Implementation of perinatal mental health screening has historically been limited due to a number of health service and individual barriers. There is support for screening from both women of refugee background and health professionals.<sup>15, 21, 23</sup> With the provision of access to digital screening, together with this implementation guide informed by prior research, health services will be better equipped to plan their implementation.

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## **Chapter seven: Discussion, recommendations and conclusions**

### **7.1 Summary of findings**

This PhD program of research had two overall aims. The first was to generate new knowledge about the prevalence of common mental health conditions in refugee and asylum seeker populations. The second was to contribute to improved health care by addressing barriers to mental health screening, related to assessment and implementation, during the perinatal period for women of refugee background.

#### **7.1.1 Systematic reviews**

The results from the systematic review on the prevalence of mental illness in adult refugees and asylum seekers indicated high rates of mental illness, in particular PTSD 31.46% (95% CI 24.43 – 38.5) and depression 31.5% (95% CI 22.64 – 40.38), with both of these illnesses persisting for many years post-displacement. This suggests ongoing suffering from mental illnesses in the post-migration environment which may be associated with a number of complexities such as isolation, limited opportunities to contribute financially and socially to their new communities, and adjustment to life in a foreign country.(20) However, this was not the case for the prevalence of anxiety disorders, which we found to be higher among those displaced less than four years. Generally, within refugee mental health literature, anxiety disorders are less frequently examined, with a heavy emphasis on PTSD. Overall, only 11 studies reporting data on anxiety prevalence met the inclusion criteria for this review, and of those 11, only six assessed the full range of DSM anxiety disorders. This was compared to 22 studies which were included for PTSD and 17 for depression. The results from this review contribute to an expansion of the current evidence base by not only focusing on PTSD but reporting prevalence for depression, anxiety, and psychosis.

The prevalence of PTSD varies according to sex and trauma type,(15) however there was a lack of sex data reported for the outcomes in the included studies. The search strategy returned no studies of pregnant women, which may reflect limitations of the search strategy which did not include any gender specific search terms. This is a major limitation of the current literature as during times of conflict, women face risks associated with migration trauma such as safety concerns, child-rearing pressures, and exploitation but particularly greater risk of sexual violence which is an established risk factor for developing PTSD.(14, 15, 39)

The results from the systematic review on the prevalence of mental illness in child and adolescent refugees showed higher rates of PTSD, depression, and anxiety. PTSD, depression, and anxiety disorders were all higher for those displaced less than two years. The findings build upon the previous systematic review by Fazel(11) by providing updated prevalence estimates, not just for PTSD but also for depression, anxiety, ADHD, and ODD, which does suggest some growth in the field since this last major review. However, despite almost half of the world's current refugee and asylum seeker population being under the age of 18 years,(1) this review identified a limited number of high-quality studies (n = 8) providing prevalence estimates of mental illness within child and adolescent refugee populations. This limits the precision of the estimates generated by this meta-analysis, as well as highlighting this population as underrepresented in the research literature.

To the best of our knowledge, these were the first systematic reviews which placed very few limits on refugee characteristics, but imposed strict inclusion criteria regarding the method of determining diagnoses in order to include high-quality, rigorous mental illness data. Previous reviews on the topic had lacked an investigation into the full breadth of mental illness or focused on only one country of origin or region. These reviews aimed to overcome some of the methodological limitations of the current body of evidence, and to establish new estimates of mental illness in these populations. With the aim of including all possible refugee populations, this

was a factor in the resulting high heterogeneity that was present in the prevalence estimates. Despite this, these estimates provide an updated foundation for progression within the field (discussed in 7.3 Future Directions). Researchers can use these results to assist with the development and evaluation of culturally appropriate mental health support and interventions.

### **7.1.2 Perinatal mental health and women of refugee background**

Despite a consistent acknowledgement that factors associated with refugee experiences can contribute to the development of mental illness during pregnancy; there is a lack of research on this topic amongst refugee populations.(26) Screening for perinatal depression and anxiety is recommended in clinical practice guidelines,(17) however one barrier to screening for women of refugee background is a lack of validated screening measures in languages from refugee source countries. The third manuscript from this PhD investigated the prevalence and severity of depression and anxiety symptoms as well as the psychometric properties of a well-used screening measure, the Edinburgh Postnatal Depression Scale (EPDS), with a Dari speaking population of women of refugee background.

### **7.1.3 Perinatal depression and anxiety**

The results showed that a high proportion of women in this study met DSM-5 criteria for a current depressive or anxiety disorder, highlighting the importance of mental health screening during pregnancy and the value of having a validated Dari version of the EPDS. These results are consistent with the current body of literature which suggests that perinatal depression and anxiety is more prevalent in women of refugee background compared to women from non-refugee populations.(26) The results from this study contribute to addressing a gap in the field where there

is a lack of prevalence data, particularly on perinatal anxiety, for women of refugee background, however further large studies are required to increase generalisability and expand the field.(26)

#### **7.1.4 Performance of the Dari version of the EPDS**

The Dari translation of the EPDS showed favourable sensitivity and specificity characteristics in its ability to detect both depression and anxiety. Applying the optimal cut-off score during administration of the EPDS is vital in identifying women at risk of depression and anxiety. The results from the comparison of cut-off scores support the use of the lowered cut-off score of  $\geq 9$ , which is recommended for culturally and linguistically diverse groups.(40) The results raised some issues with the performance of a few items on the EPDS; items 2, 7, and 10. Item 2 asks whether respondents “*have looked forward with enjoyment to things*”; item 7 asks whether the respondent has been “*so unhappy they have had difficulty sleeping*”; and item 10 assesses risk of self-harm by asking “*the thought of harming myself has occurred to me*”, which is critical in determining the need for an acute referral. It is possible that issues with translating may have resulted in the poorer performance of these items, as compared to the other items on the EPDS. Poorer performing items are an important consideration for both health professionals and interpreters when administering this translated version of the EPDS. Clinical judgement and further discussion with the woman around responses to these items, particularly item 10, is critical to ensure appropriate risk assessment and referral can occur. However, as previously reported health professionals can be reluctant to address issues of self-harm and suicidality, mostly related to a lack of confidence, training, and skills in risk assessment.(19) As demonstrated in the implementation of the perinatal screening program, featured in this thesis, adequate staff training and ongoing professional development in the area of mental health risk assessment and referral is crucial.

To the best of our knowledge, this was the first study to investigate the clinical utility of administering the EPDS for screening during pregnancy with Dari speaking women. This study

further the existing body of literature on EPDS translations by providing results on the psychometric properties of the Dari translation and validates it for use with Dari speaking women. With the continued increase in global numbers of refugees, combined with the specific vulnerabilities faced by these populations of women during pregnancy, providing refugee perinatal mental health care should be a priority for the health services of resettlement and host nations.(26) Overall the EPDS Dari version is a valid and reliable screening measure which will assist women of refugee background in accessing screening, reducing reliance on the use of interpreters, and improving privacy during screening. If screening can be provided with simple, translated, and validated measures, such as the EPDS, then a major barrier to improving health-equity and access to mental health care for this population of women can be potentially addressed.

#### **7.1.5 Perinatal PTSD and women of refugee background**

Identifying women at risk of experiencing PTSD during pregnancy is critical in order to achieve the best mental health outcomes for women and their children. Refugee and asylum seeker women have been exposed to a range of traumatic experiences including loss and displacement, sexual violence, and separation from culture and supports.(21) Those with trauma related symptoms are at risk of ongoing difficulties in their psychological experience of pregnancy as well as further impact on infant development due to exposure to high levels of trauma related hormones *in utero*.(41) This suggests there is a need for better identification of these factors in refugee and asylum seeker women seeking pregnancy care. The fourth manuscript from this PhD investigated the rates of symptomatology and diagnoses of PTSD and subthreshold PTSD as well as the screening properties of the Harvard Trauma Questionnaire (HTQ) with a sample of women from refugee backgrounds receiving antenatal care at a public pregnancy clinic.

The women participating in this study reported multiple traumatic events as a result of their refugee experiences. Additionally, this study found a higher prevalence of subthreshold PTSD

(21.15%) compared to PTSD (5.8%). The prevalence of PTSD was lower in our study than estimates from a recent systematic review (18.95%) which investigated perinatal PTSD in women of high-risk backgrounds.(42) However, the studies included in that systematic review predominantly focused on women who had experienced high-risk pregnancies or birth-related trauma, meaning that the prevalence may not be generalisable to women at risk of PTSD from other events. To date, much of the literature on perinatal mental health has focused on depression.(25) A systematic review of migration and perinatal mental health in women from low-and-middle-income countries concluded that there were insufficient studies to estimate the prevalence of perinatal PTSD, highlighting the under-investigation of this topic.(26) The results from this study contribute to a progression in knowledge regarding an identified gap in the literature.

#### **7.1.6 The Harvard Trauma Questionnaire**

The HTQ is the most widely-used screening measure for PTSD when working with refugee populations.(43) Its psychometric properties have been well-established. The HTQ has been developed specifically for adult refugee populations and is a cross-culturally valid measure. However, it has not been designed specifically for use during pregnancy and lacks consideration of aspects of the perinatal period. In contrast to the Edinburgh Postnatal Depression Scale, the Harvard Trauma Questionnaire (HTQ) is not universally recommended as a trauma screener during the perinatal period, however there is currently a lack of clinical guidance for healthcare workers on which trauma measure should be used during the perinatal period. The HTQ was selected for use in this study not only based on its psychometric performance but because it is also an accessible measure for healthcare services which allows for ease of implementation. There also continues to be some debate about the optimal cut-off score. There is some evidence to suggest that lowering the cut off score from 2.5 to 2.0 may improve case detection.(44) Our

results suggest that a cut-off score of  $\geq 2.25$  provides the best balance of sensitivity and specificity. In order to identify subthreshold PTSD, our results suggest it is a cut-off score of  $\geq 2.0$  which provides optimal screening performance.

It is critical that health professionals working with women of refugee background acknowledge the potential impact of subthreshold PTSD symptomatology on the pregnancy experience and therefore include it as part of perinatal mental health screening. There is clear recognition of the importance of perinatal mental health screening, including PTSD, amongst health professionals working in antenatal care for women of refugee background.<sup>(19)</sup> The combined prevalence of PTSD and sub-threshold PTSD among women in this study suggests that routine perinatal PTSD screening is warranted for women of refugee background, and that the HTQ is an adequate starting point and appropriate measure to use. Maternity services that provide care in areas of refugee and asylum seeker resettlement would benefit from integrating elements of trauma-informed practice into their model of pregnancy care, which includes training for staff in trauma-informed care and establishing referral pathways to respond appropriately to screening results.

### **7.1.7 Implementing perinatal mental health screening**

There is a need to develop a theory-informed, evidence-based guide for introducing and integrating perinatal mental health screening, which can be delivered equitably and consistently across many antenatal primary care settings. The final manuscript presented in this thesis delivered a synthesis of the strategies developed to address the identified barriers as part of a pilot perinatal mental health screening program using a digital screening platform. The program was implemented and evaluated at a large public maternity service delivering care to a culturally diverse population of women in metropolitan Melbourne, Australia, including women of refugee background. Barriers and enablers to implementation were identified through formative research and further strategies were developed iteratively during implementation.<sup>(19)</sup>

The learnings from each stage of the design and implementation of the program were brought together and interpreted for the first time. This novel synthesis applied the Theoretical Domains Framework (TDF),(45) a Program Logic Model,(46) and the Capability, Opportunity, Motivation – Behaviour Model (COM-B).(47) Concurrent with the implementation and evaluation of this program, a perinatal mental health screening implementation guide was developed to further assist health services implement perinatal mental health guidelines in their specific context.

The behavioural change mechanisms of the COM-B model proposes that for someone to engage in a behaviour, they must be physically and psychologically able (*capability*), have the social and physical opportunity to do the behaviour (*opportunity*), and want to do the behaviour more than other competing behaviours (*automatic and reflective motivation*).(47) For *capability*, the program delivered various modes of training to ensure staff had the knowledge and skills to conduct perinatal mental health assessment and screening. Ongoing training and onsite support staff, such as the “organisational champions”, were integral to maintaining enthusiasm for the program. Co-designed and appropriate referral pathways were readily accessible in clinic rooms as well as clear follow-up procedures for women post-screening. For *opportunity*, there was time efficient and self-administered screening, leading to enhanced privacy as delivered by the iCope digital screening platform.(48) Additionally, the availability of face-to-face interpreters, experienced in healthcare settings and specifically maternity care, further ensured screening could take place. As requested by healthcare professionals reliable and high-quality translations of the Edinburgh Postnatal Depression Scale (EPDS) were sourced and made available for women in the clinic. Finally, for *motivation* the provision of a small group of consistent interpreters within the clinic contributed to a sense of trust and confidentiality. Staff were trained to introduce and deliver mental health screening sensitively and as part of routine perinatal care.

To date, routine perinatal mental health screening has been inadequately implemented creating a critical gap in maternity health care.(49) The implementation of screening programs within antenatal services is often inconsistent as it requires action from different departments within the health service and across disciplines of health professionals. Our findings highlight the importance of a multi-strategy approach and that successful implementation is not possible without delivering strategies that address the multiple factors at play. Despite the many learnings this program provides, it remains a case study and further tailoring and adaption may be required when implementing this approach within other antenatal settings.

## **7.2 Implications of the findings**

These findings contribute new knowledge to the field of refugee mental health as the studies were designed based on identified gaps within the research literature. The results from both of the systematic reviews highlighted that all ages of refugees and asylum seekers appear to have high rates of mental illness. These results provide updated prevalence estimates to assist with greater understanding of the magnitude of this global public health issue. These results can inform host nations and health systems in the planning and provision of immediate and ongoing mental health care, as well as highlighting the critical need to effectively screen individuals arriving into countries for resettlement in order to achieve early identification for mental health intervention.

The remaining studies from this PhD deliver findings which have implications for how perinatal mental health screening for refugee and other complex populations can be implemented in clinical practice within healthcare settings in Australia and internationally. To improve health-equity in perinatal care, the barriers to implementation must be addressed for all women, including those who experience additional barriers such as women of refugee background. This research has

contributed one more validated language version of the EPDS, which is of critical relevance as Afghanistan continues to be one of the largest global refugee populations.(1) The results provide further support for the use of the recommended lowered cut-off score of  $\geq 9$  when screening women of refugee background.(40) Applying the cut-off score of  $\geq 13$ , recommended for the general population, resulted in a concerning number of false negatives; applying one cut-off score across a multicultural service population may limit the efficacy of mental health screening programs during pregnancy.

Prior to undertaking this research, there was a lack of literature on perinatal PTSD for women of refugee background.(26) There was also a lack of guidance for healthcare providers about whether PTSD screening is warranted for women of refugee background and the performance of refugee-appropriate PTSD screening measures to ensure these at-risk populations of women can be identified.(19) The investigation of the performance of the most widely used trauma screening measure for refugee populations, the HTQ, assists with addressing a current gap in clinical knowledge.(43) These results have highlighted the importance of avoiding a reliance or sole focus on PTSD, as this has the potential to underestimate the true demand for mental health services and neglect a larger proportion of individuals with subthreshold PTSD, who although may fall short of the diagnosis, are experiencing distressing symptomatology.

The final manuscript of this PhD, presented in chapter six, provides a theory-informed and evidence-based implementation guide for introducing perinatal mental health screening with populations of women who may face many barriers to screening. To the best of our knowledge, this is the first study to apply the COM-B model to the implementation of perinatal mental health screening, which allowed for a greater understanding of the interventions required for behaviour

change. With the provision of this implementation guide, which has been informed by prior research and evaluation, health services within Australia and internationally will be better equipped to plan their implementation of their perinatal mental health screening programs.

This PhD program of research has addressed current identified gaps in the literature and contributed updated knowledge regarding prevalence, assessment, and implementation. It is hoped that the results will inform current clinical practice in antenatal settings and contribute to potential improvements within the provision of health care provided to populations of refugees and asylum seekers.

### **7.3 Future directions**

The literature in the field of refugee mental health relies heavily on self-report measures which tend to overestimate symptomatology.<sup>(50)</sup> There is a need to focus on conducting comprehensive psychiatric assessments which use validated diagnostic measures in order to improve the quality of data of prevalence studies. In addition, future studies should involve large sample sizes in order to reduce bias and increase generalisability of results. Studies should also explore the full breadth of mental illness, not just PTSD, as the results from the systematic review suggest high rates of depression and anxiety. Further expansion upon the investigation of the prevalence of psychosis, ADHD, and ODD, previously underreported in the literature, is also warranted. In particular, further research is needed on the prevalence of the full range of anxiety disorders as this was less frequently examined and reported in the literature. As the results suggested that anxiety was higher among those displaced less than four years, further robust longitudinal studies are needed to investigate the influence of the uncertain nature of the resettlement process and the stressors associated with the refugee determination process. In line with best-practice research reporting, future research in the field needs to ensure outcomes are disaggregated by sex as this is likely to influence reported prevalence and highlight inequalities.<sup>(51, 52)</sup>

This PhD has highlighted the importance of further investigation in the area of perinatal anxiety and PTSD, including the recognition of subthreshold PTSD. The HTQ, while widely used and highly regarded, is not gender specific and does not account for women's prior experiences of pregnancy and birth related trauma specifically as part of refugee experiences. During migration women can spend time in refugee camps where there is inadequate access to pregnancy related healthcare and birth trauma and infant loss is common.(53) These experiences can be the basis of traumatic re-experiencing of PTSD and its associated symptomatology.(16) Therefore, further research could involve the development of a screening measure specifically for women of refugee background in order to recognise and include all of the potentially traumatic events, including that associated with birth and pregnancy trauma and loss, related to the refugee experience in order to detect symptoms of trauma. Early identification and detection of women experiencing symptoms of trauma during pregnancy is critical to ensure the best possible health outcomes for women.

## **7.4 Conclusions**

The ever-growing refugee and asylum seeker populations pose a major global public health crisis with serious implications for mental health care. The results from this PhD program of research contribute to addressing gaps in the current body of literature and knowledge of refugee mental health. By updating prevalence estimates, host nations can begin to plan, understand, and address the magnitude of this public health crisis. Without appropriate mental health intervention, a high proportion of refugee and asylum seekers are at risk of poor social integration into their new host nations, affecting their ability to fulfil their potential within their new communities. For women of refugee background, having a baby in a foreign country can be a scary and stressful time. The findings from these studies have the potential to reduce some of the barriers to perinatal mental health screening faced by women of refugee background such as the availability of

translated screening measures and the impact of trauma on perinatal care. The provision of a theory-informed implementation guide has the potential to reduce barriers related to the *capability*, *opportunity*, and *motivational* factors that are integral to implementing and sustaining behaviour change within healthcare settings. It is hoped that this implementation guide will encourage more health services in Australia and internationally to deliver perinatal mental health screening programs which are inclusive to all women, particular those from complex populations such as refugees and asylum seekers.

## **7.5 Translation of findings**

Throughout my PhD candidature I have come to understand the importance of reporting and disseminating findings from research. The first published manuscript from my PhD was the systematic review and meta-analysis on the prevalence of mental illness in child and adolescent refugees and asylum seekers. This review was selected by the Journal of the American Academy of Child and Adolescent Psychiatry (JAACAP), to be included as part of their Continuing Medical Education (CME) program for their readers. In conjunction with my primary supervisor, we prepared learning objectives based on the content of the systematic review as well as accompanying self-assessment questions. This manuscript was also used in a capacity-building session for researchers at the Monash Centre for Health Research and Implementation which was about equity in health research (65 multidisciplinary participants on 31/03/20). In May 2020, this manuscript was used in a lecture titled “An Equity Lens for Healthcare Research” (MPH5271) in May 2020 for the Masters of Public Health at Monash University.

The second published manuscript from my PhD was the systematic review and meta-analysis on the prevalence of mental illness in adult refugee and asylum seeker populations. This publication was selected by Monash University for promotion on the website of the Faculty of Medicine, Nursing, and Health Sciences. It was the subject of a university media release and an interview with the Arthur Carter Institute at New York University.

In addition to preparing and submitting manuscripts, I have presented the findings from my research at both national and international conferences and at meetings of the Refugee Health Consortium which involved healthcare providers, health service managers and cross-sectoral providers of refugee services across Melbourne. As part of the annual Monash Health Translation Precinct (MHTP) Student Showcase Symposium, I represented the Monash Centre for Health Research and Implementation (MCHRI) at the event in 2018 and presented the findings from the systematic reviews along with other PhD students representing various research centres throughout Monash University. Following my presentation at the World Congress of Public Health, representatives from the World Health Organization (WHO) and the Partnership for Maternal, Newborn, and Child Health (PMNCH), requested the results from my systematic reviews. Since that initial meeting, a relationship was established with these representatives to enable the dissemination of the results.

The perinatal mental health screening program was designed to address a common evidence practice gap in Australia. The design and implementation of this project addressed an important aspect of working with women from refugee backgrounds, which is for all health professionals to not only improve awareness of the individual barriers to screening faced by women from this population but to incorporate culturally responsive clinical practices as part of their usual duties and through ongoing professional development. The perinatal mental health screening program seeks to improve communication and health literacy for women of refugee background and aligns with a number of national standards and frameworks. In conjunction

with one of the senior investigators and a fellow PhD candidate, we presented this program as part of a workshop at the North American Refugee Health Conference in Portland Oregon in 2018. As a result of the overall success of the implementation of the pilot screening program, Monash Health have committed to scaling-up the program across all of their maternity services.

My work led to me being a contributor to a rapid review commissioned by the World Health Organization on the evidence relating to the health needs of refugees and migrants, specifically working with a small group of researchers on the section titled: Protecting and Improving the Health and Well-being of Women and Girls.

Once the remaining manuscripts have been published, plain language statements (included in the appendices) will be made available on the Monash Centre for Health Research and Implementation (MCHRI) website and sent to participants from my research, the formative research(19), and current key stakeholders.

## **7.6 Summary**

Throughout my candidature I have been involved in the dissemination of the key findings from my research. The results from the systematic review have contributed updated prevalence estimates which can be used as a powerful advocacy tool or for host nations in the planning and provision of mental health care for refugee and asylum seeker populations. These results have been used across a number of different teaching environments in order to raise awareness of some of the limitations of the current literature and to assist with the training of health professionals who work to provide health care to refugees and asylum seekers. The implementation of the perinatal mental health screening program will continue to provide learnings to both antenatal clinics within Australia and internationally regarding successful implementation of such programs to complex and at-risk populations of women. My post-

doctoral work will involve ongoing participation and further knowledge contribution to the field of refugee and perinatal mental health.

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## **Appendices**

### **Appendix A: Supplementary information for manuscript one**

Section/topic	#	PRISMA Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Title
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Abstract
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Paragraphs 1,2,3 & 4 of Introduction
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Paragraph 5 of Introduction
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Paragraph 1 of Methods
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Paragraphs 1,2 & 3 of Methods
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Paragraph 1 of Methods
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	S2 Appendix
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Paragraphs 2 & 3 of Methods

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Paragraph 4 of Methods
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Paragraph 5 of Methods
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Paragraph 8 of Methods
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Paragraph 6 of Methods
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	Paragraph 6 & 7 of Methods
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Paragraph 6 of Methods
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Paragraph 7 of Methods
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Paragraph 1 of Results
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	S1 Table
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Paragraph 7 of Results
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Figures 2,4, 6 & 8
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Paragraphs 3 – 6 of Results
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Paragraph 7 of Results
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Figures 3,5,7 &

			Paragraph 6 of Results
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Paragraphs 1 – 5 of Discussion
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Paragraph 9 of Discussion
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Paragraph 11 of Discussion
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Included with the competing interest and financial disclosure section

From: Moher D, Liberati A, Tetzlaff J, Altman DG, the PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med. 2009; 6(7): e1000097. Available from: <https://doi:10.1371/journal.pmed1000097>

### Search strategy (used across both systematic reviews; adult and child and adolescent)

1	Refugees [MeSH term]
2	refugee* [text word]
3	asylum-seek*[text word]
4	Or/1-3
5	Mental Health [MeSH term]
6	mental*[text word]
7	Mental Disorders [MeSH term]
8	mental disorder*[text word]
9	mental illness* [text word]
10	Depressive Disorder/di [diagnosis] [MeSh term]
11	depress*[text word]
12	Anxiety Disorders/di [diagnosis] [MeSH term]
13	anxiety*[text word]
14	Agoraphobia/di [diagnosis] [MeSH term]
15	agoraphobi* [text word]
16	Phobic Disorders/di [diagnosis] [MeSH term]
17	phobi*[text word]
18	social anxi*[text word]
19	Trauma [text word]
20	Stress Disorders, Post-Traumatic/di [diagnosis] [MeSH term]
21	PTSD* [text word]
22	post?traumatic stress disorder*[text word]
23	Psychotic Disorders/di [diagnosis] [MeSH term]
24	psych* [text word]
25	Schizophrenia/di [Diagnosis] [MeSH term]

26	schizo* [text word]
27	Bipolar Disorder/di [Diagnosis] [MeSH term]
28	bipolar* [text word]
29	Torture [MeSH term]
30	torture* [text word]
31	emotional disorder* [text word]
32	emotional disturbance* [text word]
33	Autism Spectrum Disorder/di [Diagnosis] [MeSH term]
34	autism Spectrum Disorder [text word]
35	autis* [text word]
36	Attention Deficit Disorder with Hyperactivity/di [Diagnosis] [MeSH term]
37	attention deficit disorder [text word]
38	ADHD [text word]
39	Or/5-38
40	[4] and [39]

## Template for risk of bias assessment

(used across both systematic reviews; adult and child and adolescent)

Document evidence from the article in quotation marks.

<b>Study ID</b>		
<b>Study citation</b>		
<b>EXTERNAL VALIDITY – IS THIS STUDY AND ITS RESULTS GENERALIZABLE TO MY SYSTEMATIC REVIEW QUESTION?</b>		
<b>Patient/population/participants</b>	Describe whether they were gender specific, had a particular condition or the general population, age and any other relevant characteristics (e.g. BMI)	
<b>N</b>	Where possible, list the number of participants that were: <ul style="list-style-type: none"> <li>• Screened</li> <li>• Enrolled</li> <li>• Allocated/randomised</li> <li>• Assessed</li> <li>• Followed up</li> </ul>	
<b>Setting</b>	List where the intervention was conducted and assessed ie. hospital, clinic, community and/or university setting.	
<b>Intervention/indicator</b>	Describe the intervention in as much detail as possible e.g. medication type, dose, duration, intervals.	
<b>Comparison/control</b>	Describe the comparison in as much detail as possible e.g. medication type, dose, duration, intervals.	
<b>Outcomes</b>	List what the study measured (e.g. weight, BMI, HbA1c) as primary outcomes and secondary outcomes. If the outcomes are not relevant to your systematic review, list these as measured but not relevant to your systematic review.	
<b>Inclusion Criteria</b>	Yes No Not reported	
<b>Exclusion Criteria</b>	Yes No Not reported	

<b>Does the study have a clearly focused question and/or PICO?</b>		Yes Partial No Not reported	Consider if the question is 'focused' in terms of:  – the population studied  – the intervention given or exposure  - the comparison(s)  – the outcomes considered
<b>Is a cohort study the appropriate design to answer this question?</b>		Yes Partial No	Consider if a cohort study is a good way of answering the question under the circumstances.
<b>Does the study have specified inclusion/exclusion criteria?</b>		Yes Partial No	Consider if the inclusion or exclusion of patients was clearly defined a priori.
<b>If there were specified inclusion/ exclusion criteria, were these appropriate?</b>		Yes Partial No N/A	Consider if:  - the eligibility criteria used to specify the patients, interventions/ exposures and outcomes of interest.
<b>Were the outcomes measured appropriate?</b>		Yes Partial No Not reported	Consider if the outcomes measured are appropriate and important outcome.
<b>Was there sufficient duration of follow-up for outcomes to occur?</b>		Yes Partial No Not reported	May need to check with clinicians regarding what is sufficient duration for important events to occur.  An acceptable length of time should be decided before quality/risk of bias assessment begins.
<b>INTERNAL VALIDITY – HAS THIS STUDY BEEN CONDUCTED RIGOROUSLY IN ORDER TO REDUCE BIAS?</b>			
<b>SELECTION BIAS</b>	<b>Other than the exposure under investigation, were the groups selected from similar populations?</b>	Yes Partial No Not reported	Consider:  - whether the different sources would affect outcomes e.g. one group recruited from hospital(s) the other from the community.  - time periods i.e. historical cohort

			- whether there is a large difference in participation rate between the two arms of the study.
	Was the exposed cohort truly representative?	Yes Partial No Not reported	<p>This item is assessing the representativeness of exposed individuals in the community relevant to the study's PICO, not the representativeness of the sample of individuals in the general population.</p> <p>Consider:</p> <ul style="list-style-type: none"> <li>- whether truly representative in the community (least bias)</li> <li>- whether somewhat representative (some bias)</li> <li>- whether selected group of users (bias)</li> <li>- no description of the derivation of the cohort (most bias)</li> </ul>
	Is it clear that the outcome of interest was not present at the start of study?	Yes Partial No Not reported	In the case of mortality studies, outcome of interest is still the presence of a disease/ incident, rather than death. That is to say that a statement of no history of disease or incident is least biased.
PERFORMANCE BIAS	Aside from the exposure, were the groups treated the same?	Yes Partial No Not reported	To be sure it's the exposure which is responsible for the effect.
DETECTION BIAS	Was exposure measured in a	Yes Partial No Not reported	Where exposure measures require any degree of subjectivity, some evidence should be provided that the

	<b>standard, valid and reliable way?</b>		<p>measures used are reliable and have been validated prior to their use in the study.</p> <p>Consider whether ascertainment of exposure was determined by:</p> <ul style="list-style-type: none"> <li>- secure record (e.g. surgical records) (least bias)</li> <li>- structured interview</li> <li>- written self-report (bias)</li> <li>- no description (most bias)</li> </ul>
	<b>Were outcome assessors blind to the exposure?</b>	Yes Partial No Not reported	<p>Consider:</p> <ul style="list-style-type: none"> <li>- If the outcome is objective (e.g. death) then blinding is less critical.</li> <li>- If the outcome is subjective (e.g. symptoms or function) then blinding of the outcome assessor is critical.</li> </ul>
	<b>Were all outcomes measured in a standard, valid and reliable way?</b>	Yes Partial No Not reported	<p>Where outcome measures require any degree of subjectivity, some evidence should be provided that the measures used are reliable and have been validated prior to their use in the study.</p> <p>For some outcomes (e.g. fractured hip), reference to the medical record is sufficient to satisfy the requirement for confirmation of the fracture. This would not be adequate for vertebral fracture outcomes where reference to x-rays would be required.</p> <p>Consider whether outcomes were determined through:</p> <ul style="list-style-type: none"> <li>- independent blind assessment or confirmation of the outcome by reference to secure records (x-rays, medical records, etc.) (least bias)</li> <li>- record linkage (e.g. identified through codes on database records)</li> </ul>

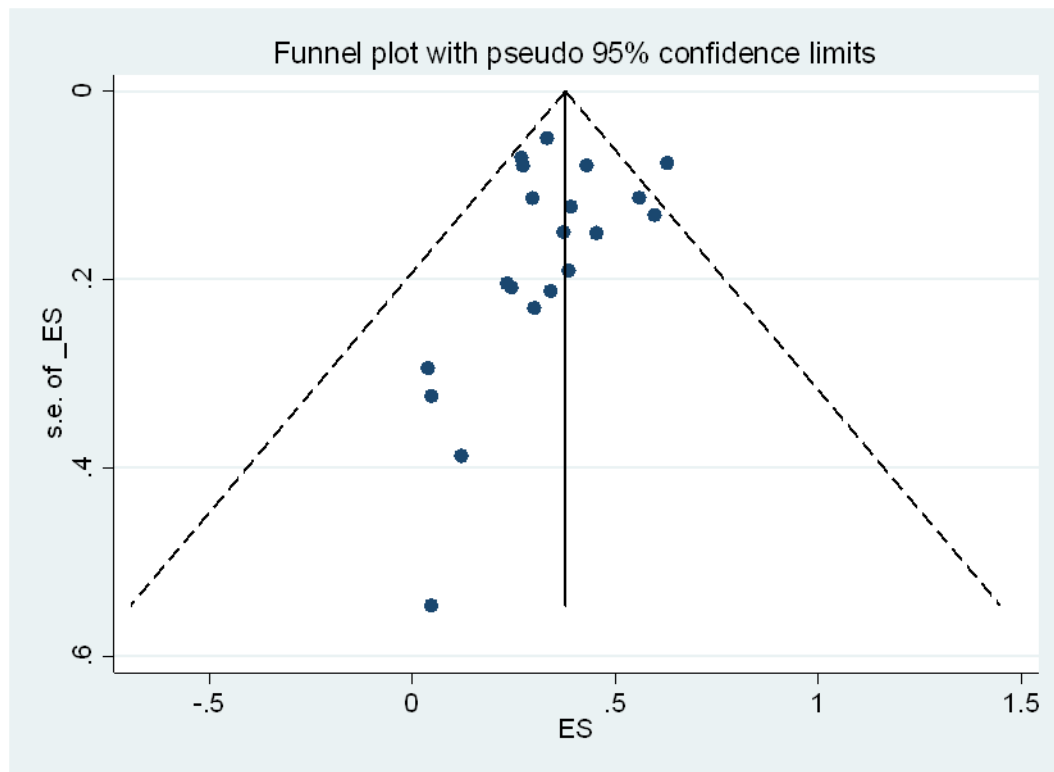
			- self report (i.e. no reference to original medical records or x-rays to confirm the outcome) (bias)  - no description (most bias)
	Were outcomes assessed objectively and independently?	Yes Partial No Not reported	Independence of assessment is important where the result of one outcome may effect the interpretation of another.  When outcomes are objectively assessed, their independence from each other is less important.
ATTRITION BIAS	What percentage of the individuals recruited into each arm of the study were lost to follow up?	X% treatment X% control/ comparison Not reported	Consider:  - if all patients who entered the trial were properly accounted for and attributed at its conclusion.  - why patients dropped out, as well as how many.  - the drop out rate may be expected to be higher in studies conducted over a long period of time.  - if comparisons were made between participants followed-up and those lost to follow up, by exposure status.
	What percentage of the individuals were not included in the analysis?	X% treatment X% control/ comparison Not reported	Consider:  - if analysis was as per protocol or intention to treat  - number of crossovers  - reason for crossover
REPORT BIAS	Is the paper free of selective outcome reporting?	Yes Partial No Not reported	Consider:  - if all the planned outcomes were measured  - if all the measured outcomes were reported  - if any additional or composite outcomes were measured.  This is difficult to determine if there isn't a protocol.

<b>CONFOUNDING</b>	<b>Are the cohorts comparable on the basis of design or analysis?</b>	Yes Partial No Not reported	<p>Consider</p> <ul style="list-style-type: none"> <li>- either exposed and non-exposed individuals must be matched in the design and/or confounders must be adjusted for in the analysis.</li> <li>- statements of no differences between groups or that differences were not statistically significant are not sufficient for establishing comparability.</li> </ul> <p>Note: If the relative risk for the exposure of interest is adjusted for the confounders listed, then the groups will be considered to be comparable on each variable used in the adjustment.</p>
	<b>Were there any conflicts of interest in the writing or funding of this study?</b>	Yes No Not reported	<p>Consider:</p> <ul style="list-style-type: none"> <li>- if any of the authors are/were employed, sponsored etc by pharmaceutical companies, or have other financial/other ties</li> <li>- if any commercial companies were involved in funding, writing, editing, data analysis or manuscript approval</li> </ul>
	<b>Was the study sufficiently powered to detect any differences between the groups?</b>	Yes Partial No Not reported	<p>Consider:</p> <ul style="list-style-type: none"> <li>- if an adequate sample size calculation was undertaken</li> <li>- if the required sample size recruited and retained</li> <li>- for which outcomes the study was powered</li> <li>- if confidence intervals include a clinically important difference, the study was underpowered</li> </ul> <p>NB this is less important if significant differences were found.</p>
	<b>If statistical analysis was undertaken, was this appropriate?</b>	Yes Partial No Not reported N/A	<p>Consider:</p> <ul style="list-style-type: none"> <li>- whether the authors performed any statistical tests or just presented figures</li> <li>- if the statistical analysis was planned a priori</li> <li>- if the data were analysed accordingly to the study protocol.</li> <li>- the type of data and the statistical tests used. (Please refer to the CCE workbook as required)</li> </ul>

		<ul style="list-style-type: none"> <li>- use of parametric versus non-parametric tests; whether the data has been checked for normality</li> <li>- if the tests used are obscure, why did the authors use them and have they included a reference.</li> <li>- if point estimates and measures of variability were presented for the primary outcome</li> <li>- if subgroups were analysed appropriately</li> <li>- if potential confounders were identified and taken into account in the analysis</li> <li>- if there was any adjustment made for multiple testing</li> <li>- if missing data was handled appropriately</li> </ul>
<b>Comments</b>	<i>Add any other relevant comments, including if this is likely to influence the results of the study</i>	
<b>What is the overall risk of bias?</b>	Low Moderate High Insufficient information	<p><i>Low - All of the criteria have been fulfilled or where criteria have not been fulfilled it is very unlikely the conclusions of the study would be affected.</i></p> <p><i>Moderate - Some of the criteria have been fulfilled and those criteria that have not been fulfilled may affect the conclusions of the study.</i></p> <p><i>High - Few or no criteria fulfilled or the conclusions of the study are likely or very likely to be affected.</i></p> <p><i>Insufficient information – not enough information provided on methodological quality to be able to determine risk of bias.</i></p>



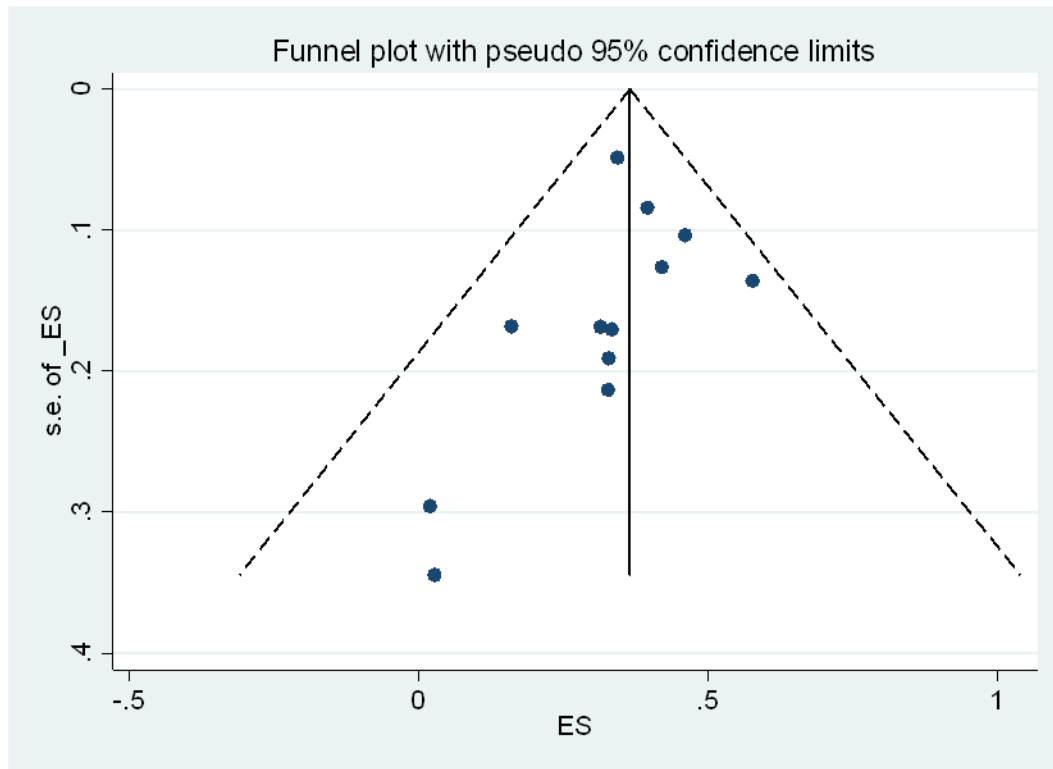
# **Egger's Test Plot – Post-traumatic stress disorder (PTSD)**



## **Egger's Test**

Std_eff	Coef.	Std. Err.	t	P> t	95% Conf. Interval	
slope	.4135485	.0581542	7.11	0.000	.2913711	.5357259
bias	-.381744	.5227679	-0.73	0.475	-1.480039	.7165507

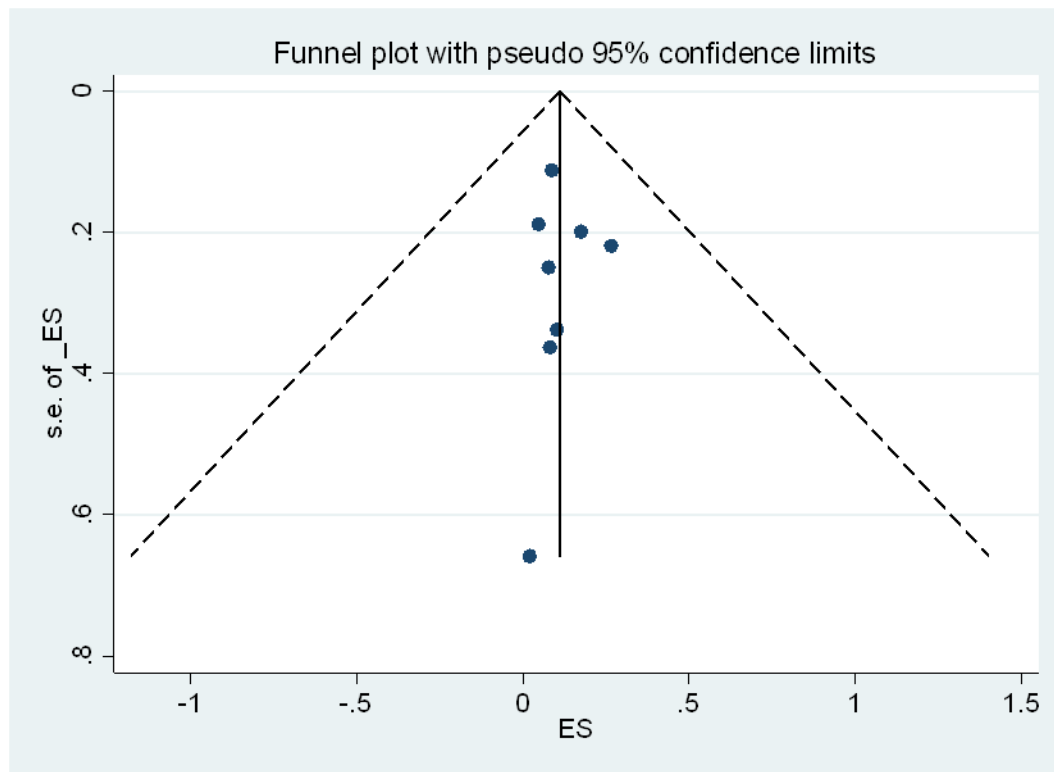
### Egger's Test Plot - Depression



### Egger's Test

Std_eff	Coef.	Std. Err.	t	P> t	95% Conf. Interval	
slope	.4070673	.0531606	7.66	0.000	.288618	.5255166
bias	-.4380024	.4732108	-0.93	0.376	-1.492382	.6163769

### Egger's Test Plot – Anxiety



### Egger's Test

Std_eff	Coef.	Std. Err.	t	P> t	95% Conf. Interval	
slope	.1008665	.0618283	1.63	0.154	-0.0504219	.2521549
bias	.0555662	.3004875	0.18	0.859	-.6797002	.7908326

## **Appendix B: Supplementary information for manuscript two**

Section/topic	#	PRISMA Checklist item	Reported on page #
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Page 1
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Page 2
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Page 3-4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Page 4
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Page 5
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Page 6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Page 5-6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Table S2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Page 6-7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Page 7-8
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Page 6-7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Page 8
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Page 7

Section/topic	#	Checklist item	Reported on page #
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	Page 7
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Page 7
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Page 7
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Page 8 & Fig. 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Page 8 & Table S4
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Page 12
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Fig.2, Fig. 4, Fig.S1, S3, S5
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Page 8-11
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Page 12
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Fig.3 & 5, Fig.S2 & S4
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Page 13
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Page 15-16
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Page 15- 16
<b>FUNDING</b>			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Page 16

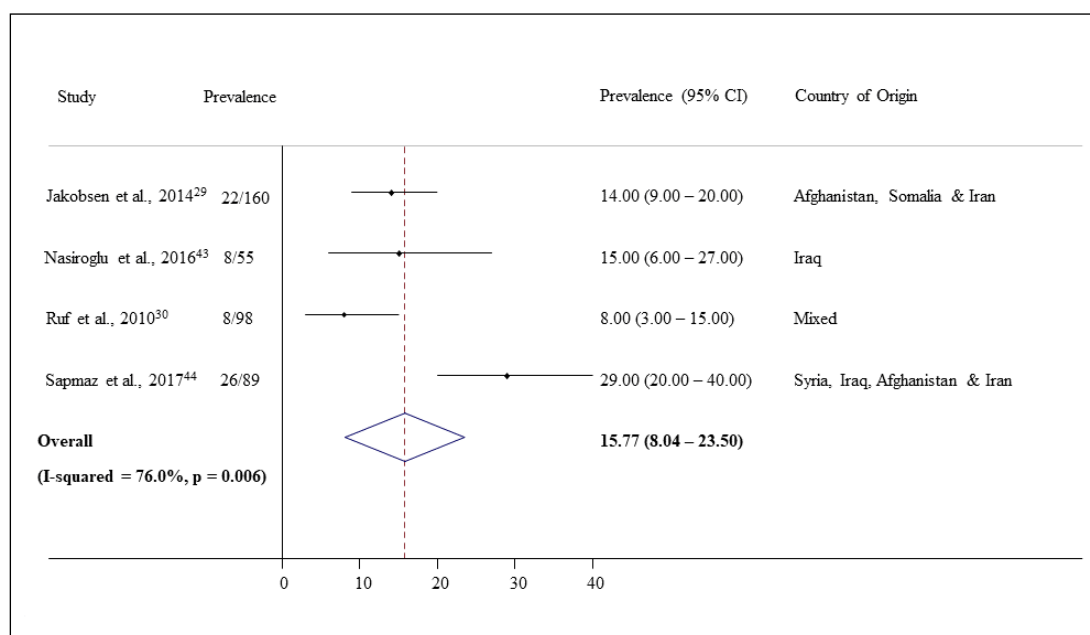
From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med. 2009; 6(7): e1000097. Available from: <https://doi:10.1371/journal.pmed1000097>

# Characteristics of included studies

Study	Country of Origin	Sampling Method	Diagnostic Instrument	Diagnostic Criteria	Native Interviewer (Y/N)	Sample Size	Mean Age (yrs.)	SD (yrs.)/ Age Range	% Female	No PTSD (%)	No Depression (%)	No Anxiety (%)	No ADHD (%)	No ODD (%)	Risk of Bias Rating
Ahmad et al., 2008 <sup>31</sup> (Sweden)	Turkey, Iran, Iraq, Syria, & Lebanon	List of names from child-care centres, school health care and two Kurdish societies in Uppsala, Sweden.	PTSS-C (Post-traumatic Stress Symptoms for Children)	DSM-IV	Y	111	11.6	6 - 18 years	58.6%	8 (7.2%)	-	-	-	-	Low
Daud et al., 2009 <sup>41</sup> (Sweden)	Iraq, Egypt, Syria, & Morocco	Recruited through Swedish Red Cross Centre for the treatment of tortured refugees.	DICA-R-C (Diagnostic Interview for Children & Adolescents)	DSM-IV TR	Y	80	Trauma Group: 12.1 Non Trauma Group: 12.5	Trauma Group: 2.1 Non Trauma Group: 2.2 7 - 16 years	50%	32 (40%)	-	-	22 (27.5%)	3 (3.75%)	Moderate
Gosnell, 2017 <sup>42</sup> (Malaysia)	Burma, Pakistan, Sri Lanka, & Iran	Students attending 1 of 8 refugee schools in Kuala Lumpur funded by the UNHCR.	K-SADS-PL (Kiddie Schedule for Affective Disorders and Schizophrenia)	Not Specified	N	90	14.22 years	2.08 10 - 19 years	51%	10 (11%)	12 (13.3%)	-	-	-	Low
Jakobsen et al., 2014 <sup>29</sup> (Norway)	Afghanistan, Somalia, & Iran	All new arrivals to transit centre in Oslo, aged between 15 - 18, were invited to participate each time testing capacity allowed.	WHO WMH-CIDI (World Health Organization World Mental Health-Composite International	DSM-IV	N	160	16.23	0.83 14 - 20 years	0%	49 (30.6%)	22 (13.75%)	22 (13.75%)	-	-	Low

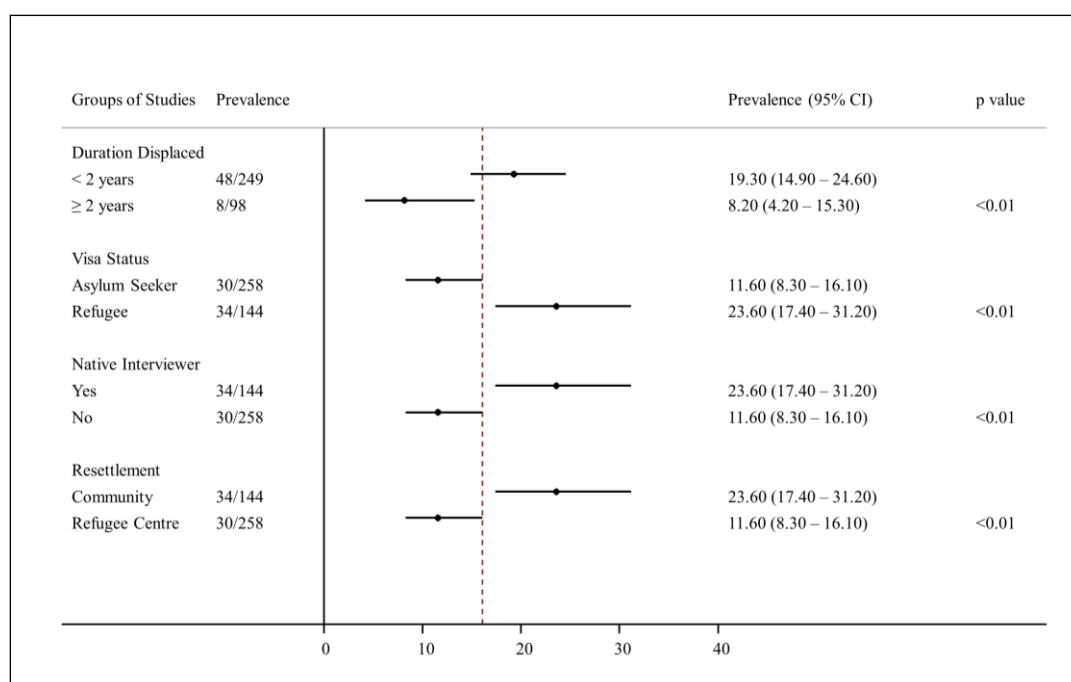
			Diagnostic Interview)												
Nasiroglu et al., 2016 <sup>43</sup> (Turkey)	Iraq	All Yazidi houses with children and adolescents, in the four villages of Batman, Turkey, were regularly visited for 10 days in the ninth month after their immigration.	K-SADS-PL (Kiddie Schedule for Affective Disorders and Schizophrenia)	DSM-IV	Y	55	11	3.67 6 – 17 years	45%	20 (36.4%)	18 (32.7%)	8 (14.54%)	1 (1.8%)	-	Moderate
<b>Study</b>	<b>Country of Origin</b>	<b>Sampling Method</b>	<b>Diagnostic Instrument</b>	<b>Diagnostic Criteria</b>	<b>Native Interviewer (Y/N)</b>	<b>Sample Size</b>	<b>Mean Age (yrs.)</b>	<b>SD (yrs.)/ Age Range</b>	<b>% Female</b>	<b>No (%) PTSD</b>	<b>No (%) Depression</b>	<b>No (%) Anxiety</b>	<b>No (%) ADHD</b>	<b>No (%) ODD</b>	<b>Risk of Bias Rating</b>
Ruf et al., 2010 <sup>30</sup> (Germany)	Former Yugoslavia, Turkey, Iraq, Syria, Chechnya, Iran, Algeria, Afghanistan, Dagestan, Georgia, Congo, Mongolia, Sudan, Russia, & Azerbaijan.	Social workers in 13 different government communal accommodation were contacted and presented with study details. These social workers were asked to invite families living in the asylum seeker accommodation centres to participate.	M.I.N.I KID (Mini-International Neuropsychiatric Interview for Children and Adolescents)	DSM-III	N	98	10.6 7 – 16 years	2.6	53%	-	3 (3.1%)	8 (8.16%)	6 (6.12%)	1 1%	Low
Sapmaz et al., 2017 <sup>44</sup> (Turkey)	Syria, Iraq, Afghanistan, & Iran	Families were contacted using addresses obtained from the immigrant-office headquarters; however, on learning that the families had moved, refugee families who had applied to obstetrics and gynaecology	K-SADS-PL (Kiddie Schedule for Affective Disorders and Schizophrenia)	DSM-IV	Y	89	9.96 5 – 18 years	3.98	56.2%	8 (9%)	12 (13.5%)	26 (29.2%)	4 (4.5%)	-	Moderate

		departments of the city hospitals were identified and contacted with two translators who help the families during their procedures at the hospital.													
Soykoek et al., 2017 <sup>32</sup> (Germany)	Syria	Families were contacted using lists of new arrivals provided by the Bayernkaserne reception camp in Munich, Germany.	PTSD-SSI (Post-Traumatic Stress Disorder Semi-Structured Interview) & Kinder -DIPS	DSM-IV	Both (native interviewer & interpreters used)	96	7.2	3.68  0 – 14 years	46%	29 (30.2%)	-	-	-	-	Low



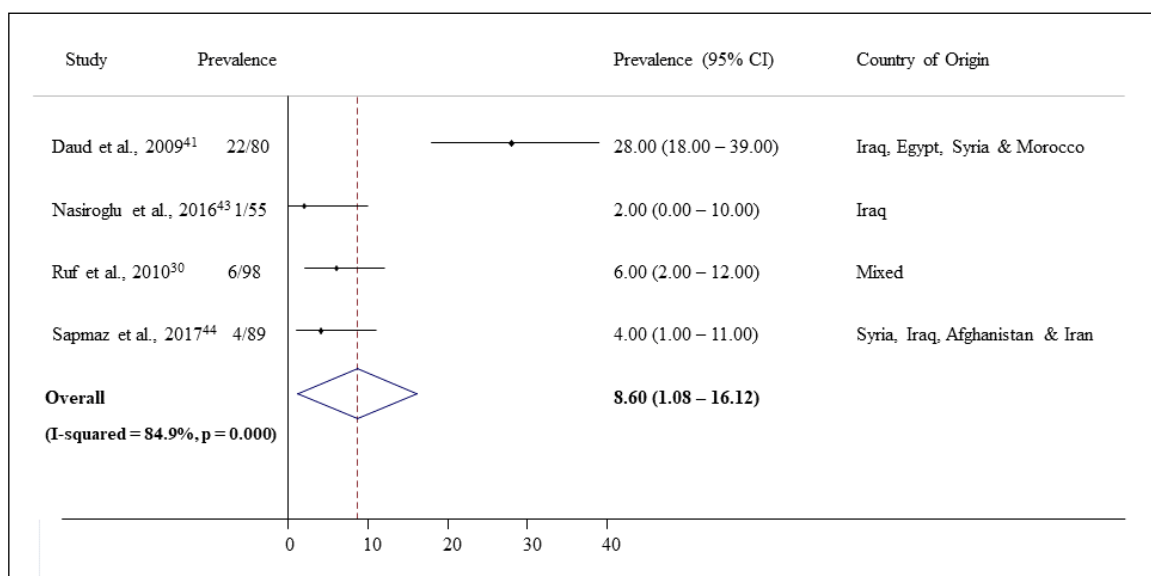
**Figure S1** Prevalence of anxiety disorders in child and adolescent refugees and asylum seekers

Horizontal lines indicate 95% CIs; and open diamond denotes subtotals

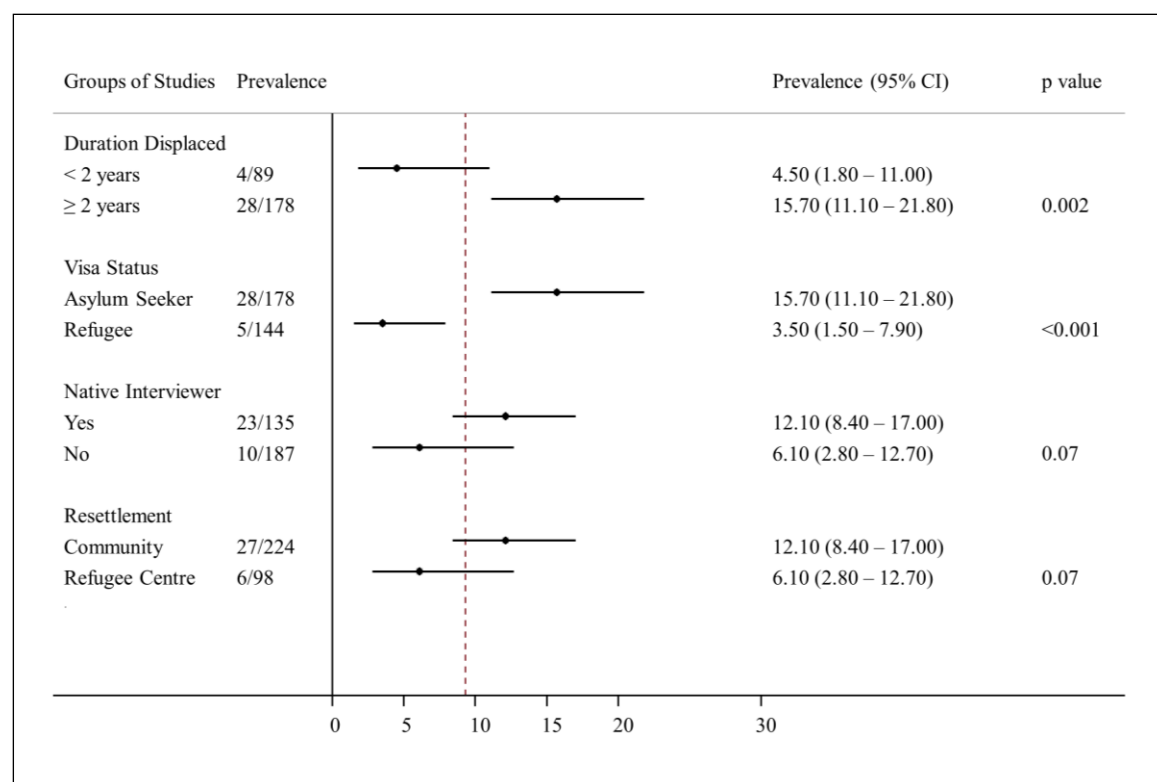


**Figure S2** Prevalence of anxiety disorders by various study characteristics.

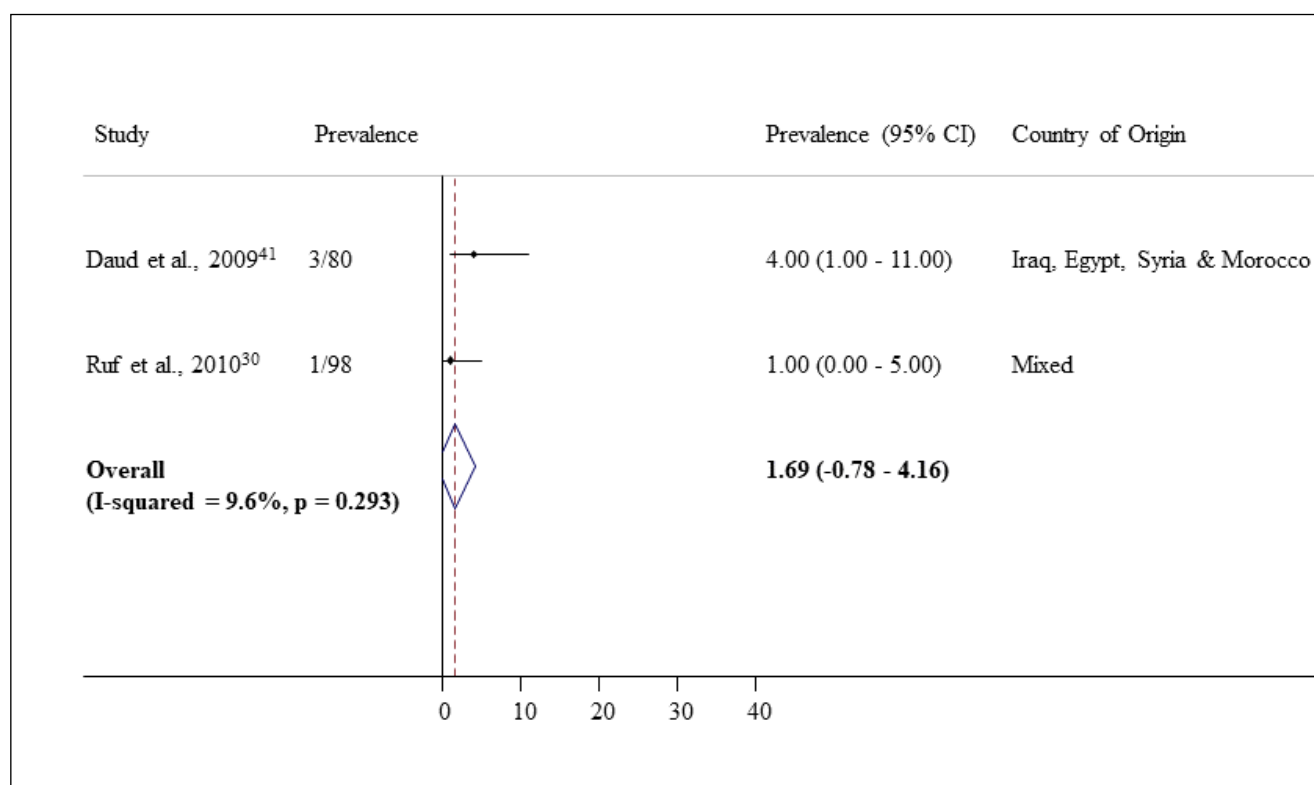
p values derived from random-effects models; horizontal lines indicate 95% CIs.



**Figure S3** Prevalence of attention-deficit/hyperactivity disorder in child and adolescent refugees and asylum seekers. Horizontal lines indicate 95% CIs; and open diamond denotes subtotals



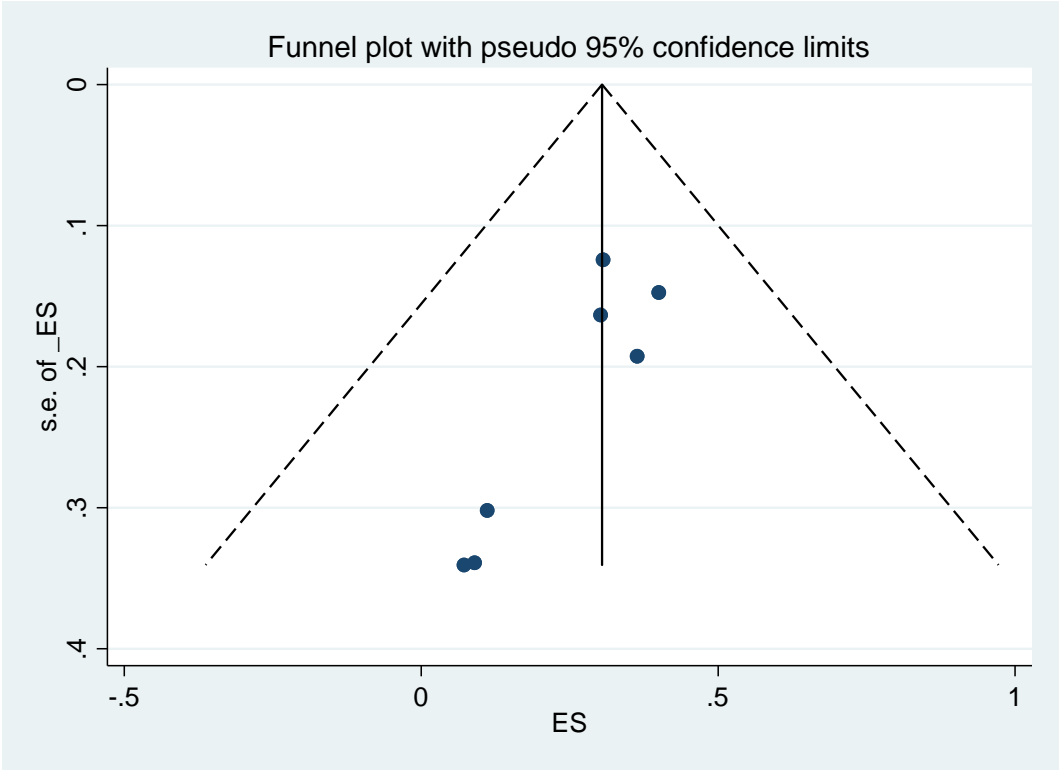
**Figure S4** Prevalence of attention-deficit/hyperactivity disorder by various study characteristics  
p values derived from random-effects models; horizontal lines indicate 95% CIs.



**Figure S5** Prevalence of oppositional defiant disorder in child and adolescent refugees and asylum seekers

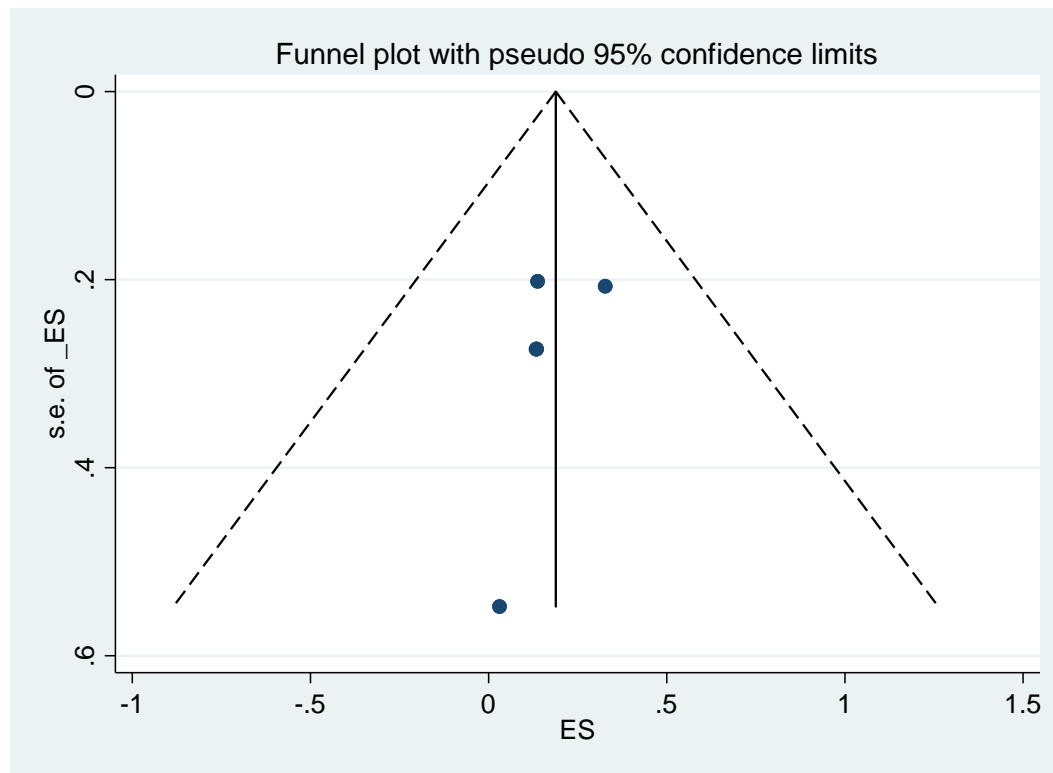
Horizontal lines indicate 95% CIs; and open diamond denotes subtotals

Egger's test plot post-traumatic stress disorder (PTSD)



Std_Eff	Coef.	Std. Err.	t	P> t	95% Conf. Interval	
slope	.5070254	.0702952	7.21	0.001	.687725	.687725
bias	-1.165716	.3790455	-3.08	0.028	-2.140084	-.1913491

## Egger's test plot depression



Std_Eff	Coef.	Std. Err.	t	P> t	95% Conf. Interval	
slope	.3498204	.161523	2.17	0.119	-.1642178	.8638586
bias	-.6639664	.6376022	-1.04	0.374	-2.693101	1.365168

## **Appendix C: Plain language statement for manuscript three**

## Asking about depression and anxiety in pregnancy. What works best for women who speak Dari?

Contact: [K.Gray.1@warwick.ac.uk](mailto:K.Gray.1@warwick.ac.uk)

**Background:** It is recommended that all women are asked questions about their emotional health in pregnancy. Asking these questions can help women find support. Women of refugee background may be at risk of depression and anxiety in pregnancy because of their experiences of war and separation from family. Dari is a language that is common in Afghanistan. Due to war in Afghanistan, women and their families have come to live in Australia. One of the most common ways to ask women about depression and anxiety during pregnancy is to use the Edinburgh Postnatal Depression Scale (EPDS). The Dari EPDS has not yet been tested to see whether it works well with women.

**Aims:** We wanted to know if the Dari version of the EPDS could be used to ask women about depression and anxiety during pregnancy to find those who need support.

**Methods:** We spoke to 52 Dari speaking women who were pregnant. The women answered the Dari version of the EPDS. The women were then asked more questions to see if they had depression or anxiety. Some women needed an interpreter to help them.

**Results:** We found that the Dari version of the EPDS could be used to ask women about depression and anxiety during pregnancy and worked well in finding those women who needed support. We also found that doctors and midwives should use a lower score for this version of the EPDS, in order to find all of the women who need extra support during their pregnancy.

### What does this mean for maternity care?

- Knowing that the Dari version of the EPDS can be used to ask women about their emotional health during pregnancy means care will be better for this group of women. It also means that Dari speaking women will be able to get support if they need during their pregnancy.
- The results from this study will also help midwives and doctors, who give pregnancy care to Dari speaking women, to use the Dari version of the EPDS.

## **Appendix D: Plain language statement for manuscript four**

## Asking about PTSD in pregnancy. What works best for women who speak Dari?

Contact: [melanie.gibson@monash.edu](mailto:melanie.gibson@monash.edu)

**Background:** Post-traumatic stress disorder (PTSD) can change the way a woman feels during her pregnancy. Women of refugee background may be more likely to have PTSD because of their experiences of war, violence, and separation from family. Asking questions about PTSD during pregnancy may help women find support if they need it. One of the most common ways to ask about upsetting events is the Harvard Trauma Questionnaire (HTQ). The HTQ has been used with many people of refugee background, but not much is known about whether it can be used during pregnancy.

**Aims:** We wanted to interview pregnant women of refugee background. We wanted to know how many women in this group had PTSD. We also wanted to test the HTQ to see whether it could be used to find women who needed support during pregnancy.

**Methods:** Due to war in Afghanistan, many women and their families have come to live in Australia. Dari is a language that is common in Afghanistan. We spoke to 52 Dari speaking, pregnant women. The women answered the HTQ, which asks women if they have ever experienced difficult or upsetting events, which are common for people with refugee experiences. Some women needed an interpreter to help them. The women were then asked other more questions to see if they had PTSD.

**Results:** We found that many women had experienced many upsetting events. A small number of women had PTSD. More women did not have PTSD but their day to day lives were being affected by past events. We found that the HTQ could be used to ask women about events in their life and worked well to find women who needed support. We also found the HTQ score that worked best to find which women need extra support during their pregnancy.

### What does this mean for maternity care?

- Asking women of refugee background about PTSD during their pregnancy is important.
- By knowing what questions to ask, it means women at risk of PTSD will be able to get support if they need.
- The results from this study will help midwives and doctors to know how to use the HTQ.