Thesis submitted in Partial Fulfilment of the Degree of Doctor of Clinical Psychology (DClinPsych)

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Doctorate in Clinical Psychology

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September 2024

Word Count by Component

Systematic Review of the Literature (SRL)	**7, 342 words**
A systematic review exploring the relationship between Islamophobia and the mental health and wellbeing of Muslims	
Service Improvement Project (SIP)	**5, 350 words**
Identifying young carers from minoritised ethnic groups – Understanding the barriers and facilitators as experienced by Early Intervention for Psychosis staff	
Theory Driven Research Project (TDRP)	**5, 500 words**
Stigma and trust in mental health services – the impact of ethnicity and immigrant generation	
Executive Summary	**982 words**
Connecting Narrative	**1, 000 Words**

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Systematic Review of the Literature

Since the September 11th 2001 terrorist attack in America, Muslims have faced increasing suspicion and hostility resulting in numerous psychosocial and health inequalities but mental health outcomes are less well understood. This systematic review aimed to synthesise existing studies on the relationship between islamophobia and the mental health and wellbeing of Muslims, including the consideration of help-seeking behaviours and attitudes. Five bibliographic databases were searched resulting in 23 relevant papers being identified. The review of these papers revealed poor mental health outcomes resulting from experiences of islamophobia including increased symptoms of depression, anxiety, Post-Traumatic Stress Disorder (PTSD) and low self-esteem. Visible signs of being a Muslim (e.g., hijab) and acculturative stress appeared to influence these outcomes, but social support and group identification lessened the impact of islamophobia on the mental health of Muslims. Help-seeking was negatively impacted by islamophobia and Muslims revealed a preference for seeking support from friends and family over mainstream mental health services. The clinical implications of these findings are considered.

Keywords: Muslims, islamophobia, anti-Muslim, mental health, inequalities, help-seeking

Service Improvement Project

Background: Young carers are young people under 18 years who provide unpaid, informal care to a relative or friend, including those with a serious mental illness. Several challenges present in the identification of young carers including a general lack of awareness of the young carer role. It is important for professionals, such as mental health services' staff, who may encounter young carers, to be aware of and supported in identifying young carers.

Aim: To understand and explore the experiences of staff in an Early Intervention for Psychosis service in Berkshire and their perspectives of the barriers and facilitators to identifying young carers so recommendations can be formulated for addressing these barriers.

Methods: Two focus groups were run with staff from the Slough and Reading EIP teams, including care coordinators, a team manager, an advanced clinical support worker, and Trainee Clinical Psychologist. A semi-structured topic guide was used to facilitate the groups. Framework analysis was used to analyse data.

Results: Five categories were identified from the focus groups: i) Impact of contextual factors, ii) Opportunities to identify young carers, iii) Staff's views about enquiring, iv) Classification and criteria of young carer, and v) Knowledge and availability of support. Suggested recommendations for the service were presented to staff in a business meeting and met with a positive response.

Conclusions: Several challenges to identifying young carers at the Berkshire EIP service were identified. Recommendations for addressing these challenges were positively received, with training on young carers being planned for September 2024.

Key words: young carers, psychosis, early intervention, mental health, ethnic minority

Theory Driven Research Project

Purpose: This study sought to investigate the role of identifying as a migrant and the impact of generation (first vs. second) in the relationship between mental health stigma and ethnicity. This study also sought to identify the relationship between stigma and trust within and between groups.

Methods: An online survey was developed to collect data on mental health stigma (public stigma, self-stigma, and label avoidance) and trust. Four groups of participants were recruited: first and second generation (British) South Asians, first generation (British) Polish, and White British. Data were analysed to identify differences in levels of stigma and trust across the different ethnic and generational groups. A hierarchical multiple linear regression was used to identify whether stigma predicted levels of trust.

Results: The analysis revealed no difference in levels of public stigma, label avoidance, self-stigma or trust according to the different ethnic and generational groups. Neither public nor self-stigma were associated with levels of trust in mental health services. Label avoidance was, however, significantly associated with levels of trust such that lower label avoidance was associated with higher trust in services.

Conclusion: This study found no evidence of an association between stigma and ethnicity, nor was there evidence of differences between first and second generation South Asian groups. Label avoidance may however be related to trust in terms of marginalised groups and their access to mental health services.

Keywords: stigma, mental health, ethnicity, trust, ethnic minority

Statements and declarations: The authors have no competing interests to declare.

Systematic Review of the Literature

A systematic review exploring the relationship between Islamophobia and the mental health and wellbeing of Muslims

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Word Count (excluding references and appendices, tables as 100 words each): 6,995
Revised word count: 7, 342
Date: 10th May 2024

Proposed Journal: Journal of Muslim Mental Health. This is a peer-reviewed interdisciplinary journal which publishes studies and reviews on psychosocial determinants of the mental health of Muslims globally. The author and submission guidelines can be found in Appendix 1A.

The authors declare no conflicts of interest.

Abstract

Since the September 11th 2001 terrorist attack in America, Muslims have faced increasing suspicion and hostility resulting in numerous psychosocial and health inequalities but mental health outcomes are less well understood. This systematic review aimed to synthesise existing studies on the relationship between islamophobia and the mental health and wellbeing of Muslims, including the consideration of help-seeking behaviours and attitudes. Five bibliographic databases were searched resulting in 23 relevant papers being identified. The review of these papers revealed poor mental health outcomes resulting from experiences of islamophobia including increased symptoms of depression, anxiety, Post-Traumatic Stress Disorder (PTSD) and low self-esteem. Visible signs of being a Muslim (e.g., hijab) and acculturative stress appeared to influence these outcomes, but social support and group identification lessened the impact of islamophobia on the mental health of Muslims. Help-seeking was negatively impacted by islamophobia and Muslims revealed a preference for seeking support from friends and family over mainstream mental health services. The clinical implications of these findings are considered.

Keywords: Muslims, islamophobia, anti-Muslim, mental health, inequalities, help-seeking

Introduction

The 11th September (9/11) 2001 terror attacks in the United States (US) were a defining moment in Western history. The attacks which were coordinated by Al Qaeda, an extremist "Islamist" terrorist organisation, led to Muslims the world over becoming the target of increased suspicion and hostility (Burrows, 2023). In the immediate aftermath, the European Monitoring Centre on Racism and Xenophobia (EUMC), suspecting a rise in potential retaliation against Muslims, implemented a reporting system to monitor anti-Islam sentiment and reactions in Europe (Allen & Nielsen, 2002). The summary report noted a substantial increase in non-violent attacks towards Muslim and those who "look" Muslim (Allen & Nielsen, 2002).

Psychological frameworks such as Social Identity Theory (SIT) – proposed to explain group processes underlying bias and discrimination (Tajfel et al., 1979) – and Integrated Threat Theory (ITT) (Stephan & Stephan, 2013) can be used to hypothesise about the motivations behind such anti-Muslim sentiment and attacks. SIT posits that the grouping and categorisation of people have important consequences for intergroup interactions as an individual's self-image is intertwined with their group memberships which are sources of pride and self-esteem (Tajfel et al., 1979). Therefore, the desire for a positive self-image serves as motivation to bolster the positive image of one's social groups (Tajfel et al., 1979). This is achieved through comparison with an outgroup who are denigrated to achieve a sense of in-group "positive distinctiveness" (Tajfel et al., 1979). The mere act of categorisation is enough to create an "us and them" mindset and resentment towards an outgroup (Tajfel et al., 1979) – members of whom suffer poor mental health as a result (Crabtree et al., 2010; McCoy & Major, 2003). ITT further emphasises the value that these social groups hold and when an in-group perceives a threat (either symbolic, e.g., to the integrity or validity of the group's values, or realistic, e.g., physical harm or loss of resources and power), this produces inter-group anxiety leading to the in-group curtailing the out-group's ability to gain power and status (Croucher, 2017). Most importantly it is the mere perception of threat that is enough to lead to cognitive, behavioural, and affective consequences including, but not limited to, dehumanisation, resentment, and discrimination (Stephan et al., 2009).

The aftermath of the 9/11 attacks saw a substantial increase in media coverage about Muslims with the vast majority reported to be negative and emphasising cultural and religious differences (Allen, 2012; Samaie & Malmir, 2017). Such coverage may have increased anxiety and the perception of threat from Muslims. According to SIT and ITT, dehumanisation and marginalisation would follow in an effort to maintain a favourable in-group image, positive distinctiveness, and reduce the perceived threat from the outgroup – Muslims.

Despite the 9/11 attacks occurring more than two decades ago, the behavioural consequences of the perceived incompatibility with, and threat from, Muslims continue to be exhibited in the marginalisation and discrimination of Muslims. Muslims can be seen as facing disadvantages in a range of domains including educational, socioeconomic, and housing (Stevenson et al., 2017). A recent United Nations Human Rights Council report (Shaheed, 2021) suggested islamophobia has become institutionalised into law, policy, and practice with an example being the UK's counter-terrorism Contest strategy which places a statutory duty upon public sector workers to identify and raise concerns if they suspect an individual of being at risk of radicalisation – a strategy which has been criticised for targeting Muslims (Aked et al., 2021; Shaheed, 2021; Younis & Jadhav, 2020).

Various organisations have attempted to define islamophobia so it can be effectively recorded and challenged, but this has been difficult because it cuts across many layers and ethnoreligious borders. There is currently no agreed definition of islamophobia. The All Party Parliamentary Group (APPG) on British Muslims in the UK consulted with a wide range of experts and proposed a working definition of Islamophobia as being:

"rooted in racism and is a type of racism that targets expressions of Muslimness or perceived Muslimness" (All Party Parliamentary Group on British Muslims, 2018) (pg.11). This definition was widely accepted by Muslim communities and organisations including the Muslim Council of Britain and adopted by various industries (Bhatti, 2021). Notably however, it has not been adopted by the UK government and police chiefs in the UK have resisted adopting such a definition for fear that it would render the country's counter-terrorism strategy effectively racist (BBC News, 2019; Dodd, 2019).

Emerging evidence suggests that islamophobia may influence health outcomes. Studies have suggested that Muslims face multiple physical health inequalities such as higher levels of diabetes (Karlsen & Nazroo, 2010), high blood pressure (Johnston & Lordan, 2012), and poor overall health and disability (Muslim Council of Britain, 2015). Several studies have reported the negative impact of discrimination – particularly racism - on mental health including increased risk of depression and anxiety disorders (Gee et al., 2007; Paradies et al., 2015; Pascoe & Smart Richman, 2009; Williams & Mohammed, 2009, 2013; Williams et al., 1997).

Evidence of the mental health impact of islamophobia is emerging but appears to be understudied and complicated by the conflation of "culture[1]" (Cambridge Dictionary, 2024a) and "religion[2]" (Cambridge Dictionary, 2024b) leading to studies with samples comprising ethnic groups with large Muslim populations, such as South Asians, and not exclusively Muslims (Walpole et al., 2013). The urgency of addressing this limitation in the evidence base is further reinforced by recent analysis of routinely collected data from the National Health Service (NHS) Talking Therapies for anxiety and depression services which showed Muslims have the lowest recovery rates suggesting a pressing unmet need within this population (Baker & Kirk-Wade, 2024).

Understanding the mental health impact of islamophobia may help to explain these poorer outcomes. Some researchers have drawn upon acculturation (Berry, 1992) to suggest that Muslims contending with islamophobia may experience acculturative stress which results from the attempt to balance one's heritage (religious) culture with the host (nationality) culture (Berry, 1992). Some studies have suggested poor psychological wellbeing can result if the expectations of the host/majority group differ from the expectations of the individual (Kalek et al., 2010; Kunst et al., 2016). Islamophobia has been identified as being associated with a preference for Muslims to abandon their religious practices in favour of integrating with the host culture but this serves to simply leave Muslims seeking comfort with their peers and increasing their commitment to maintaining their Muslim identity (Kunst et al., 2016). This can leave Muslims at the precipice of the "good" vs "bad" Muslim binary in which they are seen as good by the majority if they assimilate and adhere to Western values but "bad" if

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[1] Culture – "*the way of life, especially the general customs and beliefs, of a particular group of people at a particular time*" (Cambridge Dictionary, 2024)

[2] Religion – "the belief in and worship of a god or gods, or any such system of belief and worship" (Cambridge Dictionary, 2024)

they uphold religious practices (Shaheed, 2021). Regardless of which acculturation strategy Muslims ultimately utilise, the acculturation process can leave Muslims facing poor psychological outcomes due to the stress experienced from either incompatible expectations with the host culture or their peers if they choose to assimilate or integrate with the host culture leading to poorer self-esteem (Kunst & Sam, 2013).

Additionally, following 9/11, the so called "war on terror" led to the racialisation of Muslims leading to implicit islamophobia becoming increasingly explicit particularly the continued negative media stereotypes of Muslims (Elver, 2012; Saleem et al., 2015). As a result, it is possible to speculate that Muslims may experience cumulative and repeated exposure to traumatic experiences – the consequences of which may be transmitted across generations via biological and psychological means thus maintaining a continued stress response within these groups (Hankerson et al., 2022; Ahmad et al., 2024; Williams et al., 2019).

A systematic review from the US found islamophobia to be associated with poorer mental and physical health including higher levels of psychological distress, greater depressive symptoms, higher levels of paranoia, difficulties with regulating blood pressure, cholesterol and a higher level of coronary heart disease (Samari et al., 2018). The review also reported that Muslims reported perceived or direct discrimination as the main reason for the apprehension to seek help (Samari et al., 2018).

Samari et al., (2018) focused on the western context of islamophobia and included "Muslim-like" groups to capture the racialised aspect of islamophobia instead of focusing specifically on Muslims but the conflation of ethnicity, culture, and religion makes it difficult to understand the nuances of the impact of islamophobia as experienced by Muslims. The inclusion of Muslim-like, but ultimately non-Muslim, participants may lead to conclusions which do not take into consideration the specific context of Muslims and Islamic practices. The review further focused on studies published between 1990 and 2017 and it is therefore possible that relevant literature may have been overlooked.

Aims

This review seeks to explore whether the mental health and wellbeing of Muslim adults may be associated with the experience of islamophobia. Only adults over the age of 18 will be included as there are likely to be different considerations for children and young people.

Specifically, this review aims to answer the following questions:

I. Is there a relationship between islamophobia and the mental health and wellbeing of Muslims?
II. Where are Muslims most likely to seek help for mental health difficulties, particularly in the context of Islamophobia?

Method

This review was conducted according to the guidelines specified by the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) (see Appendix 1B for PRISMA checklist) (Page et al., 2021) and was registered with PROSPERO (PROSPERO: CRD42020206660).

Data sources

Five electronic bibliographic databases were searched in November 2023: Medline (OvidSP), PsycINFO (OvidSP), CINAHL, Scopus, and the Social Sciences Citation Index via Web of Knowledge. No limits were placed on publication year of papers, but a limit was set to retrieve papers pertaining to only human participants. An updated search in April 2024 revealed no new papers.

The search strategy covered four key terms – Muslims/Islam, islamophobia, help-seeking and mental health (see Appendix 1C for full strategy). Backward and forward citation tracking of the previous review (Samari et al., 2018) were employed to identify additional papers. Forward citation tracking was conducted using the 'Cited by' function on Google Scholar and Web of Knowledge. Grey literature databases and third-sector organisation websites were searched for relevant reports (see Appendix 1D).

Study selection

Citations produced by the search were extracted, collated, and de-duplicated in reference management software, Endnote. Twenty-five percent of the titles and abstracts were screened independently for eligibility by two reviewers (SA and SM). Cohen's kappa was calculated to test inter-rater reliability – the figure produced by this test can range from -1 to +1 with 0 representing random agreement and higher values indicating significant agreement. Figures above 0.81 indicate acceptable to perfect agreement. There was near perfect agreement between the two raters (k =0.95). Full-texts were obtained for papers identified as potentially eligible and 30% of these were screened independently by SM resulting in 100% agreement.

Studies were included if they a) included participants identifying as Muslims, b) mentioned islamophobia (including variations such as anti-Muslim, anti-Islam, and religious discrimination specifically against Muslims), c) included participants aged 18 years or above, d) addressed the mental health and/or wellbeing of Muslims (including outcomes, pathways, or barriers to access), e) included primary quantitative and/or qualitative data, f) were published in the English language and g) were either published in a peer reviewed journal or as grey literature (e.g., government and third sector organisation reports).

Studies were excluded if they a) focused on ethnic/racial discrimination against Muslims and not specifically religious discrimination, b) included participants under the age of 18 with no separate analysis for those over the age of 18, c) analysed secondary data, d) reported an individual case study, e) were dissertations/theses, f) were a review or synthesis, and g) were not written in English.

Data extraction and synthesis

Key characteristics of each study included in the final analysis were extracted and input into a data extraction table produced in Microsoft Excel. The key information extracted included study author(s) and year of publication, study setting, sample information (number and demographics such as gender, age range, ethnicity, and any other available key information), outcomes (including measures used), method of data analysis, and key findings. Only relevant findings relating to the aim of the review were extracted for studies with multiple aims.

The narrative synthesis approach was used to synthesise data which involves summarising textual data so conclusions can be drawn about the body of research (Popay et al., 2006)

Quality appraisal

The papers included in the final analysis were appraised by two independent reviewers (SA and SM) using the Critical Appraisal Skills Programme (CASP) checklists for cohort (Critical Appraisal Skills Programme, 2018a) and qualitative (Critical Appraisal Skills Programme, 2018b) studies (see appendices 1E and 1F). The cohort studies checklist was used as there are no CASP tools for cross-sectional studies. The full quality appraisal process has been outlined in appendix 1G. The CASP tools were used as these are freely available, widely used, and easy to understand and apply.

All included papers were quality assessed independently by SA and SM resulting in almost perfect inter-rater reliability (k=0.91). All studies were included in the final review regardless of quality appraisal so any methodological issues with the current literature base could be highlighted in the conclusion of the review and for consideration in future research.

Reflexivity

The first author (SA) is a British Bangladeshi Muslim Trainee Clinical Psychologist who is particularly interested in mental health inequalities faced by marginalised groups and has lived experience of being a young carer for a parent who had a serious mental illness. The second reviewer (SM) is a British Kurdish Muslim Trainee Clinical Psychologist. The review supervisor (RV) is a British Asian Hindu Clinical Psychologist.

The researchers acknowledge that their experiences and research interests may have influenced the undertaking of this review and the analysis. Attempts were made to minimise bias through double rating and continuous discussion between the study team.

Results

Overview of included studies

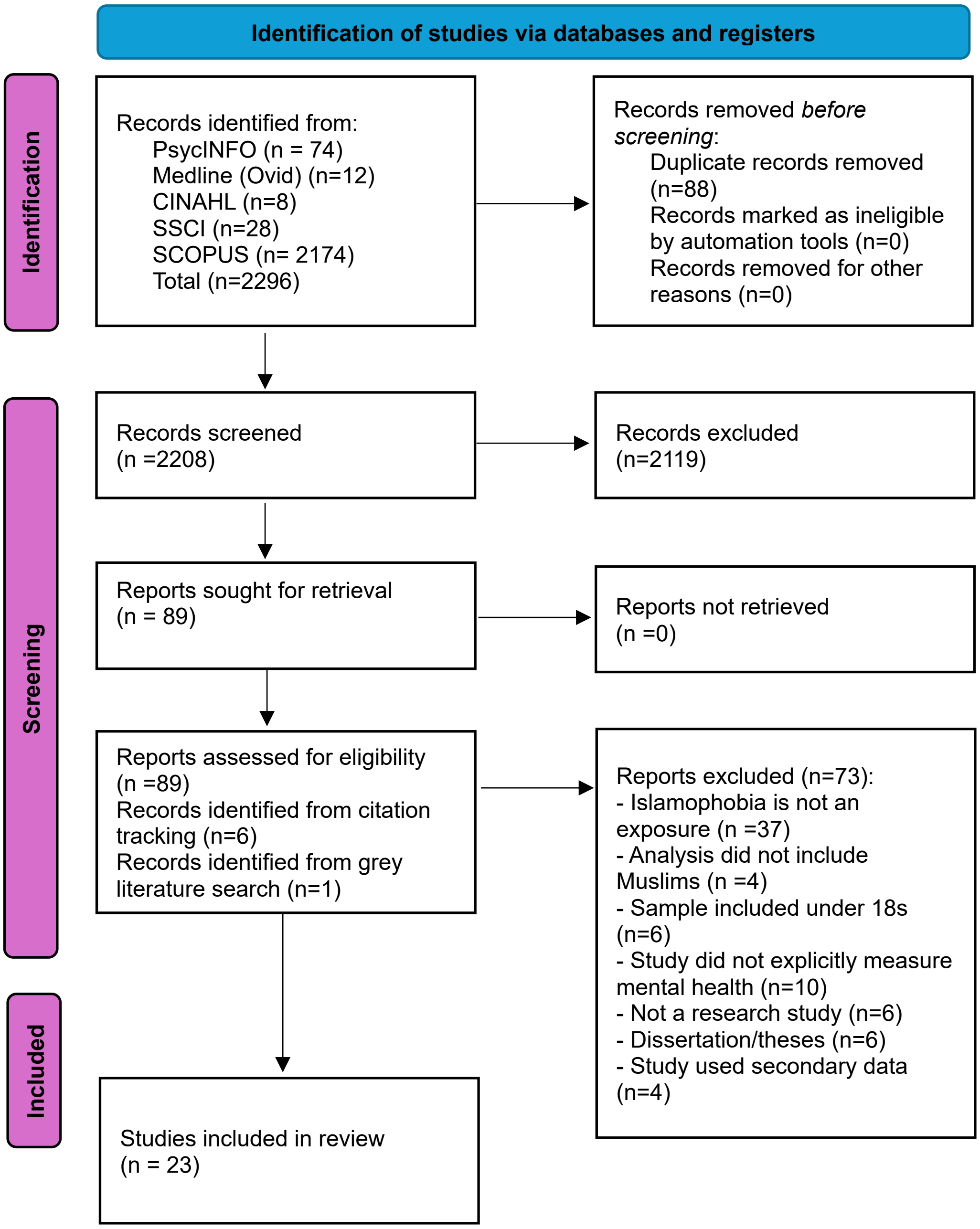
The search yielded 2296 results which reduced to 2208 following deduplication (see Figure 1). The screening of title and abstracts according to the eligibility criteria identified 89 papers for potential inclusion. Full text papers were obtained for each paper and reviewed for eligibility. This resulted in 17 papers being identified for inclusion in the final review. A further six papers were identified from backward and forward citation tracking of the previous review (Samari et al., 2018). Overall, 23 papers were included in the review.

Study characteristics

Study characteristics are summarised in Table 1. Fifteen studies were conducted in the United States (US), four in the UK (Ayub & Macaulay, 2023; Chaudry, 2021; Uddin et al., 2022; Weatherhead & Daiches, 2010), and one study each in France (Ameline et al., 2019), Australia (Every & Perry, 2014), Turkey (Görmez et al., 2021) and Canada (Zia et al., 2022). Three studies collected data through semi-structured interviews and were all conducted in England (Ayub & Macaulay, 2023; Chaudry, 2021; Weatherhead & Daiches, 2010). All twenty quantitative studies utilised self-report surveys for data collection which were delivered either online, on paper or a combination of the two. One study additionally collected qualitative data through a focus group with two women (Tetreault et al., 2019).

Figure 1

PRISMA flow diagram of study selection process and identified studies



Sample demographics

The sample sizes of studies varied, with two studies reporting a large sample of over 1,000 Muslims (Abelson et al., 2020; Abu-Ras et al., 2018) and four studies reported less than 100 Muslim participants (Ameline et al., 2019; Every & Perry, 2014; Sabado et al., 2023; Tetreault et al., 2019). The three qualitative studies reported much smaller samples as is typical for qualitative studies (Ayub & Macaulay, 2023; Chaudry, 2021; Weatherhead & Daiches, 2010). Two studies focused specifically on the experiences of Muslim women and the hijab (Görmez et al., 2021; Tetreault et al., 2019). Half of the studies had an almost equal number of men and women but ten reported samples consisting of more than 60% women (Abu-Ras et al., 2018; Ahmed & Islam, 2023; Hodge, Zidan, et al., 2015a, 2015b; Hodge et al., 2016; Hodge, Zidan, Husain, et al., 2015; Lowe, Tineo, Bonumwezi, et al., 2019; Lowe, Tineo, & Young, 2019; Tineo et al., 2021; Zia et al., 2022). One study reported a sample of more men participants than women (Rippy & Newman, 2006).

One study did not report data on age to preserve the anonymity of the small sample (Chaudry, 2021). All other studies reported ages ranging from 18 to between 60 and 75. One study reported an upper age range of 109 years (Sabado et al., 2023). Six studies sampled university students so the average ages of these samples tended to be younger (Abelson et al., 2020; Chaudry, 2021; Lowe, Tineo, Bonumwezi, et al., 2019; Lowe, Tineo, & Young, 2019; Tineo et al., 2021; Uddin et al., 2022).

Eight studies did not report data on the ethnicity of participants (Abelson et al., 2020; Ameline et al., 2019; Every & Perry, 2014; Görmez et al., 2021; Lowe, Tineo, Bonumwezi, et al., 2019; Lowe, Tineo, & Young, 2019; Tetreault et al., 2019; Weatherhead & Daiches, 2010). Two studies reported the proportion of Middle Eastern participants (Hodge, Zidan, et al., 2015b; Hodge et al., 2016) and one reported the proportion of non-Middle Eastern participants (Hodge, Zidan, et al., 2015a). Three studies included samples comprising of just South Asian Muslims (Ahmed & Islam, 2023; Ayub & Macaulay, 2023; Chaudry, 2021).

Table 1

Study characteristics and the quality assessment of each study

Study	Setting	Participant demographics	Data collection method	Quality assessment
Abelson, S., Lipson, S. K., Zhou, S. & Eisenberg, D. (2020)	US	• 75, 578 college students • 56.78% women • 2.24% Muslim • 18 years and above • Ethnicity of not reported	Survey	Moderate
Abu-Ras, W. M. & Suarez, Z. E. (2009)	US	• 102 Muslims • Aged 18-68 years (*M*=39.11; *SD*=11.59) • 50% women • *Ethnicity/race:* - Arab/Middle Eastern - 57.8% (n=59) - South/East Asian - 16.7% (n=17) - African American/Caribbean - 14.7% (n = 15) - Caucasian or Latino - 10.8% (n = 11)	Questionnaire (delivered as face to face interview)	High
Abu-Ras, W., Suarez, Z. & Abu-Bader, S. (2018)	US	• 1,130 Muslims (409 men, 706 women) • Aged 18 to 60+ years • *Ethnicity:* - White/Caucasian - 11.5% (n=129) - Black/African American - 11% (n=123) - Arab/Middle Eastern - 34.4% (n=386) - South/East Asian - 40.1% (n=450) - Hispanic/others - 3% (n=34)	Online survey	High
Ahmed, N. & Islam, N. S. (2023)	US	• 173 Muslim South Asians • 64.7% female, 0.6% Other • Aged 18 to 65+	Online survey	High

Ameline, A., Ndobo, A. & Roussiau, N. (2019)	France	• 88 Muslims • Mean age of 31.51 years (*SD*=9.53) • 47 women, 41 men • Ethnicity not reported	Self-report questionnaire (online and paper)	Moderate
Every, D. & Perry, R. (2014)	Australia	• 49 Muslims (21 women, 28 men) • Mean age – 30.1 years • Ethnicity not reported	Online survey	High
Gormez, A., Elbay, R. Y. &Karatepe, H. T (2021)	Turkey	• 101 Muslim women • Mean age of 43 years (*SD*=6.32) • Ethnicity not reported	Online survey	High
Hodge, D. R., Zidan, T., Husain, A. & Hong, P. H. (2015)	US	• 269 Muslims • Mean age of 38.36 years (*SD*=11.70) • 185 women (69%) and 84 men (31%) • Race/ethnicity: - European American/ other - 18% (n=49) - Middle Eastern - 37% (n=99) - African American - 15% (n=40) - Asian - 30% (n=81)	Survey (online and paper)	High
Hodge, D. R., Zidan, T. & Husain, A. (2015)	US	• 269 Muslims • Mean age of 38.30 years (*SD*=11.73) • 186 women (69.1%) • Non-Middle Eastern ethnicity – 63.2% (*n*=170)	Survey (online and paper)	High
Hodge, D. R., Zidan, T. & Husain, A. (2015)	US	• 265 Muslims • Mean age of 38.18 years (*SD*=11.77) • 183 women (69.1%) • Middle Eastern ethnicity – 37% (*n*=98)	Survey (online and paper)	High
Hodge, D. R., Zidan, T. & Husain, A. (2015)	US	• 265 Muslims • Mean age of 38.18 years (*SD*=11.77) • 183 women (69.1%)	Survey (online and paper)	High

		• Middle Eastern ethnicity – 37% (*n*=98)		
Lowe, S. R., Tineo, P. & Young, M. N. (2019)	US	• 141 Muslim college students • Mean age of 21.06 years (*SD*=3.57) • 73.8% women, 24.1% men, and 2.1% transgender • Ethnicity not reported	Online survey	High
Lowe, S. R., Tineo, P. Bonumwezi, J. L. & Bailey, E. J. (2019)	US	• 145 Muslim college students • Mean age of 21.21 years (*SD*=3.75) • 76.6% women or transgender and 23.4% men • Ethnicity not reported	Online survey	High
McLaughlin, M. M., Ahmad, S. S., & de Mamani, A. W. (2022)	US	• 350 Muslims • 174 women and 176 men • Mean age of 39.8 years (*SD*=14.8) • Race/ethnicity: - Middle Eastern/Arab - 13.4% (n=47) - South Asian - 24.5% (n=86) - East Asian - 1.7% (n=6) - Black/Afro-Caribbean/African - 20% (n=70) - Other - 1.0% (n=3) - Multiracial - 7.7% (n=27)	Online survey	High
Rippy, A. E. & Newman, E. (2006)	US	• 152 Muslims • 60 women and 92 men • Aged 18 to 71 years • Ethnicity: - Arab - 44% (n=62) - Southeast Asian - 22% (n=31) - African American - 18% (n=25) - Caucasian American - 16% (n=20)	Questionnaire	High
Sabado, J. A., Tram, J. M, Khan, A. N & lopez, J. M. (2023)	US	• 52 Muslims • Aged 18 to 109 years (*M*=34.38; *SD*=15.53)	Online survey	High

		• 28 women (53.8%), 2 nonbinary (3.8%), and 22 men (42.3%) • Ethnicity: - Black/African/ African American - 1.6% (n = 1) - Native American/American Indian/Alaska Native - 1.9% (n= 1) - Biracial/Multiracial - 9.6% (n = 5) - White/European American - 13.5% (n = 7) - Middle Eastern/Middle Eastern American - 21.3% (n = 11) - Asian/Asian American - 51.9% (n = 27)		
Tetreault, C., Tahir, S., Ezeamama, A. & Abbasi, F. (2019)	US	Survey: • 35 Muslim women • Aged 18 to 65 years • Ethnicity not reported Focus group: • Two women • One in her 50s and one in her 20s	Survey Focus Group	Low
Tineo, P., Lowe, S. R., Reyes-Portillo, J. A. & Fuentes, M. A. (2021)	US	• 209 Muslim college students • Mean age of 21.71 years (*SD*=4.53) • 70.7% women or transgender and 29.3% men • Race: - White - 35.4% - Asian - 24.9% - Black - 11.5% - Hispanic/Latinx - 3.8% - Hawaiian/Pacific Islander - 1% • - Other - 29.2%	Online survey	High
Uddin, M. F., Williams, A. & Alcock, K. (2022)	UK	• 457 British Muslim students • 52.5% women (n=240) and 47.5% men (n=217) • Aged 18 to 35 years (*M*=20.5; *SD*=2.1)	Online survey	High

		• Ethnicity: - Asian - 326 (71.3%) - Black - 55 (12%) - Middle Eastern - 32 (7%) - Mixed - 23 (5%) - Other - 21 (4.7%)		
Zia, B., Abdulrazaq, S. & Mackenzie, C. S. (2022)	Canada	• 238 Muslims • Aged 18 to 70 years (*M*=36.4; *SD*=11.9) • 69% women • Ethnicity: - South Asians -53.8% - Arab - 14.7% - African - 10.5% - White - 9.7% - East/Central Asian- 4.6% - Other (6.7%)	Online survey	High
		Qualitative studies		
Ayub, R. & Macaulay, J. R. (2023)	UK	• 7 British Pakistani Muslims (4 women and 3 men) • Aged 20 to 40 years	Semi-structured interviews (conducted online)	Low
Chaudry. I. (2021)	UK	• 4 Asian British/Pakistani Muslim university students • 2 women and 2 men	Semi-structured interviews	High
Weatherhead, S. & Daiches, A. (2010)	UK	• 14 Muslim participants • Aged 28 to 77 years • 7 women and 7 men • Ethnicity not reported	Semi-structured interviews	High

Note. US= United States; UK=United Kingdom.

Mental health outcomes

Studies reported on mental health outcomes including symptoms of depression, anxiety, PTSD, self-esteem, and general self-rated health (see Table 2). One study assessed symptoms of eating disorders (Abelson et al., 2020). Three studies reported symptoms of trauma (Abu-Ras & Suarez, 2009; Görmez et al., 2021; Lowe, Tineo, Bonumwezi, et al., 2019) and one study examined symptoms of paranoia (Rippy & Newman, 2006). One study investigated the impact of discrimination on substance use in Muslims (Hodge, Zidan, et al., 2015b).

A wide variety of outcome measures were used to collect data including the Patient Health Questionnaire (PHQ), Generalised Anxiety Disorder-7 (GAD-7), the Center for Epidemiologic Studies Depression Scale (CES-D), and the Beck Depression and Anxiety Inventories (see Table 2). The vast majority of studies utilised idiosyncratic measures consisting of five or fewer items devised by the study authors to capture the necessary data and only two studies reported using scales specifically measuring islamophobia (Ahmed & Islam, 2023; McLaughlin et al., 2022).

Table 2

Outcome measures used by each study

Study	Outcome measures	Islamophobia scale? (Y/N)
Abelson et al. (2020)	• Depression – Patient Health Questionnaiure-9 (Kroenke et al., 2001) • Anxiety – Generalised Anxiety Disorder-7 (Spitzer et al., 2006) • Eating Disorders – Sick, Control, One, Fat, Food (SCOFF) (Morgan et al., 1999)	N
Abu-Ras & Suarez (2009)	• Perception of discrimination – two-item idiosyncratic measure of perception of discrimination after 9/11 rated on a 6-point Likert scale and whether 9/11 resulted in job loss or not. • Perception of major life changes and sense of self-worth – six item idiosyncratic measure • Perception of feeling safe – two-item idiosyncratic measure rated on a 6-point Likert scale • Perception of PTSD symptoms – 13 item adapted version of Foa et al. (1993) measure of PTSD symptoms rated on a 4-point Likert scale	N
Abu-Ras, Suarez, & Abu-Bader (2018)	• PRD-related stress – Perceived Religious Discrimination Scale (PRDS) (Rippy & Newman, 2008) • Pre-exposure to religious-based discrimination (RBD) related stress – four-item idiosyncratic measure • Subjective wellbeing – three-item idiosyncratic measure • Perceived total impact of islamophobia on personal/family and community wellbeing – two-item idiosyncratic measure • Level of religiosity – Self-Rating Religiosity Scale (SRR) (Abdel-Khalek, 2007)	N
Ahmed & Islam (2023)	• General discrimination – Everyday Discrimination Index (EDI) (Williams et al., 1997) • Perceived anti-Muslim discrimination – Interpersonal Anti-Muslim Discrimination Index (IAMDI) and Societal Anti-Muslim Discrimination Index (SAMDI) (Ahmed, 2021) • Health risk behaviours – questions from the National Health Interview Survey (Centers for Disease Control and Prevention, 2018), National Health and Nutrition Examination Survey,	Y

	California Health Interview Survey (UCLA Center for Health Research, 2018), and Finnish Diabetes Risk Form (Zhang et al., 2014) • Depressive symptoms – Center for Epidemiologic Studies Depression Scale Revised (CESD-R) (Eaton et al., 2004)	
Ameline, Ndobo, & Roussiau (2019)	• Perception of religious discrimination in news media – six-item idiosyncratic measure • Identification with Muslim identity – six-item idiosyncratic measure • Self-esteem – Rosenberg Self-Esteem Scale (Rosenberg, 1965; "Rosenberg self-esteem scale," ; Vallieres & Vallerand, 1990) • Perceived Stress Scale (PSS-10) (Bellinghausen et al., 2009; Cohen et al., 1983)	N
Every & Perry (2014)	• The Perceived Religious Discrimination Scale (PRDS) (Rippy & Newman, 2008) • Rosenberg's Self-Esteem Scale (Rosenberg, 1965)	
Gormez et al. (2021)	• Post-Traumatic Embitterment Disorder Scale (PTED Scale) (Linden et al., 2009) • Beck Depression Inventory (BDI) (Beck et al., 1961) • Beck Anxiety Inventory (BAI) (Beck et al., 1988) • Brief Resilience Scale (BRS) (Smith et al., 2008)	N
Hodge et al. (2015)	• Health behaviours – two-item idiosyncratic measure • Psychological health – Center for Epidemiologic Studies Depression Scale (CES-D) short form (Melchior et al., 1993) • Spirituality – Religiosity of Islam Scale (Jana-Masri & Priester, 2007) • Contextual factors – idiosyncratic items measuring discrimination (Pew Research Center, 2011), spirituality, and self-rated health	N
Hodge et al. (2015)	• Discrimination – four item idiosyncratic measure (Pew Research Center, 2011) • Spirituality and religion – Religiosity of Islam Scale (Jana-Masri & Priester, 2007) • Depression – Center for Epidemiologic Studies Depression Scale (CES-D) short form (Melchior et al., 1993)	N
Hodge et al. (2015)	• Discrimination – Single item based on the Pew Research Center's survey on American Muslims' perception of discrimination (Pew Research Center, 2011)	N

	• Depression - Center for Epidemiologic Studies Depression Scale (CES-D) short form (Melchior et al., 1993) • Substance use – two item idiosyncratic measure • Spirituality – three items from Religiosity of Islam Scale (Jana-Masri & Priester, 2007)	
Hodge et al. (2015)	• Wellness – two item idiosyncratic measure (Organisation for Economic Co-operation Development (OECD), 2013) • Discrimination – single composite item based on the Pew Research Center's survey on American Muslims' perception of discrimination (Pew Research Center, 2011) • Depression - Center for Epidemiologic Studies Depression Scale (CES-D) short form (Melchior et al., 1993) • Spirituality – three items from Religiosity of Islam Scale (Jana-Masri & Priester, 2007)	N
Lowe et al. (2019)	• Depression – Patient Health Questionnaire-8 (Kroenke et al., 2009) • Anxiety – Generalised Anxiety Disorder-7 (Spitzer et al., 2006) • Perceived discrimination – adapted version of General Ethnic Discrimination Scale (Landrine et al., 2006) • Muslim American identity – adapted version of Multigroup Ethnic Identity Measure-Revised (Phinney & Ong, 2007)	N
Lowe et al. (2019)	• Lifetime exposure to DSM traumatic events – 20-item checklist (Breslau et al., 1998) • Lifetime exposure to discrimination – single item idiosyncratic measure • Past-year perceived discrimination – adapted version of the General Ethnic Discrimination Scale (Landrine et al., 2006) • PTSD symptoms – Posttraumatic Checklist for DSM-5 (PCL-5) (Weathers et al., 2013)	N
McLaughlin et al. (2022)	• Attitudes Toward Seeking Professional Psychological Help Scale - Short Form (Fischer & Farina, 1995) • Depression, Anxiety, and Stress Scale (DASS-21) (Henry & Crawford, 2005) • Self-Stigma of Seeking Help Scale (SSOSH) (Vogel et al., 2006) • Perceived Islamophobia Scale (PIS) (Kunst et al., 2013)	Y

	• Therapist Demographics and Treatment Modality Preferences – idiosyncratic measure • Open-Ended Questions	
Rippy & Newman (2006)	• Discrimination/hate crime – idiosyncratic measure informed by previous literature (Council on American-Islamic Relations, 2003; Ephross et al., 1986) • Perceived Religious Discrimination Scale (PRDS) (Rippy & Newman, 2008) • Endler Multidimensional Anxiety Scale – State (EMAS-S) (Endler et al., 1991) • Endler Multidimensional Anxiety Scale-Trait (EMAS-T) (Endler et al., 1991) • Paranoia Scale (PS) (Fenigstein & Vanable, 1992)	N
Sabado et al. (2023)	• Acculturation Scale for Muslims Americans (ASMA) (Bagasra & Mackinem, 2019) • Mental Health Behaviours – two item idiosyncratic measure	N
Tetreault et al. (2019)	• Hijab status and women's experiences of anti-Muslim aggression – idiosyncratic measure • Vulnerable situations/places and timeline for feeling unsafe – idiosyncratic measure • Emotional experiences – idiosyncratic measure of emotional experiences as a result of islamophobia • Communicative and technological coping strategies for feeling safe – idiosyncratic measure • Community organisations and activism – idiosyncratic measure	N
Tineo et al. (2021)	• Perceived discrimination – Perceived Religious Discrimination Scale (PRDS) (Rippy & Newman, 2008) • Acculturative stress – Social, Attitudinal, and Environmental Acculturative Stress Scale, Short Form (SAFE-SF) (Mena et al., 1987) • Major depression – Patient health Questionnaire-8 (PHQ-8) (Kroenke et al., 2009) • Generalised anxiety – Generalised Anxiety Disorder-7 (GAD-7) (Spitzer et al., 2006) • Religious support – participant support subscale from Multifaith Religious Support Scale (MFRSS) (Bjorck & Maslim, 2011) • Muslim identity – adapted version of Multigroup Ethnic Identity Measure-Revised (MEIM-R) (Phinney & Ong, 2007)	N

Uddin et al. (2022)	• Perceived discrimination – Perceived Discrimination Scale (PDS) devised using series of questions from existing measures (Jasperse et al., 2012; Kunst et al., 2013; Nadal et al., 2012; Noh & Kaspar, 2003) • Depression – Patient Health Questionnaire-9 (Kroenke et al., 2001) • Anxiety – General Health Questionnaire-12 (Kashyap & Singh, 2017) • Positivity – Positive Feelings Facet (PFF) (The WHOQOL Group, 1998) • Visibility of Muslim identity – idiosyncratic measure	N
Zia et al. (2022)	• Psychological help-seeking preferences – five-item idiosyncratic measure (Mackenzie et al., 2004) • Religiosity – Religiosity of Islam (ROI) scale (Jana-Masri & Priester, 2007) • Psychological distress – Kessler Distress Scale (K6) (Kessler et al., 2003) • Service use – three items modified from National Comorbidity Survey (Kessler, 1994)	N

Quality appraisal

The quality of the studies varied (see Table 1) and have been considered in more depth within the synthesis below. Most studies were rated as being of moderate to high quality. High quality studies clearly reported the aims of their research, the methodology utilised, and the recruitment strategy employed to target the necessary population. These studies further outlined their analyses clearly and framed their findings within the context of the wider literature and applicability to meeting the needs of Muslims.

The most common methodological limitation affecting the studies was the lack of standardised measures used to collect data. Only two studies reported using a tool that specifically measured islamophobia (Ahmed & Islam, 2023; McLaughlin et al., 2022). The remainder used measures of general discrimination adapted for Muslims such as the General Ethnic Discrimination Scale which was adapted to include “Muslim American Identity” (Lowe, Tineo, & Young, 2019).

All included studies relied on self-selecting samples potentially introducing a bias whereby those choosing to participate may have been different to those who did not. Two studies in particular were rated as low quality due to insufficient details about recruitment, analyses, and findings (Chaudry, 2021; Tetreault et al., 2019).

Relationship between islamophobia and mental health

Studies generally focused on the impact of islamophobia and religious discrimination on symptoms of common mental health conditions such as depression and anxiety. Islamophobia and perceived religious discrimination were associated with increased symptoms of depression and anxiety (Ahmed & Islam, 2023; Görmez et al., 2021; Hodge, Zidan, et al., 2015a, 2015b; Hodge, Zidan, Husain, et al., 2015; Lowe, Tineo, & Young, 2019; Tineo et al., 2021; Uddin et al., 2022). Symptoms of PTSD (Abu-Ras & Suarez, 2009; Lowe, Tineo, Bonumwezi, et al., 2019), low self-esteem (Every & Perry, 2014), and paranoia (Rippy & Newman, 2006) were also found to be associated with islamophobia (see Appendix 1H).

One earlier study focusing on the aftermath of the 9/11 attacks, reported a high number of PTSD symptoms with more than 90% of the Muslim sample reporting symptoms such as sadness and tearfulness and almost 20% reporting suicidal ideation (Abu-Ras & Suarez, 2009). Although this study did not find an association between perceived discrimination and PTSD symptoms, a large proportion of the sample reported feeling less safe since 9/11 and this was associated with symptoms of PTSD. The authors measured PTSD using a standardised measure (Foa et al., 1993) which they adapted by reducing the items and using a binary response option instead of the original 4-point Likert scale but it was unclear why these changes were made. The remaining outcomes were measured using items formulated by the researchers based on previous literature on Arabs and Muslims.

Abu-Ras et al. (2018) additionally reported feelings of being unsafe were associated with lower quality of life and increased stress (Abu-Ras et al., 2018). Although, the findings were strengthened by the inclusion of various confounders in the analysis including migration status, ethnicity, and income, the authors utilised short unstandardised measures. The standardised measure that was used for religious discrimination (Rippy & Newman, 2006) is 33 items long and mentioned racism and conflict within the context of war.

Specific discriminatory acts such as being called offensive names and being singled out by law enforcement were found to be associated with clinically significant levels of depression (Hodge, Zidan, et al., 2015a). This study was strengthened by the use of a standardised measure for depression, but the authors did not use a standardised measure for discrimination. Spirituality and religiosity were measured using two items chosen from a religiosity of Islam scale (Jana-Masri & Priester, 2007). It was unclear why these items were chosen and why the original response keys were changed. One item measured Friday mosque attendance despite this being an obligatory act for only Muslim men and the sample consisting of largely women.

Reports of recent discrimination in the past year were also associated with symptoms of PTSD - the severity of which was comparable to PTSD symptoms caused by traumatic events (Lowe, Tineo, Bonumwezi, et al., 2019). This study used college students from one US university and was unique in its co-production of the survey with Muslims. The measures used in this study included a standardised measure of PTSD (PTSD Checklist for DSM-5; Weathers et al. (2013)) and an adapted version of a scale originally designed to measure ethnic discrimination but few details were provided of the adaptations made. Although the authors aimed to measure the difference in PTSD symptoms as a result of discrimination compared to trauma, it is possible that the trauma may have been a result of discrimination – a limitation acknowledged by the authors.

Political decisions which disproportionately impacted Muslims had a negative impact on mental health as demonstrated by a study which found higher symptoms of depression and anxiety and a larger decline in mental health in Muslims compared to non-Muslims after a ban on people from Muslim-majority countries entering the US (Abelson et al., 2020). This study utilised standardised scales to measure outcomes, but the sample consisted of solely college students thus limiting the generalisability of the findings. The findings also showed a decline in the mental health of non-Muslims, although not as pronounced as for Muslims, but this was not commented on by the authors. It is possible that other factors such as racial discrimination may partly explain these results, but this was not accounted for by the authors.

Görmez et al. (2021) reported on symptoms of Post Traumatic Embitterment Disorder (PTED) – a disorder proposed to account for extreme feelings of embitterment as a result of negative but normal life events, such as divorce (Linden, 2020). The supposed core difference between this disorder and PTSD is the negative event is not life-threatening but rather an affront to one's values and beliefs system including injustice and discrimination (Linden, 2020). The hijab ban implemented in Turkey in 1997 resulted in Muslim women affected by the ban reporting symptoms of embitterment, depression and anxiety more than 20 years later (Görmez et al., 2021). Victims of an earthquake were recruited to compare embitterment symptoms but the choice of this comparison group was not clear as PTED was conceptualised to account for non-life threatening events (Linden, 2020). This was one of the only studies to explore the impact of islamophobia at an institutional level.

Gender appeared to play a role in the relationship between mental health and islamophobia. Women generally reported experiencing more discrimination compared to men (Abu-Ras et al., 2018; Uddin et al., 2022) and this coincided with increased reluctance to leave home, higher levels of depression and anxiety, and generally feeling less safe (Abu-Ras et al., 2018; Abu-Ras & Suarez, 2009; Uddin et al., 2022). Muslim men reported fewer depression symptoms (Hodge, Zidan, et al., 2015a) but were more likely to report feelings of exhaustion and thoughts of suicide compared to women (Abu-Ras & Suarez, 2009). It should be noted that Uddin et al. (2022) used a mixture of items and subscales from different scales to measure discrimination and it was unclear whether confounders were included in the analysis. The study consisted of a largely South Asian sample of university students limiting its generalisability. This study also collected qualitative data but did not systematically analyse the data.

Rippy and Newman (2006) additionally reported an association between subclinical paranoid ideation and perceived discrimination for men but found no relationship between perceived discrimination and anxiety. The authors adapted a 34-item scale that was originally used to measure racial discrimination within Asian American military personnel, but the adapted items made specific mention of Arabs and identification with this group despite Muslims not being tied to one ethnic group. The authors commented on the gender disparity of their findings by citing data indicating Muslim men were the target of increased suspicion and hostility following the 9/11 attacks.

Demonstrating the complex nature of the impact of discrimination, symptoms of depression were found to mediate the relationship between discrimination and subjective wellness such that experiencing discrimination was associated with depression which in turn lowered subjective wellness (Hodge et al., 2016). However, Hodge et al. (2016) used a largely female sample and measured the concept of “wellness” which did not appear to be a well-defined concept thus raising uncertainty about its measurement using two items which were not standardised. Both societal and interpersonal anti-Muslim discrimination were associated with depression and societal, but not interpersonal, anti-Muslim discrimination was additionally associated with reduced physical activity (Ahmed & Islam, 2023). Ahmed and Islam (2023) used standardised tools to measure islamophobia, but the sample consisted of only South Asian Muslims.

Discrimination was also found to exert an indirect impact on depression and anxiety through acculturative stress (Tineo et al., 2021). This study recruited college students from one university and used the aforementioned PRDS to measure islamophobia. Acculturative stress was measured using a scale originally validated for different ethnic groups and immigrants, not Muslims (Mena et al., 1987) with some items referring to accents. The different acculturation strategies, as proposed by Berry (1992), were not measured making it difficult to disentangle the different processes that may be influencing the relationship.

Religiosity and visible indicators of being a Muslim were related to increased discrimination and poorer mental health (Abelson et al., 2020; Tetreault et al., 2019; Uddin et al., 2022). The findings from Tetreault et al. (2019) should be considered with caution as this study contained a number of quality shortcomings. A survey was used to collect both quantitative and qualitative data but the survey items – developed by the authors – appeared leading. For instance, participants were presented with only negative emotions when asked about their emotional responses to islamophobia. The authors did not appear to consider confounders and reported non-significant results without highlighting that it was in fact nonsignificant. The authors mentioned that it was a pilot study in the discussion.

Social support was reported to buffer the relationship between islamophobia and poor mental health with institutional discrimination increasing self-esteem (Every & Perry, 2014) and reducing levels of stress by strengthening one's group Muslim identity (Ameline et al., 2019). Every and Perry (2014) used the previously mentioned PRDS (Rippy & Newman, 2006) – the limitations of which have been discussed. The study consisted of a young sample and reported few demographic details without comment on whether these factors were accounted for in the analysis. Ameline et al. (2019) similarly reported few demographic details of the sample but was strengthened by the use of standardised outcome measures.

Daily prayer and religious support were found to be associated with lower levels of depression (Hodge, Zidan, et al., 2015a; Tineo et al., 2021) and better self-rated health (Hodge, Zidan, Husain, et al., 2015). Hodge, Zidan, Husain, et al. (2015)'s study was strengthened by the numerous confounders that were included in the analysis. Two items from the religiosity of Islam scale (Jana-Masri & Priester, 2007) were used to measure spirituality and religiosity but few details were provided of why these items were chosen.

Help-seeking attitudes and behaviour

Five studies reported on the help-seeking behaviours and attitudes of Muslims (Ayub & Macaulay, 2023; McLaughlin et al., 2022; Sabado et al., 2023; Weatherhead & Daiches, 2010; Zia et al., 2022). Perceived islamophobia was reported to be associated with greater levels of psychological distress which indirectly led to positive views about help-seeking (McLaughlin et al., 2022). However, islamophobia was also reported to increase stigmatised attitudes towards help-seeking thus decreasing positive attitudes towards seeking help (McLaughlin et al., 2022). Overall, perceived islamophobia was reported to negatively influence help-seeking attitudes which the authors speculated may indicate self-stigma has a greater influence on the relationship between islamophobia and help-seeking attitudes compared to distress. Although this study was considered of higher quality than most of its counterparts, the study was rated down due to the use of unstandardised measures for therapist demographic and treatment preferences (McLaughlin et al., 2022). The authors described the use of content analysis for analysing the qualitative data but did not report on reflexivity.

Acculturation was identified as playing a role in help-seeking. When Muslims identified closely with their Islamic values, this lowered the likelihood of seeking help from mainstream mental health services but acculturating to American values led to a higher likelihood of seeking help from services (Sabado et al., 2023). This study used a 53-item questionnaire for data collection, including an acculturation measure described as consisting of both 16 and 14 items whilst the original measure (Bagasra & Mackinem, 2019) described only 13 items. Mental health behaviours were measured using vague and unspecific questions leaving it open to subjective interpretations. This study did not measure Berry (1992)'s original acculturation strategies or explore attitudes towards help-seeking for those who integrated both their Islamic and American values or those who experienced conflict in the process of acculturation.

Some studies explored where Muslims are likely to seek help from for psychological distress. One study reported that Muslims expressed a preference for a therapist of the same religion and ethnicity with more than half indicating a preference for a therapist of the same gender (McLaughlin et al., 2022). Attitudes towards medication and therapy did not differ but when presented with a choice, individual therapy was preferred over group or family therapy (McLaughlin et al., 2022). While there was support for involving an imam in therapy, concerns such as privacy, lack of incompatibility between religion and therapy and the imam's qualifications were expressed (McLaughlin et al., 2022).

Studies with samples consisting of more women than men found a greater preference for seeking help from family/friends as opposed to mainstream services or an imam (Tetreault et al., 2019; Zia et al., 2022) whereas McLaughlin et al. (2022) reported men were significantly more likely to indicate greater preference for treatments which include imams. This may be a reflection of imams exclusively being men but the authors of these studies did not seem to take this into consideration.

Some studies reported that previous experience of seeking help from a mental health service was associated with positive attitudes towards future help seeking from a mental health service possibly indicating that seeking help may be easier once Muslims have an idea of what treatment may look like (McLaughlin et al., 2022; Zia et al., 2022). Zia et al. (2022) used standardised measures for psychological distress, religiosity and help-seeking preferences but service use was measured by simply asking participants if they had sought help previously from five different sources including an imam. Considering the sample was largely female (69%) it is unclear why the study did not include other sources of religious help-seeking. The authors speculated that imams may not be a preferred source of help-seeking due to the reluctance to discuss potential sins but did not expand further.

A study from the US reported that a significant barrier to care can be practical issues such as cost and insurance (McLaughlin et al., 2022). This study also indicated that reviews and recommendations for the therapist can also play a role in whether they choose to seek care from mental health professionals or not highlighting the different factors at play for Muslims in different parts of the world.

Qualitative findings

Students in the UK reported isolating themselves and policing their academic contributions and clothing due to feelings of paranoia, suspicion, heightened stress, and depression and anxiety (Chaudry, 2021). While Chaudry (2021)'s study was strengthened by the attention to reflexivity and potential biases of their own positioning, the study consisted of university students from one UK university who all identified as Pakistani thus limiting the findings' generalisability. The author commented that recruitment and interviews were largely dictated by practicalities.

One study which interviewed Muslims to explore their views about mental health and mental health treatment reported that islamophobia was a barrier, amongst others, to seeking help (Weatherhead & Daiches, 2010). Muslims in this study reported a combination of both religion and life events as causing poor mental health and described relying on religion and family and friends for support and mainstream services being a last resort for 'serious' problems. Participants identified barriers to seeking help including stigma, shame, islamophobia, and service shortcomings such as not being offered therapy and previous negative experiences. Participants reported a desire for greater integration of religion into therapy and for therapists to be trustworthy and respectful of Muslims. Some reported that the religion of therapists is not important whilst others reported that demystifying therapy could reduce barriers for Muslims. Weatherhead and Daiches (2010) provided a good overview of the methods used to obtain their data including details about the development of the interview guide. The authors acknowledged they were non-Muslims, discussed contradictory findings and reported details of participants' previous experience of mental health services – a factor many studies failed to report.

Muslims additionally expressed the importance of ensuring mental health professionals are trustworthy and appropriately qualified but were apprehensive about how religion may be incorporated into therapy sessions (Ayub & Macaulay, 2023; Weatherhead & Daiches, 2010). There was a strong preference by participants for integration between mainstream services and Islamic frameworks (Ayub & Macaulay, 2023; Weathers et al., 2013) with some commenting that mainstream mental health services will not be able to meet the needs of Muslims unless there is greater integration of both a psychological framework and Islamic teachings as not doing so can fail to acknowledge a large aspect of many Muslims' life and values (Ayub & Macaulay, 2023).

Both Ayub and Macaulay (2023) and Weatherhead and Daiches (2010) reported that participants felt religion was protective and encouraged help-seeking from mainstream services where needed and this should be disentangled from cultural practices which stigmatise help-seeking. Both studies also identified themes regarding the older generation's lack of trust of professional services, compared to the younger generation's, indicating a generational difference in attitudes towards help-seeking.

While Weatherhead and Daiches (2010) considered their positioning in relation to the participants, Ayub and Macaulay (2023) failed to give such consideration to reflexivity. Ayub and Macaulay (2023) sampled only British Pakistani Muslims thereby limiting the generalisability of the findings. While the authors provided a good overview of their methods and procedures used, the interview schedule appeared to contain leading questions such that participants were specifically asked about barriers and stigma instead of allowing for participants to bring these up organically. The findings included themes on generational differences, but the authors did not appear to comment on the sample being no older than 40 years.

Discussion

This review synthesised the literature on the impact of islamophobia on the mental health and wellbeing of Muslims, including help-seeking preferences. Twenty-three papers were identified, with findings suggesting that islamophobia is associated with poorer mental health including symptoms of depression, anxiety, PTSD, and low self-esteem. Muslims revealed a preference for seeking help from family and friends over mainstream services and imams, and attitudes to help-seeking depended on acculturation, the level of distress experienced and previous experiences of helping-seeking.

This review identified factors which either worsened or lessened the impact of islamophobia on mental health. Visible signs of being a Muslim, such as the hijab, and acculturative stress resulted in poorer mental health (Abu-Ras et al., 2018; Uddin et al., 2022). Visible Muslims reported increased experiences of islamophobia which heightened acculturative stress. This is consistent with SIT and ITT which posit that such visibility would increase threat perception and exacerbate hostile responses towards Muslims including increased discrimination.

Social support, daily prayer and a strong Muslim identity appeared to buffer the impact of islamophobia on mental health (Ameline et al., 2019; Every & Perry, 2014; Tineo et al., 2021). This is consistent with previous research illustrating that outgroup members attempt to resist and challenge outgroup denigration by strengthening their relationship with the outgroup (Crabtree et al., 2010; McCoy & Major, 2003). Islamophobia on an institutional level appeared to have less of an impact on mental health than when it was experienced on an individual level. Future research is needed to further investigate this relationship as this suggests that encouraging Muslims to further explore their religious identity and seek peer support may mitigate the effect of islamophobia.

Muslims appeared to be hesitant about help-seeking from mainstream services due to islamophobia and worries about trusting professionals (McLaughlin et al., 2022; Weatherhead & Daiches, 2010) but they were keen for services to explore and offer treatments that integrated traditional psychology with Islamic principles and men expressed a preference for collaboration with imams (Ayub & Macaulay, 2023).

This review was limited by the methodological weaknesses of the included studies including the majority employing a cross-sectional design limiting the causal conclusions of the findings. While the large majority of studies were of high or moderate quality, the validity of findings was severely limited by the lack of standardised measures especially for islamophobia. Future research would benefit from the development of standardised islamophobia measures so the distinct impact of islamophobia can be considered.

Authors did not appear to interrogate their own positioning and how this may influence the design and interpretation of the study. This was prominently reflected in studies focusing on gender-specific Islamic practices such as Friday prayers - ascribed for only men. McLaughlin et al. (2022) further reported men were more likely to endorse preference for imams than women but did not comment on imams being men nor present alternative options for women. These limitations must be addressed in future studies to ensure the experiences and preferences of Muslims are captured accurately.

This review aimed to include studies focusing on Muslims' pathway to services but did not identify any such studies. This is a gap in the literature that should be addressed by future research. This review did not include dissertations or theses due to these not being peer reviewed which may have inadvertently led to important research on overlooked areas being missed.

The findings of this review suggest that islamophobia should be considered within clinical contexts and Muslims may benefit from including such experiences in psychological formulations. While interventions have been adapted for Muslims (Mir et al., 2015), these do not take into consideration the role islamophobia may play in the development of psychological problems. Academics and professionals alike may also benefit from educational training on Islam and considerations when working with Muslims, such as Muslims potentially being hesitant to voice their islamophobic experiences for fear of misinterpretation of their experiences or potential repercussion due to staff training on the prevent strategy. This may lead to Muslims self-censoring thus not addressing the root cause of their presenting challenges. It is equally possible that if clinicians providing interventions do not feel adequately supported or trained in discussing difficult topics such as racism and islamophobia, they may avoid discussing such topics while delivering interventions, which could risk disengaging Muslim service-users and potentially add to the reported poor outcomes for Muslims (Baker & Kirk-Wade, 2024).

The findings of Ayub and Macaulay (2023), McLaughlin et al. (2022), and Weatherhead and Daiches (2010) suggest that Muslims may benefit from signposting to support groups that operate through an Islamic framework and allow an opportunity to access social support. Alternatively, mental health services may support existing community groups to widen their reach through partnering programmes or consider jointly working with organisations such as mosques.

The findings of this review suggest islamophobia has a negative impact on the mental health of Muslims and may prevent help-seeking. Future research is needed to better understand mitigating factors and how these may be incorporated into mainstream mental health services to increase help-seeking.

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Service Improvement Project

Title: Identifying young carers from minoritised ethnic groups – Understanding the barriers and facilitators as experienced by Early Intervention for Psychosis staff

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Word Count (excluding references and appendix): 4, 967
Revised word count: 5, 350
Date of Submission: August 2024

Proposed Journal: BMC Psychology. This is a peer-reviewed and open access academic journal which invites articles on a wide range of topics related to psychology and human behaviour. Submission guidelines for this journal have been outlined in Appendix 2A.

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Abstract

Background: Young carers are young people under 18 years who provide unpaid, informal care to a relative or friend, including those with a serious mental illness. Several challenges present in the identification of young carers including a general lack of awareness of the young carer role. It is important for professionals, such as mental health services' staff, who may encounter young carers, to be aware of and supported in identifying young carers.

Aim: To understand and explore the experiences of staff in an Early Intervention for Psychosis service in Berkshire and their perspectives of the barriers and facilitators to identifying young carers so recommendations can be formulated for addressing these barriers.

Methods: Two focus groups were run with staff from the Slough and Reading EIP teams, including care coordinators, a team manager, an advanced clinical support worker, and Trainee Clinical Psychologist. A semi-structured topic guide was used to facilitate the groups. Framework analysis was used to analyse data.

Results: Five categories were identified from the focus groups: i) Impact of contextual factors, ii) Opportunities to identify young carers, iii) Staff's views about enquiring, iv) Classification and criteria of young carer, and v) Knowledge and availability of support. Suggested recommendations for the service were presented to staff in a business meeting and met with a positive response.

Conclusions: Several challenges to identifying young carers at the Berkshire EIP service were identified. Recommendations for addressing these challenges were positively received, with training on young carers being planned for September 2024.

Key words: young carers, psychosis, early intervention, mental health, ethnic minority

Background

Young carers are people under the age of 18 who provide informal care to a relative with a physical and/or mental health condition (1). Their caring responsibilities are substantial and would usually be expected of adults (2, 3). They include, but are not limited to, household chores, emotionally supporting the care recipient, intimate care (e.g., washing, assisting with toileting, dressing), childcare, accompanying the relative to appointments, acting as an interpreter, and financial responsibilities (e.g., helping with bills and collecting benefits) (4). It is estimated that up to half of young carers are caring for a relative with a mental health condition (4, 5), including psychosis.

Figures indicate that more than a third of people with psychosis under secondary care services are parents (6). Psychosis is characterised by ‘positive’ symptoms of hallucinations and delusions and ‘negative’ symptoms of reduced motivation and emotional expression (7). People experiencing a first episode of psychosis are managed within an Early Intervention for Psychosis (EIP) service (7). Caring for a person with psychosis can be difficult especially for a first episode where families may be unprepared (8, 9). Adult carers have described it as ‘full-time’ and feel they have to be ‘on alert’ at all times, and some report that the caring continues even after their relative has recovered (8). Although carers can describe becoming closer to the patient as a result of spending more time together (8), without support they can be vulnerable to a decline in their mental health (9, 10).

Caring responsibilities can be tougher for children, who describe feeling lonely and ‘trapped’ as a result of taking on caring responsibilities for a parent with serious mental illness (11). Unlike adult carers, who appreciate the support of mental health professionals and being treated as partners, young carers commonly describe being left out of discussions and not being acknowledged despite providing care at home (12-14).

The identification of young carers is a significant problem, with many only identified at crisis points when safeguarding concerns are identified (3, 15, 16). This is an even greater problem for minoritised ethnic young carers who, despite being more likely to be a young carer, are far less likely to be identified compared to their white peers (4, 17). Several factors contributing to this have been identified, including people from minoritised groups being more likely to experience serious mental illnesses (18) and socioeconomic conditions conducive to young people taking on caring responsibilities. A lack of accessible information about the young carer role means many young people and their families do not look for support, especially where first language is not English for the service-user (17, 19). One major barrier to revealing the young person's carer status is a fear of social services' involvement and the fear of losing custody of children (4, 19, 20).

Mental health professionals in EIP services are well placed to identify young carers, especially as minoritised ethnic young carers have been noted to accompany adult relatives to appointments to help interpret (20). However, staff may not be aware of the young carer role and available support, or feel trained to communicate with young children (21). Hence, any contact with dependants is largely borne out of safeguarding concerns (22, 23).

Improving staff's understanding of the young carer role and how to identify dependants with caring responsibilities could help to ensure that young carers are acknowledged, supported, and provided with appropriate information about the adult service-user's illness (12, 13). Talking to young carers could also help staff to gain a better understanding of the service-user's functioning at home and signs they might be relapsing, to provide tailored psychoeducation to help the whole family manage (8, 13). To make improvements, it is first necessary to gain an understanding of staff's perspectives of working with service-users with dependants and young carers.

Service context

Consistent with national data, the identification and recording of young carers is variable across the county of Berkshire. The county consists of six devolved Local Authorities (LA), each of which has its own EIP team and pathway for young carers. Each LA varies in its demographics, with East Berkshire having a larger population of minoritised ethnic individuals compared to West Berkshire. Slough in East Berkshire has an almost 40% higher proportion of South Asian individuals compared with the entirety of Southeast England (24).

The 2021 census revealed that Slough (East) and Reading (West) have the highest levels of deprivation and are most densely populated of all the six LAs in Berkshire. They also have high numbers of young carers (25), but the census data may underestimate the true numbers of young carers in Berkshire, since census data are based on self-report. It is likely that the EIP teams in Berkshire encounter young carers supporting a relative with psychosis, particularly those serving LAs with high proportions of deprivation and minoritised ethnic individuals. There is currently no clear guidance or mechanism for staff to identify and record young carers.

Aims

This project aimed to understand the experiences of staff from two EIP teams in Berkshire about working with dependants and identifying young carers, including those from a minoritised ethnic group. The project aimed to understand the barriers and facilitators to identifying young carers. The findings would be used to develop recommendations to support mental healthcare professionals within Berkshire EIP teams and other relevant professionals locally to identify young carers, including those from minoritised ethnic groups.

Methods

This project commenced while SA was a Trainee Clinical Psychologist on clinical placement in the Berkshire EIP service. The design was informed by the Institute for Healthcare Model for Improvement (26) matching the discovery phase: gathering information to understand the system and inform a future "Plan, Do, Study, Act" (PDSA) cycle to implement and evaluate suggested improvements. The Trust's clinical governance team approved the project as audit and service evaluation (ID: 9560).

Participants

Staff from two Berkshire EI teams participated. These teams serve LAs that are similar in demographics, with the only difference being in the proportion of minoritised ethnic residents (it was hoped this would enable understanding of any pertinent factors related to ethnicity).

Two focus groups were run. The first focus group (FG1) was conducted with staff from the Slough (East) team and consisted of five participants, including two care coordinators, the team lead, an advanced clinical support worker, and a trainee clinical psychologist. The second focus group (FG2) was conducted with the Reading (West) team and included three care coordinators.

Procedure

SA attended weekly multidisciplinary team (MDT) meetings and presented the aims and requirements of the project. Staff were asked to contact SA directly if they were interested in participating. Following contact, they were sent a participant information sheet and consent form (see appendix 2B) to complete. Each focus group was arranged at a convenient time for staff and was facilitated by SA. Focus groups were the chosen method of data collection as opposed to individual interviews so participants could engage in a discussion with one another about barriers and facilitators that they have experienced collectively or perhaps individually. The focus groups were one-hour long and conducted on Microsoft Teams using a semi-structured topic guide (see Table 1 for interview questions and appendix 2C for full interview schedule). They were audio-recorded on a separate secure device.

Table 1

Overview of questions and prompts used during focus groups.

Topic	**Question**	**Prompts/Optional questions**
Working with service users with children	1. What have been your experiences of working with service users from minoritised ethnic groups who have children under the age of 18?	• (if not worked with service users from minoritised ethnic groups, then just parents in general). • Have you worked with service users who are not parents but have children in their home/dependants? (e.g., siblings)
Caseload and recording	2. How many service users from minoritised ethnic groups do you have on your caseload, or have you previously worked with, that have dependants under the age of 18?	• Why do you think there are so many/few service users with dependants? • Would you consider siblings or any other children under the age of 18 living with the service user as 'dependants'?
	3. How would you typically find out that a service user has dependants?	

	4. Are there any processes that follow once you find out a service user has dependants?	• How would you usually record this information? E.g., is there a particular field on RiO you would populate with this information or would it go on their notes?
Identifying and recording young carers	5. How would you know if a service user's dependant(s) is a young carer?	
	6. What would typically happen once you find out a dependant under the age of 18 is providing care for the service user?	• What would you usually do with this information? • Have you previously spoken to a service user and their children about the possibility that the dependant might be classified as a young carer? ○ Why/why not?
	7. Have you ever offered a carer's assessment for a dependant?	• What about for a dependant from a minoritised ethnic group? • Why/why not? • How would you feel about explaining the process of a carers assessment for a young person?

	8. If a care coordinator in the team left and you were taking over their case load, how would you know if one of the service users on their caseload has a dependant that is also a young carer?	• More specifically where might you look to find this information?
	9. How would you describe the process of identifying a young carer?	• What would you say makes it difficult to identify if a dependant is a young carer? • What would make it easier to identify if a dependant is a young carer so they can be referred for an assessment?
	10. What kinds of practical recommendations would make working with young carers easier for you?	*Some examples if few responses:* • RiO • Resources • Joint working with social care • Some sort of record keeping of dependents and young carers? • A whole family approach?

Data analysis

Data were analysed using Framework Analysis (Gale et al., 2013) which allows for both inductively and deductively derived themes to be compared systematically according to predefined units of analysis such as individual cases, groups, or organisations. This facilitates the identification of key patterns in the data both within and across these units of analysis (see Table 2).

Table 2

Stages involved in Framework Analysis (Gale et al., 2013)

Stage	Description
Transcription, familiarisation, and coding of data	Initial familiarisation of, and immersion in, the data to gain a reasonable grasp of the data and the variation of the patterns present in it. Transcripts are read line by line and relevant themes, patterns and ideas are coded. It is suggested that a sample of data, that is representative of the overall data, can be used if the dataset is large.
Identifying an analytical framework	Following familiarisation of the dataset and emerging codes, more abstract concepts are drawn out to structure the analysis and subsequent interpretation. This is an iterative process that involves grouping, ranking and ordering the codes to reflect categories.
Indexing	The initial framework is then systematically applied to the remainder of the data. Further refinement of the framework may also take place with codes and categories being revised.
Charting	A matrix is then created to order the data so it can be explored systematically and in totality. The matrix typically consists of ordered rows and columns with the codes grouped according to the unit of analysis. The research questions may be used in this stage to refine and order the matrix so the data can be summarised according to the unit of analysis.
Interpretation	The data is then interpreted using the matrix and research aims/questions. Similarities and differences may be identified at this stage along with mapping connections, identifying relationships, and any causal mechanisms in the data. This allows for the analysis to move beyond simple descriptions of themes to identification of phenomena.

Focus group recordings were transcribed verbatim and anonymised by SA who then read all the transcripts to become familiar with the data. The data were entered into NVivo and SA began line-by-line coding according to common themes and ideas. A priori codes were identified using existing literature but a few of these codes were removed as they were not supported by the data. The codes were grouped into categories, and the framework was further refined through discussion with LJ (supervisor).

The framework was exported to Microsoft Excel to create a matrix alongside the unit of analysis – the EIP team (Slough, Reading). The data were summarised and entered into cells reflecting each code and further colour coded according to whether the data reflected an experience (blue), a facilitator (green) or a barrier (red). The framework allowed for interpretation and visual comparison of the data across the teams (see Appendix 2D).

Reflexivity

The first author is a British Bangladeshi Trainee Clinical Psychologist with lived experience of being a young carer for a parent with a serious mental illness. Both supervisors are White British and have substantial experience working in EIP teams. Supervisor LJ has a specific interest in supporting parents with psychosis and their children. This combined experience, along with discussions with staff about how to support dependants, helped to identify the scope and potential impact of this project.

It is possible that the authors' identities and characteristics may have biased the design of the study, data collection and analysis. To minimise such bias, the authors held regular meetings to discuss the data collection tools used and interpretation of the data. The focus group participants were aware of the first author's lived experience of being a young carer.

Results

Five categories and 17 codes were identified. The categories were structured to represent the pathway from referral to being accepted onto the caseload of the service. They are i) Impact of contextual factors, ii) Opportunities to identify young carers, iii) Staff's views about enquiring, iv) Classification and criteria of young carer, and v) Knowledge and availability of support (see Table 3 for illustrative quotes).

Impact of contextual factors

Staff were asked about their current EIP caseloads and number of service-users with dependants. Staff described their current and past experience of working with children and young people (CYP), with some staff having more direct experience than others.

EIP client demographics and number of dependants

FG1 participants estimated up to a third of their caseloads lived with dependants or other young family members, due to service-users having larger households in their locality. In contrast, FG2 said they did not currently have any young carers or minoritised ethnic dependants known to their team. It was noted that the locality impacts who presents to the EIP service, for example, Reading is a university town and hence the West EIP team largely sees younger service-users without children.

Table 3

Illustrative quotes representing each code

Category	Code	Quote
Impact of contextual factors	EIP client demographics and number of dependants	*I'd say it's at least a third from just my knowledge of the cases that are discussed. It's very usual for there to be someone under 18 in the house. Quite a lot of extended family so even if people haven't got their own children, erm who can live at home. – SL02*
	EIP staff experience of working with CYP	*it's difficult I think when we're looking after the parents and then getting access and speaking to the young people but because I was working with this young person and she yeah she told me everything and her caring role. So, it was easier if you are working with the young person and doing the referral. I think when we are working with the parent, and we don't have much access to the children… - SL01*
Opportunities to identify young carers	Referral – source and process	*"Yeah, well when the GPs refer they have to go through CPE… So those questions have already been asked. It's already been established whether or not this client has children under 18… and because it's considered that you know safeguarding is everybody's responsibility" – RD01*

	Assessment	*So, yeah, we do ask on assessment when they're referred to us. We do ask as part of the information we gather whether they've got any children and like safeguarding if there are any safeguarding concerns. So, we do ask if they've got any children and we do collect their date of birth and their ages as well and yeah, so we do gather that information when they are referred to us. – SL01*
	Existing process for identifying dependants	*In the assessment process [F: Okay]. When we go to do, go to see them to do the assessment, when we do the home visits yeah that is when we would know who else is at home, yeah. – RD03*
	Significant person in the team involved in the service user's care	*We work, we work very, very closely with our clients ... and erm we see them frequently especially in the initial stages and it's really important to as soon as possible establish a good therapeutic working relationship with our clients and, and, and we ask questions... You know, if we're aware that there are young people in the family cause we are a family-inclusive service. Okay we're there predominantly to support the person who's unwell but we also support erm all other individuals who are in their direct network, who are their support system and so if we are aware of children in the home err*

		straight away we need to be thinking about what kind of impact the client's illness is having on those other individuals particularly children." – RD01
	Recording information on RiO	*"I think when they have children, I think it is discussed when we handover and progress notes, I think it's part of the when we get the SBARS, it would be all documented and clear that you know like so and so is married, has got two children, two young children. So, it is well documented and shared with the team." – SL01*
	Staff's understanding of social care's role	*So social care yeah I know that you have a duty, you do have a duty to report to social care and then what social care will do is bring all the professionals around that fam- in that home and basically to talk about how we can support that you know how would that young person could be supported. – RD02*
Staff's views about enquiring	Children only considered according to level of risk and safeguarding	*"I think if the person's, I think if the person's well and there's no concerns then there'd be no [F: Okay] yeah there'd be you know the I think there'd be there'd be no social care inv- there'd be no social care involvement" – RD02*

	Staff's views of their role and limitations	*"we, sometimes we don't really have access to the children on a lot of occasions and it doesn't feel right sometimes to say "Can I speak to them?" because the children wouldn't necessarily want to say anything that they feel might upset their parent or their…" - SL02*
	Staff's lack of access to young people to enquire	*"It's either they're in a separate room or yeah, they're not at home at that particular time. So yeah most of the time you don't get to speak to them unless if there's an identified problem or safeguarding that's when we get to speak to them" – SL01*
	Staff's understanding of parents' fear and anxiety of working with services and authority	*"It's "do I need to be cautious about what I say to you because are you going to go and tell erm you know mention information about me to you know people from my community?" that, that's often another concern for people as well" – RD01*

Classification and criteria of young carer	Staff's perspective of criteria	*"when I used to work in crisis team, you would, you know you'd have mum very unwell and then there'd be like an 8-year-old or a 10 year old doing interpreting. That would raise sus- I'm thinking well what's, you know, I would think that's a care aspect because they're doing all the interpreting"- RD02*
	Parents' and families' perspective of criteria	*"So I guess their role was they didn't see that themselves again as a young carer. I think there's something erm in the language that someone was saying before whether being defined or labelled and told that they're doing something additional that maybe they would want to do or they have different beliefs about doing can impact on that." – SL05*
	Role of culture in caring responsibilities	*"so you know err you're expected to start erm developing independence and if there are responsibilities that perhaps an adult is not able to assume for themselves, you know, it's just expected that you would help out in you know whatever way you can." – RD01*
	Support currently offered by team	*"I think our expectation is that social care, social services will provide that information around carer, young person support and we do anything particularly in EIP around that…" – SL02*

Knowledge and availability of support		*And just maybe or the other time what I've also done with the young carer is saying to the young carer "why don't you just you know, I'm here, why don't you just you know, go out, go out and do something?" you know so they're not worrying" – RD02*
	Current and previous support offered by social care and other organisations	*"There were lots of them but now you don't see that many. There were and all had different activities err organised. I mean, around Elephant and Castle in London, for example, it was a whole centre so open at different times of the day so the children can go in if they have, they need to go in with a parent so at least they can just unwind, yeah." – RD03*

Note. SL - Slough; RD – Reading

EIP staff experience of working with CYP

Participants in both teams had experience of working with CYP in previous roles such as in Child and Adolescent Mental Health Services (CAMHS) and adult Community Mental Health Teams (CMHT). Some FG1 participants said it was easier to have discussions with young people directly in CYP services than accompanying a service-user in adult services, where service-users may deny permission to speak to younger family members. Participants in both teams had experience of supporting CYP, some of whom were also young carers under the separate CYP EIP team as service-users themselves, and continued to support them as they transitioned to the adult team.

Opportunities to identify young carers

This category reflects opportunities and barriers to identify young carers in the care pathway, with six points identified: i) Referral (source and process); ii) Assessment; iii) Existing process for identifying dependants; iv) Significant person in the team involved in the service-user's care; v) Recording information on RiO; and vi) Staff's understanding of social care's role.

Referral

Participants noted that they expected all dependants to have been identified and recorded in either the referral that arrives via the Common Point of Entry (CPE) or at the initial assessment as this is a safeguarding policy.

Assessment

Participants reported that an initial assessment is undertaken by the EIP assessors and the team that the service-user is allocated to. This includes a risk assessment which involves gathering the details of any dependants under the age of 18, including names and dates of birth, and recording this in the service-user's electronic patient record (EPR) at assessment for safeguarding purposes.

Participants noted their initial assessment can include home visits, which are useful for identifying dependants and young carers, and sometimes the adult service-user may rely on dependants to answer assessment questions thereby indicating young carer status.

Existing process for identifying dependants

Participants reported that the existing process for identifying dependants involves gathering information about dependants under the age of 18 at assessment, making a referral to social services (regardless of whether concerns are identified or not), and recording this on the service-user's EPR as a 'progress note'. This is standard safeguarding policy and part of the risk assessment. Social services will then complete their own assessment.

Participants in FG2 noted that, after the initial assessment, frequent meetings with service-users provide ample opportunity to identify young carers. Other means of identifying and sharing information about dependants include handovers, progress notes entered on the EPR by external professionals, such as health visitors and school nurses, and the SBAR[1] template which is used to communicate key information about a service-user, including any concerns, to other staff during periods of staff absence.

Significant person in the team involved in the service user's care

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[1] The template used by the teams to record key information about a client prior to any staff changes (e.g., annual leave) includes the following headings: Situation, Background, Assessment, Risk/Recommendations.

The care coordinator is significant in the service-user's care. FG2 participants emphasised this role and the importance of building an effective therapeutic relationship with the service-user and supporting their wider networks, including exploring the responsibilities dependants may have. Participants in both groups described the importance of asking questions and building a picture of the wider family context.

Recording information on RiO

The EPR, RiO, makes key information about service-users readily available. Staff in FG1 described information about dependants being well documented and clear in service-users' EPR. As mentioned, the SBAR template can be a helpful summary of important information. When asked what staff would hypothetically do with information about dependants' carer status, FG1 staff mentioned the template used to record progress notes includes a section for 'carer's views', but also noted the caveat that dependants' families may be unwilling to reveal their carer status. They did not mention a field for young carers on RiO. In addition, information about dependants is not regularly collated by Business Intelligence.

Staff's understanding of social care's role

Participants' understanding was that social care conducted an assessment following a referral of service-users with dependants under 18 years. This is a standard safeguarding policy and participants understood this could be anxiety-provoking for service-users. Participants reported that they were confident that a young carer role would be identified by social services' assessment and, where necessary, the appropriate support would be put in place. This could involve temporary accommodation, a carer's assessment or multi-agency support plans. A participant suggested that the adult EIP team could benefit from closer links with social services, as is the case in CYP EIP.

Participants in FG2 further noted that it is typical for social care to be informed when a service-user is admitted to hospital and has dependants, as this is Trust policy. However, to their knowledge, long-term social care involvement is dependent on level of risk and need.

Staff's views about enquiring

This category focused on participants' experiences of attempts to include CYP in meetings, and the individual and service level factors that either hinder or facilitate such attempts. Four codes were identified, described below.

Children only considered according to level of risk and safeguarding

Participants' accounts of interactions with dependants under 18 were punctuated by references to safeguarding and risk, a responsibility of all Trust staff. Beyond this responsibility, participants stated their focus was largely the adult service-user for whom they have responsibility.

Staff's views of their role and limitations

FG1 participants reported that working within an adult service presented limitations in their ability to interact with dependants and identify young carers, and they rely on social services to intervene where they are unable to. One participant noted it is harder to speak to young people when working in adult services compared with child services, as staff require consent before speaking to or sharing information with dependants.

Where participants have encountered CYP in meetings, such as in the role of interpreter, they described being sensitive in the questions they asked as it can be uncomfortable for CYP to discuss their parents' personal information.

Staff's lack of access to young people to enquire

FG1 participants spoke overwhelmingly about being impeded in their ability to identify young carers due to a lack of access and consent to speak to dependants and lacking consent for wider information sharing with the family.

They presented examples of service-users with young siblings whose parents reported the siblings being distressed but were reluctant to involve them in discussions and Family Intervention to avoid further distress, even though FG participants felt psychoeducation may be helpful for the siblings to understand what was happening. Some adult service-users with young siblings were noted to refuse information being shared with their parents, which further complicated staff's ability to enquire about potential young carers.

Staff's understanding of parents' fear and anxiety of working with services and authority

Participants noted that the involvement of social services can be daunting due to the potentially far-reaching implications, the removal of children being the worst-case scenario. Participants highlighted specific service-user worries such as parental ability being questioned and fear that social services would be an ongoing overwhelming presence in their lives. These fears could foster disengagement and distrust and prevent families being open about dependants' caring responsibilities. Participants attempt to mitigate these worries by emphasising their duty to refer to social services and the potential support they may offer.

One participant noted that service-users are sometimes reluctant to have service-provided interpreters, perhaps due to stigma, leading to dependants having to interpret.

Participants in FG2 highlighted cultural biases held by social workers and that it may be intrusive to be assessed by a ‘white middle class social worker’, particularly for minoritised ethnic families who may feel judged and stigmatised especially if their dependant is providing intimate care. One care coordinator recalled having to explain consent and confidentiality to minoritised ethnic services-users who may worry about their private information being shared with their wider community

Classification and criteria of young carer

This category focused on the criteria that would qualify a dependant as a young carer.

Staff’s perspective of criteria

Staff in FG1 reported feeling unsure of the criteria for a young carer and discussed factors that may impact the criteria, such as differentiating between a normal household chore and caring responsibilities, impact on schooling, how the dependant feels about their responsibilities, and whether they identify as a carer. Participants also noted that the family situation and caring needs may fluctuate.

Participants noted that caring responsibilities are not routinely asked about, although may be mentioned during conversations, and suggested it would be helpful to have clarity on the definition of a young carer. One participant noted they may have blind spots because they were a young carer themselves, but not recognising it as such, and emphasised the importance of observing families and asking questions.

FG2 participants spoke of their experience with young carers and highlighted responsibilities that would indicate ‘carer’ status, which they would query further. These include interpreting, getting medication, and helping with completing benefits forms. Staff also remarked on the interdependent relationship between the young carer’s and parent’s mental health.

Parents’ and families’ perspective of criteria

Participants in both focus groups spoke of the ‘carer’ label often being rebuffed, including by adult carers, and framed as simply caring for an unwell relative and doing chores, and that this also makes it difficult to identify young carers. One participant described circumventing such challenges by asking indirect questions to obtain information about a child’s role within the household.

Role of culture in caring responsibilities

Participants emphasised that for minoritised ethnic groups there can be a cultural expectation for younger family members to assume caring responsibilities for an unwell relative, which may not be perceived as ‘caring’. Participants stated that minoritised ethnic families tend to be ‘guarded’ with services and the ‘carer’ label may feel shaming leading to offers of external support being rejected.

Knowledge and availability of support

This category captured participants’ understanding of the: i) Support currently offered by the service; and ii) Current and previous support offered by social care and other organisations.

Support currently offered by team

Participants from both teams identified whole family interventions offered by the service including the Friends and Family group and Family Intervention (FI), neither of which have an explicit age limit for attendance but service-users typically choose not to include younger relatives. This can make it difficult to explore whether dependants have caring responsibilities.

One participant, who works across the adult and CYP EIP teams, wondered whether the adult context of the service creates the assumption that the interventions are for adults only as the CYP EIP does not encounter the same problem.

Participants in FG2 mentioned the informal support they previously provided to young carers and suggested young carers may benefit from a specific group that is informal and offers peer support.

Current and previous support offered by social care and other organisations

FG1 participants felt social services were best placed to support young carers as they had more knowledge of the available support, including parenting support. One participant, a former social worker, noted that social services were unlikely to intervene without parents' consent, however, and suggested closer working between the services may help bridge this gap.

Participants in FG2 had knowledge of available support through other roles and highlighted organisations such as Brighter Futures for Children, The Prince's Trust, and Early Help in Reading. They spoke confidently of the steps involved in social services' input, such as an assessment, convening multi-agency strategy meetings, parenting support, carers assessments and respite for young carers, all of which could be included in Section 117 aftercare following a hospital admission. Children whose parents are admitted to inpatient care or are unable to support them may require temporary accommodation. Participants noted that although some families are reluctant and find social services involvement intrusive initially, support such as respite care and financial aid is often met with relief.

Recommendations

The findings from the focus groups and previous literature were combined to identify recommendations to help staff in identifying young carers within EIP services (see Appendix 2F). The recommendations were grouped according to the framework categories and the level at which the recommendations would apply: Trust, EIP service, and service-user level.

The findings and recommendations were presented to the service in an online meeting on 27th March 2024, which was attended by several members of staff from all localities in Berkshire. Staff from Slough and Reading agreed with the findings. They remarked on the difficulties they encounter in finding time to dedicate to additional issues such as young carers but were keen to begin implementing the suggested improvements. This included appointing a young carers champion and including these recommendations in the Trust's wider carers' strategy. A list of the planned actions in response to these recommendations is in Appendix 2G.

Discussion

This service improvement project investigated how staff from two Berkshire EIP teams experience working with service-users' dependants and identifying young carers. The project aimed to understand the barriers and facilitators for staff, to guide improvement suggestions to support staff in identifying young carers, particularly those from minoritised ethnic groups. Using Framework Analysis and deductive and inductive coding of focus group data, five categories were developed: i) Impact of contextual factors, ii) Opportunities to identify young carers, iii) Staff's views about enquiring, iv) Classification and criteria of young carer, and v) Knowledge and availability of support.

Consistent with previous research, staff identified several factors that prevent families from revealing their dependants' caring responsibilities, including fear of social services involvement (5, 27, 28). Difficulties with identification of young carer status were further compounded by staff's uncertainty about whether they could intervene especially where issues of confidentiality, consent for information-sharing, and staff's difficulty with speaking to dependants separately were present. These factors left staff considering dependants mainly in terms of safeguarding. Improving the awareness of the young carer role amongst both staff and service-users could help to address some of these barriers, especially amongst minoritised ethnic service-users for whom caring is seen as a familial obligation, and improve staff's confidence in discussing this role with service-users. Such discussions may be particularly important for minoritised ethnic families who may otherwise perceive their family dynamics being questioned by social services.

The findings revealed that there are several opportunities within the EIP care pathway to identify young carers, which can be capitalised on, but staff were limited by organisational and role limitations. For instance, at referral and assessment, all staff are encouraged to identify dependants, but staff felt unsure of their role in discussing dependants beyond this. Moreover, while the electronic patient record has several fields for carer information, this does not include young carer status. Such limitations in the health record infrastructure may prevent staff from thinking about young carers when collecting information, and means young carer details cannot be recorded clearly and consistently.

Many of the barriers faced by staff could be reduced by strengthening relationships with other agencies such as General Practitioners and Social Services. Staff themselves felt they could benefit from closer working as this would allow knowledge sharing and a deeper understanding of the support each service provides. Moreover, GPs could be encouraged to provide information beyond basic details about dependants at referral such as whether they accompany the parent to appointments.

One strength of this project was it helped more staff to begin thinking about the young carer role when encountering dependants and younger siblings, with some staff making referrals to social services for young carer assessments soon after hearing about this project. The service manager also presented the recommendations to the carers lead within the Trust immediately after the feedback session via email, thus putting young carers on the agenda of wider service provision for carers.

This project was planned according to the discovery phase of the IHI (26) Model for Improvement but it was outside of the remit of the feedback session to begin planning the PDSA cycle and concrete plans for implementation of longer-term recommendations. The team appeared to be doing this organically as a young carer specific training session has been arranged for delivery to EIP staff in September 2024.

This project only had the time and resources to conduct two staff focus groups, which limits the transferability of the findings to the other Berkshire EIP teams. To gain a better understanding of the different factors that might influence the identification of young carers, future projects may benefit from sampling services in different geographical regions. While focus groups were used to allow for discussion amongst staff members, it is possible that some participants may have felt more able to speak openly compared to others. For example, those recording information about dependants regularly may have felt more confident to contribute compared to those who may have been unfamiliar with such procedures. Moreover, the inclusion of the team lead in one focus group may have contributed to an imbalanced power dynamic within the focus group such that staff may have felt less able to speak honestly about barriers faced. Individual interviews should be considered in future to address such challenges.

This project was not able to capture the experiences of service users and dependants (which would have required NHS ethical approval) in the detailed planning of the study. It is possible that this lack of wider patient and public involvement (PPI) could have limited the design of the study, such as the questions asked in the focus group, and the interpretation of results. Although, SA had lived experience of being a young carer and used this experience to inform the project, future research would benefit from interviewing these groups, including lesser heard voices such as fathers, to identify the barriers and facilitators they experience in seeking support for young carers, plus the support they would like from mental health professionals to make this easier.

In conclusion, this service improvement project identified several Trust, service and individual level barriers experienced by staff in two Berkshire EIP teams in identifying young carers. The service, and the Trust as whole, would benefit from raising awareness about the young carer role amongst service-users and its staff, providing staff with clear guidance on how to identify young carers, and strengthening the Trust's relationship with social services so the two can work in partnership.

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Theory Driven Research Project

Title: Stigma and trust in mental health services – the impact of ethnicity and immigrant generation

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Word Count (excluding references and appendices): 4, 843

Revised word count: 5, 500

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Journal for submission: Social Psychiatry and Psychiatric Epidemiology is a peer-reviewed academic journal that invites articles focusing on the effects of the social environment on psychiatric disorders. Submission guidelines can be found in Appendix 3A.

Abstract

Purpose: This study sought to investigate the role of identifying as a migrant and the impact of generation (first vs. second) in the relationship between mental health stigma and ethnicity. This study also sought to identify the relationship between stigma and trust within and between groups.

Methods: An online survey was developed to collect data on mental health stigma (public stigma, self-stigma, and label avoidance) and trust. Four groups of participants were recruited: first and second generation (British) South Asians, first generation (British) Polish, and White British. Data were analysed to identify differences in levels of stigma and trust across the different ethnic and generational groups. A hierarchical multiple linear regression was used to identify whether stigma predicted levels of trust.

Results: The analysis revealed no difference in levels of public stigma, label avoidance, self-stigma or trust according to the different ethnic and generational groups. Neither public nor self-stigma were associated with levels of trust in mental health services. Label avoidance was, however, significantly associated with levels of trust such that lower label avoidance was associated with higher trust in services.

Conclusion: This study found no evidence of an association between stigma and ethnicity, nor was there evidence of differences between first and second generation South Asian groups. Label avoidance may however be related to trust in terms of marginalised groups and their access to mental health services.

Keywords: stigma, mental health, ethnicity, trust, ethnic minority

Statements and declarations: The authors have no competing interests to declare.

Background

Stigma is a universal phenomenon that negatively impacts how an individual with a certain characteristic, deemed undesirable, is viewed by others [1,2]. Erving Goffman adopted the term stigma in the 20th century describing it as *"an attribute that is deeply discrediting"* resulting in the individual with said attribute losing credibility and being reduced *"from a whole and usual person to a tainted, discounted one"* [3,4].

A diagnosis of a mental illness is one such characteristic that has historically led to the marginalisation of people with such diagnoses due to being viewed as "flawed", "dangerous", "violent", and not in control of their behaviours and actions [5,6]. Several studies have reported poorer care is delivered to people with a mental health diagnosis leading to preventable deaths [7,8] and this is widely considered to be due to diagnostic overshadowing [9,10]. Stigmatising attitudes can also result in reluctance to seek help for one's mental health [11]. It is important to understand the nuances of stigma so it can be challenged, and its negative effects appropriately tackled. To this end, several public health initiatives have been launched in different nations to address the wider stigma and discrimination that people with mental illnesses face, demonstrating the scale of the problem [12].

The concept of stigma has also been further expanded by contemporary researchers such as Corrigan who classified three forms of stigma: public stigma, self-stigma, and label avoidance [5]. Public stigma is the endorsement of, and tendency to act upon, negative stereotypes about a certain group (e.g. those with a mental health diagnosis) by the general public. Self-stigma occurs when an individual internalises the negative prejudice applied to them by the general population. Label avoidance is the tendency to prefer not to attend mental health services in an effort to avoid a stigmatising label [5].

Whilst Corrigan focused on the cognitive and behavioural aspects of stigma, Link and Phelan drew upon labelling theory [13] to account for the power dynamics inherent within stigmatisation [14]. Scheff [13] initially proposed that societal reactions to the label of "mental illness" are often negative, leading to the marginalisation of the individual and limiting their role in society thereby maintaining their mental ill health. Link and Phelan [2] further modified labelling theory to account for the exercise of social, economic, and political power – moving away from the stigma laying within the person to the people doing the stigmatising. This happens through a process of first identifying human differences including characteristics that are undesirable. This allows the group doing the labelling to separate "us" and "them" whereby those with the undesirable label are separated from those without which results in the discrimination and status loss of the stigmatised individual.

There have been some suggestions from meta-analyses [15] that the level of stigma held may differ according to ethnicity with some ethnic groups, such as South Asians, being reported to hold more stigmatising attitudes about mental illness compared to their White counterparts [16,15]. Studies that focused on comparing stigmatising attitudes about serious mental illnesses like psychosis between South Asian and White people have reported higher levels of stigma among South Asians including expressing higher levels of anger and attributing higher dangerousness to people with psychosis, and a desire for segregation and lower intentions to provide help [17,18]. Importantly, the disparity in levels of stigma has been implicated in why marginalised groups such as these are less likely to seek help from mainstream mental health services and show increased efforts to conceal mental health difficulties [19-21,11].

People from minoritised ethnic groups themselves report that stigmatising attitudes within their communities, such as the perception of people with mental illnesses as ‘mad’, ‘crazy’ and ‘weak’, prevent them from seeking help as this would not only tarnish their reputation but that of their family too [22,21]. Factors such as lack of mental health literacy, belief in supernatural causes, and concerns about marriage prospects have been implicated in people wanting to avoid being labelled “mentally ill” [23]. People from minoritised ethnic groups instead show a preference for seeking help through other avenues such as religious figures and institutions instead of mainstream mental health services [20,21,24]. Avoidance of such services may maintain stigma as some research suggests that increased contact with mainstream services is associated with reduced stigma [18].

Following the identification of this relationship between ethnicity and stigma, there has been a focus on attempts to identify factors that help explain why some ethnic groups experience increased levels of stigma. However, several limitations of this literature appear to have been overlooked and diverted focus from factors beyond ethnicity that may influence stigma [16]. This includes, but is not limited to, small sample sizes, grouping different ethnic and racial groups into one, and most studies comparing White to non-White groups with few, if any, comparing different minoritised ethnic groups or identifying differences within groups [16,15]. Although the aforementioned meta-analysis reported ethnic minorities express significantly higher levels of mental health sigma, the overall effect size was small and the identified studies were reported to have high heterogeneity [15]. The researchers further identified significant variation in the conceptualisation and measure of stigma [15]. Further complicating this research base are findings indicating that although minoritised ethnic groups may hold higher levels of cognitive stigma, this does not necessarily correspond with behavioural consequences [16,15].

Moreover, although minoritised ethnic participants report stigma as a barrier in qualitative studies investigating barriers to help-seeking, this is often reported amongst many other factors such as a lack of trust in services and racism [16,25,20]. The emphasis on ethnic disparities has led to investigations into cultural factors supposedly unique to minoritised ethnic groups thereby creating the misleading assumption that these are otherwise not present in White Western cultures [16]. This includes concepts such as 'shame' and 'marriageability' - the idea that minoritised ethnic groups are less accepting of mental health difficulties due to fears about marriage prospects for the family as a whole [22,16]. However, several earlier studies reported similar concerns expressed by White Western populations [26,27] and more recent data indicates that there has been little change in such attitudes in England despite other aspects of stigma reducing [28].

Studies that have compared the same ethnic group in different geographical regions have also reported differences in the content of the stigma expressed (e.g., impact of mental health on stability of marriage vs concerns about self-disclosure) indicating that it is not ethnicity producing differences in stigma but rather the context the individual exists in [29]. Additionally, studies that have investigated the impact of educational attainment, level of income, and neighbourhood deprivation on stigma failed to account for the impact these factors have on the relationship between stigma and ethnicity, instead choosing to analyse the impact of ethnicity separately [30].

Furthermore, studies that have investigated the impact of public initiatives to tackle stigma have reported variable changes in attitudes according to different characteristics such as gender, migration status, and age with younger people showing less stigma post-intervention compared to older people [31]. Migrant generation has also been found to independently impact levels of stigma [32] and mental health [33,34].

Without investigation of these additional factors and the continued focus on ethnicity as the driving factor of increased stigma, it is possible that attempts to reduce stigma and improve help-seeking, including amongst marginalised groups, are being compromised. Some studies have suggested that the issue is a lack of access to mainstream services [20,35,36]. People from minoritised ethnic groups have reported racism and subsequent mistrust of services, a lack of accessibility (e.g., language barriers, lack of cultural competency) and fear of becoming enmeshed [20] with services, that discourage help-seeking [20,22]. There is also evidence to suggest that certain groups of people, such as those from minoritised ethnic groups, younger people, and those from deprived areas, report lower trust in their General Practitioner (GP) as a result of feeling they are not listened to or empowered to make collaborative decisions [37]. This can also impact trust in mental health services and practitioners [38]. However, stigma and ethnicity have continued to be the significant target of research and interventions to improve help-seeking [16].

Current Study

The current study therefore aims to further explore the role migrant generation may play in the relationship between mental health stigma and ethnicity. Studies have frequently reported higher levels of mental health stigma displayed by minoritised ethnic groups compared to their White counterparts, but few have made comparisons with other minoritised White ethnic groups, and typically combine first and later generation migrant groups. A better understanding of such factors could allow targeted interventions to be developed to decrease stigma in these underserved communities, to increase engagement with services, and build better relationships by addressing relevant concerns. The current study aims to further understand the relationship between stigma, migrant status, ethnicity and generation in terms of how such factors can influence how much trust one has in mental health services.

This study aims to explore the following questions:

- Are there differences in the levels of public stigma, self-stigma, and label avoidance of mental health between people with different cultural and ethnic heritages ((British) South Asian, (British) Polish and White British)?
- Are there differences in the levels of trust of mental and physical health services between people with different cultural and ethnic heritages ((British) South Asian, (British) Polish and White British)?
- For the South Asian group, are there differences between first and second generation in terms of mental health stigma and trust in mental health services?

The following hypotheses will be tested:

Primary hypotheses:

- First generation South Asians will report higher levels of public, self-stigma, and label avoidance compared to second generation South Asians and White British and (British) Polish participants.
- First generation South Asians will report a higher level of trust of mental health services compared to second generation South Asians, White British and (British) Polish participants.

A secondary hypothesis was developed to test the general relationship between trust and stigma across all groups in contrast to the primary hypotheses which focus on the complex generational and ethnic differences between groups.

Secondary hypothesis:

- Lower levels of trust of mental health services will correspond with higher levels of public stigma, self-stigma and label avoidance across groups.

Methods

Participants

Participants were recruited from across the United Kingdom (UK). Participants were eligible to take part in the study if they: i) identified as White British, (British) Polish, or (British) South Asian; ii) (only South Asian/Polish) identified as a first- or second-generation immigrant; iii) were aged 18 years or above; and iv) were able to read and write in English.

First generation immigrants were defined as those born outside of the current country of residence to two foreign-born parents. Second generation immigrants were defined as those born in the current country of residence with at least one foreign-born parent. The target population therefore consisted of five groups of participants.

Procedure

The survey was developed using survey development website, Qualtrics. Participants were recruited from the general population via online recruitment, word-of-mouth, and third sector organisations. To facilitate recruitment, a poster was developed detailing the aims of the study and eligibility criteria (see appendix 3B). A link and QR code were included on the poster which directed participants to the study.

Once participants clicked on the survey link/scanned the QR code, they were directed to an information sheet and asked to confirm they were over 18 and consent to participating (see appendix 3C). Those who consented were then directed to the questionnaires. Following the completion of the survey, participants were offered the opportunity to provide their email address to receive a copy of the final report. A debrief page was then displayed thanking them for their participation and signposting to the researchers' details and support organisations that could be contacted if they felt distressed by the contents of the survey. Participants were informed they had 1 month following their participation to withdraw from the study. Participants' data were identified using a four-digit code chosen by the participant themself at the beginning of the survey.

For safeguarding purposes, an alert was embedded within the survey which sent an email to the researchers if participants used trigger words such as 'suicide' and 'kill'. Overall, two alerts were received which were considered within the context of the answers provided and were deemed to be acceptable and not a risk. Therefore, no further actions were required.

Recruitment

Convenience and snowball sampling were used for recruitment. The study poster was posted across social media sites including Twitter and Facebook and hardcopies were circulated amongst charity shops and general stores. These were chosen based on convenience but were limited to South-Eastern England due to travel limitations. General stores that accommodate the needs of the Polish and South Asian communities were also targeted. Several different social media groups and organisations that specifically work with the target populations were also contacted and provided with the study details, link, and poster to be forwarded to their network members. For instance, groups on Facebook including the title "Polacy w" followed by different locations in the UK were searched to find groups with Polish people. A similar approach was used to identify groups specifically for people of South Asian descent. Some organisations were also visited and provided with hardcopy versions of the poster to be displayed on notice boards as the poster contained a QR code which could be easily scanned using an electronic device to access the survey.

Study details were also circulated via email and WhatsApp groups for various University societies such as the Islamic Society (ISoc). Members of such groups were encouraged to share the details of the studies with others they thought may be eligible to take part. Furthermore, the details of the study and recruitment materials were also circulated amongst professional and personal networks.

Power analysis

Table 1

Power calculation used to determine the number of required participants.

F Test ANOVA: Fixed effects, special, main effects and interactions	
Effect Size	0.3
A err prob	0.05
Power (1Berr)	0.8
Numerator df	3
Number of groups	6
Total number of participants	126

A power analysis conducted using power calculation software G* Power 3.1 indicated that 126 participants would be required to achieve 80% power to detect an effect size of 0.3 (Cohen’s f) at an alpha level 0.05 for the (first or second generation) South Asian, White Polish and White British groups.

Measures

Participants were asked to provide demographic information including age, gender, ethnicity, and immigrant generational status (i.e., first or second generation). Participants were further asked about their marital status, number of years living in the UK, level of education, and religion. Participants were also asked whether they had lived experience of a mental health difficulty or experience of caring for a loved one with mental health difficulties.

Standardised self-report measures were used to collect data regarding the different types of stigma (see Table 2).

Table 2

Descriptions of the measures used in the survey

Measure	Description
The Attribution Questionnaire (AQ)-9 [39,40]	- A 9-item measure of public stigma based upon the attribution model of stigma. The original questionnaire was 27 items long [39,40] but was shortened to 9 items by identifying the single highest loading items for each of the nine factors of public stigma – pity, dangerousness, fear, blame, coercion, anger, help, avoidance, and institutionalisation [41]. - The questionnaire consists of a vignette about ‘Daniel’ followed by 9 statements rated on a 9-point Likert scale with 1 indicating ‘none at all’ and 9 indicating ‘very much’. Scores can range from 9 to 81 with a higher score indicating a higher endorsement of public stigma. The subscales of the measure have been reported to have test-retest reliability ranging from .55 to .87 [41]. - The internal consistency was calculated using the current sample which was deemed to be unacceptable (=.61). Therefore, factor analysis was conducted revealing two internally consistent factors – Danger/Avoid and Blame/Segregate (see appendix 3D for details). - For the purpose of this study, the name ‘Daniel’ was changed to ‘Samuel’ as this is a name found commonly in all three cultural groups.

	- An open text box question was included at the end of the scale enquiring about participants' thoughts in response to a friend divulging their mental health diagnosis.
The Self-Stigma of Mental Illness Scale (SSMIS) [42]	- This is a 40-item scale consisting of 4 subscales, with high internal consistency, measuring the four dimensions of self-stigma – awareness (=0.91), agreement (=0.72), application (=0.81), and harm to self (=0.88) [42]. Each subscale consists of 10 statements rated on a 9-point Likert agreement scale. Internal consistency was also calculated using the current sample – awareness (=.94), agreement (=.89), application (=.90), and harm to self (=.93). - An open text box question was included at the end of the scale asking participants whether their view of themselves would change if they were referred to a mental health service.
Label Avoidance	- An idiosyncratic measure developed by the authors. This measure consisted of four vignettes describing different mental health difficulties, including depression, psychosis, social phobia, and panic. Each vignette was followed by 7 statements, outlining the different actions they may take (e.g., 'Take medication for my mental health'), rated on a 10 point Likert scale ranging from 0 ('very unlikely') to 9 ('very likely'). Lower scores corresponded with higher label avoidance. This was followed by an open text box questions asking participants how they might react if they saw a familiar person exiting a building with a sign indicating it is a mental health service.

	- Cronbach's alpha coefficients were calculated for each subscale revealing good internal consistency (Depression = .741; Psychosis = .797; Social Phobia = .807; Panic = .774).
Trust	- Trust in mental and physical healthcare was measured using an idiosyncratic measure developed by the authors due to a lack of existing validated measures. The authors located several measures of trust in physical healthcare but few, if any, address mental health care. As far as the authors are aware, there are no existing tools explicitly measuring trust in mental healthcare[1]. - The authors developed a measure of trust consisting of a vignette detailing a scenario in which the participant is asked to imagine they have been experiencing a number of physical and mental health symptoms. This was followed by 6 statements to be rated on a 10-point Likert scale (0=very unlikely; 9=very likely). Cronbach's alpha coefficient was calculated for this scale revealing high internal consistency (α= .902). - The scale was followed by two open text box questions asking participants whether they would trust the mental health service's assessment of their concerns and any alternative sources of support they may seek.

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[1] The authors considered the concept of epistemic trust (Fonagy et al. 2015) when researching tools to measure trust but deemed the concept too different to the concept of trust that the authors were attempting to measure. Moreover, epistemic trust was defined in accordance to a clinical population whereas the authors were attempting to measure general trust in mental health care.

Ethics approval

Ethics approval was sought and granted from the University of Oxford's Central University Research Ethics Committee (CUREC). This was granted in August 2022 (Ref: 77255/RE001).

Data analysis

Data were analysed using the statistical software package IBM SPSS version 29. Demographic characteristics were tabulated and compared across the groups using one-way ANOVAs and chi-squared tests. Levene's test for homogeneity was used to determine whether the groups met the assumption of equal variance, and where this was significant indicating unequal variance across the groups, a non-parametric post-hoc test (Dunnett's T3) was used. Mauchley's test was used to determine whether the assumption of sphericity was violated or not and the appropriate correction was applied where significance indicated a violation of the assumption.

Mixed model ANOVAs were used to assess the impact of ethnicity and generation on public stigma, self-stigma, and label avoidance. A one way between groups ANOVA was used to analyse the effect of ethnicity and generation on trust. A hierarchical multiple linear regression was used to analyse the relationship between the three types of stigma and levels of trust.

Quantitative content analysis was used to analyse the qualitative data collected (see Appendix 3E for full details of the analysis and results).

Results

Sample and group characteristics

A total of 248 responses were recorded. Responses from 179 participants were included in the final sample. Sixty-nine responses were removed from the sample as participants did not complete the full survey. The planned five groups of participants were collapsed into four ((British) Polish first generation, South Asian first and second generation, and White British) due to small sample sizes. Second generation Polish participants were excluded due to a small sample (*n*=4).

Participants were on average 33.8 years old (*SD*=11, range=18-90). There was an overall significant difference in age between the four groups, *F*(3, 178) = 3.55, *p*=.016; multiple comparisons indicated no specific differences between groups. There was no difference in the number of years of schooling received across the four groups, *F*(3, 170) = 1.39, *p*=.248 (see table 2). The four groups did not differ according to marital status X^2(3, 170) = 3.68, *p*= .29 or lived experience of either mental health problems, X^2(3, 172) = 2.05, *p*=.56, or caring X^2(3, 168) = 4.67, *p*=.198 (see table 3).

Table 3

Sociodemographic characteristics of sample.

Characteristic	**(British) Polish**	**(British) South Asian**		**White British**	**Total**
	First generation	First generation	Second generation		
	n=65; 26.2%	(*n*=22; 8.9%)	(*n*=36; 14.5%)	(*n*=56; 22.5%)	(*n*=179; 27.8%)
Mean Age (SD)	37.2 (9.7)	30.45 (11.2)	31.9 (13.2)	32.32 (10.2)	33.8 (11)
Mean Years of schooling (SD)	17.51 (5.4)	15.41 (6.03)	17.28 (3.72)	17.83 (3.87)	(*n*=171) 17.28 (4.8)
Mean Years resident in the UK (SD)	13.49 (5.863)	18.39 (15.027)	29.47 (9.77)	30 (11.638)	(*n*=171) 22.12 (15.537)

Table 3

Sociodemographic characteristics of sample (cont.).

	(British) Polish	(British) South Asian		White British	Total	χ2(2)
		First	Second			
Sex (n, %)						
Female	57 (89.1%)	18 (81.8%)	32 (88.9%)	39 (70.9%)	146 (82.5%)	
Male	7 (10.9%)	4 (18.2%)	4 (11.1%)	16 (29.1%)	31 (17.5%)	
Highest educational qualification						
GCSEs/AS/A-Level/Apprenticeship	10 (16.1%)	2 (9.1%)	6 (16.7%)	7 (14.9%)	25 (15%)	
Degree level or equivalent	20 (32.3%)	5 (22.7%)	11 (30.6%)	15 (31.9%)	51 (30.5%)	
Masters level or higher	32 (51.6%)	15 (68.2%)	19 (52.8%)	25 (53.2%)	91 (54.5%)	
Belonging to a religion						
Yes	26 (40.0%)	17 (77.3%)	33 (91.7%)	20 (40.8%)	98 (55.7%)	
No	41 (59.4%)	5 (22.7%)	3 (8.3%)	29 (59.2%)	78 (44.3%)	
Marital Status						3.68

Single/Separated/Divorced	36 (56.3%)	14 (63.6%)	25 (71.4%)	35 (71.4%)	110 (64.7%)	
Married/Civil Partnership	28 (43.8%)	8 (46.4%)	10 (28.6%)	14 (28.6%)	60 (35.3%)	
Lived experience of mental health difficulties						2.05
Yes	48 (73.8%)	14 (63.6%)	27 (75%)	39 (79.6%)	128 (74.4%)	
No	17 (26.2%)	8 (36.4%)	9 (25%)	10 (20.4%)	44 (25.6%)	
Lived experience of caring						4.67
Yes	29 (47.5%)	16 (72.7%)	22 (61.1%)	28 (57.1%)	95 (56.5%)	
No	32 (52.5%)	6 (27.3%)	14 (38.9%)	21 (42.9%)	73 (43.5%)	

**p*<.05. ***p*<.001

Due to a small number of participants, it was not possible to analyse whether the groups differed in sex, educational qualification, or religion. Fourteen White British and 20 (British) Polish participants reported themselves to be Christians/Catholics. Two Polish participants identified as Anglican and 4 White British participants identified as Muslim. Forty-one South Asian participants reported belonging to Islam. Five South Asian participants reported themselves to be Sikh and three identified as Hindu.

Public stigma, self-stigma and label avoidance

Three hypotheses were tested and are outlined below.

Hypothesis 1: First generation South Asians will report higher levels of public, self-stigma, and label avoidance compared to second generation South Asians and White British and (British) Polish participants.

A mixed model ANOVA was used to analyse the impact of ethnicity and generation on the two subscales of the Attribution Questionnaire as a measure of public stigma. A total of 148 participants completed the questionnaire. There was a significant main effect of the subscales, $F(1, 144) = 165.31$, $p<.001$ but there was no significant main effect of the groups, $F(1, 144) = 0.46$, $p=.71$. There was also no evidence of a significant interaction between the groups and the subscales of the questionnaire, $F(3, 144) = .54$, $p=.66$ (see table 4).

A mixed-model ANOVA was used to analyse the impact of ethnicity and generation on the different subscales of the Self-Stigma of Mental Illness Scale-Short (SSMISS). Mauchly's Test of Sphericity was significant indicating the assumption of sphericity was violated ($X^2(5) = 29.28$, $p<.001$) and therefore the Greenhouse-Geisser correction was applied. There was no main effect of group, *F*(3, 115) = 2.505, *p*=.063. However, there was a main effect of the self-stigma measure, *F*(2.52, 345) = 126.40, *p*<.001 (see table 5). This was modified by a significant interaction between the groups and the SSMISS subscales, *F*(7.56, 289.80) = 2.02, *p*=.047.

Four simple main effects ANOVAs were used to further investigate the significant interaction effect. There was no evidence of a significant difference in scores for three subscales – Awareness (*F*(3, 115) = 2.62, *p*=.054), Agreement (*F*(3, 115) = 1.89, *p*=.135), or Harm (*F*(3, 115) = 1.31, *p*=.275) (see table 5). However, a significant difference was detected in scores for the Application subscale, *F*(3, 115) = 3.25, *p*=.024). A post-hoc comparison using the Tukey HSD test revealed that (British) Polish participants' average score (*M*=24.33; *SD*=14.77*)* on the Application subscale was significantly lower than White British participants' score (*M*=34.91; *SD*=16.99; *p*=.018).

Label avoidance was measured using four different vignettes describing depression, psychosis, social phobia and panic. A mixed model ANOVA was used to analyse differences between the groups. Mauchly's Test of Sphericity was significant indicating the assumption of sphericity was violated ($X^2(5) = 20.2f$, *p*=001) and therefore the Greenhouse-Geisser correction was applied. There was a significant main effect of scale (*F*(2.63, 276.02) = 27.92, *p*<.001) but a significant difference was not detected between the groups (*F*(3, 105) = .594, *p*=.62) and there was no significant interaction between the measure and the groups, *F*(7.89, 276.02) = 1.14, *p*=.338.

Table 4

Average scores on the trust questionnaire and Attribution Questionnaire measuring public stigma across ethnic and generational groups.

Scale	(British) Polish	(British) South Asian		White British	Total
		First	Second		
	M (SD)	M (SD)	M (SD)	M(SD)	M (SD)
Attribution Questionnaire					
Danger/Avoid	10.41 (5.64)	9.94 (3.44)	9.67 (4.63)	9.78 (5.00)	10.03 (5.02)
Blame/Segregation	4.78 (2.49)	5.53 (2.48)	3.67 (1.36)	5.07 (4.11)	4.64 (2.97)
Trust	38.05 (15.54)	36.79 (15.07)	41.15 (14.85)	37.34 (11.88)	38.28 (14.29)

Table 5

Average scores on each of the Self-Stigma of Mental Illness Scale-Short (SSMISS) subscale according to subgroup.

Ethnicity		**Awareness**		**Agreement**		**Application**		**Harm to self-esteem**	
	N	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**
Total	119	54.12	18.24	20.61	9.82	29.03	16.25	32.65	19.09
(British) Polish	46	48.78	17.19	20.28	9.96	24.33	14.77	30.83	20.19
(British) South Asian									
First Generation	16	58.75	23.25	16.25	4.68	32.00	16.84	33.44	18.73
Second generation	22	60.23	17.64	20.41	8.26	27.32	15.17	28.18	17.66
White British	35	55.17	16.07	23.14	11.65	34.91	16.99	37.49	18.32

Trust

Hypothesis 2: First generation South Asians will report a higher level of trust of mental health services compared to second generation South Asians, White British and (British) Polish participants.

A total of 105 participants completed the measure of Trust producing an average score of 38.28 (*SD*=14.29, range = 6-60). A one-way between-subjects ANOVA revealed that trust did not significantly differ according to the groups, *F*(3, 104) = 74.53, *p*=.783.

Relationship between trust and stigma

Secondary Hypothesis: Lower levels of trust of mental health services will correspond with higher levels of public stigma, self-stigma and label avoidance across groups.

A hierarchical linear multiple regression was conducted to identify the impact of public stigma, self-stigma, and label avoidance on trust. A three step hierarchical approach was taken with the independent variables entered in the following order: public stigma, self-stigma, and label avoidance. The first step of the model, with only public stigma, accounted for only 0.8% of the model and did not significantly predict levels of trust, (R^2 = .008, *F*(2, 106) = .42, *p*=.66).

In the second step, self-stigma was added to the model. The model accounted for only 3.5% of the model and did not significantly predict levels of trust (R^2 =.043, *F*(6, 102) = .76, *p*= 61). In the final step, label avoidance was added to the model. This model significantly predicted levels of trust, accounting for 45.3% change in the model (R^2 = .50, *F*(7, 101) = 14.16, *p*<.001). Label avoidance was identified as the only significant predictor in this model (β = .69, *p*<.001). The results indicate that neither public nor self-stigma contributed to the prediction of levels of trust. Label avoidance exhibited a dominant and significant association with levels of trust (see table 6).

Table 6

Hierarchical multiple regression analysis results for trust and stigma.

Variable	B	SE B	β	R^2	ΔR2	Sig.
Step 1				0.008	-0.011	.660
Constant	37.29	3.13				
Public Stigma – Danger/Avoid	0.27	0.32	0.09			
Public Stigma – Blame/Segregation	-0.35	0.47	-0.08			
Step 2				0.043	-0.014	.606
Constant	41.41	5.50				
Public Stigma – Danger/Avoid	0.29	0.33	0.10			
Public Stigma – Blame/Segregation	-0.05	0.53	-0.01			
SSSI - Awareness	0.02	0.08	0.02			
SSSI - Agreement	-0.12	0.17	-0.09			
SSSI - Application	-0.07	0.10	-0.08			
SSSI – Harm	-0.06	0.09	-0.09			
Step 3				0.495	0.460	<.001

Constant	9.94	5.20	
Public Stigma – Danger/Avoid	-0.05	0.24	-0.02
Public Stigma – Blame/Segregation	0.37	0.39	0.09
SSSI - Awareness	-0.02	0.06	-0.03
SSSI - Agreement	-0.12	0.13	-0.09
SSSI - Application	0.01	0.08	0.01
SSSI – Harm	-0.03	0.07	-0.04
Label Avoidance	0.19	0.02	0.70

Discussion

This study aimed to investigate the impact of immigrant generation on the relationship between stigma and ethnicity and whether stigmatising attitudes influence levels of trust. Three forms of stigma were investigated – public stigma, self-stigma, and label avoidance – using an online survey. The results revealed that levels of stigma did not significantly differ between White, Polish and South Asian individuals or between first and second generation South Asians. Trust also did not significantly differ between the groups. While neither public nor self-stigma influenced levels of trust, label avoidance significantly predicted levels of trust with lower levels of label avoidance associated with higher levels of trust.

In contrast to previous findings [16,15], the results showed that there were no differences in public stigma, self-stigma or label avoidance according to ethnicity or between first and second generation South Asians. These findings indicate that the relationship between stigma and ethnicity is not robust [16]. This is particularly important considering this association has been implicated in the lower help-seeking seen in some marginalised groups [16,15,22,21] and indicates that additional targets must be considered when considering the lower help-seeking apparent in some groups. This study benefited from the inclusion of (British) Polish participants as previous studies have typically focused on comparisons between White and non-White groups [16]. A novel finding of this study was White British participants showed a tendency to internalise negative stereotypes about mental health compared to (British) Polish participants. This highlights the importance of an intersectional lens when considering different characteristics that may impact stigma and ensuring racial and ethnic groups are properly defined.

Using Link and Phelan's [13]'s Modified Labelling Theory, it can be argued that the focus on ethnicity within the stigma literature, specifically the idea that minoritised ethnic groups are more likely to hold negative stereotypes, has inadvertently led to the stigmatisation and othering of minoritised ethnic groups. Despite evidence to the contrary [16], heightened stigma has consistently been used to explain lower help-seeking, thereby indicating that the challenges lie within minoritised ethnic groups and their reluctance to seek-help as opposed to the challenges minoritised groups face when attempting to access such services. It is possible that this has led to minoritised ethnic groups avoiding services due to the awareness of the negative stereotypes that are attached to their cultural group, such as an overemphasis on concerns about marriage prospects and supernatural causes of mental ill health [23]. It is also possible that such a focus in the literature on ethnicity and stigma could influence the practice of services and clinicians with more resources being deployed to target stigma instead of concerns such as lack of accessibility, racism, and lack of trust [22,20,38].

The focus on stigma may minimise the larger structural discrimination faced by minoritised ethnic groups in various domains which contribute towards the development and maintenance of mental health difficulties including housing, education, and employment [44]. Recent literature has attempted to address this myopic view. Link and Phelan's concept of "stigma power" describes how structural discrimination allows for the explicit marginalisation of stigmatised groups such as minoritised ethnic individuals with mental health conditions while protecting those in positions of power enacting stigma as it occurs on a macro level [45]. It could be argued that the focus of clinicians and researchers on ethnic differences in stigma could inadvertently be maintaining such power dynamics.

This study additionally found that label avoidance was positively associated with trust across groups indicating that those with a desire to avoid services to avoid being labelled as “mentally ill” are less likely to trust services. This finding is consistent with previous reports of a lack of trust in services and professionals fostering disengagement [20,22]. Minoritised ethnic individuals have previously reported worries and concerns about becoming enmeshed with services and the worry that once they enter a system, it will be difficult to leave [22,20]; however, results here indicate that this is not specific to minoritised groups. Many people’s understanding of the mental health system is often also framed through other’s experiences such as witnessing police involvement in compulsory admission and a lack of cultural understanding and competency leading to misunderstandings and further distress [22]. It could be argued that while one aspect of label avoidance is the reluctance of being labelled as “mentally ill”, this could also include an element of avoiding services due to one’s misconceptions or understanding of the mental health system and a response to the aforementioned awareness of negative stereotypes associated with their group [45]. Indeed, previous findings have indicated that stigma can be reduced with contact with services [18] and this may indicate a need for outreach efforts to create better links between marginalised groups and services. Mental health services may consider engaging organisations and institutions that marginalised groups may choose to alternatively seek help from, such as mosques and churches [20,21,24].

Limitations of the study must be noted. Firstly, this study was limited by a small sample, particularly that of second-generation Poles, which possibly impeded the power to detect small differences in the analysis. Several steps were taken to increase participation during the recruitment stage, including identifying several Polish organisations. Feedback provided by staff from these organisations indicated that mental health is a particularly sensitive and not frequently discussed subject. Future research would benefit from the inclusion of Polish researchers who are able to build a relationship with this group of individuals to increase participation.

Another limitation of this study, one cited by Polish organisations, was the lack of translated materials which may have impeded the participation of those unable to read or write in English, particularly first generation migrants. Trust and Label Avoidance were measured using idiosyncratic and unvalidated measures devised by the authors due to a lack of existing measures. It is possible that these concepts were therefore not measured appropriately and limited the validity of the findings. Future research should either investigate the psychometrics of these measures or develop trust and label avoidance measures that are psychometrically sound. The sample in this study was self-selecting and also young and highly educated which may call into question the validity of the findings.

Future studies would benefit from further investigating the role of immigrant generation in the relationship between ethnicity and stigma and including a larger sample with different ethnic groups so comparisons can be made beyond just White and non-White groups. It would also be beneficial to identify whether this association is impacted by lived experience of a mental health diagnosis or caring.

Conclusion

The findings of this study call into question the strength of the frequently reported relationship between ethnicity and stigma indicating that there is a need for researchers and clinicians alike to consider factors beyond stigma when considering initiatives to improve the services provided to marginalised communities. Mental health services may also consider outreach efforts to improve wider knowledge of mental health services and increase trust between mainstream services and marginalised groups.

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Executive Summary

Stigma describes the negative way someone is viewed and treated for having a characteristic that is not valued by the wider society. Examples of characteristics include a criminal record, injury or disability, or a diagnosis of a mental health difficulty. People with mental health difficulties face a significant amount of stigma because of the way society views them – dangerous, unpredictable, and pathetic. This can lead to people not asking for help because they are worried about the consequences and how other people will view them if their mental health difficulties are found out.

It is important to find out what influences stigma because there is evidence that stigma can stop people from asking for help when they are experiencing mental health difficulties. This can lead to their mental health problems worsening until it is very severe and might require compulsory treatment. Research has also shown that stigmatising attitudes lead to negative outcomes for people with mental illnesses. This includes leaving school early, not being given opportunities, and even early death.

There are three different types of stigma according to researchers. Public stigma is the negative views the general public holds about a certain group like those with a mental health diagnosis. Self-stigma is when a person that belongs to that group applies those negative views to themselves, and label avoidance refers to people avoiding mental health services to avoid being labelled “mentally ill”.

Stigma exists globally, in all societies, but some research suggests that certain minoritised ethnic groups, like South Asians, might hold more stigma about mental health compared to

White groups. This research has been used to explain why minoritised ethnic groups are less likely to ask for help from mental health services. This is why it is important to find out if ethnicity causes different levels of stigma or something else may be causing these differences.

However, more recently, it has come to light that there are some weaknesses in these claims of ethnic differences in stigma. For example, the relationship reported in research is not very strong. Some studies also suggest that other factors, besides ethnicity, might better explain these differences in stigma. For example, age and whether or not someone is a migrant. Some studies have shown that where someone is living can impact the stigma they hold. For example, Indians in India hold very different ideas about mental health compared to Indians in London.

Some studies have also found that people from minoritised ethnic groups worry about racism, services not meeting their needs, and not trusting mental health services. However, the research has largely focused on higher stigma being the reason for people not using services.

Aims

This study aimed to find out how immigrant generation affects the relationship between ethnicity and stigma and trust. More specifically, this study aimed to find out:

- Is there a difference in how much stigma is expressed by different ethnic groups?
- Is there a difference in how much stigma is expressed by different immigrant generation groups (i.e., first vs. second generation groups)?
- Is there a difference in how much these groups trust health care services?

Methods

An online survey was created to collect information such as age, thoughts on mental health, and how much people would trust different services' evaluation of their problems.

A link was created to the online survey and people from the five groups listed below were asked to take part. They were given information about the study and what they would need to do. If they were happy with all of this information, they were asked to confirm consent and complete the survey.

Five groups of people were asked to take part in the study:

- First generation (British) South Asians (Bangladeshi, Indian, or Pakistani)
- Second generation (British) South Asians (Bangladeshi, Indian, or Pakistani)
- First generation (British) Polish people
- Second generation (British) Polish people
- White British

Results

Overall, 179 participants took part. Only four second generation (British) Polish participants took part. This number was too small to show meaningful differences in the data and were excluded from the final analysis. Therefore, the analysis included four groups – first generation (British) Polish, first and second generation (British) South Asians, and White British.

The study found three important results.

First, there was no evidence of differences in the three different types of stigma between the five groups. This means that there was no difference between the different ethnic or generational groups in the levels of stigma they expressed. One new finding, that does not appear to have been reported previously, is White British participants applied mental health stigma more to themselves compared to (British) Polish participants.

Secondly, levels of trust did not differ between the different ethnic groups or first and second generation (British) South Asian participants.

Finally, public- and self-stigma did not predict levels of trust. However, label avoidance appeared to predict how much someone trusts a service. This means that the more participants expressed a desire to avoid services to avoid being labelled as ‘mentally ill’, the less they said they trust services.

Conclusions

The results of this study indicate that the relationship between ethnicity and stigma may not be very strong. There is a need to continue exploring different factors that might explain why people from marginalised groups may have fewer interactions with mental health services. The study also found that overall wanting to avoid services for fear of being labelled ‘mentally ill’ was associated with less trust in services. People from marginalised groups have previously reported that their understanding of mental health services is influenced by hearing and observing others’ interactions with services, and this usually includes police involvement, forceful treatment, and professionals not understanding their culture. Mental health services should consider improving their relationship with marginalised groups by putting effort into outreach initiatives and creating relationships with other places where people might go to for support such as mosques and churches.

Connecting Narrative

I am stunned that I am finally at the stage of writing this narrative. To reflect on my research journey through the doctorate, I need to add some context. Before beginning the doctorate, I worked as a Research Assistant for a few years and although, I will never be caught saying this out loud, I really enjoyed it and learned to fully appreciate research and the capability it has for changing people's lives. I enjoyed it so much that I began to consider working as an academic if the clinical route did not work out. So, when I started the course, I felt quite confident in my research skills and was excited to begin the research component of the course, so much so that I attended the research fair just for fun knowing full well I was already pretty confident in what I wanted to do for my research projects.

What I had not considered was that excitement alone could not sustain three different research projects whilst balancing teaching and clinical work. I have to admit, I also struggled with living in Oxford for the first year. I came from London and while some people dismiss the differences between the two as being of little significance, for me – a Brown Muslim woman who was born and bred in Tower Hamlets – Oxford and London were two entirely different planets, but these projects allowed me to do research that matters to the people where I come from and identify with.

Theory Driven Research Project

My initial idea for my TDRP was focused on the Prevent project which disproportionately targets Muslims but probably not a good research project considering the barriers I would have likely faced in trying to research a sensitive and contentious part of national security...

Although it was not my initial idea, I eventually felt quite strongly about this topic. Stigma has always felt very clunky to me – we hear about it all the time when discussing minoritised ethnic groups and mental health but what actually is it?

When researching stigma, I realised that there is a large amount of stigma literature, but it is very dispersed and 'messy'. The only commonality amongst it all seemed to be the idea that certain non-White groups hold more negative views about mental health than others and that is why they avoid services. This frustrated me because it seemed to be used as a catch-all to explain away the problems marginalised groups face when accessing services. So, it was important to investigate additional factors like immigrant generation.

Some of the results were negative and surprisingly we struggled to recruit second generation Polish participants. Significant results are always touted as the aim for all research studies but in this case it actually demonstrated that an association that has been reported for decades might actually not be robust and provides evidence for researchers to investigate other concerns expressed by marginalised groups, like racism.

Critical Review of the Literature

My CRL centred on the impact of islamophobia on the mental health of Muslims. This was a project I was really passionate about from the get-go but doing an entire review by yourself can leave you with complicated feelings about what initially began as a passionate project. As a Muslim who grew up in, and continues to live in, an area of London frequently described as a 'no-go' area, I was well accustomed to living in the shadows of Islamophobia – from the periodic bomb threats sent to the local mosques to worrying about leaving the house just in case racists go through with 'Punish a Muslim Day'. Being in a position of privilege, I wanted to use this opportunity to highlight that just because we Muslims have become accustomed to these threats and continue to go about our lives, it still takes a significant toll on our mental health. Plus, knowing research has the important ability of impacting policy and practice, I knew it was important to make sure this research was conducted and published so it is in black and white.

Service Improvement Project

This project was by far the most personal to me. I grew up as a young carer and a large part of my childhood consisted of me having medical knowledge that I had no business knowing. I actually did not realise I was a young carer until I was an adult and no longer a carer. Young carers have always been a group I have been interested in, especially those from minoritised ethnic groups. This interest continued to grow the more I learned that my experience was not uncommon and that there is a whole population of essentially children doing an unimaginable load of work while balancing schoolwork and their own lives all while this goes unnoticed. So, I wanted to do a project that focused on finding out the experiences of these young people, their parents and staff so we could find out how to make sure these young people were being identified and supported. I probably overshot my shot when I first planned this project.

It was hard scaling it back because this project was really important to me and it actually took me a while to realise that if I ever wanted to complete this project I would have to scale it back.

I ended up doing this project with a team that I really enjoyed working with and they were incredible in their energy and their passion for this project.

This SIP actually made me realise just how big and complicated the NHS is and even though we can all point out just how hard these complicated parts of the NHS can make our jobs, we also seem to be resigned to the fact that it takes a lot to change the way things have always been done but that if we begin talking about it and push enough, we can bring about these changes sometimes, no matter how small.

Do I still like research? Yes.

Acknowledgements

First and foremost, I have to thank Allah (SWT) for granting me the opportunity to complete this thesis and the Doctorate. It is only by the will of Allah, the Almighty, that I have managed to reach the end of what has been a tumultuous journey.

I would also like to acknowledge and thank my father who is the reason I decided to pursue a career in Clinical Psychology. Despite no longer being here, it is his memory and experiences that guided my research projects and encouraged me to persevere despite the challenges I faced. I hope I have made you proud.

I would also like to thank my supervisors, Reena Vohora, Louise Johns, and Paul Salkovskis for their continued support and guidance as I completed these projects. I cannot put into words how incredibly grateful I am for the level of compassion that was extended towards me.

In particular, I would like to thank Louise, my course tutor, for such unwavering patience and humanity and for sticking with me through all the tough times. Thank you for constantly pushing me and not giving up on me. I know it was not easy. I will carry your kindness and compassion with me as I carve out my career as a Clinical Psychologist.

Finally, I want to thank two people who I can only describe as angels on Earth – Sazan and Cathy. I truly believe that everything happens for a reason and the reason I ended up in Oxford was to meet you both. I could not have gone through the past few years without you and Muslim Club and the endless laughs and rants and putting the world to rights. Thank you

both for the light you brought into my life when I was consumed with darkness and for being constant reminders of Allah’s mercy. I am genuinely in awe of both of you and your achievements. I pray that Allah places barakah in all of your adventures and endeavours. May you both always be blessed with ease, contentment, success, and happiness in both this life and the next.

Appendices

Appendix 1A – Submission guidelines for authors: Journal of Muslim Mental Health

Submission Checklist

The Journal of Muslim Mental Health accepts submissions to the following areas:

- Original Contributions (reviews, original research)
- Cultural Formulations
- Faith-Based Practice
- Book Reviews
- Letters to the Editor

Manuscripts must be original submissions, adhere to accepted standards of patient anonymity and informed consent, and include full disclosure of all forms of support, including conflicts of interest. All manuscripts should follow the guidelines of the *Publication Manual of the American Psychological Association*, 7th edition.

Articles shall have a maximum length of **6,000 words** (the word count limit includes title, abstract, tables, figures, and references list). During a potential revisions stage, after peer-review, authors can extend the article length to a maximum of 8,000 words to better address the reviewers and editors' comments.

All authors must approve the submissions and one corresponding author should be designated along with current contact information. Corresponding authors must:

1. Include a cover letter assuring that the manuscript has not been published in print or electronically and is not being considered for publication
2. Suggest three peer reviewers who do not have a conflict of interest with the research and are not from your own university

3. All articles must adhere to WORD formatting precision as detailed in this article and using a template from this article; especially regarding sections and nested subsections.

Peer Review

Ethical Publishing Guidelines

As a double-blind peer-reviewed publication, The Journal of Muslim Mental Health (JMMH) is committed to ensuring ethical conduct in the publication of all its content. Our Ethical Guidelines are based on the Committee on Publication Ethics's (COPE) guidelines, and set out expectations for authors, reviewers, and editors.

AUTHORS AGREE:

- To conduct research in an ethical and responsible manner and comply with all relevant laws.
- To present their results clearly, honestly, and without fabrication, falsification, or inappropriate data manipulation.
- To describe their methods clearly and unambiguously so that their findings can be confirmed by others.
- That submitted work is original, is not plagiarised, and has not been published or simultaneously submitted for consideration elsewhere.
- To disclose relevant conflicts of interest.
- That authorship accurately reflects individuals' contributions to the work and its reporting.
- To notify and cooperate with JMMH editors if a significant error or inaccuracy is discovered.

- To consult with the editors if anything about their duties is unclear.

REVIEWERS AGREE:

- To treat manuscripts for review as confidential documents.
- To be objective, and formulate reviews clearly with supporting arguments.
- To decline an assignment if they feel unqualified to review it or cannot meet the deadline.
- To accept or decline assignments within one week and submit reviews within three weeks of accepting a manuscript assignment.
- To disclose any potential conflicts of interest in performing the review.
- To identify relevant published work that has not been cited, or instances where proper attribution was not provided.
- To notify the editors promptly if at any point they realize the double-blind peer-review process has been compromised.
- To consult with the editors if anything about their duties is unclear.

EDITORS AGREE:

- To be accountable for everything we publish.
- To make fair and unbiased decisions and ensure a fair and appropriate peer review process.
- To adopt editorial policies that encourage maximum transparency and complete, honest reporting.
- To guard the integrity of JMMH’s published record by investigating any suspected or alleged research and publication misconduct and issuing corrections and retractions as needed.
- To investigate any reviewer and editorial misconduct and, as necessary, remediate it.

- To critically assess the ethical conduct of research studies.
- To communicate clearly what is expected of peer reviewers and authors.
- To disclose any personal, professional, or commercial conflicts of interest with and, when they arise, to recuse oneself from decisions involving the related article under review for publication.

Appendix 1B – PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	

Section and Topic	Item #	Checklist item	Location where item is reported
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17	Cite each included study and present its characteristics.	
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	
	23b	Discuss any limitations of the evidence included in the review.	
	23c	Discuss any limitations of the review processes used.	
	23d	Discuss implications of the results for practice, policy, and future research.	

Section and Topic	Item #	Checklist item	Location where item is reported
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	
Competing interests	26	Declare any competing interests of review authors.	
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix 1C – Search strategy for individual databases

PsycINFO (1806 to present)

Key term	Search terms	Results
Muslims	1) exp Muslims/	4354
	2) limit 1 to human	4276
	3) exp Islam/	3958
	4) limit 3 to human	3521
	5) Muslim* or Islam* or Sunni* or Shia*	13400
	6) limit 5 to human	12811
	7) 2 or 4 or 6	12811
Islamophobia	8) Islamophobi* or (religio* discriminat*) or (anti-Muslim*) or (religio* prejudice*) or (anti-Islam)	1112
	9) limit 8 to human	1050
Mental health	10) exp Mental Health/	93234
	11) limit 10 to human	90325
	12) exp Mental Disorders/	1084823
	13) limit 12 to human	1025168
	14) (mental* or psychologic* or psychiatr* or mood* or emotion*) adj2 (health or disorder* or disease* or deficien* or illness* or problem* or well-being or wellness)	547357
	15) limit 14 to human	498945
	16) 11 or 13 or 15	1269893
Help-seeking	17) exp Health Care Seeking Behavior/	10188
	18) Limit 17 to human	10018
	19) exp Help Seeking Behavior/	16741

	20) Limit 19 to human	16428
	21) (help-seek* or treat* or therap* or input* or support* or interven* or access* or service use*)	2202847
	22) limit 21 to human	1956197
	23) 18 or 20 or 22	1958217
Combined	24) 7 and 9 and 16 and 23	74

Medline (Ovid)

[Medline (Ovid MEDLINE® Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE® Daily and Ovid MEDLINE®) 1946 to present]

Key Term	**Search Term(s)**	**Results**
Muslims	1) exp Islam/	6666
	2) limit 1 to humans	6059
	3) (Muslim* or Islam* or Sunni* or Shia*)	15654
	4) limit 3 to humans	11483
	5) 2 or 4	11483
Islamophobia	6) (Islamophobi* or religio* discriminat* or anti Muslim* or religio* prejudice* or anti-Islam)	185
	7) limit 6 to humans	131
Mental health	8) exp Mental Health/	63527
	9) limit 8 to humans	62185
	10) exp Mental Disorders/	1449265
	11) limit 10 to humans	1379591
	12) ((mental* or psychologic* or psychiatr* or mood* or emotion*) adj2 (health or disorder* or disease* or deficien* or illness* or problem* or well-being or wellness))	583822

	13) limit 12 to humans	486863
	14) 9 or 11 or 13	1554760
Help-seeking	15) exp Help-Seeking Behavior/	1207
	16) limit 15 to humans	1203
	17) (help-seek* or treat* or therap* or input* or support* or interven* or access* or service use*)	19664420
	18) limit 17 to humans	12541406
	19) 16 or 18	12541406
Combined	20) 5 and 7 and 14 and 19	12

CINAHL (EBSCOhost)

Key Term	**Search terms (Limiters - Human** **Expanders - Also search within the full text of the articles; Apply equivalent subjects** **Search modes - Boolean/Phrase**	**Results**
Muslims	1) (MH “Islam”)	2,839
	2) Muslim* or Islam* or Sunni* or Shia*	16,539
	3) S1 or S2	8,795
Islamophobia	4) Islamophobi* or (religio* discriminat*) or (anti-Muslim*) or (religio* prejudice*) or (anti-Islam)	188
Mental Health	5) (MH "Mental Health")	30,386
	6) (MH "Mental Disorders")	32,030
	7) (mental* or psychologic* or psychiatr* or mood* or emotion*) N2 (health or disorder* or disease* or deficien* or illness* or problem* or well-being or wellness)	212,829

	8) S5 or S6 or S7	163,553
Help-seeking	9) MH "Help Seeking Behavior"	6,754
	10) (help-seek* or treat* or therap* or input* or support* or interven* or access* or service use*)	1,626,919
	11) S9 or S10	1,478,837
Combined	8) S3 AND S4 AND S8 AND S11	8

Social Science Citation Index (SCI-EXPANDED) – 1900-present (Web of Science) – No limits

Key term	**Search terms**	**Results**
Muslims	1) TS=Muslim*	17,230
	2) TS=Islam*	26,014
	3) ALL=Muslim*	18,095
	4) ALL=Islam*	46,184
	5) ALL=Sunni*	871
	6) ALL=Shia*	2,304
	7) #6 OR #5 OR #4 OR #3 OR #2 OR #1	60,246
Islamophobia	8) ALL=Islamophobi*	1,119
	9) ALL="religio* discriminat*"	235
	10) ALL="anti-Muslim*"	432
	11) ALL="religio* prejudice*"	68
	12) ALL="anti-Islam"	34
	13) #12 OR #11 OR #10 OR #9 OR #8	1,681

Mental Health	14) TS="Mental Health"	254,681
	15) TS="Mental Disorder*"	49,222
	16) TS=((mental* or psychologic* or psychiatr* or mood* or emotion*) NEAR/2 (health or disorder* or disease * or deficien* or illness* or problem* or well-being or wellness))	428,198
	17) #16 OR #15 OR #14	428,198
Help-seeking	18) TS=Help-Seeking Behaviour	5,767
	19) TS="Help-seek*"	13,616
	20) ALL=(help-seek* or treat* or therap* or input* or support* or interven* or access* or service use*)	3,012,791
	21) #18 OR #19 OR #20	3,012,791
Combined	22) #7 AND #13 AND #17 AND #21	28

SCOPUS (No limits)

Key term	**Search terms**	**Results**
Muslims	1) INDEXTERMS (muslim*)	2,842
	2) INDEXTERMS (islam*)	13,242
	3) Muslim* or Islam* or Sunni* or Shia*	2,136,356
	4) (INDEXTERMS (muslim*)) OR (INDEXTERMS (islam*)) OR (muslim* OR islam* OR sunni* OR shia*)	2,136,356
Islamophobia	5) islamophobi* OR ("religio* discriminat*") OR ("anti-Muslim*") OR ("religio* prejudice*") OR ("anti-Islam")	19,417

Mental health	6) INDEXTERMS ("Mental Health")	283,018
	7) INDEXTERMS ("Mental Disorder*")	182,554
	8) (mental* OR psychologic* OR psychiatr* OR mood* OR emotion*) PRE/2 (health OR disorder* OR disease* OR deficien* OR illness* OR problem* OR well-being OR wellness)	2,718,020
	9) (INDEXTERMS ("Mental Health")) OR (INDEXTERMS ("Mental Disorder*")) OR ((mental* OR psychologic*OR psychiatr* OR mood* OR emotion*) PRE/2 (health OR disorder* OR disease* OR deficien* OR illness* OR problem* OR well-being OR wellness))	2,718,020
Help-seeking	10) INDEXTERMS (“help-seek*”)	15,514
	11) help-seek* OR treat* OR therap* OR input* OR support* OR interven* OR access* OR service-use*	38,405,311
	12) (INDEXTERMS ("help-seek*")) OR (help-seek* OR treat* OR therap* OR input* OR support* OR interven* OR access* OR service-use*)	38,405,311
Combined	((INDEXTERMS (muslim*)) OR (INDEXTERMS (islam*)) OR (muslim* OR islam* OR sunni* OR shia*)) AND (islamophobi* OR ("religio* discriminat*") OR ("anti-Muslim*") OR ("religio* prejudice*") OR ("anti-Islam")) AND ((INDEXTERMS ("Mental Health")) OR (INDEXTERMS ("Mental Disorder*")) OR ((mental* OR psychologic* OR psychiatr* OR mood* OR emotion*) PRE/2 (health OR disorder* OR disease* OR deficien* OR illness* OR problem* OR well-being OR wellness))) AND ((INDEXTERMS ("help-seek*")) OR (help-seek* OR treat* OR therap* OR input* OR support* OR interven* OR access* OR service-use*))	2,174

Appendix 1D - Grey Literature Search Strategy

Third Sector & Government Organisations

Website/Database	**Search terms**	**Limits**	**Number of relevant papers identified for inclusion in review**
Department of Health and Social Care	Islamophobia	All content type Topic: Health and Social Care All sub-topics	0
	Islamophobia AND “mental health” AND muslim		
Hope Not Hate	Islamophobia	None	0
	“mental health”		
	Islamophobia AND “mental health” AND muslim		
Runnymede Trust	Islamophobia	None	0
	“mental health”		
	Islamophobia AND “mental health” AND muslim		

MEND	Islamophobia	None	0
	“mental health”		
	Islamophobia AND “mental health” AND muslim		
Social Sciences Research Network (SSRN)	Advanced search: 1) Islamophobia Search within: 2) “mental health”	None	0
National Grey Literature Collection	Anti-Islam	None	0

Global Health (via Ovid) 1973 to 2023 week 49

Key term	Search Terms	Results
Muslims	1) (Muslim* or Islam* or Sunni* or Shia*)	6102
Islamophobia	2) (Islamophobi* or religio* discriminat* or anti-Muslim* or religio* prejudice* or anti-Islam)	20
Mental health	3) exp mental health/	41951

	4) exp mental disorders/	105127
	5) ((mental* or psychologic* or psychiatr* or mood* or emotion*) adj2 (health or disorder* or disease* or deficien* or illness* or problem* or well-being or wellness))	103078
	6) 3 or 4 or 5	133181
Help-seeking	7) (help-seek* or treat* or therap* or input* or support* or interven* or access* or "service use*")	2048548
Combined	8) 1 and 2 and 6 and 7	1

Appendix 1E – Critical Appraisal Skills Programme (CASP) checklist for cohort studies

Section	Question	Yes	Can't Tell	No	Comments
Section A: Are the results of the study valid?	1. Did the study address a clearly focused issue?				
	2. Was the cohort recruited in an acceptable way?				
	Is it worth continuing?				
	3. Was the exposure measured to minimise bias?				
	4. Was the outcome accurately measured to minimise bias?				
	5. (a) Have the authors identified all important confounding factors?				
	5. (b) Have they taken account of the confounding factors in the design and/or analysis?				
	6. (a) Was the follow up of subjects complete enough?				
	6. (b) Was the follow up of subjects long enough?				
Section B: What are the results?	7. What are the results of this study?				
	8. How precise are the results?				
	9. Do you believe the results?				
Section C: Will the results help locally?	10. Can the results be applied to the local population?				
	11. Do the results of this study fit with other available evidence?				
	12. What are the implications of this study for practice?				

Appendix 1F – Critical Appraisal Skills Programme (CASP) checklist for qualitative studies

Section	Question	Yes	Can't Tell	No	Comments
Section A: Are the results of the study valid?	1. Was there a clear statement of the aims of the research?				
	2. Is a qualitative methodology appropriate?				
	Is it worth continuing?				
	3. Was the research design appropriate to address the aims of the research?				
	4. Was the recruitment strategy appropriate to the aims of the research?				
	5. Was the data collected in a way that addressed the research issue?				
	6. Has the relationship between researcher and participants been adequately considered?				
Section B: What are the results?	7. Have ethical issues been taken into consideration?				
	8. Was the data analysis sufficiently rigorous?				
	9. Is there a clear statement of findings?				
Section C: Will the results help locally?	10. How valuable is the research?				

The Critical Appraisal Skills Programme (CASP) Checklists for cohort studies and qualitative research were used for quality appraisal. These are available from: https://casp-uk.net/casp-tools-checklists/.

Appendix 1G – Quality appraisal process

Each checklist covers three sections focusing on whether the results are valid, what the results are, and whether the results can be applied locally. The cohort studies checklist consists of 12 questions (two questions about follow-up were not applicable) and the qualitative studies checklist has 10 questions with the first two questions of each checklist advised to be used as screening questions. Each question is answered as either “yes”, “no, or “can’t tell” and prompts are provided to facilitate decision making. Studies were assessed as high quality on the cohort studies checklist if nine or more of the criteria were met, moderate quality if eight to four criteria were met, and low quality if fewer than four criteria were met. Qualitative studies were considered high quality if seven or more criteria were met, moderate if six to three met, and low if fewer than 3 were met.

An MS Excel spreadsheet was developed to record the quality appraisal process for each study and a traffic light system was employed to facilitate scoring. Both reviewers initially met and discussed the checklist to ensure there was consistent understanding of the tools.

Appendix 1H – Table summarising the main findings of each study included in the review

Study	Main findings
Abelson et al. (2020)	• Differences between Muslim and non-Muslim students' mental health mostly stable over time • Before the election, mental health of Muslim and non-Muslim students changed in parallel • The proportion of Muslims experiencing clinically significant mental health symptoms post-election rose by 7.0 percentage points (10.9 percentage points for religious Muslims vs. 8.1 percentage points for non-religious Muslims) • Religious non-Muslims experienced a rise of 3.5 percentage points in clinically significant mental health symptoms vs. 2.8 percentage points for non-religious non-Muslims
Abu-Ras & Suarez (2009)	• PTSD symptoms post 9/11: o More than 90% of participants reported physical or emotional PTSD symptoms including increased arousal, sadness and tearfulness, and anger. o More than 50% reported sleeping difficulties, fatigue and exhaustion, feeling anxious or fearful, problems with concentration and, feelings of despair or hopelessness. o 19.6% reported thoughts of death or suicide. • More than 80% of both men and women reported feeling "safe to extremely safe" before 9/11 and the same number reported feeling "unsafe to extremely unsafe" after 9/11 • Gender differences in PTSD symptoms: o Men reported more feelings of fatigue/exhaustion and thoughts of death or suicide compared to women o A higher frequency of women reported reluctance to leave home compared to men. • Feeling less safe since 9/11 predicted symptoms of PTSD but experiencing hate crimes and discrimination did not.
Abu-Ras et al. (2018)	• Women reported more experience with discrimination and islamophobia • All ethnic groups reported similar levels of perceived discrimination and islamophobia • Women reported feeling less safe than men • Feeling less safe was associated with greater levels of stress, lower quality of life, preexposure to religious-based discrimination and greater levels of discrimination and islamophobia. • Greater levels of perceived total impact of islamophobia on wellbeing were associated with feeling unsafe, higher levels of stress, higher levels of religiosity and unemployment.

	• Greater levels of perceived religious discrimination were associated with pre-exposure to religious-based discrimination, living longer in the US, feeling unsafe, perceived religious discrimination related stress, and higher levels of religiosity.
Ahmed & Islam (2023)	• Interpersonal anti-Muslim discrimination was positively associated with depressive symptoms • Societal anti-Muslim discrimination was positively associated with depressive symptoms • Societal anti-Muslim discrimination was associated with reduced physical activity • General discrimination had a positive and direct effect on the rating of diet but a negative impact on diet mediated via symptoms of depression.
Ameline, Ndobo, & Roussiau (2019)	• More than half of participants agreed or strongly agreed that the news media portrays Muslims or Islam as a threat or danger to French culture • More than 90% strongly identified with Muslims • Perceived religious discrimination towards Muslims in the news media had no direct effect on perceived stress or self-esteem • Group identification had no direct effect on self-esteem • Perceived discrimination in the media had a direct effect on identification with Muslims • Perceived religious discrimination in the media had an indirect effect on perceived stress via identification with Muslims
Every & Perry (2014)	• Religious prejudice and discrimination (interpersonal prejudice) was associated with lower self-esteem • Exposure to a religiously discriminatory environment (institutional prejudice) was associated with higher self-esteem
Gormez et al. (2021)	• 48% of participants reported chronic PTED symptoms of clinical relevance • 20% of participants reported PTED symptoms of significant intensity • 32.7% of participants reported mild anxiety, 19.8% moderate anxiety, and 17.8% severe anxiety • 29.7% reported mild depression symptoms, 23.8% moderate symptoms, and 3% reported severe symptoms • When compared to women who experienced the earthquake, there were no differences in levels of anxiety, depression and resilience but victims of the hijab ban reported more embitterment symptoms • Those with family support reported lower levels of embitterment and anxiety symptoms and higher resilience compared to those without family support.
Hodge et al. (2015)	• 28% reported clinically significant levels of depressive symptoms • Clinically significant levels of depression were associated with an increased likelihood of reporting poorer self-rated health

	• Being singled out by law enforcement was associated with a greater likelihood of reporting poorer health • Increased daily prayer was associated with a greater likelihood of reporting better self-rated health.
Hodge et al. (2015)	• Men were less likely than women to report depression • Muslims that reported being offensive names in the past 12 months were more than 3 times more likely to report clinically significant levels of depression compared to those who did not report being called offensive names • Muslims that reported being singled out by law enforcement in the past 12 months were more than 2.5 times more likely to report clinically significant levels of depression. • Increased daily prayer was associated with a lower likelihood of reporting clinically significant levels of depression for discriminatory experiences including being called offensive names, being singled out by airport security and other acting suspiciously towards them.
Hodge et al. (2015)	• 38% reported being called offensive names in the past 12 months due to being a Muslim • 27% reported clinically significant levels of depression • Discrimination predicted higher levels of depressive symptoms • Higher levels of spirituality independently predicted lower levels of depression and substance use
Hodge et al. (2015)	• Discrimination predicted higher levels of depression which in turn had a strong negative effect on wellness • Spirituality had an independent effect on both depression and wellness • Spirituality impacted wellness indirectly via depression
Lowe et al. (2019)	• Higher perceived discrimination was significantly associated with higher depression and anxiety symptoms • Higher identification with the Muslim American identity was associated with lower anxiety symptoms for those reporting low perceived discrimination and higher anxiety symptoms were associated for those with high perceived discrimination
Lowe et al. (2019)	• A higher number of lifetime traumatic events and higher past-year perceived discrimination were significantly associated with higher PTSD symptoms. • Participants reported higher intrusion symptoms related to their worst DSM trauma than to lifetime discrimination experiences • Participants reporting higher past-year perceived discrimination had significantly higher discrimination-related PTSD symptoms.
McLaughlin et al. (2022)	• Perceived islamophobia had an indirect effect on help-seeking attitudes via greater self-stigma of seeking help o Greater perceived islamophobia was associated with greater self-stigma of seeking help o Increased self-stigma of seeking help was associated with negative help-seeking attitudes

	• Perceived islamophobia was associated with higher psychological distress but psychological distress was not significantly associated with help-seeking attitudes • Greater perceived islamophobia was indirectly associated with more positive help-seeking attitudes through its association with higher distress. • Perceived islamophobia contributed to more negative help-seeking attitudes overall • Past therapy experience was associated with more positive help-seeking attitudes and higher levels of distress. • Self-stigma of seeking help was associated with psychological distress Therapist demographic preference: • 41% indicated a preference for a therapist of the same religion, 5% indicated a preference for a therapist of a different religion, and 53% no preference. • 34% indicated a preference for the same ethnicity, 61% no preference and 5% wanted a therapist of a different ethnicity • 53% indicated a preference for the same gender, 5% wanted a different gender therapist and 42% had no preference. • Greater perceived islamophobia was associated with greater preference for a therapist of the same religion • Men and those with higher levels of self-stigma of seeking help expressed a preference for a therapist of the same ethnicity Treatment modality preference: • There was no difference between preference for medication and individual therapy but individual therapy was preferred over group and family therapy. • 63% indicated a willingness to attend individual therapy, 50% indicated some willingness to attend group therapy and 57% family therapy. • 60% expressed some willingness to take medication • Previous therapy experiences, positive help-seeking attitudes and being a man were associated with greater endorsement of all forms of therapy • Greater self-stigma and less perceived islamophobia were related to greater willingness to attend group therapy • Lower perceived islamophobia was related to greater willingness to attend family therapy Therapy location preference: • Community centres (55%) were less preferred to mosques and private offices and there was no difference between preference for a private office (68%) and mosque (55%)

	• Younger participants preferred therapy in a private office while older participants preferred mosques Discussing feelings and imam collaboration: • 72% expressed willingness to discussion feelings during therapy and 64% would be willing to attend therapy with imam collaboration • Positive help-seeking attitudes were associated with greater willingness to discuss feelings in therapy Barriers to care: • 20% indicated concerns about practical barriers such as cost, insurance, location and time • 9% noted stigma including concerns about judgement, family, employment and self-stigma. • 21% indicated a qualified therapist is important with training and experience mentioned. • 15% indicated a therapist's empathy is important and 5% indicated recommendations and reviews Imam collaboration: • 12% indicated benefits to imam collaboration • 63% endorsed imam involvement • 17% reported concerns including religion and therapy not being suitable for combining (7%), concerns about the imam's qualifications for therapy (5%) and concerns about privacy (5%).
Rippy & Newman (2006)	• 91.2% of Muslims reported discrimination against Muslims had increased since the 9/11 attacks, 8% reported it was the same, and 0.6 felt it had decreased • 53% reported an increase in personal discrimination since 9/11, 43.6% reported no difference, and 2.7% reported a decline in personal exposure to discrimination • 54% reported being the victim of a violent hate crime or discrimination at some point in their life with the most common form being verbal harassment. • Significant correlation was found for men between subclinical paranoid ideation and perceived discrimination but no association was reported between perceived discrimination and anxiety.
Sabado et al. (2023)	• Acculturation to Islamic values had a significant negative association with the likelihood of seeking mental health services • Acculturation to American values had a significant positive association with the likelihood of seeking mental health services • Sources of support utilised: 25% indicated family, 19.2% self-care, 17.3% religion, 13.5% do not seek support, 9.6% friends, 1.9% community, and 1.9% professional help. • Sources of support sought when stressed about experiences as a Muslim:

	o 88.5% friends, 82.7% family, 71.2% religion, 69.2% self-care, 57.7% community (e.g., mosque), 46.2% professional (e.g., therapy), and 23.1% would do nothing. • 44.2% of participants indicated previous experience of seeking mental health support
Tetreault et al. (2019)	Women's experiences of anti-Muslim aggression: • 100% indicated Islamophobia had increased since the 2016 presidential election • 85% reported experiences of islamophobia and/or racism • 83% believed hijab wearing women were more targeted by islamophobia than those who did not wear hijab • 1 participant reported hijab-wearer were not more targeted, 3 did not answer the question directly, and 2 were unsure • 46% of women reported direct personal experience of anti-Muslim aggression and 43% reported low feelings of safety • 50% of hijab-wearers reported direct experience of anti-Muslim aggression (violent speech or actions) compared to 38% of non-hijab wearers but there was no significant difference between hijab wearers and non-wearers • 34.3% reported beginning to feel unsafe since the 2016 presidential election and 25.7% indicated it was after 9/11 Emotional experiences: • Over the past year, 60% of participants reported experiencing anxiety and sadness, 45.6% reported anger, 40% fear, and 22.9% depression • 54.6% of hijab-wearers reported fear compared to 15.4% of those who did not wear hijab
Tineo et al. (2021)	• Higher perceived discrimination was significantly associated with higher acculturative stress, depression, and anxiety symptoms • Higher acculturative stress was associated with higher depression and anxiety symptoms and lower religious support • Higher religious support was significantly associated with a stronger Muslim identity • Higher acculturative stress was associated with significantly higher depression symptoms • Experiencing more perceived discrimination was not significantly associated with depression symptoms • The total effect of perceived discrimination on depression symptoms was significant • Higher acculturative stress was associated with significantly higher anxiety symptoms

	• Experiencing more perceived discrimination was significantly associated with anxiety symptoms • Acculturative stress was positively associated with depression symptoms • The direct effect of perceived discrimination on depression symptoms decreased as the level of religious support increased • The indirect effect of perceived discrimination on depression symptoms via acculturative stress was significant at all levels of religious support but the magnitude of the effect increased as religious support increased • Acculturative stress was positively associated with anxiety symptoms • The indirect effect of perceived discrimination on symptoms of anxiety via acculturative stress was significant at all levels of religious support but the magnitude of the association increased as religious support increased.
Uddin et al. (2022)	• Average scores for depression indicated a mild level of depression symptoms • Average scores for anxiety were on the borderline between mild and moderate levels of anxiety • Women on average scored higher than men for both anxiety and depression symptoms • Higher perceived discrimination was associated with higher symptoms of depression and anxiety and lower positivity • Women reported higher perceived discrimination than men • Men wearing thobes reported higher levels of discrimination compared to those not wearing thobes but the beard did not impact levels of discrimination reported • Women wearing hijab reported more perceived discrimination than those that did not wear the hijab but there was no difference in discrimination between abaya-wearers and non-wearers. • Dose-response effect of visibility – the higher the visibility of participants (thobe and beard/thobe or beard and abaya and hijab/hijab or abaya) the higher the level of perceived discrimination reported
Zia et al. (2021)	• 47.9% reported moderate and 17.6% severe psychological distress in the past month • 60.1% perceived the need for professional mental health services in the last 12 months • 48.7% reported seeking help from a mental health professional or a general practitioner (44.7%) in their lifetimes and 41.4% reported seeking psychological help from an imam • The preference to seek treatment from a mental health professional was positively correlated with a lifetime history of using services from a mental health provider but not associated with perceived need or psychological distress. • Preference to seek services from a general practitioner was positively associated with a history of seeing a general practitioner for emotional difficulties but not with perceived need • The preference to seek help from a general practitioner was negatively associated with distress

	• The preference for seeking help from an imam was positively associated with religiosity and previously seeking help from an imam but negatively associated with both distress and perceived need • The preference for seeking support from friends and family was negatively associated with distress and perceived need • Participants were most likely to indicate intentions of dealing with a future mental health by themselves or by talking to friends and family. • Participants were significantly more likely to deal with problem by themselves than by seeking services form a mental health professional, general practitioner or an imam. • There was no difference between the intention to seek support from a mental health professional and talking to friends and family but participants were more likely to speak to friends and family than to a general practitioner or an imam • The intention to speak to a mental health professional did not differ from the intention to seek help from a general practitioner but participants were least likely to report an intention to seek support from an imam compared to all other sources of support.
Qualitative Studies	
Ayub & Macaulay (2023)	Four themes: • Culture vs. religion – religion misconstrued as culture; negative influence of culture on mental health • Religion as a protective factor • Fear of public opinion – discrimination and stigma as barriers to accessing treatment; mental health as non-existent and unacknowledged • Integration of religious and professional services – training and inclusion of religious leaders in mainstream mental health services
Chaudry (2021)	Themes: • "*I remember people not sitting next to me*": experiencing Islamophobia • "*I'm often left feeling quite anxious*": the psychological impact
Weatherhead & Daiches (2010)	Seven themes: • Causes – reaction to life events; religious; life is a test • Problem management – religious response (refer to Islam, prayer/readings, ask Allah for help, religious interventions); family and friends; professional is best; internal solution (self-efficacy, patience) • Relevance of services – community support; it's normalised in the UK; faith reduces need; divine will; therapy betrays religion

	• Barriers – shame; stigma; wider societal issues; fear of stereotyping; it’s only for serious issues; bad experience of services • Service delivery – consultations; GP role; visibility and accessibility; awareness • Therapy content – religious aspects; therapeutic relationship; cultural sensitivity • Therapist characteristics – trust; therapist’s approach; quality and professional; connection with therapist; past experiences

Appendix 2A – Journal submission guidelines for BMC Psychology

Summary of journal

BMC Psychology is a peer-reviewed, open access journal that publishes articles on a topics covering psychology, human behaviour, and the mind. This includes, but is not limited to, developmental, clinical, cognitive, experimental, and theoretical psychology, as well as health and social psychology, psychology and its relationship to law, policy, personality and individual differences. The journal welcomes submissions of both quantitative and qualitative research as well as basic and translational research.

Preparing your manuscript

The information below details the section heading that should be included in your manuscript and the information that should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings.

Title page

The title page should:

- Present a title that includes, if appropriate, the study design
- List the full names and institutional addresses for all authors
- Indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications
- **Trial registration:** If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policiesfor more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

- the aim, design and setting of the study

- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons.
- the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and materials

- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

References

Examples of the Vancouver reference style are shown below.

Appendix 2B – Participant information sheet and consent form.

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Identifying Young Carers of Colour in Early Intervention for Psychosis Services
Information Sheet

We would like to invite you to take part in this service improvement project about young carers, particularly those who are from minoritised ethnic groups.

What is the purpose of this project?
Young carers are children and young people, under the age of 18, who look after a family member with a physical and/or mental health difficulty. Young people from minoritised ethnic groups are 1.5 times more likely to be young carers but less likely to be identified and provided with support. The aim of this project is to understand what might make it difficult to identify young carers and also what might make this easier for staff so young carers can be offered support.

To do this, we want to interview staff that support service user parents that access Early Intervention in Psychosis (EIP) teams.

Why have I been invited?
We are inviting mental health professionals from the Slough and Reading Berkshire Healthcare NHS Foundation Trust EIP teams to participate in focus groups about their experiences of working with service users with young children who may have caring responsibilities.

You expressed an interest in taking part, and indicated that you regularly see, or have seen, at least one service user who has a child aged between 8-17 years old.

Taking part is voluntary. If you decide to take part, you will be asked to sign a consent form that states you understand the information and agree to take part. If you decide not to take part or withdraw at a later point, this will not affect your employment or legal rights.

What will I be asked to do if I take part?
You will be invited to take part in a focus group with up to 6 other mental health professionals who work in the same EIP team as you.
The focus group will be facilitated by Syeda Akther (Trainee Clinical Psychologist) and will focus on your experiences of coordinating the care of service users with children. Topics that

will be covered include how staff might know whether a dependant is a carer or not, whether they feel confident in identifying young carers, and whether staff would feel confident in referring/signposting young carers to available support. We are also interested in your experiences of recording information about children under the age of 18 on electronic patient records and the types of conversations you may have with service users about their children.

The focus group will take place online via Microsoft Teams and will last about 60 minutes.

The focus group will be audio-recorded using a separate recording device. The recording will be transcribed verbatim following the focus group. Before recording, each member of staff will be asked to simply state their first name, job role and team name.

What are the possible benefits of taking part?
We hope that by sharing your experiences, we will be able to make informed recommendations to help staff working with services users with children under the age of 18, particular those who may have caring responsibilities. Some people might also find it enjoyable talking about their experiences with someone that is not part of their team.

Are there any possible risks from taking part?
Some people might find it uncomfortable talking about their experiences with someone that is not part of their team.

Will my responses be kept confidential?
Yes. The focus group will be audio-recorded and the recording will be stored on a secure NHS OneDrive. Syeda will listen to the recording and transcribe it, with any identifiable data removed or changed. For example, focus group members will be assigned a code to replace their name.

Confidentiality will be breached if information is revealed during the focus group that indicates your safety or the safety of others is at risk. In this case, Syeda will discuss concerns with her supervisor, Dr Sarah Armitage, or directly with the safeguarding team.

What will happen to my data?
All information about you and your participation will be stored securely in accordance with the Data Protection Act (1998) and GDPR.

What will happen at the end of the study?
The findings will be used to help staff better understand why young carers from minoritised ethnic groups might be under-identified and how to address this. The recommendations will be circulated amongst your Teams for consideration and implementation.

As this study is being completed for the fulfilment of the Doctorate in Clinical Psychology, the anonymised results will also be submitted to the University of Oxford as part of a thesis.

Who has reviewed the study?

The study has been approved by the BHFT Clinical Audit Department (REF: 9560).

Further information and contact details:

If you would like more information about this project or have any concerns, you can speak to Syeda Akther who can be reached at syeda.akther@oxfordhealth.nhs.uk.

CONSENT

Please <u>initial</u> boxes

1. I confirm that I have read and understand the information sheet for this project. I have had the opportunity to ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my employment or legal rights being affected. ☐
3. I agree that if I withdraw from the focus group for any reason, the information I have already provided can continue to be used. ☐
4. I understand and agree to being audio-recorded for the project. ☐
5. I understand that all information related to me will be kept confidential, and any identifiable information will be anonymised. ☐
6. I agree to the use of anonymised quotations in reports on the results of this project. This will be done by changing my name and changing any details in my interview that might reveal my identity or the identities of others. ☐
7. I agree to take part in the project. ☐

Name of participant ____________________

Date ____________________

Signature ____________________

Name of facilitator

Date

Signature

Appendix 2C – Semi-structured topic guide for focus groups with staff.

Staff – Focus Group Topic Guide

Introduction

Hello and thank you for coming to this focus group today. The purpose of the focus group today is to have a think about young carers – particularly what your thoughts about how we might know if a child is a young carer or not and if you've encountered young carers in your role before. A young carer is a child or young person under the age of 18 who provides unpaid care for a family member with a physical or mental health condition. The discussion will focus largely on those from minoritized ethnic groups (also known as BAME) but if you have come across White young carers then those experiences would be welcome too.

We will be audio-recording the focus group so please feel free to switch your cameras off if you'd like. After the group interview, the recording will be transcribed verbatim and the recording will be deleted.

During transcription, any identifiable information will be removed and replaced for instance with your role and a number assigned to you. The only information that will remain is reference to the service, team or locality but everything else will be removed or replaced with a code. Everything spoken about today will be kept confidential and the transcripts will be stored securely.

Do you have any questions at this point? If you require a break or would like to stop, please do just say. The focus group today will be more like a conversation so please feel free to ask any questions along the way.

Once we start, I have some specific questions that I would like to ask but other than that feel free to just chip in when you would like to.

Before I start recording, it would be great if everyone could just state their job role within the team just so I have an idea of whose views we're capturing today.

If that is all okay, I will just start recording now.

Working with service users with children

1. What have been your experiences of working with service users from minoritised ethnic groups who have children under the age of 18?

Optional questions:

- (if not worked with service users from minoritised ethnic groups, then just parents in general).
- Have you worked with service users who are not parents but have children in their home/dependants? (e.g., siblings)

Caseload and recording

2. How many service users from minoritized ethnic groups do you have on your caseload, or have you previously worked with, that have dependants under the age of 18?

- Why do you think there are so many/few service users with dependants?
- Would you consider siblings or any other children under the age of 18 living with the service user as 'dependants'?

3. How would you typically find out that a service user has dependants?

4. Are there any processes that follow once you find out a service user has dependants?

- How would you usually record this information? E.g., is there a particular field on RiO you would populate with this information or would it go on their notes?

Identifying and recording young carers

5. How would you know if a service user's dependant(s) is a young carer?

6. What would typically happen once you find out a dependant under the age of 18 is providing care for the service user?

- What would you usually do with this information?
- Have you previously spoken to a service user and their children about the possibility that the dependant might be classified as a young carer?
    - Why/why not?

7. Have you ever offered a carer's assessment for a dependant?

- What about for a dependant from a minoritized ethnic group?
- Why/why not?
- How would you feel about explaining the process of a carers assessment for a young person?

8. If a care coordinator in the team left and you were taking over their case load, how would you know if one of the service users on their caseload has a dependant that is also a young carer?

  - More specifically where might you look to find this information?

9. How would you describe the process of identifying a young carer?

  - What would you say makes it difficult to identify if a dependant is a young carer?
  - What would make it easier to identify if a dependant is a young carer so they can be referred for an assessment?

11. What kinds of practical recommendations would make working with young carers easier for you?

Some examples if few responses:

- RiO
- Resources
- Joint working with social care
- Some sort of record keeping of dependents and young carers?
- A whole family approach?

Ending

That is the end of the questions I had for you all. Is there anything we haven't covered today that you would like us to have a think about?

Thank you for taking the time to talk to me today. I will end the recording there.

Appendix 2D - Selection of matrix developed using the analytical framework and data entered across the unit of analysis (team)

Category	Code	Team SL	Team RD
Opportunities to identify young carers	Assessment	When people are referred they are asked during the assessment about any children they may have and gather any information regarding safeguarding concerns as part of the risk assessment. This is part of the assessment template. (n=2)	It is typically in the assessment process when dependants are revealed as well as during home visits. (n=1). Sometimes during the assessment you will notice the parent is relying on the child to help them answer questions and be involved in conversations that they perhaps should not be involved in and this would be a way to identify young carers. (n=1)
		It is possible that young carers are not identified during the initial assessment as it may be that their situation fluctuates and arrangements can change over time. (n=1)	In the risk assessment, there's a section that requires information about people in the household under the age of 18 to be entered. It is now a national requirement to record names and dates of birth of all dependants under the age of 18 following two incidents. It is national policy when someone is admitted to the hospital to establish who else is in the household and do a safeguarding alert (n=2).
			During the initial stages, service users are seen frequently and a good therapeutic relationship is established immediately. Lots of questions are asked during that initial stage especially about those in the person's support network. The service is family-inclusive so if dependants are identified in the home, care coordinators would immediately think about the impact the parents' illness may be having on them and any responsibilities they might have. (n=1)
			Usually by the time they are being assessed, it has been established whether or not they have children under the age of 18 as safeguarding is considered everyone's responsibility and so those important questions will have been asked as soon as they came into contact with mental health services.

Identifying dependants	Uncertain about the number of service users from minoritised backgrounds on case load with dependants. The dashboard Tableaux might be a way to capture this information and might be put forward as a way of capturing that. (n=1)	Dependants would be identified during the assessment and during home visits when we can see who else is at home. (n=1) During the risk assessment, there is a section to record information about anybody in the household that is under the age of 18 and this needs to be completed. (n=2). Service users are also seen frequently at the initial stages and questions are asked to gather information and to establish a good therapeutic relationship. The service is family-inclusive so we also support everyone in their direct network who are their support system including children.
	During assessment, information about dependants is gathered, as part of the risk assessment, to identify safeguarding concerns. Names, dates of birth and ages are collected and recorded. This is when they are referred to the EIP in general and is on the assessment template. Information about children is shared with social services as part of safeguarding as staff have a duty to make a referral to children's services even if there are no concerns so need to identify any dependants. Parents will be informed of this and social services do their own investigations. (n=2) There's some guidance around identifying young carers. Safeguarding requires looking at children's needs and their welfare. (n=1)	When someone is an inpatient, there is a policy in Reading to notify safeguarding about any dependants.
	Information about dependants would be recorded as part of the SBARs on RiO progress notes and would be well recorded and shared during any handovers. During handover it would be highlighted if there are any dependants and care coordinators are expected to	All referrals are channelled through CPE where this information is collected. Dependants have already been identified as safeguarding is considered everyone's responsibility so it is an important questions that is asked when someone comes into contact with mental health services. (n=3)

	review notes in detail but it will be recorded under the SBARs. (n=2)	Sometimes people have children but they don't necessarily live with them due to the nature of mental health difficulties which can lead to social systems breaking down, relationships coming to an end and divorce. (n=1)
		On a person's RiO records, it is possible to see the notes made by other healthcare professionals such as the school nurse and health visitors who may have seen a child so it would be possible to see on RiO if there are other family members associated. (n=1)

Note. SL= Slough; RD=Reading. Green cells represent facilitators; Red cells represent barriers; Blue cells represent an experience. N refers to the number of participants that endorsed the point mentioned in the cell.

Appendix 2E – Table with additional quotes illustrative of each category and code.

Category	Code	Quotes
Impact of contextual factors	EIP client demographics and number of dependants	*"It's very usual for there to be someone under 18 in the house. Quite a lot of extended family so even if people haven't got their own children, erm who can live at home. It's difficult isn't it now with the cost of living for people to move out so it's probably going to become even more of a factor, I guess."* –SL02)
		"I mean it was only until probably 4 years ago that they decided that the age limit should go to 65. Before then, it was more... most of the people we worked with yeah were in secondary school, were in university, starting their first jobs. So, they did not necessarily have a family, let alone have children and that is how yeah it was" set up until that bar was raised and erm yeah." – RD03
	EIP staff experience of working with CYP	*"I've had that experience in my previous job when I was working with adolescents so it was a service user, a young person who was caring for her mum who was also a service user and yeah we ended up having a referral"* – SL01
		"I mean in community mental health teams yes, I've worked with loads erm where they, they, the ethnic and minority as well as white erm families and often the children end up becoming more like the parent" – RD03
Opportunities to identify young carers	Referral – source and process	"*So, yeah, we do ask on assessment when they're referred to us. We do ask as part of the information we gather whether they've got any children and like safeguarding if there are any safeguarding concerns."* – SL01
	Assessment	*" Yeah. We work, we work very, very closely with our clients and erm we see them frequently especially in the initial stages and it's really important to as soon as possible establish a good therapeutic working relationship with our clients and, and, and we ask questions."* – RD01
	Existing process for identifying dependants	*"In the assessment process. When we go to do, go to see them to do the assessment, when we do the home visits yeah that is when we would know who else is at home, yeah."* – RD03

		“So, when we do risk assessment as well that’s one of the things they do highlight whether they’ve got any children under the age of 18.” – SL01
	Significant person in the team involved in the service user’s care	*“I think from my perspective, normally the people I work with erm the carer side of things have already been identified because I come in sort of after the fact when care coordinators have already started processes”* – SL04
	Recording information on RiO	*“Yeah it will go on their progress notes when you make that contact and also like on risk assessment so everyone’s risk assessment and that information is also shared if there are children under the age of 18 and whether safeguarding referral has been made and yeah we do record their ages”* – SL01
		“…because our progress note templates have carer erm section to it.” – SL02
		“sometimes if you go into RiO the it may came up as so, so, so you may have, it may come up with different, with other people’s records as well. So, say for example the school nurse has you know seen a child or something like that erm they would use RiO so that’s another thing that would come up in RiO that there is like there’s other family members associated” - RD02
	Staff’s understanding of social care’s role	*“So, if they’ve got err mental health problems we have got a duty to refer to children’s services as well even if there’s no concerns but we will talk to them and say this is “our duty to do that” and if there are any concerns, social services will do their own investigations. So sometimes they do also notice that maybe they are caring, and support is also given to them but mostly getting to know risk of, explore neglect and… safeguarding in particular.”* – SL01
		“they’re quite strict on if, if somebody has got mental health difficulties and they’re siblings that social care needs to be, does need to be, does need to be notified and erm and I think they either make a phone call to find out what the, what the sort of arrangements are.” – RD02
Staff’s views about enquiring	Children only considered according to level of risk and safeguarding	*“So yeah most of the time you don’t get to speak to them unless if there’s an identified problem or safeguarding that’s when we get to speak to them but yeah in terms you don’t get to see them or involve them.”* - SL01

		"So, so when someone goes there's always, they'll always do a handover of cases and children are paramount to erm... their welfare's paramount isn't it? and that even though we're an adult service that obviously is still the case with us so... yeah that would be primary things to highlight on that... support or investigations that were... and, and erm you would expect the care coordinator to review the notes as well in detail" – SL02
		"So those questions have already been asked. It's already been established whether or not this client has children under 18 and because it's considered that you know safeguarding is everybody's responsibility. So, it, it, it's, it's one of the erm really important questions that's asked when someone first comes into contact with mental health services." - RD01
	Staff's views of their role and limitations	*"So, it was easier if you are working with the young person and doing the referral. I think when we are working with the parent, and we don't have much access to the children and sometimes like I say I've got someone who's got a 17 and 12 year old but every time you go there the children are not there, it's either, maybe they're in college or they're in school."* – SL01
		"Because they are children as well, we can't just go in and start asking them questions without the consent of their parents but if we are worried then that's when we do like if it's safeguarding as well that we are worried that these children are..." – SL02
	Staff's lack of access to young people to enquire	*".. but they don't want us to like talk to her to him or get him involved or talk about you know the sister with him even though it would be helpful for him to know and give him psychoeducation so that he understands but sometimes it's the parents trying to avoid and not wanting to upset the other sibling or get him stressed about you know thing... even though it is impacting by not knowing what's going on... that that's the kind of situation."* – SL01
		"…we, sometimes we don't really have access to the children on a lot of occasions and it doesn't feel right sometimes to say "Can I speak to them?" because the children wouldn't necessarily want to say anything that they feel might upset their parent or their... and that's what we think sort of social services might come in and have that conversation on a 1:1, that's more their kind of role perhaps to do that." – SL02
	Staff's understanding of parents' fear and anxiety of working with services and authority	*"They do support but I think it's the term 'carer' they don't want to be associated ermm think that's the term for them even though they are doing things for their parents but not identifying not wanting to be identified as 'carer' or the parents*

		not wanting to share that information that they are doing these things so it’s really difficult to know that know that they are caring for their parents.” – SL01
		“I mean going back initially to identifying carers I do also think there’s a, a concern some families around social services and, and them being involved and whether they will be... I mean the worst case scenario a child being taken into care I think is, is still a very, a very real concern for families so...” – SL02
		“once you mention social services especially with a minority group, they get panicky and erm they feel they’re going to investigate into or there’s going to be a lot of interrogation so usually they avoid it and even when you tell them “you’re going to get other support like respite and other things” they really shy away from it because there’s that tendency that once they come into your life, it prolongs a lot of things and they keep digging so that is where so it’s kind of fear and panic.” – SL03
Classification and criteria of young carer	Staff’s perspective of criteria	*“Because it’s different... it is different to different people, isn’t it? And it can be a little bit subjective really in, in how you actually get that information. So I’m talking about interpretation that’s not necessarily caring is it...”* – SL02
		“I mean often if err say for example there are caring duties like erm RD01 said earlier, they will come to a meeting with them. They will, they will come to a meeting with them, they would try, at times in some cases, some assessment situations, you will see them trying to get help from the, the child “can you remind me when did this happen?” so you know the child is involved in lots of conservations which maybe a child shouldn’t be. So, that would alert you straight away that... yeah.” – RD03
		“I find a lot of the BAME carers as well er young carers, highly emotionally articulate, highly emotionally intelligent erm you know especially I’ve worked with like 15, 16,- yeah 15, 16, 18 then you know I would say their mindset as well is sometimes like a 30 year old and they even find it hard to be a, they find it very hard to be a teenager or child or actually in their thinking that “I am a child” and erm they think that they’re taking on the ‘mum’ or the ‘father’ role, yeah.” - RD02
		“I think it’s also how it about the child, how, how it feels to them because some people some children actually want to help don’t they and it’s not they don’t feel burdened by it but others would do” – SL02

		“I think as well there’s like other factors like if it’s just one child in the home or if there’s multiple children and whether they’re looking after the younger children and the ages and whether there’s an impact on school. I can just think of a family erm that I went to see and the older of the children would support the younger children more.” - SL05
	Parents’ and families’ perspective of criteria	*“I have had a couple of experiences where actually the service user is almost supporting an ill family member as well. Erm just because I suppose that’s a caring family member, isn’t it? Erm and you sort of stick together and look after each other but I couldn’t say whether that’s a long-term thing, it’s more of a short term “well family member’s ill”.”* – SL04
		“So, from my perspective I think it’s, it’s more of making your own picture from lots of different bits of information you can pick up whether it’s things you observe, things you’ve talked about with your client erm but them not directly telling you “yes, this child cares... does this that and the other”. It’s more about “oh you know how does so and so help you around the house?” you know, and you can build sort of your own picture of what that looks like and your own interpretation of the situation.” – SL04
	Role of culture in caring responsibilities	*“I think that is really difficult like when we talk about you know ethnic minority because sometimes it’s cultural that you know they need to look after they’ve got a responsibility to do some certain tasks for their loved ones or parents even if with adults as well sometimes even referring for a carers assessment is very difficult, they say “no I’m not a carer”.”* – SL01
		“I think also there’s a element of fine line between what’s everyday house life for a particular family.” – SL04
		“it could be very, very intrusive and sort of “mind your own business” type of thing and especially if you’ve got you know a child that’s maybe supporting mum or dad and doing very like… quite intimate care then I think it’s the trust element.” – RD02
Knowledge and availability of support	Support currently offered by team	*“I’ve noticed as well even with FI [Family Intervention] when we’re trying to offer Family Intervention we sometimes... they don’t get involved or they don’t want them to get involved.”* – SL01
		“There’s no age restriction but we only get the older people coming but we do invite everyone who’s responsible for... the care of the person but yeah we do get the adults coming.” –SL01

		"what I've done in the past erm is I've like you know written letters to school to say "oh by the way this is a youn- mum's under mental health erm could this young person erm could this young person have some extra time in you know for exams or could this you know erm" –RD02
		"Erm, we offer Family Intervention and erm that can include erm younger members of the family erm whether or not they're included is, is, is done on a case-to-case basis. It all depends on erm you know whether or not it's considered it will be helpful or more detrimental to that young person's wellbeing but I think that's a very good point that RD02 has raised." –RD01
	Current and previous support offered by social care and other organisations	*"so yeah most of the time when we do referrals it's either there's no concerns and sometimes they do get support as well maybe parenting support or any other support they might need and also like yeah identifying young carers as well in that"* –SL01
		"I think our expectation is that social care, social services will provide that information around carer, young person support and we do anything particularly in EIP around that" – SL02
		"so if mum is unwell and they've had to come out of- go into hospital then social- erm social care might have to do what you call a Section 20 so they may be looking at seeing putting the, the, the young, the erm, under, the minors either into foster care or into erm another household." - RD02

Note. SL Slough; RD – Reading

Appendix 2F – Recommendations identified from the focus groups.

Theme	Subthemes	Structural (Trust)/workforce level	Service/individual team level	Service user facing level
Impact of contextual factors	**EIP client demographics and number of dependants**	Consider wider routine data collection and dissemination of sociodemographic data at service, locality, and team level to identify the needs of the population.	Consider use of the Trust's Tableaux dashboard to routinely gather data on the number of dependants recorded on each locality's caseload for routine dissemination to teams.	
	EIP staff experience of working with CYP	Staff may benefit from guidance and training on managing common problems that may come up when encountering CYP in clinical meetings within adult services (e.g., information sharing)	Consider drawing on staff's experiences of working with different populations to equip team(s) with skills/resources	
Opportunities to identify young carers	**Referral – source and process**	A checklist could be incorporated into the referral process as a means to identify which members of a service user's household are responsible for different responsibilities at home. The routine nature of such an assessment could prevent service user's feeling singled out.	Consider asking referrer to highlight service users with dependants so staff may consider asking about caring responsibilities at a later date.	
		Consider including a section for additional information about dependants that may indicate they are a young carer (e.g., dependant accompanying parent to appointments).		
	Assessment		A prompt about young carers could be incorporated into the various assessments with a	Consider developing a short leaflet/document to provide to families with more information

			definition/criteria of young carers in the assessment template.	about young carers and the support available
			The assessment could be split across two sections allowing for both clinical and social factors to be assessed.	
			Consider checking information about dependants on RiO prior to assessment and consider asking about responsibilities at home if dependants' details' have already been recorded.	
	Existing process for identifying dependants	Consider providing guidance on young carers (including criteria and responsibilities) to wider Trust to ensure it is on all staff member's radar.	An additional prompt could be included on the standard questions used to identify dependants to ensure service users are asked whether their dependant also cares for them.	
	Significant person in the team involved in the service user's care		Staff could enquire about dependants' caring responsibilities at multiple timepoints such as during CPAs to capture any change in dependants' carer status.	
				Families may benefit from continuity of care with dependants made aware of a named staff member they are able to confide in (regardless of caring responsibilities).
	Recording information on RiO	The IT department could consider the addition of a specific field to record young carers which would also act as a prompt for staff.	Carer's views are currently included in the template for RiO progress notes. The addition of young carers' views could act as a prompt to enquire about	

			dependants and their responsibilities.	
	Staff's understanding of social care's role	Consider the implementation of training on the role social care play in the identification of young carers including the support available for young carers.	Closer working with social services such as joint training on working with young carers or observation of cases to promote another working between the two sectors.	Staff could be provided with information about the different types of support available for families and young carers via social services which they can discuss with service-users.
		Multi-agency training and CPD (e.g., schools, social services, local authority, mental health services) on identifying young carers.	Consider inclusion of social worker in MDTs and assessments to normalise joint working	Consider jointly with social services creating leaflets/documents to provide to service users and their families on social care's role including available support
Staff's views about enquiring	**Children only considered according to level of risk and safeguarding**	The Trust could consider cultivating a whole-family culture in which staff are empowered to consider children and young people beyond just risk and safeguarding.	Consider providing staff guidance clarifying that caring responsibilities may not meet threshold for risk/safeguarding procedures and so should be considered separately to risk procedures.	
	Staff's views of their role and limitations			Consider creating accessible psychoeducation resources for CYP which parents can share with their dependants
	Staff's lack of access to young people to enquire		Consider occasional meetings with service users and their families which do not focus on clinical concerns to normalise inclusion of wider family in care.	
	Staff's understanding of parents' fear and anxiety of working with services and authority	Guidance should be available for staff clarifying the role of and support available from social care so staff are equipped to discuss families' concerns.	Consider providing staff with prompts regarding specific concerns that families from minoritised ethnic groups may have and how to address these.	Staff could have a discussion with the service user parent about young carers' entitlement to support from social care including

				respite, recreational activities, and access to resources.
				Staff and the service user could agree beforehand the information that will be shared with the dependant/young carer.
Classification and criteria of young carer	**Staff's perspective of criteria**	Ensure all staff are provided with information about the definition and criteria of young carers.	Consider providing all staff training on young carers including the definition, criteria, and the responsibilities they may have and the contexts in which staff may see them (e.g., acting as interpreter).	Staff could receive training/specific training on how to differentiate between caring and household chores including the questions to consider asking families such as if anyone else would be able to complete the task if the young person does not.
	Parents' and families' perspective of criteria	Posters could be displayed in waiting rooms to increase awareness of the young carer role (e.g., posters developed by The Children's Society).	Consider creating running agenda item about young carers in MDT	More guidance and training for staff on how to approach conversations with families about what a young carer is that avoid evoking feelings of shame in families.
	Role of culture in caring responsibilities		Staff could be provided with a list of specific issues and concerns minoritised ethnic families may have and how to address these.	Consider providing service user's with a list of responsibilities that may indicate the young person is a young carer
			The service could consider creating leaflets with information about families' rights especially regarding confidentiality and consent.	
Knowledge and availability of support	**Support currently offered by team**		The information provided to families about whole family interventions could include an amendment stating that the interventions are suitable for children under 18	Staff and the service users can discuss any concerns they have about dependants under 18 attending interventions to identify solutions

			Staff suggested that the availability of support for young carers (e.g., a group specifically for young carers of people with mental health difficulties that would allow them to speak openly without fear of upsetting the service user) may make it easier for young people and their families to reveal their carer status.	The information about family and carer interventions provided to service users could be updated to include a statement clarifying that young people under the age of 18 can also attend these sessions and offer service users the opportunity to discuss any concerns beforehand.
	Current and previous support offered by social care and other organisations	Consider creating a flow diagram highlighting a streamlined pathway for identifying and supporting young carers and including information about the different services that may be involved (e.g., GPs, mental health professionals, social services).	Staff could be provided with information from social services about the local support and services available to young carers and their families and how to access these.	

Note. CPA = Care Programme Approach; CYP = Children and Young People; Yellow cells represent recommendations suggested by the staff during the focus groups; The recommendations for improvement were informed by the categories and codes extracted from the analysis of focus group data as well as previous data on challenges with young carer identification that corresponded with the focus group data.

Appendix 2G - Feedback received from the service in response to presentation of recommendations.

Feedback:

- Some recommendations have already begun but the project findings will help to map out where some actions have already begun and where gaps require more development.
- It was noted that there is a lot of appeal as the recommendations run across lots of different services so allow for joint working.
- Staff lamented the lack of staff availability to dedicate to such improvements but were keen to implement the recommendations including signposting and connecting with other services such as CAMHS and Early Help.
- Staff felt that the carers assessment is a good way to collect information about young carers and this could also be brought up in Family Intervention.
- Staff also agreed that parents are not always keen to let staff see the children and this can make it difficult to find out more information.
- Staff suggested they could have a named expert like a champion within the service.
- Staff also revealed their shock at social services not always being aware of available support and resources for young carers but suggested it would be good to work closer and jointly with children's social services.
- Staff also revealed that the uptake of carers assessments are generally not great, but they felt adding in a prompt to assessments would be a quick and easy way to keep young carers in mind.
- It was suggested that a similar model to social prescribers could be developed so referrals related to young carers could be sent via this model.

Actions:

- The service manager to link in with Family Action (Young Carers organisation in Royal Borough of Windsor and Maidenhead) and perhaps consider joint work along with the Early Years organisation in Berkshire, nurse colleagues and colleague working in Quality Improvement in CAMHS.
- The service manager suggested starting a Huddle ticket and a working group to think of ways to improve young carer awareness and recognition.
- Setting up task and finish groups within the next few weeks.

Plans:

- The service manager began a discussion with the Trust’s Carers Lead in March to include young carers in the Trust’s development plan for service provision to carers.
- A training session focusing on young carers has been planned for delivery in September 2024.

Appendix 2H – Lay summary of service improvement project

Young carers are people under the age of 18 who help to take care of a relative or friend that has a physical or mental health condition. They typically do tasks that would be expected of an adult such as helping the ill person with getting dressed and washing themselves. They might go to appointments with them and help to interpret and pick up medication. Caring can be quite difficult so it is important to make sure young carers are identified and provided with support. Unfortunately, a lot of young carers, including those from minoritised ethnic groups, are currently not being identified. There are a lot of reasons for this but ultimately it means that they are not being supported and this leaves them vulnerable to becoming unwell themselves.

Professionals that they might come across, like mental health staff who help look after their relative, could play an important role in identifying them. For example, if a young carer comes to an appointment with the ill relative, staff could begin a conversation with them about the young person's caring responsibilities. Staff could then tell the family about the support they could access and how to get this. One way to begin improving the identification of young carers is to help staff become more aware of the role and support them in identifying young carers and working with families to address their worries.

To do this, we carried out a project to find out what staff's thoughts are about the young carer role, what they think gets in the way of identifying young carers, and what they think can help them better identify young carers.

Two focus groups were conducted with staff members from an Early Intervention for Psychosis service in Slough and Reading. They were asked about whether they had worked with young carers before, whether they know what a young carer is, and what would help them to feel more confident in identifying young carers.

Staff revealed that they had some experience of working with young carers and children in general. However, it can be complicated when working in an adult service as the adult is usually their responsibility and while they have permission to speak to the adult, it is up to the adult whether they allow staff to speak or interact with their children. This can make it difficult to identify young carers. Sometimes families are worried that it might be emotionally tough for children to hear about serious mental illnesses or that their children will be removed from them if they reveal their caring duties, so they choose to keep the children away from staff.

On a higher level, staff are encouraged to largely think about children with regards to risk and their safety. This is why they collect information about children under 18 that the adult service-user lives with or has contact with. Besides this, staff said they had little to no contact with the service-user’s child relatives. This again makes it difficult to find out if they are caring. Staff however stated that they are thorough in recording information about children so everyone in the team is aware of their presence.

Staff said they would like more training on how to identify young carers as they feel currently it is confusing. Staff would also like to work more closely with social services so they can work together on improving the identification of young carers and make sure young carers and their families are properly supported.

Appendix 3A – Submission guidelines for preparing manuscript for journal Social Psychiatry and Psychiatric Epidemiology

About the journal

Social Psychiatry and Psychiatric Epidemiology is a peer-reviewed academic journal that focuses on the social, biological, and genetic epidemiology of psychiatric disorders. The journal particularly focuses on the effects of the social environment on psychiatric disorders and behaviour. The journal welcomes articles related to social issues within the fields of social psychology, sociology, anthropology, epidemiology, health service research, health economies or public mental health.

Submission guidelines

- Papers must be written in English
- Research papers or Reviews should not exceed 4,500 words, not including references, plus 5 tables or figures. An abstract (150 to 250 words) and 4-6 keywords are required (please see also section ‘title page’).
- Exceptions to the word limits can be made only with the agreement of the Editor-in-Chief.
- Authors are required to state the word count of their paper when submitting the manuscript.

Title Page

- Title – The title should be concise and informative
- Author information - The name(s) of the author(s); The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country; A clear indication and an active e-mail address of the corresponding author; If available, the 16-digit ORCID of the author(s)

Abstract

- Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:
    - Purpose (stating the main purposes and research question)
    - Methods
    - Results
    - Conclusion
- Keywords - Please provide 4 to 6 keywords which can be used for indexing purposes.
- Statements and Declarations – The following statements should be included under the heading “Statements and Declarations” for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.
- Competing Interests - Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Text

- Text formatting – Manuscripts should be submitted in Word; Use a normal, plain font (e.g., 10-point Times Roman) for text; Use italics for emphasis; Use the automatic page numbering function to number the pages; Do not use field functions; Use tab stops or other commands for indents, not the space bar; Use the table function, not spreadsheets, to make tables; Use the equation editor or MathType for equations; Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).
- Headings - Please use no more than three levels of displayed headings.
- Abbreviations - Abbreviations should be defined at first mention and used consistently thereafter.

- Footnotes - Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.
  - Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.
  - Always use footnotes instead of endnotes.
- Acknowledgements - Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

References

- Citation - Reference citations in the text should be identified by numbers in square brackets.
- Reference list - The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.
  - The entries in the list should be numbered consecutively.
  - If available, please always include DOIs as full DOI links in your reference list (e.g. “https://doi.org/abc”).

Appendix 3B – Poster advertisement with details of the study and instructions for taking part.

Stigma and Trust in Mental Health Services – The Impact of Ethnicity and Immigrant Generation

We are conducting an online study that is exploring the impact of immigrant generation and ethnicity on mental health stigma and level of trust in mental health services.

You are invited to complete an online survey that will take about 15 minutes.

You can take part if you:

- ☐ **Identify as White British, Polish British/Polish or British South Asian/South Asian (Bangladeshi, Indian or Pakistani)**
- ☐ **(Only Polish/South Asian) Identify as a first or second generation immigrant**
- ☐ **Are usually resident in the UK**
- ☐ **Are aged 18 years or above**
- ☐ **Able to read and write in English**

For more information and to take part in the online survey, please follow this link:

https://psychiatryoxford.qualtrics.com/jfe/form/SV_cByT5AJeAiJI6IS

For more information about the study or if you would like to speak to someone, please contact Syeda Akther:

syeda.akther@hmc.ox.ac.uk

Oxford Institute of Clinical Psychology Training and Research

Ethics ref: R77255/RE001

UNIVERSITY OF OXFORD

Appendix 3C – Participant information sheet and consent form

PARTICIPANT INFORMATION SHEET

Stigma and trust in mental health services – the impact of ethnicity and immigrant generation

Central University Research Ethics Committee (CUREC) Approval Reference: R77255/RE001

We would like to invite you to take part in our research study about the stigma that is associated with mental health and the amount of trust people have in mental health services. Our aim is to explore the impact of a person's ethnic background as well as whether they are a first or second generation immigrant on stigma and trust in mental health services.

We appreciate your interest in participating in this online survey. You have been invited to participate as you:

- Identify as White British, Polish/Polish British or British South Asian/South Asian (Indian, Pakistani or Bangladeshi)
- Identify as a first or second generation immigrant (only applicable if you are Polish/Polish British or British South Asian/South Asian)
- Are usually resident in the United Kingdom
- Aged 18 years or above
- Able to read and write in English

The Principal Researcher for this study is Professor Paul Salkovskis who is attached to the Oxford Institute of Clinical Psychology Training and Research at the University of Oxford. This project is being completed by Syeda Akther (Trainee Clinical Psychologist) under the supervision of Professor Paul Salkovskis.

Please read through this information before agreeing to participate (if you wish to) by ticking the 'yes' box below.

1. Do I have to take part?

No. Participation is voluntary and you do not have to participate in this study. You can ask questions about the research to help you make your decision before you decide whether or not to take part. If you decide you would like to take part, you may withdraw yourself from the study without giving a reason. You can do this by not completing the survey and clicking on the 'Exit' button or exiting the web browser.

If you decide to withdraw after completing and submitting your survey responses, you can contact us using the contact details provided. You will need to provide your unique code which is a string of 4 numbers of your choosing (see below). It is important you let us know within 1 month of participating. After this point, we will delete the unique code that links your survey response to you. Therefore, the anonymous data you provided until the point of withdrawal, which is your survey responses, will continue to be used. This is because we will no longer be able to identify your specific survey responses after we have deleted the unique codes.

2. What am I being asked to do?

If you decide to take part in this research, you will first need to fill out a consent form that confirms you have read this information, understood it, had the chance to speak to others and ask any questions you have and are happy to take part. You will then be directed to an online survey to complete. You will firstly be asked some questions about yourself, such as your age.

Next, you will be shown some questions which will ask for your opinion on various topics including mental health stigma and how much you trust mental health services. You will also be asked about whether you have lived experience of a mental health problem or of caring for someone with a mental health problem. You will also be provided with open text boxes to answer some additional questions about your views on mental health stigma and the amount of trust you have in mental health services. You will need to answer all the questions as otherwise you will not be able to move onto the next section. Your responses will only be recorded if you complete the entire survey and click ‘Submit’.

Once you have finished the survey, you will be thanked for your participation, given the contact details of the study team, and services you can contact if you found the survey upsetting. If you would like a copy of the report of the findings, you will be asked to provide your email address at the end of the survey. This is your decision and will not impact your participation in the survey if you choose to opt out.

Survey completion should take about 20 minutes. No background knowledge is required.

3. How will my data be used?

The information you provide during the study is the **research data**. Any research data from which you can be identified is known as **personal data**.

At the beginning of the survey, you will be asked to choose a string of 4 numbers which will be the code assigned to your data. This unique code will be stored alongside your survey responses for a total of 1 month following your participation in the study. After 1 month, this code will be deleted and you will no longer be able to request to be withdrawn from the study.

The data we will ask you for which could identify you include your age, sex, ethnicity, education level, marital status, migrant status (i.e., first or second generation) and religion. You will also be asked about lived experience of a mental health difficulty or caring for someone who has lived experience of mental health difficulties. Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential.

The data you provide, including your survey responses, will be stored in a password-protected electronic file that will be accessible only to the Principal Researcher and the student researcher named above. All identifiable data will be deleted as soon as it is no longer required for the research.

Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the research. Your consent form will be stored for at least 3 years after publication or public release of the work of the research.

If you provide your email address to receive a copy of the final report, this will only be stored for the purpose of providing you with a copy of the final report and will be deleted as soon as this purpose has been fulfilled.

Who will have access to my data?

The University of Oxford is the data controller with respect to your personal data and, as such, will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from https://compliance.admin.ox.ac.uk/individual-rights.

4. Will the research be published?

The findings of this study will be written and submitted for publication to a peer-reviewed academic journal. The findings may also be presented in the form of a poster at academic conferences. A lay summary of the findings will be written as a report to be disseminated amongst relevant third-sector organisations. It is likely we will include quotes from the responses provided in the free text boxes, but we will ensure these are non-identifiable.

The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

The research will be written up as a student's thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible.

5. Who is organising and funding the study?

The study is being funded and organised by the University of Oxford.

6. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee (Reference number: R77255/RE001).

7. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please contact Syeda Akther (syeda.akther@hmc.ox.ac.uk) or Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk), and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Email: ethics@medsci.ox.ac.uk
Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

8. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Syeda Akther (Trainee Clinical Psychologist)
Oxford Institute of Clinical Psychology Training
Isis Education Centre
Warneford Hospital
Headington
Oxford
OX3 7JX
syeda.akther@hmc.ox.ac.uk

Thank you for taking the time to read this information sheet.

Please note that you may only participate in this survey if you are 18 years of age or over.

☐ I certify that I am 18 years of age or over

If you have read the information above and agree to participate with the understanding that the data (including any personal data) you submit will be processed accordingly, please check the relevant box below to get started.

☐ Yes, I agree to take part

Appendix 3D – Factor Analysis of the Attribution Questionnaire-9 measure of public stigma

The psychometric properties of the measures were calculated to ensure the validity of the scales. The internal consistency of each measure was analysed by calculating Cronbach's alpha coefficient using statistical software package SPSS. Cronbach's alpha is a measure of the internal consistency of a scale which describes the amount of variance within items that can be attributed to the primary concept being measured by the scale. Cronbach's alpha is reflected as a value between 0 and 1 and the higher the value, the better the internal consistency. A value of .70 or above is considered acceptable.

The Attribution Questionnaire was originally 21 items long and was later updated to 27 items – three items for each of the nine factors – responsibility, anger, pity, fear, dangerousness, help, coercion, segregation, and avoidance. The psychometric properties of this measure are however unclear with some investigations revealing six underlying factors and others revealing nine factors. The internal consistency of the original 9-item scale was calculated using the current sample and found to be below the acceptable range (=.61).

Therefore, an exploratory factor analysis was conducted using a principal component analysis (PCA) and a Varimax rotation with Kaiser normalisation. This revealed three factors accounting for 63.89% of the total variance. The first factor consisted of items representing fear, avoidance, and danger. The second factor contained items representing blame, anger, and segregation. The third and final factor included items representing pity, intention to help, and coercion. The internal consistency was calculated for each of the three factors revealing only two were within the acceptable range – Danger/Avoid (=.801) and Blame/Segregate (=.730). The final factor, Pity/Coercion, yielded an alpha score of .170 and therefore was excluded from the analysis.

Results from a factor analysis of the Attribution Questionnaire – 9 (AQ9)

Attribution Questionnaire (AQ) item	Factor Loading		
	1	2	3
Factor 1 – Danger/Avoid			
3. “How scared of Daniel would you feel?”	.821		
8. “I would try to stay away from Harry.”	.787		
2. “How dangerous would you feel Harry is?”	.785		
Factor 2 – Blame/Segregate			
4. “I would think that it was Harry’s own fault that he is in the present condition”		.890	
6. “How angry would you feel at Harry?”		.879	
5. “I think it would be best for Harry’s community if he were put away in a psychiatric hospital.”	.432	.530	
Factor 3 – Pity/Coercion			
1. “I would feel pity for Harry”			.660
7. “How likely is it that you would help Harry?”	-.564		.581
9. “How much do you agree that Harry should be forced into treatment with his doctor even if he does not want to?”			.531

Note. A principal component analysis was run using a Varimax rotation with Kaiser normalisation.

Appendix 3E – Results of qualitative data using Quantitative Content Analysis

Content analysis

Quantitative content analysis was used to analyse the qualitative data gathered via the open text comment boxes [43]. Content analysis is a qualitative analysis method which allows for the systematic analysis of written or verbal communication through the categorisation and quantification of data. Content analysis typically consists of three phases – preparation (identifying the unit of analysis and familiarisation of the data), organising (open coding followed by higher order grouping) and categorisation of the codes. An inductive approach was used to allow the categories to emerge from the data.

Data were extracted from Qualtrics and entered into a Microsoft Excel spreadsheet which was used to create a coding framework. A sample of data were chosen at random and used to identify initial codes. This was then applied to the remainder of the responses with new codes being created as the data necessitated. Related codes were grouped together and categorised according to similarities and comparisons which comprised the coding matrix. The coding matrix was then used to code and quantify the remaining data.

Results

Participants were asked to list the first three words or images that they thought of when considering ‘mental health’. The analysis of this data revealed three categories – ‘Positive’, ‘Negative’, and ‘Neutral’. The majority of the responses pertained to negative words and images such as ‘sadness’, ‘crisis’, ‘isolation’, and ‘fear’ (n=93). Positive responses (n=44) included words and images such as ‘healing’, ‘strength’, and ‘recovery’. Neutral responses (n=131) pertained to responses such as ‘doctor’, ‘therapy’, and ‘brain’. Participants provided fewer positive images and words compared to negative and neutral words.

Public stigma

Following the Attribution Questionnaire which captured expressions of public stigma, participants were asked:

"If your friend told you they had a diagnosis of a mental health disorder, what would you think?"

Eight categories were identified (see Table 1). All but one of the categories were positive with participants expressing a desire to provide both practical and emotional support such as listening to their friend's difficulties and identifying strategies that may help their friend. Participants however also revealed that while they would feel confident in providing support for common mental health disorders such as depression or anxiety, they would be unsure of how to respond to serious mental illness such as psychosis and expressed worry about potential risks that they would not know how to manage.

A small number of White British participants revealed that they would respond negatively and this included attributing blame, failure, and even disgust to their friend. South Asian participants reported that they would help to conceal their friend's mental health due to concerns about the wider community learning of their friend's mental health difficulties.

Table 4

Frequency of each category pertaining to the open-ended question about public stigma according to participant groups

Category	(British) Polish	(British) South Asian	White British	Total

		First Generation	Second Generation		
Provide support	31	6	5	15	57
Provide emotional support (e.g., sympathise, listen, gain better understanding)	23	9	19	30	81
Uncertainty of type of mental health condition and how to respond	3	3	3	1	10
Mental health difficulties are normal but would worry of others' response	4	2	4	6	16
Encourage help seeking	9	4	5	9	28
Maintain friend's privacy (to avoid gossip)	0	2	1	0	3
Provide peer/lived experience support	1	1	2	0	4
React negatively (e.g., attribute blame)	0	0	0	4	4

Self-stigma

Following the completion of the Self-Stigma of Mental Illness Scale, participants were asked the following question with an open text box for their response:

"If you visited your GP for some difficulties you were experiencing and they referred you to a mental health service, would it affect how you see yourself? (Please could you briefly tell us more about your answer)."

Five categories were identified (see Table 2). Participants' responses varied from relief that their difficulties had been acknowledged and they were provided with support to feeling shame, embarrassment, and weakness as a result of not being able to manage their difficulties themselves. Some revealed that they were conflicted and while they would be pleased about receiving support, they also expressed concerns about what this may mean about them. Some participants provided reflections of their previous experiences with General Practitioners (GP) and mental health services which centred on feeling unheard, not being given options, difficulties in accessing suitable services for their needs, and reluctance to engage due to previous experiences of involuntary treatment.

(British) Polish and White British participants more frequently reported that their perception of themselves would be negative and induce feelings of shame and being weak.

Table 5

Frequency of each category pertaining to the open-ended question about self-stigma according to participant group

Category	(British) Polish	(British) South Asian		White British	Total
		First Generation	Second Generation		

No, it is normal to have mental health difficulties	7	0	0	0	7
Relief to have a diagnosis and access to services/treatment	16	9	9	10	44
Negative self-perception and worries about others' judgements	14	3	6	16	39
Previous challenges and negative experiences with services and professionals	4	2	2	6	14
Conflicted feelings	1	2	4	2	9

Label Avoidance

Following the Label Avoidance questionnaire, participants were provided with an open text box to provide their responses to the following question:

"How would you react if somebody who knows you saw you coming out of a building that had a sign outside showing it is a mental health service?"

Analysis of the responses revealed five categories (see Table 3). Responses ranged from being open and honest about the reason for the visit should someone ask to being worried about the wider community one belongs to finding out that they are seeking help for their mental health. Some participants reported that they would experience negative feelings such as embarrassment, shame, humiliation, and feelings of being judged by others. However, participants responded that their relationship to the individual would impact their reaction such that they would feel more able to be open and honest with someone they know well compared to acquaintances.

Table 3

Frequency of each category identified from the open ended question about label avoidance according to each participant group.

Category	(British) Polish	(British) South Asian		White British	Total
		First Generation	Second Generation		
Open and honest about difficulties	7	1	2	2	12
It is no different to visiting the GP and would not cause me bother	17	6	5	5	33
It depends on whether my relationship with the person is close or if they are just an acquaintance	6	2	5	3	16

Ignore or hide the truth about the reason for the visit	4	4	3	6	17
Negative reaction and worries about community finding out	9	4	9	12	34

Trust

Participants were asked two open-ended questions about trust. The first question was:

“If you were referred to a mental health service by your GP, would you trust the MH service’s assessment of your problems? Please can you tell us the reasons behind your answer?”

Participants’ responses were grouped into four categories (see Table 4). Some participants reported that they would trust a mental health service’s assessment of their mental health as staff would have specialised knowledge about mental health in comparison to a GP. Some were unsure whether they would trust a mental health service’s assessment while others reported that they would prefer to conduct their own research into the diagnosis to ensure it fits with their experiences.

Table 4.

Frequency of each category identified from the open ended question about trust according to each participant group.

Category	(British) Polish	(British) South Asian		White British	Total
		First Generation	Second Generation		
Trust expert/professional opinion	23	5	13	11	54
Would want more information and ensure the assessment is individualised and a true conceptualisation of mental health difficulties	6	5	4	10	25
No, would not trust	6	3	1	8	18
Unsure	4	0	2	3	9

Participants were further asked:

"Are there any alternative services/organisations/groups whose assessment and advice you would find more trustworthy than your GP's or that of a mental health service? Please can you tell us your reasons?"

Responses were grouped into nine categories (see Table 5). While some participants simply reported that they would or would not seek alternative help, others specified where they would seek alternative help. This included charity and third sector organisations, private practice, mainstream NHS mental health service, religious leaders or organisations, and friends and family and peer support. Some participants, particularly, first generation (British) Polish and South Asian participants reported that they would prefer to seek help from a professional who shares the same cultural or religious background as them. South Asian participants also reported they would seek help from religious leaders and organisations such as an imam as they felt mental health services do not always consider additional factors such as culture and religion. A White British participant also named the church as an alternative source of support.

Table 5.

Frequency of each category related to where participants may seek alternative support according to participant group.

Category	(British) Polish	(British) South Asian		White British	Total
		First Generation	Second Generation		
Yes (no further information provided)	3	0	1	5	9
Charity/Third sector	7	0	3	6	16
Private	9	2	1	2	14
Mainstream/NHS mental health service or professional	6	0	1	0	7
Religious leader/organisation	0	3	3	1	7
Friends/Family/Peer Support	4	1	2	7	14
Prefer same ethnicity/religion/background	4	2	0	1	7

Issues with trusting GP and other mainstream NHS services	2	0	1	0	3
No, would not seek alternative support	13	8	8	11	40