

Review Protocol:

Rapid review of the scope and nature of qualitative evidence on the experiences of children and young people from ethnic minorities in accessing and engaging with mental health care and support in the UK

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Background

Mental health conditions are common in the UK; although national data on the rates of these conditions in children and young people are outdated (the latest relevant ONS data for children were published in 2004). These data suggested that approximately 10% of female, and 13% of male adolescents (11-16 years) were experiencing a mental health condition (Green et al., 2004) and that this differed considerably according to ethnicity: 10.6%, 17.1%, 3.2% and 7.6% respectively of White, Black (including people of mixed origin), Indian, and Pakistani/Bangladeshi 11-16 year old girls, and 13.0%, 11.9%, 2.4% and 7.6% respectively of 11-16 year old boys in these ethnic groups. More recent data are available for young adults. In 16-24 year olds, symptoms of common mental disorders were particularly high in females (over 25%) and were almost 10% in males (McManus et al., 2016).

Healthcare, including mental health care, is not equally utilised by all ethnic groups in the UK, although this in itself may not be an equality issue (Essink-Bot, et al., 2012). Health inequalities arise when, after accounting for rates of ill health and health preferences, there is disproportional unmet need in one group compared with another. For example, a systematic review of British population- and clinic-based studies evaluating both prevalence of child mental health conditions and associated service use amongst different ethnic groups in the UK, suggested a potential unmet need for mental health care amongst Pakistani and Bangladeshi children (Goodman et al. 2008).

Children and young people from non-white-British ethnic backgrounds may also obtain mental health support through different routes compared with white British children or compared with other ethnic groups (e.g. informal services, community/voluntary organisations, family and friends). For example, a study by Vostanis et al. (2013) conducted in England, found that even when accounting for lower level of need, adolescents aged 13-15 of Indian ethnicity were less likely to use CAMHS than their white peers, but more likely to obtain mental health support from siblings, other non-parental family members, teachers and primary care providers.

Amongst children and young people who do use CAMHS, referral pathways (both referral sources and destinations) may differ according to ethnicity. Routine data collected from across the UK has indicated that children and young people from non-white-British backgrounds are more likely than white British children and young people to be referred to CAMHS through education, social services, child health services or the criminal justice system rather than through primary care (Edbrooke-Childs et al., 2016, Edbrooke-Childs et al., 2019). More recently, a study analysing data from the South London and Maudsley (SLaM) National Health Service (NHS) Foundation Trust found that 12-17 year olds of Black African ethnicity, and 18-29 year olds of Black African, Black British, and Asian ethnicity were more likely to be referred from secondary care rather than primary care compared to white British children and young people, and that all ethnic minority groups were more likely to be referred via the criminal justice system than their white British peers (Chui et al., 2020). There is also evidence that, compared with White British children and young people, those from non-white-British backgrounds are more likely to be referred to inpatient, and emergency services rather than outpatient or non-emergency services (Chui et al., 2020), or involuntarily rather than voluntarily (Walker et al, 2021).

The picture is clearly complex; when considering all aspects of mental health need (rates of mental health difficulties, rates of formal and informal service use, different referral pathways, and the care and support preferences of children and young people of different ethnicities) it appears that non-white-British children and young people may differ from white British children with regards to the extent and type of unmet mental health care and support needs. The reasons why these needs might be unmet are likely to differ according to ethnic group. A systematic review of both quantitative and qualitative studies of the barriers and facilitators for children and adolescents in

accessing psychological treatments reported that there were perceived cultural and language barriers or facilitators amongst people from ethnic minority groups (Reardon et al., 2017). However, this review was not specific to non-white-British children and young people, was not UK specific, and was limited to studies evaluating parents' perceptions.

It remains unclear how much qualitative evidence exists on the factors influencing access to, and ongoing engagement with, mental health care and support in the UK for non-white-British children and young people. This rapid review seeks to address this by documenting the nature and scope of the qualitative evidence in this area, and will focus on identifying studies reporting the experiences, views and perceptions of non-white-British children and young people in the UK, and those of their parents, guardians, carers or other family members, their health, social care and other professionals who provide referrals or care/support, or commissioners of mental health services.

Aim and objectives

A rapid review will be undertaken to describe the nature and scope of the qualitative research in this area (i.e. the size, study types and focus of research in relation to different ethnic groups, further divided by different mental health needs, and different types of services) and to summarise the main findings (as expressed by study authors). The following research questions will be answered:

1. What is the nature and scope of the qualitative evidence on the experiences, views and perceptions of children and young people from non-white-British backgrounds and their parents/carers in accessing and engaging with mental health care and support?
2. What is the nature and scope of the qualitative evidence on the experiences, views and perceptions of those who refer to, provide, and commission mental health care and support, about how children and young people from non-white-British backgrounds access and engage with mental health care and support?

Inclusion/Exclusion criteria

The review inclusion criteria are provided in Table 1. Further details are as follows:

Population

To be included in the review, studies should focus on non-white-British children and/or young people (aged 10-24 years) who require, are seeking or are receiving mental health care or support. Non-white-British ethnic groups will include British ethnic minority groups as determined by 2011 Census ONS categories. Studies focusing on travelling communities (including Roma, gypsy and Irish travelling communities), or on refugees, people seeking asylum, or those who are state-less will be included. Additionally, studies reporting separate data on any non-white-British group(s) alongside data from white British groups will also be included.

Participants may be non-white-British children and/or young people requiring, seeking or receiving mental health care and support. Providing the study's main focus is on access/engagement of non-white-British children or young people (aged 10-24 years) to mental health care and support, participants may also comprise parents, guardians, carers or other relatives of such children or young people; health and social care professionals that refer, or provide, care and support to such children or young people; other referrers and providers such as teachers, charity/voluntary sector staff or staff working within the criminal justice system; or commissioners of mental health care and support.

Health problem

A broad definition of 'mental health' will be used, and will encompass the following mental health issues/conditions: anxiety disorders including OCD, PTSD and other trauma-related mental health issues, depressive disorders, psychotic disorders, personality disorders, conduct disorders, eating disorders, disorders of addiction and misuse, disorders of sleep, somatoform disorders, ADHD, gender dysphoria, self-harming behaviours, *general stress*, and *mental/psychological wellbeing*. Studies focused on conditions sometimes assessed or treated by services outside of CAMHS or AMHS (e.g. autism, social communication disorders, ADHD and/or learning disabilities) will be included when the primary focus of the study is on mental health rather than the non-mental health aspects of these conditions (such as initial diagnosis).

Setting

Studies should be located in the United Kingdom (UK), but the study may focus on access and/or engagement with any service, care or support which has a mental health focus, or a clear mental health component. This will include, but will not be limited to: CAMHS, other secondary- or tertiary-care based mental health services (including specialist and highly specialist mental health services), charities/third sector mental health projects and services, community-based voluntary services (formal or informal, such as those provided by community associations or religious organisations). A broad and inclusive definition of mental health care and support will be used, and particularly in the case of charity projects and voluntary community-based services, studies including mental health support and care offered as part of a holistic wellbeing package will be eligible for inclusion.

Comparators

Studies investigating the experiences of a single group (i.e. no direct comparator) will be included. Comparators may be included and could involve comparison with other (non-BAME) populations or between different non-white-British groups. Comparison may also be made between different people involved in children and young people's mental health care and support (e.g. comparison of perceptions and experiences of children and young people with those of their parents/caregivers, or between parents and health professionals).

Phenomenon/outcomes of interest

Studies will be eligible for inclusion if they describe the included groups' perceptions, views and experiences of access to, or ongoing retention/engagement with, mental health care and support (with a view to explaining the factors impacting upon this). Any type of experience, as described by the participants is considered valid and eligible for inclusion.

Study design

Any qualitative study design will be eligible for inclusion. Commentaries, letters and opinion pieces will be excluded. Systematic reviews of qualitative studies will be included if most of the included studies are relevant to this review (otherwise they will be used for citation chasing). Quantitative studies, and policy and guidance documents not describing the perceptions, views or experiences of the study population will be excluded.

Other limits

In order to include data that are relatively recent and relevant, only studies published in the last decade (between 2012 and the present day) will be included. Of particular interest are studies published since 2016, when the Five Year Forward View for Mental Health was produced by the independent Mental Health Taskforce to the NHS in England, and those published since the 2018/2019 NHS Long Term Plan.

Studies only available in languages other than English will not be excluded for the purposes of providing information on what evidence is available, but will be excluded from any further data extraction or summaries of included studies.

Table 1: Inclusion and exclusion criteria

	Inclusion	Exclusion
Population/ focus of the research	Ethnic minority children and young people (aged 10-24 years)	Studies where the focus is not on children or young people (i.e. the study data or relevant subgroup data are mostly focused on people outside of the included age range) Studies where there is no focus or separate data regarding ethnic minority children or young people
Research participants	Non-white-British Ethnic minority children and young people (aged 10-24 years) and any associated: - Parents/guardians/carers/relatives - Health and social care professionals referring them, or providing mental health care and support - Other referrers and providers (e.g. teachers, charity/voluntary sector staff, staff working within the criminal justice system) - Commissioners of mental health care and support Ethnic minorities, as defined by the Office of National Statistics for the 2011 Census, and including Gypsy and Irish traveller people, and those defined as immigrants and asylum seekers: These include: - non-British White (Irish, Gypsy or Irish Traveller, Other White) - Mixed/Multiple ethnic group (White and Black Caribbean, White and Black African, White and Asian, Other Mixed) - Asian/British Asian (Indian, Pakistani, Bangladeshi, Chinese, Other Asian) - Black/African/Caribbean/Black British (African, Caribbean, Other Black) - Other ethnic group (Arab, Any other ethnic group)	Studies where the participants are mostly children and young people who aren't from an ethnic minority group
Health condition	The population must be requiring care and support for a mental health need including:	Studies focused on populations with

	<ul style="list-style-type: none"> -anxiety disorders including OCD, PTSD and other trauma-related mental health issues -depressive disorders -psychotic disorders -personality disorders -conduct disorders -eating disorders -disorders of addiction and misuse -disorders of sleep -somatoform disorders -ADHD -gender dysphoria -self-harming behaviours -general stress -mental/psychological wellbeing <p>Studies focused on populations with autism/social communication disorders and/or learning disabilities where the primary focus is on mental health</p>	autism/social communication disorders and/or learning disabilities where the primary focus is on the non-mental health aspects of these conditions
Setting	Any services, care or support with a mental health focus, or mental health component, based in the UK	Services not providing mental health support (e.g. providing assessment only for learning disability or autism)
Comparator	Not applicable.	None
Phenomenon / outcomes of interest	<p>Perceptions, views and experiences regarding</p> <ul style="list-style-type: none"> - access to mental health care and support - ongoing engagement with or retention in mental health care or support arrangements - any descriptions of factors influencing the above 	Studies that do not cover experiences regarding access or ongoing engagement
Study design	<p>Any qualitative research study design (including SRs of qualitative studies):</p> <p>That is, collection and analysis of qualitative data such as:</p> <ul style="list-style-type: none"> Interview data Focus group discussions Related observations field notes of researchers 	Commentaries, opinion pieces, letters, non-systematic reviews, and quantitative studies, policy and guidance documents not describing the experiences of the study population
Date Limits	Limited to studies published from 2012 onwards	Studies published before 2012

Identifying studies

Search methods

Bibliographic database searches will be designed by an information specialist in consultation with the rest of the review team. ASSIA (ProQuest), CINAHL (EBSCO), MEDLINE (Ovid), PsychInfo (Ovid), HMIC (Ovid), Social Policy and Practice (Ovid), and Web of Science (Clarivate Analytics) will be searched. Terms for the included mental health conditions will be combined with terms for the ONS ethnic minority group categories and with terms for young people and for the UK setting. A qualitative study filter will be used to find the relevant study design. A draft MEDLINE search is provided in Appendix 1.

Supplementary literature searching will be conducted as determined by the needs of the project after the assessment of the key identified papers. This may include checking reference lists, contacting authors and web searching for unpublished material and policy documents.

Process for applying inclusion criteria

Two reviewers will apply inclusion and exclusion criteria to an initial sample of search results (e.g. n=50), as an initial calibration exercise of inclusion judgments and to refine the clarity of the inclusion criteria. Where studies contain a sub-set of eligible participants, these will be included where the majority of participants reflect the target population, or where data from eligible participants is reported separately. Initial screening decisions will be discussed, to ensure consistent application of criteria, and where necessary, criteria will be revised to enable more consistent reviewer interpretation and judgement.

Titles and abstracts of bibliographic database search results then will be independently screened by two reviewers who will apply the revised inclusion and exclusion criteria, with disagreements resolved by discussion. Full text articles will be also be independently screened by two reviewers, with disagreements resolved through discussion (in consultation with a third reviewer where needed). Reasons for exclusion at full text will be reported. To detail the study selection process, a PRISMA flowchart will be produced (REF PRISMA).

Extraction and description of the data

A standardised data extraction template will be developed in Excel, and piloted by two reviewers on a selection of included studies. Retrieved records will be defined as a single study (same sample and analysis), which may include multiple reports or publications. For each study included at full text, information will be extracted by one reviewer and checked by a second, with disagreements resolved through discussion (in consultation with a third reviewer when needed). Data which will be extracted from studies will include:

- Publication details (authors, year, publication type)
- DOI/citation
- Study aim
- Study methods (shorthand description e.g. copied from abstract)
- Study location (e.g. city or region(s) where data collection took place)
- Type of service/setting (if applicable)
- Types of mental health need
- Study participant category(ies) (children, young people, parents, carers, referrers, providers, or commissioners), and related sample sizes
- Characteristics of the children/young people (ethnicity, age, sex)
- Main findings (as summarised by the study authors)

The extracted data will be used to categorise studies according to ethnicity, service type and mental health needs and thus describe the number of studies available for different ethnic groups, different types of services and different mental health needs. A brief summary of the main findings from each study will also be provided.

Study quality assessment

An assessment of the quality/rigour of the qualitative studies will only be performed if time and other resources allow.

Timeline

Searching	June 2021
Ti Ab Screening	28 June to 16 July 2021
Full text screening	19 July to 13 Aug
Data extraction	16 Aug – 3 Sept
Description of the data	6 Sept – 17 Sept
Report writing & finalisation	20 Sept – 31 Sept

References

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Appendix 1: Draft Medline search

1. mental health/ or exp mental disorders/
2. CAMHS.ti,ab.
3. ((mental* or psycholog* or psychiatr* or behavio?r or emotion*) adj2 (health or ill* or disorder* or condition or disturbance or diagnos* or symptom* or "well being" or wellbeing or syndrome*)).ti,ab.
4. exp adjustment disorders/ or exp anxiety disorders/ or exp mood disorders/ or neurotic disorders/
5. (anxi* or depress* or melancholi* or neuros* or neurotic or psychoneuro* or stress* or distress* or bipolar or dissociati* or schizophreni* or psychotic or psychosis or trauma* or phobia* or OCD or "obsessive compulsive" or phobia* or "self harm" or "gender dysphoria" or "attention deficit" or ADHD).ti,ab.
6. ((affective or mood or eat* or conduct or anger or personality or sleep* or oppositional or somatic or somatoform) adj2 (health or ill* or disorder* or condition or disturbance or diagnos* or symptom* or syndrome*)).ti,ab.
7. Self-Injurious Behavior/ or exp Sleep Wake Disorders/ or Internet Addiction Disorder/ or exp Substance-Related Disorders/ or exp "attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/ or Gender Dysphoria/ or exp Somatoform Disorders/
8. ((internet or gaming or substance* or alcohol* or tobacco or drug* or narcotic* or opiate* or cannabis or hashish or marijuana or cocaine or amphetamine*) adj2 (disorder* or addict* or depend* or abuse*)).ti,ab.
9. exp Learning Disabilities/ or exp autism spectrum disorder/ or Social Communication Disorder/
10. (autism or autistic or asperger*).ti,ab.
11. ((social communication* or kanner*) adj2 (disorder* or syndrome*)).ti,ab.
12. (learn* adj (difficult* or disorder* or disabilit*)).ti,ab.
13. (dyslexi* or dyscalculi*).ti,ab.
14. or/1-13
15. ("BAME" or BME).ti,ab.
16. ("minority ethnic*" or "ethnic minorit*").ti,ab.
17. ((racial adj5 disparit*) or (ethnic adj5 disparit*) or "people of color" or "people of colour" or POC or WOC or BIPOC).ti,ab.
18. ("racial* minorit*" or "Race Factor*" or "mixed race" or "mixed racial" or minorit* or "ethnic* group*").ti,ab.
19. *"MINORITY GROUP"/ or *"MINORITY HEALTH"/ or *"BLACK PERSON"/ or *"ASIAN CONTINENTAL ANCESTRY GROUP"/ or *"BRITISH ASIAN"/ or *"ETHNIC GROUP"/ or *"BLACK RACE"/ or *"BLACK POPULATION"/ or "MULTIRACIAL PERSON"/ or "BLACK PERSON"/ or *MIGRANT/ or *"OCEANIC ANCESTRY GROUP"/ or *"ETHNIC OR RACIAL ASPECTS"/ or *"RACE DIFFERENCE"/ or *"ETHNIC DIFFERENCE"/ or *"INDIGENOUS PEOPLE"/
20. (refugee* or immigrant* or migrant* or (minority adj (group* or population*)) or multicultur* or multi cultur* or multiethnic* or multi ethnic* or ((cultur* or ethnic* or racial*) adj1 (divers* or differen*))).ti,ab.
21. Refugees/ or exp "Emigrants and Immigrants"/ or "Transients and Migrants"/ or Minority Groups/ or Cultural Characteristics/ or Cultural Diversity/ or Cross-Cultural Comparison/
22. Minority Health/ or (emigrant* or minority health or alien* or foreigner*).ti,ab.
23. (asylum adj3 (seek* or pend* or application* or apply)).ti,ab.
24. ((displaced or exile* or stateless) adj3 (person* or people or group* or population*)).ti,ab.

25. (bangladeshi* or bengali* or indian* or pakistani* or chinese or "black caribbean*" or "black african*" or "afro caribbean*" or arab* or "irish traveller*" or gypsy or gypsies or roma*).ti,ab. or Roma/
 26. or/15-25
 27. (teen* or youth* or adolescen* or juvenile* or (young adj2 (adult* or person* or individual* or people* or population* or man or men or wom#n)) or youngster* or highschool* or college* or ((secondary or high*) adj2 (school* or education))).ti,ab. or adolescent/ or young adult/
 28. (child* or stepchild* or step-child* or kid or kids or girl or girls or boy or boys or teen* or youth* or youngster* or adolescent* or adolescence or preschool* or pre-school* or kindergarten* or school* or juvenile* or minors or p?ediatric* or PICU).ti,ab. or exp child/
 29. 27 or 28
 30. exp United Kingdom/
 31. (national health service* or nhs*).ti,ab,in.
 32. (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
 33. (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
 34. (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in.
 35. (bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
 36. (aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.
 37. (armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
 38. 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
 39. (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp australia/ or exp oceania/) not (exp United Kingdom/ or europe/)
 40. 38 not 39
 41. interview:.mp.

- 42. experience:.mp.
- 43. qualitative:.tw.
- 44. 41 or 42 or 43
- 45. 14 and 26 and 29 and 40 and 44
- 46. limit 45 to yr="2010 -Current"