NHS
HEALTH
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Ethnic Inequalities in Healthcare: A Rapid

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Foreword

The NHS Race and Health Observatory is an arm's length body. We exist to ensure that the best possible evidence is available to support the NHS to tackle ethnic health inequity. But when we speak about what we do we sometimes meet with a challenge: that we already know what the problem is, that more reports and research won't help and that what we need now is action.

In many ways I agree with this challenge. There has long been evidence of the stark health inequalities faced by ethnic minority communities in this country. But we must also accept that existing evidence hasn't led to significant change. That is why the Observatory exists. Not just to produce more evidence, but to synthesise what already exists, translate it into actionable policy recommendations, and challenge leaders to act. By drawing together the evidence, and plugging the gaps where needed, we intend to make the overwhelming case for radical action on race inequity in our health service. Put another way, we exist to remove excuses.

This report represents a foundational step in our development. Early on, we spoke to our stakeholders to determine our priorities. There are many areas that require attention, but some rose above the others – mental health, maternal and neonatal health, digital inclusion, genomics and precision medicine, the health and care workforce. But perhaps more importantly than these individual priorities we must engage with the forces that create and reinforce structural, institutional and interpersonal racism.

This is the basis of the overwhelming evidence of ethnic health inequality throug005000rm500030inclusion2nTj T* (inodu0055Ffo

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digital ethnic inequalities

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- - Reader in Sociology, Bath Spa University
- Professor Consultant in Clinical Genetics, Birmingham Women's and Children's NHS Foundation Trust
- - Lecturer in Digital Media & Society, 5 I F 6 O J W F S T J U Z P G 4 I F G m F M E
- Consultant Midwife, Walsall Healthcare Trust

Community Practitioner Stakeholders

- Acacia Family Support
- Nilaari
- Nilaari
- Wellness Journey
- Nubian Life
- * R G H I U R L G 6 H A S H Q H J D
- ASHA
- ASHA
- 2 Sickle Cell Society
- Friends, Families & Travellers
- 0 D U L H & O D L U H . R À Plasma of Hope
- , Alström Syndrome UK
- 1 East and North Hertfordshire Trust
- Teesside University, Middlesbrough
- University Hospital Birmingham
- & G m D B D Z & 7 " $ B N C S J E H F
- Participants from Cygnet Healthcare & Birmingham & Solihull Mental Health Foundation Trust and Perinatal Mental Health Team

Our approach to language

Language has power, and the terminology we use when talking about race and ethnicity can have real world policy JNQBDU "U UIF 0CTFSWBUPSZ mWF QSJODJQMFT XIFO UBMLJOH about race and ethnicity:

- 8F XJMM BMXBZT CF TQFDJGJD possible about the ethnic groups we are referring to, only using collective terminology where there is a legitimate need to do so.
- We will not use acronyms or initialisms such as BME or BAME.
- Where collective terminology is needed, we will always be guided by context, and will not adopt a blanket term. In the event that the context is not decisive, we will use collective terms such as ‘Black and minority ethnic’, ‘ethnic minority’, ‘Black, Asian and minority ethnic’ interchangeably. 5IJT JT UP SFnFDU UIF GBDU UIBU OP one term is suitable to all of our stakeholders and to respect individual and community dignity.
- We will always be transparent about our approach to language.
- We will always be adaptable and remain open to changing our approach to language in the future.

Although this will always be our approach in our own writing, some of our research is commissioned and may directly quote pre-existing research that uses terms we otherwise would not use.

These principles were arrived at following a stakeholder consultation process carried PVU JO 4VNNFS 5P mOE about it, visit our website at _____

Executive Summary

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Ethnic inequalities in access to, experiences of, and outcomes of healthcare are longstanding problems in the NHS, and are rooted in experiences of structural, institutional and interpersonal racism. For too many years, the health of ethnic minority people has been negatively impacted by: lack of appropriate treatment for health problems by the NHS; poor quality or discriminatory treatment from healthcare staff; a lack of high quality ethnic monitoring data recorded in NHS systems; lack of appropriate interpreting services for people XIP EP OPU TQFBL &OHMJTI DPOmEFOUMZ BOE delays in, or avoidance of, seeking help for health problems due to fear of racist treatment from NHS healthcare professionals.

The rapid review focussed on priorities set by UIF /)4 3BDF BOE)FBMUI 0CTFSWBUPSZ 3)0 relating to ethnic inequalities in:

- access to, experiences of, and outcomes of, mental healthcare;
- access to, experiences of, and outcomes of, maternal and neonatal healthcare;
- digital access to healthcare;
- genetic testing and genomic medicine;
- the NHS workforce.

We searched UK academic and grey literature from 1st January 2011 to 25th 0DUPCFS *O UPUBM XF TDSFFOFE references (titles and abstracts), identifying 178 studies included in our review. We also conducted a stakeholder engagement survey with academics and clinicians (with expertise across the areas of focus) and discussion groups with people working with ethnic minority people in the community (the

Ethnic Inequalities in Mental Health Services

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- Conduct primary research on the direct and indirect impacts of racial discrimination by NHS staff and institutional processes on access to, experiences of, and outcomes of mental health services.

- Establish repeated cross-sectional national community survey datasets of psychiatric morbidity and service use to provide high quality national data on the ethnic minority people's attitudes to, and experiences of, using mental health services.

- Conduct a process and outcome review of interventions to address ethnic JOFRVBMJUJFT JO CPUI UIF /)4 BOE 7$4& PSHBOJTBUJPO

5HFRPPHQGDWLRQV IRU 5HVHDUFK

- Sophisticated quantitative analyses are needed in order to describe and understand patterns of maternity care and outcomes across a wider range of ethnic groups, as well as intersectional inequalities and spatial and

Ethnic Inequalities in Digital Inclusion and Access to Health Services

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-

Black African and Black Caribbean people towards participation in the 100,000 Genomes Project suggests that apprehension about participation may also be present for younger Black people.

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- For ethnic minority people who do not speak English, interpreters must be provided at the main points at which routine genetic screening and possible

5HFRPPHQGDWLRQV IRU 5HVHDUFK

- Conduct a systematic review of racist experiences in the workforce to see

Conclusions

The review found that there were widespread ethnic inequalities in the areas reviewed, although some of the evidence that was reviewed was poor quality and for some ethic minority groups there was no research conducted on their experiences. There are m W F N B K P S B S F B T X I F S F /) 4 & O H Improvement and NHS Digital should take critical action to improve access, experiences and outcomes for ethnic minority groups.

- (Q I R U F H * X L G H O L Q H V R Q (W K Q L F , .
  - Ensure that patients' ethnicity is (1) recorded and (2) recorded accurately (i.e., self-reported ethnicity) in B M M J O U F S B D U J P O T X J U I /) 4 found that research studies using clinical data often had substantial amounts of missing ethnicity data.

- 1 NHS Digital should provide national NHS statistics on service use by ethnic group, age and gender (at a minimum) and allow for clinical data to be linked across datasets in order to improve the monitoring of clinical outcomes for ethnic minority populations and to enhance the quality of research that can be undertaken with ethnic minority populations.

- 2 2 Greater resource needs to be allocated to the provision of interpreters in NHS Trusts; we found that high quality interpreters were not being provided in mental healthcare, in GP surgeries and at various points along the maternal health care pathway. Interpreter services need to be readily available for in person, telephone and digital appointments.

- Produce and implement a plan of work to build trust with ethnic minority groups and voluntary, community and social enterprise N J O P S J U Z Q P Q V M B U J P O T 0 V S S F W J found that research studies using clinical data often had substantial amounts of missing ethnicity data. some ethnic minority people delayed or avoided help seeking for health problems due to past experiences of racist treatment by healthcare professionals or due to similar experiences of their friends and family. Improving ethnic minority people's trust in NHS services will, subsequently, improve health outcomes through increased access to these services.

- 2 W K H L P S D F W R I U D F L V P R Q K H D O W K Finally, greater investment in research understanding the mechanisms that underpin and drive ethnic inequalities in healthcare is imperative if the mechanisms and systems that give rise to ethnic inequalities are to be disrupted.

Ethnic inequalities in health outcomes are evident at every stage throughout the life course, from birth to death. Since the introduction of the Race Relations (Amendment) Act in 2000, the reduction P G J O F R V B M J U J F T I B T m H V S F E Q S P N J O F O U M Z B T a priority for the Department of Health and Social Care (DHSC) and for the National Health Service (NHS). Reduction of thesional

but also refers to acts of ignoring or avoiding people due their ethnic background.

Mental illness is, arguably, the health problem for which there are the most unjust and stark inequities for ethnic minority populations. In this illness context, racism (both interpersonal and institutional), socioeconomic inequalities and disadvantage over the life course, and at key junctures in life, can be observed in interplay, resulting in dire health outcomes for ethnic minority people. In the UK context, the over-use of coercive mental health treatment under the mental health act for Black Caribbean and Black African groups [10] and the under-use of specialist mental health services by South Asian (Indian, Pakistani and Bangladeshi) groups [11] have been two of the main concerns articulated by health policy commentators, clinicians, and health

Workplace inequalities as experienced by ethnic minority groups among the health workforce is an important area to focus on when addressing ethnic inequalities in healthcare, as previous research has shown that the greater the proportion of ethnic minority NHS staff who report experiencing discrimination at work, the lower the levels of patient satisfaction[23]. Racism and discrimination towards ethnic minority NHS staff is evident in training and recruitment processes and negatively impacts on career progression and levels of pay. Among medics, ethnic minority doctors are three times less likely to secure a hospital job than White doctors[24] a situation that has changed little in 20 years[25]. Inequities also exist for clinical excellence awards (performance related bonuses for consultant staff) and career progression opportunities, with evidence of substantial under-representation of ethnic minority staff in senior leadership positions[26,27]. Rates of discrimination, bullying, and

Methodological Approach

We conducted a rapid review of studies for each topic area. A rapid review is a “brief synthesis and judgement of available research F W J E F O D F S F M B U F E U P B T Q F D J m D Q V S Q P T F T U P B T T J T U which is appropriate for studies aiming to identify the trends and patterns in the relevant literature[29]. We streamlined the review process, particularly in assessing quality at a study E F T J H O M F W F M B M M P X J O H V T F S T timely information to support policy making. We developed a review protocol to guide the P W F S B M M S F W J F X Q S P D F T T C V U X J M M B M M P X J O H N P E J G Z T Q F D J m D T U B H F T U P needs (e.g., search strategy was adjusted to improve retrieval of literature). Unless otherwise indicated, the review process was aligned to state of the art, evidence-based methods guidance as proposed by the Cochrane Rapid Review Methods Group[30].

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for the rapid review are shown in Tables 2.1 and 2.2 respectively. We searched literature from D J m S E V B S Z T U P B T U J O D M V E F E 0 D U P C F S J O P S E F S U P Q S P W J E F D Included in review that synthesised data from a range of countries. We excluded studies that focused on health outcomes (e.g., morbidity, mortality) and we also excluded U P O J O U E S T U E F T J H O E T U B H F T U P

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	Any healthcare-related setting, such as primary, secondary or tertiary care in the four constituent countries of the UK[1]
	1. For all topic areas, include at least one ethnic minority group (whether aggregated or disaggregated) 2. Health service users [mental health, maternal and neonatal health, digital inclusion, and genomics and genetic testing] [2]; 3. Health workforce [NHS workforce inequality];
	Randomised controlled trials (RCTs), observational studies, case control studies, systematic reviews, qualitative studies, mixed-methods studies.
	Academic journal articles, reports from statutory bodies, consultation exercise reports (with staff and patients but these must include quantitative or qualitative outcome data)
.	Ethnicity (ethnic/racial groups) 1. &UIOJDJUZ DBO CF TFMG BTDSJCFE DMBTTJmFE CBTFE reported by third party (e.g., clinicians, health administrative system), or based on place of birth, nationality, or migration status (whether aggregated or disaggregated). 2. 0VUDPNF TIPVME CF TQFDJmFE CZ FUIOJDJUZ 3. The results should facilitate comparison by ethnicity. However, for studies containing one ethnic minority group, the results will be included in order to understand experiences for particular ethnic minority groups.
	1. Focus on service use/access/experience/outcomes [maternity and neonatal health, mental health, digital and genetic/genomic services]; 2. .FOUBM IFBMUI XBT EFmOFE BT FNPUJPOBM QTZDIPMPH being of an individual or group. Mental disorders include depression, bipolar disorder, schizophrenia and other psychoses, and other formally diagnosed mental disorders. 3. Digital health services focus on telemedicine, healthcare smartphone/web apps, remote monitoring and consultation. 4. Genomics and genetic services focus on the development and application of genomics advances in diagnosis, treatment of illness and predictive and preventative care. 5. Experiences of workplace inequality in the NHS workforce (including career progression, mental health effects of racism, pay gap, racism in the workforce, Covid-19's impact on the health outcomes and workplace inequalities).
	English Language

-	Evidence published before January 1st 2011
	1. Studies conducted outside the UK; 2. Not related to healthcare settings
	1. Studies only focussing on the experience or views of health professionals or healthcare providers without reporting the experiences or views from service users, [mental health, maternity and neonatal health, digital inclusion, and genomics and genetic testing]; 2.

Information Sources

We conducted our searches using four F M F D U S P O J D E B U B C B T F T . & %software (Covidence) to facilitate the 1 T Z D * / ' 0 $ V N V M B U J W F * O F Y O U I F S N W F B S F B T M J T U F E J O U I F P Duplicate removal, screening and the and Allied Health Literature (CINAHL) and Applied Social Sciences Index & Abstracts (ASSIA)) to identify literature focused on ethnic inequalities in healthcare in the UK within the m W F B S F B T M J T U F E J O U I F P Compared and the inter-rater reliability ‘grey’ literature searches were carried out using the following databases and websites: Health Management Information Consortium [HMIC] and Social Care Institute for Excellence (SCIE). We also utilised the expertise of our stakeholders (academics and clinicians working in the NHS) to provide literature for the review. The management (screening, full text review and data extraction) of these references are reported separately to the management of references resulting from the searches. The PRISMA[31] diagrams in the appendices (and referenced in each of the topic chapters) summarise the management of both types of references.

Search results were downloaded to a bibliographic management software (Mendeley) and imported to systematic review organisation of references. A pilot exercise involved 10% of abstracts of all studies being independently screened by two members of U I F S F W J F X U F B N % , + ; P S / 8 7 F S E J was high (Cohen’s kappa ranged from 81.3% to 96.7% for different topic areas. Given the acceptable level of agreement, the remaining records were distributed between the review team, and were single screened. Studies which did not meet the inclusion criteria were excluded. Full-text articles of relevant studies were obtained and reviewed by one reviewer. A sample of excluded records were reviewed by both reviewers to reduce the likelihood of records being excluded in error. In both the screening and full text review stages, where a verdict of ‘unsure’ had been recorded (in Covidence) by one reviewer these records were passed on to a second reviewer with agreement to be resolved by consensus. In the event of continued disagreement, a third reviewer was asked to arbitrate on eventual inclusion (LB).

After all eligible studies for data extraction X F S F P C U B J O F E X F J E F O U J m F E B M M U reviews and meta-analyses and any primary studies included within these reviews. All systematic reviews entered the data extraction stage. Primary studies included in these systematic reviews were eliminated to prevent double-counting. Reports of these primary studies were only consulted when the information in the systematic review was unclear or incomplete. The review followed the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) 2020 T F B S[32] m M U F S T X F S F

Search Strategy

The search strategy included thesaurus and free-text terms and relevant synonyms for the population (NHS health workforce and (potential) service users including at least one ethnic minority group), main exposure (ethnicity/disaggregated ethnic groups), relevant region (UK) and outcome terms (listed in inclusion criteria) and used proximity operators where appropriate. The search terms were combined using appropriate Boolean P Q F S B U P S T . F U I P E P M P H J D B M not utilised in the scoping search to keep it broad and ensure all relevant study types X F S F S F U S J F W F E " Q V C M J D B U J P O U Z Q F m M U F S X B T used to exclude dissertation and conference papers given that they do not share the same peer review procedure as published articles. An example of the detailed search strategy for each topic is shown in the Appendix 1.

Data Extraction

Following piloting of a data extraction form, a user-friendly Google Forms interface was VTFE UP JOQVU EBUB JOUP B (PPHMF 4IFFU 0OF reviewer extracted the data independently (DK, JZ or NW). Summary tables were cut BOE QBTUFE JOUP UIF mOBM SFQPSU BOE GSFRVFODZ counts and aggregated responses were produced for the summary report. Data items extracted include: year and location of study, the related topic area, aim of the study, sample size (age in years), number and percentage of ethnic minority participants, target population, a4A004F00510056005500030045004209d (coun05A000300560ggregate25100500053005150 4D004600030051574

screening, full-text review and data extraction, as reported in the PRISMA diagrams for each topic area. All the eligible studies obtained XFSF JODMVEFE JO UIF mOBM EBUB TZOUIFTJT Future areas for research and practical solutions highlighted by the academics and clinicians were integrated within the recommendations of the report.

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We also conducted two stakeholder engagement groups consisting of community practitioners working with ethnic minority people with health problems, or more generally, in a community setting (e.g., peer supporters, community development workers). The aim of these stakeholder groups was UP FOHBHF JOEJWJEVBMT XPSLJOH JO UIF mFME UP ascertain their views on what needs to happen on a practical level to ensure ethnic health inequalities are addressed.

These groups were conducted by two

Ethnic Inequalities in Mental Health Services

Introduction

This chapter reviews literature on ethnic inequalities in mental health services. There has been decades of research that has shown ethnic inequalities in access to, and experiences of, mental health services [8,35], although the quantity and quality of evidence is not the same across ethnic minority groups, or across different services of the NHS. The recent independent review of the Mental Health Act

Results

5 I F T F B S D I F T J E F O U J m F E B U P U B M P G S Q B Q E S T from electronic databases and grey literature databases covering the period 1st January U P U I 0 D U P C F S T F F (5 chapter for full details of databases used). A total of 2,098 duplicates were removed, leaving 5,376 records to be screened by title B O E B C T U S B D U 0 G U I F T F at the abstract screening stage, leaving 658 studies. The full text articles were sourced for these 658 studies, apart from for one study where the full text could not be retrieved [39]. At this stage, 586 studies were excluded. About 40% of studies (n=229) were excluded because they were published before 2011. There was also a substantial number of studies (n=112) that did not relate to mental I F B M U I T F S W J D F T 8 F J E F O U J m & F O E H M B S O F G F O D E T V E Z X B T B D S P T T F D from stakeholders; we assessed the full texts of these and included three in the review (a large proportion were excluded as they were E V Q M J D B U F T 0 O F Q B Q F S S F D U P N D P M E F U P B V U B 0 V U P G U I F T F T U from a stakeholder could not be retrieved as it was still under review with a journal. A total of 74 studies were included in the review for this topic area. As there was a vast amount of literature for this topic area, we focussed on extracting data from systematic reviews O m S T U B O E E J E O P U F Y U S W H U E B U G O P S T H E S I N B S Z studies (n=13, not shown in PRISMA)[40–51] that were included in these systematic reviews. " Q Q F O E J Y T V N N B S J T F T U I F n P X d i a g r a m s t a g e s , in the rapid review process in a PRISMA diagram [31].

The main characteristics of the included studies are shown in a table in Appendix 4. The studies were published between 2011 and 2021. The 74 studies were categorised into six broad categories relating to the mental health care pathway (and a separate category for youth services). However, it must be noted that a substantial number of papers reported results for more than one type of service (e.g., community treatment and inpatients admissions). Where this was the case, papers were categorised to the area of services that most of the results related to. The six categories of papers were: (1) attitudes to help-seeking and experiences of general mental health services, (2) primary and secondary care mental health services, (3) psychological and talking therapies, including P s y c h o l o g i c a l T h e r a p i e s Q B Q E S T Access to Psychological Therapy (IAPT) services, (4) secondary care mental health services (mainly outpatient services), (5) Inpatient services and (6) youth (children, adolescents and young people) mental health services.

X F S F F Y D M V E F E

H [S H U L H Q F H V R I J H Q H U D O

There were 12 papers related to attitudes to help-seeking and experiences of general N F O U B M I F B M U I T F S W J D F T 0 O F Q B Q F S systematic review conducted on studies from survey conducted in London. The remainder of the papers in this category were qualitative (n=10), using either interviews or focus groups were conducted in London, three in England, two in the UK, one in Birmingham, one in Bristol and one in Brighton and Hove. Most of the studies reviewed in this section used data from ethnic minority participants only and therefore did not allow for a comparison with White British groups. The ethnic minority groups that were most sampled across these studies were Black Caribbean, Black African (including Somali people), Pakistani, Indian, Bangladeshi and Chinese groups. There was only one study that allowed a comparison of White British and Black African women in help-seeking behaviours for mental health problems, but this was a low quality survey using convenience sampling and basic statistical analyses.

There were recurring themes across these studies. Four studies[52–55] reported a lack of trust in healthcare professionals as a reason why people would not seek help from mental health services. Bailey and Tribe [52] showed this to be the case for older (aged 65 to 79 years) Black Caribbean people living in the UK using qualitative interviews, although it must be noted that the sample size was

small (n=8). Linney and colleagues [53] found that Somali people sampled from Bristol (n=23) were also reluctant to seek help for mental health problems (and general medical problems) due to the perception of the GP as
B O B V U I P S J U Z m H V S F B O E B F J U S V T U P W J E F J O G P S N B U J P O B M
Q P T J U J P O T P G B V U I P S J U Z 0 O (outside of the NHS) Black Caribbean and
for this lack of trust in health professionals and its subsequent impact on avoiding or delaying seeking help was patients' views that healthcare professionals (GPs and mental healthcare professionals) did not either 1) understand what racism was or 2) understand how racist experiences and other individual experiences impacted both their experiences of mental health services and the outcome of the receipt of services. Memon and colleagues' [54] qualitative study with Black, Asian and Mixed groups (n=26) in Brighton and Hove provided evidence for this, with one participant stating their annoyance with having to explain 'the Black experience' (p.5) to therapists which then interfered with effective therapy. Similarly, Kalathil and colleagues' qualitative study[55] with women (n=27) from a large variety of ethnic backgrounds (Mixed (or other), Black British, Black African, Black Caribbean, Bangladeshi, Indian (Gujarati, East African Indian), Pakistani, African (Liberian, Nigerian, Ethiopian, Angolan, South African)) showed that many participants felt that mental health services and recovery frameworks did not account for their experiences of racism and other discrimination, failing to account for a
T J H O J m D B O U Q B S U P G U I F J S E J T U S F T T

Five studies[56–60] reported dissatisfaction with the experiences of navigating the health system which were rooted in systemic problems with the way mental health services are organised and operate. Shefer and colleagues' [56] study of Black African, Black Caribbean, Indian, Kenyan-Asian and Somali people (n=103) living in London concluded that participants were critical about both the psychiatric system and psychiatric staff with participants stating that the aim of psychiatric medication was 'to neutralize patients (rather than cure them)' (p.540). Patients also felt that psychiatrists disregarded their concerns about the side effects of psychiatric medications. Sisley and colleagues' [57] study of Black Caribbean women living in London found that although women generally found GPs to be sympathetic to mental health problems, they felt that what they could offer for mental health problems was limited. For example, patients stated that health professionals
failed to provide information about local
(outside of the NHS) Black Caribbean and
African service', due to lack of knowledge about these services. Women in this study also reported that mental health professionals could be 'patronising and judgemental' (p.400) which deterred help-seeking. Islam and colleagues' [59] study of Black African, Black Caribbean, Pakistani, Arab and British Bengali people (n=22) who were current or past Early Intervention Service (EIS) users also concluded that there was a failure by GPs to listen to and address their mental health concerns. Garett and colleagues' synthesis of studies[60] that reported on problems with accessing primary care health services by South Asian people concluded that there were problems navigating the health system to gain help for mental health problems;
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colleagues'[63] study (n=7) of Chinese people's experiences of seeking help for severe mental illness, with one participant stating he felt miserable on a psychiatric ward because he didn't speak English and his psychiatrist didn't understand him. Similarly, Loewenthal and colleagues'[62] focus group study of Bengali, Urdu, Tamil and Somali speaking people in the UK showed that patients felt anxious when GPs did not understand their mental health problems due to the former's lack of English speaking skills, but felt that interpreter services were unreliable and sometimes there was a perception that some interpreters may CSFBL DPOmEFOUJBMJUZ 1BSUJDJQBOUT GFMU UIFYSPH was a need for more professionally trained interpreters. Memon and colleagues'[54] study highlighted that language barriers were particularly a problem for recent migrants of Somali background.

Four papers contained data relating to ethnic inequalities in both primary and secondary DBSF NFOUBM IFBMUI TFSWJDFT 0G UIF QBQFST was a systematic review of UK studies. The remaining three studies used cross-sectional surveys; one study used an English dataset, Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC)[64] and the other two studies used a London dataset, the South East -POEPO $PNNVOJUZ)FBMUI 4UVEZ 4&-$0) [65]. All of the papers in this section allowed comparison between White majority groups and a range of ethnic minority groups. Twomey and colleagues'[66] systematic review of UK studies that predicted health service use for people with mental disorders stated that two studies in their review showed that people from non-White ethnic backgrounds were more likely to seek help from primary care services and one study showed that there was no difference in help-seeking for mental health problems between White groups and ethnic minority groups.

The evidence was also inconclusive for specialist mental health care services with two studies showing ethnic minority people were more likely to seek help from specialist mental health services and one study showing no difference between White and ethnic minority groups. Kapadia and colleagues'[67] quantitative analysis of survey data (n=2,260) of ethnic inequality in women's usage of mental health TFSWJDFT JO &OHMBOE EFmOFE BT TF GP for mental health problems or seeing a counsellor or psychologist), showed that 1BLJTUBOJ 0EET 3BUJP 03 $POm Interval (CI)=0.08–0.65) and Bangladeshi 0.3DJQBOUT $* GFMU UIFYSPHNFO XFSF MFTT likely to use mental health services compared with White women. There was no evidence of differences in usage between White women and White Irish, Black Caribbean or Indian women. The analysis adjusted for a range of covariates (age, mental illness, household income and social support variables) but the analysis used outdated data (from 2000). The remaining two studies by Gazard and colleagues[68,69] used the South East London $PNNVOJUZ)FBMUI 4UVEZ 4&-$0) UP investigate differences in seeing a GP or DPVOTFMMPS GPS NFOUBM IFBMUI QSP study published in 2015 aimed to investigate differences in migrants' and non-migrants' access to mental health services. The study showed that there were largely no differences in seeing a GP or counsellor for mental health problems between migrant and non-migrants within ethnic groups, but people who were recent migrants (moving 4&(0) UIBO ZFBST BHP JEFOUJGZJOH BT A background were less likely than non-migrants in this broad ethnic category to see a GP for B NFOUBM IFBMUI QSPCMFN 03 $* 0.88, p<0.05). However, this result tells us very MJUUMF BCPVU NJHSBOUT GSPN XIJDI HSPVQ NBZ GBDF UIFTF QBSUJDVMBS E The second study published in 2018[69] found that anticipated discrimination was associated with increased service use for mental disorder. There was no evidence from this study to suggest that discrimination experiences were acting as a barrier to health service use.

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Thirteen papers discussed ethnic inequalities in access to, and experiences of, talking therapies or psychological therapies, including Improving Access to Psychological Therapies (IAPT) services. Most of these (n=11) were cross-sectional quantitative studies (surveys, audit of clinical data, cohort studies), one was a mixed methods study (a survey and focus groups) and one was a qualitative survey (used open ended questions). Seven of these studies used data from participants in London (most used clinical data but one TUVEZ VTFE 4&-$0) GPVS VTFE &OHMJTI EBUB one used UK-wide data (the National Audit of Schizophrenia datasets) and one used data from England & Wales.

Four of the studies[70–73] in this section were related to ethnic differences in Improving Access to Psychological Therapy (IAPT) services. The report from the Health and Social Care Information Centre[73] published in 2014 showed that rates of access to IAPT in England were ~1,300 per 100,000 population for White British people; (this was calculated using 2011 England and Wales census data to estimate the size of the population (IAPT data collected 2012-2013). Access rates were lower for all ethnic groups compared to White British people, except for the White & Black Caribbean group, Black Caribbean and Any other Black background (all ~1,700/100K), any other Mixed background and any other background (over 2,500/100K). The estimates were not adjusted for need (mental illness), nor broken down by age or gender. Furthermore, ethnicity was not recorded for 30% of people in the dataset. It must also be OPUFE UIBU PVS TFBSDIFT JEFOUJmFE UIF NPTU recent report from NHS Digital on rates of access to IAPT[74] but this report was excluded from our review as it did not present IAPT referral rates by ethnic group. The other UXP TUVEJFT PO *"15 XFSF -POEPO TQFDJmD Bhavsar and colleagues'[70] study of almost 1,500 survey participants whose data were linked to IAPT records found no evidence of ethnic differences in rates of psychological treatment use. However, Harwood and colleagues'[72] larger study (n=85,800) using more recent data (collected 2013-2016) found that compared to the White British group, #MBDL "GSJDBO 03 $* o "T 03 $* o BOE .JYFE FUIOJD HSPVQT 03 $* o XFSF MFTT likely to self-refer to IAPT than be referred through their GP. The study also found that compared to the White British group, Asian 03 $* o BOE #MBDL $BSJCC 03 $* o HSPVQT XFSF NPSF likely to be referred to IAPT via secondary care UIBO UIFJS (1 #MBDL $BSJCCFBO 03 $* o #MBDL "GSJDBO 03 $* o "TJBO 03 $* o #MBDL 0UIFS 03 $* o BOE 8IJUF 0UIFS 03 $* o

that White British men were more likely to report both more needs and unmet needs in inpatient setting; the authors conclude that ethnic minority men may not be reporting what they need from services. Watson and Daley's[111] study of use of Section 135 of the Mental Health Act in London (n=63) showed that use was higher in Black Caribbean, B O E 0 U I F S # M B D L H S P V Q T T J N P N F U I O J D N J O P S J U Y J O Q B U J F O U S (analysis [T-test] performed, not adjusted for covariates). Saltus and colleagues'[108] descriptive analysis of the ethnic background of inpatients admitted to psychiatric wards in Wales between 2005 and 2010 showed that a higher proportion of ethnic minority patients were referred from the criminal justice system compared with White inpatients, and there was a consistently higher proportion of White inpatients referred from the GP compared with F U I O J D N J O P S J U Z J O Q B U J F O U S (Tan and colleagues'[112]) reported a different pattern for general hospital admission (not psychiatric X B S E T G P M M P X J O H T F M G I B S N Q F E J B W F C their study of London patients admitted or readmitted to hospital following an episode of self-harm, showed lower rates of admission and readmission for self-harm for Black and Asian ethnic groups, compared with White groups.

Two studies reported on the use of seclusion or physical restraint in inpatient settings. Cullen and colleagues'[113] study of almost 4,000 inpatient episodes in London found that there were no ethnic inequalities in rates of referral from acute wards to psychiatric intensive care wards (PICU, non-forensic), nor were there ethnic differences in the use of seclusion (patient isolated in a locked room). Payne-Gil and colleagues'[114] London study of use of physical restraint found that there were no ethnic differences in the use of physical restraint without prone position (patient lying face and chest down). But Black Caribbean people were more likely to be restrained in the prone position than White counterparts 0 3 $ * Q B T participants that did not have their ethnicity S F D P S E F E 0 3 $ * The study also found ethnic differences in the odds of being secluded; Black African 0 3 $ * o Q # M B D L $ B S J C C F B O 0 3 $ * o

Q # M B D L 0 U I F S 0 3 CI=1.27–2.44, p=0.001) and Mixed ethnic C B D L H S P V O E 0 3 $ * o p=0.019) patients had nearly twice the odds of being secluded compared with White patients. There were no ethnic differences found in rapid tranquilisation except for participants who did not have their ethnicity recorded – they had an increased chance of S B Q J E U S B O R V J M J T B U J P O 0 3 $ * p=0.04).

Bruce & Smith's study[115] of patients with severe mental illness in London (n=11,617) found U I B U # M B D L $ B S J C C F B O 0 3 $ * # M B D L " G S J D B O 0 3 $ * B O E " T J B O 0 3 $ * o H S P V Q T were more likely to stay longer on psychiatric X B S E T U I B O U I F J S 8 I J U F D P V O U F S Q B S U F U I O J D N J O P S J U Z J O Q B U J F O U S (1.47, CI=1.30–1.66) in terms of discharge, a quantitative study by Ahmed and colleagues[116] of patients discharged from the Psychosis Intervention and Early Recovery service (PIER) in Leicestershire NHS between January 2005 and December 2013, found that there was no difference between ethnic groups as to whether they were discharged to primary or secondary care.

Two qualitative studies by Lawrence and colleagues[117,118] (n=35, both papers use the same data) reported on the long term experiences of living with psychosis and navigating the mental health system, as well as aiming to understand the journey through mental health services for Black $ B S J C C F B O 8 I J U F 0 U I F S B O E 8 I J U F # S patients. Every Black Caribbean woman in the study commented upon the absence of Black doctors in the health system (and in inpatient wards) who would be more likely to understand their perspective and concerns. Many participants reported feeling powerless, forced to take medication against their will, and unable to make their concerns heard. Some Black Caribbean participants reported being X F S F to break the cycle of service use, with many having repeat admissions.

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Finally, there were 12 studies that reported on youth services; ‘youth’ here is a broad E F m O J U J P O F O D P N Q B T T J O H T F S W J D F T G P S D I J M E S F O (0-16 years), adolescents (11-18 years) and Z P V O H Q F P Q M F U P Z F B S T 0 G U I F T F studies, one was a scoping literature review of barriers to accessing child and adolescent mental health services (CAMHS) (incorporating data from the UK and ‘developing countries’). There were six cross-sectional quantitative studies using clinical or survey data, three of which were conducted in London, one using English data, one using UK-wide data and one using data from school children in London and B T D I P P M J O P O F V O T Q F D J m F E & O H M J T I D J U Z 5 I F remainder (n=5) were qualitative studies taking place in London (n=2), England, Manchester and Birmingham.

There was evidence from six studies about mental health services in youth populations[119–124] in our review to suggest that some of the same barriers to accessing services that were highlighted for adult populations in section 3.2.1 above, were also present for youth populations. These were: lack of trust in the mental health system, discriminatory racist treatment from services affecting (delaying) decisions to seek help for mental health problems, and language

statistical analysis was not adjusted for other variables (e.g., age, socioeconomic status), and the study used a convenience sample in one city, limiting its generalisability. Black African parents in the study were the most likely to say they would not seek help at all (from any source) for a child's problems (White British: 4.7%, Black African: 31.3%, Black Caribbean: 12.8%, Indian: 7.3% (Chi-squared statistic =25.520, p<0.01)), and the reasons cited for this were previous bad experiences with health services, and not wanting to be discriminated or judged by services due to their ethnic background.

Four youth studies[125–128] reported on ethnic inequalities in referral into, and experiences of, specialist mental health services. Two studies by Edbrooke-Childs and colleagues using large routine service datasets (n >10,000) showed that there were ethnic inequalities in referral routes to CAMHS. The most recent of these two studies[126] showed young people from ethnic minority backgrounds were less likely to be referred through routes that are voluntary. The authors used UK-wide data for 0 to 25 year olds to show that compared to White British young people, Black young people were more likely to be referred through education, mental health services, social care/ Z P V U I K V T U J D F 0 3 $ * and 'other' routes, and less likely to be self-referred, relative to primary care. Asian young people were more likely to be referred through F E V D B U J P O T P D J B M D B S F Z P V symptoms of psychosis (DUP) compared to their White counterparts. 95% CI = 1.34-2.54), and less likely through mental health services or to be self-referred, relative to primary care. Young people from Mixed ethnic backgrounds were more likely to be referred through education, social care/ Z P V U I K V T U J D F 0 3 $ * and other routes relative to primary care. The older of these two studies[125] showed similar results using data from 26 CAMHS in England; Black, Asian and Mixed ethnic background children were more likely to be referred to CAMHS via education, social services or other services rather than through the GP, compared with White British children. The largest inequality was seen for Black children who were almost 10 times as likely to be referred to CAMHS via social services compared with White British children. This study also showed that compared with White British children, ethnic minority children were more likely to have their cases closed because they stopped attending rather than it being closed due to mutual agreement between therapist and D I J M E S F O T G B N J M J F T 7 P T U B O J T B O E [128] study of 13 to 15 year old Indian and White British children in schools found no evidence of a difference in the use of CAMHS between these two groups. The study was conducted in London and one other English city, with a sample size of 1,087.

There was only one study (by Gurpinar-Morgan and colleagues) [129] that reported on young people's experiences of therapy. This was a small interview study (n=5) of ethnic minority young people aged 16 to 18 years who had received cognitive behavioural therapy (CBT) which concluded that therapists and patients do not need to share the same ethnic background to work effectively with clients. There was one study by Dominguez and colleagues' [130] that found greater treatment delays (as measured by duration of untreated psychosis [DUP]) for adolescent onset psychosis in White adolescents in the study, compared with Black and Asian adolescents. The authors of this study suggest that DUP is lower for ethnic minority groups as they are more likely to be referred to CAMHS via social services, education or criminal justice pathways and hence are likely to start taking B O U J Q T Z D I P U J D N F E J D B U J P O T P P O F S [K V T U J D F 0 3 compared to their

Five stakeholders responded to our survey for academics and clinicians, providing references in the area of ethnic inequalities in mental health services, as well as providing details about ongoing research studies that are J N Q P S U B O U J O U I J T m F M E 5 I F S F X F S [research projects, Tackling Inequalities and Discrimination in Health Services (TIDES) and the Synergi Collaborative Project that have already produced substantial evidence on ethnic inequalities in mental health services (some of which were included in this review). Both of these research projects will continue

to produce important evidence for the next 2-5 years; this evidence should be consulted when producing plans to address ethnic inequalities in NHS mental health services. The stakeholder survey also yielded information about two important interventions or initiatives to improve outcomes for ethnic minority people using NFOUBM IFBMUI TFSWJDFT 0OF JT UIF $VMUVSBMMZ Adapted Family Intervention (CaFI) study led by the University of Manchester which aims to test the effectiveness of a new talking therapy for Black Caribbean and Black African people. The second is the Ethnicity and Mental Health Improvement Project (EMHIP), a collaboration to attempt to reduce ethnic inequalities in access, experience and outcome of mental health care. EMHIP is a collaborative project between South West London and St Georges Mental Health NHS Trust, South West London Clinical Commissioning Group, Merton & Wandsworth Locality, and networks of ethnic minority voluntary, faith and community groups, convened by the Wandsworth Community Empowerment Network.

In the stakeholder engagement groups that were carried out by our partners, Race Equality Foundation (REF) and The Ubele Initiative, the views of the community practitioners that were involved in these groups were largely DPOTJTUFOU XJUI UIF mOEJOHT PG UIJT SFWJFX issues around the lack of adequate interpreting services in primary and secondary mental health services was more pronounced in the stakeholder groups than in the review, perhaps TFnFDUJOH CPUI UIF SFWJFX T MJNJUBUJPOT PG focusing on ethnic minority groups (rather than TQFDJmDBMMZ NJHSBOUT BOE UIF SFMBUJWF MBDL PG research on newer migrant populations in the UK. For some groups including people seeking asylum and those from the Roma community, access to a GP is the initial hurdle, which is then compounded by language barriers and a lack of interpreters. A practitioner working with the Roma community said it is extremely rare for there to be interpreting services for their traditional languages and some people have limited understanding of the language of the country of their origin, for example Poland, Slovakia or Czech Republic, so when there BSF JOUFSQSFUJOH TFSWJDFT BWBJMBCMF JU JT EJGmDVMU to communicate healthcare issues. They also said that often the interpreters carry their own stereotypes about the Roma community which can impact how they communicate with them. Stakeholders reported that people seeking asylum have been told by healthcare staff to bring a friend who can translate for them. These issues negatively affect being referred to mental health services in a timely manner.

*O MJOF XJUI UIF mOEJOHT PG UIF MJU this review, many of the stakeholder group participants expressed both a distrust of statutory services and fear of racist treatment from health professionals (as well as recounting previous racist treatment), which affected help seeking for mental health problems. The ongoing stereotypes portrayed in the media about, and the discrimination faced by, ethnic minority groups, perpetuates the distrust for statutory services. There was also concern about ethnic minority patients' safety, particularly whilst staying in inpatient QTZDIJBUSJD VOJUT 0OF QSBDUJUJPO an inquest where a young Black male who was admitted to a psychiatric hospital experienced extreme excessive force which led to his death. These incidents permeate through communities and create fear and distrust. Another practitioner who represents people seeking asylum and refugees said,

> "it's more about fear of safety in mental health services; people have reported not only being discriminated but been badly physically abused in mental health services by health professionals or other mental health patients in hospitals and because they are forgotten people who don't have any rights, so nobody will take this forward."

People representing different ethnic minority groups reported that minoritised communities do not feel mental health services are for them. There was a clear consensus across practitioners representing different ethnic minority groups that health care services were detached from the communities they are supposed to serve and have failed to properly engage with them in order to understand their needs. This was felt across the Black African, Black Caribbean, Asian, Gypsy and 5SBWFMMFS BOE 3PNB DPNNVOJUJFT 0OF QFSTPO commented that it can feel like,

> "a them and us and that, I think, is a huge problem, so there are the services that are over there that never connect with, never come out to meet the community and understand the communities which they serve."

For Gypsy and Traveller communities the need to access mental health services was surpassed by a fear of social services involvement, and this fear directly prohibited them from seeking the care they need. This fear was also noted amongst South Asian groups. For some people the lack of clear, accessible pathways to much needed mental health services meant that some people gave up (i.e.didn't seek any help; practitioners gave examples of patients with multiple suicide attempts due to lack of engagement from services).

There were also concerns that ethnic inequalities in mental health services were longstanding and that they were not going to be addressed by any current policies, nor did it seem there would be future policies UP mY B TZTUFNJD QSPCMFN commented,

> "I think that it is systematic in WHUPV RI WKHUH QRW EHLQ community led non-clinical services and so people from the Black community tend to present in a crisis and then more likely to be diagnosed with schizophrenia than their White counterparts. They're more likely once they're in the system to be discharged and have to re-enter and they're more likely to be sectioned than our White peers, so for me there is that historical context in terms of how the mental health service, well mental health institutions came in to be[ing] and how they're still operating and that's why the picture remains very bleak for Black communities trying to access mental health services."

Summary

The review found that ethnic inequalities are apparent in many different mental health services, but the quantity and strength of evidence varies across services and is more established for some ethnic groups than others. There was evidence to suggest that there are clear barriers to seeking help for mental health problems rooted in a distrust of both primary care and mental health care providers, as well as a fear of being discriminated against in healthcare. The review found evidence that this was the case for many ethnic groups but there was less evidence about the experiences of Roma, Gypsy and Irish Traveller and Chinese groups, although evidence from our stakeholder engagement groups suggest that some of these groups may also be reluctant to seek help from services that they do not trust. There was also evidence from qualitative work that the lack of appropriate interpreting services acted as a deterrent to seeking help.

There were clear ethnic inequalities in access to IAPT, although this could not be reliably ascertained from NHS Digital national data, due to the use of basic descriptive analyses of referral data (e.g., crude referral rates with no adjustment for mental illness need). Based on other data sources, the review found that overall, ethnic minority groups were less likely to refer themselves to IAPT and less likely to be referred by their GPs, compared with White British people. There was also evidence of inequalities in the receipt of CBT with ethnic minority people with psychosis less likely to be referred for CBT, and less likely to attend as

Recommendations

- Conduct primary research on the direct and indirect impacts of racial discrimination by NHS staff and institutional processes on access to, experiences of, and outcomes of mental health services.

- Establish repeated cross-sectional national community survey datasets of psychiatric morbidity and service use to provide high quality national data on ethnic minority people's attitudes to, and experiences of, using mental health services.

- Conduct a process and outcome review of interventions to address ethnic JOFRVBMJUJFT JO CPUI UIF /)4 3) organisations to establish 'what works', why and for whom. This should extend beyond simply reviewing studies that test the effectiveness of 'culturally appropriate/ adapted therapy interventions' (where there is already a review[131]) to consider systemic changes across levels of psychiatric care. A recent systematic map of interventions to improve equality in mental health services (but not just related to race) shows that there are few interventions targeted at a system level[132].

- Enforce statutory guidelines on inclusion of national ethnic monitoring data in all NHS mental health clinical data that allows robust statistical Trust-level, regional and national analysis (including data linkage between clinical datasets) to establish where the inequalities are, and for which ethnic groups. Recent work supported by UIF /)4 3) has shown that ethnicity recording remains poor in many services in the NHS, including for Hospital Episode Statistics (which records admissions and outpatient appointments). This recommendation will require a dedicated drive by NHS England and NHS Digital to emphasise the importance of collecting and reporting these data, as well as providing the infrastructure to collect, analyse and interpret them. An online learning module on recording ethnicity data on the Health Education England, or equivalent, website should be made accessible to all NHS staff, to ensure staff are trained in routine collection of ethnicity data.

- Establish relationships between ethnic NJOPSJUZ 7$4& PSHBOJTBUJPOT BOE provider services in order to provide the high quality services for ethnic minority patients. NHS England and NHS Trusts need to work with partners across public service, the voluntary sector and community organisations in order to demonstrate commitment to tackling racial JOFRVBMJUZ JO NFOUBM IFBMUI TFS way in which this is already being done to an extent is through the Patient and Carer Race Equality Forum (PCREF), which seeks to develop a competency outcome framework to ensure services are equitable for ethnic minority groups. PCREF is currently being piloted in four Trusts in England (South London and Maudsley NHS Foundation Trust, East London NHS Foundation Trust, Birmingham and Solihull Mental Health NHS Foundation Trust and Greater Manchester Mental Health NHS