# Study Title: Access to chronic pain services for adults from Minority Ethnic groups in the UK: A scoping review protocol.

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#### **Abstract**

**Background:** Chronic pain services in the UK are required to provide services which meet the diverse needs of patients, but little is known about the access and use of these services by Minority Ethnic groups. This protocol describes a scoping review that aims to assess whether adults who access secondary and tertiary chronic pain services are representative of the UK population.

**Methods:** A scoping review will be conducted, comprising comprehensive searches of the literature using EMBASE, MEDLINE and CINAHL databases, and grey literature for records that address the study aims. Studies that meet the eligibility criteria will report on: (i) access to chronic pain services in secondary and/or tertiary care in the UK, (ii) by adults and, (iii) state the ethnicity of the involved participants within the demographics. Both qualitative and quantitative methodologies will be included to draw broad conclusions of what the cumulative evidence says on this topic. Publication dates are limited to between 2004-2021 as demographic data from studies published during this period best represent the UK population recorded in the 2011 UK census. The screening and selection process will be conducted by four reviewers and data will be extracted by one reviewer. A descriptive synthesis of the extracted data will be performed.

**Discussion:** This scoping review will be among the first to explore whether the current adult population of those with chronic pain who are accessing chronic pain services in secondary and/or tertiary care across the UK are representative of the UK Minority Ethnic population.

*Key Words:* ethnicity – chronic pain – pain management – adults - United Kingdom – scoping review protocol

#### **Introduction**

Healthcare staff have a pivotal role in delivering a service which promotes equality and diversity; healthcare organisations should support the provision of equality and deliver services which meet the diverse needs of patients (Baillie & Matiti, 2013). However, the diverse backgrounds of healthcare workers and people accessing healthcare have created a number of challenges and healthcare inequalities exist (Helman, 2007). As healthcare settings are diverse communities of people from different backgrounds with various characteristics, it is important to discuss equality and diversity in healthcare. This scoping review aims to explore whether the current adult population of those with chronic pain who access secondary and/or tertiary chronic pain services across the UK are representative of the UK ethnic population.

Diversity is valuing peoples' differences and addressing their different needs and situations. Each person needs to be valued as an individual (Kandola & Fullerton, 1998), and therefore protected characteristics and other individual factors should be acknowledged, understood, and appreciated by those working within healthcare. Protected characteristics include race and ethnicity, sex/gender, sexual orientation, class and religion (Narayanasamy & Narayanasamy, 2012). This research specifically focuses on ethnicity as ethnic disparities have been shown to exist in the management of those with chronic pain (Morales & Young, 2021; Kennel, Withers, Parsons & Hyeyoung, 2019; Ezenwa & Fleming, 2012). Treating people as individuals, avoiding making assumptions, recognising diversity and individual decision-making and respecting, and upholding peoples' dignity are not only key values of equality and diversity (Stenhouse, 2021), but also important in supporting self-management of their chronic pain.

#### **Chronic Pain**

Chronic pain is defined by the International Association for the Study of Pain (IASP) as "pain that persists or recurs for more than 3 months and is associated with significant emotional distress and/or functional disability, and the pain is not better accounted for by another condition" (Nicholas et al., 2019, p.29). The physical, emotional and psychosocial burdens of chronic pain on individuals can be debilitating; chronic pain can negatively affect peoples' abilities to perform activities of daily living (Bassols, Bosch & Baños, 2002; Breivik, Collett, Ventafridda, Cohen & Gallacher, 2006) and is associated with a notable reduction in health-related quality of life (Carmona, Bellina, Gabriel, Lafon & Group, 2001; Campos & Vazquez Rodriguez, 2011; García -Campayo et al., 2008; Davies, Brophy, Williams & Taylor, 2006).

Healthcare data related to chronic pain has been inadequately recorded across care settings, giving rise to poor prevalence estimates. A systematic review by Fayaz, Croft, Langford, Donaldson & Jones (2016) estimated the prevalence of chronic pain in the UK population to be between 35.0% and 51.3%, equating to approximately 28 million adults. However, several limitations to the included studies were identified such as variability of reporting of important variables including population denominators, response rates and, participant demographics (Fayaz et al., 2016).

The latest available census data (Office for National Statistics, 2011) suggests there is broad ethnic diversity across the UK. The percentage of the UK population that is White British decreased from 87.4% to 80.5% between 2001-2011 and the percentage of the population from a Black African background doubled from 0.9%-1.8% between 2001-2011 (GOV, 2018). Studying this is important as there are considerable ethnic disparities in the prevalence, experience and perception, treatment, progression, and outcomes of chronic pain conditions documented within the literature (Campbell & Edwards, 2012; Edwards, Moric, Husfeldt,

Buvanendran & Ivanovic, 2005; Versus Arthritis, 2021; Mills, Nicholson & Smith, 2019). The mechanisms behind these variations are unclear but, several demographic and lifestyle related factors associated with chronic pain have been identified. Some studies have reported that higher levels of co-morbidity (Dahan, van Velzen & Niesters, 2014), socio-economic deprivation (Blythe, 2008; Poleshuk & Green 2008; Maly & Vallerand, 2018) and unemployment (Macfarlane, Beasley, Smith, Jones & Macfarlane, 2015) are more prevalent in Minority Ethnic groups (Janevic et al., 2018; Li & Heath 2018; Nagar, Napoles, Jordan & Marino-Ramirez, 2021).

Beasley, Jones, Macfarlane & Macfarlane (2014) estimated standardised prevalence of chronic pain by different ethnic groups in the UK (n=498 071) and indicated that the prevalence of chronic pain was similar between different ethnic groups (Table 1). However, data from the Versus Arthritis Chronic Pain Report (2021) suggests that people from Black communities are more likely to have chronic pain than people of other ethnicities and people who described themselves as Asian are more likely to report chronic pain than people of other ethnic groups.

#### Pain Treatment Settings

Because the presentation of chronic pain disorders is complex and involve physical, emotional and psychosocial factors, effective pain management strategies should target a variety of factors simultaneously through a biopsychosocial approach (Fashler et al., 2016).

Data from the national pain audit final report undertaken by the British Pain Society has shown favourable outcomes for patients accessing chronic pain services in terms of quality of life; 56% of chronic pain service providers reported post-treatment improvement in mobility, self-care, usual activities, pain/discomfort and anxiety/depression assessed through the EQ-ED-3L questionnaire, and 76% reported improvement specifically in pain-related quality of life

(British Pain Society, 2013). However, across the UK, access to chronic pain services is difficult and inconsistent. There are estimated to be one pain treatment facility for every 200,000–370,370 people living in the UK (British Pain Society, 2013). Patients have mixed experiences of chronic pain services and overall satisfaction with the support they receive is reported as fairly poor; Betteridge & Johnson (2019) suggested chronic pain services need to work in an integrated fashion across a wide geographical area, both regionally and nationally.

Pain clinics typically offer a range of approaches including medical interventions such as epidurals, nerve blocks, opioid medications, and spinal cord stimulation and conservative interventions such as physiotherapy, occupational therapy and psychological treatments (Bissett, 1998; Clinical Standards Advisory Group, 2000; Dr Foster & the Pain Society, 2003; Albazaz, Wong & Homer-Vanniasinkam, 2018, British Pain Society, 2013).

As access to chronic pain services and an emphasis on a multidisciplinary approach are recognised as important aspects of treatment for those with chronic pain conditions (National Institute for Health and Care Excellence, 2020; Royal College of Physicians, 2012), it is important to assess the current population of adults in the UK with chronic pain accessing chronic pain services in secondary and/or tertiary care.

### Barriers to the treatment of Adults with Chronic Pain from Minority Ethnic Backgrounds

There are barriers to providing the best possible care for patients with chronic pain from Minority Ethnic groups. Difficulties in communication and information dissemination and a lack of understanding of family traditions and religious beliefs are some of the cultural barriers which can hinder a strong patient-practitioner relationship and limit the support for selfmanagement (Chipidza, Wallwork & Stern, 2015; Sousa-Douarte, Brown & Mendes, 2020). This in turn can negatively influence health outcomes by decreasing patient satisfaction,

leading to reduction in patient understanding of health problems and treatments available, contributing to poorer adherence to treatment plans in chronic pain services (Chipidza et al. 2015; Sousa-Douarte et al., 2020). Attitudes towards treatment interventions for pain and coping mechanisms can be influenced by race, ethnicity and culture and consequentially, adherence to pain management plans and attendance to chronic pain services of patients from Minority Ethnic groups can be impacted (Mull, 1993; Lurie & Yergan, 1990; Cooper-Patrick et al., 1999). The National Pain Audit (British Pain Society, 2013) identified several barriers and facilitators for the successful implementation of effective pain management services and these are outlined in appendices 1-2.

#### **Problem Statement**

Little is known about the access to chronic pain services for Minority Ethnic groups. This scoping review is important to help explore existing health inequalities that can inform the best care for all.

Predominantly, current literature relating to ethnicity and chronic pain management considers chronic pain prevalence, perceptions, and outcomes of Minority Ethnic groups compared to a white population and the majority of this research has been undertaken outside of the UK Campbell & Edwards, 2012; Mossey, 2011; Morales & Yong, 2020). However, evidence relating to chronic pain services and specifically who is accessing chronic pain services within the UK is lacking. Our scoping review aims to address this gap in knowledge.

The PICO (population, intervention, comparison, outcome) model was used to formulate the research question following discussions with an academic librarian from Royal Hospitals Bath NHS Trust and pain specialist allied health professionals at the Bath Centre for Pain Services (Table 2).

**Research Question:** Is the current adult population of those with chronic pain in the UK who are accessing chronic pain services in secondary and/or tertiary care representative of the UK ethnic population?

**Aim:** To identify whether the adult population of those with chronic pain who are accessing secondary and/or tertiary chronic pain services in the UK is representative of the UK ethnic population.

#### **Objectives:**

The objectives of this study are to:

- **1.** Determine the extent to which adults with chronic pain from Minority Ethnic groups access secondary and/or tertiary chronic pain services in the UK.
- 2. Determine whether the percentage of adults from Minority Ethnic groups with chronic pain who are accessing chronic pain services in secondary and/or tertiary care across the UK is consistent with what would be expected given the ethnic breakdown of the UK population and chronic pain incidence within the UK population and different ethnic groups.
- **3.** Identify the need for further research related to ethnic disparities within secondary and tertiary chronic pain services in the UK.

#### **Definitions of Key Terms**

**Diversity:** "Valuing peoples' differences and addressing their different needs and situations. Each person needs to be valued as an individual." (Kandola & Fullerton, 1998).

**Ethnicity:** The term ethnicity is broader than race and has usually been used to refer to long shared cultural experiences, religious practices, traditions, ancestry, language, dialect or national origins (for example, African-Caribbean, Indian, Irish) (The Law Society, 2020).

**Pain:** "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage." (Nicholas et al. 2019, p29).

**Chronic Pain:** Chronic pain is defined as pain that persists or recurs for more than 3 months and is associated with significant emotional distress and/or functional disability, and the pain is not better accounted for by another condition (Nicholas et al. 2019, p29).

**Secondary Care:** Refers to medical care provided by a specialist or facility (NHS Providers, n.d.).

**Tertiary Care:** Refers to highly specialised treatment provided in specialist centres with access to more specialised equipment and expertise (NHS Providers, n.d.).

**Multidisciplinary Treatment:** Multimodal treatment provided by practitioners from different disciplines. (IASP, 2017).

Adult: A person over the age of 18.

**Chronic Pain Service:** This term is being used in this scoping review to refer to any type of specialist pain treatment setting in secondary and/or tertiary care.

#### **Methods**

#### Study Design

This is a protocol for a scoping review of literature. A scoping review is the most appropriate design as this is an exploratory piece of work where the body of literature relating to access to chronic pain services for adults from Minority Ethnic groups in the UK has not yet comprehensively been reviewed and we intend to draw broad conclusions of what the cumulative evidence says on this topic.

Several systematic reviews related to the current status of the UK population accessing different health services from ethnic communities were accessed to inform our search strategy (Zeh, Sandhu, Cannaby & Sturt, 2013; Baharoon & King 2018; Chauhan et al., 2020). Expert searching advice has been sought from academic librarians at Royal United Hospitals Bath NHS Trust and the University of the West of England to ensure the proposed search strategy is systematic, rigorous, and has a good balance of sensitivity and specificity.

#### **Information Sources**

A search of MEDLINE, EMBASE and CINAHL bibliographic databases will be conducted as it is advised to search multiple databases for relevant records (Levay, Raynor & Tuvey, 2015; Lawrence, 2008; Beyer & Wright 2013). This is because these are special topic databases with focus on medicine, nursing and allied health. A search in Google Scholar and Open Grey for grey literature including clinical guidelines, policy documents and reports will also be conducted. Contact with experts in pain management will be sought to obtain additional relevant information.

#### Search Strategy

The PICO model has been used to help formulate the search strategy by identifying key concepts (Tables 2 and 3). The outlined bibliographic databases will be searched electronically using combinations of key words (Table 3) and indexed search terms including chronic pain, secondary health care, tertiary health care, multidisciplinary team, United Kingdom, ethnic group, minority group and ethnicity. It was decided not to include *'access'* as a key word as this may narrow the outputs when undertaking preliminary searches and some relevant studies can be overlooked. Also, it can be presumed that studies relating to chronic pain services will implicate patients are accessing chronic pain services which bypasses the need for *access* to be

a key term in the search strategy. The screening and selection process will ensure that the studies identified through our search strategy are relevant to *access* to chronic pain services. Reference lists of included articles will be checked to identify any eligible studies and to reduce the risk of missing preliminary evidence (Callahan, 2014).

A Boolean search strategy will be used in the search strategy: Truncations and the 'OR' operation to maximise sensitivity and, the 'AND' operation to combine the search groups, increasing the specificity of the search. Thus, the search strategy will be both robust and manageable. Although it is generally cautioned against using the 'NOT' search operator as it can have odd implications for search results (Siddaway, Wood and Hedges, 2019), the 'NOT' search operator will be used to try to ensure only UK-specific articles are retrieved following guidance from the MEDLINE UK filter (Ayiku et al. 2017). Table 3 presents the search strategy.

The searches will be limited by historical time-constraints (2004-2021) as demographic data from studies published in this time period should represent the UK population recorded in the 2011 UK census. Searches will be limited to English language articles only as it can be presumed that any UK-based studies which are relevant to include in this review will be published in English. Following consultation with academic librarians [L.H.] and [P.H.], it was decided not to include the geographical filter as over-refining the results may cause relevant studies to be missed. If the information reported in a published study is insufficient to decide about inclusion, we will attempt to contact the author to enquire about further details and/or data.

The search strategy is considered as adequate to reduce the risk of selection and detection bias.

#### Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria outlined in Table 4 will be used in the screening of records and assessing for eligibility.

### Data Collection

Rayyan software (www.rayyan.ai) will be used to manage title and abstract and full text screening.

The initial search will yield a number of records and any duplicates will be removed and recorded within a PRISMA flowchart (see Figure 1). Four reviewers will be involved in the screening and filtering process as this will improve inter-rater reliability (Siddaway et al. 2019). The screening process will consist of checking the titles and abstracts of identified studies by [E.L.] and [J.L.]. Any records that are clearly not relevant for addressing the research question will be excluded and reason for exclusion will be documented (see Figure 1). Where it is not clear from the title and/or abstract whether a study is relevant, the full text will be obtained and screened for eligibility.

The list of studies selected for full-text screening will be divided in half and [E.L.], [J.L], [H.A.] and [S.P.] will work in pairs to check the full-text articles to confirm their eligibility against the inclusion criteria using a checklist formulated by [E.L.] (see appendix 3). Any articles which are out of the scope of the project, provide limited detail or lack rigour will be excluded. In cases of uncertainty, the reviewers will confer and come to a consensus. A select number of papers will remain following this process. The senior author [J.L.] will review the final list of included studies. The articles included and excluded, with reasons, will be reported according to the PRISMA guidelines. A detailed study flowchart will be presented as shown in Figure 1.

#### Study Quality Appraisal

Given this is a scoping review, the traditional assessment of risk of bias is not appropriate due to the heterogenicity of the sources (Tricco et al. 2018). However, quality assessment will be based on comprehensiveness of data regarding access to chronic pain services by the UK ethnic population. The strengths and limitations of the papers will be discussed and will allow readers to make informed judgements on the quality of the included papers.

#### Data Extraction

An electronic data extraction form (see appendix 4) has been developed to ensure key data related to the population being studied, participants demographics, location and treatment settings can be extracted from the eligible articles. In the case of incomplete reporting, the corresponding authors will be contacted for further clarification. Data extraction will be verified by [J.L.].

#### **Data Synthesis**

As the extracted data will be from studies with diverse methodologies and different theoretical conceptualisations, constructs, and/or relationships, a descriptive synthesis of the extracted data will be performed. The rationale for this is that it allows for investigation of the similarities and the differences between the findings of different studies, as well as exploration of patterns in the data (Ryan & Cochrane Consumers and Communication Review Group, 2013). Also, it is a useful means of linking together studies on different topics for reinterpretation and interconnection (Siddaway et al. 2019).

Extracted data related to the number of adults with chronic pain in the UK accessing chronic pain services will be appraised. Where possible, extracted data from included articles will be presented in tabular format. These will be grouped by demographic factors including chronic

pain condition and chronic pain site, ethnic group, age, sex/gender, type of chronic pain service and geographical region of the UK.

The results will be described in relation to the research question and in the context of the overall study purpose. Gap identification will detect areas, such as the need for more robust data and chronic pain services in the UK to routinely collect data on ethnicity.

Where possible, we will estimate the percentage of adults with chronic pain (categorised by ethnic group) who are accessing chronic pain services across secondary and/or tertiary care in the UK. We will then determine if this is consistent with what would be expected given the ethnic breakdown of the UK population and chronic pain incidence within the UK population. We will use ethnicity data from the 2011 UK census and data on the incidence of chronic pain in the UK determined by Fayaz et al. (2016) as currently this is the best available evidence. Through contact with the Research Action Coalition for Race Equality, we have access to the ethnicity data from the 2011 census and the Fayaz et al. (2016) systematic review is freely available.

#### **Discussion**

The planned scoping review will systematically explore the evidence available on who is accessing chronic pain services in secondary and tertiary care in the UK and whether this is representative of the UK ethnic population.

As part of the discussion, we will describe where participants (categorised by reported ethnic group) of the included studies are accessing chronic pain services in terms of both provision of care (secondary or tertiary) and geographical region of the UK where stated. We want to explore the range of chronic pain conditions that are affecting those participants. We also plan

to identify which types of chronic pain services the participants are accessing and what treatments they receive.

The review will be the foundation for informing further research on the barriers and facilitators to accessing chronic pain services for Minority Ethnic groups in the UK.

#### **Ethics**

Ethical approval is not required for this scoping review as only data already published and available in scientific databases will be included. The results of this review will be disseminated through peer-reviewed publications and conference presentations.

#### **Limitations**

The scoping review will not consider intra-ethnic differences or the paediatric population, therefore the findings will be applicable to adult populations only. As this review is relevant to Minority Ethnic groups in the UK only, the findings cannot be generalised to other countries. We acknowledge a potential source of selection bias given that the review excludes non-English language papers. The scoping review is attempting to assess the current status of adults accessing chronic pain services but data related to ethnicity from the UK 2011 Census may not represent the current UK population following the withdrawal of the UK from the European Union in 2020. Data from the 2011 UK census does not report on the ethnicity of households that did not answer the question about ethnicity or complete the census so this will need to be considered when interpretating the findings of this review.

#### **Strengths**

Broad input and consultation from clinical experts, experienced researchers, an epidemiologist with expertise in chronic pain, academic librarians and persons from Minority Ethnic backgrounds have been sought in designing a rigorous approach to this review. Unpublished

articles and grey literature will be included; thus this review aims to be comprehensive and the risk of publication bias will be minimised.

### **Conclusion**

This scoping review will be among the first to explore whether the current adult population of those with chronic pain who are accessing chronic pain services in secondary and/or tertiary care across the UK are representative of the UK Minority Ethnic population. We expect the findings to be broad and comprise descriptive and empirical data. It will highlight the need for further research that informs service improvement for equitable and people-centred chronic pain services.

#### **References**

- Albazaz R., Wong Y.T. & Homer-Vanniasinkam S. (2006). Complex Regional Pain Syndrome: A Review. Annals of Vascular Surgery, 22, 297-306. doi: 10.1016/j.avsg.2007.10.00
- Ayiku L., Levay P., Hudson T., Craven J., Barrett E., Finnegan A. & Adams R. (2017). The medline UK filter: development and validation of a geographic search filter to retrieve research about the UK from OVID medline. *Health Information Library Journal*, 34, 200-216. doi: 10.1111/hir.12187
- Baharoon H. & King J. (2018). Do racial/ethnic or cultural differences between patients influence outcomes of physiotherapy interventions? The results of a scoping review. *European Journal of Public Health*, 28, 15. https://doi.org/10.1093/eurpub/cky048.111h
- Baillie L. & Matiti M. (2013). Dignity, equality and diversity: an exploration of how discriminatory behaviour of healthcare workers affects patient dignity. *Diversity & Equality in Health and Care, 10*, 5-12.
- Bassols A., Bosch F. & Baños J.E. (2002). How does the general population treat their pain? A survey in Catalonia, Spain. *Journal of Pain Symptom Managment, 23*, 318-328. doi: 10.1016/s0885-3924(01)00415-8
- Beasley M., Jones G.T., Macfarlane T. & Macfarlane G.J. (2014). Prevalence of Pain Reporting in Different Ethnic Groups in the UK: Results from a Large Biobank. *American College of Rheumatology*, 66, pp.29-30.
- Betteridge N. & Johnson M. (2019). *Chronic Pain: Patient Voice and the NHS Long Term Plan.* Retrieved from https://www.britishpainsociety.org/static/uploads/resources/files/Chronic\_Pain\_Patien t\_Voice\_\_NHS\_Long\_Term\_Plan\_CPPC\_2019\_Pain\_Platform\_Report.pdf
- Beyer F.R. & Wright K. (2013). Can we prioritise which databases to search? A case study using a systematic review of frozen shoulder management. *Health Information and Libraries Journal*, *30*, 49–58. doi: 10.1111/hir.12009
- Bisset W.I.K. (1988). Pain relief clinics under anaesthetic management in Scotland. Annals of the Royal College of Surgeons of England, 70, 392–394.
- Blythe F. (2008). Chronic pain—is it a public health problem?. *Pain, 137*, 465-466. doi: 10.1016/j.pain.2008.04.013
- Breivik H., Collett B., Ventafridda V., Cohen R. & Gallacher D. (2006). Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *European Journal of Pain, 10*, 287-333. doi: 10.1016/j.ejpain.2005.06.009
- British Pain Society. (2013, October). *National Pain Audit*. Retrieved from <u>https://www.britishpainsociety.org/static/uploads/resources/files/members\_articles\_np\_a\_2013\_safety\_outcomes.pdf</u>
- Callahan J.L. (2014). Writing Literature Reviews: A Reprise and Update. *Human Resource Development Review*, 13, 271-275. <u>https://doi.org/10.1177/1534484314536705</u>.

- Campbell C.M. & Edwards R.R. (2012). Ethnic differences in pain and pain management. *Pain Management*, 2, 219-230. <u>https://doi.org/10.2217/pmt.12.7</u>
- Campos R.P. & Vazquez Rodriguez M.I. (2012). Health-related quality of life in women with fibromyalgia: clinical and psychological factors associated. *Clinical Rheumatology*, *31*, 347-355. <u>https://doi.org/10.1007/s10067-011-1870-7</u>
- Carmona L., Ballina J., Gabriel R., Laffon A. and Group E.S. (2001). The burden of musculoskeletal diseases in the general population of Spain: results from a national survey. *Annals of Rheumatic Diseases*, 60, 1040-1045. <u>https://doi.org/10.1136/ard.60.11.1040</u>
- Chauhan A., Walton M., Manias E., Walpol R.L.A., Seale H., Latanik M., Leone D., Mears S. & Harrison R. (2020). The safety of health care for ethnic minority patients: a systematic review. *International Journal for Equity in Health*, 19, 118. <u>https://doi.org/10.1186/s12939-020-01223-2</u>
- Chipidza F.E., Wallwork R.S. & Stern T.A. (2015). Impact of the Doctor-Patient Relationship. *The Primary Care Companion for CNS Disorders*, 17, <u>https://doi.org/10.4088/PCC.15f01840</u>.
- Clinical Standards Advisory Group. (2000). *Services for Patients with Pain.* London: UK Department of Health.
- Cooper-Patrick L., Gallo J.J., Gonzales J.J., Vu H.T., Powe N.R., Nelson C. & Ford D.E. (1999). Race, Gender, and Partnership in the Patient-Physician Relationship. *JAMA*, 282, 583-589. <u>https://doi.org/10.1001/jama.282.6.583</u>
- Dahan A., van Velzen M. & Niesters M. (2014). Comorbidities and the Complexities of Chronic Pain. *Anaethesiology*, 121, 675-677. <u>https://doi.org/10.1097/ALN.00000000000402</u>
- Davies M., Brophy S., Williams R. & Taylor A. (2006). The prevalence, severity, and impact of painful diabetic peripheral neuropathy in type 2 diabetes. *Diabetes Care*, 29, 1518-1522. <u>https://doi.org/10.2337/dc05-2228</u>
- Dr Foster and the Pain Society. (2003). Adult Chronic Pain Management Services in the UK. London: British Pain Society Publications.
- Edwards R.R., Moric M., Husfeldt B., Buvanendran A. & Ivanovich O. (2005). Ethnic Similarities and Differences in the Chronic Pain Experience: A Comparison of African American, Hispanic, and White Patients. *Pain Medicine*, *6*, 88-98. <u>https://doi.org/10.1111/j.1526-4637.2005.05007.x</u>
- Ezenwa M.O. & Fleming M.F. (2012). Racial Disparities in Pain Management in Primary Care. *Journal of Health Disparities Research and Practice*, 5, 12-26.
- Fashler S.R., Cooper L.K., Oosenbrug E.D., Burns L.C., Razavi S., Goldberg L. & Katz J. (2016). Systematic review of multidisciplinary chronic pain treatment facilities. *Pain Research and Management*, 2016: 5960987. <u>https://doi.org/10.1155/2016/5960987</u>.
- Fayaz A., Croft P., Langford R.M., Donaldson L.J. & Jones G.T. (2016). Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies. *BMJ Open*, 6, e010364. <u>https://doi.org/10.1136/bmjopen-2015-010364</u>.

- García-Campayo J., Ayuso-Mateos J.L., Caballero L., Romera I., Aragonés E., Rodríguez-Artalejo F., Quail D. & Gilaberte I. (2008). Relationship of somatic symptoms with depression severity, quality of life, and health resources utilization in patients with major depressive disorder seeking primary health care in Spain. *Journal of Clinical Psychiatry*, 10, 355-362. <u>https://doi.org/10.4088/pcc.v10n0502</u>.
- GOV.UK. (2011). *UK Population by Ethncity*. Retrieved from https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity
- GOV.UK. (2018). *Population of England and Wales*. Retrieved from https://www.ethnicityfacts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regionalpopulations/population-of-england-and-wales/latest
- Helman C.G. (2007). Culture, Health and Illness (5th ed.). Oxford: Butterworth Heinemann.
- International Association for the Study of Pain. (2017, December 14). *Task Force on Multimodal Pain Treatment Defines Terms for Chronic Pain Care*. Retrieved from <u>https://www.iasp-pain.org/PublicationsNews/NewsDetail.aspx?ItemNumber=6981</u>
- Janevic T., Zeitlin J., Auger N., Egorova N.N., Herbert P., Balbierz A. and Howell E.A. (2018). Association of Race/Ethnicity With Very Preterm Neonatal Morbidities. JAMA Paediatrics, 172, 1061-1069. <u>https://doi.org/10.1001/jamapediatrics.2018.2029</u>
- Kandola R.S. & Fullerton J. (1998). *Diversity in Action: managing the mosaic. London: Institute of Personnel and Development* (1st ed.). London: CIPD Publishing.
- Kennel J., Withers E., Parsons N. & Hyeyoung W. (2019). Racial/Ethnic Disparities in Pain Treatment. *Medical Care*, 57, 924-929. <u>https://doi.org/10.1097/MLR.00000000001208</u>
- Lawrence D.W. (2008). What is lost when searching only one literature database for articles relevant to injury prevention and safety promotion?. *Injury Prevention*, 14, 401-404. https://doi.org/10.1136/ip.2008.019430
- Levay P., Raynor M. & Tuvey D. (2015). The contributions of MEDLINE, other bibliographic databases and various search techniques to NICE public health guidance. *Evidence based practice in librarianship*, 10, 50-68. <u>https://doi.org/10.18438/B82P55</u>
- Li Y. & Heath A. (2018). Persisting disadvantages: a study of labour market dynamics of ethnic unemployment and earnings in the UK (2009–2015). *Journal of Ethnic and Migration Studies*, 46, 857-878. <u>https://doi.org/10.1080/1369183X.2018.1539241</u>
- Lurie N. & Yergan J. (1990). Teaching residents to care for vulnerable populations in the outpatient setting. *Journal of General Internal Medicine*, 5, 26-34. <u>https://doi.org/10.1007/BF02600435</u>
- Macfarlane G., Beasley M., Smith B., Jones G. & Macfarlane T. (2015). Can large surveys conducted on highly selected populations provide valid information on the epidemiology of common health conditions? An analysis of UK Biobank data on musculoskeletal pain. *British Journal of Pain*, 9, 203-212. https://doi.org/10.1177/2049463715569806

- Maly A. & Vallerand A.H. (2018). Neighborhood, socioeconomic, and racial influence on chronic pain. *Pain Management in Nursing*, *19*, 14-22. <u>https://doi.org/10.1016/j.pmn.2017.11.004</u>
- Mills S.E.E., Nicolson K.P. & Smith B.H. (2019). Chronic pain: a review of its epidemiology and associated factors in population-based studies. *British Journal of Anaethesia*, 123, 273-283. <u>https://doi.org/10.1016/j.bja.2019.03.023</u>
- Morales M.E. & Yong R.J. (2021). Racial and Ethnic Disparities in the Treatment of Chronic Pain. *Pain Medicine*, 22, 75-90. <u>https://doi.org/10.1093/pm/pnaa427</u>
- Mossey J.M. (2011). Defining Racial and Ethnic Disparities in Pain Management. *Clinical Orthopaedics and Related Research*, 2, 1859-1870. <u>https://doi.org/10.2217/pmt.12.7</u>
- Mull J.D. (1993). Cross-cultural communication in the physician's office. *Western Journal of Medicine*. 159, 609-613.
- Nagar S.D., Napoles A.M., Jordan I.K. and Marino-Ramirez L. (2021). Socioeconomic deprivation and genetic ancestry interact to modify type 2 diabetes ethnic disparities in the United Kingdom. *EClinicalMedicine*, https://doi.org/10.1016/j.eclinm.2021.100960.
- Narayanasamy A. and Narayanasamy G. (2012). Diversity in caring. In McSherry W., McSherry R. and Watson R. (Ed.), *Care in Nursing: principles, values and skills* (pp. 61-77). Oxford: Oxford University Press.
- National Institute for Health and Care Excellence. (2020, August). Chronic Pain: Assessment and Management. Retrieved from https://www.nice.org.uk/guidance/ng193/documents/evidence-review-3
- NHS Providers. (n.d.). *The NHS Provider Sector*. Retrieved from <u>https://nhsproviders.org/topics/delivery-and-performance/the-nhs-provider-sector</u>
- Nicholas M., Vlaeyen J.W.S., Rief W., Barke A., Aziz Q., Benoliel R., Cohen M., Evers S., Giamberadino M.A., Goebel A., Korwisi B., Perrot S., Svensson P., Wang S.-J., Treede R.-D. & IASP Taskforce for the Classification of Chronic Pain (2019). The IASP classification of chronic pain for ICD-11: chronic primary pain. *Pain*, 160, 28-37. <u>https://doi.org/10.1097/j.pain.00000000001390</u>
- Office for National Statistics. (2011). 2011 Census Data. Retrieved from https://www.ons.gov.uk/census/2011census/2011censusdata
- Poleshuck E. & Green C. (2008). Socioeconomic disadvantage and pain. *Pain*, *136*(3), 235-238. <u>https://doi.org/10.1016/j.pain.2008.04.003</u>
- Royal College of Physicians. (2012, May). Complex Regional Pain Syndrome in Adults UK Guidelines for diagnosis, referral and management in primary and secondary care. Retrieved from <u>https://www.rcplondon.ac.uk/guidelines-policy/complex-regional-pain-syndrome-adults</u>
- Ryan R. & Cochrane Consumers and Communication Review Group (2013, June). *Data Synthesis and Analysis*. Retrieved from <u>https://cccrg.cochrane.org/sites/cccrg.cochrane.org/files/public/uploads/AnalysisResty</u> <u>led.pdf</u>

- Siddaway A.P., Wood A.M. & Hedges L.V. (2019). Narrative Reviews, Meta-Analyses and Meta-Syntheses. Annual Reviews in Psychology, 70, 747-770. <u>https://doi.org/10.1146/annurev-psych-010418-102803</u>
- Sousa-Duarte F., Brown P. & Mendes A.M. (2020). Healthcare professionals' trust in patients: A review of the empirical and theoretical literatures. *Sociology Compass*, 14, 1-15. <u>https://doi.org/10.1111/soc4.12828</u>
- Stenhouse R. (2021). Understanding equality and diversity in nursing practice. *Nursing Standard*, *36*, 27-33. <u>https://doi.org/10.7748/ns.2020.e11562</u>
- The Law Society. (2020). A guide to race and ethnicity terminology and language. Retrieved from <u>https://www.lawsociety.org.uk/en/topics/ethnic-minority-lawyers/a-guide-to-race-and-ethnicity-terminology-and-language</u>
- Tricco A.C., Lillie E., Zarin W., O'Brien K.K., Colquhoun H., Levac D., Moher D., Peters M.D.J., Horsley T., Weeks L., Hempel S., Akl E.A., Chang C., McGowan J., Stewart L., Hartling L., Aldcroft A., Wilson M.G., Garritty C., Lewin S., Godfrey C.M., Macdonald M.T., Langlois E.V., Soares-Weiser K., Moriarty J., Clifford T., Tunçalp O., Straus S.E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*, 169, 467-473. <a href="https://doi.org/10.7326/M18-0850">https://doi.org/10.7326/M18-0850</a>
- Versus Arthritis. (2021, June). *Chronic Pain in England*. Retrieved from <u>https://www.versusarthritis.org/media/23739/chronic-pain-report-june2021.pdf</u>
- Zeh P., Sandhu H.K., Cannaby A.M. & Sturt J.A. (2013). Cultural barriers impeding ethnic minority groups from accessing effective diabetes care services: a systematic review of observational studies. *Diveristy and Equality in Healthcare*, 11. <u>https://doi.org/10.21767/2049-5471.100001</u>

# **Tables**

Table 1: Standardised prevalence of chronic pain in different ethnic groups across the UK

	Ethnic Group					
	White	Mixed	Black	Asian	Any	
		South		(Chinese)	Other	
		Asian				
Standardised Prevalence	42.6	46.7	47.7	45.2	47	
(%)						

Beasley M., Jones G.T., Macfarlane T. & Macfarlane G.J. (2014). Prevalence of Pain

Reporting in Different Ethnic Groups in the UK: Results from a Large Biobank. American College of Rheumatology, 66, pp.29-30.

# Table 2: PICO Model

PICO Element	Description
Population	Adults in the UK with chronic pain or a condition associated with chronic
	pain [from Minority Ethnic groups].
Intervention	Access to [regional/national] chronic pain services [in secondary and
	tertiary care] within the UK.
Comparison	Comparing this to what would be expected given the ethnic breakdown of
	the UK population and chronic pain incidence within the UK population
	and different ethnic groups.
Outcome	Number of adults in the UK with chronic pain from Minority Ethnic groups
	who are accessing chronic pain services – are they represented?

# Table 3: Key Words and Synonyms

	"chronic pain" or "long-term pain" or "long term pain" or "persistent pain"				
	AND				
2	"pain service" or "pain treatment" or "pain management" or "pain program*" or "pain management				
	program*" or "pain clinic" or "pain centre" or "pain center*" or "secondary care" or "tertiary care" or				
	"multidisciplinary team" or "multidisciplinary approach" or "multidisciplinary care" or				
	"multidisciplinary management" or "multidisciplinary treatment*" or "interdisciplinary approach" or				
	"interdisciplinary team" or "interdisciplinary care" or "interdisciplinary treatment*" or "collaborative				
	care" or "MDT"				
	AND				
3a	"UK" or "United Kingdom" or "Great Britain" or "GB" or "British" or "national health service" or				
	"NHS" or "England" or "Scotland" or "Wales" or "Northern Ireland" or "Scottish" or "Welsh" or or				
	"Northern Irish" or "English"				
	NOT				
3b	"British Columbia" or "New England" or "New South Wales" or "United States"				
	AND				
<b>4</b> a	AND "BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or				
<b>4</b> a					
4a	"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or				
4a	"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*" or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black				
4a	"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*"or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black people*" or "black person*" or "Asian*" or "British Asian*" or "Jew*" or "Irish traveller*" or "traveller*" or "gyps*" or "roma gyps*" or "romany gyps*" or "white*" or "white people*" or "white				
4a	"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*" or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black people*" or "black person*" or "Asian*" or "British Asian*" or "Jew*" or "Irish traveller*" or				
<b>4</b> a	"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*" or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black people*" or "black person*" or "Asian*" or "British Asian*" or "Jew*" or "Irish traveller*" or "traveller*" or "gyps*" or "roma gyps*" or "romany gyps*" or "white*" or "white people*" or "white person*" or "white other" or "white mixed" or "Caucasian" or "eastern European" or "white British" or				
<b>4</b> a	"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*" or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black people*" or "black person*" or "Asian*" or "British Asian*" or "Jew*" or "Irish traveller*" or "traveller*" or "gyps*" or "roma gyps*" or "romany gyps*" or "white*" or "white people*" or "white person*" or "white other" or "white mixed" or "Caucasian" or "eastern European" or "white British" or "people of colour" or "mixed race" or "immigrant*" or "migrant*" or "asylum seeker*" or "refugee" or "race" or "race factor" or "race difference*"				
4a	<ul> <li>"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*" or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black</li> <li>people*" or "black person*" or "Asian*" or "British Asian*" or "Jew*" or "Irish traveller*" or "traveller*" or "gyps*" or "roma gyps*" or "romany gyps*" or "white*" or "white people*" or "white other" or "white mixed" or "Caucasian" or "eastern European" or "white British" or "people of colour" or "mixed race" or "immigrant*" or "migrant*" or "asylum seeker*" or "refugee" or "race" or "race factor" or "race difference*"</li> </ul>				
4a 4b	"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*" or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black people*" or "black person*" or "Asian*" or "British Asian*" or "Jew*" or "Irish traveller*" or "traveller*" or "gyps*" or "roma gyps*" or "romany gyps*" or "white*" or "white people*" or "white person*" or "white other" or "white mixed" or "Caucasian" or "eastern European" or "white British" or "people of colour" or "mixed race" or "immigrant*" or "migrant*" or "asylum seeker*" or "refugee" or "race" or "race factor" or "race difference*"				
	<ul> <li>"BAME" or "BME" or "ethnic disparit*" or "Ethnic*" or "ethnic minorit*" or "ethnic difference*" or "ethnic group*" or "minority group*" or "mixed ethnic*" or "multiple ethnic*" or "black*" or "black</li> <li>people*" or "black person*" or "Asian*" or "British Asian*" or "Jew*" or "Irish traveller*" or "traveller*" or "gyps*" or "roma gyps*" or "romany gyps*" or "white*" or "white people*" or "white other" or "white mixed" or "Caucasian" or "eastern European" or "white British" or "people of colour" or "mixed race" or "immigrant*" or "migrant*" or "asylum seeker*" or "refugee" or "race" or "race factor" or "race difference*"</li> </ul>				

# Table 4: Inclusion and Exclusion Criteria

Inclusion	Exclusion
Report on access to pain treatment settings (including	Any non-UK-based study.
pain management clinics, pain clinics, pain	
programmes, pain management services, pain	
management programmes) in secondary and/or	
tertiary care in the UK.	
Adult population with chronic pain and state the	Population is paediatrics (under 18 years of age).
ethnicity of the involved participants within the	
demographics.	
Primary research studies including observational	Acute or malignant pain.
studies with cross-sectional or prospective research	
design, case-control studies, systematic reviews and	
studies with experimental designs, qualitative	
interviews and case studies will be included.	
Grey literature including conference abstracts, policy	Treatment in primary care only.
documents, national audits and surveys, reports,	
guidelines, and government publications will be	
included.	
Unpublished articles and poster abstracts will also be	Written in another language other than English.
included if they meet the above-mentioned criteria to	
reduce the risk of publication bias.	
Publication between 2004-2021 as demographic data	Duplicated and unavailable publications.
from studies published in this time period should	
represent the UK population recorded in the 2011 UK	
census.	
Written in English.	

# Figure Legends

Figure 1: PRISMA Flow Chart illustrating procedure

# Appendices

# Appendix 1

### Pain Management Services Barriers

The National Pain Audit (2013) identified several barriers to the successful implementation of effective pain management services:

- Appropriately skilled staff to deliver treatment are frequently not available.
- Lack of understanding as to deliver highly specialised care is very small, meaning there are is no regional leadership structure in the specialty.
- The necessity of chronic pain services to be crosscutting in nature and integrated with other services is poorly recognised, meaning access to specialist advice may be delayed.
- British Pain Society (2013). *National Pain Audit*. Retrieved from https://www.britishpainsociety.org/static/uploads/resources/files/members\_articles\_np a\_2013\_safety\_outcomes.pdf

#### Appendix 2

#### Pain Management Services Facilitators

The National Pain Audit (2013) identified several actions required to improve the delivery of chronic pain services regionally and nationally and to improve patient participation and patient satisfaction:

- Competencies developed for non-medical practitioners in pain management.
- Differing levels of service provision that can match to need.
- Guidance on standards of care expected from services.
- A review of best practice in delivery of patient education in pain.
- Clear standards for risk management on assessment of people in pain.
- Better integrated working between services across the healthcare system.
- Subgroup analysis to identify whether some cohorts of patients respond better than others.
- Guidance on best interventions to return people in pain to work.
- British Pain Society (2013). *National Pain Audit*. Retrieved from https://www.britishpainsociety.org/static/uploads/resources/files/members\_articles\_np a\_2013\_safety\_outcomes.pdf

### Access to chronic pain services for Minority Ethnic groups

Appendix 3

Screening Checklist

### **Screening of Titles and Abstracts**

### **Refer to PICO:**

- 1. What population is being studied?
  - a. Is it the adult population only?
  - b. Is it the UK population?
- 2. Does the study mention chronic pain services in secondary and/or tertiary care?
  - a. Is it looking at access to chronic pain services?
- 3. Is the study looking at ethnicity?
  - a. Does it state the ethnicity of participants?
- 4. Is the study looking at whether people from ethnic minorities are represented in chronic pain services?

# **Screening of Full Text Articles**

### Key questions to ask:

- 1. Is the study published in English?
- 2. Is the study published between 2004-2021?
- 3. Was the study based in the UK?
- 4. Did the study involve UK participants?
- 5. Did the study look at the UK adult population, specifically those with chronic pain?
- 6. Was the study conducted in a secondary and/or tertiary setting, specifically in a specialist pain treatment setting?
- 7. Did the study include ethnic grouping in the demographics?

Access to chronic pain services for Minority Ethnic groups

# If YES is the answer to all of these questions then included

### **Exclude any study where:**

- 1. Not published in English.
- 2. Not UK-Based.
- 3. Not involving UK participants.
- 4. Looking at paediatrics only.
- Looking at anything other than chronic pain or a condition associated with chronic pain i.e. acute or malignant pain.
- 6. Not in secondary and/or tertiary care.
- 7. No mention of (a) pain treatment setting(s).
- 8. No mention of the ethnicity of participants within the demographics.

# \*Document all excluded studies and why excluded\*

### Follow the screening checklist table:

		Y	N
1	Is the study published in English?		
2	Is the study published between 2004-2021?		
3	Was the study based in the UK?		
4	Did the study involve UK participants?		
5	Did the study look at the UK adult population, specifically those with chronic pain or a		
	condition associated with chronic pain?		
6	Was the study conducted in a secondary and/or tertiary setting?		
7	Did the study include ethnic grouping in the demographics?		
8	Is the study in the scope of the review?		
9	Any other reason why study should be excluded?		

# Access to chronic pain services for Minority Ethnic groups

# Appendix 4

# Data Extraction Form

Data Extraction Form			
Author			
Study design			
Geographical location			
Setting			
Description of chronic			
pain / condition			
associated with			
chronic pain			
Participant details			
Ethnicity details			
Sample size			