

Reporting and representation of underserved groups in intervention studies for patients with multiple long-term conditions: a systematic review



Zara Kayani , Andrew Willis, Shukrat O Salisu-Olatunji , Shavez
Jeffers, Kamlesh Khunti and Ash Routen



Ethnicity, Socioeconomic Status and MLTC's

- **Prevalence of MLTCs by Ethnicity and SES**
 - Lower prevalence in Black, Mixed, and Other ethnicities.¹
 - Slightly higher prevalence in Asian ethnicities after adjusting for age and SES.¹
- **Consideration of Intersectionality**
 - Important for understanding health inequalities.
 - Ethnic minority groups often face higher levels of socioeconomic deprivation.²
 - Belonging to an ethnic minority group, combined with low SES, increases the risk of early-onset MLTCs.³
- **The Problem**
 - Representation of ethnic minority and low SES groups in MLTC intervention study samples is unknown.

Systematic Review Aim

Conduct a systematic review to explore the extent to which intervention studies for individuals with MLTCs adequately report and represent underserved populations, including **ethnic minority groups** and those with **low socioeconomic status**.

Reporting and representation of underserved groups in intervention studies for patients with multiple long-term conditions: a systematic review

Zara Kayani¹ , Andrew Willis², Shukrat O Salisu-Olatunji¹ , Shavez Jeffers¹, Kamlesh Khunti^{1,3} and Ash Routen^{1,3}

¹Diabetes Research Centre, Leicester General Hospital, University of Leicester, Leicester LE1 7RH, UK

²HRB Clinical Research Facility & School of Public Health, University College Cork T12 WE28, Ireland

³NIHR Applied Research Collaboration–East Midlands, University of Leicester, Leicester LE5 4PW, UK

Corresponding author: Zara Kayani. Email: zk74@leicester.ac.uk

Abstract

Objectives: Globally, there is a growing number of people who are living with multiple long-term conditions (MLTCs). Due to complex management needs, it is imperative that research consists of participants who may benefit most from interventions. It is well documented that ethnic minority groups and lower socioeconomic status (SES) groups are at an increased risk of developing MLTCs. Therefore, the aim of this systematic review was to determine the level of reporting and representation of underserved groups (ethnic minority and low SES) in intervention studies addressing MLTCs.

Design: Systematic review. Four databases including Cochrane Library, MEDLINE, CINAHL and Scopus were searched for intervention studies from North America or Europe published between January 1990 and July 2023.

Setting: Hospital and community-based interventions. We included interventional studies focusing on improving MLTC-related outcomes.

Participants: Patients with MLTCs.

Main outcome measures: Total number of studies reporting on ethnicity and SES. Number and proportion of studies reporting by ethnic/SES group.

Results: Thirteen studies met the inclusion criteria. Only 4 of 13 studies (31%) recorded and reported ethnicity information. Of these four studies that reported on ethnicity, three studies consisted of primarily White participants. Ethnic minority groups were underrepresented, but one study included a majority of African American participants. Moreover, 12 of 13 studies (92%) reported on SES with income and educational level being the primary measures used. SES representation of higher deprivation groups was varied due to limited data.

Conclusions: For ethnicity, there was a lack of reporting, and ethnic minority groups were underrepresented in intervention studies. For SES, there was a high level of reporting but the proportion of study samples from across the spectrum of SES varied due to the variety of SES measures used. Findings highlight a need to improve the reporting and representation of ethnic minority groups and provide more

detailed information for SES through using consistent measures (e.g. education, income and employment) to accurately determine the distribution of SES groups in intervention studies of people with MLTCs.

Keywords

Ethnic studies, evidence-based practice, public health, quantitative research, statistics and research methods

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Introduction

The development of multiple chronic diseases has become widely prevalent as a result of an ageing population, lifestyle changes and other social determinants.^{1,2} In England alone, it is estimated that one in four adults have two or more long-term health conditions,^{3,4} known as multiple long-term conditions (MLTCs, also termed multimorbidity). MLTCs have implications for both the individual and healthcare services. Having MLTCs has been linked to reduced quality of life,⁵ and an increase in adverse health outcomes including premature mortality.⁶ For healthcare services, MLTCs are a significant burden in terms of expenditure, hospital admissions and medication prescriptions.⁷

In some population groups, typically described as 'underserved', the burden associated with MLTCs is higher.⁸ 'Underserved' is a term used to refer to 'populations that are underrepresented or disengaged from medical research or services despite a disproportionately high healthcare burden'.⁹ This may include those who are socioeconomically deprived, elderly people and women.¹⁰ In particular, underserved groups are often underrepresented in public health and medical research.¹⁰ Reasons for this

Impact of underrepresentation of ethnic minority groups in research



Health difference across ethnicity may reflect **different disease pathologies** and **response to treatments** (Hussain-Gambles et al., 2004; Nazha et al., 2019).



Culture and behavioral norms can shape **Patients experience of navigating a complex healthcare system.** Patients from an Asian background were among the least satisfied with aspect of care (Race Disparity Audit, 2019)



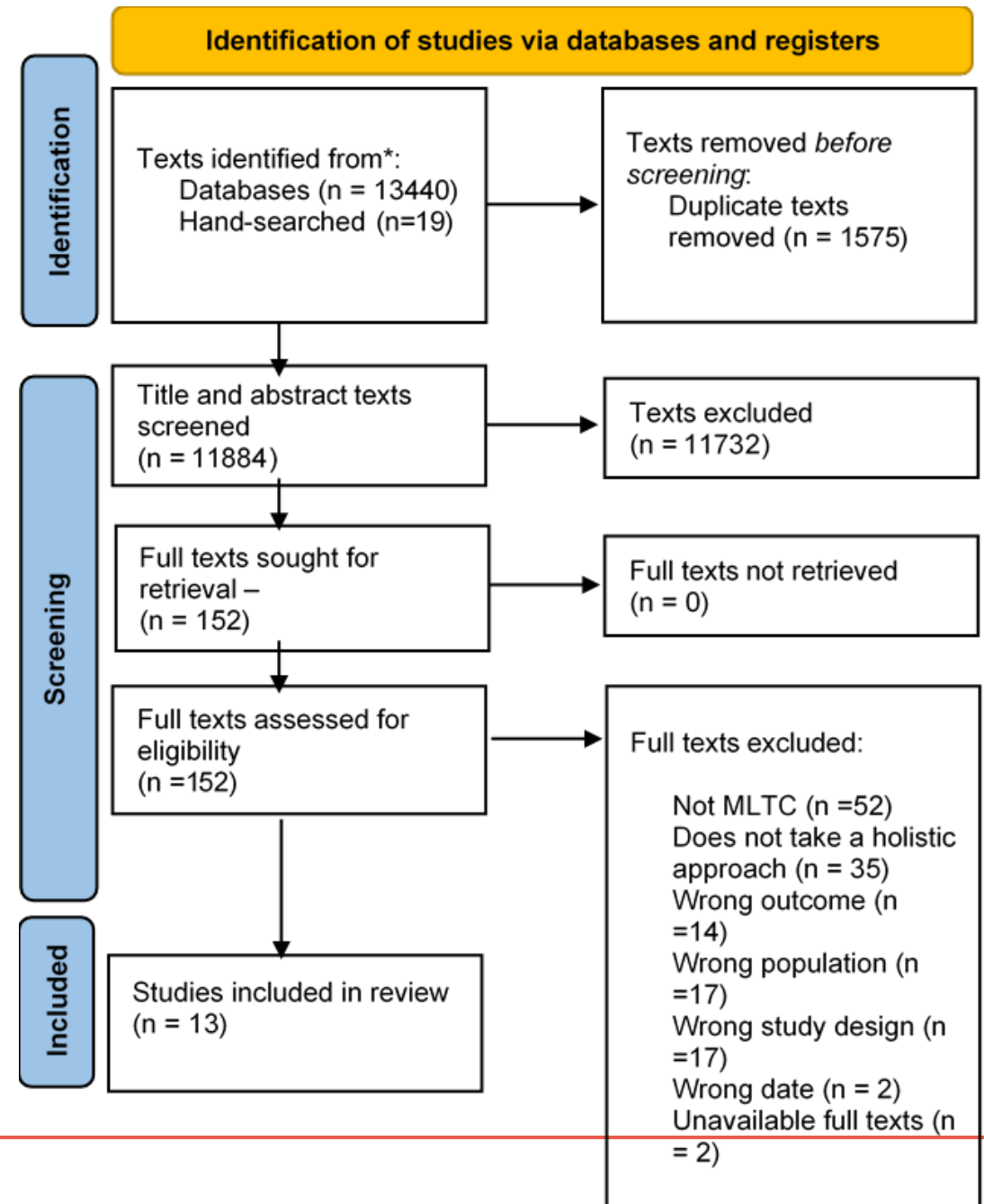
Differences in effective doses of treatments: lower doses of *Warfarin* are required to be effective in Asian American patients (3.4mg) compared to White American (5.1mg) patients. (Dang et al., 2005).



Implications: National evidence based guidelines may confer greater benefits to particular communities, particularly those who have helped shape the underpinning research.

Methods

- Searched MEDLINE, Cochrane Library, CINAHL and Scopus for articles between January 1990 – July 2023
- Any intervention with a main aim to prevent/manage burden associated with MLTCs.
- North America and Europe Only.
- MLTCs defined as 2 or more LTCs.
- Excluded Index condition + comorbidity.
- Used Effective Public Health Practice Project Quality Assessment tool



Results (characteristics)



13 studies



7/13 studies focused on populations aged 50+



4146 participants



6 of the interventions (46%) were patient-oriented and 7 (54%) organisational-based.



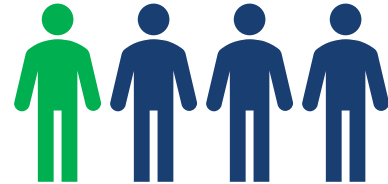
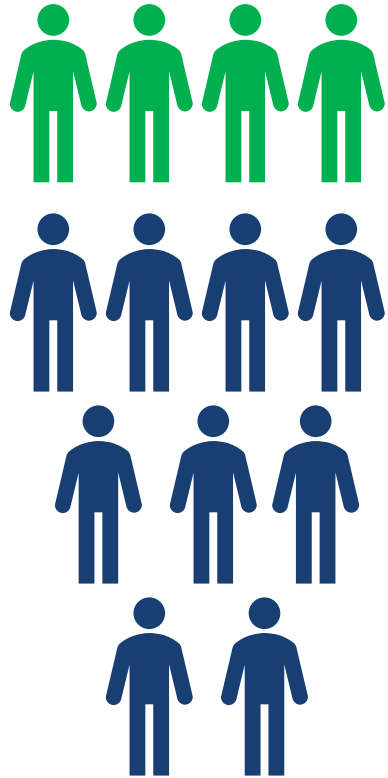
Canada (n=5), USA (n=2), Europe (n=2), UK (n=4)



6 (46%) were rated strong, 2 were moderate (15%) and 5 were weak (39%).

Results (ethnicity)

Only 4 of 13 studies reported on ethnicity



Of these 4, 3 of the samples were predominantly White (>95%).

1 was predominantly African American (>65%).

In 8 of 13, there were selection biases i.e. inclusion criteria explicitly stated participants must be able to speak English (or country's national language) or have access to a translator. 0 reported cultural adaptations or tailoring, such as translators or translated materials.



In comparison with US 2020 census data, 12.4% of the population identified as Black or African American; therefore, in this study, Black African American participants were overrepresented.

Results (socioeconomic status)

12 of 13 studies reported on SES



- Income and/or educational level were the most common indicators of SES used (9/13).
- 6 studies also included employment status to measure SES.
- 1 measured self-perceived financial status and 1 used IMD.

3 had selection biases relating to the geographical region where participants were recruited from. For example, 1 study recruited from 1 geographical region in South Germany only.



The spread of higher deprivation SES groups within study samples was varied.

Summary

- Ethnicity is poorly reported in MLTC interventions, and there is underrepresentation of ethnic minority groups in comparison to general population estimates.
- SES is well reported in MLTC interventions, but the representation of high deprivation SES groups is varied. SES indicators are heterogeneous.
- Ethnicity reporting should be improved, and it would be helpful to implement standardised ethnicity coding and SES indicator measures.

RESEARCH PARTICIPANTS NEEDED

Are you a researcher or HCP with experience in **multiple long-term conditions** or **self-management support**?

Share your experiences:



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