

Consideration of ethnicity in guidelines and systematic reviews promoting lifestyle interventions: a thematic analysis

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Background: There is a growing body of evidence supporting lifestyle interventions for the prevention of chronic disease. However, it is unclear to what extent these evidence-derived recommendations are applicable to ethnic minority populations. We sought to assess the degree of consideration of ethnicity in systematic reviews and guidelines for lifestyle interventions. **Methods:** Two reviewers systematically searched seven databases to identify systematic reviews ($n=111$) and UK evidence-based guidelines ($n=15$) on smoking cessation, increasing physical activity and promoting healthy diet, which were then scrutinized for ethnicity-related considerations. Evidence statements were independently extracted and thematically analysed. **Results:** Forty-one of 111 (37%) systematic reviews and 12 of 15 (80%) guidelines provided an evidence statement relating to ethnicity; however, these were often cursory and focused mainly on the need for better evidence. Five major themes emerged: (i) acknowledging the importance of diversity and how risk factors vary by ethnicity; (ii) noting evidence gaps in the effectiveness and cost-effectiveness of interventions for ethnic minorities; (iii) observing differential effects of interventions where these have been trialled with ethnic minority populations; (iv) suggesting adaptation of interventions for ethnic minority groups; (v) proposing improvements in research on interventions involving ethnic minority populations. **Conclusions:** Despite increasing recognition of the challenges posed by ethnic health inequalities, there remains a lack of guidance on the extent to which generic recommendations are applicable to, and how best to promote lifestyle changes in, ethnic minority populations. These important evidence gaps need to be bridged and tools developed to ensure that equity and population context is appropriately considered within evidence syntheses.

Introduction

It is well established that ethnic minority groups in most economically developed countries have different patterns of disease when compared with the majority populations.^{1–5} Data remain limited across Europe,⁶ but emerging research demonstrates large variations in the prevalence of a range of long-term conditions, such as diabetes^{7,8} and cardiovascular disease (CVD).⁹ These chronic diseases present a particular challenge for migrant and ethnic minority populations, who in many instances experience a higher burden of disease, but have paradoxically been marginalized from preventive behaviour change interventions,^{2,5,10} which tend to originate from a Eurocentric perspective.³ These interventions address causative lifestyle factors such as smoking, physical activity and diet and are henceforth referred to as lifestyle interventions.

Lifestyle interventions are increasingly required to be informed by evidence-based guidelines. As such, it is important that guidelines consider the needs of diverse ethnic groups as, if not taken into account, interventions may be rendered inequitable in reach and/or impact, and may actually widen preexisting inequalities in health.^{11,12} We were commissioned to undertake a mixed methods programme of research to examine how lifestyle interventions can be best adapted to increase their salience and effectiveness for ethnic minority groups.¹³ This work commenced with a detailed assessment of UK guidelines and international systematic reviews on lifestyle interventions of

proven effectiveness, recommended population-wide. In this article, we report and discuss the degree to which ethnic minority populations were considered within these guidelines and systematic reviews.

Methods

Search strategy

The methods used to identify relevant UK guidelines and systematic reviews are summarized here. Two reviewers (E.D./J.J.L.) electronically and manually searched for guidelines from Clinical Evidence, National Institute for Health and Clinical Excellence and Scottish Intercollegiate Guidelines Network databases. This was supplemented with a search for systematic reviews in The Campbell Collection (Campbell), Cochrane Library (Cochrane), Database of Abstracts of Reviews of Effects and National Institute for Health Research-Health Technology Assessment (NIHR-HTA) databases from 1950 to 2009. Both searches were conducted using the following key search terms:

- Diet
- Nutrition
- Obesity
- Exercise
- Physical activity
- Smoking

- Tobacco

The full text of all eligible records was retrieved; there were no language restrictions and 12 full-text articles were translated into English from Danish, French, Norwegian, Spanish and Swedish by colleagues at The University of Edinburgh to adequately assess their eligibility.

Inclusion criteria

Both reviewers independently screened and selected records for inclusion according to predefined inclusion/exclusion criteria. The population of focus was a general population (of any age), non-clinical and with no special focus (e.g. not pregnant or menopausal, nor of specific socio-economic status (SES), ethnicity, religion or gender). However, reviews or guidelines were not excluded if they contained individual studies that included special populations.

Any lifestyle intervention that promoted smoking cessation, physical activity and/or improving nutrition and had effective outcome measures related to these behaviours were included (individual, community, population, and policy-level interventions).

The aim was to extract interventions with a strong enough evidence base to be recommended for implementation. Owing to the maturity of the evidence in the field of smoking cessation we included only recommendations with strong evidence of effectiveness. For physical activity and nutrition because, in general, this body of evidence was at an earlier stage of development, we included recommendations with strong/moderate evidence of effectiveness.

Exclusions included pharmaceutical and surgical interventions; also physical activity interventions aimed exclusively at preventing falls or solely measuring weight loss outcomes.

Selection of evidence

Disagreements in the selection of evidence were resolved through discussion between the two reviewers, with arbitration by a third reviewer when necessary (A.S.). To assess consideration of ethnicity, we searched this body of evidence for statements or relevant data (e.g. subgroup analysis) specifically addressing ethnicity. The full text was searched either electronically (or manually if electronic versions were unavailable) using a set of key terms¹³ reflecting the ethnic groups of interest, and more broadly encompassing the concept of ethnicity (e.g. rac*, minorit*). The key terms used are included in Figure 1. In our broader work we undertook a considered discussion of the definition of ethnicity,¹³ which can be complex and contested, and adopted a definition widely accepted in public health,¹⁴ which acknowledges its ‘imprecise and fluid’ nature and includes the related concepts of race and nationality.¹⁴ Although identifying any consideration of ethnicity for selection, we were primarily interested in ethnic minority groups, defined as ethnic groups residing in countries where they represented a minority population.

The key terms identified were examined to determine if they were mentioned in isolation or as part of a statement relating to ethnicity. Any statement relating to ethnicity was extracted. Data extraction was undertaken independently by two researchers. The text was scrutinized and the details of the population(s) studied were recorded, including the methods used to assess ethnicity, the presence of ethnic subgroup analyses and any recommendations made. A third reviewer checked for accuracy of extracted information.

Data synthesis

Data synthesis was carried out through a process of discussion and thematic analysis¹⁵ involving the three researchers. The statements extracted from the guidelines were firstly grouped according to shared meaning and/or concept and categorized under themes.

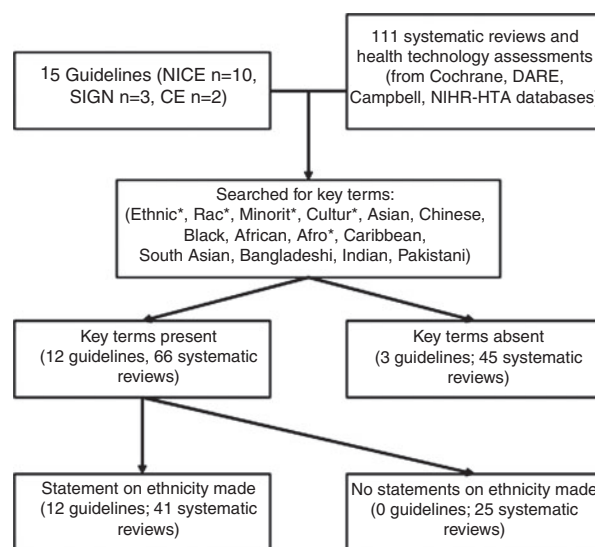


Figure 1 Identification of key terms and statements regarding ethnicity in UK guidelines and international systematic reviews

Following this, the statements from the systematic reviews were also extracted and organized under these themes.

Results

Summary of literature identified

We identified 15 relevant UK guidelines and 2399 international systematic reviews that were potentially of interest. In total, 15 guidelines and 111 systematic reviews met the inclusion criteria and were screened for key terms (Figure 1).

Of the 15 guidelines identified, 12 contained one or more key search terms, all of which were in the context of statements relating to ethnicity. Of the 111 systematic reviews identified, 66 (59%) contained one or more key search terms; however, of the 66 systematic reviews, in only 41 (62%) were these key terms in the context of statements relating to ethnicity. The remaining 25 systematic reviews contained the key term without any further information—for example, in a reference, table or figure. None of the 66 systematic reviews conducted subgroup analyses to pool ethnic-specific results and assess differential effect sizes according to ethnicity.

The statements from the guidelines and international systematic reviews are summarized in Tables, which can be accessed online. The statements from the 12 guidelines were grouped and five themes were identified (Table 1). No new themes emerged from statements extracted from the systematic reviews. Table 1 thereby represents statements from these two sources of evidence.

Theme 1: Acknowledging diversity

The guidelines and systematic reviews recognized ethnicity as an important factor in lifestyle interventions.^{r1,r2} There was acknowledgement of the variation in disease patterns and risk factors^{r1,r3–r5} between different ethnic groups,^{r1,r5} for example, smoking,^{r1,r6} stress,^{r1} physical inactivity^{r7,r8} and diseases such as obesity^{r9} and CVD,^{r4} and awareness that some health issues may in fact be unique to certain ethnic groups. Diversity in beliefs, values and attitudes were also identified (e.g. perceptions of weight and overweight)^{r9} and consequently the need to involve ethnic groups in formative work for interventions.^{r10}

Table 1 Generic statements regarding ethnicity from UK guidelines (encompassing the evidence from international systematic reviews) and the related themes

Generic statements	Themes
Importance of ethnicity in health Awareness of differential risks for/rates of disease and unique health risks Awareness of differing health beliefs, values and attitudes	Acknowledging diversity
Gap in/lack of the evidence reported on effectiveness of interventions according to ethnicity/ comparing different ethnic groups Gap in/lack of evidence on cost-effectiveness data on interventions for ethnic minority populations	Identifying evidence gaps
Awareness of varying effectiveness for recommendations and interventions according to ethnicity Some interventions and materials reach ethnic minority populations and demonstrate some effect or no clear evidence of effect Tools to assess risk should consider risk in terms of ethnicity	Observing differential effects of interventions
Awareness of a need to adapt interventions and services for ethnic minority groups and that adaptations may be effective for behaviour change Ensure interventions are appropriately adapted for psychological, social, cultural and economic determinants Examine how gender, age and SES intersect with ethnicity Ensure interventions are appropriately adapted by working with communities and families Address inequalities and avoid discrimination and stereotyping	Taking action to adapt interventions
Recommend better representation of ethnic minority populations in research, and the need for more research, due to increasing ethnic minority populations Recommend more syntheses of existing data and trends involving ethnic minority populations Recommend better data collection and reporting of 'differences in access, recruitment and uptake according to ethnicity'	Improving research design, analysis and reporting

Theme 2: Identifying evidence gaps

The second theme related to gaps in the evidence base for lifestyle interventions for ethnic minority populations. These gaps were discussed in terms of a lack of high-quality studies and randomized controlled trials^{r1, r6–r9, r11–r13} and a lack of studies examining whether intervention strategies known to be effective in the general population are also effective for ethnic minority populations (e.g. providing incentives^{r14, r15} and workplace^{r16, r17} intervention settings).^{r18, r19} Some reviews examined the reporting and analysis undertaken in studies according to ethnicity and found that there was a lack of inclusion of minority populations and, where they were included in studies, there was also often poor reporting and analysis of this.^{r2} Most reviews included studies that did not report results according to ethnic subgroups;^{r20} some included studies that statistically adjusted for ethnicity but did not analyse their results according to ethnicity;^{r21} while other reviews controlled for ethnicity as a moderating factor in their pooled analysis, but did not perform any subgroup analyses according to ethnicity.^{r22} Not surprisingly, considering the general lack of high-quality studies, there was also a major gap in evidence in relation to cost-effectiveness reported in the guidelines across all ethnic groups.^{r12, r13}

Theme 3: Observing differential effects of interventions

There was awareness of the differential effects of interventions with different ethnic minority groups and also across ethnic minority groups in various settings^{r2, r11–r13, r20, r23–r32} and contexts (e.g. different countries^{r5}). How recommendations for practice may impact the health of specific ethnic minority groups and how effective interventions are for the health of ethnic minority groups were generally not known or not reported.^{r11–r13, r29} Even within those populations where significant evidence has accrued, such as within the African American population in the USA, there was still a lack of clear evidence of effectiveness despite interventions and/or materials reportedly demonstrating increased reach and better utilization.^{r15} Some guidelines presented evidence of interventions

carried out in ethnic minority populations and reported mixed effectiveness, with no definitive conclusions.^{r13, r14, r25, r33} It was recommended that, in addition to interventions, there may also be differential effectiveness of the tools used to assess risk of ill health and that ethnicity should be taken into consideration when assessing risk (e.g. body mass index,^{r34} waist/waist circumference^{r1, r9} and blood pressure^{r1} measurements) to avoid inaccurate predictions.^{r1}

Theme 4: Taking action to adapt interventions

There was also awareness that action needed to be taken to address the gaps in evidence and to adapt interventions^{r6, r32, r35} and services^{r36} to be more appropriate for diverse populations and to produce interventions and services that are equally effective for all populations. Adaptations were discussed for ethnic minority groups^{r29, r37, r38} (e.g. language^{r9, r13, r36}) and it was suggested that adapted interventions may be effective for behaviour change.^{r3, r16, r33, r35, r39–r46} In addition to adapting for ethnicity, the guidelines suggested that interventions should examine how other factors such as gender,^{r10, r13} age^{r13} and SES intersect with ethnicity^{r12, r14} to affect health intervention achievement and influence health outcomes. Guidelines also suggested that interventions should adapt for psychological, social, cultural and economic determinants, recognizing the effects of the wider contexts of health in relation to lifestyle interventions for ethnic minority populations.^{r8, r12, r13, r17, r25, r47} Avoiding discrimination and stereotyping^{r12, r13, r20, r36} were other important considerations that were raised. The guidelines proposed that one way to approach adapting interventions was through working with communities and families (e.g. when conducting initial needs assessments and for addressing specific barriers to engagement),^{r3, r7, r9, r12, r13, r36, r48} but there was no more specific guidance identified on how to undertake the adaptation of interventions.

Theme 5: Improving research design, analysis and reporting

Improved representation of ethnic minority populations in research, along with more well-designed research studies, was recommended

as a response to increasing ethnic diversity.^{r1,r4,r15,r20,r35,r36,r40} It was suggested that research should focus on filling gaps in the evidence on, for example, effectiveness of physical activity and dietary counselling delivered in health care settings.^{r46} The need for research to address past and current levels of under-representation of, for example, African Americans and Asian Americans,^{r40} in studies for physical activity^{r49} and healthy eating was also emphasized.^{r20} It was recommended that ethnic minority groups should be proportionally represented in research in terms of their risk or rate of disease stemming from, for example, tobacco use.^{r36} Furthermore, better collection, analysis and reporting^{r2,r20,r31} of data were recommended, including the assessment of 'differences in access, recruitment and uptake (of interventions) according to ethnicity'.^{r12} Finally, more synthesis of existing data for ethnic minority health was also recommended,^{r9,r50} making use of the existing empirical studies and providing stronger evidence on which to base future interventions.

Discussion

Summary of main findings

This analysis of guidelines and systematic reviews developed for populations in general demonstrates that the available literature, even on health topics with recognized health inequalities, fails to provide evidence-based guidance on the extent to which lifestyle interventions are applicable to ethnic minority populations. Summarizing the extracted statements helped indicate the current state of the field and clearly demonstrated acknowledgment of a gap in the evidence, but little direction for those planning and implementing lifestyle interventions for ethnically diverse populations. This lack of specific guidance is likely to be a result of a gap in translating empirical evidence into major guidelines.

In systematic reviews where no studies were included with ethnic minority participants, it may be that such studies were not in existence or, alternatively, these were not considered of importance to the review question at hand. In systematic reviews including studies with ethnic minority participants, data from these studies may have been discounted from the systematic review for reasons of study quality or other issues, including, for example, the diversity of ethnic groups, the small number of ethnic minority participants and different outcome measures used, all of which may have prevented the pooling of ethnic-specific data.

The incorporation of expert opinion in guideline creation may have introduced the apparent greater consideration of ethnicity, and guidelines accordingly acknowledged this evidence gap. However, due to the lack of systematic review data, the guidelines remained unable to make recommendations as to whether interventions are effective for ethnic minority populations, or how to adapt them to increase effectiveness.

Generalizability

Our research, and search terms, focused on African-, Chinese- and South Asian-origin populations, which differ from the ethnic minority groups prominent in other European countries; however, we also included terms such as Minorit*, Rac*, Cultur*, Ethnic*, which meant that we identified statements relating to any ethnic minority group and therefore our findings and recommendations are likely to be relevant to all UK ethnic minority populations.

Strengths and limitations of the methods

A key strength was our systematic approach to assessing what consideration has been taken of ethnic minority populations in high-level evidence and recommendations. This approach remains a novel undertaking; while clinical guidelines have been examined in a comparable manner,¹⁶ we are not aware of similar undertakings

with preventive health guidelines or including international systematic reviews.

The guidelines were limited to the UK literature. However, the UK has well-established and respected guideline development procedures, which include the synthesis of international literature. To ensure international relevance, we supplemented our guideline-based searches with data derived from international systematic reviews.

We acknowledge that our search terms did not include 'immigrants' and 'refugees' and this may further limit generalizability. We also recognize the complex relationship between ethnicity and SES. SES was considered in some of the literature (see Theme 4), but it was not within the scope of this analysis to discuss in detail. We have, however, reflected on these broader contextual factors elsewhere.¹³

This review was part of a wider programme of work and so the period between the literature search (April 2009) and reporting means that some additional guidelines and systematic reviews are likely to have been published or updated since. An informal review of recent evidence, however, suggests that there has been little improvement over the intervening period.¹⁷⁻²⁰

Relationship of findings to existing knowledge

Ethnic inequalities in health are widely recognized and it is acknowledged that health care interventions have the propensity to generate, or widen existent, inequalities.^{11,12} Despite this, there is a lack of evidence to support interventions that consider ethnicity and can address inequalities.²¹ This situation is perpetuated by the fact that ethnic minority populations tend to be excluded from research,^{22,23} ethnicities are not consistently and comprehensively reported in trials,²⁴ ethnicity is inadequately considered in systematic reviews used to develop guidelines,²⁴ and therefore inequities, including those related to ethnicity, are rarely addressed in guidelines.²⁵

Accordingly, there is an increasing awareness of the need to capture the context of research, and how people's social environment, including ethnicity, may influence their health risks, the services they receive and their outcomes;²⁶ this includes the need to produce research syntheses and guideline recommendations, which incorporate considerations of equity and reducing health inequalities.²⁷ More transparent reporting and registration of systematic reviews should clarify the populations that they set out to include and the applicability of their findings;^{28,29} amongst current promising developments is the new equity extension for PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses), called 'PRISMA-E 2012'. For assessing strength of evidence, there are suggestions that Grading of Recommendations Assessment-based recommendations should be 'specific to populations and clinical, cultural and socio-economic settings'³⁰ and that, ultimately, guidelines should be generated from, and linked to, the intervention and population contexts in which they will be used to enhance their applicability.^{30,31} The World Health Organization,²⁵ Cochrane/Campbell Health Equity Group^{32,33} have also provided direction with the International Clinical Epidemiology Network creating an equity lens to use when developing clinical practice guidelines.³⁴

These documents tend to focus on socio-economically disadvantaged groups; however, they utilize overlapping dimensions²⁵ and frameworks³⁵ of equity that include ethnicity and propose the assessment of whichever dimensions are most salient in whichever context; more specific guidance on incorporating ethnicity within the research cycle is also emerging.³⁶

Nevertheless, in light of our findings, more action is required. As an example, the Appraisal of Guidelines Research and Evaluation Collaboration tool, AGREE, is specifically developed to assist guideline development, reporting and evaluation,³⁷ and underwent

considerable review and revision to create AGREE II.^{38,39} Despite revision, this tool does not consider diverse population subgroups and only includes the ‘applicability’ of interventions, which relates primarily to cost considerations. There are calls for AGREE to expand their ‘applicability’ item to include race/ethnicity and also to adopt a discrete item on equity.⁴⁰

How this work can influence future research and practice

We propose a four-pronged solution, which reflects a proposed shift in research paradigms to consider more contextual comprehensive perspectives²⁶ and includes (i) greater inclusion of ethnic minority populations in research; (ii) better design, evaluation and reporting of studies that include ethnic minority participants to provide ethnic group-specific data; (iii) the development of systematic reviews and guidelines, which incorporate the aim of searching for and synthesizing evidence of effective interventions for ethnic minority populations (with appropriate consideration of the methodological problems of subgroups analysis);^{25,35} and finally, (iv) the inclusion of considerations of equity, and more specifically ethnic diversity, in tools used to guide the systematic review and guideline development process.

Ethnic health inequities in chronic disease can then potentially be better addressed through the creation of an evidence-base to inform the design and delivery of lifestyle interventions that are effective for ethnic minority populations.

Ethics

Ethical approval for the whole body of work was sought and received from the University Of Edinburgh School Of Health in Social Science Research Ethics Committee; however, this component of the work did not require ethical approval.

Supplementary data

Supplementary data are available at *EURPUB* online. References for all citations preceded by ‘r’ are included in the supplementary material.

Acknowledgements

The authors thank Mark Deverill for his involvement in the oversight of the project on the Investigators Group; we also thank our Independent Project Steering Committee members, who provided helpful guidance and support throughout the project. In addition, we acknowledge the assistance of our project administrators for their contributions to this work and for their invaluable support.

E.D. and J.J.L. wrote the first draft of the paper; E.D., J.J.L., S.K., U.Y. and A.S. analysed the data; E.D., J.J.L., A.S., R.B., G.N., M.W., M.J., S.K. and U.Y. reviewed and edited the article.

A member of our Independent Project Steering Committee, who was not an author but had an advisory position as part of this committee during the project, was employed by NHS Health Scotland, who provided us with some funding for dissemination after the project was completed.

Funding

This project was funded by the National Institute for Health Research Health Technology Assessment Programme (HTA programme project number 07/63/03) and is published in full in Health Technology Assessment volume 16 number 44. Further information available at: <http://www.hta.ac.uk/1745>. Additional

funding to support dissemination was received from NHS Health Scotland.

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not reflect those of the NHS, the NIHR, MRC, CCF, NETSCC, the NIHR HTA programme or the Department of Health.

M.W. receives salary support from Fuse, the Centre for Translational Research in Public Health, which is funded by the British Heart Foundation, Cancer Research UK, Economic and Social Research Council, Medical Research Council and the National Institute for Health Research, under the auspices of the UK Clinical Research Collaboration (<http://www.esrc.ac.uk/about-esrc/what-we-do/our-research/ukcrc.aspx>).

No funding bodies had any role in study design, data collection and analysis, decision to publish or preparation of the manuscript.

Conflicts of interest: None declared.

Key points

- This presents a novel examination of how ethnicity is considered in guidelines and systematic reviews promoting lifestyle interventions
- We discovered a lack of consideration of ethnic minority populations in international systematic reviews and acknowledgement of this deficiency within UK guidelines
- Ethnic health inequities in chronic disease will be better addressed when there is evidence available to underpin policies and interventions that are effective for ethnic minority populations
- Tools which guide the practice of research, research synthesis and guideline development should include consideration of ethnicity and intervention context

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