



Publication title:

[Black and minority ethnic group involvement in health and social care research: A systematic review](#)

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Black and minority ethnic group involvement in health and social care research: A systematic review. Dawson S, Campbell SM, Giles SJ, Morris RL, Cheraghi-Sohi S. 15 August 2017 In: Health Expectations 2017; 00:1–20.

What was known before your paper was published?

Involving patients and members of the public in research is crucial and has received a lot of attention nationally but less so internationally. However, involvement is limited in scope, as patient and public involvement (PPI) activities do not reflect the diversity of the population. The lack of Black and Minority Ethnic (BME) involvement is clearly identified as an issue from the existing PPI literature in the area. This is the first review of BME-PPI in health and social care research. This review aims to:

1. Identify and assess relevant literature on BME-PPI in health and social care research
2. Identify any reported factors that may promote or inhibit BME-PPI in health and social care research.

What did you do?

We conducted a review of the published literature by searching electronic databases in order to characterise the studies which have looked at BME involvement in health and social care research. We also looked for any reported factors that would promote or inhibit their involvement.

What did you find?

In total, we found 45 studies focusing on BME-PPI in international health and social care research. 40 of the 45 studies were from North America focusing on African Americans and Aboriginal/indigenous populations. Of the remaining 4 studies, there were two each from UK and Australia. Involvement most commonly occurred during the research design phase and least in the data analysis and interpretation phase of the research process. Only 11 studies reported some of the factors that promoted or inhibited involvement.

Factors promoting BME-PPI include:

- compensation for recognition and contribution
- building trust and resolving conflicts gradually
- allocating time to understand PPI contributors' problems and concerns including discussion of health problems
- use of bilingual researchers, working closely with PPI contributors,
- improving trust and garner commitments
- having an open agenda to allow PPI contributors to voice concerns and explore culturally appropriate solutions.

Factors inhibiting BME-PPI include:

- cultural challenges
- lack of previous PPI experience and PPI contributors' reluctance to take responsibility
- concerns about the level of expertise and lack of understanding of how their involvement can build their skill set
- challenges in maintaining trust and avoiding distrust
- conflicts because of distrust and difference in priorities
- time commitment
- inadequate communication
- disregarding cultural beliefs and language
- friction as a result of budget cuts, leading to gaps in communication.

What insights/knowledge did you add?

This is the first systematic review characterising involvement of BME groups in international health and social care research. Overall, the evidence base is considered to be weak, as there is limited information on the nature and content of BME-PPI-related activities within health and social care studies. This requires further development in terms of understanding factors that influence BME-PPI, as opposed to involvement more generally, and how PPI can be made more inclusive.