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Title **Involving South Asian Patients in Clinical Trials**

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Aim

To extend knowledge of South Asian patients' understanding of trials, and of the processes which facilitate or inhibit their involvement in them.

Conclusions and results

Motivations for trial participation were identified as: to help society, to improve own health or that of family and friends, obligation to the doctor, and to increase scientific knowledge. Deterrents were identified as: concerns about drug side effects, busy lifestyles, language, previous bad experiences, mistrust, and feelings of not belonging to British society. There was no evidence of antipathy among South Asians to the concept of clinical trials, and younger respondents were more knowledgeable than older ones. Problems were more likely to be associated with service delivery. Lack of being approached was a common response. Lay-reported factors that might affect South Asian participation in clinical trials include: age, language, social class, sense of not belonging/mistrust, culture, and religion. Awareness of clinical trials varied among groups. Indian respondents were most likely to be aware, while less than half of the Pakistani and Bangladeshi respondents were aware of clinical trials. Attitudes toward clinical trial participation were more similar than different between South Asian and the general population. Important decisions, eg, clinical trial participation, were likely to be made by family members who were younger and fluent in English. Social class appeared to be more important than ethnicity. Older South Asians and those from working class backgrounds appeared to be more mistrustful. Approachable patients (same gender, social class, fluent in English) tended to be 'cherry picked' for clinical trials. This was justified because of inadequate time, resources, and support. South Asian patients might be systematically excluded from trials due to the extra cost and time associated with their inclusion, particularly in relation to the language barrier. Under-representation might also be due to passive exclusion associated with cultural stereotypes. Other characteristics such as gender, age, educational level, and social class can also affect trial inclusion.

Recommendations

Exclusion from trials is inequitable since evidence suggests that people who take part have better clinical outcomes. Unless South Asian people are routinely included in trials, the diseases they are disproportionately disposed to will remain poorly understood and treated. Excluding minority ethnic groups undermines the government's NHS plan to tackle inequalities. It is also important to sustain the widespread applicability of trial findings to the whole population. Excluding a sub-set of the population could have implications for the safety and efficacy of new drugs. Participation of minority ethnic groups in trials would help to reduce alienation and mistrust.

Methods

A review of the literature on minority ethnic participation in clinical trials was followed by 3 qualitative, semi-structured interview studies. Interviews were taped, transcribed (translated) and analyzed by framework analysis.

Further research/reviews required

Responses when invited to participate. Role of methodological and organizational barriers to recruitment. Complexities of recruitment from a health professional perspective. Developing culturally sensitive research methods. Magnitude of under-recruitment. Strategies to encourage inner city, single-handed GP participation. Other factors affecting trial inclusion eg age, gender, educational level, and sociocultural background.

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