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CANCER AND MINORITY ETHNIC GROUPS

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FOREWORD

The Department of Health has, through its Health of the Nation initiative, identified cancer as a key area for targeted improvements in morbidity and mortality rates. The Department is charged with seeking effective ways of achieving these targets among black and minority ethnic groups in England and has funded a number of projects to develop this area.

The Cancer Research Campaign has a broad and longstanding programme of research into all aspects of cancer. The Campaign's Education and Psychosocial Research Committee, in reviewing it's priorities, identified the needs of minority ethnic people as a neglected area. Hence discussions between the Department and the Campaign led to a jointly sponsored symposium to begin to set the agenda for the cancer research needs of minority ethnic groups in the UK.

A number of priorities and practical proposals emerged during discussions at the symposium and these are presented in the following pages.

It is the hope of both the Department and the Campaign that this publication will raise awareness of minority ethnic needs among the cancer research community, and of cancer issues among health care professionals, community workers and researchers from minority ethnic groups and that collaborations in some of the priority areas identified can be established. We see this publication as a starting point for establishing the research and development agenda on cancer and minority ethnic groups in England.

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DEDICATION

This publication is dedicated to the eminent epidemiologist Dr Calum Muir who died shortly after the symposium. A major research interest of his career was the study of cancer in different populations as a means of identifying causes and strategies for prevention.

EDITORS' NOTE

The symposium on Ethnic Minorities and Cancer which is reported here addressed four general areas: epidemiology, service provision, the community perspective and the future agenda. It was important to consider first of all such cancer statistics as are available for minority ethnic groups, in order to inform the following discussions. The editors recognise that there are difficulties with some of the data presented, due to small sample sizes, inexact classification etc., but this illustrates precisely why the topic of the symposium is so urgent. Good baseline data are essential in order to plan for effective service provision. Service uptake (including education) will be strongly influenced by the beliefs and attitudes held by the various minority ethnic groups, hence the need to consider the community perspective. Finally, participants at the symposium discussed briefly how the many issues identified throughout the day could be taken forward.

The views expressed by contributors are their own and do not necessarily represent the views of the Cancer Research Campaign or the Department of Health.

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SUMMARY OF RECOMMENDATIONS

1. Cancer Statistics

i) A workshop of cancer epidemiologists should be held to identify ways of improving cancer data relating to minority ethnic groups in the light of issues raised in this symposium.

ii) At present, ethnic data are only collected in hospital records. These data should be extended to primary care records, so that uptake of screening etc. may be properly monitored.

2. Research

i) A number of research gaps were identified at the symposium:

- perceptions of health and disease among different ethnic communities
- appropriate methods for delivering effective cancer education to people from minority ethnic groups
- the natural history of cancer among minority ethnic groups
- appropriate methodology for evaluating the outcomes of cancer treatments for different groups, including quality of life and other psychosocial outcomes
- ii) A series of critical literature reviews should be funded, to draw together existing research findings.
- iii) Statutory and voluntary research bodies should take steps to redress the under-representation of minority ethnic interests in their programmes and on their committees

3. Training

Training for health professionals at all levels should include communications skills and awareness of ethnic concerns, in terms both of sensitivity to cultural differences and needs, and of racism at the institutional and individual level.

4. Health Policy

A workshop should be held to identify how existing government policies relating to cancer (such as *Health of the Nation* and the report *A Policy Framework for Commissioning Cancer Services*) can be adapted to address minority ethnic issues. The workshop should also seek to develop a model for incorporating such issues from the outset when policies are being formulated.

TERMINOLOGY

Wherever possible in the following papers and reports of discussions the precise ethnic identity of the people referred to is specified or enough information is given for the reader to infer this. However, where studies are quoted which have used non-specific, inappropriate or even unacceptable terms, these terms are retained because of the difficulty in assigning more concise definitions and because of the danger of misrepresenting the authors' intentions. The editors have deemed it preferable to ensure that research findings are reported as accurately as possible than to impose their own best guess as to which groups of people are being referred to.

The editors recognise the following preferred generic terms for people of different ethnic backgrounds in England:

Black and minority ethnic people (groups/communities)	
South Asian	people whose ancestry is in the Indian sub-continent ¹
East Asian/ South East Asian	people from the Far East ² /South East Asian countries respectively
African Caribbean	people of African descent from the Caribbean
African	people whose ancestry is in the African continent
White	people from the majority population whose ancestry lies in Europe (unless
	specified, may include minorities such as Irish)

The editors recognise the limitations of these generic terms and that clasification by ethnic origin remains an imprecise art. In studies, individuals should be asked to assign themselves to the group they feel is most appropriate.

¹ Indian subcontinent: including India, Pakistan, Nepal, Bangladesh, Sri Lanka

² Far East: China, Japan etc.

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