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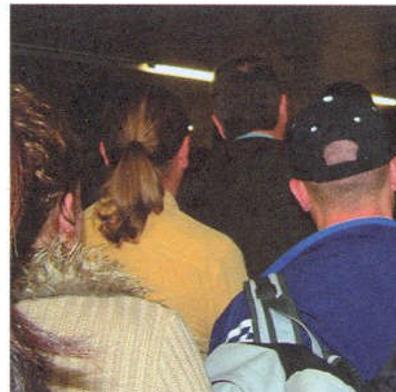
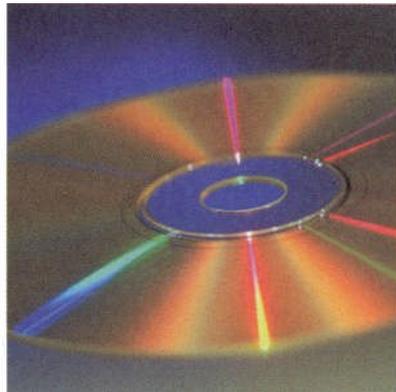
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Equity of access to NHS cancer services
for members of minority ethnic groups:
Report of findings of surveys of hospital
medical and nursing staff at the Royal
Marsden Hospital



**Peter J Aspinall, Ann Ward and
Elizabeth N Anionwu**

**Centre for Health Services Studies
University of Kent**

April 2002

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by

Peter J Aspinall, Ann Ward and Elizabeth N Anionwu

April 2002

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The Research Team

This is a collaborative study involving Peter J Aspinall (PJA), Senior Research Analyst in Public Health at the Centre for Health Services Studies (CHSS), University of Kent at Canterbury, Ann Ward (AW), Research Nurse at the Royal Marsden Hospital, and Elizabeth N Anionwu (ENA), Professor at Thames Valley University. The main duties and responsibilities of the team were as follows: ENA submitted periodic progress reports to the Project Director. PJA wrote the application for funding, designed the study and study instruments (including questionnaires based on a systematic review of the literature on ethnicity and cancer), wrote the research protocols for focus groups and other tasks, prepared the applications for the Clinical Committee for Research and Research Ethics Committee, and represented the project at these meetings as Principal Investigator and in collaboration with Ms. Shelley Dolan, Consultant-in-Charge. All members of the team (PJA, AW, and ENA) were involved in focus groups with doctors and nurses as facilitator, note-taker, or observer. The sampling frames for the study were compiled by AW from staff lists supplied by the Hospital's Human Resources Department, enhanced by other locally held information and enquiries. AW also prepared mailing lists for all stages of the study (focus groups, pilot and main studies) based on random number samples drawn by PJA. Mail-outs of the questionnaires were undertaken by PJA (pilot), AW (nurses' main study), and PJA and ENA (doctors' main study). AW undertook the first and second mail follow-ups of non-responding doctors and nurses, supplemented by telephone and in-person contact.

All questionnaires were mailed back to CHSS, where PJA copied/electronically scanned them, logged responses on an Excel database, and mailed originals to AW. AW established and maintained the Project's main Excel database of responses at the Royal Marsden Hospital, from which she prepared response rate reports. AW also entered into an Excel database all free-text responses on the completed questionnaires and was substantially responsible for undertaking the project's day-to-day administration. PJA coded the questionnaire data, entered it into the SAS System (SAS Institute Inc.), undertook quality/range checks, wrote the analytical specification, undertook the data analysis and free-text coding, and wrote the report.

Peter J Aspinall

Principal Investigator

Freedom Day 2002

Executive Summary

1. *The NHS Cancer Plan* draws attention to the inequity of access to cancer services for members of minority ethnic groups, according importance to such matters as culturally-sensitive information and different approaches to giving information. The Department of Health's latest *Cancer Services: Update* states that 'to improve the experience of patients from an ethnic background' is a significant area of risk within the development of cancer services. Again, improving access and providing information and more informed choice to ethnic minority communities is identified as a priority.
2. This research study focuses on one particular dimension of access: the attitudes of hospital medical and nursing staff to inequity of access to NHS cancer services for members of minority ethnic groups.
3. Postally-administered questionnaire surveys for hospital doctors and nurses achieved overall response rates (omitting exclusions) of 52% and 69%, respectively (valid responses, 44 and 55%, respectively).
4. 16% of doctors and nurses thought that patients from minority ethnic groups usually or sometimes presented with disease at a more advanced stage than the general population. Research is needed to establish whether members of minority ethnic groups are diagnosed in later disease stages than other patients, after controlling for socio-economic status and other confounding factors.
5. While only 5% of nurses and doctors thought that clinicians were less willing to recruit members of minority ethnic groups into clinical trials compared with other patients, 16% of doctors and 12% of nurses thought that members of minority ethnic groups were not as willing to participate in clinical trials. Significant proportions of doctors and nurses had greater concerns (compared with other patients) with respect to obtaining informed consent, fulfilling safety requirements, and ensuring follow-up. Linguistic and cultural constraints upon the participation of members of minority ethnic groups in cancer trials were identified by respondents. The extent to which ethnic minorities are excluded from trials requires investigation.
6. Between a quarter and a third of respondents perceived their gender as a barrier in treating/caring for members of minority ethnic groups, especially with respect to Muslim and Asian women and Arab/Middle Eastern men. 10% of nurses found their ethnicity a barrier.

7. Around a half of responding doctors and two-fifths of nurses reported that members of minority ethnic groups had different beliefs about the cause of their cancer, relating mainly to religious ideation, cultural beliefs, and superstitions. A smaller proportion, around a quarter, thought that the beliefs of members of minority ethnic groups had ever been a barrier to care or treatment, the barriers again being embedded within the particular beliefs and cultures of the groups.
8. Over three-fifths of nurses reported that their experience of discharge planning for members of minority ethnic groups had been different to that for other patients, mainly with respect to the greater family input amongst ethnic minority patients.
9. With respect to factors identified in the *NHS Cancer Plan* as referring to ethnic variations in the incidence of cancers, hospital medical staff (unlike nursing staff) accorded greater importance to traditional 'medical' factors as compared with service-related factors.
10. Significant proportions of doctors and nurses (44% and 32%) thought that members of minority ethnic groups were less likely to seek a second opinion, although smaller proportions (15% and 5%, respectively) thought that they were less likely to receive 3rd/4th line salvage treatments, both views that had been expressed in focus groups.
11. A very high proportion (70%) of respondents agreed with the statement that 'amongst minority ethnic groups, the patient's family assumes a greater role in caring for the patient than is the case in the general population'. This is a stereotypical view about which the Department of Health has expressed concerns with respect to service provision.
12. Around a third of doctors and nurses felt that members of minority ethnic groups were less likely to request information/advice than other patients and significant proportions (10% of doctors and 18% of nurses) thought that members of minority ethnic groups were less likely to be provided with information/advice. Again, significant proportions of doctors and nurses (22% and 37%, respectively) reported that information was not available in other languages. These findings are of concern, given the demonstrated importance of information and communication in helping people to cope with cancer and the commitment to such provision in *The NHS Cancer Plan*.
13. Around 87% of doctors and nurses had found communication difficulties arising from language a barrier to treatment or care of patients from minority ethnic groups. High proportions of respondents reported use of a child in the patient's family, another member of the patient's family, a friend of the patient, and a member of the hospital staff (not an interpreter). Interpreting,

translation, and advocacy are all extremely scarce resources in the NHS and it is clear that patients needs must be met in this area.

14. An overwhelming proportion of doctors (85%) and nurses (76%) reported that culturally sensitive written information was not available. Again, this is a matter for concern, given *The NHS Cancer Plan's* specific requirement that all NHS Trusts must make available high quality information to all cancer patients that is culturally sensitive and specific to local provision of services.
15. A fifth of respondents thought that members of minority ethnic groups had poorer access to screening and other preventive services, the most frequently suggested improvement being the provision of information in appropriate languages in community and other settings and better interpreting services. Importance was also accorded to community outreach.
16. Around 16% of doctors and nurses did not feel that members of minority ethnic groups had equitable access to cancer services in general. The most frequently mentioned barriers to access were language barriers and lack of knowledge of service availability. The language and literacy skills of the patient (and patient's difficulties in travelling to the hospital) were, again, most frequently identified as reasons for difficulty in accessing services in a given list of possible barriers.
17. 5% of doctors but 11% of nurses felt that members of minority ethnic groups did not receive the same quality of care as other patients, once again language and communications barriers being the main issue.
18. Amongst respondents the most frequently mentioned single measures thought to most contribute to improving access for members of minority ethnic groups were also improved access to written information in a variety of languages, better access to interpreting and translating services, more culturally sensitive information, and wider use of staff from minority ethnic groups in a range of roles.

1. INTRODUCTION

Access has been defined as 'the timely use of affordable personal health services to achieve the best possible health outcomes' (Millman 1993). Studies of access to medical care frequently draw upon behavioural models of access such as those developed by Andersen (1968, 1995) and Aday *et al.* (1980). In these models the process of gaining access to care is represented as dynamic interactions of diverse individuals in their social context interfacing with health care providers who are operating within variable medical care structures and environments. These models usually include both primary care providers as an important source of care for cancer patients and referrers to secondary care (and possibly as responsible for initiating screening services) and secondary care providers. Secondary care providers may be hospitals of first referral or tertiary centres. Within these models are patient-provider and provider-provider communications as key components of the model. Some of these models have been elaborated to include 'realized access' to care, comprising not just utilisation and satisfaction but all outcomes of care. These models can be applied to evaluating access to cancer care.

This study focuses on only one dimension of these models, the Royal Marsden Hospital as a cancer care provider (a hospital of first referral for breast cancer and a tertiary treatment centre for other cancers in the SW London Cancer Network). The attitudes and perceptions of hospital medical and nursing staff to issues of equity of access to cancer services for members of minority ethnic groups are assessed using a postally administered questionnaire schedule. In other work an attempt has been made to assess such equity of access using hospital episode statistics for inpatient admissions but poor ethnic coding in the other hospitals in the network has precluded such an approach. The third of the Department of Health's Patient and User Experience Surveys (as announced in the Department's *A First Class Service*) focuses on patients with cancer treated in hospital, including their first hospital treatment, their current hospital visit, experience of leaving hospital, and outpatient appointments. The collection of information on ethnic group and language spoken most often at home may enable analysis to be undertaken through a customised dataset for broad ethnic groups for the SW London Cancer Network, once the main findings have been published in 2002. This would provide the patient perspective that could not be addressed in the current work.

The way in which health care professionals perceive equity of access issues for members of minority ethnic groups is an issue of major importance for the appropriate and effective delivery

of cancer services to these groups. In the mid-90s a symposium on cancer and minority ethnic groups, held under the auspices of the Cancer Research Campaign and the Department of Health (1996) identified a number of research gaps. These included 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, and appropriate methodology for evaluating the outcomes of cancer treatments for different groups, including quality of life and other psychosocial outcomes. The symposium also recommended that 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. The findings of the survey inform several of these research and training issues.

Since the symposium, the Department of Health has published *The NHS Cancer Plan (2000)* which makes a number of references to minority ethnic groups. *The Plan* reports wide variations in cancer incidence and mortality related to birthplace, mortality rates for lung cancer being lower in groups born in the Caribbean, Asia and Africa and higher in people born in Scotland and Ireland. Deaths from cervical cancer are more common in women born in the Caribbean. *The Plan* also offers several reasons for these inequalities, including genetic factors, different levels of exposure to key risk factors (notably smoking and drinking), lower awareness of the symptoms of cancer in some social groups, later presentation to GPs, lower uptake of screening services, and unequal access to high quality services. Smoking prevalence is reported to be particularly high in Bangladeshi men (45%) and African Caribbean men (32%), £1 million being allocated for smoking cessation work with black and minority ethnic groups. With respect to tackling inequalities, *The Plan* requires all PCTs to review their own screening coverage rates and where necessary draw up plans to increase the accessibility of screening among deprived and minority ethnic groups as part of their Health Improvement Programmes. It states that people from minority ethnic groups have particular needs, with evidence to suggest that women from these groups do not come forward for breast and cervical screening. It suggests that culturally-sensitive information and different approaches to giving information can often improve the accessibility of screening to these groups, issues directly addressed in the survey. On support for patients and carers, *The Plan* addresses information needs, requiring 'all NHS Trusts and cancer networks...to make available high quality information...to all cancer patients. Information must be culturally sensitive and specific to local provision of services, as well as information about the type of cancer and treatment options'. Finally, *The Plan* reports 'that black and minority ethnic

communities and socially deprived communities have reduced access to palliative care services' and that 'patients from these groups are unlikely to take up services, which are culturally unsuitable or are delivered in an insensitive way'. The Plan allocates a total of £23.25 million via the New Opportunities Fund for the Living with Cancer initiative, funds exclusively aimed at providing palliative care, home support, support for carers and information about cancer and cancer services to black and minority ethnic communities and socially deprived groups.

The October 2001 *Cancer services update* reports that, in a critical review of progress being made in achieving the Modernisation Programme across all areas of health care, including cancer, of a number of priority concerns identified only one project - 'To improve the experience of patients from an ethnic minority background' - reflected a significant area of risk within the development of cancer services. The HIMP cancer chapter intends to support the achievement of this project through its continued development of primary and community care cancer services. New cancer and palliative care services, currently funded through the Health Action Zone (HAZ) and New Opportunity Funding (NOF), are specifically targeted at improving services to patients living within ethnic minority communities. With respect to health inequalities, the *Update* finds that there are still real inequalities in terms of who develops cancer and what happens to them when they do. It finds that in cities these groups of people are mainly from the ethnic minority communities and unskilled workers and, while the former appear to have a lower than average rate for developing cancer, they are more likely to not attend screening programmes and/or to delay seeing their GP. Their outcomes therefore, tend to be significantly poorer. The HIMP seeks to reduce these health inequalities by developing services within the primary care sector that improve access and provide information and more informed choice to ethnic minority communities and socially disadvantaged groups. According to the *Update*, a range of pump primed innovative projects led by general practitioners, primary care organisations, community services, the local hospice, and voluntary organisations, has already commenced with permanent funding for successful initiatives.

Again, the survey provides findings relevant to several of these objectives, especially the provision of information that must be culturally sensitive and specific to local provision of services. The identification of the improvement of the experience of patients from an ethnic minority background as a significant area of risk within the development of cancer services places the timeliness and findings of this survey centre stage.

2. METHODS

At the start of the study a number of research methodologies were explored, including nominal groups, focus groups, in-depth interviews administered face-to-face, and questionnaire surveys. The decision to use a structured interview schedule postally administered and mailed back was based on the resources available to the study. During the initial month of the study searches were undertaken on some 20 databases (including generic databases like *Medline* and *Embase*, specialist databases like CANCERLIT, and ethnicity databases such as CRER) using text word searches, thesaurus terms, and boolean algebra. Some 60 papers were selected as relevant to the study, procured through the BL paper acquisition service, and information extracted that was relevant to the themes to be covered in the questionnaire. On the basis of this research synthesis a list of topics was prepared and subsequently used in the preparation of questionnaire schedules for doctors and nurses.

The first of the topics included was doctor and nurse characteristics, such as gender, age, ethnicity, specialty, and years in specialty or years worked as a nurse, all of which have been mentioned as potential barriers to optimal cancer screening and treatment services. The section on patients treated from minority ethnic groups focussed on a number of issues including the important issue of stage at diagnosis and staging evaluation and involvement of minority ethnic groups in clinical trials. A third section covered experience of barriers to treatment/care of minority ethnic groups (including physician gender, age and race/ethnicity barriers) and the extent to which patients' beliefs and views about the cause of cancer might be a barrier. The fourth section of the survey listed some 11 statements drawn from the literature - for example, the literature suggests that the belief that religious faith is an alternative to medical care can act as a barrier to needed care (Womeodu *et al.*, 1996) - and sought the strength of the respondent's agreement with them. A fifth section focussed specifically on communication with members of minority ethnic groups. A final section on global views with respect to access to services was included.

Focus groups whose members were selected on a random basis (using random number tables) were held with 6/7 doctors and the same number of nurses according to a written protocol. Based on a transcript of proceedings and note-taking, three or four additional questions were added to

the questionnaire schedules. These schedules were then piloted with 12 doctors and 12 nurses randomly selected from the study's sampling frame and no changes made to their content.

Estimates of the number of hospital doctors and nurses that would be included in the initial mail-out were determined by the resources of the study and its timescale and statistical considerations. An initial decision was taken to sample all medical staff and to take a 2 in 5 sample of nurses (later revised to 0.5), with an anticipated response of 120 doctors and 120 nurses. The intention was to apply the results to the staff of the Royal Marsden Hospital only, as opposed to making inference beyond that hospital. With respect to analysis, the intention was (1) to estimate various attributes relating to each staff group and (b) compare between staff groups. The main statistics that would be used would be proportions. Given that a complete census of hospital doctors was being undertaken, any attributes of this group would be estimated without sampling error. For the nurses, it was agreed to estimate the attributes with 95% confidence intervals. For attributes with the following percentage levels, the following confidence intervals (and their widths) are given below, assuming a finite population with a sampling fraction of 40%.

<i>Proportion</i>	<i>Confidence interval</i>	<i>CI width</i>
10%	6 to 14%	8%
20%	14 to 26%	11%
30%	24 to 36%	13%
40%	33 to 47%	14%
50%	43 to 57%	14%

Such precision is adequate for the purposes of the study. That is, an observed 10% amongst nurses implies a relatively small true rate, an observed 30% amongst nurses implies a true proportion at a moderate level, and an observed 50% amongst nurses implies a relatively high true rate. The above table can be used for judging the ability to pick up differences between the nurses and the medical staff. If the confidence interval for the nurses includes the estimate for the medical staff, then there is no statistically significant difference at the 5% level. Thus, for low percentages it should be possible to detect around a 4% difference, for moderate percentages around 6%, and for percentages of around 50% about a 7% difference.

The sampling frame for the study was based on a staff listing provided by the Hospital's Human Resources Department, enhanced and validated by internal sources such as e-mail listings,

resulting in a total of 228 medical staff. This number compares with 208 staff (186.4 whole time equivalents) on the Department of Health's Medical & Dental Workforce Census, 2000, and 183 medical/dental staff in post at 31 March 2000 in *The Royal Marsden Annual Report, 1999/2000*¹. It is possible that some radiologists, histopathologists, and scientific staff were included in the sampling frame. Moreover, doctors in the registrar group are fairly mobile and it is clear that there was attrition from the sampling frame during the course of the study. A total of 91 responses were received from doctors. This represents an overall response rate of 40% and a valid response rate (completed questionnaires) of 34%. If exclusions are removed, the overall response rate was 52% and the valid response was 44%.

Survey response rates

	<i>Doctors</i>	<i>Nurses</i>
	Sample: 228 (100%)	Sample: 254 (50%)
Questionnaires returned completed	77	115
Declined participation/not completed	14	29
No reply	78	66
<i>TOTAL</i>	<i>176</i>	<i>210</i>
<i>Exclusions¹</i>		
Ineligible: PP Unit:2; X-ray: 5	7	19
Not delivered/left RMH since survey	41	25
<i>TOTAL</i>	<i>48</i>	<i>44</i>

1. Reasons for exclusions include: doctors, not clinical post, 1; nurses, PP post only, 13, bank staff only/occasional hours, 2, not clinical post, 1, has insufficient MEGp contact, 1, ineligible care assistant, 1, and ineligible on maternity leave for 1 yr+.

With respect to nurses, a sampling fraction of 0.5 was used, resulting in 254 eligible respondents. The 508 nursing staff on the sampling frame compares with 491 nursing staff (in post at 31st March 2000) reported in *The Royal Marsden Annual Report, 1999/2000*. The NHS and Community Health Services Non-Medical Workforce Census as at 30 September 2001 recorded 481 whole time equivalents and a headcount of 533 for nursing, midwifery, and health visiting staff and 463 and 513, respectively, for *qualified* nursing, midwifery, and health visiting staff. A total of 144 responses were received from nurses. This represents an overall response rate of 57% and a valid response rate of 45%. If exclusions are removed, the overall response rate was 69%

¹ The Annual Report also records 198 scientists, therapists, and radiologists and 128 laboratory and pharmacy staff.

and valid response 55%. Such response rates are acceptable for a postally administered questionnaire in a tertiary hospital setting.

These response rates were achieved using two mail follow-ups, supplemented by telephone, e-mail and in person contact.

Data was entered into the SAS System (SAS Institute Inc.), quality/range checks undertaken, an analytical specification prepared, and data analysis undertaken using mainly listing and cross-tabulation functions. All free-text was entered into a proprietary database by questionnaire number and incorporated as descriptive text and aggregates in the report.

3. RESULTS

3.1 Respondent Profile

3.1.1 Gender

Sex of respondents

	<i>Frequency</i>	<i>%</i>	<i>Cum %</i>
	Doctors		
<i>Male</i>	54	70.1	70.1
<i>Female</i>	23	29.9	100.0
<i>Total</i>	77		
	Nurses		
<i>Male</i>	4	3.5	3.5
<i>Female</i>	110	96.5	100.0
<i>Total</i>	114		

Frequency missing, Nurses: 1

70.1% of medical staff respondents were male and 29.9% female. The overwhelming majority (96.5%) of nursing staff were female.

3.1.2 Age

Age of respondents

<i>Age group</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
20-25	0	0.0	1	0.9
25-29	5	6.5	27	24.3
30-34	16	20.8	21	18.9
35-39	22	28.6	17	15.3
40-44	6	7.8	23	20.7
45-49	6	7.8	10	9.0
50-54	12	15.6	4	3.6
55-59	9	11.7	6	5.4
60-64	1	1.3	1	0.9
65+	0	0.0	1	0.9
<i>Total</i>	77	100.0	111	100.0

Frequency missing, Nurses: 4

Almost half the medical staff respondents were in the age group 30-39. Somewhat fewer nurses (34.2%) were in this age group with a substantially larger proportion (a quarter) in the <30 age group.

3.1.3 Ethnic group

Ethnic group of respondents

<i>Ethnic group</i>	<i>No.</i>	<i>%</i>	<i>Cum %</i>	<i>No.</i>	<i>%</i>	<i>Cum %</i>
	Doctors			Nurses		
<i>White British</i>	44	57.1	57.1	75	65.8	65.8
<i>White Irish</i>	6	7.8	64.9	14	12.3	78.1
<i>White Other</i>	13	16.9	81.8	9	7.9	86.0
<i>Mixed</i>	1	1.3	83.1	3	2.6	88.6
<i>Indian</i>	6	7.8	90.9	2	1.8	90.4
<i>Pakistani</i>	2	2.6	93.5	0	0.0	90.4
<i>Other Asian</i>	1	1.3	94.8	1	0.9	91.3
<i>Black Caribbean</i>				1	0.9	92.2
<i>Black African</i>	1	1.3	96.1	6	5.3	97.5
<i>Chinese</i>	2	2.6	98.7	2	1.8	99.3
<i>Any Other</i>	1	1.3	100.0	1	0.9	100.0

Frequency missing, Nurses: 1

There was a somewhat higher proportion of minority ethnic group doctors (18.2%) compared with nurses (14%).

3.1.4 Grade

<i>Grade</i>	<i>No.</i>	<i>%</i>
Doctors		
<i>Consultant</i>	41	53.2
<i>Staff Grade</i>	1	1.3
<i>Registrar Group</i>	29	37.7
<i>Senior House Officer</i>	4	5.2
<i>Clinical Assistant</i>	2	2.6
Nurses		
<i>Grade C</i>	2	1.8
<i>Grade D</i>	6	5.3
<i>Grade E</i>	38	33.6
<i>Grade F</i>	22	19.5
<i>Grade G</i>	28	24.8
<i>Grade H</i>	14	12.4
<i>Grade I</i>	3	2.7

Frequency missing, Nurses: 2

Over half of the medical staff respondents were consultants (53.2%) and a further 37.7% in the Registrar Group.

Consultants were over-represented compared with the Registrar Group, consultants comprising 31.7% of all medical staff and the Registrar Group 49.5% in the Department of Health's Medical and Dental Workforce Census of 2000.

The overwhelming proportion (77.9%) of nurse respondents were grade E, F or G.

3.1.5 Specialty

As might be expected most of the respondents worked in oncology specialties.

3.1.6 Years worked in specialty (medical staff) or as a nurse (nursing staff)

<i>No. of years</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>0-4</i>	18	23.4	10	8.7
<i>5-9</i>	20	26.0	20	17.4
<i>10-14</i>	11	14.3	23	20.0
<i>15-19</i>	6	7.8	17	14.8
<i>20-24</i>	10	13.0	23	20.0
<i>25-29</i>	7	9.1	9	7.8
<i>30-34</i>	5	6.5	9	7.8
<i>35-39</i>	0	0.0	1	0.9
<i>40-44</i>	0	0.0	3	2.6
<i>Total</i>	77	100.0	115	100.0

Around half of the medical staff respondents had worked in their specialty for <10 years. Around a further fifth had so worked for between 10 and <20 years. In contrast, around only a quarter (26.1%) of nurses had worked in their profession for <10 years. Over half the responding nurses (55%) had worked as nurses for between 10 and 24 years.

3.1.7 Years worked at the Royal Marsden Hospital

<i>No. of years</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>0-4</i>	38	49.4	63	54.8
<i>5-9</i>	15	19.5	16	13.9
<i>10-14</i>	7	9.1	13	11.3
<i>15-19</i>	10	13.0	8	7.0
<i>20-24</i>	7	9.1	10	8.7
<i>25-29</i>	0	0.0	4	3.5
<i>30-34</i>	0	0.0	1	0.9
<i>Total</i>	77	100.0	115	100.0

About half the medical staff sample had worked at the Royal Marsden Hospital for between 0.3 and 4 years and a further fifth for between 5 and <10 years. Under a third (31.2%) had worked at the Royal Marsden Hospital for 10 years or longer. A similar proportion of nurse respondents

(55%) had worked at the Royal Marsden Hospital for <5 years and a further 11% for between 5-9 years.

3.1.8 Tumour groups in which medical and nursing staff see patients

<i>Tumour group</i>	<i>Frequency</i>	<i>% of mentions</i>	<i>Frequency</i>	<i>% of mentions</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Breast</i>	39	12.7	66	11.8
<i>Lung</i>	29	9.4	58	10.4
<i>Colorectal</i>	26	8.5	57	10.2
<i>Upper gastro-intestinal</i>	25	8.1	55	9.9
<i>Urological</i>	26	8.5	59	10.6
<i>Gynaecological</i>	29	9.4	62	11.1
<i>Head & neck</i>	24	7.8	40	7.2
<i>Skin</i>	25	8.1	40	7.2
<i>Haemato-oncological</i>	31	10.1	57	10.2
<i>Neuro-oncological</i>	22	7.2	38	6.8
<i>Paediatric cancers</i>	21	6.8	18	3.2
<i>Other</i>	10	3.3	8	1.4
<i>TOTAL</i>	<i>307</i>	<i>100.0</i>	<i>558</i>	<i>100.0</i>

Most tumour groups were well represented amongst the medical and nursing staff respondents, the most frequently mentioned being breast (12.7% of all mentions for doctors and 11.8% of all mentions for nurses) and the least frequent paediatric cancers (6.8% for doctors and 3.2% for nurses).

3.2. Patients treated from minority ethnic groups

3.2.1 Minority ethnic patients treated in last 12 months

Respondents were asked about how many patients from ethnic minority groups they had treated (in all hospital settings) in the past 12 months. The numbers varied from nil to almost 1000 in the case of hospital medical staff and from 1 to 1400 in the case of hospital nursing staff. Over a half of medical staff respondents (56.5%) reported that they had treated <50 patients from minority ethnic groups and a further quarter (26.0%) 100 or more such patients. By contrast, two-thirds of hospital nursing staff (66%) reported that they had treated <50 patients from minority ethnic groups but a similar proportion (23.4%) 100 or more such patients.

<i>Minority ethnic group patients treated in last 12 months</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<10	5	7.2	17	15.9
10-19	8	11.6	21	19.6
20-49	26	37.7	33	30.8
50-99	12	17.4	11	10.3
100-250	15	21.7	16	15.0
250+	3	4.3	9	8.4
<i>Total</i>	<i>69</i>	<i>100.0</i>	<i>107</i>	<i>100.0</i>

Frequency missing: Doctors, 8; Nurses, 8.

3.2.2 Groups patients belonged to

<i>Ethnic group</i>	<i>Frequency</i>	<i>% of respondents</i>	<i>Frequency</i>	<i>% of respondents</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Black (-Caribbean, -African, -British)</i>	73	96.1	107	95.5
<i>South Asian (Indian, Pakistani, Bangladeshi)</i>	75	98.7	107	95.5
<i>Chinese</i>	51	67.1	56	50.0
<i>Other</i>	21	27.6	39	34.8

Frequency missing: Doctors, 1; Nurses, 3.

Almost all medical and nursing staff respondents reported that they had treated patients from Black and South Asian groups but around only two-thirds of doctors and just a half of nurses in the case of Chinese.

3.2.3 Numbers of ethnic minority patients treated compared with expectations

	<i>Frequency</i>	<i>% of respondents</i>	<i>Frequency</i>	<i>% of respondents</i>
	Doctors		Nurses	
<i>More</i>	1	1.4	7	6.5
<i>About right</i>	49	70.0	55	50.9
<i>Less</i>	20	28.6	46	42.6

Frequency missing: Doctors, 7; Nurses, 7.

Respondents were asked if, from their personal knowledge and experience, the number of ethnic minority patients treated was more, about right, or less than expected. Of the hospital medical staff respondents, 1.4% reported that the number was more than expected, 70% that it was about right, and 28.6% less than expected. A much higher proportion of hospital nursing staff (43%) reported that the number of ethnic minority patients they had cared for was less than expected. Although such perceptions are intuitive, the fact that over a quarter of doctors and two-fifths of nurses reported that the number was less than expected *may* be indicative of under-utilisation *at this trust* (although ethnic minority patients may be utilising the services of other trusts in terms of access across the network).

3.2.4 Stage of cancer at presentation

Respondents were asked if patients from minority ethnic groups that they treated presented with disease at a different stage to that in the general population.

<i>Stage at presentation</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
Usually more advanced	3	4.0	6	5.3
Sometimes more advanced	10	13.3	12	10.5
Occasionally more advanced	17	22.7	21	18.4
Same as general population	29	38.7	41	36.0
Less advanced	0	0.0	1	0.9
Unsure	16	21.3	33	28.9
<i>Total</i>	75	100.0	114	100.0

Frequency missing: Doctors, 2; Nurses, 1.

Around two-fifths of the hospital medical staff respondents thought that patients from ethnic minority groups presented with disease at a same stage to the general population and a slightly smaller proportion of nurse respondents so reported. However, 23% of doctors reported that disease was occasionally more advanced, 13% sometimes more advanced, and 3% usually more advanced in patients from minority ethnic groups, compared with 5%, 11%, and 18%, respectively, of nurses. Over one-fifth of medical staff respondents but almost three-tenths of nurse respondents were unsure. Again, these findings in both doctors and nurses may be

indicative of a greater frequency of presentation at a later stage in minority ethnic groups but they are perceptions and therefore can be considered only as indicative evidence.

Only 11 of the hospital medical staff respondents who replied that the disease usually or sometimes was more advanced gave reasons in the free text field for their view. These included: delayed presentation to GP/delayed referral (4), some overseas patients who may have delayed treatment (3), a misconception of not wishing to burden others with their problems/reluctance to seek medical help (3), less awareness (2), language difficulties (2), fear of diagnosis and treatment (2), a feeling that they might not be taken seriously if they complain (1), some may not seek conventional (Western) medical advice as promptly because of cultural beliefs (1), dislike of rectal examinations (prostate cancer) (1), less able to cope (1), possible biological differences (1), demographic difference (e.g. age at menarche parity) (1), education (1), less assertive (1), and cultural reluctance to see male doctors about breast problems (1).

Nurses' free text responses to this question (n=20) included the following: fear of seeing GP/fear of disease (3); reluctance to see GP (3); lack of knowledge/information (2); lack of education relating to health issues (2); language problems (2); afraid to face consequences as seen as personal let down to be ill (1); difficulty in understanding expression of pain (1); unsure whether they are aware of the screening provisions (1); private patients coming from another country are coming for second line treatment (1); difficulty accessing services/language barriers (1); failure to go to GP with symptoms at an early stage/not contacting medical teams earlier enough in the disease/delay in seeking medical assistance, difficulty in understanding the system (1); ethnic minorities like to leave responsibility with staff (1); some problems are cultural in the fact they are often ashamed to show their body to a doctor(1); seek conventional treatment as last resort (1); live with or unaware of symptoms (1); do not verbalise problems as much as health professionals (1); if person is refugee from 3rd world, could cause a patient to present late (1); cultural taboo, especially male urology and female gynaecology (1); may not push GP to act (1); late referral from GP (1); consultants' reluctance to refer to specialists (1); some ethnic groups associate cancer with immediate death or dying (1); and less incidence of breast cancer.

3.2.5 The participation of minority ethnic groups in clinical trials

Medical staff respondents were asked how many new cancer treatment trials they had been involved with over the last two years (this question was not asked of nurses).

<i>No. of trials</i>	<i>Frequency</i>	<i>%</i>
0	17	22.7
1-4	13	17.3
5-9	21	28.0
10-14	13	17.3
15-19	3	4.0
†20+	8	10.7
<i>Total</i>	<i>75</i>	<i>100.0</i>

Frequency missing: 2

† 20=5; 24=1; 40=1; 50=1.

Over a fifth (23%) of responding clinicians had no clinical trial experience, 17% experience of 1-4 trials, and 28% 5-9 trials. A few clinicians had extensive clinical trial experience.

Medical staff respondents were asked in how many trials they had actually recruited patients (this question was not asked of hospital nursing staff)

<i>No. of trials</i>	<i>Frequency</i>	<i>%</i>
0	19	25.3
1-4	16	21.3
5-9	17	22.7
10-14	11	14.7
15-19	4	5.3
†20+	8	10.7
<i>Total</i>	<i>75</i>	<i>100.0</i>

Frequency missing: 2

† 20=6; 40=1; 45=1.

Around a fifth of responding clinicians had no experience in recruiting patients into clinical trials. Around 44% had only limited experience of such recruitment (<10 trials).

Both hospital medical staff and hospital nursing staff were asked if, in their experience, clinicians were as willing to recruit members of minority ethnic groups into clinical trials or other research as the general population.

<i>As willing to recruit ethnic minorities</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Yes</i>	63	82.9	74	65.5
<i>No</i>	4	5.3	6	5.3
<i>Unsure</i>	9	11.8	33	29.2
<i>TOTAL</i>	<i>76</i>	<i>100.0</i>	<i>113</i>	<i>100.0</i>

Frequency missing: Doctors, 1; Nurses, 2.

The overwhelming majority of medical staff respondents (83%) thought that clinicians were as willing to recruit members of minority ethnic groups into clinical trials, and only 5% took the view that clinicians were less willing to so recruit. A much higher proportion of nursing staff respondents reported that they were unsure (29% vs. 12%) but the same proportion (5%) reported that clinicians were not as willing to recruit minority ethnic groups into clinical trials as the general population.

Both hospital medical and nursing staff were asked if, in their experience, members of minority ethnic groups were as willing to participate in clinical trials and other research as the general population. Over one quarter of the hospital medical staff respondents were unsure and this may reflect a similar level of inexperience in actually recruiting patients into clinical trials. An even higher proportion of nurse respondents (44%) were unsure. However, of those doctors that were able to provide an unequivocal answer (n=55), eight out of ten thought that members of minority ethnic groups were as willing to participate in clinical trials and other research as the general population. However, the fact that two out of ten felt that members of minority ethnic groups were less willing to participate is noteworthy. Of the nurse respondents giving an unequivocal answer (n=63), a similar proportion - almost 8 out of 10 - thought that members of minority ethnic groups were as willing to participate in clinical trials and other research as the general population.

<i>Ethnic minorities as willing to participate in clinical trials</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
<i>Yes</i>	43	57.3	49	43.4
<i>No</i>	12	16.0	14	12.4
<i>Unsure</i>	20	26.7	50	44.2
TOTAL	75	100.0	113	100.0

Frequency missing: Doctors, 2; Nurses, 2.

Both hospital medical and nursing staff were asked if they had any experience of recruiting members of minority ethnic groups into clinical trials or other research studies.

<i>Experience of recruiting ethnic minorities into clinical trials</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
<i>Yes</i>	54	71.1	30	27.0
<i>No</i>	22	28.9	81	73.0
TOTAL	76	100.0	111	100.0

Frequency missing: Doctors, 2; Nurses, 4.

71% of hospital medical staff respondents reported that they had had such experience, compared with just 27% of nurses. This subset of respondents was then asked, what barriers, if any, they had experienced in recruiting minority ethnic groups into clinical trials and other research. 41 hospital medical staff respondents gave a response. The following barriers were mentioned: language barrier (21), language/cultural barriers to informed consent (6), expectation of having the treatment arm of the study/difficulty in understanding randomisation to no treatment/reluctance to randomisation (2), occasionally family not wishing the patient to know the diagnosis (2), non-availability for follow-up for overseas patients (1), cultural beliefs (1), ownership of research very important (1), Asian patients do not trust trial protocols much (1), refusal usually (1), difficulty in accepting inclusion in a trial (1), perceptions of storage of tissue being against beliefs (common in Chinese population) (1), not fit enough/not of good performance status (1), much more unaccepting because of social reasons (1), sometimes education (1), excessive anxiety (1), often background knowledge of cancer virtually zero/all negative/very frightened (1), possible inadequacy of interpretation (1), lack of knowledge (1), and dislike of trials (1).

The most frequently mentioned barrier was language (including the giving of informed consent) which received 27 mentions. A few respondents reported that there were no barriers.

20 nurses gave a free-text response to this question: language barriers (11); difficulty in obtaining informed consent (2); written information rarely in spoken language (1); communication/patient understanding (1); interpreters often expensive (1); language line not always effective (1); patients from overseas less familiar with idea of participating in research (1); suspicion/fear greater problems (1); costs of translating consent forms into different languages (1); family/spouse do not wish the patient to have all information regarding their disease and often do not want them to participate in trial (1); fear of unknown side effects of trial treatments (1); difficulty explaining randomisation in a trial (1); attendance for tests and follow-up, maybe lost if return to another country (1); patients prefer family members to interpreters when discussing participation in studies (1); some patients unaware of their diagnosis of cancer (1); and difficulties with understanding the study (1).

Again, the most frequently mentioned barrier was language.

3.2.6 Issues of consent, safety, and follow-up

Hospital medical and nursing staff were asked if, in treating patients from minority ethnic groups, their concerns about ensuring informed consent, fulfilling safety requirements, and ensuring follow-up were different from the general population.

	<i>Lesser concerns</i>	<i>Same as general population</i>	<i>Greater concerns</i>
Doctors			
Obtaining informed consent ¹	2 (2.7%)	39 (53.4%)	32 (43.8%)
Fulfilling safety requirements ²	1 (1.4%)	64 (87.7%)	8 (11.0%)
Ensuring follow-up ³	2 (2.7%)	60 (82.2%)	11 (15.1%)
Nurses			
Obtaining informed consent ^a	3 (2.7%)	38 (33.6%)	72 (63.7%)
Fulfilling safety requirements ^b	2 (1.9%)	69 (64.5%)	35 (32.7%)
Ensuring follow-up ^c	2 (1.9%)	68 (64.8%)	35 (33.3%)

Frequency missing, Doctors: 1 = 4; 2 = 4; 3 = 4.

Frequency missing, Nurses: a = 2; b = 9; c = 10.

Just over half the medical respondents (53%) reported that their concerns about obtaining informed consent from minority ethnic groups were the same as the general population but almost as many (44%) had greater concerns about obtaining informed consent from minority ethnic groups. An even bigger proportion of nurse respondents (64%) had greater concerns about obtaining informed consent. With respect to fulfilling safety requirements, the overwhelming proportion of medical staff respondents (88%) had the same level of concern in treating patients from minority ethnic groups as the general population. However, 11% had greater concerns. Again, a much higher proportion of nurses - almost two-thirds (64%) - had greater concerns. With respect to ensuring follow-up, most medical staff respondents (82%) reported the same level of concern as the general population, but 15% reported greater concern. By contrast, a third of nurses reported greater concerns with respect to ensuring follow-up. Only six medical staff respondents reported additional concerns in a final free text option. Thirty-one nurses ticked a response category for 'Other concerns' (few specifying the nature of the concern in free-text), 39% of whom had greater concerns.

These findings are important and merit further research into (i) why clinicians and nurses have such concerns about obtaining informed consent, fulfilling safety requirements, and ensuring

follow-up in patients belonging to minority ethnic groups (ii) why the proportion of nurses expressing greater concerns is significantly higher than the proportion of doctors. The role of communication (and, especially, language) may be important with respect to the former.

3.3 Experience of barriers to treatment/care of minority ethnic groups

3.3.1 Respondent gender barriers

Hospital medical and nursing staff were asked if they had ever found their gender a barrier to treatment or care of members of minority ethnic groups.

<i>Gender a barrier to treatment</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Yes</i>	24	32	29	25
<i>No</i>	51	68	86	75
	75	100	115	100

Frequency missing: Doctors, 2.

Almost a third of medical respondents but only a quarter of hospital nursing staff reported that they had ever found their gender a barrier to treatment or care of members of minority ethnic groups. Respondents reporting positively were asked in what ways it was a barrier.

24 medical staff respondents gave a reply in free text, the most frequently mentioned difficulties being around issues of gender mismatch between patient and doctor: male doctors treating Muslim/Asian teenage girls/women (10), female patients sometimes prefer to see a female therapist/some women have a marked preference for a female doctor (7), female Arab patients with no English (1), attitude to risk of fertility more influential on occasions (1), some males prefer a male doctor (1), male Arab patients not keen to be treated by a female (1), cutaneous examination of females difficult for male dermatologists (1), orthodox Jewish female patients cannot be touched by a male Gentile (1), and patient/family had more confidence in a male doctor (1).

The most frequently mentioned gender barriers related to male doctors in treating Muslim/Asian women (10 mentions) and the preference of female patients for a female doctor.

24 nurses described barriers in free text: some men prefer to speak to/more willing to accept advice from a man/want a male nurse (5); Arabic male boys refuse to talk to female nurses/Muslim men have difficulty in accepting a female nurse (5); elderly gentlemen from overseas/young male patients unhappy to undress in front of female nurses (2); father of female patient only wished to speak with the consultant (1); Middle Easterners feel females should be at home looking after the family (1); expectations that because you are a female, you will fully care

for patients more capable of caring for themselves (1); female ethnic minority groups do not feel comfortable having a male nurse providing personal care (1); caring for a Muslim gentleman (Indian) who was dying - family did not want me to touch him (1); Middle Eastern female patient not happy to allow male on call doctor to examine her (1); being seen as a second class citizen, a doctor's handmaiden (1); sometimes patients from an Asian or Arabic background less willing to accept information from me as a female than from a doctor (1); some groups treat women as inferior to men and will only listen/take advice from male medical colleagues (1); difficulties in caring for women within Muslim faith due to their religious constrictions (1); and different attitudes to health and belief held by individuals (1).

The most frequently mentioned gender barriers amongst nurses were Arab/Middle Eastern patients not wishing to be treated by female nurses.

3.3.2 Respondent age barriers

<i>Age a barrier to treatment</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Yes</i>	2	2.6	2	1.7
<i>No</i>	75	97.4	113	98.3
	77	100.0	115	100.0

Respondents were asked if they ever found their age a barrier to treatment or care of members of minority ethnic groups. The overwhelming proportion of hospital medical and nursing staff respondents (97 and 98%, respectively) reported that they had not. The two free text responses given by doctors in describing the barrier were: older patients more reluctant to get involved in treatment (1) (the respondent interpreting the question as *patient* rather than respondent age barriers), and too young to inspire confidence (1). Only one free text response was given by nurses: 17 year old Arab boy was embarrassed and commented on age as well as gender of respondent and other nurses.

3.3.3 Respondent ethnicity barriers

<i>Ethnicity a barrier to treatment</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Yes</i>	4	5.2	12	10.6
<i>No</i>	73	94.8	101	89.4
	77	100.0	113	100.0

Frequency missing: Nurses, 2.

Again, when hospital medical and nursing staff respondents were asked if they had ever found their ethnic group a barrier to treatment or care of members of minority ethnic groups, an overwhelming proportion (95% and 89%, respectively) reported that they had not.

The doctors' free text responses on the nature of the barrier were: understanding in how to deal with Muslim women; difficulty in ensuring adequate understanding in counselling a patient via an interpreter; cultural understanding and language on occasions; and lack of full understanding of different cultural issues (with respect to clinical trial participation). Eleven nurses gave examples of barriers in free-text responses: language barrier (2); some ethnic minority groups would prefer to have care from a person of the same ethnic group/Orthodox Jewish patients wish to have care delivered by healthcare professionals with same cultural beliefs (2); patients being racist and not wanting a black nurse to look after them/racist abuse from bereaved relatives (1); young male patients have been embarrassed (1); don't feel trusted at times/doubt you and check on you more (1); and sometimes conscious of not fully understanding or appreciating the culture and customs of other ethnic groups (1).

3.3.4 The beliefs of members of minority ethnic groups about the cause of their cancer

Hospital medical and nursing staff respondents were asked if, in their view, members of minority ethnic groups have different beliefs about the cause of their cancer to the population in general. Just over a fifth of the hospital medical staff respondents (21%) responded that they were not sure and over three-tenths (31%) of hospital nurses so reported. However, almost half the responding doctors (48%) and almost two-fifths of nurses (39%) reported that members of minority ethnic groups frequently or sometimes had different beliefs. Just under a third of the doctors (31%) and nurses (30%) reported that they did not.

<i>Are ethnic minority beliefs about the cause of their cancer different</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Frequently</i>	2	2.6	5	4.5
<i>Sometimes</i>	35	45.5	39	34.8
<i>No</i>	24	31.2	33	29.5
<i>Not sure</i>	16	20.8	35	31.3
	77	100.0	112	100.0

Frequency missing: Nurses, 3.

Medical and nursing staff respondents reporting that members of minority ethnic groups frequently or sometimes did have different beliefs about the cause of their cancer were asked in what ways their beliefs differed. 29 medical staff respondents gave a response in free text: attribute cancer to the will of God/supernatural cause/religious ideation (6), cause arising from cultural background (e.g. evil eye)/spells against them (4), traditional folk lore, superstitions, etc. (2), more deeply held religious beliefs than the general population (1), assume cancer is a matter of destiny, especially Asians (1), holding on to culturally specific beliefs (1), view that female cancers spread (vs. male cancers) (1), experiences of alternative therapies (1), disbelief in genetic link (especially among Asian/Arab families) (1), more inclined to blame psychological factors, trauma, stress (1), "caught" leukaemia like an infection (1), guilt of a past event (1), that they may not have been responsible for the cancer (e.g. lifestyle) (1), no knowledge of what cancer is at all (1), greater tendency to seek someone to blame (1), migrants may blame their changed environment (1), more belief in their own cultural remedies (1), different ideas than general population with regard to cause, investigations, and treatment (1), less likely to think that cancer is related to smoking (1), and sometimes religious beliefs vary (1).

The most frequently mentioned reasons related to religious ideation and cultural beliefs, traditional folklore, and superstitions.

32 nurses gave free-text descriptions in their response to ways in which beliefs of minority ethnic groups about the cause of their cancer differed from the population in general. They included: punishment from God/God's will/wrath of Allah (16); black magic/bewitching (3); fatalistic attitude/fate/future destiny (3); contagious/catching (2); faults of ancestors/ancestors who are angry (2); cultural stigma associated with cancer (2); some attribute their cancer to lifestyle and some to character traits (2); bad luck (1); what to tell children (1); they think they are being used as experiment (1); sometimes believe that they have not washed and prepared their food properly (1); they cannot accept palliative care and stopping treatment and resuscitation, particularly Jewish and Moslem patients (1); beliefs and myths, that if you are strong enough in mind that you can overcome it (1); one Japanese unsure how to handle the fact that the doctors answered all her son's questions (1); tend to blame themselves, evil forces, etc. - Caribbean (1); don't always want to think why its happened (1); less guilt seeking (1); some come to terms with dying easier, as if it is a natural part of life (often very religious) (1); breast care for some cultures, e.g. need for mastectomy may mean they are shunned and alienated (and ostracised) by their husbands (1); and something they have done wrong.

Again, the most frequent response was that their religious beliefs were important, ethnic minority patients frequently seeing the cause of their cancer as God's will or divine punishment.

3.3.5 Beliefs of members of minority ethnic groups as barrier to care or treatment

Hospital medical and nursing staff were asked if the beliefs of minority ethnic groups had ever been a barrier to care or treatment.

<i>Beliefs of members of minority ethnic groups as barrier to care or treatment</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Yes</i>	19	25.0	25	22.1
<i>No</i>	46	60.5	65	57.5
<i>Not sure</i>	11	14.5	23	20.4
TOTAL	76	100.0	113	100.0

Frequency missing: Doctors, 1; Nurses, 2.

A quarter of hospital medical respondents and slightly fewer nurses (22%) thought that the beliefs of members of minority ethnic groups had ever been a barrier to care or treatment, although a significant proportion (15% of doctors and 20% of nurses) were not sure. Those who answered that such beliefs had been a barrier were asked in what ways had they been a barrier. 18 hospital medical respondents gave a reason in free text. The following reasons (with number of mentionings) were given: Jehovah's witness & refusal for blood transfusion (3), relatives do not want patient to know the patient has incurable disease or may die (2), assumption that cancer is a matter of destiny and therefore aggressive treatment unnecessary (1), belief that doctors should know the answers/incredulity at being placed in the position of partnership (1), a hurdle to be overcome (1), for some beliefs stopping active treatment and going for palliative care is considered unfair (1), deep religious beliefs reduce confidence in "school medicine" (1), black men are concerned about impotence risk from prostate cancer treatments (1), family pressure to restrict information stronger in ethnic groups (1), less willing to consider trials (1), occasional belief that alternative remedies may be a replacement to standard treatment (1), occasionally do not understand nature of cancer and often expect guaranteed cure (1), when patients will not be treated/examined by a male doctor (shortage of female medical staff) (1), for more major surgery reluctance/refusal to consider colostomy (1), and less accepting of palliative care in terminally ill patients so need much more discussion (1).

A very wide range of reasons were given, the most frequent being religious objections to blood transfusions and family's wish for patient not to know seriousness of illness.

23 nurse respondents reported in free text ways in which the beliefs of members of minority ethnic groups had ever been a barrier to care or treatment. They included: Jehovah's Witnesses have refused blood transfusions/refusing blood transfusion (3); concerns with bone marrow transplantation (2); problems of treatment preference by same sex persons (2); patient wishing for no screening as beliefs only include visiting doctors for something that is wrong (1); patients declining treatment due to their beliefs either cultural or religious (1); difficulty in finding emotional and psychological resolve, regardless of intervention (1); types of food, beliefs in herbal medicines, or alternative remedies is better than chemotherapy (1); bad future life/life after death if amputation is a choice (1); injection is better than tablets (1); in providing symptom relief within palliative care for children I have encountered reluctance from families from African cultures in providing management (1); patient displaying signs of pain but unable to verbally communicate (1); some patients dislike the concept of palliative care and feel they have to fight to the end for cure (1); special ethnic diets though no worse than vegan diets (1); sometimes minority ethnic groups have made me feel uncomfortable...they cannot maintain eye contact with me or their cultural beliefs mean that they view my profession as subservient, or that tactile nature of the nursing profession indicative of lower moral standards (1); sometimes believe medicine will cure them and cannot accept that their disease is advanced (1); think you are purposely withholding treatment when there is no effective treatment (1); when family members believe that the person should not know their diagnosis (1); expectations of family members of patients' ability to function as usual after operation/treatment (1); due to different cultures, some patients have not become more independent with self-care, resulting in complications (1); usually beliefs come into the situation when the patient is terminally ill or dying (1); and when discussing prognosis or death (1).

A very wide range of barriers were identified by nurses, many embedded within the particular beliefs and culture of members of minority ethnic groups.

3.3.6 Compliance with treatment among members of minority ethnic groups

Respondents were asked whether compliance with treatment (such as drug regimens) among members of minority ethnic groups different from that in the general population.

<i>Compliance with treatment among minority ethnic groups different</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
<i>Yes, more compliant</i>	1	1.3	4	3.5
<i>Yes, less compliant</i>	7	9.2	8	7.1
<i>Same as general population</i>	51	67.1	81	71.7
<i>Not sure</i>	17	22.4	20	17.7
TOTAL	76	100.0	113	100.0

Frequency missing: Doctors, 1; Nurses, 2.

Over a fifth of hospital medical respondents (22.4%) and 18% of responding nurses reported that they were not sure. A further two-thirds of doctors (67%) and 72% of nurses stated that they were the same as the general population with respect to compliance. However, 9% of doctors and 7% of nurses reported that members of minority ethnic groups were less compliant with treatment. Again, this is an important (if impressionistic) finding and further research is needed to establish the role played by communication in possibly reducing the level of compliance.

Hospital nursing staff (but not hospital medical staff) were asked if their experiences of discharge planning for members of minority ethnic groups had been different compared to those of the general population.

<i>Different experiences of discharge planning</i>	<i>Frequency</i>	<i>%</i>
Yes	34	30.6
No	54	48.6
No experience	23	20.7
	<i>111</i>	<i>100.0</i>

Frequency missing: 4.

Over three-tenths of nurses reported that their experiences of discharge planning for members of minority ethnic groups had been different compared to those of the general population (or 39% of all those who had experience of discharge planning).

28 responses were given in free text: more family input/family or extended family more willing to become involved in caring for a relative at home/a lot of family members involved/Asian and Afro-Caribbean families tend to want a bigger role in the care of their family members with cancer/more supportive family and tend not to live alone/many more family members often available and willing to care at home/most cultures very supportive and request less social services, especially Indian/Oriental/ families from South Asian communities tend to have a lot

more family support than British families, requiring less formal care packages/not keen for social services to interfere...family would rather care for patient's own needs (9); language barrier (3); often housing and financial difficulties, especially with asylum seekers (2); patients just coming over for treatment are not often registered with a GP/district nurses/some come to this country specifically for treatment, after they are staying in hotels or hostels or with families, don't have GP or access to community nursing services (2); language difficulty in assessing needs required at home and understanding individual anxieties (1); need to ensure interpreter available for outpatient follow-up clinic (1); wanted to stay until they were completely well before discharge/felt more secure in hospital (1); sometimes the families want a lot of the care themselves (1); often the patient did not have a GP as coming from abroad for treatment...came to us as their shared care hospital and for service that the community nurses would usually offer (1); because they have not got any one to help them, i.e. relative (1); if they have not got homes in England difficult to find suitable accommodation, often private patients stay on longer (1); only for those living abroad (1); having to deal only with male in some cultures (1); overseas patients not eligible for community health services (1); having to repatriate dying patients (1); housing problems (1); appear to have higher expectations of NHS to be able to provide all care or take over care when patient terminally ill (1); in some cases you feel that they would benefit from support groups/care from their own culture and you are not always sure what is available to them (1); sometimes being discharged to different family members (1); sometimes quite complex packages required by families, particularly Indian families (1); if going back to home country hard to organise follow-up GP, district nurse care (1); and family situations occasionally different...larger extended families living in small housing accommodation(1).

A wide range of responses identifying differences were given in free text, the most frequently mentioned being the greater family input amongst ethnic minority patients.

3.4 Level of agreement with statements about minority ethnic groups

3.4.1 Factors contributing to ethnic variations in the incidence of cancers

Respondents were asked which of six factors contribute to ethnic variations in the incidence of cancers.

<i>Factor</i>	<i>Doctors</i>		<i>Nurses</i>	
	<i>Frequency (n=76)</i>	<i>% of respondents mentioning</i>	<i>Frequency (n=101)</i>	<i>% of respondents mentioning</i>
Genetic factors	68	89.5	67	66.3
Different levels of exposure to key risk factors	65	85.5	65	64.4
Lower awareness of the symptoms of cancer	26	34.2	59	58.4
Later presentation to GPs	33	43.4	53	52.5
Lower uptake of screening services	39	51.3	62	61.4
Unequal access to high quality services	12	15.8	34	33.7

Frequency missing: Doctors, 1; Nurses, 14.

The vast majority of medical staff respondents reported that genetic factors (90%) and different levels of exposure to key risk factors (86%) contributed to ethnic variations in the incidence of cancers, but only 66% and 64%, respectively, of nurses reported these factors. However, a much lower proportion of doctors (51%) mentioned lower uptake of screening services but a fairly high proportion of nurses (61%). Only 43% of doctors thought that later presentation to GPs was a factor contributing to ethnic variations in the incidence of cancers compared with 53% of nurses. Just over a third of responding doctors (34%) - but over half the nurses (58%) - thought that lower awareness of the symptoms of cancer was a factor in this context. Unequal access to high quality services was the factor least often mentioned by doctors (16%), but around a third of nurses (34%) reported this factor (even though it got the least number of mentions).

The findings for hospital medical staff are important in according saliency to traditional 'medical' factors as compared with service-related factors. By contrast, hospital nursing staff accorded less importance than doctors to these 'medical' factors and more importance to all the service-related factors.

3.4.2 Extent to which members of minority ethnic groups with cancer are diagnosed at a different stage

Hospital medical and nursing staff were asked if, in general terms, members of minority ethnic groups with cancer are diagnosed at a different stage compared to the general population.

<i>Diagnosed at a different stage</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
More likely to be diagnosed at a late stage	26	33.8	32	28.6
Same as the general population	32	41.6	41	36.6
Less likely to be diagnosed at a late stage	1	1.3	1	0.9
Not sure	18	23.4	38	33.9
<i>TOTAL</i>	<i>77</i>	<i>100.0</i>	<i>112</i>	<i>100.0</i>

Frequency missing: Nurses, 3.

Around a quarter of hospital medical staff respondents (23%) but over a third of responding nurses (34%) reported that they were not sure. However, a third of responding doctors (34%) and over a quarter of nurses (29%) reported that they thought members of minority ethnic groups with cancer were more likely than the general population to be diagnosed at a late stage (and only 1% that they were less likely than the general population to be diagnosed at a late stage). This finding is in broad accord with the 40% of medical staff respondents and 34% of nurses who reported that patients from minority ethnic groups that they treated presented with disease that is usually, sometimes, or occasionally more advanced compared to the stage in the general population. Again, this is an important finding and suggests response consistency within the dataset.

3.4.3 Involvement of members of minority ethnic groups in clinical trials and research

Respondents were asked if, in general terms, the involvement of members of minority ethnic groups in clinical trials and research was different to that in the general population.

<i>Involvement of members of minority ethnic groups in clinical trials</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
They are under-represented	31	40.3	30	26.8
They are not under-represented	15	19.5	30	26.8
Not sure	31	40.3	52	46.4
<i>TOTAL</i>	<i>77</i>	<i>100.0</i>	<i>112</i>	<i>100.0</i>

Frequency missing: Nurses, 3.

A substantial proportion of hospital medical and nursing staff (40% and 46%, respectively) reported that they were not sure. However, two-fifths of doctors (40%) but only just over a quarter of nurses (27%) reported that they were under-represented. This compares with only one-fifth of doctors (20%) and over a quarter of nurses (27%) who reported that they were not under-represented. This is an important finding and merits further research into why medical staff think they are under-represented, what the position actually is (as measured by an audit of trial protocols and recruitment), and what the barriers are.

3.4.4 Level of confiding/trusting of members of minority ethnic groups of hospital doctors who treat them

<i>Level of confiding/trusting</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
More confiding/trusting	18	23.4	12	10.7
Same as general population	37	48.1	58	51.8
Less confiding/trusting	7	9.1	14	12.5
Not sure	15	19.5	28	25.0
<i>TOTAL</i>	<i>77</i>	<i>100.0</i>	<i>112</i>	<i>100.0</i>

Frequency missing: Nurses, 3.

Respondents were asked how confiding/trusting members of minority ethnic groups are of hospital doctors who treat them compared to the general population. About one fifth of the hospital medical staff respondents and a quarter of the responding nurses were not sure. Around a half of doctors (48%) and nurses (52%) reported that the level of confiding/trusting was the same as the general population. Almost a quarter of the responding doctors (23%) reported that members of minority ethnic groups were more confiding/trusting and only 9% less confiding/trusting; for nurses, however, the proportions were 11% and 13%, respectively.

3.4.5 Propensity to seek a second opinion on diagnosis/treatment

Respondents were asked in their opinion the extent to which members of minority ethnic groups sought a second opinion on diagnosis/treatment differed from the population in general. A focus group held with hospital doctors (the source of this question) suggested that members of minority ethnic groups were less likely to seek a second opinion compared with the general population.

<i>Seeking of 2nd opinion</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
Less likely to seek a second opinion	34	44.2	36	32.1
Same as general population	25	32.5	36	32.1
More likely to seek a second opinion	7	9.1	7	6.3
Not sure	11	14.3	33	29.5
<i>TOTAL</i>	<i>77</i>	<i>100.0</i>	<i>112</i>	<i>100.0</i>

Frequency missing: Nurses, 3.

Around 14% of hospital medical staff respondents but three-tenths of hospital nursing staff reported that they were not sure. However, 44% of doctors and around a third of nurses (32%) reported that they thought that members of minority ethnic groups were less likely to seek a second opinion. Just 9% of doctors and 6% of nurses thought that minority ethnic group members were more likely to seek a second opinion. A third of responding doctors and nurses felt that ethnic minority members did not differ in this respect from the general population.

3.4.6 Likelihood of members of minority ethnic groups receiving 3rd/4th line "salvage" treatments compared with the population in general

Respondents were asked if, in their opinion, members of minority ethnic groups were as likely to receive 3rd/4th line "salvage" treatments as the population in general. The focus group held with hospital doctors (the source of this question) suggested that members of minority ethnic groups were less likely to receive such "salvage" treatments.

<i>Likelihood of receiving "salvage" treatments</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
Less likely to receive 3 rd /4 th line treatments	11	14.7	6	5.4
Same as general population	46	61.3	65	58.0
More likely to receive 3 rd /4 th line treatments	0	0	2	1.8
Not sure	18	24.0	39	34.8
<i>TOTAL</i>	<i>75</i>	<i>100.0</i>	<i>112</i>	<i>100.0</i>

Frequency missing: 2

About a quarter of the responding medical staff (24%) and over a third of nurses (35%) reported that they were not sure. Around three-fifths of responding doctors (61%) and nurses (58%) stated that they thought minority ethnic groups were as likely to receive "salvage" treatments as the general population. However, 15% of the doctors (but only 5% of nurses) felt that members of minority ethnic groups were less likely to receive salvage treatments. This, again, is a noteworthy finding and audits of hospital treatment are needed to establish its validity.

3.4.7 Perceptions of the views of members of minority ethnic groups towards their disease and treatment

The initial literature search on cancer and minority ethnic groups identified a number of statements (some evidence-based) that it was decided to test in a survey setting. In all, 11 statements were tested, hospital medical and nursing staff being asked to indicate the extent to which they agreed or disagreed with the statements.

Doctors' responses

<i>Statement</i>	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not sure</i>	<i>Disagree</i>	<i>Strongly disagree</i>
1. Members of minority ethnic groups usually underestimate their risk of cancer compared to the general population (n=77)	2 (2.6%)	11 (14.3%)	44 (57.1%)	20 (26.0%)	0 (0.0%)
2. Members of minority ethnic groups prefer not to know whether they have cancer (n=76)	0 (0.0%)	19 (25.0%)	21 (27.6%)	34 (44.7%)	2 (2.6%)
3. The view that religious faith is an alternative to needed treatment is more prevalent amongst members of minority ethnic groups than the population in general (n=77)	1 (1.3%)	21 (27.3%)	22 (28.6%)	32 (41.6%)	1 (1.3%)
4. Members of minority ethnic groups hold more fatalistic attitudes towards cancer (n=77)	3 (3.9%)	25 (32.5%)	18 (2.4%)	31 (40.3%)	0 (0.0%)
5. Members of minority ethnic groups focus more on day-to-day survival at the expense of seeking early detection or treatment than the population in general (n=76)	0 (0.0%)	12 (15.8%)	26 (34.2%)	37 (48.7%)	1 (1.3%)
6. Members of minority ethnic groups are less likely than the general population to believe that a patient should be told the diagnosis of metastatic cancer (n=77)	3 (3.9%)	30 (39.0%)	19 (24.7%)	24 (31.2%)	1 (1.3%)
7. Members of minority ethnic groups are less likely than the general population to believe that a patient should be told of a poor prognosis (n=77)	2 (2.6%)	33 (42.9%)	15 (19.5%)	27 (35.1%)	0 (0.0%)
8. Members of minority ethnic groups are less likely than the general population to believe that the patient should make decisions about the use of life-supporting measures (n=77)	1 (1.3%)	19 (24.7%)	23 (29.9%)	34 (44.2%)	0 (0.0%)
9. Members of minority ethnic groups are more likely than the general population to believe that the family should make decisions about the use of life support	3 (3.9%)	21 (27.6%)	27 (35.5%)	24 (31.6%)	1 (1.3%)
10. Amongst minority ethnic groups, the patient's family assumes a greater role in caring for the patient than is the case in the general population	11 (14.3%)	43 (55.8%)	11 (14.3%)	12 (15.6%)	0 (0.0%)
11. Members of minority ethnic groups are more accepting of the treatment offered by doctors than the general population	3 (3.9%)	28 (36.4%)	22 (28.6%)	24 (31.2%)	0 (0.0%)

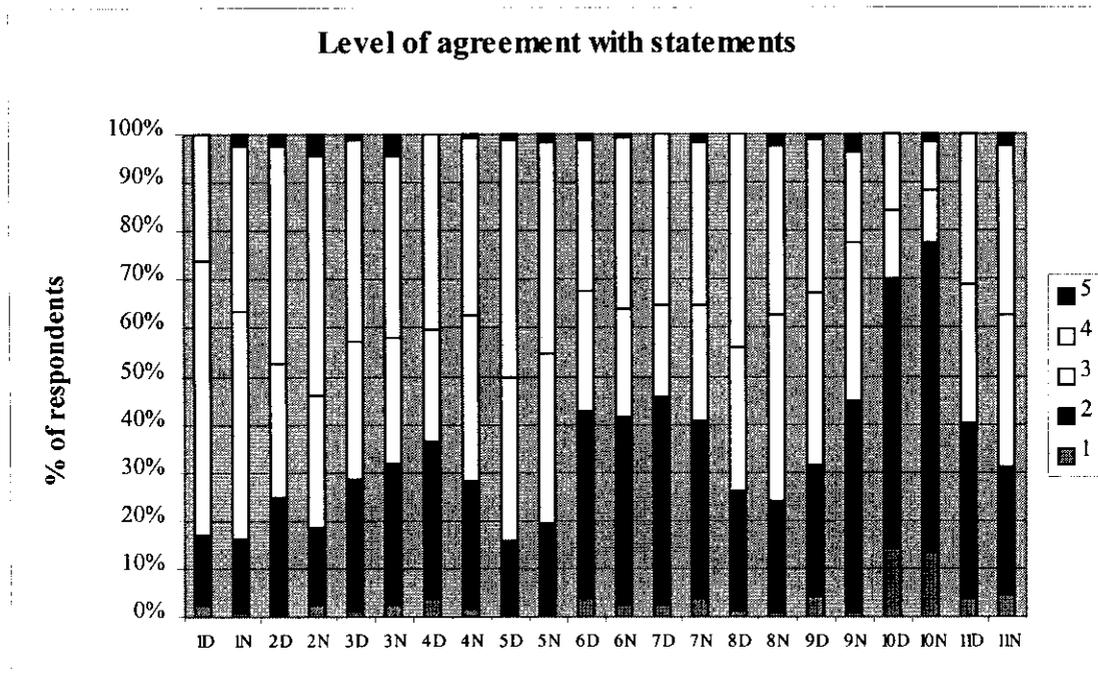
Nurses' responses

<i>Statement</i>	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not sure</i>	<i>Disagree</i>	<i>Strongly disagree</i>
1. Members of minority ethnic groups usually underestimate their risk of cancer compared to the general population (n=112)	1 (0.9%)	17 (15.2%)	53 (47.3%)	38 (33.9%)	3 (2.7%)
2. Members of minority ethnic groups prefer not to know whether they have cancer (n=113)	3 (2.7%)	18 (15.9%)	31 (27.4%)	56 (49.6%)	5 (4.4%)
3. The view that religious faith is an alternative to needed treatment is more prevalent amongst members of minority ethnic groups than the population in general (n=112)	3 (2.7%)	33 (29.5%)	29 (25.9%)	42 (37.5%)	5 (4.5%)
4. Members of minority ethnic groups hold more fatalistic attitudes towards cancer (n=113)	2 (1.8%)	30 (26.5%)	39 (34.5%)	41 (36.3%)	1 (0.9%)
5. Members of minority ethnic groups focus more on day-to-day survival at the expense of seeking early detection or treatment than the population in general (n=113)	0 (0.0%)	22 (19.5%)	40 (35.4%)	49 (43.4%)	2 (1.8%)
6. Members of minority ethnic groups are less likely than the general population to believe that a patient should be told the diagnosis of metastatic cancer (n=113)	3 (2.7%)	44 (38.9%)	25 (22.1%)	40 (35.4%)	1 (0.9%)
7. Members of minority ethnic groups are less likely than the general population to believe that a patient should be told of a poor prognosis (n=113)	4 (3.5%)	42 (37.2%)	27 (23.9%)	38 (33.6%)	2 (1.8%)
8. Members of minority ethnic groups are less likely than the general population to believe that the patient should make decisions about the use of life-supporting measures (n=113)	1 (0.9%)	26 (23.0%)	44 (38.9%)	39 (34.5%)	3 (2.7%)
9. Members of minority ethnic groups are more likely than the general population to believe that the family should make decisions about the use of life support (n=112)	1 (0.9%)	49 (43.8%)	37 (33.0%)	21 (18.8%)	4 (3.6%)
10. Amongst minority ethnic groups, the patient's family assumes a greater role in caring for the patient than is the case in the general population (n=112)	15 (13.4%)	72 (64.3%)	12 (10.7%)	11 (9.8%)	2 (1.8%)
11. Members of minority ethnic groups are more accepting of the treatment offered by doctors than the general population (n=112)	5 (4.5%)	30 (26.8%)	35 (31.3%)	39 (34.8%)	3 (2.7%)

When the response to these statements is mapped (fig. 1), it is clear that there is strongest agreement amongst *both* doctors and nurses for statement 10: 'Amongst minority ethnic groups, the patient's family assumes a greater role in caring for the patient than is the case in the general population', with 70% of respondents strongly agreeing or agreeing with this statement. There was also fairly strong agreement - again amongst doctors and nurses - for the statement 7: Members of minority ethnic groups are less likely than the general population to believe that a patient should be told of a poor prognosis, with almost half (45.5%) of hospital medical staff respondents and 40.7% of responding nurses either strongly agreeing or agreeing with this statement. For statement 6 - 'Members of minority ethnic groups are less likely than the general population to believe that a patient should be told the diagnosis of metastatic cancer' - 43% of doctor respondents and 41.6% of nurse respondents either strongly agreed or agreed. There was one other statement - statement 11 - upon which more than two-fifths (40.3%) of doctor respondents strongly agreed or agreed (but only 31.3% of nurse respondents): 'Members of minority ethnic groups are more accepting of the treatment offered by doctors than the general population'.

Statements for which there was least agreement were: Statement 5: Members of minority ethnic groups focus more on day-to-day survival at the expense of seeking early detection or treatment than the population in general, on which only 15.8% of doctor respondents and 19.5% of nurse respondents agreed; and statement 1: Members of minority ethnic groups usually underestimate their risk of cancer compared to the general population, on which only 16.9% of medical staff respondents and 16.1% of nurse respondents agreed.

Fig. 1. Level of agreement with statements: Doctors' and nurses' responses



Key: 1=strongly agree; 2=agree; 3=not sure; 4=disagree; and 5=strongly disagree.

3.5 Respondents' experience of communication with members of minority ethnic groups

3.5.1 Level of demand for information/advice

Respondents were asked if the level of demand by members of minority ethnic groups for information/advice about their disease/treatment differed from the general population.

<i>Level of demand for advice/information</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
<i>More likely to request information/advice</i>	1	1.3	11	9.7
<i>Same as general population</i>	42	54.5	59	52.2
<i>Less likely to request information/advice</i>	26	33.8	33	29.2
<i>Don't know/not sure</i>	8	10.4	10	8.8
<i>Total</i>	<i>77</i>	<i>100.0</i>	<i>113</i>	<i>100.0</i>

Frequency missing: Nurses, 2.

Around half the medical staff respondents (55%) and responding nurses (52%) felt the level of demand by members of minority ethnic groups for information/advice was the same as the general population and around a further tenth were not sure. However, a third of the doctor respondents (34%) and 29% of the nurse respondents felt that they were less likely to request information (against just 1% of doctors and 10% of nurses who reported that they were more likely to request information/advice).

3.5.2 Level of provision for members of minority ethnic groups of information/advice about their disease/treatment

Hospital medical and nursing staff respondents were asked if, in their experience, the level of provision for members of minority ethnic groups of information/advice differed from the general population.

<i>Level of provision of advice/information</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
<i>More likely to be provided with information/advice</i>	0	0.0	9	8.0
<i>Same as general population</i>	61	79.2	76	67.9
<i>Less likely to be provided with information/advice</i>	8	10.4	20	17.9
<i>Don't know/not sure</i>	8	10.4	7	6.3
<i>TOTAL</i>	<i>77</i>	<i>100.0</i>	<i>112</i>	<i>100.0</i>

Frequency missing: Nurses, 3.

The overwhelming proportion of hospital medical staff respondents (79%) and over two-thirds of responding nurses (70%) thought that the level of provision for members of minority ethnic groups of information/advice was the same as the general population. Around 10% of doctors but 18% of nurses thought that they were less likely to be provided with information/advice. 10% of doctors and 6% of nurses were unsure.

3.5.3 Methods of conveying information/advice to members of minority ethnic groups

Respondents were asked which of a number of methods of conveying information/advice to members of minority ethnic groups they had used.

<i>Methods of conveying advice/information</i>	<i>Frequency (n=76)</i>	<i>% of respondents mentioning</i>	<i>% of respondents mentioning method as most effective</i>	<i>Frequency (n=113)</i>	<i>% of respondents mentioning</i>	<i>% of respondents mentioning method as most effective (n=94)</i>
	Doctors			Nurses		
Through leaflets or brochures	63	82.9	5	94	83.2	27
By word of mouth	69	90.8	20	83	73.5	13
Via an interpreter	68	89.5	17	98	86.7	32
Via friends/relatives	67	88.2	10	107	94.7	15
Via a patient advocate	19	25.0	1	34	30.1	0
Via another member of the medical or nursing staff	48	63.1	1	79	69.9	5
Use of video	4	5.3	0	2	1.8	0
Use of audio cassette	0	0.0	0	4	3.5	0
Through referral to a support/self-help group	17	22.4	0	34	30.1	0
Through group sessions	1	1.3	0	2	1.8	0
Through the local media	3	3.9	0	3	2.7	0
Other	7	9.2	2	3	2.7	2

Around two-thirds or more of responding doctors and nurses had used leaflets or brochures, word of mouth, interpreters, friends/relatives, and via another member of the medical or nursing staff. A patient advocate had been used by only 25% of responding doctors and 30% of nurses and similar proportions of doctors and nurses (22% and 30%, respectively) had used referral to a support/self-help group. Virtually no use was made of video, audio cassette, group sessions, and local media.

Hospital medical and nursing staff were asked which of the methods they had found most effective. This question was only answered by 72% of responding doctors and 83% of responding

nurses amongst those who had ticked methods. The reported most effective methods were word of mouth, use of interpreters, and via friends/relatives and (amongst nurses only) leaflets or brochures.

3.5.4 Availability of written information in community languages

Respondents were asked if written information/advice was available to members of minority ethnic groups in any language other than English.

<i>Availability of written information in other languages</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
Yes	42	54.5	56	50.0
No	17	22.1	41	36.6
Not sure	18	23.4	15	13.4
<i>Total</i>	<i>77</i>	<i>100.0</i>	<i>112</i>	<i>100.0</i>

Frequency missing: Nurses, 3.

Around half the medical and nursing staff respondents reported that written information/advice was available to members of minority ethnic groups in any language other than English, although almost a quarter of doctors (23%) and 13% of nurses were not sure.

3.5.5 Communication difficulties arising from language

Respondents were asked if they had ever found communication difficulties arising from language a barrier to treatment or care of patients from minority ethnic groups.

<i>Language a barrier</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
Yes	66	86.8	98	86.0
No	10	13.2	16	14.0

Frequency missing: Doctors, 1; Nurses, 1.

The vast majority of respondents (87% of doctors and 86% of nurses) reported that communication difficulties arising from language had been a barrier to treatment or care of patients.

Respondents were then asked if there was a translating/interpreting service available to them when they needed it on those occasions.

<i>Translating/interpreting service availability</i>	<i>During the day on weekdays</i>	<i>Out of hours including weekends</i>	<i>During the day on weekdays</i>	<i>Out of hours including weekends</i>
	Doctors		Nurses	
Yes, a hospital service	42	10	53	10
Yes, an outside service	31	14	39	15
Yes, a telephone/dial up service	40	29	78	54
None	5	11	5	9

Frequency missing: Doctors, 1; Nurses, 4.

42 doctor respondents reported that during the day on weekdays there was a hospital service, 31 an outside service, and 40 a telephone/dial up service. 5 respondents reported that there was no service. Provision of out of hours services was lower (11 reporting no such service), although respondents may not have needed services at out of hours time as much as during the day and therefore not reported usage. 53 nurses reported that during the day on weekdays there was a hospital service, 39 an outside service, and 78 a telephone/dial up service. 5 respondents reported that there was no service. Again, reported provision of out of hours services was lower.

When there was a need for translating/interpreting services, respondents were asked if translation/interpreting was undertaken by a member of the patient's family or others.

<i>Translating/interpreting undertaken by...</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
A child in the patient's family	36	47.4	35	32.4
Other member of patient's family	67	88.2	98	90.7
A friend of the patient	58	76.3	76	70.4
A member of the hospital staff (excluding designated interpreters)	51	67.1	73	67.6

Frequency missing: Doctors, 1; Nurses, 7.

Respondents most often reported that translation/interpreting was undertaken by members of the patient's family other than children (88% of doctors and 91% of nurses), by a friend of the patient (76% of doctors and 70% of nurses), and by a member of the hospital staff (67% of doctors and 68% of nurses). However, almost half of responding doctors (47%) and a third of responding nurses (32%) reported that translating/interpreting had been undertaken by a child in the patient's family.

Medical respondents were asked in which ethnic groups language appeared to be the greatest barrier in treating patients. 59 respondents gave a response: Middle Eastern/Arabic (9), Asian (6), elderly Asians/Indians (3), Indian, Arabic, Albanian, Sudanese (1), Arabic or Chinese origin (1), African and SE Asian patients (1), not possible to generalise (1), Bengalis, Kosovars (1), European citizens, Arabics (1), S Asian, Middle East (1), Pakistan, Gulf states (1), very individual/unable to group (1), new immigrants from Eastern Europe & French West Africa (asylum seeker cases) (1), Middle East, Greek (1), Croatian, Arab (1), Chinese & Indian (1), Asian - Middle East (1), always manage to find interpreters (1), foreign private patients (1), elderly African/Asian patients (1), Greek patient (1), black-African (1), Eastern European, Chinese, Indian/Pakistani (1), Asian groups (Muslims - particularly elderly patients, Hindu, particularly elderly patients) (1), Chinese (1), elderly Chinese women (1), Middle East and European (Greece), Pakistani, Afghani, and Bangladeshi (1), no one particular group (1), uncommon dialects in Chinese & in some Asian & African patients, no idea (1), no difference (1), Indian languages (1), Sub-saharan African especially, sometimes Chinese (1), Korean (1), Indian/Bangladeshi (1), Chinese/Vietnamese (1), Albanian, Turkish (1), Asian - Indian/Bangladeshi/Chinese (1), Somalian, lack of any written information (1), Kosovan, Somalis (1), Indian and Pakistani, Thai (1), Bangladeshi (1), and some Turkish groups (1).

A very wide range of ethnic groups were mentioned, the most frequent being Arab/Middle East groups, Indian subcontinent groups, and Chinese but frequent mentions were also made of refugee communities (such as Kosovans, Croatians, and Somalis) and some European groups (e.g. Turks, Greeks).

Nurse respondents were also asked in which ethnic groups language appeared to be the greatest barrier. 86 nurses provided a free text response: Arabic (22); Asian (6); South Asian (4); South Asian and Middle East (2); Arabs, Chinese/Asian, especially women (1); Polish, Indian and African (1); Middle East, Arabic...better for males to translate to male patients to avoid the gender issue present in strict Muslim culture (1); Middle East women who live in an enclosed social structure (1); Bangladeshi (1); Indian (1); no one particular language (1); Asian, Indian, Pakistani (1); Far East (1); Somalian/Croatian (1); Muslim, Indian (1); Arabic, Greek, Portuguese, Spanish, Bengali (1); Greek. Arabic (1); those with no English at all (1); within the Arabic and Maltese population as they only visit us from the native country for chemo/high dose chemo and often do not talk or understand English (1); in more elderly patients who have remained at home to bring up children, mainly Asian (1); Indian (elderly generations) and Chinese (1); Jamaican

and Indian (1); Bangladeshi family whereby father interprets for mother and chooses to withhold information given (1); Egyptian, Greek (1); Middle Eastern, Bangladeshi and Chinese patients, most often seems likely to be women who do not speak English fluently enough to communicate without an interpreter (1); in some Indian families where I felt the patient was being told what to do rather than my words translated to her (1); Asian, Chinese (1); Sudanese dialects, Thai, Turkish, Croatia, Indian dialects (1); Arabic, Punjabi/Hindi. Spanish (1); Indonesian, Chinese, Greek, Croatian (1); Greek and Asian and Chinese (1); Asian groups/Middle East, Chinese (1); Indian - Urdu, Hindi, Gujerati, Greek, Arab (1); Arabic, Spanish/Portuguese (1); I would not say one more than the other, but Afro/Caribbean perhaps less likely (1); Spanish speaking; Somalian/Indian (1); Iraq/Iranian families and when they bring their own interpreter I don't feel that the family are told everything the doctor has said (1); Chinese (1); Asian/Indian (1); Arabic, Maltese...Arabic women have poor English, Maltese no English (1), Asian people, elderly people in ethnic groups (1); Chinese, Arabic (1); Greek and Arabic...relatives aware of diagnosis but patient left in dark or given minimal explanation (1), Gujerati (1); overseas patients from Greece, Turkey or the Arab states (1), patients from South East Asia (1), Greek (1), Arab/Chinese (1); Asian, Arabic (1); Indian dialects/languages, Middle East languages (1); Chinese, Arabs, Gibraltors, Greek (1); Arabic/Iranian (asylum seeker)/older Asian community/Ukraine patient (1); South Asian females seem less likely than other minority groups (1); and Chinese countries (1).

Nurse respondents found language the greatest barrier in caring for patients amongst Arab patients but South Asian groups were also frequently mentioned.

3.5.6 Availability of culturally sensitive written information

Hospital medical and nursing staff were asked if culturally sensitive written information was available when they needed it.

<i>Availability of culturally sensitive written information</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
Yes	11	15.5	25	24.0
No	60	84.5	79	76.0

Frequency missing: Doctors, 6; Nurses, 11.

Some of the non-respondents were not sure what culturally sensitive written information was. However, amongst responses, the overwhelming proportion of doctors (85%) and nurses (76%) reported that such written information was not available.

3.6 Access to services

3.6.1 Access to screening and other preventive services for members of minority ethnic groups

Respondents were asked if they felt that access to screening and other preventive services for members of minority ethnic groups differs from the general population.

<i>Access to screening/other preventive services</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
Same access	39	50.6	57	49.6
Poorer access	15	19.5	21	18.3
Better access	0	0	1	0.9
Not sure	23	29.9	36	31.3

Around half respondents (51% of doctors and 50% of nurses) thought that access to screening/other preventive services for members of minority ethnic groups was the same as for the general population. However, about a fifth of the responding doctors and nurses thought that members of minority ethnic groups had poorer access (and only one respondent reported better access). Three-fifths of the sample were not sure.

Respondents were asked if there were any ways in which they felt their access to these services could be improved. 38 respondents gave a free text response. The suggestions were wide-ranging and many focused on *information*: provision of information in appropriate languages in out-patients, community surgeries/community meeting places, via community groups, etc. (15), education/greater awareness of the importance of screening/teaching videos in same language/educating as to why screening is beneficial (5), increasing awareness of these services via GP surgeries, leaflets, posters & media (2), better access to interpreters (1), increasing of awareness in the whole population (1), education and information (1), barrier is poverty, not ethnicity (1), through community ethnic minority services (1), information on screening in appropriate language and more widely distributed (1), escort by staff of same ethnic group (1), need to identify why there is under usage (1), female only workers, e.g. for cervical screening/breast screening (1), leaflet campaign directed towards south Asian women so they can get information directly (1), TV programmes/dramas depicting a person's suspicions/discovery and treatment (1), adequate communication (1), community based by professionals from the same ethnic group (1), advertising on local radio (1), ignorance and fear of cancer (1), general provision of services

weaker in poorer socio-economic areas where ethnic minorities cluster (1), screening invitations via religious/cultural groups and within these groups (1), large adverts in minority languages for screening programmes (1), encouraging GPs to make services more available to members of minority ethnic groups (1), and use of local clinic advocates who would provide information to ethnic groups about screening/be available when patients attend.

Substantially the most frequent response concerned provision of information in appropriate languages in community and other settings. Worthy of particular mention is one report of advertising on local radio ("Sunrise" radio [Asian] in Southall), resulting in the uptake of the service improving dramatically.

51 nurses gave a free-text response to this question: more written information in different languages, leaflets and posters/health promotion literature in various languages/translated leaflets inviting them to access services and the way they should do this/improved leaflets, posters, and brochures (12); employment of more ethnic minority staff in GP surgeries, health centres, etc./more nurses of ethnic minorities in influential roles where the giving of information and communication is important/clinics with ethnic staff members and female doctors for women/more primary care/outreach workers from ethnic minorities would presumably be better placed to target those from communities they could identify with/having staff/employees of different races/ethnic member involved in screening programmes to encourage ethnic participation/more ethnic doctors who can communicate effectively (5); better access to interpreters/interpreting services (4); increased health promotion campaign/community health promotion for different cultures/more health education in all languages (4); education/educating men and women on needs/education in the community/education in schools, colleges (4); more information literature (3); leaflets in religious and cultural centres/more information given to cultural communities, e.g. temples, churches, community leaders, etc. (2); increased cultural sensitivity re: offering of services (2); GPs should send out reminders and information on preventive measures and screening so people are educated in what is available/invitation to use service (2); Education in minority newspapers (1); ensure they are aware of the services (1); raising awareness in home countries (1); advertisements in various languages on posters, TV, radio and brochures (1); language (1); more translators in outpatients department and chemo suites, radiotherapy department (1); group work in community centres with translators available to aid communication (1); more walk-in clinics; more information in health centres and GP surgeries/culturally sensitive information in community settings, e.g. GPs, local centres, etc. (1);

assistance with registering with GP practice (1); visiting local groups run by ethnic minorities (1); health care professionals should be accessible through local community groups, radio broadcasts, etc. (1); involving more members of ethnic groups in media campaigns advertising access to all cancer services for all races (1); full representation of minority groups in workforce, reducing barriers (1); only the more educated of the ethnic groups tend to take up the service (1); their own cultural/religious leaders need to take more responsibility....many have lived in this country a long time but have refrained from learning our language (1); monitoring of screening uptake (1); raise awareness of these services (1); and greater access at points where peoples from these minorities congregate.

Again, information in appropriate languages and better interpreting services were the most frequently mentioned ways in which nurse respondents felt screening and other preventive services could be improved. Five respondents wanted more ethnic minority doctors, nurses, and other workers.

3.6.2 Demand for complementary therapies

The medical staff were asked if the demand for a list of nine complementary therapies for cancer amongst members of minority ethnic groups differed from the general population.

<i>Demand for complementary therapies</i>	<i>Greater than</i>	<i>Same as</i>	<i>Less than</i>	<i>Don't know</i>	<i>Greater than</i>	<i>Same as</i>	<i>Less than</i>	<i>Don't know</i>
	Doctors				Nurses			
Acupuncture (Dn=75;Nn=108)	11 (14.7%)	21 (28.0%)	11 (14.7%)	32 (42.7%)	15 (13.9%)	25 (23.1%)	22 (20.4%)	46 (42.6%)
Herbal medicine (Dn=76;Nn=112)	25 (32.9%)	14 (18.4%)	4 (5.3%)	33 (43.4%)	42 (37.5%)	23 (20.5%)	7 (6.3%)	40 (35.7%)
Homeopathy (Dn=75;Nn=109)	8 (10.5%)	22 (28.9%)	13 (17.1%)	32 (42.1%)	17 (15.6%)	31 (28.4%)	14 (12.8%)	47 (43.1%)
Counselling (Dn=76; Nn=111)	1 (1.3%)	16 (21.1%)	30 (39.5%)	29 (38.2%)	2 (1.8%)	36 (32.4%)	40 (36.0%)	33 (29.7%)
Visualisation/ Imagery (Dn=76; Nn=106)	3 (3.9%)	13 (17.1%)	17 (22.4%)	43 (56.6%)	4 (3.8%)	22 (20.8%)	27 (25.5%)	53 (50.0%)
Aromatherapy (Dn=74; Nn=110)	1 (1.3%)	19 (25.0%)	17 (22.4%)	37 (48.7%)	2 (1.8%)	38 (34.5%)	25 (22.7%)	45 (40.9%)
Holistic massage (Dn=75; Nn=107)	3 (3.9%)	18 (23.7%)	15 (19.7%)	39 (51.3%)	7 (6.5%)	34 (31.8%)	21 (19.6%)	45 (42.1%)
Reflexology (Dn=76; Nn=108)	1 (1.3%)	19 (25.0%)	16 (21.1%)	39 (51.3%)	5 (4.6%)	31 (28.7%)	23 (21.3%)	49 (45.4%)
Nutritional approaches (Dn=76;Nn=111)	14 (18.4%)	21 (27.6%)	11 (14.5%)	30 (39.5%)	24 (21.6%)	41 (36.9%)	13 (11.7%)	33 (29.7%)

3.6.3 Equitable access to cancer services in general

Respondents were asked if they, personally, felt that members of minority ethnic groups had equitable access to cancer services in general (that is, equal access for equal need).

<i>Equitable access to cancer services in general</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	<i>Doctors</i>		<i>Nurses</i>	
Yes	55	71.4	65	58.0
No	12	15.6	18	16.1
Not sure	10	13.0	29	25.9
<i>TOTAL</i>	77	100.0	112	100.0

Frequency missing: Nurses, 3.

71% of medical staff respondents but only 58% of nurses thought that members of minority ethnic groups had equitable access to cancer services in general but 13% of doctors and over a quarter of nurses (26%) were unsure. Respondents answering 'no' (16% of doctors and nurses) were given an opportunity in free text to describe what they thought the main barriers to access were. The following reasons were given by doctors: language barriers (9), educational level / understanding information (3), information (including about what services are available) and access to resources (2), referring doctors/GP (2), lack of knowledge of services (1), less likely to be pushy (1), failure of GP/DGH to refer for specialist management of cancer unless pushed (1), strong very different cultural beliefs (1), Asians don't know how to seek help (1), barrier to talking about the problem (1), self selection of patients seeking what is perceived as "Best Treatment" and so favours educated, articulate people who know the system (1), and poorer access because ghettoised into poorer communities (1).

Again, language is identified as a main barrier to access.

Responses to this question were given by 20 nurses: language barrier (6); knowledge of service availability (4); reticence in seeking a second opinion/not advised for second opinion (2); talking/communication (2); Western approach to illness (2); information regarding need for screening/GP visits/lack of understanding of importance of early screening diagnosis (2); sexist attitude - Arab/Asian females do not want to be examined by a male doctor (1); family myths re illness and risk (1); lack of knowledge (1); fear/fear of future (1); transport/cost of travel to specialist hospital (1); understanding (1); reluctance to question/criticise a doctor's judgement (1); not made aware of specialist courses (1); not informed of types of treatment/failure to realise

there are other services not knowing how to register with GP (1); often being in deprived areas where primary health care services are poor (1); lower income bracket (1); there are very few ethnic minority groups at the Marsden...this must partly represent the local population...the majority of patients are white middle-class and educated who know how to access the system and have asked their GPs to refer them here. They know about the hospital and surf the Internet to ensure they know the best treatment to get and where to get it. Ethnic minority groups and white lower socio-economic populations are all under represented (1); professional referrals...patient care not transferred to specialist centres (1); poor quality GPs who don't refer; eligibility to some studies for people from ethnic minority groups is sometimes reduced for reasons of: 1. informed consent, 2. quality of life tools and study measures are not always validated or available in other languages beyond French, English, German, Swedish...as most of our studies revolve around quality of life being a measurable outcome, this is crucial...the problem is experienced internationally and not just in the UK or this Trust (1); feel that services are not suitable for them...all run by middle class white people who speak English (1); cultural variances (1); lack of confidence of ethnic minorities to seek help (1); poverty (1); overstretched GPs (1); childcare issues (1); less educated (1); and a different approach to their own care...less of a partnership approach...more of a relationship where the health care professional is viewed as the expert to say what has to be done (1).

The most frequently mentioned barriers to access by nurses were: language barriers, lack of knowledge of service availability, and reticence in seeking a second opinion.

3.6.4 Difficulties in accessing services for listed reasons

The most frequent difficulty identified by respondents was the language skills of the patient (63% of doctors and 81% of nurses), followed by patient's difficulties in travelling to the hospital (44% of doctors and 50% of nurses), and the literacy skills of the patient (43% of doctors and 45% of nurses). Additionally, a third of medical respondents (33%) and 37% of nurses mentioned patient's costs of fares, around a quarter patient's role as carer (26%), and 23% of doctors and 31% of nurses patient's difficulties in obtaining child care.

Some of these difficulties might have been reported for white respondents but the question did not explore differences between minority ethnic groups and the majority group in terms of respondents' perceived difficulties.

<i>Reason for difficulty</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
Patient's difficulties in travelling to the hospital	32	43.8%	45	49.5%
Patient's costs of fares	24	32.9%	34	37.4%
Patient's difficulties in obtaining child care	17	23.3%	28	30.8%
Patient's role as carer	19	26.0%	24	26.4%
Patient's request for presence of family members	13	17.8%	26	28.6%
Patient's concerns over lack of privacy at hospital	9	12.3%	18	19.8%
Hospital's confusion over patient's name	13	17.8%	11	12.1%
Hospital's confusion over patient's address	7	9.6%	4	4.4%
Patient's observance of religious practices	18	24.7%	19	20.9%
The literacy skills of the patient	31	42.5%	41	45.1%
The language skills of the patient	46	63.0%	74	81.3%
Patient's lack of access to technology	5	6.8%	24	26.4%

Frequency missing: Doctors, 4; Nurses, 24.

3.6.5 Quality of care in hospital

Respondents were asked if they personally felt that members of minority ethnic groups received the same *quality of care* in hospital as the general population.

<i>Quality of care</i>	<i>Frequency</i>	<i>%</i>	<i>Frequency</i>	<i>%</i>
	Doctors		Nurses	
Yes	65	84.4	88	77.2
No	4	5.2	14	12.3
Not sure	8	10.4	12	10.5
TOTAL	77	100.0	114	100.0

Frequency missing: Nurses, 1.

Only 5% of hospital medical respondents but 12% of nurses thought that members of minority ethnic groups did not receive the same quality of care in hospital as the general population, although 10% in both groups were not sure. Five medical staff respondents mentioned ways in which the quality of care for minority ethnic groups differed from that of the general population: counselling, consenting, and sexual needs (1), the limitations upon understanding related to language skills (even with trained interpreters, they cannot gain the same level of understanding as someone with fluent language) (1), language and communication prevent full access to

services (1), much of the support for cancer patients involves verbal communication, a barrier to quality of care in patients that do not speak English, and any potential communication difficulty will impinge on therapeutic and psychological aspects of care (1).

Again, language is the main issue identified.

15 nurses gave a response to this question: communication...hard to give full explanation to patients who do not speak English/limitations of language (5); food - poor choices/unable to provide diet that they wish (2); access to information not always easy (2); language barriers (1); sometimes lack of understanding of staff (1); the care available may be the same but projecting that may be difficult (1); hospital staff have made a special effort to ensure these patients understand information and are informed thoroughly and fully supported (1); you cannot give the same detail of information if someone is interpreting it (1); I feel nursing (but not necessarily medical) adopt a more reserved less open approach to those whose culture they do not understand/identify with... such patients often experience basic errors such as mispronunciation of their names, or being served inappropriate food – which presumably does little to enhance their experience of in-patient care (1); difficult to always "allow" for their problems...find it frustrating that they do not appear to have read information sent to them – even if there is a fluent member of the family, they almost expect not to have to comply with the instructions (1); purely in meeting their religious and cultural needs (not in terms of cancer care delivery)... Muslim patients have trouble accessing decent halal meals and are often not told about the prayer room (1); and some staff members (may be the minority) still lack knowledge/ability/understanding or the complexities of representing minority groups (1).

The most frequent response was language/communications barriers.

3.6.6 Single measure most contributing to improving the access of members of minority ethnic groups to cancer services

Medical and nursing staff were asked what single measure they thought would most contribute to improving the access of members of minority ethnic groups to cancer services. 48 respondents gave reasons. These comprised:

- Improved access to written information in a variety of languages (11)

- Better access to interpreters/translating services/professional interpreters/ on site translation/more communication aids (10)
- Educational outreach/more information within the community/leaflets/publicity at religious institutes/in community/schools (7)
- Improve socio-economic status of ethnic groups/relief of poverty/improve funding to socio-economically deprived areas (3)
- Seeing that health care professionals also come from ethnic minorities/more health care workers (not just interpreters/advocates) from ethnic minority backgrounds (2)
- Better communication of availability (1)
- Staff education (1)
- Make people aware of their own prejudices (1)
- Culturally-sensitive staff in primary care and hospital services (1)
- Give ethnic groups same sense of health ownership as indigenous whites (1)
- Increase in cancer services (1)
- Greater hospital links with minority groups (1)
- Changing the nihilistic attitude of some doctors (GPs & hospital consultants) (1)
- Study of what motivates action with respect to importance of keeping to treatment schedules (1)
- Increased education of screening at GP/targeted education on cancer & screening for cancer (1)
- More money spent on cancer care provision, staff, equipment, infrastructure (1)
- These groups need to feel part of society (1)
- Access to appropriate media communications (1)
- Identify perceived gaps by patients (1)
- Encouraging GPs to refer patients from ethnic minority groups to cancer centres (1)
- Improving access and resources in NHS generally (1)
- Better education of early symptoms of cancer (1)

Again, the single measures most frequently mentioned were improved access to written information in a variety of languages and better access to interpreting and translating services.

The responses of the nurses to this question were:

- Communication/more language brochures/brochures and advertising in other languages like Mandarin, Gujarati, Egyptian etc./provide different languages (29)
- Greater access to interpreting services/good translating services/more advertising for help lines-translators/effective independent interpreter/hospital translators/interpreters in person rather than language line (12)
- Improved information/increased awareness/appropriate culturally sensitive information/knowledge of what the services are and why they are important for them (9)
- More staff employed from ethnic minority backgrounds/member of staff of same ethnic background available or contact with knowledge, to help with community back-up/preferably verbal information given by ethnic minority staff/local health promotion with involvement from some people of same ethnic origin/increasing number of minority ethnic group nurses and encouraging patient information/education about cancer services and how to improve access by fellow country people (7)
- Education of staff/more teaching of their needs to staff/more awareness, training of GPs and their willingness to refer them to specialist centres/educate GPs to meet the needs of minorities appropriately/many staff know little about other cultures/religions therefore educating staff is vitally important/cultural awareness issues raised with nursing/medical staff, e.g. in mandatory training sessions (5)
- Education at appropriate places, i.e. worship areas and GP surgeries/hold groups in community centres or agree venues to help change attitudes/increased education in the community/providing community talks and talks at schools/better community liaison (5)
- Reassuring adverts in local papers with contact numbers for people to call in language known to group/more advice in their own local language papers and cinema adverts/information in ethnic media (3)
- Community representatives to liaise with these groups/liaison officers/patient representative who works within the hospital who can help with language problems and visit inpatients daily to assist medical/nursing staff with patient needs and anxieties and discharge planning (3)
- Better information at primary care level may be helpful/better information to GPs (2)
- Access to an oncologist and Macmillan nurse/oncology nurse specialist at time of diagnosis (1)
- Single sex wards in all hospitals (1)
- Better access to GPs (1)
- National strategies targeting screening (1)

- Better understanding of different cultures/religions (1)
- Education and knowledge about how to play the system (1)
- Increase in media campaigns involving ethnic groups (1)
- Proper referral criteria for medical doctors for each cancer (1)
- Implementation of Cancer Plan to ensure all cancer patients receive the same standard of care (1)
- Improved patient awareness/access to specialist centres...information leads to patient empowerment (1)
- Improving referral system countrywide (1)
- Better calibre GPs (1)
- Registering with a GP and accessing services that way (1)
- Health promotion in their own language (1)
- A video cassette in each ethnic group's language (1)
- Routine screening and close monitoring of follow-up (1)

The most frequently mentioned measures by nurses were the provision of information in appropriate languages, better interpreting/translating services, more culturally sensitive information, and wider use of staff from minority ethnic groups in a range of roles.

3.6.7 Residual free-text comments

Finally, respondents were offered the opportunity at the end of the questionnaire to provide additional comments. 21 medical respondents provided additional comments.

A number of these comments focussed on language barriers and interpreting. One respondent stated that 'provision of interpreting services is very poor in most hospitals that I have worked at'. Another said: 'the problems I have experienced have mostly related to language/communication and quality of consent understanding. These issues are greater in ethnic minority patients who have grown up abroad, speak the language less well, and have strong cultural beliefs of conventional medicine or cancer. Even the word can be a taboo'. Another respondent wrote: 'Language is the major barrier and this is sometimes confused with ethnicity. Different generations of immigrants (including those from Eastern Europe) have different problems re access and communications. There are differences between different ethnic groups - they therefore have different problems of access, etc.'.

Others focused on the quality of the current service, e.g. 'Patients at Leukaemia and Myeloma Clinic at Marsden are seen within 24 hours of referral, usually irrespective of ethnic status. It cannot get better than this anywhere in the world. Inpatient and outpatient care for NHS and private patients is exactly the same, again irrespective of ethnic status'; 'with regard to our own service for children with cancer in an area with a small ethnic minority population and a generally well-educated group with only occasional barriers of language and cultural belief'. In similar vein, another respondent commented: 'On the whole the women I see are middle class and well educated, both white and ethnic'. A similar view was expressed by another respondent: 'For all the ethnic minority groups who are "second generation" and who have English as a very good second language, I am sure that what we deliver at the RMH is in the same excellent standard as for the non-minority patients. In my experience the only problems have related to language and possibly culture issues in patients coming from abroad. I think similar problems would arise in any "foreign" patient regardless of ethnic group, if they did not have good communicating skills'. Finally, one respondent wrote: 'RMH is a tertiary referral centre with few primary referrals as in a general hospital. Access is free and open to all'.

One respondent commented on ethnic coding, asking if there was any relevant difference (ethnically speaking) between British and Irish citizens (Are they ethnically different from any other Caucasian?).

Another respondent commented: 'Please be very careful to consider poverty as a cause of worse cancer outcomes'.

An additional comment was that 'Chinese in this country are often articulate and well-educated, most problems are either cultural leading to late referral (perhaps) or language barriers that could result in late diagnosis and certainly act as an impediment to participation in certain clinical trials i.e. very experimental therapy'.

Several respondents emphasised the diversity across ethnic groups, for example, 'as with all patients there is a wide range of prior knowledge and insight into their disease. In addition, as with all patients, patients from ethnic minorities vary widely in their disease coping strategies'.

A final important comment referred to the issue of representation: 'There are surprisingly few ethnic minority members of the nursing and medical (especially) staff of the RMH at the Fulham

Road branch. The same holds true for the management team where as far as I know there are *no* ethnic minority representatives. In addition there are relatively few ethnic minority patients in the RMH in the NHS sector. I suspect there are more in the private sector'.

29 nurses provided additional comments:

Several respondents commented about terminology and what the term ethnic minorities encompasses. One respondent commented about the word 'ethnic': 'I think the word...is often confusing...these Irish, Polish and other 'white' nationalities that are minority groups and for families first generation in this country the problems are the worst'. Another wrote: 'This whole questionnaire depends on whether one is presuming "ethnic minorities" are non-English speaking immigrants or refugees OR British citizens with an education and totally absorbed into the mixed culture that is UK. There are obviously a few "ethnic minorities" for whom understanding trials etc. in English would be very difficult. However, most "minority" groups are as capable as me!'

Others commented on the generally good provision for members of minority ethnic groups at the Trust:

'The Unit I work on takes patients from abroad, who do experience problems with accessing information and whom the majority have profound problems with communication. To a much lesser degree this may occasionally affect NHS patients. I feel within our Trust once the patient has been referred information giving, communication etc. is greatly enhanced, as I would define the barriers for all patients as being GPs and hospitals not within the Trust whom either misdiagnose or do not refer promptly'.

'I encounter many patients from various ethnic backgrounds. The younger patients are well educated, speak fluent English usually, and are well informed. Problems occasionally occur with their older folk or from patients new to this country. We desperately try to ensure that all patients are fully informed, but especially using interpreters whether family or independent (in attendances) it is very difficult to ensure that what has been said has been translated. Unfortunately at this time, we do not have information booklets translated into Arabic, Hindu etc. I'm sure this would be beneficial also for these patient groups'.

'I honestly believe (perhaps naively) that patients for whom I care for, irrespective of which ethnic minority group they belong, are treated the same as the general population. If I did not believe this to be true, I would find it difficult to work at the RMH or (NHS) because it would compromise my ethical view of human beings'.

'As a practitioner I am in a position whereby I am a supportive person for paediatric patients undergoing BMT. I feel as a department we are more cautious in their case and will often see them more regularly in outpatients so that if there are any information discrepancies we will have more opportunities to find this earlier rather than later. The children may often come over with minimal carers often not the mother who normally knows the child best. So again we would keep a closer eye on the child. When consenting and working up for transplant we would allow more time in the clinic for the family, especially if interpreter present or family need longer to comprehend what is being said. Cultural needs are met on the whole with lone middle east girls being given a cubicle etc. when taking off head-dress etc and not being seen by men. One child wrote a note asking everyone to knock before entering and staff good at doing this'.

'I feel that our area does not have a high ethnic mix so most of our patients from ethnic backgrounds are very much in the minority. There are therefore not many services specifically directed to them. However, when they do attend the hospital and use other services, I feel they are treated equally and an effort is made to meet their needs. More info for staff about specific cultural needs would be helpful'.

'I feel that at the RMH all patients are treated the same and that has been my experience over the last 8 years'.

Another respondent reported problems associated with HIV comorbidity: 'Many of the patients from ethnic minority groups I meet are from the private sector, so whilst there is language and diet problems, generally other issues are the same for white patients EXCEPT in the case where HIV is involved with the cancer where I have found the patients are NHS and do have problems coping in general with the problems/treatment related to HIV/cancer'.

Several comments related to private patients, for example: 'A large proportion of ethnic minority patients seen and treated at the Marsden are "Private" patients, either self funded or funded by their own countries. A lot of the problems we encounter are because this is their first and only

visit to Britain. Overwhelmingly the problem is language. We need more visual, pamphlet information which is more reliant on pictures and diagrams than text. (I have been informed that there is a language line always available); 'Unfortunately I feel I personally have not looked after a lot of different ethnic minority groups. Most of my ethnic minority group patients were private patients mostly flown over from abroad to get second opinions or extra treatment. Being private they get a better service. Access to all clinical trials. Have the money to provide good services on discharge'.

Other respondents identified particular ways in which the service could be improved: 'I think that many patients are referred to RMH tertiary hospital for 2nd opinion or in an advanced problem. These patients I think ask for this because many of these treatments are maybe available in their local hospitals or closer centres. I think ethnic minorities are less confident in asking and may be lucky to be referred or accept the standard treatment in their hospital. I think there needs to be standard referral criteria not just if a patient is eloquent/confident enough to ask for the Royal Marsden. We have patients from all over the UK who could get treated at other centres etc. and it blocks beds for those who really need them'.

'All patients menus should include information on how they can ask for halal meals. Information should be available on the resources available in the hospital for patients of differing religions/cultures. Each ward should have a Mecca compass. Staff read education on different religions. A Registrar on call should be available for families out-of-hours for patients that die at the weekend or bank holidays. And need cremation/burial in 24 hours'.

4. DISCUSSION

This report addresses just one set of factors in behavioural models of access to medical care in general and cancer care in particular, that is, the attitudes of secondary cancer care provider staff to the patient population, in particular that segment comprising minority ethnic groups. The complex broad and interactive processes in such models also include the characteristics of the patient population, the individual's context (family, social supports, culture, language, community/neighbourhood, region, etc.), communication between the patient and primary care providers, communication between primary and secondary care providers, the wider medical care environment and context, and outcomes of care or 'realized' access. Thus, access has many dimensions and the purpose of the survey is only to assess one of these, that is, attitudes of health care professionals in a secondary care provider.

With respect to the specific findings of the survey, the section '*Patients treated from minority ethnic groups*' focuses on a number of issues, notably, whether ethnic minority groups present with disease at a different stage to that in the general population and whether the clinical trial experience of members of minority ethnic groups differs from that of the general population. There is much anecdotal evidence to suggest that members of minority ethnic groups are diagnosed with cancer at a more advanced stage than the population in general. For example, Winship (1997), a member of a health authority breast cancer advisory committee, reports comments that Asian women are referred late for treatment of a breast lump and that some GPs still believe that Asian women do not develop breast cancer or that it cannot occur in young women. There are no research studies that have investigated this issue in Britain, one of the difficulties being poor ethnic coding on cancer registry databases and also cancer staging information that is incomplete. However, one US study (Polednak *et al.*, 1992) found the proportion of cases diagnosed at the metastatic stage was higher for black patients (35.4%) than for white patients (22.1%) and age-specific incidence rates for metastatic cancer were 1.5-3.3 times higher for black patients. The investigators concluded that earlier detection in the black population was needed to reduce black-white differences in stage at diagnosis and thereby reduce overall differences in survival rates. In another study (Wells & Horn 1992), cancer incidence data from three US metropolitan areas were coupled with census tract indicators of education and income. The data suggested that both black and white cancer patients living in census tracts with lower median education/income values are diagnosed in later disease stages than are patients with higher median education/income. Moreover, within education and income strata, black women

had a less favourable stage of disease at diagnosis than white women. Only in upper education/income levels did the disadvantage for black women disappear. Studies are needed in Britain that specifically address stage at diagnosis and also control for socio-economic status and other factors such as differences in tumour aggressiveness or potential response to treatment. The fact that around 16% of doctors and nurses thought that patients from minority ethnic groups usually or sometimes presented with disease at a more advanced stage than the general population provides indicative evidence that there may be real differences in stage at diagnosis in the minority ethnic group population.

With respect to the second issue addressed in this section, ethnic minority group participation in clinical trials, there is, again, a dearth of evidence in Britain. A systematic review of the literature on cancer and ethnicity found no studies where ethnic differences in clinical trial participation had been reported. Dieppe (2001) is currently investigating the causes and effects of socio-demographic exclusions from clinical trials, one of the six linked, specific objectives being to map the extent to which older people, women and ethnic minorities are excluded from trials in the UK, with a study report date of 2003. Such evidence as we have is based on US studies. Current US data indicate that many ethnic groups are currently underrepresented in cancer clinical trials, especially those of African American ethnicity (Svensson 1989; Underwood *et al.*, 1993; Underwood 1994; Kaluzny *et al.*, 1994; Brawley 1995). In 1995 Swanson and Ward (1995) reported that overall participation rates of minorities in clinical trials was very low, ranging from 3% to 20%, particularly for racial/ethnic minority groups. In an NCI-funded Breast Cancer Prevention Trial, African American women represented only 2% of the total BCPT enrolment and the total minority enrolment was only about 3% (Day, Ganz, *et al.*, 1999). However, in the South West Oncology Group treatment trials, the proportion of African American patients was similar to the proportion of African Americans in the US population of patients with cancer (10%) (Hutchins *et al.*, 1999). Also, a study of Asian American accrual in National Cancer Institute-supported trials was found to be representative of the cancer burden of Asian Americans in the United States (although Asian Americans 65 years+ were under-represented) (Alexander, Chu, *et al.*, 2000). One of the difficulties experienced in the US is the lack of robust information regarding effective minority recruitment strategies. Descriptive studies emphasise the importance of proactive recruitment, especially for prevention and cancer control interventions, and the involving members of minority ethnic groups (as potential participants or health care providers) in the design of cancer research trials. In the US Prostate Cancer Prevention Trial (PCPT), African American men comprised 4% of the total randomized sample compared to a goal of 8%,

even though minority recruitment was emphasised through the study manual and training that occurred at trial activation (Moinpour, Atkinson, *et al.*, 2000). Clearly, lack of representation of minority ethnic groups in clinical trials limits the ability of members of minority ethnic groups to benefit from the latest preventive, diagnostic and treatment interventions.

In this survey, around 5% of doctors and nurses took the view that clinicians were less willing to recruit members of minority ethnic groups into clinical trials as members of the general population, although 12 and 29%, respectively, were unsure. 16% of doctors and 12% of nurses thought that members of minority ethnic groups were not as willing to participate in clinical trials as the general population (although, again, high percentages - 27% and 44%, respectively - were unsure). 70% of doctors and 30% of nurses had had experience of recruiting members of minority ethnic groups into clinical trials, these respondents reporting many barriers, especially language (including the giving of informed consent). In addition, greater concerns with respect to ethnic minority groups, when compared with the general population, were reported for obtaining informed consent (44% of doctors and 64% of nurses), fulfilling safety requirements (11% and 33%, respectively), and ensuring follow-up (15% and 33%, respectively). As in a US study of the influence of structural, cultural, and linguistic constraints upon the participation of minorities in cancer research (Giuliano, Mokaua, *et al.*, 2000), speaking a primary language other than English, differences in communications style, mistrust of research, fear, lack of knowledge about the origin of cancer, lack of knowledge regarding clinical research, and cultural characteristics of the ethnic minority groups were all reported as barriers.

The section of the questionnaire addressing 'experience of barriers to treatment/care of minority ethnic groups' asked about respondent gender, age, and ethnicity barriers. Between a quarter and a third of respondents did perceive gender as a barrier (mainly in the context of patient/doctor or patient/nurse incongruity, especially with respect to Muslim/Asian women and Arab/Middle Eastern men). Age was reported as a barrier in only about 2% of respondents and respondent ethnicity a barrier in 5% of doctors but 10% of nurses. Physician characteristics, such as male gender (Lurie *et al.*, 1997; Schwartz *et al.*, 1991; Battista *et al.*, 1990; and Zapka *et al.*, 1992), older age (Schwartz *et al.*, 1991; Mann *et al.*, 1987), white race (Komaromy *et al.*, 1996; Moy *et al.*, 1995), specialty (Zapka *et al.*, 1992; Schwartz *et al.*, 1991; Weisman *et al.*, 1989; Weinberger *et al.*, 1991; Mann *et al.*, 1987; Bassett 1985; Albanes *et al.*, 1988, Bergner *et al.*, 1990), and a greater number of years since graduation (Bergner *et al.*, 1990) have all been

mentioned as constituting additional potential barriers to optimal cancer screening and treatment services in the wider literature.

Almost half the responding doctors and almost two-fifths of nurses reported that members of minority ethnic groups frequently or sometimes had different beliefs about the cause of their cancer. The most frequently mentioned different beliefs related to religious ideation, cultural beliefs/traditional folklore, and superstitions. Nurses frequently reported that ethnic minority patients frequently see the cause of their cancer as God's will or divine punishment. Around a quarter of hospital doctors and nurses thought that the beliefs of members of minority ethnic groups had ever been a barrier to care or treatment, a wide range of barriers being mentioned, many embedded within the particular beliefs and culture of members of minority ethnic groups but including religious objections to blood transfusions and the family's wish for the patient not to know the seriousness of the illness. Under 10% of doctors and nurses (9% and 7% respectively) reported that members of minority ethnic groups were less compliant with treatment. Finally, over three-fifths of nurses reported that their experience of discharge planning for members of minority ethnic groups had been different compared to those of the general population, the most frequent response being the greater family input amongst ethnic minority patients.

Respondents were asked which of a list of six factors contributed to ethnic variations in the incidence of cancers, the list being drawn from *The NHS Cancer Plan (2000)*. The hospital medical staff accorded importance to traditional 'medical' factors as compared with service-related factors. By contrast, hospital nursing staff accorded less importance to these medical factors and more importance to the service issues. Responses to questions about cancer stage at diagnosis and involvement of members of minority ethnic groups in clinical trials and research confirmed earlier findings on these topics and suggested some consistency in the survey responses. A substantially higher proportion of doctors than nurses thought that members of minority ethnic groups were more confiding/trusting of professional staff who treat them than the general population. However, more doctors than nurses (44% vs. 32%) thought that members of minority ethnic groups were less likely to seek a second opinion, a view that had been reported in the focus group with doctors. More doctors, too (15% vs 5% of nurses) thought that members of minority ethnic groups were less likely to receive "salvage" treatments, again a view that had been reported in focus groups with doctors.

In the initial systematic review of the literature, a number of statements (some evidence-based, others descriptive) relating to the views of members of minority ethnic groups towards their disease and treatment were identified. Eleven of these statements were tested. The strongest agreement for both doctors and nurses was for the statement: 'Amongst minority ethnic groups, the patient's family assumes a greater role in caring for the patient than is the case in the general population'. The Department of Health/Social Services Inspectorate report on inspection of community care services for black and ethnic minority older people had, in fact, been titled "*They look after their own, don't they?*" in an attempt to address the commonly held but - what they believed to be erroneous - view that members of minority ethnic groups tend to look after their own family members and, consequently, require caring fewer services. The strength of agreement with this statement (with 70% of respondents strongly agreeing or agreeing) is noteworthy.

There was also fairly strong agreement amongst both doctors and nurses for the statements: 'Members of minority ethnic groups are less likely than the general population to believe that a patient should be told of a poor prognosis' and that 'Members of minority ethnic groups are less likely than the general population to believe that a patient should be told the diagnosis of metastatic cancer'. Responses to other questions in the survey corroborate these findings.

A major section of the survey addressed information needs and communication. Questions were asked about level of demand for information/advice and level of provision for members of minority ethnic groups. Around a third of doctor respondents and almost as many nurses felt that members of minority ethnic groups were less likely to request information/advice than the general population. Further, around 10% of doctors and 18% of nurses thought that members of minority ethnic groups were less likely to be provided with information/advice than the general population. The most effective methods of conveying information/advice were reported as word of mouth, use of interpreters, and via friends and relatives, and (amongst nurses only) leaflets or brochures. Virtually no use was made of video, audio cassette, group sessions, and local media. Around 22% of doctors and 37% of nurses reported that information was not available in other languages.

These findings are noteworthy. Many studies have demonstrated the importance of information and communication in helping people to cope with cancer (Cassileth 1980; Fallowfield, Ford *et al.*, 1995; Coulter 1998; Ford, Fallowfield *et al.*, 1995; Meredith, Symonds, *et al.*, 1996; National Cancer Alliance 1996). Research studies show that the vast majority of cancer patients wish to be informed about their illness (Meredith, Symonds, *et al.*, 1996). *The NHS Cancer Plan* addressed

information needs, requiring 'all NHS Trusts and cancer networks...to make available high quality information...to all cancer patients. Information must be culturally sensitive and specific to local provision of services, as well as information about the type of cancer and treatment options'.

Around 87% of doctors and nurses had ever found communication difficulties arising from language a barrier to treatment or care of patients from minority ethnic groups. While only a small number of respondents reported that there was no translating/interpreting service available during normal hours, high proportions of respondents reported use of non-professional persons for translating/interpreting: 47% of doctors and 32% of nurses had reported using a child in the patient's family, 88% and 91%, respectively, another member of the patient's family, 76% and 70%, respectively, a friend of the patient, and 67% a member of the hospital staff (excluding designated interpreters). Language appeared to be the greatest barrier in the Arab/Middle East groups, Indian subcontinent groups, and Chinese, but frequent mentions were also made of refugee communities and some European groups. An overwhelming proportion of doctors (85%) and nurses (76%) reported that culturally sensitive written information was not available.

Concerns about language barriers have been widely expressed in the NHS, given the shortage of interpreters and translating services, the high cost of these resources (the cost of providing an interpreter in a community setting has been estimated at £0.33 per minute²), and the widespread demand for these services. Interpreting, translation, and advocacy are all extremely scarce resources in the NHS and the needs of patients for these services frequently go unmet. The second black and minority ethnic groups national survey (Johnson, Owen, & Blackburn, 2000) found that, amongst women aged 16-29, while ≥96% of Indian and 93% Pakistani women could speak English and read English, around only 85% of Bangladeshi women could do so. The percentages able to speak and read English were markedly lower in each of the ethnic groups amongst women aged 30-49. In one practice setting (for females) around the following proportions of each ethnic group required an interpreter: Caribbean, 0.10; African, 0.40; Black Other, 0.10; Indian, 0.10; Pakistani, 0.30; Bangladeshi, 0.40; Chinese, 0.10; Other Asian, 0.10; and Other, 0.10 (Zeuner *et al.*, 1993). Clearly, information and communication must be available in community languages where needed, either through regular face-to-face interpreting or a

² Provided by the Association of Community Interpreters, Translators, Advocates, and Link Workers.

properly trained and certified telephone interpreting service (promised in the NHS Plan through NHS Direct by 2003 [Department of Health, 2000]).

Finally, some specific questions on access were asked. About a fifth of respondents thought that members of minority ethnic groups had poorer access to screening and other preventive services. The most frequent response to how these services could be improved were provision of information in appropriate languages in community and other settings and better interpreting services. With respect to demand for complementary therapies, a substantial proportion of doctor and nurse respondents said that they did not know. Significantly, a high proportion of doctors (40%) thought that the demand for counselling amongst members of minority ethnic groups was less than that in the general population. Around 16% of doctors and nurses responded that they did not feel that members of minority ethnic groups had equitable access to cancer services in general. The most frequently mentioned barriers to access were language barriers, lack of knowledge of service availability, and reticence in seeking a second opinion. Amongst a given list of reasons for difficulty in accessing services, again the most frequently mentioned was the language skills of the patient, followed by patient's difficulties in travelling to the hospital, and the literacy skills of the patient. 5% of doctors but 11% of nurses felt members of minority ethnic groups did not receive the same quality of care as the general population. Once again, language and communication barriers were the main issue. Amongst respondents, the most frequently mentioned single measures thought to most contribute to improving access for members of minority ethnic groups were also improved access to written information in a variety of languages, better access to interpreting and translating services, more culturally sensitive information, and wider use of staff from minority ethnic groups in a range of roles.

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