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BEING TREATED LIKE I WAS SOMEBODY

QUALITY HOSPITAL CARE

**Guidance for professionals working
With black and minority ethnic elders
In hospital settings**

**With support from the
Department of Health, Older
People Section**

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CONTENTS

	<i>page</i>
Section 1 Introduction	3
Section 2 Preliminary Findings And Supporting Evidence	19
Section 3 Patient Centred Model For Hospital Care For BME Elders	32
Section 4 For The Patient Centred Model	49
Section 5 Assessment For The Patient Centred Model	57
Section 6 Resources And List Of Contacts	63

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SECTION 1

INTRODUCTION

Being Treated Like I Was Somebody.....

The context

‘Service users and their carers should be able to expect that procedures are in place to identify and where possible to meet any particular needs and preferences relating to gender and personal appearance, communication, diet, race or culture and religious and spiritual beliefs’. (NSF For Older People DH 2001)

As a direct response to the NSF requirements, work done by PRIAE on the delivery of Quality Hospital Care to BME elders has resulted in three substantial products. Two of these products, the Patient Centred Model and a Kit are for professionals working in hospital settings and one, a Personal Health Notebook, is for BME elderly patients. All three products cut across all boundaries and are fundamental for all aspects of hospital care, whatever the condition BME elderly are hospitalised for. The products relate only to in-patient stays, and where admission to hospital is either elective or as an emergency.

This is a guidance document based on a project, funded by the Department of Health, on delivery of Quality Hospital Care for Black and Minority Ethnic (BME) elders. Its starting point is the Department of Health's National Service Framework For Older People (NSF), which recognises that:

- Older people are not a uniform group and have a wide range of needs.
(Setting The Scene, para 9)
- All services should be culturally appropriate, reflecting the diversity of the population that they serve and ensuring that services are accessible for those that do not have English as their first language. (Setting The Scene, para12)
- Older people from the BME groups can be particularly disadvantaged and are likely to suffer more discrimination when accessing services.
(Standard 1.5)
- Managers and professionals should recognise individual differences and specific needs, including cultural and religious differences. (Standard 2.1)
- Staff communicate in ways, which meet the needs of all users and carers, including those whose first or preferred language is not English.
Interpreting and translation must be in place. (Standard 2.8)

What the NSF, however, does not prescribe is how hospitals, primary care trusts, and community services should meet the particular needs of BME older people. The emphasis in this report, therefore, is on how professionals could identify needs of BME elders, and the steps they need to take to meet those needs. The context for this project is provided by work PRIAE did for 'Help the Aged -Dignity on the Ward' campaign, with the aim to establish BME elders' expectations of all stages of hospital

care. PRIAE reported on issues of access and cultural appropriateness from a BME elder's point of view, and on professionals' responses to meeting the diverse cultural and religious needs of BME elders.

PRIAE found that from a BME elders' point of view, the expectation was that when they were admitted to a ward they would be well looked after and that they would receive sensitive and appropriate medical care. Whilst on the ward, they wanted professionals to show willingness to listen and learn from the patient. For BME elders, being understood as a patient was most important, with doctors taking the trouble to explain things, accompanied by good nursing care. Overall their wish was to be cared for in a cheerful, friendly atmosphere where there was a multi-racial workforce. In so far as bad hospital care was concerned, what concerned them was a lack of interpreters, racism, staff insensitivity, staff not trying to understand and an inability to communicate with the doctor.

Professionals interviewed for this project defined dignity as elders having a full life, with cultural, linguistic and religious needs being met. For them, getting racial and cultural backgrounds reflected on the ward was a priority. Staff training and recruitment were crucial areas if BME elders were to lead a full life.

Whilst most BME elders interviewed described their entry onto the ward as good, or very good, these initial responses changed to negative responses when asked about their expectations at different stages of their stay in hospital. Their initial high expectations were not met either, in terms of the dignity they expected i.e. to be treated equally and with respect. Though this report came out before the publication

of the NSF, its findings provide a useful reference points for what the NSF is trying to achieve in relation to the care BME older people receive.

For example, Standard 2 of the NSF requires, ‘NHS and social care services to treat older people as individuals, and to enable them to make choices about their own care.’ This equates to the importance BME elders placed (as reported in the Dignity on the Ward campaign), to being understood as a patient, with doctors taking the trouble to explain things. Similarly, their expressed concern about being unable to communicate with the doctor, affected the extent to which they were able to make choices about their own care.

Similarly, Standard 4 (General Hospital Care) requires hospitals to ensure that, ‘older people’s care is delivered through appropriate specialist care and by hospital staff who have the right set of skills to meet their needs.’ As reported in the Dignity on the Ward campaign, BME older people expected to receive sensitive and appropriate care, and wanted professionals to show a willingness to listen and learn from the patient. One of the recommendations of Equality Standards in Health and Social Care (Khan 2001, not yet published) was that consideration should be given to setting standards that follow a format similar to that of the National Service Frameworks. It also suggested that Tool Kits provide innovative and flexible means of aiding the implementation of core standards.

Consequently, the focus of this project is on what is required of health and social care services to meet the needs of BME older people, in relation to Standard 2 and

Standard 4 of the National Service Framework. Particular emphasis is placed on some of the key interventions specified for those standards namely,

- Informed Choice: the provision of information so that elders and carers are involved in decisions about their care (2.1)
- Single Assessment Process (2.7)
- Communication (2.8)
- Emergency Response (4.6)
- Early Assessment (4.10)
- Ongoing Care (4.12)
- Hospital Discharge (4.28)

These have been chosen because they have been previously identified, through our field-work and through literature review as being the ones where hospital services have not always been appropriate for BME elders.

Methodology

Fieldwork carried out with BME elders and professionals helped match the key interventions specified for Standard 2 (Person Centred Care) and Standard 4 (General Hospital Care) to what they identified as core components in the delivery of care to BME elders. A total of six focus groups were held with BME elders in Birmingham, Leicester, London, Manchester involving 60 older People from African, Caribbean, Chinese, Indian and Pakistani communities. In addition, during the last two years, several seminars and meetings were held with professionals from both PCTs and acute Trusts In Blackburn, Burnley, Dartford, Oldham and London.

The purpose of the group discussions with older people was to hear from them about their experiences in relation to the key interventions specified for the NSF. The seminars with professionals in Blackburn and Oldham were concerned with identifying examples of good and bad practice. The seminars in Dartford and Burnley were devoted to establishing the validity of our approach to enable hospitals to satisfy the key interventions specified for Standard 2 and 4.

Summary of Focus Group Discussions and Seminars

- For BME elder's referrals from primary care were identified as being problematic. Elders themselves were concerned about the service they received from their local GP. For elders with multiple pathologies, compliance with medicine was an issue. Most BME elders were reliant on family and carers for support and information on hospital procedures throughout their stay. The main issue here was being able to communicate with the doctor, not only in explaining their condition, but also in relation to understanding the treatment proposed and the medication to be provided. Issues of language and communication were key issues raised by elders and further concerns were the provision of food, (i.e. meeting dietary requirements), and arrangements for discharge.
- For professionals, training, research and public involvement were important if hospitals were to know how to meet the needs of BME elders. A prerequisite was knowledge of the local population profile so that information on language and dietary needs, privacy needs in respect of

meditation or prayer, and the likely involvement of family in decisions around consent could be available. Insofar as enabling elders to be informed about their stay, integration of information about hospital procedures, with general information such as the layout of the hospital, was necessary. Staff needed to know how to access interpreters and elders needed to know that they could have interpreters. A variety of formats needed to be used for the dissemination of information taking into account sensory needs and language requirements for example.

- In relation to assessments, BME elderly had to have the term assessment explained to them, and to ensure that they understood what it involved and entailed. It was also important to establish from elderly BME patients what their level of understanding was about their condition, particularly where they had multiple pathologies.
- In relation to discharge, the appropriateness of referrals depended on what was available in the community and knowledge of the services available. This was necessary so that rehabilitation programmes could be tailored to individual needs.
- The importance of user involvement in the commissioning of services across the board was emphasised.

Fieldwork was followed by literature review to contextualise these findings. A review of relevant reports and publications from Primary Care Trusts, Acute Trusts, the Department of Health, the Commission For Health Improvement, and other relevant organisations was also conducted. This led to a Framework Document for consultation to seek views of managers and other medical professionals in the

National Health Service on the products emerging from this project, the Patient Centred Model and Kit for professionals and a Personal Health Notebook for BME elders. This was followed by a national seminar to disseminate the findings from the consultation and to share examples of good practice.

Summary of Responses to the Framework Consultation

The purpose of group discussions and seminar was to identify whether our approach was a valid one and whether it would work. It was also to assess whether we had identified the right core components for purposes of intervention.

- The respondents were of the opinion that our approach was valid on the whole. It was also described as being very positive as the needs of BME elders were being addressed through using the NSF for Older People as the cornerstone of our framework.
- The response in terms of whether our approach would work was also very positive, as the actions required were also based on the NSF, which was known to the professionals.
- However there was a concern that acute wards may not have sufficient staff with appropriate expertise required for the care of the elderly in general and BME elders in particular.
- There was some concern that the framework did not have sufficient detail and the proposed approach presumed a detailed and in-depth knowledge and competency on the part of the health professionals.
- With regard to our choice of core components there was an overall agreement that the components were appropriate and relevant.

Policy and Practice

This section includes some examples of how policy can be translated into practice. A good illustration is a strategy document prepared by the then Kensington and Chelsea Health Authority (now part of Westminster Primary Care Trust) entitled Facing Up To Difference (Kings Fund). The principles enshrined in this strategy document are equity of access and principles of provision, with the strategic objective of reducing variations in health status and the experience of using health services where such variations are attributable wholly or partly to ethnicity. A significant message from this document was that the actions required to achieve the strategic objective needed to be shaped by:

- Information: concerning the ethnic makeup of the communities served.
- Needs: paying particular attention to specific conditions and diseases.
- Access: recognising that access to services may be hindered by language and/or culture.
- Appropriateness: ensuring that services provided are culturally appropriate.
- Variations: acknowledging cultural and racial linguistic and religious diversity within BME communities and recognising also that their knowledge, expectations and experience of the health service will vary.

In relation to developing culturally competent services for BME elders Peterborough PCT produced, as part of its Cultural Awareness Training Programme an interesting visual representation, in the form of a jigsaw, of the pieces that together form a

culturally competent service. The factors identified by Facing Up To Difference can be easily located in various pieces of the jigsaw. For example, in order to develop health promotion education, alternative therapies, and appropriate tools for needs assessment, it is vital to recognise individual differences and specific needs, including cultural and religious differences. Similarly, joined-up thinking needs to begin with information about the ethnic makeup of the communities served in order to achieve a representative workforce, employment of key workers, and referral from primary care.

Wigan and Bolton Health Authority (now part of Bolton PCT) also drew up an ethnic health strategy as part of its response to its responsibility for meeting the health needs of all members of its population recognising that where ethnic minorities are concerned, particular factors need to be taken account of, this strategy identified five priority areas in terms of implementing a programme of action namely:

- Needs assessment.
- Involving local communities.
- Service delivery and access.
- Monitoring effectiveness.
- Their role as an employer.

The document outlines specific objectives for each of these priority areas and appropriate actions are proposed for each of these objectives. A further detailed summary of the potential issues for health needs assessment is included. It is encouraging to note that these actions are made explicit and broken down by prevention, primary care, secondary care, community care and rehabilitation. For example, in the case of stroke, each of these includes a specific reference to the needs

of BME groups. The list of actions included below is a sample and is by no means an exhaustive list.

- Health -visitors and health promotion to work with ethnic minority groups to raise awareness of the effects of obesity or risk of cardio-vascular diseases. (prevention)
- Provide culturally sensitive respite care in partnership with ethnic minority voluntary sector agencies. (Primary)
- Establish whether culturally sensitive care and services are provided in hospital settings. (Secondary)
- Review hospital discharge procedures to ensure that there is adequate and appropriate support after discharge. (Secondary)
- Ensure continuity and flexibility of care to both users and carers are sensitive to ethnicity and culture. (Community Care)
- Increase, where appropriate, the number of ethnic minority staff who provide direct services at key points-such as discharge planners, home care assistants, meals at home and community nurses. (Community Care)
- To develop a multi-agency strategy for stroke in line with the NSF which is sensitive to high risk ethnic minority population. (Rehabilitation)

The Patient Centred Model

There seems to be a remarkable degree of consensus in terms of what is needed in the general areas of service delivery for BME elders. Though some of the findings and policy initiatives relate to work done prior to the publication of the NSF for Older People, they mostly seem to meet the key interventions specified for Standards 2 and Standards 4.

There is an agreement that professionals in hospitals need to consider issues of information and communication, access in terms of language and culture, patient needs in their widest sense, appropriateness of service delivered, and the variation in terms of communities served. The outcomes that are being sought are the provision of quality hospital care, maintaining dignity and respect and ensuring privacy. Additionally, The Department of Health has an ongoing agenda to make the health service more patient centred. The model that is being offered in this report is patient centred and the focus is on how the care and services offered by hospitals address the needs of BME elders throughout their journey from pre-admission through to admission, hospitalisation and aftercare. The core components of this Patient Centred Model are chosen to reflect the discussions in the field-work and previously identified issues. It includes:

- Referral and Pre-admission- (communication and information needs so that the patient is fully informed about their care and is involved in decisions around their care)
- Admission and Hospitalisation (Single Assessment Process)
- Treatment and Medication
- Hospital Discharge and After Care

This Patient Centred Model (PCM) should enable hospitals to identify, as a matter of routine, whether or not they are able to meet religious, cultural, linguistic, and dietary needs. This means they will be able to develop policies and procedures to assist them to capture essential information around linguistic, cultural, religious and other needs, which, in turn, will allow them

to involve BME elders and their carers in decisions around their care. For example treatment plans need to be understood by patients, especially where older BME patients need to make decisions around informed consent. Similarly, aftercare services need to be better publicised to avoid inappropriate discharge and ensure satisfactory rehabilitation. The success of such a model depends on ensuring that hospital policies and procedures are informed by:

- Up-to date data on the makeup and variations within the ethnic minority communities they serve.
- The accessibility and appropriateness of the information they provide to BME elders before, during, and after the hospital stay.
- Knowledge about communication needs of BME elders in relation to assessment, diagnosis, treatment plans and discharge.
- The appropriateness and accessibility of services BME elders are referred to on discharge.

The Self Assessment

The PCM with all its components also lends itself to being used as a self-assessment mechanism to ensure that appropriate audit and benchmarking takes place with the aim of ensuring that BME elders receive appropriate and sensitive care. We have developed the Audit Tool in such a way that there are clear links shown between NSF standards, the components of the PCM and the key interventions necessary to ensure its implementation. We have further developed a self-assessment framework for health professionals to use and develop appropriate action plans. We have used a similar format to that developed for the Essence Of Care Tool Kit (DH 2003), as many professionals

will be familiar with using it. The process of self-assessment should help professionals to identify gaps in the service and develop individual action plans as necessary.

Personal Health Notebook – Learning From Elders

This is what can be described as value added outcome of this project, as it is primarily for the benefit of BME elders. What is even more significant is that the concept of this Notebook originated from an 84-year-old Asian woman, Mrs Shantaben R Patel, who believed that it is better to be prepared than face unnecessary hassle with staff who might or might not understand her language and who may also display negative attitudes towards her, thus making essential information exchange very difficult. This Notebook has been developed to help older people from black and minority ethnic communities and their carers to help make their stay in hospital as smooth as possible. In addition to relevant personal data, such as Hospital Number, name and number of their GP and next of kin, it will include information about:

- What to take to hospital,
- What they can expect while they are there
- What they will need to know before they come home
- Elders’/Carers chance to make Notes about hospital care and treatment for future reference

Personal Health Diary
Personal Health Diary

It will also allow elders to enter information about current medication, allergies, and dietary preferences. This Notebook has spaces for elders to fill in details similar to those that they will be asked to give when they go into hospital. It will be of use in emergency situations, or in situations where an elderly person is living on their own and there is no one from the family around to answer basic questions about their identity and preferences. The purpose of such a Notebook is to give elders control of key information that hospital staff, in A&E or elsewhere, would need. There are several ways in which this Notebook could be used both by BME elders and health professionals, but ultimately it belongs to the patient, who determines what is included in it and who can have access to it and when.

Summary

The approach we have adopted to delivering quality care to BME elders is an innovative one. Its major strength is that it is rooted in the NSF for Older People and the best practice identified for delivering culturally competent care is drawn from work done by PCTs and health authorities. The components for the PCM are also firmly rooted in the NSF and are linked with providing guidance on best practice. This will not require professionals to undergo lengthy training in its use as it is expected that they will be familiar with the essence of care toolkit. However, they will still require training in understanding issues relevant for the care of BME elderly.

The response of professionals to this approach has been positive and a general comment has been that the PCM core components approach can be adapted to meet

the needs of all older people as well. Another advantage of this is that it can be adapted to meet local needs, as is being demonstrated by the commitment of Newham PCT to incorporate the Audit Tool in the pilots they were running to finalise their Single Assessment Process. From their point of view, the attractiveness of the Audit Tool lay in its links with the Essence of Care Toolkit and its focus on patient centred care. Furthermore it had the potential to provide evidence of the quality of person centred care delivered in health and social care settings. During our consultations, the response to the Personal Health Notebook was also very positive. BME elders agreed that it would be very useful to have such a Notebook and health professional thought it would be useful to have such a Notebook for all elders.

Section 2

Preliminary Findings and Supporting Evidence

Being treated like I was Somebody.....

Introduction

This section includes a summary of issues arising from seminars and group discussions with BME elders and professional working with them. It also includes further supporting evidence from a range of published sources and project reports relevant to the needs of BME elders in hospital care. A standardised interview format was used for all group discussions covering all aspects from pre-entry to discharge. Group discussions were also held with professionals on what they considered good and bad practice in relation to key areas identified in Standards 2 and 4, namely patient involvement, assessments, treatment plans and discharge. The findings are organised around general issues relevant for each stage of hospital care from referrals and pre-admission, admission and hospitalisation, diagnosis and treatment through to discharge and after care.

BME Access To And Use Of Health Services

There is considerable evidence that BME access to and use of health services in general and that of BME elders in particular is significantly influenced by their race and ethnicity. The Commission for Health Improvement (CHI) in their report *Unpacking the Patient Perspective* (2004) describe the variations in the experiences of NHS patients across England. Their findings suggest that people of minority ethnic origin generally have a poorer experience of health services than their White or Irish counterparts. Similarly, *Improving Older Peoples'*

Services: An Overview of Performance (Bainbridge & Ricketts Department of Health 2003) reported that almost all the Councils inspected had gaps in their provision for meeting needs arising from minority cultures. These were for more intensive services, including respite and residential care. Where the services provided were not culturally sensitive, there was considerable potential for isolation and poor outcomes

Another report on Elders' Health: The Voice of Experience (Age Concern, London) highlighted different ways in which many minority ethnic elders suffer double jeopardy in their use of the NHS. The report questioned whether current policies and practices were suitable to meet the needs of the most vulnerable older people. The report recommended, amongst other things, *the need to review the provision of information and the time allowed for consultations, to ensure the needs of minority ethnic elders are fully taken into account and hospital discharges are carried out effectively.*

Lowdell et al. (2000) reported on the current information on the Health of BME elders in London, and the services they need and use and made recommendations for service improvement. Prior to that, Lee, Syed and Bellis (1998) summarised factors affecting the health of BME populations in the north west, exploring issues around access to services, and listing initiatives designed to remove barriers to service use. Evandrou (2000) investigated the lifestyle, resources and status of BME elders in Britain and found significant differences both between and within minority groups. Johnson and Smith (2002) also found evidence of racial and ethnic disparities in health outcomes and argued that whilst socio-economic factors are the most powerful determinants of health status, membership of a minority ethnic group is a significant predictor of reduced access to intensive, quality care. They concluded that structural modifications and increased collaborative and community based work are the key to reducing

disparities. Ren, Amick and Williams (1999), in analysing the link between (self-perceived) discrimination on the grounds of race or socio-economic status and (self-assessed) health status, found that experience of discrimination does have a strong negative association with health. Berger (1998) described how patients' perceptions and attitudes are mediated by ethnicity, and identified correlations between race/ethnicity and attitudes to treatment, organ donation and disclosure of the patient ?? is a significant factor with regard to this. There is further evidence (Gallant and Dorn 2001) that suggests that the examination of older adults' health behaviours by race and gender will lead to a fuller understanding of these behaviours.

Another significant factor influencing the access to and use of services is that of language and cross-cultural communication. Ashraf (1999) reported that advocates based in Hackney expressed concern that though the advocacy budget had been cut, the number of people requiring this service was rising. They warned of the difficulties of communication between hospital staff and the increase of racism amongst health care professionals. Galanti (2000) in *Caring For Patients From Different Cultures: Case Studies From American Hospitals*, provided examples of problems resulting from cross-cultural misunderstanding, organised around themes such as communication, pain and dietary practice. It also includes guidance on the avoidance of these and similar problems. Elderkin-Thompson, Silver and Waitzkin (2001) found that around half of all encounters result in serious miscommunication, with either the credibility of the patient's concerns or the physician's understanding of symptoms being affected. In light of the increasing requirement for untrained Bilingual staff to act as medical translators, this study examines the accuracy of their interpretations.

Culturally Competent Health Care

There are several examples of guidelines developed to help professionals deliver culturally competent health care to BME groups in general. Facing Up To Difference: a Toolkit For Creating Culturally Competent Health Services (Chandra, Kings Fund 1996), for black and minority ethnic communities, offers a guide to purchasers of and those commissioning services for ethnic minority groups and provides examples of 'good practice'. Prasaad, Steiner and Rubel (2003) also recommended core curriculum guidelines on culturally sensitive and competent health care. Culturally Competent Care Minhas et al. (2002) is another Good Practice Guide For Care Management: Developing Services For Black And Minority Ethnic Older People and Their Carers. This guide was designed as a planning and assessment tool for practitioners working with BME elders, and also has a 'best practice' checklist.

However, despite the availability of several resources giving guidance on the delivery of culturally competent health care, the situation on the ground was different. The Chinese elders we interviewed felt that their needs in terms of language, culture, religion and diet had not been adequately met. Dietary requirements were raised as an issue which hospitals were trying to meet, but could not get quite right. Chinese elders had the most difficulty with having their dietary requirements met. We were also given an example of one elderly Punjabi woman who discharged herself because she was having difficulty swallowing rice and the hospital had told her that they were unable to provide anything else other than bread. She did however discuss her intentions with her doctor and also with her son. Following her discharge she received a letter from the hospital wanting to know what had made her discharge herself. Fortunately, on this occasion, there were no ramifications in terms of her follow up treatment.

In discussion with link workers and advocates, concern was expressed about families wanting the elder to return home and forgoing rehabilitation. To some extent cultural attitudes to rehabilitation were blamed for this scenario as rehabilitation did not involve any medication and was not perceived as being able to cure the illness. Additional explanations offered for untimely self-discharge included a strong sense of duty on the part of family to look after their elders and the expectations BME elders had of their children.

One elderly person summed up the situation admirably when he said that, 'having dietary needs and other cultural and religious needs met depended on where the hospital was located'. Giving his own example, he said that he had originally been in a city centre hospital which, because it had a large ethnic minority population to serve, was better able to cope in terms of meeting his cultural and religious needs, than the hospital he was transferred to on the city outskirts, where they were unable to meet his religious and cultural needs. BME elders were more involved in decisions about their care where they were able to communicate directly with doctors and hospitals, or where interpreters were available. However, in situations where there was no family carer, interpreter or a member of staff who could speak their language the BME elders found themselves isolated and it was difficult for them to be involved in decisions about their care.

Dicicco-bloom and Cohen (2003) Study of the Occurrence of Culturally Competent Care describes how some Home Care nurses manage and orient themselves around cultural issues by using strategies, which minimise the need to address cultural differences. The study suggests that work therefore needs to be done to help them

integrate the theory and practice of Culturally Competent Care. One good example of a case study (Cohn, Lyons, Fink, and Marker 2000) using multi-method approach in assessing an ethnically diverse aging population is to be found in a multi-method needs assessment which was conducted in a large, ethnically and linguistically diverse home for older people. In this case study quantitative and qualitative methods were used to gather data on personal care, mobility, facilities and culturally specific needs and the findings were used as a basis for changes in practice.

Referrals and Pre-admission

It was felt by professionals that there were lots of issues around management of care in primary services. Disease management clinics for example, tended to be run by practice nurses (in this particular area), who would have been unable to speak other languages. In these situations where BME elders were not accessing those services because the language support was not there, it was not unusual that referrals were on the low side. In the case of mental health services, lack of interpreters meant that referrals were not being made and that led to services not being accessed by BME elders. It has also been suggested that the standardised assessment form for referral to mental health services was not culturally appropriate. Being referred to services was described as being, 'like a lottery' for BME elders. Where professionals referred them on, it depended on the knowledge of services for BME elders on the part of that particular profession.

Cawthra (1999) argued that older people's health information needs do not differ significantly from anyone else's and looked at how different information formats might be used for two specific groups such as carers and elders from BME groups. He

also emphasised the need for users to be involved in information development, and for primary care workers to become better informed as to how other services in the public and voluntary sector operate. During our seminars, group discussions and one-to-one interviews with professionals in Oldham, Blackburn, Dartford, Burnley and London, it was clear that there was a breakdown of communication on both parts. On the one hand, GPs were not spending enough time with older people, so older people felt frustrated, whilst some older people were either not aware of the services available, or because of language and communication problems were not aware how to access them. One professional described the situation as such: *'certainly for me, I mean I am quite new to this area, new to working in a multi-cultural environment and my expectation was that I was going to have a steep learning curve, and I haven't had it, because the referrals are not there.'* She went on to say: *'I mean in hospitals, there do not seem to be the numbers on the wards that I was expecting to see, and certainly on the community services referring in, the numbers that we are getting are very, very tiny.'*

The majority of BME elders we interviewed, were also of the opinion that their GP was not spending enough time with them and was not giving serious consideration to their complaints. Language problems and general difficulties with communication were cited by them as reasons for not being referred to hospital. Where referral was made the 'lag of time' between the referral their admission to hospital resulted in elders forgetting their admission date. For those elders with multiple pathologies an additional problem was that they did not know which of their complaints was being dealt with. The issue here is whether BME elders were presenting themselves late, via accident and emergency departments, to hospital as a result of not having faith in their GP. A further issue is the level of information that these elders had about procedures,

either in relation to accessing services, or providing for themselves. Most elders were reliant on family and friends for information about what was available and the danger here was that they were misinformed about what was available. There is also the issue about the lack of information and the misinformation hindering access to services.

Admission and Hospitalisation

With regard to assessments, professionals expressed concern about whether essential data relating to cultural and religious needs was being captured. The situation was worse where there were no link workers. An example was offered where a speech and language therapist who, on her own initiative, was building up a resource pack on different cultures and religions which would help her to work more appropriately with BME elders. She was particularly interested in gaining a better understanding of cultural attitudes to occupational therapy and how it impacted on the treatment of patients. Waxman, & Levitt (2000) in their assessment of whether non-English speaking patients who present to an emergency department with two specific complaints have a greater number of diagnostic tests ordered, have higher admission rates and a longer length of stay than English speaking patients, found that though more tests were ordered in relation to complaints of abdominal pain, but not in relation to chest pain, and there were no significant differences in admission rates or length of stay.

Our discussions with BME elders revealed that where people were admitted to hospital via accident and emergency department, there were some fairly long periods of waiting. One elderly person complained that he had a six hour wait, simply because an interpreter could not be found and he had to wait until that interpreter arrived. The majority of the elders who could not speak English said they were dependent on their carers or relatives for information on procedures. But the lack of knowledge of procedures was not the only problem. One Chinese elder complained that he missed his appointment because when he got to hospital he did not know where to go and because he did not speak English, there was no one he could ask. For

him having signs in Chinese would certainly have helped. Cortis (2000) study of Pakistani (Urdu speaking) Communities' perceptions and experiences with hospital-based nursing care in the UK showed a lack of parity with the group's expectations, which was attributed by participants to the continuing presence of racism in health care services. Consequently the study recommended changes at all levels of health care delivery.

A good illustration of BME elders' experiences and expectations of health care is to be found in 'Dignity on the Ward' a PRIAE report for Help the Aged (Patel 2001). This report was part of Help the Aged's Dignity on the Ward campaign, and made recommendations for service improvement by acting on the lessons from hospital experiences of black and minority ethnic older people. The report was based on interviews with 32 elders and 3 managers and includes issues such as language, food and workforce diversity.

Diagnosis and treatment

It was felt by professionals that the diagnosis process was one area where BME elders lacked awareness. For a variety of reasons, lack of communication or lack of time on behalf of the professionals to go into details with the patient, caused problems. Where trained interpreters were not available older people relied on family members, and the quality of information available depended on who the family member was at that time. It was also the case that, in the Asian community in particular, BME elders relied far too much on close family members. One consequence was that when the diagnosis was being taken, the family member might end up answering questions for the elderly person, without realising that the symptoms described by him/her might lead to a different diagnosis.

Jin, Slomka and Blixen (2002) considered the impact of problems peculiar to Asian patients on diagnosis and treatment, and argued that an awareness of language barriers, socio economic status, and different health beliefs and practices is a critical component of competent care. This was also evident from our discussions with BME elders who revealed that understanding diagnosis was problematic. Diagnosis had to be explained by relatives or carers and in some cases relatives or carers waited till the doctor came to see the elderly person so that they could ask about the diagnosis. The elderly person was also anxious in case the carer or relative might not understand precisely what the doctor had said, because they, for instance, were very unlikely to know what a normal level of blood pressure was. The inability to communicate was particularly difficult for one elderly person, who was originally admitted to hospital with spinal problems, but in the third week of his stay was diagnosed as having a kidney complaint. It was fortunate that an interpreter was available as he was able to understand the diagnosis that had been made.. In terms of medication an example of a normal response was: ‘I asked my son to tell me what I had to take’. Some complained that they did not understand when they had to take their medication and in what order. On treatment plans the professionals reported that policy in one Trust was that in terms of providing an interpreting service for people whose language was not English they did not use volunteers. They did not use children under 16 and they severely discouraged the use of family members, particularly when it came to taking informed consent, for example. In these situations professionals were required to seek the services of a properly trained interpreter. However, in another area where an interpreting service was not provided, the issue of elders understanding their treatment plans was a major concern.

Schmucker and Vesell (1999) argued that whilst the elderly are a growing sub-population, and use a disproportionately large share of health related resources - in particular medication - they are often absent from the trials of drugs destined for their consumption. If the safety and suitability of drugs is to be ensured, their participation in clinical trials needs to be more closely monitored.

Discharge and Rehabilitation

The BME elders we interviewed raised discharge procedures as an area for which they wished to have more information. The range of information they were given varied from being told 'drink more water', to being given, in the case of an elder with stroke, an active rehabilitation programme.

In terms of discharge professionals were of the opinion that the intermediate care facilities were not being widely used within BME elderly communities. The reason was they did not provide appropriate food, appropriate washing facilities, or make provision for meeting the linguistic needs of BME elders. The result was that older people tend to be very isolated in those situations. One of the institutions (Blackburn) involved has identified this as a problem and was taking steps to rectify the situation. Though they now have 36 designated intermediate care settings, none of them could be described as providing culturally appropriate care. BME elders have reported that they would rather undergo rehabilitation at home than go into an intermediate care setting which was not appropriate. George (2000) described how a social worker resolved a situation where a client is faced with either being transferred to a home where her linguistic and cultural needs would not be met, or being left at home though severely impaired after a stroke.

The issue of appropriate continuing care was a concern for the BME elders interviewed. One elder was discharged into the care of her daughter without hospital staff realising that the daughter's accommodation was not suitable as she lived on the third floor of a house and her mother was unable to climb the stairs. In this case the daughter came to live with the mother in the very cramped sheltered accommodation that the mother occupied.

Bowman and Singer (2001) examined Chinese seniors' attitudes towards end of life decision-making, and found that in general they would reject advance directives. They also argued that health care professionals must strive to understand and address these elders' culturally mediated perspectives. Hopp and Duffy (2000) also investigated differences in advanced care planning and end of life decision-making between whites and blacks over the age of 70. Logistic regression models suggest important differences between these groups, and the authors argue that health professionals need to develop greater awareness of, and sensitivity to, these preferences.

Mental Health and Social Care

Though our project did not directly address the issues related to social care and to patients in mental health hospitals, these are of serious concern for the BME elders and need to be explored further. There is some evidence in published resources of the myths surrounding access to and use of mental health services by BME groups in general, but there is very little work done with regard to BME elders experience of these services. Oduoye and Shah (1999) compared the clinical, social and demographic characteristics of elders originating from the Indian subcontinent, and of newly referred indigenous elders. Their findings do not support the traditional view

that ethnic elders do not adequately access psycho-geriatric and social services, and that they are primarily cared for by extended families. They are however likely to be younger, have had more children, be married, have more people living in their household, and to suffer from schizophrenia more often than their indigenous counterparts. Dementia appears to be less likely.

Greenwood, Hussain, Burns and Raphael (2000) described a series of interviews conducted with Asian in-patients and carers. Though many issues raised were of general relevance, several significant areas of concern linked to the accommodation of religious and cultural differences emerged. These included food, privacy and washing facilities. The terms 'depression' or 'behavioural problems' were preferred to 'mental illness', but there was not much evidence to suggest that patients felt there was great stigma associated with receiving psychiatric treatment, nor that they disagreed with their diagnosis or medication, or sanitised their problems.

Section 3

Patient Centred Model For Hospital Care For BME Elders

Being Treated Like I Was Somebody.....

It is a Department of Health requirement that

'agencies in localities should agree the shared values that will underpin their joint approach to assessment and care planning. The process by which agencies arrive at shared values can often be as important as the values themselves. In discussing shared values, agencies and professionals should attempt to appreciate each other's roles, the resources at their disposal, and the constraints under which they operate'.

The DH also recommended that, if the people worked with are to receive appropriate and effective services, these shared values should be drawn from the NHS plan and the National Service Framework For Older People, A set of shared values was produced by the DH as a foundation for localities to develop their own set of shared values that are important to them. It was suggested that these values apply beyond older people to all adults seeking health or social care support, and should be shared with other local agencies such as housing. The Department of Health also pointed out that agencies need to be aware that some principles underpinning the values, such as the need to gain consent before sharing confidential information between agencies, are required by law whereas others have greater flexibility. The DH has also recently (January 2004) produced a Self Assessment Tool for Trusts, namely Achieving Improved Access to Services Through Better Care for Older People. Though this is a useful tool, which can be used for improving better care for all older people, this does not have any specific reference to the needs of BME older people.

The proposed Patient Centred Model (PCM) for the care of BME elderly takes on a different but related approach. It puts patients at the Centre of the equation and

requires professionals in various agencies to consider what the patients need at various stages of their hospital care. The purpose of this model is to identify best practice in the delivery of quality health care to BME elders. This is done by matching key interventions specified in the NSF for Older People with issues identified, (by BME elders and professionals working with them), as critical determinants in the provision of hospital care. The components of this PCM therefore pay specific attention to Referrals and Pre-Admission, Admission and Hospitalisation, Diagnosis and Treatment, and Discharge and Rehabilitation.

Component One: Referrals and Pre-Admission

The key interventions in Person Centred Care specified in the NSF for Older People refer to providing information so the user, and where appropriate the carer, can be involved in decisions about their care. In the case of BME elderly, they need to be fully aware of:

- What to expect when they are referred for specialist consultation or when they have to stay in a hospital.
- Waiting time
- Diagnosis and Treatment Options
- Hospital procedures
- How they will be assessed.
- The proposed length of stay
- Availability of appropriate diet
- Additional support services

Patient information leaflets normally have information about facilities on the ward and what to expect in terms of meals, visiting hours, named nurse and consultants' ward rounds. But it is not clear whether these leaflets are available in languages other than English. Some hospitals, for example Dartford and Gravesham NHS Trust also have information for patients with disabilities and interpreting services. Barts and the London NHS Trust has its own bilingual health advocacy service which provides information, support, interpreting and advice to patients whose first language is not

English. The patient information includes specific information on what is available for non-English speakers, and there are bilingual phone lines. For example:

One of our health advocates can accompany you to your appointment or on your admission and, if you wish, interpret on your behalf when you speak to the doctor or other staff. They can also advise hospital staff on cultural, religious and social issues relation to your hospital visit. (Barts and London NHS Trust)

However, it is not clear whether these information sheets are available in languages other than English. As for meals, a choice of menu is offered and it claims that it also includes food that has been prepared and cooked according to “your custom or religious practices, as well as your dietary needs.”

The leaflet also has information about making plans to go home, pensions/ benefits and mixed-sex wards, but separate male and female bays. The Royal London Hospital also has two prayer rooms for Muslims, with separate prayer facilities for men and women.

Dartford and Gravesham NHS Trust offers special menus to ‘cater for vegetarians or ethnic groups’; and has an inter-denominational chaplaincy team. The use of bilingual staff as interpreters can be useful as long as being an interpreter is recognized as part of their job. The statement *‘many of the staff are able to speak other languages and every effort will be made to assist you, if English is not your first language. Please ask one of the nurses to request an interpreter if you are in any doubt about what is being said to you’*. To assist non English speakers an electronic prompt system is used, allowing patients to point to a pictorial representation of the alphabet of the language they speak. It is complemented by another prompt card – a map of the world- for those who are illiterate in their own language to point to where they come from.

There is ,however, the practical issues such as, how do you talk to an English speaking nurse if you do not speak English, and there are no prompt systems.

Guy's and St. Thomas Hospital make a very clear statement

We aim to respect your privacy, dignity and religious and cultural beliefs at all times during your stay in hospital. Please let us know about any special requirements you may have, for example, washing and praying facilities.

Section deleted is repeated on p46

Component Two: Admission and Hospitalisation

A good example of what practitioners should consider in assessment, screening and referral can be found in Culturally Competent Care (Kent County Council, Good Practice Guide For Care Management). This was produced to make sure that access to services for the BME elderly was made easier and that services were provided with respect and dignity and in culturally appropriate and acceptable ways. The checklist for assessments highlights the importance of

- Working positively with community support systems, networks and resources
- Clarifying the individual's perceptions and expectation of the service they receive
- Empowering and enabling patients/carers and giving them a voice

Additionally, the checklist recommends a holistic approach to assessment which takes into account the elder's value systems, beliefs, traditions, as well as family dynamics and roles and relationships.

The following case studies show illustrate how lack of consideration of the factors determining patient centred care can lead to unnecessary frustration and inappropriate care during hospitalisation.

Mr. Raja

Mr Raja was admitted to hospital for an operation. He thus had a 'nil by mouth' sign placed on his bed and was not allowed food for 24 hours. However, it was decided by mid-morning that his operation would not be going ahead on that day, due to competing priorities. The 'nil-by-mouth' sign was not removed and so Mr Raja went without food for a whole day unnecessarily.

The situation was made worse by the fact that Mr. Raja could not speak or read English, and was thus unaware of why he was being denied food. He was also unable to express to nurses that he needed to eat as he suffers from diabetes.

Mrs. Tam

Mrs Tam was admitted to hospital for a major operation, and spent ten days on the ward in total. However, the food she was served was too ‘English’, and she did not like it. As a result, she relied on her family to bring her meals, often twice a day. Furthermore, in common with many Chinese elders, Mrs Tam does not like drinking cold water, preferring it to be warm. As a result, she had to ask staff for boiling water every time she wanted water.

Mr. Li

Mr Li was admitted to hospital for a minor operation. When he came around from the anaesthetic, his condition was much improved but he was in considerable pain. He wanted some sleeping pills so that he was able to rest properly but as he could not speak English he was unable to ask for them. As a result, he remained in pain throughout the night, until a member of his family visited him the next day, and was able to communicate his needs to ward staff.

Mrs Patel

Mrs. Patel was admitted to hospital complaining of discomfort from stomach problems. She was kept in overnight for observation. Whilst there, she attempted to communicate something to the nurse but this was made problematic by her inability to speak English. After several attempts to get her point across, the nurse became concerned and decided to notify her emergency contact, her brother-in-law.

Upon receiving the message, her brother-in-law became very concerned as Mrs Patel was only being kept in by the hospital for some routine tests. When he arrived at the hospital, he hastened to discover what the problem was. Mrs Patel told him, ‘but I only wanted to know the time’.

Mrs. Tan

Mrs Tan was unable to leave hospital even though she was well enough to be discharged because she lived in a council flat that was several floors up, and the doorway was too small for her to get through with comfort. As a result, she remained

in hospital for 17 months. She was extremely unhappy about this, commenting that there are ‘no choices in hospital’. She did not like the regimes of the ward, and the fact that she was required to eat and bathe at certain times.

For example, Mrs Tan did not enjoy being woken up early in the morning with a cup of tea as Chinese elders do not generally enjoy English tea. She was also unhappy about being taken for a shower every morning, as this is often the coldest part of the day. Many Chinese elders do not have showers but take baths, as this is what they have been more accustomed to, and they feel warmer afterwards than with a shower.

Component Three: Diagnosis and Treatment

Key areas for discussion in this component include, expectations, perceptions of the service, and cultural differences in relation to disability, mental health sickness and increasing dependency on others.

The professionals we talked to felt that a key consideration was establishing the elders’ understanding of their own medical condition. Where elders were suffering from multiple pathologies, it was important for them to be aware of which of their conditions they were being treated for on hospital. Professionals need to spend sufficient time with them and communicate adequately about what was going to happen during their treatment. It was also considered important for professionals to understand how an elder’s background in terms of race, culture, religion might impact on treatment decisions, especially in relation to diagnosis of chronic illness and prescribed medication. For example,

Mrs Tang (95) was admitted to hospital as a day patient for testing and investigation after she complained of stomach problems. She was given a late afternoon appointment and was told that she could not eat for 24 hours beforehand, meaning that she went without food for a whole day. During the appointment, she was required to undergo an x-ray, for which she was given a liquid to drink that would make the results show up more clearly. On return home, Mrs Tang felt violently ill from the liquid she had drunk and had vomiting and diarrhoea for the following week.

Her daughter in law commented, *'they should have thought about how frail she is when they gave her an appointment and that x-ray. She was so ill, we thought she was going to die'*

Gaining consent for treatment was also identified as being of concern. In some cases it was hospital policy that only trained interpreters, link workers and advocates be used when consent to treatment was being obtained. It should be noted that the Department of Health has published consent forms in a number of languages. The person used as an interpreter to help with completing the consent form is also required to sign it. The consent form is intended to act as an aide memoir for health professionals and patients and provide a checklist of the kind of information patients should be offered. It also enables the patient to have a written record of the main points discussed during consultation.

Asian Cancer Patients And Carers (2002) identified clear information needs around understanding treatments, including basic information such as what is it? What is it for? What does it involve and what are the likely side effects? For example, the professionals should explain what is involved in chemotherapy and what kind of side effects one could expect. The combination of both general needs and personalized information is evident from the following extracts from interviews with BME elders:

The thing is our community...we don't understand what is cancer, when they diagnose and say you have got a cancer or a lymphoma or leukaemia or anything, we are very far behind. (male carer)

I was told nothing. I thought it might be just like an electric lamp or something like that (female breast cancer patient)

What is mastectomy? I didn't know what it was.....at least what it is, how he is going to do that and how it is going to help. I need that. (female breast cancer patient)

These comments by patients seem to reflect a need to understand the medical terms and what the treatment will involve.

This report also found that where patients and carers were able to understand verbal or written information in English, there was better level of satisfaction whilst non-English speakers and/or readers faced greater obstacles.

One gets tired by radiotherapy. No body explained to me in Gujerati what radiotherapy was. A nurse said jokingly that you just have to grin and bear it....they sent me a letter in English and I can't understand the English language.....nobody was with me to explain. (female breast cancer patient, translation from Gujerati).

Component Four: Discharge And Rehabilitation

Key areas for discussion in this component include appropriate referrals for rehabilitation, appropriate plan for rehabilitation, signs of relapse, dietary regime to follow, and physical activity and support services.

The message from our discussions with professionals and BME elders was that in order to ensure smooth transition from admission to discharge, more time needed to be spent on providing information on discharge procedures. However, appropriateness of referral was dependent upon the knowledge of what was available in the community and whether the appropriate service was able to meet the specific needs. It was also noted that links with BME and other voluntary sector organizations providing care for the elderly were vital to establish additional support services.

One example of good practice referred to was the From Hospital To Home Project, set up by Age Concern Leicester with a bilingual project worker. This project helped the BME elders to speed up their discharge from hospital and made their home coming easier. It also seemed to have reduced the number of readmissions, but because the project is new and only involved a small number of BME elders, it is difficult to make any definitive statements about its impact.

Another example from a BME elder's experience of the help she received from Hackney staying put hospital discharge service is evidence of what difference it can make to a person's life if appropriate financial and physical help is made available. (case study appendix a)

Another source of evidence (Ethnic Minority Elders in London by Lowdell et al 2000) points out that access to appropriate forms of residential and nursing home care is a key issue for London's elders and especially those from minority ethnic groups. The report also highlighted the substantial role of the BME voluntary sector and community groups in service provision. These links are particularly important in relation to discharge as assistance from community groups can reduce the likelihood of re-admission.

The National Audit Office (2003), in its report on ensuring the effective discharge of older patients from NHS acute hospitals, reported on the main concerns of patients and carers about lack of information with regard to:

- Range of care services available
- Whom to contact for additional help
- The level of involvement in discharge planning
- Services available after discharge
- Receipt of services such as aids and adaptations

Though the report does not make any reference to the needs of BME elders in this respect, all these factors are even more relevant when considering the needs of BME elders. The evidence from the London report suggests that Asian elders were much less likely to be discharged into an NHS nursing home. On the whole BME elders (Black African, Asian And Chinese) were more likely to be discharged directly to their homes than to another general hospital or an NHS nursing home. This may be due to the support provided by their families, in which case these families require additional financial and social support as well as respite care. It is important to note the contribution made by families of BME elders and other BME support networks to the after care of BME elderly in their homes. The following examples illustrate how professionals can sometimes make inappropriate decisions about discharge and aftercare.

Mr. Lin

Mr Lin (75) lived at home with his extended family. During the day, he had a carer who cooked a midday meal for him, and the children in the family took on some caring responsibility when they returned home from school. He was admitted to hospital briefly after he became ill. Whilst there, the consultant concluded that his care was insufficient and placed him in a nursing home. The interpreter, advocate and family lobbied hard against this decision, arguing that it would be better for Mr Lin's quality of life to remain within the family.

However, the consultant's decision was final and he refused to reconsider. Mr Lin was sent to the nursing home and is now allowed to visit his family one-day a week. He is deeply unhappy.

Mrs. Lam

When leaving hospital, Mrs Lam was unable to ask for future provision as she could not speak English fully enough and was unaware of her entitlements. As a result, she was not offered an assessment by an occupational therapist or social worker for aids that would help her to function independently. Upon going home, Mrs Lam struggled to climb the stairs to her flat and move around the flat, finding it extremely difficult to complete basic daily tasks, such as cooking and cleaning. Eventually, the local social services department discovered that she had not been assessed and, several months after leaving hospital, Mrs Lam was provided with the aids she should have had immediately on discharge.

Implementation and discussion

The draft PCM was presented to participants of seminars held in Dartford and Burnley to gauge their reaction to this model. On the whole the response was positive and it was considered to be motivating. The link with the NSF was seen as an additional bonus. For them the model could be used to:

- Increase practitioners' knowledge of issues affecting BME elders thus enabling them to deliver their services by putting the patient at the 'Centre' of their concerns.

- Identify shortfalls in service provision and getting them to consider how to address these shortfalls in their practice and provision.

The use of a case study to stimulate discussion of core components of the model led to a list of requirements as follows:

- Need for patient involvement at all stages
- Need for reassurance that the cultural religious, dietary and linguistic needs of patients will be met during their hospital stay
- Need to provide a brief but clear description of hospital procedures and a map of the hospital layout.
- Need to make a record of the patients' dietary requirement on admission and where possible to give them a choice of whether they could have meals delivered to them from home.
- Need to have information available in a variety of formats and in different languages.
- Need for interpreters and patient advocates being available when required.

PRIAE is of the opinion that patient information booklets should, as a matter of course, include information about what the hospital is able to provide for BME elders in terms of diet. The usual assumption seems to be that BME elders will only want 'ethnic' food. It should be remembered that dietary preferences are a matter of individual taste and BME elders should be able to exercise choice, like any other patient, in terms of the food they eat. It is important to consider the advice of a dietician if an individual expresses a preference for food to be brought in. A further suggestion is that, where possible, hospitals could explore the possibility of using the local authority meals on wheels service as a means of improving patient choice. The following three key areas for discussion have a bearing on all aspects of hospital care and are therefore relevant to all the four components of the Patient Centred Model described above.

Patient Profiling

Patient profiling is often described, as a process of gathering information to understand the nature of the patient population in order to develop a systematic

approach to assessing needs and resources and provide information to plan services that are responsive to community needs.

The report on Health of London's Ethnic Minority Elders noted that the level of ethnic coding in London is still low, despite the fact that ethnic diversity is an important feature of the city. Another report on ethnicity profiling at Princes Park Health Centre in Liverpool reported on significant beneficial of patient profiling.

These included:

- Employment of multilingual member of staff
- Employment of Yemeni worker to work on smoking cessation project with the Yemeni community
- Introduction of multilingual practice leaflets, appointment cards and notice boards
- Introduction of a multilingual information video
- Extension of this work to 10 other GP practices in Liverpool Primary Care Group

It is important for health service planning to ensure that services are based on proper need assessment of all its users and that they are culturally appropriate. Appropriately recorded data on ethnic origin is an essential part of this process. Patient profiling is much wider than just gathering data on ethnic origin. It also includes information on gender, disability, status, preferred written and spoken language, religious faith and related needs.

The professionals we talked to identified a need for information on the profile of local population in order for them to better understand and meet the needs of BME elders from ethnically diverse communities.

Single Assessment Process

The NHS Plan (DH 2000) proposed a single assessment process across health and social care for older people. Its purpose is to raise standards of assessment through a single assessment process used by all agencies involved in the care of older people. It also means that the needs of older people are assessed more comprehensively through this single process. Standard 2 (Person Centred Care) of the NSF suggests putting in

place a framework to ensure good assessment practice through a single assessment process. It also suggests that:

Good assessment requires that the needs and circumstances of older people be assessed in ways that are not culturally biased and by staff who are able to make proper sense of how race, culture, religion and needs may impact on each other. (2.31 NSF)

PRIAE had welcomed the Single Assessment Process and had drawn attention to the need for making services more accessible; improving the confidence of BME elderly service users; acknowledging the role and expertise of BME elderly organizations and for using supplementary formats to disseminate information about services. Attention was also drawn to the need for developing culturally appropriate assessment tools and for providing appropriate training the professionals conducting single assessment. Other issues that need to be considered in the single assessment process include:

Cultural, Religious and Linguistic Needs

It is important that the purpose and process of single assessment is made clear and that BME elders understand what is involved in the process and why they need to be carried out. Issues that need considering also include elders' value systems, family dynamics, roles and relationships. If the purpose is not clarified or misunderstood, it may be necessary to repeat the process for some people from BME elderly communities

Dietary Requirements

Promoting health and well-being is as important as reacting and responding to needs as and when they arise. The importance of healthy and active life style for the BME elderly is a key issue, as there is sometime a tendency to give up thinking about prevention with progressive years.

Social Circumstances and Family/Carer Involvement

The potential for rehabilitation should be explored at assessment and afterwards kept under constant review. This is particularly important for the BME elderly, as it is necessary to ensure how the family is going to care for the person. Knowledge of

locally available support, linked to the local population profile would also help to determine what support services could be accessed.

Culturally Competent Care (Kent County Council), as we have said earlier offers a good practice checklist which includes, amongst other things:

- Clarifying the individual's perceptions and expectations
- Empowering and enabling clients /carers and giving them a voice
- Working positively with community support systems, networks and resources
- Developing an understanding of how racism, discrimination and oppression can impact upon individual's lives and opportunities
- Seeing diversity as positive and avoid using the same approach for all users
- Recognizing the possible effect of displacement when working with older refugees and asylum seekers

In addition to above, the good practice checklist also recommend using a process of holistic assessment including a consideration of a whole range of factors such as culture, values, beliefs, traditions, interests and hobbies, family dynamics and roles and relationships.

Interpreting

Standard 2 of the NSF for Older People makes several references to the importance of ensuring that appropriate services are available to those who do not have English as their first language. It further specifies that interpreting and translation services should be made available to assist staff to communicate in ways that meet the needs of all users and carers. (NSF 2.8)

The message from our discussions with BME elders was that they were unable to communicate their needs effectively and they also complained about either not being listened to or ignored. This message was re-inforced by Age Concern Lancashire in their report *What Is Happening Behind The Smile* (2003). BME elderly women were reported to be at a considerable disadvantage as their ability to communicate in English was limited. They needed link workers and/or interpreters to explain health issues, for example further advice about diet and medication after being diagnosed for diabetes by their GP.

For professionals too, the lack of effective communication created problems at all levels and across all services. The most common concerns were about inadequate assessments, diagnosis and informed consent. At a more basic level, language barriers also affected the ability of administrative and other staff to deal effectively with general queries. At the other end of the spectrum there can be issues arising out of situations where, in the absence of qualified interpreters, clinicians and health professionals may make wrong diagnosis or act without informed consent. These scenarios could result in accusations and legal action on the grounds of malpractice.

In their clinical governance report on Bradford Hospitals NHS Trust (2001) The Commission for Health Improvement was concerned that the Trust's 24-hour interpreter service was not readily available out of hours. They noted

Staff are often forced to request translation services from relatives, members of staff, patients or relatives of patients on the wards. This practice raises serious concerns for patient confidentiality. Clinicians and nurses were aware that relatives sometimes fail to translate fully for patients to protect them from receiving bad news. (CHI 2001)

Equally significantly, the CHI Report on Birmingham Heartlands and Solihull NHS Trust (2001) recommended that cancelled appointments and cancelled operations resulting from the lack of interpreters should be treated as critical incidents' (our emphasis). The report stresses that :

There must be clear arrangements for patients who can not read English to obtain information about their condition. Patient information must also be made available on display in other languages, in the same way as those in English. (CHI 2001)

There is evidence that where there is some provision available it is usually uneven. Provision of advocacy, interpreting and translation across London was reported to be patchy and the funding required for such services was not always readily identifiable. Consequently, professionals were reliant on bilingual health workers or family members. It was encouraging that many professionals were against using children to interpret for for elders, particularly where consent was required. On the whole, where hospitals had made provision, professional interpreters were employed, and were called upon in situations where informed consent was needed. In our discussions there

were some concerns expressed that patients may sometimes insist on a family member interpreting for them, rather than a trained interpreter. Though the debate was inconclusive, the advice from PRIAE is that it should be a matter of choice for the patient.

An example of a helpful way forward is the Emergency Multi-Lingual Phrase Book produced by the British Red Cross (funded by the Department of Health and endorsed by British Association Of Emergency Medicine) for use by accident and emergency staff across the country. It is produced in 36 languages and covers over 60 of the most common medical questions. The phrase book is very useful for ‘first contact’ staff to communicate with patients who do not speak English and helps them to make an initial assessment before an interpreter is contacted. It is useful because it is easily accessible and includes helpful questions and statements from the professionals, such as:

Can you give me the name and telephone number of someone to be contacted?

Are you allergic to any medicine such as penicillin, aspirin or any other medicine?

Have you any pain? Point where. When did it start? Show on the calendar and clock.

I need to take your blood pressure

I need to listen to your chest; I need to take a sample of your blood.

Please come back if you have more problems

It also includes examples of questions that the patient might need to ask such as:

How long will I be waiting?

Where is the telephone, I need to ring my family/friend?

Will someone call my name?

Another good example of improving access to interpreting service is to be found in Hounslow PCT’s launch of a new Translation Card for patients. Patients who are unable to communicate adequately in English can pick up a card written in their own language, which explains that they are entitled to an interpreter. They can take the card to a receptionist who can organise an interpreter for them

The following case studies illustrate how some of the communication problems experienced by BME elders were resolved with the help of an interpreter

Mr Sandhu

Mr Sandhu had experienced increasingly problems as he lives alone in a one-bed flat and suffers from blindness, mobility problems, dementia and dizziness. Once he was put in touch with an interpreter, he was able to get a full assessment and appropriate aids and adaptations to his flat were provided, enabling him to have some normality in his life.

Mrs Singh

Mrs Singh had been experiencing problems with her daughter in law for some time prior to coming into hospital. She had felt unable to tell anyone about them. However, when she was given to access to an interpreter, she felt that she had at last found someone that she could trust. It was only then that she could disclose her unhappiness with the domestic situation and things could be resolved.

To conclude, it seems from our discussions that though there is plenty of good will in providing appropriate hospital care services for the BME elderly in most cases the provision is patchy and ad-hoc. The Patient Centred Model provides a framework to ensure that these services are standardized to some extent. It is hoped that the Kit in the next chapter will help professionals to assess for themselves the standard of services they provide, identify gaps in their provision and plan adequately for fulfilling these gaps.

Section 4

For The Patient Centred Model

Being Treated Like I Was Somebody.....

In developing our we drew on the principles underlying the Essence Of Care Tool Kit. These principles were about patient focused outcomes and the factors which need to be considered to achieve those outcomes. In addition, there are the shared values underpinning person-centred care which need to be taken into consideration when using this Audit Tool. Communication-listening to the patient, respecting privacy and dignity, taking a holistic approach to assessment, ensuring integrated services are in place, all play an important role. Our intention is to assist professionals to better meet the needs of BME elders, assess gaps in provision, identify best practice and develop action plans to improve both service development and delivery. Our Tool Kit relates only to in-patient stays, and where admission is either elective or as an emergency. The Tools may appear daunting, but the outcomes we have identified can, with careful thought and preparation, be achieved. We recognise that organisations, and for that matter, professionals in those organisations, will be at different levels both in terms of understanding of BME elders' needs, and the service improvements necessary to deliver patient centred care to this group of elders. To some professionals and organisations what we are proposing will be basic, whilst others might view the Tools as being ambitious.

Nonetheless, each of the four components of our patient centred model have been carefully considered to identify specific indicators/interventions necessary to achieve

quality hospital care for BME elders. These indicators have then been linked to specific Standards in the NSF for Older People to provide a template to help professionals to assess their own performance against these Standards.

Getting delivery of services right will also require hospital trusts to have regard to the duties placed on them under the Race Relations (Amendment) Act 2000. The recording of ethnic origin, or patient profiling are essential prerequisites if they are to meet those obligations and remedy deficits in service provision. The Tools complements the work necessary to draw up Race Equality Schemes and provides pointers on how to overcome those deficits.

For change to happen, responsibility for managing the process has to rest at senior management level, as part of Clinical Governance with regular monitoring and evaluation of progress.

Key Indicators

Component One: Referrals and Pre-Admission

1. Is information on what to expect on entry to hospital provided?
2. Is it in appropriate languages and formats?
3. Can elders talk to a named person prior to admission?
4. Does the information make clear that interpreting services can be provided?
5. Is a patient pathway provided, detailing what the terms assessment, treatment and diagnoses entail?
6. Does the information provided include details of the cultural, religious and dietary needs the hospital can meet?
7. Does the information indicate whether the hospital workforce reflects the local community?
8. Can elders comment on the services they receive?

Component Two: Admissions And Hospitalisation

- 1 Do staff have an understanding of the make-up of their local communities?
- 2 Are staff sensitive to differing perceptions and expectations of health services?
- 3 Can staff understand differing family dynamics and BME perspectives?
- 4 Do assessors have specific knowledge and expertise to undertake assessments of BME elders?
- 5 Are interpreters/linkworkers/advocates available if necessary?
- 6 What training is provided to staff to enable them to meet the needs of BME elders?

Component Three: Diagnosis and Treatment

Is the elder asked about their understanding of their medical condition?

Are interpreters/linkworkers/advocates available?

Has the elder been asked if relatives and carers can be told of his/her condition?

Are diagnoses and treatment explained in lay terms?

Are only trained interpreters/linkworkers/advocates called upon where consent to treatment is required?

Are translated versions of the consent form available?

Is elder told what medication contains?

Is the elder informed of religious and spiritual support available?

Are discharge options discussed?

Is the possibility of further assessments raised?

Are relatives/carers informed of bereavement support available?

Component Four: Discharge and Aftercare

1. Are staff aware of cultural attitudes to rehabilitation and aftercare?
2. Are the services the elder is referred on to able to meet his/her linguistic needs?
3. Are short term and long term care services able to meet elders' cultural, religious, linguistic needs?
4. Is elder made aware of aids and adaptations required before discharge home?
5. Is the elder given a copy of the letter sent to the GP on discharge home?
6. Are interpreting needs noted for follow up appointments
7. Are elders informed of schemes to assist with discharge home?
8. Are elders informed of BME run day centres, luncheon clubs and physical activity clubs?
9. Are alternatives to hospital care discussed?
10. Can elders access information held on them?

Being Treated Like I Was Somebody.....

For Patient Centred Model

PCM Components Referrals and Pre-admission	NSF 2.1 Informed choice	NSF 2.7 Single assessment	NSF 2.8 Communication	NSF 4.6 Emergency Response	NSF 4.10 Early assessment	NSF 4.12 Ongoing care	NSF 4.28 Discharge
1 Is information on what to expect on entry to hospital provided?	✓	✓					
2 Is it in appropriate languages and formats?	✓						
3 can elders talk to a named person prior to admission?							
4 Does the information make clear that interpreting services can be provided?	✓						
5 Is a patient pathway provided, detailing what the terms assessment, treatment and diagnoses entail?	✓	✓				✓	
6 Does the information make clear that cultural, religious and dietary needs can be met?	✓			✓	✓		
7. Does the information indicate whether the hospital workforce reflects the local community?			✓				

8. Can elders comment on the services they receive?			✓				
Audit Tool For Patient Centred Model							
PCM Components Admissions And Hospitalisation	NSF 2.1 Informed Choice	NSF 2.7 Single assessment	NSF 2.8 Communication	NSF 4.6 Emergency Response	NSF 4.10 Early assessment	NSF 4.12 Ongoing Care	NSF 4.28 Discharge
1 Do staff have an understanding of the make-up of their local communities?		✓	✓	✓	✓	✓	
2. Are staff sensitive to differing perceptions and expectations of health services held by BME elders?		✓	✓	✓	✓	✓	
3.Can staff understand differing family dynamics and BME perspectives?		✓		✓	✓	✓	
4 Do assessors have specific knowledge and expertise to undertake assessments of BME elders?		✓		✓	✓		
5. Are interpreters/linkworkers/advocates available if necessary?	✓	✓	✓	✓	✓	✓	

6.What training is provided to staff to enable them to meet the needs of BME elders?	✓	✓	✓	✓	✓	✓	
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Audit Tool For Patient Centred Model

PCM Components Diagnosis and Treatment	NSF 2.1 Informed Choice	NSF 2.7 Single assessment Process	NSF 2.8 Communication	NSF 4.6 Emergency Response	NSF 4.10 Early assessment	NSF 4.12 ongoing care	NSF 4.28 Discharge
1.Is the elder asked about their understanding of their medical condition?	✓	✓	✓	✓	✓	✓	
2.Are interpreters/linkworkers/advocates available?	✓	✓	✓	✓	✓	✓	✓
17.Has the elder been asked if relatives and carers can be told of his/her condition?	✓			✓	✓	✓	
3Are diagnoses and treatment explained in lay terms?	✓			✓	✓	✓	
4Are only trained interpreters/linkworkers/advocates called upon where consent to treatment is required?	✓			✓	✓	✓	
5Are translated versions of the consent form available?	✓			✓	✓	✓	
6.Is elder told what medication contains?	✓				✓	✓	
7.Is the elder informed of religious and spiritual support available?	✓		✓			✓	
8.Are discharge options discussed?	✓		✓	✓		✓	

9.Is the possibility of further assessments raised?	✓	✓	✓		✓	✓	
10.Are relatives/carers informed of bereavement support and counselling available?	✓		✓			✓	

Audit Tool For Patient Centred Model							
PCM Components	NSF	NSF	NSF	NSF	NSF	NSF	NSF
Discharge And After-Care	2.1	2.7	2.8	4.6	4.10	4.12	4.28
	Informed Choice	Single assessment Process	Communication	Emergency Response	Early assessment	ongoing care	Discharge
1.Are staff aware of cultural attitudes to rehabilitation and aftercare?			✓				✓
2.Are the services, the elder is referred on to, able to meet his/her linguistic needs?			✓				✓
3.Are intermediate and long-term care services able to meet elders' cultural, religious, linguistic needs?							✓
4.Is elder made aware of aids and adaptations required before discharge home?							✓
5.Is the elder given a copy of the letter sent to the GP on discharge home?						✓	✓
6.Are interpreting needs noted for follow up appointments?			✓				✓
7.Are elders informed of schemes to assist with discharge home?	✓						✓
8.Are elders informed of BME run day centres, luncheon clubs and physical activity clubs?						✓	✓
9. Are alternatives to hospital care discussed?						✓	✓
10. Can elders access information held on them?						✓	✓

Section 5

Self Assessment Using The Kit

Referrals and Pre-Admission

PCM Components and Key Indicators	Level 4	Level 3	Level 2	Level 1
1 Is information on what to expect on entry to hospital provided?	No information provided	Information being prepared	Information given on entry to the ward	Information always sent and feedback received
2 Is it in appropriate languages and formats?	Not provided in appropriate formats or languages	Consideration being given to what should be done	Available in a limited number of languages and formats	Already available in appropriate languages and formats
3 Can elders talk to a named person prior to admission?	No contact provided	General hospital number provided	Contact phone number provided	Named contact details provided
4. Does the information make clear that interpreting services can be provided?	No details given	Information provided on entry to the ward	Information given when asked, that limited services are available	Information given to all on what is available and how to access services
5. Is a patient pathway provided, taking elders through procedures	No details provided	Information provided on entry to the ward	General information available to all	Specific information provided in detail
6. Does the information provided say if the hospital can meet cultural, religious and dietary needs	No details given	Information provided on entry to the ward	General statement on aiming to meet needs	Full information provided in the information letter Prior to admission
7. Does the information indicate whether the	No indication given	Indicates diversity issues are being	Indicates that targeted recruitment campaigns	Indicates the hospital workforce reflects the

hospital has a multi-racial workforce?		addressed	are underway	make up of the local community
8. Can elders comment on the services they receive?	No information given	Information provided on entry to the ward	Information provided on making a complaint	Customer satisfaction questionnaire sent to elder after discharge
Admissions and Hospitalisation				
PCM Components and Key Indicators	Level 4	Level 3	Level 2	Level 1
9. Do staff have an understanding of the make-up of their local community?	No knowledge demonstrated	Some staff aware of population profile	Some staff have knowledge and understanding	All Staff demonstrate full knowledge and understanding
10. Are staff sensitive to differing perceptions and expectations of health services?	No sensitivity shown	Some staff show sensitivity	Some staff show awareness and sensitivity to differing perceptions and expectations	All Staff aware of and sensitive to differing perceptions and expectations
11. Can staff understand differing family dynamics and BME perspectives?	No understanding shown	Training being provided	Some staff show understanding of family dynamics and BME perspectives	All Staff understand family dynamics and BME perspectives
12. Do assessors have specific knowledge and expertise to undertake assessments of BME elders	Assessors do not have specific expertise and knowledge	Assessor s being trained	Assessors not competent in all areas or not always available	Assessors have specific knowledge and expertise
13. Are interpreting services available?	No interpreting services available	Ad- hoc provision made, and reliance placed on informal interpreters	Services available but not on 24 hour basis	Full 24 hour service available, including telephone interpreting service
14. What training is provided to staff to	No training provided	Included as part of induction training	Training provided on a regular basis	Training provided and followed up in staff

enable them to meet the needs of BME elders?				supervision
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Diagnosis and Treatment

PCM Components and Key Indicators	Level 4	Level 3	Level 2	Level 1
15. Is the elder asked about their understanding of their medical condition?	No evidence that elders have been asked	Elders asked in general terms	Elders asked but record not always made	Elders asked and record made
16. Are interpreters available?	No interpreters available	Ad hoc provision made and reliance placed on informal interpreters	Interpreters not always available	Interpreters available, including out of hours arrangements
17. Has the elder been asked if family/carers can be informed of his condition?	Elder not asked	Family and Carers have to ask staff	Some elders asked	Elders' consent obtained Before talking to family and carers
18. Are Diagnoses and treatment explained in lay terms?	Diagnoses and treatment not explained in lay terms	Elders are unclear about diagnoses and treatment	Some elders have some understanding	Elders fully understand Diagnosis and Treatment
19. Are only trained interpreters used when consent to treatment is required?	No interpreters available	Reliance placed on informal translators	Trained interpreters used when available	Only trained interpreters used
20. Are translated consent forms available?	Not aware of translated consent forms	Translated consent forms not available	Translated consent forms available sometimes, and in some languages	Translated consent forms readily available in all relevant languages
21. Is elder informed what medication contains?	Elder not informed	Only when Family and Carers ask	Elder informed but no options discussed	Elder informed and options discussed.

22. Is the elder told what religious and spiritual provision is available	No multi-faith provision available	Elder told that arrangements can be made	Some multi-faith provision available	Multi- faith chaplaincy and prayer facilities available
23. Are discharge options discussed?	Discharge options not discussed	Discharge options discussed generally	Discharge options and process discussed with some elders	Discharge options and process discussed and elders fully aware
24. Is the possibility of further assessments Raised?	No information about further assessment	Possibility of further assessment raised	Nature of further assessments discussed	Detailed information given about what could happen and when
25. Is bereavement support available for carers/family	No bereavement support available	Ad hoc provision made	Some bereavement support available, but cannot be easily accessed	Bereavement support available, and can be easily accessed

Discharge And Aftercare

PCM Components and Key Indicators	Level 4	Level 3	Level 2	Level 1
26. Are staff aware of cultural attitudes to rehabilitation and aftercare	Staff not aware of cultural attitudes to rehabilitation and aftercare	Family/Carers ask staff about rehabilitation and aftercare	Some staff have some awareness of cultural attitudes to rehabilitation and aftercare	All Staff aware of cultural attitudes to rehabilitation and aftercare
27. Are services the elder is referred on to able to meet his /her linguistic needs?	Services cannot meet all linguistic needs	Linguistic provision being reviewed	Services can meet some linguistic needs	Services can meet all linguistic needs
28. Are short term and long term care services able to meet elders' cultural, religious and dietary needs	Short term and long term care services cannot meet elders' specific needs	Care services reviewing provision	Some care services can meet some specific needs	All Care services can meet elders' specific cultural, religious and dietary needs
29. Is the elder made aware of aids and	Elder not aware that aids and adaptations		Some elders aware and arrangements being	Elders aware and arrangements finalised

adaptations required before discharge home?	required		finalised	
30. Is the elder given a copy of the letter sent to the GP?	Letter to GP Not copied to elder	Elder told that GP Being written to	Elder aware of main points covered in letter to GP	Letter to GP Copied to elder
31. Are interpreting needs noted for follow up appointments?	Interpreting needs not noted	Elder told to request interpreter prior to appointment	Elder told arrangements will be made	Interpreting needs noted and arrangements made
32. Are schemes available to assist BME elders with discharge home?	No schemes available	Schemes available but not able to meet BME elders needs	Some schemes can meet some linguistic needs	Schemes available and BME elder referred to scheme
33. Are elders informed of BME run day centres, luncheon clubs and physical activity clubs?	No provision available	Staff lack knowledge of specific BME schemes	Elders informed that some provision available, but staff unsure which communities are catered for	Elders informed of what is available and staff have good knowledge of BME specific schemes
34. Are alternatives to hospital stay discussed with the elder?	Alternatives not discussed	Reference is made to alternatives but elders unclear	Alternatives are discussed with some elders	Alternatives are discussed with elders and elders understand
35. Are elders told how to access information held on them?	No information given	Elders told that they can request such information but not how to do so	Some elders told how to request hospital records, cost and timescales	Elders told how to request hospital and GP records, cost and timescales

NB:

Section 6

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