

Black and Minority Ethnic Elders' in the UK:

Health and Social Care Research Findings

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led by PRIAE in Europe



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Minority Elderly Care (MEC) © Research Project is a PRIAE concept and led by the Institute working with European partners, in France, Germany, Netherlands, Spain, Finland, Hungary, Bosnia-Herzegovina, Croatia and Switzerland, supported by the European Commission under its Fifth Framework Research Programme. The MEC research team is listed at the end of this briefing. The MEC proposal was awarded the highest research rating in its stream and is the first research project to be supported in ageing and ethnicity in the EC's 24 years of Framework funding.

PRIAE (pronounced preeya) is an independent registered charity working to improve pensions, employment, health, social care and housing, and quality of life for black and minority ethnic older people in the UK and across Europe. The Institute aims to influence national and European policy and increase and encourage good practice in work with black and minority ethnic elders. PRIAE does this through creating and leading on often 'first of its kind projects' in research, information, service developments, training and consultancy.

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Section 1: Introduction

Setting the context for MEC research

There is a Hindi saying that ‘an old person’s teaching sets the world aright’, yet not only are the wisdom and the rich human resources of our elder populations overlooked and the contributions they can make to wider society disregarded, but the very conditions of their day-to-day existence, the social and economic backdrop to their lives, are too often characterised by shameful neglect. Of none is this more true than those who form the focus of the MEC project. While a steadily increasing population of minority ethnic elders has been growing in significance and visibility in the countries of Europe, the path to recognising that old age is an issue for Europe’s minorities has not been straightforward. Individuals working in the fields of race and/or ageing have, for some time, been raising the need for policy makers, social planners and professionals to examine the plethora of issues thrown up by the ageing of minority ethnic populations across Europe. It is to that need and those concerns that the MEC project addresses itself.

MEC stands for minority elderly care, and this publication is the third product of a three-year research cycle (the other two products are MEC Country Profiles and Summary Report both launched at the European Parliament, 2003 and 2004 respectively). The research involved 10 countries, 3277 minority ethnic elders from 26 ethnic minority backgrounds, 901 health and social care professionals, 312 voluntary organisations and employed 30 or more researchers spanning 3 years.

The MEC project germinated from a suggestion, made by Naina Patel at PRIAE to a number of researchers and different government departments, that a tripartite approach to research into ethnicity and ageing, involving service users, mainstream service suppliers and voluntary/minority ethnic organisations catering to particular communities, was essential. This message was not heard. Thus PRIAE, set up in 1998 determined, like so many other self-organised minority ethnic bodies, to make progress on this issue itself and on its own terms. To that end, it was instrumental in creating the MEC project in 2000, conceptually linking users, mainstream providers and suppliers and minority ethnic suppliers. The most prominent feature of the project, structured into it, was the importance it vested in the ‘users’ of services, in minority ethnic elders themselves. What was significant – and, in this field, revolutionary – about PRIAE’s approach to the work was that, as a priority, it sought the views of elders; first and foremost, it listened attentively to what elders themselves felt was necessary. It then supplemented this with the views of practitioners, care workers, managers of projects, and so on. Its approach, both practical and theoretical, was imbued with the concept of social justice and, therefore, racial justice.

The MEC project was designed and undertaken as a serious attempt to contribute to a health and social policy agenda relevant to the growth of the minority ethnic elderly population across Europe. The easy stereotypes hitherto underlying much thinking on social policy in many European countries, that ‘their families look after their own’ or that ‘they will return home’ and, hence, that ‘nothing much needs to be done’, were not a foundation for proper action. ‘Nothing much needs to be done’ was not an option and not borne out by reality.

Moreover, the focus in some countries on the limited range of ‘needs’ to be met had, in the past, skewed the nature of research. It is a social good that elders should have quality services, and this applies as much to minority ethnic elders. At the start of the 21st century, therefore, the search for sound empirical knowledge on which to base policy and practice meant that MEC could not be satisfied with simply developing an exploratory framework within which to conduct research. It needed to provide quantitative and qualitative information through

- investigating the perspectives of minority ethnic elders on their needs and establishing criteria for levels of acceptability in services
- assessing the perceptions of mainstream health and social care providers concerning minority elders’ needs
- assessing the services that such mainstream providers deliver and their assessments of minority organisations as providers of care
- assessing how minority organisations perceive the needs of minority elders, the services they deliver and how they assess mainstream providers.

The MEC project operates as a consortium in 10 countries – in Bosnia-Herzegovina, Croatia, Finland, France, Germany, Hungary, the Netherlands, Spain and Switzerland and the UK – in cooperation with universities, specialist institutes and NGOs. The aim is to generate knowledge to provide practical policy responses on how best to meet the health and social care needs of minority elders from different ethnic and racial backgrounds. How should we

conceptualise the organisation and delivery of services? Who currently provides them? Should such provision be ethnically separate and specialist or integrated into mainstream existing health and social care provision? What do minority elders, as users, regard as 'acceptable' or satisfactory health and social care services? What lessons can we learn and how can we identify good practice on which to build for the future as the numbers of minority elderly expand?

In May 1999, Article 13 of the Treaty of Europe came into effect in relation to racial discrimination and xenophobia. It was followed by the introduction of European Race and Employment Directives covering age, which are to be implemented in 2003. Long-established minorities and those of relatively recent origin, and those among them who are growing old, are thus becoming more 'visible' on both the 'age' and 'race relations' agendas.

As earlier MEC publications show, the growing need to address black and minority ethnic (BME) ageing emerged at around the same time that the issue of the ageing of the population generally began to be discussed in relation to policy and service provision. Ageing as an issue impacted particularly on the BME population because of its age structure at the time of its initial entry. In the UK, immigrants entering as adults soon established settled black communities. Thus, an age 'bulge' is working its way through the system of those who entered in the late 1950s and early to mid-1960s, settled as UK citizens and had families.

The same demographic issues of an ageing population that affect the UK are generalised throughout western Europe, with Germany being one of the most severely affected countries. In other EU countries, once exporters of migrant labour and more recently importers of it (such as Spain), the age structure of immigrant populations is younger, but the same issue of the 'age bulge', while not as immediate as, say, in Germany, will eventually surface. This is even more true of Finland, which, although not formerly a country of immigration, has in recent years seen increasing numbers of migrants, mainly asylum seekers and refugees and repatriates who have returned following the collapse of the Soviet Union.

In fact, the populations that the MEC project covers originate from three main sources. First, there are those who came, often from former colonial possession, to countries like the UK, the Netherlands, France and Germany during the period of post-Second World War reconstruction. Second, there are those who came more recently, fleeing today's wars and economic dispossession. A country like Switzerland, for example, with its elaborated and precise allotment of different status categories to different types of migrants, covers the whole range from those recently seeking asylum, to those who came as economic migrants in the post-war period, to those whose skills are eagerly sought. Third, and finally, there are those whose case is, in some ways, the most difficult to redress, those who have known no other homeland, yet are endemically discriminated against in their countries of origin. Some of the most deep-rooted discrimination, affecting in profound ways their life chances, is that directed against the Roma throughout Europe. However, this is an issue that affects not just the Roma, but also groups who have been turned by warfare and 'ethnic cleansing' into new targets for racism and hostility, as the tragic history of Bosnia-Herzegovina demonstrates.

The strength of the MEC project is that it offers a practical perspective on a real social issue that affects the whole of Europe – eastern, central and western – in a variety of different ways and that, until now, has scarcely registered as needing to be dealt with. Focusing on the problems of ethnic minority elders also focuses attention not only on the general social problems confronting the elderly, but also on a racism against sections of the population that urgently needs to be addressed at governmental and policy levels. Each country study, by implication, sheds light on the others. The differences are profound and illuminating, but so also are the similarities in terms of need, of the types of issues that have to be tackled and the problems facing elders who are all too often impoverished and ignored by service providers. The European MEC research summary can be downloaded from www.priae.org

This PRIAE MEC UK Research Briefing is a summary report of significant data gathered and analysed around the three dimensions' of the MEC research: from users, mainstream providers and minority organisations' perspectives. The briefing is compiled at the request of BME elders' and organisations who participated in the research and at the MEC Leeds launch in April 2005: to have a short document that can be used to inform them as well as to engage with policymakers, commissioners and funders. Further publications will follow in the next year: see www.priae.org for information.

Section 2: United Kingdom

Black and Minority Ethnic Elders' Perspectives

Acknowledgements

The PRIAE research team very gratefully acknowledges the participation in the study by the BME elders from the African-Caribbean, South Asian and Chinese/Vietnamese communities in London, West Yorkshire and Scotland. Without their time, effort and interest in the research project this work would not have come to fruition.

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- Professor Naina Patel, Dr Kathryn Watson, Samantha Turner
PRIAE MEC UK Research Team

Introduction

The UK has an ageing population. Although the profile of the black and ethnic minority populations is considerably younger than that of the white British population, the numbers of BME elders are set to increase quite dramatically over the next decades as those who migrated to the UK in the 1960s and 1970s reach retirement age.

The size of the ethnic minority population was 4.6 million in 2001 or 7.9% of the total UK population of 58.8 million. Indians were the largest minority group, followed by Pakistanis, those of mixed ethnic background, African-Caribbeans, Black Africans and Bangladeshis.

Sample Details

The survey methodology was used for this study and 390 face-to-face interviews were conducted with BME elders from three different ethnic communities. Fifty-three% of the informants were South Asian, 23% Chinese/Vietnamese and 24% African-Caribbean. Interviews were conducted in the first language of the informant. The interviews were undertaken in three locations in the UK: London, West Yorkshire and Scotland. The minimum age level for informants was set at 50 years.

Marital Status and Living Arrangements

More of the women were widowed than the men, reflecting the longer survival rate of women in the population as a whole. Interestingly, more of the women were divorced or separated than were the male informants. The combined effect of these two differences is that 58% of the women were living without a partner, compared to 26% of the men.

Seventy-five% of the informants lived with other people. There were no significant differences between the ethnic groups in respect of living alone or with others. However, when we examined living arrangements by gender, there was a significant difference with 30% of women living alone compared to 18% of men. The groups with the highest proportion of women living alone were the African-Caribbean (45%) and the Chinese/Vietnamese (32%), compared to the South Asian group (23%). There was no difference by ethnic group in the proportion of men living alone.

Language Skills

There were differences in language skills among the ethnic groups. Nearly all the African-Caribbeans could speak and read English and, for the majority, this was their only language. Sixty-four% of South Asians could speak English and 49% could read it, but only 18% of the Chinese/Vietnamese elders could speak English and only 12% read the language. The Chinese in Scotland were also less likely to speak English than their counterparts in Yorkshire or London. However, the South Asians in Scotland were more likely to speak English than their counterparts in the other two regions. There were also differences in language ability by age, with the older informants being less likely to speak English than the younger ones. While this bodes well for the future, there are currently significant numbers of South Asians and Chinese/Vietnamese who face language barriers in accessing health and social services.

Socio-economic Profile

There were differences in education levels between the ethnic groups: the African-Caribbean elders had the highest proportion of individuals with primary, secondary, tertiary or vocational education; the South Asians had the highest proportion with degree-level education and the Chinese/Vietnamese had the highest proportion with no formal or only primary education.

The state retirement pension (49%) and social benefits/allowances (43%) were the main sources of income. Eighty-two% of Chinese/Vietnamese were in the low income group (£60 - £450 per month) compared to 52% of African-Caribbeans and 48% of South Asians.¹ The younger age group had a better income profile than the older age group. In addition, the Yorkshire region had the lowest income profile. Only 10% of the sample were still in employment.

Health

There were differences in the incidence of various health problems by ethnic group. On the serious health problems the main differences were:

- African-Caribbean elders had a higher incidence of high blood pressure than South Asians who, in turn, had a higher incidence than the Chinese/Vietnamese elders
- African-Caribbean and South Asian elders had a higher incidence of diabetes than the Chinese/Vietnamese
- Heart disease and lung/breathing conditions were highest amongst the South Asians
- Osteoporosis and memory problems were highest amongst the Chinese/Vietnamese

With regard to specific health problems and gender, there were very clear differences between the sexes in respect of a number of conditions. Men had a higher incidence of diabetes compared to women (men 42%, women 26%). Women had higher incidences of arthritis/rheumatism, musculoskeletal disorders, osteoporosis and constant headaches/migraine. The differences between men and women with regard to muscle and bone disorders are quite marked:

- Arthritis and rheumatism: women 63%, men 46%
- Osteoporosis: women 17%, men 8%
- Musculoskeletal disorders: women 46%, men 29%

The serious health problems were not related to age. The age-related conditions were problems with eyesight, high blood pressure, hypertension, dental problems, sleeping problems, hearing problems and kidney/urinary tract disorders.

There were only a few regional differences with regard to health problems. Scotland had a higher incidence of dental problems and thyroid disorders. Yorkshire had a lower incidence than the other two regions of musculoskeletal disorders, kidney/urinary tract disorders and mental problems.

The Chinese/Vietnamese had a lower score than the other two groups on the index of physical limitation. This index was related to age, with the measure rising across all age groups. The South Asians had a lower score than the other two groups on the index of well-being. There were no differences in this measure by region, gender or age. The African-Caribbeans had a higher score than the other two groups on the index of self-esteem. Those aged 64 years or below had a higher score than the older age groups.

We used cluster analysis to create 4 clusters as follow:

- Informants with no problems: n =141
- Informants with physical problems: n = 121
- Informants with emotional problems: n = 42
- Informants with both physical and emotional problems: n = 84

More women had physical problems and more men had emotional problems. There were slightly more men than women with no problems at all.

Service Usage: Health

High proportions of informants used GP services, dentists, opticians and also more than half the informants had used the hospital outpatient clinic. Overall, satisfaction levels with the different services were high with all mean scores being over the value of 3. The services with the lowest level of satisfaction were hospital accident and emergency, and rehabilitation.

The Chinese/Vietnamese elders used the GP service less than the two other groups. The frequent users of GP services had a poorer standard of general health, a poorer quality of life and enjoyed life less. They needed more medical treatment to function every day and during the last month had more pain which interfered with their normal work or regular activities. They had more physical limitations and scored lower on the indices of self-esteem and well-being.

The South Asian elders were rather less satisfied than the African-Caribbeans with GP services. A high proportion of Chinese/Vietnamese elders (64%) expressed themselves 'somewhat' satisfied with their GP service.

Those less satisfied with their GP service had poorer general health, a poorer quality of life and enjoyed life less compared to the more satisfied users. There was no difference in how much medical treatment the less satisfied or the more satisfied needed to function, but those who were less satisfied suffered more interference with their daily activities from pain and had a higher score on the index of physical limitations. They also scored lower on the indices of self-esteem and well-being.

Service Usage: Social Care

The services with the highest proportion of users were the social day-care services and the transport services (the use of these two services could be linked). Excluding the residential services, those services which were regularly used (i.e., daily or once or twice a week) are home care, social day-care and transport services.

The African-Caribbeans had a higher incidence of usage of social day-care services than the other two groups. Eighty% of African-Caribbean elders used social day care compared to 44% of South Asians and 45% of Chinese/Vietnamese. Amongst those who did use social day-care centres there were differences according to ethnic group in how frequently the services were used. The African-Caribbean elders were more likely to use the services daily or once/twice per week than the other two groups.

We compared the 'frequent users' of day-care with the 'less frequent users'. The frequent users had better general health, enjoyed life more, needed less medical treatment, had less pain interfering with daily activities, and scored higher on the index of self-esteem and index of well-being than the 'less frequent users'. There were no differences between the groups with regard to their (self-assessed) quality of life, the availability of help when needed/wanted and the index of physical limitations.

Overall, satisfaction with social care services was high. The South Asians were less satisfied with home nursing, home care and day care. The older informants (75 and over) were less satisfied with day care than younger informants. There were no differences in satisfaction levels with regard to gender, but there were some regional differences.

Expectations and Perceptions

Informants were asked about their service expectations and perceptions of health and social care services. There were differences by gender and ethnic group with regard to: providing places for worship; providing professionals of the same gender; providing professionals of the same ethnic background; and enabling clients to talk freely about religious needs with staff. The highest expectations related to being treated with respect; feeling safe and comfortable; having dignity respected; and that professionals behave with integrity. The highest gaps in service provision concerned: avoidance of waiting lists and delays; provision of information about existing services in elders' languages; having the necessary staff for good services for elders; ease of communication; information to be simple and understandable; and information about rights to be given clearly.

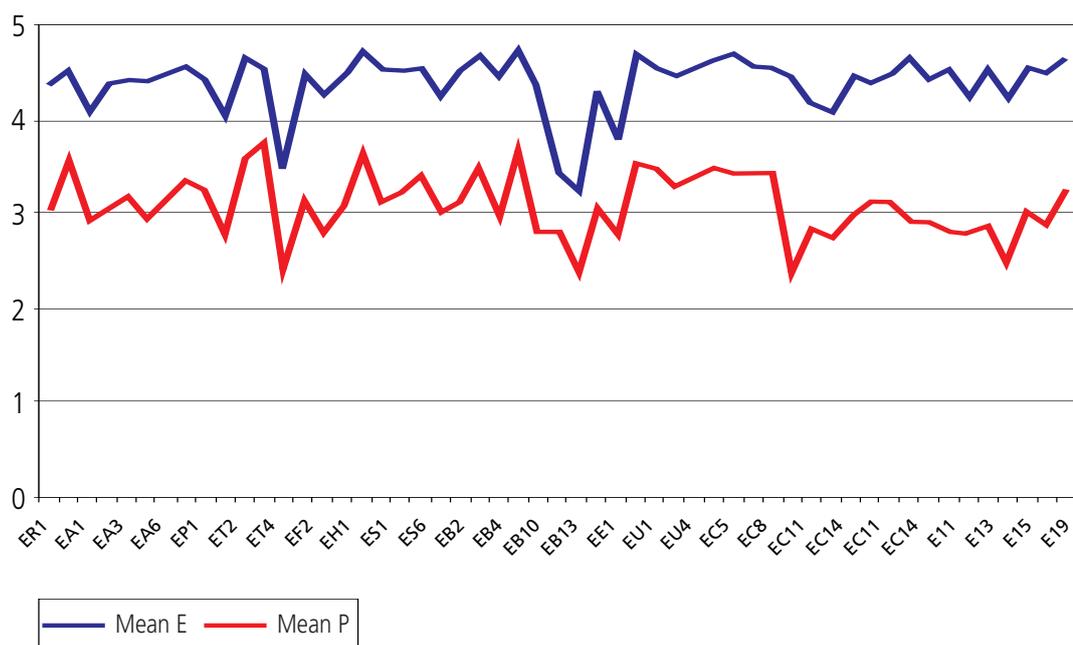


Figure 1. BME Elders' Expectations and Perceptions

Recommendations

1. There is a need to overcome the stereotype that BME communities 'look after their own' as an excuse for not developing proper policies. Families face their own pressures of normal life, career and childcare commitments and may be stretched financially, physically and mentally by caring for an elder, especially if he or she is in poor health.
2. Elders living alone must have satisfactory living conditions and appropriate support to enhance their daily lives and facilitate independent living. Families and health/social-care organisations need to be able to work together to find the best solution for an elder in the event of she or he becoming ill or unable to cope. Assessment of an elderly person in respect to health and/or social care should take into account the individual's overall quality of life and general living conditions.
3. There are currently very significant numbers of South Asian and Chinese/Vietnamese elders who face language barriers in accessing care services. It is unrealistic to imagine that people who have reached a certain level of maturity can learn a new language. Many organisations do provide translation or interpreter services and these must be considered important and essential. Furthermore, organisations should have a clear policy regarding the provision of translation/interpretation services and the role of multi-lingual staff in providing a means of communication with patients/clients. Such a policy needs to be clearly communicated to BME communities.
4. Many elders are living on low incomes and, in these circumstances, the option to pay for care does not exist. While most health services in the UK are free, some social care services do have charges, although these may be waived in certain situations. It is important that any system of charging is easy to understand and that the elder's entitlement to free services is properly explained. There should not be complicated procedures or means testing in order to get support.
5. It is recognised in the health arena that BME communities have some different health problems from the white British population. For example, the differences with regard to diabetes are well known. How far these differences are known and understood, we are not sure; we hope that results from this research add some value to the level of knowledge in this area. Nevertheless, we think that it is key for the medical profession to investigate and understand the underlying causes for the differences in the incidence of certain medical conditions and then to address what can be done about this. There is a need to understand to what extent the differences between ethnic groups are unavoidable and what can be changed and improved over time. Might there also be a strong case for more health education among certain BME communities?
6. The Chinese/Vietnamese elders used various health services (GP, district nurse, hospital outpatients) and some social services (social day care in hospital, home care) considerably less frequently than the other two groups. The results show that this was not entirely due to the Chinese/Vietnamese having better health. We suggest that there are two other possible reasons: (i) they have more reliance and trust in traditional Chinese medicine or (ii) they are worried about using UK GP services for some reason, for example, they may not be aware that services in the UK are free and open to everyone who needs them. Outreach work should be undertaken with the Chinese/Vietnamese community to ascertain the precise reasons for the lower use of services and efforts should be made to redress any problems. Furthermore, greater acceptance of proven alternative therapies within mainstream provision should be promoted.
7. Having and implementing clear, strong policies on race and equality is essential for every health and social care organisation and this should be supported by training and education in cultural competence. Together, these should provide very practical guidance on how fully and properly to serve patients/clients from very diverse backgrounds. Neither discrimination in provision, or racism from patients to staff and/or other service users should be tolerated.
8. Many of the biggest gaps between expectations and perceptions had to do with information and communication, which clearly suggests that there is an information gap in service provision. There are numerous things which can be done about this, for example: better use of the Internet as a patient source of information; hospital radio in minority languages; better liaison with BME voluntary organisations and use of social care institutions to provide information to users about other services and institutions.

Section 3: United Kingdom

Mainstream Providers' Perspectives

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- Professor Naina Patel, Dr Kathryn Watson, Samantha Turner
PRIAE MEC UK Research Team

Introduction

The National Health Service in the UK was set up in 1948 to provide healthcare for all citizens, based on need, not on the ability to pay. It is the largest organisation in Europe. Its aims are to promote health and prevent ill-health, to diagnose and treat injury and disease, to care for those with a long-term illness and disability. Funding of the NHS has been a major political issue for many years. There have been many organisational changes including the creation of Primary Care Trusts and NHS Trusts.

The Department of Health is responsible for social care policy in England; in Scotland, the Scottish Executive Health Department is responsible for social work policy and, in particular, community care and voluntary issues. Local authorities are the mainstream providers of care. National Service Frameworks have been introduced in England and National Care Standards in Scotland. Current problems include lack of capacity and workforce issues.

Survey Details

This survey in the UK focuses on 3 regions: London, West Yorkshire and Scotland. One hundred and one health and social care workers were interviewed using a face-to-face, structured questionnaire. The sample includes 54 professionals and 47 managers/planners. Two-thirds had 6 or more years' service. Ninety-three had worked with BME clients. Sixty-four respondents were white British, 18 South Asian, 11 African-Caribbean or Black British. Nearly all respondents were highly educated.

The responses were analysed by Provider Type. This categorisation is made up of 13 GP practices, 31 hospitals, 19 Trusts and 38 Social Services informants.

Survey Results

Special Circumstances of BME elders ('special' is used to mean 'different'/'specific')

There was a high level of recognition that BME elders do have specific needs, specific health problems and specific access barriers.

Special Circumstances of BME Elders (Number of Informants)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know	Mean (excluding don't know)
	1	2	3	4	5	6	
BME elders have special health and social care needs	3	6	5	42	44	1	4.18
BME elders have specific health problems	4	7	7	44	37	2	4.04
BME elders have specific access problems	1	7	7	43	42	1	4.18

Social Services were more likely than NHS respondents to agree that BME elders have special problems of access; and managers/planners were more likely than professionals to agree the BME elders have special access problems. There were no differences by ethnic group or provider type on these variables.

The top three reasons given for the special circumstances of BME elders were language problems, clients' cultural norms and values, and the experience of discrimination.

Measures to Encourage Take-up of Services

The most frequently used measures to encourage take-up of services were:

- Using interpreters and/or advocates
- Having interpreters available when needed
- Collaborating with BME voluntary organisations
- Distributing information in appropriate languages
- Collaborating with other mainstream service providers over service design for BME elders

The 23 measures were reduced to five dimensions. The mean values of the dimensions are:

- Collaboration (3.44)
- Information/awareness (3.20)
- Facilitation (2.98)
- Adaptation/Innovation (2.88)
- Human Resources (2.55)

The GPs' responses had values:

- Lower than the other three provider groups on Facilitation
- Lower than hospitals and Social Services on Adaptation/Innovation
- Lower than Trusts on Human Resources
- Lower than the other three provider groups on Collaboration.

It is necessary to bear in mind that GP practices are much smaller organisations than the other three Provider Types, and that GP services are freely available to anyone living in their catchment area.

NHS respondents scored lower than Local Authority respondents on Collaboration.

Managers/planners had a higher mean score than Professionals on Facilitation, Human Resources and Collaboration.

Demand for Services

42 respondents indicated that the financial position of their organisation was poor or very poor.

58, however, had seen an increase in resources during the last five years; those who had had an increase rated their financial position better. GP services and Trusts were more likely to have had an increase, compared to hospitals and Local Authorities.

80 had had an increase in users during the past five years (range 1 per cent to 85 per cent).

98 expected an increase in BME elderly users over the next 10 years.

90 expected there to be an increase in the range of services over the next 10 years.

Collaboration

31 respondents indicated that BME elders were involved in the design of services often or very frequently.

81 indicated that their organisations collaborate with BME organisations (9 do not collaborate and 11 responses were don't know).

GPs were less likely to be involved in collaboration.

The top three types of collaboration consisted of: liaison, consulting/advice, informing potential clients.

The level of satisfaction with collaboration was not high. Of the 89 respondents who answered the question, only 1 was extremely satisfied; 16 were very satisfied, 41 were quite satisfied, 19 were not very satisfied and 1 was not satisfied at all.

Varied reasons were given, including: lack of trust; communication difficulties; gender issues; lack of understanding; differing expectations and views; difficulties gaining access to BME groups; difficulties finding spokespeople who

represent their communities; lack of understanding of resource issues/demands on services; groups not perceiving any change; lack of capacity/small size of BME groups; and suspicion and mistrust on their part of mainstream organisations.

68 respondents indicated that they plan to take part in future consultation exercises, 5 do not, while 28 were 'don't know', or did not respond.

Service Provision

53 respondents thought that the share of BME elders using their services did not reflect their share of the population as a whole. The highest proportion of respondents who thought that BME usage was lower, comparatively, than among the population as a whole were in the Social Services. London-based respondents had the highest proportion responding "the same" or "higher" for BME elders' use of services.

The main user groups were African Caribbean, South Asian and Chinese.

Of the 101 informants, 30 thought the needs of BME elders in the UK were poorly met; 62 partly met; and 7 thought they were well met. The top 4 reasons for unmet needs were:

- Language problems (3.97)
- Lack of information (3.97)
- Lack of understanding of the complex service structure (3.92)
- Cultural differences (3.77)

Racism

77 respondents had witnessed racism at some time from health or social care professionals towards users, and 87 had witnessed racism on the part of other service users. BME respondents were more likely than white European informants to say that they had observed racism on the part of health and social care professionals. 78 stated that measures were being, or had been, implemented to counter racism; a further 9 said that measures were planned.

Expectations, Perceptions and the Gap Between

The **highest Expectations** were that: clients' dignity should be respected; service providers should treat clients with respect; clients should be able to trust staff; and care staff should behave with integrity.

The **lowest Expectations** were that: staff should be of the same ethnic background; of the same gender; services should be open at all times; organisations should provide places of worship.

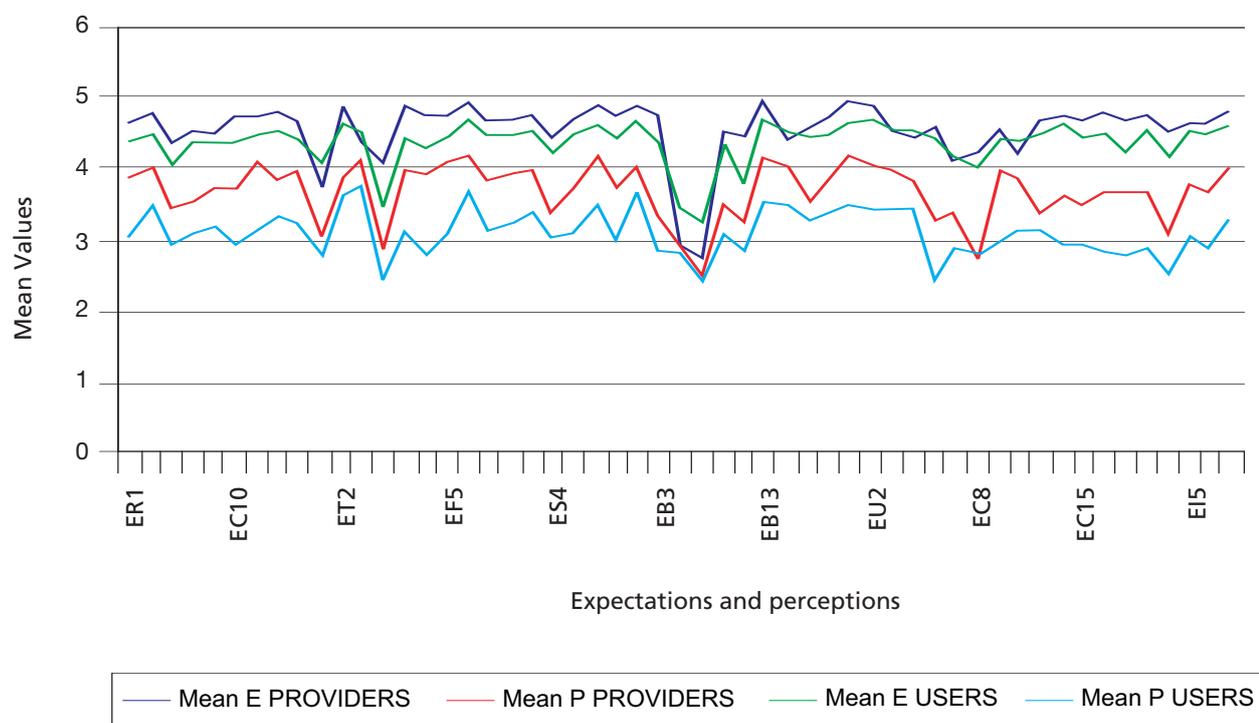
The **greatest Gaps** concerned: the possible use of alternative care methods; the provision of information in clients' own language; that staff should understand clients' cultural values; that care-providing organisations should have easy-to-follow procedures and processes.

Four of the six highest Gaps in the BME elders' survey were to do with the provision of information.

A comparison of the results of mainstream providers with those of BME elders reveals that the expectations of users and providers are quite closely matched: indeed, providers' expectations were slightly higher than those of users. However, the BME users' perceptions of services are at a considerably lower level than those of the providers, thus generating a wider gap.

The scales of Expectations and Perceptions were reduced to four dimensions, or aspects of services: Access, Tangible and Practical Matters, Responsiveness and Specific Needs. There was very little difference between the service providers in their assessments of all 4 dimensions. The GPs tended to demonstrate a slightly narrower gap between their Expectations and their Perceptions, in respect of all 4 dimensions, than did the other 3 provider types. BME user groups tended to demonstrate wider gaps, especially the South Asians when considering Access and Specific Needs.

Users and Mainstream Providers expectations and perceptions



Recommendations

1. With regard to service design, the survey showed that slightly more emphasis was given to internal discussion and procedures than to quality assessment and the use of measures involving external reviewers. It is worth making the point that looking to an external assessment of the organisation – especially if this involved BME elders and elders’ representatives – could be very beneficial in the process of service design.
2. There was a high level of recognition that BME elders do have special needs, specific health problems and specific access barriers. Such acknowledgement is very encouraging, but it is nevertheless surprising that some people still disagree with this. The main factors attributed to BME elders’ special circumstances were considered to be language and culture. While these are no doubt important, there is a need for more consolidation and dissemination of the research literature on the health differences between ethnic groups. The socio-economic situation of clients was considered the least important reason for BME elders’ special needs, and perhaps there is a need for a greater understanding or recognition of the negative influence of poverty on health and well-being.
3. The GPs had lower scores than the other providers on the use of measures to encourage take-up of services. This result should be treated with some caution due to the nature of service provision and considerable differences in organisational size (GP practices are typically small organisations, while all the others are typically very large organisations). However, because GP services are free and available to everyone in the UK, there is perhaps little recognition of any need to encourage greater take-up of the service. The results of our survey of BME elders did show that there were differences in the level of take-up of services among different BME groups, especially the Chinese/Vietnamese. Therefore, we suggest that there is a need for measures to encourage the use of services, and for efforts to overcome barriers to access among certain BME communities.
4. While the level of collaboration overall was quite high, there was a fairly high level of dissatisfaction with the collaboration process. A very broad range of reasons were given for this, which included issues of trust, understanding, communication and representation. It would be useful to look at instances where collaboration has gone well and try to understand what are the key drivers of the process that make it a success.
5. With regard to expectations and perceptions, cultural issues came out as an important area where there were differences between users and providers, especially with regard to the provision of staff of the same gender and ethnicity as the client. These factors were especially important to the South Asian elders. It is apparent that there is a need for greater understanding and acceptance of certain issues which are important to specific groups of elders. This is borne out by the fact that the understanding of cultural values is recognised as one of the major gaps in service provision. Service providers need to have clear policies on issues that are culturally sensitive and that, although not perceived by them as important, may be very important to some of their service-users.

Section 4: United Kingdom

Black and Minority Ethnic Organisations' Perspectives

Acknowledgements

The PRIAE research team would like to thank all the BME voluntary organisations who devoted their time to completing a lengthy interview and questionnaire.

We also gratefully acknowledge the contribution of the fieldworkers and administrators who persistently went about arranging interviews and collecting such an extensive amount of data on the topic of health and social care for BME elders. In particular, MEC wish to express their thanks to the following fieldworkers:

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Introduction

The UK has had a thriving and proactive voluntary sector in the black and minority ethnic community (BME) since the early 1980s. Some are well-established institutions within UK society; others are micro-organisations which struggle to survive from one year to the next. Many organisations have religious faith as their primary focus; they also provide essential social and community care to a large proportion of the BME population. In respect of social care they represent an alternative service provider to the mainstream for BME elders.

Survey Details

WP4 in the UK focuses on 3 regions: London, West Yorkshire and Scotland. Representatives from fifty organisations were interviewed in total. The main target BME groups of the organisations were South Asians, African-Caribbeans and Chinese/Vietnamese. One Jewish organisation was included in the sample. Most of the organisations were well established, with nearly half having been founded in the 1980s.

Target Group by Region

(Number of Informants)

	South Asian	African-Caribbean	Chinese/Vietnamese	Jewish	Total
Yorkshire	11	3	4	0	18
London	14	6	2	0	22
Scotland	7	0	2	1	10
Total	32	9	8	1	50

Survey Results

Organisational Characteristics

Informants were asked to state their organisation's focus. Multiple responses were permitted. Providing services; the provision of information and raising awareness; providing expert/specialist knowledge and lobbying/campaigning were important roles assumed by the organisations.

Organisation Focus

(Number of Informants)

Service provision to BME elders	50
Information provision and awareness raising	38
Providing expert or specialist knowledge	25
Lobbying/campaigning on behalf of BME user groups	20
Education/training	4
Referrals	3

Thirty-seven of the organisations operated on the basis of continuous service provision, 10 had multiple projects running concurrently and 3 operated on the basis of a single project. Fourteen of the organisations were small, 25 medium-sized, and 11 were large. There was a tendency for the South Asian organisations to be larger.

Twenty-eight organisations were based in an inner-city area, 20 in an outer city and 2 in a town. Forty concentrated their activities on their town/city, 6 extended to their county area, 3 were national and 1 was international. Of those who extended their services beyond their own town/city, one was Jewish, three were Chinese/Vietnamese and six were South Asian.

The two foremost reasons for creating the organisations were to overcome communication problems between BME user groups and mainstream service providers and to overcome the lack of cultural knowledge/competence among existing service providers.

Target Group and Needs

The organisations varied considerably in the number of users of their services per year and in a typical week. They ranged from small organisations serving only a handful of clients to those with thousands of service users annually. Twenty-six had up to 50 users per week, 11 had 51 to 100 users per week; and 9 had over 100 up to 400 users per week. We divided users per year by users per week to get a measure of turnover of users. Twenty-three had a low turnover; 10 had a high turnover (17 had missing values on one of the variables).

Eighteen organisations served only one minority ethnic group; 18 served various BME groups; 14 served both BME groups and the mainstream population.

Most of the organisations focused on providing services to elders. More than half indicated that the situation of their target groups in respect of income, employment, social status, education and health was either poor or very poor.

Twenty-one informants judged that elders’ needs were poorly met or not met at all. The main reasons for unmet needs were thought to be:

- Language problems
- Lack of information
- Inadequate services
- Lacking understanding of the complex service structure
- Lacking multicultural/intercultural competence of staff

The top 3 reasons why mainstream organisations do not meet needs were considered as:

- Not developed specific services
- Don’t recognise need
- Lack of awareness/information

Service Provision

The level of collaboration between voluntary sector service providers and users is very high. Forty-nine said that they involve users in the design and development of new services. The reasons given for collaboration were:

- Management committee/funder’s requirement
- To empower users
- To monitor services
- To provide effective/best services
- To improve the services

Various measures were used to encourage take-up of services. All measures except staff training in languages had a mean value of over 3.5. Collaboration with others had a higher priority than training and recruitment. The top 3 measures were:

- Tailoring services to specific BME needs
- Raising awareness among BME elders
- Distributing information in appropriate languages

Nearly all the organisations wished to extend their current services, but only four said they had sufficient resources for expansion.

Seventeen informants indicated that they have sufficient resources to encourage take-up of services; 31 indicated that they do not and two responded ‘don’t know’.

Forty-eight informants indicated that their organisation wished to extend its current service provision. This included both existing and new services and existing and new users. Only 4 of the informants felt that they had sufficient resources for such expansion. There was no difference in expansion plans according to ethnic group.

Desired Strategic Direction for Expansion

(Number of informants)

	USERS	
	Existing	New
Existing	42	40
New	42	35

Thirty-six informants thought that their current service provision was not adequate or satisfactory, given the size of the BME population in their area. Twenty-nine judged the number of voluntary organisations was not sufficient to meet the needs of BME elders in their locality.

Human Resources

Most of the organisations were small in terms of numbers employed. Forty had fewer than 10 staff; 8 had between 10 and 30.5 staff. Over half the organisations had more than 50% female staff; more than 50% of staff aged 35 or above; more than 50% of staff involved in administration, and more than 50% of BME staff.

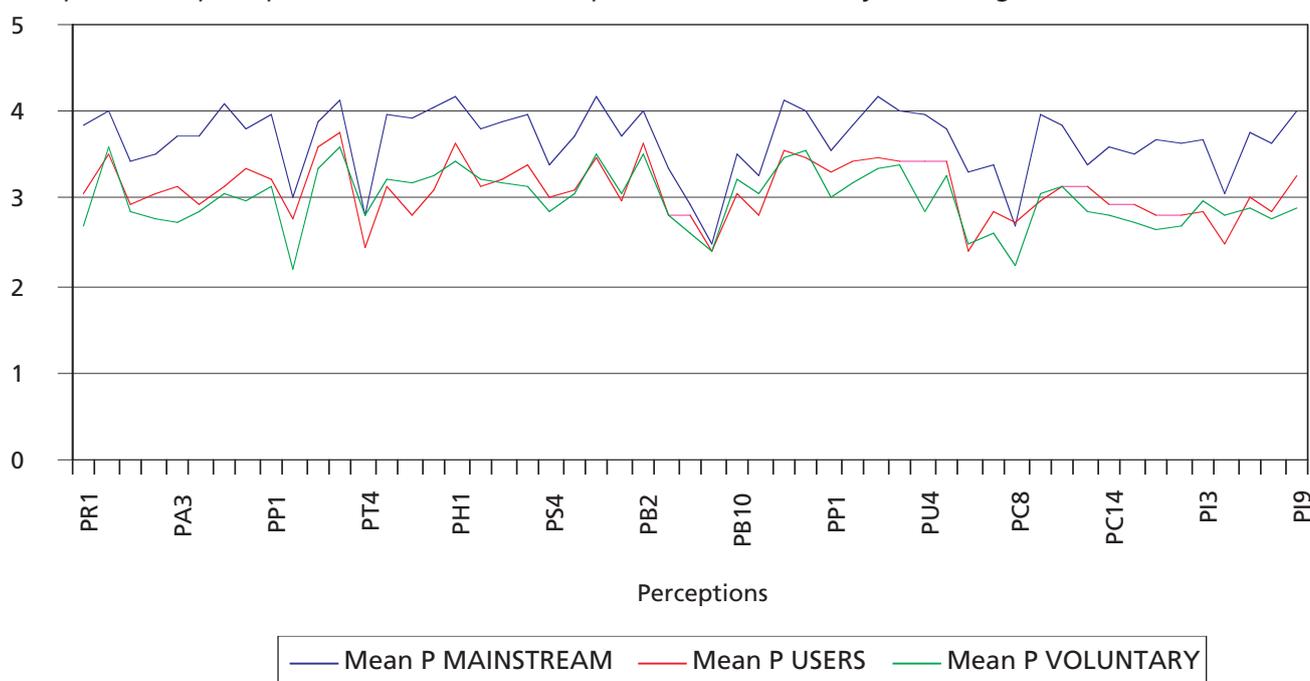
Financial Resources

Forty two percent of the organisations had funding of £35,000 - £140,000 and twenty eight percent had over £140,000 per year. Most were operating with smaller budgets relative to the services that they offered and were short term. Their main sources of income were local authorities, followed by fees and the proceeds of service operation. Some organisations were in decline, with a majority stable or growing, but this was achieved at a high cost in raising finance.

Expectations and Perceptions

Respondents' expectations of (mainstream) service quality were similar to those both of the mainstream providers and of BME users, but they rated their perceptions of how far these expectations were met in reality at a lower level than did the mainstream providers, thus occasioning a wider gap over service quality.

Comparison of perceptions: users, mainstream providers and minority ethnic organisations



The widest gaps concerned the expectations that:

- Waiting lists and delays in providing services should be avoided
- Alternative care methods should be accommodated within the existing care structure
- An interpreter should be available when minority clients are required to use care services
- Information about the clients' rights should be presented clearly
- The staff should have an understanding of the clients' cultural values when providing services

Recommendations

1. The survey findings reveal that there is a thriving and proactive BME voluntary sector in the UK. The 50 organisations surveyed varied in nature, size, target group; they demonstrated different emphases in respect of their mission and reasons for coming into existence. Nevertheless, they were all very service oriented and their main function can be seen as providing an alternative care structure to that of the mainstream providers. Most of the organisations focused specifically on elders, although some of the larger institutions catered for all age groups. There was a majority view that the situation of their service users (target groups) was either poor or very poor, especially with regard to health. Thus, we conclude that the organisations provide a very important and valuable service to a section of the community that has great need.

2. Problems in communication and related matters were thought to be an area in which mainstream provision fell down; this is consistent with the other two surveys undertaken as part of the MEC project. Our health and social institutions are large and complex organisations and it is often difficult enough for people who have lived in the UK all their lives to understand these systems. It must be even more difficult for people who have settled here from different countries, who may speak a different language, to understand how to access these services. However, it should not be necessary for users to have to learn about complex organisational structures and processes – it would make sense to design services where the client interaction and contact with the service is streamlined, easy to understand and, of course, promotes equal access for all. Matters of communication and the provision of appropriate information are areas where it should be relatively simple to make significant improvements and thus facilitate greater take-up of services.
3. Two other issues that were thought to contribute to the failure to meet needs were inadequate services and a lack of multicultural/intercultural competence among staff. Undoubtedly, there are tremendous pressures on mainstream service providers from different age groups with wide-ranging sorts of problems. However, the needs of elders must be given a high priority in service provision – everyone grows old – and ageing is often associated with ill health and increasing physical and mental limitations. It is imperative that mainstream and voluntary sector providers plan and make provision for the expected increases in the number of elders and especially for the projected increase in the BME elderly population. It is essential that all frontline service-delivery staff have training in the delivery of multicultural/intercultural services.
4. One very positive note is that most of the organisations surveyed wish to expand and increase their service provision in a variety of ways. Furthermore, the stability of the organisations should mean that they are able to build on a firm foundation for further expansion; however, the lack of funds available for expansion was clearly felt to be an issue.
5. While service quality expectations for users, mainstream providers and voluntary organisations were at a similar level, the actual delivery of services was not perceived in the same way. Both the users and the voluntary organisations posited bigger service quality gaps. The gaps highlighted in this survey and also in BME elders and mainstream providers need to be addressed.

Surveyed minorities by region

Country	Region	Ethnic group			Total
United Kingdom		African-Caribbean	South Asian	Chinese/Vietnamese	
	Yorkshire	41	62	33	
	London	46	84	30	390
	Scotland	5	64	25	
France		Algerian	Moroccan	South East Asian	
	Ile-de-France	48	45	54	
	Rhône	48	62	25	390
	Isère	60	40	8	
Germany		Turkish	Italian	Russian Repatriates	
	Berlin	50	31	54	
	Munich	50	40	50	394
	Augsburg	50	19	50	
Netherlands		Moluccan	Turkish	Surinamese	
	Alphen aan den Rijn/				
	Leiden	48	75	75	
	Amsterdam				
	Nieuw-West	45	75	77	391
Spain		Moroccan	Latin American	Roma	
	Catalonia	50	46	50	
	Andalucia	52	45	50	293
Finland		Russian	Vietnamese	Sami	
	Capital area	119	50	0	
	Lapland	0	0	126	295
Hungary		Roma	Germans	Croatians	
	Nógrad	35			
	Baranya	35	100		
	Borsod-Abauj-Zemplen	30			290
	Vas			90	
Bosnia and Herzegovina		Hungarians	Czechs	Roma	
	Federation of BiH	90	91	71	
	Republika Srpska	0	0	21	273
Croatia		Hungarians	Czechs	Bosniaks	
	Zagreb region	20	0	51	
	Slavonia-Baranja	70	91	0	271
	Istria-Primorje	0	0	39	
Switzerland		Italians	Spaniards	Former- Yugoslavians	
	Geneva	49	51	45	290
	Basle	50	50	45	

Figure 1. Methodology

A Methodology Sub-Group was created to undertake the detailed design of the research for each of the three dimensions: ME elders, health and social care professionals and managers/planners, and ME voluntary organisations. In keeping with the design of the original proposal, three ethnic groups and three geographic regions were targeted. Several focus groups were held in each country and the critical incident technique was used to aid the design of the survey instruments. Extensive reviews of literature, past survey instruments, clinical instruments, including an emphasis on examining service quality were also used to guide the topics investigated in the surveys. Survey instruments were piloted before being finally approved. Most of the surveys in all three dimensions were completed by face to face interviews using a structured questionnaire. Only in a small number of situations were self-administered interviews used – these applied when geographic distance or interviewee time meant this was a more practical approach. Survey questionnaires were translated into all relevant languages for the different ethnic groups and interviews were held in the language of choice of the respondents. The method of sampling used was quota sampling based on ethnic group and region for the ME Elders dimension, job title, sector and region for the Professionals and Managers/Planners’ dimension, and target ethnic group and region for the ME Organisations dimension. Gaining the trust and confidence of community groups was essential for gaining access in the first and last dimensions in particular. The main data analysis techniques used were frequencies, cross-tabulations and associated chi square test, T-tests and one-way ANOVA. Quality control procedures were adhered to at all times.

A snapshot of Minority Ethnic Voluntary Organisations in Europe

This dimension has not been previously studied in relation to service provision, source and scale of resources and their relationship with users and mainstream providers. At the outset, it is necessary to state, that there are ME voluntary organisations in every country surveyed and that these take a proactive role in representing the interests of ME elders as well as providing services in many instances. In Finland the number of ME organisations is small since immigration is relatively a new phenomenon taking place for the most part since 1990, except for the traditional minority group: the Sami. In view of this, the researchers in Finland adopted a case study methodology, based on 4 organisations, rather than the survey approach. The sample size for each of the other countries is set out in Table 1.

Table 1: Sample Size for Dimension 3 (ME Voluntary Organisations)

Country	Sample size
United Kingdom	50
France	50
Germany	38
Netherlands	29
Spain	30
Hungary	19
Bosnia-Herzegovina	30
Croatia	30
Switzerland	32

Table 2: Funding of ME Voluntary Organisations

	Sample size	<€5,000	€5,000 to €50,000	>€50,000 to €200,000	>€200,000	Not answered question
UK	50	4	8	21	14	3
France	50	29	12	4	2	3
Germany	38	5	2	14	12	5
Netherlands	29	6	11	2	9	1
Spain	30	6	5	5	12	2
Hungary	19	9	6	—	—	4
Bosnia-Herzegovina	30	29	1	—	—	—
Croatia	30	16	7	3	1	3
Switzerland	32	5	9	2	12	4

Table 3: Sources of Funding

	Sample size	Services	Local authority	State	Project (eg EU)	Donations	Fees	Contracts	Public funding
UK	50	21	25	21	8	17	41	4	5
France	50	21	41	14	17	18	26	9	15
Germany	38	23	23	12	6	17	14	6	9
Netherlands	29	16	20	9	16	12	11	2	12
Spain	30	5	23	21	13	11	18	4	5
Hungary	19	13	3	5	8	10	15	1	13
Bosnia-Herzegovina	30	4	8	7	18	21	19	1	-
Croatia	30	5	17	23	9	13	19	3	2
Switzerland	32	13	12	8	13	18	12	2	6

PRIAE MEC UK Research Briefing

Minority Elderly Health & Social Care in Europe

United Kingdom, France, Germany, Netherlands, Spain, Finland, Hungary,
Bosnia-Herzegovina, Croatia and Switzerland

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MEC research is a PRIAE concept, project designed and led by PRIAE

PRIAE is an independent registered charity working to improve pensions, employment, health, social care and housing, and quality of life for black and minority ethnic older people in the UK and across Europe. The Institute aims to influence national and European policy and increase and encourage good practice in work with black and minority ethnic elders. PRIAE does this through creating and leading on research projects like MEC, CEMESME in employment and enterprise, research policy, information, service developments, training and consultancy.
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This PRIAE MEC UK research briefing was launched by Stephen Timms MP Minister of State for Pensions Reform, PRIAE's Patron, Dr Chai Patel CBE, FRCP with its Chair Lord Herman Ouseley, Vice Chair Lord Dholakia OBE with Claude Moraes MEP and PRIAE conference speakers (see conference programme) on 4th October 2005, Queen Elizabeth II Conference Centre, London.

The age distribution of ethnic minority women and men in the UK, 2001

Age Group	Age Group										
	16 - 19		20-39		40-59		60-79		80 +		Total
	absolute	%	absolute	%	absolute	%	absolute	%	absolute	%	absolute
Women											
White British	1,054,596	5.5	6,175,306	32.5	6,079,965	31.8	4,292,443	22.6	1,418,195	7.6	19,020,605
White Irish	6,524	2.0	83,170	25.9	108,368	33.8	101,553	31.7	21,176	6.6	320,891
Mixed group	27,088	15.7	96,158	55.6	35,367	20.4	11,668	6.7	2,775	1.6	173,156
Indian	35,526	8.8	187,672	46.3	129,349	31.9	47,254	11.7	5,560	1.4	405,461
Pakistani	30,230	13.1	124,024	53.9	55,088	23.9	18,638	8.1	2,139	0.9	230,219
Bangladeshi	12,653	14.7	49,731	57.8	17,793	20.7	5,464	6.3	424	0.5	86,165
Black Caribbean	15,132	6.2	110,223	44.9	74,808	30.5	41,787	17.0	3,317	1.4	245,367
Black African	16,107	9.1	107,936	61.1	43,372	24.5	8,424	4.8	946	0.5	176,885
Chinese	10,261	10.5	47,130	48.4	30,758	31.6	8,056	8.3	1,206	1.2	97,511
Other ethnic groups	6,199	6.1	56,453	55.6	32,845	32.4	5,296	5.2	685	0.7	101,578
Men											
White British	1,103,689	6.3	6,086,548	34.6	6,040,403	34.3	3,699,702	21.0	679,704	3.9	17,610,146
White Irish	6,881	2.4	79,604	28.1	101,294	35.8	85,015	30.0	10,423	3.7	283,317
Mixed group	27,999	17.8	85,504	54.3	31,146	19.8	11,176	7.1	1,550	1.0	157,475
Indian	36,387	9.2	178,254	45.2	126,396	32.1	48,688	12.4	4,394	1.1	394,219
Pakistani	31,191	13.3	122,532	52.2	54,354	23.2	24,779	10.6	1,785	0.8	234,741
Bangladeshi	12,533	14.4	47,961	55.2	15,748	18.1	10,177	11.7	401	0.5	86,920
Black Caribbean	14,573	7.1	87,592	43.0	55,353	27.2	43,281	21.2	2,968	1.5	203,867
Black African	15,232	9.6	91,973	58.2	40,854	25.8	9,408	5.9	673	0.4	158,240
Chinese	10,986	12.5	43,926	49.9	24,501	27.9	7,905	9.0	630	0.7	88,048
Other ethnic groups	6,668	8.8	42,173	55.5	22,423	29.5	4,260	5.6	403	0.5	76,027

Table adapted by PRIAE (2005) from the Census 2001 (ONS 2003a p121/2)

PRIAE..... is one of the only organisations successfully lobbying this agenda across the EU'.

Claude Moraes MEP

'PRIAE's work is of enormous importance in the UK and in Europe as a whole. As the EU looks for ways to cope with its changing demography and develops a policy perspective on the internal market in healthcare, pensions and social inclusion, PRIAE becomes a crucial resource and inspiration for all decision makers.'

Jean Lambert MEP

'.... The challenges this research exposes are not theoretical – they are very real and almost upon us. It is a wake up call for policy makers in all EU institutions.'

Stephen Hughes MEP

'The needs of BME elders must be included for health and social care policy, planning and delivery. This important conference will help policy makers, managers and practitioners, as well as all those who are committed to social inclusion, to identify and translate into practice the renewed focus on the needs of BME elders.'

Professor Ian Philp, National Director for Older People's Services, Department of Health

About PRIAE

PRIAE is an independent registered charity working to improve pensions, employment, health, social care and housing, and quality of life for black and minority ethnic older people in the UK and across Europe. The Institute aims to influence national and European policy and increase and encourage good practice in work with black and minority ethnic elders. PRIAE does this through creating and leading on often 'first of its kind projects' in research, information, service developments, training and consultancy. PRIAE recently launched the largest European research in the area of health, ageing and ethnicity in ten countries called Minority Elderly Care (MEC) covering over 3,000 ethnic minority ethnic elders from some 26 ethnic groups and near 1,000 professionals and planners in health and social care with some 500 minority based organisations. The Institute's CEMESME European project on employment and enterprise is also another major initiative aimed at generating useful research information and developments including training and materials for use in organisations, to help policymakers and entrepreneurs.



European Parliament launch of MEC Country Profile Book, May 2003



European Parliament Launch of MEC Research Findings, Dec. 2004

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