



Interprofessional Institute
(Health & Social Care)

**Ethnic Monitoring in Healthcare Services in the UK as
a mechanism to address Health Disparities:
A Narrative Review**

Dr Maria Psoinos

Dr Eleni Hatzidimitriadou

Faculty of Health and Social Care Sciences, Kingston University and St George's, University of London

Dr Christina Butler

Kingston Business School, Kingston University

Professor Ravinder Barn

Centre for Criminology and Sociology, Royal Holloway, University of London

March 2011

Faculty of Health and Social Care Sciences

KINGSTON UNIVERSITY • ST GEORGE'S, UNIVERSITY OF LONDON

Kingston Business School



CONTENTS

1. Introduction	3
2. Brief history of Ethnic Monitoring	4
3. Ethnic monitoring in healthcare settings in the United Kingdom: why are services still not equitable?	5
4. Ethnicity, healthcare and health in the UK: mapping the field	8
4.1 The process of ethnic monitoring in UK public healthcare services	8
4.2 Improving pathways to care for all ethnic groups.....	9
4.3 Training in the provision of culturally competent healthcare	11
4.4 Community engagement and participation in healthcare services	13
5. A critical look at the field of ethnicity, healthcare and health in the UK	16
6. Concluding remarks.....	20
7. References	22

To be cited as follows: Psinos, M., Hatzidimitriadou, E., Butler, C. and Barn, R. (2011). *Ethnic Monitoring in Healthcare Services in the UK as a mechanism to address Health Disparities: A Narrative Review*. London: Swan IPI. ISBN: 978-0-9558329-8-7

1. Introduction

Assuring equitable treatment and care in the health and social care sector is a necessity for a world-class personalised service that the United Kingdom (UK) Government is aiming for, according to its latest policy strategies (Sallah, 2010). It is a well-known fact that the incidence, prevalence, and mortality of many diseases may vary by ethnic group; these variations are regularly linked to well-documented disparities in access to prevention, treatment, and palliative healthcare services based on ethnic group (Nazroo, 2003), as well as to reported differences in the quality of services received by different ethnic groups and of outcomes of treatment and healthcare (The Marmot Review, 2011). Several of these inequalities can be addressed and ultimately reduced but they first have to be comprehensively defined and clearly documented. Mainstreaming ethnic monitoring, that is, the systematic collection of ethnicity data, is considered to be an important component of this process (London Health Observatory, 2010).

The main justification for collecting ethnicity data within health information systems, for holding such data on clinical records and using them, is healthcare and health improvement for the ethnic groups being recorded. It emerges then that a strong rationale for systematically collecting and using ethnicity data is that of social justice (Fulton, 2010).

Indeed, ethnicity data has been collected by the Department of Health for over a decade in some areas; for example, with respect to Hospital Episode Statistics ethnic group data collection became mandatory in 1995, and data on ethnicity and children looked after began to be collected in 1998. Additionally, ethnic group data has been collected in the NHS non-medical workforce census since 1998 and in the medical and dental workforce census since 1991. Amongst community care statistics, "Referrals, Assessments and Packages of Care for Adults" contained the category of 'ethnic group' since 2000-01 (Aspinall & Jacobson, 2006). The practice of ethnic monitoring in health services intended to enable the provision of services without racial or ethnic discrimination (Gill & Johnson, 1995). Tackling growing social and health inequalities found both between and within different ethnic groups has become a key political objective worldwide and in the UK (Exworthy et al., 2003), and as a result, the Department of Health is nowadays strongly committed to mainstreaming ethnic monitoring in all its routine data.

This report explores how ethnic monitoring data are or can be utilised as a mechanism by healthcare services in the UK to address healthcare and health disparities between ethnic groups. To this end, we will conduct a narrative review of the recent extant literature and we will discuss implications for future research in this area.

2. Brief history of Ethnic Monitoring

According to Johnson (1998), ethnic monitoring is “*a process whereby information about the relevant aspects of people’s ethnic origins is collected, recorded and used to establish patterns, which can be compared with other information about their relationship with society and ‘need’*” (p. 77). Following this definition, ethnic monitoring should not be purely ethnic record keeping but should prompt the setting of targets and the development of policies to address disadvantage, and eventually to improve service provision. At the very least, this process should be used to establish facts and put forward a case for change.

In the UK, the former Commission for Racial Equality (CRE), now part of the Equality and Human Rights Commission (EHRC), has been advocating ethnic monitoring since 1978 (CRE/ADSS, 1978). Until the 80s there was little systematic effort to record ethnicity information at the national level, with the exception of some organisations which were, however, recording this data without a systematic approach, namely by using coding systems without a frame of reference and relying on random self-identification within blank fields. Also, there was frequent confusion between the concepts of ethnicity and nationality.

Systematic nationwide information on ethnicity was first recorded during the 1980s in the General Household Survey and the Labour Force Survey (London Health Observatory, 2010). Also, in the 1991 UK Census, a question on ethnicity was introduced for the first time and nine ‘Ethnic Groups’, chosen after extensive consultation with prospective Census users, were added to output tables without prior testing. These categories were much criticised in the following years for their perceived limitations (Aspinall, 1997).

In the UK National Health Service (NHS), the ‘Ethnic Group’ category was introduced as a compulsory routine data item for hospital in-patients in 1995 (NHS Executive, 1994). Additional emphasis on ethnic data collection was generated when the Race Relations

(Amendment) Act 2000 was introduced, as it imposed on public bodies the duty to demonstrate that their activities were not carried out in such a way as to discriminate or cause inequalities in the population they served. Public (including health) authorities were therefore required to consider race equality in routine policy-making, service delivery and employment practice and be knowledgeable with respect to how their policies and services affect race equality. This race equality agenda resulted in the development of the Race Equality Action Plan for the NHS (Department of Health, 2004) and an enhanced programme of ethnic-group data collection.

It should be noted that, until recently, collected information on ethnicity within the NHS has not commonly been used because of its poor quality (see following pages for a discussion of the quality of ethnicity data). Nevertheless, nowadays the collection and use of ethnicity data is the foundation on which NHS bodies can assess and address health inequalities, difficulties in access and discrimination experienced by some Black Minority Ethnic (BME) individuals and communities (Department of Health et al., 2005), and this constitutes great progress in comparison to 20 years ago when the practice of ethnic monitoring was non-existent.

3. Ethnic monitoring in healthcare settings in the United Kingdom: why are services still not equitable?

Ethnicity data in healthcare settings are typically collected as part of administrative data, or when people actually seek healthcare at health professionals' offices, hospitals or community clinics and health centres (Varcoe et al., 2009). The main approaches in collecting such data are through self-assessment, assessment by an observer on the basis of relevant data (whether self-reported or otherwise) and assignment by an observer on the basis of visual inspection. The last approach to collecting ethnicity data is now becoming unacceptable, though normal practice in the past and still seen today, particularly when staff feels embarrassed to ask the questions required (Bhopal, 2007b). As noted above, in healthcare settings in the United Kingdom (UK), collecting data on patients' and service users' ethnicity has become an established routine practice in many places.

A consistent feature of ethnic monitoring in routine healthcare settings over the last two decades has however been the very limited use made of the data collected (Aspinall & Jacobson, 2006). Aspinall and Anionwu (2002) reported a number of surveys (conducted for example in children's health services or with inpatients) which collected ethnicity data yet no use has been made of them. Possible reasons for such shortcomings include the perception that organizations may have of ethnic monitoring as another bureaucratic statistical exercise (Aspinall & Anionwu, 2002), structural inequities and institutional racism (Bhopal, 2007a) and the fact that additional resources needed for tackling such inequities may not be prioritized in the context of international healthcare reforms that have emphasized cost reductions (Varcoe et al., 2009). This situation is compounded by several persisting factors which impede the systematic collection of ethnicity data and hence limit its utility (see Iqbal et al., 2008 for a review of reasons for the lack of routinely collected ethnicity data).

In the following pages, we present a review of relevant material identified while exploring how ethnicity data are utilised by healthcare services in the UK to address health disparities between ethnic groups. For the analysis of the collected material, a narrative review approach is adopted. The term 'narrative review' has been used to describe the traditional literature reviews of the type still widely undertaken in the social sciences as well as some more methodologically explicit approaches such as 'thematic analysis', 'narrative synthesis', 'realist synthesis' and 'meta-narrative mapping' (Mays, Pope & Popay, 2005a). Narrative reviews are typically concerned with questions such as 'What do we know about the causes of a particular social and/or health problem?' 'What are the implications of evidence on causality for the type of programmes/interventions that should be developed?'. Increasingly however, narrative reviews are also addressing questions of effectiveness and cost-effectiveness (Mays, Pope & Popay, 2005b). In this report, we adopt the first traditional approach to a narrative review, that is, we are less concerned with assessing the quality of evidence. This means that we do not just focus on examples of 'good practice' in ethnic monitoring, which seem to or have actually reduced healthcare and health disparities between ethnic groups. Instead, we are more interested in compiling relevant information that provides both context and substance to our overall argument. A discussion of our key arguments is presented below.

We support that the ethnic monitoring process provides healthcare services with an essential 'template' upon which they can build their efforts to address healthcare disparities at the local organisational level and ultimately reduce health inequalities between different ethnic groups. Therefore, there is no doubt that, in the ethnically diverse context of contemporary Britain, ethnic monitoring constitutes a fundamental platform which can help achieve the above goals, and this is acknowledged both by policy makers (Department of Health et al., 2005) and academics (Aspinall & Anionwu, 2002; Bhopal, 2009).

We know however that in order to make healthcare services more equitable and to tackle ethnic disparities in healthcare and health ethnic monitoring is only one of the essential 'building blocks' (to borrow a pertinent term used by the Department of Health (2003); improving pathways to care for all ethnic groups, as well as training in culturally competent healthcare and finally community engagement and participation in healthcare services are also practices of crucial importance (Bhopal, 2007b; Bhui et al., 2004a; Randhawa, 2007). Throughout this report we argue that these four 'building blocks' of ensuring more equitable services for ethnic minority service users are not well integrated but are rather fragmented within public healthcare services. In order to build our argumentation, we map each area (i.e., ethnic monitoring process, improving pathways to care for all, cultural competency training and community engagement and participation in services) and we provide information about the current state of affairs. The report concludes with recommendations on how the above practices can be better integrated in order to reduce healthcare and health disparities between different ethnic groups in the UK.

It should be noted that the relevant material cited emerged through our search in the following databases: ASSIA (Applied Social Sciences Index and Abstracts), Social Care Online- SCIE's resources and publications, MEDLINE, CINAHL (Cumulative index of nursing and allied health literature), BMJ Group's publications, the NHS library's Specialist Library for Ethnicity and Health, London Health Observatory, Department of Health publications, Google Scholar, Sainsbury Centre for Mental Health, King's Fund publications. In addition, extensive search was carried out within the following journals: Ethnicity and Race in a Changing World: a review journal; Ethnicity and Inequalities in Health and Social Care; Journal of Public Health; Ethnicity and Health; Diversity in Health and Social Care; Health Services Research; Health Affairs; Health and Social Care in the Community; Health Services Research and Policy;

Critical Public Health; International Journal for Health Planning and Management. Due to the large number of relevant publications identified as a result of our searches, a publication date of 2000 is used as the date filter for this final review. Earlier papers are included only if they are included as 'seminal', that is, well cited articles which contribute significantly to the review.

4. Ethnicity, healthcare and health in the UK: mapping the field

4.1 The process of ethnic monitoring in UK public healthcare services

For the purposes of this review, it was important to examine the general literature on ethnic monitoring and elicit the main themes in this area. The keywords/phrases used while searching the literature were: 'ethnic profiling', 'ethnic record keeping', 'ethnicity data', 'use of ethnic records in healthcare', 'ethnic monitoring in healthcare services', 'ethnicity profiling in healthcare services'.

The emerging material can be roughly divided into the following broad areas:

- Service users', community and healthcare leaders', and health professionals' viewpoints and attitudes towards ethnic monitoring in healthcare services (Dyson, 2005; Dyson et al., 2006; Jones & Kai, 2007; Pringle & Rothera, 1996; Sangowawa & Bhopal, 2000).
- Methodological issues surrounding ethnic monitoring (for example, quality of collected data, and in particular concerns over completeness, accuracy, timeliness and confounding of ethnicity and socio-economic status variables (Aspinall, 1997; Aspinall, 2006a,b; Aspinall & Jacobson, 2007; Baradaran et al., 2006; Goddard & Smith, 1998; Jacobson, 2003; Johnson, 2008; Sultana & Sheikh, 2008), as well as practical issues which impede the process of ethnic monitoring (e.g., limited financial incentives (Jones & Kai, 2007), lack of institutional memory to learn from previous good practice (Johnson et al., 2004), or lack of training on how to collect accurate data and analyse it (Dyson et al., 2006).

- Examples of good practice of collection and use of ethnic group data on patients, service users and staff of the NHS (Department of Health, 2007), as well as examples of good practice where evidence that emerged from ethnic monitoring has been integrated into current healthcare provided to ethnic minority groups (for a comprehensive review see Aspinall & Jacobson, 2004).

Jones (2008) carried out an indicative project which a) conducted ethnic monitoring in one NHS Trust in London, b) noted that data for particular ethnic minority groups were missing and, c) actually addressed this problem so that all groups would have equal access to health services and, in particular, to physiotherapy. Specifically, in the Parkside Health NHS Trust the hypothesis was set up that there would be no statistical difference in the distribution of the ethnic groups between those patients referred to the physiotherapy service in Parkside and the population of Parkside as a whole enumerated in the 1991 census. While at the aggregate level there was a good fit between the data obtained from the community's information system and the census data, when disaggregated by sex and age, it emerged that some ethnic groups were under-represented and others over-represented: Bangladeshi children, Chinese adults and Other Asians of all ages, especially females appeared to be under-represented while African and Pakistani babies, Pakistani and 'Black Other' adults and Bangladeshi elderly were the over-represented groups. The author concluded that, unless these groups had less need for physiotherapy, which is not suggested anywhere in the literature, the physiotherapists in that Trust were failing to provide an equitably distributed service. *As a result, physiotherapy managers recognised the need to raise the awareness of GPs as well as of other health professionals about the potential benefits of physiotherapy for their patients. In addition, there was an attempt to move treatment nearer the residents of the community by locating an increasing number of physiotherapists in doctors' surgeries.*

4.2 Improving pathways to care for all ethnic groups

There is a large body of literature identifying ethnic variations in pathways into, through and out of healthcare, and also the quality of care received (Szczepura, 2005). Understanding exactly *why* there are ethnic differences in pathways to care, with some ethnic minorities

making less use of services than the 'White' majority, is quite complex as potential barriers to the use of health services among ethnic minorities seem to occur at the patient level, the provider level and the broader healthcare system level (Scheppers et al., 2006). Nevertheless, there is considerable evidence nowadays supporting the possibility that these disparities (and consequently health disparities) are largely due to socioeconomic differentials and experiences of racial harassment and discrimination, which render ethnic minority members, especially those at risk of poverty or social exclusion or those with mental health problems, particularly disadvantaged when it comes to accessing healthcare services and receiving equal quality of care (Atkinson et al., 2001; Bhopal, 2007b; Goddard, 2008; McLean, et al., 2003; Nazroo, 2003).

It should be noted that the concept of 'pathways to healthcare' is quite complex and at times rather vague (Allen, 2009). Most of the time 'care pathways' are defined as *"multidisciplinary care management tools which map out chronologically key activities in a healthcare process"* (Allen, 2009: 354). This definition is undoubtedly useful from a health services point of view, because it emphasises the importance of care pathways as a mechanism for creating the partnerships between healthcare professionals and managers necessary to bring improvements in service quality. Nevertheless, in this report we are more interested in the broader 'pathway to care' approach, which focuses on the point of access to care and the integration of care by culturally diverse carers (Bhui & Bhugra, 2002).

For the purposes of this review the keywords/phrases used while searching this literature were: 'care pathways and ethnicity', 'multidisciplinary/integrated pathways of care for ethnic minorities', 'healthcare access to ethnic minority groups'.

The emerging material can be roughly classified as belonging to the following thematic categories:

- Articles discussing the concept of care pathways as well as the most relevant theoretical frameworks for care pathway development when applied to ethnic minorities' journeys into, through and out of care (Bhui & Bhugra, 2002; Jack et al., 2001; Singh et al., 2007; Morgan et al., 2004; Sass et al., 2009; Wilson et al., 2009).

- Empirical studies examining ethnic minority patients' care pathways - quite often with an emphasis on pathways of mental healthcare. Some of these studies also drew comparisons with other ethnic groups (Borschmann et al., 2010; Commander et al., 1999; Hackett et al., 2009; Jacob et al., 2002; Leese et al., 2006; Morgan et al., 2002; Morgan et al., 2005a; 2005b; Worth et al., 2009).

The study carried out by **Savory and Jamieson (2008)** is particularly worth describing as it explored whether ethnicity information collected at primary care level could be transferred to secondary/acute care, and, if so, whether the latter sector would make use of the information to support the patient journey. The purpose of the project was to identify at least one general medical practice in the NHS Ayrshire & Arran area which was willing to collect more personal information from their population. After identifying a practice, the main objectives were outlined as follows: a) to explore whether ethnicity, communication and disability/impairments information collected and stored at primary care level (GP practice) could be transferred to secondary care using the electronic referral method, and b) if this information could be transferred, to establish whether the acute sector would make use of the information to support the patient journey. The journey from primary to secondary care was tracked and a number of positive outcomes were accomplished (e.g., all new patients registering with the practice were willing to provide the additional personal information (i.e., ethnic group, communication needs and disability/impairments information) with no negative responses received. This additional information could then be transferred to secondary/acute care and with some staff training could be auctioned). At the same time, barriers to transferring the information were highlighted (e.g., the lack of understanding of equality and diversity by colleagues within the secondary care sector) and thus *it was made clear how to allow the patient's journey from primary to secondary care to be integrated and inclusive.*

4.3 Training in the provision of culturally competent healthcare

In the US, since the early 2000s, research on culturally appropriate/sensitive/competent healthcare has been burgeoning (Betancourt et al., 2005; Taylor & Lurie, 2004). Currently, as

the cultural competency movement has reached 'the tipping point', various systemic, organizational, clinical and community-based cultural competency initiatives are underway (Like, 2007). In the UK, whilst some progress has been made in the field of social care, (Barn 2006; Barn 2008), the health domain has been rather slow (see Bhui et al., 2007 for some possible explanations) but there has been significant investment in study days, short courses and more substantive cultural competence training programmes by NHS Trusts and public healthcare services providers (Papadopoulos et al., 2004), while the need to provide culturally sensitive services to ethnic minorities is increasingly recognized as a key to reducing ethnic disparities in healthcare and health (Bhopal, 2009).

For the purposes of this review the keywords/phrases used while searching this literature were: 'cultural competence', 'culturally sensitive healthcare', 'multicultural healthcare', 'culturally appropriate health services', 'cross-cultural awareness', 'cross-cultural doctor-patient communication'.

The emerging relevant material can be roughly divided into the following areas:

- Studies which examine the views and experiences of healthcare staff caring for ethnic minority patients in general as well as their beliefs, knowledge and practice in cultural competence (Hawthorne et al., 2003; Jackson, 2007; Katbamna et al., 2002; Richardson et al., 2006; Vydellingum, 2006).
- Articles or book chapters where scholars with expertise in healthcare discuss the inadequate (i.e. monocultural) training health professionals in the West receive, the limitations of western diagnostic models, methods of assessment and western concepts of therapy when applied to ethnic minorities. These authors complete the above critique by pointing out the need to provide culturally sensitive services and describing in further detail how such services should be delivered (Anand & Cochrane, 2005; Davies, 2006; Fernando, 2005; Fleming & Gillibrand, 2009; Gerrish & Papadopoulos, 1999; Hill, 2006).
- Empirical studies which have developed culturally sensitive training programmes for healthcare professionals as well as instruments/interventions. It should be noted that some of these programmes also evaluated their effectiveness by testing them

on the majority population as well as on ethnic minority groups (Bhui et al., 2004b; Brett et al., 2009; Chevannes, 2002; Gunaratnam, 2007; Hackett et al., 2009; Hutnik & Gregory, 2008; Papadopoulos et al., 2004; Papadopoulos et al., 2008; Shah et al., 2009).

The study carried out by **Chevannes (2002)** is indicative as it aimed to examine, through a pre- and post-training phase, the training needs of a multi-professional group of participants in order to improve the provision of healthcare for ethnic minority patients and service users. The findings revealed that for most healthcare professionals, during their initial education, no attention was given to the healthcare needs of ethnic minority groups. The issue of cross-cultural communication emerged as an important factor affecting the sufficiency of caring for these patients. After the training was completed, the participants reported that they had gained a) a better understanding of the concepts of ethnicity and race, b) resources available in local communities, and c) greater confidence to engage with colleagues about different cultural values and healthcare practices as a result of the training. While a quarter of these healthcare professionals had however transferred some of the learning to practice, most of them were not able to bring about any change. *The study's findings suggested that training in cultural competency has to take place in the actual context where healthcare professionals and patients/service users interact if the positive effect of learning about ethnic minorities is to be sustained.*

4.4 Community engagement and participation in healthcare services

The approach of community engagement is commonly used to support the participation of communities in a range of activities which can improve healthcare and health outcomes and/or reduce healthcare and health disparities (Popay, 2006). Also participation of members of socially excluded groups in healthcare design is an essential element of both academic and government recommendations in the effort to reduce health disparities in the UK (Campbell et al., 2004). Sometimes the term 'coproduction' is preferred precisely for emphasizing this active involvement of service users and communities in public healthcare services (Bovaird, 2007).

There are many challenges to community engagement and participation in healthcare services, such as the culture of statutory sector organizations (where professional cultures and ideologies usually prevail), the capacity and willingness of the public to get involved, the skills and competencies of staff working in public services (Swainston & Summerbell, 2007) as well as patients' healthcare expectations exceeding planned provision (Chapple et al., 2001). In addition, there are often hidden concerns of different actors (i.e., managers, carers, service users) involved in partnerships between the public health and social care sectors (Macalpine & Marsh, 2008).

Challenges and barriers to ethnic community engagement and participation in public healthcare services have also been researched (Begum, 2006) and include cultural differences in help-seeking behaviour (Goddard, 2008), poor communication as well as distrust between statutory and community sectors, disillusionment and disempowerment within certain ethnic communities and also low levels of community capacity (Stuart, 2008).

The keywords and phrases we used while exploring this area were: 'ethnic community participation/engagement/involvement in healthcare', 'ethnic service user participation', 'community-based healthcare'.

This body of literature can be roughly divided in the following two categories:

- Articles where: a) the barriers of effective ethnic community engagement and participation in healthcare services are discussed, usually after eliciting health professionals' but also service users' opinions of what they actually need from healthcare services and b) suggestions for positive change are made (Bowes and Wilkinson, 2003; Campbell et al., 2004; Chan, 2000; Cross et al., 2005; Gerrish, 2001; Green et al., 2002; Hussain-Gambles, 2004; Karim & Bailey, 2000; Merrell et al., 2006; PRIAE, 2005; Rhodes & Nocon, 2003; Tribe et al., 2009; Vernon, 2002; Wallcraft et al., 2003; Worth et al., 2009).
- Evaluations of various public healthcare initiatives which have a commitment to engage with ethnic communities (Brett et al., 2009; Fountain & Hicks, 2010; Hackett et al., 2009; Kernohan, 1996; Patel et al., 2007; Shah et al., 2008). Also, for a comprehensive review of health promotion and prevention interventions in

particular ethnic communities related to particular medical conditions see Netto et al., 2008.

One initiative worth describing is the **Birmingham ReGAE (Research into Glaucoma and Ethnicity) Project** (Cross et al., 2005; Shah et al., 2008) as it consisted of an exploratory phase, where ethnic communities' knowledge and needs with regards to a particular health condition were investigated, and an implementation phase, where ethnically-sensitive training was developed. In more detail, the research project aimed at contributing to unraveling the complexity of glaucoma in people of African-Caribbean descent who are up to eight times more likely to develop adult-onset primary open-angle glaucoma (POAG), which appears 10-15 years earlier than in other ethnic groups. The project comprised several phases addressing issues related to POAG pathogenesis, clinical outcomes, socio-cultural influences on glaucoma-related health behaviours and utilization of the primary eye-care services by African-Caribbean people. During the first phase, semi-structured interviews and focus groups were carried out for exploring glaucoma awareness in a group of African-Caribbean participants who were not receiving treatment from a hospital eye service and thus help practitioners to understand the health beliefs of African-Caribbean people with regards to this condition. The findings showed that, while participants held positive attitudes to health promotion in general, these did not incorporate eye health. Factors such as family histories were very important in helping people to understand that glaucoma might affect them, and in what ways this might happen. Also, attitudes to blindness tended to reflect the notion of the blind person as a victim. The idea of taking action to prevent this happening depended on participants' perceptions of the credibility of both the source and the nature of the information they had received regarding glaucoma. The second phase of the ReGAE project consisted of setting up an intervention which provides ethnically-sensitive and evidence-based information. In this way, *the project has helped to inform the future commissioning and training of glaucoma care with ethnic groups and to develop a national programme of glaucoma education* (Shah et al., 2008).

5. A critical look at the field of ethnicity, healthcare and health in the UK

In the previous sections we carried out a brief mapping of those practices which are essential components of the effort of making healthcare services in the UK more equitable: the ethnic monitoring process, the improvement of pathways to care for all ethnic groups, cultural competence training and community engagement and participation in healthcare services. In each area we identified opinion articles as well as a substantial body of empirical work, that is, studies which have actually implemented some of the above practices on ethnic minority patients, service users and/or healthcare staff in the UK, and we described in detail some of these as indicative examples of good practice. However, it is important to note that in most empirical studies all the above practices are not well synthesised.

For example, some of them (Hutnik & Gregory, 2008) focus on providing cultural competence training to healthcare professionals without at the same time involving the local ethnic communities in order to understand how *they* want their healthcare needs to be met and whether these needs were addressed after the completion of the training (for a similar critique see Bennett et al., 2007). Another illustration of this lack of integrative practices can be found in empirical studies which engaged the local ethnic communities in health promotion, but then the pathways to healthcare for groups who are at risk of specific medical conditions were not necessarily enhanced. For example, Patel et al. (2007) developed a systematic approach to cardiovascular disease risk screening within communities in one multi-ethnic locality in England. This effective method in organising health screening events was developed through fruitful collaboration between clinicians and community leaders. However, it did not examine how 'at risk' ethnic minority individuals can be integrated into existing channels of healthcare once cardiovascular problems have been highlighted in the community setting.

Overall, when it comes to actual healthcare interventions, it is crucial that the practices of ethnic monitoring, care pathways-enhancement, culturally competent healthcare and community engagement, *are* integrated. One noteworthy exception at this point is the EPIC project (Brett et al., 2009; Hackett et al., 2009; Wilson et al., 2009) which has indeed synthesized the above practices while working on improving pathways into care for ethnic minorities from diverse cultural backgrounds in England.

It is hoped that future practices aiming to improve healthcare services for ethnic minorities and ultimately reduce health disparities will move towards adopting a similar integrative approach. Otherwise, each isolated practice will result in being just another tokenistic exercise of supposedly doing the 'right thing'. In such a case, ethnicity data will be collected but then it will only be stored safely somewhere without being put in use. Also, care pathways of different ethnic groups will be tracked down; however no further steps will be taken to actually improve these pathways. Finally, without adopting an integrative approach, even if healthcare professionals are trained to be culturally competent and ethnic communities get involved in planning and delivering services, there will be no follow-up of whether cross-cultural communication was enhanced, whether community engagement was sustained and whether there were long-term healthcare and health benefits.

At the same time, we support the need for the aforementioned practices to be based on solid theoretical foundations. There is a wide range of generic theoretical frameworks which are valuable when examining people's healthcare behaviours and healthcare utilization and very useful for understanding socio-cultural differences in healthcare access, quality of healthcare received and health outcomes. Such frameworks include: the Socio-behavioural Model of Health Services Utilization (Andersen & Newman, 1973; Andersen, 1995); the Health Care Systems Model (Kleinman, 1980); the Pathways into Psychiatric Care Model (Goldberg & Huxley, 1980; Goldberg, 1995); the Network Episode Model (Pavalko et al., 2007; Pescosolido, 1991; 1992; Pescosolido et al., 1998); the Help Seeking Model (Cramer, 1999); and the Process Model of Seeking Mental Health Services (Goldsmith et al., 1988). In addition, the attempt of Campbell and Jovchelovitch (2000) to develop a '*social psychology of participation*' could also be included here, as they draw on the theoretical concepts of social capital, social identity and social representations while examining the role of community participation in reducing health inequalities.

We noted that most of the cited projects which implemented ethnic monitoring, improvement of pathways to care, cultural competence training and/or community engagement in healthcare services, did not draw on theoretical frameworks. For example, the project on patient profiling by Savory and Jamieson (2008) was not based on any theory related to care pathways, even though its aim was to render a more integrated approach to the patient's journey from primary to secondary care. At best, some of the described

projects refer to a relevant theory but the particular healthcare interventions were not informed by the latter. For example, the team who worked on the EPIC project (Brett et al., 2009; Hackett et al., 2009; Wilson et al., 2009) refer indeed to Goldberg and Huxley's model (see Bhui, 2009), yet the project's setting up was not guided by other theoretical frameworks which have been widely used in initiatives aiming at improving different groups' pathways into care (e.g., Pescosolido's work). Pescosolido (1991, 1992) has attempted through her Network Episode Model (NEM) to capture the *dynamic* nature of mental health system entry, repeat use, adherence and outcome. Indeed, the NEM is a process-oriented framework which does not make assumptions about how people come into the treatment system. Rather it focuses on the dynamic processes underlying the use of healthcare services, while acknowledging at the same time that family, social network and community contacts, as well as individual factors (i.e. age, ethnicity, gender) all play a very important role on shaping when, how and if people receive healthcare. What renders the NEM different from other approaches to healthcare behaviours and utilization is that it does not conceptualise healthcare service use as an exclusively individual rational choice. Instead it supports that, in order to understand people's routes in, though and out of healthcare, one must consider simultaneously the various ways they come to obtain healthcare, their roots in community-based influences as well as the impact of contingencies (e.g. age, ethnicity and gender) (Pescosolido et al., 1998: 277).

Also, the team working on the ReGAE project (Cross et al., 2005; Shah et al., 2008) attempted first to understand glaucoma awareness and perceptions of risk among African Caribbeans and then to set up an intervention with the aim of providing ethnically-sensitive evidence-based information to help inform the future training of glaucoma care with ethnic groups. The research team drew on Roger's (1975) protection motivation theory, but we believe another less-individual-focused theory such as Andersen's socio-behavioural model of health service utilization (Andersen & Newman, 1973; Andersen, 1995) would be much more relevant and informative. Andersen's model suggests predisposing, enabling and need factors, as the main sequential components which mitigate healthcare use, but also emphasises the role of social support, whereby social influence can encourage the utilization of healthcare as well as the perception of the efficacy of a given treatment (Lorenc et al., 2009). This means that the model takes into account not only individuals'

propensity to use more or fewer healthcare services but also enabling socio-economic conditions to secure healthcare services.

Research undertaken by Campbell et al. (2004) is however a good example of a study which drew on existing theories. These authors carried out in-depth interviews and focus groups with local community stakeholders, drawn from the statutory, voluntary, user and lay sectors in a deprived community in order to explore attitudes to participation in mental-health related partnerships. The emerging material was interpreted through the theoretical lens of a 'social psychology of participation' (Campbell & Jovchelovitch, 2000), whereby the concept of social capital provides a useful framework for exploring and potentially understanding community-level influences on health, and in particular, mechanisms at the micro-social level through which health inequalities persist.

Of course the conceptual debates arising from the different theories in the broad area of healthcare and health inequalities will undoubtedly carry on (e.g., see Pavalko (2004) and Rees-Jones et al (2009) for a discussion of the multidimensional concept of 'illness career' in Pescosolido's theory and Scheppers et al (2006) on the specification of 'community enabling resources' in Andersen's model). However, such conceptual debates should not deter researchers and healthcare experts from actually using theoretical frameworks when designing and setting up healthcare interventions. The usefulness of theoretically sound interventions is undeniable because they allow for further clearer research questions to be developed but also for comparisons to be drawn between research designs, methods and findings and for generalisation of results.

Finally, we conclude this section with a methodological note: in the effort of making healthcare services more equitable, an actual synthesis of all or some of the above practices will produce great amounts of data, which will be inevitably quite diverse (e.g., ethnicity related and other demographic data from standardised forms, patients' qualitative accounts of care pathways followed, standardised measures of the units of healthcare (such as consultations, procedures etc) that people have consumed etc). Constructively synthesising such large and diverse sets of data in order to inform future interventions can be fraught with methodological difficulties. Moreover, in most cases there is risk that these combined datasets may not even shed light on the main issue they set out to explore, that is, *why*

there are healthcare and health disparities between certain ethnic groups and what can be done about it (Forbes & Wainwright, 2001; Morgan et al., 2004).

There are however some recent methodological initiatives which seem to offer a solution to the above impasse: Dixon-Woods et al. (2006) and Dowrick et al. (2009) suggest methodological approaches to managing multiple and diverse sources of evidence on access to healthcare services by vulnerable groups in the UK. Dixon-Woods et al. (2006) have offered a critical literature review technique which tackles the limitations of conventional systematic literature review approaches and Dowrick et al. (2009) have developed an approach to evidence synthesis which comprises of a systematic review of published evidence, meta-synthesis of published qualitative literature and secondary analysis of qualitative datasets as well as interviews with service users and carers. In both cases the research teams acknowledge the need for testing the validity of these methods in further contexts, however we believe that their approaches to evidence gathering and synthesis are innovative and can help inform the evaluation of integrated interventions and the design of new ones.

6. Concluding remarks

While discussing the effects of different types of interventions designed to address healthcare and health disparities in the US context, Nerenz et al. (2006) point out:

“Understanding a problem is one thing; being able to actually do something about it is another. The large number of potential underlying reasons for disparities suggests that there will be no single or dominant solution to the disparities problem. It seems more likely that there will be a variety of legitimate approaches, whose specific features will have to be tailored to local circumstances. We are just beginning to learn about the actual or potential positive effects of a variety of types of interventions designed to address disparities...” (p. 1448).

The same applies to the UK which has been among the international leaders in terms of setting targets and driving cross-government and public health policies to reduce the identified problem of health inequalities (Department of Health, 2009). Indeed, the policy

context for addressing (ethnicity related and other) healthcare and health disparities seems to be appropriate for fostering change, but much more practical work needs to be undertaken for actually bringing the desired change.

Our initial research interest in how and to what extent is ethnic monitoring carried out in public healthcare services in the UK to address disparities between ethnic groups led us to a narrative review of four interrelated practices which aim to make healthcare services more equitable: the ethnic monitoring process, the improvement of pathways to care for all ethnic groups, cultural competence training and community engagement and participation in healthcare services. By citing several opinion articles and empirical literature found in each of these areas we have identified where there has been progress but also where and what kind of improvements are needed if healthcare and health disparities between ethnic groups are to be effectively addressed.

At the beginning of the decade, the need for pilot studies examining the way in which ethnicity related information was used across the NHS and also for impact studies evaluating the effectiveness of monitoring in enhancing the quality of services was pointed out (Robinson, 2002). Since then, the increasing number of empirical studies in this area clearly shows that significant progress has been made towards that goal. Working towards gearing the NHS to meeting the needs of a multi-ethnic society is however very difficult, especially because *'funds have been scarce, competing priorities many, expertise sparse and champions of the issue at a senior level too few'* (Bhopal, 2006: 60). Moreover, in the current socioeconomic context where pressure is put on the NHS to improve the quality of care for all service users and patients at the same time as improving productivity and efficiency (Raleigh & Foot, 2010), it is certain that much more work is needed for identifying exactly 'what works best and for whom' and implementing it accordingly.

7. References

Allen, D. (2009). From boundary concept to boundary object: the practice and politics of care pathway development. *Social Science and Medicine*, 69: 354-361.

Anand, A. S. and Cochrane, R. (2005). The mental health status of South Asian women in Britain: a review of the UK literature. *Psychology Developing Societies*, 17(2): 195-214.

Andersen, R. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36: 1-10.

Andersen, R. and Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the U.S. *Milbank Memorial Fund Quarterly. Health and Society*, 51: 95-124.

Aspinall, P. (1997). The conceptual basis of ethnic group terminology and classifications. *Social Science and Medicine*, 45(5): 689-698.

Aspinall, P. (2006a). Secondary analysis of administrative, routine and research data sources: lessons from the UK. In J. Y. Nazroo (ed.), *Health and social research in multiethnic societies*, pp. 165-195. London: Routledge.

Aspinall, P. (2006b). Informing progress towards race equality in mental healthcare: is routine data collection adequate? *Advances in Psychiatric Treatment*, 12: 141-151.

Aspinall, P. and Anionwu, E. (2002). The role of ethnic monitoring in mainstreaming race equality and the modernization of the NHS: a neglected agenda? *Critical Public Health*, 12(1): 1-15.

Aspinall, P. and Jacobson, B. (2004). *Ethnic disparities in health and health care: a focused review and selected examples of good practice*. Department of Health/London Health Observatory.

Aspinall, P. and Jacobson, B. (2006). *How to analyse ethnic differences in health, health care and the workforce: a toolkit for the NHS*. London Health Observatory.

Aspinall, P. and Jacobson, B. (2007). Why poor quality of ethnicity data should not preclude its use for identifying disparities in health and healthcare. *Quality and Safety in Health Care*, 16: 176-180.

- Atkinson, M., Clark, M., Clay, D. Johnson, M., Owen, D. and Szczepura, A. (2001). *Systematic review of ethnicity and health service access for London*. Centre for Health Services Studies, University of Warwick, Coventry, UK.
- Baradaran, H. R., Jamieson, J., Gardee, R. and Knill-Jones, R. P. (2006). Scottish survey of diabetes services for minority ethnic groups. *BMC Health Services Research*, 9(6): 130.
- Barn, R. (2006). *Research and Practice Briefings: Children and Families – Improving services to meet the needs of minority ethnic children and families*, DfES.
- Barn, R. (2008). Ethnicity, Gender and Mental Health: Social Worker Perspectives, *International Journal of Social Psychiatry*, 54(1): 69-82.
- Begum, N. (2006). *Doing it for themselves: participation and black and minority ethnic service users*. London: Social Care Institute for Excellence/Race Equality Unit.
- Bennett, J., Kalathil, J. and Keating, F. (2007). *Race equality training in mental health services in England: does one size fit all?* London: The Sainsbury Centre for Mental Health.
- Betancourt, J. R., Green, A. R., Carrillo, J. E. and Park, E.R. (2005). Cultural competence and health care disparities: Key perspectives and trends. *Health Affairs*, 24(2): 499-505.
- Bhopal, R. (2006). The public health agenda and minority ethnic health: a reflection on priorities. *Journal of the Royal Society of Medicine*, 99(2): 58-61.
- Bhopal, R. (2007a). Racism in health and healthcare in Europe: reality or mirage? *European Journal of Public Health*, 17(3): 238-241.
- Bhopal, R. (2007b). *Ethnicity, race and health in multicultural societies*. Oxford: Oxford University Press.
- Bhopal, R. (2009). Medicine and public health in a multiethnic world. *Journal of Public Health*, 31(3): 315-321.
- Bhui, K. (2009). Enhancing pathways into care and recovery: from specialist services to healthy minds. *International Review of Psychiatry*, 21(5): 425-426.

Bhui, K. and Bhugra, D. (2002). Mental illness in Black and Asian ethnic minorities: Pathways to care and outcomes. *Advances in Psychiatric Treatment*, 8: 26-33.

Bhui, K., McKenzie, K. and Gill, P. (2004a). Delivering mental health services for a diverse society. *British Medical Journal*, August 14; 329(7462): 363-364.

Bhui, K., Bhugra, D., Goldberg, D., Sauer, J. and Tylee, A. (2004b). Assessing the prevalence of depression in Punjabi and English primary care attenders: the role of culture, physical illness and somatic symptoms. *Transcultural Psychiatry*, 41(3): 307-322.

Bhui, K., Warfa, N., Edonya, P., McKenzie, K. and Bhugra, D. (2007). Cultural competence in mental health care: a review of model evaluations. *BMC Health Services Research*, 7(15).

Borschmann, R. D., Gillard, S., Turner, K., Lovell, K., Goodrich-Purnell, N. and Chambers, M. (2010). Demographic and referral patterns of people detained under Section 136 of the Mental Health Act (1983) in a south London mental health Trust from 2005 to 2008. *Medicine, Science and the Law*, 50: 15-18.

Bovaird, T. (2007). Beyond engagement and participation: user and community coproduction of public services. *Public Administration Review*, 67(5): 846- 860.

Bowes, A. and Wilkinson, H. (2003). 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health and Social Care in the Community*, 11(5): 387-96.

Brett, M., Wiggins, J. and Bowman, B. (2009). The EPIC project in Easington. *International Review of Psychiatry*, 21(5): 460-464.

Campbell, C. and Jovchelovitch, S. (2000). Health, community and development: towards a social psychology of participation. *Journal of Community and Applied Social Psychology*, 41(4): 255-270.

Campbell, C., Cornish, F. and McLean, C. (2004). Social capital, participation and the perpetuation of health inequalities: obstacles to African-Caribbean participation in 'partnerships' to improve mental health. *Ethnicity and Health*, 9(3): 305-327.

Chan, C. (2000). A study of health services for the Chinese minority in Manchester. *British Journal of Community Nursing*, 5(3): 140-147.

Chapple, A., Sibbald, B., Rogers, A. and Roland, M. (2001). Citizens' expectations and likely use of a NHS Walk-in Centre: results of a survey and qualitative methods of research. *Health Expectations*, 4(1): 38-47.

Chevannes, M. (2002). Issues in educating health professionals to meet the diverse needs of patients and other service users from ethnic minority groups. *Journal of Advanced Nursing*, 39(3): 290-8.

Commander, M. J., Cochrane, R., Sashidharan, S. P., Akilu, F. and Wildsmith, E. (1999). Mental health care for Asian, black and white patients with non-affective psychoses: pathways to the psychiatric hospital, in-patient and after-care. *Social Psychiatry and Psychiatric Epidemiology*, 34: 484-491.

Commission for Racial Equality/Association of Directors of Social Services (1978). *Multi-Racial Britain: The Social Services Response*, London: CRE/ADSS.

Cramer, K. M. (1999). Psychological antecedents to help-seeking behavior: a reanalysis using path modeling structures. *Journal of Counseling Psychology*, 46: 381-387.

Cross, V., Shah, P., Bativala, R. and Spurgeon, P. (2005). Glaucoma awareness and perceptions of risk among African-Caribbeans in Birmingham, UK. *Diversity in Health and Social Care*, 2: 81-90.

Davies, K. (2006). Addressing the needs of an ethnic minority diabetic population. *British Journal of Nursing*, 15(9): 516-9.

Department of Health/Mental Health Policy. (2003). *Delivering race equality: a framework for action*. Available at:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4069427.pdf

Department of Health. (2004). *Race Equality Action Plan*. London: Department of Health.

Department of Health, Health and Social Care Information Centre & NHS Employers. (2005). *A practical guide to ethnic monitoring in the NHS and Social Care*. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4116843.pdf

Department of Health. (2007). *A practical guide to ethnic monitoring in the NHS and Social Care*. London: Department of Health. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4116927

Department of Health. (2009). *Tackling health inequalities: 10 years on*. London: Department of Health. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098934.pdf

Dixon-Woods, M., Cavers, M., Agarwall, S. et al. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6: 35.

Dowrick, C., Gask, L., Edwards, S. et al. (2009). Researching the mental health needs of hard-to-reach groups: managing multiple sources of evidence. *BMC Health Services Research*, 9: 226.

Dyson, S. M. (2005). Ethnic Question and Ante-Natal Screening for Sickle Cell/Thalassaemia (EQUANS) in England. In J. N., Yfantopolous, and G. T. Papanikos (Eds.), *Health Economics, Policy and Management*, pp. 419-432. Athens, Greece: Athens Institute for Education and Research.

Dyson, S. M., Culley, L. A., Gill, C., Hubbard, S., Kennefick, A., Morris, P., Rees, D., Sutton, F., and Squire, P. (2006). Ethnicity Questions and Antenatal Screening for Sickle Cell/Thalassaemia [EQUANS] in England: A randomized controlled trial of two questionnaires. *Ethnicity and Health*, 11 (2): 169-189.

Exworthy, M., Stuart, M., Blane, D. and Marmot, M. (2003). *Tackling health inequalities since the Acheson inquiry*. Joseph Rowntree Foundation: Policy Press.

- Fernando, S. (2005). Mental health services in the UK: Lessons from transcultural psychiatry. In D. Ingleby (ed), *Forced migration and mental health: rethinking the care of refugees and displaced persons*, pp. 183-192. New York: Springer.
- Fleming, E. and Gillibrand, W. (2009). An exploration of culture, diabetes, and nursing in the South Asian community: a meta-synthesis of qualitative studies. *Journal of Transcultural Nursing*, 20(2): 146-155.
- Forbes, A. and Wainwright, S. P. (2001). On the methodological, theoretical and philosophical context of health inequalities research: a critique. *Social Science and Medicine*, 53(6): 801-816.
- Fountain, J. and Hicks, J. (2010). *Delivering race equality in mental health care: report on the findings and outcomes of the community engagement programme 2005-2008*. Preston: International School for Communities, Rights and Inclusion, University of Central Lancashire.
- Fulton, R. (2010). *Ethnic monitoring: is health equality possible without it? A Race Equality Foundation Briefing Paper*. London: Race Equality Foundation.
- Gerrish, K. (2001). The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers. *Journal of Advanced Nursing*, 33(5): 566-74.
- Gerrish, K. and Papadopoulos, I. (1999). Transcultural competence: the challenge for nurse education. *British Journal of Nursing*, 8 (21): 1453-7.
- Gill, P.S. and Johnson, M. (1995). *Ethnic monitoring and equity*. *British Medical Journal*, April 8; 310 (6984): 890-891.
- Green, G., Bradby, H., Chan, A. et al. (2002). Is the English National Health Service meeting the needs of mentally distressed Chinese women? *Journal of Health Services Research and Policy*, 7(4): 216-221.
- Goddard, M. K. (2008). *Quality in and equality of access to healthcare services in England. CHE Research Paper 40*. Centre for Health Economics, University of York, York.

Goddard, M. K. and Smith, P. C. (1998). *Equity of access to health care. Working Paper no. 32.* Centre for Health Economics, University of York, York.

Goldberg, D. (1995). Epidemiology of mental disorders in primary care settings. *Epidemiologic Reviews*, 17: 182 -190.

Goldberg, D. and Huxley, P. (1980). *Mental illness in the community.* London: Tavistock.

Goldsmith, H., Jackson, D. and Hough, R. (1988). Process model of seeking mental health services: proposed framework for organizing the research literature on help-seeking. In H. Goldsmith, E. Lin, R. Bell and D. Jackson (Eds), *Needs assessment: It's future*, pp. 49-64. (DHSS Publication No. ADM 88-1550). Washington, DC: U.S. Government Printing Office.

Gunaratnam, Y. (2007). Intercultural palliative care: do we need cultural competence? *International Journal of Palliative Nursing*, 13(10): 470-7.

Hackett, R., Nicholson, J., Mullins, S. et al. (2009). Enhancing Pathways Into Care (EPIC): Community development working with the Pakistani community to improve patient pathways within a crisis resolution and home treatment service. *International Review of Psychiatry*, 21(5): 465-471.

Hawthorne, K., Rahman, J. and Pill, R. (2003). Working with Bangladeshi patients in Britain: perspectives from Primary Health Care. *Family Practice*, 20(2): 185-191.

Hill, J. (2006). Management of diabetes in South Asian communities in the UK. *Nursing Standard*, 20(25): 57-64.

Hussain-Gambles, M., Leese, B., Atkin, K., Brown, J., Mason, S. and Tovey, P. (2004). Involving South Asian patients in clinical trials. *Health Technology Assessment*, 8(42): iii, 1-109.

Hutnik, N. and Gregory, J. (2008). Cultural sensitivity training: description and evaluation of a workshop. *Nurse Education Today*, 28(2): 171-178.

Iqbal, G., Gumber, A., Szczepura, A., Johnson, M.R.D., Wilson, S., and Dunn, J.A. (2008). *Improving ethnic data collection for statistics of cancer incidence, management, mortality*

and survival in the UK. Available at:

<http://www.library.nhs.uk/Ethnicity/ViewResource.aspx?resID=305660>.

Jack, C. M., Penny, L. and Nazar, W. (2001). Effective palliative care for minority ethnic groups: the role of a liaison worker. *International Journal of Palliative Nursing*, 7(8): 375-80.

Jackson, A. K. (2007). Cultural competence in health visiting practice: a baseline survey. *Community Practitioner*, 80(2): 17-22.

Jacob, K. S., Bhugra, D. and Mann, A. H. (2002). A randomized controlled trial of an educational intervention for depression among Asian women in primary care in the United Kingdom. *International Journal of Psychiatry*, 48: 139-148.

Jacobson, B. (ed). (2003). *Diversity counts. Ethnic health intelligence in London: The story so far*. London Health Observatory.

Johnson, M.R. D. (1998) Ethnic Monitoring: bureaucratic construction of a 'minority' entity of identity. In C. Williams, H. Soydan and M.R.D. Johnson (Eds). *Social Work and Minorities: European Perspectives*, pp. 74-88. London: Routledge.

Johnson, M. (2008). Making difference count: ethnic monitoring in health (and social care). *Radical Statistics*, Issue 96.

Johnson, M. et al. (2004). *'Racial' and ethnic inequalities in health: a critical review of the evidence*. Centre for Evidence in Ethnicity health and Diversity at De Montfort University and Warwick University Medical School.

Jones, C. E. (2008). The Ethnic Monitoring of Patients referred to the Physiotherapy Service in Parkside Health 1995/96. *Radical Statistics*, 96.

Jones, M. and Kai, J. (2007). Capturing ethnicity data in primary care: challenges and feasibility in a diverse metropolitan population. *Diversity in Health and Social Care*, 4(3): 211-220.

Karim, K. and Bailey, M. (2000). Non-white ethnicity and the provision of specialist palliative care services: factors affecting doctors' referral patterns. *Palliative Medicine*, 14(6): 471-478.

Katbamna, S., Bhakta, P., Ahmad, W. et al. (2002). Supporting South Asian carers and those they care for: the role of the primary health care team. *British Journal of General Practice*, 52(477): 300-5.

Kernohan, E. E. (1996). Evaluation of a pilot study for breast and cervical cancer screening with Bradford's minority ethnic women; a community development approach, 1991-93. *The British Journal of Cancer*, 29: S42-6.

Kleinman, A. (1980). *Patients and healers in the context of culture*. Berkeley: University of California Press.

Leese, M., Shaw, J., Thomas, S., Mohan, R., Harty, M. A. and Dolan, M. (2006). Ethnic differences among patients in high-security psychiatric hospitals in England. *The British Journal of Psychiatry*, 188: 380-385.

Like, R. (2007). Cultural competence: Implications for clinical practice, health care organizations and public policy. In L. Epstein (Ed.), *Culturally appropriate health care by culturally competent health professionals-international workshop report*, pp. 40-52. The Israel National Institute for Health Policy and Health Services Research.

London Health Observatory (2010). *Ethnicity Coding*. Available at: http://www.lho.org.uk/LHO_Topics/National_Lead_Areas/EHIP/EthnicityCoding.aspx.

Lorenc, A., Ilan-Clarke, Y., Robinson, N. and Blair, M. (2009). How parents choose to use CAM: a systematic review of theoretical models. *BMC Complementary and Alternative Medicine*, 9: 9.

Macalpine, M. and Marsh, S. (2008). The swampy lowland: Using hyperlinks to navigate the multiple realities of partnership. In L. McKee, E. Ferlie and P. Hyde (Eds.), *Organizing and reorganizing: Power and change in health care organizations*, pp. 139-153. Hampshire: Palgrave Macmillan.

Mays, N., Pope, C. and Popay, J. (2005a). Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research and Policy*, 10: 6-20.

Mays, N., Pope, C. and Popay, J. (2005b). *Details of approaches to synthesis- a methodological appendix to the paper: systematically reviewing qualitative and quantitative evidence to inform management and policy making in the health field*. Available at: <http://www.sdo.nihr.ac.uk/files/adhoc/appendix-to-jhsrp-review-article.pdf>

McLean, C., Campbell, C. and Cornish, F. (2003). African-Caribbean interactions with mental health services in the UK: experiences and expectations of exclusion as (re)productive of health inequalities. *Social Science and Medicine*, 56: 657-669.

Merrell, J., Kinsella, F., Murphy, F. et al. (2006). Accessibility and equity of health and social care services: exploring the views and experiences of Bangladeshi carers in South Wales, UK. *Health and Social Care in the Community*, 14(3): 197-205.

Morgan, C., Hutchinson, G., Bagalkote, H. et al. (2002). GP referral and ethnicity in the AESOP first onset study. *Schizophrenia Research*, 53(3) (Suppl.1), 48.

Morgan, C., Mallett, R., Hutchinson, G. & Leff, J. (2004). Negative pathways to psychiatric care and ethnicity: the bridge between social science and psychiatry. *Social Science and Medicine*, 58: 739-752.

Morgan, C., Mallett, R., Hutchinson, G. et al. (2005a). Pathways to care and ethnicity. 1: Sample characteristics and compulsory admission. *The British Journal of Psychiatry*, 186: 281-289.

Morgan, C., Mallett, R., Hutchinson, G. et al. (2005b). Pathways to care and ethnicity. 2: Source of referral and help seeking. *The British Journal of Psychiatry*, 186: 290-296.

Nazroo, J. Y. (2003). The structuring of ethnic inequalities in health. *American Journal of Public Health*, 93(2): 277-284.

Nerenz, D. R., Hunt, K. A. and Escarce, J. J. (2006). Healthcare organizations' use of data on race/ethnicity to address disparities in health care. *Health Services Research*, 41(4) Part I: 1444-1450.

Netto, G., Bhopal, R., Khatoon, J. et al. (2008). *Health promotion and prevention interventions in Pakistani, Chinese and Indian communities related to CVD and cancer. A*

review of the published evidence in the UK, other parts of Europe and the United States.
Heriot Watt University, Edinburgh, Scotland.

NHS Executive. (1994). *Collection of ethnic group data for admitted patients.* Letter EL (94)77 (Leeds, NHSE, 30 September).

Papadopoulos, I., Tilki, M. and Lees, S. (2004). Promoting cultural competence in health care through a research based intervention in the UK. *Diversity in Health and Social Care*, 1(2): 107-115.

Papadopoulos, I., Tilki, M. and Ayling, S. (2008). Cultural competence in action for CAMHS: Development of a cultural competence assessment tool and training programme. *Advances in Contemporary Transcultural Nursing*, 28(1-2): 129-140.

Patel, J. V., Gunarathne, A., Lane, D., et al. (2007). Widening access to cardiovascular healthcare: community screening among ethnic minorities in inner-city Britain-the Health Heart Project. *BMC Health Services Research*, 7: 192.

Pavalko, E. K. *The illness career: intersecting dynamics of individual health and health institutions.* Paper presented at the annual meeting of the American Sociological Association, San Francisco, August 14, 2004.

Pavalko, E. K., Harding, C. M. and Pescosolido, B. A. (2007). Mental illness careers in an era of change. *Social Problems*, 54(4): 504-522.

Pescosolido, B. A. (1991). Illness careers and network ties: a conceptual model of utilization and compliance. In G. Albrecht and J. Levy (Eds.), *Advances in Medical Sociology*, vol. 2, pp. 164-181. Greenwich, CT: JAI Press.

Pescosolido, B. A. (1992). Beyond rational choice: the social dynamics of how people seek help. *American Journal of Sociology*, 97: 1096-1138.

Pescosolido, B. A., Brooks-Gardner, C. and Lubell, K. M. (1998). How people get into mental health services: stories of choice, coercion and "muddling through" from "first-timers". *Social Science and Medicine*, 46(2): 275-286.

Popay, J. (2006). *Community engagement for health improvement: questions of definition, outcomes and evaluation. A background paper prepared for NICE*. Available at: <http://www.nice.org.uk/niceMedia/pdf/smt/070306item13.pdf>

Policy Research Institute on Ageing and Ethnicity (PRIAE) (2005). *Black and minority ethnic elders in the UK: Health and social care research findings*. Leeds: Policy Research Institute on Ageing and Ethnicity. Available at:

<http://www.priae.org/docs/MEC%20UK%20%20Summary%20Findings.pdf>

Pringle, M. and Rothera, I. (1996). Practicality of recording patient ethnicity in general practice: descriptive intervention study and attitude survey. *British Medical Journal*, April 27, 312(7038): 1080-1082.

Raleigh, V. S. and Foot, C. (2010). *Getting the measure of quality: opportunities and challenges*. London: The King's Fund.

Randhawa, G. (2007). *Tackling health inequalities for minority ethnic groups: challenges and opportunities. A Race Equality Foundation Briefing Paper*. London: Race Equality Foundation.

Rees-Jones, I., Ahmed, N., Catty, J. et al. (2009). Illness careers and continuity of care in mental health services: a qualitative study of service users and carers. *Social Science and Medicine*, 69: 632-639.

Rhodes, P. and Nocon, A. (2003). A problem of communication? Diabetes care among Bangladeshi people in Bradford. *Health and Social Care in the Community*, 11(1): 45-54.

Richardson, A., Thomas, V. N. and Richardson, A. (2006). 'Reduced to nods and smiles': experiences of professionals caring for people with cancer from black and ethnic minority groups. *European Journal of Oncology Nursing*, 10(2): 93-101.

Robinson, M. (2002). *Communication and health in a multi-ethnic society*. Bristol: Policy Press.

Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change. *Journal of Psychology*, 91: 93-114.

Sallah, D. (2010). Ending the misery of health inequalities. *Ethnicity and Inequalities in Health and Social Care*, 3(4): 2-4.

Sangowawa, O. and Bhopal, R. (2000). Can we implement ethnic monitoring in primary health care and use the data? A feasibility study and staff attitudes in North East England. *Public Health Medicine*, 2(3): 106-108.

Sass, B., Moffat, J., Bhui, K. and McKenzie, K. (2009). Enhancing pathways to care for black and minority ethnic populations: a systematic review. *International Review of Psychiatry*, 21(5): 430-438.

Savory, E., and Jamieson, J. (2008). *Patient profiling pilot project*. NHS Ayrshire & Arran. Available at: [http://www.isdscotland.org/isd/files/Final_pugh-patient-profiling-pilot-project%20\(3\).pdf](http://www.isdscotland.org/isd/files/Final_pugh-patient-profiling-pilot-project%20(3).pdf)

Scheppers, E., van Dongen, E., Dekker, J., Geertzen, J. and Dekker, J. (2006). Potential barriers to the use of health services among ethnic minorities: a review. *Family Practice*, 23: 325-348.

Shah, A., Adelman, S. and Ong, Y.L. (2009). *Psychiatric services for Black and minority ethnic older people*. London: Royal College of Psychiatrists.

Shah, P., Sii, F. and Cross, V. (2008). Preventing avoidable glaucoma blindness in African-Caribbeans. *Ethnicity and Inequalities in Health and Social Care*, 1(1): 18-25.

Singh, S. P., Greenwood, N., White, S. and Churchill, R. (2007). Ethnicity and the Mental Health Act 1983. *The British Journal of Psychiatry*, 191: 99-105.

Stuart, O. (2008). *User participation in healthcare services. A Race Equality Foundation briefing paper*. London: Race Equality Foundation.

Sultana, K. and Sheikh, A. (2008). Most UK datasets of routinely collected health statistics fail to collect information on ethnicity and religion. *Journal of the Royal Society of Medicine*, 101(9): 463-465.

Swainston, K. and Summerbell, C. (2007). *The effectiveness of community engagement approaches and methods for health promotion interventions. Rapid Review Phase 3.* University of Teesside: NICE National Collaborating Centre.

Szczepura, A. (2005). Access to healthcare for ethnic minority populations. *Postgraduate Medical Journal*, 81(953): 141-147.

Taylor, S. L. and Lurie, N. (2004). The role of culturally competent communication in reducing ethnic and racial healthcare disparities. *American Journal of Managed Care*, 10: SP1-SP4.

The Marmot Review (2011). *Fair Society, Healthy Lives.* London: The Marmot Review. Available at: <http://www.ucl.ac.uk/marmotreview>.

Tribe, R., Lane, P. and Hearsom, S. (2009). Working towards promoting positive mental health and well-being for older people within BME communities. *Working with Older People*, 31(1): 35-40.

Varcoe, C., Browne, A. J., Wong, S. and Smye, V. L. (2009). Harms and benefits: Collecting ethnicity data in a clinical context. *Social Science and Medicine*, 68: 1659-1666.

Vernon, A. (2002). *User-defined outcomes of community care for Asian disabled people.* Bristol/York: The Policy Press/ Joseph Rowntree Foundation.

Vydelingum, V. (2006). Nurses' experiences of caring for South Asian minority ethnic patients in a general hospital in England. *Nursing Inquiry*, 13(1): 23-32.

Wallcraft, J., Read, J. and Sweeney, A. (2003). *On our own terms: users and survivors of mental health services working together for support and change.* London: Sainsbury Centre for Mental Health.

Worth, A., Irshad, T., Bhopal, R. et al. (2009). Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *British Medical Journal*, Feb. 3; 338: b183.

Wilson, M., Ramsden, S. and Clark, M. (2009). Delivering race equality in mental health in England: the importance of pathways. *International Review of Psychiatry*, 21(5): 427-429.