

# **The European Research Context**

DH Workshop, Leeds, March 2010

## *UK Research on Ethnicity & Health*

**Mark R D Johnson**

**Centre for Evidence in Ethnicity Health & Diversity**

**NHS Evidence (Specialist Collection for Ethnicity & Health)**

**Mary Seacole Research Centre**

**Editor: *Diversity in Health & Care***



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# The NHS Plan - our domestic imperative

**“The NHS of the 21st Century must be responsive to the needs of different groups and individuals within society and challenge discrimination on the grounds of race, gender, ethnicity, religion, disability and sexuality. The NHS will treat patients as individuals, with respect for their dignity. Patients and citizens will have a greater say in the NHS, and the provision of services will be centred on patients’ needs”**

- NHS Plan *Core Principles*
  - The UK has a long history of research into ethnicity, migration and health, and this has led to some notable achievements in creating a database of evidence and good practice in relation to services. At the same time, there are acknowledged areas where more is needed, and where we might learn from practice on the mainland – and where we risk falling behind or being ‘swamped’ by other political priorities.
  - NB also the ‘BME’ agenda is becoming politicised...
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## Some other “Drivers” of R & D for diversity & minority migrant needs

- Treaty of Amsterdam 1997 – Article 13 – and subsequent Regulations and Schemes
    - “sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation”
  - WHO HpH / MfH & ‘Health for All’
  - Moral and Empirical pragmatic arguments
  - “The Social Wage” – Scandinavian concerns with Healthy workplaces
  - Health Equality – but NB who / what drives that?
  - A ‘Business Case’ ?
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# Focus of the Portuguese Presidency (Ministry of Health) Lisbon Conference

- refugees and asylum seekers,
  - labour migrants
  - "migrant-descended populations".
  - concern namely about vulnerable populations of migrant origins – the effects and after-effects of migration such as:
    - Social exclusion
    - Newness
    - Lack of information accessibility
    - Poverty
    - Inappropriate services
  
    - Questions of entitlement (and perspectives of providers , users and 'society')
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- Recommendations – [www.eu2007.min-saude.pt/pue/en](http://www.eu2007.min-saude.pt/pue/en)

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# Time does not stand still

- For a long time it could be said that we looked to the USA for leadership in models of policy and practice, while rejecting some of their taken for granted actions such as routine recording of 'race'. Similarly, 'race' and migration researchers on the European mainland watched UK developments for leadership in health issues, with a few exceptions. The balance has now changed significantly. USA studies are still often descriptive....
  - Early UK research did look at *migrant* health and concentrated on 'port health', threats to public health, imported and 'exotic' disease. Cultural difference was pathologised and assimilation was expected to lead to reduced access barriers; other health inequalities would also then diminish – and for a while research on the Mainland has also followed these patterns – but note:
    - Migrants are also Asylum seekers & refugees, trafficked & undoc
    - Health is a component of Integration (Human Rights & Utilitarian)
    - More studies on Entitlement, Insurance & legal issues
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- Roma ('Traveller/Gypsy') issues are different

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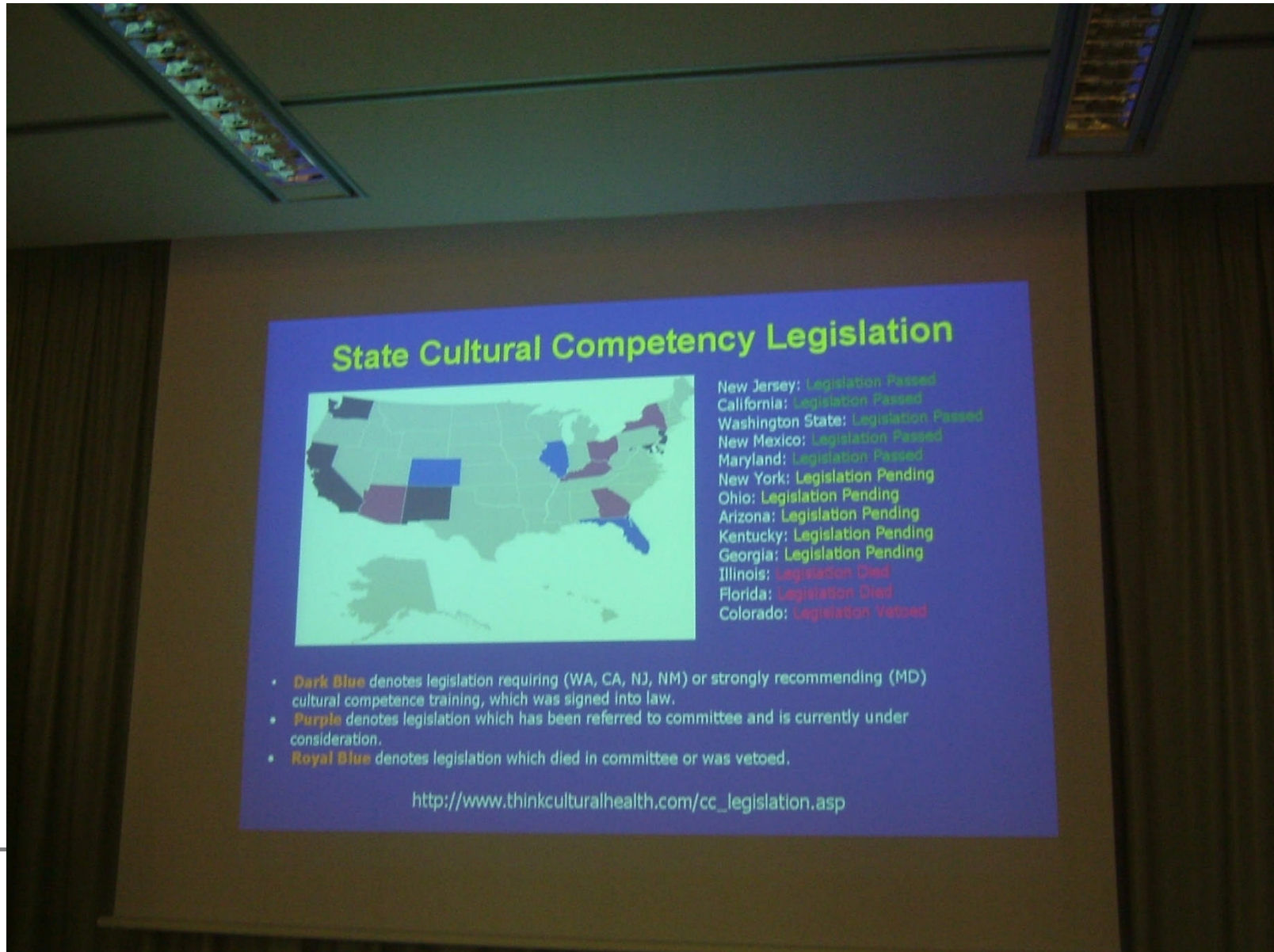
## And on the other side of the ‘pond’

- Minority populations: 34% of total USA (40% by 2030)
- DC, Hawaii, New Mexico, California, Texas ‘majority-minority’ (i.e. non Hispanic Whites)
- If health equities are not adequately addressed everyone suffers
- 54 million (19%) experience some level of disability
- Women
- The growing diversity of American society and the influx of foreign-born and non-English speaking immigrants warrants the need for improvements in the health system experience for all ... the creation of policies, programs, operations and practices that effectively address patient-provider interaction and communication ... has the capacity to foster a healthcare culture of equity and accountability. Ultimately this will reduce inequities in health and health care ...

(National Partnership for Action on Health Inequalities, 2009  
Office of Minority Health, Washington [minorityhealth.hhs.gov](http://minorityhealth.hhs.gov) )

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# A Legislative and political incentive...



# Migrant workers – essential to Europe

- Health & Safety at Work
- (Scandinavian lead)
- Shared Histories
- Experiences of Racism
- Human Rights approaches
- Barcelona
- Lisbon ...



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# Routinely Collected Data? Numerators & Denominators – and blockages.

- No – 2 – ID ... UK resistance to central records (including the NHS e-record system)
- European Data Protection Act?
  - There are exceptions – if anyone chooses to use them. But national laws:
  - French loi du 6 janvier 1978 aux fichiers et aux libertes ... & 1958 Constitution
- Census ... and wonderful ethnicity / religion questions as a result of campaigns by researchers, some communities and health policy folk.
  - Struggle (or resistance) by UK BME groups rejected the label of 'migrant' and demanded attention to ethnicity, common diseases and access or exclusion processes affecting health differentials. (But health differentials have not got less, although BME health concerns are now 'core business' and attracting campaigning activity).
- Or reliance on Surveys... (legal even where state data cannot ask)
- NB UK has excellent national sample surveys including Health & Lifestyle Survey, LFS, GHS

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  - George Ellison's paper refers

# Health databases with possibility of linkage on the individual level (has personal number) (Sweden):

- Cancer (since 1950's)
- Cause of Death (on computer since 1950's)
- Hospital Discharge Register (1987-)
- Medical Birth Register (1973-)
- Register of Military Conscription (1968-)
- Prescribed drugs (2005-)
  
- Data courtesy of **Anders Hjern** Nordic School of Public Health and Centre for Epidemiology, National Board of Health and Welfare, Stockholm, Sweden

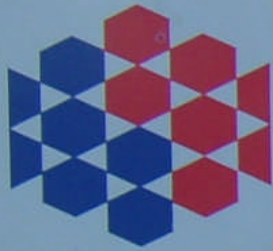


# Communication – a European Issue

- Language
- Symbols ?
- Signifiers and Directions
- Language support (Interpreters)
- Euro-QOL.....
- MfH initiative – qv
  - E.g. research in CH etc.
  - (Jan Cambridge's paper)



Europe of the regions / Minority languages protected...



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AN ROINN

**Cultúir, Ealaíon  
agus Fóillochta**

MANNYSTRIE O

**Fowkgates, Airts  
and Aisedom**

Victoria Jubilee  
Bridge

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# European Networks -

- [http://costrhome.eu/management/index.php/Main\\_Page](http://costrhome.eu/management/index.php/Main_Page)
  
  - **This site is only intended for use by members of COST Action IS0603 Health and Social Care for Migrants and Ethnic Minorities in Europe (HOME).**
  - Information for the public about this Action is available on the COST site [here](#) (see in particular the MoU or Memorandum of Understanding describing the work programme). You can also download general information about the Action [here](#) and a poster describing the first year of work [here](#).
  
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  - **Contents**
  - [1 Information about meetings](#)
  - [2 Information about the Action](#)
  - [3 Current affairs](#)
  - [4 Link to COST newsletter](#)
  
  - **Information about meetings**
  - **2010**
  - 29. [Bielefeld, 15th & 16th July](#) - Prevention, health promotion and health education
  - 28. [London, 17th & 18th June](#) - Transcultural nursing: potential, challenges and training
  - 27. [Copenhagen, 10th & 11th May](#) - Migrants and ageing
  - 26. [Sevilla, 29th & 30th April](#) - Community-based research
  - 25. [Rome, 29th & 30th March](#) - Irregular immigration in the Mediterranean region
  - 24. [Utrecht, 18th & 19th February](#) - Health of Refugees and Asylum Seekers
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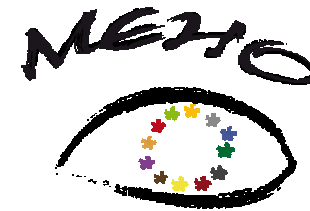
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## Other Growing European Networks for collaboration and comparison

MigHealthNet – a collaborative Wiki  
(David Ingleby NL)



MEHO – Migrant and Ethnic  
Health Observatory  
(Raj's paper – mapping data)



WHO – Health Promoting Hospitals  
taskforce on migrant friendly  
hospitals (Antonio Chiarenza, Italy)

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And other European Observatories e.g. the Vienna EUMC Monitoring Centre on Racism and Xenophobia

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## Some other Networks & Actions

- EMN UK Network (Home Office led in UK) and linking State and other interested groups
- NowHereLand (Undocumented migrants)
- EUGATE – best practice exchange
- AMAC (follow-up to Lisbon)
- AVERROES (asylum seekers)
- TAMPEP (migrant sexworkers)
- Aids & Mobility network
- IOM – PHBLM (Public health safety & Border controls)
- CINEFOGO network of excellence (Volkswagen Fdn)
- BOMEME (Birth outcomes)
- EUROMED
- PROMO (Stefan Priebe, QMUL – mental health & marginalised groups)

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And others courtesy of <http://mighealth.net> .... Thanks to David Ingleby

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# A long history but still all to play for.

- CIBA Foundation & Dodge, JS. 1969 *The Fieldworker in Immigrant Health* Staples Press.
  - Hopkins A, Bahl V (Eds) 1993 Access to health care for people from black and ethnic minorities London: Royal College of Physicians
  - WHO Regional Office for Europe: Colledge M, van Guens HA, Svensson PG 1986 *Migration & Health: Towards an Understanding of the health care needs of ethnic minorities* (Consultation -The Hague, 1983)
  - IOM - Bollini, P. 1993 'Health for Immigrants and Refugees in the 1990s. A comparative study in seven receiving countries' Innovation 6,1 :101-110 & Bollini P, Siem H 1995 'No real progress towards equity: health of migrants and minorities on the eve of the year 2000' Social Science and Medicine 41,6 :819-828
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## Some areas where UK may still have a lead

- Research into research methods
    - Sarah Salway
  - Collaborative and User-led research
    - Ghazala Mir
    - Support from BME-led groups – SAHF, REF, Afiya.
  - Research looking at and understanding religion and unpacking the components of ‘ethnicity’
    - Aziz Sheikh
    - Saffron Karlsen
  - Workforce Competences
    - Joe Kai
    - Rena Papadopoulos etc...
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## Areas where we are challenged to do better

- Language support issues
    - Jan Cambridge
  - Research into Policy
    - Mark Exworthy
  - Research showing **HEALTH OUTCOMES** from interventions!!!!
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# Policy support: NHS Evidence SC-EH!

NHS Evidence - Ethnicity and health - Mozilla Firefox

File Edit View History Bookmarks Tools Help

http://www.library.nhs.uk/ethnicity/

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## NHS Evidence - ethnicity and health

formerly a Specialist Library of the National Library for Health

NHS Evidence Home > Specialist Collections > Ethnicity and health Home

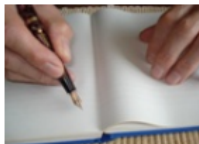
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- Cultural Competence
- Management and Policy Statistics

### NHS Evidence - ethnicity and health




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Latest evidence in ethnicity and health and RSS feed

Please note that we are making a few changes to our home page and you may find occasional faults. We are working to resolve outstanding issues. Thanks for your patience.

**Patient Information in Ethnic Minority Languages.** NHS Direct are currently in the process of moving their patient information, users of our collection may experience problems in accessing this material. We shall restore our links as soon as possible. We are actively seeking new resources of this type and welcome suggestions.

**News** The latest developments in Evidence, Consultation or Resources

**We're changing - a bit now, more later**



#### Recently Published

**Diabetes UK** has produced a toolkit to aid in the hosting of Diabetes Awareness sessions to people from south Asian communities. The toolkit includes a handbook, two powerpoint presentations, speaker notes and a quiz about food myths. Further details can be viewed [here](#).

**A good practice guide** has been published by the Thomas Pocklington Trust to assist those who commission and provide health and social care services to black and minority ethnic (BME)

Done

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## ‘Co-ordinates’ or Contact Details

- Mary Seacole Research Centre  
De Montfort University  
266 London Road, Leicester LE2 1RQ  
Tel: 0116 201 3906 (fax: 0116 201 3805)
  - seacole@dmu.ac.uk
  - website: [www.dmu.ac.uk/msrc](http://www.dmu.ac.uk/msrc)
  - [or ethnic-health.org.uk](http://ethnic-health.org.uk)
  - [www.library.nhs.uk/ethnicity](http://www.library.nhs.uk/ethnicity)
  - NB: [minority-ethnic-health@jiscmail.ac.uk](mailto:minority-ethnic-health@jiscmail.ac.uk)
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# Abstract

- The UK has a long history of research into ethnicity, migration and health, and this has led to some notable achievements in creating a database of evidence and good practice in relation to services. At the same time, there are acknowledged areas where more is needed, and where we might learn from practice on the mainland.
- For a long time it could be said that we looked to the USA for leadership in models of policy and practice, while rejecting some of their taken for granted actions such as routine recording of 'race'. Similarly, 'race' and migration researchers on the European mainland watched UK developments for leadership in health issues, with a few exceptions. The balance has now changed significantly.
- Early UK research did look at *migrant* health and concentrated on 'port health', threats to public health, imported and 'exotic' disease. Cultural difference was pathologised and assimilation was expected to lead to reduced access barriers; other health inequalities would also then diminish.
- Struggle (or resistance) by UK BME groups rejected the label of 'migrant' and demanded attention to ethnicity, common diseases and access or exclusion processes affecting health differentials. (But health differentials have not got less, although BME health concerns are now 'core business').
- European research has benefited from a presumption of recording much higher levels of personal data centrally while the UK population as a whole has resisted this, but equally, UK is almost alone in recording 'ethnicity' (but not language): mainland research is therefore more advanced in relation to issues of migration. UK policy has now to come to terms with recognition that we have still got (new) migrant populations while mainland policies have to recognise growing diversity among 'settler' populations and a disconnect with 'nationality' as a valid identity marker.
- European strengths also include greater recognition of the value or need for migration (e.g. the value of EU internal migrants, and 'workplace health' as an EU priority), less paranoia about health tourism, and an acceptance of a multilingual society – hence translation of HRQoL instruments and research into language support. Policy development around Human Rights agendas and linked initiatives have also increased collaboration: I feel UK research has become sidelined or marginalised at times or not engaged in comparative studies and networks (HfH, COST-HOME etc)
- That said, the UK still has some advantages in collaborative or minority-led research (e.g. SAHF) and a strong minority community base prepared to support research and developments.