User and Community Involvement in Health & Social Care for Migrants and Ethnic Minorities in Europe

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The Background

- .... customers are also people. The customer has a gender, an ethnic origin, and may additionally have particular healthcare needs because of disability ... In order to deliver first class services that take account of the diversity of your customers, the NHS will clearly need to be at the leading edge of equality practices ... All these good practice areas need to be planned, developed and delivered as part of what we call the mainstreaming of equal opportunities.

(Kamlesh Bahl, 1998, Speech to mark the 50th anniversary of the NHS)
Roles for the ‘User’ / Community

- Consumer (and maybe taxpayer)
- Investigator or Provider
- Research Assistant / Fieldworker
- Steering Group – or Manager
- Consultation
- & ? Dissemination ?
- Sponsorship (and Funder)
- Policy Makers
- and Voters!
Political & Legislative Drivers

- 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 and others: ‘Health for All’
- Moral and Empirical pragmatic arguments
- “The Social Wage”
- The Council of Europe Recommendations
- and in future – the Amsterdam Declaration and responses to the Lisbon Conference
Focus

- 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
- Fears of authority

- Questions of entitlement (and perspectives of providers, users and ‘society’)
Factors affecting Health & Social Care

- Ethnic Differences in Patterns of Disease
- Cultural Variations in Presentation of Symptoms of illness
- Perceptions of Health, Body and Disease
- Cultural and Language differences in Descriptions
- Accessibility of Services (time and place)
- (Previous experiences of) Encounters with Services
- Alternative Treatment Options
- Lifestyle, Socio-Economic Status, Religion and Cultural practices
- Racism – direct, personal, indirect or institutional
- Language, Education and the Availability of Information
- Attitude, Awareness and Skill of Clinical staff
## Causal Factors - Direct and Indirect

### Factors Affecting Access to Health Care Services

<table>
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<th>‘Provider’</th>
<th>Structural</th>
<th>‘Consumer’</th>
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<tr>
<td>Clinical Practitioner Competence</td>
<td>Resources/Provision</td>
<td>Cultural Differences and specificity</td>
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<td>Suitability/Adaptation of Treatment</td>
<td>Geography &amp; Timing</td>
<td>Genetic Differences ?</td>
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<td>Interpreter and Translation provision</td>
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<td>Language</td>
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<td>Referral Patterns</td>
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<td>Presentation</td>
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Doubts about the Quality of the Evidence Base

- Language and problems in translation
- Unvalidated Outcome Measures
- Trial inclusion criteria (no ‘non-English speakers’)
- Power problems in small groups

- Poor Measurement of descriptive criteria
- Inadequately theorised models of explanation
- Cultural differences in health-related practices
- Genetic variation in susceptibility or response
- Confusion of Correlation and Causation

(assuming that there is any evidence in the first place)
Defining Migrants and ‘Groups of Interest’

- Race / Ethnicity
- Language / Religion / Culture
- Citizenship / Nationality
- Black and Minority Ethnic / Migrant
- Asylum-Seeker/ Refugee
- Roma / Traveller / Gypsy
- National Minorities

Note: there are also privileged migrants
Communication – is not simple!

- Language
- Symbols, Signifiers and Directions
- Language Support (Interpreters or Bilinguals)
- Translation
  - Dialects, Literacy, Accuracy
  - Conceptual Equivalence
  - Availability, Cost, Validation
- Not forgetting sensory impairment and literacy
Channels of Communication

- Person-to-Person: Family and Friends?
- Person-to-Person: Doctors, Nurses, AHPs
- Mass Media – Papers, Broadcast, Adverts
- Pamphlets and leaflets and posters
- Religious and Cultural Centres
- Shopping and Recreation (Market & Mela)
- ‘Social Marketing’ – using community networks and ‘lay referral’ systems
Some solutions from Practical Experience

- Working with Community Centres and Groups
- Research-based Development or Development-based Research
- Natural groups in the communities and community Facilitators
- Trusting Community-based Research evidence
- Provide Information or Help (Solutions!)
- Treat Migrant Communities as Opportunities, Resources, not Problems and Demands
- Unwanted & Unused resources are Wasted resources
A Hierarchy of Involvement

- Project originators and sponsors
  - Partnership
    - Professional investigators
      - Fieldworkers and research assistants
        - Steering groups
          - Consultation and dissemination
            - ‘Research subjects’
Social Action Research Model (Participatory Action Research)

- Literature review, incorporating grey literature
- Collaborative eliciting of key factors
- Community involvement in design of data collection
- Training of community-based interviewers
- Community-based data capture
- Academic rigour in analysis and collation of data
- Validation by community feedback
- Presentation and publication
- Submission of selected material for peer review
- Publication in accessible formats
Benefits and Issues

- Diversity (recognition!)
- Sensitivity
- Access
- Language
- Expectation (risk or benefit?)
- Profile
- Short-Termism (or overcoming it?)
Conclusion (some ways forward)

- Employ Staff who are Language and Culturally Competent – if possible from local communities (NB economic benefits for the community = health!)
- Understand Religion & Culture in planning
- Translate Information and Provide Appropriate Services that match (BME) Users needs
- Reach Out (The value of positive outreach)
- Networking with Community-based organisations
- Flexibility, Respect, Time & Patience
- Record Use (‘Ethnicity Monitoring’)

and being prepared to ask for help
‘Co-ordinates’ or Contact Details

- Specialist Library for Ethnicity & Health
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- seacole@dmu.ac.uk

- website: www.dmu.ac.uk/msrc or http://www.ethnic-health.org.uk

- www.library.nhs.uk/ethnicity

NB: www.jiscmail.ac.uk/minority-ethnic-health