Background

- Accurate ‘ethnicity’ data essential to inform officials of incidence, prevalence and outcomes of specific diseases in population subgroups
- Some ethnic minorities associated with increased incidence of diabetes, hypertension, stroke and certain cancers
- 4.5 million people (8%) from UK in 2001 defined as being from an ethnic minority group
- Immigrants from Pakistan, India, Bangladesh combined into South Asian group (figure 1)
- South Asians largest ethnic group in the UK (50% of non-white population, 2001)
- Reports suggest breast and colorectal cancer incidence lower in South Asian population; however this is rapidly increasing over time
- UK Government initiatives in place to collect ethnicity data since 1995 but limited to hospital admissions
- Data remains incomplete and has not improved over time

Objectives

1. Evaluation of health care professionals’ perceptions and experiences of collecting ethnicity data in primary/secondary care
2. Evaluation of consumers’ perceptions, experiences and willingness to provide ethnicity data in primary/secondary care

Methods

1. Healthcare professionals survey
   - 2-page questionnaire distributed through: Minority-Ethnic-Health jiscmail list, ALLSTAT jiscmail list, National Cancer Research Network, Race-for-health Primary Care Trusts
   - Questionnaire was aimed at all levels of healthcare professionals involved in data collection

2. Focus groups
   - Focus groups formed from existing contacts with volunteer groups and facilitators to include main minority groups in local area
   - Facilitators used a topic guide specifically developed to focus on the five areas of interest:
     1. General opinions on the collection of ethnicity
     2. Experiences of providing ethnicity data
     3. Categories used in practice (examples provided)
     4. How should this information be collected
     5. Closing comments

Perceived importance of collecting ethnicity data

Majority of respondents personally thought collection of ethnicity data was more important than their perception of it’s value to their organisation

May be indicative of the organisations weak policies on and lack of training provision (figures 2a and 2b).

Ethnicity data collection

Table 1: Ethnicity data items collected

<table>
<thead>
<tr>
<th>Category</th>
<th>Yes</th>
<th>No</th>
<th>Missing</th>
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</thead>
<tbody>
<tr>
<td>Cancer</td>
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<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Race</td>
<td>3</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Religion</td>
<td>11</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Patient name</td>
<td>8</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Country of birth</td>
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<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Country of origin</td>
<td>13</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Language</td>
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<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
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<td>1</td>
<td>20</td>
</tr>
</tbody>
</table>

Figure 1: South Asia

Figure 2a: Please rate how important you personally think the collection of ethnicity data is

Figure 2b: Please rate the value of collecting ethnicity to your organisation

Figure 3: Disease areas

Selected quotes:
- "They should explain why they collect the data; the reason behind it; what benefit there will be for people. Also, where the data will be used and how secure this data will be. It should be kept secret [confidential]" [Bengali focus group; all participants]
- "Not routine; there is no need since these things don’t change but once or twice is ok’ [Mirpuri female]
- "The information should be collected at the GP surgery as patients are already distressed in hospital" [Punjabi female]

Conclusions

- Need more reporting of ethnicity data in the healthcare setting, in order to improve planning and delivery of services for ethnic minority groups
- Need training to raise awareness for patients and professionals: Patients - why your doctor should know your ethnic group? Professionals - how to ask/explain the importance of ethnicity data collection?
- Work towards a culture of routine data collection at GP level
- Need working groups to assess collection, completeness and validation

Focus group results

<table>
<thead>
<tr>
<th>Group</th>
<th>Country of origin</th>
<th>Language</th>
<th>Males</th>
<th>Females</th>
<th>Total</th>
</tr>
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<tbody>
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<td>Mirpuri</td>
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</tr>
<tr>
<td>2</td>
<td>Bangladesh</td>
<td>Bengali</td>
<td>8</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>Pakistan</td>
<td>Urdu</td>
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<td>10</td>
<td>10</td>
</tr>
<tr>
<td>4</td>
<td>Pakistan</td>
<td>Urdu</td>
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<td>8</td>
</tr>
<tr>
<td>5</td>
<td>India</td>
<td>Punjabi</td>
<td>3</td>
<td>5</td>
<td>8</td>
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<tr>
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<td></td>
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<td>36</td>
<td>54</td>
</tr>
</tbody>
</table>

Contact details

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