Ethnicity Questions and Antenatal Screening for Sickle Cell and Thalassaemia [EQUANS]: A Randomised Controlled Trial of Two Ethnicity Questions

Simon Dyson

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Objectives

- To evaluate two candidate ethnicity screening questions in ante-natal screening programmes in low, mixed and high sickle cell prevalence areas, and to identify time taken in administration of the questions.
Design

- Ten month (Sept 2002-June 2003) questionnaire study with random allocation to two self-administered ethnicity questions, comparison with laboratory results and results from re-interview
Settings

- Ante-natal bookings in four geographical areas of England of varying expected foetal prevalence of sickle cell disease (SCD)
  - Very High (29.75 per 10,000)
  - High (8.2)
  - Mixed high and low (1.29)
  - Low (0.18).
Participants

- 4,559 pregnant women at first booking with midwife.
Main Outcome Measures

(1) Proportions of respondents with missing ethnicity data and/or significant changes in ethnic/family origins upon re-interview.

(2) Numbers of carriers of clinically significant haemoglobin disorders (defined as requiring counselling) missed by ethnicity screening questions.

(3) Time taken to explain screening question for SCD/thalassaemia and obtain ethnic/family origins.

(4) Proportion of clients providing usable ethnic/family origins data.

(5) Reported ethnic/family origins in pregnant women at first booking with midwife.
DO YOU HAVE ETHNIC/FAMILY ORIGINS THAT ARE...

Please tick one or more boxes to indicate these origins

A. WHITE
   - English, Scottish, Welsh, or Irish
   - Other North European
   - Greek or Greek Cypriot
   - Turkish or Turkish Cypriot
   - Italian, Maltese, or other Mediterranean
   - Any other White background (please write in……………….)

B. MIXED ► Please tick all boxes in sections A, C, D and E (above & below) that apply to you

C. ASIAN OR ASIAN BRITISH
   - Indian or African-Indian
   - Pakistani
   - Bangladeshi
   - Any other Asian background (please write in……………….)

D. BLACK OR BLACK BRITISH
   - Caribbean
   - African
   - Any other Black background (please write in……………….)

E. CHINESE AND OTHER
   - Chinese
   - Japanese
   - Malaysian, Vietnamese, or Filipino
   - North African, Arab, or Iranian
   - Any other (please write in…………………………………….)

Ethnicity Information Refused
Ethnicity Question B

1. Do you or any of your known ancestors, as far back as you can recall, have ethnic/family origins from areas of the world outside of the United Kingdom or Republic of Ireland?

   Please tick one box only.

   Yes      □
   No       □
   Don't Know □

2. If Yes, then for you or for any of your known ancestors, as far back as you can recall, please write in all the countries in the spaces below:

   ………………………………………………………………………………………………………
   ………………………………………………………………………………………………………
   ………………………………………………………………………………………………………
   ………………………………………………………………………………………………………
   ………………………………………………………………………………………………………
   ………………………………………………………………………………………………………

   Ethnicity Information Refused □

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## Recruitment Rate to Study

<table>
<thead>
<tr>
<th>Area prevalence</th>
<th>Total Antenatal population</th>
<th>Invited to participate</th>
<th>Midwife Participation rate</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>3,142</td>
<td>1,061</td>
<td>33.8%</td>
<td>4,559</td>
</tr>
<tr>
<td>Mixed</td>
<td>8,948</td>
<td>2,194</td>
<td>24.5%</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>3,008</td>
<td>239</td>
<td>7.9%</td>
<td></td>
</tr>
<tr>
<td>Very High</td>
<td>4,114</td>
<td>1,717</td>
<td>41.7%</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>19,546</strong></td>
<td><strong>5,211</strong></td>
<td><strong>26.7%</strong></td>
<td><strong>4,559</strong></td>
</tr>
</tbody>
</table>

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Missing/Unusable Ethnicity Data

- Question A: 33 out of 2313 (3.2%)
- Question B: 99 out of 2247 (4.41%)
- $p < 0.001$
Re-test Reliability

- Proportion of respondents with missing ethnicity data and/or significant changes in ethnic/family origins upon re-interview were:
  - 4.33% (CI 2.63%-6.68%) for a category-based question (Question A)
  - 9.45% (CI 6.86%-12.61%) for a binary plus open-ended question (Question B)
- \( p = 0.0028 \)
Carriers missed

- Proportions of carriers missed were:
  - 5.74% (CI 2.34%-11.46%) by category-based question (Question A)
  - 9.71% (CI 4.75%-17.13%) by binary plus open-ended questions (Question B).
- \( p = 0.2615 \)
- Carriers missed by QA due to non-administration of question; QB due to structure of the question.
## Time to Administer Ethnicity Question

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Mixed</th>
<th>High</th>
<th>Very High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>2.32</td>
<td>4.78</td>
<td>2.22</td>
<td>4.68</td>
</tr>
<tr>
<td>Mean QA</td>
<td>2.29</td>
<td>4.64</td>
<td>1.86</td>
<td>4.48</td>
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<tr>
<td>Mean QB</td>
<td>2.35</td>
<td>4.92</td>
<td>2.65</td>
<td>4.89</td>
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<tr>
<td>95th Centile</td>
<td>9.00</td>
<td>15.00</td>
<td>7.75</td>
<td>14.00</td>
</tr>
</tbody>
</table>
Conclusion

- Category-based question based on elaboration of UK Census categories performed better than an alternative question on most measures.
Policy in England, circa 2005

- The type of screening programme will depend on the area concerned as whether it is defined as a 'high prevalence' (>1.5 per 10,000) or 'low prevalence' (< 1.5).
- Thalassaemia screening using routine blood indices should be offered to all women in England.
- The type of screening for haemoglobin variants (e.g. HbS, HbC etc) will depend on the prevalence of the condition:-
  - Areas, defined as low prevalence, will be required to offer, as a minimum, laboratory testing for variants based on an assessment of risk determined by a question to women about their ethnic origin.
  - Universal laboratory screening of all women to be offered in trusts defined as covering high prevalence populations.

Source: NHS Sickle Cell and Thalassaemia Screening Programme, 2005
Further Information

- NHS Sickle Cell and Thalassaemia Screening Programme

- http://sct.screening.nhs.uk/

Presentation Ends Here