Ethnic Data Collection Strategy and Methods in NHS Scotland

21st March 2016
Drew Millard
Scope of the talk

• Routine data:
  – Monitoring of completeness in health records
  – NHS Lothian data improvement work
  – The Scottish Census and national registry data
  – Routine surveys

• Data Linkage:
  – Scottish Health and Ethnicity Linkage Study (SHELS)
  – Scottish Longitudinal Study (SLS)
From the equality data review:

“Understanding the characteristics of an individual can help to improve health and health care in two ways:

1. **To directly improve individual care at the point of service delivery:** capturing information on an individual’s needs or values can assist directly when assessing a person’s requirements for care and support (e.g. action required to assist someone with physical access).”

“2. **Through aggregate analyses:** combining information for people with the same protected characteristics can help to identify patterns in prevalence, access, experience and outcomes for different groups of the population.”
Ethnicity data in hospitals

Selected trends in known ethnicity in hospital admission records

- Dumfries and Galloway
- Grampian
- Lothian
- GHN
- Western Isles
- Orkney
- Highland
- All Scotland
- Shetland
- Tayside
- G.Glasgow and Clyde
- Non-NHS Provider/Location
- Borders

Percentage completeness

Timeline:
- Oct-Dec 2013
- Jan-Mar 2014
- Apr-Jun 2014
- Jul-Sep 2014
- Oct-Dec 2014
- Jan-Mar 2015
- Apr-Jun 2015
- Jul-Sep 2015
Possible collection and sharing of information to improve individual care at the point of delivery.
Long-term limiting health problem or disability for Women, by ethnic group and age band, 2011

Source: ‘Which ethnic groups have the poorest health?’ Scottish Government 2015 http://www.gov.scot/Publications/2015/08/7995
An example of data use that counts from WHO
Routine Health service data completeness

Percentage of acute hospital discharge episode records with a known ethnic group by Health Board of Treatment; quarter ending 3/9/2015

- Dumfries & Galloway: 94%
- Orkney: 92%
- Tayside: 89%
- Grampian: 89%
- Highland: 84%
- Greater Glasgow & Clyde: 83%
- Lothian: 82%
- Lanarkshire: 82%
- All Scotland: 82%
- Ayrshire & Arran: 80%
- Fife: 78%
- Forth Valley: 72%
- Non-NHS Provider/Location: 65%
- GJNH: 64%
- Shetland: 62%
- Borders: 47%
- Western Isles: 43%

http://www.isdscotland.org/Health-Topics/Equality-and-Diversity/
Lothian Ethnic Coding Task Force

• Achieved ethnic coding up from 4% to 80% in hospital admission records, (December 2008-March 2012)

• Success factors:
  – mandatory collection in year 3
  – Staff training integrated into appraisal system
  – Information & awareness resources made available for staff & patients
Lothian Additional Needs and Diversity Information Task Force

• Additional needs for Gastroenterology and Vascular surgery outpatients

The additional needs collected were:

• Need for an interpreter/translated resources,
• Hearing impairment,
• Visual impairment,
• Learning disability.
Conclusions and Issues from the ANDI-TF

• Proof of concept

• Key challenges:
  – collecting data in primary care,
  – IT systems
    • Information flow
    • Editing letters
  – ensure use at key points in service delivery,
  – resources to meet the additional needs,
  – staff training on using the system
Routine data for the whole population

• Ethnicity is now collected on death registration

• Country of birth of mother and father

• Ethnicity in the census
## Ethnicity (Scottish Census 2011)

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>All people</td>
<td>5,295,403</td>
<td>100%</td>
</tr>
<tr>
<td>White</td>
<td>5,084,407</td>
<td>96%</td>
</tr>
<tr>
<td>White: Scottish</td>
<td>4,445,678</td>
<td>84%</td>
</tr>
<tr>
<td>White: Other British</td>
<td>417,109</td>
<td>7.9%</td>
</tr>
<tr>
<td>White: Irish</td>
<td>54,090</td>
<td>1.0%</td>
</tr>
<tr>
<td>White: Gypsy/Traveller</td>
<td>4,212</td>
<td>0.08%</td>
</tr>
<tr>
<td>White: Polish</td>
<td>61,201</td>
<td>1.2%</td>
</tr>
<tr>
<td>White: Other White</td>
<td>102,117</td>
<td>1.9%</td>
</tr>
<tr>
<td>Mixed or multiple ethnic groups</td>
<td>19,815</td>
<td>0.37%</td>
</tr>
<tr>
<td>Asian, Asian Scottish or Asian British</td>
<td>140,678</td>
<td>2.7%</td>
</tr>
<tr>
<td>Asian, Asian Scottish or Asian British: Pakistani, Pakistani Scottish or Pakistani British</td>
<td>49,381</td>
<td>0.93%</td>
</tr>
<tr>
<td>Asian, Asian Scottish or Asian British: Indian, Indian Scottish or Indian British</td>
<td>32,706</td>
<td>0.62%</td>
</tr>
<tr>
<td>Asian, Asian Scottish or Asian British: Bangladeshi, Bangladeshi Scottish or Bangladeshi British</td>
<td>3,788</td>
<td>0.07%</td>
</tr>
<tr>
<td>Asian, Asian Scottish or Asian British: Chinese, Chinese Scottish or Chinese British</td>
<td>33,706</td>
<td>0.64%</td>
</tr>
<tr>
<td>Asian, Asian Scottish or Asian British: Other Asian</td>
<td>21,097</td>
<td>0.40%</td>
</tr>
<tr>
<td>African</td>
<td>29,638</td>
<td>0.56%</td>
</tr>
<tr>
<td>African: African, African Scottish or African British</td>
<td>29,186</td>
<td>0.55%</td>
</tr>
<tr>
<td>African: Other African</td>
<td>452</td>
<td>0.01%</td>
</tr>
<tr>
<td>Caribbean or Black</td>
<td>6,540</td>
<td>0.12%</td>
</tr>
<tr>
<td>Caribbean or Black: Caribbean, Caribbean Scottish or Caribbean British</td>
<td>3,430</td>
<td>0.06%</td>
</tr>
<tr>
<td>Caribbean or Black: Black, Black Scottish or Black British</td>
<td>2,380</td>
<td>0.04%</td>
</tr>
<tr>
<td>Caribbean or Black: Other Caribbean or Black</td>
<td>730</td>
<td>0.01%</td>
</tr>
<tr>
<td>Other ethnic groups</td>
<td>14,325</td>
<td>0.27%</td>
</tr>
<tr>
<td>Other ethnic groups: Arab, Arab Scottish or Arab British</td>
<td>9,366</td>
<td>0.18%</td>
</tr>
<tr>
<td>Other ethnic groups: Other ethnic group</td>
<td>4,959</td>
<td>0.09%</td>
</tr>
</tbody>
</table>
Chart 1.24: Proportion of each ethnic group living in the most deprived 10 per cent data zones/LSOA, Scotland/England, 2011


© NHS Health Scotland
2011 census: examples of tables relating to ethnicity and health

- Long term health problem or disability by Ethnic group by age
- General Health by ethnic group by age
- Proficiency in English by age of arrival in the UK
- Ethnic group by provision of unpaid care by general health

These can be reported for a variety of geographies.

Bespoke tables

http://www.scotlandscensus.gov.uk/ods-web/standard-outputs.html
Ethnic inequalities in general health for women, 2011, by ethnicity

Ethnic groups: percentage in the most deprived areas, Census 2011
Census reports

http://www.scotlandscensus.gov.uk/ods-web/standard-outputs.html
Two reports from the Census 2011


Routine Surveys

Scottish Government Core and harmonised equality questions

Scottish Health Survey
Scottish Household Survey
Scottish Crime Survey

Scottish Surveys Core Questions 2013 (Report)
## Table 2: Ethnic Group: Self-assessed general health from Scottish Surveys Common Questions

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Response (%)</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good/Very good</td>
<td>Fair</td>
</tr>
<tr>
<td>White: Scottish</td>
<td>72.9</td>
<td>18.8</td>
</tr>
<tr>
<td>White: Other British</td>
<td>77.2</td>
<td>16.0</td>
</tr>
<tr>
<td>White: Polish</td>
<td>92.1</td>
<td>5.6</td>
</tr>
<tr>
<td>White: Other*</td>
<td>88.0</td>
<td>9.1</td>
</tr>
<tr>
<td>Asian**</td>
<td>81.7</td>
<td>15.6</td>
</tr>
<tr>
<td>All other ethnic groups***</td>
<td>86.7</td>
<td>9.3</td>
</tr>
</tbody>
</table>

* 'White: Other' includes „White: Irish“, „White: Gypsy/Traveller“ and „White: Other White Ethnic Group“
** 'Asian' includes the categories Asian, Asian Scottish or Asian British
*** 'All other ethnic groups' includes categories within the 'Mixed or Multiple Ethnic Group', ‘African’, ‘Caribbean or Black’, and 'Other Ethnic Group’ sections.
Data Linkage Studies

- Linkage is about adding value by combining datasets
- For SHELS, the census, mortality, and health service data were joined into one dataset
Risk of first heart attack at age 30–74 years, by ethnic group and sex

(a) Age adjusted only

(b) Age and education adjusted

Bansal N et al. BMJ Open 2013; http://bmjopen.bmj.com/content/3/9/e003415.full.pdf+html
SHELS: Sample findings for Asthma

Scottish Longitudinal Study (SLS): Sample output
Mortality by social class and ethnicity

<table>
<thead>
<tr>
<th>Disability</th>
<th>Ethnicity</th>
<th>Religion</th>
<th>Age group (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Males</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disabled</td>
<td>Asian</td>
<td>Roman Catholic</td>
<td>&lt;35 2.6 (1.5–4.4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Church of Scotland</td>
<td>35–44 2.2 (1.5–3.1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other Christian</td>
<td>45–54 2.5 (2.0–3.0)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other religion</td>
<td>55–64 2.6 (2.2–3.0)</td>
</tr>
<tr>
<td></td>
<td>White</td>
<td>Roman Catholic</td>
<td>65–74 2.3 (2.0–3.5)</td>
</tr>
<tr>
<td>Disabled</td>
<td></td>
<td>Church of Scotland</td>
<td>75+ 1.6 (1.3–1.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other Christian</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other religion</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>No religion</td>
<td></td>
</tr>
<tr>
<td>Non-disabled</td>
<td>White</td>
<td>Roman Catholic</td>
<td>&lt;35 1.3 (0.6–2.7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Church of Scotland</td>
<td>35–44 3.0 (2.0–4.5)</td>
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</tr>
<tr>
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<td>White</td>
<td>Other religion</td>
<td>75+ 1.9 (1.5–2.4)</td>
</tr>
</tbody>
</table>

## Advantages and disadvantages of linked and routine data

<table>
<thead>
<tr>
<th></th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine</td>
<td>Keeps up to date&lt;br&gt;Collected as part of service provision&lt;br&gt;Validated*&lt;br&gt;Relatively cheap&lt;br&gt;Available for health staff to inform appointment planning and care provision</td>
<td>Ethnicity collection may not be as complete&lt;br&gt;There is a limit to what can be collected</td>
</tr>
<tr>
<td>Linked</td>
<td>High completion for ethnicity&lt;br&gt;Link to any other suitable dataset</td>
<td>Numerators and denominators increasingly mismatched as time goes on (gets out of date)&lt;br&gt;Cost&lt;br&gt;Time&lt;br&gt;Complexity</td>
</tr>
</tbody>
</table>


Using the data: making counting count

- Individual data - for person-centred care
  - Additional needs information
  - Better care, lower costs

- Aggregated data - for service planning
  - Health inequality impact assessments
  - Equality monitoring
SMEHRS Research Priorities 2014-2019 (Summary)

1. Strengthen leadership, capability and collaborative infrastructure,
2. Harness the emerging possibilities of research linkage,
3. Identify and advocate priorities for health research relating to ethnic minority and migrant groups,
4. Encourage and conduct further public service related research,
5. Review and refocus the governance of the group to reflect changing leadership, scope and focus of research.
Learning points from Scotland

• Need for national leadership and local champions

• Ethnicity data must be used

• Gypsies/Travellers needs

• Routine and linked data can support and validate each other

• Core denominator data collection must be large-scale

• Doing nothing is not an option
Thank you for your attention

Andrewmillard@nhs.net

ScotPHO population groups pages:
http://www.scotpho.org.uk/population-groups

ScotPHO home page
http://www.scotpho.org.uk

NHS Scotland Equalities pages:

Scottish Migrant and Ethnic Health Research Strategy Group:
http://www.healthscotland.com/resources/networks/SHERRS.aspx