Formation of a Public Panel for the Scottish Health and Ethnicity Linkage Study (SHELS)

A collaboration between:
University of Edinburgh
Information Services Division (ISD), NHS National Services Scotland
National Records of Scotland (NRS)

Anne Douglas, Hester Ward, Laurence Gruer, Alex Stannard, Theresa Kirkpatrick, Raj Bhopal on behalf of the SHELS researchers

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Acknowledgements

Panel members
SHELS community engagement subgroup
National Records Scotland (NRS)
Information Services Division (ISD)
Background

Since 2007 wide ethnic variations found in health outcomes in Scotland

For example:

• Lower risk of cancer in nearly all ethnic groups
• Higher risk of alcohol related disease in White Irish people
SHELS methods

• 2001 Census linked to routine health records
• Regulatory approvals and security
• Research team access anonymised analysis datasets
• BUT without individual consent

Fischbacher et al BMC Public Health 2007;7:142
SHELS public engagement strategy

Aims & objectives

- Direct engagement with wider public by setting up a public panel
- Dedicated website
- Improved dissemination of study and findings to communities in Scotland
- Respond to concerns of approval organisations

SHELS website: ed.ac.uk/usher/Scottish-health-ethnicity-linkage
Process for Public Panel recruitment

• 10-20 people aged 18 years and over
• Travel expenses (up to £35) and a ‘High Street Stores’ voucher (£40)
• An advertisement, information sheet and application form were created
• Advertised via local and national ethnic & community organisations, research networks and targeted websites
• Informal selection process
Applicants: 29

Accepted a place on the Panel: 19

On a reserve list: 4

Sex:
- 8 male
- 11 female

Age range: 26-69

Ethnicities included:
- Indian
- Indian-Scottish
- Pakistani
- Chinese
- Persian
- Portuguese
- American
- Irish
- Mixed ethnicity
- White Scottish
Public Panel Meetings

Topics discussed:

- Background and aims of SHELS
- Data linkage methods and data security and confidentiality
- Results and findings
- The academic publication process
- Panel views and feedback on methods, study findings, benefits of SHELS, dissemination process to general public
Panel questions and feedback

- How can the 2001 Census data be used for SHELS if they are not meant to be released for 100 years from the Census date?
- How will the results be used to improve policies or practice?
- Does how long people have been living in Scotland affect the results?
- Does SHELS data contain information about illegal or undocumented people in Scotland?
- Is self-defined ethnicity from the Census reliable?
- Will the SHELS findings still be relevant in 10-20 years time?
Panel views on study methods

Overall very positive feedback
- felt important that their data is used providing it is anonymised and privacy is vital
- public need to understand - but complex

Concerns
- if data sold
- discrimination against an ethnic group if better or worse health than majority?
Panel views: What are the main benefits of SHELS research?

- Understand risks of diseases in different ethnic groups
- Inform health practitioners about diversity
- Help health service meet needs of different ethnic groups
Feedback on dissemination of study findings

• Public are not aware of the research
• Most people do not read academic papers

‘the public know very little since so little is effectively communicated’

• Information should be disseminated appropriately for different population groups
Conclusions

Public panel approach successful

Learning opportunity / lessons

Panel supported use of anonymised data for research

Increased public awareness is required

SHELS website: www.ed.ac.uk/ usher/ Scottish-health-ethnicity-linkage
@EdinUniUsher
Our huge thanks to all members of the SHELS public panel