SHELS public panel meeting 16th March 2015, Charles Stewart House, Chambers Street, Edinburgh, 1.30 pm to 4 pm

Present SHELS Team:	**Present Panel members:**	**Apologies:**
Raj Bhopal Graham Bissell Genevieve Cezard Anne Douglas Kath Ellis Laurence Gruer (chair) Arma Sayed-Rafiq Alex Stannard Hester Ward	Margaret Anderson Rod Buchanan Sandy Christie Stephen Christie Eva de Oliveira Stuart Douglas Parveen Ishaq Joanna McGregor Ivy Ng Mitra Rostami Susan Siegel Jihe Song	Laraib Daniya Shabana Diouri Dermot Fitzsimons Lilly Jenkins Nigel Masterton Raza Sadiq

1. Welcome and Apologies

Everyone was welcomed to the first SHELS public panel. It was explained that there were nineteen panel members in the group in total. Seven of the panel were unable to attend the meeting. It was agreed that the meeting would adhere to the Chatham House Rule, i.e. “participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed”.

2 Introductions - All

Introductions were given by all the Panel Members and the SHELS team.

3 Outline format of the meeting

The agenda as circulated would be followed and would include presentations, a short video and the chance for comments and questions from the Panel. Everyone was encouraged to stop any of the team at any point if something was said that was unclear. There would be more time to hear the Panel’s initial thoughts at the end. It was also agreed to keep jargon and abbreviations to a minimum.

4 Background to health & ethnicity research and why SHELS exists

An outline of the history of SHELS and why the study was started was given. This is reflected in the points below:

- Recent years have seen Scotland becoming an increasingly multi-ethnic society.
- In the early 2000s, little information was available about the health of ethnic minorities in Scotland.
- The Race Relations Amendment Act (2000) imposed a duty on all public sector organisations to deliver equitable health care to promote equality across different ethnic groups and required public bodies to be proactive in eliminating inequality in relation to race.
- A review of the existing research, published in 2001, revealed important issues about health and the use of health services by ethnic minorities and led to an agreement with Scottish Government to try to do something about these.
- The Fair For All policy published in 2002 required Health Boards to know the demography of their populations and to deliver appropriate services.
- The data were not available at that time to support a response to either the Race Relations Act or Fair for All. A proposal was sent to the Scottish Government requesting a grant to progress this work.
- At the time, data on admissions to hospital did not record information on a persons' ethnic group. At death registration, country of birth was recorded but not ethnic group. Extensive discussions led to the development of a proposal to link the 2001 census, which did record ethnic group, with the hospital and death records.
- The Registrar General acknowledged a public duty under statistics laws to use census data to produce statistical information for the benefit of our society. An independent review of the ethical issues raised by this type of linkage concluded that it was acceptable, provided a number of safeguards were in place.
- After much discussion, a secure and reliable method was developed to link the databases in a way that removed the personal identifiers (name, date of birth, address) from the files but preserved the linkage between the information on ethnicity and about the hospital admission or death. Following a consultation, permission to carry out the linkage was granted by the relevant directors and ethics committee.
- The initial study looked at two ethnic groups:

  A comparison between the White Scottish and South Asian populations showed that the incidence of heart attack was 80% higher in South Asian Women than in White Scottish Women and 60% higher in South Asian Men than White Scottish Men.

- This vindicated arguments that had been made that Scotland needed data by ethnic group because it showed a massive difference in two ethnics groups in the commonest form of death in Scotland.
- Since then, a wide range of other conditions have been looked at and many other differences found in the health of different ethnic groups in Scotland.
- In 2015 the idea of data linkage is becoming commonplace.

5 Purpose and aims for the SHELS panel

An outline was given of where the data used for SHELS analysis came from and the aims for the panel.

The slides of the presentation are attached.

6 How we adhere to data confidentiality and data privacy at National Records for Scotland (NRS) and ISD

A video about data linkage was shown.

- This was an explanation of how linkage between two databases happens in general and not specific to the SHELS project.
- It was explained that in the SHELS project no-one can see all the data on any individual in the database.
- The computer containing the SHELS database is located in NRS in a locked coded room. It is stand-alone and not connected to any other computer, the internet or a printer. Only three people can log into the SHELS PC at NRS.
- No data are taken out of NRS; only anonymised statistics can be released after checking by NRS.
- Where the number of cases is five or less, the exact number is not given to avoid even the smallest risk of disclosing someone's identity.
- One person only carried out the linkage between the Census and the Community Health Index (Scotland's unique number for the National Health Service) which in turn could be linked to the health data. In doing so he had no access to the actual health or Census data.
- A computer programme carried out the initial matching between the identifiers in the Census and the Community Health Index. Where an exact match was not achieved e.g. due to a small discrepancy in a name or date of birth, the one linkage person made a judgement as to whether or not the match was correct. By these means about 90% of the Scottish population was matched.

7 Initial questions, views and opinions from panel members.

Questions from the Panel:

What are the reasons for South Asians having much higher risks of heart attacks than White Scottish men and women?

Rates of heart attack are low among people living in India and Pakistan but, when people migrate to the UK, their lifestyle often changes towards a diet with excessive amounts of calories, sugar, fat and salt and low levels of physical activity. As diabetes is a risk factor for heart disease, the high rates of diabetes in South Asians in Scotland and the UK contribute to the high rates of heart attack in this group.

Is self-defined ethnicity from the Census data reliable?

The authority to ask about ethnicity in the census was granted by Parliament in 1920 but not acted upon until the 1981 census. Detailed plans were made but the question was ultimately cancelled due to public opposition. After further extensive work a question on ethnicity was included for the first time in the 1991 census. There was a very good completion rate. The question and the ethnic categories used were improved for the 2001 Census and the number of categories of ethnic groups was further increased in 2011. As shown below, some ethnic groups are more reliably recorded than others.

Reliable	Not so Reliable
White Scottish	Mixed Ethnic Group
South Asian	African Origin
Chinese	Gypsy Travellers

How can the 2001 Census data be used for the SHELS project if they are not meant to be released for 100 years from the Census date?

Information about individuals collected during the Census cannot be released for 100 years but many reports on different topics using anonymised statistics drawn from the Census are published by NRS after each census. With SHELS, anonymised statistics are released after being checked by a committee in NRS to ensure they do not identify any individual.

9 Examples of some results from SHELS and main aims for SHELS phase 4

The presentation is attached.

- This showed the composition of the Scottish population by ethnic group based on the 2001 Census and how it had changed substantially by the 2011 Census.
- For example the non-White ethnic population was 2% in 2001 and had doubled in size by 2011.
- The large Other White British group is mostly made up of English people.
- It was pointed out that the White Scottish population has itself diverse origins due to migration over the centuries.
- The Census asks what ethnic group you think you belong to. It also asks about what you think your national identity is (e.g. Scottish, British) and which country you were born in.
- The health areas examined by the SHELS study since 2004 were chosen because they were the Scottish Government's health priorities at that time:
    - Heart Disease
    - Cancer
    - Maternal and Child Health
    - Mental Health

    - Respiratory diseases
    - Alcohol Related Diseases
    - Gastro-intestinal Diseases

- All other ethnic groups are compared to White Scottish males and females.
- Before any particular disease can be studied, there has to be a total of at least 1000 hospital admissions or deaths due to that disease per year in Scotland. This is to ensure there are enough cases among ethnic minorities to give reasonably accurate results. Depending on the phase of the SHELS study, the results were based on hospital admissions or deaths occurring in the 7-10 years following the 2001 census.
- It was explained that Relative Risk is used to compare other ethnic groups to the White Scottish group. For example, a relative risk of 130 for ethnic group A and 80 for ethnic group B means that compared with the White Scottish population, which is given a score of 100, cases for a given disease were 30% more likely in group A and 20% less likely in group B. In making the calculation, the different ethnic groups are "age-adjusted". This is to account for differences in the age structure of different ethnic groups. As many diseases are more common in older people, an ethnic group might appear to have less of a given disease just because more of the group were younger than in the White Scottish population. The age adjustment allows the amount of the disease in each ethnic group to be considered as if it had the same age structure as the White Scottish population. Similar adjustments have been made for other factors that can vary from one ethnic group to another such as educational attainment.
- The SHELS analyses show that the differences between ethnic minority groups and the White Scottish population vary considerably from disease to disease.

- These studies provide information which it is hoped will help to reduce health inequalities between groups and enable the NHS to provide treatment more equitably and target interventions better.

10 Initial discussions.

Questions and feedback were invited from the Panel and SHELS team.

- Do we know if any of the people looked at in the SHELS study are living in Scotland illegally or are undocumented residents?

There are no reliable statistics for this, with estimates ranging between 200,000 and 500,000 across the whole of the UK. For SHELS it is not considered a huge issue in relation to interpreting our information.

The Panel was asked what additional information they would like to be given.

- How much is SHELS intending to lobby for a change to government policy and what are the plans, if any, to do that?

This is something that could be covered in future meetings and it will be put on the agenda. In summary, influencing policy is a very difficult matter and not really within our remit. SHELS works hard to make research available to those who can use it.

- Can we be given a summary of what has been done and get an idea of what SHELS has achieved so far?

It is hoped to compile a document with the abstracts of all the papers published so far. This will be circulated to the Panel in due course.

There will also be a public briefing paper which will be published by Edinburgh University. It could be possible to send this to the Panel in advance.

SHELS is about the incidence and prevention of diseases in the Scottish population – but what about postcode lottery of services – does this affect the results and how do these interact? Is it possible to break down the numbers by NHS Board?

The number of people in ethnic minority groups varies greatly from one part of the country to another and in many NHS Boards the numbers are very small. Consequently, SHELS has never published results by NHS Health Board and we can't use SHELS to say anything about a possible postcode lottery. SHELS only publishes results for Scotland as a whole.

Would you be able to say much on the question of ethnic minorities receiving more or less favourable treatment than the rest of the population?

SHELS is able to make limited comparisons by ethnic group about the quantity of treatment of certain conditions but not its quality: for example, how likely people with a certain condition are to be admitted to hospital. So far, we have found no important differences by ethnic group.

11 Any specific support/training/accessibility needs for the panel?

The panel asked for details of one example of how the work is actually done and the results produced. The team will send the panel a copy of a SHELS paper about ethnic differences in cancer in Scotland. This goes into some of the possible reasons for the differences in some detail.

12 Summary of views/opinions/feedback

The SHELS team have tried to explain to the Panel:

- How data are linked and the security measures in place
- How they are they analysed using calculations of relative risk to compare ethnic groups with the White Scottish population, adjusted by age and educational background
- What are some of the main findings so far

The Panel have asked a range of questions including:

- Does how long people have been in Scotland affect the results?
- Does SHELS data contain information about illegal or undocumented people living in Scotland?
- How will the results be used to improve policies or practice?

13 Process for communication between meetings

We will keep in touch with the panel between meetings. We will summarise the discussion at the panel meeting and send them to the panel to make sure we have recorded the discussions correctly. Panel members will approve the notes and are very welcome to add comment or thoughts that have occurred after the meeting. We will let the panel know about any new papers published or any updates to the website.

14 Next panel meeting –

5 October 2015 (time to be confirmed) in Edinburgh