

## **SHELS Public Panel Meeting**

**5 October 2015: 13.00-16.30**

**Teviot Row House, Edinburgh**

| <b>Present SHELS Team:</b>  | <b>Present Panel Members:</b>   | <b>Apologies:</b>   |
|---|---|---|
| Raj Bhopal (RB)<br>Pauline Craig (PC)<br>Anne Douglas (AD)<br>Laurence Gruer (Chair) (LG)<br>Theresa Kirkpatrick (TK)<br>Alex Stannard (AS)<br>Hester Ward (HW) | Margaret Anderson<br>Sandy Christie<br>Stephen Christie<br>Eva de Oliveira<br>Parveen Ishaq<br>Lilly Jenkins<br>Nigel Masterton<br>Joanna McGregor<br>Ivy Ng<br>Mitra Rostami<br>Susan Siegel | Rod Buchanan<br>Laraib Daniya<br>Shabana Diouri<br>Stuart Douglas<br>Dermot Fitzsimons<br>Raza Sadiq<br>Jihe Song |

### **1) Welcome and Apologies**

Everyone was welcomed to the meeting. Participants at this meeting should 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 Panel Members and the SHELS team.

### **3) Outline format of the meeting**

At the last meeting the SHELS results had been presented and this meeting would now move on to try to find out their possible uses. Raj Bhopal would talk about the research and its impact and then Alison McCallum, Director of Public Health and Health Policy, NHS Lothian would go on to describe some policies and what has been taken from the research so far.

There would then be subgroup discussions of the questions set out in the agenda (see p.5) to hear individual Panel Member’s opinions. The subgroups would then reconvene and views fed back to the rest of the group. There would be time for questions and for giving ideas as to the format for the next meeting to be held in March 2016.

The Panel agreed to the use of a digital recorder for recording discussion.

#### 4) Presentations:

##### **Research – presenting results, getting papers published, impact etc. – Raj Bhopal**

- At the last meeting, a history to the project was given. Before SHELS, it was known as the retro-coding project. In around 2000, Scotland's routine health data were examined but there was nothing relating to ethnicity.
- The Scottish Government funded some preliminary work and this first report was published in 2005. In the overall summary, it stated that, in relation to ethnicity, "routine data sources in Scotland do not include the information needed to
  - measure health inequalities;
  - assess service use and
  - demonstrate compliance with policy and legislation."

Other conclusions were:

"Routine health data in Scotland generally provide very patchy and severely incomplete information about ethnicity."

"The need for new innovative and intensive efforts to improve the situation is now evident." The objective was to describe the "status quo".

- The first major paper and foundation of SHELS was published in BMC (BioMed Central) Public Health in 2007 entitled "Record linked retrospective cohort study of 4.6 million people exploring ethnic variations in disease: myocardial infarction in South Asians." It was a peer-reviewed paper meaning that once submitted to the journal, it was sent on to independent reviewers and the decision then made as to whether it would be published. Some journals only accept 2-3% of papers sent to them; specialist journals tend to accept about 40% of papers. BMC Public Health tends to accept 50-60% of papers. This process of peer-review gives a paper credibility and provides quality control.
- A permanent record of this paper would now exist – anyone with internet access could read the paper in this journal. It was noted, however, that many peer review journals charge subscriptions or fees to view full articles.
- SHELS then became a research project funded by the Chief Scientist Office (CSO). The grant proposal took about 3 months work. The proposal went to external reviewers. The SHELS team responded to any comments/criticisms in their report and then the proposal went in front of a committee of 20/30 people, who discussed and then ranked all the applications submitted for that time period. Most grants are never funded but the process ensures accountability so that public money is not wasted.
- To date, 15 SHELS papers and a number of conference abstracts have been published;
  - posters and presentations have been made all over the world
  - SHELS is well known.
- The question of what happens beyond the research was addressed.
  - The idea that descriptive research such as SHELS should have an impact beyond publication is relatively new in academia.
  - Dissemination for SHELS has included emails to colleagues both in the UK and in the European Migrant & Ethnic Health Association.
  - All publications have been sent to the Director of Public Health at NHS Lothian, to one of the Medical Officers at the Scottish Government, to colleagues in the Scottish Migrant and Ethnic Health Research Strategy Group as well as to specific individuals working in the field.
  - Some papers are sent to the University media office and a press release may be prepared for papers thought to be of wider interest (about 1 in 4). Further dissemination may be via Twitter or the University websites.
- There is no formal route from research to policy or practice. Research diffusion is sometimes by citation by others or the work is picked up and used in books/papers/strategy documents or included in newsletters.

## **What has SHELS ever done for us? - Alison McCallum, Director of Public Health and Health Policy, NHS Lothian**

Alison stated that she would focus on five things that SHELS has done for Public Health in Scotland and beyond and speak a lot from a local perspective in Lothian.

- **SHELS has helped us find out about the population.** Before SHELS people could not be identified as belonging to a particular ethnic group, so it was not known who/where they were and what their health was like compared to the rest of the population. This has been exemplified by the Gypsy traveller population. Traditionally, some people did not reply to studies and did not self-notify needs when admitted to hospital. For example, a CHD project trying to identify high risk individuals who needed help to change their level of risk for diabetes or heart disease. Somebody was employed to go out into the community since there was no routine data available then.
- There has been change over recent years. There is a long-established Polish population in Lothian but from 2008 onwards, a new generation arrived with differing views and needs and different expectations of a health service. Inspired by the SHELS model, there are now Polish data in Lothian to address these issues.
- **SHELS has shown us how health and disease varies.** Around the time of a number of SHELS publications, the causes of death in Lothian were examined and were found to be the same as illustrated by SHELS.
- Based on information from SHELS, a lower risk of all cancers was found in some minority ethnic populations in Lothian. This is not always the case – cervical cancer, for example, varies by ethnic group and by number of years lived in Scotland. In the Polish population, the uptake of routine cervical cancer screening was lower than for those who had lived here for a while. This provided a lesson in how services need to be provided differently for different populations.
- Regarding uptake of breast screening in the Scottish population, most other ethnic populations show lower uptake than for White Scottish women. Should efforts be focussed on increasing uptake of breast screening or on other things? There was lower uptake in both the higher-risk and lower-risk populations. More sophisticated work needs to be done in this area.
- **SHELS has highlighted what services are achieving.** The Equity Audit Programme was established to:
  - look at different parts of the population and see whether services are equitable and meeting peoples' needs; and
  - to find out whether more or less of particular services are required or whether services should be provided differently.

In the South Asian population, there is an increased risk of diabetes and poor control of the condition. It is known that diabetes is a risk factor for heart disease. Avoiding acute heart attack is of great importance since outcomes might be death or long recovery times. It was reassuring to see from SHELS that despite the increased risk among South Asians, the survival rates were not worse. It is imperative that services continue to do things right but that more of them focus on prevention.

- **SHELS has helped with skills development.** This has been through the work SHELS has done and the methods it has utilised. Alison stated that she spends a lot of time helping people work through complex data linkage diagrams to enable them to link datasets e.g. to provide evidence to help reduce risk of early death after chemotherapy. She has used the SHELS methods as a template to teach public health researchers to use health data safely, securely and diligently in order to improve people's health across Europe and beyond.
- **What has been done as a consequence of SHELS.**
  - improved computerised data-collection systems;

- the need to address issues around interpretation services have been identified including what sort of interpreters are needed;
- developing standards for migrants, minority ethnic groups and other vulnerable groups who require a health service where certain things are done differently;
- DVDs have been developed on how to use the health service.
- In summary, a lot has been learnt!

### **Questions**

- Would it be possible for Panel members to receive website links to published papers?
  - Weblinks were included in the document already circulated to the Panel. *This document will be resent to Panel Members.*
- Are papers translated? Regarding DVDs – are they multi-lingual?
  - The SHELS papers have not been translated as translation is such a difficult and expensive art. Indeed, translating scientific concepts is incredibly difficult. It was suggested using “Ethnic minority media” where interviews could be conducted but once again a translator would be needed.
  - In general, translation is too expensive especially when it is not known how big the audience might be.
  - It was noted that even for public meetings, inclusion of, for example, a deaf attendee, would require an interpreter. It is not just consideration of ethnic minorities, inclusion across the board is difficult.
- How does the information get to the front line?
  - The medical journals are good at bringing forward issues both for rare and common conditions. In practical terms, only then is it recognised that a particular population has an increased risk of a particular condition and then a strategy is worked out fairly quickly. SHELS helped show that some populations have a higher risk for breast cancer than others and such populations do not have that high an uptake of breast screening. This was not known before.

## 5) Group Discussions and Feedback Summary

| Group 1   | Group 2  | Group 3  |
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| <p><b>How do you feel about the methods we use and in particular about your health and census data being used without your explicit individual consent? What are your concerns, if any?</b></p>   |  |  |
| <ul style="list-style-type: none"> <li>• Generally there were no concerns but it was suggested that bringing such issues in front of the public may generate anxieties and worries.</li> <li>• There would be concerns if the data was sold on.</li> <li>• The methods themselves are quite complex – would members of the general public actually understand them.</li> <li>• Why not get individual consent? Not economic or timely. The reason for Ethics and Privacy Advisory Committees is to do that very job and the public should trust such committees.</li> </ul> | <ul style="list-style-type: none"> <li>• The group discussed if there was a way to opt out of SHELS. This is not possible for the Census data as they are now anonymised. Patients can contact ISD (Information Services Division) to ask that their hospital data are not used in medical research.</li> <li>• Group positive about use of research and data. However, in the absence of an explicit opt in, was there understanding of why you might be asked about your ethnicity by GPs or hospital staff.</li> <li>• There was lots of discussion around the fact that it would be useful if people understood why their data were being used and then they'd be more likely to give consent. Generic leaflets in surgeries etc in plain English</li> <li>• There was general concern about data security, losing data and breaching confidentiality (but not specific to this research) but despite this the group was still supportive of SHELS research and methods used.</li> </ul> | <ul style="list-style-type: none"> <li>• The views were that there was no problem with the data because the outcomes, results and quality of research have been seen.</li> <li>• It is important research and the Panel, representing the Public, are very grateful that it is being done.</li> <li>• No reservations and we should be making maximum use of the data for all kinds of analysis in a central place. Because the data is anonymised, more than happy for it to be used and even could possibly be used drill down further and not necessarily just kept to Scotland.</li> <li>• Anonymisation used seems sophisticated and secure and safe.</li> <li>• If you asked 100 people about SHELS, they would probably all give consent for their data to be used.</li> <li>• Possibly celebrities or well-known people would have more reservations than the general population.</li> </ul> |

| Group 1  | Group 2  | Group 3  |
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| <p><b>Q2. Are the methods we use justified given the findings and results we obtain? If not, why not?</b></p>  |  |  |
| <ul style="list-style-type: none"> <li>• The process for disseminating research can end up in results being “clogged up” in the system. By luck, something may or may not happen. Is there another way it could be done?</li> <li>• Knock-on effects – SHELS has instigated a lot of other activity. Work not just in this country but all over the world has been inspired by SHELS. The Breast Cancer Screening Service on seeing the results stated they needed to take action. The Mental Welfare Commission approached Raj</li> </ul> | <ul style="list-style-type: none"> <li>• The long-term benefits on how a health board would actually use published results and take further action were brought to life by Alison’s talk.</li> <li>• Concern was raised around the fact that there could potentially be negative targeting. If an ethnic minority group</li> </ul> | <ul style="list-style-type: none"> <li>• Methods fine. Nobody concerned. The way it is being conducted is</li> </ul> |

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| <p>to comment that ethnicity had not been recorded that well in the data they had been collecting – 10 years ago nobody would have made such a comment.</p> <ul style="list-style-type: none"> <li>• The Panel now understood how difficult it is to put research into action but there are now structures: NICE (National Institute for Health and Care Excellence); SIGN (Scottish Intercollegiate Guidelines Network); Evidence into Action Group in NHS Health Scotland – trying to simplify research into policy and then action.</li> <li>• Ethnic coding – people need to know why this data is important and how it is collected. Point made that the way people are asked is also important – staff need to be sensitive and well trained.</li> </ul> | <p>was shown to have either favourable or worse health, that group could be seen to be taking up resources or not needing resources so press releases for certain findings would have to be looked at carefully.</p> <ul style="list-style-type: none"> <li>• Potentially missing data from small ethnic minority populations is very valuable data. If people are not coming forward because of language barriers and inability to access services, the population will not be fully understood.</li> </ul> | <p>as secure as possible.</p> |
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| <b>Group 1</b>   | <b>Group 2</b>   | <b>Group 3</b>  |
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| <b>Q3. What do you see as the main benefits of the SHELS work?</b>   |  |   |
| <ul style="list-style-type: none"> <li>• Researching differences in health in Scotland by ethnicity, describing diversity of the country in an attempt to improve healthcare systems.</li> <li>• Main benefit is if information gets out to the general public including health practitioners.</li> <li>• Health news is very narrow currently; needs to diversify into more interesting topics.</li> <li>• Overall, people are “warm” about SHELS. One Panel Member commented that it is “remarkable work with the potential to benefit all of us in Scotland” and</li> </ul> | <ul style="list-style-type: none"> <li>• There was discussion around it being a retrospective study - how is it now going to be made real-time? Prospectively, can we collect these data in a more ongoing way. It was explained that this is what the health service is now trying to do so that when people go to see their GP, they are asked about their ethnicity. There was discussion around why people were asked and the greater benefit such as guiding health service policies.</li> <li>• There was some concern that people with poor English skills may be travelling to their home country for health care and skewing results by suggesting certain ethnic groups have better health when in fact they just do not use the NHS when they are ill.</li> </ul> | <ul style="list-style-type: none"> <li>• Finding out about different risks/illnesses in all of Scotland’s different Ethnic minority groups was quite impressive.</li> <li>• It was suggested that the public should know more about it than they do. When SHELS is mentioned to friends and family, there is no awareness but they are so interested.</li> <li>• Allowing the Health Service to improve delivery of care and treatment. Most papers are available free but it was hoped that practitioners did review the SHELS results.</li> <li>• Could SHELS become part of Continuing Professional Development (CPD) for health practitioners? Could an information sheet be available in GP surgeries? (but not with the “SHELS” title as it doesn’t mean anything).</li> <li>• Generally, SHELS and its results are interesting and the public would find the results interesting but we need to get the message out.</li> <li>• It was questioned whether health researchers are using the SHELS results to focus on, for example, why the current Chinese population in Scotland are apparently so much healthier than other populations. In small, clinical</li> </ul> |

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| <p>another that it is “joining us all together”.</p> | <ul style="list-style-type: none"> <li>• Some people thought it would improve trust in the NHS as it is clear that this research is used to improve services.</li> <li>• People could see that the benefits were: raising questions around differences in ethnicity, being able to access health services, helping staff and the general population understand about diversity and meeting population needs.</li> </ul> | <p>trials, however, researchers may not be ensuring that participants are representative of Scotland’s population.</p> <ul style="list-style-type: none"> <li>• It was raised how much investment is being made into social issues such as integration and it may be that healthier communities are those that are less integrated since they have not adopted healthier lifestyles.</li> <li>• It was felt that the SHELS dataset should be kept up-to-date.</li> </ul> |
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## 6) Questions, Views and Opinions

- ***Would NHS Education help to get the word out?***

- NHS Health Education works to get the message out to the general public and to front-line practitioners. It was noted that NICE sets up educational programmes for practitioners and the Health Inequalities Impact Assessment is also a good channel for raising awareness. The importance of using current networks to spread information from SHELS was highlighted. Allied Health Professionals was thought to be an important group to reach.
- Could the third sector and voluntary groups help to disseminate information (since health professionals are so busy) but it was pointed out that the third sector is so vast and each organisation has its own objectives but those already working with minority populations may find the SHELS information very useful.
- How do you change perceptions of health which are sometimes inaccurate? Until recently, the general perception was that minority groups generally had worse health than the general population but SHELS has shown the situation is much more complicated - some groups have on average better health than the whole population. Others, like the traveller gypsy population, are doing much worse than any other group.

- ***How practical is it to translate SHELS work at national level down to local health board level?***

It was explained how policies relating to ethnic coding had largely failed since 1991. Around four years ago, ethnic coding for NHS Lothian's routine health information systems was about 5% - one of the worst performing health boards in Scotland. Three years later, this went up to 90% - making NHS Lothian the best performing health board in Scotland. Real-live data collected through the system was presented at a seminar in June and was first presented at a conference on 24 September in Glasgow, which four members of the Panel attended. We are about two years away from this information being routinely available in NHS Scotland.

- ***2021 Census – is it time to lobby for an accompanying information sheet that explains why ethnicity is being asked for in the Census in order to ensure good data is collected?***

- It was observed that often how data are asked for determines the quality of the data obtained and there is more compliance if the reason for asking a question is explained. There is currently no information collected on migration status.
- There would need to be evidence as to whether the ethnic group question was completed poorly last time. There would have to be quality improvement in census ethnic data that would justify such additional cost.
- Could NRS publicise why ethnicity is asked for in the next census? If the forms are online, this information could be more readily provided. Concerns were raised as to having the forms online (exclusion of elderly populations, those without computers etc.) but there are advantages over handwritten forms: no difficulties with reading handwriting and people being alerted to insertion of impossible/incorrect information.
- In 2012, NRS implemented recording of ethnicity on death certificates. Those registering the death were informed that the information was needed to enable the government to do research on health and over 95% agreed to provide the information.
- There was discussion as to how difficult recording even one's own ethnicity can be. What is now widely accepted as the best way to identify ethnicity is self-identification. The pragmatic approach is to offer a menu but "Other Ethnic Group" is included so detail can be written in. NRS agree on a question that is least offensive to the most people after consulting with representatives of the public. This process is in constant evolution as the composition of the Scottish population changes.



- **Considering the increasing complexity surrounding ethnicity, how do you see SHELS in 2031 and how you might go about the work?**

We have been moving away from broad categories (e.g. Asian was in common usage 20 years ago) and appropriate levels of disaggregation are increasingly important. Chinese should not be just one group. South Asians have been disaggregated for some time (into Indians, Pakistanis and Bangladeshis) and that has been very important.

- **Re the presentations, were you surprised by what has been done and how much has been done?**

- The Panel were generally surprised by how much has been done, in Lothian particularly, looking at health and health services for different ethnic groups. It was agreed that it would be interesting to see the statistics for other regions other than Lothian.
- NHS Lothian is the first health board to disaggregate the data. It was asked whether the process could be shared with other health boards to make it easier for them to analyse their data in a similar way. Health Boards do currently share information. There are hundreds of different codes used by health boards and the census and the work involved with matching them up is time consuming and laborious. Progress is being made, though. SHELS has used already collected data and linkage but the future lies in day-to-day routine coding in healthcare systems that produces analysis year by year using the latest information.
- There are numerous different criteria that are vying for the attention of clinicians and managers and there is only so much time and money. In order to get a certain issue to the top of the agenda, such as ethnic differences in health, requires a lot of persuasion and work and is dependent on local circumstances, leadership and resources available.
- The reassurance to advisory and ethics committee that this type of work has Panel support will help future study phases.
- One Panel Member questioned whether there was intellectual property for the SHELS methods and whether the research team could market it.

- **For the next meeting, what would you like to be discussed? Are there any aspects that require further investigation?**

- Suggestions were to invite a senior GP and nurse/front line health service representative to the next meeting although the practicalities of achieving this may be difficult or
- to invite a member of the Privacy Advisory Committee or Ethics Committee.
- Interesting to have representatives from NRS and ISD to explain their support and involvement over the years?
- Through informal discussions with various Panel Members, their desire to have greater input at future meetings was noted.

- **SHELS 5 planning – any ideas for what is to be done next?**

- How the information gathered might be best used - the strategies that need to be implemented to put research into practice.

## **7) Next panel meeting – March 2016 (date and time to be confirmed) in Edinburgh**

Theresa to arrange the date for the next meeting.