

## SHELS Public Panel Meeting

Thursday, 3 March 2016: 13.30-16.00

New Register House, 3 West Register Street, Edinburgh

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

### 1) Welcome, Apologies & Introductions

Everyone was welcomed to the meeting. Thanks were given to National Records Scotland (NRS) for use of the impressive venue. Participants were reminded of 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”. The Panel agreed to the use of a digital recorder for recording discussion.

Brief introductions were given by Panel Members, in particular those who had not attended any previous meetings, and the SHELS team.

### 2) Proposal for a paper on Community Engagement and the SHELS Public Panel – *Anne Douglas*

Over the next few months, there would be no meetings but further results from SHELS 4 would be published and the Panel would be sent papers and summaries. The proposed paper on community engagement concerns:

- the work of the Panel
- how it was set up and run
- the Panel’s feedback on research methods, use of data etc.

The matter of a Panel member being involved with writing the paper was raised.

### **3) SHELS 5 – Aziz Sheikh**

- Aziz will be the principal investigator on SHELS 5. He trained as a GP, then moved into epidemiology. He is a professor of primary care, has been working with large datasets for about 15 years and has always been interested in inequalities. Involved with SHELS since 2010, he is pleased to have been entrusted with its continuation.
- He regards the National Health Service as a fair, equitable, efficient, brilliant system but one which, admittedly, has its difficulties. In the UK, particularly Scotland, there are some of the best health datasets in the world. The existence of an electronic health record for each individual from “cradle to grave” provides an incredible opportunity to study diseases and approaches for health improvement.
- The mapping of ethnic variation across a whole population has been a major achievement but one which now needs to be capitalised upon.
- The grant application to the Chief Scientist’s Office (CSO) is a 2-stage process. If funding is granted, there would be a seamless transition from SHELS 4 into SHELS 5. It should be known whether the initial application for SHELS 5 funding has been successful by the end of March and then a full application will be submitted. The final outcome for this application would probably be known by July.
- SHELS 5 would seek to:
  - Link data to the 2011 census, which includes new ethnic groups (such as the Polish community)
  - Broaden the ethnicity focus to include other factors such as gender, age, religion, faith and disability
  - Describe the variations but identify those that are persisting over time – are there improvements? If not, why not? What can be done to proactively address the inequalities?
- If the grant application is successful, it is hoped that Panel members would continue their involvement with SHELS.
- CSO has indicated they will fund projects which must have a benefit to as wide a cohort as possible. A colleague in Glasgow is also applying to a UK funder for a ‘sister’ project to run alongside SHELS 5.
- The 2 aspects of SHELS that are unique were reiterated:
  - Linking hospitalisation data to census data
  - Linking primary care data to census data
- The panel asked how robust are the data for religion and disability. The response was that these are self-reported data from the Census and should be accurate and complete in most cases. In addition, robust analyses and interpretation methods are used.
- There has been a lot of qualitative work done on religion and health but little done quantitatively.

### **4) Primary care data linkage and use of data – Anne Douglas**

- In SHELS phase 2, the results showed an increased risk in heart disease for Pakistani men. There was information available on ethnicity and socio-economic status, for example, but not on factors such as smoking, diabetes and blood pressure. Such factors are not available in the census or hospital data but are available in primary care data.

- Data such as weight, BMI, asthma, smoking, diabetes and blood pressure were obtained from 10 GP practices.
- An independent IT company ran the program to extract the data. The data was sent securely to Information Services Division (ISD Scotland is part of NHS National Services Scotland) where all of Scotland's hospital data are held, attached to an encrypted CHI number (unique patient identifier) and then sent to the NRS census office. Here, the primary care data were linked to the 2001 census data and then linked to the SHELS phase 2 heart disease hospitalisation data.
- Primary care information is used to treat patients in general practices and so is not designed for research purposes. However, 91% of people had smoking information recorded (ie never smoked, current or previous smoker) and numbers with a diabetes diagnosis matched the levels of diabetes we would expect.
- The results seemed sensible and although the sample size was small, differences could be explained. For example, if there was a decrease in diabetes in Pakistani men, the rates of heart disease would be closer to rates for the White Scottish population. Pakistani women had very low levels of smoking – if they were to smoke at same levels as White Scottish women, their risk levels for heart disease would be twice that of White Scottish women.

### **Questions**

- *Regarding the outcomes in the Pakistani community, could unemployment and long hours of work be factors?*

There is information in the census that enables such factors to be looked at.

- *How much GP/admin staff time is taken up by providing such data?*

Hopefully very little. They had to provide consent and then the IT company completed all the data extraction.

- *Is there a need to get primary care data on a national level or would data from samples of practices suffice?*

17 GP practices were invited to take part – 7 declined. The budget was small and there was a lot of correspondence initially and a number of hurdles to overcome. The intention with SHELS 5 is to use data from a larger sample of practices.

[There was mention of the SPIRE project (Scottish Primary Care Information Resource). The SPIRE project is a collaboration between the Scottish Government and NHS National Services Scotland (NHS NSS). It aims to unlock the potential of GP records as a valuable source of information providing the potential for NHS Scotland to learn more about the health needs of the population and how best to address those needs by developing a new service to simplify and standardise the process for extracting data from GP practice systems for a number of purposes e.g. audit, disease surveillance, benchmarking, planning, research and QOF payments.]

### **5) SHELS – A GP's perspective – Rosie Dixon**

- Rosie described the demographic of her GP practice: very mixed with rich and poor patients. There is a small mosque nearby and many Pakistani families – now third generation. There is sheltered accommodation close by too which houses many workers originally from Hong

Kong and mainland China. There is also a large student population and a general Scottish population.

- Anecdotally, the SHELS findings reflect what is seen in practice with 3 exceptions. There was insufficient time during the meeting for Rosie to elaborate on the exceptions but she has since done so:
  - The first exception is Crohn's disease, a serious but not very common condition, found to be less common in South Asians. Although Rosie has never seen a South Asian patient with Crohn's, she might have put this down to chance. This is a very interesting finding as the cause of Crohn's disease is not known - perhaps this provides a clue?
  - The second is the low occurrence of acute appendicitis. Again, Rosie has never seen acute appendicitis in a South Asian patient - but again may have put this down to chance. She was unaware that this was borne out statistically.
  - The third surprise was the reference to a high rate of admissions of south Asian patients with serious asthma - because her impression is of seeing few South Asian patients with asthma. In a post-meeting discussion with Raj, he pointed out that this did not reflect the incidence or prevalence of asthma in this group but rather the frequency of attendance at hospital with severe asthma events. So irrespective of the incidence / prevalence, this may reflect late presentation and generally poorer control - which would not be that surprising.
- *How might you use these results in your practice / are you already? Are there specific practices you employ relating to the ethnicity of patients?*

The results certainly increase background knowledge and could increase awareness when making diagnoses. There are certain conditions which are known to be more prevalent in certain populations such as multiple sclerosis in the White Scottish population, sickle cell anaemia in Black Africans and Coeliac disease in the Irish. A GP, however, is responsible for the holistic care of an individual and there is a massive spectrum within each ethnic group. The SHELS information is being used informally but perhaps the important findings relating to breast cancer screening uptake should be addressed and action measures taken.

There is high use of interpreters. Currently, a Chinese warden assists with interpretation for the residents of a care home for elderly Chinese.

- *How would you feel about your practice data being used in this way? Ideally, going forward, we would like a much larger sample, but do you think GPs would be willing to provide the data? What would your concerns be, if any?*

Resource is a problem for use of GP data. Obtaining individual consent of practice patients is too time-consuming but a central Caldicott overarching approval, avoiding the need for individual consent, would be acceptable.

### Questions

- *How are the data being used to provide better care for an initial consultation?*

In a 5000 patient practice, the receptionists know who needs to be seen immediately. Many of the patients are well-known to them. Research is required into the cultural differences in presenting symptoms. Subtle differences in the language used can be very significant.

- From what SHELS has confirmed so far, if ethnicity is known, could a new GP be prompted with a screen flag e.g. a diabetes alert for South Asians?

There is some concern with over-flagging and screen space on GPs' computer systems is already at capacity. Education could play a role. Summation of all the evidence of recent research papers including SHELS could be presented in a new GP training session.

**6) How this type of work advances Public Health –from a journal editor’s perspective – Phil Mackie**

- Editors determine the communication value to wider audiences of the papers submitted and sadly there is no course to learn how to do this. Experience is gained over time.
- The abstract determines whether an individual will read a whole paper.
- As a journal editor, the vision and aspiration of the author are taken on board and editors assess whether a particular paper is worth including in a journal so that it can be communicated to multiple audiences and, in so doing, kept available in perpetuity. This may seem unnecessary but consider the H1N1 flu virus in 2009 that caused a world-wide pandemic. The last pandemic was from 1918-1921 and so the records were very important.
- In trying to communicate about the health of ethnic communities in Scotland, prevention of disease must be a key aim.
- Migration is not a recent phenomenon and doesn't stop: the first Polish miners came to Lothian in the 15<sup>th</sup> and 16<sup>th</sup> centuries. The first anti-smoking policy was in the 1650s.
- The evidence is important for communicating but also for influencing decision makers and helping formulate public policy.

**7) Group Discussions and Feedback Summary**

| <i>Group 1</i>  | <i>Group 2</i>  | <i>Group 3</i>  |
|---|---|---|
| <b>Q1. What has SHELS highlighted?</b>  |   |   |
| <ul style="list-style-type: none"> <li>• Collaborative approach</li> <li>• Feel comfortable about why their data is being used but how many people know this is happening?</li> </ul> | <ul style="list-style-type: none"> <li>• SHELS communicated with the Panel: how their data was used, how the findings were utilised by practitioners.</li> <li>• The research has a more academic focus than practical for the public or policymakers.</li> <li>• Hope the research could influence a change in policy and especially be used for education.</li> </ul> | <ul style="list-style-type: none"> <li>• In the Pakistani population, could the reduced rates of mortality from heart disease be attributable to the quality of after-care at home?</li> <li>• The good health of the Chinese may dilute down to Scottish levels in subsequent generations.</li> <li>• The use of Chinese medicines and acupuncture could be explored. The effect of such interventions may also be diluted over time.</li> </ul> |

| <b>Group 1</b>   | <b>Group 2</b> | <b>Group 3</b>  |
|--|----------------|---|
| <b>Q2. Are the methods used acceptable?</b>  |                |   |
| <ul style="list-style-type: none"> <li>• The processes involved were explained</li> <li>• There is security built into the processes which is important to build trust; privacy is vital – no names or personal details ever seen.</li> <li>• The NRS data linkage video should go viral</li> <li>• Will the SHELS findings still be relevant in 10/25+ years' time?</li> <li>• 2<sup>nd</sup> generation may change the situation e.g. breastfeeding patterns.</li> <li>• What will be the impact of new immigrant populations?</li> <li>• A real understanding of each population is required and the knowledge of how to communicate with that population.</li> </ul> |                | <ul style="list-style-type: none"> <li>• Anonymised linkage to the census was ground-breaking and resulted in the useful findings.</li> <li>• Boring down into the primary care data was very exciting. There is an immense amount of data that has potential and could be used.</li> </ul> |

| <b>Group 1</b>   | <b>Group 2</b>  | <b>Group 3</b>   |
|--|---|--|
| <b>Q3. How has the information been disseminated?</b>  |   |  |
| <ul style="list-style-type: none"> <li>• Other people, apart from GPs, should be using the information in a preventative/ educational approach.</li> <li>• people need to understand health risks and be informed by people they trust to try to achieve behaviour change to help prevent diseases. (schools, colleges, universities, pharmacies etc.)</li> <li>• Community ambassadors could be used to help the SHELS findings reach all communities and in an appropriate way for different groups. Not many of the general public read academic papers.</li> </ul> | <ul style="list-style-type: none"> <li>• The public know very little since so little is effectively communicated</li> <li>• Steps for SHELS 5 – in a multicultural Scotland, it would be more useful if there was a more holistic approach to health and ethnicity (ie include diet, culture, religion &amp; education.</li> <li>• For GPs getting consent to use patient's data, could this be done at hospital or when checking in electronically at a practice.</li> </ul> | <ul style="list-style-type: none"> <li>• SHELS must be proactive about dissemination to the general public.</li> <li>• Lay people know very little about the research and the information needs to be got out in "lay terms" e.g. YouTube video</li> <li>• The Panel were not aware of any coverage in the lay media – press or local news.</li> <li>• Possible ways of communicating the findings with professionals include: <ul style="list-style-type: none"> <li>○ seminars in medical schools run by SHELS</li> <li>○ sharing the data with appropriate professional bodies.</li> </ul> </li> <li>• There could be a lobbying role for SHELS – making the whole process a product with commercial value for use in other populations. Funding bodies would consider this.</li> <li>• The Chief Medical Officer should reconsider the status of sharing of anonymised health data. Only with a specific "opt out" should the data not be shared.</li> </ul> |

## 8) Questions, views and opinions

- *SHELS has been a legitimate area of research but there is still much to be done to get the information “out”. How would you, RB, respond to this?*

Such work can be seen to divide societies but fortunately this seems not to be the case in the UK. Regarding the methods, there was concern expressed by government, ISD and NRS but the Panel have confirmed that the use of data in SHELS, without individual consent, has not been an issue.

There has been criticism of academics not disseminating widely enough since their primary focus is on doing and writing up the research. There have been a number of press releases for SHELS papers and presenting findings at conferences but such an amount of dissemination is still far less than ideal. Improvement in this area will be attempted but resources and the required skillset may be limiting factors.

- *Should dissemination be built into the grant application for SHELS 5?*

Some funders are more receptive to this than others. A knowledge exchange strategy is required to influence policy. Policy makers require a seat at the table and to work with Panels such as this one.

## 9) Summary

The Panel members were thanked for giving up their time and it was reiterated how much their input has been appreciated and valued.