Is the linkage of census and health data justified? Views from a public panel of the Scottish Health and Ethnicity Linkage study

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Anne Douglas (Research Fellow)[1], Hester JT Ward (Consultant in Public Health Medicine)[2], Raj Bhopal (Professor of Public Health)[1], Theresa Kirkpatrick (Research Administrator)[1], Arma Sayed-Rafiq (Senior Health Improvement Programme Officer)[3], Laurence Gruer (Honorary Professor of Public Health)[1] on behalf of the SHELS researchers

[1] Edinburgh Migration, Ethnicity and Health Research Group, Usher Institute of Population Health Sciences and Informatics, University of Edinburgh, Teviot Place, Edinburgh EH8 9AG UK
[2] Information Services Division, NHS National Services Scotland, Edinburgh EH12 9EB UK
[3] NHS Health Scotland, Meridian Court, Glasgow, G2 6QE UK

Corresponding author
Anne Douglas – anne.douglas@ed.ac.uk

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Abstract

Background

Using routine health data for research aimed at improving health requires the public's awareness and trust. The Scottish Health and Ethnicity Linkage Study (SHELS) explores variations in health between ethnic groups. We aimed to establish a public panel to obtain their views on its methods, findings and dissemination, including use of routine health data without individual opt-in consent.

Methods

Adult applicants were sought via a range of sources, aiming for a balance of age, gender and ethnicity. Three half-day meetings were held in 2015-2016. Discussion covered the study's aims and governance; record linkage methods; data security; main findings, dissemination and publication processes.

Results

Of 29 applicants, 19 joined the panel. Panellists were from ten ethnic groups, 11 were female, ages 29-69 years. With some reservations, they enjoyed the meetings. After methods and security were explained, they unanimously accepted the study's use of linked data without individual opt-in consent. They thought explaining such complex methods to the general public was difficult. They recommended more should be done to communicate study findings to the public, practitioners and policy makers.

Conclusions

The panellists' support for the study methods was reassuring. Their recommendations have led to the implementation of a wider dissemination plan.

Background

Routinely collected health data provide a valuable resource for public health and epidemiological research in many countries. Advances in information technology enable linkage of electronic health records on a large scale. Linked datasets offer great potential for research at a national level on disease risk, health service use, evaluation of public health interventions and health outcomes, particularly for rarer diseases and minority populations. However, the potential benefits have to be balanced against the risks, including the public's concerns over the security and possible misuse of their personal information. Consequently, there is a need for a better understanding of the public's attitude toward the secondary use of health and other administrative data and greater public involvement in related research.

Research funders in the United Kingdom, including the National Institute of Health Research (NIHR), the Wellcome Trust and the Medical Research Council are increasingly committed to ensuring public involvement is a core part of all health research and that diversity and inclusion are important aspects of this process[1]. The Scottish Health Informatics Programme's (SHIP) public consultation in 2011-2012 concluded there was general support for the use of medical data in health research, conditional on the type of research, some level of individual control of access to personal data and improved transparency about the collection and linkage of routine data.[2,3] Similar public support for the use of health data for research has been reported in the UK and elsewhere.[4-7]

In Scotland, health records can be linked by a unique identifier, the Community Health Index (CHI) number. This offers the potential for a wide range of health related databases to be linked. The Scottish Health and Ethnicity Linkage study (SHELS) has linked NHS hospital discharge and mortality data to the 2001 Scottish Census and found wide ethnic variations in a range of important health conditions, procedures and outcomes.[8-13]

The SHELS methods and findings have been published in academic journals,[14] but the public's views on the use of their data for this specific purpose have not been explored. The project's regulatory approval organisations, the NHS National Services Scotland Privacy Advisory Committee and the research ethics committee, asked the research team to assess whether the public supported the aims and methods of the SHELS project and the use of its findings. Colleagues experienced in public engagement and online guidance, such as the NIHR's online advisory group[1], suggested the best approach might be to recruit a diverse group of members of the public to discuss these issues with the research team. This paper describes setting up the resulting public panel and the outcomes of its three meetings.

Methods

Our aims were: to establish a panel of members of the public, to explore with the research team, their views on the use by SHELS of linked, de-identified health and Census data; and to develop with the panel a strategy to explain and widely disseminate the SHELS' methods and findings. We sought advice on how to establish the panel from local research networks and organisations which already had public or

patient panels. Collaborators from NHS Health Scotland and National Records of Scotland (NRS) were involved to ensure equality of opportunity and accessibility in the recruitment process. They helped produce a list of national and local, public and community organisations, volunteer organisations, other local patient panels and targeted websites, which could assist with recruitment. An advertisement, information sheet and short application form were created to recruit panellists. The opportunity to apply was advertised for two months from December 2014. Applicants had to be aged 18 years or over, English –speaking and willing to attend three half-day meetings over 18-months. Preference was given to people not directly involved in health research. Travel expenses up to £35 and a £40 gift voucher were offered for each meeting attended. Submitted application forms were reviewed by three members of the research team and informal telephone interviews used to select a balance of age, gender and ethnicity. Successful applicants signed a Terms of Agreement form that emphasised the need for participation in open discussion and listening to and respecting others. Members could leave or be asked to leave the panel at any time.

Three meetings of the panellists and members of the research team were held between March 2015 and March 2016. Agendas and information were sent before the meeting to allow panellists to prepare. The meetings lasted 2-3 hours. At the first meeting the research team explained the study's aims, methods, main findings, governance and data security procedures, and showed panellists a SHIP video on record linkage. (https://www.youtube.com/watch?v=smnnD9ZXwP0). At the second, the lead researcher described how the results were published in scientific journals, a Director of Public Health spoke about how the findings had influenced her work, and the panellists discussed the research methods and perceived benefits of the study in small groups. At the third, the perspectives of a general practitioner and the editor of a medical journal were given and panellists further discussed the strengths and weaknesses of the study methods and how the results were disseminated and used. Meetings were governed by the Chatham House Rule (https://www.**chathamhouse**.org/about/**chatham-house-rule**) and discussions recorded (with consent) to allow detailed notes to be written up without naming individuals. Panellists were asked to complete feedback forms rating their satisfaction with the content and organisation of the meeting, and giving their suggestions for future meetings (see Supplementary appendix 1). Summaries of the meetings were placed on the SHELS website (www.ed.ac.uk/usher/scottish-health-ethnicity-linkage) with panellists named with their consent.

Feedback from the panel meetings contributed to the content of the following meeting(s) and a formal SHELS dissemination strategy, approved by the project Steering Group.

Results

Panel Recruitment

Twenty-nine applications were received. Nineteen people were offered and accepted a place on the panel with four agreeing to be on a reserve list. Of the 19 panellists, 11 were female and ages ranged from 26

to 69 years. Box 1 shows the ten different self-defined ethnicities of the 19 panellists. Two panellists subsequently withdrew for personal reasons.

Panel Meetings

Eleven to 12 panellists attended each meeting. They appeared interested, inquisitive and constructively critical. When asked to rate each meeting for overall experience, organisation, provision of information and presentations, 31 (of 35) feedback forms were completed (see appendix 1). Responses were either "very satisfied" or "satisfied", except for two ratings of "neither satisfied or unsatisfied" for overall experience and presentations at the first meeting.

Panellists said the main strengths of the meetings were: the diversity of the panellists; the amount and clarity of information provided by the research team; and the use of small group discussions, allowing them to express their opinions freely. Negative comments were: there should have been more panellists aged under 25; attending meetings during the day was difficult due to work commitments; and there was insufficient time or opportunity to discuss issues in depth, particularly at the first meeting.

Panellists showed an understanding of the research by the pertinent questions asked. For example, they questioned the reliability of the ethnic group data recorded in the Census; if the study findings would still be relevant in 20 years' time; and if individuals' length of residency in Scotland affected the results.

Panel views on use of linked data without project- specific, opt-in consent

After the methods, governance and security procedures were described in detail and discussed, all panellists supported the use of de-identified, linked health and census data by the SHELS project, without the need for individual opt-in consent. They liked the clarity of the video explaining the record linkage process, with one panellist suggesting the data linkage video should "*go viral*". Several panellists stressed the importance of the secure data anonymisation process in satisfying them that individual consent was not needed. Others thought the public would support the use of anonymised health data if they understood the aims and findings of the research: greater public awareness might mean more patients would be willing to give their ethnic group when attending hospital. Conversely, several suggested that informing the wider public about the study might generate anxiety, particularly as the methods were quite complex. For instance, one remarked "*it* (the SHELS' record linkage method) *could be beyond most people's understanding so maybe it is not explainable to the average member of the public*".

Some panellists expressed concern about data security more widely. They referred to high profile cases of lost personal data with subsequent breaches of confidentiality, and sensitive personal data being obtained by private companies. One said "*there will always be suspicions*" and another that there was "*nothing the research team could say to make them feel their data was safe, but I see no alternative way to do the SHELS research*". Despite raising these issues, the panel was still strongly supportive of the project's methods.

Dissemination of findings to the public and health service

None of the panellists had any previous knowledge of the SHELS project and were unaware of any media coverage relating to publication of SHELS academic papers. They agreed the wider public should be informed of the research as it was important and would be of interest to many people. Many were surprised that little had been done to inform the public of the SHELS results and their implications. They recommended information should be disseminated in appropriate ways to different population groups: for example through schools, colleges, pharmacies, general practices, community ambassadors and via social media.

It was suggested that if health professionals understood ethnic variations in disease outcomes they could adopt appropriate prevention initiatives. The panel thus proposed that, in addition to publishing academic peer reviewed papers, the findings should be included in heath practitioners' continuing professional development and shared with appropriate professional bodies.

In the light of the panel's feedback, the research team have developed a wider dissemination plan incorporating the use of Twitter, the SHELS and other collaborators' websites, short lay summaries of new findings, and directly communicating newly published results to the Scottish Government, Chief Medical Officer and other appropriate health professionals.

Views on participating in a research public panel

Ten (of 12) panellists at the third meeting responded to the question in the feedback form asking if their expectations of being on the panel had been met. All reported very positive experiences and felt they had been given the opportunity to convey their views effectively. All ten said they felt their involvement was valued by the research team.

Cost of the panel

The total additional cost to the project of recruiting the panel, holding the meetings and remunerating the panellists was around £2500. This did not include the time of the research team.

Discussion

Main findings of the study

We recruited a diverse group of adults to consider the methods and findings of the SHELS research, achieving a reasonable balance of age, gender and ethnic groups resident in Scotland. Attendance at meetings was good and all panellists contributed actively to discussions, particularly in small groups. After the study methods were carefully explained, panellists appeared to understand them, as evidenced by their pertinent questions and constructive criticism. Within the context of this research project, the panel strongly supported the linkage of anonymised health and census data for research purposes without the need for additional individual consent. They recommended the research team should disseminate the SHELS findings more widely and promote the use of linked health data in general to the wider Scottish population, health practitioners and policy planners.

Our findings support previous work suggesting that the provision of information about research and data security and reassurance about de-identification lead to increased public support for the re-use of health data without explicit consent.[15,16] However, our panel agreed these complexities may be difficult to explain in lay terms within a wider public information campaign. They suggested various ways of doing this, including the use of YouTube, leaflets in general practices and direct distribution of the study findings to health and policy professionals. Their main recommendation was that much more should be done to disseminate the results beyond the academic world.

What is already known on this topic

In the UK, funding bodies and government organisations increasingly require the involvement of the public and patients in health-related research, from inception to conclusion.[17-19] Domecq et al[20] reported in a systematic review that public engagement can influence research, particularly in the areas of patient recruitment, consent and materials. Many UK research organisations are committed to public and patient involvement, including the UK Farr Institute of Health Informatics Research[21]. This has established public panels in various locations in the UK with the aim of ensuring research using routine healthcare data, reflects public interests and values. However, there are very few published reports describing the best models to create, work with and evaluate the impact of research public panels.

Electronic health records and advanced record linkage techniques have provided an invaluable resource for public health and epidemiological research worldwide. However, the public are largely unaware of how their health data might be used and generally do not understand linkage methods and security requirements.[7,15,22] There is some evidence from focus groups and surveys in the UK and Australia that the public support the use of health data for research in principle and that this support is stronger with better awareness and provision of information, particularly when the data are de-identified.[15,16,22,23] Most reported some anxiety about the potential for breaches of privacy and misuse of data. Some favoured a requirement to seek individual consent, whether or not the data were anonymised, using either opt-in or opt-out models. A Canadian survey[6] concluded that despite support for the use of health information for public health research and high levels of trust in hospitals and universities, many members of the public felt it was not acceptable to use their data without prior permission or notification. The national data guardian for NHS England recently published a review making recommendations for security, sharing and consent or opt-out systems for health and social care data within the English health service, in order to increase public trust in the protection and use of their personal information.[24]

In 2015, the Scottish Government published a Health and Biomedical Informatics Research Strategy[25] including a National Data Linkage Framework for statistics and research. This was preceded by a large-scale public consultation including workshops to explore the public's views of linking personal data for research.[5] It concluded there was broad support in Scotland for the re-use of de-identified routine heath data but there were significant concerns over the trustworthiness of public bodies in relation to data security, who would have access to data and whether explicit consent should be sought for the use of identifiable data. Aitken et al's recent systematic review[7] of 25 qualitative studies from multiple countries suggested that trust in organisations may be the key to achieving public acceptability for the use of linked

health data for research. They further concluded that this may best be realised by including direct engagement within public awareness-raising initiatives.

What this study adds

As far as we are aware, this is the first published example of lay people being asked for their opinions on the linkage of a national census with routine health data and on the findings from the resulting research. It describes a successful method for achieving public engagement in a research project focusing on the potentially sensitive issue of ethnicity and health. To our knowledge it is the first example of a purposive attempt to recruit a multi-ethnic panel and we believe some lessons learned are generalisable.

Our findings resonate with many points reported by Jones et al describing their experience with the Welsh Secure Anonymised Information Linkage (SAIL) research unit's Consumer Panel.[26] They described the successful creation of an enthusiastic and committed panel, which provided valuable recommendations for further public involvement in research and emphasised the importance of informing the public in lay terms about the use of routine health data and record linkage. Other research has recommended that academics should widen their focus beyond the traditional scientific publication route.[27] We suggest further research is required to identify effective methods for giving the public information about record linkage, explaining how routine health data can be used for research and disseminating important results more effectively.

Limitations of this study

The panellists expressed their own views which may not be representative of their ethnic group or the wider Scottish population. They focused on specific aspects of the SHELS project and their conclusions may not be applicable to all uses of anonymised health data without explicit individual consent. The work was developed as a practical way of engaging with members of the public on an on-going basis with the aim of understanding and where relevant, acting upon, their views on the study's methods and findings. In retrospect, a questionnaire on panellists' knowledge and attitudes about issues such as data confidentiality and individual consent, completed before and after the study methods were explained, might have usefully enabled us to detect changes in views. A qualitative analysis of the discussions might have yielded added insights but we did not have the resources to conduct one. Although panellists were encouraged to express their opinions openly and honestly, as the meetings were facilitated by the SHELS research team, some social desirability bias in the panellists' responses cannot be excluded. The meetings allowed detailed provision of information to panellists and subsequent in depth discussions: this level of involvement may not be possible when providing public information at a national level. While the objectives for the panel were met, an independent evaluation of the panel's contribution was not carried out.

Conclusions

Forming and working with the SHELS public panel proved feasible, provided valuable lessons for the research team and a learning opportunity for the panellists. Given appropriate governance and security

processes, the panellists supported the use of de-identified health and census data for academic research without specific opt-in consent. They emphasised the importance of informing the general public, and health and policy professionals about the study's research methods and findings with the aim of maximising public health benefit.

Box 1. Self-defined ethnicity of the SHELS panellists

Self-defined ethnicity	Number
American	1
Chinese	2
Indian-Scottish	1
Indian	2
Irish	1
Mixed ethnicity	1
Pakistani	4
Persian	1
Portuguese	1
White Scottish	5

Appendix 1. SHELS Public Panel Meeting Feedback Form

	Very Satisfied	Satisfied	Neither Satisfied or Unsatisfied	Unsatisfied	Very Unsatisfied
Overall Experience					
Organisation of the Panel Meeting					
Pre-meeting information					
Presentations					
Facilities and Venue					
Refreshments					

What were the strengths of the Panel Meeting? What did you find most useful or informative?

…….

Which were the least useful parts of the Panel Meeting?

…….

Please tell us what you thought about the length of the Panel Meeting (Please circle)

Too long Too short About right

Comments:

…….

Have your expectations been met with regard to being on a Public Panel? If not, why not?

…….

Have you been able to convey your views on the SHELS methods and findings effectively? Is the Public Panel's perspective on the SHELS research useful and ready to use in reports and papers?

…….

Do you feel your involvement is valued by the SHELS researchers?

…….

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Authors' Contributions

The authorship, the authorship by-line, and note of contributions follows SHELS policy on authorship. All authors served on the community engagement subgroup of SHELS which planned the work in detail. Douglas coordinated the project and was lead writer of this paper, Bhopal was the PI of SHELS, Ward was a co-investigator, Gruer was a co-investigator and chaired the public panel meetings, Kirkpatrick was the research administrator and organised two panel meetings and Sayed-Rafiq contributed to the panel recruitment process. All authors helped plan the work, attended panel meetings, critically revised drafts of the manuscript and agreed submission of the final draft.

Data sharing

Not applicable

Conflict of interests: None declared.

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