

## ***General***

### **The SHELS Study and its methods**

[Cohort Profile: Scottish Health and Ethnicity Linkage Study of 4.65 million people exploring ethnic variations in disease in Scotland \(2010\)](#)

This paper describes the SHELS record linkage methods. These have enabled researchers to link the 2001 census, which includes ethnic group, to several health-related databases including death records, NHS hospitalisation and cancer registers. Using strict anonymisation procedures to ensure the confidentiality of the data, a cohort database with around 4.6 million people was created. This was then used to compare ethnic groups in Scotland for various important health conditions including cardiovascular disease, cancer, maternal and child health and mental health.

These methods can illuminate important health differences between the larger ethnic groups in Scotland, with potential implications for policy and practice. Similar methods could be used in other countries where gathering information about ethnic group may previously have been considered too sensitive for record linkage.

[Epidemiology Data from the Scottish Health and Ethnicity Linkage Study \(SHELS\) \(2014\)](#)

This paper provides an update on the SHELS methods and a list of the various datasets that have been created in the course of the study.

## **Cancer**

### **Cancer by Ethnic Group**

[Does the 'Scottish effect' apply to all ethnic groups? All-cancer, lung, colorectal, breast and prostate cancer in the Scottish Health and Ethnicity Linkage Cohort Study \(2012\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their ethnic group. These were linked anonymously to records of all new diagnoses of cancer during seven years from 2001 to 2008. Up to ten ethnic minority groups were compared with the White Scottish population.

Compared to White Scottish men and women, Indian, Pakistani, Other South Asian, African, and Chinese groups all had lower rates of hospitalisation or death from cancer as a whole. Looking at individual types of cancer, Pakistani men and women had the lowest rates of lung cancer, whilst Pakistani men and women and Chinese men had the lowest rates of colorectal cancer. Breast cancer rates were particularly low among Pakistani and Chinese women and prostate cancer was lowest among Pakistani and Indian men. Differing socio-economic circumstances could do little to explain the differences between the groups. The findings have implications for cancer prevention, screening and clinical care.

### **Attendance for Breast cancer screening**

[Major ethnic group differences in breast cancer screening uptake in Scotland are not extinguished by adjustment for indices of geographical residence, area deprivation, long-term illness and education \(2012\)](#)

This study analysed data on almost 140,000 women, aged between 50 and 53 when they received their first invitation to attend for breast screening between 2002 and 2008. Their 2001 Scottish Census records, including ethnic group, were anonymously linked to their breast screening records. Ten ethnic minority groups were compared with the White Scottish population.

Compared with White Scottish women, Other White British and Chinese women had similar rates of attendance for breast cancer screening whereas Pakistani, African, Indian and Other South Asian groups had much lower rates. These differences remained even after socio-economic circumstances and other factors were taken into account. The findings are worrying especially as the relatively low breast cancer rates in South Asian women are rising towards those of the White UK population. More work is needed to understand and address the low uptake of the screening service by these ethnic groups. Policymakers and health-care staff need to ensure that services and staff are culturally sensitive and competent.

### **Place of Death from Cancer**

[Policy for home or hospice as the preferred place of death from cancer: Scottish Health and Ethnicity Linkage Study population cohort shows challenges across all ethnic groups in Scotland \(2015\)](#)

This study aimed to find out whether the ethnic group of patients with cancer had any influence on where they died. It analysed data on almost 120,000 people aged over 25 who died of cancer in Scotland between 2002 and 2008. Their 2001 Scottish Census records, including their ethnic group, were anonymously linked to their hospital and death records. Seven ethnic groups were compared to the White Scottish population.

Only 0.4% of those included in the study were from non-White ethnic minority groups. Overall, 52% of patients died in hospital. Compared to White Scottish people, the White Irish and Other White British were more likely to die at home. Chinese people appeared more likely than other groups to die in hospital or a hospice but the numbers of deaths were too small to draw firm conclusions. Among the White Scottish and other White ethnic groups, more affluent patients were more likely to die at home or in a hospice than in hospital. This trend could not be seen among the non-White ethnic minority groups.

Regardless of ethnic group, significant work is required if more people are to be enabled to die at home or in the setting of their choice.

## **Cardiovascular**

### **Heart Attack in South Asians**

[Record linked retrospective cohort study of 4.6 million people exploring ethnic variations in disease: myocardial infarction in South Asians \(2007\)](#)

This landmark study aimed to explore the feasibility of linking Scottish census data to health service and other records to explore differences between ethnic groups in health and health service use

Out of 4.9 million records in the 2001 Scottish Census, around 4.6 million individuals with a recorded ethnic group could be matched to a unique Community Health Index (CHI) number. This enabled their census records to be anonymously linked to any health record carrying the CHI number. For this study, the CHI-matched Census records were anonymously linked to records of all hospitalisations and deaths in Scotland for acute myocardial infarction (heart attack) for the period April 2001 to December 2003. The rates among South Asians were then compared with those of non-South Asians.

Both South Asian men and women were found to have higher rates of heart attack than non-South Asians. However, South Asians were more likely to survive after a heart attack than non-South Asians.

The study demonstrated the methods met ethical, professional and legal concerns about the linkage of census and health data. They could be used in other countries where the census or a population register contains ethnic group or race data. The findings open up new methods for researchers and health planners.

### **Stroke**

[Ethnic variations in the incidence and mortality of stroke in the Scottish Health and Ethnicity Linkage Study of 4.65 million people \(2011\)](#)

This study analysed data on almost three million people aged over 30 in April 2001. Their records in the 2001 Scottish Census, including their ethnic group, were linked anonymously to all first cases of hospitalisation or death due to stroke during seven years from 2001 to 2008. Ten ethnic minority groups were compared with White Scottish populations.

Chinese men and Other White British men and women had rates of stroke that were clearly lower than those of White Scottish men and women. Given that stroke rates are high among White Scots, the similarly high rates of stroke among Pakistani, Indian and African men and women indicate that action to prevent stroke should embrace all ethnic groups, adapted where appropriate.

### **Chest Pain and Angina**

[Ethnic variations in chest pain and angina in men and women: Scottish Ethnicity and Health Linkage Study of 4.65 million people \(2011\)](#)

This study analysed data on almost three million people aged over 30 in April 2001. Their records in the 2001 Scottish Census, including their ethnic group, were linked anonymously to all first cases of hospitalisation or death with a diagnosis of chest pain or angina during seven years from 2001 to 2008. Ten ethnic minority groups were compared with White Scottish populations.

Compared to the White Scots, Pakistani men and women were much more likely to be admitted to hospital or die with a diagnosis of chest pain or angina, whereas Chinese and Other White British men and women were less likely.

The large variations shown by this study point to the value of focusing disease prevention programmes on population groups with the greatest need, such as Pakistanis in Scotland, and carrying out further research to explain why some ethnic groups fare much better than others.

## **Cardiovascular (cntd.)**

### **Heart Failure**

#### [Ethnic variations in heart failure: Scottish Health and Ethnicity Linkage Study \(SHELS\) \(2012\)](#)

This study analysed data on almost three million people aged over 30 in April 2001. Their records in the 2001 Scottish Census, including their ethnic group, were linked anonymously to all first cases of hospitalisation or death due to heart failure during seven years from 2001 to 2008. Ten ethnic minority groups were compared with the White Scottish populations.

The Chinese men had the lowest rates, being around half that of White Scottish men. Other White British men and women also had relatively low rates. In contrast, both Pakistani men and women had higher rates than any other ethnic group studied. Once level of education was taken into account, Indian men also appeared to have relatively high rates. However, the higher rates in these ethnic groups were modest compared to those among some ethnic minorities reported in studies in other countries in Europe and North America.

### **Heart Attack by Ethnic Group**

#### [Myocardial infarction incidence and survival by ethnic group: Scottish Health and Ethnicity Linkage retrospective cohort study \(2013\)](#)

This study analysed data on almost three million people aged over 30 in April 2001. Their records in the 2001 Scottish Census including their ethnic group were linked anonymously to all hospitalisations or death due to a heart attack (acute myocardial infarction) during seven years from 2001 to 2008. Ten ethnic minority groups were compared with White Scottish men and women.

In a country where the White Scottish are renowned for high cardiovascular disease rates, Pakistani men and women had the highest rates of hospitalisation or death due to a heart attack. The lowest rates were found among Chinese men and women. Other White British and Other White groups also had relatively low rates. In contrast, death rates following a heart attack appeared lower in minority ethnic groups compared to White Scottish people, notably among Pakistani women.

Clinical care and policy should focus on reducing the risk of heart attack among Pakistanis through more direct prevention services.

## **Community engagement**

#### [Is the linkage of census and health data justified? Views from a public panel of the Scottish Health and Ethnicity Linkage Study \(2017\)](#)

Using routine health data for research that aims to improve health requires the public's awareness and trust. The Scottish Health and Ethnicity Linkage study explored variations in health between ethnic groups in Scotland. A public panel was set up to obtain their views on the SHELS' methods, findings and dissemination, including use of routine health records, linked to national Census data, without individual opt-in consent.

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 2015–16. Discussions covered the study's aims and governance; record linkage methods; data security; main findings, dissemination and publication processes.

Of 29 applicants, 19 joined the panel. Panelists were from 10 ethnic groups, 11 were females and ages ranged from 29 to 69 years. With some reservations, they enjoyed the meetings and were actively engaged. After methods and data confidentiality and security were explained, they unanimously accepted the study's use of anonymised, linked health data without individual opt-in consent. They thought explaining the complex linkage methods to the general public may be difficult and recommended researchers should be more pro-active in communicating study findings to the public, health practitioners and policy makers.

The multi-ethnic panel's support for the study methods was reassuring. Further research is recommended to identify effective methods to inform the wider public on the use of linked routine health data for research and to disseminate results more successfully.

## ***Gastrointestinal***

### **Upper Gastro-intestinal Diseases**

[Ethnic variations in upper gastrointestinal hospitalisations and deaths: the Scottish Health and Ethnicity Linkage Study \(2015\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their ethnic group. These were linked anonymously to data on all first cases of hospitalisation or death due to four important upper gastrointestinal conditions (oesophagitis, peptic ulcer disease, gallstones and pancreatitis) occurring during nine years from 2001-10. The rates of these conditions in nine ethnic minority groups were compared to the White Scottish population.

For oesophagitis, rates were relatively high among Bangladeshi women and Pakistani men and women and low among Chinese men and women. For peptic ulcer, Chinese and other South Asian men had the highest rates whereas other White British and Other White men and women had lower rates. Chinese men and Pakistani women had higher than average rates of gallstones. There were no clear differences for pancreatitis. Poorer socio-economic circumstances provided a partial explanation for the somewhat higher rates of these conditions in White Irish men and women, but not in the non-White groups.

This is the first time that ethnic variations in these diseases have been shown in the United Kingdom. They should provide a stimulus for further research to help corroborate and explain the findings and provide a basis for more effective care.

### **Lower Gastro-intestinal Diseases**

[Ethnic variations in five lower gastrointestinal diseases: Scottish Health and Ethnicity Linkage Study \(2014\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their ethnic group. These were linked anonymously to data on all first cases of hospitalisation or death due to five important lower gastrointestinal conditions (appendicitis, irritable bowel syndrome, ulcerative colitis, Crohn's disease and diverticular disease) occurring during nine years from 2001-10. The rates of these conditions in up to nine ethnic minority groups were compared to the White Scottish population.

There were many variations between ethnic groups. For example, rates of appendicitis were comparatively high among Other White British men and low in most non-White groups. For irritable bowel syndrome, rates were higher in Other White British women and lower in Pakistani women. For ulcerative colitis, rates were higher among Indian and Pakistani men. For Crohn's disease, Pakistani men had the highest rates. For diverticular disease, rates were highest in Irish men and women of any mixed background and lower in most non-White groups.

These complex variations point to real underlying differences in rates of disease rather than differences in the use of health services by different groups. They suggest that in Scotland at least, but probably other multi-ethnic societies too, clinicians and health planners cannot assume that all ethnic groups have the same needs for gastroenterology services.

### **Liver and Alcohol-Related Diseases**

[Ethnic variations in liver disease, alcoholic liver disease and alcohol-related disease hospitalisations and mortality: the Scottish Health and Ethnicity Linkage Study \(2016\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their ethnic group. These were linked anonymously to data on all first cases of hospitalisation or death due to all liver diseases, alcoholic liver disease and specific alcohol-related diseases, occurring during nine years from 2001 to 2010. The rates of these conditions in up to ten ethnic minority groups were compared to the White Scottish majority.

Substantial variations were found. For all liver diseases, Chinese men and women, Other South Asian men and Pakistani women had around 50% higher rates. Lower rates were found among men of African origin, Other White British men and women and Other White women. For alcohol-related liver disease, Indian men had a 75% higher rate whereas Other White British men and Pakistani men had about a third lower rate. For all alcohol-related diseases, White Irish men and women of any Mixed background had about twice the rate of the White Scottish people whereas Pakistani and Chinese men and women had only one third to half the rate.

This study highlights the relatively high rates of alcohol-related disease among the White Irish and White Scots compared to the Chinese and Pakistanis, whose alcohol consumption is typically much lower. High rates of liver disease among the Chinese and Pakistani groups are likely to be largely due to chronic Hepatitis B infection. Alcohol-related diseases and hepatitis B infection are both very preventable.

## **Life Expectancy**

[Life expectancy of different ethnic groups using death records linked to population census data for 4.62 million people in Scotland \(2016\)](#)

Life expectancy is a useful measure of population health but is rarely estimated for ethnic minorities. This study used data on 4.62 million people whose records in the 2001 Scottish Census included their ethnic group. They were linked anonymously to death records for the three years May 2001 to April 2004. The life expectancies from birth of eight ethnic groups were calculated using a well-established method.

Most ethnic groups had longer life expectancies than the White Scottish and none was definitely shorter. Among the females, Pakistanis were expected to live the longest, 5.2 years more than the White Scottish average of 79.4 years, closely followed by the Chinese, Indian and other White British. Among the males, Indians had the longest life expectancy, 6.2 years more than the White Scottish average of 74.7 years, with the Pakistanis and Chinese and other White British not far behind.

The longer life expectancies of the larger ethnic minorities in Scotland may reflect the poor average health of White Scottish people as much as the good health of minority groups. This highlights the scope for continuing health improvement across the whole population.

## **Maternal and Child Health**

[Ethnicity and first birth: age, smoking, delivery, gestation, weight and feeding: Scottish health and ethnicity linkage study \(2014\)](#)

This study used the 2001 Scottish Census for all females whose ethnic group was recorded, linked anonymously to the Scottish maternity and child surveillance records. 144,344 women were identified who had had a first live birth or stillbirth during seven years from 2001 to 2008. Thirteen ethnic minority groups were compared with White Scottish women.

White Scottish mothers were on average younger than other White groups and most non-White groups. They had the highest smoking rates during pregnancy (26%) compared to other groups e.g. Pakistani (4%) and Chinese (6%) and the lowest breast-feeding rates at 6-8 weeks (23%) compared with most other ethnic groups at around 40%. Babies of non-White mothers tended to have lower birth-weights. There was little variation between groups in caesarean section rates.

On average, pregnant women and nursing mothers from ethnic minority populations in Scotland have more favourable health behaviour than White Scottish women. Further exploration of the reasons for these differences could benefit women from all ethnic groups.

## **Mental health**

[Disparate patterns of hospitalisation reflect unmet needs and persistent ethnic inequalities in mental health care: the Scottish health and ethnicity linkage study \(2013\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their self-defined ethnic group. These were linked anonymously to data on all first cases of hospitalisation for any psychiatric disorder during seven years from 2001-08 and all episodes of compulsory treatment under the Mental Health (Scotland) Act 2003) during three years from 2006-09. Nine ethnic minority groups were compared to the White Scottish majority.

Compared to the White Scottish population, Other White British men and women had lower rates of hospitalisation for all psychiatric disorders combined, mood disorder, psychotic disorder, and compulsory treatment. In the Any Mixed Background group, women had higher rates for all psychiatric disorders combined, and men and women had higher rates for psychotic disorders and compulsory treatment. Indian women had lower rates for all psychiatric disorders combined. Pakistani men and women had lower rates for all psychiatric disorders combined but higher rates for mood disorders. Rates for all psychotic disorders combined were twice as high among Pakistani women. Chinese men and women had the lowest rates for all psychiatric disorders combined and mood disorder but higher rates for compulsory treatment. South Asians had higher rates of compulsory treatment. African men and women had the highest rates for psychotic disorders and relatively high rates for compulsory treatment.

This study shows varying patterns of psychiatric hospitalisation by ethnic group in Scotland, with the differences only partly explained by socio-economic circumstances. For South Asian and Chinese groups in particular, they suggest under and late utilisation of mental health services. The findings indicate the need for culturally appropriate and sensitive mental health services that will improve access for minority ethnic groups to community and specialist mental health services.

## **Primary Care**

[Pilot study linking primary care records to Census, cardiovascular hospitalisation and mortality data: feasibility, utility and potential within the Scottish Health and Ethnicity Linkage Study \(SHELS\) \(2015\)](#)

This feasibility study anonymously linked data from the 2001 Scotland Census, to the primary care records of almost 53,000 people from ten general practices and to their records for hospitalisation or death due to cardiovascular disease for seven years from 2001-08. The census data included individuals' ethnic group and the primary care records whether they smoked or had diabetes.

Over 48,000 (91%) records had a valid smoking status recorded and 2900 (5%) people had a primary care record of diabetes. Compared to the White Scottish, Other White British men and women had fewer and Pakistani men and women had more cardiovascular events, consistent with previous analyses. The rates of smoking and diabetes helped explain some of these differences.

It proved difficult to enrol practices and extract the data from primary care records. However, the resulting data were of good quality and were successfully linked to the census and other health records. This pilot study shows the potential value of linking primary care records to other health datasets at a national level, thereby offering opportunities for public health and further research.

## **Respiratory**

### **Lower respiratory tract infections**

#### [Ethnic variations in morbidity and mortality from lower respiratory tract infections: a retrospective cohort study \(2015\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their ethnic group. These were linked anonymously to data on all first cases of hospitalisation or death due to lower respiratory tract infections, pneumonia and influenza occurring during nine years from 2001 to 2010. Ten ethnic minority groups were compared to the White Scottish majority.

Substantial differences in the rates of lower respiratory tract infections and pneumonia were found between different ethnic groups in Scotland. Compared to White Scottish people, Other White British and Chinese males and females had lower rates but Pakistani and Other South Asian males and females had higher rates. Only Pakistani males and females had higher rates for influenza, but the number of cases was too small to rule out differences among some other groups. The reasons behind these differences require further investigation.

### **Respiratory hospitalisation and death**

#### [Risk of respiratory hospitalisation and death, readmission and subsequent mortality: Scottish health and ethnicity linkage study \(2015\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their self-defined ethnic group. These were linked anonymously to data on all first cases of hospitalisation or death due all respiratory diseases among all ages occurring during nine years from 2001 to 2010. A subset of cases of chronic obstructive pulmonary disease (COPD) among people aged over 40 was also analysed. Nine ethnic minority groups were compared to the White Scottish majority.

Compared to the White Scots, rates for all respiratory diseases combined were low among Chinese men and women and Other White British men but high in Pakistani and Other South Asian men and women. Rates for COPD were higher among White Irish, Other White and Any Mixed Background men, and White Irish and any Mixed Background women, while Indian men and Chinese women had low rates. While the differences for COPD may reflect patterns of smoking, the variations for all respiratory disorders combined are complex and not easily explained. In most non-White groups, death rates following hospitalization and readmission were similar to or lower than the White Scottish population, suggesting that service provision for ethnic minorities is probably equitable.

### **Asthma**

#### [Ethnic variations in risk of asthma hospital admission, readmission and death: retrospective, national cohort study of 4.62 million people in Scotland \(2016\)](#)

This study analysed data on 4.6 million people whose records in the 2001 Scottish Census included their ethnic group. They were linked anonymously to data on hospitalisations or death due to asthma, and readmission or death after the first admission, occurring during nine years from 2001 to 2010. Ten ethnic minority groups were compared to the White Scottish population.

There were substantial ethnic variations in the rate of hospitalisation or death in both males and females. When compared to the White Scottish population, the highest rates were in Pakistani males and females and Indian males. The lowest were seen in Chinese males and females. Only males from Any Mixed Background were more likely than the White Scots to be readmitted.

Cultural factors, including self-management and health seeking behaviours, and variations in the quality of primary care provision are the most likely explanations for these differences. Targeted lifestyle and medical interventions in primary care may help reduce such risks.