

Using Name Analysis to Achieve Health Outcomes for CALD Communities

Michael Dove*, OriginsInfo, Australia

Abstract

Research linking cultural origin and health outcomes both between countries and within countries is well documented in the literature. Despite this, many health researchers and service providers do not have access to data on cultural origin, either because of constraints due to privacy or practicality, or because the data that is available is misleading or incomplete.

Onomastic (origin of names) research has demonstrated an acceptable link between the analysis of names and the inference of cultural origin. Consequently, it is now possible to build reliable profiles using nothing more than patients' names, to reveal cultural skews in the incidence of health episodes and servicing.

This advance makes it possible to develop culturally-appropriate and better-targeted communication programs and this paper briefly describes three UK cases where such an approach has enabled more effective health care management and service delivery. The conference presentation concludes with reference to two health-related applications in Australia that are currently under development.

The link between cultural origin and health

Extensive literature has documented the differences in health outcomes for different cultural groups both between and within countries (Smedley et al, 2003; London Health Observatory, 2005; Tilbury et al, 2004). Some of these differences, such as sickle cell anaemia or particular strains of tuberculosis, which are the consequence of genetic differences, require that patients from particular backgrounds are identified so their risk can be minimised.

Others, such as diabetes or differences in rates of heart disease, may be attributable to diet or lifestyle. In these cases it may be more appropriate to use communications targeted more generally at that community to promote awareness of risk and the opportunity for early diagnosis or behavioural change.

The special challenge of multiple disadvantage experienced by Australia's indigenous population, and the resultant significantly lower life expectancy, has received wide media coverage in the past few weeks and has become the focus of a range of initiatives from the new government.

Further, there is no doubt that many other differences in health outcomes are the result of cultural practices and attitudes. Sometimes these can take the form of a lack of knowledge

arising from poor understanding of English. At other times anxiety or mistrust may generate reluctance to attend screening centres or respond to public health campaigns.

The need for reliable data

Increasingly, effective management and service delivery to members of CALD communities requires reliable data about cultural origin if there are to be improvements in outcomes. Better access and equity can only be achieved with careful targeting of resources to the communities in greatest need.

To a point, census data is very good at providing an area-based perspective for communities as small as a collection district – although at this level, small counts in categories of interest, and the resultant randomisation (to ensure confidentiality) can be misleading.

But the real opportunity for efficiency and effectiveness lies with person-level data that does not compromise individual privacy.

Some health organisations in Australia collect data on country of birth or preferred language as surrogate indicators of cultural origin including, for example, many Accident and Emergency (A&E) departments of hospitals. However, it is noteworthy that the Medicare enrolment forms do not require place of birth, and even the declaration of Aboriginal or Torres Strait Islander status is voluntary.

Apart from issues of non-completion or inaccuracy (Totikidis, 2003, p 69), country of birth and language data may be an insufficient or misleading indicator of cultural origin. In an age of far greater population mobility, birthplace often bears little relation to cultural origin.

As an example, Australia's refugee population may have relocated to several intermediate countries over a period of many years with childbirth occurring along the way. And of course, place of birth for young members of CALD communities may be correctly recorded as within Australia, but this is an unhelpful indicator of cultural background in terms of understanding health risks and culturally-based resistance to participation in health management and screening programs.

Many health records have no information about cultural origin at all. For example, the cervical cancer screening registers record only name, date of test, and result of test. This means it is difficult to establish quantified evidence that cultural background is a significant driver of participation rates even though there may be strong anecdotal suspicion that this is the case.

The absence, or unreliability, of data on the cultural origin of patients, frustrates the efforts for effective delivery of services. It makes it difficult for health promotion staff to present evidence that quantifies the extent to which specific CALD groups should be the subject of particular campaigns. It also makes it difficult to evaluate how effective these campaigns have been in reaching these groups.

The use of names as a surrogate

In the United States and in the United Kingdom several medical research studies have built on the association between names and cultural origin. The intent is to examine the relationship between cultural origin and medical outcomes. These studies have mostly focused on the identification of names from an individual ethnic group, typically one with a high proportion of the immigrant population, or from a global region. These studies have historically concentrated on the identification of names from South India, from Spain and Hispanic America, and from East Asia.

US tables relating names to ethnic groups have typically relied on information sourced from pre-1997 government immigration registers. In the UK, such tables have been constructed using information collected by local authorities or, in the case of SANGRA, using expert knowledge of members of the community whose names were being studied (Nanchahal, 2001).

To address the needs of research and to enable social marketing campaigns targeted to individuals from all CALD communities, a UK commercial company, drawing on work at University College, London, has compiled a set of reference tables, currently containing 1.28m different family names and 0.48m personal names. These tables are derived from two main sources. Firstly, a mix of public and commercially available registers from the major migrant-destination countries (including Australia), and secondly, from in-depth research into all other major regions, countries and cultures from the rest of the world (Lloyd et al, 2006; Webber, 2007).

These names have been classified into more than 200 cultural types that reflect a range of cultural dimensions – geographic, ethnicity, religion, language. Each type is based on the predominant, or defining, cultural characteristics and many of the types are defined by a combination of dimensions. For example, Muslim religious culture is often more useful than a specific country of origin, and whether a person is a Mandarin or Cantonese speaker is often a better indicator than just simply Chinese. Analysis and research by the developers have determined the distinctive association between name and cultural origin.

To make the best inference of the origin of a name it is necessary to take account of both the personal name and the family name and, of particular significance in the Australian context, to ensure that the tool reflects the population profile where it is being used (Dove and Webber, 2007). The assessment of the name combination, along with the use of a confidence score, helps overcome some shortcomings such as cross-cultural marriages where, in most western cultures, the female partner adopts the family name of the male partner.

A further feature for use of this tool in Australia allows a stronger weight to be applied to, for example, Asian family names, compensating for the tendency of many East and South East Asians to adopt Anglo-Celtic personal names – eg Penny Wong.

A clear application of name recognition and cultural classification is for analysis of a database to research, identify, and quantify any notable skews. This, in turn, enables appropriate and effective social marketing opportunities through the targeting of appropriately designed communication pieces (Nancarrow et al, 2007). This innovative tool formed the basis of three health-related applications reported as follows.

Application A – Reducing A&E attendance in Tower Hamlets (Dr Foster Intelligence, 2006b)

The first initiative was managed by Dr Foster Intelligence, a UK public-private partnership providing health and social care research and social marketing services. It focuses on the Tower Hamlets Primary Care Trust (PCT). Tower Hamlets PCT is a primary care administrative body responsible for the service delivery and population health within the Tower Hamlets area of East London.

The Royal London Hospital in Tower Hamlets had been experiencing increasing demand for its Accident & Emergency (A&E) services and staff members at the hospital observed that many of their patients arrived with minor ailments better suited to GP or pharmacy treatment. The anecdotal evidence needed more substance to justify funding for a cost-effective and measurable campaign.

The name analysis tool quantified the incidence of inappropriate use of Accident & Emergency (A&E) facilities by members of the Bangladeshi community who appeared to bypass the use of local GPs. Data was analysed from 200,838 individual attendance records at the Royal London's A&E department from January 2004 to January 2006. Some 54,866 attendances were from multiple attendees.

The target audience was identified as:

- Of Bangladeshi origin, age groups 20-30 and 0-4, both males and females
- Bengali/Sylheti and English speaking

This definition of the target group led to some questions to be addressed through in-depth qualitative research to understand the attitudes and perceptions that led to this behaviour -

- Why did people attend A&E for minor ailments?
- Why were other primary care services by-passed?

Young Bangladeshi adults were invited to participate in focus groups to help answer these questions. It was found that parents and grandparents were the main influence in shaping attitudes towards health and illness. Patients of Bangladeshi origin, including those born and raised in the UK, take minor symptoms very seriously. In Bangladesh, even a stomach ache could well be life-threatening.

Expectations of how a doctor should behave are formed in the same way. In Bangladesh, it is customary for doctors to perform a full health check when a patient visits and medicine is always prescribed. When Bangladeshi patients went to see their GP in Tower Hamlets they were unimpressed with the informality (no white coats) and the service that they received (“He didn’t even get his stethoscope out!” and medicines were often not prescribed) and so they chose instead to go to A&E where they were likely to have a more thorough examination.

To enrich the qualitative findings, A&E staff members were interviewed. They felt that there was not enough information available about health and illness for the Bangladeshi community, including advice about where, when and how they should seek help and advice.

The combined evidence justified investment in a multi-dimensional campaign involving peer education, local area marketing, and some operational change within service providers. The campaign was called ‘Local Heroes’ and was scheduled for September 2006 with the intent to compare outcomes with September 2005.

The timing was significant as it was particularly important to engage with local religious leaders before the end of September because the beginning of Ramadan offered greater opportunities to spread the health messages within their communities.

The campaign aimed to

- Reduce inappropriate attendances at A&E
- Promoting the use of services such as those provided by GPs and pharmacies
- Deliver a social marketing campaign that emphasised the benefits of behavioural change without making any part of the community feel stigmatised or victimised

The PCT recognised that it needed to employ a mix of interventions to promote behavioural change. An innovative social marketing program was developed to complement methods that were more traditional. The program identified and targeted segments of the population with specially designed materials delivered through a variety of media.

The ‘Local Heroes’ campaign used a variety of interventions including:

- Direct mail from GP practices to the target audience
- A street stall in the nearby Whitechapel market for two weeks using health guides and community advocates
- A poster and leaflet campaign
- ‘Tea and talk’ training sessions for health professionals

To promote behaviour change without stigmatising any community groups, the following elements featured

- The launch event was attended by a senior public figure from the Bangladeshi community – Baroness Uddin

- A DJ from a community radio station, Club Asia, acted as compere for the event
- Club Asia promoted the campaign
- Engagement sessions involving local GPs were held at several local religious and community organisations
- Primary care centres supported and agreed to ongoing reinforcement of campaign messages by keeping posters and leaflets on display
- A high-profile PR campaign ensured that the Local Heroes message featured in a number of local publications, including Potrika, East End Life, Tower Hamlets Recorder and the East London Advertiser

The campaign design ensured a proper evaluation to measure behavioural change. The evaluative tools used included:

- Comparison of GP registrations and visits
- Monitoring A&E attendance at Royal London and other nearby hospitals
- Benchmarking with similar data from previous years
- Pre- and post-campaign questionnaire on attitudes and awareness

The campaign was independently evaluated and in summary showed that:

- There was a decline of 6.4% in total number of attendances at A&E at the Royal London Hospital between September 2005 and January 2006, and the same period in 2006/07
- Two neighbouring hospitals reported increases in A&E attendance of 3.6% and 2.6% between the two sample periods
- The difference in A&E attendances between the two reporting periods for the 20 to 29 age group was -0.4% for males and -11.1% for females
- There was a steady increase in pharmacy consultations; the PCT acknowledges the contribution of the Local Heroes campaign to this trend
- The number of males aged 20-29 using GPs has risen between 2005 and 2006, with two practices within the campaign catchment area reporting increases of 8% and 16%

Elements of this campaign that can transfer elsewhere include:

- Understanding the issues through coordinated quantitative and qualitative analysis
- Understanding and involving local communities through a complete engagement program
- Developing a multi-sectoral approach drawing on the talents of experts

- Rigorous evaluation

With the cost to the health service of an A&E attendance between A\$130 and A\$250, the financial imperative of reducing unnecessary attendances at A&E is clear. Lessons from this campaign if adopted elsewhere could make a significant long term contribution to the delivery of more effective and efficient health care and promote a better experience for CALD communities.

Application B – Tuberculosis (Evans, 2007, 2008)

Since 2004, the Health Protection Agency based in Birmingham, UK, has been responsible for a DNA fingerprinting methodology (MIRU-VNTR typing) of all *Mycobacterium tuberculosis* isolates (TB strains) in the UK Midlands.

The aim of their work is to detect unknown clusters, to identify the predominant groups to which these isolates belong, and to analyse and compare the predominant tuberculosis patient populations.

Significant associations between clades (groups of isolates) and patient populations were identified using odds ratios, a standard epidemiological measure of infection rates.

TB infection rates for the focus regions are shown in Figure 1 although within the combined East and West Midlands regions, the cities of Derby, Leicester, Oldbury/Smethwick and Birmingham have rates above 40 per 100,000 population.

Region	Rate per 100,000 population – 2006	Average Rate per 100,000 population 1982-2006
England and Wales	14.2	12.0
West Midlands	18.6	15.0
East Midlands	8.9	10.7

Figure 1 – TB Infection Rates for Selected Regions

Source: Statutory Notifications of Infectious Diseases; Office for National Statistics mid-year population estimates. Data prepared by TB Section, Health Protection Agency

Comparisons between UK-born and non-UK born provided significant evidence of variation between these two groups, as shown in Figure 2.

Year	Non-UK Born	UK Born
2000	78.2	4.0
2001	80.4	4.3

2002	89.7	4.1
2003	92.2	3.9
2004	96.2	4.1
2005	103.3	4.2

Figure 2 – TB Infection Rates – Non-UK Born and UK Born

Source: Statutory Notifications of Infectious Diseases; Office for National Statistics mid-year population estimates. Data prepared by TB Section, Health Protection Agency

A method known as genomic deletion analysis aimed to locate the prevalent clades (groups of isolates) across the range of TB strains. Two prevalent clades were detected and identified as 42235 and 32333. The 42235 clade was associated with non-respiratory, smear-negative specimens from patients originating from the Indian Sub-Continent, whereas the 32333 clade was associated with respiratory, smear-positive specimens from patients aged under 45 of European origin.

Deletion analysis placed the 42235 (Central Asian strain) clade in the East African-Indian group and 32333 (Haarlem strain) in the Euro-American lineage (Hawkey et al, 2003).

These observations prompted further drill down into the cultural origin of patients found with these strains. Name recognition analysis using Origins was used to identify cultural background based on the patients' personal and family names.

The software tool offered a major advantage over country of birth data in that it was able to classify those people who were born in the UK, but whose genetic composition was clearly determined by ancestry. The outcomes of this further analysis revealed the differences identified in Figure 3.

Origins Types (Summarised)	32333 (Haarlem isolates)	42235 (Central Asian isolates)
Afghanistan	0	3*
Bangladesh	7	55*
India	35	244*
Pakistan	36	244*
England	231*	79
Ireland	25*	13
Northern Ireland	4*	0
Scotland	21*	4
Wales	29*	7

*OR ≥1.00, 95% CI ≥1.00

Figure 3 – TB Isolates 32333 and 42235 – Origins Case Analysis

The outcomes of this research can begin to inform public health control strategies and be used to target communication and management resources at specific groups at greatest risk of contracting particular strains of TB. There is an opportunity to use the name recognition approach and apply it to public registers. Communications can proactively promote participation in screening programs or other risk mitigation initiatives.

Application C – Polish migrants in Telford (Leaman et al, 2006)

This case also focuses on the management of A&E attendance to re-direct inappropriate users to more suitable service providers.

Princess Royal Hospital is a key provider of health and emergency services in the West Midlands of England. Unemployment is low and the area is an attractive centre for willing, relatively low-cost labour from the European Union (EU). During 2005, staff noticed that increasing numbers of patients of Polish origin were attending the A&E department, and, as with Tower Hamlets PCT, they often presented with conditions that could be more appropriately treated by GPs. This increase seemed to be associated with the accession of Poland to the EU in May 2004.

No record of ethnicity had been kept by the hospital. However names were accessible for all patients who had attended the emergency department since 2000. Analysing the frequency of patients with Polish names between 2000 and 2005, it was clear that the anecdotal observation of increasing numbers was supported by evidence. While the numbers of persons attending with a Polish name had remained fairly constant prior to 2004, the numbers of such patients increased a little during 2004, but dramatically so during 2005.

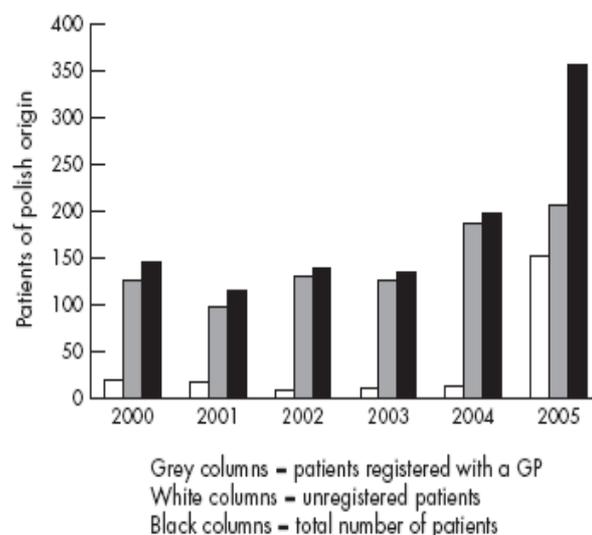


Figure 4 – Annual Attendances at the Emergency Department by Patients of Polish Origin

Of the 357 patients in 2005, 152 (43%) were not registered with a GP; this compares with a departmental norm of 7.4%. Further analysis of a sample of 90 of these patients, showed that

more than half experienced communication difficulties and two out of five presented with conditions that could have been treated by a GP. The communication difficulties contributed to a poor experience both for patients and for those responsible for service delivery.

Based on the quantitative and qualitative research, recommendations addressed the following areas:

- Providing in-language advice to migrant workers about the National Health Service (NHS)
- Include advice to attend A&E and other services with an English language speaker so that the quality of care is not compromised by poor communication
- Drawing migrants attention to the differences between conditions that are best dealt with by GPs, where they can be treated as a temporary resident
- Highlighting the criteria to be applied for attendance at the emergency department of a hospital.

As in the previous applications, patients of Polish origin were classified by software that assigns cultural origin to a patient's personal and family name.

Conclusion

In cases where there is no data on cultural origin, tools now exist to support analysis and quantification of the cultural dimension in medical research, health promotion, and service delivery. It is now possible to create social marketing campaigns that will enable better constructed and better targeted communications to promote behavioural change or deliver better outcomes for CALD communities.

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