Care.data, consent, and confidentiality

The UK Government is implementing an opt-out consent system for its care.data scheme to share patients’ health-care records with private companies. This choice is too crude in view of patients’ differing levels of trust towards various types of institution, and the differing sensitivity of various types of medical data.

Patients generally trust the NHS to use their data for research. By comparison, universities and other independent research institutes are somewhat less trusted as data-sharing partners, and private companies are regarded with some suspicion. Care.data’s all or nothing opt-out system is entirely inappropriate in this context. There might be hundreds of thousands of patients who would happily have their data shared within the NHS and universities, but not with anyone else. However, under the care.data scheme, if they object to any part of the scheme, they have to opt out of all data sharing.

A similar problem arises in terms of the different types of medical data. Here too research has shown that the public are generally happy for most of their medical records to be shared, but many would prefer certain sensitive data to remain only within their records and not be shared. For example, someone might be happy sharing routine medical data, but not anything relating to mental health problems. Again, under the care.data scheme, data sharing is all or nothing: anyone who wants to stop specific data being shared must opt out of all data sharing.

Care.data’s opt-out system will ultimately have a negative synergistic effect on the amount of data that will be shared. Anyone who objects to sharing data outside the NHS, or to sharing certain types of data will have to opt out of sharing any information with anyone. Furthermore, patients who really want to facilitate research and future patient care by sharing their data might be coerced into not opting out, because the only way they can share the data they want to is to also share the data they don’t want to, and with companies that they do not trust.

A sensible solution would be to have a sensitive and specific opt-out system, where patients can select which types of data they want to share, and with whom. Such a system might be more expensive, but the cost would surely be justified in view of the government’s purported support for patient choice.

I declare that I have no competing interests.

David Shaw
david.shaw@unibas.ch
Institute for Biomedical Ethics, University of Basel, Basel 4056, Switzerland


Global burden of stroke: an underestimate

The global burden of stroke outlined by Valery Feigin and colleagues’ Article (Jan 18, p 245) is likely to be a substantial underestimation in view of the consequences of stroke disease on conditions other than acute stroke, which substantially affect health and wellbeing. Over and occult cerebrovascular disease, both large and small vessel, have been recognised to contribute to Alzheimer’s disease and vascular dementia.

Less generally acknowledged is the role of cerebrovascular disease in a range of other conditions including gait disorders, depression, and oropharyngeal dysphagia, particularly in older people. Inclusion of these endpoints in strategies for stroke prevention not only adds to the urgency and impetus for their implementation, but will also provide a multiplier for the health benefits of such programmes.

I declare that I have no competing interests.

Desmond O’Neill
doneill@tcd.ie
Trinity College Dublin, Dublin 2, Ireland


Authors’ reply

We are pleased to respond to Desmond O’Neill’s comments on our paper about the global burden of stroke. We fully agree that the burden of stroke goes far beyond the reported data on incidence, prevalence, mortality, and disability-adjusted life-years. Stroke also has a large physical, psychological, and financial effect on patients, their families, the health-care system, and society. Cognitive outcomes, occurring in nearly half of survivors, are important, but often ignored outcomes of stroke. Additionally, as rightly emphasised by O’Neill, stroke is just one of the many manifestations (although the most catastrophic) of cerebrovascular disease, and there are clinically silent minor strokes and occult cerebrovascular disorders that contribute to the development of various non-fatal sequelae, including dementia, and mood and gait disorders. Consideration of these consequences of stroke is important, not only for a more accurate estimation of stroke burden, but also...
for addressing multiple risk factors to develop prevention strategies for all major consequences of stroke.

We agree with O’Neill that current estimates of the global burden of stroke do underestimate the true stroke burden. The Global Burden of Diseases (GBD) analysis included calculating disability for over 300 causes including stroke. First, for example, dementia is a separate cause in the GBD analysis, and its burden is accounted for within this single cause example. Secondly, the dominant paradigm used in the GBD analysis is that of categorical attribution where mortality, morbidity, and eventually burden is attributed to only one cause, in this case stroke. An alternative is the counterfactual notion in which consequences relevant to stroke such as dementia, Parkinson’s disease, and cognitive dysfunction are accounted for by calculating the total burden for a single cause. Although the idea of estimating effects by the counterfactual approach is very appealing, there are not much data for all aspects of interaction between different causes to make this possible. Therefore, estimating other aspects of the stroke burden was beyond the scope of our paper.

We declare that we have no competing interests.

The views expressed are those of the authors and do not necessarily represent the views of the National Heart, Lung, and Blood Institute, National Institutes of Health, or the US Department of Health and Human Services.

*Valery L Feigin, Mohammad H Forouzanfar, Rita Krishnamurthi, George A Mensah valery.feigin@aut.ac.nz

National Institute for Stroke and Applied Neurosciences, School of Rehabilitation and Occupation Studies, School of Public Health and Psychosocial Studies, Faculty of Health and Environmental Studies, Auckland University of Technology University, Auckland 1142, New Zealand (VLF, RK); Institute for Health Metrics and Evaluation, Department of Global Health, University of Washington, Seattle, WA, USA (MHF); and Center for Translation Research and Implementation Science, National Institutes of Health, Heart, Lung, and Blood Institute, Bethesda, MD, USA (GAM)


Health of Palestinians and chronic humiliation

In their abstract for the 2013 Lancet Palestinian Health Alliance, Brian Barber and colleagues are not maintaining “the highest scientific standards” by insinuating that the strong presence of Israeli forces at checkpoints and barriers explains the chronic humiliation suffered by Palestinians in the West Bank.

The two intifadas (uprisings), consisted of 10 years of murderous terror campaigns against Israeli civilians, which resulted in increased vigilance at the borders between areas under full Israeli control and areas under the jurisdiction of the Palestinian Authority. Amnesty International publishes two separate reports annually on political violence in the West Bank and Gaza. One deals with the actions of Israel, the other with the actions of the Palestinian Authority. The latter describes extreme political violence on the part of the Palestinian Authority during the periods that Barber and colleagues discuss. For example, during the second intifada the report describes “a situation where groups of armed Palestinians had almost free rein to carry out unlawful killings and other abuses.” In September, 2013, Amnesty International demanded that the Palestinian Authority’s police and security forces “cease using unnecessary and excessive force” against peaceful protesters. Furthermore, gender-based violence against women and girls, in the form of honour killings and domestic violence, continues to be reported in the Amnesty International annual reports on the Palestinian Authority; however, there are no such accounts in the reports on Israeli actions.

Barber and colleagues do not help the Palestinians by ignoring political violence at the hands of their own governments.

I declare that I have no competing interests.

Janice Halpern
Janice.halpern@utoronto.ca

Department of Psychiatry, University of Toronto, Toronto, ON M5R1V2, Canada


Authors’ reply

We do not agree with Janice Halpern’s concerns about our study on the effects of chronic exposure to humiliation on wellbeing in the occupied Palestinian territory (oPt). Halpern’s assertion that we “are not maintaining the highest scientific standards by insinuating that the strong presence of Israeli forces at checkpoints and barriers explains the chronic humiliation suffered by Palestinians in the West Bank” refers to the final sentence of the Findings section, which mentions