

Privacy or public good?

Why not obtaining consent may be best practice

Using medical and other data from private citizens without obtaining the consent of those citizens has been a taboo of statisticians and of society. The right to privacy is infringed; the right to confidentiality is abused. Here **Fiona Stanley** argues that, far from being unethical, using data without consent may be morally justified, and not using it may be a failure of duty.

In the late 20th century, scholars and politicians posed a key question: "What desires and needs do you have as an autonomous rights-bearing person to privacy, liberty and free enterprise?" Now it is important to ask another kind of question: "What kind of community do you want and deserve to live in, and what personal interests are you willing to forgo to achieve a good and healthy society?"¹

Introduction

Major problems affecting children and youth in Australia seem to be on the increase². These are not just health problems such as obesity and mental illness, but other "wicked" problems as well. "Wicked" problems are ones with no simple causes and no easy answers (see Box 1). Modern societies are challenged by many such problems. They are complex in causation, there are few effective treatments and they cross several agencies and professional groups in the responses

needed to address them. They are also extremely costly³.

"Wicked" problems demand the best data to measure them, to guide policy frameworks, and to evaluate whether what is being done is actually making a difference.

Psycho-social and behavioural problems among youths, risk taking (including substance abuse – particularly of alcohol), school failure, child maltreatment and juvenile crime (particularly in girls) are all problems that can be described as "wicked" and that we face in Australia as in the rest of the world. This range of child and youth problems is the focus of our research at the Telethon Institute for Child Health Research (www.ichr.uwa.edu.au). They are the focus also of a national alliance of agencies (the Australian Research Alliance for Children and Youth; www.aracy.org.au) that we have established to encourage effective policies in such areas, and their implementation.

On the whole the agencies' response to these very challenging issues has been a crisis

response. It has focused excessively on the ends of pathways, where most of these problems are harder to manage or treat and success in avoiding harm or damage is less likely. Weaning teenagers off drugs, for example, is harder than steering them clear of trying drugs in the first place. And by the time you are trying to "cure" a drug habit, the damage has already been done.

In spite of this, the agencies attempt to measure their massive investments in these areas by analysing trends in their occurrence. We are agitating for a paradigm shift. Agencies must of course provide effective services for those already harmed; but they need to appreciate that these problems demand a preventative approach as well. Most pathways to juvenile crime begin in early childhood or even in the womb, or through environments that span generations. An example is foetal alcohol syndrome and its consequences. It is the leading known cause of non-genetic mental handicap in the western world. Here solutions are more likely to come from agencies other than the traditional ones dealing with the end stage problems – the handicapped child – and from more than one agency working together. It is a problem best solved by prevention.

If prevention needs joined-up thinking from agencies, perhaps we could ease this paradigm shift by joining up data? Linking health data without consent is contentious enough – a modern taboo for statisticians. What about linking also such sensitive information as disability, child maltreatment, education, police and justice records? Privacy campaigners will shout loudly; knowledge about our personal lives equates to power; the media raise the spectre of an all-controlling state.

Box 1. Wicked problems

- Are socially complex, with multiple layers of stakeholders
- Are difficult to clearly define, and there is often disagreement about the cause
- Have no clear or correct solution
- Are interdependent and have many contributing causes
- Defy conventional approaches to problem-solving
- Are cross-cutting, do not fit into organisational boundaries

"Wicked" social problems include substance abuse, teenage pregnancy, domestic violence, complex diseases such as obesity and diabetes and juvenile crime. Climate change and environmental degradation are wicked problems too.

At a time when people appear to be more anxious about whether their personal information is being collected, used, and even linked, I believe that the solutions to many of the wicked problems facing society may come from making such data more available. I will argue, I hope convincingly, that linking medical and other data without express consent of the subject is actually best practice. In relation to individual data, debates about invasion of privacy and whatever harm that may cause rarely mention the public good which emerges from such activity. I believe that the

public good can outweigh the individual harm. I believe that our own example demonstrates this.

So here I describe a system of population-wide data linkage, without consent, developed over more than 30 years in Western Australia to study developmental pathways into “wicked” problems. The data thus linked have informed policy; they have enabled epidemiological and health and social services research. The results have helped vulnerable children in real and demonstrable ways. The harm, from invasion of privacy, has been close to zero.

The Western Australia data linkage system

We have used population health data including registers for more than 30 years in Western Australia⁴. Linkages are done regularly and routinely between all births, midwives’ notifications, hospitalisations, deaths, mental health services and our total population registers of birth defects, cerebral palsies, intellectual disabilities, autism and cancers.

These data are either statutory collections, agency data or special population registration of cases of diseases or problems. All are collected, without consent, under national and state-based guidelines, to enable monitoring and research in public health and health services⁵.

Our Institute, the Telethon Institute for Child Health Research, has a paediatric interest; other groups concentrate more on adult diseases and services^{6,7}. These linked studies have led to a large number of epidemiological and health services projects to investigate causes, suggest preventive and other strategies, evaluate medical care and suggest policy frameworks⁸⁻¹¹.

The linking of population data offers a number of important advantages compared with other research designs:

1. It is relatively cheap: it uses existing and available data.
2. It captures the total population, including those at highest risk or with characteristics that make them least likely to participate in, or to be included in, surveys, cohort studies and randomised controlled trials. Thus biased participation, and loss to follow-up, are avoided.
3. By including the total population, there is usually adequate statistical power for robust analyses.
4. By including all birth cohorts, it allows investigation of the effects of changes over time in family, societal and environmental factors (compared with single birth cohort studies).
5. It provides the basis for research and policy evaluation across all groups in the population.
6. It allows analyses of sensitive information which is hard to collect through survey methods, or indeed any other way. Mental health, child maltreatment, criminal behaviour, drug use and termination of pregnancy are examples.

In addition to these population data, our Institute engages in a range of other epidemiological studies such as population surveys, case-control and cohort studies and randomised controlled trials. All of these are done with full consent, and for all the studies done since the late 1990s, we have sought permission (and received it in well over 95% of cases) to link these studies into the population data.



Use data without consent – or abandon effective ways to help her? © iStockphoto.com/Stockphoto4u

These other studies and their linkages enable us to embed them in a total population sample. This lets us test their generalisability and investigate and measure participation bias. They also provide many opportunities to validate a range of variables in the population data such as diagnostic, demographic and ethnic information. The population data linkage expands the capacity of the sample surveys and cohort studies, converting the former into quasi-longitudinal studies, and in the latter providing some information on those lost to follow-up. As the information available in the total population agency data is limited, these linkages to in-depth studies enable better interpretation and analysis of the developmental pathways of interest.

Extending Health Data Linkage to Educational and Welfare Agency Data

The Institute, in collaboration with several government agencies, applied for a research grant to extend our extensive population health data to enable still wider linkage across agencies for a range of developmental and behavioural problems. The overall aim was to enable more “joined-up” or “integrated” or “whole-of-government” thinking about the costly and anguishing issues affecting children and youth. The Developmental Pathways Project has now been in place for five years. Box 2 shows the agencies and partners involved. As can be seen, they span the widest possible range. This novel project has had remarkable success. We have managed to obtain and link data from all agencies listed; we have engaged with them to ensure that the projects serve their policy needs and questions – in short, we have developed a system of governance that enables excellent interactions between the agen-

cies and the custodians of data, the heads of the agencies, the head of Treasury, the researchers, the data linkage unit, and the PhD students who did much of the work. A new aspect is that the students (of whom three have completed their PhD and five are in the process of doing so) were co-supervised by both academic and policy experts. This meant that, in addition to the various committees set up to link the researchers and the agencies, each project had dedicated policy input guiding it throughout. Hence, not only did the students produce publications for scholarly journals^{12–14} but they also helped to write policy briefs, presented to agency staff and conducted additional analyses specifically to serve a policy agenda.

The major aim of the project – to encourage connected or joined-up thinking – was also achieved. The heads of all the partner government agencies attend two meetings a year to decide on priority projects. The list demonstrates that the agency heads are already thinking across departmental silos, suggesting projects that appreciate the cross-agency data linkages and the developmental aspects of pathways – prevention is already high on their agendas. The leadership from the head of Treasury was key to engaging all the heads of the other agencies.

Data linkage process: protecting privacy while enabling access to sensitive linked information

The linking of population data in Western Australia is done by an independent Data Linkage Unit whose staff have developed the methods over many years as best practice to protect privacy and ensure confidentiality^{15,16}. The researchers develop their projects, usually in close consultation with data custodians (e.g. health agencies, register personnel), obtain funding for the project and seek approval from the Ethics Committee. Linkage of individual identifiers is done by the Linkage Unit, but without any of the sensitive data attached. Links are then returned to the custodians who provide a de-identified linked data file to the researchers. Thus no one ever sees both the identifiers and the sensitive information of these linked data projects. There is no one big linked file of data, but all data are linkable and linked for each specific project.

Probabilistic linkage is used and results in high proportions of successful linkages, with detailed checking of those that do not link. There are legitimate reasons for non-linkage including families moving in to or out of the state.

Why not seeking consent is best practice for population data linkage: avoiding bias

This linkage is all done without the consent of the individuals whose data are being used; and

register data are also collected without consent. The reasons for this relate to scientific rigour and costs on the one hand, and to the negligible risk of harm on the other. To seek consent for such data collection and linkage would result in incomplete data and bias – not because people would refuse to participate (in fact when we do seek consent to link in our studies, well over 95% agree) but because we do not know where they are. It would be prohibitively costly to seek written or verbal consent from the whole population.

Failure to locate people (or their relatives if they have died), has been shown in many epidemiological studies to be potentially much more common than refusal to participate^{17,18}. Major biases arise from failure to locate, as people who are mobile tend to be different in terms of risk of disease or poor outcome and to have different risk and protective factor profiles than those who are more easily traced. The analyses can thus result in significant error.

A significant difference in health behaviours and health status between responders and non-responders has been demonstrated¹⁸. The magnitude and direction of bias resulting from non-participation in studies is unpredictable and mostly unquantifiable, as in most studies data are only available on those who participate, not on those who do not. The main concern is that participation that is not randomly distributed results in biases that cannot be accurately predetermined, which has implications even for studies with high participation (for example, if all those who do not respond are the most severely ill or dead).

The Registry of the Canadian Stroke Network was severely compromised by the requirement, in some jurisdictions, to obtain written informed consent prior to registration¹⁸. The result was a rate of consent of just 44% of eligible patients. Those who participated had an in-hospital mortality rate of 6.9% compared with 21% for eligible patients who were not enrolled – a relative risk of in-hospital death of 3.13 (95% confidence interval 2.65–3.70) for non-participants compared to participants! Thus the sample enrolled in the national register was so biased as to make accurate description of natural history of stroke, evaluation of care, or monitoring quite impossible. It was abandoned. This occurred in spite of employing neurological research nurse coordinators to deal with consent-related issues at a cost of C\$500,000. This considerable financial investment still did not overcome the poor rate of participation and resulting biases.

The Canadian experience is not unique. In the United Kingdom consent for inclusion on a Paediatric Intensive Care Audit Network (PICANet) database was obtained for only 43% of children, while in the United States Melton describes the Mayo Clinic experience of being forced to seek consent after 100 years of linking and analysing 5.1 million patient records to evaluate and

Box 2. Developmental Pathways Project Agencies and Partners

- Telethon Institute for Child Health Research
- Crime Research Centre at the University of Western Australia
- Department of Health
- Department for Child Protection
- Department for Communities (Office for Youth)
- Department of Education and Training
- Department of Corrective Services
- Disability Services Commission
- Department of the Attorney General
- Western Australia Police
- Department of Treasury and Finance
- Department of Indigenous Affairs
- Department of Premier and Cabinet

improve medical care¹⁷. The Mayo study achieved 97% consent rates only with huge expenditure, and it questioned such “waste of precious health care resources”. They stress that not being allowed to use retrospective data on those people who have died may make treatments “appear more beneficial than they really are”.

Consumer and community participation

There are several reasons to explain why we have had continued access to population data with linkage – all without consent – without public opposition in Western Australia. One is that our Institute is viewed as highly credible and scientifically excellent, with a commitment to best practice in research. We have publicised our findings extensively in the local media

Obtaining consent may be a waste of precious health care resources

and we are seen as very strong advocates for children, the disadvantaged, Aboriginal issues, social justice and using research in policy and practice.

Another reason is our consumer and community participation in research activities. This includes a major advisory council. They have championed the use of data and record linkage among all the disease support groups and health consumers. This may well lead to our Western Australia community being the best informed about health data and how powerfully it can be used to improve services.

Addressing privacy concerns

What are the dangers and threats to individuals from using these existing data, linked in this way? It must be acknowledged that the potential for invasion of privacy is one about which many people are concerned. It is important that, as researchers, we are aware of these concerns. At the same time we need to educate the public about the importance of using their data for public good, and how our methods of linking their data are best practice in terms of protecting their privacy and ensuring confidentiality

What are the concerns expressed by the privacy lobby about accessing and linking these agency data sets without consent? The major fears are of being identified, and that the identifiable data might be used to harm the indi-

vidual. It might be passed on, for example, to an employer who may then discriminate against the individual; or sensitive data might be made public. In over 30 years of data linkage we have not had one breach of any identifiable information. We believe that our strict processes for protecting the identifiable information are best practice.

Doyal suggests that while not obtaining consent is morally wrong, this is tempered by the potential benefit of what can be achieved, as long as there is no violation of patient confidentiality or privacy and that patients are provided with the opportunity to refuse (opt-out)¹⁹. Balancing community needs and expectations in relation to privacy issues and the potential benefit to the community from health and welfare research will require extensive community education and consultation and a clear mandate from governments that recognises health research as a fundamental requirement for resilient and prosperous nations in the 21st century.

Discussions in the media about the collection, linkage, and use of individual data on medical and social problems as I have described here usually focus on the threats to privacy. They rarely discuss the huge opportunities for public good that are increasingly possible from such information.

If agency data exists that can improve health and well-being, reduce harm and prevent major problems, for example in children and youth, and if we are not allowed to use that data, then government agencies could be accused of not fulfilling their duty to their public. Instead of being defensive about such use, we should proclaim it. Only then can we bring the public along with us.

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