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Exploring the Ethics of the Use and Commercialisation of New Zealand Public Health System Data

This article canvasses the literature exploring issues related to the commercialisation of health data from the public health system. It examines whether commercialisation is a viable proposition in New Zealand, socially and ethically. In doing so, it provides a methodological approach to the development of an ethics and privacy policy framework for any potential commercialisation of public health data in New Zealand.

In May 2013 Kathryn Ryan of Radio New Zealand interviewed Hayden Wilson, a partner at law firm Kensington Swan specialising in health privacy and public service issues, and Graeme Osborne, director of the National Health Information Technology Board, about a range of issues connected to health databases and the sharing of health data in New Zealand. Wilson noted that commercialisation of large-scale health data 'is a very difficult policy question'. Osborne commented:

'I have noticed recently that insurance companies have been approaching GPs for patient information ... [this] must be up to the individual and they must consent' (Radio New Zealand, 2013).

The use of health data is widespread in both the public and private sectors globally (Gauld, 2004; Martin et al., 2014). The sale of health data and health-related data is now a multi-million dollar industry, involving both private and public organisations, and yet public

awareness of this industry is poor (Safran et al., 2007; Bailey, 2006). Selling health data to stakeholders with a commercial interest raises a number of ethical issues and concerns.

The commercialisation of public health data and the potential for generating supplementary health revenue has been explored by a number of countries, with many now engaged in commercial relationships with a range of entities, including research organisations (public and private) engaged in research variously in pharmacovigilance, disease epidemiology, pharmaco-economic studies, and health service provision and delivery; insurance companies; and pharmaceutical companies. In New Zealand the common argument for the commercialisation of public health data tends to rest on the following assertions: health data in New Zealand is considered 'public' because the health sector is primarily funded through central government budget allocations; the public health system is for the public good; the public health system is increasingly under financial pressure to provide services and care to an ageing population; there

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is a need to identify potential sources of revenue; commercialising health data sets provides a potential source of revenue and so in this context is in the interests of the public good and public health (Gauld 2004; Bodenheimer 2008; Nolte and McKee, 2008).

Objections to the commercialisation of public health data commonly hinge on the implications for individuals with respect to rights and privacy and the right to informed consent. In countries where health data has been commercialised, attention has been paid to the development of protocols and frameworks which address the risks to privacy and information security and of

norms and rules. Thus, commercialisation may go against social norms and rules, but if it produces greater overall well-being (generates revenue for the public health system and/or improved health outcomes) it is considered moral and ethical. The problem with this is that greater overall well-being or the happiness of the majority does not always address the well-being of the minority, and, in health, such an approach could lead to increased marginality of minorities and poorer health outcomes amongst those who are already disadvantaged (Lovelock and Lovelock, 2013). This is discussed below in relation to pharmaceutical and insurance companies.

The NHS data sets include information on prescribed primary care drugs; administered hospital drugs; laboratory data; consultations; general practitioner [etc].

impingement on the rights of individuals (Brezis, 2008). It is assumed that once these have been addressed the sale of health data can proceed, as it is in the public good. The approach has tended to be to address the privacy and consent issues at the level of the individual and then proceed with commercialisation, thus assuming that 'ethical' issues have been sufficiently dealt with and that there are no further issues with respect to the public good. As we will see, this is problematic.

Generally, the two main ethical frameworks operating here are a utilitarian framework and a rights-based framework (Smith and Duffy, 2003; Lovelock and Lovelock, 2013; Taylor, 1975). Both of these frameworks have limitations. Briefly, in the utilitarian view, actions are good when they increase the overall pleasure (well-being) of the group and when they decrease pain for the community. An act is considered superior if it produces greater overall well-being. Under this model, acts can be evaluated in terms of their own consequences, rather than being seen to be predetermined by social

Rights frameworks also have limitations, as rights are socially and politically created. We need then to ask: what understanding of rights is being embraced? Is this understanding culturally specific or universal? Universalistic approaches to rights, which are evident in this field, have been critiqued as a manifestation of a move towards global governance, underpinned by a desire of developed nations to consolidate their wealth and power (Chandler, 2002, 2003). Important in terms of the commercialisation of health data is the question of whether rights issues (patient rights to informed consent, to control over data, to confidentiality) are being addressed in practice, not just rhetoric. To date there has been no evaluative research which has examined whether the various protocols and frameworks adopted internationally are serving the interests of patients, or whether commercialisation of health data is undermining the interests or rights of patients (or the public). The argument here is not that the concept of rights is valueless; rather it is the absence of a critical appraisal of what is

happening in practice. There is evidence to suggest that rights are seldom applied equally in societies that are fundamentally unequal, and even less likely to be applied equally across societies where there are vast differences in prosperity (Chandler, 2002). We need to explore the impact of the commercialisation of health data on rights, how rights are addressed, and whose rights are likely to be compromised, at home and abroad.

Finally, and again briefly, this area would benefit from the employment of the principles of social justice. Rawls' (1971) notion of justice as 'fairness' is one of many conceptions that can be usefully employed to examine the commercialisation of health data. Central to Rawls' conception is the notion that fairness is paramount, and here – in contrast to the utilitarian approach – decisions do not rest on what is best for the majority, but on what is right for the individual and the social group. Here, just decisions are so defined not by a person's social position and self-interest, but in terms of what is fair for those who are disadvantaged or less well-off (Pogge, 2005). While it can be argued that issues relating to the sale of health data are pertinent to everyone, the impact of this practice is not necessarily shared equally. Hence, the concept of 'fairness' allows consideration of unequal impact on individuals and certain social groups. This is discussed more fully below in relation to the pharmaceutical industry and ethnic minority groups. Further, distributive or redistributive justice is within this framework considered a moral duty. Thus, if commercialisation was demonstrated to be unfair to some, this ethic would require action against commercialisation.

Finally, fundamental to any ethical decision-making is a commitment to critically appraise the issue or problem, identify where values conflict, and seek resolution to the questions they provoke via a range of ethical frameworks.

The use of health data sets by research organisations

There is evidence of the use of linked data sets for research purposes. For example, in the United Kingdom the General Practice Research Database, developed in 1993, was

merged with the Clinical Practice Research Datalink in 2011. This was a jointly-funded initiative of the National Institute for Health Research and the Medicines and Healthcare Products Regulatory Agency, overseen by the National Health Service (NHS) (Department of Health, 2011). Its purpose is to support research capability and it is linked directly to policy on increasing research and innovation in health and social care. The provision of these new data and research services is promoted in terms of what they can offer for new treatment options and insights into serious health conditions. The NHS data sets include information on prescribed primary care drugs; administered hospital drugs; laboratory data; consultations; general practitioner and hospital-coded disease data; disease registers, and cancer registers. Data can be bought for a fraction of what it would cost to conduct the primary research. The data sets provide data on 64 million patients, and partnerships with other European countries are currently being developed.

The key ethical concerns in relation to this use of the NHS data sets have focused on who has access to the database, and the importance of maintaining confidentiality. These issues are addressed through a scientific and ethical advisory group, which is responsible for granting access approval and addresses issues surrounding the scientific validity of the proposed studies and the need to ensure anonymisation. Revenue generated by sales of data to researchers and research organisations funds the database.

In the United States similar issues have been addressed with respect to access to health data by researchers. There, as in the UK, advocates of patient privacy stress the potential misuse and unethical disclosure of sensitive health data and the implications for individuals. Connected to this is the argument that misuse of sensitive health data may or can harm already marginalised or stigmatised individuals (Hodge, 2003). Conversely, others stress the importance of identifiable health data for public health practice, including monitoring and establishing patterns of injury and disease for populations, facilitating surveillance, and furthering epidemiological investigation

and the identification of health needs. The regulatory measures in this area attempt to balance individual privacy rights and the public interest in public health outcomes (ibid.). In the US, the Department of Health and Human Services Privacy Rule (discussed below) addresses this tension. Ultimately, protecting individual privacy protects public health objectives: it is argued that eroding the former leads to a loss of trust, falling participation in public health programmes, and thus poorer data for epidemiological research and informed interventions. However, protecting privacy is not always a case of closing off access. There are legitimate uses that do impinge on privacy, and this

their specific project; and (4) assure data custodians that the data that is their responsibility will be used appropriately and that security obligations will be met.

Research and commercial use in the United States

In 2003 the United States introduced the Privacy Rule, which established a national standard for health information privacy and security (Hodge, 2003). The Privacy Rule stands alongside a range of other regulatory measures at both national and federal levels. Individually-identifiable health data had always been shared with a range of both public and private sector agencies (such as pharmacies, insurance

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is usually in the event of a public health crisis. Privacy and public health have a synergistic relationship and, necessarily, privacy regulations are complicated.

In Australia, privacy and confidentiality are the central issues discussed in the literature, with the focus being primarily on the use of health data for research. For example, Kelman and Holman (2002) discuss the linkage protocol used for a study on diabetes in Western Australia. The best-practice protocol employed by this research team was designed to provide maximum protection of private and confidential information. It involved separating personal identifiers from actual health data and confining the use of personal identifiers to the initial linkage stage. Four broad principles underpin this protocol for inter-agency record linkage: (1) maximise the protection of individual privacy; (2) provide linked data files only to nominated researchers involved in specific, approved research projects; (3) provide researchers with no more than the data sets required for

companies) in the United States, and this sharing has also taken place without individual consent. US law addressing the sharing of health data is fragmented. The constitution does not grant protection of privacy of health data to individuals. Federal and state-level regulations dominate. These include, at the federal level, the Freedom of Information Act 1966, the Privacy Act 1974 and the E-Government Act (2002), and a range of federal-level privacy laws relating to research subjects and protecting confidentiality both for institutions and individuals. There are a range of statutory laws at the state level which tend to regulate specific data recipients (e.g. insurers), specific medical tests (e.g. genetic) and particular data sources (e.g. health care facilities); there are also public health laws, regulations for insurers and licensing statutes which address privacy protections. But the key measure is the Privacy Rule.

The Privacy Rule covers a range of entities – health care providers, insurers and government health programmes –

that conduct transactions electronically. There are, however, other organisations which use, disclose or store public health information that are not directly covered. The rule protects most individually-identifiable health information (PHI), electronic or paper-based, kept by the entities covered. Public health data that has been de-identified is not included (this data must have been stripped of unique identifiers). Those entities to which the rule applies must:

- provide notification to individuals regarding their privacy rights and how their PHI is used or disclosed;
- adopt and implement internal privacy policies and procedures;

- for judicial and administrative proceedings;
 - for commercial marketing;
 - to parents of un-emancipated minors;
 - to family members, friends, significant others or caregivers, in cases of emergency or during care-taking functions;
 - for health research, if a waiver has been provided by an institutional review board (ethics review committee);
 - to public health authorities for public health purposes.
- More generally, the Privacy Rule pre-empts many state-level or local laws

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- train employees to understand privacy policies and procedures;
- designate person(s) to be responsible for the implementation of privacy policies and procedures;
- establish appropriate administrative, technical and physical safeguards to protect the privacy of PHI;
- meet their obligation to health consumers who exercise their rights under the Privacy Rule to inspect and request corrections or amendments to their PHI.

There is a range of circumstances under which the information can be disclosed. Generally, disclosure cannot take place without written consent from the individual. However, there are exceptions. These are when the individual requests a copy of their PHI, and when the Department of Health and Human Services requires access to PHI to facilitate a compliance investigation under the rule. There are also certain disclosures that do not require individual consent:

- providing a PHI to law enforcement agencies;

– ‘The Rule serves as a federal floor of protections’ – but it does not pre-empt state or local laws that contain greater specificities or stringencies. Thus, all laws that are more stringent and protective of health information privacy rights remain in effect (Hodge, 2003, p.668).

With respect to public health practice, the rule, through exemption clauses, allows a balance between individual privacy and public health considerations. There is, however, always the possibility that the rule will be poorly applied – for example, through misinterpretation of who can have access to PHI – and barriers emerge for public health practice. There is also a reported misperception about how the data can be used (Hodge, 2003), where it is perceived that the rule leads to restrictions on use.

Pharmaceutical and insurance companies

While there are ethical issues connected to the use of health data by research organisations, as identified above, major ethical flags are raised with respect to insurance and pharmaceutical companies.

With respect to pharmaceutical companies, there are issues connected to the use of data for research and development purposes which may well be addressed through various research ethics bodies or committees at an industry, university or national level. We should, however, be cautious about separating out market and profit imperatives from research agendas in this industry, as often the two are closely entwined (Avorn, 2005). In addition, the use of data to identify profitable gaps in the market carries with it a number of ethical issues and concerns, in particular the potential and likelihood of targeting vulnerable populations (for example, the aged and those with chronic conditions), and where at least one component of multiple vulnerabilities can be health literacy. Direct-to-consumer advertising presents a range of ethical concerns, from challenges to individual rights to the potential for overuse of marginally effective technologies, and thus potentially poor public health care, again more likely to be taken up by the vulnerable (Moynihan and Cassels, 2005). Further, it is possible that the revenue generated for the public health system by data sales to pharmaceutical companies is undermined by the conflict of interest between the profit motive underpinning this industry and the interests and objectives of public health (Brezis, 2008). The literature also reveals that voluntary ethical guidelines often fail (Chalmers, 2006).

With respect to insurance companies, data use can also be applied to product development and targeting sales, and it is not clear what ethical processes would be put in place to ensure that this targeting did not perpetuate existing inequalities (that is, disparities in health outcomes between different societal groups) or create new inequalities in coverage requirements or entitlements. A great deal of emphasis is placed on privacy and its protection through the de-identification of data, but it is also known that it is possible to re-identify data after it has been de-identified. Thus, there are ethical issues connected to the potential for insurance companies (or any other commercial entity, for that matter) to re-identify de-identified data (MacRae, Dobbie and Ranchhod, 2012) in order

Table 1: Recommendations of potential utility for New Zealand

Recommendation	Discussion
Increase transparency of data use and promote public awareness.	Ongoing public policy discussions must explicitly and directly address the secondary use of health data. Conducting and managing these activities must enlist diverse stakeholders and fully disclose uses and safeguards through open and readily accessible processes.
Focus ongoing discussions on data access, use and control, not on ownership.	Consensus-building meetings encompassing a broad constituency must focus on data access and control policies and practices for secondary use of data. Focus should emphasise access and control, not ownership. Discussants should consider best approaches to risk management and mitigation.
Discuss privacy policies and security for secondary use of health data.	To develop consensus on pivotal issues, public and private sector organisations advancing the use of health information should promote discussions that include a range of stakeholders. Ongoing discussions must address complex issues related to private and secure secondary use of health data.
Increase public awareness of benefits and challenges associated with secondary use of health data.	A wide range of interested parties, especially consumer-orientated patient and caregiver groups, should promote public education regarding benefits of secondary use of health data. A first step is to identify appropriate organisations and agencies that have a role to play in this effort. The aim of the education is to build public awareness and trust in secondary use of health data.
Create a taxonomy for secondary uses of health data.	A taxonomy identifying possible non-clinical uses of personal health information is needed to clarify societal, public policy, legal and technical issues. The taxonomy will support more focused, productive discussions regarding health data and its use.
Address, comprehensively, the difficult, evolving questions related to secondary use of health data.	Questions to address encompass data transparency; consumer awareness and understanding; technical issues and challenges of identity management and user authentication; commercialisation and sale of data; and oversight. The de-identification and anonymisation of data merit additional attention by technical experts in authentication, de-duplication and identity management.
Focus national and state attention on the secondary use of health data.	Findings of panels should be shared with all interested stakeholders. Additional efforts should be undertaken to formulate a road map which depicts the multi-tiered use and re-use of health data; the road map should take into account all foreseeable applications and the full complexity of issues.

Source: adapted from Safran et al., 2007

to target more effectively and maximise commercial gain.

Public debate, understanding and transparency

In April 2006 the American Medical Informatics Association convened a panel of stakeholders to discuss the issues connected with the secondary use of health data (Safran et al., 2007). The stakeholders identified key findings and made a range of recommendations detailed in Table 1 (amended slightly). All of these recommendations and the discussion that surrounded them are of potential utility in New Zealand.

New Zealand

Health data in de-identified form is routinely used in New Zealand for research purposes. Under the New Zealand Health Information Privacy

Code data is provided on the basis that the individual will not be identified in any published form. To de-identify data, commonly the NHI number is removed, as is the name and address information (MacRae, Dobbie and Ranchhod, 2012). As noted above, there are a range of international protocols which address patient privacy within health information. Privacy is highlighted as a key issue and a potential barrier to the commercial use of health data, and it is typically argued that this key ethical issue can be addressed through de-identification. However, more recently concern has been raised about the risk of re-identification of health data (ibid.). The current recommendation is that de-identified data sets should contain more than 150,000 individuals, not be accompanied by meshblock data, and have age and ethnicity data aggregated. Further, agreements must be in place with ‘trusted’

organisations, as de-identified data can be re-identified readily (ibid.).

Ethics and privacy policy framework

There are a number of questions that need to be addressed in the New Zealand context if an ethical pathway is to be identified for the secondary use of health data and the commercialisation of public health data sets. Answers to some of these questions are suggested in the small body of research canvassed above, but there are some more preliminary steps which need to be taken before any ethics and privacy policy framework can be developed in New Zealand.

First, there are fundamental questions that need to be addressed by stakeholders, including (but not exhaustively):

- What are the potential benefits and risks of the secondary use of health data?
- Who owns health data, and who has the right to access the data and for what purposes?
- What obligations might exist in relation to the Treaty of Waitangi?
- What are the public trust issues with respect to patient consent for secondary use of health data?
- Do patients have the right to audit or put limits on access to their health data, even after anonymisation?
- How can we reconcile public good with the rights of individuals?
- Innovative technologies may enhance the ability and ease of widespread data-sharing and additional commercial uses: what problems may arise from this?
- What can be done about inappropriate use or exploitation of data-sharing?

What can be done if de-identified data is re-identified?

- What regulations, legislation and/or policies and procedures are needed to address these issues? (adapted from Safran et al., 2007).

In addition, there are a number of subsequent questions related to selling, payment and ownership of health data from the public health system. This is particularly an issue when a data-holding entity is an independent business that receives public funding subsidy (for

Table 2: Current legislation of relevance

The following legislation has relevance for the commercialisation of New Zealand health data. The development of an ethics and privacy policy framework would have to work within these legislative parameters.

The Public Records Act 2005 provides a comprehensive framework for the systematic creation and preservation of public archives and local authority archives. This act gives the chief archivist, who is also the chief executive of Archives New Zealand, powers of direction with respect to archiving and disposal decisions concerning health information held by the public sector.

The New Zealand Public Health and Disability Act 2000, section 3(1)(d) describes one of the act's objectives as: to facilitate access to, and the dissemination of information to deliver, appropriate, effective and timely services.

The Health (Retention of Health Information) Regulations 1996 set a minimum period of ten years for which health information must be held by health or disability service providers. They also address the form in which health information is to be retained and the obligations associated with the transferring of health information.

The Health Information Privacy Code 1994 is a code of practice issued by the privacy commissioner under section 46 of the Privacy Act which gives extra protection to health information because of its sensitivity. It covers all health agencies, and protects all personal health information relating to an identifiable individual. The Ministry of Health has a responsibility to ensure it complies with this code in respect to all health information entrusted to it.

The Privacy Act 1993 provides a general framework for promoting and protecting individual privacy. It establishes certain principles with respect to the collection, use, disclosure of and access to information relating to individuals. It applies to private and public sector agencies. The role of the privacy commissioner is to investigate complaints about interferences with individual privacy.

The Cancer Registry Act 1993, section 4 and the Cancer Registry Regulations 1994 require the director-general of health to maintain or arrange for the maintenance of a cancer registry.

The Official Information Act 1982 was established to make official information freely available. This has relevance when a request for health information to the Ministry of Health is from someone who is not the subject of the information or their personal representative, as addressed in part II of the act.

The Health Act 1956 gives the Ministry of Health the function of improving, promoting and protecting public health. It contains specific provisions in section 22 governing the disclosure of health information about identifiable individuals by and between health service providers and other agencies with statutory functions.

example, general practices). How much should providers be paid for the use of their data? And what does the payment represent? Is payment for raw material or is it for the underlying investment to capture data? (This is particularly an issue where providers fund their own information systems. It is, however, a complex issue, because in most instances providers are publicly funded to capture that data for other purposes – for example, the Integrated Performance Incentive Framework.)

Some suggestions

We believe a number of issues surrounding the commercialisation of health data in New Zealand require addressing and

suggest the following as a start.

1. To provide and focus public debate on this issue we suggest that the issue of the commercialisation of New Zealand health data be referred to the parliamentary Health Select Committee.
2. Based on the deliberations and findings of the Health Select Committee, a policy should be developed on the secondary use of health data which adequately addresses ethically its commercialisation.
3. This policy should address issues of privacy at the level of the patient (suggestions overseas include opt-in and opt-out clauses where patients 'consent' or not to the use of their

individual data). There is a need, however, to recognise that there may be differences in cultural response to this: consent, for example, may not be an issue at the level of the individual patient but may be required from a wider, related social group (e.g. whānau or iwi). Thus, in such a case consent may not be given by the individual because it is required from their group. In addition, there is a need to acknowledge that value is a contested concept, particularly among indigenous populations. In New Zealand it seems reasonable to assume that the sale of health data will be contested by Māori in terms both of ownership and of the assumed right to sell health data to commercial enterprises abroad. It also seems reasonable to assume that other members of New Zealand society will contest commercialisation of this data.

4. Any policy development needs to accept that there is no unified consumer position, which means that patient consent is going to be a complex process.
5. While in the United States it has been argued that a focus on ownership detracts from the development of policy, in New Zealand it seems likely that the issue of ownership will be important, not only with respect to the 'right to sell', but also in terms of conflicting understandings of what the 'value' of health data is. It can be argued that we have reached a point currently in New Zealand where ownership is not contested, as both the patient and provider are the stewards of health data, with both having rights to ownership such that they cannot diminish each other's right, but there remains the question of whether commercialisation of health data references the sale of something else; that is, commercialisation may challenge current conceptions of ownership.
6. It would be necessary to engage a wide range of stakeholders to ensure mitigation of future risks of commercialisation. These stakeholders would include, for example, those who

collect the data for primary use; those who use the data for non-clinical use; patients and the public; policy developers; those who inform and educate health professionals, industry, patients and the public; and non-governmental organisations which address health-related issues.

7. It would also be useful to conduct a thorough assessment of the risk of re-identification of de-identified health data.

In addition, several steps need to be taken for the commercialisation of New Zealand health data to be addressed ethically. These include:

- raising public awareness of the possibility of the commercialisation of New Zealand health data;
- transparency in the uses of health data;
- adequate public education, discussion, and debate between and across stakeholder groups;
- understanding that there are multiple meanings around 'value';

- adequate debate on and resolution of the tension between community 'good' and individual rights, and acknowledgement that recognition of individual rights does not always undermine community good;
- recognition that utilitarian ethics emphasises greater overall well-being (or social good), but when applied can also, while addressing the good of the majority, overlook good for minorities and perpetuate social and economic inequality.

Conclusion

There is an urgent need for public consultation, education and awareness about the secondary use of health data and the possible commercialisation of health data in New Zealand. It would be unethical for a decision to be made on the commercialisation ('sale') of public health data in the absence of transparent debate. It should be noted that there have already been some instances of the sale of health data in New Zealand.

It is beyond the scope of this article to explore the vast ethics literature. However, central to the debate is the understanding that when individual autonomy and rights to privacy and informed consent become the focus of ethical attention, key understandings of 'value', 'ownership' and 'social inequality' can be overlooked. Conversely, when attention is focused on what is good for the majority (the public good), minority concerns (including the impact on specific individuals) can be left unaddressed, and thus pervasive social inequalities can be inadvertently perpetuated. We need to move beyond utilitarian and rights-based models towards considering distributive justice frameworks and ethics-of-care models when addressing public health and the uses of public health data, particularly if commercialisation is being considered.

References

- Avorn, J. (2005) 'Torcetrapib and atorvastatin: should marketing drive the research agenda?', *New England Journal of Medicine*, 352, pp.2573-6
- Bailey, S. (2006) 'Your data for sale?', *Boston Globe*, 24 March
- Bodenheimer T. (2008) 'Coordinating care: a perilous journey through the health care system', *New England Journal of Medicine*, 358, pp.1064-71
- Brezis, M. (2008) 'Big pharma and health care: unsolvable conflict of interests between private enterprise and public health', *Israel Journal of Psychiatry and Related Sciences*, 45 (2), pp.83-94
- Chandler, D. (2002) *From Kosovo to Kabul: human rights and international intervention*, London: Pluto Press
- Chandler, D. (2003) 'Rhetoric without responsibility: the attraction of "ethical" foreign policy', *British Journal of Politics and International Relations*, 5 (3), pp.295-316
- Chalmers, I. (2006) 'From optimism to disillusion about commitment to transparency in the medico-industrial complex', *Journal of the Royal Society of Medicine*, 99, pp.337-41
- Department of Health (2011) 'The Government plan for a secure data service: strengthening the international competitiveness of UK life sciences research', London: Department of Health, <https://www.dh.gov.uk/publications>
- Gauld, R. (2004) 'One step forward, one step back? Restructuring, evolving policy, and information management and technology in the New Zealand health sector', *Government Information Quarterly*, 21, pp.125-42
- Gostin, L.O. and M. Powers (2006) 'What does social justice require for the public's health? Public health ethics and policy imperatives', *Health Affairs*, 25 (4), pp.1053-60
- Fennel, D.A. (2009) 'Ethics and tourism', in J. Tribe (ed.), *Philosophical Issues in Tourism*, Bristol: Channel View Publications
- Higgins-Desbiolles, F. (2010) 'Justifying tourism: justice through tourism', in S. Cole and N. Morgan (eds), *Tourism and Inequality: problems and prospects*, Wallingford: CABI
- Hodge, J.G. (2003) 'Health information privacy and public health', *Journal of Law, Medicine and Ethics*, 31 (4), pp.663-71
- Kass, N.E. (2004) 'Public health ethics: from foundations and frameworks to justice and global health', *Journal of Law, Medicine and Ethics*, 32, pp.232-42
- Kelman, C.W. and C.D.J. Holman (2002) 'Research use of linked health data: a best practice protocol', *Australian and New Zealand Journal of Public Health*, 26 (3), pp.251-5
- Lawson, D.H., V. Sherman and J. Hollowell (1998) 'The general practice research database', *Quarterly Journal of Medicine*, 91, pp.445-2
- Lovelock, B. and K. Lovelock (2013) *The Ethics of Tourism, Critical and Applied Perspectives*, London: Routledge
- MacRae, J., S. Dobbie and D. Ranchhod (2012) 'Assessing re-identification risk of de-identified health data in New Zealand', *Health Care and Informatics Review Online*, pp.24-30, www.hinz.org.nz
- Martin, G., K. Lovelock, J. Cumming and R. Gauld (2014) 'Caring and sharing: implementation issues with an electronic shared healthcare record', paper delivered at the Primary Care Research conference, Canberra, 23-25 July

- Miller, R. (2006) *New Zealand Government and Politics* (4th edn), Melbourne: Oxford University Press
- Moynihan, R. and A. Cassels (2005) *Selling Sickness: how the world's biggest pharmaceutical companies are turning us all into patients*, New York: Nation Books
- Nolte E. and M. McKee (eds) (2008) *Caring for People with Chronic Conditions: a health system perspective*, Berkshire: Open University Press
- Palmer, G. (1987) *Unbridled Power: an interpretation of New Zealand's constitution and government*, Auckland: Oxford University Press
- Pogge (2005) 'World poverty and human rights', *Ethics and International Affairs*, 19 (1), Spring.
- Radio New Zealand (2013) 'NZ's super database of health information', Nine to Noon, 8 May, <http://www.radionz.co.nz/national/programmes/ninetonoon/audio/2554343/nz-s-super-database-of-health-information>
- Rawls, J. (1971) *A Theory of Justice*, Cambridge, MA: Harvard University Press
- Safran, C., M. Bloomrosen, W.E. Hammond et al. (2007) 'Toward a national framework for the secondary use of health data: an American Medical Informatics Association white paper', *Perspectives on Informatics*, 14 (1), Jan/Feb
- Schumann, P.L. (2001) 'A moral principles framework for human resource management ethics', *Human Resource Management Review*, 11, pp.93-111
- Smith, M. and R. Duffy (2003) *The Ethics of Tourism Development*, London: Routledge
- Taylor, P.W. (1975) *Principles of Ethics: an introduction*, Belmont, CA: Dickenson
- UK Government (2015) 'Policy: research and innovation in health and social care', <https://www.gov.uk/government/policies/increasing-research-and-innovation-in-health-and-social-care>

OBITUARY

Donald Stephen Gray (22 Dec 1959 – 15 Sep 2015)



Staff and associates of the Institute for Governance and Policy Studies and the School of Government were saddened to hear of the death of Don Gray on 15 September 2015. Don had been a member of the editorial board of *Policy Quarterly* since May 2012.

Don was a graduate of Victoria University of Wellington. He worked

briefly at State Insurance, then from 1984 found his niche in policy advice roles in the Department of Social Welfare and its successor organisations (Ministry of Social Policy, Ministry of Social Development), including as Deputy Chief Executive, Social Development Policy and Knowledge, at MSD.

His career included two secondments to the OECD in Paris, a secondment to the Beehive, chairing the Social Policy Committee Senior Officials Group and advising the chair of the Committee for a number of years. From April 2010 to February 2011, Don managed the secretariat for the Welfare Working Group, based in the Institute for Governance and Policy Studies. He then returned to MSD as Chief Policy Advisor, before being appointed Deputy Director-General Policy at the Ministry of Health from January 2012.

Major policy projects Don worked on included the Social Report, the reform of disability policies in the early 1990s, the 2011 Kia Tūtahi Relationship Accord between the Government and the community and voluntary sector and every major review since the mid-1980s of the New

Zealand social security system and its interfaces with tax, employment, housing and disability policies. During the 2000s, he steered the development of Working for Families, a \$1.5 billion package and the single most significant development in New Zealand's welfare provision for a generation.

Don was a public servant of robust intellect and deep integrity, who encouraged his colleagues in the nicest possible way to maintain a distinction between the use and abuse of evidence in policy formation. He had a quick wit and wry sense of humour. (When I met up with him in April he was undergoing medical treatment and quipped that of course he was merely user-testing public health services.)

Don was a good man who treated everyone with respect and demonstrated public service excellence in working for a better New Zealand. A feature of his career was genuine concern for citizen outcomes, and he found the changes associated with the 1991 'mother of all budgets' particularly challenging. His death is a great loss to the policy community, as to his family and friends.

David Bromell