

## **D7 | POLITICS OF DATA, INFORMATION AND KNOWLEDGE**

### **Introduction**

Data, information and knowledge are core resources for policy, practice and activism in relation to healthcare and population health. However, they do not stand apart from the struggle for health equity. They are not simple representations of an objective reality ‘out there’. They are produced in social practice and bear the imprint of power. This chapter works towards a set of understandings regarding the politics of data, information and knowledge in the struggle for health.

Data, information and knowledge are abstract categories that do not map closely to the institutions and practices through which they are generated and used. We use a hybrid framework in this chapter, structuring our discussion around:

- creating, storing and accessing data
- processing data, generating and accessing information
- learning from practice,
- clinical information and exposure/risk information
- health statistics
- research
- programme evaluation
- knowledge: generation, authorization, communication and management.

### **Creating, storing and accessing data**

Of all the institutions involved in the creation, storing and accessing of health-related data, vital registration is perhaps the oldest, in particular the registration of births and deaths. Vital registration is supplemented by population surveys, including the demographic and health surveys used in many low-income countries where vital registration is incomplete. Administrative data, derived in the context of programme administration, is a major source of data, which includes the utilization and servicing of data, data about health sector resources and health financing data. Two further sets of data are from research projects and project/programme evaluations. We will return to them later.

In reflecting on some of the political issues associated with data collection we will highlight:

- data that is not collected
- data that over-claims what it measures, and
- data which is restricted through price or secrecy.

A notorious example of data that is not collected involves vital registration data in some low-income countries. Insofar as health programmes and schools are planned on the basis of a known population of children, those who are not registered at birth stand at risk of being further ignored in vaccination programmes and educational infrastructure. Insofar as preventive programmes are based on estimates of prevalence and incidence, shortfalls in death registrations, for example maternal deaths, may lead to further failures in prevention.

While shortfalls in vital registration are generally due to resource constraints in some cases, the failure to collect data reflects the power of corporate players seeking to avoid public accountability. Tax avoidance is the outstanding example, but in the health sector we can point to the widespread failure of government agencies to collect data regarding prescription and sale of pharmaceuticals, including, in particular, data regarding the clinical indications for prescribed drugs.

A different issue is where the data that is collected bears only a loose relationship to the concept it claims to represent. A well-known example of this concerns the concept of ‘social capital’, which in some cases is measured by arbitrary and culturally rooted questions, such as how many organizations the respondent belongs to.

Equally troubling is data that is restricted through price or secrecy. An example of the latter is access to doctor-specific prescribing patterns. Such data is commonly collected by agents of the pharmaceutical industry to evaluate and target their marketing strategies. This data is either not available to public-interest regulators or available at a very high price. Similar secrecy shrouds data about food retailing, which is commonly collected on behalf of the supermarket chains and which provides detailed data about shopping choices, sometimes down to identified families.

### **Processing data, generating and accessing information**

The political forces operating on the transformation of health data into health-related information may be traced in a number of different settings:

- learning from practice
- clinical information and exposure/risk information
- health statistics
- research reports, and
- programme evaluation.

*Learning from practice* We start with ‘learning from practice’ because this is commonly overlooked. Vast amounts of ‘data’ are generated in the ordinary practice of families, healthcare practitioners and, importantly, patients and people living with disabilities. This data constitutes observations about ‘What happens when I do such and such thing?’

The data is ‘processed’ through reflection and discussion where it is converted into information and knowledge, which is then carried and transmitted in culture. The learning from professional practice in the clinic finds its way into conventional wisdom through teaching and into formal expression in books and journals. The learning from the practice of patients and families is shared in communities of interest and sometimes finds its way into literature and film.

In political terms, the key issue here concerns the discounting of learning from practice by the knowledge establishment and the potential significance of systematic reflection and discussion, and the capturing and sharing of such knowledge. This is particularly true in relation to the learning from the practice of social movements, including the ‘Health for All’ movement.

*Clinical information and exposure/risk information* The focus under this heading is, first, information about patients’ clinical situation – diagnosis, prognosis, treatment options and so on; and, second, information about exposure and health risk.

Information asymmetry in the clinic is well recognized but poorly managed. Proselytizers for private healthcare would suggest that market pressures should encourage clinicians to develop communication skills and provide the information patients want. But they don’t. The US Institute of Medicine (1999, 2001), which has published several important reports on the quality of healthcare, states that good communication is an issue of clinical culture and argues that the institutions of healthcare should cultivate the attitudes, skills and practices that will ensure such communication in the clinic. And they should. However, it is also important to recognize the incentive pressures (economic and administrative) that arise in the clinical environment and which militate against the development of such a culture.

The primary healthcare approach envisages working not only to encourage a culture of respect and communication but also to change the institutional relationships and accountabilities that frame clinical practice. In Australia, Aboriginal Community Controlled Health Organizations (ACCHOs) are governed by community representatives and staffed by a mix of Aboriginal and non-Aboriginal practitioners. There are challenges in implementing this model, especially since it runs counter to so much in conventional healthcare. However, the ACCHOs are working deliberately and consciously to implement this approach. (See Chapter B2.)

A different issue under the politics of health information concerns occupational and environmental health exposures. The role of the mining industry

in deliberately concealing what it knew about asbestosis (Peacock, 2009) and black lung disease (Berman 1977, pp. 63–87) has been documented in detail. A comparable case concerns tobacco and the role of the tobacco industry in concealing the knowledge (Malone and Balbach, 2000) of the health dangers of tobacco smoking.

One of the most egregious cases of risk concealment was the Tuskegee syphilis experiment between 1932 and 1972 involving black farm workers in Alabama, around half of whom had syphilis (Reverby, 2011). It appears that the government-sponsored study commenced as a study of the natural history of the disease but after penicillin became available the study continued as before, simply observing clinical progress. Not only did the researchers fail to organize treatment for the study participants, they discouraged them from seeking treatment elsewhere.

The Tuskegee case is not an isolated instance. Since then numerous cases have come to light of drug companies undertaking clinical trials in low-income countries on poor and poorly educated populations without the informed consent provisions that would be required in high-income countries (Illes, Sahakian and Dyke, 2011).

A more systemic case, concerning data that is not collected, deals with the adverse effects of pharmaceuticals. The regulation of the marketing of new drugs takes place in two phases: the first is marketing approval and the second is post-marketing surveillance. In most countries post-marketing surveillance is weak, depending only on clinicians reporting adverse events following exposure. This means that low-incidence side effects, particularly in infrequently used drugs, may remain undetected for many years.

A different set of distortions are evident in the evolving protocols for pre-marketing approval, with the introduction of ‘data exclusivity’, which defines the period during which generic manufacturers are not allowed to rely on the initial documentation regarding safety and efficacy as part of their application for marketing approval.

Finally, food labelling provides a further instance where risk information is being systemically denied to consumers. An aggressive campaign has been waged over many years by the food and beverage industry in order to prevent regulations that might require them to provide informative and accessible information about the health risks associated with their products.

*Health statistics* The field of health statistics constitutes another domain where the politics of measurement fogs health policy analysis. The principal reason governments collect and publish health statistics is to inform public policy. Information is power in the sense that if governments know what they are doing they can modify policies to achieve their objectives more effectively. Furthermore, most governments take the view that while integrity and transparency in health statistics can inform protest as well as policy implementation, there are

significant costs related to dishonest data and secrecy. Accordingly, for health activists seeking to engage in policy dialogue the various data repositories and, particularly, visualizations can be valuable resources to refer to.

While there is much useful material in national and international health statistics repositories (and observatories) it is also necessary to appreciate how official information systems are cast within, and project, a particular ideology notwithstanding their veneer of objectivity.

DALYs, disability-adjusted life years, were developed in the context of the World Bank's 'Investing in Health' report, published in 1993. DALYs are used as a measure of ongoing disease burden consequent upon disease or injury commencing in the present period (or the disease burden averted by treatments or preventive interventions implemented in the present period). Disability-adjusted life years comprise two components: years of life lost and years lived with disability. Years of life lost compares the estimated survival following the onset of the illness or injury with estimated life expectancy at the same age without the onset of illness or injury. The value of years of life lost well into the future is discounted compared with the years immediately following the onset on the grounds that immediate years are worth more than distant years. The estimate of years lived with disability is based on estimated survival, weighted for the degree of disability. The weighting is expressed in a figure from 0 to 1 and has the effect of reducing the survival estimate in accordance with the level of disability. Thus a disability weight of 0.95 will not alter the survival estimate greatly. However, a disability weighting of 0.2 will reduce by five-fold the estimate of years lived with disability. A year of life lived with such a disability is valued at 20 per cent of a year. Finally, DALYs are further adjusted according to the age of onset. Greater value is assigned to DALYs taken from the 'economically productive' ages as compared to infancy, childhood and old age.

DALYs are conceptually attractive because they reduce to one measure the morbidity and mortality consequent upon events occurring in the present period: the onset of disease or injury, or treatments delivered, or preventive interventions. However, the incidence data and the survival data on which they are based are often very rough 'guesstimates' and the transformations involved in discounting future years by applying disability weights and adjusting for age of onset all reflect judgements about the value of human lives, judgements that are not always evident to readers of publications using DALYs. The processes involved in determining disability weightings are particularly dubious.

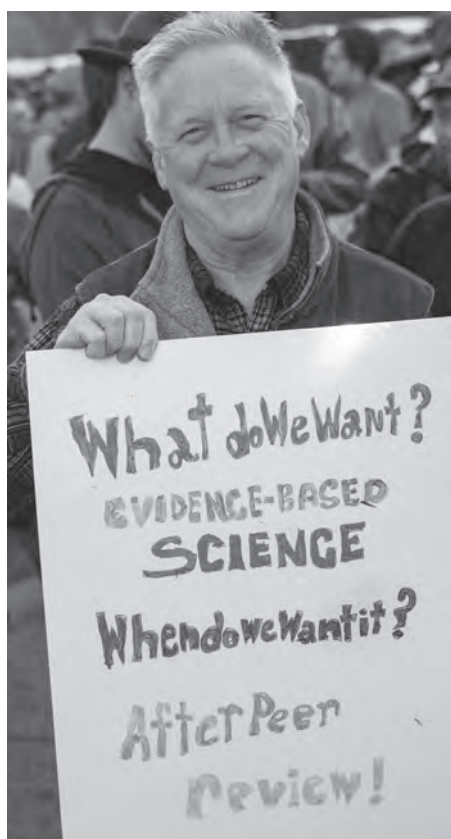
A second example of hidden value judgements in apparently objective statistics are the health system league tables published in the World Health Report of 2000. This exercise purported to compare national health systems using three measures: health status, responsiveness and fairness in financing. We do not have space here to itemize the weaknesses in the crude data assembled for this exercise or the value judgements incorporated in the selection

of evaluative criteria or the flawed logic expressed in the selection of the three principal measures. Suffice it to say that the product of this exercise was completely lacking in credibility and greatly damaged the WHO's reputation.

*Research reports* Access to research funding through both government-funded research councils and philanthropic bodies is generally dependent on the value of the anticipated knowledge and the technical quality of the research proposal. Both are subject to the gatekeepers' interpretation of both the social value of the anticipated knowledge production and the proposed methodology.

The most striking measure of political bias in research funding is the imbalance between, on the one hand, the funding of basic science and clinical medicine and, on the other, (the lack of) funding for research on the delivery of healthcare and prevention. Notwithstanding shortfalls in access, quality and efficiency in healthcare delivery, the focus of health-related research globally is on the biology of health and disease and technical advances in clinical practice.

Gatekeeping with respect to methodology favours the generalizable over the contingent, the quantitative over the qualitative, and privileges methods that are high in the 'hierarchy of evidence'.



**Image D7.1** Support for evidence-based science and peer review (By scattered1 from USA; License: CC BY-SA 2.0, <https://commons.wikimedia.org/w/index.php?curid=58260940>)

The hierarchy of evidence is a reflection of the reductionism that dominates health research funding and practice. This is epitomized by the double-blind randomized controlled trial (RCT), which is represented as producing the most compelling research. The genius of the RCT is that it controls for variations in context. The inclusion criteria and the nature of the intervention are specified and, through random allocation to treatment or control, all of the contextual factors that might affect the impact of the intervention are controlled. The paradox is that healthcare and health promotion are highly context-dependent, where context includes patient variables and environmental factors. Thus, because the treatment of blood pressure in middle age has been shown to improve outcomes, the need to control blood pressure is taken as mandatory even in the very old, amongst whom very few RCTs have been done.

One of the consequences of the increasing authority of statistics has been an increasing preference for research methodologies that yield quantitative estimates, amenable to statistical testing, over qualitative methods. There is a perception that quantitative methods are more 'objective' or less imbued with value judgements. This is not so. The big difference is that the value judgement goes into the definition of the variables *before* the data is collected in quantitative research, while in qualitative research the value judgements are present in the questions that are asked and the interpretation of the findings.

Social class is an example par excellence of an emergent phenomenon that has properties at the macro level that are not computable on the basis of micro variables and relationships. This is highly relevant to public health both in relation to the social (and political) determinants of health and the political configurations that shape health systems.

Looming over these factors is the academic citation/impact fetish. Increasingly, the research performance (and funding) of universities is being measured in terms of publication in highly cited journals and the citations achieved by individual papers. This has the effect of discounting journals that do not service a large constituency, no matter the social significance of the field covered by that journal. This has the effect of encouraging papers that offer widely applicable generalizations rather than focusing on context-specific questions. The consequence is that academic collaboration with communities, learning from practice, and locally relevant knowledge are discounted in favour of technological research-oriented material useful for the new globalized marketplace.

The drivers of industry research are much more closely tied to market opportunities and treat knowledge as private property. A field of industry research that is of particular relevance to health policy and is particularly influenced by health politics is that of clinical trials, in particular of drugs and vaccines. We have referred to Tuskegee and its modern equivalent, the use of Third World subjects for evaluating safety and efficacy. John le Carré's novel, *The Constant Gardener*, is a beacon in this context. The book was based on a clinical trial conducted by Pfizer in Nigeria on the treatment of meningitis. The trial was

carried out without authorization from the Nigerian government and without consent from the children's parents. Eleven children died.

The issues go beyond unethical recruitment and exposures. Of more general concern is the prevalence of fraudulent analyses of clinical trials data and the failure to publish negative studies. As a consequence, proposals for mandatory registration of all clinical trials and for clinical trials data repositories are gaining increasing support. The corrupting influence of corporate sponsorship of clinical trials affects methodology as well as publication. For example, trials that focus on the impact on intermediate endpoints need to be supplemented by further studies that confirm that there is a net benefit in terms of long-term outcomes. This is not always the case.

*Programme evaluation* How does politics shape the transformation of evaluation data into information and knowledge? We start by noting the tendency to discount formative as opposed to summative evaluation. Formative evaluation follows the implementation of a programme with a view to learning how to do it better. Summative evaluation sums up the outcomes of the programme, often with a view to satisfying funders that their investment has been well spent; the focus is on accountability rather than learning. The distinction is between single loop learning (What am I learning about how to achieve the original goals we established for this programme?) and double loop learning (What am I learning about how to achieve the original goals *and* what am I learning about whether these were the right goals?).

The problem arises sharply when agencies distributing funds are also accountable to original donors who need to be assured that their funds are being productively used. If the funding agency is obligated to report that promised goals are being achieved (perhaps the distribution of insecticide-treated bed nets) they will not be disposed to allow the flexibility of double loop learning to the funding recipients. So if the recipients come around to the view that some of their efforts should be applied to preventing mosquito access through improved window and door fittings and if this leads to fewer insecticide bed nets being distributed, then the funder will be disadvantaged vis-à-vis the donor. Both learning and accountability are important, but in this instance learning on the ground is sacrificed to accountability.

The concept of programme logic is central to this dynamic. Applicants for funding are required to specify the programme logic underpinning their application. This is a useful discipline; it specifies how the strategies to be implemented will contribute to the putative outcomes and suggests performance indicators that enable the project managers to determine how well the strategies are being put in place and if so whether they are working. However if that programme logic is locked into place for accountability purposes there is no space for double loop learning.



**Knowledge: generation, authorization, communication and management**

Knowledge is generated, transmitted and stored in:

- hard copy (academic research, libraries, books and journals)
- soft copy (the Internet, artificial intelligence, smart phones, digital mode)
- wet copy (teaching/learning, mentoring, culturally embedded knowledge, experiential knowledge, practical knowledge).

With the information explosion, speed of change and global integration, knowledge management (the capture, storage, access and retrieval of previously encoded knowledge) is attracting increased formal attention. At a systemic level we can identify the following institutions of knowledge management: libraries and journals, search engines, knowledge portals, observatories and knowledge brokers. Many large organizations are also exploring at a corporate level how they can better manage ‘their’ knowledge, including through corporate memory and computers or by developing a culture of recognizing and sharing the ‘wet copy’ knowledge of experienced workers.

We highlight three important issues involving the politics of knowledge: ideology, marketization, and the embeddedness of knowledge in the workforce (or human resources).

We have referred earlier to the role of hegemonic ideology in shaping how knowledge is generated, authorized, valued, and made available. Among the assumptions that are promoted by neoliberalism are these: that market mechanisms are preferable to administration, planning and regulation; that private enterprise is generally more efficient than government; that society is constituted of a myriad of separate competing consumers; that inequality reflects the necessary discipline of market forces, sorting people according to their worth (Harvey, 2005). The intellectual framework for this ideology is provided by conservative economists and philosophers, but its driving forces are rooted in the transnational capitalist class. These include the financial press and ratings agencies working in tandem with the dispersed forces of ‘market discipline’, the stock market and the money market speculators who collectively hobble political leaders.

Through neoliberal ideology the transnational capitalist class is able to influence the climate within which knowledge is generated and applied. Thus charity (international development assistance) is a proper and necessary mechanism for supporting healthcare and nutrition in low-income countries (and it would be bad form to harp on the power relations and dynamics of the global economy that perpetuate national poverty).

Hegemonic ideology can be challenged. In the mid-1990s when anti-retroviral drugs became available, there were many voices saying that treating AIDS in low- and middle-income countries was impossible and that the only rational policy was one of ‘prevention’. This position reflected an acceptance

of high prices and poor governments, an acceptance of the monopoly pricing power provided to Big Pharma through the extended intellectual property provisions of the TRIPS Agreement. However, this status quo position was not accepted by the treatment access movement, which challenged the basic assumptions of the free trade juggernaut. The delegitimation of TRIPS by the treatment access movement was a major factor motivating rich nations and philanthropists to mobilize billions for new global health initiatives and for the Millennium Development Goals.

The privatization and marketization of knowledge is fully consistent with the neoliberal celebration of market forces and the expanded protection and policing of intellectual property. Price barriers to accessing knowledge arise in part from the corporate ownership of academic journals, which restricts electronic access to journals and e-books to employees of large organizations such as universities. One of the active debates in this area is the controversy over the digitization of hard copy libraries. No one argues against the digitization of this legacy but the question is whether it should be done privately (perhaps by Google?) or as a publicly funded open access initiative.

Perhaps the largest pool of usable knowledge, including information on how to access the knowledge, is embedded in the workforce, hence the term 'human resources'. This has implications for the politics of knowledge, including the power relations of communication and of teaching and learning.

The concept of the proletarianization of knowledge workers provides a useful framework for interpreting contemporary movements in knowledge management. Braverman (1974) speaks of the appropriation of shopfloor knowledge by engineers in the 'front office'. As the engineers acquire more detailed knowledge of the production process they are able to redesign the work flow, including a greater division of labour (and reduction in the work span of individual workers), in order to increase efficiency and profit. As the workers on the shop floor are transformed from skilled artisans into assemblyline operatives they are disempowered and increasingly alienated from their work.

The transfer of wet knowledge (held in memories and culture) into soft knowledge (held in computers) is happening in the health sector, although at different rates and in different ways. Perhaps the most dramatic example is the rise in the power of health insurance corporations in the medical arena in the USA.

## Conclusion

The struggle for health is complex and difficult. A thoughtful approach to data, information and knowledge is a necessary part of effective engagement. We have reviewed some general ideas and a few specific case studies. This is just the beginning of a discussion towards a set of insights that might usefully inform practice.

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