Data, information and knowledge supporting action for Health for All

Introduction and purpose

Data, information and knowledge are core resources for policy, practice and activism in relation to health care 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; they are embedded in languages which are framed by the experiences and aspirations of those who shape their use.

In this paper I am working towards clearer understandings regarding the politics of data, information and knowledge in the struggle for health.

Data, information, knowledge and action

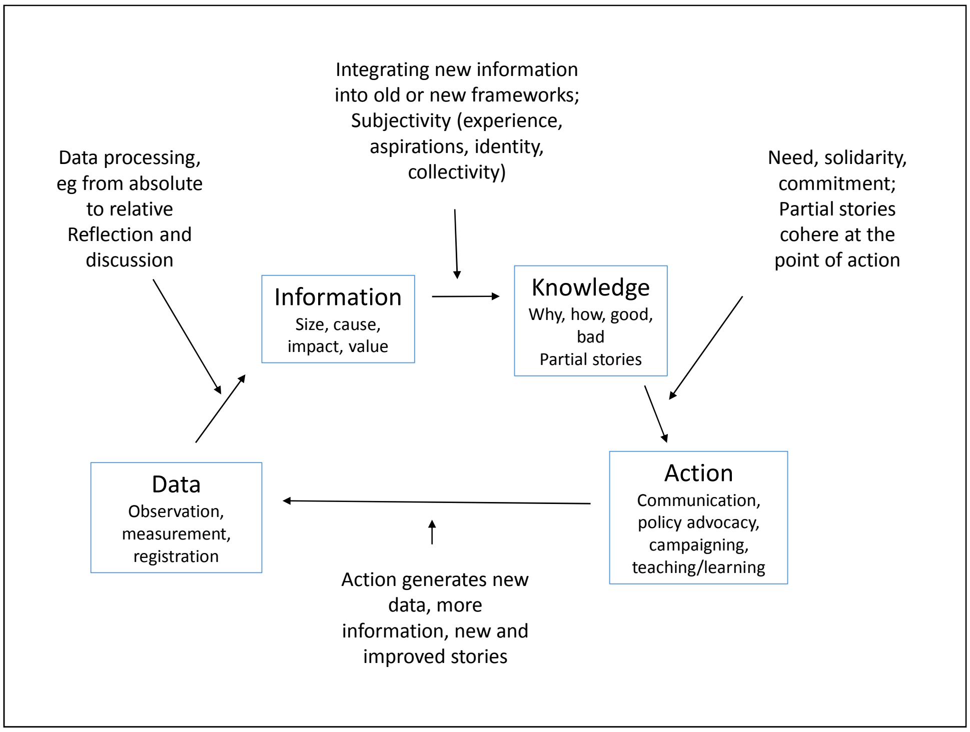

Figure 1. Data, information, knowledge and action: a framework for reflection

Figure 1 provides a framework for reflecting on the ways data, information and knowledge inform (and arise out of) action. The story Figure 1 tells is roughly as follows.

- Data refers to the unprocessed products of observation, measurement, registration, evaluation and many other human engagements with our world.
- Information tells us about the meaning of data: size, impact, value and causation.
- Data is converted into information when it is processed in particular ways for particular purposes. Thus data about the number of deaths in a period or a place makes more sense when it is converted into a rate or a rank or an age-specific death rate or an age and cause specific death rate. Data are also converted into information through reflection and discussion; where the meanings of the data are explored by testing them against prior understandings.
- Knowledge is about wheres and whats, whys and hows, goods and bads.
- Information feeds into knowledge development when it is integrated into modified or new narratives about our world, about our lived experience. Information may be interpreted differently according to the experience and purposes of the knower. Narratives of knowing are always embedded in a particular subjectivity.

- Information and knowledge inform action (communication, policy advocacy, campaigning, teaching/learning) which is driven by need, solidarity and commitment.
- Finally, action generates new data, new information and new frameworks for understanding our world.

The theory of knowledge underlying Figure 1 runs counter to the conventional correspondence (or representational) theory of knowledge in which theory corresponds directly to reality. This, the conventional theory of knowledge, fails to recognise the ways in which knowledge is embedded in world view; the ways we are present in our knowledge; the ways our knowing are shaped by our histories and context, experiences and aspirations.Knowledge, and the social processes of knowledge generation, transmission and storage, are part of the world that they are supposed, in correspondence theories of knowledge, to represent.

Another way of understanding knowledge is to think of it as carried in partial stories, not always articulating or consistent. According to this view, our practice, how we act, reflects our foregrounding a particular set of partial stories in the context of each particular action; it reflects a particular way of putting together these partial stories in the context of each particular action. For example the different schools of health promotiongive different weight to social marketing directed at behaviour change versus empowerment and community development. These different ways of valuing and putting together different ‘partial’ storiesof prevention reflect history and context of those practitioners.

This ‘relativist’ theory of knowledge, depicted in Figure 1, places less emphasis on ‘truth’ than on ‘usefulness’ (for particular agents in particular settings). The ‘realist’ correspondence theory of knowledge can be somewhat disabling in terms of listening across difference. If the listener is convinced that their understanding is ‘true’ it is difficult to listen openly to people who see the world in different ways.

The framework in Figure 1 highlights abstract categories: data, information and knowledge. In broad terms these correspond to more familiar institutions such as:

- vital registration, population surveys, crude research data, crude evaluation findings and clinical trial data (data);
- health statistics, research reports, evaluation findings (information);
- libraries, journals, teaching/learning, mentoring, intellectual property, internet searching, intellectual property, technology transfer (knowledge).

Moving from the abstract to the institution invites a closer look at the social relations of data, information and knowledge; the politics and the power relations of surveys, statistics and libraries.

Globalisation, technology, data, information and knowledge

It is commonplace to bewail the role of information technologies and social media in generating a sense of information overload.

However, the challenge of information overload is magnified for the activist seeking forms of action which address the local, in ways which also contribute to wider structural change including at the global level. With globalisation / global integration there is so much more information to absorb if we are to make sense of the dynamics of scale and term which shape our lives.

The struggle for health

Community health activists face huge challenges in working towards access to decent health care and the right to live in a safe, nourishing, sustainable environment. Beyond health specific struggles are the looming threat of global warming, the widening economic and political inequalities, and violence, war and displacement.

The local and the global

The dynamics which reproduce environmental degradation, inequality and conflict need to be understood in terms of local specifics and global generalities. Rosario's death cannot be attributed solely to local factors nor solely to global factors because these are at all times mutually constitutive. The global shapes the local specifics but is constituted in aggregate by the forces operating in a myriad of localities.

The activist operates locally at all times. Her agency stems from her control over where she puts her body, here and now. Her challenge is to adopt forms of practice which operate in the here and now, addressinglocal problems and opportunities but in ways which also contribute to changing the dynamics at the larger scale and longer term. This involves drawing on theories (partial stories) which speak about the links between the local and the global.

The agency of the individual activist is local, in the here and now. However, in collaboration with allies, both local and distant, her agency can be multiplied a thousand fold. This involve communicating across difference; generating theories of the global which are consistent with the different needs in different constituencies; generating strategies and forms of action which address local needs but in ways which also contribute to change globally.

Social relations and institutions

With globalisation there has emerged a new globalised class structure with a transnational capitalist class (TCC), coherent and self-aware,confronting a much more dispersed and fragmented assembly of national middle classes, working classes and dispossessed and excluded classes. The ascendancy of the TCC in the present era has been accompanied by a rise in xenophobia, sectarianism, racism, and sexism which fragments what could be a more convergent drive towards equality, justice, sustainability, and decent living conditions. The rise of xenophobia is in part a reflection of the personal and collective insecurities associated with neoliberal globalised capitalism: the material insecurity associated with poverty; insecure futures associated with the lack of social provision (education, housing, urban amenity) and social protection (sickness, disability, aged pension, unemployment); existential insecurity associated with alienation and unfulfillable market-created wants. However fear of the other is actively stoked by the demagogues of the TCC as part of maintaining their control.

This combination of insecurity, xenophobia and simplistic solutions points towards the challenge (for the progressive activist) of convergence: listening across difference; building solidarity across difference; collaborative action across difference.

Listening is complicated by truth, in several ways. Those of us who believe we have privileged access to truth (commonly through religion or science) cannot listen deeply to other ways of knowing if they are inconsistent with our truth. The meanings we assign to words are framed by a wider set of assumptions or beliefs about how the world works; call it 'world view'. Communicating across difference involves imagining into the other's world view and perhaps enlarging the space of shared understandings.

There are further challenges in terms of communicating complex and abstract ideas which may appear to have only tenuous links to everyday realities. The narratives which describe and explain the forces and dynamics appearing at the global level are necessarily complex and abstract. An account of the dynamics of global governance or the workings of the global economy can be alienating and disempowering rather than inspiring and enlightening if it is presented without links to the daily struggle, including links to one's own agency. By comparison, the simplistic narrative of xenophobic demagoguery can be anchored in everyday life and offer clear pathways for personal engagement.

Conversations about the dynamics of global governance or the workings of the global economy are further complicated by the distorted ways in which such issues are handled in the mainstream media and academia.

Ideology can be understood as the projection or imposition of a particular way of seeing the world. The world views so projected - patriarchy, racism, neoliberalism - cannot be seen as separate from the power relations deployed in projecting them. Neoliberalism celebrates the power of market relations and warns of the dangers of government; itrepresents a regime of corporate impunity as both beneficial and inevitable (notwithstanding its manifest failure to deal with global warming, widening inequality and prevailing conflict and displacement). The term ideology is useful, in part because of its overtones of power and imposition. However, this does not mean that the world view of progressive health activists is in some sense a truer account of the real world or that communication within social movements is always without coercion.

Understanding stability and change in terms of social relations (across class, race, gender, etc) and in terms of ideology (racism, patriarchy, neoliberalism, religious fundamentalism, etc) is necessary but not sufficient.

The struggles for decent health care, for reducing inequality, controlling global warming, and addressing the environmental and social determinants of health are necessarily focused on specific institutions, reform of existing institutions or the creation of new ones. 'Institutions'is used here quite broadly: organisational structures, established roles and relationships, ways of speaking, forms of practice. Institutional forms reflect and reproduce social relations and are stabilised (or destabilised) by ideological currents; but the immediate politics and the challenges of policy are about institutional change.

Health activists must participate in the policy debates and the political engagements through which health care and public health institutions are strengthened, reformed or created afresh. While all action is in the here and now the policy debates are framed at different levels of scale from the local to the global.

Action

We do not have space here for a comprehensive discussion of the relations of knowledge to action or action to data, information and knowledge. However, we may illustrate the usefulness of the framework presented in Figure 1 through two particular challenges: building solidarity across difference, and building big picture narratives which will inform convergence and action.

Building solidarity across difference starts with listening across difference; making sense of the message in relation to the lived experience of the other – the lived experiencewhich give meaning to the symbols which constitute the message. It starts with shrugging the burdenof knowing the Truth, including Truth about the other. Deepening communication enables the building of shared stories which link local needs and shared struggles; about shared exposure to global forces; about the possibility of a convergence of the global 99%. Such shared stories will suggest small collaborative actions which build trust and yield further learnings about shared and parallel struggles; building convergence in action.

The big picture narratives which might inform convergence would speak about the political economy of neoliberal globalisation; about the structures of global governance; about the social and cultural dynamics of insecurity and xenophobia. These ideas are complex, abstract and often quite distant. They are not truths to be conveyed. They comprise multiple partial stories which need to be explored and weighed in terms of their usefulness in different settings; explored, weighed and, if found useful, to be reassembled in relation to local circumstances.

These stories are refreshed and retold with the feedback from action. The stories which are strengthened by feedback from collaborative action will deepen and extend the basis for further trust, understanding and collaborative action; will open new opportunities for popular engagement and convergence across difference.

Critique (and appreciation) of established institutions and practices

In this section we review some salient issues regarding the politics and practices of data, information and knowledge from a health activist perspective.

Data, information, knowledge are abstract categories which do not map closely to the institutions and practices through which they are generated and used in practice. In this section we use a hybrid framework, 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,
    - program evaluation,
- knowledge generation, authorisation, communication and management.

This is not a perfect framework as some issues which might be defined in terms of data, information or knowledge arise in all of these domains of practice.

Creating, storing and accessing data

Here we are referring to a range of institutions which are central to the creation, storing and accessing of health related data. Vital registration is one of the oldest of these systems, 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 program administration, is a major source of data, including:

- utilisation and servicing data, including diagnosis, procedure and outcome,
- health sector resources: workforce, clinics, beds, equipment, etc, and
- health sector revenues and expenditures.

Two further sets of data are from research projects and project/program evaluations. We return to these below.

Finally it is important to acknowledge the observational data which is generated in practice including in the practice of workers, families and communities; in clinical practice; and in the practice of health activists. These data are commonly ‘processed’ through discussion and reflection and often make their way into cultural knowledge without formalisation of any sort.

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

- data which are not collected;
- data which over-claim what they measure; and
- data which are restricted through price or secrecy.

A notorious case of data which are not collected involves vital registration data in some low income countries. Insofar as health programs 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 programs, and educational infrastructure. Insofar as preventive programs 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 prescribing and sale of pharmaceuticals, including in particular data regarding the clinical indications for prescribed drugs. A similar case concerns private sector health service delivery data. In most countries the quality of data regarding private sector servicing and utilisation is far thinner than that collected in the public sector.

A different issue is where the data which are collected bear only a loose relationship to the concept which it is claimed they 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 organisations you belong to.

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

One particular set of data which is of significance for health policy development but which is tightly protected is drug development cost data. Pharmaceutical corporations justify high prices behind patent monopolies in terms of the cost of drug development (although commonly more than half of those revenues go into aggressive marketing). However, the expenditure data upon which the real cost of drug development might be estimated is closely guarded with published estimates varying widely from wild exaggerations from industry-associated researchers to much more modest estimates from public interest research agencies. (It would be fair to include in such estimates the effective public subsidy on account of taxes foregone through tax avoidance.) The idea of delinkage is a hot topic in pharmaceuticals policy at this time. This proposes that drug development be publicly funded so that the price of drugs, once they marketed, can be reduced to the actual cost of production. It is in the industry's interest to exaggerate the cost of drug development to discourage governments from contributing to such a fund but perhaps also to ensure that where drug companies are commissioned to contribute to drug development under a delinkage regime, they will be generously funded.

Processing data, generating and accessing information

We will discuss the conversion of data to information under five headings:

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

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, health care practitioners and importantly patients and people living with disabilities. These data are the observations about what happens when I … [do something].

These data are 'processed' through reflection and discussion where they are 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 practice of patients and families is shared in communities of interest and sometimes finds its way into literature and film.

In political terms one of the salient issues is the discounting of popular learning from practice by the knowledge establishment and the potential significance of systematic reflection and discussion and capturing and sharing such knowledge. This is particularly true in relation to the learning from practice of social movements, including the Health for All movement.

Clinical information and exposure/risk information

Our focus under this heading is first, information about patients' clinical situation - diagnosis, prognosis, treatment options etc; and second, information about exposure and health risk. We shall consider:

- information asymmetry in the clinic,
- occupational and environmental health exposures,

- adverse effects of drugs,
- food labelling, and
- evidence for regulatory approvals and subsidies.

Information asymmetry in the clinic is well recognised but poorly managed. Proselytisers for private health care would suggest that market pressures should encourage clinicians to develop the communication skills and provide the information patients want. But they don’t. The US Institute of Medicine which has published several important reports on quality of health care state that good communication is an issue of clinical culture. That the institutions of health care should cultivate the attitudes, skills and practices which might ensure such communication in the clinic. However, while this is probably true it is also important to recognise the incentive pressures (economic and administrative) which arise in the clinical environment which mitigate against the development of such a culture.

The primary health care approach envisages working to encourage a culture of respect and communication but also to change the institutional relationships and accountabilities which frame clinical practice. In Indigenous Australia, community controlled Aboriginal health organisations (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 health care. However, the ACCHOs are working deliberately and consciously to implement this approach.

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 they knew about asbestosis (Peacock, 2009) and black lung (Berman, 1977)has been documented in detail. A comparable case concerns tobacco and the role of the tobacco industry in concealing their knowledge (Malone & Balbach, 2000)of the health dangers of tobacco smoking.

One of the most egregious cases of risk concealment was the Tuskegee syphilis experiment from 1932 involving black farm workers, around half of whom had syphilis, in Alabama(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 organise 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, & Dyke, 2011).

A more systemic case, concerning data which are not collected, deals with the adverse effects of pharmaceuticals. The regulation of the marketing of new drugs takes place in two phases, first, marketing approval and second, 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 evidentin the evolving protocols for premarketing approval with the introduction of ‘data exclusivity’ which defines a period after a drug patent has expired 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 which 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 a further domain where the politics of measurement and generating information from data, 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 from shonky data and secrecy. Accordingly, for health activists seeking to engage in policy dialogue the various data repositories and particularly visualisations can be valuable resources to refer to.

National health statistics agencies worth visiting include those of Canadathe USA the UKand Australia. Examples of international health data repositories include those of the OECD the WHO and the World Bank. Examples of useful visualisation tools are the Gapminder and the Worldmapper. The health system observatories are a different kind of resource but also one which is very useful for the policy makers. The outstanding instances are the European Observatory on Health Systems and Policies and the Asia Pacific Observatory on Health Systems and Policies.

While there is much useful material in 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.

Two cases which illustrate hidden value choices embedded in ‘objective’ indicators are first, the DALY; and second, the health system ‘league table’ published in the World Health Report of 2000.

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 – 1 and has the effect of reducing the survival estimate in accordance with the level of disability. Thus a disability weight of .95 will not alter the survival estimate greatly. However, a disability weighting of .2 will reduce by 5 fold the estimate of ‘years’ lived with disability. A year of life lived with such a disability is valued at 20% of a year. Finally, the DALY is further adjusted according to the age of onset. Greater value is assigned to DALYs taken from the ‘economically productive’ ages compared with infancy, childhood and the aged.

The DALY is conceptually attractive because it reduces 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 it is based are often very uncertain guestimates and the transformations involved in discounting future years, applying disability weights and adjusting for age of onset all reflect judgements of the value of human lives; judgements which are not always evident to readers of publications using DALYs. The processes involved in determining disability weightings are particularly dubious.

Our second example of hidden value judgements 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 (and distribution), ‘responsiveness’ (and distribution), and ‘fairness in financing’. We do not have space here to itemise and evaluate 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.

The product of this exercise was completely lacking in credibility and greatly damaged WHO's reputation. Some of the outstanding absurdities include:

- treating health status as a measure of health system performance with a clumsy gesture at partitioning out the influence of social determinants as distinct from the impact of health services;
- the use of geographic variations in under fives mortality to create a measure of the distribution of 'health attainment';
- the use of disability weightings to reduce the nominal value of life year estimates as discussed above in relation to DALYs;
- the use of selected key informants from countries to estimate the level and distribution of health system 'responsiveness'(perhaps not surprisingly the USA was ranked number one in health system responsiveness);
- adjustment of health status attainment values against health expenditure data using a function relating health expenditure to health status;
- the exclusion of quality of care or efficiency or access indicators on the grounds that these are intermediate constructs which will be accommodated in the outcome measure of health attainment.

Finally, in this review of the politics of health statistics we need to highlight the areas where data are not collected or not published. These include variables associated with some critical albeit highly contested principles, such as

- the implementation of primary health care,
- the role of social class,alienation and powerlessness, shaping health inequalities, and
- exposure to occupational and environmental hazards.

Research

Under this heading we explore the politics of information in relation to:

- research funding priorities,
- reductionism,
- the academic citation impact fetish,
- industry research and the privatisation of knowledge, and
- clinical trials.

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 gate keepers' interpretations, concerning 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 the funding of basic science and clinical medicine compared with the lack of funding for research into the delivery of health care and prevention. Notwithstanding shortfalls in access, quality and efficiency in health care delivery the focus of global health related research 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 which are high in the 'hierarchy of evidence' (according to which the randomised controlled trial is valued most highly and anecdotal evaluation is seen as having limited value).

The hierarchy of evidence is a reflection of the reductionism which dominates health research funding and practice. This is epitomised by the double blind 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 are specified and the nature of the intervention is specified and through random allocation to treatment or control all of the contextual factors which might affect the impact of the intervention are controlled out.

The paradox is that health care and health promotion are highly context dependent, where context includes patient variables and environmental context. Thus because the treatment of blood pressure in middle aged 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, including but beyond the RCT, has been an increasing preference for research methodologies which 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 are collected in ‘quantitative’ research while, in qualitative research the value judgements are present in the questions which are asked and the interpretation of the findings.

Complexity theory has informed a further critique of reductionism which contrasts ‘mechanism’ to ‘emergence’. This distinction is well illustrated in different approaches to macroeconomics. Neoclassical economics has built an edifice of theory and method which assumes that the properties of the macroeconomy can be (or should be) traceable from the constructs of microeconomics, in particular, the dynamics of supply and demand and their impact on price and volume. Heterodox economists argues that while supply and demand may determine price and volume at a local level under certain circumstances, as we escalate from the micro to the macro a range of other factors, including politics and power relations, become more influential. Complexity theory highlights the uncertainty intrinsic to complex adaptive systems regarding the macro outcomes of a particular configuration of micro inputs.

Social class is an example par excellence of an emergent phenomenon which has properties at the macro level which 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 which shape health systems.

Looming over these factors in the environment of health related research is the academic citation/impact fetish. Increasingly the research performance (and funding) of universities is being measured in terms of publication in high impact journals and the citations achieved by individual papers. This has the effect of discounting journals which do not service a large constituency, no matter the social significance of the field covered by that journal. It has the effect of encouraging papers which offer widely applicable generalisations rather than focusing on context specific questions. The consequence is a discounting of academic collaboration with community and industry in learning from practice and producing locally relevant knowledge in favour of technological research oriented creating new pathways to markets in the new globalised marketplace. The drivers of industry research are much more closely tied to market opportunities; knowledge as private property. Since most industry research is conducted inside large transnational corporations it is not surprisingly also focused on global market opportunities.

A field of industry research which is of particular relevance to health policy and particularly influenced by health politics is that of clinical trials, in particular of drugs and vaccines. We have referred already to Tuskegee and its modern equivalent, the use of third world subjects for evaluating safety and efficacy. The Constant Gardener by John le Carréis 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 analysis of clinical trials data and 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 which 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 longer term outcomes. This is not always the case.

Program evaluation

In this section we are reviewing how information is generated from data and accessed in the transformation of data to knowledge. We turn our attention to program evaluation where evaluation protocols create raw data. How do the politics of program evaluation shape how these data are transformed into knowledge?

We start by noting the tendency to discount formative as opposed to summative evaluation. Formative evaluation follows the implementation of a program with a view to learning how to do it better. Summative evaluation sums up the outcomes of the program, often with a view to satisfying funders that their investment has been well spent. It serves purposes of accountability rather than learning.The distinction is sometimes captured in the distinction between single loop learning (what am I learning about how to achieve the original goals we established for this program) 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 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 to the view that some of their effort 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 a vis the donor. Both learning and accountability are important but in the context of this kind of funding hierarchy (for example, from USAID to the Global Fund to community organisations) learning on the ground is sacrificed to accountability.

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

The contradictions between learning and accountability are exemplified in the evaluation protocols which form part of WHO'sbiennial programme budget (see for example the PB2017-18). For each subprogram there are three levels in the organisation's 'results chain' - outcomes, outputs and deliverables - but only two levels for which performance indicators are identified (for outcomes and outputs) and many of these defy credibility. There is no provision for any evaluation of the lowest level of implementation which are the largely sensible 'deliverables'. The fact that many of the outcome indicators (eg, 'the number of countries who have adopted a policy relating to this issue') are literally incredible illustrates the ritualistic nature of this approach to evaluation.

Knowledge: generation, authorisation, communication and management

As depicted in Figure 1,knowledge is about wheres and whats, whys and hows, goods and bads.

We mentioned earlier the different theories of knowledge, comparing realism (the correspondence theory of knowledge) with relativism (acknowledging the recursive nature of human knowledge and its embeddness in human subjectivity). We also contrasted the grand unified theory approach to knowing versus the idea of multiple partial stories which come together at the point of action. Complexity science highlights the limits of the predictable; the concept of the hidden attractor; and the concept of emergent properties, discussed above.

We can identify three different kinds of ‘media’ in which knowledge is generated, transmitted and stored:

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

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

For our present purposes we highlight three important issues involving the politics of knowledge:ideology, marketisation, and the embeddedness of knowledge in the workforce, as ‘human resources’.

We have referred earlier to the role of hegemonic ideology in shaping how knowledge is generated, authorised, valued, and made available. Among the assumptions which are promoted by neoliberalism are: that market mechanisms are preferable to administration, planning and regulation; that private enterprise is generally more efficient than government; that society is constituted by 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. Its driving forces are rooted in the transnational capitalist class including the neoliberal media (Fox News, the Murdoch press); the financial press and ratings agencies; and the dispersed forces of ‘market discipline’, the stock market and money market activists who collectively can force political leaders to sing from the authorised hymn sheet.

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 health care and nutrition in low income countries (and it would be bad form to bang on about the power relations and dynamics of the global economy which perpetuate nation state poverty).

In the mid 1990s when antiretroviral drugs became available there were many voices saying or implying that treating AIDS in low and middle income countries was impossible; 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 was a major factor motivating rich country governments and philanthropists to mobilise billions for new global health initiatives and for the Millennium Development Goals.

The privatisation and marketisation of knowledge is fully consistent with the neoliberal celebration of market forces and 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 organisations such as universities. One of the active debates in this area is the controversy over the digitisation of hard copy libraries. No one argues against the digitisation 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 knowledge access,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 proletarianisation of knowledge workers provides a useful framework for interpreting contemporary movements in knowledge management. Braverman(1974)speaks of the appropriation of shop floor knowledge by the 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 greater division of labour, in order to increase efficiency and profit. As the workers on the shop floor are transformed from skilled artisans into assembly line operatives they are disempowered and increasingly alienated from their work.

The transfer of wet knowledge into soft knowledge is happening in the health sector although at different rates and in different ways. Perhaps the most dramatic is the rise in the power of health insurance corporations over medical work in the USA.

Conclusions

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 which might usefully inform practice.

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