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Context enrichment of health risk surveillance data for use and application: conceptual considerations from an Australian perspective

Summary

Increasing the relevance of health surveillance data for use and application remains a critical issue among users and stakeholders. However methods for displaying and communicating health risk data could do more to enrich these data for use and application. There is too much focus on developers, users and stakeholders and not enough focus on pathway models of disease and health. A greater focus on pathway models would help detail a wider explanation of the health problems across sectors and encourage better acceptance of responsibility for their occurrence within other sectors. Contextual enrichment of health data would encourage a shared theory among these players that would permit greater use and application. Better use of data and its translation into information and increased policy traction are likely to be achieved through processes that effectively: (1) establish a shared theoretical base for risk behaviour surveillance; (2) deliver data about the health and developmental status of individuals living in contexts over time; (3) maintain a systems approach to monitoring and surveillance that builds capacity for development, ownership, access to and dissemination of the data outside of the health system and (4) achieve sustainable partnerships that produce more intersectoral engagement.

Keywords: Surveillance – Risk behaviour – Systems approach – Australia.

Within Australia, the appropriate use and application of data to change the health of populations is a central challenge facing those who seek to maintain and improve the health of individuals, societies and nations through the surveillance of health risk factors in populations. How are the use and application of health surveillance data maximised to improve

health outcomes and reduce health burdens? Most specifically, are there circumstances that maximise and sustain the translation of such data into relevant and timely action?

In posing answers to some of these questions the contents of this paper have been organised to address three broad areas. First, a general outline of the problematic features of non-communicable diseases (NCDs) in terms of their cumulative risk and lifecourse persistence, causal complexity and social gradients. Second, a discussion of systems views of human health and development highlighting resistances to and influences on policy similarity within and across health and other sectors. Third, the need for the context enrichment of health risk surveillance data. This will focus upon the need to move demographic descriptions toward descriptions of human development and developmental resources. This inevitably requires a greater sharing of theory, particularly among the “intersector” of human service agencies, to enable functional partnerships capable of addressing outcomes of interest.

Problematic features of NCDs

Within Australia and other developed countries there has been an emerging concern about the prevalence and persistence of NCDs, among which predominate: cardiovascular disease, diabetes, cancer, respiratory conditions (McQueen & Puska 2003) and mental health conditions – particularly unipolar major depression (Murray & Lopez 1996). There are several over-arching features of these diseases that make their reduction particularly challenging: their persistence across the lifecourse, their causal complexity, and the social gradients that underlie their distributions in populations.

Lifecourse persistence

Normally a finding that a risk factor is only a weak cause of a disorder has resulted in little if any effort being spent

either in determining the nature of the association or in attempting to prevent it. However, as Doll points out, if a large population of individuals is exposed to a weak causal factor then preventing or interrupting the exposure to this risk factor can result in valuable reductions in health and social burden (Doll 1996). Just as importantly, where large populations are exposed to multiple risks that have weak causal associations to the development of these disorders these may have a cumulative effect on outcome. A consequence of this pattern of exposure is that a large number of individuals exposed to small risks may generate many more cases than a small number exposed to a high risk (Rose 1995). Moreover, a pattern of cumulative risk which includes inequities of access, persistent stress, and patterns of social exclusion, imparts considerable persistence of disorder across the lifespan (Evans & English 2002; Evans 2004). Added to this, determinants that predict persistence of disorder (prognostic variables) may not be the same as those that predict onset (risk variables). The former determinants are critical to treatment while the latter are critical to prevention. They may also operate at fundamentally different levels of exposure – these being well beyond the control of an individual.

Causal complexity

Prevention approaches in public health over the past 50 years have mostly been based on individual risk-factor epidemiology. Typically these approaches seek to modify risk factors by targeting “lifestyle” behaviour, aetiological agents and aspects of the environment, particularly as related to individuals. These approaches have had some success in reducing problems, mostly where there is just one or only a few circumscribed risk factors. However, they have been relentlessly focussed upon individuals and individual behaviour and have been de-contextualised from wider social and historical influences that govern whole populations (Pearce 1996). As a general point it is worth reflecting on some of the wider social and historical influences in developed countries that have occurred over the last 75 years and that have affected, nations, families, and individuals.

These influences include contraception and planned birth, legal frameworks for equal opportunity and human rights, joint responsibility for parenting, the emergence of marriage preparation via multiple relationships, prolonged autonomy as individual earners, and less dependency by women on male support (Edgar 1988). Within nations there has been globalization producing a deregulation of job markets, economies, and workplace settings, the rising necessity for two incomes with resultant changes in child care requirements, increased mobility with resultant discontinuities in

social attachments and greater exposure to the forces of migration and social and cultural dislocation.

As a result, prevention approaches have been much less successful in dealing with more complexly determined problems which now constitute the major global burden of illness and disability. Examples include COPD, obesity and the metabolic syndrome and diabetes. These create a substantial disease burden and have increased despite contributions from risk factor epidemiology. Pathways to these disease are more than just risk exposures – they include constraints on choice, activities, and environments and determine the skills necessary for coping with health and development. For example, in Australia, this is apparent in the rise of type II diabetes in Aboriginal populations as they move from one lifestyle to another.

Social gradients

Evidence shows that within and between nations there are sharp social gradients linked to health outcomes and that result in their unequal distribution within populations. The mechanisms that are theorised to link these observed social gradients to unequal population health include: 1) inadequacies in material circumstances which are related to health and that arise from the absolute income of individuals and the resultant (in)ability for them to influence their immediate and wider environment to the benefit of their health (Gravelle 1998; Wolfson et al. 1999); (2) stress diathesis and psycho-neuro-endocrine changes that arise from perceptions of relative income inequality and that cause poorer health (Wilkinson 1996; 1997), and; 3) unequal accumulation of exposures and experiences that have their source in the material world and that produce an unequal distribution of health and illness (Lynch et al. 2000).

The causal complexity of the current range of NCDs to be acted upon, the nature of their individual and cumulative risk exposures, and health outcome differentials that reflect social inequality, lead to an inevitable and known observation: the majority of the determinants of these diseases lie outside of the immediate influence of the health system. Current trends in prevention now emphasize the need for a broader analysis of determinants and outcomes at different levels, within and across contexts. The model of prevention suggested by newer analytic approaches is to locate the best leverage points for influencing the various causal pathways leading to health and other outcomes of concern (Susser & Susser 1996).

Many of the opportunities for leverage of health benefit rest with the transfer of information and knowledge across government and non-government sectors outside of the immediate health sector. While it is customary to focus on the

differences between these sectors and the manner in which these differences militate against the movement of research, knowledge and information, there are similarities in system views of human health and development that may be useful in assisting more of this movement, rather than less, of it. Moreover, these similarities are not being capitalized upon by current health surveillance methods.

System views of human health and development

Sources of resistance

The research-policy nexus has generally been dominated by the view that researchers and policy makers comprise two fundamentally different communities (Innvaer et al. 2002) and that mechanisms that bridge these communities and create a cycle of knowledge development and exchange are needed to enable the uptake and translation of research (Lomas 1997). This requires political will and leadership, structures for better communication and exchange, and individuals in both research and policy settings who are trained to bridge “the two communities”. However, as Lin points out, were it this straightforward, more might already have been achieved (Lin 2004). She notes several potential pitfalls in the assumptions underlying research-to-policy transfer and cites Peterson’s call for substantive and situational social learning (Peterson 1997) among players (e.g. researchers, interest groups, bureaucrats and politicians) suggesting that policy outcomes will depend upon “mechanisms for policy and research governance (Lin 2004, p. 183)”. While undefined, these mechanisms will, of necessity, require cross-sectoral (e.g. agency/bureaucracy, government/non-government/private) engagement in the search for and establishment of similarities in their views of human health and human development. The health system brings notable strengths and weaknesses into such an engagement.

Health bureaucracies are viewed with a mix of envy and suspicion by other government agencies such as education, family and community services, justice, housing and transport. In terms of strengths, broadly, services branded by “health” are seen by these agencies to have high consumer credibility and acceptability. This is not true of the services provided by these other agencies where their consumers may be prisoners or wards of the state rather than patients in clinics or clients in health classes. The status of the health system is based on established methodologies – not only for treatment, but in the measurement of risk, procedures for risk management, intervention technologies and frameworks, and an established and well-identified infrastructure. While the subject of envy by these other government agencies, the

weaknesses come in the form of a large share of the public purse in which health is seen by other agencies as being “predatory”, as having a focus on illness rather than health, and possessing a reified culture and language in which health, more often than not, “talks to itself”.

There are also considerable differences in the world views of health bureaucracies, these other agencies and, particularly, governments of the day.

Whatever might be said about health promotion and the maintenance of health, the health sector sees the prevention, detection, treatment and management of *disease* as its principal mission. In contrast, the problem view across other government agencies and non-government organisations is considerably wider and encompasses problems of *human development*. Across these departments there will certainly be different languages to describe aspects of concern, or departmental missions about, the problem focus. It is in these contexts, though, that non-communicable diseases can be seen to be part of a wider family of concern for government, non-government and private sectors alike. Diabetes, cardiovascular disease, cancer, respiratory disease and mental illness are merely a subset of problems that confront policy and decision makers of other sectors in deciding on a course of action and on the use and application of data.

Ultimately however, what most political systems see is concerned with very little of this. In Australia, the broad view of the political system is focussed upon forms of *participation*: economic, civic and social (Fig. 1). So the political system measures its success in terms of participation, while across government departments there is a broad interest in addressing factors that prompt, facilitate or constrain human development in the achievement of participation, and within this, the health system confronts, more latterly, the prevention of non-communicable diseases – many of which have determinants on causal pathways more accessible through the missions other government departments or through political means.

Sources of policy similarity

Freeman has discussed three mechanisms that produce cross-national similarity in health care policy. These are equally useful in considering similarities in the policies of government departments within a nation or state: *convergence* in which policy similarity occurs though similar forces acting on different systems; *diffusion* through the movement of information and technologies between them; and *internationalisation* through the imposition of a common regulatory framework (Freeman 2000). With little effort this latter mechanism could be re-titled “*intersectoralisation*” – referring to a common regulatory framework for policy in

What the government sees Participation economic social civic		
Developmental outcomes poor attachment, poor cognitive development poor speech and language Educational outcomes truancy early school leaving alienation	What other agencies see	Risk behaviour outcomes substance use, early sexual activity, physical inactivity Social outcomes institutional care, racism imprisonment, inequity, exclusion
Physical health outcomes diabetes, cancer, respiratory conditions, cardiovascular disease	What the health system sees	Mental health outcomes Attention deficit disorder depression/suicide aggression

Figure 1 Systems views of the problems of human development

government bureaucracies within the same national or state jurisdiction.

Broadly speaking, within Australia, the principal force for policy similarity operating across government departments has been achieved through fiscal and prudential regulatory frameworks that largely have sought to achieve cost containment and efficiency by regulating the competitive allocation of resources and services. This has mandated public contracting of government services with the separation of mechanisms of funding from those of purchasing and providing services. Thus intersectoralisation has been achieved principally in the conduct of government business – that is, the form of it – rather than through any coherence of policy (i.e. the content) aimed at developmental outcomes across government departments – be they outcomes for health, education, justice, welfare or otherwise. Certainly in Australia there has been a recent interest in “whole of government” policy approaches to more complex problems of human development. While the rhetoric of these initiatives suggests intersectoralisation of policy content, in the main such initiatives are linked to short term policy strategies that overarch government departments and that do not regulate joint strategic development of services and joint accountability for outcomes. Most particularly these actions are not sustained across the lives of governments in ways to produce policy coherence, fidelity and efficient progress.

Policy convergence on the other hand is being driven (at least tacitly) by the outcomes of interest summarised in

Figure 1. Whether these outcomes are regarded politically (as forms of social, economic and civic participation), or as strategic issues for the whole of government (i.e. juvenile offending) or as “core business” for specific government departments (e.g. in the case of education authorities: school failure, truancy, early school leaving) they have a similar basis. This similar basis is in the form of shared and cumulative risk exposures, lifecourse persistence of many of these problems, causal complexity, their appearance across a variety of service sectors (e.g. mental health, education, judicial) and unequal population distributions substantially linked to social exclusion and inequality.

At present, the health sector focus on non-communicable diseases confronts it with surveillance data and a theoretical and technical expertise of high relevance to the missions and interests of *other* sectors – particularly where those sectors have substantial control over the determinants. This makes the mechanism of diffusion – that is, the movement of health information and technology to other sectors – of considerable significance.

If we agree that improved health benefit could be achieved by establishing a common developmental focus amongst government departments and, that diffusion is a potential mechanism to achieve policy similarity, then the principal problem with health surveillance data is its propensity to talk to itself. It is too de-contextualised from the business of other agencies outside of health to enable them to participate. These other agencies are focussed on their

own immediate objectives (e.g. teaching, building housing, addressing crime) and not on the wider (i.e. macro) drivers of these outcomes that are shared across other sectors including the health sector. This limits policy leverage.

At the moment, health outcome (or health risk) and time are the principal axes most often used to describe health status (McQueen & Puska 2003). This gives rise to messages that more of the population is fatter and sadder this year relative to last year and leads to exhorting individuals to eat more fruit and vegetables and to increase their physical activity. Undoubtedly for some individuals this is realistic advice. However, these are small levers relative to the theoretical base driving the context of cardiovascular disease and depression and their unequal distribution within populations.

Context enrichment of risk surveillance data

Looking over global health risk factor surveillance at the turn of the century, McQueen noted four essential fundamental elements underpinning these systems: a theoretical base, time as a variable, a systems approach and enduring partnerships (2003: 285). If it is generally agreed that the determinants of current NCDs lie in sectors outside of the health system, then the enduring partnerships that enable systems approaches are going to need to be established upon a more shared theoretical base. Establishing a shared theoretical base could be facilitated were health surveillance systems to take a broader view of presenting their data. This will require, as a first step, creating a surveillance focus for inter-sectoral cooperation. This dialogue would be facilitated by more context enrichment of existing surveillance data to enable sectors (i.e. partners) to identify those modifiable exposures over which they have agency and that would produce developmental benefit for individuals and particularly, for populations.

How can greater context enrichment of health surveillance data be achieved?

From demography to human development

A first reasonable step would be to change the basic approach to the use of demographic variables in health surveillance. Despite extensive demonstrations of the relationships between social gradients and health, the mechanisms that link these observations to population health outcomes are still poorly understood. The theoretical bases is one of considerable debate (Wilkinson 1997; Lynch et al. 2000; Marmot & Wilkinson 1999). However, the commonalities among the theories – chiefly that there are social gradients and inequalities in health – are not disputed. Indeed, much of what the health sector understands about this would be of

greater benefit were it consistently displayed with data relevant to other government sectors.

Within surveillance data demographic measures need to give way to better measures of developmental resources that are relevant to the *contexts* of people's lives and that link to broader level (macro) social, environmental and economic indicators as well as individual health and human development outcomes of interest. In the first instance this need not lead to radical changes in data items and fields collected in routine surveillance – particularly where some level of traditional demographic description is already present in the collected data. What is required is a more explicit commitment to a theory of human development. This means relinquishing the belief that, in addressing the non-communicable diseases, population health gain can be reduced merely to the actions of individuals themselves. From a developmental resources framework it is then possible to move towards using the data to describe contexts in which health (and other) outcomes can be measured over time.

For example, Table 1 shows some common demographic variables in the left-hand column. The centre column expands this framework using a human development perspective – one that acknowledges that there are “resources” that are relevant to developmental health and more widely, to human development. So, for example, a traditional demographic variable measuring “employment” is broadened to include a measure of time – that is, the number of hours in paid employment. Time is frequently characterised along dimensions of both quality and quantity, and it is also regularly understood by its value in economic and social terms. Individuals supply time as well as income to a variety of activities: receiving income from time spent in the marketplace and receiving “utility” from time spent, eating, sleeping, participating in other activities including caring for children (Becker 1993). This measurement can then be used as a proxy for “time poor” in the sense that a high commitment in hours to paid (or unpaid) work may reflect little or no time to invest in one's self or others. Thus the demographic variable of employment, when modified to capture hours in paid employment, can be used to characterize contexts that are “time poor”. It is still possible to distinguish those who are employed from those who are not, however, a degree of context enrichment is gained in the process.

Many of the demographic variables in Table 1 have a reasonable analog in terms of resources for human development. Some areas, such as developmental resources corresponding to “psychological capital” are rarely represented in sets of corresponding demographic variables. Given the considerable population burden that mental health disorders pose, and their clear relationship to other NCDs, this

Table 1 Moving from demographic variables to indicators of developmental resources to descriptions of contexts

Demographic variables	Indicators of developmental resources	Descriptions of contexts
Employment	Time Hours in paid employment Hours for self	Job/no job Full time/part time/casual Time poor
Income	Income Total income Financial strain	Cash poor Low debt/high debt Assets/no assets
Marital status Education	Human capital Family structure Education Physical health	Sole parent/Step-blended/original/extended family Level of/participation in education Partner/no partner Children/no children Physical restriction/no physical restriction
	Psychological capital Mental health Parenting skills	Low stress/high stress Low control/high control
Race Gender Age Ethnicity	Social environment Social support Social exclusion Participation civic economic social	Social support/ no social support High mobility/low mobility Access/No access Participation/no participation
	Local environment Neighbourhood Community School	Urban/rural/remote Establish community/new community Disadvantaged school/not disadvantaged

absence in surveillance data will have to change. Similarly, the local environment of the neighbourhood, community and school do not constitute demographic variables per se, although there may be capacities for such measures to be linked to relevant small area data, or to be derived through aggregation. The point is, they provide critical contextual information about individuals and populations. This provides a description of the contexts in which people live their lives which moves beyond the traditional collection of “demographics” and requires displaying data that are more descriptive of social settings and contingencies. Data described this way are also more descriptive of how human service agencies do their business.

Figure 2 provides a demonstration of these principals using a single time point from cross sectional data of a large random sample (N = 2737) of Western Australian families (Zubrick et al. 1997). The academic competency and mental health of children in these families are shown with respect to the family work contexts that occur in two-parent and sole parent families. In this case the outcomes are of interest to (at least) two sectors: health and education. Measures also include: time (mean hours of employment per week), income (the lowest income quartile), human capital (maternal education, disciplinary style and family function), and psy-

chological capital (parental mental health and life stress events). These data show that developmental resources *within* families and *between* contexts are linked – for example poor human capital resources (i.e. low maternal education) occur more commonly in contexts of parental unemployment and low family income, greater levels of stressful life events, and poorer parental mental health. Children in these families are more likely to have a continuation of these characteristics between contexts in the form of a greater likelihood of attending a disadvantaged school.

From shared theory to partnerships

Several sectoral interests are represented in Figure 2. Aside from the obvious interests for the health and education sectors – in the form of the mental health morbidity and academic competency of populations of children, poor maternal mental health and the distribution of disadvantage schools – the welfare and family and community sectors have their interests represented by estimates of low family income, family conflict and coercive discipline. All of this is further contextualized by the nature of the family structure and employment arrangements within these families.

The example used here is a cross-sectional snapshot and does not reveal changes over time. However, the data

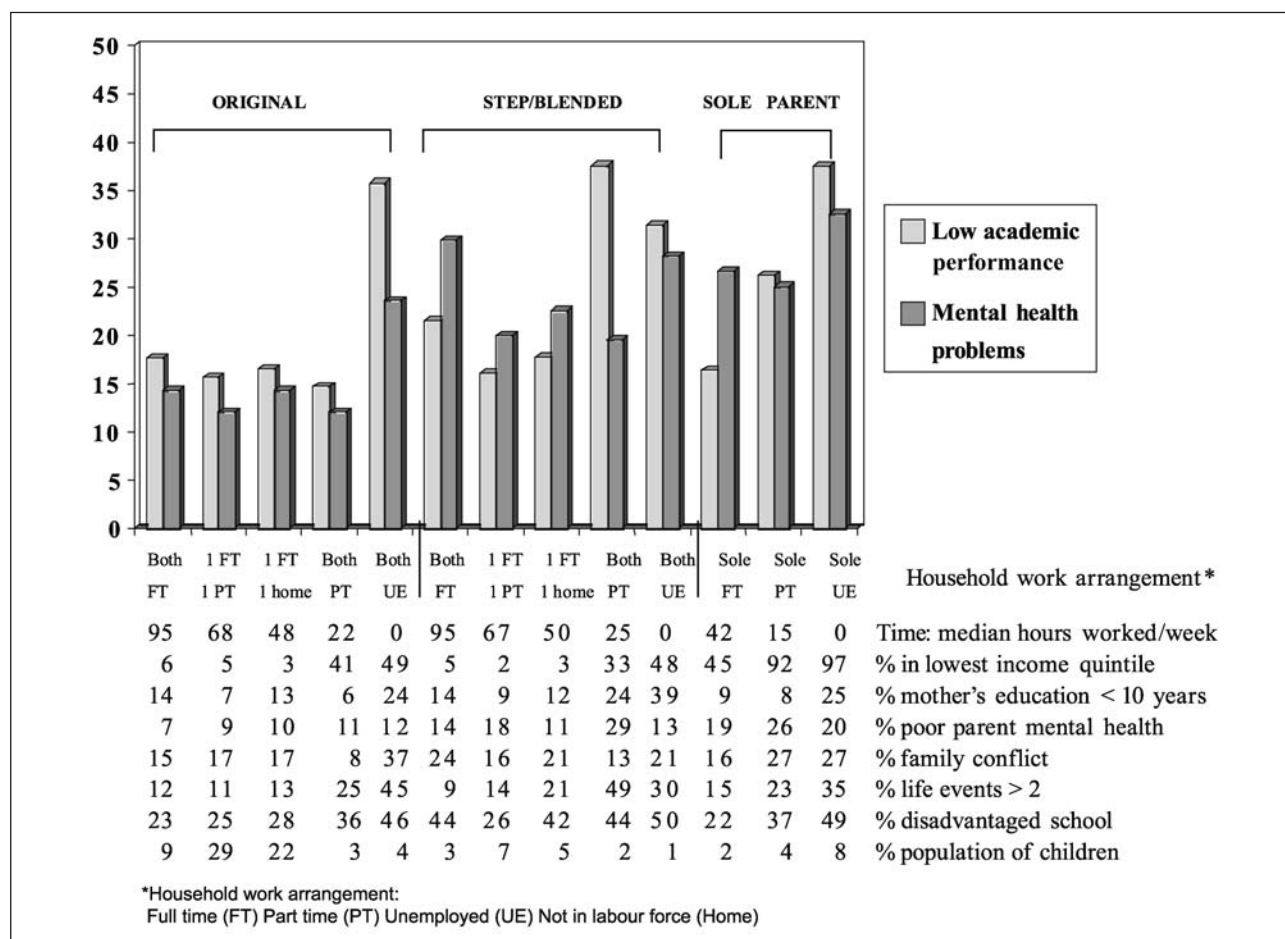


Figure 2 Context enrichment: low academic performance and mental health problems in children by family type and household work arrangement

view is more inclusive of other jurisdictional interests and widens the potential for exchange among partners – an essential step in the establishment of systems approaches where determinants of health outcomes are influenced by responses outside of the health system. In applying this approach, and deciding on the nature of the data to be collected and/or displayed, some basic questions need to be addressed:

- What are the principal modifiable determinants of health outcome(s) of interest?
- What are the pathways that lead to and from these outcomes?
- What processes that influence these paths?
- Where are the shared interests?
- How are these talked about inclusively?
- Is it worth it?

These are not novel questions and the procedures to address them are well established in the health sector. The challenge is one of moving the dialogue out of the health sector and

engaging the partners. The establishment of a shared theory along causal pathways is a critical step. With respect to the causes of specific NCDs a basic assessment of the adequacy of the underlying causal theory is important. The causal basis needs to be “good enough” to proceed. What would follow from this entails disseminating risk technology and risk management frameworks in ways that are usable by other sectors. This will, in most cases, require backgrounding the “health” word (i.e. that’s “health’s” problem), and promoting the interests and expertise of other agencies. For those who are responsible for data analysis and the creation of outputs this will require knowing the user’s contexts and work relevance to the health outcomes of interest. If this is sustained, and if causal fidelity in the data application is maintained, there should be a growing capacity to focus on “what-if scenarios”, cost modeling (of health care, prison services, educational outcomes etc.), and whole-of-government evaluation and planning.

Relevance revisited

In promoting the use and application of data there are several considerations to keep in mind. First, there is a compelling case for the monitoring and surveillance of NCDs. NCDs are forecasted to account for over 70% of global death and 60% of disease burden by 2020 (Murray & Lopez 1996). Second, developed countries predominate in the league tables of this rising epidemic. That is not to say developing countries are unaffected by NCDs, but it does suggest that there will be competing global interests in establishing a behavioural risk surveillance agenda and that these interests will be driven by differing economic, political and social priorities.

Third, primary prevention – whether it is universal, selected or indicated – is the principal mode of intervention to lower the burden of NCDs. Merely monitoring the prevalence of NCDs offers little or no avenue to reducing their prevalence. Fourth, because the pathways to these diseases are complex and entwined, intervening requires changing exposures to risk and protective factors. This commits surveillance to a program of monitoring risk exposures.

Finally, since the causal influences on NCDs are the target of the monitoring system the logical consequence of this is that surveillance systems will require firm theory and evidence to guide the selection of the exposures to monitor. So, the data we are hoping to see used and applied are a mix of prevalence data on NCDs and, quite importantly, data that monitor rates of exposure to influences on the causal pathways. These exposures are contextual as well as behavioural and need to reflect the interests and capacities of sectors other than health – particularly where these sectors have an influence on the modifiable pathways to the outcomes. Greater contextualisation will require acknowledgement that there are multi-level influences on population health that transcend, or are superordinate, to individual behaviour. These macro-level influences may well cap the extent to which population health can be improved without fundamental changes to social, cultural or political policies and practices. To fail to document these influences will not only result in blaming the individual, but in blaming agencies charged with the responsibility of effectively intervening.

McQueen and Puska (2003) summarised the current global perspective on risk factor surveillance with regard to data use and application. They noted three spheres of surveillance activity controlled by (1) system developers, (2) data users and (3) stakeholders. The underlying issue of data use rests in its application and resultant outcomes. Outcomes occur when the information arising from data are of good quality (methodologically sound, timely, and creditable) and *relevant* to stakeholders.

Relevance of data remains a critical issue because it arises from a dialogue between users and stakeholders (Ottoson & Wilson 2003). And it is here where the data themselves are impairing this process. There is too much focus on developers, users and stakeholders and not enough focus on change pathways. The data focus is on the health outcome rather than the pathway of influence. Too much effort is being made to distinguish users (e.g. users are people who work to increase public information and awareness as part of any major national health strategy – researchers, educators, policy makers and advocacy groups) from stakeholders (e.g. individuals, groups, partners, organisations or institutions with an interest in health surveillance). This distinction is not overly helpful – we are particularly interested in stakeholders and users who can influence the causal pathways to the health outcomes of interest. Presentation of data needs to empower them. More empowerment is likely to be achieved through processes that effectively: (1) establish a shared theoretical base for risk behaviour surveillance; (2) deliver data about the health and developmental status of individuals living in contexts over time; (3) maintain a systems approach to monitoring and surveillance that builds capacity for development, ownership, access to and dissemination of the data outside of the health system and (4) achieve sustainable partnerships that produce inter-sectoral engagement. These actions could foster an improved narrative of the disease experience and the causal pathways which could in turn allow action from a number of policy perspectives.

Conclusion

There is no holy grail to data use and application. Health risk surveillance systems are dominated by a preponderance of scientific method and logical positivism coupled with an overvalued focus on details. This creates a prevailing health surveillance *modus operandi*: “if only the rest of the world would see things the way we do”. While this is understandable, wishing this will not make it happen. There are numerous contradictions in the movement of evidence to policy and practice (Lin 2004) and political will may be the determining factor that governs research utilisation and its final impact (von Lengerke et al. 2004). Notwithstanding these realities, there would seem to be more scope for better multi-level context enrichment of surveillance data by appropriate extension of demographic descriptions to encompass principals of human development. There are considerable convergent influences on policy and practice within and between human services agencies that invite a more strategic approach to enable better dissemination of information and knowledge relevant to improving population health and well-being.

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