Agenda-setting in health reform: the role of community

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Abstract

This paper presents a number of issues surrounding the setting of agendas for health care reform. We argue the need for increased community involvement, as well as the necessity to wrest health-care decision-making from health care professionals, or at least to ensure that such decision-making is informed by community values.
We attempt to answer a few questions: who sets the health reform agenda and who should set it, how is the agenda set and why is this critical, when and where is the agenda set, and how should the agenda be set in the future?

Who sets the agenda? Property rights and community values

In health there is a professional environment, diverse in interest and disciplines, where the goal is to improve society, or make a difference, and serve others. Health care professionals are schooled in and imbued with an outlook that values expert knowledge, respect for others and that all humans have a right to certain things in life.

However, conflict arises when the values of one individual, with respect to a certain idea, differ from the values of another. Similarly, conflict can arise when the values of the health providers differ from those for whom the service is being provided. If health planners, managers and providers are working within a discrete environment, with its own ideology (broad church as that may be), and determine to reform services in a certain way, then it is very possible that the values underpinning those decisions may differ from the values of the communities they are trying to serve.

Because health planners, managers and providers are inculcated with an "industry" professionalism, and often work within a bureaucracy, the intention and goals of their services may differ from the community they serve. The parameters of reform are similarly restricted. This raises the question not often asked: who should set the health reform agenda? We are clear that the answer here has to be 'the community'.

This is, however, seldom the case. The community is more often presented with a fait accompli or a single take-it-or-leave-it option. Examples are the UK and New Zealand reforms of the early 1990s where neither was subject to the normal democratic voting processes at an election before being introduced, and consequently with no chance of the peoples' voice being heard in advance.

In health care policy generally there is a lack of apparent concern with community values, and indeed, explicit values at all. This is also apparent in the case of reform, and not just at a total systems level as in the UK and New Zealand examples above. While there are many examples of community consultation about hospital closures or changes, there are few where the community's values have been the driving force. Too often at the local consultation level the choice has been 'take it or leave it'.

The questions 'what does the community want from its health services?" and "what principles does it want to drive the health services?" remain unasked and unanswered. Community here is meant citizens and not simply

patients. While there are numerous problems in identifying more precisely what is meant by community and even more so in eliciting community values, these issues are not the subject of this paper.

A central concern of this paper is the simple idea that the values of the decision-maker underlie decisions and actions. We suggest that the greatest need for reform in this century is to give health services back to the communities which they are there to serve by listening to those communities, taking due account of the preferences of those communities, and responding to what the community holds to be important in a health service.

It is strange that so little is known about what citizens want of their health services. It is even more strange that so little effort has been made to find out, especially when taking into account all that has been written and discussed about the future of health care, quality, evidence-based medicine and health care, and health outcomes.

At the start of the 21st century, the health reform agenda is set by professionals operating within a culturally specific ideological framework. This is based on an assortment of "evidence", but evidence which has been gathered to answer questions framed within a world-view, where medical and scientific information are seen as the gold-standard of knowledge. It is also a world where the jump from information and evidence to "expert knowledge" is made easily, almost seamlessly, without adequate thought being given to that process and about the potential gaps and pitfalls that lie in that jump.

The agenda for reform should be one that starts by examining the appropriate distribution of "property rights" with respect to health service decision-making. We are not arguing for people power throughout health service decision-making. Our point is rather that there seems to be suspicion and confusion about the ability of individuals (who collectively comprise a community) to arrive at rational, informed and reflective preferences about health services as a systems organisation and as a social institution.

The implications of this are many. Fundamentally it would require wresting the existing value base away from medicine and science. In doing so health professionals must recognise that any health service or system is a social institution and will be culturally-based and that what the Danes want from their health services or systems may well differ from what the Australians or the Japanese want. That recognition simply strengthens the need for incorporation of community preferences.

There is an issue here with respect to which decisions should be informed by community preferences. The literature here is small. Virginia Wiseman of SPHERe is examining this question in the context of what the community wants with respect to its involvement in health service decision-making (i.e. the community's preferences about community preferences).

Instead of the nature of health services being decided by professionals whose starting point is their medical/health professional background, we suggest that the community should be charged with deciding what they want from health services, provided that the community's preferences are for the community to exercise such preferences. That community's decision can and should be influenced by evidence that is able to assist in distilling the principles that community wants to underlie its health care. It is at that level that evidence should come into play. Evidence should thus follow and not lead any debate.

To change who sets the agenda in this way is quite radical. It is important that that is recognised as such. The medical profession and the health care professions more generally have for too long dominated, even monopolised, the health care and health reform agenda, with the voices of patients and 'consumers' at best muted and the community as a whole almost non-existent. Debates about financing, hospital funding, paying GPs, prevention versus cure, inequities, and the balance of care are empty if they are not informed by what good is to be achieved through the social institution that is health care. It is for the community voice to determine the nature of the good in this context. Who else should be turned to in order establish any agenda for reform?

How does it happen?
The foundations and motivations for the health reform agenda

The foundations and motivations for the health reform agenda are based on "epidemiological evidence" and a view that limits health reform to health-related issues, institutions or services. While epidemiological evidence is sometimes used as a foundation in health reform decision-making, that same or different evidence, reported to a community, might result in different decisions being made if that community's values are allowed to underpin those decisions.

Our fundamental point is that the greatest need for reform is to give health services back to the communities to be planned according to the good as they, communities, define it. This is not to argue that epidemiology does not have its place in health service planning and priority setting. The question rather is what place? The legitimate role of evidence-based medicine and evidence-based health care cannot be resolved without first answering the question: "evidence about what?" Perhaps the questions should be what research has been done, who determined that their research would be done and whether, if other research were done, a different evidence-base might not emerge?

There are dangers in the value base of epidemiology where the only concern of health services is health status. It is then the big health problems that dominate the agenda for priorities (as has been the case with the logic underlying the "Goals and Targets" movement in Australia and indeed the World Bank and WHO's concerns with burden of disease).

In re-setting the agenda for the reform of health care there is a need to recognise anew that health care systems are first and foremost social organisations and not simply medical institutions. However, the question "what is the good of health care?" rarely gets asked. It is frequently assumed that health care systems are about maximising the health of the population only, although on occasion social justice concerns are raised. While the idea of health maximisation (subject to some concerns for equity) seems eminently reasonable, the reality seems different. If this were the case, it is expected that this value should pervade health policy. What does health policy tell us about the values of the policy makers?

It is recognised that the poor have more health problems than the rich. Efforts in NSW to move the hospital base to the less affluent citizens in the Western suburbs of Sydney failed, allegedly as a result of pressure from the powerful teaching hospital doctors in the wealthy Eastern Suburbs.

Evidence would confirm that Aboriginal and Torres Strait Islander peoples of Australia have very poor health status in comparison to Australians of non-Aboriginal and Torres Strait Islander background. It would seem to follow that there ought to be considerable resources going into services for Indigenous peoples on grounds of both efficiency and equity. The problems in delivering services that are culturally appropriate and able to serve many Aboriginal and Torres Strait Islander people living in remote areas, merits substantial research into what does and does not work and what is equitable and efficient. There seems to be very little research on these issues.

The existence of the private health insurance industry in Australia and in particular its size is neither health maximising nor equitable. It is big in international terms with most countries in the OECD having larger proportions of their health care spending coming from the public purse. Can anyone doubt that if the same money were spent in the public sector it would be more efficiently used in the sense of providing more health care to more people? It is also inequitable since it allows the better off in income to be better off in health than their poor in income and health counterparts.

The Federal government's decision to subsidise the private health insurance industry with $1.6 billion is surely the most revealing preference in the context of this discussion. That money could have tripled the spending on health services used by Indigenous people. Despite arguments that the policy reduced demand on public hospitals, those well off in income and health were seen as more deserving by the government of at least a higher standard of amenity, and at best timely access to services (provided they had an income which allowed them to be in a health fund at all).

At an international level there are problems but of a different kind. The latter part of the 20th century saw a multinational industry in comparing health care expenditures across countries. Yet it is not clear whether it is

better to be above the average or below! Australia is roughly in the middle. Is that good? How should it be judged? How illogical such work appears once one accepts that what countries are seeking from their health care systems is different.

WHO advocated for Health for All in the Year 2000. They did not ask communities what they wanted from their health services. They assumed they knew. More recently, together with the World Bank, WHO has advocated basing priorities on burden of disease and thereby encouraged health service policy makers to believe that all that communities want from their health services is a reduction in the burden of disease. They further assume that nominally equal health losses in Brazil, Belgium and Botswana are valued the same in each of these countries.

Is this a new colonialism with international or national health decision-makers sitting in judgement about the best way for a community to provide its health care when that community has not been consulted about those things it holds to be valuable? How elitist! (Australia can perhaps more readily identify this elitism given its history of providing health care for Indigenous peoples without asking them about their preferences.)

Setting the agenda for health service reform must start with the values of the communities that these health services are there to serve (recognising that different communities will bring different values to the process). Once we know what the community values are we can begin to garner the evidence to allow us to pursue more efficient and more equitable health services.

When and where does the health reform agenda get set?

We suggest that instead of the health reform decisions being taken in health service bureaucracies in response to political and financial imperatives, local reform should be influenced by communities advocating for their choice of health service. In this context it is worth considering explicitly the issue of research and its role in shaping policy decisions. Given that research probably has some influence on health decision-making, this raises the question of who determines what research gets done? Research is costly. It has to be funded. Who then determines what research funding bodies will fund? At its most democratic it may be that a panel of learned experts determines an organisation's research priorities, based on "evidence". How did that evidence come to light? Who chose to gather it? Who chose to fund the research to collect the data to find the evidence to inform the decision-making? The timing of the "determining goals, targets, priority areas" focus in research would make a useful study. What is the relationship between the social and political environment in which a research organisation operates, and the timing and type of decisions that it makes?

One of the gaps in research with respect to values underpinning health systems is that we do not know what societies want from their health services. This is largely because we have not taken the trouble to ask with the exception of international examples such as Oregon, and the New Zealand National Health Committee's Core Services Project. One of us (GM) with colleagues has recently been working with various groups (mainly policy makers, but in one case with a community) to try to tease out so-called 'principles of health care'. This work has shown that policy makers, when given the opportunity, are very ready, able and willing to try to think through the question of principles through, and a number of sets of principles have now been developed (Mooney, 2000).

The principle of equity, for example, has been set as equal access for equal need (where two individuals have equal access when they perceive the barriers they face to be the same and where health gains in meeting need may be weighted, for example, to give greater weight to nominally equal health gains for Aboriginal and Torres Straight Islander people compared with people who are not Aboriginal nor Torres Straight Islander.

So far this approach has been used in one community only but the same messages, as those from health managers, are coming through. The first sojourn into the community values issue suggests to us that there is a very real prospect of eliciting community values regarding the principles that the community wants to drive the health services of Australia. The next step is to extend this idea of principles, or what Wiseman and Mooney have called 'a constitution for health care' (essentially what and why we want health care systems) into the community to elicit the views and values of the community about what they want from their health services (Mooney, 1999).

It is this ownership issue that we see as being particularly important in this context of principles. Setting the agenda for reform is best done under the umbrella of health services as a social organisation with respect to which the community ought to set the agenda. In practice this is of course no easy task.

We do not seek to establish principles on the basis of ill-informed public opinions that might be led by the latest media story. It is here that epidemiology and evidence must come into the picture to ensure that the values that are built into the shaping of the good are well-founded, reflective and informed. This is discussed below. Science and community values need to be more equal bedfellows in this century than they were in the last.

The value system of the individual or organisation writing the agenda is inevitably reflected in the agenda. As this is the case, we again ask, why community values and explicit values more generally, are so often absent? It may be that health reform agenda setting has been influenced as much by the values of those who drafted the agenda as it has with the supposed evidence-base of the agenda. A key challenge in the 21st century is to balance the evidence about health needs with a community's broader values about the health services they want.

How to set the agenda - where to from here?

Finally, we turn to the question of "how?" The health agenda-setting process, like the health policy decision-making process, has been the subject of very limited research. In contrast, whole industries have arisen evaluating the best way to manipulate public perception/communication environments so that a certain agenda is favoured - political campaigns, advertising, perhaps all mass communication output has to do with setting an agenda to provoke some desired outcome by the person steering the communication. This would be a fine thing if the information being circulated and the outcome were always for the public good, but we know that to be not the case. We know this is very powerful: indeed health promotion initiatives that do not incorporate a setting-specific, agenda-setting strategy would seem less likely to succeed. If the health reform agenda takes on a life of its own because lucid, influential, senior decision-makers combine to promote a certain way of thinking, is there any room for challenge?

How do these decision-makers decide? What if learned experts decide on a set of health goals and targets in a hurry because one needed to catch a plane and there was no time for discussion? Could this happen? How much is "evidence" considered in health policy decision-making? The extent to which evidence about community values or any other evidence comes into agenda setting and policy decision-making is unclear. Ultimately, whether it be personal, political or purposeful, we suggest that any agenda set is a factor of four key things: the position of influence of the communicators or champions and their media, the framing of the idea, the environment in which the agenda is evolving and the language used.

We must seek to understand the values of the community we wish to serve, with respect to health reform. Otherwise, the health reform decision-making agenda is in danger of being hijacked by the language, ideology, influence and political agendas of a decreasing number of increasingly powerful national and international health decision-makers. We believe it is this reductionism that represents the greatest hazard to the provision of good health services in this century.

Ideas explored in this paper were first presented at the "Redesign, reform or revolution?" Symposium of the Australian International Health Institute, Melbourne. 11 November 1999

References

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