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GUEST EDITORIAL

Social values and health policy: a new international research programme

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Abstract

Purpose – This editorial aims to outline the context of healthcare priority-setting, and summarise each of the other ten papers in this special edition. It introduces a new multidisciplinary research programme drawing on ethics, philosophy, health economics, political science and health technology assessment, out of which the papers in this edition have arisen.

Design/methodology/approach – Key normative concepts are introduced and policy and research context provided to frame subsequent papers in the edition.

Findings – Common challenges of health priority-setting are faced by many countries across the world, and a range of social value judgments is in play as resource allocation decisions are made. Although the challenges faced by different countries are in many ways similar, the way in which social values affect the processes and content of priority-setting decisions means that those challenges are resolved very differently in a variety of social, political, cultural and institutional settings, as subsequent papers in this edition demonstrate. How social values affect decision making in this way is the subject of a new multi-disciplinary research programme.

Originality/value – Technical analyses of health priority setting are commonplace, but approaching the issues from the perspective of social values and conducting comparative analyses across countries with very different cultural, social and institutional contexts provides the content for a new research agenda.

Keywords Social values, Health organisation and management, Decision making, Resource allocation, Health priority setting, International comparisons, Multi-disciplinary research

Paper type General review

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All health care systems are facing the challenge of ensuring that high quality care is provided to all those who need it, at a cost that the country can afford. This comes at a time when people are living longer, have increasing expectations of what care should be provided, and when the speed of health care innovation continues to offer ever greater options for intervention. Because no country can afford to provide all its residents with every possible medical or public health intervention, all health systems are facing the problem of how to set priorities in the allocation of health care resources.

Setting priorities is undertaken at many different levels of decision making, from the highest reaches of policy where governments allocate overall national budgets, to the bedside where clinicians make decisions affecting individual patients. Priority setting in healthcare is also not unique to governments. Commercial healthcare organisations and private insurance companies engage in priority setting when they determine entitlements and exclusions as do global donor agencies and non-governmental organisations in their work in low and middle income countries.

Whatever process (whether implicit or explicit) is used to make these decisions, value judgements are inevitably involved. Even explicit and seemingly "scientific" criteria such as clinical and cost effectiveness are embedded in views about, for example, the value of different health states, views that are shaped by the experience and background of the analysts that conduct them and the norms governing the institutions that employ them. In addition to these formal processes, broader social value judgments affect the decisions. These social value judgments may include both the values of the population found in their civic culture as well as ethical considerations as weighed by policy-makers in their decisions and identified in their decision-making protocols. Such decision-making is informed by a number of values including justice, solidarity, autonomy, respect for persons, beneficence and compassion, and it is these values that commonly figure in debates about priority setting. But social values are also implicated in the processes by which such decisions are reached: considerations of transparency, accountability and participation are all important.

National health systems cannot provide everyone with all the care they would like to receive, and so priority-setting will mean exclusions of cover or treatment for some diseases and conditions. In this context, priority setting should aim to produce an allocation of healthcare resources that can be ethically justified, especially to those who lose out as a result of resource allocation decisions. Such an ethical justification requires articulation of social value judgments, both in terms of the process of decision-making, on which allocation decisions rest, and in terms of the content of those decisions. Such a justification is a vital element in any public legitimation of how priorities are set.

Yet, although many of the challenges are common, healthcare systems in various national settings will make different decisions about priorities, differences based on the distinctive balance of social values in each country, as well as their particular methods for capturing and incorporating values in decision making. These differences will also reflect the level of economic development of each country, its institutional arrangements for deciding on health care priorities, the balance of power between competing social groups within the decision making system and the distinctive civic culture that prevails. It is this combination of common challenges, encompassing both management challenges and ethical challenges, and distinct institutional and cultural differences that makes the cross-national comparative study of social values and health

care priority-setting so important to understand. Before systems can learn lessons or even exchange experiences with one another, they first need to locate the social value challenges in their specific circumstances. It is this task that the papers in this volume set out to achieve.

This special edition describes the genesis of a new international research and policy network established to tackle these questions. In February 2011, participants from seven countries met in London with a follow up meeting in Rio de Janeiro in June 2011. Researchers and policy makers from a range of disciplines and professions came together to share experiences, to learn from each other and to explore how decisions on health care are made and how they can be improved. The papers in this volume represent the first fruits of this meeting and constitute an initial attempt to see how cross-national policy research and development on the role of social values in priority setting might proceed. These papers include revised versions of presentations at the workshop as well as papers especially commissioned to supplement the range of cases that were the focus of the workshop. Their starting point is a draft template instrument for assessing the role of social values in health care priority setting, the object of the template being to detail the logical pattern of such values. That template is included in the first paper in this volume (Clark and Weale, 2012).

Clark and Weale divide relevant social values into two broad categories. The first includes substantive values like clinical effectiveness, cost effectiveness, justice (also sometimes called equity), solidarity and autonomy. The second category covers process values, including transparency, accountability and participation. The purpose of the template is not to describe what values are actually found in any one system, let alone prescribe a set of values that policy-makers should implement. Rather the purpose is to provide a logical mapping of what values might be found and so suggest a check-list for analysis. In particular, the paper suggests that these values may be found in varying degree of strength in different policy systems. For example, solidarity may be strongly present in some systems but not in others, where a greater stress is laid upon individual autonomy. In principle, the template should provide the basis for a "value profile" for each country, where the elements of the profile are given by the position that a country occupies in a general value space. One function such a template can serve is to help identify the value trade-offs that are involved in priority-setting. It is important to know, for example, whether in practice those countries that stress social solidarity in their health care systems also lay stress upon accountability or place less weight on individual autonomy.

Biron *et al.* (2012) take up the complexity of the issues involved in establishing ethical validity. In particular, they draw attention to the short-comings of purely procedural approaches to priority setting in health care. Because social values are complex and applying them to decision making in practice raises difficult questions about broad social acceptability, there has been a tendency among those commenting on priority setting to stress procedural values. In this way, so it is thought, even if there is not agreement on the grounds on which decisions are taken, there is at least accountability and openness in the way in which they are made. However, according to Biron, Rumbold and Faden, the difficulty and complexity of developing and applying procedural values should not lead us to ignore the substantive values that properly might determine choice. Moreover, the paper also draws attention to the complexity of

applying values when the very good that is the subject of allocation – health benefit – itself can receive different interpretations.

These conceptual and methodological questions pave the way for the empirical examination of how social values in practice shape and influence priority setting. A striking feature of the findings that emerged in the workshop and in these papers is the extent to which questions of social value arise in very different institutional and cultural settings. In Thailand, the tax-based system of the universal coverage scheme, which applies to the 75 per cent of Thailand's population has developed methods of consultation that enable various stakeholders to propose interventions for health coverage. In this way, although representatives of four groups – health professionals, academics, patient groups and civil society – are able to influence priority setting, other population groups, i.e. policymakers, industry and lay citizen, can also play part of the prioritisation process by nominating interventions for consideration. Alongside this scheme for representative participation and transparency, Tantivess *et al.* (2012) show in three fascinating case studies how the authority responsible for determining coverage took into account not only cost-effectiveness and affordability but also considerations of equity related to the burden on family budgets, disease severity, and uneven distribution of specialist providers.

Along with other systems, the Korean National Health Insurance system is facing the challenges of increased expenditure and an ageing population. Ahn *et al.* (2012) describe the way in which pharmaceuticals, medical devices and diagnostics and procedures are assessed in South Korea and show how issues of accountability are of concern to stakeholders. In the case of glucosamine for osteoporosis, they show how responding to social values, in that case the role of the product in family gift cultures, can alter the way in which decisions would otherwise be made on grounds of clinical and cost effectiveness alone.

In China the primary focus of the analysis of the influence of social values is on the financial pooling arrangements for social health insurance. Cao *et al.* (2012) show how the three major schemes of health insurance protection each cover a specific demographic group: the social health insurance scheme for urban employees; the new rural cooperative health insurance for rural residents; and the health insurance scheme for those urban residents (the elderly, students and children and the unemployed) who are not covered by the employee insurance scheme. Solidarity plays a role in the way these schemes are constructed and implemented. In the rural scheme, funds are pooled at county level, which provides some freedom for county level authorities. The solidarity of the systems comes under strain with the drug formularies, which in practice provide a more extensive reimbursement for the urban workers' scheme than for the other two. Despite this strain, the primary value that the system is to be judged by is that of equity through universal access.

In England the National Institute for Health and Clinical Excellence (NICE) has a well-developed and sophisticated decision protocol that defines an explicit place for an extensive list of social values, as described in the paper by Littlejohns *et al.* (2012a). The highly explicit and formal approach to cost-effectiveness and the search for value for money is as developed in England as anywhere in the world. Nonetheless, this does not mean that decision protocols are applied mechanistically without thought for the social value consequences of decisions. For example, in the appraisal of interventions for Crohn's disease, the evidence was not clear about the clinical and cost effectiveness

of two drugs over longer periods than a year. In the light of evidence from patient groups about the long-term difficulties of living with the disease, the appraisal committee recommended the two drugs under certain conditions, despite their cost for benefit provided being high by the standards of a conventional NICE appraisal.

Contrasts and comparisons within Europe in the way that social values are institutionalised are highlighted in the paper by Kieslich (2012) on the German system. In Germany the Institute for Quality and Efficiency in Health Care (IQWiG) was established in 2004 to produce evidence-based reports on "drugs, non-drug interventions (e.g. surgical procedures), methods for diagnosing and screening and clinical practice guidelines and disease management programmes". The Institute is also responsible for providing health information for patients and the public. The key principles are "processes and rules of decision making; accountability and transparency" and the deciding factors for maintaining the performance of the German health care system are "quality and efficiency" (IQWiG, 2011). The country has a system of statutory health insurance which is used by 90 per cent of the population and the values of "solidarity" and "self-administration" are grounded in this system. It is administered by the federal parliament and by federal and state ministries of health. A federal committee of hospitals, physicians and others makes decisions on what technologies to pay for. The health department and the federal committee commission IQWIG to compile evidence-based information on health technologies but its recommendations are not binding. Since 2007, IQWIG has to perform cost effectiveness analysis according to "international standards" in order to set an appropriate and reasonable price but it is not a comparative analysis across diseases and the use of quality-adjusted life-years are not permitted.

In the US the Patient Protection and Affordable Care Act, of the Obama administration is being implemented despite being challenged in the courts. One important aspect of those reforms was the promotion of accountable care organisations as a means of improving care for Medicare enrollees as well as children covered by Medicaid. Keren and Littlejohns (2012) survey the issues of social value that are raised by the establishment of such organisations and underline the extent to which both the process values and the substantive values identified by Clark and Weale are relevant to the sound working of those organisations.

In a survey paper of developments in Latin America, Cubillos (2012) places the growth of accountability through the courts, via the legal procedure known as a writ of protection, in the context of the constitutional changes that followed democratisation. With the growth of non-communicable diseases, patients are seeking access to medicines through court procedures, but this occurs against a general failure to define an acceptable system of health care protection on a universal basis. Thus, court decisions provide for accountability in individual cases, but this does not mean that the cumulative effect of these decisions is to move towards a more equitable system of care for the population as a whole.

As this brief review of the papers shows, there many common challenges worked out in different ways across our range of cases. Expensive pharmaceuticals, either in absolute terms or in terms of their cost-benefit ratios, are frequent causes of value-based controversy. Determining which interventions are to be included or excluded from health insurance or tax-based coverage is a recurrent issue. Extending protection against the financial risks of illness to the population at large is of special

concern to low and middle income countries, but is also found in a rich society like that of the US. Making policy accountable for their decisions is also not easy. Nor is finding ways to involve stakeholders in agenda-setting conversations. Methodologically, assessing the extent to which social values are relevant and determining considerations in the making of policy is still in its infancy. And overarching all of these questions is the ultimate ethical issue: what are the relevant social values to be used in the assessment of the performance of health care institutions when they set priorities?

Our conclusion is that in these papers we have the seeds of a new multidisciplinary research programme and a network drawing on ethics, philosophy, health economics, political science and health technology assessment and aiming to compare the decisions made about resource allocation in health care by different countries and explore the differing social values that shape those choices. To show that this is possible operationally as well as conceptually, the final paper by Littlejohns *et al.* (2012b) explores the extent to which each of these values is present in the statements of the decision making protocols of three health technology assessment agencies: the National Institute for Health and Clinical Excellence; the All Wales Strategy Medicines Group; and the Scottish Medicines Consortium. Generally speaking, all the values find some expression in the statements of decision protocols, but there are interesting differences between them. For example, the All Wales Group, when discussing clinical effectiveness, explicit refers to an assessment via "pathways of care" in a way that neither of the other two do. Similarly, the value of autonomy is explicitly mentioned by NICE but not by the other two, whereas the value of solidarity (a value most typically associated with European social insurance systems) finds only indirect expression in the guidance notes of all. What the paper does show, however, is that it is possible to find statements of operational expression of a range of social values in the description of guidelines on decision protocols used by public agencies.

Although only an exploratory study, the ability to show how values are manifested in decision making processes suggests that such values do play a practical role. Understanding this role in detail is a research task that should lead to the translation tasks of producing practical guidance for decision makers, relevant cross-nationally, and identifying best practices for incorporating social value judgments in health priority setting. A better understanding of the importance of different social values, and different ways of responding to them in priority setting, can help healthcare managers to properly design decision making processes as well as scholars to prioritise policy research. Moreover, the recognition of the social values educates and empowers stakeholders to be able to play their respective roles in decision making.

This new research programme's agenda is challenging and will require the collection of complex data from a variety of organisations in different countries. A framework initially developed to facilitate comparative country specific information and create structure for the individual country presentations proved useful and further testing showed that it had the potential to be developed into a generic multidisciplinary data gathering instrument. Researchers and policy makers often inhabit different worlds and speak different languages but our experience so far suggests that the common desire to plan and deliver sustainable health services is strong enough to overcome these barriers.

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