1. Introduction – consumer groups and the democratization of health policy

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This book examines the extent to which consumer groups engage in the development of policy affecting their members’ health and health care. Such engagement may be referred to as the ‘democratization of health’, but, as the contributions to this book show, there are considerable differences between national contexts as to what this means, both in theory and in practice. Before summarizing those differences, however, some account of the notion of democracy and the impetus to democratize human institutions is needed.

Democracy had its origins in ancient Greece, but its modern form stems from the French Revolution. In the name of the people the French Revolution cast off the shackles of the political and ecclesiastical hierarchies and proclaimed the ‘liberty’, ‘equality’ and ‘fraternity’ of all. In the spirit of the Enlightenment the traditional authority of divine revelation was supplanted by the authority of scientific reason and the ideal of individual liberty, as in Immanuel Kant’s notion of personal autonomy. This legacy subsequently developed in two streams. One of these emphasized individual liberty, which in the political sphere was conceived in negative terms as freedom from government, and in the economic sphere as market freedom. The other stream was the socialist/collectivist one, which placed the emphasis on ‘fraternity’ and thus a common good to be attained by collective action. Post-Enlightenment culture enjoins the exercise of the power of reason to bring both the physical world and the social world under human dominion.

In supporting the democratization of health policy and health care, contributors to this volume are not blind to the challenges to this culture. The tension between the liberal-individualist and the collectivist streams has already been acknowledged, and is reflected in some of the chapters that follow. But some authors also acknowledge the challenge to the status of reason – to the scientific paradigm of knowledge – found in the literature of both the philosophy and the sociology of science. The case for democracy, however, and thus for the democratization of all areas of human life, including health policy and health care, is not undermined by these challenges. If science cannot deliver
the certainty claimed for it in modernist thought, it can at least deliver proba-
bility; moreover, to the extent that individuals have to rely on the judgements
of their own reason as a result of science’s shortcomings, space is created for
democratic participation in decisions around such questions. The tension
between the liberal-leaning and socialist-leaning streams of democratic culture
can be cause as much for the fruitful development of the culture as for its
erosion.

The collapse of the Soviet empire in 1989 led many on the liberal-
individualist side of politics to proclaim it as definitively discrediting social-
ism as an alternative form of government. The global financial crisis of 2008
has prompted others to ask whether this crisis marks the demise of the liberal-
capitalist paradigm (Wade 2008). Whether one leans towards the liberal or the
social stream of democracy, it is fair to observe that the credit of democracy
has been enhanced not primarily by its superior efficiency as a way of govern-
ing societies, but rather by its supposed moral superiority over its rivals: it is
perceived rightly or wrongly as the only form of government capable of giving
due recognition to human dignity. Globalization of democracy is thus thought
to have a moral justification and perhaps even to be a moral imperative. In
democratic polities the aspiration to democratize all areas of social life – to
enable all those affected by particular policies and practices to have a signifi-
cant role in determining them – is as much a moral as a political one. The real-
ization of these democratizing aspirations is however conditioned by other
factors in the relevant social contexts, particularly their economic systems.
Since health is so central to human well-being, it is somewhat surprising that
the progress of and obstacles to the democratization of health policy and
health care have not been more fully researched. This volume tries to fill part
of that research gap by presenting snapshots of the present status of the democ-
ratizing efforts of health consumer groups in the diverse social and political
contexts of several nations.

The designation of such groups as ‘consumer’ groups immediately raises a
problem. In capitalist economies the term ‘consumer’ has for many come to
mean a purchaser of goods and services in markets, and thus to connote the
rights attendant upon that role. But this term had an ordinary-language mean-
ing before this market sense became so dominant, and it retains sufficient
currency to permit its use today in a volume like this one. Thus while in some
contexts in the following chapters the term ‘consumer’ is used in the market
sense, in others it is used in its ordinary-language sense. ‘Consumer groups’
thus generally means groups who are actively working for the rights of citi-
zens in health policy and care, though in some contexts they can be groups
fulfilling the role assigned to them in market exchanges.

However, this distinction is not merely semantic. As the contributions to
this volume show, underlying the semantic distinction is a real difference in
the understanding of the role of consumer groups in health policy and care, particularly vis-à-vis other influential stakeholders in this arena. The role aspired to by some of the groups described in these chapters is that of activism in the struggle for human rights and the deepening of democracy, in this case in health. Their aim is to achieve emancipation from the structures which restrict those rights, and their general strategy is to enlist the power of the state in a process of reform to achieve those rights. The risk they run is that, having once contributed to the election of a reformist government, they become co-opted to its processes and policies and come under pressure to compromise their critical independence (Dryzek 2002). Groups that compromise that independence beyond a certain point become in some sense co-optees of the very state and private actors whose power they were founded to challenge. The success of democratizing efforts is limited, in other words, by the powers of the dominant actors in the field of health: the providers (both state and private), and the health professionals (Alford 1975).

In recent decades a major challenge has been levelled at the power of health professionals by the implementation of neo-liberal and New Public Management (NPM) approaches to health policy and care. Governmental and other service providers have enhanced their power vis-à-vis the medical profession through these approaches, and the theory underpinning these approaches accords a role to consumers. ‘Consumers’ in this context means consumers in the market sense. As purchasers of health services, consumers are entitled to such things as choice of services, quality of service and the lowest possible price. Since such entitlements are in part dependent upon provider policy, this theory concedes consumers some right to input into health policy as well as into service delivery. Some of the European contributions describe efforts to develop free markets in health and obstacles to that development. For some of these European authors, efforts to democratize health mean attempts to extend the operation of markets in the health domain. For other authors, such as those from Canada and Australia, the equation of marketization with democratization is a subversion of democracy because it reduces quality and affordable health care to a purchaser’s entitlement rather than any citizen’s right within an organic community. These differences could obviously be explained as leanings either to the liberal-individualist or to the socialist stream of the democratic tradition, but they also surely reflect conditions imposed by different social and political contexts.

Another title advanced here to consumer authority in health is that of ‘experiential knowledge’. Structural reforms of the Irish health system purporting to enable consumer participation in shaping health policy and care have persisted in privileging professional knowledge. By doing so, according to the contribution on Irish health policymaking, they have ensured the failure of such reforms because they have systematically excluded that knowledge of health.
Democratization of health, on this argument, will require admission of experiential knowledge of health and illness to the discourse of policy and delivery.

But if, as several contributions to this volume argue, the claims of experiential knowledge are so strong, who has the strength to resist them and what is the source of that strength? According to one contributor, resistance to the admission of experiential knowledge to health discourse stems from ‘the “scientization of decision-making”, and the frequent medicalization of social problems as inevitable precursors to technical rather than social solutions, many of which directly remove power from consumers’ (Brown and Zavestoski, in Fox and Lambertson in this volume). But as the term ‘scientization’ suggests, the privileging of scientific medical knowledge has deeper and stronger roots than the process of professionalization. Those roots lie in a particular paradigm of knowledge that has dominated the sciences generally and the human sciences in particular since the scientific revolution. According to that paradigm, the only valid forms of knowledge are those attained by the empirical methods of the natural sciences. Applied to medicine, this doctrine generates what might be called the ‘pathogenic’ paradigm of health, which conceives health in terms of its opposite – disease – and defines the discipline of medicine as identification of the causes of and cures for diseases. Challenges to this paradigm, and to the account of the human sciences underpinning it, have long been common in the philosophy and sociology of science literature (see, for example, Kuhn 1970; Lakatos 1970; Mulkay 1979; Taylor 1985), but the upshot of this controversy for contributors to this volume is that the prevailing medical dominance is the result of a political rather than an epistemological contest.

Contests of power between interest groups or stakeholders, including consumer groups, would most likely result at best in realignments of power between conflicting groups. Such realignments would not be recognized by many as democratizations. As Timothy Milewa in this volume insists, ‘autonomous health activist groups’ need to develop ‘new ideas of democratic practice and dialogue’ if the discourse of democratization ‘is to be anything more than an aspirational narrative’. Since the United Kingdom has been the location of pioneering research of efforts to democratize health policy and practice, this volume begins with chapters from these researchers.

According to Timothy Milewa (Chapter 2) the debate about the consumer role in health reflects a wider debate in sociology centred on the sociology of the body. Among the key features of that debate is the uncertainty of our knowledge of all things in life generally and of health in particular. This is the ‘risk society’ thesis of Ulrich Beck (1998) and Anthony Giddens (2000: 38–53). Debates about equity, justice and rights in the health area, and political mobilizations to promote views on them, are to be understood, according
to Milewa, in the light of this wider debate about the amount of credit to be attributed to medical science, managerial expertise and lay/experiential knowledge. The focus on the body also draws into the political debate aspects of health that would previously have been excluded as belonging to the private realm, such as sexual health. This focus also exposes examples of ‘ill health’ being defined by social prejudice rather than physical condition, an egregious case of which is physical disability.

Milewa concurs with Goodin in noting the crumbling hierarchical structures of power in health policy and the consequent need for more democratic alternatives: ‘health activist groups are in the business of attempting to produce (or co-produce) dialogic procedures and spaces of a particular “actionable form” that points to, but does not determine roles, norms and appropriate behaviours in connection with desired outcomes’ (Goodin 1996: 31). The quest by consumer groups for ‘procedures and spaces’ for democratic dialogue among the three alternatives that Milewa identifies – managerial, asymmetrical co-option, and emancipatory – may, he concedes, seem fanciful. However, since it is driven by consumer dissatisfaction with existing structures, he believes the quest may not be in vain. The yearning for ever more democratic procedures and spaces can be deflected in various ways, but, if Milewa is correct, it cannot be entirely suppressed, especially in societies where hierarchies are breaking down because the knowledge which formerly authorized them has now been exposed as fallible. A case in point is the weakening of the classic pathogenic or biomedical model of health, which has been subjected to paradigmatic critiques by proponents of the social model of health and ‘salutogenesis’ (Antonovsky 1984).

Kathryn Jones and Rob Baggott (Chapter 3) draw on a pioneering study of the influence of health consumer groups on health policy and care in the United Kingdom (Baggott et al. 2005). These authors note Milewa’s acclaim of new opportunities for activism in UK health policy but point to a continuing perception of a ‘democratic deficit’ in the National Health Service (NHS). Their 2005 study showed that the assumption that health consumer groups were powerless was facile and that these groups had contributed to the reduction of this deficit. However, the power of these groups in the NHS has not increased, they found, in the 20 years since the inception of the policy of patient and public involvement in health care. Changes in operating conditions have contributed to this stasis in the quest for greater influence: the shift to an emphasis on individualism, devolution within the United Kingdom and the influence of the European Union (EU). National Voices, a coalition of more than 200 health consumer groups in the United Kingdom, offers some hope of increasing consumer group influence, but the authors fear it may be too close to government to provide an independent perspective. They argue that more research is needed to assess the influence of health consumer groups in this
changed environment, particularly at the local level. If Milewa has indicated the directions towards which consumer groups aspire in their efforts at democratization, Jones and Baggott have produced considerable empirical evidence from the English scene at least to show how far those aspirations have been realized.

Meri Koivusalo and Jonathan Tritter (Chapter 4) address the question of how EU structures and procedures affect citizen participation in policymaking in terms of representation and democratic participation in general. Who are the consumer representatives in the democratic sense, and who in the sense of front groups or stakeholders representing particular rather than common interests; and what access to the policy processes of the EU does each group have? Institutional context greatly influences groups’ potential for democratization, and the EU, these authors argue, as did Jones and Baggott in the previous chapter, exemplifies the complexity such contexts can involve. To what extent is democratization of health policy doomed to reduction to a contest between stakeholders in this context, they ask, rather than a campaign for the emancipation of consumers from the dominance of the medical and managerial professions? They conclude that a critical watch is needed over EU regulations to ensure they enhance rather than limit consumer/democratic rights.

In Chapter 5, Prem Chandran John and David Legge locate the quest for democratization of health in the ideological and historical context of the post-Enlightenment struggle to bring human destiny under ‘rational democratic control’. They see a “modernist” confidence (perhaps faith in) the possibility of rational collective control over human destiny … [as] integral to civil society/social movement activism’. The major challenges to this modernist faith, they claim, come from ‘market and religious fundamentalisms’. Markets are the mechanisms that perpetuate the economic system and enrich the few at the expense of the many, and today markets are global forces. Religious fundamentalisms see a turning to God as necessarily involving a rejection of secular rationalism. Rational democratic control over health, the authors argue, is to be sought by disempowered people collectively confronting the obstacles to it at all levels: local, regional and global. While John and Legge do not address the challenge to this modernist faith posed by the exposure of the fallibility of scientific knowledge as Milewa does, they provide an important account of a collective effort they see as flowing from that faith: the international People’s Health Movement.

In Chapter 6, Bronwyn Fredericks, Karen Adams and Rebecca Edwards present an Australian Aboriginal perspective on the democratization of health. That perspective is also cast in the terms of the post-Enlightenment quest for rational control over human destiny by disempowered people. The authors’ argument is that Aboriginal peoples’ problems in health, like their problems in other areas, are a direct result of their disempowerment, which was caused by
colonization. The solution to their health problems therefore is essentially dependent upon their re-empowerment, interpreted by these authors as taking control of their own health policy and services. They see this re-empowerment exemplified in the establishment of Aboriginal Community Controlled Health Organisations, like that established in the Australian state of Victoria. Since the rise of Aboriginal Community Controlled Health Organisations is comparatively recent, however, virtually no research into the success or otherwise of their efforts to restore power to Aboriginal peoples has yet been carried out.

In Chapter 7, Orla O’Donovan criticizes the Irish state’s claims to have redressed medical and managerial hegemony in its introduction of lay representation at the health policy table. She argues that such ‘invited spaces’ need not be entirely rejected as sources of gain for those striving for democratization; but, most importantly, they have not constrained the democratization of health in other contexts. She points to examples of groups in Ireland that have found spaces not dominated by ‘credentialized experts’, and indicates other spaces for democratizing efforts such as the media, the parliament and even the streets. Moreover, she contends that the tighter the regimes dominated by the privileged knowledge of experts the surer the weaknesses of that knowledge will be exposed – weaknesses that can be attacked by democratizers. It is the emancipation of the experiential knowledge of patients and their supporters from the hegemony of the expert knowledge of the medical and managerial professionals that must, in her view, produce ‘epistemological justice’. Rendering judgement on recent experiments with new forms of lay involvement on expert committees, she attributes their failure to research why such experiments had failed in the past to blind faith in expert knowledge. She points to evidence that the paradigm of expert knowledge is itself failing, for example, in mental health. If, as John and Legge claim, the quest for democratization of health is a fruit of the French Revolution and the Enlightenment, so too is the scientific paradigm of knowledge. Both Milewa and O’Donovan point to the need to reassess the latter but neither adverts to the consequences of such reassessment for the notion of ‘rational control’ over human affairs, the possibility of which that paradigm formerly guaranteed.

In Chapter 8, Atie Schipaanboord, Diana Delnoij and Roland Bal also plead the case for patients and their support groups to ‘capitalize’ their experiential knowledge so that they may use it to exercise their rights. However the context for the exercise of such rights is conceptualized by these authors as liberal society, where that philosophy is now interpreted as calling for the marketization of such goods as health care. In this context patients’ rights are defined as rights to choose doctors, insurers, hospitals and the like. The problems with this paradigm of rights are the standard ones that arise with the establishment of markets anywhere, such as the asymmetry of information and lack of competition between providers. Democratization in this paradigm would
amount to the strengthening of consumer power within the health market. As indicated by the authors, there are problems inherent in the application of the market model to health: difficulties in mobilizing patient choice and ensuring understanding of and access to information. But these authors argue that the failures of some existing mechanisms for mobilizing and consolidating patient involvement in health policy should lead to the design of better mechanisms rather than abandonment of the project. They recommend the use of ethnographic research techniques as one means to this end.

The Dutch contribution highlights a tension in this volume referred to earlier between conceptions of democratization. For Schipaanboord and her colleagues the marketization of health is a form of democratization. For several other contributors, however, health care is not a marketable commodity but a human right that might be undermined by marketization. Democratization in the latter case would entail abolishing the notion of health care as a commodity and reform of its structures to reflect its conception as a human right the value of which cannot be measured in monetary terms. In this perspective market-oriented reforms are viewed sceptically, and the model of health care provision in the postwar welfare states of Scandinavia, the United Kingdom and elsewhere as providing a basis for further democratization. It is of course possible that this tension reflects fundamental ideological differences in the understanding of democracy; if this is so, it will be incapable of resolution, and readers will simply have to choose which ideology they prefer. However, the tension may reflect rather the important differences in the historical, social and political contexts in which the authors are writing. In welfare systems that have become rigid in their procedures and unresponsive to consumers’ needs, marketization of health may give consumers some say where previously they had little or none. Health activists might count such an achievement as the best they can do for the moment given the time and effort required to accomplish fundamental reforms.

In Chapter 9, Jens Geissler addresses the problems of governance and representativeness in the German health system. Democratization in the German context, according to Geissler, means the development of the role of consumer groups within the multiple institutional structures of health care. While these are democratic in many of their structures and procedures, this has not always meant, and still does not necessarily mean, that consumers and consumer groups have significant influence in the system. Reforms to the German system reported by Geissler have, in his estimation, at least secured consumer groups a voice that is heard in decision-making fora, and compulsory financial support from insurers. The latter provides an interesting international precedent; provision of arm’s-length public funding for consumer groups along such lines could lessen the risk of such groups being drawn into the orbit of the pharmaceutical industry (see Chapter 16). Legislation has even
been passed in Germany requiring that training be provided to lay members of decision-making bodies to help bridge the knowledge gap between them and professional members of such bodies. Geissler does not say whether the lay members’ experiential knowledge counts for anything at the decision-making table, but he does report that 8 of 182 patient representatives on the Joint Federal Committee on health felt able to influence and support committee decisions.

Rudolf Forster, Gudrun Braunegger-Kallinger and Karl Krajic (Chapter 10) tell us that for historical reasons civil activism is underdeveloped in Austria, but is now developing. Democratization in this chapter, as in the previous one, is seen as the development of the role of consumer/patient groups within a corporate tradition of governance, both political and administrative. Thus the authors focus on strategic concepts for measuring and developing relative power within corporate systems. Here those concepts are ‘conflict capability’ and ‘organizational capability’ (Offe 1974; Geissler 2004). The authors also report their own empirical study of the role of consumer groups in Austria. Health activism, like new social movements generally, has been severely constrained in the past by Austria’s ‘consociationalist’ form of democracy. However in the last 25 years this form of democracy has been significantly eroded by ‘competition’, allowing ‘more pluralist modes of interest aggregation’ to arise. Openings for exploitation by non-corporate interest groups, including health consumer groups, are now appearing in Austria’s democracy. According to Forster and his colleagues, however, these groups need to develop the capabilities prescribed by Offe if they are to exploit these openings.

It has been taken for granted so far in this book that the political context in which the democratization of health is to take place is a Western-style liberal democratic nation, or union of nations, such as the EU. In Chapter 11, however, we are confronted with a case of the democratization of health preceding the democratization in this Western sense of the relevant nation: Malaysia. Indeed, on the evidence provided by authors Simon Barraclough and Phua Kai Lit, the achievements of Malaysian consumer groups have been considerable, particularly in the restraint they have managed to place on government neo-liberal health care reforms. If we were not already so convinced, the Malaysian example might help persuade us that there is no such thing as a perfect democracy, and that genuine democratic progress can be achieved even under relatively undemocratic conditions, whether they be authoritarian regimes or democratic ones dominated by neo-liberal and managerial approaches to health policy. These authors observe that Malaysian consumer groups lack the resources to research and disseminate consumer positions to government consultative bodies. The secrecy of government policymaking processes makes assessment of consumer group influence
almost impossible. Consumer groups themselves, the authors argue, need to
develop a more sophisticated knowledge of the workings of the policy process
in order to engage with it effectively.

In Chapter 12, Hans Löfgren, Michael Leahy and Evelyne de Leeuw assess
the democratization of health in Australia. As in other liberal polities, they
observe, there has been a division in this country between those who define
democracy in terms of the freedom of individuals to achieve self-sufficiency
without government interference (referred to earlier as the liberal-individualist
stream of the democratic tradition), and those who see it as the solidarity of
citizens constituting a state in the pursuit of a common good (the collectivist
stream). For the former, democratization of health has meant state support of
the efforts of individuals to provide for their own health care, while for the
latter democratization has meant the establishment by the state of a system of
universal care. The authors note that while consumer groups had a certain
incarnation in the many private health insurance cooperatives that flourished
until the advent of Medibank in 1975, they were perceived as institutions
supporting the dominance of the medical profession over the entire health
system. Democratization of health, they argue, has thus come to be seen as the
loosening of this dominance so as to universalize access to services and insur-
ance, and particularly to ensure that formerly excluded groups have their needs
met.

Consumer/activist groups played a significant role in loosening the domi-
nance of the medical profession. But democratization, as these groups under-
stood it, was impeded because much of the power wrested from the doctors
was assumed by the state and the medical bureaucracy. Accordingly, democ-
ratization, in consumers’ favoured sense of emancipation from the dominance
of medical and managerial interests, and the acquisition of genuine power at
the policy table, has been thus constrained. Consumer groups are now under
pressure to mitigate this quest in return for a place at the table as marginalized
participants. In short, the authors conclude, there is a tendency in Australia for
consumer groups to be co-opted to the service of the interests of the dominant
medical and managerial groups, interests which are often subordinated to the
prevailing imperatives of the state. Australia, however, lacks any comprehen-
sive and detailed study of group relations and dependencies that would enable
a more definitive assessment of this tendency.

The influence on the democratization of health of neo-liberal and NPM
theory is again assessed in Chapter 13, this time negatively. Democratization,
as Canadian authors John Church and Wendy Armstrong conceive it, consists
in restoring an ‘organic’ conception of citizenship in place of the ‘customer’
conception installed in Canada in the era of neo-liberal reform. An organic
form of citizenship, they contend, will not be driven merely by individual self-
interest but by a process which discerns the rights and responsibilities of citi-
zens as members of a community. People’s expectations of government will not, therefore, be able to be determined simply by surveys of individual preferences as the market paradigm suggests, but will need to be established through more deliberative processes. These authors lament the supplanting of the language of local citizen influence in health matters by that of central control under the influence of market-based theories. However, Church and Armstrong are optimistic about the prospects of a restoration of a more ‘organic’ relationship between government and citizens which might lead to a rollback of such neo-liberal/NPM health reforms.

The authors of the two chapters focusing on the United States agree that democratic reform has taken the form of incremental responses to periodic clamouring by aggrieved groups of consumers for more equitable access to services. In Chapter 14 Michael H. Fox and Anna Lambertson provide an analysis of those responses. Democratization for these authors consists in the acquisition by consumer groups of some of the authority over health policy and care that is at present dominated in the United States by medical and managerial professionals. The purpose of acquiring such authority is to challenge the ‘social, cultural and economic dominance’ of biomedical authority. While the problem and the proposed solution to it do not differ significantly from those identified in other Western democracies, the US context, they point out, is significantly different. There is a stronger tradition of individual self-reliance and of antipathy in some quarters to the forms of ‘socialized medicine’ that are taken for granted in the United Kingdom and Europe. Thus private health insurance dominates the American scene, and government-funded or -subsidized provision is available only to select groups deemed eligible for such support. Despite these formidable obstacles the authors show considerable faith in the ability of the political activist tradition of US voters to achieve the redress they seek in the balance of authority in health matters.

Christina Nuñez Daw, Denise Truong and Pauline Vaillancourt Rosenau, the authors of the second chapter on the United States (Chapter 15), also contrast the US political tradition of individual self-reliance in health with UK and European traditions of collective responsibility. They accept Fox’s cyclical/incremental model of the development of US health policy and predict that, while the Obama reforms offer some hope for the consumer movement, its progress will be fragmented and ‘specialized’: that the US individualist tradition of political activism will give rise to particular campaigns by groups focused on single issues – for example, diabetes care – rather than an organic activism. This individualist concept of democracy differs from the European and UK concepts in that it endorses the use of society to advance individual interests (demanded as a sacred right) but denies any collective responsibility for the welfare of society’s members. These authors conclude that rather than advancing social solidarity, the kind of democratization implied in consumers
comparing report cards on competing health services imposes unbearable cognitive burdens.

In the final chapter, Chapter 16, Agnes Vitry and Hans Löfgren report on international trends in relationships between consumer groups and the pharmaceutical industry, and on debates about them. They remark on the power asymmetries between the two parties and the potential for exploitation, particularly conflicts of interest, bound up with interdependencies between stakeholders in contemporary health policy systems. For proponents of democratization, conflicts of interest may appear as a second-order issue. It is surely of great consequence, however, that groups claiming to represent patients and their families, and often the citizen interest more broadly, should not be surreptitiously co-opted either by the short-term manoeuvrings of governments or by the powerful pharmaceutical industry. Vitry and Löfgren conclude that transparency in consumer–industry relationships is a necessary condition of consumer groups authentically advocating on behalf of their constituencies and potentially contributing to the democratization of health systems, but that it will not be a sufficient condition if such transparency simply blunts community sensitivity to conflicts of interest.

Democracy, and thus the democratization of health policy and care, is taken by all contributors to this volume to be a moral good. Different conceptions of that good are evident, however, in their contributions, or at least in the polities they describe. In the United States the aversion to what is often perceived as socialism is cause for pessimism about the prospects of consumers as citizens winning a significant say in health policy and care. Notwithstanding the robust American tradition of political agitation, it seems that the liberal-individualist ideology that is so entrenched there will always be bent to the service of the interests of the dominant actors: the medical profession and the providers. The solidaristic or collectivist understanding of the good of democracy, and thus the democratization of health policy and practice, is more widely embraced outside the United States, particularly in countries with a history of strong social democratic parties. The latter, however, are under siege from neo-liberal and NPM theory. In several nations it seems that the possibilities for democratization in the current context are limited to attaining increased rights as consumers of health services, considered as market commodities. But as several authors affirm, citizens in their nations see themselves as more than consumers in markets: they are human beings for whom health is a right demanded by their dignity. That dignity must therefore guarantee the eventual supplanting of the market conception of health consumer rights. The obstacle to the attainment of those rights, according to most contributions, is the power of the dominant actors in the health care system: the medical profession and the providers. Perhaps the most important source of this power is the very
conception of reason which was supposed to be a democratizing force: scientific knowledge. The sequestering of this form of knowledge by professionals has rendered it an anti-democratic force. The greatest vulnerability of those actors who resist the democratizing efforts of health consumer groups is the discrediting of the claims of science to the status of paradigm of knowledge. Philosophers and sociologists have long exposed the inability of science to deliver the certainty promised by that status. Several contributors press the claims for accreditation of the ‘experiential knowledge’ of consumers and their supporters in the shaping of health policy and care. Perhaps the advancing of those claims should be a major focus of future democratization strategies and research.

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NOTES

1. For a critical appraisal of the French Revolution and its consequences for Western politics, see Elshtain (2008, especially chapters 6 and 7). A more general history of the period and appraisal of the role of revolutions in it appears in Brown and Tackett (2006: i) who write: ‘Finally revolution, the political and social upheavals of the late eighteenth and early nineteenth centuries, challenged established ideas of divine-right monarchies and divinely ordained social hierarchies, and promoted more democratic government, notions of human rights, and religious toleration.’

2. The pathogenic paradigm is opposed to the ‘salutogenesis’ paradigm (Antonovsky 1984) in which the health disciplines have the causes of positive health as their focus and its promotion as their aim.

REFERENCES


