



# Democratizing Health

Consumer Groups in the Policy Process

EDITED BY

Hans Löfgren • Evelyne de Leeuw • Michael Leahy



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# Abbreviations

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ABPI	Association of British Pharmaceutical Industry
ABS	Australian Bureau of Statistics
ACCHO	Aboriginal Community Controlled Health Organisation
ACT UP	AIDS Coalition to Unleash Power
ADA	Americans with Disability Act
AFM	Association Française contre les Myopathies
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
ALP	Australian Labor Party
AMA	Australian Medical Association
BAG Selbsthilfe	Bundesarbeitsgemeinschaft Selbsthilfe
CADTH	Canadian Agency for Drugs and Technologies in Health
CAP	Consumers' Association of Penang
CHF	Consumers Health Forum of Australia
CHI	Citizens' Health Initiative
CIL	Center for Independent Living
COAG	Council of Australian Governments
CRCAH	Cooperative Research Centre for Aboriginal Health
DDB	Deutscher Diabetiker Bund
DDU	Deutsche Diabetes Union
DPWV	Deutscher Paritätischer Wohlfahrtsverband
EAG	Expert Advisory Group
ECJ	European Court of Justice
EFPIA	European Federation of Pharmaceutical Industries and Associations
EMA	European Medicines Agency
EPHA	European Public Health Alliance
ESRC	Economic and Social Research Council
EURORDIS	European Organisation for Rare Disorders
FDA	Food and Drug Administration
FOMCA	Federation of Malaysian Consumers' Associations
FQHC	Federally Qualified Community Health Center
GP	general practitioner
Health GAP	Health Global Access Project
HSE	Health Services Executive

IAPO	International Alliance of Patients' Organizations
INCADDS	Irish National Council of AD/HD Support Groups
JSA	Jan Swasthya Abhiyan
KMS	Koori Maternity Services
MHA	Mental Health Association
MMA	Malaysian Medical Association
MSF	Médecins Sans Frontières
NACCHO	National Aboriginal Community Controlled Health Organisation
NAHS	National Aboriginal Health Strategy
NAM	Non-Aligned Movement
NAMI	National Alliance on Mental Illness
NATSIC	National Aboriginal and Torres Strait Islander Health Council
NCCC	National Consumer Complaints Centre
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NORD	National Organization for Rare Disorders
NPCF	National Patient and Consumer Federation
NPM	New Public Management
PBAC	Pharmaceutical Benefits Advisory Committee
PBPA	Pharmaceutical Benefits Pricing Authority
PBS	Pharmaceutical Benefits Scheme
PCT	Primary Care Trust
PHA	People's Health Assembly
PHM	People's Health Movement
PPI	patient and public involvement
QUM	quality use of medicines
SAPRIN	Structural Adjustment Participatory Review International Network
TABD	TransAtlantic Business Dialogue
TACD	Transatlantic Consumer Dialogue
TRIPS	Trade Related Intellectual Property Rights
UAEM	Universities Alliance for Essential Medicines
UMNO	United Malays National Organization
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VACKH	Victorian Aboriginal Council on Koori Health
VHA	Veterans Health Administration

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

**Michael Leahy, Hans Löfgren and Evelyne de Leeuw**

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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.<sup>1</sup> 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 probability; 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 socialism 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 governing 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 significant role in determining them – is as much a moral as a political one. The realization 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 democratizing 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 meaning 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 citizens 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

and illness which only patients and their close supporters possess. 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<sup>2</sup> 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