Chapter 5
Securing Health–Effective Medicine in Practice: A Critical Perspective on User–Driven Healthcare

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ABSTRACT
The movement for public participation in medical practice and its governance (‘participative medicine’) lacks an understanding of the historical and theoretical contexts within which it has emerged. This paper discusses the problems with physician-centred medicine (previously called ‘the medical model’), administrator-centred medicine (‘managed health-care’), patient-centred medicine, and participative medicine. The concept of health-effectiveness of medical services is emphasised as fundamental in an applied, critical theory of medical practice that equates health-effectiveness with pro-social medical services. The critical theory provides a framework for understanding the movement’s purpose, its misuse by consumerist methods, and the problems when medicine is delivered by pro-market or provider-centred systems, as shown most notably in the Bristol Royal Infirmary Inquiry by the British government. The paper outlines the Tuke Institute model of health-effective services, secured by participative medical practice and its governance and integrated with translational science. Together, the Tuke Institute model and the critical theory provide a scientific framework by which to determine the health-effectiveness of different models of practice through properly scientific research, indicating the necessity of studying models of practice as complex interventions.

THE HISTORICAL AND POLITICAL CONTEXT
‘User-driven healthcare’ is one of the latest variants of an international movement of public participation aimed at changing the model of practice that has dominated medicine for over two hundred years. It fails, increasingly obviously, to meet the medical needs of the public. Public participation in medicine—or ‘participative medicine’—has conceptual commonalities with initiatives in participative science aimed at enhancing ‘knowledge-transfer’ to and from civil communities (Minkler & Wallerstein, 2008) and also with social movements to regulate govern-
mental misconduct, such as civil review boards of police action (Erdmann & Lundmann, 2002). These initiatives developed in the Americas from liberation theology and the post-colonial politics of participatory democracy, devolved governance, empowerment, and political autonomy.

These initiatives have two main traditions that are arguably at opposite ends of a continuum. The first, the so-called Northern tradition, stems from the work of Lewin (1946), one of the earliest figures to recognize that context-free science is meaningless and therefore useless; thus, this tradition has focused on pragmatic solutions to community-centred problems through a participative process but it has suffered from a problem of limited participation by those affected and a lack of an inherent objective of application. The other tradition, the Southern tradition, stems from the work of people like the lawyer and educator Freire (1970) who promoted action based on critical awareness. This tradition has focused partly on breaking what has been called a monopoly over knowledge-production by authoritative bodies, in order for it to be relevant to the needs of civil society; while it acknowledged the authoritative status of such bodies, it questioned their legitimacy and, thus, their value. Despite being politically necessary, the Southern tradition has suffered from a lack of scientific sophistication, relying solely on a simplistic, reductionistic approach to systemic disorders where, for example, altering causative historical elements (such as class-structure) of a systemic problem (such as economic disparity) has been proposed as the solution to that problem.

The history behind such initiatives in medicine—and the critical awareness that gave rise to them—is a fascinating one philosophically and politically, and some commonalities emerge: firstly, that the current, physician-centred model of practice is increasingly inadequate in meeting the medical needs of society; secondly, that there is a sense of a real need to find a solution to this problem; and, thirdly, that the participation of the public is somehow central to that solution. However, the nature of the problem is not even agreed upon: two of the most common issues cited are the problem of medical cost-effectiveness versus the value and survival of medicine as a service to society. Both may be arguing about the same but deeper and hitherto unidentified issue of health-effectiveness. It is worth defining ‘health-effectiveness’ before continuing: health-effective services are ones that ensure optimal health outcomes first and foremost, where ‘health’ is defined according the 1948 definition of the World Health Organization: i.e., a state of complete physical, mental, and social well-being, and not merely the absence of diseases (World Health Organization, 1948).

It may be reasonably argued that the primary goal of medicine—when it is performed as a service to society—is to be health-effective and it is this problem that is facing medicine and society. If it were easy to ‘deliver’ health to the ill, then there would not be problems with costs, the formulation of services, morale among patients and providers, public distrust, and so forth. This then begs one to raise the question: ‘how is health-effectiveness achieved?’ and the related question of ‘why is the participation of service-users considered beneficial or even necessary to this goal?’ Both of these questions are addressed below.

BAD MEDICINE

Physician-Centred Medicine

If medicine’s value lies in its ability to be health-effective, then medicine that fails to do so may, by definition, be seen as bad medicine. Of course, there is a continuum in this quality, from medicine, on one end, that is simply poorly performed by chance to overt, systemic malpractice on the other end. In Western medicine, within the context of Western political culture, there is a sharp awareness of the long and significant history of problems in the way that medicine has been practised and a
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