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.

Keywords: *Comparative Effectiveness Research, Consumer, Health Informatics, Health Services Administration, Medical Dominance, Patient-Centered Care, Patient Participation, Treatment Outcomes*

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 governmental misconduct, such as civil review boards of police action (Erdmann & Lundmann, 2002). These initiatives developed in the Americas from liberation theology

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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 recognise 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 realisation that there are fundamental problems in the way in which the practice of medicine is monitored and regulated. This awareness peaked recently in Britain in the governmental Inquiry into the fatal, experimental surgery on hundreds of children receiving medical services for cardiac disorders at the Bristol Royal Infirmary between

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1984 and 1995 (Kennedy, 2001). This Inquiry identified a coherent and self-maintaining system of practice that led to severe physician-misconduct in which from 30 to over a 100 children died or were killed, when this would not have happened with competent and properly regulated practice. In Britain, there has been a number of other governmental Inquiries into various aspects of medical practice and its practitioners, such as the Shipman (Smith, 2002, 2003a, 2003b, 2004a, 2004b, 2005), Alder Hey (Redfern, Keeling, & Powell, 2001), and Kerr/Haslam (Pleming, 2005) Inquiries; there have also been other signal problems that have not triggered governmental Inquiries, including the malpractice of Professors Sir Roy Meadow and David Southall and the multiple unnecessary deaths at Stafford Hospital in 2009 where financial concerns were given primacy over medical concerns (Rose, 2010). In the Bristol Inquiry review, the essential need for some form of accountable and—therefore—participative medical governance became evident and these later events have consolidated that position.

But these are, in fact, only exemplars, the recent tip of an iceberg of problems in the practice of medicine and are not the reason why the movement towards change was started. Over the last 80 or more years in the West, public participation in medicine and medical science emerged from a growing awareness that the physician-centred model of medical practice is inadequate to meet the needs of the ill. It was spurred initially by the increasing awareness of grossly unethical experiments by physicians, the low points being the reports of Nazi research on human radiation, bathythermia, and hormonal modification, notably on gay men and Jews, the Tuskegee experiments on the natural history of untreated syphilis in black Americans, the Beecher report on experimental surgery, and the experimental and non-therapeutic injection of live cancer cells into unwitting patients at the Jewish Chronic Disease Hospital (Emanuel, et al., 2008). While awareness of many and repeated events of criminal misconduct by physicians brought energy to the issue of medical ethics, the problem of securing health-effectiveness of treatment for any and every ill person, not just for society as a whole, had been an issue for several centuries, not least in the reforms of psychiatric 'treatment' led by the Quaker and merchant William Tuke in the late 1700s (Porter, 1997). However, these problems have persisted, as shown by the Bristol Inquiry and the later deaths at the Stafford Hospital. The consequences of ill-regulated and self-serving, physician-centred medicine have continued.

The physician-centred model of medical practice may be identified by the following commonalities: physical disease is primary and, effectively, of exclusive concern; patients' experience of illness is reduced to bio-diagnostic indicators and the rest discarded, even though it may be causative of either illness or recovery; when illness is not determined by obvious physical disease, the patient's suffering is not considered a medical problem; mental and social issues are considered to be irrelevant or, at best, non-determinative of disease; mental and social issues are addressed either in balkanised services and without reference to an integrated treatment-plan, or by the physician who, as a physician, is not qualified to address them adequately, or by staff less qualified than the physician who are stated to be 'ancillary' (literally, 'handmaids') to the physician (Wagner et al., 2001)[1]; the treatment modalities that are under the control of a physician (most usually, pharmaceutical and surgical) are considered 'medicine', while other modalities (e.g., psychotherapy, nutrition, neuro-feedback, acupuncture, etc) are considered 'alternative' although they may be more health-effective in certain circumstances; physicians' treatments are given primacy, even though they are often more costly and less effective in isolation than non-physician-controlled treatments; only the physician is afforded the title 'doctor' professionally and socially (even if, as in Britain, he does not hold a doctorate, while his 'ancillary' staff may well do so); physicians have professional and financial privileges unmerited by their level or type of training in relation to other clinicians; the basic unit of medical practice is still the sole physician rather than the multi-disciplinary medical

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team; and success is defined by elimination of physical disease, not the return of patients to overall health. In this way, it becomes obvious that 'medicine' is defined by what physicians do rather than what ill people need, whether or not that need is best met by a physician or by another medical professional.

Furthermore, the problem of health-ineffectiveness of physician-centred services is not only severe but increasing in economically developed societies where there is a shift from acute diseases towards chronic, complex diseases as the primary cause of morbidity, mortality, and cost: ironically, this shift is due, firstly, to public health treatments but, secondly, to the success of physician-based treatments. Physicians have reduced the appropriate demand for and scope of applicability of their practice but, as the nature of the demand overall has changed, they have not retained a focus on what the profession does best: the acute treatment of physical illness through pharmaceutical products and surgical techniques. Physician-centred practice is unable to address competently the social and behavioural issues that drive a lot of the most costly chronic disorders in the West: infectious illness (e.g., HIV), mental illness, cardio-metabolic illness (diabetes, heart-disease), and the inflammatory disorders (e.g., arthritis, etc.) and which are essential in the successful treatment of these conditions too; consequently, the illnesses are defined in terms of how physicians can address them. The primary reason is that to do otherwise would mean giving equal power to medical professions other than the physicians', who would then lose what are increasingly unmerited and unjustifiable financial and social advantages over other professions. In privileging the use of this (typically pharmaceutical) form of medicine to treat chronic, complex disease, the physician-profession has shown that it serves its own needs rather than those of the ill. HIV is a good example of this problem (Whitaker, Vogele, McSherry, & Goldstein, 2006).

After more than a century, since the development of the second medical profession, nursing, the essential problem in the practice of medicine remains one of power-inequalities. Historically, medicine has been 'owned' by its original providers and it has been run by physicians for physicians, who believed that they knew what patients need to get well and therefore have owned the right to define 'medicine' in terms of what they do. This misperception among physicians still persists and has been consolidated unfortunately by the business-driven development of the concepts of so-called 'healthcare' and 'allied healthcare professions'. Such distinctions are unnecessary: we already have the concept of medicine and its professions: physician, nurse, psychologist, social worker, etc. Other new professional titles—such as praxiatrist, sociatrist, the non-physician psychiatrist, physiatrist—as well as new fields—such as behavioural medicine/praxiatry, physical rehabilitation-medicine/physiatry—gain ground, are replaced by more accurate ones, or (as with physiatry) are unfortunately commandeered yet again by physicians for their own purposes. The development of the concept of 'healthcare' has avoided addressing the problem of physician-ownership of medicine, maintaining the understanding of it as based in acute treatment within medical biology and provided by physicians; medicine was not redefined to mean what patients need to become healthy—with all that that would mean for integrated service-delivery and the joint medical education of nurses, medical psychologists, and medical social workers. The consequence of the concept of 'healthcare professions' has only served to separate non-physician professions from medicine with a gesture towards putative equality, under a doctrine of 'separate but equal' with the consequence of all the health-ineffective balkanisation of medical services. The invention of 'healthcare' was good for branding and public relations in pro-market, American 'medicine' but simply

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caused further challenges to developing health-effective medicine, making society even sicker.

Administrator-Centred Medicine

The most obvious development in medicine over the last century has been that of 'managed-care'—i.e, the application of tools from business-administration to medical administration. This has been referred to in the above analysis but it is important to look at it more closely, especially in light of the fact that it has developed into, effectively, administrator-centred medicine, arrogating part of physician-power to the administrators of the medical services while maintaining the basic and ineffective form of physician-centred practice. In administrator-centred medicine, financial costs are the basic measure of success; there is an exclusive focus on technical, technological, and context-free commercial solutions to both medical and public-health problems[2]; such problems are identified in pro-social systems primarily by the use of information from public-health surveillance to justify top-down targets, in contrast to medical surveillance and bottom-up standard-setting; it uses tools from commercial practice, including advertising, social media, and public relations, which have been shown to promote competition and market-share (and, thereby, consumerism); and cause the public to suffer from its targeting financial effectiveness rather than medical effectiveness (cf. Stafford Hospital); this, in turn, links in with the pervasive lack of accountability and non-responsiveness of the system to demands for change (just as with physician-centred medicine) because it is serving its own financial needs rather than the public's medical needs. Administrator-centred medicine has consolidated self-service rather than moving towards public service, even as it dissimulates this through the extensive use of public relations and patient 'satisfaction' surveys.

As seen in the USA, however, this pro-market, administrator-centred approach has only intensified the problem of increasing financial costs. True to its perceptual framework, medical administrators have failed to see that promoting consumerism increases the demand for the latest medical products by clinicians and patients, which increases costs; as a result, a large literature on 'managing patient-expectations' has arisen, aimed almost exclusively towards reducing demand for services or for changes in practice, rather than, for example, increasing expectations for medical purposes through the placebo-effect. Here lies the nub of the problem: pro-market services look for short-term products/solutions on which to build long-term profit; pro-social services look for long-term social profit in the form of a healthy population. Consumerism—a core feature of all pro-market systems—means that it is beneficial to have sick people (as long as they can afford the insurance premiums), since it causes demand to go up, resulting in increased economic activity, but costs also increase as physician-centred practice relies on costly technological products that are often the least health-effective (and therefore are cost-ineffective too in a pro-social framework), and patients, as consumers, demand the more expensive blue pill (because that's what the pharmaceutical company told them they need, through direct advertising) rather than, say, the more health-effective but effortful challenge of non-pharmaceutical treatment. This is the conundrum of pro-market solutions to medicine: they are inherently counter-productive to solving society's medical needs.

This conundrum has resulted in a variety of ways to create incentives for patients to minimise costs through manipulating insurance premiums, the most extreme example being to exclude those who had actually been ill due to "pre-existing conditions" by refusing them insurance at all. They and their families are left in the long-term to poverty and sickness. In this system, health-effectiveness is not considered except insofar as it relates to litigation-risk. Another, related problem occurs where clinicians are unable to provide quality treatment without being forced out of practice through the Scylla of insurance-companies or the Charybdis of consumerist malpractice-litigation; insur-

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ance companies remain the only winners and society becomes sicker. Whether the reforms of Obama's presidency of the United States will lead to significant changes in these dynamics, remains to be seen.

In 'medical' business—i.e., 'services' that are pro-market—it is feasible to talk of cost-effectiveness without reference to health-effectiveness, even though this is a bastardisation of both the words 'medicine' and 'service' to mean little more than the application of commercial medical products for the benefit of corporate share-holders. Privatised medical services, such as those provided by 'health'-insurance companies, can claim with full justification that their primary duty is to their corporate shareholders, since businesses exist first and foremost to make money, not secondary public goods such as health, and that that is the role of charitable or—theoretically—governmental organisations. It is evident, therefore, that, due to this conflict of interest, it is not possible to provide health-effective services through profit-making vehicles: the experience in the USA shows that if you trade on sickness as a commodity, you make society sick. Even though the complete privatisation of the National Health Service of Britain has not been achieved despite the best efforts of successive governments[3], this is the primary problem today: it is an ostensibly pro-social service being managed as though it were a pro-market enterprise; consequently, it is failing to measure the performance of its providers in terms of their health-effectiveness, and so financial and social costs can only continue to rise.

The National Health Service of Britain is a well-established, self-maintaining system that expresses a chaotic bureaucracy against a very stable background resistant to fundamental change; any efforts to create deep change—including participative medicine, as discussed below—are resisted by interpreting initiatives within existing perceptual frameworks, through which the initiatives are neutralised and the administrator, rather than being a facilitator, becomes an inhibitor of deep change. This is the nature of a dynamically stable system. Successive governmental initiatives have caused great ferment with little result other than to consolidate the system and its products—with escalating expenditure, diminishing health-effectiveness, and public distrust being chief among those products. The colossus of pro-social medicine continues to founder; the locus of power may shift among clinicians, administrators, and the public, as between deck-chairs on the Titanic, without plotting a new course for medicine and its governance, it can only sink. It is a great irony that, in order to save this system of putatively pro-social medicine from the problem of increasingly disproportionate costs, the framework of administrator-centred medicine has been adopted from America, which is sure to destroy it, primarily through promoting consumerism rather than health-effectiveness.

Participative Medicine

In the above analysis, we see a nexus of persistent problems in the form of irrelevant, ecologically invalid and therefore health-ineffective, physician-centred services; self-service above public service; confounding by pro-market motivations and solutions; and persistent inequalities in power between physicians, other medical professionals, administrators, and service-users. It is no surprise, therefore, that diverse movements have emerged in tandem over the last 50 or more years, aimed at solving one or more of these problems: the movements for biopsychosocial medicine in the 1970s (Engel, 1977) and, in the 1990s, patient-centred practice (Frampton, Gilpin, & Charmel, 2003; Stewart, et al., 1995; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993); the motivationally dissimilar but synergistic initiatives emerging from the development of health economics and 'managed care' in the 1960s; and the much larger movement of medical modernisation that has included the professionalisation of modes of practice that are historically more recent than the physicians', most obviously in the fields of nursing, medical psychology, and medical social work. Most recently, it has been the movement towards participative medicine

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in assessment and treatment and, importantly, in governance. But there has been conceptual confusion between these various movements.

The Bristol Inquiry's Final Report states "For a healthcare service to be truly patient-centred it must be infused with the views and values of the public (as patients, past, present or future)" (Kennedy, 2001, p. 400); it is true that the public's views are necessary to patient-centred service but they are not sufficient to deliver patient-centred medical practice. It is important to disambiguate patient-centred medicine from the wider concept of participative medicine. There can be a superficial form of patient-centredness, as occurs currently, where the principle of patient-centredness is appropriated by physician-centred practice. In this situation, physicians focus on communication skills to elicit information from the patient, but the quality of this information is limited to the particular professional bias of the physician (i.e., diagnostic biology) and his inadequate competence in other domains of medicine (e.g., detection of mental or social dysfunction), so any referrals will be of limited accuracy; the patient's needs will be neither competently assessed nor provided for; the treatment-plan will be neither competent across all domains nor integrated; the resultant data on medical outcomes will be of limited value; and, as a consequence, the governance of medical practice-standards will be limited in its health-effectiveness no matter how thoroughly it is organised and how participative it is. This problem is seen in the current, physician-centred form of medical practice and in the physician-centred alternatives proposed (Bodenheimer, Wagner, & Grumbach, 2002a, 2002b; Wagner et al., 2001); they suffer from a physician-centric solipsism as to what defines a successful outcome, therefore what patients need, and therefore what medicine is and, thus, are not actually patient-centred. Equally, a superficial form of participative medicine can take place, as occurs currently in the form of patient-satisfaction surveys, without patient-centred practice. Health-effective medicine requires both patient-centredness and participative medicine in their full forms.

The above problems notwithstanding, the Bristol Inquiry's final report has had a large impact on the landscape of British medicine. In partial response to this Inquiry, the British Department of Health issued a consultation document "A First Class Service" (Department of Health, 1998), the core component of which was medical governance. During the Bristol Inquiry and following the British NHS Plan of 2000, a duty was placed on the National Health Service (NHS) by the Department of Health to involve patients and the public in the planning of clinical and community services, the development and consideration of changes in the way those services are provided, and in decisions to be made that affect how those services operate. This was enshrined in Section 11 of the Health and Social Care Act 2001 (UK) and guidance on best practice was published subsequently (Department of Health, 2003). It seemed that real change was about to be made.

PROBLEMS IN PARTICIPATIVE MEDICINE

While public participation in British medicine has a history of over a quarter-century, it has never been popular or effectively implemented (Hogg, 2007) and, despite the good intentions of the Department of Health, there have been serious problems with the way in which participative medicine has been enacted. The Department of Health guidance on strengthening accountability focused on ideas and values, but not on methods, processes, or standards; in its stated wish to be non-prescriptive, the Department of Health declined to specify types of outcomes and methods and rejected calls to create even a template of a formally-structured mechanism by which to help patients' experiences to inform the health-effectiveness of medical services. Medical administrators charged with the task of ensuring public participation were not given a clear remit, and so they did not understood the purpose of what they were to do, how to do it, what to achieve, or the competencies required in order to achieve it. At best, governmental

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bureaucrats developed lists of the most pressing issues for public participation without recognising that this simply provided further stimulus to boil a system already in turmoil by inducing change for appearances' sake: as that list of issues has changed, so have the requirements for public participation, resulting in a lack of accrual and continuity of knowledge.

In contrast to its stated wish to be non-prescriptive, the British Department of Health made a variety of auditable demands of medical service-providers to implement fully participative initiatives. These demands entailed representative participation rather than a form of monitory democracy (Keane, 2009) as occurs in the civil review boards of police-behaviour cited above. In diverse, Western society, it is virtually impossible to achieve or to measure representative democracy and it causes problems relating to a number of issues, including those members of society who cannot or will not use the dominant language of the nation in which they live; the funding of participants, which can be difficult and is not without ethical concerns about conflicts of interest; the prevention of misconduct by public participants; the intrusion of single-issue agendas, including ideological prejudice or bias; and the political pressure from providers (notably physicians) to get their 'buy-in', without which they have refused to do the jobs they have already been paid to do.

Similarly, 'patient-empowerment' through participative governance has been confused with treatments in behavioural medicine such as skilled self-management of chronic illness (Coulter & Ellins, 2006), as well as with some treatment-modalities in secondary prevention and rehabilitation. This is shown most clearly in both the administrator-centred initiative called the "Expert Patients Programme" (Rogers et al., 2006) and the Scottish national policy document "Better Health, Better Care: Action Plan" (The Scottish Government, 2007), both of which emerged as a result of the Bristol Inquiry. Such confusion occurs most often among administrators who have no clinical training, who also fail to understand the diversity of practice forms within medicine, and who consequently promote administrative/political solutions to problems by mislabelling such modalities and inserting them into imported commercial techniques.

There have been other obstacles too. In 2007, the Picker Institute Europe published a report of a survey that identified several factors preventing participative medicine, notably antipathy and apathy in clinicians, administrators, and the public towards the process, on top of a failure to understand how to achieve the goals specified (Chisholm, Redding, Cross, & Coulter, 2007). Related obstacles had been identified previously (Kennedy, 2001), including a negative culture towards empowering the public that pervades the NHS; a lack of awareness of the benefits of an empowered public; a lack of clarity about how to get appropriate public participation; the difficulties in reaching a cross-section of the public; a justified perception among the public that public participation is just an exercise in public relations and that there is a lack of real commitment to act; practical difficulties such as lack of time, skills, confidence, and knowledge; and a sense among the public participants of being a lone, powerless voice amongst professionals. Yet again, these obstacles reflect the resistance to losing power by clinicians and administrators. Among administrators specifically, they are due primarily to a lack of medically specific knowledge and a struggle with clinicians for power, while, among the public, the problems are largely due to a loss of trust. The Bristol Inquiry's Final Report (Kennedy, 2001) recognised that existent and long-standing efforts to include the public have resulted in little in terms of value due to tokenism; such tokenism has damaged public trust further and promotes apathy, disengagement, and cynicism; preserved professionals' status; and maintained the same health-ineffective services as before.

This is of enough concern in itself. But there are deeper conceptual problems with public participation in light of the pro-market solutions used to deliver services. Businesses and the market don't 'do' democracy except insofar as it is advantageous to public relations

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and market-share, so they will drop the element of public participation the moment it has ceased to be of financial value to them. In a commercial 'medical service', consumers aren't entitled to be involved in governance or to demand changes in the way services are provided so as to increase the health-effectiveness of 'medical' outcomes; in contrast, this is a reasonable expectation on the part of the service-users in pro-social services.

In response to the British government's demands for representative participation, medical administrators have responded by porting over business-solutions and introducing methods from market-research and public relations. Without a clear understanding of what public participation is for, why it came about, and its scope, NHS administrators have reduced it to administrator-chosen elements of the 'patient-experience', the 'patient-journey', 'patient-satisfaction', and 'patient-choice'. Some service-providers have demonstrated their success in public participation through opinion-gathering, including public meetings, formal consultation, satisfaction-surveys, patient-panels, and focus-groups; others—such as North London haemophilia services—have had children's picnics. Few, if any, have been aware that the primary purpose of requiring public participation was to use it to promote governance and health-effectiveness rather than to enhance public relations.

Because of the differing goals of pro-market and pro-social medical services, the use of public participation in medicine takes quite different forms in each. This is neither immediately obvious and, in a pro-social system managed as if it were a pro-market system, it becomes particularly difficult to identify. How public participation is used or misused becomes clear only indirectly, in terms of in what and how the public is invited to participate. As in pro-market 'medical' systems, public participation in the NHS serves the primary function of public relations through surveys of patient-satisfaction, supported by enchanting mobile and information technologies, and so on—methods without a clear purpose, none of which addresses the health-effectiveness of services, including protecting the public from provider-misconduct. One example of this as a problem is enough: the lack of value in 'patient satisfaction' lies in its utter inability to predict health-effectiveness. This is exemplified in the fact that many of the patients of physician Harold Shipman wrote in to the court during the trial to express their satisfaction with and support of his practice (Smith, 2002, 2003a, 2003b, 2004a, 2004b, 2005); given his subsequent criminal conviction for the murders of 200 to over 300 of his patients, no further discussion is needed of the uselessness of patient satisfaction measures in protecting patients or ensuring that medical practice is health-effective.

The user-movement has been susceptible to co-opting by pro-market methods because it has little idea of what an alternative model of medical services should look like. It has been dazzled by public relations and the entertainment of social media and mobile technologies; information technology has been promoted as the answer to the problem of health-ineffectiveness; the public is overloaded with information due to medical advertising—be it appropriate public-health messages by medical charities or inappropriate direct-marketing to patients by pharmaceutical companies—the problem of shoe-horning patients' preferences and values into medical decision-making is stated as a problem, rather than the deeper problem of physician-centred practice that gives rise to it; a false conundrum is posited of an inferential gap between patient-level decisions versus population-level evidence, rather than questioning the inappropriateness of using public-health surveillance as a top-down driver of performance targets instead of medical surveillance and a bottom-up, patient-centred driver of health-effectiveness; a technical rather than scientific conception of 'evidence-based practice' has been promoted that cannot be assured to be health-effective; and much research is market-driven rather than scientific, rarely even meeting the criteria of minimally-sufficient scientific practice. In all this disorder, the health-effectiveness of medical practice remains unidentified.

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In both pro-market and pro-social systems, public participation can reduce the costs of services in the short-term, but only in a pro-social system is public participation able to promote health-effectiveness and, thus, reduce financial costs long-term: healthy people do not require medical services, so demand goes down long-term. This is the basis of the large financial cost-savings seen when behavioural medicine is integrated into practice (Cummings, O' Donohue, Hayes, & Follette, 2001). It is no coincidence that behavioural medicine requires the active participation of the patient in order to be health-effective; patients are participants, not objects of treatment (as in the classic form of physician-centred practice), which requires ownership of illness and health and, therefore, responsibility. Patient-centred practice also identifies technological solutions such as pharmaceutical treatments as neither necessary nor sufficient for all treatment—which is where the radical cost-savings emerge in integrated practice.

Finally, as stated in the Bristol Inquiry Final Report (Kennedy, 2001; p.411), a patient-centred service does not mean a patient-dominated service, with the attendant problems of consumerism and malpractice-litigation, as occur in the USA. It is equally clear that this is just as ineffective in terms of both financial and health-costs. Patient-centredness and participative medicine are also quite different from services being 'user-driven', which proposes an expertise that users/patients/members of the public don't have and simply but nominally switches the locus of power to the service-users, as between deck-chairs on the Titanic; the system is still bound to fail. To date, participative medicine in the NHS has already had various incarnations that continue to change in form and purpose while remaining uniformly ineffective. Consequently, public participation has been reformulated and renamed/rebranded regularly by governmental fiat—i.e., without public consultation, suggesting the actual respect in which it is held and, once more, using commercial solutions to change perceptions while persisting with failure. This can only be done so many times before the public will become frustrated, even more distrustful, and refuse to participate—without knowing why the initiative has failed—which will lead the government to realise that it no longer has political value and dispense with it, claiming that it tried but the method does not work. Of course, this would be true only insofar as the concept of public participation has been appropriated for purposes other than its original ones. Still, the conclusion that public participation does not work will result in the ill-informed reflex action of privatisation, because of the fundamental pro-market framework of the government to services that are pro-social (Pollock, 2004). In fact, participative medicine will not have actually been tried. Worse, the application of pro-market methods of self-regulation in medicine will continue to be unable to prevent malfeasance and protect the public due to these inherent conflicts of interest. Such conflicts of interest result in catastrophes, whatever the field, be they the misconduct of the General Medical Council in Britain (Davies, 2007), the collapse of Enron, or the predatory lending by banks and the global recession of 2009-2010.

GOOD MEDICINE ENTAILS PARTICIPATIVE PEDICINE

Reviewing the above, it can be seen that medicine's primary problem is its being stuck in health-ineffective forms of practice, the most obvious consequence being the injury and death to patients through provider-misconduct. If the health-effectiveness of practice were measured within participative practice, these problems would be hardly possible. The reason that medicine and society face this problem is historical, firstly in the dominance of the physician-centred model of practice and then its exacerbation by administrator-centred practice. An essential part of the solution to this problem was identified in the role of public participation in medicine by the Bristol Inquiry Final Report, among many other, less compelling analyses in the literature. While public participation has a long and solid

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history internationally and in diverse fields of primary importance to society, public participation presents real challenges to the inequalities maintained by both physician-centred medicine and administrator-centred medicine. The British civil service refused to provide a working model of participative medicine that could then be tested scientifically, leaving the current medical system to design one or more models itself by which to change itself from the inside—a task that no closed and vested system can achieve. As a consequence, public participation has been appropriated by commercial practice and reduced to patient-satisfaction surveys and the like, none of which ensure health-effective services or the protection of patients. It is foreseeable that public participation will fail as a consequence of this and be dispensed with, physician-centred and administrator-centred solutions will continue to fail to meet the public's needs, and this will result, by default, in privatisation of the service to bring it in line with the perceptual framework of successive, pro-market governments. This will result in the reinvention of the wheel of insurance-based, privatised services, already shown to be broken in the USA, exacerbating the existing problems of consumerism and cost-ineffectiveness and, most notably, making society sicker.

The key obstacle to changing this highly stable problem is that, until now, no system of medical practice as a truly health-effective service has been developed and no sub-system of public participation has been developed that can drive it and maintain it as such. This is the work of the Tuke Institute, outlined below. In this solution, it is clear that public participation is essential in several areas; without such participation, medicine cannot be health-effective, patients cannot be protected from providers' self-interest, and society cannot become significantly healthier (Whitaker, 2010).

The Tuke Institute Model of Medicine

Medicine of good quality is, by definition, health-effective medicine, which means that medical outcomes must be defined through the measurement of comprehensive functionality of each individual, within his or her social context. Such measurement requires multiple benchmarking over time against a baseline illness-status and a personalised standard of health to determine progress and adequacy of services. Comprehensive measurement of illness-status requires both objective and subjective assessment using idiographic/personal as well as nomothetic/common methods that account for physical, mental, and social assets and vulnerabilities in the individual within his or her social context; ecological validity requires personalised measurement in order for the subsequent measurement of outcomes to be medically not just epidemiologically meaningful: that is, the outcomes need to relate to personal health not just public health.

But more is needed than a biopsychosocial framework with personalised benchmarks of health-defined outcomes. As we have seen, the system of medical practice/service-delivery itself has to be reformulated. Health-effective service requires integrated, comprehensive treatment that is defined by—and remains focused on—the patient's needs. Therefore, this requires the nurse-led practice of a multidisciplinary team, since nursing is the sole medical profession that values physical, mental, and social aspects of the treatment of illness equally and is not subject to the biological biases of physicians, the psychological biases of medical psychologists, and the sociological biases of medical social workers/sociatrists. Nursing is also the profession most qualified to deliver and ensure patient-centred practice. Integrated, patient-centred practice requires participative treatment, from the bare minimum of simple treatment-adherence up to the modification of entire illness and healing processes, for example through behavioural treatments of epilepsy, diabetes, or stroke, and social treatments of traumatic injury through domestic violence. This approach thereby enables each medical profession to practice what it is best trained to provide: physicians aren't required to be all things to all people, resulting in incompetent

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assessment and treatment in non-physical domains, causing cost-escalation.

But there is also more to the solution than a biopsychosocial framework, personalised and comprehensive assessment, and both patient-centred and integrated treatment. The system of health-effective medical services needs to be secured against the vulnerabilities to provider-bias and professional politics that would otherwise permit the system to revert to provider-centred practice, with all the health-risks to the public that that entails. Securing health-effective medicine in practice requires accountability of outcomes measured against standards, which is best achieved through the transparent use of data already gathered in the participative assessment and treatment outlined above. It means that participative administration is required, specifically in terms of participative governance.

Next, in order for a medical service to be health-effective, it needs to be able to provide treatments that are the most health-effective available, which requires public participation in medical science in order to identify society's needs from the bottom upwards, to translate them to a scientific framework, to identify the scientific questions and research required to meet those needs, to allocate available funds to make the research possible, to provide the data in the execution of the necessary research, and to govern the process of scientific practice—not least in ensuring that both negative and positive results are published in an accessible manner (e.g., through non-proprietary means when research is publicly funded) and that research-outcomes are applied to medical practice for the benefit of patients and society first and foremost. A system similar to the medical system outlined here was designed by the author for the Research Capability Programme of the National Institute for Health Research (UK) and accepted in March 2010 as the framework for the new national clinical trials system. This and the related initiatives towards translational medical science indicates that medical science, if not yet medicine, has an awareness of the need for deep change in order to become health-effective.

The translation of scientific research into treatments, framed and enabled by public participation, requires the final step of commissioning health-effective forms of medical service-delivery (i.e., medical practice), using within such forms of practice the currently most health-effective treatment-modalities. At this point, a distinction between a mode of medical practice and treatment becomes moot, which is consonant with the classical conception of medicine: the connection with future health is not located in the individual (as in the shaman) but in the team. It also points out that the health-effectiveness of forms of medical practice should be the subject of clinical trials: there have been no clinical trials of the long-term health-effectiveness of physician-centred practice versus multi-disciplinary, integrated, and patient-centred practice. Changes in the form of administrator-centred practice are also implemented without any evidence as to their health-effectiveness and without any monitoring of such after implementation. Likewise, different methods of public participation in medicine should also be subject to clinical trials as to their health-effectiveness. We have the theory and now it should inform scientific practice; indeed, the absence of theory is what distinguishes merely technical research from scientific research in the quest for evidential health-effectiveness of medicine in practice.

This, then, is health-effective medical science that translates from the patient, to the scientist, and back to the patient, not just from the physician to the technician/physician-researcher and back to the physician, as happens today. It is the final element in a thorough re-conceptualisation of medicine that relies on user-participation in both its practice and governance. As with other traditions in participative democracy throughout the world, such participation requires mutual learning; it commits to mutual benefit—albeit with the primary benefit going, appropriately, to society—it is focused above all on health; it involves systems-development and civil capacity-building; and promotes both autonomy and responsibility of users, which itself promotes health-effectiveness.

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Although this is a simple, practicable, if deep model of medical service-systems designed to meet individuals' and society's needs, there remains a large amount of scientific research to be done. Such research lies in the development of valid assessments of patient baseline illness-status and of clinician and administrator practice, ensuring a high determinative relationship to health-defined outcomes and with high sensitivity and specificity to the variables that are theorised to mediate that relationship. It also lies in developing the model of practice and implementing it in such a way that it can be studied scientifically, as with any other complex intervention. And it also lies in studying what regulatory sub-systems are needed to ensure that not only is health-effective medicine practised but that it continues to do so, by remaining an open system that can learn over time. Regardless of what the specifics look like eventually, one thing seems incontrovertible: where medicine itself is sick, it needs the public to make it well again. How that is done will determine how sick medicine—and society—remains.

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ENDNOTES

1 A term used in EH Wagner's model of chronic-illness treatment. It is worth noting that the root of the word ancillary is the Latin word for 'handmaid': thus, 'ancillary' providers, such as nurses, psychologists, and medical social workers are, literally, handmaids to the physician.

2 This orientation is responsible for the instance where a leisure-facilities administrator can be put into the position of administering a medical service in the belief that administering a swimming-pool is the same as administering an emergency-medicine unit; here, success is essentially about minimising financial costs.

3 This is in spite of the fact that all British primary medical services (i.e., services delivered through GPs) are—and always have been—private and commercial.

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