



Tuke Institute

FROM HUMAN SCIENCE TO MEDICINE

The Tuke Institute's Framework for Participative Medical Science and Policy

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Author(s): Dr. Rupert Whitaker

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Briefing: The Tuke Institute's framework

This briefing addresses the nature of participative science in both community/social and clinical medicine, its rationale and value, and how it relates to the value, the framework, and the methods of the Tuke Institute. Its purpose is to help the reader understand the nature of participative science and the work of the Tuke Institute in its broadest sense¹.

The Tuke Institute addresses some of the most difficult problems in attempting to protect civil society's well-being through the delivery of medical services. It bases its approach on a variation on and synthesis of a number of traditions of participative and translational science, including two particular traditions of participative science. As with science itself, participative science comprises the areas of praxis, methodology, theory, and philosophy with the added orientation of civil participation in its execution, for the purpose of civil benefit. It may be characterised by the following criteria (Minkler and Wallerstein, 2008; p. 9):

1. it is participative
2. it is collaborative
3. it requires mutual learning
4. it commits to ensuring that all parties benefit materially from the knowledge produced
5. it is solution-oriented
6. it balances science and action/praxis, translating between the two
7. it involves systems-development in the design of solutions
8. it involves civil capacity-building
9. it facilitates an increasing self-responsibility by civil members over their illness and health
10. it reduces dependency on professional providers
11. it facilitates the provision of valid and health-effective medical services by public servants², to the benefit of the individual and the wider society

Participative science is a scientifically rather than politically driven movement that emerged from the recognition of the failure of an objectivist philosophy of science in providing solutions that were adequate and relevant to society's needs. Objectivism was of limited use as it failed to address the meaning, purpose, and utility of science through its removal of context from the object of scientific study. Realising this failure, the Institute of Medicine in the USA identified participative research practice as one of the content areas in which all schools of public health should offer training, asserting

¹ An excellent introduction to participatory research in the field of public health is Minkler and Wallerstein's edited book (2008). This briefing is based on a reduction of the material available there.

² i.e., all providers in nationalised medicine

that participative research in public health is “epidemiology enriched by contemporary social and behavioral science because it incorporates what we have learned about community processes and engagement, and the complex nature of interventions with epidemiology, in order to understand how the multiple determinants of health interact to influence health in a particular community” (Gebbie et al., 2003; p. 7).

As with the science of civil and community-based medicine, so with the science of personal and clinical medicine: participative science enriches clinical medicine with behavioural, mental, and social science in order to understand how to treat the multiple determinants of illness in a given individual. The value of a participative science of clinical medicine lies in its ability to create progress that is meaningful to the people who suffer from illness; to paraphrase Krieger (2000; p. 27), participative science increases the relevance of the questions that need to be asked of the people with whom one needs to collaborate in order to develop the understanding necessary to make effective change; it enables the development and translation of relevant solutions to the problems of illness, making medicine increasingly health-effective and fit for its purpose. Participative science in medicine is not new (Green, 2007; Macaulay and Nutting, 2006; Westfall et al, 2006; Felix-Aaron and O’Toole, 2003; Wells and Norris, 2003), although it should not be necessary to state that medicine itself is not a science, in that medicine deals with individual illness and science with principles and populations; they have distinct objectives, require quite distinct skills, and have distinct forms of training.

The Tuke Institute is unusual in that it is founded on the experiences—and the unique challenges—of people who straddle more than one category: scientists with acute and chronic illness and experience as patients; clinicians with acute and chronic illness and experience as patients; and non-clinical providers who have experience with acute and chronic illness. Bringing such a group together is an important task, as the knowledge gained from experience as a patient who is also a clinician and/or a scientist is invaluable and such people realise how seriously some solutions needs to be found to the present problems of medical services. But it is also a difficult task, because there is a real concern that visibility as a person with chronic illness affects one’s career and work-life. The Tuke Institute also has scientists, clinicians, and non-clinical providers who are not chronically ill (or identified as such) and, as a consequence of the above, the Tuke Institute must make no distinction between these groups publicly. It is a significant comment on the experience of the ill in contemporary society.

The traditions of participative science and the position of the Tuke Institute

The majority of participative science relates to two, primary traditions that are arguably at opposite ends of a continuum. The first, the so-called Northern tradition, stems from the work of Kurt Lewin

(1946) and later proponents. Lewin was one of the earliest figures to recognise that context-free science is meaningless and therefore useless and this tradition focuses on pragmatic solutions to community-centred problems through a participative process. It suffered from limited participation by those affected and a lack of an inherent objective of application. The other tradition, the Southern tradition, stems from the emancipatory work of people like the lawyer and educator Paulo Freire (1970) in under-developed and post-colonial countries who facilitated action based on critical awareness; it 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. But, despite being politically necessary and admirable, the Southern tradition suffered from a lack of scientific sophistication, using a purely reductionistic ideology about systemic disorders where, for example, altering historical determinants (such as class-structure) of a systemic problem (such as economic disparity) was believed to be adequate to solve that problem.

Medicine suffers from similar problems of authority in physician-centred medicine and in the misuse of medical discourse by authoritative bodies, under a scientific pretext, to 'de-authorise' or invalidate traditional or popular forms of knowledge such as acupuncture, herbal medicine, and nutrition. As Jones and Wells (2007) state, participative medical science "might challenge physicians given their clinical training" (p. 407) as well as their social assumptions; it is one reason why only qualified scientists should lead scientific research and especially in participative science, which requires both deep and extensive—ideally trans-disciplinary—scientific training. In socio-medical science, the imbalance in authority has been partially rectified in some tribal communities, for example, where "institutional review boards directly control (and deny) access to researchers who are not fulfilling community needs" (Minkler and Wallerstein, 2008; p. 31). In contrast, in clinical medical science, particularly in Britain and the USA, access to clinical research participants is controlled primarily by non-scientist physicians and here, the 'community' whose needs are met is that of physicians rather than the public.

Having reviewed briefly these two traditions, it can be stated that the Tuke Institute bases its work on both of them: its framework and values lie in the Southern tradition of relevance, breaking the monopoly of clinicians and corporate business on the discourse of what medicine is, so that it is relevant to the needs of people who are ill. This is done with an understanding of the mental, behavioural, and social aspects of the wish for control common to both providers and the public, which is pursued for both personal gain and to equilibrate the resources and feelings of mutuality and trust (i.e., "social capital") of all parties in the delivery of medical services. That said, the Tuke Institute's methods lie nevertheless in the Northern tradition of "empirico-analytic reason", where instrumental and behaviour control over a system of problems is achieved through pragmatic, translational science. It is ironic that these methods and moral frameworks, developed in the poorest regions of the world over the past half-century, are needed to make medicine fit-for-purpose in the richest nations of the world today.

Conclusion

Participative science is a potent tool for creating relevant and, thus, health-effective medical services, designed and delivered in the public interest. It has a respected tradition in action- and results-oriented civil work and is better able to solve previously intractable problems in delivering health-effective medical services. It has shown its value in public health and social medicine and can be adapted to translating science to address the peculiar demands of clinical medicine. This is done by addressing the needs of the whole person in their lived context, rather than just their physical pathologies. The Tuke Institute has been perfectly formulated to carry out the translation of science to contextually relevant, health-effective medical practice through a participative method.

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