Tuke Institute

FROM HUMAN SCIENCE TO MEDICINE

Response to the Department of Health's National Health Service White Paper "Equity and Excellence: Liberating the NHS"

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General

1. The White Paper is a welcome and promising move forward in the redesign of the National Health Service to provide health-effective services to the public in accordance with the values and principles on which the NHS was founded.

2. The placement of health-outcomes as central to the purpose of the NHS is long overdue and the resection of managerialism in the NHS is heartening.

3. In its goal of providing a scientific evidence-base to policy-making, the Tuke Institute has already provided a model that achieves these goals, having a primary focus on health-outcomes, with democratic legitimacy, clinical autonomy, and a robust approach to transparency and accountability (Reference 1). The current White Paper is an exciting step in this direction but is at significant risk of failure.

Quality of services

1. The White paper focuses on quality of services as one of its themes. It does not consider how quality is created and make a number of assumptions that need to be made explicit in order for providers to understand how quality can be achieved.

2. Quality is equivalent to health-effectiveness of services, as services that fail to be of good quality in every aspect of patient treatment will fail to be maximally health-effective.

3. Quality is driven by standards, the positive and negative motivators to implement them, and feedback about a service's health-effectiveness. This means that standards must be readily available that specify what forms of service-design (rather than just treatments) are most health-effective and the quality of a service must be assessed in relation to patient-centred health-outcomes. Such standards do not exist to date.

4. NICE or a similarly able body needs to develop such standards. These practice-standards should complement treatment-standards and need to specify which services from which professionals need to be made available and through what sort of practice-design. This will enable integrated teams to treat illness adequately in primary and post-primary practice, as well as in simple/acute versus complex/chronic conditions.

5. In audit of service-quality, the NHS needs to ensure that quality-assessment is scientifically designed in order to measure those factors that determine health-outcomes. Health-outcomes are determined by a range of factors including aspects of the illness, of the patient, of the clinicians providing treatment, of the organisation of services, and of the funding of those services. All need to be considered in an integrated manner.

6. Public health measures of morbidity, mortality, etc are inadequate to measure quality/health-effectiveness. The use of such population-level indices are only tenuously related to quality of services and, thus, health-outcomes as they lack a direct relationship to patients' and their carers' ability to function in society. For example, "morbidity" rates for diabetes do not reflect how many of those people are disabled or why.

7. Patient-centredness therefore needs to imbue the analysis of services from the patient right out to national policy-setting. This is feasible through existing methods.

8. Ensuring patient-centredness in clinical practice is possible, but it has not yet been done significantly in Britain. Physicians are often required to achieve this but it is outside their trained competence as medical physiologists and a waste of their expensive expertise. According to scientific evidence, patient-centred services require the re-design of practice to ensure a balanced, team-based approach using the three other medical professions that are currently under-utilised: nursing, medical psychology, and medical social work. This maximises sustainable health-outcomes,

maximises the efficient use of physicians' actual expertise, maximises continuity in care, and *minimises* the demand for medical services in the future. This sort of design also makes any future integration of health-care with social care that much easier, with further savings in social and financial costs.

9. Integrated practice of this sort has been shown in solid evidence from the USA to result in sustainable reductions of over 60% in the demand for primary medical services through improving health-outcomes.

10. A failure to specify these sorts of standards and service-formulation in contracts with, e.g., GP consortia will fail to improve health-outcomes and cost-effectiveness of services (see below).

11. Feedback is an important tool in the audit and re-design of health-effective services. Feedback needs to be enabled at every level of the process of medical service. Feedback that is integrated at every level of service is required if responsibility for health-outcomes is to be ensured from the level of the individual clinician onwards. It is essential to transparency and accountability.

12. Feedback should include the opportunity for patients to readily record comments on the quality of care and its effectiveness (both in primary practice and in hospital-practice) in their own medical records (called 'open records' in the literature), being included as part of 360-degree feedback on the performance of named clinicians, and anonymous reporting online about the quality of services received.

13. Feedback of this sort also uncovers the multiple, small problems in practice before they lead to systemic failures. It identifies the pressures from financial managers or insurance-companies to shape services to meet the providers' needs rather than the patients' and helps protect the well-being of clinicians in their jobs. It helps balance the picture provided by clinicians' notes in medical records, which is often wrong (as shown through medico-legal experience).

14. Feedback-methods should be designed scientifically in such a way that it focuses on how a clinician delivers sustainable health-outcomes (i.e., 'health-effectiveness') first and foremost. It needs to measure those aspects of service that can be shown through solid scientific (not market-) research to deliver lasting health-outcomes.

15. Feedback is important for the prevention of malpractice. "Clinical negligence" needs to move from a financial-legal framework to a patient-centred practice-framework. The White Paper fails to address even indirectly the issues that arose in the Bristol Inquiry and there is no specification of sanctions to be used against providers of inadequate or negligent service.

Health-outcomes

1. In the White Paper, clinical measures (e.g., PROMS) are confused with public health measures (e.g., mortality rates) in discussing health-outcomes (see Quality of Services, point 6, above). Health-outcomes need to be measured through the accumulation of information from the ground upwards, particularly in the use of data from all patient records.

2. For this, the implementation of disease-coding to conform with the WHO's International Classification of Diseases 10 (ICD 10) should be complemented with the formulation of treatment-goals according to the WHO's International Classification of Functioning, Disability, and Health (ICF).

3. This will provide a way to ensure that the diverse range of measures of health-outcomes have a common reference for coding. Without this common reference, measuring health-effectiveness across different clinics will be like comparing apples with oranges and the data would be unusable for audit, governance, commissioning, and policy-making.

4. To use this ICF-type approach would be an important move towards patient-centredness in the service as a whole, rather than the current physician-centred, disease-oriented approaches in which patients continue to be identified as "the lung cancer in bed 4".

5. Physicians are the least competent of the cardinal medical professions to do this sort of assessment as it lies outside their professions' remit and expertise. This argues for integrated practice.

6. Continuity of care requires a continuity of information. Providing such continuity is crucial to optimising health-outcomes. Clinical information should be based in case-formulation in primary practice and should inform the treatment-goals and services provided at all levels of the NHS that a given patient interacts with subsequently, including those in hospitals etc. This continuity of information is possible only with integrated and patient-centred practice, integrated treatment-planning, etc.

7. Such principles of continuity of care and patient-centredness also require hospital-based services to be answerable to primary-care practice, through the combined governance of the two levels of service. This is to be done ideally through participative mechanisms via HealthWatch or similar. This issue has not been considered to date but it key to continuity in services and optimising health outcomes.

8. A framework for such a system of measuring health-outcomes has been designed by the Tuke Institute (Reference 1). This model has already been successfully applied to a related problem in designing the system for national clinical trials and translational science for the National Institute of Health Research (Reference 2). The elements necessary exist already and it is feasible to meet the IT requirements and scale this practice up.

Public participation

1. Valid public participation does not occur currently and the plan in the White Paper is inadequate to achieve it. Based on the experience of the past decade, it is unlikely that the NHS Commissioning Board in particular will know how to use public participation to achieve its goals without expert scientific advice. As the government does not know how to do this, local community-based groups are even less likely to know how. This has been seen in the pervasive problems experienced by the Links network.

2. Public participation lies in three distinct but linked domains: participation in clinical services; participation in the review of services, their audit and governance; and participation in commissioning and policy, right up to the national level.

3. All of the domains of public participation should be linked by a common set of data from patient-based measures of health-outcomes. Patient-participation clinically is crucial to the provision of the data necessary for clinical audit, governance, policy, and commissioning, for these latter should be built on the lived experience of illness expressed by patients. How this can be achieved is identified in Reference 1. Thus, the participation of patients and carers in case-formulation, -management, and (of course) treatment is crucial to the whole system.

4. Public participation has real risks: the NHS should *not* be patient-led. Although participative practice in medicine promotes democratic legitimacy, any one group of patients does not necessarily know what is good for others. Promoting a patient-led approach is a political solution to a medical problem with significant risks of permitting prejudice to influence the design and commissioning of services. For example, a group from a heavily religious area will not argue for sexual-health services, even though they may be very necessary.

5. Therefore, the use of participative approaches to medical practice needs to be constrained in such a way as to ensure that the public, as patients or their carers, are able to influence services only insofar as those services are delivering health-outcomes for *all* service-users. A careful, multi-layered model towards this end is included in the Tuke Institute's model (Reference 1).

6. Instead, the NHS should be patient-centred and illness-led, focused on the current reality of what patients are struggling with, not politicians' or clinicians' ideologies about democracy or (future) health. Promoting a patient-led NHS promotes unhelpful competitiveness and politics between providers and the public where collaboration is needed instead.

7. HealthWatch has great potential. However, its role in the Care Quality Commission and in the system of participative governance as a whole is inadequately designed: how it gets its data and how it uses it, how it deals with bureaucratic obstacles, and how its functions to ensure health-effectiveness of the system—none of these problems has been solved.

8. There needs to be a body of the same kind as the BMA or the Royal College of Physicians—a Royal College of Civil Health, if you will—to promote and protect the public's interests in medical and social services provide in a pro-social system such as Britain's, so as to ensure that these services are health-effective above all and resistant to the predations of commerce, provider-interests, etc. This should be led by patients, carers, and the general public, with a special role for clinicians and scientists who are also publicly identified as patients and/or carers.

GP consortia and commissioning

1. GP consortia and the NHS Commissioning Board should be required to commission services according to the scientific evidence and reasoning, otherwise services that are not delivered by physicians will not be offered even though they may be more effective. An example is the use of ketogenic diets in childhood epilepsy, neurofeedback in adult epilepsy, and psychological rehabilitation in head-injury generally, all of which are known to be cost-effective and none of which are offered at the Institute of Neurology, Britain's leading service-provider in this field; it has been reported by one of its consultant physicians to have one junior psychotherapist for the whole hospital. This is the problem with the physician-centred practices that are promoted by the White Paper and similar issues arise in GP-focused commissioning.

2. In order for the devolution of commissioning to the clinical level to be successful, NICE needs to develop quality standards for medical services in general, not just for specific disorders, (cf, Quality of Services above, point 4). Commissioning through GP consortia should stipulate that audit will include the measurement of how closely the service-providers adhere to these standards.

3. Clinics and hospitals have long been able to innovate in their services; the fact that they have not is because they do not know how to or to do so would require changing the model of practice, which currently serves them best, rather than their patients. The institution of GP-consortia will not change this without the tandem implementation of the the sort of practice-standards identified above.

4. As non-scientists, it is unreasonable to expect physicians to fully understand or keep up with the scientific literature. Thus, there needs to be access to advisory services led by those qualified in the clinical science of medical effectiveness, to remove the bias from professional advocacy-groups such as the BMA. This is in accordance with the government's affirmation of an evidence-based approach to policy-making.

5. In the absence of such NICE *practice*-standards and their inclusion in audit, the devolution of commissioning will will perpetuate the problem of physician-centred services and physicians' resistance to integrated practice. This problem relates to the perception of physicians as the only profession necessary to delivering health-outcomes—an attitude that is half-a-century out of date and is *the* biggest problem of any in optimising health-outcomes of services.

6. Health and well-being boards have little to offer other than an extra layer of bureaucracy unless they are a part of HealthWatch, in relation to its proposed role in influencing commission and delivery.

Problems with the financial approach to regulation

1. Optimal health-outcomes are not achieved by managerial and consumerist approaches. In pro-market services, commercialism is designed to *increase* public demand for a product and/or service through consumerism; given the pro-social values and principles of the NHS, a *reduction* in public demand for the service is the goal, through reduced illness. The two frameworks are incompatible.

2. The governmental belief in the value of pro-market solutions to the problems with service-standards, the loss of public trust, etc. needs to be reality-tested with an appreciation that consumerism is a destructive influence within medicine: evidence from the USA shows that it leads to increased costs, litigation, and reduced health-outcomes.

3. Providing the public with a choice of services does not ensure the quality of services. While it stimulates an orientation to patient-centredness, it is not a solution in itself or necessarily a part of patient-centred services. It is largely a public-relations diversion from addressing the delivery of health-effective/quality services.

4. Commercial approaches to quality-assessment for audit and governance are of limited use. Non-scientific, market-type surveys are of little value in maximising health-outcomes. "Patient satisfaction" is useless as an indicator of quality, shown by the fact that many patients of the serial murderer and physician Harold Shipman wrote in to support him, stating their satisfaction with his services. Despite their satisfaction, he still murdered 200-300+ patients.

5. The fact that dh_117842 "Regulating Healthcare Providers" speaks only to financial regulation indicates that the problem of market solutions to social challenges has not been solved. The governmental ideology that market-competition can deliver improved health-outcomes has never been shown to be true. Likewise, key sections in the White Paper and dh_117842 are based in health economics, a field that has little understanding of clinical practice or health-outcomes within a pro-social system.

6. A solution exists: in a nationalised, pro-social system, services can only be shown to be cost-effective if they can be shown, first, to be health-effective; thus clinical audit of health-effectiveness is of primary importance, financial regulation must be seen to serve that, and both clinical and financial regulation must rely on systemic measures of health-outcomes.

7. The delivery of improved health-outcomes will be served best by making financial regulation a part of clinical regulation, not the other way round as it is currently. They need also to be integrated into a single regulatory entity. Failure to do both of these things will permit another Stafford Hospital tragedy—a signal event in a dysfunctional system.

8. If the government wishes the Big Society and social enterprises to help the government to achieve its goals, it must ensure that its own civil service—e.g., Companies House—does not drip-feed obstacles to this, as it currently does. The failure to ensure that the the civil service is itself audited *participatively by the public* in relation to its implementation of the government's current policies is surely a primary problem to solve.

References

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