



Tuke Institute

FROM HUMAN SCIENCE TO MEDICINE

Response to
“Developing our NHS Care-Objectives:
A Consultation on the Draft-Mandate
to the NHS Commissioning Board”

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Overview

The Tuke Institute is a non-profit organisation of scientists, service-providers, and organisational-development professionals pursuing research, policy, and civil capacity-development to create truly patient-centred health-services with the focus on health-effectiveness. It uses promotes solutions to problems of public benefit in clinical and scientific health-services and focuses on new methods of promoting and enabling civil participation in the design, delivery, and governance of such services. The Tuke Institute is unique in that it relies significantly on experts who have chronic illnesses and disabilities themselves. The fundamental goal is to make health-services about what ill people need to get well and to stay well.

We welcome the draft-mandate for the NHS Commissioning Board and it is a first, good step in the direction of creating a service oriented towards health rather than just disease-treatment; patient-centredness is a crucial, essential element of such a service.

Despite the mandate's values and approach to creating a patient-centred NHS, there are significant conceptual, strategic, and technical problems. Most significantly, these are reflected in an inconsistency of understanding what patient-centredness is and therefore in being able to promote it as a reasonable alternative to the current physician-centred model of NHS services. Conceptual and operational clarifications of key concepts are needed, particularly those of patient-centredness, comprehensive services, integrated services, about how performance and progress against the mandate can be measured, about the difference between public-health interventions and clinical health-services, and about population-based, public-health indices versus patient-centred, clinical indices of services' effectiveness. Likewise, there is a lack of a proper biopsychosocial framework, where each of those domains is addressed equally, to the benefit of the patient and society as a whole.

There are also problems in the vagueness of how to address the key obstacles to cultural change, due to an inexperienced, marketing-approach to factors such as "patient-experience", which are poor indices of patient-centredness. Problems due to promoting consumerism over health-effectiveness arise through a misunderstanding that patient-centredness is equivalent to consumerism. Prioritising a 'good experience' in health-services is a consumerist approach that shows only managerial experience but little expert knowledge of health-service usage or delivery. Consumerism fails to deliver patient-centredness or health-effective services. Moving from a physician-centred model that delivers more for the clinicians than it does the patient should not then move to the other extreme of a model where the patient is the all-powerful consumer.

Culture changes slowly, in the Department of Health as much as in the NHS. The consultation's question-set is limited, preventing the ability of responders to address basic conceptual errors. This reflects the likelihood that it will be inexperienced clerks who collate the responses in a bureaucratic manner, lacking the background knowledge and critical perspective to inform the development of the mandate adequately. If the Department of Health is unable to ensure even this low level of expertise – just as the NHS looks for the least-qualified clinicians possible to provide a service – it is equally unlikely the the NHS will be able to demonstrate the necessary expertise to achieve the mandate's objectives.

There is a lack of specified objectives for the NHS Commissioning Board on how to implement reforms and establish the new commissioning system. Without this, the NHS will continue to do what it knows how to do, through experience rather than expertise, and progress will be hindered.

The mandate also struggles with identifying relevant, patient-centred methods for assessing progress against the mandate: expertise is needed to identify how the mandate can address obstacles to cultural change strategically and methodically. We indicate solutions as to how the mandate could do this, using a bottom-up, patient-centred reformulation of health-services and the measurement of their health-effectiveness.

Significantly, there is little on transparency and accountability or how they relate practically to patient-centredness. We provide a solution to that in our work on participative medical governance grounded in health-status data, so as to prevent the need for another Bristol, Shipman, or Stafford Inquiry.

The mandate is based appropriately in the NHS Outcomes-Framework, albeit that the latter is currently too physician-centred. There needs to be explicit co-development of the mandate and the NHS Outcomes-Framework. While it is outside the remit of the mandate as such, a larger point is that there are three outcome-frameworks: for the NHS, public health, and social care. All these areas come under 'health' and there should therefore be one comprehensive framework, with subsections as to the different delivery methods of outcomes in each sub-sector. This would promote the commissioning of truly patient-centred and health-effective services. In a related manner, there are conceptual problems in the approach of "separate but equal" to physical and mental health; all services should be integrated and comprehensive; with patient-centred services, physical health will not be privileged as it is now, as the model would no longer be a physician-centred one.

Similarly, the mandate's ideas about the broader contribution of the NHS to society paradoxically promotes health-inequality for single people and adults, especially those who have only recently left childhood, have disabilities, and are typically struggling with the transition. This set of proposals in the mandate is a political one unrelated to health-effectiveness of services and shows a lack of understanding about what patient-centredness looks like in practice.

Promoting research-quality and patient-centred health- and research-services requires removing the historical privilege of physicians in access to research-opportunities and providing them instead to qualified clinical scientists who have therefore the necessary competence. This would increase the quality of research and the scientific capital of the NHS as a whole, with much better outcomes for patients and the public.

Despite numerous objectives, two key objectives are lacking: firstly, to ensure health-effective patient-participation and, secondly, to ensure that services enable people to stay well following their regaining health. These are crucial for effective services for people with chronic conditions.

To this end, the Tuke Institute has addressed the core issues that the mandate is struggling to make cohere into a rational tool for delivering its objectives and we are pleased to make numerous, specific suggestions for improving the mandate and its process of development.

Signed:

A handwritten signature in black ink, appearing to read 'R. Whitaker', with a long horizontal flourish extending to the right.

Dr. Rupert Whitaker
Executive Chairman, Tuke Institute

Dated: 26.09.12

Responses to specific questions

1. “Our approach”

a. Will the mandate drive a culture which puts patients at the heart of everything the NHS does?

No. The reasons for this are as follows, in context.

Changing the culture of the NHS to one of a service oriented to health-effectiveness is crucial to protecting the nation’s health in a cost-effective manner. The NHS is based currently on an outdated, physician-centred model stems historically from an approach dedicated primarily to meeting physicians’ professional preferences, by focusing on disease. The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” Thus, health needs to be addressed comprehensively: merely treating a disease does not mean that patients become and stay healthy – as is particularly evident in chronic illnesses. To put patients at the heart of the NHS requires replacing the current model – and the culture that supports it – by creating integrated, patient-centred services that focus on comprehensive, personalised health-outcomes above all else. It is a complex challenge that requires political will and expertise in health-science unavailable from those who are just clinically qualified.

Relatedly, there is an extensive history of malfeasance by health-service providers. This is evidenced by the historic roots of the continuing tragedy of privatised health-services in the USA, where there is no national health-service delivered for the public’s benefit and, more recently, by the numerous Governmental Inquiries in Britain. As a consequence, it is necessary to integrate methods of public participation at all levels of the service, in order to keep services meeting patients’ needs first, rather than providers’ needs. This means patient-participation from the level of health-status assessment right up to national policy-making, with inherent methods of transparency and accountability. These same methods can also help ensure that patients are enabled to take responsibility for their own health as well and promotes participation of the patient as a pro-active agent in both recovery and future prevention.

To change this physician-centred – and, more recently, manager-centred – culture requires re-imagining services from the bottom up, as the Tuke Institute has done, and designing a health-service according to an agreed definition of patient-centredness with clear methods of public governance.

Culture changes slowly. This mandate seeks to change values but not the expectations of what a clinician should provide to be consistent with a patient-centred culture. There is a need for the NHS to set educational expectations as to how to integrate patient-centredness in service-provision from individual clinicians. In senior clinicians, expectations about clinical behaviours need to be a focus; it is not feasible to change entrenched cultural norms within senior clinicians and thus, for them, the focus needs to be on patient-centred performance. These behavioural changes in clinicians need to be supported by robust expectations and performance-measures relating to the delivery of patient-centred health-outcomes.

To put patients at the heart of the NHS means that personalised health-outcomes for each individual need to drive the whole service. Health-outcomes must be framed within a properly biopsychosocial model that values each domain – physical, mental, and social – equally. Only this approach enables

health. Likewise, cost-effectiveness can only be determined if you know a service's health-effectiveness first, and this is determined by personalised health-outcomes. The drivers for clinicians' and administrators' activities need to derive from health-outcomes.

The NHS Mandate focuses on some issues that are irrelevant to creating a patient-centred NHS. These include approaches that come from the commercial sector and have little to do with creating health-outcomes, including consumerism: for example, prioritising 'patient-choice' as a goal in itself. Putting the patient at the centre of the NHS means putting the patients' health at the centre of the NHS, not patients' preferences, patients' leadership, or patients' experiences. Although these are often positive factors, they do not necessarily deliver health-outcomes and are secondary to other patient-centred factors that directly determine health-outcomes.

It has been sadly evident for many years that governmental dictates for a change or increase in standards are not met by a search for the new information required on the part of the providers. Decreeing patient-centredness does not mean that providers will do the research necessary to learn what that is or how to deliver it. As a result, there will be events like children's picnics used as evidence of patient-centredness within an otherwise utterly physician-centred services, as occurred in a north London health-service specialising in haemophilia. This is ineffective in creating patient-centred services and therefore a waste of resources.

Another problem is that the NHS Outcomes Framework, on which the Mandate is based, promotes the standardised treatment of conditions rather than patients. While this approach is grounded in evidence-based medicine that promotes consistency of practice, it also suffers from the limitations of evidence-based practice in that it is a narrow, biomedical, inadequate approach to creating personalised health-outcomes, which a patient-centred NHS requires.

While it is outside the remit of the mandate itself, a larger point is that there are three outcome-frameworks: for the NHS, public health, and social care. These all come under 'health' and there should therefore be one comprehensive framework, perhaps with subsections as to the different delivery methods of such outcomes in each sub-sectors. This would promote the commissioning of truly patient-centred and health-effective services.

The mandate has some notable lacks, resulting in the following suggestions, some of which are easy to deliver and some less so:

1. formulate clearly what patient-centredness is and how it is enacted in daily service to the public; this provides a template against which to measure service-development operationally
2. create definitions of comprehensive, integrated services, specifying how they are comprehensive and how they are integrated, based on research-evidence with case-studies; use this definition to commission further development in health-services and health-services research
3. require the commissioning of patient-centred health-status assessments as benchmarks for personalised, comprehensive health-outcomes; biomarkers of disease do not equate with health
4. require the commissioning of specified methods by which health-services ensure public participation as it relates to health-outcomes
5. specify methods and strategies by which cultural change will occur – including the educational requirements for clinicians to understand health and health-services' issues beyond their own, narrow, professional remit
6. require the commissioning of measures of patient-centredness as it relates to health-outcomes, in order to ensure the health-effectiveness of services financially and for society
7. specify a requirement for cost-effectiveness to be defined at all levels of services solely within a framework of evidence-based health-effectiveness, at an individual, clinical level rather than a group, public-health level

8. demonstrate and promote evidence and expertise in health-science, rather than marketing, in relation to the efficacy of concepts such as ‘patient-centredness’, ‘patient satisfaction’ and ‘patient-choice’ in creating health-effective services
9. state a requirement for the Outcomes Framework and the NHS Mandate to inform one another, including through feedback from the Commissioning Board, especially as they relate to patient-centredness and health-effectiveness

The Tuke Institute’s work provides solutions to each of these issues.

b. Do you agree with the overall approach to the draft mandate and the way the mandate is structured?

In part. However, it is unclear what is referred to specifically by the first part of this question.

If the goal is to put patients at the centre of the NHS, then that section should come first in the structure of the Mandate, as it is patient-centredness as defined by health-outcomes.

There should be a clearer summary of the overall objectives and high-level aims and it would have been helpful to have a list of all the objectives as an appendix. The structure was confusing with nested domains, goals, objectives, etc. These should be structured separately and more clearly.

The section on health-services’ outcomes (or ‘health-effectiveness’) is problematic. Domains 1-3 are core, but Domain 2 should be defined as health, not quality of life, which is a subsidiary, subjective concept. Domain 4 is secondary to Domain 3 and risks promoting consumerism, which damages a service’s ability to be health-effective. Domain 5 is subsidiary to Domain 3. It seems that both Domains 4 and 5 were included as an ill-informed public-relations gesture. This section should also specify methods or strategies more clearly. For example, in Domain 3, if you are to measure changes, you have to benchmark on an individual level in a comprehensive manner. This is patient-centredness in practice.

Mental health and physical health should **not** be ‘on a par’ – i.e., as separate but equal: this doctrine has failed repeatedly through history. Instead, they should be integrated and only distinguished in terms of the effectiveness of a given physical or mental modality in delivering whole-person outcomes. To distinguish between them is a prime example of the physician-centred model.

It is appropriate to put Finances at the end, as cost-effectiveness can only be assessed on the basis of health-effectiveness if the NHS is to be a service focusing on the health of the whole nation.

c. Are the objectives right? Could they be simplified and/or reduced in number; are there objectives missing? Do they reflect the over-arching goals of NHS commissioning?

A number of the objectives are actually public-health objectives rather than clinical/health-service objectives. This should be clarified as the modes of delivery are distinct. Many of the objectives can be folded into larger, more comprehensive ones, as some are subsidiary to larger objectives.

Objective 4: a ‘good experience’ of services, or ‘patient-satisfaction’, does not relate to quality of service, health-outcomes, or to health-effectiveness; it is a primarily mood-related indicator and misused as a marketing and PR tool by the Department of Health and NHS managers. It reflects an approach to health-service administration that is inexpert in health-science, particularly behavioural science.

Just like clinicians, patients are not well-placed to judge the quality of services per se, only their effectiveness for them as individuals. While a good experience of services is generally part of the effectiveness of services, and services in which patients are treated poorly usually result in poor outcomes, a good experience is not necessarily an indicator of effectiveness or of patient-centredness. You can have a good experience of an ineffective service, which therefore does not meet the patient's needs and is therefore not patient-centred. Effective clinical relationships do not always consist of good experiences for the patient at every point; getting well is not easy and we, as patients, do not always like what we have to do to get well. Some of us, as patients, resist services that are essential to our health because we are afraid and therefore we choose ineffective options. Getting well is not always pleasant. Again, putting the patient at the centre of the NHS means putting patients' health at the centre of the NHS, not patients' preferences, patient-led services, or patients' experiences. These are not good indicators of patient-centredness, they do not necessarily deliver health-outcomes, and they are secondary to other patient-centred factors that do directly determine health-outcomes.

Moving from a physician-centred model that delivers more for the clinicians than it does the patient should not then move to a model where the patient is all-powerful consumer: a middle, more objective way that focuses on both clinicians and patients working together towards health-outcomes is more efficient, health-effective, and therefore cost-effective. The mandate needs to move away from commercial concepts such as short-term patient satisfaction, which is determined largely by mood, and towards longer-term concepts such as health-effectiveness. There is little more patient-centred and satisfying than regaining good health, which is achieved through an effective, reliable health-service.

Objective 5 is simply an inverse calculation of Objective 4, but specifying the cause as "avoidable harm". This is so imprecise as a term as to be meaningless; it needs to be specified carefully in order for this to have any weight. It is begging to be misconstrued in a self-serving way by providers.

Objectives 7 and 8 are public-health outcomes, not clinical/health-service ones, and how these are to be delivered needs to be specified in terms of clinical services: the Slope Index of Inequality is a public-health tool whereas a clinical tool would, for example, be the Tuke Institute's health-status assessment tool and therefore appropriate to this mandate. Generally, these Objectives are too vague.

Objective 9 promotes integration, yet how this is to be done is not understood in the NHS or the Department of Health. We recommend referring to the Tuke Institute's model of integrated health-services.

Objective 12 is an essential part of participative services but it does not ensure that patients are put first. It can be misconstrued to allow patients a choice in clinician-determined options that may not relate to optimal health-outcomes. Relatedly, the Department of Health's Choice-Framework is more about out-sourcing to the patient some of the responsibilities of the health-service and needs to be informed by expertise on patient-centred health-outcomes and their delivery.

Objective 15 is important for health-effectiveness and therefore patient-centredness. Carers should not be considered differently from a patient, if you are going to have a patient-centred system as carers are crucial to the patient's illness and recovery and is often a proxy for the patient. A comprehensive, integrated health-service would serve the carer as much as the index patient.

Objective 16's solutions are poorly formulated and top-down, rather than patient-centred.

Objective 21 should be based on research comparing alternative models, including the Tuke Institute model

There are two notable Objectives lacking:

1. requiring the commissioning of integrated systems that enable patients' full participation in services, not just commercial-style feedback. This is essential to the idea of giving the patient a voice, and thereby ensuring transparency and accountability so as to prevent another Bristol, Shipman, Stafford etc Inquiry. The Tuke Institute has designed and promotes systems for doing this to ensure patient-centred services
2. requiring the commissioning of services that help people to stay well once they have regained health. This relates to a type of prevention related to individual vulnerabilities, which are often mediated behaviourally and socially and are crucial in the effective treatment of long-term conditions. Such an objective should be specified so as to prevent chronic conditions from being treated as repeated presentations of an acute condition, as they are typically treated today.

It is not clear to the reader how the NHS Outcomes Framework informs and enables the achievement of the Objectives. The Outcomes Framework should be explicitly elaborated and referred to in the Mandate.

2. "Assessing progress"

a. What is the best way of assessing progress against the mandate, and how can other people or organisations best contribute to this?

Progress against the mandate should be assessed from the bottom up. This requires benchmarking individual patients' health-status in reference to the quality and manner of the services provided by individual clinicians, using these data to determine services' patient-centredness and effectiveness. This data needs to be accumulated anonymously across patients, across clinics, across areas, etc., to provide a consistent, patient-centred, and meaningful measure of progress against the mandate. This is specified in the Tuke Institute's model of patient-centred services and its personalised health-status assessment tool, developed for these purposes.

Equally, these data need to be published for the purposes of audit and governance at every level, to assure quality, reliability, and to promote trust. Top-down markers are not and will not be relevant to the public's needs, except at a level too gross to be meaningful.

With the implementation of a Trip-Advisor-style review system of individual clinicians' and services' health-effectiveness and patient-centredness (see below), the public as a whole can participate in assessing progress against the mandate.

b. Do you have views now about how the mandate should develop in future years?

Yes: the mandate should focus more on health-outcomes defined within a patient-centred framework as these should be the real goal of a national health-service. The mandate should develop in tandem with the NHS Outcomes Framework, each informing the other, and in reference to the related Outcomes Frameworks.

The consultation to the mandate should be more open-format, as its current questions are too self-referential and closed. For example, "A Consultation on the Draft Mandate" assumes that putting

patients first is the same as helping them manage long-term conditions; this represents a lack of basic knowledge in health-science and the determinants of health: behavioural medicine and patient-centredness are distinct conceptual areas. There needs to be a way for responders to the consultation to correct basic errors like this. Likewise, there needs to be a way for responders to discuss issues specified in the Strategic Context etc as these frame the mandate and therefore determine its potential effectiveness.

The consultations' questions should be consistent with the structure and relate directly to specific contents of the mandate, to allow meaningful consultation. Currently, the consultation's structure and question-set makes it look like a tick-box process rather than a genuine request for information and feedback. This is characteristic of a closed-system such as the NHS has been for decades and will likely continue to be, preventing progress. Effort should be made to change this.

There should be annual updates and crowd-sourced reviews of the mandate, with open consultation and responses to data-led inquiries relevant to the mandate, to ensure that it is both patient-centred and grounded in evidence. This can be done with an online interface. The Department of Health should engage in continuing feedback-exercises from experts, including patients.

3. "Improving our health and our healthcare"

a. Do you agree that the mandate should be based around the NHS Outcomes Framework, and therefore avoid setting separate objectives for individual clinical conditions?

Yes. However, the Outcomes Framework itself is currently too physician-centred and condition-/disease-oriented. Setting objectives for individual clinical conditions is regressive and contrary to the principles and practice of patient-centredness. The mandate also needs to focus on biopsychosocial outcomes more competently.

There is also little, if anything, about helping people stay well (primary prevention) or preventing emergent co-morbidities due to increased risks from a primary condition; the trajectory of illness and recovery needs to be seen as a whole. We suggest that the Department of Health commissions the necessary expertise in health-science rather than in physical disease.

A larger point is that there are three outcome-frameworks for the NHS, public health, and social care. These all come under 'health' and there should therefore be one comprehensive framework, perhaps with subsections as to the different delivery methods of such outcomes in each sub-sectors.

b. Is this the right way to set objectives for improving outcomes and tackling inequalities?

No. Some of these goals are too rooted in public-health challenges and fail to specify the necessary clinical means to achieve these emergent and indirect outcomes. The methods for bottom-up improvement of outcomes need to be delineated in the Objectives.

c. How could this approach develop in future mandates?

Focus on creating bottom-up methods that are patient-centred, as the Tuke Institute does.

4. “Putting patients first”

a. Is this the right way for the mandate to support shared decision-making, integrated care and support for carers?

There is inadequate attention paid to the obstacles to achieving the mandate’s goals, particularly the obstacles provided by the physician-centred model that dominates the NHS. Therefore, there needs to be a solid, transparent mechanism for audit and accountability of clinicians who do not collaborate with patients in achieving these objectives. This would include Trip-Advisor type reviews of services restricted in scope to variables that are known or reasoned (in the absence of clear evidence) to deliver health-outcomes, including comprehensiveness of services, integration of services, participative practice including shared decision-making, the quality of relationship with the lead-clinician (ideally, a nurse), and case-management. These factors all relate to the benchmarking provided by the health-status assessment, as described above. These factors are described and resolved in the Tuke Institute’s model of health-services.

b. Do you support the idea of publishing a “choice-framework” for patients alongside the mandate?

Yes, as it will then be clear what the scope of the choice-framework is and this can then be debated in reference to scientific evidence as to its efficacy in delivering health-outcomes. Patients and providers will also need to know what their rights and responsibilities are in choices, the degree of latitude in choices, and the reasoning in terms of health-effectiveness of providing such choices.

5. “The broader contribution of the NHS”

a. Does the draft mandate properly reflect the role of the NHS in supporting broader social and economic objectives?

No; this section reflects an ill-conceived, tick-box response to political pressures. There is no reason to focus on these areas more than others as it promotes inequalities against adults and single people, which is unwarranted in terms of both public health and medicine equally. Such a focus promotes the neglect of the needs of people with special needs or disabilities once they become adults, making the transition harder and more risky. This is evidenced in clinical experience. A focus on good-quality health-outcomes for all would include the necessary and specific services for such vulnerable segments of the population. Identifying people who are particularly vulnerable and at-risk should be considered equally for all ages and should be part of a patient-centred service. However, reducing ill-informed and under-resourced reproduction by the public should be a clinical and public-health priority, focusing on adults’ sexual health and people’s choice.

Likewise, the integration of services for health – including physical, mental, and social health – should be standard for all people, not just for offenders and ex-offenders; ensuring that each service has the competence to provide such services to all should be the focus, not a public health-based segmentation of a ‘market’. This top-down approach serves only to perpetuate the problems of disintegration of, and unnecessary specialisation in, health-services. These are top-down solutions, not patient-centred ones.

A key to promoting research-quality should be ensured by prioritising access to research-opportunities by scientists, who are therefore qualified and competent to carry out properly scientific research, and removing the obstructive privilege of physicians, who are not qualified and competent to lead scientific (rather than purely technical) research unless they also have a scientific

doctorate. Similarly, increasing patient-participation is crucial to promoting growth, innovation, and research is a behavioural aspect of research best ensured by behavioural and social scientists and which is often, in practice, obstructed by physicians. This physician-privilege is a major hindrance to research that is patient-centred, of good quality, and that focuses on health-outcomes, rather than physician-centred research that focuses largely on biology and disease-status. This would be ensure the benefit for the public as funders and for patients in terms of health-outcomes, rather than for physicians' careers.

A patient-centred framework for research in the NHS to ensure public benefit was commissioned by the Department of Health from the Tuke Institute's Executive Chairman, Dr. Rupert Whitaker. This was well-received and the objectives and general methods should be integrated into future mandates.

6. "Effective commissioning"

a. Should the mandate include objectives about how the Board implements reforms and establishes the new commissioning system?

Yes, because this would provide a template from which the system could be created and a reference -point from which further development could occur. The primary risk of the mandate is that the NHS will continue to do what it knows how to do, not what the public needs in a *national, health-service*. Thus, creating a template with fresh vision and methods would stimulate the NHS as a whole to develop the expertise it currently lacks and increase its health-effectiveness.