

**NUFFIELD
COUNCIL^{ON}
BIOETHICS**

BACKGROUND PAPER

**Funding pressures in the NHS: an ethical
response**

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Bioethics*

**Forward Look
13 May 2014**

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Background paper

Summary

- 1 This background paper provides an overview of different forms of response to funding pressures in the NHS, and seeks to identify those aspects where specifically ethical (as opposed to organisational and managerial) challenges may arise. Given the different health systems within the four countries of the UK, for the sake of brevity this paper focuses primarily on the legal position and policy initiatives within England. Similar issues, however, are likely to arise across the UK, and indeed within any other publicly-funded health system.

Introduction and background: past approaches to the issue of funding constraints

- 2 The NHS Act 2006 sets out the duties of the Secretary of State for Health with respect to the provision of health services. He or she “must continue the promotion in England of a comprehensive health service designed to secure improvement (a) in the physical and mental health of the people of England, and (b) in the prevention, diagnosis and treatment of physical and mental illness.”¹ This duty has widely been seen as guaranteeing that the NHS will meet “all reasonable requirements” for healthcare.² However, case law relating to earlier formulations of the Secretary of State’s duty has established that individuals cannot use this duty to claim an individual enforceable ‘right’ to treatment, since the reality that resources can never be unlimited may legitimately be taken into account.³
- 3 Since the very beginning of the NHS, it has been the case that not every desirable (or desired) service can be provided within the funding available. Funding pressures within the first few years of the establishment of the NHS led to the passing of legislation to enable charges to be made for prescriptions, for example,⁴ and there have been repeated challenges in the courts throughout the intervening decades by patients who have not been able to access the treatment they need in what they

¹ NHS Act 2006, section 1(1), as amended.

² See, for example, guidance on commissioning published by the NHS Commissioning Board: NHS Commissioning Board (2013) [*Commissioning policy: ethical framework for priority setting and resource allocation*](#), at page 5.

³ See, for example, R v Secretary of State for Social Services ex parte Hincks (1980)1 BMLR 93 and R v Sheffield Health Authority ex parte Seale [1995] 25 BMLR 1/.

⁴ NHS (Amendment) Act 1949.

would regard as a reasonable timeframe.⁵ Interim guidance issued in 2013 by the NHS Commissioning Board (the body responsible for commissioning specialist services across England) states explicitly that “given resource constraints, the NHS CB cannot meet every healthcare need of all patients within its areas of responsibility. The NHS CB may take a decision not to commission a service to meet a specific healthcare need due to resource constraints. This does not indicate that the NHS CB is breaching its statutory obligations.”⁶ While this guidance relates only to specialist centrally-commissioned services, it is clear that the same constraints must also apply to the much larger part of the NHS budget handled by ‘clinical commissioning groups’ (CCGs – the successors to Primary Care Trusts). Even though the NHS received unprecedented increases in funding between 2000 and 2010, both the demand for services and the costs involved in providing those services have continued to rise faster as a result of factors such as the ageing of the population, the cost of introducing new therapies, and increased patient expectations.⁷

- 4 This recognition that, despite its badging as a comprehensive service, the NHS cannot meet every possible need, has led to extensive discussion of the practicality and ethical acceptability of ‘rationing’ (also described as ‘priority setting’ or ‘resource allocation’) within healthcare. Since the creation in 1991 of the ‘purchaser/provider’ split which made a distinction between the health bodies⁸ responsible for ‘purchasing’ or ‘commissioning’ services, and the hospitals and primary care services that provide them, such allocation decisions have become much more explicit, at three levels:
- at the level of allocation to different geographical regions (using weighted capitation formulae aiming to respond to disparate needs);⁹
 - at the level of allocation between different kinds of services (the main role of CCGs who have to determine at a local level what services to commission, and hence by definition what services will *not* be available, or will be available only in limited quantity); and

⁵ See, for example, the landmark case of ‘Child B’ (R v Cambridge HA ex parte B [1995] 2 All ER 129, where the Court of Appeal held that it was not for courts to intervene in Health Authorities’ “difficult and agonising judgments” over how best to allocate a limited budget. However, the later case of R on the application of Watts v Bedford PCT and Secretary of State for Health 2004 EWCA 166, did hold that under EU law patients might be entitled to have care provided abroad reimbursed by the NHS if the NHS had been unable to provide it “within the time normally necessary”. The Court of Appeal took the view that “the time normally necessary” should be interpreted as relating to clinical judgment of an appropriate time frame for treatment, not ‘normal waiting times’.

⁶ See, for example, NHS Commissioning Board (2013) [Commissioning policy: ethical framework for priority setting and resource allocation](#).

⁷ For a useful summary, see: NHS England (2013) [The NHS belongs to the people: a call for action](#).

⁸ At the time known as District Health Authorities, whose role has in turn been subsumed by Health Authorities, then Primary Care Trusts (PCTs), and most recently by CCGs.

⁹ The Department of Health’s [written evidence](#) to the Health Select Committee’s 2014 enquiry into public expenditure on health and social care summarised the formula (currently under review, with the aim of initial findings influencing allocations in 2014-15) as being based on the principle of “equal access for equal need”, with per capita funding adjusted by age and health of population and also local variations in the cost of providing care. However, NHS England is also concerned not to destabilise local health economies by moving funding abruptly from one area to another, and hence actual allocations are moving only over time to the target allocations defined by the formula.

- at the level of allocation between individual patients (for example where clinical ethics committees in hospitals or CCG committees determine ‘exceptional case’ requests for treatment that would otherwise not be made available).¹⁰
- 5 Key ethical questions arising in such debates relate to the scope for varying definitions of both ‘need’ and of ‘fairness’/‘equity’/‘justice’. Examples include:
- How should ‘health’ need be defined? What comes under the banner of ‘health’, rather than ‘social’ need, and is there any consensus on when ‘demands’ become ‘needs’? While the threshold question of when needs are ‘health-related’ rather than ‘social’ remains an ongoing challenge for the NHS (see paragraph 33 below), the creation of the National Institute for Health and Care Excellence,¹¹ and its remit to develop evidence-based guidelines on the management of particular health conditions, provides one practical way in which a national ‘steer’ is provided on what needs local health services should be providing.
 - What approach to ‘fairness’ should be taken (and should there be a single model across all the levels of allocation)? The NHS Commissioning Board takes the approach of “equal access for equal clinical need”, but also suggests that “priority may be given to health services targeting the needs of sub-groups of the population who currently have poorer than average health outcomes”. In its cost-effectiveness appraisals, NICE makes use of ‘Quality Adjusted Life Years’ (QALYs) which provide a utilitarian tool for calculating what treatments will maximise quality and length of life.¹² However, in recognition of the strong criticisms to which QALYs have been subject on equity grounds,¹³ NICE also emphasises the importance of its *Social value judgments* in deciding whether or not to recommend an intervention as suitable for adoption by the NHS, with explicit reference to “the need to distribute health resources in the fairest way within society as a whole”.¹⁴
- 6 Distinct questions of *procedural* ethics also arise, raising such questions as where responsibility for making particular decisions should lie; how transparent the process of decision-making is; and who should determine (or be involved in determining) the criteria by which allocation decisions are made.¹⁵ The 2013 NHS Commissioning Board interim guidance on priority setting highlights the importance of these procedural factors, emphasising the need to take a “systematic” approach that “fairly”

¹⁰ See, for example, East Riding of Yorkshire CCG guidance on individual funding requests (exceptional treatments), available at <http://www.eastridingofyorkshireccg.nhs.uk/patient-zone/ifr/>.

¹¹ Initially known as the National Institute for Clinical Excellence: http://www.nice.org.uk/aboutnice/howweare/who_we_are.jsp.

¹² NICE (2010) Measuring effectiveness and cost effectiveness: the QALY, available at: <http://www.nice.org.uk/newsroom/features/measuringeffectivenessandcosteffectivenessstheqaly.jsp>.

¹³ For example, that they have the potential to discriminate against groups of people with existing disability or ill health, as the benefit of their proposed treatment may be ‘discounted’ in the QALY process because of their existing impairments. For further discussion, see: Nuffield Council on Bioethics (2011) [Hyper-expensive treatments](#).

¹⁴ NICE (2008) [Social value judgments: principles for the development of NICE guidance](#), Principle 3.

¹⁵ See, for example, the discussion of ‘accountability for reasonableness’ in Daniels N (2000) Accountability for reasonableness: establishing a fair process for priority setting is easier than agreeing on principles *BMJ* **321(7272)**: 1300-1.

distributes services across different patient groups. “It can only do so if all decision-making is based on clearly defined evaluation criteria and follows clear ethical principles”.¹⁶ National bodies such as NICE and local NHS commissioning bodies may also seek public and stakeholder input before coming to their decisions.¹⁷ Failure to satisfy stakeholders that decisions have indeed been taken in a procedurally acceptable way may lead to individuals or organisations seeking judicial review of the public bodies responsible.

- 7 Whether described as ‘resource allocation’, ‘priority setting’ or ‘rationing’, the challenges described above relate primarily to the role of *commissioners* in the NHS deciding what to do (and hence by implication what *not* to do), with the money made available to them. The discussion is thus very much at the level of ‘managerial’, rather than clinical, decision-making, although this does not, of course, mean that clinicians will not be involved in those decisions. This question of the processes by which particular services or patients, in particular areas, receive particular levels of funding has been discussed at various times as a possible topic for the Nuffield Council to take forward: in 2007 in a general workshop on NHS rationing; in 2011 in its discussion of hyper-expensive treatments; and most recently in 2013 in a discussion of expensive life-extending treatments. The issues have also been, and continue to be, extensively debated, discussed and worked through in academic, policy and political spheres. On each past occasion the Council has concluded that there is little distinctive that it could bring to that debate. In particular, the Council has been concerned that it would be misleading to look in isolation at a relatively small subsection of the NHS budget (the drugs budget), without looking at the *whole* picture of spending within the NHS: a task that is inextricably tied up with very complex questions of health systems and management which others may be much better placed to address.
- 8 However, a question that has not been raised in the Council’s discussions to date on rationing is the question of the impact of resource pressures on the *quality* of care. When looking at the basic tension inherent in the aim of providing a ‘comprehensive’ service with resources that can never being open-ended, the idea that one way of dealing with that tension is to reduce quality of care, whether explicitly, inadvertently or covertly, is hardly seen as an acceptable possible solution.¹⁸ Yet in practice, in the experience of frontline practitioners, this may be everyday reality – that they are (at least at times) not able to give what they would regard as a good, or even acceptable, quality of care, because of funding constraints, in particular where those constraints have led to far from optimal levels of staffing.¹⁹ The remainder of this paper will focus on this question of the impact of NHS funding pressures on the quality of care provided.

¹⁶ NHS Commissioning Board (2013) [Commissioning policy: ethical framework for priority setting and resource allocation](#).

¹⁷ See, for example, the NICE [citizens’ council](#) and [consultation procedures](#).

¹⁸ This does not mean, of course, that the *risks* of quality being jeopardised by pressure on resources has not been recognised in the literature: see, for example, Maxwell B (2009) Just compassion: implications for the ethics of the scarcity paradigm in clinical healthcare provision *Journal of Medical Ethics* **35(4)**:219-23.

¹⁹ See, for example, *The Guardian* (4 April 2014) [Patient care under threat as overworked doctors miss vital signs, expert warns](#).

Impact on quality: possible approaches

- 9 The question of the quality of NHS care, particularly hospital-based care, has been the subject of intense public and political scrutiny as a result of the series of inquiries into the very serious failures of care at Mid Staffordshire NHS Foundation Trust. The final Public Inquiry report,²⁰ published in February 2013, highlighted many areas of concern, including:
- The **culture** prevalent at the trust: both in terms of the attitudes of the Board (primarily concerned with obtaining Foundation status for the trust, very defensive in response to any criticism or challenge, and no culture of listening to patients);²¹ and of professionals responsible for, or directly providing, care (“habituation and passivity” leading to tolerance of low standards, and a failure on the part of senior clinicians to follow problems up assertively with managers).²²
 - **Resource constraints:** a “mismatch between the resources allocated and the needs of the services to be delivered” led to “inadequate staffing levels” and “a completely inadequate standard of nursing”. Francis stated that he had “no doubt that the economies imposed by the Trust Board, year after year, had a profound effect on the organisation’s ability to deliver a safe and effective service”.²³
 - **Inadequate systems for setting and monitoring standards:** while the Inquiry report recognised that the creation of explicit national standards in the NHS was a relatively new and welcome development, the core standards “formulated and handed down by the DH” were criticised as suffering from a number of deficiencies, including a lack of involvement by, and endorsement from, frontline clinicians. They were a “confusing mixture of the general and the specific” and the Annual Health Check by which compliance with the standards was assessed was not a satisfactory way of establishing that a hospital was providing satisfactory standards of care.²⁴ Moreover, although ensuring that quality services are being provided is a key part of the role of a health care ‘commissioner’, PCTs at the time did not have the tools necessary to monitor quality effectively.²⁵
 - **Failures of communication and co-operation:** these were identified across virtually all the organisations involved in assessing safety and quality of care, including between Monitor (responsible for awarding Foundation status), the Healthcare Commission, the Health and Safety Executive, the National Patient Safety Agency, the Health Protection Agency, and professional regulators such as the GMC and the NMC.²⁶

²⁰ [Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: executive summary](#), House of Commons Paper 947 2012-13.

²¹ *Ibid*, paras 1.6, 1.7 and 1.9.

²² *Ibid*, paras 78 and 1.8.

²³ *Ibid*, paras 1.12, 1.14 and 1.16.

²⁴ *Ibid* paras 1.60, 1.61 and 1.65.

²⁵ *Ibid* para 1.31.

²⁶ *Ibid* paras 1.53, 1.67, 1.81, 1.88, 1.95 and 1.96.

- **Failure by the DH to place quality “at the core of its policy”**: for example by considering properly how such key government policies as financial rebalance, Foundation Trust status and structural reform would have an impact on quality. While decisions or directives emanating from the DH may have been well-intentioned, they could be perceived further down the hierarchy as bullying, and implemented oppressively. “There needs to be a careful balance between avoiding tolerance of unacceptable standards of performance and incentivising short cuts to compliance by applying career-threatening pressure to uphold such standards.”²⁷
- **Constant reorganisation** of NHS structures: on the purchasing/commissioning side (PCTs reconfigured, and then becoming CCGs; reconfiguration and abolition of Strategic Health Authorities), provider side (NHS trusts becoming Foundation trusts), regulator side (the Healthcare Commission abolished and absorbed into the Care Quality Commission), and patient involvement side (Patient and Public Involvement Forums becoming Local Involvement Networks, and now local Health watch).²⁸

- 10 The report included numerous recommendations for change in the NHS, and these are discussed further below. It is notable, however, that a call for additional funds for the NHS is, pragmatically, not among those recommendations. In Mr Francis’ introduction to his report he commented robustly that “within any system there is a need to ensure a relentless focus on ensuring patient safety and the provision of at least a minimum quality of care. That should not be too much to ask of *any* system.”²⁹ He concluded by reiterating that “it should be patients not numbers which count” and that “fundamental culture change is needed”.³⁰ Yet, as indicated above, pressure on financial resources was clearly identified as being a significant factor at Mid Staffs, in particular in connection with staffing levels and year-on-year cuts in budgets. Moreover, it was the Board’s pre-occupation with financial matters (by implication balancing the books, and demonstrating the financial stability necessary for Foundation status) that was identified as contributing significantly to the dangerous culture of the trust. Clearly, resources *do* matter, but the experience of Mid Staffs (and Francis suggests it would be dangerous to assume that the situation at Mid Staffs was unique)³¹ demonstrates how many other factors are at play.
- 11 The remainder of this paper looks in turn at three approaches to quality of care, highlighted by, but certainly not unique to, the Francis report: the setting and policing of appropriate standards; the role of ‘culture’ and leadership; and what ensuring ‘patients not numbers count’ might mean in practical terms for allocating resources within a ‘provider’ organisation. It concludes with a final section, from a rather different perspective, asking the question of whether the use of funding mechanisms

²⁷ *Ibid* paras 1.109-11.

²⁸ *Ibid* paras 1.19, 1.32, 1.37 and 1.66.

²⁹ *Ibid*, para 39 (emphasis added).

³⁰ *Ibid* paras 1.236-7.

³¹ As suggested also by some of the other reports commissioned as a result of Francis: see, for example, Keogh B (2013) [Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report](#) and National Advisory Group on the Safety of Patients in England (2013) [A promise to learn – a commitment to act: improving the safety of patients in England](#) (the ‘Berwick review’).

other than nationally-allocated public funding, would have an influence on the quality of care delivered.

(i) Standards and rights

- 12 As indicated above, the Francis report was strongly critical of the approach to standard setting in place in the NHS during the time covered by the Public Inquiry, both in terms of the actual standards used, and the regulatory reliance on self-assessment and self-declaration. It recommended that the NHS Constitution should be used to enshrine and communicate “the common values of the service”, with the overarching value and principle being that “patients are put first, and everything done by the NHS and everyone associated with it should be informed by this ethos”, while recognising the rider that care must be provided “within available resources”.³²
- 13 Francis further recommended that the Constitution should include a commitment to abide by an integrated hierarchy of standards: *fundamental* standards (to be applied at all times by all who work in the NHS); *enhanced* quality standards (setting requirements over and above the fundamental standards); and *developmental* standards setting longer term goals.³³ It was emphasised that while Government endorsement was clearly needed for fundamental standards to become embedded, they should not be imposed ‘top down’ but should be the subject of extensive consultation “particularly to ensure that patients, doctors and nurses have full confidence in them”.³⁴ It was further suggested that NICE should develop evidence-based procedures and practices in order to enable the Care Quality Commission to develop meaningful indicators to monitor compliance. In particular NICE should develop evidence-based tools for “establishing the staffing needs of each service”. Where necessary other third party organisations, such as the Royal Colleges, could also be commissioned by the CQC to help develop standards. Any service (or part of a service) that did not consistently comply with fundamental standards should not be permitted to continue.³⁵
- 14 In its initial response to the Francis report, *Patients first and foremost*, the Department of Health set out a ‘statement of common purpose’ signed by senior NHS leaders that included reaffirmation of their commitment to the values of the NHS as set out in the Constitution:
- Working together for patients – putting the needs of patients and communities before organisational boundaries
 - Respect and dignity – valuing every person (patients, families, carers, staff) as individuals
 - Commitment to quality of care – striving to get the basics (safety, effectiveness and patient experience) right every time, and welcoming feedback
 - Compassion – responding with humanity and kindness to each person’s pain, distress, anxiety or need

³² [Report of the Mid Staffordshire NHS Foundation Trust public inquiry: executive summary](#), House of Commons Paper 947 2012-13, paras 1.121-3.

³³ *Ibid*, para 1.125.

³⁴ *Ibid*, para 1.130.

³⁵ *Ibid*, paras 1.131-4.

- Improving lives – striving to improve health and well-being and people’s experience of the NHS
- Everyone counts – maximising resources for the benefit of the whole community and making sure no-one is excluded or discriminated against.³⁶

At the same time, the Department published a revised version of the NHS Constitution, and promised consultation later in the year on further revisions.³⁷

- 15 In response to the recommendations on the development of clearer quality standards, *Patients first and foremost* promised that the CQC (“working with NICE, commissioners, professionals, patients and the public”) would draw up a new set of “simpler fundamental standards which make explicit the basic standards beneath which care should never fall”.³⁸ The Department of Health’s final response to Francis, *Hard truths*, clarified that those fundamental standards would form part of the legal requirements that healthcare providers would have to meet to be registered with the Care Quality Commission.³⁹ After a public consultation on how to frame the standards, carried out by the CQC,⁴⁰ draft regulations setting out proposed standards in a range of areas, including dignity and respect, consent, nutrition, safety, cleanliness, governance and adequate staffing were published for consultation in January 2014.⁴¹ Other organisations have also developed new programmes of work contributing to awareness of quality standards in the NHS: examples include the Nuffield Trust’s ‘Quality Watch’ programme,⁴² and the Equality and Human Rights Commission’s work programme in 2014/15 “working to raise compliance with equality and human rights standards in health and social care”.⁴³
- 16 As the EHRC’s interest in this area demonstrates, this focus on standards, and in particular the notion of a minimum level of ‘fundamental’ standards that must be maintained in all circumstances, has some similarities with a human rights-based approach to health. Such an approach may be understood as being based either on a moral right to health,⁴⁴ or as a positive legal right drawing either on international conventions⁴⁵ or, where available, directly on domestic law. In the UK, it has been

³⁶ Department of Health (2013) *Patients first and foremost*.

³⁷ [The NHS Constitution: the NHS belongs to us all](#), 26 March 2013; [Secretary of State letter to NHS chairs: patients first and foremost](#), 26 March 2013.

³⁸ Department of Health (2013) *Patients first and foremost*, at page 18.

³⁹ Department of Health (2014) *Hard truths*, at page 14.

⁴⁰ CQC (2013) [A new start – consultation on changes to the way CQC regulates, inspects and monitors care](#).

⁴¹ Department of Health (2014) [Introducing fundamental standards: consultation on proposal to change CQC registration regulations](#).

⁴² <http://www.nuffieldtrust.org.uk/our-work/projects/quality-watch>.

⁴³ Equality and Human Rights Commission (2 April 2014) [Commission’s new programme of work focuses on protecting people most at risk](#).

⁴⁴ James Wilson in an unpublished paper *Progressive realisation and the human right to health* distinguishes helpfully between moral and legal justifications for a human right to health, drawing on Raz and Dworkin; and the rest of this paragraph draws on his paper. See <http://www.ucl.ac.uk/cpjh/human-rights-conf> for links to an earlier conference presentation on the same issue.

⁴⁵ The most explicit international articulation of a ‘human right to health’ is that found in Article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which sets out “the right of everyone to the enjoyment of the highest available standard of physical and mental health”: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/ICESCR.aspx>. Further elaboration of this right, as found in the ‘General Comment’ produced by the Committee on Economic, Social and Cultural Rights emphasises that the right “takes into account both the individual’s biological and socio-economic

established that Article 8 of the European Convention on Human Rights (made directly enforceable in UK courts by the Human Rights Act 1998), which protects an individual's right to respect for their private and family life, may be understood as extending into the domain of health and healthcare. While the courts have been robust in accepting that resource constraints may legitimately justify limits on access to specified services in publicly funded health systems,⁴⁶ it seems likely that they would be less forgiving if 'fundamental' quality standards, regarded as the minimum acceptable standard of care, were to be shown to be breached. Indeed, in the case of particularly egregious failures in quality of care, claims have been brought alleging that Article 3 (the right to freedom from inhumane treatment) or indeed Article 2 (protection of the right to life) have been breached.⁴⁷ By contrast, domestic forms of the 'right to health' in other countries, specifically Brazil, *have* been used to enforce individual rights of access to particular services, despite very clear resource constraints making it quite impossible for such access to be made generally available within the country.⁴⁸ Such an approach raises strong equity concerns, given that access to the law to enforce this 'right to health' is by necessity limited to those able to pay.

17 The NHS Constitution sets out a number of specific patient 'rights', including several relating to quality of care:

- the right not to be unlawfully discriminated against in the provision of NHS services;
- the right "to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality";
- the right "to expect NHS bodies to monitor, and make efforts to improve continuously, the quality of healthcare they commission or provide"; and
- the right "to be treated with dignity and respect, in accordance with your human rights".⁴⁹

The accompanying *Handbook to the NHS Constitution* sets out patients' options for redress if they are not satisfied that these rights have been met: in brief, through the NHS complaint system (culminating in the Health Service Ombudsman), through civil action in the courts alleging negligence, or through application for judicial review alleging a public body has acted unlawfully.

preconditions and a State's available resources", and should be regarded as 'progressively realisable', rather than immediately enforceable: that is, that signatory states have a duty to move *over time* to the full realisation of the right, rather than to ensure it is fulfilled immediately: CESCR General Comment No 14, available at <http://www.refworld.org/docid/4538838d0.html>.

⁴⁶ See, for example, the case of Yvonne Watts: although under EU law she was in fact ultimately able to reclaim the cost of treatment obtained in France, the High Court held that she could not claim a right to treatment under Article 3 or Article 8 of the European Convention on Human Rights: *R (on the application of Yvonne Watts) v (1) Bedford Primary Care Trust (2) Secretary of State for Health* [2003] EWHC 2228 Admin.

⁴⁷ See, for example, *Holomiov v Moldova* (07/11/2006) ECHR Application 30649/05 and *Tarariyeva v Russia* (14/12/2006) ECHR Application 4353/03.

⁴⁸ Ferraz O (2011) Harming the poor through social rights litigation: lessons from Brazil *Texas Law Review* **89(7)**: 1643-68 (cited in Wilson's paper above).

⁴⁹ As set out in the [NHS Constitution](#) and in the [Handbook to the NHS Constitution](#).

- 18 None of these rights, or routes for redress, was introduced for the first time through the NHS Constitution: all derive from the existing legal framework establishing the NHS, the common law on clinical negligence, and more general equality legislation, including the Equality Act 2010 and the Human Rights Act 1998. What was new, however, was that the NHS Constitution set these rights in the context of the ‘responsibilities’ of patients to the NHS, including taking personal responsibility for one’s own health, treating NHS staff and other patients with respect, keeping appointments, following courses of treatment, and giving feedback (both positive and negative) about experiences of NHS care. The Constitution further broke new ground in including within the one document the rights and responsibilities of those *working* in the NHS, emphasising the “common set of principles and values that bind together the communities and people it serves – patients and public – and the staff who work for it” (see below paragraphs 26–27).
- 19 Although it is hard to criticise a focus on shared values and minimum standards, one response to the Francis report (and in particular to the subsequent Department of Health announcements) was to point out that the notion of patients being “at the centre of the NHS” with clinicians making “the care of your patient your first concern” was hardly new.⁵⁰ As Francis himself pointed out in his letter to the Secretary of State accompanying his report, the problem “above all” in Mid Staffs related to the *culture* that had been allowed to develop: “an insidious negative culture involving ... a disengagement from managerial and leadership responsibilities ... in part the consequence of allowing a focus on reaching national access targets ...”.⁵¹ Much of Francis’ analysis, and a significant number of his recommendations, thus relate to the question of how such cultural change might be achieved in practice, as discussed below.

(ii) Professional culture and leadership

- 20 The need for cultural change identified by Francis is widely accepted.⁵² The dilemma as to *how* to tackle such cultural change was explicitly recognised by Francis, who noted that it was not ‘top down’ pronouncements that would achieve the necessary transformation but rather the “engagement of every single person serving patients in contributing to a safer, committed and compassionate and caring service.”⁵³ Inevitably, however, it is very hard for a public inquiry report to make recommendations other than at a ‘top down’ level.
- 21 Francis’ own recommendations were targeted at a number of levels within the NHS hierarchy:
- at the Department of Health: for example ensuring senior clinical input in all policy decisions that may impact on patient wellbeing, better connection

⁵⁰ Delamoth T (2013) Culture change: Robert Francis’s prescription for the NHS, *BMJ* **346**:f979.

⁵¹ Letter to the Secretary of State, Francis Report, at page 3.

⁵² There has, however, been some degree of high profile dissent: the chief executive of the RCN, for example, has been robust in placing blame for poor standards primarily on inadequate staffing levels and has criticised “vague talk about the need for a change of culture which does not deal with the concrete concerns”: Mahony C (2014) 2013 was a horrible year for nursing – nurses are ‘burnt out’ says chief *BMJ* **348**: g126.

⁵³ [Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: executive summary](#), House of Commons Paper 947 2012-13, para 41.

between DH staff and the NHS through personal contact and visits, and promoting a shared positive culture through openness and candour when things go wrong;

- at Board level: with stronger leadership to be promoted through the creation of an NHS leadership college offering common training “to exemplify and implement a common culture, code of ethics and conduct”; accompanied by a registration scheme for senior leaders; and
- at ward level: with emphasis, for example, on ward nurse managers operating in a supervisory capacity, visible to both patients and staff and available to discuss concerns and provide feedback.

This focus on the role of leadership was accompanied by the proposal of an overarching ‘duty of candour’, requiring all NHS staff to be honest and open with patients and regulators when things go wrong, and an emphasis on the importance of placing capacity for care and compassion at the heart of the selection and education of candidates for the health professions, in particular those entering nursing training.

- 22 A report published a year later by the Nuffield Trust reviewed progress in acute trusts against these recommendations, and highlighted how interviewees “described changing culture as much more challenging to achieve than other initiatives”, such as training or data collection.⁵⁴ The Trust’s research obtained only a limited glimpse into the views of frontline (as opposed to board-level) staff but noted that “what we heard suggested that some staff still do not feel comfortable in raising concerns and, certainly, some senior managers were aware that openness was some way from being achieved within their trust”. Nevertheless, more positively, the review reported the “striking” finding that the Francis inquiries had “emboldened senior leaders in the trusts involved [in the research] to talk about prioritising the quality of care as equal to, or more important than, financial balance”.⁵⁵
- 23 While the Nuffield Trust review took a positive view of the effect on NHS boards’ attitudes to quality of care, other commentators have expressed concern that so many of Francis’ recommendations relate to board level *procedures* (relating to factors such as audit, record-keeping and the management of complaints) rather than more directly on the notion of compassion as a virtue.⁵⁶ A themed edition of the journal *Clinical Ethics*, published in November 2013, focused specifically on the question of compassion in healthcare, noting that semantic confusion over definitions of compassion (in particular the extent to which it should be elided with empathy or sympathy) may have led to the word being overused or misused to the extent that its power could be lost. The editorial for the special edition argues for a definition of compassion as “a complex entity, involving emotional (‘feeling with’) and cognitive (‘feeling for’, perspective-taking) empathy as well as distress tolerance and a motivation to help”.⁵⁷ It is suggested that such an approach to compassion appropriately uses an emotional response to galvanise positive action, but without

⁵⁴ Nuffield Trust (2014) [The Francis Report: one year on: the response of acute trusts in England](#), at page 38.

⁵⁵ *Ibid*, at page 39.

⁵⁶ Greenhalgh T (2013) The compassionate organisation article *British Journal of General Practice* September, 481.

⁵⁷ de Zulueta P (2013) Compassion in healthcare *Clinical Ethics* **8(4)**: 87-90.

professionals “becoming overwhelmed, self-focused and avoidant”, thus avoiding problems of ‘compassion fatigue’ or dehumanisation.⁵⁸

- 24 This emphasis, that the virtue of compassion extends well beyond the initial emotional response of empathy with the patient, has also been used to challenge the notion that compassion and justice are inherently in conflict in resource-limited situations. While justice (in the form of the interests of other patients also in need) may appear to demand that ‘compassionate’ but time-consuming approaches to care should be curtailed, it is argued that compassion is an intrinsic, not optional, part of care: “not caring compassionately for [sick and dying human beings] is a failure of justice as a human excellence of other-directed response.” Compassion should be understood as “a personal ethical attribute that contributes to a sense of justice”.⁵⁹ Similar arguments are made in the *Clinical Ethics* themed edition: one contributor rejects the “biomedical machismo” that “sees human understanding, kindness, emotional awareness and talking and touching as doctoring and health care for wimps”, and argues that it is a false dichotomy to separate compassion and competence: these two attributes can and must be combined in good professional practice.⁶⁰
- 25 Another contributor to the *Clinical Ethics* special edition noted the limitations of the kind of ‘value statements’ of the kind described above in the Department of Health’s response to Francis. It is argued that such statements are, on their own, insufficient to create a compassionate culture, and indeed that the imposing of unachievable values “may increase the dissonance experienced by beleaguered professionals between what they aspire to do and what is possible in a context that is fixated on targets and speed”.⁶¹
- 26 In response to these insights on the nature of compassion, it is argued that what is required is “to radically rethink how we provide care”⁶² and challenge the “convenient truth from the point of view of managerial priorities” that compassion is unaffordable.⁶³ Academic work on ‘compassionate organisations’ (not necessarily specific to healthcare organisations) asks the question “what does an organisation look like when its organising principles are based on the logic and principles of caring and compassion?” Suggested answers include not only the use of appropriate incentives, rewards and procedures, but also the need to ‘humanise’ both staff and clients as “people who suffer, people who care, and people who individually and collectively may respond with emotion to adversity”.⁶⁴ Such an approach highlights the importance of the NHS as a ‘good employer’, not simply because of an ethical imperative for a large public-sector organisation to treat its employees well, but as a

⁵⁸ *Ibid.*

⁵⁹ See, for example, Maxwell B (2009) Just compassion: implications for the ethics of the scarcity paradigm in clinical healthcare provision *Journal of Medical Ethics* **35(4)**:219-23.

⁶⁰ Gillon R (2013) Restoring humanity in health and social care: some suggestions *Clinical Ethics* **8(4)** 105-10.

⁶¹ de Zulueta P (2013) Compassion in healthcare *Clinical Ethics* **8(4)**: 87-90 at 89, summarising Gallagher A (2013) Slow ethics: a sustainable approach to ethical care practices? *Clinical Ethics* **8(4)** 98-104.

⁶² de Zulueta P (2013) Compassion in healthcare *Clinical Ethics* **8(4)**: 87-90 at 89.

⁶³ Maxwell B (2009) Just compassion: implications for the ethics of the scarcity paradigm in clinical healthcare provision, *Journal of Medical Ethics* **35**:219-23, at 222.

⁶⁴ Greenhalgh T (2013) The compassionate organisation *British Journal of General Practice* September 2013, at 481.

necessary pre-requisite for the proclaimed values of the NHS to be realised. It also highlights the importance of intangible factors such as trusting relationships – crucial both within professional teams and between clinicians and patients. It has been argued that *really* trusting patients, for example in initiatives such as ‘experience-based codesign’ (where patients identify what really matters to them as part of an organisation’s approach to quality improvement) may be “the most disruptive innovation in healthcare” yet (see paragraph 34 below).⁶⁵

27 One way in which organisations may demonstrate characteristics of being a ‘good’ or ‘humanising’ employer is in terms of its concern with occupational health: the health of its own staff. The 2013 Keogh review of 14 trusts with high levels of patient mortality, for example, found a correlation between high mortality rates and high rates of staff sickness absence.⁶⁶ While NICE has issued guidance to NHS employers in a number of areas relating to staff health, a recent audit of 73% of NHS trusts carried out by the Royal College of Physicians found that there was still significant room for improvement in the ways in which trusts care for the physical and mental wellbeing of their staff.⁶⁷

28 It is interesting to note that, despite the critique from some sides of the Francis recommendations as being too focused on Board-level procedures, the practical recommendations emanating from the literature on compassion in fact overlap to a considerable degree with those emanating from the public inquiry, to the extent that the latter also focus on the ethos of professional training and practice,⁶⁸ and on approaches to such aspects of staff management as concern for staff wellbeing (evidenced through good occupational health systems) and management styles that encourage and promote trusting relationships.⁶⁹ Francis alluded several times in his final report to the particular difficulties caused by structural change in organisations, and the extent to which management focus on such change may divert attention away from these other important aspects of management. Yet, as alluded to above, it may be the case that the only way to deliver real changes in quality of healthcare is by re-thinking in a more fundamental way how that healthcare is delivered. Achieving such a change while maintaining (or improving) morale and trust within NHS organisations may not be easy.

(iii) Reframing how services are delivered: resource allocation by provider organisations

29 As noted above, Francis did not call for additional funding, for Mid Staffordshire NHS Foundation Trust in particular, or for the NHS as a whole. However, he did explicitly comment on the ‘mismatch’ between the resources allocated (for example to staffing) and the needs of the service (see paragraph 9). He further criticised the year-on-year

⁶⁵ Jocelyn Cornwell, cited in Swinglehurst D, Emmerich N, Maybin J, Park S and Quilligan S (2014) Rethinking ‘quality’ in healthcare *Journal of Health Services Research and Policy* (online first 27 January).

⁶⁶ Keogh B (2013) [Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report](#), para 4.3.

⁶⁷ NICE press notice (29 January 2014) *NHS trusts failing to support staff health and mental wellbeing*.

⁶⁸ See, for example, Gillon R (2013) Restoring humanity in health and social care: some suggestions *Clinical Ethics* **8(4)** 105-10.

⁶⁹ See, for example, Lilius JM, Kanov J, Dutton J, Worline MC and Maitlis S (2011) Compassion revealed: what we know about compassion at work (and where we need to know more) in Cameron K and Spreitzer G (eds) *The Handbook of Positive Organizational Scholarship* (Oxford: Oxford University Press).

economies imposed by the Trust board, an implicit reference to local implementation of the 'Quality, Innovation, Productivity and Prevention' (QIPP) initiative, which aims to deliver the £20 billion worth of efficiency savings required of the NHS by 2015.⁷⁰ It is clear that if an NHS organisation is to maintain appropriate staffing levels, while finding significant economies within its budgets as a whole, it is not feasible simply to keep reducing each existing budget head by the requisite amount and expect the same standards of care.⁷¹ If economies are available to be made, this will usually be achieved by rethinking on a more fundamental scale how services are to be delivered, rather than simply continuing to do things in the same way with declining resources.

- 30 NHS England made a very public claim for the need for such an approach in its 2013 *Call for Action*, stating: "If the NHS is to survive another 65 years, it must change. We know that there is too much unwarranted variation in the quality of care across the country. We know that at times the NHS fails to live up to the high expectations we have of it. We must urgently address these failures, raise performance across the board, and ensure we always deliver a safe, high quality, value-for-money service. ... [I]ncrease in demand combined with rising costs threatens the financial stability and sustainability of the NHS. Preserving the values that underpin a universal health service, free at the point of use, will mean fundamental changes to how we deliver and use health and care services."⁷² The *Call for Action* invites all "staff, stakeholders and most importantly patients and the public" to take part in designing a "renewed, revitalised NHS", and promises that the information derived from this consultation will feed into 3-5 year 'commissioning plans' developed by each local CCG and in this way "drive real future decision making".
- 31 In making this appeal for widespread public (and staff) contribution to the debate on how services should be 'reconfigured', the Call for Action makes explicit that some options are *not* open to question. It is made clear that:
- doing nothing is not an option;
 - it would be unrealistic to expect anything more than 'flat funding' (adjusted for inflation) in the coming years; and
 - there is no question of either cutting, or charging for, NHS "core services", as set out in the NHS Constitution.
- 32 Having set out these parameters, the Call for Action then goes on to set out a number of areas where it suggests significant changes might potentially be made in the current structure of the NHS. These include:
- providing more integrated services (bridging the gaps between hospital care, primary care provided through GP practices, and social care provided by local authorities;

⁷⁰ See: <https://www.gov.uk/government/policies/making-the-nhs-more-efficient-and-less-bureaucratic>.

⁷¹ Indeed, this is explicitly recognised in the Call for Action (see below) which comments in the context of the 'Nicholson challenge' to make productivity savings of 4% each year that "there is a limit to how much more can be achieved without damaging quality or safety".

⁷² NHS England (2013) [*The NHS belongs to the people: a call for action*](#).

- availability of routine services on a seven day a week basis, both to make better use of existing facilities, and to avoid unnecessary pressures on emergency services at the weekends;
- recognition of the crucial impact on health of factors such as housing, educational attainment and exercise, and hence better co-ordination between the NHS and the publicly-funded bodies, such as local authorities and Public Health England, that can influence these wider factors;
- encouraging and enabling patients, particularly those with long term conditions, to take a more proactive role in managing their own care;
- a much greater focus on preventative medicine; and
- making use of ‘transformational technologies’ such as an ‘online banking’ model approach for patients to access their medical data and test results, book appointments and email clinicians, to make services both more accessible and more efficient to run.

33 Just as the NHS constitution does not offer new rights to NHS patients, but rather presents existing rights in a framework of explicit values (including patient responsibilities), the areas for discussion identified in the Call for Action have been the subject of extensive work in past years by research-led organisations such as the King’s Fund and the Nuffield Trust, as well as by the professional organisations such as the Royal Colleges, the BMA and the NHS Confederation. Within the last two years alone, major reports have been published on these aspects of health systems, including:

- the expansion of services provided by primary care services with the aim of bringing care closer to patients;⁷³
- how NHS care can be better co-ordinated between community nursing and GP care and hospital care;⁷⁴
- the need for change in the way A&E departments are staffed, managed and financed;⁷⁵ and
- the barriers to ‘integrating’ health and social care (particularly problematic because social care is the responsibility of local authorities, not the NHS, and may be charged for),⁷⁶ including the establishment of a Commission, yet to report, on whether the retention of these two separate systems for care remains tenable.⁷⁷

These themes are similarly debated extensively at professional and management conferences, such as the annual Nuffield Trust Health Policy Summits,⁷⁸ and many of

⁷³ King’s Fund (2014) [*Commissioning and funding general practice: making the case for family care networks*](#); Nuffield Trust (2013) [*New models of primary care: practical lessons*](#).

⁷⁴ King’s Fund (2013) [*Co-ordinated care for people with complex chronic conditions*](#).

⁷⁵ NHS Confederation (2013) [*Emergency care: an accident waiting to happen?*](#) Briefing 268, September 2013.

⁷⁶ Frontier economics (2012) [*Enablers and barriers to integrated care and implications for Monitor: a report prepared for Monitor*](#); King’s Fund (2013) [*Making integrated care happen at scale and pace: lessons from experience*](#).

⁷⁷ King’s Fund [*Commission on the Future of Health and Social Care in England*](#), due to report in September 2014, with an interim report published on 3 April.

⁷⁸ See <http://www.nuffieldtrust.org.uk/summit/2014> and <http://www.theguardian.com/healthcare-network/2014/mar/06/today-in-healthcare-jeremy-hunts-speech-at-the-nuffield-trust-health-policy-summit>.

the identified challenges (in particular the lack of co-ordination between different parts of the health and social care system) have been recognised for decades.

- 34 These ‘nuts and bolts’ questions of how services may best be organised around the needs of today’s patients, rather than around the inherited structure of NHS buildings and systems, do raise some ethical questions, in particular around the issue of legitimacy and trust: how decisions are made, what role local people actually have in steering services, and whether promises about new and at least equivalent services being provided after the closure of well-loved institutions are regarded as trustworthy. Recent legal challenge to proposed changes to hospital services in Lewisham in South East London, and subsequent moves to change the law to enable changes regarded as necessary to be forced through, regardless of local concerns, suggests that there is still something of a gap between the rhetoric of local people shaping local services, and the pragmatic need to make management decisions in the light of acute local financial pressures.⁷⁹ However, the main challenges would appear to be practical and managerial, rooted in complex questions of health systems, and, as noted above, already the subject of extensive expert review.

Alternative approaches to NHS funding?

- 35 This paper has focused primarily on those approaches to maintaining quality of care, despite the inevitable existence of funding pressures, identified in the Francis report, and endorsed by the Government in the form of the NHS Constitution and the *Call for Action*. As noted above, the *Call for Action* made quite explicit that one question that was not open for discussion was the question of how NHS services should be funded. Nevertheless, this is an issue that repeatedly arises in both academic and professional debates, and is briefly touched upon here.
- 36 Where the suggestion is put forward that changes might be made to the current model of tax-payer funding with services free at the point of delivery (with statutory exceptions), a number of possible approaches tend to emerge:
- **Expanding the range of patient co-payments** beyond those currently levied for prescription charges and dentistry. The most common suggestions relate to a fee for GP appointments (with the joint aim of increasing NHS income and reducing inappropriate use), increasing prescription charges, and reducing the number of people exempt from paying those charges. Key concerns raised in response to GP charges include the danger of diverting patients to less appropriate services such as A&E, delays in diagnosis, and inequity.⁸⁰ The suggestion put forward in recent weeks by a former health minister, that people should pay £10 a month to use the NHS, takes a slightly different approach,

⁷⁹ Although the Secretary of State for Health had been held to have acted outside his powers in taking the decision to reduce services in Lewisham, a new clause (Clause 119) has now been inserted into the Care Bill currently going through Parliament, to ensure that in future such changes may lawfully be made (although amendments were made to the clause to require consultation): <http://www.bbc.co.uk/news/health-26531807>.

⁸⁰ See, for example, Reform (2013) *The cost of our health: the role of charging in healthcare* and some of the resulting debate such as: Parker J (2013) Should the NHS charge patients for GP appointments? Yes *Pulse* 3 September 2013; and Chand K Should the NHS charge patients for GP appointments? No *Pulse* 3 September 2013.

perhaps more akin to a flat-rate hypothecated tax.⁸¹ Whatever the form in which such co-payments were introduced, however, concerns might arise that the creation of such payments within the public sector tends to be the cue for matching reductions in direct public funding, rather than genuinely adding to the existing budget.⁸²

- **Shifting to a social insurance-based system**, on similar lines to those found in many other European countries, in which universal coverage, and minimum core services, are specified by the state, but contributions handled through employers or the social security system rather than via general taxation, and services provided by a variety of suppliers. Such systems tend to include some degree of co-payment for most services, with many (but not all) patients taking out private insurance to cover these additional costs. The interim report published in April 2014 by the Kings Fund *Commission on the Future of Health and Social Care in England* reviews a wide range of ways in which additional private or public money might be drawn into the healthcare system, and invites public responses, but seems unenthusiastic about any benefits to be gained through shifting to a social insurance model.⁸³
- **Contributions in kind**: looking at other ways in which patients and their families (or the wider public) might contribute directly to healthcare: for example through expecting families to take a greater part in the care of hospital in-patients at mealtimes or in the provision of personal care; or through the greater use of volunteers in both hospitals and community services (distinct from the current practice of contracting with voluntary organisations to provide services for a fee).⁸⁴

37 The question of alternative funding models for the NHS may arise because of the perceived impossibility of increasing public funding through traditional means (for example through tax increases or dedicated NHS contributions), or may derive from the doctrinal perspective that approaches that reduce the role of the 'state' in funding and controlling healthcare are inherently preferable. However, the key question in the context of this debate is whether any of these proposals would either lead to increased levels of funding for healthcare (as opposed to substituting for funding from tax revenues or being absorbed in increased layers of bureaucracy), or would otherwise lead to higher standards and higher quality of care, for example by changing the relationship between those receiving and those providing the services.

A possible role for the Nuffield Council?

38 In the context of the policy initiatives, and ongoing research and debate, summarised in this paper above, attendees at the Council's Forward Look are invited to consider whether the Council could play a useful role in furthering current debates on how best to manage resource pressures in the NHS while maintaining appropriate quality standards. Specifically *ethical* questions raised above include: whether more could

⁸¹ The Guardian (31 March 2014) [NHS users should pay £10 a month, says former health minister](#).

⁸² See, for example, the revolution of university funding and the shift from tax-payer funded fees to repayable loans (themselves funded upfront by the taxpayer).

⁸³ King's Fund (2014) [A new settlement for health and social care: interim report](#).

⁸⁴ See, for example, King's Fund (2013) [Volunteering in health and care: securing a sustainable future](#).

be said to elaborate the values set out in the NHS Constitution; whether further ethical thinking on issues of compassion could play a useful role in embedding compassionate behaviours in such a large and complex organisation as the NHS; how greater public trust and legitimacy might be engendered in the context of service re-design; and the ethical implications of exploring alternative funding models, should these look likely to contribute to higher quality standards.

39 In selecting topics for future work, the Council must take account of its Terms of Reference which require it to “identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern”. Selection criteria developed by Council include the following factors:

- Is the topic associated with recent advances in biological and medical research and/or are there ‘new’ reasons for looking at longstanding issues or revisiting issues covered in previous Council reports?
- Does the issue raise complex ethical questions?
- Would input from the Council be timely?
- Could the Council make a distinctive contribution?
- Would action by the Council anticipate or respond to public concern?
- Is there sufficient reason to consider this topic over others?

Katharine Wright 9 April 2014