

Rationing in the English NHS and the Tension between Patient Choice and Solidarity

Maria K. Sheppard*

Queen Mary University of London, Department of Law

Abstract

Solidarity is a principle that underlies the English National Health Service (NHS). While intended to be comprehensive, since its inception financial constraints meant that limits have been placed on the availability of NHS health care. Health care has been rationed in a number of ways but English law demands that any such rationing policies by public bodies must allow for exceptions in special cases. When a patient makes an individual funding request (IFR) for such a treatment it is a question for the health authority to decide on the merits of the IFR whereas in any subsequent judicial review proceedings the court considers that decision in terms of its legitimacy, procedural propriety and reasonableness. To avoid judicial review of decisions health authorities are often inclined to accede to patients' requests because litigation, apart from being costly and time-consuming for the authority, also sets new precedents. This has led to suggestions that solidarity is being eroded in the NHS since resources that are spent on such requests by patients mean disinvestment from other areas of the NHS. This paper argues that enabling individual choice may in effect support a collective commitment to a solidaristic health care system. Rather than encroaching on the principle of solidarity (intended) litigation by patients destabilises the health care system and leads to much needed change and reform. Not only do the potential ramifications of (intended) litigation go beyond the immediate consequences for the parties to the action, but the need to account for rationing decisions by the health authority in public makes the system accessible to broader interests. Patient treatment choice can thus be seen as an affirmation of a commitment to solidarity that is also supported by the increased emphasis on patients taking responsibility for their own health with the aim of reducing NHS costs.

I. Introduction: The Backdrop to Solidarity and Choice in the NHS

Much academic work exists which discusses the values underlying the English National Health Service (NHS).¹ Although the National Health Service Act 1946 which established the NHS, did not mention the founding

* DOI 10.7590/221354020X15815920230951 2213-5405 2020 Journal of Medical Law and Ethics

¹ B. New, *A Good Enough Service – Values Trade-offs and the NHS* (London: Institute for Public Policy Research, 1999); D. Seedhouse, *Fortress NHS: A Philosophical Review of the Health Service*

values of the English NHS, from various government documents² and the latest edition of the NHS Constitution³ it is possible to condense these values to four: comprehensiveness, universality, equity of access, and a service free at the point of delivery. These are abstract values, and as abstract values they not only allow competing interpretations but are also in tension with each other.⁴ It has been asserted that these values constitute a ‘political fudge’, which in turn enables universal support.⁵ Not mentioned as one of these founding values, but nevertheless an overriding principle that can be gleaned from the wartime Beveridge Report⁶ and which underlies the foundation of the NHS is that of solidarity.

The Nuffield Council on Bioethics in its report on solidarity defines this term, which is criticised as being vague, as signifying ‘shared practices reflecting a collective commitment to carry “costs” (financial, social, emotional, or otherwise) to assist others.’⁷ Solidarity as a manifestation of both an *individual* willingness or a *collective* commitment to carry costs to assist others, comes arguably close to subsume the two NHS values of universality and equity. Thus, universality was referred to by Bevan, the architect of the NHS and its first Health Minister, as one of the purposes of the NHS: ‘to provide the people of Great Britain, no matter where they may be, with the same level of service.’⁸ ‘Everyone – rich or poor, man, woman or child’⁹ was to be covered. ¹⁰Equity on the other hand, as Dixon and others point out, rarely misses in any academic study regarding the values underlying the NHS.¹¹ It is often described as the belief that ‘the health service should be for all the British people equally.’¹² However, it is

(Chichester: John Wiley & Sons, 1995); C. Webster, *The National Health Service: A Political History*, 2nd ed. (Oxford: OUP, 2002), 24.

² See e.g. Department of Health, *The NHS Improvement Plan: Putting People at the Heart of Public Services* (London: HMSO, 2004); Department of Health, *Equity and Excellence: Liberating the NHS* (London: HMSO, 2010).

³ Department of Health, *NHS Constitution for England* (London: HMSO, 2015).

⁴ R. Klein, ‘Values Talk in the (English) NHS’, in *Devolving Policy, Diverging Values: The Values of the United Kingdom’s National Health Services*, ed. S.L. Greer and D. Rowland (London: Nuffield Trust, 2007) 22–23.

⁵ D. Seedhouse, *Fortress NHS* (note 1), 12–13.

⁶ W. Beveridge, *Social Insurance and Allied Services*, Beveridge Report, Cmd 6404 (London: HMSO, 1942).

⁷ B. Prainsack and A. Buyx, *Solidarity: Reflections on an Emerging Concept in Bioethics* (London: Nuffield Trust, 2011), xiv and 29–30.

⁸ R. Klein, *The New Politics of the NHS: From Creation to Reinvention*, 6th ed. (Abingdon, Oxon: Radcliffe Publishing, 2010), 19.

⁹ C. Webster, *The National Health Service* (note 1), 24.

¹⁰ M. Foot, *Aneurin Bevan – A Biography*, vol 1 (London: MacGibbon & Kee, 1962), 105.

¹¹ A. Dixon et al., ‘Is the NHS Equitable? A Review of the Evidence’, paper no. 11 (London: LSE Health and Social Care, 2003), 5.

¹² D. Seedhouse, *Fortress NHS* (note 1), 61 citing C. Ham, *Health Policy in Britain* (London: Macmillan, 1982).

often not clear what equity in terms of health care implies, whether it refers, for example, to equity of access or equity according to need and whether need is to be assessed according to the level or degree of ill-health, the capacity to benefit, time waiting for treatment, social factors or age. Necessarily, the lack of consensus regarding the interpretation of *need* makes it difficult to realise a fair or equitable health care system.¹³ While closely related to universality, which provides reassurance of the availability of health care in times of need, equity, unlike universality, is more concerned with the distribution of benefits in society and deals with the fairness of distribution. Universality, therefore, will allow people to avail themselves of the health service whether or not they are able to pay for it, whereas equity of access is concerned with the fairness of distribution.¹⁴ The concept of solidarity could be viewed as combining these two values within it, namely that of cohesion and togetherness, and of security and reassurance, achieved by ensuring that everyone is covered by the health care system.¹⁵

Solidarity both in terms of universality and in terms of equity appears, at least in a narrow definition, to be anathema to individualism or individualistic patient choice,¹⁶ another concept that has gained prominence in the NHS.

Choice linked with the notion of rights as a liberal value, or with the concept of the individualistic consumer in the market, exchanging money for the desired goods or services seems to question our concern for social citizenship in which we share common interests in a community of others.¹⁷ It is therefore not surprising that choice only appeared later on as a concept in the NHS, namely with the establishment of the internal health care market in 1989 in the White Paper *Working for Patients*.¹⁸ Patient choice became an important policy of the NHS with the introduction of the NHS Plan in 2000.¹⁹ Successive Department of Health Papers confirmed the government's vision of patient choice with free choice of any hospital for treatment, including private hospitals,²⁰ and choice of treatment options for patients with long-term conditions.²¹ *Liberating the*

¹³ B. New, *A Good Enough Service* (note 1), 28.

¹⁴ *Ibid.*, 28.

¹⁵ *Ibid.*, 27.

¹⁶ B. Prainsack and A. Buyx, *Solidarity* (note 7), 29–30.

¹⁷ C. Newdick, 'The European Court of Justice, Trans-National Health Care and Social Citizenship—Accidental Death of a Concept?', *Wisconsin International Law Journal* 26, Issue 3 (2009), 844.

¹⁸ Department of Health, *Working for Patients* (London: HMSO, 1989).

¹⁹ Department of Health, *NHS Plan: A Plan for Investment, A Plan for Reform* (London: HMSO, 2000); I. Greener, 'Towards a History of Choice in UK Health Policy', *Sociology of Health and Illness*, 31 (2009), 318.

²⁰ Department of Health, *Choice Matters: Putting Patient in Control* (London: HMSO, 2007), 6–8.

²¹ Department of Health, *NHS Choices: Delivering for the NHS* (London: HMSO, 2008), 14.

NHS, the White Paper published by the coalition government in 2010,²² was to enable choice ‘through an information revolution’ where patients were to have the choice of any qualified provider, choice of a consultant-led team, choice of GP practice, choice of care for long-term conditions and choice of treatment. Patient choice is also enshrined in the new edition of the NHS Constitution for England²³ and the Health and Social Care Act 2012.²⁴ Furthermore, choice of treatment for the patient has been linked with the notion of personalised health care in which patients are given a more tailored service.²⁵ Choice is also the theme in the recent NHS publication ‘*Universal Personalised Care: Implementing the Comprehensive Model*’ with personalised care being defined as ‘people hav[ing] choice and control over the way their care is planned and delivered, based on “what matters” to them and their individual strengths, needs and preferences.’²⁶ It is supposed to give people ‘the same choice and control over their mental and physical health’ that they expect in every other aspect of their life.²⁷

2. Rationing in a Comprehensive Health care Service

It has been noted that the founding value of the comprehensiveness of the NHS could not be guaranteed, even from its inception.²⁸ Although rationing and priority-setting were not contemplated when the NHS was created, as it was expected that the demand for health services would gradually decrease once the unmet need had been satisfied, the opposite happened: the demand for medical services exceeded all expectations.²⁹ It was recognised early on that the NHS was not self-limiting in that its contribution to national health did not limit the demands upon it to a volume that could be fully met.³⁰ Thus, financial constraints have always meant that limits are placed on health care so that it is affordable; and cost containment has therefore become a necessary policy goal.

²² Department of Health, *Equity and Excellence*, (note 2).

²³ Department of Health, NHS Constitution, (note 3).

²⁴ See further Health and Social Care Act 2012, s. 20(1)(2)c and s. 13I.

²⁵ See e.g. Department of Health, *High Quality Care for All: NHS Next Stage Review: Final Report* (London: HMSO, 2008); Department of Health, *Personal Health Budgets: First Steps* (London: HMSO, 2009).

²⁶ NHS England, *Universal Personalised Care: Implementing the Comprehensive Model*, page 6, www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/, 31 January 2019.

²⁷ *Ibid.*, 2

²⁸ C. Webster, *The National Health Service* (note 1), 22.

²⁹ *Ibid.*, 29–30; D. Seedhouse, *Fortress NHS* (note 1), 14.

³⁰ R. Klein, *The New Politics of the NHS* (note 8), 29.

In health care that subscribes to the principle of solidarity there should of course be a commitment to a common cause including the need for cost restriction in the NHS. In the words of Beveridge solidarity is an exhortation of ‘men stand[ing] together with their fellows’ and the ‘pooling of risks’.³¹ Such cost containment can be achieved in a variety of ways³² but in the form of explicit rationing, such as the exclusion of treatment by denial of specific interventions or by delay of treatment, it has not commanded universal support.³³ In particular, the greater visibility of explicit treatment denial in the past 25 years³⁴ has brought the issue of rationing into the public consciousness³⁵ particularly since rationing appears to stand in contradiction to policy-makers’ use of the patient choice mantra. It has therefore been argued that solidarity is being challenged by the new emphasis on patient choice³⁶ and that demanding treatment not generally available to the community of patients can be regarded as acting contrary to the underlying values of the NHS of equality and universality. In this context Pollock, for example, claims that the new ‘NHS plc’ with its new policy goal of patient choice has abandoned the founding principles of the NHS of comprehensiveness, universality and equity.³⁷

Leaving comprehensiveness aside, health care rationing is also indispensable when there are competing demands on the public purse, that is on the monies allocated to health care from taxation. In England, it is NHS England and the Clinical Commissioning Groups (CCGs) that have the unenviable task of deciding which treatments are available and which are restricted because of finite annual financial allocations.³⁸ This is despite the fact that NHS England has concurrent responsibility with the Secretary of State for Health for the discharge of the overarching duty to continue *to promote a comprehensive health service in England*.³⁹ Its duties lie in arranging for the nationwide provision of certain specialist services, to such extent as it considers *necessary* to meet all reasonable

³¹ Beveridge Report (note 6), 849.

³² R. Klein, *The New Politics of the NHS* (note 8), 28 referring to the introduction of prescription charges; A. Pollock, *NHS plc: The Privatisation of Our Healthcare* (London: Verso, 2005), 41 referring to the drive to increase efficiency by the introduction of managers to replace hospital consultants from 1989 onwards.

³³ R. Klein, ‘Values Talk in the (English) NHS’ (note 4), 22.

³⁴ K. Syrett, *Law, Legitimacy and the Rationing of Healthcare* (Cambridge: CUP, 2007), 159 pointing out that there were very few legal challenges to resource allocation decisions before the case of *R v. Cambridge Health Authority, ex parte B* [1995] 1 WLR 898.

³⁵ N. Daniels and J. Sabin, *Setting Limits Fairly* (Oxford: OUP, 2008), 160.

³⁶ J. Clarke, J. Newman & L. Westmarland, ‘The Antagonisms of Choice: New Labour and the Reform of Public Services’, *Social Policy and Society* 7, Issue 2 (2008), 250.

³⁷ A. Pollock, *NHS plc*, (note 32), 78–79.

³⁸ National Health Service Act 2006 as amended by the Health and Social Care Act 2012, s. 223H.

³⁹ *Ibid.*, Ch. 7 s.1.

requirements. In contrast, the Clinical Commissioning Groups (CCGs) established under the Health and Social Care Act 2012 to take over as commissioners from the previous Primary Care Trusts (PCTs), are responsible for the commissioning of health services only for their local area.⁴⁰

In their decision-making both NHS England and the CCGs are guided by the National Institute for Health and Care Excellence (NICE), originally established as National Institute for Clinical Excellence, to increase consistency in local decision-making.⁴¹ NICE undertakes technology appraisals of new drugs and treatments to establish clinical and cost effectiveness, and CCGs and NHS England are under a legal obligation to make available, within a period of 3 months, health technology appraisals recommended by NICE.⁴² As the NHS cannot possibly fund every health care treatment for every patient, the duty of these public bodies to balance their budgets is an important one. There are inevitable funding implications when mandatory technology appraisal recommendations have to be covered from existing budgets.⁴³ Not all guidance by NICE is mandatory, however, but public bodies do need to take note of its guidance. They can adopt, in effect, their own priorities for other health care expenditure providing they avoid a breach of legal duties and a possible legal challenge in the courts.⁴⁴

Because of the role of NICE and NHS England there is at least some consistency on a national level over funded treatment.⁴⁵ However, for their local areas the different CCGs have developed their own lists of treatments and procedures they do not routinely fund.⁴⁶ Such exclusion may be on the grounds that these treatments and procedures are of low value, that they are either relatively ineffective or that more cost-effective alternatives are available, or on the grounds that they are of low priority such as procedures relieving pain or discomfort or

⁴⁰ Health and Social Care Act 2012, s. 13(3)(1A).

⁴¹ NHS England and Wales, The National Institute for Clinical Excellence (Establishment and Constitution) Order (S.I.1999/220), www.legislation.gov.uk/uk-si/1999/220/pdfs/uk-si_19990220_en.pdf.

⁴² The National Institute for Health and Care Excellence (Constitution and Functions) and the Health and Social Care Information Centre (Functions) Regulations 2013 Sch. 1, 259 part I s. 7.

⁴³ K. Syrett, *Law, Legitimacy and Rationing*, (note 34), 31 writing in the context of Primary Care Trusts.

⁴⁴ C. Newdick, *Who should we treat?* 2nd ed. (Oxford: OUP, 2005), 94.

⁴⁵ NHS England, *Conditions for which over the Counter Items should not Routinely be Prescribed in Primary Care: Guidance for CCGs*, www.england.nhs.uk/wp-content/uploads/2018/03/otc-guidance-for-ccgs.pdf, 29 March 2018, which aims to produce a consistent, national framework for CCGs to use.

⁴⁶ J. Maybin and R. Klein, *Thinking about Rationing* (London: King's Fund, 2012), 21 stating that more than a third of PCTs had expanded the number of treatments for which they were withholding funding in 2011.

procedures which might affect people's major life events.⁴⁷ Examples of these range from specific drugs, surgery for varicose veins, cosmetic surgery, tattoo removal, vasectomy, bariatric surgery, surgery for lower back pain, knee arthroscopy, IVF to complementary alternative medicine.⁴⁸ Even if the decisions as to which treatments and procedures are generally not funded are supplemented by guidance from NICE and NHS England⁴⁹ they will continue to attract controversy. Unsurprisingly, refusal of their preferred treatment by health authorities has led many disgruntled patients taking recourse to the law to have the decision reviewed by the court but as will be explained below, judicial remedies in these cases have their limitations.

2.1 Rationing and Patient Choice: Individual Funding Requests

The expression of choice by patients who request a treatment or procedure not generally available in the NHS can be seen as underlying individual funding requests (IFRs). These are made by the patient with the support of the medical practitioner and can be for a treatment not routinely offered by NHS England or the patient's CCG. Patients will generally only succeed if they can show exceptional circumstances. This is because as a general principle of administrative law and despite public bodies' wide discretionary power regarding allocative priorities such exceptional cases to any general policy on treatment funding must be admitted. Auld LJ stated the law in the case of *A, D and G*:

The precise allocation and weighting of priorities is clearly a matter of judgment for each Authority, keeping well in mind its statutory obligations to meet the reasonable requirements of all those within its area for which it is responsible. It makes sense to have a policy for the purpose – indeed, it might well be irrational not to have one – ...It is proper for an authority to adopt a general policy for the exercise of such an administrative discretion, to allow for exceptions from it in “exceptional circumstances”...⁵⁰

Individual funding requests are significant, not only because they define what the NHS will fund but also because refused IFRs can come to the courts for judicial review where the decision of the health authority is exposed to legal and public scrutiny.⁵¹ In adjudicating, the role of the court is not to assess the

⁴⁷ Audit Commission, *Reducing Spending on Low Clinical Value Treatments* (London: Audit Commission, 2010), 2 referring to the Croydon List; N. Edwards, H. Crump & M. Dayan, *Rationing in the NHS* (London: Nuffield Council on Bioethics, 2015), 6-7.

⁴⁸ Audit Commission, *Reducing Spending*, (note 47), appendix 1.

⁴⁹ NHS England, *Guidance for CCGs*, (note 45).

⁵⁰ *R v. North West Lancashire Health Authority, ex parte A, D and G* [1999] Lloyd's Rep Med 399, 412.

⁵¹ J. Russel and T. Greenhalgh, 'Affordability as a discursive accomplishment in a changing National Health Service', *Social Science & Medicine* 75, Issue 12 (2012), 7.

merits of the patient's claim but to oversee the legitimacy, procedural propriety and reasonableness of the decision by the public body regarding the patient's exceptional circumstances. In any case, judicial challenges to resource allocation decisions have not been easy to win by patients.⁵² This is because of the nature of judicial review, which sets limits to challenging the substance of policy decisions. Even where a challenge is successful, the court will not usually invalidate the decision but refer the matter back to the authority for re-consideration in the light of the court's observations⁵³ and as long as the defects in the original decision-making process are remedied, the public body is entitled to come to the same decision.⁵⁴

2.2 The Definition of Exceptionality Criteria

Subject to these described public law grounds, as long as their policies allow for 'exceptions' public bodies are unfettered in their allocation of resources and priority-setting.⁵⁵ Exceptionality does not refer to the patient's exceptional illness but means that the patient's exceptional circumstances are such that he or she will derive significant benefit from the requested treatment, not routinely offered by the NHS. While it is not necessary to define the specific exceptional circumstances it has to be possible to envisage there being exceptions, such as the possibility of there being an overriding clinical need, since 'if it is not possible to envisage such circumstances the policy would in practice be a complete refusal.'⁵⁶ It may of course be difficult to determine exceptional circumstances in advance but 'to leave the circumstances undefined presents a considerable challenge for public bodies and results in their decisions being vulnerable to legal dispute.'⁵⁷

The volume of litigation in the courts since the decision in *A, D and G* in 1999 is evidence of this problematic. Thus, a whole series of judicial review cases have come before the courts demonstrating the difficulty encountered by many commissioning bodies in formulating a definition of what constitutes

⁵² K. Syrett, *Law, Legitimacy and Rationing*, (note 32), 132-133; B. Sheldrick, 'Judicial Review and the Allocation of Healthcare Resources in Canada and the United Kingdom', *Journal of Comparative Policy Analysis* 5, Issue 2-3 (2003), 151.

⁵³ C. Newdick, 'Accountability for Rationing – Theory into Practice', *J. Law Med & Ethics* 33, Issue 4 (2005), 661; cf C. Newdick, 'Can Judges Ration with Compassion? A Priority-Setting Matrix', *Health and Human Rights* 20, Issue 1 (2018), 115 where the author argues that the procedural response by the court in practice is often a substantive response.

⁵⁴ B. Sheldrick, (note 52), 152.

⁵⁵ *R v. North West Lancashire*, (note 50), 412 (Auld LJ).

⁵⁶ *Ibid.*; *R (Rogers) v. Swindon NHS Primary Care Trust and Secretary of State for Health* [2006] EWCA Civ 392 (Admin)[62] (Sir Anthony Clarke MR).

⁵⁷ A. Ford, 'The Concept of Exceptionality: A Legal Farce?', *Med Law Rev.* 20, Issue 4 (2012), 317.

‘exceptional circumstances’. Thus, in *Ac*, the Berkshire West PCT having refused the prosthetic breast enlargement by a male-to-female transgender patient described their policy as considering cases that are significantly outside the normal range by comparing the patient with the cohort of patients with the same condition.⁵⁸ There needs to be a comparator for something to be exceptional against, with the baseline or comparator being the cohort of people with the condition. If the patient is one of the eligible group but cannot show relevant clinical circumstances by comparison with others in the group, then the case is not exceptional.⁵⁹ To define exceptional as requiring some unusual or unique clinical factor was, however, held to be unlawful in the case of *Ross*,⁶⁰ a case of a patient with multiple myeloma who had suffered serious drug side effects and requested a different drug treatment not made generally available by the health authority. Such definitions of exceptionality would disqualify any person automatically as long as he can be likened to another rather than being merely exceptional.⁶¹ Exceptionality was to be interpreted in its dictionary sense of being ‘out of the ordinary course’ or ‘unusual’ or ‘special’ rather than in the sense of being unique.⁶²

In view of these judicial pronouncements the ambiguity of the term exceptionality persists, as it will of course always be possible for other patients to emerge who are appropriately comparable. It will depend on how wide the group label is drawn and it will be more difficult to show exceptionality if the cohort is a large heterogeneous group of people.⁶³ Many questions remain unanswered by the case law. Thus, how unusual or special does a patient wanting to avail himself of NHS treatment or NHS procedures have to be to qualify? What is an exceptional case to qualify for treatment not generally available? Are requests by more than one patient for a particular treatment always automatically excluded from consideration for an individual funding request? Must there be a possible exceptional case for every treatment?⁶⁴ Moreover, are non-clinical factors to be regarded as irrelevant in the determination of exceptional or is there an overlap between clinical and non-clinical factors?

The case of *Condliiff*⁶⁵ considered the relevance of social factors in the determination of exceptionality for obtaining bariatric surgery. The patient had dia-

⁵⁸ *AC v. Berkshire Primary Care Trust* [2010] EWHC 1162 (Admin) [31].

⁵⁹ *Rogers*, (note 56), [65] and [82].

⁶⁰ *R (Ross) v. West Sussex Primary Care Trust* [2008] EWHC 1908 [28].

⁶¹ *Ross*, (note 60), [79].

⁶² A. Ford, ‘The Concept of Exceptionality’, (note 57), 319.

⁶³ *Rogers*, (note 56), [42].

⁶⁴ A. Ford, ‘The Concept of Exceptionality’, (note 57), 330-221.

⁶⁵ *R (Condliiff) v North Staffordshire Primary Care Trust* (2011) EWHC 872 (Admin).

betes and a number of other health problems such as renal impairment, hypertension and obstructive sleep apnoea. An attempt at weight loss using standard methods had been unsuccessful but for the health authority concerned the patient's BMI had not reached the threshold for routine funding and his case was therefore not considered exceptional. Mr Condliff applied for judicial review regarding the criteria set by the PCT for determining exceptionality that excluded social factors⁶⁶ arguing they contravened Article 8 of the European Convention of Human Rights (ECHR). The court held that the Social Factors Exclusion policy of the PCT did not violate Article 8, as it did not create a positive obligation in the context of an individual funding request.⁶⁷ The judge, however, did consider the possibility of social factors that had direct clinical implications, in contrast to non-clinical social factors.⁶⁸ However, the case does not clarify what factors would constitute clinical social factors, although the judge cited the IFR non-discrimination policy to include factors such as a person's religion, lifestyle, social position, family or financial status, or intelligence as possibly relevant to the clinical effectiveness of an intervention and the capacity of an individual to benefit. Therefore, one might ask whether it is not just a question of when a social factor takes on clinical significance.⁶⁹

Health authorities therefore often grapple with the difficult question of what constitutes exceptionality in a given case while at the same time having to strike a fair balance between the interests and choices of the individual and the community of patients.⁷⁰ Both, CCGs or NHS England, are of course entitled to set an IFR policy that reflects what they reasonably consider the fairest way of treating patients claiming exceptionality. However, since there is no overall *national* list of excluded low value or low priority treatments or procedures, some patients are receiving treatments in one CCG but not in another, the so-called post-code lottery.⁷¹ It should be apparent that different lists and the different application of exceptionality criteria make for a lack of equitable distribution of health care both in terms of a lack of geographical equity and of equity according to need.

⁶⁶ *Ibid.*, [14].

⁶⁷ *Ibid.*, [52] and [54].

⁶⁸ *Ibid.*, [20] and [23].

⁶⁹ A. Ford, 'The Concept of Exceptionality', (note 57), 320; C. Newdick, 'Resource Allocation in the National Health Service', *American Journal Law & Med* 23, Issue 2-3 (1997), 309.

⁷⁰ See further NHS England, *Individual Funding Requests of Specialised Services, a Guide for Patients*, www.england.nhs.uk/wp-content/uploads/2017/11/ifr-patient-guide.pdf, 20 November 2017.

⁷¹ Audit Commission, *Reducing spending*, (note 47), 2.

2.3 Relevant Principles in the Decision-Making Framework

Individual funding requests not only pertain to the consideration of the exceptional circumstances of a patient but CCGs need to consider a number of further criteria in arriving at the decision whether a particular treatment is to be paid for and how to reduce spending in a particular area. Although NHS England has developed guidance in this respect,⁷² different CCGs have developed their own framework of further principles and their definitions, in order to enable fair, consistent, and transparent decisions and decision-making. This framework includes factors such as equity, capacity to benefit, health care need, cost of the treatment, cost effectiveness, evidence of clinical effectiveness and any national policy guidance.⁷³

It is not surprising that as in *Condliff* the assessment of some of the more subjective notions such as a patient's health care need and a patient's capacity to benefit from treatment have given rise to difficulties in the determination of whether a patient's treatment request is granted. The different assessment of these factors and decision-making frameworks adopted by CCGs renders achieving an equitable health care system, subject to equity of access and to equity in terms of need, problematic. The analysis of need is dependent on the definition of its proxies, such as the severity of ill-health, social factors, age or time waiting for treatment as well as the patient's capacity to benefit.⁷⁴ These proxies are in turn open to subjective interpretations. Capacity to benefit, for example, apart from taking into account the likely response of a patient to treatment, is necessarily subjective and must take into account other elements such as age, clinical factors and clinical social factors. Besides, defining need in terms of capacity to benefit depends on whether one considers the stage of the illness at which the patient presents or the degree of ill-health. If one uses the former qualification then clearly patients presenting at an earlier stage of their illness have a greater chance of a better treatment outcome than patients presenting with more advanced disease. If need is defined in terms of a person's health status or degree of ill-health, then the later presenter has greater need than the early presenter.⁷⁵

While the interpretation of some of these factors for decision-making may be ambiguous, it is difficult to understand why there is so little agreement on

⁷² NHS England, *Items which Should not be Routinely Prescribed in Primary Care: Guidance for CCGs*, www.england.nhs.uk/publication/items-which-should-not-be-routinely-prescribed-in-primary-care-guidance-for-ccgs/, 30 November 2017.

⁷³ C. Newdick, 'Can Judges Ration with Compassion?', (note 53), 111.

⁷⁴ B. New, (note 13)

⁷⁵ A. Dixon et al., 'Is the NHS Equitable?', (note 11), 7.

criteria that seem much less open to interpretation. An example of the latter is the criterion of treatment effectiveness. A number of IFRs have been litigated in the courts on the question of effectiveness. In the recent case of *SB v. NHS England*,⁷⁶ a child with phenylketonuria and autism applied for treatment with the drug Kuvan to reduce the high phenylalanine levels in his blood, which were likely to lead to significant intellectual impairment. Because of his autism, these levels could not be controlled sufficiently by standard dietary treatment. Although there was overwhelming evidence of the clinical effectiveness of Kuvan in about 20% of patients, namely treatment sensitive patients, the CCG panel rejected the request without giving any reason for their conclusion. Andrews J found for the claimant on the grounds of irrationality of the decision and referred the case back for reconsideration by the health authority suggesting that the panel ought to take into consideration the prospective financial burden to the NHS were the child to suffer irreversible brain damage due to the ineffectiveness of dietary control.⁷⁷

Judicial review cases where the assessment and relevance of effectiveness are the issue are not unusual. To give some examples of court rulings where the criterion of effectiveness in the IFR consideration by the health authority was challenged:-

- In reaching a decision, the health authority should consider the nature and seriousness of each type of illness and the effectiveness of various forms of treatment.⁷⁸
- A decision, which seriously affects the citizen's health, will require substantial consideration and will be subject to careful scrutiny by the court.⁷⁹
- A health authority cannot simply determine that the procedure has no proven clinical benefit while giving no indication of why it considers that is so.⁸⁰
- A health authority may not simply dismiss responsible medical opinion, even if there are differing opinions on the effectiveness of a treatment. Such opinion is relevant and must be given proper weight.⁸¹
- The health authority needs to understand the clinical efficacy data and the quality of the evidence.⁸²

⁷⁶ *SB v. NHS England* [2017] EWHC 2000 (Admin).

⁷⁷ *Ibid.*, [91].

⁷⁸ *R v. North West Lancashire HA*, (note 50), 413; *Ross* (note 60), [34] and *SB v. NHS England*, (note 76), [90].

⁷⁹ *R v. North West Lancashire HA*, (note 50), 412 and *Ross* (note 60), [39].

⁸⁰ *SB v. NHS England*, (note 76).

⁸¹ *R v. North West Lancashire HA*, (note 50), 412.

⁸² *Ross*, (note 60), [84] and [85].

- Where there are differing opinions on clinical effectiveness and the health authority's conclusions are not irrational, the court will not decide which opinion is right.⁸³

These judicial pronouncements demonstrate that for CCGs the effectiveness criteria have not always been an absolute notion with scientific evidence sometimes insufficient to provide clear conclusions as to the benefits of a particular treatment.⁸⁴

Case law further demonstrates that the problem of equity of access to health care in England with variations in the allocation of health care by different CCGs in England is quite common.⁸⁵ Differences between health authorities are apparent regarding the availability of elective surgery, as in *Condliff*, and of interventions and treatments where effectiveness is contested or has not been established.⁸⁶ These differences exist because of the absence of clear national lists of treatments excluded from public funding, of unambiguous exceptionality criteria and because of the divergent decision-making frameworks in different CCGs. Thus, health authorities will continue to be exposed to the risk of legal action. Disgruntled patients will continue to challenge the refusal of their individual funding requests by applying for judicial review of the decision by the health authority. After all, patients are often aware of the NICE guidelines for their requested treatment or the assessment criteria in neighbouring health authorities and if they are not, their doctors will be. Thus, Mr. Condliff's North Staffordshire PCT did not follow the NICE guidance on bariatric surgery to provide surgery for patients with a body mass index of 40, or 35 in the presence of other illnesses such as diabetes, but also differed in its decision-making framework from that of two neighbouring PCTs.⁸⁷

From the point of view of the health authority, judicial review proceedings involve considerable expenditure in terms of finances and staff time devoted to the case.⁸⁸ It is therefore often the case that health authorities concede indi-

⁸³ *R. (Gordon) v. Bromley NHS Primary Care Trust* [2006] EWHC 2462 [31], *Ross*, (note 60), [36], *R (Murphy) v. Salford Primary Care Trust* [2008] EWHC 1908 (Admin) [6] and *AC v. Berkshire Primary Care Trust*, (note 58), [22] and [23].

⁸⁴ C. Newdick, 'Resource Allocation in the NHS', (note 69), 313 stressing that evidence may be incomplete, ambiguous or uncertain; A. Ford, 'The Concept of Exceptionality', (note 57), 331 and note 138; see also generally R. Veatch, *Patient, Heal Thyself: How the New Medicine Puts the Patient in Charge* (Oxford: OUP, 2009), ch. 3.

⁸⁵ J. Maybin and R. Klein, *Rationing*, (note 46), 37 give the example of a 38-fold variation in the rate of bariatric surgery between the populations of different health authorities.

⁸⁶ *Ibid.*, 37.

⁸⁷ A. Owen-Smith et al., 'A NICE example? Variation in the provision of bariatric surgery', *BMJ* 346 (2013), 2453, www.bmj.com/bmj/section-pdf/187908?path=/bmj/346/7909/Analysis.full.pdf, 25 May 2013.

⁸⁸ A. Ford, 'The Concept of Exceptionality', (note 57), 332.

vidual funding requests, which do not involve major treatment costs, simply to avoid the expense of court proceedings, the possibility of a negative outcome for the CCG and the risk of setting a precedent encouraging more potential claims.⁸⁹ According to data collected from a freedom of information request by the British Medical Journal 73,900 IFRs were made to CCGs in 2016-17, a 47% rise from 2013-14 when 50,2000 were made, while compared to 2015-16 the increase was 20% from 60,400 IFRs. In 2016-17, over half of the IFRs were approved.⁹⁰ No overall figures are available for 2017-18 but as regards the approval of IFRs specifically for knee replacement and for hip surgery there was a drop in the numbers approved but this may have been due to a considerable increase in the number of requests.

3. Judicial Review Challenges: Patient Choice versus Solidarity

One might assume that a health care system where such large numbers of individual funding requests are being made for treatment that is not generally available is a system where the principle of solidarity in face of rationing has been discarded. A solidarity-based approach in a severely cash-strapped health care system with a finite budget would mandate that the approval of IFRs is kept to a minimum and that unwarranted geographical variations are reduced. This is because such individualist demands for treatments as an expression of patient choice might be challenged as being in tension with health care, which aims to be universal and equitable.⁹¹

However, this may be an erroneous conclusion. Solidarity should not simply be viewed in juxtaposition to individualist patient choice where exceptional cases represent an opportunity cost with fewer resources available for all other patients. Rather individual funding requests and judicial reviews of refused requests have a role to play in ensuring that health authorities have to provide reasons when making resource allocation decisions and their decision-making is transparent. Moreover, the effects of judicial review do not only extend to the patient litigating but judicial review has an impact on the quality of decision-making by health care authorities. Furthermore, as Bondy et al. claim, judicial review generally makes a substantive contribution to the outcome of disputes between claimants and public bodies because outcomes are not symbolic or

⁸⁹ *Ibid.*, 25.

⁹⁰ G. Iacobucci, 'Surge in exceptional funding requests', *BMJ* 358 (2017), j3188, https://www.bmj.com/bmj/section-pdf/947166?path=/bmj/358/8113/This_Week.full.pdf, 8 July 2017.

⁹¹ B. New, *A Good Enough Service*, (note 1), 44.

formal but because public bodies engage with the issues raised and reconsider their decisions rather than merely correct them.⁹²

There are therefore tangible and intangible benefits from IFR cases even if they are rarely won by patients. However, even when they lose their case patients often feel more empowered and have greater confidence in the legal system.⁹³ Moreover, judicial review challenges can be viewed as a means of bringing pressure on health care institutions in their future rationing decisions. It follows that judicial review has major policy and reform consequences enabling improvements in the quality of the public decision-making and of the services by public bodies.⁹⁴ In this light, Sabel and Simon, for example, maintain that the implications of public law litigation go beyond the immediate parties to the action, that they have a destabilising effect on the status quo and on the entire health care system.⁹⁵ The need for transparency by the health authorities and the media interest in judicial review litigation opens the system to broader interests and voices and can be a means of bringing pressure on public institutions.⁹⁶ Thus, actual or threatened public law litigation destabilises, leads to public engagement, deliberation and negotiation, and may lead to a restructuring of practices and of health care institutions in the long term.⁹⁷ Platt et al. also found in the context of judicial review of local authority decisions that an increased level of challenge appears to lead to improvements in levels of performance and is therefore helpful to authorities, rather than a hindrance.⁹⁸ Rather than considering the actual or intended judicial review solely in terms of an individual's claim or grievance, public law litigation should therefore be seen as an incentive to change and expand the parameters governing the implementation of policies.⁹⁹ Consequently, patient choice, rather than solely benefiting the individual, can have positive effects on a much wider scale.¹⁰⁰

The apparent conflict between individualistic choice and solidarity, between individualist and collectivist values, is ameliorated further by policy-makers

⁹² V. Bondy, L. Platt & M. Sunkin, *The Value and Effects of Judicial Review: The Nature of Claims, their Outcomes and Consequences* (London: Public Law Project, 2015) 2.

⁹³ *Ibid.*, 62.

⁹⁴ *Ibid.*, 46.

⁹⁵ C. Sabel and W. Simon, 'Destabilisation Rights: How Public Law Litigation Succeeds', *Harvard Law Review* 117, Issue 4 (2003), 1017.

⁹⁶ B. Sheldrick, (note 52), 155–56.

⁹⁷ C. Sabel and W. Simon, (note 96), 1017.

⁹⁸ L. Platt, M. Sunkin & K. Calvo, 'Judicial Review Litigation as an Incentive to Change in Local Authority Public Services in England and Wales', *J Public Adm Res Theory* 20, Issue suppl 2 (2010), 1252.

⁹⁹ B. Sheldrick, (note 52), 156.

¹⁰⁰ M.K. Sheppard, 'Fallacy or Functionality: Law and Policy of Patient Treatment Choice in the NHS', *Health Care Analysis* 24 (2016), 279.

linking choice with people taking responsibility. The NHS where patients can make individual funding requests for treatment not generally on offer expects patients to become more active and more involved in their own care.¹⁰¹ Individuals are asked to take responsibility for their lifestyle choices in relation to health. A considerable number of government White Papers refer to the notion of responsibilisation. Thus, *High Quality Care for All* speaks of patients who are empowered by choice being more likely to take responsibility.¹⁰² Similarly in *Personal Health Budgets: First Steps* references are made to people having independence and choice but also responsibility,¹⁰³ and people exercising their choice around support for self-care.¹⁰⁴ The White Paper *Equity and Excellence: Liberating the NHS* suggests that patients, in return for greater choice and control, should accept responsibility for the choices they make¹⁰⁵ and the need for increasing self-care.¹⁰⁶ Likewise *Liberating the NHS: Greater Choice and Control* addresses responsibilisation as patients taking more responsibility for their health and treatment choices¹⁰⁷ and building ownership of, and a shared responsibility for, managing their conditions, especially where lifestyle changes may be needed.¹⁰⁸ Patients are therefore positioned not only as conscious choosers of possible treatments but also as choosers of their lifestyle, and must therefore take greater responsibility for making healthy choices.¹⁰⁹ The current NHS publication *Personalised Care: Implementing the Comprehensive Model* speaks of better self-care.¹¹⁰ The emphasis on the individual to assume responsibility for the management of her own health and health care is also encapsulated in the NHS Constitution: 'Please recognise that you can make a significant contribution to your own, and your family's, good health and wellbeing, and take personal responsibility for it.'¹¹¹

It is expected that making patients become more active and assuming responsibility for their health by encouraging self-care and self-management might lead to resource savings overall. Linking this responsibilisation of the patient to the traditional values of the NHS, one can take it a step further and

¹⁰¹ C. Needham, 'Interpreting Personalization in England's National Health Service: A Textual Analysis', *Critical Policy Studies* 3, Issue 2 (2009), 207.

¹⁰² Department of Health, *High Quality Care for All*, (note 25), 33.

¹⁰³ Department of Health, *Personal Health Budgets*, (note 25), 38.

¹⁰⁴ *Ibid.*, 30.

¹⁰⁵ Department of Health, *Equity and Excellence*, (note 2), 16.

¹⁰⁶ *Ibid.*, 46.

¹⁰⁷ Department of Health, *Liberating the NHS: Greater Choice and Control, a Consultation on Proposals* (HMSO 2010) 23.

¹⁰⁸ *Ibid.*, 4.

¹⁰⁹ I. Greener, 'Towards a History of Choice', (note 19), 322.

¹¹⁰ NHS England, *Universal Personalised Care*, (note 26), 14.

¹¹¹ Department of Health, *NHS Constitution*, (note 3), 11.

interpret it as a commitment to the value of solidarity. The shift to patients taking more control reduces their dependence on the NHS. Taking responsibility for one's health and health care is particularly relevant in respect of the increasing number of people living with chronic conditions.¹¹² Teaching individuals to identify challenges and to solve problems associated with their illness and enabling self-management represents a promising strategy. Self-management also shows potential by establishing a pattern for health early in life and providing strategies for mitigating illness and managing it in later life.¹¹³ Thus, the policy of patient responsabilisation has the potential benefit of reducing the costs of publicly funded health care¹¹⁴ while at the same time deepening the commitment to the value of solidarity.¹¹⁵

4. Conclusion

It is known that health authorities do accede to patients' IFRs because of the risk of costly and time-consuming litigation and the risk of setting new precedents creating further individualistic demands. They therefore spend resources on these rationed treatments, which, in turn, leads to disinvestment from other areas leading to the conclusion that individualistic patient choice erodes the solidarity-base of the NHS. However, as has been shown, patient demands for treatment and procedures not generally on offer by the NHS need to be considered in a much broader light. Not only are public bodies not at liberty simply to deny treatment requests but English law demands that the rationing policies of health authorities allow for exceptions in special cases and that health authorities account for the legitimacy, procedural propriety and reasonableness of their decisions. While judicial review imposes costs on public bodies, as Bondy et al. conclude, judicial review has much wider consequences. It enables improvements in the quality of public administrative decision-making and assists public bodies to meet their legal obligations. Apart from its effect on the nature and quality of decision-making, intended or actual litigation by patients demanding a specific treatment choice has further secondary effects. Thus, Simon and Sabel suggest that intended or actual litigation destabilises the health care system and leads to change and reform of the health care system.

¹¹² M.K. Sheppard, (note 101), 279-300.

¹¹³ P.A. Grady and L.L. Gough, 'Self-Management: A Comprehensive Approach to Management of Chronic Conditions', *Am J Public Health* 104, Issue 8 (2014), e25-e31.

¹¹⁴ K. Veitch, 'The Government of Health Care and the Politics of Patient Empowerment: New Labour and the NHS Reform Agenda in England', *Law & Policy* 32, Issue 3 (2010), 320.

¹¹⁵ C Needham, 'Interpreting Personalization', (note 102), 213 referring to New Labour's avowed aim to use personalisation in order to deepen solidarity and equity within the NHS.

Thus while it has been claimed that with its emphasis on patient choice the NHS has abandoned the founding principles of NHS comprehensiveness, universality and equity, this view may be too intransigent. Patient choice does not necessarily trump the principle of solidarity of the NHS as the potential ramifications of (intended) judicial review challenges of IFRs go beyond the parties to the action. Health authorities have to account for their rationing decisions in public but also actual or intended litigation makes the health care system accessible to broader interests leading to change and improvements. Furthermore, as has been argued, patient choice is not a free-standing concept but is linked by policy-makers and public bodies with an emphasis on patients taking responsibility for their own health. The NHS enables individualistic choice including IFRs but expects patients to become more involved in their own care with the avowed aim of reducing overall health care costs. Thus, it is possible to draw the conclusion that patient choice is an affirmation of a commitment to solidarity rather than its negation.