

Health care rights and NHS rationing: turning theory into practice

Article

Published Version

Creative Commons: Attribution 3.0 (CC-BY)

Open Access

Newdick, C. (2014) Health care rights and NHS rationing: turning theory into practice. *Revista Portuguesa de Saúde Pública*, 32 (2). pp. 151-157. ISSN 0870-9025 doi: 10.1016/j.rpsp.2014.07.001 Available at <https://centaur.reading.ac.uk/39044/>

It is advisable to refer to the publisher's version if you intend to cite from the work. See [Guidance on citing](#).

Published version at: <http://dx.doi.org/10.1016/j.rpsp.2014.07.001>

To link to this article DOI: <http://dx.doi.org/10.1016/j.rpsp.2014.07.001>

Publisher: Elsevier

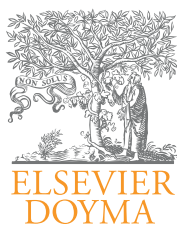
All outputs in CentAUR are protected by Intellectual Property Rights law, including copyright law. Copyright and IPR is retained by the creators or other copyright holders. Terms and conditions for use of this material are defined in the [End User Agreement](#).

www.reading.ac.uk/centaur

CentAUR

Central Archive at the University of Reading

Reading's research outputs online



Original article

Health care rights and NHS rationing: Turning theory into practice



Christopher Newdick

University of Reading, Reading, United Kingdom

ARTICLE INFO

Article history:

Received 19 June 2014

Accepted 22 July 2014

Available online 18 November 2014

Keywords:

Public rights

Procedural remedies

Substantive remedies

ABSTRACT

How should we understand the nature of patients' right in public health care systems? Are health care rights different to rights under a private contract for car insurance? This article distinguishes between public and private rights and the relevance of community interests and notions of social solidarity. It discusses the distinction between political and civil rights, and social and economic rights and the inherently political and redistributive nature of the latter. Nevertheless, social and economic rights certainly give rise to "rights" enforceable by the courts. In the UK (as in many other jurisdictions), the courts have favoured a "procedural" approach to the question, in which the courts closely scrutinise decisions and demand high standards of rationality from decision-makers. However, although this is the general rule, the article also discusses a number of exceptional cases where "substantive" remedies are available which guarantee patients access to the care they need.

© 2014 Escola Nacional de Saúde Pública. Published by Elsevier España, S.L.U. All rights reserved.

Os direitos em saúde e a racionalização no Sistema Nacional de Saúde Inglês (NHS): da teoria à prática

R E S U M O

Como compreender a natureza dos direitos dos doentes nos sistemas de saúde públicos? São os direitos em saúde diferentes dos direitos que são objeto de contratos privados de seguro automóvel? Este artigo distingue direitos públicos e direitos privados, bem como relevância do interesse comum e noções de solidariedade social. Este artigo discute também a distinção entre direitos civis e políticos por um lado e direitos económicos e sociais por outro, sublinhando a natureza inerentemente política e redistributiva destes últimos. Apesar desta natureza, os direitos económicos e sociais estão também na origem de "direitos" passíveis de serem feitos cumprir pelos tribunais. No Reino Unido (como em muitas outras ordens jurídicas) os tribunais têm favorecido uma solução jurídica "procedimental" para as questões aqui suscitadas, escrutinando de muito perto os decisores e exigindo-lhes elevados padrões de racionalidade nas suas decisões. Todavia, apesar de esta ser a regra

Palavras-chave:

Direitos públicos

Soluções jurídicas Procedimentais

Soluções jurídicas substantivas

E-mail address: c.newdick@reading.ac.uk

<http://dx.doi.org/10.1016/j.rpsp.2014.07.001>

0870-9025/© 2014 Escola Nacional de Saúde Pública. Published by Elsevier España, S.L.U. All rights reserved.

geral, discutem-se também neste artigo alguns casos de exceção onde soluções jurídicas “substantivas” foram adoptadas, garantindo aos pacientes, por essa via, o acesso aos cuidados de saúde de que necessitam.

© 2014 Escola Nacional de Saúde Pública. Publicado por Elsevier España, S.L.U. Todos os direitos reservados.

The National Health Service (NHS) in England^a works within a finite budget allocated to some 200 health authorities. State funding of the NHS matches the average of most European health care systems and is raised from general taxation (rather than insurance premiums paid to regulated health purchasers). As in any national system, the cost of the care we demand exceeds the resources we are willing to devote to health care. To some extent, therefore, in a tax-funded (or “Beveridgean” system) like the NHS, this is an electoral issue which reflects democratic choices about national spending priorities and taxation policy. This means that hard choices are required between competing demands for treatment because decisions to invest in some types of patients (e.g. children or elderly care), or treatments (e.g. CTC scanners or medicines), or diseases (e.g. cancer or mental illness) impose “opportunity costs.” Working within a finite budget, decisions to invest funds in one way preclude the opportunity for those funds being used another way. Public welfare austerity means that the mismatch between demand and supply is likely to become more severe and the consequences of opportunity cost more contentious. Once we acknowledge this challenge, it is legitimate to ask about the nature of “rights” to finite health care resources.

To do so, we should note the significance of public health care systems established to benefit the community as a whole and which are based on the principle of equal access for equal need. This is the principle of social solidarity so applauded throughout Europe, but viewed with suspicion by many in the US.^{b 1} In the US, political and economic success has arisen from a belief in the value of individual autonomy and a distrust of government (born of failing European governments from which earlier generations fled). Public welfare of this nature is sometimes referred to as “socialised” medicine, as if it is a social and political malaise. This difference is compounded when one considers that health care in the US has not generally been supported by a “system,” but rather on individual contracts of insurance with health care insurers. From that perspective it is akin to my motor insurance contract with the insurer of my car. If I am involved in an accident which is covered by my insurance contract, I expect my insurer to pay my compensation in full because the matter is subject to the rights contained in a *private* agreement. I do not expect to hear that my claim has been reduced because of the competing needs of other motorists.

There are different perceptions on either side of the Atlantic. In Europe, we do not agree that government is a necessary evil which should be restrained so far as possible to guard against the risk of enfeebling and undermining individual dynamism, initiative and self-reliance. We place greater faith in the benefits of standing together in respect of social welfare and this is the motivation for the ideas discussed here. I discuss (A) concepts of health care rights, and then (B) how those concepts have been turned into practice in the NHS.

A. Health care rights – the concepts

How should we conceptualise health care rights? Before turning to the NHS in particular, we examine some of the concepts which underlie rights of access to care arising within the NHS. We discuss the differences between (1) private and public rights, (2) negative and positive rights and (3) substantive and procedural rights.

Rights – private, or public?

We referred above to two different forms of legal rights when we compared my relationship to my motor insurer and to the NHS. If my rights are perceived to be essentially *private* legal entitlements (like my car insurance contract), then they should be immune from interference from others. I have a right to secure damages for my injury, or access to private health care irrespective of the rights of others. The matter arises simply between me and the other party. My legal relationship with my motor insurer is based on the terms agreed between us. The rights and obligations arise between two parties alone. Consequently, my claim against the insurance company arises in *private law*. Public interests are not engaged. If I am entitled to compensation, my claim rests on its own merits. The company must organise its business so that it can meet the legitimate claims of those it insures in full in accordance with its contractual obligations.

By contrast, my rights in the NHS arise in *public law*. Although patients have a distinct and enforceable “right,” it must be understood in a different way. I have no contractual relationship with the NHS. I pay no insurance premium and my entitlement to health care arises from a statute. My entitlements are not detailed in a specific list of treatments. Instead, the NHS has a duty to all those ordinarily resident in the UK to “promote a comprehensive health service.”² All citizens have equal (if non-specific) rights to NHS care. In this sense, although finite resources constrain private companies and public authorities alike, the duty of the NHS is different. The rights and duties are not agreed by the parties,

^a The health care systems of the four nations of the UK (England, Northern Ireland, Scotland and Wales) have been devolved to each of their jurisdictions.

^b Contrasting these two perspectives, see Callahan and Wasana, 2006.¹

but imposed on public authorities by statute. The duties so imposed are owed not simply to individuals whose interests are separate and severable from others, but to the community as a whole. Thus, in deciding how to accommodate the various claims made upon its finite budget, the authority is duty-bound to bear in mind the opportunity costs that arise in investing in one group of patients in preference to another. To this extent, its duties give rise to a different category of public rights. Claims arising in respect of health care entitlements are not made in Contract, but the law of judicial review. The remedy is not compensation, nor is it that the court should take the decision on behalf of the public authority because that statutory duty has been imposed on the public authority. Instead, the court's powers in these cases are normally to order that the public authority take the decision again and perform its duties properly.

Rights – negative, or positive?

This is explained by the further distinction between negative and positive rights. In principle, “negative” rights are rights to be let alone; to be free from unwarranted interference. Negative rights protect freedom of speech, freedom of association and religion. They are often described as civil and political rights which include democratic rights to free and fair elections. Negative rights are not “absolute”, are often intangible, and circumscribe the power of the state (except in connection with things like torture and inhuman treatment), but there is a strong presumption that they should not be restricted without good reason, the burden of proof being on the government to demonstrate good reason why the right should be restricted in some way.

By contrast, positive rights embrace rights *against* the state, i.e. to social welfare, health care and housing. Positive rights are referred to as social and economic rights, not to freedom from interference, but to some tangible benefit, and depend on the state having a system of taxation from which benefits are payable. Clearly, the distinction is far from simple. For example, the right to be let alone does not mean that negative rights are “free” and positive rights are costly. Negative rights involve considerable financial expenditure, for example to support the three branches of government. Also, the right to be let alone is complex. Free speech guarantees a free press, but the consequence for individuals may be considerable intrusion into private life in which we are not “let alone” at all. Note too that my negative right to be let alone by the state may also trigger a positive duty on the state to protect me if it knows I am at risk of danger from, for example, an unsafe system in the NHS, or a dangerous person. In these circumstances, it is placed under a positive duty to afford me suitable protection.

Undoubtedly, the positive/negative rights distinction can be messy, but it is coherent to this extent: public welfare entitlements cannot carry the same presumption of enforcement as rights to be let alone because they involve a different dimension of social and economic commitment. In respect of health care, for example, rights to informed consent and patient confidentiality can be conceived as negative rights enforceable by all equally. By contrast, rights of access to NHS treatment depend on funding decisions by the Treasury, the

Department of Health and local health commissioners. Within finite budgets, the extent to which we recognise one type of claim inevitably affects the resources available for others. Whereas negative rights should normally be recognised by the courts as substantive rights to the “thing” itself (e.g. freedom of the press), my positive rights to an enhanced pension, better public housing or expensive medical treatment inevitably impact upon the rights of other citizens. Entitlements of this nature are often mediated through parliament, rather than the courts, because they engage issues of distributive ethics and politics. At best, then, the difference between positive and negative rights is sometimes blurred and may be better understood on a spectrum rather than as black and white. Despite these misgivings, the potential for social and economic rights to impact on particular segments of society, and the greater difficulty of knowing whether judges are appropriate arbiters, merits the distinction when we discuss rights to social welfare, especially where significant opportunity costs are involved.

Precisely this point is acknowledged by the European Court of Human Rights when it was confronted with a case of a visitor to the UK (from outside the EU) whose permission to remain had expired. She was diagnosed with HIV and was receiving care in the UK during her stay. She argued that she should be entitled to remain in the UK order to continue her care within the NHS because adequate treatment would not be provided in her home country. The Court said no such positive right existed to the finite resources of a state's health care system under the European Convention on Human Rights. It said:

“Although many of the rights it contains have implications of a social or economic nature, the Convention is essentially directed at the protection of civil and political rights. Furthermore, inherent in the whole of the Convention is a search for a fair balance between the demands of the general interest of the community and the requirements of the protection of the individual's fundamental rights.”^c

Subject to having fair and reasonable systems for doing so, the proper place for balancing these interests was the contracting state itself, not an international court.

Rights – substantive, or procedural?

How, and to whom, should a public welfare system be held accountable? As we have noted, matters involving the distribution of social and economic rights in society are generally more amenable to democratic accountability through parliament than judicial arbitration. Nevertheless, to say that positive rights are “political” is not to say that the courts have no role to play. If we accept that social and economic rights create a different dimension of difficulty in respect of their enforcement, how can we preserve a system of judicial supervision which is not a mere sham, capable of ensuring that the system treats people fairly, equally and consistently? Procedural rights offer a way of both giving “rights” appropriate

^c N v United Kingdom (2008) (App no. 26565/05). On the need for fair and reasonable resource allocation systems, see also Van Kuck v Germany (2003) (App no 35968/97).

political recognition, yet placing the supervision of claims in the hands of the courts. How do rights work in these cases?

Because the duty is imposed on the public authority by statute, procedural rights normally lead only to judicial review capable of referring the decision back to the decision-maker to be reconsidered and re-taken in the light of the courts criticism. This must follow because the priorities identified in health care are matters of judgement for the public authority. NHS “commissioning” involves an infinite combination of polycentric trade-offs which require the exercise of discretion and about which there will be different views. For example, imagine we are commissioners with statutory duties to promote the health of a community of people. We know that elderly and disabled patients often receive less care than they need and that acute treatments grab bigger headlines in the media than long-term, chronic conditions. Should we seek to promote long-term objectives, e.g. to reduce obesity and coronary heart disease, knowing this may take years to generate results? Or should we focus on improving the survival rates of pre-term babies today by refurbishing the neonatal wards? Should neonatal care receive proportionately more funding than paediatric care, obstetric, or cancer care? Should we disinvest from acute care in hospitals to give greater support to community nurses dealing with chronic illnesses (such as heart disease, cerebro-vascular disease and arthritis)? Should we spend more on cancer drugs, or palliative care for cancer patients, or treatment for mental illness? Knowing we cannot do all these things, how should we prioritise? This acknowledges the complex nature of decision-making involving medicine, economics, social policy and politics. Judges have no special expertise in the substantive aspects of this area. Their role is to ensure that the process by which decisions have been made is robust and defensible. In this way, the courts should be able to give proper expression to procedural rights.

B. Accountability for rationing – the concepts in practice

How do these broad conceptual distinctions work in practice in the NHS? We discuss (1) judicial review and negligence, (2) procedural remedies, (3) the NHS Constitution and (4) exceptional substantive remedies.

Judicial review, or negligence?

First let us distinguish actions in medical negligence and judicial review. Negligence applies when clinicians are careless in the standard of treatment given to patients and cause damage. Negligence gives rise to a private action in which the patient's claim for damages is not affected by the impact of the claim on others. (This is so even though the damages are paid from the public authority's finite budget and will reduce the sums available to fulfil its public duties.) By contrast, judicial review is a public action against a public authority to review whether it has complied with the duties imposed upon it by statute, bearing in mind the flexibility permitted by the discretion discussed above. Judicial review may be taken on

one (or more) of the three grounds, i.e. that the decision was (a) *illegal* (for being ultra vires or otherwise contrary to law), (b) *irrational* (for taking into account irrelevant factors, ignoring relevant ones, or giving them disproportionate weight), and (c) *procedurally improper* (for failing to follow the procedures set down in the statute, or giving the claimant proper grounds to be heard under the rules of natural justice). (There are overlaps between each remedy and the same complaint may provoke all three actions.) The remedy is not normally damages. Instead, the claimant seeks an order to overturn (or, “quash”, but not reverse) the public authority's decision so that it is referred back to the decision-maker to be taken again. In legal theory, the decision-maker can come to the same decision again, provided the reasoning process is reviewed and repaired as suggested by the court. In practice, however, public authorities which fail to defend themselves in judicial review do not normally persevere with the same decision. Instead, they concede the claim and accommodate the demands made upon them.

As we have noted, the NHS in England is governed by the National Health Service Act 2006 which imposes on the Secretary of State a duty to promote a comprehensive health service. In turn, this duty is delegated to over 200 NHS commissioners responsible for promoting the care of the populations they serve. For this reason, most of the judicial review actions claiming access to NHS resources are brought against commissioners. The courts have developed a procedural remedy for “positive rights” actions of this nature, although substantive remedies are also available exceptionally.

Procedural remedy

Clearly, then, judicial review normally provides a procedural remedy. For example, in cases seeking access to health treatment, the court will test whether the decision is robust and can withstand logical scrutiny. Generalised rights to health care are sometimes called “target” duties which provide procedural remedies only. In one case, applicants for transgender surgery were refused access to treatment because evidence of the effectiveness of the treatment was not confirmed by randomised controlled trials. The court quashed the decision. The numbers seeking transgender surgery is still relatively small. It was irrational to demand that a treatment administered to so few could be assessed by trials involving many patients. Instead, the health authority should have assessed the reasoning of the doctors in the case.^d The health authority was not duty-bound to do what the doctors advised, but if it wished to depart from their advice, it had to have good reasons and be able to explain why. The decision was referred back to be taken again (after which the health authority reversed its decision and funded the treatment). On the other hand, in another case, transgender surgery was funded by the health authority in a male to female procedure. However, the claimant was not content with her absence of breast tissue and sought further funding for prosthetic breast implants. This request was

^d See *R v North West Lancashire Health Authority, ex p A, D & G* [1999] Lloyd's Rep Med 399.

rejected on the ground that the health authority normally refused “cosmetic” surgery because it was considered to be a low priority for NHS funding. The health authority reasoned that it would be unfair to other women who sought funding for a similar procedure to authorise payment for cosmetic surgery for transgender patients alone. The court agreed with the reasoning of the health authority and refused the claim.^e

A subtle matter of judicial politics is raised in respect of this procedural remedy. The question arises in connection with the intensity of the court's review. For many years before the mid-1990s, the style of judicial review in the UK was essentially passive and deferential. The extent of “trust” between the judiciary and executive was such that the norms of public authority “accountability” we take for granted today were weak. In a notorious case in 1988, a four-year old boy needed hole in the heart surgery and was placed at the top of his doctor's list of clinical priorities. Yet his surgery was cancelled twice by the hospital managers and his health was put in danger. The reason for the delay was a shortage of intensive care paediatric nurses. A claim for judicial review requested that the court order that the operation be performed. However, the court refused the application saying that it had no authority or expertise to manage the hospital's waiting lists.^f The boy died soon afterwards. The awful thing about this approach is the failure of the court to ask “why?” Why was a patient with such urgent need and clinical merit denied treatment? Even if there were nursing shortages, why was the boy not transferred to another hospital for treatment? This “passive” judicial review may be criticised for offering only a sham appearance of a “right”. Had the question been asked in this case, an appropriate clinical solution would surely have been found. By today's standards, in which scrutiny is the norm, the courts passivity was unwarranted.

However, if this is too weak, there may also be an equal risk in the opposite direction if judicial review is too intense. Bear in mind the purpose of judicial review is often to review the internal logic of a decision, the factors that have been considered and the proportionate weight allocated to each. In the nature of things, decisions may have to be taken in haste and, in hindsight, reasoning adopted yesterday could sometimes be improved today if everything was reconsidered afresh, especially under a bright forensic spotlight. If judicial review is intolerant of every slip in the process so that it would be rare for such a case to fail, then it effectively becomes a substantive remedy. This may be good for the individual applicants who succeed in achieving access to treatment, but what about the many others whose access to care is delayed, diluted, or denied as a consequence; and whose circumstances were never brought to the court's attention?

So there is a danger that over-enthusiastic courts may terrorise health authorities into conceding every claim made against them and of effectively favouring the “litigating” classes. Those that suffer as a result are often the less articulate elderly, mentally ill and disadvantaged groups of patients. Balance is crucial so that the courts are satisfied that the

decision-making process is robust, in the sense that it can explain the unenviable decisions it may have to make, but that is not to say that the court will always agree with every decision or that it could never be improved upon. Such a process has been encouraged over many years by NHS commissioners in the south of England according to an Ethical Framework within which difficult decisions about particular treatments have been taken.³ The Framework requires commissioners to assess: (a) evidence of clinical and cost effectiveness, (b) issues of equity, (c) patients' needs and the capacity to benefit, (d) costs and opportunity costs, (e) needs of the community, (f) government priorities and (g) the possibility of patients possessing exceptional circumstances. The process enables commissioners to demonstrate decisions are fair, transparent and consistent over time.

The Ethical Framework has been successful with respect to decisions about individual treatments and the costs they impose upon a limited budget during the year. But what about larger scale strategic planning? We have noted that public austerity is forcing difficult decisions upon government. One response to the need to control costs is to close some hospitals by focusing more care in the best hospitals, but enabling larger numbers of patients to be treated in the community, where it is less expensive. This is government policy, but it is hugely contentious. No-one welcomes the closure of a local hospital and whenever such a measure is proposed it is met with outcry and proceedings in judicial review. The remedy sought is normally based on a claim of procedural impropriety, i.e. that the procedures adopted in coming to the decision were defective and so the decision should be taken all over again. This is fine in principle. These decisions involve extended consultation with the public, the evidence of expert witnesses, and weighing and balancing highly detailed data. However, the documentation and process are highly complex and, in the nature of things, a detailed critique of the process in judicial review is likely to discover something that might have been done better. In a recent case, the court discovered such a flaw because the “scores” a hospital had been awarded for individual aspects of its performance by comparison to others had not been disclosed.⁸ But assuming that in many such complex cases some form of “impropriety” could be discovered if you looked hard enough, the courts could effectively block legitimate government policy in respect of NHS hospitals. This would surely take the courts outside their legitimate area of competence and trespass into an area of politics in which they have no business. It is another example of an apparently procedural remedy having a substantive impact and demonstrates the difficulty of extending ethical frameworks to strategic planning at national level. There should come a stage when the political component of the decision is more dominant than the ethics.

The NHS constitution

The need for balance between the individual, the community and the state is recognised by the English NHS in the NHS

^e *AC v Berkshire West PCT and the EHRC* (2010) 116 BMLR 125 (affirmed by CA, (2011) 119 BMLR 135 Civ 247).

^f *R v Central Birmingham HA, ex p Collier* (1988, unreported, CA).

⁸ *Save Our Surgery Ltd, R (on the application of) v Joint Committee of Primary Care Trusts* [2013] EWHC 439 (Admin) (07 March 2013).

Constitution,⁴ which is effectively a bill of rights for patients and those working in the NHS. The NHS Constitution recognises all the rights we have discussed above and imposes an obligation on commissioners to promote fairness and transparency in decision-making.^h Thus, although it does not create any new substantive rights, it requires each commissioner to publish a document explaining how it has made decisions to prioritise its resources, and with respect to individual patients, why a treatment decision has been made in their particular case. In addition, consistent with previous case-law, it requires commissioners to have a review process capable of accommodating patients who believe that their circumstances are sufficiently “exceptional” to justify their receiving treatment so that the merits of such a claim can be considered. “Exceptionality” will present difficulty because the clinical evidence to support such a case will often be equivocal and the costs of admitting too many will be unaffordable.

NHS Constitution rights are recognised by statuteⁱ and, consistent with judicial review, give applicants *procedural* rights in the sense that a failure to comply would enable the court to overturn the decision and refer it back to the decision-maker, or to insist that proper, transparent procedures are introduced in respect of health care priority setting (e.g. analogous to those contained in the Ethical Framework, discussed above).

Exceptional substantive remedies

Although the usual remedies in judicial review are procedural, substantive rights are available in a number of specific circumstances as exceptions to the general rule. First, if a statute confers particular substantive rights, then the judicial review court will provide a substantive remedy to enforce it. The most obvious cases concern *specific* entitlements to statutory financial benefit (e.g. specific pension, or welfare payments). However, a comparable case has also arisen with respect to the rights to liberty of mental health patients. Compulsorily detained patients have the right to have the lawfulness of their detention reviewed periodically by a Mental Health Review Tribunal established by statute for the purpose. Where a statute provided a specific time frame within which such a review should occur, it was not satisfactory for the Secretary of State to say that he had not appointed sufficient members of Tribunals to fulfil the duty. The case involved fundamental issues of the liberty of an individual (a negative right) who was subject to compulsory detention. The public authority was under a substantive duty to ensure the right to periodic review was exercised according to the time specified in the statutory regulations.^j The claimant was, therefore, entitled

to enforce his statutory right to have the lawfulness of his detention reviewed.

Second, even with respect to *generalised* or “target” rights, entitlements may become enforceable in the most extreme circumstances of personal hardship. In one case, an applicant for political asylum in the UK was forbidden by statute from taking paid work, or from claiming welfare benefit during the time the application was being considered. The applicant was reduced to living in the street in penury with no means of access to food or shelter. The House of Lords held that this was a breach of his human rights for being inhuman and degrading and that he was entitled to subsistence. In another case, a terminally ill man suffering HIV/AIDS was to be deported from the UK. His condition was being controlled in the UK. However were he to be deported, he would not have access to treatment during the period of time required to establish his health care rights in his native country (Portugal). This, the court said, would expose him to inhuman and degrading treatment contrary to his rights under the European Convention on Human Rights.^k

Third, the National Institute for Health and Care Excellence (NICE) is a statutory body created to advise health authorities as to the costs and benefits of medicines. It may publish *technology appraisal guidance* (TAG) in respect of a particular medical technology (i.e. medicine, or other pharmaceutical technology). TAGs have been given mandatory force under statutory regulations so that health authorities are duty-bound to fund the costs of TAGs within three months of the guidance being published if the treatment has been prescribed by a patient’s doctor.⁵ No case has yet challenged a health authority for refusing to fund the costs of a TAG. However, the prospects of success in judicial review would be good on the ground of illegality, i.e. that the authority had failed to comply with its statutory duty to support the costs of such care. In this case, the court would be entitled to award a substantive remedy by ordering that it do so.

Fourth, the European Court of Human Rights (ECHR) and European Court of Justice (ECJ) have also become involved in cases of this nature. The approach of the ECHR has been comparable to that adopted in judicial review, i.e. that every decision of this kind potentially involves sensitive issues of priority setting and opportunity costs and that these are better taken within the jurisdictions concerned, rather than a remote court sitting in Strasbourg.^l However, the European Court of Justice has taken a different view and insisted that patients generally have substantive rights to the health they need. If it cannot be provided within a reasonable time at home, then patients have a public right to obtain it elsewhere in the EU.^m This is attractive from an “individual” perspective, but given the factors we have considered above, in terms of the need

^h See the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012, SI 2012, No 2996, Part 7.

ⁱ See the Health and Social Care Act 2012 and the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012, SI 2012, No 2996.

^j *R (KB) v MHRT and Secretary of State for Health* [2002] EWHC 639; *Tomlinson v Birmingham City Council* [2010] UKSC 8.

^k *R (Limbuela) v Secretary of State for the Home Department* [2007] 1 All ER 951 and *R (Almeida) v Kensington and Chelsea BC* (2012) 127 BMLR 82. Note the difference between these cases and *N v United Kingdom* (2008) (App no. 26565/05), discussed above, where treatment was denied because the patient was not in extremis. The distinction between these cases is not wholly convincing.

^l *Pentiacova v Moldova* (2005) 40 EHRR 209.

^m *R (Watts) v Bedfordshire PCT* Case (2006) ECJ, C-372/04.

to set priorities and have regard to the impact of spending policies on the community as a whole, it has obvious funding implications and the rights of patients at home. Oddly, the ECJ has never explained the reason for this conclusion. It is stated as a “fact” of EU law flowing from the right to freedom of movement of services between the member states. The Court has not clearly discussed the opportunity costs arising from its judgments, especially on those who are too ill, elderly, or disabled to take the benefit of the right. Given the uncertainty this has created, the European Commission has passed a complex Directive on Patient Mobility which seeks to balance the “individualistic” approach of the ECJ with the communitarian way in which European health care systems are funded.⁶ We await to see how the balance between these sometimes incompatible objectives is achieved.

Conclusion

Health care resource allocation, the prioritising of patients’ rights, is inherently a political question. How should the largesse available to government be distributed amongst its citizens? Arguments about social and economic rights involve issues of politics, economics, morality, ethics and so on. In this arena, we require different mechanisms to resolve disputes. They involve competing claims between individuals and have consequences for others very different from private rights. We have discussed the extent to which law should be involved in political disputes of this nature. We have seen the UK response in judicial review is to have developed a particular notion of “procedural” rights. Procedural rights are certainly rights and carry their own specific legal remedies. They impose duties on commissioners to consider relevant information openly, fairly and consistently. Procedural rights have the benefit of enabling the courts to detach themselves from the “politics” of deciding which group of patients, or which treatments, should take priority over others in the competition for socio-economic rights.

We have also noted, however, that the precise dividing line between procedural and substantive rights is often blurred. Judges are human and will sympathise with many of the

claims that come before them. Unsurprisingly, they may find ways of imposing procedural pressures on decision-makers which effectively create a substantive remedy. To some extent this is inevitable and we are familiar with the debate about the proper role of judges. Equally, in times of welfare austerity, when difficult decisions are forced upon us, courts must respect decisions which reflect government policy. Judges are well-equipped to adjudicate over claims involving individuals alone. However, issues of health care rights involve community substantive interests and the rights of those unknown to the courts. This requires a different approach based on procedural principles of transparency, equality and consistency. Unless we are clear about the distinction, claims to public welfare are likely to undermine the interests of the most poorly represented groups whose rights are most in need of protection.

Conflicts of interest

The authors have no conflicts of interest to declare.

REFERENCES

1. Callahan D, Wasana A. *Medicine and the market: Equity v. choice*. Baltimore: John Hopkins University Press; 2006.
2. NHS. *National Health Service Act: Section 1*. London: NHS; 2006.
3. NHS. South Central Priorities Support Unit Steering Group. [Internet]. South Central Ethical Framework. London: South Central Priorities Support Unit Steering Group; 2011. Available from: <http://www.oxfordshireccg.nhs.uk/wp-content/uploads/2013/03/Ethical-Framework.pdf> [accessed 20.12.13].
4. NHS. *National Health Constitution*. London: NHS; 2013. The first edition was introduced in 2009.
5. UK Department of Health. *Directions from the Secretary of State*. London: Department of Health; 2003.
6. European Parliament. *European Directive on Patients’ Rights in Cross Border Healthcare*. Brussels: European Parliament; 2011 (2011/24/EU).