

LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



LSHTM Research Online

Mold, A; (2012) Patients Rights and the National Health Service in Britain, 1960s-1980s. American journal of public health, 102 (11). pp. 2030-8. ISSN 0090-0036 DOI: <https://doi.org/10.2105/AJPH.2012.300728>

Downloaded from: <http://researchonline.lshtm.ac.uk/285486/>

DOI: <https://doi.org/10.2105/AJPH.2012.300728>

**Usage Guidelines:**

Please refer to usage guidelines at <https://researchonline.lshtm.ac.uk/policies.html> or alternatively contact [researchonline@lshtm.ac.uk](mailto:researchonline@lshtm.ac.uk).

Available under license: <http://creativecommons.org/licenses/by-nc-nd/2.5/>

<https://researchonline.lshtm.ac.uk>



# Patients' Rights and the National Health Service in Britain, 1960s–1980s

| Alex Mold, PhD

The language of rights has long permeated discussions about health care in Britain, but during the latter half of the 20th century, patients' rights achieved a level of unprecedented prominence. By the end of the 1980s, the language of entitlement appeared to have spread into many areas of the National Health Service: consent to treatment, access to information, and the ability to complain were all legally established patients' rights. Patient organizations played a critical role in both realizing these rights and in popularizing the discourse of rights in health care in Britain. "Rights talk," however, was not without its drawbacks, as it was unclear what kinds of rights were being exercised and whether these were held by patients, consumers, or citizens. (*Am J Public Health*. 2012;102:2030–2038. doi:10.2105/AJPH.2012.300728)

**THE IDEA THAT PATIENTS HAVE** rights in relation to health care is a powerful one, but it is a concept that has often generated problems when put into practice. As recent debates about health care reform in the United States make plain, both supporters and detractors of universal health care have been able to use the language of rights to make their case.<sup>1</sup> The application of rights to health is no less challenging, however, in countries that do have systems guaranteeing population-wide access, such as Britain with its National Health Service (NHS). In

January 2009, the Labour government introduced the *NHS Constitution for England*, a document that set out a series of rights, responsibilities, and pledges designed to embody the "principles and values" that guide the NHS. Patients were told that they had 25 rights, encompassing areas such as access to health services; quality of care and the environment; access to nationally approved treatments; respect, consent, and confidentiality; informed choice; involvement in their own health care and the wider NHS; and complaint and redress.<sup>2</sup> The *NHS Constitution*, it was claimed, brought together "in one place for the first time in the history of the NHS what staff, patients and public can expect from the NHS."<sup>3</sup>

Although the introduction of the *NHS Constitution* was an important development in the reform of British health care under New Labour, it was certainly not the first attempt to formulate a list of patients' rights, or to use these to shape the future of health services. From the 1960s

onwards, a number of organizations claiming to represent the patient, such as the Patients Association, the Consumers' Association, the National Consumer Council, and the Community Health Councils, drew on the language of rights to put forward their demands. Concerns about patients' ability to complain, their access to information, and the presence of medical students during consultations and treatment were framed around the concept of rights. Patient organizations also expended much time and energy drawing up patients' charters and guides to patients' rights within the NHS. But where did this language of rights come from? What did it mean to talk about patients' rights in the context of a collective health system like Britain's NHS?

In this article, I explore how the language of rights came to enter the discourse around British health care in the 1960s, and how it was developed and applied by patient groups in the 1970s and 1980s. Drawing on the papers of patient organizations,

government records, newspapers, and medical journals, I suggest that although the language of patients' rights held rhetorical power, putting such language into practice was to prove deeply problematic.

## RIGHTS AND HEALTH IN BRITAIN

Three distinct, but overlapping, visions of health rights were articulated in Britain during the second half of the 20th century: health as a human right, as a citizen's right, and as a consumer's right. The notion that health is a fundamental human right—that it is a right that individuals possess simply by being born—is almost as old as the notion of human rights itself. Most commentators place the “invention” of human rights in the 18th century, and although the right to health was not among the initial rights established by the French National Assembly, it was added to the list of the state's obligations to its citizens by the Constituent Assembly in 1791.<sup>4</sup> In Britain, there was no such bargain between the state and citizen, and it was not until the United Nations Universal Declaration of Human Rights in 1948 that the right to health was contemplated on a global level. The UN Declaration asserted that “Everyone has the right to a standard of living adequate for health and well being of himself and his family, including food, clothing, housing and medical care.”<sup>5</sup> The right “to the enjoyment of the highest attainable standard of physical and mental health” was also central to the establishment of the World Health Organization in 1946, and was enshrined in international law through the International Covenant on Economic,

Social and Cultural Rights, which came into effect for member countries in 1976.<sup>6</sup> During the 1970s, the idea that health was a fundamental human right received added impetus from the Alma Ata Declaration on Primary Care in 1978, and through the international public health movement.<sup>7</sup> Health as a human right became linked to development goals in the 1980s and, since the 1990s, to combating HIV/AIDS.<sup>8</sup>

Although the notion of health as a human right was significant at the transnational level, in the United Kingdom the notion of rights in health took a rather different trajectory over this period. Instead of being concerned primarily with human rights, the rights discourse in Britain seemed to focus more on the rights of citizens. This could be partly explained by long-running discussions about individual rights within health in the United Kingdom. In the medical marketplace that predated the NHS, patients had contractual and common-law rights relating to health care, as with other goods and services.<sup>9</sup> Even within charitable provision, subscribers to hospital contributory schemes were entitled to some say in the way in which the institution was managed through representatives on hospital management committees.<sup>10</sup> Entitlement also lay at the heart of the gradual development of state-sponsored health care in Britain, up to and including the establishment of the NHS. The National Health Insurance Act of 1911 introduced compulsory health insurance for manual workers. In return for their financial contribution, members received benefits when sick and access to medical care without additional payment.

The National Health Insurance Act has often been seen as a harbinger of the NHS, but the precise form Britain's health system should take was the subject of much debate throughout the 1930s and 1940s.<sup>11</sup> The service that emerged was based not on insurance contributions and individual entitlement, but on the universal principle that all citizens were eligible for care regardless of whether they had paid directly toward the funding of the service. Such a collective system (at the time unique to the United Kingdom) implied a more collective view of rights with respect to health. Although the National Health Service Act (1946) was framed around the duty of the minister of health to provide a comprehensive service, not the right of the patient to receive this, the message that reached the public emphasized universal entitlement.<sup>12</sup> A leaflet distributed to all homes in 1948 asserted that the new service would “provide you with all medical, dental and nursing care. Everyone—rich or poor, man, woman or child—can use it or any part of it.”<sup>13</sup> Underpinning such promises was the notion of social rights. For the sociologist T.H. Marshall, social rights permitted the citizen access to a minimum supply of essential social goods and services (such as medical attention, shelter, and education), to be provided by the state.<sup>14</sup> The NHS, and the other achievements of the “classic” era of the British welfare state (1945–1975), appeared to offer a kind of social citizenship based on collective rights.<sup>15</sup>

Interwoven with ideas about the health rights of citizens was another set of expectations: the rights individuals could demand as consumers. The relationship

between citizenship and consumption has been the subject of much research in recent years, and the activities of citizen-consumers can be detected as far back as the 19th century and beyond.<sup>16</sup> By the middle of the 20th century, however, citizen and consumer identities were becoming welded together more tightly. The establishment of the Consumers' Association in 1956 was a significant point in the development of the organized consumer movement in Britain, introducing comparative testing and consumer activism based on rational principles. The activities of the Consumers' Association and other consumer groups helped to shift consumerism "beyond things," encompassing public goods and services as well as private ones.<sup>17</sup> By the 1960s and 1970s, this approach had found purchase inside government. Organizations like the National Consumer Council were created in 1975 to represent the consumer within public services. State-provided amenities, from housing to health care, were being discussed in increasingly consumerist terms.<sup>18</sup>

Such a language held special relevance for the NHS. Few major alterations to the health service were attempted during the 1950s, but the period from the 1960s to the mid-1970s witnessed an era of technocratic change. A series of measures were introduced to improve the efficiency and effectiveness of the NHS, culminating in a complete structural reorganization in 1973.<sup>19</sup> As part of this reorganization, 207 Community Health Councils were established at the local level to be the "voice of the consumer" inside the health service.<sup>20</sup> Consumer representation within the health service was in line with the general trend

toward the improvement of citizen-consumer representation, but could also be seen in the light of a number of high-profile failings of the NHS. Particularly significant was the revelation that NHS patients were routinely being used in medical trials without their knowledge or consent. The publication of an article (and later book) entitled "Human Guinea Pigs," which charted some of these experiments, prompted Helen Hodgson, a teacher, to set up the Patients Association in 1963.<sup>21</sup> Although patients were supposed to give their consent to participate in medical trials (following the Nuremberg Code), this was widely ignored both in the United Kingdom and in the United States.<sup>22</sup> For Hodgson, the key issue was that "Patients are not told if they are receiving new or orthodox treatment. I maintain that they *should* be told."<sup>23</sup> The patient, she asserted, "is entitled to know what treatment, if any, he is receiving."<sup>24</sup> The Patients Association was therefore keen to establish the right of the patient to consent to all treatment, whether experimental or not.

The demand for bodily autonomy made by the Patients Association echoed the kinds of rights claims made by the new social movements of this period. As the feminist historian Shelia Rowbotham commented, "Rights were not abstract or about politics alone, they were active and about sex as well as economics."<sup>25</sup> This wider conception of rights was crucial for dealing with the problems of "quality of life, equality, individual self-realization, participation and human rights," representative, for Jurgen Habermas, of a "new" form of politics.<sup>26</sup> The rights claims of the 1960s and 1970s were thus a different kind of rights claim to

that of the past, rooted not in transactional contracts and the market place, or in the social contract between state and citizen, but in the politics of everyday life. Rights discourse became a way in which individuals could articulate new demands about their ability to determine how they lived, and about the fate of their bodies. A space for the individual, autonomous patient seemed to be opening up. And, by drawing on a language of rights, this patient appeared to have found a powerful means of self-assertion.

## PATIENT ORGANIZATIONS AND PATIENTS' RIGHTS

Rights claims were essential to the work of a number of groups that attempted to represent the patient as consumer in the latter half of the 20th century. During the 1970s and 1980s, health consumer groups produced a range of guides to patients' rights. Publications included the Patients Association's *Can I Insist?* (1974); the Consumers' Association's *Guide to Your Rights* (1980); a joint Consumers' Association–Patients Association publication, *A Patients' Guide to the NHS* (1983); the National Consumer Council's *Patients' Rights* (1983); and the Association of Community Health Councils in England and Wales's *Patients' Charter* (1986).<sup>27</sup> Such a proliferation of documents listing patients' rights can be read in two ways. On the one hand, the abundance of charters points to the importance of the language of rights for patient groups, but on the other, the apparent need for these rights to be stated and restated in multiple publications would suggest that there was widespread ignorance about patients' rights.

Indeed, in some ways, the large number of charters produced by patient organizations hinted at the fragility and dubious legality of many of the rights proposed. Despite claiming to be comprehensive guides to the rights that patients held, many of these publications confessed to confusion and uncertainty about the nature and legitimacy of patients' rights. The National Consumer Council stated that

it is difficult to say precisely what health care patients are entitled to expect of the National Health Service (NHS). There are clues, but most of them are open to different interpretations, and circumstances greatly affect cases.<sup>28</sup>

This was partly because, as the Consumers' Association observed in their guide to consumers' rights across a range of different services (both public and private):

There is no comprehensive list of rights which you can consult, nor is there any specific area of law that deals with them. Your rights are scattered among hundreds, perhaps thousands, of Acts of Parliament and secondary pieces of legislation. . . . Sometimes your rights are not written down at all. They may exist because of custom and tradition, or merely because there is nothing saying that they are absent.<sup>29</sup>

Indeed, most of the rights listed in the various guides and charters had no or little legal basis. A legal conception of rights was not the only way of viewing patients' rights, and legalistic notions of rights have often been criticized for being too narrow in their focus.<sup>30</sup> Nonetheless, the legal development of patients' rights was significant, as this indicates the extent to which these rights were being taken up by other actors, most importantly by the state. During the early 1970s, the

Patients Association attempted to get a formal Patients' Rights Bill established. The association was particularly concerned about the practice of using patients in teaching hospitals for the purposes of medical education without their consent. As the leader of the Patients Association, Helen Hodgson, remarked in the *Daily Express*, patients "are not cranks or prudes. They simply want to be treated as humans—not as specimens. They want the right to preserve their human dignity and modesty."<sup>31</sup>

The association believed that the patient should also have a right to refuse to participate in teaching if they so wished, and they lobbied Members of Parliament (MPs) to get them to introduce legislation on the issue.<sup>32</sup> In April 1974, the Patients Association succeeded in sponsoring a bill in the House of Commons.<sup>33</sup> The Patients Rights Bill was intended to "Establish the rights of patients to privacy when receiving hospital treatment under the National Health Service," and it proclaimed that patients had a "right to receive all forms of hospital treatment without any person being present other than those who are necessarily concerned in the provision of that treatment."<sup>34</sup>

The Patients Rights Bill did not pass, partly because health ministers thought that the issue was an unsuitable subject for legislation, and officials believed that the bill was poorly drafted.<sup>35</sup> But there were also more fundamental reasons why the bill failed. Health officials had actively discouraged the use of the language of rights when devising a memorandum on the cooperation of patients in the teaching of medical students. Early drafts of the document included reference to the

patient's "right to refuse" to being used in teaching, but civil servants were unsure if any existing legislation actually gave patients a legal right to refuse.<sup>36</sup> Indeed, during the 1960s and 1970s, patients had few if any legal rights. Patients did appear to have a right to consent to treatment, which had grown up through case law, but unlike in the United States, there was no single British law requiring individuals to give consent to medical treatment.<sup>37</sup> Medical practitioners could be sued for

*“During the early 1970s, the Patients Association attempted to get a formal Patients' Rights Bill established. The association was particularly concerned about the practice of using patients in teaching hospitals for the purposes of medical education without their consent.”*

battery if they performed an examination on a patient without his or her consent, or they could be sued for negligence if they did not sufficiently explain the risks associated with a procedure. Some commentators argue that even today British patients do not have a formal right to consent, although seeking consent is now common practice, and this is somewhat strengthened by the Human Rights Act (1998).<sup>38</sup>

The failure of the Patients Rights Bill did not stop patient groups in their attempts to establish formal rights for patients. Two areas where patient organizations had more success were in establishing a right to access to medical records and in creating a right to complain. The right to access to medical records was introduced through two pieces of legislation—the Data Protection Act (1984) and the Access to

Health Records Act (1990)—that gave patients the right to see their own computerized and paper-based medical records.<sup>39</sup> The introduction of this legislation was driven partly by the activities of patient organizations and also by European Union directives that required member countries to open up data to individuals.<sup>40</sup> The development of the right to complain, as will be seen, was not any more straightforward.

### THE RIGHT TO COMPLAIN

Of course, patients in Britain have probably always complained about elements of the medical care that they received, but a centralized, coordinated system for dealing with these complaints is a much more recent invention.<sup>41</sup> Patients were able to complain about an individual doctor's conduct to the General Medical Council. The council, however, was not primarily a machine to handle patients' complaints but a regulatory body for doctors.<sup>42</sup> There was a system in place to deal with complaints made against general practitioners: patients could complain to the Executive Councils, later Family Practitioner Committees, and have their case heard by the local Medical Service Committee, which acted as a judicial tribunal.<sup>43</sup> However, there was no single system in place for complaints about treatment in hospital. Until 1966, when a Ministry of Health circular was issued, there was no official guidance on the establishment of hospital complaints procedures, and as a result these varied significantly from hospital to hospital. Even after the circular, much was left to local discretion, doctors handled complaints about other doctors, there was

little or no external oversight, and the complaint procedures themselves were not binding.<sup>44</sup>

Despite these difficulties, patients seemed to be becoming more willing to complain. Although patients' satisfaction with the NHS was generally high in this period—in 1961, Political and Economic Planning reported that 86% of patients surveyed were satisfied with their general practitioner—complaining was on the increase.<sup>45</sup> Between 1967 and 1971, the total number of written complaints investigated by hospital authorities in England and Wales rose from 7984 to 9614. This represented a slight rise in complaints per 1000 discharges: from 1.59 in 1967 to 1.75 in 1971.<sup>46</sup> Furthermore, written complaints were likely to represent just a fraction of the total number of complaints made. Research in Scotland found that 25% of patients interviewed in hospital claimed to have made some sort of suggestion about “desired improvements.”<sup>47</sup> The fact that few of these criticisms translated into formal complaints says rather more about hospital complaints procedures than unwillingness on the part of patients to complain.

The issue of patients' complaints was given added impetus in the wake of a series of medical scandals in the late 1960s and early 1970s, which exposed not only poor-quality care but also the inadequacy of complaints procedures. Public inquiries into long-stay treatment of the elderly and the mentally ill at Ely Hospital, the Farleigh Hospital, and the Whittingham Hospital all pointed to the suppression of complaints, the victimization of staff who complained about the treatment of patients, and the failure of members of the hospital

management committee to provide adequate safeguards or means of redress for complainants.<sup>48</sup> A coordinated, fair, open system for making complaints was clearly required.

The task of providing guidance on the establishment of a complaints procedure was given to a governmental committee chaired by Sir Michael Davies, a senior lawyer and later High Court judge. Established in 1971, the Davies Committee was made up of individuals from a diverse array of professional backgrounds, but what was particularly significant about the committee's membership was that doctors and other health professionals were in the minority: of the 17 committee members, only three were doctors. This mixed membership suggested a real willingness to investigate the complaints issue from the perspective not only of the doctor but also of the patient. This can also be seen in the way in which the Davies Committee conducted its investigation. It did hear from the various professional bodies and royal colleges, but the committee also sought the views of a number of patient groups, including the Patients Association and the National Association for the Welfare of Children in Hospital.<sup>49</sup> The opinions of these organizations were also reflected in the committee's final report.

Indeed, the Davies Committee was keen to place its findings within the context of growing consumerism. The report commented:

This is an age in which the legitimate interests of the consumer, who in the hospital service is the patient, are rightly receiving increased protection in many fields. . . . We see no reason why these general principles should not apply to the hospital service.<sup>50</sup>

Moreover, the committee contended, “Few [patients] have any serious grievances. But those who do have the legitimate right—no less—to have their dissatisfaction fully and fairly investigated.”<sup>51</sup> This was an important statement. The Davies report appeared to be the first significant step toward establishing a right for patients to complain.

Yet the fate of the report tells a rather different story. Overall, the Davies Committee made 82 separate recommendations and proposed a complex and legalistic complaints procedure based on a tribunal system. They also separated out clinical and nonclinical complaints, leaving doctors to investigate allegations about medical mistakes. Despite this concession to professional self-regulation, the report was not well received among the medical community. The joint Medico-Legal Subcommittee of the Central Committee for Hospital Medical Services of the British Medical Association and the Joint Consultants Committee argued that the report implied that “every encouragement be given to all citizens . . . to make a suggestion or complaint, not only when it is reasonable, but on any occasion, however trivial.” The effect of this atmosphere of complaining, they contended, would be “to damage the service profoundly and to the detriment rather than to the advantage of the community in which it exists to serve.”<sup>52</sup> The Council of the British Medical Association and the Joint Consultants Committee told Sir Henry Yellowlees (the chief medical officer) that “no part of the proposals put forward by the Davies Committee can be considered as acceptable to the medical profession until the considered view of the Association has been submitted.”<sup>53</sup>

Despite the fact that the British Medical Association had given evidence to the Davies Committee, doctors were obviously unhappy with its findings. By contrast, patient groups were broadly supportive. For example, the Patients Association “welcome[d] the constructive nature of the report and its sympathetic approach to the anxieties and preoccupations of patients.”<sup>54</sup> But the reception of the Davies report illustrated the relative lack of power of patient groups compared with professional groups. As Charles Webster noted, support for the Davies report “derived from the relatively powerless consumer groups, whereas within the NHS it possessed few friends and many powerful enemies.”<sup>55</sup> The report, according to the sociologist Margaret Stacey, was met with “thundering silence” and long delay.<sup>56</sup> A draft code on hospital complaints procedure was produced in 1976, and this was followed by another consultation document in 1978. In 1981, a Department of Health circular was issued to all hospitals, but the complaints procedure was still a draft and not compulsory. It was not until 1985 and the passing of the Hospital Complaints Procedure Act (12 years after the Davies report) that hospitals were actually required to have any sort of complaints procedure in place.

Moreover, even the creation of this piece of legislation was due to serendipity as much as design. In January 1984, the Conservative MP for Newbury, Michael McNair-Wilson, was taken seriously ill with kidney failure.<sup>57</sup> Following months of hospitalization, and a number of medical mishaps, McNair-Wilson published a “Patient’s Charter” which

he hoped would redress the power imbalance between doctors and patients “by laying down certain basic patients rights which will apply to every person.”<sup>58</sup> Although he was unfortunate to have been so unwell, McNair-Wilson was lucky enough to have his name drawn in the members’ ballot in 1985, allowing him the opportunity to put forward a piece of legislation.

Most MPs, when given this chance to get their name on the statue books, opted to put forward a technical piece of legislation that the government wished to see passed but that was not significant enough to be included in the main legislative program.<sup>59</sup> Lots of important legislation has been passed through private members bills, particularly on social and moral issues, such as the Abortion Act in 1967, but most of these bills resulted from pressure group lobbying. However, this does not appear to have been the case with the Hospital Complaints Procedure Act: patient-consumer groups had no direct involvement in the creation of the act. Instead, McNair-Wilson acted alone. According to Mulcahy, who interviewed McNair-Wilson before he died in 1993, the MP had wanted to use his bill to get his entire charter made into legislation, but the secretary of state for health told him that he would get government backing only if he selected just one clause from the charter to form a bill.<sup>60</sup> McNair-Wilson chose the introduction of a complaints procedure; this was duly translated into legislation, and passed unopposed in February 1985.<sup>61</sup> The Hospital Complaints Procedure Act required health authorities in England and Wales and health boards in Scotland to establish a complaints procedure

and bring it to the attention of patients.<sup>62</sup> The Department of Health drafted further guidelines on complaints procedure, and these were finally issued to all hospitals in 1988.<sup>63</sup>

## CONCLUSIONS

The introduction of the Hospital Complaints Procedure Act might seem like a rather small victory given the amount of interest in the notion of patients' rights in general, and the right to complain in particular, during this period. Although there is some evidence to suggest that the notion of patients' rights was beginning to be taken up by other actors, significant questions can be raised about whether the use of rights language actually demonstrated a shift in the power balance within British health care. It might have been largely due to chance that the Hospital Complaints Procedure Act entered the statute books, but it is possible to argue that without the broader discussions about patients' rights and complaining, and specifically the work of patient groups in producing patient guides and supporting complainants, McNair-Wilson would not have written his charter. Patient-consumer groups helped produce a language of patients' rights that was then taken up by politicians, as can be seen in the later establishment of the *Patient's Charter* by the Department of Health in 1991.<sup>64</sup> Patient-consumer groups were suspicious of the *Patient's Charter*, however, and the way in which the government appeared to have adopted their language of patients' rights and put it to a new purpose.<sup>65</sup> The Association of Community Health Councils in England and Wales, for example,

argued that the *Patient's Charter* should

do far more to address important issues at the heart of the health service—equality of access to health care, the scope for patient participation on the basis of informed choice and the quality of care and treatment.<sup>66</sup>

The consumer leader Michael Young criticized the charter because it lacked “the means to make the rights effective.”<sup>67</sup> Although the impetus for patients' rights originated with patient groups, the language of patients' rights was open to cooption by other actors with other aims.

Further questions can also be raised about the ability of patient-consumer organizations to influence health policy and practice even when the language of patients' rights remained within the control of these groups. Although patient groups played some role in getting complaints onto the agenda and in shaping the findings of the Davies Committee, the reaction of the medical profession to the report, and the fact that they were able to delay the implementation of a coordinated complaints procedure for many years, raised significant issues about the relative power of patient-consumer groups. Whatever the influence of patient groups, professional groups clearly held greater sway. This would seem to be confirmed by more recent studies suggesting that medical professionals and the state continue to dominate the health care arena, with patient groups remaining a junior partner.<sup>68</sup> Indeed, it is remarkable that patient organizations played any role at all in debates around health rights during the 1960s and 1970s. The Patients

Association was established at a time when patients were used in medical experiments without their knowledge or consent, and they had no formal, coordinated complaints system to appeal to when things went wrong. By using the language of patients' rights, organizations like the Patients Association were able to fight back against such practices, and were also able to gain a hearing in the corridors of power. That the professionals shouted down their voices should not totally eclipse the fact that they were listened to at all.

Yet the notion of patients' rights at this time only seemed to go so far. For example, as with the NHS Act, the Hospital Complaints Procedure Act was based on the duty of the secretary of state to ensure that hospitals had a complaints system, not around the right of a patient to make a complaint. It could be argued that this was in effect the same thing, but the way in which the legislation was framed was significant: again, more emphasis was being placed on the duty of the state to provide a service rather than the right of the patient to receive it. Clearly, the language of patients' rights had not fully penetrated the legislative world. Furthermore, issues remained around the effectiveness of rights claims. Even if we take the Hospital Complaints Procedure Act as giving the patient the right to complain, many patients continued (and still continue) to find it difficult to complain.<sup>69</sup>

The reason why such difficulties persisted, despite the establishment of the “right” to complain, can perhaps be attributed to a significant degree of confusion about who was complaining: was it the patient, citizen, or consumer? This also had

an impact on the nature of the rights that were being exercised: were these legal rights, human rights, citizens' rights, or consumers' rights? Or was there enough that was distinctive about patients' rights to make these into another type of rights altogether? This was important, because different types of rights laid claim to different things, and were treated in slightly different ways. For example, as a citizen, a patient might assert the right to receive a certain service, but as a consumer, he or she might instead assert the right to choose a certain service. Without a clear basis or understanding of what kind of rights were being asserted, patients' rights claims were weak, sometimes conflicting, and left open to cooption by other actors. In part, this was also because the patient as an identity category was fragmented by a range of other considerations: the disease suffered from; whether this was acute or chronic; the age, gender, race, socioeconomic status of the patient; and so on. There was no single conception of the patient within the notion of patients' rights.

What it meant to be a patient-consumer was not any clearer. As I have argued elsewhere, the notion of the patient as consumer changed over time. The patient-consumer began life in the context of discussions about autonomy and representation, and it was a figure shaped by patient groups, not by the state.<sup>70</sup> By the end of the 1980s, however, patient organizations had lost control of the agenda as the Conservative government sought to define health consumerism.<sup>71</sup> Gradual but persistent marketization of the NHS under the Conservative, Labour, and Coalition



governments has resulted in the prioritization of one right above all others: the right to choose.<sup>72</sup> The difficulties surrounding choice in health have been much examined, but it is the coupling of rights and choice that would seem to have the most significant implications for a collective health system like the NHS.<sup>73</sup> If, indeed, the right to choose has now replaced the right to receive, then it is the rights of the patient singular—not patients' rights plural—that are being prioritized. Despite the many problems associated with patients' rights, it would appear that they are here to stay. ■

#### About the Author

Alex Mold is with the Centre for History in Public Health, London School of Hygiene and Tropical Medicine, London, UK.

Correspondence should be sent to Alex Mold, PhD, Centre for History in Public Health, Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, 15-17 Tavistock Place, London, WC1H 9SH, UK (e-mail: Alex.Mold@lshtm.ac.uk). Reprints can be ordered at <http://www.ajph.org> by clicking the "Reprints" link.

This article was accepted February 1, 2012.

#### Acknowledgments

The research on which this article is based was funded by the Wellcome Trust as part of a University Award on patient organizations and the construction of the patient as consumer since the 1960s.

I thank the 3 anonymous referees for their insightful comments. I am also grateful to seminar audiences at the universities of Warwick and Glasgow who gave useful feedback on an earlier version of this work.

#### Endnotes

1. Eric A. Friedman and Eli Y Adashi, "The Right to Health as the Unheralded Narrative of the Health Care Reform," *Journal of the American Medical Association*, 304, no. 23 (2010): 2639–2640; UPI.com, "Lawyer: Healthcare Reform Violates Rights," September 1, 2010, [http://www.upi.com/Top\\_News/US/2010/09/01/Lawyer-Healthcare-reform-violates-rights/UPI-64251283390111](http://www.upi.com/Top_News/US/2010/09/01/Lawyer-Healthcare-reform-violates-rights/UPI-64251283390111) (accessed July 21,

2011); *Daily Mail*, "It IS Unconstitutional: District Judge Rules Obamacare 'Violates People's Rights' as Half of States Win Landmark Challenge," January 31, 2011, <http://www.dailymail.co.uk/news/article-1352262/US-District-Court-Judge-set-rule-Obamas-healthcare-reform-escalating-debate.html> (accessed July 21, 2011).

2. Department of Health, *The NHS Constitution for England* (London: Department of Health, 2009).

3. From "The NHS Constitution: Securing the NHS Today for Generations to Come," <http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm> (accessed July 21, 2011).

4. Lynn Hunt, *Inventing Human Rights: A History* (New York: W.W. Norton & Co., 2007); Micheline R. Ishay, *The History of Human Rights: From Ancient Times to the Globalization Era* (Berkeley: University of California Press, 2004); Dorothy Porter, *Health Civilization and the State: A History of Public Health From Ancient to Modern Times* (London: Routledge, 1999), 57.

5. United Nations, "Universal Declaration of Human Rights," Article 25 (1948).

6. World Health Organization, "Constitution of the World Health Organization," 1946, ([http://www.who.int/governance/eb/who\\_constitution\\_en.pdf](http://www.who.int/governance/eb/who_constitution_en.pdf) (accessed July 15, 2011)); United Nations, "International Covenant on Economic, Social and Cultural Rights," 1966–1976, <http://www2.ohchr.org/english/law/pdf/ceschr.pdf> (accessed July 15, 2011).

7. "Declaration of Alma Ata," declared at International Conference on Primary Health Care, Alma Ata, Soviet Union, September 1978.

8. Anne-Emmanuelle Birn, "Special Section—Health and Human Rights: Historical Perspectives and Political Challenges," *Journal of Public Health Policy* 29 (2008): 32–41; Daniel Tarantola, "A Perspective on the History of Health and Human Rights: From the Cold War to the Gold War," *Journal of Public Health Policy* 29 (2008): 42–53; Stephen P. Marks, "The Evolving Field of Health and Human Rights: Issues and Methods," *Journal of Law, Medicine and Ethics* 30 (2002): 732–754; Kenneth Cmiel, "The Recent History of Human Rights," *The American Historical Review* 109 (2004): 117–135.

9. See, for example, Catherine Crawford, "Patients' Rights and the Law of Contract in Eighteenth Century England," *Social History of Medicine* 13 (2000): 381–410.

10. Martin Gorsky, "Memorandum

Submitted to the Health Select Committee Into Public and Patient Involvement in the NHS, January 2007," [http://www.historyandpolicy.org/docs/gorsky\\_memo.pdf](http://www.historyandpolicy.org/docs/gorsky_memo.pdf) (accessed July 19, 2012); Martin Gorsky, "Community Involvement in Hospital Governance in Britain: Evidence From Before the National Health Service," *International Journal of Health Services* 38 (2008): 751–771.

11. Charles Webster, *The Health Services Since the War, Volume I* (London: Her Majesty's Stationery Office [HMSO], 1988), 10–129.

12. National Health Service Act, 1946 (chapter 81).

13. *The New National Health Service* (London: Ministry of Health, 1948); quoted in Charles Webster, *The National Health Service: A Political History* (Oxford: Oxford University Press, 2002), 24.

14. T.H. Marshall, "Citizenship and Social Class," in T.H. Marshall and Tom Bottomore, *Citizenship and Social Class* (London: Pluto Press, 1992), 3–51.

15. On the "classic" welfare state, see Rodney Lowe, *The Welfare State in Britain Since 1945* (Basingstoke, UK: Palgrave Macmillan, 2005).

16. See, for example, Frank Trentmann, "Citizenship and Consumption," *Journal of Consumer Culture* 7, no. 2 (2007): 147–158; Matthew Hilton and Martin Daunton, "Material Politics: An Introduction," in *The Politics of Consumption: Material Culture and Citizenship in Europe and America*, ed. Martin Daunton and Matthew Hilton (Oxford: Berg, 2001), 1–32; Frank Trentmann and Vanessa Taylor, "From Users to Consumers: Water Politics in Nineteenth-Century London," in *The Making of the Consumer: Knowledge, Power and Identity in the Modern World*, ed. Frank Trentmann (Oxford: Berg, 2005), 53–79.

17. Matthew Hilton, *Consumerism in Twentieth Century Britain* (Cambridge: Cambridge University Press, 2003); Lawrence Black, *Redefining British Politics: Culture, Consumerism and Participation 1954–70* (Basingstoke, UK: Palgrave, 2010).

18. On consumerism and housing, see Peter Shapely, "Tenants Arise! Consumerism, Tenants and the Challenge to Council Authority in Manchester, 1968–92," *Social History* 31, no. 1 (2006): 60–78. Examples of the application of consumerism to health include the following: D. S. Lees, *Health Through Choice: An Economic Study of the British National Health Service* (London: Institute for Economic Affairs, 1961); *Family Needs and the Social Services* (London: Political and Economic Planning, 1961); *General Practice: A Consumer Commentary* (London:

Research Institute for Consumer Affairs, 1963).

19. Rudolf Klein, *The New Politics of the NHS: From Creation to Reinvention* (Abingdon, UK: Radcliffe Publishing, 2006), 46–72.

20. Health Minister Keith Joseph in the House of Commons, *House of Commons Debates*, June 19, 1973, vol 858, column 380.

21. Maurice Pappworth, "Human Guinea Pigs: A Warning," *Twentieth Century* 171 (1962–1963): 67–75; Maurice Pappworth, *Human Guinea Pigs: Experimentation on Man* (London: Routledge & Kegan Paul, 1967).

22. Jenny Hazelgrove, "The Old Faith in the New Science: The Nuremberg Code and Human Experimentation Ethics in Britain, 1946–73," *Social History of Medicine* 15, no. 1 (2002): 109–135; David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991), 61–63.

23. Hodgson quoted in "Now a Voice for Patients," *Times (London, England)*, June 17, 1963, p. 15.

24. Helen Hodgson, "Medical Ethics and Controlled Trials [letter]," *British Medical Journal* 5431 (1963): 1339–1340.

25. Shelia Rowbotham, "Introduction," in *The Unsung Sixties: Memoirs of Social Innovation*, ed. Helene Curtis and Mimi Sanderson (London: Whiting & Birch, 2004), xi.

26. Jurgen Habermas, "New Social Movements," *Telos* 49 (1981): 33–37.

27. Patients Association, *Can I Insist?* (London: Patients Association, 1974); Which?, *Guide to Your Rights* (London: Consumers' Association, 1980); Consumers' Association/Patients Association, *A Guide to the National Health Service* (London: Consumers' Association, 1983); National Consumer Council, *Patients' Rights: A Guide for NHS Patients and Doctors* (London: HMSO, 1983); *Patients' Charter: Guidelines for Good Practice* (London: Association of Community Health Councils in England and Wales, 1986).

28. National Consumer Council, *Patients' Rights*, 5.

29. Which?, *Guide to Your Rights*, 9.

30. Thomas Pogge, *World Poverty and Human Rights* (Cambridge: Polity Press, 2008).

31. Contemporary Medical Archives Centre (hereafter CMAC), Wellcome Library, London. CMAC SA/PAT/H/2; Colin Riach, "Woman Protests at Being Hospital 'Specimen,'" *Daily Express*, October 10, 1963.

32. CMAC SA/CME/B/156, "Written Evidence Patients Association," 1965, letter from Mrs U. Miller, secretary of the Patients Association, to Lord Todd, November 4, 1965; CMAC SA/CME/B/156, "Written Evidence Patients Association," addendum, 1967; letter from Helen Hodgson to Mr M. W. Hodges, secretary of the Todd Commission, March 16, 1967.
33. "Rights of Patients," *House of Commons Debates* 829 (1972): c1404.
34. CMAC SA/PAT/E/1/2, "Bill: Rights of Patients, April 10, 1974. Presented by Joyce Butler in the House of Commons; "Rights of Patients Bill," *House of Commons Debates* 872 (1974): cc456–cc457.
35. The National Archives (hereafter TNA), Kew, MH 160/885, A.F. Taggart to Dr Ford re. Rights of Patients Bill, February 29, 1972.
36. TNA MH 160/1185 F.D.K. Williams to Mr Chambers, re. clinical teaching, October 16, 1969, and Chambers to Mr Clark, October 17, 1969, handwritten note on bottom of above.
37. Ruth R. Faden and Tom L. Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986).
38. See, for example, Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002).
39. Data Protection Act, 1984 (chapter 35); Access to Health Records Act, 1990 (chapter 23).
40. Alex Mold, "Making the Patient-Consumer in Margaret Thatcher's Britain," *Historical Journal (Cambridge, England)* 54 (2011): 509–528.
41. See, for example, Dorothy Porter and Roy Porter, *Patient's Progress: Doctors and Doctoring in Eighteenth Century England* (Stanford, CA: Stanford University Press, 1989), and *Medicine, Charity and Mutual Aid: The Consumption of Health and Welfare*, ed. Anne Borsay and Peter Shapley (Aldershot, UK: Ashgate, 2007).
42. Margaret Stacey, *Regulating British Medicine: The General Medical Council* (Chichester, UK: John Wiley and Sons, 1992), 56.
43. For a contemporary analysis of the workings of the general practitioner complaints system, see Rudolf Klein, *Complaints Against Doctors: A Study in Professional Accountability* (London: Charles Knight, 1973).
44. Linda Mulcahy, *Disputing Doctors: The Socio-Legal Dynamics of Complaints About Medical Care* (Maidenhead, UK: Open University Press, 2003), 31–32.
45. Political and Economic Planning, *Family Needs and the Social Services* (London: George Allen & Unwin, 1961).
46. Department of Health and Social Security, *Report of the Committee on Hospital Complaints Procedure* (London: HMSO, 1973), 17.
47. *Ibid.*, 7.
48. See, for example, Barbara Robb, *Sans Everything: A Case to Answer* (London: Nelson, 1967); Cmnd. 3687, *Findings and Recommendations Following Enquiries Into Allegations Concerning the Care of Elderly Patients in Certain Hospitals* (London: HMSO, 1968); Cmnd. 3975, *Report of the Committee on Inquiry Into Allegations of Ill-Treatment of Patients and Other Irregularities at the Ely Hospital Cardiff* (London: HMSO, 1969); Cmnd. 4557, *Report of the Farleigh Hospital Inquiry* (London: HMSO, 1971); Cmnd. 4681, *Report of the Committee of Inquiry Into Whittingham Hospital* (London: HMSO, 1972).
49. Department of Health and Social Security, *Report of the Committee on Hospital Complaints*. The National Association for the Welfare of Children also played a role in expanding visiting hours for parents with children in hospital, although this campaign was not framed around rights. See Harry Hendrik, "Children's Emotional Well-Being and Mental Health in Early Post-Second World War Britain: The Case of Unrestricted Hospital Visiting," in *Cultures of Child Health in Britain and the Netherlands in the Twentieth Century*, ed. Marijke Gijswit-Hofstra and Hilary Marland (New York: Rodopi, 2003), 213–242.
50. Department of Health and Social Security, *Report of the Committee on Hospital Complaints*, 3.
51. *Ibid.*, 4.
52. TNA MH 159/281, "Hospital Complaints Procedure: The Report of the Davies Committee—Report of the Joint Medico-Legal Subcommittee to the CCHMS and Joint Consultants Committee," no date [April 1974?].
53. TNA MH 159/281, Elston Grey-Turner, deputy secretary of the British Medical Association, to Dr H. Yellowlees (chief medical officer), April 25, 1974.
54. TNA MH 159/281, "The Patients Association: Comment on Report of the Committee on Hospitals Complaints Procedure," March 1974.
55. Charles Webster, *The Health Services Since the War Volume II: Government and Health Care, The National Health Service 1958–1979* (London: The Stationary Office, 1996), 640.
56. Modern Records Centre, University of Warwick, MSS.184 Box 2: "The NHS Complaints Procedure Three Years On: Opening Address by Meg Stacey." 57. See *House of Commons Debates*, February 22, 1985, vol 73, cc1370–cc1386.
58. McNair-Wilson's charter was published by the Association of Community Health Councils in England and Wales (ACHCEW). See ACHCEW Health News Briefing of November 19, 1984, entitled "The Patient's Charter," on *The Golden Age of Patient and Public Involvement: Celebrating the Work of Community Health Councils, 1974–2003, Vol 2* [CD-ROM], available from the Wellcome Library, London.
59. David Marsh and Melvyn Read, *Private Members' Bills* (Cambridge: Cambridge University Press, 1988), 42.
60. Mulcahy, *Disputing Doctors*, 41.
61. See *House of Commons Debates*, February 22, 1985, vol 73, cc1370–cc1386.
62. Hospital Complaints Procedure Act, 1985 (chapter 42).
63. Mulcahy, *Disputing Doctors*, 41.
64. Department of Health, *Patient's Charter* (London: HMSO, 1991).
65. Christine Hogg, *Patients, Power and Politics: From Patients to Citizens* (London: Sage, 1999), 43.
66. *The Patients' Agenda: What the Patient's Charter Leaves Out—The Rights You Don't Yet Have in the NHS* (London: Association of Community Health Councils in England and Wales, 1996).
67. Churchill College Cambridge, Michael Young Papers, YUNG/6/10/7, Comments on the Patient's Charter to David Brindle and Malcolm Dean at the *Guardian*, 1991.
68. See, for example, Brian Salter, "Patients and Doctors: Reformulating the UK Health Policy Community," *Social Science and Medicine* 57 (2003): 927–936.
69. Manjoi K. George and Renju Joseph, "Complaints Procedures in the NHS: Are They Fair and Valid?" *Clinical Governance* 14 (2009): 183–188.
70. Alex Mold, "Patient Groups and the Construction of the Patient Consumer in Britain: An Historical Overview," *Journal of Social Policy* 39 (2010): 505–521.
71. Mold, "Making the Patient Consumer."
72. Martin Powell and Ian Greener, "The Healthcare Consumer," in *The Consumer in Public Services: Choice, Values and Difference*, ed. Richard Simons, Martin Powell, and Ian Greener (Bristol, UK: The Policy Press, 2009), 99–117; Ian Greener, "Towards a History of Choice in UK Health Policy," *Sociology of Health and Illness* 31, no. 3 (2009): 309–324; Christine Hogg, *Citizens, Consumers & the NHS: Capturing Voices* (Basingstoke, UK: Palgrave, 2009), 75–102.
73. See, for example, John Clarke, Nicholas Smith, and Elizabeth Vidler, "The Indeterminacy of Choice: Political, Policy and Organisational Implications," *Social Policy and Society* 5, no. 3 (2006): 327–336; Rudolf Forster and Jonathan Gabe, "Voice or Choice? Patient and Public Involvement in the National Health Service in England Under New Labour," *International Journal of Health Services* 38, no. 2 (2008): 333–356; Marianna Fotaki, "Patient Choice and Equity in the British National Health Service: Towards Developing an Alternative Framework," *Sociology of Health and Illness* 32, no. 6 (2010): 898–913; Ian Greener, "Who Choosing What? The Evolution of the Use of 'Choice' in the NHS and Its Importance for New Labour," in *Social Policy Review 15: UK and International Perspectives*, ed. C. Bochel, N. Ellison, and M. Powell (Bristol, UK: Social Policy Press, 2003), 49–68.