Referral of Children to Specialists in the United States and the United Kingdom

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Objective: To compare the rates and patterns of children's specialty referrals in the United States (US) and the United Kingdom (UK).

Design: Retrospective cohort analysis of health care claims/encounter data obtained in 1996 (US) and 1997 (UK).

Setting: Children in the US were selected from 5 managed health plans that used primary care physicians as gatekeepers: 2 health maintenance organizations and 3 point-of-service plans. Point-of-service plans allow patient self-referral at increased out-of-pocket costs. In the UK, the General Practice Research Database provided data from 211 general practices.

Participants: Children, from birth to the age of 17 years, with no cost sharing for physician services in the US (n=135,092) and who were registered with general practitioners, all of whom authorize patients' access to specialty care, in the UK (n=221,312).

Main Outcome Measure: Annual percentage of children referred to a specialist.

Results: Across the 5 US plans, 18.6% to 28.8% of the patients per year were referred vs 8.7% of the patients per year in the UK sample. Referral rates were not significantly different between a health maintenance organization and a point-of-service plan administered by a single insurer. Compared with patients in the UK sample, those in the US plans were 1.9 times more commonly referred to medical specialists and 3.2 times more commonly referred to surgical specialists. There was considerable cross-national variation in specialty-specific referral rates for children with selected conditions.

Conclusions: Children in US managed care plans are between 2 and 3 times as likely to be referred to specialists compared with counterparts in the UK. Although these referral rate differences are substantial, our findings cannot be construed to mean that the US referral rates are too high or that the UK rates are too low. The greater supply of specialists and higher expectations for direct access to specialty care in the US, compared with the UK, are likely explanations for these differences in children's specialty referral rates.


How to Balance the higher costs of specialists with their potential for adding value to patient care is a significant policy quandary facing the United States (US) and other developed nations. Policy analysts have suggested that the intensive application of medical resources in the US is a result of patients' easy access to many specialists. Others argue that an ample supply of well-trained specialists is the hallmark feature of the US health care system and should be maintained because of the beneficial effects specialists have on the quality of care for health problems within their area of expertise.

As societies become increasingly global, so too does the search for potential solutions. Past studies have compared specialists' use of medical technologies between the US and the United Kingdom (UK). Such work has been fostered by the cultural affinities between the 2 countries, juxtaposed with stark differences between their health care systems. Patients in the US are more likely to undergo back surgery, cataract surgery, cesarean section, invasive cardiac procedures, and common surgical procedures than their counterparts in the UK.

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Little attention has been devoted to cross-national variation in children's use of services. A unique set of organizational and financial arrangements for children's health care argue for a separate research focus on children. For example, in the US, pediatricians function as primary care physicians (PCPs) and specialists, whereas in the UK, pediatricians are con-
consultants who receive referrals from general practitioners (GPs). Many UK referrals are made to a pediatrician, rather than a subspecialist.

In a prior report, we demonstrated that patients, from birth to the age of 64 years, in US managed health plans were twice as likely to be referred to a specialist as their UK counterparts. We extend these observations in this article by focusing exclusively on children and youth. General practitioners in the UK tightly control and authorize specialty referrals. In the US, mandatory PCP management of the referral process (“gatekeeping”) proliferated in the 1990s, although just 38% of Americans were enrolled in health plans with gatekeeping arrangements in 2000. To hold gatekeeping constant, we limited our analyses to US managed care settings that make use of a structured referral process similar to that in the UK, which requires all patients to obtain GP approval for specialty referrals. Because UK patients do not have out-of-pocket expenses for physician services, we selected patients in US health plans with no cost-sharing arrangements.

METHODS

The study population was composed of nonpregnant children and youth, from birth to the age of 17 years, with at least 6 months of plan enrollment or general practice registration and at least 1 visit with their PCP during 1996 (US) or 1997 (UK). Enrollees with a deductible for physician-approved services were excluded from the US sample to remove the confounding effects of cost sharing. Primary care physicians included family physicians, pediatricians, and general internists in the US and only GPs in the UK.

DATA SOURCES

Individuals from 2 network-model health maintenance organizations (HMOs) and 3 point-of-service (POS) health plans constituted the US sample. Patients from the HMOs had to obtain authorization from their PCP to gain access to a specialist. Patients from the POS plans were assigned to a PCP who authorized specialty referrals (similar to an HMO); however, patient self-referral to specialists was allowed at increased out-of-pocket costs (similar to an indemnity plan). Databases for the POS plans contained all out-of-network claims. Administrative databases were obtained from not-for-profit BlueCross BlueShield insurers in the Midwest (HMO and POS plan), Northeast (POS plan), and upper mid-Atlantic (HMO) regions of the US. A for-profit insurer provided data for a lower mid-Atlantic POS plan.

The upper mid-Atlantic HMO included mental health claims in its database. Other plans excluded mental health and substance abuse claims, because these services were “carved-out” benefits. We, therefore, used the upper mid-Atlantic plan only in analyses of psychiatrist referrals. All claims submitted by physicians, regardless of whether the member’s deductible had been met, were included in the database.

We assigned physicians to a specialty group according to self-reported specialties recorded in the American Medical Association Masterfile (82%-87% of all physicians across the 5 plans). The plans’ physician files were used for physicians unmatched to an entry in the masterfile. Across the 5 plans, specialty information was missing for 0% to 5.5% of physicians.

The General Practice Research Database (GPRD) was used for the UK sample. General practices contributing data to the GPRD follow guidelines for the recording of administrative, diagnostic, and referral data. The database forms a complete patient record of all primary care visits and specialty referrals. Several studies confirm the accuracy of these data. Because the UK’s National Health Service provides universal access to primary care, no portion of the population is excluded. The geographic distribution of practices participating in the GPRD is representative of the population of England and Wales, except for some underrepresentation of inner London practices. Recent comparisons of age-sex distributions with national estimates have shown these to be similar.

SPECIALTY REFERRAL DEFINITIONS

The referral rate measure was the annual percentage of patients with 1 or more new referrals to a medical, surgical, or psychiatric specialist (consultants in the UK). Pediatricians in the UK serve as consultants and, thus, were included in the medical specialist category for the UK sample.

General practitioners in the UK recorded whether each visit to their practice led to a new referral. In the US plans, patients who had at least 1 visit with a specialist were considered to have had a specialty referral. We excluded ongoing referrals using a 1-year clean period during 1993; specifically, specialist visits during 1996 (the study period) were removed if the patient had a visit to the same type of specialist during 1995. Referrals to obstetricians, gynecologists, and accident and emergency department physicians (in the UK) were excluded, because US patients had direct access to these physicians.

We conducted specialty-specific referral rate analyses for patients with various conditions. Specialties for which the databases had comparable specialty designations were chosen. We selected conditions shown in prior research to have a high level of specificity for a single type of specialist (eg, patients with acne when referred are virtually always sent to a dermatologist).

MORBIDITY ASSESSMENT

Patients with specific conditions were identified using expanded diagnosis clusters (http://www.acg.jhsph.edu). Expanded diagnosis clusters were assigned using primary care claims/encounter data only. An expanded diagnosis cluster is a set of diagnosis codes aggregated into clinically homogeneous groups, which removes some of the idiosyncratic coding behavior between physicians and regions. Some expanded diagnosis clusters are categorized as chronic conditions based on the likelihood of persistence longer than 12 months.

The Johns Hopkins Adjusted Clinical Group (ACG) system (http://www.acg.jhsph.edu) was used to measure patient health care needs and control for population health status. Individuals were assigned to an ACG based on their age, sex, and diagnosis codes, recorded by PCPs. The ACGs are a morbidity-burden classification system. Because of the clinical logic of ACGs, patients in the same ACG have a similar need for health care resources, such as specialty referrals, and similar clinical characteristics. Diagnosis codes recorded by specialists and nonphysician clinicians and those used for laboratory and radiology services were excluded from the ACG assignment. These exclusions were made because of the study’s focus on rates of specialty referrals as a function of health problems managed in primary care settings and the high rate of excluded diagnoses found in laboratory and radiology encounters. A multistep procedure was used to develop a treated morbidity index score for each individual in the study population. (The term treated is used to reflect the notion that the morbidity measured in this study depends on diagnosis codes recorded by practitioners, rather than a true measure of population morbidity.) The upper mid-Atlantic HMO served as the
reference population, chosen because it was the largest US health plan. For each ACG category in the reference HMO, the annual percentage of patients referred was determined. These ACG-specific referral rates were divided by the overall plan referral rate average to yield reference weights. Individuals' treated morbidity index scores were equal to the reference weight attached to their assigned ACG. Higher scores indicate sicker patients, a greater range and severity of comorbidities, and a greater need for specialty referral. Last, the index scores were grouped into 6 levels, from lowest (healthiest patients) to highest (sickest patients).

**DATA ANALYSIS**

The patient was the unit of analysis for all comparisons. We used the indirect method of rate standardization to obtain expected referral rates based on the ACG distributions of the samples. To adjust referral rates for population health status, we divided actual by expected referral rates. Confidence intervals for these ratios were obtained using the formula for variance of standardized morbidity ratios.

Table 1. Study Population Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Upper Mid-Atlantic HMO (n = 92,238)</th>
<th>Midwestern HMO (n = 75,511)</th>
<th>Midwestern POS Plan (n = 22,380)</th>
<th>Northeastern POS Plan (n = 92,211)</th>
<th>Lower Mid-Atlantic POS Plan (n = 37,022)</th>
<th>UK GPRD Database (n = 221,312)</th>
</tr>
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<tbody>
<tr>
<td>Age, y</td>
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<td></td>
<td></td>
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<tr>
<td>0-4</td>
<td>8.1 (5.0)</td>
<td>9.1 (5.0)</td>
<td>9.5 (5.1)</td>
<td>8.4 (5.3)</td>
<td>7.7 (4.9)</td>
<td>8.5 (5.0)</td>
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<td>5-11</td>
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<td>23.0</td>
<td>21.3</td>
<td>29.4</td>
<td>31.4</td>
<td>26.5</td>
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<td>12-17</td>
<td>41.4</td>
<td>39.6</td>
<td>36.5</td>
<td>36.3</td>
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<td>49.1</td>
<td>48.9</td>
<td>47.8</td>
<td>47.5</td>
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<td>No. of chronic conditions</td>
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<td>90.4</td>
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<td>85.4</td>
<td>82.3</td>
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<tr>
<td>0</td>
<td>12.8</td>
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<td>8.9</td>
<td>13.3</td>
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<td>15.8</td>
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<tr>
<td>1</td>
<td>1.2</td>
<td>0.6</td>
<td>0.6</td>
<td>2.1</td>
<td>1.7</td>
<td>1.9</td>
</tr>
<tr>
<td>≥2</td>
<td>1.0 (0.34)</td>
<td>1.01 (0.35)</td>
<td>1.00 (0.35)</td>
<td>1.01 (0.37)</td>
<td>0.99 (0.37)</td>
<td>1.08 (0.41)</td>
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<tr>
<td>Treated morbidity index group†</td>
<td>5.0</td>
<td>5.1</td>
<td>8.7</td>
<td>5.2</td>
<td>5.2</td>
<td>13.7</td>
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<tr>
<td>1</td>
<td>51.3</td>
<td>52.3</td>
<td>50.0</td>
<td>51.0</td>
<td>52.4</td>
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<td>2</td>
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<td>28.7</td>
<td>27.8</td>
<td>29.0</td>
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<tr>
<td>4</td>
<td>12.9</td>
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<tr>
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<td>1.6</td>
<td>2.0</td>
<td>1.8</td>
<td>3.2</td>
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<tr>
<td>6</td>
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<td>0.2</td>
<td>0.3</td>
<td>0.3</td>
<td>0.3</td>
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</tr>
</tbody>
</table>

Abbreviations: GPRD, General Practice Research Database; HMO, health maintenance organization; POS, point of service; UK, United Kingdom; US, United States.

*Data are given as percentage of children unless otherwise indicated. Percentages may not total 100 because of rounding. The study population was restricted to individuals from birth to the age of 17 years with 6 to 12 months of plan enrollment (US) or registration with a general practice (UK) and at least 1 visit during the study period with their primary care physician. Pregnant girls were excluded. To hold the effect of cost sharing constant, we further selected US patients to include only those with no deductible for physician-approved services.

†In this index, 1 indicates the healthiest patients and 6 indicates the sickest patients.

Table 2. Actual and Expected Specialty Referral Rates in the US and the UK for Patients From Birth to the Age of 17 Years

<table>
<thead>
<tr>
<th>Variable</th>
<th>Upper Mid-Atlantic HMO (n = 92,238)</th>
<th>Midwestern HMO (n = 75,511)</th>
<th>Midwestern POS Plan (n = 22,380)</th>
<th>Northeastern POS Plan (n = 92,211)</th>
<th>Lower Mid-Atlantic POS Plan (n = 37,022)</th>
<th>UK GPRD Database (n = 221,312)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral rate*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Actual</td>
<td>18.6</td>
<td>28.8</td>
<td>25.7</td>
<td>21.1</td>
<td>22.9</td>
<td>8.7</td>
</tr>
<tr>
<td>Expected†</td>
<td>18.6</td>
<td>18.8</td>
<td>18.6</td>
<td>18.9</td>
<td>18.9</td>
<td>20.1</td>
</tr>
<tr>
<td>Actual-expected referral rate ratio‡</td>
<td>1.00</td>
<td>1.53 (1.46-1.59)</td>
<td>1.39 (1.35-1.42)</td>
<td>1.12 (1.07-1.17)</td>
<td>1.24 (1.16-1.33)</td>
<td>0.43 (0.43-0.44)</td>
</tr>
</tbody>
</table>

Abbreviations are explained in the first footnote to Table 1.

*Data are given as percentage of patients referred per year.

†These rates increase with the disease burden of a population. The expected rates reflect what the overall referral rate would be if the population had referral rates within Adjusted Clinical Group categories that were equivalent to those of the upper mid-Atlantic HMO, the reference population.

‡Data in parentheses are 95% confidence intervals.
sessions showed that these rates were similar across the 5 plans. Differences between the US and the UK samples in these referral rates were determined using the $\chi^2$ statistic.

**RESULTS**

Children and youth cared for by GPs in the UK had a higher disease burden than did their counterparts cared for by US PCPs (Table 1). The percentage with a diagnosis of a chronic disease ranged from 9.2% to 15.4% in the US plans, which was lower than the 17.7% observed in the UK sample. The UK sample’s treated morbidity index of 1.08 indicates a greater need for health care resources than US patients.

The actual referral rates in the US health plans were substantially higher than the UK rate of patients referred per year (Table 2). The actual-expected referral rate ratio, which controls for population health care needs, showed that UK patients were 57% less likely to be referred than US counterparts. Within the UK sample, this ratio was 0.58 from birth to the age of 4 years, 0.42 for those aged 5 to 11 years, and 0.38 for those aged 12 to 17 years. The expected referral rates increased with age across all US plans and in the UK sample.

The average annual referral rate to medical specialists among the US health plans was 1.9 times higher than in the UK population (8.4% vs 4.5%), 3.2 times higher for surgical specialists (13.1% vs 4.1%), and 2.8 times higher for psychiatrists (1.4% vs 0.5%).

There was considerable cross-national variation in specialty-specific referral rates (Table 3). For most conditions, US patients were referred at higher rates. However, referrals for dermatitis or eczema, wax in the ear, otitis externa, congenital anomalies of the limbs, and strabismus were made at equal rates for patients in the 2 countries. Referrals for chronic tonsillitis, hearing loss, depression, and attention-deficit disorder were significantly higher in the UK than in the US.

**COMMENT**

Primary care physicians in the US practice in a highly specialized medical environment with ready access to specialists, whereas GPs in the UK work in a milieu with less abundant health care resources. Despite these and other differences between the 2 health care systems, finding the right mix of PCPs and specialists and managing access to specialty care are major policy challenges facing both countries. To inform this debate, we compared rates and patterns of specialty referrals among children seen by PCPs (general pediatricians and family physicians) in US managed health plans with those among children seen by GPs in the UK. Approximately 1 in 5 chil-

<table>
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<tr>
<th>Table 3. Specialty-Specific Referral Rates in the US and the UK for Children From Birth to the Age of 17 Years With Selected Conditions</th>
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<tbody>
<tr>
<td><strong>Type of Specialist</strong></td>
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<tr>
<td>-------------------------</td>
</tr>
<tr>
<td>Any medical specialist</td>
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<tr>
<td></td>
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<tr>
<td>Dermatologist or pediatrician</td>
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<td></td>
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<td></td>
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<tr>
<td>Neurologist or pediatrician</td>
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<tr>
<td>Otolaryngologist</td>
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<td></td>
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<tr>
<td>Orthopedic surgeon</td>
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<td></td>
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<tr>
<td>Ophthalmologist</td>
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<td></td>
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<tr>
<td>Psychiatric</td>
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<tr>
<td></td>
</tr>
<tr>
<td>General surgeon</td>
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</tbody>
</table>

Abbreviations: UK, United Kingdom; US, United States.

*The percentage of children with the condition referred to the indicated specialist.

†$P<.001$.

‡For skin problems, referrals in the UK sample were made to either dermatologists or pediatricians; similarly, for seizure disorder, referrals in the UK sample were made to either neurologists or pediatricians.

§$P<.01$.

||$P<.001$.
Though they are not at financial risk for referral costs,30 parents of young children in the US sample saw a specialist in a year, which contrasts with a rate of 1 in 12 in the UK. This large difference in referral rates was not accounted for by greater health care needs among US patients, and the effects of cost-sharing and gatekeeping arrangements were held constant. Does the US overuse specialists or does the UK underuse them? Our results do not provide conclusive answers to this question because we did not collect any information on the quality or outcomes of care.

Within the midwestern insurer, rates of referral between the HMO and POS plan were not significantly different, even though POS plan enrollees have the option to self-refer without seeing their PCP first. This finding is consistent with other research performed on nonelderly general populations that has found no difference in specialist use rates between HMO and POS plan enrollees29 and low rates of self-referral among POS plan enrollees.33

The low availability of specialists and long waiting lists in the UK are probably an important reason for the referral rate differences. The US specialist supply exceeds that for the UK by 2-fold.26 Roland and Morris27 found that geographic areas in the UK with more physician specialists had more specialty referrals. The low supply of specialists in the UK has led to long waits for specialty appointments: just 1% of US patients wait 4 or more months for elective surgery compared with 33% of UK patients.28 General practitioners believe waits for specialty appointments threaten their capacity to deliver high-quality care, rating them as the most important aspect of the referral process they are keen to change.29 In response to these waiting lists, GPs have probably reduced the number of specialty referrals they make, even though they are not at financial risk for referral costs.30 The absence of waiting lists is likely to have had the opposite effect in the US, lowering the threshold at which a PCP decides to make a referral.

Prior research suggests a less resource-intensive practice style among UK physicians compared with US physicians for patients with hypertension,31 neurologic problems,32 and coronary disease.33 Findings from our study suggest other practice style differences. The US/UK gap in referral rates was greatest for adolescents, intermediate for school-aged children, and smallest for young children. Actual referral rates increased with age in the US samples, but not in the UK sample, and expected referral rates (a proxy for population health care needs) increased with age among patients in both countries. Therefore, young children in the UK were referred at higher rates, relative to their health care needs, than older children and youth. General practitioners in the UK may feel less comfortable caring for young children’s health problems and, consequently, have a lower referral threshold for this age group.

Referrals to nonphysician clinicians were excluded from the study. This exclusion may explain why patients with attention-deficit disorder and depression in the UK were referred to psychiatrists more commonly than those in the US. Pediatricians21 and family physicians20 in the US refer a substantial share of patients with attention-deficit disorder and depression to psychologists.

Differences in population health care needs did not explain the higher US referral rates. The UK sample had a higher disease burden than all the US health plan samples. This finding is probably a result of including all socioeconomic groups in the UK sample, but limiting the US plans to children in families with employer-based health care insurance.

Divergent patient expectations and preferences could also help explain the differences in referral rates. A multinational survey20 surprisingly indicated that individuals in both countries rate the ease with which they can obtain specialty care about the same. Given the disparity in specialist availability, comparable satisfaction ratings suggest that those in the UK have lower expectations than those in the US regarding consultant/specialist access. Another factor that may contribute to differences in specialty referral rates is the more common expectation of US patients to seek specialist care without seeing a PCP first. A similar proportion (13%) of patients present to primary care with a desire to be referred in the US31 and the UK.33 Given that self-referral in the UK is rare,13 it is likely that some of the differential in overall referral rates we measured is because of more frequent patient-initiated specialist visits in the US, even within structured managed care settings.36

Differing definitions of what constituted a new referral may have led to overcounting and undercounting of referrals. After each visit, GPs in the UK recorded whether a referral was made. Not all referral decisions ultimately lead to a specialist visit. Studies from the UK27,30 have estimated specialist appointment adherence rates at about 80%, which is similar to US estimates (C.B.F., Paul Nutting, MD, MSPH, Barbara Starfield, MD, MPH, Sarah von Schrader, Charles Rohde, PhD, unpublished data, 2001).40 In the US sample, specialty referrals were defined by actual use of specialists. These alternative definitions of what constituted a referral—referrals generated in the UK and referrals completed in the US—served to narrow true differences in rates between the 2 countries. Another notable limitation of our data was the absence of pediatric subspecialist designations.

Patients referred during accident and emergency department visits (eg, referrals to general surgeons for acute appendicitis) are an exception to the rule that UK GPs must authorize all referrals. The database we used did not capture these referrals, because GPs did not generate them. Although referrals from the accident and emergency department are a source of underestimated referrals in the UK, their absolute number is small.41,42

Neither study sample can be considered completely nationally representative. The US sample was obtained from managed health plans located in 4 geographic regions. The UK sample was obtained from primary care practices that volunteered to participate in a long-term data collection project. Despite this, the total number of specialist referrals in the UK was similar to that predicted by applying the GPRD referral rates.19

Despite relatively low referral rates, some policy makers in the UK view GP referral rates as too high, contributing to the long waiting times to see specialists.35 The government in the UK aims to reduce the pressure on outpatient services in the hospital sector (where specialists are based) through the implementation of GP referral guidelines. It hopes that these guidelines will reduce...
Adults in the US are much more likely to undergo invasive procedures than adults in the UK. Less attention has been paid to variation in specialty referrals, the step preceding a specialized procedure, and variation in children’s use of services. Our findings show that US children are substantially more likely to see a specialist during the course of a year than children in the UK, even though children in the 2 samples had similar health care needs. Children’s greater use of specialists in the US may be a consequence of an oversupply of specialists and higher expectations for direct access to specialists, even in managed care settings.

unnecessary and inappropriate referrals to specialists and reduce the variation in referral rates between GPs.43,44 Given the low rates of referral in the UK relative to the US, it seems unlikely that such guidelines will dramatically enhance specialty capacity in the UK by decreasing demand. Long waits for specialists in the UK seem to be a result more of inadequate specialist supply than inappropriate GP decision making.

Despite relatively high referral rates in the US, public and private policy makers are seeking to expand access to specialists through patients’ bill of rights legislation and to reduce the restrictiveness of gatekeeping in managed health plans. Although the health benefits of these approaches are not well characterized, they are likely to increase health care expenditures. It is well documented that once a patient enters the specialty care sector, health care costs increase,45,46 because of increased use of high-cost diagnostic tests and therapeutic interventions. Greater use of technology has been cited as the primary driver of the high health care costs in the US.47 In 1998, the US spent $4270 per capita (including the uninsured) on health care, while the universally insured UK spent just $1450 per capita.48 This study suggests that one of the reasons for this large difference in expenditures is less restricted access to specialists in the US, even among those enrolled in health plans that attempt to aggressively manage resource use.

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From the Department of Health Policy and Management, Health Services Research and Development Center, Bloomberg School of Public Health, The Johns Hopkins University, Baltimore, Md (Drs Forrest and Weiner); the School of Public Policy, University College London (Dr Majeed); and the Office for National Statistics (Drs Majeed and Carroll), London, England, and the Division of General Internal Medicine, the Department of Medicine, University of California, San Francisco (Dr Bindman). Drs Forrest and Weiner are developers of the Adjusted Clinical Group system used to control for health status in some analyses in this study. The Johns Hopkins University has copyrighted this software and receives royalties from its sale, which are used toward ongoing developmental work. None of these royalties were used to fund this study.

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