

Is Congress Importing Health Care Rationing from Britain?

A national health board is a first step to picking winners and losers among patients, saving money instead of lives

Before Britain's Katie Brickell was diagnosed with cervical cancer at age 23, she tried to get a routine pap test three times, but was refused because the U.K.'s national government rationing board that controls what treatments patients may receive will only pay for screenings for women *25 or older* in an effort to cut costs.

Denied this routine test by her government's health care board, Katie's cancer was found at a late stage. Her cancer is terminal.

Katie's story is not unique, and mirrors the experiences of many of the United Kingdom's other 61 million citizens trapped in its National Health System.

As our nation goes forward in its own health care reform debate, the failures of the British system should have Americans asking some very important questions such as:

“Who should make medical decisions — me and my doctor — or a government board?”

A Failing System Called NICE

In the U.K., medical decisions are made by a government rationing board known as the National Institute for Clinical Excellence. “NICE” was set up to monitor the “effectiveness” of medical treatments and preventative measures, but its main purpose has become to contain costs by rationing patient care.

Early explanations of the need for and goals of NICE were laced with feel-good phraseology and indeed its acronym — certainly intentional — has a positive connotation. These descriptions are not dissimilar from what the U.S. government has now tasked its new health care board with while deleting any direct references to “cost effectiveness research” — NICE's fundamental underpinning and tool for cost/benefit analysis of patient care. As London's *The Guardian* newspaper reported in March 1998:

“Health ministers are setting up a National Institute of Clinical Effectiveness (NICE), designed to ensure that every treatment, operation or medicine used is the proven best. It will root out under-performing doctors and useless treatments, spreading best practice everywhere. Its watchword is evidence-based medicine.”

The ostensible reason for the establishment of NICE — to make recommendations based on “evidence-based medicine” and to “improve quality and access to services,” are the same issues facing the Obama Administration and Congress in 2009 as they look to solutions from a similar government board and comparative effectiveness research.

The Daily Telegraph

The Daily Telegraph (U.K.), August 2008: The NHS's drug-rationing body has been accused of bullying, ignoring and patronising patients in consultation, over the availability of life-altering medication.

FINANCIAL TIMES

The Financial Times, January 24, 2009:

“...with Alzheimer's drugs costing £2.50 a day per patient — some £70m a year in total, ‘Just think how many hip replacements and instant cardiac catheterizations you can do for that money; treatments that make a real difference to people's lives.’”

**Professor of Health Economics,
University of York, Alan Maynard**

QALY: Calculating the Life Value of a Patient

NICE's role may have started out as limited to appraising health care outcomes, but in practice, *NICE recommendations and guidelines are used to deny coverage to British citizens on a daily basis. NICE relies on the evaluation from the Orwellian-sounding “quality-adjusted life year” (QALY) to determine if a medical intervention is a “reasonable value for money.”*

In effect, QALYs are used to mathematically calculate the value of a patient's life. The NICE guidelines for 2009 explain the process:

“The cost per QALY gained is calculated as the difference in mean cost divided by the difference in mean QALYs for one (treatment) strategy compared with the next most effective alternative strategy.

If one intervention appears to be more effective than another, the (Guideline Development Group) will have to decide whether the increase in cost associated with the increase in effectiveness represents reasonable ‘value for money.’”¹

“[I]n general, interventions with an Institute of Clinical and Economic Review (ICER) of less than £20,000 (\$29,000) per QALY gained are considered to be cost effective. ... Above a most plausible ICER of £30,000 (\$44,000) per QALY gained, advisory bodies will need to make an increasingly stronger case for supporting the intervention as an effective use of NHS resources.”²

The Daily Telegraph

The Daily Telegraph (U.K.), April 15, 2008:
NICE Ruling 'denies treatment to 100,000 Alzheimer's patients'

Medscape
from MEDMD

Medscape Medical News, August 22, 2007:
Cancer Survival Rates Significantly Higher in United States Than in Europe

Daily Mail

The Daily Mail (U.K.) March 5, 2005: Denied treatment because they are too old

While supporters of *NICE* claim that any treatment approved by the Institute must be covered, many drugs and interventions are routinely rejected with patients unable to take advantage of new procedures and clinical trials that are currently available to U.S. patients.

The Heritage Foundation, February 2009: "Claiming that its relatively high price jeopardized the efficacy of the NHS, patients with the more severe forms of the disease (Multiple Sclerosis) were told that they would have to go on suffering in the name of politically defined equity."

Daily Mail, March 5, 2009: "Thousands of patients with terminal cancer were dealt a blow last night after a decision was made to deny them life prolonging drugs. The Government's rationing body said two drugs for advanced breast cancer and a rare form of stomach cancer were too expensive for the NHS."

The New York Times, December 2008: "A clinical trial showed that the pill, called Sutent, delays cancer progression for six months at an estimated treatment cost of \$54,000. But at that price, [U.K. cancer patient Bruce] Hardy's life is not worth prolonging, according to a British government agency, the National Institute for Health and Clinical Excellence.

The institute, known as *NICE*, has decided that Britain, except in rare cases, can afford only £15,000, or about \$22,750, to save six months of a citizen's life."

In other words, *NICE*, in its efforts to contain costs has unilaterally determined that six months of someone's life is worth less than \$23,000.

Britain's Rationed Care Model is Exported to the U.S.

One of President Barack Obama's first acts upon taking office was to provide \$1.1 billion through his stimulus package for a national health care board designed to oversee "effectiveness" of health services, modeled after U.K.'s *NICE*. Entitled the Federal Coordinat-

ing Council for Comparative Effectiveness Research (FCCER), its description sidesteps its intent of cost containment, noting that it will "coordinate the conduct or support of comparative effectiveness and related health services research."

As the bill was passed without legislators reading it, let alone studying its provisions, many concerns have been raised since its passage both in the political and public realms regarding exactly what and who this comparative effectiveness research (CER) will analyze and how those results will be implemented or enforced.

Chief among concerns is that analyzing the comparative effectiveness of medical procedures and technologies will lead the FCCER to focus not on what treatment works best across all patient populations, but which interventions cost the least. Allowing the government to pick winners and losers from the pool of American patients when it comes to treatment options will inevitably lead to reducing care available to American patients and physicians across the board, as is currently the practice of Great Britain's *NICE*.

The language included in the committee report accompanying an earlier version of the bill, makes clear that House appropriators understood the true cost containment intent of this government board and considered the evaluation of cost an important benefit of comparative effectiveness research:

“By knowing what works best and presenting this information more broadly to patients and healthcare professionals, those items, procedures, and interventions that are most effective to prevent, control, and treat health conditions will be utilized, while those that are found to be less effective and in some cases, more expensive, will no longer be prescribed.”³

While this language was later dropped from the final conference report, it provides context and clarity to the authors' original and true intent as the law was drafted.

This national board is a first step towards rationing care in the U.S. Without having the comparative effectiveness data, there would be no way for the government to approve or disapprove certain drugs or treatments. Therefore logically, the collection and analysis of this data is a first step to application of the data.

Moreover, forty-four members of the Senate were obviously not comfortable enough with the intent or language of the bill as they voted for an amendment that would have clearly prohibited any use of data obtained from comparative effectiveness research to deny coverage of a health care treatment.

“I hope this amendment will receive very strong bipartisan support because the entire essence of it is to ensure that nothing we have done so far here will allow health care in the United States to be rationed by the Federal Government. ... I have offered this pro-patient amendment that would send a clear message to the administration and clarify the Senate's intent regarding the stimulus funding.”⁴

“My amendment States two principles: No. 1, the Federal Government shall not use the data obtained from comparative effectiveness research to deny coverage of a health care treatment

Daily Mail

The Daily Mail (U.K.) March 5, 2009: Life Prolonging Cancer Drugs to be Banned Because They Cost Too Much

SKY NEWS

Sky News (U.K.) August 7, 2008: Cancer Patients Denied Treatment: Patients with advanced kidney cancer are to be denied four life-extending treatments because the NHS says they are too expensive. The National Institute for Health and Clinical Excellence (Nice) has withdrawn the drugs, saying they are not a cost effective use of NHS resources.

under a Federal health care program — very simple — and, No. 2, the Federal Government shall ensure that such research accounts for advancements in genomics and personalized medicine, the unique needs of health disparity populations, and differences in the treatment response and treatment preferences of patients.”⁵

Senator Jon Kyl, April 1, 2009

As Senator Kyl rightly stated in his remarks:

“... if nobody is intending to do it, then there’s no problem in saying you cannot do it.”

There is a strong correlation between the British system and the road that the U.S. is taking with health care reform as evidenced by recent comments from government officials:

“We’ve got finite resources as a society. We need to figure out how to use them most effectively to achieve all the things we want to achieve.”⁶

Glenn Hackbarth, Chair, Medicare Payment Advisory Commission (MEDPAC)

“The comparative effectiveness research is a way of finding out what works and what doesn’t and an important obstacle to our deciding as a society what treatments people should get and not get is that we ... do not know ...”⁷

Douglas Elmendorf, Director of the Congressional Budget Office

Cost Effectiveness Research in the U.S.

Stimulus dollars toward CER have already found their way into several agencies and programs since the bill was passed.

Although the National Institutes of Health (NIH) is a federal agency chartered for “conducting and supporting medical research,” and despite legislative language that it is not Congress’ intent to use comparative effectiveness research to “mandate cover-

age, reimbursement, or other policies,” an NIH official testified before Congress that cost may be evaluated in their studies.⁸

It appears that NIH is not merely sitting idly by and waiting for scientists to approach them with ideas for studying cost-effectiveness but is in fact actively seeking out such research. In fact, among the research areas NIH considers to be “the highest priority” for research grants using the stimulus funds is “Integrating Cost-Effectiveness Analysis into Clinical Research:”

“This initiative calls for the inclusion of rigorous cost-effectiveness analysis in the design and testing of new and innovative interventions, as well as existing interventions with demonstrated effectiveness. Cost-effectiveness research will provide accurate and objective information to guide future policies that support the allocation of health resources for the treatment of acute and chronic diseases across the lifespan.”⁹

This begs the question of how NIH will approach clinical research with a predetermination of the costs associated with such research, the results of which are by nature, not yet known.

With the creation of the FCCCER as a government board and enhanced federal funding of comparative effectiveness research, the United States is embarking on a road the U.K. has stumbled down for the past decade to the great detriment of its patient population.

President Obama’s first choice for Secretary of Health and Human Services was former Senator Tom Daschle. Though Daschle was required to step aside as HHS nominee for reasons unrelated to his health policy ideas, it is illustrative to look at his vision for health care reform. Throughout his 2008 book, *Critical: What We Can Do About The Health-Care Crisis*, Daschle looks to NICE as an example of how the U.S. can control health care costs:

“We won’t be able to make a significant dent in health-care spending without getting into the nitty-gritty of which treatments are the most clinically valuable and cost effective. That means taking a harder look at the real costs and benefits of new drugs and procedures. In Great Britain, NICE ... uses cost-effectiveness information in deciding whether to cover a new drug or procedure.”¹⁰

“In Great Britain ... (NICE), which is part of the National Health Service (NHS), is the single entity responsible for providing guidance on the use of new and existing drugs, treatments, and procedures. ... NICE also weighs what it calls ‘economic evidence,’ or how well the medicine or treatment works in relation to how much it costs.”¹¹

Former Senator Tom Daschle

And as Daschle noted in his book, the treatment choices of doctors and patients should be limited.¹²

Similar to the U.K., the U.S. is heading down a road where health cost replaces the value of health care. Injecting a government bureaucracy between patient and doctor in the name of cost can only lead to sacrificing care for those whose perceived life value cannot meet the government’s cost/benefit standards.

In fact, President Obama's HHS Secretary, Kathleen Sebelius recently told Congress that efforts to ration health care at some point in the future are a possibility:

“I can't tell you that I am not concerned about ultimately — not with comparative effectiveness research, but ultimately — reaching a point where, in order to control costs, there is some effort to ration health care.”¹³

Kathleen Sebelius, Secretary of Health and Human Services

Cost v. Care: Which Conveys the Value of Life?

As Katie Brickell battles her own cancer — she actively supports the family of Claire, another victim of NICE rationing who died of cervical cancer last September at age 23. Despite having symptoms of cervical cancer, Claire was not given a pap smear which would likely have identified the disease. Claire's family recently presented Britain's prime minister with a petition signed by 15,000 people

Daily Mail

The Daily Mail (U.K.) March 24, 2009: Cancer Survival Rates in Britain Among the Worst in Europe

requesting that the age for cervical cancer screening be lowered. But so far, Britain's government controlled health care has refused to drop the age based on the idea that providing screening to young women is too costly.

As the debate continues in the U.S. on health care reforms, we must not confuse cost with care. The FCCCER has all the ingredients to become a rationing body similar to its U.K. predecessor, NICE.

What is the value of your life? The life of a loved one? The government may soon answer that question for you.

Sources:

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- 3 House Committee on Appropriations Report to Accompany H.R. 679, The American Recovery and Reinvestment Act of 2009, Library of Congress — Thomas Website, http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_reports&docid=f:hr004.111.pdf, Jan. 26, 2009
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- 5 Senator Jon Kyl, S. Con. Res. 13, Congressional Record, p. S4128, April 1, 2009
- 6 Glenn Hackbarth, Chairman, Medicare Payment Advisory Commission (MEDPAC), Hearing on Making Health Care Work For American Families: Designing A High-Performing Health Care System, House Energy and Commerce Committee, March 10, 2009
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- 13 Governor Kathleen Sebelius Testimony, Hearing on The Nomination Of Governor Kathleen Sebelius To Be Secretary Of The Department Of Health And Human Services, Hearing Of The Senate Health, Education, Labor And Pensions Committee, March 31, 2009

Conservatives for Patients' Rights is a non-profit organization dedicated to educating and informing the public about the principles of patients rights and, in doing so, advancing the debate over health care reform. Those principles include choice, competition, accountability and responsibility. We believe the path to effective health care reform must be based on the patient-doctor relationship and not from a top-down, big government perspective. Anything that interferes with an individual's freedom to consult their doctor of choice to make health care decisions defeats the purpose of meaningful health care reform.