

Tea, Biscuits, And Health Care Prioritizing

An American visiting England observes initiatives to elicit public input on thorny health care allocation decisions.

BY MARTHE R. GOLD

PREFACE: Rationing care requires policies based on judgments about fairness—a state government decides that it will pay for this type of treatment for this age group but not that one; an insurance company determines that it will cover this procedure but not that one. How are such difficult decisions made, and would the public be happier if they could participate in crafting them? Marthe Gold, a family physician, takes us to England’s Midlands, where local government representatives are seeking the public’s input into whether the National Health Service should cover a costly new therapy. The scene she witnesses illustrates public thinking about rationing in a society long accustomed to the concept of health care prioritization. Closer to home, Kansas-based nurse practitioner Karen Roberts contemplates the equity of a system that permits one of her patients to overuse Medicaid-covered services, possibly at the expense of others who really need medical attention. She asks why Medicaid puts no checks on a patient who wastes providers’ time by compelling them to tend to psychosocial rather than medical needs and suggests that a system with built-in social support would be less costly.

IT IS MID-AFTERNOON IN DECEMBER in a community meeting room in Wolverhampton, a small city in England’s Midlands. It is damp and the wind is up, and it is nice to learn that afternoon tea will be served prior to conducting business. Daphne Austin, a public health physician from a local service agency, sets about serving tea and biscuits to nine people who have been recruited to discuss their views about National Health Service (NHS) coverage of an expensive new therapy. Since 1991, British government policy has mandated public involvement in health services decisions. Using a range of techniques for informed public involvement—polling, focus groups, and citizen juries in community and academic settings—the country has been developing methods for holding conversations with the public and feeding them back to the health care system. All of these techniques rely on deliberation—giving the public the tools and time to consider the pros and cons of various issues.

The people assembled today are middle-aged and older—three women and six men, all white but one. They are a convenience sample drawn

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from a citizens group that has agreed to consult when public input is deemed important to decision making in local venues. The Wolverhampton meeting is one of four, each with a different demographic makeup, that will advise the West Midlands Health Authority. Today's question is whether the thirty primary care trusts that are responsible for channeling funds and providing health care to the West Midlands region's 5.3 million people should extend coverage for enzyme replacement therapy to people suffering from Fabry's disease, Gaucher's disease, and other forms of Mucopolysaccharoidosis I.

I am in England on sabbatical, wearing the cloak of ambivalent advocate for the use of cost-effectiveness analysis to propel more equitable distribution of U.S. health care resources. My work in federal policy arenas has persuaded me that universal health care will come about only through rational and judicious use of health services. My work as a family physician and experience as friend and family member, however, have made me sensitive to the notion that utilitarianism in medical care has some fundamental difficulties. This is not an unrecognized issue in the policy literature back home, but in the United Kingdom explicit conversations about rationing on the basis of cost-effectiveness are being held in wide-open spaces. I am interested in seeing what regular Britons have to say about this. My notion has been that in a country with a global health care budget and relatively low (by Western standards) per capita investment in health care, the public must be more inured to the notion of rationing, or "prioritization," as it is often called here.

Painful Decisions

SHIRLEY MCIVER, A BIRMINGHAM UNIVERSITY EXPERT in processes of public involvement in health care decision making, convenes the meeting. She introduces its intent: understanding how those present view the funding of a promising but expensive therapy for a rare disease. She asks participants to complete a questionnaire on their ideas about how much is reasonable to spend on any one person, and under what circumstances (to save a life or to treat a rare condition) spending thresholds should increase. After the surveys are filled out, McIver invites those assembled to openly discuss their answers. I am surprised, yet not surprised, to hear most of the participants say that the NHS should provide treatment regardless of cost. One middle-aged woman says, "They can find the money for wars, my darling, can't they?" Another says, "At the end of the day, there's nothing so precious as your relatives. Nothing so precious as love." A retired civil servant, however, sees things differently. He notes that there is "only so much money and you can't do everything."

Next, McIver tells the group about a rare inheritable condition that is known to affect 400 of the 52 million people served by the NHS in England and Wales. The condition has differing types and levels of morbidity that can affect the kidneys,

heart, and brain. The group learns that before the development of a treatment (dubbed “Tdx” to cover a range of available enzyme replacement therapies), clinical management was aimed at relieving symptoms: dialysis for people with renal failure, medication and surgery for people with heart failure. According to McIver, treatment with Tdx is likely to allow early-treated people to live normal lives and diminish the chances of premature death for many. She cautions, however, that although evidence suggests that Tdx treatment is promising, it is a new therapy, and questions remain about the consistency of benefit across individuals and the drug’s long-term effectiveness.

McIver then turns to the issue of cost. A year’s treatment for children will cost about £125,000 (\$225,000) and for adults about £350,000 (\$630,000). Once started, treatment will generally continue for the rest of a person’s life. McIver puts these costs into context by telling the group that the average spent by the NHS in a person’s lifetime is £90,000 (\$162,000) and the median, £40,000 (\$72,000). Everyone finds this staggering; there is no doubt in the room that Tdx requires a new level of financial commitment. McIver tells the group that the drug is expensive because the company that makes it has to recover its development costs; that because only a few people will benefit from an “orphan” drug, development costs per patient treated are particularly high; and that a profit margin is added to this. She says that after a ten-year period of exclusive production, orphan drug status lapses and prices should fall, but by what amount is uncertain.

McIver reminds the group that finite budgets within the NHS mean that allocating resources in one place means rationing elsewhere. She asks about fairness: Is it right to disadvantage people with costly diseases because their condition takes a disproportionate share of care away from larger numbers of people with less costly conditions? She asks that the group also consider the precedent set by funding this therapy should a future expensive therapy come along for a different illness.

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A Sticky Wicket

THE GROUP RESPONSE IS SPIRITED and somewhat untethered. Irritation is near-universal at the government for underfunding health care. One older man complains, “There are two bloody doctors for 636 Members of Parliament,” inveighing at the injustice of this, given the shortages and queues everyone else faces. Someone says that foreign visitors come to use U.K. health services for free, and a few people question whether there should be full health coverage for “asylum seekers,” a.k.a. new immigrants. Another suggests that people with self-

inflicted illnesses should not have their care paid for. Talk turns to George Best, the fallen Manchester United soccer hero who has received liver transplantation secondary to hepatic failure on the basis of alcoholism. There is a general murmur of approval about not funding this sort of thing (as my mind wanders to Mickey Mantle), but the notion is controversial; a humanitarian country should take care of all its citizens, someone says, and there are widespread murmurs of agreement. Nothing said here strikes me as different from American sensibilities.

When McIver asks more pointedly where money should be found to pay for Tdx, the group identifies a range of options. All agree that the drug industry should be reined in (“the drug companies are holding us for ransom,” says one woman) and that development costs should be borne by government or new drugs taken over by government, which could produce them more affordably. A number of people think that there should be a separate NHS fund for “high-cost” diseases that can be drawn on for people with expensive illnesses.

The two hours allotted for this meeting are nearly gone. Daphne Austin, who has been sitting quietly at the back of the room, stands to thank the group for its comments. Her interpretation of the discussions is that there is general support for coverage of enzyme replacement therapy (ERT) by the West Midlands Primary Care Trust. Almost everyone agrees. Austin says that she is appreciative of their time and guidance, but she asks that those who believe that ERT should be covered provide some additional advice. She says that if in her report to the trusts she were to recommend coverage of ERT, she also would need to identify services to cut, to afford the new treatment. She wonders what suggestions they had. Should they get rid of the diabetes nurse program, for example? One man says “no” with the vehemence that comes from personal experience. After a moment he adds, “You have a bit of a sticky wicket here to deal with. I don’t envy you.”

Everyone nods. We all see his point. It is difficult to bear responsibility for allocation decisions such as these. No one present wants to say no to someone with the misfortune of having a devastating but costly disease. A health care system with a lean global budget certainly needs to be efficient, but maximizing the aggregate of health for the least amount of money risks the danger of creating fundamental equity problems. Why, indeed, should the life or health of someone with an expensive disease be valued less than the life or health of someone with a reasonably priced problem? Why should government pay to treat some illnesses and not others, given equal effectiveness (or ineffectiveness) of therapy? These are quandaries shared by Americans and Britons alike. I am thinking about U.S. “basic” health benefit packages that pay only so much and no more per calendar year and insurance that leaves out services such as mental health and

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dentistry. And about differential access by disease in our own version of universal coverage, Medicare, where failed kidneys gain you immediate coverage no matter what your age, but a failing heart or liver requires a two-year wait until disability, and hence eligibility, kicks in.

Unlike others in the room, I envied Dr. Austin. I envied her because the system she works in has decided to grapple with murky ethical issues in a relatively transparent fashion. At policy levels and increasingly with the lay public, considerations of cost-effectiveness and resource allocation are spoken about plainly.

Making Earnest Efforts

COVERAGE DECISIONS SUCH AS THE ONE the West Midlands was grappling with occur when there is a policy vacuum at the NHS level—specifically, when NICE (the National Institute for Clinical Excellence) hasn't yet ruled on an issue coming before local authorities. NICE is the entity to which the NHS has given authority to make decisions about coverage for new or controversial existing therapies. Reporting directly to the Department of Health, NICE was established in 1999 to help improve quality of care, use evidence to inform treatment, and heed issues of economic efficiency within health care treatment. NICE's influential appraisal committees review reports on the effectiveness and cost-effectiveness of new or common therapies. Consulting with patient representatives, scientific and industry reviewers, and, importantly, a citizens council, the appraisal committees deliver opinions on whether the NHS should provide a particular service. (This process has by no means fully evolved. NICE is struggling with how to make best use of its citizens council, which is fashioned to represent the U.K. population and which hears “testimony” from expert “witnesses” before coming to its verdict. There is no specific, endorsed method, locally or nationally, for gathering and incorporating public input into health care decision making. But serious efforts are being made to bring the public in.)

Once these committees appraise a therapy favorably, it must be made available, when clinically indicated, throughout the United Kingdom. NICE's authority is meant to denote a political and professional judgment that “post-code rationing” (referring to the U.K. equivalent of U.S. ZIP codes), where health authorities in different localities arrive at different judgments about the services they will provide, is not acceptable public policy.

This is not to imply that post-code rationing is a thing of the past or that the British public has accepted “priority setting” as fine and dandy. What is different in the United Kingdom relative to the United States is the British policy focus on equity and the efforts being made to learn what the public thinks and why. The objectives for these conversations appear to be as much about informing and educating the public about dilemmas as about obtaining the public's advice. For the sake of comparison, the most visible U.S. example of soliciting public opinion on health

care coverage, the Oregon Medicaid experiment, used public meetings to discuss health care priorities. Nearly 70 percent of attendees, however, were health care providers, not consumers.

Taking A Page From Britain's Book

THE WOLVERHAMPTON MEETING—and a three-day gathering of NICE's citizens council that I also attended—suggested that the deliberation process creates a rich public understanding of and sympathy for problem solving. Canadian and U.K. investigators have found that people may well be willing to leave some of the sticky-wicket decisions to professionals but that learning what the issues are gives them more ease in doing so. At the same time, such discussions provide insights into what the public will and will not accept, better locating policy directions within the value structure of a community and a nation.

While I was sitting in that room in Wolverhampton, the Medicare Modernization Act of 2003 was being signed into law. Like many others in U.S. policy circles, I was aware of the law's unsatisfactory distribution of dollars. Its putative centerpiece—a much-needed drug benefit for older Americans—had been vastly curtailed. A large part of the law's \$600 billion price tag was designed to encourage the growth of private-sector health care provision to the Medicare population. It appeared that special interests had been listened to but that the public—the voice of the payers of this U.S. version of universal health care—was missing. Many months later, much of the American public has become aware of how little that legislation has benefited them. Perhaps the widespread discontent with the law will cause Congress to revisit it. Maybe by the time it does, we will consider following our U.K. colleagues by turning to the public for guidance.

Our health care system has become increasingly committed to “shared” decision making in the clinical setting. At the level of the individual, we have moved to educate and offer choices to patients and consumers about their care. We make ever-greater efforts to assure that communication strategies are sound and that patients participate knowledgably in decisions that affect not only health status but life and death. We view this, correctly, as contributing to the quality and responsiveness of the larger health care system. Our next great wave of empowerment will come when we begin to think at the population level by asking the public for its views on the health care system: What should our country provide, and how should it be paid for? These are no less life-and-death decisions than those made at the bedside. Listening to public voices could help us move our stalled efforts at health care reform forward in a publicly responsive and responsible way. Maybe we'll even adopt the tradition of afternoon tea. Worse things could happen.