

Numbers We Need: Health Statistics and Health Policy

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In constructing a vision for health statistics, it is important to pay attention to the needs of people who make health policy. Policy makers and the public will be better informed, and may make better policy, if they have the numbers they need to judge the expected effects of alternative actions. Further, since policy makers also decide on funding and authority to collect and analyze health statistics, they are likely to be more favorably disposed to the health statistics enterprise if it is generating the numbers they need.

It is easy to state that health statistics should produce the numbers that are needed by health policy makers, but harder to figure out what those numbers are. The goal of this paper is to accomplish that task.

Most broadly, health policy can be defined as a set of decisions concerning how health care gets produced, consumed, and paid for. What health care services should be provided to whom by which providers under what organizational arrangements? Who should pay for these services, how much should be paid, and what should the mechanism of payment be?

Health policy is made by many different actors -- governments, employers, insurers, providers, and consumers each make health policy decisions. In the public sector legislators, executives, and bureaucrats at the federal, state, and local levels make tens of thousands of health policy decisions each year.² In the private sector, employers, insurers, health plans, and various provider organizations (e.g.,

¹ Helpful comments on an earlier draft were made by Daniel Friedman, Barbara Starfield, Paul Newacheck, Marjorie Greenberg, Robert Kaplan, Tony Dreyfus, and Amy Bridges. I am indebted to John Anderson for analysis of the NHIS reported in Figures 1 and 2. All errors are my own.

² In thinking about the government's role in health policy, it may be useful to differentiate five somewhat separate, although overlapping functions. First, much of the money, and the large bulk of the policy decisions (in sheer number) concern the government's role in purchasing (or producing) medical care services on behalf of public sector beneficiaries (primarily, Medicare and Medicaid beneficiaries, veterans, members of the armed services, public employees, prisoners, and Indians). In each of these programs many decisions are made concerning who will be covered, what services will be covered, how much will be paid for the services, and from whom they will be purchased. Second, governments make policy decisions on a variety of public health issues: for example, how many and what types of resources will be devoted to protecting the food, water, and air

hospitals and medical groups) make policy decisions for their own organizations that collectively effect health policy more broadly. Similarly, individuals make policy decisions when they choose their health plan or providers.

In an attempt to narrow my task to somewhat manageable proportions, I choose two areas of health policy for consideration. First, I consider policies designed to extend health insurance to the currently uninsured; and second, policies designed to improve the performance of managed care. I pick these two areas because each are broad and important questions that are likely to remain on the policy agenda for years to come.

The title of this paper is 'Numbers we Need', but left unstated is the identity of 'we'. Academics and other health policy analysts take for granted that the purpose of health care is to improve population health (see, e.g., Kindig, 1997). Some might fantasize about a world in which there is a benevolent dictator whose goal is to maximize aggregate population health status -- measured, for example, using a metric of quality adjusted life years (QALYs). The benevolent dictator allocates a portion of national income to health care, and, within the health care sector allocates resources to various forms of personal health care services (physicians, hospitals, home health, etc.), public health services (e.g., making the food, air, and water supply safe; community-based health promotion and disease prevention campaigns), and other actions (e.g., nutrition programs; investment in education; anti-poverty programs) which might be expected to improve population health. Within the personal health care sector, the benevolent dictator would decide which technologies, pharmaceuticals, and preventive services would be delivered.

supply; how much investment should be made in health promotion and disease prevention activities such as reducing tobacco use, the rate of teenage pregnancy, or the prevalence of sexually transmitted diseases. Third, governments regulate the purchasing of medical care services in the private sector with the goal of assuring the availability of high quality care through licensing and certification policies for providers and insurers, and with rules such as those included in recently proposed patient protection acts. Fourth, governments invest in and regulate the availability of medical care technology and resources (e.g., NIH, FDA, Hill-Burton, Health Manpower Development Act). Fifth, there are a plethora of government activities outside of the medical care arena, per se, that affect the health of the population: e.g., education policy, anti-poverty policy, nutrition policy, employment policy.

This benevolent dictator would need numbers that would provide good estimates of the effects of alternative allocations on population health outcomes. For example, how much will QALYs increase if additional investment is made in autologous bone marrow transplants for patients with fulminant breast cancer, and how does this compare to the increase in QALYs that will result from coverage of a new class of drugs for arthritis, or from increases in primary care or preventive health services? How do these increases compare to the increased QALYs that would result from investment in nutrition programs, or in education?³

The benevolent dictator would certainly want to make use of information about differences across populations in the level of QALYs and in the rate of change of QALYs to optimize allocation of resources. If she found, for example, that age-adjusted QALYs were much lower in some parts of the country than others, then she might shift resources from the high QALY areas to the low QALY areas (or at least disproportionately make new investments in the low QALY areas), on the theory that there are diminishing marginal returns -- that is, one dollar invested in a geographic area with low QALYs will likely produce a higher return than in an area that already has relatively high QALYs. Similarly, if there are some racial or ethnic subgroups with low QALYs, investments in health care for these subgroups is likely to produce greater returns. Further, if there are geographic areas or diagnostic subgroups in which the trends over time in QALYs compare unfavorably, then special attention and problem correction would be needed. If, for example, QALYs decline for people with asthma over a five year period while increasing for people with cardiovascular disease, then special attention to figuring out how to reduce environmental hazards or to improve the care of people with asthma would be warranted. If QALYs decline in one area of the country while increasing elsewhere, then again attention and corrective action would be needed.

Clearly we do not have this fantasized benevolent dictator; instead, policy is made by a

³ Information would also be needed on preferences of the population for health and other goods. How much do people value good health, and how much health are people willing to trade-off for other goods -- such as transportation, food, clothing, or leisure? Within the health care sector, patient preferences would need to be known (or accommodated) as physicians and patients shared in decision making (e.g., whether watchful waiting or surgery is a preferred option will often depend on patient preferences).

combination of politics and markets. Legislators are important actors in health policy, as are the president, governors, and political appointees in the executive branch. Most elected politicians have re-election as a preeminent goal, along with many other goals, including 'serving the common good' (Mayhew, 1974).

Bureaucrats, often with multiple goals of protecting their jobs, building their organizations, and serving the public interest have important influence on policy formation as well. In the private sector employers make health policy with the primary goal of trying to attract and retain a high quality labor force. Health plans and medical groups make policy that serve the interest of their organization -- typically to increase the number of patients and net revenues.

In the pristine world of the benevolent dictator it is relatively clear, at least hypothetically, what numbers are needed to help her accomplish her goal of improving population health status. In the much messier policy world with which we are blessed, it is less clear what numbers will satisfy the needs of actors in various positions in the policy process. If we had good estimates of the effects of alternative policy choices on QALYs, would this help legislators get re-elected, or help bureaucrats keep their jobs or expand their organization? Would these numbers help medical groups or health plans gain market share? It is not clear that the numbers needed by the benevolent dictator are necessarily the numbers that would be identified as a need by any of the participants in the policy process.

The messy world is different from the benevolent dictator's world in three important ways. First, policy makers are not rewarded directly for maximizing QALYs. Consider a politician or bureaucrat faced with the choice of investing in preventive health care or in a new life saving technology. Analysis might show that the investment in prevention will have a larger effect on QALYs than the new technology. However, the manufacturer of the technology, the providers who would use it, and the few patients who would benefit may form a powerful coalition; the politician may well decide that her chances of reelection are greater if she supports the new technology than if she supports the investment in prevention. The health plan or medical group manager might make a similar decision, especially if the investment in prevention will take many years before it pays off in increased QALYs.

Second, unlike the benevolent dictator, policy makers often do not have the freedom to consider widely different alternative investments in improving population health and decide which investments

should be made. A politician or bureaucrat who knows that investment in better coverage of primary care for the currently uninsured will likely produce a larger increase in QALYs than a 6% (as opposed to 2%) increase in premiums paid to HMOs for Medicaid beneficiaries is unlikely to be given the option -- her option is typically either to support the 6% increase or not, but she is unlikely to have the freedom to choose what to do with the extra money if she chooses the 2% option.

Third, the benevolent dictator needs information in order to make decisions about how best to improve population health status, but policy makers often seek information in order to improve their competitive position or to persuade other policy makers to support their position. For example, most supporters of universal coverage are convinced it is a good idea; additional information is unlikely to change this opinion, nor is it likely to change the opinions of diehard opponents. However, good information about the effects of a particular proposal for universal coverage might persuade some of the those wavering in the middle. Similarly, a medical group might 'know' that it provides the best health care in a community, but might need information for its marketing materials in order to convince prospective patients.

Good information on health status and the expected effects of alternative interventions on health will be less valuable in our messy policy environment than in the pristine world of the benevolent dictator, but will still be valuable. If she knew how to improve population health status at a reasonable cost, the benevolent dictator would, by definition, do so. However, as a result of institutional and market constraints, if policy makers in our world knew how to improve population health status, they would not necessarily do so. Nevertheless, good information on population health status and how best to improve it is likely to lead to real improvements in health (though perhaps with less certainty or speed) even in our messy world. This is likely to be the case for three reasons. First, there are many decisions currently for which policy makers simply do not know which alternative will do most to improve population health; if they had such information, they would be more likely to choose that alternative than if they didn't have the information. Second, there are some decisions currently where a policy maker is

strongly pressured by interest groups to adopt policies that the policy maker intuitively is not likely to do much to improve population health; evidence that confirms the policy maker's intuition will increase her ability to withstand interest group pressure. Third, as discussed below, information on the effectiveness of competing health plans and providers in improving population health is needed in a market-based system in order to systematically reward plans for producing high quality health care.

Health Policy and the Uninsured

The political and human problems created by growing numbers of uninsured Americans will continue to attract the attention of policy makers in public debate for many years to come. It will be instructive to review the policy analysis that accompanied the Clinton proposal in 1993 to investigate the numbers needed as we consider health policy for the uninsured.

The Health Security Act (HSA), proposed by President Clinton in September, 1993 supported a small industry of quantitative analysts generating estimates of the effects of the proposal. Within the administration there were at least 60 analysts who devoted substantial effort to producing or reviewing estimates of the effects of the HSA.⁴ The Congressional Budget Office devoted considerable resources to producing its estimates of the effects of the HSA. Substantial additional analysis was performed at Lewin, the Urban Institute, and other consulting firms and think tanks.

This small industry produced estimates of the effects of the HSA on government revenue and expenditures, on health care premiums, and on employment. Robert Reischauer (the former head of the Congressional Budget Office) and Linda Bilheimer (Deputy Assistant Director at CBO) list the main questions the CBO addressed: “(1) the extent to which reform would increase insurance coverage; (2) whether premiums would rise or fall as a result of reform; (3) how much choice consumers would have in a

⁴ This group of analysts included personnel from many parts of HCFA (most notably the Office of the Actuary and the Office of Research and Demonstrations, but also including other Medicare and Medicaid experts); the Office of the Assistant Secretary for Planning and Evaluation (ASPE); the Agency for Health Care Policy and Research; other parts of HHS (including units of the Public Health Service); the Office of Management and Budget; the Treasury Department; and the Department of Labor.

reformed system; (4) how the scope and depth of insurance would compare with current coverage; (5) whether the proposal would affect employment; and (6) the extent to which reform would slow the growth of aggregate health spending.”⁵ The CBO’s activity paralleled the activity within the Administration and at the think tanks and consulting firms.

Reischauer and Bilheimer do an excellent job of describing the procedures the CBO used to provide answers to these questions, the data sources used in providing answers, and the many limitations of the data. They ‘confess’ that there was substantial uncertainty in the CBO estimates of the effects of the HSA on aggregate health care spending, government revenue and expenditures, and the plethora of other estimates made by the CBO.⁶ They conclude that if more effort had been put in the late 1980s into collecting information and conducting research on

the responses of consumers, providers, and business to various changes in incentives, the uncertainty surrounding some of those estimates could have been reduced substantially. Nevertheless, a huge amount of uncertainty would have remained because the legislative proposals of 1994 called for systemic change. When proposals attempt to radically restructure the health care system and change the incentives and relative prices faced by all participants, the best data from the existing system and the most sophisticated research will be able to provide only partial insights into what that brave new world will look like.

Strikingly absent from all of this effort was any attempt to estimate the effect of the HSA on the health status of the U.S population. If we create a society in which everyone has health insurance, do we expect the health of the population will improve? If so, by how much? Nowhere in the blizzard of numbers produced by the estimators was a single number that would provide an answer to these questions.

⁵ Bilheimer and Reischauer, 1995.

⁶ As discussed by Bilheimer and Reischauer, with amplification from Nichols (1995) and Thorpe (1995) there were gaps in available data that increased the uncertainty of the estimates. Notable among these gaps were that the main source of data on household health expenditures -- the 1987 National Medical Expenditure Survey -- was dated, and that there were no good sources of data that linked individual data on income and health expenditures to employer level data on employment, wages, and employer expenditures for health care. MEPS provides a data source that at least partially resolves the problem of ‘old’ data (assuming that the expenditure data from MEPS is released soon); the lack of data linking individuals to employers still exists, and would continue to complicate estimates of the effects of employer mandates or ‘pay or play’ type proposals if such analyses were undertaken today.

To my knowledge, no one within the administration, the CBO, or any of the other organizations involved in producing HSA estimates devoted resources to attempting to provide an answer to these questions.

As a result, we had a debate in which the costs of universal coverage had ‘hard’ numbers associated with them, but the benefits of such coverage to the newly insured did not. We (the administration, the CBO, and other analysts) created estimates of the effects of universal coverage on health care utilization – the CBO estimated that the uninsured were expected to increase their health care utilization by 57% after becoming insured.⁷ We created estimates of the effects of universal coverage on public subsidies – net new federal government health insurance subsidies for low-income persons and their employers were estimated to cost approximately \$30 billion per year. But we did not provide any summary information of the expected effects of the HSA on the health status of the population.

While the costs of universal coverage were well documented, the benefits of such coverage to the newly insured were not. What would be gained by spending an additional \$30 billion per year to support the health insurance of low income workers? The promise of ‘health security’ for an anxious middle class is attractive to some, but is health security worth \$30 billion per year? Proponents of universal coverage pointed to studies showing that the uninsured put off needed care because of inability to pay; are less likely than the insured to have a regular source of care; suffer inferior health outcomes in a variety of circumstances; and suffer financial catastrophes. But none of these studies provided a metric against which to measure the cost of \$30 billion in annual subsidies.

Much more powerful would have been an estimate that universal coverage would lead to an increase of, for example, 1 million healthy years of life per year. Measured against the cost of \$30 billion per year in subsidies, each year of healthy life would cost \$30,000. We might have collectively decided that this is too much money, but at least the debate could have been engaged comparing the costs and benefits of universal coverage.

A number that health policy makers needed in 1993-94, and continue to need as universal coverage proposals are debated in federal and state capitols, is an estimate of the effects of universal health

⁷ Reischauer and Bilheimer, op. cit.

insurance on population health status.

Estimating the Effects of Universal Coverage on Healthy Years of Life

It is not an easy task to produce estimates of the effects of universal coverage on population health status. However, there is substantial uncertainty in many of the revenue and expenditure estimates of the effects of universal coverage as well, and this uncertainty does not stop the revenue and expenditure estimates from being produced; the fact that there will be uncertainty about estimates of the effects of the effects of universal coverage on health status should not dissuade us from engaging in the effort.

In this section I discuss some of the approaches that might be used to estimate the effects of universal coverage on health status. My purpose is not to specify a research design, but rather to point towards the kind of health statistics and the kinds of analysis that would be helpful in answering this question.

Direct comparison of health status for insured and uninsured persons

If we conducted a large scale social experiment, in which we implemented universal coverage in twenty communities while leaving 17% of the population of twenty other (randomly assigned) communities uninsured for four or five decades, and carefully and continuously measured the health status of the population in the forty communities, we would likely have a pretty good estimate of the effects of universal coverage on health status.⁸

In the absence of these experimental data, we can use observational data and multivariate

⁸ The closest we have come to this experiment is the Rand Health Insurance Experiment (HIE), in which a randomized group of participants were essentially uninsured for the first \$1,000 per year of medical care expenditures. The HIE found that virtually no effect of health insurance on health status. However, there are four features of the HIE that are quite different from the proposition of 'insuring the uninsured': first, in the HIE all participants were fully insured for expenses above \$1,000; second, most participants in the HIE had greater purchasing power than many of the currently uninsured; third, participants in the HIE lived in communities in which most people had health insurance and received care in systems that primarily treated insured persons; fourth, a longer time period for follow-up may be needed, since many of the largest effects of being uninsured are likely to be cumulative.

modeling techniques to assess the relationship between variations in insurance status and variations in morbidity and mortality. A basic strategy would be to use survey data -- such as MEPS or NHIS -- to compare the health status of insured and uninsured persons, controlling for all factors, other than insurance status, which might be expected to affect health. This strategy is similar to the basic strategy used by the CBO and other analysts to estimate the effects of insurance on health care utilization. The observational strategy has a variety of pitfalls. Among the many difficulties:

Insurance status is endogenous to health status. People in poor health will be more likely to be willing to pay for coverage than people in good health. Conversely, people in poor health are likely to have more difficulty obtaining coverage than people in good health. An uninsured poor person who develops a serious chronic illness is likely to become enrolled in Medicaid (and, potentially, Medicare). Since health status may affect insurance status, as well as being affected by it, teasing out the causal relationship between insurance status and health will be more difficult than if the causal relationship went in only one direction.

It is likely that the main effects of being uninsured are cumulative: a person who is uninsured for a long period of time may put off needed care, with a cumulative effect on morbidity, disability, and mortality; in contrast, being uninsured for a short period of time may have relatively little effect on health status. Most of our survey data on insurance status reflects contemporaneous insurance status, with relatively little good data on the history of insurance status.⁹ The relationship between point-in-time insurance status and morbidity is likely to be much weaker than the relationship between long-term uninsurance and morbidity.

Many of the effects of being uninsured on morbidity, disability, and mortality may become most apparent as people age. That is, someone who is uninsured for forty years from age 25 to 65 is likely to have a poorer quality of life and a shorter life after reaching 65 than someone who was insured from age 25 to 65.¹⁰ We have no data sources with good information on the pre-65 insurance status of current Medicare beneficiaries.¹¹

Lack of insurance is strongly related to poverty, and poverty is almost certainly even more strongly a cause of morbidity and mortality than is lack of insurance. It will be difficult to disentangle the independent effect of lack of insurance on health.

⁹ The Survey of Income and Program Participation (SIPP) and the Medical Expenditure Panel Survey (MEPS) do include questions about historical insurance status.

¹⁰ Some of the effect of being continuously uninsured from age 25 onwards will be manifested in shorter quantity of life and poorer quality of life even for people who are under 65. But many of the largest effects might be expected as people age and morbidity and mortality rates increase substantially, even among those who had been continuously insured.

¹¹ The Medicare Current Beneficiary Survey does have data on whether the beneficiary has employer-sponsored retiree health benefits. This could be used as a proxy to differentiate people who likely had a large amount of employer-sponsored health insurance as active workers from those who may have had a mixture of insured and uninsured spells.

The main source of information on mortality -- death certificates -- does not have information on insurance status.

Separate analyses will be needed of the short-term and long-term effects of being uninsured on the health of children, and careful analysis will be needed of the effects of being uninsured on mental health status.

This daunting list of obstacles makes it difficult to estimate the effects of providing universal health insurance on the number of healthy years of life; other analysts would almost certainly have other obstacles to suggest that I have omitted. But to say the task is difficult is not to say it is impossible. Substantial progress can be made with existing data sources. In estimating the effects of insurance on health care utilization and expenditures, the estimates relied heavily on analysis of NMES survey data to compare utilization of the insured and uninsured, controlling for other factors that are expected to effect utilization.¹² Similarly, analysis of NHIS, MCBS, and MEPS data could be conducted to estimate the independent effects of current (or former) insurance status on health status, controlling for other factors that are expected to affect health status.¹³ As discussed below, further progress could be made if additional data were collected.

¹² Alternatively, we could try a condition-treatment pair approach, as was used in Oregon. Expanding on the Oregon work, we could use literature reviews and expert judgment to estimate the effect of treatment for each 'condition' on morbidity and mortality. We would also include estimates of the effects of preventive services on health outcomes. Estimates of the prevalence of conditions would be derived from the NHIS, supplemented, as needed, by various public and private sector claims data bases. We would need to estimate the likelihood that an insured person will receive the indicated treatment (presumably close to 1.0 for many treatments) or preventive service, and the likelihood that an uninsured person will receive the indicated treatment. The estimate of likelihood of receiving treatment if uninsured will necessarily be somewhat speculative, and dependent on the resources available in the public hospital system, the existence of other charity care, and the extent of coverage of public programs. Sensitivity analysis with alternative assumptions about likelihood of receiving treatment if uninsured would be necessary. The result of this analysis would be an estimate of the effects of insurance on a variety of health outcomes. Using a scale such as the Quality of Well Being scale (QWB), these estimates could be combined into a summary estimate of the effects of insurance on well-years of life. This approach of estimating the effects of insurance on the probability of treatment, and the effects of treatment on health status will likely result in a wide range of estimates of the effects of insurance on health. However, in combination with the observational approach of using survey data to compare the health status of insured and uninsured persons, the condition-treatment pair approach can provide a sense of whether the observational approach is producing reasonable results, as well as a sense of the mechanism of effect.

¹³ One of the complications is including a component in this analysis that estimates the effects of insurance on mortality. The survey-based approaches will produce estimates of the effects on morbidity for people who are still alive. Additional progress could be made by linking multiple years of the NHIS data to the National Death Index. Then one could analyze the effects of point-in-time insurance status on mortality rates (controlling for other variables that are available in the NHIS).

These analyses might produce results of the following form: Under the status quo, the average health status of the population is 0.8 (on a scale from 0=dead to 1=perfect health). If we implement universal health insurance, the average health status of currently uninsured persons is expected to increase by 0.03, with a 95% confidence interval for this estimate from 0.015 to 0.045. Since there are 43 million currently uninsured persons, we expect that under universal coverage the health of the population will increase by 1.3 million healthy years of life, with a range for this estimate from 650,000 to 1.9 million healthy years of life.

An intensive research effort would be required to produce a credible range of answers to the question of the effects of universal coverage on the health status of the population. Sustained support would be needed from a funder with substantial resources -- either the federal government or a well-endowed foundation. I can only speculate on why this research has not yet been done. There appear to be four main possibilities.

Despite my optimism, the bulk of opinion from other researchers and funders is that we simply do not have the data needed to produce a credible estimate of the effects of universal coverage on population health status. The likely conclusion from a sustained estimation effort would be that we do not have any analysis to suggest that universal coverage would improve population health status by a measurable amount. This is not to say that we would conclude that universal coverage has no effect on health status -- rather that we do not have sufficient data to credibly estimate the magnitude of the effect.

Even more ominously, researchers and funders expect that an analysis of the effects of universal coverage on population health status would conclude that there probably is no effect on health, or that the effect is extremely small -- e.g., that insuring 43 million Americans would result in an increase of only 10,000 healthy years of life. As is well known, health care is only one of the many determinants of health, and the uninsured do receive substantial amounts of health care. Providing insurance to the currently uninsured would increase the timeliness and amount of health care, but perhaps most of this is 'flat of the curve' medicine that will have little effect on health status. If this is the expectation, then supporters of universal coverage would not be interested in funding the research effort.

Even if we had a good estimate of the effect of universal coverage on health status, and even if it showed that the health of the population would be significantly improved, this estimate would have little effect on the outcome of the policy process. Many people at least implicitly accept the notion that universal coverage would improve health. Making explicit the magnitude of the relationship will not persuade a hesitant public or reluctant legislators that the changes in the rules of health care financing required to reach universal coverage (e.g., mandates on employers, mandates on individuals, and/or the new tax revenues that would be needed to finance public provision of coverage) are worth the political pain or the economic dislocation they would cause. Would the outcome of the policy process be any different if the best estimate of the effects of universal coverage was that QALYs would increase by 4 million than if the estimate were that QALYs would only increase by 40,000?

With a very full agenda of research topics, neither the federal government nor major foundations have devoted sufficient attention to developing a research program that would answer the question.

In 1993 and 1994, in my role as Senior Health Policy Adviser in the Clinton Administration, I was not part of any discussion of the possibility or advisability of trying to create such an estimate. Despite interminable meetings on a wide variety of arcane and often unproductive matters, I was not aware of a single meeting among the many estimators within the Administration on the subject of whether we could create (or contract with others to create) an estimate of the effects of the HSA on population health status. Part of the reason is that the OMB and the CBO were required by law to estimate revenue and expenditure effects, while there was no similar requirement for estimates of the effects on health. But this is only part of an explanation: estimates were made of the effects of the HSA on many outcomes that were not required by law. For my own part, caught up in the day-to-day bustle of designing Health Alliances, figuring out how Medicaid would be melded into the HSA, and estimating the effects of the HSA on costs, I confess to not stopping to give serious thought to this problem. If I had, I could at least have arranged for relevant estimators to spend 30 minutes discussing it. We likely would have concluded that with a relatively short political window and with the resources we could bring to bear, that credible estimates would not have been possible. But at least we would have had the chance to reach that conclusion. I hope that with the benefit of less time pressure and potentially greater resources, that the federal government and large foundations will put more than thirty minutes into considering whether a sustained effort to estimate the effects of universal coverage on population health status is likely to be worthwhile.

The discussion above suggests the need for a sustained research effort to help policy makers understand the effects of a potential policy change. Progress can be made with creative use of existing data. But further progress could be made with additional data that provided continuous history information on a group of people with data on their health status, their enrollment (or lack thereof) in insurance products, and their health services utilization. These sorts of data are discussed further below.

Public Policy and Managed Care

We are in the midst of a well-publicized revolution in health care financing and delivery in the U.S. The fee-for-service payment system and 'cottage industry' medicine are being transformed.

Hospitalization rates have declined substantially, and the practice of medicine has shifted from an environment in which there were few constraints on resources (at least for the well-insured) and in which 'more was better' to an environment with some resource constraints, even for many who are insured, and in which more is not necessarily assumed to be better. Many physicians and some patients are dissatisfied. Patients and prospective patients are worried that if they get really sick, their physicians will not have the freedom (or the available resources) to treat them effectively.

Policy analysts are worried about avoiding a 'race to the bottom'. In theory a competitive market will reward high quality care, and health plans that produce poor quality either by not using enough resources or not using them effectively will lose enrollees. But if good measures of quality of care are not available, then health plans (and the providers in them) may be pressured to reduce quality below the levels that we as patients desire. These worries are particularly acute for Medicaid patients, some of whom have few choices of providers, and for Medicare beneficiaries, who are more likely to be vulnerable to the effects of poor quality care.

The stampede to managed care has occurred partially as a result of private sector decisions made by employers and employees, but public policy has had significant influences as well. Some argue that the 'signalling' effect of the Health Security Act proposal for 'managed competition' encouraged providers to organize into health plans and encouraged employers to turn to managed care (Peterson, 1998). More directly, the actions of Medicare, Medicaid, and state and federal governments as purchasers of health care increased the market for managed care.

Public policy will continue to grapple with the managed care transformation in the future. High on today's agenda are the debates over patient protection acts and other forms of managed care regulation. We will almost certainly continue to debate the extent to which public policy should encourage the growth of managed care in Medicare, Medicaid, and in the private sector, and continue to debate the relative advantages of public control over resource planning and budgets versus reliance on competition among private health plans.

In addition to broad debates about managed care, public policy is continually and contentiously concerned with the amount and form of public expenditure for public beneficiaries. How much should

Medicare and Medicaid pay managed care organizations? Shroud-waving by providers is a time honored tradition – we expect providers to argue that if reimbursement rates are not increased, then quality of care will suffer. Managed care is no different in this respect than fee-for-service: the American Association of Health Plans argues just as vociferously as the American Hospital Association or the American Medical Association that Medicare payments should increase. However, in the absence of data on health outcomes, it is difficult to assess how much credence these arguments should be given.

In assessing the managed care revolution, and making intelligent policy regarding health care financing and delivery, we are greatly handicapped by not having good measures of health system performance. Are patients with acute problems -- for example, otitis media, heart attacks, pneumonia, cancer, or trauma -- treated any more or less effectively under managed care than under fee-for-service, any more or less effectively in some areas of the country than others, or any more or less effectively now than five years ago? Do patients with chronic problems -- for example, diabetes, asthma, multiple sclerosis, osteoporosis, or congestive heart failure -- receive more effective care or better maintain their level of functioning? Has the level or effectiveness of preventive health care services changed? Have any of these outcomes changed differentially for vulnerable groups or in some areas of the country?

To a large extent we are flying blind in trying to make intelligent health policy; we don't have good answers for most of the important questions about health system performance. We have little information to help us determine whether greater investment in medical care, or different sorts of investments in medical care would improve health outcomes. It is as if we ask the Federal Reserve Board to set monetary policy with little information about whether the economy is expanding or contracting, and with no information about the trajectory of inflation, employment, and productivity.¹⁴

¹⁴ Luft and Miller (1997) reviewed the 37 peer-reviewed studies that had been published by the end of 1996 examining managed care performance, of which 15 reported results on quality of care. Most of these studies use data from the early or mid 1990s, with virtually no information available on outcomes in recent years. Most of these studies examined a small number of HMOs, and were based on ad hoc data collection. Although the research literature has expanded during the past two years, there is still little systematic evidence available concerning the effects of HMOs on quality or outcomes. If we ask whether health outcomes for people with asthma, coronary artery disease, or arthritis has changed as a result of the health care financing revolution, or whether outcomes have changed differentially for Medicaid recipients, or people of color, or the elderly or the poor, or whether outcomes have changed differentially for people living in some areas of the country compared to others, we have little idea.

In addition to a need for broad measures of health system performance to guide macro-level policy direction, there is a need for measures of individual health plan and medical group performance to guide employer, public purchasers, and consumer policy choices, and to support the development of a market in which high quality care is rewarded.

Available information on health outcomes and health system performance

Mortality statistics are the most widely available and best publicized information we have on the health status of the population. The nation's vital statistics system provides timely information on mortality rates, both for the country as a whole, as well as for geographic and ethnic subgroups. The mortality rate, by cause of death, is a useful indicator of the health status of the population and, indirectly, on the performance of the medical care system. For example, very high infant mortality rates and all-cause mortality rates in Harlem, New York are indicative of a serious problem. The observation that mortality rates in some areas of Harlem are above the levels in Bangladesh has not yet mobilized an adequate policy response, but does demonstrate the ability to use mortality statistics to monitor the health of the population. Similarly, if we were to observe increases in the mortality rate throughout the country (as has been occurring in post-Soviet Russia) we would have serious cause for concern, and likely be spurred to try to find a policy response.

Although undeniably useful, the mortality rate is a very blunt indicator of the performance of the health care system. Much of what gets done in the health care system is directed at reducing morbidity and disability, and has little effect on mortality, especially in the short run. Better (or worse) care for people with diabetes or asthma may eventually effect longevity, but most of the effect is likely to be a number of years in the future. Some medical care, such as care for people with heart attacks or cancer, may affect mortality more immediately, but much medical care will affect quality of life much more directly than mortality. (In contrast, preventive care does not effect either quality of life or mortality in the short run, but is designed to improve both quality and quantity of life in the long run).

Many public health professionals and policy analysts have a rough sense of the trend lines in mortality rates: age-specific mortality rates have been declining, as has the infant mortality rate. Mortality

rates (especially infant mortality) are much higher for blacks than whites, and the differential has not changed much over the last decade. By this measure, the health of the population is improving slightly, although we have not been successful in reducing health disparities.

Other than mortality, there is no widely publicized indicator of the health of the population that allows us to determine whether we are getting healthier or whether some subgroups are faring differently than others. Some of the requisite data are available, but not widely publicized. The NHIS has for many years collected data on self-reported health status, and for fifteen years has collected data that allows the estimation of a crude health-related quality of life index (Erickson, Wilson, and Shannon, 1995; Gold, et. al., 1998).¹⁵ Although the basic data are available, they are not widely known. I conducted an informal survey of a small number of public health professionals, policy analysts, and quality-of-life gurus and asked them whether the percentage of the population reporting themselves to be in fair or poor health has changed over the last decade, whether health-related quality of life had changed, or whether the white-black gap in the proportion in fair or poor health changed. I did not find a single person who knew any of the answers. I ask the reader, before turning to Figures 1 and 2, to consider whether you know the answers to these questions.

As shown in Figure 1, the proportion of the over-65 population reporting themselves to be in fair or poor health decreased slightly from 1983 to 1994 -- declining from approximately 35% to approximately 30%.¹⁶ Although smaller sample sizes make the estimates less stable, there appears to have been a larger improvement in the health status of the non-white elderly than in the health status of the white elderly. Among all age groups, the proportion in fair or poor health was close to constant, although this analysis has not been age-adjusted. Using this measure, the health status of the elderly appears to have improved somewhat, and we have made a bit of progress in reducing racial disparities in health status.

¹⁵ See Field and Gold, Summarizing Population Health, National Academy Press, 1998 for a discussion of the issues in constructing a summary measure of population health status.

¹⁶ I am indebted to John Anderson for providing this analysis of NHIS data. Although more recent data are available, at the time of this draft, Dr. Anderson was able to provide me with data through 1994.

Similarly, the Health and Limitations Index (HALex) suggests that health related quality of life increased among the elderly from 1984 to 1994, and appeared to increase slightly more for non-white elderly than for white elderly (Figure 2)¹⁷. HALex varies from 1.0 for persons in excellent health who report no limitations in activity to 0.10 for persons reporting poor health and limited in activities of daily living. HALex is calculated from responses to questions on self-reported health status and degree of limitation in usual activities; thus, the pattern of changes in HALex shown in Figure 2 is not independent of the pattern in Figure 1.

In contrast to the relatively wide publicity accompanying the release of new statistics on mortality rates, these data on trends in health status are not well known. I can only speculate on the reasons. First, there is, understandably, more interest in the number of people who die than in the number who report themselves to be in poor health; the finality of death makes it a health status indicator of inherently greater interest than the existence of poor health or activity limitations. Second, mortality statistics are measured with little error -- we can be confident that trends over time or differences in rates across population groups are measuring real differences in outcomes. In contrast, self-reported health status and reports of limitations in major activities may be influenced by differences in cultural expectations, subtle question wording or question ordering effects, or sampling strategies. Third, there are a variety of methods of measuring health related quality of life, without a consensus method having yet been adopted (see Field and Gold, 1998, for discussion).

Perhaps most importantly, mortality statistics are available for small geographic areas and by cause of death, while currently available data on health related quality of life (HRQOL) cannot be used to meaningfully compare small areas, or to track trends over time in HRQOL for people with various diseases and conditions. We do not currently collect data, for example, on the HRQOL of residents of south-central Los Angeles or other inner city areas, or track changes in these values over time. Similarly, we do not currently collect data on the HRQOL of people with asthma, heart disease, breast cancer, or other conditions. These gaps limit the policy relevance of quality of life data.

¹⁷ HALex is described in Erickson, et. al, 1995.

Other than mortality data and NHIS data on self-reported health status and disability, few data sources are currently available that provide any indication, for the population as a whole, of the effects of medical care on health outcomes. A review of the candidates for leading indicators suggested by the HHS Working Group on Sentinel Objectives (1998; Chrvala and Bulger, 1999) and of the measures in HEDIS 3.0 demonstrates how difficult it is to systematically measure outcomes, other than mortality and HRQOL, that are likely to be sensitive to the quality of personal health care services.

Among the candidates for 'leading indicators' suggested by the HHS Working Group on Sentinel Objectives, there are few (other than the mortality indicators and the 'reported disability' indicator) that will be sensitive to whether personal health care services are doing a good job of getting us better when we are sick (see attached 'Table 6' from the 1998 Leading Indicators Report). The asthma hospitalization rate is an exception – if this rate is high, it indicates a failure of ambulatory care. Most of the other indicators measure the effectiveness of public health services or the effectiveness of preventive health care and health promotion activities. While these are important indicators to monitor, it is striking that so little information is available to monitor the effectiveness of personal health care services, when expenditures on these services account for over 90% of total health care expenditures.

Similarly, the indicators in HEDIS 3.0 – the generally accepted state of the art in measuring health plan performance -- primarily measure process of care and provide relatively little information concerning health outcomes, particularly for those who are sick (see NCQA (1997) for a description of HEDIS measures, and McGlynn (1997) and Eddy (1998) for excellent discussions of the difficulties in measuring quality and performance). Under the 'effectiveness of care' domain, most of the suggested indicators of effectiveness are measures of process (this is true both of the 'reporting set measures' and of the 'testing set measures').

There is one measure in HEDIS 3.0 -- the Health of Seniors indicator -- which is likely to be sensitive to variations in the effectiveness of medical care. The Health of Seniors indicator is a measure of change in HRQOL -- it measures the percentage of Medicare enrollees whose self-reported physical and mental health status improved, stayed the same, or worsened over a two year period. Using survey data on approximately 1,000 plan enrollees at baseline and at a two-year follow-up, the indicator compares changes

in HRQOL among plan enrollees to the changes that would be expected based on the enrollees characteristics.

Moving Forward: Health Statistics and Health Policy

I have argued above that timely and detailed information on health related quality of life is needed to make well-informed health policy choices. This information is needed to guide macro-level policy decisions concerning health care financing and delivery, as well as to guide micro-level purchasing decisions (by employers, public purchasers, and consumers) that will support the development of high quality care in a competitive marketplace.

Production of timely and detailed information on health related quality of life should be a central part of the vision for health statistics in the 21st century. We spend \$1.2 trillion on medical care, with little indication of the effectiveness of most of this spending. Public policy makers, besieged by provider demands (supported, at times, by identifiable groups of patients in need) to put more money into personal health care services, have little ability to determine whether the requested investments will produce positive results. Lack of information on HRQOL contributes to an imbalance of spending on public and personal health care, and to an imbalance in spending on the insured and uninsured. Consumers and sponsors have limited ability to determine which, among a set of competing health plans or medical groups, will produce better health outcomes. In the absence of informed consumer choice, many worry that health plans and physicians will stint in providing medical care to those most in need.

To date, measurement of performance of the personal health care system, such as it is, has largely been left to the private sector -- organizations such as the National Committee on Quality Assurance, FACCT, and the Pacific Business Group on Health -- or to public purchasers such as Medicare and Medicaid. But measurement of the health status of our communities, and of health outcomes produced by competing health plans and provider groups is a public good that will not be produced in optimal amounts by the private sector, or even by public purchasers managing programs on behalf of a defined group of public sector enrollees. Rather, timely measurement of HRQOL at a fine level of detail should be a function for health statistics.

The quality of personal health care services is only one of several factors influencing HRQOL – genetic predisposition to illness, age, and environmental factors (e.g., poverty, nutrition, air quality) are certainly more important determinants of cross-sectional variation in health status than is the quality of medical care (at least within the range of quality of care that is provided in the U.S.) (Evans, Barer, and Marmor, 1994). Nevertheless, we should expect substantively important variations in quality of medical care to have measurable effects on health status. That is, if the quality of medical care improves (or deteriorates) in ways that matter to patients, we should be able to measure the results in improved (or worsened) health status.

One source of complication is that the effects of good versus poor quality medical care on health status are likely to be manifest for a relatively small number of people. Most people have few health related problems during the course of a year, and many of those with problems have problems that are not refractory to medical care. Of those with problems for whom medical care may matter, many have problems for which a wide range of medical care quality will be ‘good enough’ to produce the desired outcome.

With hypothetical numbers, I attempt to illustrate the order of magnitude of the problem. Suppose that under the status quo medical care system, we expect that the average HRQOL is 0.80; suppose further that if medical care deteriorates next year then we expect that 5% of people will experience a 0.20 reduction in HRQOL as a result (using the HALex scale, this would be the case if approximately 5% of people who would have reported themselves in ‘very good’ health instead report themselves to be in ‘fair’ health.) Then overall HRQOL would decline by 0.01 to 0.79. If poor quality medical care were to cause 5% of the population to experience a 0.20 decline in HRQOL, this would be a substantial deterioration and a cause of serious concern. However, if we are trying to monitor outcomes in competing health plans, or determine whether outcomes have deteriorated (or improved) in a given community, detecting a year-to-year change of 0.01 in HRQOL will require a large sample and sophisticated measurement techniques. At a minimum, an effort similar in scale to the monthly Current Population Survey that is used to track the unemployment rate would be needed.

Measurement of HRQOL at a fine enough level of detail to track substantively significant changes

in the health of communities, ethnic and racial subgroups, health plan and medical group enrollees, and among people with varying diagnostic problems and functional levels is an enormous undertaking. Assuming that it will take a number of years to generate the required political support and technical capacity to undertake such a project, starting with a demonstration project in a few metropolitan areas would be a sensible beginning.

Given our current environment, measurement of HRQOL would be accomplished by surveying a random sample of community residents. Similar to the current NHIS, the survey would need to measure key independent variables -- demographic characteristics, current and former insurance status, health plan enrollment (if any), medical group enrollment, existence of acute and chronic conditions, and use of medical care services -- in addition to the key dependent variable of HRQOL.

The sampling design could be much more efficient and the measurement of insurance status and medical group enrollment much more precise if the government collected uniform data on health plan enrollment. If we had uniform plan enrollment data that contained unique person, health plan, and provider identifiers, we would be able to measure insurance status over time with little error. We could draw stratified samples by health plan and provider group. One difficulty would be sampling of the uninsured since they would not be included in a data base constructed from health plan enrollment. A subset of the uninsured could potentially be identified from analysis of people who disappear from the enrollment data base, but additional population-based screening would be needed for full identification.

Unlike the task of timely and detailed measurement of HRQOL, which 'simply' requires money (and a bit of technical expertise), the task of generating a uniform national data base of health plan enrollment requires substantial organizational and political skill as well. Concerns about privacy must be dealt with, and concerns about burden on health plans, self-insured employers, and public programs such as Medicare and Medicaid must be overcome as well.¹⁸

¹⁸ Addressing these concerns is beyond the scope of this paper. My only contribution on the privacy issue is to remind readers that uniform Medicare enrollment and claims data have been collected and made available for public use for many years. As far as I am aware, there has not been a single instance of breach of confidentiality in the use of these

Finally, eventually policy makers will need data on the inputs to personal health care services -- that is, will need to know what health care services get delivered to whom by which providers. This can be accomplished with uniform national data on health care encounters. The survey data on HRQOL measures outputs, and these survey data can also provide some data on key mediating demographic characteristics, and on the independent variables of health plan and medical group enrollment. However, survey respondents can provide only sketchy reports on inputs -- receipt of health care services; these data, as well as physician reports of diagnoses should come from physicians and other health care providers.

Timely receipt of encounter data would also allow a much more efficient sampling strategy for the HRQOL surveys. First, the sample could be stratified to oversample those persons with significant use of the health care system, and/or persons with specified diagnoses. This sampling strategy would oversample those persons whose HRQOL is most likely to be sensitive to the quality of medical care, and allow for more precise estimates (given a fixed sample size) of the performance of the personal health care system. Second, uniform national encounter data, combined with uniform health plan enrollment data, would allow identification of uninsured persons who use the health care system, and create a sampling frame for these persons. This would leave a relatively small remaining group of uninsured persons with no health care contacts who would need to be identified through a population based screening survey.

The privacy and burden concerns raised by the specter of uniform health plan enrollment data are magnified many times by the thought of uniform encounter data. Uniform eligibility data would be supplied by a relatively small number of health plans and self-insured employers. Uniform encounter data would presumably be supplied by health care providers, who outnumber health plans and self-insured employers by two orders of magnitude. There is substantial ongoing work developing standards for such data, but we have apparently not yet reached a political consensus on the desirability or feasibility of collecting these data.

In measuring HRQOL and in generating uniform national enrollment data, it makes sense for the National Center for Health Statistics to take a leading role. However, in generating uniform national

data. Apparently it is possible to construct and implement a system with adequate privacy safeguards.

encounter data, it probably makes more sense for NCHS to work as a junior partner with the Health Care Financing Administration, which is working towards uniform data collection on health care services in the Medicare program. In addition to the privacy and technical concerns, a key difficulty in collecting uniform encounter data is figuring out how to get information from providers when there is no payment associated with the transmission of the data. A variety of statewide hospital discharge data bases have solved this problem by simply requiring hospitals to report on each discharge; however, this is much easier to do for a small number of hospitals with a relatively small number of discharges than for the many more ambulatory providers and the much larger volume of relatively low cost transactions.

As Medicare beneficiaries transition from fee-for-service to HMOs, HCFA has lost access to information on the health care services provided to beneficiaries; when health plans sub-capitate provider groups, the plans themselves may not have information from the providers on service provision. However, HCFA is now making progress in resolving this problem. As part of its effort to implement risk-adjusted capitation to HMOs, Medicare is now collecting inpatient hospital information from health plans. Further, HCFA intends to begin collecting encounter data on physician and hospital outpatient services for services provided after October 1, 2000. As HCFA institutionalizes a process of collecting information from ambulatory providers even in circumstances when no payment accompanies the information, it would be sensible for NCHS to piggyback on this process to move towards the collection of uniform encounter data (assuming that the privacy and burden concerns have been assuaged).

Conclusion

Production of timely and detailed information on health related quality of life should be a central part of the vision for health statistics in the 21st century. Health policy (both in the public and private sectors) is centrally concerned with determining how much of what types of health care services should be delivered to whom, and how much should be paid for these services. It is difficult to make intelligent policy choices when little information is available on health outcomes.

Table 6
**DATA SOURCES FOR HEALTH INDICATORS
INCLUDED IN THE CANDIDATE SETS**

Health Indicator	Data Source Level of Availability
<u>Mortality</u>	
Infant	Vital Statistics Local, State, National
Maternal	Vital Statistics Local, State, National
Motor vehicle crash	Vital Statistics, FARS Local, State, National
Alcohol-related MV	FARS State, National
Work injury	CFOI State, National
Suicides	Vital Statistics Local, State, National
Homicides	Vital Statistics Local, State, National
Firearm fatalities	Vital Statistics Local, State, National
Lung cancer	Vital Statistics Local, State, National
Breast cancer	Vital Statistics Local, State, National
Cardiovascular disease	Vital Statistics Local, State, National
Stroke	Vital Statistics Local, State, National
Diabetes	Vital Statistics Local, State, National
Unintentional injury	Vital Statistics Local, State, National
Residential fire	Vital Statistics Local, State, National
<u>Morbidity</u>	
HIV incidence	NNDSS Local, State, National
AIDS incidence	NNDSS Local, State, National
TB incidence	NNDSS Local, State, National
Measles incidence	NNDSS Local, State, National
Syphilis incidence	NNDSS Local State, National
Gonorrhea	NNDSS Local: State, National
Hypertension	BRFSS, NHANES, NHIS State, National

Hypercholesterolemia	BRFSS, NHANES, NHIS State, National
End-stage renal disease	HCFA State, National
Asthma hospitalization	NHDS some State, National
Cumulative trauma disorders	ASOII some State, National
Depression	NCS, ECAS National
Reported disability	BRFSS, NHIS State, National
Hospital days/ 100,000	NHIS some State, National
Years potential life lost	Vital Statistics local, State, National
Emerging infectious diseases	NNDSS State, National
Food/water-borne diseases	NNDSS State, National
Hospital admissions	NHDS Local, State, National

Service Delivery

Childhood immunizations	NIS, NHIS	MSA, State, National
Pneumonia/flu immunization	BRFSS, NHIS	State, National
Cervical cancer screening	BRFSS, NHIS	State, National
Mammography	BRFSS, NHIS	State, National
Preventive services delivery	PCPS	National
Primary care linkage	PCPS	National

Other Risk Conditions and Factors

Low birth wt incidence	Vital Statistics	Local, State, National
Teen intercourse	NSFG, YRBS	National
Teen pregnancy	Vital Statistics, NSFG	Local, State, National
Teen births	Vital Statistics	Local, State, National
Condom use	NSFG, YRBS	National
First trimester prenatal care	Vital Statistics	Local, State, National
Breast feeding	Ross labs, NSFG	State, National
Cigarette smoking/sales	NHSDA/NHIS/YRBS/MFS	National
Smokeless tobacco	NHSDA/NHIS/YRBS/MFS	National
Alcohol misuse/ER visits	NHSDA/NHIS/YRBS/MFS	National
Illicit drug use/ER visits	NHSDA/NHIS/YRBS/MFS	National
Seatbelt use	NHIS	State, National
Firearm Storage	BRFSS, NHIS	State, National
Overweight	BRFSS, NHANES	State, National
Sedentary pattern	BRFSS, NHANES, NHIS	State, National
Untreated dental caries	NHANES	National
Air quality exposure	AIRS	(Non-attainment areas)
Health insurance/loss	NHIS, Census, MEPS	State, National
High school graduation rate	NCES	State, National
Childhood poverty	Census	State, National

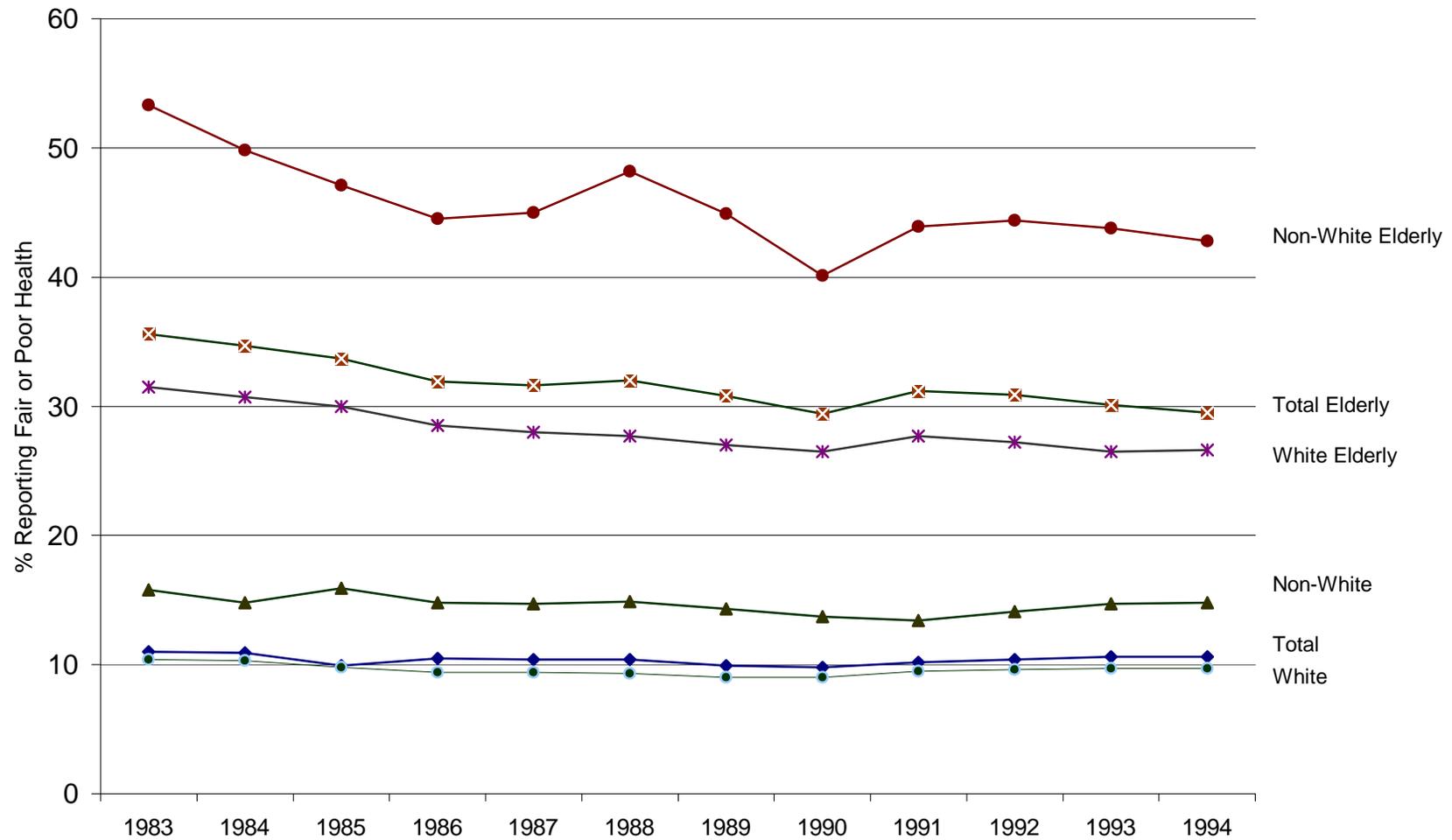
Source: Leading Indicators for Healthy People 2010: A Report of the HHS Working Group on Sentinel Objectives, U.S. Department of Health and Human Services, March 1998.

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Figure 1
Self-Assessed Health Status, 1983-1994



Source: National Health Interview Surveys, 1983-1994. Note: Results are unweighted.