

Disease Politics and Medical Research Funding: Three Ways Advocacy Shapes Policy

Rachel Kahn Best^a

Abstract

In the 1980s and 1990s, single-disease interest groups emerged as an influential force in U.S. politics. This article explores their effects on federal medical research priority-setting. Previous studies of advocacy organizations' political effects focused narrowly on direct benefits for constituents. Using data on 53 diseases over 19 years, I find that in addition to securing direct benefits, advocacy organizations have aggregate effects and can systemically change the culture of policy arenas. Disease advocacy reshaped funding distributions, changed the perceived beneficiaries of policies, promoted metrics for commensuration, and made cultural categories of worth increasingly relevant to policymaking.

Keywords

advocacy organizations, culture, health, politics, social movements

During the past 30 years, people with serious diseases have raised their political voices to an unprecedented degree, organizing to demand funding for research on their conditions. This study tracks their influence on federal medical research priority-setting. Previous studies of advocacy's political effects have focused narrowly on achievement of benefits for constituents, but I show that advocacy can produce two additional types of political outcomes, which I call distributive and systemic effects. Using data on 53 diseases over 19 years, I find that diseases with the most organized patients secured dramatic increases in research funding. I find suggestive evidence that diseases affecting primarily women and blacks tend to have lower levels of advocacy, so as disease advocacy became increasingly influential, the funding distribution shifted away from those diseases. Additionally, disease advocates made claims on the basis of dollars per death, encouraging

policymakers to use mortality as a metric to commensurate diseases and creating political pressure to standardize the National Institutes of Health (NIH) budget. Finally, the rise of disease advocacy encouraged policymakers to think of research funding as a benefit given to patients with various diseases. Once patients, rather than scientists or the public at large, were thought of as the primary beneficiaries of medical research funding, their perceived moral worthiness became increasingly relevant to funding decisions. These results bridge medical sociology and social movements research to demonstrate that

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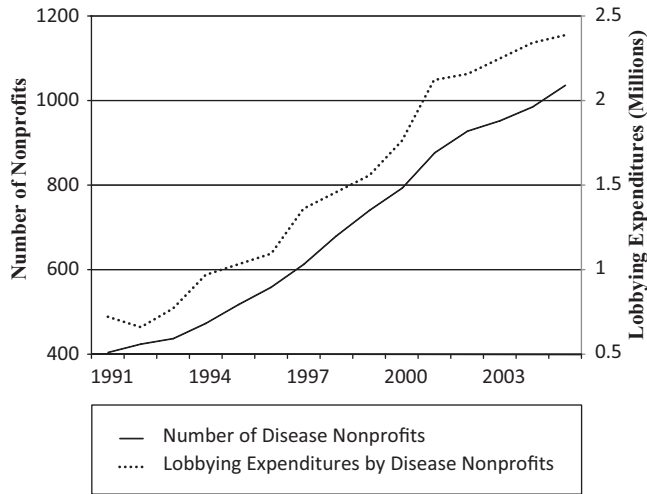


Figure 1. Expansion and Politicization of Disease Nonprofits, 1991 to 2004

Note: Disease nonprofits includes organizations targeting one or several diseases.

advocacy organizations transform the categories and meanings that shape policymaking.

DISEASES AS INTEREST GROUPS

Before the 1980s, disease patients' advocates rarely participated in the politics of federal medical research funding. A few organizations targeted diseases like tuberculosis and polio, but patients rarely played a leading role in these philanthropic public health campaigns (Carter 1961; Kedrowski and Sarow 2007). When these groups testified before Congress, they rarely competed with each other, tending to "close ranks behind a common goal: to increase the overall pot of money for biomedical research" (Marshall 1997:344). Although some groups pushed for creation of new institutes at the NIH, few lobbied Congress about the distribution of NIH funds to specific diseases (Dresser 2001).

The 1990s saw explosive growth in the number of disease advocacy organizations. In a departure from the earlier philanthropic public health model, new disease advocates viewed patients as their constituents. At the beginning of the 1990s, about 400 large nonprofits targeted diseases; by 2003, more than

1,000 did so. Their lobbying expenditures expanded even more dramatically (see Figure 1).¹ Inspired by the successes of the AIDS (Acquired Immune Deficiency Syndrome) and breast cancer movements, they lobbied Congress for medical research funding to an unprecedented degree, making competitive claims for a greater share of NIH funding (Anglin 1997; Dresser 1999).

Scholars have argued that the rise of health advocacy² transformed the social contract for science (Callon 2003; Guston 2000; see also Banaszak-Holl, Levitsky, and Zald 2010). Advocates challenged scientific autonomy (Guston 2000), changed how medical knowledge is produced and distributed (Clarke et al. 2003; Epstein 2007), and increased the prominence of lay expertise (Epstein 1996). We know relatively little, however, about disease advocacy's effects on the politics of medical research funding. Virtually all studies of disease advocacy focus on a single disease movement (for reviews, see Epstein 2008; Hess et al. 2008). Single-disease studies can neither document advocacy's effects by statistically comparing outcomes across diseases nor observe the overall effects of the increase in disease advocacy. A few researchers have conducted surveys of existing patients' organizations

(Allsop, Jones, and Baggott 2004; Keller and Packel 2007; Wood 2000), but these cross-sectional data can neither track the growth of disease advocacy over time nor conclusively document its effects on medical research policymaking. Simultaneously, a growing literature explores the determinants of NIH funding but does not measure the influence of advocacy (Gross, Anderson, and Powe 1999; Hegde 2009).³

This study is the first to analyze longitudinal data on the emergence of disease movements and also the first to demonstrate how disease advocacy affected medical research funding priority-setting. Understanding this dramatic change in health politics expands and refines theories of advocacy's political effects.

POLITICAL OUTCOMES OF ADVOCACY ORGANIZATIONS

I argue that advocacy organizations⁴ can produce three types of political outcomes: direct benefits, distributive changes, and systemic effects. Despite a growing body of research on advocacy's outcomes (Amenta et al. 2010; Andrews and Edwards 2004; Baumgartner and Leech 1998; Burstein 1999; Giugni 1999; Smith 1995), only direct benefits have been systematically studied empirically.

Direct Benefits

Most studies of advocacy's political effects focus on what I call *direct benefits*: the extent to which movements secure gains for their constituents. Researchers have looked for success in relation to a movement's stated goals (Burstein, Einwohner, and Hollander 1995; Gamson 1990) or achievement of "collective goods [for the] intended beneficiary group" (Amenta and Young 1999:40). Studies show that advocacy organizations can move issues up the agenda (Burstein 1991; Cobb and Elder 1983; Johnson 2008; King, Bentele, and Soule 2007) and influence policy content and passage (Andrews 2001; Baumgartner and Leech 1998; Skrentny 2006). However,

not all studies show political outcomes for movements, leading to some controversy over the extent to which movements influence policy (Amenta et al. 2010; Andrews and Edwards 2004; Baumgartner and Leech 1998).

Studying multiple diseases over time provides an ideal test of whether movements can secure direct benefits for their constituents. Previous longitudinal studies of social movement effects focused on organizations within a single movement (McAdam and Su 2002; Meyer and Minkoff 2004; Olzak and Ryo 2007; Olzak and Soule 2009) or a small number of movements (Giugni 2004; Soule and King 2008). Sampling 53 diseases over 19 years gives my analyses more statistical power and allows for more conclusive tests of whether advocacy organizations obtain direct benefits. Additionally, some previous studies of social movements sample on the dependent variable by only studying issues with relatively high levels of mobilization. Sampling diseases instead of movements allows me to compare diseases that were and were not targeted by advocacy, enabling stronger conclusions about causality. I draw on these unique features of my data to test whether disease advocates secured increased medical research funding. However, we cannot fully understand advocacy's political outcomes without exploring aggregate effects. When advocates enter a political arena, how do they change the distribution of resources and the decision-making process?

Distributive Changes

When advocacy organizations enter a political arena and begin receiving direct benefits, the distribution of resources shifts to favor the type of people who are most likely to organize. If traditionally excluded groups are more likely to mobilize for change, then advocacy will tend to diminish elites' political influence (Berry 1999; Dahl 1961; Lofland 1996; Loomis and Cigler 1995; McAdam 1982; Piven 2006; Radcliff and Saiz 1998). Alternatively, if socially advantaged people

mobilize more, then advocacy organizations will tend to skew the distribution of benefits toward advantaged groups (Edwards and McCarthy 2004; Hacker and Pierson 2010; Schattschneider 1960; Schlozman et al. 2007). I use the term *distributive changes* to describe these aggregate consequences of multiple groups' achievement of direct benefits. As disease advocacy expanded, some researchers hoped it would challenge inequitable funding distributions and direct resources toward minorities' and women's diseases (Callahan 2003), while others worried it would draw funds away from these groups (Dresser 1999).

Despite being the focus of extensive theoretical debates, distributive changes are rarely empirically observed due to methodological challenges. Many studies focus on a single social movement, making it impossible to observe advocacy's aggregate effects. Other studies document biases in mobilization without determining whether they lead to distributive effects on policy, in part because it is difficult to systematically classify policies by who benefits from them. Collecting data on multiple diseases over time allows me to track changes in the funding distribution. And because diseases can be classified by patients' race and gender, I can track whether the emergence of disease advocacy shifted funding to or from diseases that primarily affect minorities and women.

Systemic Effects

Direct benefits occur when advocacy organizations secure advantages for their constituents; distributive changes are the aggregate results of these individual outcomes. *Systemic effects* occur when advocates go beyond achieving benefits for their own constituents and change the structures, systems, or schemas of political decision-making. Because most researchers focus on direct benefits, systemic effects are rarely discussed. When they are mentioned, systemic effects are generally presumed to be rare, intentional, and

concrete. I argue, instead, that systemic effects may be common, unintended, and cultural.

First, many scholars assume that "social movements rarely alter political institutions" and that they can do so only when crises make institutions vulnerable (Giugni 1999:xxix; Kriesi and Wisler 1999). Second, most researchers focus on systemic effects that are intentionally sought. Giugni (1999:xxix) suggests that social movements "face a fundamental dilemma": the choice between demanding "short-term policy changes" and "long-term institutional changes." Kitschelt (1986:67) views systemic effects as an alternative strategy for achieving direct benefits: when an advocacy group cannot achieve its goals in the current political system, it "will try to broaden its demands to include those for altering the existing political system fundamentally." Third, existing studies focus on concrete changes in formal rules and systems of representation, such as the introduction of new parties (Kitschelt 1986), interest groups (Clemens 1997), government offices that serve as institutional homes for advocates (Bonastia 2000; Epstein 2007; Skrentny 2002), and direct legislation (Kriesi and Wisler 1999).⁵ Although scholars recognize that social movements often have unintended consequences and cultural effects on society at large (Andrews 2002; della Porta 1999; Earl 2004; Giugni 1999; Haveman, Rao, and Paruchuri 2007), these effects are rarely discussed in the political realm.

Growing literatures demonstrate, however, that policymaking has a strong cultural element (Berezin 1997; Campbell 2002; Skrentny 1996; Steensland 2009). Policies are profoundly affected by problem definitions (Guetzkow 2010; Rochefort and Cobb 1993; Stone 1989), cognitive and normative ideas (Campbell 2002), and logics of action (Skrentny 1996). Scholars recognize that social movement framing seeks to change the ideas that shape policy-making, but they generally describe framing as a strategic process that helps individual organizations or movements achieve direct benefits (Benford and Snow 2000; Cress and Snow 2000; McCammon et al. 2007; McVeigh,

Welch, and Bjarnason 2003).⁶ However, if advocacy organizations change the ideas that shape policymaking, effects will likely go beyond direct benefits for individual movements, changing the rules of the game for all participants (Armstrong and Bernstein 2008). Next, I discuss two systemic effects of advocacy organizations: the introduction of categories for commensuration and changes in policies' perceived target populations.

Commensuration. Political decision-making often requires comparing different entities on a single metric in a process called commensuration (Espeland and Stevens 1998; Timmermans and Epstein 2010). Advocacy organizations tend to promote metrics for comparison that favor their causes, and if policymakers adopt an organization's preferred metric, the organization will likely receive direct benefits. But criteria for evaluating claims affect all participants, not just the ones who lobbied for them, meaning that new metrics for commensuration have systemic effects on policy arenas. I will show that as some disease advocates promoted dollars per death as a way to commensurate diseases, NIH funding for all diseases drifted toward this standard.

Target populations and worthiness. Government policies vary profoundly depending on their perceived beneficiaries or target populations—that is, the groups to whom they distribute resources, whom they take resources from, or whose behavior they try to change. Beliefs about policy targets' worthiness shape which policies seem appropriate or politically feasible, influence the available frames, and are institutionalized in programs that reinforce these categories (Steensland 2006; see also Lieberman 2009; Skrentny 1996, 2002, 2006; Steinmetz 2007). Policies and laws tend to disadvantage, punish, or impose restrictions on stigmatized groups and distribute benefits to positively constructed groups (Gilens 1999; Schneider and Ingram 1993).

Most existing research treats target populations as a constant feature of policies, often

coding the target population directly from the text of bills (Donovan 2001; Schroedel and Jordan 1998).⁷ In contrast, I argue that a policy's perceived targets can change over time. Changes in perceived beneficiaries matter because they determine whose moral worthiness is relevant to the policymaking process.⁸ I will show that Congress formerly thought of scientists and the public at large as the main beneficiaries of medical research funding, but disease advocates encouraged Congress to think of disease patients as beneficiaries. Once patients were considered beneficiaries, their perceived moral worthiness was increasingly relevant to funding decision-making, which disadvantaged stigmatized diseases.

Existing research on advocacy's political outcomes focuses primarily on direct benefits. Distributive changes have rarely been explored empirically and systemic effects have been mostly ignored. The growth of disease advocacy provides an ideal opportunity to document advocacy's direct, distributive, and systemic effects.

DATA AND METHODS

I draw on quantitative and qualitative data to track the effects of disease advocacy. First, I constructed a longitudinal dataset with information on 53 diseases from 1989 to 2007.⁹ The unit of analysis is the disease. For each disease in each year, I collected data on the amount of federal medical research funding for the disease, advocacy targeting the disease, and the number and characteristics of people it killed. Table 1 provides descriptive statistics for the variables used in the analysis.

Funding Data

The dependent variable is federal medical research funding from the National Institutes of Health (NIH) and the Department of Defense—Congressionally Directed Medical Research Programs (DOD-CDMRP). In the United States, the NIH is the primary public funder of medical research, and the DOD-CDMRP also distributes a substantial amount

Table 1. Descriptive Statistics: Research Funding, Advocacy, and Mortality

	Mean	SD	Min.	Max.
NIH and DOD funding (millions)	106	178	1.5	1326
Change in NIH and DOD funding (millions)	5.8	16	-57	134
Number of nonprofits	24	37	0	211
Change in number of nonprofits	.36	5	-39	29
Total lobbying expenditures (thousands)	28	81	0	567
Number of witnesses testifying	.40	.77	0	5
Total deaths (thousands)	32	105	0	743
Change in total deaths (thousands)	.19	2.4	-33	26
Black fatalities	15%	15	.86%	98%
Female fatalities	56%	20	0%	100%

Note: Unit of analysis is the disease; variables describe funding, advocacy, and mortality for each disease in each year. All financial data are in 1987 dollars.

of medical research funding.¹⁰ I used the Freedom of Information Act to obtain historical information on NIH research funding. DOD-CDMRP funding data were available online. I converted the funding totals into millions of 1987 dollars using the CPI-URS (Bureau of Labor Statistics 2008).

Data on Disease Nonprofits

The first two disease advocacy variables come from nonprofit tax data that I aggregated by disease. I purchased the National Center for Charitable Statistics' (NCCS) Core Trend File PC,¹¹ a longitudinal dataset compiled from nonprofits' Internal Revenue Service (IRS) forms covering the years 1989 to 2007.¹² I converted all financial data into 1987 dollars using the CPI-URS (Bureau of Labor Statistics 2008).¹³ I focused on nonprofits in two categories: "Diseases, Disorders, and Medical Disciplines" and "Medical Research."¹⁴ For each of the approximately 15,000 nonprofits in these categories, I coded the disease or diseases the nonprofit was related to, if any.¹⁵ Having linked organizations to the diseases they target, I summed variables from this organization-level data to create two disease-level variables: the total number of organizations targeting the disease and their total lobbying expenditures¹⁶ in a given year. I use these measures as independent variables denoting the level of advocacy surrounding each disease.¹⁷

Congressional Appropriations Hearings

Witnesses. To measure participation of disease advocacy organizations in NIH funding deliberations, I collected data on witnesses at House appropriations hearings for Labor, Health and Human Services (HHS), and Education, which include NIH appropriations.¹⁸ For every fifth year from 1965 to 1985 and every year from 1989 to 2007,¹⁹ I downloaded lists of witnesses and their organizational affiliations from LexisNexis Congressional. With a team of seven undergraduate research assistants, I classified witnesses into 16 categories.²⁰ I then coded whether witnesses classified as health advocates represented a disease or diseases. Within each year, I summed the number of advocates testifying for each disease. I use these counts as a third measure of disease advocacy.²¹ In addition, to document the increasing prominence of disease advocates, I graph the annual percentages of witnesses in various categories.

Testimony. I also collected data on the content of witnesses' testimony. First, to document changes over time across thousands of pages of testimony, I conducted an automated content analysis using WORDij software (Danowski 2009a, 2009b). Second, to collect more nuanced data on how advocates justify their claims, two research assistants and I read

the testimony of a subsample of approximately 200 disease advocates.²² Qualitative data from this subsample provide context for the quantitative results.

Mortality Data

Next, I collected data from the Centers for Disease Control (CDC) on the annual number of deaths recorded for black, white, and other race men and women for each disease.²³ I calculated percentages of blacks and women among fatalities and also created dummy variables equal to one if over 95 percent of fatalities were women (breast, cervical, ovarian, and uterine cancers; pelvic inflammatory disease) or blacks (sickle cell anemia). I also use the total annual deaths for each disease as an independent variable.

Disease Categories

To combine these data sources, I had to align several disease classification schemes. The NIH data included information on 212 diseases, conditions, and research areas.²⁴ I selected all diseases at the lowest level of aggregation in the NIH data, matched them with the ICD-9 and ICD-10 codes used by the CDC, and classified nonprofits and witnesses based on these disease categories.²⁵ Table 2 lists the 53 sampled diseases, which include the 15 leading causes of death in the United States besides murder, suicide, and accidents.

My sample includes HIV/AIDS and breast cancer, which were targeted by unusually large and successful advocacy campaigns. When these outliers are included in the analyses, the effects of advocacy appear dramatically larger. Therefore, all models shown in Table 3 exclude HIV/AIDS and breast cancer, with notes in the text explaining when their inclusion would change the results.

Analysis

I began by using absolute funding levels as the dependent variable and including a lagged measure of funding in the regression equation. Its coefficient was very close to one,

indicating the presence of a unit root. Therefore, I first-differenced the dependent variable, yielding models that predict changes in research funding. I use the Cochrane-Orcutt transformation to correct for first-order autocorrelation. All independent variables are lagged by one year, and all models use robust standard errors to account for clustering by disease (Rogers 1993; Williams 2000). Results are robust to model specification.²⁶ All figures show five-year moving averages.

I supplement the quantitative analysis with a qualitative analysis of testimony and secondary sources. I examined the congressional testimony of a representative sample of 200 disease advocates, news coverage of NIH policymaking in newspapers (including the *Washington Post* and the *New York Times*) and scientific journals (*Science* and the *New England Journal of Medicine*), and congressionally mandated reports from the Congressional Research Service and the Institute of Medicine. These qualitative data help me document cultural changes in medical research politics.

I look for direct, distributive, and systemic effects in different ways. If advocacy organizations received direct benefits, we should observe positive coefficients for the advocacy variables, indicating that diseases with more advocacy had bigger funding increases. If advocacy created distributive changes on the basis of race and gender, we should see race and gender coefficients that are mediated by advocacy, indicating that different levels of mobilization shifted the funding distribution across demographic groups. If advocacy had systemic cultural effects, graphical and qualitative data should show changes in policy meanings that are attributable to advocacy. These changed terms of the debate should affect how all diseases fare in the competition for funds.

RESULTS

Direct Benefits

Scholars have argued that disease advocates successfully lobbied for research funds (Brown and Zavestoski 2004; Dresser 1999;

Table 2. Diseases and Conditions Included in Study

ALS	Liver cancer
Alzheimer's disease	Lung cancer
Arthritis	Lupus
Asthma	Multiple sclerosis
Atherosclerosis	Muscular dystrophy
Autism	Myasthenia gravis
Brain and central nervous system cancer	Neurofibromatosis
Breast cancer ^a	Osteoporosis
Cerebral palsy	Ovarian cancer
Cervical cancer	Pancreatic cancer
Chronic fatigue syndrome	Parkinson's disease
Chronic liver disease and cirrhosis	Pelvic inflammatory disease
Chronic obstructive pulmonary disease	Peptic ulcer
Colo-rectal cancer	Pneumonia
Cystic Fibrosis	Prostate cancer
Diabetes	Schizophrenia
Down Syndrome	Scleroderma
Epilepsy	Septicemia
Fibromyalgia	Sickle cell anemia
Heart disease	Skin cancer
Hepatitis	Spina bifida
HIV/AIDS ^a	Stroke/cerebrovascular disease
Huntington's disease	Sudden infant death syndrome
Hypertension	Tuberculosis
Influenza	Tuberous sclerosis
Kidney disease	Uterine cancer
Leukemia	

^aAll analyses were run with and without HIV/AIDS and breast cancer.

Epstein 1996). To test this claim, Model 1 (see Table 3) controls for changes in mortality and includes three measures of disease advocacy: the change in the number of nonprofits targeting a disease, their total lobbying expenditures, and the number of witnesses testifying on behalf of the disease.²⁷ The results reveal a strong relationship between advocacy and funding changes. Increases in the number of nonprofits and lobbying expenditures are both significantly associated with increases in research funding, with each \$1,000 spent on lobbying associated with a \$25,000 increase in research funds the following year. The coefficient for witnesses is also positive, but it is not statistically significant.²⁸ These findings suggest that disease advocacy organizations secured direct benefits in the form of increased medical research funding.

Distributive Changes

Contemporary observers made competing predictions about how advocacy might affect the overall distribution of research funding. Some scholars and advocates argued that disease advocacy would correct inequities, shifting funds to diseases that disproportionately affect women and racial minorities. Others worried that disease advocacy would have the opposite effect, drawing money away from diseases that affect disadvantaged groups (Callahan 2003; Dresser 1999).

The results tentatively support the latter prediction. In the aggregate, disease advocacy may have shifted money away from diseases that primarily affect women and blacks. Model 2 (Table 3) includes dummy variables indicating when at least 95 percent of a disease's

Table 3. Cochrane-Orcutt Regression Analyses of Changes in Federal Research Funding to Diseases

	1	2	3	4	5	6
Change in number of nonprofits	.244* (.102)		.244* (.102)		.259* (.106)	.259* (.106)
Lobbying (thousands)	.025** (.008)		.025** (.008)		.018* (.009)	.018* (.009)
Witnesses	.225 (.934)		.206 (.934)		-.234 (.733)	-.262 (.735)
Predominantly black		-4.673*** (1.217)	-2.635* (1.214)			-1.216 (.693)
Predominantly female		-3.950** (1.400)	-3.216** (1.173)			-2.137* (.872)
Deaths (thousands)				.065*** (.007)	.046*** (.013)	.046*** (.013)
Deaths (thou.) X witnesses					.009** (.003)	.010** (.003)
Change in deaths (thousands)	.700 (.400)	.675 (.393)	.698 (.401)	.782* (.382)	.747 (.414)	.744 (.414)
Constant	3.780*** (.889)	4.959*** (1.217)	4.138*** (.988)	2.758*** (.583)	2.696*** (.616)	2.945*** (.683)
Observations	682	682	682	682	682	682
R-squared	.047	.021	.048	.075	.104	.105
Durbin-Watson statistic	1.898	1.923	1.896	1.857	1.852	1.851

Note: Dependent variable is change in NIH and DOD funding to disease research in millions. Analyses exclude HIV/AIDS and breast cancer. All independent variables lagged by one year. Robust cluster standard errors are in parentheses.

* $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$ (two-tailed tests).

fatalities are female or black. Both coefficients are negative and statistically significant, suggesting that women's and blacks' diseases tended to receive smaller funding increases. To see whether these smaller increases are attributable to lower levels of advocacy, Model 3 (Table 3) controls for advocacy. The coefficient for blacks' diseases decreases significantly, indicating that low levels of advocacy explain some of the funding disparities. The coefficient for women's diseases also moves closer to zero, but the decrease is not statistically significant.

These results should be interpreted cautiously for two reasons. First, the disadvantage for women's diseases disappears when breast cancer is included in the analyses. Second, my sample includes only one black-dominated disease (sickle cell anemia) and only four female-dominated diseases besides

breast cancer (cervical, ovarian, and uterine cancers and pelvic inflammatory disease). The observed effects might be particular to these specific diseases and not general patterns based on patients' demographics. To address this concern, I re-ran all models with an alternate specification of the race and gender variables: the percentage of women and blacks among each disease's fatalities. The patterns are similar in these models, suggesting that the results are not particular to the small number of female- and black-dominated diseases, but the results are no longer statistically significant.²⁹

Systemic Effects

Thus far, I have shown that disease advocates secured large funding increases, and that these successes may have created funding

disparities on the basis of patients' race and gender. Turning to systemic effects, I find that disease advocates changed the political meaning of medical research, with profound consequences for the distribution of research funds.

Mortality as a metric for commensuration. Seeking increased funding for their diseases, many advocates argued that NIH funding was out of sync with the burden of disease. Mortality emerged as an influential metric for commensurating diseases and reshaped the funding distribution.

Following AIDS advocacy's successes in the 1980s, HIV/AIDS received more research funding than any other disease. These funding levels meant advocates for virtually every disease could use measures of dollars per death or per patient to claim their disease was underfunded compared to HIV/AIDS. For example, in 1984, breast cancer advocate Rose Kushner testified that the federal government was spending \$11,000 for each new AIDS patient but only \$400 per person diagnosed with breast cancer (U.S. Congress 1984:49). In 1995, a representative of the American Heart Association noted that "in fiscal year 1993, HHS spent 36 times more on research funding per death of an AIDS victim than was spent per death of a heart disease victim" (U.S. Congress 1995:129). Most advocates based their claims on mortality, but advocates for non-fatal diseases based their claims on prevalence, comparing dollars per patient (Marshall 1997).

Policymakers liked mortality and prevalence metrics because they came from official government statistics and provided a simple and seemingly rational way to compare funding across diseases (see Porter 1995). In the House, Representatives Istook (R-OK) and Nethercutt (R-WA) echoed advocates' claims that some diseases were underfunded compared to HIV/AIDS, a point Istook pushed in appropriations subcommittee meetings (Dresser 1999; Istook 1997; Marshall 1997). Representative Bonilla (R-TX) also picked up the dollars-per-death frame to push for more money for diabetes research (Marshall 1997).

All three representatives used the mortality metric to push for increased congressional intervention in the NIH budget.

These dollars-per-death claims created political pressure to standardize the NIH funding process. A Congressional Research Service report complained that advocates tended to choose the comparisons most favorable to their own diseases, offering up a "vast and sometimes confusing array of charts and tables comparing disease-specific research funding with statistics on morbidity, mortality, and health care costs" (Johnson 1998). In response to advocates' various metrics and standards, some members of Congress began requesting reports of NIH funding by mortality. In 1994, the Senate appropriations committee ordered the NIH to submit a report of funding by death rates, medical spending, and diseases' indirect economic costs (Agnew 1996). That same year, the Congressional Research Service produced a report of NIH funding and mortality rates for the leading causes of death (Johnson 1994). In 1997, the Senate held a hearing examining NIH priority-setting.

The NIH resisted the push for standardization. At the Senate hearing, NIH director Harold Varmus argued that diseases are inappropriate categories for judging the funding distribution and opposed formal commensuration as a priority-setting tool. He testified that it would be foolhardy to set funding targets by diseases because medical advances often arise from non-disease-targeted basic research or spill over across diseases. He also argued against adopting standardized formulas for commensuration, saying that "numbers are suspect" and that "assessing or designing a research portfolio from numbers alone is a very tricky, indeed a hazardous enterprise" (U.S. Congress 1997b:9, 8). Varmus was supported by a group of representatives including appropriations subcommittee chair John Porter (R-Ill), who sought to preserve NIH autonomy in setting funding priorities (Dresser 1999; Epstein 2007).

Faced with the conflict between scientific autonomy and advocates' critiques, policy-

makers compromised by avoiding earmarks but also opening the black box of NIH decision-making. Congress requested a report from NIH on its priority-setting procedures and asked the Institute of Medicine (IOM) to issue recommendations on how to improve the process (Dresser 1999). In the report, the NIH for the first time listed criteria for priority-setting between diseases. They provided five unranked criteria:

public health needs, scientific quality of the research, potential for scientific progress (the existence of promising pathways and qualified investigators), portfolio diversification along the broad and expanding frontiers of research, and adequate support of infrastructure (human capital, equipment instrumentation, and facilities). (Institute of Medicine 1998:4)

These criteria provide some information about NIH priority-setting while maintaining significant scientific autonomy over funding decisions.

Although Congress stopped short of explicitly standardizing the NIH budget, the series of reports and hearings made it clear that advocates and members of Congress would continue to question whether NIH funding lined up with mortality and other measures of the burden of disease. And as the NIH was increasingly critiqued on the basis of dollars per death, mortality gradually became a better predictor of NIH funding. Model 4 (Table 3) includes the number of deaths attributable to each disease during the previous year. The coefficient for mortality is positive and significant, showing that during the time period under study, "big killers" had larger increases in NIH funding.³⁰ As the mortality metric became increasingly taken for granted, high-mortality diseases were at an advantage in the competition for funds.³¹

Did the dollars-per-death frame advantage all high-mortality diseases or only those whose advocates used the frame? Model 5 (Table 3) includes an interaction effect between witnesses and mortality. The positive

interaction effect, showing that high-mortality diseases had a larger payoff from witness testimony, suggests that dollars-per-death claims helped witnesses secure funding increases for their diseases. Importantly, though, the main effect for mortality remains large and statistically significant, suggesting that the rise of mortality as a metric for commensuration advantaged high-mortality diseases even if their advocates did not testify.³² Thus, the dollars-per-death frame was more than a mechanism for witnesses to secure direct benefits for their diseases; the introduction of the mortality metric systemically changed the terms of the debate over medical research funding.

Perceived beneficiaries. Disease advocacy organizations encouraged Congress to think of patients with specific diseases as beneficiaries of medical research funding. Throughout most of the twentieth century, when fights broke out over the distribution of NIH funding, diseases were not generally the competitors. Midcentury congressional critiques of the NIH focused on whether money was being disbursed to unqualified researchers and whether NIH funding was "geographically elitist" (Guston 2000:74). Testifying before Congress in 1963, NIH Director Shannon argued that the large NIH budget was defensible because the scientists who received the money deserved it: "The national figures are very large. . . . But when you go from a national picture to a State . . . and begin to recognize institutions and scientists, you begin to understand the role they play in the community life" (U.S. Congress 1963:30). Although the Institutes' overarching goal was always to improve the nation's health, this rhetoric constructed scientists as the beneficiaries of NIH funding.

This construction was reflected in the characteristics of witnesses at appropriations hearings. In the 1960s and 1970s, over 15 percent of witnesses testifying at House Labor, Health, Education, and Welfare appropriations hearings represented health institutions like medical schools, research institutes,

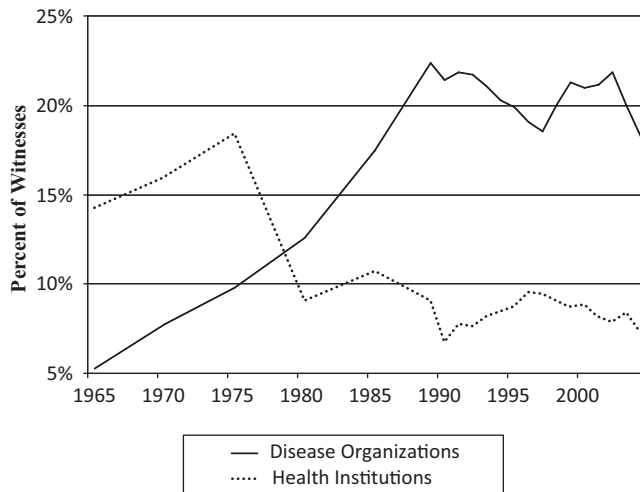


Figure 2. Witnesses at House Appropriations Hearings Representing Disease Organizations and Health Institutions, 1965 to 2004

Note: Disease organizations includes organizations targeting one or several diseases.

and hospitals (see Figure 2). As the groups most likely to receive money directly from the NIH, they were a natural constituency for NIH policy. Meanwhile, only 5 to 10 percent of witnesses represented organizations targeting diseases (see Figure 2).

Subsequent changes reveal the increasing prominence of disease patients in NIH policymaking. The proportion of witnesses representing health institutions dropped dramatically in the 1980s and 1990s, declining to fewer than 7 percent of witnesses by 2004. They were replaced by disease advocates, who made up over 20 percent of witnesses by the 1990s (see Figure 2).³³ This percentage is astonishingly high, given that the denominator includes witnesses testifying about the appropriations for all of HHS, Labor, and Education. Even though these disease advocacy organizations were not receiving money directly, they expressed an interest in the distribution of funding to diseases, and their presence as witnesses suggests that members of Congress viewed these claims as legitimate.

In their testimony, disease advocates portrayed patients as the beneficiaries of research funding. For instance, in 1992, one breast cancer advocate argued that “my daughter

Jody, the women in this room, and women everywhere deserve no less” than increased funding for breast cancer research. Another asked, “Is this too much to ask for your wife, your sister, your mother?” (U.S. Congress 1992:31, 59). These advocates depicted breast cancer patients, not scientists, as the beneficiaries of breast cancer research funding. Discussions of the distribution of funding among states and researchers did not disappear, but they were now overshadowed by discussions of the distribution of funds to diseases.

In another indication of the shift to viewing patients as beneficiaries, witnesses were increasingly likely to mention patients when they discussed the NIH.³⁴ In 1960, approximately 40 percent of references to the NIH appeared in close proximity to references to patients; by 2010, this number had increased to over 70 percent (see Figure 3). This growing discursive link between the NIH and patients supports the claim that patients were increasingly thought of as beneficiaries of medical research funding.

The relevance of deservingness. Once patients were viewed as beneficiaries of NIH funding, moral judgments about their

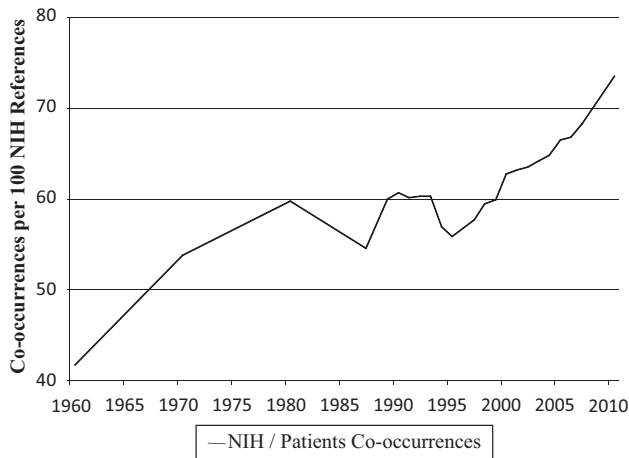


Figure 3. References to Patients per 100 References to the NIH, 1960 to 2010

deservingness became increasingly relevant to funding deliberations. When scientists and the public at large were viewed as the beneficiaries of medical research funding, it would have made little sense to argue that patients of any particular disease “deserved” more research funds. But once patients were constructed as beneficiaries, some advocates began arguing that individuals suffering from their diseases were innocent victims, with the implication that other diseases merited less support. In a letter to Representative Porter, a muscular dystrophy advocate attacked funding for research on drug abuse and alcoholism, saying that “it is shocking that over \$754 million is devoted to address the health problems of people whose irresponsible behavior causes those problems, while less than 1 percent of that sum helps children dying of Duchenne muscular dystrophy” (Havemann 1998). Such direct attacks were rare, but my analyses of congressional transcripts reveal that advocates for stigmatized and nonstigmatized diseases made different types of claims.

Witnesses for nonstigmatized diseases tended to focus their testimony on patients’ and families’ suffering. For example, one mother spoke about her 13-year-old son, saying that “Michael is not comfortable as he sits here strapped to his wheelchair. If you look into his beautiful brown eyes, he has no vision. . . . It is horrible what Batten’s disease

does to a normal healthy child” (U.S. Congress 1990:701). Another mother who lost a child to a genetic disease described her “agony [at] the thought that another child will die from this” (U.S. Congress 1997a:108). These witnesses sometimes made claims on scientific and economic grounds, but their most common strategy was to evoke sympathy.

In contrast, witnesses with potentially stigmatized diseases spent their testimony attempting to manage the stigma. For example, one witness with liver disease emphasized that he did not drink or smoke, “never experimented with drugs,” and “had one sexual partner and continue to have one sexual partner in my whole life, my wife” (U.S. Congress 1997a:132). Some advocates strategically focused on the least stigmatized subgroups of their patient populations. Juvenile diabetes advocates emphasized the differences between their disease and Type 2 diabetes, which has more behavioral risk factors (Perez-Pena 2006). Lung cancer advocates focused public awareness campaigns on types of lung cancer not caused by smoking (Griffith 2005). Additionally, witnesses for stigmatized diseases were more likely to justify funding on economic grounds. For example, a former drug user emphasized that research and treatment allowed her to go from “tax burden to tax payer” (U.S. Congress 1997a:318), and a

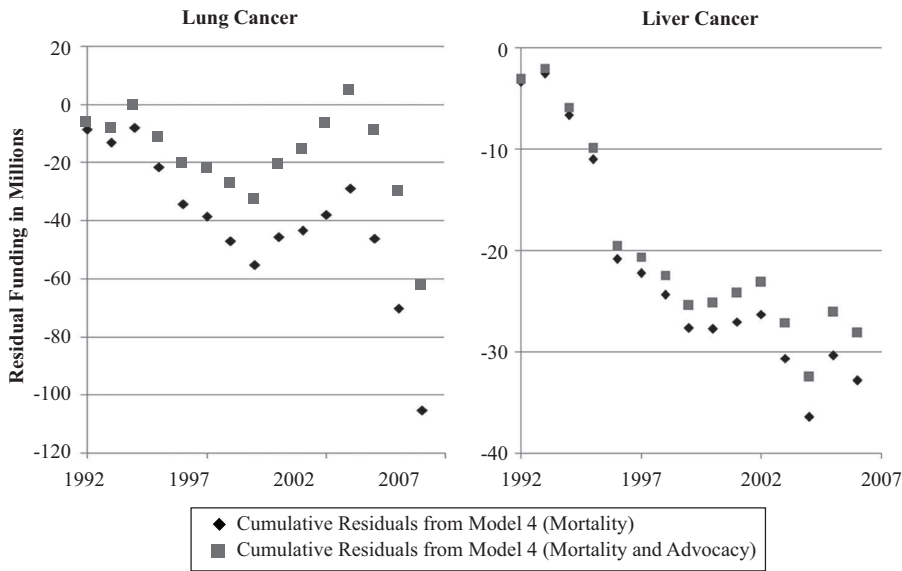


Figure 4. Lung Cancer and Liver Cancer's Cumulative Residuals from Regressions of Funding Changes on Mortality and Advocacy, 1992 to 2006

spokesman for the American Lung Association noted that “lung diseases cost the U.S. economy an estimated \$84.4 billion annually” (U.S. Congress 1997a:143). Perhaps less confident that their stories would evoke sympathy, these witnesses were disproportionately likely to rely on economic arguments to justify funding increases.

Stigmatized diseases received less funding in the new political climate. I document this pattern by tracking funding for lung cancer and liver cancer. Both cancers have potentially stigmatized risk factors (smoking for lung cancer; hepatitis infection and alcohol consumption for liver cancer). Year after year, both diseases received smaller funding increases than would have been predicted based on mortality. To document this cumulative disadvantage, I summed each disease's residuals from regression analyses over time (see Figure 4). The diamonds in the graph are the diseases' cumulative residuals from Model 4 (Table 3), which controls for mortality. By 2006, lung cancer and liver cancer were receiving about \$100 million and \$35 million dollars less, respectively, than would have been expected

based on how many people they killed.³⁵ Controlling for advocacy does not move the residuals substantially closer to zero, indicating that lung and liver cancer's disadvantages cannot be explained by lack of advocacy (see Figure 4, cumulative residuals from Model 5, Table 3). The increasingly negative residuals for lung and liver cancer suggest that once patients were viewed as beneficiaries of medical research funding, stigmatized diseases were at a growing disadvantage.

By constructing patients as beneficiaries of medical research funding, disease advocates unintentionally increased the relevance of stigma to medical research priority-setting. But the history of AIDS activism reveals complexities in the relationship between disease advocacy and stigma. The fact that HIV/AIDS disproportionately affected stigmatized groups limited the initial public health response to the emerging epidemic. The AIDS movement emerged in response to the federal government's inaction, and the movement was extremely successful in overcoming stigma and putting HIV/AIDS on the government agenda (Donovan 2001; Epstein 1996).

Subsequent campaigns targeting other diseases were inspired by the AIDS movement's successes and adopted its symbols and strategies, including ribbons, fundraising walks, and federal advocacy (Anglin 1997; Dresser 2001; Klawiter 2008). These movements inspired by AIDS advocacy expanded the influence of disease stigma on federal health policy.

DISCUSSION

Disease advocacy transformed the politics of medical research funding. By examining quantitative and qualitative data on 53 diseases over 19 years, I identified several previously overlooked effects of advocacy. In addition to securing direct benefits, disease advocacy organizations reshaped the funding distribution, introduced metrics for commensuration, changed the perceived beneficiaries of medical research, and made deservingness increasingly relevant to funding deliberations.

Regarding direct benefits, I found a strong relationship between advocacy and increases in NIH funding to diseases. These results indicate that advocacy organizations can secure large benefits for their constituents. However, we should not expect equally large effects in every policy arena. Medical research funding can be given out in small units, meaning that Congress can distribute resources widely to placate as many groups as possible (Lowi 1964). Advocacy's effects might be smaller when organizations compete over legislation. Also, congressional representatives tend to view disease advocates more favorably than other lobbyists because disease advocates do not directly profit from medical research expenditures (Cook-Degan and McGeary 2006). Advocates who are less favorably viewed might be less successful. Finally, the large funding increases occurred in the context of an expanding NIH budget. Advocacy's effects might be smaller during times of austerity.

With respect to distributive changes, I found suggestive evidence that with the exception of breast cancer, there was less advocacy for women's and blacks' diseases. Therefore,

as more disease advocates secured direct benefits, the funding distribution shifted away from women's and blacks' diseases.³⁶ This pattern suggests that contemporary inequalities in mobilization may create health disparities for future generations. However, these results are based on a small number of female-dominated and black-dominated diseases and change with inclusion of breast cancer in the analysis, so they are not definitive.

My findings concerning systemic effects reveal two processes related to categorization. Advocates first asserted that diseases were the relevant categories across which to judge the NIH funding distribution. Making these judgments then required classifying and comparing diseases through commensuration and cultural categories of worth (see Lamont and Molnar 2002).

In the first categorization process, social movements construct, maintain, or highlight group boundaries (Polletta and Jasper 2001) and then import these categories into political deliberations. In this case, advocates organized around disease categories and encouraged policymakers to judge the distribution of funds to diseases. But advocacy organizations do not create categories in a vacuum, and the move to hold the NIH accountable for funding to diseases reveals an unexpected relationship between advocacy and established disease categories. Patients mobilized around disease definitions and diagnoses provided by healthcare systems (Brown et al. 2004; Rabinow 1992; see also Bowker and Star 2000; Rosenberg 2007). They then created political pressure for the NIH to target research funding to these diseases, despite NIH officials' preference for funding research that might cross traditional disease boundaries. This pressure may have increased the likelihood that future scientific advances would fall within established disease categories. Thus, in challenging scientific authority over funding decisions, disease advocacy may actually have *reinforced* dominant disease classifications by diminishing scientists' ability to conduct research across categories.³⁷ In the same way that groups mobilize around categories

encoded in policies (Pierson 1993; Skocpol 1992), advocacy develops around preexisting disease categories and can reinforce those categories.

When advocates used the dollars-per-death frame to demand funding increases for their diseases, they created political pressure to standardize the NIH budget by mortality and to formalize NIH priority-setting procedures. Sociological theory often links standardization and expert authority (Weber 2003). However, my findings support recent observations that standardization challenges experts' autonomy (Espeland and Stevens 1998; Evans 2002; Guston 2000; Porter 1995; Timmermans and Epstein 2010). Calls for public accountability force professionals to justify their decisions on the basis of objective standards instead of expert judgment (Porter 1995). In this case, the NIH managed to avoid explicitly standardizing its priority-setting process, but the funding distribution gradually approached the standard proposed by many advocates. This implicit compromise illustrates the strong but challenged professional authority of scientists and medical professionals in the contemporary United States (Epstein 1996; Guston 2000; Pescosolido 2006).

Advocates also encouraged policymakers to think of patients as beneficiaries of medical research funding. This pattern reveals a rarely discussed pathway through which advocacy shapes policy: by changing a policy's perceived beneficiaries. Political scientists have long recognized that policies vary dramatically based on whether affected parties are attentive to and engaged in political debates (May 1991; Schattschneider 1960). But when disease advocates asserted their interest in the distribution of medical research funding, they did more than awaken a predefined group of beneficiaries: they redefined who counted as a beneficiary, making a new set of interests relevant.³⁸

Once patients were viewed as beneficiaries of medical research funding, disease stigma became increasingly relevant to NIH priority-setting. This finding suggests a new

source of variation in the influence of deservingness on policy. Even if the symbolic construction of a group remains constant—for example, if liver cancer patients face a consistent amount of stigma, or if welfare recipients are routinely disparaged—the extent to which stigma shapes policy depends on who is thought of as the policy's beneficiaries. Beneficiary groups' perceived worthiness tends to change slowly (Steensland 2006), but the political relevance of worthiness can change quickly and dramatically depending on whether a group is considered a beneficiary.³⁹ Advocates for stigmatized groups can interpret this finding either as a rallying cry or as a cautionary tale. Advocates could strategically redefine policy beneficiaries to decrease the relevance of stigma. However, the emergence of advocacy may encourage politicians to view movement constituents as policy beneficiaries, calling attention to their moral characteristics.

Political environments are not only a context for social movements—they are also a field that social movements work to reshape. In promoting mortality as a metric for commensuration and framing deserving patients as beneficiaries, advocates changed the rules of the competition for medical research funds (see Armstrong and Bernstein 2008). These cultural changes had concrete effects on the funding distribution, shifting money toward high-mortality diseases and away from stigmatized diseases.

The field metaphor should not lead us to assume that all systemic effects are strategically sought. When disease advocates used the dollars-per-death frame to push for more funding for their diseases, the pressure to formalize NIH priority-setting and the increasing influence of mortality were side effects. Similarly, when disease advocates defined patients as beneficiaries of medical research funding, they never intended to increase the relevance of stigma. These findings suggest a more subtle role for social movement framing, which researchers view primarily as a strategy for achieving direct benefits (Amenta et al. 2010; Benford and

Snow 2000; Burstein and Hirsh 2007; Cress and Snow 2000). Social movement frames can have unintended effects on metrics for commensuration, perceived beneficiaries, and cultural categories of worth in policy arenas. Because these changes affect all participants in political fields, outlast the advocates who introduced them, and contribute to institutional change (Clemens and Cook 1999), they may be the most sweeping and durable effects of advocacy.

Advocates are not the only players in political fields. Social movements and the state often interpenetrate each other, with advocates collaborating with policymakers (Armstrong and Bernstein 2008; Epstein 2007; Goldstone 2003; Santoro and McGuire 1997; Skrentny 2002; Wolfson 2001). When advocates strategically adopted the mortality metric, some members of Congress joined them in arguing that the NIH budget did not line up well with the burden of disease. Other policymakers and NIH officials responded by defending scientific autonomy. The NIH ultimately provided some information about priority-setting procedures and shifted more funding to high-mortality diseases. These outcomes depended on the actions of advocates, policymakers, and government officials. In studying political outcomes of advocacy, we should not ignore effects that depend on multiple actors; we can attribute causality to movements even when they are not exogenous shocks.

My analysis of the systemic political effects of advocacy parallels research on social movement's societal effects. While scholars have generally assumed that political effects are concrete and intentionally sought, studies of movements' effects on society at large have discovered unintended consequences and cultural changes (Amenta et al. 2010; della Porta 1999; Earl 2004; Haveman et al. 2007). Focusing on systemic effects brings these insights to the political sphere and reminds us that culture is not an isolated realm of social life that can be separated from politics (Armstrong and Bernstein 2008). Advocacy's effects include changes in the

categories and meanings that shape political decision-making.

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Notes

1. See the Data and Methods section for a description of the data. Because I exclude some disease lobbying organizations, Figure 1 provides a conservative estimate of the expansion of the disease nonprofit sector.
2. The new health advocacy has been variously described as "biosociality" (Rabinow 1992), "embodied health movements" (Morello-Frosch et al. 2006), and "the politics of life itself" (Rose 2006).
3. In one exception, Hegde and Sampat (2011) find that lobbying has positive effects on federal funding for rare diseases.
4. Researchers traditionally distinguished social movements from interest groups, arguing that the former uses noninstitutionalized or disruptive strategies (McCarthy and Zald 1977; Tarrow 1994) and makes moral claims (Lofland 1996). However, a growing number of scholars argue that these variables are continua, making it problematic to draw a clear line between social movements and interest groups (Andrews and Edwards 2004; Burstein 1998; Clemens 2005; Tarrow 1999). Because the organizations I study share some of the characteristics traditionally assigned to social movements and interest groups, I call them "advocacy organizations" (Andrews and Edwards 2004) and draw on both research literatures.

5. Clemens (1993) describes changes in the taken-for-granted rules for political action that are both cultural and material.
6. One exception is Pedriana and Stryker's (1997) finding that supporters of affirmative action recast the meaning of equal employment opportunity. This reframing reshaped subsequent debates about civil rights law and legitimated future government enforcement strategies.
7. Some researchers recognize that policies' perceived targets can vary over time or across institutional locations. Weir (1992) argues that during the 1960s, the media and politicians reframed the War on Poverty as primarily benefiting African Americans. Laumann and Knoke (1987) find that when considering capping hospital charges, actors from the health policy domain focused on impacts on patients and healthcare providers, while actors from the domestic economy domain focused on the overall economy and federal budget.
8. Skrentny (1996) shows that the relevance of worthiness depends on meanings attributed to a policy. The race riots of the late 1960s changed the rationale for affirmative action from justice to crisis management, making African Americans' perceived worthiness less relevant (Skrentny 1996). I argue that perceived beneficiaries are an aspect of policy meaning that is especially likely to change the relevance of worthiness.
9. This time frame was determined by data availability. It includes most of the expansion of disease advocacy but begins after the initial successes of the AIDS movement.
10. Because DOD-CDMRP expenditures are much lower than NIH expenditures, I also ran all analyses with only NIH funding as the dependent variable. The results were substantively unchanged.
11. This dataset includes 501(c)(3) organizations classified by the IRS as "public charities" and excludes those designated as "private foundations." (The latter make up only 10 percent of 501(c)(3) organizations). Because most private foundations distribute funds to charities, including both types of nonprofits in my sample would risk double-counting their financial data (National Center for Charitable Statistics 2006). These data also exclude nonprofits with designations other than 501(c)(3).
12. Many 501(c)(3) organizations are not represented in these IRS data, but their omission does not substantially bias the data used for this study. Many are absent because they are very small. Some local nonprofits appear to be missing but actually filed their taxes using their headquarters' addresses. Preschools and religiously affiliated nonprofits are least likely to appear in IRS data, but they are not included in this study (Grønbjerg 2002). Thus, the fact that not all nonprofits file tax forms poses few problems when studying health nonprofits at the national level.
13. Organizations with budgets below \$25,000 do not file the tax forms that yield the NCCS data. Because the IRS does not adjust this cutoff for inflation, I dropped all organizations with budgets below \$25,000 in 1987 dollars to avoid inflating the number of organizations in later years.
14. Although there are many problems with the full NCCS nonprofit classification scheme, it validly classifies organizations at this broad level (Grønbjerg 1994).
15. I was able to code disease affiliations (or lack thereof) from the names of approximately three quarters of the organizations. Web searches for the remaining (approximately 4,000) organizations allowed me to identify all but 600. I coded an additional 169 organizations using GuideStar (an online database of nonprofits). A total of 429 organizations remained uncoded out of the original 15,000.
16. 501(c)(3) organizations are allowed to lobby the government, but this lobbying must not constitute a "substantial part" of their activities (Internal Revenue Service 2010).
17. Because nonprofits have various sizes and missions, the number of organizations is a broad measure of the organizational activity targeting a disease. For example, the breast cancer organizations studied include Ribbon of Hope, which supports patients in Northeastern Wisconsin, and the Susan G. Komen Foundation, a large national organization that lobbies the government and funds research, education, and screening. The lobbying variable directly measures financial attempts to influence government bodies, but not all lobbying is focused on research funding. This heterogeneity likely biases my results downward, because not all of the measured activity is focused on lobbying for research funds.
18. Prior to 1980, the hearings are for Labor, Health, Education, and Welfare. Appropriations hearings are held in both the Senate and the House, but the House hearings tend to include the same witnesses as the Senate hearings, along with many additional witnesses. Therefore, I only analyzed House hearings.
19. I collected annual data beginning in 1989 to create independent variables for the statistical analyses.
20. We classified witnesses as representatives of professional associations, places/programs, and private companies; advocates; federal officials; local officials; members of Congress; and individuals without organizational affiliations. We split each category into health-related and non-health-related. During each week of coder training, all research assistants coded the same hearing, discussed and resolved disagreements, and refined the coding scheme. After five weeks, intercoder agreement ranged from 80 to 90 percent, with Krippendorff's alpha statistics from .75 to .8 (Krippendorff 2009). We then finalized the codebook and began coding

- for data collection. Two research assistants coded each witness list, with Krippendorff's alpha statistics from .67 to .92.
21. Compared with total nonprofits and lobbying expenditures, this variable is more narrowly focused on research advocacy. Congressional testimony is a direct attempt to influence federal appropriations, and 80 to 90 percent of witnesses focus their testimony on research funding.
 22. We coded the testimony of approximately 20 randomly selected witnesses per year. Unfortunately, we could not achieve sufficient levels of intercoder reliability until we made our codes so broad that there was little variation in the resulting variables. Fortunately, we also wrote memos about the qualitative patterns we observed in the testimony and met to discuss these patterns, yielding useful qualitative data.
 23. Mortality statistics are affected by reporting biases and by conventions for selecting a primary cause of death, making them imperfect measures of the true burden of disease. But because they are used by policymakers and advocates, they are ideal measures of mortality as it may affect policymaking.
 24. The NIH categories are not mutually exclusive. For example, a study of breast cancer would be coded as both breast cancer and cancer. To avoid double-counting research dollars, I only use data on diseases at the lowest level of aggregation.
 25. Some organizations target broad categories like cancer or lung disease, while others target narrow categories like breast cancer or tuberculosis. I collected data on the full range of disease advocacy organizations for the qualitative analyses, but I include only single-disease organizations in the counts of witnesses and nonprofits targeting each disease.
 26. To test the robustness of the results, I ran the models in various ways: using the Prais-Winsten method instead of Cochrane-Orcutt; excluding DOD-CDMRP funding from the dependent variable; limiting the sample to fatal diseases; controlling for disability-adjusted life-years lost in addition to mortality; including HIV/AIDS and breast cancer in the analysis; and coding patients' race and gender as a percentage instead of as a dichotomous variable. The key findings were very similar in all models. Results are available from the author upon request.
 27. I use the absolute number of witnesses and lobbying expenditures as independent variables (rather than changes in these numbers) because the modal value for these variables is zero. In many cases, the first-differenced versions of these variables would have negative values the year after a disease's advocacy organizations lobbied or testified in Congress. These models would implicitly predict that a disease whose advocates had been active the previous year would do worse the following year than diseases with no advocacy.
 28. When HIV/AIDS and breast cancer are included, the coefficients for lobbying and witnesses increase dramatically.
 29. Because they vary over time, these alternate measures allow me to ask whether the race and gender effects operate between or within diseases. When I include disease fixed effects, the race and gender coefficients are close to zero, indicating that within diseases, changes in patients' demographics do not affect research funding. Perhaps short-term demographic changes do not lead to substantial changes in organizing or in public perceptions of a disease. Rather, the race and gender effects are driven by diseases that are consistently "raced" or "gendered" in the public imagination.
 30. This finding is separate from the pattern in which funding responds to changes in mortality, increasing as diseases become more prevalent. These adjustments are reflected in the positive coefficient for *change* in deaths, not for the absolute number of deaths.
 31. Carpenter (2010) describes a similar case of a metric for evaluation changing a federal agency's actions. In the 1970s, academics and advocates criticized the Food and Drug Administration (FDA) for being too slow to approve new drugs. They judged the FDA's performance by the number of new chemical entities approved per year and the average lag between drug approvals in Europe and the United States. After facing public criticism on the basis of these metrics, the FDA began keeping data on them, discussing them in reports, and considering them when making decisions (Carpenter 2010).
 32. Model 5 also controls for advocacy. Holding nonprofits, lobbying, and witnesses constant, we still see a large positive coefficient for mortality, indicating that the effect is not an artifact of higher-mortality diseases being targeted by more advocacy.
 33. A similar change occurred at the FDA. In the 1960s, the FDA's main external critics were scientists, industry representatives, medical professionals, and Congress; this changed in the 1970s and 1980s as cancer and AIDS patients began to challenge the FDA's practices (Carpenter 2010).
 34. I used WORDij software (Danowski 2009a, 2009b) to track the frequency with which names of NIH institutes were mentioned in close proximity to words referring to patients: patient(s), sufferer(s), survivor(s), affected, individuals, person, people, women, woman, men, and man. Several measures of proximity revealed similar increases over time: within witnesses, within sentences, and within windows of three to ten words.
 35. These funding deficits are substantial, given that the total 2005 funding levels for lung cancer and liver cancer were \$180 million and \$50 million, respectively.
 36. I focused on patients' race and gender, but distributive changes may occur across any variable correlated with advocacy. Disease advocacy may have caused distributive changes based on other characteristics, including patients' social class or age and diseases' causes or psychiatric nature.

37. Epstein (2007) describes another case in which advocates' use of categories constrained scientific autonomy. Advocates assumed that race and gender would be meaningful biological categories for the conduct of scientific research. This successful "categorical alignment" resulted in mandates to include research subjects of varying races and genders and to analyze scientific results by race and gender.
38. This process has occurred in other realms as well, as when the crime victims' movement asserted their interest in sentencing policy (Elias 1985).
39. Smith (1984) similarly argues that although policy-makers' values change slowly, their perceptions of which values are relevant to a particular policy are relatively fluid.

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