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Going for the Cure: Patient Interest Groups and Health Advocacy in the United States

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Abstract Citizen groups, though celebrated during their sudden arrival on the lobbying scene, are vastly outnumbered by groups representing elite, occupationally based interests. Sensitive to the odds that nonoccupational groups face, this study asks what factors have allowed patient groups to form and become active in federal politics. Using three distinct data sets—a survey of patient groups, content analysis of group websites, and in-depth interviews with group representatives and policy makers in Washington, DC—this study assesses the activities of patient groups in the United States and argues that patient advocacy organizations garner stability from the relatively easy provision of selective and solidary benefits. Larger patient groups are especially likely to make use of these structural advantages to pursue congressional lobbying strategies. However, even these groups seek out noncompetitive, distributive political environments. Moreover, the study finds that patient groups rarely form coalitions across diseases, forgoing the potential to collectively speak for shared patient interests.

The study of interest groups, broadly speaking, can be characterized as a decades-long conversation between the pluralists, who champion the pressure system as an essential ingredient of democracy with the potential to support any organized interest, and their critics, who painstakingly

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document empirical departures from the pluralist ideal. Though the conversation may not be over, recent studies have added considerable weight on the side of the critics. Despite a dramatic increase in the numbers of citizen groups[1] beginning in the late 1960s, a number of studies find that such mobilizations have been—when compared to the numbers, skill, and resources possessed by traditional groups—either ephemeral or feeble, or both (Schlozman and Tierney 1986; Schlozman, Verba, and Brady 2012; Vogel 1983; Walker 1991).[2] Accepting this conclusion as valid, this article explores the recent growth in numbers and visibility of patient groups[3]—interest groups organized around a specific disease that allow patients to join as members.[4] This study asks whether the patterns of mobilization and participation exhibited by patient groups are consistent with expectations established by recent theory regarding citizen groups. This question is particularly important in light of single-case studies of prominent groups—for example, those organized around AIDS and breast cancer—that document a number of notable policy successes. We find that patient groups have some distinct advantages not typically associated with nonoccupational groups that encourage their formation and longevity. At the same time, this seemingly robust patient activism has not produced an effective lobby around a shared set of patient concerns that might unite patients with different diseases. Thus, a potential counterweight to the professionalized and corporate groups active in health policy debates has not materialized.

Although there is a growing body of research on health-related advocacy (Armstrong, Carpenter, and Hojnacki 2006; Best 2012a, 2012b; Burgin 2005; Carpenter 2002; Casamayou 2002; Epstein 1996; Strach 2010; Zavestoski et al. 2004), current research foci fail to address the political

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[1] "Citizen groups" or "nonoccupational groups" are defined here as "lobbying organizations that mobilize members, donors, or activists around interests other than their vocation or profession" (Berry 1999: 2). The two terms are used synonymously throughout the article.

[2] Research on citizen group activity at the local level, however, has found that nonoccupational groups may face fewer barriers to entry than their counterparts at the national level (Berry 2010 and Berry and Portney, forthcoming). This finding has been repeated in the domain of health advocacy, specifically with respect to those seeking to change state laws around newborn screening (Grob 2012). Additionally, a study of politics in cities in eastern Massachusetts finds that citizen groups, neighborhood groups, and nonprofits vastly outnumber business groups involved in city politics (Berry et al. 2006).

[3] Advocacy groups centered on a specific disease have a long history. See, for example, Oshinsky's treatment of the early history of the March of Dimes (2005). Such groups, however, tended to be organized around fund-raising and were not typically created by or for patients (Best 2012a).

[4] The term *patient groups* is used to refer to a subset of the more general "disease organizations," where the latter tends to include groups that restrict membership based on occupation and/or profession.

phenomenon of group advocacy that is centered on patient experiences and interests. For example, several studies that assess the impact of lobbying on health policy treat only professionalized groups and/or corporate groups in analyzing health policy outcomes (Bosso and Rodrigues 2007; Heaney 2006; Peterson 2001). Rather than overlooking the potential influence of patient groups, these studies focus on policy debates that do not attract participation of groups whose membership is dominated by patients. Several studies do include patient groups in their treatment of the more general phenomenon of "disease organizations" (Armstrong, Carpenter, and Hojnacki 2006; Carpenter 2002, 2010). However, none of these studies has the goal of distinguishing between occupational and nonoccupational groups.

Closer to the focus of this study is research that treats a single, specific patient group. However, most single-case studies analyze groups that are outliers on some metric like impact (e.g., Casamayou 2001, 2002; Epstein 1996, 2000; Strach 2010) or disease status (e.g., Panofsky 2011; Saguy and Riley 2005; Zavestoski et al. 2004), making the generalizability of their findings less certain.[5] Although these studies do not provide a representative sample of patient groups, they do illustrate a range of activities in which patient groups might engage, and they paint an encouraging picture of both mobilization and effectiveness. For example, AIDS activists were able to capitalize on a well-organized and active membership to make successful policy demands on various actors and organizations in the federal government (Epstein 1996, 2000). Breast cancer activists have built on a network of support groups to mobilize substantial numbers of patients and their families and friends to make both public (Casamayou 2001, 2002) and private claims (Strach 2010) and have generated substantial amounts of money for breast cancer research and treatment. Groups necessarily operating from small memberships—that is, groups that represent rare diseases—have found alternate strategies to pursue group goals. Panofsky (2011) argues that these groups opt for a more direct approach in trying to shape health research outcomes by breaking into professionalized research networks and pressing for studies and collaboratives that would not form without the efforts of patient groups to prod them into existence. Saguy and Riley's study of the fat acceptance movement, likewise, demonstrates the ability of a stigmatized group to bring its concerns about the failings of the professional research community directly to the actors in that community (2005).

The single-case-study research suggests that patient groups might mobilize patients and effectively deploy them in pursuit of group goals

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[5] For a review of studies of patient advocacy groups, see Epstein 2007.

(Epstein 1996, 2000; Casamayou 2001, 2002; Strach 2010; Zavestoski et al. 2004). It also demonstrates that some groups have posted notable policy wins (Epstein 1996, 2000; Casamayou 2001, 2002). This raises the question of whether or not the larger population of patient interest groups is similarly successful in mobilizing members and achieving group goals. If so, patient groups, as a class, might stand apart from the more typical conclusions drawn about the fate of citizen groups in the current interest group environment.

To explore these questions, this article aims to (1) create a portrait of patient interest groups that can account for their goals, strategies, and likely arenas of participation; (2) assess the quality of mobilization and participation that such groups afford their members; and (3) situate patient group activism in the larger context of citizen group mobilization. In the next section, we make use of the broad literature on citizen groups and studies of individual patient groups to generate hypotheses about the activities and activism of patient groups. From there, we introduce our methodology and present and discuss the study's findings.

Are Patient Interest Groups Different?

E. E. Schattschneider's critique (1960) of David Truman's disturbance theory (1951) sets out the general parameters of a long-standing interest group participation debate. While Truman, a classic pluralist, viewed interest groups as necessary for democracy and conceived of the pressure system as having the potential to support any organized interest (Truman 1951), Schattschneider argued that the pressure system worked because, in practice, it provided access only to a very limited number of elites. However, just as Mancur Olson was providing a theoretical explanation for differential access to the pressure system (1965), the groups he predicted would have the most difficulty forming and persisting—citizen groups seeking public goods—were on the rise. Several studies followed that offered explanations for why Olson's elegant theory could not account for political reality. Studies hypothesized that a broader list of inducements were available to group leaders in attracting members than the selective benefits identified by Olson (Moe 1980; Salisbury 1969). Groups with memberships satisfied by solidary and/or purposive benefits may be quite different from groups forming primarily around selective benefits, leading to a more varied interest group population than that predicted by Olson. Moreover, changes in the institutional landscape created new opportunities for nonoccupational groups to form and participate (Berry 1999; Schlozman and Tierney 1986; Walker 1991).[6]

At the same time, closer analysis of the mobilization of nonoccupational groups showed that it fell notably short of the pluralist ideal. First, although nonoccupational groups did form to become a lasting part of the interest group landscape (Walker 1991), limitations in group capacity and a compensatory increase in the numbers of business, corporate, and professional groups active in politics stymied the ability of the new participants to bring some balance to the pressure system (Golden 1998; Lindblom 1977; Schlozman and Tierney 1986; Strolovitch 2007; Vogel 1983; Yackee and Yackee 2006). Further, while some nonoccupational groups like environmental and consumer groups proved to be effective advocates for their respective causes (Berry 1999), many of these have top-down, national structures that provide few opportunities for member involvement (Skocpol 1999, 2003). Such groups, therefore, may not be mobilizing nonelites in the way that the label *citizen group* tends to imply. While recent research suggests that the most effective civic organizations devote considerable resources to creating a cadre of active members (Han 2012), the exhaustive survey of active groups by Schlozman, Verba, and Brady (2012: 319) finds that only 12 percent of interest groups have individuals as members. That is, the overwhelming majority of currently active groups are not associations of individuals. Moreover, the authors find that the poor and middle class are “vastly underrepresented” in the current interest group environment (Schlozman, Verba, and Brady 2012: 321).

If the increase in the numbers of nonoccupational groups that began in the 1960s sparked a corporate and professional countermobilization that has limited the potential impact of nonoccupational groups (Schlozman and Tierney 1986; Schlozman, Verba, and Brady 2012; Vogel 1983; Walker 1991), we might wonder what incentives such groups have to form or what structural advantages allow them to persist in an environment that clearly favors elites organized around economic interests. In fact, even though Schlozman, Verba, and Brady’s (2012) evidence substantially weakens the

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[6] To explain the dramatic rise in citizen groups, scholars point to several likely factors: (1) an increasingly educated middle class; (2) the cultural catalyst of political activism in the 1960s; (3) tax policies including tax-exempt status of not-for-profit groups, postal rate subsidies, and tax-deductible gifts; (4) expansion of government policies and programs that created incentives for new groups to defend their newly acquired benefits; (5) public- and private-sector patronage (e.g., government grants and foundation gifts); (6) laws granting citizen standing to sue the federal government; (7) sunshine laws; and (8) technologies that facilitated the ability to organize dispersed individuals, including computerized mailing systems, closed-circuit video conferencing, and toll-free numbers.

pluralist argument, they do point out that new groups—even nonoccupational ones—are forming all of the time.[7] Explanations developed by Olson and his critics (Moe 1980; Olson 1965; Salisbury 1969), show that any combination of selective, solidary, and purposive benefits could play a role in supporting interest group formation. However, the amendments to Olson's model associate the pursuit of purposive benefits with nonoccupational groups. Thus we tend not to think of citizen groups forming around selective benefits. The literature on specific patient groups suggests that selective benefits and solidary benefits may be powerful incentives for individuals to join patient groups.

The empirical literature on interest groups offers several additional predictions about the experiences of nonoccupational groups. Walker (1991: 67–68, 73), for example, argues that, because citizen groups form around ideological positions rather than occupation, such groups are likely to generate opposition. Supporting this hypothesis, he finds that the first wave of citizen group formation took place among groups whose political aims were primarily progressive. This spurred a countermobilization among conservative citizen groups, the result being that citizen groups are likely to participate in a highly competitive political environment (Walker 1991: 37).

Schlozman and Tierney (1986), in a study of 175 well-established groups in Washington, DC, find that the rise in citizen groups sparked a different type of countermobilization—specifically among corporate and professional groups—that ultimately *increased* the skew of the pressure system toward social elites.[8] Moreover, drawing on Wilson's (1989) typology of political environments (client, entrepreneurial, interest group, and majoritarian),[9] they find that groups organized around concentrated costs or benefits are often able to pursue policy goals in arenas characterized by little or no organized opposition. Here, it is not the overall exclusivity of the pressure system that matters, as Schattschneider argued (1960), but the existence of pockets of exclusivity that promise substantial and relatively uncontested benefits for some groups. To the extent that citizen groups pursue public goods rather than policies that produce concentrated benefits, we would not expect them to benefit from these

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[7] For example, groups representing lesbian, gay, transgender and bisexuals have increased in number since 1981 (Schlozman, Verba, and Brady 2012: 352–53).

[8] In a similar finding, Vogel argues that citizen groups enjoyed a period of influence that was followed by a resurgence of business group power (1983).

[9] Wilson's typology maps out similar theoretical space to Theodore Lowi's framework (1964), which distinguishes redistributive policies (majoritarian), regulatory policies (interest group), and distributive policies (client).

low-conflict political arenas. However, studies of single patient groups indicate that they do participate in the distributive politics of increasing federal outlays for disease-specific research.

As noted above, Skocpol (1999, 2003) suggests that many nonoccupational groups are professionalized and nationally organized and provide few opportunities for member involvement. Similarly, though Berry (1999) finds that environmental and consumer groups have posted some notable political wins against well-organized corporate opposition, he notes that the groups he studies are populated mostly by middle- and upper-middle class citizens such that the extent of their mobilization of previously unrepresented groups may be rather small.[10]

Responding to Skocpol's concern about the mobilization potential of nationally organized groups (1999, 2003), Minkoff, Aisenbrey, and Agnone (2008) analyze the structure of a variety of citizen groups. They find that the larger population of what we call "citizen groups" can be subdivided into five categories, only one of which is the nationally centralized, top-down organization that concerns Skocpol. Moreover, many have federated structures that are likely to create a platform for membership participation and civic engagement. Single-case studies of patient groups do not provide a unified story regarding mobilization. While some groups seem to draw heavily from their grassroots mobilization, others appear to be narrower in scope and rely on a dedicated leadership that carries out the lion's share of the organizations work by breaking into professional research and provider networks.

Drawing from the implied tension between the dispirited portrait of citizen groups provided by the interest group literature and the implications of the single-case-study research on patient groups, we articulate three hypotheses regarding the activities and activism of patient groups. First, we are interested in learning about the goals that motivate patient groups and the strategies they employ to reach those goals. Though research suggests that some patient groups are focused primarily or exclusively on the private sector (Panofsky 2011), we hypothesize that most groups will develop and pursue public-sector lobbying. Extrapolating from research on groups organized around rare diseases (Panofsky 2011) and from research showing high levels of access and impact at the state level (Grob 2012), we predict that group capacity will be correlated with the entry into federal level politics:

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[10] In a later study, Berry (2007) examines the potential for elite actors to represent the interests of the least-mobilized citizens through nonprofit activism. He finds that tax laws inhibit nonprofit advocacy, closing off another potential avenue of nonelite representation.

H1 Higher-capacity patient groups are more likely to pursue public-sector strategies at the federal level than lower-capacity groups.

Second, though Berry (1999) argues that several groups pursuing post-materialist goals have an impressive track record in agenda setting and policy change, other scholars question whether members are a motivating force behind such groups (Nownes and Cigler 2007; Skocpol 1999, 2003). If not, such groups may be an alternate avenue for elite participation. Assuming the hollow membership model, we set out the following hypothesis.

H2 Leaders operate patient groups with little regard for member interests and offer few opportunities for member involvement.

Third, research—both theoretical (Schlozman and Tierney 1986) and empirical (Berry 1999; Walker 1991)—predicts that citizen groups will find themselves in relatively competitive political environments. However, given the accounts provided by some studies of single groups (Casamayou 2001, 2002; Epstein 1996, 2000), patient groups might enter into arenas characterized by client or distributive politics:

H3 Patient groups pursue policy goals that generate little or no organized opposition.

In the next two sections, we present our methodology and analyze our findings to draw a complex portrait of patient groups.

Data and Methods

This study is based on three distinct data-collection efforts geared toward generating a more comprehensive view of patient group mobilization and activity. The first is a survey of patient groups active in 2006. We began with a rather inclusive definition of *patient groups* with the intention of surveying an array of groups that have an interest in health promotion. With this inclusive approach, we hoped the survey would tell us whether there are specific categories of groups that we might wish to exclude once we had a better understanding of characteristics of the target groups. We did, however, decide to exclude some types of groups at the outset. We defined *patient interest group* as any group organized around a particular disease, health impairment, or disability that allows those with the disease to join as members or to engage in the organization's activities by volunteering for the organization. This definition excludes professional associations unless these are open to some type of patient membership.[11] By including groups that have both occupational and nonoccupational members, we retain some capacity to examine the potential that patient groups are "patient" in name only and are driven by the activities of professional elites. At the same time, because we do not include exclusively professional disease organizations, we forgo the ability to compare them to patient groups.[12]

Our approach also excludes support groups whose activities are limited to providing a setting for those with a disease or impairment to meet to discuss care and treatment.[13] Such support groups rarely have formal membership or any capacity for those with the disease to volunteer to carry out the organization's work. Certainly, most groups in our study provide support services, but they do so in conjunction with a more comprehensive set of organizational goals that may include policy change or efforts to increase public and practitioner awareness of the disease or impairment. We included groups where parents or guardians of patients are the ones who join or volunteer for the organization, given that a number of groups are organized around diseases that primarily or exclusively occur in minors.

In order to find patient interest groups that met our definition, we conducted searches of relevant Internet directories. This method for locating groups was selected after attempting to use Jack Walker's primary approach, that is, drawing from the *Washington Information Directory* for listings of relevant groups. A review of the 2005 *Washington Information Directory* produced thirty-six groups that met our definition. Prior research pointed to several active groups that were not listed in the *Washington Information Directory* (Epstein 2007). To find groups not listed in the *Washington Information Directory*, we conducted Internet searches of

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[11] Walker (1991) makes a similar distinction when analyzing interest groups involved in policy development for the handicapped. He counts groups made up of "public-sector professionals" as nonprofits rather than citizen groups. Such groups dominate this policy space: 57 percent of the groups he finds active in policy for the handicapped are nonprofits, while only 37 percent are citizen groups (188). Walker goes on to note that citizen groups were often started by "parents of handicapped children or social service professionals concerned in general about the social status of handicapped persons" (189). This implies that he counts under the "citizen group" column those groups started by social service professionals that do not limit membership based on occupation. By focusing primarily on nonoccupational groups, this study does not consider the potentially interesting dynamics that may occur among occupational groups organized around specific diseases.

[12] This decision was driven by our primary interest in establishing a baseline understanding of variation within the patient group population that could help contextualize the findings from single-case studies of patient groups.

[13] It is not uncommon for groups to form from an existing base of support groups. Maureen Casamayou (2002) discusses this phenomenon with respect to the National Breast Cancer Coalition.

relevant directories such as the Yahoo directory of health-related organizations.[14] Candidate groups were assessed by a review of the group's webpage to find out whether patients or their guardians were allowed to volunteer for the organization or join the organization as members. Any group that met this criterion was included in the database of groups to be surveyed. These searches produced a database of 199 groups.

To check the comprehensiveness of our approach, we compared this list with that of a colleague who used several Washington-oriented directories of interest groups, including the *Washington Information Directory*, *Washington Representatives*, the *Encyclopedia of Associations*, the *Capital Source*, the *Government Affairs Yellow Book*, and *Public Interest Group Profiles* to generate a list of current interest groups.[15] This list contained fifty-eight organizations that had some health focus. Fifteen of these health-oriented organizations were professional associations that did not allow patients to join as members or to volunteer for organization activities. Using our definition, reliance on published directories of interest groups yielded forty-three patient groups—a significantly smaller number than what we found using Internet resources. In addition, the use of published directories did not yield any groups that matched our criteria that we did not find using the Internet. Walker was dismissive of groups not included in lobbying directories.[16] However, existing research on patient groups suggests that some might engage in a number of nonfederal strategies (Panofsky 2011; Saguy and Riley 2005; Strach 2010). Thus our inclusion of groups not listed in the main Washington directories seems justified.

By searching for groups using the Internet, one is clearly selecting for groups that have websites. All of the health-related groups listed in the published interest group directories have websites. This suggests that major interest groups with a federal policy focus would not be excluded as a result

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[14] The following directories were used to compile the list of patient groups for the survey: Yahoo Directory of health-related organizations, dir.yahoo.com/Health/Diseases_and_Conditions/; Internet Public Library, www.ipl.org/div/aon/browse/hea00.00.00/; Center for Policy Alternatives (State Groups), www.stateaction.org/directory/; Idealist.org, www.idealist.org/; Project Vote Smart Issue Groups Directory, www.vote-smart.org/issue_group.php; and Chico State Public Advocacy Directory, www.csuchico.edu/~kcfount/health.html. Internet searches were conducted from the fall of 2005 through the spring of 2006.

[15] We are indebted to Matthew Grossman for his willingness to share his data with us to give us a sense of how successful our Internet searches had been in finding relevant groups.

[16] Walker, in discussing efforts to use other search methods to identify groups, explains that "the groups identified through these searches were found to be very small (usually without a professional staff), or to be headquartered outside Washington and seldom to engage in efforts to influence national policy. In some cases, it was unclear whether the groups existed at all outside of a file drawer in the office of some Washington law firm" (1991: 203–5).

of locating groups by searching for their websites. In fact, it is hard to imagine a patient interest group that could function without a website. The range of sophistication of the websites we found through our Internet searches suggests that even newly formed patient groups run out of a single member's home are likely to have some Web presence. In short, our list of 199 groups is likely to include groups that have limited organizational capacity, but appears unlikely to have overlooked large numbers of the patient groups that have some presence in federal politics. Still, we are certain to have missed some groups given that we found no systematic way to search the Internet for groups organized around diseases or disabilities with membership open to patients.

Each of the 199 groups received a survey questionnaire in May 2006. The survey instrument draws on Walker's 1980 and 1985 questionnaires (1991) but was modified to ensure that questions would be well suited for patient interest groups. The modified questionnaire was tested on a focus group made up of representatives from three groups and then adjusted based on an assessment of the effectiveness of the questions in eliciting useful data from the focus group participants. Focus group participants also suggested question topics that covered issues they considered pertinent that were not included in the draft questionnaire.[17]

Survey respondents received a hard copy of the final questionnaire, a letter explaining the research, a consent form, a two-dollar incentive for completing the survey, and instructions for completing the survey online.[18] Stamped and addressed envelopes were provided to each group to return questionnaires that were completed on hard copy. Sixty-six groups responded to the survey sent out in May 2006, giving us a response rate of 32 percent. In order to increase our response rate, we telephoned groups again in April 2008 and asked them to fill out a survey over the phone, but also gave them the option of filling out the online survey.[19] With this follow-up effort, we increased our total respondents to 102, for a response rate of 51 percent.[20] We received one survey from a group that was not in our original contact database. Since this group fit our criteria, we included the data it provided in our analysis of the survey results.

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[17] The final questionnaire used for the survey is available from the authors upon request.

[18] The methods for gathering data from the focus group, survey, and interviews were reviewed and approved by the Committee for the Protection of Human Subjects, University of California, Berkeley.

[19] The delay in follow-up was the consequence of a temporary shortfall in funding.

[20] In comparing the 2008 with the 2006 survey results, we found no notable differences between the two (data available upon request).

While a response rate of 51 percent is respectable, we still would like to have some sense of whether or not respondents differ from nonrespondents. Because we found groups through searches of the Internet, we were able to collect some public information on all of the groups in our original database. On several indictors—year of group formation, geographic location, appearance in one or more Washington, DC, directories, and likelihood of indicating a public-sector strategy (e.g., targeting Congress or a federal agency), we found no significant differences between respondents and nonrespondents.[21]

These website data also allowed us to conduct content analysis that provided additional insight about characteristics of patient groups. The coding for the content analysis was a simple binary (yes/no) coding or categorical coding for several potential activities or characteristics: provision of services to members, federal lobbying activity, direct funding of private-sector research, cooperation with one or more pharmaceutical companies, and evidence of corporate sponsorship or partnership. In addition to these characteristics, we also coded organizational structure from websites. Here, we used the following categories to classify each organization in our contact database

1. National structure—organizations that display no evidence of chapters or local-level organizations and are not an umbrella organization for a group of stand-alone organizations.
2. Federated structure—organizations that do have local or regional "chapter" structures where these chapters are engaged in some kind of "civic activity" like raising awareness in the community or community education.
3. Networked structures—organizations that organize a group of stand-alone organizations into a larger network.

We also coded whether or not the organization encourages participation by patients/members either directly in advocating for policy change, such as contacting a member of Congress, or by raising public awareness at the local level.

Our third source of data comes from a series of in-depth interviews with representatives of patient interest groups, congressional staff, and personnel at the National Institutes of Health. The bulk of the interview data was collected during the summer of 2006 with groups and individuals in the Washington, DC, area. Additional interviews were also conducted by

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[21] Our analysis of contacted versus surveyed groups is available upon request.

phone with representatives from groups outside Washington, DC. Some interview subjects allowed the interviews to be digitally recorded. For those who did not approve digital recording, handwritten notes were taken during the course of the interview and transcribed immediately following the interview in order to capture details and nuances while the interviewer's memory of the interview was still fresh. Transcripts of the interviews were reviewed to find major topics and themes. This review produced a coding scheme that was then used to code each transcribed interview.

Taken together, these data provide an initial look at the goals and strategies of patient interest groups that are currently active. The three distinct data sets provide some opportunities for triangulation and, together, yield greater insights into patient group formation, goals, and strategies. We should note, however, that the groups in our sample are not necessarily independently and identically distributed, since groups are likely to learn from one another and may mimic the behaviors of the most successful groups (DiMaggio and Powell 1991). The next two sections present relevant findings from the survey and interview data. Following the presentation of the findings, we analyze the findings in light of our expectations and consider future research directions.

Findings and Analysis

Strategies and Characteristics

> *H1 Higher-capacity patient groups are more likely to pursue public-sector strategies than lower-capacity groups.*

Single-case studies of patient groups indicate that not all groups expend resources lobbying the government. In order to find out how many groups targeted public-sector actors in pursuing their goals, the survey asked respondents whether they interacted with Congress, federal agencies, or both.[22] Out of seventy-nine groups who responded, only fourteen groups reported interacting with neither Congress nor any federal agencies. That means that 82 percent of the surveyed groups reported having some interactions with the federal government. In addition, among the groups that indicated they did engage in advocacy at the federal level, 52 percent reported that they interact with Congress *and* with at least one federal agency.[23]

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[22] Survey respondents indicated little interest in pursuing advocacy through state and local governments.

[23] Since self-report allows survey respondents to either over- or underreport their federal activities, we considered a number of alternate measures. Analysis of these (available upon request) gave us no reason to suspect systematic over- or underreporting of public-sector strategies.

Table 1 Group Attributes Associated with Congressional and Agency Interaction

Group Attribute	Interact with Congress		Interact with Agencies	
	N (%)	*p*-value	*N* (%)	*p*-value
Staff of greater than 10	23 (76.7)	0.018	25 (86.2)	0.073
Staff of 10 or fewer	25 (50.0)		34 (68.0)	
Membership 5,000 or more	29 (85.3)	0.000	27 (81.8)	0.196
Membership less than 5,000	15 (39.5)		26 (68.4)	
Above or mean log revenue, FY04	25 (78.1)	0.007	28 (93.3)	0.005
Below mean log revenue, FY04	15 (45.5)		21 (63.6)	
DC area	22 (78.6)	0.019	22 (81.5)	0.262
Out of DC area	28 (51.9)		37 (69.8)	

Looking specifically at groups who report interactions with Congress, we find a number of characteristics are associated at a statistically significant level with reporting congressional activity: (1) groups with larger reported memberships,[24] (2) groups with larger staff, (3) groups whose revenue is above the median, and (4) groups who are located in or near Washington, DC, are all more likely to report interacting with Congress (table 1). While the same relationships exist for groups reporting agency interactions—that is, more staff, larger reported membership, higher revenue, and location in or near Washington, DC, are associated with agency interactions—the only relationship that is statistically significant when reporting agency interactions is revenue. In addition, groups who report agency interactions but *not* congressional interactions—seventeen groups in total—are statistically more likely to have smaller than average memberships.[25] To the extent that larger reported memberships, better financing, and larger staffs are indicators of group capacity, it does appear that

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[24] Data on membership size in our survey range from 42 to 1.2 million, reflecting a willingness of groups to self-report a dramatic array of sizes. However, we cannot rule out the possibility that some groups are biasing their estimates of group membership upward. This might be especially true among groups who report interacting with Congress, an environment where the size of one's constituency matters.

[25] Eighty percent of groups that report agency interactions but not congressional interactions have memberships of fewer than five thousand members, whereas only 46 percent of the other groups—i.e., those that report both agency and congressional interactions, only congressional interactions, or neither agency nor congressional interactions—have fewer than five thousand members ($p=0.018$).

higher-capacity groups are the ones most likely to pursue congressional strategies.[26] However, groups with fewer resources may pursue public-sector strategies by targeting agencies rather than Congress.[27]

Membership

H2 Leaders operate patient groups with little regard for member interests and offer few opportunities for member involvement.

Following Skocpol's concern that many groups we think of as "citizen groups" do not offer significant opportunities for civic engagement on the part of its members, we examine (1) the membership composition of surveyed groups, (2) group funding, (3) group structure, (4) opportunities for member involvement, and (5) evidence of leadership responsiveness to member interests. Certainly, to the extent that corporate and professional actors might wish to team up with patients in order to increase their appeal,[28] patient groups may be "patient" in name only. Even if this were not the driving force behind patient group formation, leaders might have incentives to minimize the role of members up to the point where patient members would leave the organization. None of our data collection efforts—survey, interview, and website content analysis—allow for direct observation of member involvement in group activities. To compensate for this, we draw from all three sources to shed light on the respective roles of members and leaders in patient groups.

In the majority of groups who responded to the survey, patients make up the largest proportion of group membership. Overall, the mean percentage of members who are patients is 44 percent. Patients with the disease are followed by family members (mean of 23 percent),[29] donors (12 percent),

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[26] See appendix B for a comparison of four groups that illustrate some typical distinctions between types of groups.

[27] Though we lack specific data on why groups with smaller memberships might limit their federal strategies to interactions with agencies, we suspect that barriers to entry when pursuing agencies are lower, or at least different. For example, unaffiliated individuals are able to and do respond to agency notices of proposed rule making. If this type of contact is available to individuals, one would expect that organizations that are aware of the agency rule-making calendar will face few additional barriers to submitting a comment. Additionally, small groups may be able to build personal networks with agency officials by attending professional conferences that attract those same officials (Panofsky 2011). In the health domain, groups may compete for grants or contracts from health agencies. Even unsuccessful groups may be able to use such initial interactions as a basis for continued interactions with agencies of interest.

[28] Schlozman and Tierney (1986: 104) include "appealing cause" as one of eight resources available to interest groups.

[29] In most cases, "family members" are parents of nonadult children who have the represented disease.

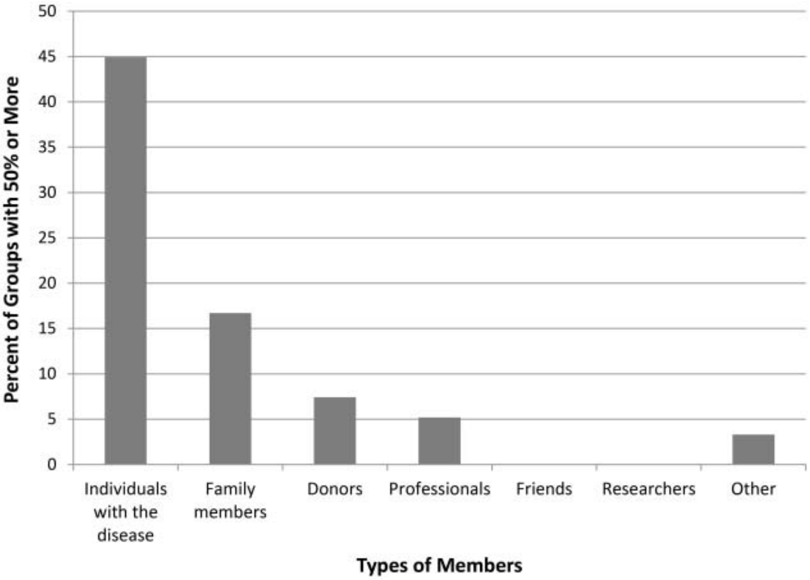

Figure 1 Percentage of Groups Reporting 50 Percent or More of Their Membership from a Specific Category

professionals (11 percent), friends (6 percent), and researchers (5 percent).[30] Figure 1 gives the percentage of groups indicating that 50 percent or more of their membership comes from a single category. This shows that, among groups who can attribute a majority of their membership to a single category, most of those majorities come from individuals with the disease or family members of those with the disease. Since our survey excluded groups that did not allow patients to join as members or volunteer for the organization, it is not surprising that surveyed groups draw heavily from patients and families for their membership.

Membership composition does not necessarily tell us much about the extent to which organization leaders are responsive to members. Since we cannot directly observe member involvement, we consider several alternate measures. First, we ask whether member composition is correlated with group size—an important indicator of group capacity. In fact, the mean percentage of group members who are patients differs significantly

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30. It is possible that the categories are nonexclusive, i.e., that donors might also have the disease themselves or be family members with the disease. However, the survey question asked respondents to sum their responses to 100 percent to reduce the likelihood of counting members in more than one category.

by group size—groups with larger reported membership are statistically more likely to have majority patient members than smaller groups ($p = 0.05$). When it comes to professional membership, a much smaller share of membership overall, smaller groups have almost double the percentage of professional members than groups with larger reported membership ($p = 0.03$).

Next, we analyzed the possibility that membership composition influences which groups lobby Congress. Here, we find that membership size independently predicts reporting congressional interactions ($p < .05$). At the same time, the regression analysis showed no relationship between percent patient membership and congressional strategy and no relationship between percent professional membership and congressional strategy (data not shown). While the small sample size limits the power associated with this analysis, our data provide no evidence that groups that mount congressional strategies are more likely to be dominated by professionals.

Turning to patient group finances, the survey asked groups to report the percentage of current income generated by several listed sources. While groups rely on a variety of sources, individual gifts outrank all other funding sources. Individual contributions achieve a mean score of 23.5 percent, followed by fund-raisers (17.4 percent), corporate gifts (16.6 percent), member dues (14.1 percent), foundation grants (11.3 percent), government grants (7.0 percent), and conventions/conferences (5.1 percent).[31] Because mean percentages across organizations could mask significant variation across groups, we looked at the funding sources for groups that could attribute 20 percent or more and 50 percent or more of their funding to a single source (fig. 2). This figure indicates that it is rare for groups to garner the majority of their financial support from a single source. However, when this does happen, the most likely source of majority funding is individual gifts: 17.3 percent of groups attribute at least 50 percent of their funding to this source. Even less likely is for majority funding to come from member dues (9.6 percent), corporate gifts (8.6 percent), or foundation grants (8.3 percent). These data suggest that most patient groups rely heavily on gifts from individuals. Such gifts might be spread across a large number of individuals, which would make the funding structure look more grassroots in nature, or it could be concentrated among a few donors who act as patrons for the organization. Importantly, the funding patterns we see in these data, when compared with the

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[31] The survey includes data on several sources of funding whose means were less than 1 percent: rent, loans, royalties, contributions from churches, contributions from unions, insurance fees, and other financing.

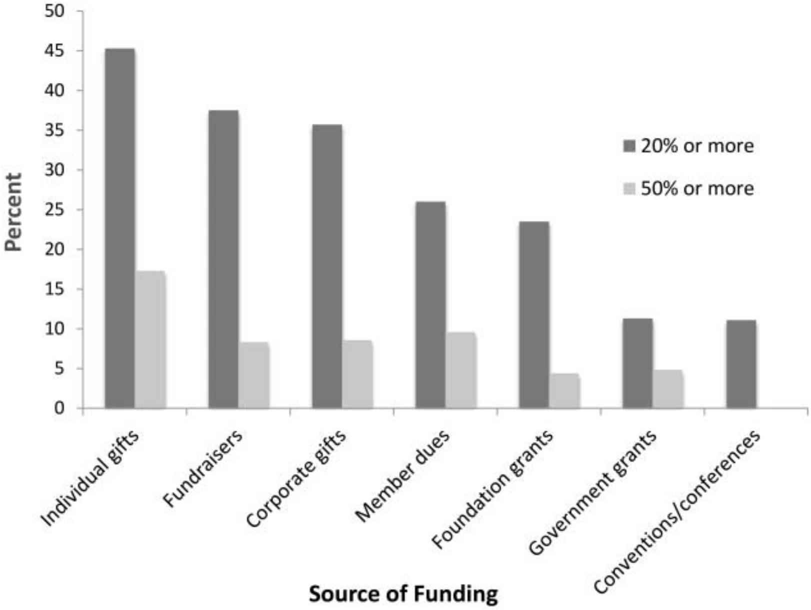

Figure 2 Percentage of Groups Attributing Indicated Percentage of Funding from a Single Source

patterns that Walker (1991: 81–85) found for profit, nonprofit, and citizen groups, correspond most closely with citizen groups.[32]

Turning to group structure, data from website content analysis revealed that nearly 60 percent of the groups in our contact database had a national structure (defined as displaying neither evidence of local chapters nor serving as an umbrella organization for a group of standalone organizations). Twenty-three percent of groups had a federated structure, while only 5.4 percent had a networked structure. Many patient groups make use of support groups that function at the local level. Some of these also act as a foundation for civic action at the local level. In this case, we included support groups that encouraged local level activism in the category of groups with a federated structure. However, to ensure that we did not overestimate the numbers of groups with a federated structure, we counted

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32. For Walker, a central characteristic that helps him classify groups is membership restriction by occupation. After setting apart citizen groups from occupational ones, Walker (1991) divides occupational groups into profit and nonprofit groups, where the latter are focused on public-sector services and resources. Bolstering the importance of these distinctions in understanding the interest groups landscape is that their funding patters are quite distinct, especially when comparing profit and citizen groups.

separately those groups with local support systems that appeared to be organized exclusively for providing support to patients. Eleven percent of groups in our database fit this category. These data corroborate the finding that groups working in the same policy space are likely to have a variety of structures (Minkoff, Aisenbrey, and Agnone 2008).

Next, we turn to content analysis of website data to examine which organizations provide opportunities for civic engagement. In fact, the vast majority of patient group websites (70 percent) contain content that encourages members to get involved in public-sector activities of the group. Examples include (1) listing and discussing relevant bills under consideration, (2) instructions for contacting congressional representatives and links to websites that help citizens find their representatives, (3) forms or sample letters to facilitate contacting one's representatives, (4) instructions for contacting specific federal agencies, and (5) guidelines for raising public awareness about a disease at the local, state, or national level. Looking at how advocacy opportunities vary according to group structure, we find support for the conclusion that federated groups are more likely than national ones to provide avenues for advocacy—88 percent of federated group websites provided opportunities for advocacy. Still, nearly two-thirds (63.6 percent) of the nationally organized groups provide similar opportunities. This difference is statistically significant ($p < .05$). While website content cannot tell us how often members take up the opportunities provided, it is clear from these data that the majority of groups do make an effort via website technology to encourage and facilitate member involvement.

Our survey data provide an additional lens for analyzing the relationship between patient group members and group activities. The survey asks about activities that (a) attract members to patient groups and (b) advance group goals. By comparing the relative priority of activities across the two survey questions, we can assess the extent to which member interests are reflected in overall group goals and prioritized activities. When asked about activities performed by the group that were important to members, groups could respond that an activity was very important (5), important (4), somewhat important (3), not important (2), and not an activity of the organization (1).[33] Figure 3 gives the mean rankings of the most important activities across groups. Not surprisingly, survey respondents report that what members value most highly, with mean scores above 4, is information regarding treatment and disease management. Also highly valued

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[33] Question wording available upon request.

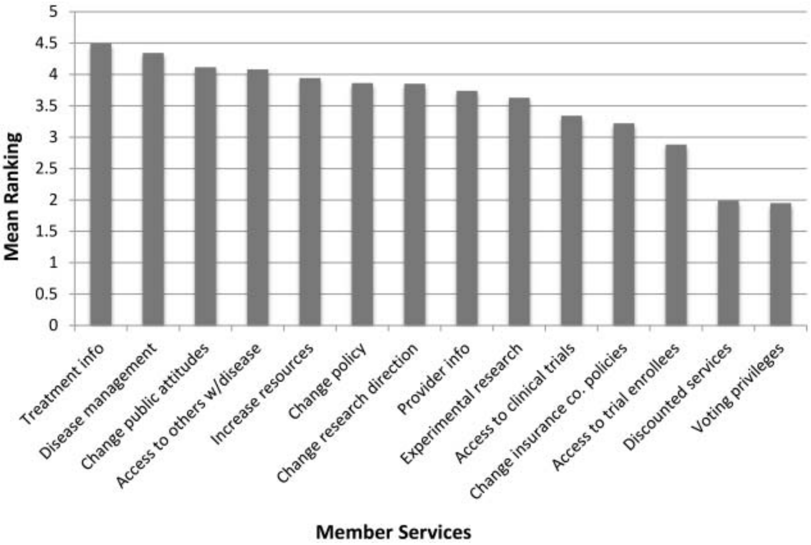

Figure 3 Services Important to Groups' Members

are access to others with the disease and the "opportunity to advocate for change in public attitudes about the disease." Though members might access group services on an individual basis without much attention to broader group goals, the high rankings given to accessing others with the disease and opportunities to change public attitudes suggest a more broadly engaged membership.

While not ranked as highly as the first set of activities, members were also reported to value policy changes, such as increasing research funding, changing the direction of research, or pursuing other policy changes (mean scores between 3 and 4). Two service-oriented activities—providing information about experimental research or access to clinical trials—also received mean scores between 3 and 4. The activities that are ranked as least important to members (mean scores below 3) are gaining access to trial enrollees, providing discounted services, and voting privileges.

Groups that want to attract and maintain members, ideally, will provide things that members want. However, it is possible for groups to pursue additional activities. If the activities that members care about do not make up the core activities of the organization, then we might question the extent to which an organization is driven by its members' interests. To assess this, the survey asked groups which activities were most important for achieving group goals. While the survey questions were not based on identical lists of

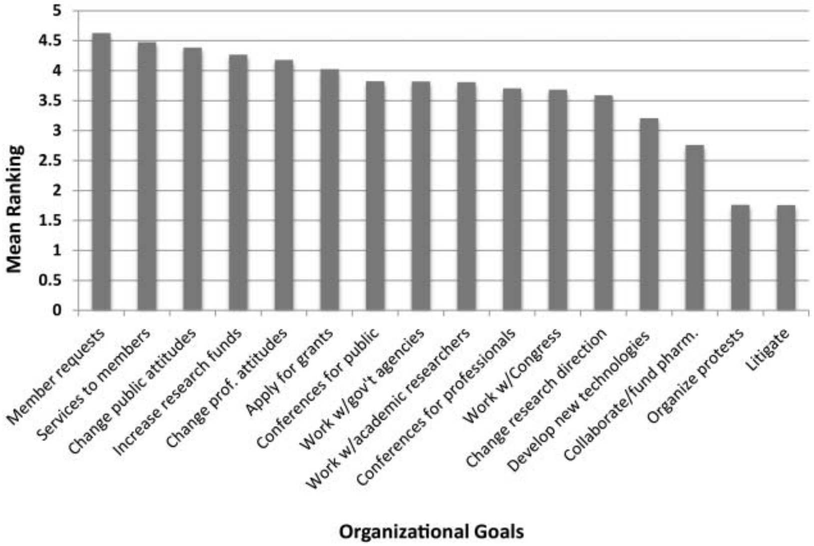

Figure 4 Mean Ranking, Organizational Goals

activities, there is enough overlap in question content to examine the relative importance of member interests to other organizational goals. Figure 4 shows results from the survey data for the activities that groups rank as important for achieving group goals. Four activities achieve mean scores above 4: responding to member requests, providing services to members, changing public and professional attitudes, and increasing research funding.[34] Activities that achieve mean scores between 3 and 4 include applying for grants, organizing conferences, working with government agencies, collaborating with academic researchers, working to change the direction of research on the disease, and developing new technologies. Less popular activities, with a mean score of less than 3, are collaborating with pharmaceutical companies, organizing protests, and pursuing issues through litigation.

These data suggest that patient groups prioritize member services over other goals the organizations might have. Moreover, the importance that members place on policy change—second to services, but still ranked as important—is reflected in the activities that groups pursue to achieve their goals. If the rankings across these two survey items showed marked differences, one might question the extent to which member interests drove organizational goals. Instead, we find substantial similarities in rankings

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[34] Note that the question regarding member interests did not include an option for changing attitudes among professionals.

across the two survey items, supporting the claim that member interests and priorities are broadly consistent with reported group goals.[35]

Bolstering our confidence in the importance of members and member interests for patient groups, we turn to a third survey question that appears three pages and four items later in the survey. This question asked respondents to indicate the degree to which their organization coordinates with a list of actors—for example, members, professional associations, politicians, researchers, health care providers, foundations, and the media—to achieve the organization's goals. The choice that received the highest mean ranking was "members of this organization." The consistent priority given to members and member interests across the three survey items strengthens our confidence in the quality of each measure.

In an effort to gain some insight into leadership-member relations, we turn to our interview data.[36] Our interview data are drawn from a convenience sample of contacted groups located in Washington, DC, and are therefore not representative. The interviews included ten groups with a health-oriented mission. Eight of these were groups or coalitions of groups organized around a disease, set of related diseases, or health concern for a specific population (interviews 1, 2, 3, 4, 5, 6, 7, 13). This same set of groups each listed some form of patient services as part of their organization's mission.[37] Two of the ten groups were public interest organizations that pursued a health concern for the entire US population (interviews 8, 10). These fit the description of Skocpol's (1999, 2003) "memberless" organizations. Seven out of ten groups, on the other hand, were founded by patients or family members of patients (interviews 1, 2, 3, 4, 5, 6, 13). For six out of these seven, group leadership remained nonprofessionalized at the time of the interview (interviews 1, 2, 3, 4, 5, 7).[38]

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[35] Because the two survey items appeared sequentially in the survey, one must be concerned that the consistency of responses was driven all or in part by the survey design. That is, if a survey respondent ranked an activity as important to a member, that respondent might be more likely to rank the same activity as important for achieving group goals. To guard against this, the survey questions were worded with the intent of signaling that activities that attract members might be different than core activities of the organization. In addition, the list of activities provided in each of the survey questions were ordered differently to reduce the likelihood that respondents would simply rank the first listed items as more important than items further down the list.

[36] A list of interviews is included in appendix A.

[37] Other activities that were ranked highly by the interviewed groups were advocacy, research, and changing public or professional attitudes about the disease.

[38] One group interviewed was a coalition of patient groups organized around the same disease. The DC-based coalition was headed by a lawyer, though the groups themselves were characterized as "patient-driven . . . mom and pops . . . started by an individual or small group" (interview 6). Another group did report a shift away from the group's original founder, a patient with the represented disease, to a board of directors. The majority of board members for this group continue to be patients or family members (53 percent). Board members with professional degrees, all in law, comprise 20 percent of the board (interview 13).

Though the interview data cannot speak to the experience of the larger population of groups contacted for this study, several interviews provided interesting accounts of leader responsiveness to group members. In one interview, the interview subject pointed to a critical shift in the organization's membership. The organization represents an often fatal birth defect for which treatment has improved over time. Originally, the group was organized by and for parents of children with the disease. However, with improvements in treatment, the organization began to have adult members with the disease. This created an entirely new constituency for the organization and led it to develop several new programs and initiatives targeted specifically for patient members surviving into adulthood (interview 4). This example demonstrates how an emphasis on member services kept leaders attuned to the interests and needs of organization members as the demographics of group membership shifted.

In a second case, the organizational representative pointed to tension between leader and member interests. Organization leaders were committed to policy changes that would expand opportunities for stem cell research—clearly a long-term strategy aimed at finding a cure for the disease. The members, on the other hand, had a more immediate interest in generous reimbursement policies for medical treatment. The interview subject used this tension to illustrate the mechanisms the organization used to communicate with its members to try and balance both goals within the organization. These included regular conference calls, a website bulletin board, and several policy committees that allowed more active members to participate in organizational decision making. In addition, the interview subject argued that the leadership is dependent on members for their volunteer time and their role in advocating for the organization's goals. Thus, the organization needed to be responsive to member interests in order to sustain membership involvement and commitment to the organization (interview 13).

A third group brought together several organizations that represented a related class of diseases. Though "members" in this case were organizations, this group was equally focused on how it could further its members' interests by coordinating advocacy through the coalition. Specifically, the coalition would look for areas of consensus across the groups and form lobbying positions only when the coalition developed majority agreement on an issue. In this case, lobbying activities grew directly from member views. Moreover, the group leadership took pains, when lobbying, to be specific about which groups, if any, in the coalition did *not* support the specific coalition position. Throughout this interview, the interviewee emphasized the patient focus of the majority of the groups within the coalition, characterizing most of them as “mom and pop” operations started by patients or their family members (interview 6).

Though we have no direct measures of member involvement in group activities or decision making, the combined data presented here suggest that, although some disease-specific organizations may function as essentially memberless, many do not. Patient groups’ memberships tend to be dominated by patients and/or their family members, and the choice to lobby Congress does not appear to be associated with more professionalized groups. While federated groups are more likely to encourage member participation—consistent with the expectations set out by Minkoff, Aisenbrey, and Agnone (2008)—a significant majority of nationally organized groups we contacted also encourage some form of membership involvement. Moreover, groups tend to prioritize those activities that rank as most important to members—member services and advocacy. Finally, survey responses show that group representatives report, on average, devote more time to coordinating with members than with any other type of actor.

Policy Environment

H3 Patient groups pursue policy goals that generate little or no political opposition.

In order to learn more about the competitiveness of patient interest groups’ environment, we examined where groups with public-sector strategies reported spending their time. Though the survey responses provide a range of political strategies used by groups who report working with Congress or with executive branch agencies, there appears to be a dominant model of public-sector lobbying on the part of the surveyed groups. First, patient groups reporting interactions with Congress cite the Appropriations Committees more frequently than any other listed committee (35 percent), though the Senate Health, Education, Labor and Pensions Committee is a close second (29 percent).[39] In addition, among groups who report working with specific agencies, the National Institutes of Health is mentioned far more

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[39] Committees listed by groups reporting interactions with Congress are Appropriations (35 percent); Health, Education, Labor, and Pensions (29 percent); Energy and Commerce (12 percent); Ways and Means (7.2 percent); Agriculture (3.6 percent), Finance (3.6 percent); Budget (2.4 percent); Education and Workforce (1.2 percent); Government Oversight (1.2 percent); Government Reform (1.2 percent); and Transportation and Infrastructure (1.2 percent). The Congressional Black Caucus (1.2 percent) and the GAO (1.2 percent) were also each mentioned by a single group.

frequently than any other agency (35.9 percent).[40] These data suggest that the public-sector strategies of most patient interest groups bring them into an arena of distributive politics characterized by easily subdividable goods that are parceled out to any number of claimants (Lowi 1964, 1972). Lowi argued that distributive politics, as compared with regulatory or majoritarian politics, are both less visible and less competitive. Thus the appropriations committees who oversee the distribution of goods, the interest groups pressing for their "fair share," and the agencies who will deliver the goods are unlikely to generate much interest from other political actors and the public. Moreover, the groups pressing for benefits do not see themselves as pitted directly against other groups active in the same space (Lowi 1964, 1972). If most patient interest groups who have public-sector strategies are lobbying Congress for additional NIH funding, it is likely that such groups are not generating much opposition.

To examine this further, we asked groups directly about the competitiveness of their environments. Most groups report moderate to significant competition for resources. Responses, however, shift considerably when groups are asked about competition for members — most groups report little or only moderate competition for members. Groups are even less likely to report working in an arena characterized by eruptions of policy conflict, fundamental disagreements over policy goals, or the presence of repeat opposition either from elected officials or from other groups.[41] Thus the congressional committees and executive branch agencies targeted and the reported level of political conflict are consistent with the view that patient groups participate in an arena of distributive politics that is not characterized by high levels of competition among groups.

Who Lobbies for Patients?

In light of these data, how should we understand patient groups? They have two characteristics that place them firmly in the "citizen group" camp. First, their memberships are not restricted by occupation. Second, their

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[40] Agencies listed by groups reporting interactions with the Executive Branch are NIH (35.9 percent); CDC (17.9 percent); CMS (9.4 percent); FDA (7.5 percent); HHS (5.7 percent); Department of Education (3.8 percent); Office on Women's Health (2.8 percent); SSA (2.8 percent); VA (1.9 percent); DOT (1.9 percent); and HRSA (1.9 percent). In addition, eight departments or agencies (8.5 percent) were each mentioned by a single patient group (Department of Labor, DOD Congressionally Directed Medical Research Program, DOJ, EPA, EEO Commission, FAA, FTC, and HUD).

[41] Data on the reported competition faced by patient groups is available upon request.

financial structures look much like other patient groups (Walker 1991). At the same time, however, patient groups are critically distinct from other citizen groups. Though they vary in size and capacity, they are united by a common emphasis on providing member services as a central function of the organization. Those services tend to concentrate around disease management, treatment information, and provider information. In this, patient groups share an important trait with trade associations.[42] That is, both types of groups, in addition to any political role they play, act as a source of information for a common set of problems faced by members. This means that both offer nonpolitical incentives for members to join the group. In both cases, these valuable services can be restricted to dues-paying members and function as classic selective benefits. Here we see that a common distinction drawn between occupational and nonoccupational groups does not apply.

For patient groups, moreover, solidary benefits—access to others with the disease—appear to be as important to members as the services that come with membership. And though policy goals ranked behind member services and access to others with the disease in terms of their value to members, purposive goals also appear to be highly valued. Thus, it seems that, once individuals are willing to identify as having a given disease,[43] there is no shortage of incentives that can be used to attract potential members. This would lead us to expect that patient groups are relatively easy to form and not as difficult to maintain over time as groups organized primarily around purposive benefits. This sets patient groups apart from most groups that attract nonoccupational memberships. At the same time, patient groups do share two very important characteristics with citizen groups more generally: their membership is nonoccupational, and their financing matches that composition.

Even though the majority of surveyed groups report having some interest in policy advocacy, patient groups are not uniform in the strategies they pursue to achieve group goals. Groups with larger reported memberships and more resources are most likely to pursue advocacy strategies that involve Capitol Hill, while smaller groups gravitate toward agency or private-sector strategies. Among groups with public-sector strategies, the focus on NIH and on congressional appropriations committees suggests

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[42] We wish to thank Kay Schlozman for calling our attention to this point.

[43] In one interview, a group leader argued that there was only a brief period of time in the course of the represented disease during which patients were likely to become members. In this group's experience, individuals identified as having the disease for only about eighteen months after treatment (interview 5). Clearly, this dynamic varies from disease to disease. For example, chronic diseases might be more likely to produce long-term disease-identities.

that patient groups engage in distributive politics. Thus, while we have presented the distributive policy environment as one that is less competitive than regulatory ones and we have argued that patient groups possess some structural advantages that should contribute to their longevity, it appears that patient groups do face some barriers to entry with respect to lobbying Congress.

Among those groups with the capacity to undertake congressional strategies, we find an interesting puzzle: patient groups rarely form coalitions that bring together groups representing different diseases. The primary mode of organization of the groups we studied speaks to the tendency to work on a disease-by-disease basis or to work within a related category of diseases. Though our initial search for patient groups did find organizations representing the general health concerns of a specific subpopulation (typically defined by gender, race, ethnicity, sexual orientation, and/or life stage; 7 percent) and ones organized around two or more related diseases (19 percent), the overwhelming majority of what we call patient groups are organized around a single disease (70 percent). In an effort to quantify rates of coalition formation, we reviewed witness appearances in congressional hearings, coding a random sample (30 percent) of the groups in our contact database. We relied on LexisNexis Congressional Hearings Summaries to determine whether a listed group participated singly or as part of a partnership or coalition and found that only 13 percent participated in at least one cross-disease coalition when appearing before Congress.

Reasons for such low rates of cross-disease coalition formation are unclear. Generally speaking, there are theoretical reasons to expect that most groups will enter into coalitions at least occasionally, if not frequently (Baumgartner and Jones 1993; Hula 2000; Salisbury 1990). At the same time, research demonstrates that an individual group's choice to enter an alliance is shaped by a number of factors, including the breadth of interest in an issue; the strength of organized opposition; and likely contributions from potential allies (Hojnacki 1997). Data from this study show that groups' goals are almost exclusively disease-specific. If we take those interests as given, then the lack of coalition formation among these groups may not be a surprise (Hojnacki 1997). However, an exclusive focus on disease specific goals is not a given; there is no a priori reason that patient groups could not pursue narrow and broad interests at the same time. Patient groups might include in their portfolios efforts to, for example, increase the status of patient representatives on NIH advisory boards or shift the balance of NIH spending away from basic toward applied research. Moreover, a collective effort to increase the overall NIH budget might be more effective than the "go it alone" strategies patient groups tend to use to press for disease-specific budget allocations.[44]

While low rates of coalition formation among groups that do not articulate a set of shared interests is not a surprise, the lack of expressed shared interests itself poses a puzzle. It may be that groups recognize their shared patient interests but fear antagonizing disease-oriented professional associations. Thus, within-disease alliances may be perceived as both necessary and fragile.[45] Because issues like the relative allocation of NIH research dollars between basic and applied research might align patients against NIH's traditional stakeholders—that is, basic science researchers—it might be more politically palatable for patient groups to lobby for increases in applied research on a disease-by-disease basis. Equally possible is that the structure of NIH, which encourages disease-specific advocacy, has simply habituated patient groups into a type of advocacy that does not encourage a shared "patient" consciousness. The selective benefits that groups provide, likely to be quite disease-specific, may have a similar effect in that they reinforce a "disease" identity over a shared "patient" identity.[46] Whatever the drivers, it is clear that patient groups are rarely bringing their collective, nonoccupational voice to bear on their advocacy efforts. Thus the disease identity that appears to play such a significant role in these groups' formation may also pose a barrier to a stronger, nonprofessional voice in the political arenas where patient groups engage.

Conclusion

This study has several limitations. First, the study attempts to characterize member participation without being able to directly observe it. Second, the study does not collect data on professionalized disease organizations. Thus we forgo an opportunity to provide context for patient group activities by exploring the resources, strategies, and goals of their professionalized counterparts. Third, while the study does show that patient groups have shied away from attempting to exert a distinct "patient" voice in the political

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[44] We would like to thank an anonymous reviewer for raising this point.

[45] In fact, patient groups *do* report working with other organizations that represent the same disease (data available upon request).

[46] The lack of generic "patient" consciousness among what we call "patient groups" forces us to consider whether or not we have chosen a misleading label. However, since the term *disease association* has entered the literature in reference to any group organized around a specific disease, we feel the "patient" label is important in distinguishing nonoccupational groups from occupational ones in this space. Though it may be more descriptively accurate, "nonoccupational disease organization (NODO)" seems too linguistically cumbersome.

sphere, it does not identify the root cause for the lack of cross-disease coalition formation among groups.

Patient groups belie easy classification in current interest group politics. We know that nonoccupational groups are vastly outnumbered in the interest group world, and we learn of numerous ways in which the citizen group ideal mischaracterizes actual nonoccupational groups. Even so, we see patient groups increasing in numbers and learn from handful of single-case studies that several groups have achieved notable policy successes. In treating a larger population of patient groups, we are able to assess which of these two images more accurately reflects the larger experience of patient groups, and we find that elements of both are correct. Although Skocpol warns of hollow membership, most patient groups seem to focus heavily on providing member services and encourage member involvement in group activities. Although Walker expects that citizen groups will be ideological in their goals and will therefore face competitive political environments, patient groups tend to engage in the less contentious arena of distributive politics. Whereas nonoccupational groups are typically associated with pursuing policies whose benefits are broadly distributed, patient groups tend to pursue policies whose benefits will accrue more narrowly to those with the represented disease.[47] Thus, while patient groups are nonoccupational and quite often appear to work from actual membership bases, they also have structural features similar to trade associations—specifically, their ready provision of selective benefits.

This portrait of patient groups raises the potential that there are at least two modes of nonoccupational organizing, neither of which fits the idealized view of citizen groups. The first, identified by prior studies, are public interest organizations that pursue public goods while relying on a professionalized, top-down structure instead of springing from an active grassroots membership. The second, suggested by the experience of patient groups, are nonoccupational groups that do mobilize members but are organized around services or policy goals that benefit narrow constituencies. Such groups, should there be others beyond the patient groups discussed here, might have the formation and staying power typically associated with occupational groups. On the other hand, we would not expect such groups to develop a "citizen" or nonoccupational consciousness that could bring some counterweight to the more typical occupational/professionalized

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47. Clearly, even for diseases that affect relatively small numbers, group efforts to increase research funding may have spillover effects to other diseases. The meaningful distinction here is that patient groups are not motivated by the potential societal gains associated with their lobbying efforts.

groups. In this study, we find that patient groups appear to benefit from characteristics that encourage their formation and stability. However, those same properties appear to work against the emergence of a shared "patient" consciousness that might form across groups.

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Appendix A: List of Interviews

1. July 7, 2006, phone interview with organization of individuals representing a single disease (outside Washington, DC, area)

2. July 17, 2006, in-person interview with organization that heads a coalition of groups organized around single disease (Washington, DC, area)

3. July 19, 2006, phone interview with an organization that heads a coalition of groups representing health concerns of specific subpopulation (Washington, DC, area)

4. July 21, 2006, in-person interview with organization of individuals representing a single disease (Washington, DC, area)

5. July 24, 2006, 11 a.m., in-person interview with organization that heads a coalition of groups organized around single disease (Washington, DC, area)

6. July 24, 2006, 3 p.m., in-person interview with organization that heads a coalition of groups organized around a family of related diseases (Washington, DC, area)

7. July 25, 2006, 11 a.m., in-person interview with organization representing health concerns of specific subpopulation (Washington, DC, area)

8. July 25, 2006, 2 p.m., phone interview with organization representing health concern for entire US population (Washington, DC, area)

9. July 26, 2006, in-person interview with congressional staff

10. July 27, 2006, in-person interview with organization representing health concern for entire US population (Washington, DC, area)

11. July 28, 2006, phone interview with NIH staff

12. July 31, 2006, 11 a.m., phone interview with NIH staff

13. July 31, 2006, 3 p.m., in-person interview with organization of individuals representing a single disease (Washington, DC, area)

Appendix B: Example of Patient Groups Drawn from Data Publicly Available on Group Websites

The following descriptions of patient groups illustrate the differences between those with significant public-sector strategies and those who operate primarily in the private sector.

The descriptions of groups in this appendix are drawn from data that is publicly available and provided by the websites for the listed groups. Though we compare these groups to the mean characteristics of the surveyed groups, the groups described here by name did not participate in our survey.

Groups with Significant Public-Sector Strategies

Lung Cancer Alliance

The Lung Cancer Alliance website encourages visitors to "get smart," "find support," and "make a difference." Each of these labels is a clickable tab that, respectively, connects website visitors to information about lung cancer, support services provided by the organization, and opportunities for public-sector advocacy. As is typical of most of the groups surveyed, this group emphasizes patient services, but also offers volunteers ways to get involved in supporting the organization's mission. This includes community-level activism as well as coordinated advocacy at the federal level. Federal policy goals include improving early detection and increasing publicly funded treatment-oriented research. The website also provides information on open clinical trials. This linkage might mean that the organization connects patients to private-sector researchers. However, the organization's primary research emphasis as expressed on the website is a public-sector effort targeting the federal government.

Given the organization's size, its public-sector focus is not surprising. In its 2011 tax filing, this organization lists thirteen employees and estimates four thousand volunteers. The same tax filing shows net assets of $4.4 million dollars. If we compare this group to those in our survey, this group is both larger and better off than the average surveyed group. The website content describes the organization as unique in its focus on support and advocacy for the disease, citing its role in creating a "nationwide lung cancer movement." The organization is led by a board of directors made up of physicians, nurses, survivors, and advocates. In addition, it has a medical and professional advisory board and a recently formed (2012) National Advocate Advisory Council made up of lung cancer patients or their family members or friends. Thus, like most organizations surveyed, the organization does create opportunities for patient involvement and is not limited to occupational membership. Notably, this group appears to be the largest in this subset.

Aplastic Anemia and MDS International Foundation

The Aplastic Anemia and MDS International Foundation is an example of a financially solvent patient interest group that provides patient services, funds research in the private sector, and actively and successfully lobbies for federal research dollars earmarked specifically for the represented diseases. The organization is clearly oriented toward patient support and patient services. Though the website includes information about the organization's research and political advocacy, both are listed less prominently than information about the disease and the group's patient services. Though the organization has a medical advisory board populated by doctors, its board of directors is drawn from individuals with a personal connection to the disease, either as a patient, family member, or friend of someone with bone marrow failure. The website provides opportunities for both community-level engagement (fund-raising and spreading awareness) and federal-level activism in the form of contacting representatives to support relevant bills. The organization has a larger budget than the average patient group responding to our survey. The group's website states that the organization is "supported through individual contributions from grateful patients, families and friends, as well as foundations and corporations." In its 2011 tax filing, the organization lists seventeen employees, an estimated one hundred volunteers, and net assets of $2.5 million. Though this organization boasts federal-level lobbying success in the form of DOD research dollars earmarked for the disease, it also has a significant private-sector research strategy.

Groups with a Private-Sector Emphasis

Glaucoma Research Foundation

The Glaucoma Research Foundation, though it allows patients to volunteer for the organization, is quite different in its origins and its mission. Typical of patient groups included in this study, the foundation highlights support for patients, especially the newly diagnosed, and states its commitment to its twin goals of improving the lives of patients and supporting research to find a cure. Notably, the website for this foundation includes no indication that it devotes *any* resources to public-sector advocacy. Moreover, volunteers for this organization are enlisted in efforts to raise money for research. Once again, the advocacy piece is absent. The genesis of the organization is also distinct from most patient groups in that it was not started by a patient or a family member of a patient. The organization was founded by three physicians who specialized in glaucoma care and felt that there was a lack of interest on the part of researchers in the disease. The physicians created the foundation in order to be a catalyst for supporting expanded research and innovation in the treatment and cure of glaucoma. In its 2011 tax filing, the organization indicates that it has six employees and estimates that it has seventy-six volunteers. In this respect, it does not differ dramatically in size from the Aplastic Anemia and MDS International Foundation. Thus this organization is typical of what we might think of as a private-sector oriented foundation that seeks to directly shape research efforts on the disease of interest rather than seeking public commitment or support for disease-specific research.

Desmoid Tumor Research Foundation

The Desmoid Tumor Research Foundation website prominently lists a two-pronged mission: funding research and providing support. This group's website includes information about the disease and treatment options. It organizes an annual meeting for patients and a fund-raiser in the form of a 5K run/walk that coincides with the patient meeting. The website also provides information for those who wish to apply for grants and lists awarded grants and associated publications. It also contains information about currently open clinical trials and a list of related publications that were not funded by the foundation. Unlike the Glaucoma Research Foundation, this organization was cofounded by a patient and a spouse of a patient and includes a page where patient members can share stories and testimonials about their motivation for joining the organization. At the same time that the group encourages patient membership, it also has a highly credentialed scientific advisory board as well as a professionalized national advisory board. This group does not post financial statements on its website. However, in addition to its two cofounders, the website gives bios for and lists seven volunteers. Thus this group may be the smallest of these four.