CITIZEN PARTICIPATION IN HEALTH POLICY AGENDA-SETTING:
PERCEPTIONS OF THOSE INFLUENCING POLICY

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CITIZEN PARTICIPATION IN HEALTH POLICY AGENDA-SETTING:
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ABSTRACT

This study explored the experiences and perceptions of citizen participation in health policy agenda-setting held by those citizens most likely to influence the health policy process: legislators and health policy advocates. Findings from a review of the literature regarding previous studies of the process of citizen participation were used to guide a qualitative research project in North Carolina. A case study approach was employed to facilitate an in-depth exploration of the meanings and perceptions of legislative members of the North Carolina General Assembly and Executive Directors of health policy advocacy organizations in North Carolina. Using a non-probability sampling procedure, study participants of the legislative case type were purposefully selected based upon membership in legislative committees and sponsorship of particular legislation, and recruited on a volunteer basis. Study participants of the other case type – Directors of health policy organizations and health programs – were recruited by referral. This interconnected system possesses behaviors and attitudes that impact the process of citizen participation in health policy decisions.

Cases were interviewed, using a semi-structured format to identify common themes regarding citizen participation in healthcare policy decision-making and agenda-setting. A total of thirteen (six legislators and seven health activists) interviews were completed: five were in-person and eight were telephone interviews. Categories of text from the interviews were analyzed for content and themes, using a holistic analysis
approach. A detailed description of each case and themes within the case (within-case analysis) and thematic analysis (cross-case analysis) permitted interpretive assertions of the lessons learned. This study revealed that the attitudes and perceptions of political actors (both case types) in North Carolina impact the methods in which citizens participate and the input of their participation in health policy decisions.
DEDICATION

IN MEMORY OF
Ms. Carolyn E. Hann
My rock, my strength, my supporter and motivator

IN HONOR OF
My children, for their understanding and sacrifices throughout this journey
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CHAPTER 1

INTRODUCTION

Citizen participation is the true cornerstone of effective democratic government functioning, upon which the United States was founded. Active citizenship, according to Immanuel Kant, provides a basis for the understanding of participatory democracy. Theories of participatory democracy assert that “individuals, groups, and institutions cannot be considered in isolation from each other” and that “decisions should be arrived at through an open and uncoerced discussion of the issue at stake with the aim of arriving at an agreed judgment” (Hillier, 2002, p. 29). In a participative government, policy making considers public interest, determined through public involvement, consultation, and negotiation.

Good policy processes rely on gathering clear information from the public about what it wants and then converting it into clear policy priorities. Habermas (1976) discusses the theory of communicative action as it relates to public policy decision-making. His basic assumption is that rational consensus is arrived at through linguistic communication and mutual understanding. He identifies two main causes of rationality: “one in which knowledge is used instrumentally as a means of successfully gaining strategic ends, and a second in which knowledge is used communicatively for purposes of understanding and discussion of issues” (Hillier, p. 33). The ideologies of Habermas are reflected in the methodologies of consultation and collaboration in agenda setting.
Ideally, the policymaking process should be treated as a collaborative effort between citizens and government. Joanne Caddy (2001) refers to “citizens as partners” and identifies key principles to making the collaborative partnership most successful. She defines information, consultation, and active public participation as key ingredients to an effective participatory government. Accordingly, with public participation, government becomes accountable to use the citizen input in the policymaking process. To facilitate accountability, governments must build trust by starting from the citizens’ perspective and delivering what is promised.

Despite the acknowledgement of the importance of public input, there remains the leading obstacle of low citizen participation in political decision-making. In all but national elections, citizen participation is very low. Attendance at local public meetings is nominal; in fact, attendance at public meetings on town or school affairs decreased by 35% between 1973 and 1993 (Putnam, 2000, p.45). Further, public meeting turnout is frequently composed of the same or similar groups of individuals. This “narrow participation” contributes to conflict and bias (a “pressure system”) within the polity and the selection of political alternatives by those “legitimate” groups already having access to the political arena (Cobb & Elder, 1983, p.5).

Dahl argued that a number of variables – concern of involvement, skill, access, socio-economic status, education, residence, age, ethnic and religious identifications, and personality characteristics – influence the variations in the participation of political decisions (as cited in Cobb & Elder, 1983, p. 10). More recent authors (Kapiriri, Norheim, & Heggenhougen, 2003; Boyce, 2001; Labonte, 1993), also attribute the same factors to low citizen participation in health care decision-making. Citizens who do not
feel that their voice carries any power are reluctant to participate in the decision-making process. A 1991 study by the Kettering Foundation found that “citizens are not apathetic about participating in the government process, but are instead frustrated and feel pushed out of the decision-making arena” (Williams, 2000, p.1).

According to Kronenfeld (1997), “A nation’s health policy is part of its general overall social policy, and as such, is influenced by the variety and array of social and economic factors that impact social policy development” (p. 49). Tenbensel (2002) further affirms that due to the high visibility of health care issues on the public agenda, “any policy formulation contributing to the setting of health priorities requires the involvement of the public” and neglecting to do so “would be cause for scrutiny” (p. 173). Additionally, the issue of health priority-setting is value-laden and therefore cannot be worked through on a solely technical front. Some health policymakers have realized that public support in health priority-setting will be easier to achieve if the public is involved in the process.

Social and economic factors such as “the nature and history of existing institutions, the general climate of opinion, ritualized methods of dealing with social conflict, attitudes and behavioral characteristics of key political actors, and the general goals and values of a society” have influenced and shaped health care policy in the United States (Kronenfeld, p. 49). Additionally, Shauer (1999) asserts that “In the United States, the degree of disagreement about welfare policy, race relations, and health care is greater than the degree of disagreement about the desirability of public nudity, the undesirability of top marginal tax rates in excess of 80 percent, and the wisdom of ending fluoridation of the water supply” (p. 17). There is also continuous debate over whether
the federal government, the states, or private industry should play a major role in health
care policy, which is defined as policy that “relates to the pursuit of health, the
employment of health care professionals, or the receipt of health care services”
(Kronenfeld, p. 50).

These conflicting views are further exemplified in the process of eliciting and
using input from citizens on health care policy decisions. One of the most common
methods of involving citizens in the policy process in the United States is the public
hearing. If utilized properly, public meetings can enhance the political power of citizens,
and thus, improve governmental responsiveness to citizens. There are, however, two
criticisms that must be addressed. One is that citizen input does not influence policy
outcomes. The other is that public meetings attract an unrepresentative sample of the
population. Tenbensel (2002) illustrates these criticisms by stating: “the undisputed fact
that information about public values is basically ignored by politicians, government
officials, and interest group leaders who make policy decisions behind closed doors due
to fears that their thoughts or interests will be threatened if policy-making is subject to
scrutiny” (p. 191). The other area of criticism is directly related to the first. It is not
uncommon for those who must live with the results of the policy decision to be
unrepresented in the decision-making process.

Statement of the Problem

Classical democratic theory asserts that widespread, active participation is a
requirement for a stable, effectively functioning democracy. However, the reality is that
low public participation rates in policy deliberation have led to the emergence of
“democratic elitism” (Cobb & Elder, 1983, p. 3), in which the elite influence decisions.
Dye (2002), in his book Who’s Running America, discusses the “power elite” (Mills, 1956) and its implications on politics. In the area of health care policy, interest group membership is frequently composed of those citizens already involved in the health care and legislative systems (such as doctors, pharmaceutical representatives, and lobbyists). In accordance with the principle of subsidiarity, those in positions of authority are required to “recognize that individuals have a right to participate in decisions that directly affect them” (Ascension Health Systems, n.d.). However, conventional methods of engaging the citizen (as health services consumer) in the policy process have failed to alleviate political alienation and democratic elitism.

The Research Issue

The issue of health has been a variable of interest for many politicians. The amount of political attention that this issue receives is contingent upon the changing perceptions of the problem it presents. Prior to the 1970s, health care spending represented less than five percent of the Gross Domestic Product (GDP) (Green-Pedersen & Wilkerson, 2006, p. 1041). Technological advances in the next two decades created a trade-off situation: a decrease in morbidity and mortality rates, but an increase in health care costs. By the mid 1990s, health care in the United States was consuming 15% of the GDP (Kronenfeld, p. 3). Rising costs in health care expenditures not only affected the United States, but “forced many OECD nations to choose between restricting access to services or devoting ever increasing shares of national income to one policy area” (Green-Pedersen & Wilkerson, p. 1042).

The majority of the industrialized nations, exclusive of the United States, have developed some form of a nationalized health care system. Most of these countries have
authorized regional or local “health authorities” to make health-related practice and policy decisions for their region or locality. In compliance with legislation, these health authorities have begun to utilize citizen participation at a local or regional level in health care decision-making. The first successful effort in regard to health care policy in the United States was the enactment of the Medicare and Medicaid programs of the 1960s by President Lyndon Johnson. All fifty states within the United States have federally funded Medicaid and Medicare programs and a State Children’s Health Insurance Program (SCHIP) (created by President Clinton’s Bipartisan Balance Budget Act of 1997). A few states (e.g., Oregon, Washington, and Minnesota) within the U.S. have implemented state health care programs and have mandated regional “health authorities” to address community policy issues. Some have successfully applied this principle and effective strategies of gathering and using citizen input in the decision-making process.

Recently, in the United States, President Obama initiated the most comprehensive change in health care policy with the passage of The Patient Protection and Affordable Care Act (2010). The Affordable Care Act, as it is commonly referred to as, provides all fifty states with the option of expanding coverage under the auspices of Medicaid. Each state will also offer a state-based health insurance marketplace, known as an exchange, where citizens can make online comparisons of all available policies and premiums. States may choose to build their own online marketplace or let the federal government run their exchange. The state of North Carolina has opted to not expand Medicaid coverage and to utilize a federal exchange. The Governor, in his announcement to the press, stated “If it becomes clear that the current course of action is not in the best interest of North Carolina, our health care system, and our citizens, we will work with the
General Assembly to pursue other options in the future.” He further states that “we have done a thorough review of the advantages and disadvantages . . . this review included discussions with our governors, the White House, health care providers, and N.C. legislative leaders” (Governor Pat McCrory, Press Release, Feb. 12, 2013). However, the issue remains that, according to the governor’s statement, the citizens (as consumers) most affected by this decision, have not participated in the decision-making process.

The Research Approach

The intent of this study was to explore citizen participation in health care policy agenda-setting, deliberation, and decision-making. Findings from a review of the literature regarding previous studies of this process were used to guide a qualitative research project in North Carolina. A case study approach was employed to facilitate an in-depth exploration of legislators’ and health activists’ perceptions and meanings of citizen engagement in the process of health care policy agenda-setting and deliberation. The case study has its origin in the disciplines of political science, sociology, urban studies, and other social sciences, making it an appropriate approach for this study. The philosophical assumptions of this study are rooted in the advocacy/participatory framework of knowledge claim positions. This approach, based on the previous work of Marx and Habermas (and others), proposes that “inquiry needs to be intertwined with politics and a political agenda” (Creswell, 2003, p. 9).

Conclusion

Health care policy has been a highly debatable topic in the United States almost since the inception of health insurance programs after World War I. Many of the stakeholders of the American health policy system are dissatisfied. Current health care
costs (both at a national level and an individual level) are increasing at staggering rates. Presidential administrations have attempted to develop policy that controls health care costs while simultaneously provides adequate, affordable care to citizens. Insurance companies and medical interest groups have been granted substantial authority in decision-making and have become the “democratic elite” in the development of health policy. Citizens most affected by health care policy, as a measure of good practice, should be involved in the health care agenda-setting process.

According to Appleby (1962), “the most important function of citizens is to choose between the alternatives most clearly identifying responsibility for what is done” (p. 97) and “the duty of the government in respect to its citizens is to determine policies, to carry on programs in realization of the policies, and to explain to and educate the citizens about these policies, programs, and the problems that lie in and behind them” (p. 127). Both of these contentions imply the need for communication between the two parties. However, in the arena of health policy, governments can be reluctant to exchange information with citizens. This study sought to ascertain the experiences and perceptions of citizen participation in health policy agenda-setting held by those citizens most likely to influence health policy initiatives: legislators and health care policy advocates.

According to Dovidio and Fazio (1992), perceptions are the ways by which a person views an object, issue, idea, or another person and are guided by, and congruent with, an individual’s attitudes. While experience influences attitude and perception, attitude and perception impact behavior.
CHAPTER II
REVIEW OF THE LITERATURE

A nation’s political ideologies impact the process of citizen engagement and participation in the deliberation of public policies. In their book, *Participation in American Politics*, Cobb and Elder (1983) analyze the critical role that agenda-building plays in the public policy-making process. They refer to an agenda as “a general set of political controversies that will be viewed at any point in time as falling within the range of legitimate concerns meriting the attention of the polity” (p. 14). The authors assert that policy issues are “socially constructed” and, that government conveys messages about whom and what are priorities, what is or is not a problem that warrants attention, and what falls within the scope of government responsibility (p. 172). It is this assignment of meaning that not only guides agenda-setting, but also, public involvement in the policy process.

Citizen Engagement and Participation in Agenda-setting

In their article, “The Question of Participation: Toward Authentic Public Participation in Public Administration,” King, Feltey, and Susel (1998) report the findings of a qualitative study aimed at identifying ways to make participation efforts “more effective for both citizens and administrators” (p. 318). In this study, citizens
define effective participation as “participation that is real or authentic.” The authors use the term authentic participation as “deep and continuous involvement in administrative processes with the potential for all involved to have an effect on the situation” (p. 320). King et al. maintain that it is authentic participation that “stimulates interest and investment in both administrators and citizens,” and necessitates “rethinking the underlying roles of, and relationships between, administrators and citizens” (p. 317).

Interviews and focus groups were used to gather in-depth information on public participation processes, barriers to the processes, and input on how more effective public participation might be achieved. Six interviews (1 in person and 5 telephone interviews) were conducted with public participation subject matter experts: two organizers who were currently engaged in “extensive participation projects,” two former executives from national foundations with a focus on “increasing the links between citizens and government,” a public participation practitioner, and one “established scholar in the field” (p. 318). Results from the interviews were used to guide the focus group discussions. Focus groups were composed of three types of participants: non-elected local government administrators, activists, and citizens who had participated in a public process during the previous year. A total of seven groups were arranged: three citizen-only groups, one administrators-only group, one activist-only group, and two groups composed of both activists and administrators (p. 318).

The findings suggest that there is a need to reframe the process of citizen participation. The authors draw on the work of others in the field of public administration to illustrate the problems associated with public involvement. While administrators acknowledge that the public should be involved in public decisions, most are
“ambivalent” about, and/or “do not actively seek,” public input (p. 319). Furthermore, findings suggest that if citizen input is obtained, it is not used in the decision-making process. This leads to citizen distrust in government and a lack of interest in participation. Some citizens then participate through group organization and confrontational protests of policy decisions.

Study participants identified three categories of barriers to authentic participation: the nature of life in contemporary society, administrative processes, and current practices and techniques of participation (p. 322). The nature of life in contemporary society is that of time constraints and other barriers such as lack of transportation, child care, and economic disadvantages that create hardships for those whom might be interested in participation. When referring to administrative processes, participants expressed concern that “participation seen as challenging the administrative status quo is blocked” (p. 322). Citizens felt that information was “controlled, and manipulated, limiting their capacity to participate” (p. 322). The public hearing was cited as the “most ineffective technique” of citizen participation. Participants gave the following reasons for its inadequacy: the time given to speak, the lack of “meaningful exchange,” the lack of follow-up, the timing of engagement in the process – after the “decisions have already been made,” and the idea that the public hearing is a “window dressing” (p. 323).

Citizens, and administrators alike, agreed that participation is a necessary component of the policy process. Participants advocated that the public needs to be part of the process from “issue framing to decision-making.” One administrator spoke on the importance of timing by saying, “If you go to the community with a totally preset agenda - that doesn’t work. Bringing people into the process too late does not work’’ (p. 320). In
addition, public administrators must be willing and able to act as “interpretive mediators,” taking on an active role of cooperative collaboration and being able to engage citizens in “open and authentic deliberation” (p. 320). Using the findings of the study, the authors propose a model of authentic participation aimed at “overcoming the barriers” (p. 323).

According to Cynthia Gibson (as cited in Moulder & O’Neill, 2009, p. 21 ), citizen engagement occurs when “ordinary citizens . . . come together, deliberate, and take action collectively to address public problems or issues that citizens themselves define as important and in ways that citizens themselves decide are appropriate and/or needed.” Reporting the results of the 2006 State of the Profession Survey conducted by the International City/Council Management Association (ICMA), Moulder and O’Neill discuss citizen engagement in local communities. As a preface to the discussion, the authors suggest that local governments are “struggling over decisions that will affect the lives of employees and citizens they serve.” These decisions include “things that matter most to citizens – employment, education, safety and security, health care, and the environment” (p. 21). The purpose of the survey was to collect information on indicators of citizen engagement in local governments.

The survey was mailed in the summer of 2006 to city-type local governments having a population of 2,500 or more, and to all counties with an appointed administrator or manager or elected executive. Those governments that did not respond received a follow-up reminder. Thirty-six percent of local governments responded (p. 21). Survey questions addressed opportunities for citizen engagement, provision of resources to citizens to assist them in solving problems and implementing decisions, and the methods
of publicizing opportunities for involvement. Ninety-seven percent of local governments reported opportunities for citizen involvement in community problem-solving and decision making (p. 26).

The two highest reported venues for citizen participation were council meetings and participation on boards and committees. However, it was noted that participation at council meetings provides an opportunity for citizen input, but not necessarily citizen contribution to problem-solving and decision-making. Participation on boards and committees and membership on an ad hoc task force groups were reported to provide more “solution activity” (p. 26). Other methods of opportunities to participate reported in the survey were: citizen surveys, public hearings, and local government websites. Yet, as one local government cited in an open-ended response on the survey, “Citizen engagement opportunities are more to receive public comments and communicate/educate/discuss community issues and not implement decisions” (p. 26).

Findings regarding the resources provided to assist citizens in making well-informed decisions show a variance and “does not generally reflect the resources necessary to implement a solution to a problem” (p.27). A follow-up question on the survey asked respondents to identify examples of resources. Examples cited included council minutes and budget documents, which the authors defend “are informational but do not financially support implementation” (p.27). Furthermore, Moulder and O’Neill maintain that giving citizens the resources they need to solve problems sends a “positive message about the value they place on the contributions of citizens” (p. 27).

Finally, the survey elicited responses on the methods of making citizens aware of the opportunities to become involved in the problem-solving and decision-making
process. Notices in the local newspaper and notices on the local government website were the two most frequently reported methods of publicizing opportunities for citizen involvement. A third, less commonly reported, method was the use of a cable TV channel. The effectiveness of these methods of publicizing opportunities for citizen involvement is contingent upon citizens’ ability to access this information. Citizens need to have access to a newspaper and know how to find the announcement, as well as have access to a computer or cable television and know where to locate the information. Only 46 percent of local governments reported sending a newsletter – a more direct form of communication - to community residents. Two hundred and ninety-one of the local governments reported using all of these methods (p. 28).

One additional finding of the State of the Profession survey was a characterization of those citizens who do not participate. Of the 1,770 local governments that replied to that question, “25 percent indicated that poverty is a factor and another 25 percent cited language barriers” (p. 28). In fact, population size seemed to be more influential on percentages of poverty and language barriers than geographic location. Localities with populations of 250,000 or more reported higher poverty rates and identified language barriers as a determinant of nonparticipation more frequently. These citizen attributes are directly correlated to having access (poverty) to methods of publicizing and knowing how to access or understand (language barrier) announcements regarding opportunities for involvement. Moulder and O’Neill support the use of outreach measures to engage these populations.

Citizen engagement necessitates two requirements of government: 1) making citizens aware of opportunities to be involved in decision-making, and 2) listening and
responding to the desires and suggestions of citizens (Moulder & O’Neill, 2009, p. 21). Barbara Cohn Berman (2012) discusses the importance of governments “listening to the public” (p. 2). In an eight year study, Cohn Berman surveyed public opinion and perception of local government performance. The study found that when governments respond to what they have learned (through “listening to”) from their publics, they can “move toward greater alignment of government’s work with the public’s needs” (p. 2).

According to Kingdon (2003), the effects of public opinion can be “either positive or negative” for policy-makers (p. 65). That is, interest in and support of an issue can lead to its placement on the agenda, and persuade the outcome of the vote. Whereas, the negative effects of public opinion can put “constraints” on governmental action (p. 65). Also of significant importance when considering the effects of public opinion, is the matter of whether the opinion is that of the mass public, or a smaller number of people with greater propensity to affect government priorities. Kingdon asserts that some issues “never cause so much as a ripple in the average person’s pond,” and that it is indeed likely “that governmental officials and other activists affect the agenda in the mass public more than the other way around” (p. 66).

Kingdon (2003), defines an agenda as “the list of subjects or problems to which governmental officials, and people outside of government closely associated with those officials, are paying some serious attention at any given time” (p. 3). Kingdon proposes that “the setting of an agenda” and “the specifications of alternatives from which a choice is to be made,” are two (of four) processes in the making of public policy (pp. 2-3). In his study, Kingdon sought to ascertain why some subjects are significant items on the agenda and others are not, and why some alternatives are given more serious consideration than
others. Over a four-year period (1976 – 1979), he conducted 247 interviews (113 in health and 114 in transportation) with people “close to decision-making” in health and transportation (p. 4). Participants included people “inside” government such as the administration, congressional staff, and civil servants; and those “outside” government including interest groups, lobbyists, the media, researchers and consultants, members of academia, and public opinion.

The findings of Kingdon’s research suggest that governmental agendas are set by three factors: problems, politics, and visible participants. A problem is described as emerging from a condition that elected officials become aware of. Indicators of the condition provide a measure of the magnitude of, and/or changes in, the condition. Participants both in and around government defined several circumstances in which conditions progress to problems and have a greater probability of rising on the agenda. They include: 1) conditions that violate important values; 2) conditions that are compared with other countries or other relevant units; and 3) the categorical classification of a condition. The attention given and treatment of the subject was said to be significantly influenced by the category (p. 198).

The political stream – public mood, election results, changes in administration, partisan or ideological distributions in Congress, and interest group pressure – was also cited as being powerful in agenda-setting. It was acknowledged that “the combination of national mood and elections is a more potent agenda setter than organized interests,” although the “opposition of a powerful phalanx of interest groups makes it difficult to contemplate some initiatives” (p. 199). Visible participants, the third influencer of the agenda-setting process, are comprised of “those who receive considerable press and
public attention” such as the president, his high-level appointees, prominent members of Congress, etc., and were reported to affect the agenda. Those considered “the relatively hidden cluster” of participants – “academic specialists, career bureaucrats, and congressional staffers” – were said to shape the alternatives (p. 199).

Among the findings of Kingdon’s study is the conclusion that policy does not develop according to a particular model of processes. Rather, political events unfold according to their own schedule. Similarly, agendas aren’t always set first, followed by alternatives being generated. However, when a policy window opens, advocates who have been waiting for the opportunity are prepared to “attach” their solutions (p. 203). At that point, “proposals that fit” are “coupled” with that political event or problem (p. 201).

Health Policy Agenda-setting

Blendon and Steel Fisher (2009) confirm that there are few studies available on the politics of health care issues, as compared with other issues such as education, poverty, and environmental policy studies (p. 1138). They state that in a search of three databases that publish health policy and educational research, they were “able to retrieve only 4 documents related to politics and health care from the Government Printing Office (GPO) database as compared with 99 related to education and politics” (p. 1139).

Harvard University’s online catalogue (HOLLIS) revealed “only about 200 titles related to politics and health care, but nearly 1,700 related to education and politics. And JSTOR. ..only 61 articles in health care and politics as compared with more than 200 related to education and politics” (p. 1139).

Green-Pedersen & Wilkerson (2006) acknowledge that cross-national studies of health policy agenda-setting are rare as well. In their article, they review the literature on
comparative public policy studies. Specifically, they focused on how agenda-setting attributes (as discussed by Cobb & Elder, 1983, and Kingdon, 1995) affect politics. They note that comparative studies on health care and health policy emphasize a difference in political structure as a rationale to explain differences in health care politics and policy development. Green-Pedersen and Wilkerson question the effects of an issue’s attributes in shaping attention to issues and policy responses “not just in one nation, but across nations” (p. 1040).

They use the political systems of Denmark and the US to examine this question. The authors begin with a discussion of the similarities and differences of the two nations. They acknowledge that while both nations are “advanced industrialized democracies,” there are “stark” differences in their political and health care systems (p. 1040). Denmark has a “unitary parliamentary system” that supports a locally administered, government-sponsored, public health care system. The governmental structure of the US is a “federal separation of powers system” that depends on private providers to deliver its health care. The authors assert that “despite these differences, we find remarkably similar trends in health-related political attention over the past 50 years” (p. 1040). They conclude that “the proportion of overall agenda space that each national legislature has devoted to health care issues has tripled or quadrupled since the early 1960s” (p. 1049).

Green-Pedersen and Wilkerson suggest that the amount of attention health issues receive is “governed by changing perceptions of the problem” – in any nation (p. 1041). They refer to Cobb and Elder’s “agenda-setting attributes” that influence policy-makers’ decisions regarding health policy (p. 1041). These five attributes are: 1) the degree of specificity, 2) the scope of social significance, 3) the extent of temporal relevance, 4) the
degree of complexity, and 5) the degree of categorical precedence (Cobb & Elder, 1983, pp. 96-97). Green-Pederson & Wilkerson support the findings of others (Stone, 1989; Schneider and Ingram, 1993) who affirm that the issue of health is attractive to politicians because of its vote-seeking potential. Because illness is viewed as being “beyond the control of the individual,” no politician (in any nation) wants to be responsible for denying access to health care (p. 1041). Furthermore, those affected by health care policy decisions are “more likely to be seen as deserving than may be the case for other issues” (p. 1041). Therefore, it isn’t an issue of whether the problem deserves a response, but rather, an issue of “connecting solutions to problems” (p. 1041). This poses challenges that “all systems have difficulty resolving” (p. 1043).

Citizen Participation in Health Policy Agenda-setting

Articulated by the World Health Organization (WHO) at Alma-Alta in 1978, the concept of community participation was forged as the “cornerstone of the strategy to achieve Health for All by the Year 2000” (Zakus & Lysack, 1998, p. 1). Zakus and Lysack review the use and value of community participation (also known as public participation, citizen participation, or consumer involvement) and examine the problems inherent in its use since its inception. They begin by defining the concept as:

“the process by which members of the community, either individually or collectively and with varying levels of commitment: (a) develop the capability to assume greater responsibility for assessing their health needs and problems; (b) plan and then act to implement their solutions; (c) create and maintain organizations in support of these efforts; and (d) evaluate the effects and bring about necessary adjustments in goals and programmes on an ongoing basis. Community participation is therefore a strategy that provides people with the sense that they can solve their problems through careful reflection and collective action…..collective wisdom holds that the core value of community participation is that it provides a mechanism for people to participate in activities that have the potential to impact positively upon their health” (p. 2).
The authors also discuss the “reputed benefits” of community participation; followed by the difficulties in implementing it. One of the benefits cited is the “heightened sense of responsibility and conscientiousness regarding health and the concomitant gain in power achieved through the acquisition of new skills and control over resources” (p. 2). Foucault’s (1982) theory of power and knowledge support this notion. Foucault asserts that power and knowledge are fundamentally related. Knowledgeable citizens possess the power to articulate themselves, resulting in a sense of empowerment. Finally, Zakus and Lysack propose the need for an “accurate understanding of a community’s needs, resources, social structure, and values, and early citizen involvement, in order to build collaborative partnerships and facilitate broad community participation” (p. 4). How better might an understanding of a community’s needs and values be gained than through communicative processes with its citizens?

Morgan (2001) reviews trends in community participation literature of the 1990s. She too contends that there exist significant difficulties and complexities involved in enhancing participation that were not conceived of when the concept was formalized at the Alma-Alta Conference. Morgan maintains that there are two distinct perspectives by which community participation in health can be defined. The first is a utilitarian model in which donors or governments use community resources to offset the costs of providing services. She notes that Nelson and Wright describe this as “participation as a means (to accomplish the aims of a project more efficiently, effectively, or cheaply)” (p. 221). The second perspective, the empowerment model, emphasizes local communities taking responsibility for identifying and solving their own health and development problems.
She notes that Nelson and Wright refer to this as “participation as an end (where the community or group sets up a process to control its own development)” (p. 222).

Morgan’s article includes an in-depth discussion of ‘process.’ She asserts that process has “emerged as the *sine qua non* of participatory endeavors: The key issue [in the first steps of project development] is the notion of *process* and the fact that community participation is not merely an input to the project but the basis upon which it will operate. Furthermore, participation cannot be assumed but has to be systematically encouraged, and means have to be created to make it effective” (pp. 223-224). The article concludes with a review of trends in the participation literature of the 1990s.

Since the end of the 1990s public involvement in decision-making has become central to some of the most popular movements in public health (Kapiri, Norheim, & Heggenhougen, 2003). However, making sure that people are actually involved in decision-making processes is the main challenge. Through an exploratory study, using in-depth interviews with health planners at the national, district and community levels (N = 12) and five group discussions with citizens (N = 51) in Uganda, Kapiri et al (2003) identified concerns about, and barriers to, public participation in health planning and priority setting. Interviews with the 12 health planners adopted key themes from the WHO decentralization analysis framework. Group discussions used main themes, allowing respondents to “exhaustively” discuss each theme.

Results indicated that although there were some different experiences amongst respondents from national and district levels of the administrative system, their concerns were primarily of the administrative nature (budgeting, managerial, etc.) and communication and relationship issues between levels (e.g., accessing available funds,
communication between the centre and the district and the district of the lower levels of decentralization). According to the local councils, participation was thought to “give a sense of ownership” but actual levels of participation were reported to be low (p. 208). Local councils offered lack of interest, lack of knowledge, cultural barriers, suspicion and love for monetary benefits (they felt citizens would attend if money was involved) as some of the reasons. They also suggest that planning and priority setting is still dominated by elected local leaders. The discussants, although expressing an interest in participation, reported that the local councils “make all the decisions and just tell them what to do” (p. 210). Poverty was another reported factor. Discussants reported feeling that they could not afford to be “presentable” and dress “properly” and therefore did not attend local council meetings (p. 210). Other reasons for low attendance/participation by group discussants were: leaders do not care, leaders do not communicate, lack of benefits, and fear.

“There is an emerging consensus in the health policy community that informed and engaged consumers have a vital role to play in improving the quality of care that the U.S. health system delivers to patients” (Arnold, 2007, p. 1). The general agreement is that when consumers are equipped with the right information they will be able “to become active participants and self-managers of their own health and health care” (p. 1). However, the topic of health care is complex and the system is difficult to navigate. Arnold, in her review of white papers on consumer engagements, acknowledges that socioeconomic factors “appear to affect how consumers perceive information, what information they prefer and what choices they ultimately make” (p. 3). She proposes that the urgent question for the policy community is: “How can we ensure that consumers
have the tools and information they need to play the active role we are asking of them?” (p. 1).

Generally, the ideal of public participation has assumed that information about public values should speak for itself. However, health policy decisions, in particular, are subject to the ideological perception that average citizens are not knowledgeable enough to make meaningful contributions to health priority setting and thus, mediating bodies are necessary to interpret the public voice. Tenbensel (2002) argues that mediating bodies are “essential to the enhancement of priority-setting processes that aspire to rationality and legitimacy” (p. 174). In his article, *Interpreting public input into priority-setting: The role of mediating institutions*, he contends that while these mediating bodies are essential, they’re decision-making processes are opaque, and “should not be judged according to the criterion of transparency” (p. 173). In an effort to develop a “best practice” of priority-setting processes, Tenbensel analyzes the “existing practices” of those institutions that are collecting and interpreting public values (p. 174).

Tenbensel begins with an assertion of two main points: 1) unmediated public input is viewed as the ideal by which rational and legitimate policy-making can be interpreted; and 2) despite the negative interpretation of mediated bodies, they “have been a constant feature of actual priority-setting processes that involved public input” (p. 175). After an explanation of these assertions, Tenbensel provides examples of exercises of public involvement (using mediating institutions as interpreting bodies) that he refers to as “those that have been widely reported and dealt with in the literature” (p. 178). They include the Oregon exercises used by the Oregon Health Services Commission in the 1990s, public consultation actions taken by New Zealand’s National Health Committee,
and public involvement activities employed by the local health authorities of the United
Kingdom.

Tenbensel discusses the concepts of transparent rationality, opaque rationality, and
legitimacy as they pertain to these examples. Through an analytical discussion, Tenbensel
concludes that mediating bodies (commission, committees, etc) go through a process of
“pluralistic bargaining” that involves “digestion of complex information,” the use of
judgment, and results in “group rationality” (p. 185). He notes that proponents of the
technocratic approach – one that relies on objectively interpreting collected information –
are “uncomfortable with the role of judgment” and perceive it as leading to less
transparent rationality. He further contends that while proponents of a more deliberative
process would find “digestion” more favorable than a more “mechanistic approach,” they
do “have grave reservations about the legitimacy of these mediating bodies because
experts dominate such bodies” (p. 187). His final argument is that information gleaned
from public involvement provides raw material for policy-makers and that if it is
“swallowed whole,” without digestion from mediating bodies, it will more than likely be
“regurgitated” in the policy process (p. 191). Therefore, he contends,
“some form of opaque transparency is essential” (p. 191).

Citizen Participation in Health Policy Agenda-setting Across Three Nations

The issue of how to involve the public in setting health care priorities is a constant
challenge for health systems. Movements such as medical consumerism, patient’s rights,
and the right of persons with disabilities, combined with growing dissatisfaction with
government, contributed to changes in traditional medical practice and policy-making.
The 1990s prompted a need, across nations, to engage citizens and gather input on health
policy agenda-setting and decision-making. One of the most widely recognized examples of public involvement in health care priority-setting in the United States is Oregon’s use of a mediating body to interpret the public’s voice on Medicaid policy.

The United States

Oregon policymakers were interested in producing information about public values and preferences in order to enhance the rationality of the framework. First, information derived from a quality-of-life telephone survey was used in the prioritization process in the early stages of development of the Oregon Health Plan. Second, the Oregon Health Services Commission (OHSC) authorized a mediating body – The Oregon Health Decisions (OHD) – to hold open community meetings with the purpose of identifying community values regarding health care and the proposed Oregon Health Plan.

There were many criticisms about the process and outcomes of the Oregon Health Services Commission’s attempt to use public participation in priority-setting. First, the information gained from the OHD forums was not aggregated – responses were simply listed as important values and interpretations were made by noting the number of times they were mentioned in the meetings. Second, meeting facilitation was not characterized as neutral, rather, they were “clearly used as opportunities to evangelize to the public about the serious nature of the issue of inadequate health insurance coverage in Oregon and in the USA more generally” (Tenbensel, 2002, p. 182). This raises the broader concern of agenda-setting. Despite the openness of the OHD meetings, the agenda had already been established prior to the meetings. Third, there were concerns about the representativeness of the participants in the forums. Most of the participants were
themselves involved in the delivery of health care services – far from being a sample of the general public. Last, it is not clear how the 17 broad categories of the eventual prioritized list related to the categories that participants discussed at the meetings.

The Oregon Health Services Committee however, consistently refers to the importance of the community meetings in providing information on public values that were used as part of their deliberative processes. The OHD continues to conduct public meetings and feed the results into the OHSC. Meeting information – including the agenda — is made available to the public and a time is designated for public comment. Likewise, in the U.S., the state of Minnesota utilizes “working groups” to report to its Legislature’s Health Care Access Commission. However, like Oregon, there are concerns about the representation of the average citizen (as health consumer) at meetings. Working groups are composed of legislatures and advocates with an expertise or interest in the area. Past surveys have been administered to members of health plan companies and hospitals – not to the unaffiliated consumer of health services.

Hiller, Landenburger, and Natowicz (1997) suggest that public participation in medical policy-making has a couple of benefits: 1) “when consumers are meaningfully engaged in decision making about their own medical care, health outcomes are measurably better, and 2) “consumer representation on committees and institutional review boards provide unique perspectives, while their absence creates the appearance, if not the reality of elitism” (pp. 1280-1281). In their 1995 study, the authors sought to assess public participation in the development of newborn-screening tests.

A survey of policies and practices of the newborn-screening programs in all 50 states and the District of Columbia was conducted between January and April of 1995.
Using the Council of Regional Networks for Genetic Services as a sampling frame, two names for each listing were provided: a person with knowledge of the policies and operation of the state’s program, and a person with expertise in laboratory issues. Telephone interviews were conducted with most of the study participants; eight were sent a written questionnaire.

The results of the study, with regard to public participation, in newborn-screening policy, report that “36 of 51 states” either had established, or were in the process of establishing, newborn-screening advisory committees (p. 1283). Of these thirty-six states, thirteen had implemented law or regulation that required advisory committees. Consumers were represented on the advisory committees in twenty-six of the thirty-six states. Only two however, Tennessee and Maryland, required consumer representation by law or regulation. In Tennessee, the Genetic Advisory Committee was required to have “at least two members at large, one of whom shall be a consumer who is affected by or who has a family member affected by a genetic disorder.” Maryland demanded that five of the 11 voting members on the State Advisory Council on Hereditary and Congenital Disorders “shall be individuals appointed by the Governor, none of whom may be: 1) a health professional or spouse of a health professional, or 2) an individual or spouse of an individual involved in the administration or ownership of any health care institution or health insurance organization” (p. 1283).

Other findings of the study relevant to the use of public participation in medical policy-making included specification of a variety of engagement mechanisms being utilized to gather public input. In addition to consumer membership on advisory committees, states reported using citizen participation in open committee meetings and
open legislative hearings, involvement in regional genetics organizations, and “open-door program policies that are receptive to inquiries or comments from consumers and advocacy groups” (p. 1284).

In the closing discussion, the authors acknowledge that “state and national committees with substantial public representation” are “necessary” to construct “proactive and inclusive genetic policy” (p. 1285). They again mention the success of The Maryland Commission on Hereditary Disorders to possess substantial consumer representation. They also recognize the endeavors of The United Kingdom’s House of Common’s Science and Technology Committee to create a panel that includes “lay citizens” in the oversight and regulation of genetic medicine in the country (p. 1285).

The Jefferson Center (1998), in collaboration with Saint Olaf College, used a citizens’ jury to deliberate policy decisions on physician-assisted suicide in Minnesota. Over the course of four days of hearings, twelve randomly selected jurors heard from a variety of witnesses who provided background, legal, medical, and ethical information related to the issue of physician-assisted suicide. Adult citizens within a thirty-five mile radius of Northfield, Minnesota were randomly selected to participate in a telephone survey. Respondents who expressed an interest in participating in the jury process were entered into a pool. Twelve jurors were randomly selected from the pool. The jurors were said to have represented the community in terms of age, gender, race, education, political affiliation, and general attitudes toward physician-assisted suicide. Witnesses were purposefully selected based on suggestions from The Advisory Committee and the individuals’ knowledge of physician-assisted suicide. After hearing from the witnesses (attorneys, social workers, nurses, and physicians), jurors began deliberation in the latter
part of day three. Day four concluded the deliberation process and culminated in policy recommendations.

Jurors were given the charge of responding to three questions based on the testimony of the witnesses:

1) How should Minnesotans respond to the recent Supreme Court ruling that urges Americans to engage in an “earnest and profound debate” about physician-assisted suicide?

2) If and when the legislature takes up physician-assisted suicide, should current Minnesota state law be changed?

3) If and when physician-assisted suicide comes before the Minnesota State Legislature, how should legislators examine the issue? (p. 3)

In response to the first question, the jurors recommended that there needs to be “more public education, discussion, and feedback” to be able to engage in “earnest and profound debate” (p. 5). They further provide suggestions regarding the parties that should be included in the discussion, as well as mechanisms for encouraging and facilitating the discussion and methods of feedback. Responses to questions two and three varied amongst jurors. Seven jurors recommended that Minnesota statute not be changed. The remaining five that recommended a change in the current law, suggested that Oregon’s Death with Dignity law serve as a model for change. Likewise, seven jurors also responded that if the issue comes before the Minnesota Legislature, some changes to the current process are needed for effective discussion and productivity. Among the changes recommended, over half were unanimously agreed upon and concerned actions of the legislators, including:
• seeking ample input from informed constituents,
• taking responsibility to become personally well-informed about the issue,
• considering all perspectives of the issue,
• monitoring what’s happening in institutions/facilities where people are dying to assess the current situation and end-of-life options,
• suspending “politics as usual” divisiveness and make it a bi-partisan issue,
• not making uninformed assumptions about people’s or institutional positions on the issue, and
• keeping current on what’s happening in Oregon (p. 8).

At the conclusion of the citizens’ jury process, an evaluation of the project was completed. Jurors, Saint Olaf political science students who participated in the planning and implementation of the project; and members of the Evaluation Committee (composed of former and current elected officials) were asked to evaluate the citizens’ jury process. Jurors and students alike appraised the learning opportunity and experience as one of the most advantageous attributes of the citizens’ jury process. The opportunity to “hear, at length, both sides of an issue and be able to interact with eleven others in reaching a conclusion we can all live with, yet not be fully unanimous about, is a valuable experience” (p. 20). The chance to be educated by the “experts from the various fields presenting their sides of the issue was an excellent experience” (p. 21). The student group also acknowledged the benefits of “creating active and informed citizens”, obtaining “informed opinions of citizens” and “promoting democracy” (p. 23).

Members of the Evaluation Committee were also asked to “comment on its potential usefulness to legislators” in not only addressing physician-assisted suicide, but
also other difficult issues (p. 4). The Evaluation Committee reported that the citizens’
jury model does have benefits: 1) it allows for a cross section of citizens to engage in a
meaningful discussion, as opposed to two polarized sides dominating the dialogue; 2) it
does generate discussion of a hot button issue; and 3) the citizens jury process could be of
“considerable help” to a legislature in dealing with difficult issues by providing insight
gained from listening to jurors and hearing about the jury’s witnesses (p. 10 - 11). The
committee suggests however, that there are some key factors to be considered. Most
important of these factors is the need for legislators to have a clear understanding of the
citizens jury process, including the careful method of juror and witness selection, and that
the goal of the process is “not to tell legislators what to do, but to open possibilities for
reasoned and respectful discussion” (p. 10).

The United Kingdom

The National Health Service in the UK views public participation from two
political ideologies. The consumerist model is service-led and associated with the “new
right;” while the democratic model is citizen-led and associated with the left (Rowe &
Shepherd, 2002, p.278). In the consumerist model, participation is conceived as a means
to elicit citizens’ preferences so that services more accurately reflect their needs. It
emphasizes the citizens’ right to information, access, and choice. Participation in the
democratic model is seen as a means to legitimize decisions by enabling citizens to
challenge those in power to justify their practices. It is intended to “bring decision
making closer to the people and mobilize them to take part in local affairs” (p.278).

Since the 1990s there has been increasing emphasis on all public authorities
consulting with their publics when developing new service plans and strategies to “ensure
closer alignment between provision and need” (Kashefi and Mort, 2004, p. 290). Spurred by the 1999 Green Paper, *Our Healthier Nation*, and the 2000 NHS Plan, legislation was passed in 2001 that detailed approaches to address the failing of “patients’ voices” influencing “the provision of services” (p. 290). Stimulated by the “Oregon exercise,” the Somerset Health Authority sought to consult the public about health service priorities (Bowie, Richardson, & Sykes, 1995, p. 1155). A research project was established with the goal of determining a method of “community collaboration” that would gather representative community values regarding health resource allocation. Eight health panels, composed of twelve local residents, were organized across the Somerset health district. Members were selected for the panel based on a quota sampling technique, with each member serving a one year term. To ensure that no one was excluded from participation on the panels, members were paid £10 for each meeting to cover any expenses, and transportation was provided, if needed.

The panels had met five times during an eighteen month period when the article was written. Panels were presented with “live issues,” such as prioritization of patients for services and fees for services that were proposed by the health authority in consultation with the research team. Each panel member received a one paragraph summary of the issue, mailed prior to the meeting, to be discussed with family and friends, and then shared in the upcoming meeting. During the meetings, members listened to the views of others and had the opportunity to explore issues in depth. Panel members would then complete a “decision sheet” on which they voted anonymously on the topics of discussion (p. 1156). An average of ten people attended each meeting. The characteristics of those who attended was said to be representative of the population of
each county, with the only significant difference being a “slight over-representation of those with experience of the health service” (p. 1156).

The results indicate that there is consistency between panels in orders of priority. Also revealed in the findings was “a clear consensus within panels . . . in over three quarters of the issues” requiring agreement one way or the other (p. 1156). The authors assert that the use of a focus group technique, in which an expert in group dynamics facilitated the discussion, encouraged people to “focus more easily on common – rather than individual – benefits (p. 1157). The authors further propose that the use of the decision sheets allowed participants, who might be hesitant to voice minority views in the group, to “give their final vote privately” (p. 1157). The group discussion provided qualitative data, while the decision sheets provided some quantitative data in the “yes” or “no” responses, or questions that required participants to prioritize items. Results were collated and reported to the health authority after each meeting.

A seminar was also held with local doctors and hospital consultants to educate them about the project and explore their responses to it. A random sample of eighty was selected. Thirty-eight of them attended, including 26 general practitioners and 12 hospital consultants. The group was presented with some information on the characteristics of the participants and asked to complete decision sheets on the validity of the process. The majority of doctors (66%) were skeptical of the results arising from public consultation; though “a higher proportion of doctors felt they would have confidence in the results than those who would not (24% compared with 10%)” (p. 1157).

Bowie et al. conclude by stating that “the system established did work to develop consensus on broad values, focused on community benefits” (p. 1157). Although the
sample sizes were small, they suggest that this is the “norm” with qualitative research, and that the consistency across panels provided a confidence that is “logical” rather than statistical (p. 1158). Furthermore, the results of the medical seminar were “more positive than expected.” The authors report that they had anticipated doctors would be “both skeptical of purchasing decisions being based on non-medical opinion and resistant to a qualitative approach to eliciting information” (p. 1158).

Litva et al. (2002) propose that little research has questioned the public’s preferences for involvement in health care rationing decisions and at what degree they are willing to participate in health care policy decisions. In their study, which is said to have emerged as a result of a “collaborative interest in public participation and priority-setting,” she and her colleagues sought to explore these questions (p. 1827). Participants for the study were composed of three “types of public”: 1) citizens of two localities in the health authority, 2) members of health-related interest organizations, and 3) members of non-health-related organizations.

Individuals were randomly selected from the 1997 electoral rolls and invited by a letter to attend a local meeting to discuss public involvement and health care decision making. Four focus groups were formed; two in each locality. A 1997 community guide was used to compile a list for the selection of health-related organizations. Two focus groups were formed from the organizations on this list. One organization provided members for one of the focus groups. The other focus group was comprised of individuals from randomly selected health-related organization. Each selected organization was invited to send two representatives. Two focus groups were also formed from the non-health-related organizations (also identified through the community guide).
These organizations were also recruited and invited to send two representatives to the group meetings.

Three decision-making levels were also identified (in consultation with the local health authority): two purchasing level decisions (at the health system level – location and types of services, and at the program level – funding of specialty services) and one micro or clinical decision level (at the individual level – determining which patient should receive a particular treatment). These decisions were discussed in the focus groups. A workbook was used to describe the three types of decisions and elicit a “yes,” “no,” or “unsure” response. Each page of the workbook also included room for any comments following the decisions. Each participant also completed a short questionnaire gathering socio-demographic data and consent for a follow-up in-person interview. Focus groups were not required to come to a consensus on the decisions, and each participant could give their own views and beliefs in the space provided in the workbook. Semi-structured interviews permitted the elaboration of comments made in groups and the workbooks.

The findings of the study suggest that the socio-demographic details for the random public groups were “basically similar.” In the health and non-health interest groups, there was “again few variations” (p. 1830). The authors did find that there were twelve participants who either currently, or in the past, worked in the National Health Service. Based on response rates, the findings also reveal that some of the public appears more willing and able to attend groups and discuss health care decision making than others. Citizens were willing and able to attend, and those from health interest groups
were more likely to attend than those from non-health-related organizations; however, response rates still yielded small numbers of people.

There were no significant differences amongst the views of those in the different types of groups regarding decision-making. Sixty-eight percent of participants in all groups agreed that the public should be involved in decisions at the health system level (regarding types of services), but the majority believed that the public should not be responsible for making those type of decisions. They believed those decisions were better made by health professionals “who were paid for and have the expertise to take responsibility for such decisions” (p. 1831). There was a strong belief in all groups however, that consultation should occur and that public opinion and ideas should be considered, and incorporated – “otherwise, the public may become cynical about the process” (p. 1831).

Over half of the participants responded that the public should be involved in program level decisions (regarding funding of specialty health services like a new cancer unit). Twenty-six percent believed that the public should not be involved in this type of decision. Similar to the rationale at the health system decision level, participants suggested that public consultation was important, but the responsibility of that type of decision should be given to health care professionals. The majority of the participants (53%) stated that the public should not be involved in deciding between two patients. The “overwhelming” view was that health professionals had the “appropriate knowledge, skills and qualifications, including their ability to deal with the emotional impact of making the decision” (p. 1833). The authors conclude that the public prefers to be “involved” in the form of “consultation” at the system and program levels, and that there
is “little desire to share in the responsibility for decision making even at the health system level” (p. 1834).

The United Kingdom has used a variety of different methods to assist in policy development and an increase in lay membership of NHS decision-making bodies. One method, citizens’ juries, has been used as a public consultation method on a range of topics in the UK since 1997, most notably by the Department of Health. According to Kashefi and Mort (2004), the process of the citizens’ jury somewhat resembles a legal jury.

Typically 12 – 16 citizens are brought together over a 4 – 5 day period with the aim of reaching a ‘verdict’ on a particular policy-related issue. The jury hears testimonies from witnesses and is given time for deliberation before reaching its decision. Facilitators transcribe and report on the proceedings and the jury’s recommendations. In contrast with legal juries however, this report is then presented to the sponsors or commissioners for consideration. Often the commissioning agency is committed to responding within a given period and may meet the jury to explain what action will follow, but is not necessarily committed to acting on the decision(s) in full. This model of the citizens’ jury was promoted by the Institute for Public Policy Research on the basis of research into similar models in the US and Germany. The major weakness of the design is that “the process simply extracts ‘the public view’ without any in-built mechanism for follow-up, scrutiny or accountability” (pp. 291-292).

Using a ‘grounded’ consultation model of the citizens’ jury, Kashefi and Mort examined whether the jury process could be used as a tool for health activism and could hold service providers and policymakers accountable to the community. The researchers were particularly interested in marginalized communities. The north-western town of Burnley in England, characterized by numerous economic and social conditions, was selected as the project site. The researchers recruited the Burnley Primary Care Group to oversee the project, as well as nominate representatives for the jury steering group. The steering group was given the responsibility of deciding whom they wanted to hear from
on the jury. This granted the jury legitimacy and eliminated the systematic exclusion that could have resulted from traditional means of jury selection. A “professional recruiter” was used to “find the jury to match the profile” that was developed by the steering group (p. 294).

Once jurors were recruited, they attended two preparatory sessions at the community center where the jury sessions were to be held. The sessions were designed to not only familiarize jurors with the process and practicalities of being jurors, but also to establish a supportive and trusting environment in which open exchange of ideas could take place. The actual jury sessions were held over 5 days. Jurors heard evidence from a number of witnesses who lived and worked in the community including: a health policy advisor, a health visitor, a nurse practitioner, two General Practitioners, mental health professionals and activists, a community development worker, etc. Additionally, jurors were presented with information from local primary school children on what they felt made them healthy/unhealthy, a videotape of discussions with older children on their sense of health and well-being, and a discussion with a young women’s group on issues they saw affecting their health.

Throughout the sessions, time was allotted for discussion in pairs and small groups, some of which were gender-specific depending on the topic. In addition to two facilitators and a chairperson, a jury investigator was present at all times to pursue answers to questions that were posed as a result of discussions. On the last day, all key recommendations were combined. Jurors were paired and assigned a theme to produce a “simple visual representation” (p. 297). This was then presented to the jury sponsors and
the local MP who engaged in discussion with the pairs about their ideas and recommendations.

The central question addressed by the jurors was “What would improve the health and well-being of residents of SWB?” After deliberation, the jurors compiled over 80 specific recommendations, including “very specific proposals about health care provision” (p. 297). The SWB Health and Social Care Group was assigned the task of following up on the recommendations. However, the group was not receptive to the idea of jury members attending their meetings as “experts” of their own communities. Jurors felt “sidelined and ignored” amongst professionals with “their own expertise” (p. 297). The steering group however, demonstrated a stronger commitment to the jury’s recommendations. Two of the jurors retained active participation with the steering group. The steering group also invited other community stakeholders to attend group meetings in an effort to “ground the jury’s recommendations in the concerns of the wider community” (p. 297).

Canada

The Canadian Health System has considered citizen participation in health policy decisions an “important feature of responsive and equitable health systems” (Pivik, Rode, & Ward, 2003, p. 254). Canada has employed a number of different strategies to engage citizens in the process of health priority setting. Throughout the 1990s, traditional one-way approaches such as surveys and focus groups were used to elicit information from the public. Towards the end of the 1990s Canada began to experiment with deliberative methods such as citizen juries and panels to promote discussion among participants and decision makers in an attempt to obtain more informed and consensual views.
The use of controlled studies to assess the outcomes of different participation methods is scarce in the literature. There is very little literature that compares the experiences of the same processes used in two different settings or different approaches of involving the public using a controlled experimental design. A group of researchers (Abelson et al., 2003) from the Center for Health Economics and Policy Analysis in Canada used a controlled, pre- and post-test design to examine the effects of introducing different approaches for deliberation in a community health goals priority setting project. The study was based on the findings of a previously completed community health status report that identified health concerns in a small Ontario community. The researchers collaborated with two local health agencies in the community to design a public consultation process that would help the agencies to prioritize local health concerns and generate possible solutions. Three approaches for obtaining citizen input were to be studied: a traditional mail survey, a telephone survey, and a face-to-face group meeting. The citizens’ panel was used as the basic consultative approach in the fact-to-face group meeting.

Study participants were selected from a list of 176 community organizations (health care organizations, health-related organizations involved in the health sector but not in direct delivery of service, and well-being organizations such as those offering parent groups or sports and recreation organizations). All organizations received a letter describing the research study and inviting the agency to identify a representative to participate in the project. Once they agreed to participate, they were asked to participate as a citizen rather than as an organizational representative. Those who agreed to participate were randomly assigned to one of the three groups of methods of data
collection (mail survey, telephone survey, group meeting). The goal was to have 20 participants per group.

Forty-six participants were recruited: mail (17), telephone (16), and face-to-face (13). All participants received a mailed baseline survey. To determine the effects of the deliberative process, participants of the telephone and face-to-face groups were asked to complete two surveys: one before and one during (phone group) or after (face-to-face meeting). The survey instrument was organized into three major sections. The results reported address only one of the three components. The component addresses the identification and prioritization of health concerns requiring action; community strengths for addressing these concerns and the prioritization of local determinants of health. Three survey questions were used to assess the impact of deliberation on participant views in the telephone and face-to-face groups.

Findings indicate that deliberation does make a difference to participant views and that as more deliberation is introduced, participants’ views may be more agreeable to change. Participants’ evaluations of each method and a comparative cost analysis of each method were said to be reported elsewhere. The authors conclude that the study was exploratory and that the ability to generalize findings outside the scope of the study is limited.

In another study, Abelson (2001) explores the role that context of a geographic community plays in shaping interest in community decision-making processes. The study was conducted between October 1995 and December 1996, when Canada was in a health services restructuring process of reallocating and reconfiguring health services delivered in the community. The goal of the restructuring process was to reduce the
overall expenditures of health services and “shift resources away from the institutional acute care sector to the community sector” (p. 778). Case studies of public participation in local health-care decision making was conducted in four Ontario communities. Interviews with community informants (N=85) and archival records (organizational documents, newspaper articles) were used as principal sources of evidence. Community informants included elected officials, senior management, community appointees, and citizen participants. Direct and participant observation was also used to provide complimentary evidence.

Abelson presents a framework for analyzing participation and its influences. In this framework, three contextual influences are identified as influencing participation. The first contextual category is pre-disposing influences – those factors like income, education, social ties and networks, etc. that deal with the structural and social context of the population. The second category – the enabling influences – deals with the institutional context for decision-making and considers the actions taken by the media and local government and other institutions to encourage participation. The third category – precipitating influences – focuses on the role of interests and interest groups in the participatory process.

Analysis emphasized the development of participation profiles for each community. Profiles for each of the contextual influences thought to explain the observed participation was also part of the analysis. Findings of this case study suggest that contextual influences do shape the ways in which communities participate in health-care decision-making. For instance, the socio-economic level (social and structural contexts) of the community impacts the style of participation. The participation style of one of the
communities with a lower socio-economic average was determined to be “friendly and informal” versus the “highly organized, sophisticated” approach in the community with the higher than [provincial] average household income and educational level (p. 790). Community values were also said to represent a “related set of influences”. Conservative values were said to “stifle” participation while the value of “preserving local identity” was felt to encourage community involvement (p.790). The enabling role played by local government and institutions was shown to be influenced by history of the relationship between the institution and the community.

Abelson, Forest, Eyles, Casebeer, and Mackean (2004), in yet another study, sought to evaluate the new structures that were (implemented by the Royal Commission on the Future of Health Care in Canada) aimed at involving citizens in the governance of the health system. In addition to the implementation of new structures, efforts were being undertaken to improve existing mechanisms to more effectively include citizens in priority-setting and resource allocation decisions. The goal of the study was to “revise a set of guiding principles to be used to inform the design and evaluation of future public participation processes in the health sector” (p. 205).

A total of six focus groups were conducted in five Canadian provinces between October 2001 and April 2002. Focus group participants were recruited based upon the criterion that they were currently, of had recently been, “active public participants in one or more regional health authority decision-making processes” (p. 207). Participants reflected different population characteristics and health needs. Focus group questions explored:

1) Participants’ experiences with public consultation processes
2) Participants’ impressions of barriers and facilitators to participation

3) The role of information and information sources on the consultative process

4) Perceptions of the effects of public consultation on participants’ views of policy issues

5) Impacts of public consultation on decision-makers and decision-making

6) Elements of successful consultation (p. 207).

Findings from the focus group discussions were categorized according to themes and assessed against a set of guiding principles of public involvement gleaned from a synthesis of the literature. The common themes were: communication, representation, procedural rules, and information. According to the authors, public participation evaluation frameworks suggest communication and information exchange as central components of a “well-designed consultation process” (p. 208). The study found that citizens in all focus groups:

Described their frustration with ‘corruptible’ consultations that are used To ‘mask’ hidden agendas, specifically those of decision-makers ‘looking for public support for predetermined agendas and outcomes’. They spoke disparagingly of ‘window dressing’ consultations where challenging stakeholders, labeled ‘troublemakers’, were excluded to protect tightly controlled agendas (p. 208).

The need to share information was said to be necessarily to facilitate a meaningful process:

…if you are going to meaningfully involve people, then you have to share the information. . .if you can’t share it then how can the public legitimately go through a consultation process? You’ve got to be able to share the information.

Participants further expressed that there is a need to “ensure that citizen views and expertise were incorporated into the consultation process” (p. 209). They also addressed the needs of having an “impartial facilitator” to ensure that decision-makers “listen” to
the public, and having “the right mix of people (i.e., ‘who’s talking’ and ‘who’s
listening’)” (p. 208).

There is a growing movement to involve citizens not only in health policy
initiatives, but also in decisions that affect their treatment options. One area of increasing
importance to citizens is the decision process affecting the technologies covered by the
Canada Health Act, and the drugs included in the formulary of drugs provided by each
province for the “most vulnerable citizens” (Pivik, Rode, & Ward, 2003, p. 254). Prior to
September 2002, when the Federal-Provincial-Territorial Ministers of Health approved
the Canadian Coordinating Office of Health Technology Assessment (CCOHTA) as the
home of the single, common drug review, each province made health technology
assessment (HTA) decisions with the help of its own committee of health experts.
However, following changes in recent years in the United Kingdom’s implementation of
models to engage consumers in health decisions, Canada has incorporated consumer
involvement in “most health care decision-making arenas with the exception of HTA”
(p. 255).

Pivok, Rode, and Ward (2003) used a four-stage approach to identifying a model
of consumer involvement: 1) a literature and International review of existing models or
methods; 2) identifying criteria for the assessment of working models; 3) evaluating the
models; and 4) surveying Canadian health associations. An extensive literature review
was conducted using nine major databases. Various keywords such as: “health
technology assessment and consumer or user involvement; drug review process and
patients; user participation; health policy and priority-setting; and, consumer
participation, health, and evidence-based” were used in the literature review search, as
well as an internet search (p. 256). The information gathered from the reviews was used to “identify evaluation criteria specific to consumers and health professional perspectives.” The criteria were then “applied to existing working models of consumer involvement to identify, strengths, weaknesses, and gaps.” Based upon the needs, a survey was designed for administration to Canadian health associations (p. 256).

Selection for survey participants was done in two stages. In the first stage, 81 groups were chosen from the database compiled from the book *Associations in Canada.* Groups were selected based on being active in advocacy and information dissemination on behalf of their members. In the second stage, Burden of Illness data was reviewed from Statistics Canada to identify the conditions and diseases “that most affect Canadians” in an effort to collect “as representative sample of health consumers as possible” (p. 258). Fifteen national chapters and their provincial chapters were added to the sample list.

Bruni, Laupacis, and Martin (2008), in a commentary, address the perceived barriers that Canada faces in fully engaging citizens in setting priorities in health care. They begin by citing various barriers from the literature and then rebutting them. First, the literature frequently states that members of the public are not objective. Bruni et al. suggest that there is no reason to believe that the average citizen is any less objective than anyone else “sitting at the priority-setting table” (p. 15). They further assert that “members of the public are not expected to be objective scientific experts, but rather to participate in value-based deliberations” (p. 16). Second, some existing literature suggests that the public is not well enough informed to contribute to priority setting. Bruni et al argue that members of the public have “life” experience as health care system
users and have insight to offer. Third, according to some literature, members of the public do not identify themselves as appropriate to be involved in priority setting. Bruni et al believe that under appropriate circumstances – with information and education – people are willing and want to participate. Fourth, those who do participate are not representative of the public. Bruni et al. suggest that focusing on misrepresentation “misframes the issue” and that rather, emphasis should be on ensuring that “fair-minded individuals from relevant constituencies” are present and “articulate a range of diverse and relevant values” (p. 16). Last, some literature suggests that involving members of the public will “make decision-making too protracted” (p. 16). Bruni et al. suggest that sometimes “you save time by taking time” meaning if time is not taken to obtain “genuine input from stakeholders, more time may be spent later addressing objections to the process and outcome” (p. 16).

**Conclusion**

Among findings of all studies – across nations – is the need to reframe, or reconstruct, the process of citizen engagement in health policy formulation. Common themes found in the review of the literature suggest that the political structure of the nation places less emphasis on the process than do the attitudes and perceptions about citizen input. The most common themes found in the literature related to:

1) information provided to citizens (about the opportunities to participate and about the issues being deliberated),

2) methods of engagement and participation, and

3) citizen input (whether it affects policy decisions and the ambivalence of policy-makers to seek, and use, it).
Additionally, the definition of a citizen is a prevalent subject matter in many of the studies. Whereas some of the studies ascertained the input of the average citizen (as health consumers), many studies recognized, and used, expert citizens (government officials, members of health authorities and organizations, etc.,) in their analyses of participation. Some of the existing literature identifies citizen variables and systemic barriers that contribute to low public engagement in health care priority-setting. Those authors then, provided suggestions on strategies and techniques that might mitigate these variables and barriers in the process of engaging citizens in priority-setting.

Research Questions

Based on review of the literature, the following questions are being raised:

1) What is the process of citizen engagement in health policy agenda-setting in the state of North Carolina?
   
   1a) How is information about health policy issues and opportunities for participation shared with citizens?
   
   1b) What methods of citizen engagement are used by policy makers and advocates?
   
   1c) When citizen input is obtained, how likely is it to influence policy decisions?

2) How do the perceptions held by legislators and health policy advocates regarding citizen participation in health policy agenda-setting and deliberation affect the process of citizen engagement?

Conceptual Definitions

Citizen engagement - occurs when “ordinary citizens . . . come together, deliberate, and take action collectively to address public problems or issues that citizens
themselves define as important and in ways that citizens themselves decide are appropriate and/or needed” (as cited in Moulder & O’Neill, 2009, p. 21). The term citizen engagement was often used in the literature synonymously with the concept of citizen participation. In this study it was accepted that a citizen must be engaged in order to participate.

Health policy - policy that “relates to the pursuit of health, the employment of health care professionals, or the receipt of health care services” (Kronenfeld, 1997, p. 50). In this study, health care policy is included in the term of health policy.

Agenda-setting – the process of narrowing “the list of subjects or problems to which governmental officials, and people outside of government are seriously paying attention to a set that actually becomes the focus of attention” (Kingdon, 2003, p. 3).

Perceptions - the ways by which a person views an object, issue, idea, or another person and are guided by, and congruent with, an individual’s attitudes. Experience influences attitude and perception, while attitude and perception impact behavior (Dovidio & Fazio, 1992).
CHAPTER III

METHODS

A review of the literature regarding citizen participation in health care policy reveals common categories of meanings and perceptions (across nations) amongst citizens and government officials. Recent research in Uganda and Canada support the earlier findings of Dahl (as cited in Cobb and Elder) on the topic of variables – citizen characteristics, community demographics, and government perceptions and experiences – that contribute to the failure of citizen engagement and participation in health policy decisions. Literature in the United States and the United Kingdom also validate the consequences of the perceptions of citizens and government officials on citizen participation in policy deliberation.

Design of the Study

This study will seek to ascertain the experiences and perceptions of citizen participation in health policy agenda-setting held by those citizens most likely to influence health policy initiatives: legislators and health policy advocates. The case study approach will be employed to explore the meanings and perceptions of legislative members of the North Carolina General Assembly and Executive Directors of health policy advocacy organizations in North Carolina. Cases will be interviewed to identify common themes regarding citizen participation and/or failure of citizen engagement in
health policy decision-making and agenda-setting. According to Stake (2000), the case is a “system,” with “working parts; it is purposive; it often has a self.” It is characterized by behavior patterns, coherence and sequence – a “specific, unique, bounded system” (p. 436). This interconnected system possesses behaviors and attitudes that impact the process of citizen participation in health policy decisions. The purpose of this study is to explore how attitudes and perceptions influence the process of citizen participation.

Design Rationale

The case study method of qualitative inquiry is being used in this study because it provides the ability to facilitate in-depth exploration of perceptions of engaging citizens to participate in health policy deliberation. Soy (1997) asserts that “case study research excels at bringing us to an understanding of a complex issue or object and can extend experience or add strength to what is already known through previous research” (p. 1). Findings of the literature review support the idea that the complexity of health policy influences perceptions about who should be involved in determining priorities and making decisions. The cases (North Carolina General Assembly Legislators and Directors of Health Policy Advocacy Organizations) will be used instrumentally to illustrate the issue (citizen participation in health policy decision-making).

According to Stake (2000), an instrumental case study is used to “provide insight into an issue or to redraw a generalization.” The case is not the primary interest in an instrumental study, “it plays a supportive role, and it facilitates our understanding of something else” (p. 437). Stake asserts that “the bulk of case study work” is done by individuals conducting intrinsic case studies – those in which inquiry is aimed at understanding what is important about the case in its own world and with “little interest
in the advance of science” (p. 439). The purpose of the use of the instrumental design is to gain a better understanding about perceptions of citizen participation in health policy agenda-setting and decision-making across cases.

Participant Selection and Recruitment

Using a non-probability, sampling procedure, study participants will be purposefully selected and recruited on a volunteer basis. Purposive sampling is a technique that “involves the conscious selection by the researcher of certain subjects or elements to include in a study” (Shorideh, Ashktorab, & Yaghmaei, 2012, p. 466). Thirty-five members of the North Carolina General Assembly have been identified and will be contacted for this research study – 21 House Representatives and 14 Senators – based on two criteria:

1) Membership in committees, and

2) Sponsorship of legislation related to health care and/or local or state government.

Selection for study participation is due to membership in:

1) Two House Standing Committees: Government, and Health and Human Services,

2) Two Senate Standing Committees: State and Local Government, and Health Care,

3) and/or membership in the Joint Legislative Oversight Committee on Health and Human Services.

Table 3.1 represents the distribution of General Assembly members in the legislative standing committees used as the sampling frame. Many of the General Assembly
members are on more than one of the committees. Some are on both committees within their legislative group. Some are on one of the standing committees and the joint legislative committee. A few are on all three.

Table 3.1 Distribution of NCGA Committee Membership in the Sample Frame

<table>
<thead>
<tr>
<th>House Standing Committees and sample size</th>
<th>Senate Standing Committees and sample size</th>
<th>Joint Legislative Oversight Committee on Health &amp; Human Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government N=9</td>
<td>State and Local Government N=8</td>
<td>House of Representatives N=7</td>
</tr>
<tr>
<td>Health and Human Services N=9</td>
<td>Health Care N=10</td>
<td>Senate N=6</td>
</tr>
</tbody>
</table>

Legislation criteria for the sample pool includes sponsorship or co-sponsorship of at least one of the following bills: (a brief description of each bill was taken from the bill – found on the General Assembly webpage)

1) H746 Citizen Participation Act – “An Act to Protect the Constitutional Right of Citizens to Participate in Government Proceedings” with the purpose “to protect and encourage citizen participation in government to the maximum extent permitted by law, support the operations of representative government by protecting public participation in government programs, public policy decisions, and other actions”

2) H126/S418 North Carolina Health Benefit Exchange Act – “The intent of the Exchange is to reduce the number of uninsured individuals and to promote both improved competition in the health care marketplace and consumer engagement in care and coverage choices”

3) H752 Revolving Door – “An Act to extend the time period during which legislators and certain public servants are prohibited from registering as a lobbyist after leaving office or employment”
4) H795 Patient Access to Pathological Materials – “An Act to require health care providers to release pathological materials and records to patients upon written request”

5) H2/S23 Protect Health Care Freedom – “An Act to protect the freedom to choose health care and health insurance”

6) H685/S344 Government Transparency Act – “An Act to strengthen confidence in government by increasing accessibility to public personnel hiring, firing, and performance records and other governmental records and meetings”

7) S412 Public Meetings and Records Law Violations – “An Act to make violations of the public records and open meetings laws a Class 3 Misdemeanor”

8) S67 Sunshine Amendment – “An Act to provide for government in the sunshine by amending the North Carolina Constitution” to include “access to public records and meetings”

9) S245 Medicaid Billing by Local Health Departments – “An Act to authorize local public health departments, district health departments, and consolidated human services agencies to bill Medicaid through an approved Medicaid clearinghouse or through the Department of Health and Human Services, Division of Public Health”

Table 3.2 illustrates the number within the sample frame of 35 who were active in supporting each legislative bill.
Table 3.2 Distribution of NCGA Bill Sponsorship in the Sample Frame

<table>
<thead>
<tr>
<th>Bill</th>
<th>Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>H746 Citizen Participation Act</td>
<td>N=9</td>
</tr>
<tr>
<td>H752 Revolving Door</td>
<td>N=2</td>
</tr>
<tr>
<td>H795 Patient Access to Pathological Materials</td>
<td>N=3</td>
</tr>
<tr>
<td>H126/S418 North Carolina Health Benefit Exchange Act</td>
<td>N=13</td>
</tr>
<tr>
<td>H2/S23 Protect Health Care Freedom</td>
<td>N=16</td>
</tr>
<tr>
<td>H685/S344 Government Transparency Act</td>
<td>N=7</td>
</tr>
<tr>
<td>S67 Sunshine Amendment</td>
<td>N=6</td>
</tr>
<tr>
<td>S412 Public Meetings and Records Law Violations</td>
<td>N=2</td>
</tr>
<tr>
<td>S245 Medicaid Billing by Local Health Departments</td>
<td>N=2</td>
</tr>
</tbody>
</table>

Study participants of the other case type – Directors of health policy organizations and programs – will be recruited by referral. Once data collection begins, a snowball sampling approach will be utilized. Legislative respondents will be asked to recommend health policy activists with involvement in the health policy decision-making arena to be contacted for potential inclusion in the study.

All study participants will receive a letter of invite to participate in the study. The letter will include the purpose and details of the study; the procedures used to collect, store, and use data; the risks and benefits of the study; how the principles of anonymity and confidentiality are to be protected; and the participant’s right to ask questions, refuse to answer questions, and right to withdraw from the study. Agreement to complete the
interview will represent the individual’s consent to participate in the study. A copy of the letter, as an email attachment, can be kept for the participants’ records.

The IRB approved letter of invite (see Appendix B) will be delivered to both case types via email. Electronic mail has been chosen as the method of contact and delivery of the letter for many reasons. First, email has become a common form of communication between state representatives and their constituents, as well as an effective method of communication between health policy advocates and citizens. Second, it is a fast and cost-effective means of communication. Third, it allows for rapid transfer of information. Finally, the contents of the email can be easily accessed at a later date, avoiding the need to try to remember pertinent information and facts. The salutation in the text of each email, as well as on the IRB letter, will be personally addressed to each individual of the sample, rather than as a mass email, to assign a more personal touch.

Data Collection

Before gathering any data from study participants, CITI Core Training is to be completed and an application filed with, and approved by, the Institutional Review Board (IRB) of the University of Akron. The research is eligible for exemption because it “represents minimal risk to subjects.” The research protocol is consistent with the federal category of Exemption 2 – research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior (The University of Akron, Office of Research Services and Sponsored Programs, 2012). The IRB approval letter can be found in Appendix A.

The method of data collection will be a semi-structured interview. Interviews are known as “one of the most common and powerful ways in which we try to understand
fellow human beings” (Fontana & Frey 2000, p. 645). Most commonly, interviews are conducted by means of face-to-face, verbal interchange. However, interviews may also occur over the telephone, or in the form of a mailed questionnaire. The two major considerations of interviews are time and cost. One of the advantages of telephone interviews is the capability to quickly obtain information in an inexpensive method. The biggest disadvantage of telephone interviews is the missed opportunity to make observation of nonverbal and gestural cues made by the respondents afforded by face-to-face interviews. However, verbal cues and tones are able to be noted by an experienced interviewer. This goal of this study is to employ the use of in person, face-to-face interviews; though, telephone interviews will be used if necessary.

A semi-structured format of the interview will provide a “core of objectives” for questions, but allow the opportunity to probe further into responses for clarification and/or depth (Newman and McNeil, 1998, p. 27). Legislative officers will have one question that differs from those of health policy advocates: How frequently and in what capacity do you communicate with local representatives in your district(s)? Otherwise, a set of questions will guide the interview. Interviews with legislative officers will follow more of a structure than those with health policy advocates. The interviews with those respondents will begin with asking them to describe their organization and position in regard to health policy. Subsequent questions will be asked as a result of their introduction and/or based off of the basic set of interview questions.

The core set of interview questions will be developed from the constant themes found in the literature review and legislators’ and other health representatives’ perceptions about citizen participation in the deliberation process of health policy.
Open-ended questions will be used to collect data from participants. Open-ended items not only allow respondents to answer questions in their own words, but also to provide the amount of detail they choose. Although “such detailed information is difficult to aggregate,” it does lend itself to classification of patterns of themes and categories (Newman and McNeil, 1998, p. 37).

Data Recording

Each participant will be asked for consent to audiotape the interview. Audio-taping the interview will allow the researcher to dialogue more openly during the interview. Audio recorded interviews will be transcribed into a Microsoft Word document (response sheet) after the interview. All response sheets will be identified by numerical code only. Each respondent will be assigned an ID number that will be recorded at the top of each transcribed document, as well as in an Excel spreadsheet with other demographic information to be listed on the coding sheet. The respondent’s ID number will not be linked with the recorded interview on the audio recorder. The audio recorder, with the raw data, will be stored in a locked file box. The researcher will have sole access to the interview materials and data.

Data Coding

Once transcribed, response sheets will be printed and thoroughly read through and prepared for coding based on the recurrent word, word phrases, or themes found. The goal is to gather a general sense of the overall meaning of the information. Responses will be read through to ascertain not “what is this about,” but rather, the underlying meaning (interpretation) of the content (Creswell, 2003, p. 192). Notes will be written in the margins to begin to reflect general thoughts about the content of the responses. From
the margin notes, a list of all topics will be generated. Similar topics will be clustered together and divided into “major topics, unique topics, and leftover topics” (p. 192). These topics will be instrumental in the coding process. Coding is “the process of organizing the material into ‘chunks’ before bringing meaning to those ‘chunks’” (Rossman & Rallis, 1998, p.171). Chunks of text data will be labeled as categories with terms in the actual language of the participants. These categories will be aggregated and used to generate themes (and issues) for analysis.

To better manage all of the data, a second data set will be created with individual responses to specific questions asked during the interview. This second data set will fulfill several purposes. First, the list of categorical topics that is identified in the markup of the first data set will then be applied to this data set to isolate chunks of text for thematic analysis around particular topics/questions. Second, it will provide a data set to be included in the Appendix that is free of any identifying information of each respondent. Third, it will facilitate a process known as familiarization, in which repeated reading of the data and additional marking up of the text can be made to better define and/or consolidate any overlapping categories.

From this repetitive process of reading and marking up the textual data set, the original list of topics can be merged to a list of most meaningful categories. The refined categories will then be abbreviated as codes and written next to the corresponding chunks of text (that which is highlighted). The most descriptive wording (in the actual language of the respondents) from the chunks of text will be used to assign subcategories to the codes for analysis.
Data Analysis

Codes (categories and subcategories) of text from the interviews will be used to generate descriptions of the cases and their contexts. The codes will also be useful in creating thematic categories for interpreting deeper meaning of the data. In other words, what assertions can be made from the patterns of themes and issues about the perceptions of health policy advocates and government officials regarding the engagement of citizens in health policy decision-making? Coding can be divided into several tasks (Ryan & Bernard, 2000, p. 780). Those most applicable to use with analyzing data from case studies are: sampling, identifying themes, marking texts, and building codebooks. These tasks will be useful in preparing the data for analysis.

Sampling

Morse (2000) suggests that using at least six participants in a case study will facilitate finding themes and building theories about the essence of an experience. This study will use the text from all completed interviews to develop the categories of text. These categories (chunks of identifiable text or message components) will become the basic unit of analysis – what Krippendorf (1980), refers to as “thematic units” (as cited in Neuendorf, 2002, p. 62). A combination of both a priori and grounded approaches will be used in the unitization of themes. A priori themes, are available in advance, and will be drawn from the synthesis of the literature review. Grounded themes, those that must be “discovered,” will emerge during the analysis (p. 72). Gottscalk and Bechtel (1993) suggest that a verbal selection of 85 to 90 words is an adequate sampling unit to “well represent the phenomenon under investigation” (p. 73).
Identifying Themes

Themes are abstract constructs that can be identified by the researcher before, during, and after data collection. Ryan & Bernard (2000) assert that literature reviews can be “rich sources for themes,” as well as the researcher’s “own experiences with subject matter” (p. 780). General themes of perceptions about citizen participation in health policy deliberation were identified in the literature review. These findings, along with the researcher’s knowledge of the themes found, will be instrumental in developing questions (before and during) for the interview. After the interviews, line-by-line reading of the text of the transcribed interviews will help to induce themes from the data. The universal message themes will become the thematic units to be examined to discover dimensions of meaning of citizen participation in health care policy agenda-setting.

Marking Texts

Human coding rather than computer coding will be used as the protocol for analysis in this study. Human coding lends itself to reading through the text of transcribed interviews and making notes on the hard copy pages. This activity permits the forming of initial codes, and the redefining of codes upon repeated reading of the text. Coding serves two discrete functions in qualitative analysis. First, codes serve as tags to mark off text for later retrieval or indexing. Second, codes acts as values assigned to fixed units. The values are nominal, ordinal, or ratio scale values that are applied to fixed, “nonoverlapping” units of analysis (Ryan & Bernard, 2000, p.782). The two types of codes are not mutually exclusive, but codes as values are commonly associated with classic content analysis and content dictionaries.
Building Codebooks

Codebooks are “simply organized lists of codes” (Ryan & Bernard, 2000, p. 781). When values are assigned to codes and listed in a codebook, they facilitate the reading and manipulation of variables of a study. At the very least, a codebook provides a mechanism for counting the frequency of a variable (in this case, a theme). A codebook should include a detailed description of each code, with space for full explanation of variables measured, and with its inclusion and exclusion criteria. In the case of particularly abstract themes, examples of the boundaries of the themes should be clarified. Ryan and Bernard suggest that Miles (1979) proposed that coding is supposed to be “data reduction, not proliferation” (p. 781). Coding categories, and thus, good codebooks, will go through refinement as the research progresses. It is often during training of coders and checking of inter-coder agreement that development and refinement of coding categories occurs. This study will have only one coder, however, it will potentially go through several stages of refinement of the codebook.
CHAPTER IV RESULTS
OF THE STUDY

Restatement of the Problem

The passage of the Patient Protection and Affordable Care Act by President Obama has placed the issue of health policy at the top of many states’ political agendas. The Affordable Care Act, as it is commonly referred to, provides all fifty states with the option of expanding health coverage to uninsured citizens under the auspices of Medicaid. According to the law, each state will also offer a state-based health insurance marketplace, known as an exchange, where citizens can make online comparisons of all available policies and premiums. States may choose to build their own online marketplace or let the federal government run their exchange.

The state of North Carolina has opted to not expand Medicaid coverage and to utilize a federal exchange. The Governor, in his February 12, 2013 announcement to the press, stated “If it becomes clear that the current course of action is not in the best interest of North Carolina, our health care system, and our citizens, we will work with the General Assembly to pursue other options in the future.” He further states that “we have done a thorough review of the advantages and disadvantages . . . this review included discussions with our governors, the White House, health care providers, and N.C. legislative leaders” (state of North Carolina). However, the issue remains that, according
to the governor’s statement, the citizens most affected by this decision, have not participated in the decision-making process. In the area of health care policy, insurance companies and medical interest groups have become the “power elite” in the development of health policy.

The Study

The aim of this qualitative inquiry was to ascertain and interpret the perceptions and meanings of those citizens influencing policy initiatives regarding the concept of citizen participation in the process of health policy agenda-setting. IRB approval was obtained on August 14, 2012 with exemption status 2 – survey research (see Appendix A). Approval for the dissertation prospectus was granted on November 30, 2012. Data was collected over a seven-week period during December, 2012 and January, 2013.

Thirteen interviews (five face-to-face and eight telephone interviews) with North Carolina General Assembly members and members of health policy organizations were completed. In-person interviews were conducted in a variety of locations, including: coffee houses (3), Legislative offices (1) and health organizations (1). Telephone interviews were conducted from the researcher’s home office and the respondents’ offices (4), home (3), and car (1). All respondents consented to audio-taping of the interview. Although the average time of in-person interviews was between 35 and 45 minutes, the range in duration varied from 36 minutes, to 1 hour and 30 minutes. The duration of telephone interviews ranged from 16 minutes to 58 minutes.

Description of the Cases and Their Contexts

Six (46%) of the thirteen participants were members of the North Carolina General Assembly (2 Senators and 4 Representatives); seven (54%) of the thirteen were
from organizations involved in influencing health policy decisions. Legislators’ years of experience in policy-making ranged from less than 2 years to 16 years. The years of policy-making experience for those from organizations that influence health policy-making was greater than that of legislators – ranging from 8 years to more than 20 years. One health policy advocacy organization executive had the experience of having been a legislator in another state before moving to North Carolina and was able to address the issue of citizen participation from the perceptions of both settings. All participants were of the same race; however, composition based on sex was fairly evenly distributed, both across, and within, cases (See Figure 4.1). Table 4.1 illustrates the organizational membership (and political party of legislators), position/occupation, and years of experience in the policy arena of the participants.

![Figure 4.1 Study Participants by Sex](Figure 4.1 Study Participants by Sex)
Table 4.1 Membership and Years of Policy Experience of Study Participants

**Case Type: Legislators**

<table>
<thead>
<tr>
<th>Position/Occupation</th>
<th>Organization</th>
<th>Years of Experience in Policy Arena</th>
</tr>
</thead>
<tbody>
<tr>
<td>House Representative (R) Retired Food Broker</td>
<td>NC General Assembly</td>
<td>Less than 2</td>
</tr>
<tr>
<td>House Representative (R) Dentist</td>
<td>NC General Assembly</td>
<td>8</td>
</tr>
<tr>
<td>House Representative (D) Retired Communications Attorney</td>
<td>NC General Assembly</td>
<td>10</td>
</tr>
<tr>
<td>Senator (D) Retired Pediatrician</td>
<td>NC General Assembly</td>
<td>14</td>
</tr>
<tr>
<td>Senator (D) Retired Attorney</td>
<td>NC General Assembly</td>
<td>16</td>
</tr>
<tr>
<td>House Representative (D) Retired Health Program Administrator</td>
<td>NC General Assembly</td>
<td>16</td>
</tr>
</tbody>
</table>

**Case Type: Health Policy Advocates**

<table>
<thead>
<tr>
<th>Position/Occupation</th>
<th>Organization</th>
<th>Years of Experience in Policy Arena</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chief Executive Officer</td>
<td>Piedmont Health Center</td>
<td>8</td>
</tr>
<tr>
<td>Executive Director</td>
<td>NC Alliance for Health</td>
<td>8</td>
</tr>
<tr>
<td>NC Government Relations Director</td>
<td>American Cancer Society, Cancer Action Network</td>
<td>9</td>
</tr>
<tr>
<td>Senior Director, Advocacy &amp; Civic Engagement</td>
<td>National Association of Community Health Centers</td>
<td>13</td>
</tr>
<tr>
<td>Director, Health Access Coalition</td>
<td>NC Justice Center</td>
<td>15</td>
</tr>
<tr>
<td>CEO &amp; President</td>
<td>NC Prevention Partners</td>
<td>15</td>
</tr>
<tr>
<td>President</td>
<td>NC Institute of Medicine</td>
<td>More than 20</td>
</tr>
</tbody>
</table>
The North Carolina General Assembly includes two bodies: the house and the senate. The House of Representatives consists of 120 members; the Senate consists of 50 members. General Assembly members are elected by the voters of their districts, each serving two year terms. The House of Representatives is presided over by the Speaker of the House (elected by House members for a two-year term). The presiding officer of the Senate, the President of the Senate, is the Lieutenant Governor of the State (elected by the citizens for a four-year term). Legislators are appointed to serve on standing committees of their body. The Speaker of the House appoints Representatives to House standing committees, while the President Pro Tempore (elected for a two-year term by members of the Senate) appoints Senators. Each committee is responsible for carefully reviewing an introduced bill and making any recommendations before it is approved and placed on the calendar for consideration by full membership of the bodies of both houses.

An interconnected component of the health policy decision-making system is health policy advocacy organizations. Policy advocates are active players in this political arena – providing technical support and scientific information to inform policy deliberation and decisions. Seven persons (referred by legislative participants as being involved in health policy agenda-setting in North Carolina) in executive positions with health policy advocacy organizations were part of this study. Below is a brief description of each respondent’s/organization’s role in health policy, in his or her own words:

*NC Justice Center, Health Access Coalition* – The Justice Center is a 50- person, non-profit, advocacy group for low-income people. We’re state-based and state-level largely, although we work on some national issues. And we’ve been in existence since ’96 - officially – well we grew out of legal services and we have grown a lot bigger over the years, and we’re a multi-issue, anti-poverty organization. . . We work on a number of different health issues, basically our focus this year is going to
be implementation of the Affordable Care Act, primarily around the expansion, whether the state will expand Medicaid, and whether or not we will have a, and what sort of, not, I don’t think whether, we will have a State Health Exchange, it’s just what it looks like.

**Piedmont Health Center** – Well, we’re active with the state association, North Carolina Community Health Center Association, which is the association of health centers in the country, in the state, there is a national association, but in the state we’re active with that… we try to work through you know, the collect, the collective power of all the health centers at one time, going to the state in, kind of like, in a unified way, we believe in that power. Uh, but we also, obviously, talk with our individual, elected officials and you know, try to keep them engaged, through events here . . . we just try to make sure we talk with them in a way that’s informative and helpful.

**NC Alliance for Health** – The Alliance is a 10 year old coalition of approximately 75 organizations from across the state that have come together to promote policies that reduce tobacco use and obesity. So, we primarily pull people together to discuss or build consensus around legislative policy proposals that we want to push. So, since everybody can’t push everything all at the same time, we try to get everybody to focus on one or two things that we can all identify as priorities and work on together. . . So, we are primarily an advocacy organization, we, all of our members have their own programs and address tobacco use or obesity in programmatic ways, but we take the policy piece and try to move it at the state level. So it could be at the General Assembly, legislatively, it could be administratively, through the executive branch.

**NC Prevention Partners** – Our primary role is inspiring leaders, and I would say that at the private leader level, almost more than the public policy leader, although we do both, but we have partnered with what’s called the NC Alliance for Health, which is an advocacy lobby group, that we actually helped found. . . we were all state employees, so we really couldn’t lobby and so we wanted to help bring together all the groups that were kind of interested in the preventive health area under one umbrella to advocate together . . So we support their state level agenda, so their executive committees set that policy agenda every year, and we support what the Alliance does at the state level, and then at the local level, and at the federal level, we have supported some things outside of what the Alliance is working on because that’s really their focus, they don’t have a huge amount of resources or staff, so they really focus at the state house and, um, we have added, another organization that we support at the state level is the Center for Non-profits, because we’re a non-profit, so, we support the Center for Non-profits legislative agenda as well.
**NC Institute of Medicine** – We were created by the North Carolina General Assembly in 1983 to study health problems facing the states. We, um, are modeled after but are not directly affiliated with, the Institute of Medicine out of the National Academies of Science out of Washington. The way we operate is sometimes the legislature will ask us to study issues, sometimes an executive agency will ask us to study it, sometimes my board will ask us to study the issue, or a community group will fund us. We bring together usually between 30 and 60 different people from across the state to look at the issue and then try to develop workable solutions to those problems. . . when we look at an issue we try to figure out all the different interest groups that need to be involved. So, for example, we just did a study on implementing the healthcare format, Obama-care, we had nine different work groups looking at that, we had providers at the table we had insurers at the table, we had consumer groups at the table, we had, um, business representatives at the table, we had legislators at the table, we had executive agency people at the table, so we looked and said, ‘Ok well who needs to be at the table?’

**American Cancer Society, Cancer Action Network - ACS-CAN,** is the advocacy affiliate for the American Cancer Society, so because ACS is a non-profit organization, it’s political advocacy is quite limited, so, uh, the organization, the society, decided to create a C-4, a non-profit C-4 organization which has more latitude in lobbying, uh the legislature on public policy changes that will help prevent cancer early, uh, detect the cancers earlier and help save more lives. That’s why we are, we’re the C-4 affiliate of ACS-CAN. And we’re a nationwide organization, we have millions of volunteers, we have government relations directors in *every* state, and our idea is, not only do we work to prevent cancer and save lives, but much of the work can be accomplished through public policy changes, for example, uh, tobacco prevention and cessation programs, a circumference of tobacco prevention uh, program in the state consisting of smoke-free laws in uh, public places, increase in sales tax of tobacco, of cigarettes, so that will reduce consumption and, and stop kids from starting to smoke, and we also promote policies, uh aimed at early detection like the breast and cervical cancer, uh, control program. And that helps individuals who are uninsured or underinsured help pay for their screens for breast and cervical cancer as well. So, we’re, we’re looking at a broad range of policies, and all at an order to save more lives every day.

**National Association of Community Health Centers** – National Association of Community Health Centers represents about 1,200 federally-qualified health centers in all 50 states and the territories. It provides both, I guess, technical assistance, operational assistance, but as well as um, advocacy and education at the federal level with Congress and the Administration and other officials. Our job is to
promote government policies, I mean federally-qualified health centers are a government program. They’re established in the Public Health Act and um, so therefore both federal and state governments have a tremendous amount of impact on what they do and on the populations that we serve, you know, and programs that affect those health centers, so our job is to make sure that those legislators at the federal level, now we have health center associations that we work with at the state level, but our job is primarily to make sure that the policies that Congress and The Administration uh, develop and enact, at the federal level, benefit, or at least don’t hurt, our health centers and the populations they serve.

Data Analysis and Findings

Familiarization, or repeated reading of the data and additional marking up of the text, facilitated the emergence of eight refined categories of themes. The refined categories were then abbreviated as codes to be used in the development of the codebook (Table 4.2). Sub-categories of each code were assigned nominal level values (to facilitate the counting of themes), including a detailed description of each code, in the descriptive words of participants’ responses Values of the subcategories were recorded on the coding form (Table 4.3). Data from the coding form was then tallied to permit the counting/frequency of common themes that would assist in the interpretation of perceptions found during the interviews.

One a priori theme (gathered from the literature on studies of perceptions of government officials) regarding citizen participation was identified: citizen lack of interest, knowledge, or experience in participation (LIKE). Seven subcategories and values were assigned based upon the chunks of text from the data set. Seven grounded codes were created from the data set and assigned subcategory values from the chunks of text. Those codes/values are defined in the codebook.
<table>
<thead>
<tr>
<th>ID</th>
<th>001-013</th>
</tr>
</thead>
</table>
| **UDC**                 | 1 – In-person interview  
                           | 2 – Telephone interview |
| **Case Type**           | 1 – Legislator  
                           | 2 – Organization Executive |
| **YIPA**                | 1 – Less than 5  
                           | 2 – More than 5, but less than 10  
                           | 3 – More than 10, but less than 20  
                           | 4 – More than 20 |
| **LIKE**                | 1 – Don’t understand/need to know how  
                           | the process works  
                           | 2 – Lack of information/need to know the  
                           | basics of what is happening  
                           | 3 – Don’t have the background/experience  
                           | of doing it  
                           | 4 – Don’t know/have never contacted their  
                           | legislators  
                           | 5 – People get involved when it’s  
                           | something they care about  
                           | participation is based on “self-  
                           | interest,” relevance, and experience  
                           | 6 – Lack of “self-responsibility” and  
                           | “accountability”  
                           | 7 – Disaffected/don’t feel as if their  
                           | participation matters |
| **COMP**                | 1 – Complicated subject/don’t understand  
                           | 2 – Slow and difficult process  
                           | 3 – Easy to get “frustrated,”  
                           | “discouraged,” or “overwhelmed”  
                           | 4 – Policies, funding, insurance is complex |
| **INFL**                | 1 – Money/Profit  
                           | 2 – Power  
                           | 3 – Big Industry/Corporations  
                           | 4 – Groups, Lobbyists, Task Forces,  
                           | Committees  
                           | 5 – Other “experts”  
                           | 6 – Time  
                           | 7 – Personal stories & testimonies  
                           | 8 – Media  
                           | 9 – Relationships |
Table 4.2 Codebook (continued)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Values</th>
</tr>
</thead>
</table>
| **VOTL** | Voting by Legislators | 1 – Vote their conscience  
2 – Vote based on constituents’ wants  
3 – Vote based on science/evidence  
4 – Vote their Caucus  
5 – Vote based on more than one factor |
| **VOTC** | Voting by Citizens | 1 – Exercise the right to vote/sacrifices made to earn the right  
2 – Not registered to vote/have never voted  
3 – Don’t think it makes a difference/don’t vote  
4 – Vote on Election Day  
5 – Majority/minority voting |
| **CORE** | Communication & Relationships | 1 – Relationships are important so legislators “will listen”  
2 – Importance of citizens to “reach out to” and “engage their representative”  
3 – Legislators’ efforts to communicate with constituents  
4 – Legislators’ relationships with advocates, lobbyists, and local representatives  
5 – Ongoing/requires follow-up |
| **GRPS** | Social and Advocacy Groups for Citizens | 1 – Collective power  
2 – Support – so citizens “won’t get frustrated”  
3 – Keep citizens informed  
4 – Networking with other groups and organizations |
| **EDEN** | Education & Engagement Efforts | 1 – Social & Mainstream Media  
2 – Indoctrinating/inculcating youth  
3 – Formal education/classes  
4 – Publications/newsletters  
5 – Rallies/forums  
6 – Town Hall/public meetings  
7 – Voter Engagement & Registration  
8 – Social groups  
9 – Identify interests/provide information |

Each response sheet was reviewed and coded onto a separate codebook (by circling the values for each subcategory). All codebook responses were then coded onto the coding form to facilitate counts of frequency of subcategory responses.
Table 4.3 Coding Form

<table>
<thead>
<tr>
<th>Code</th>
<th>ID# 001</th>
<th>ID# 002</th>
<th>ID# 003</th>
<th>ID# 004</th>
<th>ID# 005</th>
<th>ID# 006</th>
<th>ID# 007</th>
<th>ID# 008</th>
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<th>ID# 011</th>
<th>ID# 012</th>
<th>ID# 013</th>
</tr>
</thead>
<tbody>
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<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
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<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Case Type</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
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<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>YIPA</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
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<td>2</td>
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<td></td>
</tr>
<tr>
<td>INFL</td>
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<td>2, 3</td>
<td>1, 4 5</td>
<td>4, 9</td>
<td>1, 2, 3</td>
<td>4, 5</td>
<td>1, 2, 3,</td>
<td>4, 5</td>
<td>1, 2, 3, 4</td>
<td>1, 2, 3, 7, 8</td>
<td>4, 5</td>
<td>2, 4</td>
<td></td>
</tr>
<tr>
<td>VOTL</td>
<td></td>
<td>1, 3</td>
<td>1, 2, 4, 5</td>
<td>3</td>
<td>1, 2, 4, 5</td>
<td>3</td>
<td>1, 2, 4, 5</td>
<td>3</td>
<td>1, 2, 4, 5</td>
<td>3</td>
<td>1, 2, 4, 5</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>VOTC</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>1, 2, 3, 5</td>
<td>3</td>
<td>3</td>
<td></td>
<td>3</td>
<td>3, 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CORE</td>
<td>4</td>
<td>1, 4</td>
<td>2, 3</td>
<td>4, 5</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td></td>
<td>2</td>
<td>3, 4</td>
<td>2, 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GRPS</td>
<td>1, 2</td>
<td>3</td>
<td>4</td>
<td>1, 4</td>
<td>1</td>
<td>1, 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EDEN</td>
<td>2, 4</td>
<td>6</td>
<td>3, 1</td>
<td>1, 4 5, 9</td>
<td>1, 4 5, 6</td>
<td>1, 2, 3, 7, 8</td>
<td>1, 3, 4, 8, 9</td>
<td>3</td>
<td>1, 4 8</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The Themes

Two of the primary goals of the interviews were to determine the legislators’ and advocates’ perceptions of 1) how, and 2) why, citizens do or don’t participate in health policy agenda-setting. Two themes were cited to have impact on why citizens do or do not participate in health policy agenda-setting: 1) citizen lack of interest, knowledge, and experience, and 2) the complexity of health policy.
Citizen Lack of Interest, Knowledge, and Experience (LIKE)

Consistent with the existing literature, citizen lack of interest, knowledge, and/or experience in participating in policy decisions was a common theme found in this study. Seventy-seven percent (10 of 13) of the respondents discussed this theme in their interviews. Of the ten participants who discussed this theme, several (6 of 10) talked about more than one value (subcategory) of this theme. The two most frequently reported subcategories of this theme were: “lack of information” and “self-interest”. “Lack of information” and/or a “need to know the basics of what is happening” were counted in almost half of the text as a reason for lack of participation. The subtheme of “self-interest,” occurred frequently in responses and was coupled with the belief that “people get involved when it’s something they care about.” Other reasons for lack of involvement suggested by participants are included in Table 4.4 below. Figure 4.2 provides a visual representation of the perceptions (across cases) regarding why citizens do or do not participate in policy agenda-setting.

Table 4.4 Frequency of Responses Related to the Theme: Lack of Interest, Knowledge, and Experience (LIKE)

<table>
<thead>
<tr>
<th>Subcategories of LIKE</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t understand/need to know how the process works</td>
<td>2</td>
</tr>
<tr>
<td>Lack of information/need to know the basics of what is happening</td>
<td>6</td>
</tr>
<tr>
<td>Don’t have the background/experience of doing it</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know/have never contacted their legislators</td>
<td>2</td>
</tr>
<tr>
<td>People get involved when it is something they care about/participation is based on self-interest</td>
<td>5</td>
</tr>
<tr>
<td>Lack of “self-responsibility” and “accountability”</td>
<td>1</td>
</tr>
<tr>
<td>“Disaffected’/don’t feel as if their participation matters</td>
<td>2</td>
</tr>
</tbody>
</table>
Figure 4.2 Comparison of Legislators’ and Health Policy Advocates’ Responses Regarding Citizen Lack of Interest, Knowledge and Experience (LIKE)

One of the subcategories associated with the theme of lack of information or knowledge that citizens need to participate in health policy deliberation was that of having knowledge of the legislative process. Respondents reported the lack of education and experience as the two main reasons for lack of knowledge of the legislative process, and thus, lack of participation. Several respondents (4) proposed that the current North Carolina public school curriculum does not adequately prepare its students for participation in the legislative process. The generalized idea was that the brief lessons taught in an elementary or middle school social studies class, or a Civics class in high school, did not prepare them for, “now, do they know how to do it?” One respondent summed it up as:

We do a terrible job of teaching Civics. At best, there’s a civics course in high school. Years ago, and I believe still, the populace felt that the purpose of an education, really, a formal education, was to make us capable of participating in the government - That that was the main purpose of a formal education. Everything else you learn on the job, you learn in life, the main purpose was to make us – the citizens – capable of participating and that’s been lost
One (1) respondent also suggested that, even in [Public Health] graduate school, “they don’t actually have people work on policy issues - they just talk about it.” Some respondents suggested that citizens not only do not understand the process, but don’t know who their legislators are. One legislator stated many people address him as “Congressman” rather than “Representative.”

Lack of experience was directly related to personal/self interest in participating. In other words, respondents suggested that experience was gained through interaction with the legislative process, and that the desire to interact is based upon personal issues and interests. One respondent summed it up as:

… at the end of the day if you want people in your local community to walk into the barber shop and get in the face of an elected official about something or show up at a local town meeting and stand up and ask a question about something, it better be something they care about.

Complexity of Health Policy (COMP)

A second theme that emerged in the study as a perception about why citizens do not participate in health policy agenda-setting was that of the “complexity” of health policy (COMP). This theme was cited as a reason for low citizen participation in six of the thirteen interviews. Four of the six (66%) respondents who discussed this theme indicated that health policy and the policy process is a “complicated subject” that most citizens “don’t understand.” This was the most frequently noted subcategory within this theme. Three of the six suggested that the complexity “made it easy for citizens to get frustrated and/or discouraged with the policy process.” Likewise, three of the six participants specifically addressed the complexity of health care insurance and funding
(Refer to Table 4.5). Figure 4.3 provides a comparison across cases of perceptions regarding the effect of the complexity of health policy on citizen participation.

Table 4.5 Frequency of Responses Related to the Theme: Complexity of Health Policy (COMP)

<table>
<thead>
<tr>
<th>Subcategories of COMP</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complicate subject/don’t understand it</td>
<td>4</td>
</tr>
<tr>
<td>Slow and difficult process</td>
<td>1</td>
</tr>
<tr>
<td>Easy to get frustrated, discouraged, or overwhelmed</td>
<td>3</td>
</tr>
<tr>
<td>Policies, funding, insurance is complicated</td>
<td>3</td>
</tr>
</tbody>
</table>

![Figure 4.3 Comparison of Legislators’ and Health Policy Advocates’ Responses Regarding the Complexity of Health Policy (COMP)](image)

One respondent suggested that there is a legislative motive to make health care policy complicated:

Health policy is exceedingly complicated, just like every policy, whether it’s at the state or federal level. I would also argue that it is intentionally made as complicated as possible by legislators to reduce the amount of citizen input they get.
One respondent talked specifically about the complexity of the Affordable Care Act.

...health care is so complicated...the Affordable Care Act, because it’s an overwhelming aspect of our health policy...Yeah, so I think it’s a really complicated subject, and I don’t think, I don’t understand it all and I’ve followed it, lobbied to get the federal bill passed and I still don’t understand the fraction of it”

Methods of Citizen Participation

The study findings also revealed respondents’ perceptions regarding methods of citizen participation. All respondents discussed various methods of participation. In the thematic analysis of the interviews, three major themes around methods of participation emerged (Refer to Figure 4.4). The three major themes were voting (VOTC), involvement in groups (GRPS), and communicating, and having relationships, with legislators (CORE). Over half (7 of 13) of the respondents suggested voting as the most basic way that citizens can participate in the political process; six respondents talked about groups as a means of citizen participation; and eight cited communication and relationships with legislators as a vital component of the participation process.

![Figure 4.4 Methods of Citizen Participation](image-url)
Voting by Citizens (VOTC)

Many of the respondents agreed that it is the responsibility of society to make sure that people “have access to voice their opinion,” but that it’s the responsibility of the individual to exercise that right. However, the perception of many of the respondents was that citizens do not exercise their voting rights. They spoke of a number of topics relevant to citizen voting including: “sacrifices” made to earn the right to vote, citizens who are not registered to vote and/or have never voted, citizens who don’t think it “makes a difference” so they “don’t vote,” Election Day voting, and some discussed majority/minority voting. The frequency of notation of these subcategories is illustrated in Table 4.6, followed by the distribution of the two most frequently noted responses (don’t think it makes a difference/don’t vote, and vote on Election Day) according to case type (Figure 4.5).

Table 4.6 Frequency of Responses Related to the Theme: Voting by Citizens (VOTC)

<table>
<thead>
<tr>
<th>Subcategories of VOTC</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise the right to vote/sacrifices made to earn the right</td>
<td>2</td>
</tr>
<tr>
<td>Not registered to vote/have never voted</td>
<td>1</td>
</tr>
<tr>
<td>Don’t think it makes a difference/don’t vote</td>
<td>3</td>
</tr>
<tr>
<td>Vote on Election Day</td>
<td>3</td>
</tr>
<tr>
<td>Majority/minority voting</td>
<td>2</td>
</tr>
</tbody>
</table>
Of the seven respondents who discussed voting by citizens, three focused on the premise that citizens don’t vote because they “don’t feel it makes a difference.” One study participant stated that “people don’t realize how powerful their voice is, how powerful their one vote is” and as such, “many, many, eligible people don’t even vote.” Another said:

I’m much more concerned when we say to people ‘would you like to register to vote?’ and they go, ‘no, I don’t think it makes any difference,’” than I am when you say, ‘They’re going to make a decision about your health care, would you like to weigh in?’ Those people will say, ‘Oh, sure.’ . . . It’s one thing to say they don’t feel like their voice makes a difference, it’s another to say they don’t feel like their vote makes a difference.

Two respondents specifically addressed the issue of voting behaviors of marginalized populations and the underlying theme of majority/minority voting. One of them shared this:

We believe here that the health of a community is really, it’s almost a straight line – so, healthy communities vote, the least engaged voter turnout is in communities that have the worst health outcomes . . . so
it’s people who really feel like no matter what they do, it doesn’t matter. . . . you know what’s the discussion after the last national election, uh, well, if Republicans don’t pay attention to what the majority of Americans, just about are, certainly will be, which is non-white, um, then what’s going to happen? And the Republican answer, historically, has been, that might be the majority of citizens, that’s not even close to the majority of voting citizens.

One respondent alleged that “a lot of people will say they’re registered” and they’re not, and they’re “ashamed” of it. This respondent also noted that citizens are “too embarrassed to say something” about not understanding the process of voting. He discussed his experience of observing a “first time voter” at the polls for this year’s presidential election. After the voter turned in his ballot, “the person that did it for him said ‘another first time voter’ and everybody clapped.” The respondent advocated “it’d be nice if we could figure out a way to clap for people before they get there, so they feel more comfortable.”

Social and Advocacy Groups for Citizens (GRPS)

Six of the thirteen respondents (46%) referred to involvement with social or advocacy groups as a method of citizen participation. Groups were said to have beneficial value for citizens wanting to get involved in health policy issues. Three of the six respondents gave more than one value for the benefit of the group variable. The two largest beneficial values of involvement with groups were its potential “collective power” (cited by 4 of the 6 participants) and the opportunity provided to “network with other groups and organizations” (cited by 3 of the 6 participants). Two other subcategory values of the group variable were that involvement in groups “keeps citizens informed” and it offers “support – so that citizens don’t get frustrated” (with the policy process).
Table 4.7 depicts these frequencies. Figure 4.6 illustrates perceptions of the two most frequently cited subcategories of this theme across cases.

Table 4.7 Frequency of Responses Related to the Theme: Social and Advocacy Groups for Citizens (GRPS)

<table>
<thead>
<tr>
<th>Subcategories of GRPS</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collective Power</td>
<td>4</td>
</tr>
<tr>
<td>Support – so citizens won’t get frustrated</td>
<td>1</td>
</tr>
<tr>
<td>Keep citizens informed</td>
<td>1</td>
</tr>
<tr>
<td>Networking with other groups and organizations</td>
<td>3</td>
</tr>
</tbody>
</table>

Figure 4.6 Comparison of Legislators’ and Health Policy Advocates’ Responses Regarding Social and Advocacy Groups for Citizens (GRPS)

Some of the comments relating to the benefit of participation through groups included:

. . . It helps them know how to plug in . . . and I do think that, um, they need to probably try not to go it alone, they need to like band together with other smaller groups that are similar thinking . . . and so, instead of having a lot of small people do things kind of poorly . . . we can use our time better if we’re coordinating our work with others

. . . You can’t do it on your own either – you’ve got to get engaged with a group. So I think, hooking people up with groups . . . That’s why you need a group. The group really provides a support system for the individuals in the group so they won’t get discouraged.
Communication and Relationships (CORE)

The third mostly frequently mentioned method of citizen participation in health policy deliberation was communication and relationships between citizens and legislators. During the interviews six of the thirteen respondents gave this issue as being significant to citizen participation. Five subthemes of this topic were revealed in the interviews: 1) relationships are important so that legislators “will listen”; 2) the importance of citizens to “reach out” and “engage” their representatives; 3) legislators’ efforts to communicate with constituents; 4) legislators’ relationships with advocates, lobbyists, and local representatives; and 5) communication being “ongoing” and requiring “follow-up.” Several of the respondents cited more than one of these values as being beneficial to the influencing of policy agenda-setting and decision-making. Table 4.8 shows the frequency of the subcategories related to the theme of communication and relationships.

<table>
<thead>
<tr>
<th>Subcategories of CORE</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships are important so legislators will listen</td>
<td>1</td>
</tr>
<tr>
<td>Importance of citizens to reach out and engage their representatives</td>
<td>4</td>
</tr>
<tr>
<td>Legislators’ efforts to communicate with constituents</td>
<td>2</td>
</tr>
<tr>
<td>Legislators’ relationship with advocates, lobbyists, and local representatives</td>
<td>5</td>
</tr>
<tr>
<td>Ongoing/requires follow-up</td>
<td>2</td>
</tr>
</tbody>
</table>
Figure 4.7 illustrates the perceptions of both case types regarding the two most frequently recorded subcategories: importance of citizens to reach out and engage their representatives, and legislators’ relationship with advocates, lobbyists, and local representatives.

![Figure 4.7 Comparison of Legislators’ and Health Policy Advocates’ Responses Regarding Communication and Relationships (CORE)](image)

The importance of citizens’ efforts to reach out to their representatives was acknowledged as beneficial (in the policy process) in 4 (of the eight) responses. Whereas the responses relating to communication and relationships addressed the role of citizens in engaging their representatives, only two suggested that legislators should make effort to engage and communicate with their constituents. However, when specifically asked about “effective methods of citizen engagement,” both case types (legislators and organization executives) shared their perceptions and experiences of educational and engagement methods, as well as offered strategies that might be the most effective at encouraging citizen participation in health policy.
Education and Engagement Efforts (EDEN)

There were a total of nine subcategories assigned to the theme of education and engagement efforts. The three most frequently cited ways to educate citizens on health issues and to engage citizens in policy deliberation were through: 1) the media, 2) publications and newsletters, and 3) formal education and classes. Six other measures to educate and engage citizens were cited with less frequency (Refer to Table 4.9).

Table 4.9 Frequency of Responses Related to the Theme:
Education and Engagement Efforts (EDEN)

<table>
<thead>
<tr>
<th>Subcategories of EDEN</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social and mainstream media</td>
<td>6</td>
</tr>
<tr>
<td>Indoctrinating/inculcating youth</td>
<td>2</td>
</tr>
<tr>
<td>Formal education/classes</td>
<td>4</td>
</tr>
<tr>
<td>Publications/newsletters</td>
<td>4</td>
</tr>
<tr>
<td>Rallies/forums</td>
<td>2</td>
</tr>
<tr>
<td>Town Hall/public meetings</td>
<td>2</td>
</tr>
<tr>
<td>Voter engagement and registration</td>
<td>1</td>
</tr>
<tr>
<td>Social groups</td>
<td>3</td>
</tr>
<tr>
<td>Identify interests/provide information</td>
<td>3</td>
</tr>
</tbody>
</table>

Health advocates were more likely than legislators (5:1) to discuss the use of social and mainstream media to educate and engage citizens. They were also more likely to talk about classes and seminars that educate citizens about the process, including telling them “why it makes any difference that you write a letter or make a phone call,”
“showing them how to do it,” and then providing “feedback” on the difference it did or make. Figure 4.8 provides a comparison of perceptions regarding educating and engaging citizens.

Figure 4.8 Comparison of Legislators’ and Health Policy Advocates’ Responses Regarding Education and Engagement Efforts (EDEN)

One director of a health care organization suggested that an educational YouTube video would be a “neat thing to do” so that people “wouldn’t feel so afraid of” voting.

Some of the other responses from health policy advocates follow:

The media is starting to get there, but the General Assembly members, they don’t really, they kind of understand . . . but I don’t think they understand the magnitude. And so, I think that we need better education pieces to get the general public more knowledgeable . . . and that way when they’re educated, they can be demanding certain kinds of coverage in their health insurance, or they can be demanding of legislators for policy initiatives
I think one part of all of our work . . . whether it’s in health care or otherwise, is to give people a stronger voice and so whether that’s, you know, having, giving people a forum where they can talk, or providing them with information, so they can call their legislator and go “I know what’s going on” or “and here’s what I think should happen” or telling people’s stories and getting them in the mainstream media - which is what our whole video stories project is about . . . we’re gleefully distributing, with one of our partners, consumer union reports magazines, has this great, about 15-page little magazine that’s called Health Reform: Seven Things You Need to Know Now. You can read that and know the basics of what you need to know.

One respondent even suggested that there is an “hierarchy of methods that work” for citizen engagement (Figure 4.9):

So, just like with communicating or advocating with elected officials, there’s kind of a hierarchy of methods that work, and quite honestly, you have to be able and willing to use all, or as many of them as you can, so you want to start with the best, which is some sort of one-on-one or small group communication to people on why they should care, then you want to be able to go up to some sort of communication, some sort of broader communication, either in larger groups, at community forums, or at you know staff meetings, things like that, then you know, by mail or email, those kinds of things I think.

![Hierarchy of Methods of Engagement Effectiveness](image)

Figure 4.9 Hierarchy of Methods of Engagement Effectiveness – From Most Effective to Least Effective

Legislators talked more about publications and newsletters, and formal education (in high school courses) as a means of educating and engaging citizens. They were also more likely to discuss conventional methods of engagement and participation such as
town halls and public meetings. The following is an example of one legislator’s perception that a variety of methods could be effective:

And I guess the way to transmit that information is through publications, summary publications, or websites or social media. I think I just got a pamphlet in the mail from one of the advocacy groups entitled *Health Reform: Seven Things You Need to Know*. . . I think that rallies and forums are always good ways to get folks informed and energized. I think rallies are always the most effective. But in the absence of the opportunity to have these rallies, I think webinars, just newsletters, websites, like I mentioned before, social media campaigns, I think seem to be effective. . .

**Influences in Health Policy Decision-making (INFL)**

The final findings of this study focused on factors that influence the health policy decision-making process. Respondents were asked to share their perceptions of the impact that citizen input (when obtained) has on the health care policy-making process. Even when citizens have been engaged and participated in health policy deliberation, citizen input was said to not have much influence on agenda-setting and decision-making. There are many other factors that respondents stated as being more influential in the decision-making process.

Study participants identified the four major influencers of health policy decision-making as: 1) money/profit; 2) groups - such as advocacy/special interest, lobbyist, task forces, committees, stakeholder groups, etc.; 3) big industry/corporations; and 4) power (listed as the top four most frequently discussed influences in Table 4.10). All of the respondents mentioned at least one of the four as influencing health policy decisions. Several of the respondents suggested an interdependent relationship between the four; with particular pattern occurring between the relationship between money and power. In addition, the subtheme of “other experts” (such as physicians, lawyers, etc.) emerged as
having influence on policy decisions. Three of the thirteen respondents discussed the positive impacts of personal stories and testimonies on legislative decision-making.

Table 4.10 Frequency of Responses Related to the Theme:
Influences in Health Policy Decision-making (INFL)

<table>
<thead>
<tr>
<th>Subcategories of INFL</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Money/Profit</td>
<td>8</td>
</tr>
<tr>
<td>Power</td>
<td>6</td>
</tr>
<tr>
<td>Big Industry/Corporations</td>
<td>7</td>
</tr>
<tr>
<td>Advocacy/Special Interest Groups, Lobbyists, Task Forces/Committees, etc.</td>
<td>8</td>
</tr>
<tr>
<td>Other experts</td>
<td>5</td>
</tr>
<tr>
<td>Time</td>
<td>2</td>
</tr>
<tr>
<td>Personal stories and testimonies</td>
<td>3</td>
</tr>
<tr>
<td>Media</td>
<td>1</td>
</tr>
<tr>
<td>Relationships</td>
<td>2</td>
</tr>
</tbody>
</table>

Figure 4.10 shows the comparison of perceptions (across cases) of the five most frequently noted subcategories of influences on health policy decisions. Some of the textual support of these findings is cited after the table.
Figure 4.10 Comparison of Legislators’ and Health Policy Advocates Responses Regarding Influences in Health Policy Decision-making (INFL)

Comments from Legislators:

Well with state, I think that um, at the state level, I think that there are some industries and some trade associations that have an enormous amount of influence over policy. And it’s hard to counteract that. Those groups make a lot of campaign contributions and they are now funding a lot of these super PACS and it was always hard to get anything past legislature that Blue Cross Blue Shield didn’t want to happen.

The direction of health care delivery in this country, it’s gone so far in the direction of those who make the money decisions are making the decisions about health care. . . .I think hospitals are the most driven, profit-oriented groups . . . it bothers me greatly as a professional man who devoted my whole training to learning how to be a health care provider the decisions about how health care is being delivered is being made by businessmen, lawyers, and accountants – people who have not trained in delivering health care and consequently the driving force is, has more of a profit motive than it does what is in the best interest of the patient.

Two years ago, I introduced that bill. The push-back was incredible – Really incredible. Big pharmacy told me I was meddling. . . so, the Speaker of the House created a House Select Committee and made me the chairman and I took testimony for 6, 7 months . . . the committee last week made 5 recommendations to the General Assembly. . . Sounds to me like there is a very simple solution, but . . . how would you like to be running a billion dollar a year business . . . and be faced with losing 70% of it because it’s going to the bad guys?
I think some of the answers to, I think, some of the answers to health care policy is the deinstitutionalization of health care. I think that’s caused us, costing us a lot of money. I think that any time you have a monopoly, you have, inherently in monopolies, is corruption – corruption is inherent, bureaucracy is inherent, the fact that we have, to a great extent, destroyed the GP, the general practitioner, and the whole concept, the GP is now, these days virtually forced to work for a hospital. The hospitals are big business. Insurance companies are big business.

Where we’ve gone wrong in the broadest view is that we’ve got the fewest number of people making the most number of decisions. Any time you have money involved you have a lot of people who don’t care what recommendations are. A lobbyist is hired by an organization to do a job. That job is to do everything they can to benefit the bottom line of that agency. That’s their job. They have no other choice. That’s what their assignment is and that’s what they do. Everything has to do with...it doesn’t have to do with moral rights, what’s best for the patient, or what’s best in the future...it’s short term bottom line.

We had a long process...on what kind of health care benefit exchange we should have in North Carolina and we reached a consensus and a report was written and then it came time to introduce a bill and Blue Cross Blue Shield went to another legislator and wrote their own bill. And that’s the one that passed. And the reason they (BCBS) has a lot of power is because they give a lot of money in campaign contributions. Ninety-five percent of insurance is written by BCBS in the state of North Carolina. It’s either 92 or 95 percent. So, what BCBS wants or doesn’t want, they get...Pharmaceutical companies are untouchable...they’re very powerful. The Medical Society is another one.

Comments from Health Policy Advocates:

We think obviously politics has something to do with how people choose to fund things or not fund things...there’s so much money involved with health care decisions...the dollars are so huge.

Schools are so strapped for money that taking the issue in from one side makes sense to a lot of people, but then there’s just, it’s very hard to put in place, and it’s hard to pass a law that requires it (health policy and programs), because financially, especially in rural North Carolina where the monies are really, really small, because the tax base is so small, and that’s honestly where we need it the most, is in the lower-income parts of any community...our society has got to figure out that that’s the place we need to put our money because, we are paying for it somewhere.
We have these committees, and the expertise on the committees, they kind of come together, they throw out all the ideas of the legislative initiatives or priorities that we could proactively go after, or the danger signs – like what do we need to defend sort of a thing, and we go through them all and we eventually decide – ‘ok, we’re going to focus on these two things.’ And we look at our resources, we look at how much staff we have, we look at what the other members can do, and how many of them might have a presence with a lobbyist of the General Assembly, or they might have many from media, or they might have a real riled up grassroots group that wants to communicate.

I’ve also seen the, a public hearing, like say a year ago, a year and a half ago now, where we had, where the only public hearing on, in this case, was the Health Exchange Bill, was dominated by small business people and individuals who were opposed to this bill and the bill passed as is overwhelmingly because of special interest support from the insurance industry.

People just think that you know, um, reasonable decisions are made when policy-makers are voting – they don’t realize how much it is, the system is, is influenced by money, and corporations, and industry

And it just seems like in the final analysis, it’s those important interest groups that are making the decisions on what the final piece of legislation is going to look like

In general, health policy advocates held more positive perceptions about the influence of citizen input. However, both advocates and legislators, referred to members of various groups as citizens, and thus suggested that citizen input is obtained when groups are involved through consultation and negotiation. One health policy advocate offered the following with regard to the impact of citizen input on the health care decision-making process:

I think it depends on the kind of input, again, sort of the hierarchy of effectiveness, if it’s face-to-face, one-on-ones, visits to the health centers, um, you know, um personal phone calls, personal letters, have a tremendous amount of impact. Um, the other kind of input, granted we use, are like emails, mass phone calls, you know, petitions, those kinds of things, the impact, the only impact those things have is to leverage the other work that’s already done.
Whereas the impact of relationships on policy decisions was recorded in only two of the responses, legislators’ relationships with advocates, lobbyists, and local representatives was cited most frequently in the theme of communication and relationships (CORE). These relationships were listed as “important” to the policy-making process.

Voting by Legislators (VOTL)

Discussion of dynamics that influence health policy decisions also illustrated respondents’ perceptions of ways on which legislators vote (VOTL). Legislators were proposed to vote on policy initiatives based on five factors: 1) their conscience, 2) the wants of their constituents, 3) the evidence, 4) their caucus, and 5) as a combination of more than one factor. Nearly one quarter (3 of 13 or 23%) discussed voting by legislators as being based on their conscience. Frequencies of the subcategories are illustrated in Table 4.11, followed by a depiction of perceptions of the ways in which legislators vote on policy across cases in Figure 4.11.

Table 4.11 Frequency of Responses Related to the Theme: Voting by Legislators (VOTL)

<table>
<thead>
<tr>
<th>Subcategories of VOTL</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vote their conscience</td>
<td>3</td>
</tr>
<tr>
<td>Vote based on constituents’ wants</td>
<td>2</td>
</tr>
<tr>
<td>Vote based on science/evidence</td>
<td>2</td>
</tr>
<tr>
<td>Vote their Caucus</td>
<td>1</td>
</tr>
<tr>
<td>Vote based on more than one factor</td>
<td>1</td>
</tr>
</tbody>
</table>
Legislators were more likely to suggest that they were elected to vote their conscience, although most did acknowledge that knowing what their constituents wanted was important, as well as having some factual information to help in the process of decision-making:

I’m elected to exercise my best judgment . . . you voted for me to exercise judgment, you felt that in the big picture, that I could exercise a judgment that you would find acceptable by and large. I have to have enough integrity to do, regardless of how much money somebody is trying to get me to take to advocate for their position, I have to have enough integrity to do what I think is the right thing while I’m in office – and that’s to formulate an opinion based on all the facts and figures I can put my hands on to do the right thing for the majority of the people – without trampling on the rights of the minority – but at the same time majority should prevail. That’s just the way our system should work.

One respondent summed it up as such:

I’m elected to exercise my best judgment. Now, I give every consideration to the views of my constituency, but I am elected to exercise my best judgment, and if I sacrifice that judgment to the will of the majority, I betray those that elected me. . . how many people call me and say,
“I voted for you and therefore you are obligated to…” No, I’m not. No, you voted for me to exercise judgment. You felt that in the big picture, that I could exercise a judgment that you would find acceptable by and large. That’s my job and that’s the job that I’m going to try to do. But I cannot forget that this is a representative government . . . and I say to people all the time, “here’s how you make a decision – you vote your conscience, you vote your constituency second, you vote your caucus third – don’t get pressured by your caucus.

Health policy advocates were more likely to discuss legislative voting as being based on a combination of factors, with frequent reports of scientific evidence being influential. For instance, one advocated stated:

We work with, probably the more social justice kind of legislators, who do vote on just the benefit of science and the issues . . . no legislator is really going to vote for something until they see it happening in more than one place, and especially in a place that doesn’t have a huge amount of resources . . . and if it works [there], then it can work

Conclusion

The findings of this study reveal that it is the perception of this interconnected system of legislators and health policy advocates that two factors shape whether a citizen becomes involved in health policy decisions: self-interest and information. In other words, citizens participate when they have an interest in the topic being deliberated, and when they have the information necessary to participate in the decision-making process. A correlated finding was the perception of whose responsibility it is to inform citizens about health policy issues so that they can determine their level of interest and participation. Based upon these perceptions, a pattern of engagement attitudes and behaviors was revealed. Legislators expressed the attitude that it is the responsibility of citizens to take an active role by “reaching out” to them and asking for information and/or sharing their input. Health policy advocates perceived it being part of their role to engage citizens in the policy process by “showing them how” to communicate with their
representatives and “bringing their stories” to the attention of the legislators. Both case
types – legislators and health policy advocates – shared the perception that one of the best
methods of participation for citizens was involvement with an existing group.

Groups were cited to offer the benefits of support, information, networking, and
most frequently, collective power, to citizens. Legislators and advocates alike perceived
citizen participation to have the largest impact on health policy decisions when citizens
are “well-informed and well-organized, and there are enough of them.” Another
frequently cited perception was that “citizens putting a face on the issue” with personal
phone calls, letters, and stories that are “heartfelt,” and again, “when there is enough of
them,” can have a “tremendous” impact. However, the study further illustrates the
perception of both case types that the two largest influencers in health policy decision-
making are 1) money and profit, and 2) the influence of groups, such as special interest
groups and lobbyists, committees and task force groups, advocacy groups, and
stakeholder groups (discussed most frequently). The groups were proposed to have two
influential characteristics that impacted decision-making: money (that gave them
“power”) and evidence-based information (that swayed legislative votes).

The most appealing finding of this study was the view that those citizens who
participate in health policy decisions through group (advocacy groups, committees,
commissions, special interest, etc.) involvement represent the public’s voice. First, both
legislators and health policy advocates proclaim that those most influential in the health
policy process – legislators, advocate groups and lobbyists, big industry such as the
pharmaceutical and insurance companies, etc. – are all citizens of the state of North
Carolina. In every interview, participants discussed all “people” in the process as
“citizens.” Second, the relationship between legislators and advocates and lobbyists was noted as the most frequent subcategory of the theme: communication and relationships. Findings indicated that the perception from both case types was that legislators were more likely to be engaged in relationships with advocates and lobbyists, and that those groups were considered representative of citizen participation.

According to Tenbensel (2002), these groups are mediating bodies that must “digest” complex information and “use judgment” to arrive at “group rationality” (p. 185). These groups are responsible for engaging the public, collecting information, and presenting it (in its digested form) to policy-makers. The complexity of health policy issues makes it conducive to the use of mediating bodies whose composition is “dominated” by experts in the field of health policy (p. 187). The overriding perception of participants in this study was that this form of opaque transparency is a legitimate form of citizen participation in health policy decisions.
CHAPTER V
SUMMARY, CONCLUSION, AND IMPLICATIONS

Classical democratic theory asserts that widespread, active participation is a requirement for a stable, effectively functioning democracy. Good policy processes rely on gathering clear information from the public about what it wants and then converting it into clear policy priorities. Habermas (1976) proposed the importance of communicative action in public policy decision-making. Tenbensel (2002) further affirms that due to the high visibility of health care issues on the public agenda, “any policy formulation contributing to the setting of health priorities requires the involvement of the public” and neglecting to do so “would be cause for scrutiny” (p. 173). Health policymakers that follow a priority-setting agenda have realized that public support will be easier to achieve if the public is involved in the process.

Restatement of the Problem

The passage of the Patient Protection and Affordable Care Act by President Obama has placed the issue of health policy at the top of many states’ political agendas. In the area of health care policy, insurance companies and medical interest groups have become the “democratic elite” in the development of health policy. As a measure of good practice, citizens most directly affected by health care policy, should be involved in the health care agenda-setting process. However, social and economic factors such as “the nature and history of existing institutions, the general climate of opinion, ritualized
methods of dealing with social conflict, attitudes and behavioral characteristics of key political actors, and the general goals and values of a society” have influenced and shaped health care policy in the United States (Kronenfeld, p. 49).

**Restatement of the Research Issue**

The Affordable Care Act, as it is commonly referred to, provides all fifty states with the option of expanding coverage under the auspices of Medicaid. Each state will also offer a state-based health insurance marketplace, known as an exchange, where citizens can make online comparisons of all available policies and premiums. States may choose to build their own online marketplace or let the federal government run their exchange. The state of North Carolina has opted to not expand Medicaid coverage and to utilize the federal exchange. The Governor, in his announcement to the press, stated “If it becomes clear that the current course of action is not in the best interest of North Carolina, our health care system, and our citizens, we will work with the General Assembly to pursue other options in the future.” He further states that “we have done a thorough review of the advantages and disadvantages . . . this review included discussions with our governors, the White House, health care providers, and N.C. legislative leaders” (state of North Carolina). However, the issue remains that, according to the governor’s statement, the citizens most affected by this decision, have not participated in the decision-making process.

**Summary**

A case study approach was used to facilitate an in-depth exploration of legislators’ and health policy advocates’ perceptions and meanings of citizen participation in the process of health care policy agenda-setting and deliberation. The
case was the interconnected “system” of legislators and health policy advocates “characterized by behavior patterns” and attitudes (Stake, 2000, p. 436). Perceptions, the ways by which a person views an object, issue, idea, or another person, are guided by, and congruent with, an individual’s attitudes. Attitude and perception are influenced by experience, and impact behavior. The intent of this study was to explore how attitudes and perceptions influence the process of citizen participation in health policy agenda-setting.

The instrumental case study design was used to make naturalistic generalizations about what was learned regarding the perceptions of citizen participation in health policy agenda-setting across cases (legislators and policy advocates), and how these perceptions affect citizen engagement and participation. Instrumental case studies aim to portray particularity, not necessarily generalizability. The advantage of the use of the instrumental case study design is that critical issues are likely to be known in advance. Drawing from the review of the literature, common thematic units were already established (a priori themes) about the perceptions of government officials and health organization administrators regarding citizen participation in health policy agenda-setting.

Findings from the literature review were used to guide the inquiry of this qualitative research project. Cases – members of the North Carolina General Assembly and Executive Directors of health care policy advocacy organizations in North Carolina – were interviewed to identify common themes regarding citizen participation in healthcare policy decision-making and agenda-setting. A total of thirteen (13) interviews were completed: five (5) were in-person and eight (8) were telephone interviews.
Nearly half of the sample (6 of the 13) had between ten and twenty years of experience in the arena of health policy. Another 38.5% (5 of the 13) had between five and ten years of experience in influencing health policy. One participant had more than twenty years, and one had less than five years. Although this respondent had the least amount of time served, he provided a wealth of perception of issues and social relationships that contribute to the influence of policy agenda-setting and decision-making.

Review of the Central Themes and Findings

The common themes found in the review of the literature - of studies across nations - suggest that the political structure of the nation places less emphasis on the process of citizen participation than do the government officials’ and other health representatives’ attitudes and perceptions about citizen input. The most common themes found in the literature related to:

1) information provided to citizens (about the opportunities to participate and about the issues being deliberated),

2) methods of engagement and participation, and

3) citizen input (whether it affects policy decisions and the ambivalence of policy-makers to seek, and use, it).

Interview questions were developed from the constant themes found in the literature review.

Several central themes emerged from the interviews. The first is the perception that citizens get involved when two factors are present: information and interest. Two
themes in the study refer to the influence of these two factors on participation: Lack of interest, knowledge, and experience (LIKE) and the complexity of health policy (COMP).

Second, legislators and policy advocates shared the same attitudes and perceptions regarding each participant’s role(s) in the process. Citizens are perceived to take on the role of active participant by “reaching out” to their legislators and “becoming engaged” with advocacy groups. Health policy advocacy organizations are perceived to fulfill the role of engaging and educating (both citizens and legislators). Advocates were perceived to get information out to citizens – through various methods (theme: EDEN) – and to legislators so that they could use their “judgment” to vote “based on evidence” (theme: VOTL) and other factors (sharing of stories and facts from citizen input). Advocates were also perceived to be instrumental in educating and organizing citizens around an issue.

Third, the theme of relationships was central to this study. Attitudes about relationships indicated that different relationships exist, just as the different roles. The shared perception by both case types was the importance of the relationship between legislator and health policy advocate. The second perception regarding relationships was that citizens should develop relationships with their policy-makers, but that it is easier to do through group involvement. Groups were said to offer collective power (in voicing constituents’ wants and “demands”) and support (“so that citizens won’t get frustrated” with the process).

Finally, is the perception of both legislators and health policy advocates that policy-makers and influencers (members of special interest groups, etc.) are citizens of
North Carolina and therefore, provide citizen input into deliberation and decision-making. One respondent said, “Everybody at my table is a citizen [of North Carolina].”

Limitations and Continuing Problems

While this qualitative study produced a wealth of data rich in content, there are limitations within the design of the study that must be considered before drawing conclusions. As with many studies with small sample sizes, caution should be taken in generalizing the findings beyond the study sample. This study’s sample was not systematically drawn, but rather, sampled on the basis of availability and willingness to participate. Legislators were purposefully selected, based on specific criteria, as the survey population for the sampling pool. Likewise, health policy advocates were referred by legislators, and included in the sample based on willingness to participate. The small sample size affects the researcher’s ability to generalize the findings to the entire population of North Carolina General Assembly members and health policy advocacy organizations. However, the rich data and grounded thematic units that emerged (from an equally divided sample) did permit conclusions to be drawn about the distinguishing beliefs and attitudes of health policy-makers and influencers that shape the citizen engagement and participation process in North Carolina.

The sample was fairly evenly composed of legislators (6) and health policy advocates (7), as well as fairly equally comprised of both sexes – both across and within cases (depicted in Figure 4.1 on page 65). However, another limitation of the study was the lack of racial diversity within the study sample. Although the sample pool included North Carolina General Assembly legislators of diverse races, only one race was represented in the study’s sample – across both case types. Given the impact of
experience on perceptions and attitudes, the lack of diversity may have limited, or skewed, findings of perceptions and attitudes as well.

A continuing problem in North Carolina health policy making practices is the paradox of the decision-making process. In one of the interviews, one respondent claimed, “we’re a southern state; we don’t want the federal government telling us how to run our state.” However, the Governor has announced that the state will utilize a federal exchange in compliance with the Affordable Care Act requirements. He also stated in his announcement that he had consulted with health care providers and North Carolina legislative leaders in making this decision. It is true that both North Carolina health care providers and legislative leaders are indeed citizens of the state. However, as it is conceivably likely that few of them have the need to purchase health insurance coverage through the exchange, the issue remains, that the citizens most affected by this decision, according to his statement, have not participated in the decision-making process.

Conclusion

This study has explored the perceptions and attitudes of political actors (in the state of North Carolina) and their behavioral impacts on citizen engagement and participation in health policy agenda-setting and decision-making. One of the most common themes found in previous studies – across nations, as well as in this study, was the perception that citizens do not participate in health policy agenda-setting because of lack of interest, knowledge, or experience (LIKE theme). In this study, North Carolina legislators and health policy advocates most frequently stated that citizens have a lack of knowledge about what is happening with health care policy. Furthermore, if they are
interested in participation, citizens do not understand how the legislative process works and/or have no experience in involvement with their legislators.

This study has shown how the attitudes and behaviors of policy-makers (legislators) and policy influencers (health policy advocacy organizations) in North Carolina contribute to information-sharing, citizen participation, and the use of citizen input in health policy decisions. The perceptions regarding citizen participation suggested that citizens must be interested and “willing” to take part. Accordingly, citizens who have an interest in participating in decisions that affect the health of themselves and their families should seek the available information and opportunities necessary to take an active role in the process. While findings indicate that, in particular, health policy advocacy organizations are using many methods to share information with, and gather input from, citizens; findings reveal citizen participation in health policy decisions is still limited.

Implications

Policy-makers, aware that public support in health agenda-setting is easier to achieve if citizens are involved, gather input from “expert” citizens (such as physicians, hospital and insurance representatives, health organizations, etc.) who have the knowledge and experience of participating in the health policy legislative process. Several implications can be discussed from the practice of “expert” citizen participation in health policy agenda-setting. First, the simple context of the theme lack of interest, knowledge, or experience provides a justification for the gathering of input from “experts” in health policy decisions. In other words, the complexity of health policy (another theme) allows for participation in decision deliberation by those with the
knowledge and experience in the health and legislative systems. While some of the existing literature confirms perceptions held by policy-makers, and citizens, about the ability of citizens to make informed decisions regarding health policy issues due to lack of “expertise,” this attitude cultivates a comfort level held by legislators and interest groups to engage in a closed loop citizen participation process.

Second, the attitude of study participants that “everybody [who participates in the process] is a citizen,” serves as a pretext to talk only to each other – as members of a system of privileged citizens (those with systematic access to resources and power). However, under the pretense of collective representation, citizens without access to the closed loop of participation can participate in health policy decision-making by “connecting with an existing group.” The health policy advocacy organizations in this study are one form of groups that act as influential mediating bodies, representing the voice of citizens with the North Carolina General Assembly. These organizations take on the role of locating information necessary to break down complex health policy issues. In doing so, they bring experts “to the table” and make judgments on the information gathered (It should be noted that study participants suggested that “lay” citizens with personal health-related and/or health policy-related experience can also be experts.). As the mediating bodies, health policy advocates bring the digested information and sometimes, the sharing of personal stories of experienced citizens, to meetings with legislators to deliver citizen input into the policy process. Other participants at legislative hearings include legislative committees, task forces, stakeholder groups, and representatives from “big industry” such as Blue Cross Blue Shield of North Carolina and the Medical Society – all of whom are “citizens” of North Carolina.
Finally, attitudes regarding roles and relationships influence a closed loop process of citizen participation. This study revealed perceptions about how citizens can have the most influence in the process. Legislators and advocates shared the same perception that the most common way for citizens to take action is to sign up to receive email alerts about pending issues and upcoming events. Many of the health policy advocacy organizations offer information and opportunities to become engaged on their websites. The websites of the organizations involved in this research offer information in the areas of: 1) their legislative agendas and policy priorities; 2) how to find and contact a legislator; 3) some form of news, announcements, and events; and 4) a “take action” tab (among others). Citizens can sign up to receive alerts and notices on the websites of advocacy organizations. Email alerts and notices provide opportunities to volunteer to be engaged in taking “action” to participate in the process of health policy agenda-setting.

Citizens may also sign up to receive email alerts about upcoming meetings on the General Assembly webpage. However, two issues are present that deter citizen participation. One, the General Assembly is not held to a public hearing notice requirement, and hearing agendas, as stated by one study participant, can change “at the drop of a hat,” contributing to the frustration of citizens (both in and out of the closed system) who wish to participate. Two, the North Carolina General Assembly website is less user-friendly than those of the advocacy organizations. Although a “citizen guide” tab exists, the information provided is general information about how the government operates. Additionally, the site is not as easy to navigate and find information regarding health policy as the sites of the advocacy organizations. The lack of ease in navigating the website concurs with the themes of complexity and lack of knowledge. A lack of
knowledge about what information to seek, and difficulty locating it, leads to frustration and a decrease in willingness to participate. One study participant referred to the complexity of the health policy process as “intentionally made as complicated as possible by legislators to reduce the amount of citizen input they get.”

The level of complexity of navigating the General Assembly website implies the role of health policy advocacy organizations in educating and engaging citizens about health policy. The websites of the health policy advocacy organizations facilitate information sharing with the inexperienced citizen. In comparison, the North Carolina General Assembly website is better-suited for more experienced users – those knowing what to look for and where to find it – those with experience with the legislative system, such as health policy advocates. While citizens are welcome to attend General Assembly meetings, their role is often that of an observant participant, sitting in the audience. Active participation frequently is extended by invitation from someone within the closed system, such as the health policy advocates, in an effort to put a face on the issue, as a means to support the evidence being offered by the advocate to the legislators. The complexity of navigating the General Assembly website creates a barrier to participation by uninformed and inexperienced citizens; while, the active relationship between health policy advocates and legislators illustrates a bias toward the participation of insiders and experts.

Implications for Future Research

As the implementation of The Affordable Care Act takes place, a number of future studies are implicated. The issue of political party conflict and attitudes about how to address the issue of uninsured Americans and affordable health care has often been at
the forefront of public policy. The Obama Administration has experienced more success in implementing health policy than its predecessors, but not without much party conflict and resistance. Given the recent action of the Congressional Republican Party to shut down the government in an attempt to refute “ObamaCare,” a study that investigates the success of the Obama Administration in passing the legislation, despite party differences and conflict, could not only provide lessons in public policy-making, but also offer insight into mediation and conflict resolution strategies.

As with any new policy (or program), outcome evaluation will be critical in measuring the success of the Affordable Care Act. Although the Affordable Care Act delivers the federal guidelines of the policy, each state is given some choice in implementation strategies. A comparison of states that chose to expand Medicaid with those that did not, would illustrate whether the Medicaid expansion did make a difference in the rates of uninsured in the states and whether having access (through Medicaid) to health care ultimately improved the health of those individuals. This has been one criticism with the Welfare Reform Act (The Personal Responsibility and Work Opportunity Act of 1996). The goal of welfare reform was increase self-sufficiency of individuals, while decreasing the number of recipients on the welfare rolls. While studies show that, at least initially, there was a drop in the number of recipients on welfare, the issue of whether they were self-sufficient was still a concern.

A statewide comparison could also demonstrate what measures states are taking in meeting the needs of their uninsured citizens, and in particular, what methods they are using to engage citizens in the process (as with the Oregon Medicaid study mentioned in chapter two). While this study has provided insight into the process of citizen
participation in health policy agenda-setting and decision-making in North Carolina, the question still remains of how to increase meaningful participation for citizens most affected by health policy decisions. While it is true that all members involved in the North Carolina health policy agenda-setting process are citizens of the state, they are also members of an elite group within a privileged system. If policy is to reflect the interests of the general public, membership in the policy-making body should be representative of the proportion of specific groups within the general population. In North Carolina, about 1.5 million citizens are uninsured, many of whom are poor blacks, single mothers, and low-wage workers. Over one-half of these citizens would have qualified for Medicaid under the expansion available through the Affordable Care Act. (Garloch and Murawski, 2013).

Policy decisions made based upon attitudes of the elite group skews the direction of public policy. The decision to not expand Medicaid to the low-income, uninsured population in North Carolina reflects the attitudes held by the elite group about common groups of citizens and entitlement. Garloch and Murawski (2013) cite two North Carolina House Representatives in their recent newspaper article, “Affordable care? Not for the poorest.” Both representatives are Vice Chairmen of the Health and Human Services House Standing Committee, and are not in support of the Medicaid expansion. One states that “so much of our state revenue has been eaten away by the Medicaid budget that I don’t think we need to expand an entitlement program;” while the other states, that the current Medicaid program needs to be fixed “before consideration can be made as to whether you add an additional 500,000 people to the system” (p. 4A).
North Carolina has opted to offer a health exchange (marketplace) in which citizens can compare health insurance coverage options and find a plan that matches their needs. However, the options provided on the marketplace are limited - Blue Cross Blue Shield (BCBS) dominates the North Carolina exchange. Not only does the dominating presence of BCBS health plans limit citizen choice, but it validates the powerful relationship BCBS has with the North Carolina General Assembly that was discussed in this study. Informational meetings are currently being scheduled to inform citizens of the opportunities to enroll in insurance plans and to learn about financial assistance eligibility. Advocacy and community organizations are taking an active role in assisting citizens in understanding and applying for coverage. A process evaluation should be undertaken to provide a clear and compelling picture of the targeted population and to provide data for improvement, including insight on the barriers to successful implementation. Process evaluation should elicit input from the citizens engaged in the process of signing up for health care coverage, as well as those assisting citizens (navigators and certified application counselors) in completing the process.

An additional implication for future research would be to test the model for overcoming barriers to authentic participation created by King, Feltey, & Susel (1998). The authors recommend a “three-pronged approach,” with an emphasis on educating citizens and “re-educating” public administrators. Many of this study’s participants discussed the need to educate citizens and legislators. One of the suggestions to improve knowledge in the area of health policy citizen participation provided by participants in this study was a change in the public school educational curriculum. Kolb and Fry (1975) assert that part of the learning process entails completing a particular action
(experiencing) and then seeing (reflecting) the effect of that action. The addition of a laboratory component to the current Civics and Economics course in high school would allocate extra time, as well as a favorable environment for experiential learning of citizen participation in a student’s policy area of interest. Future research is needed to explore the potential of implementing the change in the high school Civics and Economics curriculum. Further study could include exploration of the recommended strategies for re-educating public administrators offered in the model by King, Feltey, and Susel.

In the summer of 2010, the North Carolina General Assembly passed House Bill 1260 – an act to provide voter pre-registration to sixteen and seventeen year-olds, so that they are automatically registered to vote upon turning eighteen. As part of the legislation, the North Carolina Department of Instruction is required to “expand instruction on the importance of voting in high school social studies curriculum” (General Assembly of North Carolina, 2009, HB 1260). The passage of this legislation implies recognition of the importance of engaging young people in the democratic process. A study that surveyed the attitudes and perceptions of young people regarding participation in the policy process could provide insight and knowledge on how to increase interest and experience in the process. While not everyone will share the same policy interests, everyone should understand the public policy process and how to be involved in the process as a citizen. Insight on how to increase education and understanding of the policy process can provide lessons for increasing active citizen participation.
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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

[Image of approval letter]

August 15, 2012

Charlotta Harris
1201 Ninth Avenue
St. Petersburg, FL 33715

From: Sharon McWhorter, IRB Administrator

Re: IRB Number 0120603 "Citizen Participation In Health Care Policy Agenda Setting"

Thank you for submitting your Exemption Request for the referenced study. Your request was approved on August 14, 2012. The protocol represents minimal risk to subjects and matches the following federal category for exemption:

☐ Exemption 1 - Research conducted in established or commonly accepted educational settings, involving normal educational practices.

☐ Exemption 2 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior.

☐ Exemption 3 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior not exempt under category 2, but subjects are elected or appointed public officials or candidates for public office.

☐ Exemption 4 - Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens.

☐ Exemption 5 - Research and demonstration projects conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public programs or benefits.

☐ Exemption 6 - Taste and food quality evaluation and consumer acceptance studies.

Annual continuation applications are not required for exempt projects. If you make changes to the study’s design or procedures that increase the risk to subjects or include activities that do not fall within the approved exemption category, please contact me to discuss whether or not a new application must be submitted. Any such changes or modifications must be reviewed and approved by the IRB prior to implementation.

Please retain this letter for your files. This office will hold your exemption application for a period of three years from the approval date. If you wish to continue this protocol beyond this period, you will need to submit another Exemption Request. If the research is being conducted for a master’s thesis or doctoral dissertation, the student must file a copy of this letter with the thesis or dissertation.

Cc: Raymond Cox – Advisor
Cc: Stephanie Woods – IRB Chair

[Signature]

The University of North Carolina at Charlotte

Approved consent forms are attached.
APPENDIX B

PARTICIPANT LETTER

Department of Public Administration and Urban Studies
The University of Akron
The Polsky Building, #265
Akron, OH 44325-7904

IRB # 20120803

Dear __________________________

Senator or House Representative Name

I am writing to ask you to allow me to interview you as part of the requirements for my doctoral degree in Public Administration. You have been purposefully selected based on your membership in committees and sponsorship (and/or co-sponsorship) of bills relevant to my dissertation topic: “Citizen Participation in Health Care Policy Agenda-setting.”

I have been a resident of North Carolina for several years; moving here from Ohio after completing doctoral coursework at The University of Akron. I am now completing the last phase of the research to finish the dissertation.

The purpose of my study is to explore the meanings and experiences of government officials regarding citizen participation in health care policy decision-making and agenda-setting. Additionally, and more specifically, the study will examine the perceptions/opinions of government officials with regard to the use of citizens’ juries as a deliberation process in healthcare policy decision-making and agenda-setting. The interview will allow the student researcher to gather opinions from government officials that will be helpful in developing a model of citizen participation in the deliberation of health care policy priorities and decisions that could be used at the local and/or state level.

During the interview, I will ask you some questions, to which you can respond in your own words. With your permission, I will audiotape the interview so that I don’t miss any valuable information from you in an attempt to transcribe what you are saying. If you decline the use of a tape recorder to audiotape the interview, I will transcribe what you say into a password-protected Microsoft document on my laptop as you respond to the
questions. Whether transcription occurs during the interview, or after (from the audiotape), all responses will be transcribed onto numerically coded answer sheets. Audiotapes for this study will be kept in a locked file box and will only be accessible to me, the investigator.

The information you provide will be confidential. In other words, in no way will I identify you by name or disclose who answered what to any specific question. Your responses will be coded and analyzed for constant themes amongst other participants. Any grouping of findings will be according to experiences, perceptions, and themes, not according to membership in particular committees or parties, or districts represented, thereby limiting the potential to identify respondents. Results will be presented to my dissertation committee, and published in the dissertation, with no specific individual being identified by name.

I am also interested in observing Senate and House Standing Committee Meetings. Those of interest are the Senate State and Local Government meetings and the House Health and Human Services meetings on Tuesdays, the Senate Health Care meetings on Wednesdays, and the House Government meetings on Thursdays. If one of those days would be convenient for you, please respond to my email, hanndow@zips.uakron.edu, with a date and time. I have also included my phone number, for your convenience.

Thank you for your time. I look forward to hearing from you.

Sincerely,

Charlesia A. Hann
Principal Investigator
Doctoral Student
The University of Akron
Department of Public Administration & Urban Studies
Akron, Ohio 44325-7904
(704) 806 - 5844
APPENDIX C

INTERVIEW QUESTIONS

1. What information do you feel citizens need to be knowledgeable enough to participate in health care policy deliberation and decision-making/priority-setting?

2. What methods of citizen engagement do you think are effective at including citizens in health care policy deliberation?

3. When citizen input is obtained, how much do you think it impacts the health care decision-making process?

4. How frequently, and in what capacity, do you communicate with local representatives in your district(s)?

5. How much consideration do you think is given to localities and their constituents when making state-wide decisions about health care policy?

6. What mechanisms are currently in place to obtain local input into statewide health policy decisions?

7. What do you know about the use of citizens’ juries as a method of engagement in policy deliberation?

I am interested in developing a citizens’ jury model of policy deliberation. In this model, 12 citizens (known as jurors) would be brought together over a 4 – 5 day period with the aim of reaching a recommendation on a particular health care policy-related issue. The jury hears testimonies from witnesses (such as health advisors, nurse practitioners, general practitioners, etc.) and is then given time for deliberation as a group. After deliberation, the citizen jurors make recommendations regarding the particular health care policy-related issue. Two advantages of this jury process vs. that of a legal jury are 1) jurors do not need to reach a verdict, but rather, compile recommendations; and 2) there is no need for a majority rule, recommendations can be expressed in numbers – such as 10 of 12 jurors recommended …..

8. What are other advantages that you can see with this model?

9. What disadvantages do you think exist?
10. What recommendations can you make for overcoming these disadvantages?

11. What do you think it would take to implement such a process, in particular at the local level of government (as a special town/city council meeting)?

12. Do you have any other thoughts that you would like to share about this topic?
APPENDIX D

INTERVIEW RESPONSES FOR THEMATIC ANALYSIS

Q1: What information do you feel citizens need to be knowledgeable enough to participate in health care policy deliberation and decision-making/priority-setting?

“Mainly they need to have experience with, be able to listen to, that if they heard information they could make, and reach a conclusion on their own.”

“They need to know that ultimately they are picking the tab up – they are paying for - either directly or indirectly and they need to realize that, and they therefore need to realize that the accountability of the system is important for them to know what is happening to them and their health”

“They must have a relationship with legislators and public officials, so that they will listen. It is easier if a relationship is established.”

“First and foremost they need to understand the structure of our government, and most do not. We do a terrible job of teaching Civics. At best, there’s a civics course in high school. Years ago, and I believe still, the populace felt that the purpose of an education, really, a formal education, was to make us capable of participating in the government - That that was the main purpose of a formal education. Everything else you learn on the job, you learn in life, the main purpose was to make us – the citizens - capable of participating and that’s been lost…. that’s first - is the structure of the government – where are decisions made? The interesting response to that where are decisions made is – everywhere. Decisions made at a town council impact the county commissioners and the state legislators and in fact, impact members of Congress and the President of the United States. Decisions made at that local level due impact. Now they impact based on scaffolding or cascading, in that, a town in here, a town there, a town over there, a town in Idaho, a town in Vermont, a town in Florida, a town in Montana, these things tend to be, to cascade, build upon each other…the second point is that, in addition to understanding how, the structure of government, we also need to put a face on government, it isn’t a marmala it’s people. I am constantly amused at how we complain about the government did this, and my response is “who?” Somebody made a decision.

“I think that they need to know what the risks, what the risk factors are. I think the media tries, but I think overall there’s a lack of information. I think it’s taken us 30 years to get where we are with tobacco and we’re pretty solid in people understanding that tobacco can do harm the media is starting to get there, but the General Assembly members, they
don’t really, they kind of understand that obesity is a general problem, but I don’t think they understand the magnitude. And so, I think that we need better education pieces to get the general public more knowledgeable about the risk factors and that way when they’re educated, they can be demanding certain kinds of coverage in their health insurance, or they can be demanding of legislators for policy initiatives, or they can demand better foods in the schools. So that’s - I don’t know if that’s exactly what you’re looking for, but that’s where I would start”

“I think you need to know the basics of what changes are happening that directly, that affect you and your health care… so for example, we’re gleefully distributing, with one of our partners, consumer union reports magazines, has this great, about 15-page little magazine that’s called Health Reform: Seven Things You Need to Know Now. You can read that and know the basics of what you need to know.”

“Well, from my perspective, because health care is so complicated, they need to know what the situation is, and what’s proposed. And, I guess what’s been enacted, but not yet implemented - which would be the Affordable Care Act, because it’s an overwhelming aspect of our health policy… And I guess the way to transmit that information is through publications, summary publications, or websites or social media. I think I just got a pamphlet in the mail from one of the advocacy groups entitled Health Reform: Seven Things You Need to Know... Yeah, so I think it’s a really complicated subject, and I don’t think, I don’t understand it all and I’ve followed it, lobbied to get the federal bill passed and I still don’t understand the fraction of it”

“Well, I think, uh, before you get to knowledge, the, I think the issue has to do with hopefulness…so it’s people who really feel like no matter what they do it doesn’t matter… And it’s really kind of how you engage citizens in their own kind of like, communities… get into the community, find out what they need for their own health… but it was also the local communities that you needed to go into places to start this, where it was local community leadership that said ‘We’re not gonna take this anymore. We just need someone to come and help up partner so that we can gain control of our lives.’”

“Good question. Um, so it depends on what you’re talking about… so when you’re saying citizens are you talking about general consumers that don’t represent anybody else or are you talking about the whole slew of citizens? - Because everybody at my table are North Carolina citizens… so I understand the perspective you’re coming from, and I have found over the years is that, consumers themselves, and we have gotten consumers involved at times but not a ton, we’ve lost there’s a difference between a consumer and a consumer representative. We often times work with consumer representatives rather than the consumers. Um, and part of the reason for that is the consumers don’t have, this gets to your questions, they don’t have the background to be very effective in meetings, um they don’t understand how the healthcare delivery system works, they don’t understand how the healthcare delivery…how the healthcare is financed, you know, they don’t understand the different partners in healthcare. And oftentimes when they get into our meetings and we do have consumer, real consumer representatives, um, they’re pretty quiet um, so, what we have tended to do, and I’m not saying this is the right thing to do,
um, cause I have some real conflicts personally about it, is to get the consumer representatives.”

“The basics, uh, an individual should know is, who they’re local and state officials are, because all politics is local, as Tipp O’Neil said many, many years ago and many of the policies that are going to impact one’s, one’s own personal health care, are gonna be dictated at the state level, and to some extent at the city and county level. And so the, the first step is determine who your representatives are, and the second is, reach out to these folks, you know send them an email, give them a phone call, meet with these individuals so they see you as a person, and they, they are there in government as your representative, because all-in-all, legislators, they will do what their conscience tells them to do unless they’re hearing from their constituents saying, “we need you to do x, y, or z. So that’s the most important thing, and then secondly, realize that the public policy, the laws that are being made, dramatically impact a person’s everyday life… So secondly is to stay abreast on current events, you know, try to read the newspaper every day and then follow those organizations that, that are supporting policies that you hold dear to your heart.”

“Well, citizens need sufficient information to understand how the policies that the government enacts or promotes affect them”

“Um, that is a tough - that is a good question and a tough question to answer. I would say, people don’t understand policy at all, I mean they get frustrated, like, you know, they don’t understand how slow and difficult the process is and the closer you get to it, the more easily it is to get frustrated (chuckle). I mean, people just think that you know, um, reasonable decisions are made when policy-makers are voting - they don’t realize how much it is, the system is, is influenced by money, and corporations, and industry, and even just the issue of the fundraising, so, I mean, so much of the process isn’t really about the decision, it’s about the political impact on the policy-maker, and what they can do to further their own, um… like their own survival, so, it’s, so, I know we work with, probably the more social justice kind of legislators, who do vote on just the benefit of the science and the issues, but, you know, but it’s a handful, um, the people who work in social justice know them by name and those people go out on a limb every single time for every single bill, and it’s tough, they’re really fighting uh, an upward battle, and you got give them credit for really hanging in there… it’s hard for a person like that to do that every day, because they don’t always have colleagues who are like-minded and you know, they’re really trying to um, get something good done, in spite of the system that is very influenced by things, having said that, we’re one of the few countries where you even have that chance, so we’re lucky that we can, and it’s important to have dollars in the system so that people do have a chance, though, I mean, it’s a catch 22, I don’t want to be philosophical, but um, but I think how most consumers don’t have any idea what the process is really like and, and they also have never thought about contacting their legislators, so you talk to a legislator, they say if they get like 5 or 6 phone calls, it’s like a tidal wave, and nobody knows that, so, you know, if they just really thought, “I really, really believe in this issue, and I want to pick up the phone and tell my legislator about anything, whatever it is, health care policy is one of them, but anything, you know if
they’re worried about the fiscal cliff, or what they want their kids’ school to have, we, we should be really teaching that civic engagement in every way possible, through rec departments, and some people say we shouldn’t be teaching that through schools, although it’s what our constitution allows us to do as Americans so, I think it’s kind of an uh, an opportunity just to engage people in ways that are meaningful to them… I just don’t think people know how and know when to, and yeah, I mean, I think even like in graduate school, like I know in the school of Public Health where they teach health policy, they don’t actually have people work on policy issues, they just talk about it, and so, I think doing it… so I think, just like everything it’s just demystifying them a little bit and getting people engaged and involved with something they care about… you’ll know how to look it up, you know call up an aide and tell them, “I’m interested in this,” and whether or not you support, or you voted for someone, you know, their aide, would be able to talk to you about that legislator’s opinion on it, and most people just don’t know that, they don’t even know that they have people who specialize in whatever the issues are, housing or charter schools, or whatever the issues are, that someone is helping that legislator make votes”

Q2: What methods of citizen engagement do you think are effective at including citizens in health care policy deliberation?

“I think hooking people up with groups… Citizen, union groups, through organized labor. So organizations that represent consumers”

The way you get citizens engaged in health care advocacy is to have somebody …. Is if a person has a problem – you have a child that has Multiple Sclerosis or Spina Bifida, they’re gonna get hooked up with a group. You get a child who has a Developmental Disability or Leukemia or some birth defect – they’re gonna get hooked up with a group.”

“I think probably the best way is to turn the direction toward more self responsibility for the payment of health care… in other words, I don’t think a person really cares if he’s not having to pick the tab up. But, if he is having to pick the tab up, he may have an interest in what procedure, what test, or what is being asked by his caregiver to do if the financial responsibility includes him – or her”

“Advocacy groups - They keep citizens informed of the issues through emails.”

“Well you go to the public hearings, you’ve got three minutes, and all of the legislators are going (tapping his watch) And you’re feeling as if everybody’s looking at you.” I love when I go to the school and talk to kids about being a legislator, I say “now imagine for a moment that there’s a question, an issue that you feel strongly about, so as a legislator, you push a little button on your desk that tells the speaker that you want to talk. Seventeen people have already pushed their button, so you’re 17th in line. So you sit there and you sit there and you sit there, you’re trying to listen, but you’re also trying to remember what your question was. Some people are smarter than others and I’m at the bottom end of that. Finally, the Speaker says “and for what purpose does the gentleman from Union County rise?” that’s your signal to stand up and say “to ask a question” or “to
debate the bill” - The Gentleman’s Recommendations. And at that point, you’re trying to remember why you pushed the button and you look around and 119 other members of the House are looking at you, the staff is looking at you, the gallery is looking down And if it’s a controversial issue, the TV cameras just came around…I tell people all the time, by the time an issue gets to the floor of the House, it’s over, that’s life, it’s not just government, that’s life, by the time it’s on the front page of the paper, it’s over. So, we gotta get ahead of it. Now, so, the question goes back to how does a citizen do that? If they understand how the government, how a government, how any government works, that’s one thing they need to do. Second thing, they need to have, they need to educate themselves, we all know that, but people won’t. They need to pick up the phone. They need to write a letter. They need to engage their representative. If you’ll recall something I said earlier, I can’t represent you if you don’t tell me how you want to be represented and I can’t vote the way you want me to vote if you don’t tell me. This government of ours is a participatory system. I’m doing my job, the people have to do theirs – which is participate”

“If you’re gonna advocate on whatever issue, whether it’s health care or whatever, that a lot of that involves advocacy in the public sphere. So that means using tools that you have at your disposal to bring stories and affect coverage of those stories in both social media and mainstream media, I think is your ultimate goal… So there’s gotta be new strategies I think in a very important environment, it’s much harder, especially with all, in an environment where regardless of what parties are purchasing with enormous amounts of money in the legislative system that if you’re just an ordinary person you have a smaller voice unless you can magnify that voice through the media.

“Well, I think that rallies and forums are always good ways to get folks informed and energized. I think rallies are always the most effective. But in the absence of the opportunity to have these rallies, I think webinars, just newsletters, websites, like I mentioned before, social media campaigns, I think seem to be effective.”

“So, so, one thing, let’s just talk about registration, voter registration… You know, a lot of people say they’re registered, they’re not really registered… they didn’t even know why they should be registered or not, they didn’t know how the process works, they don’t understand it, they don’t get it”

“There’s such a different role that consumers can play. In my task forces, we tend to get the consumer representatives upset, but often times we will then have a panel, not all the time, and we should do it more often, where we get the consumers themselves to talk about what does it really mean to them? You know, so to get away from the abstract you know talk about policy but to hear from a consumer perspective this is how your decisions are gonna impact me. This is how your decisions from the past have impacted me, you know? These are the challenges I face when I try to get the services for my kid with special needs. Those are for the reality very grounding, um, and I think that from a consumer perspective it can play a very important role in being part of that discussion. We also had a meeting recently where we talked to people who have done it differently than we do, and they brought up an interesting perspective about ways you can engage
consumers differently and that is, and we haven’t done it so I can’t tell you whether this works or not, but in some meetings, particularly at the local level, have separate meetings with the consumers themselves, so that they’re not part of and overwhelmed by the head of the hospital or the head of the insurance company but they can speak their own voice themselves. And on some of our task forces have gotten together focus groups of consumers, that step into the task force process, and as I said in some of our task forces we have panels and ask them to come speak, um…so there are different ways of involving consumers, I don’t think we do it as effectively as the consumers themselves rather than the consumer representatives and then we often times get the consumer representatives who may be consumers themselves but are sort of, not just representing their own point of view but also representing a broader point of view.”

“First is getting folks involved, and that would be contacting uh, their legislators via email and also phone calls and one-on-one personal meetings. And secondly is just social networking, and with Facebook the way it is, twitter the way it is, many elected officials have their own Facebook, you know, page, they have their following twitter. So getting involved in that social media, putting your opinions out there, sharing of your opinions with your friends, and letting them know, letting your friends know how they can impact public policy, I think those are the two dynamics that work the best - the one-on-one, the direct contact with the elected officials, and then advocacy through social networking… I definitely think that there are things that, that can and should be done - so I would reach out to the neighborhood associations, I would attend meetings, I would give my constituents legislative updates and so it’s important for not only the constituents to be reaching out to the legislator and talking about, ‘Here are my needs, here are my interests,’ but it’s also important for the legislator to be reaching out to their constituents and informing them about ‘here’s my position on this Issue, Here are issues that are being, that I’m confronting in the legislature,’ and then, and then also being open to feedback, because many, many issues are such where, a legislator, they should vote according to the majority of their, of what, of constituents’ desires… the legislator should be listening to that feedback and then following through with what their constituents desire”

“Uh, clearly any sort of one-to-one or small group communication is the most effective. However, that’s not always doable, so the question then becomes what’s the hierarchy of methods? So, just like with communicating or advocating with elected officials, there’s kind of a hierarchy of methods that work, and quite honestly, you have to be able and willing to use all, or as many of them as you can, so you want to start with the best, which is some sort of one-on-one or small group communication to people on why they should care, then you want to be able to go up to some sort of communication, some sort of broader communication, either in larger groups, at community forums, or at you know staff meetings, things like that, then you know, by mail or email, those kinds of things I think. So, I think that’s kind of a hierarchy, I think, I think, you know the methods that you want to try to communicate in, starting with the most effective to the least effective and one thing is, let me, let me, as long as I’m gonna go on about this, because this is fairly important I think, the other thing is to understand that there is no, that, that it’s an ongoing process, so whatever method or methods you choose, should not be seen as a
one-time thing - It has to be ongoing, or they don’t work… that’s really ours, I mean those who are active, I mean let’s, let’s presuppose that citizens don’t, don’t sort of do this themselves, that they are motivated or asked to do it by some organization or interest so, that’s really our job, is to, you know, those of us who want to engage citizens, our job is to both educate them about the process, which is – why does it make any difference that you write a letter or make a phone call which is both showing them how to do it, telling them why to do it, and giving them feedback on the impact that it had, cause that’s the other piece, is if they don’t think it makes a difference – they won’t do it so there’s that piece of it and then if it requires multiple contacts, it’s up to us to ask multiple times”

“You know, I think having a focal point is really helpful, so sometimes having a rally or something that’s got a date and a time where there’s a place to put your name on a line or appear that helps because if you had a petion or a rally it’s like a point of engagement, um, it helps people participate, and, I think those larger events may be good for people who are completely unaware of what’s going on but they might be part of a social group or community that’s having a conversation, it helps them know how to plug in… I think the, I think really a simple education - both of having someone having an open discussion about an issue and different sides of it, so it could be an informal thing at a book club or at a church or at an after s…or any kind of gathering, would be one, and then also helping to see it in the news, so I think helping people to learn how to share their views and write letters to the editor, or share their opinion like on a radio station or just on a panel, I mean, I think helping people move to the, move from the thinking to the doing stage : is what I think really we need to be, I think that’s both an effective thing and the critically needed thing, because thinking about doing something, isn’t doing it (laughing) so you know, you can think all you want, and talk about doing it, or getting all mad about the laws or whatever, but if you don’t know what to do or you are not doing something, so channeling that energy into something constructive um, and so I think um, I think that’s why those focal points like having a petition because then you can do something about it, or you can make a donation, if someone invites you, but you have to be asked, so people don’t just pick up a check and write it cause they’re mad um, you know, you go to a meeting, you have a discussion, um, so, but I do, I think you know, there’s a lot of different opportunities, but I think having a really structured, organized point of entry with a really specific thing that you can get done, is really important. So I think creating those opportunities is very effective”

Q3: When citizen input is obtained, how much do you think it impacts the health care decision-making process?

“I think if they’re well-informed and well-organized, and there are enough of them, I think you can have an impact… That’s why you need a group. The group really provides a support system for the individuals in the group so they won’t get discouraged… it does take leadership - it takes someone to take the lead.

“I would say minimally. Unfortunately”
“I don’t think the direction of health care delivery in the country, uh it’s gone so far in the direction of those who make the money decisions are making the decisions about health care. For instance, I think hospitals primarily are the most driven profit-oriented groups um, that’s not to say that all people involved in the health care delivery system such as the insurance companies, and the third parties, and the government, uh, that there’s not pecuniary interest there as well. But, I think that, and it bothers me greatly as a professional man who devoted my whole training to learning how to be a health care provider the decisions about how health care is being delivered is being made by businessmen, lawyers, and accountants – people who have not been trained in delivering health care and consequently the driving force is has more of a profit motive than it does what is in the best interest of the patient.”

“Well, if a relationship is established – it can make a big difference”

“Well, you know, I (laughing), I’ve seen it change in the course of my career… I’ve seen it, you know, have a huge, I’ve seen one person telling their story to a legislative committee have a huge impact… I’ve also seen the, a public hearing, was dominated by small business people and individuals who were opposed to this bill and the bill passed as is overwhelmingly because of special interest support from the insurance industry. I think it is an uphill battle especially in the last five years, and really in the last two, when you just have enormous amounts of money in politics now. And it is increasingly harder, but you know, I don’t think that means that we give up, I think we just looked at different strategies for affecting change. But it obviously, especially at the state level, the state legislative arena is small, and special interest, like, you know, like hospitals or the hospital lobby or insurance lobby are much, much, stronger at the state legislature than they are in Congress.”

“Um, that’s a good one. Well with state, I think that um, at the state level, I think that there are some industries and some trade associations that have an enormous amount of influence over policy. And it’s hard to counteract that. Those groups make a lot of campaign contributions and they are now funding a lot of these super PACS and it was always difficult to get anything past legislature that BCBS didn’t want to happen… I think citizen activism and citizen engagement is critical to represent the impacted constituency of policy. And it just seems like in the final analysis, (snickers) those important interest groups that, are making the decisions on what the final piece of legislation is gonna look like… And I guess I’m thinking specifically on our exchange legislation, we had two different versions – we had the version that BCBS backed and then we had the one that was more public input, more diverse board, and a much more democratic proposal, and that one, I mean, small d and big D, and that didn’t even get the light of day. So, I mean, you can have a lot of rallies and you can have citizens putting a face to the issue, but honestly it seems like you’ve got to have some massive, massive, grassroots and media campaign to overcome the special interests.”

“So um, uh, like a good social worker, the answer will start with two words, which is – “it depends.” (clearing throat) So, uh, it depends, uh, as an individual – it doesn’t do anything. If there really is a belief that that’s a voting block, and that’s a group that has
to be paid attention to, then it will be, and those things take time, so uh, you know what’s the discussion after the last national election, uh, well, if Republicans don’t pay attention to what the majority of Americans, just about are, certainly will be, which is non-white, um, then what’s gonna happen? And the Republican answer, historically, has been, that might be the majority of citizens, that’s not even close to the majority of voting citizens.”

“It depends on how it’s engaged and how much its engaged. So I have been, cause I used to be a lobbyist with legal services, I have seen the whole General Assembly totally change their whole perspective when they heard from enough citizens. Consumers can make a difference, when it is really heartfelt, when there is enough of them, uh…..when they are appealing to their legislators, it can make a difference. You can get these certain horror stories you hear from consumers, and they help sway public opinion… It really depends on how they’re used and whether it’s one isolated voice, or you see that this is a much bigger consumer problem.”

“I think the health care decision-making process has one of the biggest bang for the bucks in terms of impact by hearing from constituents. In some of these issues, legislators are going to vote their conscience anyway, for example, gun control, you know the NRA gun right, or abortion rights, some of those issues, you know people have their positions and their gonna vote one way or the other, and what they should do, they should be alerting their constituents during the election, you know, ‘here’s where I stand’ so that the populace realizes, ‘Ok, I support this issue, I support their position, I’ll, I’ll do this’ but in health care, you know it boils down to, one – access to care and preventing, uh, you know, preventing cancer, and saving more lives. And, so, those are issues where you know, a legislator, when they’re, when they’re armed with the, with the information… our job is to give legislators evidence-based, science-based information… And so, by presenting legislators with this information, then that allows a legislator to go and make the decision that would support their community and help improve the quality of life overall. So, I think health care is one of the areas, probably one of the few areas, where uh, citizens really can have their voice heard and have a meaningful impact”

“It depends on the kind of input, um, again sort of the hierarchy of effectiveness, if it’s face-to-face, one-on-ones, visits to the health centers, um, you know, um personal phone calls, personal letters, has a tremendous amount of impact. Um, the other kind of input, granted we use, are like emails, mass phone calls, you know, petitions, those kinds of things, the impact, the only impact those things have is to leverage the other work that’s already done. So, so that’s the other thing about citizen engagement is that various citizens are willing and able to be engaged at various levels. So, part of the work is to determine, and to recruit, citizens that are willing to be engaged at all those levels. Some, some will be glad to meet with a member of Congress, some will be glad to show up for a town meeting, some will be glad to write a letter to the editor, some will only be willing to send an email or send a text, or those kind of things. So, what you wanna do is, is, to engage the most citizens, you want to offer as many ways for them to be engaged as possible, and then over time, what your hope is, is that people will self-select and move up in the level of engagement they undertake”
“Oooh, that’s a tough question, I’m gonna be cynical and say it depends on how much money they have. I mean, I don’t think it necessarily is good, but I think it’s what it is. So, um, so, you know organizations or individuals who give dollars have, I mean anybody can write an email, or write a letter, or make a phone call, but the person who’s giving money, or the organization that’s giving a lot of money, probably has a different response so, that’s how it all works in our country, but um, but I do think the little guys can make a difference though if they, even people without money I mean, um, if they are, learn how you can actually be heard And I do think that um, they need to probably try not to go it alone, they need to like band together with other smaller groups that are similar thinking…and so instead of having a lot of small people do things kind of poorly, at least we’re all saying the same thing (chuckling) and trying not to use the same message and having a really strategic way of getting that information to legislators who have a very hard time hearing from thousands of organizations, unless they’re clear, and using clear messaging, especially those that don’t have a lot of money, but at least we can um, use our time better if we’re coordinating our work with others”

Q4: How frequently, and in what capacity, do you communicate with local representatives in your district(s)?

“I think that depends on the individual legislator…but I get lots of contact through email and answer them”

“I have contact with mayors and city councilmen on a regular basis”

“If I see that a meeting is going on, maybe I need to get there, I’m not actually invited to it, but if I know it’s going on, I need to get there”

“Oh, well, it depends. I mean, sometimes are busier than others. Like when we’re in legislative session it’s several times a week because often there’s legislation that affects our local governments and their downhill, but in the off, when we’re not in session, it’s um, maybe once or twice a week, I mean, it’s busy right now because I’m dealing with a local government issue at home and it’s been like ten times a day but when it’s not a specific issue, that’s a hot-button issue, it’s more like a couple times a week I guess.”

“I think that’s very important and I’m sure, you know, every legislator has their different style – some may be sitting, you know, up in their ivory tower and think, ‘ok, well I’ll, you know, these folks need to reach out to me,’ though really you need open communication between all levels of government and to the extent that a legislator is able to reach out to the mayors and to the city council and the county commissioners, that’s so important because those are the folks that are down, you know boots on the ground, you know, they know what’s going on in communities, they can give that legislator information that the legislator otherwise would not have access to. It’s really important to keep that, that level open and you know, reaching out through town hall meetings, sending out, you know, monthly newsletters, or having some sort of forum available where people can come in and discuss and exchange ideas.”
Q5: How much consideration do you think is given to localities and their constituents when making state-wide decisions about health care policy?

“I think that also depends on the legislator. I think a lot of legislators look to a lobbyist, they don’t think about their own districts.”

“Well, the Certificate of Need Committee .... the mission of the Certificate of Need Committee was supposed to address the question… My personal opinion is that that mission, to some degree, or large degree, if I might say, uh, has been overcome by it being more of a protected modality for those who wish to be protected from competition… but it should not be a protection of monopolies, it should be trying to see that need is – Where need exists, need is addressed.

“The best place to have contact with constituents at a local level regarding health issues is through the county health departments.”

“I can certainly tell you that many, sadly, not most, I won’t say most, I don’t know if it’s most, but many legislators, if somebody from Monroe, or somebody from Marvin calls and says “In two weeks, or on March the 12th, just picking a date, I’m inviting a group of people to my house to talk about, and I want you to come and talk about what you’re doing in the legislature – we want to talk about health care that’s really bugging us. I’m gonna have my neighbors there – a couple of them are doctors. But most of them aren’t and we want to know what you’re doing and why. And we have some ideas that we want to talk to you about.” Pretty much most, and I’ll say this, I think most legislators would be there. Now, a few would weasel out, they’ll wait til the last minute and say something’s come up, ok we’re humans”

“Um, very little. And I guess, I can’t really, I’m trying to think of a specific situation that would merit specific, special or different decision-making than that which would impact the state… but with healthcare it seems like it’s pretty, not very differential to local concerns”

Q6: What mechanisms are currently in place to obtain local input into statewide health policy decisions?

“Well, when an application, say for a Certificate of Needs you have public hearings to answer questions and so forth - People who are for or against this particular project. That’s one way. I think through your local county commissioners and your city council you have some local input there either at election time or either in public hearings about issues that affect public health or affect other health arenas by just citizens being able to go to these meetings and be heard… we have an opportunity to appear before these boards and these committees that are charged with the responsibility of trying to do these things and the more local, it seems to me, the better the results you have”

“Advocacy groups”
“Special Interest groups”

“We rely on all of our members to tell us what they think, with their expertise, what do they think are the needs… So, for instance, we have the Heart Association at the table, and they can tell us everything that’s going on with heart disease and stroke. And we have the NC Pediatrics Society at our table and so they can tell us what the doctors are hearing in the doctor’s offices with the kids. We have school nurses at the table, so we can hear what’s going on with health care provision in the school setting. That’s, I guess you know, and you just hear things and that’s how it bubbles up, and that’s how direction for policy comes together.”

“I think that, like legislators try, we do try to inform the public and get input when a decision is going to impact them, I do mine mostly through newsletters and I have occasionally had a town hall meeting and there are others in our delegation who have more town hall meetings, but I think we, we try to engage the local folks to um, if there is something big that was going to affect them, but with regard to health care reform, it’s been more, um, outside of the state health plan itself, which impacts state employees, it’s been more of a, you know, it’s been more, a lot more federal issues than state really”

“So, mechanisms are really kind of like talk to your state reps, doing those kinds of things, you know, so, (clearing throat), that’s what we see. Health departments, every county health department has to do some kind of uh, community-wide survey, assessment, in other words, so, there’s, there are those vehicles, you know health outcomes, every state, well I shouldn’t say every state, this state certainly measures health outcomes by county, so which counties are healthy, which ones aren’t, how’s it work or not work, uh, so, and that’s usually given feedback through the county commissioners, health departments, and you know state elected officials. So, that said, that’s not the usual social groupings that people belong to and so doing that through more organized ways like schools or churches, you know, especially in this uh, this state, doing something through the churches would make sense, because that’s a, kind of a social group that’s really been engaged…. we try to work through you know, the collect, the collective power of all the health centers at one time, going to the state in, kind of like, in a unified way we believe in that power. Uh, but we also, obviously, talk with our individual, elected officials and you know, try to keep them engaged, through events here, meeting with, um, trying to see them at the time when everybody else, Not seeing them only when everybody else is trying to see them, at other times, um, so, we just know that that’s important. We haven’t engaged with, as well as we should, with, um, on a county level, so county commissioners don’t really know us as well as we, you know”

“Uh, that’s a tough one because there’s a lot, there’s a big difference, Charlese, with uh, like what I’ve seen in North Carolina vs. (previous state lived in). For example in (previous state) we had, um, ultimately there’s a public hearing notice requirement, so all committees, you had to have your agenda out within 24 hours, and you had to comply, you know, you had to comply with whatever that agenda said. In North Carolina there’s no such requirement, um, you know, generally we know when the health committee’s
gonna meet or when the appropriation committee’s going to meet, but oftentimes, you don’t see an agenda until you walk in the door, and then when you see the agenda, it could change at the drop of a hat. For example, I went to a rules committee and there was on the agenda that was printed the day before it said oh that they were going to recognize one month as (removed for identification purposes) awareness month. And so when I went in there, because I was going to you know, support, you know, talk in support of this legislation, I found out, from the secretary, who said, ‘Oh, no, they’re going to do a proposed committee substitute,’ which basically is to strike everything off the bill, and they’re gonna make the stallion the horse of the state. And so it’s really, you know, North Carolina, it’s, it’s, it’s, there’s a dichotomy going because it’s so difficult, it is difficult for the average citizen to find out what’s really going on in the legislature because there’s no pub – there’s no compliance, or, with the public notice and so you don’t really know what going on in the legislature, so the, so, what we do, is we have folks sign up as adv, and tell us their interest in advocacy, so what we do is once a month we have advocacy update calls, so we talk to, we talk to our volunteers, tell them, ‘here’s what’s going on in legislature, here’s what, here’s the bills that’re up, and here’s how you might want to get involved.’ We also send action alerts… to ask you to call your representative, email your representative, so often, so in, I think particularly in North Carolina, it’s probably more important, if you’re really interested in an issue, get involved with an organization that supports, you know, that issue that you hold dear, because otherwise, it’s very, very difficult to just follow the General Assembly and following the newspaper and trying to stay involved in statewide politics”

“I think it’s really important to distinguish between health care and health policy. Health policy is exceedingly complicated, just like every policy, whether it’s at the state or federal level. I would also argue that it is intentionally made as complicated as possible by legislators to, to, to reduce the amount of citizen input they get and so, but I think, and again, people, people are only effective advocates, right, I mean, sending in a email, singing a letter or postcard, that’s, that’s sort of the minimum level of advocacy. But people, people at the local level, are only effective advocates if they actually care about something, right? So, so the idea that somehow we’re gonna give them this whole load of information about health policy, that’s somehow gonna resonate with them, uh, is a fallacy. In other words, what matters to people? Can they get health care? Can they afford health care? Are they gonna be well taken care of? You know, um, can their family get health care? Can their ch – kid – get health care? Quality health care, these are the things that matter to them. They’re not interested in, you know, Medicaid policy. They’re not interested in the exchanges or how they’re created. That, so, so, if you want uh, average citizens to be involved in the process, you don’t even discuss with them, you, you, what you do is, you offer them the basics, and give them a place to get more information if they want it… but at the end of the day if you want people in your local community to walk into the barber shop and get in the face of an elected official about something or show up at a local town meeting and stand up and ask a question about something, it better be something they care about. I think it’s really important, in, and, in part, um, this is where the distinction between advocacy and community organizing comes in - they’re two different things, and community organizing is based on the theory that you don’t go into a community and tell them what they should care about - you go into a community
and find out what they care about and then help them advocate for it right? So, I think you wanna make sure, at, at the local level, that’s the way to actually get people involved is to help them organize Not, ask them to advocate for something, OK? Find out what they care about, you know, or educate them so that they kind of know the things that impact them, and then see what they care about, and then help them organize themselves to advocate for it. That’s the most effective way local citizens can get involved in the process. so, so, I don’t think it makes a difference whether you’re talking about Congress or elected, or the mayor, or state legislators, I think the key is - is to try to create an environment, or a campaign people care about then, then you won’t have to ask them to do stuff – they’ll do it… well, there, there, you know, a lot of states have committee hearings, they have tasks force, they go out and request you know local input, local testimony, those kinds of things go on in a lot of places, I’m sure they go in at some point in North Carolina, you know, I, I, we’re not talking about things like bringing people in to testify before the legislature, but I think, you know, I, I, don’t know that I can say anything specific, but I know things go on all the time”

Questions 7-12 Citizens Juries

Q7: What do you know about the use of citizens’ juries as a method of engagement in policy deliberation?

**All respondents replied that they knew nothing about Citizens Juries

Questions from Respondents About the Jury Process

“Alright, number 1: Who selects the jury?”

“What level of authority would this jury have? In other words, other than just an opinion type thing, or would it have mandated authority?”

“Who selects?”

“Who, who selects them?

“These jurors would be making recommendations to legislators or who?”

“So, they have the ability to s-, they don’t have the ability to subpoena people?”

“So, they may only get ex-, how do, how are the, how are the experts chosen? By the steering committee?”

“Is the deliberation private?”

Q8: What are advantages that you can see with this model?

“I mean, I think it would be good. I think that this would be helpful.”
“I would favor certainly some way for people to have their voices heard or to learn, you know, have an opportunity to learn.”

“I would have to know more about citizens’ juries but it sounds very interesting and like a good idea. The details would need to be worked out. It would also need the support of legislators. Again, the relationship is very important.”

That would be very helpful to legislators (the recommendations). That whole approach would be very helpful… Policies that are juried - help filter the junk.”

“It sounds like a lot of the processes that we use here where they establish like a task force or a commission that’s basically they pull together experts on a certain issue, they hear testimony, they study it, and then they issue the recommendations. It could be, not everybody agrees, maybe they do, on this list of recommendations. And I specifically like, it reminds me of the IOM -that might be a model here in the US – both nationally and at the state - that you could look at”

“It would be nice if you could fully inform a group of people in, in a um, an unbiased way to make a decision, because I think that’s the best way decisions are made, so, so, that value piece of it I think is really, really helpful, because I think that’s really where the power does come, is from community up and having words, and I think that’s a great thing, otherwise you get strangers doing it, so that part of the concept, I think is a great idea.”

“That sounds very similar to adhoc committees… and so I think, I think there is value to having this citizens jury, or having these, these um, specific expert panels, that will, that will look at an issue, look at all sides of it, make recommendations, and then convey those on to the legislature, um, I think there’s definitely value there… but it’s definitely, a citizens jury sounds like an adhoc committee is, of investing stakeholders who have expertise in the area and I think valued, anytime you can get citizens to participate, and look at all sides of an issue, and then give some, some reason and strategic guidance to legislators, that’s, there’s a lot of value in that, because legislators, you know, they are not, you know, they’re the jack-of all-trades and a master of none, because you know, you can’t be an expert in all things and that’s the value of these stakeholder meetings, can come into play and really give some valuable guidance”

“Wow, that’s interesting…well you’re right, we do have task forces where people can go and testify and share their data, um, and there’s not really a, um, and they may be making recommendations, but they’re, this sounds much more structured, I think my first response would be, at best, well the system is slow to change, and the people with the power limits change so it might not be something that would happen quickly, but I think, I think raising the idea for more public opinion and more public awareness and more public involvement in any public policy area is a good thing… so I think the more, the more the groups that we engage in politics, in policy, that are not, they don’t have a vested interest, but just have an opinion because I think the public is usually well ahead of where policy-makers end up, um, and not just really educated public members either,
um, it’s just that the system is, has got so many checks and balances with power and dollars, that it doesn’t move as fast as society does so, the more you have public input, the more likely you’re gonna move people where I think the pulse really is of the public”

**Q9: What disadvantages do you think exist?**

“It’s the money – the special interest money”

“It’s the time “

“so the question that pops in my mind now is, it seems that you have a lot of advocacy groups now, non-profits, God knows from everywhere - constantly asking us – me, you, everybody else – for money. In other words, people that are real…you mentioned the breast cancer people they are doing, in other words, they come together in cancer, statewide vs. federal. These people, they advocate for what they think is the right thing. As we do in politics, we have a lot of different groups doing that, advocating for what they think. I don’t really know exactly why such would be needed, unless, God forbid, that we do go to a completely socialized health care system and you needed some type of citizens jury to advocate for people that are not, uh, don’t have a voice in any of their decisions other than uh, you know, if I come down here as a member of what I call a republic model of democracy, you know people keep talking about a democracy – we never were intended to be that - I seem like I’m charged to come here and to look at the facts on every bill that comes here and I make the decision on what I think is the best interest of the majority of the people. Now, if when I come up for re-election there’s enough people that says I don’t like what he advocates for, I didn’t like him going down there and voting to fluoridate the water supply – putting fluoride in the water – I think that’s rat poison – I’m voting against him. You see, there’s a recourse, but, on the other hand, I don’t think I should go out and take a poll to see what the majority of people think about a subject, especially when they don’t know nearly as much about it as I know, you see. Consequently, I have to have enough integrity to do, regardless of how much money somebody is trying to get me to take to advocate for their position, I have to have enough integrity to do what I think is the right thing while I’m in office – and that’s to formulate an opinion based on all the facts and figures I can put my hands on to do the right thing for the majority of the people – without trampling on the rights of the minority – but at the same time majority should prevail. That’s just the way our system should work.”

“We all have agendas, no matter who we are. The people who select other people themselves have agendas and sometimes litmus tests. So that’s always a concern I have, is do we have someone representing the guy that pays the bill and how much cred….what if we weight things, because we do, what’s the weight on the guy that pays the bill?... when you look at other countries and how they do things, we are, in this country, the most non-homogeneous people in the world, in probably the history of the world So I caution, always, when we look at how things are done in other countries, we are not other countries. But one of the things you said made me, all of the sudden, out of the clear blue, made me think of the debate we have going on right now on the racial justice act. The
whole reason it evolved is because of lawyers picking juries - they teach them in law school how to be that way, and then we turn to the legislature to fix it. My concern about a lot of proposed fixes is that we’re turning to the wrong people to implement the fix”

“Disadvantages are – structuring the process to ensure equanimity not equality. I’ve almost thrown the towel in on - the whole concept of equality is unbalanced - so, equanimity – ensuring equanimity, and a frequent review of the process. So that would be something that would have to be built into it. The other downside is attracting people to step up and say, “Yeah, I’ll do that” and in my view, the way you do that is you’ve got to narrow the time period, narrow the, get people to understand what it is they’re in for. We’ve got to get more people involved in the system. That’s where we’ve gone wrong in the broadest view is that we’ve got the fewest number of people making the most number of decisions.

“The problem with it is – how do you – it’s still – maybe there’s not strong enough link between what the report that they issue and getting someone to follow through and make the legislators do something with it. What they tend to do, they include legislators on those special task forces, so that they are invested in the process and own it, and it makes me think ok then they’ll want to run the bill. They’ll take that step, and they’ll own it, but that doesn’t always happen. I’ve seen time and time again how these commissions or these task forces, you know, it’s some nice report that sits on the shelf. You know, how many times have we all heard that expression? The other question I would have about that process is whether or not it would really be valued information at the end, because you might have a plumber and a lawyer, and a whatever, but not an expert on whatever the topic is. So that could be a problem as well.”

“I don’t see that that would have that much effect… I mean, I think they would, whoever was organizing it would have the meeting and then have people directly contact the legislator would be more effective.”

“…the last election cycle there was two million dollars (each word slowly and deliberately enunciated) spent by a PAC to pick a, a North Carolina Supreme Court Justice. The position probably pays $125 - $150 thousand dollars a year – 2 million dollars – and that was to make sure that there was one person who might think about overturning what the re-districting was, OK? The amount of money that’s involved with ads, and other kinds of things and we think we’re living in a pure world, it’s just um, it’s dangerous. So, that’s the hesitation I have, the concept of it, I think absolutely makes sense to me, uh, but I don’t think we can ignore the effect of what a, that citizens united decisions have on this world. The idea that a corporation with dollars has the same voice as an individual citizen is, has been, I think, has gotta be the single most dangerous thing that the Supreme has decided in decades so, before that, I might see it differently, but, that’s where we’re at now”

“And what’s very, very hard these days, is you know, how do you get folks involved and get that volunteerism? Because it’s so hard, people are so involved in their lives and they’re trying to you know, make it through every day, and stretch their dollar, you know,
live paycheck to paycheck, and raising their children so, I think a lot of times it’s hard to get folks to buy into something like this, and, and then you know, when you say citizens jury, I mean, I always wanted to serve on a jury – I never had the opportunity – but when people say, ‘Oh my God, I have jury duty,’ it’s like the end of the world was coming. So, there might be some negative conn – you know, negative like word connotations so, I would agree that may be giving people here in the U.S. resistance”

“Uh, there are so many “what ifs?” in my mind about that. I, I, I think, first of all, the, the, the singular question is, “what is it that would make any policy-maker listen to what these particular 12 people said? I mean, they get input from all, all, a whole bunch of people. Second of all, I think um, this whole process is completely dependent upon whoever the selection committee is and who they select to be on the jury so, you know, I, (sort of chuckles), the third thing is, and this goes back to your issue of civic engagement, is that one, the, the, vast majority of people who might be impacted by policies like health policy don’t have time to take off from work and sit on a jury they don’t even like to sit on a regular jury. You know what I mean? So, I think the question, I think the question would be, most, uh, the audience for the results, and the, the ability of this jury to be seen as credible in terms of its, its representation of the population that might be affected by the issue, so, I think, I think you have, I don’t know what’s happened in Canada, and I’m not exactly sure who set it up with Clinton’s health care plan, although we know what happened to that, um, I think, I think you have a huge, a huge barrier in this country, to have any kind of credibility for that kind of a group and you know, I’ll give you, I’ll give you a perfect example of the first thing that comes to mind. They don’t call, they don’t call it a jury, but in essence, this is, this is a, depending on who’s on it, it’s a version of the Simpson-Bowles Commission. Right? I mean, they didn’t have to have, they had to have a certain number of people for it to be required to be introduced into law, but they produced a report that had a minority report to it, and they looked at all this stuff, but basically it is a bunch of people that were picked, you know, who you know, none of those people are gonna be affected by cuts in Medicaid, or, or, or cuts in Amtrak, or public energy services. So, I think the question is, you know, and, and, and, this is kind of full circle to what we said before, let’s assume that you want real citizen participation then, in selecting the committee – the jury then you want t mix of people – business people, average citizens, unemployed people, uninsured people, whatever – um, some of whom will have far more knowledge, experience, education than others some would have to educated on the process, some won’t understand the experts that testify so, having been on a jury myself, I can tell you what happens is, that there’s always a dynamic on a jury where the people who are seen as more expert, more knowledgeable, have more influence over others so, and that assumes that you can even get the others who have to work for a living to be on the jury so I think that’s the singular issue to me, which is, having a jury which is not reflective of the population that will be impacted by the issues destroys the credibility of whatever they come up with”

“I would say that I would see that as being a really innovative idea, but I would see it also being a lot of people on the other side of it because it would limit their, their success the people who have vested interest would be quick to fight it, so which is, um, maybe also a little cynical, but
I mean, let’s be realistic too, like I probably used to be a little bit more Pollyannana about policy, and now, I just, I know too much (chuckles) I don’t think it’s the way I used to think it was (still chuckling)… but it also, it also does mean that we need to encourage people to move into this public service who have, and to help them know how to do it, cause it’s tough to do and it’s expensive to do, but it’s uh, it is, it is part of making those changes in the law, is um, getting different people in there, and also if we could get to determine, we could have a whole lot less of those with the power and the money making the decisions for super long periods of time, and it might change the discussions but that doesn’t mean it’s gonna happen immediately because there’s a lot of people on the side off that life”

Q10: What recommendations can you make for overcoming these disadvantages?

“Well, so, one of the ways to overcome the disadvantage of having money involved is to do it quickly. Is to have this be a one day affair, or have a group that doesn’t have any, do it before they have contact with all these moneyed interests who are gonna tell you lies – then you just get confused.”

“Accountability… and again you come back to who makes the decisions, whose on the jury: do they have to stand for election? Or do the people that appoint them have to stand for election? I think what you’re trying to say is, what you need to work on is the mission statement, the mission statement of this jury, as you call it. What is it put together to do? And its accountability if it doesn’t do what it was set-up to do. ”

“In terms of the makeup of the task force, of your committee, or your jury - I mean that would be a huge application of time and effort, you know? So, I mean, it might be, I liken it to getting people to serve on our own juries here. Everybody has to do it, if everybody had to take their time and do it, and it was random, then maybe it would work.

“I think probably having 8 separate people call that legislator and say “you know, I thought about this issue and I think we ought to expand Medicaid and here’s why I think it” If you had 8 people call, then that I think is much more effective than to have one person in that legislator’s district call and say “Well, we note that these 8 people decided that…”

“I think however you do it, you, you have to have, you know, I mean, our jury system is flawed, but however you do it, I think if you want their results to be seen as credible reflection of citizen engagement, you have to reflect the community the whole community, not just the people, and, and that’s why I say I don’t know how legislators will receive it because, and to be quite honest with you, all lot of the legislators don’t really put much stock into what poor people say and, and what I would say to you, and this is kind of where I’ve come through in my work, which is why my title now says advocacy and civic engagement, which is, what you saw in the last election was the real evidence of what happens when underrepresented populations, uh, begin to be reflected in the electorate. Right? In other words, immigration was dead until the election, now it’s not dead right? Why is that? That’s because all those Hispanics who were seen as not
gonna vote, you know, voted. Um, and I think, I think, the ultimate, I mean, one thing about our country, is the ultimate power is, does lay in the ballot box. And I think that’s it’s a much bigger challenge to be honest with you, or I think we’ve seen this, is to get those communities you’re talking about, it’s one thing to get the small number of them who might be able and willing to be engaged in the policy discussion it’s a much bigger deal to get the much broader numbers who really need to be engaged in the electoral activity. I think that, you know, I’m much more concerned when we say to people “would you like to register to vote?” and they go, “no, I don’t think it makes any difference, than I am when you say, you know, “They’re gonna make a decision about your health care, would you like to weigh in?” those people will say “Oh, sure.” like the problem is that if they’re not voting, they don’t have the same impact so, so I think that connection, you know, um, that’s the, that’s, that’s the connection, that engagement of citizens, is it’s really, it’s really, I think the biggest issues is, those citizens who feel, you know it’s one thing to say they don’t feel like their voice makes a difference, it’s another to say they don’t feel like their vote makes a difference and I think that’s the real challenge.”

Q12: What do you think it would take to implement such a process, in particular at the local level of government (as a special town/city council meeting)?

“Well, actually we have - well, it depends on the local level of government. Like in a place like in Chapel Hill where you already have a lot of citizen groups. In NC town councils don’t deal with healthcare. In NC the counties were set up to handle health and human services at the local level just like school boards were set up to handle education. So we are a southern state, we are a local decision-making state. We do not want the federal government coming in and making decisions about NC and the people of the communities don’t want the state to tell them what to do. So we have a policy of having local, of having decisions made at the local level – which makes a lot of sense – in many ways. So if you wanted to do this. You might do some of this at the county level. So we have health boards, every county has them -they’re citizen boards – you could use them.”

“Well, I mean, we do something like that now. I mean it’s not a formal process but basically stakeholder groups, which isn’t like an objective jury but you got, um, any piece of really complicated legislation that we pass in NC generally goes through a stakeholder group process… and we get them in and everybody just sort of battles it out and they come up with a compromise, that everybody can buy into, and um, and it’s served us well because it’s a way for a lot of voices to be heard, because we can’t represent all of those interests ourselves and it gives the bills a lot of momentum and it happens, so I think that there’s some merit to having an outside group that has some interest and knowledge about issues.”

Q13: Do you have any other thoughts that you would like to share about this topic?

“I can see that there’s some possibility for this new model but I guess all I’m saying is that I don’t see it being that far away from some of the things that we already do here. So maybe with a few tweaks it could be done. Anyway, I think it’s a very interesting idea –
give it to a jury. Especially, I think you should let them decide and take it out of the hands of Congress - anywhere where there is so much partisanship that there is gridlock – I think that would be a great way to do it. But, I mean, it doesn’t sound like you’re talking about giving - the legislators would still, the congressional leaders would still the ones making the final decision. So, I don’t know. I don’t know, but it’s interesting.”

“I don’t think that you could have a jury that wasn’t educated at all on health care policy, I mean, just be completely, I think you need to have people who understood the industry to be on that jury because I think that it just, you wouldn’t understand the impacts of how a particular policy might come out. So, I feel like having something like a jury – but more like a stakeholder kind of jury - where you’ve got different industries, different affected groups involved in the policy considerations. That that, hopefully that helps because we, just as individual legislators, can’t interest every outcome because we don’t have expertise in the area that we are legislating. So I think that something like what you propose is - could make some sense. And just maybe more a specific, I mean ours have been, we don’t have it written rules, it’s not something that has to happen, it’s just something, a model we follow because it seems to have led to success on some of these more contentious issues… they would always be out-gunned and out-manned by industry lobbyists…so there ought to be some way to achieve balance cause I just think that um, and particularly I think citizens, just from my experience and interaction with them, knocking on doors at election time, don’t feel like they have a voice, don’t feel like what they say or do matters. If there was some forum like this where they could actually have input I think it might get them more involved and interested and engaged With the process and with their government and with the outcomes, because what happens in Raleigh, or whatever state house, it’s really important to serve the impacting folks, so, I think it makes, that’s interesting, I hadn’t heard that they were doing this in England.”

“well, you know, so, um, I don’t know a lot about how it works, here’s uh, here’s the thing that I’m afraid of, whether it’s this way or another way, cause it’s what I see now is, there’s so much money involved with health care decisions, that uh, what drugs are made, what they’re not, Um, I worry about it being corrupted, and I worry about the presentations being done by people who are incredibly believable, incredibly polished, uh, but what is it really about, and what is the focus, that’s the one thing that I worry about – how much money is involved… you look at the amount of money involved with drugs, the investments, going into for-profit health care, uh, what’s at risk for people to make choices, that it, it’s, it’s, it’s not what we remember it as, which is “let’s all think about what really makes sense for us to decide as a community, what’s right for us, because I think that is correct, but if it was down to just 12 people, the amount, all you have to worry about then is “How do you get 6?” Ok? And the, the dollars are so huge, that someone would figure that out.”

“I can’t imagine why it would be at all helpful. It makes no sense to me whatsoever. What good does that do? What purpose does that serve? How would it be used? The way policy is made is because stake holders are advocating for or against something in a general assembly or a regulatory process. So the consumer say one thing, but they’re not the ones - - so you have this consumer jury on some issues they come up with a
recommendation but the hospital physician hates it. The hospital physician is far more powerful than the jury is. So the advocates can say “well we had this consumer jury”. By and large, they’re going to discount it. So, the question is, how does that fit in to the whole process and why would anybody who is already skeptical of that position, give it any weight? So it seems a little - - and why one jury? Why twelve people of this particular one? Why not if you’re gonna do it then it’s like focus groups? Why not just have focus groups across the state and have lots of input from people about certain issues? It just - - the reality of the way the policy process works that seems like it would have very little impact in the way the process works. The way the process works is it’s largely driven by stake holder groups who have relationships with policy makers, it’s driven by the media as well so media can really help. It’s driven by community leaders, if you have twelve Jim Hunts of the world on that panel that’s a whole different story than twelve consumers. It’s driven by money, its driven by connections, and I don’t mean to be cynical but – So the way I think consumers effectively- - if, if you could do the right thing what consumers have is that- - if you can get large groups of them. That can make a difference, and I’ve seen it happen where consumer voices will make a difference. But twelve people in a community who are part of like a mock trial just doesn’t seem like it.