

Promoting Effective Health Advocacy to Promote Global Health: The Case of the Global Advocacy Leadership Academy (GALA)

Gary L. Kreps

Center for Health and Risk Communication
George Mason University
Fairfax, VA, USA
gkreps@gmu.edu

Paula Kim

Center for Health and Risk Communication
George Mason University
Fairfax, VA, USA
pkim12@gmu.edu

Lisa Sparks

Health and Strategic Communication Program
Chapman University
Orange, CA, USA
sparks@chapman.edu

Linda Neuhauser

Health Research for Action Center
University of California, Berkeley
Berkeley, CA, USA
linden@berkeley.edu

Carol G. Daugherty

Department of Global and Community Health
George Mason University
Fairfax, VA, USA
cdaughe2@gmu.edu

Mollie Rose Canzona

Department of Communication
George Mason University
Fairfax, VA, USA
mcanzona@gmu.edu

Wonsun Kim

Department of Communication
George Mason University
Fairfax, VA, USA
wkim10@gmu.edu

Jungmi Jun

Department of Communication Studies
University of Northern Iowa
Cedar Falls, Iowa, USA
jungmi.jun@uni.edu

Abstract—Health advocacy can make significant contributions to promoting global health by shaping health promotion programs that are responsive to the needs of consumers. Health care consumers have a major stake in the health care system, yet have had difficulty influencing health policies and practices due to the limited power typically afforded them within the modern health care system. Strategic health advocacy communication can help to recalibrate the balance of power in health care and health promotion efforts, facilitating important influences on health policies and practices. Health advocates can help make health programs responsive and adaptive to consumer needs by communicating consumers' perspectives in compelling ways to key audiences using a variety of key media. This article describes the communication demands of effective health advocacy, the need to help advocates develop strategic communication knowledge and competencies, and presents a case study of the Global Advocacy Leadership Academy (GALA) program designed to promote effective health advocacy.

Keywords—*patient advocacy organizations; leadership; media relations; corporate relations; health care systems; government agencies; stakeholders; personnel management; health promotion; media advocacy.*

I. INTRODUCTION

Health care consumers around the globe have a major stake in the quality of health care, health education, and health promotion programs provided within the modern health care system. Yet consumers have had difficulty shaping health policies and practices both locally and globally due to a major longstanding power imbalance within the modern health care system that accords far more authority to health care providers and administrators than to patients and family caregivers [1, 2, 3]. This traditional power imbalance limits consumer participation and influence within the modern health care system despite the fact that a large body of research demonstrates that increases in consumer participation in health care and health promotion efforts can significantly improve the quality of important health outcomes [4, 5, 6, 7].

Health advocates, whether working as individuals, or as parts of health advocacy groups and organizations, have the potential to recalibrate the traditional imbalance of power in health care and health promotion efforts as a powerful social mechanism for promoting consumer-driven participation and change within the health care system [1, 8]. Health

advocacy leaders can actively represent the voices, concerns, and needs of consumers within the health care system. Advocates have great opportunities to help make health care programs responsive and adaptive to consumer needs through the use of strategic health communication [1]. Strategic health advocacy communication can promote important influences on the development and refinement of health policies and practices. However, health advocates must learn how to communicate patients' perspectives and needs in compelling ways to key audiences using a variety of different communication channels and media to influence often entrenched health policies and practices [9]. This article describes the important communication activities that health advocates can perform to effectively represent the needs of consumers for reforming modern health care systems. The article also examines major communication challenges facing health advocates and suggests strategies for promoting effective health advocacy around the globe.

II. THE NATURE OF HEALTH ADVOCACY

Health advocacy typically occurs on multiple levels. The two most common levels for the delivery of health advocacy are the individual and the group levels. On the individual level health advocates work directly with specific patients to promote quality of care and informed decision-making for these consumers, while on the group level advocacy groups and organizations represent the needs of many consumers confronting similar health challenges. Both of these levels of advocacy depend on effective and strategic health communication to be successful.

Individual level advocacy is delivered both informally and formally. At the informal level family members often serve as personal advocates for their own familial loved ones, particularly when these loved ones face serious health challenges or when the loved ones have difficulty representing their own health needs (perhaps due to reduced capacity related to their health conditions). Family advocates regularly support the health needs of children and elderly family members, but all health care consumers can benefit from effective personal health advocacy. There is tremendous potential for many people, particularly those who are well educated and those who are familiar with the health care system, to serve as advocates for their friends, relatives, and others who are seeking health care services. Personal health advocacy can also help others adopt healthy behaviors and reduce significant health risks through education, support, and encouragement.

Individual level health advocacy is increasingly being delivered by formally trained care professionals, including health navigators, consumer advocates, patient educators, home health nurses, personal trainers, and social workers who can be assigned to work with specific consumers to help promote the best possible health outcomes for these consumers. Research has shown that these health advocates can dramatically enhance health consumer satisfaction,

understanding, quality of care, and important health outcomes [10, 11]. Individual level health advocates provide invaluable support for health care consumers to insure these consumers receive the best care and advice to promote their health and well-being. These advocates depend on their strategic communication skills to gather relevant information concerning consumer's health concerns, interpreting health care recommendations and advice, and sharing this information clearly and compellingly with consumers.

There are also many different health advocacy groups and organizations that have been established to focus on promoting health and wellness for a large number of consumers experiencing specific similar health challenges, such as different cancers, heart disease, diabetes, and other health care issues. These advocacy organizations encourage focused research on specific health issues, influence legislation to promote consumer rights and responsive health care regulations, and help to refine health care delivery system programs, practices, and policies. Some of the larger and most well established health advocacy organizations have become familiar names such as the American Cancer Society, the Susan Komen Foundation, the Alzheimer's Association, and the American Heart Association. There are also numerous smaller (mom and pop) advocacy organizations and groups that are typically developed by consumers and/or their caregivers to address serious personal concerns they have had with the health care system based upon the care they (or their loved ones) have received. The leaders of both the large and small health advocacy groups/organizations depend on strategic health communication to achieve their goals. This article focuses primarily on the ways the leaders of health advocacy organizations can use strategic health communication to shape health policies and practices to support the needs of the health care consumers they represent.

There is a long history of health advocacy in the US that has powerfully influenced relevant health care research, as well as the development of important health policies and practices [8]. For example, the American Cancer Society which was founded in 1913 as the American Society for the Control of Cancer by a group of prominent physicians and business leaders, has developed many influential programs to enhance the quality of cancer care and provide support to cancer patients. Prominent individuals have also had major influences on consumer advocacy by establishing influential health advocacy organizations. For example, Mary Woodward Lasker, who founded the Citizens Committee for the Conquest of Cancer when her husband Albert Lasker died from intestinal cancer in the early 1950s, was instrumental in promoting the introduction of the National Cancer Act of 1971 in the US that was signed into law by then President Richard Nixon. This landmark federal legislation initiated the national "War Against Cancer," which has spurred the development of important health organizations (such as the National Cancer Institute), the

expenditure of billions of dollars of federal funding for important cancer research, the development of new cancer treatment strategies and medications, as well as the establishment of myriad new programs to support cancer prevention and control. However, it must be noted that it was not easy for individual advocates or their health advocacy organizations to accomplish such sweeping influences on public health policies. It took concerted strategic communication efforts, including the development of effective media relations programs, fundraising efforts, lobbying strategies, and the establishment of powerful public/private partnerships to achieve these important health promotion goals. Achieving similar health advocacy outcomes in other countries may be even more challenging, since there is not a long history of consumer advocacy in health care in many parts of the world.

III. THE ROLE OF COMMUNICATION AND INFORMATION IN HEALTH ADVOCACY AND HEALTH PROMOTION

Communication is at the center of effective health care and health promotion, because communication provides consumers and providers with the relevant health information they need to get the best care and make their best health decisions [5]. Relevant and timely health information is a critical resource in health care and health promotion because it is the essential resource needed by practitioners who must guide strategic health behaviors, treatments, and decisions, as well as by consumers of health care who need to make important informed choices concerning the prevention of health risks, the promotion of their health, and the best health care treatments for them [4]. Health information includes the knowledge gleaned from health care interviews and laboratory tests used to diagnose health problems, the precedents developed through clinical research and practice used to determine the best available treatment strategies for specific health threats, the data gathered in checkups used to assess the efficacy of health care treatments, the input practitioners and consumers need to evaluate bioethical issues and weigh consequences in making complex health care decisions, the recognition of warning signs needed to detect imminent health risks, and the direct health behaviors that have been determined to help individuals avoid these risks [5]. Health care providers and consumers depend on their abilities to communicate effectively to generate, access, and exchange relevant health information for making important treatment decisions, for adjusting to changing health conditions, and for coordinating health-preserving activities. The process of communication also enables health promotion specialists to develop persuasive messages for dissemination over salient channels to provide target audiences with relevant health information to influence their health knowledge, attitudes, and behaviors. Health advocacy organizations have

developed to help support these critically important health information needs.

Access to and effective use of relevant, accurate, and timely health information is critically important for guiding the important health-related decisions that consumers and providers must make across the continuum of care to promote health and well-being [12, 13]. This includes decisions about the prevention of health risks, health promotion behaviors, the detection and diagnosis of health problems, health care treatment strategies, and best practices for living with health threats (successful survivorship) [12]. Yet, health information is complex, with many different kinds of health risks, each with different causes, stages, symptoms, detection processes, and treatment strategies. Health care knowledge is rapidly evolving with advances in research and applications concerning etiology, prevention, detection, diagnosis, and treatment of health problems. It is extremely difficult for consumer, as well as many health care providers, to stay on top of all the health information they need to make their best health decisions. They need support to manage the complex and evolving health information environment.

A primary goal of health advocacy organizations is to help break through the complexity of health and health care by disseminating relevant, timely, accurate, and clear health information to consumers and providers to help guide informed health decision making. However, there are significant barriers to the dissemination of health information, especially for at-risk populations, due to limited access to health information, health literacy challenges, limited education levels, and the complexity of health research and health care processes [3; 14; 15]. Health advocacy leaders must develop strategic communication programs for gathering relevant health information, interpreting that information, and presenting the information in meaningful ways to those who most need that information for guiding important health decisions.

IV. MEDIATING THE COMPLEXITIES OF THE MODERN HEALTH CARE SYSTEM

Health advocates must learn about the complex structures and processes that have been developed for delivering care and promoting health in the modern world. These health care structures are likely to operate quite differently from one location to another, particularly across different national health systems. Effective advocacy demands a detailed understanding of the different ways that health care delivery systems are organized and managed; the ways that health care services are financed; the ways that relevant treatments, medications, and technologies are developed, tested, and implemented; the ways that research programs are conducted to study health care and the promotion of health; as well as the ways that regulatory mechanisms and guidelines for governing the delivery of care are implemented.

This means that health advocates must be able to gather a great deal of complex information about health care systems and practices. They must learn about a wide range of different relevant health industries, including health care delivery systems, pharmaceutical companies, insurance organizations, and medical technology and supply industries. They need to learn about the many local, regional, and national government agencies that regulate health care. They need to understand the ways that research programs are conducted to study health care tools, treatments, and processes. Moreover, they must learn the best ways to communicate with representatives of these different health care systems to promote cooperation and partnerships in for refining health care practices and policies. In addition, health advocates need to understand the best ways to disseminate relevant information about the health care system to key audiences, particularly in reference to specific health consumers' needs and concerns. There is clearly a lot of information for health care advocates to gather and make sense of, as well as to strategically communicate to key audience to effectively advocate for meeting the health needs of consumers!

V. COORDINATING ADVOCACY EFFORTS

There is also a daunting administrative communication demand to developing effective and influential health advocacy organizations. Health advocacy group leaders cannot possibly accomplish the complex goals of influencing health care policies and practices to promote the goals of health care consumers all by themselves. They need to actively recruit followers who will become advocacy group members and volunteers to carry the group's messages and support group causes. Advocacy group leaders need to motivate, train, direct, and supervise these members to make sure they work effectively and cooperatively on behalf of the advocacy group/organization. Effective and adaptive leadership communication skills are needed to recruit, motivate, train, direct, and supervise personnel and volunteers [1].

Advocacy group leaders also need to learn how to raise funds effectively to support health advocacy efforts. This is not an easy social influence process to accomplish! Fund raising is a complex strategic communication activity. Care must be taken to identify the most relevant audiences who are good potential sources for the donation of funds to specific health advocacy groups/organizations. Health advocacy group leaders must learn how to develop strategic development campaigns to motivate potential donors to provide financial support to advocacy organizations. These campaigns need to be strategically designed to capture the attention of key audiences of potential donors, elicit a strong sense of involvement with the advocacy organization among these audiences, and motivate commitment to provide needed financial support for health advocacy. This intricate communication process for eliciting financial support for

health advocacy is complex and challenging. Moreover, there is tremendous competition between health advocacy groups for financial and material support. Health advocacy leadership demands strategic communication to navigate the complexities of raising funds to support advocacy organizations and the important activities of these organizations.

VI. MEDIA AND HEALTH ADVOCACY

Popular media are primary tools for disseminating relevant health information concerning the health needs and issues affecting consumers. The right media coverage using the best media channels can be instrumental in helping advocacy organizations reach and influence key audiences. For example, advocacy organizations can use popular media to reach people who are concerned about the issues being championed by the organization to encourage these audience members to serve as potential members and volunteers. They need to reach potential donors to convince these audiences to provide financial and material support to the advocacy organization. They need to use the media to motivate public support for relevant legislation and policies. They also need media to encourage support from key public officials. However, it is not easy to control media messages and coverage. Strategic communication is needed to influence media cooperation with advocacy organizations.

The most direct way to control media coverage is for advocacy organization leaders to purchase media spots and advertising. Unfortunately, this can be very expensive, especially when paying for the use of the most dramatic and popular entertainment media, particularly television and film time, and to a lesser extent radio time. Another strategy for getting media coverage is for advocacy organization leaders to ask for it. For example, advocacy leaders often submit public service announcements to media outlets for free dissemination. Unfortunately, these public service announcements, even when accepted for presentation, rarely gain much exposure because they are typically programed for inexpensive time periods. It is much more cost effective for health advocacy leaders to encourage free media coverage by earning it through the use of media advocacy [16].

Media advocacy is an intricate communication strategy for motivating mass media representatives to cover key stories that enhance the visibility and legitimacy of health advocacy organizations issues because the stories are attractive to these media representatives and promise to appeal to key audiences. In essence, advocacy leaders try to create news and encourage coverage of relevant and interesting stories. They can do this by building cooperative relationships with media representatives, staging news worthy events, linking advocacy group issues to breaking news or existing stories, as well as by providing editorial pieces and commentary on relevant issues.

Advocacy leaders can also encourage media advocacy

coverage by preparing relevant stories, materials, and media kits for media representatives that make it easy for these representatives to cover the advocacy group stories [17]. They can provide succinct and persuasive summaries of advocacy organizations' positions of key public issues. They can distribute relevant fact sheets that provide compelling data and evidence in support of key issues they want covered. They can provide interesting press releases, with names and contact information of potential sources for the stories. They can also provide relevant background articles to media representatives, as well as providing clear and compelling background information about the advocacy organization.

By encouraging voluntary media coverage the health advocate hopes to encourage key support for the advocacy organization. The goal is to use free media coverage to influence and shape public debate, put pressure on policy makers, and encourage community support for the advocacy organization's key issues. Media coverage can help set the public agenda concerning health advocacy concerns by raising awareness about key issues, encouraging public discussion of these issues, and influencing private conversations about the issues to motivate support for social change [18].

Building active collaborations with media representatives is critically important for motivating effective media coverage of health advocacy issues. There are several key questions that the health advocate needs to be able to answer. Who are the media representatives for the media outlets you want to cover your health advocacy issues? Are your messages right for the specific medium selected? Who are the audiences these media channels serve? What kinds of stories do these media outlets want to cover? What problems do you want addressed by the media? What are the ideal solutions to these problems? Who has the power to address these issues and must be mobilized to enact relevant social change? What messages would convince these key audiences to act on these issues? Do your messages have "news value" for the audiences the media outlets serve? How can you pitch your story to them? Can you help the media representatives do a good job? Are you responsive to media constraints (such as media time/space available for your story, the topics the media tends to cover, adjusting the level of complexity of ideas/language used to the appropriate level for the medium, the media outlets need for good visuals and/or sound-bites, and the need for good personal testimony to humanize the story)? To utilize media channels effectively health advocacy leaders must be able to address these questions effectively. They must be able to develop strategic health communication responses to these questions so they can design compelling messages and encourage media support for disseminating these messages to key audiences.

VII. HEALTH ADVOCACY AND NEW MEDIA

An increasingly important channel for communicating health advocacy messages in the use of new, digital, e-health media [19]. For example, the website has become a ubiquitous and pervasive part of the communication mix for health advocacy organizations [20]. The website is critical in helping to establish an identity for the advocacy organization and it is also can serve as a primary portal for communication with key constituents if it is designed to be interactive. Unfortunately, too many health organization websites do not effectively utilize strategic interactive ehealth communication features and fail to maximize communication with key audiences [21]. Many health websites fail to be particularly interactive, engaging, or dynamic [22]. To be effective, digital health programs must leverage the abilities of digital media to communicate vividly, interactively, and adaptively through the use of specialized mobile and interactive applications, video, tailored message systems, message boards, and social media [21]. For example, the use of tailored information systems allows health advocacy organizations to adapt online communication to meet the unique needs, interests, orientations, and backgrounds of specific individuals, ensuring that online communication is personal and relevant for users [23].

The website has morphed from being a mere repository of health information to being a portal to a range of exciting communication opportunities to connect, inform, and engage constituents of health advocacy groups. For example, health advocacy websites are often an entry point for access to online support groups, discussion boards, webinars, news feeds, and social media. Online support groups have become a staple health communication medium for many health advocacy organizations, enabling constituents who are confronting challenging health issues to connect with others confronting similar challenges to exchange ideas and to provide needed social support [24]. Evidence suggests that online support groups can be even more effective for supporting the needs of health care consumers than in-person support groups because they afford group members greater freedom to connect when they are in need, eliminate the need for travel to participate in the support group, and afford support group members a higher level of privacy and anonymity than in-person support groups [19]. Online support groups have even begun to drive research about new therapies for challenging diseases [25]. Perhaps one of the greatest opportunities to health advocacy organizations is to leverage the use of digital media to promote collaborations, through the sharing of relevant information and the building of social action partnerships to promote change [26]. As technology advances, there will be increasing opportunities to adopt new and powerful digital communication applications to promote the use of strategic communication to achieve the goals of health advocacy

VIII. THE CASE OF THE GLOBAL ADVOCACY LEADERSHIP ACADEMY (GALA)

The Global Advocacy Leadership Academy (GALA) is a new public health educational initiative designed to facilitate needed training and support for leaders of health advocacy organizations around the world. Leadership of health advocacy organizations is a complex enterprise that demands a tremendous amount of specialized knowledge about the health care system and constituent groups, adaptability to evolving health care systems, and the ability to reach, influence, and collaborate with a wide range of individuals from different sectors of the health care system through strategic health communication. The GALA program is introducing a unique international training and support model to prepare health advocacy leaders to meet the challenges of building and sustaining strong consumer advocacy organizations to champion the needs of patients and their caregivers within the modern health care system.

Effective leadership of health advocacy organizations is a demanding and complicated enterprise. While many aspiring advocacy organization leaders are passionate about helping to improve the modern health care system and to represent the needs of health care consumers, they may not be particularly well prepared to meet the demands of achieving these goals. The development of the GALA program grew out of the work of its founders (Gary Kreps and Paula Kim) in advising new health advocacy leaders from around the globe to achieve their goals. We recognized the many challenges that advocacy leaders face in influencing health research, health care practices, and health care policies and decided the best way to assist these leaders was to develop a formal system (GALA) for building advocacy organization leadership capacity. Moreover, we realized that health advocacy organizations were situated within a global health care system, concerning many of the same health care problems that affect consumers around the world. There was a tremendous need to link health advocacy organizations within a global advocacy network to promote international cooperation and collaboration for achieving shared goals of consumer empowerment and support within an interdependent, challenging, and evolving global health care system [27]. This paper outlines the goals and strategies of the GALA program for supporting the development of effective and influential health advocacy leaders and organizations.

IX. MEETING HEALTH ADVOCACY CHALLENGES

The GALA program is designed to help leaders understand the unique sociopolitical structure of the modern health care system, both on a broad societal level and also within the unique health issue communities that address the specific areas of direct interest to different health consumer groups (for example, communities interested in lung cancer, diabetes, Lupus, kidney transplantation, hemophilia, or other challenging health issues). Strong and effective health advocacy organization leaders need to understand the lay of the land within the rapidly evolving health care system so they can help influence health care policies and practices to

reflect the needs and goals of the health care consumers they represent.

Health advocacy leaders also need to know which specific organizations and individuals exert influences in the delivery of care, development of health policies, conduct of health research, and translation of research into health practices within the health domains in which they want to support the needs of consumers. Effective leaders must build collaborative relationships with key organizational representatives to exchange relevant information and cooperate on issues of importance to consumers. There is a daunting amount of information to learn to prepare for effective advocacy group leadership and a vast number of relational connections to establish for new advocacy leaders. Often, new health advocacy leaders have serious information deficits and limited relational connections that limit their abilities to accomplish important consumer support goals.

The GALA program is introducing new and relevant training, support, advising, and collaboration training programs to help health advocacy leaders build their knowledge base and learn how to work effectively with key representatives of different segments of the health care system. GALA will help connect advocacy leaders to relevant health researchers, educators, government and regulatory agency officials, health care delivery system personnel, health product and services corporation leaders (pharmaceuticals, health equipment, medical devices, insurance companies, and health informatics firms), media, representatives, as well as leaders of other related advocacy and support organizations. Not only is the GALA program designed to teach leaders about these different relevant segments of the health care system, but the GALA program will introduce health advocacy leaders to key representatives of these health sectors to initiate development of cooperative relationships for achieving advocacy goals.

The GALA program is also designed to help educate advocacy leaders about the nature of health research, including how research is funded, who conducts health research, how research results are reported, how to make sense of health research findings, and how research is translated into relevant health care policies and practices. The GALA program will help advocacy leaders understand the intricacies of the modern health care system, including the design of health care delivery systems, the key roles performed by different professionals and support personnel working within the health care system, and the evolving policies governing health care delivery and reimbursement. The GALA program will also educate advocacy leaders about the development of government legislation for health care policies, programs, and research, corporate influences on the health care system, and the unique roles performed within the health care system by professional associations, regulatory agencies, educational institutions, support organizations, foundations, and other assorted non-profit, for-profit, and government agencies.

X. HEALTH INFORMATION DEMANDS

Access to and effective use of relevant, accurate, and timely health information is critically important for guiding the important health-related decisions that consumers and providers must make across the continuum of care to promote health and well-being [28]. This includes decisions about the prevention of health risks, health promotion behaviors, the detection and diagnosis of health problems, health care treatment strategies, and best practices for living with health threats (successful survivorship) [29]. Yet, health information is complex, with many different kinds of health risks, each with different causes, stages, symptoms, detection processes, and treatment strategies. Health care knowledge is rapidly evolving with advances in research and applications concerning etiology, prevention, detection, diagnosis, and treatment of health problems.

Health advocacy organizations have the potential to help break through the complexity of health and health care by disseminating relevant, timely, accurate, and clear health information to consumers to help guide informed health decision making. However, there are significant barriers to the dissemination of health information, especially for at-risk populations, due to limited access to health information, health literacy challenges, limited education levels, and the complexity of health research and health care processes [30]. The GALA program is designed to help health advocacy leaders develop a wide range of necessary knowledge and skills to enable them to achieve important consumer goals. For example, GALA can help health advocacy leaders learn how to support the information needs of the health care consumers they represent, providing these consumers with access to relevant, timely, and accurate health information. The GALA program is also designed to help advocacy organization leaders learn how to promote and advocate for increased funding for relevant health research needed to improve prevention, detection, treatment, and survivorship for the consumers they represent.

The GALA program will help leaders learn how to run effective advocacy organizations to serve the needs of their constituents and influence health practices. Strategies for recruiting, mobilizing, and serving the needs of organizational volunteers and personnel will be examined. Fund raising, investment, and fiscal management demands will be carefully examined. Strategies for using funds wisely for disseminating information, influencing legislation and policies, and planning and implementing influential health campaigns will also be examined.

The GALA program will help advocacy organization leaders learn how to disseminate relevant health information through a variety of media to raise awareness and educate health policy makers, health care administrators, providers, and consumers about the health issues of concern to their constituents. The GALA program will help advocacy organization leaders learn how to lobby legislators, regulators, and health care administrators to improve health care policies and practices. The health advocacy leaders will learn how to provide needed support and assistance to consumers confronting challenging health care problems, as

well as to support the needs of their caregivers, family members, and loved ones. Perhaps most importantly, the GALA program is designed to promote local and global cooperation within the health care system to support health promotion, prevention, early detection, the best treatments, and successful survivorship for the health issues of concern to their constituents.

XI. THE UNIQUE GALA DELIVERY MODEL

The GALA program is designed to provide advocacy leaders with relevant information and strategies for working effectively with key internal and external groups. For example, training programs will be conducted concerning development of effective relationships and collaborations with media representatives, government representatives, corporate leaders, researchers, and health care system representatives. Moreover, the GALA program will provide advocacy leaders with ongoing information support, consultation, updates on new opportunities/constraints, and continuing education to meet changing needs and refine advocacy knowledge and skills.

GALA programs will be delivered in several different complementary ways. Advocacy leaders will be invited to attend training programs conducted at a centralized site (George Mason University), where they will also be introduced to relevant government, corporate, and health care system representatives, researchers and scientists, legal, fiscal, and administration advisers, campaign planners and fundraising experts, as well as experienced and successful health advocacy group leaders. In addition to centralized training programs, GALA program educators will travel to advocacy organizations in different parts of the world to provide on-site training programs. Arrangements will be made on demand to provide individual follow-up personal consultation with advocacy leaders to address specific emergent issues and concerns. Field experience opportunities will also guide advocates to participate in important meetings, conferences, and other relevant events, as well as to examine with GALA personnel the implications of these meetings. GALA is also proposing to link advocacy leaders and their constituents with an online information system (a collaboratory) to provide continuous support, on-line educational modules, repositories of health information documents, case studies, and media, as well as networking/collaboration opportunities for solving problems and developing new health advocacy initiatives.

The GALA training programs will model effective health advocacy leadership strategies. Leaders will learn how to establish and build effective advocacy organizations. They will learn how to recruit volunteers, organization members, and support staff. They will develop strategies for collaborating with other advocacy groups, locally, nationally, and internationally. They will develop skills for establishing working relationship with government representatives, corporate leaders, media representatives, educators, and researchers. They will also learn how to raise, manage, and invest funds for achieving advocacy goals.

The global nature of the GALA program is designed to promote international cooperation and collaboration for

addressing advocacy issues, sharing resources, and implementing new policies and practices within the health care system. Advocacy leaders from different parts of the world who may be addressing similar issues will be linked to share information and resources for addressing these common issues. These leaders will be encouraged to build international collaborations for influencing global health practices and policies. The GALA program will combine support for leveraging research, theory, policies, and innovative applications to promote development of robust and adaptive advocacy programs to support the needs of health care consumers and their caregivers.

XII. ESTABLISHING DEMAND AND CHARTING THE COURSE FOR GALA DEVELOPMENT

The development of effective health communication intervention programs, such as GALA, depend on careful audience and needs analysis formative evaluation research efforts to guide evidence-based program design, implementation, and refinement [31, 32]. To this end, the GALA project team has conducted a series of in-depth, semi-structured, qualitative personal interviews with a purposive sample of active health advocacy leaders and influential health promotion professionals representing a range of important health care domains (including different forms of cancer, cardiac-related diseases, neurological disorders, HIV/AIDS, and chronic disease problems) across selected global health communities to learn more about the concerns of health advocacy leaders and the unique issues they face. The survey data collected is being used to expand our understanding about the unique training needs of health advocacy leaders and the best strategies we can develop for meeting these training needs.

In our first wave of survey data collection we conducted 28 in-depth personal interviews, with representatives from four different continents, and five different countries (USA, Taiwan, Estonia, Japan, and New Zealand). We described the GALA Mission Statement as “The Global Advocacy Leadership Academy (GALA) was established as a public health educational initiative of the Center for Health and Risk Communication of George Mason University to facilitate training, skills building and support for leaders of health advocacy organizations around the world.” After reading the mission statement of the Global Advocacy Leadership Academy, we asked whether the respondents agreed with the stated goals. None of the respondents disagreed with the stated goals. One respondent did not answer this question, 26 respondents agreed with the goals, and one was unsure whether to agree or disagree. Overall, there was strong support for the stated mission of GALA, with one representative respondent explaining: “GALA goals are relevant in Estonia. Skills-building is essential to maximize our effectiveness in our work. As we have a very small staff, we cannot afford to run programs that yield no or limited results. Support from larger or more experienced organizations would give us the confidence and encouragement to continue our mission work and also provide the ammunition we need to show our partners the potential for positive results.” Another respondent stated,

“Yes, I think many health advocacy organizations are well meaning but lacking in skills and knowledge.” Another respondent emphatically stated, “Yes! There is a deep need for more educated consumer advocates to participate fully in health reform in the US.”

We next asked the respondents to describe the primary goals of advocacy organizations. All 28 respondents answered this question. Goals identified included:

- breaking down barriers to care,
- promoting health education for consumers,
- identifying relevant treatment options,
- promoting patient-centered care,
- encouraging prevention,
- building capacity and access to quality health care,
- lobbying for health policy initiatives to improve the health care system,
- promoting the rights of patients,
- building positive partnerships between patients and providers,
- promoting cooperation and information sharing,
- explaining complex health care concepts to consumers,
- securing funding for health research,
- changing public policies,
- representing the needs of consumers,
- meeting patient/caregiver needs,
- improving health and wellbeing
- advancing the cause of patients and providers,
- improving prevention and treatments,
- identifying cures for health issues,
- raising awareness about diseases,
- supporting patients,
- making things better for patients/caregivers,
- promoting the agenda of pharmaceutical companies and research organizations,
- setting up new systems to promote health,
- encouraging governments to address health problems,
- improving the intersection between government and science,
- providing researchers and providers with information about patients’ perspectives,
- encouraging more participatory care,
- promoting more patient engagement in their care,
- educating the public about the health care system,
- promoting more effective health care processes,
- promoting their organizations,
- providing consulting services,
- helping consumers understand how to achieve the best health outcomes,
- promoting drug and health device safety,
- building socially coherent support networks,
- setting up standards for health communication,

- helping the health care system focus on patient needs,
- disseminating relevant health information

We asked the respondents to identify challenges that may make it difficult for health advocacy organizations to achieve these goals. Some of the primary challenges identified included the:

- need to develop programs to sustain and treat low income populations,
- lack of buy-in and support for advocacy organizations by physicians and clinical staff,
- cultural differences between participants within the health care system,
- resistance by consumers to confront their health care specialists,
- complexity and fast-changing nature of health information,
- difficulty to build group consensus,
- lack of needed communication skills by advocates,
- insufficient funds to sustain advocacy programs,
- difficulty in designing and implementing effective health campaigns,
- consumer apathy about health issues and screening,
- challenge to influence government policies and legislation,
- power discrepancies between consumers and providers in health care,
- lack of patient understanding, time, and resources,
- limited advocacy staff and resources,
- prioritization of limited public resources,
- disease war competition among advocacy groups,
- government inertia,
- need to build networks with other organizations,
- lack of knowledge,
- lack of experienced leadership,
- lack of strategy in advocacy organizations,
- the complexity of fundraising,
- resistance to change within the health care system,
- need to recruit volunteers,
- lack of traditions of effective advocacy,
- difficult economic climate,
- cynicism among the public,
- bureaucracy is difficult to overcome,
- lack of credibility with those in positions of power,
- need for training within advocacy organizations,
- opposing interests and lack of focus,
- need for research funding,
- need for support networks,
- lack of education,

- competition with food, drug, health care industries,
- difficulty building support for long-term solutions,
- lack of suitable information technology,
- pay for performance profit-driven US health care system,
- belief that collective solutions to health problems infringe on individual freedoms,
- expense of health promotion efforts

We asked what the primary benefits were providing training for leaders of health advocacy organizations. Respondents described the following benefits:

- building a solid knowledge base concerning health care,
- enhancing patient care,
- reinforcing patient rights,
- learning new techniques to improve programs,
- promoting effective lobbying,
- developing good media relations,
- teaching leaders how to lead,
- communicating advocacy skills and standards,
- providing advocates with tools to build successful organizations,
- preparing advocates with tools to be successful,
- building effective support groups,
- leveraging knowledge to promote change,
- promoting collaboration among advocacy leaders,
- focusing the missions of advocacy groups,
- increasing awareness about important health issues,
- promoting changes and societal support for combatting health problems,
- promoting skill-building and collaborative problem solving,
- establishing professional standards for advocacy,
- increasing the credibility of advocates,
- making more compelling cases for supporting advocacy goals,
- amplifying the efforts of stakeholders,
- introducing new ideas to influence public policies,
- promoting more cooperation across advocacy organizations,
- empowering advocates,
- setting quality standards for advocacy,
- advancing the field of advocacy,
- increasing the effectiveness of advocacy organizations

We asked the respondents to identify the biggest training needs of advocacy group leaders. They suggested the following areas for developing useful training and support programs for health advocacy group leaders:

- access to a centralized database for assistance and networking,

- easy access to different training programs,
- opportunities to interact with and educate other health advocates,
- workshops about sharing resources with other advocacy groups,
- strategies for gaining public and corporate support,
- best approaches for influencing health legislation at local and national levels,
- strategies for improving relations between patients and health care workers,
- leadership skills training,
- communication training,
- strategic thinking and long-range planning training,
- management skills and strategies,
- understanding public policy and politics,
- social influence strategies,
- fundraising training,
- how to build sustainable networks from grass roots activism,
- understanding regulatory and legal processes,
- staffing and management of volunteers,
- social media use training,
- new campaign and public influence strategies,
- understanding health care finance,
- grant writing skills training,
- social mobilization and empowerment training,
- new models of health advocacy,
- support for answering questions and providing recommendations,
- education about the economics of business and health care,
- not-for-profit management training,
- public speaking training,
- media relations training,
- team building and communication training,
- negotiation skills training,
- coalition building training,
- understanding the health care ecosystem,
- facilitation skills training,
- diplomacy skills training,
- government relations training,
- fiscal management training
- developing marketing strategies specific to community needs,
- developing productive partnerships with advocacy group leaders,
- educating advocacy leaders about promising medical and public health breakthroughs,
- educating advocacy leaders about applications of the scientific process,
- identifying best practices for health advocacy,
- describing recent grant funding programs, clinical trials, and new government initiatives,
- providing data on policymakers' perspective on key advocacy issues,
- establishing case studies of best practices in health advocacy,
- providing updates on the political and policy environments,
- holding regular training sessions about health research,
- updating advocates concerning relevant new research and publications,
- participating on advocacy group advisory boards,
- educating advocacy leaders about learning styles, use of social media, and providing appropriate social support,
- demonstrating the benefit of research for patients,
- including patients in developing research priorities and trials,
- giving presentations about research findings, and new areas for relevant research,
- describing research finding that help answer real-world questions,
- providing evidence to support advocacy efforts,
- providing insights into evidence-based best practices,
- including health advocacy organizations in the design and conduct of relevant health research programs,
- sharing mega-trends in public health,
- helping to create communication/education programs to help the public navigate relevant health issues,
- translating complex research findings into layperson's language,
- providing relevant case studies about health advocacy,
- training health advocates to understand and present research findings,
- conducting research on prevention, detection, treatment, and effective survivorship

We asked the respondents whether their own organizational already providing training programs for health advocacy leaders. Of the 28 respondents, 20 replied that their organizations did not provide any training for health advocacy leaders, 1 respondent was unsure about any training programs offered, and 7 other mentioned minimal training programs. This suggests that there is an unmet need for training programs designed for health advocacy group leaders.

We asked the respondents how researchers could help support health advocacy leadership. They mentioned that researchers could help with:

We asked the respondents to describe the roles that media representatives could perform for health advocacy organizations. They suggested that media representatives could:

- increase awareness about relevant issues,

- collaborate with health advocacy organizations,
- report on issues related to justice for health care consumers,
- deliver prevention messages to the general public,
- air health education film clips and public service announcements,
- publish news articles about health advocacy topics,
- distribute advocacy group campaign messages and media,
- report on advocacy group activities,
- deliver advocacy positions on important issues to key opinion leaders,
- raise policy makers awareness about key health advocacy issues,
- increase the visibility of advocacy organizations,
- provide accurate information about health issues in collaboration with health advocates,
- customize information for different audiences,
- assist with the use of social media

We asked the respondents what role leadership, teamwork, and skills building should play in developing and maintaining effective health advocacy organizations. They agreed unanimously that these were important aspects of health advocacy and suggested that advocacy organization needed:

- marketing training,
- continuing education and certification,
- develop clear missions,
- leadership, teambuilding, and skills building training,
- strategic management training,
- communication, public speaking, consensus building, and listening skills training,
- change management training,
- collaboration skills training

Finally, we asked the respondents whether there were any other issues or topics they wanted to mention. They replied that:

- nurse navigators are an important part of effective health advocacy,
- love and sharing are important aspects of effective health advocacy,
- be aware that some pharmaceutical companies are developing similar initiatives for health advocates,
- take advantage of available experts to help train health advocates,
- provide a centralized forum for sharing information with health advocacy group leaders,
- expand training programs to the boards of directors that oversee health advocacy organizations,
- help advocacy group leaders understand that the primary role of advocacy organizations is to

- help consumers and not self-perpetuation of the advocacy organization,
- help advocacy group leaders keep overhead low and services to consumers high,
- help promote high quality in health advocacy groups,
- develop a strategy for positioning GALA to stand out from other training programs,
- a training program for nurturing health advocacy leaders would be of great value,
- let me know how I can help with GALA,
- train for multiple roles that different actors can perform

The responses from the survey have clearly validated the need for training programs, like GALA, to support the development of effective advocacy group leadership. However, the list of issues that a comprehensive health advocacy training program should cover is daunting. Health advocacy leaders have important needs to develop a deeper understanding of the health care delivery system, the legal and regulatory health care environment, the corporate players in the health care system, the health research environment and processes, as well as the influences of media on achieving health advocacy goals. Moreover, the survey suggested that is critically important for health advocacy leaders to develop a number of important communication, leadership, team-building, fund-raising, and financial management competencies and skills. There is also a strong demand for building collaborations across advocacy groups and with key partners from the health care industries, government agencies, research institutions, and media organizations. To be effective, the GALA program must not only provide relevant training for health advocacy leaders. It must also facilitate partnership building, collaborative problem solving, and effective media relations. The GALA program must develop a forum for introducing representatives from different key organizations to advocacy group leaders. It must provide ongoing consultation, advisory services, and problem solving support to health advocacy leaders. It also must provide a repository for storing and disseminating key information about relevant research, best practices for health advocacy, and new opportunities and constraints that are relevant to health advocacy organizations. The results of this survey have been instrumental in guiding the development of GALA program activities and resources. We will continue to gather data and feedback from health advocacy leaders to help us refine and expand GALA programs, especially as the health care system evolves and the demands of effective health advocacy leaders and organization change. In this way, the GALA program can grow, expand, and, continually be responsive to the needs of health care advocacy group leaders.

To promote the ongoing growth and development of the GALA program, new strategies are being examined for seeking government and corporate support for GALA training and outreach programs. GALA team members are identifying leading experts to work with the program to serve

as mentors and trainers for aspiring advocacy leaders. New training modules, educational materials, and instructional guides are being designed and refined to use with the program. The GALA online collaboratory system is being designed and information is being collected to include in the collaboratory's online repository of documents, case studies, articles, research and funding opportunities, advocacy resources, and media programs. Information about the GALA program is being disseminated to key individuals and organizations around the globe to increase awareness and support for the new and exciting GALA health advocacy leadership activities.

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