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Connecting for Health Literacy: Health Information Partners

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Abstract

This article describes a community-based health information partnership to address health literacy and health information inequalities in marginalized communities. Public health, medical, literacy, and library practitioners promote health literacy through outreach, training, and professional development activities in community settings. They create learning environments for people to develop the necessary knowledge and skills to better understand health information and health policy so they can make decisions concerning personal and community health. Outreach activities focus on visits to neighborhood health centers, health fairs, health exhibits at union meetings and conferences; training programs involve hands-on, peer-led computer classes for people living with HIV and for the general public; and professional development programs connect librarians, health providers, public health workers, and literacy teachers in joint planning and learning. Several learners currently participate in and lead community health education programs and HIV advocacy. The coalition's strength develops from strongly shared objectives, an absence of territoriality, and a core active leadership group.

Keywords

Internet; health literacy; health information outreach; coalitions

The literature abounds with reports of millions of U.S. residents searching for online health information to investigate prevention options, manage chronic conditions, gain information, and make treatment decisions (Pew Internet, 2005b). Innovative projects have brought workstations and expert medical support to people and families dealing with serious health risks, such as breast cancer, HIV, and diabetes (Gustafson et al., 1999, 2001; Kreuter et al., 2006; Safran, 2003; Shea et al., 2002). People living with HIV who use Internet resources for health information have demonstrated better health information behaviors and often increased engagement in community health promotion (Kalichman et al., 2005, 2006).

Whereas increasing proportions of the online population access the Internet to research health and other topics (Pew Internet, 2006, 2005a), substantial numbers of people have little access, technology skills, and reading ability to take advantage of the many online resources on health (Carlson et al., 2006; Pew Internet, 2005a). Even avid users have little awareness of reliable health sources and important criteria for evaluating them (Pew Internet, 2002), and health care providers, health educators, and public health workers are often challenged to deliver health information that matches the health literacy proficiencies of the public (Parker & Kreps, 2005).

Starting in 2000, a group of health educators and community health center providers in the District of Columbia developed a health information outreach program to provide Internet access and training for patients and providers at community health centers (Martinez, Kind, Pezo, & Pomerantz, 2008). With funding from the National Library of Medicine (NLM), librarians and health educators at the George Washington University Medical Center (GWUMC) placed computer workstations in health center waiting rooms. The computers were equipped with Internet links to prevention and treatment information, community resources, educational programs, and newspapers from Latin America.

Students and faculty from local universities visited patients at the community health centers to help them research their health condition or other topics of interest. Health care providers invited our group to teach computer classes for their health promoters, teen peer educators, and patients with HIV and diabetes. At the same time, we collaborated with an innovative community-based HIV organization, the Project of Intermediate Advocates (PIA) that used technology to deliver health information to people living with and at risk for HIV. PIA sponsored community education presentations and monthly hands-on computer workshops for people inexperienced with the Internet and provided the opportunity to train health center providers and patients together.

As the health centers became more interested in online health information programs, they developed their own proposals and projects. A pediatric center, Children's Health Center SE, developed a survey of computer and Internet access and use among their families, and hosted "Education Station" computers in their waiting rooms (Kind, Huang, Farr, & Pomerantz, 2005). Another facility, Family and Medical Counseling Service, Incorporated, held weekly computer classes for patients with HIV taught by their HIV adherence specialists and subsequently bought laptops for 10 graduates to apply their new skills. Another major HIV treatment center, the Max Robinson Center of the Whitman Walker Clinic, sponsored weekly computer labs staffed by GWUMC faculty and students. A Latino health center, La Clinica del Pueblo, installed computers with Internet connections in their exam rooms for patient learning. In an effort to learn from each other, representatives from these organizations began to meet informally to discuss mutual problems and solutions. These meetings were formalized when planning funding was obtained from the National Library of Medicine to develop a community health information outreach partnership.

These early planning meetings resulted in a new coalition, Health Information Partners (HIPS) (see Figure 1). The initial coalition members were representatives from health centers, but soon the HIPS membership expanded to embrace public health, literacy/ESOL, and library organizations. HIPS members developed goals to address health literacy, close the gaps in information that contribute to health inequalities, and promote health advocacy. The purpose of this article is to describe the objectives, activities, and evaluation of the HIPS partnership, which may be useful for others considering this kind of approach to health information outreach.

Background/Literature Review

People of all educational levels face enormous health information challenges when making decisions about healthy living, health care, and health policies. The U.S. health care system is very complex and fragmented making it difficult for people to navigate. When people do access care, their physician visits are often brief, making it harder for providers to educate patients about complex health issues. The National Assessment of Adult Literacy (NAAL) describes the additional burdens carried by those with less education and economic assets (Kutner, Greenberg, Jin, & Paulsen, 2006). People with higher incomes often have similarly low levels of health information comprehension but are more likely to have social networks that include medical professionals who can explain and recommend health care choices (Cuban, 2006).

Although quality information cannot replace quality health services, people do need health information that is written in plain language with enough depth and substance to allow people to weigh all the options for prevention and treatment. In the District of Columbia where residents have the highest rates of AIDS of any U.S. city (DC Department of Health, 2007) and high rates of diabetes and heart disease (DC Department of Health, 2005), access to sound health information is critical to dispelling myths, promoting personal health, and advocating good health policies.

People also need strong evaluation skills to understand and detect the various biases that often accompany health information. Pharmaceutical company advertisements are abundant promoting new drugs and new “diseases,” food manufacturers promise quick health benefits from their products, and research studies often seem to contradict results of earlier studies. Scientists increasingly question the integrity of governmental public health decisions, such as FDA's handling of emergency contraception and Vioxx, and EPA's appointments of industry representatives to its advisory committees (Markowitz & Rosner, 2003; Union of Concerned Scientists, 2006). These public health issues place enormous demands on people's ability to access relevant information, evaluate its accuracy and bias, and support policy positions (Rudd, 2002; Zarcadoolas, Greer, & Pleasant, 2006). Norman and Skinner (2006) enumerated six “eHealth literacy” competencies (science, media, text, health, computer, and information literacies) that people need to locate, retrieve, evaluate, and apply relevant and reliable information. More informed community residents can become actively engaged in neighborhood *and* national level health issues as exemplified by grassroots HIV activist organizations and by literacy programs rooted in social justice perspectives (Nash, 2006).

In 2004, the Institute of Medicine (IOM) recognized the demands people face to understand and apply health information to their personal lives, calling for policies to improve the public's ability to use health information, from better clinician-patient communication to improvements in K-12 education. They specifically recommended closer collaborations between health and literacy practitioners (Nielsen-Bohlman, Panzer, & Kindig, 2003). In a review of the health literacy literature, Alexa McCray (2005) called for “all to work together to ensure that everyone has an equal opportunity to access, understand, and use health information.”

Health, library, and literacy practitioners are natural partners to promote health literacy. Medical organizations have created tools and strategies, such as “Ask Me 3,” “Teach Back,” and “Show Me,” that providers can use to stimulate better provider-patient communication (Partnership for Clear Communication, 2006).

Literacy experts can teach clinicians and public health workers how to assess literacy levels, evaluate learning, communicate information clearly, apply adult learning principles, and refer patients for literacy instruction and GED programs (Knowles, 1990; Marcus, 2006; Parker & Kreps, 2005). Adult, ESOL, and literacy educators who incorporate health into their curricula have initiated novel methods to teach their students how to achieve health and interact

successfully with practitioners (Virginia Adult Education Resource Center, 2003; World Education, 2006). They often incorporate “action” assignments that apply these health lessons, such as student presentations, health fairs, or role playing (Hohn, 2002; McKinney & Kurtz-Rossi, 2006; Muro n.d.). In turn, health practitioners can help literacy instructors develop and teach health in the adult education curriculum. Clinicians and health educators can present on key health concerns chosen by students.

Health science and public librarians can teach learners how to develop the technology and critical thinking competencies to find and filter through the enormous amount of health information online. The Medical Library Association's (MLA's) health information literacy program offers curriculum guidance and resources on health information assessment to train the trainers (MLA, 2007). Public and academic health libraries create health information programs for their communities supported by the National Library of Medicine and the Medical Library Association (MLA, 2007; Peay & Rockoff, 2005).

Method, Strategies, Interventions

HIPS created a coalition of health, medical, adult education, and library organizations to promote health literacy and overcome inequities in health information access and use. As a collaborative, HIPS operates with clear and concise goals to (a) sustain and expand community-based education programs; (b) implement identifiable strategies for the use of health information technology and health literacy methods; and (c) create environments for community residents and health professionals to have the necessary knowledge, skills, capacity, and opportunity to understand and participate in decision making concerning their personal health and local community health policies.

To achieve these goals, HIPS holds *outreach* activities to increase awareness of sound online health information and recruit to classes through demonstrations, fliers, and presentations; *training* classes during which learners gain valuable critical thinking and technology skills while learning about HIV, diabetes, nutrition, and prevention; *planning and professional development activities* to foster transdisciplinary relationships between health, education, and library providers and community members; and *dissemination activities* to prepare formal presentations and articles for publication.

The staff of the State Education Agency (SEA), PIA, and GWUMC public health faculty and students conduct most of the outreach in a variety of settings. On board the Trans.form.er, the SEA computer-equipped literacy outreach van (Figure 2), we park outside a social service agency and neighborhood health center weekly to conduct health, job, and education searches for the public and invite them to training programs. In addition, many members of the coalition organize and staff health fairs and display online resources tailored to the participants (MedlinePlus for everyone, NIH Senior Health for seniors, and Teenwire for teens).

Training Program

HIPS trains providers and the public through hands-on computer classes, presentations, and networking meetings. PIA is the lead training organization, jointly developing the training curriculum with GWUMC faculty and students, organizing formal workshops at several computer labs, including the central public library, and at community organizations. (Our basic and specialized training scripts are hosted on our Web site, <http://connectforhealth.gwu.edu/training.htm>). GWUMC staff also trains small groups of clients at several community health centers each week.

Our priority learners are working-class members of the community, especially disenfranchised people who have little or no experience with the Internet and online health information

resources. The training is based on adult learning theory: addressing learners' current needs and interests; using interactive, participatory teaching strategies; and ensuring immediate benefits of the classes (Knowles, 1990). Each workshop opens with introductions that elicit each person's health topic of interest, a discussion of evaluation criteria (Table 1), and a brief introduction to Web navigation if needed. The facilitator demonstrates sections of MedlinePlus, allowing learners to apply the skills to their own personal topics with help from technical assistants. After mastering the major sections of MedlinePlus, the class reviews other Web sites that promote HIV prevention (aidsinfo.nih.gov), nutrition (smartmouth.org), online community resource directories, and other topics suggested by the class. The classes are tailored to the skills and interests of the participants and allow time for individual exploration.

Planning

The community planning process includes building collaborations with agencies within a variety of neighborhood and community-based settings. Collectively, HIPS arranged several meetings with government agencies and faith- and community-based organizations to introduce the health information project's aims and desire for partnerships to support community health literacy and prevention education programs. In addition, we hold quarterly planning meetings and biannual conferences. These Connecting for Health Literacy conferences draw between forty-five and seventy people who break into planning groups to explore collaborations. The uniqueness of HIPS comes from this partnership among health, library, and literacy organizations.

Advocacy

Since fall 2005, the Metropolitan Washington Public Health Association's Health Disparities Committee, a coalition member, distributes HIV information, petitions for prevention and care policies, and health information to residents in the Washington Highlands neighborhood, including fliers for health information trainings and recommended Web sites. Several students from our training classes at two health centers have joined this outreach, transforming their initial personal health interests into community health advocacy. Two of our initial learners now teach health information classes and one manages the PIA outreach program.

From fall 2004 to fall 2006, HIPS the following (figures may include repeat participants):

- 170 training classes and visits for more than 1,000 people,
- 240 outreach activities for more than 5,000 people,
- 100 planning meetings with 300 people, and
- 3 networking conferences with 180 people.

HIPS Members and Learners

HIPS members include many of the nonprofit health centers in the District of Columbia and the Primary Care Coalition of Montgomery County, Maryland, PIA, the School of Public Health and Health Services at The George Washington University, the Metropolitan Washington Public Health Association, the HSC System (serving children with disabilities), St. Elizabeth's Hospital of the DC Department of Mental Health, and employees and community outreach workers of the DC Department of Health. Two major organizations representing adult education programs are members of HIPS. The State Education Agency joined HIPS in its initial planning period and has provided access to numerous adult education programs for health information trainings in the classroom and on its mobile computer van, the Trans.form.er. DC LEARNs, a coalition of literacy and workforce preparation organizations, is a newer member that connects HIPS to other literacy providers. The DC Public Library system sponsors health fairs, health resource guides, and talks at its main library and

four branches. Its Washington Highlands Library branch hosts monthly outreach visits, a health information center, and a computerized “Resource Corner” supported by two HIPS organizations.

Promotion and Marketing

HIPS promotes its program through electronic and hand-to-hand distribution of materials supplemented by outreach visits and meetings:

- a listserv for members for announcements of trainings, workshops, resources;
- bilingual (Spanish and English) wallet cards with the addresses of two health Web sites and contact information;
- bilingual bookmarks with a list of reliable Web sites and evaluation criteria;
- brochures describing our objectives, members, and recommended Web sites;
- fliers promoting our workshops and Web sites;
- community street outreach promoting health fairs, health talks, and HIV information;
- exhibits at health fairs, conferences, union meetings, community events;
- occasional mailings of event announcements to community organizations;
- occasional announcements in area newspapers;
- a HIPS banner displayed at events; and
- a Web site with announcements of trainings, basic curriculum, and links to health literacy documents (<http://connectforhealth.gwu.edu>).

Project Evaluation Strategies

Our primary evaluation methods include a journal to chronicle daily activities, pretest and posttest questionnaires to assess the hands-on computer workshops and a mail-back postcard survey given at outreach visits and trainings to ascertain subsequent use of health information or enrollment in literacy programs. In addition, HIPS members responded to an online survey to assess the value of the coalition, its challenges and benefits.

Results

Evaluation of Training Workshops

As our primary training organization, PIA organizes 2- to 3-hour hands-on Internet workshops to teach learners how to navigate the Internet, locate reliable health information online, and apply evaluation criteria. Workshop participants complete a pretest and posttest questionnaire to assess their awareness and knowledge of the Internet, specific criteria to evaluate Web sites, content of MedlinePlus, credible HIV information, and the biases of the different Internet domains. They also complete a postworkshop evaluation survey to assess their satisfaction with the workshop's content and pace, their intent to use the information gained, and their suggestions for future workshops and improvements.

Slightly less than half of the workshop participants have used the Internet. Most people who did use the Internet stated that they searched for jobs, general or research information, work-related topics, and used e-mail. Only 1 out of 52 responses indicated that the searcher used the Internet for health information.

A sample of 12 workshops including 91 people revealed a modest improvement in posttest scores, an average of an increase of 2.1 points (out of a total of 8 points) for a 26% improvement. A large majority (88%) found the workshops “very useful” and 12% rated them “useful.” None were rated “not useful.” All respondents learned new resources during the workshop. All respondents intend to use the Web resources learned during the workshops at a subsequent time for personal, family, and work purposes. Many said they would share their knowledge and handouts with others, including their students, “with the community,” at church, and with clients. Several wrote that they were going to purchase a computer, quit smoking, show the body mass index (BMI) online health check tool to students, conduct job searches, and one person wrote that he/she would use the Internet to help “find my parents.” Whereas most people rated the pace of the workshops “just right,” people with prior Internet experience found them too slow and asked for dual level workshops, one for experienced users and one for novices.

Evaluation of Postcard Surveys

Postcard surveys included questions about *subsequent use* of resources. The questions are printed on one side of a self-addressed, stamped postcard. We gave 250 postcards to people from workshops or briefer visits on the Trans.form.er or at health centers and asked people to return them in 1 or 2 weeks. We collected and analyzed 47 responses. The results reveal that

- 88% of the people who interact with HIPS learned about new health Internet resources,
- 31% learned about new community resources,
- 62% learned about new adult education programs,
- 90% learned how to use the Internet,
- 50% registered for new classes,
- 76% used a new health Web site, and
- 76% reported that the Internet health information helped them understand or make a decision about their health.

Comments added to the postcard were favorable about the trainings and coaching:

- (I have) more confidence in using the Internet.
- It (the Internet) was very informative and proves to be most beneficial in maintaining good health.
- PIA has been good for me for finding information on my HIV status.
- Very comfortable atmosphere (on board the Trans.-form.er); (the instructors) love to teach.
- I am interested to learn as much as I can. Knowledge is wisdom.
- I enjoy the class and am willing to come to another workshop that will advance my skills.
- The information was priceless. I feel I have a better understanding about my health condition.

Evaluation of the HIPS Coalition

The HIPS Steering Committee designed and administered an online survey in 2005 to elicit responses from its members about their reasons for working with the coalition, the challenges they face, and their recommendations for future activities. An anonymous survey was distributed to HIPS members using Survey Monkey, an online survey instrument. Twenty-four

people responded, matching the number of our most active participants. Answers to the following question appear in Table 2: “As a result of your participation in HIPS which of the following have you experienced (select all that apply)?” This question was modified from the New York Academy of Medicine's questionnaire on partnerships (Lasker, 2002).

The survey reported several challenges, many dealing with time, the balance of work and coalition activities, and relationships with parent organizations.

Respondents identified these factors for HIPS' success:

- Everyone's commitment to improving health literacy; being able to work together for a common goal; the people and their dedication to the mission.
- Participating agencies want to cooperate and are totally committed to community work.
- HIPS members are nonterritorial and committed to common goals and objectives. Members are caring and sharing. HIPS tries to benefit its members by sharing resources and skills rather than competing with one another.
- A core group of committed leadership and a diverse range of organizations related to health literacy; the contributions of health educators, librarians, literacy organizers, nurture the group with their initiative and insights.
- Leadership, dedication, hard work, and tenacity. Strong and sensitive leadership and the relationships between people who have met each other primarily through this work.
- The importance of the health literacy problem in the Washington, D.C., area. A very clearly thought-out plan which is effectively implemented.
- The wide variety of information offered to the people. They can find everything they want to know about all their needs. It is a complete program for information.
- The emphasis on outreach and networking.

Discussion

Partnerships

Of our 23 original collaborators, 21 continue to participate actively in HIPS activities. Three additional organizations have joined during the implementation stage, and additional branch public libraries and adult education programs have participated in HIPS meetings and sponsored health information activities. HIPS networking conferences recruit new participants and activity sponsors. A core group of five to eight people provide ongoing leadership.

As demonstrated by the member survey, the partnership is strong because of the commitment to shared objectives and values, good communication, and member diversity. The coalition uses consensus to make decisions and includes all interested members in planning and implementation. HIPS members enjoy the work they do together.

Because each organization has a role in HIPS that is often distinct from others, it was important for organizations to unite for joint activities. The three Connecting for Health Literacy networking conferences, the development of materials and evaluations, and the library-centered health fairs were essential projects that allowed members to work together. These activities generated more group cohesion.

The survey responses and the participation by HIPS members in key activities demonstrate the relationshipbuilding strengths of HIPS and its ability to forge new affiliations and transfer knowledge from different disciplines and sectors in health, education, and libraries. Whereas time conflicts affected participation, they appear secondary to the benefits gained by membership in the coalition.

Challenges Encountered

As indicated in the survey responses, balancing work and coalition activities is a major difficulty. Most organizations receive no compensation for their time and participate because the coalition furthers their organizational and personal goals. Many members participate without official institutional involvement.

HIPS would benefit from more clinician involvement. One pediatrician and two pediatric fellows consistently participate in HIPS planning and implementation, and several other providers invite us to participate in their programs. However, it is hard to determine if providers refer patients to online health information. Staff members report utilization of the health center lobby computers but are not aware of its use for health information. Many physicians are interested in health literacy and consult with HIPS, but it is not clear if they actively promote online health information during their busy clinical visits. We need to help health providers integrate health information resources into their practice. At the same time, we are working with literacy providers to help them integrate health into their classes. Beginning in fall 2007, HIPS will introduce a health curriculum into two adult education programs that will feature online health research, student-led discussions, guest presentations, and health activities.

Measuring health outcomes remains challenging. From workshop evaluations and observations, HIPS has been able to document the immediate learning of students. There are limited data on postvisit and postworkshop utilization of health and other information from the postcard survey.

Because some HIPS trainings occur with the same people over a long period of time at some health center and adult education computer classes, HIPS trainers observe the development of technology skills and resource awareness among the participants. Several people who began as students are now HIV advocates and health information trainers. This transition from novice learners to evolving health advocates is a valued achievement.

Lessons Learned

HIPS still needs to foster additional joint activities and refer our colleagues and clients to HIPS activities, such as our training workshops. We are still finding strategies that help us share our strengths and resources. It is a testament to people's commitment that several major activities have continued past the funding cycle.

We intend to continue to link our work to organizations' key missions and objectives, maintain a constant presence in several neighborhoods, continue classes with repeat participants, incorporate trainings and presentations into the work of other organizations, and foster more initiative from member groups. Not all participants encountered need health information but rather need guidance and support to find jobs and other community resources. HIPS needs to remain flexible and meet people's needs.

Conclusions

Building a coalition unified in its commitment to health information equity but diverse in its representation by discipline, education, and demographics can advance the cause of health literacy. Community residents often excluded from technology and other more pressing

necessities respond enthusiastically to the acquisition of new skills and information that they can apply to their lives.

Recommendations for Improvement

- *Evaluation/research:* HIPS needs substantial funding to allow us to measure the impacts of our trainings beyond our workshop evaluations and focus groups conducted earlier.
- *Health centers:* Whereas health centers welcome HIPS to work with patients and invite HIPS to participate in their health fairs and programs, we need to engage more health care providers and encourage them to refer their patients to our classes and inform us of strategies that will help them promote health literacy.
- *Health advocacy:* We have begun to engage more people in community education and advocacy around HIV and AIDS. Health information programs have the opportunity to apply a social justice framework rather than a purely technological perspective and acknowledge that information is a small but necessary component of improving individual health and community health status.
- *Team building:* It is important to sponsor activities that bring the individual organizations together and foster interaction directly between members as opposed to communication flowing only through the coordinator. HIPS achieved this in part through health fairs, conferences, planning meetings, and promotional materials design but needs to increase these activities.
- *Engaging the public:* Whereas HIPS works with community health educators in PIA, there were no community members recruited to become active planning members of HIPS. The increased participation in HIV advocacy activities by clients at the community health programs is a small but critical marker of success in mobilizing people for community health improvement.

For organizations considering their own health information coalitions, we recommend becoming familiar with community health and related programs and asking to contribute to them. Be conscious of inequities in power and access to resources among community and university organizations and appreciate the strengths and intelligence of many leaders of grassroots organizations who are often ignored because of their lack of academic credentials. Upholding the qualities of equity and inclusion in terms of decision making and resource allocation, using the strengths of members, and developing shared objectives make health information outreach coalitions stronger and valuable.

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FIGURE 1. Health Information Partners (HIPS) Members in 2005

FIGURE 2. Onboard the State Education Agency Computer Van, the Trans.form.er

TABLE 1
Health Information Evaluation Questions

Evaluation Questions Asked in the Trainings
What are the major Internet domain names and what are their agendas?
<i>.com, for-profit organizations</i> —selling products and services
<i>.org, nonprofit organizations</i> —selling or promoting ideas, advocacy, services; fund-raising
<i>.gov, governmental agencies</i> —representing current political policies, promoting services; health sites based on scientific research, which is often funded by industrial or pharmaceutical organizations
<i>.edu, universities and colleges</i> —recruiting students, hosting research as well as student work
<i>.net, network and communications services providers</i> —selling products and services, hosting personal web sites
How do you know you can trust the information?
Source or producers of the Web site—note their credentials and experience
Currency—note the date the information was written, reviewed, and updated
Attribution or references—note the citations of documents the Web site uses
Funding—note the type of organizations funding the site

TABLE 2
Evaluation of Health Information Partners (HIPS) Coalition: Benefits of Participation (*n* = 24)

<i>Members reported that as a result of participation in HIPS, they:</i>	<i>%</i>	<i>n</i>
Developed valuable <i>relationships</i>	86.4	19
Acquired useful <i>knowledge</i> about services, programs, or people in the community	72.7	16
Gained the ability to make a <i>contribution</i> to the community	63.6	14
Gained an enhanced ability to <i>address an important issue</i>	59.1	13
Increased the use of my expertise or services	45.5	10
Gained the ability to have a <i>greater impact</i> than I could have on my own	40.9	9
Developed <i>new skills</i>	36.4	8
Gained an enhanced ability to <i>meet the needs</i> of my constituency or clients	36.4	8
Gained a heightened <i>public profile</i>	31.8	7
Gained an enhanced ability to <i>affect public policy</i>	13.6	3
Acquired additional <i>financial support</i>	13.6	3