The Eagles e-health Project: A case study in fighting health disparities through collaborative e-health literacy training

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Abstract:

Increased e-health literacy has the potential to have many medical & social benefits, but delivering high-quality electronic health information to under-served populations can be complex. The goal of the Eagles e-health project was to develop materials to educate lay information intermediaries in under-served communities about National Library of Medicine consumer health resources. To date, little research explores how multidisciplinary, computer-based collaboration influences the development and implementation of consumer health education interventions, nor has a specific model of collaboration for e-health literacy outreach been developed. This research describes how a multidisciplinary group of researchers developed e-health literacy outreach materials for use in under-served communities. The case study approach used in this research is two-fold: (a) to describe a collaborative health literacy project's evolution & deployment, and (b) to explore a specific case of e-health literacy project development in order to help collaborators understand the process & pitfalls when adapting a multi-disciplinary research project from a traditional to an online model.

Keywords: e-health, health literacy, case study, community informatics, social informatics, under-served populations

Introduction:

Health disparities, which occur disproportionately in under-served communities, have numerous negative social consequences, including disproportionate rates of chronic illness, mortality and health care costs. Despite the fact that the NLM offers many free, high quality e-health resources to consumers, e-health literacy (the awareness of and use of online consumer health information resources) is too low. Greater awareness of these resources among under-served populations can increase health literacy and reduce health disparities. To address this need, the United Negro College Fund/National Library of Medicine – Historically Black College or University (UNCFSP/NLM HBCU) e-health ACCESS Project awards grants to promote disease prevention and wellness on HBCU campuses and in surrounding communities through the use of e-health resources provided by the NLM. The goals of the Eagles e-health project were 1) to develop materials to educate lay information intermediaries about NLM consumer health resources, 2) to evaluate the effectiveness of such interventions and 3) to provide materials that information intermediaries could subsequently share.

Insert robust case study def here. This case study focuses on the multidisciplinary group of researchers who developed and implemented an e-health literacy training program for under-served communities in North Carolina. Collaborators came from a variety of disciplines and had different proficiencies and expectations with regard to online teaching tools. The team shared enthusiasm for the potential of web applications for documentation, training, and participant evaluation, but substantial differences in awareness of and facility with web-based information delivery tools existed among investigators. The group collaboratively developed online educational resources, e-health literacy testing tools and online collaborative space for researchers to communicate and share data. **Technology use & collaboration expansion here.**

The data consist of meeting minutes, project data and post-project semi-structured interviews. **More on the appropriateness of these data elements in the light of the case study format/ boundaries defined above.** Analysis of investigator's project notes and post-project interviews with researchers demonstrates the evolution of investigator desiderata and data collection goals. Ultimately, the team opted to deploy web tools to distribute training materials, to collect assessment data and to provide access to e-health resources to project investigators.

This study describes the process of development and implementation of an e-health intervention that was the product of a multidisciplinary collaboration between public health educators, health information researchers and web-based learning specialists. The challenge for the informatics and web application specialists on the team was to coordinate with public health education experts in order to create and distribute training materials and collect data that demonstrated program effectiveness three months after the training sessions. The public health education team and participants travelled to a regionally accessible site to engage in face-to-face training sessions. During these sessions, participants completed pre-training e-health surveys. Because such sites were often geographically remote, arranging a second meeting for the necessary post-training evaluation was often logistically challenging. To help relieve the burdens imposed by distance, the project website was developed to distribute training materials and post-session evaluations. Training session participants (lay intermediaries such as librarians, public health workers, nurses and students) were from under-served areas, but most were expected to (and indeed did) have Internet access either through work or via community resources such as public libraries.

Review of the literature:

The Community:

Increasing public health literacy is an important goal because it is well known that health disparities cost lives. ((Norris, 2004)) Under-served communities tend to have health disparities and reduction of such disparities is a national priority. (Haynes MA, 1999) (Chang et al., 2004) (Kreps, 2005) Evidence suggests that increasing health information access can reduce health disparities. (Dickerson et al., 2004) (Bowen, 2003) Additionally, Fogel et al found that poor health is a strong indicator of information seeking. (Fogel, 2005) Though health professionals were identified as the primary source for health information, respondents were not averse to searching for information online where access was convenient and comfortable, such as in community centers and libraries, and Tetzlaff notes that users can read above their grade level when motivated. (Ophelia, 2007) (Jackson et al., 2005) (Tetzlaff, 1997) Furthermore, users will sometimes access information through intermediaries or surrogates who will often search on behalf of users (Abrahamson, Fisher, Turner, Durrance, & Turner, 2008). Surrogates can include librarians, community health workers, or other individuals who have Internet access and exposure to the public and are thus well positioned to disseminate information. Other examples of such lay information intermediaries include other health care professionals, educators, students, family members and community leaders such as clergy. (Mock, Nguyen, Nguyen, Bui-Tong, & McPhee, 2006) Thus, while e-health literacy rates and access to e-health materials are too low, (Miller & West, 2007) (Talosig-Garcia & Davis, 2005) there are ways for those on the disadvantaged side of the digital divide to access consumer health information. (Stavri, 2001)

Community partners, particularly information or health professionals, are key to connecting researchers, technology and target communities. (Goodrow, 2000) Kind et al. noted that a high

percentage of African American caregivers had access to both a computer and the Internet. (Kind, Huang, Farr, & Pomerantz, 2005) Many caregivers also reported using the Internet to find health information for themselves or their child. Consumers who had not used the Internet for information expressed a desire to do so and to discuss the information with a physician. (Kind, Huang et al. 2005) Ophelia noted that online resources were the second preference for African American health information seekers after health care professionals. (Ophelia, 2007) McKeehan's group assayed how residents of a county in the southern US got information about health care; the Internet was the fourth preference of respondents, after doctor, TV and family. Among Internet users, 40% agreed that they rarely use it for health information. Respondents felt that the best way to deliver health information to rural populations was though existing social service programs in schools, libraries, churches, barbershops/beauty salons, stores and community centers. (McKeehan, Trettin, & May, 2008) Hutchinson also found a strong need for culturally competent research as a complement to the promotion of health researchers from under-served populations as part of a multi-level approach to reducing health disparities. (Hutchinson et al., 2007)

Multidisciplinary collaboration:

Reduction of health disparities is a national priority and significant resources were provided by government agencies such as the US Department of Health & Human Services National partnership for action to end health disparities (DHHS, 2011) and other organizations, such as the United Negro College Fund. (UNCF, 2005) In 2010, Pomerantz et al. called for community-based information partnerships to address health literacy and health information inequalities. (Pomerantz, Muhammad, Downey, & Kind, 2010) In 2004, the Institute of Medicine (IOM) recommended closer collaboration between health practitioners and literacy experts such as

the library and information science community; the Eagles e-health project is an exemplar

of such collaboration. (McCray, 2005), (Nielson-Bohman, 2003). Thalemann & Strube noted

the effectiveness of sharing knowledge across disciplines in problem solving, finding that

shared general knowledge was better for collaborative problem solving than shared operational

knowledge. (Thalemann, 2004)

Smith describes a framework of cyclic information flow as the dynamic of sustainable

collaboration. Smith identifies several *dimensions* of information that are used to define the

problem at hand, (including information type, tools, time, space, people and process).

 with specific domains of information that are the
 was reflected during the ongoing process of articulating and facilitating individual investigator's

desired outcomes. Such outcomes included described personal project & data collection goals,

presented desiderata for information display, interface design and data collection mechanism.

and ultimately determined priorities and delegated specific tasks.

 "If researchers could agree on a common set of dimensions, projects could use them to

suggest ways that their respective agendas might be extended incrementally to make their

research more comprehensive and to identify other groups with whom they might collaborate

or share data." Smith identifies "processing sequences" or phases used for sustainable

collaboration. This is one part of the model, in which desiderata are paired to appropriate

technology for presentation and data collection.   (Smith, 1994) The evolution of the project's

online face and the evolving understanding of the uses of online resources provide insights into

a specific process model of collaboration for increasing e-health literacy.

Move this section to case study justification - A 2009 report by Leisey describes a case study of a similar health disparities mitigation program in Virginia, in which the authors found areas of congruence and key differences between social work and health librarianship. (Leisey 2009) The Leisey study bears numerous similarities to the Eagles e-health project including the development of training materials, mixed method data collection and reportage, and the recognition of key differences in the requirements and expectations of researchers in the public health and library fields.

Eagles-E-health Project Design:

Parker and Kreps propose several interdisciplinary strategies to help consumers make more informed health decisions, such as collaboration between libraries and health providers to develop educational workshops and use of printed materials for consumers, particularly those with low health literacy. (Parker and Kreps 2005) The Eagles-e-health project team included NLM specialists, public health education, digital health librarianship, instructional design, and psychology researchers that collaboratively developed a tailored information package intended to increase use of NLM consumer health resources, particularly Medline Plus and other sources thought to be relevant to the target communities. Participant groups included local students and faculty (from the Schools of Public Health Education, Nursing, Library and Information Science and departments) and lay community members such as librarians, nurses and other community leaders. The training materials were presented to participants in intensive one-day training sessions. The web-based tools allowed individuals in remote areas to follow-up on their training without imposing scheduling or travel hardships.

Training materials consisted of a workbook, a proficiency test and pre and post-training surveys of participant's e-health information use. Workbook content focused on MedlinePlus, Senior Health, AIDSLine, ToxTown and GoLocal. The training materials were developed in conjunction with representatives of the National Library of Medicine's Oak Ridge facility. All project materials, including the information packet, the questionnaire and survey results database, the public website and grant development materials were housed on a server available to project members and participants. (www.nccuslis.org/ehealth) Ultimately, the web team was directed to focus on three major tasks – the development of web-based equivalents to the printed training materials, the development of a semi-permanent repository for storing the project's webpage, training materials, project data and miscellaneous investigator resources. The team used

a suite of open-source tools (LAMP) as a platform to house the project database, distribute assessments & reminders and act as a repository for researcher documents and data.

Participants were recruited via a statewide public health education outreach network hosted by NCCU's School of Public Health Education Health Disparities Initiative. (NCCU HDI) Because the project leaders were accustomed to face-to-face training methods, investigators had to re-evaluate how content and metrics should be developed and deployed. An important task for the web team was to create online training materials that were as similar to the traditional materials as possible. For example, the health education team was accustomed to using a combination of hard copy evaluations and semi-structured interviews to gather data, allowing researchers to follow up with participants after the fact. Additionally, researchers were unaccustomed to having machine-readable interview transcripts available in the database for analysis, but were accustomed to having hard-copy results with less-structured information (notes, contact information, editorial asides) available for post-hoc review. Assumptions about best practices on the part of the web team led to the use of alphabetical scales for surveys, requiring reformatting of the surveys so that data could be collected without causing database errors. This change resulted in some delay as the appropriate changes were made to the database. Proficiency and post-hoc testing data were collected for 6 months after the last training session.

Report Methodology:

This report applies a case study approach to help document the process & pitfalls of adapting a multi-disciplinary research project from a traditional, semi-structured, face-to-face approach to a more structured, hybrid, face-to-face/online online model. This research holistically describes

a well-defined collaborative project, (in this case, an 18-month, mixed-method, community outreach project involving 8 team members, (5 academic researchers from various academic backgrounds, 2 public health education specialists and a webmaster). The case study method is a good choice for a research project of this type because it facilitates the analysis of both quantitative and descriptive data. Such flexibility is a necessary part of our effort to develop a robust model for e-health literacy assessment & intervention. (Wildemuth, 2010)

Smith (1994) described how collaborative projects are shaped by information flows between participants that rely on the definition of dimensions of the problem, including Information Type, Tools, Time, Space, People and Processes. All of these areas are appropriate for description in a case study, as some of the dimensions are quantitative and some are descriptive. Content analysis of notes and minutes and from post-project interviews provide insight regarding how the priorities of the researchers evolved with the project.

Investigator notes and meeting minutes were digitized and converted to text. The notes and minutes were sorted chronologically and divided into six 3-month sections. Stopwords were removed using the list found at (CITATION).   The content bearing words were tallied and sorted into one of the six concept groups described by Smith. (Information Type, Tools, Time, Space, People and Processes)

Results:

This case study relies on three data sources:

1) User post-test and proficiency results

2) Content analysis of project notes and minutes

3) Semi-structured interviews with team members

e-health community outreach results:

Comparison of pre and post-hoc use of e-health resources indicates an increase in awareness of and likelihood of use of NLM resources among project participants. Due to the fact that participants were self-selected and that respondent completion of post-hoc testing was low, statistical analysis of results is unwarranted. However, results from completed post hoc and proficiency tests do suggest increased awareness of and use of NLM resources, findings that are reinforced by post-training follow-up phone interviews with selected voluntary respondents. Post-training evaluation indicated a high level of proficiency with consumer e-health resources from the NLM and increased awareness of such tools post-training. (Fig 1)

Collaborative project findings.

Data for analysis of the collaborative experience was generated by examining all available investigator notes and minutes, performing a stop-word analysis and grouping all of the concept markers into the domains of information described by Smith (Information Types, Tools, Time, Space, People, and Processes). An analysis of these terms over time shows a shift in emphasis from some domains to others and the evolution of some concepts within each domain.

Collaborator Interview Findings:

Analysis of project documentation shows a clear shift in priorities (as demonstrated by the terminology used by researchers) as the project evolved. Project priorites increasingly focused

on Time and Tools, with Space and people becoming less important aspects of the information flow to the group as the project progressed. Participants were challenged by having to integrate digital teaching methods into more traditional methods of community intervention, and the role, uses and application of technology became a significant focus of the project over timeThe conversion of the training materials to electronic format was straightforward, however the development and use of the system for tracking, evaluating and rewarding participants was much more time consuming and problematic than the e-health education team had orginally anticipated. It is clear that the online aspects of the project must be defined and refined at the project's initial stages, rather than integrated into the larger project after it has been conceived and materials are prepared.

(See more complete results from collaborator interviews in appendix A.)

Results of the post-project interviews with participants revealed a number of themes:

- Investigator perceptions of the possible applications of web technologies were influenced by personal, professional and research agendas.
- More planning time should be taken to discuss content, presentation and specific data collection & reporting requirements.
- Digital technologies are useful tools for spreading e-health literacy information in under-served areas, but they must be accompanied by face-to-face interactions with trusted community members such as gatekeepers and lay intermediaries.
- Useful e-health evaluation must include assessment of technological and health related aspects of e-health literacy, as well as user's access to, selection of, and perceived trustworthiness of health information sources.

DISCUSION & LESSONS LEARNED:

From a participant training perspective, the Eagles-e-health project was a success, as the survey data demonstrate that participants experienced increased awareness of user proficiency with NLM resources. The Eagles-e-health project was successful in developing a website to present training materials, provide reminders about NLM resources discussed in the training and collect data about program participants. However, technical & collaborative challenges made data collection unexpectedly difficult; assumptions about standard best practices of web design on the part of the web team led to online survey responses being anonymous, making paired comparison of users pre- and post-training impossible.

Though it would have been preferable to have both the pre-test and post-test available online as a way of introducing users to the project's online resources, because of scheduling constraints, the initial participant assessment was delivered as a hard copy in early hands-on sessions, effectively anonymizing the participant responses and thus making paired comparisons problematic. Similarly, it would have been most informative to administer the proficiency test before the session to compare pre-training search skills, however the proficiency test was not included as part of the initial survey, again obviating paired comparisons. Further, an early version of the user survey did not force completion of both parts of the two-part assessment, thus many users did not complete both sections of the e-health resources assessment. This error was noticed well into the data collection phase, the result of which was that fewer post test were completed than pre-tests.

Ultimately, it became clear that over-reliance on phone and email contact to induce users to complete the online follow-up assessments, concerns about participant privacy combined with institutional strictures on incentive distribution all contributed to lower than desired response

rates. Investigator unfamiliarity with some of the technologies used by the web team led to significant time spent in discussion and training with investigators. In interviews, several members expressed a desire that less time be spent learning and re-learning how to use project resources (such as the data manipulation tools and shared storage location) so that more could be spent collecting data. Team members indicated that in future project iterations they would include more detailed discussion of the specific data collection needs, expectations, structure and deployment of online content. For example, future iterations will incorporate a segment into the training that will provide an anonymous, unique identifier to each participant to facilitate assessment completion & comparison as well as facilitating incentive distribution.

In post-project interviews, collaborators responded that they felt that had the development of online resources for training and data collection been an initial part of the design process, the e-health training tools could have been disseminated more widely and with better data collection. Project participants expressed limited satisfaction with the online resources, indicating that web-based tools were a useful supplement to traditional training methods (face-to-face training sessions), but were not a replacement for in-person interactions. One researcher noted that both "access" and "trust" were required to engage a participant. However, once participants were engaged with the material and trust was established, having a stable, robust information distribution and collection platform available was seen as a necessity, and one that will receive higher priority in future project iterations.

CONCLUSION:

Evaluation of participant awareness and proficiency with NLM offerings in pre- and post- training assessments shows that combining free, high quality consumer health education resources with face to face e-health information retrieval training can increase public awareness of e-health resources. Improved planning and inclusion of the web team from the outset can improve

distribution and evaluation of such projects in the future.

Because there are substantial differences between investigators regarding awareness of and facility with web-based training and education technologies, appropriate training in the use of online technologies for all participants, including investigators, is crucial. The web team was developed and incorporated into the project post-conception, so development of web tools for the project happened during deployment, rather than development. A consistent finding of the investigator interview was that researchers were not aware of the extent and power of the tools available to them via the web.   Ultimately, web tools were used to communicate, to collect & store assessment data and to provide links to e-health resources. Researchers reported that more consideration will be given to integration of web technologies as a feature of face-to-face training in the future, both as a means of improving data collection, but more importantly as a mechanism to more widely disseminate information about potentially life-saving health information.

FIGURES:

(FIG 1) Pre- & Post- training session test results:

	n	NLM	UseNLM	PubMed	UsePub	Medplus	Usemed
Prefac	28	21	19	25	21	21	15
Postfac	5	4	3	4	2	5	4
Prestu	5	4	3	4	2	5	4
Poststu	18	17	7	12	9	12	9
PreComm	33	22		14	9	17	11
Postcomm	17	11	11		10		

Figure 2:

Dimensions of information (Smith) discussed in collaboration sessions at three stages of the process: Pre, Middle and End of the project.

Figure 3:

Terms & concepts used by investigators in post-project interviews

Include interview results (sorted by question) HERE:

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