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A Librarian by Any Other Name: The Role of the Informationist on a Clinical Research Team

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Abstract

In 2012, the Lamar Soutter Library (LSL), University of Massachusetts Medical School (UMMS), successfully collaborated with two principal investigators from UMMS, as well as their research team, to receive a supplemental grant from the National Library of Medicine. The grant, an “NLM Administrative Supplements for Informationist Services in NIH-funded Research Projects,” was one of eight awarded nationally. It provides funding to support an informationist – or in-context information specialist – who serves the research team by offering expertise in the areas of data and information management.

For 18 months, the informationist is serving as a member of the research team on the grant, “Promoting Breast Cancer Screening in Non-Adherent Women” (R01 CA-132935, National Cancer Institute, National Institutes of Health), working to develop data management tools,

providing an in-depth literature review, and report on the issues facing researchers and internet technology professionals when building and implementing research tools. They will also assist with a systematic review on the effectiveness of telephone intervention protocols for preventive screenings, and will instruct members of the team in advanced searching techniques and bibliographic management.

This role serves as a new model of embedded librarianship for the LSL. It also provides opportunities for new services from the Library in the role of data and information management. Further, the acceptance of an informationist into a well-funded research team demonstrates a level of commitment by researchers to receiving research support from the Library that it has not experienced to date. This brief paper describes the study and the accomplishments to date.

Introduction

In 2012, the Lamar Soutter Library (LSL), University of Massachusetts Medical School (UMMS), collaborated with two principal investigators from UMMS, as well as their research team, to write a successful proposal resulting in receipt of an administrative, supplemental grant from the National Library of Medicine. The award, an “NLM Administrative Supplements for Informationist Services in NIH-funded Research Projects,” was one

of eight awarded nationally. It provides funding to support an informationist-- or in-context information specialist – to the research team, i.e. a librarian with a disciplinary background in biomedical, behavioral, or biological sciences, as well as library and information science, who serves the research team by offering expertise in the areas of data and information management.

For 18 months (Sept 2012 - Jan 2014), Sally Gore (the informationist) is serving as a

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member of the research team on the grant, “Promoting Breast Cancer Screening in Non-Adherent Women” (R01 CA-132935, National Cancer Institute, National Institutes of Health). Devoting a quarter of her scheduled work time to the project, the informationist is developing data management tools (a data dictionary and data request form), providing an in-depth literature review and report on the issues facing researchers and internet technology professionals when building and implementing research tools, assisting with a systematic review on the effectiveness of telephone intervention protocols for preventive screenings, and instructing members of the team in advanced searching techniques and bibliographic management.

The Study

“Promoting Breast Cancer Screening in Non-Adherent Women” (R01 CA-132935, National Cancer Institute, National Institutes of Health) is a three-armed, randomized control study comparing two forms of outreach to women coming due or overdue for a screening mammogram to the usual practice (control) of a mailed letter reminding patients to schedule a mammogram. One intervention involves following-up on the standard letter with a phone call by a scheduler, and offering to make a mammogram appointment for the subject. The second intervention is a stepped approach that begins with the standard reminder letter and then, if the subject fails to schedule a mammogram on her own, she would receive educational materials on the importance of mammograms in the screening for breast cancer. If no appointment is made after the letter and information packet, a trained motivational counselor calls the subject, employing specific behavioral change methods during the call to encourage the woman to schedule an appointment. The outcome measures of the study will compare the effectiveness of each of these intervention methods, as well as the associated costs for each.

The research team for the study is comprised of approximately 25 individuals located in four different geographical areas: University of Massachusetts Medical School, Reliant Medical Group (healthcare providers), Fallon Community Health Plan (insurer), and Claricode (computer program consultants). Likewise, data is generated and collected from multiple sites:

- Staging Data – Data from the electronic health records of Reliant patients, including office visits, historical data on labs, prescriptions, procedures, demographics, and insurance enrollment coverage.
- Claims Data – Historical data of Fallon Community Health Plan claims from 1997 through the present.
- Tracking System Data – Patient responses from counseling and scheduling interviews, including baseline survey information, log entries, and call outcomes (approximately 350 variables).
- Analytic Data – Draws from the other three sources, but also adds a number of new variables related to the specific outcomes sought.

The Informationist

Conversations with the research team revealed four specific areas where an informationist could benefit the research process: improve communication, articulate technology issues, enhance information organization and management, and assess value of an informationist on a research team.

AIM 1: Improve Communication

The skills of an embedded informationist can be utilized to improve the communication about data between members of the research team. Effective and efficient data analysis requires that investigators, statisticians, and data analysts use a common, pre-

cise language in developing and interpreting requests for data analyses. Developing this language is a time-consuming, iterative process that involves the exchange of many requests and responses before the investigators receive the product they had envisioned.

Before the informationist joined the team, investigators and the data analyst collaborated in the production of a set of analyses aimed at tracking key metrics related to the accrual of subjects and of outreach efforts. However, the types of analyses lacked categories, labels, and standards to clearly identify them from each other. The resulting requests for analyses and/or discussions about them became confusing, with different members of the team using different terminology and definitions.

To address the situation, the informationist is charged with developing two specific tools: (1) a comprehensive data dictionary that includes precise definitions of all the terms that are commonly used by members of the research team in requesting and discussing data analyses; and (2) a standardized data request form that researchers can use when seeking a particular analysis.

AIM 2: Articulate Issues Related to Technology

The research team worked closely with software developers for several years to design the tracking system used by schedulers and counselors during the phone calls to subjects. Development took a great deal of time, many versions, and raised any number of information technology issues. The team felt like the experience was one worth capturing and ultimately sharing with others as a means of improving the knowledge base for future studies utilizing this same methodology and technology. Without any familiarity with applied computer science and/or informatics literature, the team looks to the informationist to discover the current body of literature on the topic, as well as to identify a possible source(s) for the publication of an

article on it.

AIM 3: Lead Systematic Review and Enhance Team Member's Information Skills

The investigators have determined that there are now an adequate number of publications of telephone outreach interventions to promote mammography that a systematic review is needed to summarize key findings. The informationist is tasked with organizing the review process, coordinating the search strategy, tracking the progress, and ultimately leading the team towards the point where the review can be published. Additionally, the informationist shares expertise in information organization and management, searching skills, and bibliographic management tools through instruction sessions and tutorials.

AIM 4: Assess Value of Informationist

By partnering with one of the principal investigators throughout the length of the study, the informationist will find success integrating fully into the research team. One of the goals of the informationist approach is to become an equal member of a research team, rather than a support service to it. To determine how well this integration occurs and, ultimately, how much value the informationist brings to the team's work, the experience is tracked through reflections, interviews, focus groups, and the completion of the tasks associated with each of the aims.

Current Status

Eight months into the project, aspects of each of the aims of the proposal have been met:

Aim 1 of the grant seeks to leverage the skills of the embedded informationist to improve communication around the use of data from various sources. To this end, existing codebooks, data dictionaries, lists of fields and definitions, tables, etc. were gathered with the ultimate goal of producing one com-

prehensive data dictionary, and accompanying data request form based upon the dictionary, that is suitable for use across sources. As of this writing, the dictionary is not yet comprehensive, but continually growing as sources are identified and formatted. A data request form based upon the dictionary terms is being utilized and evaluated. This latter piece will continue through May 2013.

Aim 2 involves identifying and reporting on current literature addressing issues between internet technology professionals and researchers, specifically as they relate to the development and implementation of tools created for and implemented in research. A standard form to systematically gather information from team members related to the topic was created. This form allows individuals to suggest existing articles that they may be aware of, terminology they use related to the question, and sources of relevant articles and gray literature. The format also gives the informationist a means to efficiently discuss the topic during weekly meetings, to consolidate the information provided in an organized manner, and to ultimately conduct a more thorough review of the literature. This review is currently underway.

Aim 3 of the study, to enhance the capacity to report the parent study finding in appropriate context, will begin in the second year of the study.

Finally, to evaluate the value of the informationist to the parent study (Aim 4), the informationist began a weekly online reflection (<http://librarianhats.net/>) that is shared with members of the research team, health information professionals, librarians, and the general public. Since published in September 2012, the site has received more than 20,000 visitors and a number of discussions via the comments to individual posts, and on other social media outlets such as Twitter. It is proving to be a valuable tool both to the informationist and the larger professional community. For the informationist, it serves

as a platform for thoughtful reflection and learning, as well as an historical account of work on the project. For colleagues, it offers advice, tips, prompts for discussion, and a concrete example of one individual's work in an emerging field.

Conclusion

The embedded informationist role is a new one for the Lamar Soutter Library, yet it appears a type of service that the Library needs to invest in for the future. Becoming integrated into a research team gives the informationist, and thus the Library, opportunities to become more involved and ultimately, more valued, by the research community. It also allows the informationist to make use of her experience and knowledge beyond the scope of library and information skills. By utilizing this educational background and experience in a biomedical science, the informationist can bring library and information services at a greater depth than those offered via traditional support roles. So far, the experience proves to be filled with rewards and challenges, and any number of opportunities to discover ways that push traditional library services to another level. From the perspectives of both the informationist and the other members of the research team, it's an interesting experiment to be a part of and we look forward to seeing if the role is one that can be sustained in the future.

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