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Not the last word: dissemination strategies for patient-centred research in nursing

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Abstract

Introduction—Research results hold value for many stakeholders including researchers, patient populations, advocacy organizations, and community groups. The aim of this study is to describe our research team's systematic process to designing a dissemination strategy for a completed research study.

Methodology—We organized a dissemination event to feed the results of our study to participants and stakeholders and collect feedback regarding our study. We applied the Agency for Healthcare Research and Quality's dissemination framework to guide the development of the event and collected participant feedback during the event.

Results—We describe our dissemination strategy along with attendees' feedback and suggestions for our research as an example of a way to design a patient- and community-focused dissemination. We explain the details of our dissemination strategy including (a) our process of reporting a large research study into a stakeholder event, (b) stakeholder feedback collected at the event, and (c) the translation of feedback into our research team's research. We also describe challenges encountered during the dissemination process and ways to handle issues such as logistics, funding, and staff.

Conclusions—This analysis provides key insights and practical advice for researchers looking for innovative ways to disseminate their findings within the lay and scientific communities.

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Conflict of Interest:

Dr. Hagan, Dr. Schmidt, Ms. Ackison, Ms. Murphy, and Ms. Jones declare that they have no conflict of interest.

Keywords

Surveys and questionnaires; Information dissemination; Community-based participatory research; Neoplasms; Quality of life

INTRODUCTION

The research dissemination process is a crucial aspect of any study, especially research that directly involves the community. (Chen et al., 2010) The knowledge produced through systematic investigations (a) informs the development of knowledge within the scientific field; (b) ensures that the study's methods, analysis, and conclusions are open to scientific and public scrutiny; and (c) guarantees that those with a vested interest in the research understand and find benefit from the study's findings. The Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) Statement sets guidelines for ethical ways of disseminating research, stating that dissemination "honors the altruistic motivations of patient-subjects," that participants are "entitled to know the results of the research their enrollment made possible," and that dissemination is "consistent with the duty to share new knowledge." (Mann, 2005) While peer-reviewed journals, professional conferences, and professional communities remain excellent mechanisms by which to deliver results to the scientific community, researchers should capitalize on the opportunity to bolster their professional objectives by distributing research results widely to all stakeholders. (Chambers and Azrin, 2013)

As nurse researchers, we must acknowledge the value of our research across multiple audiences. (Timmons, 2015) We must strive to appreciate the potential impacts of our research for study participants, patient populations, community organizations, and policy organizations alike. Our scientific research may be valuable in ways not originally intended by our scientific question, and the dissemination process and planning of future research is an ideal time in which to engage these stakeholders. (Anderson et al., 2014)

Our research team recently experienced such a crossroads at the end of a national, cross-sectional study among adult females with a history of cancer. Our parent study aimed to develop a measure of patient self-advocacy to assess their ability to get their needs met in the face of challenge. We believe that this concept is crucial in the current climate of ongoing health inequities (Adler et al., 2016; Lyratzopoulos et al., 2013), increasingly complex medical care (Collins et al., 2009; Reyna et al., 2015), and vested interests in promoting patient engagement in their health care decisions (Frank et al., 2015). We decided to disseminate the results of our study not only to our participants, but to wider community audiences who had vested interests in discussing our results and imagining potential future steps. In this way, we could both share our results and build community with like-minded individuals and community partners interested in addressing the need for patient self-advocacy.

The purpose of our one-time dissemination strategy and activities was to inform, empower, and engage a multitude of groups interested in improving the health of women with cancer. This analysis is meant to give practical and translational guidance to researchers who are

interested in disseminating their research in novel ways, and to stakeholders who are interested in partnering with researchers in the scientific process.

METHODOLOGY

Parent Study

We sought to disseminate our mixed-mode, cross-sectional survey study testing the psychometric properties of a new measure of self-advocacy among female cancer survivors. (Authors A; Authors B) This Self-Advocacy Study took three and a half years to complete and was based on qualitative pilot work describing how patients define and enact self-advocacy. (Authors C) We recruited women locally from the western Pennsylvania area as well as nationally through cancer-related advocacy groups to complete a battery of paper or online questionnaires about their health history, cancer- and treatment-related symptoms, beliefs about their health, and personality traits. Inclusion criteria for this parent study included being female, having a previous diagnosis of an invasive type of cancer, and being able to read and write in English. Participants ($N=347$) were recruited nationally and locally from two patient research and tumor registries, cancer clinics, and seven advocacy organizations. This study received human subjects approval from the University of Pittsburgh Institutional Review Board.

While we did not design this study using community-based participatory research principles, we collected input from women with cancer, advocacy organizations, and other stakeholders at all stages of the Self-Advocacy Study. We wanted to know stakeholders' preferences and attitudes about patient self-advocacy, the design and implementation of the study, and potential uses of a self-advocacy scale we were developing. We met with leaders from the patient registries, cancer clinics, and advocacy organizations to discuss the study and potential collaborations before, during, and after the study ended. As a measure of trust-building and collaboration, we promised each of our recruitment sites that we would share the results of the study with them and their membership at the end of the study. Most organizations requested receiving the results of the study for education of their stakeholders and organization.

Dissemination Event

As we completed the Self-Advocacy Study, our research team began to consider possible strategies to efficiently and fruitfully disseminate our results to multiple groups of lay and scientific stakeholders. Despite our study being a one-time survey study, we grew close to our participants during the course of the study as we heard their stories of advocating for their healthcare and personal needs. Even though we conducted qualitative pilot work exploring patient experiences of self-advocacy, we recognized that this study was exposing patients' additional concerns. We concluded that patients and our stakeholders required a larger forum in which to discuss patient self-advocacy. We wanted to provide space to discuss the challenges to having patients speak up for their values and preferences and brainstorm ways to build self-advocacy skills in vulnerable patient populations.

Our main dissemination event consisted of a large one-day dissemination meeting and discussion in August 2015. We invited participants from the parent study, individuals from our recruitment sites, and community members who would be interested in promoting patient self-advocacy. At this event, we presented our findings of our research study, encouraged stakeholders to discuss the findings with each other, and together developed strategies for future research studies. We did not intend for this event to be a formal research study, but did want to capitalize on the opportunity to receive feedback from multiple stakeholders and collectively discuss future steps for our research team's long-term program of research.

Thirty-two individuals attended the dissemination event. Since our invitations were sent to multiple stakeholders and large memberships, we are unsure of how many individuals received the invitation. Table 2 describes the event's attendees based on feedback from thirteen people who completed the evaluation form. Each attendee was given a folder with a program of the dissemination event, a brief summary of the completed Self-Advocacy Study, a copy of the small group discussion questions that would be asked during the dissemination event, and paper to take notes. Volunteers from the University of Pittsburgh School of Nursing were located in the back of the event room offering health information, blood pressure screenings, health promotion materials, and community health resources. The event was also web-cast for attendees who were not from Pittsburgh or who were unable to attend the event in-person.

The event lasted an hour and a half and consisted of lunch, a brief presentation describing the Self-Advocacy Study's purpose and results, and a testimonial from a woman with ovarian cancer describing her experience of self-advocacy. This testimony was intended to provide a real-life description of the clinical problem and reinforce the need for research to improve self-advocacy among women with cancer.

While describing the study, we shared a brief overview of the final self-advocacy scale and its items. Rather than discuss the validity and reliability statistics supporting the psychometric strength of the instrument, we discussed the meaning of the scale (what each sub-dimension meant and how the scale could be used). We focused on data that was relevant to our audience to provide context and results of the study to our audience. We encouraged questions from the audience and received many thoughtful comments throughout the presentation.

Next, attendees broke out into small groups to discuss the Self-Advocacy Study's findings and future study directions. They were instructed that their feedback would be used by the research team in their making of patient education and future research studies. Therefore, attendees were encouraged to talk openly and freely, and that all perspectives were equally valuable. We wrote the questions below to elicit feedback on study results and brainstorm future research and patient support:

1. From what the study found out about self-advocacy, do you think the researchers are missing any critical parts of how patients advocate for themselves?

2. From what the study found out about self-advocacy, what do you think is the best way to help teach women how to advocate for themselves?
3. How would you specifically try to do this?

After the small group discussions, the entire group reconvened to share findings and discuss future research priorities. Research team members facilitated the conversation within each small group, took notes to document the discussion, and kept a log of suggestions. The same research team members recorded notes from the large group discussion.

Dissemination Framework

We searched for dissemination frameworks that would provide us with a structured method for disseminating research into the community and collecting feedback from stakeholders. The Agency for Healthcare Research and Quality (AHRQ) created the Dissemination Planning Tool (Figure 1) in an effort to support researchers in effectively disseminating their research. We selected this framework because its first step reflected our research study's status (e.g., research findings) and the framework's specific, targeted steps for creating a robust dissemination plan including identifying and defining: (a) research findings and products, (b) end-users, (c) dissemination partners, (d) communication, (e) evaluation, and (f) dissemination work plan. (Carpenter et al., 2013) This framework is intended to serve as a tool for researchers to market the unique aspects of their research to those multiple end-users.

In this article, we describe our application of the AHRQ framework to the Self-Advocacy Study's dissemination plan. Using the steps of the framework, we will expound on our planning and implementation of the dissemination event, and then describe the results of this event especially as they pertain to involving patients and community stakeholders in our research program.

RESULTS

We describe our results of our dissemination strategy as they relate to the **AHRQ Dissemination Framework**.

(A) Research Findings & Products—We designed our dissemination strategy to involve our partners in our dissemination process by presenting them with the results of our Self-Advocacy Study at our dissemination event and asking for their advice during this event. We purposefully chose not to make assumptions about how stakeholders would interpret our research findings. Rather, we specifically wanted their guidance on how the study results should be used to both inform future studies and develop patient education teaching self-advocacy skills to individuals with cancer.

Developing research products for dissemination required a shift in viewpoint among the research team. The scientific findings of our study were related to the psychometric properties of our new self-advocacy scale, and we are currently reporting these results in scientific journals and at scientific conferences. Study participants and recruitment sites were aware of these aims of the study, but we presumed these groups and other non-

scientific stakeholders would likely not be interested in our scale's psychometric results. Therefore, we altered our dissemination focus and rethought our findings from the perspective of these stakeholders to present our most interesting and useful results for discussion at the dissemination event.

(B) End-users—Given our commitment to share our results, we were obliged to share our results with our study participants and recruitment sites. All participants were invited to attend the dissemination event either in-person or virtually. Since the Self-Advocacy Study was a national study, we knew that participants outside of the Pittsburgh area would not be able to attend the event, but would be interested in the study's findings. We met with leaders of each of our recruitment sites to discuss the study findings, answer questions from the site leaders, and discuss potential partnerships during future research studies. We were also interested in sharing our results with the broader patient population and local and national community stakeholders. The scientific community was also an end-user, and a group to whom we wanted to report the rigor by which we undertook the study and the significance of the study results. Table 1 describes each of our end-users, their levels of participation in the parent study, and their interests in the results of the study.

(C) Dissemination Partners—Given our diverse end-users, we decided to streamline dissemination process by having at least one event in August 2015 that we could invite study participants, recruitment site leaders, and all interested stakeholders to attend. The University of Pittsburgh Clinical and Translational Science Institute (CTSI) was a major contributor, both as one of our most successful recruitment partner through their Research Participant Registry and as a source of funding for our dissemination process.

(D) Communication—Since we had such broad end-users, we wanted the communication of our dissemination strategy to appeal to multiple groups. We communicated our dissemination event using paper and email brochures and included a description of the event emphasizing that most of the discussing the study results. We also included a brief, two-page bulletin describing the study and highlighting our results. To encourage others who may be interested in the study and topic to attend, we asked all of our partners to share the invitation to their respective networks. Because our research study was national but our event was held locally, we invited interested parties to attend the dissemination event using video-conference and/or to privately share their thoughts about the study and ideas about potential next steps with the research team.

(E) Evaluation—Immediately after the dissemination event, we asked attendees to complete an evaluation and offer additional suggestions to our research team. These forms were primarily a programmatic evaluation of the event and additional opportunity for feedback; we did not originally intend to design these forms as qualitative questionnaires for research purposes. We also received feedback from other patients and stakeholders who were not able to attend the event, but who had received our bulletins and presentation slides.

(F) Dissemination Work Plan—Based on the evaluation feedback we received at the dissemination event, our research team developed a work plan after highlighting ways in which we could integrate the results of the research study with the results from the

dissemination event to inform our next steps in this program of research regarding patient self-advocacy. The plan consisted of (1) creating patient education materials to train patients to self-advocate and (2) designing a patient-centered intervention to train patients to self-advocate.

Table 1 describes the products and modes of dissemination for each end-user along with the research team's special considerations for each. This table demonstrates how the same products can be shared across end-users.

Feedback

Results of the dissemination evaluation were overall positive, with the lowest scores reflecting attendees' perceptions of meaningfully contributing to the study (Table 3). Attendees generally enjoyed the event, felt they learned about the study and could ask questions, and wanted to stay involved in the research going forward. While attendees who had not participated in the Self-Advocacy Study did not feel as strongly that they contributed to the study in a meaningful way, study participants did feel like they contributed meaningfully.

We transcribed the notes taken during the small and large group discussions and then organized the notes into a single document which the research team can now reference. Table 4 includes direct quotations of attendee suggestions on how the research team should disseminate study findings. Such rich, descriptive insights recorded in the small and large group discussions could not have been abstracted from the results of the Self-Advocacy Study. Moreover, attendees noted learning from each other's experiences and perspectives. Some attendees networked with each other to share resources and information related to their cancer and treatment.

Development of Patient Education Materials & Planning for Future Research Studies—The feedback we received during the dissemination event provided keen, direct guidance suggesting we develop patient education materials to help patients self-advocate. For example, attendees were adamant about the role of social support in being foundational to women being able to advocate for themselves. Therefore, our patient education (and research interventions) must address how a woman can affectively use her available support systems. One attendee who was a study participant gave an exemplary metaphor when she described the interplay between self-advocacy and social support: "It's like Uber – you are in charge of where you are going, but you don't always have to drive." This metaphor is invaluable for our research team as we move our research into designing interventions. Based on what these stakeholders suggested for our self-advocacy patient education, we developed a website (www.empowercancerpatients.com) that will engage individuals with cancer in sharing their stories of self-advocacy, hints for others who are struggling to self-advocate, and our results from previous studies regarding patient self-advocacy. We will continue to use this website to provide a space for individuals affected by cancer looking for connection and strength together.

Feedback from the dissemination event provided us with critical perspectives for our future research. Specific recommendations included the ideal timing and location of future

interventions and specific types of information that would be appealing to women who struggle to self-advocate. One attendee urged us to design research with clear, explicit instructions: “What you [the researchers] need is a primer for self-advocacy with real world examples.” Attendees also recommended having self-advocacy interventions include their healthcare providers and community resources outside of the hospital system. One woman described the difficulties of self-advocating with a rare cancer, and ended up informing other attendees about her type of cancer and the lack of available resources. Based on this feedback, we are currently designing and pilot testing a self-advocacy training intervention that uses common situations patients in our previous discussions have described to demonstrate how and when they can advocate for their needs and priorities.

Our study team learned several key lessons relevant to anyone attempting to organize a patient- and community-centered research dissemination event.

Practical Concerns—Key challenges and lessons learned during our dissemination included:

- **Attendee considerations.** In order to have as many attendees as possible, we tried to preemptively accommodate the needs of our audience to allow them to attend the dissemination event. We ensured the event’s location was centrally located next to the major woman’s hospital but not in the hospital to accommodate community stakeholders, researchers, and participants alike. The room was fully accessible and disability-friendly, restrooms were close by, and that the time of day was around the lunch hour. Still, several people noted that physical limitations or health illnesses prevented them from attending. We had eleven study participants cancel in the days immediately before the event due to health concerns.
- **Remote attendance technology concerns.** We originally had over 20 study participants indicate they would virtually attend the dissemination event. We sent them log-in information, reminder emails, copies of the presentation slides and an email address to contact in case of technological difficulties. Despite the strong interest, no one virtually attended the meeting.
- **Ethical concerns.** While conducting the Self-Advocacy Study, our study team was vigilant about protecting participants’ privacy and confidentiality. While organizing our dissemination event, we considered the ethics of having patients attend the event and having a speaker discuss her personal experiences in front of the group. We specifically gave patients the option to remain anonymous while at the event, since not all attendees were patients with cancer, and encouraged people to only share to their level of comfort. We invited a member of the National Ovarian Cancer Coalition speakers’ bureau who speaks publically about her cancer experience in the Pittsburgh community provide the testimonial during the event and worked with her prior to the event to ensure her comfort in sharing her story with the diverse group of attendees.

Facilitators of our dissemination plan included:

- **Key academic partners.** Having the CTSI support to assist in dissemination free of charge was instrumental in conducting the dissemination. The CTSI's funding was also necessary to afford the costs associated with the dissemination event.
- **Key community stakeholders.** Community stakeholders such as National Ovarian Cancer Coalition facilitated the event by organizing the catering and booking the event space. Familiar with the needs of this patient population, they proactively ensured the dissemination event space was handicap-accessible and close to the parking garage to reduce attendee burden.
- **Research study team.** Member of the Self-Advocacy Study research team were critical to setting up the dissemination event, greeting attendees, leading and recording the small group discussions, managing the webcast of the event, and ensuring the overall success of the event. These volunteers made the event run in an efficient, productive, and personable manner.
- **Food.** Providing lunch from a quality restaurant at the dissemination event encouraged attendance and demonstrated our research team's appreciation of the attendees' time, energy, and valuable feedback.
- **Parking.** Because of the relationship National Ovarian Cancer Coalition had with the event location and our funding, we were able to provide free parking to the event.

DISCUSSION

This simple, one-time dissemination strategy represents an alternative to only disseminating research for the scientific community. For non-researchers, involvement in dissemination strategy like the one described in this article provide a feedback mechanism by which to understand and critique research intended to benefit end-users like themselves. For researchers, having patients and stakeholders interested and involved in your research offers several tangible benefits in addition to ensuring that our end-users have received the results of our research.

Research participants want and expect trustworthy, timely information about the studies to which they consent to participate. (Ondenge et al., 2015) As a cross-sectional survey study, the Self-Advocacy Study offered a limited, inflexible platform for sharing ideas and concerns. Therefore, our participants and stakeholders appreciated the outlet that the dissemination event provided to raise concerns or offer suggestions about how to improve the lives of women with cancer. We received positive feedback from attendees indicating their appreciation for being included in the research endeavor and enjoyment of the event. We recommend other research groups use the AHRQ Dissemination Planning Tool to methodically consider their dissemination process and how this process can be used to spur inventive, patient- and community-stakeholder centered projects. If robustly designed, such dissemination events can succeed at both improving patient engagement and making research more relevant to all stakeholders. (Domecq et al., 2014)

Innovative partnerships between academia and community stakeholders have demonstrated the creative potential of having multiple perspectives and talents brought together. (Roy et al, 2014) Viewing research as a sustained program rather than punctuated episodes, such partners can provide tangible resources (e.g. space, staff, volunteers, and connections) and dedicated attentiveness (e.g. future collaborations) unmatched within the constraints of academia. Our partners during the Self-Advocacy Study assisted in organizing this dissemination event and actively discussed future research priorities. We will continue to nurture these partnerships for the purpose of collectively working to benefit this patient population.

Above all, dissemination processes can build trust between researchers, patients, and community stakeholders. In an era with growing public scrutiny of the research process, (Gauchat, 2012) such partnerships are critical. By ensuring all parties understand the others' priorities and activities, a more unified effort can be orchestrated to address critical health care problems. (Gradinger et al., 2013) This may lead to sustainable academic-community partnerships that can facilitate a healthy, ongoing collaboration of developing shared research questions, scientific investigations, and result dissemination. (Carney et al., 2011) Even though our dissemination event was limited in time and space, it convened a group of stakeholders together to succinctly and efficiently provide study results and request stakeholder input.

Limitations to this study include the low participant turn-out rate among research participants and the low response rate for evaluation forms among attendees of the dissemination event. While we spent considerable time working with study participants and recruitment sites advertising the event and addressing possible obstacles to attendance (e.g., having the event webcast, offering lunch, validating parking, etc.), we were limited by the availability of study participants (recruited from around the country) to hold the event at a time and location that may not have been convenient for all individuals especially those who had ongoing health issues. Finding creative ways to involve individuals with health limitations and limited travel abilities will ensure all stakeholders are able to contribute during these dissemination events. Moreover, our research assistants attempted to collect evaluation forms from each attendee, but many attendees left the event prior to the research assistant being able to remind attendees to complete the form. In future studies, we would suggest holding multiple events at times and locations that are not cumbersome to the patient population being served. We would also conduct a formal pre-post study to evaluate specific aspects of the dissemination event that impacted stakeholders.

CONCLUSION

Publication of research findings within scientific journals is adequate but not innovative. Finding novel ways to share findings can serve the interests of researchers, academics and participants. While we do not believe that our dissemination of the Self-Advocacy Study was overly elaborate, the method by which we approached and conducted our dissemination can be used by other researchers and community stakeholders interested in making mutually beneficial research partnerships.

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References

- Authors A (blinded for peer review)
- Authors B (blinded for peer review)
- Authors C (blinded for peer review)
- Adler NE, Glymour MM, Fielding J. Addressing social determinants of health and health inequalities. *JAMA*. 2016; 316(16):1641–1642. [PubMed: 27669456]
- Anderson NLR, Lesser J, ángel Oscós-Sánchez M, Piñeda, et al. Approaches to community nursing research partnerships: a case example. *Journal of Transcultural Nursing*. 2014; 25(2):129–136. [PubMed: 24391121]
- Carney JK, Maltby HJ, Mackin KA, Maksym ME. Community–academic partnerships: how can communities benefit? *American Journal of Preventive Medicine*. 2011; 41(4):S206–213. [PubMed: 21961666]
- Carpenter, D., Nieva, V., Albaghal, T., et al. *Advances in Patient Safety: From Research to Implementation, Programs, Tools and Practices*. Vol. 4. Rockville, MD: Agency for Healthcare Research and Quality; 2005. Development of a planning tool to guide dissemination of research results.
- Chambers DA, Azrin ST. Research and services partnerships: partnership: a fundamental component of dissemination and implementation research. *Psychiatric Services*. 2013; 64(4):509–511. [PubMed: 23728600]
- Chen PG, Diaz N, Lucas G, et al. Dissemination of results in community-based participatory research. *American Journal of Preventive Medicine*. 2010; 39(4):372–378. [PubMed: 20837290]
- Collins ED, Moore CP, Clay KF, et al. Can women with early-stage breast cancer make an informed decision for mastectomy? *Journal of Clinical Oncology*. 2009; 27(4):519–525. [PubMed: 19114703]
- Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Services Research*. 2014; 14(1):1151–1166.
- Frank L, Forsythe L, Ellis L, et al. Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute. *Quality of Life Research*. 2015; 24(5):1033–1041. [PubMed: 25560774]
- Gauchat G. Politicization of science in the public sphere a study of public trust in the United States, 1974 to 2010. *American Sociological Review*. 2012; 77(2):167–187.
- Gradingier F, Britten N, Wyatt K, et al. Values associated with public involvement in health and social care research: a narrative review. *Health Expectations*. 2013; 18(5):661–675. [PubMed: 24325553]
- Lyratzopoulos G, Abel GA, Brown CH, et al. Socio-demographic inequalities in stage of cancer diagnosis: evidence from patients with female breast, lung, colon, rectal, prostate, renal, bladder, melanoma, ovarian and endometrial cancer. *Annals of Oncology*. 2013; 24(3):843–850. [PubMed: 23149571]
- Mann, H. ASSERT: a standard for the scientific and ethical review of trials. 2005. [Internet] Available at: www.assert-statement.org/
- Ondenge K, McLellan-Lemal E, Awuonda E, et al. Disseminating results: community response and input on Kisumu breastfeeding study. *Translational Behavioral Medicine*. 2015; 5(2):207–215. [PubMed: 26029283]
- Reyna VF, Nelson WL, Han PK, Pignone MP. Decision making and cancer. *American Psychologist*. 2015; 70(2):105–118. [PubMed: 25730718]

- Roy UB, Michel T, Carpenter A, et al. Peer reviewed: community-led cancer action councils in Queens, New York: process evaluation of an innovative partnership with the Queens Library System. *Preventing Chronic Disease*. 2014; 11:130176. [PubMed: 24503342]
- Timmins F. Disseminating nursing research. *Nursing Standard*. 2015; 29(48):34–39.

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KEYPOINTS

1. Dissemination of study results can mutually benefit the patient- and community-stakeholders as well as investigators of research studies.
2. Applying frameworks of research dissemination can assist researchers in developing a strategic, community-based approach to sharing study results and generating imaginative, patient-focused approaches to advancing scientific discovery.
3. Building collaborations with community stakeholders through honest, open dissemination of study results and discussions of future research steps establishes trust between the lay and scientific communities.
4. Creative means of sharing and building research programs can stimulate novel forms of patient education, approaches to intervention research, and forms of stakeholder involvement in research.

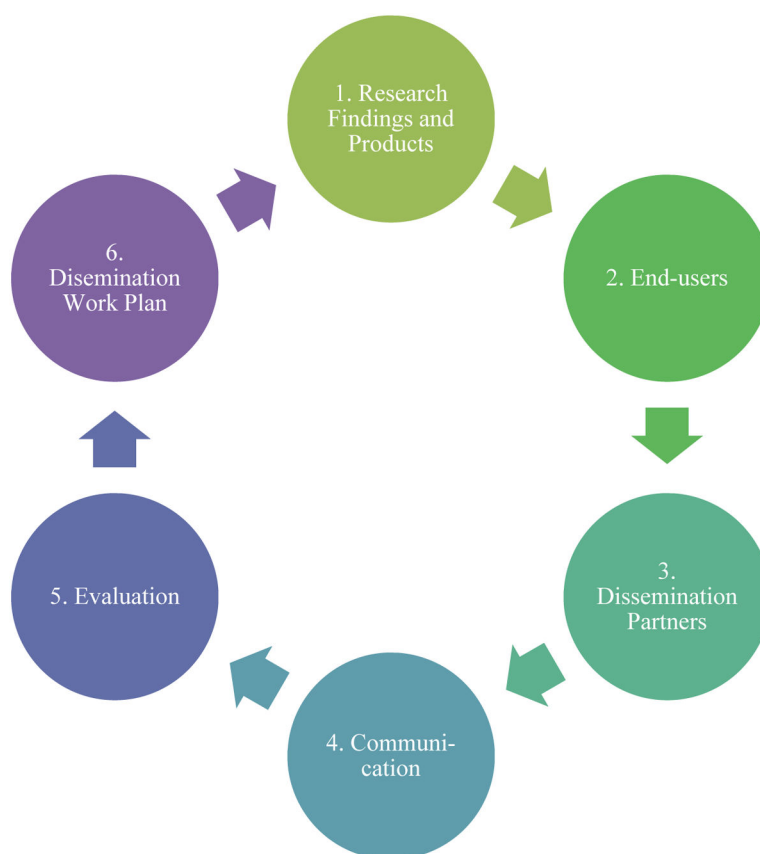


Figure 1.
Agency for Healthcare Research and Quality's Dissemination Planning Tool

Table 1

Dissemination Methods and Results by End-user

End-user	Involvement in Study	Information of Interest	Product**	Mode(s) of Dissemination	Special Considerations
Study Participants	• Completed one-time questionnaires	• How other participants performed	• Bulletin	• Emailed/mailed bulletins	• Personal and ethical obligation to share study results
		• Future directions of the research team	• Patient education	• Dissemination event	• Physical ability to attend event
Patient Population	• Only study sample accessed through recruitment sites	• Health and well-being of other women with cancer	• Bulletin	• Dissemination event	• Very broad (all adult women with a history of cancer)
		• Patient education	• Patient education		
Recruitment Sites*	• Assisted in identifying potential participants and connecting those women with the study team	• Health and well-being of other women with cancer	• Bulletin	• Dissemination event	• Acknowledging their help during the study
		• Unmet needs of population	• Patient education		• Nurturing relationship for future collaboration
		• Self-advocacy scale			
Community Stakeholders	• None	• Health and status of women with cancer	• Bulletin	• Dissemination event	• Disseminate study results widely
		• Unmet needs of population	• Patient education		• Nurture relationship for future collaboration
Scientific Community	• None	• Results of study's specific aims and conclusions	• Publications	• Main results manuscript and abstract submitted to referred journal and national conferences, respectfully	• Several publications will be published from the study along with presentations at scientific meetings
			• Presentation		
			• Future grants and research studies	• Additional manuscripts and presentations	
Funding Organizations	• Financial support	• Results of study aims and analyses	• Final funding report	• Written report	• Need to report our use of funds, achievement of goals, and success of overall grant purpose

* Dissemination partners

** Patient education materials to train cancer survivors to self-advocate are currently being developed and will be delivered to appropriate end users once the materials are finalized.

Table 2

Dissemination Event Attendees (n=13)

	N (%)
Participant in Self-Advocacy Study	
Yes	7 (53.8)
No	6 (46.2)
Participant in other study	
Yes	11 (84.6)
No	2 (15.4)
Organization membership	
National Ovarian Cancer Coalition	3 (23.1)
Clinical & Translational Science Institute – University of Pittsburgh	3 (23.1)
African American Women's Speakers Bureau	2 (15.4)
American Cancer Society – Western Pennsylvania	2 (15.4)
Cancer Caring Center	1 (7.7)

Table 3

Evaluations from Dissemination Event

	Participants (<i>n</i> =7)	Non-Participants (<i>n</i> =6)
Question (0 – 6 Likert Scale)	Mean (SD)	Mean (SD)
1. I enjoyed attending the workgroups and discussion today.	5.86 (.38)	6.00 (0.00)
2. I had an opportunity to ask questions and share my thoughts about the Self-Advocacy Study.	5.86 (.38)	5.83 (.41)
3. I learned about the results of the Self-Advocacy Study.	5.86 (.38)	5.67 (.52)
4. I would like to continue being involved in the Self-Advocacy Study.	5.86 (.38)	5.67 (.52)
5. I would like to continue hearing about the Self-Advocacy Study.	5.71 (.49)	5.67 (.52)
6. I shared my thoughts about what the “next steps” of the Self-Advocacy Study should be.	5.42 (.79)	5.67 (.52)
7. I feel I contributed to this research study in a meaningful way.	5.57 (.53)	4.60 (1.67)

Table 4**Advice from Participants on How to Support Self-Advocacy Among Women with Cancer**

“Provide a “step by step” manual describing and modeling self-advocacy for women with cancer.”
“What you [the researchers] need is a primer for self-advocacy with real world examples.”
“It’s about personal touch and people. So if you had trained people who have been through it, that would help others.”
“You may need self-advocacy teams. It’s too much. People could be too overwhelmed sometimes to do it themselves.”
“You need to think about how do you get advocacy to the professionals. How can health care providers connect people to resources?”
