

Connecting Students with Patients and Survivors to Enhance Cancer Research Training

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Introductory Statement

The professional training of cancer researchers in the basic sciences rarely involves interactions with patients. To provide nascent cancer scientists with an appreciation for and experience in interacting with the people most vested in their work, we created a program at Cornell University in which cancer researchers in training engage with the local patient commu-

nity. Through this program, trainees gain a broader understanding of cancer, beyond the fundamental biology, and learn to effectively communicate scientific information to the public. We find that trainees and community members both benefit from interacting with one another and learning together about cancer using a common language.

The traditional approach to graduate training in cancer research focuses on molecular mechanisms, disease pathogenesis, and related scientific topics (1). Interacting with the public, especially patients with cancer, is not typically a part of this professional training. As a result, many basic cancer researchers are most at home in their labs and at their computers and can be uncomfortable with public engagement. Some may give cues to their students that time spent on community engagement outside of the lab is not productive. Furthermore, basic science investigators may have a narrow perspective on cancer, with limited awareness of the spectrum of challenges that patients with cancer face (2). These issues are particularly acute at institutions without clinical programs, although even at medical schools it is uncommon for basic science trainees to interact with patients. We created a program at Cornell University (Ithaca, NY) that targets researchers-in-training for engagement with the local patient community. By doing so, we hope that the next generation of cancer scientists will be more comfortable with patient interaction and will value it throughout their careers.

Cancer Research and Patient Advocates

Scientists and patient advocates increasingly work together in a mutual desire to advance cancer research (3–6). Most visibly, patient advocates routinely serve with scientists on research review panels, typically assessing the potential impact of proposed research. The Congressionally Mandated Medical Research Programs, the American Cancer Society, the Patient-Centered Outcomes Research Institute, and other funders require this

collaboration. Patient advocates also serve as consultants or team members on specific research projects in some academic and industry settings. They provide the patient point of view and typically help in developing research protocols, writing lay abstracts, and recruiting human subjects.

In both of these situations, patient advocates are collaborating primarily with principal investigators and other established scientists. Anecdotal reports from both advocates and scientists suggest that their initial encounters with each other are novel, and occasionally awkward, experiences. We propose that it is highly advantageous to move patient–researcher interactions upstream in the professional development of junior investigators. By doing so, cancer scientists begin their careers with an appreciation for and some experience in interacting with patient advocates and the broader patient community (7).

Initiating a New Type of Collaboration at Cornell

In 2012, the Cancer Resource Center of the Finger Lakes, a locally focused cancer support organization in Ithaca, NY, contacted nearby Cornell University with the idea of connecting patients with cancer with graduate students engaged in cancer research. The Comparative Cancer Biology Program at the College of Veterinary Medicine immediately embraced the suggestion. At approximately the same time, Cornell's Physical Sciences in Oncology Center (8), based in the Meinig School of Biomedical Engineering, reached out to the Cancer Resource Center in hopes of connecting its trainees with cancer patients in the community. From these early interactions, the Cornell Cancer Partnership was created. A series of monthly seminars was initiated in which graduate students presented cancer research, in lay language, to a public audience. Audience members were encouraged to ask questions and request clarification when the language used was too technical.

After a few years of regular, but informal, presentations, the program was expanded into a formal academic curriculum with support from a curriculum development grant from Engaged Cornell, a University initiative that encourages positive change through community-engaged research and learning. A team of organizers, including faculty and students from

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Cornell's Departments of Biomedical Engineering, Biomedical Sciences, and Communication, together with community members affiliated with the Cancer Resource Center, created a curriculum that provides instruction in science communication and public engagement to cancer research trainees.

Courses include a two-day workshop that teaches students the fundamentals of communicating science to nonscientists, followed by a second communication workshop that provides structured opportunities to practice skills such as writing lay abstracts and giving oral presentations to a public audience. Community members routinely serve as workshop judges, providing immediate and constructive feedback to the students. A third course, also an intensive weekend seminar, introduces students to social aspects such as cancer drug pricing, medical decision-making, and cultural issues in cancer care. These topics are important to cancer patients and clinicians, but rarely discussed in basic science settings.

The fourth component of the curriculum is a full semester course, Community-Based Cancer Research Presentations and Discussions, that features lay-language student presentations on cancer research, exercises such as patient interviews and blog writing, and talks from professionals in a variety of cancer-related fields. The course is open to students from all disciplines, people personally affected by cancer, and the public at large.

Students who complete all four courses in the curriculum receive a Cornell Graduate Certificate of Engagement in Public Communication of Science and Technology. Grading is on a satisfactory/unsatisfactory basis because our desire is to encourage broad participation in a noncompetitive environment. The few formal assignments are evaluated qualitatively using detailed rubrics, but the focus is largely experiential and participation-based.

Research Trainee Participants

Our initial efforts specifically targeted doctoral students and postdoctoral fellows in the basic sciences because they possess some experience with cancer research but rarely have the opportunity to connect with patients with cancer. In the lab, they are prone to see cancer at the cellular and molecular levels and not on the human level. (Note that Cornell's Ithaca campus – the location of the program described here – focuses primarily on basic research. Most of Cornell's clinical research on human cancer takes place at Weill Cornell Medicine in New York City).

During their careers, these early-stage scientists will write lay abstracts, deliver "elevator pitches" to explain their research, talk with local reporters about the importance of their work, and likely serve with patient advocates on research review panels. Developing public communication skills and a broad understanding of the full range of issues and impacts related to cancer should be part of their professional development. Although it could be argued that this takes time away from experimentation, it has been our experience that time invested in this manner pays back manifold. In particular, framing research questions in the context of a broader and more personal understanding of the disease leads scientists to consider aspects of their approach and its potential applications that might otherwise have gone unrecognized. Community engagement during training also has the potential to improve

student retention. Many trainees involved in cancer research were initially motivated because of a personal connection to cancer. Students at risk for leaving their traineeships because of technical struggles or lagging interest might regain their motivation when given the opportunity to engage with the patient community.

Over the six-year history of the Cornell Cancer Partnership, students have diversified in terms of both academic discipline and class level. While the initial students were almost all graduate students in the life sciences or engineering, many now enrolled are undergraduate pre-med students, master's level students in health administration or biomedical engineering, and even the humanities.

Community Member Participants

We made a conscious decision not to focus on "patient advocates" *per se*, but to encourage involvement by any community member affected by or interested in cancer. By casting the widest possible net, we are exposing students to more types of cancer and more personalities and approaches to living with cancer. Approximately one dozen community members participate on a regular basis, while others attend more sporadically. The majority have had cancer, but some are family members. We make a special effort to invite individuals with metastatic disease.

We have settled on the term "community members" as shorthand to refer to patients, survivors, family members, and other members of the public. To avoid participation fatigue by community members, we designate some sessions as being focused on instruction for students and emphasize community participation in other sessions. Not surprisingly, many of the community members who participate are faculty, staff, or retirees from Cornell. They are educators by nature and also have the advantage of being familiar with the campus. We advertise course meetings through email, flyers on the Cornell campus, and notes in the monthly Cancer Resource Center electronic newsletter. We provide light refreshments as a small token of our appreciation for community member participation.

While community members enjoy learning about cancer science, they have not, for the most part, sought additional training or became involved as patient advocates in national organizations. We expected that some community members would have their interest sparked by our program and then pursue more intensive training (e.g., the AACR Scientist-Survivor Program), but few have done so. This may be a paradoxical result of it being so convenient for them to participate locally. Community members do not have to travel out of town or enter a competitive application process. At Cornell, they simply show up for the programs that interest them and can still have a significant impact on the development of early-stage cancer scientists.

A common comment from community members is that the science of cancer is more complicated than they had imagined. They come to appreciate the intellectual challenges that confront cancer researchers. In return, community members teach researchers that it is just as complicated on the human level. Cancer affects every individual and every family differently. By connecting researchers and community members, a more complete picture of cancer emerges.

Educational Objectives

A primary focus of the program is science communication. In all of the courses, trainees are given instruction and then practice in delivering scientific research in accessible language to audiences that include community members. In addition to oral presentations, students practice interviewing patients, writing blogs and otherwise communicating with a lay audience. During the first year of the program, we realized that presentations on broad topics in cancer research, such as tumor heterogeneity or immunotherapy, are the most effective. Interestingly, our experience has been that students give clearer presentations on topics that they initially were less familiar with, rather than on their own research area.

A second objective is to expose trainees to the human side of cancer. A highlight of each academic year is a panel discussion in which several community members describe their personal experiences with their diagnosis and treatment. This session is often the first time that students hear about the costs of care, the side effects of treatment, the uncertainty of treatment decisions, and countless other issues.

Relatedly, we want to give trainees the opportunity to talk and interact informally with community members. We do this in a variety of ways, including "speed dating" in which community members and students talk briefly with each other in small groups before switching to next group. We recognize that students might get tongue-tied and afraid of saying the wrong thing, and point out during an introductory lecture on how to approach such conversations that ours is a safe environment to make those mistakes.

A final objective is for the participants to learn more about cancer research. This is primarily targeted to the community members and undergraduates, but we have found that even the doctoral students benefit from seminars that are from outside of their own academic discipline.

Experiences to Date

At the end of each course, students provide feedback via a course evaluation. The full semester course also includes initial and final reflection pieces at the beginning and end of the course, respectively. Because our program is still relatively young, we do not have long-term outcome data but intend to poll program alumni in the future. Many students in our program report that their perspective on cancer changes from a narrow focus on a specific academic problem to something much broader that directly affects people they know (7). Their work in the lab can truly make a difference. One student commented, "I used to care about accomplishments and great publications, but now, I simply want to generate data that will be most reliable and important for the improvement of cancer therapy." Another noted that, "As scientists, we are working on very intricate pieces of the puzzle. It is easy to lose sight of the big picture. The opportunity to really see the impact and the anxieties that the cancer patients face...is powerful motivation."

Students also come to recognize the diversity of cancer diagnoses and patients with cancer. One recent panel presentation unintentionally highlighted that many patients are atypical. The panelists included an individual with ocular melanoma, one with nevoid basal cell carcinoma syndrome, a male survivor of

breast cancer, and a nonsmoker who developed lung cancer at a young age. The typical case that one reads about in a textbook often does not reflect the diversity of patients affected by the disease. Similarly, students learn that patients can have different cultural beliefs, value systems, and living situations. One student reflected that, "Interacting with people affected by cancer...creates opportunity for discussions and conversations that would not arise between scientists."

Beginning a Program

Our experience suggests that universities can create their own partnerships by initiating student-led research presentations targeted to the public, and, in turn, allowing community members affected by cancer to share their personal experiences with the students. It can begin as a simple one-time event. Identifying the community partner may be the most significant challenge for many university-based researchers. Local cancer support organizations are a natural starting point, but they vary widely in availability, resources, and interest in research. Individual cancer patients and survivors might emerge from one-time events who might be willing to engage additional community members.

Funding from a two-year Engaged Cornell grant allowed us to create the formal curriculum and to cover expenses for external speakers, a student teaching assistant, and refreshments for participants. The curriculum has continued to evolve over three years of trial and error. What has been essential is the commitment from the university and local cancer community to keep trying and to make it an on-going program. We continue to explore avenues to sustain the program financially.

Conclusions

The collaboration between cancer researchers-in-training at Cornell and community members affected by cancer in Ithaca, NY continues to grow and evolve. Whenever possible, we add community friendly elements to cancer research events on campus. For example, doctoral students give lay language "primers" immediately before research seminars by distinguished visiting scientists, to give nonscientists a basic understanding of the topic that will be discussed. And we involve community members as judges for scientific poster sessions, recognizing those trainees who are best able to explain their research in clear language. Looking forward, important strategic questions for the program include how to maintain the current high level of interest among students and community members, how to broaden the reach of the program to surrounding communities as well as other academic institutions, and how to ensure the financial sustainability of the program. We have already had doctoral students involved in our collaboration graduate, move to new organizations, and then seek out patient advocates and community members as potential collaborators. Several alumni credit the Cornell Cancer Partnership with influencing their career paths, with some choosing additional translational or public health training to complement their basic science backgrounds. As one reflected, "Talking to patients changed my perspective about how we should pursue research and with what goals."

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Authors' Contributions

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