Lower Gastrointestinal Cancers (AB Benson, Section Editor)

The Current Landscape of Research Advocacy and Education for Patients with Colorectal Cancer

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Opinion statement

Research advocacy is an evolving concept and should be tailored for the colorectal cancer research community. Research advocacy training and evaluation must be designed for the patient community with their insight included at each step of engagement, training, and implementation. Patient advocates bring a great deal of expertise to the research review process, but it is important to ensure that their insight is appropriately placed, and they bring an appropriate orientation to the research process as the most informed patient. This can be accomplished in part by providing advocates with the proper training, employing universal core competencies, and applying principles of adult learning. Additionally, the research community, advocacy organizations, and industry partners must understand the need to diversify the voices that are being leveraged to guide research, recognizing the importance of adequate mental health tools and compensation commensurate with their experience. As a community, it is necessary that we create and implement training programs, as well as evaluate and measure

their impact to continually improve and tailor the delivery of this specific education. Research advocacy has become a necessity to the field, and when implemented effectively, research advocates can have a significant impact on the delivery of health care research, improving health outcomes for all those affected by colorectal cancer.

Introduction

Research advocacy embraces the principle that research should engage the patient in order to "respectfully and compassionately achieve the best experience and outcome for that person and their family" [1]. Research advocacy aims to accomplish several common goals. First and foremost, it ensures that the proposed research incorporates the core principles of patient care, as well as the values and lived experiences of the patient community. It also helps to shape future delivery models, including the level of detail that patients wish to receive about their diagnosis, simplify use of technical jargon to make research easier to understand for the patient, and include diverse insight from advocates with different backgrounds [2]. Finally, it aims to improve scientific research by increasing research funding, improving enrollment numbers and diversity of clinical trial participation, prioritizing research questions, increasing transparency of research activities, identifying meaningful patient-reported outcomes (PROs), and disseminating study results for example [3••, 4].

While the term "research advocate" is a fairly new term, the fundamental concept behind the lay scientific advisory role is not. The history of research advocacy spans nearly 100 years. Perlmutter et al. describe the evolution of cancer advocacy beginning in the 1930s, ultimately evolving into patient support in the 1950s, and embracing a "collective action phase" in the 1980s [5]. Patient advocates for both breast cancer and HIV/AIDS set the precedent for research advocacy in the 1990s, arguing that they were the ultimate recipients of research outcomes and it was imperative that the voice and perspective of the patient were represented in decision making and research strategies. By arming themselves with basic science principles, they were able to engage with researchers and integrate the lived experiences of patients into the research process.

Since then, research advocacy has greatly expanded into cancer and across specific cancer types including colorectal, hereditary, ovarian and lung cancer. National organizations such as the National Cancer Institute Clinical Trials Network (NCTN) (which includes SWOG, the Alliance for Clinical Trials in Oncology, ECOG-ACRIN Cancer Research Group and NRG Oncology), the Patient Centered Outcomes Research Institute (PCORI), the Department of Defense (DoD) Peer Reviewed Cancer Research Program (PRCRP), the National Cancer Institute (NCI), the American Society of Clinical Oncology (ASCO), and the Research Advocacy Network all engage research advocates on various levels including reviewing patient materials, identifying factors that are most important to the patient community, and developing clinical trial protocols. Within colorectal cancer specifically, national non-profit organizations such as Fight Colorectal Cancer (Fight CRC) have made research advocacy part of their key mission, with dedicated resources for the training and development of research advocates. The goal of the research program is to help colorectal cancer patient advocates inform clinical trial design, provide insight on Institutional Review Boards (IRB), and serve as reviewers for funding agencies, including those noted above [2].

It is widely accepted that research advocacy is an essential tool to ensure that colorectal cancer research is carried out in a manner to best meet patient needs and improve patient outcomes [4]. However, there is limited information in the literature about the most effective approaches for

research advocacy training, program implementation, and evaluation. These are important to explore, particularly to legitimize and further a patient driven research advocacy movement.

The role of research advocacy

Patient advocacy organizations are one of the key groups that train research advocates and assist them in forging partnerships with various stakeholders. Researchers in industry, medical, and academic settings often partner with advocacy organizations and research advocates to ensure that they are including the patient voice across their research and patient engagement efforts. Research advocates work closely with each of these stakeholders and if engagement is properly executed with the patient's vested interest in mind, there is potential for a significant impact on both research and patient outcomes [4]. When incorporating the voice of research advocates, it is possible to see tangible results, such as increased clinical trial accrual numbers or the creation of useful information, including patient-facing materials, that are relevant for both clinicians and patients when making health care decisions [6]. Research advocacy can also assist in relationship building between researchers and underrepresented communities in healthcare [7•]. Banner et al. argue that research advocacy "is seen as a means of promoting greater accountability, authenticity, transparency, and trust in the scientific endeavor, while fostering more democratic and socially responsible practices that challenge traditional academic elitism and privileged knowledge." [3••] Tucker-Seely et al. [8] describe how advocacy is one of the primary areas that can be leveraged to address social determinants of health (SDOH) in health care settings. They argue that advocacy is necessary to create partnerships between the health care delivery system and the community in the cancer care field to improve community resources, therefore improving community health. Advocacy organizations and research advocates alike are a bridge to communities often underrepresented in healthcare and can help identify what is important to patients. For example, advocacy groups and research advocates can work with researchers to better understand whether certain communities have a preference for colorectal cancer screening options, or what type of resources are most valuable in a survivorship care program. They can also identify how to best establish trust between the patient community and providers and researchers, how to create tailored educational resources that resonate with various populations. Research advocacy has the potential to serve as a catalyst to improve research, healthcare access, education and outreach for all populations, regardless of race, ethnicity, sexual orientation, gender, socioeconomic status, or geographic location.

State of colorectal cancer research advocacy infrastructure

Research advocacy training opportunities

For patients to be effectively engaged in the research process, they must be provided with the opportunity to develop skills and tools to work cohesively

with various stakeholders and understand their role in the research process. Without a proper framework for training, the role of research advocates may be limited in scope and function.

Several organizations, including but not limited to, the British Medical Journal (BMJ) [9], Fight CRC [2], Facing Hereditary Cancer Empowered (FORCE) [10] Friends of Cancer Research (FOCR) [11], Patient-Centered Outcomes Research Institute (PCORI) [6], and the Research Advocacy Network [12], have established research advocacy training programs to increase knowledge, self-efficacy, and skills amongst research advocates. Many of these structured training programs offer both online and in-person trainings and connect trained advocates to academic and industry partners and research scientists. Both the Research Advocacy Network and PCORI's training programs can be customized, while others such as those created by FORCE and Fight CRC are more specific based on disease area. For example, Fight CRC utilizes an online training program that spans the colorectal cancer continuum (focusing on topics from bench side science through end-of-life care, including prevention, treatment, and clinical trials), and provides an in-person training to solidify research principles and create an opportunity for mentorship with professionals in the field. Organizations such as FOCR provide specific training across all cancer types to help advocates understand how to best engage with drug researchers, developers, and regulators. Organizations including the American Association of Cancer Research (AACR) [13] and the American Society of Clinical Oncology (ASCO) [14] provide various training tools for research advocates at their annual meetings to effectively engage with researchers at conferences. Table 1 describes pan-cancer and colorectal cancer research training programs, including key elements of training components and resources provided to bolster colorectal cancer research advocacy. It is important to note that this list is not comprehensive.

Based on the observations in Table 1, training in the field widely varies, yet there are several foundational similarities, including access to online components, mentorship, and support to engage alongside researchers in peer-reviewed studies and abstract submissions.

Currently, a standardized set of core competencies does not exist within colorectal cancer research advocacy. According to Mallidou et al., "learning and co-learning (e.g. researchers help patients and other stakeholders to understand the research process) are key principles in the patient-centered outcomes research." [15] They highlight how competencies for patient-oriented research (POR), such as the role that research advocacy plays, are currently ambiguous, yet defining competencies can prepare POR teams and engage relevant stakeholders in clarifying and fulfilling the proposed research agenda. The colorectal cancer research advocacy field must agree upon a set of core competencies to ensure patients are receiving training that benefits their learning experience, and ultimately their influence and impact when working with researchers.

Greenhalgh et al. describe the breadth of frameworks that can aid engagement efforts; however, they also discuss the ability and benefit of applying these trainings outside of their defined scope. An "off-the-shelf" framework may be of limited value to stakeholders and more would be gained from "using evidence-based resources to co-design their own frameworks" [16].

Training programs and educational tools must identify their specific focus, whether it be based on disease (i.e. colorectal cancer), activity (i.e. peer review

Table 1. Formalized cancer research advocacy training programs

Organization	Training components	Evaluating impact
AACR Scientist ↔ Survivor Program [13]	• Meeting with scientific mentors • Support to participate in poster sessions and networking opportunities at annual AACR meeting	• None noted
ASCO [14]	• Advocacy tools and resources (ASCO in Action, ASCO ACT Network), access to videos/podcasts etc. breaking down science for specific diseases • Networking sessions at ASCO annual meeting • Support for abstract submission	• Advocate feedback on tools provided at annual meeting • Number of research advocates and research advocacy organizations who attend each meeting
BMJ [9]	• Online presentations • Peer review exercises	• Cross sectional survey understanding motivations to review, concerns, and suggestions to improve the training materials and process
Fight CRC [2]	• In-person training at academic centers • Online modules throughout CRC continuum	• Survey to advocates understanding research knowledge, skills, and confidence • Survey to experts who have worked with advocates to understand strengths of the program, perceived impact, gaps, and satisfaction
FORCE [10]	• Self-paced, online educational course • Expert led webinars	• Requests feedback from researchers who utilized patient input on impact of having advocates involved in their study
FOCR (Progress for Patients) [11]	• Online training modules to provide tools for advocates to communicate with drug researchers, developers, and regulators	• Provide evaluation numbers for advocates who complete training to clarify research goals and refine questions in research process
PCORI [6]	• Patient Advocacy Executive review form • Designed to be implemented for other organizations conducting clinical trials	• Pre and post training survey data evaluating knowledge, confidence, skills, and self-efficacy
Research Advocacy Network [12]	• On-site training • Customized workshops and webinars via online learning resources	• Conduct evaluation of the effectiveness of advocate activities in basic, translational and clinical research

activities), or outcome (i.e. increasing clinical trial enrollment). Many of these training programs should be used in tandem, based on the goals of the specific program. Assuming a one-size fits all approach is unrealistic to accomplish the goals of the training program to improve advocate's engagement with the research community and patient outcomes.

Training program and implementation evaluation

A well-designed training program must not only benefit the research advocates, but it must also positively impact the larger research and patient community. It is necessary to evaluate (1) if the training program achieves its goals by increasing research advocate's knowledge, skills, and confidence, and (2) evaluate program implementation to understand if the advocates are effectively engaging with the research community and having an impact. A well-executed training

program and successful evaluation can also ensure that research advocates have the appropriate orientation when engaging with researchers and are representing the collective patient experience rather than their single perspective [2].

Most organizations have standardized processes to evaluate and measure impact of their training programs through various methods such as surveys and focus groups (Table 1). Both Fight CRC and PCORI distribute surveys to advocates to determine if their knowledge, confidence, and skills in research advocacy improved after completing a training program [2, 6]. The BMJ evaluates the quality of their training content, including concerns and suggestions to improve materials [9], and ASCO collects advocate feedback on tools provided at their annual meeting [14]. While many programs are able to effectively evaluate their own trainings, it is not always clear which metrics are included and how those metrics are being utilized to improve these programs.

Several organizations listed in Table 1 have attempted to evaluate implementation of research advocacy as well. FORCE conducted an evaluation to understand the impact of having advocates engaged in research studies. One researcher responded that "The FORCE advocates provided invaluable feedback on my research study and survey materials. They brought up issues that I hadn't considered, helped me clarify my research goals, and led me to refine the questions that I asked participants." [10] Fight CRC also aimed to evaluate how research advocates could impact the research process and found that the majority of researchers saw high impact and value of incorporating the perspective of research advocates [2]. Despite this, the literature identifies major gaps in evaluating the research advocacy process and outcomes. Pushparajah et al. argue that "the lack of standardized best practices and metrics has made it challenging to achieve consistency and measure success in patient engagement" [17]. Little evidence exists that concretely assesses how these training programs can improve the ability of advocates to effectively engage with researchers.

Opportunities to improve patient education, training, and advocacy initiatives

Applying advocacy training principles

The various training programs outlined have shown success in training advocates to effectively engage with researchers. If they are not already, programs can be strengthened even further by incorporating adult learning principles. Bryan et al. describe essential principles to follow for engaging adults in health promotion, specifically as community partners within public health, which include (1) ensuring adults know why they are learning, (2) motivating them to learn and by the need to solve problems, (3) building upon and respecting their previous experiences, (4) applying learning approaches that match their background and diversity, and (5) actively involving them in the learning process [18].

Leveraging principles of adult learning can support the training framework to deliver on skills/duties of the research advocacy core competencies. Frisch et al. conducted a follow-up study to better understand core competencies that could be integrated into adult learning for research advocacy and discovered that the most important competencies for patient advocates included (1) Research Methods and Principles, (2) Participatory Approaches, (3) Cultural

Competence and Context, (4) Logistics, (5) Understanding Evidence and Results, (6) Knowledge about Phenomenon of Study, and (7) Priority/Agenda Setting. The authors argue that not all research advocates need to be trained on every single competency, rather the research teams can "take these reported competencies and draw out what is needed for their particular study" [19••]. Implementing a standardized set of core competencies can improve training programs and create research advocacy opportunities that match advocate's backgrounds, interests, and strengths.

Diversifying perspectives

Incorporating principles of adult learning can also ensure that the training program incorporates various perspectives in the research process and represents a wide range of communities. This can strengthen the impact and value of research advocacy. In oncology clinical trials for example, Black Americans make up approximately 5% of participants, while Hispanic populations represent 6% of trial enrollees [20]. This is a major issue when attempting to translate clinical research findings to the broader colorectal cancer community. Research advocacy however can help authentically engage advocates and researchers in discussions on designing and disseminating clinical trials in an equitable manner.

Additionally, engaging those with diverse perspectives can help researchers understand various components of social determinants of health, including inequities due to conditions (structural factors such as stigmatization, institutional environments such as policies, living environments, such as economic, social, and physical), and disparities due to consequences (risk factors, biomarkers, and comorbidities) and how they can be addressed in research to determine health outcomes. Alcaraz et al. [21] discuss the need to understand how SDOH affects cancer research, including studying the ability of people to access and receive timely screening, treatment and survivorship resources. Incorporating diverse research advocate perspectives can help identify some of these burdens early in the design of various studies, interventions, and in cancer resources more broadly.

Advocacy organizations play a role by collaborating with researchers, diverse communities, and other sectors, which can lead to improved access to care and patient education amongst populations that are historically underserved in health care. By leveraging partnerships with researchers, subject matter experts, and other health organizations, advocacy groups and research advocates can identify and define potential approaches and solutions to effectively engage communities facing health disparities into the research process, for example, increasing recruitment of under-represented participants in clinical research, and developing measures to assess impact.

Although various frameworks may need to be modified based on disease type, goals, and other factors, Banner et al. highlight the principles that should remain constant throughout the research advocacy engagement, training, and implementation process. These include "(1) authentic and sustained engagement across the research continuum and beyond, (2) clarity in the roles and expectations of all parties engaged in the research, (3) mutual trust and respect, (4) commitment to co-learning and co-production, and (5) access to the appropriate resources, supports and training." [3••] Establishing trust between

the patient community and the scientific community is critical to ensuring research is being conducted that is representative of all individuals facing colorectal cancer, that findings can be translated to everyone, despite social determinants of health. Utilizing these principles allows for advocates to engage in the learning process and co-create trainings that are tailored towards the community they intend to impact. This provides a solid foundation in which the community educates and utilizes the advocate voice in the proper way, establishing trust and transparency throughout the process [7•].

It is now essential, rather than an idealistic goal, to work with advocates from a diverse array of communities to ensure a spectrum of patient experiences are reflected in clinical research. Hickey et al. argue, "There are often power differentials between the public and researchers. This is particularly so when the focus is on groups, perhaps considered as marginalized or seldom heard" [22]. Working alongside marginalized communities can bolster trust and transparency between the scientific field and various underrepresented communities, in turn improving research advocacy, patient education, and research outcomes.

Avoiding burnout and distress

Research advocates require scientific training, but it is also necessary to provide emotional support and acknowledge that advocates experience both grief and burnout when representing the patient community. Nasso et al. describe that while advocacy can empower and inspire patients, it can carry both mental and emotional burdens including "the grief of losing friends to cancer, the related "survivors' guilt," and the burden of repeatedly reliving their experience" [23•]. The National Coalition for Cancer Survivorship conducted both surveys and focus groups to identify factors that contribute to feelings of accomplishment or burnout and found that 97% of advocates felt that the work was rewarding. Nearly one-third of respondents reported emotional and physical burnout, and less than half of respondents admitted to setting boundaries with their personal life [23•].

Anecdotally, advocates within the Fight CRC RATS program have described similar experiences, which have been heightened by the COVID-19 pandemic. Each of the following quotes illustrates the complexities of serving as a research advocate: [2]

"I felt the need to step away from advocacy multiple times to practice self-care, especially after I lost close friends to colorectal cancer."

"After several years, I now have to set boundaries and give myself permission to decline advocacy requests."

To address this, the Patient Empowerment Network provides strategies for advocates to address burnout, including setting realistic expectations, prioritizing projects, and taking breaks between big projects [24]. It is necessary for all research advocacy training programs to provide grief management strategies. The broader colorectal cancer community, including researchers, providers, industry partners, and advocacy groups, must be aware of the signs of burnout and be mindful to avoid overburdening the advocacy community.

Adequate compensation

Although advocacy work is largely volunteer based, stakeholders are becoming aware of the importance of compensating research advocates for their expertise and time. To help provide a resource that recommends standardized compensation rates, the National Health Council developed the Patient Engagement Fair-Market Value Calculator. This calculation tool takes into account factors such as patient experience, activity type (including preparation time, activity time, and post-activity contributions), travel costs, wages lost, urgency of activity, and care support to help derive fair compensation rates [25].

The Fair-Market Value Calculator is the most comprehensive tool to calculate payment for advocacy activities to date. PCORI also utilizes a similar framework differentiating between various engagement levels including informing the work, consulting, collaborating, and stakeholder directing with pay scales increasing with each engagement type. PCORI's "fair financial compensation demonstrates that patients, caregivers, and patient/caregiver organizations' contributions to the research, including related commitments of time and effort, are valuable and valued." Compensation "demonstrates recognition of the value, worth, fairness of treatment with others involved in the research project and contributes to all members of the research team being valued as contributors to the research project" [26].

As research advocates become more integrated into research design, planning, and implementation, appropriate compensation is critical. It is likely that providing financial incentives to advocates will alleviate some of the burdens research advocates face, such as burnout, provide a higher sense of value to their work, and allow them to prioritize various projects.

Evaluating impact

Marinello et al. offer a potential solution for approaching the successful development of research advocacy evaluation frameworks. They developed a process to evaluate patient engagement within the European Reference Network (ERN), which consists of clinicians in Europe, and determined that the first step in creating a successful framework is clarifying the role, goals, and activities of patient advocates. This then can be used to develop a set of measures to evaluate impact and outcomes. The second step is to develop concrete measures, including but not limited to (1) if advocates are listed as co-authors in their guideline development, (2) the number of ERN working groups with advocates involved, (3) the perception/level of satisfaction on how advocates are working with and engaging clinicians, and (4) the number of poster presentations with advocate involvement. The authors noted the importance of working with ERN clinicians to "refine the framework to render it more relevant to the reality and priorities of the specific ERN's and more valuable as a tool to build a strong partnership culture" [27].

By clearly outlining a research advocate's role, the activities they are responsible for, and outcomes, it becomes easier to develop and implement successful training programs and tools, and subsequent evaluation metrics for both trainings and implementation. Furthermore, advocacy training programs must conduct frequent evaluations and share results and lessons learned with the field. However, the transferability of evaluation frameworks across groups and

disease types may not be appropriate, and further research and refinement of evaluation metrics are needed.

Barriers to research advocacy

While many opportunities exist to improve research advocacy, it is important we identify and understand broad barriers to successful implementation. One of the seemingly simple challenges facing research advocacy today that has been previously discussed is the lack of a common definition [1]. According to Robbins et al., "the patient's role needs to be described in a way that makes it feasible to implement health care delivery and support parameters to conduct clinical research over a sustained period of time" [28]. Possibly one reason why it is difficult to define research advocacy and patient centricity overall is the numerous roles of a research advocate. Research advocates provide direct patient support, fundraise for research, work with legislators to increase research funding for governmental agencies such as the DOD or NCI, serve as "regulators" to bring both system and research issues to light, and work alongside scientists to improve the relevancy of their research [29]. Without a common definition, it makes it challenging to establish training objectives and goals, to recruit the appropriate advocates, and outline roles and responsibilities across the trajectory of the research continuum.

Another challenge when involving research advocates in the scientific process is the balance of power. Robbins et al. describes how the field of research advocacy may have "more than we bargained for, particularly with people of limited understanding or low medical literacy or those whose decisions seem impulsive or overly influenced by emotions… we need to inject a dose of reality and not underestimate the challenges of health literacy and the fact that 'despite this emerging of an era of self-enlightenment, we are encouraging patients to challenge and evaluate the judgment of seasoned healthcare professionals who have over a decade of college'" [28]. Research advocacy requires a delicate balancing act between the patient and scientific expert; being mindful of both those that have lived experience, and those that have years of academic and medical experience.

Future directions for creating educated and empowered research advocates

Based on the review of the literature and examination of existing advocacy programs (Table 1), there are a variety of opportunities to improve how the research and patient community effectively understand and apply the patient perspective. Research advocacy programs have been more widely implemented over the past two decades but there are still challenges. To advance the field, there are specific priorities which need to be addressed.

The most critical step is that the research advocacy community must agree upon a common definition. Advocacy organizations with experience in engaging the research and patient community can help convene experts to help build consensus for a common definition and then define the scope of practice and more discretely define the roles of the research advocates.

Once the definition and scope of practice are established, there is a need for further refinement of core competencies including integrating the principles noted throughout this manuscript. By establishing a common definition, scope of practice and competencies, organizations can create or augment training objectives and goals for their program and help scientists recruit the appropriate advocates. This dedicated process also allows for researchers to understand the advocate's responsibilities throughout the research process, simultaneously providing a balance of patient expertise with scientific expertise.

Training can be disease-specific or focus on specific areas along the cancer continuum, such as clinical trial design or engaging with specific partners including regulatory agencies. It is necessary to understand the availability of current frameworks that can be applied when strengthening current training programs or developing novel trainings. We also recommend that research advocacy programs identify primary evaluation measures to identify and validate the impact that research advocates are having in the research process.

Providing support to the research advocacy community ensures that research advocacy is legitimized, that the voices of the patient community are appropriately integrated and diversified, trust is established, and advocate contributions are valued. This manuscript provides an overview, opinion, and suggestions to strengthen research advocacy programs, which will lead to improved research processes and patient outcomes.

Declarations

Conflict of Interest

Reese Garcia declares that she has no conflict of interest. Andrea J. Dwyer declares that she has no conflict of interest. Sharyn Worrall declares that she has no conflict of interest. Keavy McAbee declares that she has no conflict of interest. Anjelica Q. Davis is an unpaid advisor on NCI Working groups (NCRA, CTAC, GI Steering Committee).

Human and Animal Rights

This article does not contain any studies with human or animal subjects performed by any of the authors.

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- •• Of major importance

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