

## The Appalachian Career Training in Oncology (ACTION) Program: Preparing Appalachian Kentucky High School and Undergraduate Students for Cancer Careers

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**ABSTRACT:** The <u>Appalachian Career Training In ON</u>cology or ACTION Program is a National Cancer Institute (NCI) Youth Enjoy Science (YES) research education grant program that recruits and trains early-career undergraduate and high school students from underrepresented, socioeconomically distressed areas of Appalachian Kentucky in cancer research and outreach. The two-year program is a multifaceted experience that includes participation in cross-disciplinary, mentored cancer research projects. In addition to research projects, participants also shadow faculty mentors in clinical medical settings, engage in multiple types of educational activities, and participate in cancer-focused outreach projects within their communities. Participants also engage in peer-to-peer networking and receive career mentorship, training, and coaching. Highlights of program activities include a student-led photovoice project to promote cancer awareness and participant publications including a book featuring participant essays focused on their experiences and thoughts on cancer. Initial impact data show high school participants have a higher than state and county average four-year college-going rate and all undergraduate participants are gaining positive outcomes related to educational and career attainment. This article provides an overview of the significant benefits of the ACTION Program, the program's activities, and highlights from program implementation. Potential impacts of the program and barriers to implementation are also shared.

## INTRODUCTION

The National Cancer Institute's (NCI) Youth Enjoy Science (YES) Research Education Program funds nonprofit and government-based research programs with the dual goal of increasing cancer knowledge and awareness among underrepresented students while also preparing these students to participate in careers in biomedical research (NCI, 2021b). Programs funded by the NCI and other cancer research training programs have been shown to increase awareness of cancer and cancer prevention methods (Cameron et al., 2012); increase interest in cancer research (Hein & Kidd, 2018); increase interest in medical and/or cancer-related careers (Alfred et al., 2011); and produce a high number of students pursuing and completing medical, professional, and doctoral programs (Alfred et al., 2011; Gronemeyer, 2011; Hein & Kidd, 2018). These programs for high school and undergraduate students have primarily focused on promoting cancer research training to underrepresented racial minority youth

populations and/or students from urban areas (Alfred et al., 2011; Hein & Kidd, 2018; Qua et al., 2020).

The University of Kentucky's (UK) Markey Cancer Center (MCC) Appalachian Career Training in Oncology (AC-TION) Program builds on the success of other cancer training programs but shifts the focus of recruitment efforts to students from rural, low-socioeconomic, and low-education attainment areas in Appalachian Kentucky. The two-year program engages both early-career high school students and early-career undergraduates in a range of educational and experiential learning activities including cross-disciplinary, faculty-mentored cancer research projects. In addition to research projects, participants also shadow faculty mentors in clinical medical settings, engage in multiple types of educational activities, and participate in cancer-focused outreach projects within their own communities. Participants also engage in peer-to-peer networking and receive career mentor-

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#### ship, training, and coaching.

This programmatic paper provides an overview of the program's components and documents highlights of program implementation collected from the first four years of implementation. First, the need for the program within the context of the Appalachian region is outlined followed by a description of each program activity and the metrics utilized for evaluating the program. Then, highlights of programmatic implementation are provided that describe the demographics of participants, some of the unique activities completed over the past four years, and some preliminary data on the impact of the program. The paper concludes with a discussion of the program in relation to similar programs and some potential barriers to implementation that may affect others interested in implementing similar programs.

The Need for the Program. The ACTION Program was designed to address multiple, overlapping needs that face the Appalachian region. First, the Appalachian region as defined by the Appalachian Regional Commission (ARC) is marked by severe poverty (Commission, 2016), poor educational attainment (Commission, 2016, 2017; Commonwealth of Kentucky, 2016), and high levels of mortality from cancer and other diseases (Commission, 2017; Foundation for a Healthy Kentucky, 2017; Kentucky Cancer Registry [KCR], 2020; Rodriguez et al., 2018). The mountainous, 54-county Appalachian region of Kentucky comprises a significant portion of rural central Appalachia and contains the majority of economically distressed areas within Appalachia. Forty-one of 54 Appalachian Kentucky counties have economic indicators within the lowest 10% among all United States counties (Commission, 2016; Couto et al., 1994; Flippen, 2014; US Department of Health and Human Services [US HHS], 2017). Moreover, the area has significant cancer disparities compared to the United States as a whole. Kentucky ranks first in the nation for overall cancer incidence and mortality, with the highest burden of cancer in Appalachia Kentucky where overall cancer incidence and mortality rates are 20% and 36%, respectively, greater than the overall rates in the United States (Commission, 2017; Foundation for a Healthy Kentucky, 2017; KCR, 2020; NCI, 2021a; Rodriguez et al., 2018; Siegel et al., 2018; US HHS, 2017).

Kentucky also lags behind much of the rest of the country in terms of higher education attainment. The current high school graduation rate of 87.2% is comparable to the national rate of 88%; however, 54.7% of Appalachia's workforce hold only a high school diploma, and only 24.7% hold a bachelor's degree or more compared to the national average of 32%. In central Appalachia, which is made up primarily by eastern Kentucky, only 15.2% of eligible residents hold a bachelor's degree—a rate that is 18.3% below the national average (Commission, 2021b). While not all jobs require a bachelor's degree, these data indicate the lag in educational attainment in the region (Commission, 2021b; Hale et al., 2017). Moreover, Kentucky awards fewer than 1% of the nation's total doctoral degrees, and this disparity is even greater in Appalachian Kentucky, where rates of doctoral degree attainment are less than 1% (Commission, 2017). Similarly, social research on Appalachian student populations suggests rural Appalachian students may struggle with academic success and engagement due to a range of issues including perceived feelings of inadequacy, a lack of familial knowledge of education systems, and strong ties to local and familial culture that pull students away from their studies (Bryan & Simmons, 2009; Dunstan & Jaeger, 2016; Wright, 2012). Research suggests these school-home tensions may begin even in elementary school (Powers, 2002), indicating a potential need for early and sustained interventions.

The combination of unique cancer and socioeconomic disparities and underrepresentation in education attainment among residents of Appalachian Kentucky counties underscores the significant need to create targeted educational and scientific workforce preparedness interventions and health literacy intervention strategies for this population. This need motivated the MCC to create the ACTION Program. To impact these particular challenges, the program recruits both UK undergraduate and high school participants who hail from the 54 counties that make up Appalachian Kentucky as defined by the ARC—and engage these participants in the program's intensive two-year experiential learning and research activities.

In addition, when designing the ACTION Program, program personnel recognized the need to reduce barriers of access to potential participants. For example, while impactful learning practices like the research projects that occur during the ACTION Program have been shown to promote positive educational outcomes for both low-income and underrepresented students (Kuh, 2008; McConnell Parsons et al., 2020; Pascarella et al., 2004), these types of experiences are frequently implemented in ways that hinder these students from participating. Undergraduate research experiences are often offered primarily to upper-level undergraduates that have already selected a major (Hensel, 2018) which can limit access to underrepresented students who disproportionately leave college early (Radunzel, 2018). Similarly, students from low-income areas like Appalachia frequently have external obligations and pressures that prevent their participation in unpaid extracurricular activities like summer research experiences or research experiences outside of course hours (Ardoin, 2018; Bryan & Simmons, 2009; Hensel, 2018). Recognizing these barriers, the ACTION Program required that participants be early-career high school students (9th to 11th grade) and early-career undergraduate students (first year to junior year). Participants are also paid an hourly wage (approximately \$10 per hour) to reduce potential fiscal hardship.

## **PROGRAM DESCRIPTION**

The ACTION Program recruits both undergraduate and high school participants to take part in program activities over the course of the two-year program. Eight undergraduate students are recruited each year from students enrolled at UK who are in or plan to major in a health or biomedical sciences-related field. As a result, a total of 16 undergraduates participate in the program each year (8 first year participants and 8 second year participants). To promote undergraduate recruitment, program personnel have partnered with science and public-health related academic programs, the university's honor's college, the university's Office of Undergraduate Research and other experiential pipeline programs on campus. In addition, every two years the program recruits 20 high school students to participate in a two-year cycle, resulting in a total cohort of 36 students each year. To encourage diverse high school participant recruitment, program personnel have partnered with multiple local and regional groups including the university's Area Health Education Center that has regional offices throughout the state and regional US Department of Education-funded Upward Bound Programs. In addition, program personnel have established connections with guidance counselors and teachers in individual high schools across the Appalachian Kentucky region to enhance recruitment activities.

Undergraduate participants are engaged in activities yearround for both years of the program. Undergraduates spend at least 10 hours a week during the academic year participating in activities and approximately 40 hours a week during the summer months. High school participants also engage in year-round activities over the course of two years; however, high school participants' primary participation comes in the form of an intensive, five-week long residential experience each summer. Each week during the summer program, high school students spend approximately eight hours daily engaging in program activities and then in social activities in the evenings and weekends. In addition to the summer experience, high school participants attend monthly sessions at UK throughout each academic year. The monthly sessions occur on weekends and usually last approximately five to six hours.

Program activities include faculty-mentored research training experiences; clinical observations with a faculty mentor; a range of educational activities; community outreach projects; peer-to-peer mentoring and social support; and career mentorship, training, and coaching. Each activity is intended to contribute to the program's specific aims of increasing participants' cancer knowledge; promoting participants' eventual employment in cancer-focused careers by increasing their cancer knowledge and academic and career preparation; and providing cancer-focused outreach to Appalachian communities. Below we overview specifics of each activity performed by participants and, when applicaVol. 4, Issue 1, December 2021

**Research Experiences**. Each high school and undergraduate ACTION Program participant is paired with a primary research faculty mentor to develop a research project that creatively incorporates individual student perspectives, skill sets, and interests. Faculty research mentors recruited for the program include faculty from colleges of public health, pharmacy, engineering, education, nursing, and medicine. Faculty also represent sixteen different departments across the colleges and also a wide range of research areas within the spectrum of cancer research including basic and translational research, clinical research and behavioral/population research. Program personnel leverage this diversity of research areas, constructing pairings between students and mentors based on students' interests. In many instances, because of the multidisciplinary nature of cancer research, participants encounter multiple research mentors who provide guidance for specific aspects of their research training. Mentor recruitment has been successful by engaging those faculty that are highly active in the Markey Cancer Center's research and clinical programs. The College of Medicine offers a mentor training program that ACTION mentors can take, and many have also taken the university's unconscious bias training offered by human resources.

As part of their research experiences, participants learn to define research objectives, develop independent research protocols, apply the techniques of experimental design, perform experiments, and evaluate experimental results including learning to think analytically and critically about the scientific process and the analysis of experimental data. Based on the specific research experiences, participants are exposed to and become intimately familiar with a range of modern and state-of-the-art cancer research techniques ranging from cell and molecular biology techniques to the collection and analysis of population- and behavioral-based data. Participants are exposed to the application of these research techniques to fundamental and highly translational cancer research questions. Finally, participants have opportunities to present their research locally at large and small university-sponsored conferences and nationally at conferences such as the American Association for Cancer Research.

**Clinical Observations**. ACTION Program participants are paired with a clinical faculty mentor to shadow and observe experienced oncologists as they deliver care. The mentors participating in clinical observation represent a range of departments, divisions and specialties including radiation oncology, medical oncology, pediatric oncology, hematology, pathology, radiology, gynecologic oncology, surgical oncology, precision medicine, pharmacy, oncology social work, and genetic counseling. These mentors also have diverse sets

#### ACTION Program – Parsons et al.

of specializations and include a range of medical professions including medical doctors, nurses and nurse practitioners, physician assistants, social workers, and genetic counselors. The diversity of disciplines and specializations allows pairing between clinical mentors and participants to be based on student educational and career interests. As part of the observation, students shadow their clinical mentor in clinical care environments such as clinics, inpatient facilities, chemotherapy infusion units, and in the operating room. In addition, participants have the opportunity to attend multidisciplinary tumor board meetings with their mentor to observe the presentation of cancer cases for both clinical care and clinical research purposes. These experiences highly compliment the research that participants are conducting. For example, a participant researching breast cancer can have opportunities to observe breast cancer care in a variety of settings. As such, the clinical shadowing activities allow participants to make connections with their research and clinical cancer care.

Education Activities. In addition to their hands-on cancer research and clinical experience, participants also participate in a range of education-focused curricular experiences to boost their knowledge and skills. Common activities for both high school students and undergraduates include participating in research mentor lab meetings, attending ongoing MCC cancer research journal clubs, and attending regularly scheduled formal seminars and lectures. Seminars and lectures available to participants include clinical teaching conferences, clinical specialty-specific conferences, and weekly research-in-progress seminars by faculty at UK and those from regional and national institutions. Topics of these seminars span a range of cancer-related topics including basic, translational, clinical, and cancer prevention and control research. Participants also can attend the MCC's annual symposium that includes a keynote addressed by world-renowned cancer investigators. In addition to these common activities, ACTION Program personnel developed formal academic year coursework for undergraduates and intensive summer workshops for high school participants.

**Undergraduates**. Undergraduate ACTION participants are expected to take at least 12 academic credit hours broadly related to cancer over the course of the two-year program, enrolling in a 3-credit-hour course per academic semester. Courses covering aspects of cancer biology and therapy, cancer epidemiology, behavioral factors, cancer disparities, medical and research ethics, and career development are available to students. As part of their academic majors, participants also routinely take a number of biology, chemistry, and public health courses that prepare them more broadly for cancer careers. Importantly, this coursework is structured such that it will fit within the confines of each student's major requirements in order not to overburden each student

with additional coursework.

High School Participants. Each summer, high school students participate in three five-week long workshops developed as part of the program. Workshop topics include (1) cancer, (2) ethics in research and clinical care, and (3) educational and career readiness. The cancer workshop spans the depth and breadth of the cancer continuum including such focus areas as cancer biology, cancer disparities, cancer treatment, cancer risk factors and modifiable behaviors, and cancer epidemiology. Many topics are covered in ways that allow participants to learn about the cancer disparities in Appalachian Kentucky and the causes and consequences of those disparities. Topics are covered in grade-level appropriate manner and are delivered in such a way that concepts presented in the second year of the program builds on concepts learned in year one while also presenting more complex information.

Community Outreach. ACTION Program personnel and participants work to provide cancer research and clinical cancer education information to Appalachian Kentucky residents both during the academic year and summer. The outreach activities focus specifically on three target audiences: (1) middle school, high school, and undergraduate students; (2) parents and families of the ACTION participants; and (3) teachers, community members and civic leaders. The general topics that are covered include cancer disparities in Appalachian Kentucky, understanding the power and importance of cancer education and research; and cancer prevention and screening. Content for each topic is tailored to the three target audiences listed above in order to deliver the most meaningful and appropriate message to each group. For example, the importance of science education and the means of supporting students' pursuit of a science education is stressed to parents, teachers and school administrators. Current and former ACTION participants actively participate in the events by discussing the ACTION Program and their own personal experiences in the program as well as by conducting their own outreach activities to these groups. The outreach activities are held in schools/on campuses (middle and high schools and on undergraduate campuses) and in Appalachian Kentucky communities.

*Peer-to-Peer Mentoring and Social Support.* Peer-to-peer mentoring, networking, team building, and social support activities occur both during the summer months and during the academic year. For peer mentoring, the program recruits current UK cancer-focused undergraduate (e.g., second year ACTION Program participants), graduate (e.g., PhD students) and professional (e.g., medical students) students to act as peer mentors for ACTION participants and to form a peer-to-peer mentoring and networking group. ACTION

personnel meet with the peer mentors to discuss roles, responsibilities, and expectations and to ensure that each peer mentor understands university policies regarding interactions with other students, especially minors. Peer mentors work with the ACTION participants in their research environments acting as a peer research mentor. The peer mentors and participants also meet formally as a group where mentors offer advice (on such topics as coursework, other experiential experiences, and leadership opportunities), share experiences, and serve as role models. Peer mentors and AC-TION participants are also encouraged to meet and interact on their own. In addition, networking activities are provided for participants to connect with, for example, leaders and faculty of UK's undergraduate and professional/graduate programs as well as with career development coaches/specialists from the UK Career Center. Overall, these activities are meant to support ACTION participants' activities in the program as well as to provide a layer of short-and long-term career development support.

Social support activities include a range of evening and weekend social activities to promote engagement, cohort-building, and relationship building. Activities include visiting local cultural centers, attending university and local sporting events (e.g. university football and local minor league baseball games) as well as more regional trips that have included visiting a theme park and a dinner theater.

Career Support and Post-Participation Mentoring. During the two years of program participation, participants are provided with mentoring and career support via career development and coaching from program personnel as well as research and peer mentors. Participants can also receive group and individual career coaching from certified career coaches/ specialists at the university career center. The coaches/specialists instruct participants and assist them with tasks such as preparing for college or graduate/professional school and providing details on best practices in preparing college or graduate/profession school applications. Program personnel meet individually with students to work on their professional development plan and career development needs. During the summer learning experience, high school participants also attend a dedicated workshop directed by program personnel which covers topics including preparing and implementing individual development plans; building skills in resume and cover letter writing, interviewing, communication, and professional behavior; enhancing transferable/soft skills; networking; navigating mentorship; and applying for jobs or professional programs.

After program completion, participants are encouraged to continue engaging with career development support from the university career center and are encouraged to seek out advice on educational and career pursuits from program personnel. In addition, participants are recruited to act as peerto-peer mentors for future cohorts of participants, continuing their engagement with the program. Program personnel are frequently asked to write letters of support for participants as they apply to college or graduate/professional programs or to scholarships or other awards, and to other educational, experiential or leadership programs.

Evaluation. The evaluation of the ACTION Program is driven by the assessment of the four key aims of the program that include increasing students' (1) research knowledge, (2) cancer knowledge, (3) career and professional preparation, and (4) outreach skills and experience. Metrics utilized to assess these goals include multiple qualitative and quantitative measures and program output tracking including pre/ post surveys, interviews/focus groups, essays completed by students, counts of co-authored publications, counts of poster presentations, and counts of outreach activities completed. In addition, products created as part of outreach activities are also collected to document impact on students. Outreach projects include activities such as oral history projects and photo-voice journalism projects. Current and planned annual surveys include multiple scales and survey items intended to measure research skills, cancer knowledge, confidence/ comfortability with program activities, and programmatic feedback on quality of activities. Alumni annual surveys will also ask students to provide information related to their current educational status-if they have enrolled in a college, graduate school or a professional program and if so, where; what majors they are in; and any other activities they have completed. Program personnel are also interested in the impact of the program on faculty mentors and faculty mentors' assessment of participants' performance and progress. Therefore, the program will also collect and track data from faculty mentors. Table 1 provides a detailed overview of the current and planned evaluation metrics and the alignment between metrics and target outcomes.

## **PROGRAM HIGHLIGHTS**

Since 2016, the ACTION Program has recruited six cohorts of undergraduate students to participate in the program, with four cohorts having completed the two years of the program. In addition, two cohorts of high school students have been recruited into the program with one cohort completing the program. The following program highlights overview the demographics of participants, the unique activities completed as part of the program, and preliminary impact data collected.

**Demographics**. One of the key goals of the program is to involve students from rural Appalachian communities in a multifaceted cancer career training program. Including both high school and undergraduate cohorts, student participants

#### Table 1. ACTION Program evaluation plan.

Audience	Impact	Measurement	Schedule
Undergraduate students	Increased research knowledge as it	Poster presentations	Annually
	applies to cancer	Survey on research skills	Pre/post annually
		Exit slips or journaling – to regularly capture changes in thinking and impressions	Daily or weekly
		Interviews/focus groups	Post program annually
High school students	Increased research knowledge as it applies to cancer	Exit slips or journaling – to regularly capture changes in thinking and impressions	Daily or weekly
		Poster presentations	End of summer program
		Survey on research skills	Pre/post annually
		Interviews/focus groups	Post program annually
Faculty mentors	Increased ability to mentor students regarding research knowledge as it applies to cancer	Impacts of mentoring (citations)	Post program annually
Learning Objective 2: Incre	ase Students' Cancer Knowledge		
Undergraduate students	Increased understanding of cancer	Presentations - cumulative	Pre/post annually
	processes	Concept maps - cumulative	Pre/post annually
		Cancer Literacy Scale - revised	Pre/post annually
High School Students	Increased understanding of cancer processes	Poster presentations - cumulative	Pre/post annually
		Concept maps - cumulative	Pre/post annually
		Cancer Literacy Scale - revised	Pre/post annually
Learning Objective 3: Enha	nce Students' Career Preparation		
Undergraduate students and High school students	Increased focus on cancer majors and careers	Career and major focused survey	Pre/post annually
		Journaling	Weekly
		Case Study	One per year
Learning Objective 4: Cond	uct Effective Student-Community Outrea	ch	
Undergraduate students	Increased understanding of the cancer burden and challenges in participant communities	Essays regarding the impact of cancer in their communities	Annual
		Oral history project	Annual
High school students	Number of effective outreach activities in Appalachian counties increases	Photo-voice journalism project	Annual
		Data on the number of outreach activities conducted per community	Annual
		Essays regarding the impact of cancer in their com- munities	Annual
		Oral history project	Annual

in the ACTION Program represent 29 of the 54 ARC designated Appalachian counties in Kentucky, or approximately 54% of counties (Figure 1). Undergraduate students represent approximately 21 counties in Appalachia Kentucky while high school students represent 18 counties, 8 of which were unique (not represented by undergraduates). Of these counties, all except one are classified as rural counties by the Health Resources and Services Administration (HRSA2021) and 24 counties are classified as "economically distressed" by the ARC with the other five being either considered "at-risk" of economic distress (n=4) or "transitional" between distress and economically sound (n=1) (Commission, 2021a).

For the undergraduate student participants, 70% were female (n=28), 87.5% were white (n=35), and a quarter were first generation (n=10) and/or low-income as represented by reported parental income (n=10). The majority were either sophomores (n=17, 42.5%) or juniors (n=17, 42.5%) when they entered the two-year program; six were first-year students. Table 2 provides a breakdown of the demographics of undergraduate participants (cohorts 1-5).

High school participants were more evenly split between male and female participants with 23 female participants (57.5%) and 17 male participants (42.5%). High school participants were predominantly white (n=38, 95%), roughly half (n=19, 47.5%) were considered low-income, and 17 (42.4%) were first generation students. The majority were second year high school students (n=25, 62.5%) with the other 37.5% being made up of first-year high school students (n=15). Table 2 provides a breakdown of demographics of high school students (cohorts 1 and 2).



Figure 1. Map of Kentucky indicating the Appalachian region and counties of origin for ACTION student participants.

**Program Activities**. The following section highlights some of the works produced by participants as part of their participation in both research and outreach. In addition, feedback data on the program activities is also shared.

**Research**. As part of their participation in research experiences, multiple undergraduates participated in the production of scholarly works. To date, eleven undergraduate participants have authored or coauthored 14 publications in scientific journals, with one participant acting as first author on a paper. Topics of these scholarly articles include a range of topics that illustrate the diversity of experiences occurring through the program. Publication topics include the relationship between body composition and immunity (Al-Attar et al., 2018), prostate cancer biology (Dicken et al., 2019; Hensley et al., 2019), colorectal cancer biology (Gan et al., 2020; Stevens et al., 2018; Xiong et al., 2020), nutritional programs (Weber et al., 2021), health insurance

Table 2. Demographic	breakdown	of participants
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	High Schoolers		Undergraduates	
Parameter	Frequency N = 40	Percent	Frequency N = 40	Percent
Freshman	15	37.5%	6	15.0%
Sophomore	25	62.5%	17	42.5%
Junior	0	0%	17	42.5%
Male	17	42.5%	12	30.0%
Female	23	57.5%	28	70.0%
White	38	95.0%	35	87.5%
African American/Black	0	0%	0	0%
Hispanic	1	5.0%	0	0%
Asian	1	5.0%	5	12.5%
1st Generation	17	42.5%	10	25.0%
Low Income	19	47.5%	10	25.0%

literacy in colorectal cancer survivors (Edward et al., 2021), smoking-related cervical cancer (Borger et al., 2021; Puleo et al., 2020), novel xenograft methods (Haney et al., 2020), neuroendocrine tumors (Chow et al., 2021), and T Cell biology (Presnell et al., 2020).

Outreach. Both program participants and program personnel have participated in numerous outreach activities as part of the ACTION Program. Multiple outreach-focused publications have been produced by both program personnel and students. Two publications, one of which includes ACTION participants as authors, focus on a brief cancer education intervention in middle and high school students (Hudson et al., 2020; Hudson et al., 2021). Findings from these articles show that the intervention is effective at increasing students' cancer literacy and motivates them to share the information with family and friends. A follow-up publication to these publications describes a more extensive cancer curriculum that can be used in Appalachian Kentucky middle and high schools (Hudson et al., 2021). Another paper describes program efforts to prepare ACTION participants to be cancer advocates (Hudson et al., 2020). Program personnel also led the publication of a book of participant essays entitled The Cancer Crisis in Appalachia: Kentucky Students take AC-TION (Vanderford et al., 2020). The book includes personal essays from twenty ACTION high school participants and five undergraduate participants that describe their experiences with cancer in their lives and communities. Essay titles include "Cancer in Eastern Kentucky," "Cancer: A War on the Home Front," "A Monster That Kills," "Cancer: Kentucky's Disease," "Malignancy in the Mountains," and "Fighting Cancer in My Old Kentucky Home." The book is geared toward a general audience including young adults like those presenting the stories and is designed to promote further

# THE CANCER CRISIS IN APPALACHIA KENTUCKY STUDENTS TAKE ACTION

with contributions by Abigail Isaacs - Alyviah Newby -Andrew Davison - Brianna Reyes - Carrigan Wasilchenko - Emory Wilds - Ethan Tiller - Haleigh Thompson - Holly Dickens -Julie Kiser - Kaitlin Schumaker - Katelyn Nigro - Kinley Lewis - Lauren K. Collett - Matthew Melton - Megan Schlosser - Natalie Barker - Nolan Marcum -Rachel Collins - Shahid Jabbar - Solomon Patton - Spencer Shelton - Susanna Goggans -William Adams - Zachary Hall

NATHAN L. VANDERFORD - LAUREN HUDSON - CHRIS PRICHARD EDITORS

Figure 2. Cover page for book of essays written by ACTION participants.

awareness of cancer, cancer-risk behaviors, and cancer-prevention initiatives in Appalachian Kentucky. Figure 2 shows the cover of the book. The book was published by the University Press of Kentucky and is available widely through online booksellers including on Amazon.com. Additionally, despite the COVID-19 pandemic disrupting distribution plans, ACTION Program personnel have freely distributed nearly 400 copies of the book in Appalachian Kentucky to individual community members, libraries, schools and health care clinics. A second edition of the book, with essays written by different ACTION participants, is in process with a projected publication date in early 2022. Similar to the first edition, plans are in place to freely distribute copies of the book throughout the Appalachian Kentucky region.

Another product developed by students includes an on-going photovoice project. Students take photos in their communities of objects or activities that remind them of cancer in the area. The photos are published on the social media platform Instagram. Images include environmental polluting activities from local industries, cancer-risk behaviors like smoking, smokeless tobacco, and the consumption of processed and high fat foods. Students also take personal pictures that tell the story of a cancer experience in the students' lives. Accompanying each image is a short caption aimed at educating the public about cancer. Figures 3 provides examples of images posted as part of the photo project. The Instagram account currently includes over 100 posts of the students' images and has over 50 followers. The account can be found on the Instagram app by searching for @cancer in appalachia or at the web address https://www.instagram. com/cancer in appalachia. Additionally, in-person exhibits of some of the images is taking place at an art gallery in Lexington, Kentucky (where UK is located) and in Morehead, Kentucky, which is in the Appalachian region. Additional in-person exhibits are planned at other local and regional art galleries or cultural centers in late 2021 and early 2022.

Outreach activities have also taken the form of research projects. In partnership with the Louie B. Nunn Oral History Center at UK, students and program personnel are engaged in two oral history projects where they collect interviews with individuals discussing a range of topics including the history of cancer in the region and individuals' personal experience with cancer. Before the onset of the COVID-19 pandemic in March 2020, the program director had conducted four oral history interviews that includes interviews with two local media personalities who are experienced with the history of cancer in the region and who have had personal experiences with cancer, and an interview with two local oncology professionals who discussed their journeys toward their careers in cancer-focused medical careers and their experiences with cancer in Appalachia. In addition, prior to the onset of the pandemic, one student-led interview had been completed where the student interviewed a person working in cancer education and outreach. These interviews are available as



Figure 3. Examples of photo-voice outreach project as disseminated via the social media platform Instagram. part of the Nunn Center's online collection that is accessible to anyone and is targeted toward providing a resource for oral historian researchers. Both faculty- and student-led interviews can be found by searching for "ACTION Cancer in Kentucky" at the site https://kentuckyoralhistory.org. Plans are in place to continue this project when pandemic conditions allow.

Program Feedback. Data collected from students shows overwhelming positive perceptions of the program. Undergraduate and high school students that completed the program were asked to rate their overall experience. Eighteen high school participants and 21 undergraduate participants provided feedback. No participants reported having a negative experience in the program: the overwhelming majority for both groups indicated they had a "very positive" experience, and the rest indicated they had a "positive" experience (Figure 4). Open-ended feedback data illustrates similar satisfaction with the program. Across all iterations of the program (from the first implementation to the most recent), both undergraduates and high school students had the opportunity to provide open-ended feedback on their ACTION experience as part of the general survey administered at the end of the program. A total of 10 undergraduates (48%) since the beginning of the program provided some form of open-ended comment. Most comments were complementary and included comments on the program's positive impacts. Participants described lessons learned, discussed how the program was extremely beneficial to them, and expressed their gratitude for being able to participate in the program. Similarly, the six high school students (33%) that provided comments also indicated a generally positive perception of the program. One student mentioned that the financial session and information provided in the educational and career readiness workshop "helped me in ways that I would never have thought about." At least a few students did provide some constructive feedback. One constructive response, expressed by two undergraduate students, was the wish "to do more outreach and be able to interact more with the community." In addition, one high school student observed that



Figure 4. Overall program satisfaction ratings reported by undergraduates and high school students.

the "lab experience really differed for a lot of people." This student seemed to want more out of her experience because she acknowledged that, "I was shadowing all day and using the pipette once-an-experiment." However, overall, student experiences were overwhelmingly positive.

*Impact*. For the impact of the program on outreach as well as research knowledge and cancer knowledge, program personnel collected multiple pre and post measures for the program. However, because the program has two distinct participant groups with different starting levels of skills, knowledge, and general efficacy, data on the program's impact on research knowledge, cancer knowledge, and outreach skills will be presented via distinct analyses in future papers after additional data collection on future cohorts can be completed and independent analysis for each group can be performed. Data is available, however, on students' career and professional goals and attainment that may provide insights into the program's effect on student career and professional preparation.

For high school students, participation in ACTION may have a positive effect on their college going rate and choice of college. At the time of paper publication, 14 ACTION participants from cohort 1 had completed high school and were eligible for college enrollment. Of those students, 13, or approximately 93%, had matriculated to an institution of higher education. The average college going rate across all counties that these students come from in Appalachia is approximately 59% with the college going rate ranging from 45% to 67% (Kentucky Council on Postsecondary Education, 2021). Moreover, the national college going average is approximately 70%. In addition to the higher overall college going rate, the institution of choice for ACTION participants also appears to be different from the average choice of institute for their peers from the same counties. Table 3 below underscores this sharp contrast between ACTION participants and the college going and attainment rate of individuals within their home counties. Table 3 displays the postsecondary destination for the 13 ACTION participants that have graduated high school. The table also displays the overall college-going rate and top in-state institutions attended by the high school graduates from that county. As the table illustrates, non-ACTION graduates from the 9 counties represented by the ACTION participants frequently choose two-year public institutions or four-year public master's institutions as defined by the Carnegie classification system (Indiana University Center for Postsecondary Research, 2018). However, ACTION participants all enrolled in fouryear institutions, with the institution types including highly active research institutions and small private liberal arts institutions. While the sample size makes it difficult to draw significant conclusions, the data on college-going rates and college choices do suggest potential benefits of the ACTION Program.

ACTION Cohort 1 Participant's County of Residence (n=9 counties)	Percent of County Graduates with at least a Bachelor's Degree	Percent of County High School Graduates who Attend College*	Top In-State Institutions Attended by the County's High School Graduates	In-State Institutions Attended by the County's ACTION Graduates
Bath	13.0% F 7.9% M	55	Morehead State University (Public 4Y)	Morehead State University (Public 4Y)
Carter 2 students	14.0% F 11.4% M	55	Ashland Community and Technical College (Public 2Y)	University of Kentucky (Public 4Y)
Elliott 2 students	13.5% F 2.5% M	67	Morehead State University (Public 4Y)	Transylvania University (Private 4Y) Morehead State University (Public 4Y)
Garrard	14.4% F 15.3% M	57	Eastern Kentucky University (Public 4Y)	Transylvania University (Private 4Y)
Laurel	13.6% F 10.2% M	58	Somerset Community College (Public 2Y)	University of Kentucky (Public 4Y)
Lawrence	10.8% F 10.5% M	53	Ashland Community and Technical College (Public 2Y)	University of Kentucky (Public 4Y)
Letcher 2 students	11.5% F 9.9% M	63	Southeast Kentucky Community and Technical College (Public 2Y)	University of Kentucky (Public 4Y) Eastern Kentucky University (Public 4Y)
Rowan 2 students	23.6% F 15.3% M	66	Morehead State University (Public 4Y)	Purdue University (Public 4Y) Centre College (Private 4Y)
Whitley	19.7% F 16.9% M	а М 45	Southeast Kentucky Community and Technical College (Public 2Y)	University of the Cumberlands (Private 4Y)
			University of the Cumberlands (Private 4Y)	

\* The average college-bound rate for the 9 counties listed in the first column is 59% (range: 45-67%); The U.S. overall rate is 70%

Undergraduate participants also have shown an interest in continued education. Of the 26 undergraduate participants who have been eligible to graduate, all 26 have graduated and 22, or approximately 85%, have gone on to continue advance education: seventeen undergraduates have since moved on to medical school at a range of institutions including the University of Kentucky, University of Louisville, University of Cincinnati, Vanderbilt University, and Lincoln Memorial University. In addition, other participants have chosen to continue their studies at the University of Kentucky in a variety of fields: one participant is in graduate school working toward her doctorate, two are in pharmacy school, and one is in a physician assistant Master's program. Of the four who have not gone on to graduate or professional school, three are now working in science-related careers and one has moved into military service.

## DISCUSSION

Having completed four iterations of the program, initial findings associated with the ACTION Program suggests that the program is having success at its primary goal of recruiting and involving more underrepresented Appalachian students in cancer-related education and training. Moreover, the post-secondary attainment and choices of these students along with the post-baccalaureate career paths of undergraduate students suggests that the program may be having some effect on students' progression, degree attainment, and career choices. It is important to note that without a control group it is difficult to assess if the program is having a strong effect on participants or if the success is primarily due to selection bias where the students who would have already likely achieved similar outcomes were the ones who entered the program. In addition, the effect of the program on first-generation students and low-income income status students should be viewed with caution given the small sample size. Recruiting and engaging these students has been a challenge especially for our undergraduate program. Anecdotally, we believe that this could be do to the two-year commitment required to be part of the ACTION Program. Some undergraduates appear reticent to commit to a program that requires significant engagement over the academic year and summer. In the future we plan to better understand any concerns students have and work to address those concerns or issues.

However, regardless of first-generation status or low-income status, Appalachian students on average have been shown to struggle with the transition into college (Bryan & Simmons, 2009), are likely to select local two-year institutions over four-year institutions (Wright, 2012), and are more likely than their peers to exit college for a range of reasons (Bryan & Simmons, 2009; Hlinka, 2017; Howley et al., 1996; Wilson & Gore, 2009). These challenges can be particularly pervasive and detrimental to recruiting of participants for programs like ACTION: even when offered financial incentives like hourly pay or stipends, students from

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rural Appalachian areas have been shown to have strong community networks that rely on these students in a variety of ways—physical labor, emotional support, transportation, childcare—that require extensive time commitments that compete with both school commitments and programs like ACTION (Bryan et al., 2009; Hlinka, 2017; Wright, 2012). When the ACTION Program is placed within the context of these Appalachian educational attainment challenges, the result of the program suggests the model may be having some positive effect on educational attainment and success.

In comparison to other, similar high school and undergraduate student cancer research experience programs, the ACTION Program appears to be achieving similar if not more favorable outcomes. For example, a 2018 publication on the University of Louisville's (UofL) Cancer Research program reported that approximately a third of the students who participated in the program went on to pursue advanced education (beyond undergraduate) in health-science related fields (Hein & Kidd, 2018). It is important to note that UofL's program is not a direct comparison since it does not include the academic year research component and the total number of UofL participants (n=121) was also significantly higher than the ACTION Program to date. In contrast, the University of California at San Diego's (UCSD) Continuing Umbrella of Research Experience (CURE) program provides a slightly more direct comparison to the ACTION Program: UCSD's program recruits incoming first-year students, rising sophomores, and/or transfer students to participate in an intensive summer research program. These students are then given the opportunity to work with a mentor on further research. Moreover, like the ACTION Program, UCSD's CURE program also focuses on the recruitment of underrepresented student populations as well. As reported in their 2011 publication (Alfred et al., 2011), 61% of students that had passed through the UCSD program had gone on to advanced programs in either graduate school or medical school. When compared to the programs at UofL and UCSD, the higher percentage of ACTION undergraduates pursuing advanced degrees (approximately 85%) may suggest some additional effects occurring as result of the ACTION Program's activities that may warrant further exploration.

Like the undergraduate participants, the ACTION Program's high school participant postsecondary matriculation numbers also demonstrate similar outcomes to other cancer-focused high school research experience programs. Case Western Reserve University's (Qua et al., 2020)YES-funded program also reported that all participants who had graduated from high school had been accepted into postsecondary institutions. Like the ACTION Program, the program at Case Western and UCSD target specifically underrepresented populations, and both show similar outcomes in terms of undergraduate and high school educational attainment as the ACTION Program (Alfred et al., 2011; Qua et al., 2020).

Barriers to Implementation. While the program model does suggest potential positive outcomes, other program developers interested in modeling their programs after the ACTION Program should consider multiple factors when exploring implementing a similar program model. Most importantly, the ACTION Program's immediate proximity and privileged access to the state-of-the-art research and patient care facilities available at the Markey Cancer Center and University of Kentucky HealthCare are key factors that have enabled the program to provide unique exposure to cancer research and patient care to students. Students have easy access to basic, translational, clinical and behavioral research and patient care in the same general area in which they participate in the cancer education and career development activities of the program. Having this type of real world, hands-on experience available to students is a critical component of our program's success. In addition, the combination of a large healthcare system with a large university system also provides the added advantage of a large pool of research and clinical faculty to recruit into the program. Finally, like similar programs that focus on the recruitment of minority populations in urban areas, the proximity of the program to the target student population has been critical in the program's ability to recruit students.

## CONCLUSION

The ACTION Program is a two-year long, cancer-focused research and learning experience that recruits both undergraduate and high school participants to engage in a range of activities all designed to promote students' participation in cancer-focused careers. These students' outcomes related to engaging in cancer research and outreach illustrate the program is achieving its desired goals of engaging students in learning about cancer both academically and in the context of their community. The summer-intensive experiences combined with the academic year research and academic workshops for the two different groups appear to be successful at encouraging students to pursue both careers and further educational opportunities related to cancer and the medical field. As future iterations of the program continue to be engaged, program personnel intend to continue to collect data on the impact of both undergraduate and high school students to further evaluate the efficacy of the program across multiple time points.

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#### Author Contributions

The manuscript was written through contributions of all

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## ABBREVIATIONS

ACTION: Appalachian Career Training In Oncology; ARC: Appalachian Regional Commission; CURE: Continuing Umbrella of Research Experience; HHS: Department of Health and Human Services; KCR: Kentucky Cancer Registry; MCC: Markey Cancer Center; NCI: National Cancer Institute; UCSD: University of California at San Diego; UK: University of Kentucky; UofL: University of Louisville; YES: Youth Enjoy Science

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