



# Building relationships to connect cancer researchers with community members: ‘bench to community pipeline’

Allison R. Dahlke<sup>1</sup> · Noelle K. LoConte<sup>1,2</sup> · Angela Flickinger<sup>3</sup> · Sara Richie<sup>3</sup> · Jenna Klink<sup>3</sup> · Amy Trentham-Dietz<sup>1,4</sup> · Rebecca Shirley<sup>1</sup> · Kristin Litzelman<sup>1,3,5</sup>

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## Abstract

**Purpose** Partnerships between researchers and community members and organizations can offer multiple benefits for research relevance and dissemination. The goal of this project was to build infrastructure to create bidirectional relationships between University of Wisconsin Carbone Cancer Center (UWCCC) researchers and community educators in the Division of Extension, which connects the knowledge and resources of the university to communities across the state.

**Methods** This project had three aims: (1) create linkages with Extension; (2) establish an in-reach program to educate and train researchers on the science of Community Outreach and Engagement (COE); and (3) identify and facilitate collaborative projects between scientists and communities. Survey and focus group-based needs assessments were completed with both researchers and Extension educators and program activity evaluations were conducted.

**Results** Most Extension educators (71%) indicated a strong interest in partnering on COE projects. UWCCC faculty indicated interest in further disseminating their research, but also indicated barriers in connecting with communities. Outreach webinars were created and disseminated to community, a “COE in-reach toolkit” for faculty was created and a series of “speed networking” events were hosted to pair researchers and community. Evaluations indicated the acceptability and usefulness of these activities and supported continuation of collaborative efforts.

**Conclusion** Continued relationship and skill building, along with a sustainability plan, is critical to support the translation of basic, clinical, and population research to action in the community outreach and engagement context. Further incentives for faculty should be explored for the recruitment of basic scientists into community engagement work.

**Keywords** Community engagement · Research Dissemination · Outreach · Cancer Control · Basic science · Extension

## Introduction

The University of Wisconsin Carbone Cancer Center’s (UWCCC) Office of Community Outreach and Engagement (COE) centers their mission on reducing the burden of cancer and improving health equity through the dissemination of research and education resources, as well as in engaging communities from across the state in research. UWCCC’s catchment area is the state of Wisconsin, representing 72 counties and a population of around 5.8 million residents. Wisconsin is a largely rural state—30% of the landmass is classified as rural (Rural Urban Continuity Codes 4–9) [1], which presents challenges in access to prevention, screening, and treatment resources. Over 250,000 people in Wisconsin live beyond 15 miles from a hospital in rural census tracts. The cancer mortality rate in Wisconsin’s rural counties (166 per 100,000) is higher than in the county-level average

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✉ Allison R. Dahlke  
ardahlke@wisc.edu

<sup>1</sup> UW-Madison- Carbone Cancer Center, Madison, WI, USA

<sup>2</sup> School of Medicine and Public Health, Department of Medicine, University of Wisconsin, Madison, WI, USA

<sup>3</sup> UW-Madison Division of Extension, Madison, WI, USA

<sup>4</sup> School of Medicine and Public Health, Department of Population Health Sciences, University of Wisconsin, Madison, WI, USA

<sup>5</sup> Department of Human Development and Family Studies, University of Wisconsin School of Human Ecology, Madison, WI, USA

across Wisconsin (160 per 100,000) [2], driving the need to address the unique barriers that rural residents face when accessing or participating in cancer research, outreach, and education [3, 4].

In 2020, the UWCCC expanded their catchment area from 36 southcentral counties to all 72 counties of the state, extending our research and outreach infrastructure to rural and hard-to-reach communities. In increasing outreach and dissemination practices, the UWCCC also focused on ways for cancer researchers of all six scientific programs (Cancer Prevention and Control, Cancer Genetic and Epigenetic Mechanisms, Tumor Microenvironment, Human Cancer Virology, Imaging and Radiation Sciences and Developmental Therapeutics), with an emphasis on basic scientists, to create relationships with communities that would increase the impact of their research through feedback and discussion. Community engagement, in this context, ensures that the research topics or questions reflect the concerns of the community, enhance the relevance and applications of research, bring together partners with different skills, knowledge, and expertise to address complex problems, involve local knowledge, and ultimately improve the health and well-being of the collaborating communities [5–7].

This priority presented an opportunity to partner with the University of Wisconsin (UW)-Madison Division of Extension (hereafter referred to as Extension) [8]. Extension serves a key role in the mission of the UW as a land grant university to apply and disseminate research and education in local communities statewide. Extension connects people across the state with the UW in non-credit programs that disseminate research-based information to build skills, influence decision making and improve the lives and health of communities. Extension aims to offer timely access to knowledge through educators in county offices (both urban and rural), on seven 4-year and thirteen 2-year campuses and within three tribal nations throughout Wisconsin, with the ongoing goal of fostering positive change in communities by building capacity among residents of all ages. Specifically, Extension educators partner with organizations and community members on programs on agriculture, food safety and health, resilient and productive environments, and thriving families that meet local needs and connect evidence with action. Extension aims to impact all corners of the state, diverse groups, and otherwise hard-to-reach areas. Example programs include “Strong Bodies” which has provided community fitness, strength, and wellness sessions to more than 15,000 Wisconsin residents, and the “Supporting You(th)” Program which provides mental health resources to teens and families. [9, 10]

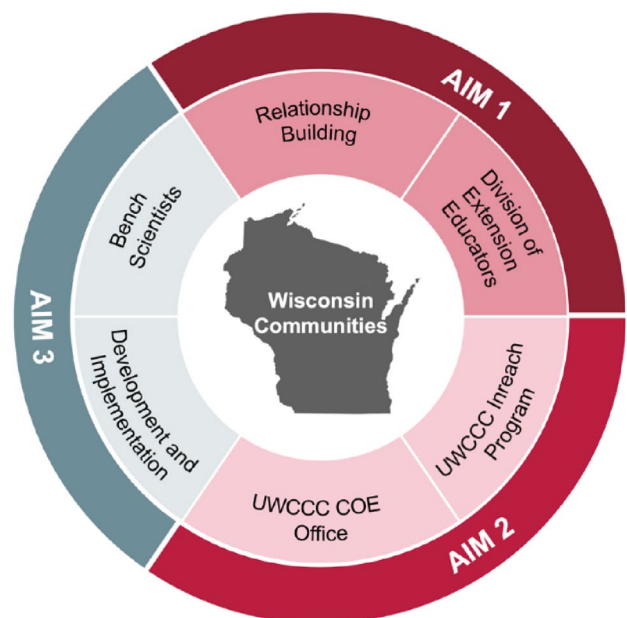
## Purpose

The goal of this project was to build infrastructure (people, processes, systems, and tools) to create bidirectional relationships between cancer researchers and Extension educators (and the communities they serve), thereby allowing scientists to provide comprehensive cancer research and educational content and collaborate on opportunities for research integration with communities [6, 7]. This was achieved through 3 aims (Fig. 1): (1) to create linkages between the UWCCC and the UW-Madison Extension’s county educator network through cancer outreach and education; (2) to establish a UWCCC COE “in-reach” initiative that educates researchers on the science of COE, its importance to the core mission of the cancer center, and how to apply that knowledge to increase the impact of their research; and (3) to identify and facilitate one collaborative pilot project where UWCCC Community Outreach Specialists and Extension educators work with a team of UWCCC researchers (population, basic science and clinical) to partner with a community member or organization.

## Methods

### Needs assessments

*Assessing cancer-related knowledge, needs, and interests of Extension educators.* To better understand Extension’s



**Fig. 1** Three specific aims with the goal to create bidirectional relationships between cancer researchers and Extension educators

interest and capacity to engage with cancer researchers and the need for cancer-related education within Wisconsin communities, the UWCCC COE Office (including the Outreach Faculty Director, the Assistant Administrator of COE and an Outreach Specialist) conducted a needs assessment. Approximately 800 Extension educators (including educators, specialists, program managers, and leadership) had access to but may not have opened the survey through an Extension Listserv. The COE Office conducted an electronic survey (Qualtrics) with the intent to understand: (1) needs and interest in cancer-related programming within their county, and (2) perceptions and needs in community-engaged research. The COE Office created the assessment in partnership with Extension educators and program managers. The survey contained 12 questions (Online Appendix A) including: “How interested would you be to mentor a cancer researcher on how to effectively disseminate their research findings to a real-world audience?” And “How interested would you be in participating in virtual ‘flash-talks’ or ‘speed networking’ with university researchers (answers were rated on a Likert scale of “Not at all interested” to “Extremely Interested).”

*Assessing knowledge and barriers to COE among UWCCC faculty.* UWCCC COE Office and Extension educators met with all program leaders from the six scientific programs. The COE Office delivered a 10 slide (5-min) presentation to program leaders on “COE 101,” shared National Cancer Institute expectations of COE, the importance of COE in their research, and the differences between community outreach, education, and philanthropy. Immediately following, the COE Office asked program leaders six open-ended questions during a guided interview to understand knowledge of COE and barriers to including COE in their research. The six program interviews took place virtually and were each 1 h in duration.

## Education and training

Informed by the needs assessments, the UWCCC COE Office and Extension faculty and staff created a community resources webpage and a series of webinars to inform, educate, and engage Wisconsin communities. Outreach Specialists from the COE Office presented webinars to Extension educators approximately every 3 months for 1 year, with topics including “Cancer 101,” “Available Resources for your Community,” “Cancer Prevention & Screening in Wisconsin,” and “Social Determinants of Health and Cancer in Wisconsin.”

In order to nurture collaboration between UWCCC scientists and community, the COE Office and Extension personnel also jointly created materials to educate UWCCC researchers. Each program member (total  $n = 218$ ) was offered a “COE 101” training and provided with a collaboratively made “Community Outreach and Engagement

Toolkit” during their monthly program meetings. The toolkit provides resources and skills to appropriately engage with communities for research dissemination, research collaboration, and community based participatory research [11]. Importantly, messaging regarding education and training efforts were sent to UWCCC faculty membership via UWCCC leadership (Director, Associate Director or Program Leader), in collaboration with the COE office.

In addition, the COE Office provided UWCCC scientists with several opportunities to network and build capacity for bi-directional engagement with community partners. The COE Office organized a seminar presented by a world renown expert in scientific communication—Dr. Dominique Brossard, Professor and Chair at the UW Madison—Department of Life Sciences Communication, entitled “Scientific Communication and Stakeholder Engagement.” Additionally, multiple networking opportunities were presented such that one scientist from each UWCCC scientific program presented a current research project, research results, or a question for Extension educators. Additionally, an Extension educator hosted a webinar on “How to Engage with Communities for Research” during a virtual networking event.

## Program evaluation

The COE Office conducted strategic, targeted evaluations of the education and training activities described above. For the *UWCCC in-reach*, a retrospective evaluation was administered following the COE 101 presentations. The COE Office e-mailed an evaluation to program members, who were asked to report their perceptions of the importance of three aspects of community-engaged research. Items were assessed on a 5-point Likert scale from not important (0) to very important (5). Participants were then asked to retrospectively identify the reason(s) they have participated in community-engaged research in the past, the perceived value of connecting with communities (4-point Likert scale from strongly disagree [1] to strongly agree [4]), and their comfort level with engaging Wisconsin community members as part of their research (6-point Likert scale from very uncomfortable [0] to very comfortable [5]).

For the *networking events*, a post-event evaluation asked participants to report the extent to which they found the event worthwhile, relevant, and helpful on a 5-point Likert scale from ‘not at all’ (0) to ‘very’ (5). Participants were also asked the extent to which they connected with a potential collaborator or created a partnership that could lead to further research or outreach activities (5-point Likert scale from strongly disagree [1] to strongly agree [5]). Participants were also asked to articulate their goal in attending the event, whether that goal was achieved, suggestions for future networking opportunities, and whether they would attend a similar event in the future. The evaluation results were

summarized using descriptive statistics and pre-post change scores (where appropriate). This project was deemed Quality Improvement and/or Program Evaluation by the University of Wisconsin IRB on 1 February 2021 and did not require further review.

## Results

### Extension educator needs assessment

In total, 88 Extension educators completed the needs assessment survey. The majority of respondents (75%) reported that cancer education was an area of need in the communities in which they work, with another 22% reporting being “unsure” about whether cancer education is an area of need. Figure 2 portrays the percentage of Extension educators that had interest in educational programming such as: understanding cancer basics, cancer screening, or cancer prevention (67%), and support for families/caregivers (52%). When asked about several opportunities to partner with UWCCC on cancer-related education and development opportunities (Fig. 3), respondents most frequently reported being interested in sharing cancer related materials (74%), having a cancer outreach specialist attend an event or program (64%), or engaging in cancer-related professional development opportunities (59%).

A subset of respondents also indicated interest in attending “office hours” with a cancer outreach specialist (44%) or mentoring a cancer researcher on effective outreach (42%).

More than half of respondents (51%) reported having offered some form of cancer-relevant educational programs, either currently or in the past. The most frequently endorsed examples were programs supporting prevention behaviors (35%), programs/initiatives addressing health disparities

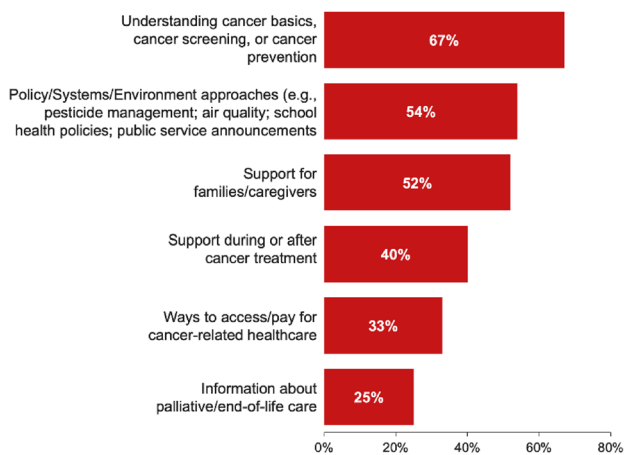


Fig. 2 Percentage of 88 UW-Madison Extension educators that had interest in programming related to cancer

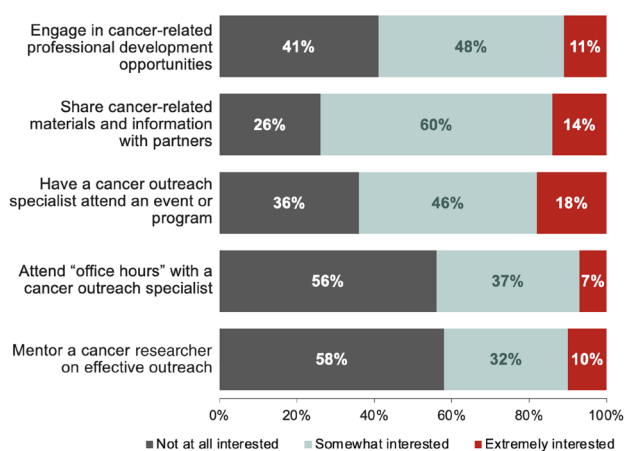


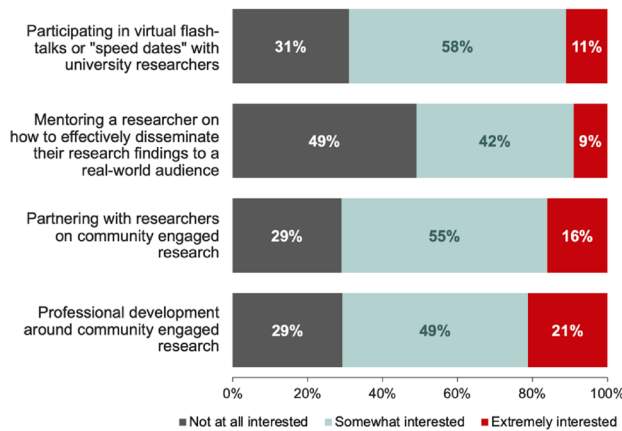
Fig. 3 Extension educator interest in partnering with UWCCC researchers on education and development opportunities

(14%), programs about cancer prevention (11%), and programs about cancer basics (10%). Those who engaged in such programming most frequently indicated that they were the program facilitator (41%) or a convener, responsible for bringing partners together (27%). They reported a diverse array of partners in this work, such as community organizations (70%), coalitions (48%), health departments (41%), hospitals, clinics or healthcare agencies (39%), and other types of partners (23%).

Two-thirds (67%) of respondents reported interest in offering programs in one or more cancer-related areas. Most prevalent was interest in policy/systems/environment-related programming (36%), followed by support for families/caregivers (29%), understanding cancer basis (23%), support during/after cancer treatment (26%), and information about palliative care and/or end of life care (15%). 30% of respondents reported that they had worked directly with an academic researcher in the past as part of their work. When asked what kinds of engagement would be of interest, respondents most frequently indicated interest in professional development around community engaged research and partnering with researchers in community engaged research (Fig. 4).

Extension respondents reported envisioning themselves in an array of roles in community-engaged research partnerships and projects that are relevant to their expertise, interests, and community (e.g., connecting researchers with community partners or stakeholders; reviewing and suggesting improvements to outreach materials). However, 14% reported they could not see themselves serving in any of the listed roles. When asked what assistance they would need to participate in community-engaged research partnerships, educators most frequently endorsed a need to understand how such work fits within their Extension job duties (75%), needing support for establishing clear roles and expectations with academic partners (58%), ensuring that their





**Fig. 4** Extension Educator interest in partnership related to Community Engaged Research

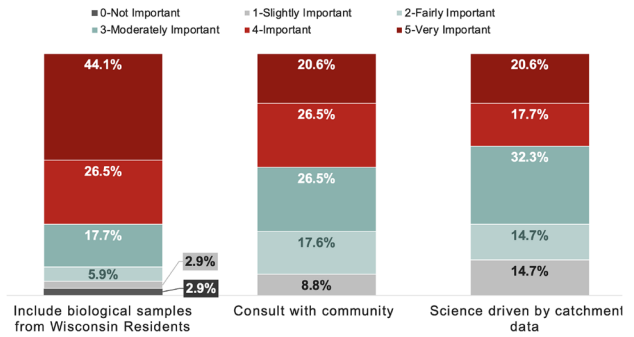
community is open to such work (55%) and needing to better understand “where to start (43%)”.

### UWCCC in-reach assessment: baseline capacity

Guided interviews with program leaders revealed important information on perceived barriers to engaging with communities for research. Leaders reported barriers of: (1) not knowing how to connect with communities, (2) not knowing how their scientific expertise could apply to the interests of communities; and (3) not knowing the benefits of community engagement for research.

Forty-eight UWCCC program members responded to the in-reach survey and represented 5 of the 6 scientific programs. Members were asked to retrospectively recall their views on the importance of different aspects of community engaged research before they viewed the COE 101 presentation. 70.6% of members found it either “important” or “very important” to include biological samples from Wisconsin residents in their research, but only 47.1% and 38.3%, respectively, found it “important” or “very important” to consult with community members on research or have their science be driven by catchment data (Fig. 5).

When asked, “please list the reasons you have engaged communities in your research (check all that apply),” the most commonly selected responses were: (1) “to build Capacity for future research and/or research dissemination (29%)”; and (2) “to better understand complex issues (23%).” The least frequently selected response field was, “To ensure the research being done in my group/lab is reflective of the needs in Wisconsin (12.5%).” Additionally, 29% indicated that they had not engaged communities in research. Twenty percent of program members disagreed with the statement “I find value in utilizing Wisconsin cancer data on rates, disparities and trends to help determine my research



**Fig. 5** Importance of community engaged research by program members

direction.” Only 12% of respondents felt “very comfortable” engaging Wisconsin communities as part of their research.

## Education and training outcomes

### Webinars for extension educators

Sixty-three percent (12 of 19) Extension educators that attended the live webinar completed the evaluation. An additional 23 individuals viewed the recording of the event at a later date. Evaluation results indicated that the webinar successfully increased respondents’ knowledge. Specifically, on a 4-point scale, participants indicated increases in their knowledge of how the UWCCC can help with cancer education needs in the community (mean score increased from 2.0 pre-webinar to 3.6 post-webinar); where to go for more information and resources about cancer risk in the community (means score of 2.4 to 3.8); where to go for more information and resources about cancer in general (mean score of 2.8 to 3.6); and basic facts about cancer burden and impacts in Wisconsin (mean score of 2.4 to 3.8). Participants endorsed several potential next steps, including an interest in sharing cancer-related materials and information with partners and participants (80%), learning more about cancer risk in their community (70%), and having a cancer outreach specialist attend an event or program to share cancer-related materials/information (60%). Sixty-seven percent of respondents requested that the UWCCC COE Office contact them following the webinar to discuss an idea or to provide further support.

### In-reach assessment of UWCCC investigators

In addition to the baseline assessment described above, participants in the in-reach presentations identified an improvement in their capacity to obtain COE support following the presentation. Specifically, participants indicated that prior to the presentation, the majority (66%) were unaware that there

was a COE group at the UWCCC that could help them link their research to communities in Wisconsin. Following the presentation, 52% were able to identify who to contact at UWCCC to help with community-engagement efforts.

### Networking events

Sixty-two UWCCC members and Extension educators attended the “Scientific Communication and Stakeholder Engagement” seminar held in May, 2021. Twenty-five participants attended our initial speed networking opportunity and the evaluations indicated that participants found the event worthwhile (mean = 4.3 on a 5-point Likert scale), relevant (mean = 4.0), and helpful (mean = 3.9). All respondents agreed or strongly agreed that they connected with a researcher or community group at the event, and the majority (88%) agreed or strongly agreed that they created a partnership that could lead to further research or outreach activities. The majority of respondents (89%) indicated that they would be interested in participating in similar events in the future. Open-ended responses indicated that researchers received valuable suggestions on how to expand their outreach, while Extension educators expanded their knowledge of the “depth of our resources and expertise” at the UW. Suggestions for potential next steps focused on continued, informal opportunities for engagement as well as formal cross-training (e.g., presentations at professional development events) and partnership (e.g., budgeting for community engagement and collaboration during the grant-writing process).

### Conclusion

In response to growing calls for community-engaged research at our nation’s comprehensive cancer centers, the UWCCC COE Office launched multiple initiatives to foster bidirectional engagement between researchers and Extension educators through in-reach and relationship building opportunities. This work provides a roadmap for other centers seeking guidance on how to foster collaboration between cancer center investigators and communities through Extension. While CBPR training has been seen to be integrated into medical and public health school curriculum [12–14], our efforts highlight the importance of professional development, education and training, and administrative support for individuals across the scientific and translational pipeline [6, 15]. As noted in our needs assessment, Extension educators identified cancer education as a need in their communities and needed professional development on the basics of cancer risk factors, prevention, and treatment. Educators particularly benefited from packaged materials (e.g., PowerPoint slides, webinars, handouts) that they could use during their educational programming with individuals in

their local communities. Cancer researchers, on the other hand, needed training on fundamentals of COE, particularly the relevance of COE and community engagement to basic science research. Cancer researchers at the UWCCC particularly benefited from learning from concrete examples of successful community collaborations and 1–1 support from the COE office on envisioning their work through a COE lens. Such efforts have clear potential to help solve the challenge of getting research evidence into the hands of those who need it most, in a way that is digestible and actionable, and hasten the translation of research to clinical, policy, and community action.

This project also presented several lessons that can guide efforts toward capacity and relationship building. First, gaining buy-in from Cancer Center administration, Associate Directors and Program Leaders allowed for UWCCC faculty to understand that collaboration with communities was a priority [16] and that engagement in webinars, networking, and review of materials was crucial to their success as cancer researchers. Secondly, since both cancer researchers and community educators expressed a need for case studies and materials that demonstrate how they could partner with each other, it is important to provide concrete, detailed information highlighting successful examples of how cancer researchers and communities can benefit from working together. Broad examples alone are not enough. Third, there is a clear need for structure and support to establish a shared language between investigators and educators. Investigators and educators often began their discussions by talking past each other. Support from a facilitator who can metaphorically speak both languages has the potential to help collaborators develop shared visions more quickly and therefore support the development of joint projects that propel engaged research and the outreach mission of the UW. Concrete examples and emphasis on the potential for generative, emergent innovations through such collaborations will be critical in both motivating collaboration and facilitating the capacity to imagine collaborative potential. Showcasing successful collaborations and providing examples of shared efforts is a critical step in generating enthusiasm. Until investigators and educators can internalize the ways in which their work intersects, they will struggle to prioritize collaborative efforts. In moving forward, we anticipate that consistent engagement efforts, networking opportunities, and reminders of collaborative potential will be critical for furthering the connections between UWCCC and the Division of Extension.

The implementation of a new infrastructure for community-academic partnerships comes with barriers and challenges. First, while about 75 distinct faculty participated in the various webinars, and networking events, it was the same faculty repeatedly engaging across activities. In the case of the in-reach survey, there was no representation in

response from one of the scientific programs. This limitation shines a light on the remaining challenge on how to engage those faculty researchers that were unengaged, remained unengaged, and/or those that continued to not find value in community engagement. Additionally, faculty response rates to evaluation surveys were consistently low. Faculty engagement in community outreach and research will need to be incentivized beyond goodwill and genuine interest in community perspectives. Suggestions include creating COE faculty champions with FTE protection and advocacy for outreach and community work to be valued in promotion and tenure discussions [16, 17]. Finally, the start of the project coincided with the start of the COVID-19 pandemic with 100% remote options for participation. While we believe remote engagement was actually beneficial to connecting with our Extension partners across the state, it is hard to say if general virtual burnout, pandemic stressors (children at home, illness etc.), or general hesitations to engage on scholarly projects [18], lead to lower engagement at times; especially pertaining to follow-up evaluation surveys.

Although the engagement efforts (aim 1) and in-reach program (aim 2) had not yet concluded with a funded community-academic partnership (aim 3), community engagement between an academic cancer center and university Extension members. Such partnerships have the potential to fuel translational efforts and engagement opportunities and facilitate efforts to eliminate health disparities [19]. Key take-aways for other cancer centers include the importance of in-reach education for both cancer researchers and community educators, the need for concrete examples of successful collaborations that can capture the imaginations of potential collaborators, and the need for ongoing, consistent relationship building efforts to continuously strengthen community connections over time. With sustained capacity-building efforts, future efforts will include the facilitation of a community-academic research projects that will guide dissemination and implementation of cancer research to help reduce cancer morbidity and mortality across the state.

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**Author contributions** All Authors contributed to the work associated with the project described within the manuscript and submitted expertise and data for the manuscript. Authors ARD, NKL, AT-D, RS, JK and KL wrote the main manuscript text. Authors ARD, AT-D, JK, KL and RS created and prepared figures. All authors reviewed and edited the manuscript.

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**Data availability** Data from surveys and evaluations are available upon request to the corresponding author.

## Declarations

**Competing interests** Authors do not hold any financial, personal, or familial competing interests in submitting this work and have nothing to disclose.

**Ethical approval** This study was deemed non-human subjects research on February 1, 2021.

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