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Acceptability and Feasibility of Community-Based, Lay Navigator-Facilitated At-Home Self-Collection for Human Papillomavirus Testing in Underscreened Women

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Abstract

Objective: Women without regular health care providers or a medical home routinely fail to complete recommended cervical cancer screening. At-home self-collection of samples to test for high-risk strains of human papillomavirus (hrHPV) can improve screening rates. This study documents acceptability and feasibility of community lay navigator (LN)-facilitated at-home self-collection for underscreened women in Appalachian Virginia. Materials and Methods: This study used mixed methods in three phases. Phase I involved focus groups of LNs to ensure cultural acceptability of self-collection, and to enhance recruitment of medically underserved women. An environmental scan of community resources and climate was created in Phase II. During Phase III, underscreened women in Appalachian Virginia (the far southwest corner of Virginia) were recruited to complete hrHPV testing using LN-provided self-collection kits.

Results: LN-facilitated at-home self-collection for HPV testing was deemed culturally acceptable and feasible to participants in this community-based pilot study. Self-kit training included 64 LNs, of which 35 engaged in the study and were provided 77 kits and instructions. A total of 59 self-kits were returned, of which 42 were correctly completed with valid HPV results, yielding a 16.6% hrHPV rate.

Conclusions: Over a quarter of the women LNs recruited had no medical home, indicating this delivery model may have potential to reach women at increased risk of being underscreened for cervical cancer. Research is needed to identify optimal approaches to increase LN participation in outreach self-collection interventions.

Keywords: HPV self-collection, at-home self-collection, lay navigator, Appalachian Virginia

Introduction

UNITED STATES PREVENTIVE Services Task Force (USPSTF) guidelines recommend women over age 30 be screened for cervical cancer every 3 years by Pap testing (cytology), every 5 years by cervical human papillomavirus (HPV) testing along with Pap testing (co-testing), or every 5 years with HPV testing alone.¹ Screening for high-risk HPV (hrHPV) DNA-the primary cause of cervical cancer-is more sensitive than cytology alone for detecting precancerous lesions.² Although HPV testing as primary screening was not recommended by USPSTF until 2018, it has been deemed acceptable for women over age 25 by the American College of Obstetricians and Gynecologists (ACOG), Society of Gynecologic Oncology, and American Society for Colposcopy and Cervical Pathology since 2016 and 2015 respectively.^{3,4}

Over 20% of U.S. women do not complete screening at the nationally recommended interval.⁵ At-home self-collection has shown great promise for improving screening rates for populations lacking access to clinics or those who do not

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screen at recommended intervals.^{2,6–10} In the United States, mailed self-collection kits have shown high acceptability, ease of use, and potential for being cost effective.^{7,8} The USPSTF has encouraged additional research into delivery methods of HPV self-collection.¹¹

Several previous studies of HPV self-collection recruited participants through clinics.^{12–16} It is likely that women who do not attend clinics have even lower rates of screening compliance. The Virginia Department of Health's Comprehensive Cancer Control Program found that lower education, lower income, and lack of health insurance were factors associated with lower levels of cervical cancer screening in Appalachian Virginia.¹⁷ This study focuses on community recruitment to capture women who do not have routine medical care, who have no medical home. We explored a community-based approach of hrHPV-DNA self-collection among underscreened women facilitated by lay navigators (LNs).

Self-collection for HPV testing through programs that employ community health workers (CHWs), is a delivery model with great utility in increasing access to screening for underscreened African American women in Mississippi¹² and underscreened women living in South Florida.¹³ Several models of health promotion using trained community members exist, including CHWs, patient navigators (PNs), and LNs, all with slightly differing training and roles.^{12,13} PNs trained in cervical cancer screening and treatment have been specifically utilized to understand patient barriers to in-clinic cervical screening.¹⁶ For this study, we utilized LNs, who are community members with special training in cancer prevention and resources specific to their communities.

Materials and Methods

This research study was approved by the University of Virginia (UVA) Institutional Review Board for Health Sciences Research, and was designed in collaboration with the UVA Cancer Center Without Walls Community Advisory Board (CAB), comprised of stakeholders from Virginia Health Planning Districts located within Appalachian Virginia.¹⁸ For this study, we targeted LNs and participants from Lee, Scott, and Wise Counties, in addition to the City of Norton, Virginia.

Phase I: LN focus groups

Three focus groups were conducted between August 2015 and June 2016, with 19 LNs (5–8 per group), who were recruited through community-based agencies. Groups discussed acceptability of HPV self-collection, logistics of selfcollection kit dissemination, referral to clinic for follow-up screening, barriers to existing Pap testing, and resources for medically underserved women in the region. They also discussed the acceptability of HPV self-collection logistics, including implementation of a self-collection intervention acceptability and implementation; and geographicspecific considerations that might impact kit distribution and collection of samples for processing.

LN feedback informed program implementation including presentation of self-collection kits, reporting of results, referral to follow-up clinic screening, ensuring inclusion of Virginia's Every Women's Life program for uninsured women who financially qualify for screening, and the LN role at each phase. Focus group participants received a \$20 prepaid gift card as incentive.

Focus group discussions were audio-recorded and transcribed verbatim. A thematic analysis approach was used to analyze descriptive qualitative data^{19,20} with Dedoose webbased data management (SocioCultural Research Consultants, LLC, Los Angeles, CA). Transcripts were independently coded by two authors, and emergent themes were identified through consensus.

Phase II: environmental scan

We conducted an environmental scan between November 2015 and June 2016, identifying clinics in the region that provide free or low-cost cervical cancer screening, where we could refer women who tested positive for hrHPV, and full results can be found in Garcia et al.²¹ The Socioecological Model^{22,23} guided our scan for existing resources, and individual, community, and system barriers to cervical screening. Phone-based interviews were conducted with clinicians at facilities in the region, with questions exploring perceptions of HPV self-collection and provider adherence to screening guidelines. Data were analyzed using a conventional content analysis approach.²⁰

Phase III: LN-facilitated at-home HPV self-collection

LNs engaged underscreened women to complete cervical cancer screening through at-home self-collected HPV kits between July 2016 and September 2016, and the study team conducted follow-up between December 2016 through February 2017. Kit completion rate was calculated, and feedback from participating LNs. Phases I and II guided questionnaire development for Phase III.

LN training. We recruited 64 LNs who had completed "Understanding Cancer" training from a community-based partner in Appalachian Virginia. LNs who agreed to participate in the study received additional training about HPV, cervical cancer, and study-specific procedures, such as self-collection of samples. LNs also received research training through the CIRTification program (University of Chicago, 2017). Of the 64 LNs originally trained, 35 (54%) ultimately engaged in the study by recruiting women to participate and facilitating kit return.

Recruiting medically underserved women. Thirty-five LNs identified women in their community who resided in Southwest Virginia, were between ages 30-64 and not pregnant, had not had a hysterectomy or pelvic radiation, and reported not having a Pap test in the preceding 4 years or HPV/Pap co-testing in the preceding 5 years. After participants signed an informed consent, participants completed the baseline questionnaire, including demographics and the Set of Brief Screening Questions²⁴ to assess health literacy. This validated the three-question screening instrument that consists of five-point Likert questions: "How confident are you at filling out medical forms?"; "How often do you have problems learning about your medical condition because of difficulty understanding written information?"; and "How often do you have someone help you read hospital materials?."

Two outreach strategies that LNs found beneficial included screening women they knew (*e.g.*, neighbors, co-workers, or family members); and recruiting at health screening events, such as at faith-based locations or Health Department sponsored screening events. LNs described the study and obtained informed consent from study-eligible women, and provided information about cervical cancer screening recommendations, a self-collection kit, self-collection instructions, and encouragement to complete self-collection.

Women chose either to complete the kit at that time with the LN returning it to the study team, or to complete it at a later time and mail it back using a preaddressed, prepaid mailer. Phase III participants received a \$40 gift card incentive for returning a completed self-collection kit and baseline questionnaire. In Phase III, descriptive statistics were used to analyze the completion rate of self-collection screening, the HPV positivity rate, and participants' perceived barriers to clinic-based screening services.

The 35 LNs who engaged in the study received one \$35 gift card incentive (they did not receive more gift cards if more than one kit they had been distributed were returned). Kits were considered returned, yet incomplete if a screening participant was not recruited, but the unused kit and an LN data collection sheet were returned. When a participant mailed the kit back, a gift card was sent to them and the LN incentive was also sent at that time.

Self-collection and laboratory testing. Self-collection kits contained a Viba brush (Rovers Medical Devices, Netherlands), a sterile vial for sample storage, illustrated instructions describing self-collection, and a prepaid envelope for returning samples. Upon receipt, samples were deidentified and tested for hrHPV using Cobas 4800 HPV DNA polymerase chain reaction at UVA's Biomedical Laboratory.

Results delivery. The study team phoned all participants with HPV results, and provided information regarding clinicbased follow-up based on their geographic location, level of insurance, availability of lower cost services, and so on. After three phone calls were attempted, hrHPV-positive participants were sent a letter informing them of their results.

Results

Phase I (focus groups)

LNs considered that the at-home HPV self-collection kits would be culturally acceptable (Table 1). LNs cited several barriers for underscreened women to obtain clinic-based screening services, including lack of sufficient insurance for testing or treatment; perceived lack of sufficient insurance or financial resources to support costs of testing and/or treatment; distance to clinics; lack of transportation; and lack of childcare.

HPV self-collection was predicted to be especially beneficial to medically underserved women who do not have a regular health care provider (or medical home) and have not had a Pap test in 3 years or more. LNs recommended that a known and trusted community member introduce the kits and that study team members deliver HPV test results. Family caregivers were identified as a group that might particularly benefit from at-home self-collection, because caregivers are predominantly female, often isolated (more so because of their caretaking responsibilities), often un- or underinsured, and may be in contact with home health aides. The LNs believed that women who would agree to use a self-collection kit would need to be "comfortable with their body."

Phase II

The study team completed semi-structured interviews with 50 clinics in the region that provided free or low-cost

TABLE 1. SELECTED FOCUS GROUP FINDINGS (PHASE I)

Emergent theme	Exemplary quotes	
Barriers women face in the region of Appalachian Virginia	 "So we have a high rate [of cervical cancer] so we have to, you know, try to determine why we have such a high rate, and it's lack of education one, it's lack of access two, what if you know embarrassment is that one, you know, you'd have to figure out all those and then address." "Maybe people don't have access to healthcare. I mean, I feel like they would probably be willing, if you could do it at your home, you know, and mail it in, you know, I think that would be good." 	
Importance of researchers/outsiders understanding barriers to health care access specific to the target geographic region	"And I mean there is such a large geographical area I mean if your navigator lives in xyz town and the person is down in xyz hill, that's a lot to ask of the navigator so thing generallypeople relate better, I think, to people that live closer to them."	
Profile of women who would benefit from LN-facilitated at-home self-collection	"So I tend to think that if people are connected with a primary care provider that providers talking to them and getting tested. I mean it is the people without insurance whothat's the barrieryou work with a lot of hourly employees I mean a lot of those are the people who don't have health insuranceand without the Medicaid expansion which people were bankin' on, they coulda been [insured]."	

TABLE 2. SELECTED FINDINGS FROM THE ENVIRONMENTAL SCAN (PHASE II, n=50 Clinics Surveyed)

	Frequency	%
Clinic offers Pap testing	49/50	98
Accepts Medicaid and uninsured patients	49/50	98
Stated awareness of USPSTF ^a screening guidelines	10/50	20
Clinic referenced screening guidelines	9/50	18
Has OB/GYN(s) on staff	10/50	20
Health care worker perceives self-collection would be acceptable to patients	35/50	70

^aUSPSTF 2012 guidelines that were in effect at the time of data collection; #Obstetrician-Gynecologists.

OB/GYN, obstetrician-gynecologist; USPSTF, United States Preventive Services Task Force.

services. All clinics except one offered Pap testing and HPV co-testing services, and accepted uninsured patients and those with Medicaid (Table 2). Many reported offering screening intervals that were not consistent with USPSTF guidelines: only 30% of clinics reported following current USPSTF/ACOG recommendations for Pap testing every 3 years for women ages 21–29 (screening intervals ranged from 1 to 5 years), and none explicitly mentioned Pap/HPV co-testing intervals. This may be attributed to lack of specialty obstetrician-gynecologist (OB/GYN) providers at 80% of the clinics. Most clinicians interviewed (70%) perceived that HPV self-collection would be acceptable in their patient population.²¹

Phase III

The study team trained 64 LNs and distributed 103 selfcollection kits in July 2016. Of the 64 LNs trained, 35 engaged in the study and facilitated the return of self-collection kits. These engaged 35 LNs received a total of 77 of the 103 kits distributed at the outset of Phase III (74%). A total of 59 kits were returned by mail (48 completed and 11 unused) (Table 3). LNs returned data collection sheets indicating the number of women approached, number of participants enrolled, distance (miles) traveled to deliver a kit, mode of travel, and duration of the encounter. LNs traveled a median of 10 miles to offer each at-home self-collection kit (median three kits). The total time ranged from 15 minutes to 2 weeks to identify potential participants, recruit and consent, provide education on HPV and cervical cancer screening, and present the self-collection kit and instructions.

Self-collection kit completion

Completed kits were received an average of 21 days after the kits were initially distributed. Of the 48 completed kits received, three were excluded due to participant ineligibility in the study, resulting in 45 completed kits. Of these 45 correctly completed kits, three yielded indeterminate HPV results, leaving 42 correctly completed kits and baseline surveys included for analysis (Table 4). Participants who were deemed ineligible or whose kits yielded indeterminate HPV results were contacted by the study team to notify them

TABLE 3. SURVEY RESULTS OF HPV SELF-Collection Intervention Among 35 Lay Navigators Engaged in Phase III

	Mean	Range
Number of women each LN approached about study enrollment	3	0–13
Number of women recruited per LN	2	0–9
Miles traveled to recruit	9.67	0-45
Time interval between kit distribution and return (in days)	21 ^a	5-52
Kits returned by the LN	59/77 ^b	76.6%
Incomplete kits	11/59	
Kits correctly completed	45/56 ^c	80.3%
Kits included in analysis	42/56 ^d	75%

^aIncludes kits returned both by LNs and by participants (total kits returned).

^bOf the 103 total kits distributed, 77 of these were distributed to the 35 LNs who were engaged in the study and ultimately facilitated returned kits.

^cEleven unused kits returned without a sample collected with only a LN data collection sheet completed. Of the 59 kits returned, 3 were from women who were study ineligible and so excluded

^dThree kits yielded invalid HPV results and so were excluded, from analysis resulting in 42 kits included in analysis.

of these issues and, as appropriate, refer to existing cervical screening resources.

Participant characteristics

Participants ranged in age from 31 to 62 (44.8 median), and had either no children (14.3%), 1–2 (57.2%) or 3 or more (28.6%). More than half of the participants smoked (56%). Fifteen percent said it would be difficult/very difficult to find childcare to attend clinic, 38% reported being primary caregiver for children under 18, and another 16% reported being primary caretaker of children over 18 or parents. Almost half (44%) received social assistance (food stamps, housing assistance, welfare payments, social security, supplemental security income, or disability payments). Health literacy scores ranged from 3 to 15, and indicated predominantly adequate health literacy (72%); more than one-third (36%) had marginal or limited health literacy. Seven (16.6%) selfcollected samples tested hrHPV positive (Table 4).

No participants reported having ever had both a Pap test and HPV test (co-testing) or an HPV test alone. Over half of all participants (55%) reported not being told by a health care provider that they needed a Pap test, despite being underscreened. Nearly all participants (91%) believed that it is easier for insured women to get Pap, and more than half (59%) believed that Pap tests would cost more than they could pay.

Attitudes toward self-collection and clinic screening among women receiving self-collection results

Among the 19 participants who were provided their test results by phone, 17 (89.4%) reported overall positive thoughts about self-collection, and the remaining two reported neutral thoughts. All said the instructions were easy to understand, and they were confident they used the test correctly. Participants reported being willing to pay a median of

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Enrollment characteristic	n	%
Age (years) 44.8 (median)	31–62	_
Parity		
0	6	14.3
1-2 3+	24 12	57.2 28.6
Mean (standard deviation) {min, max}	$1.92 (1.26) \{0,6\}$	
hrHPV ^a		
Negative	32	76.2 $(n=42)$
Positive	32 7 ^b	16.6 (n=42)
Indeterminant result ^c	3	6.6(n=45)
Caregiver of		
Children <18	16	38.1
Children ≥18	7	16.7
Parents	5	11.9
Any	23	54.8
Current smoker	. –	10 7
No	17 25	40.5
Yes		59.5
Receive social assistance		40.5
Yes No	17 24	40.5 57.1
Missing	24	2.4
Health literacy ^e	1	2.1
Adequate: ≤6	31	72.1
Marginal: 7–8	6	18.2
Limited: ≥ 9	6	18.2
Have seen a health care	e provider in the last	vear
Yes	30	71.4
No	11	26.2
Missing	1	2.4
Provider recommended	Pap test within the la	ıst year ^f
Yes	17	44.7
No	21	55.3
Missing	4	9.5
Perceived that Pap test		
Cost prohibitive	25	59
Don't know	17	41
Aware of Virginia's eve		
Yes No	8 34	20 80
140	J4	00

TABLE 4. SELF-COLLECTION KIT PARTICIPANT **BASELINE CHARACTERISTICS (PHASE III;** n = 42 Baseline Surveys)

^aIncludes hrHPV types 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, and 68. ^bOne of the hrHPV positives was HPV type 16.

 ^{c}n originally was 45, however, because there were three indeterminant results, n = 42.

^dFood stamps, housing assistance, welfare payments, social security, supplemental security income, or disability payments.

^eHealth literacy measured through the "Set of Brief Screening Questions."30

^tBased on 2012 USPSTF guidelines of a 3 year Pap/cytology screening interval.

^gVirginia's Every Woman's Life (EWL) program provides free breast and cervical cancer screening to uninsured women who financially qualify.

hrHPV, high-risk human papillomavirus.

\$25 for a self-collection kit. More than one-third (37%) reported not seeing a health care provider regularly. The most frequent reason given was a lack of health insurance. Of those who did report a regular provider, three attended local clinics at free or low-cost, and five attended an outpatient clinic of the predominant regional health system. The study team followed up with all women who had an hrHPV positive result about clinic-based follow-up for screening.

Discussion

This study explored the acceptability and feasibility of community-based LN-facilitated at-home self-collection for HPV DNA testing among underscreened women, and to describe important aspects of this delivery model. The majority of hrHPV self-collection studies conducted in the United States recruit screening participants from clinics and health care providers. This study's community-based LN delivery model yielded over a quarter of women recruited (26%) with no medical home/regular health care provider. meaning this delivery model may have particular relevance in populations not otherwise connected to sustainable primary care and screening services.

Programmatically, it was vital to include input from the LNs to inform study recruitment and access this medically underserved population. A study in South Florida¹⁴ similarly found a community-based participatory approach to be critical to widespread uptake of HPV self-collection kits through multiple delivery models among minority underscreened women. Additionally, it may result in more engagement by LNs in the study if they are involved throughout the planning process. Phase I of our study indicated because of the rurality of this geographic region we should aim to train a larger number of LNs to be geographically representative. In our experience, slightly over half of the 64 LNs whom we trained opted to actively engage in the study to facilitate the return of kits. Future programs should consider weighing the trade-off of training more LNs versus giving more in-depth or longer-term training to a smaller number of LNs to promote more engagement.

Once HPV self-collection tests are clinically accepted for primary screening, only hrHPV-positive women will need clinic-based follow-up. However, because HPV testing of self-collected samples is not yet FDA-approved for primary screening, all women (whether hrHPV positive or negative) in this study were referred to in-clinic screening, and were asked about their intentions to follow-up after receiving hrHPV test results. If a participant had a primary care provider, participants were advised to seek clinic-based followup screening with this provider. However, many did not identify a primary care provider and were referred to free or low-cost clinics. More research is needed to determine whether LN-facilitated at-home self-collection for hrHPV testing successfully connects women to more sustainable primary care, and to explore methods for clinic-based followup following positive HPV results. A recent study in North Carolina²⁵ found a 64% kit uptake rate when self-collection kits were mailed to infrequently screened women, and a similar hrHPV positivity rate to our study (15%). Women who tested hrHPV positive with the at-home self-collection kit had significantly higher clinic-based Pap testing follow-up (82%) than those who tested hrHPV negative (51%).²⁵ The role of HPV self-collection in promoting longer-term

adherence to cervical screening at recommended intervals, whether through clinic-based screening or through screening with repeat HPV self-collection, warrants further research.

For our study in Virginia, the small sample size and convenience sampling approach limit the generalizability of results. Despite the small sample size, the HPV positivity rate (16.6%) was higher than that seen in a general population.²⁵ This may be due to a higher risk for hrHPV in this population. Previous research²⁶ indicates through geospatial analysis that decreased uptake of HPV vaccination, and decreased access to screening and treatment options combine in Appalachian areas, producing a geographic region of high risk for preventable cervical cancer. Further, health-related media in Appalachian Ohio versus non-Appalachian Ohio have been found to lack vital health education content about HPV, including a lack of information about HPV as a cause of cervical cancer.²⁷ Health related media also lacked information about low-cost programs to access HPV vaccination in the region.²⁷

HPV-related cancer disparities persist throughout Appalachia, beyond cervical cancer alone.²⁸ More research is needed to explore HPV prevention, screening, and early detection strategies to reach women in this medically underserved region. As LNs in this study did recruit women with no medical home or identified primary health care provider, with further training, there is a potential for them to also provide HPV-related educational materials, and facilitate connecting women to more sustained primary care.

Many participants across all three phases of this study reiterated the importance of their geographic context in understanding both barriers to accessing current screening services, as well as strategies to increase cervical cancer screening and awareness. In a similar geographic target region in Kentucky,¹⁵ a total of 31 participants were recruited from a free primary care clinic to complete at-home HPV self-collection, and then to receive hrHPV test results and nurse-assisted navigation.¹⁵ Although these women were overdue for cervical screening, they were already accessing primary care, which was not the case for a quarter of our participants. More research into whether at-home selfcollection can sustainably connect underscreened women to primary care providers is needed, including research into whether LNs can be an impactful and cost-effective delivery model specific to this group of vulnerable women.

Among a sample of women from Appalachian Kentucky, researchers explored psychosocial correlates to ever having had a Pap test, and further in women within the sample who had had a lifetime Pap test, explored associations with abnormal Pap testing. Not having had a Pap was related to low income and fatalism.²⁹ This sample was recruited to test feasibility of community-based screening through HPV selfcollection, and while women expressed a high level of comfort in self-collecting specimens for HPV testing, importantly authors note that HPV test results and navigation at the time of results, may in and of themselves not be impactful. Compounded by challenges with re-contacting women, researchers note that of those who learn of their result, knowing hrHPV positivity may not in and of itself motivate women to follow-up for clinic-based screening services,³⁰ indicative of the need to explore both delivery models that promote initial clinic-based follow-up, and of the need for targeted education on the importance of screening and early detection and subsequent connection with clinic-based services.

There are some limitations of note in this study. First, we were not able to follow up with LNs who participated in the initial training and received kits to recruit participant underscreened women, but did not. We are therefore unable to report on the 26 kits we did not receive back. A second limitation of note is that we were not able to confirm through chart review that hrHPV-positive women followed up at a clinic. We did, however, confirm intention to follow-up for clinic-based screening from all hrHPV-positive participants.

Conclusions

This study included underscreened Appalachian Virginian women, over a quarter of them had no regular health care provider and no medical home. We provided them with a low-cost LN delivery model for at-home HPV selfcollection kits, intended to facilitate increasing access to cervical cancer screening. Further research should explore both cost effectiveness of this model, and the utility of hrHPV self-collection in connecting women without a medical home to care, to promote more sustainable primary care and screening services.

This project demonstrates that training LNs facilitating athome self-collection kits for HPV testing has the potential to improve cervical cancer screening and early detection rates among underscreened women in rural areas. Future research should examine strategies to promote LN sustained engagement, as well as longer-term exploration into whether at-home self-collection kits can be an entree to connect underscreened women to more sustainable primary care over time; and whether LNs with community-specific training on cancer control, as well as study-specific training, can facilitate this outcome. Additionally, implementation research exploring the LN model further, with considerations for cost and whether there's a need for ongoing versus one-time training, is warranted.

This LN delivery model may also have utility with screening for other preventable health conditions in this medically underserved population, including community-based screening for colorectal cancer through fecal immunochemical testing. Input from the CAB and LNs themselves provided important information that guided study procedures. Community-informed community-based research has far reaching implications for enhancing acceptability and feasibility of interventions aimed at cancer prevention efforts.

Author Disclosure Statement

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