Family Medicine and Community Health

fRAP 2.0: a community engagement method applied to cervical cancer disparities among Hispanic women

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ABSTRACT

focused Rapid Assessment Process (fRAP) 2.0 is a community engagement approach combining geospatial mapping with rapid qualitative assessment in cyclical fashion within communities to capture multifactorial and multilevel features impacting primary care problems. fRAP 2.0 offers primary care researchers a methodology framework for exploring complex community features that impact primary healthcare delivery and outcomes. The fRAP 2.0 study design expands the fRAP from a sequential design to a cyclical process of geospatial mapping and rapid qualitative assessment in search of modifiable contextual factors. Research participants are stakeholders from various socioecological levels whose perspectives inform study outcomes that they may use to then become the agents of change for the very problems they helped explore. Here, we present a proof-of-concept study for fRAP 2.0 examining disparities in cervical cancer mortality rates among Hispanic women in Texas. The primary outcomes of interest are features at the community level, medical health system level and regional government policy levels that offer opportunities for collaborative interventions to improve cervical cancer outcomes. In this study, geospatial mapping of county and ZIP code-level variables impacting postdiagnosis cervical cancer care at community, medical and policy levels were created using publicly available data and then overlaid with maps created with Texas Cancer Registry data for cervical cancer cases in three of the largest population counties. Geographically disparate areas were then qualitatively explored using participant observation and ethnographic field work, alongside 39 key informant interviews. Roundtable discussion groups and stakeholder engagement existed at every phase of the study. Applying the fRAP 2.0 method, we created an action-oriented roadmap of next steps to improve cervical cancer care disparities in the three Texas counties with emphasis on the high disparity county. We identified local change targets for advocacy and the results helped convene a stakeholder group that continues to actively create on-the-ground change in the high-disparity county to improve cervical cancer outcomes for Hispanic women.

INTRODUCTION

Cervical cancer is both preventable and curable.[1–7] Yet, each year in the USA, an estimated 13 800 new diagnoses and 4000 deaths are attributed to cervical cancer.[8] Early and timely screening with Papanicolaou (Pap) and human papillomavirus (HPV) tests, prevention with HPV vaccines for adolescents and young adults,[1–3] and treatment of non-invasive, early-stage cervical cancer[4–6] can reduce the devastating impact. Without those interventions, invasive cervical cancer can develop. Invasive cervical cancer is deadly; the US 5-year survival rate averages only 66%.[9]

Alarming differences in incidence and mortality rates exist by race, ethnicity and geographical location.[10–14] In particular, Hispanic women have higher mortality rates nationally from invasive cervical cancer than non-Hispanic white women (2.5 vs 2.0 deaths per 100 000 women, respectively).[15] A recent national study using the Surveillance, Epidemiology, and End Results programme database showed a statistically significant survival disparity between Hispanic women and non-Hispanic white women (190.3 months vs 221.7 months, p <0.001).[7 11] Pockets of high disparity have been reported in border states like Texas and California as well as in urban areas near New York City.[10 11 13 14 16] For instance, some border counties in Texas have an age-adjusted cervical cancer mortality rate that is doubled for Hispanic women versus non-Hispanic white women.[17]

Substantial evidence shows that one's social context—including socioeconomic status, education level and access to primary care and medical insurance—influences health status and contributes to these cervical cancer mortality rate differences.[17–19] In particular, research has shown that Hispanic women have less access to preventive services such as HPV vaccines and Pap tests and experience more treatment delays once diagnosed.[19 20] Recent studies illustrate how the COVID-19 pandemic has exacerbated these disparities by reducing access to cervical cancer screening and colposcopy services in medically underserved areas[21] and model how this is likely to result in higher rates of cervical cancer diagnoses.[22] However, limited studies to date have examined what barriers may exist in postdiagnosis cancer care, and whether targeted interventions may be useful in resolving them.[23]

Furthermore, few studies have described what postdiagnosis cancer care looks like in practice. Ideally, oncologists and primary care clinicians collaborate on the care of patients during this period. Unfortunately, ambiguity exists with respect to the role primary care physicians have in addressing the needs of patients who have completed cancer treatment.[23 24] More research is needed to understand how medical professionals, community resources and health policy interact to influence these care pathways.[25 26]

This study, conducted by family medicine researchers from 2017 to 2022, aimed to explore postdiagnosis cervical cancer care, and its influence on mortality disparities. The team approached an understanding of cervical cancer mortality disparities through the lens of the socioecological model.[27–29] This theoretical framework acknowledges the complex interplay of various levels of influence—individual (intrapersonal), relational (interpersonal), societal (community) and organisational (policy). Contextual factors of health at various socioecological levels impact postdiagnosis cancer care and outcomes. For example, social policy effects at the state or local community levels may contribute to disparities in access to care, thereby impacting mortality rates between patient populations. Studying these multifactorial and multilevel aspects of patients' social context has proven to be as challenging as it is imperative to understanding their effects on health outcomes.[30–34]

Novel approach to exploring contextual elements of health

A novel mixed-method framework that builds on the qualitative Rapid Assessment Process from the disciplines of anthropology and sociology has been used to capture these multifactorial and multilevel features impacting cancer survivorship care in primary care settings across the USA. This framework—the focused Rapid Assessment Process (fRAP)[35]—combines geospatial mapping with qualitative inquiry to uncover modifiable contextual and policy factors at multiple socioecological levels, as outlined above. The fRAP explanatory sequential methodology has been described in detail in previous publications.[35–37] Briefly, fRAP uses quantitative tools (eg, geographic information system (GIS) mapping, US Census results) to efficiently pinpoint where to focus an in-depth inquiry using qualitative strategies (eg, depth interviews, group interviews, content analysis of local resources) to describe the contextual factors related to the health topic of interest. The insights that emerge inform action steps to implement change at the community, medical system and/or political level. While fRAP combines elements of quantitative and qualitative research methodology, its main purpose is to identify actionable outcomes that can be implemented soon after project completion. The 'f' ('focused') in fRAP emphasises not only the goal of honing in on high-priority issues, but also references the higher level focused analysis required to ensure the project scope does not exceed the available time, financial and community resources.

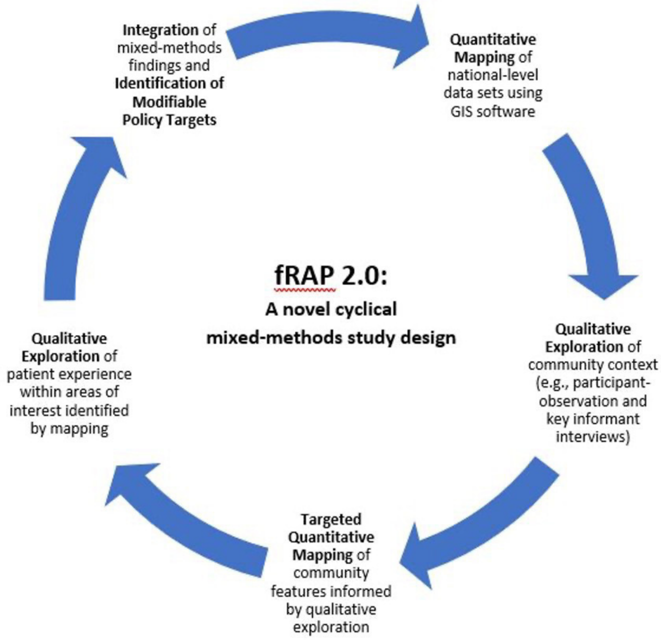

Figure 1 The novel fRAP 2.0 methodology is a cyclical mixed-method study design to uncover the modifiable contextual factors that impact population health and inform policy interventions to affect change.

The current proof-of-concept study expands fRAP from a sequential process[35] to a mixed-cyclical methodology (figure 1) that alternates geospatial mapping and community-based qualitative inquiry. Each segment of the cycle informs the next round of analysis and includes more community engagement. Using a community health and primary care lens, researchers examined postdiagnosis cervical cancer treatment and follow-up care in three Texas counties. These counties were chosen to illustrate three different disparity profiles of cervical cancer outcomes among non-white Hispanic versus non-Hispanic populations.[10–14] This research is designed to offer insights about modifiable contextual elements and new directions for clinicians, policy-makers and the public towards creating communities that provide more equitable and higher quality cervical cancer care from diagnosis through survivorship.

METHODOLOGICAL APPROACH

The mixed-cyclical fRAP method (fRAP 2.0) used in this study comprised several iterations of the quantitative and qualitative segments described in figure 1. The project began with a quantitative analysis of national-level

Box 1 Healthlandscape-embedded variables used in study

ZIP code-level data

- ⇒ Race
- ⇒ Poverty level
- ⇒ Socioeconomic status
- ⇒ Education level
- ⇒ Smoking status
- ⇒ Papanicolaou smear (% of population up to date)

County-level data

- ⇒ Disease incidence and mortality rates
- ⇒ Ratio of primary care physicians to population
- ⇒ Ratio of behavioural health specialists to population
- ⇒ Number of oncologists
- ⇒ Number of cancer centres
- ⇒ Spanish speaking (% of population)
- ⇒ Health insurance (% of population with coverage and number and names of payors within study regions)

geospatial data to identify where differences in cervical cancer survival rates existed. Once the geographical region of focus was determined, the team collected and examined data, using geospatial technologies, at three socioecological levels of analysis: the community (eg, sociodemographic variables), the healthcare system (eg, medical care access locations, disease incidence and mortality rates) and policy factors (eg, insurance coverage variables). The qualitative data collection and analysis segments explored the contextual elements influencing the patient experience of cervical cancer survivorship (eg, community services and differences in access to care). Multiple qualitative research strategies were used, including key stakeholder interviews, group interviews, content analysis of online resources, community asset mapping and participant-observation field trips.

Quantitative data collection

For this case-control comparison, the research team first performed a national scan using publicly available data from the National Cancer Institute and US Census data to select Texas as the region of the country to focus its investigation of high-disparity cervical cancer incidence and mortality rates. The team then narrowed the study sample to three Texas counties (two cases and one control) and used GIS technology within the HealthLandscape data visualisation platform to create county-level and ZIP code-level maps comparing community, medical system and policy variables (box 1). HealthLandscape (https://healthlandscape.org/) is a suite of online tools, including GIS mapping and community databases, offered by the American Academy of Family Physicians to aid in health research and improve healthcare.

Quantitative data analysis

The study team used HealthLandscape to view publicly available demographic variables overlaid with locations for accessing primary care clinicians, mental health specialists and oncologists to determine the community-level, medical system-level and policy-level variables of interest in the three Texas counties. Locations for accessing medical care were identified using the American Medical Association Health Workforce Mapper tool, which is embedded within HealthLandscape. The study team also used a customisation feature within HealthLandscape to upload and map 20-year cervical cancer incidence and mortality rates (1995–2015) provided by the Texas Cancer Registry (Cancer Epidemiology and Surveillance Branch, Texas Department of State Health Services, 1100 West 49th Street, Austin, TX 78756 (www.dshs.texas.gov/tcr)).

These maps were augmented with findings from internet search engines and online map sites identifying additional community-level features—such as social service agencies, bus lines, and voting districts—or policy-level services—such as consulates or translation/interpreter services—that also may influence the postdiagnosis cancer care experience. In addition, the principal investigator itemised the services offered at the various healthcare clinics and hospitals to determine whether geographical differences existed in access to care. All information collected on each variable of interest was assembled into data portfolios for each county, referred to by the study team as community assessment profiles.

Qualitative data collection

The qualitative inquiry was designed to further explore the variables of interest that emerged from the analysis of each county's quantitative data set. After exploring the community assessment profiles of each county, researchers highlighted a subset of variables whose outcomes suggested they might be related to disparities in cervical cancer outcomes. This data subset served as a starting point for ethnographic observations and informed the creation of question guides for key stakeholder interviews conducted within the three counties (see online supplemental material: Key informant interview guide). The first interviews were conducted with individuals in the identified counties' local American Cancer Society (ACS) offices, a strategic approach since this proof-of-concept fRAP 2.0 study was funded by the ACS.

The research team then used a snowball sampling technique to create an inclusive, community-directed list of key stakeholders in cervical cancer diagnosis, treatment and postdiagnosis care at multiple levels of influence—the local community, the medical system and the state/national policy arena. Participants included individuals from various sectors (public health; oncology and cancer centres; primary care practices; community organisations; and regulatory officials from insurance or hospital payment programmes, local health departments and hospital administrators). Data collection occurred via in-person group interviews or semistructured individual depth interviews conducted in person and by telephone. In addition, the principal investigator conducted on-site participant-observation visits that included tours of neighbourhoods, community forum attendance and conversations with potential key stakeholders to gain contextual knowledge and build trust. All in-person data collection occurred prior to the 2019 SARS-CoV-2 (COVID-19) pandemic.

Qualitative data analysis

All interviews were recorded and transcribed and then coded and analysed until saturation was reached, meaning no new information or codes were being identified. The lead author of the data analysis team independently performed in vivo coding on every transcript, capturing coded data from interviews in discrete county-specific codebooks created with Microsoft Excel. The coding team additionally verified coding through independently coding sample sections of transcripts, and then meeting to discuss consensus of codes. Entries were tagged within Excel to identify the data source. For each subsequent transcript, the analysis team noted occurrences of the previously identified codes and documented any emergent codes. The three-person coding team met at least monthly for over 18 months to discuss the codebook and emergent codes. The county codebooks contained lists of the unique codes, exemplar quotes, and a running count for codes with multiple occurrences. Transcript analysis occurred concurrently with qualitative data collection. When the analysis team determined that identification of new codes had tapered in each county codebook, no new interviews were scheduled.

After all identified codes were entered into the appropriate county codebooks, the analysis team clustered the individual codes into a set of metacodes (referred to hereafter as 'themes') for each county data set. Once complete, a cross-county comparison matrix was developed to illustrate which themes were present in all three county codebooks versus those that occurred in only one or two counties. In addition, the number of occurrences of each theme was noted. The study team colour-coded matrix cells to highlight codes and themes representing red-flag concerns (red), potential barriers/obstacles (yellow) and facilitators (green) of cervical cancer-related care. Red codes indicated high-impact problem areas, while yellow codes highlighted contextual features that were mentioned as concerns but did not represent clear barriers to care. Green codes pointed to comments about what supported wellness among women with a history of cervical cancer.

Synthesis of findings with patient and public involvement

Community engagement and member checking of the matrix themes occurred during roundtable forums with a convenience sample of key stakeholders from each county. These individuals helped the study team contextualise and make sense of findings. Additionally, the roundtable sessions helped prioritise county-specific themes for the policy action segment of the fRAP 2.0 cycle, which comprised sharing the findings from quantitative and qualitative analyses with the stakeholders in each county to create evidence-informed change initiatives. The ACS funded this research study.

RESULTS

Study findings are presented here in two sections: quantitative and qualitative results. In practice, these emerged iteratively as the study team cycled between discovery and interpretation of the data sets. The outcomes of the final segment of the fRAP 2.0 cycle, policy action, are included in the Discussion section, because they represent the interpretation and implementation of study findings to fulfil the purpose of this study: to provide insights on how to improve cervical cancer care at the community, medical system and policy levels.

Quantitative data set

GIS mapping of national rates of cervical cancer mortality and incidence confirmed the pockets of disparities within Hispanic communities in Texas as described in the literature.[11 12] National Cancer Institute state-level data revealed a set of three counties with differing disparity rates (table 1) that formed the basis for the case-control study design. Bexar (pronounced 'bear') county served as the control county because it had similar incidence and mortality rates to Texas and the USA as a whole. Dallas

Table 1 Population and cervical cancer mortality and incidence rates in three Texas counties and whole state (2009–2013)

	Dallas county	Tarrant county	Bexar county	Texas
Total population	2618148	2054475	1958578	28304596
Cervical cancer mortality rate**				
Hispanic*	3.7	5.2	3.4	3.3
White non-Hispanic*	3.0	2.6	1.7	2.3
Cervical cancer incidence rate††				
Hispanic†	13.8	13.3	11.1	11.2
White non-Hispanic†	9.1	8.1	8.4	8.3

Source: National Cancer Institute, State Cancer Profiles https://statecancerprofiles.cancer.gov/index.html.
*Mortality rates are age adjusted, annual per 100000 for 2009–2013.
†Incidence rates are age adjusted, annual per 100000 for 2009–2013.

county (case) had slightly increased cervical cancer incidence and mortality rates for both Hispanic women (13.8 vs 11.2, incidence; 3.7 vs 3.3 mortality) and non-Hispanic white women (9.1 vs 8.3 incidence, 3.0 vs 2.3 mortality). In Tarrant county (case), Hispanic women had higher cervical cancer incidence (13.3 vs 11.2) and mortality (5.2 vs 3.3) rates than in Texas overall, while the rates for non-Hispanic white women were equivalent to state and national averages.

Of note, Bexar county, home of San Antonio, was chosen as the control county solely based on this relation to cervical cancer incidence and mortality, captured in table 1, and not because of other demographics or social determinants of health. Importantly, fRAP 2.0 seeks to uncover what features within a discrete context or geography are mitigating or exacerbating underlying structural or systemic disparities for the public health concern. That said, table 2 highlights a wide diversity of population, ethnicity, age and disparate social determinants of health that exist across the three counties. Bexar county, while serving as our control county with regards to cervical cancer incidence and mortality, does show other demographics that are higher than in the two case counties (ie, % unemployed, % under the federal poverty level).

Exploration of the three identified counties using maps generated by the HealthLandscape platform revealed areas with distinct differences between ZIP codes for some of the variables explored (box 1). The variables that produced maps with the most distinct patterns of disparity, either within or between counties, were highlighted for deeper analysis in the qualitative cycle of fRAP 2.0. For example, figure 2 illustrates cervical cancer incidence in each county. The darker shading indicates higher densities of patients with a diagnosis. These 'hot spots' were then targeted for ethnographic inquiry. In addition, maps of number and location of healthcare access points (such as primary care, obstetrics and gynaecology or oncology clinics (figure 3), health insurance coverage rates, community resources and cervical cancer mortality rates also revealed disparities within and between counties. These quantitative findings helped researchers develop questions for the interview guides.

Qualitative data set

Qualitative data collection comprised 3 group interviews and 28 depth interviews with 39 key informants from community, medical and policy levels across the 3 Texas counties (see box 2). The resulting codebooks (table 3) contained 295 discrete codes and 142 themes (106 codes/42 themes in Bexar county; 114 codes/55 themes in Tarrant county, and 75 codes/45 themes in Dallas county). Codes tagged as 'facilitator' occurred most frequently in the control county (Bexar), while in the high-disparity case counties (Dallas and Tarrant) there were more occurrences of 'red-flag concerns' and 'potential barriers/obstacles' codes. Results are reported in narrative format, followed by exemplar quotes in parentheses labelled with the theme's socioecological level (community, medical or policy) and type (facilitator (+), potential barrier/obstacle (<>) or red-flag concern (−)) and data source. Additional quotes and a cross-county and cross-level organisational matrix of themes are presented in online supplemental table 1 to highlight our results.

Bexar county (control)

Overall, Bexar county had more data points coded as facilitators of post-diagnosis cervical cancer care than the other two counties, as well as more facilitators than barriers across its own three levels of analysis. The most frequently occurring themes included discussions about the county's financial assistance programme, CareLink; cancer resources available in the city of San Antonio; and strategies used by safety net health professionals. Key stakeholders from across all three levels discussed at length where and how low-income individuals could access medical services or obtain assistance, including community agencies that provided both financial assistance as well as cancer-related services (Community and Medical theme, Accessibility of Cancer Resources and Care, facilitator [+]: "Well, we do everything we can to try and get them something. And it's, honestly, it's rare for us to not be able to figure something out," medical key informant).

Meanwhile, multiple health system stakeholders noted the importance of upholding cervical cancer standards of care while also being willing to work outside traditional clinical protocols to ensure that more women had access to treatment. One medical key informant offered the example of authorising a longer hospital stay for a patient to get medications that would not be covered in the outpatient setting. At the policy level, stakeholders highlighted the need for grants and other innovative funding for cancer care (Policy theme, Innovative Grant Funding for Cancer Needs, facilitator [+]: "We've been very aggressive in pursuing grant dollars through state and federal sources … in fact, our research and information-management division [of the health system], I think, has as many or more state grants than anybody else in the state of Texas," policy key informant).

In addition, a theme emerged about how deliberate organisational planning by the healthcare board leaders in the county allowed for the community's needs to be addressed proactively. (Policy theme, Deliberate Community-Focused Health System Planning, facilitator [+]: "So, I think it was really their wisdom well in advance. I think a lot of their peers at a time when primary care really wasn't very fashionable, particularly for hospital districts because they're mostly hospitals. … The revenue generator—because of the way financing works in our country—is still the hospital. And we tried to reinvest that significantly into our ambulatory presence, so much so that about 97% of the volume that we do as a health system is outside of the hospital. And so that's another testament to kind of continue to get farther out in the community," policy informant).

Table 2 Texas counties demographics and variables of interest related to cervical cancer postdiagnosis care

	Bexar	Dallas	Tarrant
Demographic data			
Total population (2021)*, *n*	1 990 522	2 604 722	2 091 953
% Female (2021)*	50.4	50.4	50.9
Median age*, *years*	33.8	33.5	34.6
% Spanish speaking*	34.8	34.4	20.8
Race/ethnicity*†			
% American Indian/Alaskan Native	0.7	0.5	0.5
% Asian	3.0	6.6	5.7
% Black	7.6	22.5	17.0
% Hispanic	60.9	40.7	29.5
% Native Hawaiian/Pacific Islander	0.1	0.0	0.2
% White	63.9	51.8	59.5
Healthcare access			
Oncologists‡, n	178	282	99
Ratio of population to oncologists	11 183:1	9237:1	21 131:1
Primary care physicians‡§, n	3269	4157	2524
Ratio of population to primary care physicians	609:1	627:1	829:1
Behavioural health specialists‡¶	1165	1343	550
Ratio of population to behavioural health specialists	1709:1	1939:1	3804:1
Social factors			
% Below the 100% federal poverty level*	15.1	14.2	11.2
% Below the 200% federal poverty level*	34.9	35.8	28.5
% College graduates (age 25+)*	30.0	32.9	33.3
% Completed high school*	85.4	80.7	86.7
Median HH income (US$)*	62 169	65 011	73 545
Social deprivation*	82	85	55
% With no broadband internet access*	22.4	24.6	19.0
% Unemployed*	5.6	5.2	5.1
% Uninsured*	15.9	20.9	16.4
Health status			
% Diabetes**	13.5	12.7	11.2
% Current smokers**	14.6	16.4	15.9
% No annual mammogram**	32.0	37.0	38.0
% No pap smear††	22.6	22.1	23.0

*Data from the Robert Graham Center https://www.graham-center.org/maps-data-tools/social-deprivation-index.html, produced from U.S. Census Bureau American Community Survey, 2017–2021.
†Additional 'other' category for race are not included in this table, sum of all categories equal 100%.
‡Data from American Medical Association's Health Workforce Mapper.
§Includes all internal medicine, family practice/general practice and paediatrics clinicians.
¶Includes all addiction medicine, psychiatry, psychology practitioners.
**Data from University of Wisconsin Population Health Institute's 2023 County Health Rankings & Roadmap program
††Data from Center for Disease Control and Prevention's PLACES: Local Data for Better Health portal—https://www.cdc.gov/places/measure-definitions/prevention/index.html#cervical-cancer-screening.

Community, medical system and policy stakeholders agreed on the importance of the county financial assistance programme, CareLink, which is accessible to any resident—even those who are undocumented immigrants, as long as they have a photo ID card from their home country and a Bexar County address. (Policy theme, Importance of CareLink Financial Assistance Program, facilitator [+]: "I think we have a lot … of physicians who are committed to taking care of these patients irrespective of their financial background. There's folks

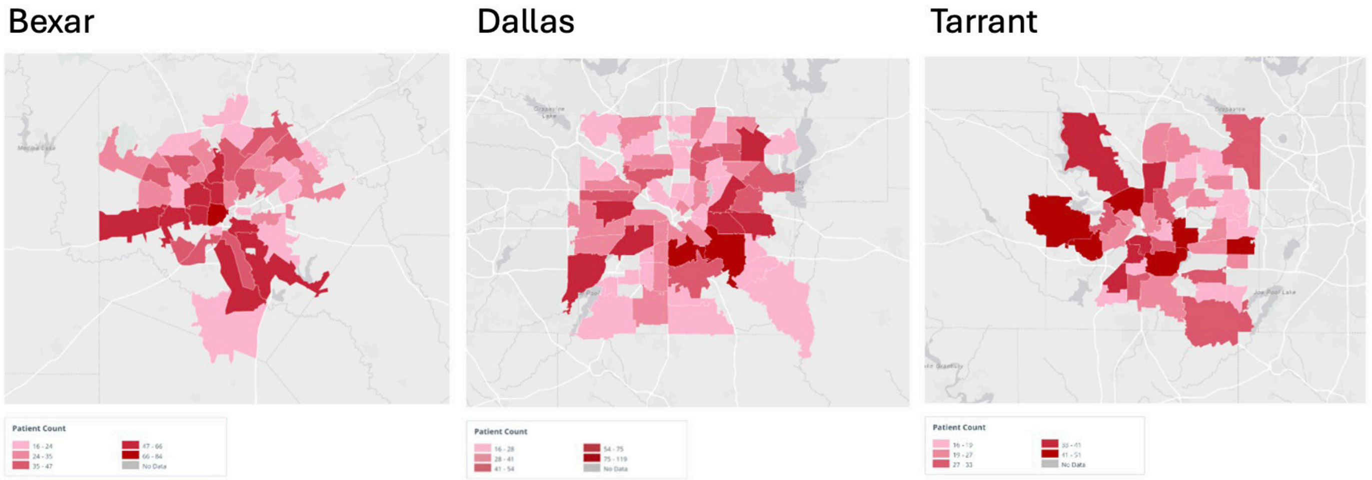

Figure 2 Geographical Information Systems maps showing cervical cancer incidence by ZIP code.

that recognize, ‘Hey, this is the right thing to do,’” policy informant).

Stakeholders from different levels of analysis discussed the collaborative environment that exists in San Antonio in which community organisations refer patients to each other to ensure patients get needed resources. (Community theme, Positive Community and Medical System Relationships, facilitator [+]: “I think that’s the one good thing in San Antonio, we’re okay with linking with each other and working together,” community key informant; and “So I don’t wanna overplay that, but I do think it’s fundamental to San Antonio as a community, and particularly in healthcare, that you can do that kind of work as a community,” policy key informant).

Collaboration between primary care clinicians and oncologists was frequently mentioned as a facilitator of cervical cancer care (Medical theme, Collaboration is Needed in Cancer Post-Diagnosis Care, potential barrier/obstacle [<>]: “And so you’re gonna probably—particularly … when it’s already been diagnosed—pick up the phone in addition to sending a consult to make sure that the communication is there. Or make sure that your support staff is following up to see if … we get that patient an appointment,” policy key informant, and “So each one of them [cancer types] have their own flavor, and in some of them you need active participation,” medical key informant).

Dallas county (case)

Dallas county was particularly notable for a balanced number of codes relating to barriers and facilitators of cervical cancer survivorship care. There, the most frequently occurring themes included cervical cancer treatment details, the need for equity in care, community resources and the county’s main safety net healthcare facility, Parkland Health. Community stakeholders discussed resources like the ACS and other organisations that focused on improving health literacy and distributing health education materials to Hispanic communities. Medical system stakeholders noted the role played by Parkland Hospital in providing all gynecological oncology and cervical dysplasia care across Dallas county and the outlying rural areas. (Medical theme, All Gynecologic Care Needs Funneled Through

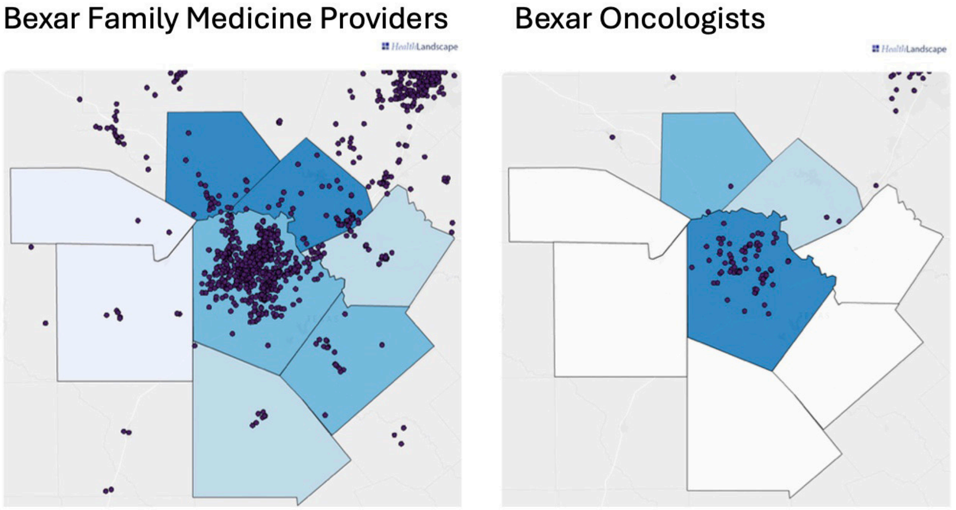

Figure 3 Healthcare facilities providing cancer survivorship care in Bexar county.

Box 2 Key informant participants across counties

Community level (n=17)

- ⇒ Staff leaders in county American Cancer Society (ACS) chapters
- ⇒ Regional health education centre staff leaders
- ⇒ Cancer community resource agency navigators
- ⇒ Locally based leaders of cancer foundations
- ⇒ Hispanic advocacy organisation leaders
- ⇒ Cancer survivorship resource agency directors and leaders

Medical level (n=13)

- ⇒ Leaders of health network primary care departments
- ⇒ Leaders of health network obstetrics and gynaecology departments
- ⇒ Leaders of health network gynecological oncology divisions
- ⇒ Leaders of federally qualified health centres/community health clinics
- ⇒ Cancer care clinical navigators

Policy level (n=9)

- ⇒ Leaders of health systems
- ⇒ Leaders of cancer care systems
- ⇒ Leaders of health insurance programmes or hospital financial assistance programmes
- ⇒ Foreign country consulate staff
- ⇒ University professors with health disparities expertise
- ⇒ ACS policy/advocacy leads
- ⇒ Leaders of agencies focused on reducing health disparities

Large County Hospital Clinic, potential barrier/obstacle [<>]: “We have several cervical cancer clinical trials through the … oncology and gynecologic oncology group,” medical informant; and “People say—this is one of the only places that actually specialize in [cervical cancer], and they actually have doctors for it,” community informant).

The political climate during the study period created concern from all three levels of stakeholders about whether Parkland Health’s financial assistance programme would continue to cover healthcare for undocumented individuals. (Policy theme, Concern about Undocumented Individuals Financial Assistance Options, red-flag concern [−]: “At the moment, we have the ability to take care of them,” medical informant; and “These patients are getting more skittish, and they’re worried about getting caught up with ICE [U.S. Immigration and Customs Enforcement],” medical informant).

Key stakeholders from all three socioecological levels of analysis agreed on one major barrier impacting cervical cancer care: the tendency for Hispanic women to delay care for gynecological health concerns and not reliably follow preventive care screening recommendations. (Medical theme, Hispanic Women with Dysplasia Delay Care and are Lost to Follow-up, red-flag concern [−]: “We, not infrequently, we’ll have patients disappear,” medical informant). Participants noted that when patient pap results indicate dysplasia, clinic employees expend great effort to locate women for follow-up care. (“When they no-show they get—bloodhounds go after them if it’s a high-grade abnormality. If it’s a low-grade, it’s a lot of letters, phone calls, that kinda thing. So, we eventually get people back in,” medical informant).

Tarrant county (case)

In Tarrant county, home to Fort Worth and Arlington, themes were focused on the significant limitations to care for undocumented women in the county, while also illuminating the community agencies attempting to address these limitations. The most frequently occurring theme referenced a single community agency tasked with providing cancer care resources and fulfilling postdiagnosis needs for the entire county. It was heralded by all who mentioned it as a critically important resource in the county; however, it was frequently noted that the agency did not have the capacity nor intention to be the standalone provider for undocumented patients’ cancer care needs. (Community theme, One Community Agency in County Cares for ALL Survivorship Needs, potential barrier/obstacle [<>]: “We kinda got into this phase where we were like, ‘Let’s do everything for everyone.’ And we were finding that’s really not helpful to cancer patients, survivors, or caregivers if we’re trying to fix everything. That’s not what our mission should be,” community informant.) But patients need the services that the agency provides. (“What started this journey … is we had one client who finished her treatment, rang the bell, … went to her car, and she just cried. And then, she drove over here and said, ‘I’ve had a team surrounding me, everybody cheering me on, and now I’m alone.’ And we realized survivors really need their own team to kinda get them back into whatever their new normal is,” community informant).

Another frequently occurring theme in Tarrant county referenced a policy that denied undocumented residents access to the financial benefits provided by the public hospital assistance programme, JPS Connections. Stakeholders across all three levels of analysis overwhelmingly pointed to this policy as the reason they believed disparities existed for Hispanic residents in cervical cancer prevention, treatment and survival rates. When this issue came up, it frequently was accompanied by intense emotions. Three different quotes from medical informants illustrate this policy as a red-flag concern: (Policy theme, County Level Policy Does Not Allow Undocumented Residents to Access County Hospital Financial Assistance Program, red-flag concern [−]: If you don’t meet the residency status … you’ll be diagnosed and not be able to get elective surgery to take care of it. … We have a JPS Connections program that is the closest thing to our charity program. But you have to be a resident to be able to take advantage of that,” policy informant) and (“It’s way above me to make that change in what Tarrant County will pay—will use their dollars for. But our office will see everyone, it just is—it becomes a difficult issue—when the surgeries are for the patients, obviously, who are undocumented” medical informant) and finally (“Well, here’s the problem: We are able to provide external beam radiation treatment—the first part of the radiation

Table 3 Screen captures of segments of each county codebook with clustered codes, themes and colour coding

Bexar county		
	Transportation barriers	*Transportation Barriers*
	Programmes and Avenues to stay healthy	*Community/Activism Programmes to improve health*
		How to be healthy
	The patient's story	The patient's story
	Issues of trust	*Issues of Trust*
		Community clinic teams of physicians
	Generalist versus specialist mindset	*Whole person medicine versus disease specific*
		PCP versus oncology approach to caring for patients
	Spanish language/culture	*Communication issues when dealing with Hispanic patients*
		Words spoken in Spanish
		Mexico references
		lack of Spanish language within clinics in San Antonio
48 codes	Hard lives affect medical outcomes	*Socal issues in these patients lives make it hard to focus medical care*
		Misery of life
		Caring for the emotional well-being of the provider
		Finding the right time in a patient's life when they can deal with medical issues
Dallas county		
	Breast cancer options	*comparison to breast*
32	Community resources	*community resources*
		online resources
		ACS in Parkland
		Referrals for ACS services
		ACS focus
	Funding issues	*funding for cervical cancer*
		charity care
		Medicaid
		lack of funding
	Vaccination	*HPV vaccination*
	Ancillary staff roles to help	*ACS hospital rep*
		role of nurses
		role of SW
29	Parkland	*Parkland hospital*
		ER, Parkland ICC
		high volume of abnormal pap/cervical cancer/Wish clinic
		cervical cancer study at parkland
		safety net hospitals/insurance barriers
		Parkland care financial assistance programme
Tarrant County		
	Crossing to Dallas	*some pts go to dallas to access care*
	Follow-up	*f/u after cervical cancer*
	Cancer care is difficult to manage for patients	*it is difficult to navigate the system as a patient*

Continued

Table 3 Continued

Tarrant County		
	Policy incentives	*policy incentives to get medical care needs met*
	Ethical obligations of providers and hospitals	*ethical obligations of doctor to treat these pts*
		'elective surgery' policy
		cancer pts admitted and cancer treatments started
		justification to start treatment
	Cervical cancer treatment	*radiation options for cervical cancer pts*
	Risk factors for cervical cancer	*sociodemographics of who gets cervical cancer*
	American healthcare	challenging American healthcare environment
	Grassroots in Hispanic community	grassroots in the Hispanic community
	Gynecologic cancers lack support	Gynecologic cancers are rarer and have less supports
	Advocacy for cancer	*advocacy for cancer care*

Colour coding indicates the theme or code category. Red-flag concerns (red/peach), potential barriers/obstacles (yellow), facilitators of cancer survivorship care (green). The peach-coloured text indicates a barrier that exists but whose severity is less than the barriers indicated in red. The analysis team used a lighter colour text so as not to overemphasise these concerns when reporting out the results.
ACS, American Cancer Society; HPV, human papillomavirus; PCP, primary care provider.

treatment. However, we do not have equipment for intracavitary treatment, which is the second part of the treatment … meaning that these patients are frequently referred outside to get the intracavitary brachytherapy. And that's where the problems start happening, because we can get them approved for the treatment here, but if they're referred for the brachytherapy and they don't have funding, they're unlikely to get that. And that decreases survival for these patients. … And I think it just breaks our heart, because we know how essential brachytherapy is," medical informant).

Another community agency referenced several times was one that served the Hispanic community directly by offering health education and a grassroots organising coalition for wellness. Community and medical stakeholders alike spoke about the cancer resource support and education the coalition provided to the county. (Community theme, Grassroots Hispanic Community Organizations Attempt to Address Large Cancer Needs, potential barrier/obstacle [<>]: "About 21 years ago, the City of Fort Worth … did an assessment of its population and realized that the Hispanic population was the one group that was in most need of continuous, regular healthcare. They didn't see their doctor for various reasons—transportation, money, insurance, those types of issues. So, the medical community got together and produced the first Hispanic Wellness Fair," community informant). It also was noted that this agency was not equipped to fulfil all the medical needs of the undocumented Hispanic population in the county. ("Doing cancer programming, it is a big need," community informant).

Cross-county comparison

Because each county codebook was constructed independently, identified themes did not always align exactly with others in the cross-county comparison matrix (table 4). The analysis team grouped similar themes together, keeping sight of the contextual differences by preserving the unique theme names (eg, 'language' vs 'language and culture' vs 'language and translation'). Once consensus was reached for organising like themes, the matrix showed 24 themes occurring in all three data sets, 19 appearing in 2 of 3 counties, and 28 emerging from a single geographical location (10 themes in Bexar, 9 in Tarrant and 9 in Dallas).

Examining the relationships between themes in the cross-county matrix revealed that when Bexar county themes overlapped with those from another county (control case), the themes often were in the 'facilitators' category, whereas when Dallas and Tarrant (case-case) themes overlapped, they were usually categorised as 'red-flag concerns' or 'potential barriers/obstacles'. For example, when informants from Dallas and Tarrant counties discussed factors relating to care, themes about Hispanic women's dependence on male family members, the impact of obesity on wellness, the high prevalence of cervical dysplasia, interpretation of 'cancer' as 'death', and financial hardship all came up as 'potential barriers/obstacles' in both data sets. Conversely, Bexar county stakeholders did not mention those aspects of postdiagnosis cervical cancer care.

In addition, compared with Bexar and Dallas counties, it was clear that Tarrant county had demand outpacing supply of postdiagnosis resources, coupled with a particularly challenging, and even toxic, environment for undocumented Hispanic residents. Across Texas, public hospitals are funded in each county with taxpayer dollars from a property tax line item that funds the 'Hospital District'. Furthermore, elected officials create the rules

Table 4 Segment of the cross-county comparison matrix codebook

Bexar (San Antonio)	Tarrant (Fort Worth)	Dallas
Transportation Barriers	**Transportation Barriers**	Transportation Barriers
Spanish language/culture	**Language issues**	Language and translation
Spanish language/culture	**Spanish language/culture**	Spanish culture
Anti-HPV	**vaccines**	vaccination
Poor health literacy and education to improve	Lack of health literacy and education	Health literacy and education
Issues of trust	**Trust and comfort**	Issues of trust
Ancillary staff roles to help	Ancillary staff roles to help	Ancillary staff roles to help
Grant funding for special healthcare projects	**Issues with Funding**	Funding issues
Survivors lost to follow-up	**Follow-up**	Lost to follow-up
Immigrants/deportation	**Undocumented women and issues**	Documentation status
Mortality disparities in cervical cancer	**Mortality disparities in cervical cancer**	Mortality disparities in cervical cancer
Young women affected/age of diagnosis	**Young women affected/age of diagnosis**	Younger age with diagnosis
Rural cancer survivors	**Rural issues**	Rural issues
EMR issues	**EMRs/medical info transfer**	EMR
Late to care for diagnosis	Late to care for diagnosis	Late to care for diagnosis
Oncology office processes	**Oncology office processes**	Oncology office processes
PCP interactions with cancer	**PCP interactions with cancer**	PCP interactions with cancer
Cervical cancer as private and shameful	**cervical cancer as private and shameful**	cervical cancer as private and fearful
Cancer resources in the city	**community resources**	community resources
Safety net providers/insurance	**JPS Health Network**	Parkland/high volume cervical care programme
		Parkland/care for pts, will get it done
"	**DPH clinic**	FQHC
"	**Northside FQHC**	"
For-profit hospitals	**Baylor**	Methodist
"	**Texas Oncology**	Texas oncology
Religious clinics/resources	Church influence	
Cancer survivorship—what is it?	Cancer survivorship—what is it?	
	Moncrief	Moncrief
Survivors caregivers	Caregivers	
The patient’s story		The patient’s story
Chronic comorbidities		Comorbid conditions
PCP-onc relationship	PCP-onc relationship	Onc-PCP relationship
	Ethical obligations of providers and hospitals	ethical obligations of providers and hospitals
	Zip code/areas of Fort Worth	zip code areas
Cervical cancer standard of care	Cervical cancer treatment	cervical cancer treatment details
Disclosure of medical diagnosis in interviewee	Disclosure of medical diagnosis in interviewee	

Colour coding indicates the theme or code category. Red-flag concerns (red), potential barriers/obstacles (yellow) and facilitators of cancer survivorship care (green).
DPH, Department of Public Health; EMR, electronic medical record; FQHC, federally qualified health center; PCP, primary care provider.

regarding which services are covered for whom by their Hospital District's public assistance programme. In Tarrant county, the Hospital District has regulated that no undocumented resident in the county is eligible for the county hospital financial assistance programme.

DISCUSSION

Synthesising and integrating the results of the cyclical rounds of quantitative and qualitative data, stakeholders were brought together often for consensus building. Roundtable discussions with key stakeholders from each county served as the space for interpreting and prioritising the outcomes from the quantitative and qualitative segments of the fRAP 2.0 cycle. A unique set of action steps at the three levels (community, medical and policy) emerged from the exploration of what influences cancer survivorship care in each county, and these were used to determine future public health and medical system initiatives.

Community-engaged and community-directed action steps were particularly activated from this project in the case county with the highest disparity (Tarrant county). In response to our findings, a community-level organisation in Tarrant county hosted a Facebook Live 'Platicas [dialogues in English]' workshop in Spanish on women's health issues, including cervical cancer. At the medical level, an online immigrant health curriculum featuring this research project as a case study was developed by a faculty member at the University of Texas at Arlington and disseminated through Johns Hopkins School of Public Health via Coursera.[38] Several policy-level initiatives also emerged from this research. A Tarrant county task force was reactivated to address the health disparities across various health conditions within the Hispanic population in certain ZIP codes. One of the county stakeholders penned an op-ed column[39] for the local county newspaper to educate the public on cervical cancer disparities and make a call to action. Political campaign decisions were considered by county stakeholders as it relates to candidates in the county hospital district that determines the rules for caring for uninsured and undocumented citizens.

In Bexar county, findings from this research were disseminated to key stakeholders across all levels, and areas were identified by consensus for continued focus on community-level projects in segregated ZIP code neighbourhoods with highly vulnerable social determinants of health, as well as a push for increased public health and medical-level education on upstream drivers of cervical cancer prevention with HPV vaccination. In Dallas county, Mexican consulate officials used data from this study to increase awareness of significant disparities impacting Spanish-speaking communities, with emphasis on bringing cervical cancer screening and prevention more to light.

Study strengths and limitations

The fact that these community-led action initiatives emerged from the research elucidates the inherent value of the fRAP 2.0 methodology: It is designed to produce actionable results, and the study participants (who are members of the community) become the mobilisers of the outcomes. The stakeholders in this study not only understood the relevance of the research topic, they also were invested in finding modifiable features of the health landscape. Similarly, these research participants were intimately familiar with the geography, demographics and sociocultural aspects of the regions under study. When reviewing the community assessment profile data sets, the stakeholders' insights were instrumental in helping researchers interpret why disparities in care existed between and within counties. The strategy of beginning the search for key informants within the ACS chapter offices also benefited the research team in that this community organisation is well connected within all three socioecological levels of analysis. Additionally, through this ACS connection, there was an element of trust and familiarity with the ACS in each of these communities that afforded the study team access to stakeholders and continued engagement from community partners.

Another strength of the fRAP 2.0 method illustrated by this study is the focus on context. Dallas and Tarrant counties are situated within the Dallas-Fort Worth metropolitan region, while Bexar county surrounds San Antonio. The geographical and political differences that exist in these counties were key to understanding the disparities in cervical cancer incidence and mortality rates of different patient populations. These differences also created a unique opportunity for studying the counties as individual cases. The multilevel outcomes serve as proof of concept for the fRAP 2.0 methodology used in this study.

The biggest limitation of this study, and fRAP 2.0 in general, is the resources required to conduct a thorough exploration at multiple contextual levels. The principal investigator spent months gathering data, which, as is common in qualitative research, included time invested in networking and relationship building to gain access to the often-sensitive information that tells the most accurate story. Building the portfolios of 'thick data' that comprised the community assessment profiles required expertise in GIS and time to assemble these data sets in accessible ways for stakeholder review. Data analysis also required significant investment in time and human resources to reduce bias through consideration of multiple perspectives of the data set. Finally, focusing on one region where disparities in cervical cancer rates exist introduces the inherent limitations of case study research, in that specific results may not be transferrable to other locations. While there are no standardised solutions, the contextual features uncovered by this mixed-method, multilevel study might serve as starting points for exploring disparities in post-diagnosis cervical cancer care outcomes that exist in other regions. In addition, the fRAP 2.0 methodological approach is certainly able to be scaled up or down to accommodate research questions on different levels of analysis, or it could be used in similar-scale studies with wholly different contextual features.

An additional potential limitation of fRAP 2.0 is by design; it does not include a patient-only level. fRAP as a methodology was initially designed to augment more standard clinical research, which often focuses on patients in practices, and often forgets the contextual features of community, medical and policy levels that impact patients' experiences outside of the practice setting. Given that, and within our stakeholders sampled, fRAP 2.0 does value and seek informants who may have lived experiences related to gynaecological cancers within all levels. Key informants with first-hand or personal impact from gynaecological cancers bring that patient voice to the dataset.

Contribution to family medicine and community health research

The results of the current study demonstrate that post-diagnosis cancer care is more complex than what happens between primary care physician and patient. The contextual factors that influence health, including the intersections of sociodemographic, geographical and regulatory variables that impact medical care, also need to be addressed. Optimal care must engage not only primary care clinicians and cancer care services, but also public health advocates, community resources and the patients themselves. The same socioecological lens must be applied when seeking solutions for the disparities in cervical cancer care outcomes between patient populations. The fRAP 2.0 methodological approach offers researchers a framework for discovering and exploring the phenomena that interact across multiple contextual levels to impact healthcare delivery and patient outcomes.

CONCLUSIONS

Through this proof-of-concept study for fRAP 2.0 that investigates cervical cancer disparities among Hispanic women in Texas, we have highlighted how this community-engaged mixed methodology has high utility in identifying potential targets for change. Most importantly, fRAP 2.0's true value lies in its ability to mobilise local stakeholders to effect meaningful change in healthcare outcomes via action items informed by the stakeholders' own knowledge and experiences. Despite unique contextual factors across multiple socioecological levels of influence, this study revealed that stakeholders saw opportunities to effect change existed across different levels. Stakeholders noted improvements in access to care and financial assistance (policy level) and collaboration between specialties (medical level) and/or community cancer resource agencies (community level) as avenues to reduce disparities. Identification of these themes resulted in the development of public health education initiatives and political activism in support of undocumented patients or those living in ZIP codes with limited resources. While this study specifically targeted three discrete locations in Texas, the research process highlighted recurrent areas for improvement that may transcend geographic boundaries. As illustrated by this project, we envision that the fRAP 2.0 framework can serve as a guide for primary care researchers who seek to partner with communities in tackling a diversity of public health problems.

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Contributors AMK-E, WLM and BFC designed the study, with assistance of MT and CRJ of content-specific areas. AMK-E enrolled participants and performed field work visits and roundtable meetings. MT and AMK-E performed all mapping. AMK-E, WLM and BFC participated in the final analyses and data interpretation. CRJ, SEH and JG participated in data interpretation of results. JG performed an updated review of COVID-specific literature related to this topic. SEH and AMK-E were the main contributors to the first draft of the manuscript. AMK-E is guarantor of this project and publication. All authors revised the draft critically for important intellectual content. All authors approved the final version of the manuscript.

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