



A descriptive study of policy and system-level interventions to address cancer survivorship issues across six United States health systems

Martha Quinn¹ · Nathan Wright² · Marylee Scherdt² · Debra L. Barton² · Marita Titler² · Julie S. Armin³ · Michelle J. Naughton⁴ · Jennifer Wenzel⁵ · Sanja Percac-Lima⁶ · Pooja Mishra⁷ · Sankirtana M. Danner⁸ · Christopher R. Friese^{1,2,9}

Received: 25 April 2023 / Accepted: 26 July 2023

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2023

Abstract

Purpose To describe policy and system-level interventions with potential to improve cancer care at six sites.

Methods In 2016, six institutions received foundation support to develop unique multi-component interventions aimed at improving cancer care for underserved populations. These organizations, located across the United States, participated in a cross-site evaluation to assess the overall initiative impact and to identify potentially promising policy and system-level solutions for dissemination and broader implementation. A health system and policy tracking tool was developed to collect data from each site and included a description of their efforts, strategies employed, and changes achieved (e.g., new policies, clinical protocols). Tracking tool data were analyzed using rapid qualitative analyses and a matrix approach. Semi-structured interviews were conducted with site leaders (N=65) and were analyzed by thematic analysis.

Results Sites reported 20 system and policy efforts, which resulted in improvements to electronic health records and telehealth strategies, changes to hospital/health system policies, and standardized clinical protocols/guidelines, among others. Efforts were aimed at: (1) coordinating care across multiple providers, supported by patient navigators; (2) expanding psychosocial and supportive care; (3) improving patient-provider communication; and (4) addressing barriers to accessing care. Interview analyses provided insights into successful strategies, challenges, and implications of the COVID-19 pandemic on cancer care.

Conclusions and implications for cancer survivors Despite advances in diagnosis and treatment, cancer care remains inequitable. System-level improvements aimed at eliminating common barriers faced by underserved populations offer opportunities to improve the delivery of equitable, effective, and efficient care.

Keywords Cancer care · Survivorship care · Care coordination · System-level interventions · Health equity · Patient-centered care

✉ Martha Quinn
marthaq@umich.edu

¹ School of Public Health, University of Michigan, Ann Arbor, MI 48109, USA

² School of Nursing, University of Michigan, Ann Arbor, MI 48109, USA

³ College of Medicine, The University of Arizona, Tucson, AZ 85711, USA

⁴ College of Medicine, The Ohio State University, Columbus, OH 43201, USA

⁵ Schools of Nursing and Medicine, Johns Hopkins University, Baltimore, MD 21205, USA

⁶ Harvard Medical School, Boston, MA 02115, USA

⁷ Grady Health System, Atlanta, GA 30303, USA

⁸ Northwestern University Feinberg School of Medicine, Chicago, IL 60611, USA

⁹ Rogel Cancer Center, University of Michigan, Ann Arbor, MI 48109, USA

Introduction

Approximately 1.9 million people are newly diagnosed with cancer each year in the United States [1]. It is estimated that as of January 2019, there were 16.9 million cancer survivors living in the US. This number is projected to increase to 22.2 million by 2030 [2]. While evidence has shown that timely, coordinated cancer care improves health outcomes and patient satisfaction [3–5], navigating complex health care systems and care decisions can be daunting for people living with cancer. Further, system-level barriers make coordination and access to care even more difficult for low income, uninsured/underinsured patients; racial, ethnic, gender, and sexual minorities; older Americans; and rural populations [6–9]. As a result, the delivery of cancer care is often considered fragmented and poorly coordinated [10]. Evidence also shows that historically underserved populations bear a greater burden of cancer [11–13], such as those who experience the effects of structural racism. Despite advances in cancer treatment over the past few decades, people from lower socioeconomic groups and some racial/ethnic minorities have lower cancer screening rates [14, 15], higher death rates [11, 16], and delayed cancer diagnosis [17].

In a landmark publication, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, the National Academy of Medicine [18] issued recommendations to improve the delivery of cancer care, including strengthening patient-centered care and reducing inequities for historically underserved and excluded

populations. Informed by this report, the Merck Foundation (the Foundation) launched a multi-site initiative, the Alliance to Advance Patient-Centered Cancer Care (Alliance), aimed at increasing care coordination, reducing disparities, and improving timely access to patient-centered care. Six grantee organizations (Fig. 1) were selected through a competitive, peer-reviewed process and funded for a five-year period (2016–2021) to implement sustainable, system-level improvements. Each site selected unique evidence-based interventions most relevant to their community and patient population(s). The Foundation also supported a National Program Office (NPO) based at the University of Michigan School of Nursing to provide oversight and technical assistance to the six sites, to lead a cross-site evaluation, and to glean collective lessons learned. In this initiative, cancer survivorship care was broadly conceptualized as the care and well-being of a person with cancer from the time of diagnosis until the end of life and is consistent with the definition put forth by the National Cancer Institute [19]. Interventions were aimed at reducing the burdens of cancer on survivors at all stages (before, during, and after treatment), and society as a whole.

While previous research suggests that system-level approaches hold the most promise for achieving sustainable, far-reaching, population-based change [20, 21], more exploration is needed into promising system-level approaches specific to cancer survivorship care. This paper describes the policy and system-level changes achieved, the strategies involved, the “on the ground” lessons learned, and implications for reducing disparities in care and improving

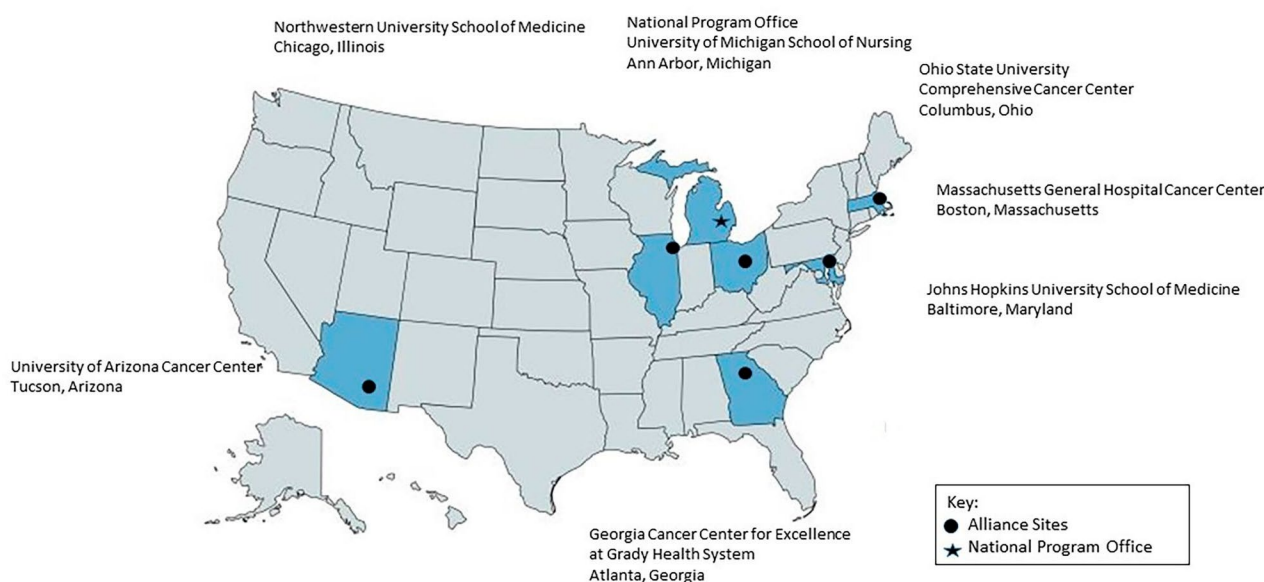


Fig. 1 Alliance Grantees

coordination and access. These findings help to inform future interventions and care delivery.

Methods

All six sites participated in a cross-site evaluation to assess the overall impact of the initiative and to identify promising policy and system-level solutions for dissemination and broader implementation. A six-person evaluation team at the NPO led the cross-site evaluation, with overall guidance provided by a larger workgroup comprised of leaders from each grantee site. While quantitative assessment of the overall reach and effectiveness of the site interventions has been described in previous literature [22], the focus of this article is a qualitative descriptive assessment of the specific policy and system-level changes implemented across the sites. This qualitative component was reviewed and deemed exempt from human subject research by the university's Institutional Review Board.

Health system and policy tracking

A health system and policy (HSP) tracking tool (Appendix A), previously used in other cross-site evaluations [21, 23], was adapted for this project. Grantee sites were asked to complete a separate tracking form for each of their main system and policy change efforts underway. Tracking tool components included: (a) description of the HSP effort; (b) the stage of the effort (e.g., development, adoption, implementation, maintenance); (c) specific strategies undertaken; and (d) changes attained to date (e.g., changes to policies or system-level modifications), including documentation of changes. In this initiative, policy changes were defined as both organizational (small p) and public (large P) policies. Sites submitted electronic tracking forms to the NPO once in May 2020 and again in May 2021. Sites were asked to report on the same HSP efforts for both years, with the recognition that system and policy change takes time and that final changes would be more prevalent in the second year of reporting. In addition, all hospitals were facing challenges in caring for patients with COVID-19. Sites used comparable methods for collecting data, which included designating one person as the contact person for documenting information on an ongoing basis; consulting with site leaders involved in the efforts; providing opportunities for others at their site to offer feedback and respond to data being reported; and uploading completed HSP forms. After receiving each set of data, the evaluation team conducted a verification process that included confirming all changes reported; reviewing annual reports submitted by sites to check for consistency in reporting; and ensuring that information on the form was

complete and properly documented. This was conducted through a document review of annual reports, and through follow-up calls and emails with site contacts and discussion during annual site visit meetings. When appropriate, additional information and clarification was added to the forms. Data were extracted from HSP forms using a rapid analysis approach [24, 25] and organized into tables and matrices which allowed us to identify common areas of focus in the work; track the stages of change for each effort; and categorize types of changes attained across all sites. It also allowed us to identify unique and innovative approaches.

Key informant interviews

In addition to the tracking tool and related analyses described above, site leaders were interviewed to better understand their HSP efforts, strategies used to bring about changes, and lessons learned during the five-year initiative. A semi-structured interview guide (Appendix B) was collaboratively developed by the evaluation team, reviewed by the larger workgroup, and used during these one-on-one interviews. Two experienced and trained interviewers (MS, NW) conducted the interviews via Zoom (Zoom Video Communications Inc., 2016) between August 2020 and February 2021. A mix of individuals serving in varied roles at each site were interviewed including site leaders, program coordinators, and those delivering interventions. An initial list of proposed participants from each site was created by the evaluation team and sent to the site PI and coordinator who reviewed the lists, and in some cases, added additional individuals or deleted names that were no longer involved in the work. All participants were invited to be interviewed via email. Interviews were audio-recorded, transcribed, and de-identified. A thematic analysis was conducted [26]. Two members of the evaluation team independently reviewed each transcript, applying line-by-line coding (using both a priori codes and codes that emerged directly from the data), and meeting regularly to discuss any differences in coding. All differences were resolved through discussion, adding new codes when identified and ensuring coding consistency. Coded transcripts were entered into NVivo 12 (QSR International Inc.) to help organize data, generate code reports, and identify key themes related to strategies and lessons learned.

All qualitative data were stored on a secure, password-protected university server. Using both tracking forms and interviews allowed us to compare our data and examine consistencies and/or contrasts between what was reported on the forms and what was discussed during interviews.

Results

A total of 20 comprehensive HSP efforts were reported by the six Alliance sites. Several distinct HSP changes emerged from these efforts and are described below. Key informant interviews with 65 site leaders provided insights on successful strategies employed to bring about these changes, as well as challenges and implications of the COVID-19 pandemic.

HSP efforts and areas of focus

HSP efforts reported by sites were concentrated around four focal areas - care coordination, psychosocial and supportive services, patient-provider communication, and access to care (Table 1). The most common focal area was *coordination of cancer care*, with efforts underway at all six sites. Coordination efforts involved using patient navigators (or community health workers at one site) to guide patients through the cancer care delivery system. Both nurse navigators and multilingual community or “lay” navigators were used to link patients with existing resources and in some cases, to address the social determinants of health (e.g., lack of transportation, insurance, etc.). Facilitating coordination between primary care providers, often located at community health centers, and oncologists was a main focus at three sites. This included developing a network of internists with expertise in cancer care and standardizing ongoing care for cancer survivors.

Expanding patient access to *psychosocial and supportive services* was reported by five sites. These efforts included

implementing screenings for common mental health conditions (e.g., emotional distress, anxiety, depression) and developing patient referral programs to other supportive services (e.g., social work, wellness education). Four sites reported efforts to improve *patient and provider communication*. These included engaging patients in developing education materials; establishing patient and family advisory councils or community advisory boards; and developing trainings/curricula for providers (e.g., unconscious bias training, health literacy communication). Lastly, efforts focused on improving *access to cancer care* were reported at all sites. These included first-time access to care and continued access to ongoing care. Examples of efforts included implementing automatic or direct physician referrals of recently diagnosed patients from community health centers or emergency departments to the cancer center; improving access to clinical trials for underserved patients; and switching to telehealth or other remote platforms to deliver services during the COVID-19 pandemic. A smaller subset of sites reported implementing screenings to identify patients experiencing non-medical barriers to care (e.g., lack of transportation or health insurance) and facilitating linkages to navigation and resources within the community.

HSP stages and types of changes reported

Of the 20 HSP efforts reported, 13 (or 65%) had advanced to the later stages of implementation or maintenance by the end of the initiative. Two efforts were in the adoption stage; five remained in the development stage. Of those in

Table 1 Health System and Policy Efforts: Areas of Focus

	Alliance to Advance Patient-Centered Cancer Care Sites					
	Grady	Johns Hopkins	Massachusetts General Hospital	Northwestern	Ohio State	University of Arizona
CARE COORDINATION						
Expansion of patient navigation/community health worker services	X	X	X	X	X	X
Other coordination between oncology/primary care	X	X		X		X
PSYCHOSOCIAL AND SUPPORTIVE CARE						
Referral programs/expanded access to supportive services	X	X	X		X	X
Screenings for emotional distress/depression	X		X		X	X
Symptom monitoring via smartphones					X	
PROVIDER/PATIENT COMMUNICATION						
Education/training for providers	X	X				X
Education/training for patients/families	X	X			X	
Patient Engagement (Patient and Family Advisory Councils/ Community Advisory Boards)	X	X				
ACCESS TO CARE						
Referral programs/expanded access to treatment	X	X	X	X	X	
Telehealth during COVID-19		X	X			X
Screening for barriers to care	X	X	X			

Note: Categories in this table are not mutually exclusive. One comprehensive effort may be listed in more than one category, or conversely, two or more efforts may be grouped in one category.

the development stage, some sites reported being stalled in their efforts due to the COVID-19 pandemic. Several distinct system and policy changes emerged from these efforts (Fig. 2). Across the six sites, the most common types of changes included: improvements to the electronic health record (EHR) system or telehealth platforms (34%); policy changes (23%); new protocols or guidelines (23%); and creation of new positions or job codes within the health system (20%).

EHR and telehealth changes

Changes to the EHR system and telehealth expansion were the most prevalent types of changes implemented across the sites. Examples included creating an innovative tool within Epic™ (Aurora, WI) to facilitate transitions between oncology and primary care; building automated patient referral systems; tracking patient encounters in a new EHR patient navigation platform; setting up automated alerts to providers when patients visit the emergency department or have a hospital stay; and developing electronic patient registries. Sites also created virtual platforms and expanded telehealth

services (e.g., video visits, phone calls) to provide needed care and offer navigation.

Policy changes

Other changes included adopting or revising policies. Examples included requiring health system employees to participate in implicit bias training or health literacy training; requiring screenings for emotional distress during clinical visits; and establishing a formal contract with a third-party firm to provide pre-paid smartphones and data plans to patients while undergoing cancer treatment. One site reported working with a local partnership on statewide policy initiatives to decrease barriers to clinical trials for underserved patients and to continue insurance coverage for behavioral telehealth visits.

Protocols or guidelines

Development of written protocols or guidelines for clinical practices in caring for patients with cancer were also reported. One site created a set of standardized treatment

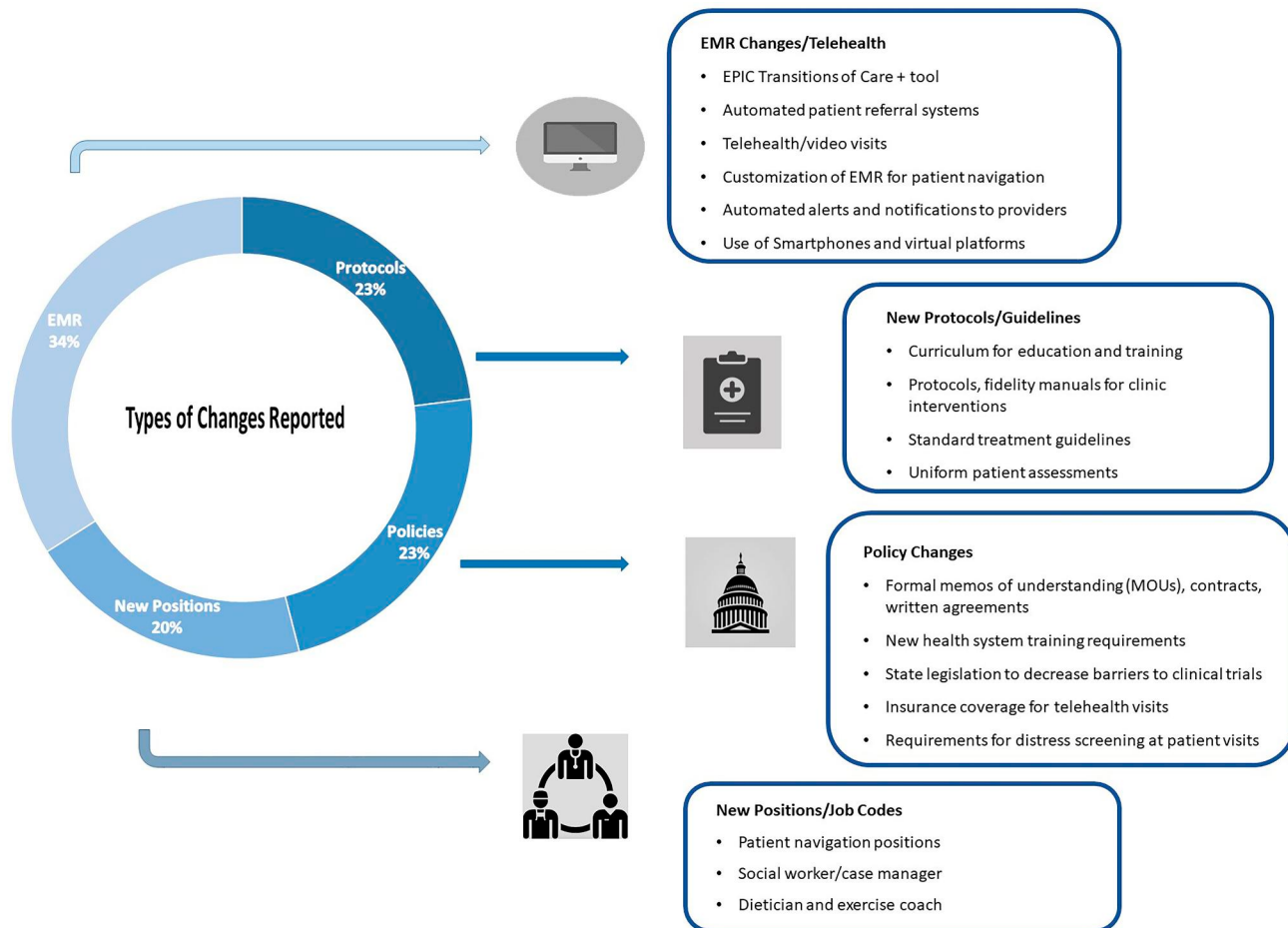


Fig. 2 Types of HSP Changes Reported Across 6 Sites

guidelines for primary care physicians providing care to patients with cancer. Other sites reported developing protocols to guide remote delivery of navigation services and protocols for patient recruitment to selected interventions.

New positions and job codes

Creating new job codes and formalized job descriptions within the health system allowed sites to establish and sustain positions formally within their health system and ensure funding mechanisms that would extend beyond the grant-funded initiative. New job codes were created for patient navigators, social workers, dieticians, and exercise coaches for provision of supportive services.

Overall, several successful system-level changes were accomplished across the six sites throughout the five-year initiative. Figure 3 provides more details on two innovative efforts - one included using smartphones for symptom monitoring and management; the other included developing an EHR tool to coordinate transitions of care from oncology to primary care.

Key informant interview findings

The 65 people interviewed included, 23 site leads (principal or co-investigators), 13 patient navigators or other intervention staff, 12 community partners or business collaborators, 9 project site coordinators, and 8 health system employees. 78% self-identified as female and 63% identified their race as white, 17% as black, 12% as Asian, and the remainder as mixed/other race. Interviewees identified several successful strategies for bringing about these HSP changes, as well as challenges and implications from the COVID-19 pandemic.

Successful strategies

Across all interviews, five strategies for system-level change were most frequent. First, *building partnerships*, primarily with community health centers and businesses (e.g., EHR software vendors and mobile phone firms) allowed sites to reach patients in low-resourced communities; leverage additional resources; and acquire technical assistance.

It took efforts from patients, from clinicians, from IT, and from researchers when it came to building the survivorship care planning medical record tool ... and so it was a collaborative effort. (site leader ID105)

Second, *engaging health system leadership and frontline staff* (e.g., patient navigators) early in the initiative to help develop interventions created more buy-in and commitment to change.

So having a meeting that involved frontline individuals where some of the changes would be, I mean they would be impacted by the changes that we were implementing so we really needed their feedback. (physician ID102)

Third, *involving patients and patient perspectives* by creating patient and family advisory groups, community advisory boards, or holding meetings/focus groups with cancer survivors facilitated patient-centered approaches.

They have a wonderful Patient Family Advisory Group or Council. They have some really engaged patients- that's the whole point of that ... this group actually works on things and they're very engaged, they're motivated, and to get that patient voice is so important. (community partner ID110)

Fourth, *identifying and utilizing "champions"* at each site (e.g., physician champions at community health centers and wellness champions at one health system) to provide leadership and motivation to others.

Our lead doc was definitely gung ho. She is like a rockstar in every aspect, just a crazy multi-tasker, but she does everything so well and like this was really important to her ... and she was really helpful in identifying which other physicians could take this on. (project coordinator ID108)

Fifth, *implementing smaller changes at one clinic or on one unit* (e.g., pilot projects) enabled sites to identify potential roadblocks and solicit feedback from individuals implementing these smaller changes before scaling up to the full health system.

COVID-19 challenges

Interviews took place during the height of the COVID-19 pandemic when the sites, along with other health systems from around the country, were experiencing surging COVID caseloads, cancellations of all non-essential appointments and medical procedures, staffing shortages, and loss of revenue. According to interviewees, these *challenges* led to declines in cancer screenings, delayed diagnosis, and subsequent delays in care and treatment. Interviewees also reported that there were high rates of cancellations and no-shows for appointments during this time because patients were not comfortable going to medical facilities.

Further, the sites' community partners (e.g., federally qualified health centers and other community clinics) became COVID testing centers and/or revised their






Health System & Policy Changes




The Ohio State University: Providing Smartphones to Patients

A partnership with a third-party firm enabled this site to provide free smartphones, including free monthly service, to underserved patients to monitor and track patients' symptoms; enhance communication between providers and patients; provide easy access to health records and patient portals; and increase awareness of available community resources.

Effective Strategies

-  Forged a partnership with Verizon to offer smartphones free of charge to low-income cancer patients
-  Gained support of university faculty, staff, and cancer center leadership
-  Increased awareness of the smartphone provision project throughout the cancer center

Health System and Policy Changes

-  Contract established between Ohio State University and Verizon for phone provision
-  Use of a Government Service Contract through the university to receive reduced rates for monthly services fees
-  Implementation of a smartphone symptom management program during cancer treatment



"... Being provided cell phones I think was really crucial because some of them actually ... did not have smartphones and they would not have been able to do it otherwise."







"... What it did was it allowed the patients to connect with the team and discuss ... symptoms that they may be experiencing that either weren't addressed in clinic or had developed in the interim between visits that were really key. I think this is really important because during a clinic visit, you're so focused on the cancer, the disease, the treatment... you have limited time."




Johns Hopkins University: Improving Transitions of Care

The Epic Transition of Care Plus (ToC+) tool was developed and implemented within the health system EHR to improve the quality of life of cancer patients from cancer treatment to primary care. ToC+ aims to standardize transitions of care, clearly define expectations and responsibilities, identify high-risk patients, and improve survivorship care.

Effective Strategies

-  Sought early buy-in from clinicians
-  Used feedback to tailor ToC+ to different disciplines
-  Utilized as a virtual tool during the COVID-19 pandemic
-  Worked closely with Epic to include software in EHR library

Health System and Policy Changes

-  Chosen by administrators as the preferred tool for survivorship care planning
-  Launched in the lung cancer clinic and planned expansion to other cancer clinics
-  Appears in the Epic EMR library for widespread use across several medical centers/systems



"... Within just four ... five ... eight weeks of pilot testing, we applied to make it the default tool, and it was approved because the clinicians saw an immediate value for it."



"... I think it makes a big difference when the message is coming from somebody who's actually going to be using the tool themselves, like on their own patients..."

Fig. 3 Highlights from Two Sites

workflow systems to focus almost exclusively on pandemic-related needs, which halted patient interventions at these sites. Temporary pauses in research caused delays in data collection and stalled participant recruitment. Interviewees also reported that their IT infrastructures were inadequate at the start of the pandemic. Subsequently, there was a steep learning curve for both providers and patients to switch to remote delivery of care and services.

Lessons learned

Despite these challenges, interviewees also reported that the care implications and *lessons learned* during the pandemic were extremely valuable, profound, and long lasting. All six sites reported that telehealth and remote delivery of services would continue to be an integral component of cancer care moving forward.

I think our health care delivery system will absolutely change and I think there will continue to be telehealth visits and hybrid visits, so that's a good thing. (physician ID101)

All sites reported successfully transitioning core components of their interventions to remote delivery, including patient navigation (e.g., over the phone or through video chats), where some sites reported increased navigation case loads; social work or other behavioral health support; video visits for some medical appointments; and tumor board conferences where attendance dramatically increased during remote meetings. Interviewees also reported developing videos (rather than in-person sessions) for meetings, trainings, and exercise classes, among others. An important lesson learned was that providers need to be very intentional in their efforts to reach and include populations who may not have access/proficiency with newer technologies (e.g., smartphones, remote platforms), particularly low-income, elderly, rural, or non-English speaking populations. Some interviewees reported that telehealth eased some access barriers such as transportation, parking, and traveling long distances for appointments. Others reported that telehealth improved safety/wellbeing for immune-compromised patients. Several informants noted that next steps should include more research on the telehealth impacts on health equity.

I think probably this idea of who has access to the virtual model, is probably what I think would float to the top as the biggest thing from the pandemic. (oncologist ID107)

Lastly, interviewees reported that a key lesson learned was that they had to be adaptable, flexible, and resilient.

The biggest lesson is to be able to turn on a dime and be able to... kind of use what you have, you know, to the best of your abilities, given whatever is going on around you. (site leader ID105)

Discussion

During this five-year initiative, the six funded sites focused on: (1) coordinating care between multiple providers, supported by patient navigators; (2) expanding psychosocial and supportive care; (3) improving patient-provider communication; and (4) addressing barriers to accessing care. Through these efforts, sites implemented several distinct system and policy changes, with the most prevalent being improvements to their EHR systems/telehealth (34%); policy changes (23%); new protocols or guidelines (23%); and creation of new positions or job codes within the health system (20%). The sites prioritized system and policy change approaches in recognition that these changes had a greater potential for sustainability and would likely live on beyond the grant-funded period. Successful strategies for change included building partnerships, engaging health system leadership and frontline staff, involving patients and patient perspectives, identifying champions, and launching pilot projects. Care implications and lessons learned from the COVID-19 pandemic included the successful transition to remote delivery of services, the continued use of telehealth in the future, and the impacts of this shift in care on health equity.

Alliance interventions described in this paper have been widely supported by previous literature and include: patient navigation services for cancer survivors [27–29]; patient-centered approaches to care [30, 31]; and inclusion of psychosocial and supportive services for cancer survivors [32–34]. In addition, findings from our qualitative assessment were consistent with other research suggesting that expanded use of telehealth and the remote delivery of services not only provided a short-term solution to care delivery during the COVID-19 pandemic but also may have long-lasting sustainability and provide far-reaching benefits to cancer survivors including reducing travel burden, lessening cancer survivors' risk of exposure to infectious disease, decreasing the need for childcare or time off of work, and allowing people to stay in their homes when they aren't feeling well [35, 36]. When addressing disparities in particular, Alliance sites found that they had to be intentional and deliberate in identifying, understanding, and overcoming system-level barriers faced by underserved patients who may experience economic, social, or environmental disadvantages. Implementing and expanding patient

navigation has been shown to be an effective approach to addressing disparities [37, 38] and was common across all Alliance sites [39]. The use of patient navigation at Alliance sites had ripple effects in terms of simultaneously improving care coordination, enhancing communication with patients, and addressing non-medical barriers to care such as lack of health insurance or limited access to technology.

While progress has been made in improving survivorship care overall [40], a recent National Cancer Institute panel and subsequent report found that gaps remain and that more research is needed [41]. We believe that the policy and system-level interventions implemented by Alliance sites hold promise for continuing to improve cancer care, provide important insights into successful implementation strategies, and offer timely, on-the-ground lessons learned.

While our findings can help to inform future interventions, we also recognize that our study has some limitations. First, it is largely descriptive and additional controlled trials may be needed. Second, Alliance sites received additional funding to implement their interventions and we recognize that health systems without additional grant funding may find it difficult to implement such changes. Further, in this initiative, sites selected their own unique approaches and tailored these to the specific needs of their patients. Therefore, findings may not be generalizable to other sites. However, the Merck Foundation strategically selected a mix of sites from geographically dispersed areas (e.g., Midwest, Northeast, South, and Southwest US) that were focused on providing care for underserved populations. As such, we believe the accomplishments and lessons reported in this paper are relevant to others doing similar work across the United States.

Conclusions

Despite advances in cancer diagnosis, treatment, and survival, certain populations continue to experience higher rates of cancer morbidity and mortality. The COVID-19 pandemic may have exacerbated these disparities [42], but also revealed some opportunities to address longstanding barriers to care (i.e., transportation, travel costs). Comprehensive, multilevel approaches and sustainable system-level changes are promising strategies to ensure a more coordinated and equitable health care delivery system for cancer survivors.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s11764-023-01440-y>.

Author contributions All authors contributed to the conception and design of the cross-site evaluation of the Alliance to Advance Patient-Centered Cancer Care. All authors participated in the collaborative

design and planning of data collection tools and interview protocols. Data collection and analysis were performed by MQ, NW, MS, CF, and MT. The first draft of the manuscript was written by MQ and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Funding This work was supported by the Merck Foundation and provided to the University of Michigan as the National Program Office and to each participating institution. The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.

Data Availability The data generated during and/or analyzed during the current initiative are available from the corresponding author on reasonable request.

Declarations

Competing interests The authors declare no competing interests.

Ethic approval This project and the related cross-site evaluation was deemed exempt by the University of Michigan Institutional Review Board.

Consent to participate Informed consent was obtained from all individuals participating in key informant interviews.

References

1. American Cancer Society., "Cancer facts and figures, 2021," 2021. <http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2021/> (accessed Dec. 06, 2021).
2. American Cancer Society., "Cancer Treatment & survivorship facts & figs. 2019–21," Atlanta, 2019.
3. Gorin SS, Haggstrom D, Han PKJ, Fairfield KM, Krebs P, Clauser SB. Cancer Care Coordination: a systematic review and Meta-analysis of over 30 years of empirical studies. *Ann Behav Med.* Aug. 2017;51(4):532–46. <https://doi.org/10.1007/s12160-017-9876-2>
4. Levit L, Balogh E, Nass S, Ganz PA, editors. *Delivering high-quality Cancer Care: charting a New Course for a system in Crisis.* Washington, D.C.: National Academies Press; 2013.
5. Loisel CG et al. "The nurse pivot-navigator associated with more positive cancer care experiences and higher patient satisfaction," *Can. Oncol. Nurs. J.*, vol. 30, no. 1, pp. 48–53, Jan. 2020, <https://doi.org/10.5737/236880763014853>
6. Blinder VS, Gany FM. Impact of Cancer on Employment. *J Clin Oncol.* Feb. 2020;38(4):302–9. <https://doi.org/10.1200/JCO.19.01856>
7. Boehmer U. "LGBT Populations' Barriers to Cancer Care," *Semin. Oncol. Nurs.*, vol. 34, no. 1, pp. 21–29, Feb. 2018, <https://doi.org/10.1016/j.soncn.2017.11.002>
8. Townsley CA, Selby R, Siu LL. Systematic review of barriers to the recruitment of older patients with Cancer onto clinical trials. *J Clin Oncol.* May 2005;23:3112–24. <https://doi.org/10.1200/JCO.2005.00.141>
9. Yabroff KR, Han X, Zhao J, Nogueira L, Jemal A. "Rural Cancer Disparities in the United States: A Multilevel Framework to Improve Access to Care and Patient Outcomes," *JCO Oncol. Pract.*, vol. 16, no. 7, pp. 409–413, Jul. 2020, <https://doi.org/10.1200/OP.20.00352>

10. Hewitt M, Greenfield S, Stovall E, editors. *From Cancer patient to Cancer Survivor*. Washington, D.C.: National Academies Press; 2005.
11. Nelson B. “How Structural Racism Can Kill Cancer Patients: Black Patients with Breast Cancer and Other Malignancies Face Historical Inequities That Are Ingrained but Not Inevitable,” *Cancer Cytopathol*, vol. 128, no. 2, pp. 83–84, Feb. 2020, <https://doi.org/10.1002/cncy.22247>
12. Lockhart JS, Oberleitner MG, Nolfi DA. The asian immigrant Cancer Survivor experience in the United States: a scoping review of the literature. *Cancer Nurs*. May 2020;43(3):177–99. <https://doi.org/10.1097/NCC.0000000000000797>
13. Islami F et al. “American Cancer Society’s report on the status of cancer disparities in the United States, 2021,” *CA. Cancer J. Clin*, vol. 72, no. 2, pp. 112–143, Mar. 2022, <https://doi.org/10.3322/caac.21703>
14. Daniel C, et al. Differences related to Cancer Screening by Minority and Rural/Urban Status in the Deep South: Population-based Survey results. *J Cancer*. 2021;12(2):474–81. <https://doi.org/10.7150/jca.49676>
15. Rauscher GH, Allgood KL, Whitman S, and Conant E. “Disparities in Screening Mammography Services by Race/Ethnicity and Health Insurance,” *J. Women’s Heal*, vol. 21, no. 2, pp. 154–160, Feb. 2012, <https://doi.org/10.1089/jwh.2010.2415>
16. Siegel DA, O’Neil ME, Richards TB, Dowling NF, Weir HK. “Prostate Cancer Incidence and Survival, by Stage and Race/Ethnicity — United States, 2001–2017,” *MMWR. Morb. Mortal. Wkly. Rep*, vol. 69, no. 41, pp. 1473–1480, Oct. 2020, <https://doi.org/10.15585/mmwr.mm6941a1>
17. Champion CD, et al. Disparities at the intersection of race and ethnicity: examining Trends and Outcomes in hispanic women with breast Cancer. *JCO Oncol Pract*. May 2022;18(5):e827–38. <https://doi.org/10.1200/OP.20.00381>
18. Levit L, Balogh E, Nass S, Ganz PA, editors. *Delivering high-quality Cancer Care: charting a New Course for a system in Crisis*. Washington, D.C.: National Academies Press; 2013.
19. National Cancer Institute., “Survivorship Care Plan.” <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship-care-plan> (accessed Jun 26, 2023).
20. Clark NM, Quinn M, Dodge JA, Nelson BW. “Alliance System and Policy Change,” *Health Promot. Pract*, vol. 15, no. 2 suppl, pp. 11S–22S, Nov. 2014, <https://doi.org/10.1177/1524839914543829>
21. *Health Promot. Pract*, vol. 19, no. 1 suppl, pp. 92S–114S, Sep. 2018, doi: 10.1177/1524839918789400.
22. Arring N, et al. Reaching populations to address disparities in Cancer Care Delivery: results from a six-site Initiative. *J Natl Compr Cancer Netw*. May 2023;21(5):481–6. <https://doi.org/10.6004/jnccn.2023.7006>
23. Kelly RP, Burke J, Waddell S, Lachance L. “Increasing Opportunities for Health in a Southeast Michigan Community Through Local Policy Change,” *Health Promot. Pract*, vol. 20, no. 1, pp. 116–127, Jan. 2019, <https://doi.org/10.1177/1524839918763588>
24. Lewinski AA, et al. Applied Rapid qualitative analysis to develop a contextually appropriate intervention and increase the likelihood of Uptake. *Med Care*. Jun. 2021;59:S242–51. <https://doi.org/10.1097/MLR.0000000000001533>
25. Taylor B, Henshall C, Kenyon S, Litchfield I. Can rapid approaches to qualitative analysis deliver timely, valid findings to clinical leaders? A mixed methods study comparing rapid and thematic analysis. *BMJ Open*. Oct. 2018;8(10):e019993. <https://doi.org/10.1136/bmjopen-2017-019993>
26. Braun V. and Clarke V. “What can ‘thematic analysis’ offer health and wellbeing researchers?,” *Int. J. Qual. Stud. Health Well-being*, vol. 9, no. 1, p. 26152, Jan. 2014, <https://doi.org/10.3402/qhw.v9.26152>
27. Bernardo BM, Zhang X, Beverly Hery CM, Meadows RJ, Paskett ED. “The efficacy and cost-effectiveness of patient navigation programs across the cancer continuum: A systematic review,” *Cancer*, vol. 125, no. 16, pp. 2747–2761, Apr. 2019, <https://doi.org/10.1002/cncr.32147>
28. Williams CP, et al. Impact of lay navigation on utilization and Medicare spending for cancer survivors in the ‘Deep south’. *J Cancer Surviv*. Aug. 2022;16(4):705–13. <https://doi.org/10.1007/s11764-021-01064-0>
29. Ramirez AG, Muñoz E, Long Parma D, Perez A, Santillan A. “Quality of life outcomes from a randomized controlled trial of patient navigation in Latina breast cancer survivors,” *Cancer Med*, vol. 9, no. 21, pp. 7837–7848, Nov. 2020, <https://doi.org/10.1002/cam4.3272>
30. Park M, Giap TTT, Lee M, Jeong H, Jeong M, Go Y. “Patient- and family-centered care interventions for improving the quality of health care: A review of systematic reviews,” *Int. J. Nurs. Stud*, vol. 87, pp. 69–83, Nov. 2018, <https://doi.org/10.1016/j.ijnurstu.2018.07.006>
31. Elkefi S, Asan O. “The Impact of Patient-Centered Care on Cancer Patients’ QOC, Self-Efficacy, and Trust Towards Doctors: Analysis of a National Survey,” *J. Patient Exp*, vol. 10, Jan. 2023, <https://doi.org/10.1177/23743735231151533>
32. Sender A, Friedrich M, Schmidt R, Geue K. Cancer-specific distress, supportive care needs and satisfaction with psychosocial care in young adult cancer survivors. *Eur J Oncol Nurs*. Feb. 2020;44. <https://doi.org/10.1016/j.ejon.2019.101708>
33. Andersen BL, et al. Screening, Assessment, and care of anxiety and depressive symptoms in adults with Cancer: an American Society of Clinical Oncology Guideline Adaptation. *J Clin Oncol*. May 2014;32:1605–19. <https://doi.org/10.1200/JCO.2013.52.4611>
34. Mehnert A, et al. Four-week prevalence of Mental Disorders in patients with Cancer Across Major Tumor entities. *J Clin Oncol*. Nov. 2014;32(31):3540–6. <https://doi.org/10.1200/JCO.2014.56.0086>
35. Paterson C, et al. The role of Telehealth during the COVID-19 pandemic across the Interdisciplinary Cancer Team: implications for practice. *Semin Oncol Nurs*. Dec. 2020;36(6):151090. <https://doi.org/10.1016/j.soncn.2020.151090>
36. Hasson SP, et al. Rapid implementation of Telemedicine during the COVID-19 pandemic: perspectives and preferences of patients with Cancer. *Oncologist*. Apr. 2021;26(4):e679–85. <https://doi.org/10.1002/onco.13676>
37. Freund KM. Implementation of evidence-based patient navigation programs. *Acta Oncol (Madr)*. Feb. 2017;56(2):123–7. <https://doi.org/10.1080/0284186X.2016.1266078>
38. Ko NY et al. “Racial and ethnic differences in patient navigation: Results from the Patient Navigation Research Program,” *Cancer*, vol. 122, no. 17, pp. 2715–2722, Sep. 2016, <https://doi.org/10.1002/cncr.30109>
39. Ver Hoeve ES, et al. Implementing patient navigation programs: considerations and lessons learned from the Alliance to Advance patient-centered Cancer Care. *Cancer May*. 2022. <https://doi.org/10.1002/cncr.34251>
40. Nekhlyudov L, Ganz PA, Arora NK, Rowland JH. Going beyond being lost in transition: a decade of Progress in Cancer Survivorship. *J Clin Oncol*. Jun. 2017;35:1978–81. <https://doi.org/10.1200/JCO.2016.72.1373>
41. Gallicchio L et al. “Evidence Gaps in Cancer Survivorship Care: A Report From the 2019 National Cancer Institute Cancer Survivorship Workshop,” *JNCI J. Natl. Cancer Inst*, vol. 113, no. 9, pp. 1136–1142, Sep. 2021, <https://doi.org/10.1093/jnci/djab049>
42. DeGroff A et al. “COVID-19 impact on screening test volume through the National Breast and Cervical Cancer early detection program, January–June 2020, in the United States,” *Prev. Med*.

(*Baltim*), vol. 151, p. 106559, Oct. 2021, <https://doi.org/10.1016/j.jypmed.2021.106559>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.