

# Health services research and advocacy in US cancer care: pathways from evidence to implementation



Nipun Gorantla,<sup>a</sup> Manju George,<sup>b,c</sup> Nishwant Swami,<sup>d,e</sup> Milit S. Patel,<sup>f,g</sup> James Fan Wu,<sup>h</sup> Joshua A. Budhu,<sup>i</sup> Divya Yerramilli,<sup>g</sup> Lindsay Sichta,<sup>b</sup> Stacey Runfola,<sup>b</sup> Julie Saliba Clauer,<sup>b</sup> Tiffany Studebaker Freeman,<sup>b</sup> Bhav Jain,<sup>j</sup> Erin Jay G. Feliciano,<sup>k</sup> Kaitlyn Lapen,<sup>g</sup> Fumiko Chino,<sup>l</sup> Fabio Y. Moraes,<sup>m,n</sup> Sean M. McBride,<sup>g</sup> Paul L. Nguyen,<sup>o</sup> Miranda B. Lam,<sup>o</sup> Nancy Y. Lee,<sup>g</sup> and Edward Christopher Dee<sup>g,\*</sup>



<sup>a</sup>Department of Neurosurgery, Stanford University, Stanford, CA, USA

<sup>b</sup>Paltown Development Foundation, 64 W Central Ave, PMB 717, Edgewater, MD, 21037, USA

<sup>c</sup>Department of Population Health Science, John D. Bower School of Population Health, University of Mississippi Medical Center, Jackson, MS, USA

<sup>d</sup>Department of Internal Medicine, Hospital of the University of Pennsylvania, Philadelphia, PA, USA

<sup>e</sup>Division of Cancer Medicine, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

<sup>f</sup>Department of Molecular Biosciences, The University of Texas at Austin, Austin, TX, USA

<sup>g</sup>Department of Radiation Oncology, Memorial Sloan Kettering Cancer Center, New York, NY, USA

<sup>h</sup>Division of Hematology and Oncology, Department of Medicine, Medical College of Wisconsin, Milwaukee, WI, USA

<sup>i</sup>Department of Neurology, Memorial Sloan Kettering Cancer Center, New York, NY, USA

<sup>j</sup>Stanford Medicine, Stanford, CA, USA

<sup>k</sup>Department of Hematology/Oncology, Northwell Health Cancer Institute, New Hyde Park, NY, USA

<sup>l</sup>Department of Radiation Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

<sup>m</sup>Department of Oncology, Global Oncology Program, Queen's University, Kingston, ON, Canada

<sup>n</sup>Department of Radiology and Oncology, University of São Paulo Medical School, São Paulo, Brazil

<sup>o</sup>Department of Radiation Oncology, Mass General Brigham, Boston, MA, USA

## Summary

Although the gap between research and implementation is frequently emphasized, examples from United States (US) cancer care demonstrate that health services research can be translated into meaningful policy and practice. This Health Policy piece examines four US oncology cases spanning state legislation, federal payment reform, patient advocacy, and clinical measurement, which are the Delaware Cancer Consortium, the Oncology Care Model and Enhancing Oncology Model, COLONTOWN, and the COST financial toxicity measure. We assess how evidence moved into routine care through top-down policy and bottom-up community pathways. Across these cases, implementation has depended on sustained political and financial commitment, durable delivery mechanisms, data-driven evaluation, and collaboration among clinicians, policymakers, researchers, and patient advocates. These cases also illustrate limitations, which include administrative burden, financial toxicity, and uneven evidence of cost, quality, and equity outcomes. Some lessons of these cases include protected funding, navigation infrastructure, incentives centered around equity, patient and community engagement, and measurement that is linked to actionable interventions. Together, these examples show how health services research can influence cancer care when evidence is paired with appropriate policy mechanisms, financing structures, and implementation capacity.

The Lancet Regional  
Health - Americas  
2026;63: 101630

Published Online xxx  
<https://doi.org/10.1016/j.lana.2026.101630>

Copyright © 2026 Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

**Keywords:** Health services research; Cancer policy; Oncology care delivery; Implementation science; Cancer control; Health equity; Value-based care; Oncology payment reform; Patient navigation; Financial toxicity; Social determinants of health; Colorectal cancer screening; Cancer disparities; Community oncology; Patient advocacy; Clinical trial access; Evidence implementation; Healthcare delivery; Oncology care model; Enhancing oncology model

## Introduction

In medicine and health policy, health services research examines how care is organized, financed, delivered, and experienced. Implementation science studies how

evidence-based interventions are adopted and sustained in routine practice, and policy implementation refers to the legal, financing, regulatory, and institutional mechanisms that convert evidence into programs or delivery infrastructure.

In United States (US) oncology, the gap between scientific discovery and real-world implementation is often cited as a major barrier to translating health

\*Corresponding author. Department of Radiation Oncology, Memorial Sloan Kettering Cancer Center, 1275 York Ave, New York, NY 10065, USA.

E-mail address: [deee1@mskcc.org](mailto:deee1@mskcc.org) (E.C. Dee).

services and public health research into practice.<sup>1-5</sup> However, this framing may obscure the broader role of health services research in informing real-world implementation. One example is the development of patient navigation. In 1990, Dr. Harold Freeman established the nation's first patient navigator program at Harlem Hospital Center after discovering that an overwhelming majority of patients in his practice presented with advanced-stage cancer.<sup>6,7</sup> The program paired free or low-cost screening with patient navigators who guided patients through their care plan. Subsequent analysis demonstrated that patient navigation was associated with improved early-stage detection and five-year survival.<sup>6</sup> These findings contributed to the passage of the Patient Navigator Outreach and Chronic Disease Prevention Act in 2005 and subsequent NCI studies that provided further scientific validation.<sup>6</sup> Today, patient navigation is a standard component of oncology care, as required by the American College of Surgeons' Commission on Cancer for accreditation. As with patient navigation policy, research-informed initiatives supported by policy mechanisms and delivery infrastructure have been associated with measurable improvements in cancer outcomes and health-care efficiency.<sup>8-11</sup>

This trajectory of work started by Dr. Freeman and colleagues frames the broader health-policy question for this Health Policy manuscript: we seek to examine how evidence becomes integrated into routine oncology care through policy mechanisms, financing structures, and delivery infrastructure. This Health Policy piece examines how evidence was translated into practice across four oncology implementation cases, focusing on the policy mechanisms, financing structures, delivery infrastructure, outcomes, equity implications, and transferability of each example.

We examine illustrative examples such as the Delaware Cancer Consortium, which utilized universal screening coverage and nurse navigation to reduce racial disparities in colorectal cancer, and the federal Oncology Care Model and its successor, the Enhancing Oncology Model, which leveraged payment reform to drive transformation of practices and to incorporate equity-related processes and social-risk indicators.

We also examine how research translation can occur beyond formal policy and institutions through patient advocacy organizations like COLONTOWN, which have disseminated emerging evidence and influenced clinical trial design, and through adoption of clinician-developed tools like the COST financial toxicity measure (Fig. 1). These cases were chosen as a deliberate set spanning legislative, payment, advocacy, and measurement levers. They are used to derive policy-relevant implementation lessons across a breadth of disciplines for applicable use in public health research and initiative advancement.

Evidence that was reviewed for this narrative policy review included federal and state program materials, health-policy analyses, and published reports describing

implementation mechanisms, outcomes, limitations, and transferability. We selected cases that illustrate distinct implementation levers relevant to oncology policy and delivery reform (Table 1). These examples should not be interpreted as universal solutions or guarantees of successful implementation across settings.<sup>4</sup> Rather, they illustrate that under specific conditions, health services research can translate into meaningful change. The examples are US-centered, and their transferability depends on local policy authority, financing, data infrastructure, patient communities, and workforce capacity.

Together, these cases trace three distinct pathways of state legislation, federal reimbursement design, and grassroots action through which evidence has reached practice, and from which transferable lessons can be drawn. By examining these illustrative cases, we aim to identify common implementation elements and to offer concrete guidance for future efforts to translate research to practice.

## Selected health policy implementation cases

### The Delaware Cancer Consortium: state-level model for reducing disparities

The Delaware Cancer Consortium (DCC) exemplifies how coordinated policy initiatives, supported by data and legislative action, can support improvements in cancer outcomes at the population level. In the late 1990s, Delaware had the second-worst in all-site cancer mortality, and numerous state and national public health analyses using the Delaware Cancer Registry and Surveillance, Epidemiology, and End Results (SEER) data raised a warning signal, prompting a comprehensive overhaul of the state's cancer control program.<sup>12,13</sup>

In 2001, Governor Ruth Ann Minner first convened the Delaware Advisory Council on Cancer Incidence and Mortality through Senate Joint Resolution 2.<sup>14</sup> This resolution established a permanent, impartial council reporting directly to the Governor to oversee implementation of evidence-based recommendations.<sup>15</sup> This council brought together leading oncologists, public health researchers, patient advocates, state agency leaders, and legislators to develop an evidence-based reform plan.<sup>15</sup> This plan was then codified into permanent law through Senate Bill 102, authored by Senator David McBride.<sup>14</sup> This bipartisan, multidisciplinary coalition ensured that DCC was not just a temporary advisory body but rather a durable committee of experts that is embedded in state code.

The DCC model is characterized by its "groundshot" approach,<sup>16</sup> which focuses on removing financial and navigational barriers to colorectal cancer (CRC) screening and treatment. The consortium realized that screening, although effective, was underused by uninsured people and many members of racially minoritized groups, particularly African American residents.

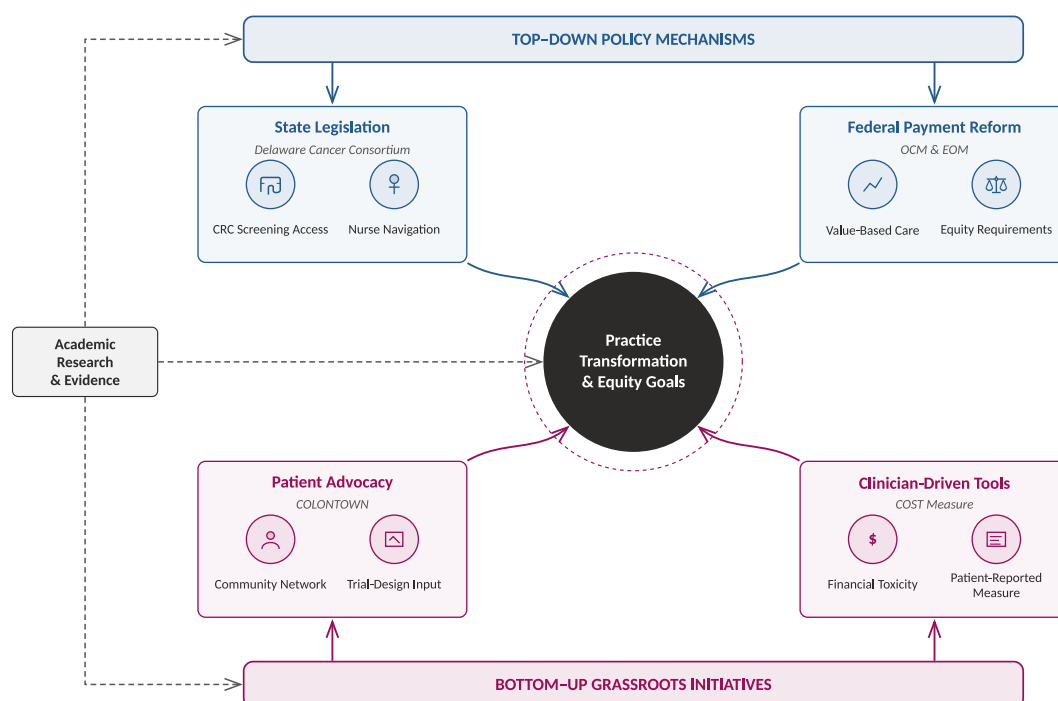


**Fig. 1: Converging pathways to practice transformation and equity in US cancer care.** Academic evidence informs two complementary routes to practice change: top-down policy mechanisms (blue), including state legislation through the Delaware Cancer Consortium and federal payment reform through the OCM and EOM; and bottom-up grassroots initiatives (crimson), including the COLONTOWN patient advocacy community and the clinician-developed COST financial toxicity measure. Together, these pathways converge on shared goals of practice transformation and equity, illustrating how formal policy can be integrated with community- and clinician-led innovation.

In response, the Delaware State Legislature fully funded a comprehensive program with three key policy components (Table 2): (1) a statewide CRC screening program that reimbursed uninsured individuals, (2) a unique cancer treatment program covering care costs for up to two years for newly diagnosed uninsured

residents, and (3) a strong network of nurse navigators to coordinate care within the community.<sup>17</sup> The program was financed primarily through the Tobacco Master Settlement Agreement (MSA), which provided the state approximately \$439 million between 1998 and 2018.<sup>18</sup> State leadership earmarked these funds for

| Case                       | Implementation lever                                                           | Evidence base                                                                                                  | Outcomes emphasized                                                                                            | Limitations                                                                                            | Transferability                                                                                                                                         |
|----------------------------|--------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|
| Delaware cancer consortium | State legislation, protected funding, navigation infrastructure                | Registry and SEER data identifying colorectal cancer disparities; evidence supporting screening and navigation | Improved screening, reduced late-stage diagnosis, and reduced racial disparities in colorectal cancer outcomes | Small-state context, sustained political commitment, and dedicated funding may not generalize directly | Most transferable where states can pair registry-guided targeting with protected financing and navigation capacity                                      |
| OCM/EOM                    | Federal episode-based payment reform and equity requirement                    | IOM recommendations, OCM evaluations, CMMI model design, and early EOM monitoring                              | Practice transformation, care coordination, end-of-life care improvements, and equity-focused model redesign   | Savings and equity effects remain mixed or under evaluation; administrative burden is substantial      | Transferable as a payment-design model if risk adjustment, quality safeguards, and social-need supports are explicit                                    |
| COLONTOWN                  | Patient advocacy and patient backed research engagement                        | Community-generated priorities, surveys, conference abstracts, guideline and trial-design participation        | Patient education, biomarker communication work, trial-design input, and patient engagement                    | Not a formal research registry. Outputs depend on self-selected members and advocate capacity          | Transferable where patient advocates and communities are trusted partners and have transparent pathways into partnership in research and implementation |
| COST metric                | Clinician-developed patient-reported outcome measurement embedded in workflows | Financial-toxicity research and validation of a 12-item measure                                                | Identification of financial distress and referral to support resources                                         | Screening does not directly reduce financial hardship unless linked to effective interventions         | Transferable where financial navigation and assistance programs can respond to positive screens                                                         |

**Table 1: Rationale for selected health policy implementation cases and transferability considerations.**

| Key feature of the Delaware model        | Policy impact and implementation                                                                                                 |
|------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|
| Delaware Cancer Treatment Program (DCTP) | Provides 24 months of treatment coverage for uninsured residents up to 650% of the federal poverty level. <sup>15</sup>          |
| Universal CRC screening                  | Reimburses providers for colonoscopies for uninsured residents; prioritizes colonoscopy as the preferred modality. <sup>17</sup> |
| Nurse navigator system                   | Established site-based and community-based navigation to reduce barriers to screening and follow-up. <sup>17</sup>               |
| Data-driven targeting                    | Uses Delaware Cancer Registry data to map late-stage diagnoses and target outreach in high-burden zip codes. <sup>15</sup>       |

**Table 2: Key features of the Delaware model and its policy impact and implementation.**

cancer and smoking prevention through the Delaware Health Fund and protected them from diversion to other budget priorities.

The DCC focused on increasing access to screening for underrepresented populations, as screening can result in measurable shifts in diagnostic stage and a reduction in overall incidence.<sup>17</sup> This approach advanced the state beyond traditional awareness campaigns, establishing a public oncology safety net that emulates the objectives of universal health coverage at the state level.

However, there are certain limitations to the generalizability of the Delaware model. While public health officials recognize the long-term success in its reduction of CRC disparities, they note that Delaware is among the smallest states in the nation, which can make it difficult to maintain high statistical power on follow-up analyses and could have contributed an advantage to Delaware's success that more geographically dispersed states do not have.<sup>19</sup> Nonetheless, Delaware's experience points to several potentially transferable features that underpinned its success. For instance, the use of public health registries and databases such as SEER enabled problem identification and localized the disparity to specific geographies and subpopulations.<sup>12,13</sup> A durable, bipartisan governance structure was codified in state law through the protected, long-horizon financing seen in the Tobacco Master Settlement Agreement, which insulated screening, treatment, and navigation budgets from political changes.<sup>18</sup> Statewide nurse navigation linked screening, diagnosis, and treatment for uninsured and high-risk residents.<sup>17</sup> Despite Delaware's small size, the state's commitment to treating expanded cancer access as a sustained budgetary priority enabled these components to translate research into measurable outcomes.

## The DCC's outcomes in health equity

Between 2002 and 2009, after the implementation of the DCC, Delaware observed a substantial reduction in racial disparities in CRC screening and incidence. Prior to the intervention, African American residents had lower screening rates and higher mortality compared to White residents. Over the period following implementation of these initiatives, the screening incidence

rates between the two groups converged, mortality due to CRC among African Americans fell by 42%, and the late-stage diagnosis rates for African Americans were cut by nearly 50% over seven years.<sup>17</sup>

For the \$6 million annual cost of the universal treatment program, the DCC was associated with persistently lower colorectal cancer rates and no notable racial or ethnic differences in incidence or mortality in follow-up reports. Economic analyses also estimated annual savings of \$8.5 million, exceeding the \$6 million annual cost of the universal treatment program, largely through fewer cancer cases and a shift toward less intensive early-stage treatment.<sup>17</sup>

## Value-based care and transformation of practice through the oncology care model and the enhancing oncology model

A second example pathway involves the shift towards value-based care, which is a system that is mainly driven by federal payment models that emphasize quality of patient outcomes over quantity of patients seen. In 2016, the Centers for Medicare & Medicaid Services (CMS) launched the Oncology Care Model (OCM), an episode-based payment model that ultimately operated for six years through June 2022, to test whether payment adjustments could generate savings and improve care for beneficiaries receiving chemotherapy.<sup>20</sup> The OCM's design was directly informed by the 2013 Institute of Medicine research report, "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis", which concluded that the US cancer care system was facing a crisis of quality, cost, and access. The OCM codified several of the IOM's core recommendations and required participating practices to develop care plans that incorporate the IOM's 13-component care management plan, provide patient navigation, ensure 24/7 clinician access with real-time medical records, and deliver guideline-concordant treatment.<sup>21,22</sup>

## Lessons from the Oncology Care Model (OCM)

The OCM was one of the largest-scale experiments in oncology payment reform, involving just under 200 practices and more than 6000 providers.<sup>23</sup> Practices that

participated in the model received a Monthly Enhanced Oncology Services (MEOS) payment to support improvements in practice activities, including adding 24/7 access to clinicians and patient navigators and scaffolding the use of evidence-based guidelines in clinical treatment.<sup>23</sup>

The OCM was associated with a \$616 reduction in total episode payments, but after accounting for MEOS and performance-based payments, the model generated an estimated net loss of \$639 million to Medicare over six years.<sup>24</sup> It was also associated with practice-wide improvements in care delivery.<sup>25,26</sup> One reported benefit identified from the OCM was a ripple effect: practices that redesigned their workflows to meet OCM requirements applied the same high-value processes to their commercially insured patients. For example, studies have shown a \$6286 reduction in total episode spending among commercially insured patients in OCM participating practices.<sup>25</sup> This suggests that federal value-based initiatives, such as the OCM, have a possible spillover effect on the efficiency of the broader healthcare market.

However, we acknowledge the scope of the structural limitations and critiques of the OCM. The model added cost-reduction incentives on top of existing payment structures instead of replacing them, which may have discouraged meaningful care redesign.<sup>27</sup> Its standard 6-month window did not account for the wide variation in treatment durations across cancer types, and because savings were measured against a practice's own historical costs, the potential for continued improvement narrowed over time.<sup>27</sup> In addition, the model also placed financial responsibility for prescription drug costs on practices that had little control over drug pricing and did not account for other major areas of cancer care spending such as surgery or radiation.<sup>27</sup>

Viewed in this light, perhaps the OCM's most durable contribution was the demonstration that paying practices to be accountable for total cost and quality can catalyze meaningful practice transformation (reductions in avoidable utilization, expanded navigation and care coordination, and more deliberate end-of-life care) whose savings can, in principle, be redirected toward expanding access and sustaining oncology services than treated solely as a mechanism for cost reduction. We summarized the OCM's evaluation metrics and respective observed impact and policy lessons in Table 3.

Although the OCM system achieved numerous successes, such as those listed above, the OCM system faced challenges in addressing racial and ethnic disparities, as this was not an initial focus of its blueprint.<sup>28</sup> Many practices found that the administrative burden of reporting quality measures was significant—and could potentially outweigh the benefits.<sup>28</sup> To remedy these

issues, the Enhancing Oncology Model (EOM) was launched.<sup>28</sup>

### The Enhancing Oncology Model (EOM) and health equity benchmarks

The EOM was developed in 2023 to address the limitations identified in OCM outcome evaluations. The model builds on the OCM's foundation by linking payment to equity-related processes and social-risk indicators (Fig. 2).<sup>29</sup> Whether these features improve equity outcomes has not yet been demonstrated. Key policy shifts and addenda of the EOM are outlined below in Table 4.

The EOM represents a new step in the US cancer policy plan. The EOM's main strategies help improve groundshot delivery by shaping federal reimbursement policies. By linking reimbursement to equity-related processes and social-risk indicators, the model is intended to support patients facing greater social risk but demonstrated equity outcomes are not yet available. Comprehensive assessments of the EOM are still underway, and effects on spending, quality, access, and equity outcomes remain under evaluation.<sup>30</sup> These initial findings support the view that value-based oncology payment models may have potential drawbacks, including administrative burdens, and could lead physicians to take actions that discriminate against medically complex patients, with the risk that short-term cost targets might obstruct long-term investments in vital areas such as equity, navigation, and supportive care. Thus, it remains important to conduct rigorous, transparent evaluations through disaggregated analyses by race, ethnicity, rurality, and insurance status to ensure that the EOM's equity framework is effectively implemented in practice. These early findings should therefore be interpreted with caution until quality, equity, access, and administrative burden outcomes are fully evaluated.

### Grassroots implementations: COLONTOWN and the COST metric

The above are illustrative examples of how health services research can be translated into tangible impact through state legislation and federal payment reform. Translation from research to practice also occurs outside formal state and federal policy channels, and can be driven by individual institutions, clinicians, and patient advocacy groups.<sup>31</sup> Two examples of how evidence generated in academic settings can be operationalized at the grassroots level are found in the advocacy community for patients with colorectal cancer and the clinical adoption of financial toxicity screening measures. These examples are included to show how implementation can also arise from community knowledge and clinical measurement, not only from formal legislation or payment policy.

| OCM evaluation metrics                   | Observed impact and policy lessons                                                                                                                                                                                                                                       |
|------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Episode payments and net Medicare impact | Episode payments decreased by \$616 per episode overall and by more than \$1200 per episode in the final year; after including MEOS and performance-based payments, the model generated an estimated net loss of \$639 million to Medicare over six years. <sup>24</sup> |
| Commercial spillover                     | Significant cost reductions (–\$6286 per episode) for commercially insured patients at participating sites. <sup>25</sup>                                                                                                                                                |
| End-of-Life Care                         | Decreased costs in the last 90 days of life and fewer emergency department visits in the last 30 days. <sup>26</sup>                                                                                                                                                     |
| Practice transformation                  | Increased ratios of medical assistants, navigators, and social workers to support psychosocial needs. <sup>23</sup>                                                                                                                                                      |

**Table 3: Oncology Care Model Evaluation metrics and respective impact and lessons for future policy.**

## The COLONTOWN community

COLONTOWN is a private, global, patient- and caregiver-led colorectal cancer community founded in 2011 to address gaps in information, education, and psychosocial support.<sup>32</sup> Hosted on a private social media platform, COLONTOWN comprises thousands of members who participate in over 100 moderated subgroups (“neighborhoods”) covering all aspects of the colorectal cancer experience.

Neighborhoods include those organized around shared clinical and disease characteristics, such as stage, tumor location, treatment type, biomarkers, and metastatic sites. COLONTOWN’s main goal is to provide patients and caregivers with accessible, evidence-based information and a supportive and confidential environment to navigate diagnosis, treatment, and survivorship. Its educational arm, COLONTOWN University, extends this mission through translating both emerging research and community-identified knowledge gaps into publicly available resources, including DocTalks, the CRC 101 Learning Center, and practical

guides such as the Second Opinion Guide, which translate complex oncology evidence into actionable knowledge.<sup>33</sup>

Within moderated COLONTOWN subgroups, members engage in ongoing peer-to-peer discussions over the course of their care: from diagnosis through treatment and survivorship or end of life, creating a longitudinal, real-world view, capturing evolving patient experiences, decision-making, and outcomes over time. Through informal pattern recognition by community moderators, rather than any formal or systematic process, recurring themes become visible, which inform both educational content development and subsequent focus.

While COLONTOWN is not designed as a research initiative, these organic discussions consistently surface challenges that extend beyond individual care. For example, community-informed observations have identified gaps in biomarker test result communication and specific aspects of treatment delivery, such as patient-led 5FU pump self-disconnect. These insights

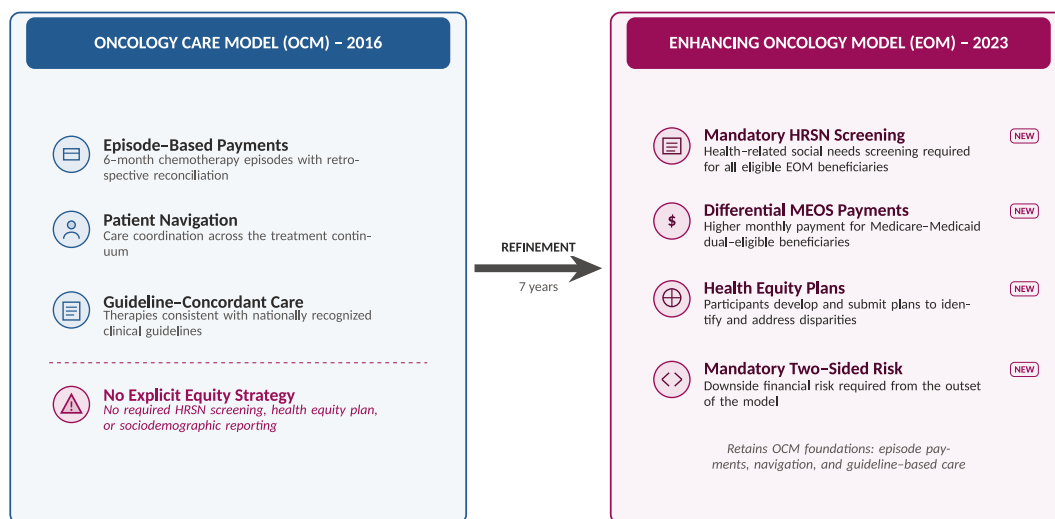


**Fig. 2: Evolution from the Oncology Care Model (OCM) to the Enhancing Oncology Model (EOM).** The OCM (2016) established a foundation for value-based oncology care through episode-based payments, patient navigation, and guideline-concordant care, but lacked an explicit model-wide equity strategy and did not require health-related social needs screening or participant health equity plans. The EOM (2023) retains these foundations while requiring health-related social needs screening for all eligible EOM beneficiaries, providing higher Monthly Enhanced Oncology Services payments for Medicare-Medicaid dual-eligible beneficiaries, requiring participants to develop and submit health equity plans, and mandating two-sided financial risk from the outset of the model. These changes embed explicit equity-focused requirements within the payment model.

| EOM policy shift                  | Impact                                                                                                                                                                                                                                                                                                                                    |
|-----------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Mandatory social need screening   | Practices must screen patients for health-related social needs (HRSNs), such as food, housing, and transportation. <sup>28</sup>                                                                                                                                                                                                          |
| Adjusted payments for social risk | The model provides a higher MEOS payment for patients who are dually eligible for Medicare and Medicaid to account for the higher cost of managing social complexity. <sup>28</sup>                                                                                                                                                       |
| Two-sided risk                    | Unlike the early OCM, the EOM requires practices to take on downside risk (i.e., financial liability to CMS if actual spending exceeds the target benchmark, in contrast to one-sided “upside-only” models in which practices share only in savings), forcing a more rigorous focus on cost-effective care from the outset. <sup>25</sup> |
| Health equity plans               | Participants are required to submit and implement formal plans to address disparities within their patient populations. <sup>28</sup>                                                                                                                                                                                                     |

**Table 4: Enhancing Oncology Model policy shifts and evolutions and their impacts.**

have been further explored through survey-based studies and presented as abstracts and posters at major GI oncology meetings, providing a pathway to bring patient-derived experiential knowledge into the broader oncology community.<sup>34,35</sup>

Patient advocates who are active members and leaders within COLONTOWN may extend these community-informed perspectives into formal research and policy settings. These individuals, often self-selected based on their interest, availability, leadership within the community, and relevant professional or advocacy experience, contribute to national and international efforts including participation in National Cancer Institute Colon and Rectal Anal Task Forces, Cancer Grand Challenges projects,<sup>36,37</sup> collaborative efforts such as CORRECT as well as ASCO guideline and other consortium activities.<sup>38–40</sup> In these roles, advocates draw not only on their personal experiences but also on insights shaped through engagement within COLONTOWN. In addition, COLONTOWN members have directly contributed to clinical trial development through community-engaged research approaches. For example, in NCTN studies such as JANUS and ERASur, patient advocates collaborated with trial investigators to design community surveys, enabling broader member participation and the incorporation of patient preferences into trial design.<sup>41–43</sup> Feedback from these surveys was shared with investigators alongside NCI Task Force and cooperative group input to help advance the JANUS and ERASur trial concepts.<sup>42,43</sup>

Together, these examples illustrate how COLONTOWN, while primarily focused on support and education, can also serve broader roles. COLONTOWN can act as an informal yet organized ecosystem where gaps in care become visible through shared experiences and can generate patient-informed insights grounded in real-world challenges. And in some cases, these insights extend to research and implementation efforts, thereby complementing traditional clinical and scientific approaches.

*The COST (Comprehensive Score for Financial Toxicity) metric*  
A related example is the clinical adoption of the Comprehensive Score for Financial Toxicity (COST).

Financial toxicity is often understood as the material, psychological, and behavioral harms that patients with cancer experience as a result of the direct and indirect costs of treatment, including out-of-pocket expenses, lost income, medical debt, and cost-related non-adherence to care. The COST score constitutes a 12-item patient-reported outcome measure that assesses financial distress in patients with cancer (including a global family-hardship item that is not included in the score).<sup>44,45</sup> The COST was developed by de Souza and colleagues in direct response to a growing body of population health research documenting the economic burden of cancer care, including studies showing that insured patients with cancer depleted savings and did not adhere to treatment due to out-of-pocket costs.<sup>45–48</sup> Drawing on this evidence, de Souza et al. developed a validated patient-reported outcome measure to quantify financial distress, capturing concerns about expenses, employment, savings, and family financial stability.

Since its inception, the COST measure has been integrated into routine clinical workflows at institutions such as Memorial Sloan Kettering Cancer Center and many others, where it is embedded directly in the electronic health record system.<sup>49,50</sup> In current practice, COST screening is increasingly leveraged to guide targeted interventions, including referrals to patient financial services, financial navigation programs, institutional assistance, and enrollment support for local state and federal resources. This illustrates a pathway in which population health research exposed a problem and clinician-led grassroots efforts produced a tool to measure it — without federal or state involvement. COST is a screening and measurement tool. It does not, by itself, reduce financial hardship unless positive screens trigger effective interventions, such as financial navigation, institutional assistance, or enrollment support for available resources.

These grassroots examples share a common thread with the broader arc of cancer care reform that is fueled by research. Just as Dr. Harold Freeman’s patient navigation model began as a community-based intervention in Harlem before being codified into federal law, adopted as a national accreditation standard, and embedded into both the Delaware Cancer Consortium and the OCM’s practice requirements, the work of patient

advocacy organizations like COLONTOWN and the development of tools like the COST metric demonstrate that research translation can move beyond simply top-down policy. It can emerge from the ground up, and as the history of patient navigation demonstrates, grassroots implementation can inform and shape policy frameworks discussed throughout this article.

## Policy lessons for US cancer care

The success achieved in cases involving the Delaware Cancer Consortium, federal value-based care models such as OCM and EOM, and grassroots efforts like COLONTOWN and the COST metric highlights several critical themes that inform efforts to strengthen the US Cancer Care System. Across all the cases that we discussed, the main policy lesson we want to highlight is that effective implementation links a defined care gap to a specific lever, infrastructure, and measurement that is fundamentally based on equity.

## Translating evidence into care

A common lesson across all three cases is that success in oncology healthcare systems may depend on the institutions' capacity to translate evidence into daily practice. Delaware reduced CRC disparities by operationalizing initiatives that focus on screening access, treatment coverage, and navigation. In terms of transferability, Delaware is the clearest example of moving from registry evidence to legislation, protected funding, coverage, and delivery infrastructure. In the federal space, the OCM directly codified recommendations from the 2013 IOM report into practice guidelines, demonstrating how expert consensus research can be translated into frameworks for structures such as payment policy. Through consistently converting evidence-supported interventions into standard care at scale, such gains from initiatives can compound, helping develop a more coordinated national cancer system.

## Equity through infrastructure

Another critical theme is that equity in cancer care systems requires durable infrastructure. In the Delaware model, disparity reduction was made possible through the state's formation of formal mechanisms, including coverage for uninsured residents, nurse navigation, and registry-guided outreach, all of which reduce the structural barriers that high-burden populations can face. This example underscores that equitable cancer outcomes depend on whether systems include the administrative and financial components that are needed to deliver services across diverse factors such as geography, race/ethnicity, and insurance status.<sup>51,52</sup>

## Incentives and quality

The incentive landscape is also critical in oncology care. For instance, value-based models like the OCM and

EOM attempt to move oncology away from reimbursement structures that often only reward service volume without emphasizing quality.

Thus, these newly updated value-based models focus on paying for navigation, care coordination, social needs assessments, and more deliberate end-of-life planning. This encourages practices to invest in components of care that are often undervalued in traditional reimbursement systems. For OCM and EOM, the transferable lesson is not the exact benchmark design, but the utilization of payment to support work that fee-for-service often leaves unfunded. In doing so, they normalize quality and centering the patient as reimbursable priorities.

The experience of the OCM and EOM also suggests that incentives are most effective when they are tied to risk-adjusted total cost of care benchmarks instead of fee-for-service line items. These incentives are enhanced when paired with prospective per-patient enhanced services payments, such as MEOS, that underwrite navigation and care coordination. There should also be an overarching, explicit linkage to quality and equity metrics, including disparities-reduction plans, so that practices cannot achieve savings by avoiding medically or socially complex patients.

## Sustaining reform

These examples show that meaningful cancer system reform must be sustained through long-term political and financial commitment. The benefits seen in Delaware required continued legislative backing and funding. Likewise, the evolution from OCM to EOM illustrates that payment reform is iterative and must be refined over time to address shortcomings such as administrative burden and inequities in health care. Thus, policy continuity is a critical factor in the longevity of these programs. This commitment has depended on deliberate coalition-building.

For instance, in Delaware, critical actors such as bipartisan legislative champions, engaged political leaders, a statutorily established cancer consortium, and local clinicians translated disparities into a shared political narrative. At the federal level, the OCM and EOM have required iterative engagement with community oncology networks, professional societies, and patient advocacy groups to co-design model parameters and keep practices in discussion across successive administrations. These experiences suggest that durable reform is rarely achieved by policy text alone and requires a structured governance forum, transparent public reporting of outcomes, and protected funding streams that outlast individual political cycles.

## Engaging actors beyond medicine

Another critical theme is that the successful implementation of cancer health services depends on interdisciplinary collaboration with actors outside the clinic,

such as elected officials, state agencies, and advocacy coalitions.<sup>31,53–55</sup> Indeed, as Krieger and colleagues argue, health outcomes are fundamentally influenced by political ideology and the policies that actors can enact.<sup>53,56–58</sup> In cancer, these political determinants are associated with preventable outcomes such as premature cancer mortality.<sup>56,57</sup> The Delaware Cancer Consortium is a concrete example of these political determinants at work. The program's success in reducing racial disparities in colorectal cancer was driven by gubernatorial leadership, legislative funding, population health specialists, and oncologists working hand in hand.

Engagement across these disparate actors was engineered through several deliberate mechanisms. For instance, registry and SEER data were used to localize the disparity to specific subpopulations, thereby enabling the development of a district-level political narrative that legislators could own. In addition, Governor Minner's initial task force co-authored a written four-year plan with measurable goals, giving stakeholders ownership of the roadmap. Senate Bill 102 then embedded formal seats for oncologists, public health officials, advocates, and legislators into state code, which insulated participation from administrative turnover, and earmarked Tobacco Master Settlement funding ensured that there were no competing budget issues.

The OCM and EOM also show that the uptake of health services interventions and their respective efficiencies can be improved when political actors align federal payment policy incentives around critical tenets such as social needs screening and formal health equity planning. At the federal level, CMMI cultivated engagement of external actors through analogous mechanisms, including requests for studies and information, visible responsiveness to professional society and community oncology feedback, most notably the pause and redesign of the Oncology Care First proposal into EOM after objections to its downside risk structure, and per-beneficiary Monthly Enhanced Oncology Services payments that underwrote the navigation, care-coordination, and 24/7 access infrastructure practices needed to participate, thus effectively paying for capabilities the model required. For these programs, advocacy among experts from diverse fields is the driving force behind tangible, widespread change, but such advocacy is sustained only when stakeholders are given protected resources and influence over the program's design.

This principle extends from formal policy or medical backgrounds to grassroots actors as well. As discussed earlier, organizations such as COLONTOWN demonstrate how incorporating perspectives from patient advocacy communities and their stakeholders can accelerate the dissemination of emerging evidence and contribute to clinical trial design. In this sequence, COLONTOWN shows that patient communities can

function as implementation infrastructure, even when formal policy channels are slow or absent.

Simultaneously, the adoption of the COST metric shows how academic research can produce clinical tools that can inform practice without legislative or regulatory mandates. Recognizing and supporting these bottom-up pathways is essential to building a cancer care system that translates evidence efficiently at every level of impact. The COST program demonstrates that solutions to issues of financial toxicity should be designed by fundamentally linking screening to navigation, institutional assistance, or benefit-enrollment support.

### Persistent challenges, limitations, and transferability

These illustrative examples are by no means exhaustive and differ in evidentiary maturity. Delaware has long-term population-level outcome data; OCM has formal evaluations; EOM remains under active evaluation; and COLONTOWN and COST primarily demonstrate community engagement and measurement rather than definitive population-level outcome improvement. The examples are also US-centered and may not transfer directly to other settings in the Americas, where financing, federalism, workforce capacity, data infrastructure, and patient advocacy ecosystems differ.

While the US has made progress in oncology care reform, several challenges still threaten the sustainability of such initiatives. Firstly, financial toxicity, the cumulative economic burden of cancer care, from visits and diagnostics to drugs and surgery, remains an increasingly recognized determinant of survival.<sup>45,48,50</sup> In one longitudinal study, more than 40% of patients depleted their entire life assets within two years of a cancer diagnosis, leading to decreased treatment adherence and a higher risk of mortality.<sup>59,60</sup> Screening for financial toxicity is becoming more common, but only a fraction of those who screen positive ultimately receive an intervention.<sup>49</sup>

While this is a severe issue, progress is being made to mitigate its impacts. The success of the "Financial Toxicity Tumor Board" at Atrium Health Levine Cancer Institute (which has saved patients over \$10 million in copays and \$393 million in pharmaceutical costs) offers a potential model for such systemic change.<sup>61</sup> Interdisciplinary collaboration across government agencies and cancer-focused non-profit organizations has led to the development of the Interagency Consortium to Promote Health Economics on Cancer, which synthesizes research at scale to inform clinical practice and policy and improve access to more affordable cancer care.<sup>62</sup>

The sustainability of critical networks that drive such research, such as the NCI's National Clinical Trials Network, is increasingly threatened by stagnant federal funding. NCI reimbursement rates have not kept pace

with the rise of trial execution costs due to regulatory complexity.<sup>63</sup> This forces many academic centers to subsidize trials through philanthropic funds or institutional reserves. To maintain the momentum of the NCTN and NCORP, future policies should streamline administrative requirements and ensure that federal funding adequately covers the true cost of community-based research.

We suggest a shift towards systems-level benchmarks associated with improvements in cancer survival to monitor progress. These include Medicaid coverage and uptake under the Affordable Care Act's (ACA) Medicaid expansion, which has been associated with reductions in the uninsurance rate among patients with cancer, earlier-stage diagnoses, and narrowing (though not elimination) of racial and socioeconomic disparities in access to timely oncologic care, and expansion rates,<sup>4,64</sup> the demographic representation of patients in clinical trials, reductions in the time from diagnosis to treatment, and gross savings against benchmarks in value-based care models such as the EOM.

## Conclusion

The US cancer burden is projected to rise sharply in the coming years. Biomedical innovations will continue to offer hope for new treatments, but the primary challenge for the US cancer care system is one of implementation and equity. The policy cases reviewed here from Delaware, the evolution of federal value-based care, and grassroots efforts like COLONTOWN and the COST metric, suggest that the research-policy disconnect can be bridged.

Groundshot efforts in the US are critical initiatives and can contribute to positive financial and clinical impact. By dedicating resources to delivery, engaging in collaborative advocacy, and leveraging federal policy levers such as Medicaid and the EOM, the US can build a more resilient oncology infrastructure. The policy cases reviewed here suggest that this goal is more achievable when cancer research and cancer policy remain strategically integrated across every level of the healthcare system, while future work tests which components transfer across regions, payers, cancer types, and patient communities.

## Contributors

NG and ECD conceptualised the manuscript. NG and MG led writing of the original draft. NG conducted visualisation. All authors provided supervision and writing-review and editing.

## Declaration of interests

MG is a part-time contractor with Paltown, the non-profit that supports COLONTOWN. LS, SR, JSC, and TSF are employees of PALTOWN Development Foundation, the non-profit that supports COLONTOWN. FYM reports receiving honoraria from AstraZeneca for an invited educational lecture and for reviewing radiation oncology educational material. PLN reports grants or contracts from Bayer, Astellas, and Janssen paid to his institution; consulting fees from Bayer, Novartis, Blue Earth, BSCI, Nanocan, MDxHealth, Janssen, and Amgen paid to

him; and stock or stock options in Nanocan, Reversal Therapeutics, and Stratagen Bio.

## Acknowledgements

ECD is funded in part through the Prostate Cancer Foundation Young Investigator Award.

## References

- Rankin NM, McGregor D, Stone E, et al. Evidence-practice gaps in lung cancer: a scoping review. *Eur J Cancer Care*. 2018;27(2): e12588. <https://doi.org/10.1111/ecc.12588>.
- Buchan H. Gaps between best evidence and practice: causes for concern. *Med J Aust*. 2004;180(S6):S48–S49. <https://doi.org/10.5694/j.1326-5377.2004.tb05944.x>.
- Osarogiabon RU. Overcoming the implementation gap in multidisciplinary oncology care programs. *J Oncol Pract*. 2016;12(10):888–891. <https://doi.org/10.1200/JOP.2016.014688>.
- Dee EC, Pierce LJ, Winkfield KM, Lam MB. In pursuit of equity in cancer care: moving beyond the Affordable Care Act. *Cancer*. 2022;128(18):3278–3283. <https://doi.org/10.1002/cncr.34346>.
- Dee EC, Arega MA, Yang DD, et al. Disparities in refusal of locoregional treatment for prostate adenocarcinoma. *JCO Oncol Pract*. 2021;17(10):e1489–e1501. <https://doi.org/10.1200/OP.20.00839>.
- Freeman HP, Rodriguez RL. The history and principles of patient navigation. *Cancer*. 2011;117(15 Suppl):3539–3542. <https://doi.org/10.1002/cncr.26262>.
- Chen M, Wu VS, Falk D, Cheatham C, Cullen J, Hoehn R. Patient navigation in cancer treatment: a systematic review. *Curr Oncol Rep*. 2024;26(5):504–537. <https://doi.org/10.1007/s11912-024-01514-9>.
- Saslow D, Solomon D, Lawson HW, et al. American Society for Colposcopy and Cervical Pathology, and American Society for Clinical Pathology screening guidelines for the prevention and early detection of cervical cancer. *CA Cancer J Clin*. 2012;62(3):147–172. <https://doi.org/10.3322/caac.21139>.
- Komajda M, Lapuerta P, Hermans N, et al. Adherence to guidelines is a predictor of outcome in chronic heart failure: the MAHLER survey. *Eur Heart J*. 2005;26(16):1653–1659. <https://doi.org/10.1093/eurheartj/ehi251>.
- McCullough ML, Patel AV, Kushi LH, et al. Following cancer prevention guidelines reduces risk of cancer, cardiovascular disease, and all-cause mortality. *Cancer Epidemiol Biomarkers Prev*. 2011;20(6):1089–1097. <https://doi.org/10.1158/1055-9965.EPI-10-1173>.
- Shapiro DW, Lasker RD, Bindman AB, Lee PR. Containing costs while improving quality of care: the role of profiling and practice guidelines. *Annu Rev Public Health*. 1993;14:219–241. <https://doi.org/10.1146/annurev.pu.14.050193.001251>.
- Odom-Walker K. Delaware cancer mortality continues to decrease; public health releases annual cancer report. *Dela J Public Health*. 2018;4(4):31–33. <https://doi.org/10.32481/djph.2018.07.005>.
- Delaware cancer incidence and mortality rates. Delaware Division of Public Health; 2005.
- Chapter - Delaware general assembly. <https://legis.delaware.gov/SessionLaws/Chapter?id=18752>. Accessed April 5, 2026.
- Brown H, Petrelli NJ. The Delaware cancer consortium. *Dela J Public Health*. 2017;3(3):8–9. <https://doi.org/10.32481/djph.2017.06.003>.
- Mutebi M, Dehar N, Nogueira LM, Shi K, Yabroff KR, Gyawali B. Cancer groundshot: building a robust cancer control platform in addition to launching the cancer moonshot. *Am Soc Clin Oncol Educ Book*. 2022;42(42):1–16. [https://doi.org/10.1200/EDBK\\_359521](https://doi.org/10.1200/EDBK_359521).
- Grubbs SS, Polite BN, Carney J, et al. Eliminating racial disparities in colorectal cancer in the real world: it took a village. *J Clin Oncol*. 2013;31(16):1928–1930. <https://doi.org/10.1200/JCO.2012.47.8412>.
- How Delaware shrunk its cancer death rate over the last two decades. <https://www.advisory.com/daily-briefing/2022/03/08/patient-navigators>. Accessed April 5, 2026.
- Ng D, Belinske S, Hollinger D, et al. Sustaining improvements in colorectal cancer across Delaware: a look at racial disparities a decade later. *Dela J Public Health*. 2024;10(3):38–44. <https://doi.org/10.32481/djph.2024.08.10>.
- Vogel WH. The oncology care model for advanced practitioners. *J Adv Pract Oncol*. 2017;8(6):655–656.

- 21 Oncology Care Model | CMS. <https://www.cms.gov/newsroom/fact-sheets/oncology-care-model>. Accessed April 6, 2026.
- 22 Committee on improving the quality of cancer care: addressing the challenges of an aging population, board on health care services, Institute of Medicine. In: Levit L, Balogh E, Nass S, Ganz PA, eds. *Delivering high-quality cancer care: charting a new course for a System in crisis*. National Academies Press (US); 2013. <http://www.ncbi.nlm.nih.gov/books/NBK202148/>. Accessed April 6, 2026.
- 23 Kline RM, Brown M, Buescher N, et al. The Centers for Medicare & Medicaid Services oncology care model halfway through: perspectives from diverse participants. *J Natl Cancer Inst*. 2019;111(8):764–771. <https://doi.org/10.1093/jnci/djz072>.
- 24 Brooks GA, Trombley M, McClellan S, et al. The oncology care model and Medicare payments, utilization, and quality. *JAMA*. 2026;335(15):1332–1340. <https://doi.org/10.1001/jama.2026.2075>.
- 25 Brooks GA, Keating NL. Oncology care model and ripple effects of value-based care. *J Clin Oncol*. 2025;43(2):115–117. <https://doi.org/10.1200/JCO.24.01983>.
- 26 Colligan EM, Ewald E, Ruiz S, Spafford M, Cross-Barnet C, Parashuram S. Innovative oncology care models improve end-of-life quality, reduce utilization and spending. *Health Aff*. 2017;36(3):433–440. <https://doi.org/10.1377/hlthaff.2016.1303>.
- 27 Thomas CA, Ward JC. The oncology care model: a critique. *Am Soc Clin Oncol Educ Book*. 2016;35:e109–e114. [https://doi.org/10.1200/EDBK\\_156883](https://doi.org/10.1200/EDBK_156883).
- 28 Patel TA, Jain B, Parikh RB. The enhancing oncology model: leveraging improvement science to increase health equity in value-based care. *J Natl Cancer Inst*. 2023;115(2):125–130. <https://doi.org/10.1093/jnci/djac194>.
- 29 Chong A, Witherspoon E, Honig B, Ela E, Cavanagh H, Strawbridge L. Reflections on the oncology care model and looking ahead to the enhancing oncology model. *JCO Oncol Pract*. 2022;18(10):685–690. <https://doi.org/10.1200/OP.22.00329>.
- 30 EOM (Enhancing Oncology Model) | CMS. <https://www.cms.gov/priorities/innovation/innovation-models/eom>. Accessed April 19, 2026.
- 31 Magsanoc-Alikpala MJK, Ylanan AMD, Rivera-Montales C, Magsanoc JM, Eala MAB, Dee EC. Breast cancer survivor-led patient advocacy: the ICanServe experience from the Philippines. *Lancet Oncol*. 2025;26(3):287–289. [https://doi.org/10.1016/S1470-2045\(24\)00632-6](https://doi.org/10.1016/S1470-2045(24)00632-6).
- 32 Home. COLONTOWN. <https://colontown.org/>. Accessed April 19, 2026.
- 33 Learn. COLONTOWN. <https://colontown.org/learn/>. Accessed April 19, 2026.
- 34 Clauer JS, Nesathurai A, George M. Communication of cancer biomarker testing results: what patients need. *J Clin Oncol*. 2025;43(4-suppl):51. <https://doi.org/10.1200/JCO.2025.43.4-suppl.51>.
- 35 Clauer JS, Gellash P, Vangilder M, Runfola S, George M. 5-FU freedom: patient perspectives from COLONTOWN on the practice of pump self-disconnect. *J Clin Oncol*. 2026;44(2-suppl):102. <https://doi.org/10.1200/JCO.2026.44.2-suppl.102>.
- 36 Alonso S, Raghav K, Morris VK, et al. Framework for cancer evolution profiling and interception in colorectal cancer: ASCEND-CRC program. *Cancer Cell*. 2026;44(3):455–459. <https://doi.org/10.1016/j.ccell.2025.12.016>.
- 37 Fritz CDL, George M, Carethers JM, Cao Y. Approach toward early detection and prevention of early-onset colorectal cancer. *Annu Rev Med*. 2026;77(1):147–159. <https://doi.org/10.1146/annurev-med-043024-025918>.
- 38 Garfinkle R, George M, Jethwa K, et al. Development of a CORE outcome set for clinical trials of RECTal cancer treatment: protocol for the CORRECT initiative. *BMJ Open*. 2026;16(4):e103072. <https://doi.org/10.1136/bmjopen-2025-103072>.
- 39 Kennecke HF, Auer R, Cho M, et al. NCI rectal-anal task force consensus recommendations for design of clinical trials in rectal cancer. *J Natl Cancer Inst*. 2023;115(12):1457–1464. <https://doi.org/10.1093/jnci/djad143>.
- 40 Scott AJ, Kennedy EB, Berlin J, et al. Management of locally Advanced Rectal Cancer: ASCO Guideline. *J Clin Oncol*. 2024;42(28):3355–3375. <https://doi.org/10.1200/JCO.24.01160>.
- 41 Hitchcock KE, Miller ED, Shi Q, et al. Alliance for Clinical Trials in Oncology (Alliance) trial A022101/NRG-G1009: a pragmatic randomized phase III trial evaluating total ablative therapy for patients with limited metastatic colorectal cancer: evaluating radiation, ablation, and surgery (ERASur). *Res Sq*. 2023. <https://doi.org/10.21203/rs.3.rs-3773522/v1>.
- 42 Carroll G. *Input from Patient Support Groups are A Critical Component of Clinical Trial Design*. ASCO Daily News; 2021. <https://dailynews.ascopubs.org/do/input-patient-support-groups-critical-component-clinical-trial-design>.
- 43 George M, Smith JJ, Miller ED, Romesser PB, Seybold N. Impact and utility of COLONTOWN, an online CRC patient and caregiver support group in clinical trial design. *J Clin Oncol*. 2021;39(3-suppl):140. <https://doi.org/10.1200/JCO.2021.39.3-suppl.140>.
- 44 de Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity patient-reported outcome in cancer: the COST measure. *Cancer*. 2014;120(20):3245–3253. <https://doi.org/10.1002/cncr.28814>.
- 45 Dee EC, Chino F. Financial hardship in cancer care—the need to define and intervene on actionable metrics. *JAMA Netw Open*. 2022;5(7):e2223149. <https://doi.org/10.1001/jamanetworkopen.2022.23149>.
- 46 Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist*. 2013;18(4):381–390. <https://doi.org/10.1634/theoncologist.2012-0279>.
- 47 Neugut AI, Subar M, Wilde ET, et al. Association between prescription co-payment amount and compliance with adjuvant hormonal therapy in women with early-stage breast cancer. *J Clin Oncol*. 2011;29(18):2534–2542. <https://doi.org/10.1200/JCO.2010.33.3179>.
- 48 Kazzi B, Chino F, Kazzi B, et al. Shared burden: the association between cancer diagnosis, financial toxicity, and healthcare cost-related coping mechanisms by family members of non-elderly patients in the USA. *Support Care Cancer*. 2022;30(11):8905–8917. <https://doi.org/10.1007/s00520-022-07234-9>.
- 49 Budhu JA, Tin AL, Steele M, et al. Screened but still struggling: challenges in delivering financial assistance after positive financial toxicity screens. *JCO Oncol Pract*. 2025;21(12):1868–1875. <https://doi.org/10.1200/OP-25-00870>.
- 50 Narayan A, Lapen K, Dee EC, Thom B, Aviki EM, Chino F. Screening for financial toxicity and health-related social risks in patients with GI cancer: results from a large cancer center. *JCO Oncol Pract*. 2026;22:868–876. <https://doi.org/10.1200/OP-25-00218>.
- 51 Dee EC, Todd R, Ng K, et al. Racial disparities in prostate cancer in the UK and the USA: similarities, differences and steps forwards. *Nat Rev Urol*. 2025;22:223–234. <https://doi.org/10.1038/s41585-024-00948-x>.
- 52 Dess RT, Hartman HE, Mahal BA, et al. Association of black race with prostate cancer-specific and other-cause mortality. *JAMA Oncol*. 2019;5(7):975–983. <https://doi.org/10.1001/jamaoncol.2019.0826>.
- 53 Dee EC, Eala MAB, Robredo JPG, et al. Leveraging national and global political determinants of health to promote equity in cancer care. *J Natl Cancer Inst*. 2023;115(10):1157–1163. <https://doi.org/10.1093/jnci/djad123>.
- 54 Patel MS, Pramesh CS, Sanford NN, et al. Machine learning reveals country-specific drivers of global cancer outcomes. *Ann Oncol*. 2026;37(4):565–573. <https://doi.org/10.1016/j.annonc.2025.11.014>.
- 55 Dee EC, Wu JF, Feliciano EJG, et al. National cancer system characteristics and global pan-cancer outcomes. *JAMA Oncol*. 2025;11(6):650–654. <https://doi.org/10.1001/jamaoncol.2025.0473>.
- 56 Krieger N, Moallem S, Cowger TL, et al. Political determinants of US states' screening-eligible cancer stage at diagnosis and premature cancer mortality. *JNCI Cancer Spectr*. 2025;9(5):pkaf073. <https://doi.org/10.1093/jncics/pkaf073>.
- 57 Krieger N, Moallem S, Chen JT, et al. Politicians, power, and the people's health: US elections and state health outcomes, 2012–2024. *Health Aff Sch*. 2024;2(12):qxae163. <https://doi.org/10.1093/haschl/qxae163>.
- 58 Ho CJ, Khalid H, Skead K, Wong J. The politics of universal health coverage. *Lancet*. 2022;399(10340):2066–2074. [https://doi.org/10.1016/S0140-6736\(22\)00585-2](https://doi.org/10.1016/S0140-6736(22)00585-2).
- 59 Gilligan AM, Alberts DS, Roe DJ, Skrepnek GH. Death or debt? National estimates of financial toxicity in persons with newly-diagnosed cancer. *Am J Med*. 2018;131(10):1187–1199.e5. <https://doi.org/10.1016/j.amjmed.2018.05.020>.
- 60 Jagsi R, Ward KC, Abrahamse PH, et al. Unmet need for clinician engagement regarding financial toxicity after diagnosis of breast

- cancer. *Cancer*. 2018;124(18):3668–3676. <https://doi.org/10.1002/cncr.31532>.
- 61 Knight TG, Hensel C, Blackley K, et al. The financial toxicity tumor board: 5-year update on practice and a guide to implementation. *J Natl Compr Canc Netw*. 2025;23(5):164–168. <https://doi.org/10.6004/jnccn.2025.7010>.
- 62 Pisu M, Martin MY. Financial toxicity: a common problem affecting patient care and health. *Nat Rev Dis Primers*. 2022;8(1):7. <https://doi.org/10.1038/s41572-022-00341-1>.
- 63 Lieu CH, Sanoff HK. Ensuring the Future of Cooperative Group cancer clinical trials: a call for comprehensive support and prioritization. *JCO Oncol Pract*. 2026;0(0):OP2500927. <https://doi.org/10.1200/OP-25-00927>.
- 64 Takvorian SU, Oganisian A, Mamtani R, et al. Association of Medicaid expansion under the affordable care ACT with insurance status, cancer stage, and timely treatment among patients with breast, colon, and lung cancer. *JAMA Netw Open*. 2020;3(2):e1921653. <https://doi.org/10.1001/jamanetworkopen.2019.21653>.