

Addressing Financial Toxicity for Patients **CAPC** and Families Facing Serious Illness

Position from the Center to Advance Palliative Care (CAPC)

CAPC recognizes the untenable financial toll that serious illness takes on patients and families. While the problem has deep roots, we recommend requirements for screening, financial navigation, and greater accountability for charity care as policies to mitigate the issue.

The Problem of ‘Financial Toxicity’

“Financial toxicity” is a term used to characterize the difficulties that patients and their caregivers face related to the high costs of their medical care.¹ First used by researchers at the Duke Cancer Institute, financial toxicity encompasses the physical, material, and financial hardships that can accompany expensive treatment for serious illness.² Because the US health care system is uniquely marked by excessive pricing for both services and medications, prevalence of financial distress for patients and caregivers can climb as high as 53%, depending on diagnosis.³⁻⁶ Some studies have found disparities in serious illness-related financial challenges associated with gender, race, and income status.⁷⁻¹⁰

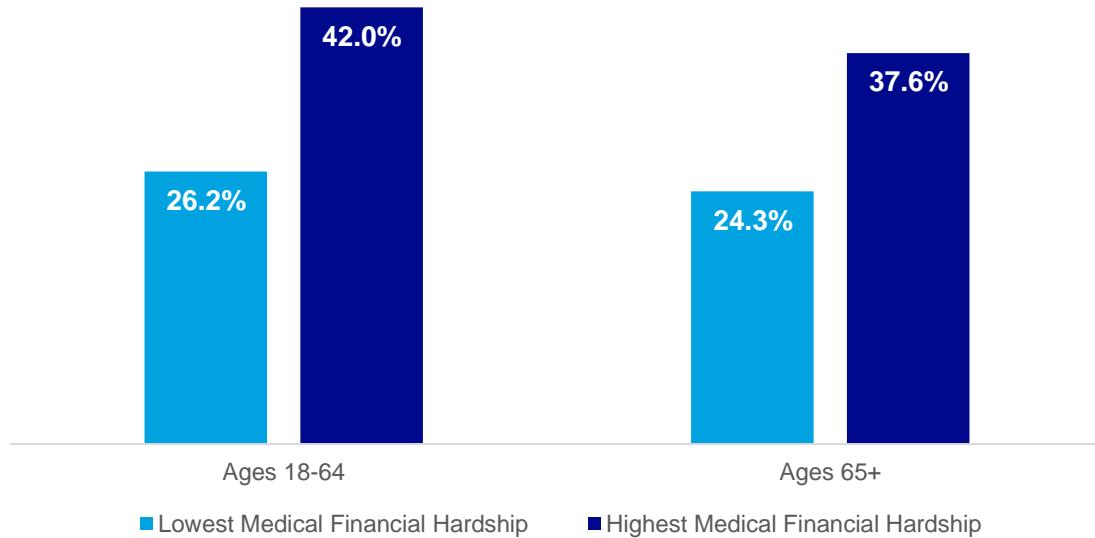
Financial toxicity manifests in medical debt, insufficient assets and savings for emergency expenses, low credit scores, and bankruptcy.¹¹⁻¹⁵ Living with a serious illness can also impact employment, as some patients and caregivers find it harder to maintain employment or stay locked in jobs to maintain health insurance.¹⁶⁻¹⁸ This has a dramatic effect on material quality of life; many patients experiencing financial toxicity report an inability to afford housing and food.^{11,13,19}

These financial burdens also negatively impact patient and caregiver health and health-related behaviors. Several studies have found an association between financial toxicity and anxiety, depression, and post-traumatic stress.²⁰⁻²² Cost-related coping mechanisms, such as delaying or forgoing medical treatment, missing doctor’s visits, and taking less of (or skipping) prescription medications, can hurt both the patient and their caregivers.^{9,16,19,23,24}

The Impact on Payers and Hospitals

The fact that financial toxicity negatively impacts both patient and caregiver health status has significant business repercussions for both payers and providers. Depression, anxiety, and poor treatment adherence ultimately increase health care costs. For example, among more than 10,000 cancer survivors surveyed in the National Health Interview Survey, those with the highest levels of medical financial hardship had significantly more visits to the emergency department in a given year.²⁵

Proportion of Cancer Survivors with Emergency Department Visits²⁵



Not only does this drive higher medical expenses for payers (and raise prices for purchasers), but financial toxicity dramatically impacts the financial health of hospitals. A 2022 Crowe Analytics report highlights stark increases in hospital bad debt across the country:²⁶

- From 2018 to 2021, the share of bad debt from self-pay-after-insurance climbed from 11.1% to 57.6%.
- In that same time span, patient statements with balances greater than \$14,000 nearly quadrupled to 17%.

And, as expected, hospitals with the highest levels of un- and undercompensated care have operating margins 6.2 percentage points lower than those with the lowest levels, resulting in higher levels of financial instability.²⁷

Certain interventions to address patient financial toxicity can improve health system financial performance and sustainability. For example, financial navigation services have resulted in significant benefits to patients and families, while reducing hospital bad debt by more than \$2 million per year per hospital.²⁸

In the next section, you can see that hospital-driven interventions to address financial toxicity can benefit hospital financial performance.

Effective Provider-Based Interventions Exist

As noted, the issue of financial toxicity largely stems from the U.S. health care payment structure. Putting that larger issue aside, we have identified a number of hospital actions that can mitigate financial toxicity for patients while improving health system financial performance. Relatively simple measures like hospital formulary management have lowered prices for patients and total costs for hospitals., while embedded pharmacy patient assistance programs can lead to substantial health system-level cost savings.^{29,30} Other replicable, impactful, and sustainable interventions are listed below:

INTERVENTION	ACTOR(S)	OUTCOMES
Medical-Legal/Financial Partnerships, with a focus on benefits and tax credit enrollments ³¹⁻³⁵	→ Hospitals → Clinics → Insurers → Local legal resources	For patients and families: → Millions of benefits and tax credits for families – ROI calculated at 673% → Reductions in hospitalizations of nearly 40% → Improved health status For the health care system: → Reductions in total health care costs
Screening and linkage to trained Financial Navigators. Variations include: EMR order set for referral; Remote navigation; and community health worker (CHW) screening ^{28,36-42}	→ Hospitals → Clinics → Sometimes → CBOs	For patients and families: → Again, substantial amounts of credits and benefits secured → Reduction in mortality (44% risk of death) → Improved quality of life and measurable reduction in financial toxicity For the health care system: → Significant reductions in hospital bad debt
Financial Toxicity Tumor Board ⁴³	→ Hospital	For the health care system: → Substantial cost avoidance (at an average of \$33,000 per patient)

Financial navigation is the most studied intervention, and has the most evidence for impact, while studies on screening and referral/linkage have highlighted the efficiency of targeting navigation interventions to those with the greatest financial need and toxicity.⁴⁴ In particular, financial navigation services have resulted in significant benefits to patients and families, while reducing hospital bad debt by more than \$2 million per year per hospital.²⁸ Less studied but still with significant results, collaborations between health care providers and legal/tax/insurer organizations can have a substantial impact on both patients and providers.

While there is some literature and clinical guidance encouraging clinicians to discuss expected out-of-pocket costs when recommending treatment and prescribing, this should not be a priority intervention.⁴⁵ Clinicians struggle to anticipate out-of-pocket costs for patients, particularly as individualized information is rarely available during the patient encounter. Instead, other members of the care team can help patients and families understand potential costs and can coordinate with the clinician when treatment alternatives should be considered.

Existing Policy Interventions

Given the burden of high medical costs on patients, federal and state policymakers have implemented protections aimed at improving hospital price transparency, regulating billing practices, and expanding financial assistance. At the federal level, non-profit hospitals must meet charity care and community benefit requirements under IRS rules.⁴⁶ However, loopholes and weak enforcement in transparency laws, charity care mandates, and other policies allow many hospitals - for-profit and non-profit alike - to obscure real costs and continue to charge high prices.

Some states have taken additional steps to curb financial toxicity and its consequences by proactively connecting patients to payment resources, capping facility fees, enforcing stricter charity care requirements, and banning aggressive debt collection practices. For example, several states (e.g., Idaho, New Mexico, and Ohio) mandate screening for insurance eligibility and other programs such as charity or discounting policies, while others retroactively extend benefits to patients who become eligible after the debt was incurred (e.g., Wyoming, North Dakota).⁴⁷⁻⁵² Illinois mandates minimum charity care spending for tax-exempt hospitals and caps the annual amount that hospitals may collect from certain patients to 20 percent of the patient's family income.⁵³⁻⁵⁴ States like Maryland have experimented with hospital rate-setting models, aiming to control excessive pricing across both for-profit and nonprofit hospitals.⁵⁵ And other states such as Indiana, Massachusetts, and Oklahoma, are currently pursuing legislation to limit hospitals prices and/or cap payments to hospitals.⁵⁶ However, gaps remain in these hospital regulations—many states lack uniform charity care regulations, and only a few actively enforce hospital price transparency compliance; it remains to be seen how price caps will be enforced.⁵⁷ Additionally, in states that have not expanded Medicaid, more patients remain uninsured and vulnerable to crushing medical debt.⁵⁸

CAPC Recommendations

People living with serious illness in the U.S. face overwhelming financial burdens that can independently exacerbate poor health outcomes for themselves and their caregivers. The financial costs extend beyond individuals and families, affecting employers, communities, and the broader health system. To address this crisis, CAPC suggests the following to mitigate the impact of financial toxicity on both patients and providers:

- All acute care hospitals should screen all patients with serious illness diagnoses (including cancer, heart disease, kidney disease, and dementia) for financial toxicity using a simple screening tool - preferably validated - to facilitate identification and referral to financial assistance.
- All patients who screen positive for financial toxicity should then have access to trained financial navigators with the ability to secure benefits, pharmacy assistance programs, tax credits, and other

financial assistance. Application to the treating hospital's own financial assistance program should be mandatory prior to any debt collection.

- States can support these recommended provider actions by adding requirements for financial screening in their licensure processes, and by supporting local or state-wide centralized financial navigation services.
- States should pass laws to limit hospital prices for services, anchoring prices to factors such as a percentage of Medicare rates and including strict enforcement with meaningful consequences for non-compliance.
- States should facilitate consumer-friendly billing reforms, such as requiring utilization of the Healthcare Financial Management Association (HFMA) standardized, easy-to-understand financial communication.⁵⁹
- States should create minimum standards for charity care for tax-exempt hospitals, with stringent enforcement.
- CMS should strengthen oversight and penalties for noncompliance with price transparency laws (including better publicizing how members of the public can submit complaints) to help ensure patients have access to clear cost estimates.
- The IRS should allow flexible spending accounts to be used by caregivers, regardless of the declared dependent status of the care recipient.

The U.S. is reaching a point of crisis in health care affordability, and hospitals, states, and federal agencies must act quickly to ensure hard-working Americans do not suffer in the gaps of our current system.

Citations

¹ Financial Toxicity. NCI Dictionary of Cancer Terms. National Cancer Institute. Accessed May 1, 2025. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/financial-toxicity>

² Zafar SY, Abernethy AP. Financial toxicity, Part I: a new name for a growing problem. *Oncology (Williston Park)*. 2013;27(2):80-149

³ Ali HR, Valero-Elizondo J, Wang SY, et al. Subjective Financial Hardship due to Medical Bills Among Patients With Heart Failure in the United States: The 2014-2018 Medical Expenditure Panel Survey. *J Card Fail*. 2022;28(9):1424-1433. doi:10.1016/j.cardfail.2022.06.009

⁴ Hastert TA, Kyko JM, Ruterbusch JJ, et al. Caregiver costs and financial burden in caregivers of African American cancer survivors. *J Cancer Surviv*. 2024;18(2):565-574. doi:10.1007/s11764-022-01271-3

⁵ Inguva S, Priyadarshini M, Shah R, Bhattacharya K. Financial toxicity and its impact on health outcomes and caregiver burden among adult cancer survivors in the USA. *Future Oncol*. 2022;18(13):1569-1581. doi:10.2217/fon-2021-1282

⁶ Khera N, Zhang N, Hilal T, et al. Association of Health Insurance Literacy With Financial Hardship in Patients With Cancer. *JAMA Netw Open*. 2022;5(7):e2223141. Published 2022 Jul 1. doi:10.1001/jamanetworkopen.2022.23141

⁷ de Souza JA, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). *Cancer*. 2017;123(3):476-484. doi:10.1002/cncr.30369

⁸ Dee EC, Nipp RD, Muralidhar V, et al. Financial worry and psychological distress among cancer survivors in the United States, 2013-2018. *Support Care Cancer*. 2021;29(9):5523-5535. doi:10.1007/s00520-021-06084-1

⁹ Knight TG, Deal AM, Dusetzina SB, et al. Financial Toxicity in Adults With Cancer: Adverse Outcomes and Noncompliance. *J Oncol Pract*. Published online October 24, 2018. doi:10.1200/JOP.18.00120

¹⁰ Wheeler SB, Spencer JC, Pinheiro LC, Carey LA, Olshan AF, Reeder-Hayes KE. Financial Impact of Breast Cancer in Black Versus White Women. *J Clin Oncol*. 2018;36(17):1695-1701. doi:10.1200/JCO.2017.77.6310

¹¹ Banegas MP, Schneider JL, Firemark AJ, et al. The social and economic toll of cancer survivorship: a complex web of financial sacrifice. *J Cancer Surviv*. 2019;13(3):406-417. doi:10.1007/s11764-019-00761-1

¹² Carlton EF, Moniz MH, Scott JW, Prescott HC, Prosser LA, Becker NV. Preexisting Financial Hardship Among Caregivers of Hospitalized Children. *JAMA Pediatr*. 2023;177(7):732-733. doi:10.1001/jamapediatrics.2023.0638

¹³ Doroudi M, Coughlan D, Banegas MP, Han X, Yabroff KR. Is Cancer History Associated With Assets, Debt, and Net Worth in the United States?. *JNCI Cancer Spectr*. 2018;2(2):004. Published 2018 Apr 20. doi:10.1093/jncics/pky004

¹⁴ Pak TY, Kim H, Kim KT. The long-term effects of cancer survivorship on household assets. *Health Econ Rev*. 2020;10(1):2. Published 2020 Jan 13. doi:10.1186/s13561-019-0253-7

¹⁵ Ramsey SD, Bansal A, Fedorenko CR, et al. Financial Insolvency as a Risk Factor for Early Mortality Among Patients With Cancer. *J Clin Oncol*. 2016;34(9):980-986. doi:10.1200/JCO.2015.64.6620

¹⁶ Baddour K, Mady LJ, Schwarzbach HL, et al. Exploring caregiver burden and financial toxicity in caregivers of tracheostomy-dependent children. *Int J Pediatr Otorhinolaryngol*. 2021;145:110713. doi:10.1016/j.ijporl.2021.110713

¹⁷ Hastert TA, Ruterbusch JJ, Nair M, et al. Employment Outcomes, Financial Burden, Anxiety, and Depression Among Caregivers of African American Cancer Survivors. *JCO Oncol Pract.* 2020;16(3):e221-e233. doi:10.1200/JOP.19.00410

¹⁸ Kirchhoff AC, Nipp R, Warner EL, et al. "Job Lock" Among Long-term Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study. *JAMA Oncol.* 2018;4(5):707-711. doi:10.1001/jamaoncol.2017.3372

¹⁹ Nipp RD, Zullig LL, Samsa G, et al. Identifying cancer patients who alter care or lifestyle due to treatment-related financial distress. *Psychooncology.* 2016;25(6):719-725. doi:10.1002/pon.3911

²⁰ Baum LV, Koyama T, Schremp EA, et al. Posttraumatic stress symptoms and financial toxicity among adolescent and young adult oncology patients and their caregivers at cancer diagnosis. *Cancer.* 2022;128(10):2005-2014. doi:10.1002/cncr.34146

²¹ Chan RJ, Gordon LG, Tan CJ, et al. Relationships Between Financial Toxicity and Symptom Burden in Cancer Survivors: A Systematic Review. *J Pain Symptom Manage.* 2019;57(3):646-660.e1. doi:10.1016/j.jpainsymman.2018.12.003

²² Khandelwal N, Hough CL, Downey L, et al. Prevalence, Risk Factors, and Outcomes of Financial Stress in Survivors of Critical Illness. *Crit Care Med.* 2018;46(6):e530-e539. doi:10.1097/CCM.0000000000003076

²³ Esselen KM, Gompers A, Hacker MR, et al. Evaluating meaningful levels of financial toxicity in gynecologic cancers. *Int J Gynecol Cancer.* 2021;31(6):801-806. doi:10.1136/ijgc-2021-002475

²⁴ 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. doi:10.1007/s00520-022-07234-9

²⁵ Zheng Z, Han X, Zhao J, et al. Financial Hardship, Healthcare Utilization, and Health Among U.S. Cancer Survivors. *Am J Prev Med.* 2020;59(1):68-78. doi:10.1016/j.amepre.2020.02.016

²⁶ Higher out-of-pocket patient bills are hitting hospitals hard. Crowe. Published August 16, 2022. Accessed May 1, 2025. <https://www.crowe.com/news/higher-out-of-pocket-patient-bills-are-hitting-hospitals-hard>

²⁷ Gaffney LK, Michelson KA. Analysis of Hospital Operating Margins and Provision of Safety Net Services. *JAMA Netw Open.* 2023;6(4):e238785. Published 2023 Apr 3. doi:10.1001/jamanetworkopen.2023.8785

²⁸ Yezefski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V. Impact of trained oncology financial navigators on patient out-of-pocket spending. *Am J Manag Care.* 2018;24(5 Suppl):S74-S79.

²⁹ Kantarjian HM, Fojo T, Mathisen M, Zwelling LA. Cancer drugs in the United States: Justum Pretium--the just price [published correction appears in *J Clin Oncol.* 2015 Oct 20;33(30):3523. doi: 10.1200/JCO.2015.64.8527.]. *J Clin Oncol.* 2013;31(28):3600-3604. doi:10.1200/JCO.2013.49.1845

³⁰ Offodile AC 2nd, Gallagher K, Angove R, Tucker-Seeley RD, Balch A, Shankaran V. Financial Navigation in Cancer Care Delivery: State of the Evidence, Opportunities for Research, and Future Directions. *J Clin Oncol.* 2022;40(21):2291-2294. doi:10.1200/JCO.21.02184

³¹ Black S, Sisco S, Williams T, et al. Return on Investment From Co-locating Tax Assistance for Low-Income Persons at Clinical Sites. *JAMA.* 2020;323(11):1093-1095. doi:10.1001/jama.2020.0545

³² Hamadi HY, Zhao M, Park S, et al. Improving Health and Addressing Social Determinants of Health Through Hospital Partnerships. *Popul Health Manag.* 2023;26(2):121-127. doi:10.1089/pop.2023.0002

³³ Beck AF, Henize AW, Qiu T, et al. Reductions In Hospitalizations Among Children Referred To A Primary Care-Based Medical-Legal Partnership. *Health Aff (Millwood).* 2022;41(3):341-349. doi:10.1377/hlthaff.2021.00905

³⁴ Marcil LE, Hole MK, Wenren LM, Schuler MS, Zuckerman BS, Vinci RJ. Free Tax Services in Pediatric Clinics. *Pediatrics*. 2018;141(6):e20173608. doi:10.1542/peds.2017-3608

³⁵ Markowitz MA, Harper A, Rosenthal MS, et al. A Medical Financial Partnership in a Pediatric Medical Home. *J Health Care Poor Underserved*. 2022;33(1):136-148. doi:10.1353/hpu.2022.0011

³⁶ Thom B, Sokolowski S, Abu-Rustum NR, et al. Financial Toxicity Order Set: Implementing a Simple Intervention to Better Connect Patients With Resources. *JCO Oncol Pract*. 2023;19(8):662-668. doi:10.1200/OP.22.00669

³⁷ Sadigh G, Coleman D, Switchenko JM, Hopkins JO, Carlos RC. Treatment out-of-pocket cost communication and remote financial navigation in patients with cancer: a feasibility study. *Support Care Cancer*. 2022;30(10):8173-8182. doi:10.1007/s00520-022-07270-5

³⁸ Parikh DA, Rodriguez GM, Ragavan M, et al. Lay healthcare worker financial toxicity intervention: a pilot financial toxicity screening and referral program. *Support Care Cancer*. 2024;32(3):161. Published 2024 Feb 16. doi:10.1007/s00520-024-08357-x

³⁹ Knight TG, Aguiar M, Robinson M, et al. Financial Toxicity Intervention Improves Outcomes in Patients With Hematologic Malignancy. *JCO Oncol Pract*. 2022;18(9):e1494-e1504. doi:10.1200/OP.22.00056

⁴⁰ Rashidi A, Jung J, Kao R, et al. Interventions to mitigate cancer-related medical financial hardship: A systematic review and meta-analysis. *Cancer*. 2024;130(18):3198-3209. doi:10.1002/cncr.35367

⁴¹ Edward J, Northrip KD, Rayens MK, et al. Financial-legal navigation reduces financial toxicity of pediatric, adolescent, and young adult cancers. *JNCI Cancer Spectr*. 2024;8(3):pkae025. doi:10.1093/jncics/pkae025

⁴² Wheeler SB, Manning ML, Gellin M, et al. Impact of a Comprehensive Financial Navigation Intervention to Reduce Cancer-Related Financial Toxicity. *J Natl Compr Canc Netw*. 2024;22(8):557-562. doi:10.6004/jnccn.2024.7030

⁴³ Raghavan D, Keith NA, Warden HR, et al. Levine Cancer Institute Financial Toxicity Tumor Board: A Potential Solution to an Emerging Problem. *JCO Oncol Pract*. 2021;17(10):e1433-e1439. doi:10.1200/OP.21.00124

⁴⁴ Sears-Smith M, Knight TG. Financial Toxicity in Patients with Hematologic Malignancies: a Review and Need for Interventions. *Curr Hematol Malig Rep*. 2023;18(5):158-166. doi:10.1007/s11899-023-00707-6

⁴⁵ Agarwal A, Livingstone A, Karikios DJ, Stockler MR, Beale PJ, Morton RL. Physician-patient communication of costs and financial burden of cancer and its treatment: a systematic review of clinical guidelines. *BMC Cancer*. 2021;21(1):1036. Published 2021 Sep 16. doi:10.1186/s12885-021-08697-5

⁴⁶ Medical Debt and Non-Profit Hospital Billing Practices. Consumer Financial Protection Bureau. Published October 1, 2025. Accessed May 1, 2025. <https://www.consumerfinance.gov/about-us/blog/medical-debt-and-non-profit-hospital-billing-practices/>

⁴⁷ Medical Debt Policy Scorecard. Innovation for Justice. Last Updated July 24, 2024. Accessed May 1, 2025. <https://www.medicaldebtpolicyscorecard.org/>

⁴⁸ 2021 Idaho Code – Medicaid Eligibility Determination. Justia US Law. Accessed May 1, 2025. <https://law.justia.com/codes/idaho/2021/title-31/chapter-35/section-31-3503e/>

⁴⁹ 57-32-3. Requirement to provide screening for insurance and program eligibility. New Mexico Compilation Commission. Accessed May 1, 2025. <https://nmonesource.com/nmos/nmsa/en/item/4423/index.do#!fragment/zoupio-Toc188354290/BQCwhgziBcwMYgK4DsDWs1QewE4BUBTADwBdoAvbRABwEtsBaAfX2zgEYAOLgZgFYALAACYAnAAYAIABpk2UoQgBFRIvBPaAHlt0iTC4EKtZp16DRkAGU8pAEKaASgFEAMi4BqAQQByAYRdpUjAAI2hSdkiJIA>

⁵⁰ Rule 5160-2-17 | Provision of basic, medically necessary hospital-level services. Ohio Laws & Administrative Rules. Last Updated July 28, 2022. Accessed May 1, 2025. <https://codes.ohio.gov/ohio-administrative-code/rule-5160-2-17>

⁵¹ Chapter 3: Provider Enrollment and Participation, Pre-Authorization, Payment and Submission of Claims. Wyoming Administrative Rules. Accessed May 1, 2025. <https://rules.wyo.gov/Search.aspx?mode=1#>

⁵² Chapter 75-02-02. 1 Eligibility for Medicaid. North Dakota Legislative. Accessed May 1, 2025. <https://ndlegis.gov/prod/acdata/pdf/75-02-02.1.pdf>

⁵³ (35 ILCS 200/) Property Tax Code. Illinois General Assembly. Accessed May 1, 2025. <https://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=003502000HArt.+15&ActID=596&ChapterID=8&SeqStart=35900000&SeqEnd=40700000>

⁵⁴ Hospital Uninsured Patient Discount Act. Illinois General Assembly. Accessed May 1, 2025. <https://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=3001>

⁵⁵ Hospital Rate Setting: Successful in Maryland but Challenging to Replicate. Healthcare Value Hub. Published June 1, 2020. Accessed May 1, 2025. <https://healthcarevaluehub.org/resource/2020/hospital-rate-setting-successful-in-maryland-but-challenging-to-replicate/>

⁵⁶ Vangeli A, Angeles J. How States Can Lower Hospital Prices and Make Health Care More Affordable. The Commonwealth Fund. Published April 11, 2025. Accessed May 1, 2025. <https://www.commonwealthfund.org/blog/2025/how-states-can-lower-hospital-prices-and-make-health-care-more-affordable>

⁵⁷ Kona M, Raimugia V. State Protections Against Medical Debt: A Look at Policies Across the U.S. The Commonwealth Fund. Published September 7, 2023. Accessed May 1, 2025. <https://www.commonwealthfund.org/publications/fund-reports/2023/sep/state-protections-medical-debt-policies-across-us>

⁵⁸ Kluender R, Mahoney N, Wong F, Yin W. Medical Debt in the US, 2009-2020. JAMA. 2021;326(3):250-256. doi:10.1001/jama.2021.8694

⁵⁹ Patient financial communication best practices®. Healthcare Financial Management Association. Accessed May 1, 2025. <https://www.hfma.org/wp-content/uploads/2022/10/patient-financial-communications-best-practices-2019.pdf>