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August 12, 2024

Rohit Chopra, Director
c/o George Karithanom, Regulatory Implementation &
Guidance Program Analyst, Office of Regulations
Consumer Financial Protection Bureau (CFPB)
1700 G Street NW
Washington, DC 20552

RE: 2024 NPRM FCRA Medical Debt Information, RIN 3170-AA54, Docket No. CFPB-2024-0023

Dear Director Chopra and Colleagues:

On behalf of the Cancer Caregiving Collaborative, thank you for the opportunity to provide comments on the proposed rule regarding a Prohibition on Creditors and Consumer Reporting Agencies Concerning Medical Information (Regulation V)ⁱ (“Proposed Rule”). We applaud the Consumer Financial Protection Bureau (CFPB) for its leadership in recognizing the crippling effects of medical debt for people with major illness, disability, or chronic disease.

The Cancer Caregiving Collaborative is an initiative of the National Alliance for Caregiving, representing those who care for an estimated 18 million cancer survivors in the United States, a number that is projected to grow to 26 million by 2040.ⁱⁱ The Collaborative is a multi-phase, cross-sector initiative working to address the unmet needs of cancer caregivers through two priorities: healthcare integration and financial health.

Financial toxicity is an inequitable and urgent need for families facing cancer.ⁱⁱⁱ Financial toxicity not only impacts the financial situation of someone with cancer or their family – it also impacts quality of life and health long after diagnosis.^{iv} As described by one researcher, financial toxicity reflects the ecosystem of stressors that impact overall health:^v

Financial toxicity is multifaceted, encompassing the psychological stress of financing care, the direct costs of medical care (including medical debt), and the harmful compensatory measures taken to mitigate health care costs, such as deferred or delayed medications. In the US, approximately one-half of people with cancer experience financial toxicity.

The Proposed Rule’s protections for people with medical debt aligns with the 2022 National Strategy to Support Family Caregivers^{vi}, a multi-stakeholder national plan created under the RAISE Family Caregivers Act of 2018. Among other goals, the National Strategy aims to “ensure financial and workplace security for family caregivers” to avoid the negative impacts that many caregivers face to their near- and long-term financial health because of caregiving.^{vii} The financial impact on caregivers includes the direct and indirect

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costs of treatment and support that they shoulder when caring for someone with cancer. The effect of the high costs of cancer treatment is stark – potentially leading to debt, bankruptcy, avoiding needed medical appointment, or forgoing treatment altogether.^{viii}

Given the role that medical debt plays in contributing to the financial toxicity in cancer care, the undersigned organizations and subject matter experts support the Proposed Rule’s provisions to restrict the reporting of medical debt and offer the following comments on behalf of the Cancer Caregiving Collaborative.

I. Medical debt impacts how people living with cancer and their families make treatment decisions, threatening to disrupt cancer treatment and increasing the risk of financial toxicity.

From diagnosis to treatment, and even advanced illness, many cancer survivors receive help with care from a friend or family caregiver. Providing care to someone with cancer is “an episodic and intense experience,” putting unique pressures on the family caregiver who spends, on average, nearly 33 hours a week helping the person with cancer.^{ix} Cancer caregivers are more likely to help with medical and nursing tasks than caregivers helping with other conditions, and these tasks include work such as administering injections, tube feedings, catheter and colostomy care, and other at-home nursing needs (72% vs. 56%). Cancer caregivers are more likely to help with managing finances (59% to 53%), putting them as one of the first points of contact for managing medical debt and related healthcare costs.^x

In short, family caregivers are part of a cancer survivor’s care team, working closely with them to support home- and community-based treatment plans and supporting financial decisions around care.

Despite relying on the unpaid care provided by cancer caregivers, health systems often under-support or even ignore cancer caregivers.^{xi} A 2023 survey of cancer centers found that one in four had no programs to support family caregivers, and only one in five had training on helping with medical nursing tasks or on caregiver self-care.^{xii} In addition to this lack of support, cancer caregivers experience greater financial toxicity compared to non-cancer family caregivers.^{xiii}

Many cancer caregivers are still in the workforce. They are more likely to experience work interruptions due to caregiving and face negative financial consequences of having to reduce hours, stop working, or retire early. Most provide this care while working full-time outside the home (60%). Loss of income contributes to this toxicity, making it more difficult for families to access necessities, such as food, housing, and transportation. Separating the reporting and collection of medical debt information, as described in the Proposed Rule, may help families access resources to address financial shortfalls in other areas of their life.

II. Medical debt makes it harder for people living with cancer to get the care they need.

A recent survey from the American Cancer Society Cancer Action Network (ACS CAN) identified how medical debt related to cancer care can undercut a survivor’s quality of life and well-being.^{xiv} Those with cancer debt were three times as likely to be behind on cancer screenings and much less likely to be able to pay for care. Nearly half of all cancer patients and survivors had to take on debt to pay for cancer care (47%), and the bulk of these individuals are mid-career (ages 35 – 44). Debt was an issue even though nearly all (98%) of cancer patients surveyed had health care coverage at the time that they accumulated debt.

Other research has shown that medical debt is associated with a greater likelihood that the person with cancer will not receive necessary medical care.^{xv} Families make decisions based on financial hardships and medical debt, resulting in either delays or forgoing therapy, longer initiation of therapy, and discontinuation of recommended regimens. For some, this may mean the choice of “optimal care” or “care they can afford.”^{xvi} Having a caregiver greatly increases the chance that someone with cancer will receive necessary medical care despite financial burden, suggesting that in some cases, the caregiver may supplement the cost of medical care and treatment.

In a peer-reviewed study^{xvii} of breast cancer survivors, patients shared how high costs of care impacted their ability to pay debts. Those who reported inadequate financial resources described “irreparable financial damage” from their cancer treatments, such as declaring bankruptcy or losing their home to pay off medical debts. For some, the medical debts compounded following the initial diagnosis, creating long-term financial hurdles. Patients often had to “borrow from their future” to pay for their current situations, through actions like delaying retirement, selling off family assets, or stopping payment on other necessities.

This experience – high medical costs followed by an inability to complete a treatment plan, plan for one’s future, or secure one own’s financial security – is common in cancer survivorship. The ACS CAN Survivor Voices surveys found a clear relationship between the presence of medical debt and negative health impacts.^{xviii} These include:

- Not being able to put money into saving (60%) or reducing spending on food to save money (47%).
- Negative impacts on mental health (47%), feelings of harassment due to repeated outreach from creditors and collection agencies (32%).
- Credit problems and difficulty qualifying for loans (30%).
- Delaying or skipping medical care to avoid further debt (25%).

III. Medical debt disproportionately impacts young adults, people in the workforce, women, and Black and Latino families – furthering health inequities in cancer and caregiving.

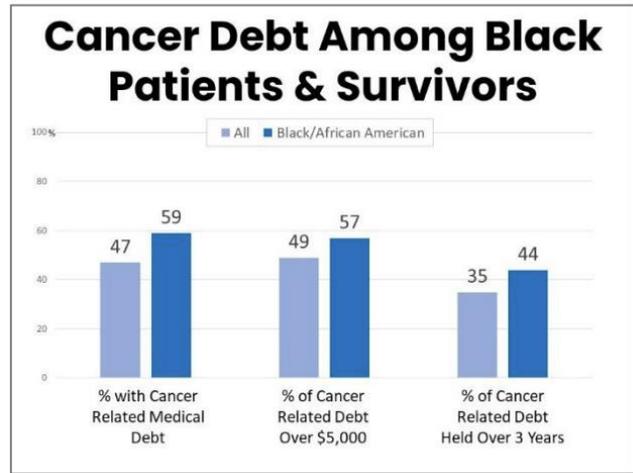
The financial impact of medical debt for cancer survivors and their family caregivers is closely related to the demographic, social, and behavioral determinants of health across diverse populations. For example, younger populations tend to face a higher risk of toxicity, as many young adults have fewer assets, cannot qualify for government programs like Medicare, or may lack health insurance. Aggressive treatment protocols for young adults with cancer often results in higher costs, leading to increased likelihood of medical debt.

As described in the ACS CAN Survivor Voices series, to pay for care, patients may change their lifestyles dramatically, “by reducing spending and by selling possessions or property.”^{xix} For caregivers who are in the same household as the person with cancer, this depletion of net worth has a trickle-down effect, where the caregiver may also be put in a more precarious financial position.

While most cancer survivors report feeling unprepared for the cost of care,^{xx} women, younger survivors, and those with lower household income are significantly more likely to say that they were unprepared for the costs. In a survey conducted last year, survivors also reported disparate impacts of medical debt.

Race and ethnic background also play a role in how medical debt can impact cancer survivorship. Black (13%) and Latino survivors (14%) were twice as likely to be denied care when compared to White respondents. Black survivors were also more likely to report being contacted by collection agencies (66%) and to feel harassed by them (44%).

Like medical debt, the negative financial impacts of caregiving – regardless of the underlying condition – are not equitably distributed.^{xxi} Low-income families experience financial strain as a higher percentage of their overall household income. Households with under \$50,000 in annual income are more likely to report that they stopped saving (42%), took on debt (38%), or stopped paying bills or other expenses (32%) compared to wealthier households.



Survivor Views on Medical Debt,
American Cancer Society Cancer Action Network, April 2024

Caregivers at the start of their careers, including young adults, are also more likely to report financial strain and at higher rates than those of adults aged 50 or older.^{xxii} The strain on lower-income households may translate directly into higher rates of medical debt, as analysis from the Kaiser Family Foundation indicated that those with household incomes under \$40,000 were more likely to carry medical or dental debts.^{xxiii}

Caregivers from diverse racial and ethnic backgrounds also report higher rates of financial strain. For example, *Caregiving in the U.S. 2020*^{xxiv} found that Black caregivers and Latino caregivers were more likely to report negative financial impacts due to caregiving. This, combined with the distribution of medical debt across communities of color, is particularly worrying. The Kaiser Family Foundation analysis found that^{xxv} at least half of Black (56%) and Latino (50%) adults have medical or dental debt, compared to 37% of Whites. More broadly, research from the Urban Institute has found similar disparities in the distribution of debt and access to credit across demographic backgrounds.^{xxvi} Protecting caregivers from the weight of medical debt can help address current inequities in the availability of and access to credit.

IV. The Proposed Rule offers new tools to protect cancer caregivers, who often shoulder financial strain and other stresses related to cancer survivorship.

The issues around the accumulation and collection of medical debt can do irreparable harm to the caregiver of the person with cancer, as Dr. Fumiko Chino of the Memorial Sloan Kettering Cancer Center eloquently described in Congressional testimony last month before the Senate Committee on Health, Education, Labor and Pensions^{xxvii}:

“Here’s the thing I know now as an oncologist about when young people get cancer, their bodies are so healthy, they can handle so much aggressive treatment, their capacity to absorb set back after set back is so high... until suddenly they can’t. It was in the grey of winter that Andrew died at age 28, leaving me in an empty house, with an empty future, and a stack of bills.

Even though Andrew was gone, the debt remained. I was hounded by debt collectors, one even called me when I was at his funeral.

The debt was like a black cloud over my head; it followed me and cast a shadow over my entire future. It wasn't until years later that I discovered that, despite the threatening phone calls and letters, I wasn't legally responsible for Andrew's medical debt. The debt died with him. Even today, I get calls from collectors trying to cash in on his sickness."

Given the close nexus of financial strain and medical debt with how families make treatment decisions, we fully support the Proposed Rule's initiatives to limit the impact of medical debt. The Proposed Rule's provisions to restrict reporting of medical debt, protect families from overly aggressive creditors and collection agencies, and prevent repossession of medical equipment is key to helping families get the care they need in the wake of cancer.

V. Thank You and Contact Information

Thank you for your ongoing support and leadership. We stand at the ready to provide any additional information as you consider this Proposed Rule and other policies that impact those who care for someone with a health care need or disability.

If you need to reach us, please contact Yadira Montoya, M.S.P.H., Programs Director, at yadira@caregiving.org or (202) 918-1038.

Sincerely,

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* Affiliations of individuals are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.

ⁱ 89 C.F.R. § 51682 (2024).

ⁱⁱ National Cancer Institute, Division of Cancer Control & Population Services, Office of Cancer Survivorship, Statistics and Graphs (NCI, 2024) <https://cancercontrol.cancer.gov/ocs/statistics>.

ⁱⁱⁱ Edward Christopher Dee, Family and Caregiver Financial Toxicity Associated with Cancer – A Global, Inequitable, and Urgent Consideration, 6 JAMA Netw Open. 6 p.e2319317 (2023), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2806480>.

^{iv} Loren Collado & Isaac Brownwell, The crippling financial toxicity of cancer in the United States, 20 Cancer Biol. Ther. 10: 1301-03 (2019), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6783117/>.

^v See supra note iii.

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- ^{vi} The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren, 2022 National Strategy to Support Family Caregivers pp.70-79 (ACL, 2022), https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers-2.pdf.
- ^{vii} *Id.* at 71.
- ^{viii} For an overview of financial toxicity, please see NCI Dictionary of Cancer Terms, “Financial Toxicity” <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/financial-toxicity> (Last visited 8/1/2024), and National Cancer Institute, Financial Toxicity (Financial Distress) and Cancer Treatment (PDQ) – Patient Version, (NCI, 2024), <https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq>.
- ^{ix} Gail G. Hunt, Margaret L. Longacre, Erin E. Kent, Lisa Weber-Raley, Cancer Caregiving in the U.S. (National Alliance for Caregiving and Cancer Support Community, 2016), https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf.
- ^x See *supra* note vii p. 19, Figure 7.
- ^{xi} *Id.*
- ^{xii} N.J. Odom, A. Applebaum, M.A. Bakitas, T. Bryant, E. Currie, K. Curry, H. Donovan, M.E. Fernandez, B. Ferrell, A. Azuero, T.F. Gray, B.A. Hendricks, D. Meier, C. Nightingale, S. Reinhard, T.S. Sannes, K. Sterba, & H.M. Young, Availability of Family Caregiver Programs in US Cancer Centers, 6 JAMA Network Open 10:e2337250 (2023), <https://doi.org/10.1001/jamanetworkopen.2023.37250>.
- ^{xiii} M.L. Longacre, L. Weber-Raley, & E.E. Kent, Cancer Caregiving While Employed: Caregiving Roles, Employer Assistance, and Preferences for Support, 26 (5) J. of Cancer Ed. 920-32 (2021), <https://pubmed.ncbi.nlm.nih.gov/31858439/>.
- ^{xiv} American Cancer Society Cancer Action Network, “Medical Debt and Cancer” (2024), <https://www.fightcancer.org/policy-resources/medical-debt-and-cancer> (last visited July 29, 2024).
- ^{xv} See, e.g., Matthew P. Banegas, John F. Dickerson, Erin E. Kent, Janet S. de Moor, Katherine S. Virgo, Gery P. Guy, Jr., Donatus U. Ekwueme, Zhiyuan Zheng, Stephanie Nutt, Loyce Pace, Alexandra Varga, Lisa Waiwaiole, Jennifer Schneider, and K. Robin Yabroff, Exploring barriers to the receipt of necessary medical care among cancer survivors under age 65 years, 12 J. Cancer Surviv. (1):28-37 (2018), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6993114/>.
- ^{xvi} *Id.*
- ^{xvii} Sachiko M. Oshmia, Sarah D. Tait, Christel Rushing, et al. Patient Perspectives on the Financial Costs and Burdens of Breast Cancer Surgery, 17 JCO Oncol. Pract. 6: e872-e881 (2021), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8257857/>.
- ^{xviii} *Id.*
- ^{xix} *Id.*
- ^{xx} See American Cancer Society Cancer Action Network, Survivor Views, <https://www.fightcancer.org/survivor-views> (last accessed 8/1/2024), and corresponding findings from Survivor Views: Cancer and Medical Debt (American Cancer Society, 2022), https://www.fightcancer.org/sites/default/files/national_documents/survivor_views_cancer_debt_0.pdf, and Survivor Views on Medical Debt (American Cancer Society, 2024), https://www.fightcancer.org/sites/default/files/national_documents/sv_debt_summary_24.pdf.
- ^{xxi} National Alliance for Caregiving and AARP, Caregiving in the U.S. 2020 p.4 (2020), <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>.
- ^{xxii} *Id.* pp. 56-61 and Figure 59.
- ^{xxiii} *Id.* pp. 56 – 61 (“H. The Financial Situation of Caregivers”).
- ^{xxiv} See *supra* note ii pp. 60 – 61 including Figure 61.
- ^{xxv} *Id.*
- ^{xxvi} Aniket Mehrotra, Daniel Pang, Jun Zhu, Jun Hyun Choi, & Janneke Ratcliffe, Evidence of Disparities in Access to Mortgage Credit (Urban Institute: Housing Finance Policy Center, 2024), https://www.urban.org/sites/default/files/2024-03/Evidence_of_Disparities_in_Access_to_Mortgage_Credit.pdf.
- ^{xxvii} What Can Congress Do to End the Medical Debt Crisis in America? Hearing Before the U.S. Senate Committee on Health, Education, Labor & Pensions (HELP Committee), 118th Cong. (2024) (statement of Fumiko Ladd Chino, MD), <https://www.help.senate.gov/hearings/what-can-congress-do-to-end-the-medical-debt-crisis-in-america> (last accessed July 31, 2024).