

EXECUTIVE SUMMARY

# THE HEALTH INSURANCE MAZE

How Cancer Patients Get Lost in the Red Tape of Utilization Management

**JUNE 2025** 

A summary of findings from CARE —
Commercial Insurance and Pharmacy Benefit Manager
Impact on Cancer Treatment Access and Quality of Life:
A Research Evaluation

A new national survey study of 1,201 adults who received cancer treatment in the past year reveals how utilization management (UM) practices, such as prior authorization, coverage changes, and formulary exclusions, create significant barriers to timely cancer care access and negatively affect people's well-being. While UM strategies are intended to control costs, they often impose severe administrative, practical, financial, and emotional burdens on people with cancer.

**READ FULL REPORT** 

The Health Insurance Maze: How Cancer Patients Get Lost in the Red Tape of Utilization Management ("Red Tape Report") explores how UM policies impact timely access to care, financial burden, and well-being from the perspective of people living with cancer. It also examines differences based on insurance type: Employer Plans, Medicare Advantage, and Traditional Medicare.

#### Key findings include:

- **High prevalence of prior authorization:** 85% of respondents faced prior authorization for cancer treatments; 76% needed authorization in the past 12 months alone (87% of those with Employer Plans, 72% with Medicare Advantage, and 57% with Traditional Medicare).
- Coverage interruptions: 14% reported treatment coverage stoppages in the past year; 18% experienced this at some point in their care.
- **Delays and inefficiencies:** Many respondents reported delays in diagnosis and treatment, with significant time lost navigating UM hurdles. Yet for 95% of respondents, their treatments were ultimately approved, highlighting the inefficient and overly broad use of UM in cancer care.
- Time burden: Tackling UM red tape led to lost time for respondents: 51% who got involved lost up to a business day, 27% lost up to 2-3 business days, and 12% lost a full business week or more dealing with a single prior authorization.
- **Practical, financial, and emotional impacts:** Problems with insurance created direct impacts on respondents: 36% reported worsened stress, 34% reported worsened finances, and 29% reported reduced trust in the healthcare system.
- Impacts by insurance type: Employer Plan enrollees faced the most red tape, followed by Medicare Advantage, then Traditional Medicare.

This research seeks to inform policymakers, insurers, pharmacy benefit managers, employers, and healthcare stakeholders about the real-world consequences of UM on cancer care access and quality of life. Only by listening to and integrating patient experiences into policy discussions can we succeed in building a system that is both efficient in its delivery and responsive to the needs of its intended beneficiaries: people living with cancer.



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## **Key Findings**

#### **Prior Authorization Creates Multi-Layered Barriers to Care**

85% of survey respondents experienced prior authorization at least once during their cancer care; 76% underwent prior authorization in the past 12 months alone.

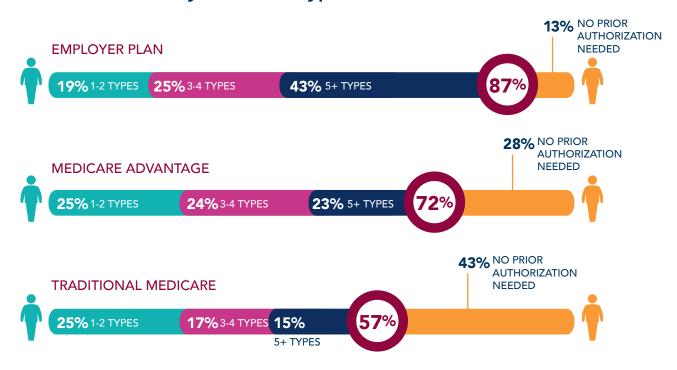
Authorization was not confined to a single treatment type; nearly 3 in 4 underwent authorization for IV chemotherapy, radiation therapy, targeted therapy, and/or surgery during their cancer.

#### **Employer-Sponsored Insurance Plans Carry High Administrative Burdens**

87% of respondents with Employer Plans underwent at least one prior authorization for their cancer care in the past 12 months, compared to 72% with Medicare Advantage and 57% with Traditional Medicare.

43% of respondents with Employer Plans reported undergoing prior authorization for 5 or more different types of cancer care (surgery, radiation, chemotherapy, imaging, etc.) in that timeframe, compared to 23% with Medicare Advantage and 15% with Traditional Medicare.

### Needed At Least One Prior Authorization for Cancer Treatment, Past 12 Months, by Insurance Type



Question: Did any treatments, procedures, tests, or medications for your cancer ever need insurance approval before you could start it? (Response options: Yes, needed insurance approval in the past 12 months; Yes, needed insurance approval more than 12 months ago; No, did not need insurance approval; Don't Know. List of treatments: imaging, biomarker testing, IV chemotherapy, oral chemotherapy, targeted therapy, immunotherapy, radiation therapy, hormonal therapy, stem cell transplant, and/or supportive medications.)

Percentages calculated out of n=569 Employer plan respondents, 408 Medicare Advantage, 224 Traditional Medicare; significant between-group differences (p<.001).



I am so angry with this insurance company... I feel my cancer spread more because it took six months to get my referrals approved... I take it day by day and hope that I will be a survivor of this cancer. I'm not ready to leave my family.

- Employer Plan Respondent

99

#### **Prior Authorization Burden Leads to "Time Toxicity"**

63% of Employer Plan respondents said they got directly involved in handling their prior authorization process, compared to 31% of Medicare Advantage and 29% of Traditional Medicare.

Among respondents and their families who dealt with their prior authorization directly, many lost substantial time: 51% lost up to a full business day, 27% lost up to 2-3 business days, and 12% lost a full business week or more dealing with a single prior authorization incident.

#### **Prior Authorization Creates Unnecessary Delays**

10% of respondents experienced an initial denial of their most recent prior authorization request; 72% of these denials were ultimately overturned following appeals, while 21% of those denied were required to try another type of treatment before insurance would pay.

95% of authorizations were eventually approved, but only after 29% experienced delays in diagnosis and 40% experienced treatment delays. Among those with delays, 1 in 5 said the delay lasted between three weeks to more than a month.

Delays in diagnosis and treatment were most common for people enrolled in Employer Plans, who also more often reported longer wait times due to prior authorization.

95% of authorizations were eventually approved, but only after 29% experienced delays in diagnosis and 40% experienced treatment delays.

## Patient and Family Time Lost to a Single Incident of Prior Authorization



Question: How much time have you/your family spent dealing with insurance approval for [treatment]? This includes contacting your insurance, care team, pharmacy, etc., any appeals you might have made, and any personal research you did. If you are unsure, please make your best guess. (Response options: None, it was handled by my care team; 1-4 hours; 5-8 hours; 9-16 hours; 17-24 hours; 25-40 hours; 41-80 hours; More than 80 hours; Don't Know.)

*n*=485 respondents who dealt with prior authorization directly (excludes respondents who said it was handled by their care team or didn't know).

CancerCare, The Health Insurance Maze: How Cancer Patients Get Lost in the Red Tape of Utilization Management (June 2025), <a href="https://www.cancercare.org/redtape">www.cancercare.org/redtape</a>.

#### **Stopping Coverage When People Need It Most**

18% of respondents reported that insurance abruptly stopped coverage of their cancer medications or supportive treatments for symptom management, with 14% experiencing this in the past 12 months.

21% with Employer Plans reported at least one coverage stoppage in the past 12 months, compared to 9% with Medicare Advantage and 8% with Traditional Medicare.

72% with Employer Plans who experienced coverage stoppages said it delayed or interrupted their treatment, compared to 49% with Medicare Advantage and 42% with Traditional Medicare.

27% of those who experienced a treatment interruption due to coverage stoppage said it lasted 3 weeks to more than a month.

Among those who switched treatment due to coverage stoppage, 45% reported worse side effects, and 38% said the new treatment cost more.

## Treatment Interrupted Due to Insurance Stopping Coverage

FULL SAMPLE (n=219) **64%** 

EMPLOYER PLAN (n=150) 72%

MEDICARE ADVANTAGE (n=45) 49%

TRADITIONAL MEDICARE (n=24) 42%

**Question:** Did having your insurance stop covering your [treatment] delay/interrupt your cancer treatment? (Response options: No; Yes, by less than 1 week; Yes, by 1 week; Yes, by 2 weeks; Yes, by 3-4 weeks; Yes, by more than a month; Yes, by more than 3 months; Yes, by more than 6 months; Don't Know.)

n=219 for full sample (150 Employer Plan; 45 Medicare Advantage; 24 Traditional Medicare); significant between-group differences (p<.05). Percentages represent the proportion of respondents who selected "Yes" their treatment was interrupted.

CancerCare, The Health Insurance Maze: How Cancer Patients Get Lost in the Red Tape of Utilization Management (June 2025), <a href="https://www.cancercare.org/redtape">www.cancercare.org/redtape</a>.



It is a nightmare waking up every day wondering if some people halfway across the country will approve what my doctors have said is my only chance.

- Employer Plan Respondent



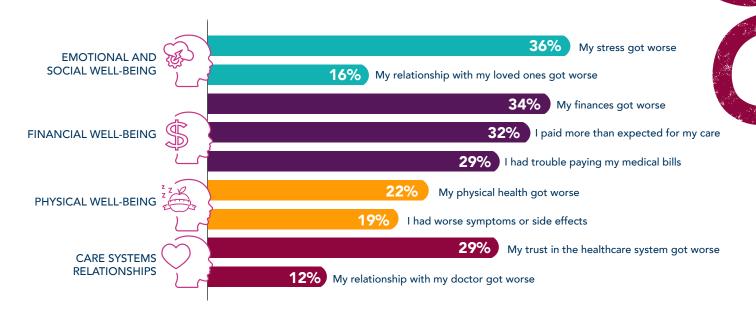
#### Impact of Insurance Problems on Patient Well-Being and Finances

About 1 in 3 respondents said problems with their insurance directly worsened each of the following: their stress, their trust in the healthcare system, their finances, and unexpected costs of care.

Employer Plan respondents reported these negative impacts more often (40-49%) than those with Medicare Advantage (20-26%) or Traditional Medicare (20-23%).

28% of Employer Plan enrollees were dissatisfied with their out-of-pocket costs, compared to 17% with Medicare Advantage and 15% of those with Traditional Medicare.

## Direct Impacts of Insurance Problems on Patient Well-Being



**Question:** Next, we would like to understand how problems with health insurance have affected your life. Please rate how much you agree or disagree with the following statements. "[X happened] as a direct result of problems with my health insurance." (Response options: Strongly disagree; Disagree; Neither agree nor disagree; Agree; Strongly agree.)

n=1201; percentages represent the proportion of respondents that "Agree" or "Strongly agree" with each statement.

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#### Improved Insurance Literacy and System Awareness Needed

About 1 in 4 had limited confidence in determining their coverage or costs for healthcare visits and prescription drugs.

77% had not heard of or did not understand the role of pharmacy benefit managers (PBMs).

41% of Employer Plan respondents were unclear on plan structure (e.g., fully-insured vs. self-funded).

77% on Employer Plans had never heard of alternative funding programs; 65% did not understand co-pay accumulators/maximizers.

## **Study Implications**

The Red Tape Report reveals that most people with cancer face multiple cycles of prior authorization, leading to care delays and excessive red tape that drain time and increase stress.

These inefficiencies do not improve cancer care—they obstruct it. Patients and their families lose valuable time that could otherwise be spent on treatment and recovery.

Utilization management and other cost-containment strategies must be designed to preserve timely access to high-quality, affordable cancer care.

When insurance systems prioritize administrative bureaucracy over outcomes, patients, families, and providers all suffer. Reforming these systems is essential to reduce burden, improve care, and ensure that administrative processes support, not hinder, treatment.

Achieving this will require coordinated action from insurers, employers, policymakers, and advocates, along with better tools and support to help people with cancer navigate insurance challenges and participate in shaping the policies that affect their care.

### Methodology Highlights

The report includes **1,201 respondents** who completed the survey between **September and December 2024**, comprising 569 individuals with Employer Plans, 408 with Medicare Advantage, and 224 with Traditional Medicare. This sample was achieved by screening 47,225 potential participants nationally, whose cancer status was unknown, for eligibility criteria. Respondents were limited to adults treated for cancer in the last year and who met additional age (26+), treatment, and insurance eligibility criteria.

Findings were documented using descriptive analyses, with additional bivariate analyses (chi-squared tests) to assess differences between groups based on insurance status.

Study strengths include the use of national survey panels with an expanded reach beyond advocacy organizations and a survey design that protected against fraudulent responses. The study focuses on a high-need population—individuals actively undergoing cancer treatment in diverse care settings—whose insurance experiences are often overlooked. A key priority was to ensure that the survey questions used language reflecting the real-world experiences of patients. This pragmatic approach resulted in a project grounded in cancer patients' lived experiences within the current healthcare system and avoided jargon that may confuse survey respondents.

Study limitations include reliance on self-reported data, potential recall biases, and constraints of non-probability sampling in generalizing study findings. The report presents primarily descriptive results. Future work will leverage multivariable statistical methods to examine topics in greater depth, accounting more comprehensively for differences between insurance groups and for subgroups warranting further exploration.

Visit www.cancercare.org/redtape for the full report.

## **Key Characteristics for 1,201 Survey Respondents**

