



**Duke Clinical Research Institute**  
DUKE UNIVERSITY MEDICAL CENTER

**REPORT:**  
**The Medicare Modernization Act and Changes in  
Reimbursement for Outpatient Chemotherapy:  
Do Patients Perceive Changes in Access to Care?**

Prepared for the National Patient Advocate Foundation

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## Executive Summary

The 2003 Medicare Prescription Drug, Improvement, and Modernization Act (MMA) changed the way chemotherapy drugs are paid for through Medicare. However, the impact of this legislation on Medicare beneficiaries is unknown. We sought to examine the real and perceived changes in access to and satisfaction with cancer care since the implementation of the MMA. Our two primary objectives were to (1) measure and compare time to initiation of chemotherapy for patients undergoing treatment either before or after the enactment of the MMA; and (2) measure and compare the location of care for patients undergoing chemotherapy either before or after the enactment of the MMA. Our secondary objective was to measure and compare patients' satisfaction with treatment before and after the enactment of the MMA. To meet these objectives, we analyzed Medicare claims data for 2002 through 2004 and conducted a Web-based survey of patients with cancer.

We used the Medicare inpatient, outpatient, and carrier standard analytic files and the corresponding denominator files for 2002 through 2004 to assess the time to initiation of treatment and the treatment location for a 5% sample of Medicare beneficiaries for whom a diagnosis of lung, breast, or colorectal cancer was reported on a single inpatient claim or for whom a diagnosis of lung, breast, or colorectal cancer and a therapeutic procedure for cancer were reported on 1 or more outpatient or carrier claims in a given calendar year. After controlling for the effects of age, sex, race/ethnicity, cancer type, region, comorbid diagnoses, and year, we found no statistically significant differences in time from diagnosis to initiation of chemotherapy or in treatment location between 2003 and 2004.

Our second, complementary study was a Web-based survey of a convenience sample of patients with cancer. The survey was designed to elicit information about respondents' experiences with chemotherapy services, particularly with regard to access to care and satisfaction with the services provided. The sample was stratified by age (patients younger than 65 and patients aged 65 and older). After adjusting for important confounders, we found no statistically significant differences in time from diagnosis to initiation of chemotherapy or in treatment location between the pre-MMA and post-MMA cohorts, among respondents 65 and older.

Overall, our findings do not support generalizations from anecdotal reports that patients with cancer have been affected by the change in reimbursement to oncologists for chemotherapy as a result of the MMA. The analysis may be confounded by payments from the Centers for Medicare and Medicaid Services to physicians in a concurrent cancer demonstration project, because these payments may have masked changes that have resulted from the MMA. Furthermore, the Medicare claims analysis provides a baseline assessment of access to chemotherapy. We strongly recommend that additional research efforts reexamine Medicare claims for services incurred after full implementation of the MMA reimbursement changes in 2005 and 2006, when those data become available.

## Introduction

The 2003 Medicare Prescription Drug, Improvement, and Modernization Act (MMA) changed the way chemotherapy drugs are paid for through Medicare. Before the implementation of the MMA, reimbursement for chemotherapy drugs exceeded the cost of acquisition, whereas reimbursement for the resources used in the administration of those drugs fell far short of the costs incurred. The MMA attempts to rectify this imbalance by restructuring payments for drug acquisition and administration. Furthermore, to facilitate the transition to the new payment schedule, the Centers for Medicare and Medicaid Services (CMS) implemented a 1-year demonstration project to evaluate how chemotherapy affects the level of fatigue, nausea, and pain experienced by patients. The changes are outlined in the following table:

Changes in Payments for Drug Acquisition and Administration Under the Prescription Drug, Improvement, and Modernization Act of 2003

	2003	2004	2005	2006
Payment rates for chemotherapy drugs	95% AWP	85% AWP	106% of ASP	106% of ASP or CAP participation
Transition payment rates for administration of chemotherapy drugs	\$0	32% increase in payment for drug administration	3% increase in payment for drug administration	\$0
Demonstration project payment	\$0	\$0	\$130	<\$130

AWP indicates average wholesale price; ASP, average sales price; and CAP, competitive acquisition program.

The MMA is estimated to save the government and Medicare beneficiaries millions in excess expenditures through modification of the average wholesale price (AWP) payment schedule, which has been widely reported to over-reimburse chemotherapy services<sup>1</sup>; however, oncologists and patient advocates have expressed concerns about the potential impact of the legislation. These groups warn that the MMA could lead to dramatic changes in the provision of cancer care by forcing many patients to receive treatment in hospitals, sometimes far from their homes, rather than in their physicians' offices.<sup>2</sup>

Anecdotal evidence suggests that patients are already feeling the effects of the new payment system, which went into effect on January 1, 2005. Some oncologists report that they have begun to eliminate nurses and other staff, reducing the attention that patients receive.<sup>3</sup> In other areas, practices report that they have started to close satellite offices, requiring patients to travel much farther for treatment, particularly in rural areas.<sup>3-4</sup>

However, a recent focus group study commissioned by the Medicare Payment Advisory Commission found that most beneficiaries did not experience any changes in their cancer treatment following the implementation of the MMA. The study also found that, although most patients preferred to undergo chemotherapy in office-based settings, they did not perceive a difference in the quality of services between physicians' offices and hospital infusion centers.<sup>5</sup>

In light of the conflicting perceptions of the effects of the MMA on patients, we sought to examine the real and perceived changes in access to and satisfaction with cancer care since the implementation of the MMA. Our two primary objectives were to (1) measure and compare time to initiation of chemotherapy for patients undergoing treatment either before or after the enactment of the MMA; and (2) measure and compare the location of care for patients undergoing chemotherapy either before or after the enactment of the MMA. Our secondary objective was to measure and compare patients' satisfaction with treatment before and after the enactment of the MMA. To meet these objectives, we analyzed Medicare claims data for 2002 through 2004 and conducted a Web-based survey of patients with cancer.

## **Section I: Medicare Claims Analysis**

We used the Medicare inpatient, outpatient, and carrier standard analytic files and the corresponding denominator files to assess the time to initiation of treatment and the treatment location for a 5% sample of Medicare beneficiaries. The inpatient files contain institutional claims submitted for facility costs covered under Medicare Part A. The outpatient files contain claims submitted by institutional outpatient providers (eg, hospital outpatient departments, ambulatory surgery centers). The carrier files contain noninstitutional provider claims for services covered under Medicare Part B. The denominator files contain beneficiary identifiers, dates of birth, sex, race/ethnicity, dates of death, beneficiary contact zip codes, and information about program eligibility and enrollment.

We obtained all files for the period from 2002 through 2004 from CMS. We eliminated invalid records and limited the analysis to persons living in the United States.

For carrier claims, we used the provider zip code in the CMS files to determine the treatment location. For inpatient and outpatient institutional claims, we linked the Medicare provider identification numbers provided by CMS to the American Hospital Association Annual Survey to obtain facility zip codes.

### **Patients**

We included beneficiaries for whom a diagnosis of lung, breast, or colorectal cancer was reported in a single inpatient claim or for whom a diagnosis of lung, breast, or colorectal cancer and a therapeutic procedure for cancer were reported in 1 or more outpatient or carrier claims in a given calendar year (Table 1).

To specify the date of disease onset (“incident diagnosis”), we used the earlier of (a) the date of the earliest inpatient cancer diagnosis or (b) the date of the earliest outpatient or carrier cancer diagnosis. To be considered an incident case, a beneficiary must not have met the diagnostic inclusion criteria listed above in the previous calendar year. We limited the sample to beneficiaries aged 67 years and older to minimize the risk of misclassifying a prevalent case as an incident case. We excluded beneficiaries with more than one cancer type of interest in the

same calendar year. Also, we considered beneficiaries who traveled more than 100 miles for treatment (n = 232) to be outliers, and we excluded them from the analysis.

Inclusion in the incident cohort was conditional on survival to chemotherapy, and the initial chemotherapy visit was required to be in the same calendar year as the incident diagnosis. Chemotherapy was defined using diagnosis and procedure codes, as follows:

**Diagnosis and Procedure Code Definitions of Chemotherapy**

Field	Codes	File
DRG	410	Inpatient
ICD-9 Diagnosis	V58.1	Inpatient Outpatient Carrier
ICD-9 Procedure	99.25	Inpatient Outpatient
CPT-4/HCPCS	96400-96549, Q0083-Q0085, J9000-J9999	Carrier

ICD-9-CM indicates *International Classification of Diseases, Ninth Revision, Clinical Modification*; CPT-4, *Current Procedural Terminology, Fourth Edition*; and HCPCS, Healthcare Common Procedure Coding System.

**Statistical Analysis**

We examined characteristics of patients in the incident cohort. We present categorical variables as frequencies and continuous variables as means with standard deviations (SDs). We identified comorbid conditions using the coding algorithms described by Birman-Deych et al<sup>6</sup> and Quan et al.<sup>7</sup> Specifically, we searched all inpatient, outpatient, and carrier claims for 365 days preceding the date of the incident diagnosis for evidence of coronary heart disease (*International Classification of Diseases, Ninth Revision, Clinical Modification* [ICD-9-CM] codes 410.x-414.x, 429.2, V45.81), hypertension (401.x-405.x, 437.2), cerebrovascular disease (362.34, 430.x-438.x), dementia (290.x, 294.1, 331.2), chronic obstructive pulmonary disease (416.8, 416.9, 490.x-505.x, 506.4, 508.1, 508.8), diabetes mellitus (250.x), peripheral vascular disease (093.0 437.3, 440.x, 441.x, 443.1-443.9, 47.1, 557.1, 557.9, V43.4), or kidney disease (403.01, 403.11, 403.91, 404.02, 404.036, 404.12, 404.13, 404.92, 404.93, 582.x, 583.0-583.7, 585.x, 586.x, 588.0, V42.0, V45.1, V56.x).

To test the statistical significance of changes from 2003 to 2004, we used *t* tests for continuous variables and Mantel-Haenszel  $\chi^2$  tests for categorical variables.

We measured days from the incident diagnosis to the date of the first chemotherapy visit. We also calculated the distance traveled for treatment using the beneficiary’s contact zip code and the zip code of the provider administering the chemotherapy. Distances were measured in miles. To examine the unadjusted relationship between study variables and the number of days from diagnosis to treatment, we employed a survival framework using a Cox proportional hazards regression model. We used a linear regression model to examine the unadjusted relationship between study variables and the mean distance traveled for treatment. We also fit multivariable models for each measurement described above using age, sex, race/ethnicity, cancer type, region, comorbid diagnoses, and year to control for these factors. That is, controlling for the other

variables in the model, we determined whether patients traveled farther or waited longer for chemotherapy in 2004 than in 2003.

We used SAS version 9.1.5 for all analyses (SAS Institute Inc, Cary, NC). This study was approved by the institutional review board of the Duke University Health System.

## Results

In the Medicare 5% sample, there were 2337 incident cases of breast, colorectal, or lung cancer in 2003, and 2396 incident cases of breast, colorectal, or lung cancer in 2004. As shown in Table 2, patients' demographic characteristics were relatively consistent between 2003 and 2004. In both years, more than three quarters of the patients received their first chemotherapy treatment in a physician's office, and less than 5% received treatment in an inpatient hospital setting. Differences in treatment location (ie, inpatient, outpatient, or physician office) between 2003 and 2004 were not statistically significant.

From 2003 to 2004, mean days from incident diagnosis to initial chemotherapy visit in inpatient settings increased slightly, and the distance traveled for inpatient chemotherapy decreased. In contrast, mean days from incident diagnosis to initial chemotherapy visit in outpatient settings decreased, and the distance traveled was slightly greater. Mean days to treatment in physician offices showed little change between 2003 and 2004, but distance traveled increased slightly (Table 3).

The unadjusted relationships between the study variables and the days from diagnosis to treatment and the distance to treatment location are displayed in Table 4. Men received chemotherapy slightly more quickly than women, and initiation of chemotherapy was fastest for beneficiaries with lung cancer than for beneficiaries with breast or colorectal cancer. Several comorbidities were associated with more rapid initiation of treatment. With regard to distance traveled for treatment, white beneficiaries traveled farther than beneficiaries of other races. Younger patients traveled farther than older patients. As compared to beneficiaries in the western US census region, patients in the northeastern region traveled significantly shorter distances, and patients in the southern region traveled longer distances. Neither days from diagnosis to treatment nor distance traveled were significantly different between 2003 and 2004.

After controlling for the effects of age, sex, race/ethnicity, cancer type, region, comorbid diagnoses, and year, time from diagnosis to initiation of chemotherapy was significantly less for patients with lung cancer than for patients with breast or colorectal cancer. Patients with chronic obstructive pulmonary disease (COPD) and patients with other types of cancer during the 365-day period before the incident cancer diagnosis also received treatment more quickly than patients without those conditions. Patients with COPD received treatment 9% more quickly than patients without COPD (hazard ratio [HR], 1.09; 95 confidence interval [CI], 1.02-1.16), and patients with a previous cancer diagnosis received treatment nearly twice as fast as those without a previous cancer diagnosis (HR, 1.74; 95% CI, 1.65-1.85). Compared to beneficiaries living in the western US census region, beneficiaries in the northeastern region received chemotherapy 20% less quickly (HR, 0.80; 95% CI, 0.72-0.89) (Table 5).

Controlling for other factors, men traveled approximately 1.3 miles farther than women for the initial chemotherapy visit. Compared to patients in the western US census region, patients in the northeastern region traveled more than 2 miles less, and patients in the southern region traveled more than 4 miles farther. Again, neither days from diagnosis to treatment nor distance traveled was significantly different between 2003 and 2004 (Table 5).

## **Section II: Web-Based Survey of Patients With Cancer**

Using a 2-by-2 factorial design, we sought to recruit 600 patients with cancer who received chemotherapy before the enactment of the MMA and 600 patients with cancer who received chemotherapy after the enactment of the MMA. With 600 respondents in each arm, the study had 99% statistical power to detect a 1-week increase in time to chemotherapy (the primary outcome variable) and 67% statistical power to detect a 0.5-week increase in time to chemotherapy. We expected Medicare beneficiaries to be differentially affected because the MMA pertains only to them. Consequently, we stratified the sample by age (patients younger than 65 vs patients aged 65 and older) and used the younger age group as a control. In addition, we ensured that there was a representative sample from each of the 10 Medicare regions. (Appendix A shows the composition of the Medicare regions.)

### **Participants and Procedures**

Respondents were adults with cancer who received chemotherapy intravenously. Respondents were included in the pre-MMA group if they began and completed an entire course of chemotherapy between January 2003 and January 2005. Respondents were included in the post-MMA group if they began the first course of chemotherapy on or after February 1, 2005.

Interactive Clinical Intelligence, Inc (ICI) administered the survey to respondents via the Internet. ICI is the market research and database development division of Cancer Consultants, Inc, an online oncology resource center and a member of the Cancer Information Network. Through its portal and syndication network, Cancer Consultants has access to more than 500,000 patients per month in over 100 major US markets. ICI has a respondent pool of 5000 from a database of patients with cancer who have agreed to receive survey opportunities from ICI via e-mail.

ICI initially used two methods to invite potential study participants to complete the survey. First, they sent an invitation via e-mail to participants in their database. Second, a link to the survey was available on the Cancer Consultants Web site (<http://www.cancerconsultants.com>). ICI encountered recruitment challenges in the cohort of older patients and had to implement two additional recruitment strategies. First, ICI sent invitations via e-mail to the e-mail distribution lists of other cancer-related organizations (eg, Gilda's Club, National Patient Advocate Foundation). Second, ICI distributed paper invitations to oncology practices around the United States. Initial recruitment e-mails were sent during the period from April to July 2006. This recruitment strategy is similar to using electronically posted advertisements, which results in a convenience sample.

## **Survey Development**

The survey was designed to elicit information about respondents' experiences with chemotherapy, particularly with regard to access to care and satisfaction with the services provided. We developed the survey by reviewing existing surveys, reviewing the literature, and soliciting expert opinion.<sup>8-10</sup> We conducted cognitive interviews with 10 patients with cancer to assess understandability and content validity, and we used information from the cognitive interviews to further refine the survey.

## **Measures**

### *Demographic and Descriptive Characteristics*

Demographic information included cancer type; type of health insurance; state of residence; rural, suburban, or urban location; sex; race/ethnicity; living situation; annual household income; and education level. We asked two questions to measure respondents' exposure to information about the potential impact of the MMA on patients with cancer. Specifically, we asked respondents whether they or their spouse or partner currently or in the past worked in a medical-related industry or profession, and whether the respondent was aware of the MMA.

### *Access to Chemotherapy*

We assessed respondents' access to chemotherapy by asking respondents to describe their experiences with obtaining a referral for treatment, the waiting time before initiation of treatment, travel to the treatment location, change in treatment location and physician, and employment status at the time of treatment. We also asked respondents if they had to stay overnight at a location other than their home as part of the treatment.

### *Satisfaction With Chemotherapy*

Respondents rated their satisfaction with specific aspects of their chemotherapy experience, such as the care provided by the oncologist and other staff members, ability to pay out-of-pocket costs, and the severity and control of side effects of treatment. We assessed general satisfaction with chemotherapy by asking respondents to describe their level of satisfaction with the coordination of care during chemotherapy sessions and the ease of obtaining answers to questions about chemotherapy. Satisfaction was measured on a 4-point scale ("very dissatisfied" to "very satisfied") (see Appendix B for the final survey).

## **Data Analysis**

We used descriptive statistics (means, SDs, medians, percentages) to summarize the data collected in the survey. We used Wilcoxon rank sum tests to assess differences between groups for continuous variables; and we used  $\chi^2$  tests to assess differences between groups for categorical variables.

To test the null hypothesis that mean days to initiation of chemotherapy did not change after enactment of the MMA, we developed a multivariable regression model in which the dependent variable was the number of days to initiation of chemotherapy. Independent variables included sex, race/ethnicity, type of cancer, a binary variable indicating age greater than 65 years, a binary variable indicating the timing of the participant's chemotherapy relative to the enactment of the MMA, and an interaction term between the age group and timing variables. We also constructed a model to test the null hypothesis that the location of chemotherapy was unchanged following enactment of the MMA. Specifically, we developed a multivariable multinomial logistic regression model in which the independent variable indicated whether the initial chemotherapy cycle was administered in a private doctor's office, hospital outpatient clinic or infusion center, community-based infusion center, or inpatient hospital setting. Independent variables were the same as those in the multivariable regression model.

In addition, we assessed differences within two subgroups of participants—those in rural locations and those with Medicare without supplemental insurance.

We used SAS version 9.1.3 for all analyses (SAS Institute Inc, Cary, NC). The institutional review board of the Duke University Health System determined that the study was exempt from the requirement for approval.

## **Results**

A total of 1421 respondents qualified for and completed the survey. Six hundred eighty-four respondents were in the pre-MMA group, and 737 respondents were in the post-MMA group (Table 6).

### *Respondent Characteristics*

Respondents were primarily female and white and had a mean age of 60 years. There were fewer women in the older age group (51%) than in the younger age group (80.5%), reflecting the relatively high number of patients with breast cancer in the group aged 65 and older. Thirty-four percent of the respondents reported breast cancer as their primary cancer diagnosis, and 51% reported private, employer-based health insurance as their main source of health insurance at the time of chemotherapy. Forty-six percent of the respondents had at least a college degree, and 47% had an annual household income of \$45,000 or more. Twenty-six percent of the respondents described their location of residence as rural, and 87% lived with a spouse or partner. Twenty-nine percent reported that either they or their spouse currently or in the past worked in a medical-related industry or profession. Thirty-one percent of the respondents in the post-MMA group was aware of the enactment of the MMA (Table 7).

### *Access to Chemotherapy*

Time to initiation of chemotherapy was similar in the two groups. Among respondents aged 65 and older, those in the pre-MMA cohort had an average waiting time to initiation of chemotherapy of 3.9 weeks, compared to 3.7 weeks among respondents in the post-MMA cohort

( $P = .74$ ). The main reason for the delay was the patient having to undergo surgery before starting chemotherapy (36% in the pre-MMA group vs 61% in the post-MMA group;  $P = .02$ ).

Among respondents aged 65 and older, most respondents received chemotherapy in outpatient hospital infusion centers or infusion centers affiliated with private practices (73% in the pre-MMA group vs 62% in the post-MMA group;  $P = .02$ ). Relatively few participants (12% in both the pre-MMA and post-MMA groups) reported that the treatment location changed during the course of treatment. Most respondents in both groups reported traveling approximately 30 minutes to their chemotherapy location. Finally, a small percentage of respondents reported having to stay overnight at a location other than home following the chemotherapy visit (5.5% in the pre-MMA group vs 5.0% in the post-MMA group;  $P = .66$ ).

Contrary to our expectations, respondents younger than 65 reported similar experiences with time to initiation of chemotherapy and treatment location as those aged 65 and older. Younger participants in the pre-MMA group had an average waiting time to initiation of chemotherapy of 3.4 weeks, compared to 3.6 weeks in the post-MMA group ( $P = .10$ ). Most respondents in the younger age group received chemotherapy in outpatient hospital infusion centers or infusion centers affiliated with private practices (70% in the pre-MMA group vs 64% in the post-MMA group;  $P = .01$ ). Table 8 shows all results related to access.

#### *Satisfaction With Chemotherapy Services*

Satisfaction in the pre-MMA and post-MMA groups was similar. Among respondents aged 65 and older, 65% of respondents in both groups reported being “very satisfied” with the care their oncologist provided. Seventy-six percent of participants aged 65 and older in the pre-MMA group were “very satisfied” with the care that the staff at the infusion location provided.

Among respondents younger than 65, there was an increase in the number of respondents who were “very satisfied” with the care their oncologist provided (58% in the pre-MMA group vs 67% in the post-MMA group;  $P < .01$ ). There was a similar finding with respect to satisfaction with the care that the infusion center staff provided (68% in the pre-MMA group vs 76% in the post-MMA group;  $P = .11$ ).

Table 9 show all results related to satisfaction.

#### *Multivariable Analysis*

After adjusting for sex, rural location, cancer type, and race/ethnicity, we found that respondents aged 65 and older in the post-MMA cohort received chemotherapy 2.8 days earlier than those in the pre-MMA cohort. However, this finding was not statistically significant (95% CI,  $-6.59$  to  $1.02$ ). After adjusting for sex, rural location, cancer type, and race/ethnicity, we found no statistically significant change in treatment location between respondents aged 65 and older in the pre-MMA and post-MMA cohorts (odds ratio [OR] [95% CI] compared to private office: 1.53 [0.81-2.89] for hospital inpatient settings; 0.68 [0.42-1.08] for hospital outpatient settings; 0.84 [0.53-1.33] for community infusion centers).

### *Subgroup Analyses*

We separately examined access to care in two subgroups of respondents—those living in rural areas and Medicare beneficiaries without supplemental insurance. Given the small number of respondents from rural areas, we could not analyze these respondents in older and younger age groups.

Among respondents in rural areas, time to initiation of chemotherapy was 3.0 weeks in the pre-MMA group and 3.9 weeks in the post-MMA group ( $P = .25$ ). Among respondents with Medicare without supplemental insurance, time to initiation of chemotherapy was 4.3 weeks in the pre-MMA group and 4.0 weeks in the post-MMA group ( $P = .95$ ).

There were differences in treatment location among respondents in rural areas and among respondents with Medicare without supplemental insurance. Among respondents in rural areas, 34% in the pre-MMA group reported receiving chemotherapy in an outpatient hospital infusion center, compared to 22% in the post-MMA group ( $P < .01$ ). Fourteen percent of respondents in the pre-MMA group reported receiving chemotherapy in a private doctor's office, compared to 30% in the post-MMA group ( $P < .01$ ). The findings were similar among respondents with Medicare without supplemental insurance. Forty percent of these respondents in the pre-MMA group reported receiving chemotherapy in an outpatient hospital infusion center, compared to 21% in the pre-MMA group ( $P = .03$ ); and 17% in the pre-MMA reported receiving chemotherapy in a private doctor's office, compared to 33% in the post-MMA group ( $P = .03$ ).

Given the limited sample size, we could not assess the robustness of these findings in multivariate analysis. Table 10 shows all subgroup results.

## **Discussion**

With the enactment of the MMA, reimbursement for chemotherapy drugs changed considerably. How the legislation will affect patients is unclear, but some commentators have expressed concern that patients' access to and satisfaction with care will suffer. To examine real and perceived changes in care, we compared time to initiation of chemotherapy, treatment location, and satisfaction with chemotherapy before and after enactment of the MMA through an analysis of Medicare claims data and a Web-based survey of patients with cancer. Overall, we found no difference between the pre-MMA and post-MMA groups with respect to mean days to initiation of treatment and treatment location.

Three findings are particularly noteworthy. First, we found no increase in the time from diagnosis to first chemotherapy visit following the enactment of the MMA. Our analysis of Medicare claims suggests that the time to initiation of chemotherapy in 2003 and 2004 was 30 days for inpatient treatment and 50 days for outpatient and office-based treatment. By comparison, respondents to the Web-based survey reported a mean time to initiation of treatment of 22 days. These estimates are generally consistent with the findings of Schrag et al<sup>11</sup> in which the mean time to initiation of adjuvant chemotherapy after colon resection was 25 to 30 days.

Second, the Medicare claims analysis revealed that the large majority of beneficiaries received chemotherapy in a physician's office (80%). Sixty-seven percent of survey respondents reported receiving chemotherapy in either outpatient hospital infusion centers or infusion centers affiliated with private practices. The distribution of patients across treatment locations was virtually unchanged from 2003 to 2004, suggesting that treatment location has not changed in anticipation of the effective date of the MMA. An alternative explanation is that the CMS demonstration project delayed changes in treatment location and that the full effect of the MMA reimbursement change may not be felt until the CMS demonstration payments are phased out.

Third, the subgroup analyses of survey respondents in rural areas and respondents with Medicare without supplemental insurance suggest that treatment locations have changed for these respondents since the implementation of the MMA. However, this finding should be interpreted with caution. The sample sizes of both groups were small (364 respondents from rural areas; 118 respondents with Medicare without supplemental insurance) and covariate adjustments were not possible. Consequently, the observed differences may reflect baseline differences between the pre-MMA and post-MMA cohorts in these subgroups. However, anecdotal reports suggest that these subgroups may be the most vulnerable to changes caused by the MMA. Further research in this area is warranted.

## **Strengths and Limitations**

The work we report here has some strengths and some limitations. First, we used Medicare claims data to document how chemotherapy is administered to elderly patients in the United States. The results provide a baseline against which to measure provider responses to the reimbursement changes made effective on January 1, 2005. It will be important to replicate the analysis after the MMA reimbursement changes are implemented fully. Second, we directly surveyed 1421 patients with cancer regarding their access to and satisfaction with cancer care. Anecdotal evidence can be useful for hypothesis generation but cannot substitute for asking patients directly about their experiences.

The major limitation to the Medicare claims analysis is that the data precede the full implementation of the MMA. As a result, our analysis provides only a baseline assessment of access to chemotherapy. Second, the claims analysis relies on accurate coding of chemotherapy services and treatment location. Finally, we were unable to assess quality of care using the Medicare claims data, which limited our ability to make comparisons with the survey data.

Web-based surveys also have limitations. First, some respondents were asked to recall experiences that occurred up to 3 years ago. We attempted to minimize recall bias by limiting the entry date of the study to January 2003 and by asking participants to focus on the first time they received chemotherapy. Second, the survey relied on responses from a convenience sample of patients, so the generalizability of the results to the wider population of patients with cancer is unclear. However, we stratified the sample by region to ensure nationwide representation. Third, since the survey was administered on the Internet and respondents were recruited through patient

resource Web sites, respondents to the survey may have a different level of ability to identify resources to help them navigate the health care system, compared to patients who did not participate in the survey.

## Conclusions and Recommendations

There is substantial concern about the effects that changes in reimbursement to physicians for chemotherapy will have on Medicare beneficiaries' ability to access care. We attempted to address this issue in two ways. First, we examined available Medicare claims data to gain an objective understanding of changes in access to care since the implementation of the MMA. Second, we conducted a survey of patients with cancer to assess their perceptions about access to therapies. There were strengths and limitations to each of these approaches, and our hope was that they would complement each other. Overall, our findings do not support generalizations from anecdotal reports that patients are being affected by the change in reimbursement to oncologists for chemotherapy as result of the MMA. The analysis may be confounded by payments to physicians in the concurrent CMS cancer demonstration project, because these payments may have masked changes that have resulted from the MMA. Furthermore, the Medicare claims analysis provides a baseline assessment of access to chemotherapy. We strongly recommend that future research efforts reexamine Medicare claims for services incurred after full implementation of the MMA reimbursement changes in 2005 and 2006, when those data become available.

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**Table 1. Codes and Descriptions of Cancer Diagnoses**

Tumor Type	Diagnostic Codes (ICD-9-CM)	Therapeutic Procedure Codes (ICD-9-CM)	Therapeutic Procedure Codes (CPT-4)
Lung	162.0-162.9	Resection (32.29, 32.4, 32.5, 32.6, 32.9)	Resection (32440-32525, 32657, 32663)
Breast	174.0-174.9	Local excision/lumpectomy (85.20, 85.21, 85.22) Auxiliary nod excision (40.51)	Local excision/lumpectomy (19112, 19120, 19125, 19126)
Colorectal	153.0-153.4, 153.5-153.9, 154.0, 154.1	Resection (48.5, 48.62, 48.63)	Resection (44140-44160, 45110-45121)

ICD-9-CM indicates *International Classification of Diseases, Ninth Revision, Clinical Modification*; and CPT-4, *Current Procedural Terminology, Fourth Edition*.

**Table 2: Demographic characteristics of Medicare claims analysis**

	<b>2003 (N=2,337)</b>	<b>2004 (N=2,396)</b>	<b>p-value</b>
<b>Mean age, y (sd)</b>	75.16 (5.36)	75.24 (5.56)	0.59
<b>Male</b>	1,034 (44.2)	1,082 (45.2)	0.53
<b>Race</b>			0.79
<b>White</b>	2,071 (88.6)	2,112 (88.1)	
<b>Black</b>	193 (8.3)	211 (8.8)	
<b>Other/Unknown</b>	73 (3.1)	73 (3.0)	
<b>Cancer Type</b>			0.02
<b>Breast</b>	479 (20.5)	445 (18.6)	
<b>Colorectal</b>	842 (36.0)	811 (33.8)	
<b>Lung</b>	1,016 (43.5)	1,140 (47.6)	
<b>Ischemic heart disease</b>	863 (36.9)	907 (37.9)	0.51
<b>Hypertension</b>	1,644 (70.3)	1,789 (74.7)	0.00
<b>Cerebrovascular disease</b>	406 (17.4)	486 (20.3)	0.01
<b>Dementia</b>	37 (1.6)	43 (1.8)	0.57
<b>Chronic obstructive pulmonary disease</b>	1,085 (46.4)	1,194 (49.8)	0.02
<b>Diabetes</b>	584 (25.0)	691 (28.8)	0.00
<b>Peripheral vascular disease</b>	469 (20.1)	524 (21.9)	0.13
<b>Renal disease</b>	98 (4.2)	148 (6.2)	0.00
<b>Any malignancy</b>	1,190 (50.9)	1,306 (54.5)	0.01
<b>Region</b>			0.39
<b>Northeast</b>	447 (19.1)	452 (18.9)	
<b>South</b>	939 (40.2)	1,006 (42.0)	
<b>Midwest</b>	664 (28.4)	632 (26.4)	
<b>West</b>	287 (12.3)	306 (12.8)	
<b>Location of first chemo treatment</b>			0.97
<b>Inpatient</b>	111 (4.7)	115 (4.8)	
<b>Outpatient</b>	379 (16.2)	394 (16.4)	
<b>Physician office</b>	1,847 (79.0)	1,887 (78.8)	

**Table 3: Comparison between 2003 and 2004 of days/distance to treatment**

	2003				2004			
	Days to treatment		Distance to treatment (mi)		Days to treatment		Distance to treatment (mi)	
	Mean (SD)	Median	Mean (SD)	Median	Mean (SD)	Median	Mean (SD)	Median
<b>Inpatient</b>	30.52 (46.28)	16	14.64 (17.78)	6.92	31.45 (45.64)	18	11.06 (16.45)	5.15
<b>Outpatient</b>	50.02 (55.64)	35	13.07 (16.62)	7.28	47.92 (54.99)	30.5	14.91 (18.40)	8.03
<b>Physician Office</b>	42.99 (46.92)	30	13.83 (17.13)	7.23	42.93 (43.42)	31	14.39 (16.75)	8.06

**Table 4: Unadjusted relationship between study variables and days/distance to chemotherapy**

	Days from diagnosis to first chemotherapy			Distance traveled for first chemotherapy		
	Hazard Ratio	95% Confidence Interval		Parameter Estimate	95% Confidence Interval	
<b>Age</b>	1.00	0.99	1.00	-0.16	-0.25	-0.07
<b>Sex</b>						
<b>Male</b>	1.13	1.07	1.20	1.00	0.02	1.98
<b>Female</b>	—	—	—	—	—	—
<b>Race</b>						
<b>White</b>	1.05	0.89	1.24	2.86	0.05	5.67
<b>Black</b>	0.97	0.80	1.17	-0.84	-4.06	2.38
<b>Other/Unknown</b>	—	—	—	—	—	—
<b>Cancer Type</b>						
<b>Breast</b>	0.65	0.60	0.71	0.15	-1.17	1.47
<b>Colorectal</b>	0.65	0.61	0.69	0.27	-0.83	1.36
<b>Lung</b>	—	—	—	—	—	—
<b>Ischemic heart disease</b>	1.03	0.97	1.09	-0.71	-1.72	0.29
<b>Hypertension</b>	1.00	0.94	1.06	-1.28	-2.38	-0.19
<b>Cerebrovascular disease</b>	1.11	1.04	1.20	-0.74	-1.98	0.51
<b>Dementia</b>	0.84	0.67	1.05	-1.28	-5.05	2.48
<b>Chronic obstructive pulmonary disease</b>	1.29	1.22	1.37	0.00	-0.97	0.98
<b>Diabetes</b>	0.97	0.91	1.03	-1.69	-2.79	-0.60
<b>Peripheral vascular disease</b>	1.07	1.00	1.15	-0.46	-1.66	0.73
<b>Renal disease</b>	1.07	0.94	1.22	-1.96	-4.14	0.23
<b>Any malignancy</b>	1.80	1.70	1.91	-0.51	-1.48	0.47
<b>Region</b>						
<b>Midwest</b>	0.96	0.87	1.06	1.14	-0.50	2.79
<b>Northeast</b>	0.84	0.75	0.93	-2.39	-4.15	-0.64
<b>South</b>	0.97	0.89	1.06	4.03	2.48	5.59
<b>West</b>	—	—	—	—	—	—
<b>Year of incidence and treatment</b>						
<b>2004</b>	1.00	0.95	1.06	0.57	-0.41	1.54
<b>2003</b>	—	—	—	—	—	—

**Table 5: Adjusted relationship between study variables and days/distance to chemotherapy**

	Days from diagnosis to first chemotherapy			Distance traveled for first chemotherapy		
	Hazard Ratio	95% Confidence Interval		Parameter Estimate	95% Confidence Interval	
Age	1.00	1.00	1.01	-0.15	-0.24	-0.06
Sex						
Male	1.04	0.98	1.12	1.27	0.18	2.36
Female	—	—	—	—	—	—
Race						
White	1.04	0.88	1.23	2.01	-0.80	4.82
Black	0.99	0.82	1.20	-2.39	-5.62	0.84
Other/Unknown	—	—	—	—	—	—
Cancer Type						
Breast	0.74	0.68	0.81	0.92	-0.63	2.48
Colorectal	0.71	0.66	0.76	0.98	-0.25	2.20
Lung	—	—	—	—	—	—
Ischemic heart disease	0.97	0.91	1.03	-0.36	-1.44	0.72
Hypertension	1.00	0.93	1.07	-0.32	-1.45	0.81
Cerebrovascular disease	1.02	0.95	1.10	-0.64	-1.92	0.65
Dementia	0.80	0.64	1.00	-0.61	-4.34	3.13
Chronic obstructive pulmonary disease	1.09	1.02	1.16	0.21	-0.90	1.32
Diabetes	1.00	0.93	1.06	-1.37	-2.49	-0.25
Peripheral vascular disease	0.99	0.92	1.07	0.10	-1.15	1.35
Renal disease	1.00	0.88	1.14	-1.41	-3.61	0.78
Any malignancy	1.74	1.65	1.85	-0.27	-1.24	0.70
Region						
Midwest	0.92	0.83	1.02	1.24	-0.42	2.90
Northeast	0.80	0.72	0.89	-2.16	-3.92	-0.39
South	0.92	0.84	1.01	4.36	2.79	5.94
West	—	—	—	—	—	—
Year of incidence and treatment						
2004	0.97	0.91	1.02	0.69	-0.28	1.65
2003	—	—	—	—	—	—

**Table 6. Medicare region distribution of respondents**

<b>Medicare Region</b>	<b>Pre-MMA Group</b>		<b>Post-MMA Group</b>	
	<b>Under 65</b>	<b>65 and Over</b>	<b>Under 65</b>	<b>65 and over</b>
<b>1</b>	30	30	31	30
<b>2</b>	33	30	45	27
<b>3</b>	36	33	58	28
<b>4</b>	67	34	67	43
<b>5</b>	47	33	60	37
<b>6</b>	30	29	37	30
<b>7</b>	30	30	30	30
<b>8</b>	30	30	19	30
<b>9</b>	40	30	41	32
<b>10</b>	30	32	30	32

**Table 7: Patient characteristics by pre/post MMA legislation cohort**

Characteristic	All Respondents			Over 65			Under 65		
	Pre-MMA (N=684)	Post-MMA (N=737)	p-value	Pre-MMA (N=311)	Post-MMA (N=319)	p-value	Pre-MMA (N=373)	Post-MMA (N=418)	p-value
<b>Female sex</b>	492 (71.9)	465 (63.1)	<.001	185 (59.5)	136 (42.6)	<.0001	307 (82.3)	329 (78.7)	0.20
<b>Age, mean ± SD, y</b>	60.2 (12.0)	59.0 (13.2)	0.12	70.8 (4.8)	71.3 (4.9)	0.17	51.3 (8.6)	49.5 (8.9)	<.001
<b>Ethnicity</b>			<.001			0.18			0.01
<b>Hispanic or Latino</b>	9 (1.3)	27 (3.7)		4 (1.3)	9 (2.8)		5 (1.3)	18 (4.3)	
<b>Not Hispanic or Latino</b>	675 (98.7)	710 (96.3)		307 (98.7)	310 (97.2)		368 (98.7)	400 (95.7)	
<b>Race</b>									
<b>American Indian or Alaska Native</b>	7 (1.0)	19 (2.6)	0.03	4 (1.3)	8 (2.5)	0.26	3 (0.8)	11 (2.6)	0.05
<b>Asian</b>	19 (2.8)	7 (0.9)	0.01	8 (2.6)	2 (0.6)	0.05	11 (2.9)	5 (1.2)	0.08
<b>Black or African American</b>	23 (3.4)	32 (4.3)	0.34	8 (2.6)	17 (5.3)	0.08	15 (4.0)	15 (3.6)	0.75
<b>Native Hawaiian or other Pacific Islander</b>	1 (0.1)	1 (0.1)	0.96	0 (0.0)	0 (0.0)		1 (0.3)	1 (0.2)	0.94
<b>White</b>	640 (93.6)	677 (91.9)	0.22	293 (94.2)	288 (90.3)	0.07	347 (93.0)	389 (93.1)	0.99
<b>Other</b>	8 (1.2)	25 (3.4)	0.01	3 (1.0)	13 (4.1)	0.01	5 (1.3)	12 (2.9)	0.14
<b>Don't know</b>	0 (0.0)	2 (0.3)	0.17	0 (0.0)	0 (0.0)		0 (0.0)	2 (0.5)	0.18
<b>Primary Cancer Diagnosis</b>			0.81			0.09			0.63
<b>Breast</b>	235 (34.4)	240 (32.6)		94 (30.2)	64 (20.1)		141 (37.8)	176 (42.1)	
<b>Prostate</b>	22 (3.2)	25 (3.4)		19 (6.1)	20 (6.3)		3 (0.8)	5 (1.2)	
<b>Lung</b>	89 (13.0)	88 (11.9)		57 (18.3)	60 (18.8)		32 (8.6)	28 (6.7)	
<b>Colon</b>	62 (9.1)	82 (11.1)		33 (10.6)	54 (16.9)		29 (7.8)	28 (6.7)	
<b>Leukemia</b>	15 (2.2)	13 (1.8)		9 (2.9)	7 (2.2)		6 (1.6)	6 (1.4)	
<b>Lymphoma</b>	80 (11.7)	97 (13.2)		37 (11.9)	39 (12.2)		43 (11.5)	58 (13.9)	
<b>Ovarian</b>	69 (10.1)	66 (9.0)		15 (4.8)	20 (6.3)		54 (14.5)	46 (11.0)	
<b>Other</b>	112 (16.4)	126 (17.1)		47 (15.1)	55 (17.2)		65 (17.4)	71 (17.0)	
<b>Health insurance coverage at first chemotherapy course</b>									
<b>Medicare (with supplemental)</b>	162 (23.7)	175 (23.7)	0.98	157 (50.5)	164 (51.4)	0.82	5 (1.3)	11 (2.6)	0.20
<b>Medicare (without supplemental)</b>	56 (8.2)	73 (9.9)	0.26	50 (16.1)	62 (19.4)	0.27	6 (1.6)	11 (2.6)	0.32
<b>Medicare managed care plan</b>	25 (3.7)	63 (8.5)	<.001	22 (7.1)	62 (19.4)	<.0001	3 (0.8)	1 (0.2)	0.26
<b>Private by individual</b>	96 (14.0)	91 (12.3)	0.35	38 (12.2)	25 (7.8)	0.07	58 (15.5)	66 (15.8)	0.93
<b>Private with employer</b>	346 (50.6)	350 (47.5)	0.24	77 (24.8)	56 (17.6)	0.03	269 (72.1)	294 (70.3)	0.58
<b>Public</b>	30 (4.4)	46 (6.2)	0.12	8 (2.6)	21 (6.6)	0.02	22 (5.9)	25 (6.0)	0.96
<b>Military</b>	31 (4.5)	16 (2.2)	0.01	12 (3.9)	5 (1.6)	0.08	19 (5.1)	11 (2.6)	0.07

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<b>Uninsured</b>	14 (2.0)	22 (3.0)	0.26	3 (1.0)	5 (1.6)	0.50	11 (2.9)	17 (4.1)	0.40
<b>Annual income</b>			0.02			<.001			0.01
<b>Under \$15,000</b>	78 (11.4)	104 (14.1)		48 (15.4)	62 (19.4)		30 (8.1)	42 (10.0)	
<b>\$15,000-\$29,999</b>	84 (12.3)	128 (17.4)		52 (16.7)	84 (26.3)		32 (8.6)	44 (10.5)	
<b>\$30,000-\$44,999</b>	98 (14.3)	95 (12.9)		49 (15.8)	68 (21.3)		49 (13.2)	27 (6.5)	
<b>\$45,000-\$59,999</b>	98 (14.3)	76 (10.3)		40 (12.9)	24 (7.5)		58 (15.6)	52 (12.4)	
<b>\$60,000-\$99,999</b>	122 (17.9)	137 (18.6)		46 (14.8)	26 (8.2)		76 (20.4)	111 (26.6)	
<b>\$100,000 or more</b>	101 (14.8)	107 (14.5)		25 (8.0)	17 (5.3)		76 (20.4)	90 (21.5)	
<b>Don't know/unsure</b>	12 (1.8)	17 (2.3)		7 (2.3)	5 (1.6)		5 (1.3)	12 (2.9)	
<b>Prefer not to answer</b>	90 (13.2)	73 (9.9)		44 (14.1)	33 (10.3)		46 (12.4)	40 (9.6)	
<b>Educational level</b>			0.24			0.04			0.38
<b>8<sup>th</sup> grade or less</b>	6 (0.9)	7 (0.9)		5 (1.6)	6 (1.9)		1 (0.3)	1 (0.2)	
<b>Some high school</b>	18 (2.6)	31 (4.2)		14 (4.5)	22 (6.9)		4 (1.1)	9 (2.2)	
<b>High school graduate</b>	126 (18.4)	162 (22.0)		76 (24.4)	97 (30.4)		50 (13.4)	65 (15.6)	
<b>Some college</b>	216 (31.6)	202 (27.4)		93 (29.9)	73 (22.9)		123 (33.0)	129 (30.9)	
<b>College graduate or beyond</b>	313 (45.8)	328 (44.5)		123 (39.5)	116 (36.4)		190 (50.9)	212 (50.7)	
<b>Don't know/unsure</b>	0 (0.0)	1 (0.1)		0 (0.0)	0 (0.0)		0 (0.0)	1 (0.2)	
<b>Prefer not to answer</b>	5 (0.7)	6 (0.8)		0 (0.0)	5 (1.6)		5 (1.3)	1 (0.2)	
<b>Residence environment</b>			0.55			0.58			0.80
<b>Rural</b>	176 (25.7)	188 (25.5)		104 (27.9)	118 (28.2)		72 (23.2)	70 (21.9)	
<b>Urban</b>	177 (25.9)	209 (28.4)		80 (21.4)	97 (23.2)		97 (31.2)	112 (35.1)	
<b>Suburban</b>	331 (48.4)	340 (46.1)		189 (50.7)	203 (48.6)		142 (45.7)	137 (42.9)	
<b>Living situation</b>									
<b>Alone</b>	123 (18.0)	118 (16.0)	0.33	79 (25.4)	60 (18.8)	0.05	44 (11.8)	58 (13.9)	0.38
<b>Spouse or partner</b>	486 (86.6)	542 (87.7)	0.58	209 (90.1)	230 (88.8)	0.64	277 (84.2)	312 (86.9)	0.31
<b>Other family members</b>	73 (13.0)	80 (12.9)	0.97	13 (5.6)	31 (12.0)	0.01	60 (18.2)	49 (13.6)	0.10
<b>Children</b>	146 (26.0)	167 (27.0)	0.70	17 (7.3)	25 (9.7)	0.36	129 (39.2)	142 (39.6)	0.93
<b>Pets</b>	201 (35.8)	221 (35.8)	0.98	57 (24.6)	53 (20.5)	0.28	144 (43.8)	168 (46.8)	0.43
<b>Roommates</b>	13 (2.3)	11 (1.8)	0.51	3 (1.3)	3 (1.2)	0.89	10 (3.0)	8 (2.2)	0.51
<b>Nursing home</b>	1 (0.2)	0 (0.0)	0.29	0 (0.0)	0 (0.0)		1 (0.3)	0 (0.0)	0.30
<b>Paid home health aide/nurse</b>	0 (0.0)	2 (0.3)	0.18	0 (0.0)	0 (0.0)		0 (0.0)	2 (0.6)	0.18
<b>Retirement home</b>	1 (0.2)	2 (0.3)	0.62	1 (0.4)	2 (0.8)	0.63	0 (0.0)	0 (0.0)	
<b>Assisted living facility</b>	0 (0.0)	0 (0.0)		0 (0.0)	0 (0.0)		0 (0.0)	0 (0.0)	
<b>Other</b>	5 (0.9)	6 (1.0)	0.89	1 (0.4)	2 (0.8)	0.63	4 (1.2)	4 (1.1)	0.90
<b>Medical Industry Employment</b>			0.30			0.09			0.41
<b>Yes</b>	201 (29.4)	244 (33.1)		61 (19.6)	86 (27.0)		233 (62.5)	258 (61.7)	
<b>No</b>	480 (70.2)	489 (66.4)		247 (79.4)	231 (72.4)		0 (0.0)	2 (0.5)	
<b>Aware of MMA?*</b>									
<b>Yes</b>	0 (0.0)	215 (31.4)		0 (0.0)	96 (32.1)		0 (0.0)	119 (30.9)	
<b>No</b>	0 (0.0)	469 (68.6)		0 (0.0)	203 (67.9)		0 (0.0)	266 (69.1)	

\*Only post-MMA group received this question

**Table 8: Access by pre/post MMA legislation cohort (N, %)**

Access Question	All Respondents			Over 65			Under 65		
	Pre-MMA (N=684)	Post-MMA (N=737)	p-value	Pre-MMA (N=311)	Post-MMA (N=319)	p-value	Pre-MMA (N=373)	Post-MMA (N=418)	p-value
<b>Experience obtaining referral</b>			0.07			0.34			0.07
<b>Very difficult</b>	15 (2.2)	20 (2.7)		7 (2.3)	10 (3.1)		8 (2.1)	10 (2.4)	
<b>Somewhat difficult</b>	53 (7.7)	33 (4.5)		24 (7.7)	18 (5.6)		29 (7.8)	15 (3.6)	
<b>Somewhat easy</b>	113 (16.5)	130 (17.6)		55 (17.7)	70 (21.9)		58 (15.5)	60 (14.4)	
<b>Very easy</b>	503 (73.5)	554 (75.2)		225 (72.3)	221 (69.3)		278 (74.5)	333 (79.7)	
<b>Type of difficulty (of those responding very difficult to somewhat difficult, n=121)</b>			0.06			0.09			0.69
<b>Plan wouldn't authorize service</b>	3 (4.4)	1 (1.9)		2 (6.5)	1 (3.6)		1 (2.7)	0 (0)	
<b>Plan authorization took too long</b>	6 (8.8)	7 (13.2)		3 (9.7)	4 (14.3)		3 (8.1)	3 (12.0)	
<b>Wait for appointment was too long</b>	8 (11.8)	18 (34.0)		5 (16.1)	13 (46.4)		3 (8.1)	5 (20.0)	
<b>Inconvenient provider location</b>	1 (1.5)	1 (1.9)		0 (0.0)	1 (3.6)		1 (2.7)	0 (0)	
<b>Doctor/plan wouldn't allow referral to provider of choice</b>	8 (11.8)	7 (13.2)		3 (9.7)	3 (10.7)		5 (13.5)	4 (16.0)	
<b>Didn't like/not confident in referred provider</b>	24 (35.3)	10 (18.9)		11 (35.5)	4 (14.3)		13 (35.1)	6 (24.0)	
<b>Provider's office hours were inconvenient</b>									
<b>Other</b>	18 (26.5)	9 (17.0)		7 (22.6)	2 (7.1)		11 (29.7)	7 (28.0)	
<b>Average waiting time to chemotherapy treatment initiation</b>									
<b>Weeks, mean ± SD</b>	3.6 (3.3)	3.7 (4.2)	0.83	3.9 (3.6)	3.7 (4.6)	0.74	3.4 (3.0)	3.6 (3.8)	0.10
<b>*Reason for the delay (for those reporting delay &gt; 4 weeks, n=304)</b>			< 0.001			0.02			0.19
<b>Surgery</b>	61 (43.6)	96 (58.9)		25 (36.2)	45 (60.8)		36 (50.7)	51 (57.3)	
<b>Additional diagnostic tests</b>	31 (22.1)	26 (16.0)		16 (23.2)	12 (16.2)		15 (21.1)	14 (15.7)	

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<b>Time to get appointment</b>	7 (5.0)	14 (8.6)		4 (5.8)	6 (8.1)		3 (4.2)	8 (9.0)	
<b>Other</b>	29 (20.7)	26 (16.0)		15 (21.7)	10 (13.5)		14 (19.7)	16 (18.0)	
<b>Don't know</b>	11 (7.9)	1 (0.6)		8 (11.6)	1 (1.4)		3 (4.2)	0 (0)	
<b>Change oncologist during chemotherapy treatment course (% yes)</b>	77 (11.3)	75 (10.2)	0.32	45 (14.5)	30 (9.4)	0.06	32 (8.6)	45 (10.8)	0.30
<b>Satisfaction with change in oncologist (for those reporting change, n=152)</b>			0.81			0.22			0.55
<b>Very dissatisfied</b>	6 (7.8)	4 (5.3)		2 (4.4)	2 (6.7)		4 (12.5)	2 (4.4)	
<b>Dissatisfied</b>	2 (2.6)	3 (4.0)		1 (2.2)	0 (0.0)		1 (3.1)	3 (6.7)	
<b>Satisfied</b>	14 (18.2)	11 (14.7)		8 (17.8)	1 (3.3)		6 (18.8)	10 (22.2)	
<b>Very satisfied</b>	55 (71.4)	57 (76.0)		34 (75.6)	27 (90.0)		21 (65.6)	30 (66.7)	
<b>Changed oncologist by choice (% no)</b>	15 (19.5)	15 (20.0)	0.94	9 (20.0)	7 (23.3)	0.73	6 (18.8)	8 (17.8)	0.91
<b>Changed oncologist because health insurance was no longer accepted (% No) (of those responding no to above question, n=30)</b>	15 (100.0)	11 (73.3)	0.03	9 (100.0)	3 (42.9)		6 (100.0)	8 (100.0)	0.01
<b>Location of first chemotherapy cycle</b>			< 0.001			0.02			0.01
<b>Hospital inpatient</b>	62 (9.1)	93 (12.6)		24 (7.7)	48 (15.0)		38 (10.2)	45 (10.8)	
<b>Hospital infusion center/clinic</b>	260 (38.0)	221 (30.0)		113 (36.3)	91 (28.5)		147 (39.4)	130 (31.1)	
<b>Private doctor's clinic</b>	111 (16.2)	156 (21.2)		53 (17.0)	61 (19.1)		58 (15.5)	95 (22.7)	
<b>Infusion center affiliated with oncologist practice</b>	227 (33.2)	246 (33.4)		114 (36.7)	108 (33.9)		113 (30.3)	138 (33.0)	
<b>Other</b>	24 (3.5)	21 (2.8)		7 (2.3)	11 (3.4)		17 (4.6)	10 (2.4)	
<b>Location change? (% yes)</b>	99 (14.5)	91 (12.4)	0.24	37 (11.9)	40 (12.5)	0.81	62 (16.6)	51 (12.2)	0.08
<b>Where did location change to? (of those responding yes to change, n=190)</b>			0.30			0.09			0.48
<b>Hospital inpatient</b>	9 (9.1)	6 (6.6)		5 (13.5)	0 (0.0)		4 (6.5)	6 (11.8)	
<b>Hospital infusion center/clinic</b>	26 (26.3)	30 (33.0)		12 (32.4)	16 (40.0)		14 (22.6)	14 (27.5)	
<b>Private doctor's clinic</b>	11 (11.1)	16 (17.6)		2 (5.4)	6 (15.0)		9 (14.5)	10 (19.6)	

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<b>Infusion center affiliated with oncologist practice</b>	38 (38.4)	32 (35.2)		13 (35.1)	15 (37.5)		25 (40.3)	17 (33.3)	
<b>Other</b>	15 (15.2)	7 (7.7)		5 (13.5)	3 (7.5)		10 (16.1)	4 (7.8)	
<b>Average travel time to first chemotherapy cycle</b>									
<b>Minutes, mean ± SD</b>	34.0 (42.3)	33.8 (42.0)	0.30	32.6 (28.5)	30.0 (25.5)	0.39	35.2 (51.0)	36.7 (50.9)	0.61
<b>Experience getting to location of first chemotherapy treatment cycle</b>			0.35			0.25			0.70
<b>Very difficult</b>	7 (1.0)	14 (1.9)		2 (0.6)	4 (1.3)		5 (1.3)	10 (2.4)	
<b>Somewhat difficult</b>	49 (7.2)	62 (8.4)		20 (6.5)	27 (8.5)		29 (7.8)	35 (8.4)	
<b>Somewhat easy</b>	170 (25.0)	193 (26.2)		77 (25.0)	95 (29.9)		93 (25.0)	98 (23.4)	
<b>Very easy</b>	454 (66.8)	467 (63.5)		209 (67.9)	192 (60.4)		245 (65.9)	275 (65.8)	
<b>First chemotherapy treatment cycle location offered ancillary services</b>									
<b>Financial counseling</b>	194 (28.4)	284 (38.5)	<0.0001	89 (28.6)	134 (42.0)	<0.001	105 (28.2)	150 (35.9)	0.02
<b>Nutrition counseling</b>	263 (38.5)	346 (46.9)	<0.001	132 (42.4)	148 (46.4)	0.32	131 (35.1)	198 (47.4)	< 0.001
<b>Psychotherapy counseling</b>	153 (22.4)	205 (27.8)	0.02	73 (23.5)	76 (23.8)	0.92	80 (21.4)	129 (30.9)	< 0.001
<b>None</b>	261 (38.2)	227 (30.8)	< 0.001	114 (36.7)	106 (33.2)	0.37	147 (39.4)	121 (28.9)	<0.001
<b>Don't know</b>	88 (12.9)	85 (11.5)	0.44	45 (14.5)	25 (7.8)	0.01	43 (11.5)	60 (14.4)	0.24
<b>Employment status at first chemotherapy cycle</b>			0.01			0.01			0.14
<b>Employed/Self-employed</b>	240 (35.3)	225 (30.6)		69 (22.4)	42 (13.2)		171 (46.0)	183 (43.8)	
<b>Employed on long-term sick leave</b>	104 (15.3)	106 (14.4)		14 (4.5)	12 (3.8)		90 (24.2)	94 (22.5)	
<b>Homemaker</b>	54 (7.9)	56 (7.6)		9 (2.9)	11 (3.5)		45 (12.1)	45 (10.8)	
<b>Student</b>	7 (1.0)	10 (1.4)		0 (0.0)	0 (0.0)		7 (1.9)	10 (2.4)	
<b>Volunteer</b>	1 (0.1)	1 (0.1)		1 (0.3)	0 (0.0)		0 (0.0)	1 (0.2)	
<b>Retired</b>	228 (33.5)	254 (34.5)		202 (65.6)	229 (72.0)		26 (7.0)	25 (6.0)	
<b>Unemployed</b>	29 (4.3)	30 (4.1)		8 (2.6)	5 (1.6)		21 (5.6)	25 (6.0)	
<b>Disabled</b>	17 (2.5)	54 (7.3)		5 (1.6)	19 (6.0)		12 (3.2)	35 (8.4)	
<b>Hours worked at first chemotherapy cycle</b>									
<b>Hours, mean ± SD</b>	31.1 (16.0)	31.0 (24.2)	0.86	26.4 (16.3)	30.2 (14.8)	0.22	33.0 (15.5)	31.2 (25.9)	0.25
<b>Employment status at end of chemotherapy course</b>			0.64			0.09			0.68

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<b>Employed/Self-employed</b>	200 (29.3)	199 (27.0)		55 (17.8)	32 (10.0)		145 (38.9)	167 (40.0)	
<b>Employed on long-term sick leave</b>	79 (11.6)	89 (12.1)		15 (4.9)	12 (3.8)		64 (17.2)	77 (18.4)	
<b>Homemaker</b>	55 (8.1)	53 (7.2)		12 (3.9)	11 (3.4)		43 (11.5)	42 (10.0)	
<b>Student</b>	5 (0.7)	9 (1.2)		0 (0.0)	0 (0.0)		5 (1.3)	9 (2.2)	
<b>Volunteer</b>	1 (0.1)	0 (0.0)		1 (0.3)	0 (0.0)		0 (0.0)	0 (0.0)	
<b>Retired</b>	240 (35.2)	264 (35.8)		206 (66.7)	236 (74.0)		34 (9.1)	28 (6.7)	
<b>Unemployed</b>	41 (6.0)	40 (5.4)		8 (2.6)	9 (2.8)		33 (8.8)	31 (7.4)	
<b>Disabled</b>	61 (8.9)	83 (11.3)		12 (3.9)	19 (6.0)		49 (13.1)	64 (15.3)	
<b>Hours worked at end of chemotherapy course</b>									
<b>Hours, mean <math>\pm</math> SD</b>	28.4 (13.8)	29.6 (13.7)	0.31	24.7 (15.8)	33.7 (14.3)	<0.001	29.8 (12.8)	28.8 (13.5)	0.65
<b>Usual transportation to chemotherapy treatment</b>			0.40			0.08			0.57
<b>Drove own car</b>	208 (30.4)	211 (28.6)		103 (33.1)	96 (30.1)		105 (28.2)	115 (27.5)	
<b>Driven by friend/family member</b>	448 (65.5)	493 (66.9)		191 (61.4)	209 (65.4)		257 (68.9)	284 (67.9)	
<b>Taxi</b>	4 (0.6)	7 (0.9)		0 (0.0)	4 (1.3)		4 (1.1)	3 (0.7)	
<b>Bus, train, other public transportation</b>	20 (2.9)	16 (2.2)		17 (5.5)	9 (2.8)		3 (0.8)	7 (1.7)	
<b>Walked</b>	4 (0.6)	10 (1.4)		0 (0.0)	1 (0.3)		4 (1.1)	9 (2.2)	
<b>Average waiting time before initiation of chemotherapy treatment</b>			0.79			0.14			0.31
<b>&lt; 5 minutes</b>	73 (10.7)	73 (9.9)		46 (14.8)	36 (11.3)		27 (7.2)	37 (8.9)	
<b>5-15 minutes</b>	262 (38.3)	303 (41.1)		136 (43.7)	139 (43.6)		126 (33.8)	164 (39.2)	
<b>16-30 minutes</b>	180 (26.3)	183 (24.8)		65 (20.9)	80 (25.1)		115 (30.8)	103 (24.6)	
<b>31-59 minutes</b>	100 (14.6)	98 (13.3)		42 (13.5)	29 (9.1)		58 (15.5)	69 (16.5)	
<b>1-2 hours</b>	52 (7.6)	56 (7.6)		17 (5.5)	25 (7.8)		35 (9.4)	31 (7.4)	
<b>&gt; 2 hours</b>	17 (2.5)	24 (3.3)		5 (1.6)	10 (3.1)		12 (3.2)	14 (3.3)	
<b>*Reason for waiting time (if &gt; 31 minutes, n=347)</b>									
<b>Patient backup</b>	96 (56.8)	87 (48.9)	0.14	34 (53.1)	30 (46.9)	0.48	62 (59.0)	57 (50.0)	0.18
<b>Pre-chemotherapy consultations</b>	57 (33.7)	65 (36.5)	0.59	14 (21.9)	24 (37.5)	0.05	43 (41.0)	41 (36.0)	0.45
<b>Additional tests</b>	58 (34.3)	44 (24.7)	0.05	23 (35.9)	17 (26.6)	0.25	35 (33.3)	27 (23.7)	0.11
<b>Prep work (e.g., a visit with the nurse to check vitals, etc)</b>	107 (63.3)	102 (57.3)	0.25	35 (54.7)	36 (56.3)	0.86	72 (68.6)	66 (57.9)	0.10
<b>Other</b>	22 (13.0)	18 (10.1)	0.40	9 (14.1)	4 (6.3)	0.14	13 (12.4)	14 (12.3)	0.98
<b>Don't know</b>	8 (4.7)	15 (8.4)	0.17	4 (6.3)	8 (12.5)	0.23	4 (3.8)	7 (6.1)	0.43

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<b>Stay overnight? (% yes)</b>	36 (5.3)	47 (6.4)	0.37	17 (5.5)	15 (4.7)	0.66	19 (5.1)	32 (7.7)	0.14
<b>Participate in clinical trial? (% yes)</b>	90 (13.2)	86 (11.7)	0.51	30 (9.6)	25 (7.8)	0.53	60 (16.1)	61 (14.6)	0.79
<b>Was chemo paid by clinical trial? (% yes)</b>	24 (26.7)	29 (33.7)	0.26	7 (23.3)	8 (32.0)	0.42	17 (28.3)	21 (34.4)	0.63
<b>Services paid for through clinical trial (of those that said yes to above, n=176)</b>									
<b>Drugs</b>	17 (70.8)	28 (96.6)	0.01	4 (57.1)	8 (100.0)	0.04	13 (76.5)	20 (95.2)	0.09
<b>Physician services</b>	13 (54.2)	14 (48.3)	0.67	2 (28.6)	3 (37.5)	0.71	11 (64.7)	11 (52.4)	0.44
<b>Nursing services</b>	8 (33.3)	9 (31.0)	0.86	2 (28.6)	3 (37.5)	0.71	6 (35.3)	6 (28.6)	0.66
<b>Other</b>	1 (4.2)	3 (10.3)	0.40	0 (0.0)	1 (12.5)	0.33	1 (5.9)	2 (9.5)	0.68
<b>None</b>	0 (0.0)	0 (0.0)		0 (0.0)	0 (0.0)		0 (0.0)	0 (0.0)	
<b>Don't know</b>	4 (16.7)	6 (20.7)	0.71	2 (28.6)	5 (62.5)	0.19	2 (11.8)	1 (4.8)	0.43
<b>Remember being asked about fatigue, nausea and pain? (% yes)</b>	478 (69.9)	582 (79.0)	< 0.001	224 (72.0)	255 (79.9)	0.06	254 (68.1)	327 (78.2)	< 0.001

**Table 9: Patient satisfaction data by pre/post MMA legislation cohort, (N, %)**

Satisfaction Questions	All Respondents			Over 65			Under 65		
	Pre-MMA (N=684)	Post-MMA (N=737)	p-value	Pre-MMA (N=311)	Post-MMA (N=319)	p-value	Pre-MMA (N=373)	Post-MMA (N=418)	p-value
<b>Satisfaction with care from oncologist</b>			<.001			0.13			<.001
<b>Very dissatisfied</b>	23 (3.4)	19 (2.6)		9 (2.9)	11 (3.4)		14 (3.8)	8 (1.9)	
<b>Dissatisfied</b>	55 (8.0)	22 (3.0)		18 (5.8)	7 (2.2)		37 (9.9)	15 (3.6)	
<b>Satisfied</b>	188 (27.5)	209 (28.4)		82 (26.4)	93 (29.2)		106 (28.4)	116 (27.8)	
<b>Very satisfied</b>	418 (61.1)	487 (66.1)		202 (65.0)	208 (65.2)		216 (57.9)	279 (66.7)	
<b>Satisfaction with care from infusion center staff</b>			0.46			0.31			0.11
<b>Very dissatisfied</b>	16 (2.3)	14 (1.9)		5 (1.6)	6 (1.9)		11 (2.9)	8 (1.9)	
<b>Dissatisfied</b>	25 (3.7)	18 (2.4)		12 (3.9)	7 (2.2)		13 (3.5)	11 (2.6)	
<b>Satisfied</b>	153 (22.4)	157 (21.3)		57 (18.3)	74 (23.2)		96 (25.7)	83 (19.9)	
<b>Very satisfied</b>	490 (71.6)	548 (74.4)		237 (76.2)	232 (72.7)		253 (67.8)	316 (75.6)	
<b>Out of pocket costs? (% yes)</b>	400 (58.5)	439 (59.6)	<.0001	153 (49.2)	164 (51.4)	<.0001	247 (66.2)	275 (65.8)	0.3815
<b>Ability to pay out-of-pocket costs (of those who said yes, n=839)</b>			0.42			<.001			0.38
<b>Money left over</b>	149 (37.3)	148 (33.7)		71 (46.4)	42 (25.6)		78 (31.6)	106 (38.5)	
<b>Little spare money</b>	79 (19.8)	96 (21.9)		26 (17.0)	41 (25.0)		53 (21.5)	55 (20.0)	
<b>Cut back on things</b>	53 (13.3)	72 (16.4)		9 (5.9)	25 (15.2)		44 (17.8)	47 (17.1)	
<b>Difficulty paying no matter what</b>	119 (29.8)	123 (28.0)		47 (30.7)	56 (34.1)		72 (29.1)	67 (24.4)	
<b>Questions about chemotherapy treatment</b>			0.82			0.19			0.11
<b>Oncologist</b>	370 (54.1)	394 (53.5)		185 (59.5)	183 (57.4)		185 (49.6)	211 (50.5)	
<b>Nurse</b>	300 (43.9)	326 (44.2)		116 (37.3)	133 (41.7)		184 (49.3)	193 (46.2)	
<b>Other staff</b>	8 (1.2)	13 (1.8)		6 (1.9)	2 (0.6)		2 (0.5)	11 (2.6)	
<b>No questions</b>	4 (0.6)	3 (0.4)		3 (1.0)	0 (0.0)		1 (0.3)	3 (0.7)	
<b>*Satisfaction with ease of obtaining answers</b>			0.12			0.53			<.001
<b>Very dissatisfied</b>	19 (2.8)	12 (1.6)		6 (2.0)	8 (2.5)		13 (3.5)	4 (1.0)	
<b>Dissatisfied</b>	53 (7.8)	44 (6.0)		17 (5.5)	19 (6.0)		36 (9.7)	25 (6.0)	
<b>Satisfied</b>	250 (36.9)	255 (34.8)		102 (33.2)	121 (38.1)		148 (39.9)	134 (32.3)	
<b>Very satisfied</b>	356 (52.5)	422 (57.6)		182 (59.3)	170 (53.5)		174 (46.9)	252 (60.7)	
<b>Severity of side effects</b>			0.08			0.65			0.03
<b>Severe</b>	199 (29.4)	174 (23.7)		82 (26.7)	77 (24.2)		117 (31.5)	97 (23.4)	
<b>Moderate</b>	340 (50.1)	381 (52.0)		151 (49.2)	158 (49.7)		189 (50.9)	223 (53.7)	

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<b>Mild</b>	125 (18.4)	162 (22.1)		63 (20.5)	75 (23.6)		62 (16.7)	87 (21.0)	
<b>No side effects</b>	14 (2.1)	16 (2.2)		11 (3.6)	8 (2.5)		3 (0.8)	8 (1.9)	
<b>Rate of control for side effects (for those reporting severe, moderate or mild, n=1381)</b>			0.09			0.13			0.23
<b>Uncontrolled</b>	29 (4.4)	29 (4.0)		15 (5.1)	19 (6.1)		14 (3.8)	10 (2.5)	
<b>Limited control</b>	218 (32.8)	193 (26.9)		99 (33.4)	77 (24.8)		119 (32.3)	116 (28.5)	
<b>Good control</b>	377 (56.8)	443 (61.8)		157 (53.0)	188 (60.6)		220 (59.8)	255 (62.7)	
<b>Complete control</b>	40 (6.0)	52 (7.3)		25 (8.4)	26 (8.4)		15 (4.1)	26 (6.4)	
<b>Satisfaction with coordination of care</b>			0.04			0.03			0.80
<b>Very dissatisfied</b>	18 (2.6)	16 (2.2)		8 (2.6)	11 (3.4)		10 (2.7)	5 (1.2)	
<b>Dissatisfied</b>	37 (5.4)	30 (4.1)		7 (2.3)	10 (3.1)		30 (8.0)	20 (4.8)	
<b>Satisfied</b>	352 (51.5)	366 (49.7)		159 (51.1)	164 (51.4)		193 (51.7)	202 (48.3)	
<b>Very satisfied</b>	277 (40.5)	325 (44.1)		137 (44.1)	134 (42.0)		140 (37.5)	191 (45.7)	

**Table 10: Rural and Medicare without supplemental insurance subgroup analyses, (N, %)**

	Rural Respondents			Medicare without Supplemental Insurance Respondents		
	Pre-MMA (N=176)	Post-MMA (N=188)	p-value	Pre-MMA (N=52)	Post-MMA (N=66)	p-value
<b>Experience obtaining referral</b>			0.21			0.35
<b>Very difficult</b>	5 (2.8)	9 (4.8)		2 (3.8)	4 (6.1)	
<b>Somewhat difficult</b>	3 (1.7)	10 (5.3)		5 (9.6)	2 (3.0)	
<b>Somewhat easy</b>	29 (16.5)	29 (15.4)		8 (15.4)	15 (22.7)	
<b>Very easy</b>	139 (79.0)	140 (74.5)		37 (71.2)	45 (68.2)	
<b>Average waiting time to chemotherapy treatment initiation</b>						
<b>Weeks, mean ± SD</b>	3.0 (2.3)	3.9 (5.7)	0.25	4.3 (3.8)	4.0 (4.2)	0.95
<b>Reason for the delay (for those reporting delay &gt; 4 weeks, n=105)</b>			0.18			0.04
<b>Surgery</b>	17 (70.8)	25 (61.0)		3 (20.0)	14 (58.3)	
<b>Additional diagnostic tests</b>	5 (20.8)	4 (9.8)		1 (6.7)	1 (4.2)	
<b>Time to get appointment</b>	1 (4.2)	3 (7.3)		0 (0.0)	0 (0.0)	
<b>Other</b>	1 (4.2)	9 (22.0)		8 (53.3)	9 (37.5)	
<b>Don't know</b>	0 (0.0)	0 (0.0)		3 (20.0)	0 (0.0)	
<b>Location of first chemotherapy cycle</b>			<.001			0.03
<b>Hospital inpatient</b>	15 (8.5)	21 (11.2)		2 (3.8)	6 (9.1)	
<b>Hospital infusion center/clinic</b>	60 (34.1)	42 (22.3)		21 (40.4)	14 (21.2)	
<b>Private doctor's clinic</b>	24 (13.6)	56 (29.8)		9 (17.3)	22 (33.3)	
<b>Infusion center affiliated with oncologist practice</b>	66 (37.5)	60 (31.9)		20 (38.5)	21 (31.8)	
<b>Other</b>	11 (6.3)	9 (4.8)		0 (0.0)	3 (4.5)	
<b>Location change? (% yes)</b>	33 (18.8)	28 (15.0)	0.34	3 (5.8)	5 (7.6)	0.70
<b>Where did location change to? (of those responding yes to change, n=69)</b>			0.04			0.16
<b>Hospital inpatient</b>	0 (0.0)	1 (3.6)		1 (33.3)	0 (0.0)	
<b>Hospital infusion center/clinic</b>	4 (12.1)	12 (42.9)		2 (66.7)	1 (20.0)	
<b>Private doctor's clinic</b>	5 (15.2)	4 (14.3)		0 (0.0)	1 (20.0)	
<b>Infusion center affiliated with oncologist practice</b>	14 (42.4)	8 (28.6)		0 (0.0)	3 (60.0)	
<b>Other</b>	10 (30.3)	3 (10.7)		0 (0.0)	0 (0.0)	
<b>Average travel time to first chemotherapy cycle</b>						
<b>Minutes, mean ± SD</b>	46.8 (35.9)	45.4 (47.0)	0.15	32.7 (17.8)	38.2 (52.2)	0.24

**Appendix A: Composition of Medicare Regions**

<b>Region</b>	
<b>1</b>	Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont
<b>2</b>	New York and New Jersey, U.S. Virgin Islands and Puerto Rico
<b>3</b>	Delaware, Maryland, Pennsylvania, Virginia and West Virginia and the District of Columbia
<b>4</b>	Alabama, North Carolina, South Carolina, Florida, Georgia, Kentucky, Mississippi and Tennessee
<b>5</b>	Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin
<b>6</b>	Arkansas, Louisiana, New Mexico, Oklahoma, and Texas
<b>7</b>	Iowa, Kansas, Missouri, and Nebraska
<b>8</b>	Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming
<b>9</b>	Arizona, California, Hawaii and Nevada
<b>10</b>	Alaska, Idaho, Oregon and Washington

## Appendix B: Final Fielded Survey

### Introduction

Thank you for agreeing to participate in this survey. Cancer Consultants is interested in your opinions regarding the delivery of health care to cancer patients. Our first few questions are primarily for classification purposes and they enable us to select the questions to ask you later in the survey.

**[All questions required throughout entire survey]**

### Section 1: Exclusion Criteria

A01. What is your age in years?

**[Range 0-99]**

**[Exclude if under 18]**

A02. What is your sex?

- 1= Male
- 2= Female

A03. If you have been diagnosed by a medical professional with cancer, what was the location of your primary cancer diagnosis? Select only one response.

- 1= Breast
- 2= Prostate
- 3= Lung
- 4= Colon
- 5= Blood (Leukemia)
- 6= Lymphatic System (Hodgkin's/Non-Hodgkin's Lymphoma)
- 7= Ovary (Ovarian cancer)
- 8= Don't know
- 9= Prefer not to answer
- 10= Other, (please specify): \_\_\_\_\_

**[Exclude if they respond "Don't know" or "Prefer not to answer"]**

**[Exclude if they respond "Male" for A02a AND "Ovary (Ovarian cancer)" for A03a]**

**[Exclude if they respond "Female" for A02a AND "Prostate" for A03a]**

Chemotherapy is defined as the treatment of cancer with drugs that destroy cancer cells, often called "anticancer" drugs. These anticancer drugs destroy cancer cells by stopping them from growing or multiplying. [\*] Chemotherapy is often given in cycles or rounds that include treatment periods alternated with rest periods. For the purpose of this survey, we use the term *chemotherapy course* to refer to the entire chemotherapy process including cycles or rounds.

**[Starting from [\*] the above paragraph to appear as a banner on each page of the survey--or as a link/definition anytime the phrase "chemotherapy cycle" is used throughout the rest of the survey]**

A04. How do you receive your chemotherapy treatments? Select all that apply.

- 1= Intravenously (given through a vein e.g., by catheter, metaport or injection into an IV unit)
- 2= By mouth (orally given in pill, capsule, or liquid form)
- 3= By injection (a needle and syringe are used to inject the drug into a muscle, under the skin, or directly into cancerous area in the skin)

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**[Exclude if they do not respond with Intravenously as at least one response]**

A05. When did you start your first course of chemotherapy treatment for [cancer type from Q3] cancer? If you don't remember exactly, please make your best estimate.

(A05a.) Start Month: \_\_\_\_\_ **[Month drop down form]**

(A05b.) Start Year: \_\_\_\_\_ **[Year drop down form]**

A06. When did you stop your first course of chemotherapy treatment for [cancer type from A03] cancer? If you don't remember exactly, please make your best estimate.

(A06a.) Stop Month: \_\_\_\_\_ **[Month drop down form]**

(A06b.) Stop Year: \_\_\_\_\_ **[Year drop down form]**

**Programming logic:**

1. If [start\_date] is less than Jan 2003 then EXCLUDE
2. If [start\_date] is greater than or equal to Jan 2003 AND [stop\_date] is less than or equal to Jan 2005 then cohort=prior-MMA
3. If [start\_date] is greater than or equal to Feb 2005 then cohort=post-MMA
4. If [start\_date] is less than or equal to Jan 2005 and [stop\_date] is greater than or equal to Feb 2005 then EXCLUDE

**[Retain all start/stop dates]**

A07A. Check as many of the categories as you need to indicate your current health insurance coverage:

- 1= Coverage through Medicare with supplemental health insurance (e.g. Medigap)
- 2= Coverage through Medicare without supplemental health insurance
- 3= Coverage through a Medicare managed care plan (e.g. Medicare Advantage or Medicare+Choice)
- 4= Private health insurance paid by yourself
- 5= Private health insurance through employer (with or without contribution from you)
- 6= Public health insurance (Medicaid)
- 7= Military health insurance (e.g. VA/CHAMPUS)
- 8= Uninsured
- 9= Refused
- 10= Don't know

A08A. Was this the insurance coverage that you had when you had your **first** chemotherapy course in [Response from A05b]?

- 1= Yes
- 2= No

**[If No, answer 8aA]**

**[Exclude if participant selects "Refused" or "Don't know" for A07A and also selects "Yes" for A08A]**

A08aA. Check as many of the categories as you need to indicate the health insurance coverage you had when you had your **first** chemotherapy course in [Response from A05b]:

- 1= Coverage through Medicare with supplemental health insurance (e.g. Medigap)
- 2= Coverage through Medicare without supplemental health insurance

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- 3= Coverage through a Medicare managed care plan (e.g. Medicare Advantage or Medicare+Choice)
- 4= Private health insurance paid by yourself
- 5= Private health insurance through employer (with or without contribution from you)
- 6= Public health insurance (Medicaid)
- 7= Military health insurance (e.g. VA/CHAMPUS)
- 8= Uninsured
- 9= Refused
- 10= Don't know

**[Exclude if participant selects “Refused” or “Don’t know”]**

**[Programming note: Only ask A07B if A07A is 1, 2, OR 3]**

A07B. Did you enroll in a Medicare Prescription Drug Plan in 2006?

- 1= Yes
- 2= No
- 3= Don't know

**[If participant meets all inclusion criteria, Informed Consent happens here]**

### Informed Consent

Thank you for answering these preliminary questions. Before continuing with this survey, please read the following detailed information about the remainder of the survey. After reading the information about the survey, you will be asked to indicate your willingness to participate. By doing so, you will be giving your informed consent to participate in this online survey. Your consent is necessary for you to participate in the remainder of this survey.

The purpose of this study is to learn about the delivery of health care to cancer patients, particularly with how you receive care and how satisfied you are with that care. If you agree to be in this study, you will be asked to participate in a 15-20 minute online survey. The survey will ask general questions about your chemotherapy treatment experience as well as how satisfied you were with that experience. You will also be asked general questions about yourself and your health. This study is being conducted by researchers at Duke University Medical Center.

Your identity will not be disclosed in the survey data or in any resulting analyses. The success of this study depends on your being as honest in your answers as possible.

You may discontinue the survey at any time without any penalty.

A09. Please select your preference below:

- 1= I agree to participate in the remainder of the survey
- 2= I decline to participate further from the survey

**[Rest of survey contains the following prompt: “For the rest of the survey, please think about your IV chemotherapy treatments for [cancer type from A03] cancer.” This prompt to be displayed as a header on each page of the survey.]**

### Section 2: Access

**[For all difficulty rating questions, use 4-point horizontal likert scale based on the following scale: 1-Very difficult, 2-Somewhat difficult, 3-Somewhat easy, 4-Very easy]**

B01. Please rate your experience in obtaining a referral (a recommendation made by your physician to see a specialist) for chemotherapy treatment services that you and/or your physician thought were necessary.

- 1= Very difficult
- 2= Somewhat difficult
- 3= Somewhat easy
- 4= Very easy

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**[If answers “Very difficult” or “Somewhat difficult” answer B01a]**

B01a. What kind of difficulty did you have? Select only the primary difficulty.

- 1= Plan wouldn't authorize service
- 2= Plan authorization took too long
- 3= The wait for the appointment was too long
- 4= Provider's location was not convenient
- 5= Doctor/plan wouldn't give referral to see the provider that you wanted to see
- 6= You didn't like or were not confident in the provider you were referred to
- 7= Provider's office hours were not convenient
- 8= Other, (please specify): \_\_\_\_\_

B02. Considering the time between the provider's recommendation for you to have chemotherapy and when the treatments started, how long did you wait for your **first** chemotherapy cycle to begin – about how many weeks? If you don't remember exactly, please make your best estimate.

a= How many weeks? \_\_\_\_\_

**[If QB02 > 4 weeks then ask QB2b]**

B02b. What was the reason for this delay?

- 1= I had to undergo surgery before receiving chemotherapy
- 2= I had to undergo additional diagnostic tests before receiving chemotherapy
- 3= It took a long time getting the appointment scheduled (e.g., the schedule was booked)
- 4= Other, (please specify): \_\_\_\_\_
- na= Don't know

B03. Did you change oncologists (physicians who treat cancer patients) during your chemotherapy treatment course?

- 1= Yes
- 2= No
- 3= Don't know

**[If Yes, answer B03a-d]**

B03a. How satisfied were you with the change in oncologist?

- 1=Very dissatisfied
- 2=Dissatisfied
- 3=Somewhat satisfied
- 4=Very satisfied

B03b. Was this change in oncologist your own choice?

- 1= Yes **-Skip to 4**
- 2= No

**[If No, answer 3c]**

B03c. Did you change your oncologist because s/he no longer accepted your health insurance?

- 1= Yes
- 2= No
- 3= Don't know

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[If No, answer 3d]

B03d. Why did you change oncologists?

\_\_\_\_\_

B04. Where did you receive your **first** chemotherapy cycle? Select only one response.

- 1=Hospital as an inpatient - I was admitted to the hospital, and received chemotherapy as an inpatient (admitted and stayed at least 24 hours)
- 2=Hospital infusion center/clinic - I went to an infusion center/clinic at the hospital
- 3=Private doctor's office - I went to a private doctor's office in the community
- 4=Infusion center affiliated with my oncologist's practice - I went to an infusion center affiliated with my oncologist's practice located in the community
- 5=Other, (please specify): \_\_\_\_\_

B05. Did the location of your chemotherapy treatment change during the treatment course?

- 1= Yes
- 2= No

[If Yes, answer 5a]

B05a. Where did the location change to? Select only one response.

- 1=Hospital as an inpatient - I was admitted to the hospital, and received chemotherapy as an inpatient (admitted and stayed at least 24 hours)
- 2=Hospital infusion center/clinic - I went to an infusion center/clinic at the hospital
- 3=Private doctor's office - I went to a private doctor's office in the community
- 4=Infusion center affiliated with my oncologist's practice - I went to an infusion center affiliated with my oncologist's practice located in the community
- 5=Other, (please specify): \_\_\_\_\_

B06. Thinking about your **first** chemotherapy treatment cycle, on average, how long did you travel to get to your chemotherapy treatment location (one way)?

a=\_\_\_\_\_ minutes

B07. Please rate your experience in getting to the location of your **first** chemotherapy treatment cycle?

- 1=Very difficult
- 2=Somewhat difficult
- 3=Somewhat easy
- 4=Very easy

B08. Thinking about your **first** chemotherapy treatment cycle, did your chemotherapy treatment location offer any of the following services? Check all that apply.

- 1= Financial counseling (e.g. someone to help you deal with paying for and financing your chemotherapy treatment services, understanding health insurance coverage, etc.)
- 2= Nutrition counseling
- 3= Psychotherapy counseling
- 4= None of the above
- 5= Don't know

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B09. Check one of the following that best describes your employment status at the time of your **first** chemotherapy cycle.

- 1= Employed/Self-employed
- 2= Employed on long-term sick leave
- 3= Homemaker
- 4= Student
- 5= Volunteer
- 6= Retired
- 7= Unemployed
- 8= Disabled

**[If responds "Employed" answer B09a]**

B09a. Please state the number of hours worked per week at the time of your **first** chemotherapy cycle.

a=\_\_\_\_\_ hours per week

B10. Check one of the following that best describes your employment status at the **end** of your chemotherapy course?

- 1= Employed/Self-employed
- 2= Employed on long-term sick leave
- 3= Homemaker
- 4= Student
- 5= Volunteer
- 6= Retired
- 7= Unemployed
- 8= Disabled

**[If responds "Employed" answer 10a]**

B10a. Please state the number of hours worked per week at the **end** of your chemotherapy course.

a=\_\_\_\_\_ hours per week

B11. How did you usually get to your chemotherapy treatment? Select only one response.

- 1= Drove your own car
- 2= Was driven by a friend/family member
- 3= Taxi
- 4= Bus, train, other public transportation
- 5= Walked

B12. If you arrived on time for an appointment, on average, about how long did you wait before starting your chemotherapy treatment? Select only one response.

- 1= Less than 5 minutes
- 2= 5 to 15 minutes
- 3= 16 to 30 minutes
- 4= 31 to 59 minutes
- 5= 1 to 2 hours
- 6= More than 2 hours

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**[If B12= 4, 5, or 6 then ask B12b]**

B12b. What was the reason for this waiting time?(Check all that apply)

- 1=Patient backup
- 2=Pre-chemotherapy consultations
- 3=Additional tests
- 4=Prep work (e.g., a visit with the nurse to check vitals, etc)
- 5=Other, (please specify): \_\_\_\_\_
- na=Don't know

B13. Do you usually have to stay overnight at a location other than your home following your chemotherapy treatment?

- 1= Yes
- 2= No

B14. Did you participate in a chemotherapy clinical trial as a part of your treatment program?

- 1= Yes
- 2= No
- 3= Don't know

**[Include definition box for clinical trial as follows: “Clinical trials are research studies conducted with people who volunteer to take part. Each study answers scientific questions and tries to find better ways to prevent, screen for, diagnose, or treat a disease. In a clinical trial, patients receive treatment and doctors carry out research on how the treatment affects the patients.”]**

**[If Yes, answer 14a]**

B14a. Was your chemotherapy paid for through this clinical trial?

- 1= Yes
- 2= No
- 3= Don't know

**[If QB14a is “yes,” then ask QB14b]**

B14b. What services were paid for through this clinical trial? (Check all that apply)

- 1=Drugs
- 2=Physician services
- 3=Nursing services
- 4=No services were paid for
- 5=Other, (please specify): \_\_\_\_\_
- na=Don't know

B15. At your last chemotherapy treatment cycle do you remember being asked about how chemotherapy affected you in terms of fatigue, nausea and pain?

- 1= Yes
- 2= No
- 3= Don't remember/unsure

**Section 3: Satisfaction**

**[For all satisfaction rating questions, use 4-point horizontal likert scale based on the following scale: 1-Very dissatisfied, 2-Dissatisfied, 3Satisfied, 4-Very satisfied]**

C02. How satisfied were you with the care your oncologist provided?

- 1= Very dissatisfied
- 2= Dissatisfied
- 3= Satisfied
- 4= Very satisfied

C02a. How satisfied were you with the care the staff at your infusion location provided?

- 1= Very dissatisfied
- 2= Dissatisfied
- 3= Satisfied
- 4= Very satisfied

C03. Did you have out-of-pocket costs (e.g. any costs not covered by your health insurance and paid for by you) for your chemotherapy treatment?

- 1= Yes
- 2= No
- 3= Don't know

**[If Yes, answer C03b]**

C03b. How would you describe your ability to pay the out-of-pocket costs required for your chemotherapy treatment?

- 1= After paying out-of-pocket costs, you still have money left over.
- 2= You have enough money to pay out-of-pocket costs, but little spare money. You have money to pay out-of-pocket costs, but only because you have to cut back on things.
- 3= You have difficulty paying out-of-pocket costs, no matter what you do.

C06. If you had questions about your chemotherapy treatment, who did you usually ask?

- 1= Oncologist
- 2= Nurse
- 3= Didn't have any questions **[Skip to question 7]**
- 4= Don't know **[Skip to question 7]**
- 5= Other staff (please specify): \_\_\_\_\_

C06b. Please rate your level of satisfaction with the ease of obtaining answers to questions about your chemotherapy treatment?

- 1= Very dissatisfied
- 2= Dissatisfied
- 3= Satisfied
- 4= Very satisfied

C06c. Please describe the severity of side effects that you experienced from your chemotherapy treatment. Select only one response.

- 1=Severe
- 2=Moderate
- 3=Mild

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4=No side effects experienced

[If answer to C06c is 1 (severe), 2 (moderate), or 3 (mild) then ask C07]

C07. How would you rate the control of your chemotherapy treatment side effects?

- 1= Uncontrolled
- 2= Limited control
- 3= Good control
- 4= Complete control

C08. Please rate your level of satisfaction with the coordination of your care during your chemotherapy treatment sessions (did you feel like you answered the same questions multiple times, underwent the same test multiple times, etc.)?

- 1= Very dissatisfied
- 2= Dissatisfied
- 3= Satisfied
- 4= Very satisfied

**Section 4: Demographics**

D01. Please indicate your state of residence at the time of your first chemotherapy course in [Response from A05b].

a= \_\_\_\_\_ [Drop down form field]

AL=Alabama	LA=Louisiana	OH=Ohio
AK=Alaska	ME=Maine	OK=Oklahoma
AZ=Arizona	MD=Maryland	OR=Oregon
AR=Arkansas	MA=Massachusetts	PA=Pennsylvania
CA=California	MI=Michigan	RI=Rhode Island
CO=Colorado	MN=Minnesota	SC=South Carolina
CT=Connecticut	MS=Mississippi	SD=South Dakota
DE=Delaware	MO=Missouri	TN=Tennessee
FL=Florida	MT=Montana	TX=Texas
GA=Georgia	NE=Nebraska	UT=Utah
HI=Hawaii	NV=Nevada	VT=Vermont
ID=Idaho	NH=New Hampshire	VA=Virginia
IL=Illinois	NJ=New Jersey	WA=Washington
IN=Indiana	NM=New Mexico	WV=West Virginia
IA=Iowa	NY=New York	WI=Wisconsin
KS=Kansas	NC=North Carolina	WY=Wyoming
KY=Kentucky	ND=North Dakota	

D02. At the time of your first chemotherapy course in [Response from A05b], did you consider your place of residence to be in a rural, urban or suburban environment? Select only one response.

- 1= Rural
- 2= Urban
- 3= Suburban

D03. Please check only one of the following options to indicate your ethnicity:

- 1= Hispanic or Latino
- 2= Not Hispanic or Latino

D04. Check as many of the categories below as you need to indicate your race:

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- 1= American Indian or Alaska Native
- 2= Asian
- 3= Black or African American
- 4= Native Hawaiian or other Pacific Islander
- 5= White
- 6= Other, (please specify):
- na= Don't know

D05. What is your current living situation? Do you live--

- 1= By yourself?
- 2= With others?

**[If responds With others, answer D05a]**

D05a. Select the statements that best describe your current living situation. Please check all that apply.

- 1= I live with a spouse or partner
- 2= I live with other family members
- 3= I live with children
- 4= I live with pets
- 5= I live with roommates
- 6= I live in a nursing home
- 7= I live with a paid home health aide/nurse
- 8= I live in a retirement home
- 9= I live in an assisted living facility
- 10= Other, (please specify): \_\_\_\_\_

D06. What is your current annual household income before taxes?

- 1= Under \$15,000
- 2= \$15,000-\$29,999
- 3= \$30,000-44,999
- 4= \$45,000-\$59,999
- 5= \$60,000-\$99,999
- 6= \$100,000 or more
- 7= Don't know/unsure
- 8= Prefer not to answer

D07. What is the highest grade or level of schooling you have completed?

- 1= No formal schooling
- 2= 8th grade or less
- 3= Some high school
- 4= High school graduate
- 5= Some college
- 6= College graduate or beyond
- 7= Don't know/unsure
- 8= Prefer not to answer

D07a. Do you or your spouse/domestic partner currently or in the past worked in a medical-related industry or profession (examples would include a hospital, physician's office, pharmacy, pharmaceutical, biotechnology or medical supply company, clinical research organization or facility, etc.):

- 1= Yes
- 2= No
- 3= Don't know

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**[Only ask if A05 is greater than or equal to Feb 2005]**

D07b. Are you aware of the Medicare Prescription Drug Improvement and Modernization Act (MMA) (i.e., legislation signed into law in December 2003 that included changes to government Medicare reimbursement for private practice physicians for chemotherapy/cancer treatment services)?

1= Yes

2= No

**Thank you for your time.** We appreciate your participation in this important study on cancer care in America.