

**How Medicare Affects Patient Care for Kidney Cancer:  
Focus Group Findings with Patients and Caregivers**

**For the Kidney Cancer Association**

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## Background and Purpose

The Kidney Cancer Association (the Association), a voluntary health association, seeks to understand and make known the health care needs of kidney cancer patients, in order that policy makers might be better informed to address those needs. Toward this end, they have requested focus group research with kidney cancer patients with particular emphasis on Medicare.

## Method

We conducted one focus group with a total of 7 individuals – 5 kidney cancer patients and two spouses. All focus group participants had Medicare coverage, and all but one had other health insurance as well. The Association recruited all focus group participants. Two professional moderators from Balch Associates conducted the group session at the Chicago O’Hare Marriott during the national conference of the Kidney Cancer Association on July 21, 2000. In general, the discussion followed a topic guide that focused on the patients’ experiences in which the health care system, and Medicare particularly, has helped or hindered their care. (~~See Appendix.~~) The focus group session was conducted in a hotel meeting room and audio recorded and transcribed with participants’ consent. The audiotape and transcript were then analyzed for common themes important to focus group participants. This report is the result of that process.

Qualitative research of this sort provides rich, in-depth data that are most useful in exploring and understanding what and how research participants think, feel, and behave. The findings are not statistically projectable to any population and are based on a single small group.

## Key Findings

### Overview

Focus group participants noted that Medicare provides medical coverage to some patients who formerly had none. Beyond this, they mentioned no specific benefits for kidney cancer treatment. However, they mentioned a variety of problems. These include difficulties and fears involved in getting covered, inadequate coverage for prescription drugs (particularly self-administered IL-2), and inadequate support for research and clinical trials for “diseases that have no cure” like kidney cancer.

### Difficulties and Uncertainty about Getting Covered

All of these focus group participants reported experiencing serious difficulties or concerns about getting on Medicare when they were under 65 years old (except for one who automatically received Medicare at age 65). None found a clear, straightforward, risk-free process. Several participants had experienced uncertainties and deep fears about whether they

could get covered at all, how it might affect their private insurance, and what insurance coverage they might keep or lose as their illness or employment situation changed.

These fears may be well grounded. For example, one participant was unable to get covered until he turned 65, despite having had metastatic kidney cancer at the age of 62.

*Patient: I got this [kidney cancer] when I was 62 they cut me three ways. I couldn't work. I couldn't even get out of bed. So I had to quit but because I owned my own corporation, not only would they not put me on Medicare they wouldn't even let me retire on my Social Security which I thought that we had the right to do. I didn't get either one. And I had a letter from some consultant someplace that said kidney cancer is an easily treatable affair, it's not a cause for disability. And I can't even move. How many years did it take us ... five years to get that straightened out.*

*Spouse: I don't remember now but you did finally get disability checks. They let him draw his Social Security but then we didn't get Medicare. But you did get it but you didn't have any Medicare coverage until you turned sixty-five. We couldn't get any kind of coverage for him until he turned sixty-five. Well, we were paying sixteen thousand dollars a year in our private company for coverage. And we stayed terrified that they would walk. And they did walk. But it was the year he was sixty-five.*

*Patient: There was a fourteen-day window that I had no insurance of any kind.*

Another participant ended up with Medicare in addition to private insurance and found herself paying for three insurance plans but confident of using the benefits of only one. She signed up for a MediGap policy out of confusion as to precisely when she needed to decide. Now she does not use the policy because she fears that her secondary policy will not cover her if she does. So, she uses neither the secondary policy nor MediGap.

*And because of that six month window [to sign up for MediGap insurance or lose the opportunity] and nobody could tell me if the six months was starting when the Part A started or not I went ahead and got a MediGap policy even though I had primary insurance from work and I was on my husband's policy. But when I signed up ... it was unlikely that I would actually live long enough to have this problem. But I do. And I'm not using my secondary insurance because of this Medicare coverage. Because I think that the secondary would probably disallow my coverage if they knew I had Medicare.*

Even the most technically knowledgeable found the process confusing and risky.

*[Medicare] came to me unsolicited after I had been on Social Security and Disability for a year. They sent me a notice that I was eligible and would receive*

*Part A and I had thirty days to decide whether or not to buy Part B. Part B I had to make a decision within the thirty days at this cost. If I didn't take it every year it would go up unless I could prove that I was currently insured by somebody else. In which case I could get that lower cost whenever I lost the insurance here. It's a complicated process. And thank God I'm a lawyer.*

*This fear, I think, is the real core issue. I'm a health care professional, or was, ... and so as crusty and knowledgeable that we are there was some effort to get some clarity. So you can imagine the person who is worried about bills and this kidney cancer is kind of a repetitious kind of thing. I mean if you go after it aggressively you're running a hundred thousand dollars every three or four years. And so people get pretty anxious if they're not real clear about where they stand. ... From where I'm sitting that would be terrifying to somebody that just can't get their hands around the implications of having got it.*

Indeed, participants found that the process was so confusing and risky that it might require help from a knowledgeable advocate.

*The people who answer the phones aren't really equipped to answer the questions. They don't know the answers and the laws and the rules around Medicare are literally changing every year as the system is upgraded. And the people who answer the phones do not know how to answer the questions and the new publications do not reflect the changes.*

*There's in fact lawyers that specialize in [helping people get SSI and Medicare]. They're paid fifteen hundred dollars or something and they go through a process. But that's something I think needs to be fixed. Because the thing that I worry about is back to the original issue and somebody has got to be an advocate for the average person on the street that gets this disease that can't get their arms around the complexity of the questions. And it's not fair for a disease with a median survival ... of eleven to twelve months. What your decisions really be focused on is what's the right therapy option for me? And what you're hurled into is the games around who's going to pay for what.*

*I think the reason I didn't have to [get a lawyer] is [that] I'm sure [my company] did. Because they were obligated to pay my disability until Social Security kicked in. And so I think they were probably the ones that brought the lawyer in and made SSI do it. I certainly filled all the paperwork out. But they were on the hook if SSI didn't start.*

## Inadequate Coverage for Prescription Drugs

Focus group participants are concerned about Medicare's lack of coverage for prescription drugs, particularly for outpatient administered drugs, such as Interleukin-2 (IL-2). They consider this particular restriction entirely without justification and very serious. However, they are wary of simple solutions to the overall problem of covering prescription drugs.

### Interleukin-2 (IL-2)

Medicare restrictions on coverage of outpatient medications affect kidney cancer in particularly insidious ways. Interleukin 2 (IL-2) is the only FDA approved drug for metastatic kidney cancer. Medicare covers IL-2 only if it is administered on an outpatient basis. Participants believe that this rule imposes great inconvenience, personal suffering, and cost on them and on their families. It makes treatment inaccessible for many others. It inflates the cost of treatment. The only patient in the focus group who had received IL-2 treatment had received it at home, via private insurance.

*I think from both a humanitarian and a cost standpoint, [if would be good] if you get somebody to address this issue of allowing IL-2 patients to take it home under the administration and supervision of an RN. Now there are several reasons for this, one of which is [that it costs] about a tenth as expensive to the government. But it's the humane aspect of it. I had tumors that were ... pretty much written off but if I had had to go through the misery of driving in December through the traffic two or three hours and get this med shot into me and then make my way back home I think my odds of survival would have been ... five percent of what they were. Now here's the regime[n] we did. I had my supper. I would get me a shower. I would have a quiet time of meditation or whatever I wanted to. My daughter would come in and pop me just as I was going asleep. The first thing, I ain't sick any more.*

*You might do everybody a favor ... this is my thing ... at least make it legal for those who wish to do so and have the opportunity to get their subcu[taneously injected] IL-2 at home. Their chances of survival are so much better. ... And the safety issues -- there are no safety issues. How many people do you hear dying of an IL-2 injection?*

*[If I had not been able to take it at home] ... I would be dead. And the government would have paid a hell of a lot more money to the hospitals .... Yeah, I would have never gotten through it, because obviously I could not drive. So somebody was driving me to my appointments. And they would have had to drive me to the appointment ... I had shots in the morning and in the afternoon. It*

*would have been absurd. Essentially I would have ended up hospitalized for five months or I would have had to have a private driver who would have taken me down there for the three hours in the morning and then three hours in the evening. Because it's forty-five minutes to get there and get the shot.*

## **Drug Coverage Solutions**

Some participants are wary of apparently simple solutions to the problem of paying for prescription drugs. They consider it important to retain people's opportunity to have private insurance, as well as to avoid reducing incentives to conduct research and development for "diseases without a cure" like kidney cancer.

*Participant 1: Bill Clinton ... when he looked at his Medicare reform bill his original Medicare reform proposal was two thousand dollars a drug coverage.... I mean there are other details but it was only two thousand dollars a year coverage, period. Meaning if you were on Interleukin- 2, Interferon Alpha or whatever, two thousand dollars is a drop in the bucket.*

*Participant 2: It was three hundred thousand dollars for me to get to a drug free, cancer free point after doing my three drug therapies and four surgeries. Over two years. So unless it has stop loss protection .... then two thousand dollars of drug coverage ... don't even bother. I mean two thousand is nothing, an illusion of coverage.*

*Participant 1: So yes, Medicare needs drug coverage. Yes, we need stop loss protection. But we need to be really careful how it is implemented. Because we cannot capsize the boat because the Price Waterhouse Cooper Study went on to say that it is basically a step towards socialization of medicine. Because it was like three to five billion dollars that currently private industry is covering today which the federal government would be picking up the tab for. And it's kind of like modeling after the England and Canadian systems, where the government is now paying for peoples' coverage instead of private industry. And longer term it's going to impact research. Because with the two thousand dollars he's viewing that you use generic drugs instead of brand name drugs. I mean to get the two thousand dollars to work, to make it work, there was a lot of thought behind how you do that. And it all stymies research. And for diseases without a cure, a known cure, we need research. So anything that is done has to be done carefully so that the boat is not capsized.*

## **Inadequate Coverage for Clinical Trials**

None of these patients had been in a clinical trial. For one, this was because she was too sick to wait for one. Fortunately, her doctor, the government and her private insurance made it possible. It would not have been possible with Medicare, in any case, since they did not cover

any care for clinical trials. For others, it may be because Medicare did not cover care for clinical trials.

*I actually wouldn't have been alive long enough to make it to the trial so I actually got the drugs on a compassionate patient exemption. FDA Compassionate Patient Exemption. Because the groundwork was set to set the trial up but it was like six months down the line and I wasn't going to make it. And so they got the FDA Compassionate Patient Exemption so that I could do it. ... And it worked which is why I'm sitting here. And fortunately I was on my private insurance and they covered it. Had I been on Medicare they would not have thought of covering it. First off, because they wouldn't have covered clinical trials. Second off, because I really didn't make it to the clinical trial. It was a compassionate case.*

Moderator: *So, if I'm hearing you right, no one here has had actual experience with Medicare coverage and clinical trials. Right?*

Participant: *That's because Medicare wouldn't cover it. I mean up until Clinton's executive order in June, in terms of covering routine patient care costs associated with clinical trials, Medicare did not cover that.*

### **Low Reimbursement to Providers**

Participants are aware that Medicare reimburses providers at low levels. Their views differ on the consequences of low levels of reimbursement to providers. Some are just pleased that Medicare gets providers to accept a much lower level of payment and bring down their own personal payments. Some wondered how this might affect the practice of medicine.

*I'm tickled that the medical profession will sit still and accept twenty or twenty-five percent of their bill ... of their invoices. ... I'm tickled that they're about to put that kind of pressure on the medical profession to get that kind of rates. And I'm saying that if I were not covered ... think of the horrendous invoices that I would have to pay. If I didn't have Medicare as a gatekeeper for me I would be paying three and four times as much for the doctor's services.*

*When we go for CT scans and all, under private, they had to pay the doctors a lot more money than Medicare pays. But if your doctor takes assignment then he's stuck with whatever they allow.*

*But what I'm saying is where is the slack in this? How can Medicare get by with dictating to the medical profession what a reasonable charge for their services are?*

## Conclusions

These kidney cancer patients are clearly among the fortunate few. They have been surviving kidney cancer for years. No doubt this is partly due to good fortune. But they would not have been able to take advantage of that good fortune without the personal resolve, financial and mental resources, and family support that they brought to bear. For the most part, they did not rely on Medicare.

What might be done to improve Medicare for kidney cancer patients? From these patients' point of view, several possibilities for action may seem worth considering::

- Simplify, clarify, and communicate effectively to patients the process and significance of getting Medicare coverage.
- Do not rush gravely ill people into complicated, potentially high-risk decisions.
- Provide up-to-date, clear information and have knowledgeable staff available to answer questions.
- Create and fill Ombudsman or Patient Advocate positions within Medicare.
- Cover self-injection for IL-2.
- Cover prescription drugs without compromising investment or incentives for research and development (including clinical trials) for “diseases without a cure” such as kidney cancer.
- Cover patient care costs associated with clinical trials.

These findings and recommendations would be greatly strengthened by conducting additional focus groups with more typical kidney cancer patients, those who:

- rely primarily on Medicare
- lack the resources of these focus group participants
- have been more recently diagnosed with metastatic kidney cancer
- have been less fortunate in their disease progress.



## APPENDIX: DISCUSSION GUIDE FOR KIDNEY CANCER ASSOCIATION PHYSICIAN FOCUS GROUPS

**Objectives:** (for moderator only) Identify views of physicians who treat kidney cancer patients, on Medicare, to determine

- What they see as problems and areas of concern with Medicare
- Changes in Medicare that they would welcome
- What aspects of Medicare they perceive to work well

### Introduction

(5-10 minutes)

- Welcome, thanks for coming, fill out name tents
- Topic: Discuss your views on Medicare and Kidney Cancer, so the Association can represent your views to Congress
- Process: Open, confidential discussion, taped so researcher can write a report. No one will be identified by name.
- Personal introductions: first name, city you are from, medical specialty

### Problems experienced with Medicare

(55 minutes)

- Who here has had problems in the last 6-12 months with Medicare related to kidney cancer? [SHOW OF HANDS AND COUNT FOR TAPE] What kinds of problems? [LIST ON EASEL – TO EXHAUSTION]
- Now, let's get an idea of *how important* these are. Here are 5 sticky dots. I'd like you to walk up to the easel and stick them onto the problems that concern you the most. Place as many dots as you want next to a problem – the more dots you put on a problem, the more of a difference it would make to fix it. You can put all of your dots on one problem, one dot on each of 5 problems, or spread them out any way you like. Any questions about this? [ANSWER QUESTIONS AND HAVE PARTICIPANTS GO TO THE EASEL]
- [FOR AS MANY TOP PROBLEMS AS TIME PERMITS] Let's talk about these problems with the most dots first. What makes [name of problem on list] important to you? [KEEP GOING DOWN THE LIST]
- [IF NOT A TOP PROBLEM OR NOT MENTIONED, PROBE ON:]
  - S *Prescription drugs*
  - ⇒ How many of you have prescribed Interleukin 2? [COUNT FOR TAPE]
  - ⇒ How does Medicare cover the cost? (Covered only for medical center administration, not at home) → What consequences for patient care?

⇒ How well does Medicare cover cost of other drugs as a result of kidney cancer or its complications? → What consequences for patient care?

S *Clinical trials*

⇒ How many of you have tried to enter kidney cancer patients in a clinical trial?  
[COUNT FOR TAPE]

⇒ What problems, if any, were there with Medicare coverage → what consequences for patient care?

S *Limits on newer treatments?*

S *Guidelines* that Medicare sets for physicians? How does Medicare affect how you treat patients? [PROBE IF NOT MENTIONED: Frequency of CT scans, prescribing less preferred therapies – which? How does this affect patient care?

- Do you have kidney cancer patients who are covered by private insurance rather than Medicare? What differences do you see between the way private insurance and Medicare deals with kidney cancer patients, especially problems like the ones we have been discussing?

**Solutions**

**(20 minutes)**

- Let's go down that list one more time. For each of these problems, what changes in the Medicare system would make it easier for you to provide the best treatment to your kidney cancer patients? [FOR EACH:] How would that help?
  - What other changes in Medicare, if any, would help you care for your kidney cancer patients? How?
- Now, let's turn to the other side: how has Medicare helped you in the care of your kidney cancer patients? [NEW LIST ON EASEL] Is that something you want Congress to keep as is?
- How involved is your medical institution in medical (Medicare) policy reform? What do you see as the barriers to their involvement? What helps them get involved?

**Wrap Up**

**(5 minutes)**

- Is there anything else about Medicare and Kidney Cancer that you would like to add before we close?
- Thank Participants