

# Improving Informed Consent for Palliative Chemotherapy

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## What was the research about?

Palliative chemotherapy is a treatment for advanced cancer that isn't curable. This treatment may help slow the cancer's growth or help patients to feel fewer effects from cancer.

To get permission to use this treatment, doctors give patients an information sheet and a consent form to read and sign. But even after reading these materials, many patients don't understand that palliative chemotherapy won't cure their cancer.

In this study, the research team made a video and booklet for patients that explained the goals of treatment for advanced cancer. The team wanted to see if the video and booklet helped patients to better understand treatment goals compared with those who got only the usual forms.

## What were the results?

The group that got the video and booklet reported that palliative chemotherapy would not cure their cancer just as often as the group that got the usual forms.

Patients who got the video and booklet understood more about the risks of palliative chemotherapy compared with those who received the usual forms. But the research team didn't find differences between the two groups in

- Knowing the goals of treatment
- Feeling confident about their decision

- Regretting their decision
- Feeling satisfied with the talks they had with doctors about the treatment
- Feeling emotional distress
- Understanding the likely outcomes of their cancer

## Who was in the study?

The study included 186 patients getting care at five hospitals. Of these patients, 87 percent were white, 9 percent were African American, and 4 percent were Asian or other races. In addition, 58 percent were men, and 58 percent had graduated from college. Patients had colorectal cancer or pancreatic cancer. The average age was 59.

## What did the research team do?

The team made a booklet and a video about palliative chemotherapy. The booklet included a link to a website to watch the video. Patients in the video talked about getting treatment, its side effects, and the quality of their lives while having treatment. Doctors and nurses in the video talked about the purpose, benefits, risks, and side effects of treatment.

The research team asked patients to be part of the study when they were either making decisions about palliative treatment for their cancer or had started treatment in the past two weeks. After patients agreed to be in the study, the team assigned patients by chance to one of two groups. One group got the usual information sheet and form to give consent. The other

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group got the booklet with the link to the video along with the usual forms.

Patients filled out surveys at the start of the study, two weeks after deciding about having the treatment, and three months after the start of the study. The surveys included questions about what patients knew about the treatment goals and how they felt about making a decision.

Patients, caregivers, doctors, and nurses worked with the research team on many parts of this project, including making the video and booklet.

### **What were the limits of the study?**

Not everyone in the group who got the booklet read it or watched the video. Results may be different if people receive regular reminders to read the booklet

and watch the video. People in the study were mostly white, and more than half had graduated from college. The results might be different for other groups of people.

In the future, researchers could test different ways to get patients to read the booklet and watch the video. Future studies could also test the booklet and video with people from different backgrounds.

### **How can people use the results?**

Researchers can use these results to find ways to help patients understand the goals of palliative chemotherapy when making decisions about treatment.

*To learn more about this project, visit [www.pcori.org/Schrag105](http://www.pcori.org/Schrag105).*