In 2007, Dave deBronkart was diagnosed with stage IV kidney cancer. He was given six months to live. But thanks to advice he received from an online patient community, deBronkart found a drug that saved his life.

This is a report for iHealthBeat, a daily news service of the California HealthCare Foundation. I'm Kenny Goldberg.

The online patient group that helped deBronkart, ACOR.org, is a collection of virtual cancer communities. One of them includes hundreds of patients who live and breathe kidney cancer and its treatment options.

deBronkart says he discovered that clinicians aren't the only source of medical information.

(deBronkart): "What a smart patient community talks about is often a great supplement."

And deBronkart says his experience gave him a new attitude.

(deBronkart): "Rather than expecting the doctors and nurses to do everything, you think, you say and you embody, 'How can I help?'"

Name a disease, and you'll likely find an online group for it.

Some online communities, including PatientsLikeMe, have hundreds of thousands of members. Others, like one dedicated to the rare condition known as systemic capillary leak syndrome, have less than 300 participants.

Regardless of size, these virtual communities offer education, recommendations and support for patients who share the same condition.

The online patient community movement is attempting to redefine the relationship between doctors and their patients, and it represents a major challenge to the way the medical system operates.

Danny Sands, a primary care doctor and professor at Harvard Medical School, believes the status quo is no longer acceptable.
Sands is the co-founder of the Society of Participatory Medicine. The group encourages patients to become more active in their own health and to collaborate more effectively with health care providers.

Sands says that's what the online patient movement is all about.

Sands says there's a growing body of evidence that shows shifting to this more collaborative model improves cost effectiveness, outcomes and satisfaction for all stakeholders.

But some physicians have reservations about online patient communities.

Sherry Franklin is a pediatric endocrinologist in Encinitas, Calif.

She welcomes the parents of her patients who want to take a more active role in their care. And Franklin believes online groups provide good patient support. But ...

Franklin: "I know it's hard to prevent patients from sharing inaccurate information, but that does concern me. There's also over- and under-estimates of the seriousness of illness by patients. And there's also some recommendations, not all, of treatment options that really don't have scientific support."

What's more, Franklin says some people aren't aware that insurance plans won't pay for every test and treatment that they might read about online.

Franklin: "And so in that case, I'm concerned that patients think, 'Well, if I go into my doctor, and I share this information, automatically I'll get it.' And it's not that we don't want them to have whatever they think would be best for their care, as long as we think it's based on evidence-based medicine, it's that sometimes we don't have a choice."

Nonetheless, online patient groups have driven home a message: Patients should be seen as equal partners in their care.
Eric Topol is a cardiologist, the director of the Scripps Translational Science Institute and author of the recently published book "The Patient Will See You Now." He says these days, with easy access to medical information on the Internet and with the help of online support groups and smartphones, patients are better equipped to manage their conditions.

Topol believes the medical community needs to get with the program.

*(Topol): "I think the doctors who don't support this will ultimately become disintermediated by these activated, empowered consumers."

Topol says this new reality of informed, engaged patients requires doctors to redefine their role.

*(Topol): "It's providing the guidance, experience, the wisdom and treatment and healing, rather than being so much engaged into the ordering of tests and the diagnosis and monitoring aspects."

But will the participatory model of medicine lead to the destruction of the doctor-patient relationship? Topol doesn't think so. Instead, he argues it will take it to another level.

This has been a report for *iHealthBeat*, a daily news service from the California HealthCare Foundation. If you have feedback or other issues you’d like to have addressed, please email us at IHB@chcf.org. I'm Kenny Goldberg. Thanks for listening.