People looking for health care resources on Facebook have mixed success with their searches according to a new study from the Center for Connected Health. However social networking sites are increasingly acknowledged as an important tool for clinicians. What does the future look like for social networking and health care? This is an audio report for iHealthBeat, a daily news service of the California HealthCare Foundation. I'm Rachel Dornhelm.

Research Scientist Timothy Hale is the lead author on the Facebook study. He is walking me through a search exercise on the dominant social networking site.

_Hale: "If you type in 'breast cancer' ... you know you'll get a lot of big hits right off the bat that are pretty relevant..."

_Dornhelm: "Yes, I have Breast Cancer Action, California Breast Cancer Research Program ..."

In fact, the team found cancer was the dominant health condition represented on Facebook. Hale says in the study, cancer accounted for almost 90% of the total "likes" on the health pages they surveyed even though the illness only accounted for about 12% of the total health care pages they counted. Hale says this is likely because many people may have known someone with cancer and want to signal support. On the flip side, Hale says there are diseases that are far underrepresented on Facebook.

_Hale: "If you try stroke, we can try that and see what it comes up with."

_Dornhelm: "Oh wow, I have The Strokes, the band."

_Hale: "Yeah, that's what I have as my top one. So the term for that medical condition is kind of generic so it's not very good in being able to predict what you're looking for."

Some of the variability may also come from stigma associated with certain diseases. Diarrhea is not a well-represented health condition on Facebook.
Meanwhile diseases with a possible marketing angle and merchandise like breast cancer’s pink ribbon had a large number of pages. Hale says his team trying to figure out how to best use social media to reach a wide range of populations and create new types of health interventions.

**Hale:** “You know groups like Facebook they can be an important way for people to find and connect with other people around those conditions. And generate more of a political support and sense of identity around those conditions.”

But he says the implications of the study are that search results on Facebook would need to be refined to better connect people with those supports.

Robert Wah -- global chief medical officer at the Computer Sciences Corporation -- says while the bonding and information sharing that occurs on social media may be beneficial to patients, more study is needed on ways to control for accuracy.

**Wah:** "Some people over-interpret, 'if it's on the Internet, it must be true' [laughs]. So we have to be careful about that, that people don't get a bad source of information either through the Internet or through social media."

One solution is using private pages on social networking sites or private sites, says Christina Thielst, a health administration contractor focusing on social media. She expects social media adoption in health care to follow a generational shift. She says doctors seem increasingly interested in social media supports for patients.

**Thielst:** "You’re going to always have a few that shy away from it just because of their perceptions and maybe past experiences. But I think as our physician population becomes a little younger, new generations that’s going to go away."

Thielst says in part this is because it solves a very practical problem.

**Thielst:** "There’s a recent study that says people with chronic diseases spend a total of six hours per year in front of their providers. But think about all the other hours in the year that they are actually out managing their conditions by themselves."

While providers may fear people are getting bad information, she says, that finding suggests doctors may become more active in directing patients to a social networking system appropriate to their needs. For access to a wide network, some who already use Facebook voraciously may prefer that platform. For patients who do not use Facebook or have a specific need, she says health care providers may suggest specific alternatives.
Thielst: "If I already trust that system for my health care, then I am going to trust them to host a social networking platform. It all comes down to trust and working as a team with the provider and the patient, so the patients are going to the right places."

One of the health care-centric social media platforms is PatientsLikeMe. Co-Founder and President Ben Heywood says the company has found concrete clinical benefits from increased patient engagement. The more online connections users made on PatientsLikeMe, he says, the more offline benefits they report.

Heywood: "So depression patients who are reducing hospitalization. Epilepsy patients going to the ER less, understanding their disease better. We've looked at that in many different ways. And because we're a research platform, we've actually published it in journals as well."

Heywood says the research the platform enables allows patients not just to connect with each other, but to pioneer new treatments. Patients track their disease progression and treatment regimen online. This data in turn give researchers insight into effectiveness of the various interventions.

Heywood: "What we have done in a handful of diseases, is really having deep disease modeling, so we can predict future outcomes of patients. And you can utilize that to compare different effectiveness of drugs and other things patients are doing in the wild anyways."

Heywood says combining this element of traditional clinical research with social engagement for patients offers a new avenue for improving the quality of health care. He says possibilities beyond the human support benefits abound. Experts agree there are many clinical trials and studies of social media yet to come.

This has been an audio report for iHealthBeat, a daily news service of 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 Rachel Dornhelm, thanks for listening.