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The Growing Clout Of Online Patient Groups

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When researchers at Harvard University were looking for a gene mutation in a group of rare blood cancers, they turned to Joyce Niblack, who put the word out to an online patient mailing list she manages, spurring more than 300 members to send in mouth swabs and bone-marrow samples.

Later, Ms. Niblack mustered 1,179 participants from 30 countries for a Mayo Clinic-led study of how the cancers, known as myeloproliferative disorders, affect quality of life. The Mayo researchers are now running the clinical-trials page on her foundation's Web site, mpdinfo.org¹, to keep participants up to date on developments.

Online patient groups have become an increasingly powerful force for health-care consumers over the past decade, raising funds for research and offering patient information and support. Now, as the cumulative power of their memberships grows, these groups are becoming invaluable partners to researchers and physicians searching for cures.

Making the Connection


Online patient groups with ties to medical researchers:

Group / Web site	Comment
Association of Cancer Online Resources ACOR.org	159 online cancer groups work with researchers and inform patients of clinical trials, tissue banks and genetic studies.
LMSarcoma Direct Research Foundation lmsdr.org	Patients with leiomyosarcoma, a rare soft-tissue cancer, contribute to a tissue bank; raises funds for research.
Life Raft Group Liferaftgroup.org	Conducts drug side-effects studies of patients with gastrointestinal tumors; sponsors new research.
Myeloproliferative Disorders MPDINFO.org	Blood-cancer group helps provide DNA samples to researchers; participates in quality-of-life studies.

Patient groups are stepping up their participation in medical and public-health research and entering far-reaching collaborative efforts with researchers, scientists and drug developers. They are raising funds and taking part in studies to evaluate the impact of online patient sites. They are even conducting their own studies on side effects of medications, and working with researchers to recruit clinical-trial participants, provide DNA samples and start tissue banks.

In the case of Ms. Niblack's efforts, the results of collaboration are already apparent. The DNA gathered from the

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group's mouth swabs and bone-marrow samples helped researchers identify a genetic mutation that could be a target for new therapies. The finding could lead to new drugs or other substances that attack specific cancer cells without harming normal cells.

"Groups like those led by Joyce immensely serve the needs of patients," says Ayalew Tefferi, a Mayo physician and researcher who works with the group. Her foundation's Web site is "one-stop shopping for clinical trials and breaking news in research."

Other online groups are having a similar impact. An online group for patients with a rare cancer known as leiomyosarcoma sent more than 300 tissue samples to researchers at Stanford University for a tissue bank that is being used to study genetic and molecular changes that occur in the disease.

The International Myeloma Foundation conducted an online survey of patients that helped identify jaw bone deformities in some patients taking the **Novartis** drug Zometa, which is used to reduce or delay bone damage that may occur with the disease. Novartis now advises patients to avoid invasive dental procedures while taking Zometa.

Spreading the Word

To spur more widespread collaboration, a group of experts in patients' use of the Web just launched a new Web site and blog, e-patients.net, originally developed by Tom Ferguson, a physician who received funding from the Robert Wood Johnson Foundation and the Pew Charitable Trusts. Following Dr. Ferguson's death last year after his own 15-year battle with multiple myeloma, his cohorts completed his study, "e-Patients: how they can help us heal health care," which is available free on the site.

Co-authors of the blog include Daniel Hoch, a neurologist at Massachusetts General Hospital, and Susannah Fox, a researcher at Pew's Internet and American Life Project.

Another member of the team, Gilles Frydman, founder of the Association of Cancer Online Resources, recently launched a patient-focused "wiki" -- a collaborative Web site that visitors can add to and edit -- called lo-wiki.acor.org. The site helps consumers build and maintain online discussion groups and aid researchers who want to study such online communities or use the online groups to conduct research. Mr. Frydman, who started ACOR more than a decade ago when his wife was diagnosed with breast cancer, is also developing other sites, including one that will provide links to medical research papers for patients.

ACOR, which offers access to 159 mailing lists for cancer and other disorders, including the one managed by Ms. Niblack, had about 110,000 cancer patients and caregivers using the online communities over the past year, according to Mr. Frydman. But there are tens of thousands of such groups on sites such as Yahoo; last year, about 17 million adults, or 12% of Internet users surveyed by Pew, participated in an online discussion or group forum that helps people with personal issues or health problems.

Reaching Patients

"We can bring information about studies, clinical trials and meetings to any patient world-wide who has computer access," says Ms. Niblack, a retired patent attorney who runs both an ACOR mailing site and

the MPD Foundation and has been fighting the disease for almost 20 years. "People have told me the information has saved their lives."

The University of North Carolina at Chapel Hill teamed up with ACOR for the first large-scale scientific analysis of medical online communities, publishing its findings last month in the *Journal of Medical Internet Research*. Using software that analyzes message content to examine the type of support provided by the groups, the researchers found that the most common topics in messages were about treatment information and how to communicate with health-care providers.

"One of the real values in the mailing lists is their role in getting patients to seek second opinions and ask questions about clinical trials," says Barbara Rimer, dean of North Carolina's School of Public Health and an author of the study.

Patients' Main Concerns

The software programs enabled researchers to study messages without identifying who wrote them. But Deborah Bell, an ovarian-cancer survivor who manages the ovarian-cancer list for ACOR and participated in the North Carolina study, says members of the group are already aware that what they are writing is on a public forum, and privacy is not a major issue. With a potentially deadly cancer diagnosis, she notes, their main concern is finding information and coping with doctors who say snide things like "and where did you go to medical school?" when confronted with questions from a patient.

Raising New Issues

Of course, the rush to link communities and researchers and the move by patient groups to conduct their own research raises some thorny new issues. While the nonprofit, patient-run online groups have no financial interest in research or recruiting for trials, some for-profit health Web sites see their online communities as a way to make money. Such sites, supported by drug-company advertising, may seek to recruit patients for drug-company clinical trials, often without going through physicians who may advise patients about the pros and cons of such trials.

Also, the research organized by online patient communities makes some scientists nervous because such efforts don't use the gold standard of randomized controlled clinical trials.

The Life Raft Group, an organization of patients suffering from rare gastrointestinal tumors known as GIST, conducts its own surveys about the side effects of the Novartis drug Gleevec, commonly used to treat GIST. The group recruits participants from among its members and publishes results on its liferaftgroup.org Web site. Norman Scherzer, a retired public-health official who started the group when his wife was diagnosed with GIST, notes that the study turned up different reactions among men and women to the drug, and was the first to report that side effects decrease over time.

"At minimum it is a surveillance system," says Mr. Scherzer, who says the group isn't trying to pass off its research as pure science. Mr. Scherzer recently persuaded Novartis CEO Dan Vasella to give the group \$2 million for a research program that will recruit experts from major cancer institutions to work together to study patients who become resistant to Gleevec.

Working Together

George Demetri, head of sarcoma and bone-cancer research at Dana Farber Cancer Institute in Boston,

who treats GIST patients and has worked closely with the Life Raft Group, says that doctors need to work in partnership with patient groups. Doctors should take the self-administered surveys seriously, to understand the impact of side effects, for example.

But in cancer research, he cautions, "the challenge is keeping the patient voice in, but also staying as rigorous as possible and not being swayed by inaccurate, premature or misleading data."

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<http://online.wsj.com/article/SB118168968368633094.html>

Hyperlinks in this Article:

(1) <http://www.mpdinfo.org>

(2) [mailto: informedpatient@wsj.com](mailto:informedpatient@wsj.com)

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