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## **About Us**

The ICTCR facilitates patient-centered research through the combined strengths of its founders: Mercy Medical Center, and Des Moines University along with its partners Drake University College of Pharmacy and Health Sciences and Mercy College of Health Sciences and welcomes inquiries from interested clinicians and scientists.

For more information, please call (515) 247-4435.  
[www.iowatranslationalresearch.org](http://www.iowatranslationalresearch.org)

## **The First MIRIAM Colloquium on Medical Informatics**

In August, the informatics arm of the ICTCR organized a small meeting of individuals interested in medical education and research from both the Des Moines area from several institutions nation-wide. Attendees represented graduate and undergraduate medical education as well as public health and biomedical and health services research interests in general. In addition, the Iowa Department of Economic Development was represented and there was a discussion of entrepreneurial opportunities in informatics. Attendees were introduced to Iowa companies working in this area, of which there is an unexpectedly large number.

This one day meeting was designed as a brainstorming session to engage those in attendance on a variety of topics with the purpose of discovering how pursuit of collaborative engagement with local and national partners might advance research agendas and develop new informatics tools to enhance research productivity. A provocative introduction to the day was a presentation by Mr. Erin Phillips who is doing graduate work in the area of Human Computer Interactions. He described how some of the contemporary social networking tools are becoming methods for obtaining qualitative research data that despite coming originally from the worlds of marketing or journalism, can be adapted to medical topics.

Several opportunities for MIRIAM to bring value to medical and health services research were discussed under the following topics:

- Specialized Electronic Medical Records (electronic SOAP Note) and specialty-defined clinical assessment tools
- National Databases to collect de-identified SOAP Note Data via Web
- Electronic case record forms for investigator-initiated research
- Customized medical registries for specialties and key diagnoses
- Evidence-based-medicine support through electronic resources
- Training opportunities for students, faculty and attending physicians to establish high impact in data use
- Information literacy and confidence in selecting proper tools and selection and engagement of key collaborators and statistical consultants
- Medical uses of Geographical Information Systems
- The human simulation laboratory as a human computer interaction that supports education and research.

The robust discussion identified this group to be a source of information and consultation to clinical researchers in Des Moines and other locations around the country. Readers of the "Update" are encouraged to contact the ICTCR to discuss how our organization can help with the data gathering needs of your project.

## Controversial aspects of patient-initiated research

Patient-initiated research is related to "Participatory Medicine", a concept focusing on patients who join together, often as support groups, collectively serving as collaborative (virtual) treatment teams.

Patients are increasingly taking responsibility for their care and exercising autonomy, thereby changing (and sometimes challenging) medicine. This trend, well-known to the medical community has conceptual support expressed by former NIH head, Elias A. Zerhouni, MD, "As opposed to the doctor-centric, curative model of the past, the future is going to be patient-centric and proactive. It must be based on education and communication. This is what I am pushing for at NIH. I like to change things and believe we need to be ahead of the curve. The challenge is to channel the energy of this outstanding organization to help the public better care for itself. No one knows exactly how to do this. It requires voluntary, intelligent participation, not passive acceptance. We can provide the information, but you have to do something for yourself"

Research agendas – not just treatment options - are also pushed by patients who have specific conditions. Disease-related advocacy groups do more than work together to identify best treatment options from those already available, but actually point researchers in a direction they deem promising. The Liferaft Group' president, Norman Scherzer said "one of the great benefits of patient-initiated research is its speed. Professional research has a built-in lethal lag time—a period of delay between the time some people know about an important medical break-through and the time everyone knows. And as a result, many patients who could have been saved by the latest treatments die unnecessarily."

Arguably, the aforementioned time lag that concerns participatory research proponents supports the self-correcting nature of science and allows for safety checks on new drugs, devices or procedures. The peer review process, considered a fundamental tenet of establishing scientific verity is also time-consuming, but valuable.

Is there a good middle ground between established methods for evaluating treatments and patient enthusiasm for early reports that create high optimism? Can there be balance between the concept of "fast at any cost" versus "as fast as possible"?

Regardless of these issues, movement toward participatory research will undoubtedly continue to influence research and practice well into the foreseeable future.

-Bryan Larsen, ICTCR

## Mining patients' online data: a new model for research

Some researchers are pioneering a way to bridge the gap between researchers, clinicians and patients. By capturing patients' own words about their diseases using a Web 2.0 social networking approach, they are bringing patient voices into the evidence-based medicine equation.

When the term evidence-based medicine is mentioned, methodology such as randomized controlled trials or meta-analyses comes to mind. However, some researchers and patients are concerned that this traditional approach to research is only telling part of the story. Evidence-based medicine ideally should consist of three elements: the best available evidence, clinical expertise, and patient values.

As patients share their perceptions, symptoms, and experiences in online media blogs and discussion boards, researchers can now mine their words as data sources to discover the "[wisdom of the crowds.](#)" This open-source research has proven especially useful for rare diseases where it is difficult to find enough patients or funding for clinical trials. In addition, entrepreneurs and informatics specialists are exploring other ways to mine and use this data.

Proponents of this new qualitative data mining acknowledge that potential problems exist. One is the lack of IRB oversight for patient protection such as informed consent and privacy guidelines that other researchers must adhere to. Another is the possible inaccuracy of patient reports leading to "garbage in, garbage out" scenarios. Critics warn that sacrificing quality and power of studies for access and speed is not in patients' best interest in the long run.

Nevertheless, advocates of this qualitative approach point to the benefits of hypothesis generation and exploratory analysis. Combined with traditional quantitative data analysis, mining these online social networks has the potential to transform medical research, ultimately revealing a more complete picture for effective patient care. For examples of this model in action, visit [PatientsLikeMe](#) and [LAM Treatment Alliance](#). The web addresses for these items are provided below. See also page 3.



*-This article was contributed by Ann York PhD, (left), faculty member in the DMU Healthcare Administration Program. Dr. York has special expertise in evidence-based-medicine and she has developed an online training program to provide introductory competence with evidence-based medicine. She was a recent participant in the first MIRIAM colloquium.*

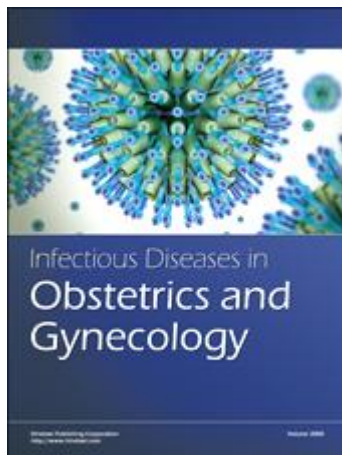
### Information Cited:

"Wisdom of the Crowds" <http://randomhouse.com/features/wisdomofcrowds/>

"Patients like me" <http://www.patientslikeme.com/research>

Patient site for lymphangioma: <http://lamtreatmentalliance.org> (this site is worth a look, as it includes interviews with experts and celebrities and encourages patients to contribute tissues to research tissue banks. It also suggests from the patient standpoint what research agendas ought to be pursued. Clearly, affected patients are engaged and exercising a degree of autonomy in self-care that has rarely been seen before.

**More about Community-Based Participatory Research:** Did you know that there is a journal that is devoted to the concepts of CBPR? *Progress in Community Health Partnerships: Research, Education and Action* began publication in 2007. Research that collaboratively links community representatives and academic or governmental organizations is at the core of CBPR. The topics of this type of research are issues critical to the community and for which the combined strengths of all partners can meld to improve health outcomes, cause positive social action and relieve health disparities. For example, a recent article (2009; 3:241) reports on a “salon-based” education and health promotion effort directed at Latino and African-American individuals served by a community-based-organizations linked to an academic institution. The challenges and successes reveal research opportunities abound in our own backyards.



Mercy Medical Center physician *Joseph Hwang, MD* and *Bryan Larsen, PhD* (ICTCR) are joining an international editorial team to produce a special issue of **Infectious Diseases in Obstetrics and Gynecology** to appear next summer. This effort is joined by Mario Meriardi, MD (World Health Organization), F. DeSeta, MD (University of Trieste) and Jose Tiran, MD (IMIGO, Monterrey, Mexico). Pre-term birth affects more than 12% of births in the US and accounts for millions of deaths worldwide. Advances in the field will be addressed from the basic science and clinical points of view and emphasize opportunities for research and potential for new interventions.

### **The ICTCR Develops a Formal Relationship with a Major Contract Research Organization (CRO)**

Recently, the ICTCR entered into an agreement with an internationally known CRO that has a long history of being a clearinghouse for sponsored clinical research projects. The company has been involved with placement of studies on all blockbuster drugs that have been approved in the last decade and has a reputation of careful and conscientious involvement with clinicians. This agreement will reduce the amount of paperwork needed for individual studies because most of the legal matters are encompassed in a master agreement and only study-specific details need to be negotiated with individual investigators.

The CRO plans to contact the ICTCR regularly about upcoming studies to allow MMC physicians the opportunity to express interest and receive study details in the shortest amount of time feasible, so physician access to clinical studies is facilitated. While access to many studies is possible, there is no obligation on the part of our physicians to participate in any study, nor are physicians excluded from dealing directly with industries directly.

As a part of this agreement, Mercy Medical Center will have access to a local representative of this CRO. Our local person is Judi Greene, RN, BSN, who has worked with Mercy research groups in the past. She will be available to discuss individual projects, the fit with our patient mix and with individual physician interest. Of particular note, Judi will be available to serve as a study coordinator for projects that are taken on by our physicians.

Details of this arrangement, information about study opportunities and information on how to discuss studies with Ms. Greene may be arranged by contacting the ICTCR office at 247-4435.

### **Statement of Purpose**

The ICTCR is a research enterprise: that facilitates productive research collaboration between its partners by sharing intellectual and infrastructure resources for the purpose of advancing patient-centered research that seeks better health for our communities and education and research opportunities for our faculty, staff, students and trainees. We believe the comprehensive training of medical students, residents and other health care professionals must be accompanied by a working knowledge of clinical research methods and best practices and that the best way to accomplish this is through active research endeavors. The ICTCR is dedicated to ethical and compassionate care for all individuals who participate in clinical research studies and actively supports the principles of autonomy, beneficence and justice in clinical research programs.