Where Is the Patient in Patient-centered User-oriented Design in Health Care Systems Development?

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Panelists:
Diana Forsythe, University of California, San Francisco, USA
Richard M. Frankel, University of Rochester and Highland Hospital, USA
Nancy Lelievre, Ellora Software, Inc., USA
Toomas Timpka, Linköping University Hospital, Sweden

INTRODUCTION
Health care systems development is distinguished by two attributes that are self-evident in their simplicity. Systems design of patient care information systems carries with it a responsibility to patients as well as to health care workers as systems users. And each of us is a patient.

The panel will focus on health care workplaces and the development of patient-centered clinical information systems and patient care processes. It will feature concrete case study experiences in participatory design and/or co-development strategies, exploring the complexities of multi-disciplinary design for computer-based patient care systems and dilemmas in their development and implementation when looked at from the perspectives of participatory design and the participation of a patient in his or her own care. Based on these experiences, the panelists and participants will raise future strategies for discussion.

Panelists will discuss the consequences and potentials of new tools meant to promote collaboration in care between patients and patient care teams, and among multi-professional members of patient care teams. These include:

- interaction models to improve communication between clinicians and patients;
- externalized care paths, protocols and disease algorithms that may be shared with patients and among care providers;
- legislative frameworks and principles for both patient participation in care planning and worker co-determination in systems design;
- computer-based explanation systems for severe diagnoses and/or chronic illnesses entailing complex care plans that often prove difficult to integrate into patients' life worlds;
- networking systems that link distributed members of patient care teams and networks—without yet including patients as actors.

QUESTIONS FOR DISCUSSION
How can patient participation be "designed into" health care computer systems and processes?

How is it that the patient tends to disappear in design discussions, despite the rhetoric of "patient-centered" systems development?

In multi-disciplinary design teams, how is argumentation over different needs, agendas, priorities, motivations, and models for patient care addressed and incorporated—or not?

How do standards of care—evolving concomitantly with computer-based patient records and care networking systems—affect patient interactions and work experiences?

Who owns a patient's clinical data generated through the means of computer-based patient records systems?

What participatory design strategies and qualitative research methods exist for improving the design of systems to meet the needs of patients, diverse patient care team members, and health care institutions?

PANEL MEMBERS (in alphabetical order)
Diana Forsythe is Associate Professor in the Division of Medical Anthropology, Department of Epidemiology and Biostatistics, University of California, San Francisco. Since 1986, she has been investigating problems of
artificial intelligence and medical informatics, and studying
the contributions that ethnographic techniques and an
anthropological perspective can make to clinical
information systems development. She will highlight
experiences from her participation in a four-year NLM­
sponsored research project to design, build and evaluate an
explanation system for migraine sufferers.

Richard M. Frankel is Professor of Medicine,
University of Rochester, School of Medicine and Dentistry,
and Director of the Primary Care Institute, Highland
Hospital, Rochester, New York. His current work in the
PCC project involves three efforts: (1) a qualitative
assessment of the introduction of the PCC model,
employing both participation observation and videotaping
of patient-provider interactions; (2) in-depth interviews
and staff surveys to assess the impact of PCC on those who
deliver and are responsible for the patients' care; and (3)
on-going assessment of the impact of the PCC model on
patient experiences.

Judith Gregory works in the Electronic Health Record
(EHR) Project, Kaiser Permanente Southern California
Region, and is a Ph.D. candidate in the Department of
Communication, University of California, San Diego. She
has long-standing commitments to issues of technology and
work. Her dissertation research explores reciprocal
modifications of the design and use of new clinical
information technologies and their consequences for patient
care teams and networks.

Barbara Katzenberg is Clinical Information Systems
designer for Ellora Software, Inc. and a Ph.D. candidate at
the Stanford University School of Education. Her interest
is in customer engagement methods that enable the rapid
tailoring of generic applications to site-specific needs.
With Nancy Lelievre, she is engaged in incremental co­
development of guideline-based clinical information
systems. Among their interests is how explicit
representations of treatment paths can be used to support
patient-focused care.

Nancy Lelievre is Principal Software Engineer at Ellora
Software, Inc. Her primary focus is user interface design,
with special interests in cooperative development and
clinical information systems. With Barbara Katzenberg,
she will discuss her current project work involving the
development of protocol-based care systems and practices in
two United States Navy women's health clinics.

Toomas Timpka is consultant physician in Clinical
Social Medicine, Linköping University Hospital, Sweden,
where he is dually appointed as Associate Professor in
Medical Informatics in the technical faculty and Associate
Professor in Social Medicine in the medical faculty. Since
1988, he has led the MDA group (People, Computers and
Work) which has been involved in several inter-disciplinary
research projects in management of health information. He
has published extensively on topics ranging from
participatory design of information systems to patient-care
provider interaction and refugee medicine.