

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

Judith Gregory (organizer, moderator)
Department of Communication
University of California-San Diego &
Kaiser Permanente Southern California Region
393 East Walnut St.
Pasadena, CA 91188
+1 310 399 2291
judith.j.gregory@kp.org

Barbara Katzenberg (organizer, panelist)
Ellora Software, Inc. and
Stanford University School of Education
367 Concord Avenue
Lexington, MA 02173
+1 617 863 0348
katzen@world.std.com

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

In *PDC'96 Proceedings of the Participatory Design Conference*. J. Blomberg, F. Kensing, and E.A. Dykstra-Erickson (Eds.). Cambridge, MA USA, 13-15 November 1996. Computer Professionals for Social Responsibility, P.O. Box 717, Palo Alto CA 94302-0717 USA, cpsr@cpsr.org.

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.