BARRIERS

- Insufficiency
- Poor Project Management
- Inherent in Medicine
- Physician Resistance

Same barriers for the past 50 years


THE EVALUATION EVIDENCE BASE: “FIT”

- WORK
  - Work flow, work routines, users' definitions of their work
  - Patient-clinician and clinician-clinician consultation patterns
  - Users' models and representations of work routines
- USERS
  - Users' skills and levels of expertise
  - Users' cognitive processes
  - Users characteristics and preferences
- ORGANIZATION
  - Organizational communication patterns
  - Business models and strategic partners
  - Organizational structure, division of labor, management style
- PROFESSION
  - Professional goals, values, norms, aspirations, status, culture
  - Status and control relationships

“FIT” ???

- Evaluation Example

TLC-HealthCall

- Emulate conversation with health professional
  - interactive voice response technology
  - pre-recorded digitized human voice
  - keypad input

- Eat and Run
  - 5 minute conversations
  - weekly for 26 weeks
CONCLUSIONS

- People form relationships with IT
  - treat them as social objects
- Machines as evocative objects
  - people project identities onto machines
  - people assume different identities
- Relationship formation not anticipated
- “The same” people using “the same” application - but not “the same”
OTHER EXAMPLES

- **Telehealth**
  - home monitoring equipment
  - on-line or telemedicine consultations
- **Consumer Health Informatics**
  - health information web sites, on-line support groups
- **Home sensors - ubiquitous computing**
- **Assistive robots**

DESIGN ISSUES

- **How to design e-health applications**
  - affective aspects of technology
  - values embedded in/projected onto applications
  - for different populations
- **How to anticipate how people will react**
  - usability
  - will they use it and why?
  - meaning
- **How to (& should we) support patient-provider-IT partnership**
  - physician-centric vs multiple stakeholders
  - shift focus from clinicians and clinical settings/workflow
  - social and ethical consequences
e-HEALTH ETHICAL ISSUES

- Content, Quality, and Access
  - QA and improvement of on-line information
  - gaps in content and application development
  - access and digital divide
- Information integration, transmission, and use
  - privacy, confidentiality, security
  - data standards and integration for linking patient and personal information for interoperability, e.g. individual record, personal health management, public health


NEW ETHICAL ISSUES

- Are persuasive technologies okay? - TLC works
  - Is it right to encourage relationship formation?
  - Can/should relationship formation be prevented?
  - Is it right to use IT this way for behavior change?
  - Is this patient/consumer empowerment?
- Does IT humanize or dehumanize health care by replacing interaction with health professionals with e-health applications?
  - How does IT use change patient-clinician relationships?
- What’s “informed” consent?
RESEARCH ETHICS ISSUES

- Research ethics
  - Respect for Person
    - Vulnerable populations
    - Informed consent
    - Altering motor skills, behaviors, cognitions, and attitudes
    - Bonding and other emotional issues
    - Dependence and autonomy
    - User empowerment
  - Beneficence
    - Safety
    - Risk management
    - Limits on technological autonomy
  - Justice
    - Population selection

- Researchers’ and developers’ goals, values, assumptions

SOCIAL, LEGAL, & POLICY ISSUES

- Cost/benefit
- Impact on human jobs, family
- Humanization and dehumanization of care
- Equity and access to technology
- Privacy and surveillance, monitoring
- Power issues and relationship between production and consumption of e-health and assistive robotics
- Health and safety outcomes
- Intended and unintended consequences
SOCIAL SCIENCE ISSUES

- Ease of use and transparency
- Responses to e-health
  - trust
  - affective
  - behavioral responses
  - cognitive responses
- How individuals and groups attribute meaning to e-health
- How does how people relate to e-health technologies affect how they relate to people?

EVALUATION RECOMMENDATIONS

- Address concerns of the many individuals involved in or affected by informatics applications.
  - e-health developers, consumers
- Conduct studies in different type and size sites, and with different scopes of systems and different groups of users. Do multi-site or multi-system comparative studies.
  - Where people live, work, go to school, have emergencies, participate in recreation
- Incorporate evaluation into all phases of a project.

1. Conduct investigations at different levels of analysis.
   - Disaggregate groups, e.g. “disabled”
2. Integrate findings from different applications and contextual settings, different areas of health care, studies in other disciplines, and also work that is not published in traditional research outlets.
   - Other relevant disciplines, e.g. social sciences, information systems, bioethics
3. Develop and test theory to inform both further evaluation research and informatics practice.


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1. Study failures, partial successes, and changes in project definition or outcome.
2. Employ evaluation approaches that take account of the shifting nature of health care and project environments, and do formative evaluations.
3. Incorporate people, social, organizational, cultural, and concomitant ethical issues into the mainstream of medical informatics.

EVALUATION
RECOMMENDATIONS

- Diversify research approaches and continue to develop new approaches.
  - Multidisciplinary teams that include consumers
  - How to study new technological capabilities and ways of promoting health, e.g.
    - images
    - visuality
    - touch
    - virtuality
    - emotion


OTHER
ISSUES/RESEARCH AVENUES

And how to address/study them?
NEW RESEARCH AVENUES

e-HEALTH RAISES INTRINSICALLY ETHICAL, PEOPLE, & SOCIAL ISSUES

- Develop
  - design approaches
  - methods to identify and address social & ethical issues throughout all parts of project
  - ethical framework
  - research venues

- Create/Revamp
  - Reward structures
  - Curriculum

Shape future, make choices