

# NEW AVENUES for e-HEALTH RESEARCH

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## RESEARCH AVENUES

- Barriers
- Evaluation Example
- Design Issues
- Social & Ethical Issues
- Evaluation Issues



# BARRIERS



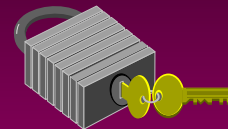
- Insufficiency
- Poor Project Management
- Inherent in Medicine
- Physician Resistance

Same barriers for the past 50 years

Kaplan B. The medical computing 'lag': perceptions of barriers to the application of computers to medicine. *International Journal of Technology Assessment in Health Care* 3(1):123-36, 1987.

# THE EVALUATION EVIDENCE BASE: “FIT”

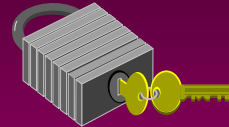
- WORK
  - Work flow, work routines, users' definitions of their work
  - Patient-clinician and clinician-clinician consultation patterns
  - Users' models and representations of work routines
- USERS
  - Users' skills and levels of expertise
  - Users' cognitive processes
  - Users characteristics and 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



Kaplan, B., Shaw, N., "Future Directions in Evaluation Research: People, Organizational, and Social Issues," *Methods of Information in Medicine*, 43:(3-4): 215-231, 2004.

## “FIT” ???

- Evaluation Example

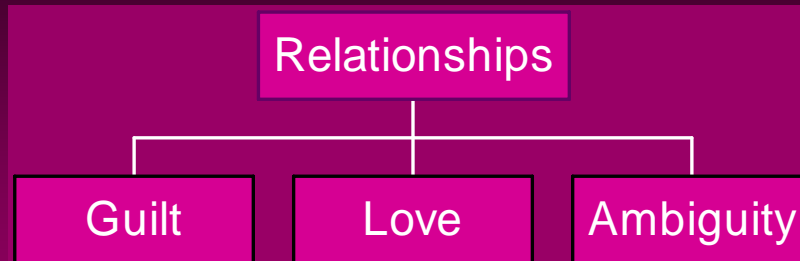


## TLC-HealthCall



- 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

# Individuals Form Relationships with TLC



Kaplan, B., Farzanfar, R., Friedman, R.H., "Personal Relationships with an Intelligent Interactive Telephone Health Behavior Advisor System: A Multimethod Study Using Surveys and Ethnographic Interviews," *International Journal of Medical Informatics*, 71(1): 33-41, 2003.



## CONCLUSIONS



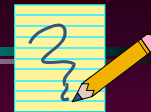
- People form relationships with IT
  - treat them as social objects
- Machines as evocative objects
  - people project identities onto machines
  - people assume different identities
- Relationship formation not anticipated
- "The same" people using "the same" application - but not "the same"

## 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



Eng, TR. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation, 2001.  
<http://www.rwjf.org/publications/publicationsPdfs/eHealth.pdf>

## 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.

Kaplan, B., Shaw, N., "Future Directions in Evaluation Research: People, Organizational, and Social Issues," *Methods of Information in Medicine*, 43;(3-4): 215-231, 2004.



## EVALUATION RECOMMENDATIONS



- Conduct investigations at different levels of analysis.
  - *Disaggregate groups, e.g. "disabled"*
- 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*
- Develop and test theory to inform both further evaluation research and informatics practice.

Kaplan, B., Shaw, N., "Future Directions in Evaluation Research: People, Organizational, and Social Issues," *Methods of Information in Medicine*, 43:(3-4): 215-231, 2004.



## EVALUATION RECOMMENDATIONS



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

Kaplan, B., Shaw, N., "Future Directions in Evaluation Research: People, Organizational, and Social Issues," *Methods of Information in Medicine*, 43:(3-4): 215-231, 2004.



# 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

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## 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

