



The Technological Transformation of Self-care:
Challenges for Building Systems and
Standards for Patient Use

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29 March 2006



Acknowledgements

- Canadian Institutes for Health Research (CIHR), the Institute for Health Services and Policy Research (IHSPR)
- Program in Health Care, Technology and Place, Faculty of Nursing, University of Toronto



Key Questions

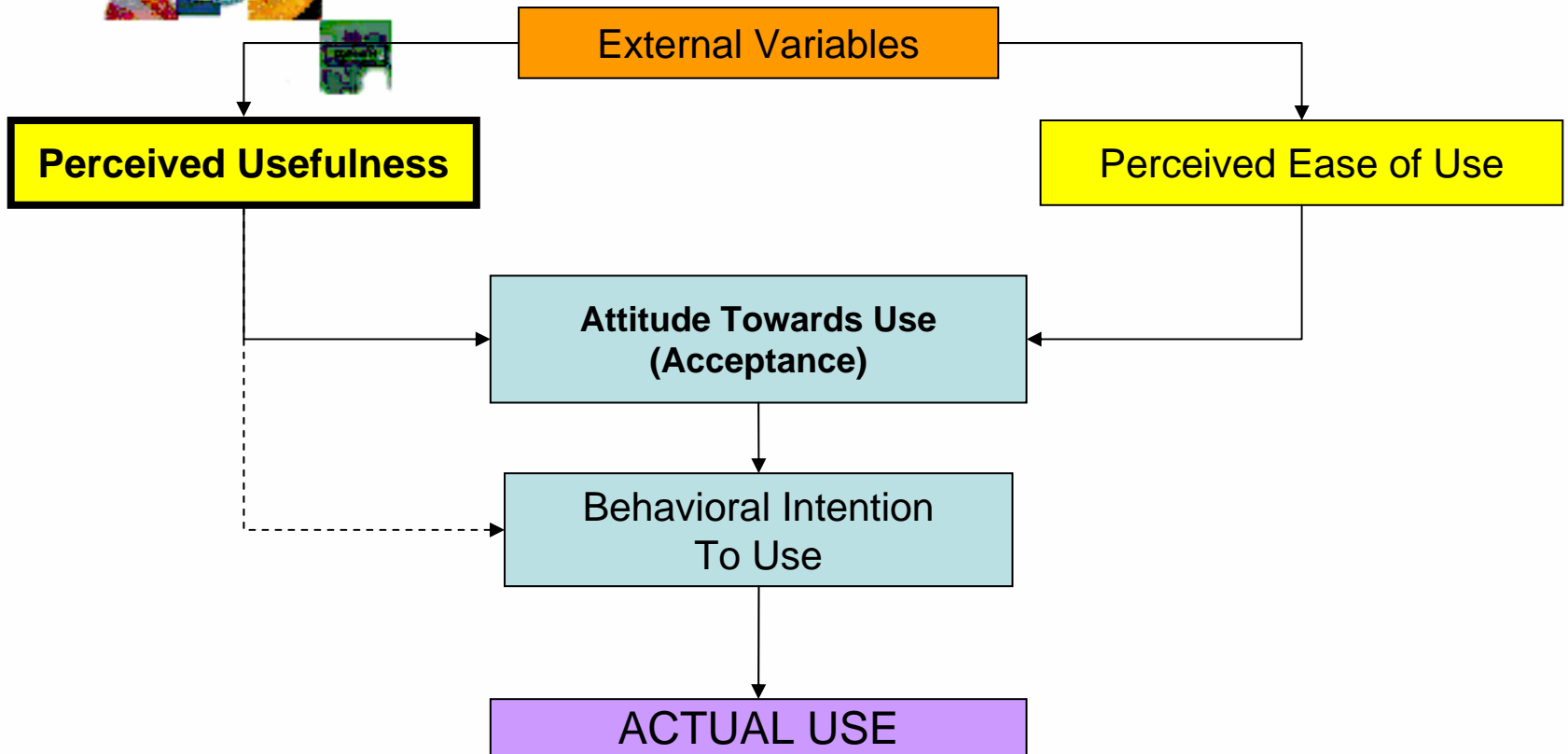
- What do patients do with Health IT systems?
- How do patients perceive value of Health IT systems?



Key Points

- User-centered evaluation models for standards and technologies may, in fact, be *inadequate* to evaluate patient use in the context of chronic illness self-care/self-management.
- To measure the real impact of IT and standards on patient-perceived health outcomes, our thinking may need to be *adapted* in a way that reflects both the social relationships and emotional-affective nature of the illness experience.
- Critical approaches to research and development provide a useful *adjunct* to traditional post-positivist (cause-and-effect) thinking to explicate the patient-IT interaction, thus helping to build better and more useful patient-accessible IT and more appropriate health IT standards for patient use.

Technology Acceptance Model*



*Source: Davis, MIT, 1986; MIS Quarterly, 1989



TAM -- Assumptions

- Expectancy-value theory based on the assumption of a rational individual (*are ill people rational??*)
- Motivation = intention = acceptance
- Work/task/job context in an organization (*are patients organizational workers???*)
- System features and characteristics are what motivate people to use system (for their job) (*patient's job??*)
- System features are not under the users' control



Paradoxes of Technology

- Failed System Implementation
- Sabotage, Shadow systems, technophobia
- Productivity Paradox
- Internet Paradox
- Minimal to no improvement in health or self-assessed health outcomes



Patient-accessible electronic medical records (PA-EMR) as a case study of patient-use IT



Impact on Outcomes

- Why is the positive *impact* of patient-access to EMR minimal to none?
 - There are elements in healthcare that can act as either *barriers or facilitators* that impact the translation of patient access to EMR into positive health outcomes



Barriers and Facilitators

- Responding to the legal-regulatory-political environment
 - The development and implementation of standards (Ouch!)
 - The focus and fixation on “outcomes” (who determines what constitutes a *valued* outcome for a patient?)
- Physician (hospital) centeredness
 - Canada Health Act (well-meaning, but fixes power structures and determines the social organization of knowledge in healthcare in ways that may squelch innovation...)
- Collaborative culture
- Patient centeredness
 - Caution: Patient Centeredness may not necessarily be patient-driven...ruling relations in the social system of healthcare may simply reframe physician and hospital centered care as patient-centered...

*Source: Winkelman and Leonard
(2004, JAMIA)



Whose IT is it?

- **ORGANIZATION - HEALTH SYSTEM**
 - Orientation towards a single, lifelong EHR may not be for the patient's benefit
 - Standard, universal language is not designed for patients
- **PHYSICIANS**
 - EMR is a tool for physician work
 - Power Differential between physicians and patients
- **PATIENTS**
 - The patient should be viewed as user AND creator of knowledge
 - Patient Access to personal data should be viewed as having value
 - Customization (not all patients are the same)
 - Valuing patient contributions to the medical record

*Source: Winkelman and Leonard
(2004, JAMIA)



Patients

- What is a patient?
 - Defined by medical condition
 - Defined by the length of time with medical condition
 - Defined by emotional-affective relationships with providers, organizations, healthcare institution (culture)
 - Is a self-care “agent”
- What do patients do with EMR?
 - Access vs. utilization (in self-care)
 - Reactive vs. Proactive self-care
- How do patients perceive value of EMR utilization?



How patients measure value of IT*

- Illness *Ownership*
- Patient-driven *Communication*
- *Personalized* support
- Mutual *Trust*

*Source: Winkelman, Leonard &
Rossos (2005, JAMIA)



Patient-perceived value

- Ownership
 - Perceived control
 - Patient Definition of illness
 - Power-sharing with professionals
- Communication
 - Responsive to patient needs and preferences
 - Not physician-driven
 - Dynamic and evolving over illness trajectory
- Individualization
 - Adaptability

*Source: Winkelman and Behrens
(2005, JAMIA, in press)



Patient-perceived value

- Trust

- Individuals have a propensity to trust others
 - Patients trust physicians (fiduciary, interpersonal trust)
 - Perceived risky situation (illness)
 - Based on perceived ability, benevolence and integrity
 - Reciprocity of trust (mutual, interpersonal trust)
 - Based on perceived ability, trustworthiness and integrity
- Individuals have a propensity to trust themselves (Perceived self-trust)
 - Self-efficacy, internal health locus of control
- Positive experiences with practitioners, information and information technology confirm trustworthiness and/or create trust
- Transferability of trust

*Source: Winkelman and Behrens
(2005, in press)



Patient-perceived value

- Social relationship

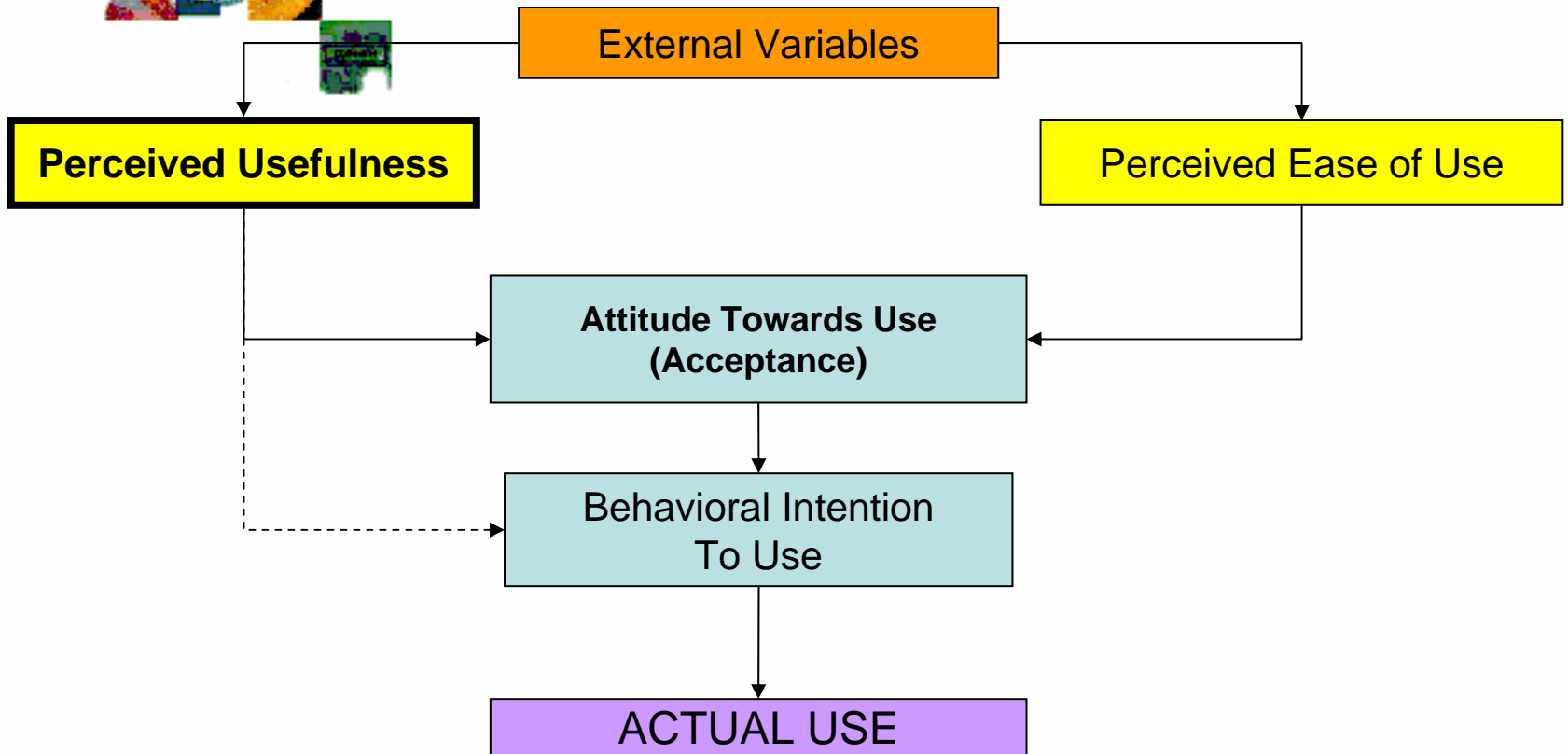
- User-technology relations are socially-constructed (Bijker, 1995; Resnick, 2002)
- Emotional-affective relationship with technology
- Patient-ICT relationship is surrogate and complementary to PPR



The Primacy of Trust*

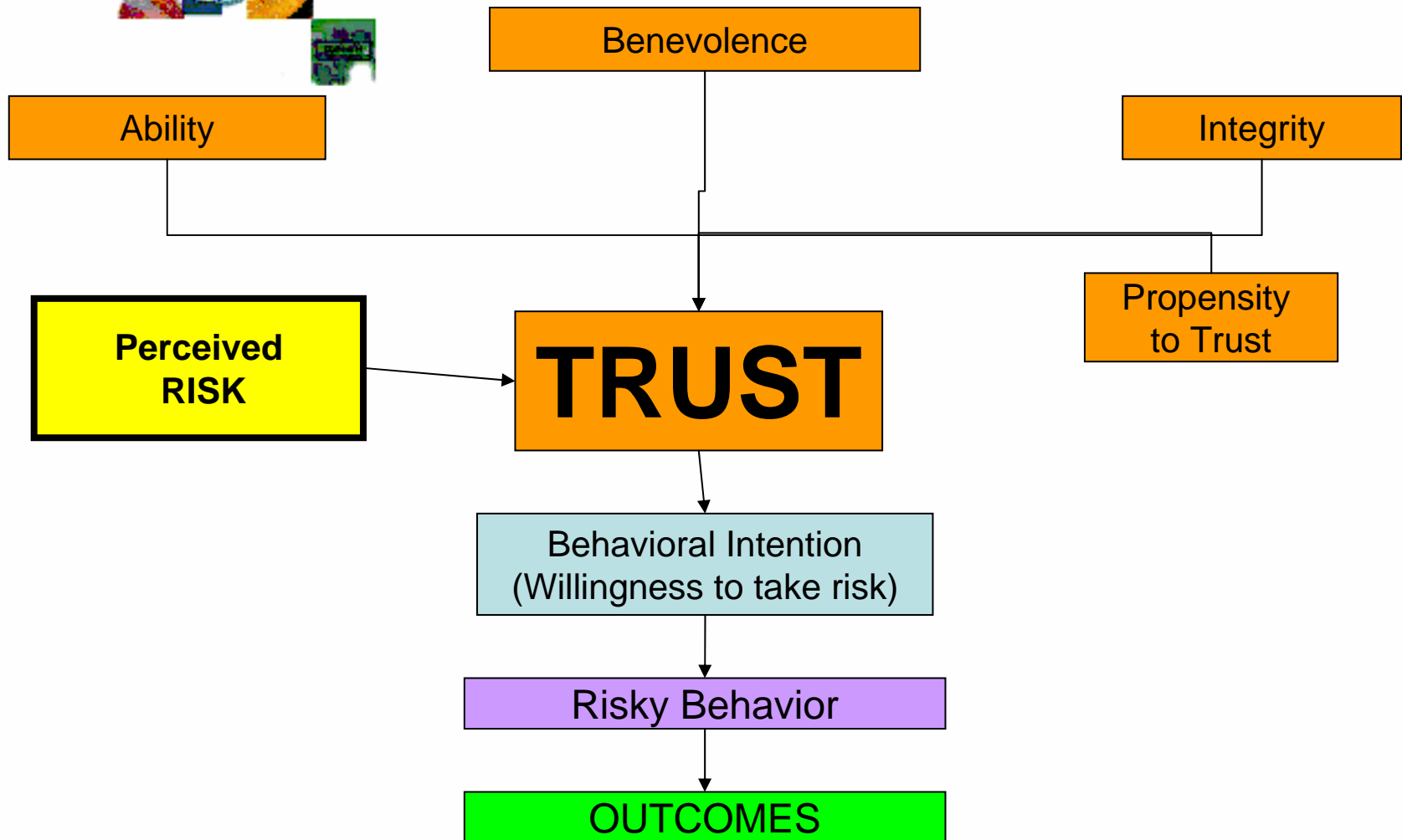
- *Trust* is an integral, emotional-affective component (interaction variable??) to patient perceptions of ownership, communication, personalization.
- *Promotes utilization* of ICT.
- Trust is an *antecedent* and a *product* of patient utilization of ICT.

Technology Acceptance Model*



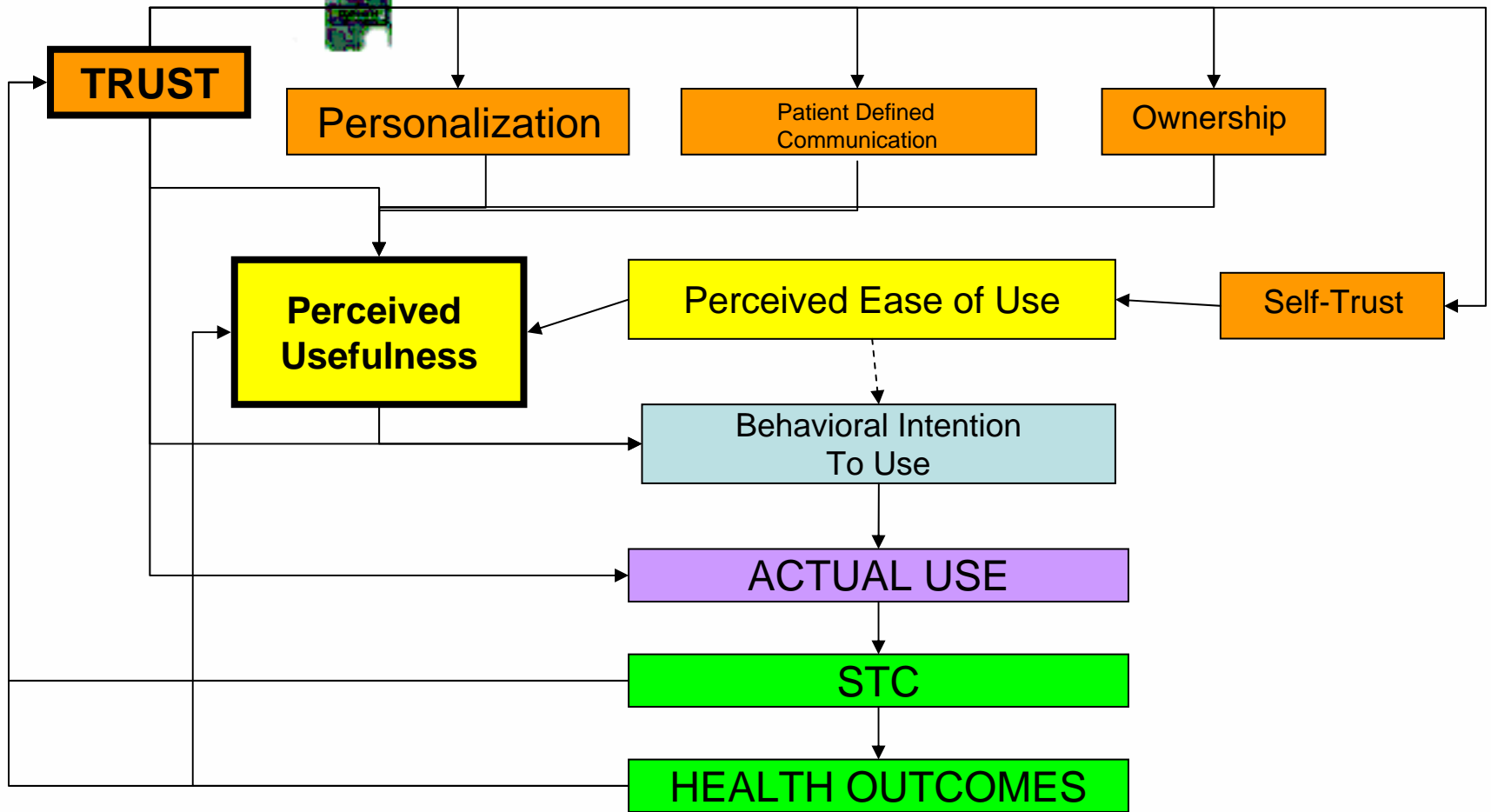
*Source: Davis, MIT, 1986; MIS Quarterly, 1989

Organizational Trust Theory*



*Source: Mayer et al, 1995 (p. 715)

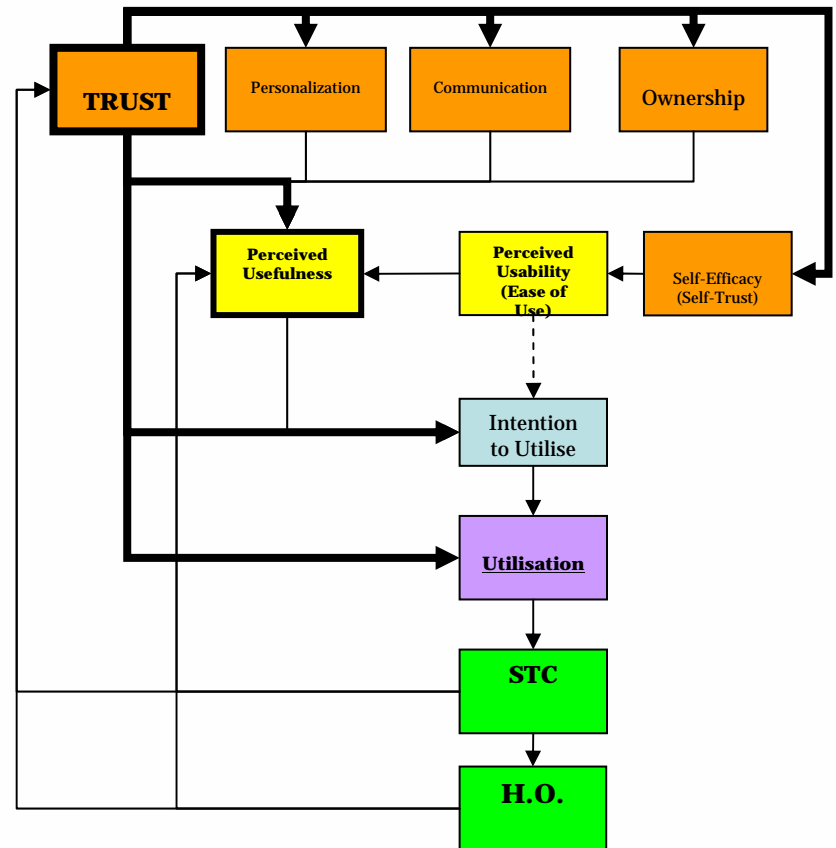
Final Model



*Source: Davis, MIT, 1986; MIS Quarterly, 1989

System/Standards Designers

- Explicate how patient-users intend to use PA-EMR system in the real world
 - Patient work = self-care
 - Patient-perceived benefits are important
 - Patient interactions with other healthcare providers need to be considered
- Patient centered approaches to design, development and formative evaluation
 - Patients are unique, variable, emotion-driven
 - Experienced patients have different informational needs than recently-diagnosed patients
 - Patient participation necessary for research and useful system development





Thus...

- Successful *utilization of IT by patients* is dependent on shared participation and reciprocal understanding
- *Trust is the currency of healthcare discourse*; it is an emotionally-driven currency of primary importance in patient interaction with health services, including between patients and IT
- The *development and evaluation of IT standards* must take into consideration both the rational and emotional-affective characteristics of the patient-user and the fiscal and geo-political restrictions (power structures) that define the healthcare social context
- Our thinking needs to be adapted to patients' contexts to enhance the validity of the standards we propose!



Thank you

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