

Best Practices for Mobile Technology for Health Management and Independence: Overview and Highlights from the October 2018 State of the Science Conference

Michelle A. Meade, Ph.D.
Director, UM TIKTOC RERC
University of Michigan



University of Michigan
Rehabilitation Engineering Research Center
Technology Increasing Knowledge: Technology Optimizing Choice



Disclosures

- The presenter, Dr. Michelle Meade, discloses the following activities and sources of support
 - Co-inventor of SCI HARD app described in this presentation, Invention Report File # 6349 - Mobile Game for Health Interventions and Behavioral Change
 - Consultant with the Medical University of South Carolina to assist with grant-funded research activities
 - Editorial Board member for the journal *Topics of Spinal Cord Injury Rehabilitation*
 - Executive Committee for the Psychologist and Social Worker Section of the Academy of Spinal Cord Injury Professionals
 - President of Rehabilitation Psychology, Division 22 of the American Psychological Association (APA)
 - PI or Co-PI of grants from the National Institute of Disability, Independent Living and Rehabilitation Research and the Craig H. Neilsen Foundation
- Commercial Support was not received for this activity.
- Funding Agency
 - The RERC is funded by Grant # 90RE5012 from the National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR)



Thank you and Acknowledgements

- The TIKTOC RERC and its State of the Science Conference was funded by NIDILRR through a RERC grant (# 90RE5012)
- Presenters, Panel members and Participants
- My Co-Investigators in the RERC
 - Ed Durfee
 - Mark Newman
 - Mark Ackerman
 - Karen Farris
 - Seth Warschausky
 - Chuck Merbitz

Need and Target Population



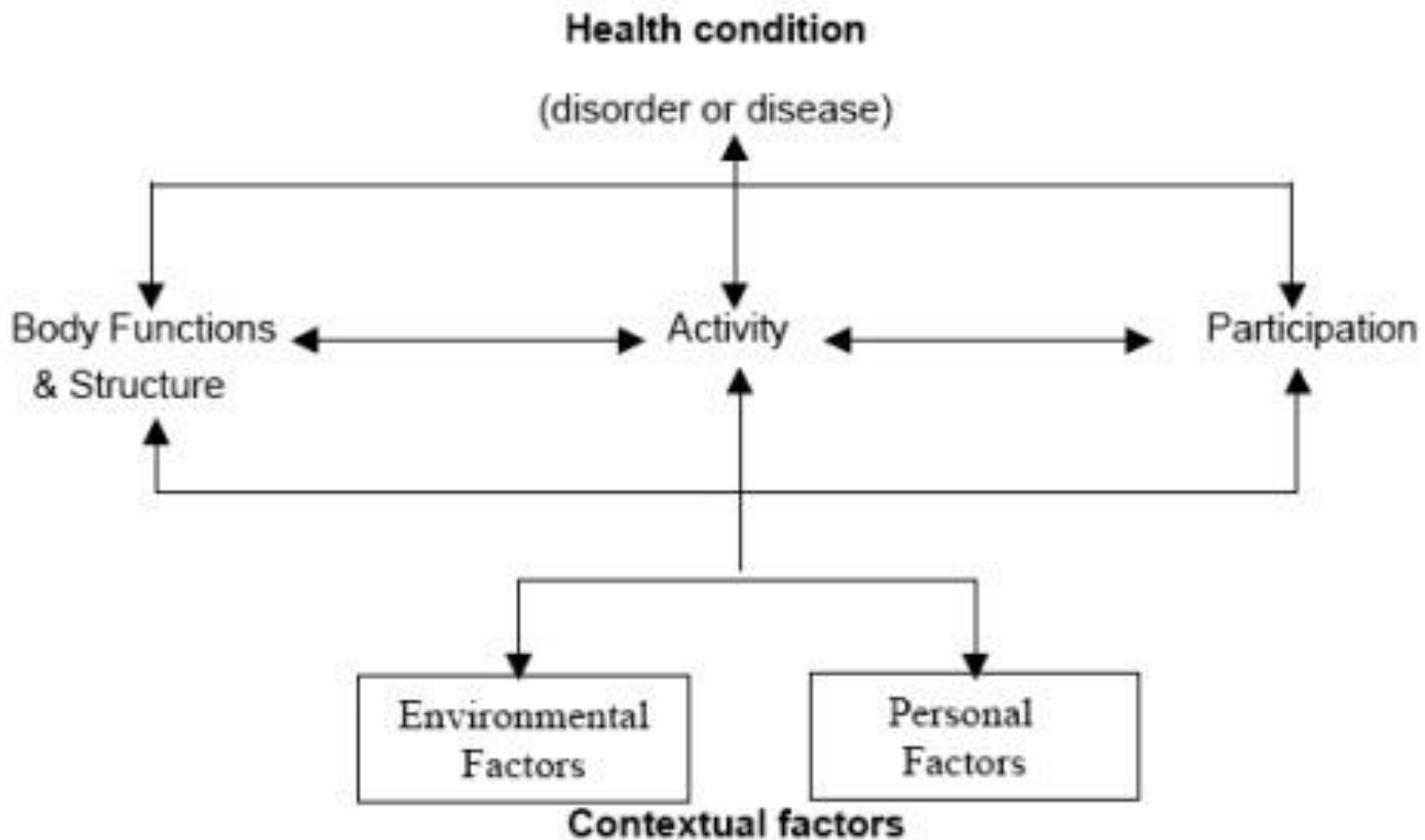
- Adolescents and Young Adults with disabilities
- Transitioning to self-management of health
- Transitioning to independence and adulthood
- Individuals with congenital and acquired disabilities
 - Physical
 - Cognitive
 - Neurodevelopmental



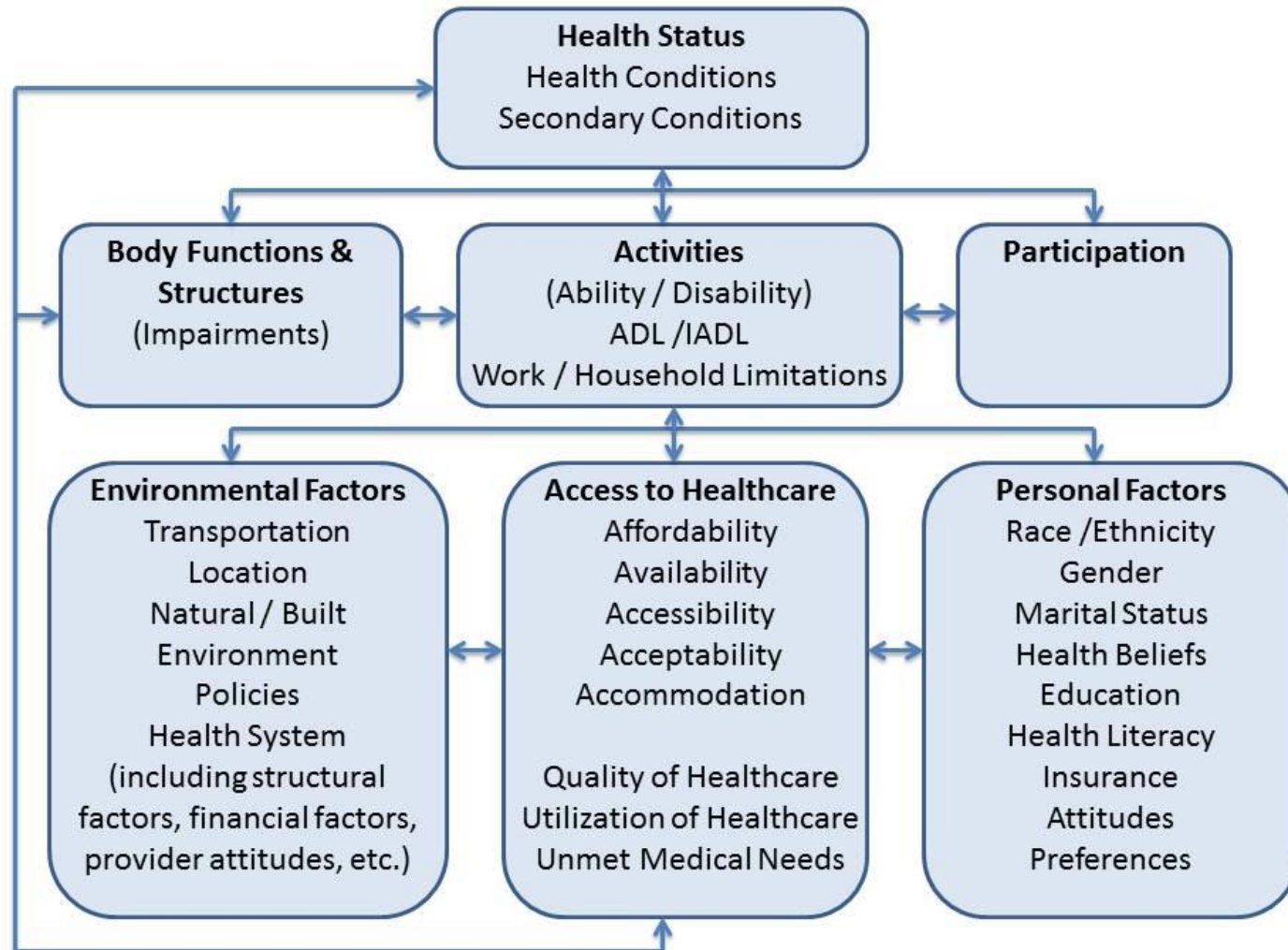
Self-Management

- Refers to the ability of an individual with a chronic condition or disability to manage his or her health and its physical and psychosocial consequences
 - Self-management can also refer to the processes and decisions employed by any individual to manage their life.
- *Self-management support*
 - “systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem solving support” (Institute of Medicine [IOM], 2003; Pearson, Mattke, Shaw, Ridgely, & Wiseman, 2007).

Defining Disability: the International Classification of Functioning, Disability and Health (ICF; 2001)



Model of Healthcare Disparities and Disability (Meade, Mahmoudi & Lee, 2015)





Increasing Knowledge – Optimizing Choice

- Focused around facilitating the independent management of health among transition-age adolescents and young adults with physical, cognitive and neurodevelopmental disabilities through:
 - the development of new technologically-based interventions, as well the adaptation of existing programs, interventions and protocols, that are tailored to the specific needs, strengths, abilities and personal characteristics of rehabilitation populations and
 - the integration and use of those interventions within existing health care practices and systems
- Includes a coordinated set of research, development, capacity building and knowledge translation projects built around theories of self-management and behavioral change and focused on promoting health , increasing functioning, independence and participation, and preventing secondary conditions



Mobile Technology – Promises & Opportunities

- **Broad accessibility**
 - 24/7 reach, evidence-based tailored content
 - Mixed media – text, audio, video, animation
- **Motivation and expertise related to technology increases in adolescence**
- **Best conceived as an accelerator/facilitator**
 - Is it needed and helpful? Risk of translation loss

TECHNOLOGY CAN

- Support / Encourage
- Entertain
- Engage
- Remind
- Provide information to assist with decision-making
- Monitor
- Assess
- Track changes and trends
- Calculate
- Display / Enhance Visualization
- Facilitate communication and connection



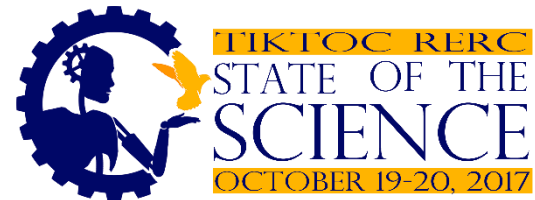
Mobile Technology –Challenges

- Developing and innovating in a space where there is an opportunity for shared understanding and discussion.
- Knowledge and expertise of individuals with disabilities and their families should inform development and innovation processes
- The systems, structures, and processes associated with healthcare, educational, and employment environments in which the technology needs to be embedded – or at least interacted with

MOBILE TECHNOLOGY CANNOT

- Force
- Compel
- Fix
- Communicate for you
- Make you focus
 - In fact, can serve as a significant distraction
- Keep clinician in the loop
- Share data
- Ask questions
- Trigger clinical response
- Influence patient-clinician communication & relationship
- Enable adolescents autonomy under clinical supervision

The Event and Participants



State of the Science

October 19-20th, 2017

*Facilitating Health Self-Management
and Independence among Adolescents
and Young Adults with Disabilities :*

**The Development, Efficacy, Integration,
Sustainability of Mobile Technology to
Support the Transition Process**



University of Michigan
Rehabilitation Engineering Research Center
Technology Increasing Knowledge: Technology Optimizing Choice





Focus and Goal of Conference

- **Focus:** Identify best practices and the state of the science as related to mobile technology applications for individuals with physical, cognitive, and developmental disabilities.
- **Goal:** Bring together a diverse mix of researchers, clinicians, and developers as well as representatives from disability organizations, funding agencies, and business, insurance, and technology-related companies to consider how best to integrate mobile technology into systems and lives.

Who Participated

- Clinicians / Health Care Providers
- Computer & Engineering Scientists
- Information Scientists
- Representatives of Disability Organizations
- Individuals Living with Disabilities
- Policy Specialists
- Business owners
- Educators
- Advocates
- Transition Specialists
- Representatives from Healthcare systems
- Representatives from Funding Agencies

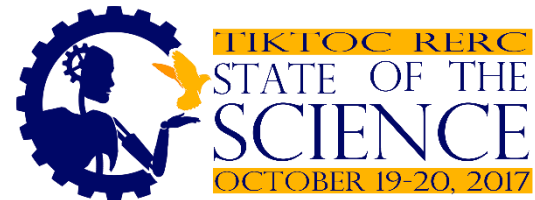




Flow of Conference

- Plenary Presentations
- Panel Presentations & Work Groups
 - Engagement and Tailoring
 - Innovation
 - Research
 - Integrating Technology into Health Care
 - Sustainability and Technology Transfer
- Summary & Discussion Sessions
- Showcase

THE CONTENT





TIKTOC RERC
STATE OF THE
SCIENCE
OCTOBER 19-20, 2017

Engagement and Tailoring

of Mobile Technologies for Health Self-management

Panelists:

Seth Warschausky, PhD; University of Michigan

Lisa Jacobson, PhD, ABPP-CN; Johns Hopkins University, Kennedy Krieger Institute

Ronald Seel, PhD, FACRM; Shepherd Center

Daniel Joye; CEO, Mindfulware

Eric Maslowski; CTO, MoxyTech





Key Factors to Consider / Address

- Psychosocial Context
 - Developmental Stage
 - Social Environment and Context of Use
 - Patterns of Use
- Engagement & Mastery Motivation
- Executive Functioning
- Physical Functioning
- (Other) Issues / Challenges specific to Impairment / Disability / Chronic Health Condition



Psychosocial Context

DEVELOPMENTAL FACTORS & NEEDS

- Autonomy – exercise of free will
- Competence – sense of efficacy
- Relatedness – connectedness with other
- Independence

SOCIAL ENVIRONMENT

- Social Determinants

- Health and mental health access
- Education and employment
- Housing, food security
- Social support

- Differing perspectives and concerns of different groups

- Adolescents vs Parents vs. Friends
- Clinicians vs. Families
- Acceptance, understanding and use by others

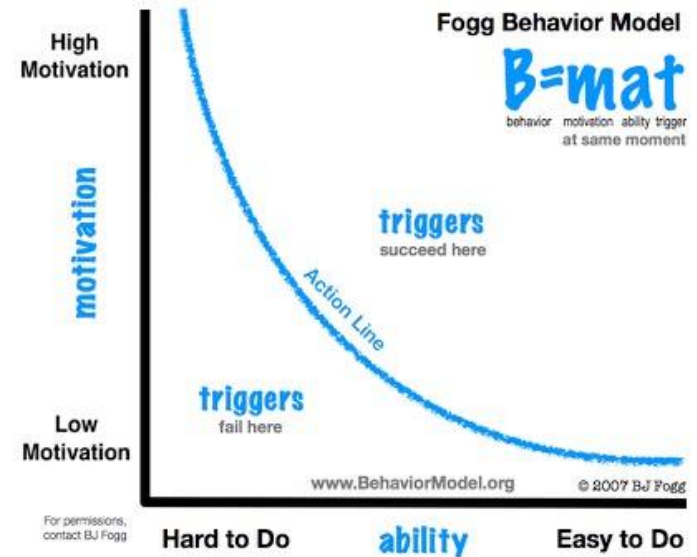


Existing patterns of Technology use

- Wide range of consumer preferences
 - Amount and level of detail desired
 - Number of activities and time willing to spend
 - Health privacy concerns
- Common elements
 - Make personal choices that are best for them
 - “Just in time” solutions tailored based on identified need
 - Visual display of data versus numbers/tables
- Ease of use is critical
 - Easy to see (hear/touch)
 - Easy to understand, e.g., can “alligator brain” it
 - “Thumb interface”
- Data collection “burden” is tied to ease and relevance, not volume
- Language and context is important
 - Positive framing of interventions,
 - No one likes being “supervised” by their spouse or parent

Engagement / Motivation

- Risk for low mastery motivation, or persistence in the face of challenge.
- And mastery motivation appears to be related to executive functions and behavior
- Persistence in cause and effect problem-solving involves
 - Keeping a goal in mind: Working memory
 - Inhibiting other responses
 - Shifting/Cognitive flexibility if conditions/demands change



Executive Functioning

- Beyond IQ
- Domains /Skills
 - Task Initiation
 - Impulse or Inhibitory Control
 - Working Memory
 - Planning / Problem- Solving
 - Organization
 - Flexibility / Set-shifting
 - Self-monitoring
- Challenges
 - Executive Dysfunction can hinder access to technology because of accessibility, usability, understandability
 - And technology can exacerbate Executive Dysfunction !
 - Development + expectations
 - **Inhibitory Control** (don't look at Facebook, don't play games, don't google every question I have ever....)
 - **Working Memory** (remember the directions and goal of the task as well as the controls for the application/what comes next).
 - **Flexible Thinking** (trouble shoot technical difficulties, problem-solve, consider alternative approaches using different digital tools ons = moving target



Physical Functioning

Motor

- Motor Control Impairment
- Muscle Weakness
- Muscle Tone
- Balance
- Range of Motion Limitations

Cognitive

- Attention
- Memory
- Executive Function
- Visual Perceptual
 - Processing speed
 - Perceptual complexity/vision
 - Reading level (5 cent words)
 - Procedural complexity

Vocal & Communication

- Speech,
- Language
- Muteness

Vision

- Vision Loss
- Color Blindness
- Visual Motor impairment
- Visual Field Loss

Hearing

- Loss
- Familiarity / use of other types of communication



Recommendations from Workgroup

- Know your audience and be able to identify who your end user is.
- Tailor to the need, problem or issue that you've identified.
- Leverage topical expertise.
- Use an iterative design process
- Build in fun.
- Consider sustainability.



TIKTOC RERC
STATE OF THE
SCIENCE
OCTOBER 19-20, 2017

Innovation in the Development of Mobile Apps

Panelists:

Mark Ackerman (University of Michigan)

Ed Cutrell (Microsoft Research)

Dan Ding (University of Pittsburgh)

Ed Durfee (University of Michigan)

Amy Hurst (University of Maryland Baltimore County)

Mark Newman (University of Michigan)



Some Areas of Technological Innovation

- Technology for sensing the world (Mark Newman)
 - Ubiquitous computing and personal informatics
- Technology for improving accessibility (Amy Hurst)
- Technology for training and education (Dan Ding)
- Technology for fostering interaction among people (Ed Cutrell)
- Technology for drawing on community knowledge (Mark Ackerman)
- Technology for assisting/augmenting human cognition (Ed Durfee)



Best Practices for Applied Innovation

- Consider end-user habits and preferences instead of only ability (Hurst)
- Assess the technology relevance and practicality in the intended context of use by involving target users (Ding)
- Understand existing practices thoroughly; develop empathy and insight to guide design (Newman)
- Recruit a small set of target users as co-designers and testers. This allows them to travel along with your journey of technical discovery and to spot how designs or ideas might play out in their own context (Cutrell)
- Knowing when to optimize and when to satisfice: adjusting research objectives when moving from academic perspective to applications (Durfee)
- Use technical designs as probes to deepen understanding (Ackerman)

Understanding and Incorporating User Needs

- Long-term studies including interviews and field work (and probes) (Ackerman)
- Working with a consumer organization and including a lead user in the development team (Ding)
- Grounding discussion on representative scenarios focused on the central challenges, and redirecting discussion away from tangents (Durfee)
- Longitudinal field work and volunteering (Hurst)
- Diary studies and experience sampling (Newman)
- Advocacy organizations can be great for connecting to users. But care should be taken; these organizations have their own agendas and their goals may not perfectly align with the everyday needs of their membership. Don't take their word as a proxy for the voice of the people they represent (Custal)





Involving/Integrating Stakeholders and Disciplines

- Teams that combine qualitative user research, technologists and designers can be AMAZING, but it can be very challenging keeping them all on the same page. Epistemological impedance matching FTW! (Cutrell)
- Participatory design – including user representatives on the design team (Newman/Ackerman)
- Understand the individual needs of each stakeholder or discipline, and accommodate them in the design and research process (Ding)
- One successful model: a champion to make it happen, such as Defense Department's tech development for warfighter safety (Durfee)
- Get out of the lab and into the field to minimize our bias as researchers (Hurst)



Innovations Worth Investing In

- (Environmental/social/etc) context-aware automation: Self-limited machine behavior to minimally disrupt environmental/social context (Durfee)
- Natural language interaction will be revolutionary for people with motor and visual disabilities. We're just starting to see this with phone and in-home devices like Amazon Echo, Google Home (Cutrell)
- Better coordination within care teams around data and privacy (Ackerman)
- Personalized, meaningful data management and sensemaking (Newman)
- Support convenient, reliable, and accurate self-monitoring via sensors (Ding)
- Education and training for young adults to continue to learn employable skills and technical literacy beyond data entry and disposal (Hurst)



Work Group Highlights, Challenges & Recommendations

- Challenges of interdisciplinary collaboration
- Challenges of going from a research prototype to a production system
- Issues with proprietary software
- Possibility of building research infrastructure



TIKTOC RERC
STATE OF THE
SCIENCE
OCTOBER 19-20, 2017

Research on Self-Management Interventions to Facilitate Health Management and Independence of Adolescents and Young Adults with Disabilities

Panelists:

Tom Baranowski (Baylor College of Medicine)

Bethlyn Houlihan (MGH Institute of Health Professions, Boston)

Spyros Kitsiou (University of Illinois, Chicago)

Michelle Meade (University of Michigan)

Stephen Wegener (Johns Hopkins University)

Howard Wills (University of Kansas)



Research – Foundational ideas

- Focus on Value Based research - simultaneous pursuit of three aims (Berwick, 2008)

- improving the experience of care
- improving the health of populations,
- reducing per capita costs of health care

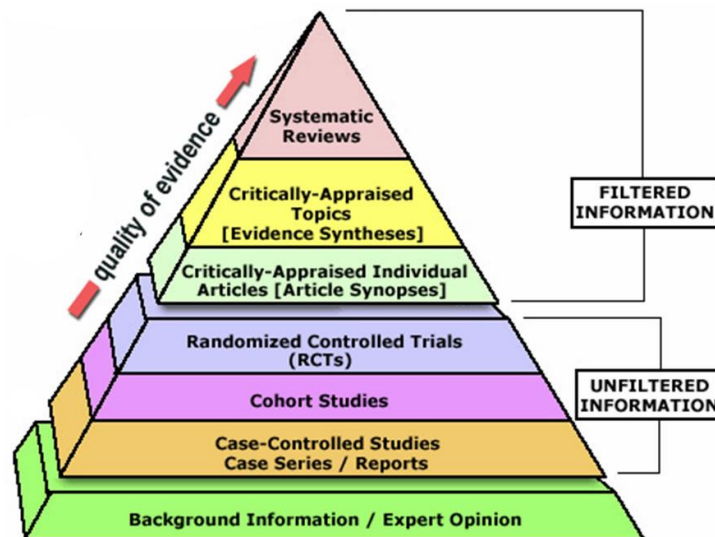
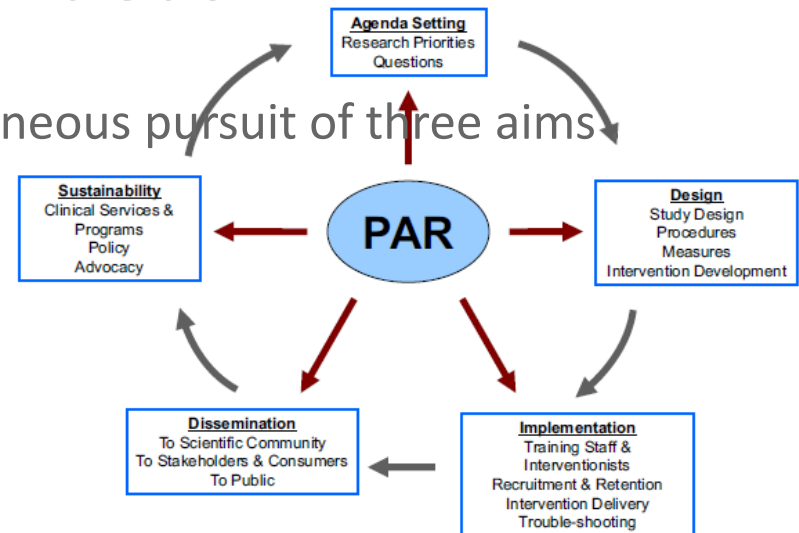
- Participatory Action Research

Ehde, Wegener et al, 2009

- Hierarchy of Evidence

Unfiltered information

Filtered information





State of the research

- Still in initial stages / Relatively few studies focused on disability
 - Pilot intervention studies assessing feasibility and acceptability of new care approaches; validity and reliability of instrumentation or apps; and preliminary efficacy
 - Disconnect between research and commercial development
- Mobile technology for use in School, Work, and Community Settings LAGS BEHIND
MEDICAL SELF-MONITORING
- Inconsistent use of theory based approaches
- Heterogeneity of Assessment Measures
- Lack of standardization or understanding of technology and reliability of data provided
- Need to determine best timing and groups to use techniques with
- Many studies are not adequately powered, especially to
 - Detect differences
 - Examine the impact of different behavioral change tools on different behaviors
 - Examine the many factors can influence the effectiveness of these interventions (i.e., trial quality, participant factors, disease status, the country setting, intervention factors)
- Mechanism of change not well understood



Recommendations

- Improve standardization of methodology and outcome assessments
 - Problem solve recruitment / sample size issues
 - Move beyond approaches that depend on size of patient population
 - Include economic / cost-effective analysis for interventions with promising effects
 - Conduct systematic reviews on both single types of Mobile Technology interventions as well as interventions combining mobile technologies
 - Need to provide evidence about reliability, validity and efficacy of applications across range of disease and disabilities so as to facilitate Integration in the delivery of healthcare
 - Increase interactions between development of commercial apps and mHealth related research and scientific publications
 - Collaboration between clinicians, health informaticians, and the industry is essential for the design and optimization of new mHealth technologies and care delivery approaches
- Funding organizations need to create strategic initiatives to bridge the present gap in making grants that involve all key stakeholders



Solutions / Possible Steps

- Consumer Participatory Research and “so what” question
- Improve methodology and rigor of study design
 - Include assessments of mediating and moderating factors
- Develop consensus standards / recommendations, in collaboration with funding agencies
 - For assessment measures
 - For what aspects of data from technology should be reported
- Push for the standardization of terms / definitions
- Create national networks to promote engagement and recruitment in participants
 - Consider working in partnership with disability organizations
- Partner with technology companies to see about conducting observational studies on the technology that they are releasing



Priority research areas

- Understand the why behind what works / what are the core principals that will be able to be utilized beyond a specific generation of technology
- Examine the decision making process for mHealth development
 - Expert systems and modeling the process
- Provider feedback reports and algorithms
- Economic variables and cost-effectiveness of interventions
 - Provide value added and increased efficiency
- Assistive technology that is aimed at the environment and so not dependent on individual action
- Research on commercially available apps and technology
- Research in school and community settings
- Specific research areas
 - Cognitive Orthoses
 - Virtual assistants



TIKTOC RERC
STATE OF THE
SCIENCE
OCTOBER 19-20, 2017

Integrating Technology into Healthcare, Rehabilitation and Independent Living

Karin Farris, PhD – UM College of Pharmacy

Devin Mann, MD - NYU Langone Medical Center; NYU School of Medicine

John F. Butzer, MD, Director, John F. Butzer Center for Research and Innovation at Mary Free Bed

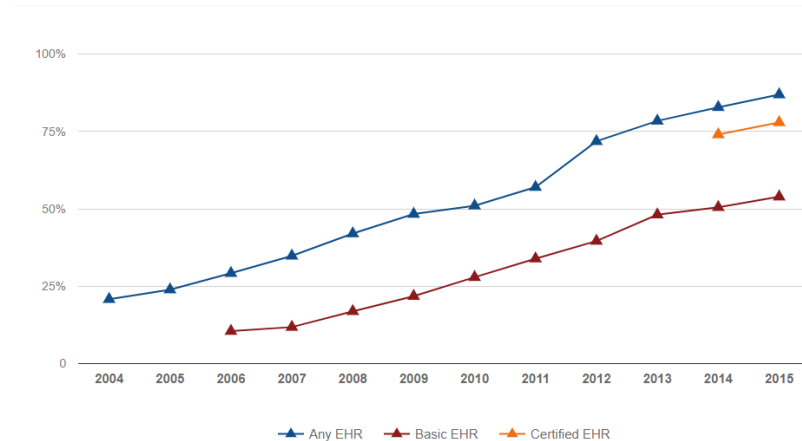
Andrea Fairman, PhD, MOT - MGH Institute of Health Professions

Sarah Lord, PhD – Dartmouth College



Electronic Health / Medical Records (EHR / EMR)

- Recognize relatively short time since EHRs and Cell phones developed
- Pro's
 - Accessibility, engagement
 - Tighten feedback loop to promote behavior change
 - Potential richer connection between patient and clinician
 - Remote Patient integration
 - Device agnostic
 - Visualize trends
 - Clinician notifications



Cons

- Evolving standards
- Integration > deep integration
- Data ≠ Insights
- Burden >> Help
- Remote Patient Data Integration
- Inflexible
- Lacks engagement facilitators
- Rudimentary visualizations
- Few connected clinical actions



Learning Health System

- The goal of a Learning Health System, a focus on ongoing improvement by capturing data from the health encounter and applying those data to improve practice and delivery
- Using data from Mobile Technologies
- There must be a plan.
 - Monitoring data without plan is *NOISE*.
- The data must be actionable.
 - Too much frustration with poor EHR usability



Premises agreed upon by work group

- (1) We cannot wait on the large RCT for mHealth applications.
- (2) We need to figure out how to connect or bridge the academic – industry divide



Recommended strategies for moving forward

- mHealth development should reflect strong methodology, but agile development
 - Both development and evaluation should be iterative
 - Funding agencies and other should require partnerships between individuals in different systems (e.g., health systems, disability organizations, industry partners, academia) in order to move forward on a product that can be useful.
 - Think about implementation from day one
- Develop a prototype with as little money as possible. Put it into the marketplace, and the funding supports the continued development and evaluation
- Write both literature review and user reviews. Who is going to use this? How is it going to be useful? What's the uptake? What's the audience?
- When we're developing and implementing, use cases can help you focus and most likely be more successful.



Other Principles & Recommendations

- As related to big data and data science, as it relates to mHealth, IEPs in education, employment data:
 - You have to understand the validity of that data.
 - The data must be useful , it has to be quick, it has to be visual, and it has to be available when the person is right in front of them; and/or there's a big signal, meaning something drastic is happening to the patient; somebody needs to respond.
- To get our mHealth data used and results supported, we need a trusting relationship with the leaders of our organizations.
- Must remember that transition is interactions between systems so it is critical to consider how those systems (EHR, education, employment, etc) are going to work together and how data is going to be moved from one to the other.



TIKTOC RERC
STATE OF THE
SCIENCE
OCTOBER 19-20, 2017

Technology Transfer & Sustainability Models and Best Practices

Panelists:

Drew Bennett - University of Michigan

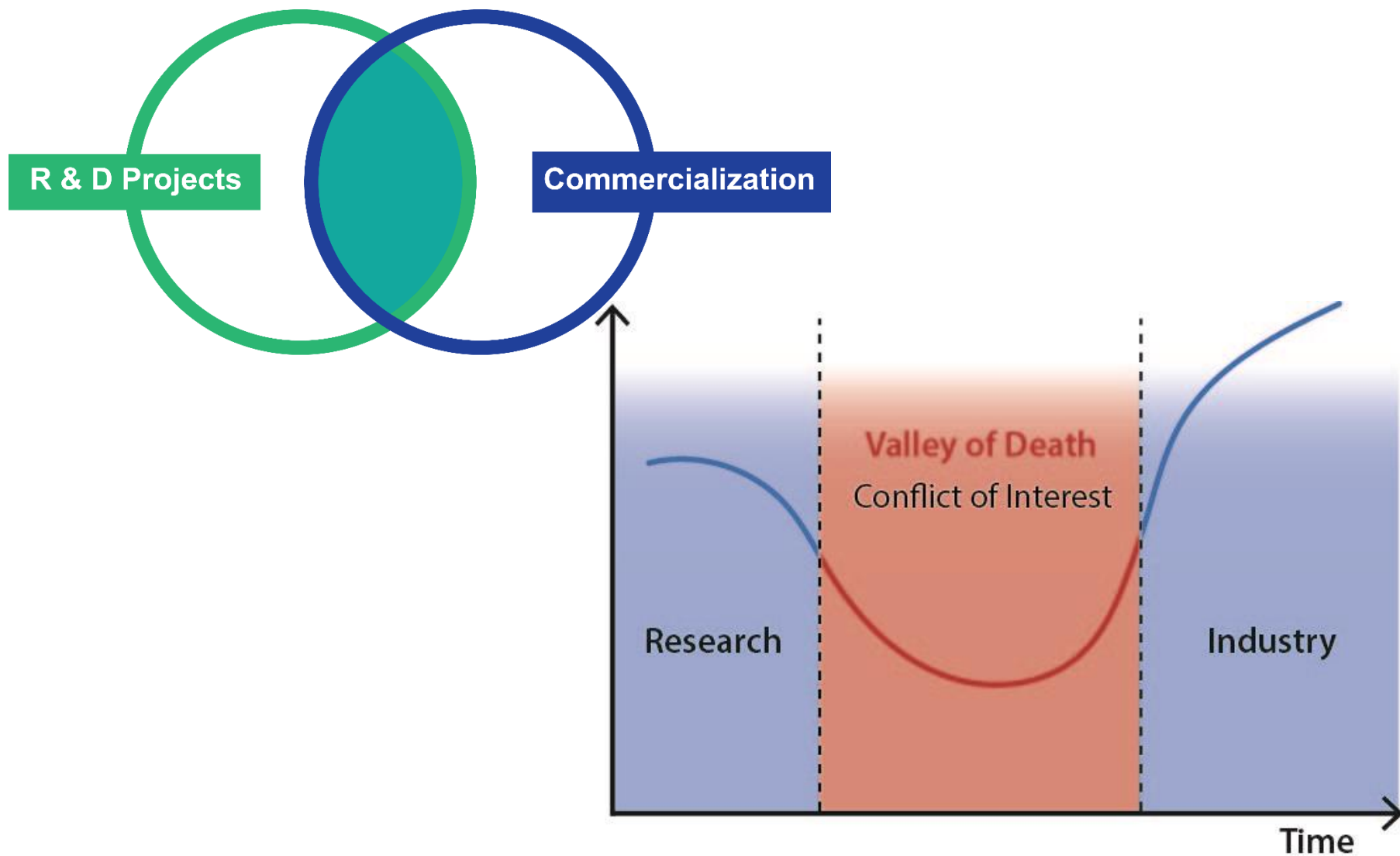
Eric Maslowski - MoxyTech

Bambang Parmanto - University of Pittsburgh

Rich Herold - AbleLink Technologies



Difficulty in jumping from research to marketplace



TECH TRANSFER

Mission

Commercialization and dissemination of inventions based on intellectual property



Services

Licensing, Venture, Legal, Marketing and Business Operations Professionals

People / Entities Involved

PI and Team; customer; Public; Investors; Licensee; Market ; Partners

TECH TRANSFER

Licensee (T)



Partnerships (P)



a. Cause Based



a. Professional Based

b. Community Based



Platform (P)

Open Source(P)





Great Projects and Partnerships

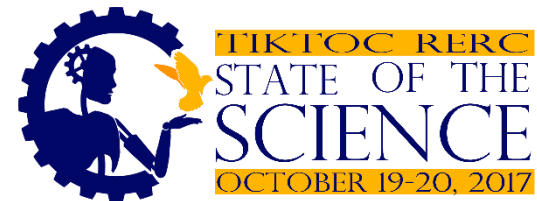
- Know your target market and competing technology
- Identify your path to market
- Common Purpose
- Clear, Consistent Communication
- Trust
- Aligned Expectations and Goals
- Tech. Transfer: Flexibility, Creativity & Tenacity
- Know your unique currency
- Initial revenue base
- Sustainability
- Lifelong benefit for customers
- Keys
 - Long-range vision paired with short-term evaluation
 - Maximizing strengths in collaboration
 - Shared research and development
 - Shared marketing
- Barriers
 - Failing to build a foundation of trust
 - Poor communication
 - Lack of organizational commitment
 - Low expectations of hands-on staff



Workgroup Recommendations

- Begin with the end in mind
- Alternative partners for an endpoint
- Technical Obsolescence
- Recognize transactional nature of transfer process and keep each partner involved and connected
- Really important to spend more time up front with respect to the work you're doing.
- Licensing approach vs Freeware
- Adjacency

IN SUMMARY





Start with the end in mind



Partner with the community



Build collaborations and work across disciplines



Design interventions and technology to
optimize engagement, motivation
and ease of use




Tailor based on ability and functioning



Incorporate theory into design and assess effectiveness of components of interventions



Standardize assessment practices



Test Effectiveness but don't rely on RCTs
before applying or integrating practices



Acknowledge and Work to Address questions of Sustainability



For more information

<https://tiktoerc.com/>

<http://cthi.medicine.umich.edu/>

Or e-mail

mameade@med.umich.edu