Ethical Opportunities and Challenges Using Digital Media for HIV and Drug Abuse Prevention Research

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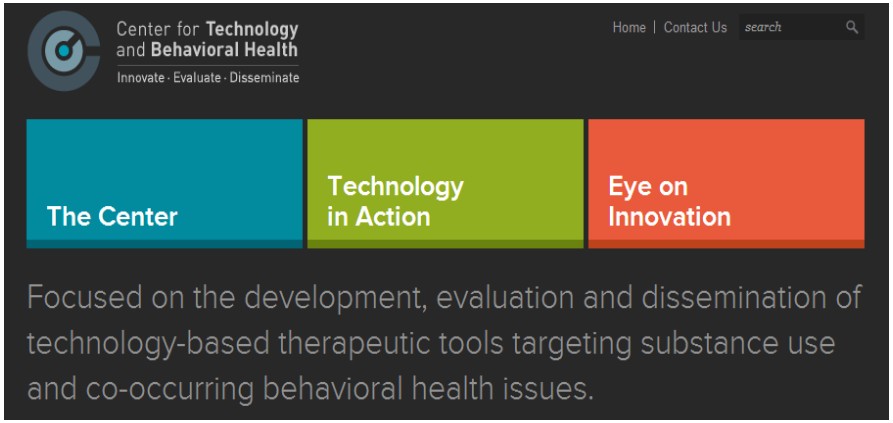

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- Enhance quality, pace of achievement, and impact of innovative scientific research focused on the development, evaluation, and dissemination of technology-based therapeutic tools
- Harness existing and emerging technologies with effective learning and intervention strategies
- Transform the delivery of evidence-based behavioral health care

Why Technology?

- Technology can help address current service gaps
  - Strong and growing evidence that technology-based approaches to substance use and mental health care produce outcomes comparable to trained behavioral health clinicians
  - Across care continuum: screening, assessment, education, prevention, brief intervention, treatment and recovery support

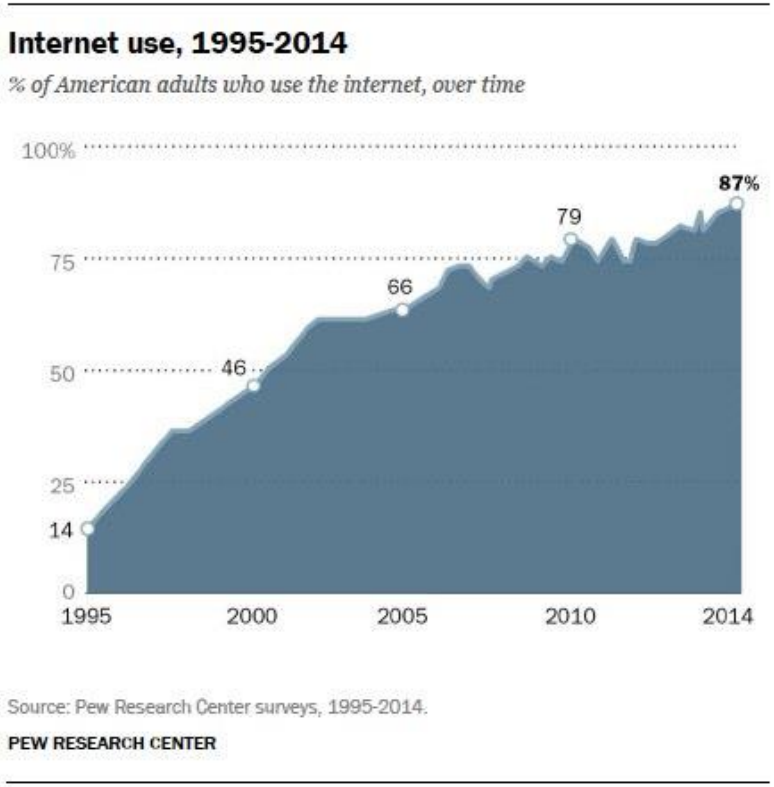
Promise of Technology: Does it Work?

- **Research has demonstrated that technology-based behavioral health tools can:**
  - Be useful and acceptable to diverse populations
  - Have a large impact on health behavior and health outcomes
  - Produce outcomes comparable to clinicians
  - Increase quality, reach, and personalization of care
  - Be cost-effective
  - Be responsive to individuals' health behavior trajectory over time

If developed well and in collaboration with the target audience

Ubiquity of Technology

- 90% of individuals worldwide have access to mobile phone services, totaling about **6.8 billion mobile phone subscriptions worldwide**
- 1.4 billion **smartphones** in the world, and smartphone access is expected to triple globally to **5.6 billion by 2019**
- Internet and mobile access is high and growing among **even the most traditionally underserved and vulnerable populations**



Broadband and smartphone adoption

Among all American adults ages 18 and older, the % in each group who…

		Have broadband at home	Have smartphone	Have home broadband or smartphone	Have smartphone, no home broadband
All adults		**70%**	**56%**	**80%**	**10%**
a	Men (n=1029)	71	59[b]	**81**	10
b	Women (n=1223)	69	53	**78**	9
Race/ethnicity					
a	White, Non-Hispanic (n=1571)	74[bc]	53	**80**	6
b	Black, Non-Hispanic (n=252)	64[c]	64[a]	**79**	15
c	Hispanic (n=249)	53	60	**75**	22
Age					
a	18-29 (n=404)	80[cd]	80[bcd]	**95**[bcd]	15
b	30-49 (n=577)	78[cd]	67[cd]	**89**[cd]	11
c	50-64 (n=641)	69[d]	45[d]	**77**[d]	8
d	65+ (n=570)	43	18	**46**	3
Education attainment					
a	No high school diploma (n=168)	37	36	**52**	15
b	High school grad (n=630)	57[a]	46[a]	**70**[a]	13
c	Some College (n=588)	78[ab]	60[ab]	**87**[ab]	9
d	College + (n=834)	89[abc]	70[abc]	**93**[abc]	4
Household income					
a	Less than $30,000/yr (n=580)	54	43	**67**	13
b	$30,000-$49,999 (n=374)	70[a]	52[a]	**79**[b]	10
c	$50,000-$74,999 (n=298)	84[ab]	61[a]	**91**[ab]	7
d	$75,000+ (n=582)	88[ab]	78[abc]	**95**[ab]	7
Urbanity					
a	Urban (n=763)	70[c]	59[c]	**80**[c]	10
b	Suburban (n=1037)	73[c]	59[c]	**83**[c]	10
c	Rural (n=450)	62	40	**70**	8

Source: Pew Research Center's Internet & American Life Project Spring Tracking Survey, April 17 – May 19, 2013. N=2,252 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. The margin of error for results based on all adults is +/- 2.3 percentage points.

Note: Percentages marked with a superscript letter (e.g., [a]) indicate a statistically significant difference between that row and the row designated by that superscript letter, among categories of each demographic characteristic (e.g. age).

Digital Solutions

- Devices
  - Computers, laptops, tablets, mobile phones, wearables
- Platforms
  - Internet, mobile apps (native, web-based), text message, phone call, video, virtual environments, games
  - Social media
    - Facebook, Instagram, Snapchat, Twitter, Grindr etc.
  - Radio-frequency/bluetooth “beacons”
- Passive/Wearable sensing
  - Mobile phones
  - Other wearable devices
    - Heart rate, skin conductance, electroencephalogram (EEG)
      - Commercial
      - Researcher developed

CTBH Examples

- Web-based and mobile apps for substance use and mental health screening, assessment, prevention, treatment, recovery support
  - Alcohol, marijuana, tobacco, opioids
  - HIV/STI, co-occurring conditions
- Mobile apps to support self-management of psychotic symptoms associated with serious mental illness
- Use of social media as survey assessment and implementation platforms
  - Tobacco, marijuana, opioid recovery support groups
- Wearable sensors and mobile phone sensing to gather data to inform predictive models of stress, substance use relapse or mental illness symptom exacerbation – with ultimate goal of just-in-time interventions
- Care management platforms to enhance delivery of evidence-based supported employment and other patient-centered, team-based care approaches
- Proximal marketing approaches to college student stress – health promotion

Digital Potential

- Practice:
  - Education, prevention, screening, assessment, treatment, recovery support
- Research:
  - Survey, real-time ecological momentary assessment, natural language processing, ethnography, recruitment, focus groups, intervention development, testing, and implementation, “Big Data” prediction, just-in-time algorithms

Ethical Considerations: Principles of Research with Humans

- Nuremberg Code 1947
  - Autonomy – voluntary, informed consent
  - Beneficence – good science, benefits outweigh risks
  - Justice – equal opportunity to participate and not to participate

- With these principles in mind, how can we think about our work with digital media?

Ethical Considerations

- Technology significantly outpaces science
  - Rush to use, perceived panacea
- Privacy and security associated with use of mobile phones, text messages, mobile applications, social media
  - Recruitment, consent – How ensure recruiting intended target population (e.g., 18 and over)?
  - Data collection, data storage, data sharing, data ownership and 3rd party use
  - Effective, transparent communication needed
- Accessibility an issue
  - technologies, connectivity
- Trust: Academic-Industry-Community Partnerships