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

Sarah Lord, Ph.D. and Brenda Curtis, Ph.D.
Geisel School of Medicine at Dartmouth College
University of Pennsylvania

Fordham University HIV Prevention Research Ethics Institute
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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

www.c4tbh.org
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
• 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...

<table>
<thead>
<tr>
<th></th>
<th>Have broadband at home</th>
<th>Have smartphone</th>
<th>Have home broadband or smartphone</th>
<th>Have smartphone, no home broadband</th>
</tr>
</thead>
<tbody>
<tr>
<td>All adults</td>
<td>70%</td>
<td>56%</td>
<td>80%</td>
<td>10%</td>
</tr>
<tr>
<td>a. Men (n=1029)</td>
<td>71</td>
<td>59&lt;sup&gt;b&lt;/sup&gt;</td>
<td>81</td>
<td>10</td>
</tr>
<tr>
<td>b. Women (n=1223)</td>
<td>69</td>
<td>53</td>
<td>78</td>
<td>9</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>a. White, Non-Hispanic (n=1571)</td>
<td>74&lt;sup&gt;bcd&lt;/sup&gt;</td>
<td>53</td>
<td>80</td>
<td>6</td>
</tr>
<tr>
<td>b. Black, Non-Hispanic (n=252)</td>
<td>64&lt;sup&gt;c&lt;/sup&gt;</td>
<td>64&lt;sup&gt;a&lt;/sup&gt;</td>
<td>79</td>
<td>15</td>
</tr>
<tr>
<td>c. Hispanic (n=249)</td>
<td>53</td>
<td>60</td>
<td>75</td>
<td>22</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. 18-29 (n=404)</td>
<td>80&lt;sup&gt;cde&lt;/sup&gt;</td>
<td>80&lt;sup&gt;bcd&lt;/sup&gt;</td>
<td>95&lt;sup&gt;bcd&lt;/sup&gt;</td>
<td>15</td>
</tr>
<tr>
<td>b. 30-49 (n=577)</td>
<td>78&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>67&lt;sup&gt;d&lt;/sup&gt;</td>
<td>89&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>11</td>
</tr>
<tr>
<td>c. 50-64 (n=641)</td>
<td>69&lt;sup&gt;d&lt;/sup&gt;</td>
<td>45&lt;sup&gt;d&lt;/sup&gt;</td>
<td>77&lt;sup&gt;d&lt;/sup&gt;</td>
<td>8</td>
</tr>
<tr>
<td>d. 65+ (n=570)</td>
<td>43</td>
<td>18</td>
<td>46</td>
<td>3</td>
</tr>
<tr>
<td><strong>Education attainment</strong></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>a. No high school diploma (n=168)</td>
<td>37</td>
<td>36</td>
<td>52</td>
<td>15</td>
</tr>
<tr>
<td>b. High school grad (n=630)</td>
<td>57&lt;sup&gt;a&lt;/sup&gt;</td>
<td>46&lt;sup&gt;a&lt;/sup&gt;</td>
<td>70&lt;sup&gt;a&lt;/sup&gt;</td>
<td>13</td>
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<tr>
<td>c. Some College (n=588)</td>
<td>78&lt;sup&gt;ab&lt;/sup&gt;</td>
<td>60&lt;sup&gt;ab&lt;/sup&gt;</td>
<td>87&lt;sup&gt;ab&lt;/sup&gt;</td>
<td>9</td>
</tr>
<tr>
<td>d. College + (n=834)</td>
<td>85&lt;sup&gt;abc&lt;/sup&gt;</td>
<td>70&lt;sup&gt;abc&lt;/sup&gt;</td>
<td>93&lt;sup&gt;abc&lt;/sup&gt;</td>
<td>4</td>
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<tr>
<td><strong>Household income</strong></td>
<td></td>
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<tr>
<td>a. Less than $30,000/yr (n=580)</td>
<td>54</td>
<td>43</td>
<td>67</td>
<td>13</td>
</tr>
<tr>
<td>b. $30,000-$49,999  (n=374)</td>
<td>70&lt;sup&gt;a&lt;/sup&gt;</td>
<td>52&lt;sup&gt;a&lt;/sup&gt;</td>
<td>79&lt;sup&gt;b&lt;/sup&gt;</td>
<td>10</td>
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<tr>
<td>c. $50,000-$74,999  (n=298)</td>
<td>84&lt;sup&gt;ab&lt;/sup&gt;</td>
<td>61&lt;sup&gt;a&lt;/sup&gt;</td>
<td>91&lt;sup&gt;ab&lt;/sup&gt;</td>
<td>7</td>
</tr>
<tr>
<td>d. $75,000+  (n=582)</td>
<td>88&lt;sup&gt;ab&lt;/sup&gt;</td>
<td>78&lt;sup&gt;abc&lt;/sup&gt;</td>
<td>95&lt;sup&gt;ab&lt;/sup&gt;</td>
<td>7</td>
</tr>
<tr>
<td><strong>Urbaneity</strong></td>
<td></td>
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<tr>
<td>a. Urban (n=763)</td>
<td>70&lt;sup&gt;c&lt;/sup&gt;</td>
<td>59&lt;sup&gt;c&lt;/sup&gt;</td>
<td>80&lt;sup&gt;c&lt;/sup&gt;</td>
<td>10</td>
</tr>
<tr>
<td>b. Suburban (n=1037)</td>
<td>73&lt;sup&gt;c&lt;/sup&gt;</td>
<td>59&lt;sup&gt;c&lt;/sup&gt;</td>
<td>83&lt;sup&gt;c&lt;/sup&gt;</td>
<td>10</td>
</tr>
<tr>
<td>c. Rural (n=450)</td>
<td>62</td>
<td>40</td>
<td>70</td>
<td>8</td>
</tr>
</tbody>
</table>

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., <sup>a</sup>) 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