Youth and New Media: New and Old Challenges for Human Subjects Protections

JOHN SANTELLI, MD, MPH
HEILBRUNN DEPARTMENT OF POPULATION AND FAMILY HEALTH
COLUMBIA UNIVERSITY

Just/Us:

A SOCIAL NETWORKING HIV PREVENTION INTERVENTION FOR YOUNG ADULTS OF COLOR
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New Media and Social Media

Web 2.0
Social networking
Mobile phones
-Internet
-Apps
-SMS
Tablets/e-readers
consider this:
The average 16-24 year old spends 70 hours a week in front of 3 screens, sometimes simultaneously.

93% of teens are online
80% use social media
87% sleep with their phones

There is NO difference in technology usage based on socio-economic status or race/ethnicity.
Concerns about Youth and New Media

- Cyber-bullying
- Sexting
- Pornography
- Sexual predators
- Reputation harm

Cyber-Bullying

Online bullying
- Threats and harassment
- False rumors
- Sending lewd photographs
- Disclosure of personal information to harm

Worse than physical bullying?
- Anonymity (emboldens bully and makes identification difficult)
- Bully is not aware of distress they cause
- Breadth of potential audience

89% of Urban youth of color
who have questions about sex use search engines.

“First thing, I google.”
“Sexting”

- “Sending, receiving or forwarding sexually explicit messages, photographs, or images via cell phone, computer, or other digital device”
- 20% of teens have posted nude or seminude photographs or videos of themselves
- Consequences:
  - Threatened with felony child pornography
  - Although many states are changing to juvenile law misdemeanor
  - Suspension
  - Emotional distress

Benefits of Internet Use

- Socialization and Communication
  - Connecting with family and friends
  - Fostering creativity and self expression
- Enhanced Learning
  - Connect with others for homework and group projects
  - Blogs for written expression
- Accessing Health Information
  - Anonymous source of health information
  - Although quality of information an issue!

Youth in the United States

- By 19th birthday, 7/10 teens have had intercourse.*
- 15-24-year-olds = 25% of the population, but = nearly 50% of all new STI cases every year.*
- Young people age 13-24 make up 17% of all HIV/ADS diagnoses in U.S. 2008.*
- >50% of HIV infections are among African Americans, who make up only 13% of population.*

*Guttmacher Institute Research
Ethical Issues Related to Internet Research

- Privacy and confidentiality
- Obtaining and documenting informed consent, assessment of competence
- Equity in patient selection
- Risks and benefits of survey research, educational and behavioral interventions
- Duty to report or treat
- Risk of the internet?

Other Issues Related to Internet Research

- Role of Facebook and other internet providers
- Payment, lotteries
- Minors and age verification

Privacy and Confidentiality

- Observation of public behavior?
  - A walk in the park or eavesdropping?
  - Perceptions of privacy on the web
- Identity on the web
- Deductive identification
  - Direct identifiers: names
  - Internet tracking data: IP addresses, email addresses, web names, cookies
- Working with social networks
Obtaining and Documenting Informed Consent

- Belmont trinity: information, voluntary comprehension
- Assessment of comprehension?
- Great autonomy, less volunteer expectancy
- Written documentation of IC
- Waiver of documentation
  - Documentation vs. privacy
- Waiver of parental permission

Minor Adolescents and New Media Research

- Need to adhere to Belmont Principles
- IRBs have broad latitude in approving research with minor adolescents
- Guidelines on Adolescent Health Research (Society for Adolescent Health and Medicine)
- Adolescent capacity, cognition, and judgment

DEFINITION OF "CHILDREN" IN THE FEDERAL REGULATIONS

"Children are persons who have not attained the legal age for consent to treatments or procedures involved in the research, under the applicable law of the jurisdiction in which the research will be conducted"
STATE LAW ALLOWING MINOR CONSENT FOR CLINICAL CARE

- Age of majority
- Emancipated minors
  - (motherhood, marriage, military)
- Specific medical conditions
  - (STDs, pregnancy, drug use)
- Mature minors

WAIVER OF PARENTAL PERMISSION

- SECTION 46.408(c)
  - Permission is “not a reasonable requirement”
  - E.g., child abuse
  - Alternative procedure(s) to protect the child
- SECTION 46.117 (c)
  - Waiver of documentation of informed consent
- SECTION 46.116 (d)
  - Waiver of informed consent

WAIVER OF PARENTAL PERMISSION

- National Commission

- Conditions for which adolescents may legally receive treatment without parental consent
- Mature minors and no more than minimal risk
- Children in need of supervision
- Children whose parents are legally or functionally incompetent
Summary: Youth and New Media

- New media poses new challenges for IRB
- Certain challenges best handled by going back to basic bioethical principles
- Other challenges will require common sense!