

Use of Mobile Technology in Research: Ethical and Privacy Considerations

Camille Nebeker, EdD, MS

Assistant Professor, Behavioral Medicine

Department of Family Medicine and Public Health

School of Medicine, UC San Diego

@cnebeker

CTTI Expert Meeting: Stakeholder Perceptions of Mobile Technology Use in Clinical Trials

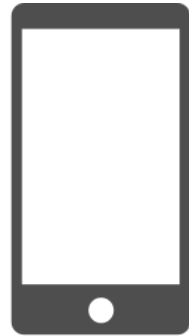
January 9-10, 2018

Bethesda, MD

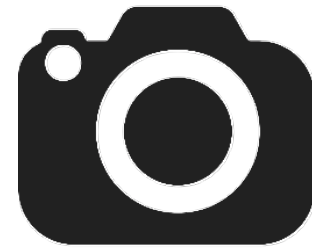
Major Influences on Health



Image courtesy of Dr. Kevin Patrick, Principal Investigator of the Health Data Exploration Project and Director of the Center for Wireless and Population Health Systems



Mobile



Imaging



Sensing

MISST



Tracking



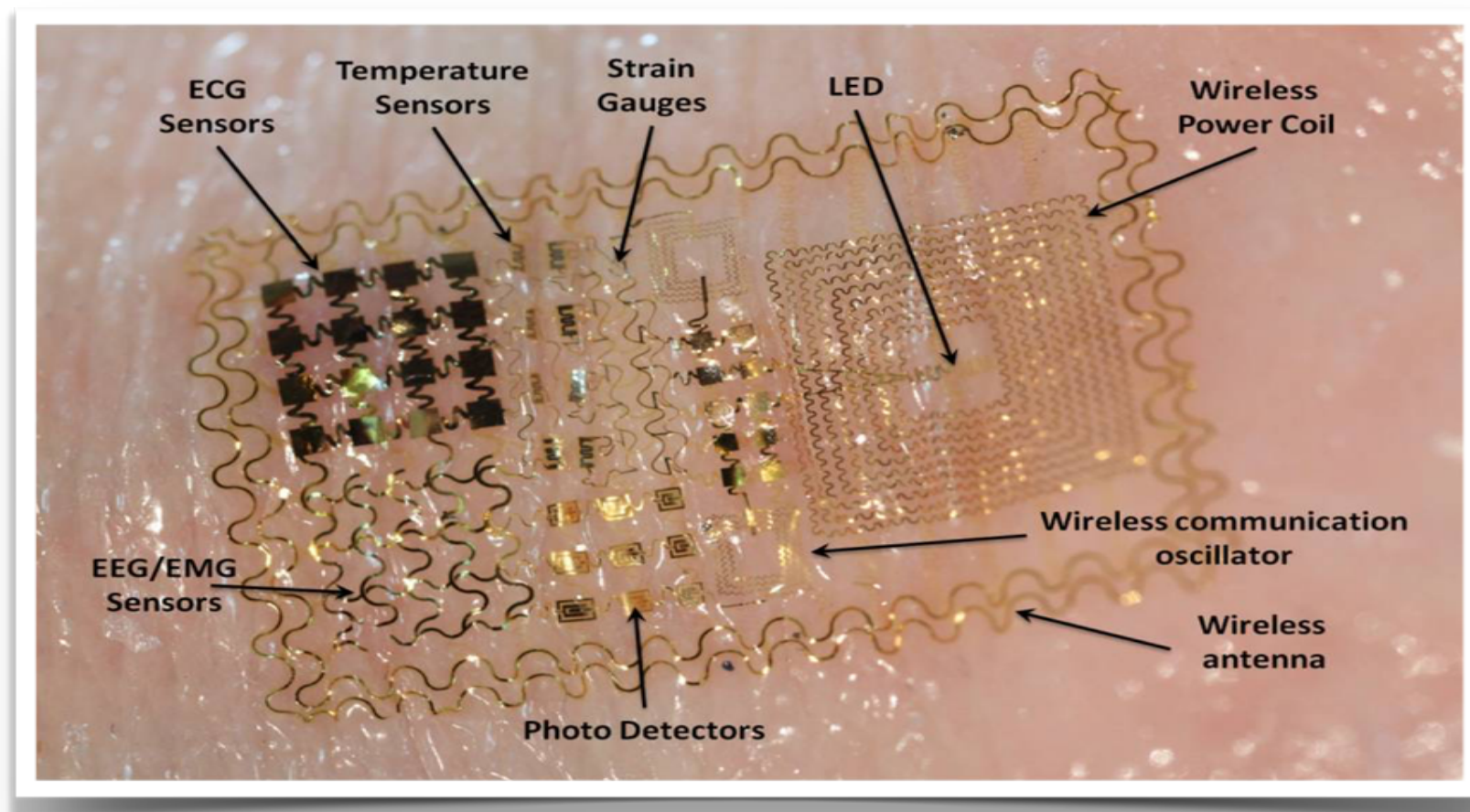
Social

Visual Methods

Increasing interest in studying “free-living” behavior “in the wild” prompts increased use of visual methods.



Sensing Methods



Passive, Pervasive, Ubiquitous



Social Media Methods



 **RunKeeper**



mood



UC San Diego



Commercial Products



**Jawbone
Up 24**



**Garmin
Vivofit**



**Fitbit
Flex**



**Basis
B1 Band**



**Misfit
Shine**



**Withings
Pulse O2**



**Nike
Fuelband
SE**









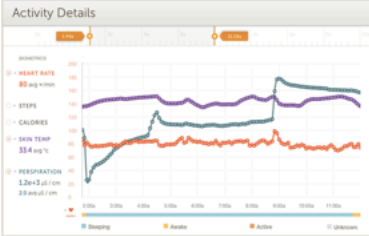

**BodyMedia
LINK
Armband**



UC San Diego



New Methods = New Data

Wearable Cameras	GPS Tracking	Smart Phones	Social Media
			 <p>The CORE UCSD @UCSDtheCORE - Apr 5 Rasheed Al Kotob proudly represents our #COREethics team @UCSDH #PublicHealthWeek #mHealth #DigitalHealth #research_ethics @APHA</p>
			



Ethical, Legal, Social Issues

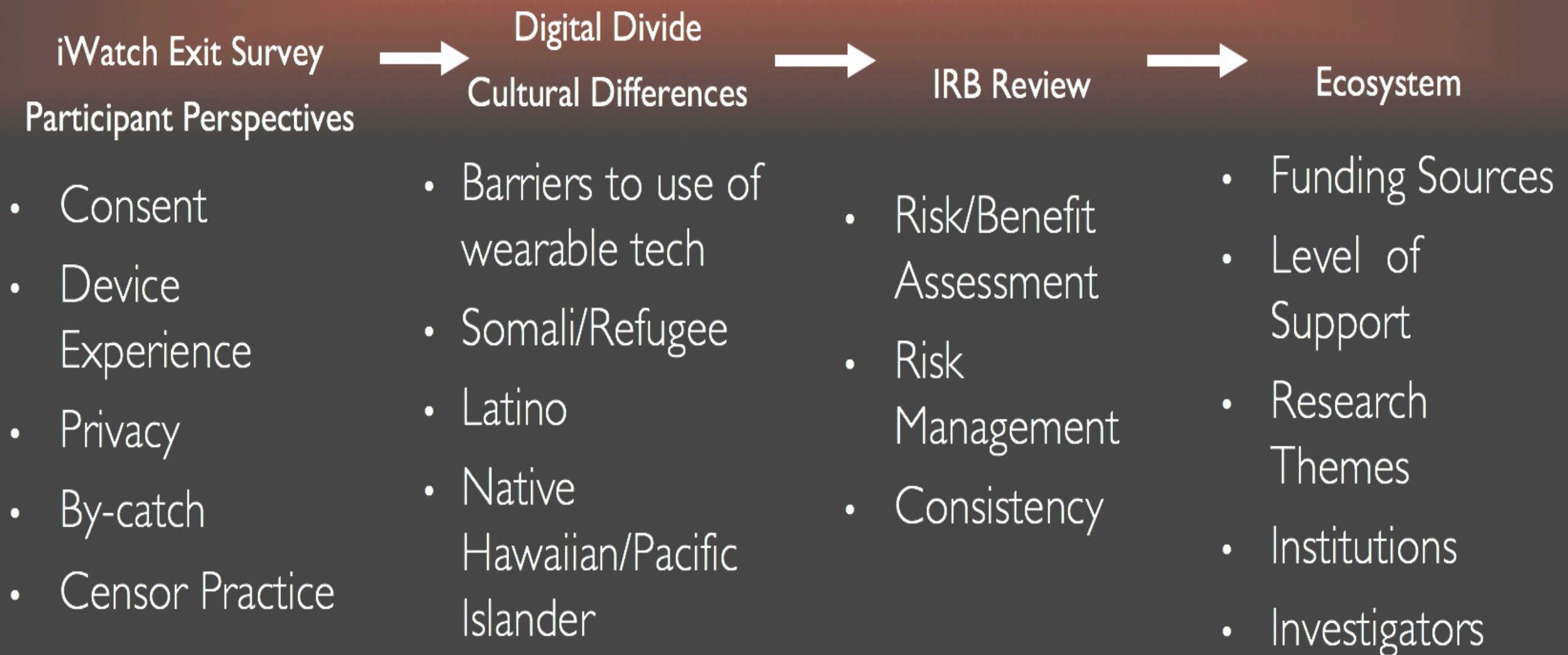
- **Informed Consent:** How can we make consent more informed?
- **Risks and Benefits:** How should the probability and magnitude of harm or benefits be determined?
- **By-Catch:** What about the rights of people who are not research participants?
- **Data Management:** What are best practices for storing and sharing health data when not protected by HIPAA?

How will participants be involved in these conversations?

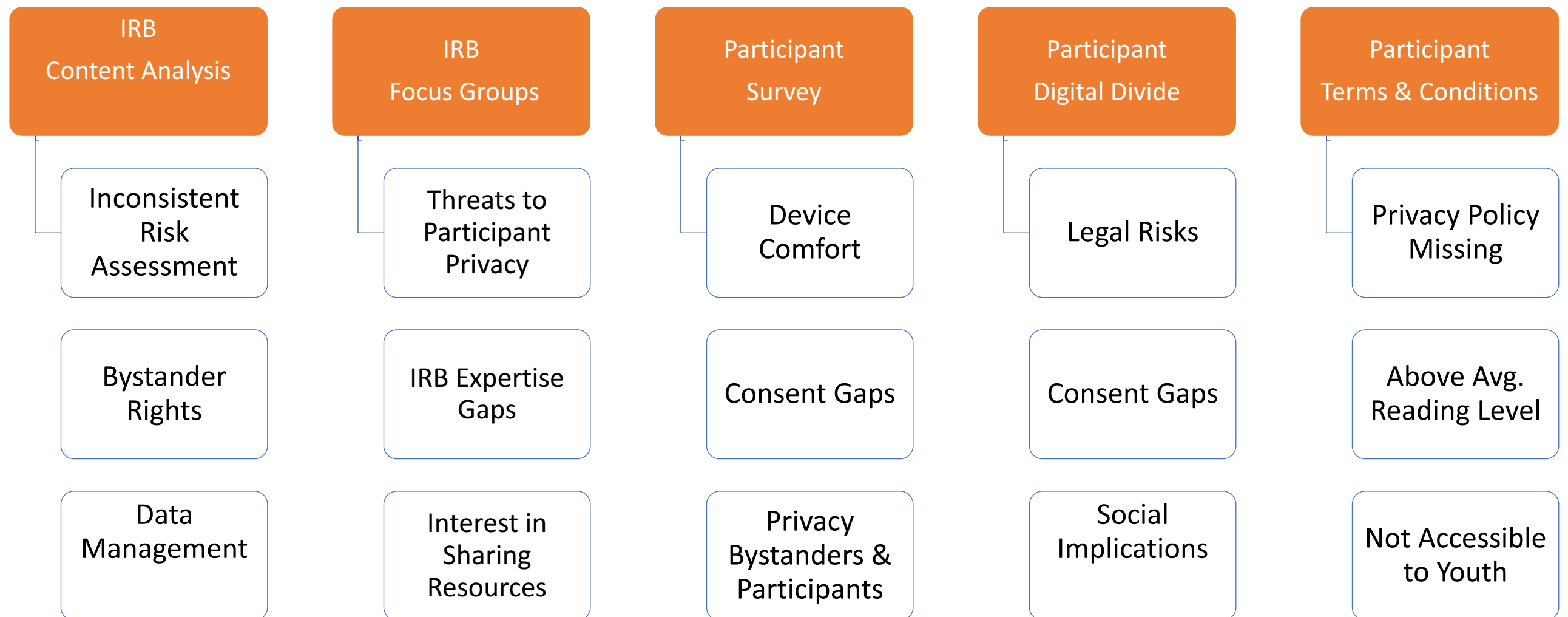
Tech Research Stakeholders



Empirical Research Ethics



Snapshot of Results

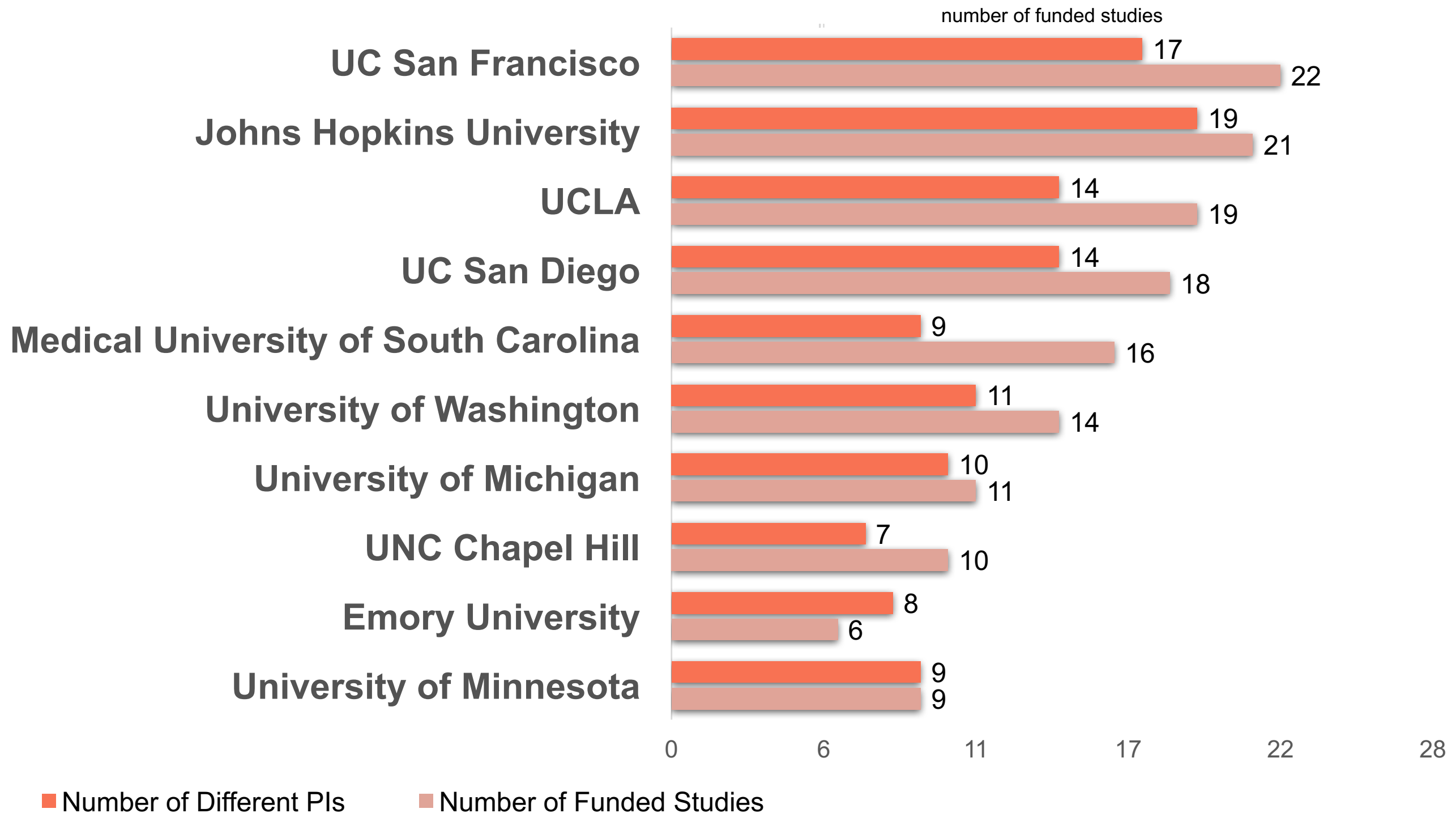


NIH RePORTER MISST Scan

Mobile	Imaging	Sensing	Social	Tracking
Cell Phone	Camera Based	Accelerometer	Facebook	Geographic
mHealth	Camera-Based	Actigraph	Instagram	Information Systems
Mobile App	Camera Sensor	FitBit	Instant Messenger	GIS
Mobile Application	Outward Facing	Fitness Tracker	MySpace	Global Positioning
Mobile Based	Camera	Pedometer	Skype	System
Device	Outwardly Facing	SenseCam	Social Media	GPS
Mobile Device	Camera	Wearable Sensor	Twitter	Location Tracking
Mobile Health	Photovoice	Wearable Sensors	YouTube	
Mobile	Wearable Camera	Wearable		
Technologies		Technology		
Mobile Technology		Wearable		
Mobile-based		Technologies		
Device				
Palm Pilot				
Personal Digital				
Assistant				
Smart Phone				

Dunseath, S.E., Weibel, N., Bloss, C.S., Nebeker, C. (2018). NIH support of mobile, imaging, pervasive sensing, social media and location tracking (MISST) research: laying the foundation npj Digital Medicine (2018) 1:1 ; doi:10.1038/s41746-017-0001-5

NIH-Supported MISST 2015





The CORE brings together people who share expertise and lessons learned with a goal of shaping the ethics of technology-enabled research.



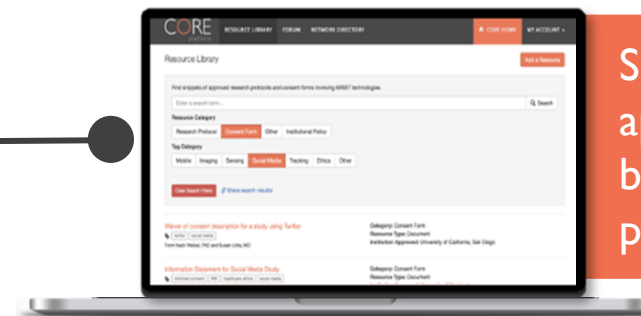
thecore.ucsd.edu



Mobile
Imaging
 Pervasive **S**ensing
Social Media
 Location **T**racking

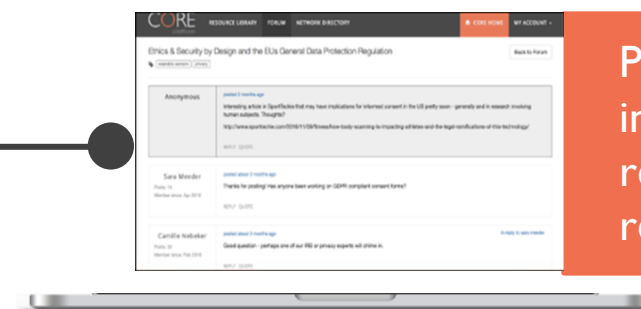


The Resource Library



Search for and share IRB-approved research protocols, best practices, and institutional policies.

The Q&A Forum



Post questions and share interdisciplinary expertise (i.e., research, privacy, technology, regulations).

The Network Directory



Connect with our global network who share an interest in the ethical design and appropriate review of MISST

References

- Dunseath, S.E., Weibel, N., Bloss, C.S., Nebeker, C. (2018). NIH support of mobile, imaging, pervasive sensing, social media and location tracking (MISST) research: laying the foundation npj Digital Medicine (2018) 1:1 ; doi:10.1038/s41746-017-0001-5
- Das G, Cheung C, Nebeker C, Bietz M, Bloss C (2018). Privacy policies for apps targeted toward youth: Descriptive analysis of readability. *JMIR Mhealth Uhealth*;6(1):e3 URL: <http://mhealth.jmir.org/2018/1/e3> DOI: 10.2196/mhealth.7626 PMID: 29301737
- Nebeker, C., Harlow, J., Giacinto-Espinoza, R., Linares-Orozco, R., Bloss, C., Weibel, N. (2017) Ethical and regulatory challenges of research using pervasive sensing and other emerging technologies: IRB perspectives, *American Journal of Bioethics: Empirical Bioethics* 8:4, 266-276, DOI: 10.1080/23294515.2017.1403980
- Nebeker, C., Murray, K.E., Holub, C., Haughton, J., and Arredondo, E. (2017). Acceptance of mobile health in communities underrepresented in biomedical research: Barriers and ethical considerations for scientists. *JMIR Mhealth Uhealth* 2017;5(6):e87 URL: <http://mhealth.jmir.org/2017/6/e87> DOI: 10.2196/mhealth.6494 PMID: 28659258
- Torous J, Nebeker C. Navigating ethics in the digital age: Introducing Connected and Open Research Ethics (CORE), a tool for researchers and Institutional Review Boards. *J Med Internet Res* 2017;19(2):e38 URL: <https://www.jmir.org/2017/2/e38> DOI: 10.2196/jmir.6793 PMID: 28179216 PMCID: 5322198.
- Bloss C, Nebeker C, Bietz M, Bae D, Bigby B, Devereaux M, Fowler J., Waldo A, Weibel N, Patrick K, Klemmer S, & Melichar L. (2016) Re-Imagining Human Research Protections for 21st Century Science. *J Med Internet Res.* ; 18(12):e329. doi: 10.2196/jmir.6634.
- Nebeker, C., Lagare, T., Takemoto, M. et al. (2016) Engaging participants to inform the ethical conduct of mobile imaging, pervasive sensing and location tracking research, *Translational Behavioral Medicine: Practice, Policy and Research* doi:10.1007/s13142-016-0426-4. <https://www.ncbi.nlm.nih.gov/pubmed/27688250>
- Nebeker, C., Linares-Orozco, R., & Crist, K., (2015). A multi-case study of research using mobile imaging, sensing and tracking technologies to objectively measure behavior: Ethical issues and insights to guide responsible research practice. *Journal of Research Administration* 46(1):118-137

Thank You!

Contact Info:
Camille Nebeker
nebeker@eng.ucsd.edu



@COREethics



thecore.ucsd.edu

Robert Wood Johnson
Foundation

