### **TOPICS**

- 1. Data driven approaches to observation and problem formulation
- 2. Scalable approaches to individualized and personalized interventions
- 3. Facilitate divergence and convergence thinking around unintended consequences
- 4. Bringing Theory to Life for People who Need it
- 5. Research and Sociotechnical Responsibilities (Ethical, Legal, and Social Issues)
  - 1. How do we know we are doing good? How do we know when we aren't doing good? What do we do if we don't do good?
- 6. What is Real World success?
  - 1. E.g., vs. disciplinary success
- 7. What do we need to measure and why?
  - 1. What do we need to measure? What is the state space?
  - 2. So we can say who is this working for and in what context?
- 8. When is tech beneficial and for whom?
  - Space for risk (pop, tech, methods, collection)

Time	Topic
9:00-10:30	Ignite Talks
10:30-10:45	Coffee Break
10:45-11:00	Morning Charge
11:00-12:00	Breakouts
12:00-1:00	Report Outs (6 minutes each)
1:00-2:00	Lunch
2:00-2:15	Afternoon Charge
2:15-2:30	Post-It Voting
2:30-3:30	Push it Forward
3:30-3:45	Coffee Break
3:45-4:30	Presentations
4:30-5:15	Documenting
5:15-5:30	Next Steps



# Data Driven Approaches - 1 (Kathy, Syed, Ashutosh)

- Description of the problem
  - Traditionally data is collected to prove a hypothesis
  - Models/theories are a small "projection" of a large state-space of human behavior (personal and social)
  - Models and theories often miss the dynamics of human behavior
  - (Models and theories may be limited by human researcher's cognitive abilities)
  - As a result, we are potentially missing out on vast amount of rich new data which is either being collected or could be collected
  - We need methodologies that can learn both new "hypothesis" and construct new theories or extend current theories using data, and adapt as more data and data types come up.

# Data Driven Approaches - 2

- Description of the significance of the problem
  - Behavior is a complex system
  - We need new approaches to go beyond the current state-of-the-art of theory and practice divide
- How would we know if we were making progress on this problem? What would success look like?
  - Healthcare system perspective: Data driven theoretical models that provide improved predictive and explanatory power.
  - Patient perspective: Data-driven models should enable achieving individual "optimals"

# Data Driven Approaches - 3

- What are the critical barriers that stand in the way of this success?
  - Access to data which already exists
  - Behavior is complex, so is the data around it, making sense remains an "open" question
  - Interpretation of new data science approaches for handling these new forms of data
- Who needs to be involved in solving the problem? (e.g., disciplines, areas of expertise, funders, communities, nonprofit organizations, industry, patients)
  - How will they work together in a feasible and sustainable manner (e.g., benefits, needs)?
  - Patients, Behavior Scientists, Practitioners, Data Scientists, Computer Scientist, HCI, Health researchers

# Data Driven Approaches - 4

- How can research contribute to solving this problem and achieving success?
  - Continue to run into each other (when is the next workshop?)
  - Collect more data
  - Trans-disciplinary approach
  - Behavior Scientists train on new Data Science techniques
- What research questions needs to be asked?
  - Value of different data types to improve predictions
  - Value of different data types over time.
- What research methodologies and/or novel techniques are most important in addressing these questions?
  - Learning is an iterative process, therefore the system should be learning and informing the practitioners
  - Learnings should be human interpretable

### Scalable Approaches-Beth, Robert, Elisabeth, Holly, Marissa, Cynthia, Robert, Young-Ji

### Description of the problem

- Different populations and different individuals require different technology intervention approaches to be most successful. Yet we can't afford to develop separate approaches from scratch.
- Which of the many variables need to be adapted for which individual/population for which intervention?
- Our How do we keep these systems updated and improving?
- Need scalable reach to populations with health disparities
  - What social systems exist? How do we connect them?

### Description of the significance of the problem

- Health care costs drive new policy and reimbursement; need scalability
- Important to have best practices in all interventions being tested and adopted
- Reduce health disparities by facilitating the adaptation to multiple, different underserved populations

### Scalable Approaches

- How would we know if we were making progress on this problem? What would success look like?
  - Multiple Consumer Health Informatics Centers as part of a consortium that coordinates research and measures across studies with Training Institute
  - Industry / Academic / Payer / Provider / Community partnership
  - Platforms for delivering low-cost, rapid implementation tailored effective interventions
- What are the critical barriers that stand in the way of this success?
  - NIH promotes Common Data Elements that don't include (and don't encourage)
    - Home monitoring data from sensors (e.g., sleep quality, physical activity)
    - Guidance for EMA assessments (content of just-in-time short questions) (better sensitivity and accuracy than long occasional questionnaires)
    - Diet assessment (it's not objective/accurate)
  - Time and cost to develop shared systems
  - Researchers not motivated to share data, approaches, ideas
  - Community and potential participants don't always trust the researchers
  - Science community not trained for scalability thinking or for being transdisciplinary

# Scalable Approaches

- Who needs to be involved in solving the problem? (e.g., disciplines, areas of expertise, funders, communities, nonprofit organizations, industry, patients)
  - Multiple Consumer Health Informatics Centers as part of a consortium that coordinates research and measures across studies
  - Industry / Academic / Payer / Provider / Community partnership
    - Organizations for community access and scalability of reach (e.g., churches that are focused on spiritual health but not physical/mental health)

# Scalable Approaches

- How can research contribute to solving this problem and achieving success?
  - Reusable platforms; shared algorithms; shared data; shared messages and tailoring techniques; techniques for recruiting
  - Consortium to facilitate the research and shared knowledge
  - Evaluation techniques (e.g., Step-Wedge) to find the components that work/don't
- What research questions needs to be asked?
  - Best practices for dynamic assessment (when to ask which EMA questions; which sensors / how often)
  - Interaction analyses of components of health tech interventions
  - Guidelines for translating successful interventions to new communities?
- What research methodologies and/or novel techniques are most important in addressing these questions?
  - Technology that is highly modular and adaptable to rapid implementation of culturally tailored interventions for new populations.

# Facilitate Divergence and Convergence on Unintended Consequences

Wanda Pratt, Tammy Toscos, Sarah Miller, Jamilia Sly, Kay Connelly

#### PROBLEM

- We do a lot of work without knowing all the possible outcomes (e.g., Facebook, Youtube).
- Example of unintended consequence: Disadvantaged populations are excluded from our studies (technology access, eligibility criteria, refusal to participate, lost to follow up)
  - Miss the benefits of the intervention potentially worsening health disparities
- We make assumptions that aren't valid for diverse populations.
- Significance of the problem
  - Further disadvantage marginalized populations

# Solutions & Success Signs

#### Research

- Involve diverse/unreached people involved at very early stages of research design
- Exit interviews and continual monitoring of unintended consequences analogy to oversight board watching for adverse events but would be looking for unintended consequences in whole process of our research
- Designs that include non-tech options for similar support (e.g., human patient advocate vs. tech patient advocate vs. none vs. combo)
- Always explicitly think about who is being left behind
- Examine characteristics of people who decline to participate

### Reporting

- Include as an explicit publication section instead of just "limitations" section
- Encourage whole papers on unintended consequences
- Section to report these issues in our grant progress reports
- Panels and workshops to support lessons learned exchanges
- Systematic review of unintended consequences!!!

### Unintended consequences - Barriers

- What are the critical barriers that stand in the way of this success?
  - Lack of attention to the problem
  - Limitations of being able to adjust during RCT
  - o If marginalized populations aren't involved early on the problems snowball
  - Incentive structures to encourage participation but not coerce
  - Lack of trust
  - Hard for participants to articulate the problem or challenges they experience
  - Small word count limits in publications that make it hard to describe these issues
  - Uncomfortable to admit that these problems happened
  - Can't publish work acknowledging the problems
  - IRBs not understanding these potential problems
- Who needs to be involved in solving the problem?
  - People/patient partners from diverse populations the affected (people getting the unintended consequences) into the research team

# Unintended consequences - questions & methods

- What research questions needs to be asked?
  - What are the potential unintended consequences of my research, particularly for diverse or disadvantaged populations?
  - What would the outcomes be in these unreached populations?
- What research methodologies and/or novel techniques are most important in addressing these questions?
  - Continual mixed methods
  - Just in time, adaptive interventions (JITAI pronounced JEDI)
  - Must include open-ended follow-up to even notice unintended consequences

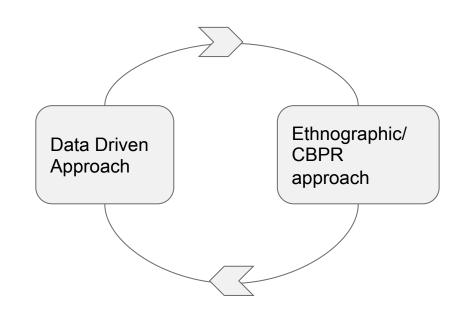
# Bring Theory to life

#### Data:

- Epi
- Social media
- Mobile/wearables

### People:

- What does this data mean?
- Does this make sense to you?



# Bring Theory to Life

- Description of the problem
  - Old theories → on new diverse population
  - There is always an implicit theory even if not using a theory
  - Choosing a theory makes certain assumptions
  - Need to articulate assumptions
  - Theory is  $A \rightarrow B$  but behavior is not  $A \rightarrow B$ ; behavior is dynamic
  - New types of tech data can't be applied to old theories
    - Theories can't handle time and place, the dynamic system captured via tech
  - Theories don't tell you mechanisms of action (we have a theory but what do we do now?)
  - Focus is typically on a single level of the system (individual vs. social network vs. system- how do we get theories that integrate more than one level)

# How to Bring Theory to Life

- How we know if we we're making progress? What would success look like?
  - Living theories
  - A mutual understanding of language
  - Ontologies that make it machine readable
  - Fit diverse population and new data models
  - Provide mechanisms of action ("how shit works")-- tell us what to do
  - Our theories actual predict behaviors and outcomes of interest
  - Framework→ Theory → Model
- What are the critical barriers that stand in the way of this success?
  - We don't refill buckets or consider new buckets
  - Differences in approaches across disciplines
  - Boring and unaccessible

# How to Bring Theory to Life

- Additional Points
  - There is space for exploration of new theories and constructs given newly available data
  - Pick a theory, be flexible, refill the buckets
  - Validate or debunk existing theories/constructs
  - Identify new constructs
  - Measures not designed to explain health disparity populations
  - Need dynamic and iterative validation of new theories
    - Is there another definition of what's valid
    - How often do we need to refill the theory bucket
    - How do we decide that a construct doesn't hold any longer

### Sociotechnical Responsibilities - Jessica, Katie, Haley, Gabi, Rupa, Laura, Sue

#### How do we know when we do good?

- Who defines what good is?
- Giving data/findings back to participants without negative consequence
- Consent is not seen as a barrier or burden for researchers, but as an empowerment for participants

#### How do we know when we are not?

- When we read about it in NYT and WaPo
- When what we have done is not viewed as meaningful or actionable by the target community
- When a community is reluctant to engage with other researchers

#### What do we do if we don't do good?

- Safe and encouraging spaces for sharing exemplars garnering resources, understanding expectations, making shared experiences accessible
  - Can we learn from patient safety community and how they share adverse experiences in research?
- Create action plans to standardize how we respond and report

### Description of the problem

- Belmont principles are not operationalized for the digital world
- Are ethical frameworks are not flushed out enough what is the new report?
- How do we define a "person"? How do we detangle shared accounts/packets?
- Misalignment of ethics and policies of the technologies and the communities that use them
- IRBs, who is providing oversight, and the power dynamics that go into these issues.
- How would we know if we were making progress on this problem? What would success look like?
  - Greater representation of researchers
  - Participants that understand the research and outcomes at a deeper level

- What are the critical barriers that stand in the way of this success?
  - Cultures
  - Policy
  - Individual interpretations
  - Community representation in the role of researcher
- Who needs to be involved in solving the problem?
  - All of us
  - Ethicists, members of communities, industry partners, policy
  - Educators
  - Representatives from funding agencies

### What research questions needs to be asked?

- What does informed consent look like with a 1 million + data set?
  - How would requiring social media researchers to obtain consent for every account used impact their research field? What if accounts are AI and not actual individuals?
- Do we need 3rd parties to assess + / 0 / impacts of data follow-up?
- How do we ensure the data we give back to communities is actionable/meaningful/ understandable? What happens when that data requires additional resources (e.g TB of data)? What happens if this data is not accessible and drives people away from the research?
- What is the balance between training, ethical considerations, and being able to actually do the research?
- Can we develop a toolbox of materials and resources people have found helpful?

- What research methodologies and/or novel techniques are most important in addressing these questions?
  - Using storytelling as a tool to describe and tell
  - Toolkits for health literate communication
  - Novel ways for disseminating research findings
    - How do we incentivize this?
  - Creating sea change within organizations
  - Creating ethical and legal considerations for common methodologies/theories/ frameworks

### Real World Success (Eric, Jasmin, Julie, Maia, Stephanie)

### Description of the problem

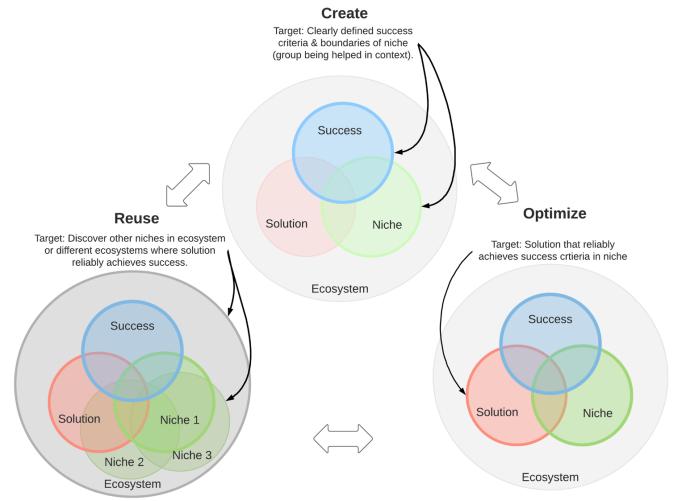
- Tools & methods have implied criteria for success (e.g., significant difference, usable);
- disciplines/groups/each are partially defined by the tools and methods they use;
- Therefore tools/methods and criteria of success are conflated.
- How do we move towards enabling discussion on what real-world success is among the stakeholders involved in this?

### Description of the significance of the problem

 If we don't do this, we run the risk of solving the wrong problems and not having a clear sense of dynamic risks and unintended consequences

### What are the critical barriers that stand in the way of this success?

- Success as a researcher and impact in the real world do not necessarily align, particularly from a timeline perspective
- Funding is based on a linear project plan not based on how science actually works (e.g., iterative, trial and error, etc.)
- Epi/health sciences starts at death and goes back; HCI starts from interactions and goes forward. How do we bring them into alignment?
- Attention to disciplinary success can distract focus on achieving real world impact
- Academic burnout; feelings of hopelessness about making an impact, lose passion



- What research methodologies and/or novel techniques are most important in addressing these questions?
  - Research on doing robust pilot/feasibility study work; defining the contributions of prework as part of science
    - Starting conditions of projects matter, but we aren't funded to get the starting conditions right; doing science on getting the starting conditions right.
  - Research on alternative ways of funding that is better linked to real-world success
    - From funding PI's to funding diverse networks of individuals with agency
      - CCC contribution is the CSCW aspects that support networks and agency
  - Research on facilitating adoption/hand-offs/sustainment/reuse;
    - Acknowledge that there is a science of reuse
  - Research on the incentives of the scientific enterprise; better aligning incentives with helping people

- Who needs to be involved in solving the problem? (e.g., disciplines, areas of expertise, funders, communities, nonprofit organizations, industry, patients)
  - Everyone! The key is to figure out how to help them align; we think they can bond if there is careful link on this.
- How will they work together in a feasible and sustainable manner (e.g., benefits, needs)?

- How would we know if we were making progress on this problem? What would success look like?
  - People in greatest need are getting the support they need
  - Circumstances are created that enable more people to help themselves, communities to help themselves; cities to help themselves and then share insights with others

# Real World Success - Other Random Thoughts

- We should fund diverse networks of people with agency, not projects e.g., you give them money to do what they
  want to solve problems in the way they think is best
  - NCI is doing something similar to this, MacArthur Foundation's model of funding people not projects downside is that this could be discriminatory and hard for people to break into
- Add a fourth "impact" pillar for hiring, promotion, and tenure criteria in addition to research, teaching, and service
- Every researcher sets a career target of "1,000,000" of something they can define how they get that million 1
  million minutes of app use, 1 million downloads, 1 million YouTube page views, (or multiple things that add up to 1
  million)
- Funding people to think about revamping funding models
- ~80% of our grants go toward funding people and chasing grants takes up a big chunk of time what if NIH/NSF just funded more full time professors (at all levels) with small discretionary budgets and PhD students, and researchers only had to apply for actual non-people costs on their grants?
- One way to close the gap in health disparities is to make health worse for "over served" populations is this ethical?
   Or is it better to increase the health of everyone at a baseline if you increased overserved populations more than underserved populations, which increases disparity?

# Alternative Funding Idea

Modeling after RoboCup

Science"





Pedja, John, Andrea, Misha, Lauren, Sean, Bonnie

- How do we determine the right set of things to measure and how often, balancing tradeoffs in Practicality, Comprehensiveness, Strategicness, Risk?
- A range of problems area: are we trying to figure out what measures matter or are useful (informative or actionable), or are we designing an intervention that applies known measures? (also a range of "we": researchers vs. implementation designers vs. people)
- How much future proofing do you need to do? e.g., if you have one goal or set of questions, you might be able to pare down what you collect. However, when the researcher's / patient's / intervener's goals change, they might wish they had collected it in a more comprehensive way to support re-use.
- We have theory to guide what to measure, but this can also introduce blindspots.

How would we know if we were making progress on this problem? What would success look like?

- Improving an outcome we care about while understanding the mechanism and side effects
- Reproducibility
- Robust understanding of causality
- Once we go into production with an intervention, are we parsimonious in what we collect?
   (Do we use everything we collect?)
- Fewer regrets about what we wish we did/didn't collect (hah, but how do we measure that?)

#### What are the critical barriers that stand in the way of success?

- Patient-centered measures and goals are often individualized, not standardized.
- We aren't sure what reproducibility should mean in mHealth, where norms and technology are moving quickly.
- Bias toward collecting as much as possible (and risk of having these data)
- Complex relationships involved in data collection and use (e.g., parent-child; patient-provider)
- Technical capabilities
- Precision of modeling vs. interpretability of model
- Limited understanding of when we should sense vs. self-report
- What do you do when sensed and self-report data don't align?
- People may not agree on what a measurement *means*
- Follow-up (long after intervention) is key -- also don't assume cessation of engagement is cessation of

Who needs to be involved in solving the problem? (e.g., disciplines, areas of expertise, funders, communities, nonprofit organizations, industry, patients)

- \\_ Everyone \_/
- Need to keep people with perspective on the key concepts involved

How can research contribute to solving this problem and achieving success?

- Measures and scales that are more focused on patient goals.
   (but how do measures like that get used in an FDA approval process? Plus, people's priorities change.)
- More study of self-reports versus automated sensing: how do they relate to each other? What do they each
  contribute to interventions? How can they best work together? Models for combining different data sources.
- More study of how to represent measurements to non-experts: how certain are the recommendations? How accurate are the measurements? What are the limitations?
- More tools for helping researchers and practitioners decide what and how to measure (theory-driven, but also for anticipating unintended consequences and side effects, also for being parsimonious)
- What does reproducibility mean in the era of generative models?

What research methodologies and/or novel techniques are most important in addressing these questions?

- Rather than measuring all the same things across arms, we might do more studies in which we're studying measurements and varying what / how we measure
- Heterotypic versus homotypic measurements -- you change your assessment tools over time. How do we understand continuity?

# What do we need to measure and why?

Measurements need to be meaningful, actionable, and reproducible.

## When is tech beneficial for whom?

Madhu Reddy, Yunan Chen, Tawanna Dillahunt, Sarah Iribarren, Sarah Mullane, Lyndsay Nelson

- How will we know, what data do we need, space for risk (able to report failures along side success). How do we
  make the argument for success?
- Description of the **problem**:
  - technology is primarily a magnifier of existing institutional forces ("rich get richer") (Toyama, 2011; 2015)
  - o Problem of benefits: pushing out apps whose agenda is it, for research
  - What assumptions are we making? access to smartphone, internet
  - Problem: not easy to publish negative or neutral results → need shared lessons learned
    - Need to talk about failure
      - Frame with socio/technical evaluation?
  - o Problem: is technology necessary? When reappropriated in other populations/modified design or interface
    - Example of misuse tracking app for eating disorder made worse ->taking an app break
    - Individuals may not need tech as a solution
    - Deliver what they want and what need?
    - Need to understand if needs / negotiate / don't want to be prescriptive
    - Are technologies the reasons for success/failure?
- Description of the **significance** of the problem: if we don't understand the benefit can't develop, improve, if we do not recognize we will contribute to another widening gap. We can't move forward if we do not document failures.

### When is tech beneficial for whom?

- How would we know if we were making progress on this problem? What would success look like?
  - Individual/digital phenotypes that can be used to deliver tailored supportive interventions
  - Learning something new
  - Participant positive experience?
- What are the critical barriers that stand in the way of this success?
  - Not getting participant perspective on what success/benefits means
  - \$, time, resources, ...
- Who needs to be involved in solving the problem? (e.g., disciplines, areas of expertise, funders, communities, nonprofit organizations, industry, patients)
  - All the above
  - How will they work together in a feasible and sustainable manner (e.g., benefits, needs)?

### When is tech beneficial for whom?

- How can research contribute to solving this problem and achieving success?
  - Thinking outside the box. E.g., barber shops?
  - Digital phenotyping
  - Documenting failures aka LESSONS LEARNED!
  - Sociotechnical evaluation
  - Do not get too caught up in the technology. Driven by strengths/needs not capability set of technology.
  - Being transparent about purpose of study, at all stages. E.g., why you are accessing GPS data.
- What research questions needs to be asked?
  - How do we conceptualize 'beneficial', how does this differ at the individual and group level and for different user personas?
  - What, when, who, why, where? (Tech can then fill in the how).
- What research methodologies and/or novel techniques are most important in addressing these questions?
  - Digital phenotyping- ethics?
  - Present back to participants for feedback and review
  - Merging datasets and reanalyze with different questions
  - Community investment / partners

# Upstream Interventions: beyond individual effort, behavior, and choice

Michelle Odlum, Lena Mamykina, Jessica McCurley, Tiffany Veinot, Kim Unertl, Shawna Sisler, & one other!

#### <u>Description and significance of the problem</u>

- Individual-targeted strategies work better for individuals of middle to higher income, and often make health disparities worse
- The environment gets under the skin
- Categories of root causes: residential segregation, poverty, stigmatization, discrimination, inaccessible environments, community/social network, prestige/power, freedom, institutions, policy, insurance status
- Fundamental cause theory: disparities emerge because people have differential access to flexible resources
- Pathways: inflammation, chronic stress, allostatic load, primary and secondary prevention
- In marginalized populations: many institutions involved in influencing health outcomes (e.g., churches with LGBT groups) and these institutions vary by marginalized group

#### How would we know if we were making progress on this problem? What would success look like?

- Improvement in health of marginalized groups
- Amelioration of health disparities; increase in health equity
- Access to, utilization, and uptake of preventive care (intermediate outcomes)

#### What are the critical barriers that stand in the way of this success?

- Alignment of research and academic priorities with community priorities the challenge of establishing the direction of research
- Technology is continually iterating, and we often stop at the point of developing the prototype.
- Challenges with community engagement and funding design (e.g., length of research grants)
- Data that is privately owned difficulty and expense to access.
- Evaluation methods for multilevel interventions are premature, flawed, and very complex.
- A need to account for the dynamic nature, multifactorial causation, multilevel interactions of effects
- Deciding where we want to intervene? Which levels? Health behaviors, empowerment, culture change, values, knowledge, self-efficacy?

### What research questions needs to be asked?

Where can we intervene with technology? How can technology help?

- Education
- Self-organizing
- Mediate or increase communication
- Increase information available
- Increase access to information
- Support decisions
- Support and design/re-design work flows and processes
- Helping communities use data to re-define power structures
- Optimizing distribution of resources
- Understand and defining problems and scope of work needed

## **NEXT STEPS**

Our Organization & Funding Strategy

**Grants & Partnerships** 

**News & Resources** 

### 2018 Cultivating Healthy Communities Grant Program

This will be a highly competitive funding opportunity with a two-stage application process. All Stage 1 applications must be received by April 18, 2018 at 3PM ET. We will not accept any late or incomplete applications. You must submit a Stage 1 application in order to be considered for Stage 2.

Thank you again for your for commitment and interest to make the communities you serve, healthier places to live, work, learn, play and pray.

- · A video tutorial to help navigate our online application system
- Tips for writing a strong Stage 1 application
- Examples of types of projects we'll consider
- Guidance for writing your "Statement of Need" and "Project Activities" sections
- An overview of our application review process

If these materials do not address your questions, you can contact us. Please include "CHC RFP" in the subject line. We will do our best to respond within 2 to 3 business days. During periods of heavy email traffic, we may need some additional time. Please note we can't review or comment on ideas/concepts related to Stage 1 applications during the open submission period.





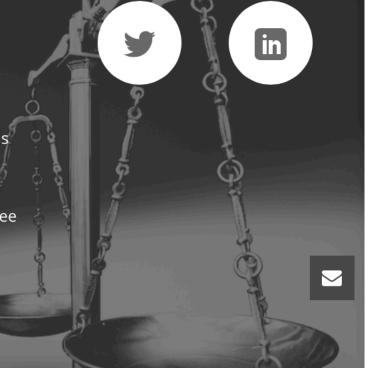


Get Started with the CORE Tutorial

Access the CORE Resource Library

# What is CORE?

Research that involves pervasive sensing and/or computational methods raise new ethical challenges for both scientists and Institutional Review Boards. In response, we asked stakeholders to design a solution and, subsequently, built Connected and Open Research Ethics. CORE has three main features including a: 1- Network 2- Q&A Forum and, 3- Resource Library.



### Free SBM Annual Meeting Attendance

#### Thursday, April 12, 2018

SBM is free for all to attend on Thursday

**Events of Interest** 

7:00am Behavior Informatics and Technology SIG "Tech Madness" Ballroom A

3:15pm WISH Overview and Networking Marlborough

7:00pm BIT SIG and Digital Health Council SIG Social Grand Isle Restaurant & Oyster Bar

Special thanks to SBM Board of Directors



