2/25/20

HUMANS Study Activity

Until now, large-scale longitudinal studies of people have focused on specific domains of inquiry and subsets of populations. The HUMANS study will look at dynamic patterns and feedback mechanisms between human behavior, biology and environment across the lifespan of 10,000 people. Learning how these domains interact will enable the development of research, treatments and policies intended to improve the human condition. Study participants will provide or agree to release data over a 20-year period that includes: physical, psychological, social, education, employment, financial and a variety of other data (see Data Types below). The study team will capture these data and secure them in a state-of-the-art secure vault.

Data Type 1: Traditional Medical: genome, proteonome, metabolome, microbiome, blood chemistry, EMR, environmental toxins, household air quality.

Data Type 2: Financial: wealth, labor, taxes, swipe-level purchases, cash flows

Data Type 3: Social Network: SMS, MMS, phone, email, search terms, geo-tracking, MAC/Bluetooth locations

Data Type 4: Surveys: behavior, education, personality, mental health, education

Data Type 5: Family Interactions: tracking parent/child interactions and elder family interactions

Data Type 6: Criminal Justice: legal record, incarceration

Some of these data will be existing. Other data will be captured in real time using wearable recording devices, sensors, apps, etc.

Task: You are to evaluate the study benefits, risks and risk management solutions associated with the various data being collected. You will be assigned to one of three groups. Each group will represent a specific stakeholder's interest: 1) researcher, 2) research participant, 3) Institutional Review Board. You will need to identify a note-taker to record your responses to the questions below and a speaker who will report back to the larger group.

Time: You will have 15-20 minutes to discuss with your small group and then we will discuss as a large group.

Questions: Evaluate the probability and magnitude of potential harm associated with the study as well as benefits. Think about risks and benefits from the individual, group represented by the individuals, and society perspectives.

1. Possible Benefits: What are the potential benefits? What is the probability of these benefits? What is the magnitude of these benefits?
2. Possible adverse consequences: What are the potential harmful outcomes? What is the probability of these outcomes? What is the magnitude of these outcomes?
3. Do the potential benefits outweigh the potential harmful outcomes?
4. How can the risk of harmful outcomes be mitigated?
5. What else should be considered?