Year 1 Update: Stakeholder Engagement

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Project Goal: Ethical, Efficient, & Sustainable UC Biobanking System

• Ethical
  – Aim 1, Stakeholder engagement
  – Identify how to build public support for biobank research

• Efficient
  – Aim 2, Compare methods for obtaining consent
  – Determine what works for obtaining informed consent

• Sustainable
  – Aim 3, Policy translation
  – Inform system-wide policies & action
Public Engagement
What do Californians want from UC?

• Survey; focus group; ask advocates *(Not 1st step)*
  – Biobanks not well known to general public

• Deliberative Community Engagement *(Done!)*
  – 30 random deliberants, 4 days face-to-face, LA & SF
  – *Education*: Briefing book, website, expert talks
  – *Deliberation*: Facilitated small & large group discussions to develop recommendations
  – *Recommendations*: Identify areas of consensus & persistent disagreement; make proposals for consideration by other stakeholders
Deliberative Community Engagement: Consensus (preliminary)

- Support for biobank research as a whole
- More education, outreach, & marketing
  - Public education via video or other universal means
- Going forward, obtain informed consent for all samples
  - Clearly communicated: easy to understand, multiple languages, multimedia, in-person
  - Obtain well in advance of donation
  - Obtain at a time when donor is not stressed
Deliberative Community Engagement: Persistent Disagreements (preliminary)

• Most deliberants want legacy/remnant samples retained and used for medical research even if samples were collected without consent or with less-stringent consent; however, some felt these samples should be discarded.

• Views were divided about the need for re-consent and/or re-contact for future uses.

• Views were also divided about the necessity and logistics of returning research results to donors.
Deliberative Community Engagement: Proposals for Consideration (preliminary)

- Deliberants support sharing data to advance research but many are concerned about sharing overseas and some are concerned about sharing with government
- Deliberants want strong governance and oversight of UC biobanks that includes the public having meaningful input into UC biobank policy
Engaging Institutional Officials & IRB
What is institutionally possible?

• Identifying stakeholders
  – Researchers and coordinators
  – Institutional Officials
  – IRB Directors and members
  – University of California policymakers

• Key issues to consider
  – The clinical context in which samples are collected
  – Federal and state human subjects/privacy protections
  – System-wide harmonization of policy and process
Aim 3: Policy Translation Activities

*Los Angeles Times* | ARTICLE COLLECTIONS

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California lawmaker proposes privacy protections for genetic data

February 21, 2013 | By Patrick McGreevy

SACRAMENTO-- Delving into an area once reserved for science fiction, state Sen. Alex Padilla (D-Pacoima)

*SFGate*

Wednesday Oct 02, 2013 9:54 PM PT

UC advances medical research through trust

Elizabeth A. Boyd and Daniel Dohan

Updated 4:41 pm, Friday, March 1, 2013
Next Steps

• Continuing public engagement (aim 1)
  – Convene LA/SF deliberants & other stakeholders to discuss community role in biobank governance
  – Engage other Californians, especially rural areas
  – Pursue funding for the above

• Compare methods to obtain consent (aim 2)
  – Pre/post test of newly-developed consent methods in diverse clinical and research settings
  – Outcomes: Knowledge, Feasibility & Staff Burden, Participation Rate, Participant Experience
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