



EngageUC

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

← Back to Original Article

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)

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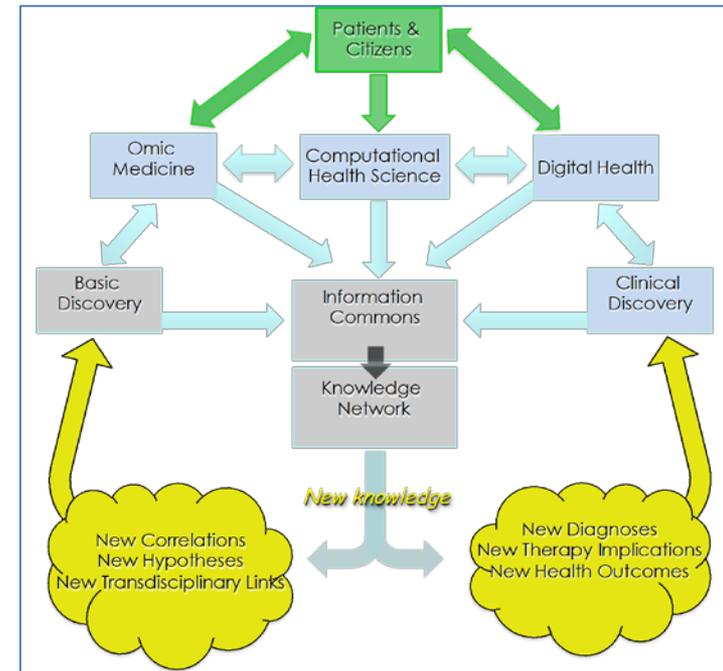
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UC advances medical research through trust

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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