

**Report 64:** Protecting our investments by providing infrastructure and support to biorepositories, cohorts, and datasets to expand our ability to study new and emerging hypotheses

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**Brief History:** Many clinical and population studies have been supported over the last decades which enrolled large populations and accumulated massive amounts of data and specimens. There is the potential to use these data and specimens to answer new and emerging scientific questions on hypotheses not yet defined. Specimens are being stored in freezers in various formats with varying methods. Technologies are now available to more effectively track, organize and retrieve samples and link them to databases in order to expand the universe of scientific questions that can be addressed. Databases are currently unconnected and not readily open to new users. Now is the time to build an infrastructure that will support data sharing and discovery science and maximize the utility of data that has been collected in the past. With the recognition of the importance of the effects of early life exposures on adult diseases and health outcomes, it is critical to maintain cohorts and other population resources in order to study emerging hypotheses in the future.

**Discussion Highlights:**

Biospecimens

Need to build biorepositories in a way that saves a diversity of tissues and specimens collected and processed in ways that allow for and not limit future analyses on known and emerging analytes. There is a need to create or apply standards for EH repositories to assure responsible stewardship.

Need for guidelines for specimen storage for EH research and 'how to' resources for investigators

Promote ways to use clinical samples which might be discarded for EH research

Broaden the use of core facilities to support the long term storage of specimens for EH research. Promote EH research within the CTSA network and become part of the CTSA programs in order to utilize CTSA resources to protect study investments (specimens, cohorts, data)

Create and incentivize opportunities for specimen and data sharing within collaborative groups and give access to new investigators. Reduce barriers to sharing specimens by simplifying Material Transfer Agreements, consider consent and IRB issues, and confidentiality and privacy issues

Create new models for collaborations around existing study resources. One example is an auction which would reward bidders with access to specimens and study materials based on collaboration parameters (bids)

Encourage new/young investigators to use already collected specimens and data to test emerging hypotheses by granting access to study resources

**Cohorts:**

Create study framework with long term goals and needs for preservation of resources for study follow-up, specimen storage, data preservation over the appropriate time frame (Don't just think in 5 year cycles)

Tie maintenance of cohorts to relevant study goals and prepare for active and passive follow-up. Provide support for both types of follow-up irrespective of hypothesis testing.

Utilize creative funding mechanisms to keep study infrastructure intact in order to pursue long term scientific questions. These can include community partnerships, passive or active follow-up, critical data collection not tied to main hypotheses but tied to possible future questions. Find ways to fund additional data collection at time sensitive windows

**Data:**

Change the paradigm from local use to use by the greater EH community. Identify barrier and solutions to assuring privacy and confidentiality and the responsible use of EH data

Promote secondary data analyses and create incentives to use datasets beyond initial hypotheses by a single study team

Support the creation of datasets available for sharing and provide financial support for data sharing activities.

**Recommendations:**

NIEHS can provide leadership to support the increased use of investments to answer new and emerging scientific questions within study populations that have been previously created. They can do this by supporting long term support for biorepositories, long term maintenance and tracking of study populations, and by promoting more open access to properly created data sets (with privacy and confidentiality protection assured).

NIEHS should think strategically about study populations and resources that would be needed to answer emerging scientific questions in the future and should actively plan to support and maintain those resources.

NIEHS should create financial and resource incentives to promote sharing of study resources by the wider community in order to maximize its investments

NIEHS should catalogue study resources (cohort characteristics, specimens, and data), advertise them, and actively promote their use throughout the wider EH community. This can include web-based catalogues of information, presentations about resources, and other notifications about the availability of resources.

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