

# Biorepositories versus Registries: Points of Similarity and Difference

- Purpose/procedures/duration:
  - Link to registry data, if any.
  - Excess clinical specimens or collection for research?  
(Will routinely involve clinician/pathologist unlike registry)
  - Open-ended use?
    - Types of research anticipated -- option to limit use?
    - Identification of “sensitive” research to be conducted

- Purpose/procedures/duration:
  - Process and conditions of access by researchers
    - Criteria for access perhaps especially important since biospecimens are a limited resource (unlike data).
  - Additional consent anticipated for future research? Perhaps less than research using registry data.
  - Right to withdraw – no future specimen collection, possibility to request destruction of specimen held in bank?
  - Verification of specimen/diagnosis

- Reasonably foreseeable risks:
  - If research collection – Risk of specimen collection
  - Greater potential for objectionable research to be conducted than research using registry data?
- Reasonably foreseeable benefits:
  - Greater potential for direct benefit? Greater potential for results of research to be clinically useful and valid than research using registry data?
  - More likely individual results will be returned?
  - Should subjects have opportunity to opt-out of receiving certain/all research results?