



# Real Time Specimen and Sample Analysis for The National Children's Study

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# Real Time Data Analysis



- To date, assumption has been that vast majority of samples and data would be analyzed in the future, unknown timeframe, not all participants' samples to be analyzed at once
- Prospect of real time analysis may change this approach
- At present real time analysis is being explored through formative research, may or may not become routine throughout NCS

# Relevant Considerations for Today's Discussion



- Personal health information may be important to participants even if analyses are conducted sometime in the future
- Some types of analyses for the evaluation of samples are known at the time of collection; others are not yet determined
- Some research results require lab analysis, others can be reported immediately
- Some tests could inform current or future medical care; others have unknown implications
- The timeliness of availability for some test results, as well as their salience of analysis for these tests can change over time
- In context of children's research results, not only availability of research results, but children's age and developmental stage are relevant to decisions about returning results

# Implications of real time analysis for human subject protections in the NCS



- Does the timeframe in which research results become available have implications for which research results should be reported to participants?
- Does the prospect of real time analysis and real time availability of individual research necessitate a change to our return of results policy?
  - What may not be clinically relevant today may become relevant in the future
  - The concept of “clinical relevance” may not be uniformly applicable across geographic regions, across communities, and across time