Understanding Personal Preferences Regarding use of De-Identified Residual Clinical Samples

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Biobanking forum (CCTST)
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Better Outcomes for Children

• CCHMC is undertaking a project to collect remnant clinical specimens, remove identifiers, and provide the samples for research purposes.
Cincinnati Community Input

• As part of project development, we talked to 2 community groups
• Family Advisory Council (Kay Fricke)
• Community Partner Council (Monica Mitchell)
Response to Hypothetical Statement

“While you are registering your child at CCHMC you are told that CCHMC routinely retains leftover blood and tissue samples for research purposes unless you state here that you would not like your samples included in this work.”
What Questions Do You Have?

• What research will be done (17)?
• Can samples be associated with a patient (9)?
• When/how will this be presented to families (8)?
• Will additional samples be taken (5)?
• Will individual results be returned (5)?
Will Results be Returned?

- Different requests
  - Want to know all results.
  - Want general information about results.
  - Want to know results that will affect the life or health of the child.
  - Do not want ANY results.

- Issues with these results
  - Research results/tests
  - Research done in non-CLIA labs, i.e. not clinical

- Solution: Ask if they would like to know.
Conclusions

• There are groups to help with getting community input. Use them to understand the local community.
• Biobanking of residual bloods/tissues is viewed positively.
• Many different questions and we can proactively address these.