Patient Perspectives on Biospecimen Quality

Paula Kim, TRAC- Translating Research Across Communities
NCI Biospecimen Research Network Symposium
March 14, 2008
OBBR NCI – NIH, U.S. Department of Health and Human Services
Across The Scientific Spectrum

Physical
Behavioral
Social
Cultural
Economic
Political
Spiritual
Technological

HOPE
The Art of Translation...

“From the standpoint of medicine as an art for the preparation and cure of disease, the man who translates the hieroglyphics of science into the plain language of healing is certainly more useful.”

-William Osler, Physician
100 Years and Counting...

- Taken more than a century, and now biospecimens, technology, and science for patient benefit is coming of age
- Biospecimens are precious human resources filled with unique genetic information
- The privilege of using biospecimens to advance research into clinical application brings great responsibility not to be taken lightly
- Biospecimens are part of resource toolkit
Patient Dilemma with Words and Decisions…

Invasive? Non-invasive?
Academic Center? Local?
Informed Consent?
How to pick treatment?
Do my kids need genetic testing?
Where is my tissue?
Eligible? Insurance?
Am I Going to Live?

Personalized medicine?
Biospecimen?
Biopsy? 2nd pass?
Targeted Therapies?
EGFR Inhibitor?
Proteomics?
The Promise

- Personal Targeted Therapies
- Seek and Control instead of Search and Destroy
- Genetic Testing
- Reduced Toxicities
- Predictive/Preventive Capability
- Reduced drug failure rates
- A CURE

Hype or Not?
Connect The Dots

Patients, Volunteers, Groups & Public

Academic & Community

Public Agencies & Policy Makers

Industry & Private Sector

B = Biospecimen
Consequences of Poor Quality

- False + and False -
- Inaccuracy; non-reproducibility
- Erodes public confidence
- Wastes time & money
- Impedes clinical benefit
- Takes another 100+++ Years
Benefits for All

Commitment for:
Infrastructure + resources + best practices
can yield high-quality annotated biospecimens

The Potential Upside

Data + specimen with integrity becomes
Information into knowledge that puts real
discovery into real life in real time for
patient benefit
Biospecimen Best Practices Are More Than Just Freezer Temperature and Hold Time

- Partnering with the public and community
- Privacy and patient protection, cultural sensitivity
- Data Sharing and bioinformatics
- Handling of biospecimens
- SHARE, promote and provide research access
- Balancing Intellectual property
- Patient treatment and profile resource
- Special populations- Ethnic, age specific, gender, familial syndromes
Achieving Quality: Barriers or Building Blocks??

- New frontier requires new attitudes
- Each sector depends on one another
- Patient-Clinician-Pathologist-Researcher
- Expectations are all over the place
- Translate into better care for patients
- Spend the time and money and do it right
- Financial and operational issues
- Have to stand tall- Do good by doing right
## Treatment Decision Making: Outside Sources of Info for Patients

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<th>Answer Options</th>
<th>Greatly influences</th>
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<th>Barely influences</th>
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<td>Information received from a patient advocacy organization</td>
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Source: TRAC Perspectives on Costs of Cancer Care Survey-2006
Who is in the Biospecimen Sandbox?

**Advocacy**
- Patients
- Caregivers
- Public
- Organizations

**Research and Medical**
- Researchers
- Clinical Trial PI
- Community MDs
- Academic Center MDs and PhDs
- Pathologist

**P&P Agencies and Industry**
- NCI
- FDA
- CMS
- HRSA
- AHRQ
- NIH
- 3rd Party Payers
- Industry
Confidence, Public Trust, Quality

Confidence in you and your team
Confidence in the reason
Confidence in the test
Confidence in the system
Confidence in the procedure
Confidence in the test results
Confidence in the diagnosis
Confidence in the recommendation
Confidence in the outcome
Confidence...period
Why We Must Get This Right...

“...We must harness the scientific, industrial, and social will to accelerate discoveries into accessible and meaningful clinical applications. Patients, families, friends, and loved one are counting on us...Because in the end, it’s not about you, or me, or the science, it’s about the patient.”

Paula Kim - Research & Patient Advocate
Patient & Advocate Perspectives
Don’t Leave Home Without Them

www.tracnetwork.net