

# Creation of a Secure HIPAA-Compliant Bioinformatics System to Support a Bi-Institutional Biomarker Discovery and Correlative Quality of Life Study

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## BACKGROUND

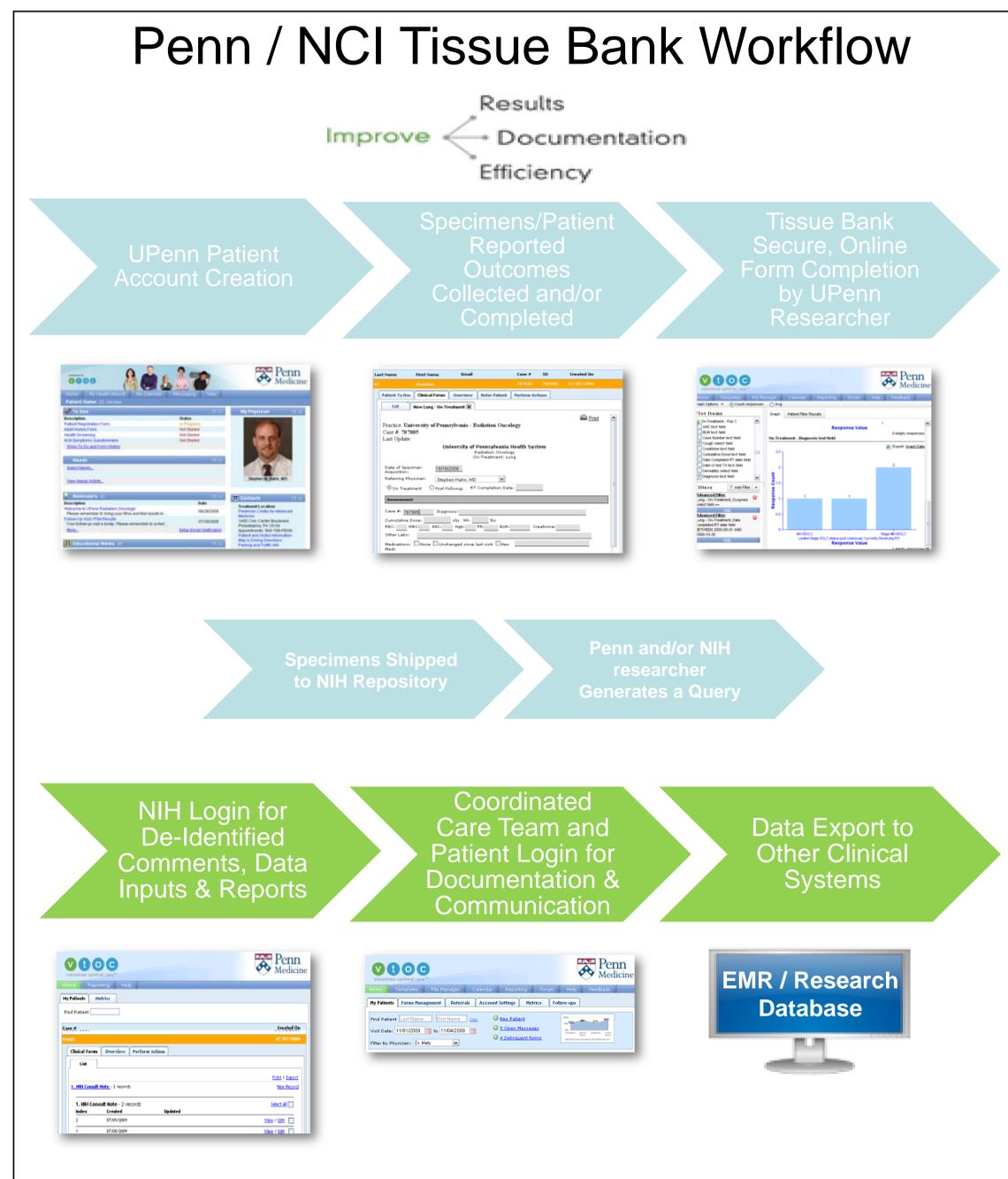
- The University of Pennsylvania's Department of Radiation Oncology (UPENN) has established a cooperative Quality of Life and Tissue Banking initiative with the National Cancer Institute (NCI).
- This initiative was founded as a means to collect biological specimens and Quality of Life data from consented UPENN patients for the purposes of a bi-institutional biomarker discovery and correlative quality of life study.
- Collected specimens are de-identified, shipped, and stored at the NCI for future research.
- De-identified Quality of Life data, demographics, toxicities, and treatment parameters are collected in conjunction with each specimen and shared between institutions

## PURPOSE

- The goal of this project was to develop a bi-institutional, HIPAA-compliant, web-based informatics system to facilitate data exchange between UPENN and the NCI for the purposes of the Quality of Life and Tissue Banking initiative

## MATERIALS & METHODS

- A secure, web-based data management system (VTOC) provided by VisionTree Software, Inc. was used to collect, import, aggregate and report data in a patient-centric system
- This secure, online patient portal was created to permit logon from any computer with internet access.
- Roles-Based Log-Ins were designed to allow four unique views in VTOC:
  1. UPENN view containing patient identifiers
  2. UPENN view without patient identifiers
  3. NCI view without patient identifiers
  4. Patient view to promote self-reported health information
- Test patient data with a de-identified case number and clinical information were manually entered into forms stored within the test patient's web-based record by the primary institution (UPENN).



## RESULTS

- Test patient view displayed QOL assessments auto-delivered via a templated system with corresponding reminders and educational material.
- Test patient QOL data was tagged with time point and demographic information and stored in the central database for reporting and analysis.
- Primary institution (UPENN) was able to log-in with two separate views: one with identifiers, one de-identified.
- Secondary institution (NCI) ran a test query to retrieve clinical outcomes data and upload comments to a test patient record identified only by case number.
- Reminders and report profiles were generated and shared between the two institutions in a HIPAA-compliant manner.

## CONCLUSIONS

- UPENN maintained all identifiable Protected Health Information and both UPENN and the NCI were able to run secure queries of de-identified clinical and QOL outcomes data.
- Successful demonstration of the web-based system provided by VisionTree Software facilitated report generation, analytics, and record-specific comments.

## CURRENT STATUS & FUTURE OBJECTIVES

- At present, protocol procedures have been implemented including subject enrollment and employment of VTOC for research data management.
- Future objectives relate to secure auto-population of patient form fields from hospital EMR as well as increased communication between patient and their medical team, with automated reminders being generated for completion of research protocol tasks.

## RELEVANCE

Design and implementation of the bioinformatics system detailed above improves documentation and analysis of results in a manner that maximizes research potential while ensuring regulatory compliance. The architecture of this system encourages multi-institutional research initiatives to attain mutual goals.