Building Bridges

with

Hospital Registries:
Louisiana Experience

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Building Bridges with Hospital Registries: Louisiana Experience

Outline:

- Background
- Purpose
- Methods
- Results
- Implications/Next steps
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Background:

- Collaborative relationship between central and hospital registries can be less than ideal

- “We” vs. “you” instead of “We all”
Background:

- Hospital registries often consider the state’s only interests are to
  - obtain cancer cases from them
  - nothing to offer in return
  - one-way traffic instead of two-way communication
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Purpose:

Share the Louisiana Tumor Registry (LTR) experience of a long process of:

- building bridges of strong & trustful relationship
- harmonization with hospitals
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**Methods:**

- Louisiana applied for NAACCR Performance Improvement Project, focusing on communication with regions and hospitals
- Define common interests and goals between LTR and hospital registries
- Identify the needs and resources
- Optimize the limited resources and develop means of sharing
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Common goals and interests:

- Education and training material
- Education opportunities and CE hours
- Follow-up information
- "Complete" first course of cancer treatment
- Upgrade registry infrastructure
"Education is all a matter of ....... building bridges."

Ralph Ellison
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1. Education & Training resources:
   - Share LTR education and training material
     - NAACCR recorded webinars
     - Training & educational material from SEER, NPCR and NAACCR
     - DVD (Anatomy & Physiology courses)
   - LTR QC Coordinator serves as LCRA Education Committee Chair
   - Utilize LCRA newsletter as a media for sharing the information timely (weekly)
2. Education Opportunities and CE Hours:

- Resourceful Registrar page in LTR web site
  - one-stop site for cancer registrars
  - e-manuals and links
  - excellent resource for registrars during hurricane evacuation

- Partial support for the state cancer registrars’ annual meeting which provides the needed CE hours
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3. Follow-up (FU) Information:

- Hospital registries
  - FU information (active)

- Louisiana Tumor Registry
  - Death information
    - Online Host-on Demand
    - Linkage with state mortality file
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3. Follow-up (FU) Information (cont.):

- Louisiana Tumor Registry
  - Follow-up information via linkages
    - National Death Index
    - Medicare
    - SSA
    - Interstate data exchange
    - Major hospitals (St Jude, MD Anderson, Texas Children)

- Electronic FU file and automated update

- Provide FU information for CoC survey
4. First Course of Treatment:

- Hospital registries
  - adjuvant therapies
  - additional treatment after data submission

- LTR
  - develop Hospital Sharing Web Application
  - allow hospitals to view other reports and consolidated records on “shared” cases
  - can obtain stage, tumor biomarkers, Tx, FU in real time
5. Infrastructure Upgrade:

- Software upgrade
  - AIM for epath reports
  - partial support of initial installation of CAS (epath)
  - PHIN-MS

- Legislative rules
  - passed the law of electronic reporting from all pathology labs within 2 months of diagnosis
  - leveraging the 6-month reporting requirement to get additional resources for hospitals
Results:

- Establish a solid and trustful collaborative relationship among LCRA members (state and hospitals)
- Share resources and pool what we have
- Working together harmoniously to provide relevant, timely and high quality data to clinical community and stakeholders
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Results:

- Hospital Registries
  - submit cancer cases more completely, timely and of higher quality
  - share FU information & adjuvant therapies
  - provide additional information for special studies
  - participate in pattern-of-care or quality of care studies and use them as their special studies
  - actively participate in LCRA meeting
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Implications/Next Steps:

- Central registry can build bridges with hospital registries, leading to collaborative relationship that benefits all

- Share vision and set goals
  - provide relevant and timely data for current clinical practice
  - participate jointly in PoC studies and other special studies such as CDC-funded CER project
Example: Transition from “Group” to “Individual” Care for Breast Cancer

- In the Past:
  - Tumor size
  - Lymph node status
  - Metastasis
  - Surgery
  - Adjuvant therapy
    - Radiation
    - Chemotherapy
    - Hormonal therapy
Example: Transition from “Group” to “Individual” Care for Breast Cancer

- **Current Practice:**
  - Tumor size
  - Lymph node status – chain and level
  - Isolated tumor cells
  - Histological type - favorable?
  - Patient’s age and menopausal status
  - Family history, including BRCA1/2
  - ER/PR
  - HER/2
  - Triple negative
  - Nottingham or Bloom-Richardson score/grade (histologic grade, nuclear grade, mitotic rate)
  - Multigene signature
Example: Transition from “Group” to “Individual” Care for Breast Cancer

- **Current Practice:**
  - Surgical Procedure
  - Adjuvant therapy
    - Radiation
    - Chemotherapy (regimen, dosage)
    - Hormonal therapy
    - Biological response modifier
  - Neo-adjuvant treatment
  - Response
  - Side effect and toxicity
Relevant and timely Data

- Complete and detailed stage information including subgroups (e.g. T1a)
- Biomarkers and prognostic data for “customized individual” cancer care
- Prediction of prognosis
- Complete treatment including adjuvant therapies
- Treatment response
- Disease free/recurrence and survival data
- Measures of standard or guideline quality of care
- Timely data
“The hardest thing in life is to know which bridge to cross &
which to burn.”

David Russell
Twin Span in Louisiana (after Katrina)
Greater Mississippi Bridge
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