Do All Registries Have to Do All Things?

The Finish Line
NAACCR Annual Meeting 2011
Louisville, Kentucky

Or.....

Can we think of other possible data collection methodologies and/or approaches?

Short Answer: *YES*

If our funding sources/federal partners require it, we must collect it.

Existing Funds + Expanding Dataset = Burden on Data Collection System

Step outside of that reality:

Brainstorm solutions

Keep pace with

- Policy
- Science
- Technology

Provincial, State & National Level

Step outside of that reality:

Brainstorm solutions

While Improving

- Data Quality
- Timeliness
- Completeness

Most efficiently using existing resources

Do All Registries Have to Do All Things?

Revised Answer: Probably Not

While all registries need to collect data elements critical to CORE surveillance activities….

We can estimate national trends using state/provincial-based samples and possible do this better through focused resources.

Questions to ask each registry (National/Provincial/State) regarding collection of specific data elements:

1. Is it CORE to your mission?
2. Is there a plan for utilization?
3. Are you able to collect the data completely & accurately?
4. Can you financially and feasibly collect it without jeopardizing your CORE data?

What, if anything, would you be willing to give up?

Treatment

Demographics

SSF-Prognostic

Cancer identification

Collab Stage

Follow-up (Survival)

Summary Stage

Alternate Proposed Solutions to: "Do all registries need to collect all things?"

1. Sentinel Registry
   - Every registry collects CORE dataset and then different samples of registries collect different non-CORE elements

Alternate Proposed Solutions to: "Do all registries need to collect all things?"

2. Reduced Registry
   - Every registry collects CORE dataset plus … but selected data elements are dropped from registry collection all together (or for specific cancers)

Alternate Proposed Solutions to: "Do all registries need to collect all things?"

3. Low/High Resolution Registry
   - Every registry collects CORE dataset (low) and then random sample data collection for other elements (high….patterns of care)

Alternate Proposed Solutions to:
"Do all registries need to collect all things?"

4. Augmented (Partnered) Registry
   - Every registry collects CORE dataset and partnered solutions are developed for data collection that can be passed down to all registries.

Alternate Proposed Solutions to:
"Do all registries need to collect all things?"

5. Modified CORE Registry
   - Every registry collects CORE dataset but variation is allowed for definition of CORE (Collaborative Stage vs. Summary Stage)

Example of Alternate Methodologies of Data Collection

CORE Data

Demographics

Cancer identification

CORE Data

Demographics

Cancer identification

Modified CORE

Collab Stage

Summary Stage (CS Lite)

Variation is allowed for definition of CORE (Collaborative Stage vs. CS Lite vs. Summary Stage)

Reduced

SSF

Other Misc

CORE Data

Demographics

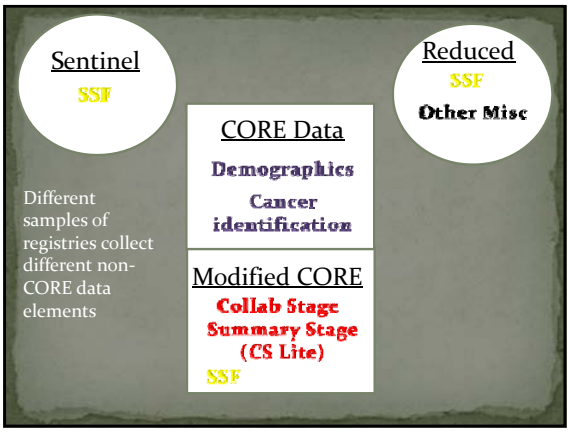
Cancer identification

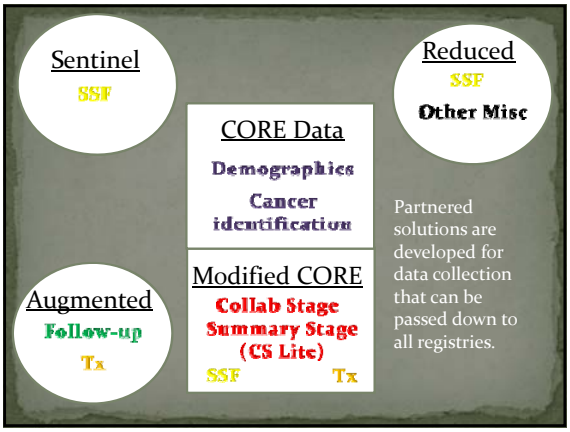
Modified CORE

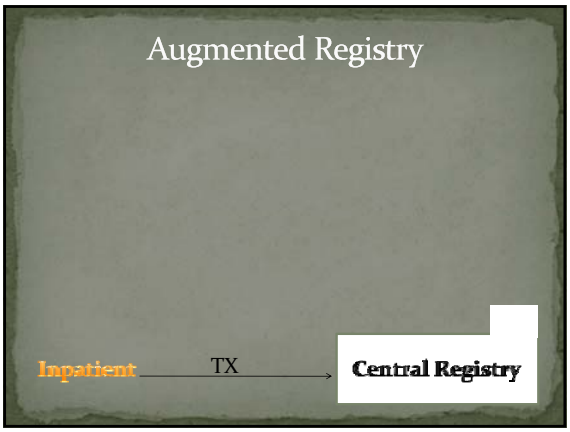
Collab Stage

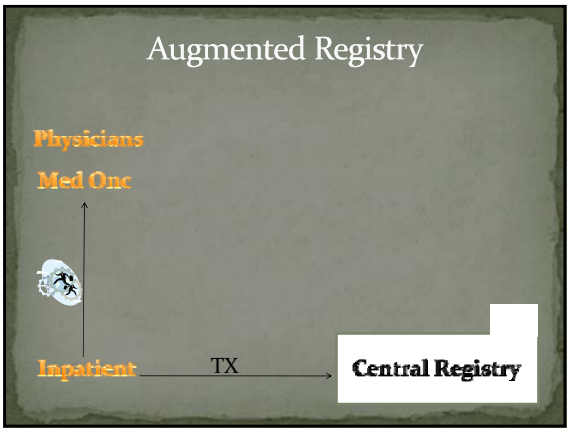
Summary Stage (CS Lite)

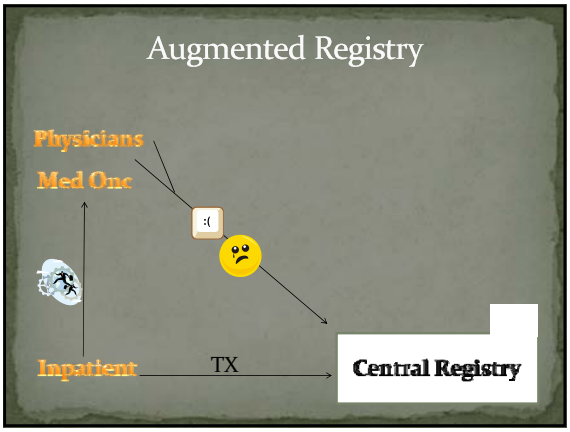
Selected data elements are dropped from registry collection all together (or for specific cancers)


Sentinel
SSF
Reduced
SSF
Other Misc
CORE Data
Demographics
Cancer identification
Modified CORE
Collab Stage
Summary Stage (CS Lite)
SSF
Different samples of registries collect different non-CORE data elements


Sentinel
SSF
Reduced
SSF
Other Misc
CORE Data
Demographics
Cancer identification
Modified CORE
Collab Stage
Summary Stage (CS Lite)
SSF
Tx
Augmented
Follow-up
Tx
Partnered solutions are developed for data collection that can be passed down to all registries.


Augmented Registry
Inpatient
TX
Central Registry


Augmented Registry
Physicians
Med Onc
Inpatient
TX
Central Registry


Augmented Registry
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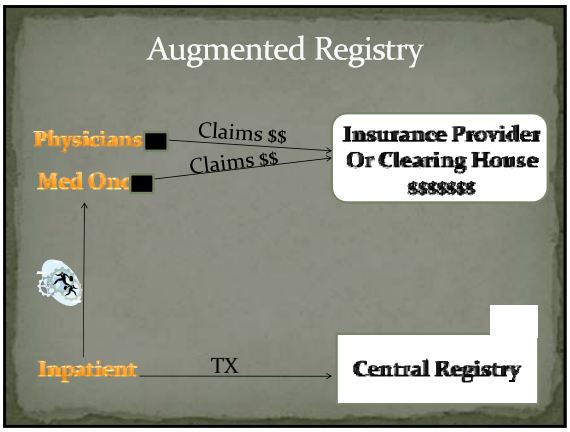
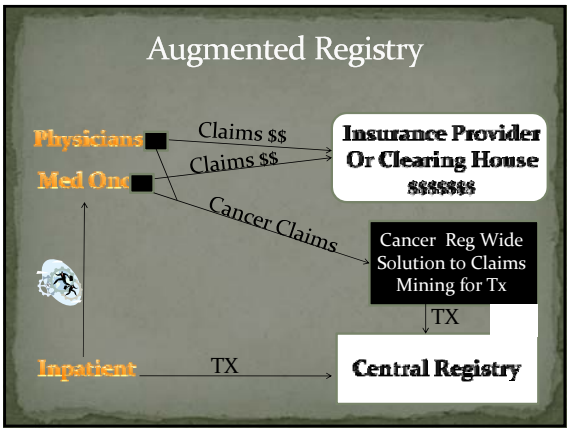
TX
Central Registry


Augmented Registry
Physicians
Claims $$
Claims $$
Med Onc
Insurance Provider
Or Clearing House
$$$$$$$
Inpatient
TX
Central Registry


Augmented Registry
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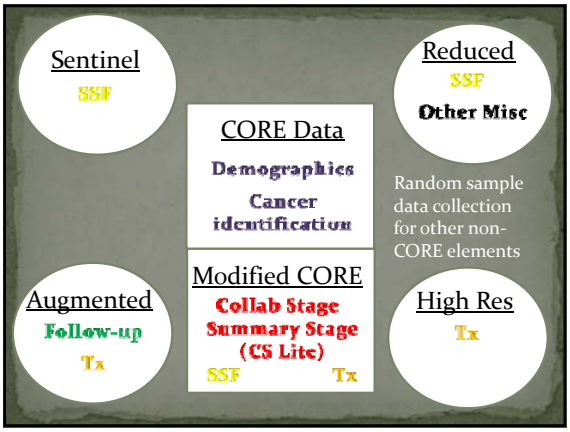
Cancer Claims
Cancer Reg Wide
Solution to Claims
Mining for Tx
TX
Inpatient
TX
Central Registry


Sentinel
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Other Misc
Random sample
data collection
for other non-
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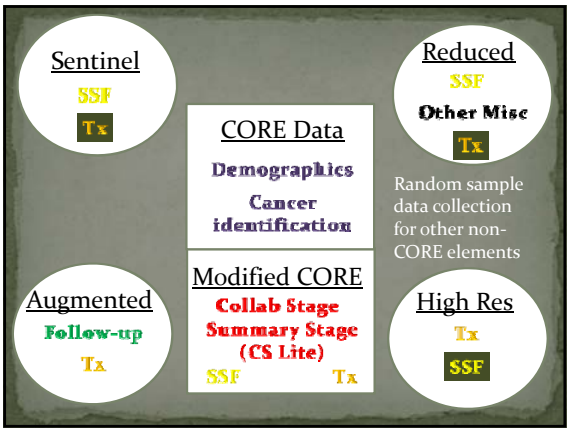
Augmented
Follow-up
Tx
Modified CORE
Collab Stage
Summary Stage
(CS Lite)
SSF
Tx
High Res
Tx


Sentinel
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Tx
SSF

Other Ideas?

Discussion