

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 possibly 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)

CORE Data
Demographics
Cancer
identification

Modified CORE
Collab Stage
Summary Stage
(CS Lite)

Reduced
SSF
Other Misc

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




















