NAACCR Perspective on METRIC

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••• Goal:

- Create software to access, create, and visualize environmental measures related to cancer health behaviors and resources.
- Cancer incidence and mortality = outcomes
 - Spatially-enabled
 - NAACCR Geocode
- Relevance of cancer registry data
 - Surveillance versus research
 - Advocacy for cancer surveillance



••• Targeted User

• Environmental epidemiologist or exposure scientist who lacks the technical expertise to automate access to diverse data resources from interactive and frequently updated web sources.

-also....cancer surveillance researchers
- Ease of use of system balanced by expertise
- Team Science approach



Confidentiality and Data Sharing

- Barrier
- Legal limitations
- Cultural or perceived limitations

- Encryption, hashing, geospatial cryptology
- Education & Resources
 - Aimed at administrators to encourage release of data
- Group-level disclosure in addition to individual-level
 - More variables = more uniqueness



••• VPR-CLS

- Facilitates national-level linkage
 - Currently focused on cohort studies
- State-level has small-area based geographic data
 - Nothing below county available in CiNA
 - Additional hurdles to obtain tract from NPCR/SEER
 - Long/lat only at state
- Link done behind each state's firewall & confidential data released directly by the states
- Coordination of data request proposals and IRB requirements



••• Cancer clusters/concerns/hotspots/increased risk

- Proactive assessment preferred
- Resources required for registry to respond
 - Team Science/collaborations
- Bridge to program implementation/policy development
 - Team Science/collaborations
- Residential hx
- Software stand alone and "easy" but research is not
- How to communicate to community?
- What resources offered to community?



••• Access & Resources

- Access to care defined by distance
 - Shortest Path
 - Radiation facilities
 - Revise/update?
- Access to care defined by resources
 - ACS data ease of use; National Provider
 - update
- Risk Behavior data
 - Regional level assessment and above



••• Summary

- Support high for both research direction and METRIC software
- Significant barriers to data sharing
 - May require time to address
- Significant benefits to expanding use & utility of cancer surveillance data
- Potential for harm if research is promulgated without dovetailing with additional programs, services, policy, and/or education
 - Both communities/populations and registries
 - Does not outweigh benefits & can be largely addressed

