

Research and Data Use Steering Committee Minutes

November 14, 016, 1:00-2:00 pm EST

Phone: 877 926-5038 (# 3270142)

Agenda

Note: the above phone number has been corrected to reflect the standing meeting request

1. Roll

Name	<i>Steering Committee</i>	Institution	Title
Boscoe, Francis	<i>Board Liaison</i>	New York State Cancer Registry	Research Scientist: present
Copeland, Glenn	<i>Member</i>	Michigan Cancer Surveillance Program	Director;absent
Cronin, Kathy	<i>Member</i>	NCI	Statistician:present
De, Prithwish	<i>Member</i>	Cancer Care Ontario	Director of Surveillance: absent
Gershman, Susan	<i>Co-chair</i>	Massachusetts Cancer Registry	Director:present
Hofferkamp, Jim	<i>Staff</i>	NAACCR	Program Manager of Education:absent
Kohler, Betsy	<i>Observer</i>	NAACCR	Executive Director:absent
Kosary, Carol	<i>Member</i>	NCI	Statistician:absent
Jemal, Ahmedin	<i>Member</i>	ACS	Director, Surveillance: present
Johnson, Chris	<i>Board Liaison</i>	Cancer Registry of Idaho	Epidemiologist:present
Ryerson, Blythe	<i>Member</i>	CDC	SRT Lead:present
Schymura, Maria	<i>Member</i>	New York State Cancer Registry	Director:present
Shaw, Amanda	<i>Member</i>	Public Health Agency of Canada	Manager, Cancer Surveillance:absent

Sherman, Recinda	<i>Staff</i>	NAACCR	RDU Program Manager:present
Turner, Donna	<i>Member</i>	Manitoba Cancer Registry	Director:absent
Ward, Kevin	<i>Member</i>	Metropolitan Atlanta SEER Registry	Director:absent
Weir, Hannah	<i>Co-Chair</i>	CDC	Senior Epidemiologist:absent
Wiggins, Chuck	<i>NAACCR President</i>	New Mexico SEER	Director:absent
Xiaocheng, Wu	<i>Member</i>	Louisiana Tumor Registry	Director:absent

1. Roll - Susan took role (see above)
2. Review notes from October 7, 2016 (see below) - Susan requested any corrections be sent to her directly.
3. Updates from October RDU call (see notes below). - All

Wu provided the Louisiana's Data Quality Indicator reports for the group to review. CDC/NPCR did not require the Derived AJCC-7 so 60% did not report so missing does not necessary equate unknown for NPCR registries. If components are missing in Collaborate Stage System, Derived AJCC-7 stage is not calculate but some institutions directly record summary stage. Maria clarified that this report is what central registries send to hospitals/facilities—so we would need to adapt as a fitness for use approach for population based registries.

Action Items:

1. Members are requested to review and provide comments back to Hannah via email
2. Recinda & Susan will then follow up with next steps (including discussion further with Prithwish (alternative report) and Wu to further discuss and to ensure Data Assessment Workgroup is in loop since this approach of additional fitness for use items are connected with data assessment, registry assessment, & potentially new platinum certification.

4. Topics for journal club and surveillance webinar (see attached) - Recinda/ Susan

We had 3 recent webinars. Recinda and Susan are following up to set the schedule for next year (2017). It came up that Sean Alterkruse has left NCI.

Action Items:

1. Recinda will need to f/u with Sean Alterkruse to switch PIs for CiNA projects he is attached to.

5. New business:

1. Match SMP and TF/WG list (end of this document) - Hannah

Susan went over the SMP update and TF/WG list briefly. The group decided to wait until Hannah was on the call to address (wait for Hannah) review & send to Hannah;

Action Items:

1. Recinda will need to f/u with Sean Alterkruse to switch PIs for CiNA projects he is attached to.

2. Other business? Cancer Control Indicators WG

Susan and Recinda are wrapping up this and moving towards identifying how to assist local comp cancer programs make local indicator rankings. Recinda presented the rankings at NAACCR in St. Louis and has a plenary talk at this years NPCR. Susan and Recinda are working with CDC and Comp Cancer to find a host and layout for presenting the state-based rankings.

Recinda will update the list annual around June when new data is available.

6. Adjourn Monday Dec 12, 1pm EST

Brief Notes: Research and Data Use (RDU)

October 7, 2016

Present: Glen Copeland, Susan Gershman, Prithwish De, Betsy Kohler, Blythe Ryerson, Maria Schymura, Recinda Sherman, Hannah Weir, Chuck Wiggins, Wu Xiaocheng

1. SMP Workplan Draft; Priority Area 3 Research and Data Use: At the November conference call the group will align workgroups and task forces with the Strategic Management Plan.
2. Confidentiality Task Force: Recinda and Susan will have a conference call to discuss the goals of the committee. Serban Negoita has volunteered to serve on the committee; additional recommended committee members will be invited to participate.
3. NAACCR Certification Enhancement Task Force: The Task Force met to review the issue, but further discussion required before any decision is made. Any modifications to the present certification process must be attainable for all registries.
4. Fitness for Use Task Force: Wu provided the Louisiana's Data Quality Indicator reports for the group to review. This generated a lengthy discussion regarding the indicators. Some of the issues: 2009-2013 CDC/NPCR did not require the Derived AJCC-7 so 60% did not report so maybe missing but not unknown; in Collaborate Stage System if components missing cannot calculate Derived AJCC-7 stage; certain institutions directly record summary stage; additional evaluation of primary payer field needed. Recinda and Susan will meet with Prithwish and Wu to further discuss.
5. Census Tract Population Estimates: Still in progress.
6. Pediatric Staging: Susan will continue to update group on project with Children's Hospital and Lindsay Frazier, pediatric oncologists, Dana-Farber Cancer Institute.
7. Survival Workgroup: Speak to Chris to reconvene following call-for-data.
8. CINA Editorial Workgroup: Call for Data materials have been released. Consider organizing a webinar for more general information.
9. Webinars: Recinda and Susan provided the committee with a list of future webinars. Two recent webinars:

September 29, 2016: **Registry of the Future** (Nancy Stroup)

October 12, 2016: **Data Visualization** (Dave Stinchcomb)

Parking Lot

- Census Tract Population Estimates: Still in progress.
- Pediatric Staging: Susan will continue to update group on project with Children's Hospital and Lindsay Frazier, pediatric oncologists, Dana-Farber Cancer Institute.
- Survival Workgroup: - when to record a death for survival
- Bibliography task force Recinda / Dustin to update as necessary. (on going)
- Primary payer field (send information to Recinda & Susan & Blythe)
- Ideas for future surveillance webinar topics: (Kathy Cronin & Recinda will work it out)
 - CI*rank tool - survival data? Rocky project
 - Funnel plots – for incidence, survival, mortality
 - SEER*stat cancer survival tool (Rocky F – for patients).
 - APC model website (<http://analysistools.nci.nih.gov/apc/>) (Bill Rosenberg (Division of Epi and Genetics))
 - Survival age, case mix standardization – methods
- When should a registry record a death (ask Survival WG if they would take on this task after call-for-data)
- Data Evaluation report. Put out a query to registries to share their common and unique evaluation reports.
- Scientific Editorial Board – review policy for review of papers using CINA data. –can take off
- Sharing information between the central registry and the reporting facilities (Obj 3, goal 2). Shared with Reg Ops. LA has a web-based data sharing system where reporting facilities can log on to get updates on their patients. Possible webinar topic.
- Handbook for Data Analysis TF (Recinda)
- 12 month data taskforce (is meeting)

Research and Data Use - SMP work plan

Goal 1: Develop efficient, centralized processes to improve access to North American population-based cancer registry data for cancer linkages, research, surveillance, and other applications.

Objective 1: Promote the use of high-quality and timely registry data by enhancing the annual Call for Data and the various NAACCR CINA data products.

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees, CINA Editorial Subcommittee

Key Strategies:

1. Review all CINA products annually to evaluate if consumer needs are being met, including the need for additional data elements and completeness of data.
2. Link via NAACCR and CINA products to partner and SMO websites (trends, prevalence estimates, etc). Revise and update all CINA products based on findings. Initiate expansion of CINA publication to include selected stage, survival and treatment information
3. Encourage analytical assessments of stage, treatment, and survival/vital status data using CINA Deluxe and incorporate data quality findings into considerations for future publications and advice to researchers.
4. Create a synthetic dataset for use in training and testing purposes.
5. Explore need for modification to current Gold and Silver level certifications, or addition of new level of certification. .

Expected Outcomes: CINA and CINA Deluxe are continuously timely and comprehensive. Platinum certification level will be established, and ultimately data quality will improve.

Timeline: Ongoing with first changes in 1-2 years

Objective 2: Develop a voluntary process to combine limited data from multiple registries to facilitate record linkage research.

Responsible Parties: Data Use and Research, Data Evaluation and Certification Committees

Key Strategies:

1. Evaluate legal and liability issues.
2. Identify ways to reduce IRB burden and barriers.
3. Develop the methodology for creating the datasets for linkage including encrypted and enhanced publically available data.
4. Develop a secure process using unique identifiers to provide linked data to researchers through a neutral third party.

5. Test, evaluate and revise process as needed.
6. Consider a fee-based service to research community.
7. Improve quality of linkage variables—investigate use of SSDI and other linkages that would improve follow-up variables in addition to demographic variables.
8. Develop set of rules to handle duplicate cases between registries.
9. Investigate approach for national de-duplication efforts
10. Update white paper on best practices regarding data confidentiality

Expected Outcomes: Increased number of multi-state linkage studies.

Timeline: 4 - 5 years

Objective 3: Maintain and enhance tools to inform researchers about state- and province-specific research experience, interests, and processes to initiate research.

Responsible Parties: Research and Data Use Committee

Key Strategies:

1. Work with researchers and experienced central registries to identify key data elements and limitations, critical data access requirements and best communication practices.
2. Develop a web-based communication portal on the NAACCR website for the above information with query capabilities for researchers.
3. Establish a mechanism for registries to update registry-specific information and set a requirement to review on an annual basis.
4. Promote the sharing of data use and research through webinars and other learning tools.

Expected Outcomes: Provide a more thorough understanding of strengths, weaknesses and appropriate uses of registry data. Increase access to registry data by researchers.

Timeline: 1-2 years

Objective 4: Increase accessibility to NAACCR's CINA products by periodically evaluating data access policies and processes.

Responsible Parties: Data Use and Research Committee

Key Strategies:

1. Review and revise current data request and registry consent procedures to identify improvements and ways to streamline.
2. Pilot test the proposed templates, review form and information sheet.
3. Revise and implement documentation.
4. Develop an online tool for proposal submissions and communication between applicants and reviewers.
5. Develop a comprehensive plan for disseminating information regarding CINA data request procedures to NAACCR members and the broader cancer surveillance and research community.
6. Produce a public access CINA data set that meets the needs of researchers while satisfying NAACCR data release policies.
7. Promote the use of the data by students

Expected Outcomes: Increase the number and timely processing of data requests. Registries and researchers will use CINA data more often and promote importance of cancer registry data for cancer prevention and control.

Timeline: 2-3 years

Objective 5: Increase the value and relevance of central cancer registries to the cancer control community, clinicians, researchers, and the public.

Responsible Parties:

Key Strategies:

1. Improve the timeliness of registry data by requesting incidence data submission at 12 months after the end of the diagnosis year.
2. Establish “fitness for use” guidelines to improve data quality/completeness for specific purposes such as cancer control, survival, outcomes evaluation, comparative effectiveness research, and spatial analysis.
3. Develop software tools for use by central cancer registries that will generate comprehensive data assessment reports that registries can use to periodically evaluate the quality and completeness of their data.
4. Develop state and province-specific cancer control profiles and evaluation measures, using population-based data. Provide technical assistance to registries to implement on a local level.
5. Identify the hallmarks of registries with high quality/complete/timely data, and develop best practice guidelines based on identified measures.
6. Facilitate sharing of technical resources and tools among NAACCR member organizations.

7. Meet the geographic information systems needs of the NAACCR membership, including maintenance of relevant data items, acquisition and assessment of census data, and development of software tools and educational materials related to spatial analysis. Specifically, develop standard tract-level population files for use in SEER*Stat.

Expected Outcomes: Increase research capacity at the central cancer registry level and among cancer researchers.

Timeline:

Task Force/ Work Group	Purpose	Chair/ Co-Chairs	Members	SMP Objective / Number
Cancer Control Indicators Task Force	To identify core indicators for use in cancer control, to create a report with state (province) rankings on these indicators and to provide documentation for use on the local level	Recinda Sherman/Susan Gershman	Susan Gershman, Betsy Kohler, Annie MacMillan, Recinda Sherman, Tom Tucker, Donna Turner, Mike Underwood, Chandrika Rao,	5.4
Case Completeness Task Force	To estimate new methods for estimating case completeness	Kevin Ward	Kathy Cronin, Ron Dewar, Brenda Edwards, Andy Lake, Lihua Liu, Jennifer Rico, Blythe Ryerson, Maria Schymura, Donna Turner, Kevin Ward, Nancy Weiss, Charles Wiggins, Reda Wilson, Li Zhu	
CINA Editorial Work Group	Oversee annual Call for Data activities. This is part of the objective to promote the use of (high) quality and timely registry data by enhancing the annual Call for Data and the various CINA data products	Glenn Copeland	Glenn Copeland, Prithwish De, Rick Firth, Jim Hofferkamp, Betsy Kohler, Andy Lake, Maria Schymura, Recinda Sherman, Brad Wohler, Xiao-Cheng Wu	1.1
Confidentiality Task Force	Update white paper on best practices regarding data confidentiality			2.10
Review Certification	Explore need for modification to current Gold and Silver level certifications, or addition of new level of certification.	Hannah Weir Tom Tucker	Betsy Kohler, Chris Johnson, Hannah Weir, Tom Tucker, Kevin Ward, Recinda Sherman, Jeannette Jackson-Thompson, Susan Gershman. Lori Koch, Cindy Nikiforuk	1.5

Data Release Task Force	To update, streamline, and address issues with CINA data release; to evaluate the consent process.	Recinda Sherman	Ann Hamilton, Kevin Henry, Lori Koch, Xiaocheng Wu, Recinda Sherman (Betsy Kohler and Maria Schymura are consultants)	1.2
Duplicate Cases Task Force	Develop guidance to help identify and to resolve duplicate cancer incidence cases between and among registries	Randi Rycroft/ Hannah Weir	Rashid Ahmed, Castine Clerkin, Glen Halvorson, Marcia Hamilton, Alana Hudson, Chris Johnson, Jessics Jungk, Lori Koch, Mireille Lemieux, Gary Levin, Serban Negoita, Rich Pinder, Randi Rycroft, Susan Schwartz, Recinda Sherman, Laura Williamson, Hannah Weir	2.9
Fitness for Use Task Force	Establish "fitness for use" guidelines to improve data quality/completeness for specific purposes such as cancer control, survival, outcomes evaluation, comparative effectiveness research, and spatial analysis	Brad Wohler / Meichin Hsieh	Meichin Hsieh, Bin Huang, Xiangrong Li, Carol Kruchko, Baozhen Qiao, Maria Schymura, Recinda Sherman, Helmneh Sineshaw, Brad Wohler, Manxia Wu, Xiao-Cheng Wu, Qingzhao Wu	1.3 5.2
Geographic, Spatial and Demographic Data Work Group	Meet the geographic information needs of the NAACCR membership, including maintenance of relevant data items, acquisition and assessment of census data, and development of software tools and educational materials related to spatial analysis.	Recinda Sherman	Justin George, Dan Goldberg, Kevin Henry, Carol Kosary, Kim Miller, Mary Mroszczyk, David O'Brien, Liora Sahar, Recinda Sherman, David Stinchcomb, Laura Williamson	5.7

IRB Work Group	Reviews issues related to the distribution and use of NAACCR data	John Fulton	<u>Voting Members:</u> Ron Dewar, Jack Finch, John Fulton, Cynthia O'Malley, John Morgan, Antoinette Stroup; <u>Alternate Members:</u> Vivine W. Chen, Joanne Hartnack, Anne Marie Hill, Annie MacMillan, Martin Whiteside, Iris Zachary	
NAACCR Geocoder Task Force	Maintain, enhance and publicize the NAACCR Geocoder, Shortest Path, and related tools	Dan Goldberg	Philip Crider, Dan Goldberg, Chuck May, Recinda Sherman, Hannah Weir	5.7
Research Application Review Work Group	Review CINA research proposals	Xiao-Cheng Wu	Glenn Copeland, Jeannette Jackson-Thompson, Chris Johnson Betsy Kohler, Andy Lake, Jim Martin, Maria Schymura, Recinda Sherman, Rebecca Siegel, Reda Wilson, Xiao-Cheng-Wu	
Registry Certification Work Group	Maintain and systematically evaluate updates to the existing certification process for population-based registries with a focus on using certification to help drive data quality, timeliness and completeness	Kevin Ward	Betsy Kohler, Andy Lake, Maria Schymura, TomTucker, Kevin Ward	
Research Webinar Work Group	Organize periodic research-themed webinars, either as part of regular NAACCR webinar series or something separate	Chuck Wiggins	Susan Gershman, Chuck Wiggins	3.4
Scientific Editorial Board Work Group	Review publications using CINA data for face validity	Myles Cockburn	Myles Cockburn	
Synthetic Dataset Task Force	Deveop synthetic testing dataset	Dave Stinchcomb	Frank Boscoe, Chris Johnson, Rich Pinder, Bruce Riddle, Dave Stinchcomb	1.4.

Twelve Month Data Task Force	Perform quality control on twelve month data and develop plans for preliminary release	Frank Boscoe	Frank Boscoe, Mary Beth Culp, Susan Gershman, Alana Hudson, Recinda Sherman, Reda Wilson	5.1
Virtual Pooled Linkage Work Group	Develop a voluntary process to combine limited data from multiple registries to facilitate record linkage research	Castine Clerkin / Dennis Deapen	Castine Clerkin, Dennis Deapen, Chris Johnson, Betsy Kohler, Andy Lake, Lynne Penberthy, Maria Schymura, Recinda Sherman, Hannah Weir	2.1 – 2.8

Webinar Schedule 2016/2017

Title of Webinar	Presenters	Scheduled Date
Registry of the Future	Nan Stroup	September 29, 2016
Data Visualization	Dave Stinchcomb	October 12, 2016
Virtual Pooled Registry <i>Virtual Pooled Registry Pilot Linkages with Large Cohort Studies</i> <i>Value of a Central Institutional Review Board for Multi-Centered Studies Using the Virtual Pooled Registry</i> <i>Value of Virtual Pooled Registry Process to Improve Data Quality in Central Registries</i>	Castine Clerkin, Sue Stoyanoff, Lynne Penberthy	
CDCs Vision of Registry of the Future	Lisa Richardson	
NCI Tools Overview	Kathy Cronin ?	
Protecting Human Subjects	Randi Rycroft, Nan Stroup, Recinda Sherman	
Standards of Care	Tom Tucker, Eric Durbin, Frances Ross	
California Research Highlights <i>Cancer Incidence and Mortality patterns Among Chinese Americans</i> <i>Hispanic Childhood Leukemia Incidence in CA: High and Rising</i> <i>Breast Cancer in Marin County: A Hotspot Grows Cold</i>	Dennis Deapen, Brenda Giddings, Christina Clarke-Dur	
Survival & Survivorship Methods & Techniques <i>Improving the Accuracy of Survival Estimates: Use of the SSA Epidemiology File to Identify Invalid Social Security Numbers</i> <i>Modelling All—Cause Mortality to Produce Life Tables by Socio-Economic Status for Canadian Provinces</i> TBD	Paulo Pinherio, Devon Spike, Chris Johnson	
Lymphoma Research Highlights	Eric Engles, Meredith Shiels	

<p><i>Contributions of HIV to Non-Hodgkin Lymphoma Mortality in the U.S. (2005-2012)</i></p> <p><i>Trends in Primary Central Nervous System Lymphoma Incidence and Survival in the U.S.</i></p>		
<p>Novel Approaches to Improving Data Quality</p> <p><i>Utilizing State Databases to Improve follow-up: The Louisiana Vaccination Experience</i></p> <p><i>Analysis of External Databases to Ascertain Vital Status</i></p>	Christina Lefante, Scott Van Heest, Laura Stephenson	
<p>NAACCR V. 16 Edits Metafile Update</p>	Jim Hofferkamp	
<p>Geo-spatial mapping and modelling presentation</p>	Prithwish De	
<p>Virtual Tissue Repositories</p> <p>The SEER Virtual Tissue Repository Pilot: Leveraging Population-Based Bio –specimens</p>	Radim Moravec	
<p>Introduction to Biomarkers &/or Personalized Medicine</p>	Susan will check with DFCI	