

Research and Data Use Steering Committee

March 13, 2017, 1:00-2:00 pm EST

1. Present: Frank Boscoe, Susan Gershman, Betsy Kohler, Maria Schymura, Recinda Sherman, Hannah Weir, Chuck Wiggins, G Xiaocheng Wu
2. Updates from December call: According to Kevin Ward, case completeness task force has completed work and TF is disbanded.
3. Review and recruit RDU steering committee membership: Need to develop a policy for who should be invited to as member of RDU (WG and TF leads, representatives to national surveillance organization) and expectations for participation.

Action: Hannah to draft terms of membership. Hannah and Susan to reach out to non-engaged members. Add Castine Clerkin to the roster.

1. Strategic Management Plan (develop 1 year work plan)
 - Identify priority areas for the next year and develop a 1-year work plan.
 - Priority areas include
 1. Data indicators matrix: Using the information from the Fitness-for-use workgroup, update and expand the matrix (<https://www.naacr.org/research-capabilities-by-registry/>). Could lead to including more elements to Certification levels.
 2. Encourage data use for the purpose of promoting CINA and building of capacity within the registries for data analysis and interpretation.
 - Use the NAACCR Forum (electronic bulletin board). The RDU can identify relevant topics such as rare cancers, wait time, etc. **Action item: Hannah to draft notice to go on listserv.**
 - **Action item: at the annual meeting, encourage attendees to suggest presentations for webinars – could award prize to people who submit suggestions for presentations. Perhaps limit one “card” per person for drawing. If a presentation (oral or poster) goes from NAACCR meeting to webinar – then recognize the presenter.**
 3. Confidentiality task force: Need to update what is on the web and include hashed data for linkages and spatial data issues. Dennis Deapen and Glenn Copeland wrote first paper and may be able to suggest volunteers.
 4. Certification TF Use matrix information from above to identify which data items to be included in expanded Certification.

- Cancer control indicators

Work to be highlighted at NCRA meeting and at CDC Cancer Conference. Might want to expand to include other systems' indicators such as wait time between diagnosis and treatment.

- Next webinar

NCI/NIH – vulnerable populations April or May date

2. Calendar

- Next RDU call April 10, 2017
- June – RDU meet on Tues, June 20, 2017, 7-8 am.

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.
- Bibliography task force
- Primary payer field
- Ideas for future surveillance webinar topics:
 - 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
 - NCI and the virtual tissue repository.
 - NCI tools – Kathy Crohin (Recinda to follow up)
- 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.
- 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)

Research and Data Use Steering Committee - Task Force and Work Group List

Task Force/ Work Group	Purpose	Chair/ Co-Chairs	Members	SMP
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 #7
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	1.1,1.2 #1-3
Confidentiality Task Force	To write a Best Practice Paper on Confidentiality Issues using a draft from Dennis Deapen	Susan Gershman and Recinda Sherman		2.1
Certification Task Ford (WOW!!! Initiatives)	Explore need for modification to current Gold and Silver level certifications, or addition of new level of certification	Hannah Weir, Tom Tucker	Susan Gershman, Chris Johnson, Lori Koch, Betsy Kohler, Cindy Nikiforuk, Recinda Sherman, Jeannette Jackson-Thompson, Kevin Ward	1.5
Data Release Task Force (as needed)	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 (future)	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	2.8,2.9
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, 5.3, 5.5
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 # 5
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	2.2 # 8

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 #5
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	#9
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, Recinda Sherman	3.4 #6
Scientific Editorial Board Work Group	Review publications using CINA data for face validity	Myles Cockburn	Myles Cockburn	#8, #10
Synthetic Dataset Task Force	Develop synthetic testing dataset	Dave Stinchcomb	Frank Boscoe, Chris Johnson, Rich Pinder, Bruce Riddle, Dave Stinchcomb	1.4
Twelve Month Data Task Force (in collaboration with Reg Ops)	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	2.1-2.9 #4

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
Geo-spatial mapping and modelling presentation	Prithwish De	November 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	
NCI Tools Overview	Kathy Cronin ?	
Protecting Human Subjects	Randi Rycroft, Nan Stroup, Recinda Sherman	
Standards of Care	Mary Potts	
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 <i>Contributions of HIV to Non-Hodgkin Lymphoma</i>	Eric Engles, Meredith Shiels	

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