Minutes

**NAACCR Institutional Review Board Biannual Meeting**

**October 28, 2016**

**11:30 aM ET, 10:30 AM PM CT, 9:30 AM MT, 8:30 AM PT**

Call-In Info:

Toll free number: 1-877-953-0411

Passcode: 9206148

1. Welcome & Report from the Chair John Fulton

Board Members Present:

John Fulton, Ann Marie Hill, Ron Dewar, Martin Whiteside, Cynthia O’Malley, Nan Stroup, Iris Zachary, Vivian Chen

Quorum was reached

NAACCR Staff Present:

Recinda Sherman

1. Minutes from April 8, 2016 John Fulton

Cynthia moved to approve the minutes as presented.

Ann Marie was 2nd to the motion.

Minutes from April 8, 2016 were accepted as posted.

1. IRB Membership John Fulton/Recinda Sherman

*Members moving off:*

1. John Morgan, served from 2007-2015

2. Joanne Hartneck, served 2015

3. Nan Stroup, served from 2013-2016

*Members continuing another term (2 years continuing term):*

1. Iris Zachary, term continues to December 31, 2018

2. Martin Whiteside, term continues to December 31, 2018

3. Annie MacMillan, term continues to December 31, 2018

*New Members (3 year initial term):*

1. Paula Cohen: term ends December 31, 2019

The group discussed methods of recruiting new members and the need for diversity of subject expertise and Canadian representation. Recinda has mentioned the need for volunteers in the 2016 Fall NAACCR Narrative.

***Actions:***

* Recinda will have the NAACCR IRB letters sent for the above members.
* Recinda will follow-up with Cynthia for contact information on Paula Cohen and to get her certification.
* Cynthia will write a listserv asking for volunteers. She will send to John and Recinda for review and distribution.
* Recinda will investigate whether the request for volunteers can be highlight as a standalone section in Fall 2016 NAACCR Narrative.

1. Misc Recinda Sherman

Volume of applications—happily, the use of CiNA data has been on the rise. The type of researcher has expanded to include researchers outside of the large cancer agencies. The cycle runs from July to June—so at 4 months into the year, we have as many proposals as 12 months last year. This has reinforced the need for streaming and automating processes.

New NAACCR Website—NAACCR is revamping their website.

Updating Forms/On-line Forms—Recinda is conducting a review of all IRB materials and hopes to create put some documents on-line.

VPR-CLS IRB activities –This project (Virtual Pooled Registry Cancer Linkage System) aims to streamline national level cohort linkages with cancer registry data. As part of this process, there are IRB activities. The goal is to coordinate and standardize an IRB and Registry approval process with the individual state registries. This group is using the NAACCR materials as a foundation for creating common or templated application for use by states. Vivian, who is also involved in this project, discussed how wide the range of approach to IRB and research approval is by states. She would like NAACCR IRB assistance to develop education materials discussing various issues and to provide support for the smaller states. Ann Marie mentioned that we need to ensure the NAACCR IRB and the VPR-CLS IRB work is well coordinated.

***Actions:***

* Recinda, Cynthia, and John will meet to improve efficiency of our application process and renewal system.

1. Manuscript Reviews since April 8, 2016 Recinda Sherman

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| **IRB Application No.** | **Manuscript Title** | **Notes** |
| 14-02 | Comparison of latitude gradients for testicular cancer, melanoma, and remaining cancers in Australia and the United States (Henry, Temple) |  |
| 14-07 | Lymphoid Malignancy Statistics in the US, 2001-2012 (Henry, Temple) |  |
| 14-08 | State Variation in Contralateral Prophylactic Mastectomy Among U.S. Women Diagnosed with Unilateral Early Stage Breast cancer, 2004-2012 (Ward, ACS) |  |
| 15-07 | Future of testicular germ cell tumor incidence in the US: Forecast through the next decade (Ghazarian, NCI) | Pending—received 10/27/16 |

1. Projects requesting additional years of data since April 8, 2016 Recinda Sherman

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| **IRB Application No.** | **Project Title** | **Notes** |
| 14-10 | Examining cancer disparities in the Philadelphia Metro Area (New Jersey, Pennsylvania & Delaware) (Henry, Temple) |  |
| 15-06 | Assessing the relationship between rural-urban residence and cancer using the NAACCR urban-rural indicator codes (Henry, Temple) |  |

1. Expedited IRB Reviews since April 8, 2016

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| **IRB Application No.** | **Project Title (PI)** | **Approval Date** |
| 16-01 | Trends in incidence rates of biliary tract cancers by age group and cancer site among adults in North America (1999-2013) and trends in obesity rates  Van Dyke, NCI | 5/6/16 |
| 16-02 | Trends in incidence of esophageal and gastric cancer by histological/anatomical subtype and race in the US, 2003-2012 Jemal, ACS | 4/22/16 |
| 16-03 | Incidence of hepatocellular carcinoma and intrahepatic cholangiocarcinoma by racial/ethnic group in the US  McGlynn, NCI | 10/7/16 |
| 16-04 | Imputing hormone receptor and HER2 status for defining breast cancer molecular subtypes using US population-based cancer registry data  Howlader, NCI | 10/12/16 |
| 16-06 | Geographic patterns in lung cancer incidence in the US  Lewis, NCI | 10/7/16 |
| 16-07 | Age- and subsite-specific trends in incidence of gastric and esophageal cancers in North American adults  Camargo, NCI | 10/11/16 |
| 16-09 | Analysis of cancer among transsexual and intersex patients in the US using national surveillance data  Goodman, Emory | 10/11/16 |

1. Review pending Expedited IRB Reviews:

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| **IRB Application No.** | **Project Title (PI)** | **PI** | **Notes** |
| 15-13 | Incidence trends and current burden of oral cavity and oropharyngeal cancers in North America | Chaturvedi, NCI | On hold per PI; not yet sent to IRB |
| 16-05 | The Affordable Care act and cancer stage at diagnosis | Han, ACS | Pending materials from researcher |
| 16-08 | Forecast of trends in esophageal and gastric cancer in the US through 2030 | Petrick, NCI | Pending materials from researcher |
| 16-10 | Measuring observed incidence of prostate cancer by grade and extent of disease for race/ethnic groups in the US & Canada | Balise, UM | Pending RApR approval |
| 16-11 | Oregon Hereditary Cancer Surveillance | Parkman, OHSU | Pending materials from researcher |
| 16-12 | State-level lung cancer burden | Jump & Deapen, Lung Association | Pending materials from researcher |

1. Annual monitoring compliance since April 8, 2016

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| **IRB Application No.** | **Project Title (PI)** | **Renewal Date** | **Notes** |
| 05-13 | Cutaneous malignant melanoma (CMM): Differences in epidemiology between U.S. adults and children, 1995-2002 (Paddock, NJ State Cancer Registry) | 7/1/16 |  |
| 07-05 | Projecting estimates of cancer incidence for every US state both spatially and temporally (Siegel, ACS) | Pending materials from researcher | Due Sept but materials sent in Oct |
| 12-03 | Analysis of ethnic disparities in colon cancer suggests a potential need for early colon cancer screening in Asians living in the USA (Jackson-Thompson, Missouri Cancer Registry) | 9/2/16 | Closed |
| 12-05 | Priorities for cervical cancer control based on disparities in race, social position, screening, vaccination, incidence and mortality, 1995-2009 (Sean Alterkruse, NCI) | 4/25/16 | Closed |
| 13-01 | Survival Data 2013-Ovarian cancer mortality and survival trends in relation to changing patterns of menopausal hormone therapy in the United States - Delayed for Survival Data (Sherman & Yang, NCI) | Pending materials from researcher | Data Release Delayed: received data March 2016; not overdue |
| 13-02 | Trends in hormone related female cancer incidence in relation to changing patterns of menopausal hormone therapy in the United States (Sherman & Yang, NCI) | Pending materials from researcher | Data Release Delayed: received data March 2016; not overdue |
| 13-04 | Insurance coverage expansion and disparities in cervical, prostate, and lung cancer (Hanchate, Boston University Medical Center) | 4/25/16 | Closed |
| 13-05 | Health insurance and cancer stage at diagnosis (Xuesong Han, NCI) | 4/26/16 |  |
| 13-09 | The burden of cancer in the USA in 2012 by race/ethnicity (Lortet-Tieulent, ACS) | 4/27/16 |  |
| 14-02 | Comparison of latitude gradients for testicular cancer and remaining cancer in Australia and the United States (Baade, Cancer Council Queensland) | 4/26/16 |  |
| 14-03 | Geographic clustering of invasive melanomas in the US (Gimotty, UPenn) | 9/26/16 |  |
| 14-05 | The epidemiology of pediatric brain cancers in Appalachia (Huang, KSCR) | 4/24/16 | Closed |
| 14-06 | The variations in receipt of curative-intent surgical treatment for early stage non-small cell lung cancer (NSCLC) among racial/ethnic groups and within racial ethnic groups across states in the US (Sineshaw, ACS) | Pending materials from researcher | Due Nov |
| 14-07 | Lymphoid malignancy statistics in the US, 2001-2012 (Jemal, ACS) | Pending materials from researcher | Due Nov |
| 14-08 | Demographic and regional/state variation in DCIS and early stage breast cancer incidence and treatment (Ward, ACS) | Pending materials from researcher | Due Nov |
| 14-10 | Examining cancer disparities in the Philadelphia Metro Area (New Jersey, Pennsylvania and Delaware) (Henry, Temple) | Pending materials from researcher | Due Nov |
| 15-01 | Recent trends in incidence of testicular germ cell tumors in the US (Ghazarian, NCI) | 5/6/16 | Closed |
| 15-03 | US CONCORD-2 Study, Incidence 1995-2009 (Weir, CDC) | 10/27/16 | Closed |
| 15-05 | Testicular cancer in men age 50 years and older | 10/27/16 |  |
| 16-06 | Assessing the relationship between rural-urban residence and cancer using the NAACCR urban-rural indicator codes | Pending materials from researcher | Due July but materials sent in Oct |
| 15-07 | Forecasting trends in testicular germ cell tumors in the US | 10/27/16 | Closed |
| 15-10 | Rates of childhood cancer in the US (Shiels, NCI) | Pending materials from researcher | Due Oct |
| 15-11 | The association between the incidence of chronic lymphocytic leukemia among adults in the US and rural-urban residence (Oancea, NDCR) | Pending materials from researcher | Due Oct |

1. Complete list of (active and terminated) CINA Projects (separate attachment)
2. Next call – tentative 2nd Friday in April 14th, 2017; 8:30 am PST,9:30 MST,10:30 CST; 11:30 EST