Greetings From the Surveillance Research Program (SRP)!

As acting Associate Director of SRP, I would like to congratulate all of our colleagues in the registry community and everyone who works diligently to put the Surveillance, Epidemiology, and End Results (SEER) data together. In 2013, SEER will celebrate its 40th Anniversary, and we are planning many activities to commemorate this momentous occasion. Look for more information about these activities in SRP’s Spring/Summer e-Newsletter. We also are developing updates to the SEER website; you can read about them in this edition of the e-Newsletter.

During the past year, I have enjoyed working with the SRP Leadership Team and all of SRP on a variety of exciting initiatives in my capacity as the temporary Associate Director. 2012 brought us many successes, including the launch of the updated Geographic Information Systems & Science website and the new “Did You Know?” series of animated videos highlighting key cancer statistics for the public. In 2013, I look forward to SRP’s continued progress and growth and to welcoming a permanent Associate Director into the program.

Happy Holidays,

Kathy Cronin

Improving SEER Data Usage With Imputed Datasets and Synthetic Data

Imputed Datasets

The SEER Program provides a rich source of data for analyzing trends in cancer incidence and survival. Individual cases captured in registry data, however, often are missing information on important variables for monitoring cancer trends. The amount of missing information can vary between subgroups and change over time, and ignoring missing information can lead to biased results. Imputation...
methods can be used to account for missing data. At SRP, Nadia Howlader, M.S., a Mathematical Statistician in the Data Analysis and Interpretation Branch (DAIB), has made significant contributions to imputing missing and unknown variables in the SEER database. For instance, variables used to determine a cancer’s molecular subtype often are incomplete in cancer registry data, making it difficult to assess trends by tumor subtype. To address this, Ms. Howlader developed and applied an imputation model to breast cancer cases in the SEER data to evaluate trends by estrogen receptor status. She plans to expand this model to include additional variables, such as HER-2 status.

These imputed datasets will be made available on April 15, 2013, through SEER*Stat (http://seer.cancer.gov/analysis/index.html) to facilitate accurate estimation of breast cancer incidence trends. To ensure that the imputed data sets are used correctly, Ms. Howlader and colleagues published a paper in the American Journal of Epidemiology that provides detailed, step-by-step directions for conducting data analyses. In addition, Ms. Howlader—along with statisticians from Westat and the Kentucky Cancer Registry—will conduct a workshop on imputation methods at the 2013 North American Association of Central Cancer Registries (NAACCR) Annual Conference. This workshop, “Use of Imputation Techniques for Modeling Missing Information in Population-Based Cancer Registry Data,” will supply information on how to assess missing data, compare and contrast different imputation models, and demonstrate various applications of imputation techniques in cancer registry settings. For more information on imputation methods, please contact Nadia Howlader at howladern@mail.nih.gov.


Synthetic Data

Researchers have expressed interest in analyzing census tract-level variables for cases included in SEER data, but this type of data has not been released yet because of concerns regarding the confidentiality of information. To address this issue and increase the utility of SEER data, Mandi Yu, Ph.D., a Mathematical Statistician in DAIB, has used imputation methods to construct synthetic census tracts for SEER’s population-based data. Importantly, this partially synthetic data is anonymized in that the synthetic census tracts cannot be traced back to a specific individual. As a result, these data have the potential to be disseminated in place of the real data and maintain participant confidentiality and privacy. Furthermore, Dr. Yu and colleagues are testing their models for generating synthetic data to evaluate the utility of the synthetic data compared to the original data.

Although these analyses currently are under way, Dr. Yu reports that interim results on a pilot study using California data are very encouraging. Eventually, Dr. Yu would like to extend this effort to all of SEER and make the synthetic data sets available for use with SEER*Stat, which would give researchers the opportunity to conduct analyses using census-level variables while minimizing the risk of disclosing patient information. Mandi Yu can be contacted at yum3@mail.nih.gov to provide more information about SEER’s synthetic data sets.

The Health Disparities Calculator: A Valuable Tool for Research and Public Health

Scientists often use measures like relative risk—the risk of a certain event happening in one group of people compared with the risk of the same event happening in a second group—to assess health disparities. However, the use of such measures is inherently limiting, it is difficult to monitor trends, and only two groups can be compared at a time. The Health Disparities Calculator (HD*Calc), statistical software that generates multiple summary measures to evaluate and monitor health disparities, allows scientists not only to note differences between demographic groups but also to calculate the magnitude of disparities.
HD*Calc, which was developed by the National Cancer Institute’s (NCI’s) SRP and Applied Research Program (ARP), can function as an extension of SEER*Stat software and allows users to import SEER data or their own population-based health data. Although originally designed to evaluate cancer-related health disparities, HD*Calc can be used with any population-based health data set. Cross-sectional and trend data categorized by disparity group can be used with HD*Calc to generate four absolute and seven relative summary measures of disparity. Although many different measures of health disparities exist, the measures included in HD*Calc are used widely by epidemiologists and appear in research publications. To analyze and interpret their data correctly, researchers should select at least one absolute and one relative summary measure for analysis. HD*Calc displays results as data tables and graphs that are exportable for use in other applications.

HD*Calc software and training materials are available as free downloads on the SEER website. NCI releases HD*Calc updates as new features are added, and improvements are made as user suggestions are discussed and approved. For example, users can now export their HD*Calc data to the Joinpoint Regression Program, which allows them to test trends for statistical significance. The currently available version of HD*Calc, version 1.2.3, was released in October 2012 and includes the ability to adjust disparity measures for scaling when multiple measures are viewed together in a single chart.

HD*Calc has been presented at numerous scientific conferences, including at a special session led by the National Center for Health Statistics at the 2011 American Public Health Association (APHA) Conference and a talk at the National Health Promotion Summit in April 2012. A webinar that reviews health disparities measures and demonstrates the use of HD*Calc was presented to the North American Association of Central Cancer Registries (NAACCR) in 2011 and is archived on the HD*Calc Web page. In July 2012, HD*Calc was the focus of a Research to Reality (R2R) cyber-seminar. The cyber-seminar, available on the R2R website, includes an overview and demonstration of HD*Calc, as well as a detailed explanation of how the King County Health Department in Washington state uses HD*Calc to evaluate health disparities and inform programmatic priorities.

The HD*Calc team at SRP and ARP is working to expand the use of HD*Calc and has planned numerous initiatives—such as developing disease-specific disparity fact sheets in collaboration with state health departments—for fiscal year 2013 as part of a long-term promotion plan. Discussions also are under way to decide how to incorporate the use of HD*Calc into the Healthy People (HP) 2020 program, which provides science-based objectives for improving the health of all Americans. HD*Calc’s ability to analyze and monitor health disparities over time correlates well with the HP initiative’s overarching goal of achieving health equality. Current research projects at SRP include using HD*Calc to evaluate how factors such as the economic downturn affect the trends for various cancer sites.
Residual Tissue Repository (RTR) Program Assessment Under Way

The SEER RTR Program was established in 2003 to maintain biospecimens obtained from three of SEER’s population-based cancer registries: Iowa, Hawaii, and Los Angeles. In addition to maintaining onsite residual tissue repositories at these registries, the RTR also supplements these biospecimens with those housed at pathology laboratories across the registry catchment areas. The RTR collection is a unique resource because it contains specimens that are linked to population-level SEER data and covers more than 60,000 cancer cases from diverse geographical regions and racial/ethnic populations. It also includes high-quality information on population demographics, tumor characteristics, treatment data, and patient vital status.

Investigators at government, academic, and nonprofit institutions may apply to the program to obtain specimens to study biomarkers, etiology, and other aspects with a population-based sample of cancer cases. The number of requests for RTR biospecimens is increasing, with 59 peer-reviewed research articles in print and new findings using this resource being published monthly. The best way to move forward with this program has been unclear. To better understand the needs of potential users, SRP—in collaboration with NCI’s Epidemiology & Genomics Research Program (EGRP)—recently invited members of the National Institutes of Health’s (NIH’s) intramural and extramural communities to participate in a survey to assess the SEER RTR Program. This online survey was designed to evaluate researchers’ past experiences with the RTR Program and gain information to improve this research resource. The RTR survey was successful in generating substantial responses, with more than 170 individuals providing feedback. Overall, the responses indicated that the RTR is a unique and highly valued resource, but that it could better serve investigators’ research needs by providing higher quality biospecimens, increasing biospecimen annotation, collecting more ethnically diverse samples, adding additional treatment data, and streamlining the application process.

Dr. Sean Altekruse of SRP’s DAIB provided updates on the RTR Program at the November 2012 SEER Principal Investigators meeting. Currently, working groups from SRP and EGRP are analyzing responses to the RTR survey to develop future directions for this program to maximize its value to the research community.

For more information about SEER’s RTR Program, please visit the RTR website at http://seer.cancer.gov/biospecimen/index.html.

Announcements

CISNET Lung Working Group Receives Award for Special Issue in Risk Analysis

The Editorial staff of Risk Analysis: An International Journal selected the special monograph, “The Impact of Tobacco Smoking on U.S. Lung Cancer Mortality (1975-2000): Collective Results from the Cancer Intervention and Surveillance Modeling Network (CISNET),” as the Best Issue of 2012 for this journal. This is the first time that Risk Analysis has given an award for Best Issue, making this a significant achievement for the monograph’s editors, Dr. Eric Feuer of SRP and his collaborators, Drs. Suresh Moolgavkar, David Levy, Marek Kimmel, and Lauren Clarke. Dr. Feuer and colleagues were awarded certificates at the Society for Risk Analysis Annual Meeting in San Francisco, CA, on December 11, 2012.

About the Article

Smoking rates in the United States have declined dramatically since the first Surgeon General’s Report on Smoking and Health in 1964. To explore the impact of smoking reduction on lung cancer mortality, the NCI-sponsored CISNET Lung Working Group reconstructed cigarette smoking histories for people born from 1890 through 1970 and described how many lung cancer deaths were prevented because of changes...
in smoking behavior, along with how many deaths could have been averted had cigarette smoking been completely eradicated after the first Surgeon General’s Report. According to CISNET’s models, 20th century tobacco control policies and interventions prevented nearly 800,000 lung cancer deaths in the United States between 1975 and 2000. Although such smoking interventions have been effective—smoking prevalence dropped from 40 percent in the 1960s to less than 20 percent today—continued tobacco control efforts are critical to further reduce the burden of lung cancer. For instance, if tobacco control measures had completely eliminated smoking just after the first Surgeon General’s Report in 1964, an additional 1.7 million lung cancer deaths could have been prevented.

As Dr. Feuer, chief of SRP’s Statistical Methodology and Applications Branch (SMAB), commented in a March 14 NCI press release, “The progress that has been made by tobacco control programs and policies in reducing lung cancer deaths represents about a third of the progress that could have been made if all cigarette smoking had ceased in 1965.” The United States has come a long way in reducing tobacco use, but additional progress still is necessary.

The results of this study were first published in March 2012 in the Journal of the National Cancer Institute. The special issue in Risk Analysis, published in August 2012, expanded on this work by providing more details about the comparative modeling methods that were used in this study.

CISNET is a national consortium of researchers funded by NCI who use statistical modeling methods to study five different cancer sites (breast, colorectal, esophageal, prostate, and lung) to inform public health research and guide policy-making decisions regarding cancer control. More information about CISNET can be found at http://cisnet.cancer.gov.

References


“Know Your Chances” Website in Development

SRP is developing the “Know Your Chances” website in collaboration with IMS and researchers from the Dartmouth Institute for Health Policy and Clinical Practice. Recent evidence suggests that risk charts are important tools for helping people understand their disease risks (Woloshin et al., 2008). By using charts to compare the chance of dying in the next 10 years from different diseases, individuals can better identify which health threats are more serious and should be addressed and which threats are less severe. Based on this, the “Know Your Chances” website will feature four different risk charts that can be customized by the user and will serve different functions for assessing risk. The Big Picture Chart will provide users with information regarding the risk of death in the next 10 years for a range of ages, plus a list of the more common causes of death. Users also will be able to explore specific causes of death using the Custom Chart. In addition, the Know Your Chances Chart will allow users to determine the causes of death that are ranked highest for their specific age, race, and gender, and the Cancer Tables will let them specifically compare the risk of being diagnosed with and dying of different types of cancers. Data for these charts will come from DevCan, a statistical methodology and software application developed previously by SRP. SRP plans to release the “Know Your Chances” website in early 2013.

NCI’s Geographic Information Systems & Science (GIS) website gis.cancer.gov provides a central source of information about GIS and related resources for use by the public, cancer researchers, and the GIS Special Interest Group. The GIS website was updated recently to facilitate access to tools for analyzing and visualizing geographic data, provide information about GIS research applications and publications, and give links to current GIS funding opportunities and program announcements. The new homepage features four “targets” that provide entry to main elements of the GIS site, plus a “Spatial Context Matters” screen that depicts rotating images related to geographic and environmental factors that impact cancer risk. In addition, the GIS website recently launched a new feature called NCI Map Stories, which leverages current Web-based mapping technologies to create narratives about the geographic patterns of cancer. This series allows users to visually compare cancer incidence and mortality by state. Map Story: Breast Cancer debuted in October 2012 in honor of Breast Cancer Awareness Month, and subsequent Map Stories will be released in accordance with future National Cancer Awareness Months. The GIS website will soon feature the SEER GIS Portal, a collaborative geospatial content management system that will host a variety of GIS Web-based mapping tools and services. Tools provided by this portal will enable users to aggregate and visualize large, multidimensional data sets, including population-based cancer statistics.

The GIS website represents the collective contribution of Zaria Tatalovich, Hillary Hoffman, and Heather Lasseter of SRP; and NCI’s contractors, David Stinchcomb of Westat and Brian Downey of IMS. For more information about upcoming tools and features, or to provide comments on the current website, please contact Zaria Tatalovich at tatalovichzp@mail.nih.gov.

Did You Know? Communicating Cancer Statistics

Cancer statistics reveal noteworthy trends—for example, that the number of U.S. cancer survivors is increasing even as the number of cancer diagnoses drops—but such statistics are notoriously difficult to explain to lay audiences. NCI’s recently launched “Did You Know?” (DYK) series of animated videos communicates key cancer statistics to the public in an easy-to-understand, meaningful way. Scientists and communication specialists from SRP and NCI’s Office of Communications and Education collaboratively create the 90-second DYK videos, which are hosted on NCI’s Statistics Portal. SRP scientists glean timely facts about cancer and its risk factors from dense, 100+-page statistical documents such as the
**SEER Cancer Statistics Review.** The DYK production team distills this complex information into a “news you can use” message designed to raise public cancer awareness and promote healthy behaviors. The first animated DYK module, “Melanoma of the Skin,” debuted in May 2012 and has received more than 2,000 views. Since then, five additional modules have been launched.

The DYK team plans to release new videos monthly based on cancer research news and in accordance with national cancer awareness months. Look for the latest video at [www.cancer.gov/statistics](http://www.cancer.gov/statistics), or view the entire series on the SEER website.

**New Variables Coming Soon to State Cancer Profiles**

**State Cancer Profiles** (SCP), an online resource that provides dynamic views of cancer statistics across the United States, soon will add small area health insurance estimates, data from the Health Information National Trends Survey (HINTS), and data on childhood obesity. All three additions are expected to be available in January 2013.

SCP will add small area health insurance estimates to the Demographic Data section, which generates tables of expanded census data. The Census Bureau released small area estimates of health insurance coverage for the first time in 2011. SCP will provide both state- and county-level information about the percentages of uninsured persons by poverty level. This new feature will help in the evaluation and planning of programs and initiatives geared toward serving uninsured or low-income populations.

SCP also plans to add a section entitled “Cancer Knowledge” based on data from HINTS, which collects information about the American public’s access to and use of cancer-related information. This new section will contain a knowledge report and “knowledge maps” that illustrate how people in certain geographic regions answered HINTS questions. Cancer control planners will be able to use these maps to see what people do and do not know about cancer risks, screening, and mortality. Planners can use this knowledge to direct local cancer communication efforts.

Obesity is an established risk factor for certain cancers, and SCP currently includes data on the prevalence of overweight and obesity among adults in its Screening and Risk Factors section. SCP will soon add data on the prevalence of childhood obesity from the CDC’s Youth Risk Behavior Surveillance System.

Visit [statecancerprofiles.cancer.gov](http://statecancerprofiles.cancer.gov) to take advantage of the site’s new and existing features.
SEER Website Undergoes Redesign

The SEER Program’s website is undergoing a redesign to enhance the communication of SEER cancer statistics and increase the website’s impact by tailoring materials to different audiences. Redesign efforts include giving the website a fresh new look, developing a set of SEER Cancer Statistics Fact Sheets that include easy-to-understand graphs of key statistics, and creating SEER Data Explorer, an interactive tool that will allow users to visualize cancer statistics.

The redesigned SEER website will be easier for users to navigate and will feature an updated color scheme. The SEER logo and tagline will be updated and modernized and will be featured prominently in a banner at the top of the home page.

Currently, SRP staff and contractors are developing a template for a new set of SEER Cancer Statistics Fact Sheets aimed at cancer patients, their families, and the media. Six members of the public, three members of the media, and 14 NCI employees reviewed an initial draft of the template, and updates currently are under way based on their recommendations. Once the template has been finalized, SRP will develop updated fact sheets for all cancer types. These revised fact sheets will feature new visual content aimed at increasing readers’ understanding of the statistics presented. Each fact sheet will include an At a Glance section that will provide a quick overview of new cases, deaths, and survival statistics for each cancer type. Although the fact sheets will focus on presenting cancer statistics, they also will include links to relevant materials about cancer screening, treatment, risk factors, and prevention.

The SEER Data Explorer, a tool aimed at public health practitioners, policymakers, and researchers, is in the early stages of development. Although the updated fact sheets will include static visuals, the Data Explorer will be an interactive tool, allowing users to visually explore SEER data. Users will be able to graph incidence, mortality, and survival data and compare rates and trends by cancer site, sex, age, race/ethnicity, and stage. Using the SEER Data Explorer, users will be able to produce tables and figures that they can download for use in other applications. Usability testing of an initial prototype based on Google Data Explorer revealed numerous issues with the user interface. SRP staff and contractors currently are developing a new, more user-friendly version of the Data Explorer.

The SEER website’s new look and many new features should become available in 2013. Visit seer.cancer.gov for updates. Please use the anonymous online suggestion box to provide your feedback and comments.
Healthy People 2020: Progress Review on Cancer

Healthy People is a set of science-based goals and objectives with 10-year targets designed to improve the nation's health. Released by the U.S. Department of Health and Human Services in December 2012, HP2020 provides objectives for a number of diverse topic areas—such as cancer—that represent significant threats to the public’s health. With respect to cancer, the overall goal of HP2020 is to reduce the number of new cancer cases and decrease the burden associated with this disease in the United States. To this end, the 20 main objectives reflect the importance of promoting evidence-based screening for cervical, colorectal, and breast cancer; as well as monitoring the incidence of invasive cervical and colorectal cancer and late-stage breast cancer, as these provide intermediate markers for cancer screening success.

According to the HP2020 objectives, it is important to determine whether health programs achieve their target goals. Therefore, monthly progress reviews are conducted to brief the Assistant Secretary for Health on the latest data for HP2020 and on advances being made toward achieving each objective’s targets. Progress reviews for HP2020 began in 2012 and will be conducted twice for each focus area. The first progress review for cancer is anticipated to occur in February 2013. Materials from the progress reviews will be posted after they are complete. To view progress reports for the previous decade’s objectives, please see the Healthy People 2010 Final Review.

2012 SEER-Medicare Linkage Data Available

File descriptions for the 2012 SEER-Medicare linkage data will be available soon. The SEER-Medicare data are unique population-based sources of information with a variety of applications. Among other research initiatives, investigators use SEER-Medicare data to study patterns of care for cancer patients, examine the use of cancer tests and procedures, and assess the costs of cancer treatment.

The SEER-Medicare data reflect the linkage of clinical, demographic, and cause of death information for persons with cancer collected by the SEER Program of cancer registries and the Medicare claims for covered health care services from the time of a person’s Medicare eligibility until death. This linkage is a collaborative effort of the NCI, SEER registries, and Centers for Medicare and Medicaid Services and is described in detail in “Overview of the SEER-Medicare Data: Content, Research Applications, and Generalizability to the United States Elderly Population.” Please see the Instructions for Submitting Requests for a detailed overview of how to request access to the SEER-Medicare data sets.

The SEER-Medicare data sets are large and complex and have a number of unique qualities and anomalies. Researchers are encouraged to read the Analytic Support for Researchers section of the SEER-Medicare website prior to beginning their analyses. In addition, a SEER-Medicare training workshop is scheduled to take place on April 25 and 26, 2013. Details about the workshop will be posted on the SEER-Medicare website as they become available.

NCI Provocative Questions Project Seeks Applications for Funding

NCI’s Provocative Questions (PQs) Project currently is seeking new applications from researchers interested in tackling potentially game-changing scientific questions that may drive progress against cancer. The PQ Project aims to encourage researchers to leverage laboratory, clinical, and population sciences in imaginative ways to address a list of important but not obvious questions related to cancer.
The first round of “Research Answers to NCI’s Provocative Questions” Funding Opportunity Announcements (FOAs), based on an initial set of 24 PQs, was published in 2011. NCI has developed an updated set of 24 PQs, some old and some new, for the 2012 Requests for Applications (RFAs). NCI has divided these updated PQs into four thematic groups, each of which is associated with two FOAs that utilize the R01 and R21 funding mechanisms. The groups include the following: Cancer Prevention and Risk (R01, R21); Mechanisms of Tumor Development or Recurrence (R01, R21); Tumor Detection, Diagnosis, and Prognosis (R01, R21); and Cancer Therapy and Outcomes (R01, R21). To select the appropriate funding opportunity, researchers are encouraged to view the PQ Notice in the NIH Guide.

The next deadlines are May 20, 2013, for letters of intent, and June 20, 2013, for completed applications. Letters of intent and any questions should be directed to Emily Greenspan (greenspanej@mail.nih.gov) at NCI’s Center for Strategic Scientific Initiatives.

### Current NIH Funding Opportunities for Surveillance and Epidemiology Research

**PA-11-238** (R01), **PA-11-239** (R21), and **PA-11-240** (R03)—Spatial Uncertainty: Data, Modeling, and Communication; expires September 8, 2014

**PA-11-298** (R03) and **PA-11-297** (R21)—Pilot Studies in Pancreatic Cancer; expires January 5, 2015

**PAR-12-039** (R03)—Small Grants Program for Cancer Epidemiology; expires November 19, 2014

**PA-11-250** (R01); Ethical, Legal, and Social Implications (ELSI) of Genomic Research Regular Research Program; expires September 8, 2014

**PA-11-073** (R01) and **PA-11-074** (R21); Mitochondria in Cancer Epidemiology, Detection, Diagnosis, and Prognosis—Trans-NCI Program Announcement; expires January 8, 2014

**PA-10-026** (R21) and **PA-10-025** (R01)—Development, Application, and Evaluation of Prediction Models for Cancer Risk and Prognosis; expires January 8, 2013

**PAR-11-167** (UM1)—FOA for Core Infrastructure and Methodological Research for Cancer Epidemiology Cohorts; expires November 9, 2013

**PA-10-031** (R01) and **PA-10-032** (R21)—Epigenetic Approaches in Cancer Epidemiology; expires January 8, 2013

**PA-10-290** (R01) and **PA-10-291** (R21)—Research on Malignancies in the Context of HIV/AIDS; expires September 8, 2013

**PAR 12-257** (R01)—Time-Sensitive Obesity Policy and Program Evaluation; expires September 11, 2015

**PA-10-027** (R01), **PA-10-028** (R21), and **PA-10-029** (R03)—Obesity Policy Research: Evaluation and Measures; expires January 8, 2013

### SRP Grants Awarded in Fiscal Year 2012

The NIH grant funding process includes three overlapping cycles per year, each of which includes the receipt, review, and award decision for research grant applications. The first level of review is conducted by a Scientific Review Group, during which grant applications (Competing Grants) are reviewed and evaluated. The second level of review is performed internally and by the NCI National Advisory Councils or Boards. In the first level of review, grant applications that receive scores within the established NCI Funding Policy Ranges typically are funded automatically. Applications outside of these ranges are reviewed for program/public health relevance by SRP grants management staff and branch chiefs, who then decide which ones will be presented to DCCPS Senior Staff for further funding consideration.
Newly funded SRP grant awardees for Fiscal Year 2012 are listed below. In addition to these 14 newly funded grants, SRP reviewed and currently manages about 80 existing, Non-Competing Grants that were processed for continued funding.

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<td>Swati Biswas</td>
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DAIB – Data Analysis and Interpretation Branch  
DMB – Data Modeling Branch  
SMAB – Statistical Methodology and Applications Branch