| Table 28: Disease Registry Collaborations - FY 2009 = 4 | | | | NIH Funding = $35,527,005 | | | | |
|---|---|---|---|---|---|---|---|---|
| Collaboration Title and Link | Collaboration Type with Various Additional Links | Brief Description of Collaboration | HHS Participating Agencies | HHS Strategic Priority Alignment | NIH Participating Institutes/Centers/ Office of the Director *(Activity Submitting Office(s) Bolded)* | NIH Strategic Priority Alignment | Year Collaboration Originated | NIH Funding Contribution in FY 2009 |
| Alaska Native Tumor Registry | Disease Registry | The Alaska Native Tumor Registry is part of the SEER Program. | CDC/IHS | Accelerate Discovery to Improve Patient Care: Disseminate health information to the public. | **NCI** | Health Care Reform: Health Disparities. | 1999 | 200,000 |
| INTERMACS - Interagency Registry for Mechanically Assisted Circulatory Support | Disease Registry | INTERMACS is a national registry for patients who are receiving mechanical circulatory support device therapy to treat advanced heart failure. This registry was devised as a joint effort of the National Heart, Lung, and Blood Institute (NHLBI), the Centers for Medicare and Medicaid Services (CMS), the Food and Drug Administration (FDA), clinicians, scientists, and industry representatives, in conjunction with the University of Alabama at Birmingham (UAB) and the United Network for Organ Sharing (UNOS). | CMS/FDA | Accelerate Discovery to Improve Patient Care: Innovative Biomedical Technologies, and Patient-centered Research. | **NHLBI** | Regulatory Science. | 2005 | 1,277,005 |
| Northwest Portland Tribal Registry Project | Disease Registry | Over the past 10 years, health care delivery for Northwest American Indians and Alaska Natives has evolved from a centralized system maintained by the Indian Health Service (IHS) to a diverse and complex environment. The Northwest Tribal Registry Project was developed in January 1999 by the Northwest Tribal Epidemiology Center, a tribally operated program located at the Northwest Portland Area Indian Health Board (NPAIHB) in Portland, Oregon. | IHS | Accelerate Discovery to Improve Patient Care: Disseminate health information to the public. | **NCI** | Health Care Reform: Health Disparities. | 1999 | 50,000 |
| Surveillance, Epidemiology, and End Results (SEER) Program | Disease Registry | SEER is the premier source for cancer statistics in the United States. It collects information on incidence, prevalence and survival, from specific geographic areas representing 26 percent of the U.S. population. Through SEER, we develop reports on all of these information areas plus cancer mortality for the entire country. The site is intended for anyone interested in U.S. cancer statistics or cancer surveillance methods. | CDC | Accelerate Discovery to Improve Patient Care: Disseminate health information to the public. | **NCI** | Health Care Reform: Health Disparities. | 1973 | 34,000,000 |