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Outcomes Agency for Healthcare Research and Ouality/AHRO, 2014-04-01 This User's Guide is intended to support the design, implementation, analysis, interpretation, and guality evaluation of registries created to increase understanding of patient outcomes. For the purposes of this guide, a patient registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes. A registry database is a file (or files) derived from the registry. Although registries can serve many purposes, this guide focuses on registries created for one or more of the following purposes: to describe the natural history of disease, to determine clinical effectiveness or cost-effectiveness of health care products and services, to measure or monitor safety and harm, and/or to measure quality of care. Registries are classified according to how their populations are defined. For example, product registries include patients who have been exposed to biopharmaceutical products or medical devices. Health services registries consist of patients who have had a common procedure, clinical encounter, or hospitalization. Disease or condition registries are defined by patients having the same diagnosis, such as cystic fibrosis or heart failure. The User's Guide was created by researchers affiliated with AHRO's Effective Health Care Program, particularly those who participated in AHRQ's DEcIDE (Developing Evidence to Inform Decisions About Effectiveness) program. Chapters were subject to multiple internal and external independent reviews.

an example of passive follow up in cohort studies is: A Nationwide Framework for Surveillance of Cardiovascular and Chronic Lung Diseases Institute of Medicine, Board on Population Health and Public Health Practice, Committee on a National Surveillance System for Cardiovascular and Select Chronic Diseases, 2011-08-26 Chronic diseases are common and costly, yet they are also among the most preventable health problems. Comprehensive and accurate disease surveillance systems are needed to implement successful efforts which will reduce the burden of chronic diseases on the U.S. population. A number of sources of surveillance data-including population surveys, cohort studies, disease registries, administrative health data, and vital statistics-contribute critical information about chronic disease. But no central surveillance system provides the information needed to analyze how chronic disease impacts the U.S. population, to identify public health priorities, or to track the progress of preventive efforts. A Nationwide Framework for Surveillance of Cardiovascular and Chronic Lung Diseases outlines a conceptual framework for building a national chronic disease surveillance system focused primarily on cardiovascular and chronic lung diseases. This system should be capable of providing data on disparities in incidence and prevalence of the diseases by race, ethnicity, socioeconomic status, and geographic region, along with data on disease risk factors, clinical care delivery, and functional health outcomes. This coordinated surveillance system is needed to integrate and expand existing information across the multiple levels of decision making in order to generate actionable, timely knowledge for a range of stakeholders at the local, state or regional, and national levels. The recommendations presented in A Nationwide Framework for Surveillance of Cardiovascular and Chronic Lung Diseases focus on data collection, resource allocation, monitoring activities, and implementation. The report also recommends that systems evolve along with new knowledge about emerging risk factors, advancing technologies, and new understanding of the basis for disease. This report will inform decision-making among federal health agencies, especially the Department of Health and Human Services; public health and clinical practitioners; non-governmental organizations; and policy makers, among others.

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California. Dr. Piantadosi is one of the world's leading experts in the design and analysis of clinical trials for cancer research. He has taught clinical trials methods extensively in formal courses and short venues. He has advised numerous academic programs and collaborations nationally regarding clinical trial design and conduct, and has served on external advisory boards for the National Institutes of Health and other prominent cancer programs and centers. The author of more than 260 peer-reviewed scientific articles, Dr. Piantadosi has published extensively on research results, clinical applications, and trial methodology. While his papers have contributed to many areas of oncology, he has also collaborated on diverse studies outside oncology including lung disease and degenerative neurological disease.

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