#	Submitted By	Comment	Author Response
1	Ramin Ahmadi, MD, MPH and Joann R. Petrini, PhD, MPH of Western Connecticut Health Network	The Western Connecticut Health Network currently supports the state of Connecticut's only Lyme disease Registry. The mission of the Lyme disease Registry is to create a comprehensive database of patients with Lyme disease that will serve as the basis for multidisciplinary research leading to a better understanding of: - The course of the disease and how people are affected; - Causes of persistent symptoms; - Improved diagnosis and treatment. As such, we welcome the creation of a *Registry of Registries (RoPR)* by the Agency for Healthcare Research and Quality as outlined in the Federal Register on February 23, 2012. Like ClinicalTrials.gov, RoPR would provide a valuable resource that will facilitate collaboration and reduce redundancy in the development and implementation of patient registries. In addition, we would look to RoPR as an opportunity to promote our registry to eligible and interested patients. Dr. Petrini attended the initial RoPR stakeholders meeting in January 2011 and offered input into the components of RoPR. We congratulate AHRQ for compiling the group's recommendations into a system that will have practical utility for those of us who administer patient registries. Thank you for the time and energy that has been devoted to this important initiative.	No response required.
2	Gordon F. Tomaselli, MD, FAHA; President, American Heart Association	On behalf of the American Heart Association (AHA), including the American Stroke Association (ASA) and over 22 million AHA and ASA volunteers and supporters, we appreciate the opportunity to submit our comments in response to the Agency for Health Research and Quality's comment request for its proposed information collection, entitled "American Recovery and Reinvestment Act Developing a Registry of Registries." The Mission of the American Heart Association/American Stroke Association (AHA/ASA) is Building healthier lives free of cardiovascular disease and stroke, with a 2020 impact goal to improve the cardiovascular health of all Americans by 20%, while reducing deaths from CVD and stroke by 20%. One of the AHA/ASA's approaches to achieving its mission is to continually raise the bar on quality patient care by advocating for and creating systems, programs, and partnerships that ensure evidence-based medical guidelines are effectively translated into standard patient care. The flagship of these efforts is the Get With The Guidelines® (GWTG) suite of inpatient quality improvement programs which have impacted the care of more than 3 million patients and resulted in over 4 million patient records being entered in their supporting registries. The GWTG programs include in-hospital modules for myocardial infarction, heart failure, stroke, and resuscitation. In 2010, the AHA launched an outpatient program, The Guideline AdvantageTM (TGA) that supports consistent use of evidence-based guidelines for prevention and disease management through existing health care technology. All of these quality improvement programs use a patient registry as the primary data collection tool to facilitate data aggregation and analysis, as well as feedback reporting to providers and hospitals. It is the over ten years of experience developing, refining, and expanding these programs and their associated registries that allows us to provide the input below. It is this same ten years of experience that makes AHRQ's potential information collection "Registry of Patient Registries (RoPR)" project very exciting to us as an organization. The American Heart Association/American Stroke Association supports AHRQ's overall goal in proposing RoPR, as we believe the creation of such a database could greatly increase the awareness, accessibility, use, and impact of patient registries. Additionally, the AHA/ASA is particularly supportive of the investigator-led research that such a project could foster.	No response required.
3	Gordon F. Tomaselli, MD, FAHA; President, American Heart Association	The Federal Register notice outlining the initial details of the program, however, is very general and leaves many unanswered questions. While we understand and appreciate AHRQ's request for input at the early conceptualization of the project, we also believe that more details are needed in order for responders to understand the project's impact and assess the willingness of their organizations, including ours, in participating. Additionally, without this additional information and detail, it is difficult for us to realistically identify potential pitfalls that the project could encounter. Below we highlight our main questions regarding the project. What information, specifically, will AHRQ request of those participating? The Federal Register notice does not provide any detail as to what information AHRQ has in mind to collect from each registry owner. It provides some indication of the quantity of data in the annualized burden section that estimates 45 minutes for initial data entry and an additional 15 minutes each year to update that information. These approximations suggest that the extent of information that AHRQ intends to collect is not that great and would change minimally from year to year. To this end, we would be interested in the specific data elements that AHRQ intends to request. While we recognize that the data burden should not be too large that it creates a barrier to broad participation in RoPR, at the same time, we would encourage AHRQ to make sure that the information requested is sufficient to be meaningful as to what it can present about the registries contained in the database and how meaningful a search of the database would be for a user.	The selection of data elements to be collected within the RoPR has been informed by both registry holders (i.e., sponsors), who must input the informaiton about their registry programs, and other registry users, who are seeking information about existing programs. Given that entering information about a registry is voluntary, AHRQ is seeking to balance the tradeoffs between the burden on registry holders to input and update their profiles and the value of comprehensive data. The data elements have been vetted by numerous stakeholders and continue to be revised pending real-world usage and ongoing development efforts. There are a total of 9 data elements that are required to complete a RoPR record, and additional data elements are optional or conditionally required (e.g., if 'other' is selected, a description is required). The comprehensive list of data elements collected will be available on the RoPR search page in a help file, located at http://www.patient-registries.com/help. No changes made to OMB submission.