

PRESS RELEASE

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**SECOND EDITION OF USER'S GUIDE FOR PATIENT REGISTRY  
DEVELOPMENT PUBLISHED BY AGENCY FOR HEALTHCARE  
RESEARCH AND QUALITY**

**--"REGISTRIES FOR EVALUATING PATIENT OUTCOMES: A USER'S GUIDE"  
TO BE INTRODUCED AT AHRQ'S 2010 ANNUAL CONFERENCE--**

**Cambridge, MA – SEPTEMBER 27, 2010** – Outcome Sciences, Inc. (OUTCOME), the leading provider of patient registries, studies, and technologies for evaluating real-world outcomes, today announced that the Agency for Healthcare Research and Quality (AHRQ) has published the second edition of, "Registries for Evaluating Patient Outcomes: A User's Guide," a Federal publication that provides information on designing, implementing, and evaluating patient registries.

The second edition of the User's Guide, which reflects the work of more than 80 contributors from government, academic and private sectors, includes:

- New methodological developments;
- Emerging topics in registry science, including updates on safety;
- Technological advances; and
- Operational examples and case studies from around the world.

Updates to the original 11 chapters from the 2007 version of the handbook are included, as well as four new sections:

- Use of Registries in Product Safety Assessment
- Planning for the End of a Patient Registry
- Interfacing Registries and EHRs

- Linking Registry Data

OUTCOME was selected by AHRQ in 2005 to lead the effort to create the patient registries guide. OUTCOME's Drs. Richard Gliklich and Nancy Dreyer served as the guide's senior editors and authors for several chapters. The second edition includes 38 case studies, which illustrate real-life challenges in the design and conduct of registries. Contributors came from industry, academia, and government, with representation from various agencies in the U.S., as well as the National Institute for Health and Clinical Excellence in the U.K. The work was performed under contract to OUTCOME through its role as an AHRQ DECIDE Research Center, a component of AHRQ's Effective Health Care Program.

“Patient registries have become a vital component to evaluating outcomes for a particular population for scientific, clinical, or policy purposes. Physicians are now using registries to help determine the clinical effectiveness or cost of health care services or products, measure or monitor safety and harm, describe the natural history of disease, and measure quality of care,” said Richard Gliklich, MD, president and CEO of OUTCOME. “‘Registries for Evaluating Patient Outcomes: A User’s Guide, Second Edition’ now provides even more in-depth information and ‘how-to’ knowledge on best practices for all stakeholders that use patient registries. Outcome is pleased with the additions to the handbook and would like to thank all of the many contributors over the years, who have helped make this document a tremendous resource.”

AHRQ will introduce the second edition of the document, “Registries for Evaluating Patient Outcomes: A User’s Guide” at its 2010 Annual Conference during a session entitled, “New and Improved: Registries for Evaluating Patient Outcomes and HIT.” A live webcast of this session can be accessed on Monday, September 27, 2010 from 8:00 – 9:30 a.m. ET via the following link:  
<http://www.effectivehealthcare.ahrq.gov/index.cfm/about-the-webcast1/>.

The guide will be available in on AHRQ’s website ([www.effectivehealthcare.ahrq.gov](http://www.effectivehealthcare.ahrq.gov)) and will also be available in print.

**About the User’s Guide**

The guide, developed in 2007, is divided into three sections—creating, operating, and evaluating registries—which lay out the basic information on key areas of registry development and operations and highlight the spectrum of practices in each of these areas, including their potential strengths and weaknesses. The final chapter describes the basic elements of good registry practice and potential enhancement that can be used to strengthen the rigor of registries. The second edition contains four new sections: Use of Registries in Product Safety Assessment; Planning for the End of a Patient Registry; Interfacing Registries and EHRs; and Linking Registry Data.

To request a free copy of *Registries for Evaluating Patient Outcomes: A User’s Guide, Second Edition* (AHRQ Publication Number 10-EHC049):  
Call: 1-800-358-9295

E-mail: [ahrqpubs@ahrq.hhs.gov](mailto:ahrqpubs@ahrq.hhs.gov)

**About AHRQ**

The Agency for Healthcare Research and Quality (AHRQ) is the lead Federal agency charged with improving the quality, safety, efficiency, and effectiveness of health care for all Americans. As one of 12 agencies within the Department of Health and Human Services, AHRQ supports health services research that will improve the quality of health care and promote evidence-based decisionmaking. The Effective Health Care Program funds individual researchers, research centers, and academic organizations to work together with the AHRQ to produce effectiveness and comparative effectiveness research for clinicians, consumers, and policymakers. For more information on the AHRQ Effective Health Care Program, please visit <http://www.effectivehealthcare.ahrq.gov/>. For additional information, please contact AHRQ Public Affairs: (301) 427-1998 or (301) 427-1855.

**About Outcome**

Outcome is the leading provider of patient registries, studies, quality improvement programs, and integrated technologies for evaluating real-world outcomes. Outcome provides services and technologies focused on evaluating the safety, effectiveness, and quality of healthcare products and services. The company has designed, developed, and managed more than 175 patient registries, including many of the largest and most well-recognized programs for disease outcomes and patient safety.

Outcome is also an Agency for Healthcare Research and Quality (AHRQ) DEcIDE Research Center, a component of the “Effective Health Care” initiative sponsored by the U.S. Dept. of Health and Human Services. Outcome was selected by AHRQ to lead the effort to create the patient registries handbook “Registries for Evaluating Patient Outcomes: A User’s Guide,” released in May 2007 and updated with a second edition in September 2010. For more information, please visit [www.outcome.com](http://www.outcome.com).

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