

New technologies fuel patient participation and data collection in research

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The changing dynamic of health studies driven by "big data" research projects will empower patients to become active participants who provide real-time information such as symptoms, side effects and clinical outcomes, according to researchers at Duke Medicine.

The analysis, published in the July 2014 issue of *Health Affairs*, lays out a new paradigm for health research, particularly comparative effectiveness studies that are designed to assess which therapies work best in routine clinical practice.

Fueled by new technologies—including [electronic health records](#) and monitoring devices that people can wear as clothing or accessories—health studies are now poised to integrate data from a much larger pool of information. The new data is immediate and actionable, providing not only research material, but also clinical information that can improve the patient's care in the short term.

"When linked to the rest of the available electronic data, patient-generated health data completes the big data picture of real people's needs, life beyond the health care system, and how changes in health and health care lead to meaningful changes in people's lives," said senior author Amy Abernethy, M.D., Ph.D., professor of medicine and director of the Center for Learning Health Care at Duke.

Abernethy and colleagues advance the perspective that big data and comparative effectiveness research have the potential to greatly enhance

the health of both individual [patients](#) and whole populations.

They argue that using new ways of acquiring and aggregating data directly from clinical care offers an alternative to randomized controlled trials, which are currently the gold standard of medical studies, particularly for new therapies.

"Generalizing data from these trials to larger, more heterogeneous populations to determine treatment effectiveness can be problematic," Abernethy said. "Further, it takes years—often more than a decade—for a trial to progress from the idea stage to actionable information, and cost and complexity mean that some important questions go unanswered."

Abernethy said electronic health records provide a huge volume of information from a much wider and diverse pool of participants than has typically been available. The clinical information can be used for research to improve care for current patients as well as future patients.

Electronic [health records](#) can also be augmented with patient-driven data, with real-time reporting directly to the health record during a clinical visit, or via the patient's personal input of symptoms, side effects, quality of life assessments and other factors.

With the increasing availability and popularity of wearable monitoring devices that track such outcomes as heart rate, blood pressure and blood sugar levels, patients are now able to be active participants in their daily health needs, while also adding to the broader data collection.

The researchers noted that this new reliance on patient-driven data is already being incorporated in studies funded by the Patient-Centered Outcomes Research Institute, the NIH Collaboratory and many others.

"The value of engaging with patients to generate the information needed

to provide care that is truly patient-centered and individualized will benefit society as a whole," Abernethy said. "With this kind of [information](#), [health](#) care and [health care](#) research can be truly patient-centric."

In addition to Abernethy, the paper's authors include Lynn Howie, Bradford Hirsch and Tracie Locklear.

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More information: *Health Affairs*, [content.healthaffairs.org/content/33/7/1220.abstract](https://www.healthaffairs.org/content/33/7/1220.abstract)

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