Using an Electronic Health Record for Research

By Joel Goldwein, MD

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Common Questions

I want to use an electronic health record (EHR) for clinical and administrative research. Is that possible?

Among the many advantages of EHR systems is their utility for supporting research endeavors. While sometimes considered a secondary use,[1] EHR-supported research can have direct and primary practice rewards related to education and policy development, practice refinement, and clinical discovery. EHR systems can help to streamline the research data collection process, manage the data itself, and be used to warehouse, analyze, and report on the data in near real time.

Can I use my EHR for a pharmaceutical-type clinical trial?

EHR systems generally are not designed to be primary repositories of research data for pharmaceutical industry-type clinical trials, as today that is the purview of specialized software. However, EHRs can be used as primary source documents in support of such systems.

So, now that I have an EHR system, how should I proceed?

Successful use of an EHR system for research support hinges on a proactive approach that requires significant planning, beginning even before system implementation.

By following a few key steps, it is far more likely that an EHR-based research endeavor will have a positive outcome. Done properly, an initial modest outlay of time, effort, and resources may lead to significant returns down the line. Some practices have found the following guidelines helpful:

Develop Consensus

Using the EHR for research is a team sport, and success demands participation of all the players—even the intransigent ones.

Assemble an EHR Research Committee

Consider appointees both within and outside your department who may not only have an interest, but also would be willing to participate in the collection and management process. Cancer registrars are ideal candidates. Participation of the clinical and support staff is important, as those who will most use the EHR tend to accept its use in a research project more when they were involved in the consideration process.

This committee should be charged with developing the program and defining criteria for success. They should serve as the focal point for any research-related EHR issues. Not only will they need to identify research questions, but they also will need to implement systems for collection, management and use of research data. And, of course, they will serve as the champions of the system when it is implemented.

The research committee will also be tasked with assuring regulatory compliance. This may include institutional review board requests and notifications along with the incorporation of a statement related to data collection in patient consent forms.

Develop a Project Plan and Stick to It

Seek assistance developing this plan from your vendor. The actual plan serves as the schedule to which everyone is held accountable. Slipping dates threaten the program, so establish reasonable time lines and hold to them as much as possible.

Begin Small

I recommend beginning with a question of limited scope in terms of data management, but wide applicability in terms of research outcomes. For example, reporting survival rates across all patients requires systematic collection of patients' vital status. This, in turn, requires vital status data be entered in a consistent manner. You may ask, "Isn't my cancer registry already doing that?" Yes, and they are getting some of their data from you.

Establish Scalable Processes

Using the earlier example of vital status, make sure that whatever process is being used to collect, enter, and manage data can generally be applied across all your clinicians and across your local and satellite practices. In addition, use this process as a means to develop methods for data collection and management of other parameters.

Standardize and Structure Data and Data Collection

For obvious reasons, your committee should develop strict standards for data entry. If possible, leverage existing standards. This means not just the data itself, but also the circumstances and means by which it is collected (responsible individuals, triggering events, location, etc). EHR systems are particularly adept at the collection of clinical data, and can

generally be configured and optimized to manage and structure it. Without such structure, the data may be useless.

As an example, not only should you use a standard, facility-wide scale to quantify a pain assessment, but also standardize encounters and events during which pain is assessed.

Avoid Redundancy

In the routine course of patient care, EHR systems collect innumerable data. Much of these data are transparent, and it may not be obvious that they are being collected. Other data elements may be more obvious in terms of the collection issue, but not so clear in terms of the questions they could be used to answer. For example, data entry is often time stamped, introducing an opportunity to examine flow through a facility without the need for additional data entry keystrokes. Another example: A patient is seen in follow-up, and has a CBC, blood pressure, and pulse entered into the EHR. In the calculation of an actuarial survival, in the absence of a "censored" data element, the above criteria arguably suffice.

Use and Develop Reports

Once the structured data resides in the EHR, there always is a way to extract it. You should explore built-in reports and data visualization tools that accompany most EHR systems. Custom reporting tools require a higher level of expertise, but such expertise is invaluable in developing your research program. An in-depth knowledge of the underlying database and its structure along with the means by which one can extract data is the power needed to turn the collected data into knowledge.

Show Proof of Concept

No better evidence of success exists than a pilot program that shows early positive results. High-level summary reports speak volumes to the effort and will serve as compelling evidence of success.

Iterate and Refine

The process of deploying any component of an EHR never ends. Expect that what you implement today you will supplant in the future. Consider that your facility is investing as much in the development of sound processes and data codification as in the resultant research reports. The processes above will iterate and require tweaks and refinements as your facility itself experiences change. Once you have comfort that your program has achieved a level of maturity and stability to meet your needs, do not let complacency become the norm.

Seek Help From Your Vendor

Your vendor may be the best source for technical and process-related assistance. You should take advantage of this resource, as they may be able to point you to useful information along with other practices that have similar interests.

Final Thoughts

While the preceding tips are far from exhaustive, they do serve as a basis for leveraging oncology EHR systems for research. As we become more adept at using these systems and as standards for oncology data collection and exchange are further developed, the use of EHR systems for research is likely to become the norm.

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Reference

1. Institute of Medicine: Key Capabilities of an Electronic Health Record System (Electric Health Record Functional Model: Letter Report). Washington, DC, Institute of Medicine National Academies Press, 2003