Hurdles to Data Collection in

by Al B. Benson III, MD, FACP; Matthew Farber, MA; and Jason Peller

Today, we have unprecedented potential to amass and analyze data in the service of improved patient care and evidence-based medicine. And yet, the demand for more and more data may be a double-edged sword. On the one hand, more and better data hold the promise of more efficient, evidence-based patient care. On the other hand, the twin pressures of increasing demands for data acquisition from private payers and standards and accreditation organizations, and increasing regulatory requirements from the U.S. government and Medicare and Medicaid are creating significant challenges for community cancer centers.

Comparative effectiveness research (CER) has potential to inform evidence-based medicine, and in recent years the federal government has made a substantial investment to enhance CER. New CER-related requirements, which will include oncology and cancer registry reporting, will add to the demands for data acquisition.

In 2011 the Association of Community Cancer Centers undertook a national survey of its membership to explore the impact of demands for data acquisition on community-based cancer programs. What types of data are currently being collected and by whom? Is the demand for data affecting community-based cancer programs? What barriers to data collection are community cancer centers experiencing?

In Brief

In early 2011 ACCC sent by email an invitation to 2,600 members to take an online survey, *Determining Hurdles to Data Collection in the Oncology Community*. One hundred and ninety one ACCC members, representing more than 120 cancer programs, took the survey (a 7.3 percent response rate). Of respondents, 87 percent reported pressure due to the increased demand for data acquisition. Two-thirds (66 percent) attributed this pressure to standards and accreditation requirements; 14 percent to increased government regulations; and 12 percent to Medicare/Medicaid (see Figure 1, page 47). A significant concern among respondents is inadequate financial support to fund data collection. (See Figures 2 and 3, pages 48 and 49.)

Top respondent job categories were administrators (36.5 percent), medical oncologists (20.6 percent), and registrars (18 percent). They represented a cross section of ACCC membership, including hospital cancer centers or outpatient departments (60.2 percent), oncology private practices (25.7 percent), and academic medical centers (14 percent). Of the hospital-based respondents, a majority had more than 300 beds (60.4 percent). For all responses, most (74.2 percent) saw more than 500 new analytic cancer cases annually.

Results

Survey results reveal that a growing number of oncology practices and hospitals are dealing with an increasing demand for data collection. In addition to the traditional data reporting related to enrollment of patients in clinical trials, most respondents are also involved in other types of data reporting, including comparative effectiveness research (26.1 percent) or registry reporting (86.2 percent). This data reporting is attributable to a significant portion of the patient population in a practice or cancer center, as more than one third of respondents stated that over 20 percent of their patients were involved in some kind of research, including clinical trials, registry reporting, and CER (see Figure 4, page 49).

At the same time, it appears that this increased demand for data can be attributed to data collection unrelated to clinical trials, as most respondents reported that a very low percentage of their patients are enrolled in clinical trials (53 percent enroll only between 0-5 percent of patients in clinical trials, and another 22 percent of respondents

enroll between 6-10 percent). (See Figure 5, page 49.)

Survey respondents report data to a variety of end users, including private payers, the pharmaceutical industry, and government regulators and payers, such as Medicare. This data reporting can be for clinical trials, comparative effectiveness research, or registry reporting.

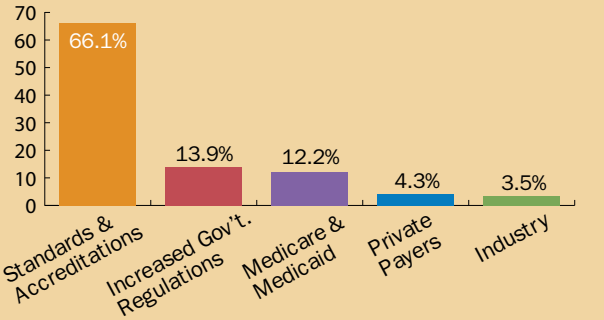
Nearly 90 percent of respondents state that they are concerned about the increase in registry data retrieval and reporting requirements. While demand for data is increasing, most registrars and others are not experiencing a corresponding increase in registry funding. A majority (63.7 percent) report that their registry is not adequately funded, while 31 percent report that the funding deficiency is so great they need more than $200,000 in supplemental funding to support data reporting requirements.

Among survey respondents, insufficient funding is a recurrent barrier to increased data collection. The increased demand for data requires an increased time commitment to retrieve that data with no corresponding increase in reimbursement. A majority of respondents (68.5 percent) report that they do not engage in more CER because they are not reimbursed for the time they spend collecting data (Figure 2). Funding issues are also impacting data collection related to clinical trials; 61.7 percent of respondents report not enough money and lack of reimbursement as reasons for not doing more clinical trials research (Figure 3). Directly tied to a lack of funds is a lack of necessary resources, most notably staffing. Respondents cite lack of staff as the reason for not participating in more CER and clinical trials research (66.1 percent and 51.7 percent respectively).

While the vast majority (81 percent) of respondents report that the personnel cost for data acquisition falls under the operating budget, 20 percent report taking a loss on personnel cost for data acquisition. When asked to estimate the supplemental funds needed from either philanthropy or the institution to support clinical research programs or other data reporting requirements, 31 percent reported needing more than $200,000, and 28 percent reported needing between $50,001 and $100,000.

Results of the survey revealed additional barriers to CER and clinical trial participation. Survey respondents reported lack of physician interest as a hurdle to both CER (34.7 percent) and clinical trials research (36.7 percent). This response raises some interesting questions not addressed in the scope of ACCC's survey: does lack of physician interest mean that physicians are just too busy treating patients? Are other factors involved? If physicians were more adequately compensated for the time required for data collection would interest increase? A pilot program or data reporting initiative in this area might be something of interest to private insurance carriers as they may have the resources to implement different solutions to this problem.

Figure 1. Areas of Most Pressure for Data Acquisition



Another hurdle faced by most survey respondents is the lack of cooperation with local academic institutions. Of respondents that did not identify as an academic medical center, 77.7 percent reported that they do not work in cooperation with the local academic institution in data collection. The survey asked whether respondents perceive academic institutions as helping or hindering the process of data collection in the community setting. Nearly half (45.5 percent) answered that, even if they did not cooperate with academic institutions, still these institutions were helpful in participation in research activities. One respondent commented that academic institutions help, because they can have "more trials open and available [than we can]." However, a quarter (24.4 percent) report that academic institutions actually hindered participation in research. One respondent commented, "Academic centers and community centers have used the CCOP (Community Clinical Oncology Program) program to their advantage while ignoring the real intentions: extension of clinical trial accessibility to rural and non-metropolitan centers." Another wrote that the local institution is "disinterested in cooperation."

The final hurdle to data collection reported by more than one third of respondents related to problems with logistics, specifically those involving electronic medical records (EMRs). This was also a hurdle in terms of clinical trials participation (17.5 percent reported logistics as a problem). When asked if EMRs are helping practices to participate in more research, 46.3 percent reported yes. Interestingly, another 26.9 percent reported that they do not yet have an EMR implemented. Respondents were asked if data collection and sharing will become simpler with the advent of EMRs; 53 percent reported yes, 10 percent reported no, and 37 percent reported "yes, but not in the near term."

This last set of responses alludes to the current logistical problems many practices and hospitals face with their present EMR systems. In open-ended responses, survey participants

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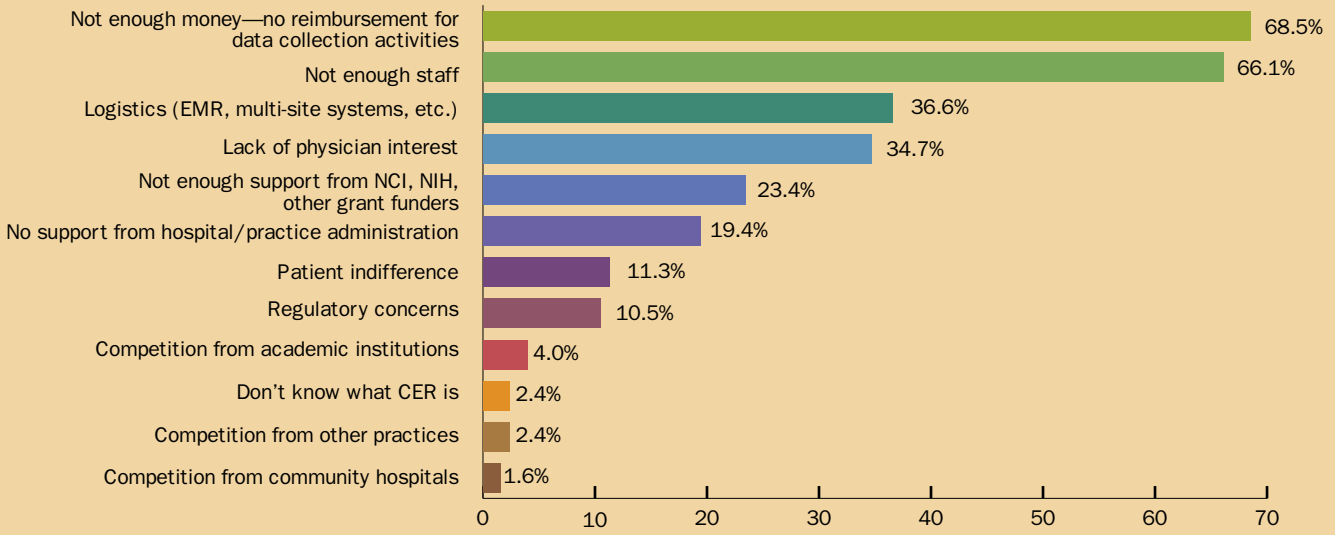
Figure 2. Top Barriers to CER Participation*



*Respondents were asked to select top 3 reasons they were unable to participate in CER.

highlighted a host of current barriers. Many indicate that the systems in place now are not well suited for oncology practices. In addition, many report major interoperability problems. Many systems do not talk to each other, making the sharing of data, or the reporting of data to a central registry more difficult. Respondents were asked: "If you could talk directly to EMR vendors about specific features related to improving data collection and sharing, what would you tell them?" Of the open-ended responses collected, more than 31 percent said that systems need to have improved interoperability and a similar language in order to improve communication. Other respondents (7.6 percent) suggested installation of a clinical trials eligibility check. Respondents felt that if the system were to alert physicians to research activities, participation would increase for all forms of research.

Conclusion

In summary, ACCC's survey demonstrated that the vast majority of respondents are feeling pressure due to increased demand for data acquisition. At the time of the survey, the greatest demands for data related to standards and accreditation requirements; however, pressure was also reported from increased government regulations and data collection requirements for Medicare/Medicaid.

Lack of adequate funding to support data collection activities is reported to be a barrier to meeting these increased

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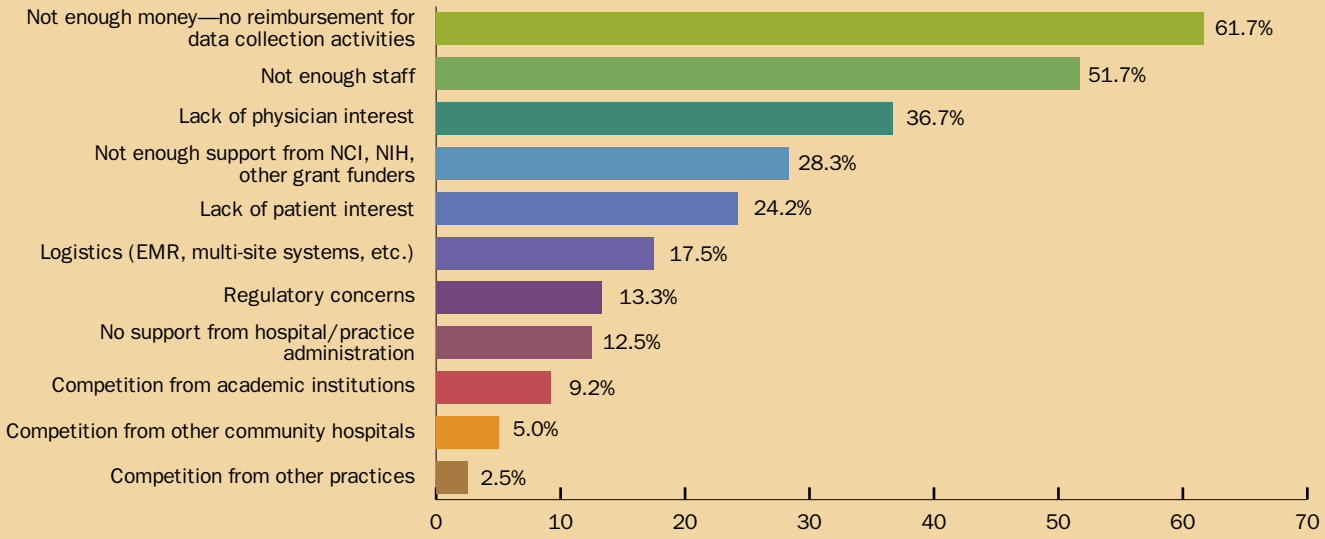
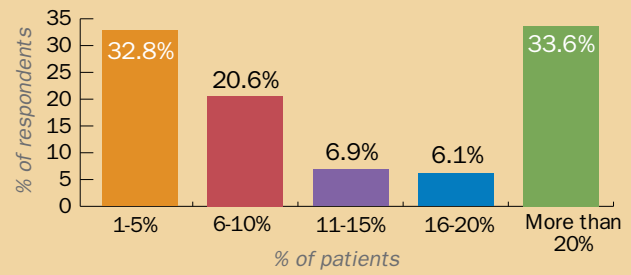
Figure 3. Barriers to Participation in Clinical Trials*



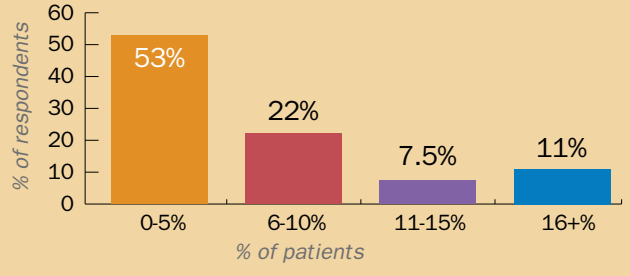
*Respondents were asked to select top 3 reasons they were unable to participate in more clinical research.

Figure 4. Percentage of Patients Involved in Some Type of Research*



*Clinical trials, CER, registry reporting

Figure 5. Percentage of Patients Accrued to Clinical Trials Annually



demands for data. However, insufficient financial resources are not the only barrier to data collection in the community oncology setting. Oncology practitioners report a variety of other issues, including a lack of physician interest in data reporting, a perceived lack of cooperation with local academic institutions, and logistical problems mainly surrounding the implementation and interoperability of EMR systems.

How can the oncology community address these problems? Increased funding would mitigate many of the barriers; however, identifying sources for additional funding is yet another challenge. Many respondents indicated that while their own institutions provided a great deal of support, other entities including pharmaceutical companies, the NCI, and others provided little or no support.

Addressing the logistical issues around EMRs and data sharing, respondents commented that data resides in individual silos, and that numerous barriers stand in the way of data sharing. One respondent suggested creating software compatible with all EMRs that would allow data to be imported and exported from existing registries. Another mentioned that the lack of private practice and institution interfaces leads to gaps in information for the patients. In order to address this barrier, practitioners and EMR system developers must be on the same page to allow for the best interoperability and communication possible.

In addition to increased funding and improved data sharing, survey respondents (4.7 percent) called for increased physician education on data collection. One respondent wrote: "Physicians lack understanding of data collection rules especially for the registry." To overcome this barrier, the respondent suggests increasing the education of physicians, as early as medical school, and suggests the standardization of all data, to make learning much simpler.

Ultimately achieving greater data collection and data sharing in the community oncology setting will require a joint effort by all stakeholders, including physicians, hospitals, academic institutions, payers, government agencies, EMR vendors and software designers, and medical educators. Provider advocacy groups and trade associations, such as ACCC, stand ready to assist in the dialogue among these interested parties.

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