Selecting Your Cancer Registry
Software

by Herman Menck, M.B.A., C.D.P.

Choosing the right software

for a hospital cancer registry is serious business that requires much thought, planning…and, of course, money. You can either dedicate effort up front in the planning or spend time *and* money later in repairs.

A cancer registry software system can cost $10,000 for purchase and $5,000 per year thereafter for support and updates. That price may be reasonable given the fact that it takes $300,000 to $1.5 million to design, test, and market a new cancer registry software system. Customizing a system will cost more money and delay implementation. As with most other products, you get what you pay for—cheaper is not always better.

WHAT IS THE BEST SOFTWARE?

First and foremost, top-notch hospital cancer registry software must be user-friendly. All facets of the system—from data entry and abstracting to coding and follow-up—must be easy to learn and use. Moreover, the software must be capable of generating data analysis and reports, including case subset selection and a variety of tabulations, graphics, and statistics (observed and relative survival rates as well as percentage distributions).

Top-notch hospital cancer registry software must be flexible enough for the user to add, modify, or remove hospital-defined items and must accommodate multiple users.

Hospital cancer registry software must also:
- Have direct online access
- Make efficient use of computer resources, such as allowing access to additional information in other windows while the registry program is operating
- Meet the needs of the registrar, not the programmer
- Allow data to be easily backed up onto external media and amenable to easy restoration
- Conform to established industry standards, such as the North American Association of Central Cancer Registries (NAACCR) patient record design and coding schemas.

In some states or regions, the central registry provides, supports, and updates appropriate software for hospitals in its
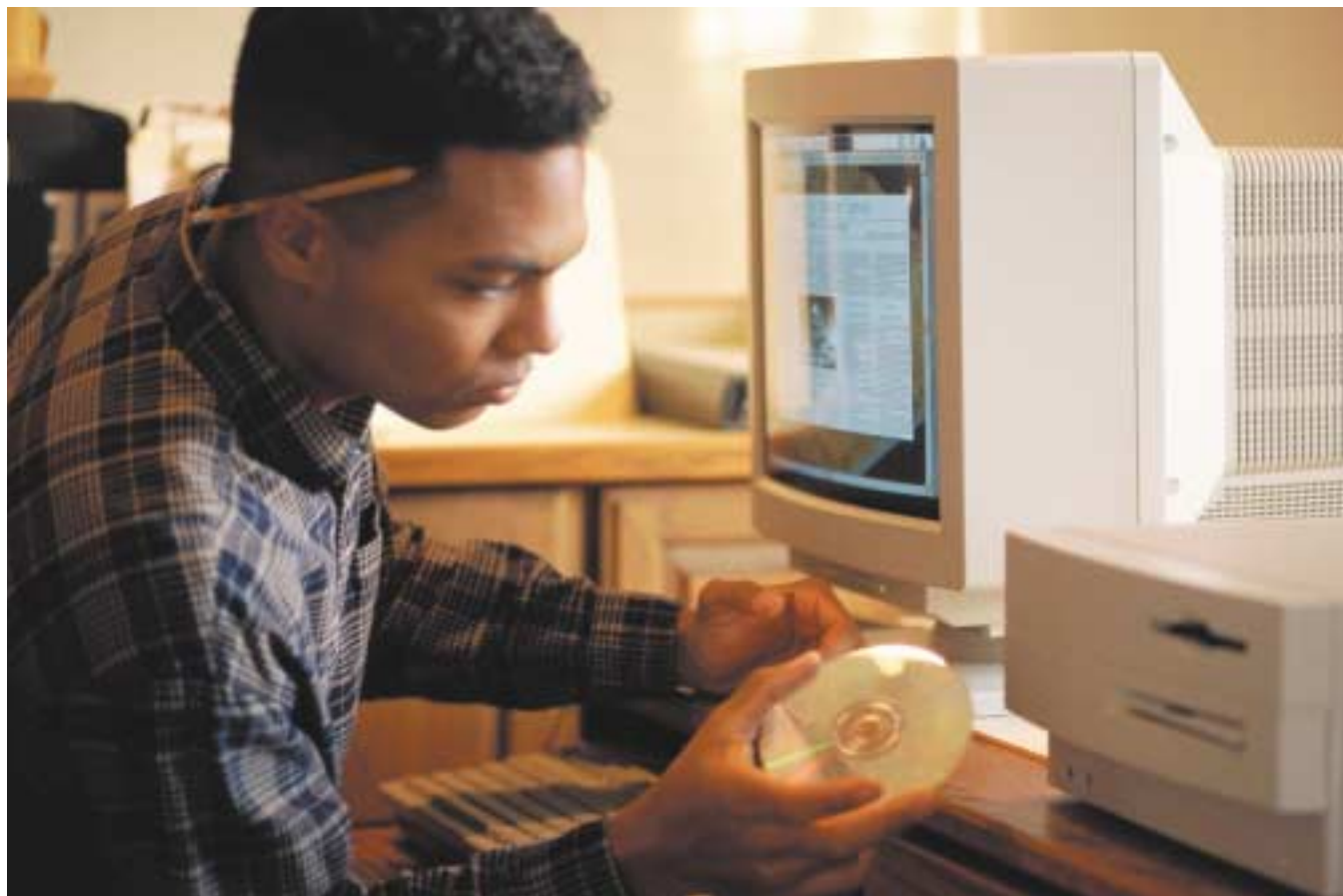
catchment area at reduced or no cost. If the central registry software is acceptable, using it obviates the need for a selection process and may minimize cost considerations. However, ask for a demonstration before you agree to use it.

A NEW SYSTEM VS. CONVERSION

Conversions can include changing from one software provider to another or converting the data items and coding definitions within the same registry system. Conversions are sometimes necessary, but are almost always onerous and should be avoided or delayed whenever possible. Sometimes, however, events external to the registry require conversion. For example, the registry may be required to use a new, changed, or improved data set because of new state reporting regulations.

All registry data must be recorded using standardized codes, data item definitions, and format. In the event a data item or code changes, the old data for each patient must be converted to the new schema. In general, only clean data stored according to standard form can be effectively converted. Unless coding has been consistent, the full set of patient cases cannot be effectively analyzed.

If you choose to change your software provider, the new provider should work closely with the former provider and the registry staff. Often it is harder to convert data from one software system to another than it is to enter the data originally. Always select a software provider with significant market share: You don't want the provider to go out of business.

THE SELECTION PROCESS

Software selection is a complex process. Although the selection process may vary from one medical center to another, you can make the process for your cancer registry much easier by following the seven steps indicated below. Be aware that assigning a time period to each step in the process is difficult, and the order of the steps may differ based on surrounding circumstances. For example, some organizations prepare a budget first, while other organizations consider budgetary needs much later in the process when more facts are known. In general, the entire selection process can be expected to take six to 12 months when handled expeditiously. Many purchases and/or conversions have taken more than one year.

Step 1 *Plan your budget and assess your goals.* How much do you propose to spend? What do the cancer registry and administration expect from the new software? Often their expectations are stated generally, such as "doing the job better, quicker, and more cheaply." Although these benefits may be achieved, the first six to 12 months may actually be slower and harder for the registry staff than before because of the steep learning curve that accompanies all computer projects.

Make sure to solicit comments from both clinical and administrative management, and tie down management's expectations as specifically as possible. Avoid generalizations such as the software must be "faster and cheaper." Instead look carefully at the reports, capabilities, and functions of the software, so you don't have to hear, "we've spent two years and $100,000, and the system still doesn't do what I want it to." In setting goals, be realistic and conservative.

Cancer Registry Software Vendors

- Cancer Patient Data Management System (Kentucky Cancer Registry)
  www.kcr.uky.edu

- C/NET Solutions
  www.askcnet.org

- Electronic Registry Systems
  www.ers-can.com

- IMPAC Medical Systems
  www.impac.com

- Medical Registry Services
  www.medregistry.com

- Oncolog
  www.oncolog.com

- Registry Plus
  www.sph.emory.edu/GCCS

- Rocky Mountain Cancer Data Systems
  http://rmcds1.med.utah.edu

- SoftMed
  www.ihsinc.com

Administrators may want the software to allow them to better describe and understand the diagnoses and demographics of the hospital's cancer patients. They may also want the software to be capable of generating time-trend data and quick reports on kinds of cancer patients and what is happening to the caseload. Finally, they may want the software to tabulate caseload data by admitting and treating physician.

Registrars are primarily concerned with the medical usefulness of the system, whether it meets approval and accreditation requirements, and how user friendly it is.

Step 2 *Pick a software selection team.* Usually the core members of the team will include the primary user (cancer registrar) and a computer representative from your hospital information technology (IT) department, who usually supports the software once it is installed. Essential to the success of the software selection are the primary physician advisor to the registry (cancer committee representative), the administrative manager who will approve the purchase, and the purchasing representative. These people may not choose to participate in the actual selection of software, but they should be kept advised of what the team is doing and the choices team members have made.

Step 3 *List your requirements.* All specifications should be documented and shared with the software

selection team. Establishing the specifications, requirements, and timeline is an ongoing process subject to change and improvement until procurement takes place.

These specifications include:

- Whether the system will be new or a conversion
- Data set requirements (standardized data sets are advisable)
- Required data edits (standardized edits are advisable)
- Any other quality assurance considerations such as amenability to external audit
- File import and export capabilities
- Reporting requirements
- Statistical programs
- Printing capabilities, including the complete patient abstract, lists of cases as specified, and statistical summaries (cross tabulations) of specified cases
- Any additional requirements of any agencies to which the hospital will be reporting (such as the state central registry or the National Cancer Database of the Commission on Cancer)
- Hospital computer (PC) and operating system preferences
- Transmission/communication (modem, network) requirements
- Timeline for implementation.

Each member of the selection team should be asked to comment on the specifications and any proposed changes.

Step 4 *Query other registries.* Ask staff from nearby hospital registries and the state central registry about their software. If possible, make visits to other hospitals to see live demonstrations of their registry computer systems. Here are some questions you should ask:

- What is the registry's annual caseload?
- What are the advantages and disadvantages of the registry system?
- After the software was selected, how well did it meet the expectations of the medical and registry staff, the cancer committee, administration, and IT?
- What are the major uses of the registry system and who uses it?
- What was the approximate timeline of the planning, installation, and implementation of the system?
- How long did it take for registry staff to learn how to use the software?
- How good has support been from IT and the software provider?

Step 5 *Get to know the vendors.* Find out how long the vendors have been in the cancer registry software business and the vendors' market share. Generalized software design experience is not necessarily a suitable substitute for specific cancer registry software experience. Find out who your vendor support person will be. Ask vendors for referrals to other cancer registries that are presently using their system and visit these registries for demonstrations. Check out the user manuals provided by each vendor. Don't consider a system still under design. Make sure the vendor will support and update its system after the sale.

Step 6 *Finalize specifications, requirements, and timelines.* After the fact-finding phase is completed and all interested parties have critiqued the specifications and requirements, write up the final specifications and distribute them with a timeline to team members.

Step 7 *Solicit bids.* Your request for bids must contain well-documented specifications and requirements. Verbal orders are not permitted! Each vendor should supply a well-documented proposal. If you are getting bids from several vendors, fairness should prevail. Each vendor should be given the same amount of information. You cannot informally change the specifications once they are out. A change means redistribution of the revised bid request to all parties, with adequate time for response. After the bids are received and comparatively evaluated, the software selection team can select a vendor.

Software providers should insist that the registry's programmers be fully familiar with the full scope of registry operations—from identification of the data to be entered to transmission of the data in standard form to central registries to routine and specialized internal data analysis.

OPTIMIZING USE OF THE CANCER REGISTRY

Once the software selection team has chosen and purchased the registry software, a new set of tasks awaits: installation, training, data conversion, and testing. Hopefully, the vendor you have selected will be responsive to your needs and timeline.

With your software up and running, the computerized cancer registry should provide an organized system for recording, accessing, and reporting information about the occurrence of cancer as well as all aspects of cancer care and survival within a hospital. Such information should be used by the oncology departments as well as by administration, nursing, and social services.

From the patient's perspective, a well-functioning, computerized cancer registry guarantees lifetime medical contact about the cancer diagnosis and facilitates annual follow-up. From the hospital's perspective, the cancer registry allows the hospital to maintain continuing and medically relevant contact with its patients. In addition, hospital administration can track where cases are being referred and where cases are coming from—information that can help hospitals find out why they might be losing cases and assist them in marketing services.

In the end, the major shortcoming of cancer registries may not be undesirable software, but rather that hospitals underutilize the registry both medically and administratively. The most successful registries are those facilitated by a registrar who aggressively suggests innovative uses to administration and works to make them happen.

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