Treating Small-Population Cancers in the Community Setting

A survey of current practices in the treatment of chronic myeloid leukemia and a screening tool to identify effective practices

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TREATING SMALL-POPULATION CANCERS

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Introduction and Key Findings

The Association of Community Cancer Centers (ACCC) launched a ground-breaking educational program in 2010 to provide the community-based cancer care team the resources they need to improve the quality of care for patients with "small-population cancers." This educational project, entitled "Treating Small-Population Cancers in the Community Setting," was initiated with a focus on chronic myeloid leukemia (CML). ACCC's objectives were to:

- determine information and resource needs of cancer programs that ACCC has the ability to address
- identify effective practices that promote quality care in the management of CML patients
- determine which cancer programs had the more effective practices
- assess current practices at cancer programs (ACCC members), and determine where current practices of community cancer programs differ from practices determined to be more effective.

Many community-based cancer care providers see a large number of patients with breast, lung, colon, or prostate cancers. Practice patterns are relatively well-established for these cancers, and resources are available for both providers and patients. Many other cancers, however, are seen less often in the community setting. These low-incidence or small-population cancers present different challenges for community-based cancer care providers because 1) patients usually come from underserved or elderly populations and do not have the resources or desire to be treated at large academic institutions; 2) physicians treating small-population cancers have limited time and resources to incorporate emerging clinical data into practice; and 3) other health professionals, including nurses, social workers, and pharmacists, see these cancers less frequently and need information to better support their physicians and patients.

> **What Are Small-Population Cancers?**
>
> - Sometimes referred to as low-incidence cancers or forgotten cancers
> - Less than 20,000 cases/annually, although no single, widely accepted definition exists
> - Less frequently occurring cancers: CML = 1-2 cases per 100,000 people annually (NCI SEER, 2009)

To assess current practices used in managing CML and other small-population cancers and to identify those cancer programs with more effective practices, three surveys were developed that address the adequacy and effectiveness of 1) overall resources and processes, 2) specific clinical processes, and 3) support services used in patients with CML and other small-population cancers. The surveys were developed by ACCC and an advisory panel of oncologists, nurses, and social workers, along with Health2 Resources, a healthcare consulting company. The surveys were based on one-hour interviews with an advisory panel of oncologists, nurses, and social workers.

The online survey was administered during January and February 2011. Of 670 invitations to take the

survey, 61 partial responses and 27 complete responses were received. The analysis was conducted using the 27 completed surveys.

The sample of cancer programs completing the three surveys is not thought to be representative of all cancer programs, but is, instead, likely composed of institutions that maintain a stronger focus on CML and have introduced more effective processes for managing CML.

Key Findings

For most cancer programs, the experience with CML is limited and will remain so. More than 60 percent of the 27 responding programs report fewer than 10 new CML patients annually, and even those small numbers are likely divided among several oncologists within the program. Even in cancer programs with a high volume of CML cases (case load above 25), CML cases represent only a small share of the cancers seen (less than 5 percent of the total).

Because direct patient experience is more limited for small-population cancers, keeping current about new treatments is particularly important. Annual CML training for clinical and support professionals keeps them up to date on new therapies and processes and up to speed on existing ones. Given that the financial implications of CML drug costs can be unique and somewhat daunting, the whole team, including financial counselors, would benefit from training about the needs of patients with CML.

> **CML: Ready Reference**
>
> - **About 5,050 new cases of CML are diagnosed yearly (2,930 in men and 2,120 in women) (2009).**
> - **About 470 people will die of CML (2009).**
> - **CML accounts for about 10 to 15 percent of all leukemias.**
> - **The average person's lifetime risk of getting CML is about 1 in 625. This disease is more common in men than in women. It is also more common in Whites than in African-Americans.**
> - **The average age at diagnosis of CML is around 66 years. Over half of cases are diagnosed in people 65 and older. This type of leukemia mainly affects adults, and is only rarely seen in children.**
> - **There has been dramatic progress in treatment over the past several years, so most people with CML are now surviving at least 5 years after diagnosis.**
>
> *Statistics are from The American Cancer Society's most recent estimates for CML in the United States, 2009.*

A high percentage of respondents indicated they would like to have resources from ACCC that address the needs of patients with CML and other small-population cancers. Of the 27 responding cancer programs, 87 percent indicated that patient education resources would be helpful. Resource lists, education programs for professionals, and model policies and checklists also were requested by more than 60 percent of respondents.

Clinical and support resources used in managing CML patients
- **Critical mass of clinicians available.** More than two-thirds of the 27 responding cancer programs evidence at least a minimum critical mass of clinicians, including at least five board-certified medical oncologists, at least two hematologists, and at least .5 oncology-certified RNs for every oncologist, including radiation and surgical oncologists. In addition, more than 80 percent of the respondents rate their oncologists' training and experience as above or well above average.
- **Most advanced therapies available.** Most responding programs offer tyrosine kinase inhibitor therapies, and thus are offering the most advanced therapies, which have transformed survival rates. However, electronic health record (EHR) support for CML treatments (EHR with flags, or integrated with computerized order entry systems) remains limited to less than half of the respondents.
- **Comprehensive support services.** Most cancer programs offer a broad array of support services in-house and help patients and their families coordinate those services. The support services,

however, are unlikely to be tailored to CML, and many cancer programs report that their support service professionals have little training or experience with CML.

Management, clinical, and support services processes used in management of CML patients
- **Monitoring process and outcomes.** The cancer registry is used by all cancer programs; most respondents (81 percent) indicate the registry data is shared with their executives, their clinicians, or both. Among the one in four respondents conducting telephone surveys, almost all (84 percent) shared the data with executives or clinicians. However, among those conducting a mailed survey, only 24 percent managed to share it with executives or clinicians, suggesting that the results of mailed surveys are perceived to be of only limited value.
- **Accreditation.** All but one respondent indicated that their programs were accredited, and most (85 percent) were accredited by the American College of Surgeons Commission on Cancer.
- **Clinical guidelines.** All responding cancer programs have access to national clinical guidelines. However, in only about half the programs are guidelines incorporated into practice protocols. In only 15 percent are guidelines incorporated into protocols through an EHR component.
- **Managing drug therapy.** More than 80 percent of the programs schedule regular visits to check compliance with drug regimens and also check for drug side effects. However less than half follow up between visits to check whether drug prescriptions have been filled (41 percent), and only one cancer program has specific policies or guidelines concerning actions to ensure drug compliance.
- **Support staff training.** Among support staff, those most closely involved in direct clinical care (RNs, social workers, and nutritionists) are also most likely to have experienced CML-specific training (more than half of the cancer programs provide such training). However, only one-third of the cancer programs had provided training to other key support professionals (e.g., mental health professionals or financial counselors). Most (89 percent) responding programs offer at least some types of support staff training about CML.

Performance in managing clinical and support functions
- **High ratings on clinical performance.** Most respondents gave their cancer program a very high clinical performance rating. More than half (56 percent) of the respondents rate their program above or well above average on all five performance measures. Particularly important among the clinical ratings is that most of the respondents assess their clinicians' knowledge of the latest CML research and use of effective treatments to be above or well above average.
- **Lower ratings on support services performance.** Fewer respondents rate their program's performance in providing support services as highly (on average) as they rate clinical performance.

Since community cancer programs will see few cases of CML, most programs will need continuing external support to help their clinicians remain current and to better target their support services to patients with CML. ACCC's newly established Community Resource Centers, which can supply expertise and resources, are expected to be well received by the Association's membership.

Because guidelines can help make up for the lack of experience that many programs have in treating rare cancers, raising awareness around the need for clinical guidelines for both treatment and support services for CML patients is important. Equally important is to encourage more cancer programs to integrate their guidelines (and EHR software) into protocols. The issue is particularly important for cancers that are rare and thus infrequently seen by clinicians and support staff.

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Methods

Advisory Panel

ACCC established an advisory panel of four physicians, an RN, and three social workers (one representing the Leukemia & Lymphoma Society). All the physicians were board-certified in hematology and oncology. One oncologist practiced at a university medical center cancer program, and the other three clinicians practiced in community cancer centers.

Pretest Design and Administration

Members of the advisory panel, along with Health2 Resources, helped to design a test to evaluate general knowledge about and treatment approaches for CML. The test was designed to be administered twice: 1) as a pretest; 2) a year later to evaluate the effectiveness of educational programs. Between Sept. 16 and 27, 2010, 148 ACCC members took the pretest on-line. At the ACCC annual meeting, 10 more members completed a hard-copy version. (See Appendix I for the survey instrument.)

All nine questions were multiple choice, with three to five possible responses plus a "Don't know" option. The questions were designed so that one or more choices could be correct. For some questions, only one answer was correct, but for others more than one answer was correct.

The overall average was 3.8 (of 9) questions correctly answered. Physicians performed the best (5.6 correct), followed by pharmacists, nurses, and administrators. Relatively few responding physicians have significant gaps in knowledge; rather, any lack appears to be lack of *complete* knowledge about an area of questioning rather than lack of *any* knowledge. The most often missed treatment questions involved when not to prescribe imatinib and the clinical signs when imatinib is not working.

Pharmacists and nurses had fewer correct answers than physicians; nurses scored well below pharmacists. The knowledge gap for nurses seems rather large across all clinical and almost all general questions. (See Appendix IV for a more detailed explanation of the pretest results.)

The follow-up test will be administered in late 2011.

Survey Design and Administration

Advisory panel members were interviewed to document the important elements in managing patients with CML, and the results of the interviews were used to construct a screening survey questionnaire. Advisory panel members were asked to review a draft of the survey, and then, following changes, took the survey on behalf of their own cancer centers in a trial run.

The survey was undertaken in response to the availability of newer therapies that have greatly improved outcomes for CML, while introducing new challenges to providing longer term monitoring and care. Most individuals with a diagnosis of CML have been transformed from patients facing almost-certain death within a few months or years to persons with a chronic condition (analogous to diabetes) that can be managed, but not cured, and who can live a fairly normal life.

The survey instrument was broken into three separate questionnaires, each focusing on different aspects of caring for patients with CML.
- Survey 1 (management) assessed overall resources and processes used to manage care for CML and other small-population cancers.
- Survey 2 (clinical) assessed specific clinical processes used with CML and other small-population cancers.
- Survey 3 (support) assessed support services used in care of patients with CML and other small-population cancers.

All three surveys were designed on the SurveyMonkey web portal.

An email was sent to the 670 organizational representatives of cancer programs with ACCC memberships on January 5, 2011. Each representative was sent a link to all three surveys and asked to distribute the three surveys to the individuals within the cancer program who were most likely to be able to complete the surveys. Each of the surveys took less than 10 minutes to complete, although some information (e.g., number of annual CML cases) may have required the respondent to reference documents containing statistical information about case loads and personnel to obtain accurate information.

Survey responses were received between January 5 and February 17. Several prompter emails were sent to encourage survey completion, and a final effort was made to get those respondents who had completed one or two surveys to complete the remaining surveys. While more than 100 organizations started at least one of the three surveys, only 61 completed at least one of the three surveys (including providing name and address information), and 27 organizations completed all three surveys.

This level of full and partial response was less than anticipated, and may be due to several factors, including 1) the survey asked for some information that may have been difficult to retrieve, leading some cancer programs to start, but not complete, the surveys; 2) CML is a rare cancer, and many cancer programs may have decided they didn't have enough experience with the cancer to respond; and 3) the target audience is both busy and may receive frequent requests to complete surveys. As a result, respondents may have decided not to complete a survey that targeted a cancer involving such a small portion of their clinical resources, despite being members of ACCC and receiving the survey from a trusted source. A final factor that may account for the low response rate is that the survey was multidisciplinary, requiring input from both clinical and support staff and making it more difficult to complete.

Responding Cancer Programs

Of the 670 cancer programs invited to complete the three surveys, approximately 100 started a survey (completed at least one page of one of the three surveys, each with two or more pages), 61 programs completed at least one survey, and 27 programs completed all three surveys.

We compared cancer programs that completed one or two surveys with those completing all three surveys on case load and determined little difference between the two groups, although programs completing only one or two surveys were more likely to have fewer new CML patients annually than programs completing all three surveys.

However, in responding to questions in the first survey in which the respondents rated their cancer program's services or resources, the 15 programs that completed that survey, but not all three surveys, were less likely to rate their services and resources as being above or well above average than programs completing all three surveys. Results of that comparison are presented in Table 1.

These differences between the two groups suggest that cancer programs completing all three surveys may have thought they were more likely to be considered as having "effective practices" in managing CML and thus had a stronger motivation to complete the survey. (Those identified having more effective practices knew they might be interviewed and possibly highlighted in ACCC publications.)

The remaining analysis was conducted using the results from the 27 cancer programs completing all three surveys. We think these cancer programs are representative of programs with a stronger than average focus on CML and that have introduced more effective practices to help manage CML patients. They are, then, not taken to be representative of all cancer programs.

Table 1. Percentage of Programs Rating Their Cancer Program Above Average or Well Above Average for the Service

	Centers completing one or two surveys	Centers completing all three surveys
Financial services	50%	74%
Clinical resources	44	65
Written policies	6	35
Tech support	19	48
Guidelines	50	70

Note: N=15 for centers completing only one or two surveys and N=26 for centers completing all three surveys.

Our Approach to the Analysis

The goals of this study are:
- to determine information and resource needs of cancer programs that ACCC has the ability to address
- to identify effective practices that promote quality care in the management of CML patients
- to determine which cancer programs had the more effective practices

- to assess current practices at cancer programs (ACCC members), and determine where current practices of community cancer programs differ from practices determined to be more effective.

To assess current practices used in managing CML and other small-population cancers, and identify cancer programs evidencing more effective practices (combined with adequate resources), questions were asked and rating scales developed within the following three broad categories:
- Clinical and support service resources (Are they adequate?)
- Management, clinical, and support processes (Are they effective?)
- Clinical and support performance (Is it effective?)

Within each broad area, subscales were developed around clinical services, support services, and program management. As a result, separate scale scores were developed in each of the following areas:

I. Resource adequacy
   A. Volume of CML cases
   B. Clinical resources
   C. Support resources

II. Effective processes
   A. Management processes
   B. Clinical processes
   C. Support processes

III. Effective performance
   A. Clinical services
   B. Support services

As part of the assessment, we scored responses to survey items on the subscales above and used the combined subscales as a screening tool to rank the cancer programs on their management of CML patients.

The results and analysis are divided into four major sections. The first section assesses information needs and is built around a single question asking respondents to indicate whether specific types of resources would be helpful. The other three sections review our findings in screening these 27 programs for effective management of care for CML patients, looking at resource adequacy, effective processes, and effective performance.

> **"CML is an ideal proxy for the study of small-population cancers because of the number of patients diagnosed each year and the fact that there has been an increasing amount of exciting, new clinical data and information about monitoring and treating patients."**
>
> *Christian Downs, JD, MHA*
> *ACCC Executive Director*

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Results

Section 1. Information Needs

Respondents were asked to indicate what kinds of support, including patient education material and professional education courses, would be helpful in managing CML patients (Table 2). The question was asked on each of the three surveys (resource adequacy, effective practices, effective performance) and there were often different individuals responding for each survey.

Patient education material was selected as helpful by most cancer programs (87 percent of respondents). Resource lists were also selected by a large majority of programs. Support group information was selected by the least number of respondents.

Resources from ACCC that are related to CML and other small-population cancers will likely be well received by most cancer programs.

Table 2. Percentage of Respondents Indicating That Support Would Be Helpful, by Type of Support	
Patient education material	87%
Support group information	51
Resource lists	74
Professional education programs (CML)	62
Model policies and checklists	69
N=27	

Results
Section 2. Resource Adequacy

CML Case Load

> **Key Findings**
>
> - For most cancer programs, the experience with CML is limited. Most cancer programs report only a small number of new CML cases each year (more than 60 percent report fewer than 10 new CML patients annually), and even those small numbers are likely divided among several oncologists within the cancer program.
> - Even in cancer programs with a high volume of CML cases (above 25), CML cases are typically less than 3-5 percent of the total cancer caseload.

One of the key indicators of quality is sufficient volume for practitioners to maintain the experience needed to effectively provide care. There are approximately 5,000 new cases of CML diagnosed annually in the United States and, with increased survival following the introduction of more effective treatments, the number of patients with CML is gradually rising.

Nevertheless, the volume of new and existing cases nationwide is small compared to the more common cancers such as prostate and breast, and the volume at any particular community cancer program is likely to be very limited. Even the much higher volume of CML cases at major referral centers is likely to be a small fraction of total cancers seen at those cancer programs.

In Table 3, the volume of CML cases (new cases and current caseload) is presented for the 27 cancer programs participating fully in the survey.

Thirty-one percent of the cancer programs indicated they have fewer than five new cases of CML annually or that they have a current case load of fewer than five. Fully 85 percent of responding cancer programs indicate they have fewer than 25 new cases each year, and 57 percent indicate their existing case load is less than 25. In contrast, these same cancer programs report high volumes of cancer cases overall (data not shown). More than half of these programs report that they see 1,000 or more new cancer cases each year, and almost two-thirds report a current case load above 1,000.

In all but two cancer programs, the percentage of CML cases is estimated to be less than 4 percent of all cancers seen at the program (data not shown), and in a third of the programs, it is less than or equal to about 1 percent of all cancers under the institution's care. Thus, CML is confirmed as a rare cancer that makes up a small portion of the cancers seen at these programs, even though the 26 institutions responding to this question probably treat about 6-7 percent of the new cases nationwide. (Based on

survey results, we estimate that these 26 cancer programs treat between 300 and 400 new CML cases each year—in the aggregate—and have a current aggregate caseload of around 500 CML patients.)

In assessing cancer programs for effective practices and in selecting ACCC community resource centers (CRCs) for CML, we limited final consideration to cancer programs with a volume of at least five new cases or an existing case load of at least five. Seven programs did not meet this minimum volume requirement.

Table 3. Volume of New and Existing CML Patients Treated by the Responding Cancer Program

	New cases	Current active caseload
Less than 5	31%	33%
5 to 9	31	14
10 to 24	23	10
25 to 99	12	33
100 or more	4	10

N=26 for new cases and N-21 for current caseload

Clinical Resources

Key Findings

- Most responding cancer programs (more than two-thirds) evidence at least a minimum critical mass of clinicians (board-certified medical oncologists and hematologists and oncology certified RNs).
- Most responding programs offer the tyrosine kinase inhibitor therapies (the therapies that have transformed survival rates).
- Most respondents (more than 80 percent) rate their oncologists' training and experience as above or well above average.
- EHR supports for CML (EHR with flags, or integrated with CPOE systems) remain limited to less than half of the responding cancer programs.

In assessing clinical resources for treating patients with CML, we reviewed survey responses for the type and number of specialists available, their training and experience with CML, the therapies offered by the cancer program, and clinical supports available through access to proficient labs and availability of EHR support.

In Table 4, the number of clinicians (physicians and RNs) active on the cancer programs' treatment teams and who would be potentially involved with CML patients are presented by professional position.

Table 4. Average Number of Clinicians Active in the Responding Cancer Programs, by Type

Medical oncologists   10.1
Board-certified hematologists   7.1
Oncology certified RNs   15.7

N=27
Note: Board-certified hematologists are a subset of the medical oncologists.

A key element for effective practice is having a critical mass of professionals who interact with each other on a regular basis. Based on input from the advisory panel, we used the following rules of thumb in estimating whether a cancer program had a critical mass of professionals: oncologists (five or more), hematologists (two or more), and oncology-certified RNs (.5 RNs for every oncologist, including radiation and surgical oncologists). Among the responding cancer programs, 69 percent had five or more active medical oncologists; 96 percent had two or more hematologists; and 63 percent had at least .5 oncology-certified RNs for every oncologist.

In Table 5, the range of therapies offered by the cancer programs for CML treatment is presented. Most respondents (at least 75 percent) offer chemotherapy, biologic therapies, and tyrosine kinase inhibitor therapies, while only about one in four offers stem cell transplants and donor lymphocyte infusion therapies.

Table 5. Percentage of Programs Offering CML Treatment, by Type of Treatment

PO chemotherapy   84%
IV chemotherapy   80
Biologic therapies   76
Therapies with a tyrosine kinase inhibitor   88
Stem cell transplants   24
Donor lymphocyte infusion   20

N=25

In determining scaling for these therapies, we reasoned that having a broader scope of therapies would give the patient a fuller set of options. Accordingly, in rating cancer programs for therapies (as resources), programs obtained more points for the broader range.

In Table 6, the responding cancer programs evaluate their clinical resources using a 5-point scale, going from 1 (well below average) to 5 (well above average). The percentage of cancer programs rating themselves as above or well above average for the indicated metrics is provided. A high percentage of the respondents (84 percent) rate their clinicians' training and experience related to CML as strong (above or well above average).

Most cancer programs rate their lab services as strong (above or well above average), but only half of the programs indicated that their EHR systems deserved an above or well above average rating. Lab services, of course, may be in-house, but, if necessary, can be obtained from regional or national labs. With the broader range (regional or national) of choices, a strong clinical team can identify and use a lab that offers the needed expertise.

EHR systems, while now widely used by oncologists, are not as likely to be well targeted to small-population cancers such as CML.

Table 6. Percentage of Programs Reporting Above Average or Well Above Average Ratings on Clinical Resources Metrics Related to CML

Training and experience of oncologists	84%
Adequate technology support (EMR/EHR with flags, integrated CPOE)	48
Diagnostic lab work meets quality standards	83
Adequacy of clinical resources	65

Note: Ratings were on a five-point scale

Clinical Resources Scale

Following consultation with the advisory panel, we constructed a clinical resources scale by assigning points for each of the following criteria. The percentage of cancer programs receiving a point is given in parentheses. This percentage may differ from those in the tables since the percentage is taken of all 27 cancer programs rather than the number of programs answering a particular question or providing a specific rating.

- Two or more board-certified hematologists (85 percent)
- At least .5 oncology certified RNs for every oncologist (including medical, radiation, and surgical) (63 percent)
- Five or more medical oncologists (67 percent)
- Offer targeted therapies with a tyrosine kinase inhibitor (81 percent)
- Offer chemotherapies and biological therapies (up to 3 points depending on the number of different therapies offered) (89 percent offer at least one of three)
- Offer stem cell transplants or donor lymphocyte therapies (1 point if either offered) (26 percent offer at least one)
- CML training and experience of oncologists (self rating) (above average or well above average=1 point) (78 percent)
- Diagnostic lab work on CML meets quality standards (self rating) (above average or well above average=1 point) (74 percent)
- Clinical resources (self rating) (above average or well above average=1 point) (63 percent)
- Technology support for treatment (self rating) (above average or well above average=1 point) (44 percent)

Table 7. Clinical Resources Scale Scores
    (Available points 12)

Scale score points	Number in category		
1-5	5	**Average score**	8.1
6-10	17	**Range**	1-12
11-12	5		

Support Services

Key Findings

- Most cancer programs offer a broad array of support services in-house and also provide someone to help the patient and family coordinate those services.
- Among all the support services queried, only hospice was more likely to be offered by external agencies than through internal resources.
- Most of the support services queried were available either internally or externally at more than 85 percent of the cancer programs. The exception was mentoring services, available at only 64 percent of the programs.
- Only a small number of cancer centers provided support services with a specific focus on CML.

Support services are used to help patients and their families cope with the illness and its consequences, including help determining which services are actually needed as well as arranging finances and group sessions with other cancer patients.

Cancer programs were asked to indicate whether 10 specific support services were provided, either in-house or externally (Table 8). Also, they were asked to indicate whether the services included features that were targeted specifically to CML or were more generally targeted.

Given the broad range of support services that may be needed, coordination is critical. Almost all (93 percent) of the cancer programs do coordinate support services.

Table 8. Support Services Offered and the Percentage Offered Internally at the Cancer Program or Through External Agencies

	Internal only	External only	Available internally & externally	Not available
Coordination of services support	78%	7%	15%	0%
Nutrition counseling	89%	4%	7%	0%
Symptom management services	81%	4%	11%	4%
Financial counseling	70%	19%	11%	0%
Mental health services	59%	26%	11%	4%
Cancer support (face-to-face)	59%	22%	15%	4%
Cancer support (telephone)	56%	26%	4%	14%
Educational sessions	52%	22%	15%	11%
Mentoring services	30%	30%	4%	36%
Hospice services	26%	56%	15%	97%

Note: services offered internally include the sum of column 1 (internal only) and column 3 (available internally and externally).

Table 8 indicates that nutrition counseling (96 percent offered internally) and symptom management (92 percent offered internally) are most often offered in-house, and only rarely through external agencies alone. Hospice is far more likely to be offered through external agencies (71 percent external versus 41 percent internal).

Most responding cancer programs offer a broad range of support services in-house; when the programs do not offer a specific service, patients can be referred to services provided externally, if necessary.

Only a small number of cancer programs (4) provided any of these support services with a specific focus on CML. For most programs, CML is too small a portion of the case mix to secure dedicated resources.

Support Resource Scale

This scale was constructed by providing one point for each category of support service offered externally, two points for each service offered internally, and an extra point if the service was specific to CML. A specific kind of service could receive up to four points.

Table 9. Support Resource Scale Scores
        (Available points: 40)

Scale score points	Number in category		
12-15	7	Average score	17.8
16-19	11	Range	12 to 27
20-27	9		
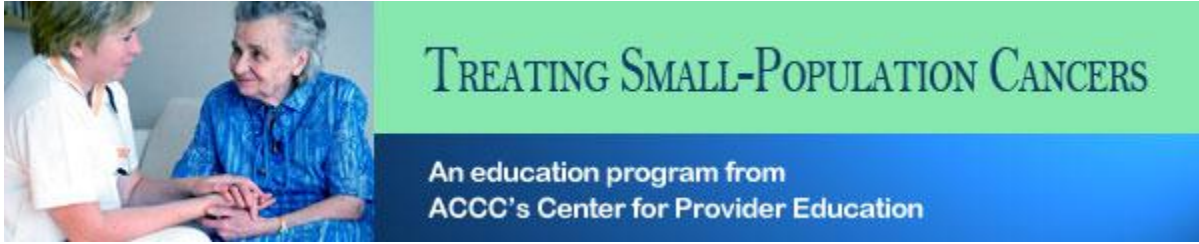
Results

Section 3. Effective Processes

The survey examined specific processes that would lead to more effective management of CML patients. Processes were differentiated, again, by whether they focused on clinical or support services, or overall management issues.

Management Processes

Key Findings

- The cancer registry is used by all cancer programs and most (81 percent) share the registry data with their executives, their clinicians, or both.
- All cancer programs except one reported that they were accredited, most (85 percent) by ACOS.
- Among the one in four cancer programs conducting telephone surveys, almost all (84 percent) shared the data with executives or clinicians. However, among the larger number conducting mailed surveys, only 24 percent shared data with executives or clinicians.

To examine overall management of the cancer program we asked whether the institution was accredited and whether the institution systematically followed up on patient perceptions of quality of care (satisfaction) and on outcomes (survival, quality of life).

All except one of the respondents indicated that their cancer program is accredited. Most (85 percent) of respondents indicated that their cancer program had received accreditation from the American College of Surgeons (ACOS), but a significant minority (33 percent) had received accreditation from the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI). A few cancer programs had received other accreditations.

Table 10. Percentage of Cancer Centers Using Specific Methods for Assessing Patient Care and Outcomes and Sharing Data with Executives and Clinicians

	% using	% sharing data with executives/clinicians
Cancer registry	100%	81%
National QA guidelines	89%	85%
Mailed survey	93%	22%
Telephone survey	26%	22%

All cancer programs use the cancer registry, and most (81 percent) share the registry data with either their executives or their clinicians, or both. Most also have implemented national quality assurance guidelines and also share that data.

The mailed survey is easy and popular, but the results are rarely shared with executives or clinicians, suggesting they are not viewed as providing useful data. The telephone survey, however, though rarely used is almost always shared with clinicians and executives. The telephone survey is more expensive to administer, but typically obtains a more representative sample of patients, and can potentially include more clinically important data.

Management Processes Scale

The management processes scale was constructed by giving a point for accreditation, and points for each type of monitoring activity used. Additional points (up to 2) were added for sharing the results with executives (1 point) and clinicians (1 point).

Table 11. Management Processes Scale Scores
(Available points: 13)

Scale score points	Number in category		
1 to 5	5		
6 or 7	16	Average score	7.3
8 to 13	6	Range	1 to 13

Clinical Processes

Key Findings

- Eighty percent of cancer programs participate in clinical trials of some type, but only one-third of the programs participate in clinical trials involving CML.
- All cancer programs have access to national clinical guidelines. However, for half of the programs, guidelines use varies by oncologist practice patterns, and for half the programs guidelines are incorporated into practice protocols. In only 15 percent of cancer programs are guidelines incorporated into an EHR.
- A large majority of cancer programs (80 percent plus) schedule regular visits to check compliance with drug regimens and also check for drug side effects. However very few follow up between visits about whether drug prescriptions have been filled (41 percent), and only one program has specific policies or guidelines concerning actions to ensure compliance.

A number of questions were asked about clinical processes to assess indicators of quality, including questions about whether the cancer programs conducted clinical trials, used clinical guidelines, or used processes to improve drug regimen compliance.

Participating in clinical trials is seen as an indicator of quality because of the rigorous approval process required to conduct trials and the oversight during trials. In Table 12, the percentage of cancer programs participating in clinical trials is presented.

The table indicates that just over one-third of the cancer programs participate directly in CML clinical trials. A larger share, more than half, participated in clinical trials with other small-population cancers. Another third of the cancer programs participate in clinical trials through partnerships with other centers or facilities. Only one in five cancer programs does not participate in clinical trials at all.

Table 12. Percentage of Cancer Programs Conducting Clinical Trials, by Type of Clinical Trial

CML trials	36%
Other small-population trials	52
Clinical trials through partnerships	32
Other clinical trials	24
No clinical trials	16
Not approved for clinical trials	4

N=25

Another indicator of higher quality is the routine use of clinical guidelines. Two question sets were asked about clinical guidelines: first, whether guidelines are used for managing CML, and the second asking how guidelines are incorporated into clinical practice.

In Table 13, the percentage of cancer programs using national guidelines, or that have adapted (modified) guidelines for their own use, or that have developed their own guidelines is given.

Table 13. Percentage of Cancer Programs Using Clinical Guidelines

Have access to and use national guidelines	93%
Have modified national guidelines for own use	52
Have developed own guidelines	15

Almost all cancer programs have access to and use national guidelines (such as those from NCCN) for treatment of CML and other small-population cancers, and almost half of those have also adapted (modified) those guidelines to some extent to fit their particular situations. A few cancer programs with access to national guidelines have developed their own guidelines, although they have access to national guidelines. Only one respondent indicated that his or her cancer program developed its own guidelines and that clinicians at the program don't have access to national guidelines.

In Table 14, information is presented on how those guidelines are incorporated into the practice pattern of the oncologists.

Table 14. Percentage of Cancer Programs Incorporating CML Guidelines into the Practice Pattern of the Oncologists, by How Incorporated

Guidelines incorporated into EHR	15%
Guidelines incorporated into practice protocols	54
Guidelines part of QA policies	31
Guidelines use varies by oncologist	50

N=26

CML-related guidelines are only rarely incorporated into EHRs. However, in about half the cancer programs guidelines are part of practice protocols, while in another half guidelines use is said to vary, depending on the practice pattern of the oncologist. While all cancer programs have access to clinical guidelines, it appears that only half of the programs have fully integrated the guidelines into the physician's practice.

In the treatment of CML, new therapies have rendered the disease chronic rather than rapidly fatal. As a result, much of the effort that focused on acute care has now been extended into a chronic care environment. Since the therapies are not curative, they must be continued indefinitely, or else the condition may reassert itself. As a result, a key element in effective treatment is ensuring that the patient acquires the drugs and continues to take the drugs through his or her life. The drugs are expensive and can have side effects.

As a result of the new therapies, effective treatment means continuous management of the drug regimen. Specific approaches taken by cancer programs to ensure drug compliance are presented below in Table 15.

Table 15. Percentage of Cancer Programs with Indicated Processes in Place to Ensure Patient Compliance with Cancer Drug Regimen and Treatment Protocols

Regular oncology visits scheduled	85%
Drug side effects assessed at visits	81
Phone follow-up for missed appointments	78
Support service needs assessed at visits	70
Phone follow-up if prescriptions not obtained	41
Specific policies or guidelines for non-compliance	4

Most programs' oncologists schedule regular oncology visits for CML patients, assess drug side effects, and initiate phone follow-ups for missed appointments. Also, most programs assess support service needs at each visit.

Less than half of the cancer programs follow up with the patient if a prescription is not obtained, in large part because those programs don't know whether a prescription was obtained until the patient's next visit. Very few programs—only one—have a specific policy ensuring drug compliance for CML patients.

Clinical Processes Scale

If the cancer program was involved in conducting clinical trials for CML, or other small-population cancers, one point was assigned.

All programs were found to have access to clinical guidelines, so access did not differentiate the programs.

If clinical guidelines were incorporated into practice through protocols, electronic medical records, or as a consistent part of QA standards, the cancer program received one point. If respondents rated their program above average or well above average on use of tumor boards and on use of hematology conferences, they received a point for each. Finally, programs received a point each (up to 5 points) for specific drug regimen compliance activities. The scale items and percentages of cancer programs receiving points are given below:

- Conduct clinical trials (56 percent)
- Use of tumor boards (above average or well above average) (67 percent)
- Use of hematology conferences (above average or well above average) (56 percent)
- Incorporate clinical guidelines into standard practice (56 percent)
- Use specific practices to ensure compliance with therapeutic drug regimens:
  - Scheduled regular oncology visits (85 percent)
  - Visits include assessment of support service needs (70 percent)
  - Visits include assessment of drug side effects (81 percent)
  - Phone follow-up for missed appointment (78 percent)
  - Phone follow-up if patient fails to obtain prescriptions (41 percent)
- Have a policy regarding patient non-compliance (4 percent)

Table 16. Clinical Processes Scale Scores
       (Available points: 10)

Scale score points	Number in category		
1 to 5	7	Average score	5.9
6 or 7	13	Range	1 to 10
8 to 10	7		

Support Processes

Key Findings

- Among support staff, those most closely involved in direct clinical care (RNs, social workers, and nutritionists) are most likely to have participated in CML-specific training.

- EHRs have become widespread in cancer programs, but tailoring to CML has occurred only in a minority of programs.

- Most (89 percent) of responding cancer programs offer at least some form of support staff training about CML.

Support processes are practices and procedures designed to improve the provision of support services for CML patients. A series of questions was asked concerned with the following:
- Are there policies and related checklists and forms to help assess the CML patient's support needs?
- What CML-specific training and experience do support staff have?
- What procedures and activities are there to ensure effective communication of support staff with each other, with physicians, and with patients?
- What education opportunities are support staff afforded annually to maintain their currency with CML and other small-population cancers?

In Table 17, the percentage of cancer programs that use policies, checklists, forms or guidelines for the assessment of CML patients' support needs is indicated.

Table 17. Percentage of Cancer Programs that Have Policies, Checklists or Forms, or Guidelines for the Assessment of CML Support Needs

Policies	57%
Checklists/forms	50
Guidelines	67

N=27

Two-thirds of the cancer programs follow guidelines for making needs assessments for patient support services, and more than half of respondents have developed policies about assessments, with most of those developing policies also developing checklists or forms to help implement the policies.

A key element in the ACCC initiative is to provide education and educational resources to clinical and support professionals concerning effective management of CML. In Table 18, the percentage of cancer programs with support staff having CML-specific training or experience is provided.

Table 18. Percentage of Cancer Programs Providing CML-specific Training to Support Staff, by Type of Support Staff

Oncology RNs	78%
Social workers	56
Nutritionists	48
Mental health counselors	33
Patient navigators	26
Financial counselors	22
Administrative support staff	22

N=27

The results indicate that as the support function moves away from more direct care towards administrative or financial support, the support staff is less likely to have any CML-specific training.

Given that the financial implications of CML drug costs can be unique and somewhat daunting, even financial counselors would benefit from training about CML and its costs, including the cost of support services.

An important component of support services is coordination among support and clinical team members. For example, effective coordination requires communication among the different providers with the patient and family. In Table 19, the percentage of cancer programs using different techniques to promote effective communication is indicated.

Table 19. Percentage of Cancer Programs Using Indicated Method of Communication Among Clinical and Support Professionals

Informal conversations	69%
Support professionals attend tumor boards	62
Automatic notification of missed appointments	42
Support team meets following initial visits	23
EHR flags important information	19
Only limited communication	12

N=26

Only 12 percent of cancer programs indicate that communication with and among support professionals is limited. However, for most programs the opportunities for communication seem to rest mostly on informal conversations. In less than half of the programs is there automatic notification of support staff if an appointment is missed, and the support team meets after the initial patient visit in less than 25

percent of respondents. EHRs are becoming fairly common in oncology practices, but the EHR is not yet in widespread use for support services around CML and other small-population cancers.

Table 20 shows the percentage of cancer programs offering a broad array of approaches to educating support staff about CML.

Table 20. Percentage of Cancer Programs Offering the Following Approaches for Support Staff Training About CML

Invited speakers	67%
Vendor sponsored sessions	56
In-house training sessions	48
Periodic tumor boards	44
Continuing education requirements	30
Individual initiative only	30

N=27

Table 20 indicates that many cancer programs have offered a variety of education sessions for support during the past year that include information on CML. All told, 89 percent of the cancer programs offer some form of support staff education (other than the "individual initiative" response) focused on the specifics of CML and other small-population cancers. However, only about one-third of the programs have built CML and other small-population cancer training into CEU requirements.

Support Processes Scale

To construct the "support processes" scale score, the following items were assigned a point each and aggregated:

- Policies/checklists regarding support assessment (almost always required or used) (56%)
- Use of guidelines in support assessment (almost always required or used) (67%)
- CML-specific training of support staff (percent with moderate training/experience or more)
  - Oncology RNs (78%)
  - Social workers (56%)
  - Mental health counselors (33%)
  - Patient navigators (26%)
  - Financial counselors (22%)
  - Nutritionists (48%)
  - Fertility counselors (15%)
  - Physical/occupational therapists (19%)
  - Spiritual counselors (11%)
  - Administrative support staff (22%)
- Effective communication among clinical and support personnel and patients
  - Automatic notification of missed appointments (41%)
  - EHR/EMR flags important information (19%)
  - Support personnel attend tumor/hematology boards (59%)
  - Support team meets following initial visit (22%)

- - - o   Informal conversations among clinical/support personnel (67%)
  - Education opportunities
    - o   CEU requirements (30%)
    - o   In-house training (48%)
    - o   Vendor-sponsored information sessions (56%)
    - o   Periodic tumor boards (44%)
    - o   Periodic hematology boards (26%)
    - o   Grand rounds (22%)
    - o   Invited speakers (67%)

Table 21. Support Processes Scale Scores
>   (Available points: 24)

Scale score points	Number in category
1 to 5	5
6 to 9	11
10 to 21	11

Average score	9.2
Range	1 to 21

Results

Section 4. Effective Performance

Respondents were asked to rate the clinical and support performance of their cancer programs on a wide range of parameters. The ratings used a 5-point scale (well below average, below average, average, above average, and well above average). The results of these assessments are given below.

Clinical performance

> **Key Findings**
>
> - Most respondents gave their cancer programs a very high clinical performance rating (56 percent of the respondents gave their program an above or well above average rating on all five measures).
>
> - A particularly important finding is that most (85 percent or more) of respondents assess their clinicians' knowledge of latest CML research and use of effective treatments to be above or well above average.

Clinical performance was measured by whether the cancer programs' treatments were effective and oncologists were up to date, whether the programs managed patient transitions (to other centers or practices) well, and whether patients were satisfied with care and experiencing good outcomes.

The clinical performance (self-rating) results are presented in Table 22. The Table depicts the percentage of respondents giving their programs the highest rating of well above average on each of five scales.

> **Table 22. Percentage of Cancer Programs Rating Their Performance as Well Above Average on the Following Scales**
>
> | | | |
> |---|---|---|
> | Oncologists abreast of CML research | 52% | (N=25) |
> | Oncologists use most effective CML therapies | 43 | (N=23) |
> | Transitions and referrals to and from other major cancer centers | 35 | (N=23) |
> | CML patients' satisfaction with care | 52 | (N=23) |
> | CML patient outcomes (survival, quality of life) | 26 | (N=23) |
>
> *Note: Performance scale is a five-point scale from 1 (well below average) to 5 (well above average).*

The respondents give their cancer programs very high ratings on the clinical performance measures. The most likely explanation is that these programs responded fully to the survey because they are more focused on these conditions than cancer programs that did not respond. In other words, there is likely a response bias encouraging the response of programs that have more effective processes in place to manage CML effectively.

If above average is combined with well above average (data not shown), then more than 80 percent of the respondents give their cancer program the above or well above average rating on four of the five scales. For example, 87 percent of the respondents rate their program above or well above average on the outcomes measure (quality of life, survival).

On the questions involving "oncologists abreast of CML research" and "oncologist use most effective CML therapies," more than 40 percent of the respondents rate their program well above average, and more than 85 percent of the programs rate their clinicians above or well above average. Most of the respondents, then, view their program as effective in their clinical performance (on the chosen measures).

Clinical Performance Scale

The clinical performance scale was constructed from the question asking respondents to rate their program on eight clinical parameters. The scale assigned a point for each parameter that was rated above average or well above average on five of the eight items (shown in Table 23), for a total of five possible points.

- Oncologists abreast of latest CML research (88%)
- Oncologists' use most effective therapies (87%)
- Transitions and referrals (74%)
- Satisfaction with care (91%)
- CML outcomes (survival, quality of life) (87%)

Table 23. Clinical Performance Scale Scores
       (Available points: 5)

Scale score points	Number in category		
0 to 3	5	Average score	4.0
4	6	Range	0 to 5
5	14		

Support Services Performance

Key Findings

- Quality and effectiveness of support services are rated lower than clinical performance.

- On one critical item, responsive to patients, 85 percent of respondents rated the effectiveness of support services as above average or well above average.

Cancer programs were asked to rate their programs' performance on seven parameters indicative of quality of support services. The parameters were rated on a 5-point scale running from 1 (well below average) to 5 (well above average). The results are presented in Table 24.

A smaller percentage of the respondents rated their support services performance as highly as their clinical performance, with one exception.

The percentage of respondents ranking their program's performance as above or well above average was well below 50 percent on three items and in the 50 percent range for two other items (use guidelines and monitoring drug compliance). However, on a very critical item, responsive to patients, 85 percent of the cancer programs rated their performance as above average or well above average.

Table 24. Percentage of Cancer Programs Rating Quality and Effectiveness of Support Services for CML as Above Average or Well Above Average

Responsive to patients	85%
Comprehensive services	63
Monitoring drug compliance	52
Use of clinical guidelines	48
Education on drug interactions	37
Current on CML research	33
Protocols	30

N=27

The three items with the lowest percentage of above average ratings involved education about drug interactions, being current on CML research, and the use/availability of effective protocols for support services. A somewhat higher percentage (approximately 50 percent) rated themselves above average on use of clinical guidelines in support services and on monitoring drug compliance.

Support Performance Scale

This scale was constructed from the question asking respondents to rate the performance of the support staff at their cancer program on seven parameters. Again, a program was given a point for each

item in which an above average or well above average rating was given, for a maximum scale score of seven. Specific items in the rating were as follows:

- Comprehensiveness of support services (63%)
- Use of clinical guidelines (48%)
- Support staff abreast of CML research (33%)
- Monitoring of patient compliance with drug therapy (52%)
- Effective protocols for support services (30%)
- Education on drug interactions (37%)
- Responsiveness to patient concerns and questions (85%)

Table 25. Support Performance Scale Scores
        (Available points: 7)

Scale score points	Number in category
0 to 2	9
3 to 5	12
6 to 7	6

Average score	3.5
Range	0 to 7

Summary of Scale Scores

The total "effective practices" score is the weighted sum of the seven individual scale scores. The subscales were weighted by dividing each actual scale score by the average score for that scale and then summing across all the scales to compute an overall score with each individual scale receiving equal weight. The total scale score averaged 7.0 (the subscales were normalized and the total represented the sum of the seven subscales). The scale scores of individual cancer programs ranged from 2.8 to 11.1.

Table 26. Summary of Scale Scores

	Available Points	Average Score
Clinical resources	12	8.1
Support resources	40	17.8
Management processes	13	7.3
Clinical processes	10	5.9
Support processes	24	9.2
Clinical performance	5	4.0
Support performance	7	3.5

Conclusions and Next Steps

The Need for Resources and Education

Because CML and other small-population cancers are rare, community cancer programs will see few cases. As a result, direct daily experience (which will be lacking) will have to be supplemented or replaced by easily accessible third-party information, including guidelines, educational programs, and expert consults provided by third parties such as NCCN, ACCC, the Leukemia & Lymphoma Society, or ACCC-organized Community Resource Centers (CRCs).

ACCC's CRCs will specialize in a particular small-population cancer (such as CML) and, with support from ACCC, share their expertise and resources with other community cancer programs. These Community Resource Centers, which will be organized by ACCC, should provide a useful advance towards more effective management of CML and other small-population cancers throughout the nation.

Identified through the survey process and in-depth follow-up interviews, ACCC's advisory panel selected four cancer programs to serve as ACCC's CML CRCs:

- Florida Hospital Waterman Cancer Institute, Tavares, Fla.
- Harbin Clinic, Rome, Ga.
- Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, Grass Valley, Calif.
- The Nebraska Medical Center, Omaha, Nebr.

Providers across the country can contact the CRCs, whose members will act as mentors and facilitators to assist ACCC-member programs by providing timely information, advice, and responses to questions about care for patients with CML.

For support staff, especially those who are not directly tied in to clinical care, education may be the more important effectiveness factor, by raising awareness of the special needs of patients with CML or other small-population cancers. For example, with CML, long-term survival means that a new set of financial, drug compliance, and social issues come into play. Support staff can play a big role in helping patients successfully cope with the new set of issues arising with a chronic condition. Education about treatment costs, drug side effects, drug compliance, and patient prospects need to be part of the support staff's annual training.

The Need to Incorporate Guidelines

Clinical guidelines for treatment of CML and other cancers were found to be generally available (purchased by the group or the cancer center) to clinicians at cancer centers, but those guidelines are not yet universally incorporated into protocols. Only about half of the cancer programs have incorporated clinical guidelines into protocols, and only 15 percent have guidelines incorporated into their EHR.

ACCC can support the introduction of protocols and of EHR-based protocols in particular by highlighting those cancer programs with effective protocols and EHR applications, and pointing out how processes

and outcomes have been affected at those institutions. This focus on effectiveness should raise the awareness levels of those programs without guideline-supported protocols.

For support staff, about two-thirds have access to guidelines, and about half of the cancer programs have incorporated guidelines into the support staff's daily round by having policies, or by having forms or checklists to help implement the policies.

The Need for More Effective Use of Health Information Technology
Even the most effective programs face challenges with health information technology. Often, there are multiple EHR systems with little interoperability.

The Need for More Sophisticated Ways to Monitor Medication Compliance
Cancer programs do manage side effects, educate patients about drug therapy, and address many medication-management issues. But the one exception reveals a larger challenge: monitoring compliance. There appears to be a marked lack of tools to determine if a prescription was filled and whether a patient is adhering to therapy. That said, among most of the centers interviewed, the support offered by staff (ranging from the familiarity with patients to nutritional consults) appears to promote compliance/adherence with regimens. The patient-centered, team-based, supportive approach to care appears to create an environment in which patients will discuss their side effects or other issues rather than simply ceasing therapy.

Moving forward, the project will address all these needs, especially as they relate to long-term survivorship.

As we wrap up the first year of the project, the need for ACCC to develop resources is clear. A high percentage of survey respondents indicated they would like to see ACCC develop resources that target CML and other small-population cancers. In particular, respondents indicated they would like to see patient education resources, educational programs for professionals, and model policies and checklists. Most cancer programs will need continuing external support to help their clinicians remain current and their support services to be well targeted.

ACCC has already initiated a number of new resources in addition to its CML Community Resource Center:
- "ASK - Answers, Solutions, and Knowledge" is an active online discussion community dedicated to CML and is facilitated by CRC members.
- ACCC's CML web portal features patient education resources, professional resources, and news, as well as peer-reviewed articles.
- Six podcasts are online, hosted by Dr. Stuart Goldberg and Dr. Terrance Cescon, about issues associated with drug resistance, tyrosine kinase inhibitors, and appropriate use of the PCR test.
- The "Effective Practices in CML" webinar is posted on ACCC's website.
- A number of postings about CML have appeared on ACCC's blog, "ACCCbuzz," and on ACCC's members-only online community.

As the project continues into the second year, ACCC will continue to offer expertise, resources, and guidance to the ACCC membership about caring for patients with CML as well as addressing the gaps in knowledge and needs identified during year one.

TREATING SMALL-POPULATION CANCERS

An education program from
ACCC's Center for Provider Education

Identifying Exemplary Programs

The survey results allowed ACCC, in consultation with the advisory board and the H2R team, to identify cancer programs that offer exemplary services for managing and treating CML patients. Five were selected, based on survey responses and geography: Sutter Medical Center, Sacramento, Calif.; Florida Hospital Waterman Cancer Institute, Tavares, Fla.; Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, Grass Valley, Calif.; The Nebraska Medical Center, Omaha, Neb.; and Lexington Medical Center in West Columbia, S.C. Their survey responses suggested effective strategies and innovative tools for management of patients with CML.

In-depth interviews were conducted with each of these centers, which yielded deeper insights into effective practices. ACCC also invited four of these cancer programs—Florida Hospital Waterman Cancer Institute, Sutter Medical Center, Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, and The Nebraska Medical Center—to become ACCC Community Resource Centers.

Detailed interviews with specific cancer centers whose survey responses suggested patterns of effective strategies and innovative tools for management of patients with CML provided greater insights into effective practices. The interviews also yielded specific examples—some of which can be embraced by other community cancer centers. From these interviews, discussions with the advisory panel and the analysis of the surveys, we identified 13 "domains," or factors, that may increase the likelihood that a cancer program is performing at a higher level than other institutions.

The 13 Domains

1. **Accreditation.** Effective programs are accredited. Most responding cancer programs received accreditation through the American College of Surgeons' Commission on Cancer or the American Society of Clinical Oncology Quality Oncology Practice Initiative.

2. **Clinical guidelines.** Most cancer program oncologists and support staff have access to a set of clinical guidelines for CML (such as those offered by the National Comprehensive Cancer Network). Many effective programs incorporate the guidelines into protocols (in some cases, into the electronic health record) or have them integrated into quality assurance policies.

3. **Managing drug therapies.** Tyrosine kinase inhibitor therapies, or TKIs, have transformed the treatment of CML. Effective use of those therapies includes not only clinical diligence in assessing drug side effects and monitoring the progress of the disease, but also managing the financial issues facing the patient. The drugs are very expensive, and many of the centers surveyed work to ensure that uninsured or underinsured patients have access to them. The more effective programs assess drug side effects during visits and make sure patients purchase their drugs and use them appropriately between visits. Florida Hospital Waterman Cancer

Institute prescribes medicine one month at a time to monitor compliance. Nurses discuss medication and side effects, provide extensive education—in person and via handouts—about the therapy and side effects, and monitor lab work. If necessary, someone from Florida Hospital Waterman Cancer Institute will check on the home situation to identify challenges to adherence. At Sutter Medical Center, and at Sierra Nevada's Comprehensive Community Cancer Center, patients bring in their medications and nurses count pills. Nutrition consults, timely lab tests and easy access to the physician and social worker are three effective ways Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, helps address side effects; Sutter Medical Center cites education, care coordination, dietitians, and pharmacy support (including access to an infusion center). At The Nebraska Medical Center, the physician or outpatient midlevel can assess a patient same day. Moreover, because the providers have such focused areas of expertise (and extensive experience) they know, for instance, that a rash may not be just a rash; it could be a sign of something serious. This, of course, is true of other cancer programs, too; nurses can assess the side-effect symptoms and respond accordingly.

4. **Immediate and long-term patient monitoring.** Effective management includes care monitoring through follow-up physician visits at appropriate intervals. In addition to clinical monitoring (physical exam, blood counts, metabolic panel), effective programs also include monitoring for support service needs. Closely following guidelines allows patients to get the optimal treatment when they need it. At the Nebraska Medical Center, adherence to guidelines allows for early referral (to trials or transplantation) of patients not responding to therapy. Long-term monitoring is required since the patient is not cured by the therapies, but instead is stabilized with an ongoing need for the drug therapies to be continued and monitored.

5. **Team-based, coordinated care.** Many successful programs take a team-based approach, deploying case managers/navigators to coordinate care. At Sierra Nevada's Comprehensive Community Cancer Center, a relatively small cancer center, everyone is part of the team. Patient familiarity with the staff and staff familiarity with the patient ensure continuity of care. Volunteers are trained to watch for signs of distress and inform a staff member. The nutritionist and social worker are on site, so the nurse can just walk someone down the hall to get the services they need. During chart rounds, the entire staff comes together to discuss a patient, compare notes and discuss issues that have arisen. Sierra Nevada also offers a pain-management team, including palliative care physician. At The Nebraska Medical Center, each physician is paired with an RN case manager who coordinates the patient's care. Generally, the team focuses on a particular type of cancer.

Sutter Medical Center has a separate hematology/pathology tumor board that includes physicians—including a pathologist—pharmacists, and nurses. It also includes support staff—social worker, nutritionist, care coordinator, financial coordinator, and sometimes the nutritionist. They work together to formulate a best-practice treatment plan. In addition, Sutter has a weekly steering committee meeting to discuss patients, regardless of disease, who are getting ready for transplant. Florida Hospital Waterman Cancer Institute takes a multidisciplinary team approach to care: Clinical and non-clinical staff sit in on the cancer conference, which sometimes includes physicians from other practices. The specialists coordinate closely with the primary care physicians (although they don't generally attend the cancer conference). Informal meetings on patient care keep the entire team apprised. The center has low turnover–none in the last two years–so patients and staff bond. As with Sierra Nevada, another smaller center, patient familiarity helps ensure continuity of care.

6. **Support services.** Most cancer programs provide access to a broad array of support services, including financial support, emotional or mental health support, and patient education. A key to effective provision of support services is a staff professional (RN, social worker) to help the patient or family navigate among the needed clinical and support services, some of which may be provided by external organizations. Immediately upon diagnosis, Sutter Medical Center will conduct a psych-social assessment and identify any needs, including financial, caregiver and transportation concerns. The social worker meets with each patient in person. It offers music therapy, art therapy, pet therapy, dance therapy, massage therapy, etc. (These therapists must be certified in their fields and trained by Sutter Medical Center). It also offers a variety of on-site support groups, including one for children of cancer patients. For inpatients, music therapists go into patient rooms and take requests. It has an integrative medicine program that includes yoga, nutritional supplements and acupuncture (the latter is offered offsite). The Nebraska Medical Center provides some support services on site and works closely with the Leukemia & Lymphoma Society for others. At Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, the social worker and nutritionist are both on site and in the same building, so patients can receive the support services they need right away. The center uses a distress scale (modified from one provided by the American Cancer Society) to assess a patient's support needs. Volunteers are trained to monitor for signs of depression or distress and report them to the staff. It provides an array of support services, including patient navigation, collaboration with major medical centers and free psychological and nutritional support. It also offers 19 support groups. Some of these are disease focused, but others, such as those devoted to writing and art, are not. Florida Hospital Waterman Cancer Institute also uses the ACS distress scale. The social worker's office is in the waiting area, and patients are welcome to call or drop in. A monthly Leukemia & Lymphoma Society meeting (run by a nurse) is conducted onsite. Waterman offers a general cancer support group as well as one for lymphoma and leukemia. Other support services include pet therapy ("puppy day"), twice-weekly high teas (which creates bonding and socialization in the waiting area), and pastoral care.

7. **Financial guidance/assistance.** Most centers provide in-house financial support services. Sutter Medical Center, for example, helps patients complete paperwork for disability, Family & Medical Leave Act, scholarships, etc. It connects patients with programs, such as those through pharmaceutical companies, transportation options through the American Cancer Society and assistance through the Leukemia & Lymphoma Society. At Florida Hospital Waterman Cancer Institute, the social worker and financial counselor have a robust–and ever-growing—list of resources for patients who need assistance. They can be referred to the appropriate community agencies and/or to the Leukemia & Lymphoma Society. The team actively gathers information on assistance resources from national meetings, networking, pharmaceutical reps and professional organizations, such as the Lake County Oncology Nursing Society.

8. **Monitoring of processes and outcomes.** Systematic monitoring of patient outcomes (and patient satisfaction) provides a gauge of how well a program and its clinical staff are doing. An effective program will systematically monitor performance to target improvements. Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, uses a cancer registry to monitor patient outcomes; it has followed each of its cancer patients since 1995. In addition, the weekly tumor board is routinely attended by 50 healthcare professionals (25 physicians, 25 allied health professionals), including the non-oncology physician. At The Nebraska Medical Center, the tumor board (or "bone marrow conference") is a multidisciplinary conference that includes the nurse case manager, the social worker and other non-MD team members. Many successful centers also assess patient experience, using the feedback to drive quality improvement. The Nebraska Medical Center, among others, uses Press Ganey to send surveys to

oncology patients; the responses can be broken down by diagnoses so each provider team can review its results. Certain metrics can be targeted for improvement. One recent target: management of and education about side effects. The Nebraska Medical Center began updating its printed information, determining the best time to provide such information, and coordinating with the case manager. The center now provides written information in a "nice packet" for patients to review at their leisure, and the provider team offers ongoing reinforcement. As a result, the satisfaction scores have improved. Sutter Medical Center and Florida Hospital Waterman Cancer Institute also share Press Ganey results with the entire team. At Sutter Medical Center, all managers and directors review the scores during a weekly meeting, results are published in a weekly internal newsletter. On the inpatient side, each floor posts its results.

9. **Meaningful use of health IT**. From integrating guidelines into the EHR to the use of registries, many successful programs use health information technology to improve processes and procedures. At Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, the entire provider team can access the hospital medical record system, including support staff. Clinicians enter notes, as do the nutritionist and the social worker. All lab and radiology reports are available; so are ER visits. The center was able to increase the number of patients who visited with the nutritionist by flagging the records for the receptionist. The receptionist would remind the patients. Nutrition consults increased 15 percent (the target) almost immediately.

10. **Annual CML training for staff professionals.** Annual CML training for clinical and support professionals keeps them up-to-date on new therapies and processes and up-to-speed on existing ones. Direct patient experience is more limited for small-population cancers, making training an important component of remaining current. At Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, some of the training is handled by physicians: The social worker meets with the physician to discuss each CML patient and identify what the specific needs and/or challenges may be. At Florida Hospital Waterman Cancer Institute, staff can attend LLS programs on site. Most of the nurses also get ongoing education through the Lake County Oncology Nursing Society.

11. **Patient education.** Effective programs provide systematic patient education about CML and about how to effectively manage both the condition and one's life, given the illness. Patient education can take many forms, including brochures, group or individual educational sessions, mentoring relationships and support groups. At Sutter Medical Center, the physician explains the diagnosis; the RN then confirms the patient understands, and addresses the patient's concerns. The patient receives a booklet–available in English and Spanish–about leukemia, and the caregiver receives a similar one targeted at caregivers. Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, makes extensive use of the free resources from NCI and is working on updating its webpage so patients will have a single portal to access a range of educational materials. Specifically mentioned as a good resource: Johns Hopkins Medicine: *Patients' Guide to Leukemia*. Florida Hospital Waterman Cancer Institute provides extensive handouts to patients–much of it from ACS or LLS. It has a dedicated library and patients can access information from home through the center's website.

12. **Access.** Many effective programs provide patient access to services beyond traditional schedules. For instance, The Nebraska Medical Center staffs its infusion center 24/7; it functions as an emergency department for cancer patients, including those with CML. Patients who have issues after hours can go to the center and be seen by a resident immediately. At several of the centers interviewed, labwork doesn't necessarily need to be scheduled in advance; it is available on site on an as-needed basis. For example, at Florida Hospital Waterman Cancer Institute, if a

patient is worried, he or she can come in and have blood work done. (It's cheaper than having the anxiety fester; that could lead to a costly ER visit.) Florida Waterman doesn't have 24-hour access to the clinic, but patients have 24-hour access to a staff member who can either meet them at the ER or open the clinic and meet them there. Many patients also have their doctor's personal cell number.

13. **Outreach and early intervention.** Sutter Medical Center prides itself on early intervention. It actively markets to area emergency departments and lets them know that it has an acute leukemia program. Sutter is a transplant center, and it promotes its program actively in the community. As a result, it is able to achieve earlier diagnosis and treatment.

Opportunities for Education and Support

The surveys, the interviews, and subsequent discussions with Advisory Board members revealed several deficiencies in these 13 domains, especially in the use of health information technology and in some aspects of medication management and compliance.

Effective use of health IT: Even the best practices face challenges here. Often, there are multiple EHR systems–for example, one for the hospital, one for the private practice, and sometimes a different one for the cancer center – and often, there is little interoperability. One of the centers surveyed (Florida Hospital Waterman Cancer Institute) explained that it is working toward health IT interoperability, but there are challenges. It has three different HIT systems at play: the hospital's EMR system (Cerner); the cancer center's (Alexis Mosaic) and Lake County Oncology's (Onco EMR). The cancer registry is populated by the hospital's EHR; the practices' data need to be scanned in.

Medication management/compliance. Most of the cancer programs surveyed have procedures in place to manage side effects, educate patients about drug therapy, and address many medication-management issues. But one exception reveals a larger challenge: monitoring compliance. Pill counting is the most common approach to monitoring compliance; there appears to be a marked lack of tools to determine if a prescription was filled and whether a patient is adhering to therapy. That said, among the cancer programs interviewed, the support offered by staff (ranging from the familiarity with patients to nutritional consults) appears to promote compliance/adherence with regimens. The patient-centered, team-based, supportive approach to care appears to create an environment in which patients will discuss their side effects or other issue rather than simply ceasing therapy.

Profiles of Five Centers

Site 1: Florida Hospital Waterman Cancer Institute

Florida Hospital Waterman Cancer Institute (FHWCI), Tavares, Fla., has a case load of 500-799 cancer patients, 25-99 have CML. The program takes a collaborative, multidisciplinary team approach to care. The hospital is a 204-bed acute care facility.

For CML patients, the social worker handles care coordination. Clinical and non-clinical staff sit in on the cancer conference, which sometimes include physicians from other practices. The specialists coordinate closely with the primary care physicians, although they don't generally attend the cancer conference.

"It's all about communication," says David S. DeProspero, MA, FHWCI's director. Physicians talk to each other and to the staff; there are not many egos in the program, he says.

In addition to regularly scheduled meetings, physicians and staff have informal discussions about patients' clinical, psychological, and financial concerns.

Barbara Jean Lane, RN, BSN, MS, OCN, CCRC, CCRP, the clinical research coordinator, adds that the physicians make detailed notes about the care plan for each patient, which also enhances care coordination.

The center has low turnover–none in the last two years–so patients and staff bond. Such familiarity helps ensure continuity of care, Lane says. It also leads to more coordinated care.

Connecting Patients to Resources

At FHWCI, the social worker and financial counselor choose from robust–and ever-growing in numbers—resources for patients. They can be referred to the appropriate community agencies and/or to The Leukemia & Lymphoma Society. The social worker can also help patients apply for Medicare or Medicaid–and if need be, put them in touch with the local Medicare advocate.

The team actively gathers information on assistance resources from national meetings, networking, pharmaceutical reps, and professional organizations, such as the Lake County Oncology Nursing Society.

FHWCI's cancer center offers a range of other support services, and the social worker (who coordinates care for the CML patients) is always available to chat. Her office is in the waiting area; patients are welcome to call or drop in. Patients often talk to a social worker about concerns more readily than they would speak with a clinical staff, Lane says.

Key Contacts and Stats

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Accreditation: American College of Surgeons Commission on Cancer (medical center)

Medical oncologists	4
Radiation oncologists	2
Surgical oncologists	1
General surgeons	4
Other physician specialties	1
Nurse practitioners	3

Board-certified in hematology 4
Oncology-certified RNs   3

The Institute uses the American Cancer Society distress scale to assess a patient's support needs. A monthly Leukemia & Lymphoma Society meeting (run by a nurse) is conducted onsite. Waterman offers a general cancer support group as well as one for lymphoma and leukemia. Support groups are of particular help to newly diagnosed patients who are going through a tough time, says Maen Hussein, MD, of Lake County Oncology & Hematology. Other support services include pet therapy ("puppy day"), twice-weekly high teas in the waiting area, which creates bonding and socialization, and pastoral care.

Because most support services are offered onsite, care is coordinated and patients don't have to travel to get what they need.

DeProspero adds that the campus itself contributes to patient well-being. The facility was named one of the 20 prettiest in the country; patients are reassured by its beauty. FHWCI also offers free valet parking.

Access and Education
Another way FHWCI supports patients is by providing access. If a patient is worried about her white cell count, she can come in and have blood work done. The hospital doesn't offer 24-hour clinic access, but patients have 24-hour access to a staff member who can meet them either at the ER or the clinic. Many patients also have their doctor's personal cell number. (One physician, on a mission in Haiti, nonetheless continued to speak with his patients by phone.)

Lane sees education as a way to relieve anxiety. FHWCI provides extensive handouts to patients–much of it from the American Cancer Society or The Leukemia & Lymphoma Society. It has a dedicated library and patients can access information from home through the Institute's website. Patients may not read the information right away, but when they wake at 2 am, anxious about their CML, they have access to many of the answers they need, either through the Internet or in the handouts, Lane says. It provides reassurance. Patients also have access to education onsite, such as during the monthly Leukemia & Lymphoma Society meetings.

The staff is very open to answering questions about the information a patient finds, even if it appears questionable. Patients can bring in information they find online and, "We'll follow up and give them an answer. It may be hooey, but if it is, we'll tell them it's hooey." If the information is important enough for them to bring in, it merits a response, she says. It may be time-consuming to follow-up, but that sort of attention pays off in the long term.

Lane tells a story from her days as a home health nurse; the situation isn't related to CML, but it captures her approach to the value of patient-centered care. During one home visit, she spent 45 minutes trying to talk to an older woman. The woman was distracted and wasn't providing the information Lane needed. "Finally, I asked, 'what do you need me to do?'"

The woman was worried her dogs hadn't had been taken outside or fed. It took 10 minutes to take care of them. In 10 more minutes, Lane had all the information she needed.

"So sometimes, it may seem like it *takes* you a lot of time, but really, it can *cut down* a lot of time."

Translating the anecdote to CML is easy, she says. If, on a Friday morning, a CML patient is anxious, worried whether her white count is up, "Wouldn't it be easier to come in, have a CBC done and find out?" Not doing so may mean the patient presents at the ER on Saturday. Doing the lab work saves time and money in the long run–and reassures the patient, Lane explains.

Education and Training
Staff can attend the Leukemia & Lymphoma Society programs onsite. Most nurses also get ongoing education through the Lake County Oncology Nursing Society. The nutritionist specializes in oncology and has attended several CML education programs. She works with patients to identify their needs.

Clinicians attend meetings and invited speakers have come to speak on CML advances.

Medication Management
Florida Hospital Waterman Cancer Institute prescribes medicine one month at a time to monitor compliance. "When they don't request a refill, we know there's something wrong," says Lane.

Nurses discuss medication and side effects, provide extensive education in person and via handouts about the therapy and side effects, and monitor labwork. If necessary, someone from FHWCI will check on the home situation to identify challenges to adherence.

There's no generic approach; it depends on the care plan for each patient. "A 30-year old may forget to take his pills. A 90-year old may be playing checkers with them," says Lane. Nurses are trained to deal with treatment side effects and understand the side-effect profile of each drug. They get first call; if they can't manage the problem they have the patient come in to be evaluated. Only nurses or physicians deal with side-effect issues, because it's a medical issue, Hussein explains.

Pharmaceutical companies provide abundant resources, including printed material and in-service presentations, to help clinicians manage side effects,

Adherence
One of the things FHWCI indicates that it does exceptionally well is promote adherence to treatment *and* appointments. Part of that is attributable to education and communication, Hussein says: explaining to patients the importance of close follow-up to avoid delaying the discovery of resistance or progression.

Adherence also involves follow-up.

Patients are called the day before their appointment, they are called immediately when they miss an appointment and, if there's no answer, they get another call the following day. If that's unsuccessful, the staff sends out a letter. In addition, clinical and support professionals are automatically notified of missed appointments.

Although there is a protocol in place, noncompliance isn't a problem, says Lane. She attributes that largely to the sense of community. DeProspero says it relates to their overarching philosophy—a patient-centered approach to care.

Guidelines, Protocols, and Surveys
Clinicians follow ASCO and NCCN guidelines in general but tailor therapy to each patient's needs. "Guidelines are to guide us, not to dictate to us," Hussein said, adding FHWCI is in the process of incorporating guidelines into its protocols and EMR, but none of them are specific to CML. (Guidelines on addressing side effects of CML therapy are incorporated into the workflows.)

The organization is working toward health IT interoperability, but there are challenges. One of them is that there are three different HIT systems at play: the hospital's EMR system (Cerner); the cancer center's (Alexis Mosaic) and Lake County Oncology's (Onco EMR). The registry is populated by the hospital's EHR; the practices' data need to be scanned in.

FHWCI uses Press Ganey to assess patient satisfaction, but the results are not broken down by type of cancer.

Unlimited by Size
If Lane has a message for other smaller centers, it's this: Smaller centers such as FHWCI may not have the resources, "but we know where to find the resources." That may mean Internet research or a call to a larger center, "wherever we need to find the answer," she says. FHWCI will also refer to larger centers, if it's necessary.

But patients appreciate the environment, say Hussein, Lane, and DeProspero. The advantage of its size is that it's very personal; it's like a family, Lane says. The center is growing, but it strives to keep that sense of community.

"All of us live and work here in the area. These people are our friends and neighbors," Lane says.

"I hear from patients who have gone to larger centers that they feel like a number. Here, they don't," says Hussein.

Site 2: The Nebraska Medical Center Cancer Center

What sets the Cancer Center at The Nebraska Medical Center apart, says Ann Yager, cancer center director, is access and the expertise it offers as a major academic cancer program. Nebraska Medical Center, the teaching hospital for the University of Nebraska Medical Center, is a 624-bed acute-care bed facility. The cancer center has a case load of more than 1,000 cancer patients; however, it has fewer than five active CML cases. It generally sees five to nine new cases a year.

The Nebraska Medical Center Cancer Center offers same-day access–even after hours. It staffs its infusion center 24/7; it functions as an emergency department for cancer patients, including those with CML. Patients can go to the center any time and be seen by a resident, NP or PA —someone who can handle their issues immediately. If a patient's condition changes, the staff respond very quickly which, Yager explains, is essential to CML. Lab work is also done onsite.

Teamwork and Coordination
At The Nebraska Medical Center Cancer Center each physician is paired with an RN case manager who coordinates the patient's care. The team also includes NPs and PAs. Generally, the team focuses on a particular type of cancer. As an added advantage to patient and provider, the approach allows each nurse case manager to develop a real specialization in a type of cancer.

Key Contacts and Stats

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Accreditation
American College of Surgeons Commission on Cancer (medical center); American Society of Clinical Oncology; Quality Oncology Practice Initiative (QOPI) (oncology group); FACT; NCI; Founding member of NCCN

Medical oncologists	26
Radiation oncologists	5
Surgical oncologists	17
Nurse practitioners	3
Physician assistants	10
Board certified in hematology	5
Board-certified in hospice and palliative medicine	1
Oncology-certified RNs	29

The case manager and the physician are the primary coordinators of care. The Nebraska Medical Center Cancer Center has inpatient and outpatient case managers that communicate patient status and needs. A CML flow sheet helps case managers keep track of the patients' labs and treatment plan.

The nurse case manager works closely with the patient, family and providers, making sure the patient gets to appointments and is getting prescriptions filled.

The tumor board (or "bone marrow conference") is a multidisciplinary conference that includes the nurse case manager, the social worker, and other non-MD team members.

Guidelines and Protocols
The Nebraska Medical Center Cancer Center uses NCCN guidelines. They are "very straightforward," says Yager. The clinicians understand and follow them, although at present, they are not specifically written into any "concrete pathways."

Not only is The Nebraska Medical Center Cancer Center a member of NCCN, but one of its physician experts is the NCCN CML panel rep. Being part of developing the guidelines means utilization of those guidelines is a pretty natural transition.

At The Nebraska Medical Center Cancer Center, adherence to guidelines allows for early referral (to trials or transplantation) of patients not responding to therapy.

Health Information Technology
The Nebraska Medical Center Cancer Center has a largely paper-based records system, which is undergoing overhaul. "We are in the process of replacing our overall electronic health record across the organization," says Yager. It's moving from GE Centricity to EPIC. (The EPIC oncology module is called Beacon.)

The registries are separate from the EHR. They have two: The hospital-based tumor registry abstracts cases that are diagnosed or have first line of therapy at Nebraska. It lets them look at survival rates, etc. The Nebraska Medical Center Cancer Center also has a CML transplant registry. The two are not connected.

The website is also a "work in progress," Yager says. Once the new system is in place, she hopes to have a portal that allows patients to not only access educational information, but also their personal health records.

Assessing Satisfaction
The Nebraska Medical Center Cancer Center uses Press Ganey to send surveys to oncology patients; the responses can be broken down by diagnosis so each provider team can review its results. The results–as well as the comments–are reviewed by everyone involved. "We use those results to choose things to work on," she explains.

The center uses a "balanced scorecard" approach that requires each area to choose specific metrics to track and then develop appropriate performance improvement activities, she says.

Medication Management
One recent target for improvement: management of and patient education about side effects. The Nebraska Medical Center Cancer Center began updating its printed information, determining the best time to provide such information, and coordinating with the case manager. The center now provides written information in a "nice packet" for patients to review at their leisure, and the provider team offers ongoing reinforcement. The packet includes educational sheets the center has developed, as well as contact numbers for the staff. As a result, the satisfaction scores have improved.

Same-day access also helps enhance medication management. Moreover, because the providers have such focused areas of expertise they know, for instance, that a rash may not be just a rash– it could signal something serious, Yager says.

Frequent evaluation of patients, especially at initiation of a drug, helps increase adherence and decrease the incidence of side effects. When patients are first started on a therapy, the case manager will call the patient to verify they were able to pick up the medication. At each doctor's visit the case manager follows up with the patient to see if they need any refills or are having any difficulties taking their medication. Moreover, many of the specialty pharmacies make follow up calls with the patients and relay any variances to the case manager.

Long-term monitoring is required since the patient is not cured by the therapies, but instead is stabilized with an ongoing need for monitored drug therapies.

Ultimately, good medication management means sticking to guidelines for milestones (e.g., genetic testing). Yager says the philosophy is this: Stick to the guidelines--don't jump to the "latest and the greatest," because that limits options later on. "Don't change medications too soon."

Support groups also help a patient deal with side effects. Some of those are onsite; some are in the community.

"Unlike intravenous medications, the staff cannot document that the patient is actually taking the medication. We can only trust their verbal affirmation when we ask them. Having a single nurse case manager to communicate the patients' needs and difficulties helps keep that open communication with the doctor," explains Caralee Detwiler, RN, BSN, a case manager in the program. "The patients seem to trust the case manager since they know them by name and see them on a regular basis with the doctor. Therefore, the patients are more apt to disclose problems and/or difficulties that they experience with the medication that would prevent them from taking it consistently."

Patient Support Services
The Nebraska Medical Center Cancer Center offers an array of standard support services, and it works closely with The Leukemia & Lymphoma Society. The Leukemia & Lymphoma Society also provides patient-education resources.

The center also offers an innovative in-patient option–mostly for transplant patients—called cooperative care. Most of the care is provided by a care partner (a family member or friend) who stays with the patient. "It's a mix between a hotel room and a hospital room," says Yager.

Education and Training
Many support staff receive ongoing education around leukemia/lymphomas. In addition, there is constant dialogue among members of care teams. Finally, many of the residents and fellows who trained at Nebraska end up working there.

Site 3: Sierra Nevada Comprehensive Community Cancer Center

Sierra Nevada Memorial Hospital is a 121-bed acute hospital. Sierra Nevada Comprehensive Community Cancer Center (SNCCCC) serves a small rural area in northern California. The nearest major cancer centers, UC Davis and Stanford, are about two and four hours away, respectively. SNCCCC has a caseload of 300-499 cancer patients, of which 10-24 are CML patients. The center's cancer registry follows 2,000 patients. It received American College of Surgeons Commission on Cancer approval as a community hospital comprehensive cancer program in 1998.

Personal Attention

Asked what one thing sets Sierra Nevada Comprehensive Community Cancer Center apart, Ayse Turkseven, MA, CTR, SNCCCC's director, didn't hesitate: "I think it's the attention the person gets." Patient familiarity with the staff and staff familiarity with the patient ensure continuity of care, she says. "You can see if someone is pale, sweating, not walking well." In a larger organization, the physician or staff may not notice changes, she says. In fact, in other, larger centers, the patient may see a provider who is a virtual stranger. Not so at Sierra Nevada.

Key Contacts and Stats

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Accreditation: American College of Surgeons Commission on Cancer (medical center)

Medical oncologists	2
Radiation oncologists	2
Surgical oncologists	0
General surgeons	3
Other physician specialties	5
Nurse practitioners	0
Physician assistants	0

Board certified in hematology	2
Board certified in hospice and palliative medicine	1
Oncology-certified RNs	2

Even the volunteers who come in to play music for patients are trained to watch for signs of distress and depression and to let a staff member know. It's very much like a family, Turkseven says. Patients visit her in her office; she also runs into them at parties and while she's shopping.

"There's a support system for patients. If something's going wrong, they aren't just sitting in waiting room." They know the nurses, doctors, and support staff–including the nutritionist and social worker, who are housed on site. "It's a good safety net for our patients."

Support and Education

The center offers an array of support services; this fits into its approach to care. The disease is just one part of the whole person, and Sierra Nevada Comprehensive Community Cancer Center treats the whole person, says Turkseven.

Free psychological and nutritional support are available onsite for all patients. The center has developed a "distress scale" questionnaire to assess the patient's need for support. (Staff follow up with those who don't complete it.) It also offers some 19 support groups; some are disease focused, but others are centered on activities such as writing and art. (She points out that some patients want to take their minds off their condition.)

Sierra Nevada Comprehensive Community Cancer Center sponsors newsletters, picnics, open-mike sessions, and similar activities. It's very much a family environment, Turkseven says.

"I've had dozens and dozens of patients tell me they are sad to leave our center." They are glad to be cured–or at least able to stop treatment—but they miss care they got.

She tells of a patient's widow who started a food program for cancer patients and families: It provides comfort food that's prepared in a commercial kitchen.

Sierra Nevada Comprehensive Community Cancer Center makes extensive use of the free resources (handouts, booklets, etc.) from several sources, including NCI, the NIH and the American Cancer Society. (Specifically mentioned as a good resource: Johns Hopkins Medicine: *Patients' Guide to Leukemia*.) It is working on updating its website so patients will have a single portal to access a range of educational materials.

Access to the Lab

If the patient comes in looking pale or if something just doesn't seem right, he or she can have lab work done right away and get immediate results. "It could be a lifesaving intervention." At Sierra Nevada Comprehensive Community Cancer Center, all the patient has to do is walk down the hall to the lab.

This is by design, she explains: It arose out of cancer committee discussions. The lab director committed to doing whatever needed to be done to get the lab work completed quickly.

Collaborative, Coordinated Team-based Care

It's a collaborative, team-based, patient-centered approach that contributes to continuity of care. The social worker serves as a patient navigator, keeping track of when patient are coming in, helping them coordinate financial issues, answering questions, and meeting with them as many times as necessary.

The patient knows the entire team, so care is coordinated. And because Sierra Nevada Comprehensive Community Cancer Center is relatively small, everyone is part of that team. It even includes a pain-management team, including a palliative care physician.

There is excellent communication among departments, says Turkseven. One way the center fosters that communication and continuity is through chart rounds. The entire staff comes together to discuss a patient, compare notes, and look at issues that have arisen, clinical or otherwise. For instance, a patient coming in alone without a friend or family member could be a sign that he or she lacks an adequate support system.

These meetings are in addition to the weekly tumor board, which is routinely attended by 50 healthcare professionals (25 physicians, 25 allied health professionals). SNCCCC also cultivates collaboration with major cancer centers, especially Stanford and UC Davis.

The Role of Health IT

Health IT helps promote care coordination: The entire team, including support staff, can access the hospital medical record system. Clinicians enter notes, as do the nutritionist and the social worker. All lab and radiology reports are available. So are ER visits. The center was able to increase the number of patients who visited with the nutritionist by flagging the records for the receptionist, who reminded the patients. Nutrition consults increased 15 percent (the target) almost immediately.

Nevertheless, there are challenges, including different systems in different areas. The registry, CNExT, doesn't work with Sierra Nevada's EHR, but it has allowed the center to follow every patient since 1995.

Guidelines

Sierra Nevada Comprehensive Community Cancer Center uses NCCN and ASCO guidelines, which are incorporated into workflows. With a small staff and low turnover—and a small patient population—there haven't been any challenges to following the guidelines. Doctors are very well aware of what works, and they've had the same staff—in some cases for decades. Guidelines are discussed at the tumor board. "Our team is very experienced…so it's second nature."

Staff Education and Training

Some of the staff training occurs in-house. For instance, for each CML patient, the social worker meets with the MD to discuss the patient and what their needs or challenges may be.

Physicians "read constantly" and attend ASCO meetings. There's also a lot of information sharing in-house. They may be in a remote location, she says, "but we are constantly teaching ourselves and learning from colleagues."

The ACCC discussion board provides an educational resource, too. Turkseven forwards it to colleagues. "I love that thing," she says. A recent post dealt with what colors are soothing for cancer patients. (It was particularly helpful when someone in the C-suite wanted to decorate the hospital bright orange and green.)

Medication Management and Compliance

Patients bring in their medications and nurses count pills. Nutrition consults, timely lab tests, and easy access to the physician and social worker help the center address side effects and keep the patient adherent.

Medicine can be provided by physicians themselves, local pharmacies, or an onsite pharmacy. (A compounding pharmacy—half a block away—works with doctors.) The hospital pharmacist is a member of the cancer committee.

Nursing staff makes follow-up phone calls and follows up on cancelled appointments. The staff doesn't have to dig deeply to find out if a patient isn't adhering to therapy: Patients often acknowledge they aren't taking their medication, says Turkseven.

It's an "old fashioned," intimate environment, she says. And that's intentional. The center works to create an open, safe environment where patients feel comfortable speaking up if they want to stop taking their medication. The physician and staff understand that keeping the dialogue going—keeping the patient engaged—makes it easy for him or her to return to therapy.

Staffing Matters

Having the right staff has been crucial to Sierra Nevada's success. Team members are carefully selected for their patient-focused orientation, Turkseven says.

"You can do all the behavioral interviewing you want, but seeing people in the trenches is the best way to assess staff." She has no qualms about letting go of people who are not well suited to Sierra Nevada's culture. But, she adds, most of the staff has been on board for years.

Turkseven has worked in various facilities but never before has she experienced the same level of teamwork. "I've never seen quite as cohesive a group as we have here."

Site 4: Sutter Medical Center, Sacramento, California

Sutter Medical Center includes 29 acute care hospitals. The cancer center has an active caseload of more than 1,000 patients, of which five to nine are CML patients. The downtown Sacramento medical center is made up of several facilities including Sutter General Hospital, a 306-bed specialty medical center and Sutter Memorial Hospital, a 46-bed specialty medical center.

Early intervention and a whole-person orientation characterize Sacramento's Sutter Medical Center's approach to CML management. It's imperative to get patients into the system as quickly as possible, says Mary Swimley, cancer center services development manager at Sutter. That means educating referring doctors.

"What we do best is early intervention," says Linda Lambert, RN, Sutter's program manager, blood and marrow transplant. She and her team accomplish this by raising awareness about Sutter's acute leukemia program, both in the community and among other providers –in particular, emergency department physicians and referring oncologists. Quite a few come to the center via referrals from the ER, she says.

As a transplant center, Sutter has a high profile in the community at large, which helps increase awareness and drive early referrals.

Key Contacts and Stats
Linda Lambert, RN Program Manager Blood and Marrow Transplant Sutter Medical Center, Sacramento 916-606-9291 LamberML@sutterhealth.org
Mary Swimley Cancer Center Services Development Manager Sutter Medical Center, Sacramento 916-453-5916 swimlem@sutterhealth.org
Accreditation: American College of Surgeons (ACoS) Commission on Cancer FACT accredited for Autologous and Allogeneic Transplant Accreditation

Medical oncologists	9
Radiation oncologists	15
Surgical oncologists	3
General surgeons	3
Other physician specialties	9
Nurse practitioners	2
Physician assistants	0
Board-certified in hematology	4
Oncology-certified RNs	11

Once the patient comes to the center, the team focuses on making sure he or she has the resources to begin and successfully continue therapy.

Lessening the Burden of Worry
Educational, financial, and social services are integrated into the care plan for Sutter patients.

At diagnosis, the patient is probably worrying about how to afford treatment, says Lambert. The staff wants to put the patient at ease as early as possible.

Psychosocial needs are addressed immediately upon diagnosis. Both Swimley and Lambert emphasize: The support cannot be divorced from the clinical. Many times, the reason these patients don't survive is because they lack access to knowledge, information, and resources. Financial, psychological, and social issues must be managed along with their disease, Lambert says. "Treat the whole person, not the disease."

Financial coordination is an integral part of the intake process; addressing financial concerns is essential to ensuring long-term survivorship.

Sutter Medical Center has a dedicated financial coordinator as well as an oncology social worker in its clinic. When a patient receives a diagnosis, the social worker immediately conducts a psychosocial

assessment and identifies his or her needs and concerns—financial, caregiver, transportation. Soon– although not necessarily that day, since the patient is already overwhelmed—the financial coordinator helps the patient complete paperwork for disability, Family & Medical Leave Act, scholarships, etc. Sutter connects patients with programs such as those offered through pharmaceutical companies, transportation options through the American Cancer Society, and assistance through the Leukemia and Lymphoma Society.

"We truly do provide a well-rounded approach to care for the patient's psychosocial needs," she says.

Education, too, begins early. When the physician finishes talking to the patient and explaining the diagnosis ("and our physician who treats CML is a master educator"), the nurse talks to the patient, reviews what the physician has said and tries to address questions. She also provides booklets on AML/CML/MM from The Leukemia &Lymphoma Society—one for patients, one for caregivers. (Both are available in Spanish and English.) Patients have access to a library and the Sutter system has a patient portal so the patient can access its site from home.

Patient-Support Services
"If you are going to have a CML program, it is imperative to have the support staff to care for that patient population," Lambert says.

Sutter Medical Center offers a broad array of ongoing support services for all its cancer patients: music therapy, art therapy, pet therapy, dance therapy, massage therapy. These therapists must be certified in their field and trained by Sutter. It also offers various support groups, including one for children of patients with cancer.

The approach is proactive. "We don't wait for patients to schedule support services," Lambert explains. For instance, musicians go into the hospital rooms, play and take requests. Sutter also offers an integrative medicine program that includes yoga, nutritional supplements, and acupuncture. Acupuncture is off site.

Care Coordination
With such tight integration of support clinical services, care is coordinated. (However, the only *written* care coordination program applies to transplant patients.)

All patients are assigned coordinators as they come into the program, and a given coordinator follows each patient. There's also an inpatient care coordinator who makes daily visits to patients who are onsite, be they in the hospital or the infusion center. That coordinator sees 8 to 28 patients a day. Transplant patients are also followed by the bone marrow transplant patient coordinator. The outpatient coordinator has a load of up to 60 patients; if the load exceeds 60, Sutter will hire another coordinator.

Sutter Medical Center has a separate hem/path tumor board that includes physicians (including a pathologist), pharmacists and nurses. It also includes support staff--social worker, care coordinator, financial coordinator, and sometimes the nutritionist. This approach promotes care coordination, Swimley says. "All the different treatment modalities are at the table and work together to formulate a best-practice treatment plan." In addition, Sutter has a weekly steering committee meeting to discuss patients, regardless of disease, who are getting ready for transplant; that committee includes, among others, physicians, the social worker, nutritionist, financial coordinator and nursing staff.

Technology

EHRs are supported only in the outpatient setting; the individual practices use the same system and are able to communicate with each other. The registry has access to information it needs through Sutter's EHR. In the inpatient setting, the only automated system is what Lambert and Swimley call an "antiquated, but robust" patient database. Charts and progress notes are still on paper.

Access

Sutter Medical Center maintains an on-call person who can counsel and advise patients 24/7–and if need be, direct them to the ER. Lab draws can be done onsite as needed.

Tracking Patient Satisfaction

Sutter Medical Center uses Press Ganey to assess patient satisfaction. Everyone on the team reviews the surveys and reports on how to address changes, Swimley says. All managers and directors review the scores during a weekly meeting; results are published in a weekly internal newsletter and, on the inpatient side, each floor posts its results, promoting total transparency.

Understanding patient concerns can drive quality improvement. For example, knowing that call-light issues are a common challenge, Sutter address that during the hourly rounds by asking, "Is there anything you might need before I come back the next hour?" If you let them know when you are going to return, they are less inclined to use the call button in the interim.

Medication Management

Sutter Medical Center refers patients to nearby specialty pharmacies for medication. The choice is up to the patient. The pharmacists have access to scholarships, grants, and other programs.

Wherever they pick them up, patients are told to bring their medications with them on their visits. Nurses review the meds with patients to make sure they know how to take them and why they are taking each. The nurse also reviews adherence through pill counting; if the patient brings a full bottle and they should only have 15 pills left, the nurse will address the reasons for not taking the medication, Lambert explains. "We have a very robust effort around medication compliance."

Finances can be an issue, but the financial counselor and the social worker help find financial resources to promote adherence to therapy.

Because side effects are such a significant issue with CML medication, Sutter Medical Center has resources in place to help patients deal with them. Not only does it offer education and meetings with the nutritionist, but onsite access to the infusion center is available if a patient is dehydrated.

Survivorship: An Increasingly Important Issue

More people are being identified with CML and require treatment. "If done successfully, we can have a larger group of people who will become survivors than we have seen in years past," Lambert says.

That creates different challenges, she says. Support and medication management become increasingly important and require centers to focus on quality-of-life issues.

"If we can help them have a better quality of life then, in my opinion, we have a successful program. It's not the number of people who live to be 90; it's the number who have a better quality of life until the age of 90."

Site 5: Lexington Medical Center

Lexington Medical Center is a 414-bed medical complex in West Columbia, South Carolina, that anchors a comprehensive network of 600-plus affiliated physicians. The center sees about 10-20 CML patients. It has an active cancer caseload of more than 1,000 patients.

"Diagnostically, we have a good program for CML," says Steven Madden, MD, of Lexington Oncology Associates. The center also offers strong blood bank support, he says; it has two, soon to be three, hemapathologists and is developing a flow cytometry service.

Collaboration

Cases are presented at a multidisciplinary treatment conference, but management is generally limited to the physician and the NP or the PA. There are two nurse navigators at the cancer center; one is devoted to breast cancer, the other handles everyone else. Lexington hopes to add another navigator soon. In the interim, CML patients may not see a nurse navigator.

Although Lexington has no active trials, the center is exploring an affiliation with Duke University. That affiliation would not be CML-specific, Madden notes.

Guidelines and Protocols

The center uses NCCN guidelines; patients get a copy of them. The center identified the use of/compliance with national treatment guidelines as one of the things it does best. The guidelines are not a core part of the EMR yet, but that may happen down the road. Stacey W. Bannister, director of the center's physician network, says the center will soon be launching Varian's ARIA EHR system.

Lexington Medical Center also has a basic tumor registry that can glean from the EHR.

Madden identified no significant barriers to incorporating guidelines into the workflow.

Medication Management

Clinicians count pills to make sure patients are adhering to therapy, and monitor lab studies to ascertain response to therapy. The center follows standard guidelines for molecular studies. In addition, some of the area specialty pharmacies offer assistance in monitoring patient compliance. Medication adherence is an area that needs improvement, Madden acknowledges. "We don't have a good mechanism in place to ensure medication compliance." he says. Soon, however, the center will be hiring several new RNs, which will help with those issues. The ideal situation, he says, is to dedicate an FTE to that function.

Frequent appointments and education also help address side effects and the attendant compliance issues. Lab work doesn't have to be scheduled; it can be done onsite immediately.

Patient Experience/Satisfaction

The hospital uses Press Ganey. The physician group to which Lexington Oncology Associates belongs mails surveys; the results are shared and can be used for quality improvement.

However, the hospital policy is not to send out surveys on newly acquired practices, so none has been send out on Lexington Oncology Associates, which was acquired last year.

Patient-Support Services

Among Lexington's strongest support services is financial counseling. The social worker helps identify sources of funding for patients who cannot afford medication. There's also a strong community outreach focus.

The center offers a library for patients where there is free material from the American Cancer Society, among other sources. It provides handouts and directs patients to appropriate websites.

Education and Training

Clinician education comes through CME, self-education, and pharmaceutical reps. There is no direct CML education for support staff.

TREATING SMALL-POPULATION CANCERS

A new education program from
ACCC's Center for Provider Education

Appendix I:
Pretest

Treating Small-Population Cancers in the Community Setting

Thank you for taking the chronic myeloid leukemia (CML) self-test. Here are the answers.

How Much Do You Know About CML in General?

1. **CML is a likely example of a small-population cancer because it best represents the challenges faced with all small-population cancers. These include (select all that apply):**

   - a. It is seen mainly in rural communities.
   - b. Patient prognosis has not substantially improved with advent of tyrosine kinase inhibitors (TKIs).
   - c. It falls outside the category of more prevalent cancers, such as lung, breast, or prostate cancers, but is still seen with moderate frequency by cancer care providers.
   - d. Current quality of CML patient care depends on the number of oncologists in a practice.

   The correct answer is c.

   For more information, see accc-cancer.org/education/education-CML.asp.

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2. **Small-population cancers present different challenges for community-based cancer care providers for several reasons. These challenges include (select all that apply):**

   - a. Limited physician and cancer team knowledge of emerging clinical data
   - b. Difficulties in incorporating new clinical information into practice
   - c. Complex managerial and administrative processes

- o d. Administrative costs/personnel involved in keeping track of oral drug adherence
- o e. Drug reimbursement issues

The correct answers are a through e.

For more information, see accc-cancer.org/education/education-CML.asp.

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3. **Landmark discoveries that have had an impact on the treatment of CML include (select all that apply):**

- o a. Discovery of the Philadelphia (Ph) chromosome
- o b. Characterization of breakpoint cluster region on chromosome 22
- o c. Demonstration of the BCR-ABL fusion gene
- o d. Discovery of the direct pathophysiology of the tyrosine kinase ABL-driving signaling pathways to cause the disease

The correct answers are a through d.

For more information, see accc-cancer.org/education/education-CML.asp.

For more information on the Philadelphia chromosome, click here.

For more information on landmark discoveries and CML (Jamieson CH, Chronic Myeloid Leukemia Stem Cells, *Hematology*, 2008), click here.

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4. **Chronic myeloid leukemia (select all that apply):**

- o a. Accounts for about 15 percent of adult leukemias in the United States
- o b. Annual incidence is estimated to be about 5,000 new cases
- o c. Is growing in prevalence due to improved survival
- o d. Accounts for almost 50 percent of adult leukemias in the United States

The correct answers are a through c.

For more information, see "CML Fast Facts," accc-cancer.org/education/education-CML.asp.

How Much Do You Know About Treatment for CML?

5. **Treatment for patients with CML has changed dramatically because (select all that apply):**

   o a. Stem cell transplant survival has increased and has been shown to be the only curative treatment.
   o b. Molecular diagnosis now easily confirms the diagnosis of CML, although it is not helpful in managing the disease.
   o c. Advances in intravenous cytotoxic chemotherapy have improved survival.
   o d. New drugs have been developed that target the molecular changes in CML.

   The correct answer is d.

   For more information, visit the American Cancer Society's "Detailed Guide: Leukemia—Chronic Myeloid (CML)."

6. **BCR-ABL tyrosine kinase inhibitors such as imatinib are the mainstay of treatment of CML. When should imatinib not be prescribed for a CML patient? (Select all that apply.)**

   o a. If a bone marrow/stem cell transplant is being considered
   o b. If the CML cells are negative for BCR-ABL
   o c. If there is an allergy or intolerance to the medication
   o d. If standard chemotherapy or interferon has not yet been tried

   The correct answers are b and c.

   For more information, visit the American Cancer Society's "Detailed Guide: Leukemia—Chronic Myeloid (CML)."

7. **One of the challenges in treating CML is that patients sometimes need alternative therapeutic options to imatinib because of drug resistance or intolerance. What are the signs that a patient is not responding to BCR-ABL tyrosine kinase therapy (imatinib)? (Select all that apply.)**

   o a. The CBC normalizes, but the molecular tests for BCR-ABL are still elevated.
   o b. There is a fever and an increase in the white blood count.
   o c. The molecular tests for BCR-ABL (FISH or PCR) showed initial decline but are now increasing.
   o d. There is increasing spleen size or peripheral blasts.

   The correct answers are a, c, and d.

For more information, visit the American Cancer Society's "Detailed Guide: Leukemia—Chronic Myeloid (CML)."

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8. **What are the treatment options for a CML patient whose disease has progressed on imatinib? (Select all that apply.)**

   o   a. Increase the dose of imatinib
   o   b. Switch to an alternative tyrosine kinase inhibitor (dasatinib, nilotinib)
   o   c. Switch to erlotinib

   The correct answers are a and b.

   For more information, visit the American Cancer Society's "Detailed Guide: Leukemia—Chronic Myeloid (CML)."

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9. **Untreated, CML usually progresses through three phases within 3 to 5 years. What is true about the final phase, blast crisis? (Select all that apply.)**

   o   a. Tyrosine kinase inhibitors can delay the onset of blast crisis, in some patients indefinitely.
   o   b. Tyrosine kinase inhibitors cannot be used to treat CML in blast transformation.
   o   c. Any CML patient with a fever should be considered to have blast transformation.

   The correct answer is a.

   For more information, visit the American Cancer Society's "Detailed Guide: Leukemia—Chronic Myeloid (CML)."

   Blast crisis is the final phase in the evolution of CML and behaves like an acute leukemia, with rapid progression and short survival. Blast crisis is diagnosed if any of the following are present in a patient with CML: >20 percent myeloblasts or lymphoblasts in the blood or bone marrow; large clusters of blasts in the bone marrow on biopsy; or development of a chloroma (solid focus of leukemia outside the bone marrow).

Appendix III:
The three survey instruments

(See accompanying PDF file)

Appendix IV:
"Best Practices" Project
Knowledge Pretest Results

(See accompanying PDF file)