

ASSOCIATION
OF COMMUNITY
CANCER CENTERS

PRECISION MEDICINE:
INTEGRATION OF
PATHOLOGY WITH
THE CANCER CARE TEAM



PATIENT-CENTERED CARE:
REPORTING & COMMUNICATING
PATHOLOGY & ANCILLARY
TEST RESULTS

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INTRODUCTION

In 2018, the Association of Community Cancer Centers (ACCC) began a multi-year project titled, “Precision Medicine: Integration of Pathology with the Cancer Care Team.” To initiate this project, ACCC held a summit, bringing together interdisciplinary experts to identify and discuss critical issues facing the oncology community with regards to clinical advances in precision medicine, the increasing necessity for biomarker testing, and current ways in which the involvement of pathologists and pathology in quality cancer care delivery is evolving. During the summit meeting, some of the breakout group conversations centered on how the information in pathology and ancillary test reports (e.g., molecular or germline genetic test results) can be used to empower patients (see *Table 1*). These lengthy clinical reports hold vital information that could help patients better understand their cancer, their diagnosis, and more fully engage in shared decision-making. However, a bridge is needed to convey the key points from these dense, complex clinical reports into a patient-accessible and patient-understandable format.

Table 1. Improving Patient-Centered Communication on Pathology and Ancillary Test Results

NEEDS	IDEAS
<p>Pathology and ancillary test reports are not written at a level for patients to understand. However, some patients will spend the time to read their reports and may misunderstand what is written. Reports may also be organized in ways that are confusing to both clinicians and patients.</p> <p>While some patients may meet or speak with pathologists, most pathologists do not have the time or training to explain their findings directly to patients.</p>	<ul style="list-style-type: none"> • Provide a patient-friendly summary that highlights the key points of the report. • Create opportunities for patients to have access to trained pathologists who can explain pathology reports in detail. • Provide patients with trusted educational resources that will help them understand the information that is in these reports.
<p>Some patients have a very limited understanding about their cancer (e.g., “I have lung cancer.”). If they knew a few more things about their cancer (e.g., molecular subtype, what makes their cancer unique), they could be more empowered in their care.</p>	<ul style="list-style-type: none"> • Create patient-focused educational flyers that address the major types of cancer and provide nuance in understandable, lay language. • Ensure that patients know all the key aspects of their cancer that relate to treatment (e.g., rather than simply having a diagnosis of “lung cancer,” the patient would know they have a diagnosis of “ALK+ NSCLC”).
<p>Patients should have easy access to their reports (for their own records, to share with other healthcare providers, etc.). Many current processes are very cumbersome, largely because different reports may be stored in information systems that do not fully communicate with each other.</p>	<ul style="list-style-type: none"> • Promote stories/examples of health systems where patients have direct access to their reports and information to empower other patients to demand such access elsewhere. • Aspirational: Provide a single point of entry (e.g., patient portal) where patients can access all of their reports.
<p>Clinicians also have difficulty accessing all the pathology and ancillary test reports for a single patient.</p>	<ul style="list-style-type: none"> • Promote multidisciplinary communications (bidirectional) focused around the patient journey. • Aspirational: All members of the cancer care team have easy access to integrated reports. Fully interoperable information systems across all health systems and labs would make this possible.

Consistent Testing Terminology Working Group

To encourage the use of consistent patient-friendly language, ACCC and many other societies support the work of the Consistent Testing Terminology Working Group. To best serve the needs of cancer patients, the working group encourages the consistent use of common terms for biomarker and germline genetic testing.

These terms can be found here: commoncancertestingterms.org.

To explore the concept of patient-centered reporting and communication on pathology and ancillary test reports, ACCC conducted stakeholder interviews with pathologists, medical oncologists, surgeons, radiologists, nurses, genetic counselors, administrators, industry experts, and patients. Informed by these conversations, this white paper summarizes key insights and aspirational goals for the future.

PATIENT-CENTERED CARE

The National Academy of Medicine (previously named the Institute of Medicine) identifies patient-centeredness as crucial to quality healthcare. Being patient-centered means “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”¹

In its 2013 oncology-focused report, “Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis,” the National Academy of Medicine further defines patient-centered care as “. . . fostering effective communication between patients and their cancer care team; developing and disseminating evidence-based information to inform patients, caregivers, and the cancer care team about treatment options; and practicing shared decision making.”²

As scientific advances lead to deeper understanding of multiple cancers and cancer subtypes and drive development of precision oncology treatment options, the complexities surrounding cancer diagnosis and treatment planning have grown. Good communication about key findings from the pathology report and ancillary test results is integral to patients fully understanding their disease, treatment options, and participation in shared decision-making. Put another way, when patients can access the key information from their pathology and ancillary test reports, in patient-accessible formats, patients can be empowered to better understand their disease and treatment options, and engage in the shared decision-making process with their care team. As cancer programs consider the current state of conveying pathology report information to patients and an aspirational future state, the questions in Table 2 may be helpful as a discussion guide.

Table 2. Toward Patient-Centered Reporting of Pathology Results: Key Questions for Consideration

KEY QUESTION	CURRENT STATE	ASPIRATIONAL FUTURE STATE
<p>1. How do patients prefer to receive the information contained in pathology and ancillary test reports?</p>	<ul style="list-style-type: none"> • Patients do not routinely receive a patient-centered summary of their pathology and ancillary test reports; however, this information would help them better understand the information in these complex, technical reports. • Patients want easy access to their records. However, those with low levels of technology literacy may experience disparities if they have difficulty using a patient portal to access these reports. • Some patients may prefer to have printed copies of these reports but can experience delays receiving access to all of their reports. 	<ul style="list-style-type: none"> • Patients will be asked how they would like to receive this information (e.g., electronic vs. paper). • A patient-friendly guide explaining various core report components and how to understand results will accompany pathology and ancillary test reports. • A clinician would go through the report carefully and explain it to patients and their families, allowing them to take notes and ask questions. • Printed copies will be readily available upon the patient's request.
<p>2. How do the needs and values of patients impact how they receive and use this information?</p>	<ul style="list-style-type: none"> • Patients may be inconvenienced if they need to access different patient portals to retrieve pathology and ancillary test reports. • Patients are not receiving this information based on their level of health literacy. They often do not receive simple explanations that may help them interpret the test results. As a result, many patients do not have an accurate understanding of their cancer diagnosis and may experience confusion and anxiety. • Patients may not be receiving information that pertains to what they value (e.g., prioritizing survival time vs. maximizing quality of life). • Some patients may value sharing this information openly with their family members; others may want to maintain strict privacy. They may have difficulty controlling these privacy settings. 	<ul style="list-style-type: none"> • Patients will gain easy access to all their pathology and ancillary test reports by connecting to a single patient portal that aggregates results from multiple sources. • Patients will be presented with information based on their level of health literacy. • Patient values and cultural beliefs will guide discussions with members of the cancer care team about diagnosis, prognosis, and treatment (informed by pathology and ancillary test results). • Caregivers will be included in education as approved by the patient.

Continued on next page

Table 2. Toward Patient-Centered Reporting of Pathology Results: Key Questions for Consideration (Continued)

KEY QUESTION	CURRENT STATE	ASPIRATIONAL FUTURE STATE
<p>3. How can patients be educated and empowered by this information?</p>	<ul style="list-style-type: none"> • Patients may search the Internet and find misinformation. • Patients may not be aware of advocacy and support groups for their unique type of cancer. • Patients may not be aware of clinical trial opportunities. 	<ul style="list-style-type: none"> • Patients will be given a list of reliable sources for additional information about their cancer. • Patients will be connected to cancer-specific advocacy and support groups. • Patients will receive patient-centered education and resources for additional information such as clinical trials.
<p>4. How can this information facilitate communication between patients and their cancer care team?</p>	<ul style="list-style-type: none"> • Cancer clinicians may have difficulty finding different pathology and ancillary test reports that are contained in disparate information systems. • Some cancer clinicians may have difficulty understanding the complex, technical information contained in pathology and ancillary test reports. • Patients may be missing opportunities to engage in shared decision-making conversations based on this information. • Patients are often confused when clinicians use varied terminology (e.g., molecular testing vs. tumor testing) when speaking with patients. 	<ul style="list-style-type: none"> • Fully interoperable information systems that provide complete access to all test results will allow clinicians and patients to easily access this information from a single access point. • Clinicians will have access to experts and resources designed to help them better understand the information contained in pathology and ancillary test reports. • Clinicians will use this information to guide shared decision-making conversations about treatment plans. • Patients will use this information to refresh their memory about the details of their condition before speaking with clinicians.

COMMUNICATION NEEDS AND PREFERENCES

When patients face a cancer diagnosis, they often receive an overwhelming amount of information in the setting of emotional distress, confusion, and uncertainty. As cancer clinicians explain the diagnosis to patients, they should consider patient preferences, needs and values as they communicate this information in a sensitive, compassionate way. Clinicians should recognize and respond to patients' emotions, provide empathy and support, and assess how much information the patient is able to receive and understand.³ While historically this initial conversation has mostly occurred in a face-to-face meeting, clinicians are also recognizing that patients may have different preferences on how they wish to receive this information. In an era of ubiquitous digital communication and the new environment caused by the COVID-19 pandemic, some patients may prefer a telephone or video notification rather than an in-person visit to discuss important test results.

In one study, researchers asked patients how they would want to receive the results of a skin biopsy (e.g., telephone call, in-person visit, patient portal, text message, etc.) and found that 67.1% preferred to speak directly by telephone to receive their results; 19.5% wished to be notified in-person at a clinic visit; 5.1% preferred to receive a voice message or read their report on the online patient portal. The researchers observed that the most important consideration for patients was a communication method that provided test results in the most rapid manner (e.g., telephone call):

- 51.7% wanted a method that was rapid
- 40.5% would prefer a different mode of notification (e.g., in person visit) if their results revealed cancer⁴
- Younger and more highly educated patients favored the online portal

During the ACCC stakeholder interviews, participants emphasized the importance of face-to-face conversations to effectively respond to the emotional needs of patients, provide support, and assess the quality of communication. So, while some patients may prefer to receive information electronically, cancer clinicians should still offer to set up a face-to-face conversation to review test results, answer questions, and provide comfort.

Many patient advocacy organizations have resources and initiatives focused around improving patient-centered communication. "Can We Talk?" is National Patient Advocate Foundation (NPAF) education campaign to increase awareness around effective patient-centered communication.⁵ This campaign encourages patients to tell their clinicians how they prefer to receive information. Some patients may like to hear facts and statistics while others may want a summary of the key points. NPAF also encourages patients to write down questions ahead of their medical appointments so they are prepared to review their concerns.

In addition to offering patient-directed resources, NPAF delivers skills-based training for healthcare professionals who wish to improve their communication skills as they engage in shared decision-making conversations with patients.⁶ In the current state, many patients with cancer experience suboptimal communication with members of the cancer care team, especially early in their cancer journey.⁷ Hence, there are opportunities to improve how clinicians share and discuss the information contained in pathology and ancillary test reports.

Future Aspirations

- Patients should be asked how they wish to be notified about pathology and ancillary test results. This will enable clinicians to deliver information in a patient-centric manner. Regardless of how patients prefer to be notified about these results, cancer clinicians should offer a face-to-face opportunity to review the results, answer questions, and provide emotional support.
- Patients should be asked how much detail and information they wish to receive. At a minimum, a patient-friendly summary of the pathology and ancillary test reports should be provided to patients who prefer key points. Upon request, patients may be offered more extensive information and resources, especially those offered by patient advocacy groups.
- Patients should receive a structured discussion guide to help them review their results, prepare for questions, and reinforce the key points of their pathology and ancillary test reports.
- Clinicians should acknowledge that patients are receiving a lot of information, may not understand everything they read or hear, and may have new questions in the future.
- Clinicians should incorporate principles of effective communication and offer an opportunity to engage in shared decision-making as they discuss the clinical implications of pathology and ancillary test results with patients.

HEALTH RECORDS AND PATIENT PORTALS

Patient portals are intended to allow patients to have quick, easy access to all their health records. While many cancer programs have made great efforts to optimize the patient portal experience, some continue to struggle with portals that are difficult to use or that do not provide access to complete health records. Since hospitals, labs, and medical group practices may use different electronic information systems, patients may need to access several different patient portals (e.g., the outpatient oncology portal, the hospital portal, and the specialty lab portal) to retrieve all of their pathology and ancillary test reports.⁸ This suboptimal user experience makes it cumbersome for patients to collect and potentially share their health records with family members or with institutions that are conducting a second opinion consultation.

While patient portals make it more convenient for patients to access their health records, it is not uncommon for test results to be released into the portal before a clinician has a chance to contact and speak with the patient about those results.⁹ As such, patients who undergo biopsies and read the pathology report in their patient portal may discover a diagnosis of cancer before they have had a chance to speak with a clinician. Therefore, patients should be informed about this possibility and warned not to check the patient portal until they have been contacted by their healthcare provider if they prefer to receive such information over the phone. Some hospitals may delay releasing some types of critical test results until a clinician speaks with the patient about those results.¹⁰ Such delays in releasing results may exist as a matter of policy to allow clinicians to answer questions and provide emotional support as they discuss sensitive results with patients.

Future Aspirations

- Patients should have seamless access to all their pathology and ancillary test reports by logging into a single patient portal.
- Patients should be informed that test results may appear on the patient portal before they have been contacted by a clinician.
- Informatic ways to prevent the uploading of sensitive test results to the patient portal until it is released by the clinician should be considered.
- Patient results should include a live link to “understanding my results” that links to internal or external resources such as interactive web pages with customized educational content.

PATIENT EDUCATION AND EMPOWERMENT

Patients who are educated and empowered can more effectively engage in meaningful discussions about their treatment options and care plans.¹¹ Four components are fundamental to the process of patient empowerment:¹²

- Understanding by the patient of their role
- Acquisition by patients of sufficient resources, education, and knowledge to be able to engage with their healthcare provider
- Patient skills (e.g., communication skills, health literacy level, ability to self-advocate, language or cultural barriers)
- The presence of a facilitating environment

By incorporating these components, empowerment may be defined as:

“A process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation.”¹³

During the ACCC stakeholder interviews, participants agreed that most patients will not understand most of the technical information contained in pathology and ancillary test reports. Hence, patients should receive a summary, in a patient-friendly format, and be directed to additional educational resources. This way, the right level of information can be offered to patients based on their expressed needs and preferences.

Today, most pathology and ancillary test reports are not routinely accompanied by patient-friendly summaries or comments. In some cases, laboratories that perform germline genetic or biomarker testing may offer patient guides and other educational materials designed to explain the information contained in the test reports. Patients who wish to learn more about their cancer should be directed to reliable educational resources designed for patients to help deepen their knowledge, answer questions, and empower them to discuss treatment options and participate in shared decision-making. Patient education materials should be offered in a variety of languages and formats (e.g., print, audio, video, etc.) to meet the needs and different learning preferences of patients. It is also important that terminology used in the report be the same terminology used by the provider in interactions with the patient. New recommendations

from a working group comprised of numerous pan-cancer stakeholders encourage the use of “biomarker testing” when speaking to patients about testing for somatic (acquired) mutations and other biomarkers and the use of “genetic testing for an inherited mutation” when addressing testing for inherited mutations.¹⁴

Some pathologists take the extra time to enter patient-friendly comments into the pathology report and invite patients to contact them if they have any additional questions.¹⁵ Others may choose to implement a patient-pathologist consultation program where they invite patients to see their biopsy samples and discuss their findings during a face-to-face visit.¹⁶ During the ACCC stakeholder interviews, pathologists remarked that most pathology groups lack the capacity or infrastructure to provide direct patient-pathologist consultations. Moreover, pathologists receive very little communication-skills training to explain complex information using patient-friendly language.¹⁷ To bridge these gaps, the American Society of Clinical Pathology (ASCP) has started to offer communication training courses at its annual meeting.

Patient education is especially important for sensitive and complex topics such as inherited mutation (germline genetic) and biomarker (somatic mutation and other biomarkers such as PD-L1) testing. Patients are often confused by these tests and may mistakenly think that genetic testing for inherited mutations and biomarker testing are synonymous. As these tests are integral for clinical decision-making in an increasing number of cancer types, there is a need for cancer clinicians to explain the different types of tests and their purposes, and to apply principles of shared decision-making so that patients understand how testing will impact their care. When genetic testing for an inherited mutation is indicated, patients should receive pre-test and post-test counseling from genetic counselors who are specially trained to discuss delicate information and explain the complexities of cancer genetics and heritable risk in ways that patients will understand. While many cancer programs lack access to on-site genetic counselors, some are bridging these gaps by offering video-based counseling and other telehealth solutions.¹⁸

Empowered patients who undergo appropriate ancillary testing will be able to participate more meaningfully in conversations about how these results may impact their cancer treatment options. For example, a patient with lung cancer may discover that she has ALK+ non-small cell lung cancer (NSCLC) and may benefit from an ALK inhibitor. Another patient with ovarian cancer may discover that she carries a BRCA mutation and may be eligible for a PARP inhibitor. Information about cancer-specific biomarkers may enable patients to seek out relevant clinical trials or find advocacy and support groups that are specific to their type of cancer. In addition to well-established, respected patient advocacy organizations, in recent years, a host of biomarker-specific support groups have arisen supporting various cancer types (see *Table 3*).

Table 3. Examples of Biomarker-Specific Lung Cancer Support Groups*

GROUP	WEBSITE
ALK	alkpositive.org
ALKFusion	alkfusion.org
EGFR Resisters	egfrcancer.org
Exon 20 Group	exon20group.org
KRAS Kickers	kraskickers.org
MET Crusaders	metcrusaders.org
NTRKers	twitter.com/ntrkers
RET Renegades	facebook.com/groups/RETLung
ROS1 ders	ros1cancer.com

* Some support groups have many members and are well-moderated while others are still growing and being established.

Future Aspirations

- Patients should receive a patient-friendly, integrated summary of their pathology and ancillary test reports.
- Patients who wish to learn more should have access to reliable resources that are designed to educate them about their specific type of cancer.
- Patient education should be delivered via multiple formats and options such as print, video, interactive websites, etc.
- Patient resources should be offered in a variety of different languages.
- Clinicians should use these patient-friendly resources to guide discussions with their patients.
- Patients should be offered the option to connect with established and well-moderated patient advocacy and support groups based on their specific type of cancer.
- Patients should be offered potential clinical trial opportunities based on their specific type of cancer.

SUMMARY

As the multidisciplinary cancer community continues to strive to provide more patient-centric care, it should embrace the opportunity to improve how the information contained in pathology and ancillary test results is being used to educate and empower patients. Ongoing advances in targeted therapies, molecular biology, and immuno-oncology are leading to more complex pathology and ancillary test reports, so cancer clinicians have a tremendous opportunity to incorporate this information into shared decision-making conversations about personalized treatment options. Clinicians should ask patients about their preferences and needs so they can effectively deliver the key information contained in pathology and ancillary test reports and direct patients to educational resources. By improving communication and the delivery of pathology information to patients, cancer programs will deliver more patient-centered care in their communities.

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The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 25,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit acc-cancer.org or call 301.984.9496. Follow us on Facebook, Twitter, LinkedIn, and Instagram; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

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