INSTITUTE FOR THE FUTURE OF
ONCOLOGY

Cancer Care in the Age of Electronic Health Information Exchange

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ACCC
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Executive Summary

Community cancer centers across the country see great opportunity in the integration of electronic health record systems (EHRs) and Health Information Exchanges (HIEs) into community care settings. The expectation is that instantaneous electronic exchange of healthcare information has the potential to improve care coordination—an important benefit for all patients but particularly important for cancer patients given that anticancer treatments often involve multiple services from multiple specialists in multiple locations.

Health information exchange encompasses two related concepts:
- electronic sharing of health-related information among organizations, and
- an organization that provides services to facilitate the electronic sharing of health-related information—i.e., providing a virtual platform for the healthcare providers to share and access patient data.[1]

The push for adoption and integration of electronic health records (EHRs) has been a first step toward realizing the capabilities and benefits of electronic health information exchange. Adoption of and engagement in HIEs, organizations that enable electronic sharing of patient data, is the next step.

On June 27, 2013, the Association of Community Cancer Centers (ACCC) Institute for the Future of Oncology held its first forum in Chicago, Illinois, to explore the topic of health information exchange within the oncology community as well as key issues that are impacting community cancer centers today and those anticipated in the future. Forty participants, comprising oncologists and cancer program executives from hospitals, practices, and healthcare systems across the country, provided insight and perspective to help community cancer centers better meet the challenges facing the oncology community. This white paper includes their discussions.

Stakeholders at the ACCC Institute for the Future of Oncology 2013 forum recognized that seamless, instantaneous communication through electronic exchange of health information is already happening—but *only* in certain areas of the country and *only* within certain health systems and practices. They expressed concerns about information "silos," where some cancer care providers and cancer patients have access to systems that freely exchange data across multiple organizations, while other communities remain largely in the dark with limited or no access to a standardized, interoperable information exchange system.

"How do you break down these silos—with pockets of data here and pockets of data there—to ensure that all cancer care providers have access to health information exchanges?" was a key question for discussion.

Stakeholders agreed that:

- Health Information Exchanges have the potential to improve patient care, reduce redundancies, lower costs, and demonstrate quality, for example, by allowing participating providers to benchmark interventions within their own patient population against others.
- The oncology community is experiencing uneven adoption and implementation of HIEs across the country.
- Surprisingly, many within the oncology care community are unaware of the opportunities or services that HIEs offer.
- Challenges remain as to how to achieve interoperability so that data can be exchanged seamlessly across large geographic areas while best ensuring privacy and security.
- HIE initiatives will need to focus on how information can best be streamlined so that providers can easily exchange and use it and patients can view it.
- Patient portals are an important avenue for patient empowerment and engagement; however, oncologists are concerned about the need for protocols around the release of information so that providers have input on both the information released and the timing of that release, as well as the ability to answer patient questions about the information.

With multiple forces driving adoption of both EHRs and HIEs, cancer programs and oncology practices are increasingly integrating cancer care by unifying patient information and implementing data collection systems. This trend will continue to be important as ACOs, medical homes, and other care delivery models evolve, and as healthcare transitions from volume-based payment models to value-based reimbursement.

Although the full potential and promise of comprehensive, integrated systems that exchange health information are still evolving, this white paper offers a snapshot of how, in some locations, the oncology care providers and the patients they serve are already benefiting from engagement in an HIE that is working well, while in other geographic areas HIE opportunities remain largely unknown or out of reach.

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I. The Promise of HIE for Community Cancer Programs and Patients

"An HIE is a complex set of technologies which enables the aggregation of health-related information for an individual, as well as offering a number of specialized services for the community it services." [2]

While the technologies comprising an HIE may be complex, the potential benefits are not difficult to envision. Whether it's a clinician's ability to instantly access test results for a patient vacationing out of state, or a hospital and private practice to analyze data to improve care coordination or collaborate to reduce hospital re-admissions, or a patient being able to view his or her survivorship care plan and treatment summary with a primary care provider—electronic exchange of health information holds promise for improving patient care coordination, reducing waste, advancing quality measurement and performance improvement efforts, and increasing patient engagement.

Nationwide the trend is toward increased electronic exchange of health information. This trend is being driven, in large part, by healthcare reform and the federal government's e-health initiatives, including "meaningful use" incentives. Payers are also interested in the potential for electronic exchange of health information to reduce costs, streamline administrative workflows, improve care coordination, and demonstrate quality.

A recent study of health information exchange activity in U.S. hospitals found significant growth in hospital electronic health information exchange between 2008-2012.[3] In 2012, nearly six in ten hospitals actively exchanged electronic health information with providers and hospitals outside their organization, an increase of 41 percent since 2008.[4] But while EHR adoption and HIE participation were associated with significantly greater hospital information exchange activity, the majority of hospitals still do not exchange crucial patient data such as clinical care summaries and medication lists.[5]

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II. How Is Community Oncology Being Affected by the Evolution of Health Information Exchange?

Among community cancer programs, the use of electronic health records (EHRs) systems is increasing but is not yet universal. In ACCC's 2013 *Trends in Community Centers* survey, 79 percent of respondents report use of EHRs.[6]

The federal government has been a key force driving EHR adoption through the Health Information Technology for Economic and Clinical Health (HITECH) provisions of the American Recovery and Reinvestment Act. Enacted by Congress in 2009, HITECH calls for the electronic exchange of health information and the adoption of health information technology in healthcare practices and hospitals. The goal is not adoption alone but "meaningful use" of EHRs, such that through their use providers achieve significant improvements in care.

The main components of "meaningful use" include:
- The use of certified EHR technology in a meaningful manner, such as e-prescribing
- The use of certified EHR technology for electronic exchange of health information to improve quality of healthcare
- The use of certified EHR technology to submit clinical quality and other measures.

In other words, providers need to show they are using certified EHR technology in ways that can be measured significantly in quality and in quantity.[7]

Since 2011, practitioners have been able to take advantage of incentives for "meaningful use" of health information technology. These incentives provide practitioners Medicare or Medicaid bonus payments when they show "meaningful use" of certified EHRs. By 2015, all physicians will be required to implement EHRs and begin sharing data in "meaningful" ways or face reimbursement adjustments.

HIE Participation: The Next Step

With EHRs being the core system in which data are entered, the next step is creating a platform for health information exchange across multiple facilities and geographic areas. This raises a number of questions:

- How can information be exchanged securely and "seamlessly" among healthcare providers at multiple locations? (In this case "seamlessly" refers to the interoperability among EHR systems, standardization of the data, and the ease with which data is exchanged across multiple organizations regardless of politics, the market, or geographic location.)
- How can data be "normalized"? (That is, how can metrics be standardized and multiple EHR systems become interoperable across different organizations so that healthcare providers and patients can freely access and exchange information?)
- What data should be exchanged and by whom?

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Ideally, Health Information Exchanges are the entities that can provide the answers. As defined by HIMSS:

> An HIE automates the transfer of health-related information that is typically stored in multiple organizations, while maintaining the context and integrity of the information being exchanged. An HIE provides access to and retrieval of patient information to authorized users in order to provide safe, efficient, effective and timely patient care.... An HIE is not an information system within a single organization, nor is it one that has a single directional flow of information. A true HIE involves multi-directional flows of information electronically between providers (hospitals, physicians, clinics, labs) and other sources of administrative or clinical information provided by consumers, health plans, employers, local, state, or national organizations.[8]

An HIE provides a technology platform that facilitates the electronic exchange of data in a secure, private manner, and allows information to follow a patient where and when it is needed across organizational, vendor, and geographic boundaries. HIEs may include such services as physician web portals, personal health records, clinical messaging, clinical interoperability and exchange of data from electronic medical records, as well as the security services to ensure that the data is used appropriately.[9]

From the provider prospective, HIEs can offer a clinical data repository, results delivery, clinical messaging (i.e., secure, electronic automated delivery of healthcare data to any site where clinical care decisions are made),[10] and fully integrated electronic health records.

HITECH allocated $2 billion to support Health Information Exchange activities. Of those funds, the State HIE Cooperative, which funds states' efforts to rapidly build capacity for exchanging health information across the healthcare system both within and across states, received $564 million. The Cooperative works to increase connectivity, enable patient-centric information flow to improve the quality and efficiency of care, and ensure security of information.[11]

Discussion at the ACCC Institute forum revealed that some oncology programs and practices are already benefiting from participation in an HIE.

"I'm in a large private practice and have a large community health information exchange," said one forum participant, a cancer program executive. This practice participates in an HIE that serves medical providers and institutions within a large area of the Midwest. Its network stores discrete data, text, images, and voice dictation from many

provider sources, including inpatient and outpatient laboratory results and radiology reports; reports from hospital service departments such as surgery, oncology, and emergency services; and medical records reports such as discharge summaries.
"All hospital records, all lab reports, everything you sign off in the hospital, automatically comes to . . . our EMR [electronic medical record system]," said this participant. "It goes into an approved status. Information from an op report, if I sign it, automatically feeds into our EMR. We outbound to the HIE our lab reports and our radiology reports [though not the image itself]."

"The HIE becomes our integration engine such that all our disparate systems interface—MOSAIQ in our medical and gynecologic, ARIA® in the radiation oncology department, the PACS (medical imaging) system, and e-prescribing," the participant said.

With six locations this practice employs two programmers, an IT network manager, and a help desk.

That repository of data within the HIE connects to a large academic health system and a large number of hospitals within the exchange network.

"If we send patients to a tertiary center, that center can upload directly from us. If one of our patients walks into the ER, the system queries anything done in the last 90 days from any provider in the exchange." The ER knows, for example, that a CT scan has been done and which labs were done in the practice's office. Benefits for HIE participants include improved care coordination, elimination of duplicative tests, reduced costs, and benchmarking opportunities.

Information is available to the practice via the HIE as soon as it is resulted or transcribed in the source system at the hospital, lab, or imaging center. Clinical information such as notes and medications are integrated with the results of services performed outside the practice for a single-view, historical record. Notes concerning phone messages, medication refills, and other pertinent information are also stored in the practice's EMR and are available through the HIE.

From both a workflow perspective and as a business tool, HIE provides the capability to streamline processes and conduct internal benchmarking. For example, with HIE, faxed documents are received electronically, allowing the inbound fax server to categorize incoming documents. "So manpower FTEs are significantly reduced in handling incoming documents," the participant noted.

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The ability to benchmark interventions within a patient population is another benefit that some forum participants are already realizing. With the help of an analytics firm, one participant was able to benchmark hospitalization rates of the practice's patients on chemotherapy compared with oncology medical home metrics. "That's what I love about the exchange. It has every ER visit and every hospitalization and reason for it. Those data sets are there, discrete and extractable," said one participant. As payment models shift to value-based versus volume-based care, the ability to benchmark data is increasingly important to demonstrate the most cost-effective, quality cancer care.

Not One-Size-Fits-All

Private HIEs, such as the example above, have centralized ownership and governance where the owner or company manages cost and determines operations, services, and memberships.

At present there are private and public HIEs with no one single model of HIE being dominant. Not only is there geographical variance in availability of HIEs across the country, there is great variation in how HIEs work, such as the services they provide, the cost of participation, and the benefits to participants.

Some healthcare provider systems have developed their own HIEs. "In these private hospital-based HIEs, hospitals control the exchange, including determination of the technical criteria for participants and what data other hospitals or providers will have access to," said forum facilitator Pam Matthews, RN, MBA, of HIMSS. "For example, they may support exchange of lab results, radiology results, and medication lists for patients discharged from the hospital."

HIEs are market-driven with the landscape currently being made up of both public and private HIEs across the country. Matthews noted that what works in one state may not necessarily be replicable in another state. Providers should identify the HIE options available within their geographic location. Service offerings are specific to the HIE and can range from sharing diagnostic test results, discharge summaries, consultations, to claim submission to payers. In areas without significant HIE presence, some hospital providers are establishing their own HIE to fill the void. In addition, the industry is seeing activity with other types of private HIEs such as payer-based HIEs.

Currently, public, state, and regional collaborative HIE organizations are already active in all 50 states, with vendor-specific customer-to-customer HIEs serving many communities. Many EHR products, including those from Epic and Cerner, two of the

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largest vendors of integrated healthcare information software, already integrate with or have functionality with HIEs.

Although some forum participants reported participation in HIEs, many attendees were not aware of the opportunities or services that HIEs offer.

"I'm in a big integrated health system, but this hasn't touched me in any way, shape, or form," said a forum participant from a large academic medical center.

"Talk to your institution," advised forum facilitator Matthews. "Is your institution aware of HIEs? Do they have plans to connect? If so, when? Remember that quite a few pockets across the country do *not* have access to HIEs. Some states may only have one viable HIE in the state. Others may have a state-wide HIE with several regional HIEs. Several states have HIE network-to-network availability where several HIE networks tie into a larger one. Some HIEs may offer a wide variety of exchange services; some may offer much less."

Forum participants voiced concern as to how community cancer centers can overcome these barriers to ensure that all cancer care providers have access to HIEs.

"Since the goal of an exchange in a community is to freely exchange data across multiple organizations, regardless of politics or the market, we need to figure out how to break down the silos," said forum facilitator Matthews. "The focus needs to be on standardized, interoperable data and systems." HIE initiatives, she noted, will need to focus on how information can best be shared and streamlined across large geographic areas so it can be easily used by providers and patients.

Currently, great variation exists in the costs attached to participation in an HIE.[12] In some cases, HIEs may involve implementation fees and monthly maintenance fees for providers. In others, there may be low or no cost options for participation and provision of exchange services. Individual oncologists or practices may not have to pay to develop an HIE in an area that lacks one or to join an existing HIE. "Our local exchange was funded by the two local hospital systems, the lab, and federal grant money for start up," said the same cancer program executive. "Different healthcare systems pay to be a partner. The only thing we pay for is if we do some hybrid programming." For example, if the practice wants genetic testing in a discrete data set, it pays a fee for that programming time.

HIEs offer great value to the oncology community, according to Matthews. "HIEs easily transmit information across broad stakeholder groups and large geographic areas," she

said. During their journey with cancer, patients may visit a number of specialists at different locations, including medical and radiation oncologists, surgical oncologists, and other health professionals such as nurses, oncology pharmacists, supportive care specialists, physical therapists, and social workers. As the ranks of cancer survivors continue to grow and the population aged 65 and older increases, so does the need to share health information between specialists and primary care providers. HIEs offer the potential to benefit these providers and patients as well as streamline access to health information.

HIEs can not only demonstrate time and cost savings, but may also impact patient behavior by allowing healthcare providers to identify noncompliance with care or treatment plans.

Forum participants agreed that implementing comprehensive data collection systems has the potential to create opportunities to develop large databases of outcomes, provide resources for the growing stream of comparative effectiveness research, and improve the quality of care for patients with cancer.

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III. Challenges and Next Steps

Participants at the ACCC Institute forum noted that challenges remain as how to best ensure privacy and security while exchanging data seamlessly across large geographic areas. Providers don't want all their records "out there." They also don't want an overwhelming barrage of information. Patients want their privacy protected, but at the same time want instant access to their healthcare information.

Both federal and state laws and regulations apply to HIE activities, including governing the privacy and security of patient's healthcare information. Although HIEs are generally not covered entities (i.e., health plans, healthcare clearinghouses, or healthcare providers) under the Health Insurance Portability and Accountability Act (HIPAA), they are considered to be business associates of HIPAA-covered entities. As such, an HIE must enter contracts or other agreements with participating covered entities—including physicians—that require the HIE, as a business associate, to safeguard and appropriately protect the privacy of protected health information.[13] Thus, any system used by an HIE must comply with the privacy and security provisions of HIPAA.[14]

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Some forum participants voiced concerns about ensuring the validity of information entered into the patient record, particularly as patients begin entering data into and retrieving data from the HIE through a patient portal. A significant challenge is how to authenticate patient information. "Authentication services are a critical piece in integrating a patient's personal health record with the HIE," said forum facilitator Matthews. "HIEs are responsible for authenticating the patient and ensuring security of the information."

Forum participants noted additional challenges related to meaningful use of electronic health information and patient portals.

Several Stage 1 objectives for "meaningful use" from the Centers for Medicare & Medicaid Services (CMS) are behind the push for patient portals. Stage 1 objectives call for providing electronic copies of and electronic access to health information so that patients may view, download, or transmit their health information or hospital admission information online. Beginning in 2014,[15] Stage 2 "meaningful use" objectives mandate that patients be provided the ability to view online, download, and transmit their health information within four business days of the information being available to the eligible professional. In addition, eligible hospitals must provide patients the ability to view online, download, and transmit their health information within 36 hours after discharge from the hospital.

Patient portals usually start with patients' ability to see a snapshot of their health information, and obtain all important health information that may otherwise have been difficult to find. Portals may allow patients to add comments to their existing records, so that physicians can take into account patient feedback when they follow-up and access that patient's information. Some portals will enable patients to input information such as adverse side effects to a medication or feedback from a specialist. While patients are unable to change, add, or delete health information from a record, this commenting capability can be powerful in assuring that any discrepancies a patient catches in the record will be addressed at the source of the information (i.e., doctor's office, hospital, diagnostic center, etc.).

The patient portal may also hold administrative capabilities and serve as a platform for reminders, online scheduling, online bill paying, and even secure messaging between patient and provider. Allowing patients to update their contact and insurance information through the portal can streamline administrative workflows. Perhaps most importantly, portals give patients the tools to become more engaged in their own healthcare. Empowering patients through access to their own data and the resources to

make informed health decisions aligns perfectly with HIE's overarching goal of achieving better health outcomes.[13]

While none would disagree with the importance of increasing patient engagement, for some oncologists at the Institute forum the idea that a patient portal could allow access to all tests, images, and treatment information raised concerns that patients might misinterpret information, resulting in unnecessary distress or worry.

Forum participants expressed a need for protocols around the release of patient information so that providers have input both on the information released and the timing of that release, as well as the ability to answer patient questions about the information.

"We have a patient portal that caused some consternation," noted one forum participant, "but we can put a delay on the release of information." For example, this physician's program has opted to pull out all tumor markers except PSAs and put a one-week delay on release of this information. The goal is to ensure that a patient visit is scheduled within a week of when test result information is released, so that there is an opportunity for the provider to discuss the information with the patient.

 "With a little foresight," the forum participant said, "oncologists can have a say in what information in their private electronic medical record (EMR) system is released and when."

Some participants at the forum voiced concerns that as meaningful use goes through subsequent phases, healthcare providers will have less control of the patient portal. "As transparency gets more baked into this, more information will be released," said another participant.

The discussion highlighted the necessity of building and maintaining a strong framework of trust with both providers and patients in order to have successful HIE participation and to realize the goal of achieving better health outcomes through access to data and data sharing.

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IV. Summary

Electronic health information exchange continues to evolve and grow, fueled by new policy initiatives. For example, the Centers for Medicare & Medicaid Services and the

Office of the National Coordinator for Health Information Technology recently unveiled a plan to promote health data exchange among providers and healthcare organizations. The agencies signaled they would focus on incorporating HIE requirements into existing Medicare and Medicaid policies and aim to give patients greater access to their healthcare data. CMS also indicated it could implement programs to encourage HIE activities among providers by offering incentives that evolve into payment adjustments, with the ultimate goal of making HIE a condition of participation in the Medicare and Medicaid programs.[16]

Technological and scientific advances will also continue to drive health information exchange. "We are seeing new relationships, new innovations with technology, which is expanding exchange capabilities," said Matthews. "Mobile devices will help push innovation in patient portals, and patients will push more data to their healthcare providers. What's more, we are seeing new partnerships and collaborations across a wide range of industry stakeholders—all of which will only facilitate the continued growth of information exchange capabilities."

Real-time electronic exchange of healthcare information has the potential to cut down on duplicative tests and to facilitate care coordination for patients with cancer. Anecdotally, we know that HIEs can lower costs and streamline workflows. We know that HIEs offer the promise of benchmarking treatments across large populations. Future data analytics will allow us to quantify the savings and assess exactly if and how HIEs improve the delivery of cancer care.
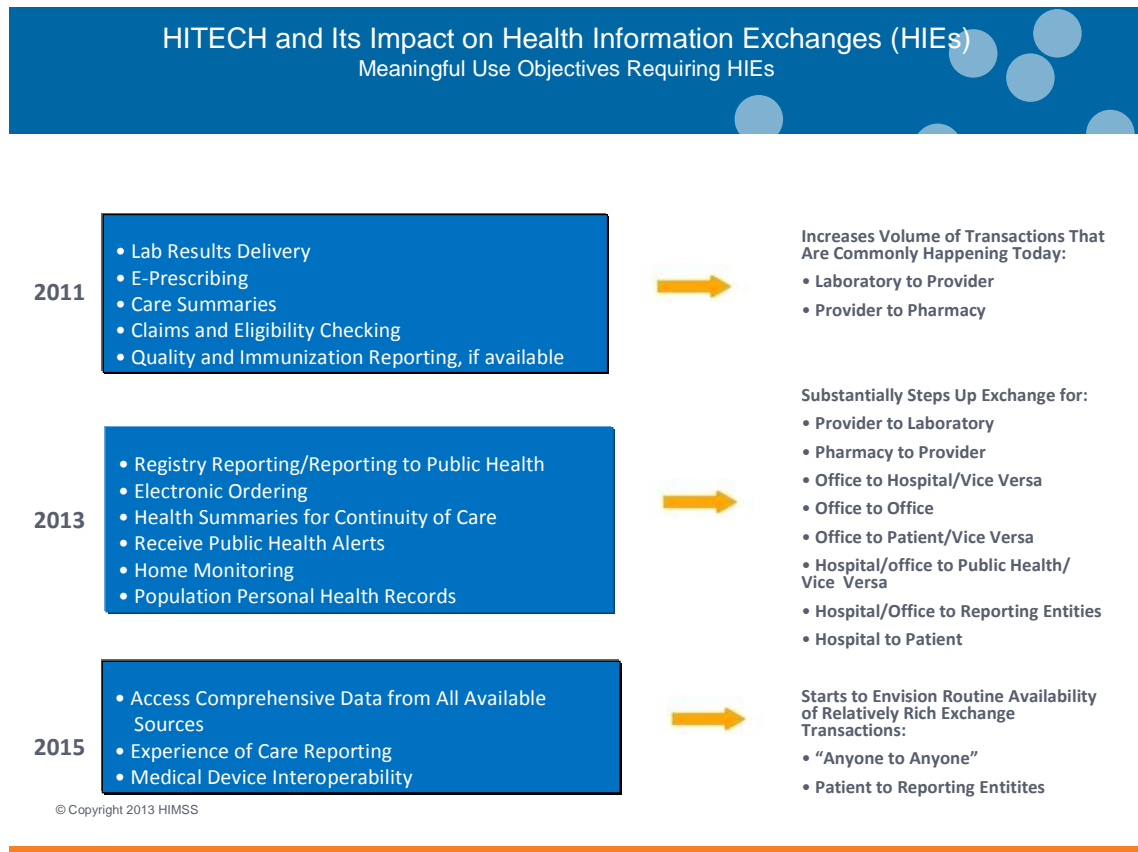
The ACCC Institute forum revealed an understanding of the potential for electronic exchange of health information to improve cancer care delivery, reduce waste, and increase patient engagement, and the reality that while some cancer programs and patients are realizing these benefits, many are not. The discussion reflected some of the hurdles to participation that remain, including variation in models, costs, and services.

Despite the potential that electronic health information exchange holds for improving care coordination, reducing redundancies, lowering costs, engaging patients in self care, and benchmarking data to demonstrate quality and value, the Institute forum participants' comments reflect the reality of uneven adoption and implementation of HIE across the country. The forum participants also voiced a need for more and better information on HIEs, implementation best practices, and resources.

Appendix

"Meaningful use" requirements will drive new and emerging uses of HIE. "Meaningful use" objectives requiring HIEs are shown in Table 1.[17]

Table 1

HITECH and Its Impact on Health Information Exchanges (HIEs)
Meaningful Use Objectives Requiring HIEs

2011
- Lab Results Delivery
- E-Prescribing
- Care Summaries
- Claims and Eligibility Checking
- Quality and Immunization Reporting, if available

Increases Volume of Transactions That Are Commonly Happening Today:
- Laboratory to Provider
- Provider to Pharmacy

2013
- Registry Reporting/Reporting to Public Health
- Electronic Ordering
- Health Summaries for Continuity of Care
- Receive Public Health Alerts
- Home Monitoring
- Population Personal Health Records

Substantially Steps Up Exchange for:
- Provider to Laboratory
- Pharmacy to Provider
- Office to Hospital/Vice Versa
- Office to Office
- Office to Patient/Vice Versa
- Hospital/office to Public Health/Vice Versa
- Hospital/Office to Reporting Entities
- Hospital to Patient

2015
- Access Comprehensive Data from All Available Sources
- Experience of Care Reporting
- Medical Device Interoperability

Starts to Envision Routine Availability of Relatively Rich Exchange Transactions:
- "Anyone to Anyone"
- Patient to Reporting Entitites

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End Notes

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About the Association of Community Cancer Centers

The Association of Community Cancer Centers (ACCC) serves as the leading advocacy and education organization for the multidisciplinary cancer care team. More than 19,000 cancer care professionals from approximately 1,900 hospitals and private practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers. For more information, visit ACCC's website at www.accc-cancer.org. Follow us on Face book, Twitter, LinkedIn, and read our blog, ACCCBuzz.

Comments expressed by forum participants are their own and do not represent the opinions of the Association of Community Cancer Centers or the institution with which the participant is affiliated.