Maryland Chronic Disease Health Information Gap Analysis: White Paper

Maryland Department of Health and Mental Hygiene
Center for Chronic Disease Prevention and Control

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EXECUTIVE SUMMARY

This report examines the policies, procedures, technologies, and systems used to facilitate communication, data sharing, and health information exchange (HIE) among three segments of the healthcare community in Maryland: health system/care practices, payers, and community programs/providers. The research takes the form of a gap analysis that envisions an ideal and improved state and compares that to the current state of information sharing. Research efforts include a literature review, a survey, and four focus group discussions that took place during the spring and summer of 2015.

An improved, or more ideal, state of information exchange can be described as enhanced access to information and the ability to share that information with three key stakeholder groups: healthcare providers, community programs, and public and private payers. The literature review and focus group discussions led to an envisioned system in which each healthcare stakeholder would have:

- access to a health information system for tracking health data electronically;
- the ability to transfer and receive health information electronically from different types of providers, local health departments, community disease prevention programs, insurers, and public payers;
- the ability to participate in HIEs, including the state HIE and other local exchanges or national exchanges, as appropriate.

The current state of information sharing can also be assessed by looking at these stakeholder groups. Data from the online survey indicate that many of these stakeholders are infrequently exchanging information electronically, with the exception of exchanges between affiliated providers or payers. Measures provided by the Office of the National Coordinator for Health Information Technology (ONC) also suggest that providers in Maryland are lagging slightly behind national figures in several areas related to information exchange, such as the capacity to exchange messages securely with patients and to provide patients with clinical care summaries.

Information sharing and healthcare providers

The state of information sharing for providers can be described in terms of system adoption and use according to the stages of meaningful use (MU). Although hospitals and integrated systems appear to enjoy higher rates of adoption and use, many office-based physician practices are in the earlier stages of adoption or have not yet adopted an electronic health record (EHR) system. According to ONC data from 2013, the current state of adoption by hospitals with at least a basic
EHR system is estimated at 73 percent in Maryland, and the current state of adoption for office-based physicians is estimated at 37 percent (ONC 2015a). These data suggest that many office-based physicians are still using paper systems.

The literature also suggests that providers often do screen for chronic diseases using the Body Mass Index (BMI), blood pressure readings, and fasting blood glucose measurements, and that they ask about tobacco use and smoking. In many instances, this screening results in a conversation where the physician notes the value of improving dietary habits, decreasing smoking, and increasing physical activity. For some patients, the discussion will prompt behavioral change, but other patients may need more.

**Information sharing and community programs**

Many community programs that focus on the prevention of chronic diseases are beginning to form referral relationships with healthcare providers; however, some have not yet developed these relationships. A few dental and pharmaceutical programs were noted as bridging the barrier between healthcare providers and community programs. In the case of dental programs, they receive a referral triggered by an emergency department visit. When asked about one of the program’s referral methods, it was noted that the referral was a paper fax. The paper fax was also the method used to close the communication loop to inform the referring provider that arrangements had been made for services and about compliance with those arrangements.

Additionally, for community programs, discussion revolved around three frequently mentioned types of programs—diabetes prevention programs, faith-based programs, and telephonic programs (often used for reporting hypertension)—that are akin to early screening and prevention for chronic diseases. These programs are often challenged by resource constraints. Resources are strained by the need for additional outreach to eligible participants. In the face of limited budgets for outreach, many programs are directed at groups where people already have an affiliation (for example, religious groups). Because many programs are funded by grants, sustainability is a common concern. Some stated that charging copays would likely decrease participation. In the case of worksite wellness programs, marketing was not a concern, though many felt there was duplication of effort associated with ineffective communication with providers.

Some survey and focus group participants noted that cultural challenges—such as low socioeconomic status, the stigma of disease, education level, access to technology, cultural literacy, and health literacy—can impact the success of prevention programs. In addition, a
provider’s willingness to participate in the referral process was thought to influence the success of the program.

Information sharing and public and private payers

Changes in payment methods have altered the incentives for engaging in activities that impact chronic disease prevention. In recent history, providers were paid for services provided (for example, diagnostic tests) and treatment plans for diseases. In redesigning the reward system, payers have been faced with the challenge of paying for services in ways that focus on keeping people well and avoiding expensive hospital stays, while also relating payments to services performed by the physician.

Two concepts can be used to design a reimbursement system that is better aligned with the incentives of chronic disease prevention: one is to focus on overall population health outcome measures and the other is to focus on an episode of care. Both approaches rely on the collection of outcome and process measures. Outcome measures are central to assessing quality and may include a range of health data (for example, test results or, more specifically, blood pressure readings). Process measures are related to the delivery of care services. For instance, health outcomes linked to heart attack survival could include factors related to services delivered by many different healthcare professionals (for example, paramedics, emergency room teams, cardiac catheterization laboratory staff, and rehabilitation professionals) and factors unrelated to care services (for example, comorbidities).

Strategies to create linkages between evidence-based community resources for prevention and primary care could have a meaningful impact on improving the delivery of preventive care. Recommended actions to both create linkages and to close information-sharing gaps were provided in a few priority areas, including:

- technology
- policy
- culture and workflow
- resources
- ongoing learning

Technology

Recommendations related to technology include actions to increase adoption of EHR systems by health practices and actions to increase the interoperability of those systems. These strategies
include discouraging information blocking, supporting the development of data standards, and supporting access to interfaces that allow for connectivity either among programs or to the state HIE. The development of data standards will likely involve the new data exchange technology, Fast Healthcare Interoperability Resources (FHIR) standard, which will improve on Consolidated Clinical Document Architecture (C-CDA) by enabling faster data exchange.

Policy

Policy recommendations prioritize the need to ensure privacy and security and to clarify existing policy with respect to Health Insurance Portability and Accountability Act (HIPAA) compliance. In 2015, health plans, hospitals, and government agencies reported serious and massive data breaches, which indicate that these security concerns are ongoing. These high-profile breaches suggest that health organizations should perform a risk assessment with regard to security measures. Additionally, the focus groups and survey data noted concerns about the wide variation in interpretation of existing HIPAA policy. HIPAA was frequently noted as a key barrier to information exchange.

Culture and workflow

In terms of culture and workflow, there is a need to promote administrative simplicity. Simplicity can be reflected in changing from secure paper faxes to secure email (for example, the Direct Project, which allows for direct secure messaging). There is also a need to change work patterns to make the reporting of quality measures more routine and less time intensive for staff. Efforts should be made to promote coordination between health systems, community preventions, and payers and to develop procedures for routine screening, risk assessment, and referral.

A priority of the National Quality Strategy is ensuring that patients and families are engaged as partners in patient care. Strategies for more participation include increasing patient access to their health data, providing relevant health education resources, and designing information systems that allow for the opportunity to include patient-generated health data. These data include blood pressure readings, monitoring activity, and weight or BMI.

Resources

Resource needs include both administrative tools and financing. Administrative tools (for example, a continuously updated online directory of community programs, searchable by location and condition, and containing information relevant for a referral [location, times, days]) would increase awareness of available community prevention programs. Other helpful tools that could
be developed and standardized for the prevention and control of chronic diseases are partnership agreements, referral forms, screening procedures, evaluation systems, and reimbursement-related forms. An online forum in which information about such coordination efforts could be shared would be beneficial.

The importance of aligning financial incentives with public health goals cannot be understated. New financing methods are being designed in healthcare as part of the reform of the delivery system involving the value-based purchasing program. These methods offer financial incentives to providers in the form of rewards and penalty adjustments based on their performance on pre-specified measures. Success at value-based purchasing often involves setting appropriate performance targets and using health information technology to support the collection of data. This alignment is a key area to address so that financial resources are available for the sustainability of efforts.

**Ongoing learning**

The final set of recommendations is connected to ongoing learning in the area of interoperability. The first recommendation is to create a discussion forum to explore ways to extend the use of secure interoperable health information technology tools and HIE services. The second recommendation is to promote knowledge of the existing infrastructure (for example, the state HIE and the Chesapeake Regional Information System for our Patients [CRISP]). Part of this effort will involve determining which of CRISP’s features are of value, which are still needed, and how CRISP can be expanded to further the prevention and control of chronic diseases. As future efforts are discussed, it might be useful to consider how to develop and facilitate the implementation of the FHIR standard as a means to accelerate HIE efforts among health systems and practices, community programs, and public and private payers.
INTRODUCTION

The University of Baltimore’s Schaefer Center for Public Policy partnered with the Center for Chronic Disease Prevention and Control at the Maryland Department of Health and Mental Hygiene (MDMH) to evaluate the effective use of health information technology to improve chronic disease outcomes, particularly in the areas of hypertension and diabetes control. This research examines policies, procedures, technologies, and systems used to facilitate communication, data sharing, and HIEs among three segments of the healthcare community: health system/care practices, payers, and community programs/providers. A gap analysis is employed that involves understanding the current state of information sharing and an ideal or improved state approximately five years from the present.

In the next five years, new partnerships among healthcare practices, community programs, and public and private payers are expected to bring about clinical improvements more effectively than a single-sector design. Efforts to improve information sharing between healthcare practices and community groups will likely include enhanced endeavors to improve patient engagement and education for self-management when appropriate. Increased access to information should include more opportunities for patients to receive information about their health and/or condition and to communicate with healthcare practices using emails, telemedicine, and remote patient monitoring. In time, with the continued development of wearable health technology, there may also be a trend for the patient to submit patient-generated health data.

Also likely in the near future is an increase in the number of healthcare practices, especially unaffiliated physician practices, that will begin using EHRs to capture quality metrics for use in the improvement of care. This change is likely to involve not only added technology but also teamwork and collaborations with other healthcare professionals. Strategies could include increasing the number of practices collecting population-based data for clinical preventive services (for example, blood pressure control, tobacco and nicotine use and cessation, hemoglobin A1c control, and BMI) and developing information-exchange functionality so that healthcare practices can use tools that support chronic disease control. These tools include alerts, patient reminder systems, clinical decision supports, clinical quality measures (CQM), and patient registries.

A role for private and public payers could involve developing payment systems that support changes to increase the use of high-value procedures and reduce the use of low-value procedures. These often include sharing the financial risk with healthcare practices or providing incentives for beneficiaries. A tricky aspect for payers is appropriately linking quality metrics to the actions of providers. For example, community health could be influenced by changes in marketing strategies for sugary drinks rather than physicians’ health messages. Insurers and payers also provide claims
data that can offer some insights into patient care (for example, diagnoses and procedural codes). These data may be useful in the absence of EHR information.

Strategies to create linkages between evidence-based/community-based resources and primary care could have a meaningful impact on improving the delivery of preventive care. These could involve piloting a physician referral model with lab values to make the appropriate referral and monitoring CQMs to gauge improvement of program participation and feedback. This could be achieved by creating a centralized referral system to provide access to programs, expanding the number of evidenced-based disease prevention programs, and finding ways to increase ease of participation for those patients who would benefit.
BACKGROUND

Chronic diseases, such as diabetes and cardiovascular disease, are a leading cause of poor health status, high health costs, and disability in Maryland. An encouraging approach to enhancing the delivery of preventive services is for healthcare providers to collaborate with community programs that share an interest in improving health, preventing diseases, and providing these services. From the viewpoint of the provider, the coordination effort would involve assessing patients who are at risk for chronic diseases, providing counseling on risk factors, and referring patients to a community-based prevention program when appropriate.

Community programs need to take on the role of communicating the status of patients to primary care physicians. Information with respect to behavioral changes in areas such as nutrition, physical activity, or smoking cessation can potentially be integrated into a patient’s EHR. The development of collaborative efforts has coincided with policy efforts to accelerate the adoption of health information technology and exchange, but interoperability has not been fully realized for many healthcare organizations.

Policies – The Health Information Technology for Economic and Clinical Health Act and HIPAA

The influential Health Information Technology for Economic and Clinical Health Act of 2009 has provided financing for the Centers for Medicare and Medicaid Services EHR Incentive Programs, which promote the adoption of EHR systems by eligible hospitals and eligible providers. Hospitals and health systems tend to have higher rates of adoption compared with office-based providers. Even so, challenges include problems with interoperability, health information sharing, and patient engagement.

Another policy that has provided some guidance for the secure sharing of protected health information is the HIPAA of 1996, which is associated with the Breach Notification Rule. This rule requires individuals to be notified following a data breach. HIPAA’s security rule and its privacy rule ensure that health information is protected from unauthorized access and is shared appropriately for payment, treatment, and healthcare operations through patient authorizations (Koontz, 2015).

Technologies – Registries and HIEs

Computerized disease registries allow for the tracking and sharing of information. Immunization information systems, or registries, have been used as a tool to provide a central location for vaccination records from multiple healthcare practices within a given state. Registries also provide
some information about the progress of national public health objectives for the Healthy People 2020 initiative. These registries have had a longer history of standardization, but the rules and policies vary somewhat from state to state in terms of such factors as mandated participation and consent requirements.

The state HIE for Maryland is CRISP. It provides a secure HIE for Maryland’s hospitals to track patient care records. CRISP also provides a platform to support the Prescription Drug Monitoring Program (PDMP) (Jones, 2015). It is noted in recent literature on HIEs that interoperability is still problematic. Information on HIEs is not always easy to import and download into an EHR. A report by the U.S. Government Accountability Office (GAO, 2014) reviewed four states and noted the following problems:

1. lack of standards (for example, differing terminology for allergies);
2. lack of clarity on privacy issues;
3. difficulty matching patients to their health records; and
4. costs (such as those associated with establishing data exchange interfaces).

The Context in Maryland

In Maryland, many health information innovations are being devised to offset the burden of chronic diseases. As noted in the previous section, CRISP provides a secure HIE for Maryland’s hospitals to track patient care records. It provides a platform that supports the PDMP. The PDMP oversees the dispensing of drugs that contain controlled substances (schedules II–V) to reduce prescription drug abuse (CRISP, 2015; ONC, 2013). Although the PDMP is not focused on treating chronic diseases, it is associated with better prescribing decisions and represents a model in the monitoring of medication dispensation.

There have been other efforts in Maryland aimed at information sharing. These include the development of local health improvement coalitions to share and track key population health measures (State of Maryland, 2014). According to the United Health Foundation, Maryland has improved in the 2014 state rankings with respect to public health improvements in increased immunizations and reductions in preventable hospitalizations, smoking, and binge drinking (MDMH, 2014b).

Maryland has plans for increased support of the “community-integrated medical home” to connect community health and primary care, for greater participation in Medicaid, and for the development of “behavioral health homes” for those with mental illness or substance abuse disorders, as well as continued efforts to develop the workforce to bridge communities with care
(MDHMH, 2014a). In terms of healthcare financing, Maryland has been modifying its all-payer model to emphasize “pay for value” to incentivize hospitals to focus on improving health outcomes. As part of this effort, the state has awarded funding to eight regional partnerships (MDHMH, 2015).

The preceding background and context frame this report into strategies for improving care coordination. Stakeholder input was obtained to ascertain the use of technologies for sharing patient data, accessing HIEs, and engaging patients, with a focus on chronic disease care as described in the next section, Study Design and Methods.
STUDY DESIGN AND METHODS

The report was designed as a gap analysis to provide insights into the current state of health information sharing. Material was used from a literature review and collected survey responses. Additionally, input was received from focus groups for more in-depth learning about the current and the ideal states of information technology. Further, this input provided approaches for improving information sharing among healthcare practices and systems, community programs, and public and private payers.

The literature review, conducted in the spring of 2015, explored relevant policy, adoption, and use of EHR systems; the benefits and barriers to using EHRs and HIEs; and efforts in selected states. Its methodology involved a multi-step process. First, articles were selected from a search of EBSCO Discovery Service, limiting the dates from 2013 to 2015 (March 30, 2015) with broad search terms around information exchange and limiters on dates and location. Second, the search terms were narrowed and the limiters were broadened to include dates from 2010 to 2015 (April 28, 2015). Through the late spring and early summer of 2015, additional searches were made of government and media websites for chronic disease prevention and information sharing, with some outreach to contacts from state and federal government agencies and programs.

In addition to the literature review, an online survey was designed. The online survey served a couple of purposes: (1) to ascertain the organization’s interest in participating in focus groups or interviews to discuss their use of health information technology, patient engagement, and information sharing; and (2) to provide some foundational information to guide the development of focus group discussion guides.

The survey, shown in Appendix A, was available online along with an email invitation in June and July of 2015. Survey outreach included a combination of telephone and email outreach to healthcare practices and systems, community programs, public health departments, and public and private payers. For healthcare practices and systems outreach, methods consisted of telephone contact of hundreds of practices (including clinics, medical centers, and primary care). Additionally, outreach efforts were assisted by two associations: the Mid-Atlantic Association of Community Health Centers and the Maryland Medical Group Management Association.

The response rate for the online survey was limited, with only 12 percent of those contacted agreeing to participate in the survey. This may have resulted in a response bias toward those health practices or systems that have better access to the internet and are more technically savvy than the average practice. At the conclusion of the online survey, respondents were invited to participate in focus groups; nearly two-thirds (65 percent) of the respondents expressed an
interest in receiving an invitation. Due to the limited overall response rate, we would encourage further efforts to enhance participation and increase learning in future studies in this area.

Focus groups were designed to provide in-depth learning about the current and the ideal state of information technology and communication among healthcare practices, community groups, and others. Research questions included the areas of quality measurements, health outcomes and workflow, the patient’s role, the development of healthcare learning systems, and reimbursement models. A copy of the focus group questions is available in Appendix B. To capture the views of a statewide group of health information-sharing stakeholders, focus groups were conducted in Baltimore City, Prince George’s County, Washington County, and Wicomico County from August 3, 2015 to August 11, 2015.
RESEARCH FINDINGS SUMMARY

Research findings are taken from three areas of exploration: a literature review, an online survey, and focus group discussions. Each is summarized in the following sections.

LITERATURE REVIEW SUMMARY

Care coordination across the spectrum of health providers has become an overarching goal for the US health system. Information technology is a critical component of such coordination; specifically, the use of electronic medical records by providers. The focus of this literature review¹ is to identify and analyze evidence on the strategies used by providers, payers, and community groups to communicate and share information. Chronic diseases, including diabetes and cardiovascular disease, are leading causes of poor health status, high healthcare costs, and disability in the United States. Lifestyle choices, such as diet, regular exercise, maintaining a healthy weight, and not smoking, are associated with the prevention of chronic diseases. Although the benefits of following these preventative factors have been documented in research studies, primary prevention and health promotion activities are often overlooked during patient–provider encounters.

The pace of commitment to adoption of EHR systems has been accelerating, due in large part to funding provided by the Medicare and Medicaid EHR Incentive Programs. The creation of value for healthcare is associated with MU stages that set goals and thresholds and provide exclusions and exemptions. Analysis of the exclusions and exemptions for earlier stages can provide guidance in the development of later stages. Changes in MU stage two, in addition to increasing threshold measures, include the transition of care summaries and options for increasing patient engagement. MU stage three is anticipated to include changes to the CQM requirement for better alignment with existing measures to improve population and public health, more efforts to improve care coordination, and increased efforts to engage patients. Patient engagement could be reflected in the inclusion of patient-generated health data, secure messaging, and improved access to patient education resources.

Researchers note that adoption and use have been more challenging for providers than hospitals. Bidirectional information sharing is seen as an important area for MU in the next few years, allowing for communication between many health-related organizations. A potential vision for

¹ This report is a summary of the full literature review and briefly introduces some of the main topics discussed in the full review. The full literature review can be found in its entirety in a separate document.
information sharing driven by enhanced technology could be characterized by community outreach efforts that involve large interdisciplinary care teams sharing information through mobile technology.

Measures of adoption rates of EHR systems reflect greater adoption among hospitals in Maryland than office-based physicians. ONC data from 2013 indicate that, in Maryland, 73 percent of acute hospitals have adopted an EHR system as compared to 37 percent of physician practices (ONC, 2013). Smaller and solo practices tend to lag behind, while practices that are part of an integrated network tend to have higher adoption rates.

In considering efforts to promote adoption at community health centers, Goldwater and his colleagues (2014) examined the use of an open-source EHR system in five community health centers. This open-source system was developed in an effort to redesign the care system and to support more effective management of chronic diseases for indigent patients. Its use was noted as accelerating the redesign of the care delivery system prior to the acquisition and implementation of chronic care disease management programs, which included diabetes, hypertension, and tuberculosis vaccinations for those experiencing homelessness.

Implementation concerns include the need for training on the new systems. Examples include learning to read and write in the clinical notes section and learning about changes in workflow. Studies on the use of EHR systems to improve quality note that the systems depend on accurate inputs.

Research on the use of EHR systems to manage and treat chronic diseases often include efforts beyond the adoption of the EHR system. These additional efforts were prioritized either for their successful contributions or for missing elements in their explanation of why the effort did not result in the anticipated health outcome. These efforts include:

- The addition of community outreach professionals such as community health workers and certified diabetes educators (Calman et al., 2013).
- The addition of referral and feedback looks and connected reimbursement codes. This added effort was often in the form of improved medication management through the inclusion of pharmacists (Goldstein & Abelson, 2015).
- The addition of strategies to change physician behavior with regard to screening and referrals and to increase patient engagement (Julliard et al., 2012).

The key benefits associated with the use and adoption of EHR systems include the ability to improve direct care to patients and to coordinate care, to use EHR information for prevention, to
use EHR information for patient engagement, and to use EHR systems to develop population health measures.

In an effort to promote patient engagement, healthcare providers are increasingly providing the ability for patients to view, download, and transmit their health records through patient portals. There are some challenges experienced by patients when using patient portals. These include lack of awareness on the part of the patient and poor usability (Furukawa et al., 2014). Dubois Medical Center employed information technology and education programs to instruct patients beyond the use of the health portal, and encouraged patients’ health literacy by using LPNs to work with patients to access lab results. These efforts underscore the idea that health literacy needs to be considered along with digital literacy (Galbraith, 2013).

Adler and Stead (2015) discuss the use of EHRs to capture social and behavioral determinants of health, such as financial-resource strain, alcohol use, social isolation, and intimate partner violence. EHRs can also support communication between clinicians and other service providers, such as community agencies, so that follow-up from referrals can be included in the patient’s health record. Along the theme of adding patient self-reported data, Peck (2014) states that Peter Basch, medical director for MedStar Health’s ambulatory health information technology policy in the development of portals and educational materials, mentioned an opportunity to collect information prior to visits by emailing a pre-visit screening tool and risk assessment to patients, who would then submit their responses electronically.

Some of the value of using EHR systems goes beyond the transactional system. Patient-level data can provide alerts and reminders in an EHR and benefit patients who come in for care. Population-level health data can include proactive outreach to patients who are due for a screening or an annual visit. At the population level, discussions can include the development of patient registries to facilitate outreach and care coordination for a specific condition, such as diabetes. A more advanced function can include surveillance to identify high-risk patients and then to provide intensive, individual case management.

A key goal of the EHR Incentive Programs is the reporting of CQM performance data to be used for population-level quality data. Many of these measures are endorsed by the National Quality Forum (NQF). In making CQM calculations, providers are required to use a certified EHR system for both the aggregate numerators and denominators. Three measures are reported: blood pressure control (NQF 18), aspirin use when appropriate (NQF 68), and cholesterol management (NQF 64) (Heisey-Grove, Wall, Helwig, & Wright, 2015).
These benefits often provide the incentives to push past the barriers that discourage the use of EHRs for referring at-risk patients to community-based programs. Potential barriers discussed in the literature include:

- cultural differences and policies that do not allow for the provision of information sharing and resources for at-risk patients;
- lack of administrative support for providers on EHRs to alert them regarding patient information, and to help coordinate and manage patients’ health and relevant conditions;
- questionable accuracy and soundness of data from information systems based on patient-level data from EHRs;
- limited workforce development and staff training, particularly in information exchanges and interoperability;
- patient privacy and confidentiality issues;
- perceived lack of return on investment;
- other concerns such as pricing clarity for upgrades and interface development, information blocking, restrictions on financing options, and a growing awareness of the limits of data security and of problems thwarting cyberattacks.

Health providers are responding to changes in the healthcare industry by adopting, or modifying, their EHR systems to comply with health reform efforts and by demonstrating MU. For many healthcare providers, this means developing a relationship with an EHR vendor or, sometimes, multiple vendors. The costs associated with purchasing an EHR system, making upgrades, providing support, and developing interoperability are influenced by many industry trends. For the EHR industry, these trends have coincided with policy changes, technology changes, pricing regulation changes, and a growing public awareness of security issues.

- The influence of policy changes on the EHR industry. These trends include growth followed by consolidation, multi-vendor partnering, and standards development. Trends in standards development include the development of the FHIR standard promoted by the Argonaut project (Conn, 2014a).
- The influence of technology changes. These trends include a shift to web-based and cloud-based systems and the development of wearable technology.
- The influence of regulatory interest in pricing. These trends include interface changes, information blocking, and restrictions on alternative forms of financing.
- The influence of growing public awareness of the limits of data security. Recent high-profile breaches include CareFirst (Goldstein & Abelson, 2015) and those at the federal government level, including at the Internal Revenue Service (IRS Data Breaches, 2015) and
the Office of Personnel Management (Larter & Tilghman, 2015). These breaches continue to stoke patient privacy concerns.

HIE metrics provided by the ONC using 2013 data suggest that Maryland lags slightly behind the nation in all areas for office-based physicians (see table 1).

Table 1. Health Information Exchange Metrics

<table>
<thead>
<tr>
<th>Health Information Exchange Metrics</th>
<th>Maryland</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent of office-based physicians with capability to send orders for lab tests electronically</td>
<td>40%</td>
<td>53%</td>
</tr>
<tr>
<td>Percent of office-based physicians with computerized capability to view lab results</td>
<td>72%</td>
<td>77%</td>
</tr>
<tr>
<td>Percent of office-based physicians with EHR/electronic medical records that can automatically graph a specific patient’s lab results over time</td>
<td>38%</td>
<td>47%</td>
</tr>
<tr>
<td>Percent of office-based physicians with capability to exchange secure messages with patients</td>
<td>39%</td>
<td>49%</td>
</tr>
<tr>
<td>Percent of office-based physicians with capability to provide patients with clinical summaries for each visit</td>
<td>58%</td>
<td>68%</td>
</tr>
</tbody>
</table>

Source: ONC, 2015a

Efforts to improve information exchange include the development of statewide HIEs. These efforts began with federal funding for the provision of secure information-exchange pathways. Some states built their own entities for information exchange, while others chose to bolster existing HIEs.

In the literature review, the noted key concerns surrounding the use of statewide HIEs by physician practices include: workflow disruption, ease of use of interfaces, costs or fees for use, and competition among provider groups. For policy makers and payers, concerns include sustainability and costs, lack of standards or interoperability, legal/liability and ethical issues, the plethora of technology, and mandates. Patients’ key concerns are related to privacy and security issues and controls (for example, permissions for sharing and use). Additionally, interoperability concerns reflect a difficulty with importing the data from the HIE directly into a given patient’s EHR. Concerns also arise regarding liability if the imported data is incorrect or attached to the wrong patient.

ONLINE SURVEY SUMMARY

In June and July of 2015, an online survey on health information sharing was prepared with outreach to three healthcare stakeholders: healthcare practices and systems, public and private
payers, and community programs. The findings should be reviewed with the knowledge that the response rate of 12 percent was limited.

The study findings suggest that many respondents (69 percent) use an EHR system, which is a step toward better tracking of chronic conditions and sharing of information on care processes. Reviewing the data by type of organization, most healthcare practices or systems and most public and private payers are using at least a basic EHR system. In contrast, most community programs do not use an EHR system.

The electronic transfer of data among and between types of organizations does not appear to be seamless or complete even among affiliated entities within a single health system. Within a health system, most affiliated entities are likely to be using the same inpatient software and the same ambulatory clinical software for their outpatient practices. In many health systems, these two systems (inpatient/outpatient) are not completely interoperable, although the use of a single system could be a goal to improve information sharing over the next few years.

Although inpatient and ambulatory systems may be different, they should be connected through interfaces so both a hospital employee and a physician in an affiliated physician-owned practice can share information from a single source without making additional phone calls or accessing multiple systems. This would allow providers to track patient vital signs and test results from other providers within the system and make treatment decisions for conditions such as hypertension and diabetes.

When there is limited information exchange among providers via a shared EHR, the information gap is sometimes filled by claims data shared by insurers and payers; however, this data is limited by rules surrounding billing procedures and excludes non-billable services. Although non-reimbursable information is not included, claims data can still provide some insights into a patient’s care process (for example, diagnoses and procedures). Claims data are associated with a given payer and are limited to patients who are insured through the health plan and to the time of coverage. The comparatively high rate of exchange of protected health information between healthcare practices and systems may be reflecting the use of claims data.

Over a third of survey respondents (39 percent) reported electronic transfer of protected health information to insurers and payers. Similarly, nearly a third (32 percent) reported receipt of health information from insurers and payers. These percentages are high in comparison to other groups (see tables 2 and 3).
Table 2. The Transfer of Protected Health Information

<table>
<thead>
<tr>
<th>Does your health organization transfer protected health information to any of the following?</th>
<th>Yes, transferred electronically</th>
<th>Yes, not transferred electronically</th>
<th>No</th>
<th>Don't know</th>
<th>Total applicable responses¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affiliated Hospital</td>
<td>26%</td>
<td>23%</td>
<td>31%</td>
<td>20%</td>
<td>61</td>
</tr>
<tr>
<td>Unaffiliated Hospital</td>
<td>12%</td>
<td>30%</td>
<td>32%</td>
<td>26%</td>
<td>69</td>
</tr>
<tr>
<td>Private Healthcare Practice</td>
<td>20%</td>
<td>44%</td>
<td>18%</td>
<td>18%</td>
<td>71</td>
</tr>
<tr>
<td>Community Clinic or Federally Qualified Health Center (FQHC)</td>
<td>15%</td>
<td>40%</td>
<td>26%</td>
<td>19%</td>
<td>68</td>
</tr>
<tr>
<td>Local Health Department</td>
<td>21%</td>
<td>31%</td>
<td>32%</td>
<td>16%</td>
<td>68</td>
</tr>
<tr>
<td>Community Chronic Disease Prevention or Control Programs²</td>
<td>21%</td>
<td>25%</td>
<td>39%</td>
<td>15%</td>
<td>72</td>
</tr>
<tr>
<td>Insurer/Payer</td>
<td>39%</td>
<td>16%</td>
<td>29%</td>
<td>16%</td>
<td>69</td>
</tr>
<tr>
<td>Other</td>
<td>20%</td>
<td>10%</td>
<td>50%</td>
<td>20%</td>
<td>40</td>
</tr>
</tbody>
</table>

¹ Non-applicable responses were removed from total responses (75).
² For example, Chronic Disease Self-Management Program, Diabetes Self-Management Program, Diabetes Prevention Program, nutrition or physical activity programs, and tobacco cessation.

Claims data could also be useful to insurers or payers that endeavor to provide access to chronic disease programs. Even if health insurers and payers recognize the value of prevention programs, they are often not a covered benefit. Very little information exchange between community programs and insurers/public payers was reported in the survey.

The ability to transfer data electronically to a community chronic disease prevention program was reported as follows: 21 percent were able to transfer the data electronically, 25 percent were able to transfer the data but not electronically, and 39 percent were not able to transfer the data at all (see table 2). The receipt of protected health data from community chronic disease prevention programs was most often reported as not received (36 percent) or not received electronically (32 percent) (see table 3).
Table 3. The Receipt of Protected Health Information

<table>
<thead>
<tr>
<th>Does your health organization receive protected health information from any of the following?</th>
<th>Yes, transferred electronically</th>
<th>Yes, not transferred electronically</th>
<th>No</th>
<th>Don't know</th>
<th>Total applicable responses¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affiliated Hospital</td>
<td>35%</td>
<td>22%</td>
<td>24%</td>
<td>19%</td>
<td>63</td>
</tr>
<tr>
<td>Unaffiliated Hospital</td>
<td>15%</td>
<td>32%</td>
<td>27%</td>
<td>25%</td>
<td>71</td>
</tr>
<tr>
<td>Private Healthcare Practice</td>
<td>18%</td>
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<td>21%</td>
<td>24%</td>
<td>72</td>
</tr>
<tr>
<td>Community Clinic or Federally Qualified Health Center (FQHC)</td>
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<td>39%</td>
<td>23%</td>
<td>19%</td>
<td>69</td>
</tr>
<tr>
<td>Local Health Department</td>
<td>13%</td>
<td>35%</td>
<td>32%</td>
<td>19%</td>
<td>68</td>
</tr>
<tr>
<td>Community Chronic Disease Prevention or Control Programs²</td>
<td>12%</td>
<td>32%</td>
<td>36%</td>
<td>21%</td>
<td>73</td>
</tr>
<tr>
<td>Insurer/Payer</td>
<td>32%</td>
<td>16%</td>
<td>25%</td>
<td>26%</td>
<td>68</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
<td>7%</td>
<td>49%</td>
<td>29%</td>
<td>45</td>
</tr>
</tbody>
</table>

¹ Non-applicable responses were removed from total responses (75).
² For example, Chronic Disease Self-Management Program, Diabetes Self-Management Program, Diabetes Prevention Program, nutrition or physical activity programs, and tobacco cessation.

A second analysis of the data was made to determine if organizations were able to share data electronically with any of the specified organizations. The analysis found that 62.7 percent of respondents were able to transfer protected health information with specified groups and 55 percent received protected health information from specified groups. The survey data also suggest that health information sharing among unaffiliated health practices (unaffiliated hospitals, private practices, and Federally Qualified Health Centers [FQHCs]) is most often not electronically shared.

The barriers and facilitators to electronic information sharing are as follows. Barriers include issues with the interoperability of different EHR systems. There are also concerns with privacy and security (for example, compliance with policies such as HIPAA). Facilitators include appropriate staff knowledge and skills, appropriate policies and/or processes, interoperability of health information systems, technical assistance, and support from information technology vendors.

The option to bolster HIEs using local, state, and regional health information networks was recognized by many survey respondents. This network would also represent an opportunity to provide clinical decision support systems to practices by improving their interconnectivity.
Currently, CRISP participation is mandated for hospitals and is most commonly associated with providing a benefit to emergency care coordination. For this survey, just under a third reported participating in the statewide HIE and a smaller percentage reported participating in a local HIE.

The following comments provide some added insight into the online survey results:

“All information that is sent must have the written HIPAA signed on the chart by the patient which states that the information can be sent. The consent also must contain who the Health Department is allowed to send it to. Some of the results we have in our Cancer Screening Programs may only be sent by the Hospital if performed at the hospital or provider site.”

“We use fax and also send excel files but not information directly from our system directly into their system.”

In the comment section on participation in a local HIE, the Delaware Health Information Network exchange was mentioned. Another comment cited the Million Hearts initiative as providing a mechanism for de-identified health data exchange related to patients with hypertension.

“Through the Million Hearts initiative, local primary care providers send us patient panel information—i.e., the number of hypertensive patients in their practice—but there are no patient identifiers attached to the data.”

The survey concluded with a request to participate in focus group discussions to expand on the discussion of health information sharing. Nearly two-thirds (65 percent) of the survey respondents expressed an interest in participating in the focus groups.

**FOCUS GROUP DISCUSSIONS**

The Schaefer Center for Public Policy conducted four focus groups across the State of Maryland with participants recruited from the online gap analysis survey. Focus group participants came from local health departments, hospitals, community groups, FQHCs, and payers. The focus groups were held at Prince George’s Community College, the Schaefer Center for Public Policy, Washington County Health Department, and Wor-Wic Community College.

As noted earlier, the focus groups were designed to provide in-depth learning about the current and the ideal state of information technology and approaches to communication among
healthcare practices, community groups, and others. Research questions covered quality measurements, health outcomes and workflow, the patient’s role, development of healthcare learning systems, and reimbursement models.

Key themes discussed by focus group participants suggest some problem areas that could be improved on to strengthen information sharing. These themes include:

- problematic standards as a key barrier to interoperability;
- privacy and security concerns;
- patient engagement strategies;
- workflow and quality reporting;
- reimbursement models and public health goals; and
- potential benefits to expanding information exchange via CRISP.

**Problematic standards as a key barrier to interoperability**

Standardization is the first key topic selected based on the focus group discussions. Statements related to standardization were frequently mentioned in every focus group. Specifically, challenges related to data standards and data reporting standardization were brought up by numerous focus group participants.

Data standards are documented agreements on representation and definitions of common health data, including clinical data and public health reporting. For MU stage one, the Continuity of Care Document is the standard, and it is based on Health Level 7 clinical document architecture (CDA) (D’Amore et al., 2011). Another common standard is the C-CDA (ONC, 2013). The C-CDA uses templates or an implementation guide to C-CDA and is the base standard for building clinical documents. A drawback to C-CDA is that it transfers entire documents rather than a single piece of data or a list or structured data (Ahier & Doeringsfeld, 2015).

In some cases, the CDA file might not be available. One participant explained the problems in trying to import flat files, which are data files that contain no structured relationships.

"I can't give you a [flat] file that you can import and use it meaningfully to do reports or to gather data. It's very difficult."

Many focus group representatives felt frustrated with having to report the same data in multiple ways to different grants and programs, because there is no standard and accepted way to report data.
“For one program, just internally I may get data from three different sources. Or on the other side, from the data that I have, I may have to get data to three outside sources in three different formats. So it would be nice if it were all in the same format that we could push it out the same way, just like they did when we went through HIPAA in the early 2000s, when we went with the standardization of data elements for billing. That would be nice. If we had a standard that we could start from, then we can build around it.”

Privacy and security concerns

Privacy concerns, security measures, and the constraints and various interpretations of HIPAA make up the next key topic identified by the research team. Most comments pertained to HIPAA and its associated privacy and security rules. The privacy rule permits sharing of health information without patient authorization for treatment, payment, and healthcare operations; however, all other information sharing requires written authorization from the patient. The security rule is designed to ensure that health information is protected from unauthorized access and designates controls (Koontz, 2015). HIPAA is associated with creating a “privacy culture” that, when taken to an extreme, can result in a lack of information sharing even when the sharing is appropriate and useful. A couple representative quotes are:

“Regulations, and HIPAA violations, and who can get access to what, is a big hindrance in helping us have that continuum of care.”

“I don't think [HIPAA was] ever intended to impede provision of care, to impede access to records that people might legitimately need, and yet the way it's over-interpreted is unbelievable. There are people here who will not share a patient’s name from one division to another [within the same organization].”

Patient engagement strategies

Patient engagement strategies can include shared communication, such as referrals and reminders, for patients concerning follow-on or follow-up services. As an example, a participant noted the value to the patient of referral systems and reminder systems. In arranging for follow-on care, some information systems facilitate arrangements with follow-on providers, often a specialist, and provide patients with reminders, such as a text to the patient’s smartphone. These two tools, referrals and reminders, add conveniences for setting up and remembering appointments.

Focus group discussions included several references to the use of smartphone technology and the inclusion of patient-generated health data. For example, one program—“What’s Your
Number?”—encourages patients to share blood pressure numbers at a program-provided website. Another program, “Check. Change. Control.,” which also targets hypertension control, asks providers to provide a list of their patients with hypertension and to select a few patients from that list to receive a blood pressure cuff for home use. The program encourages participation through outreach provided by a community outreach worker and provides information on how patients can transmit their blood pressure readings through the program’s health portal. A chronic care coordinator has access to the submitted readings through the portal and passes those results along to the patient’s primary care provider. A focus group participant noted that the same participation effort could be added to other disease-management programs (for example, diabetes programs).

“Most people have access to computers or cell phones. How great would it be for somebody to put their blood sugar results in? How great would that be to be able to see that? I think that it would be very helpful. They’ve tried it in some places. They’ve actually given smartphones to patients in areas where they’re testing where it’s difficult for them to get in. So it’s an incentive. ‘We’ll give you a cell phone. Put your data in.’”

Workflow and quality reporting

Focus group participants also commented on secure ways of communicating that would not involve the direct use of an EHR system but would still have major benefits for treating chronic diseases. Many participants agreed that secure email helps make up for some of the interoperability deficiencies in EHR systems. Many participants thought that communicating using a secure email system would be more efficient than a secure fax. Statements on secure email include:

“Versus [a fax], a [secure] email seems like a much more efficient, faster method [to send patient data].”

“I do agree that, in terms of having secure email, it'd be wonderful. Lots of times I want to email a provider about something and we can't do that because we don't have a secure email system.”

One comment also noted that standardized consent forms would help with work efficiencies.

“If we had the universal consent [form], you needed information, you needed some behavioral help, or you needed everything but behavioral health, you would sign the same consent form as they would in Washington County or Baltimore City. We would have these
statewide universal consent forms that would cover everything.... [Our form] took months to develop. Why should [another jurisdiction] spend months to develop one?”

Reimbursement models and public health goals

Focus group participants were asked about reimbursement models and how they align public health incentives with the efforts of providers and/or community groups for disease prevention. Participants were also asked to think of and suggest what would be an ideal reimbursement model. There was much discussion about the financial alignment of public health goals and the financing models for these goals.

For many community programs, funding often relies on grants. Grant funders frequently want the programs they fund to document the value of the services provided using data. As grants often provide short-term funding, programs may need to reapply each year. Sometimes, the process of applying for a grant can be time consuming. Some relevant comments include:

“Resources, funding through grants, sustainability, it's all going to rely on outcomes in data. And when there is nothing in place to get that, you're throwing a lot of money around with no mechanisms to say that was a successful program.”

“We have a Medicare reimbursement process for...diabetes self-management and it is so complicated. It's taken a year with a Federal consultant working for us for free to figure it out and get it approved and rolling.”

For managed care organizations, value-based purchasing (that is, “pay for performance” or “pay for value”) provides financial incentives that are tied to achieving better health outcomes. Clinical outcomes, such as better quality of life or longer survival, are too difficult to measure, so pay-for-performance systems measure process outcomes (for example, measuring blood pressure or counseling patients on smoking cessation). These incentives can be set up to be upside risk sharing only or downside/upside risk sharing. In the latter, there can be a penalty (that is, less reimbursement) if the value goal is not reached.

A few statements from the focus groups about the challenges of risk sharing or the value-based purchasing model are:

“Obviously, the managed care organizations are very focused on value-based purchasing measures, because there are dollars attached to those.”
“The state has incentivized the [managed care] organizations to [achieve pre-specified goals] for a certain level of the key measures. So if we don’t hit a certain level, we get penalized; if we get above a certain level, we get rewarded. They’re the ones that are important to the state.”

“Is it worth doing? I think there are times there are services that if we really look down and analyzed outcomes, costs, we might realize that we should probably follow a different path, but sometimes they feel good or look good.”

Payers mentioned the problematic alignment between value-based financial incentive options and public health goals for chronic disease prevention. For value measurement, the payer may have a shared risk measurement system that tries to reflect changes in outcomes using population health measures or measures related to an episode of care. The outcome measures are valuable, but it can be hard to relate those measures to actions on the part of the provider or the community program. Thus, process measures are often selected over outcome measures.

An example discussed in the focus group involved selecting a process measure for value. There are a range of options that could be reflective of care during pregnancy, such as the percentage of pregnant women who begin their prenatal care during the first trimester. As the practice or payer has little influence over when a pregnant woman enters the care process and it is believed that many enter late in the pregnancy, the selected measure is associated with care further along the care continuum; that is, postpartum care. Thus, the validity of the measurement, how well it measures the desired outcome, might be questionable.

“Except even the [postpartum care] is really just ‘did they follow-up,’ because it’s not even, ‘did they get the pre-natal care,’ …. But it’s the pre-natal care we know is the most important.”

Challenges in data collection were also discussed. Payers can provide financial incentives to motivate patients to share information with them (for example, a risk assessment). However, despite financial incentives, patients might not be interested in sharing the health data. When information is shared from programs, it often is in the form of a secure paper fax.

“This (acquiring the risk assessment) is a faxing process for us. They send these sheets, a one-page sheet....”
Other comments on reimbursement and chronic diseases include:

“There is no reimbursement for chronic disease management in a lot of cases for community-based programs."

“Reimbursement is dependent on data. But there's not a good source for [data].”

“[Because of] reimbursement, [providers] don't feel they have the time to really go into in-depth education around chronic diseases.”

“If preventive services could be reimbursed, that would be the best.”

“It would be really great if we could reimburse doctors for making referrals [to community prevention programs].”

Potential benefits to expanding information exchanges via CRISP

During many of the focus group discussions, there was lively conversation among the participants about CRISP. Some viewed CRISP as a major asset with the potential to improve their ability to track and treat patients with chronic diseases. For example, a hospital-affiliated outpatient clinic described CRISP as a “revelation” in terms of providing data on age groups that have chronic heart failure. Another provider formed a “population health team” to review CRISP data along with reports from an insurer. Most thought that CRISP had useful features but was still an unfinished product. Focus group members not participating in CRISP at the time mentioned an interest in receiving information from and contributing to the exchange.

As an alternative to statewide HIEs via CRISP, a specialty practice representative mentioned inclusion in a micro HIE provided by a specialty health professional association. This association has developed analytic tools that continually pool data from their system along with data from participating practices. These efforts enable the association to then benchmark and share the data with the participating practices. Additional efforts at standardization were required on the part of the participating practices.

One of the main themes that came out of the focus groups was the desire to expand the capabilities of CRISP. Many representatives wanted to see more consolidation around CRISP. They also wanted to see a greater effort at the state level to push for increased participation in CRISP.
Some statements about CRISP, its usage, and possible expansion include:

“CRISP does have some really good aspects to it. Right now, it's used mostly for the hospitals. The providers can get the information, but they can't currently contribute without getting into that cost factor of having to dish out thousands of dollars to pay your vendors, to build the interface. There're people still using paper. I think they'd be very open to expanding it.”

“CRISP is underutilized from the [primary care] practice point of view.”

“The biggest takeaway you'll get from this meeting is we don't need anything new. We just need to make the things that we're supposed to have work, and work together and then start taking away.”

“Let's stop with all these little offshoots. If CRISP is going to work, and it does work remarkably well, I understand, for the emergency room positions, let's just go with CRISP. Tell them what user requirements we would have to make this work. We as end users provide them with the requirements. And then they need to go get the funding to get all the programmers that they need to make that happen.”
SYNTHESIS AND DISCUSSION

This section aims to synthesize the findings from the research, the literature review, the survey, and the focus groups to describe the benefits and barriers of information sharing, to portray the current state of information sharing, and to provide a gap analysis. This synthesis includes discussion of:

- information-sharing models;
- the benefits of information sharing for chronic diseases;
- the current state of information sharing among health systems and practices, payers, and community programs;
- the gap analysis – the gaps in policies and procedures, technologies, and systems related to HIEs specific to chronic diseases.

INFORMATION-SHARING MODELS

HIEs among health systems, community groups, and payers have the potential to create value in the areas of improving quality of care, safety, population and public health, care coordination, and patient engagement. Information sharing can involve several methods of communication. The types of messages and security practices can involve different devices. There are significant communication challenges for those providing health services in a shared care model in the community. The shared care model, sometimes called team model, means that different health service providers are likely to be involved at different points in the full cycle of care. Activities such as receiving a lab report or providing a referral can involve many healthcare stakeholders and, with that, many opportunities for inefficient communication that can contribute to delayed services.

One common model involves very limited information sharing and, if any, an informal referral network. In this model, a prevention program communicates using health fairs and direct marketing efforts (for example, fliers, community bulletins, and workplace announcements). In some cases, prior to beginning a program, the participant is asked to confirm that some form of screening has taken place. The program administrator relies on the participant to inform their primary care physician of their participation. These models are associated with less formal arrangements and allow for autonomy. However, there can be limited awareness on the part of the provider that the community prevention program is available, as the marketing is directed at the participant. Additionally, community programs may not be aware that a similar service is being
provided by others. This can lead to duplication of effort, with a few programs vying to provide the same type of intervention to an overlapping target population. In some cases, these community prevention or workplace wellness programs have collected substantial amounts of information that the program has no method of sharing with healthcare providers in a primary care setting.

Some have improved this communication model by adding a secure fax and/or a secure email. This second model was noted as being in use by a few programs that provide follow-up communication following an emergency room visit. For example, a patient arrives at the emergency room in need of dental services, but there is no dentist available. A fax then goes from the emergency room to a community outreach program so that a community health worker can contact and assist the patient with getting a dental appointment. This added communication tends to be associated with more formal arrangements and shared processes. It can be very helpful in trying to form a more collaborative arrangement in circumstances where there is no adoption of an EHR or where information exchange is limited by interoperable systems or privacy and security concerns.

A third model can be thought of as the shared EHR communication model. This model is one that is more challenging to set up. However, it allows the provider and the community program to create partnership agreements and have a shared EHR system to exchange information (for example, referrals or relevant clinical data). This model has been used by some programs to include pharmacy services for medically complex cases where a patient has an unmanaged disease and would benefit from a medical review. Another benefit in this case is that the shared EHR often enables the pharmacist to have a billing code for reimbursement. Although this model has added formality and may improve communication and data collection, it is often challenging to set up, particularly when the EHR systems are not interoperable. Other concerns are that the model requires some degree of trust among the stakeholders, technical sophistication to set up, and a working financial arrangement if a billing code is added.

A fourth model relies on the use of a local or state exchange to share secured health information. To facilitate this model, community programs first developed partnership agreements with providers to allow for information exchanges of data. A recent pilot focused on reducing emergency room readmissions and had a similar goal of encouraging collaboration among payers, hospitals, and community providers. It found value in a system of notifications through a local exchange. This program notification system, or micro HIE, functioned similarly to those provided by CRISP.
In some instances, these models may involve the use of a mobile device, such as a smartphone, to record an individual’s health data (for example, blood pressure) and to share that data with the provider. Other programs that have a similar model may use a community outreach worker to assist the patient in the collection, tracking, and sharing of data. This model, adding patient-generated data, has the additional benefit of encouraging more patient participation and access to their health data. A challenge is that it may require more patient education and engagement in sharing their data, which might require additional effort for those with low health literacy and low technology literacy. It also may require expanded access to a local HIE.

These later models tend to be more formal and require more collaboration, data sharing, interoperable systems, information exchanges, and efforts at patient engagement. Moving from the more limited information-sharing models to more collaborative models (for example, a shared EHR or use of an information exchange) is associated with some benefits, including improvements in work integration.

**BENEFITS OF INFORMATION SHARING FOR CHRONIC DISEASES**

The more integrated information exchange models have some benefits for chronic disease prevention in terms of connecting different stakeholders and allowing for greater collaboration. Conversely, inefficiencies with these models can occur when there is a very limited approach to information sharing. This approach makes it likely that those at risk will be unable to take advantage of prevention services in the community, community prevention programs will be less likely to succeed at prevention and health plans, and payers will be less likely to realize associated cost savings.

The benefits to better information sharing include:

- continued adoption and use of an EHR by health practices;
- better integration and collaboration;
- patient engagement;
- an integrated prevention model to reduce healthcare costs;
- learning for future efforts.
The benefits of continued adoption and use of an EHR by health practices

More collaborative and integrated models tend to require more technical sophistication and an EHR system. The adoption and use of an EHR system itself is associated with benefits for those patients in a given health system.

Accelerated by the EHR Incentive Programs in MU stage one, many providers have adopted and implemented the basic functionalities for capturing quality data electronically. This data capture can provide some insights into healthcare quality for treatments and specific conditions such as diabetes and hypertension. In a few noted studies, the use of EHRs, especially when coupled with additional community outreach, had positive impacts (for example, a reduction in emergency room visits, improved access to care, lower costs, and better health status as measured by improved clinical outcomes over time for those patients associated with a given health system or practice). Thus, there is some value to adoption and use, even for a practice where integration is problematic.

There have been efforts to encourage providers to adopt EHRs. While progress continues, ONC data do suggest that many primary care providers have not yet adopted EHRs. Where they have adopted EHRs, they often are not interoperable with other systems.

The literature review noted that EHR adoption might be aided by the prior use of an open-source EHR system, particularly in low resource settings. Goldwater and his colleagues (2014) examined the use of an open-source EHR system in five community health centers. This open-source system was developed in an effort to redesign the care system and to support more effective management of chronic diseases for indigent patients. Its use was noted as accelerating the redesign of the care delivery system prior to the acquisition and implementation of chronic care disease management programs, which include diabetes, hypertension, and tuberculosis vaccinations for those experiencing homelessness.

The benefits of better integration and collaboration

Models incorporating information sharing and collaboration build on a rich ecosystem of prevention and wellness programs in a variety of settings. These programs are currently largely untapped resources for those at risk of disease, partly due to the need for marketing efforts that can result in under participation or over participation of the target population. The benefits of collaboration can be characterized in terms of better integration of services and the potential for better quality alignment based on shared goals and outcomes.
Integration can be viewed in terms of increased efficiencies in workflow, sharing, and fit (Malone, Laubacher, & Johns, 2011). The concept of flow, or workflow, is one of tasks occurring in a sequence, with later tasks dependent on the outcomes of earlier ones. Workflow could be improved by integrating the tasks associated with delays in the progression of chronic diseases. These tasks include screening by primary care providers, referrals to a prevention program, participation in a prevention program, feedback on referrals, and monitoring.

The concept of sharing is related to the time people potentially have available to do the tasks. It is commonly understood that primary care providers often do not have the time to focus on individual behavioral change associated with preventing chronic diseases or delaying their progression, beyond giving advice on the benefits of behavioral change. Efficiency is increased when this task is shared between providers and community programs.

The concept of fit is related to integration. Without integration, the patient comes into contact with separate entities—the health practice, the community program, and the payer. When integrated, these different bodies create an awareness of each other and are informed about the value of the experience.

Improvements in information sharing can also be described in terms of quality measurements. When there is limited information sharing, quality can still be measured and reflected in terms of the credentials of those involved in the prevention process. The trend in healthcare has been to reflect quality through health outcomes and to tie payment for services to the value added by efforts to change outcomes. As collaborative information sharing includes the tracking of clinical measures, it could provide additional information about the value of the program to individual participants (e.g., delay of progress of chronic disease or reversal of disease indicators). The value to the patient based on savings from delayed disease could be aligned with the financing of the community prevention program.

**The benefits of patient engagement**

Patient engagement is an important element in the care of those with chronic diseases. It is noted in the National Quality Strategy as ensuring that patients and families are engaged as partners in patient care. Engaging patients in, and having them actively pursue, their health goals through behavioral change are key strategies for preventing and improving chronic disease outcomes. Patients can also be active participants by tracking their health metrics over time. This priority is likely to be reflected in policy. The outlook for patient engagement in the later stages of MU is likely to include provisions for patient-generated health data and increased patient access to relevant health education resources.
The benefits of an integrated prevention model to reduce healthcare costs

Formalizing information exchanges ensures that programs that are successful at delaying chronic disease progression will be sustainable and that the savings associated with prevention efforts will be realized. Community programs, if successful at motivating individual behavioral change, can impact the progression of chronic diseases for participants in the community. Participants could potentially reverse some of the harmful effects of chronic diseases and avoid situations where they need additional and often more expensive treatments, usually provided in hospital settings. For participants in later stages of the disease process, prevention programs and related behavioral changes could still help them avoid comorbidities, again saving healthcare costs. In addition to cost savings, prevention efforts can also be reflected in a better quality of life.

The benefits of learning for future efforts

Improving information exchange for chronic disease prevention could be used to address other problems in a community. These problems include treatments for addictions and suicide preventions. In time, partnerships in Maryland could lend or add their efforts to similar undertakings in other areas.

Although the benefits of improved information sharing hold promise for furthering the goals of adoption and use, for more integration and collaboration, for more patient engagement, and for more patient participation, there are challenges to realizing these benefits given the current state of information sharing.

THE CURRENT STATE OF INFORMATION SHARING

The current state of information sharing among health systems and practices, payers, and community programs was described earlier under research findings. It reflects the likelihood of continuing gaps in adoption for office-based physicians; often limited information exchange among payers, community programs, and health practices; and problematic interoperability.

The current state of information sharing is characterized by factors related to computer systems, such as the adoption of EHR systems and the interoperability of those systems. The literature review suggests that hospitals and large health systems have made substantial progress in their adoption of EHR systems. Office-based physicians are not as far along in doing so. ONC data from 2013 suggest that 37 percent of physician practices in Maryland have adopted at least a basic EHR system (ONC, 2015a). The progress among hospitals could be related to their ability to participate
in both the Medicare and Medicaid EHR Incentive Programs, whereas eligible providers are only able to participate in one or the other. It could also be tied to their ability to support and benefit from an in-house health information technology staff. HIEs among office-based physicians in Maryland is slightly less far along in comparison to the nation for a variety of metrics.

In contrast to the data in the literature review, survey results suggest that the adoption of EHR systems is higher than the ONC’s estimate, as 69 percent of respondents reported having adopted an EHR system. This finding could reflect a lack of participation in the survey by office-based physician practices that did not have EHR systems. Another possible explanation is that significant progress in adoption was made in this group over the past couple of years.

The literature review noted that limited information sharing was likely related to interoperability of systems. The interoperability of EHR systems is due to a need to develop better data standards and to information blocking. Regarding standards development, the literature noted that vendors are forming partnerships to develop standards, such as FHIR. A common standard is the C-CDA, which, as noted, has the drawback of transferring data as a single document rather than pieces or lists of data. This drawback makes searching for a single piece of data difficult, as a provider might have to search through multiple documents. The new standards will make searches and exchanges faster and provide for more efficient exchanges (Ahier & Doeringsfeld, 2015). In the literature review, a report by the ONC suggested that there may be additional obstacles to information sharing, referred to as “information blocking” (ONC, 2015b). The literature review also found that interfaces could be purchased to integrate two separate information systems; however, these often represented new charges.

The survey provided some insights into electronic information exchange as a communication device among representatives of health practices, community programs, and payers. The ability to transfer protected health data electronically to a community chronic disease prevention program was described by 21 percent as transferred electronically, by 25 percent as transferred but not electronically, and by 39 percent as not transferred at all. The receipt of protected health data from community chronic disease prevention programs was most often reported as not received (36 percent) or not received electronically (32 percent). The survey data also suggest that health information sharing among unaffiliated health practices (unaffiliated hospitals, private practices, and FQHCs) is most often not electronically shared. Survey respondents were most likely to identify barriers to electronic information sharing as (1) issues with interoperability of different EHR systems and (2) concerns about HIPAA compliance or patient confidentiality.

Privacy and security concerns were noted in the literature review, the online survey, and the focus groups as key areas influencing information exchange. In the literature, Wang and Huang (2013)
noted that many organizations find the guidance on protected health information vague. In addition, health systems sometimes implement added security controls to ensure HIPAA compliance. Also in the literature review and noted earlier, there is a growing public awareness of the limits of data security.

While barriers are often associated with computer systems and policies, facilitators are associated with culture and workflow. Facilitators include appropriate staff knowledge and skills, appropriate policies and/or processes, interoperability of health information systems, and technical assistance or support from information technology vendors.

The focus groups were able to provide two key barriers to information exchange: (1) the lack of standardization impeding efforts at interoperability and (2) misunderstandings related to HIPAA requirements concerning privacy and security. Additional discussion included inefficiencies in workflow, quality reporting, and limited resources (for example, problematic alignment between financial incentives and public health goals for chronic disease prevention). Some focus group participants also noted the need for behavioral change efforts when it comes to getting physicians to make referrals and patients to follow up with their prevention programs.

Figure one identifies the multiple factors influencing the current state of information sharing, with an eye toward developing recommendations. A difficult element to capture in the diagram was the use of HIEs to address the problem of interoperability. CRISP was seen as having some potential in the literature review, survey responses, and focus group discussions, and appears to be an area associated with some potential for guiding public health efforts and providing for a notification system.
Figure 1. Information-Sharing Cause and Effect

- Culture and Workflow
  - A fax-based communication system is the norm
  - Patient is not engaged in care
  - Provider does not refer

- Staffing - need for new skill set
- No screening and risk-assessment procedures in place; no routine collection of quality data

- Computer Systems
  - Concerns about workflow disruption, difficulty of use, costs/fees, etc.
  - Limited IT staff
  - No information plan
  - No adoption

- Limited Information Sharing for Chronic Disease Prevention
  - Adoption but lack of interoperability
  - Misunderstandings related to privacy and security compliance requirements
  - Lack of policy support of chronic diseases for screening/referral

- Policy
  - Complicated policies for Medicare reimbursement for disease prevention programs

- Resources
  - No directory of programs in community
  - Sustainability concerns for chronic disease prevention programs

- Long-term payout problematic for value calculation
  - No universal forms for referral, feedback, or partnership agreements

- EHR Incentive Programs - MU stage 1 did not require interoperability
  - Limited information plan

- Lack of data standards
  - No interfaces
  - Limited IT staff

- Information blocked
  - Adoption but lack of interoperability

- Limited Information Sharing for Chronic Disease Prevention
GAP ANALYSIS

This section explores the gaps in policies, procedures, technologies, and systems related to HIEs specific to chronic diseases. These findings are synthesized in the following gap analysis tables (tables 4 to 6). The tables are separated into three different categories: health providers, community programs, and payers. Additionally, a concept model for a referral network is available in Appendix C.

Table 4. Gap Analysis—Health Providers

<table>
<thead>
<tr>
<th>Improved State</th>
<th>Current State</th>
<th>Possible Reasons for Gaps</th>
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<tbody>
<tr>
<td>Employ an effective screening strategy for at-risk patients; discuss risks with patients and options for reducing those risks; routinely refer at-risk patients to preventative services in the community using an EHR system; share health risk information appropriately using information-sharing tools; provide patients with appropriate educational resources and information; report quality measures using an EHR system; follow and monitor patients’ clinical measures and experiences with community programs; receive information from community programs on patient progress in terms of behavioral changes. An improved state could also offer some health information via smartphone. The provider could review patient-generated data. In an ideal system, savings associated with improved health outcomes would be associated with correct incentives for prevention efforts.</td>
<td>Many health systems, physician practices, and FQHCs have adopted EHR systems, but integration is problematic. Many providers currently screen for diseases rather than risks for diseases. Providers report quality metrics, but they oftentimes obtain data from paper charts and employ spreadsheet software to prepare reports, as opposed to using a simplified automated reporting tool. There is a need to bring clinical processes into alignment with information technology tools. Some providers are able to send and receive information in the form of care summaries through CRISP, but not others. Added HIE concerns for providers include data blocking and a misunderstanding of policies related to information privacy and security (e.g., HIPAA).</td>
<td>Problems integrating quality measures into workflow; limited progress in adopting and reaching MU milestones for many office-based physicians; limited integration in different parts of the health systems; limited knowledge of available resources; limited use of risk assessments for chronic diseases; misalignment of incentives.</td>
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### Table 5. Gap Analysis—Community Programs

<table>
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<tr>
<th>Improved State</th>
<th>Current State</th>
<th>Possible Reason for Gaps</th>
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<tbody>
<tr>
<td>Communicate with at-risk patients following referrals; encourage behavioral/lifestyle changes; track behavioral changes; share information appropriately with referring practices.</td>
<td>Most community programs have limited funding for additional services such as marketing and outreach. Many are reliant on grant-based funding.</td>
<td>Most community programs have limited funding for additional services such as marketing and outreach. Information sharing between providers and community programs is often done via paper fax.</td>
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<td>The community program would be able to track the progress of participants’ health outcomes, as well as their participatory data.</td>
<td>Programs often need to supply specified data to the grant about the success of the program. These data-collection efforts can be challenging to collect.</td>
<td>Some community prevention programs have been collecting data from the patient, such as blood pressure, and that data could be of value to both payers and providers.</td>
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<td>In an ideal system, savings associated with improved health outcomes would be associated with correct incentives for prevention efforts.</td>
<td>Some programs track clinical outcomes and participation over time for individual participants and may receive patient-generated health data, but many do not.</td>
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### Table 6. Gap Analysis—Payers

<table>
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<tr>
<th>Improved State</th>
<th>Current State</th>
<th>Possible Reason for Gaps</th>
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<tr>
<td>Align financial incentives to encourage providers and community groups to provide added value to at-risk patients.</td>
<td>Payers are often tasked with determining the value of a service to the patient; however, data are very limited, especially outcomes data.</td>
<td>Problems exist in (1) determining the best reimbursement model for added value for the physician, given the many factors that impact health; and (2) determining an appropriate method for sharing the savings among providers and community programs.</td>
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<tr>
<td>Determine how to adjust incentives for added value and shared savings using clinical measures and patient input where appropriate.</td>
<td>Additionally, payers find that they are asked to measure long-term quality, when plan members may have a short-term period of insurance coverage.</td>
<td>The longer term nature of healthcare cost savings is problematic if the payer is providing for members who are insured for a short term.</td>
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<td>In an ideal system, savings associated with improved health outcomes would be associated with correct incentives for prevention efforts.</td>
<td>Payers mentioned the problematic alignment between metrics and public health goals, using the example of postpartum care.</td>
<td>Financial incentives sometimes fail to produce the intended behavioral change.</td>
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<td>Payers also mentioned the sometimes unsuccessful efforts to incentivize patients to share information.</td>
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RECOMMENDATIONS

The purpose of this study is to develop a stronger understanding of how information is shared among health systems and providers, payers, and community programs in the specific area of chronic diseases. The gaps in information sharing on chronic diseases are substantial and are likely to continue well into the future. Closing those gaps will require reshaping technologies and expectations about cooperation throughout the system.

The overall goals associated with recommended actions include the following:

- Increase adoption and interoperability of EHR systems
- Ensure privacy and security
- Promote administrative simplicity
- Ensure patients are engaged as partners
- Align financial incentives
- Provide opportunities for ongoing study of approaches

The recommended actions associated with each goal, as well as a justification for those actions, are provided in the tables 7 to 13.
### Table 7. Increase Adoption of EHR Systems

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<td>Develop an outreach plan for those practices without EHRs.</td>
<td>Findings from the literature review suggest that many office-based providers in Maryland have not yet adopted health information systems.</td>
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<tr>
<td>Track adoption rates, follow provider adoption rates, and track characteristics of users and systems.</td>
<td>ONC data from 2013 suggest that 37 percent of physician practices in Maryland had adopted at least a basic EHR system at that time.</td>
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<tr>
<td>Provide access to training on the implementation and use of EHR systems.</td>
<td>Many physician practices do not have an in-house health information technology staff, which has made adoption more difficult for physician practices than for hospitals. Without this staffing, there may be a need to both promote adoption of an EHR system and provide staff training.</td>
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<tr>
<td>Develop and promote the option for an open-source EHR system.</td>
<td>Barriers noted in the literature review also include financial concerns, such as a lack of return on investment. To address financial concerns, it might be useful to develop and promote a lower-cost, open-source EHR system as a starting point. Goldwater and his colleagues (2014) examined the use of an open-source EHR system in five community health centers that served as a starting point for the redesign of their care system and supported more effective management of chronic diseases for indigent patients.</td>
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<tr>
<td>Support incentive models and programs, such as the Medicare and Medicaid EHR Incentive Programs, to provide financial incentives to eligible providers.</td>
<td>The noted incentive model in the literature review is the Medicare and Medicaid EHR Incentive Programs, which provide financial incentives for adoption. Support for this incentive model could include outreach to providers who may be unaware of the program or are still considering participation.</td>
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<tr>
<td>Use health information technology to design innovative health delivery and payment models.</td>
<td>Other incentive models directed at delivery reform could use such financial incentives to support increased and routine use of health information technology. Focus group discussions with input from Medicaid managed care organizations noted the importance of focusing on pre-set goals established by the state and the challenges of capturing the value of the service to patients in the absence of health data.</td>
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### Table 8. Increase Interoperability of EHR Systems

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| Promote and support the effective use of standards that meet electronic health information management goals, and exchange needs by engaging stakeholders (for example, standards developers and health information technology vendors). | The literature review, online survey, and focus groups provided evidence that lack of interoperability is a significant barrier associated with HIEs.  
The literature review noted that vendors are forming partnerships to develop standards, such as FHIR. FHIR is expected to both improve on a drawback to the common standard today (C-CDA, which can only import entire files) and make exchange more efficient.  
Focus group discussions related the lack of interoperability to both the lack of standards and problematic standards. |
| Discourage information blocking.                                        | In the literature review, a report by the ONC suggested that there may be additional obstacles that impede information sharing, referred to as “information blocking.” Information blocking occurs when an organization knowingly and unreasonably interferes with the exchange of electronic health information through ways such as systems design features or excessive fees. |
| Assess potential value and availability of interfaces that integrate clinical information from different systems. | Interfaces can be purchased to integrate two systems. These interfaces often represent added work for the vendor and new charges for the provider. These costs can be a barrier to interoperability for physician practices. |
Table 9. Ensure Privacy and Security

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<td>Providers should purchase systems that are certified to be “secure by design” and inform patients of the security measures. Providers should also assess the risk of a security breech. An external organization should ensure that a security risk assessment is performed. Educate the patient on security by communicating what security measures have been taken and how the information is shared.</td>
<td>Privacy and security concerns were noted in the literature review, online survey, and focus groups as key areas influencing information exchange. Also noted in the literature review was the influence of growing public awareness of the limits of data security. The concerns about privacy policies were discussed in the focus groups and survey responses as barriers to information exchange.</td>
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<tr>
<td>Advocate for clarification of HIPAA. Improve health information technology, stakeholders’ understanding of existing HIPAA rules, and how they support interoperable exchange through permitted access, use, and disclosure for treatment, payment, and healthcare operations. Align policies adopted by stakeholders with existing HIPAA regulations for health information that is regulated only by HIPAA.</td>
<td>The success of interoperability is dependent on patients’ trust that their health information will be kept private and secure. Noted in both the literature review and the focus groups, HIPAA is a policy area that influences interoperability. Focus group discussions focused on HIPAA as a concern and a policy area that was interpreted differently by different organizations. The Maryland focus group discussions echo a larger national discussion. These recommendations, although not all-inclusive of the full set of recommendations, were written in similar language to recommendations in the ONC (2014) report, “Connecting Health and Care for the Nation.”</td>
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### Table 10. Promote Administrative Simplicity

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<td>Facilitate notifications. Find and use ways to access health information from external sources and incorporate into existing everyday provider workflows.</td>
<td>Work efforts connected to information exchanges that facilitate information sharing and reporting for chronic diseases should be built into work patterns. In terms of information exchanges with external providers, an example would be the provision of a clinical summary or medication reconciliation at transitions. Focus group discussions noted that considerable staff time was spent on notification efforts, which are often accomplished through faxes. A change to a secure email via the Direct Project would be a more efficient option.</td>
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<tr>
<td>Enable coordination between health systems, community prevention programs, and payers. Promote the value of community prevention programs to address those at risk for chronic diseases. Provide an online directory of community prevention programs. Enable community programs to keep the directory up to date.</td>
<td>In the literature review, a noted benefit of EHR adoption and use was the building of referral networks for chronic diseases. A toolset could include the development of standardized forms for referrals and notifications. Barriers include limited policies to make resources available for at-risk patients. Focus groups noted that many providers do not have access to a directory of community prevention programs for patient referrals. There was also some thought that keeping the directory up to date would be of added value.</td>
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### Table 11. Ensure Patients are Engaged as Partners

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<th>Justification</th>
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<tr>
<td>Increase patient access to health data and relevant health education resources. Allow for patient-generated health data through mobile devices, including blood pressure readings, HbA1c, and activities.</td>
<td>A priority of the National Quality Strategy is ensuring that patients and families are engaged as partners in patient care. This priority was reflected in both the literature review and focus group discussions. Patient-generated health data were seen by focus group participants as one way to engage patients. For example, in the Million Hearts initiative, patients can share their blood pressure readings via smartphone. The “What’s your Number?” program offers patients web-based or telephonic support. In interview and focus group discussions, it was suggested that patient engagement may need to begin with discussions on privacy and security measures (see recommendations on privacy and security).</td>
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### Table 12. Align Financial Incentives

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<th>Justification</th>
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<tr>
<td>Provide incentives to enable coordination between health systems and community prevention programs. Reimburse practices for making referrals; reimburse community programs for tracking participation and for program completion. Design tools to assess the value of referrals and participation with long-term health savings.</td>
<td>The value-based purchasing program was a key discussion topic at the focus groups. These programs offer financial rewards and penalties to providers based on their performance on pre-specified measures. Success at value-based purchasing often involves setting appropriate performance targets and using health information technology to support the collection of data. There are a few measurement challenges: (1) there is often an inability to assess value associated with outcomes, so many measures are process measures; (2) it is challenging to measure health problems that did not occur; and (3) health savings from prevention efforts may occur in the longer term, but individuals may have a short-term relationship with a health plan.</td>
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**Table 13. Provide Opportunities for Ongoing Study of Approaches**

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<th>Justification</th>
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<tr>
<td>Create a forum for consistent information exchanges to help communicate the progress made by some groups so that efforts are not duplicated by similar groups.</td>
<td>There is a need to develop a forum to provide strategies on how to extend the use of secure interoperable health information technology tools and HIE services. This group could also provide workflow recommendations (the development of standardized forms and procedures for screenings, referrals, and feedback loops) and a recommended reimbursement model.</td>
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<tr>
<td>Promote knowledge of the existing infrastructure to encourage information exchanges and provide notifications. Determine which of CRISP’s features are of value, which are still needed, and how CRISP can be expanded to further the prevention and control of chronic diseases.</td>
<td>One option for improving information exchanges for chronic diseases involves more rigorous use of the statewide HIE, CRISP. Focus group discussions suggest that CRISP may, at this time, have some usefulness to providers, community programs, and payers in terms of tracking episodes of care by zip code.</td>
</tr>
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**APPENDIX A: ONLINE SURVEY**

**Section 1: Characteristics of your organization**

Q1: Which county is your organization located in? [Drop down menu]

Q2: What type of organization do you represent? *(If a Healthcare Practice/System, complete question Q3. All other participants should skip to Section 2.)*
   - Healthcare Practice/System
   - Public or Private Payer
   - Community Program
   - Other (please specify)

Q3: What is your healthcare setting? *(If a practice, continue to Q4-Q6. If not a practice, skip to Section 2.)*
   - Independent practice
   - Group practice
   - Hospital-affiliated practice
   - Hospital
   - Federally Qualified Health Center
   - Other (please specify)

Q4: What is your practice type?
   - Primary Care
   - Pediatrician
   - Specialist (please specify)
   - Other (please specify)

Q5: Approximately how many physicians does your practice have?
   - 1-4 physicians
   - 5-9 physicians
   - 10-19 physicians
   - 20+ physicians
Q6: Does your practice have National Committee for Quality Assurance (NQCA) Patient-Centered Medical Home (PCMH) recognition?
- Yes, level 1
- Yes, level 2
- Yes, level 3
- Yes, but I do not know the level
- No
- Don’t Know

Section 2: Use of electronic health records

Q7: Does your organization use an electronic health record (EHR) system? (If yes, proceed to Q8-Q11. If no or don’t know, skip to Section 3.)
- Yes
- No (Please explain how your organization maintains client information: _______)
- Don’t Know

Q8: Please name the electronic health record system in use: ______________

Q9: Is your organization’s electronic health record system ONC-certified (i.e., certified by the Office of the National Coordinator for Health Information Technology)?
- Yes
- No
- Don’t Know

Q10: Does your organization produce reports with standardized, aggregated data on quality measures, such as National Quality Forum (NQF) or Healthcare Effectiveness Data and Information Set (HEDIS) measures, and use them for quality improvement?
- Yes
- No
- Don’t Know

Q11: If yes to the previous question, does your organization publish or share these reports?
- Yes (These reports are shared with: _______)
- No
- Don’t Know
- Not Applicable
### Section 3: Use of health information technology and transfer of health information

**Q12:** Does your organization transfer protected health information/data to any of the following:

<table>
<thead>
<tr>
<th>Yes, transferred electronically</th>
<th>Yes, but not transferred electronically</th>
<th>No</th>
<th>Don’t Know</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>Affiliated hospital?</td>
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<tr>
<td>Unaffiliated hospital?</td>
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<td>Private healthcare practice?</td>
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<tr>
<td>Community clinic or Federally Qualified Health Center?</td>
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<td>Local health department?</td>
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<td>Community chronic disease prevention or control program (e.g., Chronic Disease Self-Management Program, Diabetes Self-Management Program, Diabetes Prevention Program, nutrition or physical activity programs, tobacco cessation, etc.)?</td>
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<tr>
<td>Insurer/Payer?</td>
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<td>Other?</td>
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**Comments:**

**Q13:** Does your organization receive protected health information/data from any of the following:

<table>
<thead>
<tr>
<th>Yes, transferred electronically</th>
<th>Yes, but not transferred electronically</th>
<th>No</th>
<th>Don’t Know</th>
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<tr>
<td>Local health department?</td>
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<tr>
<td>Community chronic disease prevention or control program (e.g., Chronic Disease Self-Management Program, Diabetes Self-Management Program, Diabetes Prevention Program, nutrition or physical activity programs, tobacco cessation, etc.)?</td>
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<tr>
<td>Insurer/Payer?</td>
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<tr>
<td>Other?</td>
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</tbody>
</table>

Comments:

Q14: What factors facilitate the sharing or exchanging of protected health information/data with other healthcare providers, payers, and/or community programs? (Select all that apply)
- Interoperability of health information systems
- Partner buy-in
- Technical assistance or support from information technology vendor(s)
- Appropriate staff knowledge and skills
- Appropriate policies and/or processes
- Financial incentives
- Practice culture and commitment to improving health outcomes using health information technology
- Not sure/Don’t know
- Other (please specify)

Q15: What factors discourage your organization from sharing or exchanging protected health information/data with other healthcare providers, payers, and/or community programs? (Select all that apply)
- Issues with the compatibility and interoperability of different systems
- Concerns about Health Insurance Portability and Accountability Act (HIPAA) compliance or patient confidentiality
- Concerns about workflow or staff capacity
- Issues with lack of training or ability to fully use electronic systems
- Financial barriers or inadequate financial incentives
- Not interested in sharing or exchanging health data with others
- Not sure/Don’t know
- Other (please specify)

Q16: Does your organization participate in the state health information exchange (i.e., CRISP)? (check all that apply)
- Yes, my organization sends protected health information to the state health information exchange
- Yes, my organization receives protected health information from the state health information exchange
- No, my organization does not participate in the state health information exchange
- Don’t Know

Comments:

Q17: Does your organization participate in a local health information exchange? (check all that apply)
- Yes, my organization sends protected health information to a local health information exchange
- Yes, my organization receives protected health information from a local health information exchange
- No, my organization does not participate in a local health information exchange
- Don’t Know
- Other (please explain)

Comments:

Section 4: Focus Groups

The University of Baltimore would like to invite you to participate in a focus group to discuss referral networks, care coordination, meaningful use, and interoperability of health information technology systems. The focus groups will be held during summer 2015 with locations to be determined. Would you or a representative of your organization be interested in attending a focus group?

Yes/No

If yes, please provide the contact information for the invitation.
APPENDIX B: FOCUS GROUP QUESTIONS

We are working with the Maryland Department of Health and Mental Hygiene’s Center for Chronic Disease Prevention and Control to conduct a study to examine policies, procedures, technologies, and systems used to facilitate communication, data-sharing, and health information exchanges among three segments in the healthcare community: Health System/Care Providers, Payers, and Community Programs/Providers.

One of our goals is “gap analysis”—an analysis that will help us understand the current state of information sharing and compare it to the state where we’d like to be in five years or so. Your opinion is valuable to us in achieving that goal. But a focus group like this one is not about developing a consensus. Each of you comes from a unique perspective. Each of you has different job experiences and different backgrounds.

In this discussion today, we are looking for your particular perspective and whether or not others share it. While you might not have an opinion on one question, you might have a lot to say about another question.

I’d like to talk a little bit about how these kinds of focus groups work. The idea behind focus groups is to gather your opinions, so it is important that everyone contribute to the discussion. There are no right or wrong answers to the questions that I will be asking. In our discussion, you don’t always have to address your comments to me but please feel free to respond to something that another participant has said.

1. I would like to start by discussing the current state of information sharing

   Question: How would you describe the current approach to information sharing between community programs and healthcare providers and payers? What types of information technology tools does your program currently use for information sharing among participating individuals, providers, or insurers/payers?
   Probe: Consider the direction of information sharing and who information is shared with.

2. Communication - the ideal state of information sharing

   Question: In considering about the system of the 2020, how would you describe the best approach to information sharing between community programs and healthcare providers and payers? What types of information technology tools would be best for information sharing among participating individuals, providers, or insurers/payers?
Question: What factors facilitate or discourage the sharing or exchanging of protected health information/data with other healthcare providers, payers, and/or community programs?

3. Quality measures – health outcomes - workflow

Question: What current quality measures does your program track and report to reflect improved health outcomes for chronic health? How well is the collection of quality data currently integrated with the workflow pattern?

Question: In 2020, what quality measures should be reported? Are there barriers to integrating these measures into workflow patterns? How might the collection of quality data be better integrated into the workflow patterns?

4. Later stages of meaningful use - patient role/learning systems

Question: What is the current approach to patient engagement used by community programs? What types of patient-generated data are currently shared by patients? Do you see this changing in 2020? How?

Probe: For hypertension? For diabetes?

Question: What types of (de-identified) data are now collected and shared to promote learning about how to best prevention chronic disease and improve population health? Do you see this changing in 2020? How?

5. Potential approaches to create better tools might include designing a pilot study for developing an online referral system, increasing health information exchange via CRISP, and/or developing online chronic disease registries.

Question: If in 2020 there was an e-referral system using an online mobile platform, what might that look like and how would we get everyone on board?

6. Reimbursement models

Question: In considering the current system, how does the reimbursement model align the incentives of public health with the efforts of providers and/or community groups for disease prevention?
Question: In considering the ideal system, are there reimbursement models that seem to align the incentives of public health best with the efforts of providers and/or community group for disease prevention?
Figure 2. Concept Model for Referrals for the Prevention of Chronic Diseases

<table>
<thead>
<tr>
<th>Inputs</th>
<th>Stakeholders</th>
<th>Materials</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare systems/inpatient and outpatient</td>
<td>Directory—community resources</td>
<td></td>
</tr>
<tr>
<td>Health departments</td>
<td>Registry tool—generate list of patients for programs</td>
<td></td>
</tr>
<tr>
<td>Community program staff</td>
<td>Standard screening tools/risk assessments</td>
<td></td>
</tr>
<tr>
<td>Insurers/payers</td>
<td>Information technology/monitoring devices</td>
<td></td>
</tr>
<tr>
<td>Patients (at risk)</td>
<td>Standard referral forms</td>
<td></td>
</tr>
</tbody>
</table>

Activity

- **Health system - inpatient**
  - Later stage treatment
  - **Outpatient - PCP**
    - Risk assessment
    - Screening tools
    - Resource directory
    - Generates patient lists for program
    - Monitors risk status
    - Reviews need for Rx/more care
    - Tracks referral completion

- **Insurer/payer**
  - Verifies eligibility
  - Gauges value/financing
  - Benchmarks

- **Eligibility data**
  - Benchmarking data

- **Public health (govt.)**
  - Program development
  - Evaluation
  - Promotion/marketing
  - Screening & referral

- **Community program**
  - Behavior change plan
  - Participation/progress on plan
  - Outreach/messaging tools

- **Patient (at-risk)**
  - Reviews risk assessment w/PCP
  - Gets referral, reviews program info.
  - Sees if plan covers it, if app.
  - Is contacted or contacts community program
  - Makes participation decision
  - Self monitors/sends patient-generated health data (mobile)

- **Partnership agreement**
  - Referral form
  - Participation data

- **Provide program info to directory**
  - Partnering agreement

- **Eligibility data**
  - Benchmarking data

- **Public health (govt.)**
  - Program development
  - Evaluation
  - Promotion/marketing
  - Screening & referral

- **Community program**
  - Behavior change plan
  - Participation/progress on plan
  - Outreach/messaging tools
<table>
<thead>
<tr>
<th>Information-Sharing Concerns</th>
<th>Priorities</th>
<th>Discussion Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interoperability</td>
<td>Ease of use</td>
<td>Design referral systems</td>
</tr>
<tr>
<td>Lack of standards</td>
<td>Use of standard forms</td>
<td>Increase use of state or local exchanges</td>
</tr>
<tr>
<td>Lack of clarity on privacy</td>
<td>Be sustainable over time</td>
<td>Develop online registries</td>
</tr>
<tr>
<td>Limited awareness of programs</td>
<td>Address at-risk patients</td>
<td></td>
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</table>
### APPENDIX D: LIST OF ACRONYMS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>C-CDA</td>
<td>Consolidated Clinical Document Architecture</td>
</tr>
<tr>
<td>CDA</td>
<td>Clinical Document Architecture</td>
</tr>
<tr>
<td>CQM</td>
<td>Clinical Quality Measures</td>
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<tr>
<td>CRISP</td>
<td>Chesapeake Regional Information System for Our Patients</td>
</tr>
<tr>
<td>EHR</td>
<td>Electronic Health Record</td>
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<tr>
<td>FHIR</td>
<td>Fast Healthcare Interoperability Resources</td>
</tr>
<tr>
<td>FQHC</td>
<td>Federally Qualified Health Center</td>
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<tr>
<td>HIE</td>
<td>Health Information Exchange</td>
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<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
</tr>
<tr>
<td>MDHMH</td>
<td>Maryland Department of Health and Mental Hygiene</td>
</tr>
<tr>
<td>MU</td>
<td>Meaningful Use</td>
</tr>
<tr>
<td>NQF</td>
<td>National Quality Forum</td>
</tr>
<tr>
<td>ONC</td>
<td>Office of the National Coordinator for Health Information Technology</td>
</tr>
<tr>
<td>PDMP</td>
<td>Prescription Drug Monitoring Program</td>
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</tbody>
</table>
WORKS CITED


