Future of Health

Imperatives for advancing data sharing to support digitally enabled care

Research collaboration led by

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The American Medical Association is the powerful ally of and unifying voice for America's physicians, the patients they serve, and the promise of a healthier nation. The AMA attacks the dysfunction in health care by removing obstacles and burdens that interfere with patient care. It reimagines medical education, training, and lifelong learning for the digital age to help physicians grow at every stage of their careers, and it improves the health of the nation by confronting the increasing chronic disease burden.

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Executive summary

Traditional brick-and-mortar health care organizations and digital health companies are increasingly partnering to provide novel, digitally enabled care models to patients. Given the potential of digitally enabled care, it is critical that these models do not inadvertently increase the fragmentation of health care services. As highlighted in AMA's "Future of Health" report, "Closing the Digital Health Disconnect: A Blueprint for Optimizing Digitally Enabled Care," optimizing technologies and policies that reduce fragmentation are key to enabling the effectiveness of digitally enabled care for patients, physicians, and caregivers.

Seamless and secure data exchange that prioritizes the surfacing of critical and actionable insights early, often, and in an accessible format is vital for digitally enabled care. It allows clinicians to have a window into the care their patients receive outside of their office, it enables patients to receive timely, coordinated, and connected care, and it reduces duplicative or unnecessary tasks for administrative staff. Leaders shared that barriers to seamless data sharing and interoperability are no longer primarily technical in nature, given significant advances in standards development and health information exchange platforms. Instead, organizations experience cultural and operational roadblocks that stand in the way of meaningful data exchange and purposeful utilization of clinical information.

The AMA is committed to realizing the full potential of digitally enabled care and brought together a diverse group of stakeholders, including clinical, policy, patient advocacy, and technology leaders, in a facilitated workshop to explore how brick-and-mortar health care organizations and digital health companies can best work together to advance meaningful data sharing in support of effective digitally enabled care models. The following four imperatives were identified during the workshop:

1. Increase organizational readiness for data-sharing activities, including actively participating in data exchange platforms and simplifying contracting;
2. Prioritize and build goal-oriented relationships between partnering organizations and align early on data exchange;
3. Ensure the integration of identified data aligns with the needs of clinicians, and prioritize integration into clinician workflow to ensure data are actionable; and
4. Support the patient experience with functionality that addresses patient needs and preferences and integrates patients as part of the care team.

Imperatives for advancing data sharing to support digitally enabled care

Imperative 1: Increase organizational readiness for data-sharing activities, including actively participating in data exchange platforms and simplifying contracting.

There has been significant policy progress over the last several years to both protect and enable the exchange of health information, including the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the Federal Trade Commission Health Breach Notification Law and Unfair and Deceptive Trade Practices Act, the 21st Century Cures Act, and myriad state laws. Despite the level of protection the laws offer, they are complex to navigate, and legal and regulatory issues can still be roadblocks to executing relationships that involve data sharing. There are opportunities for health care organizations and digital health companies to increase organizational readiness to expedite the assessment and execution of new data exchange relationships, as outlined in the chart below. By doing this work in advance of relationship discussions, hard conversations and negotiations may be less complicated.

FOR BRICK-AND-MORTAR HEALTH CARE ORGANIZATIONS

1. Review your privacy and information security policies to make sure they are consistent with applicable state and federal regulations, and ensure your organization has developed data-sharing policies and procedures.
2. Encourage your staff and clinicians to standardize data collection as much as possible during patient registration and visit documentation, avoiding local or unique data entry approaches.
3. Participate in national (eg, DirectTrust), state (eg, Massachusetts Health Information Highway), or commercially available data exchange programs (CommonWell Health Alliance, Carequality), to limit the number of direct integrations.
4. Define the business rationale for data sharing up front and educate key business stakeholders.
5. Engage your security and information technology (IT) teams early to review the offering or product.
6. Engage with your privacy office or legal department on the offering or product and determine whether a business associate agreement (BAA) may be needed.
7. Provide threshold requirements (eg, privacy and security requirements, BAA template, contract template, and minimum insurance requirements) to the partner early in the process.
8. If your organizations begin with a pilot project, negotiate the entire agreement up front to enable more seamless program expansion.
9. Account for the resources needed for data sharing and integration (eg, project managers, legal resources, IT support, vendor support) in your annual budget process.

FOR DIGITAL HEALTH COMPANIES

1. Organize data in a way that aligns with new national standards (eg, Health Level 7 (HL7®), Fast Healthcare Interoperability Resources or FHIR®) while allowing for flexibility to support legacy data standards, profiles, frameworks, and technology.
2. Organize data in a structured format and limit use of PDFs, email, and fax.
3. Partner with national, state, or commercially available data exchange programs.
4. Explain up front how, when, and why you need access to or rights to use the customer's data (and how you will limit the use).
5. Articulate what specific actions you are taking to ensure you are abiding by the data-sharing agreement.
6. As much as possible, do not require a separate login or portal for clinicians at a health care organization to use your technology.
7. Have a HIPAA compliance program if needed and, if not, a legal explanation as to why HIPAA does not apply.
8. Be able to articulate and be willing to provide your security standards.
9. Adopt and utilize best practices to incorporate privacy-by-design methods within product design, eg, AMA's Privacy Is Good Business resource.
10. Start with your customer's contract template, and if they don't have one, offer to draft it.

Imperative 2: Prioritize and build goal-oriented relationships between partnering organizations and align early on data exchange.

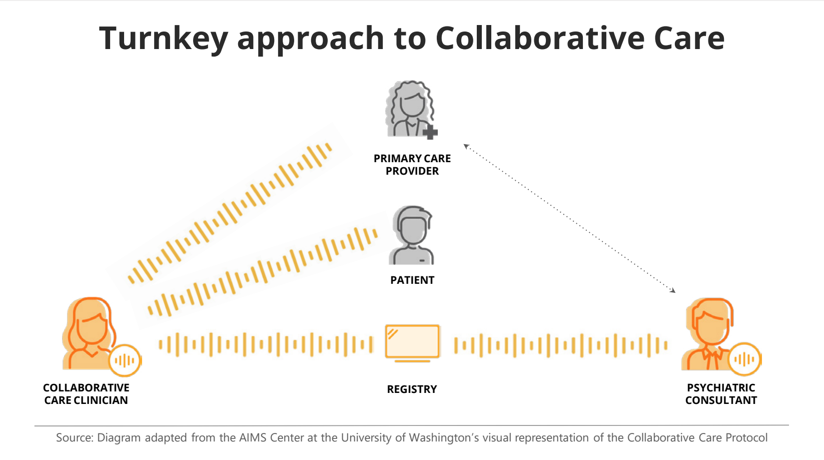
Data-sharing arrangements will be easier to establish when both organizations are aligned on **why** they are sharing data, the **value** it creates for each organization, and what **key concerns** each organization has in developing that arrangement. The chart below illustrates the key areas that organizations should jointly explore and select examples that answer questions about why organizations should share data, the value data create, and the concerns an organization may have.

	CLARIFY THE WHY	ALIGN ON THE VALUE	ADDRESS CONCERNS EARLY
Purpose	• Alignment on the **"why"** ensures partnering organizations can articulate their joint goal(s), which supports each in making an internal case about resources needed to support data sharing and integration.	• Alignment on the **"value"** of the data helps to rationalize the specific data required to achieve stated goals and can reduce each organization's discomfort around the potential misuse of the data.	• Alignment on the **"key concerns"** of each organization focuses early discussions and enables each organization to address up front the other's concerns before significant time and investment go into contracting and planning.
Examples	• The data support a seamless patient experience between organizations. • The data improve the provider experience and promote coordinated care. • The data enable one source of truth for the medical record.	• The data allow the organizations to measure program impact and outcomes. • Sharing data reduces duplication of data gathering or clinical care.	• Privacy concerns and the misuse of data (eg, commercialization). • Data storage and security standards. • Format of data and ease of use by receiving organization.

The decision to share data requires trust, transparency, and alignment on shared goals. The below figures feature an example of how aligned data sharing relationships have positive impacts for each partner.

FIGURE 1

Concert Health, a virtual behavioral health medical group, works with health systems across the United States to augment brick-and-mortar behavioral health care services. Concert Health shared how their strong partnerships with health systems are reinforced by a shared commitment to providing seamless care experiences through data sharing. Concert Health and their health system partners coordinate on providing behavioral health services using the evidence-based, team-based Collaborative Care Model, whereby primary care providers, care managers, and psychiatric consultants partner on patient care.



Turnkey approach to Collaborative Care

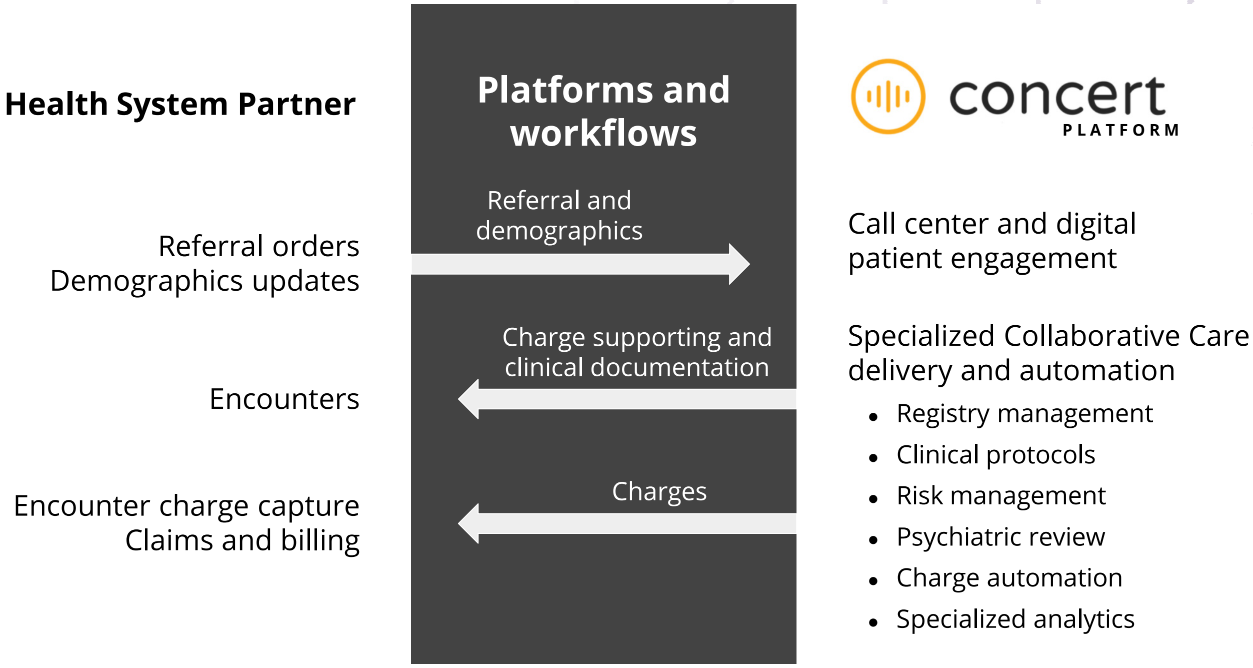
Source: Diagram adapted from the AIMS Center at the University of Washington's visual representation of the Collaborative Care Protocol

Typically, patients are referred to Concert Health by clinicians in adult and family medicine, women's health, or pediatrics for virtual behavioral health services. Concert Health's care teams, including a psychiatric consultant and a Collaborative Care clinician (behavioral health clinician), engage, either telephonically or by video, with the patient and are deeply embedded within their patients' primary care teams for optimal care coordination.

Concert Health has been successful in aligning with potential partners on the **why, value, and key concerns** up front. As an example:

- **WHY**: Concert Health and its health system partner are providing virtual behavioral health services to the health system's patients. They are sharing data to coordinate care delivery and seamless operations between the two organizations.
- **VALUE**: Concert Health and its health system partners typically share data related to referrals, clinical documentation, and billing. Shared demographic information enables cleaner data, and clinical documentation eliminates double entry, allows for faster reimbursement and fewer denials, and provides the ability for both organizations to jointly review clinical outcomes.
- **KEY CONCERNS**: Concert Health is concerned about the continued complexity of data sharing, continuing to develop new functionality to optimize data sharing, and ensuring appropriate protocols for joint research and data use. Its health system partners are typically concerned about how the data will be stored and utilized by Concert Health clinicians.

FIGURE 2



Concert Health and its health system partners build stronger relationships through transparency around how the data will be used and valuable to both organizations, fostering trust between the two organizations.

Guidance for developing goal-oriented data-sharing arrangements

- ✓ Align on **why** your organizations should share data.
- ✓ Understand the **value** each organization gets from participating in data exchange.
- ✓ Discuss up front any **concerns** or organizational limits regarding data exchange.

Imperative 3: Ensure the integration of identified data aligns with the needs of clinicians, and prioritize integration into clinician workflow to ensure data are actionable.

Clinical data must be shared and presented in a way that is actionable, timely, and reliable for clinician end users. Clinicians often become frustrated when they receive too much information or duplicate information—instead of a synthesized, actionable set of clinical data that can be used at the point of care to support care and treatment planning. Data are often provided in a PDF format or through a separate application that falls outside the clinician workflow or "single window" in the electronic health record. Using human-centered design approaches, engaging physicians in data exchange planning, and identifying the most critical pieces of information a clinician needs and exactly when they need the pieces to provide "just in time" information promotes the smart use of data.

> Vendors and digital health companies are finally starting to understand what it means to truly integrate into the clinician workflow. We have a lot of work to do as an industry to ensure that our solutions meet the needs of our end users in terms of a truly seamless, efficient user experience that furthers patient health.
>
> **Stephanie Zaremba, athenahealth**

One Medical, a membership-based primary care practice serving consumers, enterprise clients, and seniors under value-based care contracts, described their strategy for data sharing: to minimize the challenges related to accessing external data and intelligently organize the information to optimize for clinical action. They have data-sharing integrations with health system partners, health information exchanges, labs, interoperability vendors, state registries, and other clinical entities to support availability of data. They are investing in HL7® FHIR® as a mechanism to push as well as pull information, and they invest in data science, clinical informatics, and software development teams to best interpret and structure the information coming in. They also work with an internal clinical technology advisory team and shadow clinicians to both observe gaps and understand how clinicians use their platforms and clinical data. Together, these strategies enable One Medical to thoughtfully intake and utilize shared data.

In the past several years, the number of "point solutions," or companies that focus on a narrow clinical scope (eg, musculoskeletal, diabetes), has significantly grown. It is difficult for health care organizations and practices to manage relationships and integrations with each, and "platforms" that enable an organization to work with several point solutions through one interface at once have entered the market. For example, the Froedtert & the Medical College of Wisconsin health network partners with Xealth, a company that provides an integration layer and connection point to several digital point solutions for clinicians to prescribe to patients. Providers can prescribe these solutions directly through the electronic health record (EHR), and Xealth supports the Froedtert & MCW health network in standardizing the data from other digital health companies on the platform (eg, remote patient monitoring data) such that care teams know where to reliably access and view the clinical information. While there is still some manual inputting of data, this integration layer with Xealth offers a more streamlined approach than building separate integrations with each solution.

> There is an opportunity to free up the clinician and their care teams to do what they're really passionate about doing, by making it easier for them to do the jobs that they trained for.
>
> **Dana Brandenstein, Privia Health**

Stakeholders shared that it is important that vendors and digital health solutions aren't perceived as just "one more thing" for the clinician to do but also as trusted partners in their patients' care. Vendors can support this level of integration in several ways; for example, they can enable direct writing into the health care organization's medical record, automatically deduplicate or reconcile data when possible, and apply smart technologies to filter for the most critical pieces of information that can support decision-making at the point of care.

Guidance for ensuring data aligns with clinical needs and workflows

- ✓ Engage clinicians early in data-sharing exchange planning and workflow integration.
- ✓ Work with digital health companies that support data integration with the health care organization's EHR.
- ✓ Limit the number of integrations and unique point solutions.

Imperative 4: Support the patient experience with functionality that addresses patient needs and preferences and integrates patients as part of the care team.

In designing digitally enabled care models, it is critical to consider the patient and caregiver user experience, and to empower them with access to and understanding of their health care information. Experts advise that as organizations establish new digitally enabled care models through partnerships with external companies, they must be careful not to duplicate and exacerbate the fragmentation that has existed in the traditional brick-and-mortar health care environment. To optimize the patient and caregiver experience in digitally enabled care partnerships, organizations must ensure that patients can:

- Access health information from both organizations in a single place
- Access health information in a timely manner
- Maximize the information available to patients, empowering them to be active members of their care team

As the number of point solutions continues to grow, health care organizations are considering how best to streamline and strengthen the patient experience. As an example, the Froedtert & MCW health network has a custom mobile application where they have created a single sign-on experience for patients to access all of the point solutions they may be prescribed as part of their care. This has led to a positive patient experience.

As the number of point solutions continues to grow, provider organizations are considering how best to streamline and strengthen the patient experience. Froedtert has a custom mobile application where they have incorporated point solutions for patients to self-enroll as part of their care when appropriate. This has led to a positive patient experience.

> “We're potentially putting ourselves in a position where we create the same type of siloing and fragmentation in the digital realm. That is a big challenge with our physical health care system. So that's what we have to fight against.”
>
> **Greg Weidner, MD, One Medical**

Critical to any health system is building trust with patients. When a health system develops a relationship with a digital health company and subsequently refers a patient to that digital health solution, it is their brand and reputation on the line. It is important for digital health companies to consider this when designing their programs and data-sharing capabilities and to articulate this understanding when establishing relationships with health care organizations.

Health care organizations, vendors, and digital health companies should be aware of federal and state laws and regulations that govern health information exchange and patients' access to their health records. HIPAA and information-blocking regulations that originated from the 21st Century Cures Act will play a critical role—both in promoting information exchange and establishing guardrails. State information exchange laws and regulations have their own unique requirements. Make sure to plan and allocate staff and other resources to understand the ins and outs of information exchange policies. The AMA has created several resources to help physicians learn about these laws and regulations.

Guidance for supporting the patient experience

- ✓ Minimize the number of places patients have to go to find health information.
- ✓ Maximize the information available to patients and their caregivers.
- ✓ Include patients and caregivers in the design of digitally enabled programs.

Looking forward

Policies and technologies to support clinical data sharing and interoperability have come a long way. The growth in the number of organizations that can and do participate in information exchange has been a significant step forward, and advances in policy, data standards, and data science show great promise for optimizing both utilization and protection of this information. In the coming years, the industry will need to focus its attention on the most meaningful ways to organize, analyze, and display clinical information. The imperatives articulated in this brief support building organizational culture and relationships that support meaningful data sharing. By embracing these imperatives and supporting information exchange, health care organizations can contribute to achieving the promise of digitally enabled care, improving clinical outcomes and both patient and clinician experiences.

As a key stakeholder, the AMA is committed to advancing these discussions; clinician perspectives and input are essential to broad adoption of new models of care and utilization of information exchange.

Contributors

The AMA and Manatt Health convened a panel of experts for a virtual workshop on Aug. 23, 2023, for a collaborative discussion on how to further empower physicians to adopt and scale evidence-based digitally enabled care models and the role data sharing and interoperability play in successful digitally enabled care partnerships. We thank the below individuals for sharing their time and expertise to inform this issue brief.

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