Defragmenting Heart Failure Care: Medical Records Integration

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Keywords

INTRODUCTION

The enormous public health burden of heart failure continues to grow. Between 2009 and 2016, the number of patients living with heart failure (HF) in the United States grew by an estimated 5.7 million.[1] The prevalence of HF is projected to increase 46% between 2012 and 2030, affecting nearly 3 out of every 100 Americans.[2] It is projected that in 2030, the total

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annual cost of HF in the United States will amount to $69.8 billion, or $244 for every adult.[2] The burden of HF is compounded by high rates of rehospitalizations,[3] driven in part by a lack of transitional care systems that can meet the complex medical needs of HF patients.[4] Accordingly, a major barrier to delivering the best care for HF patients is the fragmentation of their healthcare experience.

Fragmentation refers to dealing in individual parts rather than the whole.[5] Patients who receive care in many different healthcare settings are exposed to unnecessary medical procedures[6] and diagnostic tests.[7] Patients with fragmented care also experience longer hospital stays,[8] while patients with better continuity of care have fewer preventable HF hospitalizations.[9] In a fragmented model, care decisions are made by multiple independent providers who have limited means of transmitting information between themselves.

For example, several trials have consistently shown improved outcomes among HF patients with diabetes who are treated with a sodium/glucose cotransporter 2 (SGLT2) inhibitor.[10–12] In the near future, indications for these medications may expand to non-diabetic patients with HF.[13] Prescribing them necessitates ongoing monitoring for efficacy and side effects, which requires close communication with other providers.[14] Specifically, patients starting an SGLT2 inhibitor should be counseled on the risks of hypoglycemia and volume depletion and may need titration of their anti-glycemic medications and diuretics. This task represents a significant care coordination challenge for patients who are simultaneously managed by multiple providers (their primary care clinician, cardiologist, nephrologist, endocrinologist, etc.). If these patients are hospitalized and their HF medications are put on hold or decreased in dose during an admission, determining which provider is responsible for restarting which medication upon discharge requires expedient health information transfer and communication. Ideally, to defragment HF care, providers must be able to 1) quickly and easily access all available patient health information and 2) instantaneously have their own management decisions known to the patient and all other treating providers, regardless of location or specialty.

Goals of this review

In this review, we will explore why defragmenting HF care through the exchange of health information in the electronic health record (EHR) era has proven to be a persistent and complex challenge. Our discussion on initiatives related to improving care fragmentation will focus on the regulatory landscape that drove EHR adoption and now aims to democratize data access to improve patient care. Additionally, we will explain the central role that data standards and record linkage play within the realm of health information exchange and interoperability as it pertains to HF patients. Finally, we will discuss new information technology priorities for HF that are are poised to allow patient-generated data to be collected and integrated into clinical decision making.

INITIATIVES RELATED TO CARE FRAGMENTATION

The advent of the electronic health record (EHR) engendered the hope that clinical information would no longer be trapped in a paper chart and instead would be digitally accessible at the moment of medical decision making. Free-flowing health information

exchange between clinics and hospitals, unbounded by geography, would reduce medical errors, adverse events, and costs.[15] Instead, EHR adoption has been characterized by a myriad of competing vendors and noncommunicative software systems, so that missing clinical information outside one's specific practice site remains common.[16] This phenomenon, a key driver of fragmented care, is known as a *lack of interoperability.*

Interoperability defines the capacity of disparate health IT systems or devices to exchange, interpret, and make available shared data without special effort on the part of the user.[17] Without interoperability, clinically useful health information exchange is dramatically impaired and care fragmentation soars. Nevertheless, implementing interoperable health IT solutions to defragment HF care has been riddled with challenges that are only now beginning to improve through dedicated regulatory policy and stakeholder alignment.

Regulation

Incentivizing Electronic Health Record Adoption—President George W. Bush catalyzed the federal government's involvement in national health IT with his signing of Executive Order 13335 in 2004 (Table 1). Intended to "provide leadership for the development and nationwide implementation of an interoperable health technology infrastructure," the Order established the Office of the National Coordinator for Health Information Technology, or ONC, within the U.S. Department of Health and Human Services.[18] Though the ONC mission statement and priorities have evolved over time, its central role in the uptake and regulation of EHR products was cemented through congressional mandate in 2009 as part of the Health Information Technology for Economic and Clinical Health (HITECH) Act.

HITECH provided financial rewards for achieving meaningful use of EHR platforms, intended to encourage the use of health IT above and beyond a basic implementation. With its primary intent being to bring the entire US health system into the digital era, less emphasis was placed on ensuring interoperability of the new software systems – only a 10% electronic transmittal rate of a summary of care document during a patient transfer was required to meet the meaningful use requirement.[19] Although HITECH was successful in stimulating the shift from paper charts to EHRs for the vast majority of hospitals and clinics, any resultant association between EHR adoption and improved patient outcomes remained questionable.[20] Among ambulatory HF patients, the differences in rates of GDMT between outpatient cardiology practices using paper charts versus those using an EHR were small and inconsistent.[21] Patients admitted for HF to hospitals using EHRs fared no better than their counterparts at paper-based hospitals with respect to HF quality metrics, readmissions, and mortality.[22]

Reducing Readmission Reimbursements—In 2010, the Patient Protection and Affordable Care Act became law. The three major provisions of the Affordable Care Act included health insurance regulation, insurance expansion, and health delivery system reform. The latter was meant to prioritize quality of care over quantity of care. One way the law aimed to achieve these quality gains was through cuts to the Centers for Medicare and Medicaid Services (CMS) reimbursement rates for hospitals with higher than expected 30-

day readmission rates. The initiative, known as the Hospital Readmission Reduction Program (HRRP), began penalizing hospitals starting in 2013 for readmissions of patients with a selection of common conditions including chronic obstructive pulmonary disease, pneumonia, hip or knee replacement, acute myocardial infarction, and HF. Of these, the most commonly readmitted patients were (and still remain) those with HF.

For patients who are readmitted after a heart failure hospitalization, fragmentation of care is associated with worse outcomes. Those readmitted to a different hospital than that of their index admission generally experience longer stays and higher mortality risk than those readmitted to the same hospital.[23] Though there may be multiple institutional and situational variables driving this association, a lack of universal medical records integration is a likely contributor. With disparate institutions utilizing different EHRs, none of which were designed to "talk" to each other, inter-institutional health information exchange has traditionally been sparse and unincentivized. To address this deficit, lawmakers introduced new legislation designed to spur EHR interoperability under the growing regulatory auspices of the Office of the National Coordinator for Health IT (ONC).

Mandating Interoperability—The Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) created a new incentive program called the Quality Payment Program (QPP) that rewards quality of care and phases out the traditional fee-for-service reimbursement model. Within the QPP, the Merit-based Incentive Payment System (MIPS) adjusts provider payments based on performance within four categories. The quality category, as it relates to HF patients, measures and adjusts for functional outcomes, readmissions, and the percentage of patients prescribed GDMT.[24] The promotion of interoperability category awards points for ONC-certified EHR use demonstrating (without minimal use thresholds) the capabilities of e-prescribing, electronic referral, patient access to health information, and clinical data exchange.[25] Given the recent implementation of these programs, few data are available to judge their effects on HF patient care or outcomes.

In 2016, the 21st Century Cures Act was passed which tasked the Office of the National Coordinator for Health IT (ONC) with bolstering interoperability and stimulating health information exchange through mandates that a) define interoperability, b) prevent information blocking, c) develop data sharing standards, and d) call for Application Programming Interfaces (APIs) that allow patients to access their health information without special effort.[26] An API is a communication tool that allows one computer program to talk to another and request data in a very efficient way; APIs are used in countless mobile apps and software programs that download data from the internet. Deciphering the potential effects of these types of federal IT regulations on fragmented HF care requires an understanding of the different types of health information exchange that currently exist.

Health information exchange

Interoperability allows for health information exchange, which is the electronic access and transmittal of a patient's vital medical information.[27] Participants in health information exchange may include physicians, nurses, caregivers, pharmacists, and any others that have cared, are caring, or will care for that patient, in addition to patients themselves. The Office

of the National Coordinator for Health IT (ONC) has defined three specific types of health information exchange, each distinguished by a specific clinical workflow and direction of information transfer (Figure 1).[27]

Directed Exchange—First, a directed exchange refers to health information sent over the internet in a secure fashion, encrypted and reliably transmitted (Figure 1A). Senders and receivers generally have a pre-existing relationship, and information is sent in anticipation of need or by request between individuals. Directed exchange at its simplest might be a primary care physician sending a patient's past medical history to a consulting cardiologist by means of encrypted email.

Query-based Exchange—Second, a query-based exchange refers to health information that is available at all times for providers to query when needed (Figure 1B). This type of exchange is more helpful than a directed exchange for unplanned medical care like emergency department visits where quick information retrieval is imperative to guide clinical decision making. Ideally, information from a query-based exchange would be seamlessly integrated into the clinician's workflow and relevant data uploaded the moment a new patient's chart is opened. Unfortunately, the availability and reliability of query-based exchanges has been limited by competing business motivations. Though there have been a few successfully formed health information exchanges in certain states with geographically-linked care networks, the majority of healthcare institutions remain wary of sharing valuable patient data without a clear value proposition or regulatory requirement to do so.[28]

Consumer-mediated Exchange—Third, a consumer-mediated exchange refers to health information that is owned by and personally curated by patients themselves (Figure 1C). Patients might review their data for missing or inaccurate details, and they have the ability and responsibility to transfer that information to their care team at the appropriate time. This type of health information exchange is classically compared to online banking, where customers are able to securely track, send, and receive their currency on the internet and through interoperable ATMs across the country.

Early attempts to encourage consumer-mediated exchange were met with failure. Google Health, introduced in 2008, offered a centralized service where customers could volunteer their health records from different providers and have them stored in one easily accessible online repository. Adoption among the general population was low, and Google cancelled the program in 2012. In parallel, Microsoft introduced its similarly structured HealthVault in 2007, highlighting its ability to collect medical device data like step counts from fitness monitors and readings from integrated home blood pressure cuffs to generate personalized health insights. After a protracted struggle with poor adoption, HealthVault was discontinued in 2019. In retrospect, the failures of these consumer-mediated exchanges can be partially blamed on a lack of universally agreed upon standards for sharing health data.[29]

Standards

A standard refers to an idea or an object that others are compared to for purposes of compatibility and consistency. Applied to health information exchange, standards represent

agreed upon ways of using computer code to record and digitally transmit medical information so that the recipient knows exactly what information is present and can translate the code back into a piece of medical information. Google Health and HealthVault relied on poorly adopted and implemented standards like the Continuity of Care Record (CCR) that resulted in long, complicated documents that were challenging for both machines and humans to read.[30] As a result, users of these and other early consumer-mediated exchanges ended up with disorganized and unwieldly personal health records.

EHR vendors also rely on standards to comply with interoperability laws. For example, Epic Systems Corporation's Care Everywhere interoperability platform includes data from the Consolidated Clinical Document Architecture (C-CDA) standard to allow for point-to-point transfer of health information during transitions of care (thereby satisfying meaningful use requirements).[31] Though widely adopted, this standard also produces a lengthy document containing a potentially vast amount of longitudinal patient data that is difficult for humans to read. Given the usability challenges that arise when too much clinical information is presented at once, the health IT community has gravitated towards a promising new standard: Fast Healthcare Interoperability Resources (FHIR).

SMART on FHIR—Fast Healthcare Interoperability Resources (FHIR) was developed by a non-for-profit group called Health Level Seven International (HL7), a standards-development organization focused on the exchange, integration, sharing, and retrieval of electronic health information. As an improvement on prior efforts, FHIR aims for ease of implementation while ensuring consistency and modularity in how data are represented and presented to both machines and humans. In line with the 21st Century Cures Act that stipulates all EHRs must provide APIs to promote health information exchange, FHIR-formatted EHR data is easily accessible through the FHIR API.

On top of the FHIR standard, the app development community SMART (Substitutable Medical Apps, Reusable Technology) coded a technology layer around FHIR that makes it easier to develop FHIR-based apps. Apps that manage data using the FHIR standard with SMART technology are called SMART on FHIR apps. Instead of requesting and then sifting through vast piles of health information, users of SMART on FHIR apps can quickly request a specific piece or set of data, like their most recent medication list, constructed and verified through EHR and pharmacy record data.[29]

Although early efforts at broad adoption of personal health records stumbled, Apple is now generating excitement around Apple Health. Apple Health is a patient-facing, SMART on FHIR app that quickly produces an integrated view of medical record details selectively extracted from multiple EHRs. Patients can elect to share this information with their providers, researchers, or other apps designed to help manage their disease (Figure 2D). Additionally, SMART on FHIR apps can be customized to directly appear within the EHR, pre-populated with individualized patient information and displayed via external links, embedded windows, or pop-ups. For example, Titus et. al[32] have developed a SMART on FHIR app called *Chest Pain Dashboard* that searches the statewide clinical data repository for a patient's prior cardiac studies and presents that information within an EHR window to emergency department physicians caring for patients with chest pain. Their preliminary

results show promising reductions in the number of clicks and minutes spent searching for relevant information as compared to their EHR vendor's more cumbersome interoperability platform. Whether SMART on FHIR will improve patient outcomes remains to be seen.

Individual Health Record Linkage—As important as which data are exchanged is whose data are exchanged. Reliable identification of the same patient across care settings remains an incompletely solved challenge. Although some countries have adopted the use of a universal ID for healthcare purposes,[33] current U.S. regulations prohibit use of federal funds to develop a unique patient identifier. Use of social security numbers (SSNs) as a proxy unique identifier has proven challenging for a variety of reasons, including fraudulent use and diminishing capture of full SSNs at registration.[34] In the absence of a unique identifier, a variety of linkage methods to match patient records across care sites are in use or under development today.

Deterministic record linkage uses exact matches of patient-specific features (e.g. first name, last name, date of birth) to assert that records are the same. Probabilistic matching, pioneered through work at the U.S. Census Bureau uses patient-specific features alongside common or similar variants to create a probability score for a match. Depending on the use case, a threshold level is set above which matches are presumed accurate and below which they are considered non-matches or require further manual review. Most EHRs and health information exchanges that provide record linkage functionality use probabilistic record linkage methods.

A newer method, referential matching, makes use of additional patient-specific features (e.g. voter registration records) to increase match confidence. To reduce the need to share protected health information for matching purposes, privacy preserving record linkage methods use irreversible encryption algorithms to create a unique code for each patient based on available features, and only this encrypted code is shared for generating matches.[35] Regardless of the matching method, the availability and quality of patient-specific features contribute substantially to match quality.[36] Record linkage methods and novel technologies adapted to matching (e.g. biometrics) will continue to evolve and play a crucial role in achieving interoperability.

CARE FRAGMENTATION PRIORITIES FOR HEART FAILURE MANAGEMENT

Medication Management

Beyond driving EHR-based information exchange, interoperability gains may improve our ability to capture and transmit data generated outside the hospital. For example, outpatient medical management therapy (pharmacist-led comprehensive medication review, treatment plan formulation, and patient education) has been included in Medicare Part D since 2013, but all documentation is done on paper in isolation from the EHR, rarely finding its way back to prescribers.[37,38] Proponents of FHIR can imagine an app that links medical management therapy data from pharmacy databases to the EHR so that actionable alerts for a specific patient can be routed to the care team or prescriber's inbox (Figure 2A).[39] In this way, a HF patient seen by a pharmacist for medication review and found to be on suboptimal GDMT doses would instantaneously have this information delivered to the clinical team.

Similarly, Surescripts has developed a SMART on FHIR app that transfers prescription refill history directly into the EHR workflow and outputs an estimated proportion of days covered, allowing clinicians to identify non-adherences issues early on.[40]

Social Determinants of Health

Some of the most important patient health data are external to the healthcare setting. Social determinants of health (SDOH) are the extrinsic, overlapping social constructs and economic systems that can lead to poor clinical outcomes and include inadequate housing, food, social support, transportation, physical environment, and insurance coverage (Figure 2B). The importance of SDOH in HF care has been validated by the 2019 American Heart Association/American College of Cardiology Guideline on the Primary Prevention of Cardiovascular Disease, which acknowledges that "failure to address the impact of social determinants of health impedes efficacy of proven prevention recommendations."[41] Deriving robust patient-specific treatment plans based SDOH requires that SDOH data be accurately and comprehensively recorded and addressed. Unfortunately, clinicians often lack the time and resources to document and meaningfully consider these complex issues.[42] Instead, patients typically are screened using pre-visit surveys that ask about basic social determinants (like intimate partner violence, financial strain, and education level) to satisfy federal requirements for SDOH documentation within the EHR. Some health groups have also added community-level social determinants like Census Bureau rates of poverty and unemployment into their EHRs for providers to view.[43] Although the emphasis on SDOH documentation has increased the amount of information captured, clinicians have not settled on what to do with it, opening the space for vendor solutions. NowPow[44] is one example of a company that leverages FHIR resources to securely integrate SDOH into routine care for the purpose of connecting patients to the most personally relevant community resources.

Home-based Monitoring

At home daily weights for HF patients are notoriously difficult for physicians to track and act upon, as the onus has traditionally been put upon the patient to log these values accurately and report them in a timely fashion. As discussed above in the context of failed consumer-mediated exchanges, many patients are not willing or are unable to manage their own health data, including self-generated data like daily weights. Learning from the challenges of Google Health and Microsoft HealthVault, new health IT companies have found solutions that combine the tenets of consumer-mediated exchange (where the patient generates and stores data) with query-based exchange (where that stored data can be viewed remotely by providers), as depicted in Figure 2C. For example, Rimidi used a SMART on FHIR app to allow connected home scales to securely transmit data to an EHR dashboard that alerts providers to rapid weight gain.[45] Taken to the next level, performing advanced analytics on this type of data could deliver personalized clinical decision support for diuretic dosing to prevent HF deterioration more successfully than generalized weight thresholds.[46]

Implantable Device Monitoring

Based on the concept of closely monitoring volume status to prevent HF rehospitalizations, the CardioMEMS implantable device was approved in 2014 by the FDA for wireless pulmonary artery pressure monitoring in New York Heart Association (NYHA) Class III HF

patients.[47] The European Society of Cardiology lists CardioMEMS implantation as a Class IIb, Level B recommendation that "may be considered … to reduce the risk of recurrent HF hospitalization,"[48] consistent with before-and-after and matched cohort studies that have demonstrated impressive reductions in HF hospitalizations among patients who received a CardioMEMS device.[49,50] Though some have raised concerns about the real-world applicability of these studies,[51] having continuous intravascular pulmonary artery pressure and heart rate data available to guide HF care appears to be useful for a subset of patients with HF. Unfortunately, obtaining this information is also a fragmented process. Clinicians must log on to an external, proprietary web portal to view patient device data and are instructed to rely on email alerts for notifications of impending patient crisis. Finding and accessing this data can be prohibitively difficulty for inpatient physicians without CardioMEMS platform knowledge who might otherwise act on this data to deliver improved care during a HF hospitalization. Developing ways to integrate these types of device-generated data into the EHR using tools like SMART on FHIR would represent a powerful step towards individualized, defragmented HF care (Figure 2D).[52]

DISCUSSION

Heart failure continues to grow in prevalence and care complexity. Robust clinical trials have generated high-quality, evidence-based recommendations and guidelines shown to improve quality of life and mortality. Paradoxically, the more guideline directed medical therapies that emerge, the more fragmented patient care can become. Comprehensively treating the whole patient, including comorbid conditions and social determinants of health, often requires the addition of more care providers and more detailed management plans. Frequent hospitalizations and readmissions compound the fragmented care that HF patient receive.

Because care coordination requires clinical data, early efforts to defragment care were focused on legislation to encourage EHR adoption, assuming that digitized data inherently would be more accessible to providers than paper charts. Clinicians quickly realized that computerized data alone were not enough; rather, health information had to be quickly and easily transferrable. Health information exchange though interoperability has become the new goal for those wanting to improve the quality of HF care delivery. Motivated by legislative mandates, improved standards like FHIR are being adopted to allow for fast and succinct clinical data transfer.

In response to the Hospital Readmissions Reduction Program incentivizing reduced HF readmissions, vendors have created a plethora of novel solutions for capturing patient-generated data that might warn of impending decompensation. Each of these solutions, whether it be a WiFi-enabled home scale or an implantable cardiac device, runs the risk of perpetuating fragmented care if its data remain siloed outside of the patient's health record and inaccessible by the care team.

While legislative efforts to improve secure health information exchange continue to evolve, advocating for interoperability and patient access to data should remain a top priority for the HF providers. Companies that benefit from control over access to data, including EHR vendors, can impede efforts to defragment care, and regulation intended to support

interoperability may help offset this self-interest. Above all, patients should be the ones who benefit the most from their electronically collected health information – achieving the rapid, seamless exchange of these data is key to realizing healthcare improvements in the EHR era.

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Key Points

- Fragmented heart failure care occurs when providers make clinical decisions in the setting of incomplete information

- Electronic health information exchange is accelerating, driven by federal regulations and evolving data standards

- New heart failure technologies capture valuable patient-generated data but will not improve care fragmentation in isolation

Synopsis

Heart failure management requires intensive care coordination. Guideline directed medical therapies have been shown to save lives but are practically challenging to implement because of the fragmented care that heart failure patients experience. Electronic health record adoption has transformed the collection and storage of clinical data, but accessing this data often remains prohibitively difficult. Current legislation aims to increase the interoperability of software systems so that providers and patients can easily access the clinical information they desire. Novel heart failure devices and technologies leverage patient-generated data to manage heart failure patients while new data standards make it possible for this information to guide clinical decision making. Defragmenting heart failure care depends on our ability to effortlessly synthesize these disparate data into a cohesive medical picture to act upon.
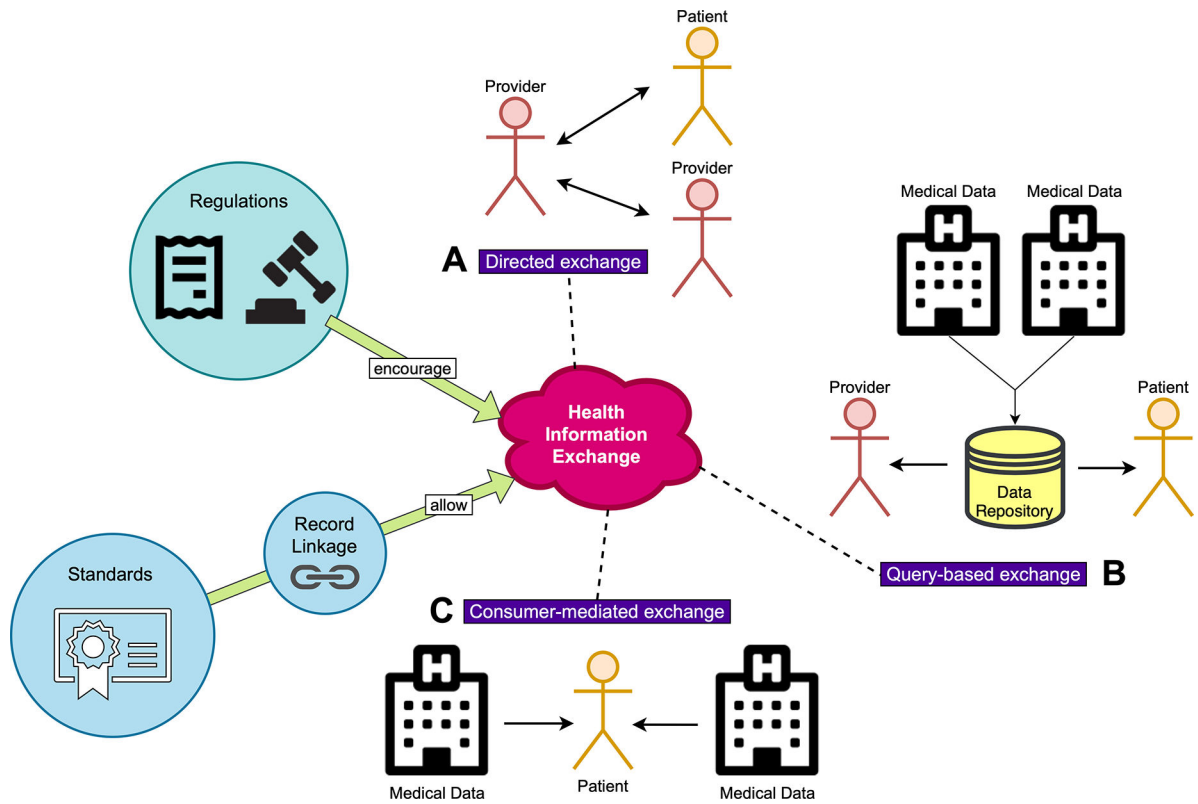
Figure 1.
Models of health information exchange. *Green arrows*: legislation tied to health provider reimbursement motivates the use of interoperable health IT; agreed upon data standards and record linkage provide the framework to securely transmit digitized health information. *Thin arrows* represent direction of information exchange. A) *Directed exchange*: participants directly send clinical information to and from each other. B) *Query-based exchange*: multiple data sources (i.e. patient data from different hospitals) are stored in a repository that users can request specific information from. C) *Consumer-mediated exchange*: health data is collected and stored by the patient who controls who uses the data.
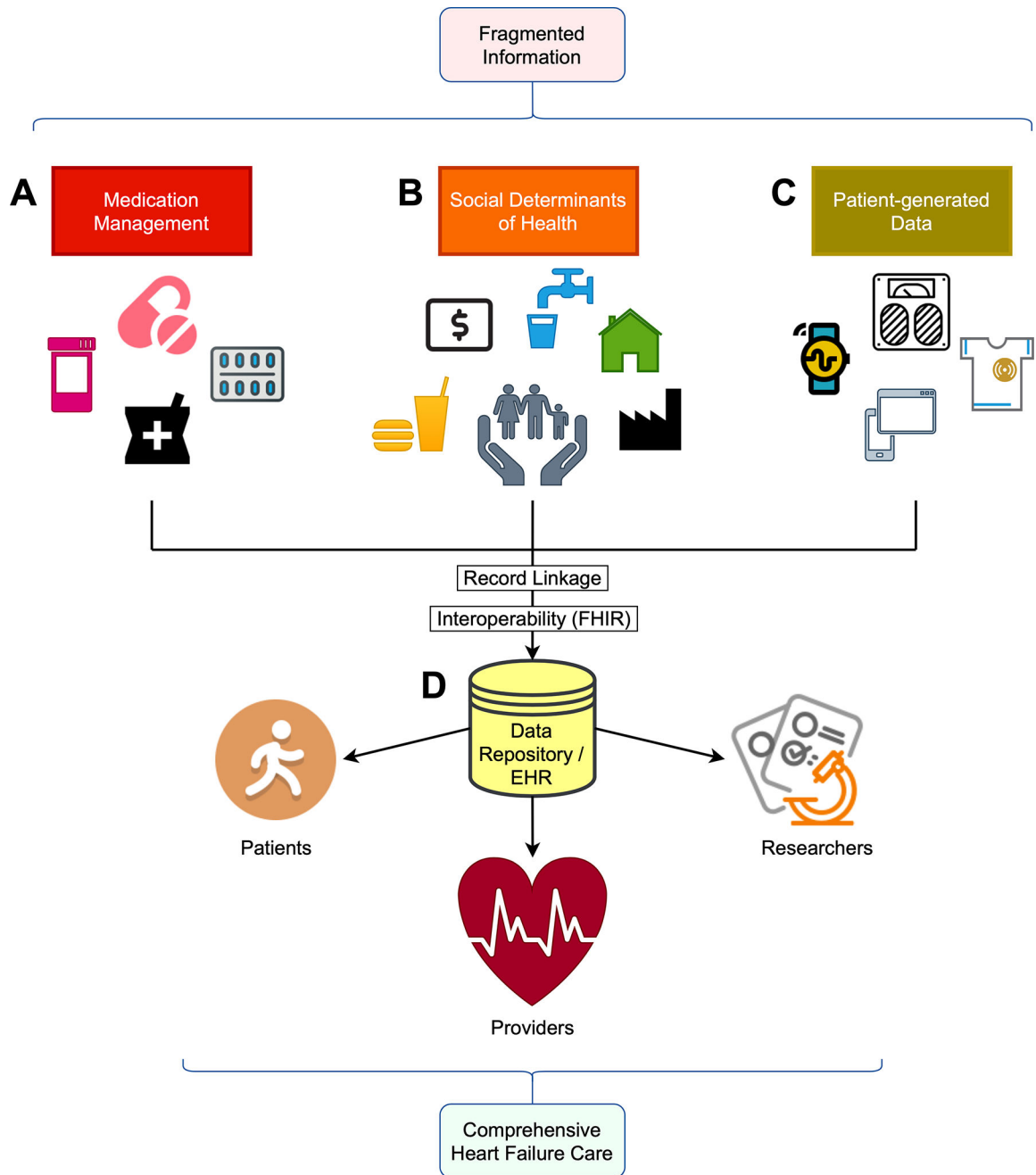
Figure 2.
Comprehensive heart failure care requires interoperability between fragmented data sources.
A) *Medication management* data includes prescription information, refill history, insurance copay, and pharmacist documentation. B) *Social determinants of health* include patient-reported and census-derived information on poverty, insurance status, food available, living environment, and community resources. C) *Patient-generated data* includes readings from home scales or blood pressure cuffs, sensor data from wearable devices like watches, data from implantable cardiac devices, and information entered through web portal and smartphone apps. D) These data can be transmitted using through FHIR resources to a

central database or EHR where they can be used by patients, researchers, and healthcare providers.

Table 1.

Summary of legislative efforts to reduce healthcare fragmentation though information technology

Legislation	President	Year	Health IT Component	Intended Effect
Executive Order 13335	George W. Bush	2004	Established the Office of the National Coordinator for Health Information Technology (ONC)	Provide leadership for the development of a nationwide health technology infrastructure
Health Information Technology for Economic and Clinical Health (HITECH) Act	Barack Obama	2009	Set meaningful use requirements for adoption of ONC-certified EhRs; tied to Medicaid incentive payments	Encourage use of EHRs to achieve significant improvements in patient care
Affordable Care Act (ACA)	Barack Obama	2010	Established the Hospital Readmission Reduction Program (HRRP); tied to Medicare reimbursement payments	Reduce the prevalence and cost of hospital readmissions nationwide to reduce healthcare spending
Medicare Access and CHIP Reauthorization Act (MACRA)	Barack Obama	2015	Established the Quality Payment Program (QPP); adjusts Medicare payments based on quality and use of ONC-certified interoperable EHRs	Reward quality of care over fee-for-service; reward use of interoperable health IT
21st Century Cures Act	Barack Obama	2016	Mandates interoperability through health IT regulations and prohibits information blocking	Advance interoperability and support the access, exchange, and use of electronic health information