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Strategic Value of an Unbound, Interoperable PHR Platform for Rights-Managed Care Coordination

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Abstract:

Health care reform requires an information-system paradigm shift. We present an innovative implementation involving an unbound, interoperable PHR platform that enforces patient permissions while exchanging structured data via Web services with certified EHRs. We draw on a strategic health information technology framework and a disruptive-innovation argument for the underlying conceptual basis. We describe how the platform's three-tier architecture supports rights-managed care coordination. Finally, we discuss future observational and experimental research on the platform's cost-effectiveness.

Keywords: care plan, care coordination, disruptive innovation, health care reform, interoperability, meaningful use, patient privacy, personal health record, PHR

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I. INTRODUCTION

Successful reform of U.S. health care, with its dispersed patient care and fragmented record keeping [Arrow et al., 2009], calls for an information-system paradigm shift [Baker et al., 2011]. The conventional health information system paradigm involves personal health records (PHRs) for patients, which are tethered to the electronic health record systems (EHRs) of health care providers [Archer et al., 2011]. Tethered PHRs have no demonstrated value [Tenforde et al., 2011] for chronically ill patients as they struggle to achieve care coordinated across their many isolated providers. Nor do tethered PHRs assist providers as they struggle to coordinate patients' complex care, while adhering to emerging policies for meaningful use of certified EHRs and for disclosures of patient information. We describe an unbound, interoperable PHR computing platform, which enforces patient permissions while exchanging structured data via Web services with certified EHRs. We examine the platform's potential for strategically disrupting status quo health care delivery [Christensen et al., 2009; Raghupathi and Tan, 2008] by empowering patients and providers with capabilities for rights-managed care coordination.

The Mediation-Collaboration Strategic HIT Framework proposed by Raghupathi and Tan [2008] and Christensen's disruptive-innovation argument [2009] provide the underlying conceptual basis for the PHR platform implementation. We argue that the platform's three-tier architecture, which supports rights-managed care coordination, is a strategic necessity for confronting the challenging contemporary health care environment. We recognize that future observational and experimental research must test our hypotheses about the platform's comparative cost-effectiveness. In the rest of the article, we review current health care challenges, set forth the platform's conceptual basis, describe the structure and function of the platform's three-tier architecture, and discuss conclusions and future directions.

II. CHALLENGES IN THE CURRENT HEALTH CARE ENVIRONMENT

Dispersed Care

Chronic conditions are consistently more prevalent among low-income people. These individuals more often receive dispersed rather than coordinated health care [Wilper et al., 2008]. Approximately 20 percent of U.S. adults receive care for multiple chronic physical, mental, and substance abuse conditions from two or more dispersed providers. This group accounts for nearly 50 percent of total U.S. health care spending [Druss et al., 2001]. Furthermore, dispersed care of complex patients, with five or more chronic conditions accounts for greater than 90 percent of Medicare spending [Thorpe and Howard, 2006]. Dispersed care is so unsatisfactory, dangerous, ineffective, and costly that it threatens the U.S. economy [Arrow et al., 2009]. Paradoxically, at all income levels in the U.S., dispersed care is the general rule and coordinated care the exception. As a patient's frequency of co-morbid chronic conditions increases, so does the dispersion of the patient's care across multiple providers. In a single year, the typical Medicare beneficiary sees two primary care physicians and five specialists in four different practices [Pham et al., 2009]. Thus, no one provider is held accountable for the safety, quality, and costs of an individual patient's care.

Fragmented Records

Electronic health record systems (EHRs) are maintained by providers for patients in their practices. Typically, patients deal with multiple EHR-equipped providers. This poses major challenges due to the resultant provider-to-provider misunderstandings, information gaps, and diffusion of responsibility. Since 2001 [Committee on Quality of Health Care in America, 2001], the U.S. has encouraged provider adoption of EHRs to make health care safer and more efficient [Hillestad et al., 2005]. But current EHR adoption rates are insufficient to overcome the diffusion of responsibility for complex patients [Shields et al., 2007].

Electronic Health Records (EHRs)

Contrary to expectations, widespread use of EHRs does not seem to mitigate the limitations of dispersed chronic care [Clancy et al., 2009]. Built for intra-enterprise use, EHRs are unsuited to the delivery of inter-enterprise chronic care. Interoperable EHRs do enable inter-provider sharing of machine-readable HL7 continuity of care documents (CCDs) [Ferranti et al., 2006; Health Information Technology Standards Panel, 2010] during referrals and care transitions, if providers opt for more costly EHRs with interoperability capacity. However, even interoperable EHRs are insufficient for coordinating care across a patient's medical, dental, mental health, and social service and substance abuse providers. Providers who augment EHRs with disease registries certainly are better prepared for disease management within their practices. But these improvements do not benefit their patients' through cross-

provider and cross-condition care coordination [Metzger, 2004]. Even when equipped with interoperable EHRs and registries, such as those available in integrated delivery networks (IDNs), providers in independent practices cannot coordinate shared patients' care or achieve the cost effectiveness apparently characteristic of IDNs [Enthoven and Tollen, 2005].

Tethered Personal Health Records (PHRs)

PHRs are patients' electronic records of their own health information. The most prevalent type of PHR is a Web-based so-called patient portal that is tethered to a provider's EHR [Archer et al., 2011]. Patients with many EHR-equipped providers may have access to many tethered PHRs, generating many provider-to-patient and provider-to-provider information gaps. The utility of tethered and stand-alone PHRs is questionable for patients receiving dispersed care from multiple providers [Kim and Johnson, 2002; Reti et al., 2010]. Indeed, although approximately 86 percent of U.S. adults rate electronic access to tethered PHRs as important, only 9 percent use the Internet to access such PHRs [Wen et al., 2010].

Unbound Interoperable Personal Health Records (PHRs)

An interoperable PHR that is not bound to EHRs of providers or payers and can automatically consolidate data from all relevant repositories of patient data might remedy dispersed care [Kahn et al., 2009] and attract higher patient utilization rates than a PHR that is tethered to EHRs [Fricton and Davies, 2008]. Given widespread provider and patient use, an interoperable PHR has the potential to reduce U.S. health care spending by an estimated \$19 billion annually, compared to \$11 billion in savings for PHRs tethered to payer and third-party EHRs, and compared to \$29 billion in increased costs for PHRs tethered to provider EHRs [Kaelber and Pan, 2008]. Of course, only when providers have compelling economic reasons to use interoperable PHRs and encourage patient use will it be possible to determine the actual value of interoperable PHRs [Tang et al., 2006]. For highest perceived value to patients and providers, interoperable PHRs must be dynamically embedded in the chronic care clinical workflow rather than functioning as merely static data repositories [Greenhalgh et al., 2010]; even more secure, given multiple data feeds, than EHRs [Patel et al., 2011]; and, marketed aggressively to racial/ethnic minority patients with chronic conditions [Yamin et al., 2011].

Meaningful Use

The Health Information Technology for Economic and Clinical Health Act (HITECH) included in the American Recovery and Reinvestment Act of 2009 (ARRA) (Pub. L. 111-5) conditions \$17 billion in incentive payments to eligible Medicare and Medicaid professionals (EPs) and eligible hospitals on their meaningful use of certified EHR technology. From Stage 1 in 2011, to Stage 2 in 2013, and Stage 3 in 2015, the pool of meaningful use objectives will expand, and criteria for their successful achievement will increase. In July 2010, the Centers for Medicare and Medicaid Services (CMS) published a Final Rule for HITECH incentive payments to eligible providers and hospitals [Department of Health and Human Services, 2010]. In June 2011, the Office of the National Coordinator for Health Information Technology (ONC) published a Final Rule [Department of Health and Human Services, 2011a] specifying certification criteria for EHR technology that supports Stage 1 meaningful use by eligible professionals (EPs) and eligible hospitals and approved the American National Standards Institute (ANSI) to accredit certifying bodies under the Permanent Certification Program.

III. CONCEPTUAL BASIS FOR THE SMARTPHR PLATFORM

Raghupathi and Tan [2008] proposed a framework to identify HIT applications of high strategic value for improvements in U.S. health care quality and safety. Their framework, as Figure 1 shows, categorizes HIT applications on two dimensions: mediation (direct vs. indirect) and collaboration (insular vs. collaborative). An insular-indirect application is the least valuable meriting a value score of 1 and a collaborative-direct application, such as the interoperable SmartPHR platform, is the most strategically valuable, meriting a value score of 4. Christensen et al [2009] proposed, as Figure 2 illustrates, that an interoperable personal health record such as the SmartPHR platform represents a disruptive innovation of great strategic value because it can fill communication gaps between health care providers and encourage cross-provider care coordination for shared patients despite providers' reliance on low strategic value EHRs. Together, Raghupathi and Tan's HIT framework and Christensen et al.'s disruptive technology argument provide the underlying conceptual basis for the SmartPHR platform, which we discuss in this section of the article.

Indirect and Insular HIT Applications

Exemplifying indirect applications in the top row of Figure 1 is a practice management system that simplifies the administrative workload through sequential intermediate steps (e.g., capture patient demographics, schedule appointment, confirm benefits, generate clinical summary as attachment to claim, submit claims to insurance payer) that indirectly contribute to a clinical process (e.g., provider obtains medical history, examines patient, reviews lab

and imaging reports and diagnoses a condition). Indirect applications have low strategic value because they include bare minimum clinical data and offer no clinical decision support. Exemplifying insular applications in the top row of Figure 1 is a legacy EHR system that stores clinical data as scanned images or as unstructured text, obstructing the exchange of machine-readable structured data with other EHR systems. Insular applications have low strategic value because they cannot create the multi-source, auto-populated, comprehensive patient records that chronically ill patients, family caregivers, and organizationally unrelated clinicians need for continuous informed collaboration.

		DEGREE OF COLLABORATION	
		INSULAR	COLLABORATIVE
DEGREE OF MEDIATION	INDIRECT	<p>Standalone PHR Value Score=1</p> <ul style="list-style-type: none"> Sequential health data processing Mix of manual and paper-based records No mutual exchange HIT primarily for administrative functions Very limited interoperability 	<p>Tethered PHR Value Score=2</p> <ul style="list-style-type: none"> Sequential health data processing mostly Ad hoc applications One on one exchange of data with external entities HIT still primarily for administrative functions and basic storage High interoperability
	DIRECT	<p>Tethered PHR Value Score=3</p> <ul style="list-style-type: none"> Functions participate directly in health data processing Multi-capability applications Mutual exchange, limited internal Advanced HIT application Limited interoperability 	<p>Unbound Interoperable SmartPHR® Value Score=4</p> <ul style="list-style-type: none"> Functions participate directly in health data processing Multi-function application Mutual exchange, internal and external Advanced HIT applications Complete interoperability HIS, RHIN, NHIN

Figure 1. Role of the Unbound, Interoperable SmartPHR Platform in the Strategic HIT Framework [adapted from Raghupathi and Tan, 2008]

Strategic Value of Standalone PHRs

Standalone PHRs, which patients manually populate with information about their health history and status and maintain on portable storage devices and on websites, exemplify the insular, indirect HIT applications in the top left cell of Figure 1. Standalone PHRs have the least strategic value because patients rarely have sufficient knowledge for unassisted entry of comprehensive accurate data related, for example, to their drug allergies, medications, conditions, and family medical history; because some patients will not enter critical data about behavioral health conditions and medications and because providers have no reason to trust the data standalone PHRs contain. Patients who have conscientiously entered data in their standalone PHRs must still endure repetition of the same questions before and during each health care encounter. Therefore, we have assigned standalone PHRs a value score of 1 compared to PHRs in the three other cells of Figure 1.

Strategic Value of Tethered PHRs

PHRs, which are tethered to individual payers' EHRs and enable patients to view their explanations of benefits (EOBs) and access condition-specific self-management tools, exemplify the collaborative, indirect HIT applications in the top right cell of Figure 1. PHRs, which are tethered to individual providers' EHRs and enable patients to view their clinical summaries, describe chief complaints and complete intake questionnaires online, exemplify the insular, direct HIT applications in the bottom left cell of Figure 1. Both payer- and provider-tethered PHRs supply patients with information and tools that they would not get from standalone PHRs. Patients do receive paper EOBs but rarely get clinical summaries on paper and so we have assigned a value score of 2 to payer-tethered, collaborative-indirect PHRs and a value score of 3 to provider-tethered, insular-direct PHRs. Even provider-tethered PHRs lack strategic value for patients with one or more chronic conditions whose claims and clinical data reside in many payer and provider repositories.

Strategic Value of the Unbound, Interoperable SmartPHR Platform

Standalone and tethered PHRs, which are the only PHRs with marketplace visibility, still leave a critical gap in Raghupathi and Tan's framework. Neither of these conventional PHRs can satisfy the strategic need for a collaborative-direct HIT application described in the bottom right cell of Figure 1, meriting the highest value score of 4. A PHR that filled this HIT gap would reconcile the seemingly incompatible care-coordination needs of chronically ill patients and the regulatory-compliance needs of health care providers. As our assignment of value scores in

Figure 1 suggests, we hypothesize that the collaborative-direct SmartPHR platform will contribute the most to health care safety and quality, insular-indirect applications will contribute the least, and insular-direct and collaborative-indirect applications will make intermediate contributions. We consider research methods for testing this hypothesis in the concluding section of this article.

A Disruptive Technology Argument

Christensen et al. [2009, p. xx] viewed an interoperable PHR as a potential disruptive technology, simplifying problems “that previously required unstructured processes of intuitive experimentation to resolve.” This argument expands our understanding of the potential strategic value of the SmartPHR platform. Status quo fragmented health care involves only the isolated patients, providers, payers, enterprises, and data repositories at the bottom and top of Figure 2 and their insular, low strategic value HIT applications. Problems of mutual technological accommodation, patient privacy preferences, and care coordination workflow result in the delivery of uncoordinated, unsafe, ineffective, and wasteful services to shared patients. The multi-tier SmartPHR platform enforces patient-, role-, and policy-authorized user privileges when patients, providers, payers, and enterprises access, update, and exchange patient information with each other and with data repositories. Figure 2 shows the platform’s role in three simultaneous rights-managed scenarios involving patient to payer, provider to provider, and provider to repository information exchange, each of which augments the consolidated, multi-source, longitudinal data stored in one patient’s SmartPHR. The platform’s rights-managed Web access and Web services enable providers, payers, and enterprises to continue using their insular HIT applications without duplicative effort. The SmartPHR adds the benefits of streamlined access to a continuously updated comprehensive patient record for documented adherence to patient privacy preferences, public privacy policies, individual patients’ care plans, and generic meaningful use and quality reporting requirements.

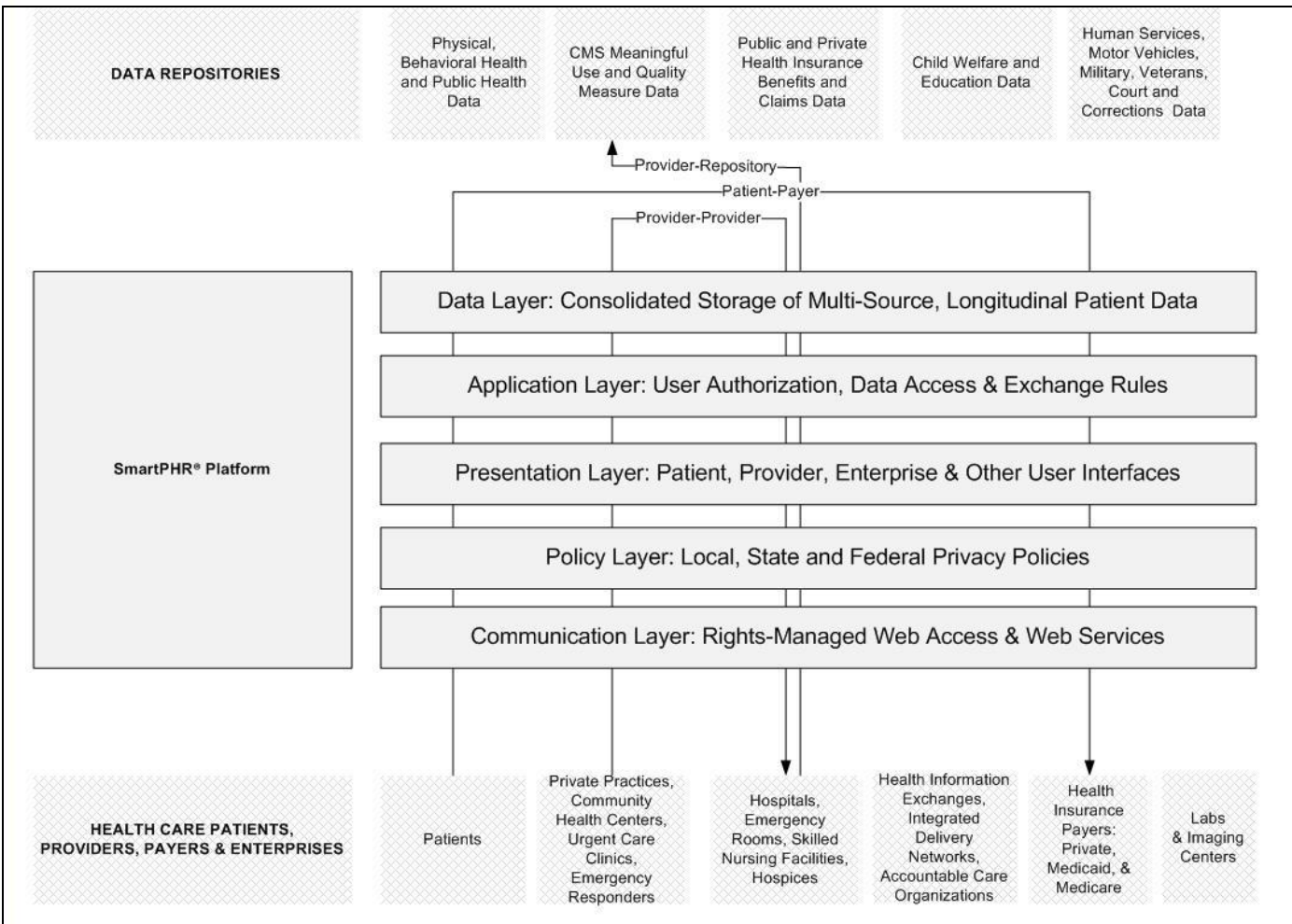


Figure 2. Role of the Unbound, Interoperable SmartPHR Platform as a Disruptive Innovation [adapted from Christensen, Grossman and Hwang, 2009]

The Mutual Accommodation Problem

Since 2004 when President Bush called for the widespread use of interoperable EHRs, efforts to agree upon uniform methods for exchange of machine-readable data between EHRs have encountered obstacles [Kuperman et al., 2010]. The U.S. Office of the National Coordinator of Health Information Technology (ONC) has sponsored competing Connect (connectopensource.org) and Direct (wiki.directproject.org) strategies for health information exchange across the Nationwide Health Information Network. Specialties from oral medicine [Schleyer et al., 2011] to oncology [Johnson et al., 2010] are adding to continuity of care data standards initially designed for patient transitions between primary-care physicians. Vendors are crafting EHRs to meet the practice requirements of specialists. As Christensen et al. pointed out, in this formative stage of interoperable HIT, health care enterprises act rationally when they resist mutual accommodation and acquire HIT applications that satisfy their own business requirements despite limited strategic value for inter-enterprise information exchange. The mutual accommodation problem, involving difficulties that local enterprises face in accommodating to each others' HIT practices, has threatened the survival of regional health information exchanges [Adler-Milstein and Bates, 2011] and limited the uptake of strategically valuable, interoperable EHRs [Ford et al., 2009]. The communication layer of the SmartPHR platform, with its rights-managed Web access and Web services, gives providers options for accessing their patients' SmartPHRs through the SmartEHR user interface, their native interoperable EHRs, or both. In this way, the platform requires no mutual technological accommodation from providers.

The Patient Privacy Preference Problem

EHRs that are certified consistent with the Stage 1 meaningful use criteria in Table 1, must be able to record demographics, maintain an up-to-date problem list, exchange clinical information, encrypt information during exchange, and account for disclosures under HIPAA [Department of Health and Human Services, 2011b]. Assuming that local health care enterprises are all equipped with certified interoperable EHRs, they might expect that during exchange of information about shared patients, their EHRs will minimize improper disclosures of patients' personally identifiable health information (PII and PHI) [McAllister et al., 2010] including diagnoses of chronic illnesses, substance abuse or mental health diagnoses in the problem list. However, certified EHRs cannot detect, and, therefore, cannot prevent, improper disclosures. Certified EHRs cannot recognize emerging and often conflicting local, state, and federal privacy policies that apply to particular patients or determine and enforce shifting patient privacy preferences that increasingly govern exchange of PII and PHI in public policies (e.g., Carli et al., 2011).

Disclosures of Patient Information

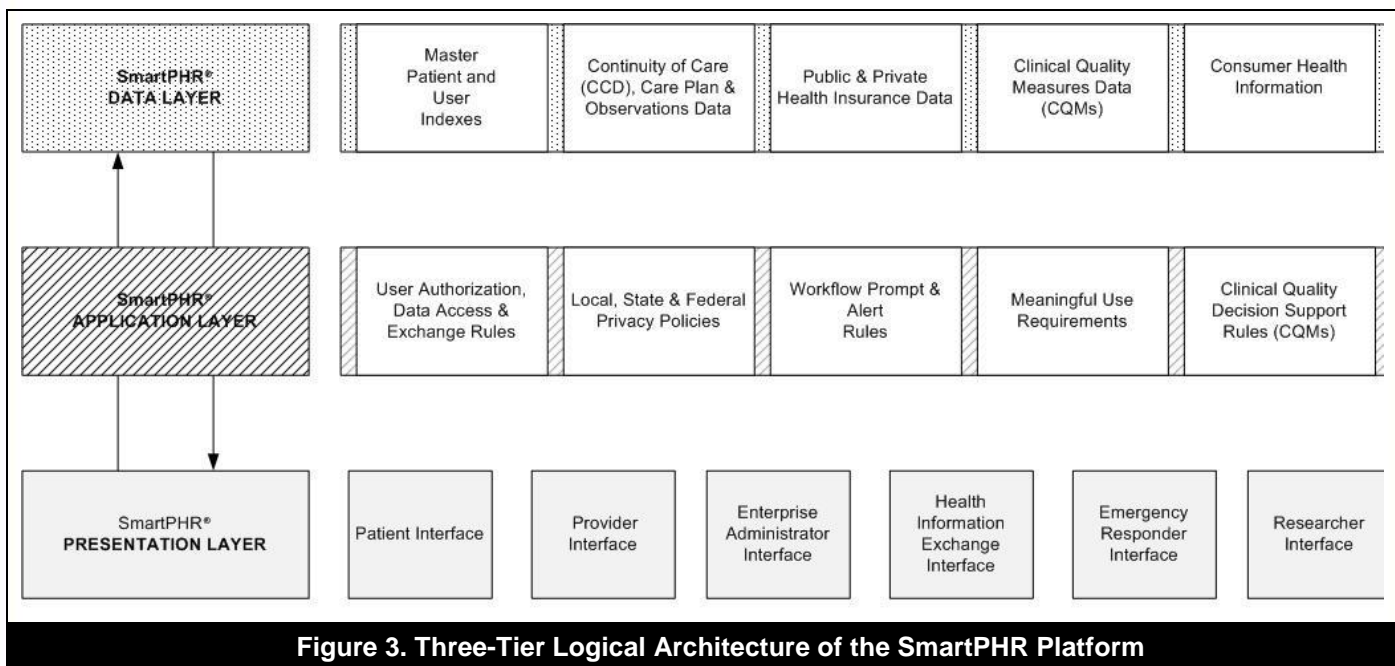
Providers using certified EHRs to exchange data for clinical purposes with business associates are no longer exempt from disclosure accounting requirements [DHHS, 2011]. As Christensen pointed out, regardless of legal disputes about who owns patient data, health care enterprises act rationally when they assume patients own the data in their records and have ultimate discretion about data access. The patient privacy problem, involving risks to enterprises from electronic information exchange for clinical purposes, may encourage just enough utilization of strategically valuable, interoperable EHRs to qualify for meaningful-use incentives, but not enough to increase health care quality, safety, and efficiency [Jones et al., 2010]. The application layer of the SmartPHR platform, with its establishment and enforcement of bottom-up patient-authorized user permissions for data access and exchange and of top-down role- and policy authorized user permissions, enables providers to document their adherence to patients' privacy preferences while accessing patients' comprehensive records, through native EHRs or the SmartEHR Web portal, as often as their clinical judgment dictates.

The Care Coordination Workflow Problem

McAllister et al. [2007] identified twenty-four medical-home, care-coordination workflow processes involving collaboration among patients, families, payers, providers, and community agencies via constantly updated written care plans. Health care enterprises with certified interoperable EHRs might expect their EHRs to simplify the medical-home, care-coordination workflow for patients receiving services from other enterprises in the region. However, certified EHRs lack capabilities, as we mentioned above, for solving mutual accommodation and patient privacy preference problems. Like their low-tech, EHR-deprived business associates, enterprises equipped with certified EHRs must pay for unsystematic, labor-intensive care coordination via telephone and fax that has, as the top left cell in Figure 1 shows, minimal strategic value. The costs of care coordination put providers (who are not reimbursed for care coordination) and patients (who can turn only to providers for care coordination) at odds. The presentation, application, and data layers of the SmartPHR platform detailed in Figure 3 enable providers to receive patient-specific workflow prompts and alerts through native EHRs or the SmartEHR user interface; to conduct patient encounters consistent while simultaneously documenting adherence to meaningful-use, clinical quality decision support and health insurance payment criteria; and to supply updated care plans to patients and patients' other providers with minimal administrative expense.

IV. SMARTPHR PLATFORM DESCRIPTION

The SmartPHR platform, written in Java and centrally hosted in the [Internet cloud](#), is offered in Software as a Service (SaaS) mode. The platform exchanges structured data with EHRs and other information systems via Web services using [Extensible Markup Language](#) (XML) messages that follow the [SOAP](#) standard. The platform supports multiple SmartPHR accounts, each of which includes health and other data of an individual who is the account owner. The platform strictly enforces the privacy preferences of account owners. Regardless of who pays for a SmartPHR subscription, the individual (patient, beneficiary, or consumer) whose data are stored in a SmartPHR account is considered the owner of those data and has invariable default rights, including the right to appoint another individual as account administrator; to access electronically all the data stored in his or her accounts anytime, anywhere; to grant, audit, modify, and terminate data-specific and function-specific user privileges (patient authorization); to approve or reject user privileges for unfamiliar individuals recommended by users the patient has authorized, such as primary-care physicians (role authorization); and, to request permanent deletion of his or her data from the platform. Consumers may purchase SmartPHR subscriptions for themselves or their family members including access through the patient interface. Health care providers, payers, health plans, employers, and regional health information exchanges may purchase SmartPHR subscriptions and distribute them to patients, beneficiaries, or employees. SmartPHR subscription packages include patient- and role-authorized access to patient data through patient, provider, enterprise, and researcher interfaces and through Web services that exchange information with native EHRs and other information systems.



Three-Tier Architecture

The three-tier logical or conceptual architecture of the SmartPHR platform, as Figure 3 shows, includes an encrypted presentation layer, an encrypted application layer, and an encrypted data layer. The rules and policies in the application layer not only separate users' views of the database in the presentation layer from the physical representation of the database in the data layer, they also govern what the presentation layer allows users to see and do. As the arrows in Figure 3 indicate, the only path to a patient's SmartPHR is through the rules and policies in the application layer, either from a user interface or from Web services communicating with users' native EHRs. Rules for patient- and role-authorization of individual users to access and exchange information in specific patients' SmartPHRs supersede all other criteria in the application layer. Interfaces in the presentation layer include tools useful to patient- and role-authorized users in the authorization, auditing and revision of user permissions, and information disclosures. The patient interface illustrated in Figure 4 enables a patient or patient-authorized account administrator to grant, audit, change, and withdraw content- and function-specific privileges for identified individuals, such as friends and family, and for identified providers. The provider interface illustrated in Figure 5 enables a patient-authorized primary-care provider to grant a consultant role-based and time-limited permissions to view and update the patient's SmartPHR care plan. The enterprise interface in Figure 6 enables a patient-authorized health care business, such as a health care practice, community-health center, or accountable-care organization, to authorize role-based permissions for enterprise-affiliated providers on patients' SmartPHRs consistent with patient-authorized permissions.

Data Layer

The data layer of the SmartPHR platform in Figure 3 comprises logical data schemes, which govern the physical representation of data in the platform's relational database tables. Each data scheme anticipates permanent storage and future reuse of patient data and structure such data consistent with applicable industry standards. When more than one standard applies (e.g., ICD9, ICD10, and SNOMED CT for clinical terminology), the data scheme anticipates mapping and conversion needs. To keep pace with new developments in health care, the data layer can accommodate additional data schemes. Independence of the data layer from the application and presentation layers facilitates updates to data schemes without ill effects for business logic or user interfaces. Independence of data schemes simplifies updates to a particular scheme and to related database tables as, for example, when the National Library of Medicine updates its consumer health information.

The Master User Index

Of all data schemes, the most important is the master user index, which references identifiers for all authorized platform users, the past and current patient- and role-authorized permissions of all users, their histories of platform usage, and their current requirements and preferences. The master user index data scheme supplies the criteria for user authorization, data access, and exchange rules in the application layer, governing the access of all users, including patients, providers, and providers' business associates, to data and functionality. Together, the master user index in the data layer and the user rules in the application layer enable providers, consistent with their permissions, to search, find, and access individual patients' accounts and to view aggregate-identified or aggregate-de-identified reports about groups of patients. The master user index in combination with other data schemes in the data layer, such as patient-specific care plans and observations, supply the criteria for workflow prompt and alert rules in the application layer. This means, for example, that patients can be prompted to implement procedures that providers have recommended in their care plans by a certain date, and providers can be alerted when they do not receive reports about recommended procedures by that date.

The Continuity of Care (CCD) Data Scheme

Primary-care physicians have long advocated electronic methods of coordinating patient care [Starfield et al., 1977]. Their efforts led to the continuity of care data categories in the ASTM CCR, the larger list of data categories in the HL7 CCD, and the all-inclusive list of data categories in the HITSP C83 CDA [Ferranti et al., 2006; Health Information Technology Standards Panel, 2010]. Resulting structured data reference the patient's personal information, health insurance coverage, healthcare providers, problems (diagnoses, conditions), advance directives, allergies, medications, immunizations, and lab results, while the plan of care category is a largely unstructured place marker for physician-dictated encounter notes and the subject of several public-private standardization efforts. The CCD data scheme in the SmartPHR data layer includes all the above structured data categories. The user interfaces in the presentation layer filter CCD data consistent with patient- and role-authorized permissions, protecting sensitive substance abuse and mental health information from improper disclosure as the public privacy policy rules in the application layer require. As a result, users without permission to view mental-health data will see no mental-health diagnoses in patients' problem lists.

The Care Plan Data Scheme

The plan of care data category in the HITSP C83 CDA, as mentioned above, is unstructured and rarely used, due to a lack of agreement about care plan structure and content between and among different medical and behavioral health care specialties [Ennis et al. 2011; Hahn and Ganz, 2011]. The resulting gap requires a structured care plan that enables any health care provider to recommend evidence-based interventions (related to prevention of future problems and treatment of current problems) and intervention-related observations (for collection by patients, caregivers, and remote monitoring devices). For this reason, the SmartPHR data layer includes a care plan data scheme that works with the provider interface to structure recommendations of interventions and observations related to problem lists (e.g., diet and exercise for an obese patient with diabetes) and to structure recommendations of daily quantitative observations. The care plan data scheme works with the patient interface prompting patients to enter provider-recommended observations into their SmartPHR accounts from mobile devices (e.g., weight) or to upload observation data from remote monitoring devices (e.g., blood glucose). From patient and provider interfaces, consistent with their privileges, users can view chronological care plan summaries of provider recommendations for interventions and observations and timelines showing provider recommendations and related patient- and device-collected observations.

The Clinical Quality Measure (CQM) Data Scheme

The Department of Health and Human Services requested that the National Quality Forum (NQF) (http://www.qualityforum.org/Projects/e-g/eMeasures/Electronic_Quality_Measures.aspx) convert 113 NQF-endorsed quality measures from a paper-based format to an electronic format. In July, 2010, forty-four of these

measures were referenced in the Centers for Medicare and Medicaid Services' Electronic Health Record Incentive Program Final Rule (http://www.cms.gov/QualityMeasures/03_ElectronicSpecifications.asp). By 2012, certified EHRs must support electronic reporting of these forty-four CQMs. One of the twenty-five Stage 1 meaningful use (MU) requirements is to report CQMs to CMS. Providers must employ certified EHRs to report numerators and denominators across all applicable patients for three of six core CQMs (e.g., blood pressure, smoking, weight), and for three of thirty-eight provider-selected chronic illness CQMs (e.g., hemoglobin A1c, lipid panel). Each CQM is the basis for a provider-recommended intervention related, for example, to high blood pressure, daily smoking, or overweight. The SmartPHR data layer includes a CQM data scheme that works with the provider interface, the care plan data scheme, and the workflow business logic to prompt recommendations of interventions related to CQM scores and problem lists (e.g., diet and exercise for an obese patient with diabetes) and of associated observations (e.g., duration of daily exercise). These prompts support MU requirements for CQM reporting and clinical decision support.

Application Layer

The application layer of the SmartPHR platform in Figure 3 comprises business logic schemes, the functional algorithms that handle information exchange between the platform's data and presentation layers. To keep pace with new developments in health care, the application layer can accommodate additional business logic schemes. Independence of the application layer from the data and presentation layers facilitates updates to business logic schemes without ill effects for data schemes or user interfaces. Independence of business logic schemes simplifies updates to a particular scheme and to related algorithms as, for example, when CMS introduces Stage 2 meaningful use requirements.

Business Logic

For end user authorization, data access, and exchange rules, the business logic enforces permissions so users can access data in the data layer through interfaces in the presentation layer. User-specific permissions include viewing, updating, annotating, archiving, de-identifying and aggregating particular patient data content (e.g., medical, substance abuse, and mental health), receiving alerts contingent upon data values, and exchanging data via Web services with EHRs. For public privacy policies, the business logic enables an administrator, via the enterprise interface, to associate a particular policy set (e.g., applying to information exchange in the State of Virginia) with the permissions of relevant patient- and role-authorized users (e.g., health care providers who practice in the State of Virginia or who practice in bordering states and refer patients to Virginia providers). As a result, a health care provider who practices in the State of Virginia without state-approved substance-abuse credentials would see an edited version of the patient's care plan, excluding the patient's alcohol and cocaine abuse diagnoses.

Meaningful Use (MU) Business Logic

For providers who qualify as eligible professionals (EPs) to receive federal Medicare incentives, the website of the CMS EHR incentive program (<http://www.cms.gov/ehrincentiveprograms/>) lists twenty-five MU Stage 1 requirements (e.g., use computerized order entry [CPOE], report clinical quality measures [CQMs] to CMS or state Medicaid, provide patients with an electronic copy of their health information) and supplies a detailed protocol for each MU requirement. The MU business logic scheme creates relationships with all the other business logic schemes in the application layer and with all the data schemes in the data layer. As a result, the provider interface, illustrated in Figure 5, prompts and alerts providers about the use case for each MU requirement as needed for incentive payments from CMS and state Medicaid.

Presentation Layer

The presentation layer, as Figure 3 shows, comprises seven user interfaces (on display at www.thesmartphr.com) that enable diverse health care stakeholders, consistent with their patient- and role-authorized permissions, to view, update, exchange, and aggregate patients' most recently updated continuity of care, CCD data sets. All interfaces offer users access to the same CCD data set for a particular patient; each interface offers tools for operating on CCD data that are relevant to a user subgroup's normative workflow processes. A patient and her many providers see the same set of CCD data, but with different tools. The patient interface in Figure 4 includes context-specific consumer health information from the National Library of Medicine (<http://www.nlm.nih.gov/medlineplus/>) such as a plain language explanation of an ICD9 diagnosis in the patient's problem list. The provider interface in Figure 5 includes context-specific prompts for fulfillment of meaningful-use requirements, such as a reminder to update the patient's problem list of current and active diagnoses. The enterprise administrator interface in Figure 6 includes tools for monitoring patients with particular diagnoses consistent with patient-centered medical home objectives [Stevens et al., 2011].

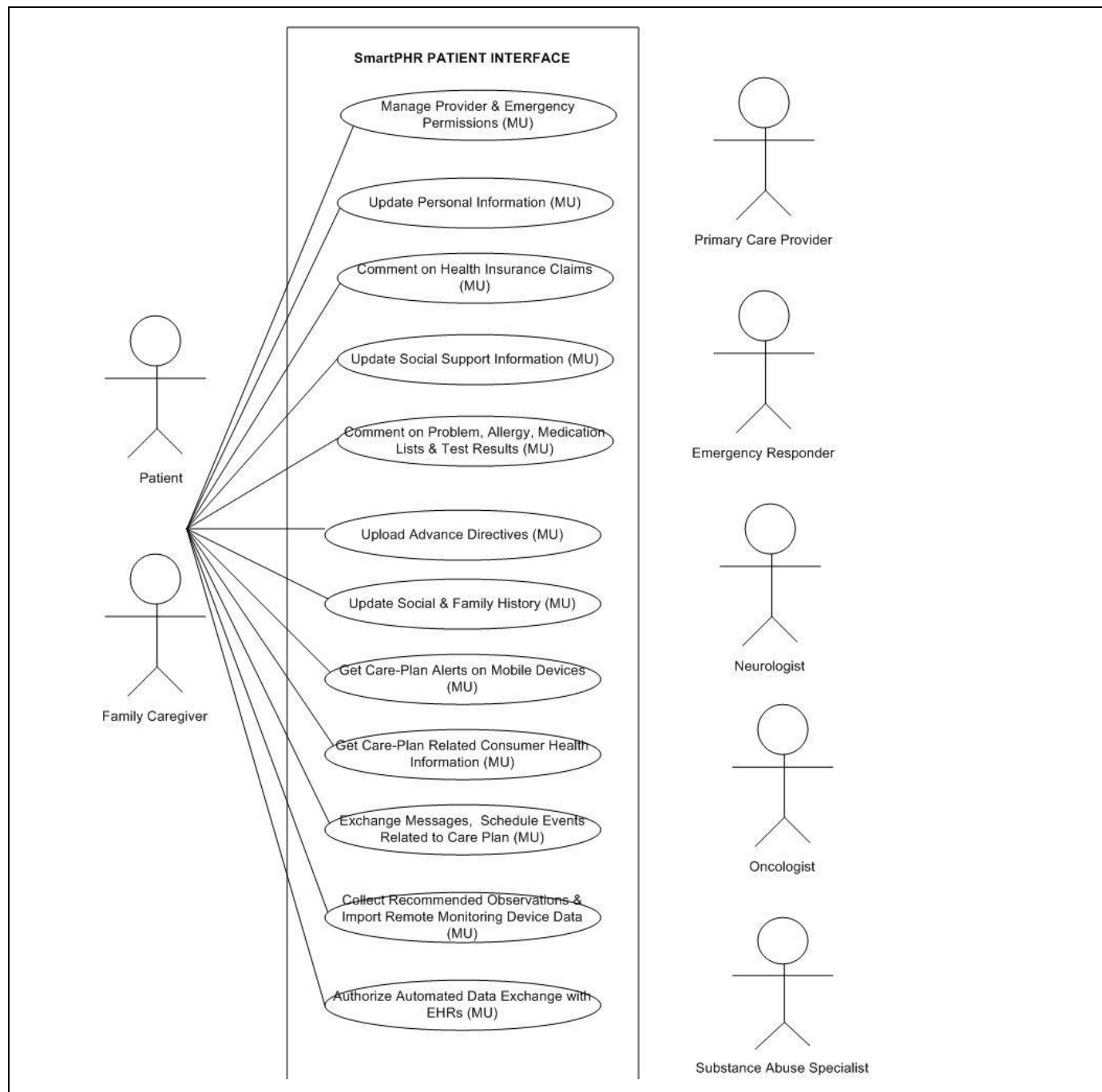


Figure 4. Patient Use Cases in Relationship to Meaningful Use (MU) Requirements

Use Case Diagrams

The use case diagrams in Figures 4, 5, and 6, following caBIG® life sciences business architecture modeling methods [Boyd et al., 2011], depict how patients, health care providers, and enterprise administrators interact with the SmartPHR platform through user interfaces to achieve their high-level goals. For example, a patient use case in Figure 4 involves viewing latest care plan recommendations for interventions and observations. A provider use case in Figure 5 involves updating patient care plans with recommended interventions and observations. And an enterprise administrator (or care coordinator) use case in Figure 6 involves monitoring progress with care plan recommendations. Indicating the number of goals of health care stakeholders, there are twelve patient use cases in Figure 4, twenty-seven provider use cases in Figure 5 and twenty-five enterprise administrator use cases in Figure 6. Indicating the complexity of these goals, the provider use cases in Figure 5 includes one use case related to HIPAA, twenty-one use cases related to meaningful use, and five use cases related to a provider’s business relationships with patients, colleagues and regional provider organizations. Indicating the partial overlap between the goals of different users, five of twelve patient use cases and twenty-one of twenty-seven provider use cases and

fourteen of twenty-five administrator use cases concern meaningful use (MU) requirements. For the sake of brevity, we have not included use case diagrams related to interaction with the SmartPHR platform through the platform's health information exchange, emergency responder, and researcher interfaces.

V. CONCLUSIONS: RIGHTS-MANAGED CARE COORDINATION

Taken together, Raghupathi and Tan's framework and Christensen et al.'s disruptive technology argument point to gaps in rights-managed care coordination that conventional HIT does not fill. The SmartPHR platform's conceptual basis derives from filling these gaps, empowering health care stakeholders to contend with fragmented, unsafe, and inefficient health care processes. In a rights-managed care coordination process that transcends the boundaries of health care roles, organizations, and disciplines, stakeholders comply with patients' privacy preferences and public policy, working toward their own goals while contributing to shared patients' care. The SmartPHR platform offers information capabilities relevant to stakeholders' diverse use cases, business actors, and external information systems. At the same time, the platform facilitates rights-managed care coordination by automatically updating SmartPHR care plans, summarizing recommendations of a patient's many providers for interventions and observations and displaying unified timelines of provider recommended interventions and of patient- and device-collected observations. Consistent with their permissions, patients, providers, and other users view the same up-to-date and comprehensive patient-specific care plans, so that everyone is literally "on the same page" without having to accommodate to other users' technological capabilities, practice workflows, or business models.

Hypothesis Testing

We hypothesize that the SmartPHR platform, by engaging patients, providers, and other users in rights-managed care coordination, improves the safety, quality and efficiency of patient outcomes better than certified EHRs alone or in combination with tethered PHRs. A test of this hypothesis requires systematic research that incorporates computer science and behavioral science methods. We envision a research agenda that sequentially evaluates the platform's technical performance, perceived usability and utility, actual usage and value to stakeholders. In this iterative research agenda, failure at one task requires platform refinement followed by task repetition.

Observational Research

We expect early stages of research to observe how users interact with the platform. The first and ongoing research task involves evaluations of the platform's technical performance against National Institute of Standards and Technology (NIST) certification procedures for current Stage 1 and future Stages 2 and 3 meaningful use criteria. The second research task involves evaluations of the installed platform's actual rates of usage by patients and providers and correlation of usage rates with perceived usability and utility. Controlling for patients' and providers' characteristics (e.g., disease status, age, computer literacy), perceived usability and utility should significantly predict usage rates. The third research task involves evaluations of the installed platform's engagement of patients and providers in rights-managed care coordination (e.g., How often do providers update or annotate recommendations in patients' cross-provider care plans; how often do patients collect provider-recommended observations?). Controlling for patient and provider characteristics, engagement in care coordination should significantly predict satisfaction with the quality of care and the protection of patient privacy. The fourth research task involves evaluations of patient outcomes and correlation with engagement in care coordination. Holding all else constant, patients who are highly engaged in care coordination and whose providers are also highly engaged, should receive more cost-effective care than less-engaged patients with less-engaged providers as indexed by Quality Adjusted Life Years (QALYs) (e.g., Glazener et al., 2011).

Experimental Research

Ideally, later stages of research will involve randomized clinical trials that compare the PHR platform to certified EHRs alone and in combination with tethered PHRs, employ latent growth modeling techniques to understand longitudinal effects [Serva et al., 2011], and search for unintended adverse consequences [Medaglia and Andersen, 2010]. Compared to certified EHRs, alone and in combination with tethered PHRs, the PHR platform condition should yield greater patient and provider engagement in rights-managed care coordination and, indexed by QALYs, more cost-effective care. Such findings would help disprove the null hypothesis, which contends that the PHR platform is no more valuable than alternative health information systems. Replicated over time and across installations, such findings would strengthen the empirical basis for health care reform policies.



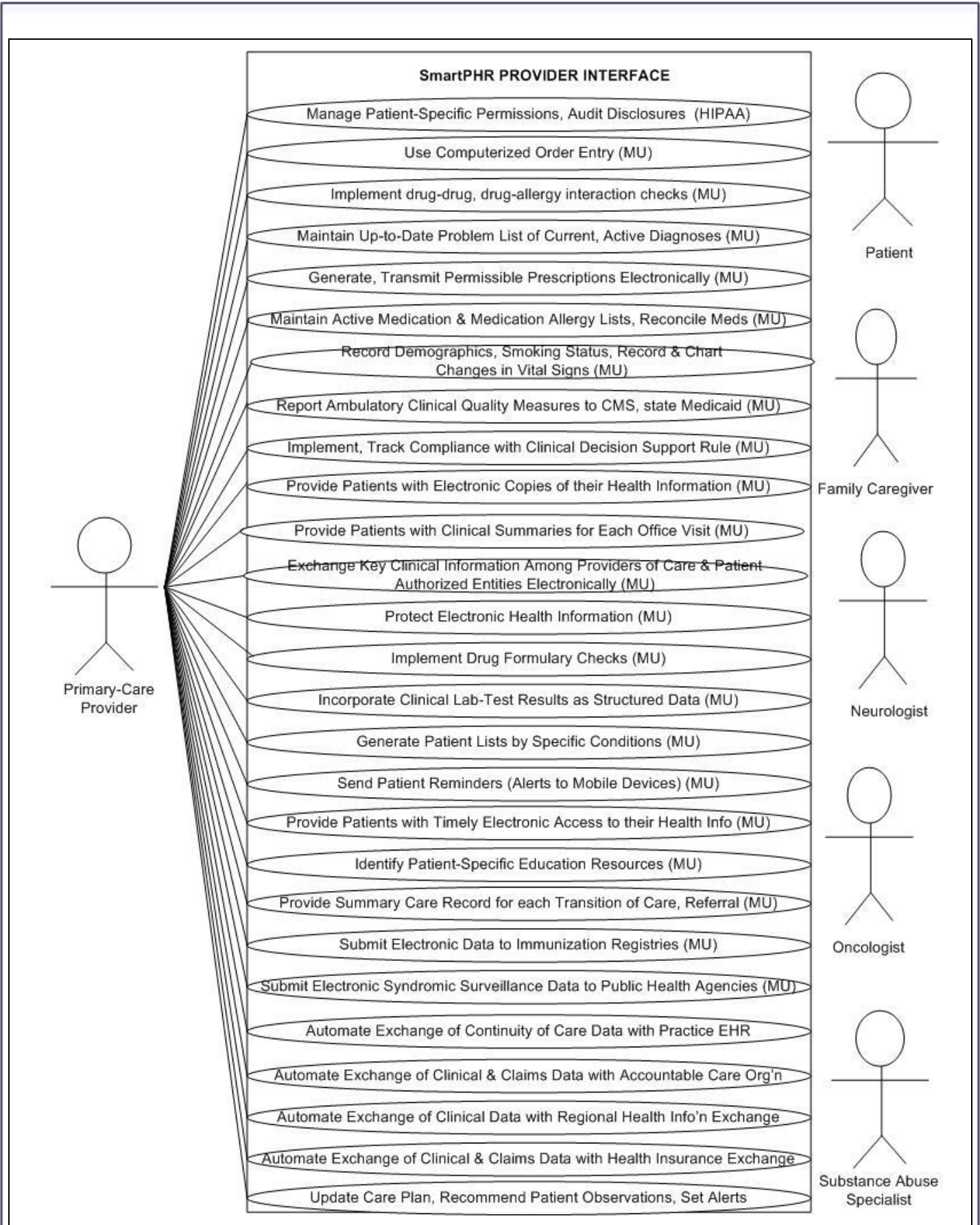


Figure 5. Provider Use Cases in Relationship to Meaningful Use (MU) Requirements

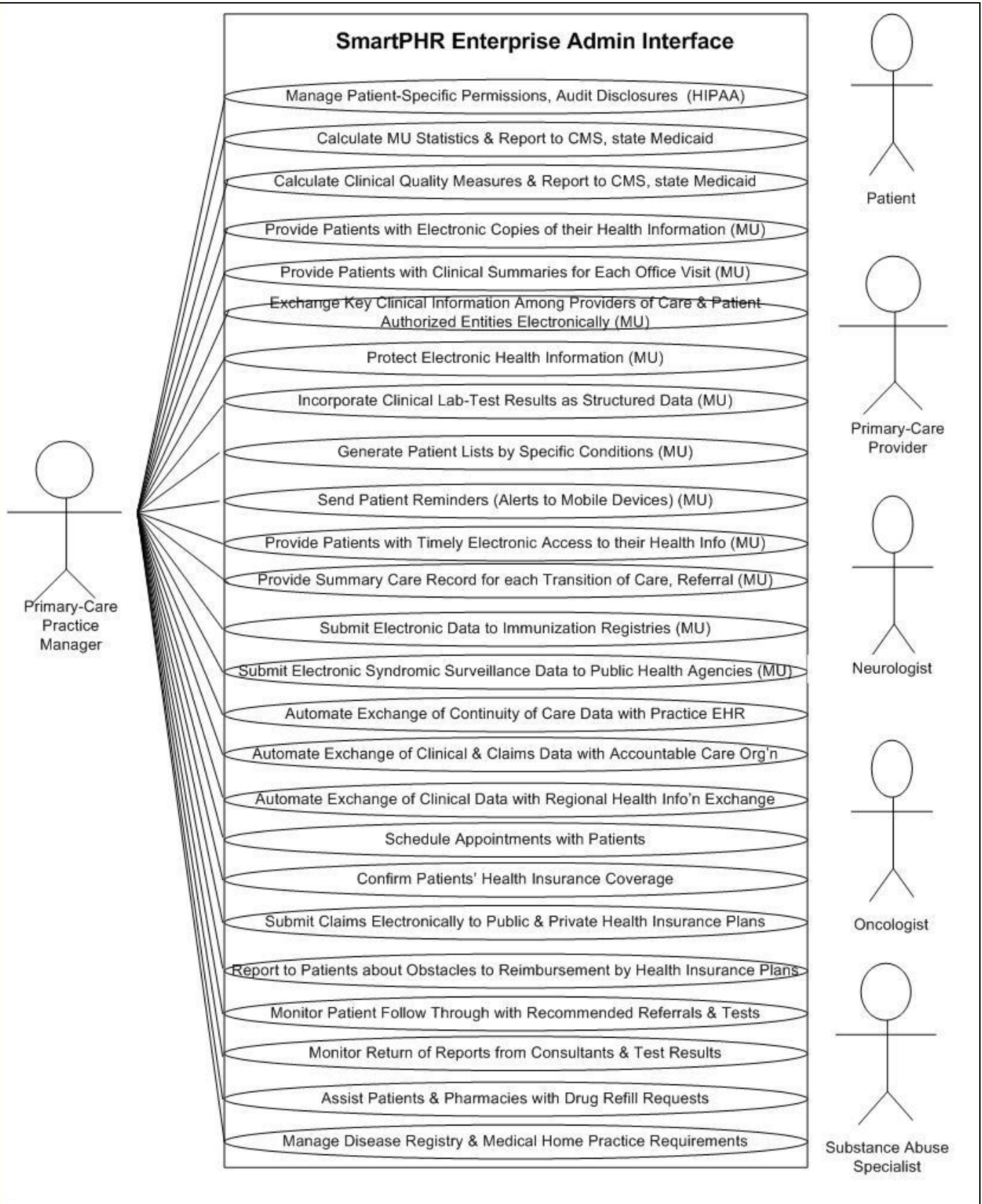


Figure 6. Enterprise Administrator Use Cases in Relationship Meaningful Use (MU) Requirements

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