U.S. Department of Health and Human Services
Office of the National Coordinator for Health Information Technology

Consumer Empowerment:
Consumer Access to Clinical Information
Detailed Use Case

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Table of Contents

List of Figures

1.-1 Introduction

1.1 Use Case Description

Enhancing a consumer's ability to make well informed decisions about their healthcare and healthy lifestyles can be supported by the consumer having access to their health information. Consumers may also want to have the ability to make their information available to their healthcare providers in ways which respects the consumer's needs for privacy and confidentiality. A secure Personal Health Record (PHR) has the potential to become a key enabler for the consumer to gather and share this information with adequate safeguards.

In March 2006, the Office of the National Coordinator for Health Information Technology (ONC) published a Harmonized Use Case for Consumer Empowerment (Registration and Medication History.) In January 2007, the American Health Information Community (AHIC) approved a recommendation to extend the use case to include consumer access to additional types of clinical information as well as to address aspects related to privacy and access controls. The recommendations discussed the following AHIC prioritized needs:

- Lab results as needed by the patient: Ability for the consumer to retrieve, store, graph and share laboratory test results;
- Lists of conditions and allergies, including:
    - Health problems: Ability for consumer to retrieve and store lists of current and previous health conditions;
    - Medication allergies: Ability for consumer to retrieve and store lists of current medication allergies; and
    - Allergies: Ability for consumer to retrieve and store lists of current environment, dietary or medical supply allergies.
- Diagnosis codes: Ability for a consumer to retrieve and store a list of diagnosis codes;
- The ability to access results, conditions, allergies, and diagnosis codes in layperson terms;
- PHR portability: Ability for a consumer to move their information between PHRs;
- Privacy and access control: Ability for a consumer to identify those providers which are permitted to access information in the consumers' PHR, and which of those data they are permitted to access. Ability to communicate the consumer's decisions to other entities which also hold data about the consumer;

- Audit and logging exchange: Ability for a consumer to request, consolidate, and access audit log information from multiple sources to create logical views of access to their information;

- Vocabulary for role-based access control: Ability to describe a consumer's access decisions using information which can be communicated among systems involved in information exchange; and

- Provider lists: Ability to identify and maintain a list of all providers involved in the care of a specific patient. Ability to use the provider list to communicate information about patient to all or selected providers. Ability to forward the list of providers to another provider or entity.

This use case is being developed by ONC to represent these AHIC priorities, with opportunities for review and feedback by interested stakeholders within both the public and private sectors. To facilitate this process, the use case is being developed in two stages:

- The **Prototype Use Case,** which describes the flows of the use case at a high level and facilitates initial discussion with stakeholders; and

- The **Detailed Use Case**, which documents all of the events and actions within the use case at a detailed level.

This document is the Detailed Use Case.

1.2 Scope of the Use Case

This use case describes at a high level specific capabilities that would enable consumers to access their clinical information via their PHR. PHR concepts, capabilities and expectations are evolving rapidly as consumers gain experience with PHRs. A number of business and technology models have emerged to provide PHR capabilities to the consumer including:

- Web-based solutions provided by, commercial vendors, payors, providers, HIEs, etc.;

- Desk-top solutions with or without networking capabilities; and

- PHR solutions where the data is integrated with EHR systems or HIE-provided systems.

PHR capabilities needed by the consumer could include:

- Data storage and stewardship – storing, protecting, securing and controlling access to the consumers' PHR information;

- Ability to participate in information exchange activities with providers and others – retrieving and providing access to the consumer's health information to those individuals and organizations designated by the consumer;
- Ability to define and manage the consumer's decisions about who can access their PHR information; and
- Ability to manage their information over time.

The use case includes three scenarios which describe highlights of the processes, roles and information exchanges which could enable a consumer's access to clinical information via a PHR. The three scenarios are:

- Consumers receive and access clinical information;
- Consumers create provider lists and establish provider access permissions; and
- Consumers transfer PHR information.

While out of scope for this particular use case, capabilities for a consumer to self-report information about medications and allergies to providers is included in the 2007 Medication Management Use Case. The ability for a consumer to provide interoperable registration information and assign permissions to consumers who are not the direct recipients of care i.e. – family members, caregivers, etc. was addressed by the Harmonized Use Case for Consumer Empowerment (Registration and Medication History).

This use case does not attempt to describe in detail all steps in this process nor all the roles and functions that are present during this complete cycle. Rather, the intent is to focus on the interoperability and information flows that would provide access to additional clinical information in a secure manner while respecting the consumer's need for privacy and security.

This use case assumes the presence of electronic systems such as EHRs, PHRs, etc. The use case recognizes the issues and obstacles associated with these assumptions. This approach promotes the development of longer-term efforts.

This use case focuses on the exchange of information between organizations and systems rather than the internal activities of a particular organization or system. However, certain internal processes have been included in order to provide a context for the information exchange needs.

2.0 Use Case Stakeholders

Figure 2-1. Consumer Access to Clinical Information Use Case Stakeholders Table

Stakeholder	Working Definition
Ancillary Entities	Organizations that perform auxiliary roles in delivering healthcare services. They may include diagnostic and support services such as laboratories, imaging and radiology services, and pharmacies that support the delivery of healthcare services. These services may be delivered through hospitals or through free-standing entities.
Consumers	Members of the public who may receive healthcare services. They may have one or more PHRs which may be used to access and maintain information about their personal health. These individuals may include: caregivers, patient advocates, surrogates, family members, and other parties who may be acting for, or in support of, a patient in the activities of receiving healthcare and/or using a PHR.
Health Information Exchange (HIE)	A multi-stakeholder entity that enables the movement of health-related data within state, regional, or non-jurisdictional participant groups.
Health Information Management Professionals (HIM)	Personnel who manage healthcare data and information resources, encompassing services in planning, collecting, aggregating, analyzing, and disseminating individual patient and aggregate clinical data.
Health Information Service Provider (HSP)	Companies or other organizations that support health information exchange activities by providing participants with operational and/or technical health exchange services.
Health Record Banks	Entities/mechanisms for holding an individual's lifetime health records, which now may reside in dozens of hospitals, doctors' offices, clinics, etc. They would be released to other doctors and hospitals with the patients' consent.
Healthcare Entities	Organizations that are engaged in or support the delivery of healthcare. These organizations could include hospitals, ambulatory clinics, long term care facilities, community-based healthcare organizations, employers/occupational health, school health, psychology, dental clinics, care delivery organizations, and other healthcare facilities.
Healthcare Payors	Insurers, including health plans, self-insured employer plans, and third party administrators, providing healthcare benefits to enrolled members and reimbursing provider organizations. As part of this role, they provide information on eligibility and coverage for individual consumers, as well as claims-based information on consumer medication history. Case management or disease management may also be supported.
Personal Health Record Service Providers	Organizations which assist in providing PHR capabilities to consumers. These capabilities may include providing services using information which is gathered/ stored from a separate organization. Organizations that provide these capabilities may include: vendors, healthcare providers, health data banks, healthcare payors, etc.
Personal Health Record System Developers	Organizations which provide specific PHR solutions to consumers such as applications, data repositories, web services, etc.
Pharmacy Benefit Managers (PBM)	These entities manage pharmacy benefits on behalf of payors, interacting with pharmacies and providers via a medication network intermediary. As part of this role, they can provide information on pharmacy benefits available to an individual consumer and an individual consumer's medication history.

Stakeholder	Working Definition
Providers	Clinicians within healthcare delivery organizations, or the organizations themselves, with patient interaction in the delivery of care including physicians, nurses, and other clinicians. Can also refer to healthcare delivery organizations.
Public Health Agencies (local/state/federal)	Local, state, and federal government organizations and personnel that exist to help protect and improve the health of their respective constituents.
Registries	Organized systems for the collection, storage, retrieval, analysis, and dissemination of information on individual persons to support health needs. May include emergency contact information/ next-of-kin registries, etc.

3.0 Issues and Obstacles

Realizing the full benefits of health information technology capabilities mentioned above is dependent on overcoming a number of issues and obstacles in today's environment. Inherent in this use case is the premise that some of these, like data normalization, will be addressed through health information technology standardization and harmonization activities, policy development, health information exchange networks and other related initiatives.

Confidentiality, Privacy, Security, and Data Access

Confidentiality, privacy, and security. Consumers may be reluctant to make information in their PHR accessible to others unless they have adequate assurance that their concerns about confidentiality, privacy and security have been addressed. There must be ways to ensure that the information transmitted is reliable, accurate, secure, representative of the appropriate consumer, and is transmitted to the appropriate recipients. Providing adequate safeguards to protect the data during information exchange activities is another dimension of this need.

Access controls. Mechanisms for consumers to control who can access their PHR, what parts they can access and when, are key dimensions of confidentiality, privacy and security. Interoperable safeguards for the protection of information during data exchange are also needed. In certain situations, clinicians involved in the care of the consumer may also need to have the capability to "break the glass" in order to gain access to information which has immediate relevance to the clinician's decisions about the care needed during necessary situations. When the glass is broken the consistent recording of appropriately defined reasons for access may also be required.

Along with allowing consumers to control who can access their PHR information the consumer may also be able to control what specific information can be accessed. This blocking capability presents challenges in regards to consumer education, provider usage, etc.

Access and disclosure logs. The ability to create an integrated view of who has accessed the consumer's information across multiple markets and timeframes may be challenging without standards for access-related information and for exchanging this information among networks. In order to create access and disclosure logs for consumers to review, mechanisms need to be available which can create, manipulate, and condense access logs which collect information across multiple organizations, geographic regions, or health information exchanges.

Furthermore all confidentiality, privacy, security, data access, disclosure, etc. functions and processes must comply with all applicable state and federal regulations.

Policies for Consumer's Ability to Control Information

Consumers may need the ability to modify, annotate, and/or request changes to the health information which they retrieve from other sources. Policies must be developed to guide decisions about which data the consumer should be able to modify. Likewise, there may be situations in which the consumer wishes to annotate information without changing the received data. Providers may need to know how to identify information in a PHR which has been entered, blocked or changed by consumers.

Translation of Medical Terminology into Layperson Terms

Information retrieved by consumers from other sources may be described in the medical terminology of clinicians, rather than in terms which the consumer can readily understand. There may be a need for the ability to also offer information in layperson's terms, while still preserving the original form of the medical information. Mechanisms to accomplish translation would be highly dependent on the initial use of standardized terminologies for medical content.

Limited Integration of PHRs with Provider Workflows

In order for care providers to readily retrieve information available in a consumer's PHR, there may need to be some level of integration with provider workflow. Barriers to accomplishing this integration today include the lack of EHR penetration into the provider's care settings, as well as, the lack of available interoperable PHR solutions which could exchange the data electronically. Furthermore, providers must be assured that information received via the PHR and other sources is valid, reliable, and accurate.

State Laws Regarding Laboratory Results

State laws would need to be analyzed and potentially altered in order to enable timely access to laboratory test results which may require clinician interpretation. Others also suggest that there may be a need to physicians to have the ability to interpret, review, and/or have a set period of time between the receipt of lab results and having them reviewable by the consumer. The need for physician interpretation and/or having a set time prior to consumer review may also apply to other types of results.

4.0 Use Case Perspectives

The Consumer Access to Clinical Information Use Case focuses on communicating the consumer's health information to support interactions among consumers, providers and others who are involved in the consumer's care. The perspectives portrayed are role-based and functional in nature, and are not indicative of physical location. Within the scope of the use case the following perspectives have been defined:

- ***Consumer***

  The consumer perspective includes those who may receive healthcare services and have one or more PHRs which may be used to access and maintain their health information. This perspective also includes: caregivers, patient advocates, surrogates, family members, and other parties who may be acting for, or in support of, a patient in the activities of receiving healthcare and/or using a PHR.

- ***Provider***

  The health care provider perspective includes physicians, nurses and other clinicians, who may need access to clinical information from other sources including the consumer's PHR.

These perspectives are the focus of the events described in the following scenarios.

5.0 Use Case Scenarios

Three scenarios are included in the use case in order to illustrate the need for specific types of information exchanges among the perspectives.

5.1 Scenario 1: Consumers Receive and Access Clinical Information

In this scenario, the consumer has the ability to access and incorporate their available health information from other sources into their PHR. Consumers who have multiple PHRs may choose to identify their PHR of choice in order to receive information automatically from other sources, or receive notifications that new information is available. Consumers may also choose to request all available and/or additional information for access and incorporation. Consumers may also wish to annotate or request a correction of information retrieved from other sources.

5.2 Scenario 2: Provider Lists & Permissions

In this scenario, consumers create and/or update their list of providers and determine the access permissions that should be granted to those providers for the purpose of accessing information in their PHR. The consumers may view access and disclosure logs for the purpose of reviewing who has had access to their information. The scenario also includes a capability to communicate the consumer's access decisions to HIEs. HIEs could implement the permissions while carrying out information exchange functions. HIEs could communicate the permissions to other HIEs and possibly to other systems.

5.3 Scenario 3: Transfer of PHR Information

In this scenario, consumers transfer information from an existing PHR (A) to another PHR (B) including the transfer of provider lists and provider permissions.

Systems involved in information exchange may need a mechanism to provision target systems with information needed to assign access permissions and communicate access control lists to other systems have the option to implement the access controls.

6.0 Scenario 1: Consumers Receive and Access Clinical Information

Figure 6-1. Consumers Receive and Access Clinical Information

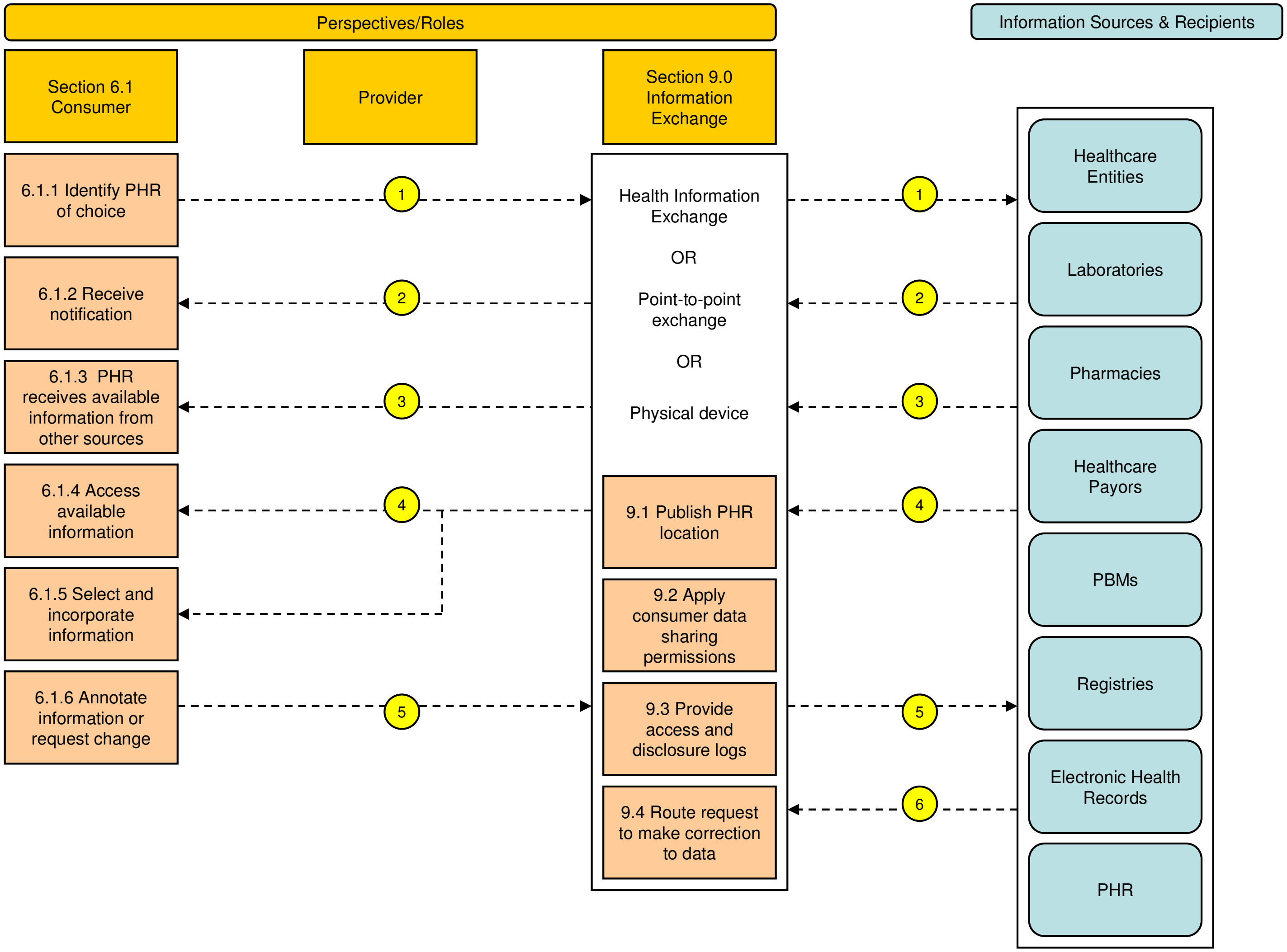


Figure 6-2. Consumers Receive and Access Clinical Information Scenario Flows

Scenario Flows

① Consumers identify their PHR of choice for information exchanges.

② In some instances consumers may receive notification that new information is available in their PHR. Notification can be sent via HIEs or other sources.

③ Consumers receive available information from other sources via their PHR of choice. This information can be auto-populated, requested and populated, etc. by consumers.

④ Consumers access available information and select and incorporate the information of their choice into their PHR.

⑤ Consumers may annotate information that has been incorporated into their PHR or request changes to information that has been incorporated into their PHR.

⑥ Request for change is accepted and communicated via HIEs or other sources.

Figure 6-3. Consumers Receive and Access Clinical Information, Consumer Perspective Events and Actions Table

Code	Description	Comments
6.1.1	**Event:** Identify PHR of choice	
6.1.1.1	**Action:** Identify and communicate PHR of choice.	Consumers identify and communicate their PHR of choice in order to inform health information exchanges and other sources of information that this is their preferred location to receive their health information. This could enable the automatic routing of health information to the preferred PHR.
6.1.2	**Event:** Receive notification	
6.1.2.1	**Action:** Receive notification.	Consumers may receive notifications that new or updated information is available. Notification could be initiated through the PHR by information sources containing the information or by health information exchanges. This action may occur prior or in parallel with action 6.1.3.1.

Code	Description	Comments
6.1.3	**Event:** PHR receives available information from other sources	
6.1.3.1	**Action:** Receive information.	Consumers may prefer that their PHR automatically receives information from other sources as it becomes available. Routing of this information to the PHR could be performed by an HIE or point-to-point exchange. A generalized process for matching patients is described in Appendix A: Arbitrating Identities.
6.1.3.2	**Action:** Information is automatically populated for access using appropriate translations or transformations.	Information automatically routed to the PHR may be available. There may be a need for the ability to offer transformed/translated information in layperson's terms, while still preserving the original form of the medical information for consumer access.
6.1.4	**Event:** Access available information	
6.1.4.1	**Action:** Request information.	Consumers access information which was previously incorporated into their PHR and/or may request additional information from other sources. A generalized process for matching patients is described in Appendix A: Arbitrating Identities. Consumers may also choose to give certain caregivers, family members, and others access to information in their PHR as described in the 2006 - "Harmonized Use Case for Consumer Empowerment (Registration & Medication History)."
6.1.4.2	**Action:** Access information.	Consumers access their health information which may or may not be transformed/translated into layperson's terms. The transformation/translation could occur entirely within the PHR however other approaches for providing this capability may also be available. The original untranslated/untransformed clinical data is preserved in the PHR and available for consumer access.
6.1.5	**Event:** Select and incorporate information	
6.1.5.1	**Action:** Select information.	After accessing the available and/or requested information, consumers select items which they would like to incorporate into their PHR.
6.1.5.2	**Action:** Incorporate selected information into the PHR.	Information selected by consumers is incorporated into the PHR. The PHR will retain information describing the original source of the data so that this information can be provided during retrievals from the PHR. Data distinguishes between consumer-supplied/entered information, information provided by other sources, and whether or not information has been updated.

Code	Description	Comments
6.1.6	**Event:** Annotate information or request change	
6.1.6.1	**Action:** Annotate information.	Consumers annotate the information they have retrieved and incorporate the information into their PHR. The original form of the information is preserved, supplemented by annotations which are provided by consumers. Within the context of this use case, the concept of annotation does not include the ability to directly alter or modify (edit) information retrieved from other sources. The concept of modifying consumer-entered information was addressed in the 2006 AHIC Consumer Empowerment – Registration and Medication History Use Case.
6.1.6.2	**Action:** Request change.	Consumers request a modification be made to information offered from other sources (e.g. to request corrections to errors or omissions). The request for a change is forwarded to the system which originated the data. It may be appropriate for the system which originated the information to acknowledge the request and reply with the modified information if the request is accepted.

7.0 Scenario 2: Provider Lists & Permissions

Figure 7-1. Provider Lists & Permissions

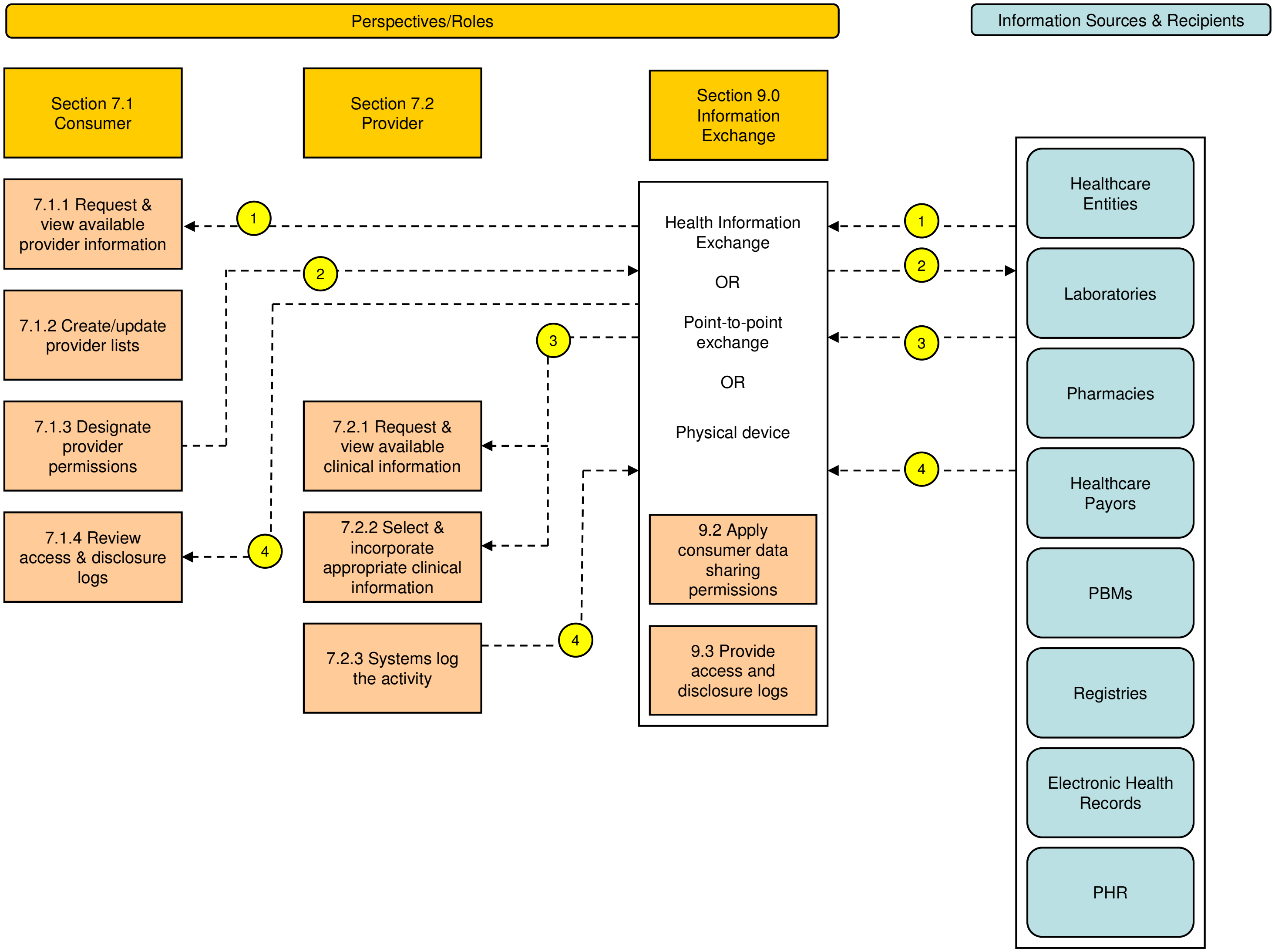


Figure 7-2. Provider Lists & Permissions Scenario Flows

Scenario Flows

① Consumers retrieve information about providers.

② After consumers create/update their provider lists and provider permissions the information is stored within their PHR. HIEs may also receive and utilize this information. HIEs may also communicate this information with other sources.

③ Providers retrieve information from other sources including consumer's PHR based upon permissions established by consumers.

④ Consumers retrieve access logs from PHRs, HIEs, and other sources in order to review who has viewed their information.

Figure 7-3. Provider Lists & Permissions, Consumer Perspective Events and Actions Table

Code	Description	Comments
7.1.1	**Event:** Request and access provider information	
7.1.1.2	**Action:** Request provider information.	Using the PHR, consumers request information about providers who they may wish to add to their provider list. Providers may include individuals, practices, and/or organizations. The PHR retrieves provider information from an HIE registry, EHRs, payors, etc.
7.1.1.4	**Action:** Access provider information.	Consumers access the requested provider identifying information. Identifying information may include: services, place of practice, etc.
7.1.2	**Event:** Create/update provider lists	
7.1.2.1	**Action:** Select and incorporate provider information.	Consumers select the desired provider information and create and/or update their lists of providers in their PHR.

Code	Description	Comments
7.1.3	**Event:** Designate provider permissions	
7.1.3.1	**Action:** Designate provider permissions.	Consumers designate which information in their PHR can be accessed by which providers. Methods for designating the consumer's decisions could include designating access for individual providers, designating access based on roles assigned to providers, designating access for provider practices or organizations, designating access by type of health information or some other criteria. In addition, the models may need to accommodate various approaches or a combination of approaches for designating permissions. These approaches may include; an inclusive model, an exclusive model, and/or the utilization of pre-determined defaults. A generalized process for access control is described in Appendix A: Create and Maintain Access Control Lists. Consumers may have the ability to allow (or not allow) providers to override the permissions in necessary situations. Reasons for "breaking the glass" are recorded in a consistent manner and incorporated into access and disclosure logs.
7.1.4	**Event:** Review access and disclosure logs	
7.1.4.1	**Action:** Review access and disclosure logs.	Consumers review information describing who has viewed their health information. The ability to merge or integrate this information from multiple sources into a time-sequence or other logical view may also be important for consumers. Information describing access to and disclosure of PHR information, "break the glass" access, HIE information exchange information access, and, at times, may include access to information in EHRs, etc.

Figure 7-4. Provider Lists & Permissions, Provider Perspective Events and Actions Table

Code	Description	Comments
7.2.1	**Event:** Request and access available clinical information	
7.2.1.1	**Action:** Request and access information.	Providers request and are able to access information from the consumers' PHR and other sources based upon access permissions established by the consumer. Providers may be informed that some information is not accessible as a result of the consumers' access decisions. Providers are able to identify the original source of the data as well as whether the information has been subsequently modified. If modification has occurred, the identity of the source of the modification is also available to providers. A generalized process for access control is described in Appendix A: Create and Maintain Access Control Lists. A generalized process for matching patients is described in Appendix A: Arbitrating Identities.
7.2.2	**Event:** Select and incorporate clinical information	
7.2.2.1	**Action:** Select information.	After accessing the available consumer information based upon permissions set by consumers, providers may choose to incorporate selected information into EHRs. Providers select the information that they would like to incorporate into their EHRs. This information may be selected at various levels of specificity. Such as discrete pieces of information and/or groups of information (e.g. data sets).
7.2.2.2	**Action:** Incorporate data into EHRs.	The providers' EHR incorporates the selected information. The original source of the data is also incorporated into the EHR.
7.2.3	**Event:** Systems log the activity	
7.2.3.1	**Action:** Log access to information.	The consumers' PHR and data intermediaries create logs of the information exchanges. The logs identify who has accessed the consumers' information. The access and disclosure logs could be reviewable by the consumers. It may be helpful to combine log information from several systems in order to establish a complete view of who has accessed the consumers' information over a period of time.

8.0 Scenario 3: Transfer of PHR Information

Figure 8-1. Transfer of PHR Information

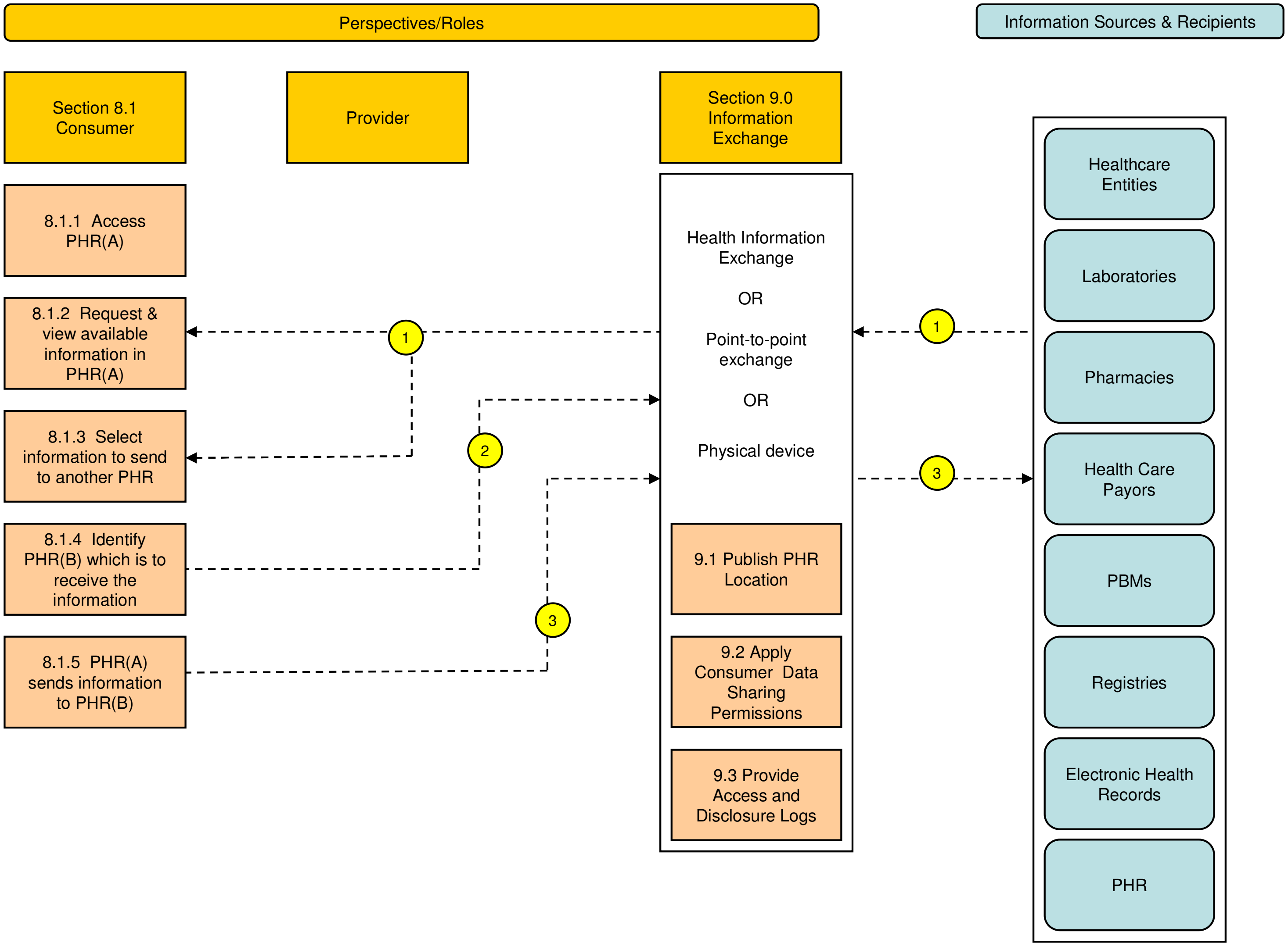


Figure 8-2. Transfer of PHR Information Scenario Flows

Scenario Flows

① Consumers request, view, and select information in PHR (A) which will be forwarded to another PHR.

② Consumer identifies PHR (B) as the PHR to receive the selected information.

③ PHR (A) sends the selected information to PHR (B). Information may also be sent to other entities.

Figure 8-3. Transfer of PHR Information, Consumer Perspective Events and Actions Table

Code	Description	Comments
8.1.1	**Event:** Access PHR (A)	
8.1.1.1	**Action:** Access PHR (A).	Consumers access an existing PHR (A). The 2006 - "Harmonized Use Case for Consumer Empowerment (Registration & Medication History)" addresses the creation of PHR Accounts, etc.
8.1.2	**Event:** Request and access available information in PHR (A)	
8.1.2.1	**Action:** Review PHR (A) Information.	Consumers review the information available in PHR (A) including provider lists and provider permissions.
8.1.3	**Event:** Select information to send PHR (B)	
8.1.3.1	**Action:** Select data elements and/or data sets.	Consumers select the information that they would like to incorporate into another PHR. This information may be selected at various levels of specificity. Consumers may select discrete pieces of information, choose to select groups of information, and/or choose to select all. Information could possibly be sent to other entities in addition to a PHR.
8.1.3.2	**Action:** Select providers and permissions.	Consumers select the information permissions information that they would like to incorporate into their PHR. As discussed in the 2006 - "Harmonized Use Case for Consumer Empowerment (Registration & Medication History)" permissions for consumers including: caregivers, family members, etc. may also have the ability to be selected.

Code	Description	Comments
8.1.4	**Event: Identify PHR (B) which is to receive the information**	
8.1.4.1	**Action:** Identify PHR (B) which is to receive the information.	Consumers identify PHR (B) as the PHR to receive the selected information. The 2006 - "Harmonized Use Case for Consumer Empowerment (Registration & Medication History)" addresses the creation of PHR Accounts, etc.
8.1.5	**Event: PHR (A) sends information to PHR (B)**	
8.1.5.1	**Action:** Forward information to PHR (B).	Consumers authorize PHR (A) to send the selected information to PHR (B). In addition to clinical registration information, this may include the provider lists and the provider permissions as designated by the consumers. The original source of the information may need to be preserved in the data transmission process. The information may be transmitted to PHR (B) via HIEs, point to point, physical devices, etc.
8.1.5.2	**Action:** Confirm delivery of information to PHR (B).	Confirmation could be accomplished by messaging from PHR (B) to PHR (A) or other mechanisms, etc. Consumers may also want to be able to review what information was routed where, when, etc.

9.0 Information Exchange

This section describes at a high level the role of information exchange in the scenarios described in this use case. The information exchange activities may be carried out by a health information exchange, by point-to-point exchange, and/or physical device. All of the activities listed below would be relevant for a health information exchange, however, some activities may not be applicable to the other methods of information exchange.

Figure 9-1. Consumer Access to Clinical Information: Information Exchange Table

Code	Activity	Comments
9.1	Publish PHR Location	Identify where the consumer's PHR data is stored and publish the location as specified by the consumer. The publications of the PHR is based on the consumer's preferences, to make known the location of the consumer's PHR record.
9.2	Apply Consumer Data Sharing Permissions	Consumers may identify providers who may access their PHR data. These preferences are shared with the HIE so that they can be enforced by the HIE in responding to data queries or when routing data or are used by the PHR in direct data exchange.
9.3	Provide Access and Disclosure Logs	The HIE maintains audit logs of accesses to data, disclosures and sharing of data. A consumer may request to review these records. The HIE provides to the consumer's PHR copies of the access and disclosure log records. These may be provided in response to a query from the consumer or they may be copied to the consumer's PHR as they are recorded at the HIE. Consumers may also view HIE records of accesses to and disclosures of their records.
9.4	Route Request to Make Correction to Data	Consumers request a modification be made to information offered from other sources (e.g., to request corrections to errors or omissions). The request for a change is forwarded to the system which originated the data. It may be appropriate for the system which originated the information to acknowledge the request and reply with the modified information if the request is accepted.

Health Information Exchange: A multi-stakeholder entity that enables the movement of health-related data within state, regional, or non-jurisdictional participant groups.

Point-to-point exchange: A direct link or communication connection with defined endpoints. Clearinghouses may serve a point to point function in the exchange of information.

Physical Device: A Portable-Storage PHR in which information that pertains to an individual is recorded and stored on a portable-storage device such as a CDROM, DVD, smart card, USB flash drive, smart tag device and/or memory stick.

Health information at rest and during an exchange should meet security standards in areas such as node authentication, identity credentials, document integrity, access controls, audit trail, non-repudiation, and consistent time tracking.

10.0 Consumer Access to Clinical Information Dataset Considerations

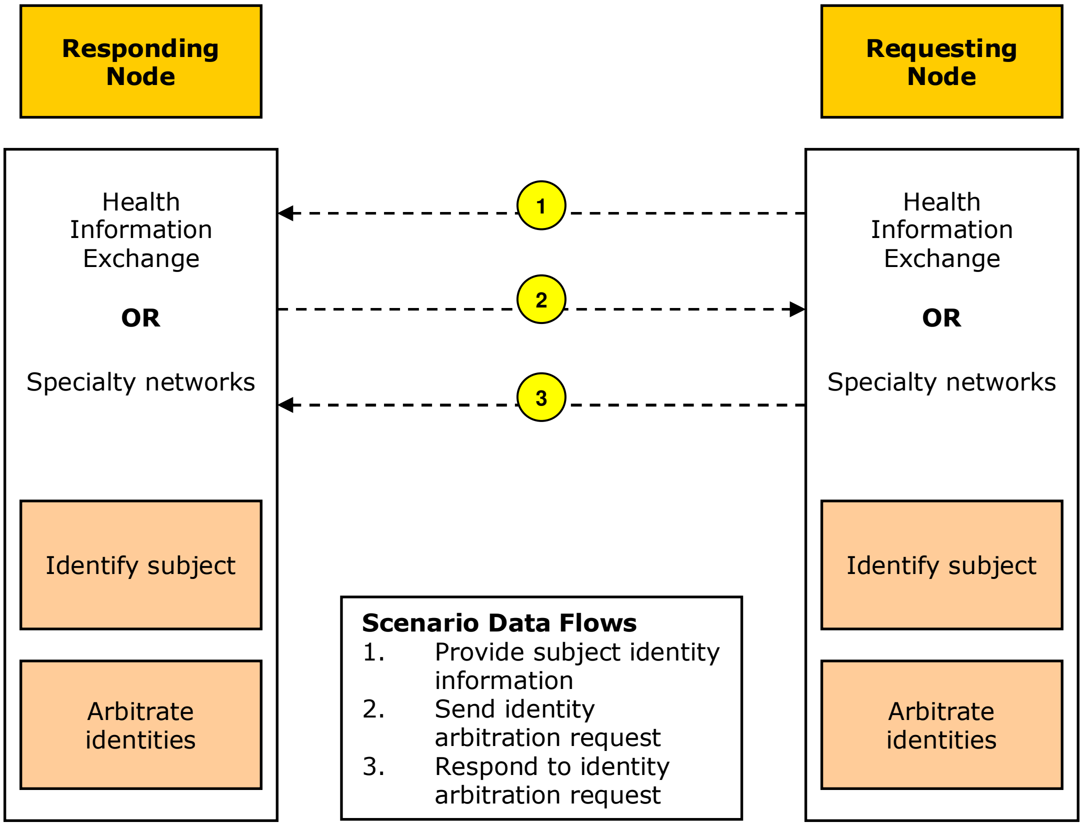
For the purposes of addressing the scenarios in this use case, the following information categories may be considered:

- Demographics/Person Information
- Person Relationship/Support Information
- Insurance Information
- Emergency Contact Information
- Advanced Directives
- Medication/Allergy History
- Laboratory Results
- Problems/Conditions/Diagnosis Codes
- Healthcare Provider List Information
- Healthcare Provider Permissions Information
- Original Data Source Information
- Attribution and Validation Information
- Access Information
- Disclosure Information

Appendix A: Common Processes

A1.0 Arbitrating Identities

Figure A1-1. Arbitrating Identities



Scenario Data Flows

1. Provide subject identity information
2. Send identity arbitration request
3. Respond to identity arbitration request

Concept - Systems involved in exchanging patient-specific information need mechanisms to reconcile person identity between nodes (e.g., between health information exchanges) without a universal identifier.

Generalized information flow – The requesting node has a need to determine if the responding node has information about a specific individual (a "subject" such as a provider or patient). The requesting node sends subject identifiers to the responding node. The responding node determines whether it can:

- Match the provided identifiers to a subject known to the responding node;
- Identify a match that has some conflicting information such as an old address; and

- Not match to any subject known by the responding node.

Identity arbitration represents the reconciliation of identify information between two nodes to ensure that data are correctly associated with the right subject. The responding node identifies a match, or in some circumstances, replies with information about a match which might not exactly correspond to all the information provided by the requesting node. The requesting node evaluates the information provided for the candidate subjects and determines whether there should be a link to the subject of interest. If the requesting node determines that there should be a link, it transmits information about the link to the responding node. Processes to maintain the linkage may also be operational between nodes (e.g., if one of the nodes becomes aware of changes to the information which was used to create the match).

Identity arbitration occurs between two nodes in a network when data must be transacted between those nodes. This process does not imply that all identities are reconciled between nodes, only that they are reconciled on an as needed basis.

Examples

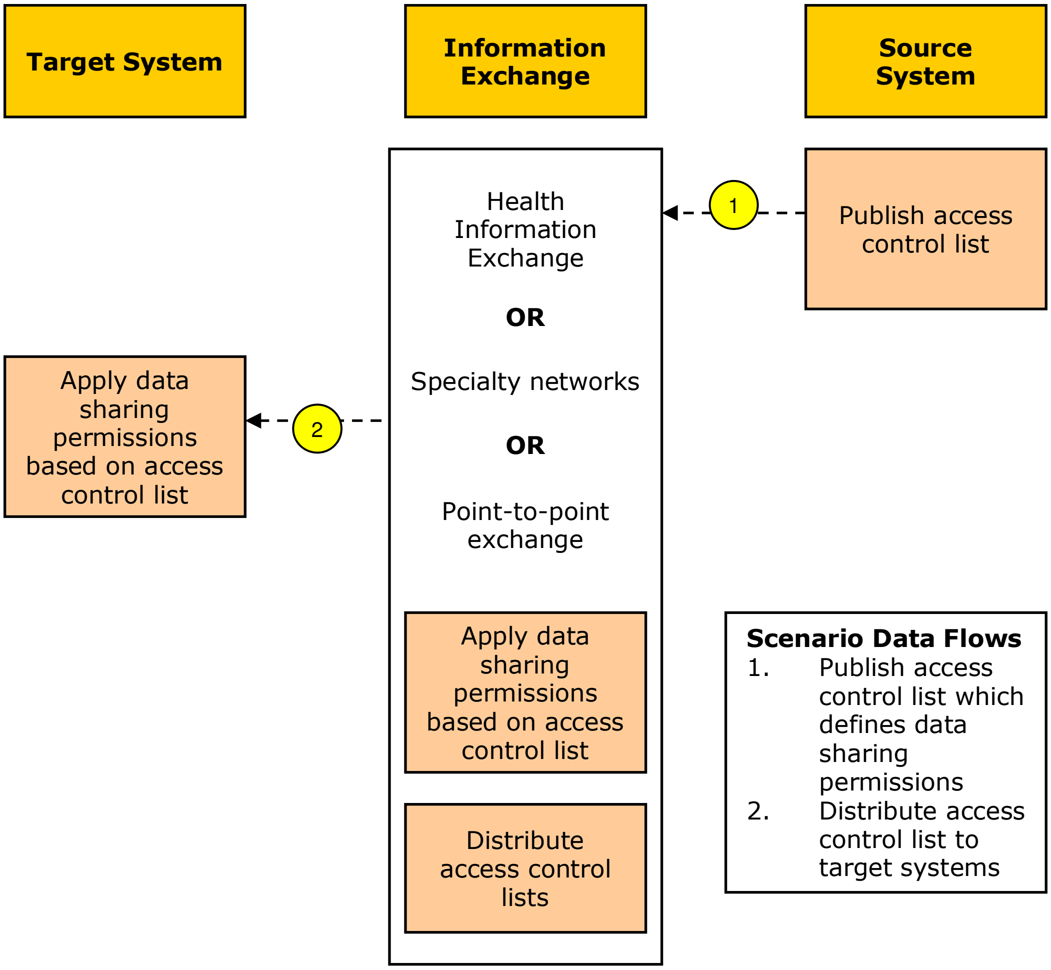
- HIE to HIE interactions
- CDO – HIE interactions
- PHR – HIE interactions

Figure A1-2. Arbitrating Identities Scenario Data Flows Table

Flow	Description	Comments
1	Provide subject identity information	The requesting system sends information describing the subject of interest to the responding node.
2	Send identity arbitration request	Using the information provided by the requesting node, the responding node carries out a process to match the subject of interest to those known to the responding node. If the responding node determines that there is a match, it replies as such. In appropriate cases, if the responding node determines that it has a match that does not completely correspond to the provided information (such as an old address), the responding node sends information on the match and any conflicts to the requesting node. If the responding node determines that it cannot match the subject of interest, it responds accordingly.
3	Respond to identity arbitration request	The requesting node assesses the match information provided by the responding node and determines whether there should be a link with the subject of interest. If the requesting node determines that there should be a link, it communicates to the responding node, which also maintains the linkage between nodes.

A2.0 Create and Maintain Access Control Lists

Figure A2-1. Create and Maintain Access Control Lists



Concept - Systems involved in information exchange may need a mechanism to provision target systems with information needed to assign access privileges and communicate access control lists to other systems to implement the access controls. Access control can be extremely burdensome to manage normally, and with providers covering for each other, etc. may need to be implemented very conservatively.

Generalized information flow – A source system needs to communicate access control lists to one or more target systems for implementation in the target system processes related to access to data and data exchange. The source system develops the access control list and distributes it to the target system(s). The target system receives and implements the controls defined in the access control list. Permissions may be persistent, may be temporally constrained or defined using other logical constructs.

While this flow describes interaction between a single target system and single requesting system, it is likely that there will be multiple target systems which need to receive the access control list.

This information flow describes a push model for delivering data from the source system to the target system. However, it may also be possible for the target system to query the source system for the access control list.

Examples

- Consumer-defined access decisions

Figure A2-2. Create and Maintain Access Control Lists

Flow	Description	Comments
1	Publish access control list which defines data sharing permissions	The source system enables a user to designate data sharing permissions to individuals, groups, entities, etc. The types and granularity of data which could be controlled by permissions might include: ▪ Meta-data; ▪ Full data; ▪ Partial data; ▪ Individual data; and ▪ Portions of documents. Individuals, groups and entities to which the data sharing permissions could be applied include: ▪ Individuals; ▪ Groups of individuals; ▪ Organizations; and ▪ Roles. The permissions could also be defined temporally: ▪ Persistent until revised; ▪ Persistent with an expiration date; ▪ Time-based with various mechanisms to define the duration of the permission; and ▪ Other logic may also be present, including such things as access during a specific encounter or episode of care.

Flow	Description	Comments
2	Distribute access control list to target systems	Information exchange mechanisms distribute the access control lists to the target systems. This could be accomplished by point-to-point exchanges, specialty networks or health information exchanges. ▪ Point-to-point exchange – Could include direct (push) transmission of the access control list from the source system to the target system or delivery upon a request initiated by the target system (pull). ▪ Specialty networks – May exist which manage the routing of access control lists among specific groups of entities. These networks may also provide additional capabilities related to access control. ▪ Health information exchange – May have the capability to manage the distribution of access control lists on behalf of source systems. This could include determining which connected systems should receive the access control list based on the target system capabilities identified in HIE registries and routing the access control list to those systems. The target systems and health information exchange implement the data sharing permissions as defined by the access control as they carry out data access and data exchange activities.

Appendix B: Glossary

Access Logs: An integrated view of who has accessed the consumer's health information for the purposes of direct or indirect patient care.

AHIC: American Health Information Community.

Ancillary Entities: Organizations that perform auxiliary roles in delivering healthcare services. They may include diagnostic and support services such as laboratories, imaging and radiology services, and pharmacies that support the delivery of healthcare services. These services may be delivered through hospitals or through free-standing entities.

Attribution and Validation Information: Methods/Information – i.e. – digital signature which is used to identify in-tact and affiliate information with its originating or updated source.

Audit Logs: A chronological sequence of audit records, each of which contains evidence directly pertaining to and resulting from the execution of transactions. Audit logs may collect information across multiple organizations, geographic regions, health information exchanges, and potentially specific systems.

"Break the Glass": Refers to a quick means for a provider who does not access permissions to certain information to gain access when necessary.

Consumers: Members of the public who may receive healthcare services. They may have one or more PHRs which may be used to access and maintain information about their personal health. These individuals may include: caregivers, patient advocates, surrogates, family members, and other parties who may be acting for, or in support of, a patient in the activities of receiving healthcare and/or using a PHR.

Data Augmentation: Supplementing data already available, usually through manual entry into a system.

Department of Health and Human Services (HHS): This is the federal agency responsible for human health, and has oversight over many other federal agencies such as FDA, the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), CMS, the Agency for Health Research and Quality (AHRQ), the Substance Abuse and Mental Health Services Administration (SAMHSA), and others.

Disclosure Log: An integrated view of who has accessed the consumer's health information for legal, audit, and other purposes.

Electronic Health Record (EHR): The electronic health record is a longitudinal electronic record of patient health information generated in one or more encounters in any care delivery setting. This information may include patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory information and radiology reports.

Health Information Exchange (HIE): A multi-stakeholder entity that enables the movement of health-related data within state, regional, or non-jurisdictional participant groups.

Health Information Management Professionals (HIM): Personnel who manage healthcare data and information resources, encompassing services in planning, collecting, aggregating, analyzing, and disseminating individual patient and aggregate clinical data.

Health Information Service Provider (HSP): Companies or other organizations that support health information exchange activities by providing participants with operational and/or technical health exchange services.

Health Information Services (HIS): Services provided by Health Information Networks for information exchange and interoperability.

Healthcare Entities: Organizations that are engaged in or support the delivery of healthcare. These organizations could include hospitals, ambulatory clinics, long term care facilities, community-based healthcare organizations, employers/occupational health, school health, psychology, dental clinics, care delivery organizations, and other healthcare facilities.

Healthcare Payors: Insurers, including health plans, self-insured employer plans, and third party administrators, providing healthcare benefits to enrolled members and reimbursing provider organizations. As part of this role, they provide information on eligibility and coverage for individual consumers, as well as claims-based information on consumer medication history. Case management or disease management may also be supported.

Health Record Banks: Entities/mechanisms for holding an individual's lifetime health records, which now may reside in dozens of hospitals, doctors' offices, clinics, etc. They would be released to other doctors and hospitals with the patients' consent.

Information Annotation: Extra information may be associated with the previous information within an EHR/PHR. There may be policies, procedures, regulations, etc. which determine who and what information may be annotated.

Laboratory: A facility that provides controlled conditions in which scientific research, experiments, and measurement may be performed.

Notification Model: A data exchange model where a notification (e-mail, text to PDA, regular mail, etc.) is sent (to a clinician, consumer/patient, network administrator, etc.) alerting participating entities that data is available for retrieval.

ONC: Office of the National Coordinator for Health Information Technology.

Personal Health Record (PHR): See section 1.2.

Personal Health Record Service Providers: Organizations which assist in providing PHR capabilities to consumers. Organizations that provide these capabilities may include: vendors, healthcare providers, health data banks, healthcare payors, etc.

Personal Health Record System Developers: Organizations which provide specific PHR solutions to consumers such as applications, data repositories, web services, etc.

Pharmacy Benefit Managers (PBM): These entities manage pharmacy benefits on behalf of payors, interacting with pharmacies and providers via a medication network intermediary. As part of this role, they can provide information on pharmacy benefits available to an individual consumer and an individual consumer's medication history.

Physical Device: A Portable-Storage PHR, in which information which pertains to an individual is recorded and stored on a portable-storage device such as a CDROM, DVD, smart card, USB flash drive, smart tag device and/or memory stick.

Point to Point Exchange: A direct link or communication connection with defined end points. Clearinghouses may serve a point to point function in the exchange of information.

Population Health: A population health perspective encompasses the ability to assess the health needs of a specific population; implement and evaluate interventions to improve the health of that population; and/or provide care for individual patients in the context of the culture, health status, and health needs of the populations of which that patient is a member.

Providers: The healthcare clinicians within healthcare delivery organizations with direct patient interface in the delivery of care, including physicians, nurses, and other clinicians. Can also refer to healthcare delivery organizations.

Public Health Agencies (local/state/federal): Local, state, and federal government organizations and personnel that exist to help protect and improve the health of their respective constituents.

Registries: Organized systems for the collection, storage, retrieval, analysis, and dissemination of information on individual persons to support health needs. May include emergency contact information/ next-of-kin registries, etc.