



Metropolitan Portland Health Information Exchange Policies 1.0

Results and Reports Retrieval System

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Introduction

The purpose of the Metropolitan Portland Health Information Exchange (MPHIE) is to fulfill the vision:

“Meaningful health information is widely and securely available among authorized persons in a usable form anytime and anywhere it is needed in order to improve the overall safety, effectiveness and efficiency of an individual’s care and the public’s health.”

The following policies are intended to provide a framework for, and are referenced by, materials critical to the establishment and operation of the MPHIE:

- Terms and conditions
- Business associate agreements
- Stakeholder participation agreements (including data sharing agreements)

1. Fair Information Practices Policy

Policy Premises

- The MPHIE study team recognizes that a fundamental requirement in the collaborative sharing of health information is the confidence of patients and providers that information is held privately and securely;
- The team desires to ensure a balance between the privacy and security interest of patients with the needs of making that information available for the benefit of the individual and population health, while at the same time, instilling patient and provider trust in MPHIE;
- The study team wishes to provide guiding privacy and security principles that all stakeholders, employees, and agents may refer to in implementing the MPHIE purpose;

Policy Resolutions

The MPHIE study team adopts the following fair information practices.

Principle	Description
Choice	Individuals should be informed regarding the collection of their personal information and be afforded the opportunity to decline to participate in the MPHIE.
Openness and Transparency	Individuals should be aware of what information is being collected and for what purposes. They should be able to review the information that has been collected, to whom it has been released as well as the purposes of the release.
Collection and Use Limitation	The information collected and its uses and re-disclosure should be limited to the parameters of the individual's authorization or within the bounds of legal requirements for use of de-identified data for public health, research, and other legally-sanctioned purposes.
Data Validity, Integrity, and Quality	The MPHIE should be constructed to ensure the validity and integrity of the data and preserve its quality and usability. The individuals who are subjects as well as others in a position to review and evaluate the validity, integrity, and quality of data should be able to update, correct, and/or annotate the data as appropriate.
Security Safeguards and Controls	All data should be protected by reasonable security and privacy safeguards against loss, unauthorized access, destruction, use, modification, or disclosure.
Availability	Individuals' data should be readily available for the purposes agreed upon by the individual given technical limitations.

Accountability and Oversight	The entity collecting the data should be accountable for abiding by these principles and for oversight to ensure that they are followed by those who may be authorized to access and use the data according to the individual's authorization.
Notice and Enforcement	Where information is released outside the bounds of the individual's authorization, the individual is entitled to notice of the release and methods should be available to apply penalties to violators of the authorization and to mitigate, to the extent possible, the violation.

Scope of Resolution

These fair information practices shall be a set of guiding principles for MPHIE stakeholders, employees, agents, and representatives to refer to, as well as for the development of the technical architecture and operational policies and procedures.

2. Data Access & Use Policy

Policy Premises

- The MPHIE study team recommended to employ the use of a federated health information architecture to enable retrieval of laboratory results, diagnostic imaging reports, dictated summaries, and other available electronic data from providers' source systems;
- The team desires to limit access and use of data in the exchange;
- The team believes that permitted access and use of the data in the exchange should be consistent with the mission to make health information widely and securely available among authorized persons.

Policy Resolutions

Any Protected Health Information (PHI) accessible via the exchange should be made available to, or denied to, the following groups of individuals or entities, or for the following purposes:

- Patients should be given access to their own PHI consistent with MPHIE's Fair Information Practices as well as within the bounds of applicable law and technical feasibility;
- Providers should be granted access to the exchange for the purposes of payment, treatment, and operations within the bounds of legal restraints and in compliance with the patient's authorization via the notice of privacy practices.
- Payors should not be granted access to the MPHIE at this time, except for the purposes of accessing or being provided de-identified data regarding patients enrolled in MPHIE.
- IRB-Approved research studies should have access to only de-identified health information from the exchange within the parameters of the study.
- Public Health Departments should be entitled to receive legally required reporting of disease and other legally compelled health data and other de-identified data to further their Biosurveillance capabilities. MPHIE should work with them in good faith to negotiate Limited Data Set Agreements within the bounds of HIPAA and other applicable federal and state laws.
- Marketing shall be limited according to the HIPAA definition.
- Required Disclosures may be made according to law.
- Disclosure requests not covered above should be reserved until such time as the MPHIE is more fully developed. Authority is given to the Executive Director to bring requests requiring special attention to the MPHIE board.

Scope of Resolution

The study team, in conjunction with this resolution, makes no decision hereby as to the process for making requests for access and use of data, the particular populations involved in such access and use, or the precise data elements involved in such access and use.

3. Passive Enrollment Policy

Policy Premises

- A fundamental question in the collaborative sharing of health information is the means and methods by which patients are enrolled in the system;
- The MPHIE mobilization study team has considered the impact of both Active Enrollment (“Opt-In”) and Passive Enrollment (“Opt-Out”) on its ability to make health information widely and securely available among authorized persons;
- The study team believes that a Passive Enrollment model for the MPHIE will make its benefits available to the widest number of patients and physicians, while still giving patients the right to control the sharing of their information through dis-enrollment.

Policy Resolutions

MPHIE shall support and encourage a Passive Enrollment system of health information exchange, incorporating the following hierarchy:

- Patients will be given the right and responsibility to dis-enroll and re-enroll in the MPHIE by a means and in a manner that is as expedient as possible, but which is also consistent with sound clinical practice as well as privacy and security principles;
- Providers and other participants, at the time they execute a data sharing agreement, shall be given the option to choose whether their patient populations will be entered into the MPHIE either under a Passive or Active Enrollment model.

Scope of Resolution

The study team, in conjunction with this resolution, does not address the granularity of control patients may have over the sharing of information; whether by individual provider, date of service, or other discernable and definable segments of care.

4. System Architecture & Data Storage Policy

Policy Premises

A fundamental question in the collaborative sharing of health information is the mechanism for storing, retrieving, and analyzing patient data and other medical information. The MPHIE Mobilization study team has considered the impact of various technical approaches to the problem, including a central data repository, a federated or distributed architecture, point-to-point interfaces, “smart cards”, and hybrid architectures.

The team believes that a federated architecture will best fulfill the community’s goals to make meaningful health information widely and securely available. The system will utilize only a limited central repository to contain patient demographic information and pointers to data in providers’ native systems; this does not preclude the future development of more robust centralized clinical data storage, or hybrid architectures. The advantages of the distributed model are:

- Allows providers to retain control over their patients’ clinical data while exposing it for retrieval via the MPHIE data exchange;
- Minimizing the need for large, heavyweight centralized data services together with their necessary operational and cost burden to the community;
- Separating the storage of patient demographic data from the clinical information in order to minimize the risk of exposing significant amounts of protected health information for an individual;
- Allowing centralized and distributed user authentication, authorization, audit trails, and access control.

Policy Resolutions

MPHIE shall establish and make available a federated health information exchange to include laboratory results, diagnostic imaging reports, dictated summaries and other electronic data from health care provider systems, to the extent that any such provider is willing to participate and contribute to such an exchange.

MPHIE shall work with other authorized providers and data consumers to permit access and retrieval of data from the exchange.

Scope of Resolution

The study team, in conjunction with this resolution, does not address the discrete data elements to be included in the exchange or limited central repository, the minimal elements a provider must contribute in order to participate in the health information exchange, or what if any data may be used in various MPHIE programs.

Appendix A – Background, Sources, Related Documents

The MPHIE Mobilization Planning effort was commissioned and financed by the Oregon Business Council's Health Information Exchange Leadership Group. The project leadership team (Tiger Team) provided oversight and leadership in guiding the development of the planning included:

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The Mobilization Planning effort was staffed by Oregon Health Care Quality Corporation. Staff and sub-contractors who contributed to various portions of this report include:

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The Mobilization Planning effort builds upon the report to the Oregon Business Council (OBC) Data Exchange Group titled “Oregon Health Information Exchange Options” dated May 15, 2006 available at <http://www.q-corp.org/q-corp/images/public/pdfs/OR%20HIE%20Options.pdf>.

The Mobilization Planning effort report relies on a number of sources of information including published studies, publications and reports of major organizations involved in health information exchange, and information collected from other regional health

information organizations (RHIOs) and health information exchanges (HIEs) and interviews and discussion with clinicians and other stakeholders in the community.

Key Mobilization Planning documents include

- MPHIE Final Report
- Metropolitan Portland Area Health Care Environment.
- MPHIE Technology Plan.
- MPHIE Privacy and Security Assessment.
- MPHIE Governance Plan.
- MPHIE Business Plan.
- MPHIE Operations Plan.