Sponsors of the Oregon Chronic Disease Data Clearinghouse And Tracking System Pilots

Chronic Disease Data Clearinghouse Pilot Project

September 2005

Evaluation Assessment Report[1]

Executive Summary

The three-year Chronic Disease Data Clearinghouse Pilot Project represents an unprecedented collaboration between twelve Oregon health plans, physician practices and other stakeholders to demonstrate the potential for a clearinghouse to improve the care of asthma and diabetes patients in Oregon by providing clinicians with consolidated reports of information about the care of their patients. As a pilot, the project was highly successful in demonstrating that the political, legal, and technical issues for such a clearinghouse can be addressed. The pilot dealt with complex technical issues and identified changes necessary to establish an ongoing operational clearinghouse. The issues identified and lessons from the project have direct bearing on plans for other Oregon initiatives to develop pay for value incentive payment systems and regional health information organization (RHIO) infrastructure development.

Report Organization

This report describes the various components of the Chronic Disease Data Clearinghouse (CDDC) Pilot Project, issues encountered, accomplishments and opportunities to build on the pilot. The report is organized with sections describing:

- Developing a Consensus for a Clearinghouse pilot
- Assessing Physician Interest and Needs
- Making the Clearinghouse Pilot a Reality – Phase I
- Phase I – HIPAA Compliance

[1] Prepared by Witter & Associates with support from Northwest Health Foundation grant 2003-245.

- Phase II – Working with Health Plan Data
- Phase II – Data Management Issues
- Identifying Patients with Asthma and Diabetes
- Matching Patients with Physicians and Practices
- About Clearinghouse Asthma and Diabetes Patients
- Reports for Physicians and Practices
- Asthma and Diabetes Outcome Measures
- Reactions from Physician Practices
- Project Management
- Accomplishments and Opportunities
- Summary Conclusions

Attachment A identifies organizations involved in project planning, the Clearinghouse Steering Committee, participating health plans and physician practices, project staff, and financial supporters. Attachment B provides an outline of the Steering Committee's evaluation questions for use in monitoring and assessing the project.

Developing a Consensus for a Clearinghouse Pilot

In 1999 and 2000, Oregon Diabetes Coalition participants, a number of health plan medical directors, the Oregon Department of Human Services and other stakeholders began discussing opportunities to improve the care of diabetes patients in Oregon by improving the data and tools available to practicing physicians. Early discussions focused on the development of the use of tracking systems and registries for diabetes in physician practices and a systematic process for providing physicians with consolidate reports of information available from health plans about their patients. In 2001, the Practice Variation Subcommittee of the Oregon Health Care Quality Corporation (Quality Corp) began discussing practice improvement opportunities and building on the work of the Oregon Diabetes Coalition.

By April 2002, a working group of health plans and other organizations were developing a consensus that to better manage chronic disease, physicians need systems that identify patients with the condition, keep track of the patient's status on specific items of interest, and utilize existing available data without extensive data entry. A vision evolved for a chronic disease tracking project that would serve the diverse needs of a variety of stakeholders. The stakeholder groups included early adopter physician groups already developing their own electronic records and tracking systems, care managers in clinics and hospitals, small physician practices, health plans, purchasers, public health, people with disease, and potential funding organizations. The clearinghouse vision identified various project components including consolidated health plan information for encounter, laboratory and pharmacy claims, laboratory results; development of local health care data infrastructure, potential for internet tracking systems, tracking report feedback mechanisms, HEDIS and disease management results and aggregate quality outcome reports. Various stakeholders liked different parts of the vision but there was collective interest in supporting the vision to pilot a chronic disease clearinghouse for diabetes and asthma patients. The envisioned pilot would standardize and consolidate data from several health plans, provide paper reports for physicians and care managers who want them,

provide electronic data and interface to DEMS diabetes tracking system users to update their systems, test the confidentiality and technical issues using a common vendor for consolidating data and reporting.

By August 2002, the project concept for the Chronic Disease Data Clearinghouse was well developed. Sponsorship was organized under the auspices of the Quality Corp, Oregon Diabetes Coalition and the Oregon Asthma Network with staffing provided by the Oregon Diabetes and Asthma Programs of the Oregon Department of Human Services. The purpose of the project was to:

- use health plan data to identify patients who may be appropriate for diabetes and/or asthma care management from their physician or clinic,
- provide recent health plan visit, laboratory and pharmacy information about those patients in a common integrated format to the appropriate physician,
- design an electronic and paper format for the information that is useful to physicians,
- obtain feedback on the accuracy of the patient-level information and the utility of the overall process, and
- identify legal and logistical issues that need resolution to continue the effort.

The planning anticipated the selection of a vendor to support and conduct essential clearinghouse functions including:

- execute agreements with each participating health plan to provide the necessary legal and technical protections of patient confidentiality as an agent of the health plans,
- merge and de-duplicate the data exchange between the participating health plans and physician practices,
- provide feedback from the physicians to the health plans,
- provide aggregate information regarding the accuracy, completeness and utility of the information to the health plans and sponsoring organizations, and
- destroy the data on completion of the project.

By October 2002, the planning process had generated initial drafts of proposed criteria for identifying asthma and diabetes patients, data element (variable) definitions and specifications for information to be submitted by health plans to the Clearinghouse, variables to be included in reports to physicians and a request for proposal to select a vendor to operate the Clearinghouse.

Attachment A: Clearinghouse Project Participants identifies the Organizations Participating in Planning the Clearinghouse Initiative (1999 – 2002).

Essential elements in the project plan included:

- Select a vendor to operate the pilot Clearinghouse that would develop HIPAA compliant data sharing agreements with the participating health plans, merge the data from the health plans, provide consolidated reports to participating physician practices, and identify issues to be addressed in order to make a clearinghouse operational.

- Select a vendor to survey physician practices about their views on the Clearinghouse concept, identifying physician practice information needs for the proposed consolidated reports, and assess their views on the reports produced by the Clearinghouse.
- Create a Steering Committee to oversee the Clearinghouse pilot project appointed by the three sponsoring organizations with stakeholders representing health plans, physician practices, public health, and other interested parties. See Attachment A for a list of Steering Committee participants.
- Recruit at least four health plans and fifteen physician practices to participate in the Clearinghouse pilot.
- Participating health plans would submit two years of claims data to the Clearinghouse for possible asthma and diabetes patients. A first round submission of claims data would be used to test the ability of the Clearinghouse to (1) standardize data between plans and merge data for patients and providers across plans, (2) properly identify asthma and diabetes patients using standards developed in the planning process and consistent with national guidelines and (3) properly match patients to a primary care physician and a practice group or clinic. A second round submission of claims data would be used to provide timely reporting of information to participating physicians.
- Assess the desirability and feasibility of developing an ongoing Chronic Disease Data Clearinghouse functionality based on information gained from the Clearinghouse pilot.

Assessing Physician Interest and Needs[2]

In early 2003 Riley Research Associates was selected to conduct the surveys of physician practices to determine their potential interest in the Clearinghouse concept. In August and September 2003, Riley Research Associates conducted in-person and telephone interviews with fifty individuals from sixteen physician/provider groups including physicians, nurses, practice managers and support staff. The physician/provider survey solicited feedback about the level of interest in the Clearinghouse concept, concerns about the Clearinghouse Project, and desired content and format for reports. Fifteen of the sixteen groups were receptive to the Clearinghouse concept with nine groups judged to have a high level of support and enthusiasm for the project with no predominant concerns. Six practice groups expressed some skepticism noting various concerns including perceptions about the inaccuracy problems in using claims data, lack of incentives for using Clearinghouse data, unclear nature of how Clearinghouse reports could be actionable or improve care, a history of distrust about non-local efforts based on prior negative experiences, and the need to include Oregon Health Plan and Medicaid/Medicare patients in the Clearinghouse. Overall the survey was judged supportive of the Clearinghouse concept and the utility of the pilot project to address the expressed concerns.

[2] The full Riley Report can be found at http://www.q-corp.org/images/users/1/RileyReport%20-%20PUBLIC%20Dec03.pdf.

Making the Clearinghouse Pilot a Reality – Phase I

In December 2002, a request for proposals was issued to solicit applications for a Clearinghouse vendor. In February 2003 a committee of seven individuals evaluated and scored four proposals from potential Clearinghouse vendors. The committee recommended the selection of OMPRO as the Clearinghouse vendor.

In April, May and June 2003, the major project participants (OMPRO, Riley Research Associates and DHS staff supporting the project) refined and clarified the scope of the pilot, drafted evaluation criteria, developed plans for surveying physician practices, and recruited participants for the Steering Committee.

In July 2003, the Steering Committee was appointed and met for the first time. Since then the Steering Committee has met periodically ranging from monthly to quarterly to support the project. The Steering Committee was charged with providing oversight of the project including:

- Maintain accountability for the project vision and keep work on track.
- Provide practical advice for making the project successful.
- Champion the cause and enlist participation from health plans and providers.
- Write final reports (based on input from contracted vendors) and recommend next steps.

In October 2003, the Steering Committee approved Proof of Concept Evaluation Questions as shown in Attachment B.

In September 2003, the contract between Quality Corp and OMPRO as the Clearinghouse vendor was executed. The extended timeframe for finalizing the contract was due to delays in securing project funding and the need to refine the scope of the project and contract provisions. The contracted scope of work identified two phases. Phase I covered finalizing project plans, specifications and legal agreements for the Clearinghouse. Phase II covered receiving data from health plans, data merging and processing, generating reports, and preparing a final report. The contract authorized OMPRO to undertake the Phase I scope of work with the Phase II scope of work dependent on securing additional project financing.

At the time of OMPRO's selection as the Clearinghouse vendor (February 2003), the project schedule anticipated two months time from the start of the project to accomplish the Phase I objectives of (1) drafting the data management design with responsibilities and timelines, (2) drafting a data security plan, (3) finalization of data submission specifications, anticipated processes for imputing primary care physicians and crosswalks for the plans' disparate systems to identify providers and clinics, (4) execution of data sharing agreements with the participating health plans to receive and manage their data in compliance with HIPAA, and (5) collaborating with Riley Research Associates on the development of the physician survey process and design of reports.

The development of a standard HIPAA-compliant data sharing agreement and finalizing the data specifications were accomplished in about three months following the September

2003 execution of the OMPRO contract. The Phase I work scope was completed in early January 2004.

At the completion of OMPRO's Phase I work, the fund-raising for Phase II was not complete. OMPRO was not formally authorized to proceed with the Phase II scope of work to process the data submitted by the health plans until June 2004 although preparatory work on the project continued. OMPRO was only able to proceed with merging the health plan data files when all the data files were available, all the plans had signed data sharing agreements and the Phase II work scope was authorized and funded.

Phase I – HIPAA Compliance

HIPAA Compliance: Early in the project planning, it was believed that compliance with HIPAA privacy and confidentiality requirements might be an insurmountable obstacle to developing a clearinghouse. At the time HIPAA regulations were just being implemented. The full spectrum of health care organizations were trying to assess the impact of HIPAA and implement it within their organizations. OMPRO developed a standard data sharing (business associate) agreement for use between each health plan and OMPRO as the Clearinghouse vendor. Under the agreements, OMPRO acted as a business associate of the health plans for processing the submitted patient, provider, claims and pharmacy data. Each health plan retained ownership of their data. Specific provisions in the data sharing agreements required validating the relationship between patients and their physician providers to be sure there would not be inappropriate disclosure of patient information. It was therefore determined that it would be unnecessary to use additional agreements between OMPRO and physician practices before receiving reports.

The standard data sharing agreement developed by OMPRO was signed by five health plans without any modifications. Six health plans collaborated in developing a modified version of the standard data sharing agreement that refined several provisions. Those six plans all executed the modified standard data sharing agreement. The Oregon Medical Assistance Program and OMPRO already had a data sharing agreement in place that was judged sufficient to cover Clearinghouse activities.

As noted in Table 1, execution of the data sharing agreements by the twelve participating health plans occurred over an extended period from mid December 2003 to early June 2004. Health plans proceeded to submit their data files to OMPRO beginning in November 2003 and extending to early May 2004 sometimes in advance of executing the data sharing agreements.

Table 1. Data Sharing Agreement and Submission Highlights

	First Data Submission	Second Data Submission
Data coverage period	July 1, 2001 to July 31, 2003	April 1, 2002 to March 31, 2004
Data submission due date	November 21, 2003	August 31, 2004
Data sharing agreements executed	December 19/2003 to June 2, 2004 (5-1/2 months)	Already executed
Actual data submissions	November 21, 2003 to May 7, 2004 (5-1/2 months)	August 16, 2004 to September 2, 2004 (less than 2 weeks)
Plans submitting data	12	12
Plans with useable files	11	11
First date when files could be standardized and merged	June 22, 2004	September 3, 2004

Phase II – Working with Health Plan Data[3]

Scope of Work: The Phase II scope of work included OMPRO's management of the Clearinghouse functions to (1) manage the receipt of data from the health plans (2) match and merge the data for physicians and physician practice groups, (3) provide paper and electronic output to the participating physicians, (4) receive feedback from physicians about the accuracy of the information, (5) provide updated information back to the health plans, (6) create an analysis file with no personal identifiers for aggregate analysis and summary statistics of the process, (7) destroy all patient-identified data unless the participating health plans and physicians authorize the use of the data in an ongoing Clearinghouse, and (8) provide a written report that describes the success and failures of the pilot and recommends technical and legal steps to further the creation of an ongoing chronic disease data clearinghouse.

Expected Health Plan Participation: The goal of the Clearinghouse pilot was to engage the participation of at least four health plans. Twelve health plans agreed to participate, signing data sharing agreement and submitting data to the Clearinghouse. While the broad participation was highly desirable for many reasons, the broader participation added significant operational and processing burdens to the Clearinghouse pilot project.

Generating Health Plan Data Files: Each participating health plan had to create computer programs that would retrieve patient information, provider information, encounter claims and pharmacy claims from their internal claims systems and create data files for submission to the Clearinghouse that met the project data specifications. The data specifications provided (1) criteria to select plan members with a possible asthma or diabetes condition, (2) the structure and format of the data files, and (3) preferred and alternative processes for the secure submission of data files to the Clearinghouse. The effort required of each health plan to generate the initial set of data files varied but was

[3] Also see OMPRO's Final Report available at http://www.q-corp.org/.

significant. As noted in Table 1, each of the twelve participating health plan had to generate a first round submission of data that covered twenty-five months of claims information from July 1, 2001 through July 31, 2003. The first health plan submitted data files in late 2003 with the submission process extending into May 2004.

Standardizing Clearinghouse Data: In June 2004, OMPRO began work on the submitted data files. Each set of health plan data files required a series of processing steps before the files could be used including:

- convert ASCII, Access, Excel and SAS data files to Clearinghouse standard,
- review the data submitted for compliance to the data specifications,
- identify consistency and capture issues within a health plan's files, e.g., claim records submitted without matching patient or provider records,
- standardize non-conforming data to the specification, e.g., date formatting, gender coded as M or F rather than 0 or 1,
- remove duplicate patient or provider records,
- consolidate multiple claims files, e.g., separate inpatient and outpatient claim files, multiple pharmacy claim files,
- standardize name formats where multiple conventions used, and
- standardize formatting of records for consistency across plans, e.g. diagnosis and procedure coding, convert date text fields to date/time formats.

OMPRO's efforts to standardize the first round submission of health plan data occurred in June and July 2004. In one case, it was not possible to solve the problems for linking patients and providers with the claims data for one health plan, resulting in the use of data from eleven rather than twelve health plans. Once each of the health data files were standardized, the Clearinghouse was able to undertake the essential work to (1) assign CDDC ID numbers to patients and providers so records could be linked across plans and then added the CDDC ID numbers to the encounter and pharmacy claims records, (2) identify patients with asthma and diabetes using the Clearinghouse criteria and the broad base of claims data from the eleven health plans, (3) identify the primary care physician (PCP) for the patient using a PCP imputation algorithm.

In July 2004, OMPRO and Clearinghouse project staff met with analysts and programmers from the health plans to review a number of issues identified in the first data submissions. That meeting proved helpful in developing strategies to review the data files and complete the standardizing process. In some cases, plans resubmitted their data to address data capture or file structure issues. The health plan analysts confirmed that the initial effort to extract the data was significant but that it would be considerably easier to rerun the programs to generate the second round data submission. In order to speed-up the project, the Clearinghouse staff decided to have the health plans proceed with the second data submission in late August 2004.

In August 2004, several test clinics/practices were provided with lists of patients to confirm the linkage of the patients to the particular practices and confirm the asthma or diabetes condition. While it took one to two months to receive the feedback, the clinics and practices noted that there seemed to be errors and omission or flaws in the

identification process. In October 2004, updated patient lists were provided to several test practices with initial test reports in November 2004. Feedback from the revised patient lists and initial reports confirmed that there were problems with the algorithms for identifying and selecting the targeted patients, especially diabetes patients.

In November and December 2004, Clearinghouse staff reviewed the spectrum of issues involved with data standardization and algorithms for identifying asthma and diabetes patients. The staff considered the relative timeliness of the submitted data, cleanliness and accuracy of working with the first/initial data submission versus the second data submission, the second submission having fewer issues. The staff decided that the most effective use of the limited Clearinghouse resources would be to focus on the standardization and use of the second round data submissions. Statistics about the second round data submission are shown in Table 2.

Table 2. Scope of the Second Data Submission

	Second Data Submission
Data coverage period	April 1, 2002 to March 31, 2004
Data submission due date	August 31, 2004
Actual data submissions	August 16, 2004 to September 2, 2004 (less than 2 weeks)
Plans submitting data	12
Plans with useable files	11
Patient records submitted by 12 plans to CDDC	645,376
Provider records submitted by 12 plans to CDDC	298,671
Claim records submitted by 12 plans to CDDC (outpatient, inpatient, emergency and laboratory claims)	13,189,152
Pharmacy claims submitted by 12 health plans to CDDC	10,174,642

In January and February 2005, the data from the second submission was standardized and coded with CDDC IDs. The corrected algorithms to identify asthma and diabetes patients were applied to the consolidated claims data base for eleven health plans. Patient lists were provided to several physician practices to confirm that the patients were being seen by the clinic or practice and that the patient had asthma and/or diabetes.

Based on the confirmed patient lists received in March 2005, diabetes and asthma report sets were generated for ten physicians from three practices. As it turned out, producing the reports took considerable Clearinghouse staff time given the need to assure that that patients appeared on the proper physician reports and that physicians were grouped by practice.

When the reports were generated the practices/clinics noticed that some of their known patients were missing or not matched with the proper physician. From April through July 2005, project staff investigated these issues. The investigation concentrated on diabetes

patients from a particular clinic practice (Legacy Clinic Good Samaritan) that was utilizing a registry to track their diabetes patients. Data from several health plans was reviewed to determine possible causes for missing or mismatched patients. The registry of patients from the clinic was reconciled with patients in the Clearinghouse. Forty-seven percent of the diabetes registry patients were included in the Clearinghouse database. This seems reasonable given the health plan coverage mix for the clinic and the health plans participating in the Clearinghouse. Ninety-six percent of the patients who had data submitted to the Clearinghouse by the health plans met the Clearinghouse criteria for diabetes. The Clearinghouse was able to impute a PCP for 99% of these patients. However, about two-thirds of the PCP imputations were not matched to the proper physicians or the clinic. See additional comments below regarding the PCP issue.

Originally the Phase II work scope was projected to take about five months to process two rounds of data submissions from four to six health plans, identify asthma and diabetes patients, validate the patient lists with physician practices, and produce reports for twelve to fifteen practices. The pilot project required substantially more time and effort than expected to accomplish the core objective of determining the feasibility of the Clearinghouse, but was not able to fully accomplish the intended scope for all the objectives.

Phase II Data Management Issues[4]

Health Plan Cooperation and Performance: All the participating health plans demonstrated an outstanding spirit of cooperation in submitting their data and working with the Clearinghouse staff to resolve various data issues. Most plans did very well in trying to follow the data specifications and meet the needs of the Clearinghouse to carry out the pilot project. Nevertheless, there are some opportunities for streamlining the processes and improving data quality that involved providers, health plans and the Clearinghouse that should be addressed for an ongoing Clearinghouse operation to be successful.

Problems with Claims Data and Billing Practices: Reporting systems that use claims data are often criticized because they do not provide a complete picture of a patient's condition since they lack specific clinical detail. Claims data is also criticized because it frequently has errors or other problems. Claims data can however provide useful information about encounters including outpatient visits, physician services, outpatient laboratory tests performed, and prescriptions filled. Indeed the goal of the Clearinghouse is to make such information available to physicians on a systematic basis and assess its utility. The Clearinghouse pilot encountered many of the known problems in working with claims data. Some problems were tracked back to issues with the systems and processes used for billing by physician practices and other providers. Examples of such issues include services billed in the name of physicians no longer involved with a clinic, lags in updating provider information by billing offices, laboratory service orders submitted for multiple physicians in the name of a single physician. Some problems relate to the

[4] Also see OMPRO's Final Report available at http://www.q-corp.org/.

realities of delivering health care in a complex system. Examples include patients seen by providers other than their usual PCP, physicians who practice in multiple locations, county or other clinics staffed by a multiple clinicians where the services are billed in the name of the clinic, and clinics with resident physicians are not billed in the name of the resident.

Data Specifications: The data specifications for the pilot were developed during the planning and consensus building process for the Clearinghouse in 2002 with the participation of health plans and other stakeholders including information technology analysts and managers. The specifications recognized that health plan information systems varied in terms of content and capabilities of the corporate organizations, types of product offerings, the historic evolution of the products and the information systems to support them. The specifications were focused on collecting the essential data, allowing health plans to submit "raw" data that they had readily available. There was no expectation that all plans would be able to provide data on all the specified variables.

The specifications allowed some discretion including:

- multiple formats for submitting data, e.g., ASCII text, Access database, Excel spreadsheet, SAS datasets, others by arrangement,
- primary and alternate means to submit the data files,
- submission of multiple separate files for claims, providers, or patients, and
- for some data elements plans were ask to submit the data along with documentation of how the variable functioned and/or were coded.

For some variables better data formatting specifications would have minimized the work required to standardize the data, e.g., identifying number fields, date formatting, diagnosis and procedure coding.

In order to encourage broader plan participation in the pilot, the project staff elected to make the process as simple as possible for the health plans. For a pilot project, this was a reasonable approach rather than trying to reconcile, understand the differences in health plan data sets, and develop a tighter set of data specifications and standards. The Clearinghouse took on the role of understanding the differences in health plan data sets and standardizing the data files. It appears that the magnitude of the role to sort out the variations in health plan submissions and the work to prepare the data files for use in the Clearinghouse was significantly underestimated. The Clearinghouse assumption of this role would not have been such an issue with a small number of participating plans but became a bigger problem with twelve participating plans.

Efforts to develop an operational version of the Chronic Disease Data Clearinghouse or any other initiative that will merge data across health plans should capitalize on the experience from the Clearinghouse pilot to develop more rigorous data specifications.

Compliance with Data Specifications: While the data specifications allowed some flexibility in structuring data for submission to the Clearinghouse, some plans did not follow all of the specifications. The compliance issues included such things as gender coding (M and F rather than 0 and 1), inconsistent name formats, data in incorrect locations (names and others), and multiple variables combined in the single field.

To minimize the impact on the health plans for the pilot project the Clearinghouse corrected these problems rather than ask the health plans to correct the problems and resubmit the data. Such practices in an operational Clearinghouse would not be reasonable or sustainable.

Scope/Consistency of Data Submission: Participating health plans were asked to identify members with particular criteria for diagnoses, drugs or other indications of asthma or diabetes. Once the members/patients were identified, the plans were to submit the demographic and claims information related to those patients. It appears that some plans were quite diligent in applying the member identification criteria, other plans were quite liberal in using the criteria and a least one plan did not apply the criteria (submitting data on all plan members). This was not a major problem for the Clearinghouse operations other than requiring standardizing, managing and storing more data than necessary. For a few plans, inconsistencies were noted between their data files, e.g., claims information was provided without relevant patient or provider information. For one health plan, the Clearinghouse staff was unable to resolve the data linkage problems tying patient and provider with the claims data. Due to time constraints, patients and claims for that health plan could not be used in the pilot project.

Technology Infrastructure Support: The information technology infrastructure used to conduct the Clearinghouse pilot was suboptimal to support the volume of data, the tasks involved in standardizing data, efficiently managing the data, generation of statistics, and producing reports. Information technology resources (hardware and software) that were expected to be available to support the project turned out not to be available. The protracted schedule, funding delays, and staff turnover exacerbated the technology support issues due to losses of project momentum and continuity.

Identifying Patients with Asthma and Diabetes

Patient Identification and Selection by Health Plans: Participating health plans were asked to submit data about members that either have or possibly have asthma or diabetes. The criteria for submission of data by the health plans were more liberal than the criteria used by the Clearinghouse for acceptance of patients in order to maximize the potential for properly identifying the appropriate pool of patients. Health plans were ask to use the following inclusion and data submission criteria:

- Health plan members who have at least one asthma or diabetes transaction for inpatient, outpatient, emergency department, or pharmacy services transactions in the preceding one-year period for asthma or in the preceding two-year period for diabetes should have their data submitted to the Clearinghouse.
- Inpatient, emergency and outpatient visit transactions should be used to identify eligible plan members if they contain specified diagnosis coding:
    - Asthma case identification: If a claim contains any asthma-related ICD9-CM diagnosis code (493.xx) that member meets the asthma criteria for inclusion in the clearinghouse. (Based on *HEDIS 2004* definitions)

    - Diabetes case identification: If a claim contains any diabetes-related ICD9-CM diagnosis codes (250, 357.2, 362.0, 366.41, 648.0), that member meets the diabetes criteria for inclusion in the clearinghouse. (Based on *HEDIS 2004* definitions)
- Pharmacy claim transactions should be used to identify eligible plan members if their pharmacy claim transactions contained codes for drugs related to asthma or diabetes as articulated by HEDIS criteria.
- Once a patient is identified for inclusion in the Clearinghouse data submission, all claims associated with that patient for a two year period (April 1, 2002–March 31, 2004 for second data submission), including pharmacy claims should be supplied to the Clearinghouse.

Clearinghouse Inclusion Criteria for Asthma and Diabetes: Once the data standardization process was completed and Clearinghouse patient ID numbers were assigned to all claims transactions, the Clearinghouse began the process to identify patients that should be eligible for inclusion for reporting purposes. The Clearinghouse inclusion criteria was more specific and stringent than the health plan data submission selection criteria in order to maximize the accuracy for selecting the appropriate patients of interest. The algorithms for including asthma and diabetes patients were:

Asthma: Compute asthma = yes using the definition developed by Oregon's Asthma Data Workgroup:

A. Three or more asthma medication dispensings (using list of asthma medications) **OR**
B. One or more acute inpatient discharge(s) with a primary diagnosis of asthma **OR**
C. One or more emergency department visits with a primary diagnosis of asthma **OR**
D. Two or more outpatient visits with asthma listed anywhere as one of the diagnoses.

Diabetes: Compute diabetes = yes using the HEDIS 2004 definition:

A. Dispensed insulin or oral hypoglycemics/antihyperglycemics during the two-year period (using list of medications provided) **OR**
B. Two face-to-face encounters with different dates of service in an ambulatory setting or nonacute inpatient setting with a diagnosis of diabetes **OR**
C. One face-to-face encounter in an acute inpatient or emergency room setting during the two-year period with a diagnosis of diabetes.

Table 3 show the total number of patients identified by the twelve participating health plans and the number of patients from the eleven health plans with useable data. As noted above, the plans varied in how they determined which patients should be included in their data submissions.

Table 3. Patients possibly eligible for meeting CDDC inclusion criteria

	Asthma Patients	Diabetes Patients
Total patient records submitted by 12 health plans in second data submission	645,376	
Total patients records submitted by 11 health plans with useable data files#	623,439	
Unduplicated number of patients across the 11 health plans	581,834	
Total patients meeting CDDC inclusion criteria	62,634	88,248

The various data files submitted by one health plan could not be linked together within the available processing timeframe and were therefore not included in the subsequent processes for selecting patients.

After application of the Clearinghouse selection algorithm, 62,634 asthma patients and 88,248 diabetes patients were identified for inclusion in the Clearinghouse. Table 4 indicates the number of asthma and diabetes patients that met the various inclusion criteria. It is particularly noteworthy that over 80% of patients were identified as having asthma or diabetes based on the pharmacy claims data.

Table 4. Patients meeting CDDC inclusion criteria

	Asthma Patients	Diabetes Patients
Total patients meeting CDDC inclusion criteria	62,634	88,248
Patients meeting drug inclusion criteria	50,977 (81.4%)	76,300 (86.5%)
Patients meeting outpatient inclusion criteria	20,552 (32.8%)	56,559 (64.1%)
Patients meeting emergency department visit inclusion criteria	5,959 (9.5%)	6,947 (7.9%) combined ED visits and hospitalizations
Patient meeting inpatient inclusion criteria	1,699 (2.7%)	

It appears that the process for identifying patients as having diabetes or asthma was highly accurate as confirmed by four test clinics (over 90% for diabetes and over 80% for asthma with COPD patients confounding the identification of asthma cases). The 62,634 asthma patients and 88,248 diabetes patients identified seems consistent with the expected prevalence for these conditions based on the estimated covered lives for the participating health plans.

Matching Patients with Physicians and Practices[5]

A fundamental goal and design principle for the Clearinghouse was the desire to provide individual primary care physicians with reports about their patients from the merged encounter and pharmacy claims files. Sending reports to the correct physician requires a means to accurately link patients to the appropriate primary care physician (PCP). At early planning meetings in 2000, 2001 and 2002, health plan representatives discussed their issues and frustrations in trying to accurately identify the appropriate PCP since most plans try to provide information about patients to their physicians through various reports. Plans described various algorithms and processes that they have evolved. Most plans seem to acknowledge that getting information about patients to the appropriate PCP was a difficult challenge. For many situations the matching of patients and primary care physicians was relatively straight forward and accurate. In other situations accurate matching was not possible.

Another fundamental principle built into the Clearinghouse pilot (through the data sharing agreements signed by each participating health plan) was that Clearinghouse reports could only provide information about a particular patient to a single participating physician. The language from the standard data sharing agreement specifies:

> Data dissemination is limited to Participating Physicians and Participating Plans. OMPRO shall aggregate data received from Health Plan and other Participating Plans and provide to and produce a report for each Participating Physician who regularly and primarily cares for a health plan member and who has been identified by (i) Health Plan as such member's primary care physician or (ii) by OMPRO using an imputation algorithm. OMPRO will provide a report to only one Participating Physician per health plan member. Prior to transmitting reports to Participating Physicians, OMPRO will send such Participating Physician a verification list of health plan members designated or imputed to be under such physician's care. Each Participating Physician will be required to verify this health plan member list prior to report transmission by OMPRO.

Clearinghouse PCP Algorithm: After the selection of OMPRO as the Clearinghouse vendor in early 2003, OMPRO and Clearinghouse staff worked to refine an algorithm that could be used for the Clearinghouse. The algorithm was finalized in the fall 2003. The planned algorithm determined a PCP for Clearinghouse reporting purposes as follows:

- if a patient is covered by a single health plan and has a plan-assigned PCP, the Clearinghouse should consider that physician the designated Clearinghouse PCP and send reports to that physician,
- if a patient is covered by a single health plan and did not have a PCP assigned by the plan, the Clearinghouse imputed a PCP assignment to the physician with the largest number of visits; in the case of equal visit counts the most recent physician became the designated PCP, and
- if a patient was covered by multiple plans, the plan with the most visits is identified as the major plan; then a PCP assignment was imputed to the physician with the

[5] Also see OMPRO's Final Report available at http://www.q-corp.org/.

largest number of visits; in the case of equal visit counts the most recent physician became the designated PCP.

However, OMPRO encountered a number of issues in applying the planned PCP assignment process. Health plans typically identified PCPs for patients where (1) the provisions of the particular coverage plan provided for a contractually assigned PCP, or (2) the health plan had its own process for imputing a PCP. In many cases contractually assigned PCPs were clinics or group practices rather than individual physicians, which is contrary to what had been expected. Some patients were flagged as having an assigned PCP, but the PCP name was missing. Some dates associated with the assigned PCP did not seem reasonable in the context of individual patients. The accuracy or consistency of plan assigned or imputed PCPs could not be determined from the information available at the time.

As a result, plan assigned or imputed PCPs were not used as originally intended. Instead, the Clearinghouse PCP assignment algorithm was used to impute a PCP for each patient as if there were no plan identified PCP. Thus, there is an opportunity to compare plan assigned or imputed PCPs with those imputed by the Clearinghouse algorithm but such analysis was beyond the scope that could be accomplished in the pilot.

With the knowledge gained in the course of the pilot, there were clearly some flaws with the assumptions underlying the Clearinghouse PCP algorithm process as originally planned. The planned Clearinghouse process assumed and expected that:

- PCPs would be identifiable at the level of the individual practitioner when in fact the responsibility for the care of many patients is at the clinic of practice level,
- provider data within and across health plans would be sufficiently consistent to generate reasonable PCP assignment results without extensive customization or analysis for each health plan's data, and
- providers would be accurately identified in the claims transactions.

None of these assumptions proved workable. Without further analysis, it is not possible to determine whether the PCP algorithm assignment process could have performed more favorably.

Fundamental PCP Philosophy Issue: The design philosophy for the Clearinghouse pilot was to focus reports on individual clinicians who were primarily responsible for the care of patients with asthma and diabetes. Indeed, in some cases patients are assigned to specific primary care physicians. However, even where there is an explicit assignment process, it may be that a clinic or practice group is identified as the assigned PCP. PCP assignments at a clinic or practice-level are quite prevalent where clinics are operated by various counties or non-profit organizations as well as teaching clinics with resident physicians. After working with the health plan data sets, it appears that there is no consistent means by which individual clinicians can be accurately identified across health plans and in some cases within a health plan. The best common level for linking patients with providers seems to be at the practice level, that is, the organizational entity that generated the claim billing to the health plan. In some cases, the billing entity is an individual clinician. Most frequently it is a clinic or practice group.

The design philosophy for the Clearinghouse pilot was to identify the primary care physician for patients for generating the reports and then aggregate information about a clinic or practice from the collection of data for the involved clinicians. This proved workable for some groups of physicians and their practices and some health plans but not across the spectrum of patients, physicians and practices in the Clearinghouse pilot. A focus on linking patients with clinics or practices first and then identifying specific individual clinicians will likely be a better approach for an ongoing Clearinghouse.

Another Fundamental Issue – Clinical Care is a Team Effort: The Clearinghouse pilot not only assumed that it was possible to identify the appropriate PCP but also that a single provider was the regular, consistent and ongoing clinician working with the patient that should be the sole recipient of reports about the patient. The pilot included a specific prohibition against providing information to any clinician other than the single identified PCP. The reality demonstrated by the project is that many clinicians are routinely involved in the care of individual patients. Even where there is a contractually assigned PCP, that clinician may only be one of many clinicians the patient sees. Every clinician who encounters a chronic care patient has the opportunity to see that the patient gets the services they need. Future efforts need to consider appropriate policies so that the benefits of the Clearinghouse reporting tools are available to the spectrum of clinicians caring for a patient with appropriate confidentiality and security safeguards (HIPAA compliance).

About Clearinghouse Asthma and Diabetes Patients

As noted above the algorithm for identifying asthma and diabetes patients appears to work well after some initial programming problems were identified and corrected. Table 5 shows some basic demographic information about the included patients.

Table 5. Demographic Characteristics of Included Patients

	Asthma Patients	Diabetes Patients
Gender mix (female/male)	58.7% / 41.3%	54.0% / 46.0%%
Ages 0 – 5 years	5,369 (8.6%)	97 (0.1%)
Ages 6 – 18 years	10,358 (16.5%)	1504 (1.7%)
Ages 19 – 55 years	26,402 (42.2%)	33,844 (38.4%)
Ages 56 – 64 years	8,594 (13.7%)	18,837 (21.3%)
Ages 65 and over	11,911 (19.0%)	33,965 (38.5%)
Total included patients	62,634 (100.0%)	88, 247 (100.0%) (1 missing)

Table 6 identifies the numbers of patients included from the three categories of participating health plans. The five insurance-based health plans represent the companies licensed by the Oregon Department of Commerce, Insurance Division as insurance companies. The five capitated health plans represent health plans that are not licensed as insurance companies. The five capitated plans and the Providence Health Plan (a licensed insurance company) are Fully Capitated Health Plans (FCHP) serving the Oregon Health Plan, Medicaid and CHIP populations. The Oregon Medical Assistance Program – Fee for

Service (OMAP-FFS) represents Oregon Medical Assistance Program clients not covered by FCHP.

Table 6. Patients identified by Health Plan Category

	Asthma Patients	Diabetes Patients
By 5 insurance-based health plans*	44,246	68,684
By 5 OHP capitated health plan**	12,033	13,697
By OMAP-FFS	17,412	20,822
Total patients identified by plans (may count the same patients multiple times)	73,691 (100.0%)	103,203 (100.0%)
Patients with multiple health plans records	11,057 records for 10,208 patients	14,955 records for 12,477 patients
Unduplicated number of patients	62,634	88,248

* Includes ODS, Lifewise, PacificSource, Providence and Regence
** Includes CareOregon, ClearChoice, FamilyCare, MPCHP and Tuality

Table 6 indicates that there are more than ten thousand asthma and twelve thousand diabetes patients that were covered by more than one health plan during the two-period covered by the claims data. The overlapping involvement reflected is made up of (1) some patients that have coverage by multiple plans at the same time (e.g. a husband and wife each having employer sponsored health plan coverage from different plans) and (2) patients moving between plans within the two year period. Although the Clearinghouse data has not been analyzed to determine the health plan coverage patterns, it is believed that the latter situation is dominant. Indeed, discussions with Oregon Health Plan staff suggest that there has been significant movement between some health plans and OMAP-FFS as the program eligibility and plan offerings have changed over time. Overlap is also significant in the commercial licensed insured patient population.

As reflected in Table 7, multiple plan coverage situations most frequently involve two plans but overall 16.3% of asthma patients and 14.1% of diabetes patients were served by more than one health plan.

Table 7. Patients served by Multiple Health Plans

Patients Served by	Asthma Patients	Diabetes Patients
- by 2 health plans	9,577 (93.8%)	11,661 (93.5%)
- by 3 health plans	612 (6.0%)	796 (6.4%)
- by 4 health plans	18 (0.2%)	19(0.2%)
- by 5 health plans	1 (0.0%)	1 (0.0%)
Total patients served by multiple health plans	10,208 (100.0%)	12,477 (100.0%)
Total patients in CDDC with target condition	62,634	88,248
Proportion served by multiple health plans	16.3%	14.1%

Many if not most of the participating health plans provide one or more services to assist physicians and patients with chronic disease including such things as performance reports to physicians, alerts to physicians about possible patients' care needs, case management coordination, educational materials, nurse-on-call or other disease management services. To the extent that patients are involved with multiple plans, the information about a patient that is available to each health plan may be incomplete. In such circumstances reports or alert notices to physicians from the health plans may be incomplete and/or patients may appear on multiple reports/alerts, each with incomplete information.

Patterns of multiple health plan involvement are illustrated in Table 8 based on the situations where just two health plans are involved. For asthma patients covered by two plans, 24% involve two commercial insurance-based plans, 41% involve a commercial insurance-based health plan with some other plan, and over 70% involved OMAP-FFS as one of the two parties. For diabetes patients covered by two plans, nearly 40% involve two commercial insurance-based plans, 59% involve a commercial insurance-based health with some other plan, and over 56% involved OMAP-FFS as one of the two parties.

Table 8. Patients Served by Two Health Plans

	Asthma Patients	Diabetes Patients
Just among 5 insurance-based plans*	2,311 (24.1%)	4,638 (39.8%)
Just among 5 OHP capitated health plan**	128 (1.3%)	137 (1.2%
Between any of the 5 insurance-based plans* and any of the 5 OHP capitated health plan**	201 (2.1%)	343 (2.9%)
Between any of the 5 insurance-based organizations* and OMAP-FFS	1,484 (15.2%	1,932 (16.6%)
Between any of the 5 OHP capitated health plan** and OMAP-FFS	5,483 (57.3%)	4,611 (39.5%)
Total patients served by two health plans	9,577 (100.0%)	11,661 (100.0%)

* Includes ODS, Lifewise, PacificSource, Providence and Regence
** Includes CareOregon, ClearChoice, FamilyCare, MPCHP and Tuality

From a health plan's perspective, it may be relevant to know the proportion of their patients that have a prior, current or subsequent relationship with another plan. Table 9 identifies the proportion of patients served by a second health plan for the cluster of insurance-based plans, OHP capitated health plans, and OMAP-FFS.

Table 9. Proportion of Health Plan Patients Served by a Second Plan, excluding situations with more than two plans)

	Asthma Patients	Diabetes Patients
For the 5 insurance-based plans*	14.2% (range: 9.9% to 22.9%)	16.8% (range: 10.1% to 24.2%)
For the 5 OHP capitated health plan**	49.4% (range: 43.0% to 53.7%)	38.2% (range: 30.9% to 45.8%)
For OMAP-FFS	39.8%	31.8%
Overall	26.0%	22.6%

* Includes ODS, Lifewise, PacificSource, Providence and Regence
** Includes CareOregon, ClearChoice, FamilyCare, MPCHP and Tuality

Reports for Physicians and Practices

The primary Clearinghouse product is the reports provided to physicians and practices about their asthma and diabetes patients. The design of these reports was a paramount concern throughout the project in order to maximize the utility of the information to practices. The report design process included reviews of various sources regarding asthma and diabetes chronic disease care management including:

- sample reports collected from various Oregon health plans,
- recognized asthma and diabetes evidence-based patient management criteria,
- performance measurement tools used nationally and in various communities,
- responses to specific questions about reporting needs collected from the initial Riley survey of physician practices, and
- data to be available from the Clearinghouse.

Based on these reviews, Clearinghouse staff developed draft asthma and diabetes report formats. The reports were subsequently reviewed by several physicians and practice managers, and the Clearinghouse Steering Committee.

The set of reports provided to each participating physician include:

Report A – Most Recent Services Provided: list of patients with asthma or diabetes for the physician with dates of last known service for key guideline measures,

Report B – Take Action Report: list of patients with asthma or diabetes for the physician with dates of last know service for key guideline measures with potential action items flagged based on guidelines,

Report C – Individual Patient Progress Reports: provides available encounter and pharmacy data related to the patient's asthma or diabetes with a separate report for each patient, and

Report D – Practice Summary Report: presents (1) summary counts of patients eligible for each for each guideline (quality of care) indicator/measure and the number and percentage meeting the criteria, and (2) a graphic comparison for each indicator showing the percentages of patients meeting the criteria for the provider, the clinic or overall practice, and all Clearinghouse patients.

Sample sets of asthma and diabetes reports can be found at http://www.q-corp.org.

Asthma and Diabetes Outcome Measures

Performance statistics for Clearinghouse asthma and diabetes patients computed from the Clearinghouse data were included in the reports to physicians about their own patients. Measures derived from Clearinghouse data include:

Asthma Measures:

- Inhaled medication ratio (inhaled corticosteroid / (inhaled corticosteroid + short-acting inhaled $beta_2$-agonist): > 0.5 over last 12 months.
- Short-acting inhaled $beta_2$-agonist: < 6 dispensings of in past 12 months
- Inhaled corticosteroids: > 1 dispensing of in past 12 months
- Outpatient visits: at least one visit in past 12 months
- ED visits: <1 visit in past 12 months
- Follow-up after ED visit: outpatient visit within 30 days
- Hospitalizations: <1 visit in past 12 months
- Follow-up after hospitalization: outpatient visit within 30 days

Diabetes Measures:

- Outpatient diabetes visit in last 12 months
- Dilated eye exam in last 12 months
- HbA1c within last 6 months
- Lipid panel within last 12 months
- Nephropathy test within last 12 months

It should also be noted that for some measures, the Clearinghouse process and specific computational methods may need review and modification based on feedback received from clinicians. As an example, the follow-up visit measure for asthma patients after an emergency visit or hospitalization may be overly restrictive; follow-up visits were not counted if asthma was not coded on the claims.

Aggregate and Plan Performance Reports

Many of the participating health plans routinely measure the level of performance of their provider network for their patients using national standards such as the HEDIS® (Health Plan Employer and Data Set) measures of the National Committee on Quality Assurance (NCQA). It would have been possible to compile comparable aggregate results by health plan, geographic area, or all patients. Resources were not available to compile the aggregate performance measures or develop reports that could provide each participating health plan with information about their patients.

In discussions with several health plans, they routinely find higher levels of performance when they review patient records than the rates they calculate using claims data. Some of the differences in performance rates could be attributable to patients being covered by multiple plans over the measurement period with each plan having only a portion of the claims data used in the measurement calculation. Clearinghouse data could be used to assess the impact of the multiple coverage situations on claims-based measure calculations.

Reactions from Physician Practices[6]

In April 2005, Riley Research Associates conducted follow-up surveys of four physician practices to determine

- the accuracy of the process,
- the usefulness and of each report, and
- the overall value of the Clearinghouse program.

Participants included physicians, nurses, practice managers and quality coordinators. In addition to assessing content, character, format, and usefulness of the Clearinghouse output, Riley also asked participants to contrast and compare the Clearinghouse reports with existing sources of patient information, and probed their perceptions regarding future use of – and support for – the Clearinghouse concept.

The Riley follow-up survey plan contemplated surveying a larger number of physician practices/providers for the final evaluation phase. However, timing constraints for Clearinghouse production of patient lists, validation the patients lists by practices, and then producing the asthma and diabetes reports severely limited the scope of the follow-up evaluation surveys. Even so, the four practices surveyed provided some diversity in types of practice organizations and settings. At best, the scope of the survey should be considered as exploratory.

As noted in the Riley report:

- The overwhelming issue raised by the medical practitioners, was *missing data*,
- Nevertheless, there was also strong agreement that the Clearinghouse *concept* has great potential.

Specific excerpts from the Riley report are that:

> The missing data were most often manifest in terms of known patient visits, which were determined to have occurred within the timeframe of the report, but did not appear in the report. Two of the practices (Portland Family Practice and Legacy) were pleased with the accuracy, and were committed to sharing the results with their physicians, while the other two (Salem Clinic and Maple Street), felt the missing data rendered the content of these reports unusable.
>
> There was some speculation as to the reasons for the missing data. Inconsistent coding for patient visits was suspected as a prime reason. Some indicated that when patients

[6] The complete Riley Research Associates report can be found at http://www.q-corp.org/.

visit for multiple reasons, other codes (besides asthma or diabetes) are often used, especially if the other conditions were more complex and/or are reimbursed at higher levels. Similarly, if the patients' visit was scheduled for a different purpose, the asthma or diabetes treatment may not have been recorded. One practice manager said: "There's not a lot of consistency from one practice group to another, about how things are coded."

Without improvements in the comprehensiveness of the records (at the physician practice), the effort would likely fail. The two clinics with the most missing data concerns did not, and would not distribute the current reports to the patients' physicians. Their experience suggests that once a physician deems a source unreliable, he/she will never take the time to give it a second chance.

Despite the missing data, there was broad belief in the potential value of the Clearinghouse program. Current versions of patient reports from insurance providers are said to "pile up for months," and one clinic reported that physicians routinely "toss them" (unexamined). The Salem and Maple Street Clinic representatives saw less value in the individual patient reports, because they have their own Electronic Medical Records (EMR) systems.

All four clinics expressed great interest in the summary page (Report D), which provided a comparison of results for their clinic (or practice) versus the State of Oregon. Some pointed out, however, that due to the significant missing data, their stats were underreported, thus diminishing the value of the current report.

Missing data aside, the planned content and refined formats portend great usefulness. There were a few exceptions: some felt that office staff requires less complex data, particularly if the report was likely to be reviewed by a manager or clerical staff member, rather than by a physician.

One respondent thinks that in order for the information to be viewed as effective by the doctors, the Clearinghouse will need a "champion" at the practice, who will train and promote the information.

Most of the reports were highly valued (assuming the accuracy and completeness can be improved). Two practices gave lower usefulness ratings on some patient reports because their internal electronic medical records system was already accomplishing the same goal.

Overall Program Value Rating

When asked to make an overall assessment of this program, versus the traditional methods of reports, the ratings were clear and highly positive toward the program.

Please contrast and compare the value of the traditional approach of receiving patient information (multiple sources/formats), to this "Clearinghouse" approach (single source/format) *(1 – 10 Scale):*

Traditional Approach	Rating: 1.4	Clearinghouse Approach	Rating: 8.5
	"Doc's toss them"		"If accurate"

Key Benefits

Participants think a properly implemented system would increase healthcare efficiency, saving time for the doctors, the practices, and potentially providing patients with more proactive treatment. "The health plans would be the real winners," said one.

Some believe the Clearinghouse could save patient and staff time, resulting in fewer emergency room and hospital visits. One characterized the Clearinghouse as: "An awesome statewide system (and a) great first step."

Report D (Aggregate / Comparative Report) was a very compelling report. Medical staff and doctors alike were very much interested in comparing their practices with others. "But if our results are incomplete, it's not fair."

Future Considerations

Two of the participants already have an Electronic Medical Registry, and one other anticipates the possibility. The consensus is that reports need to be in an electronic "downloadable" format (such as Excel or Access), if not for importation, at least so that the clinic director can better format and deliver the reports within the practice.

The complete Riley Research Associates report on the follow-up survey can be found at http://www.q-corp.org/.

Summary of the Physician Practice Survey Responses: The follow-up survey by Riley Research Associates of the small group of participating clinics indicated the merged reports are dramatically more useful than reports supplied separately by multiple health plans. On a ten-point scale on the overall value of reports, median scores for the traditional approach with multiple reports and formats was 1.4 (highly unfavorable, clinicians often toss them out) compared to 8.5 (highly favorable) for merged reports. Practices noted the potential for increased efficiency by saving time for doctors and their staff, providing patients with more proactive treatment thereby benefiting the patients and health plans including fewer emergency room and hospital visits. Physicians found the pharmacy data very helpful because this is the only source of information about what drugs their patients are actually obtaining. Clinicians and practice managers indicated a strong interest in the quality measures report comparing standard performance measures within their practice and with aggregate data for other practices. **The timely reporting of accurate and complete information is critical for the reports to be useful to clinicians and for Clearinghouse credibility.** Unfortunately, the limited scope for testing the reports could not assess the level of interest from a sufficiently broad-base of physician practices to draw conclusions regarding utility of the reports in relation to the cost to produce them.

Project Management

Early Planning - Developing a Consensus for the Clearinghouse: The early planning and consensus development activities for the Clearinghouse would never have occurred without the collaborative orientation of the participants in the Oregon Diabetes Coalition and the Chronic Disease and Prevention section of the Oregon Department of Human Services, the interim leadership for the Quality Corp provided by the Oregon Coalition of Health Care Purchasers, the Quality Corp board members and the medical directors and other leaders of Oregon's health planned. As noted above, the needs identified early in the process to facilitate the development of tracking systems and registries along with sharing available information from health plans through a pooled database were crucial to initiating and moving the Clearinghouse pilot project forward. The process was also accelerated by the early recognition that the many chronic conditions face the same issues as managing diabetes, leading to the expansion of the Clearinghouse pilot to include asthma patients. The facilitating roles of Quality Corp and the Chronic Disease and Prevention sections of DHS, as neutral parties cannot be overstated in creating the forums and dialogue to enable the various stakeholders to collectively advance improvements in health care for Oregonians by working together collaboratively. The various stakeholders participating in the planning contributed substantial time and effort to develop the Clearinghouse concept, project plans and specifications that enabled the pilot project to become a reality.

Making the Clearinghouse a Reality: After a consensus was developed to proceed with the Clearinghouse, continuing staffing support for the process was provided by the Asthma and Diabetes Programs and other staff of the Chronic Disease and Health Promotion section of DHS as part of funding from the CDC. Without this facilitating and coordinating support, the Clearinghouse project would have faltered. This DHS staffing facilitated selection of the Clearinghouse vendor, establishment an ongoing support of the Steering Committee, recruitment and liaison with physician practices and relationships with OMPRO and Riley Research Associates as project contractors. Again, it is hard to overstate the importance of the coordinating and facilitating roles played by DHS in carrying out the Clearinghouse pilot project.

Monitoring and Evaluation of the Clearinghouse Project: In the Fall of 2003, the Northwest Health Foundation provided a grant to Quality Corp to monitor and evaluate (a) six pilot project efforts to develop diabetes and asthma tracking systems in physician practices and (b) the Clearinghouse project. Witter and Associates was engaged to monitor and evaluate the projects. This project report was developed as part of that engagement.

Project Financing: The Clearinghouse pilot project was conducted without adequate up-front financing for Clearinghouse operations and project management. In retrospect, the overall pilot project probably represents total costs by all participants of around $1.5 million considering the direct expenses to operate the clearinghouse, contracted survey and project monitoring/evaluation services, contributed effort by the participating health plans and participating physician practices, and coordinating support by the Chronic Disease and Health Promotion section of DHS and Quality Corp. Without substantial contributions from DHS and OMPRO it would have been impossible to finish the pilot.

Contracted services with OMPRO as the Clearinghouse vendor, Riley Research Associates and Witter and Associates totaled around $150,000. These funds only became available in a piecemeal fashion. The project sponsors were unable to authorize OMPRO as the Clearinghouse vendor to proceed with the Phase II scope of work to process submitted health plan data for nearly six months because funds were not available. The delays caused by the lack of sufficient upfront funding caused project delays, disrupted the momentum and continuity of the project (further exacerbated by staff turnover), nearly jeopardized the entire project as well as testing the goodwill of health plan and clinic partners. Future Clearinghouse or other similar initiatives should better recognize the scope of planned effort and be adequately funded prior to commencing the project.

Accomplishments and Opportunities

Accomplishments: The Chronic Disease Data Clearinghouse proof-of-concept pilot has been highly successful in exploring the issues that need to be addressed in developing an operation clearinghouse or similar efforts that utilize pooled health plan claims data. The Clearinghouse pilot demonstrated that health plans and other stakeholders can work collaboratively to overcome the political and other issues in order to improve the delivery of health care. The pilot demonstrated that the legal and HIPAA regulatory requirements related to patient confidentiality and security can be addressed. The technical operations for a Clearinghouse pose significant challenges. The lessons learned in the pilot are valuable in identifying solutions to the technical challenges for an operational version of the Clearinghouse.

Physician reaction to the concept of consolidated Clearinghouse reporting system seems positive, **if the reports are timely and accurate.**

Unfinished Work: While the Clearinghouse pilot project was successful in addressing the core objectives of testing the Clearinghouse concept, the project was unable to accomplish everything originally contemplated due to (1) funding and timing constraints, and (2) the complexity of understanding and addressing the technical and operational challenges. Most importantly, the pilot was unable to provide reports to large number of clinicians and get their feedback to determine if they would use claims-based encounter and pharmacy reporting tools and if the benefits of the reporting would be worth the investment required to produce them.

The pilot was also unable to accomplish such things as:

- fully utilize data from the first submission or combine the two data submissions,
- develop electronic options for providing reports to physician practices,
- develop electronic interfaces to download Clearinghouse data into physician practice electronic record systems and/or registries,
- provide Clearinghouse data to the three diabetes and three asthma demonstration tracking projects,
- provide a full spectrum of statistics about the merged data sets,
- work with clinicians to refine the reports,

- calculate aggregate outcome measures by health plan, and
- explore alternative approaches for matching patients to physicians and practices.

Opportunity - Learning More About Asthma and Diabetes Care in Oregon: Data gathered in the Clearinghouse pilot represents **a unique and invaluable resource** that could be used to better understand asthma and diabetes in Oregon. The pilot project has not been able to analyze the Clearinghouse data sufficiently to gain insight into many of the Clearinghouse operational issues, let alone, use the data to better describe asthma and diabetes care in Oregon. There are a variety of public health, health policy and academic research issues that could be addressed with the Clearinghouse data but were clearly beyond the scope of the pilot. The Clearinghouse pilot will produce an analytical file that could be used for non-commercial policy and research purposes. The analytical file will be fully HIPAA-compliant to protect patient confidentiality and governed by strict policies still under development.

Opportunity - Clearinghouse as a Bridging Strategy: There is growing momentum to encourage physician adoption of electronic health record systems (EHR) by physicians, develop regional systems for exchanging clinical information, and to differentially reward providers for utilizing best practices and providing high quality health care. EHRs, regional health information organizations (RHIO), pay-for-value (P4V), pay-for-performance (P4P), and pay-for-quality (P4Q) will all take time to accomplish. Implementing P4V or similar programs will require systems that try to access and merge data from multiple health plans much in the same manner as the Clearinghouse pilot. Those efforts **will face the same hard challenges of the Clearinghouse but on a much broader scale** as they cover more health plans and disease conditions. Extending the Clearinghouse pilot and/or operationalizing the Clearinghouse could be an effective a bridging strategy to work toward a RHIO and/or P4V programs.

An ongoing operational Chronic Disease Data Clearinghouse (or Chronic Disease Data Exchange) that supports clinicians with robust chronic disease tracking systems and reporting tools would be a positive intermediate step toward P4P, P4Q, and/or a RHIO. **In an environment that increasingly encourages increased quality transparency and that is moving toward outcomes-based reimbursement to providers, the Clearinghouse model offers an important constructive approach to quality improvement based on collaboration between health plans and physicians.** Plans and providers need a common means to define accountability and produce trusted data. The Chronic Disease Data Clearinghouse could offer that opportunity.

Opportunity – Support Health Plan Disease Management Program Efforts
Most of the health plans participating in the Clearinghouse pilot are involved in some form of case management or disease management (DM) programs for chronic care conditions such as asthma and diabetes. These efforts are designed to supplement and support the efforts of clinicians with patient-centered support services. At least three opportunities were identified during the pilot whereby an ongoing Clearinghouse could support DM programs to the benefit of the health plans, clinicians and patients. First, the Clearinghouse could help improve communication between DM programs and clinicians

by including DM service transactions as another Clearinghouse data source. Consistent and efficient feedback about DM services provided to patients is an issue to many clinicians. The Clearinghouse created data specifications for submission of DM service information but it was not used in the pilot. Second, the Clearinghouse could be a resource to health plans in shortening the time lags to identify chronic care patients when they switch coverage between health plans. Currently, plans identify patients for DM programs only after they accumulate sufficient claims experience. This can lead to gaps in the timely provision of DM services to patients. Third, the Clearinghouse could be a resource to DM programs to provide them with prior health care encounter information on individual patients covered by DM programs. These latter two opportunities would require HIPAA compliance mechanisms with appropriate authorization processes to assure the confidentiality and security of patient information.

Opportunity – Stakeholder Benefits From An Operational Clearinghouse

An ongoing Clearinghouse covering various chronic conditions would provide a number of benefits to a wide variety of stakeholders. The benefits include the direct benefits to patients of systems that better support higher quality care, the broad social goal of improving the quality of care for patients with chronic conditions, and the economic goals of improving the efficiency and delivery of higher quality services on a consistent basis. The benefits that could be derived by various health care delivery stakeholders include:

Health Plans

- Improve care for chronic disease members, lower long term costs.
- Improve provider relations with physician practices.
- Improve results on HEDIS and other performance measures.
- Minimize independent low-yield data distribution efforts.
- Improve disease management program coordination with physician practices.
- Support developments essential to implement pay for performance (P4P).
- Support developments essential for maximizing the benefits of health information technology (HIT) initiatives.

Physician Practices

- Improve care for chronic disease patients.
- Receive regular flow of information on patients not otherwise available or usable.
- Develop systematic processes for chronic disease patients with covered conditions.
- Improve practice operational efficiencies (less hassle, fewer processes, lower cost).

IPAs

- Improve support for member physicians (e.g., better practice infrastructure, IPA provided services, quality improvement efforts).
- Measure relative performance of member physicians to facilitate improvements.
- Encourage movement toward improve delivery systems and effective use of electronic records.
- Support developments essential to consider implementation of pay for performance (P4P).
- Support developments essential for maximizing the benefits of health information technology (HIT) initiatives.

Purchasers

- Improve care for chronic disease covered population, lower long term costs.
- Improve disease management program coordination with physician practices.
- Encourage movement toward improve delivery systems and effective use of electronic records.
- Support developments essential to consider implementation of pay for performance (P4P).
- Support developments essential for maximizing the benefits of health information technology (HIT) initiatives.

Patients and public

- Improved care for chronic disease patients with covered conditions.
- Improved coordination of care and timely follow-up.
- Improved accountability and visibility of the healthcare system.

Public health community

- Improved care for chronic disease patients with covered conditions.
- Improved knowledge and information about chronic care.
- Improved visibility and accountability of the healthcare system.
- Encourage movement toward improve delivery systems and effective use of electronic records.
- Support developments essential for maximizing the benefits of health information technology (HIT) initiatives.

Policy makers

- Encourage movement toward improve delivery systems and effective use of electronic records.
- Improved visibility and accountability of the healthcare system.
- Support developments essential to consider implementation of pay for performance (P4P).
- Support developments essential for maximizing the benefits of health information technology (HIT) initiatives.

Summary Conclusions

The Chronic Disease Data Clearinghouse proof-of-concept pilot was highly successful. It demonstrated that the political, legal, and technical challenges can be addressed. The pilot did not solve all the problems but it achieved the primary goal of any pilot which is to identify what must happen for an ongoing enterprise to work effectively

The project also reinforces that there are significant gaps in the access to relevant and available data about patients that could be used to improve the delivery of health care. That is, nobody has all the relevant data about a patient – not the patient, not the clinician, not the health plan. There are tremendous benefits to be derived by all the stakeholders concerned with the care of patients by effectively and efficiently sharing available data (with appropriate privacy and confidentiality safeguards) to provide patients with the best care possible. There are many efforts to improve the quality of health care by facilitating the wide-spread use of electronic health records, developing regional health information organization (RHIO) infrastructures for sharing data, and creating incentives through pay for value programs. These longer term efforts must all address the many issues identified in the Clearinghouse Pilot. An operational chronic disease data clearinghouse could serve as a useful and cost effective bridging strategy to achieve near term benefits as part of the longer term initiatives.

Attachment A: Clearinghouse Project Participants

Organizations Participating in Planning the Clearinghouse Initiative (1999 – 2002)

AstraZeneca
CareOregon
Glaxo Smith Kline
Health Net
InterHospital Physicians Association
Kaiser Permanente Northwest
Legacy Good Samaritan Clinic
Lifewise
ODS Health Plans
OMPRO
Oregon Asthma Program, Department of Human Services
Oregon Asthma Network
Oregon Coalition of Health Care Purchasers
Oregon Diabetes Coalition
Oregon Diabetes Program, Department of Human Services
Oregon Health Care Quality Corporation
Oregon Medical Assistance Program
PacifiCare
PacificSource
Providence Health Plans
Regence BlueCross BlueShield of Oregon

Chronic Disease Data Clearinghouse Steering Committee (2003-2005)

Greig Anderson	Oregon Diabetes Coalition
Beverly Bauman, MD	OHSU, Pediatric Emergency Services
Lynn Bentson, MD	Albany Internal Medicine Group
William Hersh, MD, FACP	OHSU
Sean Karbowicz, Pharm.D.	Regence Blue Cross Blue Shield of Oregon
Lisa Kranz	Portland Family Practice
Karen Main	Oregon Asthma Network
Csaba Mera, MD	The ODS Companies
Melinda Muller, MD	Legacy Clinic Good Samaritan
Douglas Perednia, MD	Kietra
Jody Pettit, MD, Chair	Oregon Health Care Quality Corporation (previously Interhospital Physicians Association)
Mike Rohwer, MD	Performance Health Technology
Karen Stral	Mercer Human Resource Consulting
Colleen Sealock	SAIF Corporation
David Witter, Jr.	Witter and Associates

Attachment A: Clearinghouse Project Participants

Chronic Disease Data Clearinghouse Project Staff (2002-2005)

Nancy Clarke	Oregon Health Care Quality Corporation (2005), Oregon Department of Human Services (2002-2005)
Vickie Gates	Oregon Health Care Quality Corporation (2003-2005)
Rachel Ginocchio	Oregon Department of Human Services and the Oregon Asthma Program (2002-2004)
Kirsten Jensen	Oregon Department of Human Services and the Oregon Asthma Program (2004-2005)
Tonia Holowetzki	OMPRO (2003-2005)
Neal Hickman	OMPRO (2003-2004)
Yelena Rozenfeld	OMPRO (2004-2005)
Veena Hegde	OMPRO (2003, 2005)
Jeff Lucas	OMPRO (2004-2005)
Michael Riley	Riley Research Associates (2003-2005)
Sabine Welling	Riley Research Associates

Health Plans Participating in the Chronic Disease Data Clearinghouse

CareOregon
Clear Choice
Family Care
Lifewise
Mid-Valley IPA
The ODS Companies
Oregon Medical Assistance Program
PacifiCare
PacificSource
Providence Health Plans
Regence BlueCross BlueShield of Oregon
Tuality Health Alliance

Participating Physician Practices

Interview participants regarding CDDC feasibility and practice reporting needs	**City**	**County**
Bend Memorial Clinic	Bend	Deschutes
Calcagno Pediatrics	Gresham	Multnomah
Corvallis Clinic	Corvallis	Benton
Doctors Clinic	Salem	Marion
Good Shepherd-Hermiston Medical Center	Hermiston	Umatilla
Grants Pass Clinic	Grants Pass	Josephine
Legacy Clinic Emanuel, Children & Adolescents	Portland	Multnomah
Legacy Clinic St. Helens Pediatrics	St. Helens	Columbia
Maple Street Clinic	Forest Grove	Washington
Mid-Valley IPA	Salem	Marion

Attachment A: Clearinghouse Project Participants

Interview participants regarding CDDC feasibility and practice reporting needs	City	County
OHSU Internal Medicine	Portland	Multnomah
Peace Health Medical Group	Eugene	Lane
Salem Clinic	Salem	Marion
Samaritan FirstCare Physicians (now Albany Internal Medicine Group)	Albany	Linn
Samaritan Internal Medicine	Corvallis	Benton
Southern Oregon Pediatrics	Medford	Jackson
Tuality Health Alliance	Hillsboro	Washington

Practice participants reviewing CDDC patient lists and initial reports	City	County
Bend Memorial Clinic	Bend	Deschutes
Legacy Good Samaritan Clinic	Portland	Multnomah
Maple Street Clinic	Forest Grove	Washington
Portland Family Practice	Portland	Multnomah
Salem Clinic	Salem	Marion
Albany Internal Medicine Group	Albany	Linn

Interview participants regarding utility of CDDC reports and improvement opportunities	City	County
Legacy Good Samaritan Clinic	Portland	Multnomah
Maple Street Clinic	Forest Grove	Washington
Portland Family Practice	Portland	Multnomah
Salem Clinic	Salem	Marion

Clearinghouse Financial Supporters

Asthma and Diabetes Programs, Department of Human Services
AstraZeneca
GlaxoSmithKline
Regence BlueCross/BlueShield
Northwest Health Foundation

Attachment B: Chronic Disease Data Clearinghouse
Proof of Concept Evaluation Questions

Clearinghouse Concept: Pooled health plan data, provided in the right formats through a clearinghouse, is useful to some physicians who want to provide systematic care for their patients with asthma and diabetes.

Issue	Source of Data	Evaluation Questions
1. Have we completed all the steps of the pilot?	Project staff	Did the legal, technical and political processes result in plans submitting data (inpatient, outpatient, emergency department, pharmacy and laboratory) for diabetes and asthma to the clearinghouse? Why or why not?
		Did the Clearinghouse successfully merge and match data from the plans for participating physician groups? Why or why not?
		Were physician groups solicited regarding the content and format of the data from the Clearinghouse? Why or why not?
		Did the Clearinghouse provide data to participating physician groups? Why or why not?
		Did physician groups provide feedback on the quality and utility of the data? Why or why not?
		Did the Clearinghouse provide health plans with data as modified by physician groups? Why or why not?
		What did the project cost the providers, plans, vendors, and the sponsoring organizations? Were allocated funds sufficient? How and why did project costs differ from estimated costs?
		What unanticipated barriers were identified?
2. What is the magnitude of the data merging?	OMPRO	How many health plans participated?
		How many patients with diabetes and asthma were identified? For each health plan, what percept of their patient population did this represent?
		How many patients had data from multiple physicians?
		How many patients had data from multiple plans?
		How many physicians had data from multiple plans?
		What were the characteristics of the patients, providers, and plans included in the pilot data?
		What were the challenges to merging patient, provider, and claims data?
3. What is the quality of the individual-level data?		
a. Matching to physician	OMPRO	What was the degree of agreement between the Clearinghouse / plan designation of primary care provider and whether the provider regarded him/herself as that patient's primary care provider? What were the challenges in designating the primary care physician?
b. Diagnosis		What was the degree of agreement between the Clearinghouse / plan identification of patients with diabetes and asthma and the physicians' diagnosis? What were the challenges in determining a correct diagnosis?
c. Completeness		How many health plans included inpatient, outpatient, and emergency department visit data? How many patients did this represent?

Attachment B: Chronic Disease Data Clearinghouse
Proof of Concept Evaluation Questions

Issue	Source of Data	Evaluation Questions
		How many plans included laboratory test and test results data? How many patients did this represent?
		How many plans included pharmacy data? How many patients did this represent?
d. Currency		How current were the inpatient, outpatient, emergency department, laboratory and pharmacy data the plans were able to provide? What were the challenges to obtaining current data?
4. What are the practice summary / benchmarking statistics?	OMPRO	What percent of the patients met HEDIS and other eligibility criteria for inclusion in practice summary and benchmarking statistics?
		What summary statistics and benchmarking data were provided to physicians about their practice?
		How much variation was there by physician group (what was the range, blinded by group)?
		How much variation was there by plan (what was the range, blinded by plan)?
		Is the number of cases large enough at the individual provider and group-level to be meaningful?
		What unanticipated barriers were identified?
5. What is the value (if any) of the clearinghouse to health care providers?	Riley Research	What individual level data was useful/not useful to providers?
		What aggregate level data (both practice summary data and benchmarking data) was useful/not useful to providers?
		What format (paper vs. electronic) was most/least useful to providers?
		How did the clearinghouse data add value/not add value to the systems, tools and resources currently employed by physicians?
		Could physicians envision integrating the clearinghouse data into their practice? Who would use/not use clearinghouse data and to what end? What 'systems' changes would need to happen?
		What incentives/inhibitors need to be in place for providers to use and incorporate the Clearinghouse data?
		What were providers' visions around medical data/information for the future? Did the clearinghouse fit into this vision? Why or why not?
		What unanticipated barriers were identified?
6. What have we learned that guides us to the next step?	Steering Committee	Does the Chronic Disease Data Clearinghouse have merit? Why or why not?
		What political, technical, legal and financial issues need to be resolved to move forward with collaborative data management?
		Was the work completed in the projected time frame? If not, what steps required an unexpected length of time?
		What is the next step?