

REASONS TO DECLINE A REQUEST FOR DATA

A. INTRODUCTION

Chapter 43.371 RCW directs the Office of Financial Management (OFM) to establish and adopt rules for a statewide All Payer Claims Database (WA-APCD). RCW 43.371.050(2) authorizes the lead organization to decline a request for information for reasons set forth in rules enacted by OFM. Paper 6 provides background information for developing rules on reasons to decline a request for data.

By way of background, RCW 43.371.050(1) authorizes the release of claims or other data from the WA-APCD in processed form to public and private requesters.¹ The purpose of data release is to provide data to support transparent public reporting of health care information to:

- Assist patients, providers, and hospitals to make informed choices about care.
- Enable providers, hospitals, and communities to improve by benchmarking their performance against that of others by focusing on best practices.
- Enable purchasers to identify value, build expectations into their purchasing strategy, and reward improvements over time.
- Promote competition based on quality and cost.

The data that can be released include direct patient identifiers, indirect patient identifiers, proprietary financial information and other data. Other data include procedure codes, diagnoses codes, age, gender, claim paid date, billed, allowed and paid amounts (in some circumstances), service date and provider information. See Data Access under Chapter 43.371 RCW: Statewide Health Care Claims Data at <http://www.ofm.wa.gov/healthcare/pricetransparency/>.

Chapter 43.371 RCW contains provisions about the data release process. Data requesters must submit completed and signed data request forms to the lead organization to request data. At the direction of OFM, the lead organization and data vendor convene an advisory committee to establish a data release process and provide advice regarding formal data release requests. The lead organization can approve or deny a request.

For this paper, OFM:

- Reviewed Chapter 43.371 RCW provisions to decline a data request.
- Researched reasons to decline data requests in other states.
- Reviewed recommendations from the report “Washington Health Alliance All-Payer Claims Database Data Release Advisory Committee Summary of Recommendations.”²

1. See Background Paper 5 Procedures for Data Release for an explanation of data release for the WA-APCD and in other states.

2. In September 2014, OFM contracted with the Washington Health Alliance to convene a data release work group to provide technical advice on data release requirements for the WA-APCD. This work was completed before the Washington State Legislature passed Chapter 43.371 RCW. OFM submitted the final report as a deliverable for the Centers for Medicare & Medicaid Services, Center for Consumer Information and Insurance Oversight, Health Insurance Rate Review Grant Program, Cycle III grant that OFM received October 2013. For the full report, see the OFM Health Transparency website at http://www.ofm.wa.gov/healthcare/pricetransparency/pdf/data_release_recommendations.pdf.

Paper 6 is divided into the following sections:

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B. FINDINGS ON REASONS TO DECLINE A DATA REQUEST

Colorado, Maine and Oregon are the only states that list specific reasons in either rule or policy to decline a data request. The APCD administrator in those states has several options:

- Decline the entire data request.
- Decline part of the request. For example, in Maine, data elements in a data request can be denied but otherwise the rest of the data request can be approved.
- Decline the data request contingent upon receiving more information. The data request is reviewed again after the information is received.

The reasons for declining a data request are:

- The requester has previously violated a data use agreement.
- Any person who will have access to the data has previously violated a data use agreement.
- The proposed privacy and security protections are not sufficient.
- The information provided is not sufficient to approve the data request.
- The data release advisory committee³ determines if supplemental information is required to make a recommendation to the APCD administrator.⁴
- The proposed purpose for accessing the data is not allowable under policies or state or federal statutes, rules or regulations.
- Full payment is not included with the application. This is required in Oregon. The other states collect payment prior to data release.

Maine can decline a data request even after approval and stop access to data when the APCD administrator concludes it is necessary to protect the privacy, integrity or security of the data. The APCD administrator will demand and secure the destruction or return of the released data.

There are timelines for reconsidering a declined a data request. In Colorado, if the data request is incomplete, the APCD administrator may require supplemental information and will notify the data requester of its decision within 45 days of receipt of such information. In Oregon, if the data review committee requests clarification, the requestor has 30 calendar days to provide the requested information. After 30 calendar days, applications with incomplete requests for clarification are discarded without further notification to the requester.

³ The states have a data release advisory committee that is responsible for reviewing the data requests and making a recommendation to the APCD administrator to release or not to release the data. The committee may obtain assistance from outside entities such as privacy and security experts to help with the data request review.

⁴ In Colorado, if there is a minor deficiency (or deficiencies), the data review committee may issue a conditional recommendation for approval pending submission of supplemental information that resolves the issue(s) to the satisfaction of the APCD administrator.

A data requester can appeal the decision to decline a data request. In Oregon, the appeal must be filed within 30 business days of the denial. The requester has the burden to prove that the APCD administrator unreasonably denied the application.

In Maine, a data applicant or a data provider can appeal:

- The executive director's decision to decline a data request for de-identified data (Level I) or limited data (Level II), or any elements of a data request for Level I or Level II data. The Data Release Subcommittee hears the appeal, and then the Maine Health Data Organization (MHDO) board of directors hears the appeal.
- The Data Release Subcommittee's decision to decline a data request for direct patient identifiers (Level III data) or any elements of a data request for Level III data. The MHDO board of directors hears the appeal.

With respect to the WA-APCD, the data release workgroup's report recommended additional reasons that should be considered to decline a data request:

- The proposed data use is for anti-competitive purposes.⁵ Examples of anti-competitive purposes are:
 - ◆ Entities using APCD data to collaborate to set market prices to control or prevent competition.
 - ◆ A low-cost provider using APCD data to evaluate and raise prices to be in line with higher-cost providers.
 - ◆ Using data to create agreements among competitors.

The report clarified that the data may be used to identify geographic areas with a high incidence of a particular health condition for the purpose of public health education. This would not be considered an anti-competitive purpose.

- Proposed data use is an unacceptable "commercial" use. Examples of unacceptable "commercial" uses are:
 - ◆ For-profit vendors that create new products for sale, such as a quality scoring website.
 - ◆ A pharmaceutical company using APCD data to identify patients using particular drugs and developing marketing campaigns to target those patients.
 - ◆ Data that is used to target patients for fundraising purposes.

The report clarified that there may be important "commercial" uses such as a hospital using the data to determine whether a new service should be developed in a particular area, given utilization patterns. This would not be considered an unacceptable "commercial" use.

⁵ Committee members suggested using Federal Trade Commission anti-competitive guidelines as the basis for establishing rules for the state APCD.

C. CONSIDERATIONS

RCW 43.371.050 (2) authorizes the lead organization to decline a data request for the following reasons:

- The data request does not include the information required.
- The data request does not meet the criteria established by the lead organization's data release advisory committee.
- For reasons established by rule.

The law allows incomplete applications and those not meeting the data release advisory committee's criteria to be handled administratively. The reasons in rule should address issues that should not be subject to administrative discretion. The reasons in rule should also provide direction in potentially gray areas. For example, if there was a willful violation of a data use agreement, it makes sense not to approve the data request. What if the violation was inadvertent? Should the data requester be prohibited from requesting and receiving data indefinitely or for a fixed period of time?

Thoughtful consideration of short- and long-term impacts of the reasons to decline a data request are important in developing the rule.

D. REFERENCES FOR REASON TO DECLINE A REQUEST FOR DATA

1. Colorado

See Data Release Committee Policies and Procedures

<http://civhc.org/getmedia/13204cf0-0cb8-4415-8dde-06214136c42e/CIVHC-DRRC-Policies-and-Procedures-2-3-12.pdf.aspx/>

2. Maine

Rules: Chapter 120 Release of Data to the Public, Section 11

<https://mhdo.maine.gov/rules.htm#recentlyproposed>

(Provisionally adopted rule March 3, 2016)

3. Oregon

Rules: http://www.oregon.gov/oha/OHPR/rulemaking/notices/409-025_PermComplete_2.1.13.pdf