



A driving force for health equity

Submitted via email to: Oregon.DATA@oregon.gov

December 18, 2020

Kathryn Helms
Chief Data Officer
Enterprise Information Services
Executive Building
4th Floor, 155 Cottage St NE
Salem, OR 97301

RE: Oregon's Data Strategy 2021-2023

Dear Chief Data Officer,

OCHIN appreciates the opportunity to comment on Oregon's Data Strategy. We are highly encouraged by the efforts to increase collection of actionable data to improve health care delivery, with a particular focus on historically marginalized, hard-to-reach populations. Overcoming health care disparities is crucial for Oregon's population health, as well as supporting the state's providers and reducing their rate of burnout. With the rise of the COVID-19 pandemic, it is critical to utilize stakeholder input to ensure we do not add to the burden that many providers are already experiencing today.

OCHIN is a national nonprofit health IT organization with two decades of experience transforming health care delivery. We provide leading-edge technology, data analytics, research, and support services to more than 500 community health care sites, reaching nearly 6 million patients across the country. Our extensive experience supporting community health care providers gives us great insight into health data collection and utilization, as well as issues surrounding provider burden and burnout. In Oregon, we serve a total of 34 member organizations. All of these members provide primary care services, 14 provide dental services, and 13 provide behavioral health services. This year alone, these 34 members have had 900,000 total patient encounters in Oregon.

Over the last several years, national efforts have expanded to collect information on social determinants of health and gather greater diversity data. This initially caused a great burden on providers, as it increased reporting requirements and multiplied the amount of data to be collected and analyzed by each provider when treating a patient. It also created a dilemma for patients seeking to maintain their privacy and avoid becoming the target of discriminatory practices. All of these factors have resulted in poor data collection. For example, 72% of ethnicity and 59% of race queries are devoid of responses, with only 25% of providers reporting data other than "unknown" and only half reporting primary language data.¹

¹ Oregon Health Authority. (2018, November 27). Oregon All Payer All Claims Database (APAC) Data User Guide 2011-2016 Dates of Service Release APAC 2018.2.
https://www.oregon.gov/oha/HPA/ANALYTICS/APAC%20Page%20Docs/APAC%20Data%20User%20Guide%20v2018_2_Final.pdf

A. Increase Timely Data Sharing

With the creation of an Oregon-based data repository of unprecedented size, it must be bidirectional and actionable for the end user and provide this data in a timely manner. Currently, OCHIN receives data through APAC, but it generally takes 18 months from patient date-of-service to OCHIN receipt. Research studies then can take months to years, and, therefore, do not lend support to time-sensitive issues. This means, for example, that we are at least several months out from analysis of COVID-19 APAC data. In the hopes of shedding light on COVID-19 treatment disparities and how to compensate this in vaccine delivery, more immediately available data sets are required. Quickly turning around these data sets must be a core goal of the Oregon Data Strategy to improve care coordination and workflows, and to reduce disparities in care.

B. Utilize Federal Standards

To efficiently improve data collection without increasing burden on providers, we strongly suggest Oregon align reporting requirements and data collection standards with national and current state programs. We instead suggest increasing efforts behind creating resources to utilize and improve current data sets in conjunction with streamlining data collection to reduce burden. Utilizing current data sets will save money by preventing the need for further electronic health record (EHR) customization and by mitigating the burden on providers and staff who would have to leave the EHR system to export data. The latter also invites errors that could negatively impact patient safety.

Oregon is currently implementing the REAL D data collection and there are already unintended consequences of this expanded data collection effort. As stakeholders weigh in, the greatest concern is increasing the burden on providers who are already struggling with overlapping data reporting requirements. Although we are supportive of collection of expanded data, we must be thoughtful on how this information is collected, so that we do not increase provider and provider support staff burnout, and how this data is used, so that we ensure patient privacy.

C. Reduce Provider Burden and Expand Provider Resources for Patients

Adding in new data collection fields to expand current data sets overlooks many of the current issues impacting data collection efforts as they exist today. Providers and their support staff are overwhelmed by the level of reporting requested of them on top of their already highly demanding job of treating patients. They are also not given strong incentives to collect data that is not critical to treatment of their patient. While data collection could be improved by being either mandated or incentivized, mandating the collection of an extended data set will add to provider burden and increase rates of burnout that are already at staggering levels and exacerbated by the COVID-19 public health emergency.

One method to improve the collection of data around social determinants of health, such as housing security, is an automated health record integrated network to generate referrals to community-based services. Adding in this level of support will serve two purposes. First, providers and their staff will feel more confident asking personal questions because they will know that they can provide a path of support to the patient. Consequentially, patients may be more apt to share this personal information if they know they will be offered the support they need, as opposed to just sharing information without receiving any benefit. However, when a patient is not interested in receiving assistance, they are unlikely to divulge their situation to protect their own privacy.

D. Prioritize Patient Privacy

The Oregon Data Strategy seeks to combine data sets from the health sector through the EHR with other agency data to improve the lives of Oregonians. This elicits a number of concerns based on both the evolving health data landscape, as well as commercial access to combined data sets. For example, the Federal Information Blocking Rule was recently finalized, driving interoperability and increasing health data flow exponentially. Although generally patient health information is exchanged between Health Insurance Portability and Accountability Act (HIPAA) regulated entities, patients can now direct their data to a third party not regulated under HIPAA. Expanded data sets of social determinants of health and sexual orientation and gender identity (SOGI) data could potentially exit the EHR and put patients at risk of discriminatory practices.

The risk to patients becomes even greater if other agency data is combined with health data and placed into a single data set. As with All Payer All Claims (APAC) data, these sets are deidentified, but cross-combining data across agencies increases the likelihood of patients being identified. With this extremely personal data in the hands of commercial bodies, including insurance companies, apartment rental companies, and others, we could see discriminatory practices proliferate. It is critical that we protect patients' privacy and ensure this information cannot be resold or used for commercial purposes. However, we must find a balance between patient privacy and ensuring this data is bidirectional and actionable by community partners and providers.

We appreciate your consideration of our comments. Please contact Jennifer Stoll at stollj@ochin.org should you have any questions.

Sincerely,

A handwritten signature in blue ink that reads "Jennifer Stoll". The signature is cursive and fluid.

Jennifer Stoll
EVP, Government Relations and Public Affairs
OCHIN