

January 7, 2022

Dana Hittle
Interim Deputy State Medicaid Director
500 Summer St. NE, E65
Salem, OR 97301
Submitted via email to 1115Waiver.Renewal@dhsosha.state.or.us

Re: Comments on the Oregon's 1115 Demonstration Waiver for the Oregon Health Program

Dear Deputy Director Hittle:

The Arthritis Foundation appreciates the opportunity to submit comments on the Oregon 1115 Demonstration Waiver for the Oregon Health Program. Arthritis is an umbrella term to describe more than 100 types of diseases related to the bones and joints. This chronic disease is America's number one cause of disability and is expected to conservatively impact nearly 80 million Americans by 2040. By any measure, arthritis is an urgent national priority that remains underappreciated in the spheres of federal public health research and medical innovation. While life-changing medicines have undoubtedly transformed the lives of people with arthritis, many challenges remain, from high out-of-pocket costs to continuous administrative burdens, all on top of managing their disease symptoms.

The Arthritis Foundation supports a holistic approach to care for people with arthritis, with the understanding that people with this chronic disease often rely on multiple care providers to manage their symptoms, ranging from primary care physicians to rheumatologists, orthopedic surgeons to physical therapists. We advocate for patient-centered care that recognizes the importance of patient access to multiple providers and services, and the importance of self-management for forms of the disease like osteoarthritis (OA) that have no disease-modifying therapeutics.

The Arthritis Foundation is committed to ensuring that Oregon's Medicaid program provides quality and affordable healthcare coverage. The Arthritis Foundation appreciates the focus that the Oregon Health Program has placed on equitable access to healthcare in the 1115 Demonstration Waiver. In addition, Oregon's request to provide multi-year continuous enrollment for children under six and continuous eligibility for all beneficiaries ages six and over will help to eliminate gaps in coverage.

Unfortunately, this waiver request contains multiple proposals that undermine access to care for patients with arthritis. We are concerned with the proposed closed formulary for adult beneficiaries, which would make it harder for patients to access the medications they need to stay healthy. We also oppose Oregon's proposals to limit retroactive coverage for nearly all Medicaid beneficiaries and to waive the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit for beneficiaries over the age of one, as both proposals will significantly jeopardize access to care for patients we represent.

The Arthritis Foundation offers the following comments and suggested changes on the 1115 Demonstration Waiver for the Oregon Health Program.

Continuous Eligibility

The Arthritis Foundation supports the request for continuous enrollment for children aged 0-5 (until their sixth birthday) and two-year continuous eligibility for beneficiaries over the age of five. Continuous eligibility reduces gaps in coverage that prevent patients from accessing the care that they need, especially for children of color, as studies show they are more likely to experience coverage gaps.¹ Research also shows that individuals with disruptions in coverage during a year are more likely to delay care, receive less preventive care, refill prescriptions less often, and have more emergency department visits.² Specifically for arthritis patients, the previously mentioned delays in care can lead to joint damage and joint destruction and other negative health outcomes. In addition, the Centers for Medicare & Medicaid Services has addressed the importance of continuous coverage by stating that “eliminating the cycling on and off of coverage during the year reduces state time and money wasted on unnecessary paperwork and preventable care needs.”³ Continuous eligibility will help reduce these negative health outcomes and administrative burden issues.

Closed Formulary

We are concerned by the proposal to transition to a closed formulary for adult beneficiaries. Diseases present differently in different patients, and it is often difficult to know which treatment will work best for any given patient. In fact, our surveys among rheumatoid arthritis patients show that patients cycle through an average of 2.5 medications before they find one that works for them. Prescription drugs have different indications, different mechanisms of action and different side effects, depending on the person's diagnosis and comorbidities. A closed formulary limits the ability of providers to make the best medical decisions for the care of their patients, effectively taking the clinical care decisions away from the doctor and patient and giving them to the state.

Our organization is disappointed that Oregon's proposal does not include an appeals process for patients to access non-formulary medications. However, even an appeals process or exemption for certain classes of drugs would not eliminate the barriers to care patients would face with a closed formulary. Arthritis patients will often report that their medications can become less effective over time and they have to work with their health care provider to find a new medication that works for them. A closed formulary will restrict an arthritis patient's ability to find medications that work best for them.

Additionally, Oregon's proposal to exclude prescription drugs that the state deems to have “limited or inadequate evidence of clinical efficacy,” including those approved through FDA's accelerated approval processes, will also harm patients by restricting access to novel and lifesaving therapies. In the past few years, many new treatments that benefit patients have been approved through an accelerated approval process. Patients with chronic diseases like arthritis need uninterrupted access to their treatments to maintain their health and this proposal could impede their ability to access the best treatment for them, potentially leading to negative health outcomes. All patients enrolled in Oregon's Medicaid program should have the opportunity to access treatments that could extend or improve their quality of life.

¹ Osorio, Aubrianna. Alker, Joan, “Gaps in Coverage: A Look at Child Health Insurance Trends”, Center for Children & Families (CCF) of the Georgetown University Health Policy Institute, November 21, 2021. Gaps in Coverage: A Look at Child Health Insurance Trends – Center For Children and Families (georgetown.edu)

² <https://aspe.hhs.gov/sites/default/files/private/pdf/265366/medicaid-churning-ib.pdf>.

³ <https://www.medicaid.gov/medicaid/enrollment-strategies/continuous-eligibility-medicaid-and-chip-coverage/index.html>

The Arthritis Foundation requests that the Oregon Health Program remove these requests and provide a robust, open formulary for all beneficiaries that will allow patients to access the medications that their providers believe are best for them.

Retroactive Coverage

The Arthritis Foundation is concerned by the proposal to continue to eliminate retroactive coverage for nearly all beneficiaries, excluding the aged, blind and disabled. Retroactive eligibility in Medicaid prevents gaps in coverage by covering individuals for a set amount of time prior to the month of application, assuming the individual is eligible for Medicaid coverage during that time frame. It is common that individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. Eligible applicants may also delay necessary health care until the Medicaid enrollment process is complete, which can increase their health risks and exacerbate any health conditions that they may have.

Retroactive eligibility allows patients who have been diagnosed with a serious illness, such as arthritis, to begin treatment without being burdened by medical debt prior to their official eligibility determination. In Indiana, Medicaid recipients were responsible for an average of \$1,561 in medical costs with the elimination of retroactive eligibility.⁴ Without retroactive eligibility, Medicaid enrollees could then face substantial costs at their doctor's office or pharmacy.

Patients with underlying health conditions who are unable to access regular care are often forced to go to emergency rooms and hospitals if their conditions worsen, leading health systems to provide more uncompensated care. For example, when Ohio was considering a similar provision in 2016, a consulting firm advised the state that hospitals could accrue as much as \$2.5 billion more in uncompensated care as a result of the waiver.⁵ Increased uncompensated care costs are especially concerning as safety net hospitals and other providers continue to deal with limited resources and capacity during the COVID-19 pandemic. Limiting retroactive coverage increases the financial hardships to rural hospitals that absorb uncompensated care costs. We oppose the continued limitations to retroactive coverage and encourages the state to expand retroactive coverage to include all Medicaid beneficiaries.

EPSDT Benefit

The Arthritis Foundation is opposed to the restricted coverage for treatment under Early and Periodic Screening, Diagnosis and Treatment (EPSDT). The purpose of the EPSDT benefit is to ensure that children receive appropriate healthcare. However, the limiting of that care to a prioritized list of services leaves families vulnerable to the cost of care for non-prioritized services. Many of the services that have not been prioritized are for serious and concerning conditions, and these limitations to services can place low-income families under financial strain to cover the cost of necessary services that fall outside of the prioritized list.

While the state has demonstrated other efforts to increase equitable access to healthcare, the continued restriction of the EPSDT benefit is a step in the opposite direction. For example, children

⁴ Healthy Indiana Plan 2.0 CMS Redetermination Letter. July 29, 2016. Available at: <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-lockouts-redetermination-07292016.pdf>

⁵ Virgil Dickson, "Ohio Medicaid waiver could cost hospitals \$2.5 billion", Modern Healthcare, April 22, 2016. (<http://www.modernhealthcare.com/article/20160422/NEWS/160429965>)

of color are enrolled in Medicaid at disproportionately higher rates⁶ and as mentioned before, are also more likely to be affected by gaps in coverage.⁷ These children are likely to be disproportionately affected by the limitations to the EPSDT benefit.

The Arthritis Foundation supports the removal of the restrictions to the EPSDT benefit to allow children full and equitable access to healthcare, in keeping with the purpose of the EPSDT benefit.

Again, thank you for the opportunity to comment on your state's 1115 Demonstration Waiver for the Oregon Health Program and we look forward to future opportunities to engage with you. Please contact me at ahyde@arthritis.org with any questions or if we can provide additional information.

Sincerely,



Anna Hyde
Vice President, Advocacy and Access
Arthritis Foundation

⁶ Brooks, Tricia. Whitener, Kelly. "At Risk: Medicaid's Child-Focused Benefit Structure Known as EPSDT," Center for Children & Families (CCF) of the Georgetown University Health Policy Institute, June 2017. EPSDT-At-Risk-Final.pdf (georgetown.edu)

⁷ Osorio, Aubrianna. Alker, Joan, "Gaps in Coverage: A Look at Child Health Insurance Trends", Center for Children & Families (CCF) of the Georgetown University Health Policy Institute, November 21, 2021. Gaps in Coverage: A Look at Child Health Insurance Trends – Center For Children and Families (georgetown.edu)