

Submitter: Oregon Pain Action Group

On Behalf Of: Oregonians with intractable medical conditions

Committee: Senate Committee on Health Care

Measure: SB492

Thank you, Chair Patterson, Vice-Chair Hayden, and the Senate Committee on Health Care, for this opportunity to present our testimony on SB 492.

There are positive parts to SB 492. We are in favor of those changes, but we have huge concerns with the language surrounding quality of life.

As a group made up of many disabled intractable patients with painful conditions, we fear the bill could be interpreted to mean that medical decisions should not consider the patient's quality of life to approve certain medical treatments. We've found that often the intent of a bill will be changed based on the person or people deciphering it. As it is the section that says, "The commission may not rely upon any quality of life measures, either directly or by considering research or analysis that takes into account a measure of an individual's quality of life, in determining: (A) Whether a service is cost-effective; (B) Whether a service is recommended; or (C) The value of a service," could mean that someone who has an intractable condition that has no cure is excluded from services because their primary benefit (or reason for treatment) is improvement of quality of life. Often with people in pain, pain reduction (via treatments) greatly improves their quality of life, though it doesn't cure the patient. Should that patient be denied treatment because they cannot be cured and if we aren't considering the quality of their life, there is no benefit? Often the benefit in treatment for our members is all about improving quality of life.

The CDC and other federal policy changes have reinforced the need for Health-Related Quality of Life to be considered as an important factor in bridging "boundaries between disciplines and between social, mental, and medical services." They "underscore the need for measuring HRQOL to supplement public health's traditional measures of morbidity and mortality." Without a measurement of quality of life, we miss one of the most important aspects of a person's health, their lived experience, which is critical to whole-person centered medical care. A patient's report of their quality of life also gives providers the opportunity to ensure their care is patient centered. This information can be found at: [HRQOL Concepts | CDC](#)

In reading other testimonies, we noticed one that was in favor of the bill, but it focused on the concept of Quality Adjusted Life Years (QALY) and assumed this bill is saying not to consider it in denying treatment to patients. However, **QALY isn't mentioned one time in the bill**. If the intended purpose of the bill is to prevent people from being denied medical treatment based on QALY, because the benefit isn't adequate since the patient is too old or their life is limited, then please rephrase the bill to represent this.

With all of these issues affecting disabled patients, we need more protections. If this was the intent of the bill, may we suggest a Rare Disease council be formed in Oregon to represent some of the most underserved populations. This is desperately needed to protect Oregonians. [OSU study suggests Oregon create rare disease council to understand quality of life issues | KTVL](#)

As it is written, this bill seems potentially dangerous to an already vulnerable group of people struggling to recover from recent restrictions on their medical treatments. We oppose this bill in its current form and please vote no on this confusing bill that could be easily misunderstood and misused.

Thank you for your time.

Warmly,

The Oregon Pain Action Group