

An Act advancing health care research and decision-making centered on patients and people with disabilities

William Smith, Visiting Fellow in Life Sciences
Testimony in Support of House Bill 201

Madam Chairwoman, Mister Chairman:

My name is William Smith. I am a Research Fellow in Life Sciences at the Pioneer Institute in Boston. In my role at Pioneer, I study the biopharmaceutical industry and public policies that may impact patient care and access to high quality medicines. Recently, I have done a great deal of research and writing on the Quality Adjusted Life Years (QALYs) methodology that is utilized by a number of foreign nations in evaluating the value of medicines. Thank you for the opportunity to share my thoughts on House Bill 201.

I want to testify in favor of House Bill 201 because, I believe, it addresses a number of flaws and infirmities in the QALY methodology.

First, those health economists who utilize the QALY methodology, such as the Institute for Clinical and Economic Review (ICER) here in Boston, rely upon surveys of the general public when making judgements about, for example, the value of improvements in the quality of life that a medicine may initiate. House Bill 201 specifically requires that patients themselves be surveyed to establish “relevant outcomes within a disease area.” Asking patients themselves why a medicine may be valuable is a very helpful improvement to methodologies that only rely upon surveys of the general population who may be unfamiliar with the symptoms or challenges of various conditions.

Second, House Bill 201 requires that decisions about access to healthcare treatments and services consider the impact of these decision on patient subgroups. This is important, I believe, because the QALY as currently utilized, discriminates against a number of important patient subgroups such as those living with disabilities, older Americans, and patients with rare diseases.



Third, House Bill 201 says that in order to “comply with good research practices” studies of the value of healthcare treatments must “allow time for conduct of additional research.” In the United States for example, ICER’s QALY evaluations are, many times, conducted solely on the basis of clinical trial data. This is insufficient for a variety of reasons. For example, clinical trials for oncology treatments many times enroll patients who are not representative of the patients who will actually use the medicine. Through off label prescribing and experimentation, an oncologist may discover that a medicine approved by the FDA to treat prostate cancer is far more effective in treating lung cancer. In these cases, an economic evaluation of the treatment based solely on clinical trial data is quickly obsolete because of the way the medicine is used in the real world.

While I would not recommend the adoption of the German system for evaluating medicines, the German system has one admirable feature. Germany requires a drug to be in the marketplace for one year before an economic evaluation can occur. This way, when the medicine is evaluated, there is not only robust data from many thousands of patients, but the medicine is also evaluated based upon how it is actually used in the real world.

Finally, House Bill 201 would ban the use of the QALY in Massachusetts’ health programs such as Medicaid. This is a very important step, and it concurs with the policy of the Biden Administration who released a report on September 9th which concluded that “there are important concerns about the equity implications of certain methodologies, such as Quality Adjusted Life Years (QALYs), for people of all ages with disabilities and chronic conditions.”

The reasons for the Biden Administration’s concerns are likely related to the QALY formula itself which values medicines according to their ability to extend life and improve the quality of life. When you adopt the standard of valuing medicines more highly if they extend life longer, you are, by definition, valuing medicines for young people more highly than medicines for older people, who have fewer “life years” to give. Likewise, when you value medicines more highly when a patient enjoys a perfect quality of life, you are going to devalue medicines for people living with disabilities who may not recover a perfect quality of life but may very much value a medicine that extends their life or improves it in some other way.

I want to commend the authors of House Bill 201 for their focus on improving patient access to high quality medicines. Thank you.