

Connecticut Healthcare Cabinet Draft Recommendations on Pharmaceutical Costs
Public Comment

Approved by Connecticut SIM Consumer Advisory Board
January 9, 2018.

The Consumer Advisory Board commends the Connecticut Healthcare Cabinet for undertaking the enormous effort to address the crippling costs of prescription medications. It was very positive that the Healthcare Cabinet added a representative with patient and family experience to each of the Workgroups addressing this problem. The result is a significant, comprehensive set of complex recommendations rightfully seeking to protect consumers from the threat of growing pharmaceutical costs.

Our initial recommendations are as follows:

Recommendation 1: Given the complex and extensive nature of these recommendations and the potential benefit and harm some of them pose to consumers, twelve days is not sufficient time to obtain needed public comment. Understanding that legislative proposals are on a particularly short time line, Consumer Advisory Board has encouraged first public comment on Legislative proposals by January 15th. **Consumer Advisory Board recommends that additional time be provided for Public Comment until February 13, 2018**

Recommendation 2: The Consumer Advisory Board supports legislation to establish a Drug Review Board empowered to investigate potential abuse in drug pricing decisions by manufacturers. **It is essential that this Board is comprised of one third patients and families with actual experience obtaining and utilizing medication for serious and complex health conditions.**

Decisions by this Board are likely to have significant impact on patients and families. It is important the Board fully consider the risks and impacts that their decisions will have. Significant and meaningful consumer participation in this process is needed to balance the benefits and enormous risks in this process and to enable the Board to achieve its goals.

Recommendation 3: The Consumer Advisory Board supports all efforts to increase transparency and sees it as the first most essential step to addressing the high cost of pharmaceuticals.

It is unclear why patient advocacy organizations appear to be highlighted in the recommendation for transparency legislation when the New England Journal of Medicine study cited is based on financial information that advocacy organizations are already required to publicly disclose.

Consumer Advisory Board supports transparency requirements for manufacturers, PBMs, health insurers and other payers. Any individuals and/or organizations participating in policies and decisions relating to pharmaceutical costs should be required to disclose their sources of funding/income.

Closing Comment

The Consumer Advisory Board (CAB) serves a vital role in the State Innovation Model Healthcare Innovation process. **We don't seek to be the voice of the consumers but to ensure that the voice of consumers (patients and families) is considered in the complex decisions that affect them.**

To achieve this goal, CAB has conducted statewide outreach to recommend over sixty (60) consumer representatives for Advisory Groups. We provide information to Connecticut consumers on healthcare innovation efforts and seek their feedback on what works or does not work in their community. It is our hope to continue to be helpful to the Healthcare Cabinet in this important effort.

Respectfully Submitted,

Arlene Murphy
Chair