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May 14, 2015

The Honorable Ricardo Lara Chair, Senate Appropriation Committee State Capitol, Room 2206 Sacramento, CA 95814

RE: Senate Bill 26 (Hernandez) California Health Care Cost and Quality Database – Oppose Unless Amended As Amended May 5, 2015 Senate Appropriations Committee - May 18, 2015

Dear Senator Lara:

The Consumer Federation of California (CFC) has met with Senator Hernandez' staff and with proponents of SB 26 to express our concerns with the bill as currently drafted. We appreciate the Senator's willingness to consider and work to address our patient privacy concerns.

However, we regret that we must continue to oppose SB 26, unless it is amended to include the definition of "medical information" under California's Confidentiality of Medical Information Act (CMIA) (Cal. Civ. Code section 56.05(j)), thereby incorporating a broader definition of what medical information is to be protected under those "policies and protocols developed... [to] ensure that the privacy, security, and confidentiality" of Californians' sensitive medical information.

As amended, SB 26 employs the federal Health Insurance Portability and Accountability Act's (HIPAA) definition of "individually identifiable health information" which is narrower than California's own higher standard under CMIA. HIPAA only speaks to the identity of the individual or information that can be used to identify the individual. CMIA, goes further by covering a patient's address, email address, phone number, social security number or any other information that *can be combined* with publicly available information to reveal the individual's identity.

We are greatly encouraged by recent amendments to SB 26 that explicitly reference CMIA and state that "[a]ll uses and disclosures of data…" are to comply "with all applicable state and federal laws for the protection of the privacy and security of data, including, but not limited to, the Confidentiality of Medical Information Act". This is important progress, but "medical information" must be defined with precision in order to provide consistent protection for sensitive information.

CFC agrees that greater analysis and transparency of the cost, quality and utilization of various health services will enable healthcare consumers, purchasers and policymakers to contain costs and make better treatment choices. However, the more information is shared, the more opportunities exist for sensitive

personal medical information to fall into the wrong hands. SB 26 creates a new health care entity to administer the California Health Care Cost and Quality Database.

This entity will collect and analyze personally identifiable health records, and made available to the public information regarding cost, quality and utilization of health services and procedures at various providers. We understand that this public data will be in a format that aggregates and anonymizes health care consumer information. However, the sharing of personally identifiable health information of tens of millions of Californians with this new entity makes it essential that the entity be subject to the strictest privacy and confidentiality regulations.

We urge you to vote "No" on SB 26, unless amended.

Sincerely,

Richard Holober

Richard Holober Executive Director

cc: Members and Staff, Senate Appropriations Committee Senator Hernandez