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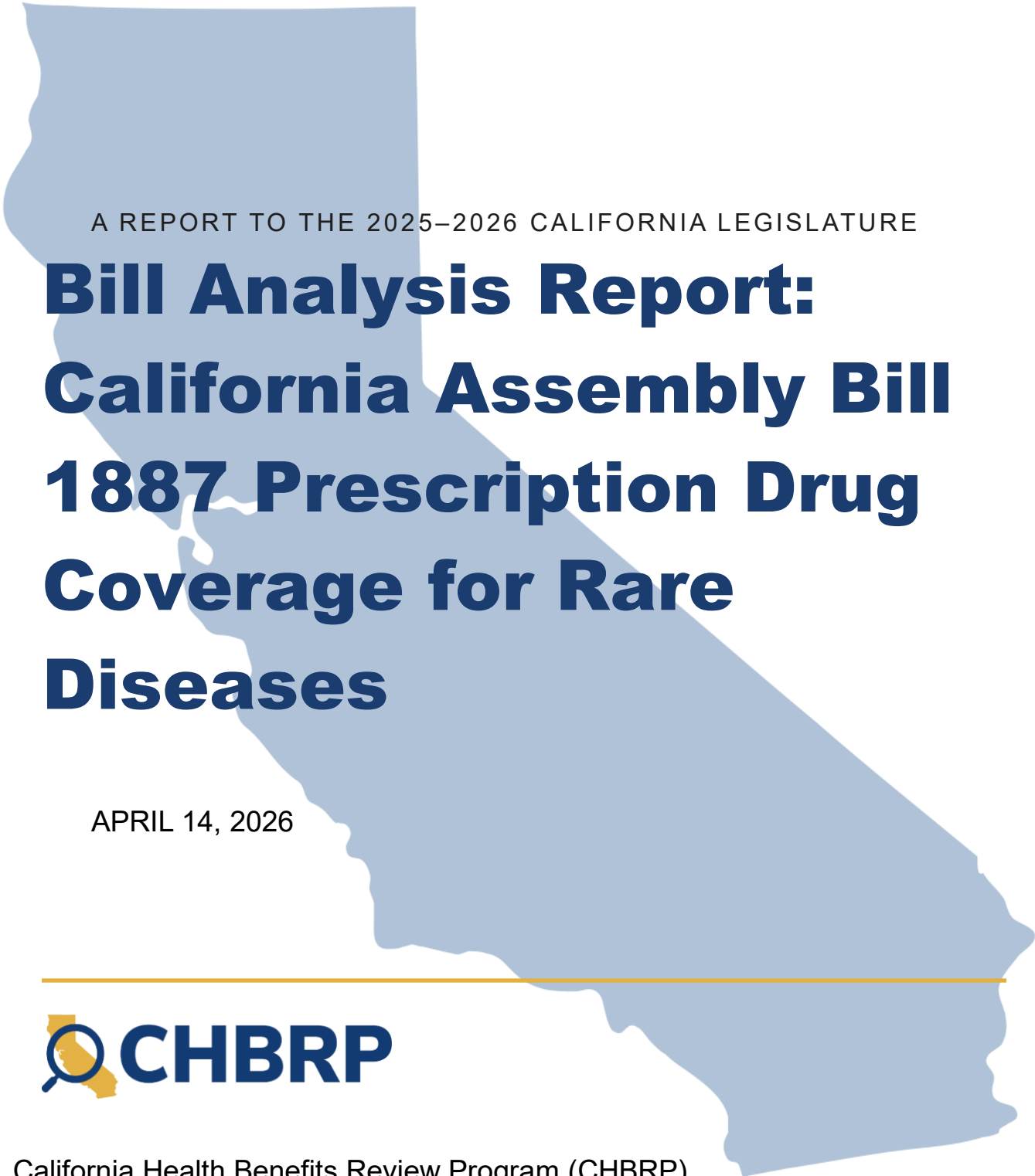
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A REPORT TO THE 2025–2026 CALIFORNIA LEGISLATURE

Bill Analysis Report: California Assembly Bill 1887 Prescription Drug Coverage for Rare Diseases

APRIL 14, 2026



California Health Benefits Review Program (CHBRP)
University of California, Berkeley

chbrp.org

Analysis of California Assembly Bill 1887 Prescription Drug Coverage for Rare Diseases

Summary to the 2025–2026 California State Legislature, April 14, 2026



Summary

The version of California Assembly Bill (AB) 1887 analyzed by the California Health Benefits Review Program (CHBRP) would prohibit utilization management for U.S. Food and Drug Administration (FDA)-approved prescription drugs indicated for the treatment of a rare disease, unless a biosimilar, interchangeable biological product, or generic version of the drug is available. Utilization management includes prior authorization, step therapy, and other utilization reviews.

In 2027, of the 22.8 million Californians enrolled in state-regulated health insurance, 13.8 million of them would have insurance subject to AB 1887. Medi-Cal managed care plans are exempt from the bill.

Background

Rare diseases are defined as those that impact less than 200,000 people in the United States. Approximately 1 in 10 Californians are living with a rare disease. Only 5% of the 5,000 to 10,000 rare diseases currently have FDA-approved drugs indicated for their treatment. The time to receive a correct diagnosis of a rare disease can vary widely, with 4 to 5 years as the average.

Benefit Coverage

At baseline, no enrollees with health insurance subject to AB 1887 have coverage that is compliant with AB 1887. Postmandate, 100% would have compliant coverage. AB 1887 would not exceed essential health benefits (EHBs).

Medical Effectiveness

CHBRP found no literature on the impacts of utilization management on the use of prescription drugs for rare diseases. CHBRP found *some evidence* that utilization management leads to delays in treatment of non-rare diseases. Prescription drug treatments for rare diseases may differ from prescription drugs for other chronic diseases as there is typically one treatment available for rare diseases compared to multiple generic and/or non-generic treatments. Therefore, utilization management

may impact access to prescription drugs for rare diseases differently than those for non-rare diseases.

Cost Impacts

Postmandate, CHBRP estimates that the removal of utilization management under AB 1887 would result in approximately 8,200 people starting an additional 17,000 new prescriptions for a medication to treat a rare disease within a plan benefit year. The bill would lead to an approximate \$148 million increase in total annual premiums paid by employers and enrollees for newly covered benefits. Enrollee premiums calculated include premiums for enrollees using and not using the benefit. Annual enrollee expenses, including cost sharing and noncovered expenses, would increase by between \$900 and \$1,200, depending on the market segment, for those enrollees using drugs subject to AB 1887.

Public Health Impacts

CHBRP projects no measurable public health impact at the population level. However, AB 1887 would likely yield health and quality-of-life improvements at the person-level, such as faster access to medications, potential reductions in unnecessary health care utilization while awaiting prior authorization for medications, and reduced stress and administrative burden for patients, their families, and their clinicians by removing prior authorization requirements.

Long-Term Impacts

Over time, utilization of FDA-approved drugs for rare diseases is likely to increase as new drugs are developed and receive FDA approval. As awareness of rare disease diagnoses improves and diagnostic capabilities advance, the number of individuals diagnosed with rare diseases may also grow, contributing to increased utilization. These factors would contribute toward increases in premiums. However, as biosimilar alternatives become available for currently covered biologics, some drugs may no longer be subject to the mandate, which could moderate utilization growth and fiscal impact over time. The extent to which these factors would affect long-term utilization is unknown.

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Acronyms and Terminology

Acronyms

AB – Assembly Bill

CA – California

CalPERS – California Public Employees' Retirement System

CDI – California Department of Insurance

CHBRP – California Health Benefits Review Program

COHS – County Organized Health System

DHCS – Department of Health Care Services

DMHC – Department of Managed Health Care

EHBs – essential health benefits

FDA – U.S. Food and Drug Administration

SB – Senate Bill

Terminology

CHBRP uses the following terminology for this analysis:

Orphan drug – a pharmaceutical product developed to treat rare diseases or conditions.

Rare disease – a condition affecting fewer than 200,000 persons in the United States.

Utilization management: Utilization management techniques are used by health plans and insurers to control costs, ensure medication compatibility, and manage safety. Examples include benefit coverage requirements related to prior authorization, step therapy, quantity limits, and limits related to the age or sex of the enrollee (such as prescription-only infant formula or prostate cancer screening for men).

Prior authorization:¹ Also known as precertification, prior approval, or prospective review, prior authorization is a utilization management technique commonly used by health insurance carriers to ensure that a given medical intervention meets the insurance plan or policy's criteria for coverage (Newcomer et al., 2017). Prior authorization was developed as a tool for insurers to assess the appropriateness of treatment that would result in a hospital admission or a high-cost procedure (Resneck, 2020). The primary uses of prior authorization include:

- **Coverage evaluation:** Allows evaluation of whether a test, treatment, or service is medically necessary and otherwise covered.
- **Safety:** Acts as a safeguard to confirm that a patient's medications are compatible and provides an opportunity to check that proper diagnostic testing has been completed to ensure patient safety prior to use of a requested treatment. Prior authorization also reduces inappropriate patient care by stopping unsafe or low-value care that is inconsistent with the most recent clinical evidence.
- **Cost control:** Imposition of prior authorization for nonpreferred medications can encourage the use of preferred medications that can be procured at lower price.

Step therapy: Also known as "fail-first" protocols, step therapy may be applied to prescription medications by health plans and insurers to control costs, ensure medication compatibility, and manage safety. Health plans/insurers may use step therapy protocols to apply clinical guidelines established by professional societies and other recognized organizations to treatment plans. They require an enrollee to try and fail one or more medications prior to receiving coverage for the initially prescribed medication. Step therapy protocols usually recommend starting with a medication that is less expensive (generics) and/or has more "post-marketing safety experience" (PBMI, 2015).

¹ More information about prior authorization is available in CHBRP's 2023 analysis [Prior Authorization in California](#).

Overview: AB 1887 and Prescription Drugs for Rare Diseases

The California Assembly Committee on Health requested that the California Health Benefits Review Program (CHBRP)² conduct an evidence-based assessment of the medical, financial, and public health impacts of Assembly Bill (AB) 1887 on prescription drugs for rare diseases, as amended on March 26, 2026.

Bill Language of AB 1887

AB 1887 would prohibit prior authorization, step therapy, or other utilization review of FDA-approved prescription drugs indicated for the treatment of a rare disease;³ the bill would only apply to prescription drugs that do not have a generic, interchangeable biological product, or biosimilar available and that have been prescribed by a specialist with expertise in the condition or disease being treated. See the full bill text in CHBRP's Technical Brief on AB 1887.

If enacted, AB 1887 would apply to the health insurance of approximately 13.8 million enrollees (36.2% of all Californians) (see Figure 1).

- **Includes:** enrollees in commercial or California Public Employees' Retirement System (CalPERS) health insurance regulated by the Department of Managed Health Care (DMHC) and the California Department of Insurance (CDI).
- **Excludes:** Medi-Cal beneficiaries enrolled in DMHC-regulated plans and county organized health system (COHS) plans.

It should be noted that DMHC regulates the plans and policies of approximately 74% of enrollees associated with CalPERS, and 80% of Medi-Cal beneficiaries, in addition to commercial enrollees.⁴

What Are Rare Diseases?

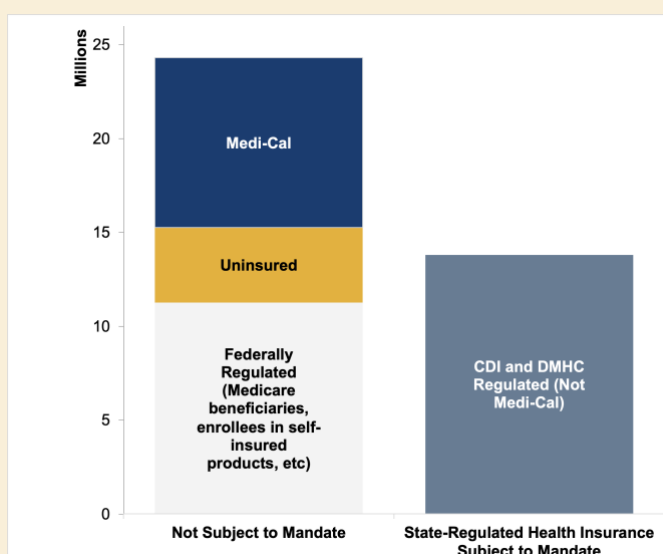
Rare diseases (sometimes referred to as "orphan diseases") are medical disorders, illnesses, or conditions that affect a relatively small number of individuals. According to the National Institutes of Health and the Orphan Drug Act, rare diseases are those that affect fewer than 200,000 people in the United States, which is the definition used in this report

² See CHBRP's [authorizing statute](#).

³ Utilization review is also known as utilization management. It includes tools, such as prior authorization and step therapy, that require safety, medical necessity, and coverage evaluation prior to payment for services. Prior authorization is when proof of medical need and patient safety checks must be completed before coverage for a service is determined. Step therapy requires a patient to try and fail one or more prescription drugs prior to coverage the initially prescribed medication. CHBRP provides an overview of common utilization management practices that are addressed by AB 1887 in its explainer [Utilization Management: An Overview](#).

⁴ For more detail, see CHBRP's [resource, Sources of Health Insurance in California](#).

Figure 1. Health Insurance in CA and AB 1887



Source: California Health Benefits Review Program, 2026.

Note: CHBRP generally assumes alignment of Medi-Cal managed care plan benefits, with limited exceptions.¹

Key: CDI = California Department of Insurance; DMHC = Department of Managed Health Care.

(Congress.gov, 2024). Rare diseases are often chronic, serious, and progressive diseases that are life-threatening or life-limiting (NLM, 2017; Zhao et al., 2023).

Signs of rare diseases are often present at birth or in childhood, although there is a subset of rare diseases that do not appear until adulthood (NIH, 2024; NLM, 2017). Rare diseases can affect any organ system and might affect multiple body systems. Approximately 80% of rare diseases are caused by genetic mutations (referred to as “Mendelian disorders”) and may be inherited (passed down through families) but can also be new mutations (de novo) (Marwaha et al., 2022; NIH 2024). Rare diseases may also be caused by infections or environmental factors (NIH, 2024).

There are an estimated 5,000 to over 10,000 rare diseases in the United States (FDA, 2026a; NIH, 2024). It is estimated that 1 in 10 Californians, or close to 4 million Californians, are living with a rare disease, based on national estimates (NIH, 2024). See Table 1 for examples of rare diseases.

What Medication Treatments Exist for Rare Diseases?

The diversity of the conditions and the symptoms they cause mean that there is not one treatment or set of treatments for all rare diseases. Each rare disease needs its own treatment or set of treatments, and appropriate treatments are determined by specialists with expertise in the condition or disease being treated (Han et al., 2022). Medications to treat rare diseases are also called “orphan drugs.”

Medications for rare diseases can be split into three categories, only the first of which is included in the scope of AB 1887:

- **On-label usage:** An orphan drug is used on-label when it is administered to treat an indication (e.g., a disease or symptom) according to the FDA-approved labeling. Table 1 shows examples of rare diseases and the number of FDA-approved medications to treat the disease. See the *Background on Rare Diseases* section in CHBRP’s Technical Brief on AB 1887 for the names of the FDA-approved orphan drugs. In 2023, a study estimated around 5% of rare diseases have a disease-specific FDA-approved medication (Fermaglich and Miller, 2023).

The other two categories of medications which are not included in the scope of AB 1887 are:

- **Symptom management:** Some orphan drugs are FDA-approved medications that treat symptoms that are present in patients with a rare disease, but the medication is not specific for treatment of that rare disease, for example, anti-seizure medication to manage symptoms of Dravet syndrome, which causes seizures (Strzelczyk and Schubert-Bast, 2022).
- **Off-label usage:** An orphan drug is used off-label when it is administered for an indication not listed on its FDA-approved labeling (Adachi et al., 2023). For example, prednisone is often used off-label for Duchenne muscular dystrophy to slow progressive muscle weakness (Kourakis et al., 2021).

Table 1. Examples of Rare Diseases and FDA-Approved Medications Indicated for the Disease (Orphan Drugs)

Disease	Description of Disease	Estimated Prevalence in California	Number of FDA-Approved Orphan Drugs for Disease
Cystic fibrosis	A genetic disorder that affects the lungs, gastrointestinal tract, and other body systems, causing severe respiratory issues	1 in 6,899 newborns in California	9
Duchenne muscular dystrophy	A genetic disorder that leads to progressive loss of muscle function and weakness	1 in 5,000 male children in the United States (approximately 7,800 male children in California) (a)	1

Disease	Description of Disease	Estimated Prevalence in California	Number of FDA-Approved Orphan Drugs for Disease
Fabry disease	A genetic disorder that leads to a harmful buildup of fat, which affects the heart, kidneys, central nervous system, and skin	Ranges from 1 in 40,000 to 170,000 depending on form of disease and gender (b) (approximately 200 to 1,000 Californians) (a)	1
Huntington's disease	A genetic disorder that causes nerve cells in the brain to break down, severely affecting movement and balance	1 in 20,000 people in the United States (approximately 2,000 Californians) (a)	2
Phenylketonuria	A genetic disorder that prevents the body from processing phenylalanine (an amino acid), which can lead to brain damage or severe intellectual disabilities if untreated by medications and a strict low-protein diet	1 in 25,000 people in the United States (approximately 1,500 Californians) (a)	3
Pompe disease	A genetic disorder that leads to the buildup of glycogen in the body's cells and muscle weakness, which affects the heart and liver, leading to severe respiratory movement issues	1 in 40,000 people in the United States (approximately 1,000 Californians) (a)	1
Sickle cell disease	A genetic disorder affecting red blood cells, which leads to damage in the bones, spleen, and other organs as well as severe pain crises	Approximately 7,000 Californians	3

Source: California Health Benefits Review Program, 2026, based on CDC, 2025; FDA, 2026b; Hillert et al., 2020; Kharrazi et al., 2015; Lerario et al., 2024; Medina et al., 2022; NIH, 2013; NLM, 2016, 2021, 2022, 2024a, 2024b, 2025a, 2025b; Reeves et al., 2024.

Notes: (a) Calculated estimate based on California population of 38 million people.

(b) Fabry disease is X-linked (see the *Disparities in Rare Diseases* section of CHBRP's Technical Report on AB 1887 for more details) and has multiple forms and more severely affects male children and adults. Female children and adults usually have milder symptoms, and a small percentage could have no symptoms.

Key: FDA = U.S. Food and Drug Administration.

It should also be noted that orphan drugs may be either small molecule drugs or biologics (large molecule). Small molecule drugs are chemically synthesized compounds, typically taken orally, that can be copied. Biologics are complex, large molecule drugs that are derived from living cells and are typically administered by injection or infusion. Biologics also include a category of drugs called biosimilars, which are biologics that are very similar to a brand-name biologic. In general, small molecule drugs are significantly less expensive than biologics (Vogel et al., 2025). AB 1887 would apply to small molecule drugs and biologics.

What Is Utilization Management for Medications, and Why Does It Matter for Rare Diseases?

Briefly, utilization management techniques are used by health plans and insurers to control costs, ensure medication compatibility, and manage safety. Examples include:

- **Prior authorization:** the insurance carrier grants permission for use of the medication after the clinician prescribes it, before the patient can begin treatment.

- **Step therapy:** the insurance carrier requires a certain medication for the medical condition to be used as a first step, before different prescription medication is approved. Step therapy is not typically used for rare diseases as most have only a single FDA-labeled medication, if any, and thus no other steps are typically available.⁵

For more information about utilization management and prior authorization please see CHBRP's 2026 overview, [Utilization Management: An Overview](#) as well as CHBRP's 2023 analysis, [Prior Authorization in California](#).

Prior authorization is the utilization management technique that is commonly used for treatments for rare diseases. A 2017 study analyzed coverage for 138 identified orphan drugs between 2000 and 2016 through a review of formulary decisions from 20 leading commercial payers. The study found that the average payer assigning 45% of orphan drugs with prior authorization, which was higher than the use of prior authorization for non-orphan drugs (Cohen and Awatin, 2017). None of the payers in this study reported the use of step therapy for orphan drugs (Cohen and Awatin, 2017).

Disparities in Rare Diseases and Barriers to Accessing Rare Disease Diagnoses and Treatment

For people with rare diseases, there are disparities in access to diagnosis, treatment, and in the populations of patients involved in studies for the development of medication treatments by race/ethnicity, sex/gender, income, age, and geography, contributing to general challenges to diagnosis and treatment of rare diseases.

Although California does screen newborns for a number of rare diseases, there are still challenges in obtaining a timely diagnosis for some diseases, which often require many diagnostic tests at specialty clinics (Marwaha et al., 2022; Reisin et al., 2017). Compared to people without rare diseases, people with rare diseases experience more out-of-pocket costs to diagnose and treat the disease, often making it difficult for individuals and their families to afford diagnosis and treatment (Adachi et al., 2023; Chaudhary and Kumar, 2025). There are also a limited number of rare disease clinicians and specialty clinics that can diagnose and treat patients with rare diseases (Penon-Portmann et al., 2020; Wojcik et al., 2023).

Additionally, there are disparities in the populations of patients involved in studies to the develop new orphan drugs. There are limited medication treatment options for many rare diseases, and it is challenging to obtain a representative sample of patients to develop new treatments for rare diseases given the small number of people with rare diseases (Bell and Tudur Smith, 2014; Fermaglich and Miller 2023; Rath et al., 2017). Studies have observed that participants in clinical trials for orphan drugs are predominantly White, and that non-White individuals and children with rare diseases are often underrepresented as participants in the development of new drugs, which could lead to limited treatment options for these populations (Goel et al., 2021; Serrano et al., 2023).

Societal Impact of Rare Diseases

Since rare diseases are often life-limiting and associated with substantial medical needs, the presence of these diseases has direct and indirect economic and societal costs, which can vary for different rare diseases. Individuals with rare diseases or their families may need to miss work, retire early, or require constant caregiving, especially if travel is necessary to access specialty care. A 2022 assessment in the United States estimated that the total economic burden of rare diseases amounted to \$997 billion, and indirect costs made up 44% of the economic burden (\$437 billion) (Yang et al., 2022).

⁵ Per discussion with content experts, Drs. V. Ma and M. Martin. March 2026..

Utilization Management and Access to Prescription Drugs for Rare Diseases

CHBRP’s medical literature review summarized evidence on the potential impact of utilization management – including prior authorization, step therapy, and other utilization review – on delays or denials of coverage of prescription drug treatments for rare diseases.

CHBRP found no studies that directly evaluated the impacts of utilization management on prescription drug treatment for rare diseases (Table 2). CHBRP did identify studies that assessed utilization management techniques on prescription drugs and other health care services *not* specific to rare diseases. Although these conditions differ from rare diseases, they are the closest available evidence to assess the impact of utilization management on prescription drug access for rare diseases. It should be noted that prescription drug treatments for rare diseases may differ from prescription drugs for other chronic diseases as there is typically one treatment available for rare diseases compared to multiple generic and/or non-generic treatments. Therefore, utilization management may impact access to prescription drugs for rare diseases differently than those for non-rare diseases.

There is *some evidence*⁶ that utilization management is associated with delays in access to prescription drugs to treat non-rare diseases and the delays impact utilization of health care services such as hospitalizations and emergency department visits, in addition to clinical outcomes (e.g., morbidity for non-rare diseases). There is *conflicting evidence*⁷ on the impact of utilization management on denials of prescription drug treatments for non-rare diseases.

Table 2. Summary of Evidence on the Impact of Utilization Management on Access to FDA-Approved Orphan Drugs

Outcomes	Impact of Utilization Management on Access to FDA-Approved Orphan Drugs*
Delays in treatment	
Denials of treatment	

Source: California Health Benefits Review Program, 2026.
Note: **Not enough research* indicates that there are no studies of the treatment, or the available studies are not of high quality, meaning there is not enough evidence available to know whether or not a treatment is effective. It does not indicate that a treatment is not effective.
Key: FDA = U.S. Food and Drug Administration.

Policy Context

Existing California Law and Regulations

Prior authorization and utilization review

State-regulated health plans and insurers must follow specific requirements when deciding whether to approve, modify, or deny payment for requested medical services. For example, the guidelines used to determine the criteria for coverage decisions must be aligned with clinical principles, and certain communications must be made to the patient. Determinations to modify or deny a service based on medical necessity must be made by a licensed physician or a

⁶ *Some evidence* indicates that a small number of studies have limited generalizability to the population of interest and/or the studies have a serious methodological concern in research design or implementation. Conclusions could be altered with additional evidence.
⁷ *Conflicting evidence* indicates that a similar number of studies of equal quality suggest the treatment is effective as suggest the treatment is not effective.

licensed health care professional skilled in the clinical issues involved in the service requested.⁸ Coverage decisions must be made in a timely manner. The specific timeline depends on when the coverage review occurs and the type of benefit:

- **Medical benefit services:** Coverage decisions for services delivered before or at the same time as a patient is receiving care must be made within 5 business days of the health plan/insurer receiving all necessary information; those for services after care has been given must be made within 30 days of receiving all necessary information. If a health plan/insurer cannot make a coverage decision due to a lack of information (e.g., clinical notes, test results), existing law allows for an extension of the review timeline. The extension is typically 14 calendar days but may be granted to up to 28 days.⁹ Health plans and insurers must fast-track coverage decisions when a patient's health or recovery is at risk and they require urgent care services.¹⁰
- **Pharmacy benefit services:** Coverage decisions must be made within 72 hours of nonurgent requests and 24 hours of urgent requests. Health plans/insurers may request additional information but must do so within the same 72- or 24-hour timeframes.¹¹

Step therapy

California law allows health plans and insurers to require step therapy if there is more than one clinically appropriate drug available for treatment. Step therapy exceptions must be granted in specific situations, including if the required prescription drug is contraindicated or expected to be ineffective based on the patient's clinical circumstances. Patients may appeal denials of exception requests.¹²

Oversight of health plans

California law requires DMHC to conduct an evaluation of each licensed health plan at least once every 3 years. The department assesses each plan's compliance on program areas such as utilization management, quality assurance, access and availability, and meeting enrollees' health care needs.¹³

Essential Health Benefits and the Affordable Care Act

When a state requires health plans/insurers to cover more than the federal essential health benefits (EHBs), it is considered "exceeding EHBs." In these cases, the state – rather than the federal government or the health plan/insurer – is responsible for paying the extra cost of that care. Because AB 1887 does not require coverage for any additional prescription drugs, the proposed mandate would not exceed the current definition of EHBs in California.

Similar Legislation in Other States

In 2025, Minnesota and New Mexico enacted legislation similar to AB 1887. Minnesota's law prohibits health plans from restricting where an enrollee receives services for the diagnosis, monitoring, or treatment of a rare disease. The law also mandates that cost sharing and service limitations for rare diseases cannot be more restrictive than those for in-network care.¹⁴ The New Mexico law bans health insurers from requiring step therapy or prior authorization for FDA-approved, including off-label, medications used to treat rare diseases or conditions. Oklahoma is currently considering legislation that would establish guidelines for step therapy protocols for rare diseases and other conditions.¹⁵

⁸ HSC 1367.01; INS 10123.135.

⁹ Title 28 California Code of Regulations (CCR) 1300.67.2.2.

¹⁰ HSC 1367.01; INS 10123.135; 28 CCR 1300.67.2.2; 10 CCR 2562.09.

¹¹ HSC 1367.241; INS 10123.191.

¹² HSC 1367.206; INS 10123.201.

¹³ HSC 1380.

¹⁴ Minnesota Statute 62Q.451.

¹⁵ Oklahoma Senate Bill 1064.

Similar Legislation in California

CHBRP was also requested to analyze SB 1094 Prescription Drugs, as introduced on February 13, 2026, which contains provisions that may overlap with AB 1887 if both were to be enacted.

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Analytic Approach and Assumptions

CHBRP analyzes bills in the current environment given current law and regulations at both the state and federal levels. All estimates are based on current data and do not take into consideration any future or potential changes to factors that may influence the impacts of AB 1887, unless otherwise specifically mentioned.

Language Interpretation

CHBRP made the following assumptions based on the language of AB 1887:

- **On-label use:** Medications are FDA-approved for a specific purpose but can also be used “off-label” for other purposes. Off-label use refers to the practice of prescribing or using a medication for a purpose, dosage, route of administration, or patient population that is not explicitly approved by the FDA. Under existing law, plans and policies cannot limit or deny coverage for off-label use of prescription drugs.¹⁶ CHBRP assumed AB 1887 would only apply to on-label use of prescription drugs, that is, only those drugs that are prescribed and used as indicated on the FDA label would qualify for the prohibition on utilization management per AB 1887.
- **Utilization management:** CHBRP uses the term “utilization management” to include prior authorization, step therapy, and other utilization review throughout this analysis. Based on existing literature and discussion with content experts, CHBRP determined that prior authorization is typically the only type of utilization management used when reviewing access to coverage for FDA-approved orphan drugs.¹⁷

Pharmacy Benefit Coverage

- As of January 1, 2022, outpatient prescription drugs are covered on a fee-for-service basis by DHCS for all Medi-Cal beneficiaries through the Medi-Cal Rx program.¹⁸ Their pharmacy benefit is “carved out” of the coverage provided by Medi-Cal managed care plans, and so AB 1887 would not be expected to impact their benefit coverage.
- For this analysis, CHBRP has assumed that AB 1887 applies to plans and policies that cover prescription drugs on both the medical benefit and pharmacy benefit. In general, CHBRP assumes that drugs that are physician-ordered and administered under the supervision of a physician (typically in a hospital, a provider’s office, infusion center, or similar medical facility), along with the hospital stay or office visit, are generally covered through a medical benefit. Pharmacy benefits cover outpatient prescription drugs by covering prescriptions that are generally filled at a retail pharmacy, a mail-order pharmacy, or a specialty pharmacy.

WHAT BENEFIT DO PRESCRIPTION-BASED SERVICES FALL UNDER?	
 MEDICAL BENEFIT	 PHARMACY BENEFIT
 Prescription drugs administered under supervision of physician (generally in hospital, doctor’s office, infusion center, other medical facility)	 Self-administered drugs (e.g., oral medications, self-injections, patches, inhaled medications, suppositories)

¹⁶ HSC 1367.21 and INS 10123.195.

¹⁷ Per discussion with content experts, Drs. V. Ma and M. Martin. March 2026.

¹⁸ For more on outpatient prescription drug coverage among Californians with state-regulated health insurance, see CHBRP’s [resource](#) *Pharmacy Benefit Coverage in State-Regulated Health Insurance*.

Cost-Related Analytical Approach and Assumptions

This analysis reports the estimated incremental impact of full-scale implementation of AB 1887 on benefit coverage, utilization, and cost for a single year.¹⁹ Full-scale implementation typically requires a “ramp up” period which may include educating enrollees, providers and insurance carriers on the new benefits or coverage, updating procedures and policies, and increasing provider capacity for marginal utilization resulting from AB 1887. Furthermore, some policies may have staggered implementation or longer-term changes in utilization. The incremental impact estimates below assume there is no “ramp up” period and represent ongoing annual costs at full-scale implementation of AB 1887, including potential short-term offsets. CHBRP further assumes that state and industry policies and provider and patient behaviors would remain constant throughout the time period it takes for the full impact of the bill to be realized.²⁰ For a discussion of long-term impacts of AB 1887, see the *Long-Term Impacts* section.

CHBRP made the following assumptions:

- All enrollees with state-regulated commercial insurance coverage face utilization management for FDA-approved medications that are indicated for the specific rare disease on the FDA label (orphan drugs) without a generic or biosimilar available.
- Approximately 5% of rare diseases have an available FDA-approved orphan drug. As a result, the population of enrollees subject to the utilization management requirements addressed by AB 1887 represents a subset of all enrollees with rare diseases.
- Utilization management leads to a 60-day delay in access to all new prescriptions for users, i.e., individuals with rare diseases starting an FDA-approved orphan drug. The 60-day delay estimate reflects clinical expert opinion from a specialist in rare metabolic diseases with extensive experience managing utilization management requirements for this patient population. Unlike the studies reviewed, which examined utilization management delays in more common conditions over shorter timeframes, rare disease prior authorization processes are typically more burdensome, often requiring detailed diagnostic documentation, genetic testing results, and specialist attestation, justifying a longer estimated delay than those observed in the published literature.²¹
- 10% of enrollees with a rare disease who are eligible to take FDA-approved orphan drugs start a new drug each year.²² The postmandate utilization of these drugs will depend on the disease and orphan drug in question:
 - For some new prescriptions, removal of utilization management requirements is assumed to reduce delays in accessing their medication by 60 days, or two 30-day fills.
 - This reduction in delay means that new prescriptions would be filled 12 times in 1 year rather than 10 times. In other words, eliminating utilization management would result in those users receiving two additional 30-day fills per year.
 - The resulting increase in prescriptions varies by drug type, as injectables and infusions are typically administered less frequently (e.g., quarterly) than oral medications, meaning the 60-day delay displaces fewer administrations and produces a smaller percentage increase in fills for those drug types.
 - Some enrollees with rare diseases may be taking more than one FDA-approved drug specifically indicated for the rare disease.
- Utilization management does not impact existing users, i.e., individuals already taking FDA-approved orphan drugs. While it is possible that utilization management could impact a small proportion of individuals who may experience gaps or delays during the beginning of plan years,²³ CHBRP was unable to quantify this number. The cost impact of AB 1887 reflects an acceleration effect rather than induced demand, that is, costs increase because patients access

¹⁹ For some analyses, impacts as a result of changes to health insurance benefits may occur over multiple years (e.g., impacts in pregnancy and childbirth rates resulting from changes to utilization of fertility services, staggered implementation, or long-term changes in utilization). CHBRP's estimates represent the full impact of the mandate in 1 year even if changes in coverage, utilization offsets, and costs may be realized in more than 1 year.

²⁰ CHBRP's Cost and Coverage Model also assumes enrollees maintain one form of health insurance for the entire calendar year. Examples of state and industry policies and behavior include medications that may be developed or approved in the future, health insurance market changes beyond what is known at the time of publication of this analysis, and statutory changes resulting from other health benefit mandates.

²¹ Per discussion with content experts, Drs. V. Ma and M. Martin. March 2026.

²² Per discussion with content experts, Drs. V. Ma and M. Martin. March 2026.

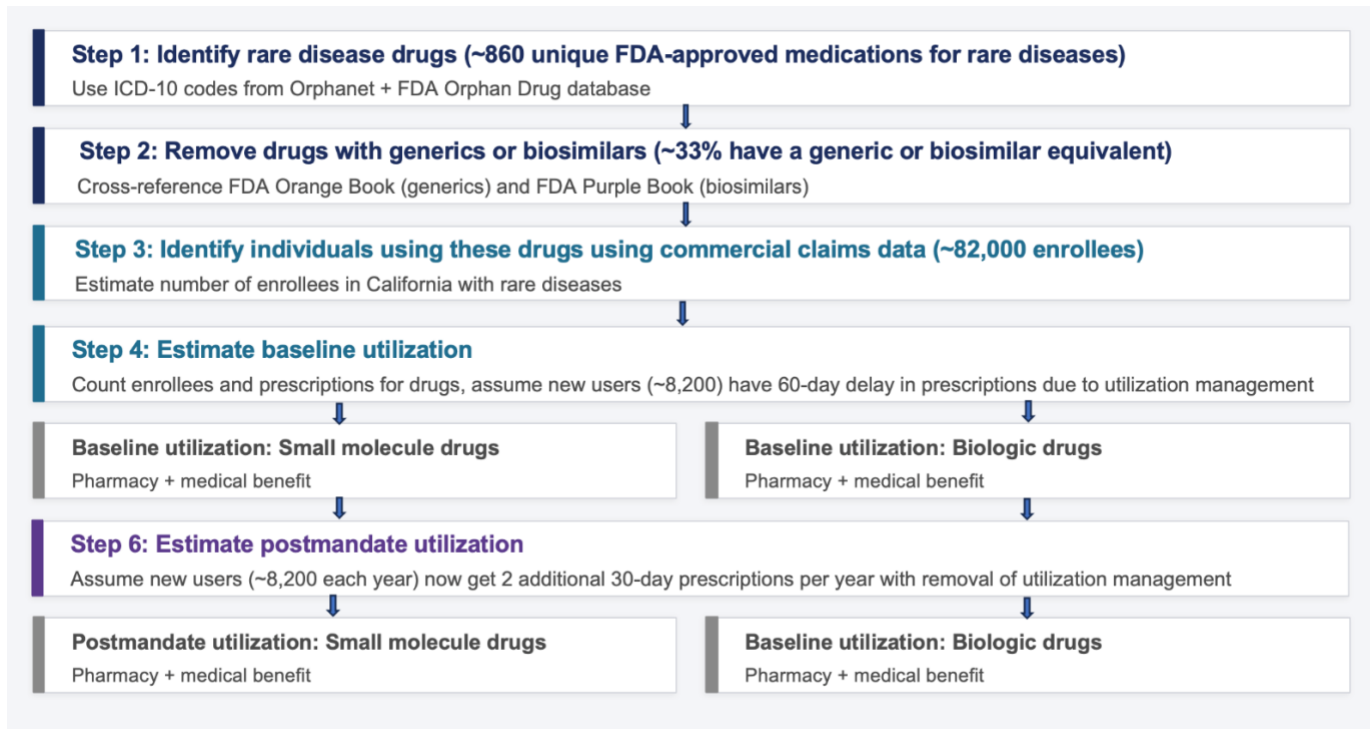
²³ Per discussion with content experts, Drs. V. Ma and M. Martin. March 2026.

medications sooner than they otherwise would, not because new patients begin treatments they would not have otherwise received.

- New prescriptions replace a delayed start to the same medication, not a switch from an alternative therapy or the addition of a new drug on top of an existing regimen.
- Gene therapies for rare diseases are covered under reinsurance programs²⁴ and therefore excluded them from the utilization and cost estimates, as increases in the use of these treatments would not affect expenditures.
- AB 1887 specifies that the prohibition on utilization management applies only when a drug is prescribed by a specialist with expertise in the condition or disease being treated. CHBRP assumed that all FDA-approved orphan drugs are prescribed by specialists with relevant expertise, as the complexity of rare disease diagnosis and management typically requires specialist involvement.

CHBRP estimated utilization for both small molecule and biologic drugs, and presents them separately, given the differences in cost for these two medication types. CHBRP also estimated utilization for drugs that fall under the pharmacy benefit and the medical benefit separately. To estimate utilization at baseline, CHBRP used ICD-10 codes for rare diseases from Orphanet and the Food and Drug Administration's (FDA) Orphan Drug database to estimate the number of individuals in California with rare diseases using FDA-approved medication that are indicated for the specific rare disease (FDA, 2026b; Orphanet, 2026). To identify drugs that would not be subject to the mandate, CHBRP then cross-referenced this list of drugs with lists of drugs from the FDA's Orange Book and Purple Book, which detail generic and biosimilar drugs, respectively. CHBRP then estimated the number of individuals and individual prescriptions of the remaining drugs without an available generic or biosimilar equivalent (Figure 2).

Figure 2. CHBRP Methodology to Determine Baseline and Postmandate Utilization for AB 1887.



Source: California Health Benefits Review Program, 2026.

Key: FDA = U.S. Food and Drug Administration.

²⁴ Reinsurance programs provide financial protection to health plans against high-cost claims by transferring a portion of the risk to a secondary insurer. Reinsurance purchased by an insurance company or health maintenance organization allows the company to pass all or part of its risk to another insurance company, either on a per-person basis or on a pooled basis. Typical reinsurance policies cover medical expenses surpassing \$250,000–\$500,000 per individual annually, a threshold into which all currently approved cell and gene therapies would fall. Given the high cost of gene therapies for rare diseases, with many therapies priced between \$2 million and \$4 million per treatment, health plans rely on reinsurance or stop-loss coverage specifically designed for gene therapies.

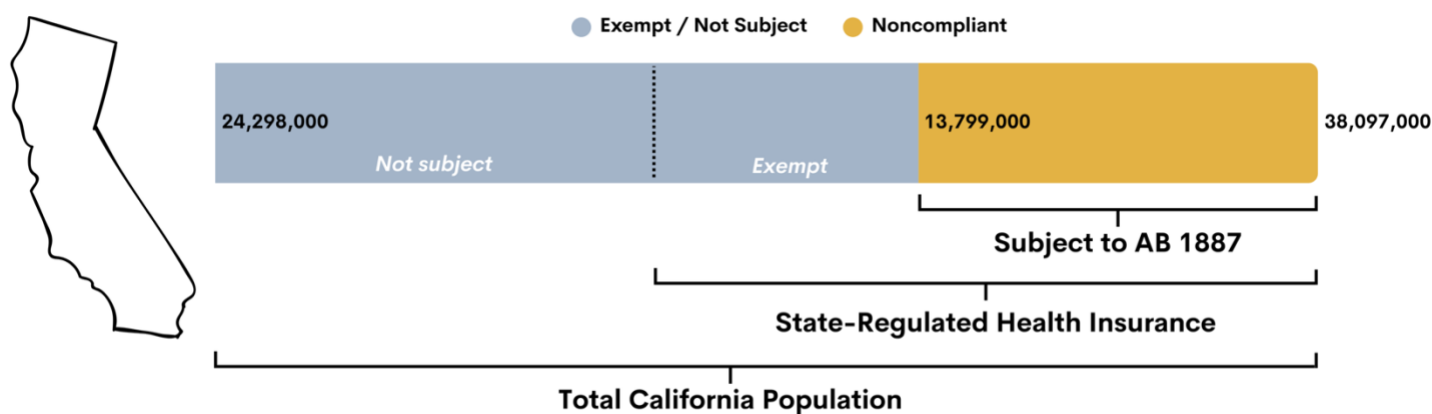
For further details on the underlying data sources, methods, and assumptions used in this analysis, please see CHBRP's Technical Brief on AB 1887, available at www.chbrp.org.

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AB 1887 Impacts: Benefit Coverage and Cost

CHBRP estimated that at baseline, of the 13.8 million Californians with health insurance subject to AB 1887, there are 1,379,900 Californians with rare diseases (10%) (Table 8). Of those with rare diseases, zero Californians (0%) are enrolled in plans or policies that are compliant with AB 1887 (Figure 3). Postmandate, CHBRP estimates 100% of Californians with state-regulated insurance subject to the mandate would have coverage compliant with AB 1887. Please note that CHBRP's approach is to assume full compliance postmandate on the part of all health insurance subject to the proposed mandate. For additional details on impacts to benefit coverage, see the Appendix.

Figure 3. California Health Insurance and Baseline Compliance With AB 1887



Source: California Health Benefits Review Program, 2026.

Utilization and Unit Cost

At baseline, CHBRP estimates that 82,000 enrollees receive orphan drugs. Of these, CHBRP assumes 10%, or approximately 8,200, start a new prescription in any given year, and it is this subset of new starters whose prescriptions are estimated to be subject to a 60-day utilization management delay and whose access would be accelerated under AB 1887.

For pharmacy scripts, CHBRP estimates 165,000 pharmacy scripts for FDA-approved small molecule orphan drugs and 222,000 pharmacy scripts for biologic orphan drugs at baseline. For physician-administered drugs, CHBRP estimates 50,000 physician-administered drugs for FDA-approved small molecule drugs indicated for rare diseases and 84,000 physician-administered drugs for FDA-approved biologic drugs indicated for rare diseases.

Postmandate, CHBRP assumed that the elimination of utilization management would remove the 60-day delay in prescription initiation for new users, such that users starting new drugs would receive 12 months-worth of prescription fills in the mandate year. CHBRP estimates that AB 1887 would result in these approximately 8,200 enrollees potentially accessing their new prescriptions up to 2 months sooner, amounting to an additional 17,000 prescriptions, due to the removal of utilization management requirements.

Postmandate, CHBRP estimates 171,000 pharmacy scripts for FDA-approved small molecule drugs and 227,000 pharmacy scripts for FDA-approved biologic drugs postmandate, 4% and 2% increases from baseline, respectively. For physician-administered drugs, CHBRP estimates 54,000 physician-administered drugs for FDA-approved small molecule

drugs and 86,000 physician-administered drugs for FDA-approved biologic drugs postmandate, an 8% and 2% increase from baseline, respectively.²⁵

CHBRP estimated unit costs separately for pharmacy scripts and physician-administered drugs, and for FDA-approved small molecule and biologic drugs. At baseline, the average cost per pharmacy script is \$12,700 for small molecule orphan drugs and \$6,800 for biologic orphan drugs. The average cost per physician-administered drug is \$700 for small molecule orphan drugs and \$17,400 for biologic orphan drugs. CHBRP estimates no change in unit costs postmandate. Table 3 shows estimates of the impacts of AB 1887 on utilization and unit cost of FDA-approved orphan drugs.

Table 3. Impacts of AB 1887 on Utilization and Unit Cost, 2027

	Baseline	Postmandate	Increase/ Decrease	Percentage Change
Enrollees with rare diseases				
Number of enrollees with rare diseases*	1,379,900	1,379,900	0	0%
Number of enrollees with rare diseases receiving treatment	82,000	82,000	0	0%
Utilization				
<i>Small molecule</i>				
Pharmacy scripts	165,000	171,000	6,000	4%
Physician-administered drug	50,000	54,000	4,000	8%
<i>Biologics</i>				
Pharmacy scripts	222,000	227,000	5,000	2%
Physician-administered drug	84,000	86,000	2,000	2%
Unit cost				
<i>Small molecule</i>				
Pharmacy scripts	\$12,700	\$12,700	\$0	0%
Physician-administered drug	\$700	\$700	\$0	0%
<i>Biologics</i>				
Pharmacy scripts	\$6,800	\$6,800	\$0	0%
Physician-administered drug	\$17,400	\$17,400	\$0	0%

Source: California Health Benefits Review Program, 2026.

Note: * Rare diseases are diseases with fewer than 200,000 affected individuals in the United States.

²⁵ Small molecule drugs administered in a physician's office may have a shorter dosing interval than biologics (e.g., weekly or biweekly vs. monthly or quarterly for biologics), meaning a 60-day delay displaces more administrations proportionally, producing a larger % increase when that delay is removed.

Expenditures and Premium Impacts

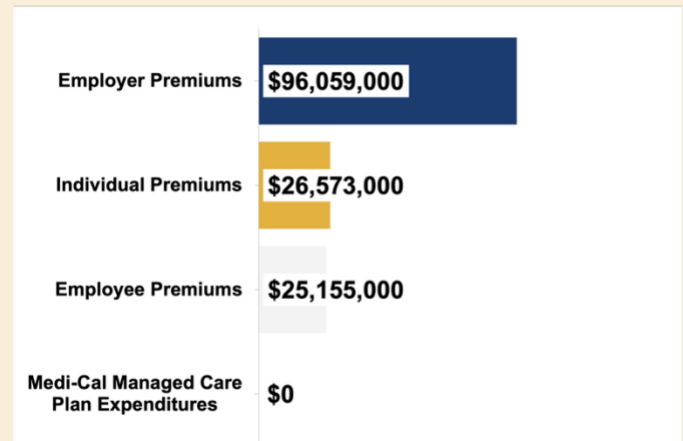
Policies affecting health insurance benefits, such as benefit coverage mandates, impact stakeholders in distinct ways. In terms of direct costs, these stakeholders can generally be grouped into two categories: (1) enrollees who pay for the benefit and utilize the benefit,²⁶ and (2) those who pay for the benefit but do not utilize it. All enrollees within a risk pool share in these costs through the benefit's impact on plan premiums. Enrollees who use a benefit may be responsible for paying premiums and any out-of-pocket expenses related to the benefit.

Expenditure Impacts on Employers and All Enrollees

As shown in Figure 4, for DMHC-regulated plans and CDI-regulated policies, AB 1887 would increase total premiums paid by employers and enrollees for newly covered benefits by approximately \$148 million (0.08%). Medi-Cal enrollees see no change in premiums or expenditures, as the mandate does not apply to Medi-Cal.

Premium impacts vary across market segments. Among DMHC-regulated commercial plans, small group enrollees would see the largest total premium change (\$0.97 per member per month), followed by individual (\$0.89) and large group (\$0.89). Among CDI-regulated commercial plans, individual market enrollees would see the largest premium change (\$1.04 per member per month), which is the highest of any market segment. CalPERS enrollees would see a smaller premium impact (\$0.78 per member per month), while Medi-Cal enrollees would see no premium change because the mandate does not apply to Medi-Cal.

Figure 4. Expenditure Impacts of AB 1887 on Employers and Enrollees



Source: California Health Benefits Review Program, 2026.

CHBRP projects no change to copayments or coinsurance rates but does project an increase in utilization of FDA-approved orphan drugs and therefore an increase in enrollee cost sharing. Cost-sharing impacts follow a similar pattern, with small- and individual-market enrollees in both DMHC-regulated plans and CDI-regulated policies seeing higher cost-sharing increases than large-group enrollees. Cost-sharing increases range from \$0.04 per member per month for CalPERS enrollees to \$0.06 for DMHC-regulated individual market enrollees. There are no changes in expenses for noncovered benefits across any market segment.

The percent change in insured premiums is largest for DMHC-regulated large- and small-group enrollees, and CDI-regulated individual market enrollees (0.12%) and smallest for CalPERS and CDI-regulated large-group enrollees (0.09%), with all other commercial market segments falling within a range of 0.10% to 0.11%. For more details on postmandate changes in premiums and total expenditures by market segment, see Table 10 in the Appendix. Enrollee premiums calculated include premiums for those enrollees using the benefit in addition to those not using the benefit. No measurable offsets are projected (Table 5; see also Table 9 and Table 10 in the Appendix).

²⁶Depending on their health insurance and the benefit in question, enrollees may or may not also pay for the benefit. For example, most Medi-Cal beneficiaries do not have cost sharing and do not pay health insurance premiums, whereas enrollees with a health insurance plan in the individual market may pay both insurance premiums and cost sharing or other out-of-pocket expenses.

Table 4. Premium Impact Ranges of AB 1887 by Market Segment

Market Segment	Premium Impact Range (PMPM)
Commercial plans/policies	\$0.89–\$1.04
CalPERS	\$0.78
Medi-Cal	\$0.00

Source: California Health Benefits Review Program, 2026.

Key: CalPERS = California Public Employees' Retirement System; PMPM = per member per month.

Below, Table 5 provides estimates of the aggregate impacts of AB 1887 on premiums. CHBRP estimates that AB 1887 would increase total premiums by \$148 million (0.08%) postmandate. For non-enrollee premiums, employer-sponsored premiums would increase by \$89 million (0.12%), and CalPERS employer premiums would increase by approximately \$7 million (0.09%). For enrollee premiums, premiums for individuals with individually-purchased insurance would increase by \$27 million (0.10%), with increases of \$10 million (0.11%) for those enrolled outside Covered California and \$17 million (0.10%) for those enrolled through Covered California. Premiums for enrollees with group insurance would increase by \$25 million (0.12%).

Table 5. Impacts of AB 1887 on Premiums, 2027

	Baseline	Postmandate	Increase/ Decrease	Percentage Change
Non-enrollee premiums				
Employer-sponsored (a)	\$75,730,916,000	\$75,819,615,000	\$88,699,000	0.12%
CalPERS employer (b)	\$8,611,855,000	\$8,619,215,000	\$7,360,000	0.09%
Medi-Cal (c)	\$42,982,384,000	\$42,982,384,000	\$0	0.00%
Enrollee premiums				
Enrollees, individually purchased insurance	\$25,775,325,000	\$25,801,898,000	\$26,573,000	0.10%
Outside Covered California	\$9,551,761,000	\$9,561,847,000	\$10,086,000	0.11%
Through Covered California	\$16,223,564,000	\$16,240,051,000	\$16,487,000	0.10%
Enrollees, group insurance (d)	\$21,828,135,000	\$21,853,290,000	\$25,155,000	0.12%
Total premiums	\$174,928,615,000	\$175,076,402,000	\$147,787,000	0.08%

Source: California Health Benefits Review Program, 2026.

Notes: (a) In some cases, a union or other organization. Excludes CalPERS.

(b) Includes only CalPERS enrollees in DMHC-regulated plans. Approximately 49.0% are state retirees, state employees, or their dependents. About one in five (20.4%) of these enrollees has a pharmacy benefit not subject to DMHC. CHBRP has projected no impact for those enrollees. However, CalPERS could, postmandate, require equivalent coverage for all its members (which could increase the total impact on CalPERS).

(c) Includes only Medi-Cal beneficiaries enrolled in DMHC-regulated plans.

(d) Enrollee premium expenditures include contributions by enrollees to employer (or union or other organization)-sponsored health insurance, health insurance purchased through Covered California, and any contributions to enrollment through Medi-Cal to a DMHC-regulated plan.

Key: CalPERS = California Public Employees' Retirement System; CDI = California Department of Insurance; DMHC = Department of Managed Health Care.

Enrollee Expenses for Benefit Users

The per-enrollee cost impact of AB 1887 is modest, reflecting the narrow population affected, approximately 0.06% of most plan types, with annual premium impacts ranging from \$1.49 to \$10.69 depending on market segment. Because the elimination of utilization management delays would result in new users receiving an additional 60-days worth of prescriptions in the mandate year (i.e., two additional 30-day prescriptions in the first year of use), average annual enrollee expenses for users are estimated at \$1,000 for large-group, \$1,100 for small-group, \$1,200 for individual, and \$900 for CalPERS enrollees (Table 6). These users represent approximately 0.06% of the large-group, small-group, and individual populations and 0.05% of CalPERS enrollees. The average annual enrollee premium impact for users is \$1.90 for large-group, \$3.80 for small-group, \$10.69 for individual, and \$1.49 for CalPERS enrollees. The impact of AB 1887 on average enrollee out-of-pocket expenses for those enrollees not utilizing the benefit is limited to the premium impact, as non-users would experience no change in cost sharing or expenses for noncovered benefits. Average annual enrollee premium impacts for non-users mirror those for users: \$1.90 for large-group, \$3.80 for small-group, \$10.69 for individual, and \$1.49 for CalPERS enrollees (Table 7). It is possible that some enrollees incurred expenses related to FDA-approved orphan drugs for which coverage was denied, but CHBRP cannot estimate the frequency with which such situations occur and so cannot offer a calculation of impact.

The presence of a deductible not yet met for the year²⁷ could result in the enrollee paying the full unit cost, but hitting the annual out-of-pocket maximum²⁸ would result in the enrollee having no further cost sharing.

Other Cost Considerations

The literature identifies direct financial barriers, particularly high out-of-pocket costs and restrictive formulary tiering, as the primary drivers of reduced utilization and treatment abandonment for FDA-approved orphan drugs. Higher patient cost sharing is consistently associated with lower rates of medication initiation and persistence, with abandonment rates ranging from 32% to 75% for specialty drugs when cost sharing exceeded \$100 (Ismail et al., 2023). This relationship is particularly pronounced for biologics, where abandonment rates rose from 1.3% at the lowest cost levels to 32.7% for patients facing out-of-pocket costs exceeding \$550, and for PCSK9 inhibitors, where abandonment ranged from 7.5% at a \$0 copay to over 75% for copays greater than \$350 (Hopson et al., 2016; Navar et al., 2017). Formulary placement compounds these challenges – on average, 85% of orphan drugs on Medicare Part D formularies were placed on the highest cost-sharing tier, often with coinsurance rates of 25% to 33% (Yehia, 2020). In exchange plans, orphan drugs frequently appear on the highest tiers with coinsurance rates of up to 50% and first-month costs exceeding \$6,000 (Robinson et al., 2014). Beneficiaries without low-income subsidies had a 37% higher rate of non-initiation for specialty drugs compared to those receiving subsidies (Dusetzina et al., 2022). These findings suggest that while AB 1887 would address delays associated with utilization management, cost barriers represent a significant and ongoing challenge for enrollees with rare diseases that the mandate would not directly address.

For more information, see the Technical Brief on AB 1887, including what else policymakers should consider.

WHAT ELSE SHOULD POLICYMAKERS CONSIDER?

The full impacts of legislation may affect more than benefit coverage, utilization, and cost. See more details on each in the fiscal technical brief.

 State spending targets	 Changes in the number of uninsured persons
 Administrative and other expenses	 Potential cost of exceeding essential health benefits

²⁷ For estimates of enrollees in plans and policies with deductibles, see CHBRP's [resource Deductibles in State-Regulated Health Insurance](#).

²⁸ For most enrollees in most plans and policies regulated by DMHC or CDI, applicable copays and coinsurance for prescription medications is limited to \$250, or \$500 for enrollees in the "bronze plans" available from Covered California, the state's ACA marketplace (HSC 1342.73; INS 10123.1932). Cost sharing could be higher for an enrollee in a plan or policy that includes a deductible.

Table 6. Impact of AB 1887 on Average User Enrollee Expenses

	Large Group	Small Group	Individual	CalPERS	Medi-Cal
% of population with enrollee expenses impact due to AB 1887	0.06%	0.06%	0.06%	0.05%	0.00%
Average annual enrollee premium impact for users	\$1.90	\$3.80	\$10.69	\$1.49	\$0.00
Average annual enrollee expenses impact for users*	\$1,000	\$1,100	\$1,200	\$900	\$0

Source: California Health Benefits Review Program, 2026.

Notes: Average enrollee expenses include cost sharing (e.g., deductibles, copays, etc.) for covered benefits and out-of-pocket expenses for noncovered benefits. Average annual enrollee premium impact includes the employee portion of the premium only.

* Benefit coverage for Medi-Cal beneficiaries does not generally include any cost sharing.

Table 7. Impact of AB 1887 on Average Non-User Enrollee Expenses

	Large Group	Small Group	Individual	CalPERS	Medi-Cal
% of population without enrollee expenses impact due to AB 1887	99.94%	99.94%	99.94%	99.95%	100.00%
Average annual enrollee premium impact for non-users	\$1.90	\$3.80	\$10.69	\$1.49	\$0.00
Average annual enrollee expenses impact for non-users*	\$0	\$0	\$0	\$0	\$0

Source: California Health Benefits Review Program, 2026.

Notes: Average enrollee expenses include cost sharing (e.g., deductibles, copays, etc.) for covered benefits and out-of-pocket expenses for noncovered benefits. Average annual enrollee premium impact includes the employee portion of the premium only.

* Benefit coverage for Medi-Cal beneficiaries does not generally include any cost sharing.

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AB 1887 Impacts: Public Health

The public health impact analysis includes estimated impacts in the short term (within 12 months of full implementation) and in the long term (beyond the first 12 months following full implementation). This section estimates the short-term impact²⁹ of AB 1887 access to medication treatments and health outcomes. See the *Long-Term Impacts* section for a discussion of the potential impact on disparities and on the health care workforce.

As presented in the *Utilization Management and Access to Prescription Drugs for Rare Diseases* section, CHBRP found there is not enough research on the impact of utilization management on access to orphan drugs. In studies of non-rare diseases, CHBRP found *some evidence* that prior authorization results in delays for initiation of prescription drug treatments and *some evidence* that these delays may contribute to hospitalizations, emergency department visits, and increased disease morbidity. However, prescription drug treatments for rare diseases may differ from chronic diseases as there is typically one treatment available for rare diseases compared to multiple generic and/or non-generic treatments for non-rare diseases. Utilization management may impact access to prescription drugs for rare diseases differently than prescription drugs for non-rare diseases. CHBRP found no evidence to distinguish the differences.

As presented in the *AB 1887 Impacts: Benefit Coverage and Cost* section, CHBRP estimates that in the first year postmandate, AB 1887 would result in 8,200 people who are starting new prescriptions for a medication to treat a rare disease to potentially access their prescriptions up to 2 months sooner (amounting to an additional 17,000 total prescriptions during that time period), due to the removal of utilization management.³⁰

Since rare diseases are often chronic, serious, and progressive in nature and are often life-threatening or life-limiting, AB 1887 may improve the health and quality-of-life for people with rare diseases depending on the symptoms, severity, and efficacy of the medication. If people with rare diseases can access medication treatments more quickly, there may also be reductions in unnecessary health care utilization while awaiting access to medication, as shown in the *Utilization Management and Access to Prescription Drugs for Rare Diseases* section, which found evidence that delays in care may contribute to increased health care utilization and increased disease morbidity for patients with non-rare chronic diseases.

CHBRP finds that AB 1887 would result in 8,200 people starting new prescriptions for a medication to treat a rare disease to potentially access their prescriptions up to 2 months sooner (amounting to an additional 17,000 prescriptions during that time period, with some patients potentially starting more than 1 medication), due to the removal of utilization management.

CHBRP projects no measurable public health impact at the population level because people with rare diseases may receive other treatments for symptoms while awaiting approval for a medication subject to utilization management and because there is a lack of rare disease-specific evidence in the literature regarding the impact of a 60-day delay in treatment on health outcomes. However, AB 1887 would likely yield health and quality-of-life improvements at the person level, such as faster access to medications, potential reductions in unnecessary health care utilization while awaiting prior authorization for medications, and reduced stress and administration burden for patients, their families, and their clinicians by removing prior authorization requirements.

²⁹ CHBRP defines short-term impacts as changes occurring within 12 months of full implementation of an enacted law.

³⁰ Despite literature on non-rare diseases estimating that delays in access to drug treatments could range from 3.6 to 44 days, CHBRP assumes that for rare diseases, the delay could be 60 days, based on clinical expert opinion from rare disease specialists, Drs. V. Ma and M. Martin. See *AB 1887 Impacts: Benefit Coverage and Cost* section for more details.

Impact on Disparities³¹

Disparities in rare diseases exist by race/ethnicity, sex/gender, age, geography, and income. More information on disparities in rare diseases can be found in the *Background* section in the Technical Brief on AB 1887. CHBRP estimates AB 1887 would not change these disparities in the first 12 months postmandate.

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³¹ For details about CHBRP's [methodological approach](#) to analyzing disparities, see the *Benefit Mandate Structure and Unequal Racial/Ethnic Health Impacts* document.

AB 1887 Impacts: Long-Term

In this section, CHBRP estimates the long-term impact of AB 1887, which CHBRP defines as impacts occurring beyond the first 12 months after legislation is fully implemented.³² These estimates are qualitative and based on the existing evidence available in the literature. CHBRP does not provide quantitative estimates of long-term impacts because of unknown improvements in clinical care, changes in prices, implementation of other complementary or conflicting policies, and other unexpected factors.

Long-Term Utilization and Cost Impacts

Utilization Impacts

Over time, utilization of FDA-approved drugs for rare diseases is likely to increase as new drugs receive FDA approval and are added to the Orphan Drug database. As awareness of rare disease diagnoses improves and diagnostic capabilities advance, the number of individuals diagnosed with rare diseases may also grow, contributing to increased utilization. Additionally, as the rare disease drug market continues to expand, new FDA-approved small molecule and biologic drugs without generic or biosimilar equivalents may enter the market, increasing the number of drugs subject to the mandate. Conversely, as biosimilar alternatives become available for currently covered biologics, some drugs may no longer be subject to the mandate, which could moderate utilization growth over time. The extent to which these factors would affect long-term utilization is unknown.

Cost Impacts

Additional use and payment by health plans and insurers after year 1 is likely, with premiums expected to increase concurrently with increased utilization of FDA-approved orphan drugs. As mentioned above, the elimination of utilization management delays would result in increases in utilization in the mandate year for new users; in subsequent years, utilization increases would be limited to the annual cohort of new users starting FDA-approved drugs for rare diseases. The long-term cost implications of AB 1887 may be influenced by market dynamics and the availability of generic and biosimilar alternatives. As more biosimilar drugs enter the market for rare diseases, some drugs currently subject to the mandate may become ineligible as biosimilar equivalents for them become available, which could moderate long-term cost impacts.

Long-Term Public Health Impacts

Some interventions in proposed mandates provide immediate measurable impacts (e.g., maternity service coverage or acute care treatments), whereas other interventions may take years to make a measurable impact (e.g., coverage for tobacco cessation or vaccinations). When possible, CHBRP estimates the long-term effects (beyond 12 months postmandate) to the public's health that would be attributable to the mandate, including impacts on disparities.

The long-term public health impacts of AB 1887 are expected to be similar to those described in the short-term impact section. At the person-level, AB 1887 could yield health and quality of life improvements for people with rare diseases and allow them to access medication treatments more quickly, depending on the symptoms, severity, and efficacy of the medication. Additional research is necessary to understand the long-term impacts of utilization management on administrative burden and burnout of health care professionals.

³² Full-scale implementation typically requires a "ramp up" period which may include educating enrollees, providers and insurance carriers on the new benefits or coverage, updating procedures and policies, and increasing provider capacity for marginal utilization resulting from AB 1887. Furthermore, some policies may have staggered implementation or longer-term changes in utilization. The short-term, incremental impact estimated by CHBRP assumes there is no "ramp up" period and represent ongoing annual costs at full-scale implementation of AB 1887, including potential short-term offsets. CHBRP further assumes that state and industry policies and provider and patient behaviors would remain constant throughout the time period it takes for the full impact of the bill to be realized.

Impacts on Disparities and the Social Drivers of Health³³

While there are disparities and differences in the diagnosis and treatment of rare diseases, CHBRP projects no changes in these disparities that would be attributable to AB 1887. AB 1887 would not address other barriers to timely treatment such as delays in the diagnosis or screening of rare diseases, geographic access to specialty care and clinicians, out-of-pocket costs (including transportation costs, special equipment costs, and costs for treatments not covered by insurance) and limited medication treatment options, which impact the health and quality of life for people with rare diseases (see the *Background* section of CHBRP's Technical Brief on AB 1887 for more information).

Impacts on Premature Death

Premature death, measured by years of potential life lost (YPLL), is often defined as death occurring before the age of 75 years (NCI, 2019).³⁴ Rare diseases can be life-limiting and life-threatening, and medications for rare diseases could reduce YPLL. However, the removal of prior authorization itself would not meaningfully impact YPLL, as it is assumed that the medications eventually are approved as clinicians go through the prior authorization and appeals process.

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³³ For more information about SDOH, see CHBRP's [Public Health Impact Analysis and Research Approach](#).

³⁴ For more information about CHBRP's public health methodology, see CHBRP's [Public Health Impact Analysis and Research Approach](#).

Appendix. Impacts of AB 1887 on Benefit Coverage and Expenditures, 2027

Table 8. Impacts of AB 1887 on Benefit Coverage, 2027

	Baseline	Postmandate	Increase/ Decrease	Percentage Change
Total enrollees with health insurance subject to state benefit mandates*	22,842,000	22,842,000	0	0.00%
Total enrollees with health insurance subject to AB 1887	13,799,000	13,799,000	0	0.00%
Percentage of enrollees with fully compliant coverage for mandated benefit	0%	100%	100%	0.00%
Number of enrollees with fully compliant coverage for mandated benefit	0	13,799,000	13,799,000	0.00%

Source: California Health Benefits Review Program, 2026.

Note: * Enrollees in plans and policies regulated by DMHC or CDI. Includes those associated with Covered California, CalPERS, or Medi-Cal.³⁵

Key: CalPERS = California Public Employees' Retirement System; CDI = California Department of Insurance; DMHC = Department of Managed Health Care.

³⁵ For more detail, see CHBRP's [resource Sources of Health Insurance in California](#).

Table 9. Baseline Per Member Per Month Premiums and Total Expenditures by Market Segment, California, 2026

	DMHC-Regulated						CDI-Regulated			Total
	Commercial Plans (by Market) (a)			Publicly Funded Plans			Commercial Plans (by Market) (a)			
	Large Group	Small Group	Individual	CalPERS (b)	Medi-Cal (c)		Large Group	Small Group	Individual	
					Under 65	65+				
Enrollee counts										
Total enrollees in plans/policies subject to state mandates (d)	7,929,000	2,097,000	2,444,000	931,000	8,078,000	965,000	315,000	42,000	41,000	22,842,000
Total enrollees in plans/policies subject to AB 1887	7,929,000	2,097,000	2,444,000	931,000	8,078,000	965,000	315,000	42,000	41,000	22,842,000
Premiums										
Average portion of premium paid by employer (e)	\$619.33	\$539.05	\$0.00	\$770.84	\$367.89	\$632.17	\$780.34	\$573.31	\$0.00	\$127,325,155,000
Average portion of premium paid by enrollee	\$134.02	\$263.52	\$864.90	\$145.41	\$0.00	\$0.00	\$184.88	\$242.16	\$832.16	\$47,603,460,000
Total premium	\$753.35	\$802.56	\$864.90	\$916.25	\$367.89	\$632.17	\$965.22	\$815.47	\$832.16	\$174,928,616,000
Enrollee expenses										
Cost-sharing for covered benefits (deductibles, copays, etc.)	\$56.38	\$184.07	\$271.63	\$70.59	\$0.00	\$0.00	\$126.72	\$213.52	\$192.93	\$19,432,815,000
Expenses for noncovered benefits (f)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0
Total expenditures	\$809.72	\$986.63	\$1,136.53	\$986.84	\$367.89	\$632.17	\$1,091.94	\$1,029.00	\$1,025.09	\$194,361,431,000

Source: California Health Benefits Review Program, 2026.

Notes: (a) Includes enrollees with grandfathered and nongrandfathered health insurance acquired outside or through Covered California (the state's health insurance marketplace).

(b) Includes only CalPERS enrollees in DMHC-regulated plans. Approximately 51.6% are state retirees, state employees, or their dependents. About one in five of these enrollees has a pharmacy benefit not subject to DMHC.³⁶ CHBRP has projected no impact for those enrollees. However, CalPERS could, postmandate, require equivalent coverage for all its members (which could increase the total impact on CalPERS).

(c) Includes only Medi-Cal beneficiaries enrolled in DMHC-regulated plans. Includes those who are also Medicare beneficiaries.

(d) Enrollees in plans and policies regulated by DMHC or CDI. Includes those associated with Covered California, CalPERS, or Medi-Cal.³⁷

(e) In some cases, a union or other organization, or Medi-Cal for its beneficiaries.

(f) Includes only those expenses that are paid directly by enrollees (or other sources) to providers for services related to the mandated benefit that are not covered by insurance at baseline. This only includes those expenses that will be newly covered postmandate. Other components of expenditures in this table include all health care services covered by insurance.

Key: CalPERS = California Public Employees' Retirement System; CDI = California Department of Insurance; COHS = County Organized Health Systems; DMHC = Department of Managed Health Care.

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³⁶ For more detail, see CHBRP's [resource Pharmacy Benefit Coverage in State-Regulated Health Insurance](#).

³⁷ For more detail, see CHBRP's [resource Sources of Health Insurance in California](#).

Table 10. Postmandate Change in Per Member Per Month Premiums and Total Expenditures by Market Segment, California, 2027

	DMHC-Regulated						CDI-Regulated			Total
	Commercial Plans (by Market) (a)			Publicly Funded Plans			Commercial Plans (by Market) (a)			
	Large Group	Small Group	Individual	CalPERS (b)	Medi-Cal (c)		Large Group	Small Group	Individual	
					Under 65	65+				
Enrollee counts										
Total enrollees in plans/policies subject to state mandates (d)	7,929,000	2,097,000	2,444,000	931,000	8,078,000	965,000	315,000	42,000	41,000	22,842,000
Total enrollees in plans/policies subject to AB 1887	7,929,000	2,097,000	2,444,000	931,000	8,078,000	965,000	315,000	42,000	41,000	22,842,000
Premiums										
Average portion of premium paid by employer (e)	\$0.7296	\$0.6492	\$0.0000	\$0.6588	\$0.0000	\$0.0000	\$0.6906	\$0.6556	\$0.0000	\$96,059,000
Average portion of premium paid by enrollee	\$0.1579	\$0.3174	\$0.8887	\$0.1243	\$0.0000	\$0.0000	\$0.1636	\$0.2769	\$1.0377	\$51,728,000
Total premium	\$0.8875	\$0.9666	\$0.8887	\$0.7831	\$0.0000	\$0.0000	\$0.8542	\$0.9325	\$1.0377	\$147,786,000
Enrollee expenses										
Cost sharing for covered benefits (deductibles, copays, etc.)	\$0.0469	\$0.0572	\$0.0605	\$0.0398	\$0.0000	\$0.0000	\$0.0463	\$0.0585	\$0.0583	\$8,357,000
Expenses for noncovered benefits (f)	\$0.0000	\$0.0000	\$0.0000	\$0.0000	\$0.0000	\$0.0000	\$0.0000	\$0.0000	\$0.0000	\$0
Total expenditures	\$0.9344	\$1.0238	\$0.9491	\$0.8229	\$0.0000	\$0.0000	\$0.9005	\$0.9911	\$1.0960	\$156,144,000
Percent change										
Percent change insured premiums	0.1178%	0.1204%	0.1027%	0.0855%	0.0000%	0.0000%	0.0885%	0.1144%	0.1247%	0.0845%
Percent change total expenditures	0.1154%	0.1038%	0.0835%	0.0834%	0.0000%	0.0000%	0.0825%	0.0963%	0.1069%	0.0803%

Source: California Health Benefits Review Program, 2026.

Notes: (a) Includes enrollees with grandfathered and nongrandfathered health insurance acquired outside or through Covered California (the state's health insurance marketplace).

(b) Includes only CalPERS enrollees in DMHC-regulated plans. Approximately 51.6% are state retirees, state employees, or their dependents. About one in five of these enrollees has a pharmacy benefit not subject to DMHC.³⁸ CHBRP has projected no impact for those enrollees. However, CalPERS could, postmandate, require equivalent coverage for all its members (which could increase the total impact on CalPERS).

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(f) Includes only those expenses that are paid directly by enrollees (or other sources) to providers for services related to the mandated benefit that are not covered by insurance at baseline. This only includes those expenses that will be newly covered postmandate. Other components of expenditures in this table include all health care services covered by insurance.

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³⁸ For more detail, see CHBRP's [resource Pharmacy Benefit Coverage in State-Regulated Health Insurance](#).

³⁹ For more detail, see CHBRP's [resource Sources of Health Insurance in California](#).

References

- Adachi T, El-Hattab AW, Jain R, et al. Enhancing equitable access to rare disease diagnosis and treatment around the world: a review of evidence, policies, and challenges. *International Journal of Environmental Research and Public Health*. 2023;20(6):4732.
- Bell SA, Tudur Smith C. A comparison of interventional clinical trials in rare versus non-rare diseases: an analysis of ClinicalTrials.gov. *Orphanet Journal of Rare Diseases*. 2014;9(1):170.
- Centers for Disease Control and Prevention (CDC). Data Summary: Muscular Dystrophy. Last Updated January 7, 2025. Available at: <https://www.cdc.gov/muscular-dystrophy/research/summary.html>. Accessed March 24, 2026.
- Cohen JP, Awatin JG. Patient access to orphan drugs. *Expert Opinion on Orphan Drugs*. 2017;5(12):923-932.
- Congress.gov. The Orphan Drug Act: Legal Overview and Policy Considerations. Last Updated March 5, 2024. Available at: <https://www.congress.gov/crs-product/IF12605>. Accessed March 16, 2026.
- Chaudhary A, Kumar V. Rare diseases: a comprehensive literature review and future directions. *Journal of Rare Diseases*. 2025;4(1):33.
- Dusetzina SB, Huskamp HA, Rothman RL, et al. Many Medicare beneficiaries do not fill high-price specialty drug prescriptions. *Health Affairs (Millwood)*. 2022;41(4):487-496.
- Fermaglich LJ, Miller KL. A comprehensive study of the rare diseases and conditions targeted by orphan drug designations and approvals over the forty years of the Orphan Drug Act. *Orphanet Journal of Rare Diseases*. 2023;18(1):163.
- Goel K, Hon SM, Farber HW, George MP. Pulmonary arterial hypertension: what rare diseases tell us about disparities in disease registries, clinical trials, and treatment algorithms. *Chest*. 2021;160(5):1981-1983.
- Han Q, Fu H, Chu X, et al. Research advances in treatment methods and drug development for rare diseases. *Frontiers in Pharmacology*. 2022;13:971541.
- Hillert A, Anikster Y, Belanger-Quintana A, et al. The genetic landscape and epidemiology of phenylketonuria. *American Journal of Human Genetics*. 2020;107(2):234-250.
- Hopson S, Saverno K, Liu LZ, et al. Impact of out-of-pocket costs on prescription fills among new initiators of biologic therapies for rheumatoid arthritis. *Journal of Managed Care & Specialty Pharmacy*. 2016;22(2):122-30. doi:10.18553/jmcp.2016.14261
- Ismail WW, Witry MJ, Urmie JM. The association between cost sharing, prior authorization, and specialty drug utilization: A systematic review. *Journal of Managed Care & Specialty Pharmacy*. 2023;29(5):449-463. doi:10.18553/jmcp.2023.29.5.449
- Kharrazi M, Yang J, Bishop T, et al. Newborn screening for cystic fibrosis in California. *Pediatrics*. 2015;136(6):1062-1072.
- Kourakis S, Timpani CA, Campelj DG, et al. Standard of care versus new-wave corticosteroids in the treatment of Duchenne muscular dystrophy: Can we do better? *Orphanet Journal of Rare Diseases*. 2021;16(1):117.
- Lerario S, Monti L, Ambrosetti I, et al. Fabry disease: a rare disorder calling for personalized medicine. *International Urology and Nephrology*. 2024;56(10):3161-3172.
- Marwaha S, Knowles JW, Ashley EA. A guide for the diagnosis of rare and undiagnosed disease: beyond the exome. *Genome Medicine*. 2022;14(1):23.
- Medina A, Mahjoub Y, Shaver L, Pringsheim T. Prevalence and incidence of Huntington's disease: an updated systematic review and meta-analysis. *Movement Disorders*. 2022;37(12):2327-2335. doi:10.1002/mds.29228
- National Cancer Institute (NCI). NCI Dictionary of Cancer Terms: Premature Death. 2019. Available at: www.cancer.gov/publications/dictionaries/cancer-terms/def/premature-death. Accessed August 29, 2019.

- National Institutes of Health (NIH). Rare Diseases FAQ. National Human Genome Research Institute. Last Updated December 13, 2024. Available at: <https://www.genome.gov/FAQ/Rare-Diseases>. Accessed March 5, 2026.
- National Library of Medicine (NLM). Pompe disease. MedLinePlus. Last Updated February 1, 2016. Available at: <https://medlineplus.gov/genetics/condition/pompe-disease/>. Accessed March 8, 2026.
- National Library of Medicine (NLM). Rare Diseases. MedLinePlus. Last Updated June 5, 2017. Available at: <https://medlineplus.gov/rarediseases.html>. Accessed March 5, 2026.
- National Library of Medicine (NLM). Cystic fibrosis. MedLinePlus. Last Updated July 6, 2021. Available at: <https://medlineplus.gov/genetics/condition/cystic-fibrosis/>. Accessed March 8, 2026.
- National Library of Medicine (NLM). Fabry disease. MedLinePlus. Last Updated July 29, 2022. Available at: <https://medlineplus.gov/genetics/condition/fabry-disease/>. Accessed March 8, 2026.
- National Library of Medicine (NLM). Duchenne muscular dystrophy. MedLinePlus. Last Updated June 11, 2024a. Available at: <https://medlineplus.gov/ency/article/000705.htm>. Accessed March 8, 2026.
- National Library of Medicine (NLM). Sickle Cell Disease. MedLinePlus. Last Updated September 6, 2024b. Available at: <https://medlineplus.gov/sicklecelldisease.html>. Accessed March 5, 2026.
- National Library of Medicine (NLM). Huntington's disease. MedLinePlus. Last Updated November 18 2025a. Available at: <https://medlineplus.gov/huntingtonsdisease.html>. Accessed March 8, 2026.
- National Library of Medicine (NLM). Phenylketonuria. MedLinePlus. Last Updated September 17, 2025b. Available at: <https://medlineplus.gov/phenylketonuria.html>. Accessed March 8, 2026.
- Navar AM, Taylor B, Mulder H, et al. Association of prior authorization and out-of-pocket costs with patient access to PCSK9 inhibitor therapy. *JAMA Cardiology*. 2017;2(11):1217-1225.
- Newcomer LN, Weininger R, Carlson RW. Transforming prior authorization to decision support. *Journal of Oncology Practice*. 2017;13(1):e57-e61.
- Orphanet. Knowledge on Rare Diseases and Orphan Drugs. 2026. Available at: www.orpha.net. Accessed on March 27, 2026.
- Penon-Portmann M, Chang J, Cheng M, Shieh JT. Genetics workforce: distribution of genetics services and challenges to health care in California. *Genetics in Medicine*. 2020;22(1):227-231.
- Pharmacy Benefits Management Institute (PBMI). 2014-2015 Prescription Drug Benefit Cost and Plan Design Report. Plano, TX: PBMI; 2015.
- Rath A, Salamon V, Peixoto S, et al. A systematic literature review of evidence-based clinical practice for rare diseases: what are the perceived and real barriers for improving the evidence and how can they be overcome? *Trials*. 2017;18(1):556.
- Reeves SL, Horiuchi S, Zhou M, et al. Case ascertainment of sickle cell disease using surveillance or single administrative database case definitions. *Public Health Reports*. 2024;139(2):187-194.
- Reisin R, Perrin A, García-Pavía P. Time delays in the diagnosis and treatment of Fabry disease. *International Journal of Clinical Practice*. 2017;71(1):e12914.
- Resneck JS. Refocusing medication prior authorization on its intended purpose. *JAMA*. 2020;323(8):703-704.
- Robinson SW, Brantley K, Liow C, Teagarden JR. An early examination of access to select orphan drugs treating rare diseases in health insurance exchange plans. *Journal of Managed Care Pharmacy*. 2014;20(10):997-1004.
- Serrano JG, O'Leary M, VanNoy GE, et al. Advancing understanding of inequities in rare disease genomics. *Clinical Therapeutics*. 2023;45(8):745-753.

- Strzelczyk A, Schubert-Bast S. A practical guide to the treatment of Dravet syndrome with anti-seizure medication. *CNS Drugs*. 2022;36(3):217-237.
- U.S. Food & Drug Administration (FDA). Rare Diseases at FDA. Last Updated February 24, 2026a. Available at: <https://www.fda.gov/patients/rare-diseases-fda>. Accessed March 5, 2026.
- U.S. Food & Drug Administration (FDA). Search Orphan Drug Designations and Approvals. 2026b. Available at: <https://www.accessdata.fda.gov/scripts/opdlisting/ood/index.cfm>. Accessed March 24, 2026.
- Vogel M, Feldman WB, Phil D, et al. Revenue differences between top-selling small-molecule drugs and biologics in Medicare. *JAMA Health Forum*. 2025;6(10):e254720. doi:10.1001/jamahealthforum.2025.4720.
- Wojcik MH, Bresnahan M, del Rosario MC, Ojeda MM, Kritzer A, Fraiman YS. Rare diseases, common barriers: disparities in pediatric clinical genetics outcomes. *Pediatric Research*. 2023;93(1):110-117.
- Yang G, Cintina I, Pariser A, Oehrlein E, Sullivan J, Kennedy A. The national economic burden of rare disease in the United States in 2019. *Orphanet Journal of Rare Diseases*. 2022;17(1):163.
- Yehia F. Utilization Controls for Orphan Drugs: Prior Authorization Does Not Correlate With Lower Drug Use [dissertation. Baltimore, MD: Johns Hopkins University; 2020.
- Zhao H, Du C, Yang G, Wang Y. Diagnosis, treatment, and research status of rare diseases related to birth defects. *Intractable & Rare Diseases Research*. 2023;12(3):148-160.

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CHBRP is an independent program administered and housed by the University of California, Berkeley, under the Office of the Vice Chancellor for Research. A group of faculty, researchers, and staff complete the analysis that informs CHBRP reports. The CHBRP **Faculty Task Force** comprises rotating senior faculty from University of California (UC) campuses. In addition to these representatives, there are other ongoing researchers and analysts who are **Task Force Contributors** to CHBRP from UC that conduct much of the analysis. The **CHBRP staff** works with Task Force members in preparing parts of the analysis, and manages external communications, including those with the California Legislature. As required by CHBRP's authorizing legislation, UC contracts with an independent actuarial firm, **Milliman, Inc.**, to assist in assessing the financial impact of each legislative proposal mandating or repealing a health insurance benefit. The **National Advisory Council** provides expert reviews of draft analyses and offers general guidance on the program to CHBRP staff and the Faculty Task Force. Information on CHBRP's analysis methodology, authorizing statute, as well as all CHBRP reports and other publications, are available at chbrp.org.

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CHBRP assumes full responsibility for the report and the accuracy of its contents. All CHBRP bill analyses and other publications are available at chbrp.org.

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Please direct any questions concerning this document to: California Health Benefits Review Program, MC 3116, Berkeley, CA 94720-3116; info@chbrp.org; or chbrp.org.

About CHBRP

The California Health Benefits Review Program (CHBRP) was established in 2002. CHBRP's mission is to inform and support policymaking in California through the creation of impartial, evidence-based resources. As per its authorizing statute, CHBRP provides the California Legislature with independent analysis of the medical, financial, and public health impacts of proposed health insurance benefit-related legislation. CHBRP is dedicated to providing academic rigor on a Legislature's timeline.

The state funds CHBRP through an annual assessment on health plans and insurers in California.

An analytic staff based at the University of California, Berkeley, supports a task force of faculty and research staff from multiple University of California campuses to complete each CHBRP analysis. A strict conflict-of-interest policy ensures that the analyses are undertaken without bias. An independent actuarial firm helps to estimate the financial impact. Content experts with comprehensive subject-matter expertise are consulted to provide essential background and input on the analytic approach for each report.

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Disclaimer

CHBRP analyzes bills in the current environment given current law and regulations at both the state and federal levels. Each analysis assumes that policy frameworks and stakeholder behaviors remain constant, unless otherwise noted. All estimates are based on current data and do not take into consideration any future or potential changes to factors that may influence the impacts of the legislation, unless otherwise specifically mentioned. Differences between CHBRP's estimated impacts and actual impacts of legislation will depend on alignment with the assumptions used in this analysis, the timeline of implementation, and the final language of the legislation, should it be signed into law. Since actual experience is unlikely to match assumptions perfectly, final impacts will differ from those projected in this analysis.

This analysis is based on existing literature and public sources identified through systematic search methods. This evidence informs the California Legislature about potential impacts of proposed health benefit legislation and does not constitute a policy recommendation from CHBRP.

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