



State of Utah

SPENCER J. COX
Governor

DEIDRE M. HENDERSON
Lieutenant Governor

Insurance Department

JONATHAN T. PIKE
Insurance Commissioner

2022 Utah In Vitro Fertilization and Genetic Testing Report

The *2022 Utah In Vitro Fertilization and Genetic Testing Report* was prepared by Jeffrey E. Hawley, Ph.D. of the Health & Life Insurance Division for the Utah Insurance Commissioner pursuant to Utah Code § 31A-22-654. Publication date: January 31, 2023.

For questions about this report contact:

Jeffrey E. Hawley, Ph.D.
Research Consultant
Health & Life Insurance Division
Utah Insurance Department
4315 S. 2700 West, Suite 2300
Taylorsville, Utah 84129
801-957-9284
jhawley@utah.gov

Shelley Wiseman
Director
Health & Life Insurance Division
Utah Insurance Department
4315 S. 2700 West, Suite 2300
Taylorsville, Utah 84129
801-957-9296
swiseman@utah.gov

Table of Contents

Overview.....	1
Statute	2
31A-22-654. Study of coverage for in vitro fertilization and genetic testing -- Reporting -- Coverage requirements	3
49-20-420. Coverage for in vitro fertilization and genetic testing.....	4
Qualified Insurer Reports.....	5
Regence BlueCross BlueShield of Utah	6
SelectHealth, Inc.	8
UnitedHealthcare Insurance Company	9

Overview

Utah Code § 31A-22-654 requires a qualified insurer to conduct a study related to insurance coverage for in vitro fertilization services and genetic testing for a qualified enrollee with a qualified condition as defined in Utah Code § 49-20-420. The qualified insurer shall study whether providing the coverage for the services described in Utah Code § 31A-22-654(3)(a) and (b) for qualified enrollees will result in cost savings for the qualified insurer.

A qualified insurer shall provide the information required under Utah Code § 31A-22-654(2) to the Utah Insurance Department by January 1, 2022, for a plan year beginning on or after January 1, 2022, but before December 31, 2022, and by January 1, 2025, for a plan year beginning on or after January 1, 2025, but before December 31, 2025.

The Utah Insurance Department shall report the information received under Utah Code § 31A-22-654(2) to the Health and Human Services Interim Committee on or before November 1, 2022, for information submitted for a plan year beginning on or after January 1, 2022, but before December 31, 2022, and by November 1, 2025, for a plan year beginning on or after January 1, 2025, but before December 31, 2025.

The Utah Insurance Department received information from three qualified insurers for the plan year beginning on or after January 1, 2022, but before December 31, 2022. The information received is reported in the Qualified Insurer Reports section starting on page 5.

Statute

31A-22-654. Study of coverage for in vitro fertilization and genetic testing -- Reporting -- Coverage requirements.

- (1) As used in this section:
 - (a) “Qualified condition” means the same as that term is defined in Section 49-20-420.
 - (b) “Qualified insurer” means an insurer that provides a health benefit plan as defined in Section 31A-1-301 to more than 25,000 enrollees in the state as of December 31 of the preceding reporting year.
 - (c) “Qualified enrollee” means an enrollee of a qualified insurer who:
 - (i) has been diagnosed by a physician as having a genetic trait associated with a qualified condition; and
 - (ii) intends to get pregnant with a partner who is diagnosed by a physician as having a genetic trait associated with the same qualified condition as the enrollee.
 - (2) (a) A qualified insurer shall submit the information described in this Subsection (2) to the department for a plan year beginning:
 - (i) on or after January 1, 2022, but before December 31, 2022; and
 - (ii) on or after January 1, 2025, but before December 31, 2025.
 - (b) A qualified insurer shall study whether providing the coverage for the services described in Subsections (3)(a) and (b) for qualified enrollees will result in cost savings for the qualified insurer.
 - (c) (i) If a qualified insurer determines that providing the coverage described in Subsection (3) for qualified enrollees will result in cost savings for the qualified insurer, the qualified insurer shall submit a summary of the results of the study described in Subsection (2)(b), and:
 - (A) describe how the qualified insurer intends to provide the coverage described in Subsection (3); or
 - (B) submit an explanation of why the insurer will not provide the coverage described in Subsection (3).
 - (ii) If a qualified insurer determines that providing the coverage described in Subsection (3) will not result in cost savings to the qualified insurer, the qualified insurer shall submit a summary of the results of the study described in Subsection (2)(b).
 - (d) A qualified insurer shall provide the information required under this Subsection (2) to the department no later than:
 - (i) January 1, 2022, for a plan year beginning on or after January 1, 2022, but before December 31, 2022; and
 - (ii) January 1, 2025, for a plan year beginning on or after January 1, 2025, but before December 31, 2025.
- (3) A qualified insurer shall consider coverage for:
 - (a) in vitro fertilization services for a qualified enrollee; and
 - (b) genetic testing of a qualified enrollee who received in vitro fertilization services under Subsection (3)(a).
- (4) The department shall report the information received under Subsection (2) to the Health and Human Services Interim Committee on or before:
 - (a) for information submitted under Subsection (2)(a)(i), November 1, 2022; and
 - (b) for information submitted under Subsection (2)(a)(ii), November 1, 2025.

49-20-420. Coverage for in vitro fertilization and genetic testing.

- (1) As used in this section:
 - (a) “Qualified condition” means:
 - (i) cystic fibrosis;
 - (ii) spinal muscular atrophy;
 - (iii) Morquio Syndrome;
 - (iv) myotonic dystrophy; or
 - (v) sickle cell anemia.
 - (b) “Qualified individual” means a covered individual who:
 - (i) has been diagnosed by a physician as having a genetic trait associated with a qualified condition; and
 - (ii) intends to get pregnant with a partner who is diagnosed by a physician as having a genetic trait associated with the same qualified condition as the covered individual.
- (2) For a plan year that begins on or after July 1, 2020, the program shall provide coverage for a qualified individual for:
 - (a) in vitro fertilization services; and
 - (b) genetic testing of a qualified individual who receives in vitro fertilization services under Subsection (2)(a).
- (3) Before November 1, 2022, and before November 1 of every third year thereafter, the program shall:
 - (a) calculate the change in state spending attributable to the coverage under this section; and
 - (b) report the amount described in Subsection (3)(a) to the Health and Human Services Interim Committee and the Social Services Appropriations Subcommittee.

Qualified Insurer Reports

Regence BlueCross BlueShield of Utah

Summary of Study Findings Under Utah Code Ann. § 31A-22-654

We examined the financial impact of providing the coverage as required under Utah Code Ann. § 31A-22-654 and determined that adding this coverage will not result in cost savings to Regence BlueCross BlueShield of Utah (RBCBSU). Currently, the coverage described in this statute is not covered for RBCBSU's fully insured enrollees. Therefore, any payments for these and related services will result in an increase to costs and premiums.

Expected cost impact

- The services covered by this bill can be extremely expensive.
 - We looked at the experience of self-insured RBCBSU groups that chose to cover *in vitro* fertilization services over the past several years. The experience was highly variable from year to year due to cost differences across geographical areas, utilization and demographic characteristics, and the type of coverage offered. The cost per year for an enrollee receiving infertility services generally ranged from \$2,000 to \$25,000, although it could be higher in some cases.
 - In addition to the direct costs of covering fertility services, RBCBSU expects additional costs associated with pregnancies resulting from these treatments. Maternity costs average over \$10,000 per case. However, pregnancies arising from infertility treatments are more likely to result in multiple births, premature births, and complications, and we expect pregnancy and childbirth to be more costly than typical pregnancies for both mothers and newborns.
- The conditions listed in U.C.A. § 49-20-420 are rare. The average premium impact of covering the services for enrollees with the listed qualifying conditions is expected to be low. However, since these services are not currently covered, RBCBSU's costs and customer premiums will increase.
- An increase in complicated pregnancies could lead to increased long-term health care costs that would be borne by RBCBSU, other health plans, and their customers.
- The additional costs associated with any coverage mandate for infertility treatment will be incurred by the State of Utah for Individual and Small Group, as we believe they are not Essential Health Benefits, as required under federal law and U.C.A. § 31A-30-118. Higher premiums would be incurred by Utah families and businesses in the large group market.
- There could be erosion of the fully insured market if businesses self-fund to avoid the mandate.

Additional concerns

- Implementing this statute will be challenging.
 - It is difficult to identify enrollees with the qualifying conditions described in the law. RBCBSU likely would require significant changes to our claims processing systems and processes, increasing administrative costs. Utilization of genetic tests to detect qualifying conditions could also increase, further increasing costs.

- The law requires both the enrollee and partner to have the same qualifying condition. There is no mechanism in typical health plan administrative systems to identify the enrollee's partner or their health conditions, even if they are on the same fully insured health benefit plan.
- Offering infertility services to a small subset of the population may be perceived as discriminatory to patients that seek infertility treatment for other reasons. Because the statute requires coverage only for those with qualifying conditions, we would be treating enrollees with qualifying conditions more favorably than enrollees without these conditions, which may not comply with federal or state laws and rules.
- Certain individuals and businesses also have sincerely held religious or personal objections to infertility coverage. Those concerns may be heightened with this mandate, as it only applies when a qualifying condition is present in both partners.

Actual results likely will vary significantly from expected, and experience will vary for any given population or group depending on their demographics and health care use. Costs could be higher if RBCBSU sees fully insured enrollment increases from those who wish to utilize these services. RBCBSU also may experience an initial claims spike due to potential pent-up demand for infertility treatment.

SelectHealth, Inc.

Utah Legislative Bill 31A-22-654

Data Collected

We have reviewed our internal claims data pertaining to the described bill and listed conditions impacted. We also have reviewed national data of average treatment costs for these conditions. The number of people with these conditions is available for some of these conditions but the estimates can be a wide range.

Review of Potential Cost Savings

The qualified conditions listed are high-cost services that involve intense medical treatment and expensive prescription drugs. The long-term savings estimates would depend on the probability of members retaining health insurance for the long term and staying within the same market. To estimate and rely on savings due to adding this coverage is limited.

Risk Selection Issues

There are also risk selection issues that need to be addressed if a new covered benefit is offered

- Offering new benefits can change the risk mix
- There could be differences among carrier access and providers which would cause more costs paid by certain carriers
- There might be an incentive for someone to enroll and get the covered benefit and drop or move coverage. Most plans can be cancelled after high-cost services are offered.

Summary of Coverage Impact

The cost benefit analysis result of a short-term cost with potentially long-term savings is hard to define based on the number of years to recoup costs. As noted, costs are known and savings are speculative.

UnitedHealthcare Insurance Company

Preimplantation Diagnostic Testing Study Summary (§ 31A-22-654)

Background

Genetic tests are medical tests that may be used to identify changes in genes or chromosomes, which can rule out or identify specific genetic conditions. Preimplantation genetic tests (PGT) are performed prior to pregnancy. PGT is performed on the embryo being transferred during the in vitro fertilization (IVF) process.

These tests, when used when an offspring is known to be at-risk for a genetic condition where the gene changes are known, can provide valuable information for informed reproductive decision making.

PGT for genetic conditions provides members who are at risk for passing genetic diseases to their offspring with the disease to their offspring with the ability to have unaffected children while avoiding ethically and emotionally challenging decisions.

Scope of Study

We focused on the types of PGT that can help to identify and prevent genetic conditions which can result in significant health problems or severe disability and are caused by a single gene (PGT-M) or structural changes of a parents' chromosome (PGT-SR). Specifically, we focused on Cystic Fibrosis, Fragile X, Spinal Muscular Atrophy, Tay Sachs, Beta Thalassemia, Sickle Cell Disease, and Congenital Deafness. While our study did not specifically look at Morquio syndrome or Myotonic Dystrophy, the overall analysis and the benefits of PGT for these conditions are comparable to the diseases that were part of our study.

The study involved reviewing national data and national studies completed primarily from 2016 – 2019. The study's objective was to identify gaps in coverage where PGT is not a covered benefit and the member meets the clinical criteria to carry serious genetic conditions. Once the gaps in coverage were identified, we reviewed the benefits of PGT including, providing member with genetic information about the embryo prior to implantation for reproductive decision making which could decrease the risk to members who are carriers of serious genetic conditions of having children affected with the disorder and the substantial cost avoidance that could occur.

Cost Benefit Analysis

The Cost Benefit Analyses (CBA) for this study is not exact and numerous outside factors may impact the accuracy of any cost benefit analysis. These outside factors include the following:

- The study does not take into account individuals who move from one payer to another. The PGT cost could be borne by one insurer/payer while the cost of medical care associated with one of these genetic conditions could be borne by another insurer/payer.

In our study, we assumed that the individual continued to be covered by the same insurer/payer for a three-year period.

- The study does not take into account whether an individual with one of the genetic conditions outlined in UT Code 49-20-420 who was initially covered by a commercial insurance plan would ultimately be covered by a government plan, such as Medicaid.
- While PGT for monogenic disorders (PGT-M) and structural rearrangements (PGT-SR) has known benefits, testing results may not be accurate or multiple tests may be needed. PGT for aneuploidy screening (PGT-A) is still unproven.
- The cost impact would be affected by the success and failure rate of implantation.
- Since PGT was not generally covered in this time period, any anticipated cost savings could be minimal or speculative.
- Our CBA was based on national cost data on IVF, medication, consultation, ICSI, and PGS. Specific state cost would impact any state specific cost analysis.
- There are a number of ethical considerations that should be considered when performing PGT. Parents would have to make decisions on what to do if an embryo is found to contain the genetic markers for a genetic condition that could cause a severe disability.

Our CBA looked at the cost of the PGT and cumulative medical cost associated with PGT over a three-year period. Our study found that over a three-year period, cumulative savings would not be seen until at least year three. The savings in year three are minimal and only exist if the member or child continue to be with the same insurer for the three-year period. In our study, we found that the estimated testing cost was nearly identical to the medical cost avoidance. We did not factor in the cost of new gene therapy treatments as part of the medical cost avoidance some of which are estimated to be \$1 million per year.

Summary

While our CBA showed a minimal cost savings over a three-year period, for our fully insured employer groups, we plan on covering PGT and associated IVF services required to perform PGT that can identify and prevent genetic conditions which would result in significant health problems or severe disability and are caused by a single gene (PGT-M) or structural changes of a parents' chromosome (PGT-SR). This testing includes the qualified conditions outlined in UT Code 49-20-420, which are considered a severe disability caused by a single gene. This benefit is available to an ERISA self-funded employer if that employer group decides to provide such coverage.