FLORIDA HOUSE OF REPRESENTATIVES **BILL ANALYSIS**

This bill analysis was prepared by nonpartisan committee staff and does not constitute an official statement of legislative intent.

BILL #: CS/HB 1553

COMPANION BILL: SB 1728 (Rodriguez)

TITLE: Uterine Fibroid Research Database

LINKED BILLS: None **RELATED BILLS:** None

SPONSOR(S): Dunkley and Valdés

Committee References

Health Professions & Programs 15 Y. 0 N

Health Care Budget 12 Y, 0 N, As CS

Health & Human Services 24 Y. 0 N

SUMMARY

Effect of the Bill:

CS/HB 1553 requires health care providers to submit identified information to the Department of Health (DOH) for inclusion in the Uterine Fibroid Research Database. The bill also adds uterine fibroids to the list of infectious or noninfectious diseases of public health significance, which requires health care providers to submit identified uterine fibroid data to DOH for epidemiological research purposes.

Fiscal or Economic Impact:

The bill has a \$1 million fiscal impact on the Department of Health, which is accounted for in the House proposed budget for Fiscal year 2025-2026. See Fiscal or Economic Impact.

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EFFECT OF THE BILL:

Uterine Fibroids Research Database

Current law requires health care providers to submit deidentified information relating to the diagnosis and treatment of patients with uterine fibroids to the Department of Health (DOH) for inclusion in the Uterine Fibroid Research Database. 1 DOH is unable to determine if the submitted deidentified information is related to a unique individual or related to the same individual whose information has been reported multiple times by various health care providers. Due to the lack of fidelity in the deidentified data it would receive under the current law, DOH has not yet implemented the Uterine Fibroid Research Database.

The bill requires health care providers to submit *identified* information to DOH for inclusion in the Uterine Fibroid Research Database. This will allow DOH to successfully implement the database. (Section 1)

The bill also adds uterine fibroids to the list of infectious or noninfectious diseases of public health significance under s. 381.0031, F.S. This requires health care providers to submit identified uterine fibroid data to DOH for epidemiological research in addition to the reporting requirement for the Uterine Fibroid Research Database. (Section 1)

The bill provides an effective date of July 1, 2025. (Section 2)

¹ S. <u>381.9312, F.S.</u>

STORAGE NAME: h1553e.HHS

DATE: 4/7/2025

FISCAL OR ECONOMIC IMPACT:

STATE GOVERNMENT:

The bill will have a \$1 million nonrecurring fiscal impact on the Department of Health (DOH), which is accounted for in the House proposed budget for Fiscal Year 2025-2026.²

DOH will use the funds for the development and licensing of the Uterine Fibroid Research Database; to ensure the cloud-storage and maintenance operation of the database; and to provide for one OPS Data Scientist to support the development, monitoring, and analysis of data for a comprehensive uterine fibroid disease registry. ³

RELEVANT INFORMATION

SUBJECT OVERVIEW:

Uterine Fibroids

Uterine fibroids, which are tumors that grow in a woman's uterus,⁴ place significant financial burdens on the United States health care system and economy, with an estimated \$34 billion in associated annual health care costs.⁵ These growths are typically benign (noncancerous) and are the most common benign tumor affecting women.⁶ Uterine fibroids are rare before puberty, increase in prevalence during the reproductive years, and decrease in size after menopause. As many as one in five women have fibroids during their childbearing years and half of all women have them by age 50. Fibroids are also more common in Black women, women with high blood pressure, obesity, early onset of periods, late age of menopause, older women, and women with a family history of fibroids.⁷

Although the exact cause of fibroids is unknown, they are thought to be caused by hormones in the body and family history or genes.⁸ In addition to age, race and ethnic origin, and family history, other known risk factors include:⁹

- **Obesity:** Overweight or obese women are two or three times more likely to get fibroids than normal weight women.
- **Eating habits:** Eating a lot of red meat and ham is linked with higher risk of fibroids.
- **Vitamin D deficiency:** Vitamin D inhibits fibroid growth, but studies indicate only 10 percent of Black women have adequate levels.¹⁰

Diagnosis of Fibroids

Fibroids vary in size and weight¹¹ and can grow in different parts of the uterus.¹² Although it is possible for just one fibroid to develop, most often there are multiple. Fibroids are not always easy to diagnose, as some women have no

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² Fiscal Year 2025-2026, HB 5001, House Proposed General Appropriations Act, line 512,

https://www.flhouse.gov/Sections/Documents/loaddoc.aspx?FileName=HB+5001+As+Introduced.pdf&DocumentType=Bill&BillNumber=5001&Session=2025 (last visited Apr. 4, 2025).

³ Department of Health, Agency Bill Analysis HB 1553 (2025), p. 3, on file with the Health Care Budget Subcommittee.

⁴ The uterus is a hollow muscular organ that nourishes the developing baby during pregnancy. University of Florida Health (UFHealth), *Hysterectomy*, https://ufhealth.org/hysterectomy (last visited Feb. 13, 2025).

⁵ Yang Q, Ciebiera M, Bariani M, Ali M, Elkafas H, Boyer T, and Al-Hendy A, Endocrine Society Oxford, Endocrine Reviews, 2022, Vol. XX, No. XX, 1–43 *Comprehensive Review of Uterine Fibroids: Developmental Origin, Pathogenesis, and Treatment*, (Nov. 2021) available at https://academic.oup.com/edrv/advance-article/doi/10.1210/endrev/bnab039/6422392 (last visited Feb. 13, 2025).

⁶ National Center for Biotechnology Information (NCBI), *Uterine Leiomymomata*, https://www.ncbi.nlm.nih.gov/books/NBK546680/ (last visited Feb. 13, 2025).

⁷ UFHealth, *Uterine Fibroids*, https://ufhealth.org/uterine-fibroids (last visited Feb. 13, 2025).

⁸ *Id*.

⁹ Florida Department of Health (DOH) Hernando County, *Uterine Fibroids, 2021 Florida Data Report*, https://hernando.floridahealth.gov/files/FibroidsReport_2021.pdf (last visited Feb. 13, 2025).

¹⁰ Id. Sunlight in moderation, supplements, and certain food sources can help improve Vitamin D levels.

¹¹ Supra note 7. Some fibroids are microscopic, while others fill the entire uterus and weigh several pounds.

symptoms. However, common symptoms are bleeding between periods, heavy bleeding during periods, periods that last longer than normal, urinary frequency and urgency, pelvic cramping or pain with periods, feeling fullness or pressure in the lower belly, and painful intercourse. 13

Fibroids can also be diagnosed through a pelvic exam, which may show a change in the shape of a woman's uterus, or through the following tests:14

- Ultrasound, which uses sound waves to create a picture of the uterus.
- Magnetic resonance imaging, which uses powerful magnets and radio waves to create a picture.
- Saline infusion sonogram, where saline is injected into the uterus to make it easier to see the uterus using ultrasound.
- Hysteroscopy, which uses a long, thin tube inserted through the vagina and into the uterus to examine the inside of the uterus.
- Endometrial biopsy, which removes a small piece of the lining of the uterus to check for cancer if a woman has unusual bleeding.

Treatment of Fibroids

Treatment of fibroids depends on a woman's age, general health, symptoms, type of fibroids, whether she is pregnant, and her desire to have children in the future. Treatment ranges from minimally invasive hormonal and medical treatments to major surgical interventions, such as hysterectomy, 15

Non-Surgical Treatment

There are various treatments for the symptoms of fibroids, such as intrauterine devices (IUDs) that release hormones to help reduce heavy bleeding and pain and tranexamic acid to reduce the amount of blood flow.¹⁶ There are also medical or hormonal therapies to shrink fibroids, ¹⁷ including a type of IUD that releases a low dose of the hormone progestin into the uterus each day. 18 Medical procedures used to directly treat fibroids include:19

- Endometrial ablation, a procedure used to treat heavy bleeding associated with fibroids; and
- Uterine artery embolization, a procedure that stops the blood supply to the fibroid, causing it to shrink and die.

Surgical Treatments

Surgical procedures used to treat fibroids include:²⁰

- Hysteroscopy, a procedure that removes fibroids growing inside the uterus;
- Myomectomy, a procedure that removes fibroids from the uterus, but does not prevent new fibroids from growing; and
- Hysterectomy.

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¹² Supra note 7. Fibroids can grow in the muscle wall of the uterus (myometrial); just under the surface of the uterine lining (submucosal); just under the outside lining of the uterus (subserosal); or on a long stalk on the outside the uterus or inside the uterus (pedunculated).

¹³ Supra, note 7.

¹⁴ *Id*.

¹⁵ Supra, note 6.

¹⁶ Other examples include iron supplements to prevent or treat anemia due to heavy periods; and pain relievers, such as ibuprofen or naproxen, for cramps or pain.

¹⁷ Other examples include birth control pills to help control heavy periods and hormone shots to help shrink fibroids by stopping ovulation.

¹⁸ Supra, note 7.

¹⁹ *Id.*

²⁰ *Id*.

Hysterectomy is a major surgery to remove all or part of a woman's uterus. The fallopian tubes and ovaries may also be removed during the surgery.²¹ Hysterectomy is the second most frequently performed surgical procedure, after cesarean section, for women of reproductive age in the United States. Between 2012-2020, one in five women, and half of the women aged 70 years or older, reported undergoing a hysterectomy in the United States;²² fibroids are the number one reason for hysterectomies in the United States.²³

In addition to the general risks of surgery,²⁴ hysterectomy specific risks include:²⁵

- Injury to the bladder or ureters;
- Pain during sexual intercourse;
- Early menopause if the ovaries are removed:
- Decreased interest in sex; and
- Increased risk of heart disease if the ovaries are removed before menopause.

Uterine Fibroid Research Database

In 2022, the Legislature required the Department of Health (DOH) to establish a Uterine Fibroid Research Database, which includes, but is not limited to:26

- Incidence and Prevalence of women diagnosed with fibroids in Florida;
- Demographic attributes of women diagnosed with fibroids in Florida; and
- Treatments and procedures for fibroids in the state.

To populate the database, physicians and physician assistants licensed under chapters 458²⁷ and 459,²⁸ F.S., and advanced practice registered nurses licensed under ch. 464,29 F.S., must submit to DOH deidentified information relating to their diagnoses and treatments of women with fibroids to DOH, for inclusion in the database.³⁰ DOH is prohibited from including any personal identifying information of women diagnosed with or treated with uterine fibroids in the database.31

As a result of not being able to include any personal identifying information in the database, DOH has not been able to implement it. A woman may see many doctors before receiving a diagnosis and treatment for uterine fibroids. Without collecting personal identifying information, DOH is unable to deduplicate the data. If DOH were to add the information to the database, it can lead to an over or under representation of the public health issue.³²

In 2022, the Legislature appropriated \$802,900, including \$681,048 in nonrecurring funds and \$121,852 in recurring funds to procure, develop, and implement the database, as well as train health care providers on the

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²¹ UFHealth, *Hysterectomy*, https://ufhealth.org/hysterectomy (last visited Feb. 13, 2025).

²² Sameer V. Gopalani, Sabitha R. Dasari, Emily E. Adam, Trevor D. Thompson, Mary C. White, and Mona Saraiya, Variation in Hysterectomy Prevalence and Trends Among U.S. States and Territories—Behavioral Risk Factor Surveillance System, 2012-2020, (Oct. 2023), available at https://stacks.cdc.gov/view/cdc/135504 (last visited Feb. 13, 2025).

²³ Johns Hopkins Medicine, Fibroids, https://www.hopkinsmedicine.org/health/conditions-and-diseases/uterinefibroids#:~:text=Hysterectomy%20for%20Fibroids,eliminates%20the%20possibility%20of%20recurrence (last visited Mar.

²⁴ Risks include blood clots, which may cause death if they travel to the lungs, allergic reactions to medicines, breathing problems, bleeding, infection, and injury to nearby body areas.

²⁵ Supra, note 21.

²⁶ *Id*.

²⁷ Ch. 458, F.S., governs licensure and regulation of allopathic physicians (medical doctors) and physician assistants by the Florida Board of Medicine, in conjunction with DOH.

²⁸ Ch. 459, F.S., governs licensure and regulation of osteopathic physicians and physician assistants by the Florida Board of Osteopathic Medicine, in conjunction with DOH.

²⁹ Ch. 464, F.S., governs licensure and regulation of APRNs by the Board of Nursing, in conjunction with DOH.

³⁰ Supra, note 1.

³¹ *Id.*

³² Supra, note 3.

reporting requirement.³³ DOH has since reverted back \$646,998 of the appropriated funds since they were unable to implement the database.

Public Health Reporting

DOH is required to periodically issue a list of infectious or noninfectious diseases of public health significance for purposes of epidemiological monitoring and research.³⁴ Current law requires any licensed physician, chiropractic physician, nurse, midwife, or veterinarian licensed in this state to immediately report the diagnosis or suspected diagnosis of a disease of public health significance to DOH.³⁵ The practitioner must report the disease or condition on a form developed by DOH, which includes information such as the patient's name, demographic information, diagnosis, test procedure used, and treatment given.³⁶ The practitioner must make the patient's medical records for such diseases available for onsite inspection by DOH.³⁷

Uterine Fibroids Data

Currently, the main uterine fibroids data source in the state is through a data-sharing agreement between DOH and the Agency for Health Care Administration (AHCA). If a woman has a hospitalization related to fibroids, this information is captured via the hospital discharge record. Current law requires hospitals to submit hospital discharge data to AHCA,³⁸ which AHCA then transmits to DOH per the data-sharing agreement.

In 2023, there were 17,589 hospitalizations related to uterine fibroids among Florida women ages 15-54 years.³⁹

RECENT LEGISLATION:

YEAR	BILL#	HOUSE SPONSOR(S)	SENATE SPONSOR	OTHER INFORMATION
2022	<u>CS/CS/CS/HB</u> <u>543</u>	McClure	Gibson	The bill was enacted, but it has not been fully implemented.

BILL HISTORY

COMMITTEE REFERENCE	ACTION	DATE	STAFF DIRECTOR/ POLICY CHIEF	ANALYSIS PREPARED BY
Health Professions & Programs Subcommittee	15 Y, 0 N	3/13/2025	McElroy	Clenord
Health Care Budget Subcommittee	12 Y, 0 N, As CS	3/26/2025	Clark	Day
THE CHANGES ADOPTED BY THE COMMITTEE:	Removed the appro	priation on the bil	l.	
Health & Human Services Committee	24 Y, 0 N	4/7/2025	Calamas	Clenord

https://www.flhealthcharts.gov/ChartsDashboards/rdPage.aspx?rdReport=UterineFibroids.Dataviewer&cid=0901 (last visited Mar. 1, 2025).

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³³ Ch. 2022-50, Laws of Florida.

³⁴ S. 381.0031, F.S.

³⁵ *Id.*

³⁶ Rule 64D-3.030, F.A.C.

³⁷ *Id*.

³⁸ S. <u>408.061, F.S.</u>

³⁹ FLHealthCharts, Hospitalization from Uterine Fibroids,



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