

Equity in Insurance Coverage of Fertility Services for People with Sickle Cell Disease

by

Elizabeth Roy

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This essay is submitted

by

Elizabeth Roy

on

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and approved by

Essay Advisor: Ryan L. Minster, PhD, MSIS, Assistant Professor, Human Genetics, School of Public Health, University of Pittsburgh

Essay Reader: Jacqueline Ellison, PhD, MPH, Assistant Professor, Health Policy and Management, School of Public Health, University of Pittsburgh

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Abstract

Definitions of infertility by insurers in the US as “the inability to conceive during a 12-month period of unprotected [heterosexual] sex” reinforce barriers to reproductive autonomy for people who are queer, single, and for those with medically induced infertility as this language may preclude eligibility for fertility preservation and/or infertility services. Sickle cell disease (SCD) is the most common genetic condition in the US, and people with SCD often experience iatrogenic infertility in response to symptom management and treatment. SCD disproportionately impacts Black and Hispanic people, as only 1.8% of SCD patients are non-Hispanic white. Given inequities in SCD prevalence, this document examines the public health significance of state-level differences in the language of insurance mandates for infertility and fertility preservation services, with a focus on whether infertility definitions allow coverage for infertility and/or fertility preservation services for people with SCD relative to people with cancer. A secondary goal was to assess eligibility for queer and single people relative to cis heterosexual couples. We conducted a scoping review of published literature to identify and analyze language from these mandates. Comparisons between state-level mandates demonstrate gendered language and a skewed focus on iatrogenic infertility among cancer patients with causes for iatrogenic infertility including “surgery, radiation, chemotherapy or other medical treatment affecting reproductive organs or processes”. This language excludes people with SCD who have not undergone curative treatment.

Findings suggest that people with SCD, single, and queer people are not equitably covered for infertility or fertility preservation services even when these services are included in their benefits.

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Preface

Thank you to my essay readers Dr. Ryan Minster and Dr. Jackie Ellison. Your guidance, support, and expertise were sincerely appreciated and valued throughout this project. This has been a whirlwind of a program and I appreciate all the support from my family, friends, mentors, peers, roommates, significant other, and my cat Chloe.

Abbreviations

ACOG – American College of Obstetricians and Gynecologists

APPs – Advanced Practice Providers

ART – Assisted reproductive technology

FP – Fertility preservation

HCST – Hemopoietic stem cell transplantation

HU – Hydroxyurea

IFPS – Infertility and fertility preservation services

IVF – In vitro fertilization

pw – People with

SCD – Sickle cell disease

SCDIC – Sickle Cell Disease Implementation Consortium

US – United States

1.0 Introduction

1.1 Acknowledgement for Language Standardization

Investigating fertility related services for people with sickle cell disease (SCD) makes distinguishing terms for sex and gender important for clarity. In this document, when primary literature and policies use terminology that confuses sex and gender or limit their work to a gender binary based on sex assigned at birth, those terms will be maintained. The reasoning for this includes accurately citing the author's work and to highlight where this language creates barriers to clinical care. When my thoughts and analyses are present, I will use gender inclusive language including but not limited to people with the capacity for pregnancy and pregnant people. My use of the terms 'male' and 'female' will refer to sex assigned at birth and 'men' and 'women' as self-identified gender identity terms. With this essay I hope to also draw attention to the need for more inclusive language related to sex, gender, and partnerships to increase accessibility and awareness.

1.2 US Infertility Context

The American College of Obstetricians and Gynecologists defines infertility as not achieving a successful pregnancy after 12 months of regular unprotected intercourse.¹ This is a widely reproduced definition seen across organizations from clinical to insurance context and informs a foundation of this work with its exclusion of single individuals and the queer community. Nationally infertility impacts over 12% of women of reproductive age. Infertility is equally

common in males and females and has a wide variety of causes which all increase a person's risk for developing leading chronic health conditions including type 2 diabetes and cardiovascular disease.²⁻⁶ As infertility itself contributes to increased mortality by increasing a person's risk for leading chronic health conditions, properly diagnosing and treating infertility is an impactful risk reducing measure.² Infertility, however, is frequently an unavoidable direct and indirect cause of medical treatments referred to as iatrogenic infertility. This type of infertility is most commonly the result of chemotherapy treatment which has multiple applications outside of cancer treatment including in preparation for curative treatment for SCD.

1.3 Context of Diagnosis and SCD Management

Sickle Cell Disease (SCD) affects over 100,000 people in the United States,⁷ making it the most common genetic disease in the country. It impacts hemoglobin in the blood which causes a shortage of red blood cells, and for the cells that remain they group together to form blockages that cause pain as insufficient oxygen and nutrients are circulating throughout the body. Pain is one of a wide range of signs and symptoms people with SCD experience daily.^{7,8} Over the past several decades treatment for the two forms of SCD, Sickle Cell Anemia and Beta-Thalassemia, has drastically improved including the development of a curative treatment called HCST which utilizes bone marrow stem cell transplantation from a donor to restore the person's ability to make normal red blood cells.⁹⁻¹² HCST successfully cures SCD in 90% of cases opening a future where people with SCD survive well into and past their reproductive years.¹² A modified form of HCST which removes the need for a donor was recently FDA approved, Casgevy™.^{13,14} This is the first approved use of CRISPR/Cas9 which for this therapy, allows a person's own cells to be used to

cure their SCD. European and North American countries are the only places where curative treatment is available.

A more accessible and common treatment to manage SCD for the past 50 years has been with regular doses of hydroxyurea.¹⁵⁻¹⁸ This daily oral pill is used to promote the sickled blood cells to take a rounder shape which restores the cell's function and reduces the frequency of pain crises. Outside of North American and Europe access to hydroxyurea is inconsistent or inconsistently adhered to making this the primary public health concern for managing the majority of worldwide SCD cases.¹⁸

Infertility and the need for access to IFPS for pw SCD is affected by pain crises, hydroxyurea, and the process for curative treatment.¹⁷ Pain crises are caused by blockages to blood flow from aggregated sickled blood cells. These blockages over time cause irreparable organ damage that indirectly reduces fertility. Long-term use of hydroxyurea is known to reduce sperm counts after puberty to the threshold of infertility where a period of 2-3 months discontinuing daily use is required to bring levels back into the normal range.¹⁸⁻²² Additionally, long-term use of hydroxyurea is supported as a risk factor for diminishing ovarian egg reserve limiting fertility.^{17,23-25} This however is not advised by physicians given the risk of harm and pain from unmanaged SCD symptoms. The process for curative treatment involves chemotherapy known to cause iatrogenic infertility where cancer patients, the population who is most frequently prescribed this treatment, are routinely referred to IFPS, see section 4.2.1 for details.

1.3.1 Barriers to Comprehensive SCD Care

The current system for managing SCD is a single provider point of contact.^{8,26} This provider is specialized as a hematologist. Limiting care to one specialist most notably leads to a

drastic increase in mortality when people look to change providers. This consistently happens in the transition between a pediatric practitioner to adult where there is a 50% increase in mortality attributed to people not finding a new provider and discontinuing their hydroxyurea treatment.^{15,16,18} Patients describe their general lack of trust in providers whether it is related to racial microaggressions or living with SCD as a chronic condition dissuades them from finding a new provider.²⁷⁻³⁰ These reasons additionally include moving to a new county or state, changing insurance so the current provider is no longer covered, or feeling discouraged in the search for a provider who they can trust.^{15,26-35} Distrust in clinical providers is informed by institutional racism and medical racism as well as the history of eugenics in the US, see section 1.4. These systems that fuel medical mistrust and requires both efforts to dismantle institutional and medical racism as well as intentional effort on the part of the provider to demonstrate a healthy relationship that could begin rebuilding trust. This however is an additional facet to building trust where a primary barrier is in pw SCD not having a network of specialized providers to connect with and trust.

1.3.2 Importance of SCD Comprehensive Care

Comprehensive care for SCD would decrease morbidity due to the expanded expertise of staff, improve continuity and consistency of care, and provide a greater network of providers to build trust with.^{27,36-41} Having advanced practice providers (APPs) available and accessible with expertise in hematology, chronic pain management, internal medicine, and infertility and fertility preservation services (IFPS) to name a few would work to actively combat SCD morbidity and promote health. One direct way morbidity would be reduced is through improved adherence to hydroxyurea treatment.^{15,16,18} As a daily medication requiring prescription that is self-administered, inconsistency in use, whether it is unintentionally forgotten or intentionally stopped,

these increases the likelihood of pain crises and long-term organ damage result in emergency department visits opposed to routine care visits when symptoms are consistently well managed.^{15,23,42,43} The current system asks hematologists to make clinical decisions and recommendations in all aspects of care for pw SCD. Specifically, lack of provider education about infertility and fertility preservation services (IFPS) coupled with the lack of provider coordination leaves patients vulnerable to receive unbalanced advice from a provider that could coerce them into a decision when providing balanced advice is preferable to empower the patient to make an educated decision.⁴¹ An example of this is a provider strongly recommending against conception for a person with the capacity for pregnancy due to the risks associated with their SCD without referring them to an expert or outlining in a balanced or neutral way what the risks with a pregnancy would be and allow a patient to make their own informed decision. It is vital to preserve patient autonomy and provide informed consent to minimize coercion.

1.4 Impact of Past US Eugenic Policies

Resistance to covering IFPS are not new and are rooted in racial health-care limitations and inequities.^{27,44-47} In the 1970's high profile scientist Linus Pauling endorsed the Sickle Cell Control Act, a eugenic policy aimed to reduce the incidence of SCD which posed a significant risk to testing for SCD as it could lead to being rejected a marriage license and reproductive coercion and forced sterilization.⁴¹ The aim of the Sickle Cell Control Act was to restrict people with Sickle Cell Trait, one copy of this recessive genetic condition as well as people with SCD, from having children to prevent future generations from having SCD. The US has a long history of forced pregnancy, state-sanctioned forced sterilization, and rape all disproportionately affecting Black

communities who are also the most likely to be affected by SCD.⁴¹ These histories and contexts intersect to interfere on a large scale with the reproductive justice and autonomy of one group. This incorporates stratified reproduction, that fertility for certain populations is socially valued over others.⁴⁸ Stratified reproduction is reflected across social and health care policies including insurance coverage of ART and infertility services. The populations that currently have access to these services are in the top 1% income bracket supporting meaning they are also unaffected by the limitations and restrictions placed by insurance coverage. Understanding this key intersection between health-care inequities, infertility, and incidence of SCD supports that lack of insurance coverage of infertility and fertility preserving measures is a function of a societal devaluation of Black lives.

1.5 Language in Insurance Mandate and their Impact on SCD Management

Thirteen states currently have Medicaid policies in place requiring private insurance to cover in vitro fertilization (IVF) and eleven states require fertility preservation.^{7,49,50} See section 3.4 for more policy details. Since the implementation of such policies, racial disparities in fertility preservation and infertility treatment have decreased, demonstrating accessibility to care is sufficient to make a measurable difference in minimizing reproductive health disparities.⁴⁸ In states where both private and public insurance do not cover these services, people, particularly racially minoritized groups, are unable to access them due to their prohibitive cost.^{45,46,51-53} Despite the recommendation by the American College of Obstetricians and Gynecologists (ACOG) to universally offer preconception counseling to couples where a partner is undergoing medical treatment that is known to cause infertility either directly or indirectly,⁵⁴ this is not reaching

patients with SCD consistently or systematically.⁵⁴ The policies of all states requiring private insurance coverage of infertility and fertility preservation services directly stipulated that the diagnosis and treatment of infertility is deferred to ACOG definitions when otherwise unavailable. This gap in policy and practice underscores that future policy modification addressing IFPS coverage by insurance needs to explicitly include people with hemoglobinopathies or undergoing treatment that diminishes fertility if not ultimately causes iatrogenic infertility.

1.6 Impact of Policies that Differ at both the State and Federal Level

States have enacted a full spectrum of insurance coverage for infertility preservation services with Massachusetts providing the most accessible coverage and others not having any as well as additional barriers. Across all states however, Medicaid does not cover these services and when private insurance does it is infrequent and still unaffordable. Thirteen states have successfully mandated infertility treatment for private insurance for decades resulting in less than a 1% increase in premiums.⁵⁵ See Figure 1 for more details on the 13 states. This legislation takes a significant step in recognizing reproductive autonomy. It is essential to also recognize that about 60% of people with SCD are covered by Medicaid, meaning very few have coverage for IFPS.

1.7 Impact of the Model of Care Coming from Cancer Patients

Cancer today is routinely treated by a team of providers modeling comprehensive care to address the intersecting needs of people beyond physical health but social, emotional,

occupational, and spiritual to name a few. This comprehensive care includes fertility preservation services where cancer patients are systematically referred to consult a counselor to discuss desire for future parenthood and their options so the patient and their family can make an informed decision. Although not a perfect system where this referral process is more seamless for cancers that target reproductive organs it is a valuable system to adopt for people with SCD.^{41,56-61} What makes SCD patients a unique group within people experiencing infertility is that fertility preservation measures are infrequently if ever mentioned prior to their treatment with chemotherapeutic agents and treatment in preparation for HCST. Both treatments are known to cause medically induced infertility, but the providers working with SCD patients are not trained to provide fertility counseling to their patients.¹² Additionally, these health care providers are interested in avoiding conversations about the implication of medically induced infertility out of concern that it would deter patients from undergoing general treatment and curative treatment.¹⁰⁻
¹² As pain crises are a frequent symptom of SCD lasting between hours and days, providers are understandably concerned that the risks associated with fertility preservation procedures like will increase the likelihood of a patient with SCD experiencing one of these crises, however, it is the health care provider's duty to inform their patient of these risks and allow them to make an informed decision themselves. The ability to have biological children, if someone desires, is an essential aspect of reproductive justice.

1.8 Perspectives, Positions, and Values of People with SCD on their Fertility Options

Two primary research publications were identified where people with SCD were asked about their perspectives, positions, and values related to their fertility options.^{61,62} This is a

particularly complex topic as curative treatment for SCD occurs in the adolescent period, so parents and guardians were also included and additionally asked for their views on fertility options for their child in relation to curative treatment.⁶² Guardians were not consulted in the publication with international scope.⁶¹ All candidates for curative treatment were actively considering their fertility options as they had been assessed as eligible to proceed with curative treatment. Given pw SCD are living beyond their reproductive years with the development and utilization of symptom management treatments, specifically hydroxyurea, these adolescents are the first generation to imagine a future into their 50's and 60's. Nearly 76% of study participants, 82 of 108 pw SCD reported a 'considerable or strong desire' for future parenthood.⁶¹ This statistic was independent of the minor's sex, education, diagnosis, or subjective health status. This substantiates that future fertility is an essential part of the envisioned future for adolescents seeking curative treatment and ensuring their access to it reflects their high desire for biological parenthood and the majority of these adolescents reported that having access to fertility counseling and services was essential to moving forward with curative treatment for their SCD. That not having access to fertility preservation services would dissuade them from moving forward with curative treatment. This is consistent in the solely US based study where guardians were also consulted. There was an unequal relationship between the willingness of the adolescents and their guardians to accept infertility after curative treatment where adolescents were less willing to accept infertility at ~40% compared to ~60% for guardians.⁶² This resistance to moving forward with curative treatment by adolescents was not echoed by their guardians where the majority of guardians advocated for their child to move forward with curative treatment regardless of the likelihood of iatrogenic infertility.

1.9 Provider Opinions on Informing SCD Patients of their Fertility Options

Hematologists as the specialists who serve the majority of pw SCD as the sole provider attending to their SCD overwhelmingly discourage pregnancy for their female patients. There are numerous publications included here describing the risks associated with pregnancy for pw SCD citing risks related to bringing on pain crises and other dangers associated with blood clots.^{42,63-68} Equally reported from the majority of hematologists includes discouraging pw SCD from undergoing procedures to use assisted reproductive technologies (ARTs) including but not limited to infertility and fertility preservation services (IFPS).^{10,12,20,25,37,47,56,65,67,69-77} It is widely accepted that managing SCD symptoms with hydroxyurea itself reduces fertility, but undergoing curative treatment for SCD which causes iatrogenic infertility.^{16,17,21,22,24,43,56,63,68,78-93} This is largely achieved by omitting to inform people about ARTs including IFPS. There is ethical debate in the literature about necessitating to offer fertility preservation services to pw SCD, particularly prior to curative treatment, but many factors inform the barriers to accessing and utilizing IFPS with the first barrier being knowledge of IFPS.^{41,74,76,94-96} However, this is not a balanced debate as providers go as far as to push pw SCD to sterilization given the risks of pregnancy.⁹⁷ This STAT news article includes Whitney's experience as a mother with SCD and the consistent lack of support from her providers about conceiving and the warnings about the risks during pregnancy and delivery. She did experience several complications related to her SCD both individually and risks to the fetus and was ultimately coerced into sterilization by her obstetrician. Decision about future fertility are being unilaterally made by providers without prioritizing reproductive autonomy or making any attempt at education to inform patient decision making. A main goal of this work is to underscore that providing effective and engaging education to pw SCD is an essential first

step to integrate into routine care, especially related to fertility preservation before HSCT. 15,41,57,61,75,76,94,96,98-100

2.0 Methods: Policy Review

Sources were identified through NexisUni as an associate of the University of Pittsburgh conducted on February 2nd, 2024. Advanced search terms and order are displayed in Figure 1. Direct counts of results from the search are included in Appendix section A.1. Variations of search terms yielded redundant or inconclusive results, specifically related to synonyms and more technical jargon for hemoglobinopathies or infertility including iatrogenic infertility, so only two variations, ‘A’ and ‘B’ are included. Refer to tables 1 and 2 in Appendix A for counts of returned results generated for Figure 2 in section 3.1.

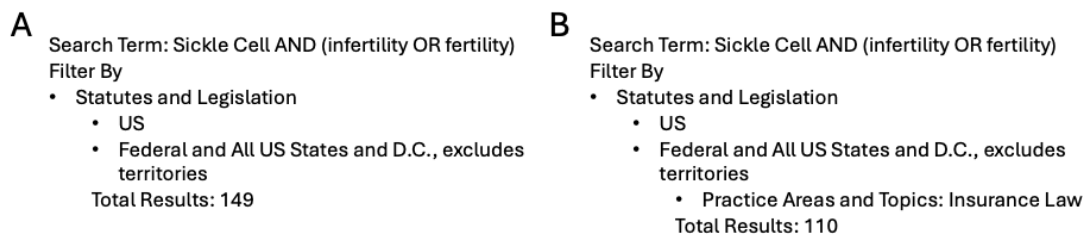


Figure 1 NexisUni search criteria.

(A) describes general search criteria for all federal and state policies and is inclusive for the items in (B). (B) describes the selection of results from (A) for policies specific to insurance law and practice areas and topics. It was results from (B) that were selected for further review.

3.0 Results: Scoping Policy Review

This academic project takes a broader approach than a systematic review as a scoping review allowing a greater variety and volume of documents to be included across the introduction and this section. With the approval of Casgevy from Vertex Pharmaceuticals by the FDA in December 2023 it can be expected that IFPS will become a more visible policy issue for pw SCD. The final clinical trial phases for Casgevy included fertility counseling and access to fertility preservation services at no cost to participants highlighting that this is a recognized service to offer pw SCD planning to undergo curative treatment. IFPS do largely remain under used and unaffordable to the general public regardless of whether the infertility or reduced fertility is a result of clinical intervention. This can be attributed to multiple intersecting factors including the high price, invasiveness for people with the capacity for pregnancy, and institutional and medical racism. Section 1.4 briefly addressed the impact of past eugenic policies in the US for Black Americans in particular as an additional barrier to seeking these services or trusting providers to counsel them to promote their reproductive autonomy and not coerce them into a decision. The policies included are state level insurance laws and academic publications evaluating access to insurance or the state of policies that impact IFPS issues for pw SCD. Sixteen states and the federal level policies were examined as the only states with policies related to SCD and infertility or fertility (Figure 2). These states only include three of the top five states with the most cases of SCD, Florida, New York, and Georgia, but not Texas and Maryland.¹⁰¹

3.1 SCD Policies

The 16 states with insurance law policies include Arkansas, California, Florida, Georgia, Illinois, Indiana, Massachusetts, Minnesota, Missouri, New York, Ohio, Oregon, South Carolina, Tennessee, Utah, and Wisconsin and are indicated in Figure 2.

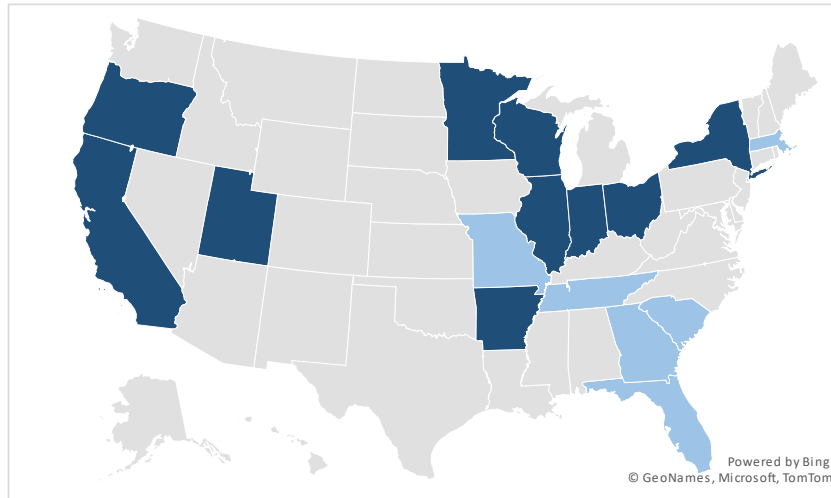


Figure 2 NexisUni search results by jurisdiction.

Dark blue depicts states with policies across all topics including insurance law with search terms from Figure 1A. Light blue depicts states with no policies in insurance law, but results in other topic areas with search terms from Figure 1B. *US federal policies not shown, but policies across all topics were identified including insurance law using the search terms from Figure 1. Refer to tables 1 and 2 in Appendix A for counts of returned results generated for Figure 2.

3.2 Infertility Definitions

There are currently 20 states with state-level infertility definitions where the earliest definition was established in 1985 (Figure 3).³⁶ Maryland established the first infertility definition

but has since completed three revisions with the most recent revision occurring in 2020. The oldest current standing infertility definitions were established in 1987 and still hold in the states of Arkansas and Texas followed by California in 1989. All three states allow for religious exemptions by employers and self-insured policies to cover of IFPS. The Texas policy still maintains that IVF is included in coverage when employers do not opt-out.¹⁰² Seven states have definitions that were established or last updated by 2010 while the remaining 10 states have updated their definitions since 2017. These 10 states with updated definitions do not necessarily represent definitions that reflect more inclusive language for sexual and gender minorities or broader stipulations about reasons for infertility, however New Jersey's 2017 update did amend to include single females explicitly. In fact, Delaware's mandate includes vague language of "to obtain a successful pregnancy with reasonable effort", which allows for providers to fall back on the exclusive definition of 12 months of consistent unprotected heterosexual sex. This is consistent across several states with updated definitions including Colorado who first established a definition in 2020, Connecticut in 2017, Illinois in 2019, Rhode Island in 2017, and Utah in 2021. West Virginia requires HMOs to cover infertility services as a part of 'basic healthcare services' but does not define infertility lending itself to follow the trend for consistent unprotected heterosexual sex. New Hampshire's definition does not specifically use the '12 months' language, but does require the diagnosis of infertility which routinely requires 12 months of consistent unprotected heterosexual sex. Many states also include the requirement that the female's partner, assumed male, be the sperm donor. Beyond the barrier for queer people, this presents a barrier for people who either have a family history of a genetic condition that significantly impacts their life or have undergone testing and identified they are a carrier for such a genetic condition. This limitation prevents people from pursuing sperm donation as an alternative opposed to preimplantation diagnostic testing,

which given the limitations on IVF and increasing restrictions being imposed on reproductive technologies could be a realistic option for many people. Covering sperm donation and removing the restriction for a partner to be the sperm donor is being advocated for here as an additional option that both removes a potential barrier for queer people and serves as an additional option for individuals who themselves may object to pursuing technologies that screen for a genetic condition. It is important to recognize that this should not be the sole option for people and should be offered across the US in addition to ARTs with fewer barriers and reliable coverage by insurance so it is affordable.

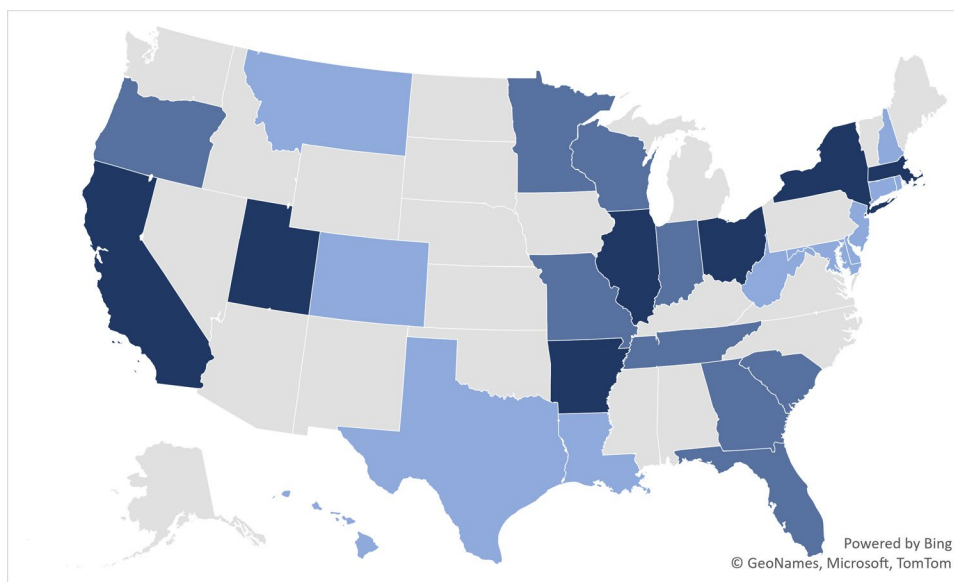


Figure 3 States with infertility definitions and/or have insurance covered IFPS for pw SCD.

The infertility mandates were identified by Kawass et al. in 2021. Dark blue depicts states with policies across all topics including insurance law and additionally have state level infertility insurance mandates. The intermediary blue depicts states with only insurance law related to IFPS, the results from Figure 2. Light blue depicts states with only infertility mandates, these states are not part of Figure 2. *US federal policies now shown, but policies across all topics were identified including insurance law using the search terms from Figure 1. Refer to tables 1 and 2 in

Appendix A for counts of returned results generated for Figure 2.

3.3 Drafted Policies Addressing Comprehensive Care for SCD

The Sickle Cell Disease Comprehensive Care Act introduced identical bills from the House and Senate, H.R.1672 and S.904 or S.966, concurrently from the 118th congress demonstrate united intention to provide comprehensive care to youth and pregnant women with SCD through Medicaid. The house bill was referred to the Subcommittee on Health on March 31st, 2023, ten days after introduction and the senate bill was referred to the Committee on Finance on March 28th, 2023, on the same day it was introduced. With bipartisan co-sponsors on each bill both attempting to implement a first wave of comprehensive care through Medicaid to between five and ten states supports plausible interest in pushing this policy through committee. As of April 7th, 2024, there have been no updates to any of the three bills since their referral to committee.

4.0 Discussion

Having access to IFPS aligns with the wants and needs of people with SCD as this chronic condition is being better managed and curative treatment becomes a more accessible and extending life expectancy well beyond the reproductive years. In other clinical scenarios, like cancer treatment, where interventions that result in iatrogenic infertility are used people are more consistently and likely to be referred to fertility preservation services. Although there are risks to pw SCD associated with IFPS and pregnancy, including pain and worsening symptoms, clinicians should be required to provide their patients with the resources and access to IFPS. Despite this need, IFPS regardless of the reason for the need remains inaccessible due to lack of coverage from insurance providers. With the high upfront cost associated with IFPS procedures and lack of insurance coverage, these services remain underused, especially by people who face one or multiple systemic barriers to healthcare and reproductive wellbeing. For pw SCD these systemic barriers include medical racism, the history of eugenics in the US, and ablism. Ablism directly impacts the access pw SCD have to achieving financial stability due to the burden of chronic disease on employment and educational attainment. Providing equitable access to IFPS generally as well as specifically for pw SCD requires amending the definition of ‘infertility’ in insurance policies and mandates to remove the burden for consistent unprotected heterosexual sex when there are contributing factors that render this barrier non-applicable. Federal mechanisms to substantiate change include amended definitions of infertility by ACOG and for Medicaid to outline a definition that departs from ‘consistent unprotected intercourse’ and make it inclusive for anyone with the capacity for pregnancy. A portion of this definition should also be dedicated to single people with the capacity for pregnancy as in New Jersey’s most recent policy update. Given

that coverage of IFPS varies so widely within and among states a standardized definition of infertility is reasonable to incorporate access for single people and the queer community.

These additional reasons include diagnosis of a disease chronic or otherwise that is known to reduce fertility, as well as inability to have vaginal sex to achieve conception as is the case for single females and people in the queer community. The direct next steps that can allow for equitable access to IFPS include greater access and use of comprehensive care facilities with the standardization of referral to fertility counseling and/or fertility preservation services and expanding the scope of when people can be diagnosed as ‘infertile’ to qualify for any insurance covered IFPS. The long-term goal for equitable access to IFPS includes covering IFPS for those who desire parenthood at low or no cost to eliminate the financial burden and make reproductive autonomy and justice possible for all regardless of financial status.

4.1 Policy Review Between States

States that have undertaken infertility definition updates in the last 5-10 years have more descriptive definitions that lend themselves to being more inclusive of services for single people assigned female at birth and people with iatrogenic infertility, but not queer people. See Kawwass et al 2021 for a table comparison of states. The federal definitions seem to set a bar for state definitions where states opt in for updated language that reflect inclusion of the queer community where requiring 12 months of regular unprotected heterosexual sex is not the sole way to be diagnosed with infertility. Until insurance providers consistently cover the near or full cost of IFPS these services will continue to be under used by pw SCD among other groups seeking access to these services, but trust in providers and promoting reproductive autonomy through education are

the primary barriers to using IFPS regardless of coverage. This has previously been demonstrated for IVF specifically, but not ART or IFPS generally.⁴⁵

4.2 Limitations and Future Directions

This scoping literature and policy review provides an opportunity to specify the gaps and impact of medical racism on reproductive autonomy and justice for people with SCD. Denying people with SCD the knowledge of and opportunities for infertility and fertility preservation is a form of eugenics that can be mitigated by building equity in policies that influence the knowledge, access, and affordability of infertility and fertility preservation services.

This review is significantly limited by the lack of primary peer-reviewed literature that qualifies or quantifies the experiences, preferences, and desires of people with SCD, and their guardians and families. Without the partnership of people with SCD, and their guardians and families in both research and policy decisions there cannot be meaningful change to dismantle medical racism and improve their clinical experience.

4.2.1 Modeling Access to IFPS for pw SCD from Comprehensive Cancer Care

Cancer patients largely have systematic access to counseling about fertility preservation before treatment and presents itself as a model for referring pw SCD.^{52,59,60,103} Cancer care is commonly treated at facilities that house specialists related to all dimensions of health. These centers typically have access to the resources of a larger hospital or medical system allowing for specialists to have close physical proximity to patients throughout their treatment. Physically

housing providers in this manner encourages collaboration and sets the expectation that specialists will be consulted at various points in the treatment process. This allows a framework to be established by cancer type where counselors about IFPS are incorporated in the treatment process early on with continued contact.^{59,60} This means both patients and providers can easily coordinate among one another about treatment plans in the process. For pw SCD who are more vulnerable and wary of coercion and harm when accessing clinical care, the transparency of following a similar system would allow pw SCD and their families to be a part of their treatment team and find success and autonomy generally in their clinical care including reproductive autonomy.

Appendix A Appendices and Supplemental Content

Table 1 Count of results returned from scoping NexisUni policy review.

Category	All Topics	Insurance Law
Bill Text	102	81
Public Laws/ALS	19	18
Legislative Histories	15	8
Congressional Record	13	3

Table 2 Count of results returned by jurisdiction from scoping NexisUni policy review.

	Returned Results	
	All Topics	Insurance Law
U.S. Federal	30	11
Arkansas	3	3
California	11	10
Florida	4	0
Georgia	1	0
Illinois	4	4
Indiana	7	7
Massachusetts	2	0
Minnesota	18	18
Missouri	5	0

New York	34	34
Ohio	11	10
Oregon	3	2
South Carolina	2	0
Tennessee	2	0
Utah	9	9
Wisconsin	2	2

Appendix B Methods for Background Literature Review

A scoping literature review was conducted for studies over the past 10 years, from 2014-2024, for primary peer-reviewed literature addressing SCD and infertility or fertility preservation. Secondary sources including reviews were sparingly included to inform the background and introduction, not the literature review component of this document. Searches were limited to data collected from US populations to directly relate to the state level insurance mandates. All internationally referenced literature is only included in the policy options discussion. These international sources were identified through negating the search line attempting to filter out publications based on international data. It was important to include international sources in this review with respect to proposed policy options to demonstrate the relative success or difficulties associated with similar policies across health systems. Figure 1 depicts the search lines and order for the Medline database search using Ovid conducted on November 11th, 2023. PittCat, the online database for publications accessible to associates of the University of Pittsburgh was conducted to complement the Medline search. Table 1 lists the advanced search terms used in this search conducted on February 2nd, 2024. Advocacy and governmental websites were included to inform background on this project as well as policy options as sources of partnership and reliable accessible data to the general public over peer-reviewed primary literature.

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