

**LEGAL IMPLICATIONS OF DOCUMENTATION IN THE ELECTRONIC MEDICAL
RECORD FOR PRENATAL GENETIC COUNSELORS POST-ROE V. WADE**

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ABSTRACT

Prenatal genetic counselors play an important role in coordinating abortion services for patients. The overturning of *Roe v. Wade* in 2022 led to new restrictions on abortion which have raised questions about GC's documentation practices in the electronic health record (EHR). The purpose of this study is to understand what impact current abortion restrictions have had on GC documentation practice, and what the current level of concern is regarding the potential impact of EHR information on patients and clinicians. An eleven-question survey containing multiple choice, likert scale, and open-ended questions was distributed to prenatal genetic counselors through the National Society of Genetic Counselors and social media. Data from 120 participants were analyzed. Participants were grouped as practicing in one of three types of states based on existing state laws governing abortion: protective, intermediate, and restrictive. Most participants, 83.9%, reported that concerns about what goes into the medical record have been discussed in their workplaces, and 50% noted changes in practice since June 2022. In response to open-ended questions, a number of our participants suggested that healthcare providers are turning to the use of vague or coded language for documentation of information related to abortion care. Many participants also noted that patients have changed their behaviors, and show increased reluctance to discuss abortion (58.7%) or share information related to their current pregnancy (53.4%). Among GC's answering this survey, 96% were very or somewhat interested in legal guidance to determine if pregnancy-related information in the medical record could create legal jeopardy for them and their patients. Participants from intermediate states were significantly more likely than those from protective ($p=0.0094$) or restrictive ($p=0.0056$) states to express an interest in legal guidance.

INTRODUCTION

Genetic Counselors (GCs) are a vital part of patients' prenatal care, especially those who require abortion services following a prenatal diagnosis. The overturning of *Roe v. Wade* in 2022 has led to the introduction of new restrictions on abortion and new concepts like “fetal personhood,” raising questions about genetic counseling practice with regard to information in the electronic health record (EHR) and how it might create legal jeopardy for practitioners or patients.

Roe v. Wade challenged Texas abortion laws as unconstitutional, in a case which was eventually brought to the Supreme Court in 1973 (*Roe v. Wade* :: 410 U.S. 113 (1973)). Since this ruling, the Supreme Court has several times affirmed that the Constitution protects abortion as a part of what it called the right to privacy. In *Roe v. Wade*, the court ruled that the government cannot ban abortion before viability, regardless of the reason, making state abortion bans illegal and abortions more accessible throughout the country (Cornell Law Legal Information Institute, 2022). In 1992, *Roe v. Wade* was reaffirmed in *Planned Parenthood v. Casey*. However, in this ruling the Supreme Court amended the strict language of *Roe* to permit restrictions on abortion prior to viability as long as they did not pose an “undue burden” on people seeking the procedure (Cornell Law Legal Information Institute, 2022). Under *Casey*, states have passed multiple laws restricting abortion, increasing in both number and scope in the years since 2010. Many of these laws have been challenged in the courts, which have allowed a proliferation of abortion restrictions while upholding the central finding of *Roe*. The most recent challenge to *Roe* to reach the Supreme Court was *Dobbs v. Jackson Women’s Health Organization*.

In 2018, Mississippi passed the Gestational Age Act, which prohibited abortion after 15 weeks except for medical emergencies or severe fetal abnormalities (Cornell Law Legal Information Institute, 2022) and penalized providers involved in abortion care. The only remaining abortion clinic in the state, Jackson Women's Health Organization, challenged the constitutionality of the act. In 2021, the Supreme Court agreed to hear *Dobbs v Jackson*. Their June 2022 response denied that privacy was a fundamental right and argued that support for abortion rights was not rooted in history, or traditions of the nation (Center for Reproductive Rights, 2022). The ruling overturned *Roe v. Wade* and left abortion under the regulation of each state.

Post-Roe, it has been predicted that eventually 24 states will have near or total bans against abortion (Nash & Guarnier, 2023; Nash & Ephross, 2022). Since June 2022, 12 states have implemented total bans (Nash & Guarnier, 2023). These included new bans as well as trigger laws which went into effect when *Roe* was overturned. Two other states, North Dakota, and Wisconsin have made abortion unavailable through the elimination of all clinics that offer abortion services. Four states have gestational age bans, which were not in place pre-Roe (Nash & Guarnier, 2023). Indiana, Wyoming, and Ohio currently have passed bans that were subsequently blocked by the courts but may go into effect by the end of 2023 (Nash & Guarnier, 2023).

While many states have increased restrictions, other states have worked to protect abortion access. In 2022, 77 abortion protection laws were enacted, the highest number ever in a single year (Nash & Guarnier, 2023). Provisions of protective laws included allocation of funding for abortion, improvement of abortion access, and shield laws intended to reduce potential liability for abortion providers treating patients who travel out of state to receive their

abortion care (Center for Public Health Law Research, 2022). Overall, shield laws work to protect both providers and patients (Nash & Ephross, 2022; Zubrzycki, 2022). For example, in California, AB 1242 protects reproductive digital information handled by companies incorporated or headquartered in California (Bauer-Kahan, 2022). Additionally, the bill prevents the arrest of individuals or the disclosure to law enforcement of information related to any abortion already legal in California, protecting those seeking or providing reproductive health care against wrongful prosecution (Bauer-Kahan, 2022). To date, shield laws have been passed in California, Illinois, New York, Connecticut, Massachusetts, Delaware, and New Jersey (Center for Reproductive Rights, 2023).

These laws recognize that the new legal landscape has the potential to create legal jeopardy for healthcare providers. In a number of states there are laws that criminalize abortion care, including those which put providers at risk of committing felonies and facing prison time. The idea of fetal personhood has been adopted by many state legislatures, with the intent of ensuring that a fetus has the same legal rights and status as a person. At least 27 states, mainly in the South and Midwest, include fetal personhood or adjacent language in their abortion laws (Pregnancy Justice, 2022). Kentucky's law states that an unborn fetus is a member of the human species throughout the entirety of embryonic development (Pregnancy Justice, 2022). Similarly, Arkansas criminalizes any harm to the fetus. These laws do not explicitly state how they can be applied to other laws, but these laws could be used to prosecute both providers and patients for murder, assault or child endangerment (Pregnancy Justice, 2022). Recently, Arizona passed House Bill 2427 which lowers the barrier to file aggravated assault charges against someone who knowingly attacks a pregnant person and increases the sentencing for a person who hurts a pregnant victim during a domestic assault (Arizona House Bill 2427, 2023). Fetal protection

laws of this sort can have broader implications and have been used to criminalize the actions of pregnant individuals (Pregnancy Justice, 2022; Goodwin, 2018).

In September 2021, Senate Bill 8 (SB8) went into effect in Texas, introducing a new sort of risk for anyone even tangentially involved in the abortion process (87(R) SB 8). This act restricted abortion after 6 weeks of pregnancy and authorized a private civil right of action (Texas SB8: 2021-2022: 87th legislature). SB8 allows healthcare providers and others to be held criminally liable for aiding and abetting patients seeking an abortion. The act authorized individuals to sue those providing any sort of assistance in the procuring of an illegal abortion for no less than \$10,000 (Texas SB8: 2021-2022: 87th legislature). Now, many healthcare providers are increasingly concerned about the liability for themselves and their patients when providing services (Millhiser, 2021; Getchell *et al.*, 2022). SB8 is unique because it gives the public an incentive to help criminalize behavior such as helping patients navigate appointments for abortion care.

In South Carolina, the Equal Protection at Conception-No Exceptions-Act was introduced which would make aiding, abetting, or conspiring with someone to obtain an abortion a crime (South Carolina Bill 1373: 2021-2022). The bill, if passed, would have made it a felony, mandating federal prison time, to offer any information to a patient about abortion, including referring a patient to a website where information on abortion was available (South Carolina Bill 1373: 2021-2022). These laws have implications that would hinder prenatal GC as current practice and could make it difficult even to participate in conversations with patients where the topic of abortion might occur.

Current measures in place to protect patient privacy may not be adequate to ensure that their health information is not used against them or their providers in a legal proceeding. Health

Insurance Portability and Accountability Act (HIPAA) protects patient privacy but does not shield healthcare providers or organizations from potential criminal charges, or protect patients from criminal investigations (Shachar 2022; Zubrzycki, 2022). During legal proceedings, disclosure of health information can be subpoenaed. This limits HIPAA's ability to protect patient privacy on matters related to abortion procedures in states where they are illegal. Another concern for healthcare providers is the possible use of de-identified health care facility records to incriminate health care professionals discussing or providing abortion services, which could include notes in the EHR, employee emails, paging information, and reports (Spector-Bagdady & Mello, 2022). Legal experts have suggested that clinicians should not assume more documentation is better, but think carefully about what information needs to be documented to ensure safe and quality care (Spector-Bagdady & Mello, 2022).

Though most laws banning abortion penalize only health care providers, future laws or current laws used in new ways may have serious implications for patients as well. Genetic counselors are now seeing patients worried about disclosing information on intake forms or questioning what is safe to say in appointments about their abortion history (Hercher, 2022). Patients who are seeking an abortion should be aware that documented information in the health record could have exceptions for judicial proceedings (Shachar, 2022; Zubrzycki, 2022). Fetal personhood laws also create concerns for patients who may endanger their fetus in any way during pregnancy, this includes exposure to drugs or alcohol, injuring themselves, and potentially abortion (Goodwin, 2018). The punishments could include sentencing for threatening fetal health to first-degree murder (Goodwin, 2018).

Some states have started making it more difficult to gain access to abortion records for lawsuits to protect both patients and providers (Zubrzycki 2022). However, the 2016 21st

Century Cures Act, prohibited information blocking, any practice that interfered with access and exchange of electronic health information (42 U.S.C. 300JJ-52 (a)(1)). This act was intended to make it easier to share medical records across state lines but may make it more difficult for patients in states with strict abortion laws to go out of state to get an abortion without making the information available to future healthcare providers in their home state.

Connecticut was the first state to pass a law intended to make the state a “safe haven” for abortion seekers. This 2022 law prohibits providers from handing over abortion records in response to subpoenas (2022 Connecticut Acts No. 22-19). Law professor C. Zubrzycki contends that it may nonetheless be difficult to shield information from providers in states where abortion is criminalized, potentially allowing law enforcement in those states to access that information (Zubrzycki, 2022). If the information is in the medical record, there is no protective law stopping providers from other states from accessing it. As the future of abortion legislation continues to develop, practitioners may need to anticipate further efforts to criminalize abortion or penalize anyone involved.

The role of the GC in the prenatal setting includes facilitating testing, helping to make and communicate a fetal diagnosis, assisting in the decision-making process following fetal diagnosis, and supporting patients through abortion services when necessary. For abortions related to a prenatal diagnosis, GCs are often the medical professionals most involved in the coordination of abortion appointments for their patients.

A standard component of post-test counseling for abnormal genetic testing results includes discussion of the option of termination of pregnancy (Friedman & Chasen, 2020; Society for Maternal-Fetal Medicine, 2015; Grossman & Chasen, 2020). The discussion of

abortion can happen at any time during a pregnancy and plays an important role in a patient's preferences in preconception and prenatal testing.

It is important to have confirmation of abnormal genetic screening results before proceeding with termination and diagnostic testing should be performed before a patient makes the decision to have an abortion (ACOG, 2020). Diagnostic testing such as Chorionic villous sampling and amniocentesis are typically performed during the second trimester to avoid risk for spontaneous miscarriage (ACOG, 2016 ; Alfirevic *et al.*, 2017; Beta *et al.*, 2019). Additionally, most structural anomalies are also not identified until the detailed 20-week anatomy ultrasonogram (Raymond *et al.*, 2023). Due to these defects occurring with or without fetal aneuploidy this procedure is ideally performed between 18 and 22 weeks of gestation (ACOG, 2016). There has been evidence that providers may begin to adopt first trimester and early second-trimester ultrasounds to help provide more information before gestation age bans (Harper *et al.*, 2016; Liao *et al.*, 2021; Raymond *et al.*, 2023). Since fetal diagnoses are typically provided at a later gestational age, patients' options for termination are limited in states with restrictive abortion laws.

As restrictions on abortion have increased throughout the United States, GCs have struggled to adhere to the NSGC Code of Ethics. NSGC's Code of Ethics states that GCs must “enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences.” (NSGC, 2017). In a previous study, some GCs indicated that they needed to adopt a more directive style of counseling because of pressures related to restricted access to abortion, and others indicated that they felt a need to emphasize quick decision-making for patients considering abortion (Jayaraman *et al.*, 2021; Cooney *et al.*, 2017). In a recent study, several GCs said that they felt

obliged to initiate conversations about abortion care earlier in the pregnancy, since follow-up might have to be more aggressively timed to keep abortion as an option (Getchell *et al.*, 2022). Still, others indicated that some of their patients could not access abortion care at all. Overall, laws restricting abortion not only alter GC practice but limit a patient's access to abortion or the option to terminate (Jayaraman *et al.*, 2021).

GCs are taught to document information obtained from patients in the medical record, which in the prenatal setting not infrequently includes past pregnancy history (Hunt Brendish *et al.*, 2021). Often, terminations for either spontaneous, personal, or medical reasons are also noted if this was discussed with the patient. Legal scholars have noted that medical caregivers may need to take precautions in documenting prenatal patients' experience in the EHR (Spector-Bagdady & Mello, 2022). As per the limits to protections under HIPAA noted earlier, HIPAA does not protect information relating to a lawsuit (Spector-Bagdady & Mello, 2022). Therefore, medical records of patients who have had or are seeking an abortion could be obtained without consent for legal purposes by law enforcement if law enforcement had probable cause to issue a subpoena.

GCs are one of the main liaisons for patients seeking abortion care. Increasing restrictions on abortion, laws criminalizing aiding and abetting, and potential criminalization of pregnant persons for behavior during pregnancy may affect what information they feel comfortable putting in the medical record. The purpose of this study is to understand what impact, if any, current abortion restrictions have had on GC practice with regard to documentation, and what the current level of concern is regarding the potential impact of EHR information on colleagues or patients.

METHODS

Participants

Recruitment was completed through the use of National Society of Genetic Counselors (NSGC) listserv E-Blast service and social media circulation, including Twitter, Instagram, Facebook, and LinkedIn. Participants could be prenatal genetic counselors practicing in any state in the U.S.. The survey was open for three weeks in January 2023. Those who participated were, if they agreed to provide an email for this purpose, entered to win one of eight \$25 Amazon gift cards. This study was deemed exempt by the Sarah Lawrence College's Institutional Review Board in November 2022.

Survey

For this study we constructed a survey consisting of eleven multiple choice, Likert-scale, and open-ended questions. The survey included questions about demographics, current institutional practices, and thoughts about potential changes in practice related to new or pending legislation (**Appendix 1**). Specifically, survey questions inquired into what prenatal genetic counselors are currently documenting in the EHR with regard to past pregnancy outcomes, motivation for genetic testing, prenatal exposures and concerns, and plans regarding abortion. We also asked if there have been any changes to practice in terms of documentation or patient concerns about sharing information related to their pregnancy. And lastly, we asked GC's about their current perceived need for legal guidance with regard to documentation. Our survey was administered through an online survey platform, Qualtrics. All responses were anonymous. Participants were not required to answer any question to complete the survey, although failure to complete at least 50% of the questions or to follow skip-wise logic disqualified participants from data analysis and participation in the gift card raffle.

Data Analysis

A total of 511 responses were received, of which a significant number appeared to be automated responses, a consequence of the raffle which we had not anticipated. A filtering process was created in order to exclude ineligible participants. First, we removed those who did not complete >50% of the survey and those who answered they currently do not see patients in a prenatal setting. Second, participants were removed if they did not follow skip-wise instructions. Lastly, since automated accounts were unable to appropriately answer open-ended questions, we omitted those who did not fill in a state when asked: "Which state do you currently practice in?". 391 participants were eliminated, leaving a total 120 responses for analysis.

Descriptive statistics were calculated for each Likert scale and multiple-choice questions. This included mean, standard deviation, and ranges. States were broken up into three categories: protective, intermediate, and restrictive, based on current categorization using Guttmacher Institute "Interactive Map: US Abortion Policies and Access after Roe". Protective states included: AK, CA, CO CT, DC, IL, MA, MD, NY, OR, and WA; intermediate states included: DE, MN, MI, PA, VA; restricted states included: AL, AR, FL, GA, ID, IN, KS, KY, MO, MS, NC, NE, OH, SD, TN, TX, UT, WI. One way ANOVA tests were completed to determine statistical significance between the three groups ($p < 0.05$). If statistical significance was determined, t-tests were completed ($p < 0.05$).

RESULTS

Demographics

Half of our participants had 1-5 years of genetic counseling experience (50.8%), 12.5% had <1 year of experience, 23.3% had 5-10 years, and 13.3% had 10+ years of genetic counseling

experience. Respondents practiced in 36 different states. The three most frequently reported states were California (10.8%), Illinois (7.5%), and Massachusetts (7.5%) (**Table 1**).

Demographics	Frequency	Percentage
<i>Years of experience as a genetic counselor (n=120)</i>		
<1 year	15	12.5%
1-5 years	61	50.8%
5-10 years	28	23.3%
10+ years	16	13.3%
<i>State category* (n=120)</i>		
Restrictive states	56	46.7%
Intermediate states	13	10.8%
Protective states	50	41.7%
Counseled in all states	1	0.83%

*Protective states included: AK, CA, CO CT, DC, IL, MA, MD, NY, OR, and WA; intermediate included: DE, MN, MI, PA, VA; Restricted states included: AL, AR, FL, GA, ID, IN, KS, KY, MO, MS, NC, NE, OH, SD, TN, TX, UT, WI.

Pregnancy History

Prenatal GCs were asked about what they ask a patient during a session. 75% (n=120) of respondents regularly or routinely ask patients if termination is an option for them (**Figure 1**).

Just over half, 50.8% (n=120) rarely or never ask about the history of past termination of pregnancy (TOP). Most of the respondents regularly or routinely ask if prior TOP's were due to medical findings in the fetus (74.2%, n=120). Just over half of the respondents noted they never or rarely ask about if prior TOP's were due to medical findings in the mother (50.8%, n=120).

The majority of respondents, 75% (n=120), routinely or regularly ask about the history of

exposures during pregnancy. A complete list of responses to questions about what GC's ask during a prenatal counseling session is available in Figure 1.

Respondents in protective states were more likely to regularly or routinely ask patients if previous history of prior TOP's were due to medical findings in the mother. This difference was statistically significant ($p=0.0492$). This was also true about responses from states that are intermediate when compared to responses from protective states ($p=0.00445$).

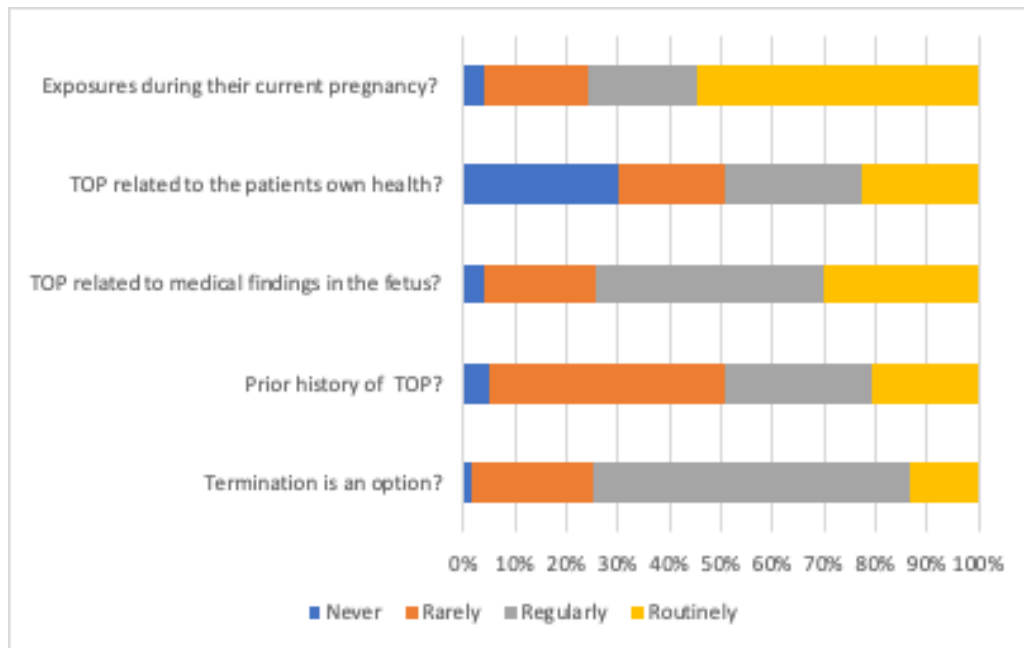


Figure 1: Information prenatal genetic counselors typically document in the medical record.

How often do you ask patients about any exposures during their current pregnancies to teratogens, including drugs and alcohol, that might affect a fetus?

How often do you ask patients with a prior history of TOP if the procedure related to the patients own health?

How often do you ask patients with a prior history of TOP if the procedure was related to medical findings in the fetus?

How often do you ask patients to tell you about any prior history of elective TOP?

How often do you ask patients in the pre-test setting about whether or not termination is an option for them?

TOP= termination of pregnancy

Out of State Practices

Prenatal GCs were asked about the practice of referring patients out of state for abortion care. The majority of respondents (89.1%, n=119) have had patients travel out of state for abortion care. The majority have provided logistical support to patients traveling from other states for abortion care (79.8%, n=119). Of those who have provided logistical support, the majority do not warn their patients about other providers being able to see their medical record post-abortion (59.8%, n=102), while 40.2% of respondents do warn their patients about other providers accessing their medical record.

Prenatal GCs were asked about their level of concern related to referring patients out of state. More than half were concerned or very concerned (57.4%, n=47) about what information related to the abortion would be placed in their patient's medical record (**Figure 2**). Most respondents (69.1%, n=55) were not at all or only slightly concerned about information in their patients' medical records creating legal jeopardy after obtaining an abortion out of state. And 56.3% (n=55) of respondents indicated they are concerned or very concerned about providing logistical support for patients to obtain an abortion out of state due to the possibility of it creating legal jeopardy for them and their institution. A complete description of GC's responses to questions about out-of-state travel for abortion care can be found in Figure 2.

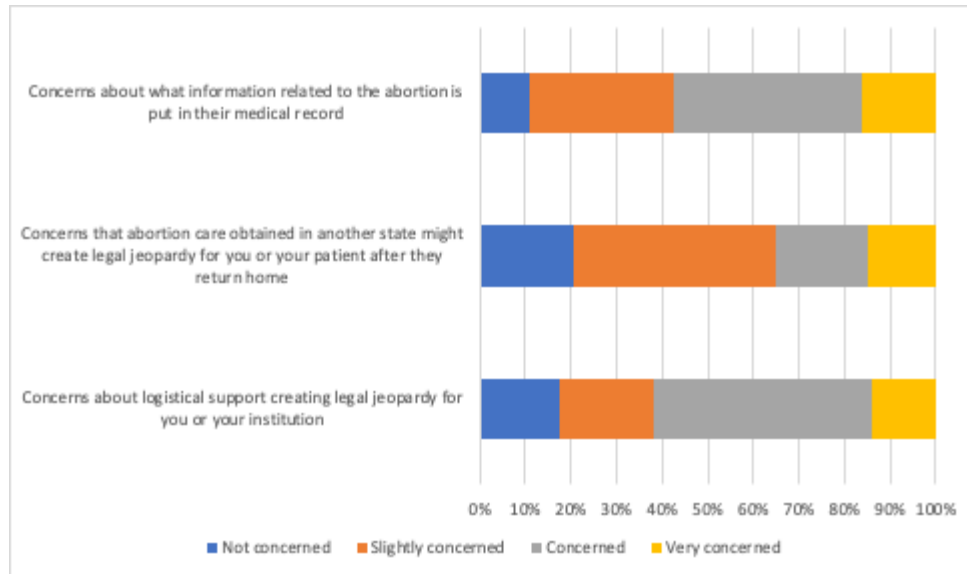


Figure 2: Prenatal genetic counselors concerns for legal jeopardy when providing support for out of state abortions.

There was a statistically significant difference in responses between genetic counselors who have had patients travel out of state for an abortion across the three groups. When comparing protective states to intermediate states, a higher percentage of those in intermediate states noted that they have had patients travel out of state ($p=0.0021$). The difference between protective and restrictive states was also significant ($p=0.029$).

Post-June 2022

Prenatal GCs were asked about changes to their practices and behaviors with regard to the medical record post-June 2022 when *Roe v. Wade* was overturned. They were also asked about changes in patient behaviors during the same time frame. A majority of participants (83.9%, $n=118$) reported that they have discussed with colleagues concerns about what goes into the medical record and 50% ($n=118$) have altered their practice in regard to what is recorded in the medical record. More individuals from restrictive states responded that they have changed

their practice (52.72%, n=55) while 50% of respondents (n=14) in intermediate states and 45.10% (n=51) of respondents in protective states noted a change in practice. These differences between state groups were not statistically significant.

When asked about changes in patient behaviors since June 2022, most respondents noted some changes in their patients' willingness to share information (**Figure 3**). Just over half of participants (53.4%, n=116) noted at least some reluctance on the part of their patients to share information about their current pregnancy. Fewer participants reported increased patient reluctance to share information about prior pregnancies, with 86.2% (n=116) of participants noting little change or no change, but more than half (57.8%, n=109) reported at least some reluctance to share information when discussing abortion. In general, participants' views on changes in patient concerns what is included in the medical record were split: 30% (n=110) of respondents noted no change, 32% (n=110) noted very little change, 20% (n=110) noted some increased reluctance to share information, and 17.2% (n=110) noted much more reluctance to share information.

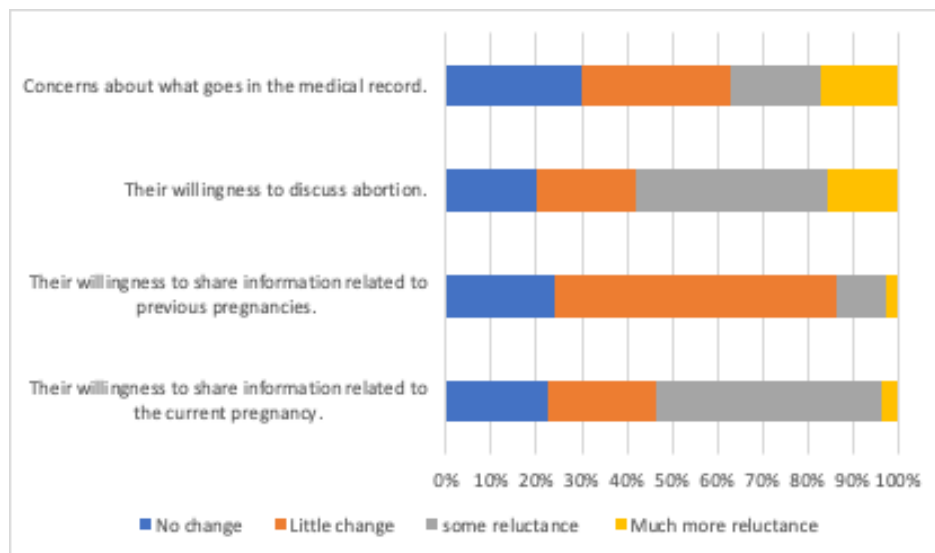


Figure 3: Post-June 2022 changes in prenatal genetic counselors' views on patients behaviors in terms of their willingness to share information.

Legal Advice

Prenatal GCs were asked about their desire for legal guidance pertaining to the potential of the medical record to create legal jeopardy for themselves and others post-Dobbs. The majority of respondents (71.6%, n=116) felt they needed legal guidance to determine if pregnancy-related information in the medical record could create legal jeopardy for them (**Figure 4**). Fewer (43.5%, n=115) reported that they needed legal guidance to determine if pregnancy-related information in the medical record could create legal jeopardy for other healthcare professionals involved in their patients' care. Most respondents reported the need for legal guidance to determine if pregnancy-related information in the medical record could create legal jeopardy for their patients, with just over half (50.8%, n=114) reporting concerns about legal jeopardy for patients related to a miscarriage or fetal loss, and the majority (76.7%, n=116) of respondents reporting concerns about legal jeopardy for patients who have an abortion.

Participants from intermediate states were most likely to express concern for how they may be affected by legal jeopardy ($p=0.042$). Respondents from intermediate states were significantly more likely to report a need for legal guidance than respondents from restrictive states ($p=0.0056$) and significantly more likely to report a need for legal guidance than respondents in protective states ($p=0.0094$).

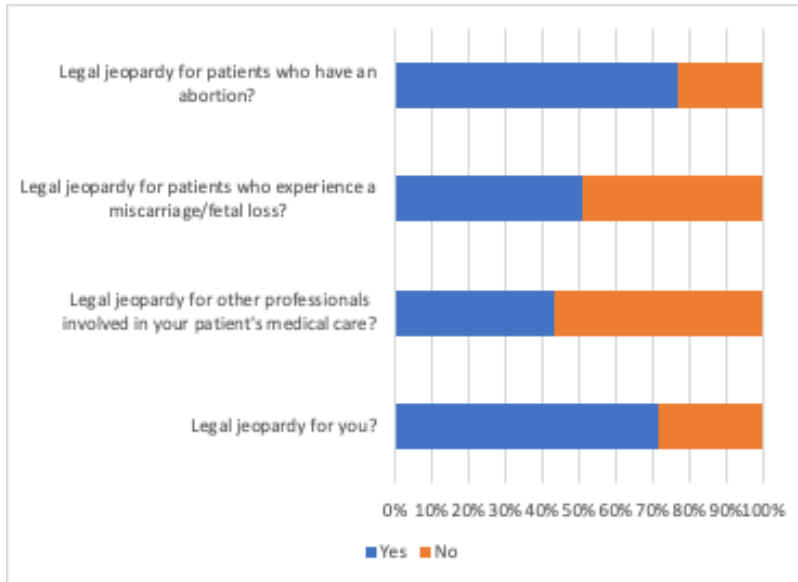


Figure 4: Prenatal genetic counselors desire for legal guidance surrounding various aspects of practice.

The majority of respondents (96%, n=116) were at least slightly interested in legal guidance related to best practice around documentation in the EHR (**Figure 5**). Of that total, 49% (n=116) of respondents described themselves as slightly interested, 30% (n=116) described themselves as interested, and 17% (n=116) described themselves as very interested in legal guidance around what goes into the EHR.

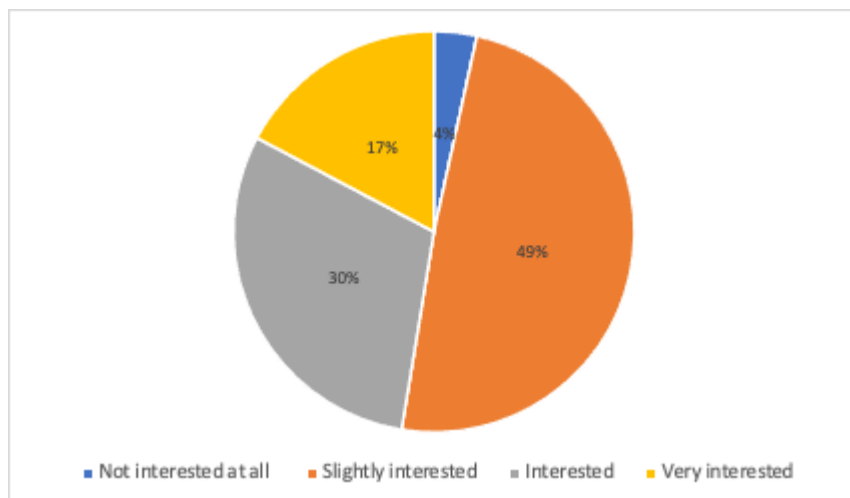


Figure 5: Prenatal genetic counselors' interest in legal guidance for best practices regarding information related to abortions and miscarriage in the EHR.

DISCUSSION

To our knowledge, this is the first study to focus on the issue of practitioner concerns about legal implications of what goes in the medical record in the wake of the changing legal landscape following the overturning of *Roe v Wade*. Our results suggest that GC's are concerned that information in the medical record may create legal jeopardy for both providers and patients.

Many new laws regulating abortion, including those that embrace the concept of 'fetal personhood,' open the door to increased criminalization of abortions. Documentation of prior and current pregnancy history has had legal implications for patients in prior cases (Goodwin, 2018; Pregnancy Justice, 2022). Of surveyed GCs in this study, 75% ask patients about current exposures to the pregnancy, including all teratogens, information which has been used by prosecutors in prior cases to accuse pregnant individuals of criminal harm to a fetus (Carlisle, 2022). According to our study, most prenatal genetic counselors also ask patients if termination is an option for them, which is not surprising in that it can affect decisions on genetic testing and pregnancy management. Of our participants, 75% responded that they are regularly or routinely asking if termination is an option for the patient regardless of referral reason. Given concerns about legal jeopardy, we might have expected restrictive laws may make GC's less likely to bring up the subject of abortion, this was not the case. One answer from a restricted-state participant to an open-ended question may help explain why:

"I have found myself bringing up the option of termination first most of the time to allow that avenue of conversation and identify myself as a safe person. A lot of people have expressed concerns about which other providers they can tell and being scared to request follow-up care with their OB as they do not always know where they stand."

The majority of prenatal GCs in our study population (79.8%) have provided logistical support to patients traveling from other states for abortion care, further indication of how involved GCs are in the process of arranging abortion care for patients. This finding supports evidence from other studies which have noted GCs are heavily involved in their patients' abortion care, and that this role may be imperiled if GC's do not feel comfortable putting any evidence of an abortion into the EHR. Jayaraman *et al.* found that GCs assist with coordination of appointments, institutional regulations, navigating legislation, and providing guidance for abortion care. However, several GCs in our study mentioned that they are no longer able to assist in the process of scheduling abortions out of state. These results align with what was concluded in Jayaraman *et al.* Their study found that many GCs identified their ability to provide abortion support was restricted, and this extended to institutional policies and provider referral patterns based on biases of individuals and institutions (Jayaraman, 2021). A GC located in a restrictive state from our study said:

“I am not legally allowed to help patients schedule their abortions out of state. I have had several patients ask for help doing so because they are confused, there is a language barrier, etc., and I am unable to help them.”

Another stated:

“We don't typically mention whether or not we have sent records or helped coordinate in other ways. We also are sure to specify that it is outside our state (restrictive state).”

In other open-ended responses, GC's expressed other concerns related to institutional pressures that restricted what they could safely record in the medical record. A GC from a restrictive state noted that their institution felt the need to use language that avoided direct mention of abortion:

“We are now able to refer for a "second opinion" at institutions that are also in states that are able to offer TOP. We are not able to refer for TOP (restrictive state).”

Of the GCs in our study who have referred patients out of state for abortion care, the majority (59.8%) did not warn their patients that their medical records may be seen by future providers, but a substantial minority, 40%, did. With restrictions on abortion increasing throughout the United States, many GCs are worried that a history of an abortion may put their patients at risk.

Our study suggested that subsequent to June 2022, a majority of GC’s (83.9%) have had discussions with their colleagues to reassess should or should be included in the EHR regarding abortions and, notably, 50% of GCs in our study have altered their practice on what is being recorded in the EHR. In open-ended questions, respondents added that they are utilizing vague or abstract language in documentation to describe their conversations with patients in regard to abortions. One respondent from a restrictive state said:

“We are being vague in the medical record, such as ‘considering all pregnancy management options’ rather than saying ‘considering pregnancy termination.’”

In addition to this, some respondents have noted that they have to use language approved by their institution or coded verbiage. Multiple examples of this were provided by respondents from restrictive states:

“We ask if the patients would consider termination, but do not write this in the patient note. Instead, we use a secret indicator in the electronic medical record message board to indicate the patient's response. We also no longer document when a patient elects termination if they are from (state name redacted)”.

“I have gone from very specific documentation to using approved phrases from admin and legal that may or may not capture the entirety of the nature of the conversations I am having, (restrictive state).”

“My wording about discussion of ETOP always now includes: patient made aware that legal restrictions prevent termination of pregnancy for fetal anomalies in our state and, if chosen, she will need to seek care at another facility outside (restrictive state). I also never document whether, if a patient travels out of state for ETOP, the particular type/method of procedure done, when it was done.”

There have been other reports of doctors and healthcare providers speaking in ‘code’ when talking about abortion. A National Public Radio article published in March 2023 describes one Texas OBGYN who says that colleagues may tell patients “The weather is really nice in Colorado this time of year, you should check it out” (Simmons-Duff, 2023). The suggestion is that it is up to the patient to pick up on the hint and coordinate care. In our study, several responses from GC’s suggested that this is a response to tighter regulation in some institutions. The use of code might avoid some problems but could create others, since it fails to capture information in the EHR which may have implications for future care, and disadvantages vulnerable individuals such as younger patients, patients with intellectual disabilities, or non-English-speaking patients who may be less likely to understand a ‘coded’ response.

Prenatal GCs also noted a change in their patients' behaviors when it came to sharing information post-June 2022. Over half of respondents, 53.4%, noted some reluctance on the part of their patients to share information about their current pregnancy and 57.8% of respondents noted that their patients showed increased reluctance about discussing abortion. Some

participants (37.3%) elaborated on patient concerns about what was being documented in their medical record. One restrictive-state respondent noted:

“Not just patient "willingness" to discuss abortion, but their overall comfort during that conversation has changed. Patients are much more aware of legal considerations now and often seem very uncomfortable discussing abortion and scared of legal penalties, much more than before.”

It appears likely that some prenatal patients perceive increased risk associated with sharing information about their pregnancies, which could interfere with prenatal best practices.

Of our respondents, 96% were at least slightly interested in receiving legal guidance on what should be included in EHR documentation. Most participants, 71.6%, were in search of legal guidance on how pregnancy-related information could create legal jeopardy for themselves while 76.7% felt they needed legal guidance for their patients who seek abortion care. A substantial minority of respondents were interested in legal guidance related to risks for other healthcare professionals involved in their patients' care or for patients who have experienced a miscarriage. Interestingly, there was no significant difference when comparing GCs responses from restrictive, intermediate, or supportive states in terms of their desire for legal guidance.

Previous studies have also noted fears of legal repercussions related to evolving legislation. Most recently, Getchell *et al.* reported on GCs concerns about what they could document and the risk of being taped in phone calls to patients in restrictive states. These concerns dated back in January 2022, before *Roe v. Wade* was overturned, they noted that this was a dominant issue for GCs working in Texas under SB8 (Getchell *et al.* 2022). Given that SB8 likely provided an early glimpse into a post-Roe world, our findings of widespread concerns about legal jeopardy are not surprising.

In open-ended responses, respondents focused on what should be documented in the EHR, what should be left out, the type of verbiage used when documenting, and what language should be used when speaking with patients about terminations. Multiple respondents noted conversations with legal departments within their institutions related to their concerns about legal jeopardy. This respondent described a lack of legal support from her institution, a theme echoed by others, and one which may help explain the near-universal interest in legal guidance:

“I have asked for legal guidance from my healthcare system's legal support team regarding any verbal or documented discussion about abortions and whether this places me or any patients in harm's way for litigation. I never received a response or true guidance from my place of employment, and therefore I gathered as much information as possible on my own via webinars, etc. to understand whether I should be altering my practices. I am very disappointed in the response from my own healthcare system, as well as state-wide response (or lack thereof) regarding legal guidance for patients and healthcare providers re: understanding how to protect ourselves and our patients from potential litigation (intermediate state).”

Limitations

Our study had multiple limitations. First, of the 500 responses to our survey, many appeared to be bots. We attempted to rectify this by eliminating all responses that left blank an early question asking the respondent to indicate the state where they practiced. We believe this eliminated all bot responses; however, we cannot be sure that there were not some bots remaining, or that some legitimate responses were not eliminated if the respondent declined to indicate where they practiced.

Our sample size after applying all filtering criteria was 120. Using the Professional Status Survey, we estimated that there are about 1500 prenatal genetic counselors working in the United States (Professional Status Survey, 2022). Therefore, 120 responses represents approximately 8% of prenatal genetic counselors in the US. Lastly, this is a sensitive topic with potential legal implications for genetic counselors and their institutions. Although anonymous, it is possible that respondents may have skipped questions or not provided full responses in fear of possible legal consequences.

Future Directions

Further research is needed to understand how legislation continues to impact prenatal genetic counselors and to establish best practices in terms of documentation. Our study discovered that half respondents have altered what they put in the EHR subsequent to June 2022. Investigations on how GCs workflow has been changed may be beneficial in understanding how legal changes are affecting GC's and patients. Additionally, our study noted the use of "vague" or "coded" language within the EMR. Qualitative studies might help determine how this language is used and what implications it has for patient care as well as legal liability.

Conclusion

This study surveyed prenatal GCs to understand what impact, if any, current abortion restrictions are having on GC practice with regard to documentation, and what the current level of concern is regarding the potential impact of EHR information on colleagues or patients. Most GCs in our survey report being at least slightly concerned about providing logistical support for out of state abortions and how that could impact themselves, their institutions, and their patients.

GCs also report that concerns about what goes into the medical record have been discussed in their workplaces, and that changes in practice have been adopted since June 2022. Some GC's suggested that healthcare providers are turning to the use of vague or coded language for documentation of information related to abortion care. GCs noted that patients have also changed their behaviors, and show increased reluctance to discuss abortion or share information related to their current pregnancy. Many GCs reported a need for legal guidance to determine if pregnancy-related information in the medical record could create legal jeopardy for them and their patients. Results from our survey suggest that GCs would benefit from guidance and that professional organizations like NSGC should consider creating practice guidelines to address best practices for the documentation of pregnancy-related information in the post-Roe era.

REFERENCES

Alfirevic Z, Navaratnam K, Mujezinovic F. 2017. Amniocentesis and chorionic villus sampling for prenatal diagnosis. *The Cochrane Database of Systematic Reviews*. 9. Art. No.: CD003252. doi: 10.1002/14651858.CD003252.pub2

American College of Obstetricians and Gynecologists Committee (ACOG). 2016. Prenatal diagnostic testing for genetic disorders. Practice Bulletin No. 162. *Obstet Gynecol*. 127:e108–22. doi:10.1097/aog.0000000000001405

American College of Obstetricians and Gynecologists. (ACOG). Screening for fetal chromosomal abnormalities. ACOG Practice Bulletin No. 226. *Obstet Gynecol* 2020;136:e48–69. doi: 10.1097/aog.0000000000004084

American College of Obstetricians and Gynecologists (ACOG). 2016. Ultrasound in pregnancy. Practice Bulletin No. 175. *Obstet Gynecol*. 128:e241–56. (Level III)

Beta J, Zhang W, Geris S, Kostiv V, Akolekar R. 2019. Procedure related risk of miscarriage following chorionic villus sampling and amniocentesis. *Ultrasound Obstet Gynecol* 2019;54:452–7. doi: 10.1002/uog.20293

Bauer-Kahan, R., 2022. *Reproductive Rights*. Bill Text - AB-1242 Reproductive rights. Retrieved March 24, 2023, from https://leginfo.ca.gov/faces/billNavClient.xhtml?bill_id=202120220AB1242

Carlisle, M. 2022.. Fetal personhood laws: What to know after Roe v. Wade. *Time*. Retrieved March 16, 2023, from <https://time.com/6191886/fetal-personhood-laws-ro-abortion/>

Center for Public Health Law Research. 2022. Post-dobbs state abortion restrictions and protections. *Policy Surveillance Portal*. Retrieved March 7, 2023, from <https://lawatlas.org/datasets/post-dobbs-state-abortion-restrictions-and-protections#:~:text=While%20some%20states%20moved%20quickly,that%20is%20increasingly%20becoming%20criminalized.>

Center for Reproductive Rights. 2023. Abortion Laws by State. Retrieved March 7, 2023, from <https://reproductiverights.org/maps/abortion-laws-by-state/>

Center for Reproductive Rights. (n.d.). US Supreme Court Case: Dobbs v. Jackson Women’s Health Organization. Retrieved March 7, 2023. <https://reproductiverights.org/case/scotus-mississippi-abortion-ban/>.

Cornell Law Legal Information Institute. (n.d.). 42 U.S. Code § 300JJ–52 - information blocking. *Legal Information Institute*. Retrieved February 9, 2023, from <https://www.law.cornell.edu/uscode/text/42/300jj-52>

Cornell Law Legal Information Institute. (n.d.). Jane Roe, et al., appellants, V. Henry Wade. *Legal Information Institute*. Retrieved February 9, 2023, from <https://www.law.cornell.edu/supremecourt/text/410/113>

Cornell Law Legal Information Institute. 2022. DOBBS v. JACKSON WOMEN'S HEALTH ORGANIZATION. *Legal Information Institute*. Retrieved February 9, 2023, from <https://www.law.cornell.edu/supremecourt/text/19-1392>

Cooney, C., Hercher, L., & Bajaj, K. 2017. Genetic Counselors' Perception of the Effect on Practice of Laws Restricting Abortion. *Journal of Genetic Counseling*, 26(5), 1059–1069. doi:10.1007/s10897-017-0083-x

Friedman, C. F., & Chasen, S. T. 2020. Abortion for fetal indications: Timing of prenatal diagnosis and abortion for structural and genetic abnormalities. *Contraception*, 101(5), 293–295. <https://doi.org/10.1016/j.contraception.2020.02.002>

Getchell, G., Horan, S., Sagaser, K. G., & Hercher, L. 2022. Prenatal genetic counseling in states hostile to abortion in the final days of *roe v. wade* : A qualitative study. *Journal of Genetic Counseling*. <https://doi.org/10.1002/jgc4.1664>

Goodwin, M. 2018 If Embryos and Fetuses Have Rights.. *Law & Ethics of Human Rights*. 11(2), 189-224, UC Irvine School of Law Research Paper No. 2018-27, SSRN: <https://ssrn.com/abstract=3163829>

Grossman, T. B., & Chasen, S. T. 2020. Abortion for fetal genetic abnormalities: Type of abnormality and gestational age at diagnosis. *American Journal of Perinatology Reports*, 10(01). <https://doi.org/10.1055/s-0040-1705173>

Guttmacher Institute. Interactive Map: US Abortion Policies and Access After Roe. Retrieved from: <https://states.guttmacher.org/policies/>

Harper LM, Wood S, Jenkins SM, Owen J, Biggio J. 2016. The performance of first-trimester anatomy scan: a decision analysis. *Am J Perinatol*. 33:957–65. doi: 10.1055/s-0036-1579652 34.

Hercher, L. 2022. Genetic counselors scramble post-roe to provide routine pregnancy services without being accused of a crime. *Scientific American*. Retrieved March 7, 2023, from <https://www.scientificamerican.com/article/genetic-counselors-scramble-post-roe-to-provide-routine-pregnancy-services-without-being-accused-of-a-crime/>

Hunt Brendish, K., Patel, D., Yu, K., Alexander, C. K., Lemons, J., Gunter, A., & Carmany, E. P. 2021. Genetic counseling clinical documentation: Practice resource of the

National Society of Genetic counselors. *Journal of Genetic Counseling*, 30(5), 1336–1353.
<https://doi.org/10.1002/jgc4.1491>

Jayaraman, Koenig, S., Fiddler, M., Simi, E., Goldenberg, A., Magasi, S., & Wicklund, C. 2021. Prenatal genetic counselors' perceptions of the impact of abortion legislation on counseling and access in the United States. *Journal of Genetic Counseling*, 30(6), 1671–1682..
<https://doi.org/10.1002/jgc4.1>

Liao Y, Wen H, Ouyang S, Yuan Y, Bi J, Guan Y, *et al.* 2021. Routine first-trimester ultrasound screening using a standardized anatomical protocol. *Am J Obstet Gynecol* 224:396.e1–15. doi: 10.1016/j.ajog.2020.10.037

Millhiser, I. 2021. SB 8, Texas's anti-abortion law, is back at the supreme court. Here's what's different this time. Vox.
<https://www.vox.com/2021/10/19/22728389/supreme-court-doj-texas-sb8-abortion-jackson>

Nash, E. & Guarnieri, I. 2023.. Six Months post-roe, 24 US states have banned abortion or are likely to do so: A roundup. *Guttmacher Institute*. <https://www.guttmacher.org/2023/01/six-months-post-roe-24-us-states-have-banned-abortion-or-are-likely-do-so-roundup>

Nash, E., & Ephross, P. 2022.. State policy trends 2022: In a devastating year, US Supreme Court's decision to overturn Roe leads to bans, confusion and Chaos. *Guttmacher Institute*. <https://www.guttmacher.org/2022/12/state-policy-trends-2022-devastating-year-us-supreme-courts-decision-overturn-roe-leads>

National Society of Genetic Counselors. 2017. NSGC code of ethics. NSGC. <https://www.nsgc.org/Policy-Research-and-Publications/> Code-of-Ethics-Conflict-of-Interest/Code-of-Ethics

Pregnancy Justice. 2022. When Fetuses Gain Personhood: Understanding the Impact on IVF, Contraception, Medical Treatment, Criminal Law, Child Support, and Beyond. Retrieved from: <https://www.pregnancyjusticeus.org/wp-content/uploads/2022/12/fetal-personhood-with-appendix-UPDATED-1.pdf>

NSGC Professional Status Survey Service Delivery and Access. 2022. National Society of Genetic Counselors.

Raymond, M. B., Barbera, J. P., Boudova, S., Vinekar, K., Horgan, R., McLaren, R., & Al-Kouatly, H. B. 2023. Implications for prenatal genetic testing in the United States after the reversal of Roe v Wade. *Obstetrics & Gynecology*, 141(3), 445–454.
<https://doi.org/10.1097/aog.0000000000005094>

Shachar, C. 2022. HIPAA, privacy, and reproductive rights in a post-*roe* era. *JAMA*, 328(5), 417. <https://doi.org/10.1001/jama.2022.12510>

Simmons-Duff, S. 2023. 3 abortion bans in Texas leave doctors ‘talking in code’ to pregnant patients. *National Public Radio (NPR)*. Retrieved on March 7th, 2023, from <https://www.npr.org/sections/health-shots/2023/03/01/1158364163/3-abortion-bans-in-texas-leave-doctors-talking-in-code-to-pregnant-patients>

Society for Maternal-Fetal Medicine. #36: Prenatal aneuploidy screening using cell-free DNA. (2015). *American Journal of Obstetrics and Gynecology*, 212(6), 711–716. <https://doi.org/10.1016/j.ajog.2015.03.043>

Spector-Bagdady, K., & Mello, M. M. 2022. Protecting the privacy of reproductive health information after the fall of *roe v wade*. *JAMA Health Forum*, 3(6). <https://doi.org/10.1001/jamahealthforum.2022.2656>

Zubrzycki, C. (2022). Abortion’s interoperability trap: How the law of medical records will facilitate interstate persecution of contested medical procedures, and what to do about it. *SSRN Electronic Journal*. <https://doi.org/10.2139/ssrn.4147900>

42 U.S.C. 300JJ-52 (a)(1)). https://www.govregs.com/uscode/expand/title42_chapter6A_subchapterXXVIII_partC_section300jj-52

87(R) Texas SB 8 - enrolled version - Texas. 2021.. Retrieved March 7, 2023, from <https://capitol.texas.gov/tlodocs/87R/billtext/pdf/SB00008F.pdf>

1973 *Roe v. Wade* :: 410 U.S. 113. <https://supreme.justia.com/cases/federal/us/410/113/>

2021-2022 Bill 1373: Abortion - South Carolina Legislature Online. (n.d.). Retrieved March 7, 2023, from https://www.scstatehouse.gov/sess124_2021-2022/bills/1373.htm

2022 Conn. Public act no. 22-19 - *Connecticut General Assembly*. (n.d.). Retrieved March 21, 2023, from <https://cga.ct.gov/2022/ACT/PA/PDF/2022PA-00019-R00HB-05414-PA.PDF>

2022 Arizona House Bill 2427 <https://www.azleg.gov/legtext/56leg/1r/bills/hb2427p.htm>

APPENDIX

Appendix 1: Survey

Post *Dobbs*, the introduction of new restrictions on abortion and new concepts like “fetal personhood” have raised questions about whether or not information in the EHR could create legal jeopardy for practitioners or patients.

Our names are Cameron Soriano and Cassidy Welsh. We are second-year genetic counseling students at Sarah Lawrence College. For our thesis project, we are documenting what information with potential legal consequences goes into the medical record and the level of concern about the potential impact of EHR information on colleagues or patients.

We are asking prenatal genetic counselors in abortion restrictive and abortion-friendly states about current practice and concerns they may have about what goes into the medical record.

This survey is anonymous. It consists of 11 questions and should take no more than ten minutes to complete. We appreciate your participation, and you are free to withdraw or skip questions at any time. Due to the sensitive nature of the subject, we will remove all identifying information, including information on the state where you practice, from any report based on this study.

SURVEY

Your practice:

1. Do you currently see patients in the prenatal setting? Y/N
2. In which state do you practice? _____
3. How many years have you been working as a genetic counselor? (<1, 1-5, 5-10, >10)
4. Information relating to pregnancies past and present – including pregnancy loss or termination – could have legal consequences for caregivers or patients. The following questions will help us get a sense of what information is in the medical record. Please indicate how likely you are to ask about each of the following:
NOTE: LET’S DO THESE ON A LIKERT SCALE:
NEVER/RARELY/REGULARLY/ROUTINELY
 - A. How often do you ask patients in the pre-test setting about whether or not termination is an option for them?
 - B. How often do you ask patients to tell you about any prior history of elective termination of pregnancy (TOP)
 - C. How often do you ask patients with a prior history of TOP if the procedure was related to medical findings in the fetus?
 - D. How often do you ask patients with a prior history of TOP if the procedure related to the patient’s own health?

- E. How often do you ask patients about any exposures during their current pregnancies to teratogens, including drugs and alcohol, that might affect a fetus?
5. If there are other examples of information you collect from patients that you are concerned about putting into the medical record, please share it with us here:
 6. Have you had patients travel out of state for abortion care? (Y/N with skip logic: if N, go to question 7; if Y, include the following questions:)
 - A. Do you provide logistical support for patients who seek abortion care to travel out of state? Y/N
 - B. Are you concerned that providing logistical support could create legal jeopardy for you or your institution? (LIKERT SCALE: NOT CONCERNED/SLIGHTLY CONCERNED/CONCERNED/VERY CONCERNED)
 - C. Are you concerned that information about abortion care obtained in another state in your patient's medical record might create legal jeopardy for you or your patient after they return home? (LIKERT SCALE: NOT CONCERNED/SLIGHTLY CONCERNED/CONCERNED/VERY CONCERNED)
 7. Have you provided logistical support for patients traveling from other states to get abortion care? (Y/N with skip logic: if N, go to question 8; if Y, include the following questions:)
 - A. Do you warn patients that their other providers may be able to see information about their abortion when they access their medical record?
 - B. For patients who travel from other states for abortion care, are you concerned about what information related to the abortion is put in their medical record? (LIKERT SCALE: NOT CONCERNED/SLIGHTLY CONCERNED/CONCERNED/VERY CONCERNED)
 8. In general, regarding information related to pregnancy and/or abortion in the medical record:
 - A. Have you and/or your colleagues discussed any concerns about what information you are putting in the medical record? Y/N
If yes, please specify:
 - B. Have you in any way altered your practice at all in regard to what goes in the medical record? Y/N
If yes, please specify:
 9. Since June 2022, how much change if any have you seen in your patient population with regard to: (LIKERT SCALE: NO CHANGE/VERY LITTLE CHANGE/SOME RELUCTANCE TO SHARE INFORMATION/MUCH MORE RELUCTANCE TO SHARE INFORMATION)
 - A. Their willingness to share information related to the current pregnancy.

- B. Their willingness to share information related to previous pregnancies.
 - C. Their willingness to discuss abortion.
 - D. Concerns about what goes in the medical record.

 - E. Please describe any concerns or changes seen in your patient population not listed here:
10. Do you feel in need of legal guidance related to:
- A. If pregnancy-related information in the medical record could create legal jeopardy for you?
 - B. If pregnancy-related information in the medical record could create legal jeopardy for other professionals involved in your patient's medical care?
 - C. If pregnancy-related information in the medical record could create legal jeopardy for patients who experience a miscarriage/fetal loss?
 - D. If pregnancy-related information in the medical record could create legal jeopardy for patients who have an abortion?
11. On a scale of 1-5, please rate the extent to which you feel the need for legal guidance related to best practices around recording information related to abortion or miscarriage in the EHR (NOT INTERESTED AT ALL/SLIGHTLY INTERESTED/INTERESTED/VERY INTERESTED)