



# Care Post-Roe: Documenting cases of poor-quality care since the *Dobbs* decision

Preliminary findings, May 2023

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## **Table of Contents**

Executive Summary	4.
Introduction	5.
Results	
Figure. States where patients were reported to reside and abortion policy post-Dobbs	6.
Obstetric complications in the second trimester	7.
Ectopic pregnancy	10.
Underlying medical conditions complicating care	12.
Fetal anomalies	13.
Early miscarriage	14.
Delays obtaining abortion care	15.
Delays obtaining care unrelated to abortion	16.

Discussion	17.
Table: Characteristics of patients in	
Care Post-Roe narratives	19.

Methods	20.
Glossary	21.
Appendix: Current standard of care for management of selected conditions	23.
References	25.



#### **Executive Summary**

Since the US Supreme Court decision in Dobbs v. Jackson Women's Health Organization in June 2022, total bans on abortion have gone into effect in 14 states, and severe restrictions have been enacted in others, including bans before many people know they are pregnant. In addition to restricting access to abortion care, these new laws have affected obstetric and gynecologic care and general medical care more broadly. The Care Post-Roe Study seeks to learn about how clinical care has changed by documenting cases of care that was different from the usual standard due to abortion laws that went into effect since the Dobbs ruling. This study allows health care providers to share these narratives anonymously and confidentially, at a time when they are being forbidden by their employers or hospital leadership from speaking with the press about these cases.

This report presents the preliminary findings of the Care Post-Roe Study. Between September 2022 and March 2023, we received 50 submissions from health care providers describing detailed cases of care that deviated from the usual standard due to new laws restricting abortion. The patients described in the narrative submissions lived in one of 14 states that banned or restricted abortion following *Dobbs*. Patients described in the narratives submitted by health care providers represent a range of different ages, income levels, and racial and ethnic backgrounds, with a notable proportion involving patients reported to be Black or Latinx.

Cases in the narratives fell into several categories:

- Obstetric complications in the second trimester prior to fetal viability, including preterm prelabor rupture of membranes, hemorrhage, cervical dilation, and hypertension;
- Ectopic pregnancy, including cesarean scar ectopic;
- 3. Underlying medical conditions that made continuing a pregnancy dangerous;

- 4. Severe fetal anomalies;
- 5. Early miscarriage;
- 6. Extreme delays in obtaining abortion care; and
- Delays obtaining medical care unrelated to abortion.

The post-Dobbs laws and their interpretations altered the standard of care across these scenarios in ways that contributed to delays, worsened health outcomes, and increased the cost and logistic complexity of care. In several cases, patients experienced preventable complications, such as severe infection or having the placenta grow deep into the uterine wall and surrounding structures, because clinicians reported their "hands were tied," making it impossible for them to provide treatment sooner. One physician described a case of a patient who had ruptured membranes at 16-18 weeks' gestation but was denied an abortion because of a new state law. She was sent home and developed a severe infection requiring management in the intensive care unit. The patient subsequently delivered her fetus but required a procedure to remove her placenta. The physician wrote, "The anesthesiologist cries on the phone when discussing the case with me-if the patient needs to be intubated, no one thinks she will make it out of the OR." Health care providers described feeling moral distress when they were unable to provide evidencebased care, and some reported considering moving their practices to a state where abortion remains legal.

These preliminary findings from the Care Post-Roe Study document a wide range of harm to people with the capacity for pregnancy in states with bans or severe restrictions on abortion care. Clinicians must be able to use their medical judgment to provide evidence-based care for their patients and prevent medical emergencies, without risk of criminal prosecution.



#### Introduction

Shortly after the Supreme Court decision in *Dobbs v. Jackson Women's Health Organization* in June 2022 and subsequent enforcement of bans on abortion care in a number of states, reports began to surface in the media about medical care that differed from the accepted standard.<sup>1,2,3</sup> Some of the cases involved delays in the treatment of conditions that were life-threatening, such as ectopic pregnancy, while others chronicled the difficult barriers patients needed to overcome to obtain abortion care when pregnant with a fetus with severe anomalies incompatible with life.

As this media coverage increased, so did reports of clinicians being told by their employers or leadership of the hospitals where they practiced not to speak with the press about these cases.<sup>4</sup> In an effort to provide a venue for health care providers to anonymously share information about cases of poorquality care due to new restrictions on abortion care, we launched the Care Post-Roe Study on September 29, 2022. The study invites health care providers to submit written or audio narratives describing cases of clinical care that deviated from the usual standard due to new laws since June 2022. Providers who submit cases have the option of participating in a follow-up in-depth interview. To protect provider confidentiality, anonymous submissions are permitted, and to protect patient confidentiality, submitters are instructed not to submit any protected health information (PHI). This report is a preliminary analysis of the submissions received during the first six months of the project, through March 2023.

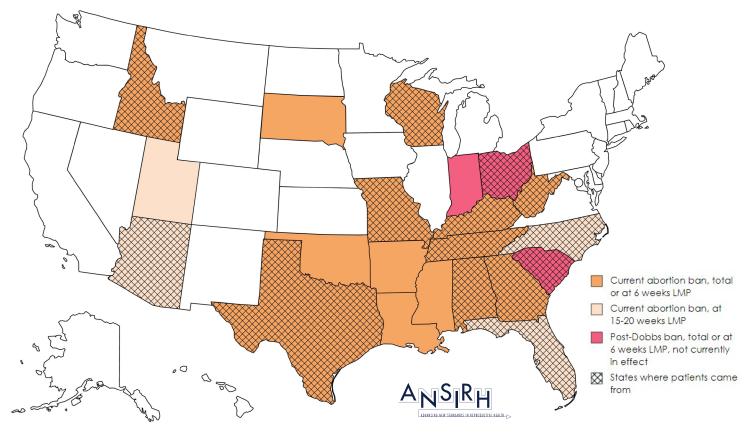


#### Results

Between September 29, 2022, and March 30, 2023, we received 50 submissions describing detailed cases of care that deviated from the usual standard due to laws restricting abortion that went into effect after *Dobbs*. Although not presented here, during this period we also conducted 16 in-depth interviews with study participants who submitted narratives. The patients described in the 50 narrative submissions lived in one of 14 states that banned abortion following *Dobbs*, shown on the map (Figure). The reported age, race, and ethnicity of patients are included in a table at the end of the report. The cases occurred between June 2022 and March 2023.

Health care providers described a range of clinical scenarios in the narratives. Below are summaries of the different categories of clinical scenarios with representative quotations from the narratives. Some details have been generalized (denoted through the use of brackets within quotations) when such information might enable identification of the patient and/or clinician. We include at the end of the report a glossary of medical terms used in the narratives, as well as an appendix with information about the standard of care for managing many of the conditions described in the narratives.





Note: LMP refers to weeks since last menstrual period. Abortion policies current as of March 30, 2023. See Center for Reproductive Rights (<u>https://reproductiverights.org/maps/abortion-laws-by-state/</u>) for more information.

### **Obstetric complications in the second trimester**

Health care providers submitted narratives related to obstetric complications in the second trimester that would usually be considered an indication for abortion (see Appendix). The most common scenario involved preterm prelabor rupture of membranes (PPROM) in the second trimester. Contrary to the standard of care prior to *Dobbs* (in which patients immediately would have been offered the option of a dilation and evacuation (D&E) or induction termination), in most of the narratives, patients were instead sent home after rupture of membranes was confirmed and told to return when labor started or when they experienced signs of infection. In several of the cases, patients developed a severe infection, including cases where the infection required management in the intensive care unit (ICU). One physician described a patient who experienced PPROM at around 16-18 weeks of pregnancy in a state with an abortion ban and had been sent home following the initial diagnosis. The physician wrote:

"I meet her 2 days later in the ICU. She was admitted from the ER with severe sepsis...and bacteremia. Her fetus delivers; she is able to hold [the fetus]. We try every medical protocol we can find to help her placenta deliver; none are successful. She is now on 3 pressors and in [disseminated intravascular coagulopathy]. The anesthesiologist cries on the phone when discussing the case with me—if the patient needs to be intubated, no one thinks she will make it out of the OR. I do a D&C."

Continuing to describe the case, the physician noted that, unlike in a typical D&C, the patient "bleeds from everywhere." Miraculously, the patient did not die. But even after this harrowing experience, the patient expressed fear that she has broken the law by ending her pregnancy. The physician recounted, "She asks me: could she or I go to jail for this? Or did this count as life threatening yet?" In several narratives of patients with PPROM, the patient traveled to another state where abortion care was still legal because their local hospital and/or physician declined to provide them with a D&E or induction termination. In some cases, the patient arranged care themselves, while in other cases the patient's medical team in the state with a ban advised them to travel to another state and even connected them with an out-of-state provider. Having to travel resulted in delays in obtaining care as long as several weeks. In one narrative, during this delay, the patient developed an infection requiring hospitalization.

One physician in a state where abortion was legal described their experience receiving a patient with PPROM at 18-20 weeks of pregnancy who was referred from a state with an abortion ban. The patient had a complicated medical history and, although she desired a termination, the team caring for her in the state with the abortion ban was unable to perform the procedure because the fetus had cardiac activity. The physician who accepted the referral wrote:

"On her 4th day of [her membranes] being ruptured, we received a text about this patient and accepted the request. However, she was asked by her [sending] hospital to self-transfer with her mother, driving almost 4 hours, through [another state], to get to our facility. This transfer was not initiated until 5 days after she had ruptured. In [the intervening state], she noticed there was umbilical cord in her vagina and some vaginal spotting. They hurried to our hospital."

The physician went on to describe the tremendous amount of work required to arrange this kind of care across state lines:



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"The burden placed on health care providers should also be noted... The degree of coordination between Ob/Gyns in different states was heroic; however, this effort took away from other patients that our providers were caring for. The fact that her own Ob/Gyn could not provide evidence-based, standardof-care treatments because of a state policy is unacceptable."

Health care providers described similar cases of patients who presented with significant bleeding or evidence of inevitable pregnancy loss in the second trimester, who would have been offered a timely abortion prior to *Dobbs*. One physician described a patient who had an undesired pregnancy and presented with brisk vaginal bleeding at 20-24 weeks in a state with an abortion ban, writing:

"Our hands are tied. She is hemodynamically stable. This is a threatened, not inevitable, abortion. The pregnancy may continue. So we have to simply wait, either for bleeding to get worse or for her to get to viability [when she could be delivered]. ... She may get to be cared for out of state, but she has social circumstances which seem to make that untenable."

In another case, a patient pregnant at 15-18 weeks' gestation in a state with an abortion ban experienced significant bleeding and was admitted to the hospital for observation. By the following morning, her anemia had worsened, and she needed a transfusion. At that point, the medical team determined she met criteria for the state's "life-ofthe-mother exception" and underwent a termination. Regarding this decision, the physician wrote: "When I objectively look at her case, there is no way that this woman['s pregnancy] was going to make it to [fetal] viability (6+ [additional] weeks) and [she] was becoming clinically unstable. The paralysis that the overnight team exhibited by not treating this inevitable abortion as such again demonstrated that physicians are perseverating about whether they can legally provide standard-of-care medical treatment."

Another physician based in a state with an abortion ban described a case of a patient pregnant at 19-20 weeks who presented initially with painless cervical dilation and protrusion of the amniotic sac through the cervix. After being evaluated, she was found to be stable and was sent home. The following day, she presented to the emergency department in severe pain and in advanced labor. The physician described how multiple members of the health care team declined to be involved in her care because of the state law in effect:

"Anesthesiology colleagues refused to provide an epidural for pain. They believed that providing an epidural could be considered [a crime] under the new law. The patient received some IV morphine instead and delivered a few hours later but was very uncomfortable through the remainder of her labor. I will never forget this case because I overheard the primary provider say to a nurse that so much as offering a helping hand to a patient getting onto the gurney while in the throes of a miscarriage could be construed as 'aiding and abetting an abortion.' Best not to so much as touch the patient who is miscarrying... A gross violation of common sense and the oath I took when I got into this profession to soothe my patients' suffering."



The treatment of this patient so upset this physician that they have contemplated leaving the state. This was not the only submission in which a clinician reported that they considered relocating to a state with legal abortion to enable them to offer the standard of care for their patients.

A couple of narratives involved patients who developed severe pregnancy-related hypertension or preeclampsia in the second trimester. In one case, the physician described how the patient was pregnant with a fetus with multiple anomalies that were incompatible with life and how her care diverged from what she would have been offered before *Dobbs*:

"We expectantly managed her due to the fact that she couldn't be offered abortion care in our state and did not have the funds or transportation to travel out of state. At 20-22 weeks she presented with new elevated blood pressures and the fetus had significant hydrops, [and] I had significant concern for [her] developing mirror syndrome... I coordinated for her to be transferred to [state with abortion access] for appropriate care."

The physician went on to describe how the need to travel for care delayed necessary treatment and negatively impacted the patient's health:

"She had labs done at our facility prior to the transfer via ambulance that were normal. By the time she reached [receiving state] 4-6 hours later, she had [an elevated] creatinine and severe-range blood pressures. She underwent an induction and delivered [in the receiving state] thankfully." Another physician described a case of a patient pregnant with twins at 17-19 weeks in a state with an abortion ban. The patient experienced a demise of one of the fetuses and developed HELLP (hemolysis, elevated liver enzymes, and low platelets) syndrome, which, prior to *Dobbs*, would have been treated by ending the pregnancy. Because her care team could not offer a termination under existing state law, they decided to transfer her to a state with abortion access. The physician wrote:

"[The patient's] condition worsened during the duration of transport time. The patient was separated from family and resources. Astronomic hospital costs. Ultimately at the time of procedure [the patient] had demise of the second twin. This delay in care was a 'near-miss' and increased morbidity."



#### **Ectopic pregnancy**

Health care providers submitted several narratives related to ectopic pregnancy. Ectopic pregnancies are never viable, will become life-threatening, and are generally treated with methotrexate or surgery according to standard of care.<sup>5</sup> However, submitters reported cases of ectopic pregnancy in which extra steps, including consulting multiple physicians, were required to provide the needed care post-Dobbs. One physician who practiced in a state with a ban on abortion described being consulted about the treatment of such a patient:

"In this particular case, the [obstetrician (OB)] had a patient with a presumed ectopic pregnancy (met defined clinical criteria) and had opted for management with methotrexate. Methotrexate is usually administered by the Emergency Department in outpatient scenarios. The OB had sent her patient into the ER and received a page from the [Emergency Medicine] physician there questioning whether he was permitted to give the methotrexate given the 'new legal climate.' He expressed concern for legal liability for treating with methotrexate given the ectopic was only presumed. The OB paged me as the on-call physician asking what to do. She (as have I) had had patients rupture their [fallopian] tubes with HCG levels such as this patient. While the patient was currently clinically stable, [the OB] was dismayed she was potentially being refused the treatment option she had chosen and is considered a standard of care choice in this situation. I confirmed this with [the OB] and with our dual opinion and documentation the patient did get the methotrexate."

A few of the submitted narratives described cases of ectopic pregnancy where care was delayed because the patient was fearful or wary of seeking any pregnancy-related care in their home state where an abortion ban was in effect. In these cases, the patient traveled to another state where abortion care was legal, and eventually received a diagnosis and surgical treatment for ectopic pregnancy. Because of the delay, one patient had a ruptured ectopic pregnancy and required surgery to remove her fallopian tube. The physician wrote, "This patient now has had major surgery away from her home and support system, an outrageous expense for her care (travel and lodging) and is lucky to be alive." In another case, the patient's delay in seeking care because of her home state's abortion ban similarly had negative health consequences. The reporting physician wrote:

"If [the patient] had seen [a] provider in [her home state] when bleeding started..., she would have had the ectopic diagnosed about 6 weeks earlier, potentially eligible for [methotrexate] and therefore potentially avoided surgery, and even if [she] needed surgery [it] would have been at home with her family and support. Instead [she] had to... recover alone in a hotel room in a random state she had never been to before."

There were three narratives describing delays in care for cesarean scar ectopic pregnancy. Because of the high risk of serious complications with these pregnancies, including hemorrhage, growth of the placenta into surrounding organs, and uterine rupture, the Society for Maternal-Fetal Medicine and other major medical organizations recommend that cesarean scar ectopic pregnancies be terminated early in gestation.<sup>6</sup> One physician described a case of a patient seeking a medication abortion who traveled from a state with an abortion ban to an abortion clinic in a state where care was legal.



She was found to be pregnant at 6-8 weeks with twins, one of which was implanted in the cesarean scar. Only after presenting for abortion care was the cesarean scar ectopic discovered. While she was within the recommended window for safe treatment, her twin pregnancy complicated her care. The physician wrote:

"I told her that it would not be safe to do a medication abortion, and we arranged for her to be seen at the local community hospital. They did a formal ultrasound followed by an MRI and made the diagnosis of a c-section scar [ectopic] pregnancy. They offered to treat her there, but she opted to go back to [her home state] for management, and they communicated with [her] physician [there]."

After returning to her home state to pursue treatment there, the patient faced additional barriers to care. The physician continued describing the case:

"Four days later she saw the doctor [in her home state], and they told her they would not be able to treat her because Twin B [had cardiac activity]. Their 'hands were tied' and there was no way they could treat her. She would have to continue her pregnancy and they would monitor her closely to see if she developed a placenta accreta. She called [our] clinic and asked if she could come back to [state with abortion access] to be seen in the hospital for management. So now we are arranging for her to be treated at the hospital [here]. She will have to drive the many hours back and will likely have to be admitted." Another patient with a cesarean scar ectopic in the second trimester of pregnancy was unable to travel out of state for care. A physician in a state with an abortion ban described the case:

"We offered her abortion care via D&C but told her that we recommended uterine artery embolization pre-op in order to minimize the risk of bleeding and need for emergent [hysterectomy]. Interventional Radiology was approached but declined to [embolize] while there were heart tones and said if the [maternal-fetal medicine (MFM) physicians] could inject her, and the tones stopped, they would. MFM ... said they did not feel legally protected. We offered the patient referrals outside the state, but she did not have means to travel. We ultimately did not offer her a D&C, only the options for gravid [hysterectomy] and continuing the pregnancy. She is [now 17-19] weeks and on imaging has a developing percreta."



## Underlying medical conditions complicating care

In several of the narratives, physicians described cases where patients had underlying medical conditions that complicated their care; the delays that patients faced due to the need to travel out of state often exacerbated their conditions. As one physician described:

"The patient presented in her home state for [abortion] care... and was turned away [because a law banning abortion recently went into effect]. It took six weeks to find an appointment, and she had to drive 10 hours to get to [state with abortion access]. As a result, she was mid-second trimester [16-18 weeks] when she presented. She has [more than 5] children at home and had severe postpartum cardiomyopathy when she gave birth a year ago, which has persisted. ... The risk of her dying from childbirth would have been extremely high-but she was unable to find anyone in her state willing to do the procedure. She had a routine D&E and went home, but at great personal sacrifice, as it was extremely difficult to leave with so many children."

Another physician described how the abortion ban in a patient's home state exacerbated her underlying mental health challenges by requiring that she travel out of state to get abortion care and spend additional time and money doing so:

"A [patient] came today seeking an abortion. She traveled on an airplane for the first time ever [from a state with an abortion ban], using her whole paycheck to buy tickets, rent a hotel. She left our clinic today by [emergency medical services], transported to the local [emergency department (ED)] for suicidal ideation. She was raped two months ago. Each episode of morning sickness causes [post-traumatic stress disorder (PTSD)] so intense she tried to take her life yesterday. If abortion was legal in her home state, several things would be different 1) she could have accessed an abortion more promptly 2) perhaps therefore she wouldn't have had an escalation of PTSD such that she tried to kill herself, [and] 3) she'd have more money in her bank account, super important given she's a single parent and her family who doesn't support abortion even in cases of rape, just kicked them both out. She did not get her abortion in our clinic today because she felt she was too emotionally unstable, that she wanted to go to the ED first. I fully support her decision to know herself best, and to decide for herself. I fear for her life, the ongoing pregnancy, her young child. I fear she won't have money to return and get her abortion. I fear she could kill herself first."



#### **Fetal anomalies**

Several submitted narratives described patients whose pregnancies were complicated by fetal anomalies, most of which were described as being incompatible with neonatal life. Termination was not possible in the states where the patients lived because their lives were not threatened (the only allowable exception to the abortion ban). Physicians described cases where patients who did not want to continue their pregnancies experienced delays of several weeks as they arranged care in a state where abortion was legal. One physician explained how complicated counseling these patients had become:

"[The] patient presented for her routine anatomy scan and a rare, lethal fetal anomaly was noted. [She] was referred to [a] higher level of care in another city for consultation and given [the] prognosis and likelihood of demise intrapartum or shortly after birth."

The physician explained how care for this patient would have transpired before *Dobbs*: "Prior to *Dobbs*... [the] patient could have had the option of D&E in our facility." Because of the state's abortion ban, however: "[She] was counseled at that facility about her options [which were] limited by state laws. [She] was given information for [an] abortion clinic out of state who could serve her, who she contacted. [The] patient was counseled that she would need to make [a] multipleday trip out of state for [the] procedure which would be performed by a doctor she did not know, and her husband would have to stay in the waiting room during the procedure. [She] would also have to coordinate childcare while she and her husband were gone. Someone also counseled the patient that there was a risk that someone could decide to sue her husband... for accompanying her and helping her get the abortion. There were also financial concerns. Given all of this, [the] patient and her husband decided to continue the pregnancy and will have an induction with her primary doctor, and her husband can be present with her. [The] patient said to me, 'It is really easy for doctors to suggest this (abortion), but they don't realize how hard it is.' ... It is frustrating that the patient had to consider so many nonmedical issues when deciding which plan of care she wanted."



#### **Early miscarriage**

Clinicians submitted several narratives that described cases related to early miscarriage care that was challenging in a state with an abortion ban. In one case, a patient recently had moved from a state where abortion was legal to a state with an abortion ban, where she was diagnosed with a miscarriage. The pregnancy tissue had not passed (also known as a missed abortion), but the health care professionals she sought care from declined to provide treatment because of the state's abortion ban. She opted to travel back to the state where she had lived previously and had "an uncomplicated manual uterine evacuation and returned to [the other state] 2 days later."

In another case, a patient living in a state with an abortion ban was diagnosed with a missed abortion and, following consultation with her physician, decided to use medications to hasten the expulsion process, which is a common approach to missed abortion. Her clinician explained why she was unable to follow this protocol:

"The pharmacy refused to fill the medication until they had confirmation of its use but was unable to list what that confirmation needed to include. The back and forth delayed the care and ultimately the client could no longer face attempting to pick up the medication and decided to utilize expectant management due to the trauma of being refused her prescribed treatment."

Other narratives described patients living in a state with an abortion ban who had bleeding while pregnant and were too scared to seek care in their home state due to the risk of criminalization. One clinician wrote: "The patient described how she has confirmed pregnancy with tests and ultrasound at her ob/gyn and then 1-2 weeks after the ob/gyn appointment she experienced symptoms of miscarriage and believed she passed the pregnancy. She was still having positive pregnancy tests and was worried that there might be retained tissue, so she scheduled with us in [state with legal abortion] to confirm that she didn't need further care or get a D&C if needed. After ultrasound evaluation and physician confirmation, it showed that she was no longer pregnant with no evidence of retained tissue or infection. But she had to fly out of state and get care for her other children in order to confirm this. She stated she was too scared to go to the hospital or her regular ob/gyn to confirm this due to current news and knowledge that her ob/gyn was openly religious and anti-choice. She had not necessarily been seeking abortion care for this pregnancy but was worried that the miscarriage would be misconstrued."



#### **Delays obtaining abortion care**

Several of the narratives involved cases of patients experiencing long delays obtaining abortion care because of bans in the state where they lived. Arranging care out of state was logistically complicated and expensive, and long wait times for appointments at out-of-state clinics created even longer delays. While delays in care certainly occurred prior to *Dobbs*, these submissions were notable for how long delays were due to congestion at the nearest clinics in surrounding states. One physician wrote:

"[An adolescent <15 years old] living in an abortion ban state told her mom... that she needed help. Because there are far more callers than appointments, it took her mom 7 weeks to get into the clinic where we saw her for an abortion [at 16-18 weeks' gestation]. The procedure was much harder on her than it needed to be—she was hoping for an at-home pill abortion."

In some cases, delays in care put abortion out of reach when a patient passed the gestational duration limit of the state. One narrative involved an adolescent under age 15 in juvenile detention in a state with an early abortion ban. She faced a number of barriers that delayed her care until later in pregnancy and was unable to travel out of state for care despite wanting an abortion. She went on to have the baby.

In some cases, patients forced to travel to another state for abortion care faced additional delays when their condition was found to be medically complex. Follow-up care was difficult when patients had to return home, sometimes before they were able to obtain the abortion. A physician explained one case: "[The] patient had to go out of state for a termination. Once there, imaging was concerning for an accreta [at 15-17 weeks' gestation]. She could not stay for an [ultrasound with a specialist] because she had to make her flight back to [state with abortion ban]. I was contacted by one of our family planning faculty who was in touch with the clinic out of state in order to do a scan for an accreta. It has now been 2 weeks and she has not been able to secure a ride to the ultrasound clinic to get this scan."

At the time of submission, the patient had still not had the abortion; if the placenta accreta were confirmed, abortion care with this condition later in gestation would be even more complicated than providing care earlier.



#### **Delays obtaining care unrelated to abortion**

Physicians submitted several narratives where bans on abortion limited medical care unrelated to pregnancy termination. One case involved a patient with a postpartum hemorrhage who needed a D&C, and labor and delivery staff initially refused to participate, stating that "D&Cs were now illegal for any reason." In another case, a patient's elective gynecologic surgery was postponed because of a remote possibility she might be pregnant and "concern about possible legal ramifications." In yet another case, an abortion ban led to the unnecessary cancelation of a patient's liver transplant. The submitting physician describes:

"Patient with... [an intrauterine device (IUD)] in place came in for liver transplant after there was a donor match found. On routine pre-surgical testing she had a positive urine pregnancy test, and her bHCG quant was in the 1000s. Her transplant was cancelled because of her positive pregnancy test despite it being an undesired, very early pregnancy."

In most settings where abortion care is legal, a uterine aspiration would be performed in this scenario either before or after the transplant to avoid delaying this life-saving surgery.

Another case involved a patient pregnant at 10-12 weeks' gestation with an IUD positioned in the cervical canal. In such a situation, the standard of care is to remove the IUD to reduce the risk of infection, miscarriage, and preterm delivery.<sup>7</sup> A physician in a state with an abortion ban described being consulted by another physician in a rural area more than two hours away. The patient was from Mexico, spoke primarily Spanish, and had limited financial resources. The physician who received the consult wrote: "The supervising physician called the next day... to discuss the case. Despite many years of pulling IUDs (in pregnancy and otherwise) and experience in [obstetrics], the doctor did not feel comfortable removing the IUD because it could cause a miscarriage. The context provided was concern over the recent changes in law that create [the] possibility for felony charges for providers causing abortion in our state shortly after the Roe decision was overturned. During a heated exchange, the doctor [said] the patient had... been examined by the nurse practitioner, who was unable to visualize the IUD, and that 'even if I could see it and it was easily removable. I wouldn't remove it because of the law.""



#### Discussion

These preliminary findings from the Care Post-Roe Study document a wide range of harm that is occurring among people with the capacity for pregnancy living in states with abortion bans. The large number of cases involving obstetric complications in the second trimester confirms findings from Texas showing how changes in practice after the state's 2021 6-week abortion ban were associated with a doubling of severe morbidity for patients presenting with preterm prelabor rupture of membranes and other complications before 22 weeks' gestation.<sup>8</sup> Our findings about the challenges treating ectopic pregnancy-particularly cesarean scar ectopic pregnancy-are very concerning, given clear recommendations for terminating these pregnancies to avoid serious complications and risk of death.<sup>6</sup> While this study is so far only able to collect information about immediate and shorter-term harms, it is likely there are also longer-term effects of being delayed and denied care for patients in situations similar to those described in the narratives. Longer-term effects could include loss of fertility and chronic pelvic pain due to infection or surgery. or heart attack and stroke related to uncontrolled hypertension, as well as effects on mental health.

In addition to documenting serious and immediate health risks experienced by pregnant patients, the cases presented in this report also provide evidence of the emotional and financial costs of being denied care close to home in the post-Dobbs era. These burdens were made more severe when they were overlaid upon the complex situations in which these patients found themselves, including being pregnant with a fetus with anomalies incompatible with life, having limited financial resources, or being a young adolescent. The logistical challenges were particularly acute for those who had to arrange care for their children, get time off work, or pay for travel to a distant state. While it is the patients in these narratives who faced risks to their health from care denied or delayed, it is clear that the clinicians who care for these patients are also suffering. Health care providers described feeling moral distress when they were unable to provide evidence-based care that put their patients' health at risk, as well as frustration about the additional work involved in trying to find options for care in other states. In some cases, the dissatisfaction was so extreme that clinicians considered moving to a state with fewer restrictions on care. In addition, health care providers highlighted how these restrictions on care increased resource utilization, both by increasing the cost of services, particularly for treating complications, as well as by diverting clinician time away from other patients.

This project is primarily gualitative and aims to describe the range of scenarios that health care providers are facing post-Dobbs. We cannot estimate the incidence of these deviations from the standard of care, nor can we draw conclusions about patient characteristics associated with these scenarios. That said, it is important to note that these are not "one-off" situations, and each category of clinical scenario was described by more than one clinician. Similar scenarios were reported in many of the states that have imposed new restrictions on abortion care since the Dobbs ruling. Given that reproductive harms disproportionately affect people of color in the US,<sup>9</sup> it is also notable that patients described as Black or Latina/Latinx/Hispanic, as well as those who primarily speak Spanish, account for about half of all cases in our analysis.

These narratives identify scenarios where clearer guidance from professional medical and nursing organizations, as well as state medical boards and hospital and clinic systems, could help to reduce delays and to improve access to care for patients in states with bans. However, it is unlikely that clinician



confusion will be eliminated by simply making a list of conditions that would be considered acceptable exceptions to the bans. Instead, clinicians must be trusted to use their medical judgment to provide appropriate evidence-based care to their patients so as to prevent a patient's condition from escalating to the point of a medical emergency, and they should not face the risk of being legally prosecuted for doing so.



## Table. Characteristics of patients inCare Post-Roe narratives

Patient characteristic	n (%)
Age (years)	
Under 18	2 (4%)
18-24	19 (38%)
25-30	14 (28%)
31-35	9 (18%)
36-40	5 (10%)
Missing/not known	1 (2%)
Race/ethnicity	
Asian	1 (2%)
Black	11 (22%)
Latina/Latinx/Hispanic	12 (24%)
White	18 (36%)
White and Latina/Latinx/Hispanic	1 (2%)
Missing/not known	7 (14%)
Primary language	
English	44 (88%)
Spanish	6 (12%)
Clinical scenario	
Obstetric complications in the second trimester	18
Preterm prelabor rupture of membranes	11
Bleeding	2
Inevitable pregnancy loss	3
Hypertension	2
Ectopic pregnancy	8
Underlying medical conditions complicating care	3
Fetal anomalies	7*
Miscarriage early in pregnancy	4
Delays obtaining abortion care	6
Delays obtaining care unrelated to abortion	4

\*An additional patient pregnant with a fetus with anomalies developed hypertension and is counted in that category.





#### **Methods**

We solicited narratives for the Care Post-Roe Study by posting on listservs, community forums, and social media accounts that target health care providers. Interested participants accessed a Qualtrics survey to submit their narratives at http://carepostroe.com, which redirects to https:// carepostroe.ucsf.edu on the University of California San Francisco (UCSF) server.

Participants confirmed their eligibility and provided informed consent, after which they provided information about the case that would not identify them or the patient. After submitting the narrative, participants were invited to participate in an in-depth interview. If they were interested in the interview, they were taken to a separate Qualtrics survey that was not linked to their narrative submission to leave their preferred contact information. Interview findings are not included in this report. We did not remunerate participants for submitting cases or completing an interview.

Submissions that did not contain information about a specific case or did not pertain to a change in care since the *Dobbs* ruling were excluded from the analysis. Two physicians reviewed each submission and categorized the clinical scenario. Frequencies of variables were calculated in Excel. Representative quotes from the narratives were selected for this report to describe the range of scenarios submitted by study participants. The study was approved by the UCSF Institutional Review Board. Data collection is ongoing.

### Glossary

- **Bacteremia:** a condition in which bacteria enter a patient's bloodstream
- Cesarean scar ectopic pregnancy: a pregnancy that implants in the scar of a previous cesarean section
- **Creatinine:** a waste product of metabolism that is filtered by the kidneys; an increasing creatinine level may indicate worsening kidney function
- Dilation and curettage (D&C): a procedure to remove the contents of the uterus, usually up to 13-15 weeks' gestation, to treat miscarriage or to perform an abortion; D&C is also used to remove retained products of conception, placenta, or blood in the setting of postpartum hemorrhage
- Dilation and evacuation (D&E): a procedure to remove the contents of the uterus, usually after approximately 15 weeks' gestation, to treat fetal demise (miscarriage) or to perform an abortion
- Disseminated intravascular coagulopathy (DIC): a life-threatening condition where blood clotting factors are depleted, often caused by heavy bleeding and leading to more bleeding
- Ectopic pregnancy: a pregnancy that implants outside of the endometrial cavity of the uterus, most commonly in the fallopian tube
- Expectant management: a management approach characterized by close observation, rather than medical or surgical treatment
- Gravid hysterectomy: surgical removal of the uterus in pregnancy (often performed due to life-threatening bleeding or very high risk of such bleeding)
- Heart tones: cardiac activity of the fetus indicating that the fetus is living
- HELLP (hemolysis, elevated liver enzymes, and low platelets) syndrome: a severe form of preeclampsia that involves the breakdown of red blood cells (hemolysis), liver dysfunction, and low platelets. This is a life-threatening complication of pregnancy.
- **Hemodynamically stable:** a patient's blood pressure and heart rate are stable

- Human chorionic gonadotropin (bHCG, HCG, or bHCG quant): the hormone that is released by an early pregnancy. The HCG level increases in a predictable fashion with a normal pregnancy as it develops; abnormal changes in HCG level may be indicative of a miscarriage or ectopic pregnancy.
- Hydrops: a condition where a fetus has abnormal build-up of fluid in areas such as the chest or abdomen, which could eventually lead to the death of the fetus
- Induction or induction termination/abortion: a procedure where medications are given to induce labor to deliver the fetus and placenta, usually at 16 weeks of pregnancy or later
- **Inevitable abortion:** a patient is experiencing bleeding in pregnancy and their cervix is open
- **Intrapartum:** the time frame during which a pregnant person is in labor
- Intrauterine device (IUD) positioned in the cervical canal: a displaced IUD that is located in the cervix and no longer effective at preventing pregnancy
- **Intubated:** having a tube inserted in the trachea to assist in breathing when the patient is unable to breathe on their own
- Manual uterine evacuation: a technique to perform an abortion or to treat a miscarriage using a hand-held suction device
- Medication abortion (or pill abortion): an abortion using either mifepristone and misoprostol or misoprostol only
- **Methotrexate:** a medication used to treat an ectopic pregnancy
- Mirror syndrome: a rare and dangerous syndrome involving excess fluid levels in the fetus, placenta, and pregnant person. This occurs in pregnancies complicated by fetal hydrops; the pregnant person may then develop abnormal fluid levels (often in vital organs like the lungs and around the heart), high blood pressure, abnormal liver or kidney function, and potentially neurologic symptoms. This brings with it a high rate of intrauterine fetal death (over 50%) and maternal morbidity.<sup>10</sup>



- 22
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- Missed abortion: a miscarriage in which the • pregnancy is in the uterus, and there are no signs of it being expelled; this may be treated with medications, such as mifepristone and misoprostol, or with uterine aspiration
- Near-miss: Serious error or mishap that has the potential to cause an adverse event but fails to do so because of chance or because it is intercepted<sup>11</sup>
- Periviable: the time period between 20 weeks and up through the 25th week, around the point of viability. Twenty-two weeks is generally considered the earliest gestational duration at which survival is possible. The fetus is not expected to survive without resuscitative efforts and significant medical support.<sup>12,13</sup>
- Placenta accreta: a condition where the placenta is abnormally attached to the uterus and growing into the muscle of the uterus, which can lead to life-threatening bleeding and usually requires treatment with a hysterectomy (surgically removing the uterus)
- Placenta percreta: a condition where the placenta • is abnormally attached to the uterus and growing through the uterine wall, into surrounding organs or structures, which can lead to life-threatening bleeding and usually requires treatment with a hysterectomy (surgically removing the uterus)
- Postpartum cardiomyopathy: a condition where a pregnant person develops heart failure in the last month of pregnancy up to 5 months postpartum, without another identifiable etiology, and characterized by failure of the left ventricle to pump blood in a manner needed to sustain the body, causing death in up to 10% people who develop the condition. There is a high rate of recurrence in future pregnancies (about 20-50%). The risk of death is even higher if a person with signs of ongoing heart strain becomes pregnant again.14,15
- Postpartum hemorrhage: heavy bleeding in pregnancy after delivery of the baby

- Preeclampsia: a condition characterized by elevated blood pressure and protein in the urine of a pregnant person that usually develops in the later second trimester, with the potential to cause damage to multiple organs
- Pressors: medications used to increase blood pressure when a patient's blood pressure is dangerously low
- Preterm prelabor rupture of membranes (PPROM): a condition where the pregnant person's amniotic sac (bag of water) breaks prior to 37 weeks' gestation, and prior to the onset of labor. Delivery occurs within one week of PPROM in 50% of patients.16
- Previable: a term used to denote the time period where a fetus would be unable to survive on its own outside of the pregnant person's body
- Retained tissue: pregnancy tissue that is left inside of the uterus after a miscarriage or abortion
- Sepsis: the body's extreme and life-threatening response to an infection. Sepsis happens when an infection triggers a chain reaction throughout the body that can rapidly lead to tissue damage, organ failure, and death.<sup>17</sup>
- Threatened abortion: a patient is experiencing bleeding in pregnancy and their cervix remains closed
- Uterine artery embolization: a treatment performed by interventional radiologists to block one or both main arteries to the uterus, therefore reducing blood flow to the uterus and reducing the risk of bleeding in a variety of settings, including when the placenta has grown deeply into the wall of the uterus



# Appendix: Current standard of care for management of selected conditions

**Preterm prelabor rupture of membranes (PPROM):** Up to 35% of pregnant people with PPROM develop infection intrapartum and up to 25% develop infection postpartum. Up to 5% will develop abruption (bleeding between the placenta and uterus which can be life-threatening for the pregnant person and fetus when severe). Effects on the fetus depend on the gestational duration at which PPROM and delivery occur but can include severe neurologic dysfunction and underdevelopment of the fetal lungs. Standard of care depends upon gestational duration and the health status of the pregnant person and fetus. If signs of fetal compromise are present (concerning fetal testing), infection develops, or an abruption occurs, delivery is recommended for the safety of the pregnant person and baby. Standard of care for periviable PPROM involves offering counseling regarding the expectations for long-term prognosis, often with support from the maternal-fetal medicine and neonatology teams; offering a D&E, an induction termination, or expectantly managing the patient unless or until health concerns arise in the pregnant person (such as infection or abruption); and considering a course of multiple antibiotics for a total of 7 days while closely monitoring for signs of infection (as early as 20 weeks, through 23-24 weeks).<sup>16</sup>

**Vaginal bleeding:** The management of vaginal bleeding in pregnancy depends on the gestational duration, amount of bleeding, and pregnancy desires. If bleeding is significant and a threat to the pregnant patient's life or health, prompt delivery (if at viability) or uterine aspiration or evacuation should be recommended if previable, as appropriate; within the periviable period, the patient should be offered both options of delivery or termination. The cause of bleeding should be investigated and treated.

Preterm labor: Preterm labor occurs when regular contractions and a change in cervical dilation or effacement (i.e., how dilated or thin the cervix is), or when regular contractions and dilation to 2 cm, occurs after 20 weeks and before 37 weeks of pregnancy.<sup>18</sup> Standard of care for preterm labor involves consideration of gestational duration. Likely short-term and long-term prognosis should be discussed with the pregnant person. All efforts should weigh potential benefits to the fetus against potential harm to the pregnant person. The pregnant person should be offered the option of pregnancy termination for an anticipated periviable birth. If continuing the pregnancy is desired, the patient should be transferred to a hospital that can accommodate resuscitation and care for an extremely premature newborn. Prior to 22 weeks, neonatal resuscitation efforts are not standard of care and are not recommended; assessment for likelihood of effective resuscitation efforts are considered beginning at 22 weeks, and are recommended beginning at 24 weeks. However, a patient's or family's personal values may not align with resuscitative efforts at this gestational age in favor of comfort care. For context, recent studies have found that babies born in the 22nd week of pregnancy have a 97-98% mortality rate, and only a 1/100 chance of having a life without severe neurologic impairments.<sup>12</sup>



**Severe pregnancy-induced hypertension:** Preeclampsia and gestational hypertension are pregnancy-induced hypertensive disorders that may occur as early as the later second trimester. Both can lead to significant organ damage and are managed similarly. For pre-eclampsia with severe features, delivery at 34 weeks is recommended. Prior to 34 weeks, if the pregnant person and fetus are stable, expectant management is offered with close monitoring of blood pressures, lab values, and symptoms of progression of the disease. Expectant management is not standard of care when the disease is severe, including in cases of HELLP syndrome, and there is a threat to the life of the pregnant person, if fetal testing is abnormal, or if the fetus is not expected to survive.<sup>19</sup>

**Cesarean scar ectopic pregnancy:** Standard of care is to recommend termination due to the exceedingly high risk to the pregnant person's life, including uterine rupture, developing placenta accreta spectrum, or having life-threatening bleeding. The ectopic pregnancy may grow within the uterus or into the abdomen. While the optimal approach for management is not known, it is clear that expectant management does not have a role in therapy, with the possible exception of early pregnancy loss or demise. However, even in the case of pregnancy loss or demise, expectant management has been associated with arterial-venous malformations (abnormal communications between blood vessels that can lead to life-threatening bleeding). Management options include surgical (laparoscopic or transvaginal resection, or uterine aspiration under ultrasound guidance) or medical approaches (including intra-sac methotrexate or compression of the pregnancy with a foley balloon).<sup>6</sup> If a patient develops placenta accreta spectrum (which includes placenta percreta), delivery usually requires cesarean section followed immediately by hysterectomy, which is often complicated by severe hemorrhage.<sup>20</sup>



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