

Establishing Vigilant Care

Data Infrastructures and the Black Birthing Experience

by Joan Mukogosi

DATA & SOCIETY



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Executive Summary

In the United States, Black birthing people face disproportionately high rates of pregnancy-related deaths, and these rates continue to *increase* over time. Set against this backdrop, many of the most prominent interventions in birth-related care rely on forms of intensified data collection. The electronic health records used by hospitals, access to Medicaid and other forms of insurance — even new at-home femtech products — are all based around voluminous data collection. This reliance on data, however, overlooks the risk of its incorporation into carceral systems that monitor, constrain, and discipline Black individuals — a risk exacerbated by a post-*Dobbs* climate of increasingly restrictive reproductive health policies.

If existing technologies are underserving Black birthing people, both in terms of health outcomes and also the risk of exposure to carceral systems, then what is the alternative? How might digital technologies meant to improve health outcomes for Black birthing people actually accomplish their goals?

This report investigates these questions through extensive interviews with maternity-care professionals, including clinicians, midwives, doulas, and other support staff for a range of birth venues. I've spoken to people who work in hospitals, at birth centers, and who support home births, to understand the role data plays in Black birth outcomes.

This report identifies a specific subset of maternity-care professionals — **Black-centered birth workers** — who not only provide prenatal care for Black birthing people, but also incorporate an awareness of obstetric racism into their work. The result is a form of vigilant practice, which protects Black birthing people from potentially harmful experiences of data collection and guides them through institutional encounters with special care to the carceral realities of birthing technologies.

Understanding this subversive practice, and the forms of negotiation required to support Black birthing people, also reveals how existing attempts at providing independent data tools — most notably bespoke electronic health records and at-home femtech products — are unlikely to address the underlying risks of carceral data collection.

Introduction

We are in the midst of a crisis: Black women are dying from preventable pregnancy-related complications at three to four times the rate of white women — a trend that has worsened over time.¹ Navigating a system that can be hostile to their health, Black pregnant people are forced to make crucial decisions about childbirth during this perpetual emergency. Black birthing people's choices about their experiences — where and from whom they receive care, types of pain management, interventions in case of a crisis during labor — occur under a context of deadly risk, dismissed fears, and systems of control. These life-and-death scenarios are far too common. Famously, even Serena Williams faced near-death postnatal complications that were made worse by medical staff who repeatedly dismissed her cries for medical intervention² — a high-profile instance which implies the dire state of birth care for Black patients.

As these racial disparities persist, Black pregnant patients' experiences are datafied in a number of ways. Across the board, pregnancy and childbirth involve comprehensive data collection. Providers gather patient data through conversations and medical instruments during clinical encounters, and enter it into electronic health records (EHRs). Attending patients' holistic needs, doulas and midwives collect data about patients' preferences. Insurance programs — most notably Medicaid — gather demographic and population health information. At home, patients can collect their own data using remote patient monitoring devices and femtech apps. Yet for Black pregnant patients, these instances of data collection carry gendered and racialized consequences that place them at risk for harm — including inequitable health outcomes and forms of criminalization.

This report places the specific risks that digital health technologies introduce at the forefront of considerations about where, how, and by whom maternity care is delivered to Black birthing people.

Through an investigation of birth workers' use of digital health technologies, this report identifies friction between technological and human infrastructures. I examine three sites of data collection — the EHR, Medicaid insurance, and femtech devices — that proliferate in the maternal health ecosystem. Patient data collected through these sites carry the potential of reducing maternal health disparities by minimizing implicit bias, improving clinical decision-making, and increasing patient engagement and access to care.³ Yet, I argue that these interventions also expose Black patients to carceral systems, create information silos where interoperability is desired, and fail to meet basic privacy standards.

By considering the ways digital health technologies shape birth work and how birth workers shape digital technologies, this report reveals methods of constructing and obfuscating health information systems. It confronts how systems of classification marginalize, pathologize, and even criminalize Black birthing bodies, and how datafication is embedded in these processes — inside and outside of the medical system. This report reckons with these harms to raise a critical question often overlooked when considering solutions to the Black maternal health crisis: How might digital technologies meant to improve health outcomes for Black birthing people be producing new forms of harm?

This report is the result of a months-long study of how experts who are invested in improving maternal health outcomes think about and operationalize digital technologies in their work. I examine how birth workers — both clinical and nonclinical maternity experts — perform data work through the use of digital objects in different care contexts: the hospital, the birth center, and the home.

To understand how birth workers navigate the digital infrastructure in each of these care contexts, I interviewed physicians, midwives, doulas, and health informaticists from across the United States who are responsible for managing EHRs, administrating birth centers, developing digital health tools, and teaching patients about their data. I also attended conferences that gathered birth workers and femtech developers to discuss the future of maternity care in an increasingly data-driven world. These methods are supported by health equity, science and technology studies, and Black feminist literature that examines how birth workers use digital health technologies and their impact on Black birthing people. They also emphasize the need for further research into the potential for these tools to improve maternal mortality.⁴ This multi-pronged approach offers insight into how different clinical contexts and their associated forms of data collection affect how care is delivered to Black birthing people by different birth workers.

In the midst of a revolution of digital health technologies designed for women, my research shows that these innovations expose Black birthing people to additional forms of carcerality. It is this reality that has led Black-centered birth workers to adopt a vigilant practice that constantly negotiates the benefits of data collection against their capacity for harm. The result is care relationships that are designed to protect and care for not only Black birthing people's bodies, but also their data. In addition, I show that these same risks apply to the current rise in at-home femtech, which do not promise a meaningful escape from larger carceral systems. To address the critical systemic failures that affect Black pregnant people, data collection practices that affirm their dignity and promote their safety — as exercised by Black-centered birth workers — must become a reproductive justice imperative⁵.

Background

Obstetric Racism and the Black Maternal Health Crisis

The United States has long been a negative outlier in maternal and infant mortality — a crisis driven by the disproportionate deaths of Black mothers.⁶ Black women are dying from preventable pregnancy-related complications during pregnancy, labor, and up to a year postpartum, at three to four times the rate of white women.⁷ Despite advancements in medical care, maternal deaths continue to rise and racial disparities persist.⁸

Research shows that neither socioeconomic status nor education put a dent in the risk that Black people face during childbirth, indicating that the defining feature of this crisis is a combination of systemic racism and sexism.⁹ Ranging from individual cases of physician bias and mistreatment to broader systemic factors such as weathering — the detrimental health effects of cumulative socioeconomic stress — Black birthing people face a matrix of threats to their health.¹⁰

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In this report, I focus on “obstetric racism,” a germinal term developed by anthropologist Dána-Ain Davis to describe the threats to Black maternal health that persist in the “afterlife of slavery.”¹¹ Davis defines obstetric racism as the combination of obstetric violence, “a form of gender-based violence experienced by people giving birth who are subjected to acts of violence,” and medical racism which occurs when “the patient’s race influences medical professionals’ perceptions, treatments and/or diagnostic decisions.”¹² Although obstetric racism describes acts of abuse and lapses in judgment, it speaks to the systemic failures that place the Black birthing body at risk of harm. This report approaches obstetric racism not just as it is enacted through physical violence, but also through the epistemic and numerical violence that codifies the subjugation of Black

motherhood as an inescapable fact. In other words, this report pays close attention to the ways datafication is implicated in obstetric racism.

Extending the frame of obstetric racism into health data infrastructures, I consider the way the Black birthing body is numerically contained and constrained by medicine and technology by examining birth workers' and technologists' methods to manage and navigate these systems. I propose that, through their work to improve Black maternal health outcomes, these experts also confront the presence of obstetric racism in health data as it is captured in information systems and as it organizes their labor.

Black Maternity Is Not a Monolith

Although the Black maternal health crisis speaks to systemic inequities that affect all Black birthing people, every pregnancy is different. Despite the overwhelming attention on Black birthing experiences that go wrong, Black families do have safe, healthy, and happy birthing experiences. Similarly, birth workers' practices and experiences vary. While some birth workers are aware of racial disparities in maternal health, and shape their care to address these disparities, others do not take up this mission. With this understanding, this report centers the work of healthcare professionals and technologists who are dedicated to improving Black maternal health. This focus is informed by Black feminist theory which asserts that because Black women face interlocking systems of oppression, focusing on their liberation will also liberate other oppressed people.¹³

Finally, the relegation of Black trans, non-binary, and queer people, and their experiences with childbirth to the margins of discourse, research, and care is also a key feature of obstetric racism.¹⁴ In an intentional effort to uplift queer experiences and reject their displacement from narratives about Black maternal health, I use the term "Black birthing people" to describe the subjects of this report: Black people who are attempting to conceive, are pregnant, or have given birth. I use this language to explicitly affirm the experiences of Black people who do not identify as cisgender women, or who have same-sex partners, and counteract the idea that their experiences are not central to issues of racism and sexism. Most research on the Black maternal health crisis is conducted on or about Black people who identify as women. For this reason, when referring to research that uses gendered terms such as "women" or "mother," I will adopt those terms.¹⁵

The Death Toll Becomes the Source

I use the crisis of Black maternal health and the disproportionate death rates for Black birthing people as the foundation for my analysis, but relying on such statistics is not without consequence. Focusing our attention on the collection, analysis, and dissemination of data on Black maternal mortality absolves the role of systemic failures in producing this crisis.¹⁶ While we wait for more data to measure maternal health disparities, the systems that produce these disparities continue to operate, despite existing proof of failure.¹⁷ Relying on mortality data as the starting point for interventions can also have the unintended effect of making the death toll the most accessible source of knowledge about Black birthing people.¹⁸ This focus fixes the Black birthing body in a state of perpetual crisis and turns Black birthing people into a problem to solve.¹⁹

At the same time, it is impossible to ignore the value of making the public aware of the severity of the Black maternal health crisis. Several interviewees for this study referenced Linda Villarosa's

reporting on the stories of Black infant and maternal mortality in 2018 as a catalyst for greater attention to the work they had been doing to improve outcomes.²⁰ In the time since Villarosa's article, social pressure stemming from the COVID-19 pandemic and the simultaneous resurgence of the Black Lives Matter movement resulted in increased material support from the US government for resources to improve Black maternal health. The Centers for Disease Control and Prevention is funding Maternal Mortality Review Committees for state and local governments; anti-bias training for healthcare providers is now mandated in some states; in 2023, the Health Resources and Services Administration announced nearly \$90 million in awards for multi-level interventions.²¹ Despite greater attention and more resources, the maternal mortality rate, counted as deaths per 100,000 live births, continues to increase year after year. According to the most recent data, the maternal mortality rate for Black women in 2021 was 69.9, compared with a rate of 44 in 2019.²²

Carceral Institutions and Reproductive Control

A key organizing feature of obstetric racism in digital health systems is that it captures health information about Black birthing people in connection with larger carceral institutions. Dating back to slavery, carceral institutions operated by the state single out Black mothers as targets for criminality and reproductive control. Black maternity became a focal point for the continued subjugation of Black people through reproductive violence including rape, forced sterilization, and the indiscriminate separation of families. This systematic and institutionalized assault on reproductive rights is a defining feature of gendered and racialized violence against Black women in the United States that persists in the criminal legal system, immigration enforcement, and child protective services.²³

Digital health technologies perpetuate this assault on the reproductive rights of Black people through the weaponization of clinical encounters and personal health data. Far from neutral pieces of biomedical information, health data captured in clinical notes, stored in EHRs, and documented in health apps, are crucial modes by which reproductive health is both racialized and criminalized.²⁴

The abysmal state of health care for Black birthing people renders them hypervisible as dead and dying and invisible as human beings deserving of the joy of pregnancy. This dynamic stems from slavery and the middle passage. Terroristic efforts to strip enslaved Africans of their personhood during the middle passage included gendered violence. As Hortense Spillers explains, “the African female subject, under these historic conditions, is not only the target of rape- in one sense, an interiorized violation of body and mind - but also the topic of specifically externalized acts of torture and prostration that we imagine as the peculiar province of male brutality and torture inflicted by other males.”²⁵ Slavery further transformed the category of Black women. Treated as both property themselves and the producers of property through childbirth, Black women “became the principal point of passage between the human and the non-human world.”²⁶

This layered dehumanization of enslaved women serves as the foundation for modern obstetric medicine. J. Marion Sims, known as the “Father of Gynecology,” infamously tortured enslaved women by conducting medical experiments and performing surgeries without anesthesia.²⁷ Although enslaved Black women were regarded as “less than human,” the result of their suffering is seen everywhere — including the founding of modern medicine — yet is rarely acknowledged. In other words, by treating Black women as “a living laboratory,” their pain is diminished as an ordinary feature of progress.²⁸ Although this form of American chattel slavery no longer exists, Black birthing people and Black people writ large, live in the afterlife of slavery — “skewed life chances, limited access to health and education, premature death, incarceration, and impoverishment.”²⁹

The experience of interacting with technologies can be considered carceral in two distinct, yet related ways. The first is functionally, in which a technology enacts the same logics as carceral settings — that is, to constrain, surveil, and discipline. When obstetric technologies enact these logics into the care context of a Black birthing person — preventing certain actions, recording behavioral data, or delivering punishments — they serve a carceral function. Further, a technology can become functionally carceral not only through the specifics of its design, but also through the experiences of those birthing people who must interact with them. So while a regime of data collection might function as state-of-the-art care for some birthing people, the same system can be functionally carceral for others.

Second, obstetric technologies can be literally carceral, connected to other existing structures of social control. Data collected during clinical encounters can be made available to government agencies and forms of law enforcement in ways that criminalize and discipline Black birthing people — literal imprisonment, separation of birthing person and child, and introduction into other forms of surveillance. As a result, data gathering in clinical settings can render Black birthing people hyper-visible to carceral systems, thus adding a layer of risk to these encounters.

The 2022 *Dobbs v. Jackson* Supreme Court decision that resulted in the overturning of *Roe v. Wade* has fueled ongoing racialized assaults on reproductive rights. To date, 14 states have enacted total bans on abortion access, placing patients and providers at risk of prosecution for undergoing or performing abortion services.³⁰ Many of these bans are in southern states where more than half of the nation’s Black population resides. Little to no access to abortion services in communities of color are compounded by lower rates of health insurance coverage and limited access to quality care.³¹ Depending on which state a patient seeks abortion care, all forms of digital documentation about terminated pregnancies, including internet searches, text messages, health records, and data from health apps, are subject to legal scrutiny. This threat of surveillance compounds the real-time hardships of existing in a pregnant body while seeking to terminate the pregnancy.

By detailing the various ways that data about Black birthing people are made vulnerable to state and local agencies, I take on Ruha Benjamin’s call to “remain attentive to the many forms of subversion and resistance” to carceral imaginaries that are enacted in health care.³² I highlight the methods of evasion, compromise, and refusal that birth workers develop as they seek to protect themselves and their patients from potential harm.

Birth Workers as Health Data Infrastructure

In the wake of this spectacle of Black maternal health disparities, the looming threat of carceral control, and thousands of lives lost, the burden of action is placed upon those who are living. Prospective Black parents face a deluge of information that predicts unhealthy pregnancy, horrendous childbirth experiences, unwell infants, and postpartum dangers, erasing the joy of pregnancy no matter their proximity to privilege. This is the future that our current data-driven understanding of the Black maternal health crisis gives to Black birthing people — a sociotechnical imaginary defined by death, dying, violence, incarceration, and mistreatment.³³ This is also the future that birth workers and other advocates for Black birthing people are tirelessly working to prevent.

Birth workers are delivering vital maternal care within a healthcare ecosystem that is filled with gaps. In the United States, the kind, quality, and cost of healthcare services vary, depending on systemic

factors such as insurance coverage, broadband access, and proximity to care. These systemic factors are in turn influenced by socioeconomic factors such as race, gender, income, and location. As a result, people who experience multiple marginalities — such as Black birthing people — often slip into the cracks where care becomes carceral. Navigating this disparate infrastructure can be challenging, placing the onus of filling the gaps in care on individual choices, rather than by addressing institutional harms. By focusing on individual attempts to navigate these gaps, I hope to synthesize a broader approach to addressing the data collection practices that harm Black birthing people.

To achieve this, I highlight the voices of clinicians, midwives, doulas, and technologists as they describe their use of digital technologies in their work. In the tradition of infrastructure studies, I extend the notion of infrastructure to these experts, using their varying proximities to structure their roles in and outside of the medical system. In particular, I draw upon AbdouMaliq Simone’s conceptualization of “people as infrastructure,” which focuses on sites where objects, spaces, persons, and practices intersect.³⁴ Researchers have since turned to the intersections between technological and human infrastructures, revealing a reflexive relationship in which technology mediates social relations and, in turn, humans respond, adapt, and shape technology.³⁵ Research on human and technological infrastructures in maternity care demonstrates that medicine is a profession ripe for inquiries into this reflexivity.³⁶

Infrastructures of Care

The United States has a patchwork healthcare system in which insurance coverage, access to providers, and available services vary by state and by person.³⁷ Each site of care has different benefits and risks for Black birthing people and each type of birth worker provides different services, producing a spectrum of care settings and professionals that range from highly medicalized to decidedly separate from medical institutions. As a consequence, each Black pregnant person's care is affected by where their care is delivered, who is delivering it, and — crucially — how care is digitally documented within racialized contexts.³⁸

At hospitals, patients receive institutionalized medical care from a team of clinicians. In the home, patients can receive non-medicalized care from midwives and doulas whose care is attentive to patients' holistic needs. Birth centers occupy an in-between space where patients can receive medical care while retaining some distance from medical institutions, unless complications that require specialized intervention arise. Birth workers traverse each of these care contexts. Clinicians typically operate in hospitals and birth centers, while midwives and doulas work at all three sites of care. For Black birthing people, access to care that is attentive to their specific needs is vital.³⁹ This report focuses on the work of Black-centered birth workers, who provide this much-needed care by helping Black birthing people navigate interactions with other birth workers at each site of care.

Where Is Care Delivered?

The vast majority of births in the United States take place in a hospital. This wasn't always the norm. Before the twentieth century, childbirth mostly happened in the home and was attended by midwives. The formalization of medical training and the development of anesthesia contributed to a shift toward medicalized childbirth that saw more than 98 percent of births happening in hospitals as of 2017.⁴⁰ Hospitals are equipped to treat complicated, high-risk pregnancies, with access to the tools and expertise to address emergencies quickly and comprehensively. However, hospitals also carry risks for Black patients.

Hospitals have historically been a site of anti-Black, misogynistic, and obstetric racism.⁴¹ Today, increased attention toward the Black maternal health crisis is shining a light on instances of obstetric violence and medical racism in hospitals that contribute to adverse birth experiences and outcomes.⁴²

As an alternative to the hospital, birth centers provide birthing people with a childbirth experience that is integrated with the healthcare system, while retaining close relationships with providers and flexible access to services.⁴³ Birth centers are healthcare facilities that specialize in childbirth. They operate under regulations that dictate the scope of care, staffing, facility standards, and services by state. Some birth centers qualify for reimbursement under Medicaid, while others rely on grant funding or private insurance. As of 2018, only 33 states allow Medicaid to cover birth centers, and some enforce explicit stipulations on what kinds of care can be delivered.⁴⁴

Some birth centers operate in partnership with hospitals, while others are designed to create a distinctly nonmedical environment where birth workers provide more holistic care. However, as one doula interviewed for this study warned, “just because it’s not in a hospital doesn’t mean you’re not going to get treated like you’re in a hospital.” According to data collected by Birth Center Equity — a nonprofit that works to expand access to BIPOC-led birth centers — as of 2020, less than five percent of the nation’s birth centers are led by people of color.⁴⁵ Some birth centers can also transfer patients to the hospital if complications arise.

The COVID-19 pandemic introduced temporary restrictions on in-hospital births, upending birth plans and introducing new factors for pregnant patients to consider. These new considerations, combined with the fear of contracting COVID-19, caused a spike in out-of-hospital births at birth centers and at home.⁴⁶ Home births allow patients to maximize the amount of control they have over their childbirth experience. Often attended by midwives or doulas, people opting for a home birth are free to invite their support systems and use nontraditional methods of inducing labor. As this report will demonstrate, just because a patient decides to receive care at home, they are not entirely free from datafication.⁴⁷

Who Is Delivering Care?

The term “birth workers” encompasses clinical and nonclinical maternity experts, including obstetrics and gynecological physicians, labor and delivery nurses, midwives, and doulas. Within this group of workers, clinicians are a distinct category of medical professionals who provide direct patient care using a recognized knowledge base from a specific medical discipline.

In response to the rising Black maternal health crisis and medical institutions’ role in perpetuating it, some have turned to doulas and midwives as a solution. Doulas are care workers who provide holistic support to birthing people throughout every stage of pregnancy. Midwives are clinical health workers who also care for birthing people throughout their pregnancy and postpartum. The scope of doula and midwifery care includes helping pregnant people make informed decisions about their care, curating a birth plan, advocating for these decisions, and performing medical practices to improve birth outcomes. While doulas and midwives often attend births in hospitals, they also operate in the home and in birth centers.

Certified nurse midwives are licensed healthcare providers who complete training on rendering obstetric and gynecological services, while lay midwives practice without official certification. Like lay midwives, doulas complete training through formal and informal accreditation processes, ranging from well-established training programs to one-on-one apprenticeships. As the doulas interviewed for this study noted, formal certification is not a requirement — doulas can be a friend or family member and can assist clients through other life transitions such as grief, abortion, or adoption.

Doulas and midwives faced more than a century of organized attacks against their expertise, despite a track record of minimizing poor outcomes for Black births. Lay midwives were the standard birth attendants for pregnant people up until the early nineteenth century when growing enrollment in medical schools spurred an expansion of the medical industry. In the early twentieth century, the American Medical Association began a systematic campaign to delegitimize lay midwives' expertise.⁴⁸ Through media campaigns designed to sow mistrust in midwives, and legislation that required midwives to be licensed and limited their scope of work, lay midwifery was effectively eliminated in favor of a white, male-dominated field of obstetrics.⁴⁹ The legacy of this systematic erasure reverberates through modern midwifery. As of 2023, eight percent of certified midwives identify as Black.⁵⁰

Increased attention toward racial disparities in maternal and fetal health has ushered in a resurgence of doulas and midwives as vital elements of care teams for Black birthing people. While it is common to see midwives and doulas represented as anti-hospital, in reality, they work closely with hospital systems — as employees and as birth attendants for their clients — and their decades-old practice still informs the way babies are delivered in hospitals.⁵¹

Black-centered Birth Workers

Black pregnant patients seek care from midwives and doulas instead of, or alongside, care from medical institutions because they deliver trustworthy, holistic care that other medical providers have historically failed to provide. These birth workers are particularly meaningful for Black birthing people for whom a dedicated advocate can positively affect the quality of care they receive.⁵² However, not all birth workers place Black birthing people at the center of their practice. Cultural competence is not a prerequisite for birth workers and some birth workers echo obstetric racism in their practice through implicit biases.⁵³

Black-centered birth workers are a distinct category of birth workers who provide care that is designed to address the specific needs of Black birthing people. Black-centered birth workers emphasize choice and consent during pregnancy and childbirth; they affirm and advocate for the dignified treatment of birthing people and families, including queer, non-binary, and trans people; they embrace the de-medicalization of childbirth by integrating spiritual and ritual practices; and they deliver care that is community-based and hyper-local. They emphasize the importance of providing care that is meaningfully detached from medical and carceral systems, while simultaneously demonstrating their extensive experiential knowledge about how these systems operate. They develop and deliver care models that are rooted in reproductive justice, the right to control one's gender, sexuality, and reproduction.⁵⁴

Black-centered birth work is rooted in African American tradition connected to the African diaspora. Faced with the particular terrors of American chattel slavery and its afterlives, Black Americans continue to find ways to resist the totalizing effects of racism. As Christina Sharpe writes, “Even as we experienced, recognized, and lived subjection, we did not simply or only live in subjection and as the subjected.”⁵⁵ Unfolding this praxis, Sharpe develops the term “wake work,” to describe the “particular ways of re/seeing, re/inhabiting, and re/imagining the world” in the wake of slavery.⁵⁶ This conscious apprehension of racism's harms is evident by the three main ways Black-centered birth workers use to protect their patients: evasion, compromise, and refusal. Each of these methods require vigilance — a wakeful and attentive awareness of how obstetric racism can and does operate.

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In addition to providing care that is designed for Black people, the Black-centered birth workers also serve non-Black clients. Their knowledge about systemic inequities that affect Black birthing people helps to inform the care they deliver to non-Black patients. The Black-centered birth workers featured in this study recognize the ubiquity of challenges during childbirth, while also emphasizing the impact that race has on these experiences. As one Black-centered birth worker explained:

Black birth experiences are so different than what's happening kind of across the nation for birthing people. I think there are some common threads that are through birthing people's stories. Not feeling supported, not feeling listened to, these are things that are pretty common, but... I was a witness to a lot of violence, obstetric violence, and I think that was largely racial.

As a whole, the birth workers interviewed for this study are racially and ethnically diverse. The Black-centered birth workers are distinct from this larger group not because they are Black, but because they expressed an explicit commitment to providing care that is attentive to the specific needs of Black birthing people. At the same time, because Black birth workers have experiential knowledge about obstetric racism, they are uniquely positioned to deliver Black-centered care. Research shows that racially concordant care, which occurs when a patient and a provider share the same racial identity, can improve health outcomes and the quality of care.⁵⁷ As one Black-centered birth worker who is also Black stated, "You can't put a number on the value of knowledge that comes from other Black people about Black experiences."

Infrastructures of Data Collection

	Electronic Health Records (EHR)	Medicaid	Femtech
What is the purpose of this data collection?	A digital system that practitioners use to collect and store patients' health information (e.g., MyChart). EHRs are dominated by three major companies — Epic, Oracle Cerner, and Meditech — which control over two-thirds of the market share in the United States.	A joint federal and state healthcare coverage program for children, adults, birthing people, people with disabilities, and seniors who qualify due to low income or other criteria.	A subsector of digital health care that focuses on women's health care. It encompasses various digital health tools such as apps, wearables, and medical devices designed to promote women's health (e.g., Flo Health , Natural Cycles , Oura Ring).
How does this data collection address equity?	Accessibility and efficiency. It streamlines clinical decision-making. Patients can have access to and engage with their healthcare information.	Lowering costs. It reduces the cost of receiving maternity care and expands coverage.	Asynchronous care. It allows providers to monitor patients and patients to collect their own health data.
What kind of harm does this data collection raise toward Black birthing people?	State and local authorities can access information stored in the EHR, which exposes Black birthing people and providers to potential prosecution — a harm heightened by the repeal of <i>Roe v. Wade</i> .	Medicaid policies enforce excessive data collection from pregnant people (e.g., education/employment, reading level, history of previous pregnancies, etc.).	Femtech users are at risk for privacy breaches (e.g., Facebook and Google provided software-development kits to app developers like Flo, who collected user data and shared it with Facebook and Google (i.e., third parties) so they could tailor ads to those users ⁵⁸).

How Is Data Collected?

No matter who is delivering care or where it is delivered, birth workers collect data about their patients. During prenatal check-ins, providers document a patient’s medical history, information about past pregnancies, and details about their support system. This information helps birth workers assess risk factors, design an appropriate birth plan, and provide patients with access to support services. The birth workers interviewed for this study used a number of methods to collect this information, ranging from highly technical systems to analog note-taking. The most ubiquitous tool used for data collection across care contexts and professionals is the EHR.

The EHR is the keystone of digital health information infrastructure. The EHR’s core function is to eliminate the medical system’s reliance on paper-based information management. According to data collected by the Office of the National Coordinator for Health Information Technology between 2015 and 2017, more than 80 percent of all non-federal acute care hospitals had an EHR system.⁵⁹ The EHR market is dominated by three major companies — Epic, Oracle Cerner, and Meditech — which control more than two-thirds of the market share in the United States.⁶⁰ Each EHR contains a patient’s medical history, including diagnoses, prescriptions, treatment plans, test results, and clinical notes.⁶¹ Providers house individual records in an EHR system that facilitates digital communication about the records between providers and patients and across care settings.

Patients can interact with the EHR through patient portals such as MyChart that also contain tools to communicate with providers. On the provider side, EHRs perform administrative and regulatory tasks around billing and performance assessments. Larger EHR systems house analytical tools that health plans can use to make decisions about a patient’s care and to assess population health. EHRs also automate aspects of provider workflow. Ultimately, the EHR and its associated digital tools create an interconnected web of digital interactions over which information about patients’ health travels between stakeholders. Describing how health data travels through the EHR, one clinician explained, “We go from the [body] of a patient to an electronic health record, to a population health tool, back through that team of people providing communication back to the patient through a patient portal.”

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In the case of the practitioners I spoke with, the EHR was also a site of negotiation. On one hand, the EHR assists clinical decision-making and streamlines administrative processes, ultimately revolutionizing how clinicians think. At the same time, the EHR posed significant challenges for birth workers and Black birthing people. Accessible by state and local authorities, information documented in the EHR exposes patients and providers to potential criminal prosecution — a risk that

heightened following the repeal of *Roe v. Wade*⁶². For Medicaid recipients, health data is also a site of excessive data collection that makes them vulnerable to the state. This tension between the EHR as an assistive tool and as an obstructive instrument adds new layers of consideration for birth workers and Black birthing people as they navigate maternity care.

EHR Transforms Clinical Labor

For medical issues with categorical diagnoses and treatments, the EHR can be an effective tool for streamlining the journey from screening to action. For example, preeclampsia — high blood pressure during pregnancy — is one of the leading causes of maternal mortality worldwide and, in the United States, Black women are more likely to die from postpartum blood pressure and heart disorders than white women.⁶³ Preeclampsia benefits from early screening and can be treated with aspirin. Risk factors for preeclampsia include a combination of biological, social, cultural, and economic conditions.

One physician walked me through their standard workflow as an ob-gyn treating a patient for preeclampsia with assistance from an EHR. Starting with a prenatal visit, this physician speaks with a patient about risk factors, collects clinical notes, and enters this information into the EHR. Then, an automated alert within the EHR pops up. The EHR identifies that “someone has a preeclampsia risk factor and needs aspirin,” then through the alert, it prompts the clinician by saying, “Hey, a patient needs aspirin. You should talk to her about aspirin, and by the way, here’s a button you can click that will order the aspirin.”

In this case, the EHR houses the record of the clinical encounter, identifies and flags a health risk, and reduces the amount of “clicks” it takes to order a prescription. To further augment these capabilities, informaticists are developing EHR tools to facilitate patient education; enable bidirectional communication about risks; and automate certain processes. Fitted with all of these functionalities, the EHR incorporates different stakeholders and organizes their collaboration to promote a patient’s health. One clinician explained, the EHR is more than just a record: “It is, when done right, the communication tool, the risk prediction tool, the documentation tool that [providers] need.”

However, the EHR isn’t always done right. From a labor perspective, the work to maintain the EHR through clinical documentation and its integration into medical analysis and decision-making has transformed how medicine is practiced.

Care teams in obstetrics and labor and delivery face intense pressures on their work from charting and engaging with the EHR. A recent study of labor and delivery nurses’ perceptions of the EHR’s impact on their work found that it “disrupted nurses’ ability to locate and synthesize information, maintain an overview of the patient’s status, and connect with patients and families.”⁶⁴ In addition to the standard EHR, labor and delivery nurses interact with an electronic fetal monitoring system (EFM) system — a tool that hosts admission and perinatal documentation. The EFM is separate, or loosely integrated with, the EHR, introducing a second digital health tool containing data that the nurses are responsible for managing and synthesizing. In emergencies, nurses gave up on these systems altogether and used paper documentation to track care, thus entirely defeating the EHR’s core function as a digital replacement for paper notes.⁶⁵ Because standard EHRs are not designed for pregnant patients, the features such as alerts and alarms that aid

in clinical care were rendered ineffective in labor and delivery, adding to the complexity of nurses' information management.

These issues are further complicated by a labor crisis that was exacerbated by the COVID-19 pandemic, which saw an increase in the number of sick patients and a wave of deaths, retirements, and burnout among clinical workers already facing low wages and exploitative conditions.⁶⁶ Despite the strain it places on medical labor, the EHR has become a fixed feature of medical practice. Reflecting on the EHR's permanence in medicine, one clinician said "The EHR has changed the brain of doctors and nurses, indelibly has changed it. They think differently." This shift is reflected in existing research on interactions between clinicians and the EHR, which demonstrates that clinical technology mediates medical labor while also being adapted by human action.⁶⁷ As the EHR continues to solidify its role as a principal mediator of medical labor and clinical decision-making, the experiences of clinical teams as they maintain and synthesize are of critical importance to understanding the EHR's impact on how medicine is practiced.

The Technical World for Birth Centers

Large healthcare providers such as hospitals often contract with health informatics companies that provide secure EHRs, communications systems, and patient portals. However, grassroots birth centers are too small to be clients of large EHR companies, leaving them to source their own independent health informatics infrastructure. As one birth worker who works in an independent birth center explained, "The technical world for a birth center, for out-of-hospital intrapartum, an actual labor and delivery workflow, is so bad. There are so few options. An Epic is never going to work for us and an Epic would never work for us because we're too teeny, teeny tiny."

Excluded from the larger EHR market, birth workers who operate independent birth centers have to find, vet, and implement smaller EHR systems that don't account for their specific approach to care and sometimes fail to meet Health Insurance Portability and Accountability Act (HIPAA) privacy standards. HIPAA requires companies that collect protected health information to implement comprehensive safety standards, including encrypted communications, controlled access to records, staff training, detailed logs, and an auditing process.⁶⁸ In their search for an EHR for a birth center, one interviewee said, "The first EHR I looked at, I knew within minutes that they did not understand what HIPAA meant." Showing me an example of one such EHR, they pointed out a clear red flag: the use of a Gmail address to submit protected health information. Confirming this observation, other birth workers described encountering data collection tools that were simply "not that safe." Without a detailed understanding of what HIPAA compliance means for their data infrastructure, birth center operators might opt to use an insecure EHR contractor.

Beyond safety protocols, birth centers often want specific fields that are not included in third-party EHRs so they can provide better care to patients with marginalized identities and diverse needs. The rigid design of birth center EHRs clashes with their radically inclusive care models:

We believe there's a weathering effect on the pregnant body based on microaggressions and lived experience as a Black woman. And this form does nothing to capture how that's going to impact their need for additional services or care. And it doesn't capture if you like, survive... a natural disaster, and it's very

heteronormative. It just does not do justice to capture things that we care about and we think would help us provide better care.

EHRs used in large hospitals aren't always designed with pregnant patients in mind.⁶⁹ Compared to better-resourced hospitals, birth centers have fewer options for record systems. Among these options, an EHR system that is aligned with their specific care model is hard to find.

Many EHRs designed specifically for birth centers are branded as software “for moms” or “maternity patients.” This branding is problematic for birth centers that operate with care models offering services for people who aren't pregnant, have suffered a loss of pregnancy or of an infant, or service clients whose birthing experience does not align with these terms: “We also have people who have, let's say, miscarried and are feeling very tender about that and they don't want to, it doesn't feel good to log into [a portal] for them, or [people who] are trying to conceive and haven't been able to, or don't identify as being maternal. They may be having a kid, but “maternity” is not the term that they want to use.” Some birth center operators settle for an EHR service that checks some, but not all of their boxes, opting for a service that is secure but might not allow them to exercise the full breadth of an inclusive care model.

If a birth center can find an EHR service that is compliant with HIPAA standards, interoperability issues remain. The health information stored in small EHR services is not easily transmittable to larger services. In an emergency, interoperability failures matter. As one birth worker notes, “If an EHR is clunky for intrapartum and we have a real emergency, that's bad. We decided we had to prioritize that above all other functionality because that's where we're most likely to have a life-and-death scenario where we need that documentation to be clean, easy to do, easy to output, easy to transfer.”

Doulas' and birth centers' struggle to find secure, interoperable EHR software further marginalizes them from the larger healthcare industry. Although birth centers are gaining more traction as a vital component of maternity care infrastructure, they are being left behind in the rapid digitization of medical records and clinical practice.

Clinical Notes and Carceral Systems

Hidden in the shadow of the spotlight on the EHR's failures is the role of “clinical notes” in codifying obstetric racism. Clinical notes are physicians' observations about a patient's state, including their health conditions and treatments, as well as their emotional affect and demeanor. Unlike the quantitative data captured about patients during clinical encounters, such as heart rate and blood pressure, clinical notes are largely subjective. As a result, clinical notes can reflect biases, power imbalances, and inequitable treatment.⁷⁰ Clinical notes are shared between physicians, so one doctor's observation of a Black patient as “difficult” or “rude” may affect another physician's perception of them. In maternity care, stigmatizing language has appeared in birth admission clinical notes.⁷¹

Clinical notes are one of the most prominent means of turning health care into a data collection and analysis operation. Determining what sort of notes are appropriate and how those notes are incorporated into digital systems for health care provision has a long history of contested professionalization. Past work on the information infrastructures of health care reveals the need for constant negotiation around what categories of action are relevant, and who has the expertise to categorize and record such actions — transforming them into health data.⁷²

For the Black birthing person, categorization in and through clinical notes is a process that renders them vulnerable. Clinical notes provide insight into physicians' perceptions of patients, the care that patients receive, and the services they're connected with. If, for example, a pregnant patient shares information that a clinician believes could harm them or their child, such as an inability to support their basic needs, this information does not remain in the medical record — it leaves the confines of the hospital system and becomes the purview of state or local authorities. As one provider described to me:

If you go to the hospital to have your baby and they see on your record that you haven't done any type of prenatal care, they will flag you and try to call [child protective services (CPS)]. We saw this a number of times... A client that decides to take a reduced intervention approach might not have as many appointments and might choose to not seek out as much care. And we would see both of those cases where CPS would be notified.

The child welfare system claims to conduct non-adversarial interventions that protect and promote the well-being of parents and children. However, as reproductive justice scholars Dorothy Roberts and Lisa Sangoi explain, “this claim obscures the oppressive political role it plays in monitoring, regulating, and punishing poor families and Black, brown, and indigenous families.”⁷³ Family separation policies are rooted in slavery and colonization and are marred by racial bias as is evident in day-to-day experiences of Black families.⁷⁴

Racial bias in clinical suspicion, evaluation, and reporting on pregnant patients, infants, and children is well documented: Black pregnant patients are more likely to be tested for drugs than non-Black patients and to face an increased likelihood of being reported to child welfare services after delivery, despite equal rates of test positivity.⁷⁵

The Dobbs Supreme Court decision in the summer of 2022 added new stakes to this problem. Several states have signed into law protections for providers, thereby ensuring that providers who prescribe abortion pills for out-of-state patients will be shielded from prosecution.⁷⁶ However, other states are attempting to pass laws that could target these providers with lawsuits or prosecution.⁷⁷

Clinical notes and other medical information kept in patient records are not fully protected by HIPAA or doctor-patient confidentiality laws. In certain cases, HIPAA permits clinicians to disclose protected health information to law enforcement. Suspicion of a crime, court orders, and administrative requests can provide law enforcement with the grounds to access information collected by clinicians.⁷⁸ Law enforcement can subpoena digital health information collected by clinicians and the data stored in menstrual tracking apps, and use it to inform prosecution.⁷⁹

Excessive Data Collection for Medicaid Recipients

Alongside the EHR, Medicaid is a site of heightened surveillance on Black birthing people. Medicaid is the largest insurance plan in the country, financing roughly four in ten births in the United States and 65 percent of births to Black mothers.⁸⁰ Medicaid recipients must meet with a long list of social service workers and divulge personal details that go beyond basic health information.⁸¹ In “A Poor Mother's Right to Privacy: A Review,” Danielle Keats Citron describes this data collection process:

When pregnant women seek government assistance for medical care, the State demands a dizzying array of personal information. In addition to the expected health exams to determine pregnant women's physical health, state Medicaid rules require assessments of their "nutritional status, health education status, and psychosocial status." Data is collected about poor pregnant women's "formal education and reading level," "religious and cultural influences," "history of previous pregnancies," "general emotional status and history," "wanted or unwanted pregnancy," "personal adjustment to pregnancy," "substance use and abuse," "housing/household," and "education/employment."⁸²

Sharing this personal information is a precondition for coverage, positioning data collection under Medicaid as "an opportunity for state supervision, management, and regulation of poor women" that renders them vulnerable to carceral systems.⁸³ Research on Medicaid data policies show that this excessive data collection preys upon poor women by collecting their data in exchange for insurance coverage and serves as an extension of negative stereotypes that portray poor Black women as untrustworthy and thus deserving more state supervision.⁸⁴ Crucially, this exorbitant collection also reveals an interplay between mechanisms of visibility — in which Black birthing people are made legible to the state via inordinate data collection — and mechanisms of invisibility — in which medical institutions overlook the collection of highly personal data about disenfranchised patients as routine. Simultaneously rendered vulnerable to carceral systems and left unseen by medical institutions, Black birthing people struggle to be recognized holistically.

Infrastructures of Vigilance: Black-centered Birth Work

Faulty health data systems are failing birth workers and Black birthing people. The EHR — designed to streamline workflows — creates friction for birth workers in and outside of the hospital. Data collection policies for Medicaid recipients, and new laws permitting criminal prosecution for abortion services, thrust maternal health data into a contested arena. My interviews with birth workers revealed that they confront these challenges by developing protective strategies to evade carceral potentials, find compromise with EHR systems, and resist data collection methods that are misaligned with their hands-on method of delivering care.

“It’s my business, but I don’t want it to be anybody else’s business.”

Black-centered birth workers are particularly attuned to the ways Black birthing people are made vulnerable by technological and healthcare systems. Like other birth workers, Black-centered birth workers provide prenatal care, attend labor and delivery, and offer postnatal support in the home, birth centers, and hospitals. However, Black-centered birth workers approach each of these care settings with Black patients’ well-being front-of-mind and pay close attention to instances in which obstetric racism appears. For this reason, some choose to provide maternity care outside of hospitals as a function of their practice and thus tend to “stay away from systems,” as one Black-centered birth worker puts it. However, they can’t avoid systems altogether. Black-centered birth workers accompany clients for planned and unplanned hospital births. During these clinical encounters, Black-centered birth workers rely upon their experiential knowledge of obstetric racism to actively intervene to protect their clients.

Before entering the hospital, Black-centered birth workers translate medical language for their clients and help them navigate hospital systems by preparing them for appointments and teaching them what to expect during labor at a hospital. In the heat of the moment, Black-centered birth workers can step in when they feel a clinician is mistreating their client. They pair their knowledge of how hospital systems work, including their digital systems, with their proximity to their client,

coaching them through the experience. In this way, Black-centered birth workers empower their clients to skillfully navigate a web of standardized decisions that are otherwise hidden.

This ability to traverse various sociotechnical systems also informs how Black-centered birth workers determine the contours of confidentiality. Black clients who have experienced or fear experiencing obstetric racism place their trust in doulas precisely because they are not bound to the same mandated reporting standards as other birth workers. As one doula explained, “there’s some things that [clients] may share with us that’s going on in their personal life that they’re not going to share with the provider because they don’t want their provider to get the social worker or child protective services or whatever involved.” Black-centered birth workers take this responsibility seriously by guarding the information that their clients share. The Black-centered birth workers I spoke with made it clear; when it comes to sensitive health information, “As long as it’s not putting them or me in danger, then I’m not going to share it.” As one birth worker put it, “It is my business, but I don’t want it to be anybody else’s business.”

Black-centered birth workers approach each of these care settings with Black patients’ well-being front-of-mind and pay close attention to instances in which obstetric racism appears.

In this sense, Black-centered birth workers act as intermediaries — delivering care by interfacing between medical professionals and clients.⁸⁵ As advocates for their clients’ safety, Black-centered birth workers operate as go-betweens for patients and clinical staff. They are trained to recognize obstetric racism in action. For example, one doula recounted an instance in which hospital staff threatened to call border police on their client — a Black foreign-born immigrant — in response to perceived noncompliance with the birth plan. Understanding how hospitals work is a key feature of doulas’ organizing to mitigate harm. As one Black-centered birth worker explained, they share this experiential knowledge with patients:

There are certain questions that will get you flagged at a hospital. And oftentimes we have to tell our clients, “These are the things that they will ask questions about. But depending on how you answer them, you will get flagged further for institutions to come in and start talking to you about ‘should you be bringing home your baby today?’... This is how you answer that question so you don’t get flagged.”

The decision to advise a client to withhold information from hospital staff is made with the support of an alternative network for care and support. One Black-centered birth worker interviewed for this study made it clear that their clients are connected to support services before clinical encounters: “Getting people connected with housing assistance or food assistance, anything like that, before they’re having these appointments, was kind of vital.” This determination to arrange access to alternative support systems is indicative of Black-centered birth workers’ unique approach to care.

Instead of placing clients' well-being in the hands of state and local authorities, Black-centered birth workers connect clients with trusted community-based services. One Black-centered birth worker shared, "Honestly, I've witnessed doulas tell their clients to just lie. And then when we get out of here, we'll make sure you're connected to mental health resources. We make sure you have a therapist. We'll make sure you have a postpartum doula." She saw this as an essential function of their work to protect their clients. She singled out moments when doulas coach clients on how to evade carceral systems as the time when "doulas are really protecting their clients as much as possible. And then also to protect doulas as well, not taking certain clients if we felt that that wouldn't be secured or it wouldn't be possible to get it secured."

In addition to advising clients on what not to say to nurses and other medical professionals, Black-centered birth workers will also intentionally leave information about their clients out of the notes they record or communicate to physicians. Information about LGBTQIA+ identity or family structures and immigration status, for example, are data points that doulas might incorporate into their care plan but refrain from sharing with external care providers — particularly those connected to hospital systems: "I like to avoid things that could be weaponized."

Black-centered birth workers' efforts to help clients conceal information from clinicians can be read as anti-hospital, painting clinicians as the ultimate villains. However, doulas made it clear that clinicians are not the enemy. Instead, the medical institution stood out as a focal point for obstetric violence where clinicians sometimes, but not always, acted as the conduits for harm. Just as they warn each other to "watch out" for physicians that cause harm, they also tell clients and other doulas which physicians they trust: "Talk to this physician. They're really receptive to doulas being in the room."

"I'm not putting that in a clinical note."

Reflecting the diversity of approaches among physicians, some obstetrics and gynecological physicians build practices designed to provide culturally attentive care to Black patients within or adjacent to hospital systems. They know that patients may have bad experiences with medical professionals and, because of this, one Black-centered birth worker noted being "super sensitive to not add any additional burden onto a human that walks [through] our door." This sensitivity shows up in many ways, including in a clinician's interactions with patients and in their data collection practices.

Clinicians have the power to decide what to enter in clinical notes and the EHR. In the post-Roe environment, clinicians are reconsidering the types of patient information they document. One clinician explained how she approaches clients who are seeking abortion services from out-of-state:

If you just walked in the door and said, "I need help. And I'm here for an abortion," or something like that I say, "Fine." I don't require to see an ID...And [if] you put down 123 Main Street do I give a shit? I don't. I care that you're here now. I'm not putting that in a clinical note.

In this way, clinicians can take ownership of their power to protect patients and themselves from potential prosecution by leaving things out of the digital record. By refusing to collect incriminating data, clinicians demonstrate an ability to control the contents of clinical notes, an understanding of how carceral systems access and weaponize these notes, and the agency to organize against these

systems. This evasive maneuver shows that what clinicians capture in health records is just as important as what they don't capture. Clinicians' refusal to collect data can help patients receive vital care without fear.

“...A balance between collecting data and providing care.”

Birth center operators, who are often also birth workers, must consider what data to include and exclude from their workflows, assessing features including privacy, cost, and usability. No single EHR holds all the answers to this careful consideration. With privacy problems and rigid data categories, birth workers are forced to make difficult decisions about what features they must sacrifice in order to provide care.

For example, during their visits with clients, doulas ask patients to fill out forms about their experience or capture notes that are later manually entered into a central database. While most of this basic data collection helps doulas secure continued philanthropic funding for their work, they also collect sensitive health information from clients, such as their medical history. In some cases, asking patients to divulge information can impede their willingness to accept care. One birth worker shared, “We could collect all kinds of data about the people who use [a service] but every piece of data we collect makes it less accessible. It makes it more of a barrier to getting to get the resource you need.” As previously discussed, collecting information related to abortion can also place patients and providers at risk for potential prosecution.

Another way to approach the decision over how much and what kind of data to collect is by allowing patients to decide what data they want to enter about themselves. Describing the benefit of this practice, a birth center operator explains:

Clients have the ability to fill in all of their demographic information in our EHR. They can tell us all the things about who they are and how they identify and what their background is and everything. But we don't require them to fill it in. If they don't want to talk about their ethnicity then they don't have to talk about their ethnicity with us or identify their ethnicity with us... Having that one piece of demographic data, to me, is less important than giving the client the time and space they need to receive the care they want to receive.

In these ways, birth centers engage in an ongoing negotiation over what data is important and what data can be sacrificed. As one birth worker stated, “there's always a balance between collecting data and providing care... Collecting data enables better provision of care. But it can also hinder provision of care.”

“It's real caveman days here.”

Doulas who work independently or as a part of a small organization are responsible for maintaining their own digital records. In individual practices, handwritten notes usually stay with the doula, are solely for their reference, and are rarely shared with external parties. When they work for a collective, doulas also collect demographic information and data about their clients' outcomes to send to donors for validating grant funding. Mostly, these records help doulas track their clients' health

history, birth plans, and care preferences. Doulas use basic methods to collect their clients' data, including Excel spreadsheets, Google Forms, or even handwritten notes. One doula explained, "I'm literally rearranging columns and counting with my fingers... it's real caveman days here." Another confirmed, "I did a lot of stuff by hand, where I just kept a journal and tried to remember my clients."

Although handwritten note-taking might seem tedious or unmanageable, doulas typically manage a small number of clients at a time. Moreover, handwritten notes match up with the deeply personal care that doulas deliver. As one doula explained, it prioritizes "human connectivity... hands-on support, picking up and holding babies, and giving affirming words." This kind of analog note-taking allows doulas to maximize their time focusing on their clients. Unlike in hospitals, where nurses and other staff continuously engage with the EHR, doulas are not bound to digitization, which allows them to practice while being relatively unbound by standardization.⁸⁶ For these reasons, the doulas I spoke with expressed an ambivalence toward integrating digital health technologies with their work. As one doula explained, "a lot of our work is so personal that for me, I have found that [digital] connection doesn't help my work."

Past work on doulas' technological skills demonstrates a reflexive relationship between this "high-touch" nature of their work and the "low-tech" nature of their data collection.⁸⁷ Using basic methods for data collection frees up time and space for doulas to build close connections with their clients and practice hands-on care. In contrast to the ways digital health records can depersonalize and endanger patients and health workers, doulas' low-tech data collection facilitates personal connections and pairs well with their hands-on care.

"Interfacing with Medicaid is awful."

The problem with analog data collection in the increasingly digitized arena of maternal health is made clear through doulas' attempts to register as providers through Medicaid. Currently, federal law requires states to provide pregnancy-related Medicaid coverage through 60 days postpartum, with 47 states exercising an option to extend coverage up to one year postpartum.⁸⁸ Efforts to improve Black maternal health often call for the expansion of Medicaid benefits, including expanding coverage to include doula care.⁸⁹ As of 2022, more than half of all states are providing — or are in the process of providing — Medicaid coverage for doulas' services.⁹⁰

Continuing to expand Medicaid coverage for doulas can reduce cost and increase access to care, making it seem like a clear-cut solution to the maternal health crisis. However, when asked about efforts to expand Medicaid coverage to include doulas, the birth workers interviewed for this study all expressed a similar sentiment: "Wonderful idea, but the details are where it becomes a headache."

The headache starts with an antiquated user interface. Doulas recounted frustrating experiences and described the Medicaid platform as outdated, hard to use, and "not very user-friendly." After they learned how to navigate the site, doulas reported a lengthy approval process. Then, once approved, they decried the billing process as "a complete utter nightmare." One doula put simply, "Interfacing with Medicaid is awful."

On top of being difficult to use, getting set up with Medicaid introduces an administrative burden for which doulas have to spend extra time managing billing. "The resources required just to maintain being able to...bill Medicaid is an enormous overhead." This overhead multiplies when doulas

attempt to bill managed care plans in which Medicaid coverage is administered by private insurance companies. The complexity of the managed care system adds even more administrative overhead: “That’s additional paperwork that you have to submit for each [managed care plan] that you want to become a provider with.”

This additional online paperwork directly contrasts with the analog data collection methods that doulas prefer. In order to be approved as a provider and receive reimbursement through Medicaid, all providers have to document the full extent of patient care “completely, accurately, and in a timely manner.”⁹¹ Federal and state auditors enforce these requirements. As one doula explained, Medicaid documentation requirements do not pair well with how they currently practice: “I’d love to have the Medicaid reimbursement but the implications of accepting Medicaid and what it would mean for [doulas’] documentation, [and] how they communicate with clients is so tricky.” While doulas welcome the benefits derived from Medicaid coverage — including the ability to provide affordable care to more clients — they’re wary of the pressure to digitize their long-standing analog workflows.

Organizations such as the National Health Law Program Doula Medicaid Project are working to provide doulas with technical assistance.⁹² However, in order to maintain standardized medical records documentation, doulas will have to alter their current practices to allow for more formal note-taking. Doulas require a health data documentation system designed to integrate into their practice to preserve the high-touch, deeply personal work that makes doulas uniquely valuable. Otherwise, as one doula notes, “You’re just going to have a bunch of non-compliant people, just sitting ducks for when you decide to go audit later.”

Although these issues presented significant challenges to working with Medicaid, birth workers do not want to do away with this benefit. Instead, they suggest changes to the platform and better resources for doulas applying to the program:

If [a state] wants to have Medicaid for doulas, don’t go out and make them figure out how to get a Microsoft 365 subscription or a G-Suite for their one-person practice and pay those fees... [or] make them go figure out how to be a Windows administrator and figure out what domain management means... What you need to do is you need to provide a single platform for doulas who want to get Medicaid reimbursement that is HIPAA-compliant. And that needs to be the state’s obligation.

This suggestion echoes the feelings of other birth workers in this study, who expressed a desire for better tools that help instead of hinder their current practices. While some of these suggestions included ideas for digital health tools, others called for options that don’t have solely technical solutions.

Femtech Infrastructures for Black Birthing People

For all the work that doctors, nurses, midwives, and doulas do to provide comprehensive care to pregnant patients, even the best interventions fail if patients don't make it to their appointments. In the sensitive pre-, post-, and perinatal periods, regular visits with a healthcare professional are critical for screening and preventing serious complications. Patients miss their appointments for many reasons, including issues with transportation, employment, childcare, and access to maternity health services. More than two million women of childbearing age reside in maternity care deserts — places where there are no hospitals, birth centers, or providers offering obstetric care.⁹³ These issues are compounded by gendered, racialized, geographic, and poverty-induced forces that raise barriers to accessing health care. Missed visits and inaccessible care mean that treatable conditions such as preeclampsia and postpartum depression go unnoticed and unaddressed.

Femtech companies — a subset of the digital health industry — are working to fill this gap by extending maternal health care into the home.

Femtech encompasses digital health tools, ranging from apps, wearables, and medical devices designed to promote women's health. These tools offer services, including pregnancy, postpartum, and parenthood support; primary and preventive care; fertility support; sexual and reproductive health services; chronic disease care; menopause care; menstruation tracking, and behavioral health resources.⁹⁴ One major criticism of the femtech industry is the use of design principles that cater to a user who is white, wealthy, cisgendered, and heterosexual.⁹⁵ Increased attention toward the Black maternal health crisis is seeding a revolution in digital tools designed specifically for marginalized women and birthing people. Apps that gather reviews from Black women about their experiences with hospitals and physicians⁹⁶; connect providers with real-time data from at-home wearable devices⁹⁷; and empower patients to collect and understand their own data⁹⁸ are already on the market and available for Black pregnant people to use.

By combining synchronous and asynchronous care, femtech can extend care touchpoints beyond healthcare facilities and into the home. In a landscape where maternity care is distributed across different settings and care professionals, femtech devices can also help birth workers bridge gaps in care. However, for Black birthing people, the value of being connected to femtech is curtailed by

the risk of privacy breaches and unequal access to devices and internet, contributing to a lack of confidence in the ability of these tools to improve equity.

However, for Black birthing people, the value of being connected to femtech is curtailed by the risk of privacy breaches and unequal access to devices and internet, contributing to a lack of confidence in the ability of these tools to improve equity.

The informaticists I spoke with emphasized that without reducing disparities in access and improving confidence in femtech and other digital health tools, the benefits derived from asynchronous care will not be distributed to the patients who need it most.

“If you’re not electronically connected, you don’t get to benefit.”

Providers’ ability to access health data that patients collect at home — known as remote patient monitoring — is useful for insurance companies and providers because they enable asynchronous care, extending health services beyond the healthcare setting and reducing costs. One provider noted that, “[The remote monitoring tool] gives freedom... I can use it as an additive tool. They are showing that... there’s somebody monitoring it in the universe, that they put the little blood pressure cuff on, or they do the scale, so that we know if the person’s going into heart failure, we know if the person’s having a problem. And these are wins.” However, these wins are only accessible to patients who are connected with the proper infrastructure to support digital health services. As this provider went on to explain, “How they integrate into a healthcare system, and how a patient can control some of that is... really tricky.”

Patients have to use the right devices and use them correctly, have the right insurance plan, and have reliable internet connectivity.

A patient seeking care outside of large health systems can do everything “right” to obtain and receive prenatal care, but still miss out on services designed to improve their health because they are not connected to the digital infrastructure used by large systems. As previously discussed, smaller health centers are not connected to larger EHR systems. As a result, their patient records are siloed, and patients who opt to receive services outside of the hospital are not connected to well-resourced digital health systems. As one clinician explained, “You’re getting prenatal care, you’ve surmounted all those barriers. You’ve identified a pregnancy, you’ve come early, you go get care, providers are seeing you. [If] you’re not electronically connected, you don’t get to benefit.”

“...A prescription for a fucking cell phone?”

Patients’ ability to connect with providers is dependent on access to devices and the internet. Most Americans have a mobile phone, but how sophisticated that device is, and its ability to reliably

connect to the internet, varies by location and income.⁹⁹ As telehealth becomes more popular and is uplifted as a solution to care inequities, connectivity issues counteract progress and leave the most vulnerable behind. Even if people seeking maternity care have access to a smartphone or a laptop, they might share that device with a parent, partner, or sibling. They might have spotty service and have to go to public places to connect to Wi-Fi. These factors limit their ability to use the device for confidential communication with providers or access to health information and reduce their options for how to receive care once they are connected.

Disparities in access to reliable technology and the internet can place critical digital interventions entirely out of reach. Providers rely on the EHR to facilitate communication and implement patients' care plans. A provider stated, "We need you to be connected to the EHR to be able to talk to you, bidirectionally with you." If clinicians can't communicate with their patients, it limits their ability to track their progress. This instability frustrates clinicians who want to connect their patients to these services that they've worked hard to implement:

I would like to write a prescription for a cell phone that has these little bells and whistles. I don't care if they're using it to call their grandma. She's part of this system, too. Just give it — it's so cheap. And I would like to write a prescription that it was required because I need to talk to this person. Because this is the way we're going to communicate about their heart failure. Or this is the way we're going to communicate about this postpartum very busy mom's blood pressure. Can I just write her a prescription for a fucking cell phone?

In lieu of a prescription for a cellphone, patients struggling with access to a smart device or using unreliable technology to access health services might be more inclined to choose the lower-tech option. Research shows that Black patients, patients living in rural areas, and patients using Medicaid insurance are more likely to use audio-only services instead of video visits for telehealth appointments.¹⁰⁰

On top of the connectivity barrier, differences in insurance reimbursement rates for audio-only visits erect yet another barrier to receiving care. When clinicians provide a service to a patient, they send the bill either directly to the patient or to an insurance company to receive reimbursement. Insurance companies decide what kinds of services providers can receive reimbursement for, weighing the value and cost of the service. The COVID-19 pandemic spurred insurance companies to expand coverage to include telehealth services. While some insurers instituted pay parity policies for audio and video visits, it is unclear how long these policies will remain in place. One informaticist described the current landscape, explaining that varying incentives in the reimbursement rate for video and audio visits lead providers to opt for video services, even if they aren't as accessible for marginalized patients:

The video visits reimburse at better rates. So whether or not their patients struggle to use it, they start getting reimbursed... They're still in some cases trying to figure out ways to reimburse [audio visits], which is probably why a lot of providers may not necessarily want to offer audio-only. Because they can't be reimbursed for that.

Yet again, a patient who seeks care and does everything “right” — they have a device that connects to the internet and they opt to attend an audio visit — is still penalized with fewer choices for care, due to varying reimbursement rates.

Rather than moving forward with inaccessible technologies and services, clinicians want to make data actionable. Clinicians already work in highly digitized environments. At well-resourced hospitals, clinicians have access to a wealth of data, risk assessments, and other metrics about patient health. Instead of focusing on developing more precise tools, the clinicians interviewed for this study emphasized the importance of making actionable the wealth of patient data that is already available:

If I could tell you with incredibly great precision that your risk of preterm birth is 70 percent to 75 percent, and I could then make the model better, so I could more precisely tell you, no, it's 72, not 74, to me, that's gilding the lily. That's not the point. Our problem is not precision in that estimate. Our problem is, I think, largely actionability from a health system perspective, an individual provider perspective, and a patient perspective is making those assessments actionable.

“Confidence in the technologies.”

In the post-*Roe* era, apps that allow self-tracking information about menstruation and pregnancy have come under increased scrutiny.¹⁰¹ Instead of increasing patient autonomy and promoting health, femtech can bring carceral surveillance into the home. Some femtech apps explicitly state that they retain the right to disclose personal data at the request of law enforcement.¹⁰² In a review of 25 reproductive health apps and wearables, Mozilla found that most apps did not provide clear guidelines or even lacked a privacy policy altogether.¹⁰³ In states where abortion is illegal, law enforcement can subpoena the health data stored in these apps and use it to inform prosecution.¹⁰⁴

Inequitable access and outsized privacy risk for Black patients not only reduces the power of digital health interventions to address disparities, but also reduces patients' belief in this power.

While fear and uncertainty around data privacy on femtech platforms is growing, more basic digital activity such as web searches or text messages are more likely targets for law enforcement.¹⁰⁵ Searches of digital devices containing search history, text messages, purchase history, and emails have been used by state agencies to surveil Black people, particularly those dependent on state resources.¹⁰⁶

Inequitable access and outsized privacy risk for Black patients not only reduces the power of digital health interventions to address disparities, but also reduces patients' belief in this power. Negative experiences with patient-facing devices run the risk of diminishing patients' confidence that these tools will work for them. One informaticist described conversations with Black patients who raise questions such as, “Is my device approved for this telemedicine? Do I have to download this app to

my phone? Can I do it on my desktop? What type of data is collected or is it recorded? Who has access to the notes that might be automatically in the chat feature?”

These kinds of questions indicate that as long as systemic barriers to digital health remain, Black patients won't have “confidence in the technologies” nor “confidence in the information or the things that they do.”

Conclusion

This report has explored the ways in which data collection in maternal health care introduces a unique set of risks for Black birthing people and challenges for the birth workers who collect, manage, and use this data. Faced with issues of interoperability, privacy concerns, exposure to carceral systems, disconnects from their hands-on work, and an increasingly data-driven healthcare landscape, Black-centered birth workers engage in a vigilant practice to protect their patients. By refusing to collect sensitive data, connecting patients with external support systems, and making-do with clunky data collection tools, these birth workers are spearheading methods to affirm Black birthing people’s reproductive rights — the right to joyful pregnancy, fully recognized humanity, and freedom of choice.

Across the country, Black families are doing their best to find a path to healthy childbirth amid layered roadblocks. Black-centered birth workers are stepping up to help families navigate this journey safely. As one Black-centered birth worker stated succinctly, “Patients need to be protected.” Black-centered birth work asserts that no matter where or from whom they receive care, Black patients deserve an experience free from mistreatment and from the threat of potential incarceration. Their work shows that, in order to improve maternal health for Black birthing people, addressing systemic issues is paramount.

When asked about how they envisioned the future of data-driven maternity care, birth workers expressed a cautious optimism contingent upon structural changes to technological, health care, and socioeconomic systems.

In the technological space, birth workers suggested fixes to data collection tools such as improving the utility of the EHR and democratizing patient data. Birth workers want a say in how these digital health technologies are designed, developed, and deployed. In healthcare systems more broadly, Black-centered birth workers expressed a need for better financial support for community-based care models, increasing the numbers of Black clinicians, and improving integration between birth workers and hospital systems. They emphasized that their efforts are only one part of the fight to improve outcomes for Black patients. Their work must be supported by structural changes that expand access to housing, healthcare services, and food, while diminishing the negative impacts of the criminal legal system and family separation policies.

Going beyond data collection, birth workers emphasized the need to consider “the intangible things that are never going to be captured in data that matter here to ensure that equitable outcomes happen.” Within the handwritten birth plans and the side conversations about how to engage with clinicians are valuable insights into how autonomy can be enacted, even while living in a maternal health crisis. While the slow gears of structural change turn, Black-centered birth workers are doing the everyday work to reduce disparities by paying attention to carceral harms and intervening to protect Black patients’ rights to digital health equity. To improve pregnancy and childbirth for all people, we should follow their lead.

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Appendix: Methods

This research was conducted using qualitative methods that included semi-structured interviews with experts in maternity care and participant observation at in-person conferences and online webinars.

I recruited experts by screening research institutions related to maternal health, medical centers that provide maternity care, and public services geared toward pregnant people. After developing an outreach list, I screened and enrolled participants via email. I conducted 11 semi-structured interviews on Zoom. The interviews consisted of three doulas, two midwives, two physicians, three informaticists, and one payer. I received a written response to the interview questions from a femtech company. These experts work in a range of locations across the United States and practice in various capabilities. Some clinicians worked at federally qualified health centers; others worked at hospitals. All of the doulas had experience working as independent birth workers and as a part of doula collectives or organizations. The informaticists also had varied backgrounds with different approaches to developing healthcare technologies for Black patients. The semi-structured format of the interviews provided space for the interviewees to guide the conversation, combining predetermined questions with organic insights.¹⁰⁷

As follow-ups to select interviews, I attended two virtual webinars put on by a femtech company and a maternal health advocacy group. During these webinars, I took notes that focused on the way health data was framed in relation to the stated organizational mission. While I signed up for webinars using my name and work email, I refrained from answering questions and engaging in interactive polls.

In addition to online research, I attended two in-person conferences. One conference was geared toward birth workers, and gathered around 50 people from across the United States engaged in birth equity advocacy to discuss the role of data in their work. The second conference gathered around 100 experts from a broad range of disciplines, including tech developers, venture capitalists, payers, providers, birth workers, nonprofits, and entrepreneurs to discuss the future of maternity care. Data collection for both conferences consisted of detailed note-taking, conversations with participants, and questions for panelists.

The interview results were qualitatively coded on a web-based analysis platform using conventional content analysis to organize and identify themes from respondents.¹⁰⁸ Reading each transcript line-by-line, I used an inductive approach to develop categories and apply codes. These codes were then applied to the field notes I captured from the webinars and conferences.

Following the Dobbs Supreme Court decision, maternal and fetal health professionals are facing increased scrutiny on the care they deliver. In this contentious climate, the stakes are high for medical professionals to answer questions about their clinical practices and data practices. In some states, clinicians face the potential for criminal prosecution. As a debutant in the maternal health space, I prioritized establishing trust between myself as a researcher and the participants for this study. To preserve their privacy and honor these trusting relationships, the identity and location of all respondents are anonymized. This project was overseen by an external Institutional Review Board, which classified the research as exempt under the US Common Rule.

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