

# HEALTH AND HUMAN SERVICES (HHS)

Resolution HHS-24-11

## A RIGHT TO PRIVATE HEALTH DATA

WHEREAS, the U.S. Supreme Court's 2022 decision in *Dobbs v. Jackson Women's Health Organization* held that The Constitution does not confer a right to abortion, and overruled *Roe v. Wade* and *Planned Parenthood of Southeastern Pennsylvania v. Casey*;

WHEREAS, that decision returned the authority to regulate abortion to the states through their people and their elected representatives;

WHEREAS, the Supreme Court's decision to overturn these landmark cases ends nearly 50 years of federal abortion rights, ultimately, no longer offering women the protection needed to make choices regarding their own bodies;

WHEREAS, CDC presented data that demonstrates that Black women are two to three times more likely to die from pregnancy-related complications than white women, with most of the maternal deaths being preventable;

WHEREAS, Black women in the United States (U.S.) disproportionately experience adverse pregnancy outcomes, including maternal mortality, compared to women of other racial and ethnic groups;

WHEREAS, data shows how overturning *Roe v. Wade* disproportionately impacts women of color as they have more limited access to health care, and face underlying inequities that would make it more difficult to travel out of state for an abortion compared to their White counterparts;

WHEREAS, the *Dobbs* decision prompted many advocates, stakeholders, and lawmakers to pursue state-level consumer health data privacy legislation, as well as federal agencies to take action;

WHEREAS, these policies created a new category of protected data and offered new protections for Americans' sensitive health information, specifically, to protect information about individuals seeking and receiving reproductive health services through various technology platforms;

WHEREAS, the new category of protected data is commonly referred to as "consumer health data", and it reaches beyond what is traditionally considered "health information" as defined under current federal and state health information laws;

WHEREAS, establishing the definition for "consumer health data" on a state-based approach is resulting in widely varied definitions and uneven applicability standards, creating a patchwork of laws and regulations, especially when it comes to health data;

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WHEREAS, in order to ensure black women feel protected and empowered when seeking health care services and to create a universal standard for those protections, it is important to establish a sound approach in creating standard consumer health data privacy policy, while also balancing the rights of individuals with their interests to use, access and receive reproductive health care services; and

WHEREAS, the conversation and policy development around the protections of consumer health data impacts the conversation around reproductive health care as well as health equity.

THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL) supports legislation that, protects reproductive health by providing adequate privacy protections while also preserving critical access to care, and further supports increasing investments for medical facilities in communities color where much more progress needs to be made;

BE IT FURTHER RESOLVED, in the wake of the Supreme Court's Dobbs decision, expanding access to sexual and reproductive health is critical, and technology can potentially serve as a tool;

BE IT FURTHER RESOLVED, a uniform minimum federal standard, that allows states the flexibility to exceed those requirements for data privacy is critical to provide individuals, states, and businesses of all sizes clarity on how to use, collect, and store data;

BE IT FURTHER RESOLVED, definitions of key terms in data privacy legislation should be narrowly-tailored, precise and clear, creating a uniform standard which can be easily interpreted and applied by healthcare and non-healthcare entities collecting, using, and storing said information, leaving no room for ambiguity or interpretation;

BE IT FURTHER RESOLVED, that certain data directly related to an individual who is receiving treatment for reproductive health care services should be protected from compelled disclosure by law enforcement, as such information could be used in reproductive rights legal proceedings;

BE IT FURTHER RESOLVED, that collection, use, and sharing of an individual's consumer health data should be transparent, and entities should provide this information to individuals accessing said services, further the consumer health data should only be shared with the express consent of patient and not be used for financial gain;

BE IT FURTHER RESOLVED, individuals accessing health services should have the right to choose if they want to hear about a product or service, and should be able to control how their data is used without creating an onerous user experience or exposure to criminal penalties;

BE IT FURTHER RESOLVED, that when possible, a state seeking to enhance protections for consumer health data should update already existing data privacy laws, rather than creating a new, potentially duplicative regime;

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BE IT FURTHER RESOLVED, that state attorneys general are in the best position to protect consumers in their states, including enforcing consumer data privacy laws, and state attorneys general should exercise such authority to protect consumer data;

BE IT FURTHER RESOLVED, in a post-Dobbs era, the protection of consumer health data privacy is critical, and reasonable standards that consider the impact of the use of such data and historical health inequities should be considered when creating good policy that will protect all communities that will evolve with technology; and

BE IT FINALLY RESOLVED, that a copy of this resolution be transmitted to the President of the United States, the Vice President of the United States, members of the United States House of Representatives and the United States Senate, and other federal and state government officials as appropriate.

**Resolution ID: HHS-24-11**

**Sponsored by: Sen. Karla May (MO) and Sen. Barbara Washington (MO)**

**Policy Committee: Health and Human Services (HHS)**