My body, my choice, my data

June 24, 2022, was a dark day in US history. The decision to overturn Roe v Wade eliminated the constitutional right to abortion and has set the reproductive rights of women and people who give birth back 50 years. Now, the spread of abortion-related misinformation online and state-level restrictions on remote abortion services further threaten reproductive autonomy. In these crucial times, the public needs clarity on how digital technology can help or hinder their search for evidence-based reproductive options.

The repeal has generated confusion over state-level access to abortion services. While the public attempts to educate themselves on their reproductive options online, they encounter substantial amounts of information varying in quality and clinical accuracy. Similarly, policies applied to abortion-related content by big tech platforms are unevenly enforced, with reports of the medically unsubstantiated abortion pill reversal procedure being promoted while content on abortion services is suppressed. Big tech has a responsibility to safeguard the public from information that could endanger their lives by regulating content shared on their platforms. Stronger government policies are needed to enforce online safeguarding and provide independent oversight.

The spread of misinformation about abortion also highlights the crucial need for access to medically qualified professionals, and an important way to provide this is telemedicine. Multicountry evidence has shown that telemedicine-supported, self-managed medication abortion is safe and effective, and the UK government made telemedicine for early abortion care permanent in England in March, 2022. In December, 2021, the US Food and Drug Administration announced that it would remove the in-person dispensing requirement for the medication abortion drug mifepristone, meaning the drug could be dispensed by mail after a telemedicine consultation. However, in the wake of Roe v Wade, state-level regulations could restrict or prevent access to the drug, for example, by mandating it be taken in the physical presence of a physician.

Restrictions on telemedicine abortion care are likely to exacerbate existing social and racial health inequities. Women and people who give birth are already crossing state lines to obtain abortions in states where this service remains legal, but not everyone has the ability or financial means to do so. “We now have substantial evidence that telehealth for medication abortion is safe and effective and expands access for those who live far from in-person care”, says public health social scientist and abortion safety expert Ushma Upadhyay from the University of California, San Francisco, US. “However, the Supreme Court’s decision to overturn Roe v Wade will open women and pregnant people who try to use these healthcare services to increased criminalisation, which we know disproportionately affects people of colour and low-income people.” State-level continuation of telemedicine abortion care is essential to ameliorate these disparities.

Criminalisation could also occur if personal health data are weaponised against those seeking abortions and the physicians providing these services in a state in which abortion is now restricted or banned. Unfortunately, the US Health Insurance Portability and Accountability Act (HIPAA) is no longer able to capture all health data types and uses, with data from consumer health apps (including fertility-tracking apps) not falling within its remit. Therefore, these data could be shared with third parties, such as law enforcement, and used for abortion-related prosecutions and civil action. This shows the need to reform data privacy laws to keep pace with developing technology. Similarly, consumer health technology companies should prioritise the protection of data, not data commodification. Protecting patient and consumer privacy is a core tenet of the executive order President Biden issued following the repeal.

The Supreme Court’s decision is an affront to reproductive choice. In the interest of promoting public health, big tech should develop and apply stringent policies against misinformation, guiding users to evidence-based information and advising them of potentially harmful content. Federal authorities and state-level abortion advocates should fight to retain access to telemedicine-supported medication abortion to widen reproductive health-care choices and mitigate health inequities. The public also need strong assurances of their data privacy and protection, and HIPAA and other data privacy laws should be reviewed and updated. Now is the time to act and fight for the rights of women and people who give birth. ■ The Lancet Digital Health

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