The Protected Status of LGBTQ+ personal data under data protection laws

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Goals of this Presentation



Goals

- Getting acquainted with the legal concept of personal information.
- Understanding why certain categories of personal information receive specific treatment under data protection laws, the legal requirements for the processing of this information.
- Understanding the challenges with processing information related to LGBTQ+ persons in the digital world.
- Discussing the Supreme Court's recent *Dobbs* decision overruling *Roe v. Wade*, and the personal information implications for reproductive healthcare.
- Recommendations for organizations processing personal data related to LGBTQ+ individuals.

What is personal information?

Any information related to an identified or identifiable natural person



Are certain types of personal information more "sensitive" than others?

Examples of categories of personal information considered 'sensitive' or falling under the 'special categories of data' regime



Few examples of health-related data

Administrative and demographic information Physical and Mental health conditions

Serological status

Information related to reproductive choices

Data collected via fertility apps

Diagnosis, treatment, prescription drugs, laboratory test results, etc. Information related to an individual's sex life or sexual orientation could include any personal information*:



What are the requirements for processing "sensitive information" under data protection law? Legal requirements for the processing of information related to sensitive data

- Some jurisdictions establish a general prohibition against processing "sensitive information" except in certain limited circumstances specified in the law.
- As new data protection laws emerge and there is a need for a harmonized set of rules to enable data flows, the exemptions that allow the processing of sensitive data are becoming similar across different jurisdictions.

U.S. and global laws

- US Federal
 - Health Insurance Portability and Accountability Act (HIPAA)
 - Gives individuals rights over certain categories of protected health information (including sexual orientation and gender identity information) when collected by "covered entities"
 - But if collected by orgs that aren't "covered entities" (i.e., most mobile apps), such data is generally not protected by HIPAA
 - Americans with Disabilities Act (ADA)
 - Protects against discrimination individuals with HIV, those perceived to have HIV, or associate with individuals who have HIV

U.S. and global laws (continued)

US State

- California Consumer Privacy Act (CCPA)
 - Does not include a definition of, or heightened protections for, sensitive data
 - However, the California Privacy Rights Act (CPRA) will provide a new right to limit the use and disclosure of "sensitive personal information," including data pertaining to an individual's sex life or sexual orientation
- Virginia Consumer Data Protection Act (VCDPA) and Colorado Privacy Act (CPA)
 - More recently passed state laws will create an affirmative consent standard for collection of sexual orientation data.

U.S. and global laws (continued)

Global

- EU: General Data Protection Regulation (GDPR)
 - Restricts the processing of "special categories of personal data" including data concerning a natural person's sex life or sexual orientation
- EU: Digital Services Act (DSA)
 - Will ban the use of advertising based on special categories of data
- Brazil: General Personal Data Protection Law (LGPD)
 - Defines "sensitive personal data" which includes data concerning health or sex life and provides specific requirements for its processing
- China Personal Information Protection Law (PIPL)
 - Sensitive personal information is information that is likely to result in damage to the personal dignity of any natural person or damage to his or her personal or property once disclosed or illegal used (non-exhaustive)

What are the conditions for processing data about sexual orientation or sex life?

Where the individual has granted their consent

manifestly made public such information

to protect the vital interest of the individual

establishment, exercise or defence of legal claims for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care

public interest, scientific or historical research purposes

Consent is the most common condition used by companies for the processing of sensitive data

- Organizations need to be able to prove that they have obtained the necessary consents in a compliant way.
- The requirements for what is considered "valid consent" vary by jurisdiction (implied / opt-in).
- Regulators issue non-binding guidance re how the consent should be obtained.
- Their recommendations are not sector-specific and are not always possible to follow to the finer detail from a technical perspective.
- On going debate re how to obtain a valid consent (e.g.: granularity, information to be provided in advance, consent renewal, etc.).



Why these categories of personal information deserve a different

treatment?

Good intentions...

- John Rawls Veil of Ignorance
- Human Rights: these categories of information relate to the most intimate sphere of an individual
- To support ethical, equal treatment and equal opportunity for all: no one shall be treated differently because of their sexual orientation or gender identity
- Intention to fight against discrimination: "if there is no collection or no discussion of sensitive data, there is less risk of discrimination"
- Nuanced issues implicating this data (e.g., implied biases, "scientific" research)



may also lead to poor outcomes...

- Additional protections for data concerning LGBTQ+ people can perpetuate a heteronomative mindset (only focused on diverse sexual orientations / gender identities).
- This approach could contribute to a lack of visibility and perpetuate stigma and discrimination (see laws re unsolicited nudes).
- Overly restrictive laws may make it more difficult for organizations to respond to the specific needs of the LGBTQ+ community.



The unlawful processing of data related to LGBTQ+ people in the digital world may lead to serious damage not only for an individual but for the society as a whole



- E.g.: Misleading Ads About PrEP threatened Progress to End the HIV Epidemic.
- Towards the end of 2019 Facebook users started noticing advertisements targeting those taking Truvada as a HIV treatment or as PrEP.
- These ads were not only misleading but through use of scare tactics (e.g.: with frightening warnings like "Life-Threatening Side Effects" in bold letters) they put people's health at risk.

Processing of personal information related to LGBTQ+ orientation in the digital world: challenges arising from the data protection legal frameworks

What does the legal data protection framework applicable to the processing of data related to LGBTQ+ orientation in the digital world looks like?



Conditioned by the historical background

How the historical background conditions the interpretation of the scope of data protection laws for the LGBTQ+ community

- Discriminatory laws and traditional socio-cultural norms have marginalized and excluded lesbian, gay, bisexual, trans and gender-diverse persons from all sectors, including education, health care, housing, employment and occupation.
- Political campaigns, parliamentary debates and public manifestations still today reveal social prejudice and misconceptions about the nature and moral character of LGBTQ+ individuals in all regions of the world.
- Such discrimination is still visible in our democratic societies today, and public bodies and regulators sometimes adopt a protective approach that may not be uniformly applied beyond platforms that serve the LGBTQ+ community.
- Public bodies and regulators need to understand that "LGBTQ+" acronym is a notion that transcends the classical notion of sex life and sexual orientation. The processing of LGBTQ+ data should not be automatically be subject to the default rules applicable to "sexual orientation" or "sex life" data.

Subject to different interpretations (Theory vs Practice)

The notion of information concerning a natural person's sex life or sexual orientation is a broad concept (in theory)

- Information on sexual orientation is any information that provides information on whether a person is, for example, heterosexual, bisexual, homosexual, asexual, cisgender, transgender, or gender nonconforming/gender fluid.
- Sexual life includes every form of expression of sexuality. This includes not only traditional classifications such as homosexuality or heterosexuality, but also other conceptions of LGBTQ+ orientation (fluidity, situational-dependent, etc.).
- This notion must be interpreted in a way to allow for an enhanced protection for every individual to protect their most intimate sphere, regardless of their individual orientation.
- This interpretation refers to any sexual orientation, including heterosexuality (equitable protections and equitable applications)

...but in practice it is sometimes applied in an unequal way

- Personal data related to LGBTQ+ people may be assumed to be related to sex life or sexual orientation data by default even if that is not the purpose of the processing.
- Companies serving the LGBTQ+ community in the digital world are often confronted by inaccurate, ungrounded assumptions about the implications of users' association with a specific product or service.
- As an example, data protection regulators may make their own assumptions about the specific sexual orientation of someone merely for being the user of a service, whereas, for the organisation providing the service, the data point of simply being a user reveals nothing about the user beyond the fact that they are a user of the platform.
- As a result of loose application of the notion of information related to sex life and sexual orientation, companies providing good and services to the LGBTQ+ community could be subject to more stringent legal requirements, because they are answering the needs of a specific audience, traditionally marginalised, even if they do not processing any individual's sexual orientation.

Geographically Fragmented

Heatmap: Data Protection Laws in the world



How is the processing of information on sexual orientation regulated under different legal regimes?

- The processing and transfer of personal information are ruled by national data protection laws. We can establish a distinction between:
- Countries <u>without</u> data protection legislation
 - Usually, the LGBTQ+ community is persecuted in these jurisdictions and non-heterosexual or non-genderconforming behaviors, are punished by law, therefore, the protection of personal information related to sexual orientation is not foreseen in their legal framework.
- Countries with data protection legislation
 - In countries where different sexual orientations other than heterosexuality and non-conforming gender identities are not allowed or marginalized, the data protection legislation does not grant a protected status to the data revealing an individual's sexual orientation or gender identity. On the other hand, a protection is typically granted to information related to a heterosexual individual's sex life.
 - Data Protection laws in jurisdictions like US, Canada, EU, Australia, New Zealand, etc. include specific provisions regarding the processing of information on sexual orientation and gender identity. There is a general prohibition to process this information unless the data subject has consented to their processing.

Stringent data protection laws are not a guarantee of protection for the LGBTQ+ community.

Certain countries who are undergoing a digital transformation still criminalise same-sex sexual activity between men and between women. The gender expression of non-cisgender people is also criminalised.

Consequently, their data protection laws, although they have been conceived to allow the free flow of data to other jurisdictions, do not grant any protected status to the processing of personal data related to sexual orientation (as heterosexuality is the only sexual orientation allowed). Examples: UAE, Saudi Arabia.



Organizations serving the LGBTQ+ community across the globe face challenges related to the processing of personal data

- In countries where LGBTQ+ and nonconforming identities <u>are not</u> recognised:
 - Organizations operating in these • jurisdictions tend to adopt a more conscious and protective approach to ensure the protection of individual's data, as they are aware that the mere use their services could put the individual at risk (e.g.: more stringent security measures to prevent invest more unauthorized access, resources to guarantee the protection of the user, liaise with local agents, restrictions on sharing of location, safety tips, etc.).
- In countries where LGBTQ+ and nonconforming identities <u>are</u> recognised:
 - Organizations may be subject to a closer scrutiny by regulators, as they may assume that all information related to LGBTQ+ falls under the special regime applicable to sensitive information. This approach opens the door to the mere fact of association of certain services or platforms with special category of personal information.
 - Organizations are confronted to targeted regulatory enquiries and barriers for the sole fact of addressing the needs of the LGBTQ+ community in the digital world, companies serving a predominant heteronormative audience are not confronted to these challenges.



Few notes on the most recent legal developments related to the processing of data related to LGBTQ+ orientation

FROM POLITICOPRO

European Parliament pushes to ban targeted ads based on health, religion or sexual orientation

The move could prohibit platforms like Facebook and Google from using such sensitive data to target users with commercials.

117TH CONGRESS 2D SESSION

^{ss} H.R.

To prohibit targeted advertising by advertising facilitators and advertisers, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Ms. Eshoo introduced the following bill; which was referred to the Committee

Discussion draft of the American Data Privacy and Protection Act: "The term "sensitive covered data" means the following forms of covered data: □

(x) Information identifying the sexual orientation or sexual behavior of an individual in a manner inconsistent with the individual's reasonable expectation regarding disclosure of such information.

A BILL

To prohibit targeted advertising by advertising facilitators and advertisers, and for other purposes.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,
- **3 SECTION 1. SHORT TITLE.**
- 4 This Act may be cited as the "Banning Surveillance

Using digital evidence to prosecute abortion?

- Sensitive personal information can be mishandled and used for purposes far more damaging than targeted ads.
- The U.S. Supreme Court's recent decision in *Dobbs*, overturning *Roe v. Wade*, raises the specter of individuals' digital information being used to criminally prosecute unlawful abortions.



Dobbs v. Jackson Women's Health Organization
- *Roe v. Wade* (1973): constitutional right to an abortion before the third trimester of pregnancy, which is around week 27. 7-2 decision.
- Planned Parenthood v. Casey (1992): affirmed Roe's "essential holding"; constitutional right to abortion prior to the viability of the fetus. Set "undue burden" standard for restrictions on constitutionally permitted abortions. 3-2-4 decision. Viability – 24 weeks.
- States tested the bounds of *Casey*.
 - *Whole Women's Health v. Hellerstedt* (2016): struck down TX restrictions (admitting privileges, ambulatory surgery) as undue burden. 5-3 decision. Ginsburg, Kennedy.
 - June Medical Services LLC v. Russo (2020): struck down LA restrictions like TX's. 5-4 decision. CJ Roberts joined majority, Kennedy no longer on court (Kavanaugh).
- Justice Ginsburg passed away 3 months later, replaced by Amy Coney Barrett. Now 6-3.

- On May 17, 2021, Supreme Court granted cert in *Dobbs*: 15-week abortion ban in MS. Enjoined by lower courts under *Roe* and *Casey*, which allow up to week 24.
- Two days later, on May 19, 2021, TX governor Greg Abbott signed SB 8 the "TX Heartbeat Bill." 6-week ban subject to "bounty" enforcement by private individuals only. Clearly unconstitutional but designed to evade review.
- Whole Women's Health v. Jackson (2021): Court decided the attempted challenge to the TX law first, after letting it take effect and after argument in *Dobbs*. Sign that *Roe* was going to be overturned because TX law blatantly violated *Roe*. SCT said narrow challenge to law may be possible but sent back to lower courts, which extinguished case.

• *Dobbs* draft opinion leaked in early May 2022, overturning *Roe*.



- On June 24, 2022, Court issued its opinion in *Dobbs*. 6-3 decision.
 - Majority (Alito, Thomas, Gorsuch, Kavanaugh, Barrett): "Roe was egregiously wrong from the start. It is time to heed the Constitution and return the issue of abortion to the people's elected representatives." Now, only "rational basis" review of abortion laws.
 - Thomas: "[I]n future cases, we should reconsider all of this Court's substantive due process precedents, including *Griswold* [contraception], *Lawrence* [private, consensual sex acts], and *Obergefell* [same-sex marriage]."
 - Kavanaugh: "Overruling *Roe* does not mean the overruling of those precedents, and does not threaten or cast doubt on those precedents."
 - Roberts: Abortion "right should therefore extend far enough to ensure a reasonable opportunity to choose, but need not extend any further."

- Dissent: Breyer, Sotomayor, Kagan.
 - Now, "from the very moment of fertilization, a woman has no rights to speak of. A State can force her to bring a pregnancy to term, even at the steepest personal and familial costs."
 - "Whatever the exact scope of the coming laws, one result of today's decision is certain: the curtailment of women's rights, and of their status as free and equal citizens."
 - Re *Griswold*, *Lawrence*, and *Obergefell*: "Either the mass of the majority's opinion is hypocrisy, or additional constitutional rights are under threat. It is one or the other."

Dobbs: What's Next?



- 8 states currently under near-total ban.
- Other near-total bans expected or currently blocked.
- Likely that at least half of states will have bans or limits beyond *Roe*.
- [Graphic Credit: NYT, as of 7/22/22]

Dobbs: What's Next?

- Only Justice Thomas expressly targeted other rights, particularly ones implicating individuals who are LGBTQ+.
 - But as the dissent pointed out, the majority's rationale appears to have the implications that Justice Thomas stated expressly.
- Litigation challenges under state law, state constitutions, and potential federal law.
- Legislation in states. Potential travel bans.
- Potential federal legislation and federal government efforts to protect (medical abortions, emergency care).

Dobbs: What's Next?

- Efforts to detect and prosecute unlawful abortions via digital data?
- To detect and prosecute future measures targeted at LGBTQ+ individuals?

New York Times, July 13, 2022 In a Post-Roe World, the Future of Digital Privacy Looks Even Grimmer

In states that have banned abortion, some women seeking out-ofstate options to terminate pregnancies may end up following a long list of steps to try to shirk surveillance — like connecting to the internet through an encrypted tunnel and using burner email addresses — and reduce the likelihood of prosecution.

Even so, <u>they could still be tracked</u>. Law enforcement agencies can obtain court orders for access to detailed information, including location data logged by phone networks. And many police departments have their own surveillance technologies, like license plate readers. July 19, 2022

(WASHINGTON) — The Center for Democracy & Technology (CDT) today announced the formation of the **Task Force on Protecting Reproductive Health Information**, a multistakeholder group of experts representing tech companies, academia, and civil rights and privacy organizations aimed at identifying ways to protect the privacy and access to information of people seeking reproductive health care.

"The Supreme Court's decision to overturn *Roe v. Wade* has created complex privacy, data, and content moderation issues," says **CDT President and CEO Alexandra Reeve Givens**. "This task force will identify and discuss concrete steps companies can take to protect their users' data, what policies can be put in place to support reliable reproductive health information online, and appropriate boundaries on law enforcement requests for data about providers and people seeking reproductive health care."



Companies and regulators strive to find the right balance

- Companies providing services to the LGBTQ+ community have the responsibility to ensure an adequate protection of the personal information and be aware of the potential consequences of the misuse of the data they hold.
- Regulators need to understand that the notion of LGBTQ+ goes beyond the traditional concept of sexual orientation and that a strict interpretation of the notion of sexual orientation may have some unwanted consequences.
- Where there is room for debate, there is an advocacy opportunity to increase the visibility of the LGBTQ+ community in the physical and digital world.



Tips for organizations processing personal data related to LGBTQ+ individuals

Few tips for organizations processing information related to LGBTQ+ individuals

Be as transparent as possible and understand user's expectations	Understand and manage the risks associated to the processing	Keep it up with legislative and regulatory requirements	Avoid dark patterns
Collect only the data you need	Give the users the power to choose what information they want to disclose	Engage in open discussions with regulators	Discuss with your peers

Closing Remarks

Thanks! Time for questions, discussion, etc.