

10. Reproductive Health Client Data Privacy Act

Issue Overview

Unregulated Pregnancy Clinics (UPCs) often present themselves as free medical clinics to mislead clients seeking abortion. Their primary goal is to prevent clients, through persuasion, misinformation, or delay, from having an abortion.¹⁴³ While these organizations have the right to oppose abortion, most use misleading tactics, including ads, signs, and websites presenting their facilities as conventional medical clinics, even, at times, as abortion providers.^{144,145} Inside, they often resemble medical offices, with waiting rooms and exam rooms outfitted with medical equipment, and staff in lab coats and scrubs. Clients must often fill out intake forms that ask for private health information.¹⁴⁶

Presenting themselves as conventional medical providers, many UPCs solicit and document a great deal of sensitive personal data and private health information. UPCs collect and retain client information in various ways, including on appointment request forms and intake forms completed on premises, reports of interviews before and after testing, written results of STI/STD tests or ultrasound examinations, write-ups from counseling sessions, and via centralized chat services and online client data management platforms.^{147,148}

UPC intake forms are often invasive. Even though they are not medical providers, many UPCs ask clients for prescription drug lists, past or current illnesses, and medical conditions unrelated to their services. Some ask inappropriate questions like the name or age of the person who impregnated the client, whether the client is living with someone they aren't married to, when they first had sex, or whether they have multiple partners or same-sex partners. Collecting such information is unnecessary and unethical, given that most UPCs only provide over-the-counter pregnancy tests, STD/STI tests without treatment, lay counseling, and material resources like diapers and wipes. Further, even though they don't bill insurance, UPCs often ask for clients' government identification documents, insurance information, income, employer, or eligibility for public assistance.¹⁴⁹

Because the vast majority of UPCs are not medical clinics, they can and do violate clients' privacy. Traditional medical clinics must follow the privacy, confidentiality, and records security requirements of the Health Insurance Portability and Accountability Act (HIPAA). UPCs are not subject to HIPAA¹⁵⁰ and, therefore, are not required to protect clients' private health information. On the contrary, many UPCs maintain client records in online databases accessible by third parties outside the UPC.¹⁵¹ A digital system called eKYROS feeds personal client information into a central database linked with the national

UPC umbrella groups Heartbeat International and Care Net.¹⁵² Other central databases used by UPCs include Next Level¹⁵³ and CoolFocus.¹⁵⁴

The national UPC umbrella organizations collect client records in “digital dossiers” on pregnant people around the country who have contacted or visited a UPC. As a brief by the Alliance reports: “the CPC industry is now functioning as surveillance infrastructure for the anti-abortion movement, amassing data that could be used in pregnancy- and abortion-related prosecutions....”¹⁵⁵ The global anti-abortion group Heartbeat International reports using this data to create “digital dossiers,” stating “Big data is revolutionizing all sorts of industries. Why shouldn’t it do the same for a critical ministry like ours?”¹⁵⁶

Many states have laws requiring medical privacy and security, and the UPC industry should be subject to such laws. According to a 50-State Survey of Health Care Information Privacy Laws, most states have privacy laws that cover at least some medical facilities.¹⁵⁷ Similarly, the American Health Lawyers Association explains, “Most states have enacted laws and regulations related to the privacy and confidentiality of individuals’ health information. Such regulations are usually set forth in facility and/or professional licensure laws, requiring both licensed health care facilities and licensed health care professionals to maintain the privacy and confidentiality of patients’ health information.”¹⁵⁸ Such laws should be enacted or amended to cover UPCs.