

Trans*+ and Intersex Representation and Pathologization: An Interdisciplinary Argument for Increased Medical Privacy

Jaydi Funk,[†] Steven Funk,^{††} & Sylvia Blaise Whelan^{†††}

DOI: <https://doi.org/10.15779/Z380C4SK4F>

[†] Dr. Jaydi Funk is a clinical pharmacist serving as a reviewer for several domestic and international journals of the pharmacological sciences and as an invited guest lecturer at various universities and conferences. Dr. Funk has conducted research (qualitative, quantitative, and mixed methods) and published on pediatric dosing, medicine and gender, and healthcare privacy. Dr. Funk's most recent research will be published in a book entitled *(Un)Educating Against the Manufacturing of Gender in Media and Medicine* (Cambridge Scholars, 2020). In this piece, Dr. Funk and a research colleague examine the connections among media and healthcare education to offer recommendations for the future of trans*+ health, trans*+ healthcare education, and a more gender equitable future for medicine. Dr. Funk enjoys camping in the Big Sky with their partner and three children, snowboarding in fresh powder, exploring the therapeutic powers of non-medicinal sources, and cooking new recipes that highlight the healing capacities of foods that encourage sustainable living.

^{††} Dr. S.S. Funk is a lecturer and student advisor at Montana State University, Billings, and Veterans Upward Bound. Named by the American Educational Research Association as an "Emerging Scholar" in 2013 for research in Critical Media Literacy, Dr. Funk serves as an editor for several journals and publications committed to advancing the education of traditionally underrepresented students and promoting the advancement of media literacy. Funk's recent book chapter, *A Trans*+ Media Literacy Framework for Navigating the Dynamically Shifting Terrain of Gender in Media: Considering Assessment of Key Competencies*, draws upon Critical Media Literacy, Feminist, and Disabilities Studies to underscore the need for the critical analysis of trans*+ representation in and engagement with media. Dr. Funk's collaborative book, *(Un)Educating Against the Manufacturing of Gender in Media and Medicine* will be published by Cambridge Scholars, forthcoming in 2020.

^{†††} Sylvia Blaise Whelan, J.D. is a Deputy Public Defender for the Fresno County Public Defender's Office. Ms. Whelan is a graduate of the University of California, Santa Barbara, where she earned a Bachelor's in History, and the Dale E. Fowler School of Law at Chapman University in Orange, California. An advocate for LGBTI rights, Ms. Whelan has served as co-president of the Chapman University chapter of OutLaw and authored the article *Whither Lies the Self: Intersex and Transgender Individuals and a Proposal for Brain-Based Legal Sex*, published by the Harvard Law and Policy Review. Ms. Whelan would like to thank her co-authors, Drs. Jaydi and Steven Funk, for contacting her and asking her to be involved in

ABSTRACT

As other countries continue to expand cultural, medical, and legal distinctions of gender, practices of the United States often reify the gender binary. Subsequently, this Article underscores the need for a critical interdisciplinary examination of the gender binary and its effects on the (re)production of gender stereotypes in media, within the medical sciences, and in law. By exploring the cultural, medical, and legal reification of the gender binary, we argue that the United States healthcare system should begin to acknowledge the spectrum of gender and to broaden patients' legal protections regarding non-disclosure and privacy.

Keywords: Gender, Gender Identity, Intersex, Transgender, Trans+ Media Literacy, Healthcare Privacy, Gender Medicine, Legal Gender, Gender Law, Non-disclosure, Sex, Pharmacokinetics, Sex Based Medicine, HIPAA, Transgender Health, Medical Ethics*

INTRODUCTION.....	118
I. TRANS*+ MEDIA LITERACY FRAMEWORK: A CULTURAL STUDIES	
APPROACH TO GENDER.....	121
A. Media Representations Pathologize Trans*+ and Intersex Identities and Normalize Invasions of Their Medical Privacy.....	124
II. MEDICAL PATHOLOGIZATION OF TRANS*+ AND INTERSEX INDIVIDUALS CAN LEAD TO NEGATIVE HEALTH OUTCOMES.....	127
A. Gender-Based Medicine: Promulgating the Myth of Unnecessary Distinctions.....	129
B. Challenging the Binary in Medicine: Changing the Patient Intake Process	132
C. Medications and Natal Sex Marker (In)Significance.....	136
III. LEGAL CONSIDERATIONS IN TRANS*+ & INTERSEX HEALTHCARE: THE NEED FOR INCREASED PRIVACY	141
A. HIPAA: Its Limitations Regarding Sex	142
B. The Murphy Bill: Evidence of the Ongoing Struggle for Trans*+ and Intersex Healthcare Privacy	143
C. Legal Solutions: The Need for Greater Privacy Protection.....	145
CONCLUSION: USING A TRANS*+ POSITIVE FRAMEWORK TO EXPAND GENDER AND MEDICAL PRIVACY	146

INTRODUCTION

The ideas proposed in this Article arise from the interdisciplinary space that emerges at the intersection of cultural narrative, science, and law. Positioning

this project, her colleagues in the Public Defender's Office for their inspiring commitment to justice and unwavering moral support, and her fiancée Ashley for her unconditional love.

medical and legal data within a cultural studies framework, this Article seeks not only to further the dialogue about trans*+ and intersex individuals, but also to increase autonomy across the spectrum of gender. We argue that patients must have increased non-disclosure and privacy rights. In support, we offer a reframing of the gender binary in medicine and medical law through a critical framework we call Trans*+Media Literacy.¹

Glancing at the contemporary American media landscape, one may surmise that much progress has been made regarding trans*+ and intersex autonomy and rights. Using a cultural studies approach to analyze media representations of trans*+ and intersex individuals, however, we find that the privacy of these individuals is seldom honored. In addition, media narratives often reinforce the stigma associated with non-cisgender and non-binary identities.²

A cultural studies approach reveals that trans*+ and intersex personhood is continuously undercut by dominant forces in culture, health care, and modes of governance. According to Judith Butler, one's sense of personhood is based upon whether the individual is identifiable:

The very criterion by which we judge a person to be a gendered being, a criterion that posits coherent gender as a presupposition of humanness, is not only one that, justly or unjustly, governs the recognizability of the human but one that informs the ways we do or do not recognize ourselves, at the level of feeling, desire, and the body, in the moments before the mirror, in the moments before the window, in the times that one turns to psychologists, to psychiatrists, to medical and legal professionals to negotiate what may well feel like the unrecognizability of one's gender and, hence, of one's personhood.³

Importantly, as Butler argues, one's gender identity is neither internal nor external, neither constructed nor perceived. Rather, it is complexly linked with the private and public spheres, and more critically, it is the most basic aspect of personhood by which our identities as human beings are designed, both by others and ourselves.⁴

As we progress into the twenty-first century—an era marked by instant communication and the neologisms of newly recognized genders and sexualities that challenge entrenched ideologies—we must ask if we are ready to challenge one of the most influential ideologies governing our society: the gender binary of the American health-care system, and more specifically patient privacy. Reified through Western culture (and exemplified through popular media), reinforced by

-
1. Steven S. Funk, "A Trans*+ Media Literacy Framework for Navigating the Dynamically Shifting Terrain of Gender in Media: Considering Assessment of Key Competencies," in *Promoting Global Competencies through Media Literacy*, 216 (2018).
 2. For an explanation of the term cisgender, see Sunnivie Brydum, "The True Meaning of the Word 'Cisgender,'" *The Advocate* (31 Jul. 2015), <https://perma.cc/DWQ2-USA2>.
 3. Judith Butler, "Doing Justice to Someone: Sex Reassignment and Allegories of Transsexuality," 7 *GLQ: A Journal of Lesbian and Gay Studies* 621, 621 (2001).
 4. *Id.*

medical practices, and policed by the legal system, the gender binary present in the United States health-care system operates as, arguably, the single most effective ideological state apparatus.⁵ The very existence of diagnoses for trans*+ individuals in the Diagnostic and Statistical Manual (DSM), published by the American Psychological Association (APA), underscores the pathologization trans*+ individuals face and how gender operates not merely to categorize, but to regulate.

The gender binary pervades every aspect of society, sets up varying matrices of power and production, and was considered “natural” until recent feminist, humanist, and post-modern critiques have suggested otherwise. These academic fields suggest that the categories of “female” and “male” are not an inevitable or innate human instinct, but rather a socially constructed set of behaviors, relationships, and rules. The rise of “gender-based medicine,”⁶ during the 1990s, while well-intentioned, has done more to develop this binary myth than to reveal the spectrum of complexities each human body exhibits. Although the Health Insurance Portability and Accountability Act (HIPAA),⁷ passed into law in 1996, grants protections for personal health information (PHI), “[t]here are no laws that specifically address [the trans*+ and/or intersex] population.”⁸ Thus, medical professionals interpret PHI and dictate some trans*+ and intersex individuals’ right to privacy. Yet, challenging the gender binary may present a rather simple solution for increasing patient privacy.

Problematizing the gender binary may be the most effective way to further social justice for trans*+⁹ and intersex¹⁰ people, who have long been silenced and marginalized by the very communities that should offer them care and protection. For these reasons, the new frontier of the struggle for gender equity will involve

-
5. See Louis Althusser, “Ideology and Ideological State Apparatuses: Notes towards an Investigation,” in *Lenin and Philosophy and Other Essays*, 85 (1971), <https://perma.cc/K4H5-HK5H>.
 6. See e.g. Josanne Vassallo, “Gender Specific Medicine in Endocrinology and Metabolism,” 20 *Journal of the Malta College of Pharmacy Practice* 24 (2014).
 7. See Health Insurance Portability and Accountability Act of 1996, Public Law 104-191, 110 Stat. 1936 (codified as amended at 26 U.S.C. §106 (1996)).
 8. See Kerryn Butler-Henderson et al., “Using Population Health, Inclusive HIM Practices to Better Treat LGBTQ Patients,” 89 *Journal of AHIMA* 24, 24-29 (2018).
 9. See sj Miller, “Trans*+ing Classrooms: The Pedagogy of Refusal as Mediator for Learning,” 5 *Social Sciences* 1, 2 (2016); Trans Student Educational Resources, “Why We Used Trans* and Why We Don’t Anymore” (last accessed 29 Mar. 2019), <https://perma.cc/KG82-DQXH> (providing information on transgender terminology and activists’ disagreements regarding the use of the asterisk after the term “trans”). We prefer the term trans*+ because some people are culturally trans*+ while some are genetically trans*+, and the term trans*+ has the disruptive potential to integrate all non-binary gender identities (including intersex, depending on the individual) and to parse out the “T” from “LGBTQ” to end the conflation of gender identity and sexuality in the popular imagination. This is a debate that will evolve in untold ways, and the use of trans*+ is by no means an attempt to erase or unnecessarily binarize any individual.
 10. While common medical literature continues to pathologize intersex individuals by their condition, we refer to intersex as a natural genetic variation that may or may not coincide with one’s gender identity as trans*+ or cisgender. See U.S. National Library of Medicine, “Intersex,” <https://perma.cc/ZGZ9-JMWT> (defining “intersex” as a “group of conditions”).

dismantling use of binary language by medical practitioners and the legal structures that buttress them.

I. TRANS*+ MEDIA LITERACY FRAMEWORK: A CULTURAL STUDIES APPROACH TO GENDER

A cultural studies approach to media literacy (“critical media literacy”) seeks to highlight constructions of normality, challenging the myth that media portrayals of culture are neutral and revealing that these portrayals often enforce societally constructed norms of acceptable behaviors and gender presentation.¹¹ Critical media literacy examines the ways that media position audiences to reproduce dominant ideologies that perpetually privilege certain identity markers while disadvantaging others.¹² The framework we use in this Article (applying Trans*+ Media Literacy) follows from a specific application of critical media literacy. Trans*+ Media Literacy challenges popular media through four core concepts:

1. Social Constructivism (Gender as Ideology): “All media are made by individuals and institutions influenced by a matrix of gender roles and expectations that influence various contexts.” People make media, and as such, people embed the ideological construct of gender into media.
2. Politics of Representation (Normalizing the Cisgender Condition): “Media and their various modes of access and delivery influence and are influenced by the representation of profit, privilege, and power related to binary gender roles.” The ideology of gender can be used to increase power and profit. Cisgender representations can drive the market, and media can exploit trans*+ individuals while ostensibly increasing representation.
3. Positionality (Production for the Cisgender Gaze): “Media messages are negotiated by individuals and groups based on myriad intersections of identity, with gender being highly salient.” All media are produced for an audience, and that audience is assumed to be cisgender.
4. Activism (Media as Contestation Sites): “Media may be used to perpetuate and/or challenge hegemonic ideologies that reinforce and/or challenge gender expansiveness.”¹³ By utilizing media as a tool of empowerment, trans*+ individuals may trans*+form the gender binary to create gender-inclusive spaces of media representation for individuals of all genders.

11. Steven S. Funk et al., “Critical Media Literacy as Transformative Pedagogy,” in *Handbook of Research on Media Literacy in the Digital Age*, 1 (2015).

12. Id. at 19 (“As heterosexual love and gender conformity are ubiquitous among media, they are assumed to be the dominant mode of living, or the only option. As a result of this dearth of representation among media, non-heterosexuals and the gender-creative suffer negative consequences.”).

13. Id.; see also Funk, note 1, at 226.

This section considers media representations of trans*+ and intersex individuals from a Trans*+ Media Literacy perspective.

To understand the rights of trans*+ and intersex individuals, it is imperative to consider the ways in which the media portrays trans*+ and intersex people as duplicitous for “deceiving” the American public.¹⁴ This notion of trans*+ deceit played out in a highly publicized case, *Colorado v. Andrade*. After killing a trans*+ woman, the defendant justified his actions by relying, “on two critical points: first, that [the victim] ‘deceived’ him about her ‘real’ sex or gender; and second, that this ‘deception’ reasonably caused [the defendant] to lose control.”¹⁵ However, this defense was ineffective, and the defendant was convicted of a hate crime. The trans*+ panic defense had been so successful until this case that media outlets were shocked to reveal that the defense was unsuccessful.¹⁶ Indeed, the lack of focus on the heinous nature of the murder (Andrade bludgeoned the victim to death with a fire extinguisher) reveals a deeply-rooted trans*+-hatred carried out by dominant news media outlets.¹⁷ It is within this mediated forum that the struggle for trans*+ and intersex rights is being cast for a nationwide audience, including health-care providers, mental-health workers, and lawmakers who are not immune to the influences of popular culture. Healthcare and legal policies are not created within a vacuum. Rather, policies are created by individuals who are steeped in this mediated cultural milieu, which succeeds at creating and maintaining a homeostasis of “normalcy.”¹⁸ And this normalcy was rigidly maintained throughout the twentieth century—particularly so with the rise of “gender-based medicine” in the 1990s.

Even as lesbian, gay, and bisexual rights came to the fore of the political discourse of the 1990s, popular culture and media representations of gender signaled the continued dominance of a rigid gender binary.¹⁹ For example, John Gray’s *Men are from Mars, Women are from Venus*, portraying men and women as “opposites,” was a bestseller.²⁰ Political arguments about “gay rights” flourished while RuPaul’s drag was considered scandalous on the pages of *Sassy*

14. Emma Brown, “Parents Wrote About Their Transgender Five-year-old, and Readers Had Strong Reactions,” *The Washington Post* (8 June 2016), <https://perma.cc/VD7W-6TNC>.

15. Morgan Tilleman, “(Trans)forming the Provocation Defense,” 100 *Journal of Criminal Law and Criminology* 1658, 1658-88 (2010).

16. Ernest Luning, “Andrade Guilty on 1st Degree Murder, Hate Crime Charges in Zapata Slaying,” *Colorado Independent* (22 Apr. 2009), <https://perma.cc/UF55-X33V>.

17. “Transgender Murder, Hate Crime Conviction a First,” *CNN* (23 Apr. 2009), <https://perma.cc/6JFQ-BTRY>.

18. For more on the relationships among media, policy, and education, see generally Joaquin Chapa et al., “Comparative Analysis of the Factors Associated with Citation and Media Coverage of Clinical Research,” 112 *Scientometrics* 1271 (2017); Michael Tesler, “Priming Predispositions and Changing Policy Positions: An Account of When Mass Opinion is Primed or Changed,” 59 *American Journal of Political Science* 806 (2015).

19. Garance Franke-Ruta, “How America Got Past the Anti-Gay Politics of the ‘90s,” *The Atlantic* (8 Apr. 2013), <https://perma.cc/ESF5-M2M4>.

20. Ben Beaumont-Thomas, “How We Made Men Are from Mars, Women Are from Venus,” *The Guardian* (26 Nov. 2018), <https://perma.cc/CHP4-DJRN>.

and *Jane* magazines.²¹ Within this 1990s American media landscape—undulating with feminist progress and conservative backlash—“gender-based medicine,” which first emerged in the 1980s as response to traditional feminist critiques that researchers and scientists largely neglected women’s health issues, also gained further traction.²² While increased attention to women’s health was a sign of progress for the feminist movement, categorizing health issues in terms of the binary further exemplifies the exclusion of trans*+ intersex individuals from the cultural narrative.

The average American media consumer faced a cultural landscape that consistently conflated sex and gender; however, academics in the fields of cultural studies, feminist, humanist, and queer theory increasingly challenged the “naturalness” of the sex/gender binary.²³ By the late 1970s, some researchers began using “gender” and “sex” as two separate terms, with “gender” referring to a cultural signifier and “sex” referring to one’s chromosomal makeup and sex organs.²⁴ In 1990, however, Judith Butler’s seminal work *Gender Trouble: Feminism and the Subversion of Identity*, not only articulated an influential critique of the gender binary but also criticized the categorization of sex (as a biological reality) when, like gender, it is also a societally created identifier used to categorize people.²⁵ Butler argued that gender is performative, meaning “[w]e act and walk and speak and talk in ways that consolidate an impression of being a man or being a woman . . . we act as if that being of a man or that being of a woman is actually an internal reality or simply something that is true about us . . . [when] actually it is a phenomenon that is being produced or reproduced all the time.”²⁶

Though decades have passed since the rise of cultural theory critiques of the gender binary,²⁷ American popular media continue to reinforce popular norms of binary gender and heteronormativity.²⁸ The predominance of these identity

-
21. Suzanna Walters, *All the Rage: The Story of Gay Visibility in America*, 248 (2001).
 22. Alyson McGregor & Esther Choo, “The Emerging Science of Gender-specific Emergency Medicine,” 98 *Rhode Island Medical Journal*, 23-24 (June 2015) (noting that gender-specific medicine first emerged in the 1980s; in 1985, for example, the National Institutes of Health established a Public Health Task Force on Women’s Health and in the 1990s began to implement its recommendations regarding the women’s health issues in studies and trials).
 23. Id. at 25 (“[G]ender-specific science is becoming a priority area of growth within [the field of emergency medicine]. A number of recent publications have drawn attention to sex- and gender-specific topics or gaps in our knowledge about sex- and gender-specific issues.”); Peter Drucker, “Conceptions of Sexual Freedom in Marcuse, Foucault and Rubin,” 2 *Journal of the International Network for Sexual Ethics and Politics* 31 (2014).
 24. Rhoda K. Unger, “Toward a Redefinition of Sex and Gender,” 34 *American Psychologist* 1085 (1979).
 25. See Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (1990).
 26. Judith Butler, *Your Behavior Creates Your Gender* (6 June 2011), <https://www.youtube.com/watch?v=Bo7o2LYATDc>.
 27. The field of cultural studies began at the University of Birmingham in 1962 and legitimized popular culture as a field worthy of academic investigation, and as a means through which social justice advocacy could advance. “About CCCS: History and Project,” *University of Birmingham* (12 Sept. 2018), <https://perma.cc/42A2-T7AW>.
 28. See Funk, note 11, at 219.

markers in popular media are so ubiquitous that they may cause trans*+ and intersex individuals to see their positionalities as having little significance in the social order.

A. Media Representations Pathologize Trans*+ and Intersex Identities and Normalize Invasions of Their Medical Privacy

Although popular media representation of intersex individuals remains nonexistent, the trans*+ discourse exploded in recent years. While trans*+ individuals have gained more media coverage and acting roles during the past decade than ever before, it remains unclear whether this increased representation has actually led to increased civil rights and quality of life for trans*+ and intersex individuals.²⁹ Contemporary media portrayals of trans*+ individuals medicalize and pathologize trans*+ identities, normalizing intrusions into the private lives of trans*+ individuals by pressuring them to disclose medical information that cisgender people have no social pressure to disclose. All too often, media representations pathologize the trans*+ identity as something that needs to be “fixed” or requires surgery to “correct,” while emphasizing the medical risks involved with transitioning.³⁰

Popular television series often aid this trend by limiting trans*+ characters to storylines that frame their trans*+ness as a medical infirmity. The popularity of television shows featuring trans*+ characters such as *Transparent*, *I Am Cait*, *Orange is the New Black*, and *Glee*, suggests a new trend in television: a defining moment for trans*+ issues being featured in popular media. Yet, only a few new media representations cast trans*+ actors in trans*+ roles, and most cast cisgender actors to play the part.³¹ Moreover, these roles continue to largely emphasize the trans*+ness of a character, rather than to focus on the character’s profession or relationships, as is common with cisgender characters. The problem is not merely that the trans*+ experience is portrayed through a cisgender lens, but also that the crux of the trans*+ character’s narrative commonly hinges upon whether they will get “the surgery,” implying that trans*+ people require alteration and lack bodily integrity and a right to privacy.³²

Cisgender characters’ narratives rarely revolve around discussions of their sex organs or medical alterations of their bodies. Rather, the interrogation of the trans*+ individual’s physicality is normalized as habitual. This is currently playing

29. GLAAD Media Institute, “Where We Are on TV,” 36 (2018), <http://perma.cc/3GNG-BCL8>; see also Shon Faye, “Trans Visibility is Greater than Ever—but that’s a Double-Edged Sword,” *The Guardian* (30 Mar. 2018), <https://perma.cc/PA54-ZTXX>.

30. See Funk, note 11, at 218-19; Michael Brown, “What the Sex-Change Industry Doesn’t Tell You,” *Charisma News* (4 Oct. 2013), <https://perma.cc/827P-WR9W>; Walt Heyer, “Fifty-Six Shades of Gender Insanity,” *The Federalist* (10 Mar. 2015), <https://perma.cc/ACJ9-HU4E>.

31. Sam Levin, “‘Third-Class Citizens’: Trans Actors See Stereotyping and Exclusion in Hollywood,” *The Guardian* (9 Jul. 2018), <https://perma.cc/4Y9B-NCBJ>.

32. See e.g. Steven Funk & Jaydi Funk, “Transgender Dispossession in *Transparent*: Coming Out as a Euphemism for Honesty,” 20 *Sexuality and Culture* 879, 883 (2016).

out on *I am Jazz*, a documentary of a young trans*+ woman living in Florida. Although the show began chronicling her life when she was in the sixth grade, it immediately focused on her body and questioned when Jazz would undergo gender affirmation surgery to make her body conform to cisgender standards. *I Am Jazz* represents a current trend in reality TV that positions transgender stars in a state of perpetual conflict, showing how their public mediated selves require reaffirmation to maintain rather than disrupt normative culture.³³ By repeatedly televising the trope of perpetually conflicted trans*+ individuals, media reinforce the dominant cisgender perspective.

The entertainment news industry also reinforces the cultural narrative that trans*+ people merit less privacy by virtue of not being cisgender. This industry has long taken for granted that it can interrogate trans*+ stars about their genitalia and sex lives in a manner that most viewers would recognize as invasive if the questions were directed towards cisgender actors.³⁴ Ironically, because of the normalization of this media dialogue, Caitlyn Jenner herself contributed to the abnegation of privacy of the trans*+ individual in her show, *I Am Cait*. As Jenner discusses the intricacies of gender affirmation or “reassignment” surgery, she gives the largely cisgender audience what it has come to expect over the years: the answer to what she has “down there.”³⁵ The cisgender perspective accounted for in all major American media conglomerates, often referred to as the “cisgender gaze,”³⁶ expects the trans*+ character to answer this question and defend their trans*+ness to a cisgender audience. As Hilton-Morrow and Battles explain:

All of these questions [about trans*+ genitalia] focus on areas of the body generally considered private but associated with deep-seated cultural assumptions of what it means to be a man or a woman. By the mere adoption of the identity of transgender, people find themselves under the powerful and disciplining cisgender gaze.³⁷

Regularly, genital surgery is treated among mainstream media as the final “litmus test” one must pass in order to be considered “fully” transitioned.³⁸

Katie Couric’s interview with Carmen Carrera, a model, and Laverne Cox, a model and actress, provides an oft-criticized example of this line of questioning.

33. Jessica Johnston, “The Reality of ‘Messy Real Life’: Jazz Jennings and the Dramatization of Young Transgender Celebrity on TLC’s *I Am Jazz*,” 9 *Celebrity Studies* 455 (2018).

34. Alicia Menendez, *Interview with Janet Mock* (29 Apr. 2014), <https://www.youtube.com/watch?v=ISsdSvJhniQ>.

35. Mehera Bonner, “‘I Am Cait’ Recap: Caitlyn Jenner Considers Gender Confirmation Surgery, Meets with Surgeon,” *Us Weekly* (18 Apr. 2016), <https://perma.cc/2W92-EGD5>.

36. Wendy Hilton-Morrow & Kathleen Battles, *Sexual Identities & the Media: An Introduction*, 240 (2015).

37. *Id.*

38. See generally Funk & Funk, note 32; Lenny Bernstein, “Here’s How Sex Reassignment Surgery Works,” *The Washington Post* (9 Feb. 2015), <https://perma.cc/6RG7-2DXS>; Jessica Wakeman, “Life-Changing’ Surgery Gives Transgender Man a Penis Made from His Own Body,” *Healthline* (19 Jul. 2018), <https://perma.cc/2AFE-WS6F>.

In this televised interview, Couric crudely and persistently asked both women if they had undergone gender-affirming surgery even as both deflected and attempted to point out the invasive nature of such questioning.³⁹ When ABC news reported Chaz Bono's gender transition in 2012, it framed his possible genital surgery as the "final step in his transition from female to male."⁴⁰ Moreover, the news site detailed his trepidation about genital surgery and gave the (overwhelmingly cisgender) audience a detailed account of the procedure and how it would affect Bono's genitalia.⁴¹ The media's invasive line of questioning directed at trans*+ individuals is something trans*+ activist Janet Mock actively opposes.⁴²

To reveal the effects of cisgender privilege, Mock reversed roles with cisgender reporter Alicia Menendez by asking questions such as, "Who was the first person you told that you were cis?" and "What is the one thing viewers need to know about cis people?"⁴³ The Mock/Menendez interview effectively underscores how trans*+ individuals are generally regarded as spectacles to be studied for entertainment, rather than as autonomous human beings with the right to privacy. This discrimination against trans*+ people may be defended by a long-held belief that being trans*+ is a mental disease.⁴⁴ As such, cisgender people may presume that their intrusiveness is justified by innocent curiosity to understand this medical or mental condition.⁴⁵ The presumption that trans*+ bodies are a medical anomaly normalizes that cis bodies have a right to privacy and simultaneously justifies cisgender curiosity about trans*+ bodies.

In contrast, intersex representation among mainstream media remains unseen. Intersex, a naturally occurring state that adds variety to the human genome, is similar to trans*+ in that both have been pathologized for the sake of

39. At one point, Carrera had to go so far as shush Couric as she asked, "Your, your, your private parts are different now, aren't they?" See J. Bryan Lowder, "Katie Couric Offers a 'Possibility Model' for How to Conduct a Really Offensive Transgender Interview," *Slate* (7 Jan. 2014), <https://perma.cc/D7EX-S9YK>.
40. Susan Donaldson James, "Trans Chaz Bono Eyes Risky Surgery to Construct Penis," *ABC News* (6 Jan. 2012), <https://perma.cc/6LHS-Y5VA>.
41. *Id.*
42. See Stephen Russell, "Janet Mock and the Complexity of Speaking Up," *Special Broadcasting Service* (29 Aug. 2017), <https://perma.cc/BC59-Y2RY> ("That's one of the most difficult things about being a writer from a marginalized community, that you then get pigeonholed not just as a single person with a single experience, but your marginalized experience, because it's so rarely heard, becomes seen as representative of an entire community . . .").
43. Janet Mock, "Why I Asked Alicia Menendez about Her Vagina & Other Invasive Questions," *JanetMock.com* (1 May 2014), <https://perma.cc/9ESS-Q775>; see also Menendez, note 34.
44. See generally Michael W. Chapman, "Johns Hopkins Psychiatrist: Transgender Is 'Mental Disorder;' Sex Change 'Biologically Impossible,'" *CNS News* (2 June 2015), <https://perma.cc/4FXG-PEDT>; Michelle Cretella, *Dr. Michelle Cretella on Transgenderism: A Mental Illness is Not a Civil Right* (14 Nov. 2017), <https://www.youtube.com/watch?v=s57T27M1ZXk>.
45. Sam Dylan Finch, "130+ Examples of Cis Privilege in All Areas of Life for You to Reflect on and Address," *Everyday Feminism* (29 Feb. 2016), <https://perma.cc/2MRY-S6X7>; Christin Scarlett Milloy, "The Top 19 Questions Trans* People Get Asked," *Slate* (26 Feb. 2014), <https://perma.cc/N9JM-37C7>.

upholding the construction of the gender binary.⁴⁶ However, despite lively contemporary debates over intersex rights, the media frontier for representations of intersex individuals remains a vast space of silence.⁴⁷ In contrast to the increasing frequency with which trans*+ characters are featured in popular media, intersex characters are not represented in media.⁴⁸

Unfortunately, media silence surrounding intersex individuals may propagate the belief that there is something “wrong” with intersex individuals, that something “needs to be fixed,” and as such, that they should be rendered invisible.⁴⁹ The myths promulgated by media are created and reinforced by medical and mental health-care providers who serve as gatekeepers to care and legal rights.⁵⁰ In turn, the myths of pathology become self-propheying, moving cyclically from professional communities through media, and back to professional communities. Breaking this self-feeding loop will be a critical step in protecting the rights of trans*+ and intersex individuals to protect their privacy, autonomy, and bodily sovereignty.

II. MEDICAL PATHOLOGIZATION OF TRANS*+ AND INTERSEX INDIVIDUALS CAN LEAD TO NEGATIVE HEALTH OUTCOMES

Contemporary research for the rights of trans*+ and intersex individuals argues that the pathologization of trans*+ and intersex individuals by the American Psychological Association (APA) and the American Medical Association (AMA) caused a cultural ripple effect of stigmatization.⁵¹ Rosemarie Garland-Thomson, a specialist in the interdisciplinary study of English and bioethics within a critical disability studies framework, argues, “[t]he medical commitment to healing, when coupled with modernity’s faith in technology and interventions that control outcomes, has increasingly shifted toward an aggressive intent to fix, regulate, or eradicate ostensibly deviant bodies.”⁵² The ways that the

-
46. See Margaret Schneider et al., “Answers to Your Questions about Individuals with Intersex Conditions,” *American Psychological Association* (2006), <https://perma.cc/C32D-EM4R>.
 47. See generally Alice Dreger & Amy Herndon, “Progress and Politics in the Intersex Rights Movement: Feminist Theory in Action,” 15 *GLQ: A Journal of Lesbian and Gay Studies* 199 (2009); Morgan Carpenter, “The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change,” 24 *Reproductive Health Matters* 74 (2016).
 48. See Stephen Kerry, “Representation of Intersex in News Media: The Case of Kathleen Worrall,” 20 *Journal of Gender Studies* 263 (2011).
 49. See generally Angela Onwuachi-Willig, *Good Silences, Bad Silences, Unforgivable Silences*, *The Chronicle of Higher Education* (29 Oct. 2012), <https://perma.cc/3AKQ-AEZK>; Sara Radin, “Intersex Stories Need to Be Heard, and this Multimedia Project is Amplifying Them,” *them.us* (26 Oct. 2018), <https://perma.cc/RD5P-H5WK>.
 50. See generally Evan Urquhart, “Gatekeepers vs. Informed Consent: Who Decides When a Trans Person Can Medically Transition?” *Slate* (11 Mar. 2016), <https://perma.cc/7879-P49Y>; Walter Bockting et al., “Patient Satisfaction with Transgender Health Services,” 30 *Journal of Sex & Marital Therapy* 77 (2004); see also Rupert Raj, “Towards a Transpositive Therapeutic Model: Developing Clinical Sensitivity and Cultural Competence in the Effective Support of Transsexual and Transgender Clients,” 6 *International Journal of Transgenderism* 1 (2002).
 51. Funk & Funk, note 32.
 52. Rosemarie Garland-Thompson, “Integrating Disability, Transforming Feminist Theory,” 14

APA and AMA have aided in the criminalization and pathologization of trans*+ people profoundly affects how these individuals are imagined, policed, and treated by health-care professionals, as well as the general population.⁵³ This general stigmatization leads to myriad negative health outcomes.

According to the Institute of Medicine, “LGBT[IA] youth face not only the same challenges as their heterosexual [cisgender] peers, but also stigma that may contribute to the identified disparities in health status between sexual- and gender-minority youth and heterosexual youth.”⁵⁴ While medical facilities are traditionally known to “do no harm,” the mental and medical diagnoses of trans*+ and intersex may have eroded these individuals’ right to privacy. Like trans*+ individuals, people with disabilities are often viewed as “abnormal” by medical professionals. This can fuel a perception that people with physical differences lack a fully-realized sense of personhood, and therefore deserve different civil liberties and/or protections.⁵⁵

In addition, most medical practitioners require a letter from a mental health specialist detailing the patient’s history with “gender dysphoria,” as well as a record of psychotherapy, in order to provide gender-affirming treatments, such as hormones and surgery.⁵⁶ The high cost of medical transition is well-documented and a significant barrier to many.⁵⁷ At the same time, trans*+ and intersex individuals (and often their guardians) try to, or are coerced to, conform to binary sex categories because few states allow for patients to legally identify themselves as anything other than male or female.⁵⁸ Because there is no guidance regarding what constitutes a proper “gender dysphoria letter,” mental health professionals

Feminist Disability Studies 1, 14 (2002).

53. See Cathy Kelleher, “Minority Stress and Health: Implications for Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) Young People,” 22 *Counselling Psychology Quarterly* 373 (2009); Stanley R. Vance et al., “Opinions About the DSM Gender Identity Disorder Diagnosis: Results from an International Survey Administered to Organizations Concerned with the Welfare of Transgender People,” 12 *International Journal of Transgenderism* 1, 142 (2010).
54. Institute of Medicine et al., “Childhood/Adolescence,” in *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, 4-1, 4-1 (2011).
55. Bill Hughes, “Disability Activisms: Social Model Stalwarts and Biological Citizens,” 24 *Disability & Society* 677 (2009); Maayan Agmon et al., “The Person in the Disabled Body: A Perspective on Culture and Personhood from the Margins,” 15 *International Journal for Equity in Health* 147 (2016).
56. Stephanie Budge, “Psychotherapists as Gatekeepers: An Evidence-Based Case Study the Role and Process of Letter Writing for Transgender Clients,” 52 *Psychotherapy* 287, 294 (2015) (noting that while most laws vary by state, practitioners typically require such letter).
57. Alyssa Jackson, “The High Cost of Being Transgender,” *CNN* (31 Jul. 2015), <https://perma.cc/BX2U-9W5Z>.
58. Annie Tritt, “States are Starting to Recognize a Third Gender. Here’s what that Means for Nonbinary Youth,” *Vox* (2 Apr. 2018), <https://perma.cc/ZY3V-2AHG> (“Nonbinary gender identity is not recognized by most states. . . . Oregon became the first to recognize a nonbinary gender option on driver’s licenses. . . . Washington, DC, and three more states followed suit: Washington, New York, and California, which became the first state to allow nonbinary residents to change their gender on all relevant legal documents, including birth certificates, to a gender-neutral option.”).

are left to decide whether a patient is ready to and worthy of transition.⁵⁹ Consequently, this has created an industry comprised of complex systems and criteria that one must navigate to begin the medical transition process or secure legal forms of identification,⁶⁰ employment,⁶¹ benefits, and medical procedures.⁶²

Discrimination against trans*+ and intersex individuals does not end once they have successfully maneuvered through the APA requirements⁶³ to “qualify” for medical treatment. Unfortunately, as explained in the next section, trans*+ and intersex individuals suffer the *most* discrimination in medical settings—from microaggressions⁶⁴ to overt hostility from medical providers.⁶⁵ In turn, current medical and legal practices often justify the behavior of perpetrators.

A. Gender-Based Medicine: Promulgating the Myth of Unnecessary Distinctions

The notion of “gender-based medicine” has only recently come under scrutiny, as many in the health sciences field are highlighting limitations of the gender binary. Take for example the United States Food and Drug Administration (FDA), which implemented “gender difference” guidance to more adequately tailor healthcare.⁶⁶ While the FDA’s intent was to capture data and provide more equitable and effective care for everyone, the creation of gender-based medicine may have only served to propagate myths about the “differences” between men and women, rather than to increase medical efficacy. Moreover, the term “gender” seems to have become common nomenclature for what has been called “sex”—both clinically and historically.⁶⁷

59. Id.

60. See Tiq Milan, “Transgender Women Denied Updated License Photo at West Virginia DMV,” *GLAAD* (10 Jul. 2014), <https://perma.cc/DFD5-P6TA>.

61. See Melanie Brewster et al., “Voices from Beyond: A Thematic Content Analysis of Transgender Employees’ Workplace Experiences,” 1 *Psychology of Sexual Orientation and Gender Diversity* 159 (2010).

62. World Professional Association for Transgender Health, “Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People” (2011), <https://perma.cc/AQ6T-Z495>.

63. See American Psychological Association, “Guidelines for Psychological Practice with Transgender and Gender Nonconforming People,” 70 *American Psychologist* 832 (2015).

64. See Anneliese Singh et al., “Strength in the Face of Adversity: Resilience Strategies of Transgender Individuals,” 89 *Journal of Counseling and Development* 20 (2011).

65. See Judith Bradford et al., *The Health, Health-Related Needs, and Lifecourse Experiences of Transgender Virginians*, 4 (2007) (noting that 24 percent of transgender Virginians experienced discrimination by a doctor or other healthcare provider).

66. United States Food and Drug Administration, “Evaluation of Gender Differences in Clinical Investigations” (25 Jan. 2016) (“On July 22, 1993, the FDA published the Guideline for the Study and Evaluation of Gender Differences in the Clinical Evaluation of Drugs, in the Federal Register [58 FR 39406]. The guideline was developed amidst growing concerns that the drug development process did not provide adequate information about the effects of drugs or biological products in women and a general consensus that women should be allowed to determine for themselves the appropriateness of participating in early clinical trials.”).

67. Wolfgang Aichhorn et al., “Gender Differences in Pharmacokinetics and Side Effects of Second Generation Antipsychotic Drugs,” 3 *Current Neuropsychology* 73 (2005); see also

A search for peer-reviewed journal articles on dosing medications reveals that there is a dearth of research in several areas, including terminology usage, hormone effects on drug metabolism, hormone interactions with or effects on comorbidities, and genetic sex marker effects on drug metabolism.⁶⁸ And there appears to be a lack of understanding regarding terminology. The terms “gender” and “sex” are used incorrectly in many medical research articles.⁶⁹ Even in articles purportedly addressing sex and gender specifically in medicine, the two terms are conflated.⁷⁰ The term “sex” should be used to describe “presence of the kind of chromosome present in the somatic cell without regard to the phenotypic manifestation.”⁷¹ Because the most individuals will not have genetic testing, sex chromosomes may not always be known. While genitals visible at birth typically coincide with one of two sexes and foretell what hormones an individual will produce, and what hormone receptors their bodies will express without medical treatment, there is a range of genetic sexes.⁷² It is important to note that genetic sexes other than XX female and XY male are *atypical* (not typical or uncommon), not *abnormal* (deviating from the norm in a problematic way).⁷³

The spectrum of intersex individuals makes clear that sex among the human genome is not strictly dimorphic. One estimate of the frequency of babies born with atypical genitalia is currently around 1 in 1,500 births.⁷⁴ Some infants appear (phenotype) to be intersex, but are not genetically (genotype) intersex (having sex chromosomes other than the dimorphic XX or XY combination) as they may have a developmental complication, such as chryptorchidism (undescended testicle(s)), which occurs in 1.6 percent to 9.0 percent of live births of individuals typically of XY sex chromosomes.⁷⁵ When accounting for phenotypic variations and genotypic sex chromosome combinations other than XX and XY, current medical literature estimates the frequency of intersex live births at between 1.7 percent and 4.9 percent.⁷⁶ Others are born with intersex conditions (non-dimorphic) that are

Teresa Chu, “Gender Differences in Pharmacokinetics,” 39 *U.S. Pharmacology* 40 (2014).

68. Search terms included: gender-based dosing, intersex dosing, intersex medicine, narrow therapeutic index drugs, pharmacogenomics, pharmacokinetics, sex-based dosing, transgender based dosing, and transgender medicine.
69. See e.g. E. Tanaka, “Gender-related Differences in Pharmacokinetics and Their Clinical Significance,” 24 *Journal of Clinical Pharmacy and Therapeutics* 339 (1999).
70. Alyson J. McGregor & Esther Choo, “The Emerging Science of Gender-Specific Emergency Medicine,” 98 *Rhode Island Medical Journal* 23 (Jun. 2015).
71. Biology-Online Dictionary, “Genetic Sex,” (9 Dec. 2009), <https://perma.cc/Y4QV-NG3A>.
72. Athletes competing in women’s division have been subjected to high rates of required genetic testing, demonstrating how sex chromosomes are not inherently linked to a person’s perceived “sex.” For more information see Ruth Padawer, “The Humiliating Practice of Sex-Testing Female Athletes,” *New York Times Magazine* (28 Jun. 2016), <https://perma.cc/PP3E-ZTDN>.
73. World Health Organization, “Genetic Components of Sex and Gender,” <https://perma.cc/FN5D-PNXH>.
74. Intersex Campaign for Equality, “How Common is Intersex? An Explanation of the Stats,” (1 Apr. 2015), <https://perma.cc/W2YB-LRV6>
75. Katrine Bay et al., “Testicular Descent: INSL3, Testosterone, Genes and the Intrauterine Milieu,” 8 *Nature Reviews* 187, 190 (2011).
76. Tiffany Jones, “Intersex Studies: A Systematic Review of International Health Literature,” 8 *SAGE Open* 1, 1 (2018).

not noticed until puberty or beyond, bringing the percentage of people whose bodies differ from the standard male or female estimated to be 2 percent.⁷⁷

Myriad combinations of sex genotypes, other than XX female and XY male, are possible and recorded in the literature⁷⁸ Among the most common are XXYY, XX male, XXX, XYY, XXY, and XO.⁷⁹ Beyond the numerous non-dimorphic karyotypes, there are conditions that can cause a dimorphic XY carrier to develop the secondary sex characteristics commonly associated with XX carrier bodies, and that can cause a dimorphic XX carrier to develop the secondary sex characteristics commonly associated with XY carrier bodies. One such condition is androgen insensitivity syndrome (AIS), which renders an XY male incapable of absorbing androgens (“male” sex hormones, such as dehydroepiandrosterone, dehydroepiandrosterone sulfate, androstenedione, and testosterone).⁸⁰ Individuals with AIS have XY sex chromosomes and, typically, female phenotypes. Congenital Adrenal Hyperplasia is a condition that causes the adrenal glands to produce excess androgens.⁸¹ XX females with this condition are sometimes labelled male at birth because of testosterone’s effects on their genitalia in utero.⁸² Literature addressing the frequency of intersex conditions notes that “developmental biology suggests that a belief in absolute sexual dimorphism is wrong.”⁸³ Because of the non-dimorphic conditions prevalent within the human genome, it is increasingly important that language distinguish between sex and gender.

The term “gender” should be used to describe a range of characteristics (phenotypical, psychological, behavioral, and cultural) that make one feel masculine, feminine, or any combination of these and other presentations.⁸⁴ This concept is aptly captured by Butler:

Gender is not passively scripted on the body, and neither is it determined by nature, language, the symbolic, or the overwhelming history of patriarchy. Gender is what is put on, invariably, under constraint, daily and incessantly, with anxiety and pleasure, but if this continuous act is mistaken for a natural or linguistic given, power is relinquished to expand the cultural field bodily

77. Melanie Blackless et al. “How Sexually Dimorphic Are We? A Review and Synthesis,” 12 *American Journal of Human Biology* 151 (11 Feb. 2000) <https://perma.cc/856L-KPG7>.

78. Xuqi Chen et al., “The Number of x Chromosomes Causes Sex Differences in Adiposity of Mice,” 8 *PLoS Genet* (2012); J.C. Link et al., “Metabolic Impact of Sex Chromosomes,” 2 *Adipocyte* 74 (2013); Eric Chang et al., “Gender and Sex Differences in Adipose Tissue,” 18 *Current Diabetes Reports* 68 (2018).

79. Blackless et al., note 77, at 152-54.

80. “Androgen Insensitivity Syndrome,” *U.S. National Library of Medicine*, <https://perma.cc/SH2B-C9SK>.

81. Courtney Finlayson et al., “Baseline Characteristics of Infants with Atypical Genital Development: Phenotypes, Diagnosis, and Sex of Rearing,” 3 *Journal of Endocrine Society* 264 (2019).

82. *Id.* at 267.

83. Blackless et al., note 77, at 153.

84. Judith Butler, “Performative Acts and Gender Constitution: An Essay in Phenomenology and Feminist Theory,” 40 *Theatre Journal* 519 (1988).

through subversive performance of various kinds.⁸⁵

Gender is performed, assigned, debated, and fluid. While many patients may feel a strong sense of gender identity that is immutable, some may not. Sex and gender are not always synonymous, and it is important for healthcare providers to understand that sex and gender may be both sensitive and (ir)relevant for each patient.

For example, consider a patient who consults with a physician for a sore throat. The patient presents as phenotypical male (facial hair, prominent larynx, broad shoulders), identifies as agender, and knows their chromosomes are XXY. It is worthy to question whether that physician should know that the patient's sex is XXY. The patient's birth certificate could be male or female (according to the state in which they were born), and the patient declines to mark a binary sex (or gender if the form conflates the two) designation box on their intake form.

To start, the physician should address the patient by their appropriate pronouns, which should be identified by asking the patient—not by simply inferring from the patient's name. The physician should think about whether that information might help determine the course of treatment. If this physician is not a specialist in endocrinology, obstetrics and gynecology, or urology, for example, then they should not ask merely for curiosity's sake. In this case, knowing the patient's gender is unlikely to assist in treating a sore throat. Additional inquiry should be limited to questions that will ensure proper care for the patient.

Sex and gender are not binary, and healthcare providers should be sensitive to the information provided on intake forms (even if it appears to be a basic identifier). To patients whose sex and gender are not binary or normative, navigating the healthcare system can be complicated. The intake process, including both intake forms and physician consultation, could be more comprehensive and inclusive. This would allow healthcare partners to collect required information and encourage patients to share information that is essential to their care.⁸⁶

B. Challenging the Binary in Medicine: Changing the Patient Intake Process

Gender appears to be medically significant because hospital rooms are separated by gender, vitamins and medications are frequently marketed to male *or* female customers, and because gender (or sex) is one of the first markers of identification that patients divulge on medical forms. Yet, to understand the extent to which identifying one's sex or gender identity is necessary to administer appropriate care, we must first review the way medicine works.

85. Id. at 531.

86. See generally Madeline B. Deutsch, & David Buchholz, "Electronic Health Records and Transgender Patients—Practical Recommendations for the Collection of Gender Identity Data," 30 *Journal of General Internal Medicine* 843 (2015).

Medications are dosed based on pharmacokinetics, pharmacodynamics, and physiology.⁸⁷ Pharmacokinetics involve the absorption, bioavailability, volume of distribution, metabolism, excretion, and protein binding of drugs.⁸⁸ Pharmacodynamics involve receptor binding and chemical interactions.⁸⁹ Physiological characteristics that influence a drug's pharmacodynamics include body weight, age, organ size, body fat, glomerular filtration rate, and gastric motility.⁹⁰

A significant physiological difference between cisgender male (XY sex chromosomes) and female (XX sex chromosomes) patients is gastric motility. Cisgender men typically clear drugs 15 percent faster than do cisgender female patients, which is accounted by the Cockcroft-Gault (CG) method for calculating creatinine clearance.⁹¹ Developed in 1973, CG used data from 249 (assumedly) cisgender men.⁹² “A coefficient of 0.85 was arbitrarily assigned for women due to their reduced muscle mass compared to men, and this coefficient is widely used today.”⁹³ According to the National Kidney Foundation, however, the CG method is “no longer recommended for use because it has not been expressed using standardized creatinine values.”⁹⁴ However, because studies have historically used the CG method to determine levels of kidney function for dosage adjustments in drug labels, it remains in use clinically.⁹⁵

Typically, cisgender female (XX) bodies have less muscle mass than do cisgender male (XY) bodies, and “[t]he main factors affecting creatinine generation are muscle mass and diet.”⁹⁶ Meaning, cisgender female (XX) bodies have less creatinine generation when compared to cisgender male (XY) bodies.⁹⁷ It is important to note, however, that the genetic sex markers of a person do not necessarily determine creatinine production. Take for example those who follow a vegan diet, which will likewise lead to a decrease in creatinine generation.⁹⁸

-
87. Louis J. Gooren & Guy T'Sjoen, “Endocrine Treatment of Aging Transgender People,” 19 *Reviews in Endocrine and Metabolic Disorders* 253 (2018).
 88. Jaime A. Yáñez et al., “Flip-flop Pharmacokinetics – Delivering a Reversal of Disposition: Challenges and Opportunities During Drug Development,” 2 *Therapeutic Delivery* 643 (2011).
 89. Yu-hong Li et al., “Influence of Age and Sex on Pharmacodynamics of Propofol in Neurosurgical Patients: Model Development,” 27 *Acta Pharmacologica Sinica* 629 (2006).
 90. Offie P. Soldin et al., “Sex Differences in Drug Disposition,” 2011 *Journal of Biomedicine and Biotechnology* 1 (2011).
 91. National Kidney Foundation, “Frequently Asked Questions about GFR Estimates,” <https://perma.cc/CE3C-J7ML>.
 92. Id.
 93. “Pharmacokinetics and Drug Dosing: Back to Basics,” *Therapeutic Research Center*, Course Number 217 (2017).
 94. National Kidney Foundation, “Cockcroft-Gault Formula” (2017), <https://perma.cc/L7U7-4UMA>.
 95. Elliott Perlin et al., “Clinical Pharmacokinetics: A Simplified Approach, Part 1,” 77 *Journal of the National Medical Association* 475 (1985).
 96. National Kidney Foundation, note 91.
 97. Perlin, note 95, at 476.
 98. S.V. Subramanyam et al., “Treatment of Chronic Kidney Disease Patients with a Supplemented Low Protein Diet and a Supplemented Very Low Protein Diet,” 31 *Kidney Research and Clinical Practice* A61 (2012).

Moreover, the cultural changes that have transpired in the United States since the 1970s, specifically the rise in obesity and the decrease in physical activity, may have narrowed the gap (which the CG method never determined scientifically) in creatinine production and clearance between patients with XY and XX sex chromosomes.⁹⁹ The CG method was developed in an era when gender and ethnic minorities were underrepresented in scientific research.¹⁰⁰ Similarly, today, the paucity of research on trans*+ and intersex individuals is palpable.

Because most scientific research examines the results of hormone supplementation among cisgender patients, much of the medical literature explaining the changes hormones induce does so through citing treatments for androgen (testosterone) and estrogen deficiencies, not replacement/supplementation for the purposes trans*+ or intersex individuals. To date, no empirical evidence can tell a health-care practitioner how a trans*+ female body (XY) on hormone therapy generates creatinine and how this affects her response to medications. Medical literature details the visible changes estrogen induces, such as losing muscle and shifting fat deposition.¹⁰¹ For example:

Fat will begin to collect around [the] hips and thighs and the muscles in [the] arms and legs will become less defined and have a smoother appearance as the fat just below [the] skin becomes a bit thicker. Hormones will not have a significant effect on the fat in [their] abdomen, also known as [the] “gut.” [They] can also expect [their] muscle mass and strength to decrease significantly.¹⁰²

As opposed to how “[a]ndrogen deficiency account[s] for decreases in lean mass, muscle size, and strength,”¹⁰³ testosterone supplementation/replacement will cause one’s body to gain muscle mass.¹⁰⁴

Yet, while there is evidence regarding the external changes that hormones cause, virtually nothing is known about how the organs of a trans*+ or intersex body absorb, secrete, and process medications. Until more studies are conducted, the pharmacokinetic responses of trans*+ and intersex individuals remain

99. R. Pasquali et al., “Sex-Dependent Role of Glucocorticoids and Androgens in the Pathophysiology of Human Obesity,” 32 *International Journal of Obesity* 1764 (2008); David W. Haslam & W.P.T. James, “Obesity,” 366 *The Lancet* 1197 (2005); Jesse Roth et al., “The Obesity Pandemic: Where Have We Been and Where Are We Going?” 12 *Obesity Research* 88S (2004).

100. Jill Fisher & Corey Kalbaugh, “Challenging Assumptions About Minority Participation in US Clinical Research,” 101 *American Journal of Public Health* 2217 (2011); “Estimating Glomerular Filtration Rate,” *National Institute of Diabetes and Digestive Kidney Diseases*, <https://perma.cc/BZ7Y-3TTC> (noting limitations of the CKD-EPI and MDRD equations).

101. Maddie Deutsch, “Information on Estrogen Hormone Therapy,” *UCSF Transgender Care*, <https://perma.cc/9UV2-2HZA>.

102. Id.

103. See Joel Finkelstein et al., “Gonadal Steroids and Body Composition, Strength, and Sexual Function in Men,” 369 *New England Journal of Medicine* 1011, 1021 (2013).

104. Wylie Hembree et al., “Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons: An Endocrine Society Clinical Practice Guideline,” 102 *Journal of Clinical Endocrinology & Metabolism* 3869, 3886 (1 Nov. 2017), <https://perma.cc/2Q59-2BQM>.

unknown. With so many unknown variables, trans*+ and intersex bodies should be treated no differently than cisgender bodies. However, increasing social justice for all genders and sexes in medical settings will need to start with completely revising the way the American healthcare industry thinks about patients, their sex, their gender, and their privacy.

Before individuals see a care provider, they must complete a medical history form. Such a form may not initially seem problematic, but the binary option of “male” or “female” may demonstrate indifference or bias on the part of the healthcare provider—regardless of that provider’s intention. Unfortunately, prejudices against trans*+ or intersex individuals exist and create “barriers to accessing timely, culturally competent, medically appropriate, and respectful care.”¹⁰⁵ Recent research has confirmed that trans*+ individuals face discrimination, both overtly hostile and subtly passive aggressive, in medical settings. In a recent study, “19% of respondents reported having been denied health care by a provider because of their gender identity, and 28% reported verbal harassment in a medical setting. More than a quarter (28%) of respondents postponed care because of discrimination and disrespect, and a third (33%) postponed preventive care.”¹⁰⁶

Check-boxes on medical intake forms that only solicit binary sex responses should be altogether eliminated. After all, a patient’s sex listed on a birth certificate offers little more than an identifying mark not medically important to treatment. Instead, forms should ask for a patient’s medical history, allowing patients to list body parts (or check them off from a comprehensive list) that may need annual check-ups, such as a breast or prostate exam. A more comprehensive form will allow patients to communicate what they feel is important for that visit. Patients should be informed that they can choose to not disclose information about their genitals or reproductive organs when visiting an unrelated specialist, such as an ear/nose/throat doctor. In other words, patients deserve to know that they can protect their right to privacy.

For example, consider the aforementioned XXY agender patient being seen for a sore throat. This individual should be able to choose whether to disclose their intersex status and/or gender identity. In turn, the patient would feel more comfortable and would be more likely to share relevant information, ensuring a comprehensive and successful examination. By acknowledging that gender is a spectrum, the medical field could better serve patients. Medical intake forms allowing for a broad range of genders and bodily configurations would not only help trans*+ and intersex patients navigate the sometimes-complicated terrain of medical settings, but it would also afford cisgender patients opportunities to discover whether they could also benefit from hormone therapy. Because cisgender binary bodies have been the historical medical norm, cisgender

105. Daphna Stroumsa, “The State of Transgender Health Care: Policy, Law, and Medical Frameworks,” 104 *American Journal of Public Health* 31 (2014), <https://perma.cc/6WSE-3DPS>.

106. *Id.*

individuals may forget that among their bodies a wide range of hormonal fluctuations occur, and that hormone supplementation/replacement is not merely for trans*+ and intersex individuals.

By creating a more gender inclusive and comprehensive medical intake form, health-care providers could reduce the cisgender privilege that has contributed to the current ideological state regarding binarism while validating those who identify as something other than cisgender. Shifting cultural norms will not fully satisfy this endeavor. Rather, we must create legal protections that acknowledge gender as a spectrum and protect patient privacy to increase safety and autonomy.

C. Medications and Natal Sex Marker (In)Significance

Considering that researchers do not understand the physiological changes that occur during a gender transition, we propose that knowing the natal sex marker of an individual does not always help when dosing medication. Many factors are unknown: an individual's organ sizes, their fat distribution, their volume of distribution, or their gastric transit times based upon their natal sex marker. Thus, generalizations about how cisgender bodies operate are just that—generalizations. And they do not necessarily aid in determining the best medical treatment possible.

There is insufficient clinical proof of the effectiveness of gender-based medicine. Moreover, data examining sex differences “are mostly obtained by *posthoc* analysis and, therefore, the conclusions that can be drawn are limited. For a better understanding of the basic mechanisms of sex differences, future studies should be designed with a primary focus on this topic.”¹⁰⁷ Medical scientists have recently begun to understand that the relationships among biological sex, gender, and health need more research, because “gender-based medicine” is not data driven.¹⁰⁸ Even less research investigates trans*+ and intersex health.¹⁰⁹ For example, there are no dosing guidelines for patients who are trans*+ or intersex. Nor have studies explored trans*+ or intersex responses to medications, other than those conducted on hormone replacement therapies.¹¹⁰

One such study, considered whether there is a correlation between estrogen therapy and the prevalence of cardiovascular disease, cerebrovascular disease,

107. Offie Soldin & Donald Mattison, “Sex Differences in Pharmacokinetics and Pharmacodynamics,” 48 *Clinical Pharmacokinetics* 143, 154 (2009).

108. Elisa Chilet-Rosell, “Gender Bias in Clinical Research, Pharmaceutical Marketing, and the Prescription of Drugs,” 7 *Global Health Action* 1 (2014); Katherine A. Liu & Natalie A. Dipietro Mager, “Women’s Involvement in Clinical Trials: Historical Perspective and Future Implications,” 14 *Pharmacy Practice* 1 (2016).

109. Martino Deidda et al., “The Need of a Gender-corrected Evidence Based Medicine,” 255 *International Journal of Cardiology* 156, 156-57 (2018).

110. K. Wierckx et al., “Prevalence of Cardiovascular Disease and Cancer during Cross-Sex Hormone Therapy in a Large Cohort of Trans Persons: A Case-Control Study,” 169 *European Journal of Endocrinology* 471, 471 (2013).

diabetes, and cancer in trans*+ persons.¹¹¹ Its findings are of limited use, however, because the study ignored a number of variables that may be relevant to the medical needs of trans*+ persons in favor of relitigating the safety and effectiveness of hormone therapy.¹¹² In this study, three trans*+ women, all of whom were current or former smokers, suffered myocardial infarctions.¹¹³ Such literature can make a spurious connection between hormone therapy and adverse outcomes while ignoring the literature that indicates individuals with XY sex chromosomes are twice as likely than individuals with XX sex chromosomes to suffer a myocardial infarction.¹¹⁴ Moreover, the trans*+ women in the study had a suicide rate that was 170 times the national average.¹¹⁵ This study overlooked data that could be useful to study more pressing issues, such as whether these individuals had adequate support systems and access to education and financial stability. Rather than trying to prove whether these vital medications are safe (the safety and effectiveness of hormone therapy has already been proven in previous decades of use among cisgender patients), studies should help find the right dosing and delivery for these individuals to thrive.¹¹⁶

Only recently have clinical studies measured the responses of cisgender women to medications during their menstrual cycles, during pregnancy, and during menopause.¹¹⁷ To understand how trans*+ and intersex individuals on hormone replacement therapy respond to medications other than hormones, researchers should include them in medical trials as well and report on their stage of hormone therapy while participating in the trial.

The body of research on trans*+ health is limited, typically addressing the safety of hormone treatment and HIV prevention. “Most US studies evaluating transgender health focus on substance use and abuse, sexual health, and mental health issues. Relatively little emphasis has been placed on other relevant issues such as healthcare access and utilization patterns over time, determinants of hormonal and surgical treatment complications, and rates of chronic age-related conditions thought to be affected by hormone exposures.”¹¹⁸ This means the medical community knows very little about trans*+ or intersex individuals’ responses to atypical antipsychotics.

A number of factors, including the severity of the psychological disorder,

111. Id.

112. Id.

113. Id.

114. “Throughout Life, Heart Attacks are Twice as Common in Men than Women,” *Harvard Health Publishing* (Nov. 2016), <https://perma.cc/4XAT-2Y5Y>.

115. Wierckx et al., note 110, at 475; “Suicide Statistics,” *American Foundation for Suicide Prevention*, <https://perma.cc/43GN-3AT4>.

116. Andrew M. Kaunitz, “Menopause,” 28 *OBG Management* 38 (2016); Manthos G. Giannoulis et al., “Hormone Replacement Therapy and Physical Function in Healthy Older Men. Time to Talk Hormones?,” 33 *Endocrine Reviews* 314, 353 (2012).

117. Reagan Wetherill et al., “Ovarian Hormones, Menstrual Cycle Phase, and Smoking: A Review with Recommendations for Future Studies,” 3 *Current Addiction Reports* 1 (2016).

118. Sari L. Reisner et al., “Advancing Methods for US Transgender Health Research,” 22 *Sexual Medicine* 1, 2 (2015).

appear to affect a patient's response to antipsychotics. While some studies have considered sex in the dosing of atypical antipsychotics,¹¹⁹ this connection is overgeneralized, and researchers rely heavily upon body mass and organ function, both of which are assumed to differ according to sex. For example, one study connected a variety of factors contributing to a shorter duration of action (time during which the medication works) for antipsychotics in men (assumedly cisgender with XY sex chromosomes), including higher gastric acidity, gastrointestinal transit times, higher body mass index, larger organs and higher plasma protein-binding capacity, and larger distribution volume.¹²⁰

Although cisgender men have higher gastric acidity, gastrointestinal transit times and, therefore, higher antipsychotic bioavailability, they also have a higher body mass index, larger organs, and higher plasma protein-binding capacity.¹²¹ This results in a lower proportion of protein-free drug molecules available to cross the blood-brain barrier.¹²² Cisgender men typically have a larger distribution volume than do cisgender women, which results in lower initial plasma and cerebrospinal fluid concentration of active molecules.¹²³ In addition, cisgender men typically have less fat storage than do cisgender women, leading to a shorter duration of action for antipsychotics, which are mostly lipophilic.¹²⁴ Studying the ways in which hormones may change gastric acidity, gastrointestinal transit times, and other factors influencing bioavailability is critical to ensure that trans*+ and intersex patients are not over- or under-medicated. Given the high rate of self-harm and suicidality in trans*+ individuals verified in the literature,¹²⁵ antipsychotic dosing in trans*+ individuals is a vital area to consider in future studies.

Trans*+ respondents to the National Transgender Discrimination Survey reported suicide attempts at a rate of 41 percent, which surpasses the United States average of 4.6 percent and outpaces the 10–20 percent of LGB adults who attempt suicide.¹²⁶ While the percentage of trans*+ individuals reporting suicidal thoughts and self-harm should decrease as trans*+ discrimination decreases, more research needs to be conducted on antipsychotic medications to aim for optimal patient care for all patients.

119. See e.g. Mary Seeman, "Gender Differences in the Prescribing of Antipsychotic Drugs," 161 *The American Journal of Psychiatry* 1324 (2004).

120. Wolfgang Aichhorn et al., "Second Generation Anti-psychotics: Is There Evidence for Sex Differences in Pharmacokinetic and Adverse Effect Profiles?" 29 *Drug Safety* 587, 589-90 (2006).

121. *Id.*

122. Soldin & Mattison, note 107.

123. *Id.*

124. See generally *id.* at 593.

125. C. Wolford-Clevenger et al., "Correlates of Suicide Ideation and Behaviors among Transgender People: A Systematic Review Guided by Ideation-to-Action Theory," 63 *Clinical Psychology Review* 93, 93 (2018).

126. Ann P. Haas et al., "Suicide Attempts Among Transgender and Gender Non-Conforming Adults: Findings of the National Transgender Discrimination Survey," *American Foundation for Suicide Prevention & The Williams Institute* (2014).

Trans*+ men (with XX sex chromosomes) who take testosterone will experience muscle and fat redistribution and fluctuating hormone levels depending upon the dosing and timing of the administration of their testosterone.¹²⁷ However, current research speculates that they may respond to medications in the same way as cisgender males would:

Sex-differences in these parameters may account for differences in the concentration of a drug at the target site and result in varying responses. On average, total body water, extracellular water, intracellular water, total blood volume, plasma volume, and red blood cell volume are greater for men than women. Therefore, if an average male and an average female are exposed to the same dose of a water soluble drug, the greater total body water, plasma volume, extracellular water, and intracellular water will increase the volume of distribution thus decreasing drug concentration.¹²⁸

What the scientific literature calls “sex differences” are patterns of water, blood, and plasma volumes, all of which affect how most drugs are metabolized by the body. It follows that as a trans*+ man takes testosterone and achieves desired masculinizing traits, such as increased muscle and changed fat distribution, his body may also begin to process medications differently than it did before it was exposed to cisgender male levels of testosterone. Put simply, as hormone therapy effectively changes secondary sex characteristics by changing fat distribution and metabolism, it likely changes internal organ function as well.¹²⁹ The same could be true for trans*+ female (with XY sex chromosomes) patients. We hypothesize that as the hormones change fat distribution and metabolism, they likely affect drug metabolism and patients’ dosing needs. Thus, dosing trans*+ male patients by cisgender female standards might under-medicate them. Likewise, giving trans*+ female patients a dose appropriate for cisgender males could over-medicate them. Without conducting a full genetic workup, physicians may be dosing these individuals incorrectly.

Looking only at hepatic metabolism (liver function), researchers have begun to identify certain cytochrome isoenzymes responsible for metabolizing many drugs.¹³⁰ These enzymes are named “CYP” with a numerical suffix that indicates to clinicians their specific function.¹³¹ It is significant to note that “sex-related differences have been shown in the pharmacokinetics of CYP enzymes with higher activity in females for CYP3A4. However, even if there are true sex-differences

127. Madeline B. Deutsch, “Overview of Masculinizing Hormone Therapy,” *Center of Excellence for Transgender Health*, <https://perma.cc/G5RL-7MA6>.

128. Soldin & Mattison, note 107, at 147.

129. Regina Schaffer & Guy T’Sjoen, “Cross-sex HT Induces Sex-specific Changes in Android, Gynoid Regions,” *Helio* (5 Dec. 2017), <https://perma.cc/5M23-A6YG>.

130. Catherine K. Yeung et al., “Effects of Chronic Kidney Disease and Uremia on Hepatic Drug Metabolism and Transport,” 85 *Kidney International* 522 (2014).

131. Eric Chang et al., “Gender and Sex Differences in Adipose Tissue,” 18 *Current Diabetes Reports* 68 (2018).

in drug pharmacokinetics, only few drugs exhibit significantly different plasma concentrations in women.”¹³² The importance of these findings should not be understated. By focusing on the natal sex marker of patients, health-care partners may place unneeded emphasis on their patients’ genotype, which may not provide useful information for medical treatment. Further, these health-care partners may cause unnecessary trauma to patients who already experience discrimination in many other facets of life.

The most common cases in which some medical providers need to know about natal sex is when a trans*+ male patient has ovaries and/or a uterus and when a trans*+ female patient has a prostate. Because so much ignorance surrounds terminology and few American medical schools have educated health science students on these matters, many practitioners are unaware of what the term trans*+ may mean. As the stereotype of the “man with a vag”¹³³ is reiterated in popular culture, many practitioners believe that a trans*+ male patient always needs a pap smear, or forget that most, but not all, trans*+ female patients need routine prostate exams.¹³⁴ This ignorance also places the burden on patients to educate their providers when they may need dire medical attention.¹³⁵ This can lead to complications with, and unnecessary delays from, health-insurance providers who only assign “male” and “female” markers to patients while believing that these sex markers have significant clinical values for the medical care they need.

Some may argue that natal sex must be known to dose narrow therapeutic index (NTI) drugs. Having small differences between their therapeutic and toxic doses, NTIs with small changes in dosage or interactions with other drugs could cause adverse effects; however, “clinical relevance will most probably be achieved for drugs with narrow therapeutic index, and dose selection of those is often already individualized to the patient’s needs by default.”¹³⁶ This individualized medicine is based upon a complete lab profile.¹³⁷ The FDA does not provide a comprehensive list of NTI medications. However, they do categorize warfarin, levothyroxine, carbamazepine, lithium carbonate, digoxin, phenytoin, tacrolimus and theophylline as NTIs.¹³⁸

Personalized medicine would allow all patients—trans*+, intersex, cisgender, non-binary, and binary alike—to receive more effective drugs and more

132. Soldin & Mattison, note 107, at 149.

133. Funk & Funk, note 32, at 895.

134. Linda Wesp, “Prostate and Testicular Cancer Considerations in Transgender Women,” *Center of Excellence for Transgender Health* (2018), <https://perma.cc/R4XG-C8GM>.

135. See *National Kidney Foundation*, note 91.

136. Bernd Meibohm et al., “How Important are Gender Differences in Pharmacokinetics?” 41 *Clinical Pharmacokinetics* 329, 338 (2002).

137. See generally Hege S. Blix et al., “Drugs with Narrow Therapeutic Index as Indicators in the Risk Management of Hospitalized Patients,” 8 *Pharmacy Practice* 1, 50-55 (2010).

138. Juan Tamargo et al., “Narrow Therapeutic Index Drugs: A Clinical Pharmacological Consideration to Flecainide,” 71 *European Journal of Clinical Pharmacology* 549, 551 (2015).

accurate dosing. “The debate over clinical utility of genetic tests needs to be resolved with consensus on evidentiary standards. Physicians, as gatekeepers of prescription medicines, need to increase their knowledge of genetics and the application of the information to patient care.”¹³⁹

Personalized medicine considers a person’s entire genetic makeup, rather than using a standard workup (e.g. reviewing a patient’s medical history and lab results, conducting a physical examination, and inspecting a patient’s family history) that may not pertain to every patient. For example, patients who are outside of the “normal” range of height, such as little people, do not have a CG equation to help determine clearance creatinine (the amount of blood one’s kidneys clean every minute). Therefore, when dosing these patients, clinicians must use their best judgment to dose appropriately, review lab results, and then adjust doses accordingly. This is the case with warfarin, commonly known as Coumadin, which “has traditionally been dosed by trial-and-error.”¹⁴⁰ Contemporary research suggests that genetic-based dosing offers faster, more effective care.¹⁴¹ The future of medicine must reflect and respect the kaleidoscopic human genome by changing long-held ideologies and binary medical practices that do a disservice to all patients by reifying strict biological dimorphism, which simply does not exist.

III. LEGAL CONSIDERATIONS IN TRANS*+ & INTERSEX HEALTHCARE: THE NEED FOR INCREASED PRIVACY

As in medical diagnoses and practice, cissexist, dyadic, and heterosexist thinking pervades the laws governing medical privacy in the United States. A society’s laws, which should protect a populations’ best interests, reflect the values, preoccupations, and assumptions of that society.¹⁴² By that token, American medical privacy law assumes that all individuals are men or women, that all such individuals are unambiguously so, with anatomical traits all uniformly indicative of one binary sex or the other, and that an individual’s sex (and gender) is readily apparent and never a matter of personal privacy. These assumptions, injurious as they are in social contexts for trans*+ and intersex individuals, are

139. Lawrence Lesko & Stephan Schmidt, “Clinical Implementation of Genetic Testing in Medicine: A U.S. Regulatory Science Perspective,” 77 *British Journal of Clinical Pharmacology* 606, 606 (2013).

140. Yidan Pan et al., “PGWD: Integrating Personal Genome for Warfarin Dosing,” 8 *Interdisciplinary Sciences: Computational Life Sciences* 23, 23 (2016).

141. See generally Nicholas Ware, “The Role of Genetics in Drug Dosing,” 27 *Pediatric Nephrology* 1489 (2012).

142. Donald W. Light et al., “Institutional Corruption of Pharmaceuticals and the Myth of Safe and Effective,” 41 *Journal of Law, Medicine & Ethics* 2, 3 (2013) (“Just as a proper electoral democracy is devoted to the public good, health-care systems are founded on the moral principles of beneficence, nonmaleficence (‘first, do no harm’), respect for autonomy, and the just distribution of scarce resources. Based on these principles, health-care workers are obliged to use the best medical science to relieve suffering and pain, treat illness, and address risks to health. The institutional corruption of health care consists of deviations from these principles.”).

especially harmful when encoded into law. They deny trans*+ and intersex people privacy and medical autonomy and expose them to bias and mistreatment at the hands of healthcare practitioners. This Section will demonstrate that the main health-care privacy law in the United States—the Health Insurance Portability and Accountability Act—is woefully inadequate for the protection of trans*+ and intersex individuals. Another health-care privacy law, the Murphy Bill, further diminishes the privacy rights of patients considered mentally ill. This Section concludes with recommendations for legal reforms necessary to protect the privacy of trans*+ and intersex individuals.

A. HIPAA: Its Limitations Regarding Sex

The Health Insurance Portability and Accountability Act (HIPAA), enacted in 1996, requires the Department of Health and Human Services (HHS) to issue privacy regulations governing identifiable personal medical records.¹⁴³ Accordingly, in 2000, HHS enacted its proposed regulation, “Privacy Rule,” after a period of public comment to carry out this statutory mission.¹⁴⁴ The Privacy Rule prohibits health-care providers from releasing certain types of health information including medical records, billing records, and diagnoses¹⁴⁵ without a patient’s authorization.¹⁴⁶ Patients are also entitled to revoke authorization at any time.¹⁴⁷ “Protected health information” under the Privacy Rule includes genetic information, genetic test results, and manifestations of genetic disease in family members.¹⁴⁸ Crucially, however, the Rule’s protection of genetic information does not include age or sex.¹⁴⁹

Despite its lack of specific reference to age or sex, HIPAA does offer some privacy protection and control of personal health information. For example, a diagnosis of “Gender Dysphoria”¹⁵⁰ (previously known as Gender Identity Disorder) would constitute “protected health information” under the Privacy Rule. Likewise, by withholding permission to grant access to certain practitioners’ records (such as physicians who treated the patient when they had a different legal name or sex), a patient could shield a current health-care provider from knowing about their transition. Such a tactic can likewise be used to prevent one’s psychologist from accessing mental-health records from another psychologist or

143. Health Insurance Portability and Accountability Act (HIPAA), Public Law No. 104-191, 110 Stat. 1936 (2012).

144. “The HIPAA Privacy Rule,” *United States Department of Health and Human Services* (16 Apr. 2015), <https://perma.cc/U6PT-44JZ>; see also 45 C.F.R. §§ 160, 164(A), 164(E).

145. 42 U.S.C. § 1320d(4); see also 45 C.F.R. § 160.103.

146. 45 C.F.R. § 164.508(a).

147. 45 C.F.R. § 164.508(b)(5).

148. 45 C.F.R. § 160.103.

149. 45 C.F.R. § 160.103.

150. Labelling the individual experience of transgender individuals in relation to their gender as “dysphoric” or diagnosable, we argue, is highly problematic, as it continues to stigmatize individuals who are not binary and/or cisgender. However, the scope of this Article is not broad enough to fit a lengthy discussion of the APA’s decision regarding this “diagnosis.”

institution. This lack of access can prevent a mental health-care provider from limiting a trans*+ individual's access to needed hormone therapies or surgeries on the grounds that their dysphoria was the product of unrelated mental illness or trauma.

Where HIPAA fails is in its presumption of biological and genetic sex. The fact that HIPAA's protection of genetic information does not protect sex speaks volumes about the presumptions of its authors. Congress clearly did not consider that some individuals' "genetic sex" (the configuration of one's twenty-third pair of chromosomes, most typically XY or XX) would not align with their other anatomical indicators, presentation, identification, or legal sex. Nor does it appear that congress considered that disclosure of such information might expose a patient to harm, be it discrimination, denial of medical services, or even violence.¹⁵¹ If any input was received from trans*+ and intersex advocates in drafting HIPAA, it seems to have been unheeded. To address the concerns of parents of intersex youth, Advocates for Informed Choice published a guide to make patients aware that there are channels they can file complaints through if a breach of privacy or other inappropriate behavior has occurred in a medical setting.¹⁵²

B. The Murphy Bill: Evidence of the Ongoing Struggle for Trans*+ and Intersex Healthcare Privacy

In 2016, the House of Representatives passed the Helping Families in Mental Health Crisis Act of 2016 (known as the Murphy Bill), which sought to diminish privacy protections under HIPAA concerning mental health diagnoses and treatment.¹⁵³ The Murphy Bill, which died in the Senate but could be resurrected in the future due to its passage under a Republican-controlled House, ostensibly sought "to make available needed psychiatric, psychological, and supportive services for individuals with mental illness and families in mental health crisis, and for other purposes."¹⁵⁴

However, the Murphy Bill diminished the protection afforded to mental health-care information on the spurious grounds that mentally ill individuals cannot recognize that they are mentally ill, cannot make treatment decisions for themselves, and will suffer grievous neurological and physical harm if not forced into treatment.¹⁵⁵ In addition, the bill threatened privacy protections for individuals by relaxing protection for mental health information, by disempowering the Substance Abuse and Mental Health Services Administration,

151. For information regarding contemporary violence against trans*+ people, see Chase Strangio, "Deadly Violence Against Transgender People Is on the Rise. The Government Isn't Helping," *American Civil Liberties Union* (21 Aug. 2018), <https://perma.cc/9CZW-J86C>.

152. Advocates for Informed Choice, "Questions & Answers About Medical Privacy Rights for Parents of Children with DSDs or Intersex Conditions" (2007), <https://perma.cc/855K-RYSV>.

153. 45 CFR § 160.103.

154. Helping Families in Mental Health Crisis Act, H.R. 2646, 114th Cong. (2016).

155. *Id.*

and by diminishing legal protections afforded to patients.¹⁵⁶

First, the bill relaxed privacy protection for mental health information, allowing disclosure in myriad circumstances, such as when:

[T]he patient does not consent, but the patient lacks the capacity to agree or object and the communication or sharing of information is in the patient's best interest; the patient does not consent and the patient is not incapacitated or in an emergency circumstance, but the ability of the patient to make rational health-care decisions is significantly diminished by reason of the physical or mental health condition of the patient; [and most disturbingly,] the patient does not consent, but such communication and sharing of information is necessary to prevent impending and serious deterioration of the patient's mental or physical health.¹⁵⁷

This last change is especially concerning because if gender dysphoria remains a mental health condition in the DSM, and if a patient's right to gender autonomy is not protected by their home state, then mental health professionals, physicians, and family members of trans*+ and intersex individuals could potentially abuse this clause to prevent their family member from seeking hormone therapy, or to force them to undergo genital normalization surgery or conversion therapy.

Second, the Murphy Bill threatened to disempower the Substance Abuse and Mental Health Services Administration, transferring all duties and authority currently held by the Administrator to a new position of Assistant Secretary for Mental Health and Substance Use.¹⁵⁸ These duties include determining the standards for grant programs and reviewing existing federal programs for the diagnosis, treatment, and prevention of mental illness and substance abuse.¹⁵⁹

Third, the bill diminished the legal protections afforded to patients concerning their mental health records by prohibiting any "lobbying using Federal funds by systems accepting Federal funds to protect and advocate the rights of individuals with mental illness,"¹⁶⁰ potentially ending the important work done by organizations like the Protection and Advocacy for Individuals with Mental Illness¹⁶¹ and Institutions for Mental Diseases¹⁶² on behalf of the mentally ill and

156. "Long-delayed Mental Health Reform Bill Passes Unanimously Out of Committee," 18 *Brown University Child & Adolescent Psychopharmacology Update* 4 (28 June 2016).

157. Helping Families in Mental Health Crisis Act, H.R. 2646, 114th Cong., § 403(a)(5) (2016).

158. *Id.* at § 101(a)-(b).

159. *Id.* at § 101(d).

160. *Id.* at § 105.1.

161. "Protection and Advocacy for Individuals with Mental Illness," *Benefits.gov* (PAIMI "is administered by the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Center for Mental Health Services (CMHS)" and pursues protection for people with mental illness through investigation, legal action, and legislative activities.), <https://perma.cc/5GU6-B2HM>.

162. Leah Harris, "Washington's Horrible Mental Health Legislation," *HuffPost* (23 Nov. 2015), <https://perma.cc/MCH4-KJ99>.

their families. Finally, the Murphy Bill would have required involuntary outpatient treatment, a dangerous step backwards towards the era of straightjackets and electroconvulsive therapy.¹⁶³ Thus, the possibility that it could be reintroduced in a future congress or that its policies might find their way into other bills should be concerning.

C. Legal Solutions: The Need for Greater Privacy Protection

Rather than granting broader access to family members, as the Murphy Bill would have, congress should amend HIPAA to enact more robust safeguards on Protected Health Information. To better serve the health care needs and protect the privacy of trans*+ and intersex patients, HIPAA should be modified to allow patients granular control over health records, especially in areas concerning gender and sex. This would grant patients greater access to their own records, including psychiatrists' notes and information compiled for legal purposes, such as criminal prosecution, name change, gender marker change, social security card change, etc. A patient would have the option to allow current health-care providers access to relevant history without disclosing prior names and gender-related health-care that would have no bearing on the conditions being treated. An emergency room physician, for example, should be able to access, with patient authorization, an individual's history to know that they are hemophiliac or diabetic, so they know how to perform emergency appendectomy surgery accordingly. However, whether that patient was assigned male or female at birth should not be accessible to that doctor without separate and explicit authorization.

In addition, HIPAA should be amended to classify genetic information relating to sex as Protected Health Information. Doing so would represent a much-needed legal recognition that "biological sex" is, in fact, a facet of the social matrix of signification that is gender; would empower trans*+ and intersex individuals by granting them more control over their medical disclosures; and would shield trans*+ and intersex patients from potential discrimination in health care by allowing more precise medical disclosures that would make it less likely that their medical histories would be weaponized against them.

Lastly, provisions for trans*+ individuals must be added to the Murphy Bill.¹⁶⁴ Given the fact that a mental health diagnosis is still a requirement for trans*+ individuals to receive transition-related treatment,¹⁶⁵ and that trans*+ individuals are considered a medically underserved population,¹⁶⁶ this proposed legislation is especially worrisome to advocates of LGBTQIA rights for myriad

163. H.R. 2646 § 503.

164. Intersex is not considered a mental health condition in the DSM.

165. Lore M. Dickey et al., "Mental Health Considerations with Transgender and Gender Nonconforming Clients," *The Center of Excellence for Transgender Health*, <https://perma.cc/R9SK-DUPZ>.

166. "The Case for Designating LGBT People as a Medically Underserved Population and as a Health Professional Shortage Area Population Group," *The Fenway Institute* (2014), <https://perma.cc/2FS7-UBJK>.

reasons.¹⁶⁷ Of particular concern is the possibility that the relaxed protection for mental-health-related personal information could result in disclosures to family members who did not know that their relative was trans*+. And outing that individual exposes them to potential social ostracization and violence.¹⁶⁸ This can be especially problematic for trans*+ children because transphobic parents might attempt to change their child's gender identity through reparative or conversion therapy.¹⁶⁹ Most psychologists and pediatricians decry this abusive treatment regime as ineffective and psychologically damaging.¹⁷⁰ To date, only fourteen states prohibit anti-LGBT reparative or conversion therapy, and "68 percent of LGBT population lives in states with no laws banning conversion therapy for minors."¹⁷¹ What the law needs for trans*+ and intersex patients is more privacy, not less.

CONCLUSION: USING A TRANS*+ POSITIVE FRAMEWORK TO EXPAND GENDER AND MEDICAL PRIVACY

Recent media attention surrounding trans*+ individuals (and the lack thereof for intersex individuals) underscores the need to disrupt—if not dismantle—the gender binary in medicine, and to buttress this ideological shift through legal protections. One's gender identity should never be wielded as a weapon against them, especially in a place for healing. When a patient's doctor refuses to treat them, claiming that instead of needing chemotherapy for cancer, the trans*+ patient needs psychological counseling for their gender presentation,¹⁷² there is clearly a health-care crisis. Because gender identity discrimination is so rampant and genomic medicine is the new frontier of the twenty-first century, our healthcare system must begin to accommodate the spectrum of gender identities expressed by patients, including corresponding legal protections.

People should have the right to privacy if they choose, and the American medical system should accommodate this request not only on medical forms, but also in a patient's medical record.¹⁷³ The disclosure of patients' natal sex markers, secondary sex characteristics, and gender presentation/expression should be data

167. "Oppose the Helping Families in Mental Health Crisis Act of 2015," *The Leadership Conference on Civil and Human Rights* (8 Mar. 2016), <https://perma.cc/9E87-D6C8>.

168. "2018 LGBTQ Youth Report," *Human Rights Campaign* (2018) (noting that trans*+ children report the highest levels of depression and suicidal ideation), <https://perma.cc/75EE-N7C2>.

169. Jack Drescher et al., "The Growing Regulation of Conversion Therapy," 102 *Journal of Medical Regulation* 7, 7-12 (2016).

170. *Id.*

171. "Conversion Therapy Laws," *Movement Advancement Project* (11 Sept. 2018), <https://perma.cc/VM8T-VKTN>.

172. Colleen Curry, "Navigating Cancer as a Trans Person is a Nightmare," *Newsweek Magazine* (21 Jul. 2016) (noting that a trans patient's doctor failed to inform the patient of a cancer diagnosis and justified the lack of care "by saying his first impulse was to recommend psychiatry instead of chemotherapy or radiation" for the patient), <https://perma.cc/R8LN-GCAM>.

173. Megan McNamara & Henry Ng, "Best Practices in LGBT Care: A Guide for Primary Care Physicians," 83 *Cleveland Clinical Journal of Medicine* 531 (2016).

controlled by the patients and made available to medical practitioners treating patients for specific issues relevant to them.

To date, cisgender individuals have exerted (albeit often unknowingly) their privilege to create and reinforce the gender binary, an ideology that has, thus far, served to cause unnecessary trauma to trans*+ and intersex individuals. Contemporary medical research is beginning to recognize individualized genomic medicine, based on genetic testing, as the ultimate clinical goal.¹⁷⁴ While the efficacy of genomic medicine has been upheld over other methods (such as gender-based and race-based medicine), scholars have also called for increased legal protections for patients.¹⁷⁵ Medical privacy laws in the United States should protect the privacy of all individuals, especially those most vulnerable, rather than preserving and reifying an inequitable and unscientific gender binary.

Eleven countries, four of which require no medical treatment or sterilization to change genders legally, allow their citizens to self-declare their gender and to update legal documents accordingly and expediently.¹⁷⁶ To date, no empirical investigations of how patients visiting from other countries presenting their legal genders as “x,” “agender,” or “trans” have been conducted. The United States medical system, including insurance billing, as of now cannot allow the medical records of these patients to reflect their authentic sense of self. Rather than foisting antiquated binary ideologies upon patients,¹⁷⁷ the laws of this nation should protect the privacy and respect the autonomy of trans*+ and intersex individuals. The United States should not only adapt to these challenges, but also become a global leader, living up to its promise of affording individuals freedom and autonomy.

It is critically important that we examine the relationships among media, medicine, and law and create interdisciplinary connections between the fields. Not only will this protect the rights of trans*+ and intersex individuals, but it will also expand notions of gender and privacy. In turn, all patients can be validated and protected when seeking optimal care.

174. Jonathan Kahn, “The Troubling Persistence of Race in Pharmacogenomics,” 40 *Journal of Law, Medicine, & Ethics* 873 (2012).

175. Eric Green et al., “Charting a Course for Genomic Medicine from Base Pairs to Bedside,” 470 *Nature* 204 (2011).

176. Aron Macarow, “These Eleven Countries are Way Ahead of the US on Trans Issues,” *ATTN* (9 Feb. 2015) (including Argentina, Australia, Bangladesh, Colombia, Denmark, Germany, India, Ireland, Malta, Nepal, and New Zealand), <https://perma.cc/4BYZ-379L>.

177. Erica L. Green et al., “‘Transgender’ Could Be Defined Out of Existence Under Trump Administration,” *The New York Times* (21 Oct. 2018), <https://www.nytimes.com/2018/10/21/us/politics/transgender-trump-administration-sex-definition.html> (noting that under President Trump, “the Department of Health and Human Services is spearheading an effort to establish . . . an explicit and uniform definition of gender as determined ‘on a biological basis that is clear, grounded in science, objective and administrable.’ The agency’s proposed definition would define sex as either male or female, unchangeable, and determined by the genitals that a person is born with, according to a draft reviewed by The Times. Any dispute about one’s sex would have to be clarified using genetic testing.”).

