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## A Presence in the Past: A Transgender Historiography

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# A PRESENCE IN THE PAST

## *A Transgender Historiography*

**Genny Beemyn**

*This article provides an overview of the literature written about individuals who are referred to today as transgender people, with a focus on material from the United States. Influential studies are discussed, particularly works by trans people. The article concludes by suggesting useful directions for future research, including the need to document trans political, legal, and cultural campaigns; considering a greater range of transgender people and experiences; and specifically examining the lives of trans people of color.*

Any attempt to write “transgender history” is complicated by the contemporary nature of the term “transgender” and its cultural specificity. Do we include individuals in past centuries who might appear to be transgender from our vantage point, but who would quite likely not have conceptualized their lives in such a way? And what about individuals today who have the ability to describe themselves as transgender, but choose not to for a variety of reasons, including the perception that it is a White, middle-class, Western term? Should they be left out of “transgender history” because they do not specifically identify as transgender?

Given the rich histories of individuals who perceived themselves and were perceived by their societies as gender nonconforming, it would be inappropriate to limit “transgender history” to people who lived at a time and place when the concept of “transgender” was available and used by them.<sup>1</sup> But at the same time, it would also be inappropriate to assume that people who are “transgender,” as we currently understand the term, existed throughout history. The best that we as historians can do is to acknowledge individuals whose actions would seem to indicate that they might be what we would call “transgender” or “transsexual” today without necessarily referring to them as such and to distinguish them from individuals who might have presented as a gender different from the one assigned to them at birth for reasons other than a sense of gender difference. Admittedly, someone’s motivations are not always clearly discernible, but seeking to make this distinction is critical to present a specific “transgender history.”<sup>2</sup>

Medical professionals began to recognize gender-nonconforming individuals in the mid-to-late nineteenth century and to undertake the first studies of what would become known as transgender people in response to the growing visibility of individuals who crossdressed or lived cross-

gendered lives. These early works, written mostly by U.S. and European physicians, typically categorized those who transgressed gender norms and expectations as psychosexually disordered. For example, psychiatrist Richard von Krafft-Ebing, who had the greatest influence on the Western medical profession's views toward sexual and gender difference in the late nineteenth century, classified gender-nonconforming individuals by the degree to which they identified as a gender different from their assigned gender, which, in his view, corresponded to the extent to which they were mentally disturbed. He considered those who felt they were the "opposite" sex and had been assigned the wrong sex at birth to be suffering from a form of psychosis.<sup>3</sup>

Most of the literature on gender different individuals through the 1940s continued to be written by non-transgender medical practitioners, who based their research on client case studies and treated gender nonconformity as a pathology. A notable exception was physician and sexologist Magnus Hirschfeld, who coined the word "transvestite" in his epic 1910 work *Transvestites* to refer to individuals who were overcome with a "feeling of peace, security and exaltation, happiness and well-being...when in the clothing of the other sex."<sup>4</sup> Hirschfeld found that "transvestites" were not suffering from a form of psychopathology, nor were they masochists or fetishists. Contrary to other researchers, he also recognized that they could be of any sexual orientation (including asexual) and assigned either male or female at birth.

The one known transgender person to write about the subject prior to the 1950s was Michael Dillon, a British physician who was the first recorded female-assigned, non-intersexed individual to have taken testosterone for the purpose of transforming his body and to have undergone female-to-male genital surgeries. In 1946, Dillon wrote *Self: A Study in Ethics and Endocrinology*, a book that argued for the acceptance of people who felt that they were a gender different from the gender assigned to them at birth. Making the case that such individuals were not mentally unbalanced, he was especially critical of the clinicians who believed that they could change the sense of self of gender different individuals through therapy, when what their clients really needed was access to hormones and genital surgeries. But because *Self* was not widely circulated, and Dillon himself sought to avoid public attention, his groundbreaking arguments had little effect on the medical profession. Instead of Dillon, endocrinologist Harry Benjamin became the leading advocate in the 1950s and 1960s for "adjust[ing] the body to the mind" of transsexual individuals through hormones and surgeries.<sup>5</sup>

The late 1960s and 1970s saw the proliferation of clinical studies about transsexual people, following the publication of Benjamin's *The Transsexual Phenomenon* and the opening of the first gender identity clinic at Johns Hop-

kins University, both in 1966. Some of this literature continued to pathologize transgender people, especially texts by psychologists and psychiatrists, like the studies of Robert Stoller and Richard Green.<sup>6</sup> But the formation of the first transgender organizations in the 1960s also made possible less biased research involving non-clinical samples. At the same time, transgender individuals began documenting their own lives and communities, such as Virginia Prince's 1962 survey of readers in her crossdressing publication *Transvestia* and Christine Jorgensen's best-selling 1967 autobiography.<sup>7</sup>

Jorgensen's book was especially groundbreaking, as the stories of transsexual women that had been published in the U.S. until then were generally lurid exposés of female impersonators, strippers, and prostitutes with tabloid titles like "I Changed My Sex!" and "I Want to Be a Woman!" Following the success of Jorgensen's work, a wave of autobiographies of well-known, successful transsexual women were published from the mid 1970s through the early 1980s, which included Jan Morris's *Conundrum*, Canary Conn's *Canary*, Renée Richards's *Second Serve*, and April Ashley's *Odyssey*. While these texts drew substantial attention to the lives of transsexual women, the lack of autobiographies by transsexual men meant that they remained largely invisible in the dominant society. The only full-length narrative by a Female-To-Male (FTM) individual to be published in the U.S. prior to the 1990s was Mario Martino's 1977 book *Emergence: A Transsexual Autobiography*.<sup>8</sup>

A rapidly growing number of transgender groups and openly transgender individuals in the late 1980s and 1990s provided greater opportunities to give voice to gender-nonconforming people. Cultural anthropologist Anne Bolin, for example, studied a Midwestern Male-To-Female (MTF) transgender support group in the early 1980s and then again nearly a decade later, finding that members embraced a wider range of possible gender identities for themselves and others over time. In the first in-depth research on transsexual men, Aaron Devor interviewed 45 individuals about their lives before, during, and after transitioning for his 1997 book, *FTM: Female-To-Male Transsexuals in Society*.<sup>9</sup>

The development of queer theory in the 1980s and 1990s also brought further attention to transgender people, as literary critics including Judith Butler, Diana Fuss, Eve Kosofsky Sedgwick, and Teresa de Lauretis, began to deconstruct gender and examine its performative nature.<sup>10</sup> Some trans academics and activists have criticized this scholarship, which is mostly by cisgender writers, for often using transgender people to further their theoretical positions while ignoring the lived experiences of many trans individuals.<sup>11</sup> These criticisms aside, this body of work has led to a more nuanced understanding of gender and has been instrumental in legitimizing the academic study of transgender people. Theory that is more rooted in

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transgender experience has recently been collected in the *Transgender Studies Reader 1* and 2 and in the historian A. Finn Enke's anthology *Transfeminist Perspectives in and beyond Transgender and Gender Studies*.<sup>12</sup>

The first book-length histories of transgender communities were published in the 1990s. Both Leslie Feinberg's *Transgender Warriors: Making History from Joan of Arc to RuPaul* and Pat Califia's *Sex Changes: The Politics of Transgenderism* are noteworthy for being written by transgender activists, rather than historians, and for seeking to counter anti-trans critics by presenting gender-nonconforming people as having a clear, rich past. In the case of Feinberg's text, the result is a sweeping work that assumes that "transgender people" existed in vastly different eras and cultures. The medical historians Vern and Bonnie Bullough's 1993 study *Cross Dressing, Sex, and Gender* likewise covers a broad timeframe—from the ancient world to modern society—but, unlike Feinberg, the authors avoid creating stable, ahistorical categories for individuals who wore clothing traditionally associated with a gender different from their own. By simply recounting instances of cross dressing in different times and cultures, however, the text adds little to a specific "transgender history."<sup>13</sup>

A sort of middle ground is provided by another historical work published in the 1990s, the cultural anthropologist Jason Cromwell's *Transmen and FTMs: Identities, Bodies, Genders, and Sexualities*. Cromwell does not make the kind of generalizations of Feinberg, but goes beyond the Bulloughs in seeking to understand the motivations behind cross-gender behavior to trace a history of individuals who might have been what we would call transsexual men today. He creates a framework for distinguishing between female-assigned individuals who presented as male for various reasons but who seemingly identified as their birth gender (people who might be described as cross dressers, passing women, female husbands, etc.) and female-assigned individuals who apparently identified and lived as men, which included presenting as male (people who might be more accurately characterized as transsexual).<sup>14</sup>

The two major transgender histories published in the 2000s, the historian Joanne Meyerowitz's *How Sex Changed: A History of Transsexuality in the United States* and the historian Susan Stryker's *Transgender History*, are studies of the U.S. in the twentieth century. Meyerowitz's *How Sex Changed* is a comprehensive, well-researched, and insightful examination of how transsexuality has been understood in U.S. society over time and how "the topic of sex change has served as a key site for the definition and redefinition of sex in popular culture, science, medicine, law, and daily life." Meyerowitz demonstrates that transsexual history predates not only the development of the synthetic hormones and plastic-surgery techniques, but also the terminology of transsexuality itself. Stryker's *Transgender History*, part of

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Seal Press's series of concise introductory texts on different topics in gender studies, focuses on trans political and social activism from the mid twentieth century to today. She details how transgender people have experienced and responded to discrimination from the medical profession, the police and legal system, and some leading lesbian feminists. While the standard historical narrative roots transgender organizing and resistance in the Stonewall Riots, Stryker shows that the uprising was actually the culmination of more than a decade of trans people challenging instances of harassment and police brutality, much of which has not been well-documented.<sup>15</sup>

While few book-length transgender histories have been published to date, the number of transgender autobiographies proliferated in the 2000s, including notable texts by Jennifer Finney Boylan, Jamison Green, and Matt Kailey. While simply being known as transsexual had made Jorgensen a celebrity in the 1950s and 1960s, the abundance of transgender autobiographies published in the last decade means that a trans person today practically needs to be a celebrity first, like Thomas Beatie and Chaz Bono, to interest a major press in their story.<sup>16</sup> In contrast to the plethora of autobiographies, few biographies of transgender individuals have been published—the most significant are works that examine the lives of Jack Bee Garland, Billy Tipton, Michael Dillon, and Christine Jorgensen.<sup>17</sup> Scholars will hopefully write additional profiles of transgender individuals, especially trans people of color (Sylvia Rivera, Marsha P. Johnson, and Miss Major immediately come to mind) in the near future.

An even more pressing need for future research is in histories of specific trans communities and movements. For example, Tri-Ess, a national organization for cross-dressing heterosexual men and their partners, has existed for more than fifty years and has chapters across the country, yet it has not been the subject of a detailed history. As a consequence, it is largely unknown, even in the larger transgender movement. The oldest continuing organization consisting primarily of gay male cross dressers and drag queens, the International Court System, has been considered in a handful of sociological studies, but, similarly, has not caught the attention of historians, despite being arguably the largest transgender member organization in the United States and existing for nearly fifty years.<sup>18</sup>

Another useful direction for future research would be to document the political, legal, and cultural campaigns that have led to tremendous progress in the struggle for transgender rights in the last two decades and will likely result in even greater success in the next few years. For example, transgender people have been able to shift the dominant view of the medical profession from assuming that transsexual individuals are mentally disordered to recognizing that they could be emotionally distressed because of the incongruence between their gender identity and assigned gender. Also

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important to document are the strategies and organizing efforts behind the legal gains made by transgender activists and allies at the state and local levels. Prior to 2000, only one state (Minnesota) had passed a nondiscrimination law that included gender identity/expression; by 2013, seventeen states and the District of Columbia had done so. The number of cities and counties with transgender rights ordinances, similarly, has grown from three municipalities in the 1980s to more than 150 today, so that more than forty-five percent of the U.S. population is now covered by a transgender-inclusive nondiscrimination law. Among colleges and universities, more than 600 campuses have added "gender identity/expression" to their nondiscrimination policies in the last seventeen years, and many have begun to implement other transgender-supportive policies to create institutions that are more welcoming and inclusive.<sup>19</sup>

But no matter the subject, all future research needs to consider a greater range of transgender people and experiences. To date, transgender histories have focused primarily on transsexuals and transsexuality, even though a growing number of gender-nonconforming people identify outside of a gender binary, particularly many transgender youth. In surveying close to 3,500 individuals for our book, *The Lives of Transgender People*, Sue Rankin and I found that the respondents offered more than a hundred different descriptions for their gender identity, from very detailed labels, like "FTM TG stone butch drag king," to vague explanations like "no easy definition, some other kind of man."<sup>20</sup> By naming themselves in different and complex ways, transgender youth are vastly expanding the meaning of gender and raising societal awareness of the concept of gender identity.

Future histories also need to be more racially inclusive and specifically examine the lives of trans people of color. As a reviewer for several LGBT journals, I am regularly asked to provide feedback on transgender-themed manuscripts, and more often than not, these studies include few, if any, people of color. There is no excuse for this kind of "whitewashing" of transgender people today. At the same time, Black and Latin@ trans communities in the twentieth century have been understudied. While some researchers, most notably the historian George Chauncey, have discussed the rich tradition of drag balls in urban Black communities in the early and mid twentieth century, there has yet to be an extensive treatment of this culture.<sup>21</sup> Nor has there been much in-depth scholarship on the contemporary ballroom culture among Black and Latin@ youth, beyond the pioneering work of the gender studies scholar Marlon Bailey on the Detroit ball scene.<sup>22</sup>

At the outset of this article, I referred to the difficulties of writing "transgender history," whether in considering past centuries or the last decade. But with a rapidly growing number of transgender people coming out publicly today and challenging societal assumptions about gender, it

becomes even more important to try to recognize and document where we have been, so that we have a better sense of where we are going.

## NOTES

<sup>1</sup>For a discussion of individuals who lived gender-nonconforming lives in the United States (or in what would become the United States) before the development of the concept of “transgender,” see, for example, Sabine Lang, *Men as Women, Women as Men: Changing Gender in Native American Cultures* (Austin: University of Texas Press, 1998) and Peter Boag, *Re-Dressing America’s Frontier Past* (Berkeley: University of California Press, 2011).

<sup>2</sup>For more on defining transgender history, see Genny Beemyn, “Transgender History,” in *Trans Bodies, Trans Selves*, ed. Laura Erickson-Schroth (New York: Oxford University Press, 2014).

<sup>3</sup>Richard von Krafft-Ebing, *Psychopathia Sexualis, with Special Reference to Contrary Sexual Instinct: A Medico-Legal Study* (Philadelphia: F.A. Davis and Co., 1893).

<sup>4</sup>Magnus Hirschfeld, *Transvestites: The Erotic Drive to Cross Dress*, trans. Michael A. Lombardi-Nash (Buffalo, NY: Prometheus Books, 1991), 125.

<sup>5</sup>Pagan Kennedy, *The First Man-Made Man: The Story of Two Sex Changes, One Love Affair, and a Twentieth-Century Medical Revolution* (New York: Bloomsbury, 2007), 71; Michael Dillon, *Self: A Study in Ethics and Endocrinology* (London: William Heinemann Medical Books, 1946), 52–53; Harry Benjamin, *The Transsexual Phenomenon* (New York: Julian Press, 1966).

<sup>6</sup>Dallas Denny, “A Selective Bibliography of Transsexualism,” *Journal of Gay & Lesbian Psychotherapy* 6 (2002): 38; Robert Stoller, *Sex and Gender: The Development of Masculinity and Femininity* (New York: Jason Aronson, 1968); and Richard Green, *Sexual Identity Conflict* (New York: Basic Books, 1974).

<sup>7</sup>C. V. Prince, “166 Men in Dresses,” *Sexology* (1962): 520–25 and Christine Jorgensen, *Christine Jorgensen: A Personal Autobiography* (New York: Paul S. Eriksen, 1967).

<sup>8</sup>Hedy Jo Star, “I Changed My Sex!”: *The Autobiography of Stripper Hedy Jo Star, Formerly Carl Hammonds* (Chicago: Novel Books, 1963); Gayle Sherman, “I Want to Be a Woman!”: *The Autobiography of Female Impersonator Gayle Sherman* (Chicago: Novel Books, 1964); Jan Morris, *Conundrum: From James to Jan — An Extraordinary Personal Narrative of Transsexualism* (New York: Harcourt Brace Jovanovich, 1974); Canary Conn, *Canary: The Story of a Transsexual* (Los Angeles: Nash Publishing, 1974); Renée Richards, with John Ames, *Second Serve: The Renée Richards Story* (New York: Stein and Day, 1983); Duncan Fallowell and April Ashley, *April Ashley’s Odyssey* (London: Jonathan Cape, 1983); and Mario Martino, with Harriett, *Emergence: A Transsexual Autobiography* (New York: Crown Publishers, 1977).

<sup>9</sup>Anne Bolin, *In Search of Eve: Transsexual Rites of Passage* (New York: Bergin & Garvey, 1998); Bolin, “Transforming Transvestism and Transsexualism: Polarity, Poli-



tics, and Gender," in *Gender Blending*, eds. Bonnie Bullough, Vern L. Bullough, and James Elias (Amherst, NY: Prometheus Books, 1997), 25–32; and Holly Devor, *FTM: Female-To-Male Transsexuals in Society* (Bloomington: Indiana University Press, 1997).

<sup>10</sup>Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (New York: Routledge, 1990); Diana Fuss, *Essentially Speaking: Feminism, Nature and Difference* (New York: Routledge, 1989); Eve Kosofsky Sedgwick, *Epistemology of the Closet* (Berkeley: University of California Press, 1990); and Teresa de Lauretis, "Queer Theory: Lesbian and Gay Sexualities," *differences: A Journal of Feminist Cultural Studies* 3 (1991): iii–xviii.

<sup>11</sup>See, for example, Viviane K. Namaste, *Invisible Lives: The Erasure of Transsexual and Transgendered People* (Chicago: University of Chicago Press, 2000).

<sup>12</sup>Susan Stryker and Stephen Whittle, eds., *The Transgender Studies Reader* (New York: Routledge, 2006); Susan Stryker and Aren Z. Aizura, eds., *The Transgender Studies Reader 2* (New York: Routledge, 2013); and Anne Enke, ed., *Transfeminist Perspectives in and beyond Transgender and Gender Studies* (Philadelphia: Temple University Press, 2012).

<sup>13</sup>Leslie Feinberg, *Transgender Warriors: Making History from Joan of Arc to Ru-Paul* (Boston: Beacon Press, 1996); Pat Califia, *Sex Changes: The Politics of Transgenderism* (San Francisco: Cleis Press, 1997); and Vern L. Bullough and Bonnie Bullough, *Cross Dressing, Sex, and Gender* (Philadelphia: University of Pennsylvania Press, 1993).

<sup>14</sup>Jason Cromwell, *Transmen and FTMs: Identities, Bodies, Genders, and Sexualities* (Urbana: University of Illinois Press, 1999), 81.

<sup>15</sup>Joanne Meyerowitz, *How Sex Changed: A History of Transsexuality in the United States* (Cambridge, MA: Harvard University Press, 2002), 285 and Susan Stryker, *Transgender History* (Berkeley, CA: Seal Press, 2008).

<sup>16</sup>Jennifer Finney Boylan, *She's Not There: A Life in Two Genders* (New York: Broadway Books, 2003); Jamison Green, *Becoming a Visible Man* (Nashville, TN: Vanderbilt University Press, 2004); Matt Kailey, *Just Add Hormones: An Insider's Guide to the Transsexual Experience* (Boston: Beacon Press, 2005); Thomas Beatie, *Labor of Love: The Story of One Man's Extraordinary Pregnancy* (Berkeley, CA: Seal Press, 2008); and Chaz Bono, *Transition: The Story of How I Became a Man* (New York: Dutton, 2011).

<sup>17</sup>Louis Sullivan, *From Female to Male: The Life of Jack Bee Garland* (Boston: Alyson Publications, 1990); Diane Wood Middlebrook, *Suits Me: The Double Life of Billy Tipton* (New York: Houghton Mifflin, 1998); and Kennedy, *The First Man-Made Man*; Richard F. Docter, *Becoming a Woman: A Biography of Christine Jorgensen* (New York: Haworth, 2008).

<sup>18</sup>See, for example, Steven P. Schacht, "Four Renditions of Doing Female Drag: Feminine Appearing Conceptual Variations of a Masculine Theme," *Gendered Sexualities* 6 (2002): 157–80. While Tri-Ess and the International Court System do not specifically refer to themselves as transgender organizations, they share with explicitly transgender groups the goal of challenging a gender binary in heterosexual and gay communities, respectively, and many of their members do identify as transgender.

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<sup>19</sup>National Gay and Lesbian Task Force, "Jurisdictions with Explicitly Transgender-Inclusive Nondiscrimination Laws," last modified June 2012, [http://www.thetaskforce.org/downloads/reports/fact\\_sheets/all\\_jurisdictions\\_w\\_pop\\_6\\_12.pdf](http://www.thetaskforce.org/downloads/reports/fact_sheets/all_jurisdictions_w_pop_6_12.pdf); National Gay and Lesbian Task Force, "State Nondiscrimination Laws in the U.S.," last modified June 21, 2013, [http://www.thetaskforce.org/downloads/reports/issue\\_maps/non\\_discrimination\\_6\\_13.pdf](http://www.thetaskforce.org/downloads/reports/issue_maps/non_discrimination_6_13.pdf); and Genny Beemyn, "Campus Pride Trans Policy Clearinghouse," last modified July 25, 2013, [www.campuspride.org/tpc](http://www.campuspride.org/tpc).

<sup>20</sup>Genny Beemyn and Sue Rankin, *The Lives of Transgender People* (New York: Columbia University Press, 2011).

<sup>21</sup>George Chauncey, *Gay New York: Gender, Urban Culture, and the Making of the Gay Male World, 1890–1940* (New York: HarperCollins, 1994).

<sup>22</sup>Marlon M. Bailey, "Performance as Intervention: Ballroom Culture and the Politics of HIV/AIDS in Detroit," *Souls* 11 (2009): 253–74; and Bailey, *Butch Queens Up in Pumps: Gender, Performance, and Ballroom Culture in Detroit* (Ann Arbor: University of Michigan Press, 2013).

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# Trans\* Collecting at the Schlesinger Library

## *Privacy Protection and the Challenges of Description and Access*

LAURA PEIMER

**Abstract** This article discusses how the Schlesinger Library on the History of Women in America has addressed issues related to privacy, access, and description with three of its trans\* collections: The Ari Kane Papers, the International Foundation for Gender Education (IFGE) Records, and the Mark Ethan Smith Papers. The Kane Papers and the IFGE Records contain extensive materials with potentially sensitive third party content. While legally most personal third party content can be made available to users, librarians and archivists have an ethical responsibility to take personal privacy into consideration when determining how open a collection should be to users. This article also touches upon the limitations of the Library of Congress subject headings for the Smith Papers, acknowledging the challenges of applying these subject headings to describe an individual whose identity falls outside their limited scope.

**Keywords** privacy, access, description, identity, Library of Congress subject headings

The mission of the Schlesinger Library on the History of Women in America at the Radcliffe Institute for Advanced Study, Harvard University, is to document women's lives. The library accomplishes this by acquiring and providing access to collections of personal papers and organizational records, audio-visual collections, photographs, and published materials—from rare books to zines. The library's holdings contain collections that document sexuality and gender, women's rights and feminism, work and family life, education, activism of all kinds, and culinary history, as well as the history of women's health and reproductive lives. Our collections include narratives of women whose primary relationships were, or are, with other women; the papers of people who identify themselves as lesbian, gay, bisexual, or trans\*; and documentation from individuals and organizations focused on lesbian, gay, bisexual, transgender, and

queer activism. Seeking to provide a more complete account of the many facets and presentations of gender, the Schlesinger Library actively solicits collections whose creators self-identify as trans\* or whose lives and experiences fit within a definition of transgender.

Currently, the Schlesinger Library holds four trans\*-related manuscript collections: papers of trans\* activist and counselor Ari Kane; records of the International Foundation for Gender Education, an organization dedicated to promoting understanding and acceptance of transgender people through advocacy and educational initiatives; papers of Mark Ethan Smith, a former Naval aircraft electrician who does not identify as trans\* but as a “biological female who lives as a person without regard to sex”; and papers of Abraham Bartlett Smith, a trans man who underwent sex reassignment surgery in the 1970s.<sup>1</sup> These collections document one or more of the following issues: identity and personal freedom, trans\* activism for political rights and social acceptance, and community building within the trans\* population. The papers of Ari Kane and the records of the International Foundation for Gender Education also include materials revealing the trans\* identities of third-party individuals who have not participated in, and are not aware of, the transfer of these archival collections to a research library. Many of these individuals may not want their personal information made available to researchers. With this in mind, the library, sometimes after consultation with the donor, will instill safeguards to protect an individual’s personal information. Generally, this involves closing sensitive materials for a period of time, thereby limiting access to potentially historically significant content for current researchers. Without a legal framework to dictate policy in this matter, the archivist tries to balance the library’s concern for an individual’s privacy rights, with its main objective to make archival collections available to researchers.

Making archival collections available for research also requires that the collections are findable by researchers. This can sometimes be a challenge when describing trans\* collections using controlled vocabularies, such as the Library of Congress (LC) subject headings, which we generally apply to all our bibliographic catalog records at the library. The LC authority file’s vast popularity as a taxonomy has been useful in streamlining and standardizing searching and cataloging, but it can be insufficient when a person’s gender or sexual identity falls outside the authority file’s lexicon, or when the subject terms are not sufficient to describe that identity.

Below is a brief description of how the library has tried to balance access to researchers, concerns about privacy, and donor preferences in the three trans\* collections that I have processed. Both the Ari Kane Papers and the International Foundation for Gender Education Records are examples of collections that presented us with multiple privacy concerns. In the case of the Mark Ethan Smith

Papers, LC's limitations were apparent when I attempted to describe Smith accurately and in the way he prefers.

### **Ari Kane Papers**

In the early 2000s, transgender activist Ari Kane began a conversation with the library's head of collection services, and in 2003 the library signed an agreement with him to acquire a collection of his papers. Kane has worked on behalf of the transgender community since the early 1970s and founded the Outreach Institute of Gender Studies in 1975. Activities and programs of the institute included leadership in the founding of Fantasia Fair, an annual gathering in Provincetown, Massachusetts, which started in 1975 through the efforts of Kane and other members of the trans\* community. Through social gatherings, seminars, and other activities, the Fair, under a new management team since 2000, provides a supportive environment for individuals expressing alternative gender identities and roles. The Ari Kane collection includes Fantasia Fair program books, registration and general program information, evaluation forms, audio-visual materials, and numerous photographs, which document many of the activities and programs of the fair.

Other materials in the Ari Kane Papers include printed materials and event files for other programs sponsored by the institute; correspondence with board members; Kane's client files from Theseus Counseling and Consulting Service, the social services agency he founded in 1985; and Kane's writings and research, including his 1998 dissertation, "Gender Attitude Reassessment: A Program for Changing Attitudes and Ideas about Gender and Sexuality," for his EdD in human sexual science from the Institute for Advanced Study of Human Sexuality in San Francisco, California.

Many individuals represented in the papers often used an alternative name, but not all the time. In order to address potential privacy concerns, all researchers who want to use the collection must sign a condition-of-use form in which they agree that they will not divulge any individuals' full names that I may have overlooked for closure when screening the collection. We closed materials containing personal identifying information of individuals who were not actively engaged in the work of the Outreach Institute, and where it was apparent that they were not community activists, until the likely deaths of the individuals involved. We closed Kane's Theseus Counseling and Consulting Service files, which include session notes and correspondence with clients and doctors, because they contain identifying information on clients who were dealing with their trans\* identities. These papers are rich in content but also highly sensitive. The Schlesinger Library typically restricts access to health information about individuals until the individual's likely death, usually eighty years from the date of the most recent document in the file. In the case of Kane's client files, we have the birth years for the

majority of these individuals. I sorted the client files by client birth year, and then grouped them by decade. To reduce the number of multiple closure dates, files are closed for one hundred years from the last year of the decade of the client's birth year; for example, for individuals born between 1950 and 1959, files are closed until January 1, 2060.

Visual documentation provides another challenge for privacy. The Fantasia Fair photographs of individuals participating in fashion shows, workshops, and so forth are wonderful visual documentation and ones that we want to make available on the web through Harvard's online catalog for visual resources. The catalog presents a digital copy of an image with an associated catalog record, which contains usually extensive descriptive content, including names of individuals in the images when available. We were unsure of the wishes of most of the individuals who appeared in the photographs in the Ari Kane Papers and wanted to apply reasonable safeguards to protect any personal identifying information when providing access to the photographs. Since the Schlesinger Library does not have permission from the individuals who were photographed in these images, I conferred with Kane about digitizing the materials. We agreed that we would make the images digitally accessible only if the full names of individuals identified in the photos would not be included in the associated catalog record. To ensure sufficient privacy, we would make names available when there was just an alias—or alternative gender name—such as *Donna T.*

In the Ari Kane Papers, I also redacted names and other personal identifying information from some of the materials in the collection, closing the originals and keeping the redacted copies open for research. Ideally, redaction is preferred over closure since it allows information to be made available to users much sooner. We were able to apply this redaction on a small scale, but it could be applied on a larger scale to materials currently closed for an extensive period of time—such as Kane's client files—thereby allowing the redacted copies to be open to researchers. Unfortunately, the time-consuming nature of redaction is currently prohibitive without the resources, time, and staff to commit to it.

### **International Foundation for Gender Education Records**

Issues of privacy and access appear again with the records of the International Foundation for Gender Education (IFGE), the nonprofit membership organization founded by Merissa Sherrill Lynn in November 1986. The mission was stated in IFGE materials in our collection as promoting understanding and acceptance of transgender people through advocacy and educational initiatives. For many years they provided a speakers bureau, maintained a library of publications on transgender issues, published the transgender magazine *Tapestry*, and held an annual convention. In 2010, we learned of their impending move from offices in Waltham, Massachusetts, to Washington, DC. At that time, we contacted the IFGE

director Denise Leclair and completed a donor agreement for the library to become a repository for the organization's records then at the Waltham office.

The IFGE Records consist of administrative files for the organization, including board of directors meeting minutes, correspondence, by-laws and constitution drafts, as well as IFGE's annual convention materials and audio tapes of board of directors meetings. Also included are completed membership and *Tapestry* subscription forms and letters from individuals sharing personal stories, seeking relationships and connection, or requesting help or support. Due to the identifying information in these materials, the IFGE director and library staff agreed that the files would be closed until 2040 to protect the privacy of individuals. However, while processing the records, I found additional materials dating from the 2000s and believed that the 2040 closure may be insufficient to protect privacy. I was concerned that individuals may likely still be alive when the records would be made available for use. I brought these concerns to the Schlesinger Library's access review board, who ultimately decided that library staff would revisit the closure date in 2040 and probably extend the closure before officially opening the records to researchers.

As with the Ari Kane Papers, I screened the unrestricted parts of the IFGE Records for names and additional identifying information for those members, donors, convention participants, and others who were not publicly identified activists. And, as with the Kane collection, the library also requires researchers to sign a condition-of-use form. By signing this form, the researcher agrees to protect the privacy of any individuals whose names or other identifying information may have been overlooked for closure. A condition-of-use form may not be the ideal solution to ensure privacy, since it puts the obligation directly on the researcher to be responsible to not divulge names and to adhere to library policy. But our experience has been that most researchers understand the responsibility they assume when working with archival collections and do recognize the potential consequences of their own work.

### **Mark Ethan Smith Papers**

The Mark Ethan Smith Papers present issues related less to privacy matters and more to the complex nature of gender identity, self-naming, and descriptive access. The library acquired Mark Smith's papers after he sent a letter expressing interest in donating his collection. Mark Smith was born Marcia Ellen Bazer in 1940. Smith lived an eclectic and nomadic life for many years, including traveling to Mexico, Honduras, Thailand, and Afghanistan and founding a hippie commune in California. Marcia Ellen married a man named Smith in 1960, a marriage that ended in divorce one year later. In 1981, Smith legally changed his name from Marcia Ellen Smith to Mark Ethan Smith. He began work as an aircraft electrician apprentice at a naval facility in California in 1982. Two years later, he was

suspended without pay and discharged. He subsequently filed suit against the Navy and with the Equal Employment Opportunity Commission, alleging unlawful discrimination. The court briefs, transcripts, evidence and rulings, psychiatric evaluations, and written testimonies related to Smith's claims of harassment and discrimination compose the bulk of the collection.

Importantly, Smith did not identify as a woman or a man. For the biographical note in the finding aid, Smith preferred that we use the pronoun *he*, and he requested that we identify him as a "biological female who lives as a person without regard to sex." Smith did not characterize himself as trans\*, and since there is meaning for researchers in how Smith self-identifies, we did not add the Library of Congress (LC) subject heading terms *Transgenderism* or *Transgender people—Identity* to the collection's catalog record. To be frank, I did want to add these terms to Smith's catalog record, although this may partly reflect my own biases and limited understanding of his identity. As K. J. Rawson notes, the term *transgender* can be used too liberally by archivists who may assume that it is applicable even if the creator does not identify with it (2009). By imposing *transgender* on all collections related to gender variance, the archivist may be applying it inappropriately. If we added *transgender* as a subject heading knowing that Smith himself would not have used it, we would be "disrespectfully and oppressively re-naming an identity (from a more privileged perspective) that already has a name" (Rawson 2009: 131). However, at the same time, not applying the term has the potential to limit access for researchers who may miss the collection because they are searching for trans\* materials. This was a concern for me when deciding not to add the term to the catalog record because I did think that researchers interested in trans\* content would want to see Smith's papers.

In an attempt to apply some standard terminology to Smith's catalog record, I added the much broader LC subject term *Gender identity*. The LC heading of *Gender identity*, however, is problematic for other reasons. As Ellen Greenblatt notes, the heading is somewhat ambiguous since it includes the UF (Use For—equivalency) *Sex identity (Gender identity)* and *Sexual identity (Gender identity)*, conflating the concepts of sex and gender (Greenblatt 2011: 221–22). In short, the LC authority file does not work effectively for Mark Smith. There are no applicable terms in the vocabulary that matches his self-description, and the term *Gender identity*, being quite general, may not be particularly helpful to researchers. K. R. Roberto clearly articulates the frustration with Library of Congress-based cataloging practices by noting that schemas like LC are "lacking in any sort of mechanism to acknowledge people's sometimes amorphous and often fluid identities" (Roberto 2011: 56). While it is true that finding the relevant terminology in an authority file is not possible for Mark Smith, it is helpful that the biographical description in the catalog record and the finding aid presents his identity in the language he prefers.



### Conclusion

Balancing access to collections with privacy concerns and applying appropriate description to a collection involves navigating the rights of donors, third parties, and the needs of users. Since concerns about privacy and the limitations of subject headings as they relate to identity are not specific to trans\* materials, library staff often discuss the challenges of privacy, access, and description. Closing materials protects the privacy of individuals but also limits the availability of historically significant information to current researchers who are in the process of shaping the historical narrative. Discussion continues about relying more on a condition-of-use form to protect privacy, which may be a satisfactory alternative to closure for certain materials, and finding the resources to apply redaction on a larger scale to highly sensitive material. As for description, the lack of dynamic and more inclusive subject headings in widely used systems such as LC can be frustrating to the creator, user, and the archivist. While the ongoing evolution and expansion of LC subject headings is good, moving beyond controlled vocabularies through practices such as the application of user-created metadata (i.e., tags) may be most useful to researchers and creators. It would, for example, give Mark Smith the opportunity to add his own tags to his collection's bibliographic record.

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### Notes

1. Finding aids for these four collections are available online.  
 Ari Kane Papers: [nrs.harvard.edu/urn-3:RAD.SCHL:scho1269](https://nrs.harvard.edu/urn-3:RAD.SCHL:scho1269); [nrs.harvard.edu/urn-3:RAD.SCHL:scho1279](https://nrs.harvard.edu/urn-3:RAD.SCHL:scho1279).  
 International Foundation for Gender Education Records: [nrs.harvard.edu/urn-3:RAD.SCHL:scho1444](https://nrs.harvard.edu/urn-3:RAD.SCHL:scho1444).  
 Mark Ethan Smith Papers: [nrs.harvard.edu/urn-3:RAD.SCHL:scho1407](https://nrs.harvard.edu/urn-3:RAD.SCHL:scho1407).  
 Abraham Bartlett Smith Papers: [nrs.harvard.edu/urn-3:RAD.SCHL:scho0043](https://nrs.harvard.edu/urn-3:RAD.SCHL:scho0043).

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# “Counting” Transgender and Gender-Nonconforming Adults in Health Research

*Recommendations from the Gender Identity in US Surveillance Group*

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**Abstract** *Gender minority* refers to transgender and gender-nonconforming people whose sex assigned at birth is different from their current gender identity. US health surveillance systems do not routinely include questions to identify gender minority respondents, resulting in a lack of representative health data that can be used to evaluate the health of gender minorities. This omission represents a missed opportunity to understand the health and well-being of transgender and gender-nonconforming people as well as to learn more about sex and gender differences that may be relevant for the health of all people—gender minority and majority alike. In 2011, the Williams Institute at the University of California, Los Angeles, School of Law convened the Gender Identity in US Surveillance (GenIUSS) Group, bringing together a multidisciplinary and multi-institutional group of experts to increase population-based data about gender minority people through the inclusion of gender-related measures (e.g., assigned sex at birth, gender identity, transgender status) in surveys, with a particular consideration for publicly funded data-collection efforts. Drawing on the expertise and experience of the GenIUSS Group, this article provides an overview of challenges and opportunities and makes eight recommendations for “counting” gender minority adults in health research, with an emphasis on adult population-based surveys.

**Keywords** transgender, gender minority, disparities, health surveillance, measurement

**G**ender minority is an inclusive umbrella term that refers to transgender and gender-nonconforming people—people whose sex assigned at birth (natal sex) is different from their current gender identity (IOM 2011). US health surveillance systems monitoring adult health do not routinely include questions to

identify gender minority respondents, resulting in a lack of representative health data that can be used to evaluate the health of gender minorities (IOM 2011). This omission represents a missed opportunity to better understand the health and well-being of transgender and gender-nonconforming people who disproportionately face social stressors such as transgender stigma, discrimination, and violence that negatively impact their health and well-being (Bockting et al. 2013; Bradford et al. 2013; Clements-Nolle et al. 2001; Clements-Nolle, Marx, and Katz 2006; Grant et al. 2011; Herbst et al. 2008; Kenagy 2005; Lombardi et al. 2001; Nuttbrock et al. 2010; Reisner et al. 2014a, 2014b, 2014c) as well as to learn more about how sex and gender may be relevant for the health of all people (Krieger 2003), gender minority and gender nonminority alike.

In 2011, a landmark report by the Institute of Medicine identified the lack of brief, validated tools with which to identify gender minority respondents in health research as a current barrier to monitoring the health of the gender minority population (IOM 2011). In 2011, the Williams Institute at the University of California, Los Angeles, School of Law convened the Gender Identity in US Surveillance (GenIUSS) Group, bringing together a national multidisciplinary and multi-institutional group of experts to increase population-based data about gender minority people through the inclusion of gender-related measures (e.g., natal sex, gender identity, transgender status) in surveys, with a particular consideration for publicly funded data-collection efforts. To achieve this goal, the group mapped the landscape of current practices in gender-related population research, assessed methodological and other challenges to data collection, and generated a set of recommendations for gathering scientifically rigorous data about the needs and experiences of transgender and gender-nonconforming individuals (GenIUSS Group 2013). GenIUSS also funded two mixed-methods cognitive-testing studies of gender-related measures for use in population-based research (Lombardi et al., in preparation; Reisner 2013; Reisner et al. 2014d).

Drawing on the expertise and experience of the GenIUSS Group, this article provides an overview of opportunities, challenges, and recommendations for “counting” transgender and gender-nonconforming adults in US population health research. First, we situate transgender and gender-nonconforming adult health research within a framework of sex and gender health disparities. Second, we review considerations for measurement of gender identity in adult population-based surveys and offer recommendations of measures that identify gender minority respondents and will enable inclusive health surveillance efforts. This article contains eight recommendations proposed by the GenIUSS Group to guide inclusive sex and gender adult population-based research (see appendix). A full report and list of recommendations can be found elsewhere (GenIUSS Group 2014). Additional measures and recommendations pertaining to adolescents

and youth specifically can also be found elsewhere (Conron et al. 2014; GenIUSS Group 2014).

### **Sex and Gender as Social Determinants of Health**

Sex and gender are recognized globally as social determinants of health and well-being across a wide variety of geographic settings and contexts (Doyal 2001, 2003; Krieger 2003; Nieuwenhoven and Klinge 2010; Nowatzki and Grant 2011; Vlassoff 2007; WHO 2008). Social determinants of health are root causes of health disparities (WHO 2008). Health disparity refers to “a particular type of difference in health . . . in which disadvantaged social groups—such as poor, racial/ethnic minorities, women, or other groups who have persistently experienced social disadvantage or discrimination—systematically experience worse health or greater health risks than more advantaged social groups” (Braveman 2006). Reducing health disparities is a core aim of Healthy People 2020 (US Department of Health and Human Services 2010), the science-based roadmap with ten-year national measurable objectives and goals for improving the health of all Americans. Bettering the health of all people includes addressing health inequities in the United States—defined as unfair and avoidable differences in health—related to sex and gender (Gorman and Read 2006; Read and Gorman 2006). Gender minority people are positioned at the intersection of complex sex and gender pathways; that is, causal mechanisms that cause poor health are both sex and gender related (Reisner et al. 2014e). Thus learning more about the social determinants of gender minority people’s health and well-being is an important task to inform health equity for everyone.

US population-level surveys do not utilize standardized questions to collect information about sex and gender (Conron et al. 2014). Most surveys measure sex with a self-reported demographic question (male or female). Some surveys rely on telephone interviewers to assess perceived sex or gender based on the vocal tone of respondents (Conron et al. 2012, 2014). The lack of standardized measures of both sex and gender impacts the empirical rigor of research on sex and gender differences in US population health by obfuscating differences between natal sex (biological) and gender (social) pathways. Underlying non-standardization of measures is a lack of conceptual clarity about sex and gender that fails to recognize that (1) sex and gender represent distinct constructs; (2) sex and gender are multidimensional and dynamic; and (3) gender identity is not synonymous with sexual orientation.

*Recommendation 1: That standardized self-report questions about both sex and gender be included in all surveys of the US population.*

Despite the imprecise and often interchangeable use of sex (“female” and “male”) and gender (“woman” and “man”) in the scientific research literature (Krieger

2003), sex and gender are not one and the same. *Sex* refers to biological differences among females and males, such as genetics, hormones, secondary sex characteristics, and anatomy (Haig 2004). The assignment of sex at birth (female or male) is made by medical providers and is typically based on the appearance of external genitalia. Sex is then labeled and categorized as female or male and is usually documented on a birth certificate to become a legal construct. *Gender* typically refers to cultural meanings ascribed to or associated with patterns of behavior, experience, and personality that are labeled as feminine or masculine (IOM 2011). The lack of recognition that sex and gender are distinct constructs can be seen in US population survey practice. Some surveys rely on interviewer judgment to assess the sex of respondents (Conron et al. 2012; Conron et al. 2014). For example, neither sex nor gender are self-reported on the Behavioral Risk Factor Surveillance System (BRFSS); rather, these constructs are noted by the telephone interviewer (as sex based on interviewer-perceived tone of respondent voice) and confirmed with the respondent if needed (Conron et al. 2012). This would be a source of significant measurement error for gender minority respondents. Thus, the consequences of these measurement techniques are inappropriate data collection on gender minority populations. They also can lead to error in other situations, such as with people who smoke, or who have unusually high or low speaking voices. Measuring sex and gender in US population surveys will contribute to understanding and ameliorating sex and gender health inequities.

*Recommendation 2: That multiple aspects of gender be measured in US population-based research, including gender identity.*

Gender is a multidimensional construct (Egan and Perry 2001) that requires additional empirical and theoretical attention. Understanding gender means attending to the psychological, social, and behavioral dimensions that influence individual health and well-being and contribute to population-level health disparities. A key dimension of gender that represents an underinvestigated social determinant of population health is gender identity (IOM 2011). *Gender identity* refers to a person's internal sense of being man, woman, transgender, or another gender. US population-level surveys do not routinely include survey items to identify transgender and/or gender-nonconforming respondents; therefore, there is a lack of routine health surveillance data to monitor health disparities by gender identity (Conron et al. 2014; IOM 2011). Representative data that allow comparisons between gender minority and majority people are essential to document health inequities as well as to reduce sex and gender health disparities in the United States (Schwartz and Meyer 2010).

Despite the dearth of probability-based national-level data on the health of gender minority people (Conron et al. 2012), local, regional, and national studies suggest that transgender and gender-nonconforming people face stigma, prejudice, violence, and institutionalized discrimination in areas of everyday life such as health care, housing, employment, education, and legal recognition of their gender. As a result of these social stressors and socioeconomic marginalization, gender minority people appear highly burdened by adverse health outcomes including psychological distress, suicidality, substance use and abuse, tobacco use, HIV, and sexually transmitted infections (STIs) (Bockting et al. 2013; Bradford et al. 2013; Clements-Nolle et al. 2001; Clements-Nolle, Marx, and Katz 2006; Conron et al. 2012; Grant et al. 2011; Hendricks and Testa 2012; Herbst et al. 2008; Kenagy 2005; Nuttbrock et al. 2010; Reisner, Bailey, and Sevelius 2014; Reisner et al. 2014b, 2014c). Negative health outcomes appear to be exacerbated for transgender- and gender-nonconforming-identified people who experience intersecting oppressions as members of other disadvantaged social groups (Bowleg 2012), for example, people of color and/or those who are economically marginalized and living in poverty (Garofalo et al. 2006; Herbst et al. 2008). In addition to adverse health outcomes among people who identify as transgender and gender nonconforming, the negative health sequelae of having a nonconforming gender expression have also been documented (D'Augelli, Grossman, and Starks 2006; Rosario, Schrimshaw, and Hunter 2008; Sandfort, Melendez, and Diaz 2007; Skidmore, Linsenmeier, and Bailey 2006; Toomey et al. 2010), including recalled childhood nonconforming gender expression measured retrospectively (Calzo et al. 2014; Roberts et al. 2012, 2013; Rosario et al. 2014). Together these data suggest the need for routine health surveillance that takes gender identity into account.

Gender pathways are multilevel and sociohistorically and culturally dependent, and they dynamically change over time. Understanding gender means not only conceptualizing and measuring different dimensions of gender but also considering its dynamic nature. Gender is relational and fundamental to the social structuring of power and privilege (Courtenay 2000). Dimensions of gender affect people's health and well-being at multiple levels of influence (Ferrant 2014). Thus, gendered pathways can be best conceptualized using a social-ecological model (McLeroy et al. 1988) whereby individual, interpersonal, organizational, community, and public policy levels influence population health (see fig. 1).

Gender is also sociohistorically and culturally dependent, meaning gender diversity manifests differently in various contexts and settings and over time. Dimensions of gender are dynamic and may change across a person's individual development; for example, a person's gender expression may change from young adulthood to middle age. These changes have implications for health across the life course (Pearlin et al. 2005). Dimensions of gender may also change over time

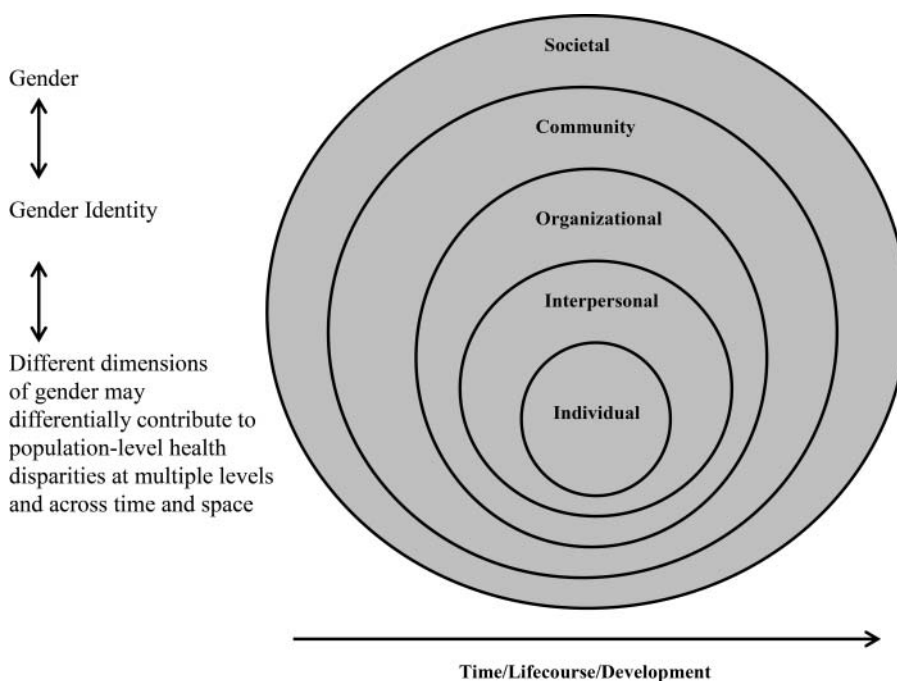


Figure 1. Understanding gender as a social determinant of health

and throughout sociopolitical history—for example, intergenerational and age cohort shifts in gender-nonconforming expression or even what is acceptable as gender-nonconforming behavior (e.g., women wearing pants). These changes affect how gender diversity is conceptualized in population research. For example, over the past fifteen years there has been a paradigm shift in gender minority health research from a disease-based model (transgender and gender nonconforming as disorder) to an identity-based model (transgender and gender nonconforming as identity) (Bockting 2008, 2009). Conceptualizing transgender and gender-nonconforming people as having diverse, nonpathological gender identities and gender expressions rather than as “disordered” reformulates how a “case” is defined and measured in population research. Such redefinition of a case also affects prevalence estimates as to the number of gender minority people in the United States.

*Recommendation 3: That questions specific to gender minorities be asked using skip patterns.*

Gender minorities represent an underserved and underresearched population with specific medical and mental health needs (Grant et al. 2011; Grossman and D’Augelli 2006; Mayer et al. 2008), many of which remain unexplored. Collecting

more high-quality data on the disparities associated with a transgender or gender-nonconforming identity and other social, economic, and health concerns of gender minority communities is essential if federal, state, local, and nonprofit agencies are to adequately serve transgender and gender-nonconforming people. Improved data are also necessary to allow researchers to better understand the backgrounds and needs of gender minority people and to help transgender advocates and their allies develop effective strategies for improving the circumstances of transgender and gender-nonconforming people's lives, including addressing inequities.

Many aspects of the needs and experiences of gender minority people remain unexplored (IOM 2011). Adding gender identity to surveys allows for skip patterns (a question or series of questions associated with a conditional response that can be skipped); thus questions specific to gender minorities can be asked. An example of questions that can be asked of gender minority respondents in skip patterns are those relating to gender affirmation (Sevelius 2013). Gender affirmation can be conceptualized across three domains: social (name, pronoun, disclosure of gender to others, passing), medical (hormones, surgery, etc.), and legal (name change, gender marker change, document amendments). All three domains may be relevant for the health of gender minority people and should be queried. Another example of questions for skip patterns are those relating to antitransgender discrimination (Bradford et al. 2013), resilience processes (Bockting et al. 2013), and coping (Budge, Adelson, and Howard 2013) in response to chronic adversity. Adding a gender minority-specific module of questions that a relatively small subset of respondents will be asked is a cost-effective endeavor. Although some cost will be incurred, this additional cost will be offset by the benefit of rendering visible the lives, experiences, and health of gender minority people.

*Recommendation 4: A measure of gender identity does not replace sexual orientation (identity, attraction, behaviors). Measuring both gender identity and sexual orientation is recommended for US population-based surveys.*

Gender identity is often mistakenly conflated with sexual orientation. As an example, the National Center for Health Statistics sexual identity question, which was added to the National Health Interview Survey (NHIS) in 2014 (CDC 2014), is an inadequate and inaccurate measure of gender identity. "Transgender" is one response option in a subset of "Something else" on the sexual orientation identity measure. The NHIS sexual orientation identity measure queries respondents as follows: "Which of the following best represents how you think of yourself?" with response options "Gay," "Straight, that is, not gay," "Bisexual," "Something else," "Refused," "I don't know the answer." If respondents answer "Something else," a subsequent question is asked that includes a response option for gender minority people: "What do you mean by something else?" with response options: "You are



not straight, but identify with another label such as queer, trisexual, omnisexual or pansexual," "You are transgender, transsexual or gender variant," "You have not figured out or are in the process of figuring out your sexuality," "You do not think of yourself as having a sexuality," "You do not use labels to identify yourself," "You mean something else," "Refused," "Don't know."

There are several factors related to this measure that make it a decidedly poor measure for gender minority populations. A gender minority person who identifies their sexual orientation as any response option other than "Something else" will not be "counted" as a gender minority. Yet transgender and gender-nonconforming individuals, like anyone else, may identify as gay, straight, bisexual, or another sexual orientation; they may be attracted to people of any gender; and they may engage in sexual behaviors with people of any gender (Grant et al. 2011). The NHIS measure will likely underestimate the proportion of respondents who identify as transgender or gender nonconforming; thus we do not recommend this measure for population-based research in gender minority health. Survey designers should be aware that this question was not tested with the intention of capturing population prevalence estimates of gender minorities. This question assesses sexual orientation; thus a gender minority question should always accompany this measure.

Systematic data collection is key to the reduction of known health disparities (WHO 2008). After more than a decade of sustained effort by activists, researchers, and policy experts, there is now consensus around the importance of systematically collecting information related to sexual orientation (IOM 2011; SMART 2009). Similarly, precise measurement of sex and gender identity is needed in population-based research or else misclassification bias in sexual orientation-related data will occur. For example, a natal female who identifies her gender identity as a woman and who is sexually attracted to men may identify as "straight." However, a natal female who identifies his gender as a man and is sexually attracted to men may self-identify as "gay." Capturing sex only, without measurement of current gender identity, would result in misclassification of these sexual orientation identity data. In addition, the discriminatory treatment that some transgender and gender minority people suffer may be based in others' perceptions and understandings of gender identity and gender expression or sexual orientation (Gordon and Meyer 2007; Lombardi 2009). Therefore, data should be collected on sexual orientation and gender identity in order to fully study and understand the health disparities people face. Best practices for asking questions related to sexual orientation, including the three recommended dimensions of identity, attractions, and behaviors, have been described elsewhere (SMART 2009).

### **General Considerations for Measurement of Transgender and Gender-Nonconforming People on Population-Based Surveys**

Transgender and gender-nonconforming people live in communities across the country and complete general population surveys; however, they are invisible due to the absence of measures that would allow their responses to be identified and compared to those of gender majority respondents. The crucial first step in building the knowledge base about gender minority health is adding gender-related measures to publicly funded population surveys that can help characterize the needs of gender minority respondents and enhance the precision of the measurement of sex and gender differences in population health. The landscape of major federally supported surveys provides a key opportunity to gather demographic information about the US gender minority population as well as to gather information about the experiences of transgender and gender-nonconforming individuals across fields of inquiry where disparities affecting the gender minority population have been documented, including education, employment, health, military service, and criminal justice. Some of the largest and most important federally supported surveys in these fields include the American Community Survey, the Current Population Survey, the Survey of Income and Program Participation, the National Crime Victimization Survey, the National Health Interview Survey, the Behavioral Risk Factor Surveillance System, the National Inmate Survey, and the National Survey of Veterans. These surveys represent important sources of information about population-level health disparities in the United States, including by age, sex, and race/ethnicity. Adding gender identity to these and other publicly funded population surveys offers the unique opportunity to compare gender minorities and gender majorities.

*Recommendation 5: Build on “best practices” for asking about minority groups on US population-based surveys: (1) gear questions asking about transgender and gender-nonconforming status toward gender majority respondents; (2) offer response options beyond binary “female”/“male” or “woman”/“man” categories; (3) aggregate data over multiple years to ensure adequate sample sizes.*

Three key issues related to collecting information about minority groups on population-based surveys are applicable and warrant consideration in the context of measurement of gender minority respondents. First, questions used to identify minority group members should be geared toward the majority group. Because a fairly small proportion of the US population is believed to be transgender (Conron et al. 2012; Gates 2011), it is imperative that questions included on general population surveys be easy for nonminority respondents to answer correctly. If even a small percentage of gender majority respondents incorrectly select answers

that lead them to be classified as gender minority (scientifically termed "false positives"), the data collected will be of questionable utility.

Second, questions needed to identify minority group members must be acceptable to, and provide appropriate response options that resonate with, group members, even if the questions do not have the breadth and depth desired by minority group members. At the most basic level, this means offering more than two response options ("female"/"male" or "woman"/"man") on population-based surveys to allow for transgender and gender-nonconforming people to have an opportunity to identify themselves as gender minorities. This does not mean all gender minority people will select this option, as some do identify with the terms "female"/"male" or "woman"/"man." However, findings from the National Transgender Discrimination Survey (NTDS) (Grant et al. 2011), a community-based survey that sampled more than 6,400 US transgender adults, illustrate the importance of having a nonbinary response option in order to capture the diversity of gender identities and expressions that fall within the gender minority umbrella. In the NTDS, respondents were asked "What is your primary gender today?" with the responses "male/man," "female/woman," "part time as one gender, part time as another," and "a gender not listed here, please specify." More than one in ten respondents ( $n = 860$ ) opted to write in a gender identity that was "not listed" (Harrison, Grant, and Herman 2011).

Third, the heterogeneity of gender minority identity and experience that is explored in community-specific surveys (Grant et al. 2011; Harrison, Grant, and Herman 2011) cannot be gathered in population-based surveys. Population-based surveys are intended to provide policy makers and public health planners with basic information about the needs and characteristics of geographically defined populations and of large sociodemographic groups within that population. Thus, unless they are designed to purposively oversample gender minority groups, population-based surveys typically do not have enough gender minority respondents to produce information about subgroups (e.g., female-to-male Latino young adults) within the gender minority population. As with any rare population data, aggregation over years is one of the primary methods for getting a sample size large enough to constructively analyze the health of transgender and gender-nonconforming people. For additional examples, approaches, and best practices associated with aggregation of data, please see the full GenIUSS report (GenIUSS Group 2014).

### **Recommended Measures for Gender Identity for Population-Based Surveys**

Numerous examples exist of how to collect information about the gender minority population. Questions that would measure gender identity and enable survey respondents to be classified as gender minority or gender nonminority,

often used in combination, include natal sex, gender identity, and transgender status. There are different strengths and limitations to measures and measurement approaches to gathering data about the health and sociodemographic characteristics of gender minority people. However, which questions to ask in order to produce data about the health needs and socioeconomic characteristics of transgender or gender-nonconforming respondents depends upon the goal of such an endeavor (i.e., purpose of data collection, outcome of interest, population that one wishes to generalize and serve), the measures already collected in existing surveys, and sample size considerations (GenIUSS Group 2014). Although future research is needed, particularly with more diverse, representative samples, there is already evidence of appropriate measures to include questions that classify gender minority and gender nonminority respondents in population-based surveys now.

*Recommendation 6: When two demographic items can be added to an adult survey (or, in most instances, a standing measure of sex replaced and a measure of current gender identity added), inclusion of measures of assigned sex at birth and current gender identity is recommended.*

Collecting information about assigned sex at birth (male, female) and current gender identity (e.g., man, woman, transgender) is often referred to as the two-step method to assess gender minority/gender nonminority status. First developed in 1997 by the Transgender Health Advocacy Coalition for use on a survey of transgender people in Philadelphia (Singer, Cochran, and Adamec 1997), the two-step method was subsequently adapted and used in the Washington Transgender Needs Assessment Survey (Xavier et al. 2005) and the Virginia Transgender Health Information Study (Bradford et al. 2013; Xavier, Honnold, and Bradford 2007). The two-step method uses two questions (assigned sex at birth and current gender identity) to cross-classify respondents as gender minority (discordant sex/gender responses) or gender nonminority (concordant sex/gender responses). The two-step method appears the most likely to have high sensitivity as well as high specificity with adults. Table 1 shows recommended measures for assigned sex at birth (a) and gender identity (b). It is unclear whether assigned sex at birth should precede or follow current gender identity; future studies should investigate ordering effects.

A 2013 study found that the two-step method was far more successful in identifying transgender respondents than a single, stand-alone gender identity item that offered a transgender response option (Tate, Ledbetter, and Youssef 2013). This study also found that some transgender individuals identify their gender as male or female and not as transgender and thus will be missed if a gender identity measure is used alone. Additional research by GenIUSS Group members that conducted cognitive testing of survey items supports the validity of a two-step method implemented using different response options (Conron,

**Table 1.** Recommended gender measures from the GenIUSS group*(a) Assigned sex at birth*

What sex were you assigned at birth, on your original birth certificate? (check one)

- Male  
 Female

*(b) Current gender identity*

How do you describe yourself? (check one)

- Male  
 Female  
 Transgender  
 Do not identify as male, female, or transgender

*(c) Transgender status*

Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person who was born into a male body but who feels female or lives as a woman. Do you consider yourself to be transgender?

- Yes, transgender, male to female  
 Yes, transgender, female to male  
 Yes, transgender, gender nonconforming  
 No

*Note—Additional information for telephone interviewer if asked about definition of transgender:*

Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person who was born into a male body but who feels female or lives as a woman would be transgender. Some transgender people change their physical appearance so that it matches their internal gender identity. Some transgender people take hormones and some have surgery. A transgender person may be of any sexual orientation—straight, gay, lesbian, or bisexual.

*Note—Additional information for interviewer if asked about definition of gender nonconforming:*

Some people think of themselves as gender nonconforming when they do not identify only as a man or only as a woman.

*(d) LGBT identity*

Do you think of yourself as (please check all that apply):

- Straight  
 Gay or lesbian  
 Bisexual  
 Transgender, transsexual, or gender nonconforming

If yes to transgender, then probe:

- Transgender, male to female OR  
 Transgender, female to male OR  
 Gender variant  
 Transsexual

Scout, and Austin 2008; Lombardi et al., in preparation; Reisner et al. 2014d). A two-step approach has also been used in online research by GenIUSS Group members in Latin America/the Caribbean, Portugal, and Spain (Reisner et al. 2014e). In 2011, the US Centers for Disease Control and Prevention added sex and gender identity data elements to the US HIV/AIDS surveillance system, including the Adult Case Report Form, as well as to its electronic case-reporting surveillance

system, called the Enhanced HIV/AIDS Reporting System (eHARS) (CDC 2013a). A unique strength of the two-step method is that it takes into account both natal sex (biological) and gender (social) processes, which are key for health research and epidemiological studies of health (Krieger 2003).

A visual schematic of measurement using this method is shown in figure 2, illustrated using the two survey items and response options from the 2010 wave of the Growing Up Today Study (GUTS), a national cohort of more than sixteen thousand adolescents and young adults followed prospectively since 1996 (Reisner 2013). A gender minority person endorsing a male sex assigned at birth may identify their current gender identity as female (cross-sex identity), male-to-female transgender (transgender identity), or another gender identity (do not identify as male, female, or transgender); all individuals who fall into these categories can be counted as gender minorities. Further, differences by identity can be investigated, assuming adequate sample sizes. Thus cross-sex-identified respondents can be compared to transgender-identified respondents or to non-binary gender-identified people, or assigned female sex at birth can be compared to assigned male sex at birth. This item has been tested with “check one” instructions (Reisner et al. 2014d); however, based on the GenIUSS Group’s collective experience in the field and work with gender minority communities, additional testing of this item using “check all that apply” instructions is suggested.

Since 2007, the Center of Excellence for Transgender Health at the University of California, San Francisco, has advocated the use of a specific two-step question protocol in health care settings where data are collected by a second party (e.g., a health provider) (Sausa et al. 2009). An applied example of how the two-step method can aid in culturally competent care in clinical settings and avoid epidemiological misclassification can be found in prostate health. Natal males have a prostate and natal females do not. Therefore, natal males need routine preventive prostate cancer screening regardless of their current identity (CoE 2011; Deutsch et al. 2013; Feldman 2007; Feldman and Goldberg 2006) and should also be in the denominator of a population prevalence estimate documenting utilization of preventive screening for prostate cancer.

*Recommendation 7: When valid self-report measures of assigned sex at birth and current gender identity are not on a survey and cannot be added (or replace existing measures) and a valid measure of sexual orientation is already on a survey, then the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) stand-alone demographic item is recommended.*

In 2007, a single-item measure of gender minority/gender nonminority status was added to the MA-BRFSS. The BRFSS is a national collaborative health surveillance effort between the CDC and state departments of public health. Each year, a

**STEP 1: SEX**











*What sex were you assigned at birth, on your original birth certificate? (check one)*

- Male
- Female

**STEP 2: GENDER IDENTITY**

*How do you describe yourself? (check one)*

- Male
- Female
- Transgender
- Do Not Identify as Male, Female, or Transgender

	Assigned Sex <sup>a</sup>	
	Male (male sex on original birth certificate) 	Female (female sex on original birth certificate) 
<b>Current Gender Identity</b>		
Male	<b>Cisgender Male<sup>b</sup></b> (male birth sex, male gender identity) 	<b>Cross-Sex Male Identity</b> (female birth sex, male gender identity) 
Female	<b>Cross-Sex Female Identity</b> (male birth sex, female gender identity) 	<b>Cisgender Female</b> (female birth sex, female gender identity) 
Transgender	<b>Transgender Identity</b> (male birth sex, transgender identity) 	<b>Transgender Identity</b> (female birth sex, transgender identity) 
Do Not Identify as Male, Female, or Transgender	<b>Do Not Identify</b> (male birth sex, some other diverse gender identity) 	<b>Do Not Identify</b> (female birth sex, some other diverse gender identity) 

**Figure 2.** Conceptual overview: natal sex and current gender identity measurement using a two-step method in the Growing Up Today Study 1 (Reisner et al. 2014d).

<sup>a</sup>Infants born intersex are assigned either a female or male birth sex by a medical provider at birth.

<sup>b</sup>The term *cisgender* is used to refer to non-transgender individuals. The prefix *cis-* in Latin means “on this side of,” opposed to *trans* or *ultra*, meaning across or beyond. Gender minority would be operationalized by collapsing people with a cross-sex identity, transgender identity, or who identify with a gender other than male, female, or transgender.

household probability sample of adults who can be reached by telephone is drawn using random digit dial methods. Topics such as health insurance coverage, cancer screening, and sexual behavior are assessed with core questions provided by the CDC. States may add supplemental questions to their own state surveys. A single-item measure that would permit respondents to be classified as gender minority and gender nonminority was initially developed by transgender community leaders and research allies for inclusion on the 2001 Boston BRFSS survey. Analyses of MA-BRFSS data collected between 2007 and 2009 indicate that 0.5 percent of eighteen- to sixty-four-year-old adults answered yes to this question and were classified as gender minority (Conron et al. 2012). The nonresponse rate (1.4 percent) for this item was very low; in fact, it was lower than the nonresponse rate for sexual orientation and much lower than the nonresponse rate for income on the same survey. A slightly modified version of this item is shown in table 1 (c) as well as a sexual orientation identity item; together, these questions were adopted by the Centers for Disease Control and Prevention in 2013 as an optional “sexual orientation and gender identity” module that states can include on their Behavioral Risk Factor Surveillance Surveys.

*Recommendation 8: When valid self-report measures of assigned sex at birth and current gender identity are not on a survey and cannot be added (or replace existing measures), and a valid measure of sexual orientation identity is not already on a survey and cannot be added, then a stand-alone demographic item is recommended (without a write-in response option) that includes sexual orientation and gender identity.* In 2008, the National Network for LGBT Tobacco Control (now the Network for LGBT Health Equity) developed and tested a single-item measure of gender identity and sexual orientation for Blue Cross Blue Shield of Minnesota. This question is a measure of LGBT status and queries about sexual orientation and transgender identity in a format that allows both aspects of identity to be independently reported through a “check all that apply” mechanism (table 1, d). In 2008, this measure was cognitively tested in a diverse sample (including oversamples of people of color, LGB, and transgender people) in Minnesota and has been part of the state’s surveillance system since then. Importantly, this item successfully prevented false positives by steering gender nonminority respondents, including those who did not understand what *transgender* meant, away from the transgender response option.

## **Discussion**

A critical first step in building the knowledge base about gender minority health is adding gender-related measures to publicly funded population surveys. These measures can help characterize the needs of transgender and gender-nonconforming



respondents and gain precision in sex and gender differences in health more broadly. One of the challenges that has been raised related to transgender data collection is the relative value of adding measures that are only expected to collect data from 0.5 percent of the general population (Conron et al. 2012). This is an estimated 1.569 million US citizens. Federally funded national surveys collect and report data on subpopulations and health conditions that affect far fewer than this number of citizens (CDC 2013b).

To reduce the widening inequities in health across a variety of social determinants, including gender, the World Health Organization recommends that researchers “measure and understand the problem and assess the impact of action” (WHO 2008). Incorporating gender-related measures that allow for identification of gender minorities in national and federal surveys will allow public health data systems to document and understand a range of health disparities by transgender and gender-nonconforming identity and allow for the development of targeted public health efforts that are responsive to the lived realities of populations at the highest risk of poorer health. The potential “cost” of the few survey items that will need to be added is far outweighed by the public health benefits of the resulting knowledge.

The GenIUSS Group has identified additional gender-related measurement research that needs to be undertaken. Cognitive testing of survey measures in Spanish represents a key area for future measurement research. Research with more diverse samples is also needed, including by race/ethnicity and socioeconomic status. For example, anecdotal evidence and qualitative data (Hwahng and Nuttbrock 2007; Valentine 2007) show that there may be differences in nomenclature for transgender and gender-nonconforming identities based on race/ethnicity. Further research is needed to determine whether and how differences in the language of self-identity among people of color impacts our ability to accurately capture and reflect their experiences in population-based research. Another area of needed research is how to accurately identify intersex people on population surveys—people with a “difference of sexual development” or other intersex condition (GenIUSS Group 2014; IOM 2011).

We have focused on gender identity in this article. However, gender expression represents an important determinant of health (Calzo et al. 2014; Corby, Hodges, and Perry 2007; D’Augelli, Grossman, and Starks 2006; Egan and Perry 2001; Roberts et al. 2012, 2013; Rosario, Schrimshaw, and Hunter 2008; Rosario et al. 2014; Sandfort, Melendez, and Diaz 2007; Skidmore, Linsenmeier, and Bailey 2006; Toomey et al. 2010). People with gender-nonconforming gender expression may or may not self-identify as transgender, and they may or may not identify as sexual minority (Wylie et al. 2010). Survey respondents can be characterized along a continuum of current and/or recalled childhood

gender conformity and nonconformity. Indeed, recalled childhood gender-nonconforming expression has been shown to be a critical determinant of health (Calzo et al. 2014; Roberts et al. 2012, 2013). It is important to note that accurate characterizations of respondents as gender nonconforming also depend upon the availability of accurate data about assigned sex at birth. Future research is needed to identify recommended gender-expression measures for population-based surveys.

The GenIUSS Group notes that population-based research is not the only source of meaningful data about gender minorities. Diversifying sources of information that contribute to the knowledge base in gender minority health is important for future research efforts. Community-based surveys represent an important and valuable source of information about transgender and gender-nonconforming health. Research that uses community-based participatory research (CBPR) principles and that works *with* transgender and gender-nonconforming communities to identify and address their specific health-related needs (Leung, Yen, and Minkler 2004) is especially vital for gender minority health research, given that transgender and gender-nonconforming people largely represent a “hidden” population. Large samples of transgender and gender-nonconforming people are efficiently reached through social network linkages to other gender minority people and their allies. The best example of large-scale application of CBPR principles with gender minority communities to gather information about specific health-related issues affecting gender minority adults is the US NTDS (Grant et al. 2011). Between September 2008 and March 2009, more than 6,400 transgender adults were recruited using multimodal data collection methods (in person and online) to ensure a sociodemographically and geographically diverse national sample (Reisner et al. 2014a). NTDS remains the largest sample of US gender minorities to date. Data from NTDS led to widespread advocacy and policy changes that benefit the health and well-being of transgender and gender-nonconforming individuals. Surveys such as NTDS can lead to rigorous community-based research that engages communities and contributes to transgender and gender-nonconforming health, including methodological innovations (Reisner et al. 2014a).

Survey research is only one means of collecting data to assess the experiences of the gender minority population. Clinical settings and electronic health records (EHR) have been identified as important and underutilized sources of information about sexual and gender minority health disparities (Cahill and Makadon 2014; Deutsch et al. 2013). Clinical settings and EHR are particularly valuable in light of the dearth of comparative data that exist to understand the health and well-being of gender minorities relative to gender nonminorities.

Other sources include administrative data such as the data collected by government agencies to monitor compliance with civil rights laws, cohort studies that offer unique longitudinal and developmental data, and other cohort-related surveillance systems such as those maintained by the Department of Veterans Affairs. Addition of gender-related measures—along with measures related to sexual orientation—to clinical settings, EHR, and other administration data collection systems represents an important way forward to reduce health disparities and improve population health.

In coming years, the addition and refinement of questions that measure gender identity will allow researchers, policy makers, and transgender and gender-nonconforming individuals themselves to add to the science about transgender and gender-nonconforming health and, in time, to monitor and evaluate efforts to eliminate health disparities and achieve health equity. Such an endeavor also offers the opportunity to learn more about sex and gender differences that may be relevant for the health of all people—gender minority and majority alike.

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**Appendix.** Eight recommendations from the GenIUSS Group

*Recommendation 1:* That standardized self-report questions about both sex and gender be included in all surveys of the US population.

*Recommendation 2:* That multiple aspects of gender be measured in US population-based research, including gender identity.

*Recommendation 3:* That questions specific to gender minorities be asked using skip patterns.

*Recommendation 4:* A measure of gender identity does not replace sexual orientation (identity, attraction, behaviors). Measuring both gender identity and sexual orientation is recommended for US population-based surveys.

*Recommendation 5:* Build on “best practices” for asking about minority groups on US population-based surveys: (1) gear questions asking about transgender and gender nonconforming status toward gender majority respondents; (2) offer response options beyond binary “female”/“male” or “woman”/“man” categories; (3) aggregate data over multiple years to ensure adequate sample sizes.

*Recommendation 6:* When two demographic items can be added to an adult survey (or, in most instances, a standing measure of sex replaced and a measure of current gender identity added), inclusion of measures of assigned sex at birth and current gender identity is recommended. The two-step approach appears the most likely to have high sensitivity as well as high specificity with adults (table 1, a, b).

*Recommendation 7:* When valid self-report measures of assigned sex at birth and current gender identity are not on a survey and cannot be added (or replace existing measures) and a valid measure of sexual orientation identity is already on a survey, then the BRFSS stand-alone demographic item is recommended (table 1, c).

*Recommendation 8:* When valid self-report measures of assigned sex at birth and current gender identity are not on a survey and cannot be added (or replace existing measures), and a valid measure of sexual orientation identity is not already on a survey and cannot be added, then a stand-alone demographic item is recommended (without a write-in response option) that includes sexual orientation and gender identity (table 1, d).