Transgender healthcare coverage: Prevalence, recent trends, and considerations for payers

By Andrew L. Naugle, Susan Philip | 28 July 2016

Recently, the concept of gender identity and what it means from a health insurance coverage perspective has been receiving increased attention. This paper lays out recent trends, including recent federal and state laws affecting health insurance benefits for transgender individuals. We also examine health insurance clinical coverage policies related to gender reassignment surgery as well as prevalence estimates. Finally, we provide future considerations for healthcare payers, including appropriately capturing data relevant to the healthcare needs of the transgender population.

According to the U.S. Department of Health and Human Services (HHS), the term "gender identity" is defined as:

> ...an individual's internal sense of gender, which may be different from an individual's sex assigned at birth. The way an individual expresses gender identity is frequently called "gender expression," and may or may not conform to social stereotypes associated with a particular gender. Gender may be expressed through, for example, dress, grooming, mannerisms, speech patterns, and social interactions...an individual has a transgender identity when the individual's gender identity is different from the sex assigned to that person at birth; an individual with a transgender identity is referred to in this part as a transgender individual.[1]

In most cases, to qualify for gender reassignment surgery, a patient must have a persistent, well-documented diagnosis of gender dysphoria. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM), 5th Edition (DSM-5), gender dysphoria (formerly referred to as gender identity disorder) occurs when there is a noticeable difference between the gender an individual expresses or believes he or she is and the birth gender, and when this disparity is persistent for at least six months.[2] This difference, when unresolved, may lead to clinically significant mental distress, which is a defining characteristic of gender dysphoria. It is important to note that only a subset of individuals who are transgender (or gender non-conforming) will be diagnosed as having gender dysphoria because not all individuals who are transgender will experience clinically significant mental distress that can be diagnosed as gender dysphoria.

The need for healthcare services for the transgender population, including reassignment surgery, is not new. One of the first documented cases took place in 1952, when a former U.S. Army private underwent male-to-female (MTF) surgery in Denmark. In more recent years, increased awareness, changing public perceptions, evolving research and medical evidence, changing regulatory environments, and potential changes in demand may create a "tipping point" to expand the availability of healthcare services and health insurance benefits for the transgender population. Medicare, the Federal Employee Health Benefits Program (FEHBP), state Medicaid programs, and commercial insurers are all reexamining coverage policies and changing them in light of evolving standards of care and laws and regulations. Health insurers will need appropriate data and analytics to support changes in coverage policies and understand their impacts.

Prevalence and healthcare use estimates

There are an estimated 1.4 million adults (0.6%) in the United States who self-identify as transgender, according to a recent study based on the Centers for Disease Control and Prevention (CDC) 2014 Behavioral Risk Factor Surveillance System (BRFSS).[3] The BRFSS survey asked respondents whether they considered themselves to be transgender, and if yes, whether male-to-female (MTF), female-to-male (FTM), or gender nonconforming. This 2014 estimate is twice that of a prior estimate, which found there were approximately 700,000 individuals (0.3%) who identified as transgender in 2011.[4] This increase can be attributed to several factors, including study design changes and individuals being more willing to self-identify in 2014 than in 2011.

To estimate use of particular healthcare services, health insurance claims data are usually a good source of information, especially when there is a substantial population that may use the services and when those services are covered by insurance. In this case, claims-based sources are not currently reliable for estimating the number of individuals who are transgender or who have gender dysphoria and their related healthcare utilization. Milliman conducted a review of proprietary claims data sources containing about 2 million lives over a four-year period (2009 to 2012). We found that 0.004% of members had an insurance claim related to gender dysphoria (previously called gender identity disorder). If extrapolated to the entire U.S. population, this represents only a small fraction of those self-reporting transgenderism in the BRFSS survey.

Health insurance claims are not currently a reliable information source for estimating prevalence of gender dysphoria for a variety of reasons:

- Until recently, services related to gender dysphoria have not been covered by health insurance and thus no claims were generated.
- Patients may not identify as transgender because of stigma or for other reasons.
- Patients may not present symptoms of gender dysphoria during a healthcare visit.
- Treating clinicians may not ask or record the appropriate diagnostic code in the claim, especially if there was no obvious clinical reason to code for gender dysphoria.
- Clinicians may use other diagnosis codes such as "ovarian dysfunction/failure," "testicular dysfunction," or adrenogenital disorder in lieu of a gender dysphoria diagnosis.

Patients who can afford it may opt to pay directly for healthcare services related to gender dysphoria and thus claims-based sources will not pick up services that were paid for outside of health insurance.

Currently, lack of claims-based data is a challenge for health insurers attempting to estimate costs. However, the credibility of claims-based sources to better understand prevalence of gender dysphoria and for related utilization and cost studies will improve over time, especially as health insurers begin to provide coverage for related healthcare services. For now, however, self-reported information provides the most credible view of prevalence.

Healthcare use of services related to gender transition and reassignment surgery

Not all individuals who have gender dysphoria will want to, need to, or are able to undergo medical treatment or surgical procedures for gender transition. Some individuals will opt for nonmedical options such as change in clothing and gender expression. Others will opt for counseling or mental healthcare services. Some will undergo limited gender affirmation or reassignment surgery-- for example facial reconstruction, tracheal shaving, and breast augmentation. Others may opt for full transition, including removal of gonads and reconstructive surgery, which could include a host of surgical procedures to change an individual's primary or secondary sex characteristics. (See the table in Figure 1 later in this paper for further details on the bundle of services related to gender reassignment surgery.) One study from 2007 estimates that, of those who identify as transgender, between 0.1% and 0.5% have taken some steps to transition from one gender to another.[5] In Europe, 1 per 30,000 adult males and 1 per 100,000 adult females seek gender reassignment surgery.[6]

Health insurance coverage

Recent federal and state laws and regulations have clarified how nondiscrimination policy applies to health benefits involving an individual's gender identity or expression. These regulatory changes are driving health insurers to make changes to policies governing covered benefits, utilization management, and medical necessity criteria.

On July 18, 2016, a set of final rules called "Nondiscrimination in Health Programs and Activities" became effective. These new rules implement Section 1557 of the Patient Protection and Affordable Care Act (ACA), which prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities. This includes discrimination based on gender identity. The new rules are applicable to every health program or activity that receives some federal financial assistance, is administered by HHS's health programs, or is established under Title 1 of the ACA, including all federally facilitated and state-based marketplaces. HHS's Office of Civil Rights makes clear that it does not require health insurers to cover any particular benefit or services, such as gender reassignment surgery, but it emphasizes that coverage cannot be discriminatory. Specifically, it states that "coverage for medically appropriate health services must be made available on the same terms and conditions under the plan or coverage for all individuals, regardless of sex assigned at birth, gender identity, or recorded gender." It goes on to state that an "explicit, categorical (or automatic) exclusion or limitation of coverage for all health services related to gender transition is unlawful." Finally, it clarifies that blanket exclusions on the basis of cosmetic or experimental categorizations are "outdated and not based on current standards of care."[7]

Medicare and FEHBP coverage policies

In May 2014, the HHS Appeals Board issued a decision that invalidated a National Coverage Determination (NCD) regarding "transsexual surgery." The Appeals Board stated that the NCD was invalid because the coverage exclusion is "no longer reasonable." Evidence presented to the Board demonstrated that transsexual surgery is currently considered safe and effective and not experimental.

Therefore, local coverage determinations used to adjudicate Medicare claims can no longer use the old NCD to deny gender reassignment surgery.[8]

Medicare Advantage plans must adhere to Medicare coverage policies. After May 2014, Medicare Advantage plans revised their coverage policies, stating that they will cover reasonable and medically necessary services for gender reassignment surgery and that coverage determinations need to be made on a case-by-case basis. In addition, the FEHBP followed suit and removed gender reassignment surgery from its list of general exclusions.[9]

On June 2, 2016, the Centers for Medicare and Medicaid Services (CMS) released a proposed decision memo stating that it does not plan to issue a revised NCD that explicitly states that gender reassignment surgery is covered. Instead, CMS proposes to maintain its current policy and leave coverage determinations on an individual claim basis and at the local level. CMS is currently seeking comments on the proposed decision memo and professional societies and advocacy organizations are currently responding.[10]

State laws applicable to commercial, Marketplace, and Medicaid policies

Currently 10 jurisdictions, including the District of Columbia, prohibit health plans from using blanket exclusions for transgender healthcare services. In addition, eight states explicitly require coverage of transgender benefits for their state employee health plans.[11] Twelve states explicitly cover gender transition services for their Medicaid populations.[12] As stated above, Marketplace plans are subject to the federal nondiscrimination rule that recently went into effect, but they are also subject to state coverage requirements and thus benefits related to gender dysphoria treatment and services vary from state to state.

State laws that prohibit exclusions of services based on gender identity may still allow plans to deny services based on medical necessity. In some cases, coverage may be denied for particular services that are considered experimental or investigational. In addition, particular procedures that are considered purely cosmetic and not medically necessary may also be denied.

In California, the Insurance Gender Nondiscrimination Act (IGNA) prohibits plans from limiting benefits based on gender identity or gender expression.[13] In a letter clarifying this law, the California Department of Managed Health Care (DMHC) made clear that plan denials

for “individual’s request for services on the basis that the services are not medically necessary or that the services do not meet the health plan’s utilization management criteria… is subject to review through the Department's Independent Medical Review (IMR) process.”[14] Since 2013, there have been 21 cases reviewed under the IMR process related to transgender services, 14 of which were overturned (i.e., decided in favor of the patient) in part or in whole, and seven of which were upheld. Cases that were commonly overturned include transgender females’ requests for hormone therapy, breast augmentation, facial laser hair removal, and facial reconstructive surgery. Most of these services were found to be medically necessary based on the case details and the reviewer’s interpretation of the World Professional Association for Transgender Health (WPATH) Standards of Care or other peer-reviewed published sources. Health plan denials that were upheld were done so because specific requested services did not meet the standards of care or were considered unsafe or experimental. In some cases, the standard of care for the requested treatment was not definitive and thus the determination relied on the reviewer’s clinical judgment regarding whether the requested treatment was safe and medically necessary.[15]

Details on clinical coverage policies

Health insurance clinical policies governing coverage of gender reassignment surgery vary, but there is convergence in terms of the standards of care upon which they are based. (Note that clinical coverage policies are guidelines that give detail on what specific services may be covered and the medical criteria upon which coverage is based.) In addition, there are certain medical necessity criteria and preauthorization requirements for gender reassignment surgery that appear to be standard across policies. We reviewed 48 policies that were publicly available from various carriers, including those covering members in Medicare Advantage, Medicaid, commercial plans, state employee benefits, FEHBP, and ACA marketplace plans. Note that we relied on those policies that had been updated or reviewed in 2014 or later. This ensured that the policies referenced the latest version of the DSM-5, which was updated in 2013 and redefined the term “gender identity disorder” to “gender dysphoria.” Key findings of our review are summarized in this section.

Reliance on WPATH Standards of Care: Virtually all of the clinical policies included in our review heavily relied on the WPATH Standards of Care, 7th version.[16] WPATH is an international association whose mission is to “promote evidence-based care, education, research, advocacy, public policy, and respect in transsexual and transgender health.” The organization, composed of over 600 clinicians, social scientists, legal professionals, and other researchers, updated its most recent Standards of Care in 2012. The latest update reflects the then-available research and professional consensus on treatments appropriate for individuals with gender dysphoria. Health plan clinical policies typically relied on the WPATH Standards of Care supplemented by other subsequently completed research.

Bundle of services included in gender reassignment surgery: Clinical policies usually point out that treatment for gender dysphoria with gender reassignment surgery is a multistep process, typically taking years, and involving multiple specialists and a wide range of services. While these services vary from person to person, there is a bundle of services typically considered part of gender reassignment surgery as described in the table in Figure 1. Note that not all services listed below are covered by all policies as coverage can be restricted by the terms and conditions of the member’s plan contract and medical necessity criteria. For example, whether certain services are considered medically necessary or purely cosmetic is up for debate. Several clinical policies stated that services such as rhinoplasty, facial bone reduction, blepharoplasty, breast augmentation, liposuction of the waist (body contouring), reduction thyroid chondroplasty, hair removal, voice modification surgery, chin implants, nose implants, and lip reduction and other aesthetic or plastic surgeries are considered cosmetic. And because cosmetic procedures are a blanket exclusion for all members, they are excluded for gender reassignment surgery.

Figure 1: Services typically included under gender reassignment surgery clinical policies

Treatment or service	Description and examples
Change in gender expression/role	For certain individuals, a recommended course of action involves living in a manner consistent with the individual's gender identity. Some plans' clinical policies require change in gender expression/role for a significant period of time (e.g., at least one year) as a criterion for certain surgical interventions.
Mental health screening and assessment	Mental health screening and assessment includes obtaining patient history and developing and making the diagnosis of gender dysphoria, if applicable. Assessment of other coexisting mental health conditions, if applicable, is typically included. This would also involve referral for psychotherapy, hormone therapy, and/or surgery as appropriate. Diagnosis of persistent, well-documented gender dysphoria by a qualified mental health professional is a prerequisite criterion for hormone therapy or surgery.
Hormone therapy to feminize or masculinize the body	Hormone therapy may be useful for patients who do not wish to, or are unable to, undergo surgery. Hormone therapy is typically a prerequisite criterion for some but not all surgical interventions. Hormone therapy following gonad removal surgery is typically required for the rest of the individual's life and requires adjustment for age and other health conditions. MTF hormone therapy may include estrogen and androgen-reducing medications (anti-androgens). FTM hormone therapy may include testosterone and progestins for a short duration to effect menstrual cessation.
Surgery to change primary sex characteristics	FTM surgical procedures may include mastectomy, male chest construction, hysterectomy and oophorectomy (removal of ovaries), urethraplasty, vaginectomy, scrotoplasty, and/or implantation of prostheses. MTF surgical procedures may include breast augmentation, penectomy, orchiectomy, vaginoplasty, clitoroplasty, and vulvoplasty.
Surgery to change secondary sex characteristics	FTM surgical procedures may include liposuction/lipofilling, pectoral implants, and other aesthetic or plastic surgery procedures. MTF surgical procedures may include facial feminization surgery, liposuction/lipofilling, voice surgery, thyroid cartilage reduction, gluteal augmentation, hair reconstruction, and other aesthetic or plastic surgery procedures
Psychotherapy	May include individual, couple/family, or group therapy. May be helpful at various stages throughout an individual's life.
Speech and voice therapy	Speech and voice therapy can help patients communicate in a manner consistent with their gender identities.
Urogenital care	This may include postoperative counseling by surgeons and counseling by primary care clinicians or gynecologists regarding urogenital care.

Key: MTF=Male to Female; FTM= Female to Male

Medical necessity criteria for gender reassignment surgery: Clinical policies include details regarding the medical necessity criteria the plan will use to consider a member to be eligible for gender reassignment surgery. Typically, these involve:

Documentation of persistent gender dysphoria. All policies with an effective date in 2014 require documentation of gender dysphoria and refer to DSM-5 definitions. The criteria usually include persistent, well-documented gender dysphoria, meaning the individual has had transgender identity for a significant period of time, usually for at least one year.

Capacity to make informed decisions, give consent for treatment, and be 18 years of age or older. Because hormone therapy and gender reassignment surgery lead to irreversible changes, informed consent is typically required. For example, informed

consent for hormone therapy involves understanding the risks, benefits, and limitations of treatment in the context of the individual's age, physical and mental health status, socioeconomic situation, and any prior experiences with transition.

Medical or mental health concerns or conditions must be well-controlled. If the patient has another health condition that is a contraindication—one that would place that person at risk during hormone therapy or during the surgery—the criteria for gender reassignment surgery may not be met. Patients also may not meet the criteria if they have mental health conditions that are not well controlled, such as uncontrolled bipolar disorders or schizophrenia.

Letter(s) of referral from qualified mental health professional(s). Most policies require letters from two qualified mental health professionals, though some require a letter from just one for limited gender reassignment surgery—for example, for an FTM patient seeking mastectomy only.

Hormone therapy. Some policies require continuous hormone therapy for a specified duration of time (typically 12 months) to meet gender reassignment surgery criteria. However, this criterion may not be required for limited gender reassignment surgery—for example, for an FTM patient seeking mastectomy only.

Living in gender role congruent with gender identity. Some medical policies require that the patient has been living as the identified gender for a specified duration of time before undergoing gender reassignment surgery that involves removal of the gonads and full genital reconstructive surgery.

Considerations for payers in light of antidiscrimination laws and trends

In the coming years, we expect to see an increase in claims for services to treat gender dysphoria, especially as antidiscrimination laws reduce barriers to care, as the standards of care become more widely adopted, as coding practices change, and perhaps as public attention on the issue reduces stigma. In light of these trends, there are questions that payers and healthcare providers should consider that affect healthcare operations and delivery:

How will laws and regulations and subsequent decisions to expand coverage for individuals with gender dysphoria affect coverage for individuals with other conditions? For example, Section 1557 of the ACA would require that coverage provided to a transgender individual be available for others if it is considered medically necessary. If a plan adds coverage for facial hair removal for an MTF patient with gender dysphoria, then it may also need to consider adding coverage for female patients with diseases, such as hirsutism, requesting the same service.

How will evolving medical necessity criteria affect utilization and costs? Medical necessity criteria have been reasonably well established, with the exception of procedures that may be considered aesthetic or cosmetic. Tracking federal coverage determinations, appeals, and states' IMR decisions may be an informative exercise to assess the evolution of the evidence base, clinical coverage policies, and how they are interpreted and applied.

Are billing, claims, and electronic health record (EHR) systems appropriately identifying members according to their birth genders and their current gender identities? Systems need to be modified to capture additional data fields and new data elements. The WPATH Electronic Medical Records Working Group, composed of both expert clinicians and medical information technology specialists, made recommendations for developers, vendors, and users of EHR systems with respect to transgender patients in 2013. They recommended use of a two-step method, which entails asking a member for both gender at birth as well as current gender identity. The table in Figure 2 provides the data fields as well as the data element options that can be included in billing, claims, and EHR systems.[17]

Figure 2: Data element options

Data field	Current gender identity	Sex assigned at birth
Data element options:	Male	Male
	Female	Female
	Trans-male/trans-man/female-to-male (FTM)	Other
	Trans-female/trans-woman/male-to-female (MTF)	
	Gender-queer/gender-nonconforming	
	Different identity: please state_____	

Allowing systems to capture both birth gender and current gender identity has been shown to improve data capture and related demographic studies. Entities such as the CDC have adopted this method for population-based studies.

Do billing system and claims adjudication programming need to be revised to ensure appropriate identification and review of gender-sensitive claims? Certain billing practices have been originally put into place to prevent mistaken, fraudulent, or abusive billing and claims payment, such as automatic denials in cases of "gender mismatch" (e.g., claims for a pelvic exam for a male or a prostate exam for a female). Such claims adjudication practices would need to be reviewed and potentially reprogrammed to meet compliance.

Do EHR systems need to be reprogrammed to allow for clinically appropriate tests, diagnostics, and interventions regardless of the gender identity? For example, will the EHR system allow a provider to order a medically necessary mammogram for an individual registered as a male?

Does the plan network have adequate capacity to deliver safe and quality care for patients with gender dysphoria and for those requiring gender reassignment surgery? Which services can be provided by the plan's existing network and for which services will the plan need to develop new contracts? For example, rather than building capacity for certain FTM surgical procedures requiring highly specialized knowledge and skill, a plan may seek to contract with a regional center of excellence. If the plan contracts with a managed behavioral health organization, does the vendor have mental health professionals and therapists with appropriate training and skills to appropriately serve transgender individuals?

Do the case management programs have the capacity to competently care for individuals with gender dysphoria and those requiring gender reassignment surgery? Case managers should include clinical licensed social workers or nurses who are trained in providing culturally competent support for transgender individuals and can help guide them through the complex transition processes.

Do the primary care providers within the plan's network need additional training to care for transgender patients? A recent survey of 246 primary care physicians and medical students in a graduate medical center showed that approximately 75% of providers and 33% of students had some experience with transgender patients. About half of these individuals were worried about causing offense during the patient encounter or did not feel they had enough training. Knowledge of appropriate documentation (e.g., gender identity, diagnosis) in the EHR was an area identified for improved provider education. The American College of Obstetrics and Gynecologists (ACOG) recommends training practitioners to improve sensitivity in order to facilitate a positive patient experience, reduce barriers to care, and improve use of necessary preventive care among the transgender population.[19]

Do plans' cultural competency programs sufficiently address issues related to the transgender population? The National Standards for Culturally and Linguistically Appropriate Services (CLAS) issued by the Office of Minority Health identifies gender identity as a marker for healthcare disparities. In other words, individuals who identify as transgender have historically been linked to discrimination or exclusion in society and within our healthcare system. The CLAS Standards and its related "Blueprint" outline strategies that the healthcare sector can adopt for mitigating these historical disparities.[20] In light of the recent changes in laws and policies, including the final rule on nondiscrimination, it would behoove plans to review, update, and implement their CLAS-related policies, training materials, and programs.

Acknowledgements

The authors would like to acknowledge review and input by Tri D. Do, MD, MPH, FACP, Chief Medical Officer of API Wellness Center, and by Gibson R. Sims III, Director, Federal Employee Health Benefits Program Benefits, Products and Administration, Kaiser Permanente.

Contact

Susan Philip is a senior healthcare management consultant with Milliman's San Francisco healthcare management consulting practice. Contact her at: Susan.Philip@milliman.com, +1 415 394 3788.

Andrew Naugle is a principal and healthcare management consultant with Milliman's technology and operations solutions practice. Contact him at: Andrew.Naugle@milliman.com, +1 206 504 5707.

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