

## Transgender Health Care in Greater Boston

### INTRODUCTION TO THE HEALTH EQUITY ROUNDTABLE

The Health Equity Roundtable (“Roundtable”) is a program of the Harvard Pilgrim Health Care Foundation, designed to help Harvard Pilgrim and the health care industry tackle some of the important health disparities by soliciting input and information from those individuals most directly impacted by disparities in health and health status.

The Roundtable convenes groups consisting of 25 to 50 individuals in neutral locations. The questions presented to the Roundtable participants are chosen by the senior leaders of Harvard Pilgrim Health Care and represent issues of importance to insurers and providers.

The goal of the Roundtable is to improve health care by seeking the input of representatives of the communities impacted, uncovering new information, exploring the ways in which a particular community makes meaning of important ideas, and facilitating the transfer of knowledge from communities to the health care professionals who are tasked with creating solutions. The findings from the group discussions are reported back to the Harvard Pilgrim Health Care Foundation, and are then reported more broadly through a variety of outlets.

### Health Equity Roundtable on Transgender Health

Transgender health was the first area selected for exploration. There were a number of considerations that led to transgender health being chosen:

- In New England, Massachusetts, Vermont and Connecticut have state mandated insurance coverage for medical services related to the health of transgender people, including gender affirming medical services.
- There is little to no formal medical education on transgender health in the training received by most medical and mental health professionals.
- The World Professional Association for Transgender Health (WPATH) has generated standards of care based on decades of research, but there is not universal agreement among insurers as to what should and should not be included in insurance coverage.

- There is minimal agreement on standards of care, few established networks for provision of care, and no known certification for providers.
- There is broad interest in the issues confronting transgender individuals and their families in the popular news and media (“Orange is the New Black,” Caitlyn Jenner, Jazz and others).

While insurers in New England have worked to provide coverage and contracts that will support the coverage, there remain many questions. What do those impacted think about the coverage and services they are receiving? Is the quality of care on par with that for other conditions? What might we be missing?

The first group session was held in March 2016 in greater Boston, home to a number of well-respected and influential organizations that represent the interests of the transgender community. This density of expertise was helpful in recruiting and inviting participants to the group discussions. (For information about the process of recruitment, see Appendix A. For a description of the structure and facilitation of the convening, see Appendix B. For a listing of the participating organizations, see Appendix C.)

### Who Participated?

A total of 33 people participated in the Boston session. In addition, two Harvard Pilgrim executives participated: Harvard Pilgrim’s Vice President and Chief Inclusion Officer, Karen Young; and Harvard Pilgrim’s Director of Health Equity, Inclusion and Quality Management, Araceli (Celi) Esquivel. These two senior executives were selected as they have direct responsibility for converting the information gathered into specific action steps for Harvard Pilgrim Health Care. Demographic information collected at the session revealed that 24% were under 25, 56% were between 25 and 45 years of age, and 20% were over 45. A total of 63% identified themselves as “transgender.” The group had more trans masculine (female to male) individuals than transfeminine (male to female) individuals. Four participants identified themselves as parents of transgender children or adolescents and four people identified themselves as spouses/partners of transgender people. A total of 73% of participants described themselves as “White, non-Hispanic”, and 36% identified themselves as African American, Latino, Asian or Native American. (Note: Percentages do not total to 100% as participants could select more than one category.) Among the participants were four physicians, two nurses, three behavioral health clinicians and three community health/outreach staff. Participants were asked to complete a post-session evaluation survey. (For demographic data and results of evaluation survey, see Appendix D.)

### ACKNOWLEDGEMENTS:

Harvard Pilgrim Health Care Foundation thanks the participating organizations for their assistance in helping us reach into communities and bring participants to the Roundtable session. Most of all, we would like to express our deepest gratitude to the Roundtable participants for their honesty and openness and for the trust they offered in sharing their stories and their perspectives.

## THE FINDINGS

Thematic analysis sorted the data into ten themes. (For the full list of themes, see Appendix E.) For the purposes of this report, the ten themes have been condensed into four:

- I. ISSUES RELATED TO INSURANCE COVERAGE AND ACCESS TO COVERAGE
- II. ISSUES RELATED TO SEEKING AND ACCESSING CARE
- III. ISSUES RELATED TO PROVIDER/CLINICIAN KNOWLEDGE/EXPERTISE
- IV. ISSUES RELATED TO TREATMENT IN THE HEALTH CARE SYSTEM

### I. ISSUES RELATED TO INSURANCE COVERAGE AND ACCESS TO COVERAGE

#### Variations in Coverage Across Insurers

Coverage is not seen by the participants as universally accessible. Different carriers were described as using different “screening criteria” to access gender affirming services. Some carriers were seen as using Gender Dysphoria as a behavioral health diagnosis that limited access to any services that were not behavioral health. In addition, carriers were described as varying in their coverage for gender affirming interventions, especially in the following areas:

- Out-of-state coverage for gender affirming care
- Repairs or corrections needed after surgery
- Differing varieties of hormones (for example, intramuscular hormones may be covered, but subcutaneous may not be covered)
- Amount of hormones prescribed (for example, some insurers offer one month at a time, others are more flexible)
- Visiting nurse follow-up at home post-surgery
- Limitations on gender affirming surgery
- “Living full time as...” guidelines are not consistent across insurers, with some insurers requiring more time living in the gender of identity than others
- Exactly what is covered for surgical interventions
- Difficulties in accessing care when gender designations are legally changed (e.g., coverage for endometrial ultrasounds for trans men or prostate exams for trans women)

These variations were seen as important, especially in cases where a job change or change of carrier by the employer interrupted or altered care. Loss of coverage may mean high out-of-pocket costs for patients, interruptions in care, and incomplete transitions for those who cannot afford to complete interventions designed to support living in the gender of identity. These variations also required “work-arounds” by physicians and other clinical professionals who cared for patients with a variety of insurance plans.

## Coverage Issues Relating to Insurers

Most participants agreed that having coverage improved their overall wellbeing, made their lives more manageable, and reduced the amount of stress and trauma experienced. However, there were gaps in coverage that were seen as extremely important to members of the trans community. There were also issues in information collection, diagnostic coding and payment models that emerged as important to providers caring for transgender individuals and their families.

### Gaps in Coverage

#### **Electrolysis**

Most surgeons were said to require electrolysis to be completed six months prior to facial feminization or genital reconstruction surgeries, but electrolysis is not covered by insurers. This places a financial barrier for those seeking surgery. Trans women who were employed at higher earning jobs could afford the procedures, but lack of coverage for electrolysis was seen as creating a barrier for those in lower earning positions, and those who were un- or underemployed.

In addition, the lack of access to electrolysis was seen as a safety issue. One trans woman stated that before her surgery, she could “pass” on the street as a woman until the afternoon when her formerly heavy beard would begin showing through her make-up. She described being physically and verbally assaulted when her beard made her stand out as “not a real woman.” The lack of access to electrolysis was seen as particularly difficult for younger trans women, especially teenagers and youth, who were more vulnerable to violence in schools and other social venues.

#### **Chest Binders and “Tucking” Supplies**

Used to flatten the chest before “top” surgery, chest binders are said to be frequently excluded from coverage. The use of a chest binder is important as a safety issue, allowing trans men to more easily live as male publicly before “top” surgery and may be required by surgeons before “top” surgery. Exclusion of binders from coverage creates a hardship especially for young adults, low wage earners and un- or underemployed individuals. For trans women, the use of appropriate undergarments (called “gaffs”) provides a smooth contour when dressed according to their gender of identity. For those who cannot afford gaffs, resorting to inappropriate under garments, or in some cases “duct tape,” can result in skin lesions, testicular pain and epididymitis. Several participants noted that trans people and especially trans people of color are more likely to be un- or underemployed and those who are unable to afford such supplies are more likely to be poor and to come from diverse communities. The lack of appropriate binders and gaffs may heighten the risk of verbal or physical assaults when individuals are seen by others as not “real” women or men.

#### **“Top” Surgery for Trans men**

This was an area where coverage was seen as incomplete. “Bilateral mastectomy is NOT top surgery,” stated one participant. Some insurers treat top surgery as a mastectomy, and cover the

removal of the breast itself, but do not cover necessary ancillary procedures such as nipple resizing and grafting, liposuction and chest contouring. “Out-of-pocket fees for the ‘cosmetic’ portion of top surgery can run \$2,000-\$3,000,” stated a physician participant.

### **Drug Coverage for Hormone Therapy**

There were a number of complaints about restrictions on the type of hormone covered, and on the size of the prescription given. Typically, hormones are said to be restricted to 1 ml per prescription. Participants gave several suggestions:

- “Offer easy refills. 10 ml vials are MUCH easier to manage than 1 ml bottles.”
- “Help with advocacy to change state laws restricting the amount of hormone that can be prescribed.”
- “Unnecessary limitations on type of hormone covered.” Some insurers’ coverage restricts the types of medication delivery that is covered, e.g., intramuscular injectables are covered, but subcutaneous injectables, creams, patches or gels may not be covered.

### Issues in data collection, diagnostic coding and payment models

#### **Diagnostic Coding**

This topic area emerged repeatedly as needing attention. It was pointed out that the diagnostic codes used to identify Gender Dysphoria lack modifiers that permit coding for acuity. The providers who attended the Roundtable felt that this was a significant problem for a number of reasons. The lack of acuity modifiers for the diagnostic codes used to qualify patients for gender affirming care meant:

- Insurers were unable to track the influence of acuity on risks for mental health and/or health problems.
- Health care insurers and providers were not able to identify the differences between someone requiring gender affirming medical interventions including gender affirming surgical care versus someone who might require some, or no particular medical intervention.
- It was nearly impossible to conduct good research, since combining all those with “Gender Dysphoria” into the same category required any researcher to, in the words of one physician, “compare apples and oranges.”

Participants also felt that it should be possible to access gender affirming care without having to have a mental health diagnosis at all. For example, participants suggested that health insurers could provide coverage under a “wellness” model that would not require a mental health diagnosis.

#### **Binary Gender Coding**

Gender coding that is binary (male or female, male-to-female, female-to-male) is seen as restricting access for those who identify as “gender queer” or other non-binary identifications. Participants spoke to the difficulties of accessing care if one did not fall into the binary models of identity. Insurers were seen as biased and unwilling to cover procedures unless the ultimate goal was a transition into a binary identity as either “male” or “female.” Some participants felt that this restriction and lack of understanding forced them to lie in order to access care.

In general, the issue of gender coding of medical and insurance records was seen as a very important issue. Participants stated that most insurers and medical providers would not change name or gender until transition was “complete,” and there was a legal name change document presented. This lag in changing gender identification resulted in difficulty accessing care and in the increased risk of being “outed” when mail arrived addressed to the natal name, not the name used in everyday life. This was seen as dangerous for those already living in the gender of identity, but not yet in possession of a legally approved gender and name change. (Generally those who request gender affirming care are required to live in the gender of identity for some period of time before being eligible for gender affirming surgical care.) One participant spoke of being evicted from his apartment when mail arrived addressed to him by his female name.

For those who had not completed transition, or who identified as “non-binary” or “gender queer,” (e.g., not identifying with either male or female genders) the problems were even more glaring. Lack of flexibility and specificity in gender screens in information systems led to coverage refusals for care that did not match the binary gender algorithms built into health care systems. Participants reported having requests for prostate exams refused for trans women, or pap tests for trans men denied because the test did not fit the gender and was rejected by the insurer’s algorithms for coverage. (Transgender individuals may retain some or all of the reproductive organs associated with their natal sex, and therefore may require routine medical screening appropriate to the natal sex, even after transitioning to the gender of identity.)

### **Global and Capitated Payments**

Providers who treated a larger number of trans men and trans women were seen as disadvantaged by the terms of capitated models of payment. “If I approve ‘too many’ surgeries, I am seen as providing unneeded care, since many of my patients would be seen as young and healthy. I get penalized for following the guidelines,” stated a physician provider. “The payment models don’t take into account the needs of this population at all, and because the diagnostic codes lack any acuity adjustment, I can’t account for why this patient got surgery, another patient got hormones, and someone else got basic primary care.”

### **Summary:**

- Participants were extremely grateful to finally have coverage to support their access to gender affirming care, but many felt that the lack of consistency across insurers made it difficult to actually get the necessary care.
- Out-of-pocket expenses were seen as disproportionately impacting trans people, who tend to be un- or underemployed, and continued to be a barrier to care, especially for underserved communities and low-income people. Gaps in coverage had the real-life effect of making it impossible to access needed services, despite the service being “covered.”
- Diagnostic coding was seen as needing acuity modifiers that would allow providers and insurers alike to more accurately describe their patient.

- Accurate and flexible gender coding was seen as a necessity to insure privacy and safety, access to services (e.g., pap smear for a trans man, or prostate exam for a trans woman) and to avoid rendering people with non-binary identities invisible and ineligible for services.
- Individuals who did not identify with the binary genders (male or female) described encountering bias, pressure to “choose a gender and stick to it,” and ridicule from health care professionals.

## II. ISSUES RELATED TO SEEKING AND ACCESSING CARE

### Finding Competent Providers

Most participants described frustrating and anxiety-provoking challenges in accessing health care providers of all specialties who were competent in medical issues important to transgender people and their families. Wait lists for trans-competent providers can be years long and there are few, if any, directories of providers which identify trans-competent providers. Competent providers may not be listed as “in-network” for certain insurers or insurance products, resulting in less than competent care, or high out-of-pocket costs to access “out-of-network” providers. For children entering early adolescence, wait lists of up to two years to access pediatric endocrinologists who are trans-competent can have extremely negative impacts on long-term health and mental health, as beginning so-called “puberty blockers” must be timed to the child’s physical development. Missing the stage of adolescent development (Tanner 2) when these drugs can block the development of secondary sexual characteristics (e.g., breast development, facial hair, Adam’s apple, broad shoulders, etc.) can have lifelong negative impact on the developing adolescent.

Mental health services emerged as a particular problem. All insurers require a therapist’s letter to access gender affirming surgery, yet the pool of trans-competent therapists is extremely small, and geographically limited to the greater Boston area. Rates of anxiety and depression are high among trans people and their families, and seeing a therapist may not be a short-term service, making it harder for others to access these professionals.

Accessing in-network providers was seen as very challenging, as there were rarely trans-competent providers listed in an insurer’s in-network directories, and the processes for accessing out-of-network providers were said to be cumbersome, lack transparency and presented a significant barrier to receiving care.

For gender affirming surgical care, accessing providers is even more daunting. There is currently only one surgical center in all of New England with expertise in gender affirming genital surgeries (located at Boston Medical Center), and those services are only available to trans women. As this team is a new one, there was a good deal of skepticism expressed by participants about the new team’s ability to handle the intricacies of the needed

procedures. Some New England insurers cover medical costs associated with using out-of-area surgeons, but none cover associated travel and lodging costs. This creates a class-based disparity. The costs associated with out-of-state travel create a burden on those seeking care, especially for poor or working class trans people and their families. Some insurers were described as “rigid” in enforcing guidelines against the use of out-of-network surgical teams, and thus making surgical care inaccessible.

### Primary Care and Emergency Room Care

In addition to problems in accessing trans-competent clinicians for gender affirming surgical and hormonal treatments, accessing routine primary care services was also problematic for most of our respondents. Getting routine screening and routine physicals was reported as a serious problem since so few clinicians had received any training in transgender health in medical school or residency years, particularly for those clinicians who were in their training many years ago. Several participants described being turned away from care because of a lack of comfort on the part of clinicians and other health care staff. Trans men and trans women reported difficulty in getting services related to their natal sex, after having transitioned to their genders of identity (e.g., prostate exams for trans women, or pap tests for trans men). This difficulty in accessing care related to natal sex is connected to both insurer guidelines and algorithms, as noted above, as well as to provider discomfort and lack of knowledge.

In Massachusetts, the Fenway Health Center in Boston was seen as the “go to” institution for high quality primary care for transgender individuals. However, having only one place that was both safe and competent presented other challenges. Patients who spoke a language other than English often did not feel comfortable at the Fenway. Confidentiality became an issue for some, as friends and neighbors may either work at the facility or receive care there. People of color often did not feel comfortable there due to the lack of sufficient numbers of staff, particularly clinical staff members who were people of color. For its part, the staff of Fenway were described as doing their best to make everyone feel welcome, but were aware of the impossibility of “being all things to all people.” The lack of alternative trans-competent primary care sites creates a significant barrier to accessing primary care services of all kinds. “Having a specific community resource is wonderful, but it should be one of, not *the only* health resource for a community,” stated a participant.

Emergency rooms were described as particularly frightening places to receive care. Nearly half the participants described negative or even harmful experiences in seeking care at emergency rooms. For gender queer and trans people, being placed in a milieu such as an emergency room waiting area can be fraught with risk, up to and including physical assault. One participant reported having very difficult and upsetting encounters each time he presented at his local emergency room for treatment of his asthma. “I moved two states over so I could get the care I needed. Otherwise, I knew I was going to die,” he stated. Extremely high levels of anxiety were reported by nearly all participants whenever they had to confront using an emergency room for needed care. These experiences resulted in trans participants frequently delaying care or avoiding care altogether when an emergency

room visit was indicated. No emergency room in greater Boston was seen as either “safe” or competent by participants.

### Lack of Access to Reproductive Care

Participants described great difficulty in accessing reproductive care, and in obtaining information about reproductive options before and after transitions. “It’s as if it shouldn’t be very important to us,” commented one participant. Access to birth control, information about risks and benefits of hormone treatments as they relate to birth control, counseling about STD’s, and options for egg and sperm storage and IVF were seen as difficult, and sometimes non-existent. Participants described being made to feel that they should not even be asking about reproductive health care. A man who identified as trans commented that he had no discussions about reproductive choices at any time before or during his transition. “I was focused on my transition after waiting for so long, and nobody brought it up even though I saw quite a number of providers.”

In addition, rigid information screens sometimes created barriers to getting birth control, especially for trans men, who were coded “male” in information systems. This was an area in which both insurers and providers were seen as doing a very poor job of providing good health care. Coverage rules, created by and for cisgendered (a person whose gender identity corresponds with that person's biological sex assigned at birth), heterosexual people were seen as being applied to trans people with little or no thought given to the particular needs of this population. A participant commented: “It makes sense that cisgendered heteronormative couples should have to ‘try’ to conceive for a certain number of months since they might actually conceive. But why are we using that same requirement with same-sex couples and couples where one partner is trans, and has transitioned, when we know there is no way they could possibly conceive?” This was seen by participants as “practicing equality, but not achieving equity” since an additional burden was placed on the same sex and trans couples by having incurred out-of-pocket costs for frozen sperm and for the office visit needed for insemination. Bias and negative attitudes of health care professionals were seen as adding to the barriers to obtaining information and care.

### Summary:

- Accessing trans-competent providers was described as both frustrating and anxiety provoking. Word of mouth was the most frequently cited way of finding providers, however wait lists were far too long, resulting in substandard care, especially for young adolescents where timing of treatment is critical.
- Participants described a great lack of clarity around in-network and out-of-network providers, especially since trans competency is not built into the provider contracts that support a wide variety of insurance products (HMO, PPO, etc.). Primary care services were especially hard to access, and participants described poor treatment and lack of safety in many primary care settings.

- Access to trans-competent reproductive care was described as universally difficult or non-existent. Participants described experiences with providers who had strong negative biases around trans people and reproduction and reproductive health. These negative attitudes created a significant barrier for those seeking services. There were also perceived inequities in the way that reproductive health needs were covered by insurers.
- Emergency room care emerged as a treatment setting fraught with risk and lack of safety for most trans participants. Being treated poorly, being treated as an “exhibit,” and being refused care were all described as frequent experiences. Most participants reported avoiding or delaying needed care because of fear of being treated in ways that were intrusive and humiliating when seeking care in emergency room settings.
- Neither insurers nor providers were seen as normalizing trans health care in the design and implementation of health care services. Trans care was seen as being an “add-on,” and over-focused on gender affirming transitional services, to the neglect of broader health care needs. “I’m sick of hoping for trans inclusivity! I want it now!” stated a participant forcefully.

### III. ISSUES RELATED TO PROVIDER/CLINICIAN KNOWLEDGE/EXPERTISE

#### Provider Knowledge/Expertise

As noted above, most health care professionals were seen as lacking knowledge and skills in the area of medical care for trans people and their families. Very few physicians, nurses, mental health professionals and other health care professionals received any training in issues related to caring for trans people. Each aspect of the health care encounter was described as potentially problematic, due to lack of knowledge and expertise on the part of the provider. Participants heavily endorsed the need for cultural competency training with a focus on the health care needs of the transgender communities.

Participants highlighted the need for training not only for health care providers, but for all staff who interact with patients including reception, billing, admissions, etc. Negative experiences from the front desk staff were described as often difficult (rudeness, misgendering, refusal of service) and sometimes “terrifying,” resulting in some people leaving without receiving the services or care needed.

Participants wished that providers would understand that their gender identity is not a “problem” or a “deficit.” They saw a clear need for training that helped providers of care “embrace the new language that offers more gender options: male, female, both or neither,” in the words of a participant. Providers’ difficulties understanding and embracing non-binary identities was also seen as a barrier that could be addressed by better training and more knowledge.

Specialty medicine practices were seen as especially in need of training, as they were perceived as not seeing themselves “needing to know about people like that” as one participant described. Participants described a general attitude among health care professionals that unless they were working in a practice dominated by gays and lesbians, knowledge of trans people was not relevant to their practices.

Participants felt strongly that medical schools, schools of nursing, and schools that train mental health clinicians and other health care professionals should be providing students with training in trans health. They also felt that there should be more continuing education training available to clinicians already in practice. Insurers were seen as potentially influential in incentivizing professionals to receive such training.

A theme that emerged repeatedly was the burden placed on patients to educate their providers. “All the work is on the shoulders of the trans people and their families,” said one participant. This was seen as very difficult especially for young adults, those with less formal education, and those who spoke languages other than English. For individuals and families from these groups, there are significant status barriers that make it nearly impossible to push providers to change or modify behaviors. Trans youth leaving home for independent living were seen as particularly vulnerable to poor care from poorly educated clinicians. These youth may have only recently begun treatment with hormones, or begun to use surgical interventions to transition to their genders of identity, and may still be in need of specialized care. Parents expressed great concern that they understood that their young adult child might be less likely to seek care, ask questions or question their clinician and that this could easily lead to substandard care.

### Mental Health Clinicians

Mental health clinicians were seen as particularly important in receiving care, since they served as “gatekeepers” for many insurers. Most trans people seeking gender affirming medical care are required to present a letter from at least one mental health clinician attesting to their appropriateness for care in order to have services covered by an insurer. Mental health clinicians were also seen as biased, and as lacking knowledge. Trans people might invest a great deal of time and money seeing a mental health clinician, only to be denied approval for care. Insurers’ directories rarely list trans-competent mental health clinicians that can be accessed, or even “LGBTQ” providers, and those few who are listed are described as “always closed.” Those providers who were considered both knowledgeable and competent tended to have practices that were overbooked, with long waits for appointments for even routine care. These practices are often closed to new patients.

The health care system is experiencing a shortage of mental health clinicians who treat children, and getting an appointment for a child or adolescent is typically fraught with long waits and many rejections due to practices that are closed to new patients. The wait times for children and their families to be seen for issues related to gender identity are even longer, as there are few child and adolescent clinicians who are competent in gender identity issues, and these issues are not seen as emergencies. Depending on the age of the

child, delays in receiving needed care may have lifelong consequences. Parents of trans children and youth also described a great deal of fear of referral to state child protective services because having a trans child is seen by some mental health clinicians as indicating inappropriate parenting.

### Standards for Clinicians

Participants described a lack of standards and policies for determining who is competent to care for trans people. They felt that insurers could do more to influence providers to create and/or adopt such standards through their contracting guidelines. A participant who was also a physician remarked, “If a clinical group could not get a contract unless they could show that they could also care for trans people, it would begin to normalize trans health as just part of medical care.”

In addition, other medical specialists were seen as needing education in trans health. Oncology, Endocrinology, Cardiac Care, OB/GYN, Emergency Medicine and Pediatrics were all mentioned by participants as specifically important. Pediatricians, in particular, were seen as needing a basic education in gender and gender fluidity. Understanding the differences between sexual orientation and gender identity, and the recommended interventions were seen as necessary to help reduce the high rates of cutting and self-harm, depression and suicide in transgender youth.

Participants recommended moving toward a certification program that would make it easier to identify trans-competent providers, and to insure that they indeed have basic competencies in this area of medicine and mental health. Health care organizations were asked to be intentional about hiring trans professionals, who could help raise the level of awareness and expertise of trans health issues among their colleagues. In addition, participants recommended that health care organizations hire trans people in front desk roles. “I would love for my daughter to see someone like her when she goes to the pediatrician’s office,” commented a parent of a trans child.

### Research

Participants highlighted a need for research into health issues important to members of the trans communities. They noted a lack of information about the long term effects of hormone treatments, and a lack of knowledge about potential interactions between hormone treatments and treatments for a number of other conditions such as cancer, heart disease and diabetes. There is little to no research available on the special issues in caring for aging trans people. There is little research available on those with non-binary identities and the particular health care needs and challenges of this population. Insurers and academic organizations were seen as potential allies in helping to identify and incentivize more and better research in the area of trans health. Participants highlighted that future research should not be solely focused on gender transition. “I’m forty years old. What if I have a heart attack? What are the recommendations for cardiac care for someone like me? We don’t really know,” said a participant.

### Summary:

- In general, participants described a very large gap between the need for trans-competent clinical care in all settings, and the ability of our present clinical and health care system to be able to provide that care.
- Most health care professionals were seen as lacking even basic knowledge about trans health issues, and demonstrating a reluctance to seek training for themselves. Participants felt that the burden was on the patient to educate the clinician, a pattern that places disadvantaged trans people and families at a high risk of receiving sub-standard care, or of not receiving needed care.
- Colleges and universities that train health care clinicians were seen as being behind the curve in providing even basic education about trans health to the professionals they trained. Trans health was seen as something that should be integrated into every clinician's and health care professional's education during their training. In addition there was a recommendation for more continuing education training in the area of trans health for all health care disciplines.
- Insurers should create provider directories which list those providers with expertise in LGBTQ health and in trans health in particular.
- Participants felt that insurers could play a role in influencing provider and health care organizations to provide better training, and to create, adopt and enforce certifications and standards of care. Provider certification could help reduce the uncertainty in selecting a provider, and help insure better quality of care.
- Services for children and youth were seen as especially compromised due to lack of provider knowledge and expertise in both medical care and mental health care. Participants felt that being able to access competent services for their children in a timely way would help avoid poor outcomes, depression and suicidal feelings.
- Participants repeatedly cited the need for much more robust research into trans health issues. They also felt that the research should not be restricted to surgical interventions, but broadened to learn about general health conditions in the trans communities.

## IV. ISSUES RELATED TO TREATMENT IN THE HEALTH CARE SYSTEM

### Bias on the Part of Clinical Providers

Experiences of unwelcome and unprofessional curiosity were reported as a frequent experience, as were experiences of being treated as “other” and as less than human. Roundtable participants reported verbal abuse, denial of care, being “misgendered” by staff and unprofessional “fascination” as creating problems in accessing and receiving care.

One participant described a registration clerk "...loudly insisting that I had to be either male or female, so which one was it." This person left without receiving needed care. One participant described going to an emergency room for treatment of his severe asthma and having the physician call several colleagues into the treatment room to "come have a look at this." A participant stated, "We are not a Discovery Channel documentary for you! We are sick, help us!"

A parent participant recalled the experience of having a petition for abuse and neglect filed when she accompanied her then ten-year-old transgender child to the emergency room for care. The pediatrician told the parents that there must be something "inappropriate going on in the family." For this participant, a routine emergency room visit became a family crisis and was extremely traumatizing for the child and the parents. Parents also highlighted concerns about their children leaving home for college and now needing to interact with health care systems without the parents available to "run interference." One parent stated, "I know they are supposed to be adults at 18, but I also know how my child has been treated by doctors and nurses. It scares me."

Some participants who identified as non-binary described being pressured, sometimes openly and directly, sometimes more covertly, to choose a binary identity and presentation. This was said to occur in both primary care and mental health settings. Several participants described being treated "as if we were not trans enough, like we didn't meet some secret criteria." Several participants described being refused services unless they opted for a clear binary ("male" or "female") identity.

A number of participants spoke of health care providers confusing sexual orientation and gender, or using sexual orientation to discredit the person's gender identity. A person who was gay and transgender, was seen as "confused and needing to make up their mind." Paternalistic attitudes were encountered frequently, with doctors contesting the patient's assertion of their gender identity. "If you are a medical doctor, you are NOT qualified to validate or invalidate someone's identity. Butch trans women exist, femme trans men exist and there a lot of people who are non-binary," asserted a participant.

Participants experienced frequent recommendations from providers to stop hormone therapy, even when there was no medical reason for such recommendations. In addition, health issues were sometimes inaccurately attributed to hormone therapy, or cessation of hormone therapy was presented as the only way to resolve a health issue. Physicians were seen as uncomfortable around people who were trans or gender queer, and were seen as demonstrating a lack of knowledge about the hormones and drug interactions. "Do what you do when you don't know something: call somebody who does know!" a participant stated.

Another area of concern in interacting with clinicians was the common experience of being called by the wrong gender pronoun. Participants described not being asked about their correct pronouns, and finding that even when they asserted their correct pronouns, they were ignored, or the correct pronouns were not documented in the medical record. This meant that

the patient had to have the same conversation each time they encountered the health care system. “Gender me correctly!” stated a participant.

### Coordination and Management of Care

This area of concern received a great deal of attention from participants. The consensus was that insurers did a poor job of making it easy to find information about what was covered and what was not covered. Navigating in-network and out-of-network services was seen as extremely difficult, and little if any help was offered by either insurers or providers. “What are the steps necessary to access services (letter from therapist, etc.)? In what order? Suppose I have to stop, or I change jobs?” asked a participant. “There are a million ways to get stuck along the way.”

Harvard Pilgrim Health Care and Blue Cross Blue Shield of Massachusetts were cited as the two insurers who provided the best care and access to information. Harvard Pilgrim was also praised for its use of a dedicated care manager, who served as the point of contact for those seeking care related to transgender health. “This should be called out as a ‘best practice.’ It makes everything so much easier: I know who to call, and I don’t get handed off and passed around,” stated a participant.

This lack of assistance in navigating the system was seen as extremely problematic for patients with low literacy, and for those who did not speak English as a first language. “Some languages don’t even have terms for ‘trans’ or ‘queer’,” stated a bilingual participant. In addition, medical interpreters were seen as not receiving training in trans health and as demonstrating bias in how they managed the interpretation of the medical encounter when the patient was trans or non-binary.

Receiving care in in-patient and residential settings was seen as problematic. Being placed in gendered hospital units according to natal sex rather than gender of identity, having one’s natal name listed in public places (e.g., behind nursing stations, on meal trays, wristbands, etc.) and being assigned to rooms with others who share natal sex, but not gender of identity were all described as problematic for patients. Staff members were described as rarely asking those being admitted about their gender identity. Youth were seen as being at heightened risk for negative experiences, and as less able to advocate for themselves with adult staff.

Getting referrals was seen as typically difficult, with little help being offered. “XXX Hospital couldn’t offer hormones at all. ‘We can’t help you. So sorry! Go where you need to.’ It should be easier to make connections without lots of transitions – that’s frustrating!” Most medical practices had no idea of how to refer, or to whom. This left the management to the patient, and severely impacted those who were from disadvantaged communities. Participants of color noted that practices that were accustomed to caring for multilingual and multiethnic populations were seen as often making trans people and their families feel uncomfortable and unwelcome.

A participant noted that “Navigating for trans-related care requires finesse, self-advocacy and lots of time. It should not have to be this way.” Quite a number of participants recommended having patient navigator services available on both the insurer and the provider side. In addition there were recommendations to streamline all non-clinical tasks to be more efficient and less burdensome to both provider and patient, including such tasks as data collection, referrals, pre-authorizations, gender changes in medical records and patient education materials, etc.

### Summary:

- Most participants had negative and painful experiences in their encounters with health care systems and professionals. Negative bias was experienced in both statements and actions by medical providers and by ancillary support staff (e.g., receptionists, billing clerks, technicians, etc.)
- A number of participants described experiences of having their gender identity questioned, and of being pressured to adopt a binary gender identity. Some who identified as “gender queer” or “non-binary” reported being refused gender affirming care if they did not adopt a binary identity.
- Parents of transgender children and adolescents shared painful experiences of having their parenting questioned and experiencing threats from health care professionals to “investigate” their families. Parents of college-age children had concerns about how their young adult child would manage without some degree of parental protection when they interacted with the health care system.
- Nearly all participants agreed that navigating the systems of care, getting information about coverage, and getting referrals for services were extremely difficult, time-consuming and frustrating. Those who spoke languages other than English, and low-literate readers were seen as especially disadvantaged.

### RECOMMENDATIONS FOR ACTION

The following recommendations emerged from the group. These recommendations hold promise for making it easier for transgender individuals and their families to access appropriate health care with fewer barriers and less frustration and anxiety. The recommendations have the potential to make it easier for insurers to deliver coverage with less ambiguity, to track health care status and outcomes, and to more accurately assess treatment needs and outcomes of members who are transgender.

- Develop acuity indicators to accompany the diagnosis of Gender Dysphoria. This would permit tracking and quality assessment of patients all along the gender continuum.
- Encourage provider networks to list trans-competent providers, to insure that they can collaborate to provide effective referrals for care, and that the clinical staffs are educated in the basics of trans health.

- Develop and use more precise and flexible gender screens on enrollment forms and patient records. Insurers and providers should collaborate to use more inclusive language.
- Educate staff at emergency care settings, including per diems and locum tenens physicians, in the basics of caring for trans individuals. Consider pursuing disciplinary action when poor treatment or refusal of care is documented.
- Include electrolysis and coverage for medical equipment related to gender affirming medical services.
- Provide basic training on issues related to transgender health to health care providers and clinicians. Require clinicians to receive continuing education on issues related to trans health.
- Incentivize and support more research in the area of trans health and health care that explores health issues beyond those associated with transitions.
- Integrate basic knowledge of transgender people and their health needs into college and university training provided to health care professionals as they prepare to enter the health care professions.
- Hire trans people at all levels in health care organizations in order to create greater internal awareness and competence in caring for transgender individuals and their families.
- Help advocate for changes to state regulations which would allow for more flexibility in prescribing larger amounts for hormonal therapy.
- Expand coverage to include multiple forms of hormone delivery systems, e.g. patches, gels, creams, etc. and provide for the dispensing of larger amounts of the hormone being prescribed.
- Insure coverage for out-of-state, or out-of-area services for gender affirming surgical care until such care is widely available in-state or in-area.
- Insure that access to information about reproductive health options and access to reproductive care is equitable and does not require trans and same sex families to adhere to standards designed to meet the needs of heterosexual people.
- Include gender identity on in-patient admissions forms and in intake and admissions processes. Develop protocols for in-patient settings to safely accommodate transgender, gender queer and non-binary patients admitted to their services.
- Locate all information pertaining to transgender health care and coverage in one, easy-to-find location. Insure that information is accessible to those with low literacy.

- Provide clear descriptions of necessary approvals and processes required to access care. Include information relating to the timing of approvals and processes.
- Identify designated staff (e.g., navigators or care managers) who will serve as primary points of contact for individuals or family members seeking access to transgender health services.

***About the Author:** Shani Dowd serves as the Director of the Health Equity Roundtable, a program of Harvard Pilgrim Health Care Foundation. She is an experienced clinician who has practiced in a variety of health care delivery systems. She has contributed to the development of health policy at both the state and national level. She holds an appointment as an Assistant Clinical Professor of Psychiatry at Boston University Medical School.*

## Appendices

Appendix A: Recruitment of Participants

Appendix B: Structure and Facilitation of Convening

Appendix C: Participating Organizations

Appendix D: Results of Post Convening Evaluations

Appendix E: Complete List of Themes in Findings

## Appendix A: Recruitment of Participants

The first question to be addressed was that of location. Most large majority-culture organizations are not the kinds of places that immediately engender trust in a community that for many generations has not only been ignored but actively denigrated. Boston is home to Fenway Health Center, one of the nation's premier organizations providing care to transgender individuals. However, there are those who do not feel comfortable at the Fenway, for a wide variety of reasons. Dimock Community Health is a highly regarded health center in a racially and economically diverse community. In addition, the community that Dimock calls home also has a large LGBTQ population, and easy access to public transportation. Dimock was invited to host the first Roundtable. Dr. Myechia Minter-Jordan, CEO of Dimock Community Health, felt this was an opportunity for Dimock clinicians to learn more about the needs of the transgender community. The selection was vetted with the Transgender Health Program team at the Fenway, who concurred with the choice of Dimock as the host organization.

Meetings were held with activists from a number of leading organizations in the transgender community. The meetings served to introduce the Director of the Roundtable, the concept of the Health Equity Roundtable and to solicit, where appropriate, the organization's or individual's support in enlisting participation. These were all leaders whose opinions were important in the transgender communities of the region. These leaders were asked to solicit participants on behalf of the Roundtable, as they would have the trust of the communities in ways that Harvard Pilgrim might not. (For a list of participating organizations, see Appendix C.)

Participants were invited to attend if they identified as “transgender”, “gender non-conforming” or “gender queer”, or if they were medical professionals who routinely saw transgender patients. Parents of transgender children and teens and spouses and partners of transgender and gender queer individuals were also invited to attend. No further effort was made to screen participants (for example, whether participants had sought medical care to transition to their gender of identity) and a great deal of effort was committed to engaging younger participants. Any participant who met the criteria noted above, and was recommended by one of the partnering organizations, was welcomed. Participants who were not seeking medically supported gender affirming services were welcomed, as were those who did not identify with a binary (male OR female) gender model. Every effort was made to solicit participants of color of any age or identification, as this is a community typically invisible and underserved.

## Appendix B: Structure and Facilitation of Convening

The meeting was held in the early evening, from 6:30 to 9:00 p.m., to accommodate students and those who could not take time away from work. The Director of the Health Equity Roundtable offered to serve as facilitator. (The director identifies as an African American, masculine “butch” lesbian, and was known to some of the participants.) The first half hour was devoted to dinner, then participants were welcomed, thanked for their participation, and ground rules were set. The participants were then asked: “What is important to you about your health and health care that we in the health care industry need to do a better job with?” The question was designed to be as open-ended as possible and to invite participants to offer anything they believed to be important. Since many people do not know exactly what an insurer does beside pay bills, or what a provider organization does except see patients, it was important not to put participants in the position of having to decide if their input was relevant or reasonable.

Each table was instructed to engage in conversation with their table partners in response to the question and to take notes. Each person was asked to take notes themselves, to insure that no ideas were lost. The first round was given thirty minutes to talk and take notes. At the end of this period, each table was asked to select a “historian.” The historian would remain at the table, while the others changed tables and selected a new group to join. The historian was asked to review for the newcomers the key points raised in the first conversation, and to solicit from the new table partners what key points emerged from their table discussions. Each group was then asked to continue the conversation with different partners, and to continue taking notes individually. At the end of the second round participants were invited to return to their original tables, but were also offered the alternative of staying where they were. The last hour of the session was devoted to a large group discussion of the key themes and issues. During this phase of the meeting, notes were taken on flip charts at the front of the room. The facilitator was assisted in note-taking by a research assistant.

This model of facilitation is a modification of the “World Café” model of facilitation (<https://www.worldcafe.com>). Beginning with small groups at tables creates an environment where those who find it hard to speak up in a larger group can feel less exposed and the “big voices” are less likely to dominate. Asking each person to take notes resulted in some duplication, but also insured that ideas did not get lost, especially if they were not repeated by others.

## Appendix C: Participating Organizations

Boston Alliance of Gay and Lesbian Youth (BAGLY)

14 Beacon Street, #301

Boston, MA 02108

(617)227-4313

[info@bagly.org](mailto:info@bagly.org)

<http://www.bagly.org/>

Boston Gay and Lesbian Adolescent Social Services (Boston GLASS)

75 Armory Street

Boston, MA 02119

(857)399-1920

[outreach@jri.org](mailto:outreach@jri.org)

<http://jri.org/services/health-and-housing/health/boston-glass>

Boston Health Care for the Homeless

780 Albany Street

Boston, MA 02118

(857)654-1000

[info@bhchp.org](mailto:info@bhchp.org)

<http://www.bhchp.org/>

Community Catalyst

One Federal Street

Boston, MA 02110

(617)338-6035

[info@communitycatalyst.org](mailto:info@communitycatalyst.org)

<http://www.communitycatalyst.org>

Dimock Community Health

55 Dimock Street

Roxbury, MA 02119

(617)442-8800

<https://www.dimock.org>

Fenway Health

1340 Boylston Street

Boston, MA 02215

(617)927-6000

[Information@fenwayhealth.org](mailto:Information@fenwayhealth.org)

<http://www.fenwayhealth.org>

Greater Boston PFLAG

85 River Street

Waltham, MA 02453

(781)891-5966

[info@gbpflag.org](mailto:info@gbpflag.org)

<http://www.gbpflag.org/>

Massachusetts Trans Political Coalition (MTPC)

P.O. Box 960784

Boston, MA 02196

(617)778-0519

[info@masstpc.org](mailto:info@masstpc.org)

<http://www.masstpc.org>

Transformative Justice Legal Services

14 Beacon Street, Suite 718

Boston, MA 02108

(617)720-4200

[rj@transformativelaw.org](mailto:rj@transformativelaw.org)

<http://www.transformativelaw.org>

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# Appendix D: Results of Post Convening Evaluations

## **Demographic Data**

35 individuals participated in the Roundtable, and 30 filled out post-convening evaluations.

### **Age of Participants:**

12-16: 2  
17-20: 2  
21-25: 3  
25-29: 1  
30-34: 7  
35-39: 4  
40-44: 5  
45-49: 1  
50-54: 3  
55-59: 2  
60-64:  
65 + :

### **Summary:**

6% under 16\*  
23% under 25 years  
56% between 25 – 45 years  
20% over 45 years

\*Invitations to participate were not extended to anyone under the age of 16.

### **Gender:**

Female: 4  
Male 5  
Trans 9  
Queer 8

### **Other:**

Woman: 1  
Two Spirit: 1  
Transfeminine: 2  
Transmasculine: 8  
Androgynous: 1

### **Summary:**

19 (63%) Participants described themselves as “Trans”.  
Of these, 8 (27%) identified as both “Trans” and “Masculine”  
Two participants (6%) identified as both “Trans” and “Female”

8 (27%) identified as “Queer”  
4 (13%) identified as Female

5 (17%) identified as Male

Woman, Two-spirit and Androgynous were “write-in” categories chosen by one person each (10% total).

This category of demographic information presented challenges. Those who checked off BOTH “Trans” and “Female” were described as “transfeminine”

Similarly, those who checked off BOTH “Trans” and “Male,” were described as “trans masculine.” However, these adjustments were made after the fact, and without consultation with the people who checked these categories off together. There is really no way to be certain that the interpretation of the author is the correct one.

To add to the complexities, “Queer” was subscribed by some who also chose “trans”. We lack information about the nuances of “queer” in the context of medical care, since those people who identify as “queer” may appear to be gender variant or not, and social, romantic and sexual behaviors may vary considerably.

Since the participants included both Trans- and Cis-gendered people, the categories used for the post-event survey may not have been the most “user-friendly”. It was clear during the discussion that trans men and queer participants greatly outnumbered trans women. Given the distinctly different experiences of masculine-appearing trans people and feminine-appearing trans people, this is probably an important issue, not to be quickly glossed over. There was also no category for “non-binary”. Again, the experiences in health care of non-binary people, that is those whose gender expression did not correspond neatly to either male or female, were different than those of the community whose gender presentation more neatly aligned with “male” and “female.”

This has great significance, as this issue came up repeatedly as an area of concern for participants, both in “gendering” them accurately and consistently in their medical records, as well as in gathering accurate data to allow further research.

**Is a member of your family transgender?** Nine participants responded, “Yes.”

Has a transgender child: 3

Has a Transgender Spouse or partner: 3

Other relative: Sibling 2, Cousin 1

**Race: (Check all that apply to you)**

Caucasian, White, Non-Hispanic	<b>22</b>	<b>73%</b>
Hispanic, Latino or Spanish Origin, Any Race	<b>3</b>	<b>10%</b>
Black, African American, African Descent	<b>3</b>	<b>10%</b>
Asian	<b>4</b>	<b>13%</b>
American Indian or Alaska Native	<b>1</b>	<b>3%</b>
Middle Eastern or North African	<b>0</b>	<b>0</b>
Native Hawaiian or other Pacific Islander	<b>0</b>	<b>0</b>
Some other race, ethnicity or origin (Please specify)		

**\*Note: Percentages do not total to 100%, as respondents may choose more than one category.**

Note:

- Three respondents endorsed both “Caucasian” and “Hispanic”
- One respondent endorsed both “Black, African American, African Descent” and “Asian”
- One respondent endorsed both “Caucasian, White” and “Asian”

**Demographic Summary:**

The participant group was heavily weighted toward male/masculinity, white/Caucasian race and age between 25 and 45 years. Despite the fact that 17% (5 of 30 respondents) identified as people of color, there was a lack of true racial/ethnic diversity. This outcome was not unexpected, since word of mouth was the primary tool for recruitment, and with one exception (Dimock Community Health) the organizations participating in recruitment were predominantly white.

Participants also reflected a distinct middle class bias in socio-economic status, with most having college or post-graduate degrees. The youth were also overrepresented by college students or recent graduates. Again this outcome was not unexpected. All participating organizations spoke of the difficulties of reaching into economically disadvantaged communities, and of engaging robustly across racial and ethnicity.

The gender disparity with trans women being greatly underrepresented must also be taken into account, given the great differences between transfeminine people and trans masculine people in their need for gender affirming services, the kind of services needed, and the differences in risk encountered in living as a trans person in the US.

**Roundtable Meeting Evaluation Survey Results**

Questions	1	2	3	4	5	Response Range	Total Number Responses	Avg. Rating
1. How would you rate this meeting overall? (5=Excellent, 1=Poor)	0	0	1	8	21	3-5	30	4.1
2. How would you rate the organization of the meeting? (5=Excellent, 1=Poor)	0	0	3	4	23	3-5	30	4.6
3. Was the meeting well facilitated? (5=Excellent, 1=Poor)	0	0	0	3	27	4-5	30	4.9
4. Did you feel welcomed as a member of the group? (5=Completely agree, 1= Do	0	0	0	1	29	4-5	30	5.0

not agree at all)								
<b>5. Did you feel that your opinion was treated respectfully?</b> (5=Completely agree, 1= Do not agree at all)	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>29</b>	<b>4-5</b>	<b>30</b>	<b>5.0</b>
<b>6. Did you feel that other participants were treated respectfully?</b> (5=Completely agree, 1= Do not agree at all)	<b>0</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>28</b>	<b>4-5</b>	<b>30</b>	<b>4.9</b>

## Appendix E: Complete List of Themes in Findings

Theme 1 - Coverage and Coverage Limitations

Theme 2 - Treatment by Health Care Professionals

Theme 3 – Coordination and Management of Care

Theme 4 – Reproductive Health Care

Theme 5 - Managing Gender in Systems of Care

Theme 6 - Lack of Trans-Competent Health Care and Mental Health Providers

Theme 7 - Social Conditions Which Impact Health and Health Care

Theme 8 - Access to Care

Theme 9 - Research

Theme 10 - Other Issues