

Affirming Transgender Youths' Names and Pronouns in the Electronic Medical Record

Transgender youths experience significant health disparities compared with their cisgender peers. Recent data suggest that use of gender-affirming language, specifically name and pronouns, in more life contexts is associated with improved mental health outcomes.¹

The use of electronic medical records (EMRs) has become ubiquitous in medicine. However, limitations built into these systems can restrict the provision of gender-affirming care. In 2015, the Office of the National Coordinator for Health Information Technology began recommending that EMRs collect gender identity data to be certified for meaningful use.² Many practices have moved to the “2-step” model of asking patients about both their gender identity and sex assigned at birth. Unfortunately, neither of these questions provides information about the name and pronouns a patient would like to use, which are critical to ensuring that a clinical encounter is respectful and affirming.³⁻⁵ A clear gap exists in the literature as there is a limited understanding of transgender youths' preferences regarding name and pronoun documentation in the EMR. The objectives of this study were to: (1) assess transgender youths' preferences regarding EMR-wide name and pronoun documentation and (2) investigate how these preferences differ by demographic and gender-related characteristics.

Methods | A survey that included items investigating youths' preferences regarding EMR-wide name and pronoun documentation was administered to transgender youths aged 12 to 26 years who were accessing care in a specialty gender clinic (Table 1). This study was approved by the University of Pittsburgh Institutional Review Board, with waiver of permission for youths younger than 18 years; verbal assent was obtained from each participant prior to participation. In total, 211 youths

were approached about participating in the study. Six individuals were screened out after indicating their gender identity was only cisgender. Of those who remained, 204 completed the survey for a participation rate of 99.5%. To examine responses by specific patient characteristics, χ^2 and Fisher exact tests were used. Data analyses were conducted using Stata statistical software, version 14.2 (StataCorp).

Results | Of the 204 participants surveyed, 138 of 200 (69%) used a name different from their legal name. Most of the youths (156 of 198 [79%]) (Table 1) reported they would prefer to have both their name and pronouns documented EMR-wide. While 34 of 37 nonbinary youths (92%) indicated that they would like their name documented, this was true for only 28 of 42 trans-feminine youths (67%) ($P = .007$); similar results were seen for pronouns (Table 2). Interest in name and pronoun documentation also varied significantly with whether youths were “out to everyone” vs “out to few or no one.” No differences were seen regarding name or pronoun documentation preferences by age, race/ethnicity, or perceived level of parental support. Among the 7 youths who did not desire EMR-wide name and pronoun documentation, 6 (86%) noted that because they already “passed” they did not feel name or pronoun documentation was necessary. Only one participant raised concerns about confidentiality as the reason they did not desire name or pronoun documentation occur. Despite these stated preferences, only 17 of 197 youths (9%) indicated that they were always or often asked outside of specialty gender centers if they wanted to have their name and pronouns documented in the EMR.

Discussion | Our study findings suggest that most transgender youths accessing care in a specialty gender center desire EMR-wide name and pronoun documentation despite this

Table 1. Survey Constructs and Measures

Construct	Assessment Item	Response Options	No. (%)
Gender identity	How do you describe your gender identity?	Transmasculine	121 (59)
		Transfeminine	43 (21)
		Nonbinary ^a	40 (20)
Age	How old are you?	<18 y	105 (56)
		≥18 y	83 (44)
Race/ethnicity	How do you identify your race/ethnicity?	White	166 (86)
		Nonwhite ^b	26 (14)
Outness	Outside of health care, how out are you about your gender identity right now?	Out to everyone	82 (42)
		Out to most	68 (35)
		Out to some	28 (14)
		Out to few or no one	17 (9)
Parental support	On a scale of 1 to 10, how supportive would you say your most supportive parent/legal guardian is of your transition (1 being not supportive at all and 10 being extremely supportive)?	10	37 (20)
		7-9	72 (39)
		1-6	77 (41)
Desire EMR-wide documentation ^c	Would you want to have a note made in your EMR so all members of the health care team outside of the gender clinic (eg, emergency department staff, people drawing blood, schedulers) would be able to see the name or pronouns you use?	Name and pronouns	156 (79)
		Name not pronouns	7 (4)
		Pronouns not name	5 (3)
		Not sure	23 (12)
		No	7 (4)

Abbreviation: EMR, electronic medical record.

^a Participants who selected nonbinary, genderqueer, gender fluid, gender nonconforming, agender, demiboy or demiman, demigirl or demiwoman, gender variant, androgyne, gender questioning, or 2-spirit were coded as nonbinary.

^b Response options included black, Hispanic/Latino/a/x, Asian, multiracial, and other.

^c Percentages may add up to more than 100% because of rounding.

Table 2. Bivariate Analysis of Factors Associated With Preference for EMR-wide Name and Pronoun Documentation Among 204 Respondents

	Desire EMR-wide Name Documentation		Desire EMR-wide Pronoun Documentation	
Demographic Characteristic	No. (%)	P Value	No. (%)	P Value
Gender identity				
Transmasculine	101 (85)	.007 ^a	100 (84)	.003 ^a
Transfeminine	28 (67)		27 (64)	
Nonbinary	34 (92)		34 (92)	
Age, y				
<18	87 (84)	.29	85 (82)	.48
≥18 y	62 (78)		62 (78)	
Race/ethnicity				
White	131 (81)	.79	129 (80)	.55
Nonwhite	22 (85)		22 (85)	
Gender-related characteristics				
Outness				
Out to everyone	71 (88)	.02 ^a	71 (88)	.06
Out to most	57 (88)		54 (83)	
Out to some	19 (68)		20 (71)	
Out to few or no one	11 (65)		11 (65)	
Parental support ^b				
10	61 (83)	.95	62 (83)	.39
7-9	59 (83)		59 (83)	
1-6	30 (81)		27 (73)	

Abbreviation: EMR, electronic medical record.

^a Statistically significant ($P < .05$).

^b Rated on a scale of 1 to 10, with 1 indicating not supportive at all and 10, extremely supportive.

being infrequently offered in clinical encounters. We identified important variation within the sample by gender identity and how “out” individuals were. Perhaps transfeminine patients may be less likely to desire name and pronoun documentation because of increased pressure to conform to traditional gender norms, but whether this is moderated by “outness” warrants further investigation. Although the majority of youths desire EMR-wide documentation, it remains important to discuss the implications this documentation has on confidentiality, particularly with regard to parental access to medical records for individuals younger than 18 years.⁶

While limited by the fact that these data were obtained from a convenience sample of transgender youths with access to gender-affirming care, they illustrate that most transgender youths desire opportunities for EMR-wide name and pronoun documentation. To better support this vulnerable group of youths, health systems and EMRs should allow for EMR-wide name and pronoun documentation, even when a patient has not legally changed their name.

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1. Russell ST, Pollitt AM, Li G, Grossman AH. Chosen name use is linked to reduced depressive symptoms, suicidal ideation, and suicidal behavior among transgender youth. *J Adolesc Health*. 2018;63(4):503-505. doi:10.1016/j.jadohealth.2018.02.003
2. Cahill SR, Baker K, Deutsch MB, Keatley J, Makadon HJ. Inclusion of sexual orientation and gender identity in stage 3 meaningful use guidelines: a huge step forward for LGBT health. *LGBT Health*. 2016;3(2):100-102. doi:10.1089/lgbt.2015.0136
3. Thompson HM. Patient perspectives on gender identity data collection in electronic health records: an analysis of disclosure, privacy, and access to care. *Transgend Health*. 2016;1(1):205-215. doi:10.1089/trgh.2016.0007
4. Guss CE, Inwards-Breland DJ, Ozer E, Vance SR Jr. Experiences with querying gender identity across seven adolescent medicine sites. *J Adolesc Health*. 2018;63(4):506-508. doi:10.1016/j.jadohealth.2018.05.021
5. Dunne MJ, Raynor LA, Cottrell EK, Pinnock WJA. Interviews with patients and providers on transgender and gender nonconforming health data collection in the electronic health record. *Transgend Health*. 2017;2(1):1-7. doi:10.1089/trgh.2016.0041
6. Maragh-Bass AC, Torain M, Adler R, et al. Is it okay to ask: transgender patient perspectives on sexual orientation and gender identity collection in healthcare. *Acad Emerg Med*. 2017;24(6):655-667. doi:10.1111/acem.13182

Potential Emerging Risks Among Children Following Parental Opioid-Related Overdose Death

The incidence of unexpected deaths from opioid overdoses sharply increased in Allegheny County, Pennsylvania, in recent years. In 2017 alone, the county's opioid-related overdose rate was 51.5 per 100 000, more than triple the US rate (14.9 per 100 000). This represented more than 90% of all unintentional overdoses.

The opioid epidemic is also affecting families and, most importantly, children. People who died of an overdose were most frequently between age 25 to 54 years and in their child-rearing years. Substance use in the household is considered an adverse childhood experience and is associated with health risks and disease in adulthood.¹ A recent longitudinal study

found that bereavement by sudden parental death was associated with an increased incidence of depression, primarily during the first 2 years, along with posttraumatic stress disorder and functional impairment.² Yet, little is known about the number of children who experienced these losses.

The goal of this study was to determine the number of children who experienced unexpected parental loss because of opioid-related overdoses in Allegheny County. It also sought to understand their human service encounters and mental health services use subsequent to parental loss.

Methods | Using integrated public system data that existed within the county's data warehouse, we identified a cohort of individuals who had died of an unintentional drug overdose between July 2002 and December 2017 who were also listed as a parent on a birth certificate between January 1999 and December 2017. The result was a cohort of children and adolescents born in Allegheny County who were 18 years or younger during this period and who may have been affected by an unexpected death of a parent.

We then summarized their involvement with human services and other public systems in the months and years following the parent's death (when appropriate and age-eligible) and presented cumulative percentages (Table). This study was conducted by the department using information that already existed in the department as records of operations from the delivery of health and human services. It was conducted for planning purposes and to improve the quality of services the department delivers to county residents and qualified as exempt research.

Results | There were 664 individuals listed as parents on the birth certificates (392 [59%] were fathers) of 1008 children (989 [98%] were younger than 18 years): 252 (25%) were younger than 5 years, 373 (37%) were between age 5 to 9 years,

Table. Eligible Cohort Observed Over the 5-Year Period

Characteristic	At time of parent's death	After parent's death					
		1 mo	3 mo	6 mo	1 y	2 y	5 y
Child welfare involvement							
Cumulative count of bereaved children, No. (%)							
Involved with child welfare	105 (10.6)	138 (14.0)	139 (14.1)	160 (16.2)	183 (18.5)	190 (19.2)	196 (19.8)
Involved in child welfare and placed out of home	33 (3.3)	48 (4.9)	53 (5.4)	60 (6.1)	72 (7.3)	79 (8.0)	84 (8.5)
Cumulative count of children who were age 0-17 y during observation periods, No.	989	989	989	989	989	989	989
Mental health services (Medicaid only)							
Children who received ≥1 mental health services, No. (%)	71 (9.3)	84 (11.0)	110 (14.5)	132 (17.3)	149 (19.6)	169 (22.2)	189 (24.8)
Children who were Medicaid-enrolled during ≥1 of the observation periods, No.	761	761	761	761	761	761	761
Family court involvement for dependency reasons							
Cumulative count of children in family court for dependency, No. (%)	71 (7.2)	87 (8.8)	91 (9.2)	96 (9.7)	104 (10.5)	108 (10.9)	112 (11.3)
Children age 0-17 y during observation periods, No.	989	989	989	989	989	989	989
Family court involvement for delinquency reasons							
Cumulative count of children in family court for delinquency, No. (%)	13 (2.0)	13 (2.0)	15 (2.3)	17 (2.6)	20 (3.0)	22 (3.3)	24 (3.6)
Children age 10-17 y during observation periods, No.	665	665	665	665	665	665	665