People-First Language – Activity Key

Match the number in the text to the corresponding explanation, starting on page 3.

Chief Complaint: Evaluation for positive human immunodeficiency virus (HIV) rapid test

History of Present Illness: Mr.[1] Green is an unfortunate[2] 40-year-old man referred for further evaluation after a positive HIV screening test[3]. The patient was tested at a community health screening booth that was part of a gay pride[4] event about 2 weeks ago. The rapid test was positive[3], and the patient has scheduled an appointment at this clinic for further evaluation.

Mr.[5] Green says that his test was a "surprise," despite the fact that he has had sex with a lot of men in the past[6]. His last HIV test was about 5 years ago at a health department, and he says that "it must have been negative because they never called me." He says he is a "transgender woman" but does not take any medications or had any surgery[7].

In regard to HIV risk factors, he has had sex with men in the past. When I asked how many, Mr. Green said he wasn't sure (perhaps because he can't remember how many)[8]. He also is an addict[9] and an injection drug user; he regularly uses methamphetamines as well as other drugs including heroin, marijuana, and cocaine. He has multiple tattoos, some of which appear as if they may have been placed in jail or prison.[10]

He reports feeling tired. He says he is "depressed" about his diagnosis and what this means for his health in the future.

Review of Systems: All systems reviewed and negative other than noted above.

Past Medical History: Prior diagnosis of gonorrhea and syphilis treated at another state's health department. History of depression, not currently on treatment.

Past Surgical History: Appendectomy at age 15.

Family History: Mother with hypertension and diabetes. Father was an alcoholic with liver disease[11].

Social History: Smokes 1 pack of cigarettes per day. Alcoholic[12]; drinks 4-6 drinks per day and more on weekends. Intravenous drug addict[12], predominantly methamphetamines and sometimes heroin. Abuses[13] marijuana and cocaine. Unemployed, has never held a job more than 6 months at a time[14].

Medications: No current prescription medications.

Allergies: No known drug allergies.

Physical Exam:

Vitals: Temperature 97.6 deg F, Pulse 89 beats/min, Blood Pressure 135/80 mm Hg, Respiratory rate 16 breaths/minute, Oxygen saturation 98% on room air

General: Appears generally well, inappropriately dressed as a drag queen[15], nervously looking around[16]

Head: Normocephalic, atraumatic, wearing a wig[14]

Eyes: Pupils equal, round and reactive; no conjunctival icterus

Nose: Nasal piercing of left nare

Mouth: Prior dental work noted; tongue piercing noted; no oral thrush

Cardiovascular: S1 and S2 heard, no murmurs or rubs

Lungs: Clear to auscultation bilaterally, no crackles, no wheezes

Abdomen: Nontender, nondistended, bowel sounds present in all four quadrants

Genitourinary: Uncircumcised penis without skin lesions

Extremities: No cyanosis, clubbing, or edema

Skin: Multiple tattoos on all four extremities; no rash or bruises noted

Neurologic: Moving all 4 extremities; ambulates without aid

Laboratory and Radiology Studies: Reviewed in medical record.

Assessment: Mr. Green is a 40-year-old man referred for further evaluation after a positive HIV screening test. The patient certainly has multiple risk factors for HIV infection, including promiscuous[8] homosexual sex and intravenous drug abuse[17]. He will be assessed with the tests noted below. In addition, he is at risk for sexually transmitted diseases and will be screened appropriately. Finally, he is confused regarding his sexual orientation and warrants mental health assessment[18].

Plan By Problem:

1. Acquired Immune Deficiency Syndrome (ICD10 B24)[19]
    a. Check HIV p24 antigen and antibody tests
    b. Check HIV RNA PCR tests
    c. Check flow T-cell subsets (i.e. CD4 count)
    d. If tests positive and confirm active infection, obtain further testing
2. High risk homosexual behavior (ICD10 Z72.52)[20]
    a. Screen for syphilis with Treponemal IgG and RPR
    b. Screen for gonorrhea and chlamydia with urine G/C PCR
    c. Patient counseled regarding importance of using condoms to reduce risk of transmission
3. Gender dysphoria (ICD10 F64.9)[21]
    a. Refer to psychiatry for further evaluation

This list is by no means meant to be exhaustive, nor do we suggest that this is the definitive authority on how you may and may not write about your patients. Instead, this note meant to serve as a jumping-off point for more conversation about language, and how the way we speak might affect the way we think about patients or groups of patients. We invite you to note the places that you may have missed, and consider the ideas behind why those words or phrases might be stigmatizing.

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1. Consider using the patient's preferred full name here, rather than a gender-specific salutation like Mr/Ms/Mrs.

Given the specifics of this patient's story, it would be reasonable to say something like "Jane Green is a 40-year old transgender woman…" as the introduction of the sentence. There's no "best" way to document this, medically. Some advocates prefer descriptors like "transmasculine" or "transfeminine" instead of "transgender man" or "transgender woman" (respectively). Best practice would be in general to avoid outdated or inaccurate terms like "transvestite," "transsexual," or unnecessary additional descriptors like "male-to-female" or "female-to-male" (since that's essentially included in a description of being transgender woman or transgender man (respectively).

Separately, it's probably a best practice with big EMRs like Epic to verify with the patient that it's OK to include her preferred name and pronouns in the "official" demographics of the system. Once you make a change, it's visible to everyone system-wide, and some pts may not be ready for that - or may present to one clinic as female, another as male. Think about some kind of informal "informed consent" before changing things that are accessible system-wide.

2. It's generally best to avoid editorializing in notes, whenever possible. That means avoiding terms that are subjective, such as "very pleasant" or "unfortunate."

3. "Reactive" might be a better description of the test result, but "positive" and "reactive" are essentially interchangeable. This would (arguably) matter more if you want to move away from language like "HIV-positive"; if you start actively thinking about eliminating the "positive" part everywhere, then it may help (hopefully) to push "HIV-positive" out of your writing/descriptions.

From a clinical standpoint, it might also be worth describing if this was a rapid/point-of-care test or not - and if it was an oral test, a fingerstick test, or a blood-based test from a draw.

4. One could argue that it should just be called a "pride event" – since pride events tend to include folks who aren't necessarily gay-identified, e.g. trans folks, people who identify as queer or genderfluid, bisexual people, and "straight" allies, friends, and family members.

5. Here it's going to be tempting for providers new to caring for transgender folks to default to "the patient" instead of using a name or pronouns… and sometimes it is easier to go that way, but it really isn't in keeping with people-first language principles. Instead, the provider could: use the patient's preferred pronoun, use "they" as a catch-all/non-specific pronoun, or use their preferred first name.

6. The reference to the patient having sex with "a lot of other men" is another editorialization, and comes across as very judgmental and not clinically relevant. Some people who teach sexual history-

taking encourage providers not to ask about the number of lifetime sexual partners, since it's not necessarily very informative or helpful, though it may be useful to know the number of partners a patient has had over a certain amount of time (e.g. 1-3 months) to determine whether PrEP is appropriate. A mentor of mine once said to me that "every question we ask is a diagnostic test," and the corollary to that is: "how is this test going to change your management of the patient?" If someone has had 5 versus 500 lifetime sexual partners, and they're in your clinic for a new diagnosis of HIV, then in some ways it doesn't really matter – and opens the door for inadvertent "slut shaming" of the patient, especially if the provider doesn't have a good poker face if the number the patient gives is surprising to the provider.

7. There are several problems here. If the patient identifies as a transgender woman, and/or has indicated preferred pronouns of she/her/hers, then continuing to use the pronoun "he" after this point is misgendering the patient – and also implicitly disrespecting her identity. Would encourage the provider to embrace the preferred pronouns, be consistent, and not make judgments. Being consistent or forcing oneself to use them in print is also going to help the provider get in the habit over time – this is especially useful if the provider isn't used to having trans patients already. Also could consider saying "She identifies as…" instead of "She says that she is a 'transgender woman'…" since the "she says" statement and scare quotes around "transgender woman" could suggest or indicate that the provider is skeptical or doesn't believe the patient's statement.

The back half of the sentence is good to document somewhere, since this is related to preferences and medication history and is important to know to provide optimal care (and be mindful of future plans or needs for referrals or additional support/training/guidance).

8. See comment above about lifetime # of sexual partners. The parenthetical here is editorializing and doesn't contribute meaningfully to the story.

9. This is an unnecessary label applied to the patient by the provider. Like "HIV-infected homeless woman," this term is loaded and makes the person's humanity sort of a second thought. Fundamentally, she's a person who's using drugs and should just be described as such. Generally, it's probably a better idea to stick to PWID (person who injects drugs) or PWUD (person who uses drugs), and use terms like "in recovery" for someone who's not actively using (rather than "clean" or "sober").

10. This one is tricky. It might be tempting to argue that it is clinically relevant to speculate on the origin of her tattoos. Realistically, though, the only reason to delve into the origin of the tattoos would be to suss out risk of other bloodborne pathogens, like hep C or hep B – which you'll be testing for anyway as part of a standard, recommended new patient panel for newly diagnosed patients with HIV. As it is, this part is unnecessarily judgmental and hard to substantiate. Knowing whether or not she has been incarcerated should be a part of the history, at some point – but speculating on where she got her tattoos isn't useful at this point.

11. If this is what she told the provider, it would be OK to keep, though I would generally put it in quotes to show that the word came from her, not me. Otherwise, would rephrase to something like "liver disease due to alcohol"

12. This is a judgment and is not helpful. Just the facts are needed, and they are documented next. Labeling the patient as "an alcoholic" or "an addict" isn't appropriate here.

13. "Abuse" is sort of a slippery slope; there are diagnostic codes for drug abuse, but if you're sticking to just the facts, then it's more objective to say "uses" rather than "abuses."

14. It's hard to argue why this would be clinically relevant, and instead sounds more like passing judgment on the patient.

15. Fundamentally, it's not relevant what she's wearing. Some providers (e.g. psychiatry or MH) like to describe the neatness or cleanliness of attire as a way of helping to describe (or infer) the living situation of the patient. But that would refer to whether the patient is "well-groomed" or "unkempt," or "dressed inappropriately for the weather."

What's more, this patient has not indicated that she is a drag queen. Drag is different from gender identity and expression, and these terms are not synonymous. Transgender people aren't transvestites, and it's inappropriate to use this term unless the patient has expressed a preference for it.

A transfeminine patient would be expected to present with women's clothing, but their expression is on a spectrum just like sexual attraction, romantic attraction, and gender identity. (I personally love the Genderbread Person as a model for helping providers learn about these terms and keep them in mind: https://www.itspronouncedmetrosexual.com/2015/03/the-genderbread-person-v3/).

16. The more appropriate and objective term might be "hypervigilant."

17. "Homosexual" here feels outdated and judgmental, ignoring the patient's gender identity as a woman. It can be a loaded term for many gay/queer people. The best, most accurate descriptor here would be "sex with men and injection drug use."

18. She hasn't indicated that she's confused about her gender; this is how she identifies. This statement seems to be more the opinion of the provider based on his own confusion, and it invalidates the patient's input. I agree that she could probably benefit from some mental health assessment – but because she sounds like she has been through a lot of trauma in her lifetime, not because she's confused about her gender.

19. There are no objective physical findings or other clues in the history to point to a provisional diagnosis of AIDS over simply "asymptomatic HIV infection" (ICD-10 Z21) or "HIV disease" (ICD-10 B20)… and those would be preferred in the absence of an AIDS-defining criterion being met. (It is probably a good idea to check with the billing & coding specialists in individual clinics about what's preferred, and go with that.)

20. This is a real diagnosis code, but so is "Sucked into jet engine, subsequent encounter." (That is to say, not all ICD codes are good ones). I use this code for patients on PrEP, but I **always** take a second to explain to them on their "after visit summary" that this is one of the codes I have to use in order to get their insurance to cover things – it's not a judgment I'm making. Here, it might be better to use one of the exposure to STD codes in conjunction with the high risk sexual behavior code – or in place of.

21. This diagnosis code is a real problem, since not everyone who is transgender experiences gender dysphoria. In this use/context, the provider is using it incorrectly, classifying the provider's own perception/understanding of the patient's "confusion" as gender dysphoria. Nothing in the history says that she is unhappy with or upset by her gender identity – so using this code is a problem (and inaccurate). And unfortunately, there aren't good replacements yet. In ICD-10, there's a

"transsexualism" code (F64.0) but that term is really outdated and some trans folks will find it offensive in their paperwork – more so than gender dysphoria. Plus it was entirely removed from the ICD officially by the WHO in 2018. In the replacement (ICD-11), there's a new descriptor, gender incongruence (HA60), but ICD-11 hasn't been adopted in the US yet (probably at the earliest in 2022 or 2023). So for the moment, the "best" way to document this with coding is via one of the F64.x codes – maybe transsexualism (F64.0) if they're not dysphoric, or the gender dysphoria code (F64.9) if they are dysphoric.