The Value and Process of Inclusion: Using Sensitive, Respectful, and Inclusive Language and Images in NCCN Content

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ABSTRACT

A core component of NCCN’s mission is to improve and facilitate equitable cancer care. Inclusion and representation of diverse populations are essential toward this goal of equity. Within NCCN’s professional content, inclusivity increases the likelihood that clinicians are prepared to provide optimal oncology care to all patients; within NCCN’s patient-facing content, it helps ensure that cancer information is relevant and accessible for all individuals. This article describes changes that have been made in the language and images used in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) and the NCCN Guidelines for Patients to promote justice, respect, and inclusion for all patients with cancer. The goals are to use language that is person-first, nonstigmatizing, inclusive of individuals of all sexual orientations and gender identities, and anti-racist, anti-classist, anti-misogynist, anti-ageist, anti-ableist, and anti-fat-biased. NCCN also seeks to incorporate multifaceted diversity in images and illustrations. NCCN is committed to continued and expanding efforts to ensure its publications are inclusive, respectful, and trustworthy, and that they advance just, equitable, high-quality, and effective cancer care for all.

Overview

NCCN is an organization dedicated to improving and facilitating quality, effective, equitable, and accessible cancer care. NCCN content should thus avoid stigmatizing, alienating, or excluding anyone based on sexual orientation or gender identity (SOGI), race and/or ethnicity, age, health condition, weight, ability, socioeconomic circumstances, education, employment status, religion, or any other specific identity or experience.

Inclusive content improves the visibility and representation of people who have been marginalized, especially those who have experienced intersectional discrimination and oppression. It provides implicit preparation for oncology clinicians to treat patients with various identities and experiences, including those who have been historically excluded from medical discourse and research. Therefore, NCCN has made a concerted and ongoing effort, starting more than a decade ago, to incorporate inclusive, nonstigmatizing language across NCCN clinical content, including in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) and the NCCN Guidelines for Patients. NCCN has also made a deliberate effort to reflect diversity in the photographs and illustrations selected for the NCCN Guidelines for Patients. These measures have been approached with humility and respect and are a key part of NCCN’s commitment to minimize healthcare disparities and increase equity, safety, and trust in cancer care.

NCCN has several approaches to help ensure the appropriateness of language changes. For instance, patient advocates serve on most of the NCCN Guidelines Panels to provide important perspectives. Furthermore, in situations when the NCCN panels or staff do not have the expertise on a specific topic related to inclusive content, they will seek input from outside expert advisors. Finally, NCCN has a mechanism for anyone to submit a recommendation or request for changes to any NCCN Guidelines Panel (https://www.nccn.org/guidelines/submissions-request-to-the-guidelines-panels) and includes links in the NCCN Guidelines for Patients to a survey that allows readers to provide feedback.
Language
The language changes in NCCN publications described in this article are focused on several categories to advance the goals of equity, inclusion, and representation outlined earlier: person-first terminology, language without blame or stigma, and wording that is inclusive of people of all sexual orientations and gender identities. Additional changes are currently being implemented to standardize language in other areas across NCCN publications as well (eg, regarding race and ethnicity).

These language changes are being made in the NCCN Guidelines for Patients, which are patient- and caregiver-facing, and in the NCCN Guidelines, which are mainly used by healthcare professionals. The updated style with changes to improve inclusivity in the NCCN Guidelines for Patients aims to help every patient and caregiver feel that the content is accessible and applies to them personally, without feeling excluded, blamed, or stigmatized. The language in the NCCN Guidelines helps educate professionals who interact with and care for people with cancer, and models language that they can use in their interactions with people with cancer. In all cases, NCCN encourages healthcare professionals to have open conversations with patients regarding what name they desire to be called, what pronouns they use, and how they prefer to be described demographically (eg, woman). NCCN also encourages clinicians to consistently use the language that patients use when communicating with the patient and with colleagues, and within electronic health records.1

Several of the specific changes that NCCN has made across its clinical practice and patient guidelines are discussed in this article. They have also been codified in an internal language guidance document that is used by NCCN staff to operationalize these changes. This document is also available at https://www.nccn.org/home/about/’NCCN’s Commitment to Diversity, Equity, and Inclusion in Our Content.’ With each language alteration that has been made, NCCN staff and the Guidelines Panels have sought to ensure that the clinical context is considered, and the intended meaning of each guideline recommendation is maintained. Being sensitive, respectful, inclusive, and accurate is a priority of NCCN, and these ideals are a central component of the ultimate goals of educating and empowering healthcare professionals and nonprofessionals and providing clear, precise, clinically relevant, trustworthy recommendations.

Recognizing the broad impact of language on clinical care and outcomes, other cancer organizations are also promoting the use of patient-centric, respectful, and inclusive terminology.2–4

Person-First Language
Patients are individuals first and should not be defined by their disease. Person-first language literally puts the person before their diagnosis (eg, a person with lung cancer rather than a lung cancer patient). An illness or disease is something individuals have (ie, it is used grammatically as a noun) rather than a descriptive, defining characteristic of who they are (ie, it is not used as an adjective). Person-first language avoids dehumanizing individuals. This linguistic concept was borne out of the disability community in the 1970s and is now used more broadly in healthcare.5 Beginning around 2014, NCCN has strived to exclusively use person-first language for people with cancer.

Furthermore, as a means of reminding readers that all patients are people and to avoid stigmatizing patients, the authors of the NCCN Guidelines for Patients also strive to omit the word “patient” within the body of the text when feasible.

Identity-First Language
Although person-first language is used for individuals with a current cancer diagnosis, identifying the community of people with a history of cancer using a common term may be useful for communicating recommendations and improving care across broad groups. In these instances, the use of identity-first language is used. Identity-first language puts a disability, medical condition, or other physical or cognitive difference first in a description, allowing a person or group to reject stigma and identify themselves as part of a community (eg, a deaf person). Likewise, although there are differences across age groups, diagnoses, and prognoses, most individuals who have completed cancer treatment identify as “cancer survivors.”7–12 The term survivor has therefore been used in NCCN publications. However, many individuals who are alive after cancer treatment or living with chronic cancers prefer other terms, such as alivers or thrivers, and others do not consider their history of cancer as part of their identity and reject the use of such labels.8,12–14 NCCN Guidelines for Patients uses the term survivorship, but also opts for life after treatment and living with and beyond cancer.

Language Without Blame and Stigma
Disease Progression, Treatment, and Treatment Completion
NCCN strives to ensure there is no implied fault or blame on individuals for their illness or the course of their disease in NCCN content. With the prevalence of war metaphors describing cancer and cancer treatment in the mainstream media (eg, she is fighting cancer; they lost their battle with cancer; the war on cancer), words such as failure or failed can suggest that people with cancer did not fight hard enough or were insufficiently strong, and that disease progression is somehow their fault.15 The word salvage may also connote that people with cancer have failed and now need to be saved or rescued.
Since approximately 2012, the NCCN Guidelines and NCCN Guidelines for Patients have tried to avoid language about patients failing treatment, treatment failure, and salvage treatment, instead preferring language focused on the disease course and lines of therapy. For instance, subsequent or enumerated line of therapy is preferred over salvage therapy as a term to indicate treatment after first-line therapy. As an example, instead of “patients who fail treatment should receive salvage therapy,” NCCN Guidelines use language such as “patients with progressive disease should receive second-line therapy,” with the NCCN Guidelines for Patients further replacing “patients with disease progression” with “those with disease progression.”

When discussing treatment, NCCN strives to be mindful of the words manage and management. Cancer and other medical conditions can be managed; however, using language that infers that patients are managed is patronizing and paternalistic. The use of such language introduces hierarchy, condescension, or even coercion to patient care. NCCN, therefore, uses language such as care or treatment of patients, depending on the context.

Many factors can contribute to incomplete or abandoned treatment plans.16 There may be system and provider barriers, such as unrealistic treatment plans, lack of evidence for specific treatments in a specific patient population, ineffective communication from the healthcare team, inadequate support for managing side effects, un trustworthy healthcare providers, and systemic discrimination and stigma. There may also be individual barriers, including lack of family/community support, individual response to treatment, lack of financial resources/insurance, time constraints, lack of transportation, and other barriers related to social determinants of health. The term noncompliance is commonly used but implies that patients should passively comply with instructions and suggests blame on the patient if the treatment does not work. It also places blame on individuals for what may not be an individual patient barrier. Nonadherence may be less stigmatizing because it implies that the patient can be involved in formulating the treatment plan, is not solely responsible if the treatment plan is not followed, and can contribute to solutions to overcome difficulties.16 When possible, however, NCCN strives to include discussions on barriers to treatment completion for people with cancer—and on possible solutions—rather than rely solely on unidimensional terms, including nonadherence. More work is needed to facilitate systemic interventions to support the completion of proposed treatment plans.

Weight
Language should not stigmatize people based on their weight. Overweight and obesity are medical conditions with complex etiologies.17 Among other factors, social determinants of health can play a major role.18–20 Many healthcare providers incorrectly believe overweight and obesity are caused mainly by individual behaviors, and these clinicians may show implicit or explicit weight bias.21,22 Individuals who have higher body mass indexes (BMIs) can therefore be disparaged and even discriminated against in healthcare.23 This prejudice can result in poor physical and psychological health and a lower likelihood of receiving adequate/appropriate healthcare.23

NCCN content builds on guidance developed by the Obesity Action Coalition regarding the use of nonstigmatizing language around overweight and obesity.24 Instead of using the adjective forms of overweight or obese, NCCN Guidelines started using these terms as nouns in 2021. Thus, rather than using “individuals who are overweight or obese,” the NCCN Guidelines use “individuals who are affected by overweight or obesity,” “individuals with overweight or obesity,” or “individuals with higher BMI.” When it is practical and appropriate, the NCCN Guidelines and NCCN Guidelines for Patients use specific BMI ranges.

In addition, people with BMIs below the normal range can also feel stigmatized and self-report discrimination for having underweight.25 As with overweight and obesity, underweight is a recognized medical condition with associated health risks.26,27 NCCN therefore also views underweight as a noun and prefers to use specific underweight BMI range definitions.

Age
Individuals should not be denigrated or experience discrimination based on their age. Age bias or ageism by healthcare providers toward patients is common.28,29 It can be implicit or explicit and can impact treatment decisions and outcomes in people with cancer.28–30

Words that imply stereotypes or prejudice, such as seniors and the elderly, are avoided in NCCN content.31,32 NCCN uses specific age ranges and avoids adjectives to describe the range whenever possible. For example, in 2022 the guidelines used patients ≥65 years rather than older patients (≥65 years), which was used previously (see Figure 1A). When it is not possible to specify specific age ranges, NCCN uses phrases such as “people who are older” but remains conscientious about framing the language and the recommendations in the most sensitive way possible.

NCCN Guidelines for Patients applies health literacy and numeracy principles by avoiding technical symbols such as > or <, and preferring under and over a given age, rather than younger and older, as illustrated in the phrase “those 65 years of age and over.”

SOGI-Inclusive Language
Sexual and gender minority (SGM; a term mainly used in academic settings) or LGBTQ+ populations (also referred
Respect and Inclusion in NCCN Content

A

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Acute Lymphoblastic Leukemia

2021

PRINCIPLES OF SYSTEMIC THERAPY
Treatment of Older Adults (≥65 years)

• Older adults (defined as those aged 65 years and older) benefit from

2022

PRINCIPLES OF SYSTEMIC THERAPY
Treatment of Adults ≥65 years

• Adults who are ≥65 years benefit from

B

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Prostate Cancer Early Detection

2021

The guidelines are specifically for men opting to participate

2022

The guidelines are specifically for individuals with a prostate opting to participate

C

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Breast Cancer Screening and Diagnosis

2020

PRESENTATION IN MEN

2021

PRESENTATION IN MEN (sex assigned at birth)

2022

PRESENTATION OF SYMPTOMS IN INDIVIDUALS ASSIGNED MALE AT BIRTH

D

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Survivorship

2021

Sexual function and management of hormone-related symptoms are important aspects of quality of life for all cancer survivors. The recommendations here are intended for cisgender survivors based on the availability of data in this population, but should be followed for transgender survivors as applicable, with the involvement of the appropriate health care specialists.

Figure 1. Examples of language changes over time in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines). (A) Anti-ageist language that removes the unnecessary label “older adults.” (B) Language that is organ-based, and therefore more accurate. (C) Use of “sex assigned at birth” to provide recommendations for certain populations based on currently available data. (D) Language that acknowledges the lack of data in some areas for certain populations.

to as the LGBTQIA2S+ populations) include individuals who identify as asexual, bisexual, gay, intersex, lesbian, queer and/or questioning, transgender, and/or 2-spirit, and those who define their sexual orientation and gender identity in other nonheterosexual/noncisgender ways (for a glossary of terms, see the article by Alpert et al on SOGI-based inequities in the 2022 ASCO Educational Book.33) According to a recent Gallup poll, at least 7.1% of Americans identified as bisexual, gay, lesbian, transgender, or “other than heterosexual” in 2022, up from 5.6% in 2020 and 3.5% in 2012.34 Transgender individuals are more visible than in prior polls, at 0.7% of all US adults and 2.1% of those born from 1997 to 2003.

A significant proportion of LGBTQ+ people report discrimination in healthcare settings, leading many to avoid seeking care.35,36 LGBTQ+ people also face discriminatory laws and policies, inadequately trained providers, targeted attacks on communities (eg, focused advertising by tobacco companies, which have contributed to higher rates of tobacco use), and other inequities related to social determinants of health.37–40 As such, the LGBTQ+ populations experience health and healthcare disparities, including in cancer-related care.41 Cancer care disparities in this population can span prevention, screening/early detection, treatment, survivorship, and end-of-life care.41–47

Gendered language may render invisible the bodies and experiences of transgender and intersex people and thus leave oncologists unprepared to care for such patients. Qualitative data suggest that when clinicians are not adequately trained to consider or care for transgender people, they may respond by stigmatizing them.33,48 Thus, incorporating language that alerts clinicians that they will interact with transgender or intersex patients into the guidelines can decrease discrimination. An ongoing NCCN initiative that began in 2020 stipulates that the guideline recommendations should fully address the needs of individuals of all sexual orientations and gender identities, with language and content that is inclusive and affirming.

Using SOGI-Inclusive and Gender-Neutral Language

NCCN Guidelines and NCCN Guidelines for Patients omit mention of sex or gender whenever possible. Gendered terms are often unnecessary when a specific organ is mentioned. For example, the guidelines might have previously stated, “...the risk of HPV cervical infection in women.” The last 2 words can simply be deleted, making the sentence more accurate given that the presence of a cervix is not limited to women and not all women have a cervix.

Recognizing the need for change, NCCN now uses gender-neutral terms whenever appropriate. For example, instead of “women with ovarian cancer,” the NCCN Guidelines use phrases such as “individuals with ovarian..."
cancer” or “those with ovarian cancer.” Ovarian cancer is not limited to women.

In the context of cancer, anatomy is often more relevant than the sex an individual was assigned at birth, and NCCN recommendations are written in an organ-specific way when possible. All individuals—including intersex, transgender, and cisgender people—can have diverse constellations of organs from birth or through various surgeries over their lifetime. Organ-based language is thus critical in cancer care to guide needed screening, diagnosis, treatment, and surveillance. It is especially important so that patients and the members of their caregiver and healthcare teams can have a better understanding of which of NCCN’s recommendations apply to them and how. For example, the NCCN Guidelines for Prostate Cancer Early Detection were updated in early 2022 to specify that the recommendations are “for individuals with a prostate opting to participate” in an early detection program (see Figure 1B).

**Use of “Sex Assigned at Birth”**

Sex assigned at birth refers to the designation made at birth based on a baby’s external anatomy, and NCCN Guidelines use this construction when necessary. For example, NCCN provides recommendations for the treatment of breast cancer in “individuals assigned male at birth” given that data regarding breast cancer have historically been divided into the subpopulations of people assigned male and female at birth. Given current data norms and availability, providing information regarding breast cancer based on sex assigned at birth allows NCCN to provide complete information on what is known about breast cancer and its treatment in these subpopulations. Figure 1C shows the progression NCCN has made in this space: moving from “men” in 2020 to “men (sex assigned at birth)” in 2021 to “individuals assigned male at birth” in 2022. In NCCN Guidelines for Patients, the language reads, “Anyone can develop breast cancer, including those assigned male at birth.” Sex assigned at birth designations have limitations, however. For example, this concept may stigmatize or pathologize transgender or intersex people. Sex assigned at birth is also an imperfect and often inaccurate proxy for anatomy, hormonal milieu, karyotype, and other factors and thus may encourage the use of imprecise data. It is possible that the ways data are collected and conceptualized will change in the future, thus abrogating the need to classify people by sex assigned at birth.

**Continued Use of Gendered Terms**

The terms female and male can be used as either adjectives or nouns and refer to the 2 most common sex constellations across species. In contrast, men and women are social constructs used to describe gender that only apply to humans and are related to self-perception. NCCN therefore avoids use of men and women as much as possible.

NCCN Guidelines will continue to use the terms men, women, female, and male, however, when citing statistics, recommendations, or data from other organizations or sources that do not, or did not, use inclusive terms. If an organization reports breast cancer as the most common malignancy in women in the United States, for example, it would be inaccurate to state this statistic as referring to those assigned female at birth. However, there are limitations to the use of gender- or sex-based terms as they are reported in data and research: most studies do not report how sex and gender data are collected, and inappropriately use these terms interchangeably or inconsistently. Thus, the data presented are unclear and difficult to apply to populations based on sex or gender. NCCN will mirror the language used in external sources but will bring visibility to these limitations of definitions as appropriate. NCCN encourages researchers to collect more specific data in future studies, and organizations to use more inclusive and accurate language in their future recommendations.

Use of the words female and male will also continue to be used to differentiate between organs that have important differences based on sex constellations that have not been otherwise characterized or conceptualized. For example, NCCN content includes the adjective female or male to describe organ systems when deemed necessary to promote understanding (eg, the female urethra). NCCN also acknowledges that more work is needed to delineate how anatomic, physiologic, and hormonal differences apply to cancer care. For example, more research is needed to understand cancer risk based on hormonal states for individuals assigned female at birth with functional ovaries, without functional ovaries, with functional ovaries on testosterone, and without functional ovaries on testosterone.

**Other SOGI-Inclusive Issues**

The guidelines use inclusive language surrounding menstruation and pregnancy. Many transgender men, intersex individuals, and gender nonconforming, nonbinary, or genderqueer individuals menstruate and may become pregnant. NCCN strives to use inclusive language regarding menstruation, pregnancy, and related reproductive health needs. NCCN Guidelines, therefore, use language such as “individuals of childbearing potential,” “those who can become pregnant,” and “individuals who are postmenopausal” without the use of gendered terms. NCCN Guidelines for Patients uses similar language, or in some cases relies on anatomy (eg, “those with ovaries” or “those with testicles” to describe how cancer treatment might affect fertility in people of all genders).

NCCN Guidelines strive to use language that reflects the fact that sexual practices vary widely. For example,
the guidelines formerly included a recommendation that “female” patients should be counseled on the need for contraception to prevent unintended pregnancy; the guidelines now note that this only applies to people whose “… sexual activity could result in pregnancy.” The language does not mention the sexual orientation or gender of the individual, but instead defines the population for which the recommendation applies.

In some cases, the NCCN Guidelines Panels do not believe they have the expertise or clinical evidence to formulate recommendations that fully account for individuals of all gender identities and sexual orientations (eg, regarding the management of hormone-related symptoms or sexual side effects). In such situations, panels are encouraged to acknowledge the lack of data or expertise and seek non-panel expertise when appropriate. See Figures 1D as an example of language that was added to the NCCN Guidelines in 2021.

**Images**

Studies have shown that white or lighter-skinned individuals are overrepresented in the medical literature, in professional and patient education materials, and in health organizational outreach. In addition, images in medical education materials may not reflect the affected population in terms of age, body type, and gender expression. Evidence suggests that individuals are more receptive to healthcare messages when images represent them. Images in patient education material should thus reflect diversity in skin color, age, weight, physical ability (eg, through use of assistive devices), partnerships, and gender expression. Care is also needed, however, to ensure that images do not reinforce harmful stereotypes (eg, images of individuals with obesity eating unhealthy food), in which cases health messages may perpetuate stigma and not be well received by oncology clinicians or people with cancer.

The NCCN Guidelines for Patients incorporate diverse, inclusive, age-sensitive, and culturally sensitive photographs and illustrations (ie, ones that do not perpetuate stigma) to reach a global readership. Use of images of diverse populations promotes visibility and justice, improves health literacy, enhances comprehension, clarifies and reinforces content, promotes learning, adds visual appeal, and encourages relatability (eg, Figure 2).

**Ongoing and Future Efforts**

NCCN staff and panel members have become increasingly aware of the potential of NCCN’s language and images to affect equitable cancer care, and understand that further improvements are needed. NCCN has ongoing initiatives to adopt the use of nonstigmatizing, nonblaming language regarding race and ethnicity, substance use (eg, smoking, alcohol use), and HIV across all NCCN publications and content.

**Summary**

Efforts to minimize and ultimately eliminate cancer care disparities and to increase equity and trust require multifaceted approaches and are a shared responsibility throughout oncology care systems and institutions. Continuous evaluation, feedback, and ongoing research will lead to further advances in this arena. Inclusive recommendations, language, and images play a critical role in promoting equity. NCCN remains humble and open to listening and learning from others, particularly people from marginalized populations. NCCN is committed to continuing to improve NCCN content so all people with cancer and caregivers can live better lives.

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References


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