National Comprehensive Cancer Network®

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May 20, 2024

Office of the National Coordinator for Health Information Technology (ONC)
U.S. Department of Health and Human Services
330 C St SW, Floor 7
Washington, DC 20201

RE: Draft 2024-2030 Federal Health IT Strategic Plan

Dear Dr. Tripathi:

The National Comprehensive Cancer Network® (NCCN®) appreciates the opportunity to comment on the Draft 2024-2030 Federal Health IT Strategic Plan as it relates to NCCN's mission of improving and facilitating quality, effective, equitable, and accessible cancer care. NCCN will focus our comments on the delivery and experience of care.

NCCN Background
As an alliance of 33 leading academic cancer centers in the United States that treat hundreds of thousands of patients with cancer annually, NCCN® is a developer of authoritative information regarding cancer prevention, screening, diagnosis, treatment, and supportive care that is widely used by clinical professionals and payers alike.

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are a comprehensive set of guidelines detailing the sequential management decisions and interventions that currently apply to 97 percent of cancers affecting patients in the United States. The NCCN Guidelines are transparent, continuously updated, available free of charge online for non-commercial use and are available through a multitude of health information technology (HIT) vendors.

NCCN EHR Oncology Advisory Group
The NCCN EHR Oncology Advisory Group (EHR Group) was established in 2017 and is comprised of one representative from each of the 33 NCCN Member Institutions who have extensive experience with oncology Electronic Health Record (EHR) optimization and management. The purpose of the EHR Group is to share challenges and innovative practices regarding the optimization of oncology EHR systems, promote constructive dialogue with EHR vendors and oversight bodies about oncology-specific needs, and support standards and interoperability among oncology EHRs. NCCN obtained input regarding the Draft 2024-2030 Federal Health IT Strategic Plan from the EHR Group in preparation for these comments.

Federal Health IT Strategic Plan
NCCN applauds the ONC for the development of a comprehensive and thoughtful strategic plan. We appreciate the emphasis on crucial topics such as improving health equity, increasing interoperability, reducing provider and administrative burden, ensuring the safety and transparency of artificial intelligence (AI) tools, and improving health IT access for patients, providers, and underserved communities. NCCN believes this plan is an important step forward towards supporting sustainable improved access to health IT that is actionable.

Goal 2: Enhance the Delivery and Experience of Care

Objective A: NCCN would like to highlight the importance of improved interoperability for achieving the goal of providers delivering safe, equitable, high-quality, and improved cancer care. We support the strategies focused on interoperability and would specifically like to emphasize that key structured data elements summarizing the patient journey should be interoperable. We respectfully suggest ONC consider providing greater specificity regarding where data is stored and how it is structured, noting the central importance of the EHR for storing this data given that EHRs are the current vehicle for care delivery. This would help address the current need for an outside body to set standards for which minimal data should be captured as structured and interoperable data for transmission between systems for patients, especially those patients with cancer. Currently, vendors (e.g. Epic, Cerner) do not have any standards to follow, and cancer centers are not held to any standards about how much cancer related data is captured in a structured and transmissible format, nor how much is located within the EHR as structured data.[1]

Objective B: NCCN would also like to thank the ONC for including Objective B to expand access to quality care and reduced or eliminated health disparities. We have launched several initiatives and advocated for numerous policies aimed towards improving health equity and appreciate the ONC's collaborative efforts in this area. NCCN supports the expanded use of secure telehealth including audio-only telehealth. NCCN has heard from member institutions and patient advocacy organizations that both access to and comfort with video technology is a significant challenge for many patients with cancer and the requirement for both audio and video capability would serve to widen existing health disparities. Requiring video capability would put patients without access to or familiarity with this technology at greater risk of the inability to access needed medical services altogether.

The EHR Group conducted a survey of providers at NCCN Member Institutions to help assess the role of telehealth in care delivery. With over 1,000 responses from 26 cancer centers, clinicians reported a substantial portion of visits for patients with cancer could be effectively and safely conducted using telemedicine.[2] Respondents estimated 46% of post pandemic visits could be virtual, but challenges included (1) lack of patient access to technology, (2) inadequate clinical workflows to support telemedicine, and (3) insurance coverage uncertainty post-pandemic. While this survey was conducted in 2020, telemedicine remains a vital tool for providers to treat patients. The continued and expanded use of telehealth services, especially audio-only telehealth, can provide more equitable access to care.

NCCN again thanks ONC for its commitment to reducing disparities through advancing the collection and use of Social Determinants of Health (SDOH) and is pleased to provide information about the NCCN Distress Thermometer and Problem List, a resource to aid in this effort. The NCCN Distress Thermometer and Problem List is a well-known and widely used screening tool among global oncology providers. The Distress Thermometer measures distress on a 0 to 10 scale and the Problem List includes five areas of life: practical, family, emotional, spiritual/religious, and physical problems. Within the Problem List, patients are questioned about housing, transportation, and food security among other variables offering providers flexibility in how they implement the tool. The Distress Thermometer and Problems List has been

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[1] Tevaarwerk AJ, Karam D, Gatten CA, et al. Transforming the Oncology Data Paradigm by creating, capturing, and retrieving, structured cancer data at the point of care: A Mayo Clinic pilot. *Cancer*, 2024. doi.org/10.1002/cncr.35304.

[2] Tevaarwerk AJ, Chandereng T, Osterman T, Arafat W, Smerage J, Polubriaginof FCG, Heinrichs T, Sugalski J, Martin DB. Oncologist Perspectives on Telemedicine for Patients With Cancer: A National Comprehensive Cancer Network Survey. JCO Oncol Pract. 2021 Sep;17(9):e1318-e1326. doi: 10.1200/OP.21.00195. Epub 2021 Jul 15. PMID: 34264741; PMCID: PMC9810123.

extensively studied and utilized and has been incorporated into Health Information Technology.[3,4,5,6] The Center for Medicare and Medicaid Innovation (CMMI) Enhancing Oncology Model recently referenced the Distress Thermometer and Problem List as a tool for providers to address health-related social needs.

Objective D: Additionally, NCCN greatly supports reducing the regulatory and administrative burden on providers outlined in this objective. NCCN is acutely aware of the additional stress such tasks add to the healthcare workforce and its impact on burnout.[7,8] It is critical that we reduce the regulatory and administrative burden on healthcare professionals to ensure a future of accessible, high-quality care. NCCN has launched several successful innovative models with commercial payers that use real-time clinical decision support tools to ensure guideline adherence in lieu of traditional prior authorization. NCCN is pleased to share within this comment letter the results of these successful models.

Numerous independent studies have found adherence to NCCN Guidelines improves care delivery and outcomes for patients with cancer. Improved health outcomes proven through concordance with NCCN Guidelines include: improved rates of survival for colon cancer, ovarian cancer, gastric cancer, nasopharyngeal cancer, and pancreatic cancer; decreased locoregional recurrence of melanoma; and improved pain control.[9,10,11,12,13,14] Non-adherence to guidelines has also been identified as a key contributor to inequities in care outcomes across race and ethnicity with some studies finding these disparities greatly

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[3] Cutillo A, O'Hea E, Person S, Lessard D, Harralson T, Boudreaux E. The Distress Thermometer: Cutoff Points and Clinical Use. Oncol Nurs Forum. 2017 May 1;44(3):329-336. doi: 10.1188/17.ONF.329-336. PMID: 29493167; PMCID: PMC5839660.

[4] Ma X, Zhang J, Zhong W, Shu C, Wang F, Wen J, Zhou M, Sang Y, Jiang Y, Liu L. The diagnostic role of a short screening tool--the distress thermometer: a meta-analysis. Support Care Cancer. 2014 Jul;22(7):1741-55. doi: 10.1007/s00520-014-2143-1. Epub 2014 Feb 8. PMID: 24510195.

[5] Cormio C, Caporale F, Spatuzzi R, Lagattolla F, Lisi A, Graziano G. Psychosocial distress in oncology: using the distress thermometer for assessing risk classes. Support Care Cancer. 2019 Nov;27(11):4115-4121. doi: 10.1007/s00520-019-04694-4. Epub 2019 Feb 20. PMID: 30788626.

[6] Snowden A, White CA, Christie Z, Murray E, McGowan C, Scott R. The clinical utility of the distress thermometer: a review. Br J Nurs. 2011 Feb 24-Mar 9;20(4):220-7. doi: 10.12968/bjon.2011.20.4.220. PMID: 21471860.

[7] Tai-Seale M, Baxter S, Millen M, et al. Association of physician burnout with perceived EHR work stress and potentially actionable factors. JAMIA, 2023. doi.org/10.1093/jamia/ocad136.

[8] Gajra A, Bapat B, Jeune-Smith Y, et al. Frequency and Causes of Burnout in US Community Oncologists in the Era of Electronic Health Records. JCO Oncology Practice, 2020. doi/full/10.1200/JOP.19.00542.

[9] Erickson Foster J, Velasco JM, Hieken TJ. Adverse outcomes associated with noncompliance with melanoma treatment guidelines. Annals of Surgical Oncology. 2008;15(9):2395-2402. doi:10.1245/s10434-008-0021-0.

[10] Visser BC, Ma Y, Zak Y, Poultsides GA, Norton JA, Rhoads KF. Failure to comply with NCCN guidelines for the management of pancreatic cancer compromises outcomes. HPB. 2012;14(8):539-547. doi:10.1111/j.1477-2574.2012.00496.x.

[11] Bristow RE, Powell MA, Al-Hammadi N, et al. Disparities in ovarian cancer care quality and survival according to race and socioeconomic status. JNCI Journal of the National Cancer Institute. 2013;105(11):823-832. doi:10.1093/jnci/djt065.

[12] Bristow RE, Chang J, Ziogas A, Randall LM, Anton-Culver H. High-volume ovarian cancer care: Survival impact and disparities in access for advanced-stage disease. Gynecologic Oncology. 2014;132(2):403-410. doi:10.1016/j.ygyno.2013.12.017.

[13] Mearis M, Shega JW, Knoebel RW. Does adherence to National Comprehensive Cancer Network guidelines improve pain-related outcomes? An Evaluation of Inpatient Cancer Pain Management at an Academic Medical Center. Journal of Pain and Symptom Management. 2014;48(3):451-458. doi:10.1016/j.jpainsymman.2013.09.016.

[14] Schwam ZG, Sosa JA, Roman S, Judson BL. Receipt of care discordant with practice guidelines is associated with compromised overall survival in nasopharyngeal carcinoma. Clinical oncology (Royal College of Radiologists (Great Britain)). https://www.ncbi.nlm.nih.gov/pubmed/26868285. Published June 2016.

reduced or eliminated when guideline adherent care is received.[15,16] As such, guideline adherence is a key tool to combat inequities in care outcomes across race and ethnicity.

Guideline adherent care has also been shown to decrease costs. A peer-reviewed, published study by United, eviCore, and NCCN entitled "Transforming Prior Authorization to Decision Support" demonstrated mandatory adherence to NCCN Guidelines and NCCN Compendium® using a real-time Clinical Decision Support Mechanism significantly reduced total and episodic costs of care while also reducing denials and increasing access to guideline-concordant care. In Florida, United Healthcare adopted a prior authorization tool using NCCN real-time decision support over one year and explored 4,274 eligible cases. At the conclusion of the study, United Healthcare found that adding decision support to prior authorization reduced denials to 1 percent. Additionally, despite reducing denials, when compared to United Healthcare's cancer drug cost trends nationwide, the study found that mere adherence to NCCN Guidelines and Compendium within the pilot reduced chemotherapy drug costs trends by 20 percent; a savings of more than $5.3 million in the state of Florida. Administrative burden was also reduced through the integration of the decision-making tool as oncologists obtained immediate approvals online for 58 percent of cases without further interaction with the health plan required. Approval was granted for 95 percent of the remaining cases requiring further interaction in less than 24 hours.[17]

NCCN Guidelines have also been shown to lower healthcare costs to the patient. A recently published study "Guideline Discordance and Patient Cost Responsibility in Medicare Beneficiaries with Metastatic Breast Cancer" by Williams, et.al found median cost for metastatic breast cancer patients receiving guideline-discordant treatment was $7,421 versus $5,171 for those receiving guideline-concordant care. This study found an additional $1,841 in out-of-pocket costs for patients receiving guideline-discordant care versus patients who received guideline-concordant care.

Expanded facilitation of clinical practice guideline adherence through clinical decision support can improve cancer care outcomes, reduce costs to payers and individual patients, reduce administrative burden, improve timeliness of care, and reduce disparities in care.

Objective E: NCCN appreciates the focus on the health care workforce using health IT with confidence outlined in Objective E. The strategy for supporting health care professionals with using health IT as part of their workflows is critical. NCCN would like to emphasize that how providers are able to access health IT data greatly impacts the ability to use the data within clinical workflows. It is important that the data be accessible within the EHR system, and ideally within the clinical workflow context. Moreover, high-value cancer data should be directed towards the provider (i.e. "pushed"), instead of the provider having to search for the data (i.e. "pulled"). Additionally, NCCN agrees with the strategy to leverage health IT expertise from different health care settings, and we hope that this includes sharing successful platforms, structures, and templates to prevent healthcare systems from repeating work already completed elsewhere.

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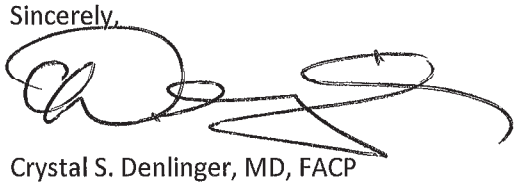
[15] Fang P, He W, Gomez D, Hoffman KE, Smith BD, Giordano SH, Jagsi R, Smith GL. Racial disparities in guideline-concordant cancer care and mortality in the United States. Adv Radiat Oncol. 2018 May 4;3(3):221-229. doi: 10.1016/j.adro.2018.04.013. PMID: 30202793; PMCID: PMC6128037.

[16] Blom EF, Ten Haaf K, Arenberg DA, de Koning HJ. Disparities in Receiving Guideline-Concordant Treatment for Lung Cancer in the United States. Ann Am Thorac Soc. 2020 Feb;17(2):186-194. doi: 10.1513/AnnalsATS.201901-094OC. PMID: 31672025; PMCID: PMC6993802.

[17]. Newcomer LN, Weininger R, Carlson RW. Transforming prior authorization to decision support. Journal of Oncology Practice. 2017;13(1). doi:10.1200/jop.2016.015198.

Thank you, again, for the opportunity to comment on the Draft 2024-2030 Federal Health IT Strategic Plan. NCCN is happy to serve as a resource and looks forward to working together to advance access to equitable, high-quality cancer care.

Sincerely,



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