Translated Tool From NCCN Measures Mental Health “Temperature” of People With Cancer

The NCCN Distress Thermometer has now been translated into 46 languages. This free resource helps providers worldwide identify and address the multifactorial aspects of distress patients with cancer can experience.

NCCN defines “distress” as an unpleasant experience of a mental, physical, social, or spiritual nature that can affect the way people think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment. Using a tool like the NCCN Distress Thermometer normalizes and encourages discussion without any stigma that can cause some patients to avoid talking about psychological or deeply personal issues.

“The NCCN Distress Thermometer acknowledges that undergoing treatment for cancer is distressing for everybody. This simple chart gives patients an easy way to let their doctor know how well they’re coping,” explained Robert W. Carlson, MD, Chief Executive Officer, NCCN. “We’ve found that a score ≥ 4 is an indication for further evaluation and possible intervention. The thermometer includes a corresponding list of problems to help healthcare providers determine if a patient’s distress stems from practical problems, family problems, emotional problems, spiritual/religious concerns, physical problems, or a combination thereof.”

The NCCN Distress Thermometer was first created in 1997 by psycho-oncology pioneer Jimmie C. Holland, MD. The late Dr. Holland was Founding Chair of the NCCN Guidelines Panel for Distress Management and Founding President of the American Psychosocial Oncology Society. Her goal was to make discussion of distress a routine part of oncology patient visits in order to improve both the psychosocial and physical well-being of people with cancer.

“Managing a patient’s emotional distress as well as physical pain is an essential part of medical treatment,” said Dr. Sonali Johnson, Head, Knowledge, Advocacy and Policy, Union for International Cancer Control, the world’s largest international cancer-fighting organization, also behind World Cancer Day held every February 4th. “Patients with cancer are particularly vulnerable to anxiety and depression, as well as stress at work and at home, all of which can affect their recovery and quality of life. The NCCN Distress Thermometer provides patients and caregivers with a valuable tool in addressing the psychological impact of illness.”

The NCCN Distress Thermometer translations are part of ongoing efforts by the NCCN Global Team to make NCCN Guidelines and derivative products more accessible to non-English speakers. More than 100 new translations have published this year alone, including clinical guidelines and patient-friendly versions. NCCN also provides NCCN Framework for Resource Stratification of NCCN Guidelines (NCCN Framework) and NCCN Harmonized Guidelines with optimal recommendations alongside pragmatic approaches to improve treatment in resource-constrained settings, such as low- and middle-income countries. Visit [NCCN.org/global](https://www.nccn.org/global) and join the conversation online with the hashtag #NCCNGlobal.

The translated NCCN Distress Thermometer can be found at [nccn.org/global/international_adaptations.aspx#distress](https://www.nccn.org/global/international_adaptations.aspx#distress). Recently-updated NCCN Guidelines for Patients: Distress are also available at [nccn.org/patients](https://www.nccn.org/patients).

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The NCCN Distress Thermometer provides patients and caregivers with a valuable tool in addressing the psychological impact of illness.

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What People With Cancer and Their Caregivers Need to Know About CAR T-Cell Therapy

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On July 1, 2020, NCCN announced the completion of the new NCCN Guidelines for Patients: Immunotherapy Side Effects series, with the publication of a book focused on CAR T-cell therapy. This closely follows the publication of a separate book on immune checkpoint inhibitors, both created with support from the NCCN Foundation.

"These guidelines explain, organize, and streamline a complex and rapidly evolving concept," said Olalekan Oluwole, MD, Vanderbilt-Ingram Cancer Center, a member of the NCCN Guidelines Panel for Management of Immunotherapy-Related Toxicities. "Traditional chemotherapy treatment affects all cells, and often fails to completely eradicate cancer. It can also leave patients with long-term complications, including other forms of cancer. CAR T-cell therapy is new in that, unlike chemotherapy, it focuses on using qualities of the immune system to target cancer. The targeting is akin to a heat-seeking missile that won't stop until it takes out any cell with the target, leading to potential long-term or permanent remission. CAR T is given one time, unlike chemotherapy, which is given over multiple cycles and could go on for months or years. However, patients are often surprised to learn that the single CAR T infusion includes a 28-day monitoring period during which they need to stay in close proximity to their treatment center."

During that monitoring period, the healthcare team is primarily watching for 2 things: cytokine release syndrome (CRS)—in which immune cells affected by the treatment release proteins called cytokines into the blood, stimulating an intense systemic inflammatory response—and immune effector cell-associated neurotoxicity syndrome (ICANS)—a range of neurological side effects. Both CRS and ICANS are generally reversible if treated promptly.

"Before starting CAR T-cell therapy 2 years ago, my doctor warned me and my wife that it might be a wild rollercoaster ride for a month, but then I would have an excellent chance to be in a long remission," said Brian Koffman, MDCM (retired), MSED, Co-Founder, Executive VP, and Chief Medical Officer, CLL Society, Inc. "The NCCN Guidelines for Patients let people know CAR T-cell therapy is a powerful cell-based treatment capable of offering very durable responses in difficult to treat blood cancers, but in some cases the cancer killing can be so intense that the collateral damage may manifest as frightening symptoms. Fortunately these adverse events tend to be predictable, manageable, and short-term. I told my doctor to 'sign me up,' and I would say that again today."

"CRS can set in rapidly, pushing the patient's body to very high temperatures and taking quite a toll," cautioned Dr. Oluwole. "However, researchers are learning more about how to collaborate to predict toxicities and sharing knowledge on recognizing and treating them more quickly. The new NCCN Guidelines for Patients are yet another example of how we're sharing this important information."

NCCN Guidelines for Patients are based on the NCCN Guidelines used by clinicians worldwide, which have been found to improve the likelihood of successful treatment and longer survival while also reducing costs, according to numerous independent studies. They cover every major type of cancer as well as prevention, supportive care, and specific patient populations. The NCCN Guidelines represent the consensus of a multidisciplinary panel of experts for each cancer type or clinical scenario based on the latest evidence. The NCCN Guidelines for Patients put the clinical recommendations into easy-to-understand

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The NCCN Guidelines for Patients: Immunotherapy Side Effects explain, organize, and streamline a complex and rapidly evolving concept.

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These NCCN Guidelines for Patients are designed to educate patients and to help them recognize immune side effects so that effective interventions can be started promptly.

language alongside illustrations, suggested questions, and a glossary of terms and acronyms.

NCCN Guidelines for Patients are available for free online at [NCCN.org/patients](https://www.nccn.org/patients), or via the NCCN Patient Guides for Cancer App, thanks to funding from the NCCN Foundation. Printed copies are available at [Amazon.com](https://www.amazon.com) for a nominal fee. The immunotherapy patient guidelines have been endorsed by Be The Match/National Marrow Donor Program (NMDP), Good Days, The Leukemia & Lymphoma Society (LLS), and Stupid Cancer.

Visit [NCCN.org/patients](https://www.nccn.org/patients) to learn more or make a donation to the NCCN Foundation in support of these and other comprehensive, frequently-updated resources for people with cancer and their loved ones.

How to Recognize Side-Effects From Immunotherapy? New NCCN Guidelines for Patients Can Help

NCCN has announced the publication of new NCCN Guidelines for Patients: Immunotherapy Side Effects—Immune Checkpoint Inhibitors. Over the past decade, immunotherapy—a treatment that helps the patient’s own immune system recognize and destroy cancer cells—has become an important option for some cancers, and adds to traditional approaches like chemotherapy, radiation, and surgery. Often, immunotherapy is fairly well tolerated. However, emerging research shows immunotherapy can result in different side effects than chemotherapy, including severe adverse events. In fact, researchers have found 43% of patients have stopped treatment with immune checkpoint inhibitors (or ICIs, a common type of immunotherapy), as a result of serious side effects.¹

“These NCCN Guidelines for Patients are designed to educate patients and to help them recognize immune side effects so that effective interventions can be started promptly,” explained Seattle Cancer Care Alliance’s John A. Thompson, MD, Professor of Medicine, University of Washington, Member, Fred Hutchinson Cancer Research Center, and Chair, NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) Panel for Management of Immunotherapy-Related Toxicities. “Immune checkpoint inhibitors have revolutionized our approach to the treatment of cancer. ICIs are now approved by the FDA for treating more than a dozen forms of cancer and the list is growing every year. However, by virtue of stimulating the patient’s immune white blood cells, ICI therapy sometimes causes serious side-effects that mimic autoimmune disease, including significant rash and/or inflammation of the thyroid, liver, lungs, nervous system, glandular system, heart, or other organs.”

NCCN Guidelines for Patients are available for free online at [NCCN.org/patients](https://www.nccn.org/patients), or via the NCCN Patient Guides for Cancer App, thanks to funding from the NCCN Foundation. Printed copies are available at [Amazon.com](https://www.amazon.com) for a nominal fee. The immunotherapy patient guidelines have been endorsed by Be The Match/National Marrow Donor Program (NMDP), Good Days, The Leukemia & Lymphoma Society (LLS), and Stupid Cancer.

“The Leukemia & Lymphoma Society is endorsing these NCCN materials about immunotherapy because we believe that patients should understand all aspects of their care,” said Meredith Barnhart, Director of the Information Resource Center of The Leukemia & Lymphoma Society. “As patients understand more about managing toxicity, they can take better care of themselves

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and be prepared to ask their healthcare team the right questions to increase their quality of life.”

The book stresses that immune-related adverse events can start at any point during or after immunotherapy. Most side effects can be managed effectively if identified and treated early, generally via corticosteroids. The most-common adverse effects are skin disorders. Visit nccn.org/immunotherapyguide for a quick glance at the types of adverse events that may require medical attention.

NCCN will soon add a second patient guideline on another type of immunotherapy: chimeric antigen receptor (CAR) T-cell therapy. NCCN Guidelines for Patients cover all major cancers, including breast, prostate, colon, lung, pancreatic, and many more. The immunotherapy books join other supportive care manuals for cancer-related distress and nausea.

Visit NCCN.org/patients to learn more or make a donation to the NCCN Foundation in support of these and other comprehensive, frequently-updated resources for people with cancer and their loved ones.

Reference

1. Schadendorf D, Wolchok JD, Hodi FS, et al. Efficacy and safety outcomes in patients with advanced melanoma who discontinued treatment with nivolumab and ipilimumab because of adverse events: a pooled analysis of randomized phase II and III trials. *J Clin Oncol* 2017;35:3807–3814.

The Charitable Foundation “Leukemia Foundation,” Supported by the Company Janssen Russia, a Pharmaceutical Product Sub-Division of Johnson & Johnson LLC, Has Provided the First Russian Translation of the NCCN Guidelines for Patients on Treating Multiple Myeloma

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The guideline on multiple myeloma is the first guideline on oncohematologic diseases available in Russian.

When a person is diagnosed with cancer, they immediately start looking for information about their diagnosis. However, it is easy to get lost in the heaps of information out there. Furthermore, not all of this information can be useful, and in fact, some may even be harmful. That is why NCCN is releasing patient guidelines on treating certain types of diseases. At the moment, this is the most reliable and authoritative source of information.

The guideline on multiple myeloma, translated by the Leukemia Foundation in collaboration with the Doctor Laskov’s Oncological Clinic and supported by the company Janssen Russia, a pharmaceutical product sub-division of Johnson & Johnson LLC, is the first guideline on oncohematologic diseases available in Russian. It is designed to help people get a better understanding of the disease with which they have been diagnosed and how to treat it. The guideline on multiple myeloma contains useful information on treatment options that can have the maximum impact. It is based on treatment protocols that are used all over the world. How is the diagnosis made? What are the initial symptoms? How is treatment determined? What kind of monitoring is required during treatment? People diagnosed with multiple myeloma can find the answers to all of these questions in the guideline. This will help them when discussing their diagnosis with their attending physician.

The guideline can be downloaded using the following link:

https://leikozy.net/uploads/files/PAT-N-1109-0519%20MYELOMA%20DIG-ITAL_RU.pdf

or via the NCCN website and app

<https://www.nccn.org/patients/guidelines/content/PDF/myeloma-russian-patient.pdf>

Mikhail Savelyevich Laskov, Oncologist, Hematologist and Director of the Dr. Laskov Clinic:

"Multiple myeloma is a fairly common hematological disease, but its considerably difficult to treat. Treatment includes chemotherapy, targeted therapy, supportive therapy, and bone marrow transplantation. The list of analyses and examinations which need to be performed for multiple myeloma diagnosis is extensive. They include PET and MRI scans, complex blood tests, bone marrow aspiration, and genetic analyses. The approach to diagnosis and treatment of multiple myeloma is so complex that even doctors can struggle. So, can you imagine what it is like for patients? I initiated a project to translate the NCCN's cancer and hematology guidelines 2 years ago and I thank the Leukemia Foundation for their work on this. The guidelines we have translated are the most well written in the world for patients and are produced by the most advanced and widely recognized professional medical association. They allow the patient to keep control over their situation at all times."

Katerina Pogodina, Managing Director of Janssen Russia and the CIS, General Director of Johnson & Johnson LLC:

"Supporting patients is one of the key areas of our work in Russia. The availability of reliable and credible information about the disease and patient awareness helps build a more constructive and trust-based dialogue with doctors, and therefore potentially improves the disease management process as a whole. We were happy to support our partner's project to translate the guidelines from an advanced international medical association on the treatment of multiple myeloma and we very much hope that this project will benefit a large number of patients and their families as well as the professional community."

NCCN Works to Improve Global Cancer Care for Children With Newly Translated Recommendations

NCCN has announced the publication of translated versions of the NCCN Guidelines for Pediatric Acute Lymphoblastic Leukemia (ALL) into Chinese, French, Japanese, Portuguese, and Spanish. Pediatric ALL is the most common type of cancer in children, but is highly curable when treated with contemporary and evidence-based approaches.^{1,2} NCCN Guidelines are written and updated by leading authorities across various health disciplines. They include the most comprehensive and up-to-date recommendations for treating patients, including children, with cancer outside of a clinical trial setting.

"More young lives could be saved through the application of widely-available, evidence-based treatments," said Robert W. Carlson, MD, Chief Executive Officer, NCCN. "Advances in the fight against pediatric ALL have been remarkable in recent years. We can improve the cure rate even further by making sure best practices are reaching every corner of the earth. We get closer

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NCCN has announced the publication of translated versions of the NCCN Guidelines for Pediatric Acute Lymphoblastic Leukemia (ALL) into Chinese, French, Japanese, Portuguese, and Spanish.

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to achieving this goal by making evidence-based, expert consensus-driven NCCN Guidelines more accessible to non-English speakers.”

The English-language version of NCCN Guidelines for Pediatric ALL was first published in May of 2019. The recommendations cover typical treatment algorithms, such as multiagent chemotherapy regimens, as well as emerging innovations in targeted therapy and chimeric antigen receptor (CAR) T-cell therapy, a type of immunotherapy. The guidelines are intended for the management of patients from birth through adolescence and into young adulthood.

“These NCCN Guidelines include a strong focus on supportive care in order to reduce potentially dangerous side-effects for children undergoing treatment,” explained Dr. Carlson. “They also help identify vulnerable populations, such as infants or patients with Down syndrome, and provide specific recommendations for keeping them as safe as possible, both short- and long-term.”

The translated guidelines are available free-of-charge for non-commercial use at [NCCN.org/global](https://www.nccn.org/global) or via the Virtual Library of NCCN Guidelines App.

The NCCN Global Department constantly updates and expands adaptations and translations of NCCN Guidelines for all major cancer types plus supportive care and prevention. More than 40 new translations have published this year alone, including clinical guidelines and patient-friendly versions. NCCN also provides NCCN Framework for Resource Stratification of NCCN Guidelines (NCCN Framework) and NCCN Harmonized Guidelines with optimal recommendations alongside pragmatic approaches for reducing treatment in resource-constrained settings, such as low- and middle-income countries. Visit AlliedAgainstCancer.org to learn about NCCN's ongoing work in Sub-Saharan Africa with the African Cancer Coalition, American Cancer Society, Clinton Health Access Initiative, and IBM.

Free recommendations for self-care and stress management for cancer patients, caregivers, and providers during the COVID-19 pandemic are now available in English, Chinese, and Spanish at [NCCN.org/covid-19](https://www.nccn.org/covid-19).

Visit [NCCN.org/global](https://www.nccn.org/global) for more on everything the organization is doing to improve cancer care worldwide, and join the conversation online with the hashtag #NCCNGlobal.

References

1. Esparza SD, Sakamoto KM. Topics in pediatric leukemia-acute lymphoblastic leukemia. *MedGenMed* 2005;7:23.
2. Ma H, Sun H, Sun X. Survival improvement by decade of patients aged 0-14 years with acute lymphoblastic leukemia: a SEER analysis. *Sci Rep* 2014;4:4227.

NCCN Policy Summit Explores 21st Century Cures Act and the Impact of Health Information Technology

On June 10, 2020, NCCN hosted a Virtual NCCN Policy Summit titled Accelerating Advances in Cancer Care Research: A Lookback at the 21st Century Cures Act in 2020. The program included a conversation between the bipartisan sponsors of the landmark legislation, Representatives Diana DeGette (D-CO) and Fred Upton (R-MI), who discussed their plans for Cures 2.0. Amy Abernethy, MD, PhD, Principal Deputy Commissioner of Food and Drugs, FDA, held a fireside chat on clinical trials, data, and how real world evidence is changing the research landscape. Don Rucker, MD, MBA, MS, National Coordinator for Health Information Technology, Office of the National Coordinator for Health IT (ONC) spoke about increasing the use of electronic medical records.

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The Office of the National Coordinator for Health Information Technology’s 21st Century Cures Act Final Rule will give patients unprecedented access and control over their medical records.

"The Office of the National Coordinator for Health Information Technology's 21st Century Cures Act Final Rule will give patients unprecedented access and control over their medical records," said Dr. Rucker. "For patients and caregivers affected by cancer, the rule, when fully implemented, will improve care coordination by allowing patients to aggregate and share records across clinicians, increasing a patient's agency to take their records and seek further opinion. The rule will also allow new opportunities for patients to participate in clinical trials and contribute data to researchers working on new treatments and cures."

The need for improving patient access to medical records was also a key theme for the panel discussion moderated by Clifford Goodman, PhD, Senior Vice President of The Lewin Group and featuring Jenny Ahlstrom, Founder, CrowdCare Foundation and Multiple Myeloma Patient; Clay Alspach, JD, Principal, Leavitt Partners; Anobel Odisho, MD, MPH, Urologist, UCSF Helen Diller Family Comprehensive Cancer Center and Clinical Informatics Lead, UCSF Center for Digital Health Innovation; and Susan Stiles, MHA, MBA, Executive, Oncology Business Unit, Cerner Corporation.

"Today, it takes an extraordinary effort for patients to access their records at multiple facilities in order to share it so it is correlative with other patients and relevant for research," explained Ahlstrom. "Our current process and lack of data makes it difficult for patients to make life and death decisions around their care. Easing this process will enable the generation of faster new hypotheses from the research community which will in turn save patient lives. Many forget that patients are not just data sets, they can and should be active participants in this interoperability process."

The speakers examined the impact of the ongoing COVID-19 pandemic on medicine as a whole and cancer care in particular. They discussed how the 21st Century Cures Act laid groundwork that can be helpful in the global fight against the pandemic, and also looked at new lessons to be taken from the fight against COVID-19 and applied toward improving cancer care in the future.

"The dramatic and rapid uptake of telehealth has shown great promise for patient care but also exposed deficiencies in the existing software solutions for providing remote care," said Dr. Odisho. "Providers have been able to transition to video visits and telehealth, but the field is immature and there are significant opportunities to improve the quality of care and efficiency of care delivery. Now that the Cures Act rule has been finalized, allowing patients to access their own data, provisions against information blocking, and clear timelines, health information technology (HIT) developers are empowered to develop solutions for improving remote patient care—such as video visits, automated workflows, and asynchronous virtual care. We will have to keep a close on eye on utilization of information blocking exemptions to ensure they are having the intended effect and are not being exploited outside of the intended scope."

The summit also included a presentation by Jeff Allen, PhD, President & CEO, Friends of Cancer Research and Ronald S. Walters, MD, MBA, MHA, MS, NCCN Board Chair & Breast Medical Oncologist, The University of Texas MD Anderson Cancer Center. Drs. Allen and Walters presented recommendations for future policy improvements according to an NCCN working group of multi-disciplinary experts from across the country. The group's recommendations include:

- Provide robust, sustained, and predictable annual funding increases to guarantee continued clinical advancements and clinical trial success
- Encourage increased interagency collaboration and communication to enhance the oncology product approval process and benefit future coverage processes

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The dramatic and rapid uptake of telehealth has shown great promise for patient care but also exposed deficiencies in the existing software solutions for providing remote care.

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- Establish parameters for the use of real-world data including patient reported outcomes, post-market analysis and the representation of diverse population groups to leverage the use of real-world evidence
- Encourage and incentivize widespread patient participation in clinical trials to increase diverse study populations
- Build upon the regulations of the Office of the National Coordinator for Health Information Technology to expand available standardized data elements in a manner that is actionable to the patient and the provider
- Promote policies and reimbursement mechanisms that support interoperability and encourage the aggregation of patient data that will promote shared decision-making and increase understanding between patients, providers, and payers
- Maintain and increase advancements made during the COVID-19 pandemic to enhance patient access to telehealth services and increase access to tumor boards to improve patient care

For more information and background on these policy recommendations, plus a look at upcoming NCCN Policy Summits, visit [NCCN.org/policy](https://www.nccn.org/policy). Join the conversation online with the hashtag #NCCNPolicy.

ERRATUM

Erratum to: Nipp et al. Pilot Randomized Trial of a Transdisciplinary Geriatric and Palliative Care Intervention for Older Adults With Cancer. *J Natl Compr Canc Netw* 2020;18(5):591–598.

In the May 2020 issue of *JNCCN*, the article by Nipp et al (*J Natl Compr Canc Netw* 2020;18[5]:591–598; doi: 10.6004/jnccn.2019.7386) was published with an error.

The name of one of the authors, Ardeshir Z. Hashmi, MD, was inadvertently omitted. Dr. Hashmi's affiliation is Department of Internal Medicine and Geriatrics, Cleveland Clinic, Cleveland, Ohio.

This has been corrected online. The authors apologize for the error.

doi: 10.6004/jnccn.2020.0041