



American Society for
Transplantation and Cellular Therapy

May 5, 2023

National Center for Health Statistics (NCHS)
ICD-10 Coordination & Maintenance Committee
Via email to: nchsicd10CM@cdc.gov

Re: ASTCT comments on the March 7-8, 2023 ICD-10-CM diagnosis coding meeting

Dear Ms. Pickett, Ms. Bullock, and NCHS staff:

The American Society for Transplantation and Cellular Therapy (ASTCT) is a professional membership association of more than 3,000 physicians, scientists, and other healthcare professionals who promote blood and marrow transplantation and cellular therapy through research, scholarly publication, and clinical standards. We are dedicated to improving the application and success of hematopoietic cell transplants (HCT) and cellular therapies such as Chimeric Antigen Receptor T-Cell (CAR-T) therapy. Ensuring that appropriate diagnosis codes are available to accurately capture HCT and other types of cell therapies and their related complications is important to us for both clinical and research purposes.

As the field of hematology, stem cell transplantation, and cell and gene therapy continues to advance, so too does the need for additional codes to capture associated diagnoses. The information gained from several of the new code requests will be important to clinicians treating patients; the broader medical field; researchers pioneering new therapies; analysts; and other stakeholders.

As a result, we urge the NCHS to finalize several coding proposals discussed during the March 8-9, 2023 ICD-10 Coordination & Maintenance (C&M) Committee meeting on diagnosis coding: those for new codes for Fanconi anemia, lymphoma in remission, and primary central nervous system lymphoma. We also request that the C&M Committee consider holding a dedicated stakeholder meeting to obtain input on how best to incorporate new codes for genetic disorders involving specific genetic variants into the framework of the ICD-10-CM diagnosis coding system.

- **New diagnosis code request for Fanconi anemia**

The ASTCT supports the coding proposal to create a new diagnosis code, D61.02, for Fanconi anemia. Patients with Fanconi anemia have a high rate of bone marrow failure and increased risk for hematologic malignancies, and thus may receive hematopoietic stem cell transplants. A new diagnosis code for this specific disorder (and the corresponding tabular and index modifications) will be useful to track these patients and conduct future research.

- **New diagnosis codes request for lymphoma in remission**

The ASTCT supports the coding proposal to create new diagnosis codes for lymphoma in remission. Patients with hematologic malignancies may be treated with stem cell transplant or cellular therapies and go into remission. It would be useful to have codes to indicate this status of the patient in remission for patient tracking, and research.



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- **New diagnosis codes request for primary central nervous system lymphoma**

The ASTCT also supports the other lymphoma-related proposal for new codes that was discussed at the March, 9 2023 ICD-10 C&M Committee meeting. The creation of new codes for primary central nervous system lymphoma will add to ICD-10-CM additional detail on a type of lymphoma that existed previously in ICD-9, and will allow for more granularity in tracking, and research, including for patient outcomes for this type of lymphoma.

- **NCHS should engage stakeholders about genetic disorders coding involving the creation of specific genetic variant codes**

The March 8-9, 2023 meeting agenda contained an unusually high number of proposals for genetic disorders that included requests for multiple new codes with genetic variant-level information. The NCHS indicated in verbal comments during the course of the meeting that it was considering multiple options for how to create new codes and approach future requests that involved the creation of specific codes for genetic variants.

Given the importance of any framework adopted by the NCHS and the ICD-10 C&M Committee for genetic disorders diagnosis coding, the ASTCT asks the Committee to consider holding a separate session to engage stakeholders further on this topic. We think that focused discussion on this topic is warranted, given the applicability of any framework across body systems and disease types.

We also think a separate discussion of the issue is important, given the need to achieve balance between granularity in the code set that allows the capture of specific diagnoses for genetic disorders, the need to avoid a rapid expansion of the code set, and to ensure the useability and reportability of specific codes by coding professionals. A separate discussion would allow for time for stakeholders to dialogue on the level of granularity necessary and provide feedback on the degree of genetic variant information that is necessary to distinguish different diagnoses that may involve different tracking, monitoring, and treatment decisions for patients.

The ASTCT thanks the NCHS for the opportunity to present these comments and if you have questions, please contact: Alycia Maloney, Director of Government Relations for the ASTCT at (202) 367-1254 or amaloney@astct.org.

Sincerely,

A handwritten signature in blue ink, appearing to read "M. A. P." followed by a horizontal line.

Miguel-Angel Perales, MD

ASTCT President

Chief, Adult Bone Marrow Transplantation Service

Attending Physician and Member

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