December 14, 2018

American Society for Blood and Marrow Transplantation
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American Society of Hematology
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National Center for Health Statistics
ICD-10 Coordination and Maintenance Committee
Via email to nchsicd10cm@cdc.gov, Patricia.Brooks2@cms.hhs.gov, and Marilu.Hue@cms.hhs.gov

Re: Coding request for Cytokine Release Syndrome and Neurotoxicity codes

Ms. Brooks and Ms. Hue:

The American Society for Blood and Marrow Transplantation (ASBMT) and the American Society of Hematology (ASH) write to you today in support of the Alliance of Dedicated Cancer Centers’ (ADCC) coding request to add Cytokine Release Syndrome (CRS) and CAR-related encephalopathy syndrome (CRES) to the ICD-10 code set. CRS and CRES are both common side effects of chimeric antigen receptor T-cell (CAR-T) therapy and it is critical that providers who deliver this therapy have precise codes available to reflect these adverse advents.

The ASBMT is a professional membership association of more than 2,200 physicians, scientists, and other healthcare professionals promoting blood and marrow transplantation and cellular therapy through research, education, scholarly publication and clinical standards. The ASBMT is dedicated to improving the application and success of hematopoietic cell transplants (HCT) and other cellular therapies, such as CAR-T.

ASH represents more than 17,000 clinicians and scientists worldwide who are committed to the study and treatment of blood and blood-related diseases. These disorders encompass malignant hematologic disorders such as leukemia, lymphoma, and multiple myeloma, as well as non-malignant conditions such as sickle cell anemia, thalassemia, bone marrow failure, venous thromboembolism, and hemophilia. In addition, hematologists are pioneers in demonstrating the potential of treating various hematologic diseases and continue to be innovators in the field of stem cell biology, regenerative medicine, transfusion medicine, and gene therapy. ASH membership is comprised of basic, translational, and clinical scientists, as well as physicians providing care to patients in diverse settings including teaching and community hospitals, as well as private practice.
The ASBMT and ASH (the Societies) have been working in conjunction on issues related to CAR-T therapy as our joint membership community of hematologists and blood and marrow transplant physicians are the providers primarily administering CAR-T therapies.

The ASBMT undertook several initiatives in 2017 which were focused on understanding the coding options for use with Chimeric Antigen Receptor T-cell therapy (CAR-T), a type of immunotherapy for which two products were recently approved (Kymriah® and Yescarta®) for certain types of hematologic malignancies. While most of our members currently consider the inpatient setting to be most clinically appropriate for the average patient, due to the likelihood of adverse events occurring in the days post-infusions, a significant portion of CAR-T cases are expected to transition to the outpatient setting over time as refinements are made to products and clinical protocols aiming to predict and mitigate post-infusion complications. In 2018, the ASBMT submitted a letter of support for the creation of new codes for Cytokine Release Syndrome (CRS) and Neurotoxicity related to cellular therapy. As discussed in this previous letter, the absence of CRS and Neurotoxicity codes prevents a clear process for identifying patients who have experienced complications of cellular therapy. ASH joins ASBMT in support for adding new codes; we urge the ICD-10 Coordination & Maintenance Committee to take action to create new codes to support complications of cellular therapy for the FY 2020 code set update. In addition, we ask the Committee to release a new status code that allows code capture of patients seen in the outpatient setting post CAR-T therapy, so they can be tracked. This would be status post-cellular therapy code not unlike the existing status post-transplant code.

We understand the ADCC, an organization representing 11 Cancer institutions across the country has submitted a proposal for codes to support complications of cellular therapy. We applaud the ADCC for dedicating the time and resources of its expert coders to research and analyze the code structure needed. The ADCC shared with the Societies the two options they are proposing for the Committee’s consideration around complications of cellular therapy. We understand the Committee will review the ADCC’s proposal along with any others received prior to the March 2019 meeting. The Committee should be aware that clinicians are working across institutions to finalize a grading scale that scores the various complications that can occur, and it is for this reason that an array of codes will be needed to capture the various types and levels of complications that are expected.

Additionally, we understand the ADCC has submitted a proposal for status post cellular therapy codes within Chapter 21 of the ICD-10-CM code set. The Societies recognize that a request for new codes describing different combinations of current codes is a complex undertaking and one that is likely beyond our level of expertise. Therefore, we are providing our strong support to the ADCC’s coding proposal seeking both complications of cellular therapy and the status post cellular therapy codes. Their coding professionals have engaged in the due diligence required and are proposing clear and viable options for your consideration. We ask that the ICD-10 Coordination & Maintenance Committee move forward in the FY 2020 ICD-10-CM update to include complications of and status post cellular therapy codes. The Societies would be happy to engage with the Committee and share expertise and opinions as requested.

For questions related to this letter, please contact:
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Sincerely,

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