Appendix F
Non-Reportable List for Hematopoietic Diseases

DISCLAIMER: If there are terms that you feel should be on this list, please send your question to Ask a SEER Registrar**.**

The following are non reportable terms that are similar to reportable Hematopoietic neoplasms. These terms have been received in Ask a SEER Registrar. This list was provided at the 2013 SEER Workshop. We have decided to include this list as part of the manual. The terms on this list are not reportable to national standard setters (NPCR, SEER, CoC) but may be required by your central registry or cancer committee.

Non-Reportable Term	Comments
Amyloidosis [by itself] • Primary amyloidosis	Disorder in which abnormal proteins build up in tissue and organs. Clumps of the abnormal proteins are called amyloid deposits and may be treated with chemotherapy.
Anemia • Anemia of chronic disorders • Hemolytic anemia	Decrease in the number of red blood cells.
Anemia in neoplastic disease	This phrase is used to indicate anemia which has been caused by neoplasm. This diagnosis of anemia by itself is not reportable, but "anemia in neoplastic process" indicates there is an underlying neoplasm. This is the code description for ICD-9-CM code 285.22
Angiocentric immunoproliferative lesion (AIL) • Lymphomatoid/lymphoid granulomatosis	Non reportable condition listed in ICD-O-3 with code 9766/1.
Angioimmunoblastic lymphadenopathy	Non reportable condition listed in ICD-O-3 with code 9767/1.
Aplastic anemia	Blood disorder where bone marrow doesn't make enough new blood cells.
Autoimmune hemolytic anemia	Group of immune system disorders in which autoantibodies are produced
Castleman's disease [by itself]	Must be Castleman's disease **associated** with a lymphoma to be reportable.
Chemotherapeutic atypia	Condition caused by chemotherapeutic agents.
Chronic thrombocytosis	Persistent thrombocytosis. See thrombocytosis, NOS.
Common variable immunodeficiency	Also known as "acquired hypogammaglobulinemia." This represents a group of approximately 150 primary immunodeficiencies which have a common set of symptoms but different underlying causes, both benign and malignant. This would not be reportable unless the immunodeficiency diagnosis is accompanied by a diagnosis of a cancer or a reportable hematopoietic or lymphoid neoplasm.
Erythrocytosis [by itself]	Must state "erythrocytosis megalosplenic" to be reportable (9950/3).
Evolving myelodysplasia/evolving leukemia	These are not reportable. Only evolving myeloma is reportable.
Familial polycythemia/Familial polycythemia vera	This is a benign clinical course except for the complications of excess red blood cells. There are some instances where polycythemia vera occurs in families, which has resulted in the familial polycythemia. For the polycythemia to be reportable, it still has to meet the usual requirements for the diagnosis of polycythemia vera.
Graft versus Host disease (GVHD)	Complication of stem cell or bone marrow transplant where the transplanted donor cells

Non-Reportable Term	Comments
	attack the recipient's body.
Hemophagocytic lymphohistiocytosis • Hemophagocytic syndrome	Caused by an over stimulated immune system (infection, etc.) Clinical syndrome associated with a variety of underlying conditions. To be reportable, it must state "fulminant hemophagocytic syndrome" (in a child) to be reportable (9724/3).
Hypogammaglobulinemia • Acquired • Common Variable Immunodeficiency (CVID)	Immune deficiency disorder caused by lack of B-lymphocytes and results in a low level of immunoglobulin.
Idiopathic refractory anemia	Cause of refractory anemia is not known.
Idiopathic thrombocytopenic purpura (ITP)	Isolated low platelet count (thrombocytopenia) with normal bone marrow.
Immunoglobulin deposition disease • Heavy chain • Monoclonal • Primary amyloidosis • Systemic light chain disease	Non reportable condition listed in ICD-O-3 with code 9769/1.
Iron-refractory iron deficiency anemia (IRIDA)	This is an autosomal recessive disorder.
Light chain deposition disease	Blood cell disease characterized by deposits of immunoglobulins which deposit in organs and cause damage.
Lymphocytosis	Without further specification, means an increase of lymphocytes, which may occur for several reasons, but does not indicate a leukemic process without further data. Lymphocytosis by itself is not reportable.
Macrocytic anemia	Anemia refers to a condition having a low count of red blood cells. The term "macrocytic" refers to the enlarged size of the red blood cells. Macrocytic anemia is usually caused by vitamin deficiencies, alcohol use, medications or thyroid disorders.
Mast Cell Activation Syndrome (MCAS)	Group of disorders based on complex of symptoms with no increase in mast cells. Not part of the systemic mastocytosis/mast cell leukemia/mast cell sarcoma spectrum.
Mastocytosis	Not stated as malignant or systemic.
Myelofibrosis [by itself] • Secondary myelofibrosis	Must state "primary myelofibrosis" to be reportable.
Monoclonal gammopathy of undetermined significance (MGUS)	Non reportable condition listed in ICD-O-3 with code 9765/1.
Monoclonal B lymphocytosis of uncertain significance (MLUS)	MLUS (or MBL) is associated with CLL and in some patients is a precursor to CLL. Not all patients with MLUS will develop CLL.
Myelodysplasia	The term myelodysplasia covers a group of disorders that result in the inability to produce enough healthy mature blood cells. Those disorders include: Anemia, leukopenia, thrombocytopenia, MDS, refractory anemia, refractory anemia with excess blasts in transformation, refractory anemia with ring sideroblasts, refractory anemia with excess blasts, chronic myelomonocytic leukemia, acute myeloid leukemia.
Plasma cell dyscrasia	Diverse group of neoplastic diseases involving proliferation of a single clone of cells. Patient usually has plasma cell morphology, such as multiple myeloma/heavy chain

Non-Reportable Term	Comments
	disease. Do not report unless there appears to be a reportable diagnosis. Plasma cell dyscrasia (PCD) (9765/1) is not reportable.
Plasma cell neoplasm	According to WHO, 'Plasma cell neoplasms' is the umbrella term that includes MGUS, plasma cell myeloma, solitary plasmacytoma of bone, immunoglobulin deposition diseases, extraosseous plasmacytoma, and osteosclerotic myeloma. Of these, only plasma cell myeloma, solitary plasmacytoma of bone, and extraosseous plasmacytoma are reportable. Note: This terminology was added to the 2012 Hematopoietic Manual and Database for 1/1/2012. This should not have been added. If the only diagnosis is "plasma cell neoplasm," this would not be reportable. If the diagnosis is "plasma cell neoplasm c/w multiple myeloma (or another reportable disease)", then that would be a reportable disease.
Plasmablastic hyperplasia	Non reportable condition listed in ICD-O-3 with code 9971/1.
POEMS (Polyneuropathy, organomegaly, endocrinopathy, monoclonal gammopathy and skin)	POEMS by itself is not reportable. It is associated with myeloproliferative disorders, not all of which are reportable (e.g. MGUS). Can be associated with multiple myeloma.
Polycythemia [by itself] including: • Idiopathic • NOS • Secondary • Secondary to volume depletion	Polycythemia (also known as polycythemia or erythrocytosis) is a disease state in which the proportion of blood volume that is occupied by red blood cells increases. Blood volume proportions can be measured as hematocrit level. It can be due to an increase in the mass of red blood cells; "absolute polycythemia"; or to a decrease in the volume of plasma ("relative polycythemia"). Other non reportable terms include: idiopathic polycythemia, secondary polycythemia and polycythemia secondary to volume depletion. To be reportable the diagnosis must be polycythemia vera, or some of the other alternate names listed in the Hematopoietic database.
Reactive lymphoid hyperplasia	Enlargement of lymphoid tissue secondary to antigen stimulus.
Refractory iron deficiency anemia	Condition of iron deficiency anemia which is unresponsive to oral iron treatment
Serum hyperviscosity syndrome	Hyperviscosity refers to increased viscosity of the blood. This syndrome results from increased immunoglobulins in the blood. Can also occur with leukemia, polycythemia vera and thrombocythemia.
T-gamma lymphoproliferative disease	Non reportable condition listed in ICD-O-3 with code 9768/1.
Thrombocythemia	Presence of high platelet counts in the blood. See thrombocytosis, NOS.
Thrombocytopenia [by itself] including: • Essential thrombocytopenia • Autoimmune thrombocytopenia • Thrombocytopenia of unknown etiology	Decreased number of platelets in the blood
Thrombocytosis, NOS [by itself] including: • Reactive thrombocytosis • Secondary thrombocytosis	Presence of high platelet counts in the blood. Can be primary (also known as essential thrombocytosis which is reportable) or secondary (which is not reportable)

References

Fritz, A. G. (2000). *International classification of diseases for oncology: ICD-O* (3rd ed.). Geneva: World Health Organization.

National Cancer Institute at the National Institutes of Health. (2013). *PDQ - NCI's comprehensive cancer database*. Retrieved from http://www.cancer.gov/cancertopics/pdq/cancerdatabase

Swerdlow, S. H., Campo, E., Harris, N. L., Jaffe, E. S., Pileri, S. A., Stein, H., Thiele, J., & Vardiman, J. W. (Eds.). (2008). *WHO classification of tumours of haematopoietic and lymphoid tissues* (4th ed.). Lyon, France: International Agency for Research on Cancer.