#### NEBRASKA HEALTH AND HUMAN SERVICES REGULATION AND LICENSURE

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TITLE 186 HEALTH REGISTRIES AND RELEASE OF INFORMATION

CHAPTER 1 CANCER REGISTRY

1-001 SCOPE AND AUTHORITY: The purpose of the cancer registry is to provide a central data bank of accurate, precise, and current information which may be used to achieve the goals of prevention, cure, and control of cancer through research and education. These regulations apply to each hospital or health practitioner within the State of Nebraska. The regulations implement the laws governing the establishment and maintenance of a registry that includes records of cases of cancer and benign brain-related tumors diagnosed or treated within the state and such information that the Department determines necessary and appropriate for the prevention, cure, and control of cancer. The regulations set forth procedures for the reporting by hospitals and health practitioners of data concerning such cases to the Department and providing procedures and standards for governing access to registry data, pursuant to Neb. Rev. Stat. §§ 81-642 to 81-650.

#### 1-002 DEFINITIONS:

#### Cancer means:

- 1. A large group of diseases characterized by an uncontrolled growth and spread of abnormal cells;
- 2. Any condition of tumors having the properties of anaplasia, invasion, and metastasis;
- 3. A cellular tumor the natural course of which is fatal; and
- 4. Malignant neoplasm.

Cancer shall be deemed to include, but not be limited to, carcinoma, sarcoma, melanoma, lymphoma, Hodgkin's disease, and myeloma, but shall not include precancerous conditions, benign polyps, or benign tumors.

<u>Cancer Registry</u> means the system of reporting established by <u>Neb. Rev. Stat.</u> §§ 81-642 to 81-650 in which the cases of cancer in this state are reported and recorded in order to achieve the goals of prevention, cure, and control of cancer through research and education.

<u>Department</u> means the Nebraska Department of Health and Human Services Regulation and Licensure.

<u>Diseases Reportable to the Cancer Registry</u> includes all cancers as defined above and, beginning January 1, 2004, all benign brain-related tumors.

<u>Health Practitioner</u> means an individual licensed to practice medicine and surgery pursuant to <u>Neb. Rev. Stat.</u> §§ 71-1,102 to 71-1,107.04; to practice osteopathic medicine and surgery pursuant to

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Neb. Rev. Stat. §§ 71-1,137 to 71-1,141 and to practice dentistry pursuant to Neb. Rev. Stat. §§ 71-183 to 71-193.35.

<u>Initial Diagnosis</u> means the recognition of cancer in a patient by a health practitioner, medical examiner, facility, or coroner.

<u>Proper Identification</u> means driver's license or other identification containing photograph, name and signature, and a written statement from the Department that such person is an authorized representative of the Department.

<u>1-003 DATA REQUIREMENTS:</u> Attachment 1 incorporated by this reference lists the data elements that must be provided for each reportable disease.

<u>1-004 HOSPITAL REPORTING REQUIREMENTS:</u> The following are the reporting requirements for hospitals within the State of Nebraska.

<u>1-004.01</u> Each hospital within the State of Nebraska that initially diagnoses more than 50 cancer cases in a calendar year must:

- 1. Submit the data specified in 186 NAC 1-003 Attachment 1;
- 2. Submit data on disk or in encrypted electronic form in a manner specified by the Department;
- 3. Report data on an ongoing monthly basis, within six months from the date of initial diagnosis;
- 4. Report supplemental and follow-up data on previously reported cases on the next reporting period following receipt of the data.

<u>1-004.02</u> Each hospital within the State of Nebraska that initially diagnoses less than 50 cancer cases in a calendar year will make available:

- 1. The data specified in Attachment 1, in the manner prescribed in 186 NAC 1-004.01, or
- A list of the names of patients diagnosed with cancer, corresponding medical record numbers, and medical records which document the diagnosis and treatment of cancer; or
- 3. On an abstract form which contains the information set forth in the Attachment 1.

<u>1-005 HEALTH PRACTITIONER REPORTING:</u> Health practitioners within the state must produce and make available to the Department or its authorized representative, upon the request of the Department or its authorized representative, and upon presentation of proper identification by the Department's representative, data from each medical record of cancer or benign brain-related tumor

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under the health practitioner's custody or control. The data must be submitted as set out in 186 NAC 1-004.01 and 1-004.02.

1-006 CONFIDENTIALITY AND RELEASE OF INFORMATION: All data obtained from medical records of individual patients is for the confidential use of the Department and private or public person or entities that the Department determines may view these records in order to carry out the intent of Neb. Rev. Stat. §§ 81-642 to 81-650. The information will be privileged and will not otherwise be divulged or made public so as to disclose the identity of an individual whose medical records have been used for acquiring data.

<u>1-006.01</u> The Department may approve individuals or entities who submit written application to obtain access to case-specific data or case-specific and patient-identifying data to assist in their research for the prevention, cure and control of cancer. These individuals or entities must show that the applicant is a qualified researcher, that the data requested will be used for bona fide scientific or medical research for prevention, cure or control of cancer, and that the applicant will maintain the confidentiality and security of the data obtained. The application must contain, but is not limited to the following information:

- 1. Applicant's name and address;
- 2. The name of the entity, if any, which the applicant represents, its address and a brief description of the entity;
- 3. Name and address of the principal investigator, if other than the applicant;
- 4. The qualifications of the applicant and of the principal investigator, if other than the applicant, including education, experience, prior publications, and recommendations of professional colleagues who have knowledge and experience of scientific or medical research;
- 5. The purpose of the research project, a summary of the project and the anticipated time of the completion of such project;
- 6. The location where the research project will be conducted and the equipment, personnel, and other resources available to the applicant to carry out the projects:
- 7. The identity of the individual or entity funding the research project, a description of the availability of funds for the research project and any conditions of the receipt or continuation of such funding;
- 8. The specific data requested and a description of the use to be made of such data and, if patient-identifying data is requested, a substantiation of the need for access to the patient-identifying data;
- 9. A description of the measures to be taken to secure the data and maintain the confidentiality of the data during the research project, for disposal of the data

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upon completion of the study and to assure that the results of the study will not divulge or make public information that will disclose the identity of any individual. If contact with patient or patient's family is planned, approved researcher must substantiate the need for the contact and describe the methods to be used to obtain permission from the patient or patient's family for the contact.

- Additional information as the Department determines to be necessary to assure that release of data to the applicant is appropriate and will further the purposes of Neb. Rev. Stat. §§ 81-642 to 81-650.
- <u>1-006.02</u> Any de-identified data (other than Class III data) asked for by and furnished to a researcher may not be intentionally re-identified in any manner. Should a recipient of de-identified information unintentionally or accidentally be able to identify any individual they must not use that information in any way. The recipient must also notify the Department of the means of accidental re-identification in order for the Department to consider additional procedures to safeguard against breaches in confidentiality.
- <u>1-006.03</u> The cost of data retrieved and data processing will be paid by the researchers and private or public entities or individuals requesting data from the cancer registry.
- 1-007 SUBMISSION OF REPORTS: The approved researcher must submit the reports or results of the research project to the Department at no cost. The Department reviews the reports or results and prohibits publication of confidential information or patient-identifying data. A person or entity must acknowledge the Department and its cancer registry in any publication in which information obtained through the registry is used.
- 1-008 RELEASE OF DATA TO GOVERNMENTAL HEALTH AGENCIES: Data contained in the cancer registry may be released to local health departments in Nebraska, the Centers for Disease Control and the National Cancer Institute upon written application and compliance with the provisions of Neb. Rev. Stat. §§ 81-663 to 81-675 and 186 NAC 1.
- <u>1-009 PATIENT CONTACT PROVISIONS:</u> No person who seeks information or obtains registry data pursuant to this regulation will contact a patient on the registry or the patient's family unless the registry has first obtained the permission of the patient or patient's family. The registry will coordinate its activities with the person desiring the contact and may authorize the person desiring the contact to perform these contacts under the direction of the registry.

# DATA ITEMS REQUIRED BY THE NEBRASKA CANCER REGISTRY FROM CANCER REPORTING SOURCES

The following table presents data required by the Nebraska Cancer Registry along with Version 10 of the NAACCR required status table summarizing the requirements and recommendations for collection of each item by standard-setting groups.

The following abbreviations and symbols are used in the table:

NAACCR committees are reviewing and will make Recommendations in

Version 10.1.

**NPCR** Refers to requirements and recommendations of the NPCR regarding data

items that should be collected or computed by NPCR state registries.

Note: Personal identifying data items that are collected are not transmitted to

CDC.

**COC** Refers to requirements of the COC. Facilities should refer to the COC FORDS

Manual for further clarification of required fields.

**SEER** Refers to requirements of NCI's SEER Program. Facilities and central

registries should refer to the SEER Program Code Manual for further

clarification of required fields.

Codes for Recommendations: R = Required. RH = Historically collected and currently transmitted. <math>S = Supplementary/ recommended. D = Derived.  $\bullet = Not$  in dataset but available. \* = When available. # = Central registries may code available data using either the SEER or COC data item and associated rules.  $^{\wedge} = These$  text requirements may be met with one or several text block fields.

Item#	Item Name	Provider Required	NCR Required	NPCR	Source of Standard
10	Record Type		R	•	NAACCR
20	Patient Identification Number		R	R	Reporting Registry
30	Registry Type		R	•	NAACCR
35	Federal Identification Number Coding System		R	S	NAACCR
40	Registry Identification		R	S	NAACCR
50	NAACCR Record Version		R	R	NAACCR
70	Address at Diagnosis–City	R	R	R	COC
80	Address at Diagnosis–State	R	R	R	NAACCR
90	County at Diagnosis	R	R	R	FIPS/SEER
100	Address at Diagnosis–Postal Code	R	R	R	NAACCR
110	Census Tract 1970/80/90		R	RH	SEER
120	Census Coding System 1970/80/90		R	RH	SEER
130	Census Tract 2000		R	R	SEER
150	Marital Status at Diagnosis	R	R	S	SEER
160	Race 1	R	R	R	SEER/COC
161	Race 2	R	R	R	SEER/COC
162	Race 3	R	R	R	SEER/COC
163	Race 4	R	R	R	SEER/COC
164	Race 5	R	R	R	SEER/COC
170	Race Coding System–Current	R	R	•	NAACCR
180	Race Coding System—Original	R	R	•	NAACCR
190	Spanish/Hispanic Origin	R	R	R	SEER/COC
220	Sex	R	R	R	SEER/COC
230	Age at Diagnosis	R	R	R	SEER/COC
240	Birth Date	R	R	R	SEER/COC
250	Birthplace	R	R	R*	SEER/COC
260	Religion	*	*	•	Varies
270	Occupation Code–Census		R	S	Census/NPCR
280	Industry Code–Census		R	S	Census/NPCR
290	Occupation Source		R	S	NPCR
	Industry Source		R	S	NPCR
300 310	Text–Usual Occupation	*	R*	R*	NPCR NPCR
	*	*			
320	Text–Usual Industry	*	R*	R*	NPCR NPCR
330	Occupation/Industry Coding System	*	R *	S	
340	Tobacco History	*	*	•	Varies
350	Alcohol History	*	*	•	Varies
360	Family History of Cancer	*	*	•	Varies
362	Census Tract Block Group			•	Census
364	Census Tract Certainty 1970/80/90		R	RH	SEER
365	Census Tract Certainty 2000		R	R	SEER
380	Sequence Number-Central		R	R	NAACCR
390	Date of Diagnosis	R	R	R	SEER/COC
400	Primary Site	R	R	R	SEER/COC
410	Laterality	R	R	R	SEER/COC
419	Morphology-Type & Behavior ICD-O-2	RH	RH		
420	Histology (92-00) ICD-O-2	RH	RH	RH	SEER/COC
430	Behavior (92-00) ICD-O-2	RH	RH	RH	SEER/COC
440	Grade	R	R	R	SEER/COC
450	Site Coding System–Current	R	R	S	NAACCR
460	Site Coding System–Original	R	R	•	NAACCR
470	Morphology Coding System–Current	R	R	S	NAACCR
480	Morphology Coding System–Original	R	R	•	NAACCR

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Item#	Item Name	Provider Required	NCR Required	NPCR	Source of Standard
490	Diagnostic Confirmation	•	R		SEER/COC
500	Type of Reporting Source	R R	R	R R	SEER/COC
521	Morphology—Type&Behavior ICD-O-3	R	R	K	SEEK
522	Histologic Type ICD-O-3	R	R	R	SEER/COC
523	Behavior Code ICD-O-3	R	R	R	SEER/COC
540	Reporting Hospital	R	R	S	COC
550	Accession Number–Hospital	R	R	S	COC
560	Sequence Number–Hospital	R	R	S	COC
570	Abstracted By	R	R	•	COC
580	Date of 1st Contact	R	R	R	NAACCR
610	Class of Case	R	R	S	COC
620	Year First Seen This Cancer	*	*	•	COC
630	Primary Payer at Diagnosis	R	R	•	COC
670	Treatment Hospital–Surgery Primary Site	R	R	•	COC
672	Treatment Hospital–Scope Regional Lymph Node Surgery	R	R	•	COC
674	Treatment Hospital—Surgery Other Regional/Distant	R	R	•	COC
700	Treatment Hospital–Chemotherapy	R	R	•	COC
710	Treatment Hospital–Hormone Therapy	R	R	•	COC
720	Treatment Hospital–Inmunotherapy	R	R	•	COC
730	Treatment Hospital—Other	R	R	•	COC
740	Treatment Hospital—Diagnosis/Staging Procedure	R	R	•	COC
759	SEER Summary Stage 2000	R	R	R	SEER
760	SEER Summary Stage 1977	RH	RH	RH	SEER
780	Extent of disease—Tumor Size	R	R	KH	SEEK
820	Regional Nodes Positive	R	R	S	SEER/COC
830	Regional Nodes Examined	R	R	S	SEER/COC
880	TNM Pathologic Tumor	R	R	•	AJCC
890	TNM Pathologic Nodes	R	R	•	AJCC
900	TNM Pathologic Metastases	R	R	•	AJCC
910	TNM Pathologic Stage Group	R	R	•	AJCC
920	TNM Pathologic Descriptor	R	R		COC
930	TNM Pathologic Staged By	R	R		COC
940	TNM Pathologic Staged By TNM Clinical Tumor	R	R	•	AJCC
950	TNM Clinical Tuniol TNM Clinical Nodes	R	R	•	AJCC
960	TNM Clinical Nodes TNM Clinical Metastases	R	R	•	AJCC
960			R	•	AJCC
	TNM Clinical Stage Group	R		•	
980	TNM Clinical Descriptor	R	R	•	COC
990	TNM Clinical Staged By	R	R	•	COC
1060	TNM Edition Number	R	R	•	COC
1150	Tumor Marker 1	R*	R*	•	SEER
1160	Tumor Marker 2	R*	R*	•	SEER
1170	Tumor Marker 3	R*	R*	•	SEER
1200	Treatment Date-Surgery	R	R	S	COC
1210	Treatment Date–Radiation	R	R	S	COC
1250	Treatment Date-Other	R	R	S	COC
1270	Date of 1st Course of Treatment–COC	R	R	#	COC
1280	Treatment Date–Diagnosis/Staging Procedure	R	R	• D	COC
1290	Treatment Summary–Surgery Primary Site	R	R	R	SEER/COC
1292	Treatment Summary–Scope Regional Lymph Nodes Surgery	R	R	R	SEER/COC
1294	Treatment Summary–Surgery Other Regional/Distant	R	R	R	SEER/COC

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T. //	I. N	Provider	NCR	NIDCD	Source of
Item#	Item Name	Required	Required	NPCR	Standard
1320	Treatment Summary–Surgical Margins	R	R	•	COC
1340	Reason for No Surgery	R	R	S	SEER/COC
1350	Treatment Summary–Diagnosis/Staging Procedure	R	R	•	COC
1380	Treatment Summary–Surgery/Radiation Sequence	R	R	S	SEER/COC
1390	Treatment Summary-Chemotherapy	R	R	S	SEER/COC
1400	Treatment Summary–Hormone Therapy	R	R	S	SEER/COC
1410	Treatment Summary–Immunotherapy	R	R	S	SEER/COC
1420	Treatment Summary-Other	R	R	S	SEER/COC
1430	Reason for No Radiation Therapy	R	R	S	COC
1460	Treatment Coding System–Current	R	R	R	NAACCR
1510	Radiation–Regional Dose: cGy	R	R	•	COC
1520	Radiation–Number of Treatment Volume	R	R	•	COC
1540	Radiation—Treatment Volume	R	R	•	COC
1550	Radiation–Location of Treatment	R	R	•	COC
1570	Radiation–Regional Treatment Modality	R	R	S	COC
1660	Subsequent Treatment 2 <sup>nd</sup> Course Date	R*	R*	•	COC
1670	Subsequent Treatment 2 <sup>nd</sup> Course Codes	R*	R*		
1671	Subsequent Treatment 2 <sup>nd</sup> Course Surgery	R*	R*	•	COC
1672	Subsequent Treatment 2 <sup>nd</sup> Course Radiation	R*	R*	•	COC
1673	Subsequent Treatment 2 <sup>nd</sup> Course Chemotherapy	R*	R*	•	COC
1674	Subsequent Treatment 2 <sup>nd</sup> Course Hormone Therapy	R*	R*	•	COC
1675	Subsequent Treatment 2 <sup>nd</sup> Course Immunotherapy	R*	R*	•	COC
1676	Subsequent Treatment 2 <sup>nd</sup> Course Other	R*	R*	•	COC
1677	Subsequent Treatment 2 <sup>nd</sup> –Scope Lymph Nodes Surgery	R*	R*	•	COC
1678	Subsequent Treatment 2 <sup>nd</sup> —Surgery Other	R*	R*	•	COC
1679	Subsequent Treatment 2 <sup>nd</sup> —Regional Lymph Nodes Removed	R*	R*	•	COC
1680	Subsequent Treatment 3 <sup>rd</sup> Course Date	R*	R*	•	COC
1690	Subsequent Treatment 3 <sup>rd</sup> Course Codes	R*	R*		
1691	Subsequent Treatment 3 <sup>rd</sup> Course Surgery	R*	R*	•	COC
1692	Subsequent Treatment 3 <sup>rd</sup> Course Radiation	R*	R*	•	COC
1693	Subsequent Treatment 3 <sup>rd</sup> Course Chemotherapy	R*	R*	•	COC
1694	Subsequent Treatment 3 <sup>rd</sup> Course Hormone Therapy	R*	R*	•	COC
1695	Subsequent Treatment 3 <sup>rd</sup> Course Immunotherapy	R*	R*	•	COC
1696	Subsequent Treatment 3 <sup>rd</sup> Course Other	R*	R*	•	COC
1697	Subsequent Treatment 3 <sup>rd</sup> —Scope Lymph Nodes Surgery	R*	R*	•	COC
1698	Subsequent Treatment 3 <sup>rd</sup> –Surgery Other	R*	R*	•	COC
1699	Subsequent Treatment 3 <sup>rd</sup> –Regional Lymph Nodes Removed	R*	R*	•	COC
1700	Subsequent Treatment 4 <sup>th</sup> Course Date	R*	R*	•	COC
1710	Subsequent Treatment 4 <sup>th</sup> Course Codes	R*	R*		
1711	Subsequent Treatment 4 <sup>th</sup> Course Surgery	R*	R*	•	COC
1712	Subsequent Treatment 4 <sup>th</sup> Course Radiation	R*	R*	•	COC
1713	Subsequent Treatment 4 <sup>th</sup> Course Chemotherapy	R*	R*	•	COC
1714	Subsequent Treatment 4 <sup>th</sup> Course Hormone Therapy	R*	R*	•	COC
1715	Subsequent Treatment 4 <sup>th</sup> Course Immunotherapy	R*	R*	•	COC
1716	Subsequent Treatment 4 <sup>th</sup> Course Other	R*	R*	•	COC
1717	Subsequent Treatment 4 <sup>th</sup> –Scope Lymph Nodes Surgery	R*	R*	•	COC
1718	Subsequent Treatment 4 <sup>th</sup> —Surg Other	R*	R*	•	COC

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		Provider	NCR		Source of
Item#	Item Name	Required	Required	NPCR	Standard
1719	Subsequent Treatment 4th–Regional Lymph Nodes Removed	R*	R*	•	COC
1720	Subsequent Treatment 5th Course Date	R*	R*	•	NAACCR
1730	Subsequent Treatment 5th Course Codes	R*	R*		
1731	Subsequent Treatment 5 <sup>th</sup> Course Surgery	R*	R*	•	NAACCR
1732	Subsequent Treatment 5 <sup>th</sup> Course Radiation	R*	R*	•	NAACCR
1733	Subsequent Treatment 5 <sup>th</sup> Course Chemotherapy	R*	R*	•	NAACCR
1734	Subsequent Treatment 5 <sup>th</sup> Course Hormone Therapy	R*	R*	•	NAACCR
1735	Subsequent Treatment 5 <sup>th</sup> Course Immunotherapy	R*	R*	•	NAACCR
1736	Subsequent Treatment 5th Course Other	R*	R*	•	NAACCR
1737	Subsequent Treatment 5th–Scope Lymph Nodes Surgery	R*	R*	•	NAACCR
1738	Subsequent Treatment 5 <sup>th</sup> –Surgery Other	R*	R*	•	NAACCR
1739	Subsequent Treatment 5th–Regional Lymph Nodes Removed	R*	R*	•	NAACCR
1750	Date of Last Contact	R	R	R	SEER/COC
1760	Vital Status	R	R	R	SEER/COC
1770	Cancer Status	R	R	•	COC
1790	Follow-Up Source	R	R	•	COC
1800	Next Follow-Up Source	R	R	•	COC
1810	Address Current–City	R	R	•	COC
1820	Address Current–State	R	R	•	NAACCR
1830	Address Current–Postal Code	R	R	•	NAACCR
1860	Recurrence Date–1st	R	R	S	COC
1880	Recurrence Type–1st	R	R	S	COC
1910	Cause of Death		R	R	SEER/COC
1920	ICD Revision Number		R	R	SEER/COC
1930	Autopsy	R*	R	•	COC
1940	Place of Death	R*	R	S	NAACCR
1980	ICD-O-2 Conversion Flag	R	R	•	SEER
1981	Over-ride Summary Stage/Nodes Positive		R	•	NAACCR
1982	Over-ride Summary Stage/TNM-Nodes		R	•	NAACCR
1983	Over-ride Summary Stage/TNM-Metastasis		R	•	NAACCR
1984	Over-ride Summary Stage/Distant Metastasis 1		R	•	NAACCR
1985	Over-ride Accession/Class of Case/Sequence	R	R	•	NAACCR
1986	Over-ride Hospital Sequence/Diagnostic Confirmation	R	R	•	NAACCR
1987	Over-ride COC-Site/Type	R	R	•	NAACCR
1988	Over-ride Hospital Sequence/Site	R	R	•	NAACCR
1989	Over-ride Site/TNM-Staging Group	R	R	•	NAACCR
1990	Over-ride Age/Site/Morphology	R	R	R	SEER
2000	Over-ride Sequence Number/Diagnosis Confirmation		R	R	SEER
2010	Over-ride Site/Laterality/Sequence Number		R	S	SEER
2020	Over-ride Surgery/Diagnostic Confirmation	R	R	R	SEER
2030	Over-ride Site/Type	R	R	R	SEER
2040	Over-ride Histology	R	R	R	SEER
2050	Over-ride Report Source		R	R	SEER
2060	Over-ride Ill-define Site		R	R	SEER
2070	Over-ride Leukemia Lymphoma	R	R	R	SEER
2071	Over-ride Site/Behavior	R	R	R	SEER
2072	Over-ride Site/Extent of Disease/Diagnosis Date		R	S	SEER
2073	Over-ride Site/Laterality/Extent of Disease		R	S	SEER
2074	Over-ride Site/Laterality/Morphology	R	R	R	SEER

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		Provider	NCR		Source of
Item#	Item Name	Required	Required	NPCR	Standard
2081	CRC CHECKSUM	1	R	•	NAACCR
2090	Date Case Completed		R	•	Varies
2100	Date Case Last Changed		R	•	Varies
2110	Date Case Report Exported	R	R	S	NAACCR
2111	Date Case Report Received	R	R	R	NAACCR
2112	Date Case Report Loaded	R	R	S	NAACCR
2113	Date Tumor Record Available	R	R	S	NAACCR
2116	ICD-O-3 Conversion Flag	R	R	R	SEER/COC
2140	COC Coding System–Current	R	R	S	COC
2150	COC Coding System-Original	R	R	S	NAACCR
2170	Vendor Name	R	R	•	NAACCR
2230	Name-Last	R	R	R	NAACCR
2240	Name-First	R	R	R	NAACCR
2250	Name-Middle	R	R	R	COC
2270	Name-Suffix	R	R	•	COC
2280	Name-Alias	R	R	S	COC
2290	Name-Spouse/Parent	R*	R*	•	Varies
2300	Medical Record Number	R	R	S	NAACCR
2310	Military Record No Suffix	R	R	•	COC
2320	Social Security Number	R	R	R	COC
2330	Address at Diagnosis–Number & Street	R	R	S	COC
2335	Address at Diagnosis–Supplemental	R	R	S	NAACCR
2350	Address Current–Number & Street	R	R	S	COC
2352	Latitude		R	•	NAACCR
2354	Longitude		R	•	NAACCR
2355	Address Current–Supplemental	R	R	•	NAACCR
2360	Telephone	R	R	•	COC
2380	DC State File Number		R	S	State
2390	Name-Maiden	R*	R*	S	NAACCR
2410	Institution Referred From	R	R	•	NAACCR
2420	Institution Referred To	R	R	•	NAACCR
2440	Following Registry	R	R	•	NAACCR
2460	Physician–Managing	R	R	•	COC
2470	Physician–Follow-Up	R	R	•	COC
2480	Physician–Primary Surgery	R	R	•	COC
2490	Physician 3	R	R	•	COC
2500	Physician 4	R	R	•	COC
2520	Text–Diagnosis Procedure–Physical Exam	R	R	R^	NAACCR
2530	Text–Diagnosis Procedure–X-ray/scan	R	R	R^	NAACCR
2540	Text–Diagnosis Procedure–Scopes	R	R	R^	NAACCR
2550	Text-Diagnosis Procedure-Lab Tests	R	R	R^	NAACCR
2560	Text–Diagnosis Procedure–Operative	R	R	R^	NAACCR
2570	Text-Diagnosis Procedure-Pathology	R	R	R^	NAACCR
2580	Text–Primary Site Title	R	R	S	NAACCR
2590	Text-Histology Title	R	R	S	NAACCR
2600	Text-Staging	R	R	R^	NAACCR
2610	Treatment Text-Surgery	R	R	R^	NAACCR
2620	Treatment Text-Radiation (Beam)	R	R	S	NAACCR
2630	Treatment Text-Radiation Other	R	R	S	NAACCR
2640	Treatment Text-Chemotheaphy	R	R	S	NAACCR
2650	Treatment Text-Hormone Therapy	R	R	S	NAACCR
2660	Treatment Text-Immunotherapy	R	R	S	NAACCR

Codes for Recommendations: R = Required. RH = Historically collected and currently transmitted. <math>S = Supplementary/ recommended. D = Derived.  $\bullet = Not$  in dataset but available. \* = When available. # = Central registries may code available data using either the SEER or COC data item and associated rules.  $^{\land} = These$  text requirements may be met with one or several text block fields.

Item#	Item Name	Provider Required	NCR Required	NPCR	Source of Standard
2670	Treatment Text-Other	R	R	S	NAACCR
2680	Text-Remarks	R	R	S	NAACCR
2690	Place of Diagnosis	R	R	S	NAACCR
2800	Collaborative Stage Tumor Size	R*	R*		AJCC
2810	Collaborative Stage Extension	R*	R*		AJCC
2820	Collaborative Stage Tumor Size/Extension Evaluation	R*	R*		AJCC
2830	Collaborative Stage Lymph Nodes	R*	R*		AJCC
2840	Collaborative Stage Regional Lymph Nodes Evaluation	R*	R*		AJCC
2850	Collaborative Stage Metastasis at Diagnosis	R*	R*		AJCC
2860	Collaborative Stage Metastasis Evaluation	R*	R*		AJCC
2880	Collaborative Stage Site-Specific Factor 1	R*	R*		AJCC
2890	Collaborative Stage Site-Specific Factor 2	R*	R*		AJCC
2900	Collaborative Stage Site-Specific Factor 3	R*	R*		AJCC
2910	Collaborative Stage Site-Specific Factor 4	R*	R*		AJCC
2920	Collaborative Stage Site-Specific Factor 5	R*	R*		AJCC
2930	Collaborative Stage Site-Specific Factor 6	R*	R*		AJCC
2940	Derived AJCC Tumor	R*	R*		AJCC
2950	Derived AJCC Tumor Descriptor	R*	R*		AJCC
2960	Derived AJCC Lymph Nodes	R*	R*		AJCC
2970	Derived AJCC Lymph Nodes Descriptor	R*	R*		AJCC
2980	Derived AJCC Metastasis	R*	R*		AJCC
2990	Derived AJCC Metastasis Descriptor	R*	R*		AJCC
3000	Derived AJCC Stage Group	R*	R*		AJCC
3010	Derived Summary Stage (SEER)1977	R*	R*		AJCC
3020	Derived Summary Stage (SEEK) 1977  Derived Summary Stage 2000	R*	R*		AJCC
3030	Derived AJCC–Conversion Flag	R*	R*		AJCC
3040	Derived Summary Stage 1977–Conversion Flag	R*	R*		AJCC
3050	Derived Summary Stage 2000–Conversion Flag	R	R		AJCC
3100	Archive Federal Identification Number	R	R	•	COC
3110	Comorbidities/Complication 1	R	R	•	COC
3120	Comorbidities/Complication 2	R	R	•	COC
3130	Comorbidities/Complication 3	R	R	•	COC
3140	Comorbidities/Complication 4	R	R	•	COC
3150	Comorbidities/Complication 5	R	R	•	COC
3160	Comorbidities/Complication 6	R	R	•	COC
3170	Treatment Date–Most Definitive Surgery	R	R	S	COC
3180	Treatment Date—Surgical Discharge	R	R	•	COC
3190	Readmission Same Hospital within 30 Days	R	R		COC
3200	Radiation–Boost Treatment Modality	R	R	•	COC
3210	Radiation–Boost Dose cGy	R	R		COC
3210			1	•	
	Treatment Date—Radiation Ended	R	R	•	COC
3230	Treatment Date—Systemic	R	R	S	COC
3250	Treatment Summary-Transplant/Endocrine Procedures	R R	R R	S	COC
3270	Treatment Summary–Palliative Procedure			•	COC
3280	Treatment Hospital–Palliative Procedure	R	R	•	COC
3300	Rural Urban Continuum 1993		R	D	NAACCR
3310	Rural Urban Continuum 2000		R	D	NAACCR

Codes for Recommendations: R = Required. RH = Historically collected and currently transmitted. <math>S = Supplementary/ recommended. D = Derived.  $\bullet = Not$  in dataset but available. \* = When available. # = Central registries may code available data using either the SEER or COC data item and associated rules.  $^{\land} = These$  text requirements may be met with one or several text block fields.

EFFECTIVE NEBRASKA DEPARTMENT OF 6/23/12 HEALTH AND HUMAN SERVICES

186 NAC 2

TITLE 186 HEALTH REGISTRIES AND RELEASE OF INFORMATION

CHAPTER 2 BRAIN INJURY REGISTRY

<u>2-001 SCOPE AND AUTHORITY:</u> The purpose of the brain injury registry is to provide a central data bank of accurate, precise and current information concerning persons with brain or head injury. The information from the data bank will assist in the statistical identification, the need for treatment, the rehabilitation of persons with brain or head injury, and the prevention of such injury. These regulations are authorized by and implement the Brain Injury Registry Act, <u>Neb. Rev. Stat.</u> §§ 81-653 to 81-662.

In classification of brain or head injuries, the Department is guided by the standards and definitions of the International Classification of Disease, Ninth Revision, Clinical Modifications (ICD-9-CM). This is the uniform system of classification used by the World Health Organization to identify brain or head injury that is consistent with medically and clinically accepted standards and definitions for use in reporting. Specific ICD-9-CM codes are identified in 186 NAC 2-003.01, item 6.

186 NAC 2 applies to each treating physician and psychologist licensed to practice in the State of Nebraska, all hospitals, and each rehabilitation center located within a hospital within the State of Nebraska. 186 NAC 2 sets forth procedures for the reporting of such cases and information to the Department by health practitioners, hospitals, and each rehabilitation center located within a hospital in the State of Nebraska. 186 NAC 2 also provides procedures and standards that govern access to registry data pursuant to Neb. Rev. Stat. §§ 81-663 to 81-675.

#### 2-002 DEFINITIONS

<u>Brain or head injury</u> means clinically evident neurotrauma resulting directly or indirectly from closed or penetrating brain or head trauma, infection, febrile condition, anoxia, vascular lesions, toxin, or spinal cord injury, not related primarily to congenital or degenerative conditions, chemical dependency, or aging processes, which impairs mental, cognitive, behavioral, or physical functioning.

Department means the Department of Health and Human Services.

<u>Disposition upon discharge</u> means, for the purpose of this Registry, the destination of the patient following dismissal (i.e. home, skilled care, rehabilitation care, nursing home, transfer to another acute care hospital, against medical advice, expired, etc.).

<u>2-003 DATA REQUIREMENTS:</u> Data to be abstracted from medical records or made available through medical records for abstracting as specified by reporting requirements as set forth in 186 NAC 2-004 through 2-007.

<u>2-003.01 Physician, Psychologist, Hospital, and Rehabilitation Center Reporting:</u> A report must contain the following information about the person who has sustained the brain or head injury, if known:

- 1. Name:
- 2. Date of birth;
- Gender:
- 4. Residence;
- 5. Date of the injury;
- 6. Final diagnosis or classification of the injury in the following categories, according to the International Classification of Disease, Ninth Revision, Clinical Modification Coding System of the World Health Organization (ICD-9-CM), incorporated herein by reference and available for viewing at the Nebraska Department of Health and Human Services, Division of Public Health, Office of Health Statistics, 301 Centennial Mall South, Lincoln, Nebraska 68509-5026:

800.0-801.99: Fracture of the vault or base of the skull

803.0-804.9: Other and unqualified and multiple fractures of the skull

805.0-805.9: Fracture of vertebral column without mention of spinal cord lesion

806.0-806.9: Fracture of vertebral column with spinal cord lesion

850.0-854.19: Intracranial injury, including concussion, contusion, laceration and hemorrhage

907.0: Late effect of intracranial injury

907.2: Late effect of spinal cord injury

950.1-950.3: Injury to optic chiasm, optic pathways, and visual cortex

952.00-952.9: Spinal cord lesion without evidence of spinal bone injury

953.0-953.9: Injury to nerve roots and spinal plexus

959.01: Unspecified head injury

995.55: Shaken infant syndrome

- 7. Cause of the injury, and, if practicable, whether the injury resulted from an accident involving the use of alcohol:
- 8. Place or site of occurrence of the injury;
- Identification of the reporting source;
- 10. Disposition upon discharge;
- 11. Payor source; and
- 12. Any additional information the Department deems necessary and appropriate to carry out the purposes of the Brain Injury Registry Act.

<u>2-004 HOSPITAL REPORTING REQUIREMENTS:</u> If a person with brain or head injury is admitted to or treated at a hospital or a rehabilitation center located within a hospital in this state, the hospital

or rehabilitation center must provide a report of the injury to the Department within 30 days after the discharge of the person from the hospital or rehabilitation center.

2-005 PHYSICIAN OR PSYCHOLOGIST REPORTING REQUIREMENTS: If a person with a brain or head injury is treated in this state in the office of a physician or psychologist licensed to practice in the State of Nebraska but is not admitted to a hospital within this state, the treating physician or psychologist must provide a report of such injury to the Department within 30 days after such treatment and identification of the person sustaining the injury.

<u>2-006 AVAILABILITY OF MEDICAL RECORDS:</u> Each facility must make available medical records which document the diagnosis and treatment received by individuals with head and brain injury. For the Department's purpose of recording and auditing specific data, such medical records must be made available to the Department or its authorized representative on the premises of the facility during normal working hours. The Department or its authorized representative will present proper identification.

2-007 CONFIDENTIALITY AND RELEASE OF INFORMATION: No patient identifying data as identified in Neb. Rev. Stat. § 81-664 will be disclosed, made public, or released by the Department to any public or private person or entity. All data and information obtained from records of individuals with brain or head injury are classified as Class I, Class II, or Class IV data as defined by Neb. Rev. Stat. § 81-667 and 186 NAC 5 Release of Medical Records and Health Information.

<u>2-007.01 Release of Statistical Information:</u> Statistical reports developed pursuant to <u>Neb. Rev. Stat.</u> § 81-656, containing information obtained from patient data, will be considered Class I data as described in <u>Neb. Rev. Stat.</u> § 81-667.

<u>2-007.02</u> Any de-identified data (other than Class III data) asked for by and furnished to a researcher may not be intentionally re-identified in any manner. Should a recipient of de-identified information unintentionally or accidentally be able to identify any individual, they must not use that information in any way. The recipient must also notify the Department of the means of accidental re-identification in order for the Department to consider additional procedures to safeguard against breaches in confidentiality.

<u>2-008 INFORMATION REGARDING SERVICES:</u> Within 30 days after receiving a report of brain or head injury, the Department will provide relevant and timely information to the person with the injury to assist the person in accessing necessary and appropriate services relating to the injury. The Department may develop the information or utilize information developed by other sources and approved by the Department. The Department may provide the information directly or contract with an appropriate entity to provide the information.

## NEBRASKA HEALTH AND HUMAN SERVICES REGULATION AND LICENSURE

186 NAC 3

TITLE 186 HEALTH REGISTRIES AND RELEASE OF INFORMATION

CHAPTER 3 EXTERNAL CAUSE OF INJURY REGISTRY

<u>3-001 SCOPE AND AUTHORITY:</u> The purpose of the External Cause of Injury Registry is to provide a central data base of accurate, precise and current information regarding the external causes of injury to be utilized for research, analytical and statistical purposes and for injury prevention.

These regulations apply to each hospital within the State of Nebraska. They implement the laws governing the establishment and maintenance of a registry that includes a record of the external causes of injuries, poisonings and adverse effects, and such information that the Department determines is necessary and appropriate for the statistical identification and planning for injury prevention purposes. These regulations set forth procedures for the reporting requirements for hospitals of the State of Nebraska of data concerning external causes of injury, poisoning and adverse effects, and provide procedures and standards for governing access to registry data pursuant to Neb. Rev. Stat. §§ 71-2078 to 71-2082 and Neb. Rev. Stat. §§ 81-677 to 81-680.

#### 3-002 DEFINITIONS:

<u>Department</u> means the Nebraska Department of Health and Human Services Regulation and Licensure.

<u>Diagnosis Codes</u> refers to the codes for diseases and health-related conditions determined in accordance with Volumes I and II of the International Classification of Diseases, 9th Revision, Clinical Modification ("ICD-9-CM"), incorporated herein by reference and available for viewing at the Nebraska Department of Health and Human Services Regulation and Licensure, Division of Public Health Assurance, Section of Data Management, 301 Centennial Mall South, 3<sup>rd</sup> floor, Lincoln, Nebraska, 68509-5007.

<u>E Codes</u> refers to the codes for the external causes of injury, poisoning, or adverse effects, to be entered on the hospital uniform billing form pursuant to <u>Neb. Rev. Stat.</u> § 71-2080, which are determined in accordance with the Supplementary Classification of External Causes of Injury and Poisoning of the International Classification of Diseases, 9th Revision, Clinical modification ("ICD-9-CM"), incorporated herein by reference and available for viewing at the Nebraska Department of Health and Human Services Regulation and Licensure, Division of Public Health Assurance, Section of Data Management, 301 Centennial Mall South, 3<sup>rd</sup> floor, Lincoln, Nebraska, 68509-5007.

<u>Hospital</u> shall have the meaning found in <u>Neb. Rev. Stat.</u> § 71-419.

Hospital Uniform Billing Form means the Health Care Financing Administration claim form, number 1450 mandated for the medicare program pursuant to Sections 1814(a)(2) and 1871 of the Federal Social Security Act, as amended, commonly referred to as the UB-92 form, a copy of which is attached as Attachment 1 and incorporated herein by this reference;

### NEBRASKA HEALTH AND HUMAN SERVICES REGULATION AND LICENSURE

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<u>Procedure Codes</u> means the codes for procedures in medicine, determined in accordance with Volume III of the International Classification of Diseases, 9th Revision, Clinical Modification ("ICD-9-CM"), incorporated herein by reference and available for viewing at the Nebraska Department of Health and Human Services Regulation and Licensure, Division of Public Health Assurance, Section of Data Management, 301 Centennial Mall South, 3<sup>rd</sup> floor, Lincoln, Nebraska, 68509-5007.

<u>3-003 DATA REQUIREMENTS:</u> Data are to be abstracted, for each patient discharged from a hospital, receiving outpatient services, or released from observation, for whom an external cause of injury code is recorded. Data to be abstracted from medical records or made available through medical records for abstracting as specified by reporting requirements set forth in 186 NAC 3-004 are as follows:

- 1. Diagnosis codes, as defined in 186 NAC 3-002;
- 2. E codes, as defined in 186 NAC 3-002;
- 3. Procedure codes, as defined in 186 NAC 3-002;
- 4. Admission date:
- 5. Discharge date;
- 6. Disposition code;
- 7. Birth date;
- 8. Sex:
- 9. City and county of residence;
- 10. Zip code of residence.
- 11. Identification of hospital reporting information

3-004 HOSPITAL REPORTING REQUIREMENTS: Each hospital within the state must assign an E-code to each patient discharged, receiving outpatient services, or released from observation, for whom an E-code is appropriate. The hospital must submit data to the Department on a quarterly basis. The data may be submitted to the Department via an agreement between the Department and the Nebraska Hospital Association or any other entity that has such data collection agreement. This submission may be in electronic or written format.

3-005 AVAILABILITY OF MEDICAL RECORDS: Each hospital must make available to the Department or its authorized representative, upon presentation of proper identification, medical records which document the diagnosis and treatment of individuals for whom an E-code was appropriate for the purpose of recording specific data required by Neb. Rev. Stat. §§ 71-2078 to 71-2082 and 186 NAC 3. These records must be made available on the premises of the hospital and during normal working hours.

3-006 CONFIDENTIALITY AND RELEASE OF INFORMATION: All data provided to the Department pursuant to Neb. Rev. Stat. §§ 71-2078 to 71-2082 and 186 NAC 3 will be classified as Class I and Class II data pursuant to Neb. Rev. Stat. § 81-667 (1) and (2). The aggregate data reports will be considered public documents.

## NEBRASKA HEALTH AND HUMAN SERVICES REGULATION AND LICENSURE

186 NAC 4

TITLE 186 HEALTH REGISTRIES AND RELEASE OF INFORMATION

CHAPTER 4 PARKINSON'S DISEASE REGISTRY

<u>4-001 SCOPE AND AUTHORITY:</u> The purpose of the Parkinson's Disease Registry is to establish and maintain a compilation of cases of Parkinson's disease and related movement disorders occurring among residents of the state of Nebraska to achieve the goals of statistical identification for research, planning for health care requirements, and education of health care providers and persons with Parkinson's disease and related movement disorders.

186 NAC 4 applies to each physician licensed under the Uniform licensing law and the pharmacist in charge of each pharmacy located within the state or doing business in the state. 186 NAC 4 sets forth procedures for the reporting of such cases and information to the Department by physicians and pharmacists. 186 NAC 4 also provides procedures and standards that govern access to registry data pursuant to Neb. Rev. Stat. §§ 81-663 to 81-675.

#### 4-002 DEFINITIONS:

<u>Department</u> means the Nebraska Department of Health and Human Services Regulation and Licensure.

<u>Parkinson's disease</u> means a chronic, progressive disorder in which there is a lack of the chemical dopamine in the brain as a direct result of the destruction of the dopamine-producing cells in the portion of the brain called the substantia nigra. Clinical features of the disease include tremor at rest, slow movements, rigidity, and unsteady or shuffling gait and may be indicated by improvement after using medications used for Parkinson's disease.

<u>Related movement disorder</u> means a disorder that resembles Parkinson's disease in some way, such as another kind of tremor.

4-003 LIST OF DRUGS REQUIRED TO BE REPORTED FOR PARKINSON'S DISEASE: The Department will issue a list of drugs used for the treatment of Parkinson's disease to be reported under this section. A copy of the list is provided in Attachment 1. This list will be reviewed and revised annually. The annual list will be revised before January 1 of each year. During January of each year, the Department will distribute the list to each pharmacy located within the state or doing business in the state. The list distributed in January will be used for all cases reported in that calendar year.

<u>4-004 DATA REQUIREMENTS:</u> Data to be reported to the Department for each individual resident of this state who is diagnosed with Parkinson's disease or related movement disorder as specified by reporting requirements set forth in 186 NAC 4-004.01 to 4-004.03.

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<u>4-004.01 Physician reporting requirements</u>. Each physician licensed under the Uniform Licensing Law must report the diagnosis of Parkinson's disease or related movement disorder and required information for all Nebraska residents within 60 days after the diagnosis is made. The report must contain the following information about the person diagnosed with Parkinson's disease or related movement disorder:

- 1. Name:
- 2. Social security number;
- 3. Date of birth;
- 4. Gender:
- Address at time of diagnosis;
- 6. Current address:
- 7. Date of diagnosis;
- 8. Physician;
- 9. Identification of reporting source; and
- 10. Any additional information the department demonstrates is reasonable to implement the Parkinson's Disease Registry Act.

4-004.02 Pharmacist reporting requirements. The pharmacist in charge of each pharmacy located within the state or doing business in the state must report dispensation of drugs that are included on the list of drugs to be reported for Parkinson's disease issued by the Department each January. The report will be filed on a semi-annual basis. The report for the months of January through June must be due on or before the following July 31st, and the report for the months of July through December must be due on or before January 31st of the following year. Data to be reported to the Department for each individual resident of this state to whom the pharmacist has dispensed drugs as specified on the list of drugs required to be reported for Parkinson's disease, as specified in 186 NAC 4-003 are as follows:

- 1. Name:
- 2. Address:
- 3. Social security number;
- 4. Name of the prescribing physician; and
- 5. Address of the prescribing physician.

<u>4-004.03 Individual reporting</u>. Any individual resident of this state who has been diagnosed with Parkinson's disease or a related movement disorder by a licensed physician may file a report with the Department providing the following information:

- 1. Name;
- 2. Social security number;
- 3. Date of birth;
- 4. Gender:
- 5. Address at time of diagnosis;
- 6. Current address:
- 7. Date of diagnosis;
- 8. Physician;
- 9. Identification of reporting source; and

186 NAC 4

10. Any additional information the department demonstrates is reasonable to implement the Parkinson's Disease Registry Act.

The Department must validate all individual reports as specified in 186 NAC 4-005.

<u>4-005 VALIDATION OF INDIVIDUAL REPORTS:</u> The Department must provide for validation of reports made by individuals who have been diagnosed with Parkinson's disease or related movement disorder. This validation will consist of finding a corroborating report within the information having been reported by physicians.

4-006 AVAILABILITY OF MEDICAL RECORDS: Each physician must make available medical records that document the diagnosis of individuals with Parkinson's disease or related movement disorders. Each pharmacist must make available patient drug profiles that document the prescribing of the reportable drugs. For the Department's purpose of recording and auditing specific data such medical records or patient drug profiles must be made available to the Department or its authorized representative in the offices of such physician or pharmacist during normal working hours. The Department or its authorized representative will present proper identification to the physician or pharmacist.

4-007 CONFIDENTIALITY AND RELEASE OF INFORMATION: All data and information obtained from records of individuals with Parkinson's disease or related movement disorders will be subject to and comply with Neb. Rev. Stat. §§ 81-663 to 81-675. For the purposes of the Parkinson's Disease Registry data may be released either as Class I, Class II, Class III, or Class IV data as described in Neb. Rev. Stat. §§ 81-667 and 186 NAC 5 Release of Medical Records and Health Information.

Any de-identified data (other than Class III data) asked for by and furnished to a researcher may not be intentionally re-identified in any manner. Should a recipient of de-identified information unintentionally or accidentally be able to identify any individual they must not use that information in any way. The recipient must also notify the Department of the means of accidental re-identification in order for the Department to consider additional procedures to safeguard against breaches in confidentiality.

4-008 RELEASE FROM LIABILITY: Any physician, pharmacist, or medical professional required to make reports under the Parkinson's Disease Registry Act and 186 NAC 4-004.01 and 4-004.02 is immune from liability, civil, criminal, or otherwise, that might result from divulging such information. Any physician, pharmacist or medical professional required to make reports is immune from liability, civil, criminal, or otherwise, for filing an incomplete report as a result of the failure of an individual to provide the information necessary to make such a report.

4-009 PENALTY FOR IMPROPER DISCLOSURE: Any private or public entity, individual, or approved researcher who wrongfully discloses confidential data obtained from the medical record and health information registry or uses such information with the intent to deceive will be guilty of a Class IV misdemeanor for each offense. Any person or entity that fails to make reports in good faith as provided by the Parkinson's Disease Registry Act will be guilty of a Class V misdemeanor for each offense.

EFFECTIVE JANUARY 1, 2014

## NEBRASKA DEPARTMENT OF HEALTH AND HUMAN SERVICES

186 NAC 4 ATTACHMENT 1

# REPORTABLE LIST OF DRUGS Effective January 1, 2014

Nebraska Parkinson's Disease Registry Nebraska Department of Health and Human Services

To fully implement the Nebraska Parkinson's Disease Registry, the following is a list of drugs, which if dispensed in any combination or in any generic form, require reporting of certain items to the Nebraska Department of Health and Human Services. These items are patient name and address, Social Security number and prescribing physician name and address.

Azilect

Carbidopa/levodopa (if prescribed for times other than evening or bedtime only)
Mirapex (if prescribed for times other than evening or bedtime only)
Neupro
Requip (if prescribed for times other than evening or bedtime only)
Selegiline (except Emsam)
Stalevo

# PLEASE NOTE: <u>DO NOT</u> REPORT PATIENTS IF THE <u>PHYSICIAN</u> INDICATES THAT THE DRUG IS PRESCRIBED FOR RESTLESS LEG SYNDROME ONLY OR IF THE DRUG IS PRESCRIBED FOR EVENING OR BEDTIME USE ONLY

Please submit this information to: Jill Krause DHHS Public Health/Health Statistics PO Box 95026 Lincoln NE 68509-5026

For more information, please send an email to <u>iill.krause@nebraska.gov</u>, call (402) 471-8582, or visit our website <u>www.dhhs.ne.gov/parkinsons</u>.

Thank you for your support of the Nebraska Parkinson's Disease Registry!

## NEBRASKA HEALTH AND HUMAN SERVICES REGULATION AND LICENSURE

186 NAC 5

TITLE 186 HEALTH REGISTRIES AND RELEASE OF INFORMATION

CHAPTER 5 RELEASE OF MEDICAL RECORDS AND HEALTH INFORMATION

5-001 SCOPE AND AUTHORITY: This regulation governs the release of medical record and health information Neb. Rev. Stat. §§ 81-663 to 81-675 which are contained in the registries that record certain medical conditions occurring in this state, as prescribed by law. The information is recorded and reported from these registries and is maintained in order to achieve the goals of prevention, cure and control through research and education. These registries include the Birth Defects Registry established in Neb. Rev. Stat. §§ 71-646 to 71-649, the Cancer Registry established in Neb. Rev. Stat. §§ 81-642 to 81-650, the Brain Injury Registry established in Neb. Rev. Stat. §§ 81-653 to 81-661 and the Parkinson's Disease Registry established in Neb. Rev. Stat. §§ 81-681 to 81-696;

#### 5-002 DEFINITIONS:

<u>Aggregate Data</u> means data contained in the medical record and health information registries maintained by the Department which is compiled in a statistical format and which does not include patient-identifying data.

<u>Approved Researcher</u> means an individual or entity which is approved by the Department pursuant to <u>Neb. Rev. Stat.</u> § 81-666 to obtain access to data contained in the medical record and health information registries maintained by the Department to assist in the scientific or medical research for the prevention, cure or control of a disease or injury process.

<u>Case-Specific Data</u> means data contained in the medical record and health information registries concerning a specific individual other than patient-identifying data.

<u>Certain Diseases or Injuries</u> means cancers, birth defects, head and brain injuries and Parkinson's disease or related movement disorders.

<u>Department</u> means the Nebraska Department of Health and Human Services Regulation and Licensure.

Medical Record and Health Information Registry means the system of reporting certain medical conditions occurring in this state, as prescribed by law, which are reported and recorded in order to achieve the goals of prevention, cure and control through research and education, and includes the Birth Defects Registry established in Neb. Rev. Stat. § 71-646, the Cancer Registry established in Neb. Rev. Stat. §§ 81-642 to 81-650, the Brain Injury Registry established in Neb. Rev. Stat. § 81-6653 to 81-661 and the Parkinson's Disease Registry established in Neb. Rev. Stat. § 81-684.

# NEBRASKA HEALTH AND HUMAN SERVICES REGULATION AND LICENSURE

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<u>Patient-Identifying Data</u> means the patient's name, address, record number, symbol, or other identifying particular assigned to or related to an individual patient.

Permission means written consent or written authorization.

<u>Research</u> means study specific to the diseases or injuries for which access to data is requested and which is dedicated to the prevention, cure, or control of the diseases or injuries.

<u>5-003 CLASSIFICATION OF MEDICAL RECORDS:</u> Medical records provided to the Department for use in its medical record and health information registries must be classified for release according to the following categories:

- Class I data is confidential with release only in aggregate data reports created by the Department on a periodic basis, usually specified in the statutes creating the registry. These reports are public documents;
- 2. Class II data is confidential with release only in aggregate data reports created by the Department at the request of an individual. These reports are public documents;
- 3. Class III data is confidential with release of patient-identifying data to approved researchers for specific research projects. The approved researcher must maintain the confidentiality of the information; and
- Class IV data is confidential with release of case-specific data to approved researchers for specific research projects. The approved researcher must maintain the confidentiality of the data.

#### 5-004 CONFIDENTIALITY AND RELEASE OF INFORMATION

<u>5-004.01</u> All case-specific and patient-identifying data obtained from medical records of individual patients is for the confidential use of the Department, those reporting data to the Department, and public health agencies and approved researchers that the Department determines may view such records in order to carry out the intent of <u>Neb. Rev. Stat.</u> §§ 81-663 to 81-675.

<u>5-004.01A</u> The information is privileged and must not otherwise be divulged or made public so as to disclose the identity of an individual whose medical records and health information have been used for acquiring data.

<u>5-004.01B</u> Case-specific and patient-identifying data may be released to those individuals or entities who have reported information to the Department. The data may be released for the purpose of confirming the accuracy of the data provided and to coordinate information among sources.

<u>5-004.01C</u> All case-specific and patient-identifying data furnished and any findings or conclusions resulting from the data are privileged communications which may not be

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used or offered or received in evidence at any legal proceeding of any kind, and any attempt to use or offer any such information, findings, conclusions, or any part thereof, unless waived by the interested parties, constitutes prejudicial error resulting in a mistrial in any such proceeding.

<u>5-004.01D</u> Any de-identified data (other than Class III data) asked for by and furnished to a researcher may not be intentionally re-identified in any manner. Should a recipient of de-identified information unintentionally or accidentally be able to identify any individual they must not use that information in any way. The recipient must also notify the Department of the means of accidental re-identification in order for the Department to consider additional procedures to safeguard against breaches in confidentiality.

<u>5-004.02</u> Aggregate data collected must be open and accessible to the public and the statistical information will not be considered medical records pursuant to <u>Neb. Rev. Stat.</u> § 84-712.05.

<u>5-004.03</u> The cost of data retrieved and data processing will be paid by the researchers and private or public entities or individuals requesting data from a certain disease or injury registry.

5-005 APPROVED RESEARCHER: The Department may approve individuals or entities who submit written application to obtain access to case-specific data or case-specific and patient-identifying data to assist in their research for the prevention, cure and control of certain diseases and injuries. These individuals or entities must show that the applicant is a qualified researcher, that the data requested will be used for bona fide scientific or medical research for prevention, cure, or control of certain diseases and injuries, and that the applicant will maintain the confidentiality and security of the data obtained. The application must contain, but is not limited to the following information:

- 1. Applicant's name and address;
- 2. The name of the entity, if any, which the applicant represents, its address and a brief description of the entity;
- Name and address of the principal investigator, if other than the applicant;
- 4. The qualifications of the applicant and of the principal investigator, if other than the applicant, including education, experience, prior publications, and recommendations of professional colleagues who have knowledge and experience of scientific or medical research:
- 5. The purpose of the research project, a summary of the project and the anticipated time of the completion of such project;
- 6. The location where the research project will be conducted and the equipment, personnel, and other resources available to the applicant to carry out the projects;
- 7. The identity of the individual or entity funding the research project, a description of the availability of funds for the research project and any conditions on the receipt or continuation of such funding;

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- 8. The specific data requested and a description of the use to be made of such data and, if patient-identifying data is requested, a substantiation of the need for access to such patient-identifying data;
- 9. A description of the measures to be taken to secure the data and maintain the confidentiality of such data during the research project, for disposal of the data upon completion of the study and to assure that the results of the study will not divulge or make public information that will disclose the identity of any individual patient;
- 10. If contact with patient or patient's family is planned, approved researcher must substantiate the need for such contact and describe the method to be used to obtain permission from the patient's physician for such contact; and
- 11. Such additional information as the Department determines to be necessary to assure that release of data to the applicant is appropriate and will further the purpose of <a href="Neb.Rev. Stat.">Neb. Rev. Stat.</a> §§ 81-663 to 81-650 or the laws governing the specific registry.

<u>5-006 SUBMISSION OF REPORTS:</u> The approved researcher must submit the reports or results of the research project to the Department at no cost. The Department reviews the reports or results and prohibits publication of confidential information or patient-identifying data. The approved researcher must acknowledge the Department and its medical record and health information registries in any publication in which information obtained from the medical record and health information registries is used.

<u>5-007 RELEASE OF DATA TO GOVERNMENTAL HEALTH AGENCIES:</u> Except as otherwise provided by the law governing a specific medical record and health information registry, the Department may release information contained in a registry to official public health departments and agencies as follows:

- Upon request by an official local health department within the State of Nebraska, the Department may release the data to the requesting local health department. The official local health department must not contact patients using data received under Neb. Rev. Stat. §§ 81-663 to 81-675 without approval by the Department of an application made pursuant to Neb. Rev. Stat. § 81-666; and
- 2. Upon approval of an application by federal, state, or local official public health agencies made pursuant to Neb. Rev. Stat. § 81-666, the Department may release the data.
- 3. The information released by the Department will be limited to the minimum amount reasonably necessary to achieve the purposes for which disclosure is made.

<u>5-007.01</u> The receiving agency, under 186 NAC 5-007, must not further disclose data to any third party but may publish aggregate statistical reports, except that no patient-identifying data will be divulged, made public, or released to any public or private person or entity. The receiving agency must comply with the patient contact provisions of <u>Neb. Rev. Stat.</u> §§ 81-663 to 81-675. The receiving agency must acknowledge the Department and its medical record and health information registries in any publication in which information obtained from the medical record and health information registries is used.

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<u>5-007.02</u> The release and acknowledgment provisions of 186 NAC 5-007 do not apply to cancer registries located in another state which receive data through approved data exchange agreements.

<u>5-008 PATIENT CONTACT PROVISIONS:</u> No person who seeks information or obtains registry data pursuant to this regulation will contact a patient on the registry or the patient's family unless the registry has first obtained the permission of the patient or patient's family. The registry will coordinate its activities with the person desiring the contact and may authorize the person desiring the contact to perform these contacts under the direction of the registry.

5-009 IMMUNITY FOR RECEIPT AND RELEASE OF INFORMATION: Any person who receives or releases information in the form and manner prescribed by Neb. Rev. Stat. §§ 81-663 to 81-675 and 186 NAC 5 will not be civilly or criminally liable for the receipt or release unless the receipt or release is done with actual malice, fraudulent intent, or bad faith.

<u>5-010 WRONGFUL DISCLOSURE OF INFORMATION:</u> Any private or public entity, individual or approved researcher who wrongfully discloses confidential data obtained from the medical record and health information registries or uses the information with the intent to deceive will be guilty of a Class IV misdemeanor for each offense.

EFFECTIVE DATE NEBRASKA HEALTH AND HUMAN SERVICES 186 NAC 6

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TITLE 186 HEALTH REGISTRIES AND RELEASE OF INFORMATION

CHAPTER 6 OUTPATIENT SURGICAL PROCEDURES DATA

6-001 SCOPE AND AUTHORITY: The purpose of the outpatient surgical procedures database is to provide for: (1) the collection and compilation of outpatient surgical procedure information from hospitals and ambulatory surgical centers; (2) the use and disclosure of such information for public health purposes; and (3) an annual statistical report. These regulations apply to each hospital or ambulatory surgical center within the State of Nebraska licensed under the Health Care Facility Licensure Act. The regulations set forth procedures for the reporting by hospitals and ambulatory surgical centers pursuant to Neb. Rev. Stat. §§ 81-6,111 to 81-6,119.

#### 6-002 DEFINITIONS

<u>Facility Portion of Billed Charges</u> means the total charges for all services related to a claim for outpatient surgical procedures, excluding professional fees.

<u>Department</u> means the Department of Health and Human Services Regulation and Licensure.

Medicaid means the medical assistance program established in Neb. Rev. Stat. § 68-1018.

<u>Medicare</u> means Title XVIII of the federal Social Security Act, as such title existed on January 1, 2003.

<u>Outpatient surgical procedure</u> means a surgical procedure provided to patients who do not require inpatient hospitalization.

<u>Primary payor</u> means the public payor or private payor which is expected to be responsible for the largest percentage of the patient's current bill.

Private payor means any nongovernmental source of funding.

Public payor means medicaid, medicare, and any other governmental source of funding.

<u>6-003 DATA REQUIREMENTS:</u> Every hospital or ambulatory surgical center licensed under the Health Care Facility Licensure Act must report the following outpatient surgical and related information to the Department:

- 1. The name of the reporting facility;
- 2. The facility portion of billed charges for each patient served at the facility;
- 3. The county and state of residence by zip code for each patient served at the facility;

- 4. The primary outpatient surgical procedure performed for each patient at the facility, reported by Current Procedural Terminology (CPT) codes or Health Care Financing Administration Common Procedure Coding System (HCPCS) codes: and
- 5. The primary payor for each patient served at the facility, reported as follows:
  - a. Private payors must be reported as either self-pay, commercial insurance, or workers compensation; and
  - b. Public payors must be reported as either Medicaid, Medicare, or other governmental source.

The information must be reported to the Department no later than May 1 of each year for the preceding calendar year, and must be submitted in an electronic format.

6-004 CONFIDENTIALITY AND RELEASE OF INFORMATION: All data obtained from medical records of individual patients is for the confidential use of the Department. The information will be privileged and will not otherwise be divulged or made public in order not to disclose the identity of an individual whose medical records have been used for acquiring data. All information reported to the Department pursuant to 186 NAC 6-003 will be privileged communications, will not be discoverable or subject to subpoena, and may not be used or offered or received in evidence in any legal proceeding of any kind or character.

<u>6-005 ANNUAL STATISTICAL REPORT:</u> The Department will publish an annual statistical report from information collected under 186 NAC 6-003, which will include:

- 1. The 20 most frequently performed outpatient surgical procedures by type of procedure;
- 2. The total number of persons served for each procedure identified in 186 NAC 6-005 item 1;
- 3. The total number of persons served by county and state of residence and by region of service for all procedures performed, cumulatively; and
- 4. The average billed charges for the procedures identified in 186 NAC 6-005 item 1 by county and state of residence.

The Department will use the Outpatient Surgery Service Regions (map attached) for the purpose of aggregating and reporting information.

#### 6-006 FAILURE TO REPORT:

6-006.01 The Department will impose a late fee after May 1 for failure to report pursuant to 186 NAC 6-003 of \$50 per day, to a maximum of \$1000.

<u>6-006.02</u> At the discretion of the Department a late fee may be waived on a case-by-case basis upon a showing of good cause.

