March 15, 2018

TO: Julie Kotchevar, Ph.D., Administrator  
Nevada Division of Public and Behavioral Health

THROUGH: Julia Peek, MHA, Deputy Administrator  
Nevada Division of Public and Behavioral Health

Brian Parrish, OPHIE Section Manager  
Nevada Division of Public and Behavioral Health

FROM: Christine Pool, Nevada Cancer Registry Program Manager  
Office of Public Health Informatics and Epidemiology

RE: Data Exchange Agreement

The Nevada Central Cancer Registry (NCCR) requests approval to enter into an agreement with the North American Association of Central Cancer Registries (NAACCR) to exchange resident cancer case information between participating member registries of the NAACCR.

If approved, the NCCR will receive cancer incidence reports for Nevada residents who were diagnosed or treated in another state. This will improve cancer reporting completeness rates in Nevada.

Should you have any questions about this application, please contact Christine Pool at 684-3221.
North American Association of Central Cancer Registries
Agreement for Administering the Central Cancer Registry
Inter-Registry Resident Data Exchange

This Agreement establishes the terms and conditions for the exchange of resident cancer case information between participating member registries ("Trading Partners," collectively) of the North American Association of Central Cancer Registries ("NAACCR"). This Agreement will be executed in counterparts by each Trading Partner, with each such signed Agreement deemed to be an original, and all such counterparts together shall constitute one and the same instrument. The executed counterparts of the Agreement shall be maintained by NAACCR, but NAACCR is not a party to the Agreement.

Each Trading Partner agrees to specify in detail any additional permissions and/or restrictions affecting the use, release and re-release of its information by other Trading Partners. These specifications will be included in the Addendum, hereby incorporated into this Agreement. Each Trading Partner agrees to update and keep current all information in the Addendum by informing NAACCR in writing of any changes to law statute, regulation or policy that impact this Agreement and expressly authorizes NAACCR to provide a copy of the Trading Partner’s executed counterpart (and any Addendum thereto), as may be revised or modified, to any other Trading Partner at any time.

Each Trading Partner may rescind or modify its participation in this Agreement by sending a written notice of rescission or a copy of revisions to NAACCR. Each Trading Partner acknowledges that it is its responsibility to provide written notification to NAACCR of any rescission or modification of its participation in this Agreement, including any revision of the Trading Partner’s Addendum or this Agreement.

By signing this Agreement, the central cancer registry listed below agrees to become a Trading Partner in the exchange of cancer incidence data, acting as the Sending Registry and/or the Receiving Registry with regard to resident cancer data for all other Trading Partners and hereby agrees that:

1. The Sending Registry will provide all cancer registry records and information concerning diagnosis and treatment of cancer occurring in non-residents and contained in the Sending Registry to the Receiving Registry where the reported cancer cases reside, except information specifically exempt from release by the Sending Registry in accordance with the restrictions in the Addendum.

2. Information will be provided electronically, whenever practical. The latest data core edits will be run on the data by the Sending Registry, and the data shall be formatted to follow the most current NAACCR data exchange record layout, shall contain sufficient information to be used for statistical and administrative purposes, and shall be transmitted through a mutually agreed-upon secure method that ensures against inappropriate access to the information.

3. All transmittals of cancer registry records are to be made following a timetable mutually agreed upon by Trading Partners. To ensure optimum utilization of the records, Trading Partners shall make every reasonable effort to forward all cancer case reports within eighteen (18) months of the end of the diagnosis year.

4. The information exchanged under this Agreement may only be used by the Receiving Registry for purposes authorized in Paragraph 7 of this Agreement or any other purposes authorized in writing by the Sending Registry. The Receiving Registry agrees to use records containing identifiable information exchanged under this Agreement in full compliance with the terms and conditions of this Agreement and any specific conditions required by the Sending Registry in the Addendum. Identifiable information exchanged under this Agreement may not be re-released by the Receiving Registry without written permission of the Sending Registry.

For the purpose of this Agreement, identifiable information shall be defined as in the HIPAA Privacy Rule (45 CFR 164.514).

5. Any and all data that may lead to the identification of any patient is strictly privileged and confidential, and the Receiving Registry agrees to keep all such data strictly confidential.

6. A Receiving Registry shall maintain the confidentiality of the exchanged patient identifying data and has legal protections in place under state and/or federal law to be able to protect the data from release in
any manner contrary to the terms of this Agreement. Such confidentiality shall be maintained
notwithstanding termination of this Agreement.

7. The cancer incidence data provided under this Agreement may be used for the following purposes and
as specified by the Sending Registry for:

a. Aggregated statistical tabulations and analyses;

b. Linking with appropriate databases [e.g., death certificates, hospital discharge databases, Indian
Health Service, National Death Index] as necessary for cancer registry activities intended to acquire or
enhance cancer case information;

c. Research conducted by the Receiving Registry that has been approved by the Receiving Registry’s
Institutional Review Board, unless otherwise specified in the Addendum; All other research, including
re-release of records, requires written permission of the Sending Registry;

d. Sharing of partially de-identified information with local and/or national public health agencies,
including NAACCR and the CDC/NPCR Coordinated Call for Data, and the National Cancer
Institute’s Surveillance, Epidemiology, End Results (NCI/SEER) Call for Data, and for the support of
public health programs, with an agreement that provides appropriate restrictions on the use and release
of the shared information;

e. Conducting linkages with and providing case information to the Breast and Cervical Cancer Control
Program and Colorectal Cancer Control Program under the terms of a written Memorandum of
Understanding or other means that provides for the appropriate restrictions on the use and release of
the shared information;

f. Sharing records with State Health Departments for surveillance or community health assessment
activities; and

g. Sharing of case data with other central registry entities in the Receiving Registry’s state.

8. The Receiving Registry will restrict access to cancer incidence data or identifiable information on a
cancer patient that was supplied by a Sending Registry under the terms of this Agreement from being
released to anyone not employed in the direct operation of the Receiving Registry, except as specifically
authorized within the terms of this Agreement. Employees may include those involved in the processing,
administration, quality control review, and statistical surveillance of cancer incidence data.

9. All officers, agents and employees shall keep all such data strictly confidential; and that the Receiving
Registry shall communicate the requirements of this Agreement to all officers, agents, and employees, shall
discipline all persons who may violate the requirements of this Agreement, and shall notify the Sending
Registry in writing within two working days (48 hours) of any violation of this Agreement, including full
details of the violation and corrective actions to be taken.

10. The Receiving Registry will notify the Sending Registry if, in the conduct of approved research or
other activities involving the Sending Registry’s data, there is a breach or misuse of a cancer patient’s
identifying information or potentially identifying information. Should a breach or misuse take place, the
Receiving Registry must notify the Sending Registry in writing within forty-eight (48) hours of the release
of the data, and shall take all feasible measures to mitigate loss or damages related to such breach or
misuse, including, but not limited to, bearing sole responsibility for reasonable costs, including attorneys’
fees, related to mitigating the breach or misuse.

11. Any other use or release of information from records provided to the Receiving Registry that is not
authorized by the terms of this Agreement requires the written permission of the Sending Registry.

12. In the event that the Receiving Registry receives a subpoena or other compulsory legal process
compelling disclosure of confidential data, the Receiving Registry agrees to notify the Sending Registry
within forty-eight (48) hours of receipt of the subpoena or other compulsory legal process. Additionally,
should the Receiving Registry receive such a subpoena or other compulsory legal process, it shall take all
legal steps reasonably necessary to oppose the subpoena or other compulsory legal process.
13. This Agreement shall remain in effect as to any Trading Partner from the date of its execution until a duly authorized representative of that Trading Partner notifies the other Trading Partners of a change or termination of this Agreement through written notification to NAACCR.

14. All notices required or desired to be made to this Agreement by any Trading Partner shall be sent to NAACCR as well as to any Receiving Registry of the Trading Partner.

Trading Partner:
Nevada Central Cancer Registry (NCCR)
Agency: Division of Public and Behavioral Health (DPBH)

[Signature]
DBPH Administrator
Title
Date

CONTACT PERSON:
Name: Christine Pool
Title: Program Manager
Address: 4126 Technology Way, Ste. 200, Carson City, NV 89706
Email: cpool@health.nv.gov Phone: 775-684-3221 Fax: 775-684-5999

CONTACT PERSON FOR ELECTRONIC EXCHANGE:
Name: Cathy Short
Title: Quality Assurance Coordinator
Address:
Email: cshort@health.nv.gov Phone: 702-486-0799 Fax: 702-486-0490

MAIL RECORDS TO:
Name: Christine Pool
Title: Program Manager
Address: 4126 Technology Way, Ste. 200, Carson City, NV 89706
Email: cpool@health.nv.gov Phone: 775-684-3221 Fax: 775-684-5999
Addendum to Trading Partner Agreement of Nevada

Additional permissions and restrictions on the use of cancer registry information from this Trading Partner.

Cancer case information supplied by the Nevada Cancer Registry (NCCR) can be used for any registry related purpose as outlined in the North American Association of Central Cancer Registries Agreement for Administering the Central Cancer Registry Inter-Registry Resident Data Exchange except for 7.c. The re-lease of identifiable or potentially re-identifiable NCCR data is not permitted without the prior written approval of the NCCR. This includes release for research as listed in item 7.c of the inter-registry resident exchange standard agreement.

The Receiving Registry shall indemnify, defend, save and hold harmless the State of Nevada, its departments, agencies, boards, commissions, universities and its officers, officials, agents, and employees (hereinafter referred to as “Indemnitee”) from and against any and all claims, actions, liabilities, damages, losses, or expenses (including court costs, attorneys’ fees, and costs of claim processing, investigation and litigation) (hereinafter referred to as “Claims”) for bodily injury or personal injury (including death), or loss or damage to tangible or intangible property caused, or alleged to be caused, in whole or in part, by the negligent or willful acts or omissions of Receiving Registry or any of its owners, officers, directors, agents, employees or subcontractors. This indemnity includes any claim or amount arising out of or recovered under the Workers’ Compensation Law or arising out of the failure of such Receiving Registry to conform to any federal, state or local law, statute, ordinance, rule, regulation or court decree. It is the specific intention of the parties that the Indemnitee shall, in all instances, except for Claims arising solely from the negligent or willful acts or omissions of the Indemnitee, be indemnified by the Receiving Registry from and against any and all claims. It is agreed that the Receiving Registry will be responsible for primary loss investigation, defense and judgment costs where this indemnification is applicable. The Receiving Registry agrees to waive all rights of subrogation against the State of Nevada, its officers, officials, agents and employees for losses arising from the performance of the inter-registry data exchange agreement on the part of the Receiving Registry.

Authority and Legal Requirements

NRS 457.260 Publication of reports; provision of data.

1. The Division shall publish reports based upon the material obtained pursuant to NRS 457.230, 457.240 and 457.250 and shall make other appropriate uses of the material to report and assess trends in the incidence of cancer in a particular area or population, advance research and education concerning cancer and improve treatment of the disease.

2. The Division shall provide any qualified researcher whom the Division determines is conducting valid scientific research with data from the reported information upon the researcher’s:

   (a) Compliance with appropriate conditions as established under the regulations of the State Board of Health; and
(b) Payment of a fee to cover the cost of providing the data.
(Added to NRS by 1983, 1677; A 2003, 1248; 2015, 387)

NRS 457.270 Consent required before disclosure of identity of patient, physician or health care facility. The Division shall not reveal the identity of any patient, physician or health care facility which is involved in the reporting required by NRS 457.250 unless the patient, physician or health care facility gives prior written consent to such a disclosure.
(Added to NRS by 1983, 1678; A 1993, 174)

NAC 457.140 Disclosure of information: Scientific research into cancer. (NRS 457.065, 457.240)

1. A person who desires to use the confidential records of individual patients or the statistical data of the registry for the purpose of scientific research into cancer must apply in writing to the Chief Medical Officer. The applicant must:
   (a) Set forth in the application:
      (1) His or her qualifications as an epidemiologist, physician or employee of a bona fide program of research into cancer or other qualification for using confidential information and statistical data in the registry; and
      (2) A description of the research project in which that information will be used.
    (b) Sign a statement, on a form furnished by the Chief Medical Officer or a designee thereof, in which the applicant agrees not to make any copies of the records, and to maintain the confidentiality of the information in the records in the manner required by NAC 457.010 to 457.150, inclusive.
    (c) Agree to submit to the Chief Medical Officer or the designee for review and approval any proposed publication which is based on or contains information obtained from the registry.

2. The Chief Medical Officer or the designee must:
   (a) Before a researcher is allowed access to information in the registry, make a written finding that he or she is qualified as a researcher and has a need for the information; and
   (b) Before any material based on or containing information from the registry is published by the researcher, examine, and give written approval for the proposed publication.
(Added to NAC by Bd. of Health, eff. 12-3-84; A 1-24-92; R075-98, 11-18-98)