Whereas, Congress and the Centers for Medicare & Medicaid Services (CMS) have indicated that physician-led quality measure development is a priority and many specialty societies have developed both meaningful quality measures and qualified clinical data registries (QCDRs) for physicians to demonstrate quality and report for federal Medicare payment incentives in Merit-based Incentive Payment System (MIPS); and

Whereas, Medical specialty societies devote extensive resources to measure development, data collection, data validation and ongoing measure stewardship. The data collected through QCDRs are used not only for MIPS reporting, but also for research and analysis used to support guideline development and quality initiatives; and

Whereas, CMS proposes that, as a condition of a QCDR measure’s approval for purposes of MIPS, QCDR measure owners be required to enter into a license agreement with CMS such that once a QCDR measure is approved for reporting in MIPS, it would be generally available for other QCDRs to report on for purposes of MIPS without a fee for use and without a direct license with the measure owner; and

Whereas, The CMS proposal undermines QCDR measure ownership and development and violates the intellectual property rights of QCDR measure owners, as QCDR measures are subject to copyright protection; and

Whereas, This proposal is a sudden and unwarranted reversal of the current policy that CMS adopted just last year to protect the intellectual property rights of QCDR measure owners; and
Whereas, Without the ability to license measures and collect fees to offset the cost of
developing and stewarding measures, QCDR measure owners have no way to control the
appropriate use of their measures and cannot responsibly invest in measure development; and

Whereas, QCDRs should be able to enforce their ownership rights in the QCDR measures they
develop, and to require third parties to enter into licensing agreements with measure owners
that before they can properly use QCDR measures, and these licensing agreements could
include appropriate financial remuneration and responsibility for data integrity; therefore be it

RESOLVED, That our American Medical Association actively oppose any Centers for Medicare
& Medicaid Services (CMS) proposal that would require qualified clinical data registry (QCDR)
measure owners, as a condition of measure approval for reporting in the Merit-based Incentive
Payment System and other Medicare quality payment programs, to enter into a license
agreement with CMS that would allow other QCDRs to use the owner’s measures without a fee
or without a direct license with the measure owner. (Directive to Take Action)

Fiscal Note: Not yet determined

Received: 10/31/18

RELEVANT AMA POLICY

Clinical Data Registries H-450.933
1. Our AMA encourages multi-stakeholder efforts to develop and fund clinical data registries for the purpose of
facilitating quality improvements and research that result in better health care, improved population health, and lower
costs.
2. Our AMA encourages national medical specialty societies, state medical associations, and other physician groups
to join the National Quality Registry Network and to participate in efforts to advance the development and use of
clinical data registries.
3. Our AMA supports flexibility in the development and implementation of clinical data registries. The following
guidelines can help maximize opportunities for clinical data registries to enhance the quality of care provided to
patients:
   a. Practicing physicians must be actively involved in decisions related to the development, maintenance and use of
      clinical data registries and registry data.
   b. Data elements, risk-adjustment models and measures used in the registry should be fully transparent.
   c. Registries should provide timely, actionable feedback reports to individual physicians or entities reporting at the
      organizational level.
   d. Registries and electronic health records should be interoperable, and should be capable of sharing and integrating
      information across registries and with other data sources in a HIPAA-compliant and confidential manner.
   e. Registry stewards should establish a formal process to facilitate the modification, expansion, or dissolution of the
      registry in order to accommodate advances in technology and changing clinical data needs to ensure continued utility
      of their registry.
4. Our AMA encourages physicians to participate in clinical data registries, and will encourage efforts that help
physicians identify existing registries suitable for and of benefit to their patient populations and their practices.
5. Our AMA will continue to advocate for and support initiatives that minimize the costs and maximize the benefits of
physician practice participation in clinical data registries.
6. Our AMA supports that, with the consent of the participating physician, physician-specific clinical registry data may
be used to meet third-party quality reporting requirements, in accordance with the following principles:
   a. Data should be used to improve the quality of patient care and the efficient use of resources in the delivery of
      health care services.
   b. Data related to resource use and cost of care must be evaluated and reported in conjunction with quality of care
      information.
   c. Effective safeguards must be established to protect against the dissemination of inconsistent, incomplete, invalid or
      inaccurate physician-specific medical practice data.
   d. Case-matched, risk-adjusted quality measure and resource use data are provided to physicians to assist them in
determining their relative utilization of resources in providing care to their patients.
   e. When data are collected and analyzed for the purpose of meeting quality reporting requirements, the
      methodologies used to create the profiles and report the results are developed in conjunction with relevant physician
      organizations and practicing physicians, and are disclosed in sufficient detail to allow each physician or medical
group to re-analyze the validity of the reported results prior to more general disclosure.
06, A-18