## CDC Guidance Regarding Use of Data by NHSN Groups April 16, 2019

The National Healthcare Safety Network (NHSN) group functionality is a technical feature within the NHSN application that enables healthcare facilities to share some or all of their NHSN data with a NHSN group user, i.e., a third party (other than the facility and CDC) such as a state or local health department, corporate headquarters, or End Stage Renal Disease (ESRD) Network Organization for a mutually agreed to purpose, e.g., performance improvement, required reporting. This document provides background information and guidance for prospective healthcare facility participants in NHSN groups and the NHSN group users on their roles and responsibilities and the relationship of CDC to the facilities and group users.

## For NHSN group users:

- NHSN group users are responsible for communicating to prospective healthcare facility participants in their group the group user's purpose(s), plans for data use, and the safeguards that the group user will use to protect the confidentiality of the NHSN data to which it seeks access.
- As a result of the NHSN group user's communications, facilities participating in a group should have a clear and accurate understanding of how their NHSN data will be used and by whom. Any changes to the purpose or scope of analyses should be communicated in writing to all facility users within the group and opportunities provided for facilities to consent or refrain from consenting to use of their NHSN data for the additional analytic use(s).
- NHSN group users are custodians of the data to which they gain access via the NHSN group functionality, and they are responsible for establishing, using, and maintaining appropriate administrative, technical, and physical safeguards to prevent unauthorized access or use of the NHSN data to which they have gained access. The confidentiality protections that CDC commits to providing healthcare facilities that participate in NHSN cover CDC's custodianship and use of the NHSN data for the purposes listed in the NHSN Agreement to Participate and Consent Form. However, CDC's confidentiality protections do not extend to NHSN groups; NHSN group users are responsible for assuring the confidentiality of the data to which they gain access.
- NHSN group users assume data governance responsibilities for how analysts and researchers within their organizations or external to them gain access to and use the accessible NHSN data. These responsibilities include use of data non-disclosure agreements and, when appropriate, data use agreements (DUAs), such as DUAs with external analysts and researchers whose access to NHSN data has been enabled by the NHSN group user. A DUA for analytic work that goes beyond the purposes and plans that a NHSN group user previously communicated to the healthcare facilities participating in the group should be accompanied by an informed consent process, which can be accomplished via email communications, in which facilities have the opportunity to reject use of their NHSN data for the additional purpose(s).

## For NHSN facility users:

The NHSN Agreement to Participate and Consent Form completed by healthcare facilities that
participate in NHSN describes <u>CDC's surveillance purposes</u> and provides CDC's guarantee that the
agency will restrict its use of the data submitted to the stated purposes. Further, the assurance of
confidentiality included in the NHSN Agreement to Participate and Consent Form stipulates that CDC will



- not disclose or release data without the consent of the healthcare facility other than for the stated purposes. These purposes include CDC, under specified conditions or circumstances, submitting or making NHSN data accessible to state, local, and territorial health departments or to the Centers for Medicare and Medicaid Services (CMS).
- The NHSN Agreement to Participate and Consent Form does not preclude additional uses of NHSN data by the healthcare facilities that have submitted those data to NHSN. Indeed, CDC encourages facilities to use their NHSN data for prevention and other purposes that align with the mission and goals of the participating facilities. These additional uses of NHSN by healthcare facilities include participation in NHSN groups that are established using the NHSN group functionality for research, prevention, quality improvement, or other purposes.
- Importantly, when healthcare facilities participating in NHSN decide to join a group by conferring data rights to a third party, i.e., the NHSN group user, that third party assumes responsibility for assuring confidentiality of the data that the facilities have made accessible to it. The assurance of confidentiality that CDC provides to healthcare facilities that participate in NHSN applies only to CDC's own use of the data that facilities have submitted to NHSN and not to use of data by a NHSN group user.
- When a healthcare facility participating in NHSN decides to join a NHSN group, the NHSN Facility Administrator operationalizes that decision by using the NHSN application to confer data rights to the NHSN group user. The availability of the NHSN group functionality, use of that functionality by a NHSN group user, and activities undertaken by the group user to elicit participation in their NHSN group should not be construed as CDC endorsement or approval of that group or a recommendation by CDC for a healthcare facility to join that group. It is the responsibility of the healthcare facility to understand the purpose(s) of the NHSN group, its plans for data use and sharing, and its safeguards over the NHSN data to which it seeks data access. CDC cannot be held accountable for how NHSN group users use the data made accessible to them by a healthcare facility using the NHSN group functionality.
- Healthcare facility users that join NHSN groups can expect that NHSN group users will inform the
  facilities in their groups in writing if and when the purpose or scope of the groups' analyses change.
  Additionally, NHSN facility users can expect that opportunities will be provided for facilities to consent
  or refrain from consenting to use of the groups' NHSN data for the additional analytic use(s).

