Guiding Principles of Data Sharing

- Data shall be shared according to National Institutes of Health (NIH) and NIAID guidelines. Data should be made as widely and freely available as possible while safeguarding the privacy of participants and protecting confidential and proprietary data.
- The rights and privacy of human subjects who participate in the Center’s clinical studies shall be protected at all times.
- Rapid public dissemination of influenza data and information relies upon
  - Unobstructed internal data sharing between the Center and the Center’s subcontractors and key partners.
  - Sharing of information and data within the network of Centers. Sharing information with the NIAID Center of Excellence Network in as timely a manner as possible is an essential component of being a good network partner.
  - Sharing of information and data outside of the network of Centers.
    - NIAID recognizes the need to share and disseminate surveillance data to industry, local, State, and Federal animal and human health authorities at the earliest opportunity so that, as appropriate, they can act on the information to institute disease prevention and control measures, and can develop and disseminate accurate and timely risk communication messages to the public and other key audiences. Information will be shared with animal and human health authorities ahead of public release by the Centers for the timely use of the information for instituting disease prevention and control measures. Examples of the data type that may be shared would include any avian influenza virus that has transmitted directly human-to-human or if a HPAI virus is detected in the United States, all data associated with these viruses will be released immediately to the stakeholders.
    - Data generated by the Centers must be released to the scientific community as rapidly as possible via deposition into a searchable, public international database as designated by the project officer. This principle is based on an expectation that users of the data will act responsibly to promote the highest standards of respect for the quality and the priority of the CEIRS scientific contribution and that normal standards of scientific etiquette and “fair use” will be respected within the broad scientific community using pre-publication data. Release of data also includes peer-reviewed publications, press releases, and presentations at local, national and international meetings.
    - Release of influenza virus gene and complete genomic sequences generated with Center funding will follow the NIAID Data Release and Usage Plan, which includes releasing sequence data within 45 calendar days of being generated to GenBank, a publicly searchable, international database of genetic sequences provided by the NIH National Center for Biotechnology and Information.
    - Data associated with a publication by the Center or its subcontractors, and scientific collaborators will be made available through a publicly accessible web site(s) to include the appropriate NIAID Bioinformatics Resource Center (or a similar site designated by the NIAID Project Officer) within 2 months of publication.
    - The release of various types of data, including unpublished data, from each site shall be deposited into a publicly accessible web site(s) to include the appropriate NIAID Bioinformatics Resource Center (or a similar site designated by the NIAID Project Officer) within 12 months from generation.

It is recognized that each scientific project may pose specific opportunities or challenges with respect to public data release, and therefore efforts will be made to tailor the data release guidelines accordingly with the approval of NIAID.