



Legal and Legislative Issues in Newborn Screening Workgroup COVID-19 Legal and Ethics Technical Assistance Request Form

Newborn screening programs face a number of unique ethical, social, and governance challenges during COVID-19 that may require new practices and policies to maintain their programs and meet the needs of parents, clinicians, researchers, and other NBS stakeholders. Programs are facing the difficult challenge of maintaining current program operations, potentially with a reduced workforce and less resources. Additionally, these challenges may be further complicated by the need to balance the primary goals of NBS programs with the potential uses of NBS resources and data for COVID-19 related research and public health response. To help address the potential legal and ethical challenges to NBS programs during the COVID-19 pandemic, the Legal and Legislative Issues in Newborn Screening (LLINBS) workgroup is offering technical assistance services to any NBS program officials or staff.

The workgroup provides support for APHL and state NBS programs to assess and address ethical, legal, and social issues related to public health practice and research activities related to newborn screening. The workgroup is made up of NBS lab staff, legal experts, bioethicists, public policy experts and other NBS stakeholders.

While technical assistance (TA) from the LLINBS workgroup, is NOT a substitute for advice from your state's legal counsel, we can provide a sounding board and starting place for evaluating and discussing ethical and legal challenges for NBS programs during the COVID-19 pandemic. You may not act on the basis of any TA or insight received from the LLINBS workgroup until you have sought the appropriate legal or other professional advice from your state's legal counsel.

What are the primary ethical or legal issues for which you are seeking technical assistance?

Ethical or legal challenges related to NBS programs or follow-up during COVID-19 (e.g. patient privacy and telework)

Data Sharing Agreements related to COVID-19 data or otherwise

Navigating IRB or research questions related to COVID-19 research

ELSI questions on usage of dried blood spots or other program resources for COVID-19 related work

Other

Please briefly describe the nature of your legal or ethical question or need for technical assistance:

State:

Name of Contact Person:

Email:

Please send TA request form to [Funke Akinsola](#). After submitting your request, APHL staff will review your request and coordinate a call to review your request with our Legal and Legislative workgroup experts. Please attach any additional supporting documents as needed.