



Genetics Technical Assistance Team Site Review Process



1. A request for technical assistance is sent to the NNSGRC using the application form provided for this activity. The application form denotes the nature of the review (unbiased technical assistance), its purpose (assistance in integrating genetics into public health programs), the review procedure (2 ½ day review including exit interview), and necessary ancillary items to be supplied (organizational chart, advisory committee members, listing of internal stakeholders, related documents, etc.). The assistance request must be from an appropriate health official (e.g. state health director, chair of a statutory genetics advisory council) suggesting possible dates (either Monday through Wednesday, or Wednesday through Friday) and outlining specific questions to be addressed during the review. The health official requesting should have decision-making authority and is responsible for informing all appropriate health department personnel of the request (e.g. MCH Director, Laboratory Director, Occupational and/or Environmental Health Director, Vital Statistics Director, Chronic Disease Director, Office of Public Policy, etc.).
 - a. If there is a state Genetics Advisory Committee, the chairman needs to acknowledge this request.
 - b. The request is in the form of a letter with specific issues and/or questions to be addressed by the site review team.
 - c. Enclosed with the letter should be:
 - the NNSGRC application form;
 - a tentative schedule for the visit
 - a departmental organization chart including indications of personnel and programs involved with genetics activities
2. The NNSGRC office surveys its Genetic Technical Assistance Team regarding availability and responds to the request with a suggested date for the site review and a request for additional background materials (outlined in the application) for the team including:
 - documents describing genetic-related programs in the current public health system and/or a copy of the state genetics plan;
 - reports on activities implementing genetic-related programs in the current system or activities implementing the state genetic plan;
 - copies of all appropriate genetic legislation and associated rules or regulations;
 - genetic-related sections of the Title V and Chronic Disease block grants;
 - genetics laboratory and follow-up protocols;
 - educational materials for consumers and providers; and
 - pertinent financial information (e.g. allocation of funding for genetic services).
3. The host site and NNSGRC office agree upon dates for the two and one-half day site review.
4. The NNSGRC coordinates the travel arrangements for the Genetic Technical Assistance Team through UTHSCSA according to university travel regulations. Hotel rooms are reserved at a hotel usually recommended by the state host. Travel expenses are reimbursed by NNSGRC and a modest honorarium is provided for non-state and non-federal team members upon completion of the final written report.

5. NNSGRC sends a letter of confirmation to the host site reminding them about submitting 5 copies of the program materials listed in item (2) no later than two weeks before the site visit. Materials are sent to Team members from NNSGRC when received from host.
6. NNSGRC and site set an agenda for the site visit predicated on the needs of the state host. A prototype agenda for a minimum of 2 ½ days is listed below. States with complex programs with multiple, distant sites may require an additional day for review.
 - a. Day 1: 8 a.m. to noon – NNSGRC Genetic Technical Assistance Team members meet with personnel assembled by the host site to review the current (or anticipated) program and to ask questions. Meeting generally will consist of an overview followed by presentations concerning details considered to be important to addressing the issues of the review.
 - b. Day 1: 1 p.m. to 5 p.m. – Genetic Technical Assistance Team tours host facility and meets with advisory committee members, physicians, program staff, etc. that have been selected and organized by host site as a means of addressing the issues.
 - c. Day 2: 8 a.m. to 5 p.m. - Continue meetings with program staff, physicians, and others considered to be stakeholders either onsite or at offsite facilities, as arranged by the host site. Meetings may include travel to separate cities. This travel is arranged by mutual agreement between NNSGRC and host site with the intent of accessing information helpful to the team in addressing the issues.
 - d. Day 2: 5 p.m. to 9 p.m. – Genetic Technical Assistance Team meets to assimilate answers to questions and make assignments for oral and written reports.
 - e. Day 3: 8:30 a.m. to 11:00 a.m. – Genetic Technical Assistance Team and representatives of host site meet for Exit Review. Host coordinator selects and coordinates invitations of attendees who may include the state health officer, advisory committee members, program managers, consumers, representatives of professional groups, etc. One by one, each issue or question submitted by the host, as well as any additional issues or questions raised by the Genetic Technical Assistance Team, are reviewed. [Option exists to extend travel time to allow for partial completion of written report by team members following Exit Review.]
7. NNSGRC Office coordinates completion of a written report addressing the issues initially outlined and any others that team members might identify with specific reference to the publication, *Integration of Genetic Services into Public Health – Guidance for State and Territorial Programs from the National Newborn Screening and Genetics Resource Center*, Community Genetics 2001; 4:175-196. A final written report with multiple copies is provided to the requestor 6 to 8 weeks following the Review.