

Update on Genetic System Assessment Project

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Project Aims

1. Identifying a set of measures to be included in a Genetic Services Assessment Program
2. Testing the feasibility of reporting on the list of measurements
3. Assessing the feasibility of adoption and implementation of a Genetic Services Assessment Program

List of Measures to Consider

- From literature review, existing guidelines, and key informant interviews, 61 measures were identified for expert panel review.

Domains Covered

- Access
- Data management
- Health information technology
- Medical home; care coordination and integration; patient-provider interactions
- Workforce
- Quality improvement
- Process of care outcomes (screening, referrals)

A Group Process

- Expert panel met in person in May to decide on a set of measures to include in the assessment tool that would improve the quality of genetics services.
- Each expert panel member ranked each measure according to 3 sets of criteria on relevance, evidence, and feasibility.
- Scores were computed for each measure and then the measures retained were discussed further to achieve consensus.

Relevance

- Meaningfulness
- Health importance
- Financial importance
- Cost effectiveness
- Strategic importance
- Controllability
- Variance among systems
- Potential for improvement

Scientific Soundness

- Clinical evidence
- Reproducibility
- Validity
- Accuracy
- Risk adjustment
- Comparability of data source

Feasibility

- Precise specification
- Reasonable cost
- Confidentiality
- Logistical feasibility
- Auditability

Delphi Process

Summary

Domains Identified

- Domain (# of measures)
 - Access (1)
 - Data linkage and management (4)
 - Patient tracking and registry (4)
 - Performance reporting and improvement (3)
 - Workforce (4)
 - Service integration (1)
 - Care management (8)

Access: Access to genetic services

- Practice has established processes, standards, or policies on:
 - Scheduling appointments
 - Coordinating visits and referrals with other health care providers
 - Providing same day visits or urgent care
 - Triaging how soon a patient needs to be seen
 - Providing telephone advice
 - Consulting via secure email with physician
 - Providing consultation via telemedicine
 - Having outreach clinics

Data Linkage: Utilization of data sources

- The state genetics program uses the following data sources:
 - State level clinical genetics database
 - Newborn screening database
 - Vital statistics: birth, fetal death, death certificates
 - Statewide hospital discharge data
 - Medicaid or Medicare eligibility, claims, provider datasets
 - Cytogenetics registry
 - Birth defects registry
 - Population based cancer/tumor registry
 - Directory of genetic service providers and referral sources
 - Cytogenetics laboratory databases collected by ACT
 - Federal census data

Workforce: Training and education

- A well-prepared community of health care and public health practitioners with genetics expertise is available in numbers sufficient to meet the needs of the public. These practitioners are capable of communicating the benefits, risks, limitations, and implications of genetic testing and accurately interpreting and appropriately utilizing genetic information in clinical and public health practice.
 - State provides for implementation of a needs assessment to assess current and future capacity of genetic service providers.
 - State implements strategies to increase the number of health care providers and public health professionals with genetics expertise, particularly among minorities, and to provide funding to support them.

Service Integration

- Genetics services include integration of genetic medicine into public health programs and health systems:
 - State provides for access to medical support services necessary for the diagnosis and management of genetic and congenital disorders.
 - Laboratories associated with a genetics unit participate successfully in available proficiency testing programs.
 - State ensures adherence to licensing requirements, published guidelines, standards, and regulations.

Next Steps

- Expert panel to review the limited list of measures and finalize the language
- Determine weights and scoring for each measure
- Conduct pilot test to assess the feasibility of implementing the measures at two sites

Patient Tracking and Registry: Newborn Screening

- % of infants screened for all state-mandated screenings

Care Coordination: Tertiary prevention

- The state has the following secondary prevention programs:
 - Prenatal screening - Maternal serum alpha-fetoprotein and associated marker screening, maternal infections, maternal disease, carrier status, fetal ultrasonography, AMA, and family history
 - Newborn screening - All newborns are screened at birth for certain treatable and preventable heritable disorder and appropriate follow-up
 - Newborn hearing screening – All newborns receive hearing screening and appropriate follow-up
 - Childhood screening - Screening for genetically determined developmental disabilities, sensory deficits, and other disorders
 - Adulthood screening – Presymptomatic testing, diagnostic testing/screening, carrier testing/screening for neurodegenerative diseases in selected populations, cancer susceptibility, and diseases related to aging

Thank you

Questions or Comments?