

# Genetic System Assessment Project

Heartland States Genetics Regional  
Collaborative Annual Meeting

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## Background

- Using metrics to track quality has been a common strategy in chronic disease management, but it has been critically lacking in assessing genetics services.
- As genetic testing and screening programs expand, there is an urgent need to develop quality measurement to evaluate genetic services.

## Health Care Quality

- Institute of Medicine (IOM) outlined 6 attributes of health care:
  - Safety
  - Effectiveness
  - Patient-centeredness
  - Timeliness
  - Efficiency
  - Equity

## Definition of Quality

- Right Care
- Right Patient
- Right Way (e.g., technical; touch quality)
- Right Time
- Right Amount

## Measuring Quality

- Donabedian model
  - Structure
  - Process
  - Outcome
- Measures of quality – examples
  - Structure: Policy on staffing ratio (counselor/patient)
  - Process: checklist for assuring right patient gets right screenings
  - Outcome: number of patients getting screened

## The Heartland Genetics Project

- The goal of the project is to develop, pilot, and assess the feasibility of a Genetics Services Assessment program in the Heartland Region, in consultation with regional and national colleagues

## Specific Aims

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

## Aim 1: Methodology

- Creating a set of quality measurement:
  1. Conducted literature review
  2. Compiled a list assessment measures
  3. Held expert panel conferences
  4. Determined final list of metrics

## 1. Literature Review

- Compiled a library including references from MEDLINE search, web searches, and key informant interviews
- Reviewed all references and limited references to those that met the criteria addressing quality assessment in genetics
- Generated an evidence table including all relevant references
- Published a manuscript on the literature review

## 2. Compile a list of measures

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

### 3. Expert Panel Conference

- Recruited experts in both genetics and quality to serve on the panel
- Had Panel members review a preliminary list of measures and applied Delphi Technique to create a smaller set of metrics for consensus discussions

### **Delphi: A Group Process**

- Expert panel met in person 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 on a 5-point Likert scale.
- Scores were computed for each measure and then the measures retained were discussed further to achieve consensus.

## Delphi Process and Panel Consensus

- Conducted 3 iterations of the Delphi process and consensus discussions
- Expert panel identified 25 measures for pilot testing

## Aim 2: Methodology

- Pilot testing the metric set
  - The states of Hawaii and Washington served as pilot sites. Both states are consistent high performers in providing a large scope of genetic services and therefore have the capability to provide information on every measure.
  - The state genetics coordinator completed the instrument based on feedback from state genetic counselors and other clinicians. Study team conducted site visits.

## Pilot Testing

- Results generated from the pilot test informed changes in language to enhance clarity, identified processes to improve feasibility for data collection, and provided support documentation to demonstrate how a measure may be met.

## Pilot Testing Results

- Based on pilot results, the final metric set contains 16 measures, classified into 5 domains:
  - Service capacity- 5
  - Access to genetic services- 3
  - Clinical processes and quality improvement- 2
  - Performance reporting- 4
  - Workforce-2



## Domains Identified

- 1) **Service capacity**
  - Preconception services; Early screening and diagnosis; Information referral and coordination; Quality improvement; Family or patient feedback
- 2) **Access**
  - Access; Staffing; Accessibility/availability to genetic services
- 3) **Clinical processes and quality improvement**
  - Genetics/medical records; Patient ratings of physician-patient interaction

## Service Capacity: Preconception Services

- The state has the following programs:
  - Folic acid education
  - Preconception screening
  - Teratogen information services

## Domains Identified

- 4) **Performance reporting/improvement**
  - Security of electronic information; Documentation of data sources; Data linkages; Newborn screening information system
- 5) **Workforce**
  - State staffing; Workforce training adequacy

## Performance Reporting: Documentation of Data Sources

- The state genetics program has or uses the following data sources:
  - Newborn screening database
  - Birth defects registry
  - Cytogenetics registry
  - Birth defects registry
  - Population based cancer/tumor registry
  - Directory of genetic service providers and referral sources
  - Child health profile including medical home
  - Claims or reimbursement
  - Pregnancy risk assessment monitoring system

## Conclusion

- Measures describing data systems, service capacity and delivery assess the process of providing care and potential for improvement.
- This study is the first opportunity to develop a comprehensive set of genetics-specific quality measures for both clinical and public health genetics.

## Public Health and Policy Implications

- The application of these metrics may quantify progress made in the field and identify areas for quality improvement.
- This study may help focus policy-makers' attention to the evaluation of quality and cost effectiveness of genetic services and additional outcome-oriented, health services research in genomic medicine.

## Next Steps: Aim 3

- States Genetics Coordinators to review the finalized metrics for implementation
- Evaluate implementation of metrics within the Heartland states:
  - Determine weights and scoring for each measure
  - Identify documentation/evidence in support of achievement of metrics
  - Assess barriers and facilitators of implementing the measures

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