



PREMISES AND SUMMARY OF CLUSTER 2 ACTIVITIES

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Premise 1:

- Inequities in access to genetic health care have diverse origins

Premise 1B:

- Inequities in access to genetic health care have diverse origins
 - Inequities include those secondary to geography

Premise 1C:

- Inequities in access to genetic health care have diverse origins
 - Inequities include those secondary to geography
 - Inequities may arise secondary to age

Premise 1D:

- Inequities in access to genetic health care have diverse origins
 - Inequities include those secondary to geography
 - Inequities may arise secondary to age
 - Inequities include those secondary to an inadequate, geographically uneven and educationally non-uniform genetic work force

Premise 1E:

- Inequities in access to genetic health care have diverse origins
 - Inequities include those secondary to geography
 - Inequities include those secondary to an inadequate genetic work force
 - Inequities include those deriving from the need for ‘supersubspecialist’ expertise – individually rare and complex disorders

Premise 1F:

- Inequities in access to genetic health care have diverse origins
 - Inequities include those secondary to geography
 - Inequities include those secondary to an inadequate genetic work force
 - Inequities include those deriving from the need for 'supersubspecialist' expertise
 - Inequities include those secondary to diagnostic class – extraordinary disproportion of money devoted to the tiny proportion of individuals with genetic disorders and birth defect identifiable through newborn screening

Premise 2:

- Clinical Genetics activities should be a central focus of this HRSA initiative – along with laboratory and public health efforts

Premise 3:

- Each Region should be a crucible within which ideas are tested
- Corollary – Premature ‘nationalizing’ of activities and prematurely creating explicit objectives at a national level are counterproductive
- Corollary – Failure is to be expected; i.e. not all tested ideas are going to be winners

DESIGN OF CLUSTER 2

- Develop an Advisory Core – clinical geneticist representatives from each State
- Develop objectives that correspond to the listed premises
- Create a central resource for coordination of actions related to those objectives

OBJECTIVES OF CLUSTER 2

1. Improve geographic maldistribution of access to ‘supersubspecialists’ through exchange clinics
2. Improve geographic maldistribution of access through formalizing of long-distance consultation
3. Improve geographic maldistribution of access through telemedicine approaches
4. Decrease problems related to access by age through exploration of issues of transitions to adulthood
5. Increase dissemination of expert knowledge through regional visiting professorships
6. Increase dissemination of expertise through sharing of patient-oriented resources

Objective 1: Exchange Clinics

- Five exchange clinics have been arranged and completed
- Over 35 families were seen by the visiting geneticist as part of a consultation with the host geneticist.

Overall grade: D (near failure)

Objective 2: Long Distance Consultation

- Online directory being explored
- Reviewing licensure, liability, and reimbursement issues
- Will contact other specialties/individuals using formal long-distance consultations

Overall grade: I (incomplete)

Objective 3: Telemedicine

- Conducted literature review
- Contacted centers in the United States with telegenetic services
- Draft of the summary document has been created

Overall grade: A- (successful)

Objective 4: Transitions to Adulthood

- Transitions to Adulthood conference, held in Milwaukee on November 18th and 19th, 2005, and attended by a total of 54 individuals from six of the seven states in Region 4
- List of transition resources posted on the Region 4 website
- Submitted a proposal with suggested committee members to the American College of Medical Genetics (ACMG) to create policy statement on transitions

Overall grade: A (highly successful)

Objective 5: Visiting Professorships

- Six visiting professorships have taken place, two in conjunction with exchange clinics
- Evaluations have been positive
- Two upcoming visiting professorships this fall

Overall grade: B (partially successful)

Objective 6: Sharing of Patient-Oriented Resources

- Letters have been sent out to genetics clinics in Region 4 requesting patient-oriented resources.
- Resources will be made available on the Region 4 website.

Overall grade: I (incomplete)

What have we learned –

Efforts to reduce inequities of access to care require time and time commitments of a clinical genetics community that, for the most part, is already stressed for time to complete the essential activities of their jobs.

What have we learned –

Future emphases should include

- ✓ Exploring ways to increase the workforce of counselors and physician geneticists
- ✓ Identifying efficiencies that can be incorporated into genetic practices
- ✓ Testing alternative models of care

CLUSTER 2

- Inequities in access to genetic health care have diverse origins
- Clinical Genetics activities should be a central focus of this HRSA initiative – along with laboratory and public health efforts
- Each Region should be a crucible within which ideas are tested
- Efforts to reduce inequities of access to care require time that is unavailable within the genetics care community