

HRSA Genetics Collaboratives Feedback Survey

November 2010

Please indicate the regional collaborative you represent:

- _____ Region 1 –New England Genetics Collaborative
- _____ Region 2—New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services
- _____ Region 3—Southeast NBS & Genetics Collaborative
- _____ Region 4—Region 4 Genetics Collaborative
- _____ Region 5—Heartland Genetics and Newborn Screening Collaborative
- _____ Region 6—Mountain States Genetics Regional Collaborative Center
- _____ Region 7—Western States Genetics Services Collaborative

Questions about Your Regional Collaborative (RC)

Please take a moment to reflect on the previous 7 years...

1. What have been your RCs biggest successes?
 - a. For each of the successes above, what steps has your RC taken to ensure sustainability?
Which of these was most successful?

 - b. What steps does your RC hope to take to move these successes forward? (E.g. continued funding, moving to National Coordinating Center (NCC)/nationalize, activity has become self-sustaining.)

2. What are the top **two or three** biggest challenges or failures that your RC has had over the past 7 years?

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November 2010

- c. In thinking about the genetic and newborn screening service needs for your region as well as the major outcomes to be addressed by your collaborative in the years to come, are there any gaps between the needs that you see and the services that your collaborative will be able to provide? Please describe.

Questions about the collaborative work between the RCs, NCC, and HRSA

1. Please describe what your RC feels should be the major outcomes of the collaborative work between the RCs, NCC, and HRSA for the next 10 years:
 - a. What NEW activities are integral to achieving these outcomes?
 - b. Please describe what existing activities your RC believes should be a PRIORITY for the collaborative work between the RCCs, NCC, and HRSA for the next 10 years:
2. HRSA has identified four major theme areas of focus in the years ahead: delivering genetic services via a life course approach, meeting state public health needs, improving genetic literacy of the public, and improving genetic literacy of providers.
 - a. What does your RC see as the role of the RCs and NCC in collaboratively addressing each of these areas of focus?
 - b. To address each of these areas of focus, what specific kinds of activities could be undertaken by the RCs and NCC collaboratively?

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November 2010

3. Please comment on how you feel the HRSA Genetics Collaboratives should be structured and funded (e.g. base and priority funding). What worked in the past? What did not? Should there be any changes or re-arrangements to the current infrastructure?

4. Please comment on how you feel the National Coordinating Center should be structured and funded. What worked in the past? What did not? Should there be any changes or re-arrangements to the current infrastructure?

Any other observations you'd like to share: