



National Coordinating Center
for the Regional Genetic Service Collaboratives

***NCC
Today and
in the Future***

***Heartland Annual Meeting
April 30, 2015***



What I will cover today

- NCC/RC Healthcare Access and Financing Meeting June 15, 2015
(a project of the NCC/RC system)
- ACT Sheet update
- Brief NCC workgroup update
- NCC activities during the next 2 years
- What NCC and RC's can do to prepare for the 2017 funding cycle



NCC/RC Healthcare Access and Financing Meeting



Save the Date

**June
15, 2015**

**A Dialogue: Addressing and Paying
for Genetic Services
Across Delivery Systems**

Register [HERE](#) and learn more

Bringing together insurers, genetics providers, primary care providers, consumers, public health, and federal partners for a discussion about the genetic/genomic services needed, barriers to accessing those services, and solutions in delivering and covering genetic services by developing frameworks/algorithms for delivering and paying for genetic services across delivery and payment environments.

Sponsored by the:



**Where?
Hyatt Capitol Hill,
Washington, D. C.**

Additional Questions? Contact Alisha Keehn: akehn@acmg.net, or (301) 718-9603



ACT Sheets

- Secondary Findings ACT Sheets under review
- Algorithms for LSDs developed and under review
- LSD NBS ACT Sheets revised and under expert review

Expect ACT Sheets and Algorithms to be on website by end of summer 2015, pending ACMG board approval.



NCC/RC Funding Cycles 2004-present

- RC's 2012-2017: third funding period (5-year awards)
- NCC: 2012-2015, cooperative agreement, ending May 31, 2015.
- March 23, 2015 received NOA for a 2-year funding period (June 1, 2015 -May 31, 2017)



NCC Year 3 In Brief

- NCC/RC system evaluation: data collection tool for final 3 years of RC funding finalized
- NCC Medical Home Workgroup
 - Excellent Care Coordination Practices Project
 - Identified 30 practices, 24 interviewed
 - White paper with results to be shared 5/15
- NCC Telegenetics Workgroup
 - Multiple national meeting presentations and publication in draft, 2013 survey on current genetic professional utilization of telemedicine



NCC June 1, 2015 –May 31, 2017 (New Grant Period)

- **3 Goals of NCC:**

- Develop a Framework for regional genetic care centers (RGCC) that reflect the needs of diverse regions;
- Provide an infrastructure that strengthens communication and collaboration between the RCs, offers technical and clinical expertise as needed, promotes and disseminates outcomes of RC activities of national significance, facilitates partnerships with federal and non-federal entities, and evaluates the impact of RC activities; and
- Implement a national genetics education and consumer network (NGECN) that provides access to genomic information and resources that cover the lifespan for consumers and the public.



NCC June 1, 2015 –May 31, 2017
(New Grant Period)

- **NGECN** and NCC will be even more completely integrated together. Genetic Alliance will continue to lead the NGEEN effort within NCC. NGEEN will continue to focus on developing tools and resources that link patients to information and services.

- NCC will devote considerable effort to developing recommendations for a **regional genetic care center model**:
 - 2 new workgroups to be formed: Direct Service and Public Health Infrastructure
 - Needs assessment (to be completed by 12/15)
 - Recommendations to HRSA spring 2016



NCC: What will remain similar for 2015-2017

- NCC will continue to provide an **infrastructure that strengthens communication** and **collaboration** between the RCs through:
 - *NCC Collaborator*, monthly PD/PM calls; and an annual in-person PD/PM meeting
 - *NCC Workgroups*. NCC will continue to convene subject matter workgroups in order to bring together the 7 RCs and national experts around common topics/themes/work
- NCC will continue to offer **technical assistance** and clinical expertise as needed
 - E.g. Telemedicine support through Dr. Flannery's expertise
- NCC will continue to promote and disseminate outcomes of RC activities of national significance
- NCC will continue to **facilitate partnerships** with federal and non-federal entities
 - E.g. AAP, AUCD-LEND, Title V
- NCC will continue to **evaluate the impact of RC activities** through the NCC/RC system evaluation framework established in the current funding cycle with the same evaluation measures through 2017.
- NCC will bridge between public health **long-term follow-up** and the NBSTRN LTFU work through facilitating pilots of the public health common data elements (CDEs) in the longitudinal pediatric data resource (LPDR).



What else will remain similar

- NCC will continue to offer **technical assistance** and clinical expertise as needed
 - E.g. Telemedicine support through Dr. Flannery's expertise
- NCC will continue to promote and disseminate outcomes of RC activities of national significance
- NCC will continue to **facilitate partnerships** with federal and non-federal entities
 - E.g. AAP, AUCD-LEND, Title V
- NCC will continue to **evaluate the impact of RC activities** through the NCC/RC system evaluation framework established in the current funding cycle with the same evaluation measures through 2017.
- NCC will bridge between public health long-term follow-up and the NBSTRN LTFU work through facilitating pilots of the public health common data elements (CDEs) in the longitudinal pediatric data resource (LPDR).



NCC June 1, 2015 –May 31, 2017

What will be different:

- NCC Workgroups will be reduced in number and call frequency.
- NCC evaluation workgroup will focus on needs assessment development. (Core set of common needs assessment elements that all 7 RCs will utilize in their needs assessment activities in the next 12-18 months.)



Looking toward the 2017 Funding Cycle

- NCC and RC's will be simultaneously applying for renewed funding
- In preparation for this, beginning June 1, 2015, NCC will engaged in a focused, time-sensitive information gathering and data analysis at the regional and national levels regarding the future needs for genetic services
- This information will help shape NCC and RC's proposals for the 2017 NCC/RC grants



What is different about this next cycle?

- The US healthcare system is rapidly changing, and these will continue regardless of the Supreme Court decision(s) about ACA:
 - Alternative payment models will grow
 - “Bundled payments” – to systems, caring for populations
 - Payment tied to value and outcomes
 - Less care will be provided in hospitals and physician’s offices
 - Rise of technology, like virtual visits
 - Patient self-care
 - Precision Medicine Initiative
 - See Modern Healthcare e-mail newsletter, Eric Topol’s books, etc.



The Big Question: In Light of these changes, how should NCC/RC System Mission and activities change?

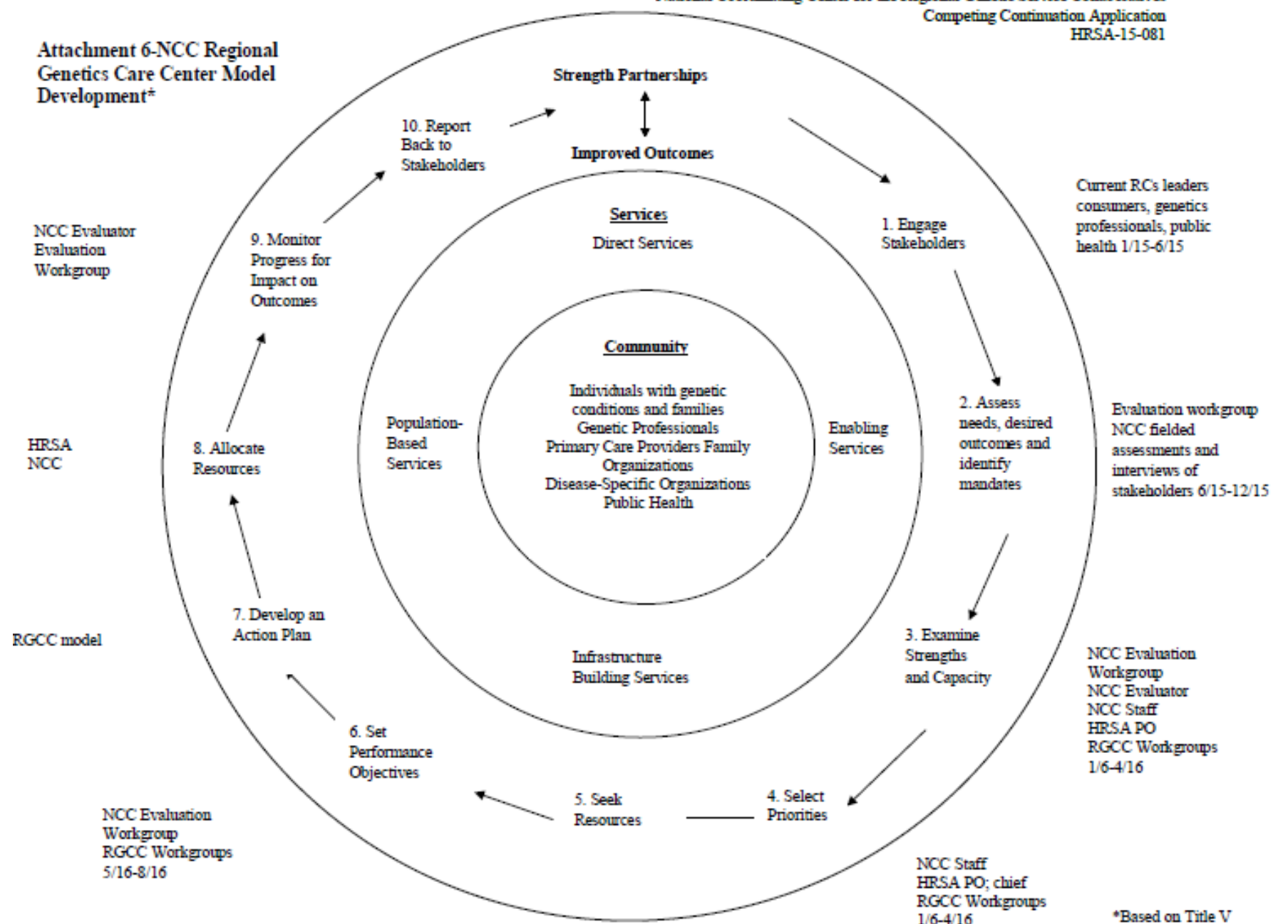
- This is your opportunity to help!
- In essence you can help inform what HRSA will be looking for in the FOA's for NCC and RC's in 2017,
 - We can anticipate that these FOA's will be forward-looking and already confronting the changing healthcare environment



What NCC is doing now to prepare for June 2015 and 2017?

- Holding listening sessions at ACMG Annual Clinical Genetics Meeting, building off of the initial discussions at the November 2014 NCC/RC PD/PM Annual Meeting around what constitutes genetic services.
- Finishing current NCC workgroup projects by June 1, 2015 (exception to this is NCC ACA activities)
- Engaging with national partners around needs assessments (e.g. Title V needs assessments)
- Utilizing the NCC/RC evaluators through the evaluation workgroup to develop a common core set of needs assessment measures that all RCs will utilize in conjunction with their own needs assessments.

**Attachment 6-NCC Regional
 Genetics Care Center Model
 Development***



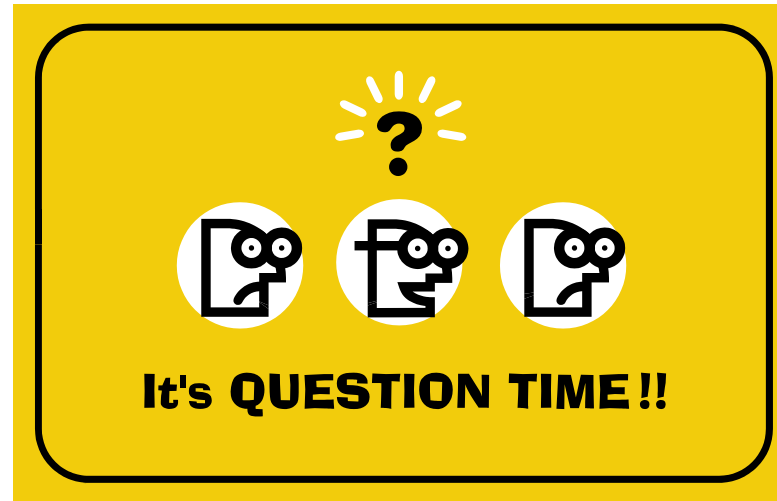


Link to complete listening session questions/discussion online

- <https://www.surveymonkey.com/r/Q5DFQP9>
- Fillable pdf file available
- Word document available



Questions?



Contact us:

NCC Project Director, Michael S. Watson, PhD, mwatson@acmg.net

NCC Medical Director, David Flannery, MD, dflannery@acmg.net

NCC Project Manager, Alisha Keehn, MPA, akeehn@acmg.net

NCC LTFU Project Manager, Amy Brower, PhD, abrower@acmg.net

NCC Evaluator, Debbie Maiese, MPA, dmaiese@acmg.net

NCC Project Coordinator, Megan Lyon, BA, mlyon@acmg.net