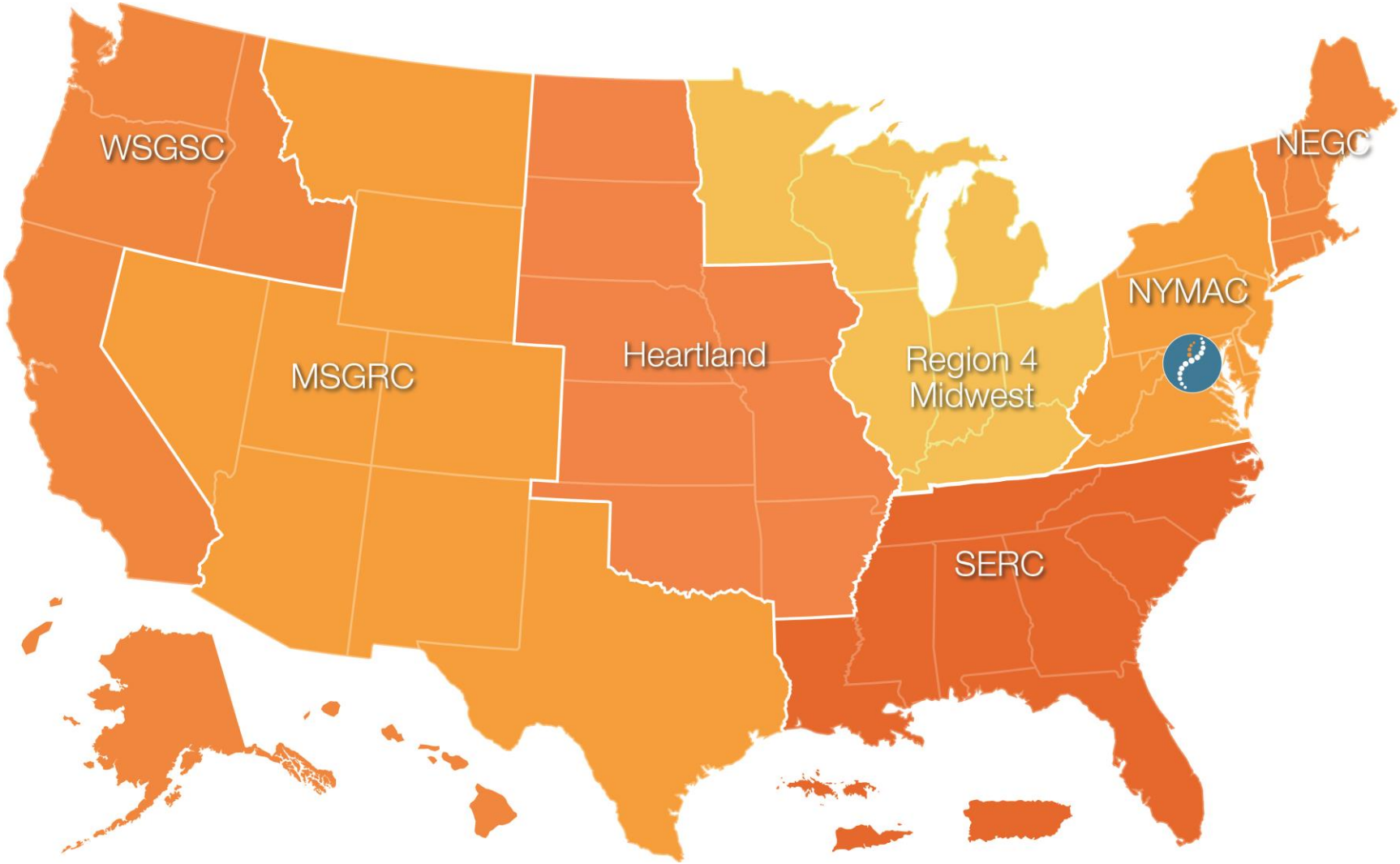
NCC
National Coordinating Center
for the Regional Genetic Service Collaboratives

2014 Updates from the National Coordinating Center for the Regional Genetic Service Collaboratives (NCC)

Providing Resources for Bridging Genetics, Primary Care, and Public Health, and for Bringing Genetics to Local Communities

The NCC is funded by *U22MC24100*, awarded as a cooperative agreement between the Maternal and Child Health Bureau/Health Resources and Services Administration, Genetic Services Branch, and the American College of Medical Genetics.

NCC/RC System

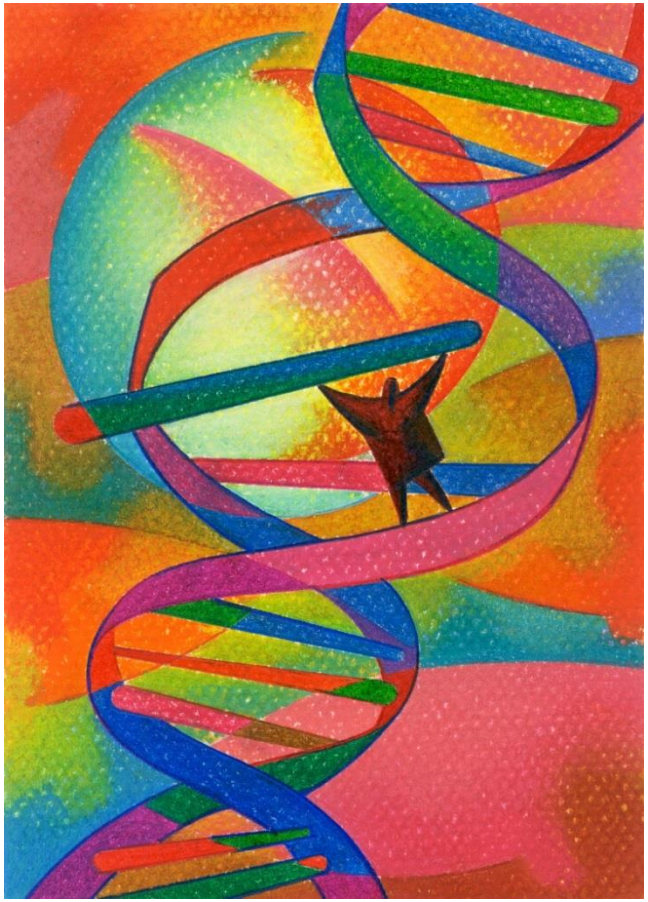


Structure of NCC

- Cooperative agreement between GSB/MCHB/HRSA and American College of Medical Genetics and Genomics (ACMG) awarded for 3 years

- National Genetics Education and Consumer Network (NGECN) is part of the NCC and is led by Genetic Alliance (via subcontract through ACMG).

- Broad charge to facilitate the work of the RCs (as a centralizing convener)



Topics of this Talk

- National Evaluation
  - Process
  - Results
  - Future Plans
- NCC Activities
- NCC Workgroups
- ACMG Updates

Evaluating Our Work and Showing our Impact

How much did we do?

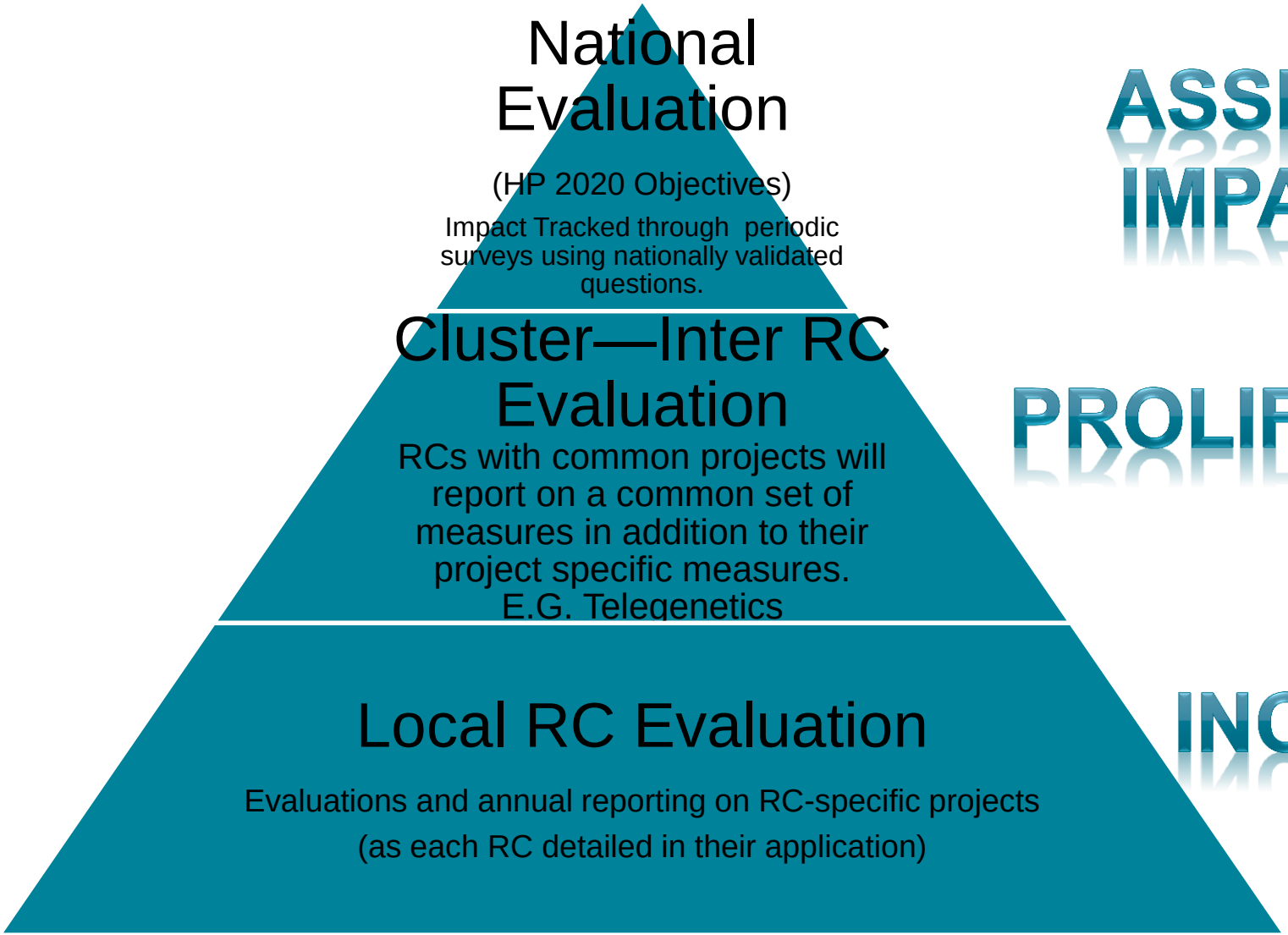
How well did we do it?

Is anyone better off?

– Goals of the NCC/RC Evaluation Program:

- Show that funds expended for the collaboratives are having a real and measurable impact, and are worth sustaining
- Demonstrate the value of a regional approach
- Measure NCC/RC activities in the context of national indicators, *Healthy People 2020*

3-Tier Evaluation Process
ASPIRE



ASSESS IMPACT

PROLIFERATE

INCUBATE

Year 1: Establishing the System

- Developed a Framework
  - *Healthy People 2020* Objectives:
    - MICH-30, MICH-31, MICH-32.2, MICH 32.3, DH-5
  - NCC/RC Grant Guidance
  - HRSA Priorities
    - Medical Home
    - Newborn Screening (NBS) Capacity Building
    - Collaboration
    - Patient Protection and Affordable Care Act
    - NBS Long-term Follow-up
    - Transition from Pediatric to Adult Care

Sources: HRSA-12-138 and 12-139, 2012 Grant Guidance

- Identified Activities for Common Measurement
- Achieved Consensus on Measures and Protocols
- Established First-year Baselines
- Conducted Consumer and Genetic Provider Surveys
- Guiding Principles:
  - Include partners' activities partially supported by RCs' funds
  - Provide unduplicated counts of participants and activities
  - Standardized categories of reporting professional disciplines
  - Used existing measurement protocols

Parallel Structures

NCC-Collected

National Data Collection

Using CSHCN Survey Questions

- ACMG Clinical Directory
- GA Organizational Network

Aims to answer the "good to know" common questions about individuals with heritable conditions *prior* to ACA Implementation:

- Medical Home
- Care Coordination
- Transition

Collected & Reported
2013, 2015, 2017

National Evaluation

HP 2020 Objectives

Impact tracked through periodic surveys using nationally validated questions.

RC-Collected

NCC/RC system Common Priority Selection and Measurement

- **5+ RCs=National Evaluation Priority**
- **Selection of a *minimum common set of questions* for each measure.**
  - **Medical Home**
  - **Collaborators**
  - **Education/Training/**
  - **Website/Social media Utilization**

Aims to show the value of regionalized structure

- **Highlight common priority areas**

Collected & Reported Annually

First Year Common Measures and Findings

(June 2012- May 2013)

- Common Measures:
  - Education & Training In-person, Webinars, and Teleconferences
  - Public Information Websites and Social Media
  - Collaboration Consumer & Organizational Engagement
  - Access to Care - Medical Home RC Activities
  - Newborn Screening Capacity Building State & Territorial Adoption of CCHD and SCID RUSP
  - RC Activities highlights

- Findings:
  - RCs work with 442 organizations and more than 4,400 providers and consumers
  - 145 RC education and training sessions reached more than 2,100 participants, nearly a third of whom were consumers

Collaboration Findings

- From the Working Together Survey*
  - Context of the Collaboration –well timed & responsive to issues
  - Structure of the Collaboration – effectively communicates and are working together
  - Collaboration Process – advanced by strong leadership & high trust
  - Collaboration Process – goal oriented, but monitoring & feedback could be improved

* *Working Together: A Profile of Collaboration* (Chrislip & Larson, 1994)

National Evaluation Successes

- Excellent demonstration of the system-wide collaboration and partnership:
  - 9-month process
  - NCC and RC staff contributed considerable time and effort.
- Collected year-1 baseline data and reported to HRSA and to each RC.
- NCC/RC system committed to demonstrating IMPACT of the system as a whole. (It's easy to tell the story of one, it gets harder to tell the story of the whole group.)
- Conducted Consumer and Genetics Professionals surveys.
- Recommended to HRSA a Genetics Condition Question on future Child Health Surveys.

Year 1 Activity-- NCC Genetics Professional Care Coordination and Transition Survey

Respondents:

- Practice Settings (n=85)
  - 42% university hospitals
  - 22% children's hospitals
  - 29% other clinical practice settings
  - 6% unknown (respondent ID not available)

Disciplines

- 53% medical geneticists
- 28% genetic counselors
- 1% genetic nurses
- 12% other
- 5% unknown (respondent ID not available

- MHI and Got Transition? instruments use a four-level scoring system (Level 1 – 4).
  - Level 1 is the lowest level
  - Subsequent levels include the items in Level 1 and build in additional items

- Considered a "continuum of quality." (Source: Cooley 2003)

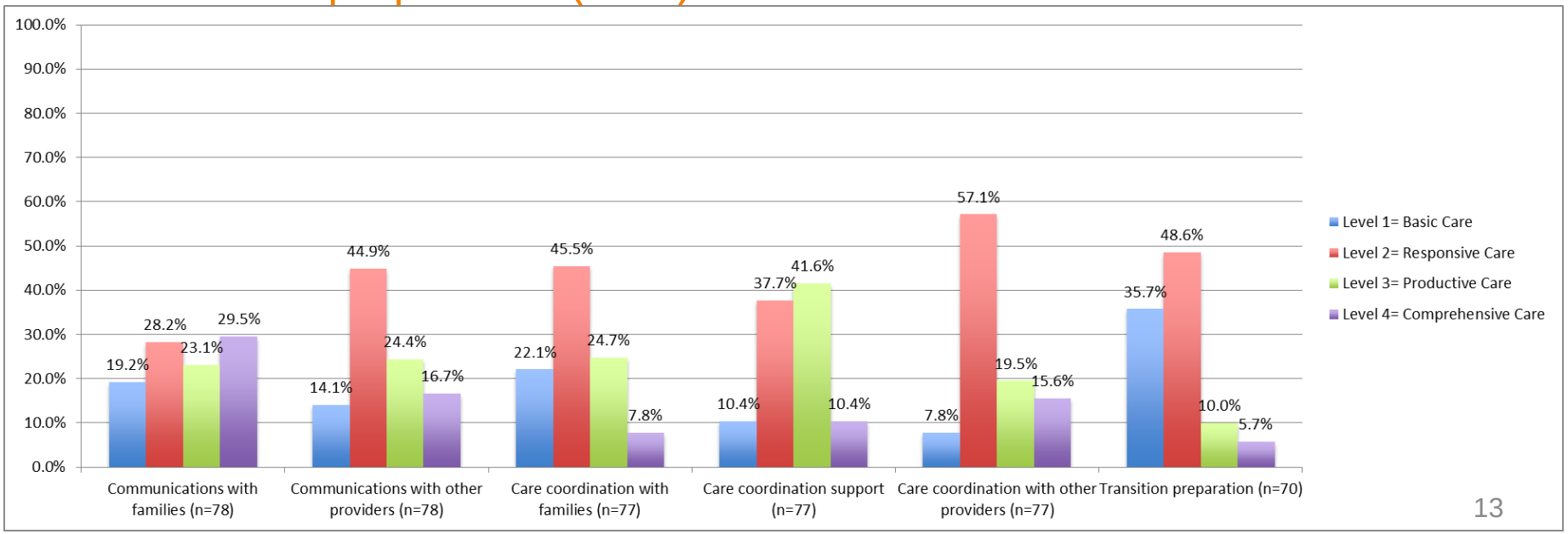
  - Level 1 = basic care;
  - Level 2 = responsive care;
  - Level 3 = productive care;
  - Level 4 = comprehensive care (Source: McAllister 2013)

Results

- Levels 1-2 (50% or greater of respondents):
  - Communication with other providers (59%)
  - Care Coordination with families (68%)
  - Care Coordination with other providers (65%)
  - Transition preparation (84%)

- Levels 2-3 (50% or greater of respondents):
  - Care Coordination Support (80%)

- Levels 1-4 even distribution:
  - Communication with the family



New Year 2 Common Measures

- Regional approach:
  - RC to RC collaborations (inter-regional)
  - 2+ state collaborations (intra-regional)
    - E.g. LEND and CSHCN
  - All RCs will provide qualitative information that NCC will synthesize

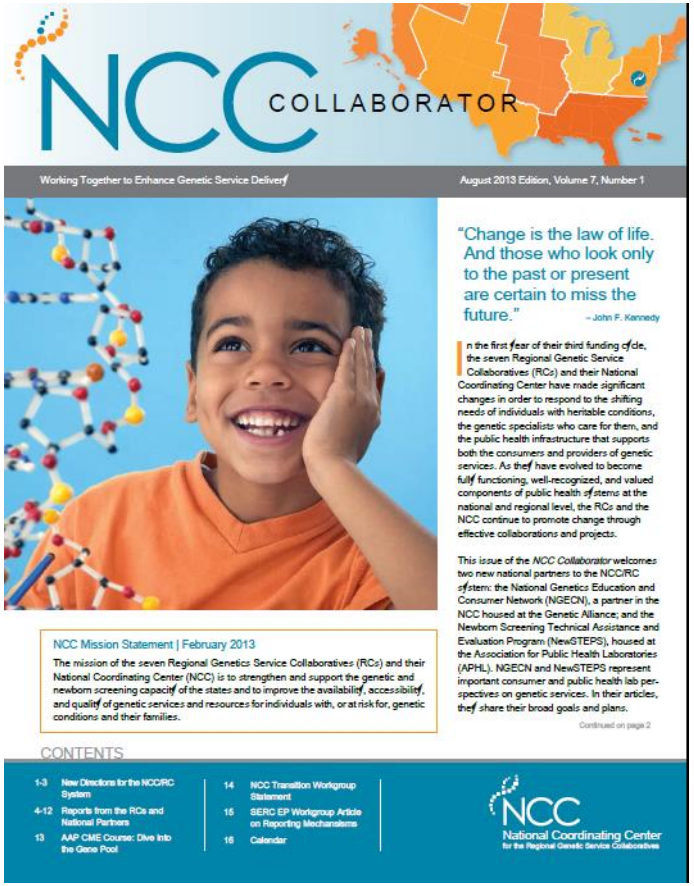
- Cluster Measure data collection (Telegenetics, Family Health History [tool tbd], and Emergency Preparedness [tool tbd])

- Acquired Knowledge*
  - Participants in RC sponsored educational and training activities

- Volunteer hours*

*pilot by NCC and 1-2 volunteer RCs in year 2. Pilot results will determine whether or not this becomes part of national evaluation.

Communication Strategies



NCC COLLABORATOR

Working Together to Enhance Genetic Service Delivery

August 2013 Edition, Volume 7, Number 1

"Change is the law of life. And those who look only to the past or present are certain to miss the future." – John F. Kennedy

In the first year of their third funding cycle, the seven Regional Genetic Service Collaboratives (RCs) and their National Coordinating Center have made significant changes in order to respond to the shifting needs of individuals with heritable conditions, the genetic specialists who care for them, and the public health infrastructure that supports both the consumers and providers of genetic services. As they have evolved to become fully functioning, well-recognized, and valued components of public health systems at the national and regional level, the RCs and the NCC continue to promote change through effective collaborations and projects.

This issue of the *NCC Collaborator* welcomes two new national partners to the NCC/RC system: the National Genetics Education and Consumer Network (NGECN), a partner in the NCC housed at the Genetic Alliance; and the Newborn Screening Technical Assistance and Evaluation Program (NewSTEPS), housed at the Association for Public Health Laboratories (APHL). NGECN and NewSTEPS represent important consumer and public health lab perspectives on genetic services. In their articles, they share their broad goals and plans.

Continued on page 2

NCC Mission Statement | February 2013

The mission of the seven Regional Genetics Service Collaboratives (RCs) and their National Coordinating Center (NCC) is to strengthen and support the genetic and newborn screening capacity of the states and to improve the availability, accessibility, and quality of genetic services and resources for individuals with, or at risk for, genetic conditions and their families.

CONTENTS

NCC National Coordinating Center for the Regional Genetic Service Collaboratives

NCC Collaborator
(tri-annual newsletter)

Inter-RC communication via monthly conference calls with all PDs, NCC, and GSB/MCHB

NCC/RC Exhibit booth at national meetings

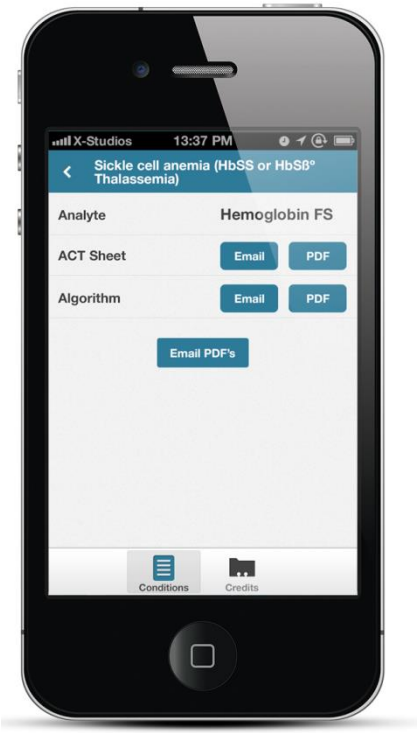
Ongoing Activities—Partnership Building between Providers and Individuals and Families

- **Community Conversation**
  - Annually at the ACMG Clinical Genetics Meeting
  - March 18, 2014: Bumps in the Transition Road: Novel and Innovative Ways for Ensuring Access to Care

- **Consumer Leaders' Program**
  - 2012 -2014 featured advocate leaders from RCs and genetic counseling student mentors
  - August e-zine edition of the *NCC Collaborator* featured a summary of the 2013 program.
  - The program will be offered in 2014, with extensive program expansion, 20+ attendees.

Year 2 Activity Updates—ACT Sheets

- ACT Sheets
  - Workgroup has developed ACT Sheets on Incidental Findings that are undergoing expert review:
    - APC
    - BRCA
    - FBN1
    - Long QT
    - MEN1
    - Neurofibromatosis Type 2
    - RB1
    - RET
    - RYR1
    - TGFBR1 and TGFBR2
    - WT1



- **There's an app for that!!!**

Year 2 Activity Updates—ACA Implementation

- September 2013 NCC received a NCC/RC system-wide supplement to:
  - Develop a cost element template for 3 model conditions—PKU, Sickle Cell, and Fragile X.

    (MSGRC and NEGC in partnership)
  - State-by-state coverage analysis of the model conditions (all RCs)
  - Guidelines for a standardized genetics component in integrated care systems

    (NYMAC)

Oversight provided by NCC ACA Implementation workgroup

Year 2 Activity Updates—Partnership Building

- **Association of University Centers on Disabilities (AUCD)**
  - Leadership Education in Neurodevelopmental and Related Disabilities (LEND)
  - November 2013 joint in-person meeting
    - 100% attendees (n = 29) agreed or strongly agreed that:
      - The meeting was a valuable learning experience
      - The meeting helped develop a plan for working together.
  - Collaboration webinar June 26, 2014
  - Planned joint meeting for November 2014

NCC Workgroups (1)

- **Medical Home**
  - Activities:
    - Workgroup published an article in *Genetics In Medicine*, "An approach to family-centered coordinated co-management for individuals with conditions identified through newborn screening" (*Genet Med* 2013: 15(3): 174-77)
    - Workgroup identified 2 national projects. Exemplary Coordinated/Team Care and Understanding Services and Resources Needs of Patients and Families (collaborative project with NGECN and AAP).
  - Chair: Chuck Norlin, MD (MSGRC Medical Home Project Lead)

- **ACT Sheets (Clinical Decision Support Tools)**
  - Activities:
    - Periodic review of existing ACT sheets
    - Developing new ACT Sheets related to Incidental Findings (topic of meeting 9/20-9/21)
    - APP developed and released October 2013
  - Chair: Harvey Levy, MD

NCC Workgroups (2)

- **Telegenetics**
  - Activities:
    - Cluster Telegenetics Project Evaluation measure development (year 1) and implementation (year 2).
    - Clinical Genetic Services Survey (5/10/13-6/10/13): genetics professional survey about the use of telegenetics. Workgroup now reviewing data, plans to share each RC level data and publish an article.
  - Chair: Sylvia Mann, MS, CGC (WSGSC Project Director)

- Heartland Clinical Genetic Services Data:
  - 18 Respondents (8% of total responses [233])
  - 10 Respondents utilize telemedicine (55.5%, all respondents indicating yes: 35.3%)
  - Billing: Private third party payer, Medicaid, and patient/family are billed for telemedicine services. State and Federal funding exists, and one site uses charitable funding and another does not bill.

NCC Workgroups (3)

- **Transition**
  - Activities:
    - Common Measure development for NCC/RC evaluation
    - Informal project sharing among RCs and participating partners (Got Transition, Family Voices, smaller family organizations, state/regional transition projects)
    - National Project in development
  - Chair: Susan Waisbren, PsyD

- **Family History**
  - Activities:
    - Informal RC and partner (NCHPEG, Genetic Alliance) updates
    - Potential November Family History month marketing
  - Chair: Luba Djurdjinovic, MS, CGC (NYMAC Family History Project Lead)

NCC Workgroups (4)

- **ACA Implementation**
  - Activities:
    - Supplement to NCC/RCs recently awarded to allow the system to conduct a 2 condition model analysis of current cost of care over the lifecourse (PKU and Sickle Cell); state-by-RC analysis of cost of care of the two model conditions; and to define and standardize the genetic component of an Affordable Care Organization (ACO).
    - Goal is to build evidence and data to support interactions with Title V programs, ASTHO, and others to get identified gaps in coverage addressed and improve access to care.
    - This activity is foundational and expected to continue beyond this supplemental funding period.
    - In-person meeting November 16, 2013
  - Chairs: Sue Ginsburg (NYMAC Evaluation Consultant), and Meg Comeau, MHA (Catalyst Center, NEGC Project Lead)

NCC Workgroups (5)

- **Long-Term Follow-Up**
  - Activities:
    - Using 30 public health related questions from the standardized data sets developed by the Newborn Screening Translational Research Network (NBSTRN), the LTFU workgroup is defining and mapping those questions to a public health module for the Longitudinal Pediatric Data Resource (LDPR).
    - Working to identify pilot states.
  - Chair: Sharmini Rogers, Carolyn Anderson

- **Evaluation**
  - Activities:
    - Year 1: developed a NCC/RC system-wide evaluation program with common measures and data collection (3-tier evaluation ASPIRE model). Report in draft form now, to be submitted to HRSA by end of September.
    - Year 2: data collection on common measures; addition of new measures around ACA Implementation and other common projects (5 or more RCs)
  - Chairs: Debbie Maiese, MPA (NCC Evaluation Consultant), and Lisa Gorman, PhD (Region 4 Midwest Project Director)

ACMG Update

- Molecular Testing Coverage
- Physician Productivity and Benchmarking

Questions?

Thank you!

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