



Education and Training Subcommittee Report



SACHDNC Advisory Committee Meeting
January 26-27, 2012

Subcommittee Charge

- ▶ Review existing educational and training resources, identify gaps, and make recommendations regarding five groups:
 - ▶ Parents and the public
 - ▶ Parents
 - ▶ The public
 - ▶ Health professionals
 - ▶ Health professionals
 - ▶ Screening program staff
 - ▶ Hospital/birthing facility staff



Current E&T Subcommittee Members

▶ SACHDNC Members

- ▶ Don Bailey (chair) Catherine Wicklund
- ▶ Stephen McDonough Jeffrey Botkin
- ▶ Joe Bocchini Andrea Williams

▶ Organization Representatives to SACHDNC

- ▶ Frederick Chen Joyce Hooker
- ▶ Beth Tarini (co-chair) Colleen Buechner
- ▶ William Hogge Mary Willis
- ▶ Natasha Bonhomme Joe Leigh Simpson

▶ Consultant Members

- ▶ Jaimie Higgs Cate Walsh Vockley
- ▶ Jana Monaco Jacque Waggoner
- ▶ Deborah Rodriguez



Goals for January 2012 meeting

- ▶ Review current activities
- ▶ Review subcommittee charter and discuss possible linkages with other SACHDNC subcommittees
- ▶ Begin discussion about future education and training needs for
 - ▶ Parents and the public
 - ▶ Health professionals



Major Current Activities

- ▶ **Parents and the public**

- ▶ Newborn Screening Awareness Campaign
- ▶ 2013 newborn screening 50-year celebration
- ▶ NBS Clearinghouse
- ▶ Other

- ▶ **Health professionals**

- ▶ Genetics and Primary Care Initiative
- ▶ Family History for Prenatal Providers
- ▶ Professional organizations
- ▶ Others



Parents and the Public

- ▶ **Newborn Screening Awareness Campaign**
 - ▶ Phase I media scan completed (report presented at last SACHDNC meeting)
 - ▶ Next step: Convene a strategy session to determine the goals, objectives, audiences, and approach to a campaign
 - ▶ Steering committee formed to nominate attendees for strategy session
 - ▶ 1.5 day meeting will be held in late March or early April
 - ▶ Report from meeting will be discussed by the Education and Training Subcommittee prior to and during the May meeting
 - ▶ Summary report to SACHDNC in May
 - ▶ Results will inform next steps to be determined by HRSA



Parents and the Public (continued)

- ▶ **CDC/APHL 2013 50th anniversary plans**
 - ▶ Goal: to create a public informed about newborn screening
 - ▶ APHL will take lead in implementation
 - ▶ Multiple activities planned over the next 18 months
 - ▶ Culmination in 50th anniversary celebration in 2013, joint APHL/ISNS meeting in Atlanta
- ▶ **Genetic Alliance updates**
 - ▶ Challenge awards
 - ▶ 21 applications received this year
 - ▶ Range of interesting topics from a diverse array of groups
 - ▶ Formal announcement of awardees in February
 - ▶ Consumer Task Force
 - ▶ Baby's First Test



Subcommittee Thoughts And Reflections About Next Steps with Parents & the Public

- ▶ Huge and diverse audience requiring diverse input and multiple strategies
- ▶ Need to add at least one new committee member representing parent/public communities
- ▶ Applaud collaboration to date between HRSA and CDC on awareness campaigns, urge continued integration of activities to minimize redundancies, harmonize messages, maximize resources
- ▶ Two major questions about awareness campaigns:
 - ▶ What problem are we trying to solve?
 - ▶ How can we move awareness beyond a fixed-term campaign to an ongoing activity?
- ▶ HRSA and SACHDNC should continue efforts to view advocacy groups as a target audience, with one goal being the creation of materials and/or website guidance on “how to get your condition ready for SACHDNC review.”



Health Professionals

- ▶ **Genetics in Primary Care Initiative**
 - ▶ HRSA and MCHB Funding
 - ▶ 3-year (June 2011 – May 2014) cooperative agreement to American Academy of Pediatrics
 - ▶ Beth Tarini and Robert Saul, Co-PIs
 - ▶ **Advisory Committee**
 - ▶ American Academy of Pediatrics
 - ▶ American Academy of Family Physicians
 - ▶ American College of Medical Genetics
 - ▶ Genetic Alliance
 - ▶ Maternal & Child Health Bureau
 - ▶ National Association of Pediatric Nurse Practitioners
 - ▶ National Coalition for Health Professional Education in Genetics
 - ▶ National Society for Genetic Counselors
 - ▶ Other federal & state partners



GPCI Vision

To increase PCP knowledge and skills in providing genetic-based services.

Goals:

- ▶ **Mobilize a community of learners** to develop, implement, and evaluate strategies to enhance PCP knowledge, practice and attitudes regarding the provision of genetic-related services
 - ▶ **Implement a strategy to address systems and policy** to accelerate the provision of genetic medicine via the establishment of a technical assistance center
 - ▶ **Assess and address residency training needs** in order to more fully imbed the practice of genetic medicine into the future PCP workforce
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GPCI Goal 1: Quality Improvement Project

- ▶ Subcommittee of project advisory committee has been established to develop change packet through review of existing materials/information and developing new information as needed
- ▶ Utilize established AAP QI network: Quality Improvement Innovation Network (QIIN) to test implementation of change package through modified learning collaborative
 - ▶ Model for Improvement; Plan, Do, Study, Act; small tests of change
 - ▶ 20 practices will identify 3 members (eg, physician, nurse, office staff, family member)
 - ▶ Practices will be paired with genetic experts from community/region as identified by regional collaborative



GPCI Goal 2: Technical Assistance and Education

- ▶ Technical Assistance Center (TAC)—includes staff, project leaders, others
- ▶ Website—flagship component of TAC—will be developed
- ▶ Ongoing educational activities (eg, webinars, online educational module) regarding science, practice improvement, partner activities, new technologies, and more!
- ▶ Translate key genetic concepts/policies into EHR functional requirements
- ▶ Embed genetic principles into *Bright Futures*
- ▶ Convene colloquium on genetic literacy



GCPI Goal 3: Residency Training

- ▶ Assess current residency curricula regarding genetic-related training by surveying residency training program directors
- ▶ Develop genetics residency training curriculum and/or instructional strategies (Year 2)
 - ▶ Curriculum will supplement the existing Accreditation Council for Graduate Medical Education (ACGME) Core Competencies



Family History for Prenatal Providers (NCHPEG)

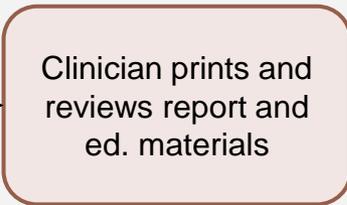
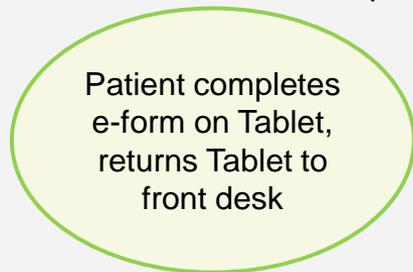
- ▶ **Goal: Develop and evaluate a family history and genetic screening tool for primary-care prenatal providers**
 - Collect patient personal and family history data
 - Perform e-risk assessment for clinician
 - Provide clinical decision support & education



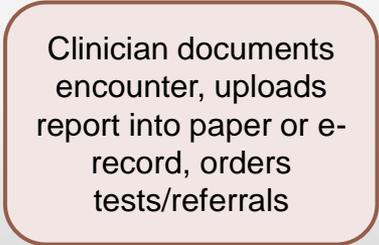
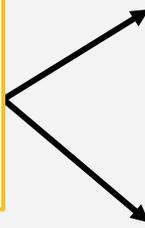
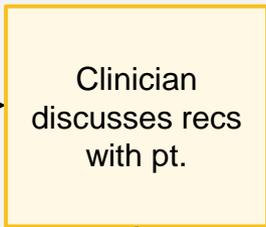
How it Works

Waiting Room or Exam Room

e-risk assessment and
report generated



Patient & Provider Meet



Clinician makes updates to input data as needed

Summative Evaluation Questions

1. What level of effort, resources, and provider education/support were needed to integrate the tool into clinical practice?
 2. How well did the tool fit into the clinical flow of four clinical settings?
 3. How well did the tool collect family history and general obstetric information?
 4. How satisfied were patients with the tool and the educational information received?
 5. How useful did providers find the tool and clinical decision support?
 6. Did the tool improve provider knowledge?
 7. Did the tool increase adherence to guidelines for genetic screening and risk assessment?
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Subcommittee thoughts about next steps with health professionals

- ▶ Several important activities are underway – it will be important that they be evaluated well so that we can know what has been accomplished
- ▶ Training of faculty should be considered as a key to assuring appropriate training of students, residents, fellows
- ▶ The subcommittee and the SACHDNC would benefit from input from the nursing community – ideally there would be a nursing organizational liaison to the SACHDNC, with subsequent appointment to E&T



Other Thoughts from the Subcommittee

- ▶ A number of individuals have expressed interest in serving on the subcommittee
 - ▶ The breadth of our charge means that there are many different stakeholders and people who want to make a difference
 - ▶ We would benefit from more perspectives, but at 19 members already, would the group become too big to function efficiently?
 - ▶ Should we consider a sub-subcommittee structure, a liaison arrangement, etc.?
- ▶ We need to figure out ways to promote cross-subcommittee communication, especially around overlapping concerns
- ▶ What changes are on the near horizon that we should anticipate and begin considering the E&T ramifications?
- ▶ As “products” are developed from subcommittee initiatives, what role should the subcommittee and the SACHDNC play in endorsing, recommending, or promoting them?

