

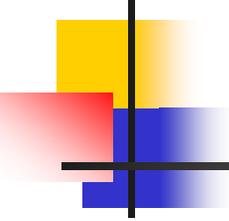
Report to the ACHDGDNC

Anne Gramiak, MPH

American Academy of Pediatrics

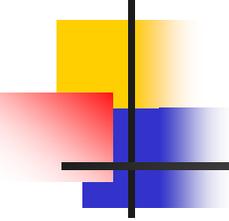
DEDICATED TO THE HEALTH OF ALL CHILDREN™





Overview

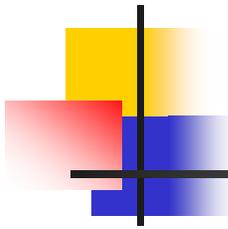
- Current program activities
 - Resource promotion
 - NBS Parent and Provider Materials
 - E-supplement to *Pediatrics*
 - ACT sheet flyer in AAP News
 - AAP Fact Sheets
 - Clinical Report
- ACT Sheet survey results



Resource Promotion

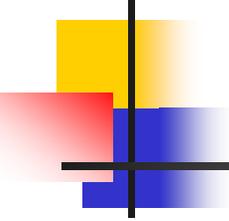
- Copies of the newborn screening parent and provider materials were mailed to all Academy members in Winter 2005
- Additional copies are available by request
- To date, 185 requests were made for almost 30,000 copies
- Link to pdf files on the National Center website





Resource Promotion

- *Pediatrics* E-supplement “A Look at Newborn Screening: Today and Tomorrow” published in May 2006
- On-line content is accessible to the public
- <http://pediatrics.aappublications.org/content/vol117/issue5/index.shtml#SUPPLS1>

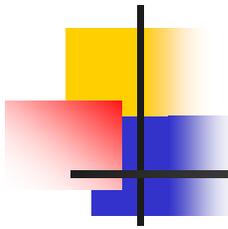


Resource Promotion

- AAP Fact Sheets, Committee on Genetics
- September issue of *Pediatrics*

- Introduction (print and on-line)
 - <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/3/1304>

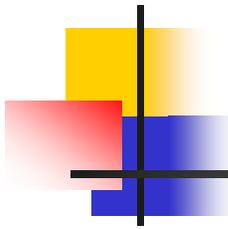
- Disease fact sheets (on-line)
 - <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/3/e934>



Clinical Report

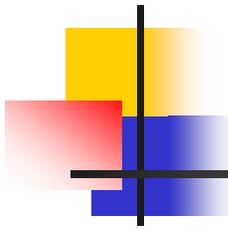
Goal of the report is to:

1. To introduce an algorithm that will guide pediatricians in assuring that newborn screening is conducted, screening results are received, positive results are responded to in an appropriate and timely manner, and that affected children receive coordinated and comprehensive care within the context of a medical home.
2. To make recommendations for local, State, and federal policies that will support PCPs in providing appropriate and timely care to children with these conditions, by promoting the optimal function of State newborn screening programs.



Clinical Report

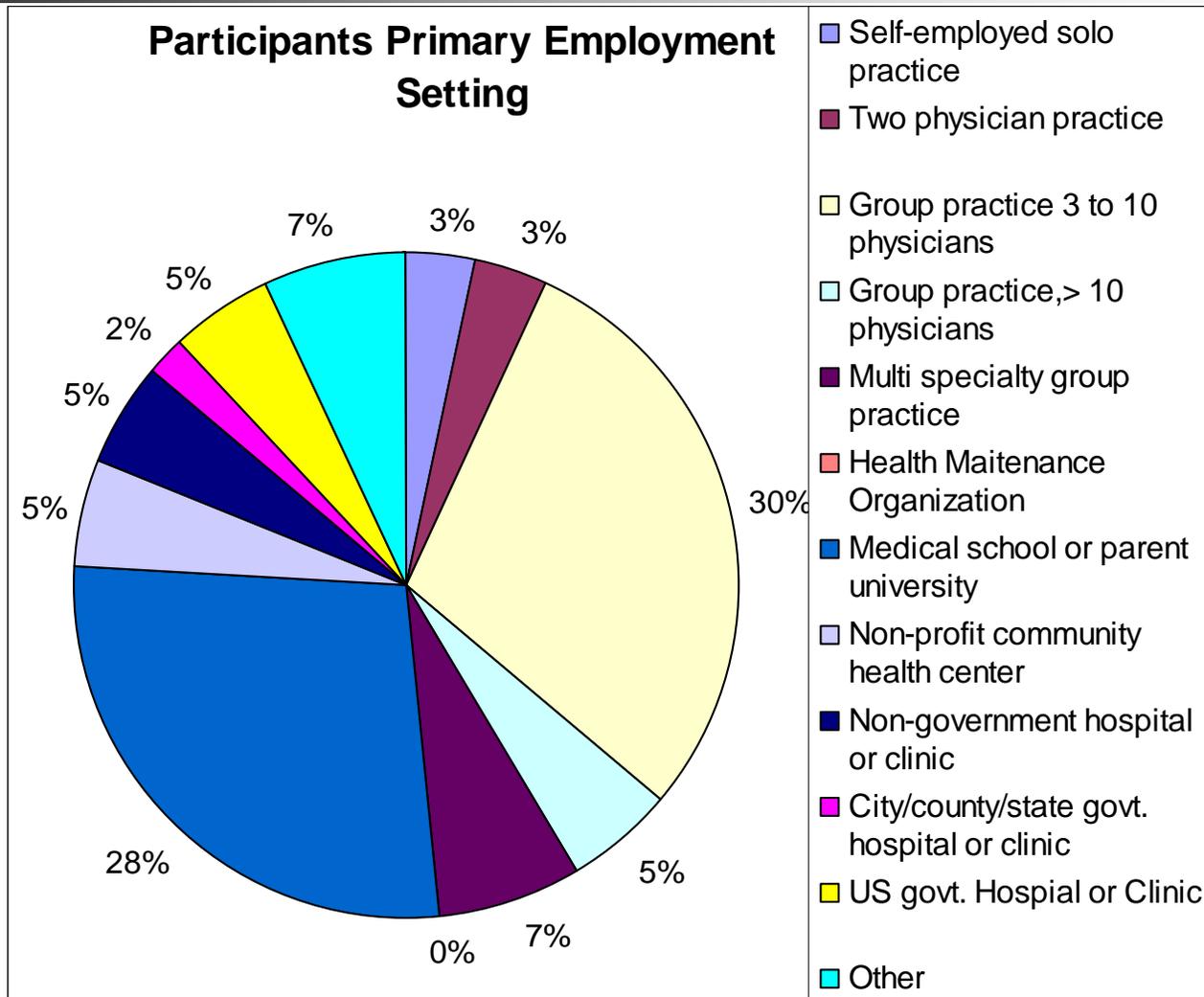
- Interdisciplinary group of authors representing several AAP committees, MCHB and ACMG
- In progress since January 2006
- Next step will be internal and external review
- Published in 2007
- Part of the AAP's Partnership for Policy Implementation project



ACT Sheet Survey Results

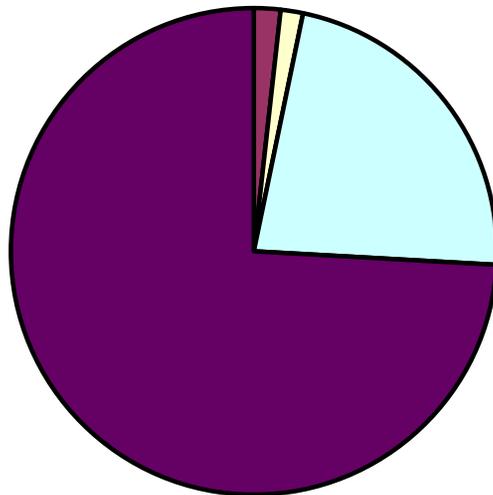
- Survey conducted in the summer of 2006 using Survey Monkey
- Convenience sample, participants self-selected to participate
- Participants were asked to review several ACT sheets before completing survey
- Incentive items were sent to participants providing an address
- 60 total participants, 36 pediatricians and 24 family physicians

ACT Sheet Survey Results: Participant Background



ACT Sheet Survey Results: Question 1a

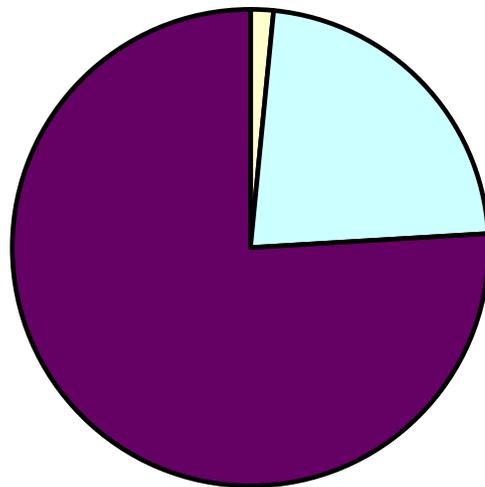
**The ACT sheet's purpose is clearly stated and
the content is germane to primary car providers**



- Not At All True
- Somewhat Not True
- Not Sure
- Somewhat True
- Definitely True

ACT Sheet Survey Results: Question 1b

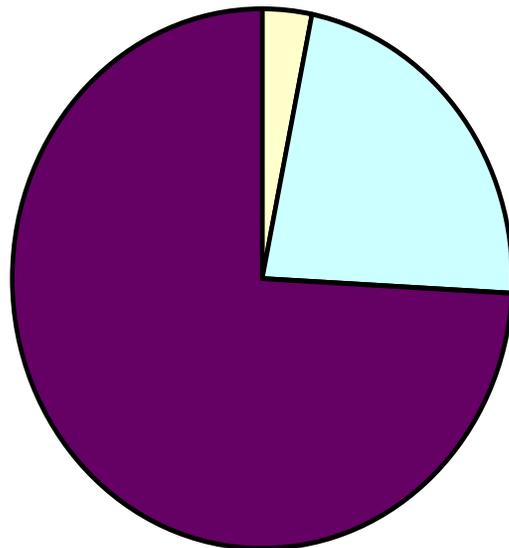
I would use the ACT sheets after receiving notice that a patient screened positive for a heritable disorder or genetic disease.



- Not At All True
- Somewhat Not True
- Not Sure
- Somewhat True
- Definitely True

ACT Sheet Survey Results: Question 1c

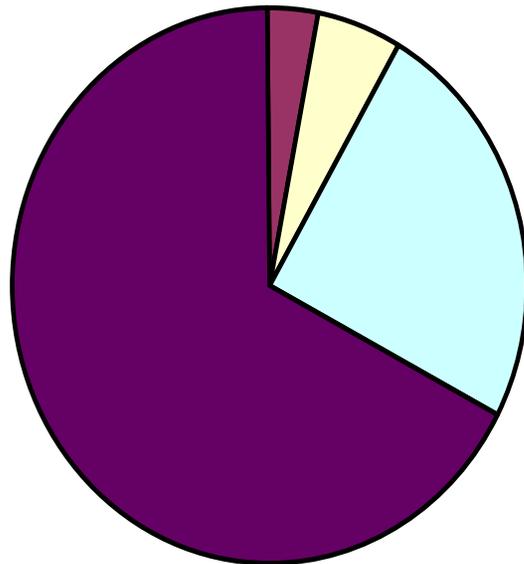
I would recommend that my colleagues use the ACT sheets.



- Not At All True
- Somewhat Not True
- Not Sure
- Somewhat True
- Definitely True

ACT Sheet Survey Results: Question 1d

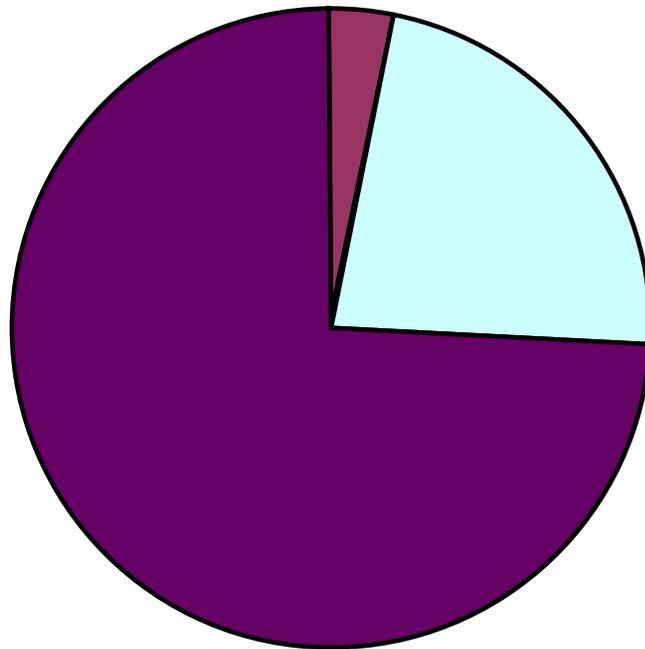
The content was organized in a manner that would facilitate easy action on the part of the physician.



- Not At All True
- Somewhat Not True
- Not Sure
- Somewhat True
- Definitely True

ACT Sheet Survey Results: Question 1e

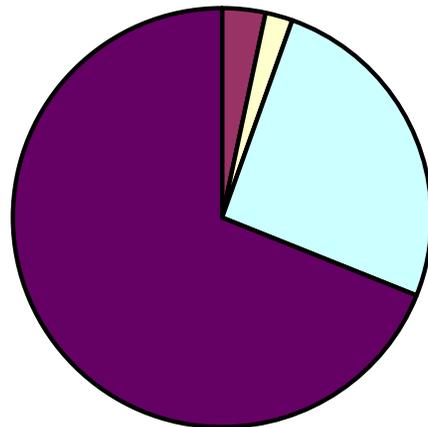
Recommendations and key points are explicit.



- Not At All True
- Somewhat Not True
- Not Sure
- Somewhat True
- Definitely True

ACT Sheet Survey Results: Question 1f

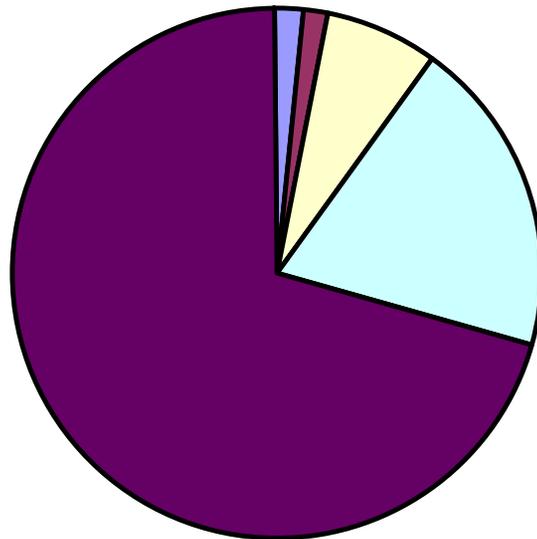
The inclusion of a diagnostic algorithm provides clear and concise summaries of how clinicians should proceed with treatment of a patient testing positive for a heritable disorder or genetic disease.



- Not At All True
- Somewhat Not True
- Not Sure
- Somewhat True
- Definitely True

ACT Sheet Survey Results: Question 1g

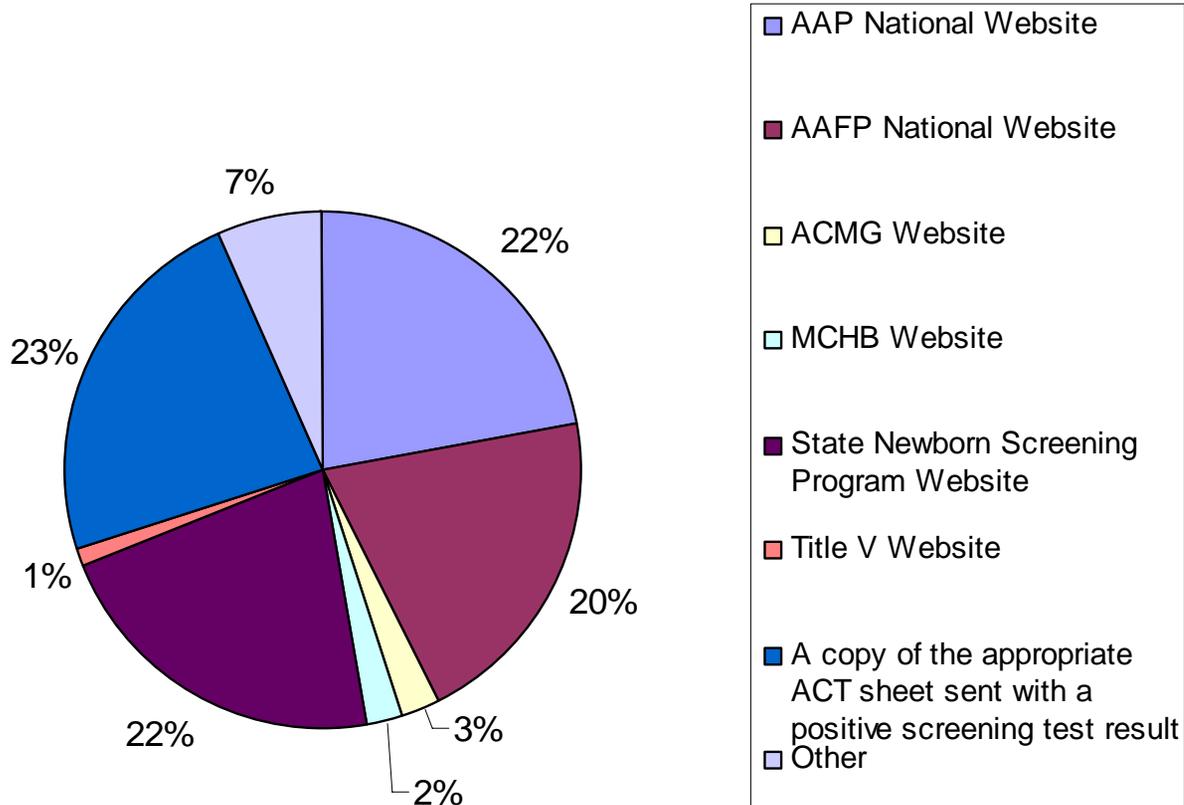
I think having the local resources section of the ACT sheets completed will help me to quickly access local genetic resources.

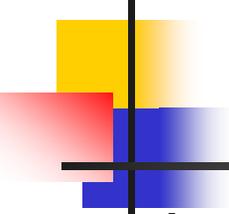


- Not At All True
- Somewhat Not True
- Not Sure
- Somewhat True
- Definitely True

ACT Sheet Survey Results: Question 2

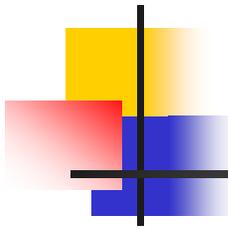
Electronic Locations to Access ACT Sheets





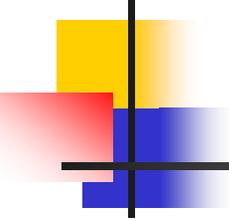
Question 2 "Other"

- American Academy of Physician Assistants (AAPA) National Website: www.aapa.org
- Up to Date
- Local tertiary care referral site
- Children's hospital website
- Genetests
- Web site of the organization running the results
- PubMed
- Would put it into favorites on my computer or in a link in our knowledge base of our EMR



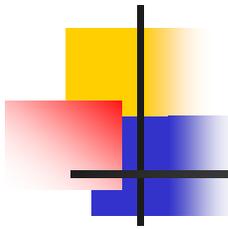
ACT Sheet Survey Results: Question 3

- Recommended format changes:
 - Make them less 'busy'
 - Less abbreviations, at least until we get use to using it
 - Maybe bright red color for those that need attention immediately.
 - I think they are very user friendly. Maybe have some state specific information and a resource for care coordination for these children.
 - Seems to be a nice useful adjunct to what currently exists. The only real current issue is as the # of tests expand the # of false positives become more common.
 - Color choices
 - My computer took a long time to open the flowcharts and ACT. This is most likely a product of my computer but if it is not, then it would be helpful to make changes that allow for these to appear faster.



ACT Sheet Survey Results: Question 3 Continued

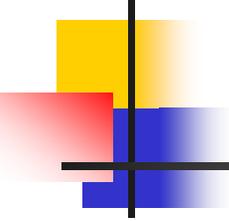
- Find an automatic way for the state labs to send us the link to these algorithms with EVERY newborn screening test which is done
- Inclusion of appropriate local information will be helpful. Otherwise, no changes necessary.
- Wider distribution
- I like the forms. For busy clinicians, the bang is in the buck-- specifically, the forms need to be brief, visually appealing and to the point. For the most part, they are. For me, however, they just don't have quite enough 'eye appeal'.
- If a condition is benign, don't recommend referral.
- Local contact resources will be very useful. Alaskan physicians often have to go out of state for resources.
- MUST have relevant info about the positive predictive value (and negative predictive value would be nice) for these tests, so that the post-test probability of disease can be explained to very anxious parents



ACT Sheet Survey Results:

Question 4: Information to Add

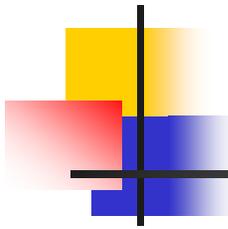
- More information on disorders, plan of action
- The ACT sheets are very complete. I like that the first information provided is what action to take and how urgent the intervention needs to be.
- phone #'s-many offices have more than one. Add partner's names i.e. the designated endocrinologist may have fellows or associates 'on call' and available as this information often arrives on a Saturday
- Add signs of decompensation as in CAH
- Maybe some parent information so that when you call the parents you would have all the information that you need to tell them in front of you
- An indication of the likelihood of the test representing a false positive for each of the conditions. Include variant hemoglobin as these are showing up on our tests



ACT Sheet Survey Results:

Question 4: Information to Add

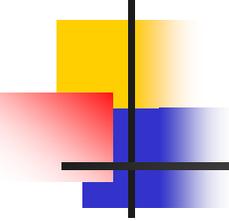
- Add Hemaglobin Barts as a result
- Maybe the contact info of the 3 closest tertiary care facilities with appropriate consultations available.
- State specific information and resources for care coordination (special formulas, etc.) for these children, who to call in an emergency
- Need to have more specifics on labs to order if patient doing well and there's no specialist available. For false positives, PCP could change diet and order repeat screen or specific labs with directions on the ACT sheets. More on treatment centers for the rarer disorders.
- Screening for fetal alcohol spectrum disorders Pre-adoption screening protocol



ACT Sheet Survey Results:

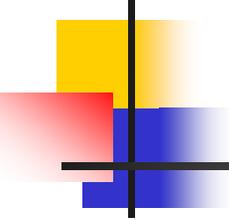
Question 4: Information to Add

- A short description of the condition written for the layperson to explain to the family what their baby is being tested for that the PCP can send to the family
- critical to have local resources included. instead of recommending 'consult specialist' on each sheet say consult resource identified below as many primary care physicians will NOT have easy access to a metabolic specialists unless a specific contact source is applied.
- The forms need to have incidence data and references somewhere, the patient and primary care physicians knowledge will be so important to management even initially. Families will have lots of questions right away.
- Resources for finding your local state genetics support facilities.
- I would like 1-2 pages of information on the disease
- A clear time line of when to act: Act immediately with , say ****, act in a week ***, act soon **,raise issue at next visit *



ACT Sheet Survey Results: Question 5

- Suggestions for marketing:
 - Professional bulletins and e-mail alerts
 - AAP/AAFP website and mailings
 - Listserv announcements
 - Specialty websites
 - Send directly to primary care physicians
 - State NBS programs/send with results
 - Review articles in key publications



Questions?

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