

ACHA's VISION 2020 FORUM: FROM PLANNING TO IMPLEMENTATION

Conducted April 23, 2010

Report Date: May 2, 2010

SECTION I: INTRODUCTION

On April 23, 2010, the Adult Congenital Heart Association (ACHA) convened the second Forum on Vision 2020, an initiative designed to accelerate the development of adult congenital heart care in the United States. The vision for 2020 is that ACHD is an established field that delivers quality lifelong care for adults in the United States. In so doing, the aim is to prevent premature death and disability and prolong health and well-being for congenital heart patients nationwide. The purpose of the Forum was to be a culminating event for the end of Phase I and the platform from which to begin Phase II of the initiative. The Forum's structure engaged participants in a process of peer to peer dialogue and learning designed to:

- Solicit feedback from the community's key stakeholders and ACHA members regarding next steps for implementation of the recommendations from Phase I as well as implementation challenges.
- Create the momentum to move from planning to implementation of the recommendations developed in Phase I.

Over one hundred (100) individuals were invited to attend the Forum. There were forty-eight (48) attendees representing a wide range of stakeholders. Participants included individuals from adult and pediatric practices, hospitals, and ACHD clinics from all over the United States. The agenda for the Forum can be found in **Appendix A** of this report.

SECTION II: BACKGROUND

In December 2008 the Adult Congenital Heart Association (ACHA) established a new initiative, ACHA Vision 2020. Over the past year and a half, ACHA established four working groups charged with conducting research on what needs to be done in the field of American ACHD care over the next 10 years to meet the vision. The working groups focused on: accreditation, regional care planning, workforce planning, and business model development. The outcome of each workgroup was to provide initial recommendations to the V2020 Steering Committee and the ACHA Board of Directors on how to develop an approach based on their findings and how to accelerate progress in the identified areas. These working groups have brought together national leaders in congenital heart disease to address major existing barriers to providing adequate care for the adult congenital population in the United States.

By 2020, the goal is that upon turning eighteen every complex CHD survivor will have access to life-long ACHD care which is:

- High-Quality

- Age-appropriate
- Research- Based
- Coordinated and integrated
- Available in all regions of the country.

The Forum began with an overview of the recommendations from the paper, **Interim Recommendations from Phase I**, provided by Dr. Gary Webb, Chair of the V2020 Steering Committee and ACHA's Medical Advisory Board (MAB). Participants then engaged in four small group discussions to discuss each of the four areas that Vision 2020 addresses.

The day ended with an overview of the next steps moving to Phase II of the Vision 2020 initiative. The Vision 2020 Steering Committee will:

- Review the feedback and refine the recommendations if necessary;
- Continue to solicit feedback on the initial recommendations and implementation challenges thru the blog and webinars;
- Develop resources to acquire the funds and staffing required to further develop the papers, tools, and documents recommended for each area;
- Solicit funds to carry out the implementation in each area; and
- Create a structure for the next Phase that will further engage ACHA members and other key stakeholders. The current workgroups that were part of Phase I have completed their work.

This resource development phase is expected to go thru December 2010.

SECTION III: SUMMARY OF KEY POINTS

During each discussion for each area, participants addressed the following four questions:

- In your mind, what are the challenges to implementation of the recommendations (as described in the paper Recommendations from Phase I) in each area (Accreditation; Regional Care Planning, Workforce Planning; Business Model Development)
- What are quality practices that have been developed locally or are known to you through research that help/might help to address these challenges?
- What are key elements that should be incorporated into any design to ensure program/system implementation of the recommendations for each area?
- What should ACHA's role be in implementation of these recommendations?

Three ***fundamental premises*** emerged from the dialogue at the Forum:

- We believe that ACHA has a strategically important role to play in each area that makes up Vision 2020 to create effective strategies for change and high quality, effective service delivery;

- We believe that local delivery systems can have a significant impact on barriers to lifelong ACHD care if we work together to strategically choose the problems to address; and
- If the recommendations, in general, are implemented in the four areas, they are likely to have a significant impact on positioning ACHD as an established field that delivers quality lifelong care for adults in the United States.

The following *five trends* emerged as consistent themes across each of the four issue areas:

- ❖ ACHA needs to form partnerships and strategic alliances with other organizations for implementation and to achieve the vision, particularly for accreditation, workforce planning and regional care planning;
- ❖ There is a need for common metrics and common data collection across programs and between service providers especially for regional care planning and accreditation;
- ❖ Competition makes it hard to collaborate especially for regional care planning;
- ❖ ACHA can provide tools, templates, incentives, and facilitate processes toward implementation of the recommendations; however, they must ensure that there is no conflict of interest especially with regard to regional care planning and accreditation; and
- ❖ There is a need for education of hospital administrators on the differences between pediatric care and adult care in this arena.

BIG IDEAS

Each group was asked to identify two or three big ideas based on their table discussions. These big ideas support the five trends identified above.

Accreditation

- Credential should be self-fulfilling and provide value in and of itself.
- Self assessment will be beneficial.
- The process must be objective and transparent.

Regional Planning

- Joint planning and cooperation is difficult in U.S. due to competition.
- Defining a region should be narrow and specific; regions should form organically from de facto systems.
- The value of collaboration will have to be proven.

Workforce Planning

- Clear distributed training guidelines that are inclusionary, flexible, position specific, affordable with reliable options for employment need to be developed.

- Collaboration of the ACHA with the ACC and other groups (ABIM, Pediatric cardiology groups, NIH, nursing, and others) to provide DATA for current and projected workforce needs that can be utilized to present for funding for workforce planning strategies and for training programs.

Business Model

- There must be better education around coding, something ACHA could assist with.
- ACHA could be instrumental in providing a flexible business model, as well as education and mentoring around best practices, etc.

SECTION V: SUMMARY

The information contained in this report will be used by ACHA and the Vision 2020 Steering Committee to refine recommended strategies and to move forward. The next steps will be designed to develop strategies to address the many challenges identified at the Forum to fully implement the Vision 2020 vision.

Attachment A: Forum Agenda

ACHA Vision 2020 Forum – From Planning to Implementation

April 23, 2010

Forum Purpose: To present highlights from the first phase of the work and to gather feedback on the recommendations and taking the next steps to implementation.

Registrants are expected to go to <http://achavision2020.wordpress.com/> to print the paper

Recommendations from Phase I: From the Vision 2020 Steering Committee, read and bring it with you.

1:00 – 1:15

Welcome and Introductions

Purpose of the Forum

What is Vision 2020

Dr, Gary Webb, ACHA Vision 2020 Chair

Barry Meil, ACHA Board Chair

Amy Verstappen, ACHA President/CEO

1:15 - 1:45

Overview of the Recommendations

Dr, Gary Webb, ACHA Vision 2020 Chair

1:45 – 2:00

BREAK

2:00 – 4:00

Break into Small Groups

Facilitated by Lori Strumpf

- Groups will be sorted by workgroup topic area
- Individuals will have 25 minutes at each table to provide feedback based on a set of discussion questions (individuals will rotate around tables by topic)

4:00 to 4:15

BREAK

4:15 to 5:00

Report out and Discussion

5:00 to 5:30

Next Steps and Adjourn

Attachment B: Facilitator Notes Each Table Discussion on Challenges to Implementation, Current Practices and ACHA's Role.

Workforce Planning Notes
Moderator: Disty Pearson, PA-C

1. In your mind, what are the challenges to implementation of the recommendations (as described in the paper Recommendations from Phase I) in the area of Workforce Planning?

- Population is demanding, requires more time than others (x4)
- Funding for training, program, clinicians, certification (x3)
- Malpractice insurance is high for private practices
- Address variance of hospital administrations who may not see priority for ACHD (x2)
- Community cardiologists and general fellows are not targeted for ACHD recruiting (x2)
- Lack of awareness of the field (x2)
- Lack of imaging education for pediatric and adult
- Not enough people to fill the ACHD fellowship spots at existing centers
- Not enough professionals in the field
- Big centers are saturated with ACHD providers
- Competition between pediatric /adult programs (x2)
- Need Partnerships—ACHA, accrediting organizations (ABIM), pediatric and adult, nursing
- Hard to recruit into the field:
 - Training mechanism is undefined and expensive (x4)
 - Low pay (x2)
 - Length of training (x3)
 - ACHD is only a percentage of time, not a full time position
 - No job security (x4)
- Cumbersome training guidelines:
 - Defining how to grandfather in qualified practitioners after certification (x2)
 - Mentoring is key (x3)
 - Fellows should train in 4 years. Two of cardiology, 2 of adult congenital (x2)
 - Apprenticeship, expanding exposure and seeing practice is essential (x2)
 - Should multiply, not limit avenues to enter the field
 - Need research to be foundational to guidelines (x2)
 - Needs assessment and guidelines are needed for funding (x2)

2. What are quality practices that have been developed locally or are known to you through research that help/might help to address these challenges?

- Use money and staff efficiently and at appropriate levels (x3)
- Support staff should be educated in ACHD as well (x2)
- Alignment with pediatrics for imaging/consulting/referral
- Less formal, flexible training to keep costs down (x2)
- Sharing information, training, collaboration (x4)
- Clinics with community cardiologists, collaborations WITH current medical providers (x2)
- Bridge the gap between pediatric and adult practices to increase education
 - ACHD education day for pediatric and adult nursing staff
 - Clinic providing ACHD case-presentations for those in general cardiology (x2)
 - CHD specific seminars addressing pediatric and adult cases (x2)
 - Sharing ACHD cases with other specialties and practitioners treating ACHDs
 - Quarterly inter-institutional case-study presentations from ACHD fellows
 - Tele-medicine
 - Adult and Pediatric Interventionalists meet weekly
 - Requiring fellows in both general and pediatric cardiology have to spend a rotation in the other discipline
 - Split case presentations between pediatric and adult hospitals
 - Core Pediatric group will attend adult case presentations weekly

- Free food at ACHD seminars to entice residents and fellows early on (x3)
- Patient forums
- Increase number of fellowship spots
- Make ACHD education enticing
- Demonstrate growth and need for ACHD care to institutional administration (x2)
- Fostering an inclusionary cultural change amongst all sub-specialties in cardiology (x2)

3. What are key elements that should be incorporated into any design to ensure program/system implementation of the recommendations?

- Stop being self-pitying and start being self-changing
- Training should be phased. Start flexible to include existing providers, crystallize by 2020
- Community cardiologists must be utilized
- Communication, collaboration, and integration between centers, for pediatric and adult cardiology
- Formation of regional 'teams' between centers to promote
- Make sure in collaboration that we aren't "stealing patients," but providing alternative options
- Business barriers must change
- Need to define projected needs of this population to plan care (x3)
- Workforce should be planned for all patients, including children and those lost to care (x2)
- Recruit workforce through education/outreach to NPs, PAs, RNs, sonographers etc.
- Provide incentives to join the field
- Increase ACHD-specific continuing education at all levels (x3)
- Increase the workload by maximizing use of mid-level professionals (x2)
- Certification should provide defined training and legitimacy in the field
- Educate collaborating specialties (such as OB/GYN) in ACHD-specific knowledge
- Establish efficient systems to streamline training
- Must address the difficulty of ACHD private practice to remain inclusionary
- Training of ACHD surgeons is important

4. What should ACHA's role be in implementation of these recommendations?

- Write White paper
- Create written guidelines for ACHD certification and promoting legitimacy (x3)
- Make guidelines less stringent, increase people's increase and participation in the field (x3)
- Stay inclusionary, simple, and flexible with accreditation (x2)
- Partnerships
 - With ACC and ACPC (x3)
 - Between ACHD and community cardiologists
 - Between pediatric and adult cardiologists/programs
- Provide the patient voice, need for ACHD centers and bring the customers to the table (x3)
- Facilitate communication between training, clinics, patients, providers (x2)
- Raise awareness of the need for ACHD in the community (x2)
- Lobby on a local and national level--NIH, ABIM, pediatrics, funders (x2)
- Needs assessment on current state of ACHD care (x4)
- Provide national and regional workforce plan based on projected needs (x2)
- Market ACHD to and recruit from pediatric and community cardiologists (x2)
- Facilitate regionalized group conferences where practitioners and institutions shares ideas, transfers patients, and anyone can attend
- Form a coalition of ACHD providers regionally
- Expand the resources and facilitate transfer of knowledge about ACHD (x2)
- Accreditation should include dissemination of education as part of the requirement
- ACHA should have the resources to provide answers, resources, and transfer between centers

Business Model Development Notes

Moderator: Dr. Curt Daniels

1. In your mind, what are the challenges to implementation of the recommendations (as described in the paper Recommendations from Phase I) in the area of Business Model Development?

Group Silver Star

- Hospitals won't provide support unless you can prove your program is a money-maker (lack of administrator support/expertise for business planning within program to oversee day to day)
- How to gather data about patients and how to plan for them (downstream revenue, etc)
- Care coordination – adults are more complex, insurance is more complex – needs nurse/social worker combined
- Limitations on sharing proprietary information
- Regional differences in insurance/staffing/programs/populations (one size will not fit all)
- Disconnect between contract negotiations and care provider team
- Inadequacy of RVU model

Group Red Star

- Deciphering the Health Reform bill
- Preexisting condition limitations re: insurance (unfavorably viewed by hospital admin)
- Must justify salary (to provide proof of money-making ability)
- Private practice vs university model (one size will not fit all)
- Pressure to generate revenue
- Missing appropriate coding (re: insurance, revenue)

Group Green Star

- Money (where will the money come from to improve programs)
- Deciphering Health Reform bill and impact on Vision 2020
- Improvements on surgical coding needed (mismatch in coding vs what insurance companies will pay for – adult procedures)
- Lower productivity seeing adult patients because of complexity of adult patients
- Hospital administrators need more education about the differences between peds and adult CHD patients
- Politics with administrators/division directors of being able to send a patient to the best place to get care/procedures
- Disconnect between what administrators/div directors expect – peds vs adults
- No clue how to develop a business model to improve growth (no education/training)
- One size will not fit all (business model)

Group Blue Star

- Silo concept of most medical centers (in patient money and out patient –procedural stuff - money doesn't balance out)
- Getting credit for downstream funding
- Lack of coding education to maximize revenue
- Unclear policy about consultations (billing)
- Patients take longer time in clinic (complexity)
- Hospital administrators don't understand ACHD needs/the # of ACHD patients that can be seen in a day
- Dealing with multiple hospital administrations/models
- Insurance (preexisting conditions, bulk of patients uninsured/uninsurable)
- No way to track patients and where they are in terms of insurance

2. What are quality practices that have been developed locally or are known to you through research that help/might help to address these challenges?

Group Silver Star

- Quarterly meeting with cross-section of players (CFO/Strategic Planning/docs/etc)
- Encourage ACHD leaders to get involved in leadership training/ops at hospitals
- Yearly self-assessment of program/business model
- Working closely with insurance companies (manager of nursing)
- Count your own beans/ know your patients and populations in terms of working with insurance and reporting to larger hospital boards
- Alternative reimbursement model (alternative to RVU model)
- Development of coding manual (early adoption)

Group Red Star

- Development of downstream revenue model
- Coding education
- Electronic charting system
- Coordination between private practice and hospital administrators (referrals, insurance)
- Meetings between program and hospital admin to maximize revenue, determine goals
- Develop group targets for revenue

Group Green Star

- Having a board containing business people
- Provide an annual report to board every year highlighting goals, revenues, expenses
- Count your own beans
- Demonstrate growth through budget (with full needs outlined)
- Strategic planning about growth
- Incorporate well-educated coder on staff

Group Blue Star

- Be able to maximize billing
- Share best practices to develop national model
- Top administrators looking down to avoid politics (what's best for patients vs what's best for division)
- Education for administrators about needed workforce
- Integration of PA's for maximized revenue

3. What are key elements that should be incorporated into any design to ensure program/system implementation of the recommendations?

Group Silver Star

- Formal commitment of long term support to program by hospital/medical school (part of business planning)
- Dedicated services for patients (adults/in-person services/etc)
- Define resources being paid for and being used (some programs using shared resources)

Group Red Star

- Better education about coding
- Plan for 65+ patients/Medicare
- Develop interest/make field competitive – to attract Fellows
- Institutional commitment
- Looking closer at downstream revenue
- Education of hospital administrators about value of long-term patients

Group Green Star

- Education for government about adult procedures (insurance/coding)
- Define what ACHD is to CMS
- Education for docs about how to develop business model
- Database to track all patient info (CONGENERATE)
- Staff education (to increase program growth)
- Intra-program coordination to learn best practices for business models
- Being able to determine projected growth
- Determine goals for growth
- Get buy-in from division directors/hospital administrators re: heart defect surgeries seeing ACHD specialists

Group Blue Star

- Integrate social worker to help with insurance problems
- Provide education to administrators about workforce needs to maximize revenue (looking at downstream revenue)
- Education around best practices for growth
- Create business model to demonstrate what is needed for growth
- Fit clinical research into business model
- Development of downstream models to justify workforce needs

4. What should ACHA's role be in implementation of these recommendations?

Group Silver Star

- Write business plan and engage staff to assess quality

Group Red Star

- Providing formulas/booklets/tools
- Supporting educational programs
- Supporting education of hospital administrators (hold event for administrators)
- Improve awareness of insurance companies
- Coding manual creation

Group Green Star

- Help define why a patient would want to go to a certain clinic
- Provide a blank business model
- Provide education and help on how to develop business models, soup to nuts
- Disseminate data (eg, downstream revenue, projection model) that could be helpful
- Webinars on education for business administrators on business models
- Explain downstream projection, business models (slides on website)

Group Blue Star

- Provide strategies for people to get insurance (per state)
- Facilitate bringing in lost patients to clinics
- Provide business model templates that are flexible and broad to accommodate diversity
- Having a group of consultants able to provide education and help on business models
- Publicize success stories
- Coordinate site visits for successful models

Accreditation

Moderator: Dr. Bill Davison

1. In your mind, what are the challenges to implementation of the recommendations (as described in the paper Recommendations from Phase I) in the area of Accreditation?

Group 1

- Can ACHA be an accrediting body?
- Does the accreditation mean anything? Does it lead to something?
- Do we need to recreate the wheel? Why can other more experienced organizations do the accreditation?
- Is this not overlapping with other organizations?
- This is a very expensive project; does ACHA want to spend the time or money?
- Can ACHA do the accreditation in conjunction with another agency with more gravitas? ACC, AHA.
- It would be more likely to succeed if done in conjunction with a more well know group. It would also be more cost efficient.
- What does the accreditation really mean?
- We have an inadequate number of CHD docs now. It will reduce the number because of docs who are part of non-accreditation organizations.
- I like ACHA as an accreditation group. ACC and AHA are very ineffective with CHD.
- This is a good idea because it will eliminate clinics that open up and just say they are experts in CHD, when they really are not.

Group 2

- What do we mean by accreditation? Approval based on what degree?
- Great potential.
- How do we actually do it? What do the questions mean?
- Communicating in two languages; patient and docs. We will need to find a common language.
- V2020 is not clear. What are you measuring; what are you expecting?
- If we know the criteria up front, this could be a good program.
- What is in it for me?
- I will probably take the rating (negative) very personally.
- It needs to be fair and transparent.

Group 3

- The time and money required to complete paperwork. Forms should not take more than 2 hours to complete
- Do not water down the parameters.
- Standards must continually be reviewed. This is very costly.
- Potential legal liability for ACHA.
- The institution may not see value to accreditation
- What does the institution get out of it?
- The criterion is not clear. It needs to be more specific and meaningful.
- Who would be the accreditation body? There must be site visits.
- There must be long term commitments. One year accreditation is not enough.
- We should have a simplified re-accreditation process.
- Once you are accreditation-who cares?
- What does the accreditation mean to the public?
- How do we continue to qualify the institution? What is key staff leaves in between accreditation reviews?

- What qualifies as a “center”? Can it be multi-site.

Group 4

- Is ACHA the proper organization to accreditation?
- ACHA should like with another organization to do the accreditation
- The process should be non-partial.
- Why would an organization want to go through this process?
- Will patients demand that a center be accreditation?
- Have ACC be part of the governing body. It will give us more professional recognition.
- Will insurance companies recognize the accreditation?
- Pay for performance. Will accreditation drive the market?
- Will accreditation stimulate new business?
- Potential bias/lack of experience.
- Who would measure the standards?
- Money! The cost to ACHA as well as the institution.
- Lack of viability of ACHA (people never find me via the ACHA web site).
- This would not guarantee a quality program.
- Can we live up to expectations and really deliver?

2. What are quality practices that have been developed locally or are known to you through research that help/might help to address these challenges?

Group 1

- Management guidelines (white paper) are already in place. If everyone followed these guidelines, that would eliminate the need for accreditation. I have read the guidelines; I know what I am doing.
- We have to be careful about how others react to the accreditation.
- Cystic Fibrosis successfully accredits their programs.
- If we do not have all possible CHD diagnostic programs, can we still get accreditation? Would we be precluded?
- The Univ. of Cal. works well with other organizations that provide services we do not provide. Work together to earn accreditation
- I have a problem with all or none accreditation. Sliding scale would be better.

Group 2

- ACHA is currently working on a process of quality measures.
- It needs to be multi-discipline quality measures; a collaboration between disciplines.
- We already do an evaluation program. We document patient education, whether the Passport is given to patient, flu shots, discussions about possible pregnancy.

Group 3 (Questions 2 and 3 combined)

- Two to three hospitals working together is tough.
- Structure of criteria should be flexible.
- There must be quality metrics.
- Monitor outcomes within range of national standards.
- There should be an impact trial.
- The criteria should follow published guidelines (frequency of return visits, tests, etc.)
- Quality of care should be based on a measurable data base.

Group 4

- Self assessing program.
- Patient advisory committee.

- Define the accreditation program; what is the structure?
- Make sure there is leadership training available to all clinic management.
- Accreditation should create permit links with other institutions.

3. What are key elements that should be incorporated into any design to ensure program/system implementation of the recommendations?

Group 1

- Insure quality of care by setting quality metrics.
- Funding.
- Should have a teaching program. Broadly defined; succession planning.
- Hard factual technical elements should be the measurements.

Group 2

- Organizations working on accreditation need an advisor.
- Objective criteria; tiered.
- Have the ability to submit an anonymous submission to determine how the clinic measures up to criteria and whether you want to go through with it; an option to pull out.
- We need to know what the criteria are up front.
- What is ACHA's responsibility for working with a group who does not pass?
- This could/should be similar to the nursing accreditation program.

Group 4

- Outcome measures; who develops them; ACHA?
- Administrative support.
- Define "leader" and "organization" (in the indicators).
- Are you judging the department or the entire hospital?
- Expand the current clinic questionnaire.
- The database; who maintains it?
- Accreditation may lead to administrative (institutional) support.
- Get something back for earning the accreditation
- May be too exclusive; leaving out small institutions.
- Could build a network to earn accreditation

4. What should ACHA's role be in implementation of these recommendations?

Group 1

- Should not have a vested interest in the process.
- Best able to assess the quality of a program.
- Interest (AHA, ACC) versus commitment (ACHA) to CHD.
- Will need to outsource evaluations.
- Do other organizations have similar guidelines that could be used by ACHA?
- There can be an award for accreditation clinics, similar to CF (CF provides funding when a clinic is accreditation). This could also be a conflict of interest.
- Can there be a small clinic accreditation as well as a large clinic/hospital accreditation.
- Pediatric cardiologists will be able to refer patients with confidence.

Group 2

- What is the difference in what we want to do and what CF is doing?
- There is a conflict of interest for patients to do accreditation

- We need to work as a team; not just patient, nor just docs do the accreditation
- The future of the medical field is to have a partnership with patients and professionals.
- We should have provisional accreditation
- This could lead to better communications with patients.

Group 3

- The process should set us up to succeed.
- Short forms.
- Put the process on line so that when filling out forms, you can work on it; leave; then come back without loss of data.
- ACHA should work with a group such as ACC or AHA who has gravitas-clout.
- Similar to magnet nursing.
- What is essential for accreditation?
- How does ACHA pay for this?
- ACHA should pay for the accreditation to assure they keep control of the process; ownership, partners, funding.
- Would the certification of staff be included (credit for certified staff)?
- ACHA should remain the leader in the field.

Group 4

- Is there a financial incentive?
- Increased revenues.
- ACHA should partner with another organization.
- Develop quality metrics.
- ACHA should interface with hospitals, versus the physicians, for the accreditation
- Cost.

Regional Care Planning
Moderated by Dr. Gary Webb

1. In your mind, what are the challenges to implementation of the recommendations (as described in the paper Recommendations from Phase I) in the area of Regional Care Planning?

- Coordinating pediatrics/adult cardiology
 - How do you pull in adult cardiologists?
- How do you find the docs seeing 5 ACHD patients?
 - How do you influence care of these patients?
- Challenges are at a city/state level; not regional (per plan)
 - Solutions likely to be local
- In US, no control over hospital growth
- Competition
- Institutional barriers to referral
- No collaboration across Institutions
- Reaching rural areas
- Running outreach clinics
 - Remote imaging challenging
 - Funding/staffing shortages
 - Outreach clinics in pediatrics are marketing efforts
- People won't care about accreditation
- Medicaid barriers to crossing state lines
- Putting together review teams that appear neutral will be a challenge
- Building confidence and trust
- "Little Fish" programs will be afraid they will be engulfed
- Referral patterns are confusing
 - Cases referred out of region
 - Don't even know extent of problems
- Fear of big programs taking over (again)
- Programs are territorial
- Centers will feel threatened
- Centers won't want to answer questions if they fear what will happen to info
- Integrating pediatric and ACHD patients
- 6 regions are too big
 - Need smaller units
- Competition (again)
- Major urban areas – tradition of competition
- Pride will be a barrier
- Building collaboration/cooperation will be barrier
- Many services state-specific
- Rural services (again)
- Outreach clinics a stretch
- Centers have no plan for collaboration
- Care currently concentrated in certain areas
 - Several big centers close by

- Conflict between collaboration and competition (again)
- Many programs will have no interest in collaborating
- Territorial – institutions actively “steal” patients from each other
- Center pricing (?)
- Centers don’t tell the truth
- Competition (again)
- Filling in the map – rural areas
- Many centers are an “empty shell”
- Insurance/business barriers
 - Collaborating conflicts with existing hospital business practices
- People don’t want to share referral networks
- Hospitals do not want to share information
- Danger that ACHA will look biased
 - Some centers have a louder voice
- Risk ACHA will not appear impartial
- Competition (again)
- Patients travel from out of state
- Challenges to picking regional leaders
 - How to pick, how to be impartial
- Implementation – what do we want? What are we trying to achieve?
- Diversity of regions will be a challenge- each region, area different
- Rural areas a challenge – long distances, sparse population
- Insurance barriers to networking care
- Program growth built of surgeons and institutional needs and interests, ACHA will have little influence on “supply side”
- ACHA efforts will have limited impact
- Rural areas a challenge
- Regionalization will not be implementable in some parts of country
- No incentives to collaborate

2. What are quality practices that have been developed locally or are known to you through research that help/might help to address these challenges?

- STS collaboration – improving surgical quality
 - Congenital heart database proposed to be separate
- Regional case sharing
- Bay Area group
- Pediatric outreach (not described)
 - CME dinner
- ECHO society is a model
- FI-Shands – outreach clinics, once a week visit from ACHD doc
- Hospitals in TX cooperated to address TX congenital heart funding issues

3. What are key elements that should be incorporated into any design to ensure program/system implementation of the recommendations?

- Leadership has to be neutral
- “Kumbaya”
- Identified “kick off moment”
 - Start conferences
 - Start video link
- Education
- Use ACC Chapters to partner for education
 - ACC’s job is knowledge translation
- Work with insurers to educate on referral
 - Get insurers to know about ACHD; direct to correct care
- IT resources/efforts
 - Remote EHR; PHR
- Talk together about patients
- Facilitate getting everyone in the room – even fierce local competitors
- Must be consumer-driven
 - Marketed to patients
- Educate insurance companies
- Educate families on how to get care
- Must be based in clear accreditation
- Invite insurers to meetings
- Two – prong approach – value team approach, good local care
- Insurance education
 - Data essential – what helps, hurts ACHD patients
 - Who should stay away
- ACC as a regional partner
 - CME education
 - Help leverage resources
 - Access to mailing list
- Get local political face time
- Aligning with ACC adds to impartiality
 - ACC has state chapters – align with chapters
 - ACPC section at ACC
- Customer service/consumer reviews
 - Measure patient satisfaction, consumer voices
- Should be impartial
- Bring in ACC
- Work with AHA
- ACC, AHA, and ACHD joint education efforts
- Bring everyone together to build collaboration
 - Get everyone in the same room
- Create/build on existing networks in specific areas
 - Research networks
 - Clinical Networks
 - Can disseminate specific best practices

- Allow “Parallel play”
 - Good programs side by side who will not “play nice”
- Promote concept of networking
- Outreach will be essential
- Regional educational programs
- Regional meetings
- Personal relationships across barriers will be essential
- Must be inclusive not exclusive
- Collaborative not competitive
- Disseminate new ideas – provoke a challenge
- Engage with state planning organizations
 - Ensure everyone in state adequately covered
- Relationships with state government

4. **What should ACHA’s role be in implementation of these recommendations?**

- Educating community
- Educating Insurance companies
 - Wasted \$\$\$ when in non-ACHD care
 - Blue cross/BS
- ACHA has independence – it is neutral
- Right group to implement collaboration because we are neutral (again)
- Identify regional needs
- Speak up for underserved areas
- Facilitate relationships
- Speak up re: gaps in care
- Outreach to non-ACHD centers
- ACHA has role in educating docs
- ACHA role to be neutral
- Define regional needs
 - Survey all parts
- Education
 - Who ACHA is and what we do
- Create ACHA chapters
 - Beef up patient side of things
- List all resources
- Create regional teams – can look for funding
- ACHA’s job to identify regional issues
- ACHA can educate parents
- Educate pediatrics
- Educate parents (again)
- Hold regional professional/patient meetings
- Regional events
- Rational planning
- In-service/education

- Host best practice events
- Educate IM cardiologists
- Get to EP society meetings
- Hold meetings (again)
- Conference to leverage collaboration
- Neutral player
- Accreditation body
- Perceived facilitator
 - Not dictators
- Partner of ACC
- Outcomes – show good/bad
- Voice for insurance reform
- Source of neutral info on ACHD programs