Think Tank Survey Monkey

2016
Follow-up Survey
39 questions
The 2nd Annual Think Tank on Prevention of Sudden Cardiac Death in the Young: Developing A Rational, Reliable and Sustainable National Health Care Resource
Survey Monkey 2016

- Survey sent to organizations that are involved with screening for risk factors for SCA
- Screening includes H and P, ECG, echocardiography and all combinations
- Includes organizations polled in the last survey and then some
- United States and International
- 72 organizations received survey; 40 responses (55.5%); last year 50%
Survey Monkey 2016

• Questions were multi-fold questions
  – What do you do?
  – Who do you do it to?
  – What data do you collect?
  – How do you collect it?
  – How do you store it?
  – What do you do with the data?
  – Do you follow-up? How do you follow-up?
  – Suggestions and comments?
  – How can you/we help you do it better?
Are you willing to share your data in a central repository?

In order to eventually define normal...
Categories

1. Data about screening groups themselves
2. Data about the screening protocols and what data is being collected and who is helping collect and analyze the data
3. How is the data obtained and stored
4. Follow-up after screening
5. Participation in a national data repository?
1. Data about screening groups themselves
Q1 What type of screening organization are you?

Answered: 41  Skipped: 0

- Private foundation (non-profit, 501c3) 73.17% (30)
- University or college athletic department (team physician and/or cardiologist) 19.51% (8)
- College of professional sports organization 7.32% (3)
- For profit screening company
- Other
How is your screening organization funded? (check all that apply)

Answered: 40  Skipped: 0

- Private donations or...
- Unfunded – volunteer work
- Research grant
- For profit – Charge a fee...
- Hospital-sponsored program
- Federal or state...
- University/college athletic...
- Other (please specify)
Q5 Which age range of individuals do you screen? (check all that apply)

Answered: 41   Skipped: 0

- Youth in primary school (age 1...): 24.39%
- High school age youth (age 8-12...): 90.24%
- Middle school age (age 18-25 years): 39.02%
- College age (age 26-35): 41.46%
- Young people age 36 years and over: 12.20%
- People 36 years and over: 7.32%
- Other: 14.63%
Q6 What school population do you screen?

Answered: 41  Skipped: 0

- All students (both athlete and non-athlete): 75.61%
- Student athletes only: 12.20%
- Do you screen through a system other than schools? Please explain: 12.20%
Q7 How many individuals do you screen annually? (all types and all ages)

Answered: 41  Skipped: 0

- Less than 100: 4.88%
- 101-500: 34.15%
- 501-1000: 24.39%
- 1001-3000: 19.51%
- More than 3000: 17.07%
2. Data about the screening protocols and what data is being collected and who is helping collect and analyze the data

And other logistics such as “where” do you do your work
What does your screening protocol include? (check all that apply)

Answered: 40   Skipped: 0

- ECG
- Limited Echocardiogram
- Complete Echocardiogram
- Discrete Data Elements (age, gender, race, height, weight)
- Other information
- Age
- Gender
- Race
- Height
- Weight
- Blood pressure
- Heart rate

[Bar chart showing the percentage of respondents who selected each option]
Q12 In which setting do your screenings typically take place?

Answered: 39  Skipped: 2

- School: 82.05%
- College/University campus: 5.13%
- Physician office: 2.56%
- Hospital: 10.26%
- Other: 0%
Who is performing physical evaluation and cardiac auscultation? (check all that apply)

Answered: 38  Skipped: 2

- Primary care physician
- Sports medicine
- Pediatric cardiologist
- Adult cardiologist
- Nurse practitioner
- RN
- Chiropractor
- EMT/First responder
- This step is not being done
- Other (please specify)
Who is interpreting results of the ECG? (check all that apply)

Answered: 38  Skipped: 2

- Primary care physician
- Sports medicine...
- Pediatric cardiologist
- Adult cardiologist
- Nurse practitioner...
- RN
- Chiropractor
- EMT/First responder
- Automatic computer...
- Other (please specify)
Q15 Where are ECG results interpreted?

Answered: 39   Skipped: 2

- On site: 69.23%
- Remote/telemedicine: 30.77%
3. How is the data obtained and stored

Is the information protected?
Do you collect and store History and Physical examination data?

Answered: 38  Skipped: 2

Yes

No
How is the History and Physical examination data collected and stored?

Answered: 38    Skipped: 2

- Paper
- Electronically (hard copy...)
- Electronically (digital...)
- Combination of paper and...
- N/A
Q18 Do you de-identify (remove protected health information) History and Physical data before it is stored?

Answered: 39   Skipped: 2

Yes: 53.85%   No: 46.15%
Q19 Do you collect and store ECG data?

Answered: 39  Skipped: 2

- Yes: 71.79%
- No: 28.21%
How is the ECG data collected and stored?

Answered: 36   Skipped: 4

- Paper: 20%
- Electronically (hard copy...): 5%
- Electronically (digital...): 30%
- Combination of paper and...: 40%
- N/A: 5%
Q21 Is your ECG data being stored in any of the following formats?

Answered: 37  Skipped: 4

- 18.92% (7) Text
- 35.14% (13) Vendor-specific raw or binary data
- 21.62% (8) Vendor-specific XML
- 8.11% (3) HL 7 Annotated ECG (FDA XML)
- 8.11% (3) DICOM ECG Waveform
- 5.41% (2) DICOM PDF
- 2.70% (1) PDF
- 8.11% (3) Excel
- 1.35% (1) REDCap
- 0.27% (1) N/A
- 2.70% (1) Other
Do you de-identify the protected health information before ECG data is stored?

Answered: 36   Skipped: 4

- **Yes**: 40%
- **No**: 60%
Do you collect and store ECHO data?

Answered: 36   Skipped: 4

Yes

No
How is the ECHO data collected and stored?

Answered: 36  Skipped: 4

- Paper
- Electronically (hard copy...)
- Electronically (digital...)
- Combination of paper and...
- N/A
Q25 Do you de-identify the protected health information before ECHO data is stored?

Answered: 37   Skipped: 4

- Yes: 21.62%
- No: 37.84%
- N/A: 40.54%
Who interprets the echocardiogram?

Answered: 35  Skipped: 5

- Pediatric cardiologist: 70%
- Adult cardiologist: 30%
- Emergency physician: 0%
- Internist: 0%
- This step is not being done: 10%
- Other (please specify): 0%
4. Follow-up after screening
Is there any follow-up after the screening?

Answered: 35   Skipped: 5

- Yes: 90% - 100%
- No: 0% - 10%
If yes, how does the follow-up occur?

Answered: 33  Skipped: 7

- E-mail
- Phone call
- Snail mail
Is there a mechanism to assure that follow-up does occur for a positive test?

Answered: 35   Skipped: 5

- Yes, please describe.

- No
Are you providing services for underprivileged youth at risk?

Answered: 35    Skipped: 5

Yes

No
5. Participation in a national data repository?
Would your screening organization be interested and willing to participate in the development of a national health care resource by submitting collected screening data into a central data repository?

Answered: 35   Skipped: 5

Yes

No
Q36 If answer is "Yes" to question 35:

Answered: 30   Skipped: 11

- 33.33% (10): Our organization is willing to submit data regardless of source of funding
- 66.67% (20): We would only consider submitting data if there was external funding
Narrative (Open-ended) Questions

1. What additional information would you like to collect in addition to what you are currently collecting?

2. What limits you from collecting all of the information that you feel is important?

3. What would make your screening efforts better?
Themes of the Narrative Comments

a) Interest in collecting more historical risk data and trying to correlate with SCA

b) Ability to achieve more consistent follow-up of the screened

c) Need more time

d) Need more money

e) Need to enhance data collection and storage and improve the current technology
Themes of the Narrative Comments

f) Frustration that everyone, especially physicians and the AHA, has not embraced ECG screening

g) Desire to own the equipment

h) More consensus on abnormal findings and what would require follow-up;

UNDERSTANDING WHAT IS NORMAL (my words)

i) Getting more physicians (cardiologists) involved
Themes of the Narrative Comments

j) Digital storage capabilities on a more uniform basis

k) More volunteers from the medical profession, not only physicians. ECG techs, echo techs, nurses, etc.
SUMMARY

1. The highest screened population are high school students.

2. There is a variation in number screened per organization; a few with 30-40K screened.

3. Variables screened are multi-fold.

4. 55% of organizations do it for free; 15% charge a fee.

5. Screenings are done mostly at schools but not exclusively so.
SUMMARY

6. The ECGs are interpreted mostly by pediatric cardiologists.

7. 70% of the H and P data is stored but by various mechanisms: paper, electronic, etc.

8. 70% of the ECG data is stored but by various mechanisms: paper, electronic, etc.

9. 70% of the echo data is stored but by various mechanisms: paper, electronic, etc.

10. Who gets an echo is also variable but mostly as a result of an abnormal ECG (onsite eval).
SUMMARY

11. Echoes interpreted by cardiologists: both pediatric and adult.
12. 90% have follow-up after screening mostly via an e-mail or phone call.
13. Almost 70% assure that follow-up does occur after a positive test but 35% do not.
14. There is overwhelming support for the development of a national health care resource and would be willing to participate by contributing their data = 95%
GOAL IN GOING FORWARD
“THE DELIVERABLES”

Define the “uniform data set”
The core set of info
Ultimately: can we define “normal”? 
Goals/Implications

1. Recap last year and recreate the momentum towards a screening data warehouse.

2. Screening is occurring and we would like to organize the data to learn the most that we can.

3. Discuss “the uniform data set” and have an action plan to agree upon and achieve it.
Goals/Implications

4. There is not necessarily a “best way” to screen and store. Need to come up with a mutually agreed upon plan.

5. All of us will be part of “a bigger picture” to get to the stated goals.

6. Our academic colleagues will accept a wider viewpoint and that getting the answers will be critical.

7. Industry and the FDA will be key partners to endorse and even financially support our endeavors.
Thanks to everyone for their hard work

AND FOR THEIR CONTRIBUTIONS TO THE SURVEY!!!!
What region of the country do you work in? (check all that apply)

Answered: 40  Skipped: 0

- Northeast (ME, VT, NH, MA, ...)
- Mid-Atlantic (PA, NJ, MD, ...)
- Southeast (NC, SC, GA, KY, ...)
- Midwest (OH, MI, WI, IN, ...)
- South (AL, MS, AR, LA, OK, TX)
- Southwest (NM, AZ, NV)
- West (MT, WY, CO, UT, ID)
- West Coast (WA, OR, CA, ...)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Q4 What year did your organization start doing cardiac screening?

Answered: 41  Skipped: 0

- 1995: 2.44% (1)
- 1996: 2.44% (1)
- 1999: 2.44% (1)
- 2000: 4.88% (2)
- 2001: 2.44% (1)
- 2005: 2.44% (1)
- 2007: 7.32% (3)
- 2008: 2.44% (1)
- 2009: 2.44% (1)
- 2010: 4.88% (2)
- 2011: 14.63% (6)
- 2012: 17.07% (7)
- 2013: 12.20% (5)
- 2014: 7.32% (3)
Q10 Is there a fee for the screening?

Answered: 41  Skipped: 0

- Free: 56.10%
- Fee for service - specified amount: 14.63%
- Suggested donation: 29.27%
ECG equipment used at your screenings is:

Answered: 35   Skipped: 5

- Owned
- Borrowed

[Bar chart showing ownership percentages]
ECHO equipment used at your screenings is:

Answered: 35  Skipped: 5

- Owned
- Borrowed
- N/A
Q30 ECHO equipment used at your screenings is:

- Owned: 44.44%
- Borrowed: 41.67%
- N/A: 13.89%

Answered: 36   Skipped: 5
Do you de-identify the protected health information before ECHO data is stored?

Answered: 36  Skipped: 4

- Yes
- No
- N/A