

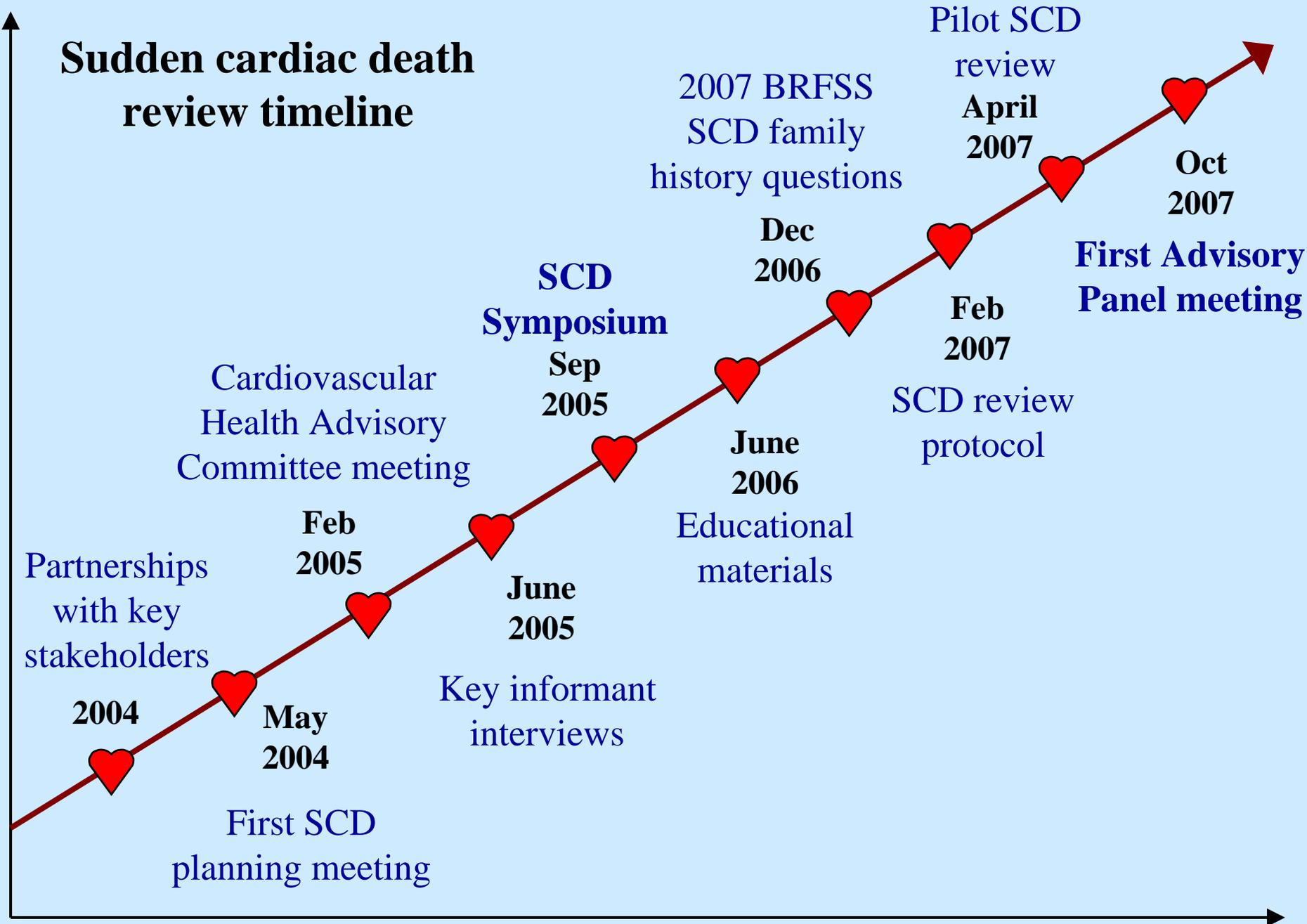
Sudden Cardiac Death of the Young in Michigan



Ann Annis Emeott
Genomics Program



Sudden cardiac death review timeline





Sudden Cardiac Death

- Defined as an unexpected sudden death due to cardiac cause and occurring within 1 hour of symptoms
- Etiologies vary with age

Age 1-20:

28% Myocarditis

24% Congenital HD

Age 21-30:

28% Atherosclerosis

23% Cardiomyopathy

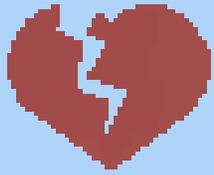
6% Myocarditis

Age 31 and older:

60% Atherosclerosis

17% Cardiomyopathy



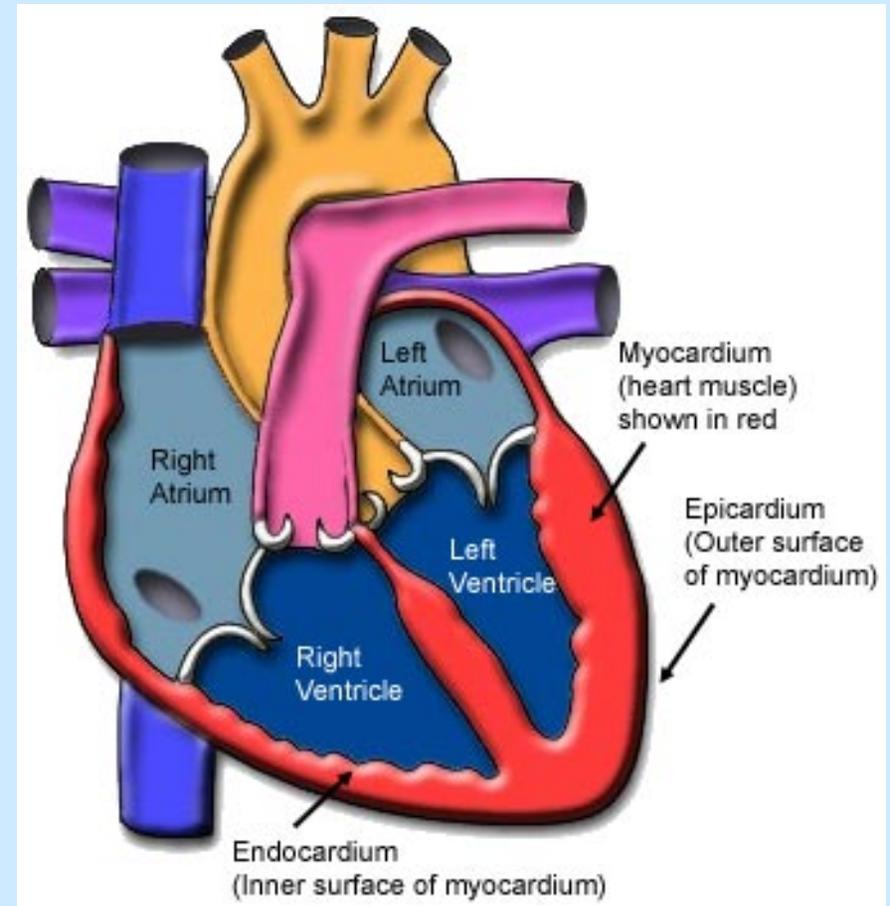


Genomics & SCD

Hypertrophic
Cardiomyopathy

Long QT Syndrome

Atherosclerosis



www.texasheartinstitute.org





SCD of the Young Pilot

Objectives

- Implement a SCD of the young mortality review system in Michigan
- Identify unmet needs for education, support, medical/genetic resources and referrals for relatives who may be at increased risk of SCD
- Develop consensus-based recommendations to guide public health prevention efforts for reducing the burden of SCD in Michigan





SCD Case Definition

Tentative SCD case definition:

- Michigan resident
- Aged 1-29
- Death occurred out of the hospital or in the emergency room
- Underlying cause of death is cardiac-related or ill-defined / unexplained



Michigan Deaths (Jan-Dec 2006)

84795 Total

83808 (98.8%)

Michigan residents

987 (1.2%)

Non-Michigan residents

917 (1.1%)

Infants < 1 year of age

2848 (3.4%)

Age 1-29

80043 (95.5%)

Age 30 years and older

103 (3.6%)

Underlying cause of death met selection criteria

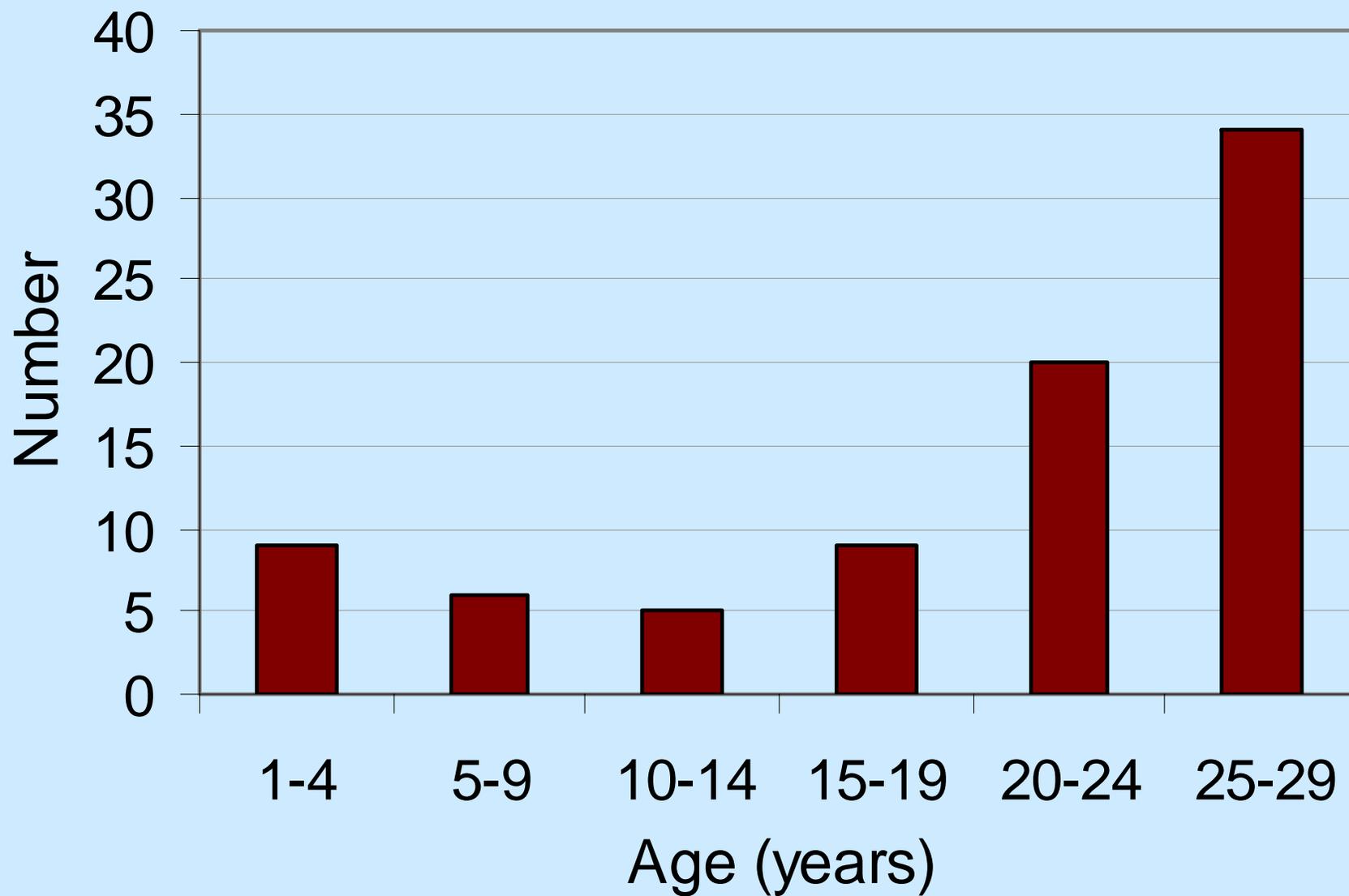
83 (80.6%)

Out of hospital deaths

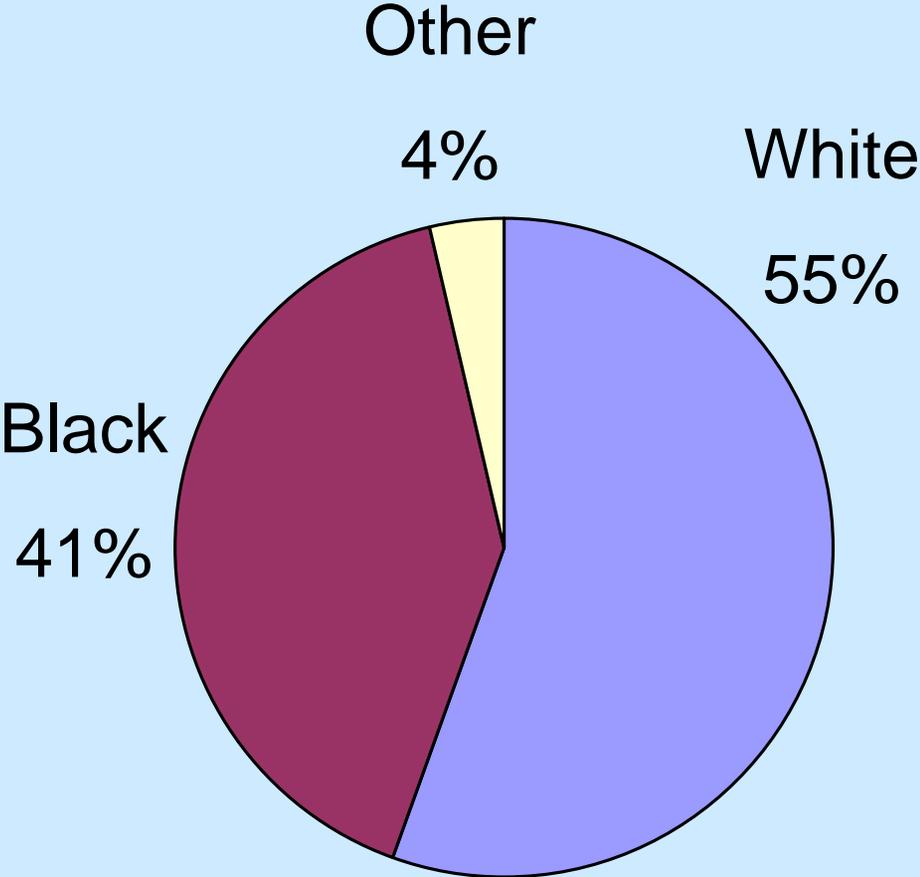
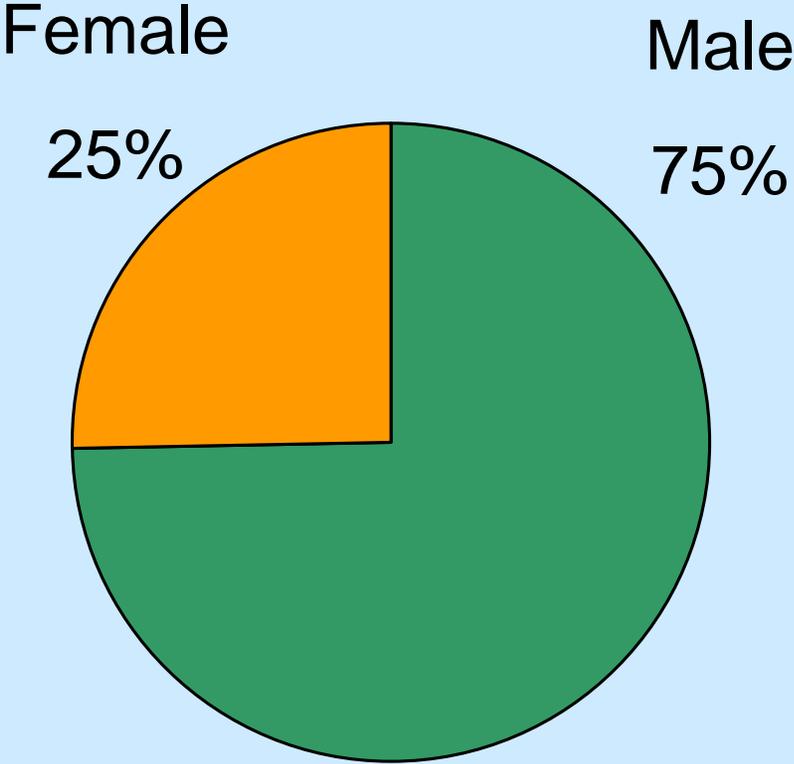
20 (19.4%)

In hospital deaths

Age of SCD victims, Michigan 2006



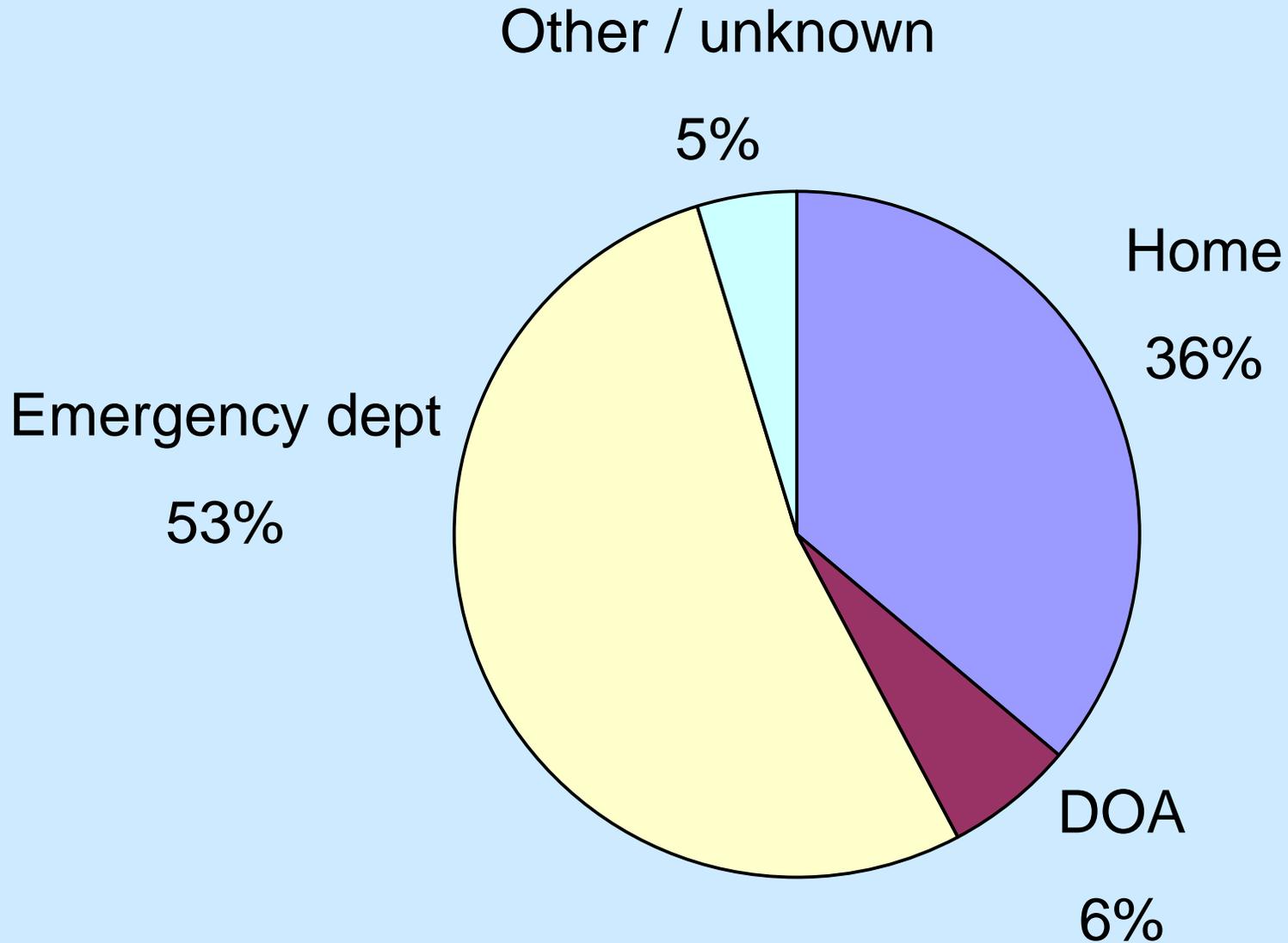
Gender and Race of SCD victims, aged 1-29, MI 2006

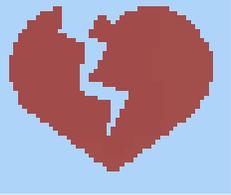


Underlying cause of death of SCD victims, aged 1-29, MI 2006

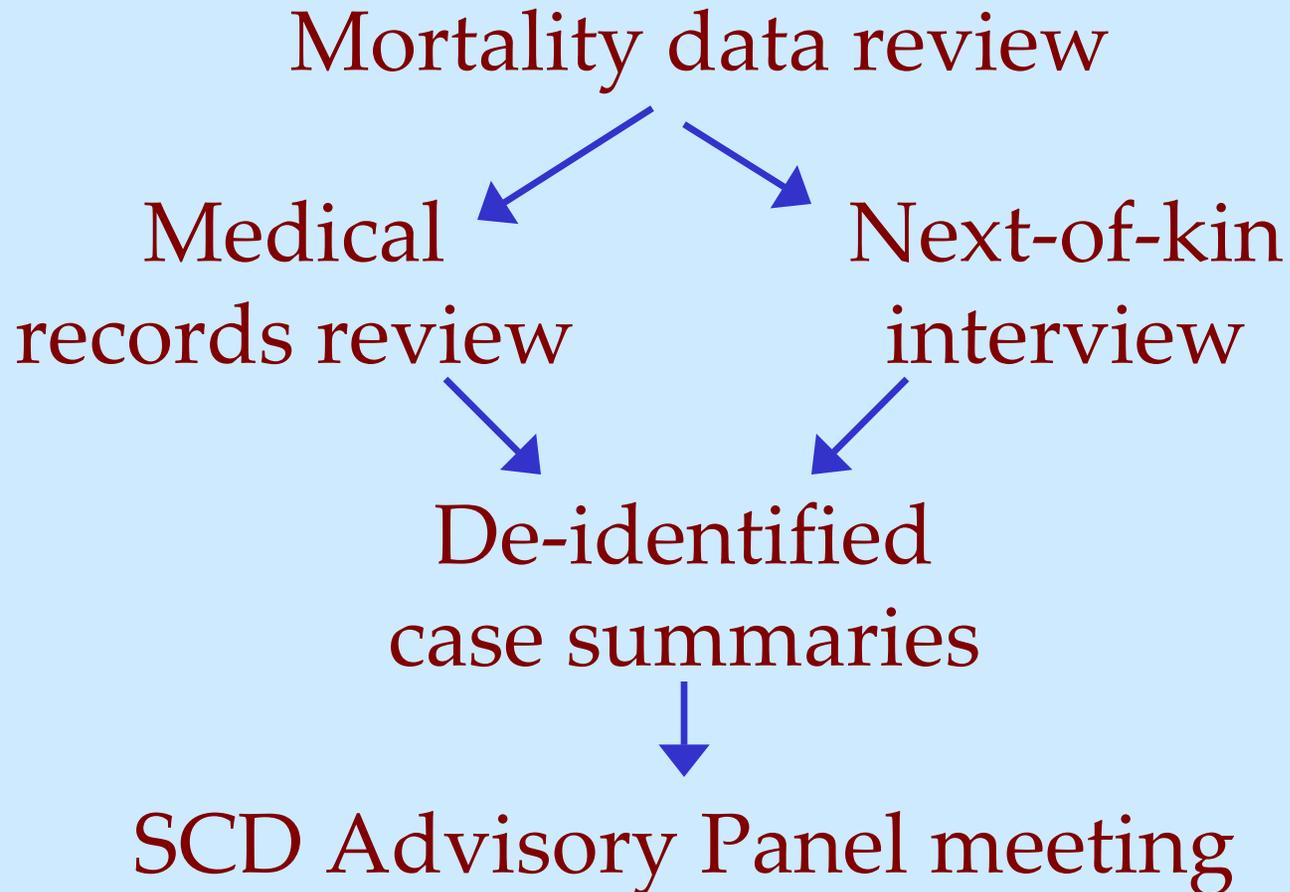
Underlying cause of death	Percent
Cardiomyopathy	28.92
Congenital malformations	12.05
Heart disease, unspecified	10.84
Ill-defined / unknown	8.43
Cardiac arrhythmia	7.23
Atherosclerotic heart disease	7.23
Myocarditis / endocarditis	7.23
Hypertensive heart disease	6.02

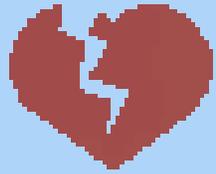
Place of death of SCD victims, aged 1-29, MI 2006





SCD Review Process





SCD Case #1

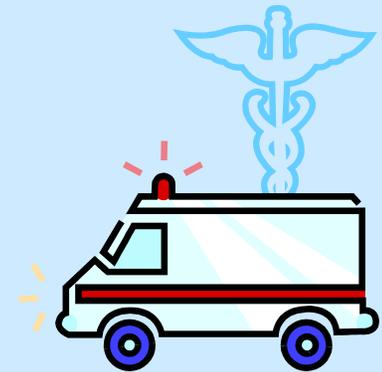
White female, age late 30's developed chest pain while out with a friend. The friend attempted to drive her to a hospital, but got lost. She became unresponsive on the way. 911 called. Found in V-fib. Death- CAD.

- Previous MI
- Hypercholesterolemia
- Smoker
- Family history of CHD, MI, HTN, high cholesterol
- Unemployed, uninsured
- Not taking meds
- Had not seen MD recently





Case #1 Issues



Patient-related factors

- Education (chest pain)
- Non-compliance (smoking, meds, MD)
- Family screening / follow-up (children)

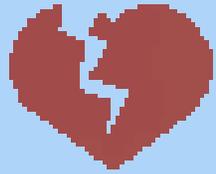
Physician-related factors

- Reinforce standard education messages
- Need to address financial situation of patient

System-related factors

- Lack of health insurance
- Availability of defibrillators for 1st responders
- Mechanism to pay for screening of family



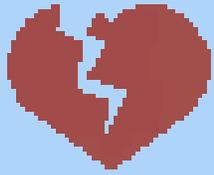


SCD Case #2

White male, age 30's, collapsed at home. Wife began CPR and called 911. Minimal electrical activity, then pulseless. Death- dilated cardiomyopathy

- Cold symptoms 1 week prior
- Excellent health
- No previous cardiac history
- Half-sister with HTN, otherwise unremarkable
- Non-smoker
- Physically active
- Not taking medications





Case #2 Issues

Patient-related factors

- Questionable symptoms
- Family screening / follow-up (children)

Physician-related factors

- Awareness of need to screen family members, and when genetics referral indicated

System-related factors

- Mechanism for family contact, including assuring autopsy report reaches PCP
- Storage of biologic specimen / DNA

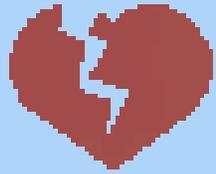




Limitations

- Source of death information
- Case definition
 - Sensitivity / specificity
- Accuracy / reliability
 - Cause of death (ICD codes)
 - Death certificates
- Novel approach with no defined protocol for state health departments
- Lack of evidence based guidance for population and high risk family screening
- \$\$\$\$\$

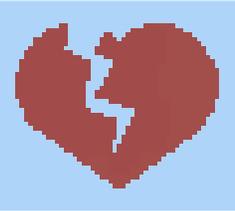




Next Steps

- Refine case definition and protocol
- Consider other sources of death information
- Involve local HD and medical examiners and genetics specialists in process of family contact
- Address patient, physician, and system-related factors
- Develop recommendations for interventions for communities and providers
- Disseminate findings (medical / PH / public education)
- Secure \$\$\$\$\$

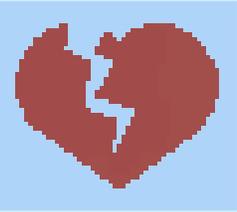




**“I thought we were forgotten....
I thought no one cared...”**

—Mother of 18 year old
victim, upon being
asked for an interview.





SCD Review Team

MDCH Genomics

- Janice Bach
- Ann Annis Emeott
- Deb Duquette

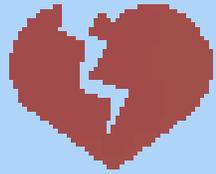
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- Marsha Jacobson

SCD Advisory Panel

Mark Caulder & Michael Lehmann

