



Community Counts Bleeding Disorders Surveillance

Vanessa R. Byams, DrPH, MPH

Lead Health Scientist

Division of Blood Disorders

Centers for Disease Control and Prevention

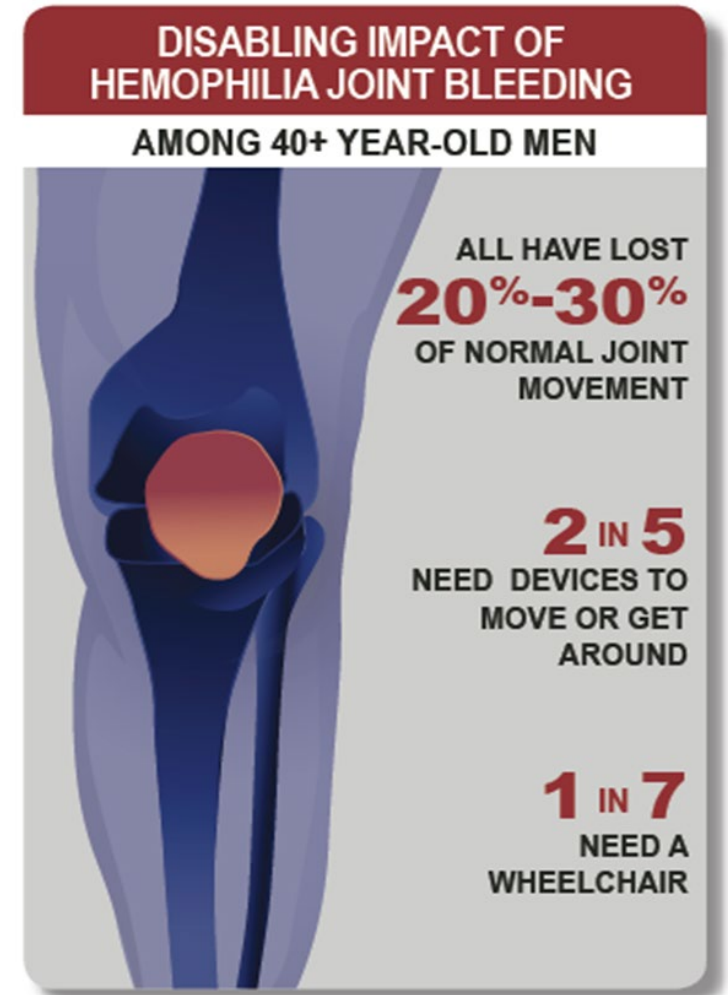
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Disclosure

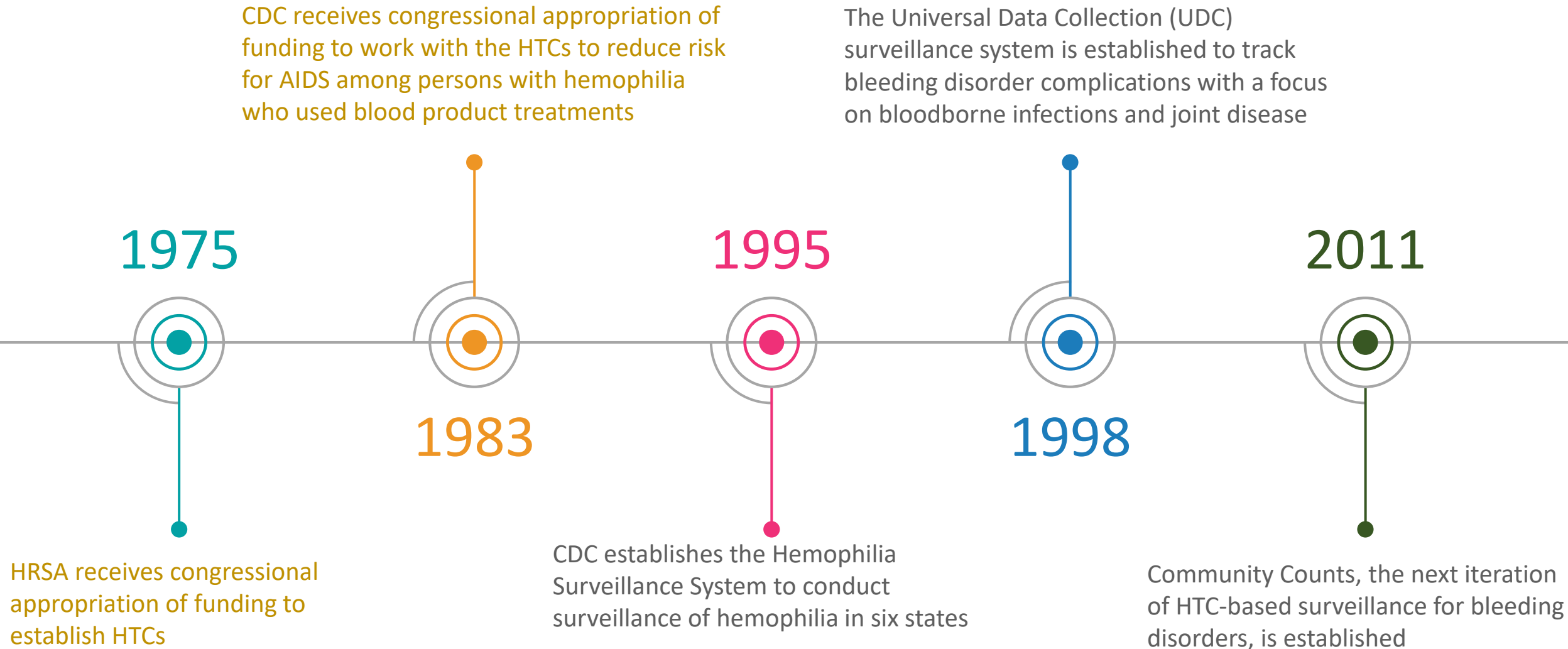
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Overview of Hemophilia and Bleeding Disorders

- Hemophilia is an inherited bleeding disorder in which the blood does not clot properly and causes bleeding
- About 30,000-33,000 males in the United States are living with hemophilia
- People with hemophilia suffer from spontaneous bleeding, particularly into joints, the brain, muscles and soft tissue
- Preventive treatment is critical to avoid long-term adverse outcomes



History of CDC Hemophilia Surveillance Activities



Evolution of bleeding disorders surveillance

1993 - 1998



Hemophilia Surveillance System (HSS)

Six State Surveillance
Hemophilia Complications and Outcomes

1998 - 2011



Universal Data Collection (UDC)

Registry within the Hemophilia
Treatment Center Network
Primary focus on treatment-related
infections and joint disease

2011 - 2020

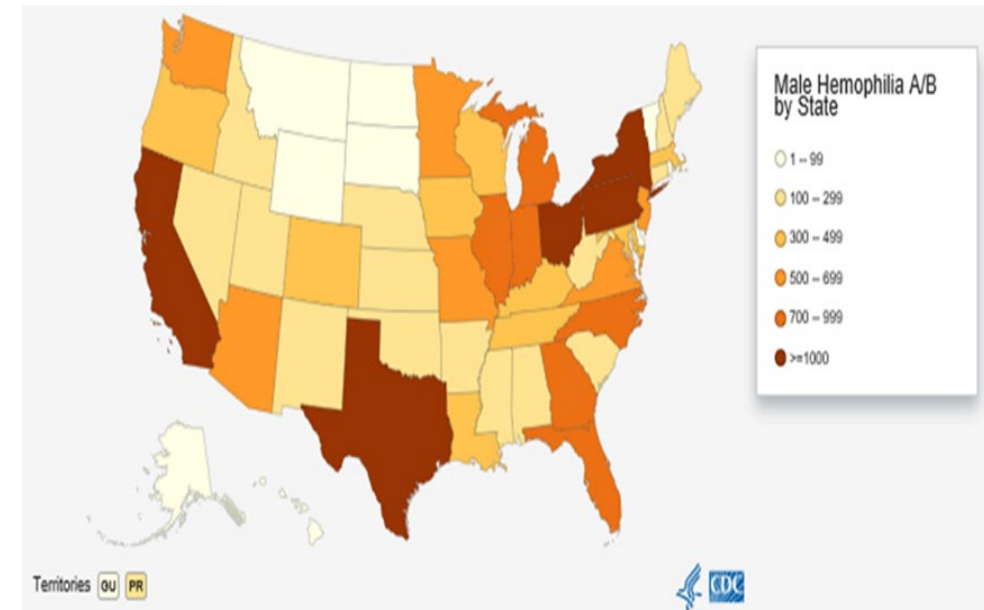


Community Counts

HTC Population Profile
Registry for Bleeding Disorders
Surveillance
Mortality Reporting

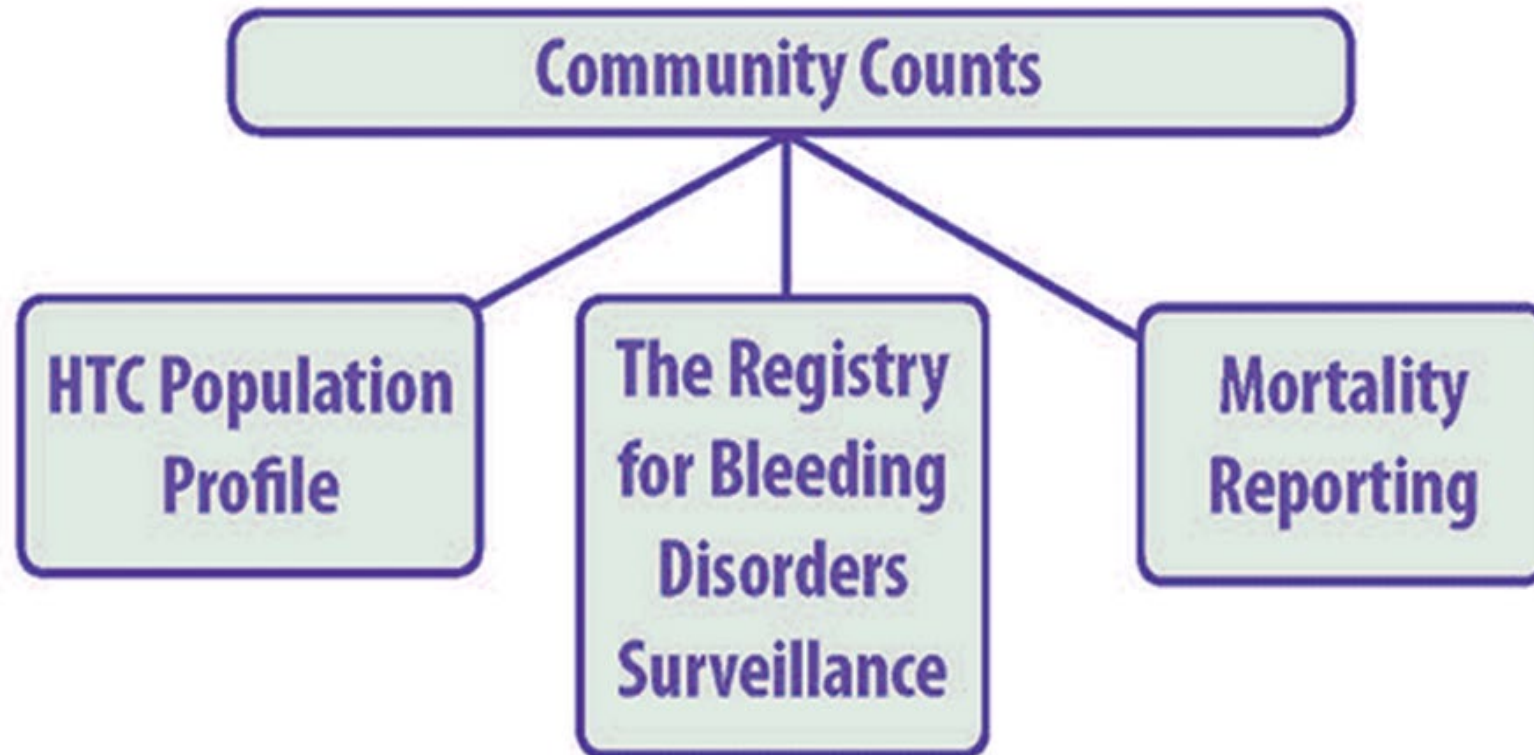
Community Counts Bleeding Disorders Surveillance System

- **Collects information about health indicators and complications**
 - Diagnoses, bleeding events, treatment practices, inhibitors, chronic diseases, pain, health services utilization
 - Baseline and subsequent visits
- **Collects specimens for infectious disease and inhibitor testing**
 - Inhibitor surveillance- annual screening and centralized testing at CDC
 - Infectious disease testing- HIV, HCV



Community Counts Components

Community Counts Program Structure



HTC Population Profile

Collects basic information on all HTC patients with bleeding disorders or blood clots

- Race
- Ethnicity
- Gender
- Year of Birth
- Zip Code (3 digit)
- Insurance Status
- Year of HTC Visit
- Primary Bleeding or Clotting Disorder
- Baseline factor activity level / VWD labs
- VTE Occurrence
- HCV Status
- HIV Status

Registry for Bleeding Disorders Surveillance

Gathers more detailed information on risk factors, treatment and complications of HTC patients with bleeding disorders

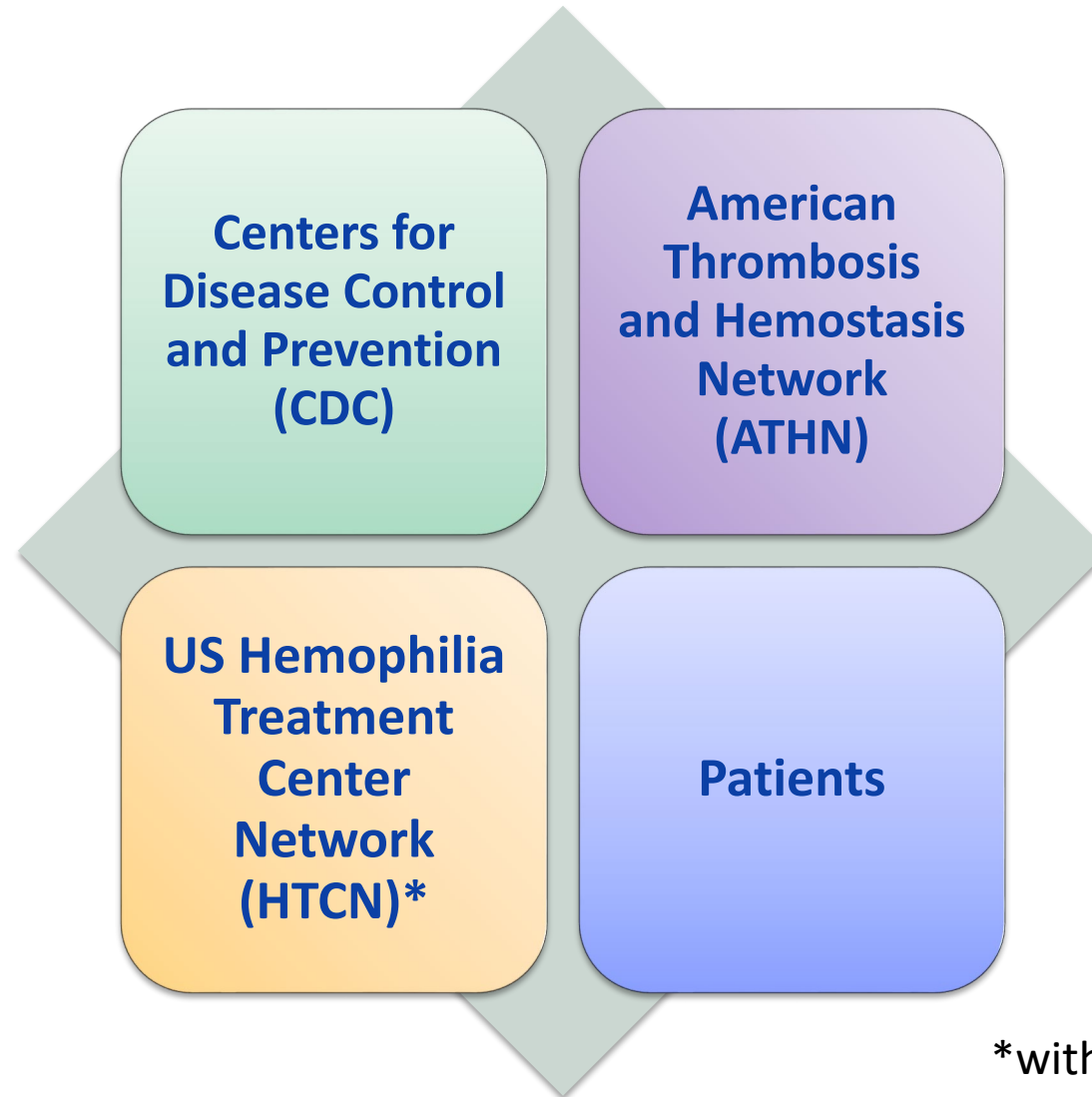
- Patient characteristics
- Diagnoses
- Bleeding events
- Inhibitors
- Prophylaxis and treatment product use
- Other medical conditions
- ER and hospital visits
- Specimen(s) collected for inhibitor screening and/or infectious disease testing
- Inhibitor surveillance – follow-up on incident inhibitors

Mortality Reporting

Information will be used to monitor trends in the causes of death and to identify causes of death that occur more often among people with bleeding disorders

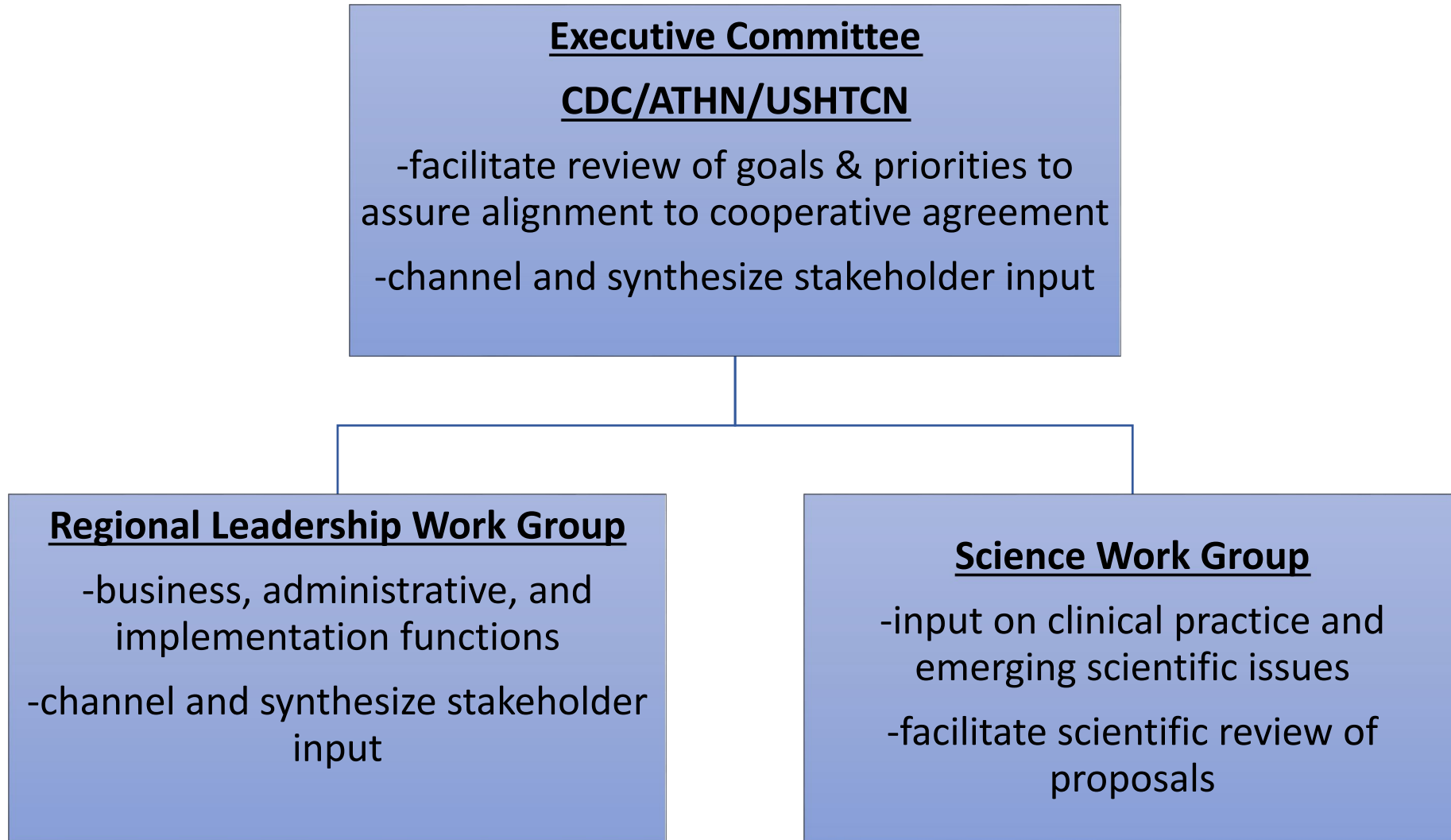
- Age at Time of Death
- HCV Status
- Year of Death
- Sources of Information about Death
- Autopsy Information
- Causes of Death (Primary and Contributing)
- Category of Primary Cause of Death

Collaborative Partnership



*with regional leadership

Additional Infrastructure



Strengths and Challenges

Strengths

- Partnerships
- Scope and longevity
- High participation of HTC and patients
- Flexibility to update periodically
- State-of-the-art laboratory testing methods

Challenges

- Shifting landscape of hemophilia complications, treatments
- Data systems modernization
- Data dissemination
- HTC funding and infrastructure

Conclusions

- Community Counts is a public health monitoring program for hemophilia and other bleeding disorders.
- CDC's hemophilia surveillance program can serve as an example of how to conduct surveillance for a complex chronic disease by involving stakeholders, improving and building new infrastructure, expanding data collection, establishing a registry with specimen collection, and integrating laboratory findings in clinical practice for individual patients.

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U.S. HTC Network

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HTC

Participants/Parents

Thank you!

vbyams@cdc.gov

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

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