



# Community Counts Bleeding Disorders Surveillance

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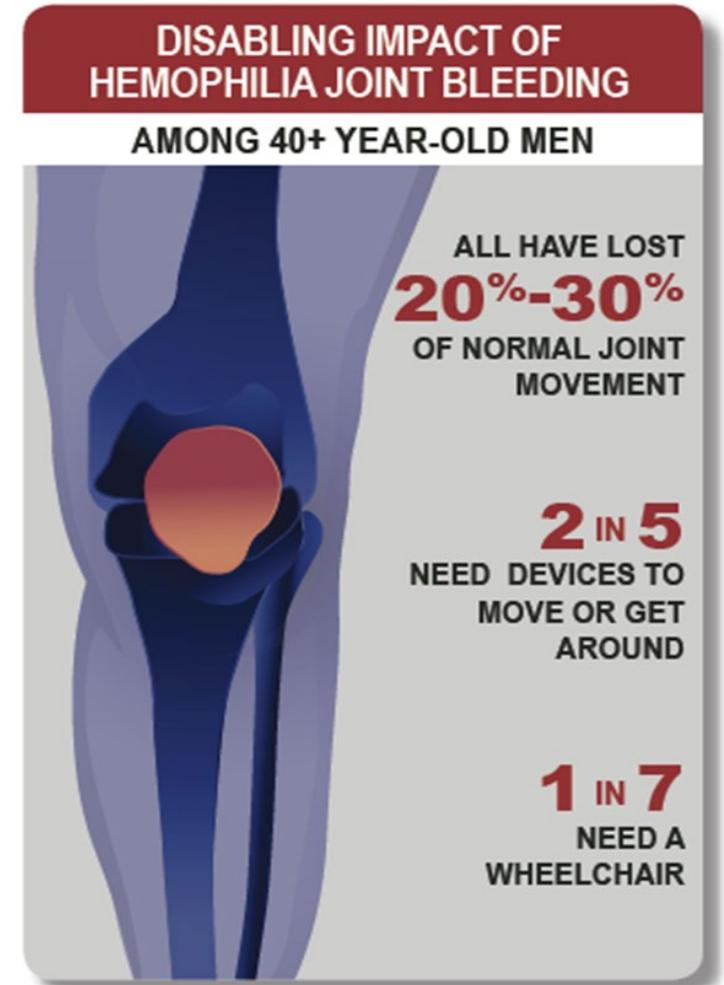
**August 13, 2021**

# Disclosure

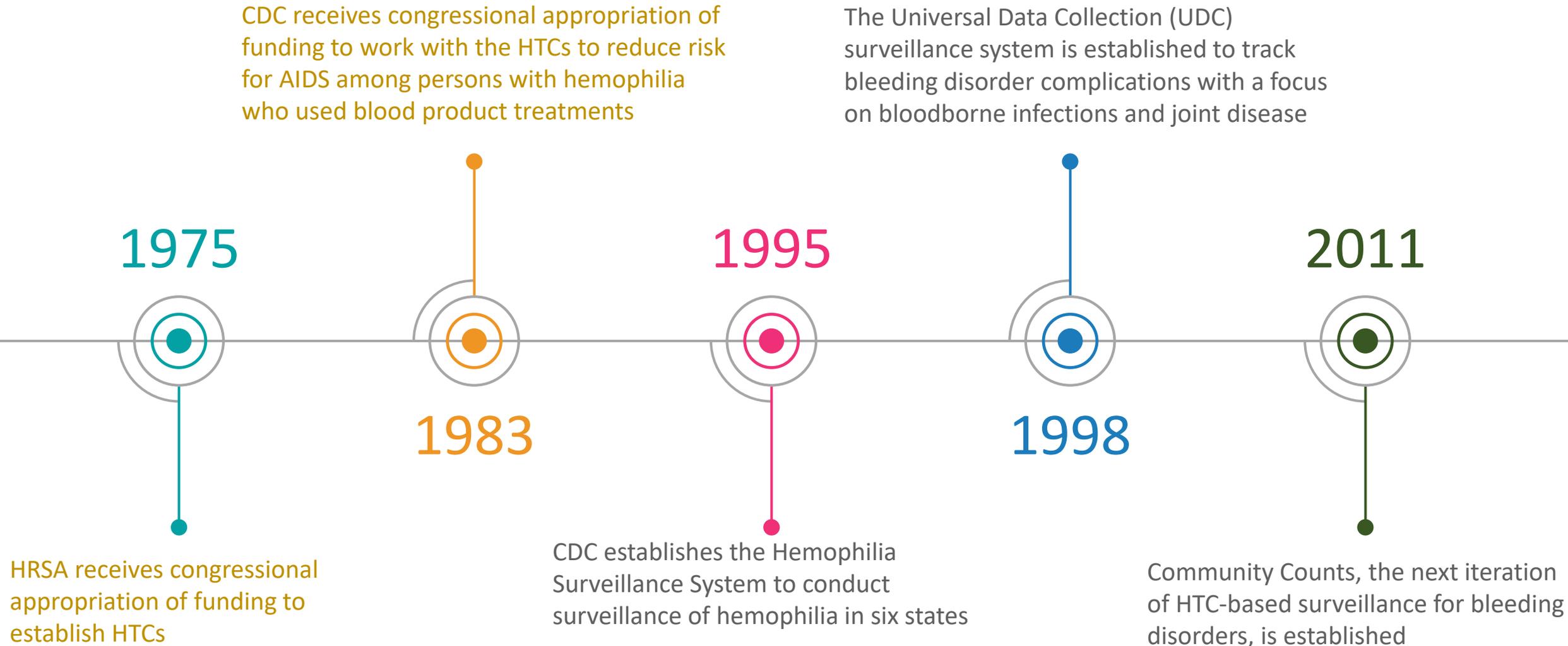
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# Overview of Hemophilia and Bleeding Disorders

- 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

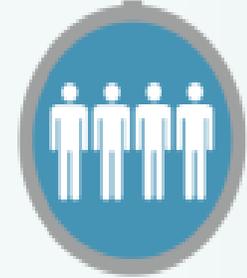
1998 - 2011



## Universal Data Collection (UDC)

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

2011 - 2020

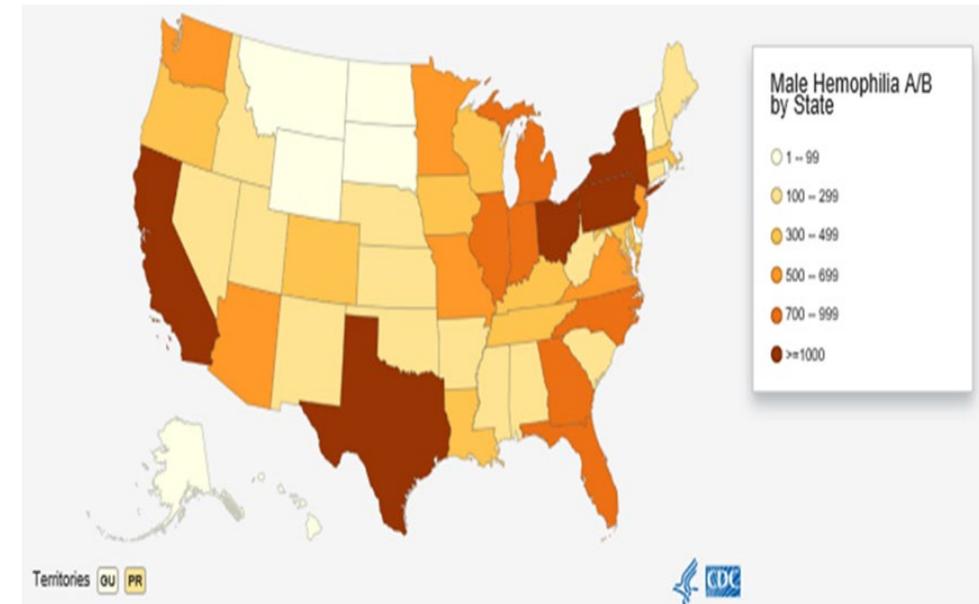


## Community Counts

HTC Population Profile  
Registry for Bleeding Disorders  
Surveillance  
Mortality Reporting

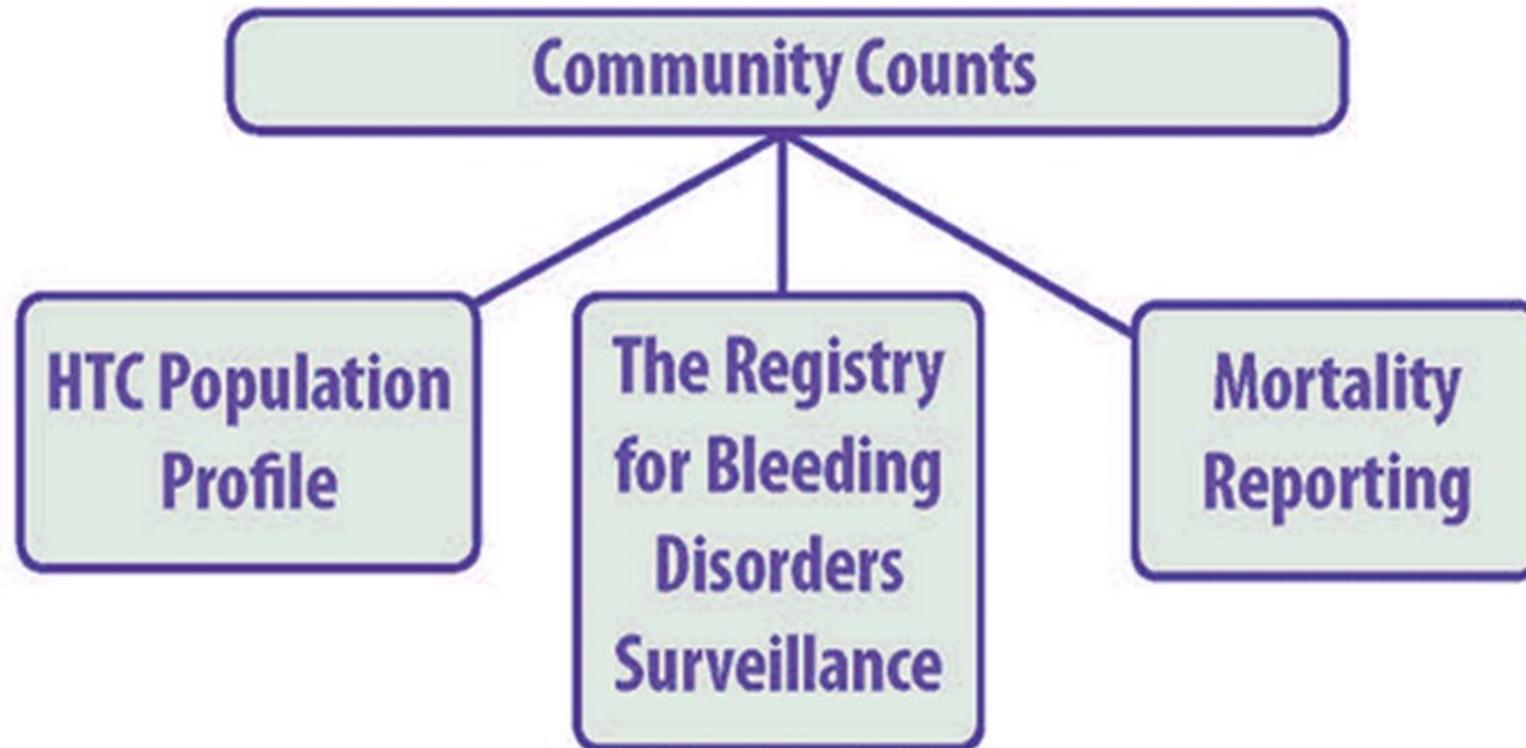
# Community Counts Bleeding Disorders Surveillance System

- **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

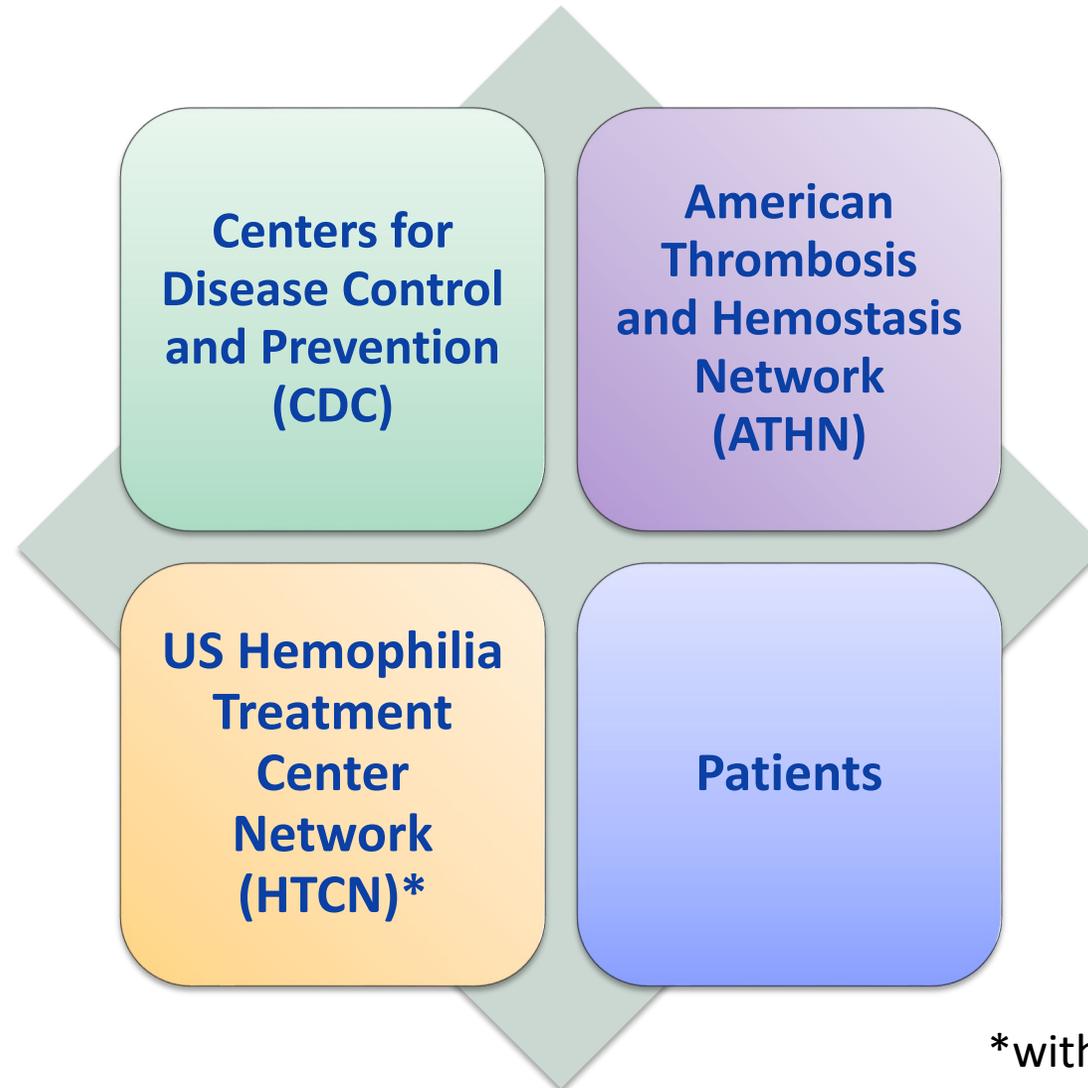
- Patient characteristics
- Diagnoses
- Bleeding events
- Inhibitors
- Prophylaxis and treatment product use
- Other medical conditions
- ER and hospital visits
- Specimen(s) collected for inhibitor screening and/or infectious disease testing
- Inhibitor surveillance – follow-up on incident inhibitors

# 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

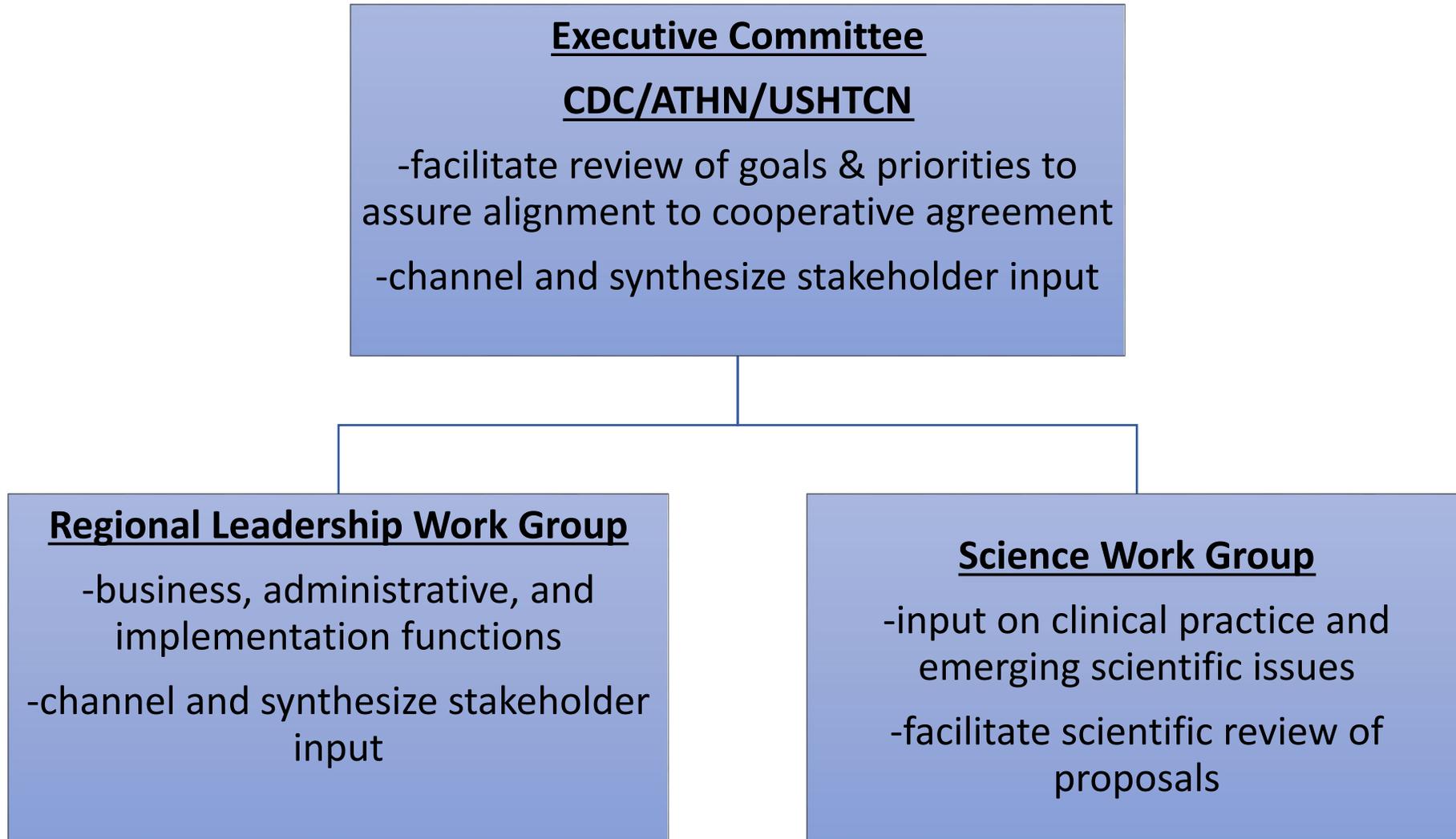
- Age at Time of Death
- HCV Status
- Year of Death
- Sources of Information about Death
- Autopsy Information
- Causes of Death (Primary and Contributing)
- Category of Primary Cause of Death

# 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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- Regional Administrators, Directors, & Medical Directors

## HTC

## Participants/Parents

# Thank you!

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