The Impact of Systems Improvements: A Progress Review of Healthcare-Associated Infections & Blood Disorders and Blood Safety







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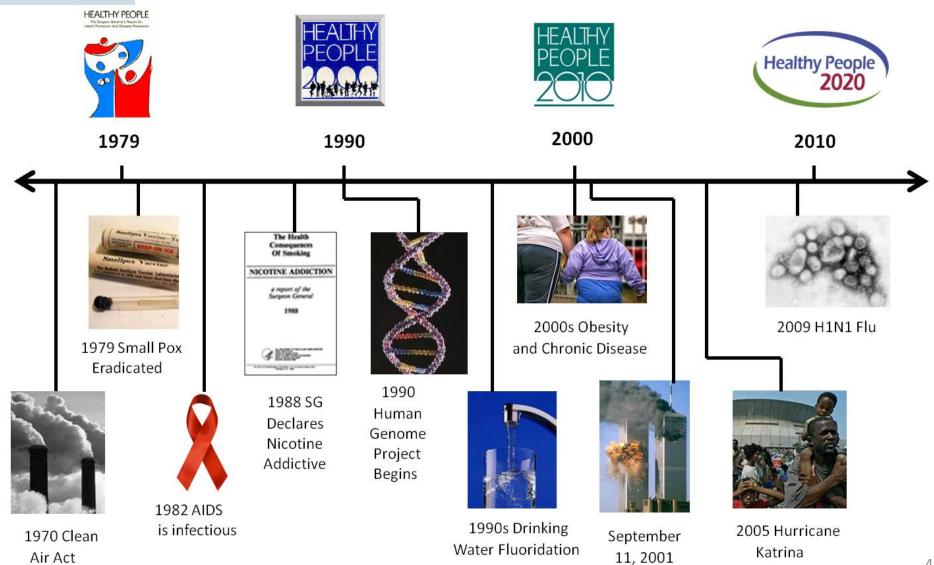
Progress Review Overview

- Systems improvements with substantial impacts in Healthcare-Associated Infections and Blood Disorders and Blood Safety
- Provide an update on the progress of Healthy People 2020 objectives
- Examine what is being done to achieve the Healthy People 2020 objectives





Healthy People 2020 Remains Relevant





Healthy People 2020

- Can be customized to meet needs of diverse users
 - -Federal
 - -State
 - -Local
- Guided by collaborative stakeholder-driven process







Healthcare-Associated Infections (HAI) Definition

Infections that people acquire while they are receiving treatment for another condition in healthcare settings:

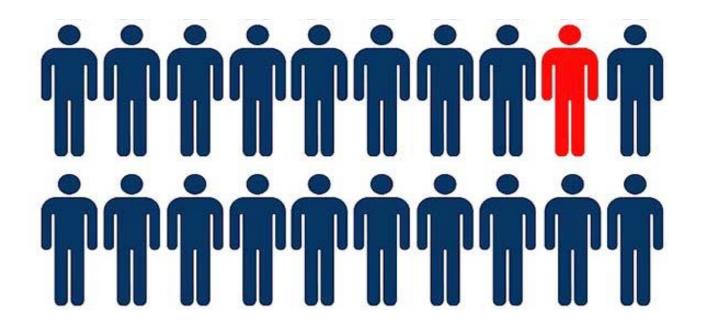
- Inpatient Hospitals
- Ambulatory settings
- Long-term care facilities
- HAIs of unknown origin





HAI Burden

Each year, 1 in 20 U.S. hospital patients acquires a healthcare-associated infection.



\$33 billion in potentially preventable health care costs annually.



HAI Risk Factors

- Transmission of communicable diseases between patients and healthcare workers
- Use of indwelling medical devices e.g. central line or urinary catheters and endotracheal tubes
- Contamination of the healthcare environment
- Surgical Procedures
- Injections
- Overuse or improper use of antibiotics

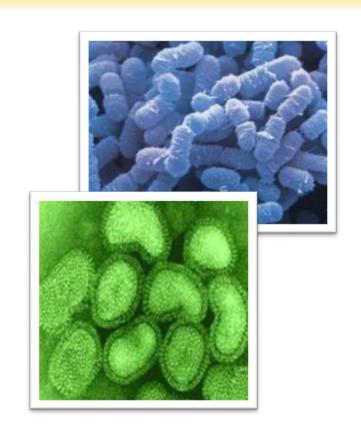






Infectious Agents that Cause HAIs

- Bacteria
- Fungi
- Viruses
- Other less common types of pathogens







Types of HAIs

- Central Line-Associated Bloodstream Infections (CLABSI)
- Catheter-Associated Urinary Tract Infection (CAUTI)
- Ventilator-Associated Events (VAE)
- Surgical Site Infection (SSI)
- Clostridium difficile gastrointestinal infection
- Methicillin-Resistant Staphylococcus aureaus (MRSA)





Blood Disorders and Blood Safety

Blood Safety

Hemoglobinopathies



Bleeding and Clotting





Blood Safety

- Each year, 5 million people in the U.S. need a blood transfusion
- Blood transfusions are lifesaving for people with:
 - Cancer
 - Inherited blood disorders
 - Liver disease or infection that stops blood production
 - Blood loss due to accidents
 - Surgical requirements
- Blood availability is critical







Infectious Threats to Blood Supply

- Bacteria
- Fungi
- Viruses
- Less common pathogens

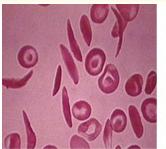


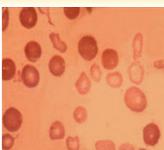


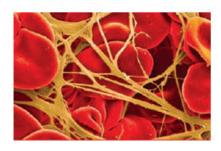


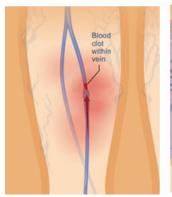
Inherited and Acquired Blood Disorders

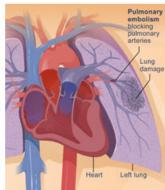
- Inherited Disorders
 - Hemoglobinopathies
 - Sickle Cell Disease (SCD)
 - Thalassemias
 - Bleeding Disorders
 - o Hemophilia
 - Von Willebrand Disease (VWD)
- Acquired Disorder
 - Venous Thromboembolism (VTE)
 - Deep Vein Thrombosis (DVT)
 - Pulmonary Embolism (PE)















Hemoglobinopathies: Emergency Department and Hospital Utilization

All Ages	Emergency Depa	rtment (2010)	Hospitalizations (2011)	
	#Visits	#Admissions	#Admissions	Avg.
			Charge	
Sickle Cell Disease	199,470	79,085 (40%)	83,452	\$27,082
Thalassemia	4,626	2,941 (64%)	4,175	\$28,237





Bleeding Disorders

- Hemophilia ~22,000 U.S. males affected¹
 - Affects males, females are carriers
 - Damages joints and inhibits clotting
 - \$3 billion annual in hemophilia care and treatment (\$150,000 per person/year)²
- Von Willebrand disease (VWD) ~ 1.4 million people in the U.S. affected^{3,4}
 - Most common bleeding disorder
 - 1 in 1,000 have bleeding symptoms^{5,6}
 - Women experience more severe symptoms (heavy menses, bleeding after child birth)



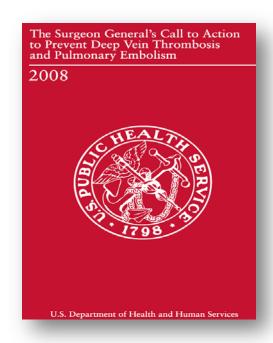
Joint disease





Clotting Disorders: Venous Thromboembolism (VTE)

- 900,000-1.2 million Americans experience VTE and 350,000 to 600,000 Americans experience DVT/PE each year^{1,2,3}
 - Risk of recurrence in 1-2 years is high and can lead to chronic cardiopulmonary problems ²
 - At least 100,000 deaths related to DVTs/PEs, but may be an underestimate ¹
 - Diagnosis often missed¹
- Approximately \$10 billion each year in VTE-associated healthcare costs in the U.S³







Presenters

Chair

Howard K. Koh, MD, MPH
 Assistant Secretary for Health, U.S. Department of Health and Human Services

Data Presentation

Irma Aripse, PhD
 Associate Director, National Center for Health Statistics, CDC

Healthcare-Associated Infections

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Blood Disorders and Blood Safety

- George A. Mensah, MD
 Special Advisor, Office of the Director, National Heart, Lung and Blood Institute, National Institutes of Health
- Michael Lu, MD, MS, MPH
 Associate Administrator, Maternal and Child Health Bureau, Health
 Resources and Services Administration

Community Highlight

John Boyce MD, Diane Dumigan RN, Carrie Guttman RN
Yale-New Haven Hospital



Irma Arispe, PhD

Associate Director, National Center for Health Statistics
Centers for Disease Control and Prevention









Presentation Outline

- Healthcare-Associated Infections
- Blood Disorders and Blood Safety





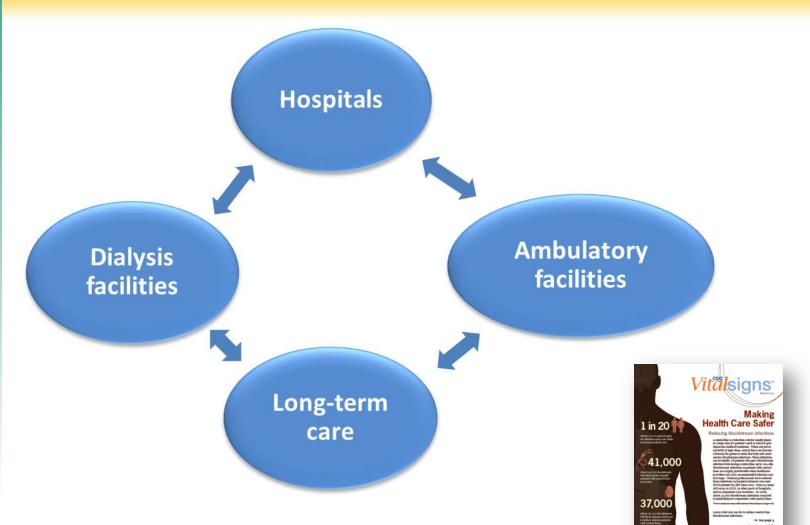
Burden of Healthcare-Associated Infections

- Healthcare-associated infections include:
 - Central line-associated bloodstream infections (CLABSI)
 - Catheter-associated urinary tract infections (CAUTI)
 - Surgical site infections (SSI)
 - Clostridium difficile infections (CDI)
- Estimated more than 1 million healthcare-associated infections across healthcare settings each year.
- 5 HAI cases per 100 hospital admissions or 1 in 20 patients acquires HAI annually.





HAIs in Healthcare Settings







National Action Plan to Prevent Healthcare-Associated Infections: Roadmap to Elimination

- Federal steering committee to coordinate and maximize prevention efforts
 - Department of Health and Human Services
 - Department of Defense
 - Department of Labor
 - Department of Veterans Affairs
- Phase one: Acute Care Hospitals
- Phase two: Ambulatory Surgical Centers, End Stage Renal Disease Facilities, and increasing influenza vaccination among health care personnel
- Phase three: Long-Term Care Facilities





HAI Surveillance Systems

- National Healthcare Safety Network (NHSN) → CDC
 - Web-based surveillance system
 - More than 12,000 facilities reporting
- Active Bacterial Core surveillance (ABCs), Emerging Infections Program (EIP) → CDC
 - An active laboratory- and population-based surveillance system
 - Data from 10 states, 44 million persons





Data Systems and Sources

- Nationwide Inpatient Sample (NIS) → Healthcare Cost Utilization Project, Agency for Healthcare Research Quality (AHRQ)
 - The 2011 NIS has all discharge data from 1,045 hospitals in 46 States
- U.S. Renal Data System → National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health
 - Records on all ESRD patients in the U.S.
 - Data originate from CMS, United Network for Organ Sharing, the CDC, and the ESRD Networks

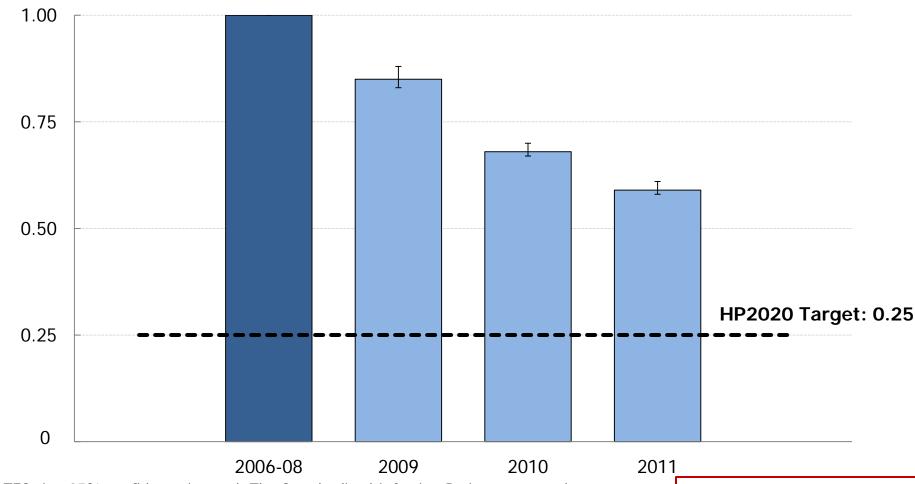


Progress Toward the National Action Plan Targets: Elimination of HAIs in Acute Care Hospitals

Metric	Source	National 5-year Prevention Target	On track to meet 2013 HHS Targets?
Central line bloodstream infections*	NHSN	50% reduction	√ Yes
Adherence to central-line insertion practices	NHSN	100% adherence	√ Yes
Clostridium difficile (hospitalizations)	HCUP	30% reduction	X No
Clostridium difficile infections	NHSN	30% reduction	Only baseline data are available
Urinary tract infections	NHSN	25% reduction	X No
MRSA invasive infections (population)*	EIP	50% reduction	√ Yes
MRSA bacteremia (hospital)	NHSN	25% reduction	Only baseline data are available
Surgical site infections	NHSN	25% reduction	√ Yes
Surgical Care Improvement Project Measures	SCIP	95% adherence	√ Yes

Central Line-Associated Bloodstream Infections (CLABSI), 2006–2011

Standardized Infection Ratio

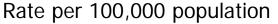


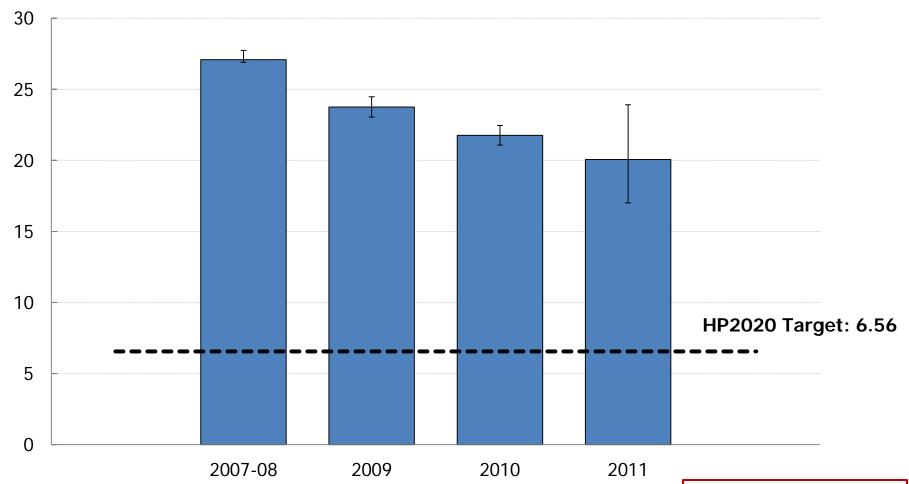
NOTES: I = 95% confidence interval. The Standardized Infection Ratio compares the observed number of HAI cases during a reporting period with the 2006-08 baseline number of HAI cases.

Obj. HAI-1
Decrease desired

SOURCE: National Healthcare Safety Network (NHSN), CDC/NCEZID.

Invasive Methicillin-Resistant *Staphylococcus Aureus* Infections (MRSA), 2007–2011





NOTES: I = 95% confidence interval. The rate is per 100,000 persons and adjusted for age, race, sex, and receipt of chronic dialysis.

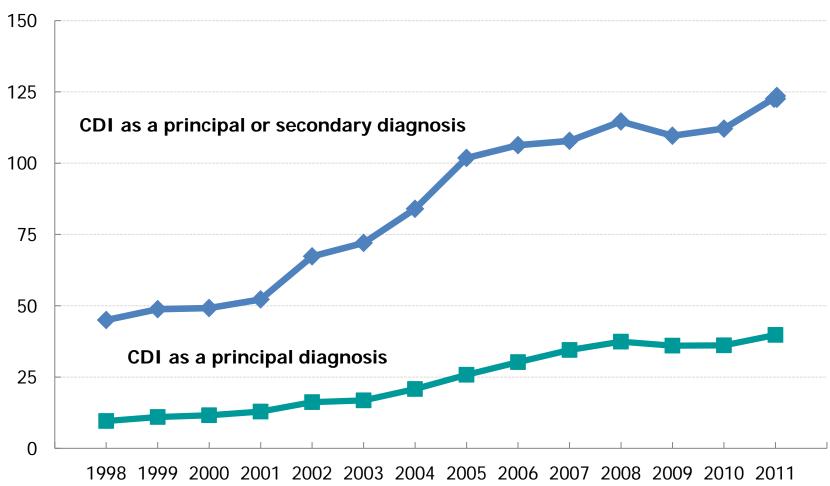
Decrease desired

Obj. HAI-2

SOURCE: Active Bacterial Core surveillance, Emerging Infections Program (EIP), CDC/NCIRD.

Clostridium Difficile Infection (CDI) Hospitalizations, 1998-2011

Rate per 100,000 population

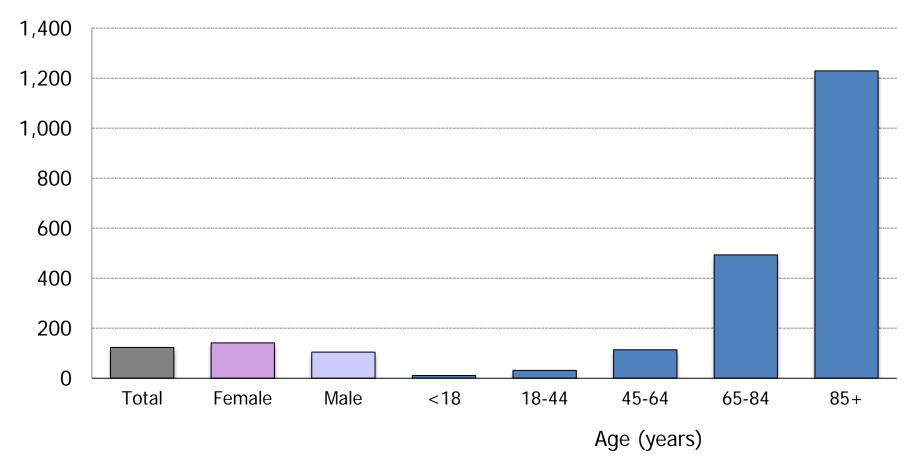


NOTES: The CDI hospital stays include hospitalizations with a principal or secondary diagnosis of CDI.

SOURCE: National Inpatient Sample (NIS), Healthcare Cost and Utilization Project (HCUP), AHRQ

Clostridium Difficile Infection (CDI) Hospitalizations, 2011

Rate per 100,000 population



NOTES: Rate of CDI stays per 100,000 population. The CDI hospital stays include hospitalizations with a principal or secondary diagnosis of CDI.

SOURCE: National Inpatient Sample (NIS), Healthcare Cost and Utilization Project (HCUP), AHRQ



Infections in Patients with End Stage Renal Disease

- Infections, including HAIs, are the second leading cause of death among patients with ESRD.
- Total death rate due to infections was 21.4 per 1,000 patient-years in 2008-2010.
 - Septicemia was responsible for 70% of these infection-related deaths.
- Estimated 37,000 CLABSIs occurred among hemodialysis patients in 2008.



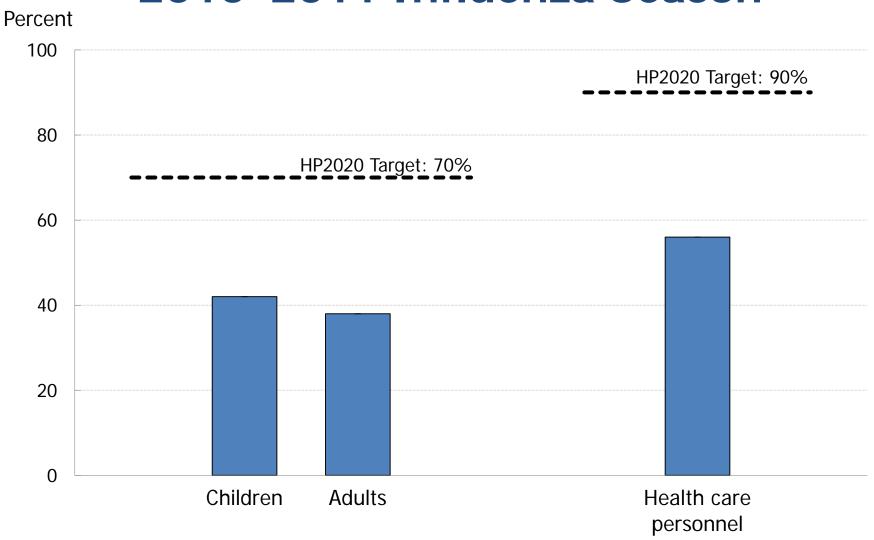


National HAI Action Plan Phase II & III: Data Development

- Ambulatory Surgical Centers (ASCs)
 - CDC is piloting strategies for tracking SSIs in ASCs.
 - Reporting of health care worker vaccination in ASCs proposed to begin in 2014.
- End Stage Renal Disease Facilities
 - Over 6,000 dialysis facilities have enrolled in NHSN since 2012.
- Long-Term Care Facilities
 - NHSN long-term care facility module has been activated in September 2012.



Influenza Vaccination Coverage, 2010–2011 Influenza Season



NOTES: Data are for children ages 6 months to 17 years and adults ages 18 and older. Data are for the total US population.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Obj. IID-12.11 through 12.13 Increase desired

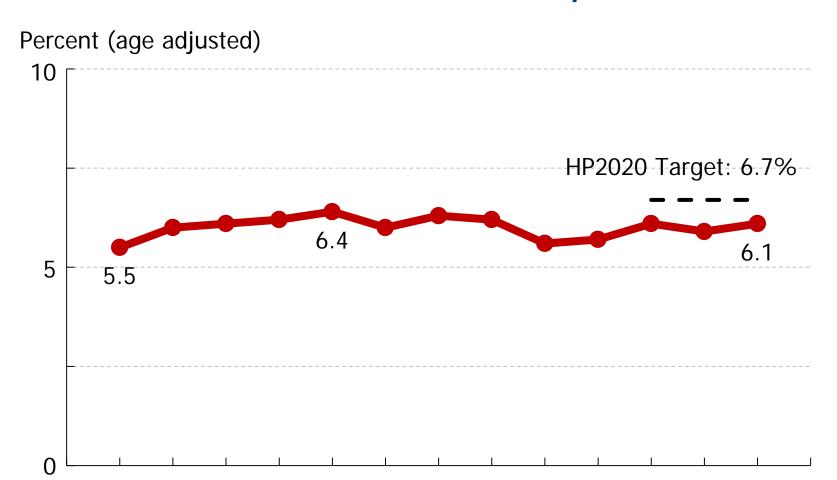


Presentation Outline

- Healthcare-Associated Infections
- Blood Disorder and Blood Safety
 - Blood Donation and Safety
 - Hemoglobinopathies
 - Bleeding disorders
 - Clotting disorders



Blood Donations: Adults 18 Years and Older, 1998–2010



2006

NOTES: Data are for adults who have donated blood in the past 12 months, and are age adjusted to the 2000 standard population.

2002

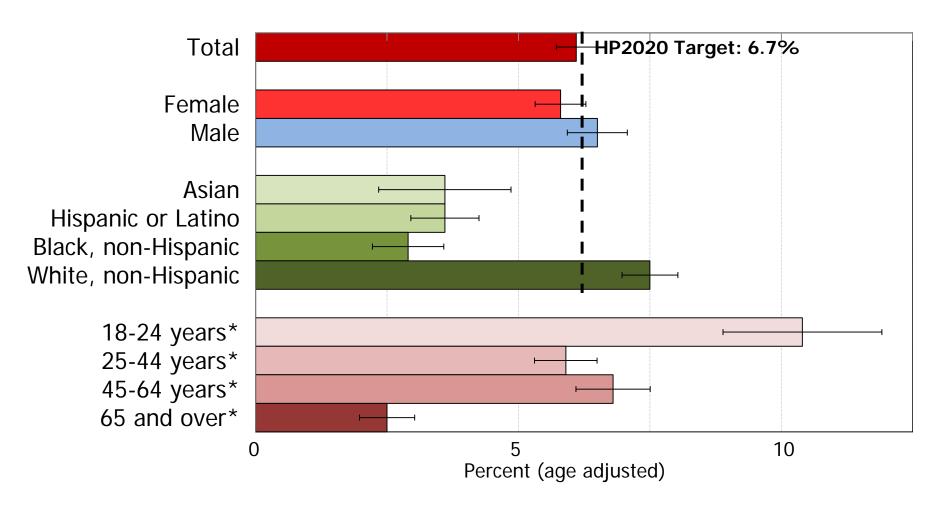
SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

1998

Obj. BDBS-17 Increase desired

2010

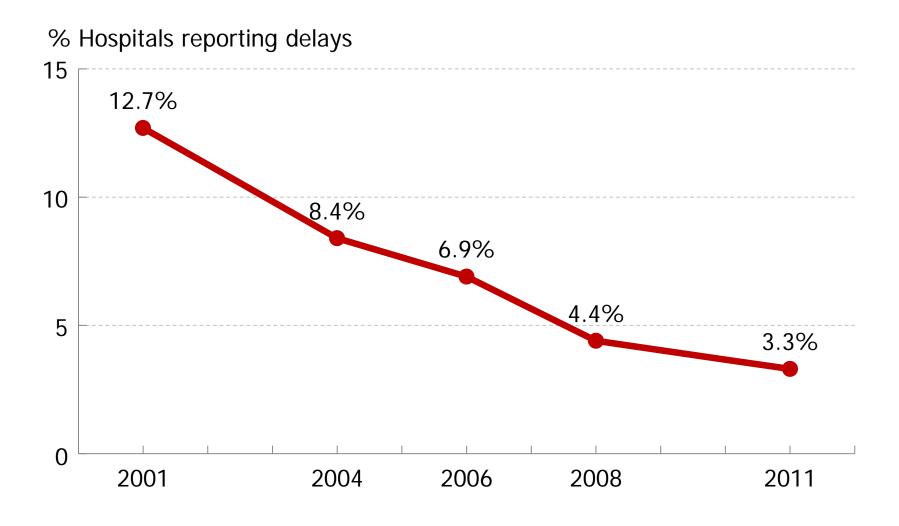
Blood Donations: Adults 18 Years and Older, 2010



NOTES: Data are for adults who have donated blood in the past 12 months, and are age adjusted to the 2000 standard population, except data by age group*. Persons of Hispanic origin may be any race. Respondents were asked to select one or more races. Data for the single race categories are for persons who reported only one race. SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Obj. BDBS-17 Increase desired

Elective Surgeries Postponed due to Blood Inventory Shortages, 2001–2011



Transfusion-Related Adverse Reactions in 2011

Number of transfused units 20,933,000

Number of adverse reactions that required diagnostic or therapeutic interventions

50,570

Transfusion-related acute lung injury 327 (TRALI)

Acute hemolysis due to ABO 42 incompatibility

Post-transfusion virus transmission 36

Obj. BDBS-18.1, 18.2 and 18.3 Reduce transfusion-related adverse reactions: TRALI, ABO incompatibility and post-transfusion virus transmission



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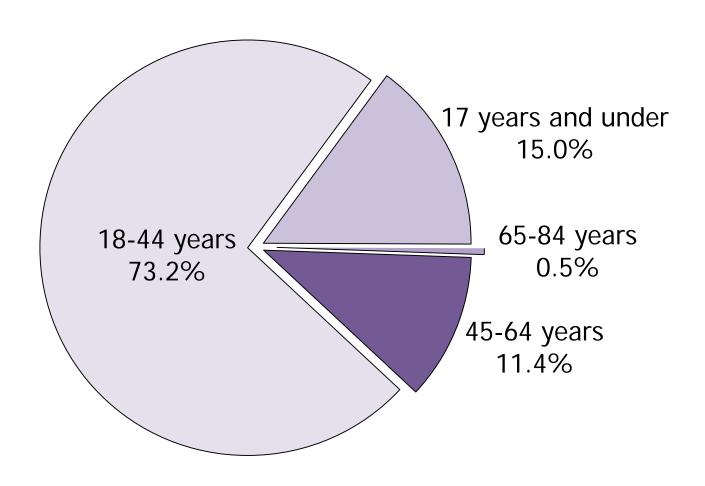


Hemoglobinopathies: Sickle Cell Disease (SCD)

- Estimated 1 out of every 500 Black or African-American births
- The death rate for children younger than 4 years of age fell 42% between 1999 and 2002.
- An estimated 90,000 100,000 persons are living with SCD in the U.S.
- In 2011, there were approximately 83,000 hospitalizations with principal diagnosis of SCD, or a rate of 27.1 per 100,000 discharges.



Hospitalizations for SCD by Age, 2011





Hemoglobinopathies: Thalassemia

- An estimated 1,000 people have severe thalassemia (or Cooley's anemia) in the U.S.
 - Survivability depends on access to frequent blood transfusions
 - At increased risk for transfusion-related adverse reactions and healthcare-associated infections
 - Most common among people from the Mediterranean, Middle East, Africa, and parts of Asia (southern China, India, and southeast Asia)
- About 4,626 ED visits in 2010; 64% resulted in hospital admission.





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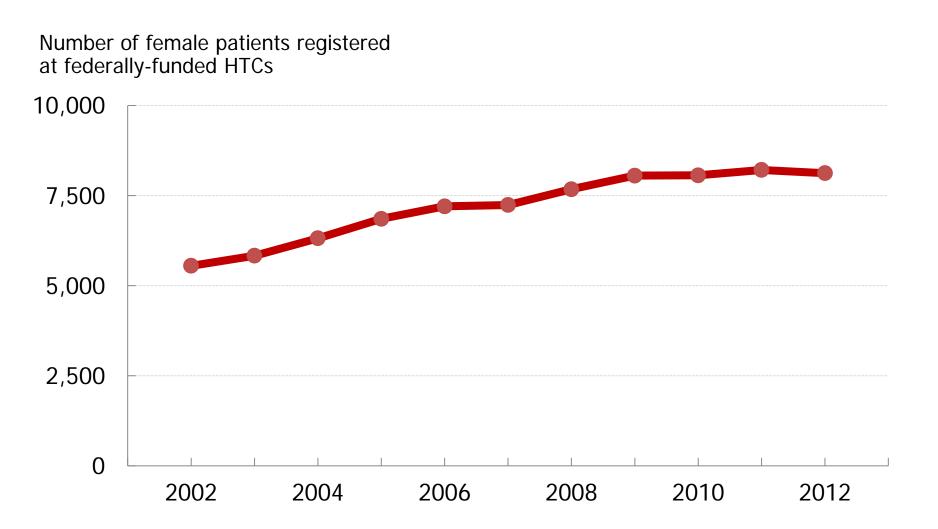


Bleeding Disorders: Hemophilia and Von Willebrand Disease

- Hemophilia
 - Estimated 20,000 individuals (mostly males) with hemophilia in the U.S.
 - 1 in 5,000 male births each year
 - In 2011, 1,476 hospitalizations with a primary diagnosis of hemophilia
- VWD affects males and females
 - Estimated to affect 1% of population
 - Women more likely to notice symptoms



Female Von Willebrand Disease Patients at Hemophilia Treatment Centers, 2002–2012



SOURCES: Baker JR et al. US Hemophilia Treatment Center population trends 1990–2010: patient diagnoses, demographics, health services utilization. Hemophilia 2013 Jan;19(1):21-6; and Hemophilia Data Set (HDS), HRSA.



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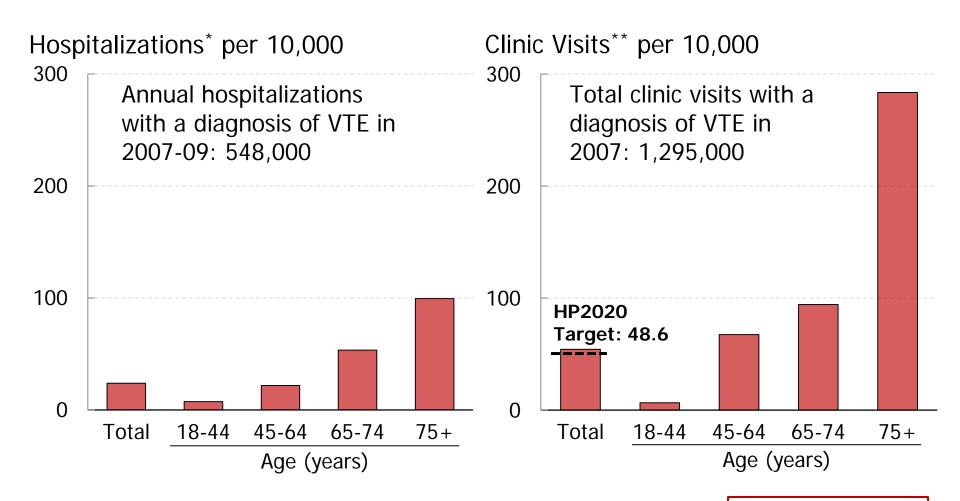


Clotting Disorders: Venous Thromboembolism (VTE)

- 350,000 to 600,000 new cases of VTE each year
 - An estimated 1.2 million Americans are living with VTE
 - Estimated 168,000 hospitalizations due to VTE in 2011
 - At least 100,000 deaths due to VTE
- Risk factors for VTE: age, hospital admission, surgery, prior VTE, and cancer
- \$10 billion each year in VTE-associated health care costs in the U.S.



Hospitalizations and Clinic Visits with a Diagnosis of VTE, by Age



NOTES: *Annual rate of hospitalizations with a discharge diagnosis of VTE, 2007-09. **Number of clinic visits with a diagnosis of VTE, 2007.

SOURCES: National Hospital Discharge Survey (NHDS), CDC/NCHS; National Ambulatory Medical Care Survey (NAMCS) and National Hospital Ambulatory Medical Care Survey (NHAMCS), CDC/NCHS.

**Obj. BDBS-12 Decrease Desired



Key Takeaways

- Health care-associated infections account for a substantial portion of health care-acquired conditions.
- National Action Plan is tracking HAIs in acute care settings, and moving toward targeting HAIs in ambulatory and long term care settings.
- CLABSI and MRSA rates are declining, but have not yet met Healthy People targets.
- National estimates are not available for many BDBS objectives; however, hemoglobinopathies, bleeding and clotting disorders are conditions that significantly impact those affected.



Don Wright, MD, MPH

Deputy Assistant Secretary

Director, Office of Disease Prevention and Health Promotion U.S. Department of Health and Human Services









Cross-Federal Collaboration

U.S. Department of Health & Human Services

- Administration for Community Living (ACL)
- Agency for Healthcare Research & Quality (AHRQ)
- Centers for Disease Control & Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- Food and Drug Administration (FDA)
- Health Resources & Services Administration (HRSA)
- Indian Health Services (IHS)
- National Institutes of Health (NIH)
- Office of the Secretary (OS)
- U.S. Department of Defense (DoD)
- U.S. Department of Labor (DoL)
- U.S. Department of Veterans Affairs (VA)





Contributions

	Coordination	Surveillance	Research	Education	Communication	Incentives
Office of Secretary	*	*	*	*	*	*
CDC		*	*	*	*	
AHRQ		*	*	*		
CMS		*				*
VA		*	*	*		
DoD		*	*	*		
Private Entities					*	*





Centers for Disease Control & Prevention: Surveillance

- National Healthcare Safety Network (NHSN)
 - Standardized data reported through internet
 - >11,000 facilities across United States
 - Data drives incentive payment programs
- Emerging Infections Program (EIP)
 - Population-level data
 - Information on pathogen-induced HAIs

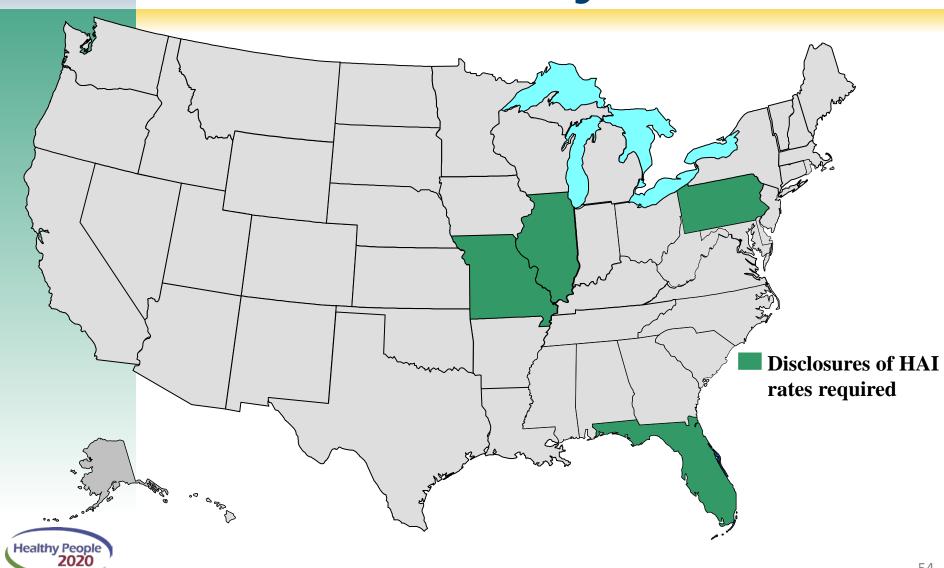


Emerging Infections Program



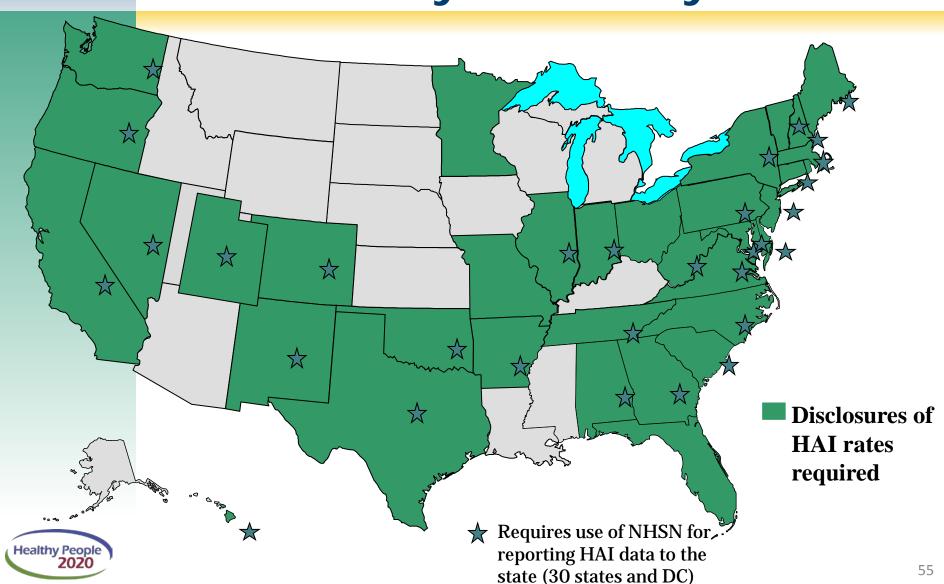


State-level Public Reporting HAI Policy, 2004





State-level Public Reporting HAI Policy – January 2013





Facilities Submitting Data to NHSN

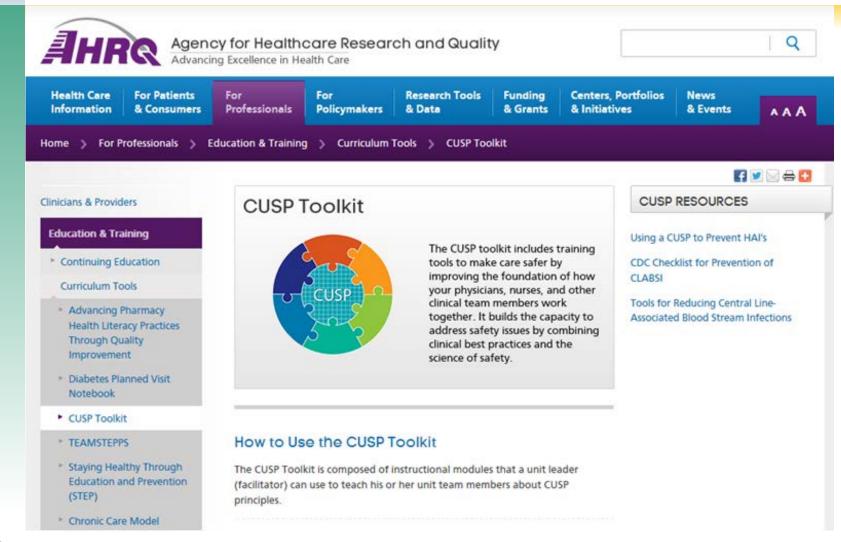
HAI Event	Number of Facilities Enrolled in NHSN*	Target Number of Facilities	CMS Reporting Start Date	
Acute care hospital	5,500	5,000		
CLABSI - ICU	3,400	2.400	11-Jan, 2011	
CAUTI - ICU	3,350	3,400	12-Jan, 2012	
SSI	3,800		12-Jan, 2012	
MRSA Bacteremia	4,000 4,000		13-Jan, 2013	
C. difficile Lab ID Event	4,050		13-Jan, 2013	
Dialysis facilities	6,150	5,600	12-Jan, 2012	
Long term acute care facilities	545	430	12-Oct, 2012	
Inpatient rehabilitation facilities	1,100	1,200	12-Oct, 2012	
Ambulatory surgical centers	285	5,300	14-Oct, 2014	



NOTES: *Data as of July 31, 2013: Total number of facilities enrolled – 12,150; number of facilities actively submitting data – 11,100.



Agency for Healthcare Research & Quality (AHRQ)







Centers for Medicare & Medicaid Services: Payment Incentives

CMS Inpatient Prospective Payment System

- Prospectively set payment rates for hospitals
- Additional payments for more costly episodes
 - NOT including secondary diagnoses resulting from HAIs

Hospital Value-Based Purchasing Program

- Affordable Care Act mandated incentive program
- Must include HAI measures for the initial year (FY 2013) of the program
- HAI measure list will expand to include SCIP,
 CLABSI, CAUTI, SSI, MRSA and Cdif by FY 2017





Office of the Assistant Secretary: Patient Safety Educational Video

Partnering to Heal

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Click on a character below to begin.







Partnership for Patients

Medicare

Medicaid/CHIP

Medicare-Medicaid Coordination Private Insurance Innovation Center Regulations and Guidance Research, Statistics, Data and Systems Outreach and Education



About the Partnership

Where Partnerships are in action

Get involved

Resources







National Awards Recognition Programs

Critical Care Societies Collaborative (CCSC) National Awards Program

- Partnership between HHS and CCSC
- Public recognition of critical care professionals in eliminating HAIs

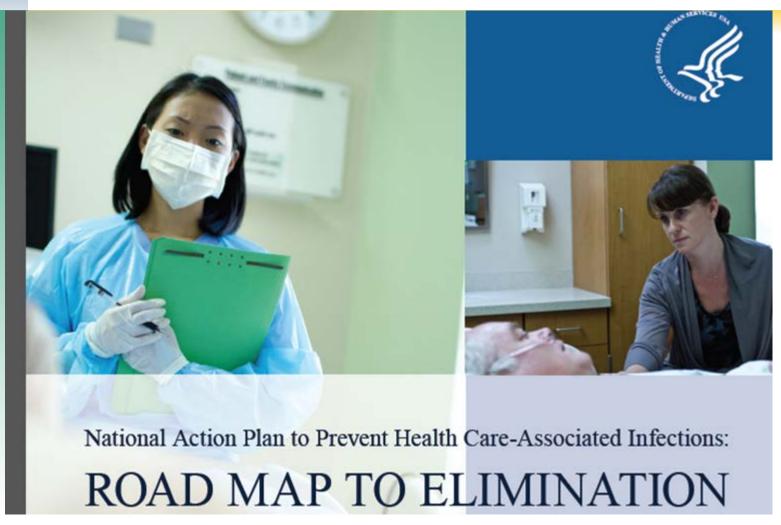
Partnership in Prevention Award

- Partners:
 - Association for Professionals in Infection Control and Epidemiology
 - Society for Healthcare Epidemiology of America
- Recognizes single multidisciplinary team





HAI Action Plan







For More Information

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Office of the Assistant Secretary for Health
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Subscribe to the HAI listsery:

HAI Listserv





George A. Mensah, M.D. Special Advisor to the Director National Heart, Lung, and Blood Institute (NHLBI) National Institutes of Health (NIH)









Translating Discoveries into Clinical and Public Health Practice

Bench Bedside **Practice** Basic Science Research Human Clinical Research Clinical Practice Delivery of Recommended Care Case Series Controlled Observational Preclinical Studies to the Right Patient at the Right Time Studies Phase 1 and 2 Animal Research Identification of New Clinical Questions Phase 3 Clinical Trials Clinical Trials and Gaps in Care TRANSLATION TO HUMANS



Modified from: Westfall et al. JAMA. 2007;297(4):403-406



Systems and Procedures to Protect Blood Supply

- Federal infrastructure and Public-Private Partnerships
- Donor recruitment and screening
- Blood testing
- Preparation of blood and blood products
- Investigation of problems





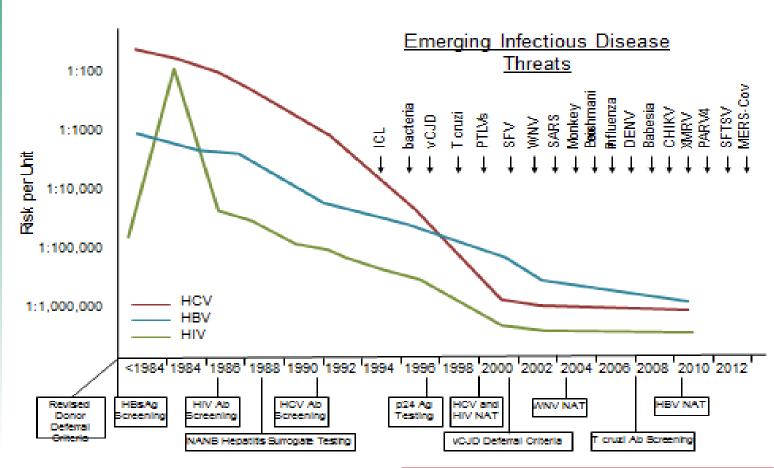


Contributions to a Safe and Adequate Blood Supply

	Coordination	Surveillance & Tracking	Research	Regulatory	Education & Communication	Reimbursement & Incentives	Service Delivery
os	•	•	•	•	•	•	
CDC		•	•		•		
FDA		•	•	•	•		
NHLBI/ NIH		•	•		•		
CMS		•		•		•	
HRSA					•	•	•
Blood Centers	•	•	•	•	•	•	•



Historical Transfusion Risks of HIV, HCV, and HBV Have Declined





Busch, et. al., Transfusion, Oct 2013, in press. Used with permission

Objective: BDBS-18.3 reduce transfusion-transmitted infections



Blood Safety Includes the Availability of Blood and Blood Products

NIH BLOOD BANK

DONATE BLOOD

Save a Life.... Become a Blood Donor Today!

7/29/13 - 8/5/13 Blood Shortages:

- B-
- B negative
- 0-
- O negative
- O+
- O positive

LATEST NEWS

Keep informed on our urgent blood donation needs:

- Listen to our <u>Podcasts</u>
- Watch videos on <u>CC TV</u>
- Set updates via Facebook
- Follow us on <u>Twitter</u>

7/29/13 – 8/5/13 African American whole blood donors urgently needed to support patients with sickle cell disease. These patients have made antibodies, so that only very closely matched donors can be used.

Local television station covered the NIH Blood Bank

on the increased need for blood and platelet donor over the holidays http://clinicalcenter.nih.gov/blooddonor/urgentupdates.html

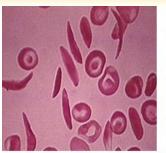


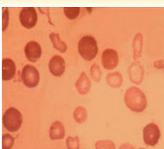
Objectives: BDBS-17 increase the proportion of persons who donate blood, BDBS-18.4 decrease persons with hemoglobinopathy who develop alloimmunization, BDBS-19.1 reduce blood shortages

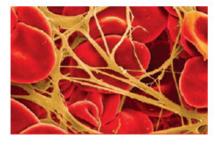


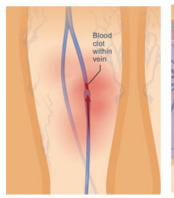
Inherited and Acquired Blood Disorders

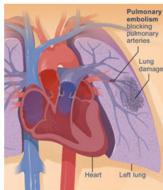
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 - Hemoglobinopathies
 - Sickle Cell Disease (SCD)
 - Thalassemias
 - Bleeding Disorders
 - o Hemophilia
 - Von Willebrand Disease (VWD)
- Acquired Disorder
 - Venous Thromboembolism (VTE)
 - Deep Vein Thrombosis (DVT)
 - Pulmonary Embolism (PE)







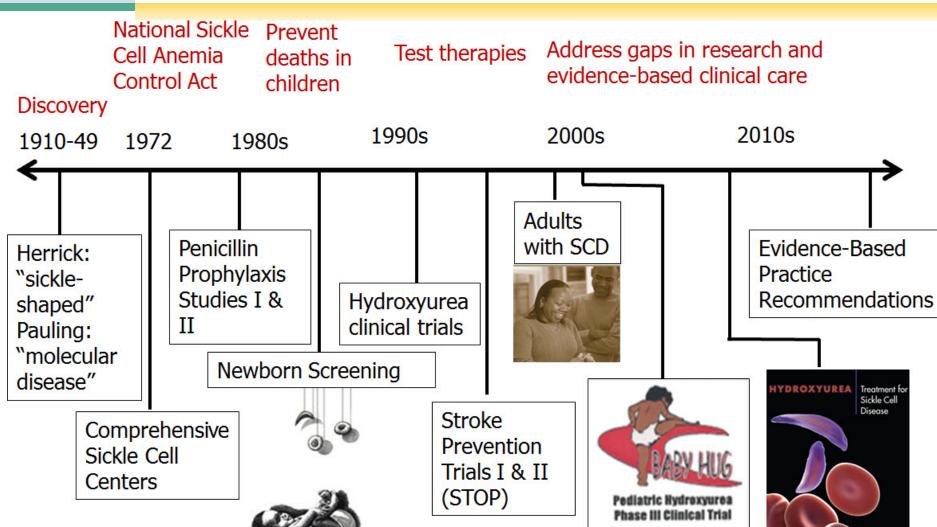






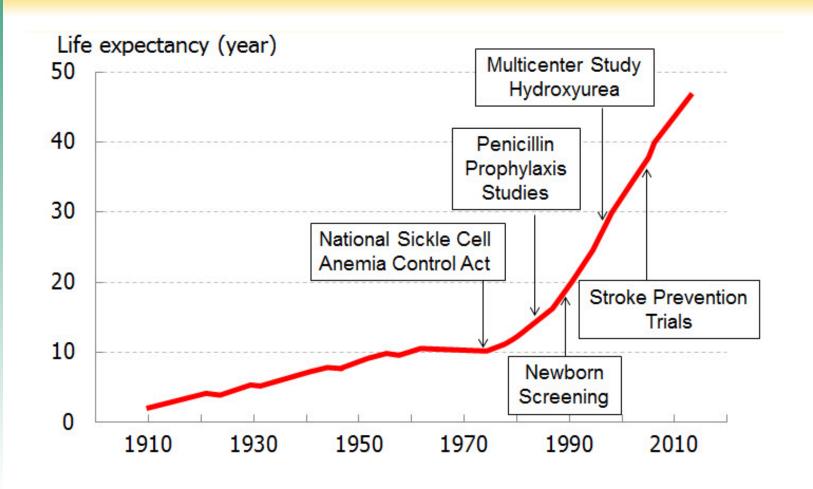


Sickle Cell Disease Research: From the Molecule to the Community





Life Expectancy of Patients with Sickle Cell Anemia has Increased

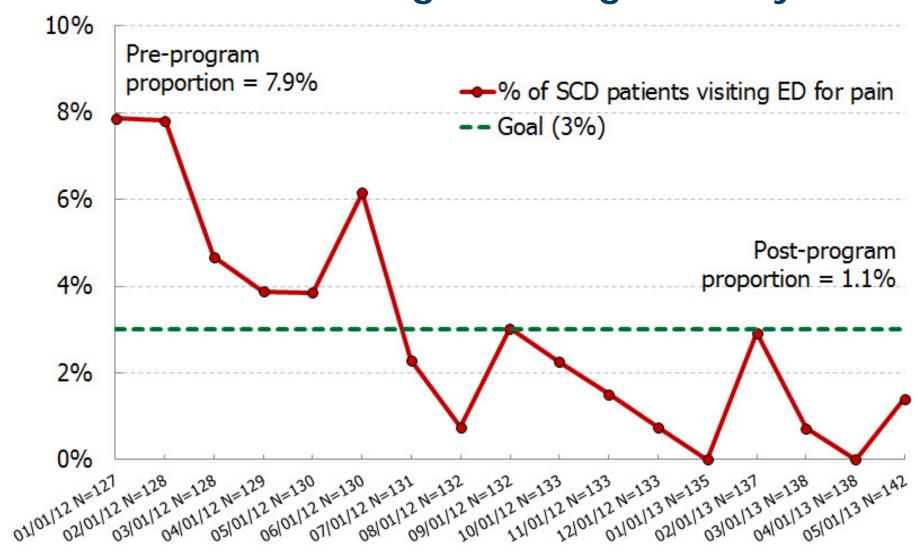




Objectives: BDBS-2 increase referrals for evaluation and treatment, BDBS-4 increase screening for complications, BDBS-5 increase therapies, BDBS-6 increase penicillin



Preventable ED Visits for SCD Pain Children and Young Adults ages 5-21 years

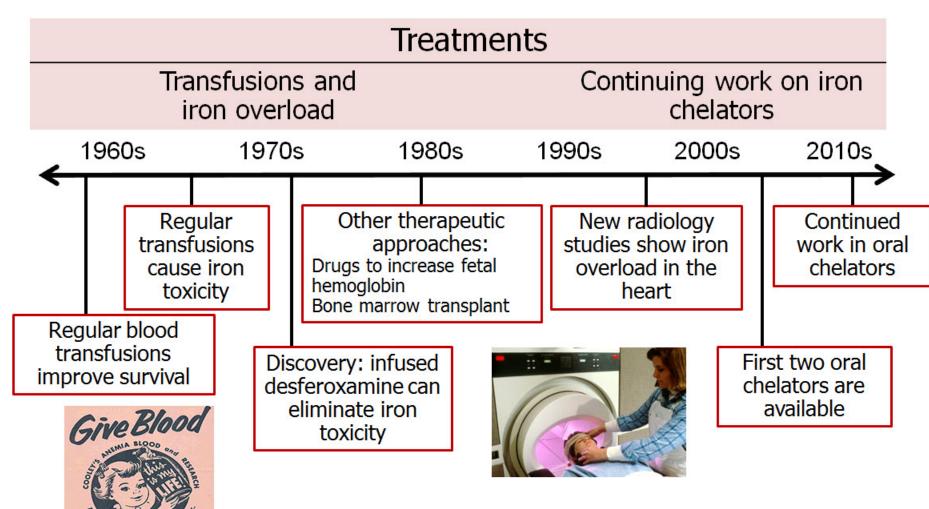


SOURCE: Kalinyak, K, Crosby, L, et. al. Funded by Cincinnati Children's Hospital and Medical Center. Used with permission

Objective: BDBS-7 Reduce preventable hospitalizations in SCD children



Thalassemia Research: Improved Understanding but a Long Way to Go



SOURCE: American Society of Hematology

http://www.hematology.org/SearchResults.aspx?searchtext=50%20years%20milestones
Give Blood Logo: Used with permission of the Cooley's Anemia Foundation



Thalassemia: Comprehensive Care for Patients and Families



Comprehensive Care Checklist

Recommended Annual Comprehensive Evaluation Test for Thalassemia Patients





<u>Pulmonary function studies - post splenectomy</u>

Every three years or as indicated.

Cardiac Evaluation

The following tests should be performed at least once per year.

 Assessment by a cardiologist knowledgeable in problems of iron overload and thalassemia.

<u>Immunizations</u>



Iron chelation

Annual assessment of the effectiveness of the chelation

<u>Genetics</u>

- Globin genotype (once)
- ☐ HLA typing (once)
- ☐ HLA typing for new siblings after birth
- Genetic counseling

Objectives: BDBS-1 increase vaccinations, BDBS-2 increase referrals for evaluation and treatment, BDBS-4 increase screening, BDBS-5 increase therapies, BDBS-10 increase knowledge of carrier status



SOURCE: Abridged version of http://cooleysanemia.org/updates/CompCare3.pdf. Used with permission of the Cooley's Anemia Foundation



Thalassemia + Blood Safety: A Collaboration of the Cooley's Anemia Foundation and the CDC

Blood Safety

Objective: BDBS-18.3 decrease transfusion-transmitted infections



Blood Safety is Knowledge







The Thalassemia Data and Blood Specimen Collection System (commonly called the Blood Safety Program) provides much needed knowledge.

And Knowledge is Power

So Blood Safety is Power

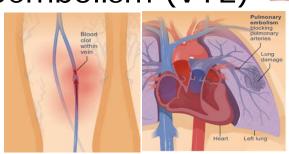
SOURCE: Abridged version of http://www.thalassemia.org/ learn-about-thalassemia/blood-safety/. Used with permission 76





Research in Bleeding and Clotting: Basic Science to Clinical Application

- Molecular basis of hemophilia
 - Discovery of recombinant factor
- Molecular genetics and proteins in von Willebrand Disease (VWD)
 - ELISA assay to diagnose defects
 - NHLBI Report
- Venous Thromboembolism (VTE)
 - Risk factors
 - Therapies





Objectives: BDBS-14 increase referrals for women with bleeding disorder symptoms, BDBS-15 increase VWD diagnosis

von Willebrand Disease



VTE Healthcare Quality Measure



"Venous Thromboembolism (VTE): percent of patients who received VTE prophylaxis or have documentation why no VTE prophylaxis was given the day of or the day after hospital admission or surgery end date for surgeries that start the day of or the day after hospital admission"

The Joint Commission

National Hospital Inpatient Quality Measures



Objective: BDBS-13 reduce VTEs during hospitalization



Are federal partners* and stakeholders taking steps to help make progress toward HP2020-BDBS Objectives?

Steps	Hemoglobinopathies	Bleeding/Clotting	Safety
Yes	1-Vaccinations 2-Referrals 4-Regular screening 5-Therapies 6-Penicillin prophylaxis 7-Preventable hospitalizations 10-Carrier status	13-VTEs during hospitalization 14-Referrals for bleeding 15-VWD diagnosis 16-Hemophilia joints (HRSA)	17-Blood donations 18.3-Adverse Events, Infections 18.4 Adverse Events, Alloimmunization 19-Blood Shortages
Not yet	3-Medical home 9-HS diploma/GED	12-VTEs out of hospital	

*excluding HRSA, which will present its progress



Michael Lu, MD, MS, MPH

Associate Administrator, Maternal and Child Health Bureau Health Resources and Services Administration









Health Resources and Services Administration (HRSA)

HRSA is the primary Federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable.

Tens of millions of Americans get affordable health care and other help through HRSA's 100-plus programs and more than 3,000 grantees





Maternal and Child Health Bureau (MCHB)

The mission of the Maternal and Child Health Bureau (MCHB) is to provide leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of the maternal and child health (MCH) population which includes all of the nation's women, infants, children, adolescents, and their families, Including fathers and children with special health care needs.















HRSA BD/BS Infrastructure

- The National Hemophilia Program
- Sickle Cell Treatment Demonstration Programs
- Sickle Cell Newborn Screening Program
- Thalassemia Program





The National Hemophilia Program

Funded since 1975 with two primary structured activities:

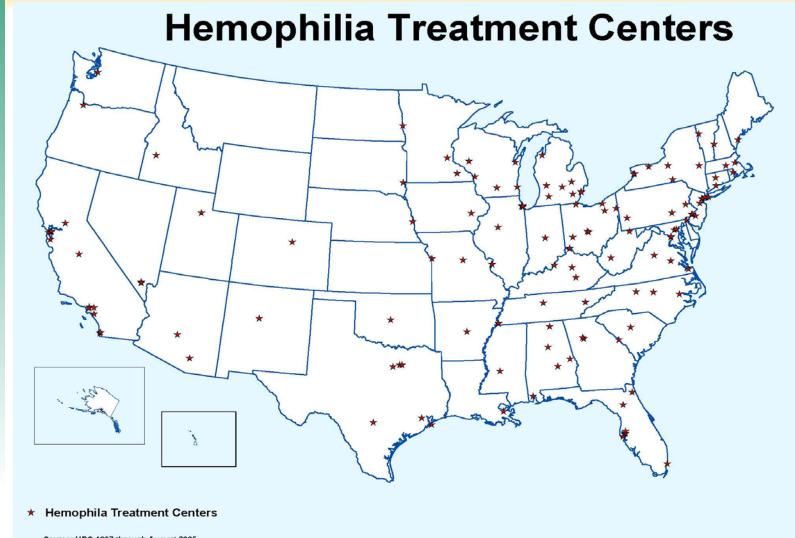
- National Hemophilia Program Regional Network (RHN)
 - 8 Regional Networks containing 135 Hemophilia Treatment Centers
- National Hemophilia Program Coordinating Center (NHPCC)
 - The American Thrombosis and Hemostasis Network (ATHN) was awarded funding in June 2012

The Regional Networks through ATHN will be providing data for several Healthy People 2020 objectives





Hemophilia Treatment Center Distribution

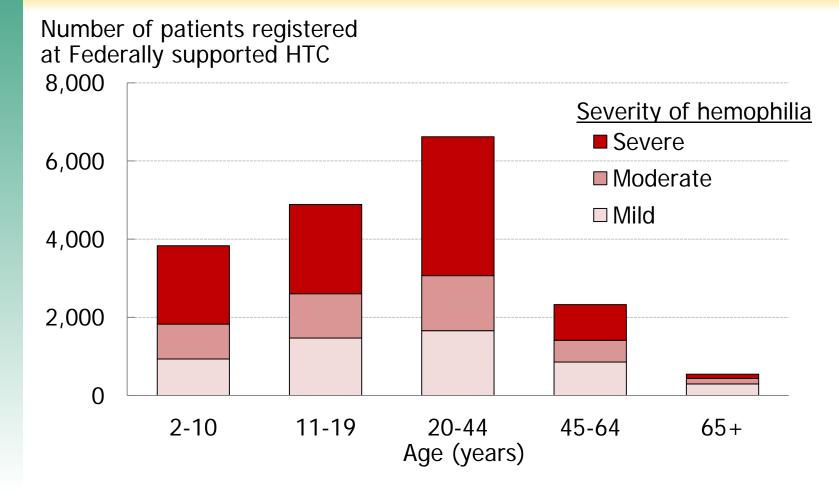




Source: UDC 1997 through August 2005



Hemophilia Registration at Hemophilia Treatment Centers, 1998-2011

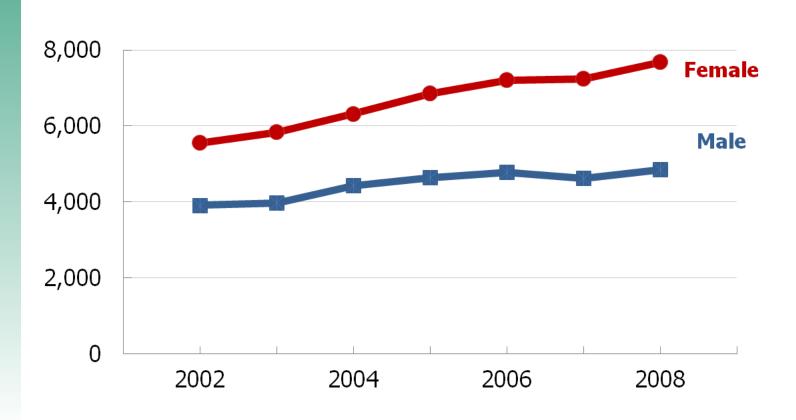






Von Willebrand Disease Registration at Hemophilia Treatment Centers

Number of patients registered at federally funded HTCs





SOURCES: US Hemophilia Treatment Center population trends 1990–2010: patient diagnoses, demographics, health services utilization. JR Baker, B Riske, JH Drake, AD Forsberg, R Atwood, M Voustis and R Shearer. Hemophilia 2013 Jan;19(1):21-6. Universal Data Set, 1998-2011, National Regional Hemophilia Network, HRSA.



Hemophilia Comprehensive Care Model







American Thrombosis & Hemostasis Network (ATHN)

- Not-for-profit organization
- Founded July 2006
- ATHN's mission is to provide stewardship of a secure national database used to support:
- Outcomes analyses
 - Research
 - Advocacy
 - Public Health
- Ultimate vision is to advance and improve care





ATHN: Current Data Initiatives

- CDC Public Health Surveillance for Bleeding Disorders
- HRSA National Hemophilia Program Coordinating Center
- ATHNdataset
 - Over 16,000 patients opt-in as of June 1, 2013
- ATHN-1: Cardiovascular Disease in Hemophilia
 - Standard data within ATHN database plus new data
- My Life Our Future
 - Genotyping data; linked to ATHNdataset phenotypic data





CDC Public Health Surveillance Project for Bleeding Disorders

- Building on the 13 year longitudinal surveillance in the CDC's Universal Data Collection Project (UDC)
- Provide descriptive knowledge about the populations of hemophilia, von Willebrand disease (VWD), other bleeding disorders and VTE receiving care at HTCs (HTC Population Profile)
- Monitor health indicators among populations with bleeding disorders (Registry)
 - Assess trends over time
 - Measure rates of, and risk factors for, complications
 - Identify high risk populations for prevention
 - Identify issues that require research





CDC Public Health Surveillance Project for Bleeding Disorders: Two Data Sets

HTC Population Profile (HTC PP)

- Individual level data
- De-identified data set (all 18 identifiers removed)
- Population based data for hemophilia, VWD, other disorders needed for HP 2020
- Launched 9/2012
- Over 24,000 forms from 115 HTCs submitted

Registry for Bleeding Disorders Surveillance

- More detailed individual level data
- Limited data set
- Data elements related to identified HP 2020 measures included
- A subset of patients in HTC Population Profile
- Data collection beginsSummer 2013





Thank You

Regional Hemophilia Networks

- New England Region
- Mid-Atlantic Region
- Southeast Region
- Great Lakes Region
- Northern States Region
- Great Plains Region
- Mountain States Region
- Western States Region

National Hemophilia Program Coordinating Center

American Thrombosis & Hemostasis Network

Colleagues at the Center for Disease Control and Prevention (CDC)

CDC Public Health Surveillance Project Science Committee





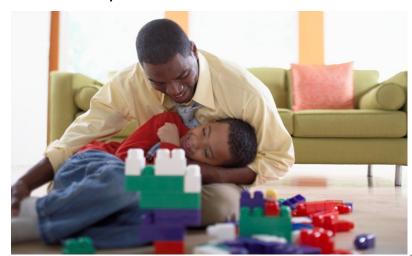
Sickle Cell Newborn Screening Program

Sickle Cell Disease for Newborn Screening Program

- Established in 2002
- Community-based networks partner with State Title V and state newborn screening programs, comprehensive sickle cell treatment centers, and other stakeholders to provide support to infants
- Projects work with the SCD National Coordinating Center to implement models of follow-up for individuals with sickle cell diseases and trait
- Works with Sickle Cell Disease Association of America (SCDAA) to work on Newborn Screening Educational project

SCD National Coordinating Center

- Coordinates and supports grantee networks through technical assistance and information exchange.
- Led by the National Initiative for Children's Healthcare Quality (NICHQ).
- Holds hemoglobinopathy learning collaboratives so network teams may learn from each other and from national expert faculty.







Sickle Cell Treatment Demonstration Program

- Established in 2004
 - To improve access to services for individuals with sickle cell disease,
 - Improve and expand patient and provider education,
 - Improve and expand the continuity and coordination of service delivery for individuals with sickle cell disease or who are carriers of the sickle cell gene mutation.
- Grantee networks have two main goals:
 - To support the provision of coordinated, comprehensive, culturally competent and family-centered care for individuals living with sickle cell disease, and
 - To work collaboratively with our non-federal partners.
- Originally 4 grantees and a National Coordinating Center; recently expanded to 6 grantees for sickle cell model system of comprehensive care and medical management treatment demonstration project





Thalassemia Program

■ In existence for over 30 years

Purpose: to support the demonstration of a model system of comprehensive care and medical management for individuals and families at risk or affected by Thalassemia.

- Program initiatives:
 - Developing and expanding outreach strategies and patient support groups
 - Establishing statewide newborn screening for thalassemia
 - Supporting successful transition to independent adult life including healthcare & employment
 - Developing and implementing program sustainability
- Grants held:
 - Children's Hospital Oakland Hematology Department; California
 - Ann & Robert H. Lurie Children's Hospital of Chicago Comprehensive Thalassemia Program; Chicago
 - The Children's Hospital of Philadelphia; Pennsylvania





Key Points

- HRSA is dedicated to developing, growing, and maintaining the critical infrastructure necessary to provide health care services to those with unmet needs, in conjunction with our federal partners and stakeholders.
- Development of systems of care and the infrastructure necessary requires multi-stakeholder buy-in.
- Validated data collection is necessary to track longitudinal trends and improve process and health care outcomes.
- Data collection and program evaluation within rare diseases/condition is a significant challenge (cost, burden, time, etc), but can be accomplished.



Reducing Central Line-Associated Bloodstream Infections

John M. Boyce, MD
Diane G. Dumigan, RN, CIC
Carrie Guttman, MSN
Sean Boyle, RN

Yale-New Haven Hospital New Haven, CT



- Private, non-profit teaching hospital that includes two inpatient campuses, Yale-New Haven Children's Hospital, Yale-New Haven Psychiatric Hospital and Smilow Cancer Hospital at Yale-New Haven
- Primary teaching hospital of Yale School of Medicine
- 1,500 inpatient beds
- Staff: More than 13,000 employees,
 4,800 university and community physicians



Our Mission

To provide sensitive, high-quality,

cost-effective health care to all

patients, regardless of ability to pay

Reduction of Central Line-Associated Bloodstream Infections

- In 2009, the Hospital of Saint Raphael (now the Saint Raphael campus of Yale-New Haven Hospital) joined the Comprehensive Unit-Based Safety Program (CUSP) to reduce central line-associated bloodstream infections (CLABSIs)
 - Utilized a number of CUSP tools when implementing our program
- In 2010, despite making progress, our CLABSI rates were still above expected levels, so the hospital re-organized our CLABSI prevention committee
- A multidisciplinary committee was formed
 - included front-line care givers involved in insertion and care of central lines

Methods for Reducing CLABSIs, Saint Raphael Campus, Yale-New Haven Hospital

Brainstorming: We used affinity diagrams to clarify current knowledge



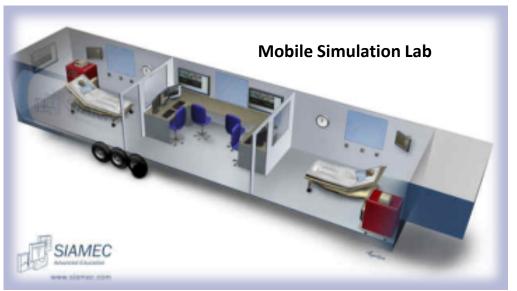
Understanding variation and selecting processes to improve

Results of Brainstorming Sessions: Four Common Areas Needing Improvement

*Should we limit blood cultures off line *Discomfort to stop procedure *Lack of knowledge of sterile *Reluctance to implement chain of command *Having too many inserters *Lack of skill *Which type of line to use *What should be the placement sites *PICC team unavailability *Allowing too many attempts *Should we limit blood cultures off line *Should we limit other labs off line *Should we limit other labs off line *Should we validate dressing change skills *Should we validate dressing change skills *Should we validate dressing change skills *Should we change lines placed during codes/from outside *Are we scrubbing hub *Are we scrubbing hub *How frequently should we be changing the Clave® *In Utilization *Knowledge of line duration *Should we change lines placed during codes/from outside *Are we removing lines soon enough discussed	Line Insertion	Line Access	Line Maintenance	Line Removal
	*Discomfort to stop procedure *Lack of knowledge of sterile technique *Reluctance to implement chain of command *Having too many inserters *Limited teamwork *Lack of skill *Which type of line to use *What should be the placement sites *PICC team unavailability	blood cultures off line *Should we limit other labs off line *Need to develop line sepsis evaluation process *Are we scrubbing hub *Should we remove the	*Should we validate dressing change skills *The suture line is too tight for BioPatch® *Secretions are draining into dressing *How frequently should we be changing	*Knowledge of line duration *Should we change lines placed during codes/from outside *Are we removing lines soon enough *Is daily line assessment being

Intervention Tools

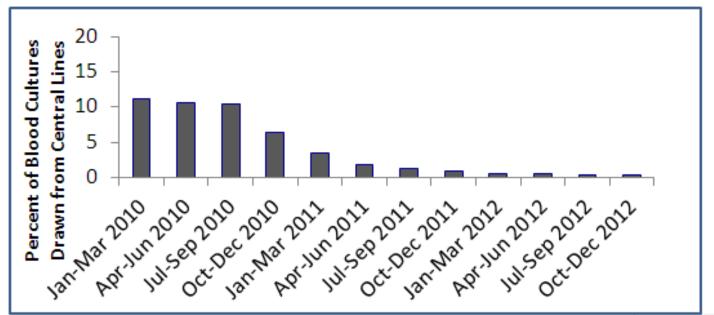
- Hired mobile simulation lab to retrain residents on catheter insertion technique
 - Khouli H et al. Chest 2011;139:80
- Re-certified all nurses who insert PICC catheters
- Re-educated physicians and nurses on use of new checklist
- High-level administrative support for nurses who reported physicians with suboptimal insertion technique
- Developed process for monthly review of checklists
- Daily central line rounds to assess post-insertion care



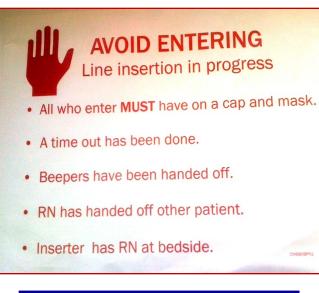


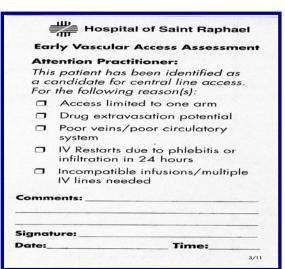
Intervention Tools

- Several cases reported as CLABSIs appeared to represent contaminants in blood cultures drawn from central catheters
- Reduce blood cultures drawn from central catheters
 - Memo to physicians recommending venipuncture as preferred site
 - 2-nurse protocol developed for drawing blood cultures from central catheters
 - Special kit developed for drawing blood cultures from central lines



INTERVENTIONAL TOOLS





- Have nurse at bedside for entire procedure
- Nurses and physicians hand-off patients



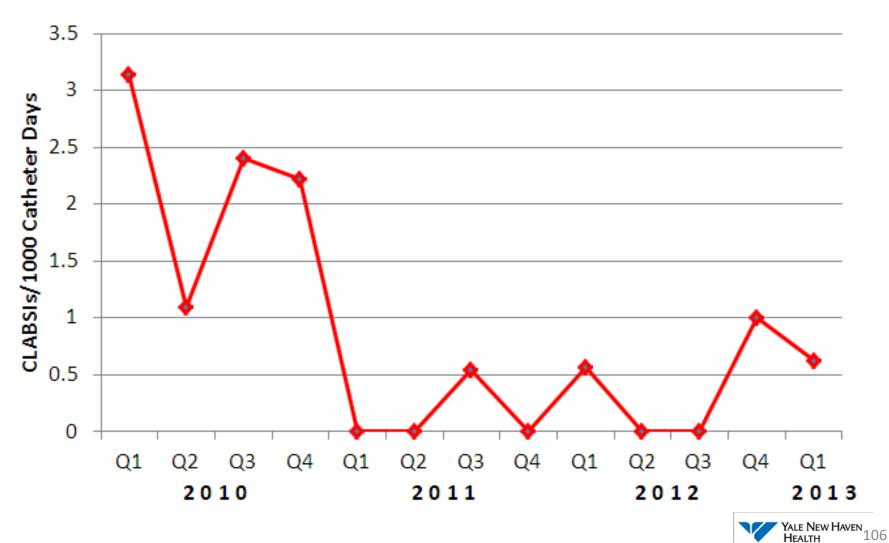
HHS/SHEA/APIC Partnership in Prevention Award



Saint Raphael campus team members, front row (left to right), John M Boyce, MD, Jeannette Bronsord, RN, Diane G Dumigan, RN, Alan S.Kliger, MD



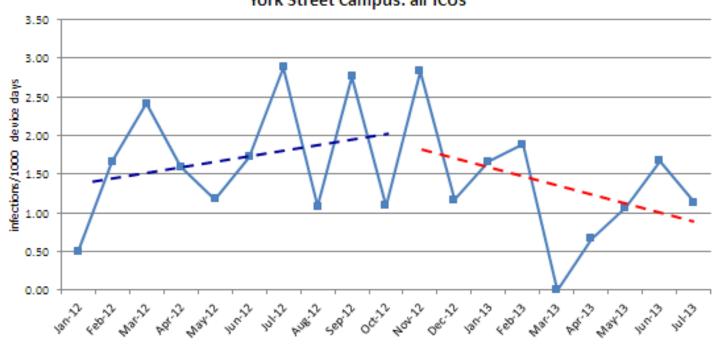
CLABSIs/1000 Catheter Days, Saint Raphael Campus, Yale-New Haven Hospital Q1 2010 – Q1 2013



Expanding Interventions to ICUs, York Street Campus, Yale-New Haven Hospital

Intensified interventions at York Street campus began November 2012

Central Line-Associated Blood Stream Infection Rates Jan. 2012-July 2013 York Street Campus: all ICUs



Reducing CLABSIs on the Comprehensive Sickle Cell Specialty Unit York Street Campus, YNHH

Why did we target the specialty unit?

- high number of CLABSIs
- a majority of reported CLABSIs appeared by clinical criteria to represent contaminants recovered from central line blood cultures

Project components: focus on line maintenance

- multidisciplinary team with local champions
- tackled barriers particular to patients with sickle cell disease
- process mapping
- clinical rounding tool: prevention "bundle"



Left to right:
Jack Gorero, RN, Unit Manager
Darren Lawrence
Diane Vorio, RN, MSN, Vice President Patient Services
Victor Morris, MD, Associate Chief of Staff



Reducing CLABSIs on the Comprehensive Sickle Cell Specialty Unit York Street Campus, YNHH (continued)

Pilot unit results:

58 weeks without CLABSI on sickle cell specialty unit

Spread phase:

 Interventions and processes spread to other units in the Department of Medicine

• Department results:

- Reduction of CLABSIs on all Medicine floors:
 - CY 2012 39 infections
 - CY 2013 to date 11 infections

Partnership for Patients Recognition



Eliminate Blood Stream Infections on Sickle Cell Specialty Unit - Oct. 15,2012 Yale-New Haven Hospital, New Haven, Connecticut

Self Assessment Score = 4, (1=Planning; 2=Some Activity; 3=Some Improvement; 4=Significant Improvement; 5=Outstanding Results; See AHA/HRET Assessment Scale document for more detail)

Aim Statement

- -Unit Aim:100 % of all blood cultures on unit will be drawn per evidence based guidelines by January 1, 2013 (peripheral draw strongly preferred)
- -Hospital Wide Collaborative Aim: Eliminate Central Line Associated Blood Stream Infections (CLABSIs) at Yale-New Haven Hospital.(YNHH)
- Patients with Sickle Cell disease are vulnerable, typically have poor peripheral access, and have a high incidence of central line usage

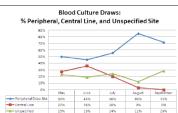
Changes Being Tested, Implemented or Spread

- Educate staff on best practice (I) July
 Standard algorithm for blood culture process including draw site & pain management protocol (I) August
- •Daily charge nurse dressing rounds (I)

 August
- •Staff hand hygiene education (I) July
 •Develop interdisciplinary scripting to improve patient education and collaboration around
- use of peripheral draws (T) October
 •Critical Care Resource Nurse off shift role in
- blood culture draws for patients who are a difficult stick (T) launch in November

HEALTHCARE

Run Charts





YNHH is a large academic medical teaching center. The Comprehensive Sickle Cell/General Medicine Unit opened on April 2, 2012 and has eight beds designated for Sickle Cell patients and 15 general medicine beds.

© 2012 Institute for Healthcare Improvement

Lessons Learned

- Frontline engagement, interdisciplinary collaboration, and strong sponsor leadership are keys to success
- Resources, direction, and oversight from a hospital wide charter helped overcome barriers
- It is essential to test new processes through PDSA to smooth out wrinkles and build buy-in

Recommendati and Next Ste

- Evaluate Critical Care Nurse off
- Integrate practice evidence into a
- Change electronic record to force draw site in blood culture MD/LIP
- For draws off central line to redupositives and to prevent infection: testing two nurse process using pr kit of sterile supplies

Team Memb

Jack Goren RN, Patent Sendens Manager, 6-7
John Roberts MD, Director, Audit Solds Gell Progue
Sean Boyle RN, Assistant Patent Services Manager,
Carrie Guiman MSN, Patent Saley Coordinato, Medical
Diana Campion APRN, Adult Scide Cell Program
Madeline De Los Santos, Charge Nurse, 6-7
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Sonia Clark, Clinical Nurse, 6-7
Sonia Clark, Clinical Nurse, 6-7
Limi Amet Mo, Mognifast Medical Director, 6-7

William Cushing PA, Hospitalist Team Manager Jonathan Siner MD, Hospital Wide Sponsor, BSI Cha Francine LoRusso RN, Hospital Wide Sponsor, BSI C Kathleen Kenyon RN, Nursing Director Medicine Sen

November 2012 HEN Week



Left to right:

Rich Umbenstock, President and Chief Executive Officer, America Hospital Association Carrie Guttman, Safety Coordinator, YNHH

Charisse Coulombe, MS, MBA, CPHQ Senior Director of AHA/HRET HEN

Maulik Joshi, Dr.P.H, President, HRET and Senior Vice-President, American Hospital Association

Photo credit: Eric Craig

Lessons Learned

- Multidisciplinary team must include personnel involved in catheter insertion and maintenance
- Executive leadership and administrative support is essential
- Educate personnel and implement best practices for line insertion and care
- Implement processes to minimize catheter-drawn blood cultures
- Monitor processes and CLABSI rates; provide feedback



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 Assistant Patient Services Manager
 Comprehensive Sickle Cell General Medicine Unit





BSI Prevention Daily Rounds

Date:	Shift:	Clinical Observer:
-------	--------	--------------------

Patient Name/MRN	Nurse's Last Name	Type of Central Line (Note: Midline is not a central line)	Dressing Change Date	CVAD Maintenance Orders Present?	Dressing C/D/I?	Dressing Correctly Labeled?	Dressing Changed Within 7 Days?	Needleless connector Changed Within 96hrs?	Action Taken/Comments If any column checked "No." Unable to assess = No.
				Yes / No	Yes / No	Yes / No	Yes / No	Yes / No	
				Yes / No	Yes / No	Yes / No	Yes / No	Yes / No	
				Yes / No	Yes / No	Yes / No	Yes / No	Yes / No	
				Yes / No	Yes / No	Yes / No	Yes / No	Yes / No	
				Yes / No	Yes / No	Yes / No	Yes / No	Yes / No	
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				Yes / No	Yes / No	Yes / No	Yes / No	Yes / No	

CG/SB 3.4.13



Please submit your questions through the Q&A function







Healthy People 2020 Team

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Online Resources and Tools







Stay Connected

Join the Healthy People Listserv & Consortium



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LINKEDIN Healthy People 2020



YOUTUBE ODPHP (search "healthy people")

