



Public Health Framework for Congenital Heart Disease

Babies are born every day with congenital heart disease (CHD). Their outcomes have never been better. Treatment and care has improved dramatically, leading to better survival and function over the lifespan. Yet, people with CHD at all ages still face many challenges – medical, social and personal. A public health framework identifies opportunities that can make their lives longer, healthier and more productive. Clear and factual answers to many of the unanswered questions are critical in order to map the way forward.

Identify and Investigate

Monitor

Public health systems to monitor burden (i.e., prevalence, morbidity, mortality, disability) of CHD at all ages in the population

Investigate Determinants and Modifiers

Population-based studies to identify determinants of occurrence of CHD and of adverse outcomes

Develop Interventions and Policies

Unite and Align

CHD consortium to inform, educate public, policy makers and health professionals

Reduce Risk

Public health systems and policies to reduce risk of CHD

Improve Outcomes

Public health systems and policies to improve outcomes in people with CHD

Equal Access

Public health systems and policies for equitable access and utilization of care for CHD

Implement and Evaluate

Prevention Education

Public health programs to reduce risk of CHD

Quality Care

Healthcare delivery system provides high quality care for people with CHD

Public health programs link people with CHD to health care and ancillary services

Evaluation

Public health data to monitor and evaluate policies, systems and outcomes for people with CHD



CHD occurs in 1% of births (1 in 110) and **25% are life threatening.**



Hospital costs for individuals with CHD exceeded \$6.1 billion in 2013.

This represents 27% of all birth defect-associated hospitalization costs.



Over half of people living with a CHD are 18 years of age and older.



50-75% of children with complex CHD are at risk for developmental delay.



Most causes of CHD are unknown. **Only 15-20% of all CHD are related to known genetic conditions.**

