



# HHS Public Access

Author manuscript

*Hematology*. Author manuscript; available in PMC 2015 July 27.

Published in final edited form as:

*Hematology*. 2012 April ; 17(0 1): S144–S146. doi:10.1179/102453312X13336169156537.

## Public Health Surveillance and Data Collection: General Principles and Impact on Hemophilia Care

**J. Michael Soucie, PhD**

National Centers for Birth Defects and Developmental Disabilities, Division of Blood Disorders, Centers for Disease Control and Prevention, Atlanta, GA

### Abstract

Public health surveillance is the ongoing collection, analysis and dissemination of health related data to provide information that can be used to monitor and improve the health of populations. Such surveillance systems can be established in many settings to study a variety of populations and conditions. The most effective systems are designed around specific, well-defined objectives, collect data in a standardized fashion, analyze the data frequently and disseminate the results to those who need to know the information.

Surveillance has been used to determine the occurrence rates of hemophilia and to characterize the population affected by this rare but potentially serious congenital disorder. Data from surveillance systems have been used to identify risk factors for complications that, once identified, have been modified through public health interventions. The effectiveness of these interventions can be assessed by continued surveillance, thereby assuring improvement in care of people affected by hemophilia around the world.

### Keywords

Surveillance; data collection; hemophilia; comprehensive care; public health

---

Public health surveillance is traditionally defined as the ongoing systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practice, closely integrated to the dissemination of these data to those who need to know and linked to prevention and control [1].

The components of public health surveillance are ongoing data collection, regular and frequent data analysis and the provision of the results of these analyses to those who need to know. The data collected in such systems typically include demographic, socioeconomic and clinical characteristics of the population under surveillance, data on key outcomes such as disease complications and mortality, and data on potentially mitigating or aggravating behaviors or co-morbid conditions referred to as risk factors.

Data can be collected from a variety of sources. For example, health data can be collected as part of surveys that can be population-based (i.e., designed to collect data from populations that are regionally or nationally representative) or they may be healthcare provider-based (i.e., designed to collect data from populations receiving health care services). For example, sentinel surveillance systems have been established in health care sites such as hospitals, clinics or care providers' offices to monitor key health events such as cases of influenza or cancer. The main purpose of such provider-based surveillance systems is to obtain timely information on changes in the occurrence of a disease or condition that can inform preventive public health activities.

Data can also be collected for a wide variety of purposes using a registry. There are different types of registries including patient organization, medical and health ministry registries. Because patient organization registries typically have a minimal amount of health-related data they are generally more suited to facilitating communication and the distribution of educational material. Health ministry registries tend to be more public health oriented and national in scope. Because most are designed to be representative of the entire population these registries are the best sources of data for common diseases and conditions. People with rare diseases or conditions (generally defined in the U.S. as affecting fewer than 200,000 individuals) are under-represented in these national databases. Medical registries are designed to collect information about a disease such as the occurrence, type, extent and the treatment provided and can be very useful for public health surveillance of rare conditions. Data from medical registries can be used not only to monitor disease trends over time and determine disease patterns in various populations but can also be used to guide planning and evaluation of disease control programs (e.g., determine whether prevention, screening, and treatment efforts are making a difference), help set priorities for allocating health resources and advance clinical, epidemiologic, and health services research in these disorders.

Data collection is instrumental to any surveillance system and it is important that efforts to collect data follow several key principles. First and foremost there must be clearly defined objectives for the surveillance which will in large part direct the choice of data elements. Measurement standards are critical and case definitions must be clear and, for some systems, diagnostic data may be required to validate events. Standardization of the data collection is essential for comparing population groups, geographic areas, or trends over long periods of time. All data elements should be clearly defined and should be easily available to the individuals assigned to collect them. Emphasis should be placed on collecting the minimum amount of data required to meet the surveillance objectives. Excessively large and complex data collection tools can substantially increase the burden of data collection which may adversely affect both the amount and quality of the data collected.

Also critical is the identification of the proper target population and choice of an adequate sampling strategy if the data are to be representative. Data should be gathered using an appropriate information gathering style (e.g., patient interview, clinical record review) such that the responses will most likely be valid and the data reliably reflect the true status of the condition under study. In all cases it is extremely important to apply ethical principles during the collection of data and to respect the privacy of the individuals under surveillance.

Laws and regulations concerning the confidentiality of data collected are universally available and should be adhered to as a matter of standard practice.

Once the data have been collected it is important to have secure database systems in place along with proper data management and quality control procedures. Data should be periodically evaluated for accuracy, consistency and completeness using standard data management procedures. Systems and procedures should be in place to protect data integrity as well as safety and security from natural disasters, computer virus attack, theft and other threats.

The analyses of surveillance data most often include cross-sectional descriptions of the population, outcomes and risk factors which can be further analyzed for trends over time. These kinds of analyses are useful for estimating the burden of the disease in the population, determining whether this burden is increasing or decreasing in the population as well as making assessments about whether certain segments of the population are more at risk for the disorder or its complications (so-called high-risk or target populations).

The results of these analyses should be shared widely not only with the public and healthcare workers but also with public health authorities and local and national governments and policy makers. More sophisticated analyses of these data can be used to look for associations between disease outcomes and risk factors. Such associations can provide the basis for the development of interventions designed to decrease the risk of complications or perhaps lessen spread of communicable disease. Once developed, the effectiveness of interventions implemented in the population can be assessed by continued disease surveillance and monitoring.

## Surveillance and hemophilia

Surveillance has been used to address issues of great importance to the hemophilia population of the United States and around the world. In the U.S., the Centers for Disease Control and Prevention (CDC) working with the health departments of six states sponsored the Hemophilia Surveillance System (HSS). The purpose of this population-based system was to identify all people with hemophilia living in those states and collect detailed information about their demographic, clinical and health care characteristics from medical records. Data collected on over 3,000 males with hemophilia over a six-year period (1993–1998) were used to describe occurrence rates and to study complications and outcomes of care [2].

A network of hemophilia treatment centers (HTCs) was developed in 1975 with federal funding to provide comprehensive multidisciplinary care to people with hemophilia in the U.S. [3]. Data from the HSS showed that about 70% of all people with hemophilia were receiving some care from these centers in the early 1990s. More importantly, when outcomes were compared, it was found that those who had received at least some care from an HTC over a 3-year period were 40% less likely to die [4] and a similar proportion were less likely to be hospitalized for a bleeding complication [5]. Subsequently, data from the HSS were used to study other complications of hemophilia including intracranial hemorrhage [6], heart disease [7] and renal disease [8]. HSS data were also used to

determine the extent of infections with hepatitis and the human immunodeficiency virus in the hemophilia population as a result of contaminated treatment products [9].

Based upon the request of the hemophilia community to provide a sensitive surveillance system that could monitor the population and protect it from further infectious disease threats to treatment products, a new surveillance system was established in the US HTC network in 1998 called the Universal Data Collection (UDC) system [10]. Patients receiving care in HTCs could volunteer to participate in UDC each year and provide a blood specimen that was tested for known viruses and stored for future blood product safety investigations. The results of data from this surveillance have provided assurance to the community that current treatment products are very safe [11]. Using other data collected as part of UDC, researchers have contributed to the knowledge about other aspects of hemophilia including joint disease [12], inhibitors [13], educational achievement [14] and physical functioning [15].

Since 1998, the World Federation of Hemophilia has conducted surveillance by means of an annual global survey [16]. Data are collected from over 100 countries on various aspects of hemophilia and other blood disorders using a standardized data collection form. Data from these surveys have been used to estimate the world hemophilia population and to examine the effects of comprehensive hemophilia care throughout the world. For example, using survey data combined with economic data Evatt and Robillard [17] were able to show that even in the poorest of countries the organization of hemophilia care resulted in greater patient survival.

It should be noted that the success of the CDC and WFH surveillance systems in meeting the needs of the hemophilia community required a substantial commitment from governments, healthcare providers and people with hemophilia receiving care in HTCs. Government participation is often needed to provide the organizational and capacity infrastructure necessary to support national and regional surveillance activities. Healthcare providers have important roles not only in patient recruitment but also in data collection and assuring the safety of participants and the privacy and security of the collected patient data. Finally, it is critical that participants in any surveillance understand what is being asked of them and how their individual data will be used. In addition, it is important that patients understand that surveillance is an ongoing process and its full impact often requires a substantial period of time to be fully realized.

## Conclusion

Data collected as part of a public health surveillance system can be used to estimate the magnitude of a problem, identify groups at higher risk of having poorer outcomes, examine relationships between risk factors and outcomes, develop interventions and with continued monitoring assess the effectiveness of the interventions to modify the complications or outcomes.

The results of analyses from surveillance data can be useful for many purposes including health care and patient advocacy, providing a basis for priority setting and allocation of

health care resources, ensuring the availability of better data on population health and supporting medical care quality assurance and quality improvement efforts.

## Acknowledgments

The findings and conclusions in this report are those of the author and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

## References

1. Teutsch SM, Thacker SB. Planning a public health surveillance system. *Epidemiological Bulletin: Pan American Health Organization*. 1995; 16:1–6.
2. Soucie JM, Jackson D, Evatt B. The occurrence of hemophilia in the United States. *Am J Hematol*. 1998; 59:288–294. [PubMed: 9840909]
3. Baker JR, Crudder SO, Riske B, Bias V, Forsberg A. A model for a regional system of care to promote health and well-being for people with rare chronic genetic disorders. *Am J Public Health*. 2005; 95:1910–1916. [PubMed: 16195525]
4. Soucie JM, Nuss R, Evatt B, Abdelhak A, Cowan L, Hill H, Kolakoski M, Wilber N. the Hemophilia Surveillance System Project Investigators. Mortality among males with hemophilia: relations with source of medical care. *Blood*. 2000; 96:437–442. [PubMed: 10887103]
5. Soucie JM, Symons J, Evatt B, Brettler D, Huszti H, Linden J. the Hemophilia Surveillance System Project Investigators. Home-based factor infusion therapy and hospitalization for bleeding complications among males with hemophilia. *Haemophilia*. 2001; 7:198–206. [PubMed: 11260280]
6. Nuss R, Soucie JM, Evatt B. the Hemophilia Surveillance System Project Investigators. Changes in the occurrence of and risk factors for hemophilia-associated intracranial hemorrhage. *Am J Hematol*. 2001; 68:37–42. [PubMed: 11559935]
7. Kulkarni R, Soucie JM, Evatt BL. Prevalence and risk factors for heart disease among males with hemophilia. *Am J Hematol*. 2005; 79:36–42. [PubMed: 15849761]
8. Kulkarni R, Soucie JM, Evatt BL. Renal disease among males with hemophilia. *Haemophilia*. 2003; 9:703–710. [PubMed: 14750936]
9. Soucie JM, Richardson LC, Evatt B, Linden J, Ewenstein BM, Stein S, Leissinger C, Manco-Johnson M, Sexauer C. the Hemophilia Surveillance System Project Investigators. Risk factors for infection with hepatitis B and hepatitis C viruses in a large cohort of hemophilic males. *Transfusion*. 2001; 41:338–343. [PubMed: 11274587]
10. Soucie JM, McAlister S, McClellan A, Oakley M, Su Y. The universal data collection surveillance system for rare bleeding disorders. *Am J Prev Med*. 2010; 38(4 Suppl):S475–S481. [PubMed: 20331946]
11. CDC. Blood Safety Monitoring Among Persons with Bleeding Disorders --- United States, May 1998--June 2002. *MMWR*. 2003; 51:1152–1154. [PubMed: 12553567]
12. Soucie JM, Wang C, Siddiqi A, Kulkarni R, Recht M, Konkle BA. Hemophilia Treatment Center Network. The longitudinal effect of body adiposity on joint mobility in young males with hemophilia A. *Haemophilia*. 2011; 17(2):196–203. [PubMed: 21332880]
13. Kempton CL, Soucie JM, Miller C, Hooper C, Escobar MA, Cohen AJ, Key NS, Thompson AR, Abshire TC. In non-severe hemophilia A the risk of inhibitor following intensive factor treatment is greater in older patients: a case-control study. *J Thromb Haemost*. 2010; 8:2224–2231. [PubMed: 20704648]
14. Drake JH, Soucie JM, Cutter SC, Forsberg AD, Baker JR, Riske B. High school completion rates among men with hemophilia. *American Journal of Preventative Medicine*. 2010; 38(4 Suppl):S489–S494.
15. Monahan PE, Baker JR, Riske B, Soucie JM. Physical Functioning in Boys with Hemophilia in the U.S. *AJPM*. 2011; 43:S360–S368.
16. Evatt BL. Observations from Global Survey 2001: an emerging database for progress. *Haemophilia*. 2002; 8:153–156. [PubMed: 11952853]

17. Evatt BL, Robillard L. Establishing haemophilia care in developing countries: using data to overcome the barrier of pessimism. *Haemophilia*. 2000; 6:131–134. [PubMed: 10792469]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript