

# Measurement of Sexual Health in the U.S.: An Inventory of Nationally Representative Surveys and Surveillance Systems

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## ABSTRACT

**Objectives.** To identify opportunities within nationally representative surveys and surveillance systems to measure indicators of sexual health, we reviewed and inventoried existing data systems that include variables relevant to sexual health.

**Methods.** We searched for U.S. nationally representative surveys and surveillance systems that provided individual-level sexual health data. We assessed the methods of each data system and catalogued them by their measurement of the following domains of sexual health: knowledge, communication, attitudes, service access and utilization, sexual behaviors, relationships, and adverse health outcomes.

**Results.** We identified 18 U.S.-focused, nationally representative data systems: six assessing the general population, seven focused on special populations, and five addressing health outcomes. While these data systems provide a rich repository of information from which to assess national measures of sexual health, they present several limitations. Most importantly, apart from data on service utilization, routinely gathered, national data are currently focused primarily on negative aspects of sexual health (e.g., risk behaviors and adverse health outcomes) rather than more positive attributes (e.g., healthy communication and attitudes, and relationship quality).

**Conclusion.** Nationally representative data systems provide opportunities to measure a broad array of domains of sexual health. However, current measurement gaps indicate the need to modify existing surveys, where feasible and appropriate, and develop new tools to include additional indicators that address positive domains of sexual health of the U.S. population across the life span. Such data can inform the development of effective policy actions, services, prevention programs, and resource allocation to advance sexual health.

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Public health issues related to sexual behavior pose significant challenges in the United States. Each year an estimated 19 million sexually transmitted disease (STD) infections and almost 50,000 new human immunodeficiency virus (HIV) infections occur;<sup>1,2</sup> 1.2 million people are living with HIV and acquired immunodeficiency syndrome (AIDS); 800,000 to 1.4 million people are living with chronic hepatitis B virus (HBV) infection;<sup>3,4</sup> more than 1.8 million women experience unintended pregnancies;<sup>5</sup> and 1.3 million women are raped.<sup>6</sup> Economically disadvantaged or socially marginalized people are disproportionately affected due to social, economic, and environmental conditions that put them at increased risk for a wide range of adverse health outcomes.<sup>1,2,7-9</sup> In response to these public health issues, in 2001 the Surgeon General released “The Surgeon General’s Call to Action to Promote Sexual Health and Responsible Sexual Behavior,” which articulated the importance of engaging the nation in the promotion of sexual health and responsible sexual behavior based on a public health approach.<sup>10</sup> During the past decade, a growing number of organizations around the world have recognized sexual health as an intrinsic aspect of overall health and well-being, and have called for improved public policy, education, and research to advance sexual health.<sup>11</sup>

Sexual health has been defined as “a state of well-being in relation to sexuality across the life span that involves physical, emotional, mental, social, and spiritual dimensions. Sexual health is an intrinsic element of human health and is based on a positive, equitable, and respectful approach to sexuality, relationships, and reproduction, that is free of coercion, fear, discrimination, stigma, shame, and violence. It includes: the ability to understand the benefits, risks, and responsibilities of sexual behavior; the prevention and care of disease and other adverse outcomes; and the possibility of fulfilling sexual relationships. Sexual health is impacted by socioeconomic and cultural contexts—including policies, practices, and services—that support healthy outcomes for individuals, families, and their communities.”<sup>12</sup>

Human sexual and social development follows a unique progression throughout childhood, adolescence, young adulthood, and adulthood,<sup>10,13</sup> making sexual health an important and evolving aspect of health for all individuals across the life span. The promotion of sexual health to encourage healthy and responsible sexual behavior, thereby reducing adverse outcomes, may greatly impact public health.

Regularly conducted surveillance can be useful for tracking and understanding important public health issues, such as those relevant to sexual health, espe-

cially given the emergence of new technology, policy changes, and cultural shifts regarding sexuality and sexual behavior.<sup>14</sup> Population-based surveys of sexual health can provide evidence to characterize normative, diverse, and evolving aspects of various domains of sexual health to inform community health priorities. In addition, such data can contribute to the development of effective policy actions, age-appropriate and culturally sensitive services and prevention programs, and resource allocation for optimizing public health activities.<sup>15</sup>

We wanted to identify key measures to characterize the state of sexual health in the U.S., allowing both assessment of the current situation and the tracking of meaningful change over time. To identify potential indicators of sexual health within nationally representative surveys and surveillance systems, we reviewed and inventoried existing data systems including a range of parameters relevant to sexual health. An organized, accessible inventory of metrics for measuring sexual health may serve as a useful tool for organizations interested in national measures of sexual health.

## METHODS

We reviewed health surveys and surveillance systems that have recently been or are currently being administered to allow future tracking. Our aim was to identify ongoing data systems that (1) focused on the U.S. population, (2) were nationally representative, (3) provided individual-level data, (4) addressed elements of sexual health, and (5) had a high likelihood of future data collection.

We searched electronic and print publications, and queried Centers for Disease Control and Prevention staff and external colleagues with expertise in sexual health about existing sexual health-related data systems. We studied each to determine survey methodology, including population, sample size (estimates or most recent sample size), frequency, and period of data collection (as relevant to questions related to sexual health) as of January 2012. For data systems in which methodology or sample size had changed over time, we included information relevant to the most recent version of the survey.

The content of each data system was reviewed and catalogued by its measurement of seven important domains of sexual health relevant to the definition presented previously: knowledge (information that a person knows and can use), communication (an exchange of information), attitudes (lasting patterns of beliefs and opinions that predispose reactions to objects, events, and people), service access and

utilization, sexual behaviors (a person's response or action related to internal or external stimuli), relationships (emotional or other connection between two people), and adverse health outcomes.

## RESULTS

We identified 18 U.S.-focused, nationally representative surveys and surveillance systems that have recently been or are currently collecting individual-level data related to sexual health. Six of these systems address a broad proportion of the general population (Table 1) while seven address special populations (Table 2). The remaining five data systems are primarily focused on collecting information about health-related outcomes (Table 3).

### General population sexual health-related surveys and surveillance systems

The six surveys and surveillance systems that address the general population (Table 1) include two that focus primarily on issues related to sexual health (the National Survey of Family Growth [NSFG] and the National Survey of Sexual Health and Behavior [NSSHB]), with the rest covering a range of topics broader than sexual health. All surveys are ongoing, except for NSSHB, the future status of which is unknown. Key attributes of each system are as follows:

- The General Social Survey conducts basic scientific research on the structure and development of American society both to monitor societal change and to compare the U.S. with other nations.<sup>16</sup> It includes questions on sexual behavior and attitudes related to sexual health.
- The Healthcare Effectiveness Data and Information Set measures performance on important dimensions of care and service, including effectiveness of care measures and access to and use of services.<sup>17</sup>
- The National Health and Nutrition Examination Survey assesses the health and nutritional status of adults and children through a combination of interviews and physical examinations.<sup>18</sup> The survey includes questions on sexual behaviors and access to general and reproductive health care, and includes the collection of samples to assess biomarkers for STDs, HIV, and viral hepatitis.
- The National Health Interview Survey monitors a broad range of health topics, including questions regarding HIV/STD testing and health-care access and utilization.<sup>19</sup>

- NSFG gathers information on family life, marriage and divorce, pregnancy, infertility, use of contraception, and men's and women's health. It includes questions on sex communication, sex education, attitudes, sexual behavior, use of sexual health services, and disease and other health outcomes.<sup>20</sup>
- NSSHB provides a snapshot of contemporary Americans' sexual health, including condom education, sexual behavior, relationships, and adverse outcomes.<sup>14</sup>

### Special population sexual health-related surveys and surveillance systems

Of the seven surveys and surveillance systems addressing special populations (Table 2), four focus on children, adolescents, and young adults; two focus on midlife and older adults; and one focuses on people infected with HIV. Key attributes of each system are as follows:

#### *Children, adolescents, and young adults.*

- The National Immunization Survey (NIS) and NIS-Teen survey households (verified by immunization providers) to monitor coverage for all vaccines recommended by the Advisory Committee on Immunization Practices for children and adolescents, including those to prevent human papillomavirus and HBV.<sup>21</sup>
- The National Longitudinal Study of Adolescent Health (Add Health) follows a cohort of adolescents into young adulthood and combines individual data (including sexual behavior, relationships, pregnancy, and HIV/STD outcomes) with contextual data to study how social environments and behaviors in adolescence are linked to health and achievement outcomes in adulthood.<sup>22</sup>
- The National Longitudinal Surveys include a family of ongoing studies that examine the employment, education, training, and family experiences of children and young people. Two recent studies (National Longitudinal Survey of Youth [NLSY] 1979 Children and Young Adults study and NLSY 1997 study) survey young people about attitudes, sex education, communication, sexual behaviors, relationships, and health outcomes that can be matched with data collected from mothers.<sup>23,24</sup>
- The Youth Risk Behavior Surveillance System (YRBSS) includes national, state, and large urban school district-based surveys to monitor priority health risk behaviors that contribute to the leading causes of death, disability, and social problems

**Table 1. General population sexual health-related surveys and surveillance systems in the U.S. (n=6 surveys/systems)<sup>a</sup>**

Survey (abbreviation)	Responsible organization	Scope	Population	Sample size <sup>b</sup>	Type	Frequency	Period of data collection <sup>c</sup>	
							First year	Most recent year
General Social Survey (GSS) <sup>d</sup>	National Opinion Research Center, University of Chicago	National	General	3,500	Rotating panels; in-person interview	Biennial	1972	2010
Healthcare Effectiveness Data and Information Set (HEDIS) <sup>e</sup>	National Committee for Quality Assurance	National	General	Individual patient observations from 411 health plans	CS; administrative data abstraction	Annual	1991	2011
National Health and Nutrition Examination Survey (NHANES) <sup>f</sup>	CDC/NCHS	National	14–69 years of age (sexual behaviors)	5,000	CS; in-person interview with ACASI, biomeasure collection	Annual	1988	2009–2010
National Health Interview Survey (NHIS) <sup>g</sup>	CDC/NCHS	National	≥18 years of age	100,000	CS; in-person interview	Annual	1987	2011
National Survey of Family Growth (NSFG) <sup>h</sup>	CDC/NCHS	National	15–44 years of age	5,000	CS; in-person interview with ACASI	Ongoing	1973 <sup>i</sup>	2006–2010
National Survey of Sexual Health and Behavior (NSSHB)	The Center For Sexual Health Promotion, Indiana University	National	14–94 years of age	5,865	CS; Internet survey	Unknown	2010	2010 <sup>k</sup>

<sup>a</sup>Most recent as of January 23, 2012. For data systems in which methodology has changed over time, we included information relevant to the most recent version of the survey.

<sup>b</sup>Estimates or most recent sample size

<sup>c</sup>As relevant to sexual health

<sup>d</sup>National Opinion Research Center (NORC) at the University of Chicago. General Social Survey [cited 2012 Nov 13]. Available from: URL: <http://www3.norc.org/GSS+Website>

<sup>e</sup>National Committee for Quality Assurance. HEDIS & quality measurement [cited 2012 Nov 13]. Available from: URL: <http://www.ncqa.org/tabid/59/Default.aspx>

<sup>f</sup>National Center for Health Statistics (US). About the National Health and Nutrition Examination Survey [cited 2012 Nov 13]. Available from: URL: [http://www.cdc.gov/nchs/nhanes/about\\_nhanes.htm](http://www.cdc.gov/nchs/nhanes/about_nhanes.htm)

<sup>g</sup>National Center for Health Statistics (US). About the National Health Interview Survey [cited 2012 Nov 13]. Available from: URL: [http://www.cdc.gov/nchs/nhis/about\\_nhis.htm](http://www.cdc.gov/nchs/nhis/about_nhis.htm)

<sup>h</sup>National Center for Health Statistics (US). National Survey of Family Growth [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/nchs/nsfg.htm>

<sup>i</sup>Never-married women were first included in 1982; men were first included in 2002.

<sup>j</sup>Reece M, Herbenick D, Schick V, Sanders SA, Dodge B, Fortenberry JD. Background and considerations on the National Survey of Sexual Health and Behavior (NSSHB) from the investigators. *J Sex Med* 2010;7 Suppl 5:243-5.

<sup>k</sup>Future status is unknown.

CS = cross-sectional

CDC = Centers for Disease Control and Prevention

NCHS = National Center for Health Statistics

ACASI = audio computer-assisted self-interview

**Table 2. Special population sexual health-related surveys and surveillance systems in the U.S. (n=7 surveys/systems)<sup>a</sup>**

Survey (abbreviation)	Responsible organization	Scope	Population	Sample size <sup>b</sup>	Type	Frequency	Period of data collection <sup>c</sup>	
							First year	Most recent year
<i>Children, adolescents, and young adults</i>								
National Immunization Survey (NIS) <sup>d</sup>	CDC/NCHS	National	19–35 months of age	17,004	CS; telephone interview; mail survey to provider	Annual	1994	2011
NIS-Teen <sup>d</sup>	CDC/NCHS	National	13–17 years of age	19,488	Longitudinal; in-person interview with ACASI	Annual	2006	2011
National Longitudinal Study of Adolescent Health (Add Health) <sup>e</sup>	Carolina Population Center, University of North Carolina	National	Grades 7–12	15,197	Longitudinal; in-person interview with ACASI	Four waves	1994–1995	2007–2008
National Longitudinal Survey of Youth	U.S. Department of Labor	National	10–21 years of age	7,660	Longitudinal; in-person/telephone interview	Biennial	1986	2008
NLSY79 Children and Young Adults <sup>f</sup>			12–16 years of age	7,561	Annual	Annual	1997	2010
Youth Risk Behavior Surveillance System (YRBSS) <sup>g</sup>	CDC	National/state/large urban school district	Grades 9–12	16,410 (for national; varies by state and large urban school district)	CS; in-school paper survey	Biennial	1993	2011
<i>Midlife and older adults</i>								
National Social Life, Health, and Aging Project (NSHAP) <sup>h</sup>	NORC, University of Chicago	National	57–85 years of age	3,377	Longitudinal; in-person survey, biomeasure collection, mail survey	Periodic	2005–2006	2010–2011
Sex, Romance, and Relationship Survey (SRRS)	American Association of Retired Persons	National	≥45 years of age	1,487	CS; telephone interview	Every five years	1999	2009
<i>People with HIV infection</i>								
Medical Monitoring Project (MMP) <sup>i,j</sup>	CDC and state and local health agencies	National/local	≥18 years of age, HIV+, and receiving care in representative areas	25–50 facilities/area; 400 patients/facility	CS; in-person interview, medical record abstraction	Ongoing	2005	2009

<sup>a</sup>Most recent as of January 23, 2012. For data systems in which methodology has changed over time, we included information relevant to the most recent version of the survey. For longitudinal studies, age represents that at first interview.

<sup>b</sup>Estimates or most recent sample size

<sup>c</sup>As relevant to sexual health

<sup>d</sup>National Center for Health Statistics (US). National Immunization Survey [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/nchs/nis.htm>

<sup>e</sup>University of North Carolina at Chapel Hill, Carolina Population Center. Add Health [cited 2012 Nov 13]. Available from: URL: <http://www.cpc.unc.edu/projects/addhealth>

<sup>f</sup>Department of Labor (US), Bureau of Labor Statistics. National Longitudinal Surveys: NLSY79 Children and Young Adults [cited 2012 Nov 13]. Available from: URL: <http://www.bls.gov/nls/nlsy79ch.htm>

<sup>g</sup>CDC (US). National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of Adolescent and School Health. Youth Risk Behavior Surveillance System (YRBSS) [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/HealthyYouth/yrbss/index.htm>

<sup>h</sup>National Opinion Research Center (NORC) at the University of Chicago. National Social Life, Health, and Aging Project (NSHAP) [cited 2012 Nov 13]. Available from: URL: <http://www.norc.org/Research/Projects/Pages/national-social-life-health-and-aging-project.aspx>

<sup>i</sup>Fisher L. Sex, romance, and relationships: AARP survey of midlife and older adults. Washington: American Association of Retired Persons; 2010. Also available from: URL: [http://www.aarp.org/relationships/love-sex/info-05-2010/srr\\_09.html](http://www.aarp.org/relationships/love-sex/info-05-2010/srr_09.html) [cited 2012 Nov 13].

<sup>j</sup>CDC (US). National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. Medical Monitoring Project (MMP) [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/hiv/topics/treatment/mmp/index.htm>

<sup>k</sup>CDC (US). National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. Surveillance brief: surveillance systems supported by the Division of HIV/AIDS Prevention [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/surveillance.htm>

CDC = Centers for Disease Control and Prevention

NCHS = National Center for Health Statistics

CS = cross-sectional

ACASI = audio computer-assisted self-interview

NORC = National Opinion Research Center

HIV = human immunodeficiency virus

among young people and adults, including sexual behaviors that are associated with unintended pregnancy, STDs, and sexual violence.<sup>25</sup>

#### *Midlife and older adults.*

- The National Social Life, Health, and Aging Project (NSHAP) examines the interactions among physical health, illness, medication use, cognitive function, emotional health, sensory function, health behaviors, and social connectedness in the older U.S. population. It also includes questions regarding sexual relationships, interest, pleasure, and functioning.<sup>26</sup>
- The American Association of Retired Persons' Sex, Romance, and Relationship Survey (SRRS) assesses factors affecting sexuality and quality of life of midlife and older adults, including sexual attitudes, behaviors, and relationships; sexual satisfaction; and overall health and quality of life.<sup>27</sup>

#### *People with HIV infection.*

- The Medical Monitoring Project (MMP) is a supplemental surveillance project that assesses knowledge, communication, behaviors, service utilization, and quality of care of HIV-infected people who are receiving medical care.<sup>28,29</sup>

#### **Sexual health-related outcome surveillance**

Of the five surveillance systems focused on health-related outcomes (Table 3), all collect data representative of the entire population, except for the National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP). Key attributes of each system are as follows:

- NEISS-AIP collects data regarding nonfatal injuries (including sexual assault) reported in U.S. hospital emergency departments.<sup>30</sup>
- The National HIV Surveillance System compiles data on confirmed diagnoses of HIV infection in the U.S. and dependent areas.<sup>31</sup>
- The National Intimate Partner and Sexual Violence Survey (NISVS) collects detailed information on sexual violence, stalking, and intimate partner violence victimization of adults, including the context and consequences of the violence experienced.<sup>32</sup>
- The National Notifiable Diseases Surveillance System aggregates infectious disease surveillance data for notifiable infectious diseases, including HIV, AIDS, chlamydia, gonorrhea, syphilis, chancroid, and viral hepatitis.<sup>33</sup>
- The National Vital Statistics System includes data

from vital registration systems operated in the various jurisdictions, including births, deaths, and fetal deaths that are used to calculate pregnancy and birth rates and are a fundamental source of demographic, geographic, and cause-of-death information.<sup>34</sup>

All surveys and surveillance systems collect nationally representative sexual health-related data. Each includes both males and females, although some surveys have questions that vary between men and women (e.g., NSFG). Several federal government-sponsored surveys also provide state-level estimates (e.g., YRBSS and NISVS). While the majority of these surveys are cross-sectional, describing a particular point in time, several of the age-focused surveys utilize a longitudinal study design (e.g., Add Health and NSHAP). Additionally, some data systems utilize methods that enhance the quality of self-reporting of sensitive or stigmatizing information due to the safe and confidential manner of data collection (e.g., audio computer-assisted self-interview and Internet surveys), which is of particular importance when discussing issues related to sexual health.<sup>35,36</sup>

The Figure summarizes the domains of sexual health measured in the 18 surveys and surveillance systems summarized in Tables 1–3. Generally, the number and type of measures for each system within and across domains varied widely. Although it is not possible to list specific measures for each system, we provide an overall summary of our findings and example measures. Across the inventoried systems, measures related to the domains of service access and utilization, sexual behaviors, and adverse outcomes were measured most frequently. Eleven systems included sexual health service measures including access to and utilization of preventive and clinical services (e.g., immunizations, prevention programs, voluntary screening and counseling, and treatment). Twelve of the systems assessed sexual behaviors, measuring healthy and responsible sexual behaviors (e.g., delay of sexual debut and contraceptive use) as well as risky sexual behaviors (e.g., having multiple partners). Measures of adverse health outcomes related to sexual health, including HIV/AIDS, STDs, unintended pregnancy, and sexual violence—a primary focus of public health prevention efforts—were measured in 13 of the systems. Across the data systems, measures of knowledge related to sexual health were included in only five, measures of communication about matters related to sexual behavior and services in only six, measures of attitudes related to sexual health in only four, and measures of relationships that can impact sexual health in only seven of the surveys.

**Table 3. Sexual health-related outcome surveillance systems in the U.S. (n=5 surveys/systems)<sup>a</sup>**

Survey (abbreviation)	Responsible organization	Scope	Population	Sample size <sup>b</sup>	Type	Frequency	Period of data collection <sup>c</sup>	
							First year	Most recent year
National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP) <sup>d</sup>	Consumer Product Safety Commission and CDC	National	General	66 hospitals	Emergency department record abstraction	Annual	2000	2009
National HIV Surveillance System (NHSS) <sup>e</sup>	CDC	National/state	General	NA	Case report	Ongoing	1982	2009
National Intimate Partner and Sexual Violence Survey (NISVS) <sup>f</sup>	CDC	National/state	≥ 18 years of age	12,500	CS; telephone interview	Annual	2010	2011
National Notifiable Diseases Surveillance System (NNDSS) <sup>g</sup>	CDC	National	General	NA	Case report	Ongoing	1961	2010
National Vital Statistics System (NVSS) <sup>h</sup>	CDC/NCHS	National	General	NA	Case report	Ongoing	1933	2010

<sup>a</sup>Most recent as of January 23, 2012. For data systems in which methodology has changed over time, we included information relevant to the most recent version of the survey.

<sup>b</sup>Estimates or most recent sample size

<sup>c</sup>As relevant to sexual health

<sup>d</sup>CDC (US), Injury Center. 5.3 Type of data captured and coding methods in NEISS-AIP [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/ncipc/wisqars/nonfatal/datasources.htm#5.3>

<sup>e</sup>CDC (US), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. HIV surveillance report: diagnoses of HIV infection and AIDS in the United States and dependent areas, 2010. Vol. 22. Atlanta: CDC; 2012. Also available from: URL: [http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/pdf/2010\\_HIV\\_Surveillance\\_Report\\_vol\\_22.pdf](http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/pdf/2010_HIV_Surveillance_Report_vol_22.pdf) [cited 2012 Nov 13].

<sup>f</sup>CDC (US), National Center for Injury Prevention and Control, Division of Violence Prevention. The National Intimate Partner and Sexual Violence Survey (NISVS) [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/violenceprevention/nisvs>

<sup>g</sup>CDC (US). National Notifiable Diseases Surveillance System (NNDSS) [cited 2012 Nov 13]. Available from: URL: [http://www.cdc.gov/osels/ph\\_surveillance/nmdss/nmdsshis.htm](http://www.cdc.gov/osels/ph_surveillance/nmdss/nmdsshis.htm)

<sup>h</sup>National Center for Health Statistics (US). National Vital Statistics System [cited 2012 Nov 13]. Available from: URL: <http://www.cdc.gov/nchs/nvss.htm>

CDC = Centers for Disease Control and Prevention

HIV = human immunodeficiency virus

NA = not available

CS = cross-sectional

NCHS = National Center for Health Statistics

**Figure. Domains of sexual health measured in selected U.S. surveys and surveillance systems (n=18 surveys/systems)<sup>a</sup>**

Survey	Knowledge <sup>b</sup>	Communication	Attitudes	Service access and utilization <sup>c</sup>	Sexual behaviors	Relationships <sup>d</sup>	Adverse outcomes <sup>e</sup>
General population							
GSS			X		X		
HEDIS				X			
NHANES				X	X		X
NHIS		X		X	X		X
NSFG	X	X	X	X	X	X	X
NSSHB	X			X	X	X	X
Special population							
Children, adolescents, and young adults							
NIS				X			
Add Health					X	X	X
NLSY	X	X	X	X	X	X	X
YRBSS	X			X	X		X
Midlife and older adults							
NSHAP		X			X	X	
SRRS			X	X	X	X	X
People with HIV infection							
MMP	X	X		X	X		
Outcome surveillance							
NEISS-AIP							X
NHSS							X
NISVS							X
NNDSS		X		X	X	X	X
NVSS							X

<sup>a</sup>The number and type of measures for each domain by system vary widely.

<sup>b</sup>Includes receipt of informal and formal education

<sup>c</sup>Includes preventive and clinical services

<sup>d</sup>Includes relationships of various types that can impact sexual health

<sup>e</sup>Includes HIV/AIDS, sexually transmitted diseases, unintended pregnancy, and sexual violence

GSS = General Social Survey

HEDIS = Healthcare Effectiveness Data and Information Set

NHANES = National Health and Nutrition Examination Survey

NHIS = National Health Interview Survey

NSFG = National Survey of Family Growth

NSSHB = National Survey of Sexual Health and Behavior

NIS = National Immunization Survey

Add Health = National Longitudinal Study of Adolescent Health

NLSY = National Longitudinal Survey of Youth

YRBSS = Youth Risk Behavior Surveillance System

NSHAP = National Social Life, Health, and Aging Project

SRRS = Sex, Romance, and Relationship Survey

HIV = human immunodeficiency virus

MMP = Medical Monitoring Project

NEISS-AIP = National Electronic Injury Surveillance System--All Injury Program

NHSS = National HIV Surveillance System

NISVS = National Intimate Partner and Sexual Violence Survey

NNDSS = National Notifiable Diseases Surveillance System

NVSS = National Vital Statistics System

AIDS = acquired immunodeficiency syndrome



## DISCUSSION

Our review identified a diverse repository of nationally representative surveys and surveillance systems from which to assess a variety of key health determinants and outcomes that can enhance our understanding of the sexual health of the U.S. population. The data systems we identified include a broad range of existing indicators measuring individual-level sexual health of both general and special populations and cover multiple domains, with particular emphasis on service access and utilization, sexual behaviors, and adverse health outcomes. Information from these systems can help inform sexual health research and surveillance efforts as well as the development of effective policy actions, services, and prevention programs. However, in addition to identifying the potential of existing systems to inform efforts to assess and track important indicators of sexual health, we also identified gaps and challenges.

We limited our search to existing, nationally representative data systems that provided individual-level data. Several other important studies that provide relevant sexual health information exist but were not included in our inventory because they are no longer being administered (e.g., the National Health and Social Life Survey,<sup>37</sup> National Sexual Health Survey,<sup>38</sup> National Survey of Adolescent Males,<sup>39,40</sup> and National Survey of Adolescents and Young Adults: Sexual Health Knowledge, Attitudes, and Experiences<sup>41</sup>) or because they were not nationally representative (e.g., the Pregnancy Risk Assessment Monitoring System<sup>42</sup> and National HIV Behavioral Surveillance System<sup>29</sup>). However, these studies may contain well-developed indicators that could be used to address gaps within existing surveys. In addition, while individual-level data are an important measure of population health, other perspectives are important. For example, institution-level data could be a key indicator of education provision (e.g., School Health Policies and Practices Study<sup>43</sup>).

Different populations experience different sexual health outcomes and needs throughout the life span. However, population-based surveys are frequently not large enough to assess the sexual health of population subgroups,<sup>44</sup> such as older adults and lesbian, gay, bisexual, and transgender (LGBT) individuals. Notably, apart from NSHAP and SRRS, there are limited sexual health-related data from nationally representative, ongoing surveys on older adults—of particular importance when considering issues of sexual functioning. Similarly, the lack of questions about sexual orientation and gender identity in national surveys limits our understanding of health disparities affecting LGBT individuals across the life span.<sup>45</sup>

The breadth and domains of measured sexual health

data varied among the data systems we inventoried. In general, apart from measures of preventive and clinical service access and utilization, we found that routinely collected, national data related to sexual health are currently focused primarily on negative aspects of sexual health (e.g., risk behaviors and adverse outcomes), rather than more positive attributes (e.g., healthy communication and attitudes, and relationship quality), as negative outcomes are often easier to quantify and measure than positive outcomes.<sup>46</sup> In addition, indicators measuring specific items of sexual health knowledge were lacking in all data systems, requiring us to use measures of exposure to sex education as a proxy for knowledge. In our inventory, we identified measures of school-based (e.g., NSFG and YRBSS) and provider-based (e.g., MMP) education as indicators of knowledge. Measures of communication about matters related to sexual behavior and services were also limited and included items regarding parent-child communication (e.g., NSFG and NLSY) and communication with providers about various sexual health topics (e.g., NSFG and NISVS), but did not include sufficient measures of communication with others, such as partners, peers, and mentors. Additionally, we were interested in the measurement of relationship quality between partners as well as with peers, parents, providers, and others that can affect sexual health. Ongoing data systems focused primarily on sexual relationships (e.g., NSFG and SRRS), with only a few focusing on other relationship types such as parent-child (e.g., NLSY). Finally, while several of the data systems gauged attitudes on a wide range of sexual health topics (e.g., homosexuality, cohabitation, and condoms), very few attitudes are measured in ongoing, frequent national surveys.

Although not included as a primary focus of public health efforts, sexual satisfaction, pleasure, and functioning are important domains of sexual health.<sup>46</sup> However, these topics do not appear on ongoing, frequent national surveys. In fact, of the few nationally representative studies that assessed sexual satisfaction or pleasure (e.g., NSSHB and SRRS) and sexual functioning (e.g., NSHAP and SRRS), most were infrequently repeated. Finally, some of the broader societal determinants of sexual health (e.g., stigma and discrimination) as well as important individual predictors (e.g., self-efficacy) that influence sexual behavior are not sufficiently available in existing national data systems. These gaps clearly indicate the need to modify existing data systems, where feasible and appropriate, to include a broader set of indicators.

Finally, data systems summarized in our inventory generally included differently defined populations and reported data disparately, making aggregation of

measures from different systems challenging. In addition, as noted previously, some sexual health indicators addressing important topics are on discontinued surveys, making tracking of such data impossible. Therefore, to address current gaps in populations and domains covered, a new comprehensive national survey on sexual health could be useful to better measure and monitor our nation's sexual health, as has occurred with the British National Survey of Sexual Attitudes and Lifestyles<sup>47</sup> and is being planned for Canada.<sup>48</sup> While such a coordinated effort is costly, regular surveillance of sexual health would enable us to measure changes over time, enhancing the implementation of timelier and more effective responses.

## CONCLUSION

We developed an inventory of 18 existing, nationally representative surveys and surveillance systems that contain individual-level data related to sexual health. This collation includes a comprehensive repository of well-developed existing indicators to inform sexual health research and surveillance efforts. Although current metrics are extensive, significant gaps remain, thus limiting our ability to address important domains of sexual health. Efforts are needed to broaden existing surveys, where feasible and appropriate, as well as develop new measurement tools, providing data that can better inform the development of effective policy actions, services, prevention programs, and resource allocation to advance sexual health.

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