



Washington State Public Health Data Sharing Law & Policy Review

Blueprint Outline

(as of October 31, 2023)

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PREFACE

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Scope. Access to accurate and reliable health data is essential to effective and ethical public health practices. However, legal and policy requirements can present perceived or actual barriers to data sharing or exchanges. Numerous statutes, regulations, judicial interpretations, and policies at the state and federal levels shape the acquisition, use, disclosure, and exchange of public health data. Laws and policies, for example, authorize public health data collection for surveillance, reporting, or research purposes. Yet, laws may also limit activities in the interests of data privacy, anti-discrimination, and security. Balancing these dynamic facets—authorizing data exchanges, protecting privacy, avoiding discrimination, and assuring security—is essential to achieving improved population health outcomes through legally and ethically sound data sharing practices.

This project comprehensively assesses and analyzes the legal and policy framework underlying public health data sharing in Washington State. ASU's CPHLP will review and assess relevant Washington State and federal statutes and regulations, case law, and applicable policy interpretations, including state agency privacy principles. A final report evaluating the legal landscape surrounding public health data sharing in Washington will identify strengths, weaknesses, and opportunities to facilitate improved public health data sharing. The table of contents, below, provides an initial illustration of themes to be addressed in the final report, subject to re-organization based on research findings, partner input and guidance, and other determinations. The overriding goal is to enable public health actors (including data owners and requesters) to legally navigate public health data sharing in Washington in furtherance of communal health and safety.

Limitations. Though comprehensive, this project does not attempt to exhaustively assess all Washington data laws and policies. Rather, it provides illustrative descriptions of the legal environment (through February 28, 2024). The project's focus on state-level laws precludes closer reviews of local laws and legal distinctions. Finally, project investigators will not assess or advise on technological or IT-based issues.

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¹ Washington Disease Reporting System (WDRS), WADOH (last visited Oct. 20, 2023); Syndromic Surveillance (RHINO), WADOH (last visited Oct. 20, 2023); National Syndromic Surveillance Program (NSSP), CDC (last updated Sept. 22, 2023); see also WADOH Data Matrix; Washington State Health Assessment, WADOH (2018) (providing key information on health outcomes, health behaviors, healthcare access and preventive care, the physical and built environment, and social determinants of health in Washington State).

² <u>Notifiable Conditions</u>, WADOH (providing information on notifiable conditions, including a list of conditions and links to legal requirements) (last visited Oct. 20, 2023); <u>Wash. Rev. Code § 43.70.057</u> (requiring hospitals to submit emergency department information to WADOH).

³ New Data Requirements for Revised Notifiable Conditions Regulations, WASH. STATE HOSP. ASS'N (Sept. 30, 2021) (bulletin for hospitals about changes to notifiable conditions regulations in WAC 246-101 effective Jan. 1, 2023); see also <u>List of Notifiable Conditions</u>, WADOH (last visited Oct. 3, 2023); <u>Wash. Admin Code</u> § 246-101-005 et seq.

⁴ <u>Disease Reporting Requirements for King County Health Care Professionals</u>, KING COUNTY PUBLIC HEALTH (includes link to WAC chapter with rule on notifiable conditions, Q&A for reporting to county or state departments, and requirements for different entities) (last visited Oct. 20, 2023).

⁵ <u>Washington State Local Health Jurisdictions</u>, WADOH (state map with links to local health authority websites) (last visited Oct. 20, 2023).

⁶ <u>Department of Health Agency Standards for Reporting Data with Small Numbers</u>, WADOH (May 2018) (including discussion of confidentiality analysis related to identifiers from federal and state laws (p. 7-8) and a list of relevant policies, laws, and regulations); see also <u>Wash. Admin. Code § 246-455-085</u> (discussing data types, including direct and indirect patient identifiers, that may be included in released patient discharge data files and requirements for release to different parties).

⁷ See, e.g., James G. Hodge, Jr. & Lawrence O. Gostin, <u>Revamping the Federal Common Rule:</u> <u>Modernizing Human Participant Research Regulations</u>, 317 JAMA 1521 (Feb. 22, 2017).

⁸ Wash. Rev. Code § 42.48 (release of records for research); Wash. Admin. Code § 388-04-030 (statement of policy for human research); see also <u>Human Subjects and Public Health Practice: Guidelines for Ethical Data Collection</u>, WADOH (Dec. 2008) (assessing ethical issues and other concerns arising in human subjects research, including IRB review).

⁹ Wash. Rev. Code § 70.02.210 (describing conditions around disclosure of health care information for research without patient authorization).

¹⁰ See, e.g., James G. Hodge, Jr., Chapter 8: Public Health Information Management, Privacy & Security, in Public Health Law in a Nutshell 261 (4th ed. 2022); James G. Hodge, Jr. & Lawrence O. Gostin, Public Health Practice vs. Research: A Report for Public Health Practitioners Including Cases and Guidance for Making Decisions, Council of State and Territorial Epidemiologists Advisory Comm. (May 24, 2004). See, e.g., State v. Johnson & Johnson, No. 84140-8-I, 2023 Wash. App. LEXIS 1433, at *1 (Wash. Ct. App. July 31, 2023) (applying HIPAA de-identification requirements to discovery request for Medicaid claims database information for opioid prescriptions); see also Wash. Admin. Code § 246-08-390 (providing WA DOH rules for acquiring, securing, retaining, disclosing, and destroying health care information and health-related data).

¹² See Wash. State Legis. Senate, <u>Final Bill Report: ESSB 5432</u> (July 25, 2021) ("Encryption standards for category 3 and 4 data are specified [by OCIO policy]."); see also <u>Washington Chief Information Officer's Standard No. 141.10</u>, OFF. CHIEF INFO. OFF. (Nov. 13, 2017) (requiring encryption "using industry standard algorithms validated by the National Institute of Standards and Technology (NIST)" in sections 4.3 and 4.4). ¹³ See, e.g., James G. Hodge, Jr., JAMES G. HODGE, JR., *Chapter 8: Public Health Information Management, Privacy & Security*, in Public Health LAW IN A NUTSHELL 261 (4th ed. 2022).

- ¹⁴ Public Records Department of Health Authority of State Records Committee to Set Retention Period for Certain Records Produced by Department of Health, 1997 Att'y Gen. Op. 2 (Mar. 13, 1997) (applicability of public records law to health information, specifically diet information forms related to treatment of possible exposure to radioactive releases from Hanford Nuclear Reservation); see also HIPAA & Washington State, WASH. STATE UNIV. (last accessed Sept. 26, 2023) (includes list of laws that apply to health information privacy covered by the HIPAA privacy rule plus employee health sciences training); Washington State Agency Privacy Principles, WATECH (last visited Oct. 20, 2023); Privacy Framework for State Agencies, WATECH (Oct. 2022) (based on NIST Privacy Framework).
- ¹⁵ Latanya Sweeney, <u>Matching Known Patients to Health Records in Washington State Data</u>, Harvard Univ. Data Privacy Lab White Paper 1089-1 (June 2013) (demonstrating re-identification of patients using Washington state hospitalization data and news articles and suggesting specific redactions or limits on access to more sensitive data); <u>Department of Health Agency Standards for Reporting Data with Small Numbers</u>, WADOH (May 2018); see also <u>Wash. Rev. Code § 70.02.010(6)</u> and (17) (defining "Deidentified" and "Health care information").
- ¹⁶ See, e.g., Miriam Farhi, <u>Washington Sectoral Privacy Overview</u>, OneTrust Data Guidance (June 2023) (Washington privacy overview with list of key privacy laws and section on health data).
- ¹⁷ See <u>Admin. Policy 13.01: Use and Destruction of Health Care Information</u>, WASH. STATE DEP'T CHILDREN, YOUTH, & FAMILIES (July 1, 2018) (citing to relevant code sections and providing steps for notification of improper disclosure).
- ¹⁸ See Volk v. DeMeerleer, 386 P.3d 254, 258, 270 (Wash. 2016) (holding that psychiatrist's special relationship with outpatient required psychiatrist to act with reasonable care to protect foreseeable victims of patient's violent actions; "[D]espite the protection afforded mental health records by chapter 70.02 RCW and the Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936, the protection is conditional and will yield to greater societal interests.").
- ¹⁹ The Washington My Health My Data Act, H.B. 1155, 68th Legis., 2023 Reg. Sess. (Wash. 2023) (enacted at Wash. Rev. Code § 19.373 and Wash. Rev. Code § 44.28.819); see also Wash. State Legis. House of Representatives, Final Bill Report: ESHB 1155; WA DOH Policy: Responsibilities for Confidential Information & WA DOH Policy: Release of Confidential Data/Information (encompassing WA DOH Policies 17.005 and 17.006); see also WASH. CONST. art. I, § 7 ("No person shall be disturbed in his private affairs, or his home invaded, without authority of law."); Peninsula Counseling Center v. Rahm, 105 Wash. 2d 929 (Wash. 1986) (citing Whalen v. Roe, 429 U.S. 589 (1977), in upholding a required disclosure of certain mental health data to DSHS); Alsager v. Bd. of Osteopathic Med. & Surgery, 196 Wash. App. 653 (2016) (citing Murphy v. State, 115 Wash. App. 297 (2003) for holding that "a patient has only a limited expectation of privacy in prescription records"); Berger v. Sonneland, 144 Wash. 2d (2001) (addressing available remedies for disclosure of confidential health information).
- Wash. Rev. Code § 70.02 (chapter on health care information access and disclosure); see, e.g., Wash. Rev. Code § 70.02.050 (describing disclosures of health care information that do not require patient authorization) and Wash. Rev. Code § 70.02.270 (requiring recipients who use health care information to provide services for a health care provider or facility to limit use or further disclosure); see also Peninsula Counseling Center v. Rahm, 719 P.2d 926, 935-36 (Wash. 1986) (finding DSHS disclosure requirements for mental health information "are not overbroad and are carefully tailored to meet the State's legitimate, and laudable, interests"; "While disclosure of intimate information to governmental agencies is permissible if it is carefully tailored to meet a valid governmental interest, the disclosure cannot be greater than is reasonably necessary."); Kristal K. Wiitala, Public Records Act Deskbook: Washington's Public Disclosure and Open Meetings Laws § 11.1, Wash. State Bar Ass'n (Lexis 2020); see also WA DOH Policy: Legitimate Reasons for Sharing Data; Washington State Agency Privacy Principles, WATECH SOLUTIONS (last visited Oct. 20, 2023).
- ²¹ Wash. Rev. Code § 19.373.100 (listing exemptions to the My Health My Data Act).
- ²² Privacy Impact Assessment for WAVerify (addressing a WAVerify privacy analysis but references HL7 Fast Healthcare Interoperability and Patient Access Final Rule, which CMS incorporated in its rulemaking as applicable to providers receiving CMS funds); *How NCHS Protects Your Privacy: Confidentiality and Security of Information Collected by The National Center for Health Statistics*, CDC: NAT'L CTR. HEALTH STATS. (last reviewed Mar. 27, 2023) (includes links to applicable federal laws and the NCHS Staff Manual on Confidentiality).

- ²³ See, e.g., James G. Hodge, Jr. & Lindsay Wiley, <u>An Assessment of Legal Issues Concerning Public Health Disclosures Pursuant to Proposed Rulemaking Re: the Family Education Rights and Privacy Act (FERPA), COUNCIL STATE & TERRITORIAL EPIDEMIOLOGISTS (May 5, 2008) (published at 73 FR 15574).</u>
- ²⁴ Wash. Rev. Code § 49.60.180 (defining discrimination in hiring, discharge, compensation, conditions of employment, or hiring ads and applications as an unfair practice by employers); Wash. Admin. Code § 162-16-200 (stating protection from discrimination in employment generally and with respect to actual or perceived HIV infection, and including definition of "protected status" that includes "any sensory, mental, or physical disability" or the use of a service animal by a disabled person).
- ²⁵ Wash. Rev. Code § 49.60.178 (defining discrimination in cancelling, refusing to issue, or refusing to renew "insurance or a health maintenance agreement" as an unfair practice).
- ²⁶ See <u>Wash. Rev. Code § 49.60</u> (on discrimination and creating Washington State Human Rights Commission); <u>Wash. Rev. Code § 49.60.510</u> (limits on waiver of health care privilege from claiming noneconomic damages under the discrimination chapter, including claims of disability discrimination).
- ²⁷ Wash. Rev. Code § 49.60.030 (listing protected classes in a declaration of civil rights); Wash. Rev. Code § 71A.10.040 (protection from discrimination based on disability).
- ²⁸ WASH. STATE OFF. ATT'Y GEN. BOB FERGUSON, <u>WASHINGTON HEALTH FACILITIES: GUIDANCE AND MODEL POLICIES TO ASSIST IN THE IMPLEMENTATION OF THE KEEP WASHINGTON WORKING ACT</u> 13 (2020) ("Information pertaining to a patient's immigration or citizenship status should therefore also be considered a protected identifier if included as part of a record of medical care.").
- ²⁹ See <u>Wash. Rev. Code § 70.170.060</u> (hospital requirements for charity care including data requirements to identify patients receiving charity care); <u>Wash. Rev. Code § 70.129.005</u> (residents of long-term care facilities retain "basic civil and legal rights"); <u>Wash. Admin. Code § 388-472-0005</u> (rights and responsibilities of people receiving public assistance).
- ³⁰ See Wash. Rev. Code § 70.127.140 (patient bill of rights for in-home care including right to freedom from discrimination); Wash. Rev. Code § 9.02.100 (prohibiting discrimination against individuals exercising right to reproductive privacy); Wash. Rev. Code § 74.09.875 (prohibiting discrimination in providing reproductive health care through public assistance); Wash. Rev. Code § 74.09.675 (prohibiting discrimination in providing gender-affirming care through public assistance).
- 31 See S.B. 5432, 67th Legis., 2021 Reg. Sess. (Wash. 2021) (act creating the Office of Cybersecurity under the Office of the Chief Information Officer (OCIO) and including requirements for written agreements before agencies share "category 3 or higher data" with a contractor or other agency); see also Wash. State Legis. Senate, Final Bill Report: ESSB 5432 (July 25, 2021) (defining classification categories as category 1: public information, category 2: sensitive information, category 3: confidential information, category 4: confidential information requiring special handling). Additional general standards exist for securing IT-based information, per Washington Chief Information Officer's Standard No. 141.10 (includes data classification descriptions in section 4.1 and minimum contents for data sharing agreements in section 4.2) (updated Data Classification Standard dated Feb. 11, 2023), etc. See also Wash. Rev. Code § 70.02.150 (security safeguards required from health care providers); Privacy and Cybersecurity Best Practices, WATECH, OFFICE OF CYBERSECURITY (Dec. 2021) (including sections on cybersecurity, privacy, and data sharing agreements).
- ³² <u>Telehealth in Washington State</u>, WADOH (last visited Oct. 20, 2023) (providing links to relevant state laws and guidance documents for healthcare professionals).
- Wash. Rev. Code § 70.02.290 (requiring state and local agencies to adopt rules for health care record retention); Wash. Rev. Code § 19.215.020 (requirements for destruction of personal health information); State Agencies Records Retention Schedules, WASH. STATE ARCHIVES (last visited Oct. 16, 2023) (listing general retention schedule and specific retention schedules for specific government sectors and state agencies).
- ³⁴ Public Records Act Deskbook: Washington's Public Disclosure and Open Meetings Laws § 4.2, WASH. STATE BAR ASS'N (Lexis 2020); Wash. Admin. Code § 388-01-090 (when and how DSHS must respond to a public records request); see also Planned Parenthood of the Great Nw. v. Bloedow, 350 P.3d 660, 666 (Wash Ct. App. 2015) ("While DOH makes '[a]ny data, research, or findings' available to the public under RCW 43.70.050(5), RCW 43.70.050(2) specifically provides that health-related data submitted to DOH by health care providers shall not be disclosed or subject to disclosure under the PRA 'in any form where the patient or provider of health care can be identified.'"); Seattle Children's Hospital v. King County, 483 P.3d 785, 793, 795-96 (Wash. Ct. App. 2020) (holding that hospital records provided to the county and state public health authorities do not fall under the quality improvement or infection reporting exemptions of the

- public records act; "[C]urrent rules and regulations give DOH the discretion to apply the specific and robust HIPAA protections when deidentifying health care information from records it intends to release for public inspection."). See also Wash. Rev. Code § 43.105.351 (addressing and facilitating public access to records in electronic formats).
- ³⁵ See <u>IT Strategic Plan 2024</u>, WADOH (Sept. 2023) (requiring the "[e]stablish[ment] of principles and a data governance framework to guide appropriate access and data-sharing."); see also <u>Wash. Admin. Code</u> § 246-08-390(6) (conditions for allowing public inspection and copying of health information).
- ³⁶ See <u>Interim Guidelines for Purposeful and Responsible Use of Generative Artificial Intelligence</u>, EA-01-01-G, WATECH, WASH. STATE OFFICE CHIEF INFO. OFFICER (OCIO) (Aug. 8, 2023) (announcing intent to follow NIST AI Risk Framework, advising against entering any non-public data (non-Category 1 data) into generative AI systems).
- ³⁷ See, e.g., Wash. Rev. Code § 43.105.470 (requiring agencies to report cybersecurity incidents to the state office of cybersecurity).
- ³⁸ Washington Data Matrix.
- ³⁹ Wash. Admin. Code § 246-102-040 (data collection and submission requirements for cancer registry).
- ⁴⁰ Wash. Rev. Code § 70.24.450 (requiring confidentiality and reporting of unauthorized disclosures of STI data); Wash. Admin. Code § 246-101-635 (limits on disclosure of health care information related to cases of HIV/AIDS).
- ⁴¹ <u>Behavioral Risk Factor Surveillance System (BRFSS)</u>, WADOH (last visited Oct. 20, 2023); <u>Wash. Rev. Code</u> § 43.70.444 (requiring data related to suicide as part of state plan for prevention); <u>Wash. Rev. Code</u> § 71.40.140 (addressing disclosure of behavioral health records).
- ⁴² Wash. Rev. Code § 70.225.40 (giving confidentiality requirements for prescription monitoring program); Wash. Admin. Code § 246-470-090 (listing confidentiality requirements related to prescription monitoring program).
- Wash. Admin. Code § 246-490-110 (prohibiting public disclosure of abortion statistics that identify an individual or facility with limited exception for legal proceedings); Protected Health Care Services—Reproductive Health Care and Gender-Affirming Treatment, HB 1469, 68th Legis., 2023 Reg. Sess. (Wash. 2023) (applying limits on out-of-state subpoenas for information about protected health care services); Reproductive and Gender-Affirming Care: Shielding Providers, Seekers, and Helpers from Out-of-State Legal Actions, WASH. OFFICE OF ATT'Y GEN. (last visited Oct. 20, 2023) (FAQ on the AG's role in the Washington Shield Law).
- ⁴⁴ Wash. Rev. Code § 70.168.090 (requiring statewide trauma data registry including traumatic brain injury).
 ⁴⁵ Abigail English, *Adolescent & Young Adult Health Care in Washington: A Guide to Understanding Consent & Confidentiality Laws*, CTR. ADOLESCENT HEALTH & L. (Mar. 2019); Wash. Admin. Code § 110-01-0205 and Wash. Admin. Code § 388-01-150 (listing confidential records that require child's consent for disclosure even to a parent).
- ⁴⁶ Wash. Rev. Code § 43.70.435 (requiring annual report of student concussions).
- ⁴⁷ Washington: Statistics on Children, Youth and Families in Washington from the Annie E. Casey Foundation and the Children's Alliance, ANNIE E. CASEY FOUND. KIDS COUNT DATA CTR. (listing reports filtered by health topics, including birth outcomes, health insurance, vital statistics, dental health, mental health, and nutrition); Wash. Rev. Code § 70.54.450 (data requirements for maternal mortality review panel); Wash. Rev. Code § 71.24.610 (requiring interagency agreement to coordinate identification, prevention, and intervention programs for prenatal substance exposures).
- ⁴⁸ <u>Guidance Concerning Immigration Enforcement</u>, WASH. STATE OFF. ATT'Y GEN. (Apr. 2017) ("Best Practice: Only collect and retain information needed to serve the public, do not collect citizenship or immigration-related information unless required, and ensure nondiscriminatory access to benefits and services." "Best Practice: If possible, do not collect information about citizenship, place of birth, or immigration status. Be aware of privacy laws that make certain information confidential or otherwise limit the sharing of information.").
- ⁴⁹ See, e.g., <u>Wash. Rev. Code § 43.70.595</u> (addressing use of population health data to identify potential health equity zones and develop projects to address health disparities); <u>Wash. Rev. Code § 70.123.076</u> (addressing requirements for disclosing information about recipients of assistance from domestic violence programs); <u>Wash. Rev. Code § 43.185C.180</u> (management information system for persons experiencing homelessness); <u>Wash. Rev. Code § 70.129.050</u> (providing right to privacy and confidentiality of medical records for residents of long-term care facilities).

- ⁵⁰ Wash. Rev. Code § 43.70.052(5) (requiring WA DOH collaboration on an "American Indian-specific health data, statistics information system"); Wash. Rev. Code § 71.24.665 (requiring reporting on psychiatric treatment for American Indians and Alaska Natives available to "tribes, urban Indian health programs, and the American Indian health commission for Washington state").
- ⁵¹ Wash. State Hosp. Ass'n, <u>Hospital and Law Enforcement Guide to Disclosure of Protected Health</u> Information (4th ed. Aug. 2010).
- ⁵² Wash. Admin. Code § 246-440-100 (describing data collection and submission requirements for health care-associated infections).
- ⁵³ Notifiable Conditions Reporting for Clinical Laboratories, WADOH (last visited Oct. 20, 2023).
- ⁵⁴ Wash. Admin. Code § 246-101-420 (listing duties of schools to report notifiable conditions).
- ⁵⁵ See Wash. Rev. Code § 39.26.340 (requiring written data sharing agreement to share category 3 or higher data with a contractor); *Data Sharing Policy*, SEC-08, WATECH OCIO (Feb. 11, 2023) (providing guidelines for data sharing agreements when agencies share category 3 or 4 data outside the agency); *Safety Research: Ongoing Projects: Occupational Respiratory Disease*, WASH. STATE DEP'T LAB. & INDUS., (example of inter-agency agreement that splits responsibility for receiving case reports for notifiable conditions); Wash. Admin. Code § 246-492-400 (data sharing agreements for vital statistics); see also *Data Sharing Agreement Implementation Guidance*, WATECH SOLUTIONS (Dec. 2021) (descriptions of data classification categories on pg. 5); Internal and External Data Sharing Agreement Templates; WA DOH Flowchart: When a DSA is Required; Release of Confidential Data Procedure DSA; see also *Health Statistics*, WADOH (last visited Oct. 3, 2023) (explaining that "[s]tarting January 1, 2021, there is a new vital records law requiring a data sharing agreement (DSA) with the department. A DSA is required for CHARS, birth, fetal death, infant death, death, marriage, and divorce data").
- ⁵⁶ Data Owner and Data Steward Responsibilities.
- ⁵⁷ See <u>Wash. Rev. Code § 39.34.240</u> (requirement in the Interlocal Cooperation Act for written agreements to share category 3 or higher data between state agencies).
- ⁵⁸ See <u>Wash. Rev. Code § 43.376.020</u> (requirements for government-to-government relationship between state agencies and tribes).
- ⁵⁹ See Wash. Rev. Code § 70.05.060 (re: Powers and duties of local board of health, including "Each local board of health shall have supervision over all matters pertaining to the preservation of the life and health of the people within its jurisdiction and shall: (1) Enforce through the local health officer or the administrative officer appointed under RCW 70.05.040, if any, the public health statutes of the state and rules promulgated by the state board of health and the secretary of health; . . . (3) Enact such local rules and regulations as are necessary in order to preserve, promote and improve the public health and provide for the enforcement thereof;").
- ⁶⁰ Washington State has 29 federally recognized tribes that WA DOH regards as Public Health Authorities. See <u>Tribal Public Health</u>, WADOH (providing examples of consultation and collaboration procedure).
- 61 <u>Data Sharing Agreement for Confidential Information or Limited Dataset(s)</u>, WADOH (revised Nov. 2019) (form and general terms and conditions for sharing with tribe or tribal entity); <u>Data User Agreement</u>, CDC: NCHS (last reviewed June 11, 2020) (terms and conditions for using NCHS survey data).
- ⁶² See, e.g., Lawrence O. Gostin, James G. Hodge, Jr. & Ronald Valdiserri, <u>Informational Privacy and the Public's Health: The Model State Public Health Privacy Act</u>, 91 Am. J. Pub. HEALTH 1388 (Sept. 2001).