VIRGINIA DEPARTMENT OF HEALTH

Healthy People in Healthy Communities
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Communicable Disease Surveillance Data Release Policy

Application

The policy applies to anyone working as a representative of VDH, whether in a full-time or wage position, as a contractor, a fellow or intern, or a volunteer. It supplements the Virginia Department of Health (VDH) Confidentiality Policy (OCOM 1.01).

Purpose

This policy pertains specifically to the release of communicable disease surveillance data collected by the Office of Epidemiology, including data gathered by local health departments as part of the reportable and emerging disease surveillance process. Such data may include information collected on an individual case or location, during the course of an outbreak investigation, or in statistical reports. The policy applies to any manner of information release, including that posted on the website, shared in response to a FOIA request, included in media releases, provided in response to written or oral inquiries, disseminated in reports shared at meetings and within the community, or any other form of information sharing related to communicable disease surveillance data. The document is not intended as a stand-alone, all-inclusive guide to privacy protections for public health data. Additional guidance is available in the VDH Confidentiality Policy.

Requirements for Protecting Public Health Information

Public health data are collected to be used immediately in disease investigation and control activities and to provide indicators of the health of Virginia communities so that programs can be implemented to improve health status. To protect community members who could potentially be at risk of disease from a person reported to have a contagious illness, physicians, laboratory directors, and persons in charge of medical care facilities (defined in §32.1-102.1) are required by law to report confidential information about persons with certain medical conditions to the local health department (*Code of Virginia* §32.1-36 and §32.1-37). All these health professionals plus 'the person in charge of any residential or day program, service or facility licensed or operated by any agency of the Commonwealth, school or summer camp' are required to report outbreaks of disease (§32.1-37).

The identities of the patient and the 'practitioners of the healing arts' whose medical records are examined in the course of conducting surveillance and investigation of diseases must be kept anonymous (§32.1-41). Practitioners include physicians, others who report on behalf of physicians (e.g., nurse practitioners, office managers), laboratorians, directors of medical care facilities, and those who report on behalf of those directors (e.g., infection preventionists, directors of nursing), and others reporting individual cases of disease. No action on the part of VDH staff should lead to the identification of an individual.

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Additionally, "neither the Commissioner nor any local health director shall disclose to the public the name of any person reported or the name of any person making a report pursuant to this chapter" (§32.1-38). That extends the protection of confidentiality to information that would identify anyone as a disease or outbreak reporter, including facilities and businesses that make reports to the health department under §32.1-37. §32.1-38 also provides immunity from liability for persons reporting diseases to the health department.

Requirements for Releasing Public Health Information

Special Session I of the 2020 Virginia General Assembly enacted two new statutes that require VDH to release certain data publicly. A section (§32.1-37.01) was added that requires VDH to make information about outbreaks of communicable diseases of public health threat available to the public on a VDH website. The information must include the name of the place at which the outbreak has occurred and the number of confirmed cases and deaths resulting from the disease reported by that place.

Another new statute applies only for the duration of the emergency declared by the Governor in response to COVID-19. It requires VDH to make available to the public on an agency website data on confirmed cases of COVID-19 in Virginia by week and health district. The data must include the total number of confirmed cases, number confirmed by age group and by race and ethnicity and the percent of cases known to be associated with nursing homes, assisted living facilities, or correctional facilities. This law also requires VDH to make available on an agency website certain indicators and thresholds, including case incidence rates, percent of molecular tests that are positive, rate of COVID-like illness visits to emergency departments, rate of current confirmed intensive care unit hospitalizations, and the percent of hospital beds that are currently occupied.

Both of these statutes specify that the data must be released as long as the release does not violate the provisions of §32.1-41 of the Code.

Release of Information about an Individual Case to Protect Public Health

VDH staff cannot confirm or deny the identity of any individual reported to have, or to have died from, a particular disease, even when the information is being discussed publicly, unless the person or a legal representative has granted permission for VDH to do so. VDH has established a standard for routine release of information about an individual case that is intended to preserve the anonymity of identities. That is, VDH programs and districts are authorized to report the age group and region of residence when discussing individual cases, including deaths. The following age groups are standard for individual case release at the regional level: preschool (age 0-4 years), young school age (age 5-12 years), teenage (age 13-17 years), young adult (age 18-24 years), adult (age 25- 64 years), and older adult (65 years of age or older). If a program uses other standard age groups, such age groups may be substituted for the ones listed above as long as the groups are broad enough to ensure that the identity of an individual cannot be deduced from the information.

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Publicly releasing information about a location (e.g., facility or business) where disease exposure has occurred may be needed for surveillance and investigation purposes when there is no other way to identify those at risk. Quickly identifying people who may have been exposed allows the health department to conduct the investigation, identify individuals who need prophylactic therapy, and determine other disease prevention strategies. Examples of when the health department may need to publicly release information about a location (not the person involved) to quickly alert exposed individuals include, but are not limited to:

- Food server with poor personal hygiene worked at a restaurant while ill with a disease transmissible through food
- Potentially contaminated product was sold at a grocery store
- Person ill with a highly infectious disease, like measles, attended an event

Exceptions:
The health department has to balance the requirement to keep patient and disease reporter identities anonymous with using the information to take action to prevent disease. The *Code of Virginia* contains some exceptions to allow private information to be released when the information is needed to protect the health of others. These exceptions should be applied only if authorized by the State Health Commissioner and when every other available option has been exhausted. Whenever possible, the person (or facility or business) whose identity needs to be released should be informed in advance, and would preferably consent to the release.

Pursuant to §32.1-36.D, the State Health Commissioner can release a person's identity and disease to an employer if the person's employment requires contact with the public and the nature of the disease and the contact pose a risk to public health. This section of Code is usually applied at the individual level, such as when the health department has to notify a restaurant manager that a foodhandler has an enteric disease when the foodhandler is not willing or able to disclose that information to the employer.

The Commissioner is also authorized in §32.1-41 to release information 'if pertinent to an investigation, research, or study'. Any person to whom identities are divulged under this provision of the Code must preserve the anonymity of those identities. Release of information pertinent to research or a study is usually granted following VDH Institutional Review Board approval. This communicable disease data release policy pertains to the release of information that is pertinent to an investigation, which is hereby interpreted to mean that a public health need and justification exists for the Commissioner to approve an exceptional release of information beyond the routine data release standards.

Section 32.1-41 of the *Code of Virginia* may be applied at the individual or group level. An example of the Commissioner authorizing the release of information when necessary for public health purposes at the individual level is when the health department needs to provide information that an individual case of a particular disease has occurred in a city/county when the occurrence of that disease (case or death) means that residents of a community need to take specific actions to protect their health (e.g., for a vector-borne disease). Information that would be released would be that the disease has been diagnosed in someone in the city or county and steps residents need to take to protect themselves, not

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any details pertaining to the individual who has the illness. Even though confidential details about the individual would not be released in those situations, VDH staff will attempt to inform the individual (or legal representative of the individual in the case of a death) prior to sharing information about the illness occurring in the locality.

Additional examples of information the Commissioner might elect to share about an individual include alerting emergency medical services providers, directors of funeral homes, or representatives of a congregate setting (e.g., jails/prisons) if a person being transferred into their care has been diagnosed with the disease covered by an emergency declaration or posing a public health threat.

Two relevant examples of when the Commissioner would authorize the release of information at the group level are: 1) if the Commissioner authorizes the sharing of information about one employee in a company who has a communicable disease and authorizes future disclosures about other employees who work there who get the same disease, or 2) if the Commissioner authorizes the sharing of information about an employee's illness with an employer in order to protect others who could be exposed to the disease through interactions that occur within the work (or school or other) environment.

When the Commissioner grants an exception that authorizes the release of information, the request for the exception and the approval will make clear whether it applies to one individual or to a group and specify the duration of the approval.

Release of Information about an Outbreak to Protect Public Health

Outbreak data must also be protected. The health department has to be a trusted partner in every community, staffed by people to whom constituents can talk about disease situations of concern. Protecting the information shared is important to upholding that trust so that a representative of any business or facility is comfortable sharing concerns about illness in their setting with the health department. Releasing private information unnecessarily or inappropriately can destroy the trust and prevent the health department from being able to work to prevent additional illnesses from occurring.

In the course of investigating an outbreak, the health department will assess whether those in the setting associated with the outbreak are striving to prevent disease adequately and if the setting poses a risk to the health of the community. Every effort will be made to collaborate in a confidential manner. Only in the rare occurrence in which release of the information is needed to protect the health of the community would a local health department or program need to ask the facility or business for permission to release its name publicly. Oral consent is sufficient, and any permission that is given should be documented. If release of information is necessary for a public health purpose and the facility or business does not grant permission, then a request must be made to the Commissioner to consider authorizing the release of specifics about the location of an outbreak.

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Exceptions:
The Commissioner may choose to release additional information in accordance with § 32.1-41 of the *Code of Virginia*. Examples of information that might be produced about outbreaks include reporting data at a geographic level smaller than city/county, by facility type, or by individual facility.

Legislation enacted during the 2020 Special Session I of the Virginia General Assembly added §32.1-37.01 to the *Code of Virginia*, which requires the Commissioner to release outbreak data at the level of the place of occurrence of the outbreak if the outbreak is of a communicable disease of public health threat [definition] as long as the release does not violate the mandate to preserve anonymity provided in §32.1-41.

Protecting Identities in Statistical Data Releases

The *Code of Virginia* gives the State Health Commissioner broad powers related to distributing information necessary to prevent disease. A general provision about publication of information is set forth in § 32.1-23.A., which states that "The Commissioner may provide for the publication and distribution of such information as may contribute to the preservation of the public health and the prevention of disease".

Principle -- A vital role of VDH is to produce statistical information that describes the health of communities and different population groups across Virginia. Statistical information included in public health surveillance reports are counts, rates, or percentages by geographic (e.g., city/county, health district, region) or demographic (e.g., age group, race group, ethnicity, sex) determinants. Reports will not release data by individual ages or by disease reporter, including facilities, unless authorized by the Code or as authorized by the State Health Commissioner. The latter is most likely to occur in certain exceptional circumstances as needed to protect public health.

While producing these surveillance reports is an important function of the agency, confidential information must be protected in statistical reports produced by the health department. Every effort must be made to minimize the possibility of identifying an individual through any data released by the health department. This requires standards and procedures designed to maintain anonymity of individuals and a careful review of data before release.

Problems with Small Numbers -- The risk of failing to preserve the anonymity of an individual in a statistical report is greater when:

- Number of persons affected by a health condition is small,
- Geographic level of the data included in the report is small,
- Population size from which cases could have arisen is small, or
- Information about a case has been made public.

For many communicable diseases, the counts are often small. This can present a problem not only related to confidentiality protection but also for data interpretation. Rates based on small numbers can

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be unstable, fluctuating a lot from year to year, and unreliable, not providing the true picture of the public health problem.

To overcome these potential problems, VDH statistical reports will employ methods of data aggregation and cell suppression. A degree of data aggregation is always practiced in that continuous data are categorized into groups in VDH reports. Rather than reporting individual ages and dates, those data elements are aggregated into age groups and time periods. The section below on cell suppression describes the instances and manner in which VDH will release small numbers and additional considerations when working with small numbers.

Cell Suppression -- The primary means that VDH uses to protect anonymity in its statistical reports is through cell suppression. The rules that are followed for cell suppression are:

- Counts and rates by disease at the region or state level can be reported, even when data are stratified by demographic grouping(s).
- Current Year - Total counts and rates for a particular disease can be reported at the district or city/county level when the count is zero or greater than 4; total case counts and rates are suppressed if the count is 1-4 cases.
    - When data at this geographic level are stratified by a demographic group, cells containing 1-4 cases are suppressed.
    - If a district or program wants to release data from the current year for an area smaller than an independent city or county, then a request for approval must be submitted to the Commissioner. If release of the data is approved, cells containing 1-4 cases are suppressed.
- Prior Years - Total counts and rates for a particular disease can be reported at the district or city/county level.
    - When data at this geographic level are stratified by a demographic group, cells containing 1-4 cases are suppressed.
    - Prior year data can be released in time frames shorter than a year (e.g., monthly counts within that year) and aggregated at geographic areas smaller than an independent city or county (e.g., zip code or census tract) as long as cells containing 1-4 cases are suppressed.

Additional methodological considerations regarding cell suppression are:

- Data will be reported at the highest level necessary to meet the objectives of the report. Total counts or counts by individual demographic groups will be provided according to these rules.
    - Cross-tabulations of multiple demographics (e.g., age group by race group) could lead to so much cell suppression that usefulness of the data would be minimal.

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- Tables will be reviewed carefully to assess risk of inadvertent disclosure of confidential information and assure that the anonymity of identities is preserved prior to release of the data.
- Counts could be for cases, hospitalizations, deaths or tests.
- Demographic groups include age group, race group, ethnicity, and sex.
    - Reporting of other descriptors can only be done with District Health Director or Office Director approval
- Suppression rules apply to tables, graphs, and maps.
- Suppression would be done for cases and for rates or proportions based on those cases. That is, where suppression needs to occur, case counts in the cells of tables (or in graphs or maps where numbers are visualized) will be suppressed if the count is 1-4, and rates or proportions based on counts of 1-4 will also be suppressed.
- Additional cells in the table might need to be suppressed to prevent someone from being able to deduce the count from other available information. It must not be possible to compute the size of a suppressed cell by subtracting from data that are provided in other table cells or by linking to other tables included in the report or from other sources.

Exceptions:

- The Commissioner may approve release of current year statistical data based on communicable disease surveillance for areas smaller than an independent city or county.
- The Commissioner may choose to release additional information and not apply cell suppression rules. Examples of statistical information that might be produced include reporting data at a geographic level smaller than city/county, by facility type, or by individual facility. This would most likely occur during an emergency when the data are determined to be necessary for emergency response.

- Statutes Passed by Special Session 1 of the 2020 General Assembly require specific information to be released during either an outbreak of a communicable disease of public health threat or during the COVID-19 declared emergency. The statutes include provisions that the anonymity of data required in 32.1-41 of the Code must be preserved in these data releases. Thus, the above cell suppression rules will be applied when VDH releases the following data:
    - Information about outbreaks of communicable diseases of public health threat must be made publicly available on a VDH website, including the name of the place at which the outbreak has occurred and the number of confirmed cases and deaths resulting from that disease reported by that place.
    - During the COVID-19 declared emergency, data on cases of COVID-19 by week and health district must be made publicly available on a VDH website, including number of confirmed cases – total, by age group, and by race and ethnicity – and percent of cases known to be associated with a nursing home, assisted living facility, or correctional facility.
    - During the COVID-19 declared emergency, data indicators and thresholds must be made publicly available on a VDH website, including case incidence rate, percent of molecular

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tests that are positive, rate of COVID-like illness visits to emergency departments, rate of current confirmed intensive care unit hospitalizations, and percent of hospital beds that are currently occupied.

Additional Analyses for Small Numbers -- When a VDH program or health district wants to release a statistical report and rates are based on small numbers and trends over time vary widely and are difficult to interpret, additional aggregation of data will be done. This means increasing the time period to more than one year, widening an age range, and/or combining geographic areas to increase the case count, improve stability of the data, and ensure individual identities are well protected.

- Confidence intervals can also be calculated around any reported proportion or rate. A confidence interval of 95% is commonly used and indicates 95% confidence that the true rate lies within that interval.

Counts and rates should be reported because it is important to understand both when assessing the health of a community. A note advising users of the report to use caution in interpreting data based on small numbers should be included.

A Note About FOIA Requests – The principles and practices outlined in this guideline will be applied when responding to requests for information VDH receives under the Virginia Freedom of Information Act (FOIA), including requests and inquiries received from members of the media. VDH supports open access to government public records and will abide by all provisions of the law. Complying with the law does not extend to granting access to protected confidential information.

VDH is required to preserve the anonymity of patients and practitioners whose medical records are examined during the course of a disease investigation. To preserve anonymity, when data records are released in response to a request received under FOIA, the data will be redacted according to the HIPAA Safe Harbor de-identification method.

Two provisions of FOIA are noteworthy with respect to this current guidance document. One is that VDH is not required to create a new record if the record does not already exist (§2.2-3704.D.). The other is that while VDH must make a reasonable effort to provide electronic records as provided for in FOIA, the agency is not required to produce records from an electronic database in a format that is not regularly used by the agency (§2.2-3704.G).

VDH uses large, complex information systems to manage communicable disease data. Reports generated from these systems are predefined and run for pre-specified purposes. Developing these reports requires in-depth knowledge of the system and advanced technical skills. Defining additional reports that have not already been created within the system is not required in response to a FOIA request. Only generating data or records using options already pre-programmed into the system at the time of the request, and applying all needed practices to withhold confidential data and preserve patient anonymity, is required.

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Mechanism for Approval and the Release of Confidential Information

This policy describes what communicable disease surveillance data VDH staff members have the authority to release and what exceptions the State Health Commissioner can make. Only the State Health Commissioner is authorized to approve sharing potentially identifiable information collected during disease surveillance and investigation. District health directors and office directors who believe that, for a public health purpose, potentially identifiable information needs to be released beyond what is routinely authorized, as described in this policy, should submit a written request to their respective Deputy Commissioner, with a copy to the State Epidemiologist. The request should describe the circumstance, what information needs to be released, and the purpose of the exception to the policy. The *Code of Virginia* requires that the information release is pertinent to an investigation, which is interpreted in this policy to mean that a public health need exists for the data to be made available. The Deputy Commissioner will review the request and, if approved, make the request of the Commissioner. The State Health Commissioner will weigh the purpose for the request, input from the State Epidemiologist, and the importance of protecting private health information in determining whether to approve the release of information.

Specific guidelines for submitting a request for authorization of potentially identifiable data release are as follows:

- The request should be made on the VDH Decision Memo template for a Recommended Exception to the Communicable Disease Surveillance Data Release Policy available on the VDH intranet here: http://vdhweb.vdh.virginia.gov/administration/administration-forms/.
- The Memo should be sent by email to the Deputy Commissioner responsible for the district or program, with a copy to the State Epidemiologist.
    - The district or program may choose to also copy the Public Information Officer and/or the Deputy Commissioner for Governmental and Regulatory Affairs, or other individuals who might be involved in the information sharing.
- If the approval needs to be granted on an expedited timeline, that must be communicated clearly in the written request.
    - The urgent nature of the request may be communicated by additional means as well, such as a phone call to alert the recipients that the request is forthcoming and is time-sensitive.
- The request should specify explicitly whether it applies to an individual or group of people in a particular setting.
- The Central Office will review the request and document the status of the approval via email.

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Related Policies & Resources

- VDH Decision Memo Template - Recommended Exception to the Communicable Disease Surveillance Data Release Policy
- ASTHO – Public Health and Information Sharing Toolkit - https://www.astho.org/Programs/Preparedness/Public-Health-Emergency-Law/Public-Health-and-Information-Sharing-Toolkit/Collection-Use-Sharing-and-Protection-Issue-Brief/
- Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research, Institute of Medicine (US) Committee on Health Research and the Privacy of Health Information: The HIPAA Privacy Rule; Nass SJ, Levit LA, Gostin LO, editors. Washington (DC): National Academies Press (US); 2009. Chapter 2 The Value and Importance of Health Information Privacy https://www.ncbi.nlm.nih.gov/books/NBK9579/
- Partners in Information Access for the Public Health Workforce https://phpartners.org/ph_public/health_stats

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