

The Use of Geographic Information Systems
(GIS), Geocoding, and Confidentiality
Guidelines in
STD Programs: Survey Results

Prepared by the
Outcome Assessment through Systems of Integrated Surveillance (OASIS) GIS
Workgroup

*“[GIS] requires rethinking
and reorganizing the way
that data are collected,
used and displayed.”*

Clarke et al. *On Epidemiology and Geographic Information Systems: A Review and Discussion of Future Directions*. Emerging Infectious Diseases. Vol 2. No 2. April-June 1996

Disclaimer:

The perspectives expressed in this summary report are those of the authors and do not necessarily represent the official views of the CDC or NCSD.

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Executive Summary

This document summarizes the results of the Geographic Information Systems (GIS), Geocoding, and Data Confidentiality Survey as a product of the Outcome Assessment through Systems of Integrated Surveillance (OASIS) Project GIS Workgroup. The purpose of the survey was to assess the use of GIS technology within STD programs and how programs are currently addressing confidentiality issues. It was distributed to all STD Project Directors in late 2004. The results provide a snapshot of GIS technology use within STD programs and how GIS is being employed programmatically. Specific software applications used, the extent of mapping capabilities, and related confidentiality rules and guidelines are also assessed, as well as obstacles to GIS use.

Eight-two percent (55) of the 65 currently funded STD project areas responded to the survey, providing a good assessment of GIS capacity nationally. More than half (58%) of the project areas that responded to the survey use GIS. The type of GIS software being employed by programs is largely based on Environmental Systems Research Institute (ESRI) products. Geocoding activities are being performed by approximately half of all those programs that use GIS. Most program areas use GIS and/or geocoding for the purposes of enhancing data visualization (mapping), spatial analysis and intervention targeting. Barriers to GIS implementation were also identified, most notably lack of training and budgetary/staffing constraints. The need to provide information related to the benefits of GIS use was also identified.

The majority of program areas are currently addressing GIS confidentiality issues informally; however, a handful of programs have incorporated GIS in written documentation. Variability in the use and definitions of numerator rules for data confidentiality purposes was also verified. Attempts are being made by some STD programs to protect personally identifiable information based on restricted use of point-level GIS data, but the lack of, and need for, readily available confidentiality guidance related to STDs is apparent.

This survey highlighted the use of, variability in, and capacity to conduct GIS-related activities within STD programs. Continued GIS advancements, including increased program capacity and data confidentiality guidance, will be imperative if disease surveillance is to truly benefit from the added tools that GIS technology affords. However, such advances will require resources in order to expand the GIS knowledge base, and ensure adequate training, software accessibility, and appropriate guidance documentation.

Background

A Sexually Transmitted Disease (STD) program's ability to effectively analyze data is critical for surveillance efforts. Advancements in the use of surveillance tools, such as visualization techniques, may lead to improved targeting of prevention and intervention activities. Since the 1990's, interest in Geographic Information Systems (GIS) technology, an automated system for the capture, storage, retrieval, analysis and display of spatial data (Clarke et al), has increased within the public health community. This technology allows use of data previously not easily accessible or used for public health surveillance, i.e. small geographic boundaries such as block groups, raster imagery, improved scalability, etc. STD programs are increasingly finding that GIS can enhance surveillance activities by providing the ability to map, perform spatial analyses and assess health-related disparities and resources through time and space. These types of analyses may often be viewed as added clues for disease surveillance efforts and are valued for their stimulating visual effects. As such, presentations including maps of STD outbreaks, analyses and case reports have become meaningful resources for disease surveillance, investigation and prevention activities.

In addition to the various spatial analysis techniques afforded by GIS technology, another key function for enhancement of STD surveillance is the use of geocoding. Geocoding is "the process by which an entity on the earth's surface, a household, for example, is given a label identifying its location with respect to some common point or frame of reference" (Cromley & McLafferty). Hence, a geocoded datum will have corresponding latitudinal and longitudinal points. This process allows for the determination of the exact (within a certain range of error) location of a place, such as a patient's residence. Prior to geocoding, zip codes were the smallest geographic area of detail commonly displayed on maps. However, geocoding can also serve to improve and standardize data cleaning practices and ensure appropriate morbidity assignments, both of which improve data quality management.

The Outcome Assessment through Systems of Integrated Surveillance (OASIS) Project, a demonstration project funded by the Centers for Disease Control and Prevention (CDC) from 1998 through 2005, was established to promote innovative surveillance techniques. Several STD project areas (STD programs funded by CDC at the state and/or city level) implemented the use of GIS/geocoding technology through OASIS initiatives. The use of GIS/geocoding technology enabled OASIS participants to begin point-level mapping and enhanced spatial analyses. As use of GIS technology expanded, OASIS participants were confronted with data confidentiality issues, which led to additional discussions for existing procedures.

In July 2004 an informal GIS workgroup was created by OASIS participants. The specific aims of the workgroup were to: 1) discuss and address STD issues related to GIS/geocoding; 2) determine the extent of GIS technology and related confidentiality standards in use in STD programs nationally; and 3) develop recommendations for GIS-related best practices that could be shared with other STD programs. The OASIS GIS workgroup was comprised of individuals from the following OASIS sites: Baltimore, California, Massachusetts, Michigan, New York State, San Francisco, Virginia and Washington State. The CDC's Division of STD Prevention also participated in the workgroup.

The workgroup developed the GIS/Geocoding and Data Confidentiality Survey in order to understand the spectrum of how STD project areas across the country currently use this technology. The survey was designed to collect information related to human and software capacity, as well as how confidentiality surrounding geocoded and mapped data is addressed locally.

Methods

The GIS/Geocoding and Data Confidentiality Survey was developed by STD program staff from the Virginia Department of Health (VDH) in collaboration with the GIS workgroup. The web-based survey contained six sections; Program Summary, GIS, Geocoding, Mapping, Confidentiality Rules, and Guidelines. Questions within these sections related to generic use of this technology, specific software applications, the types and methods by which GIS data are distributed and whether written confidentiality guidelines have been developed. If the technology was not used, subsequent questions were asked pertaining to the rationale, along with relevant follow up questions.

Customized questions were developed based on varying degrees of GIS capacity. Skip logic was included to navigate respondents efficiently through the survey. As a result, the number of questions elicited from a given project area varied from 8 to 22 depending on specific GIS capacity. The average time for survey completion, based on a pilot conducted internally by VDH staff, was approximately two minutes for project areas not using GIS and seven to eight minutes for those using GIS. Respondents were able to stop the survey and continue at a later time, if needed.

Project areas were asked a series of questions related to the confidentiality rules they applied to all types of STD data. Numerator rules, whereby data is not released if the frequency of the event (i.e. counts of STD cases) is less than a predetermined size (threshold), were given as examples of confidentiality rules. Among STD programs these rules are commonly referred to as the Rule of X, where X is the threshold value, such as 3 or 5. Project areas were also asked to provide details regarding the actual cell values used to define their rules and the geographic level at which the rule is applied.

Survey distribution was conducted via email by the National Coalition of STD Directors (NCSD) on behalf of the OASIS GIS workgroup in November 2004. The email, sent to all STD Project Directors, discussed the rationale for the survey and provided an embedded link to the web-based instrument. Reminder emails were distributed in December 2004 to encourage survey participation. In Jan-March 2005, OASIS workgroup staff made final attempts, by phone, to contact the remaining program areas that had not responded. The survey was officially closed on April 15, 2005.

Results

Fifty-five (85%) of the sixty-five currently funded STD project areas responded to the survey. Six project areas did not answer all survey questions and two only answered the first four

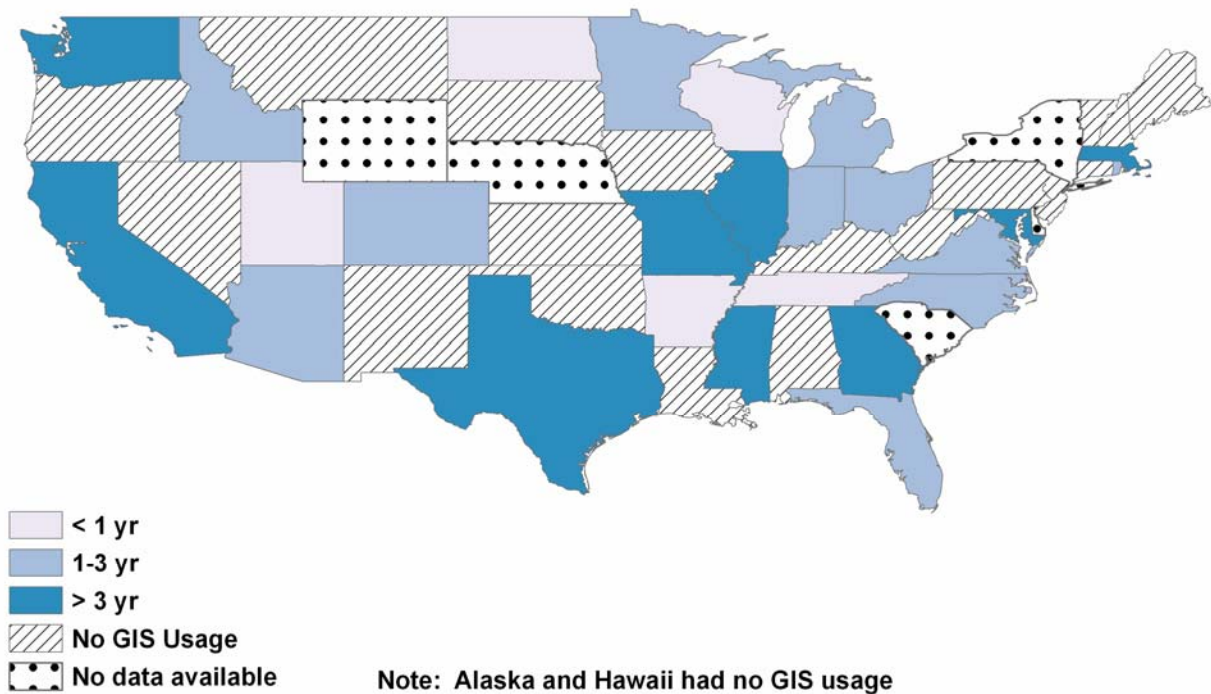
questions. The latter two sites were excluded from analyses. Therefore, final survey results are based on data collected from eighty-two percent of STD project areas (N=53).

Job descriptions of survey respondents varied by project area and include program managers, data managers and epidemiologists. Twenty-nine (53%) project areas that responded to the survey were integrated STD and human immunodeficiency virus (HIV) programs. For this report, an integrated program refers to a program that integrates STD and HIV/AIDS prevention and control activities within the same administrative and programmatic infrastructure.

GIS

Fifty-eight percent of the 53 STD project areas that completed the survey indicated use of GIS. Staff experience using this technology varied. Fourteen (45%) project areas have used GIS for over four years, six (19%) project areas have used GIS between 2-3 years and 10 (32%) began use within the past 2 years. Eighteen (58%) project areas have GIS functions performed by STD program staff. The STD program areas that use GIS are scattered throughout the United States (Figure 1).

Figure 1: GGDC survey, 2004-2005; STD Project Areas that Use GIS, N=53*



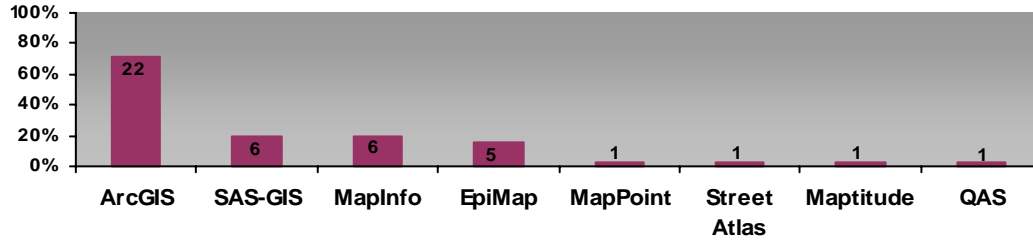
*Includes the following cities: Baltimore, Chicago, Los Angeles, San Francisco

The most common software used was ArcGIS (22, 71%). Nine (29%) of the project areas use two or more software programs for GIS activities. Project areas that did not use ArcGIS were three times more likely to use more than one software program for GIS activities than those

using ArcGIS. Project areas using MapPoint, Street Atlas or QAS used these applications only in conjunction with other GIS software programs.

Figure 2: GGDC survey, 2004-2005; Types of GIS software used (N=31)

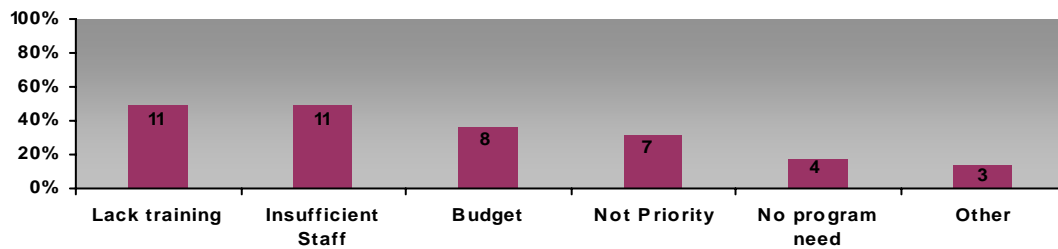
* Project areas could choose multiple responses. The data below includes all responses and does not equal the number of project areas [N]



Twenty-two (42%) of STD project areas that responded to the survey indicated they did not use GIS. The most prominent reasons for not using GIS were lack of training (11, 52%) and insufficient staff (11, 52%) followed by budgetary constraints (8, 38%) (Figure 3). Four (19%) of the project areas did not believe use of GIS would benefit their program. However, 12 (57%) of the project areas indicated they would use GIS if the technology and training were made available and 5 (24%) project areas indicated they would like more information on the uses of GIS. One project area did not answer the question.

Figure 3: GGDC survey, 2004-2005; Reasons GIS not used (N=21)

* Project areas could choose multiple responses. The data below includes all responses and does not equal the number of project areas [N]

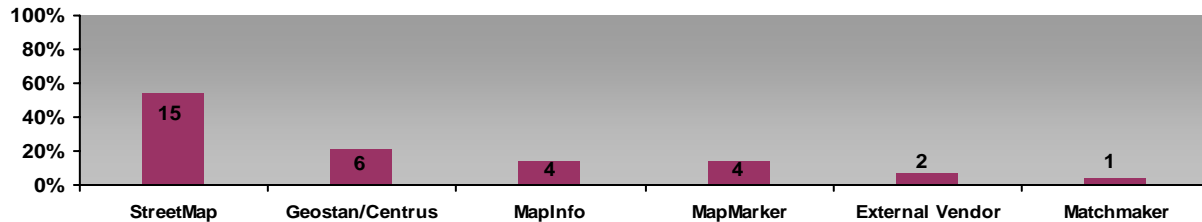


Geocoding

Twenty-eight (54%) of the 52 project areas that responded to this question perform some version of geocoding for STD data; 13 (46%) of these project areas have employed geocoding for over 4 years. The majority of project areas use one geocoding software and 15 (54%) indicated the use of StreetMap making it the most commonly used geocoding software (Figure 4).

Figure 4: GGDC survey, 2004-2005; Types of geocoding software used

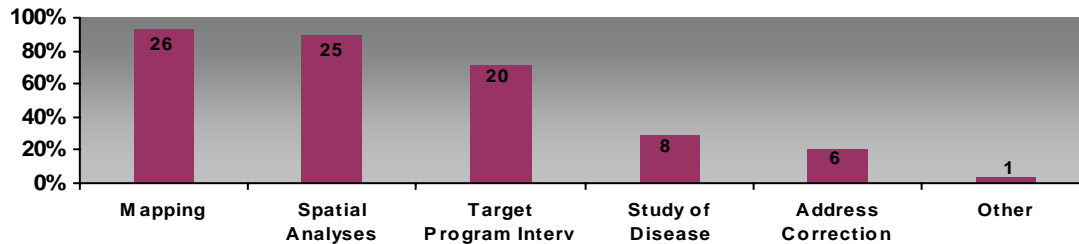
* Project areas could choose multiple responses. The data below includes all responses and does not equal the number of project areas [N]



All project areas that geocode data use GIS applications; however, three (10%) project areas that used GIS did not geocode data. The majority of programs use geocoding for the purposes of mapping, spatial analyses and to target program intervention (Figure 5).

Figure 5: GGDC survey, 2004-2005; Use of Geocoding (N=28)

* Project areas could choose multiple responses. The data below includes all responses and does not equal the number of project areas [N]



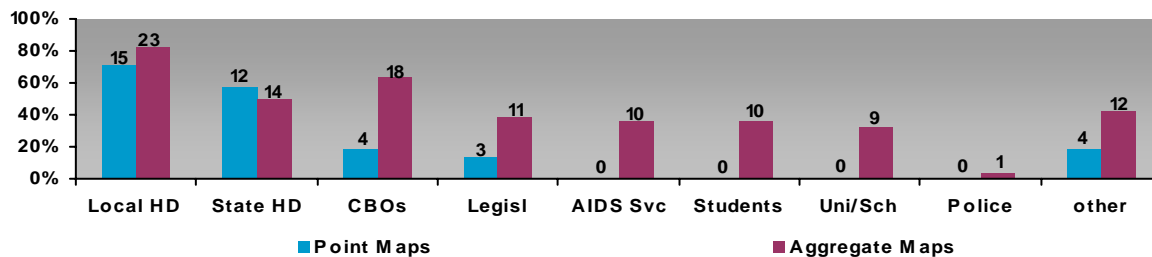
Mapping

Based on survey comments, project areas indicated GIS and geocoding assists in mapping disease by high risk groups and/or select community areas at various levels of detail. Project areas that did not geocode automatically skipped questions related to point level maps and were directed to aggregate level mapping questions. Consequently, there were 28 total respondents for the point level mapping questions and 31 for aggregate level mapping questions. There were 21 (75%) respondents that mapped point data and 28 (90%) that mapped aggregate data. Although the assumption would be that areas mapping point data also perform aggregate mapping, 2 project areas indicated this to be an inaccurate assumption. As expected, some project areas (9) map aggregate data only. This is not surprising given the additional data confidentiality issues surrounding GIS.

Project areas that mapped data were asked to indicate to whom and the means by which this data is provided. One STD project area indicated they mapped aggregate data but did not answer the follow up questions. Of the project areas that map point data, 15 (71%) release the data only to local or state health departments (Figure 6). Four (19%) project areas provide these maps to Community Based Organizations (CBO) and 3 (14%) release them to legislators.

Figure 6: GGDC survey, 2004-2005; To whom maps with point (N=21*) & aggregated (N=28*) data provided

* Project areas could choose multiple responses. The data below includes all responses and does not equal the number of project areas [N]



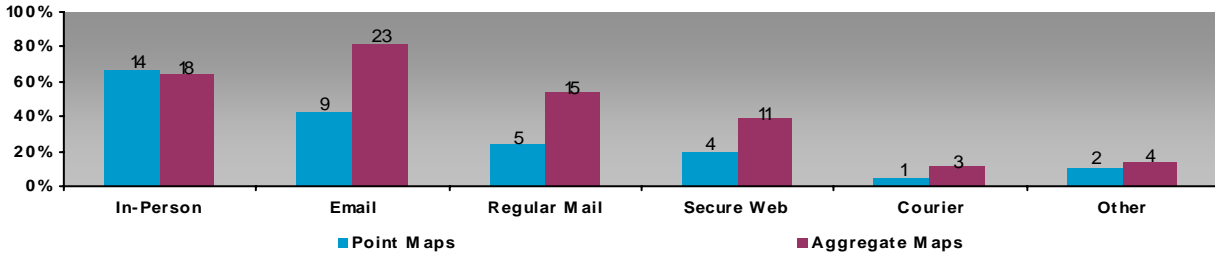
Abbreviation Key: Local HD = local health dept.; State HD = state health dept.; CBOs = community based organizations; Legisl = legislators; AIDS Svc = AIDS service organizations; Uni/Sch = universities/schools.

The methods by which point level maps are disseminated varied; 14 (67%) project areas provide point maps in-person and 9 (43%) release them via E-mail (Figure 7). Project areas are less restrictive on the release of maps containing aggregate data with 18 (64%) of project areas

releasing these maps to CBO's and 11 (39%) releasing them to legislators. The means by which aggregate level maps are distributed are also less restrictive with 23 (82%) indicating these maps are sent via E-mail and 15 (54%) are sent via regular mail.

Figure 7: GGDC survey, 2004-2005; How maps with point (N=21*) & aggregate (N=27*) data are provided

* Project areas could choose multiple responses. The data below includes all responses and does not equal the number of project areas [N]



Confidentiality Rules

Twenty-five project areas responded to the question of confidentiality rules. Three of the project areas that mapped aggregate data did not complete this section.

The survey was developed on the assumption that most project areas that employ numerator rules use either a Rule of 3 or a Rule of 5. However, project areas could provide responses as “other” and specify their numerator rule of choice. In total, 25 project areas responded to this question, with 19 employing some classifiable form of a numerator rule. An additional 5 project areas indicated use of an “other” rule and 1 indicated no rule is used. The most common rule used is the Rule of 5, as 14 (56%) of the 24 project areas use some variant of this rule. The Rule of 3 is used by only 2 project areas. Other rules included 0, 6 and 10. The 14 project areas using a Rule of 5 defined the rule four distinctly different ways; approximately one-third either defined the rule as cell sizes 1-4, 0-5 or 1-5 (Figure 8).

Figure 8: GGDC survey, 2004-2005; Numerator Rules (N=25)

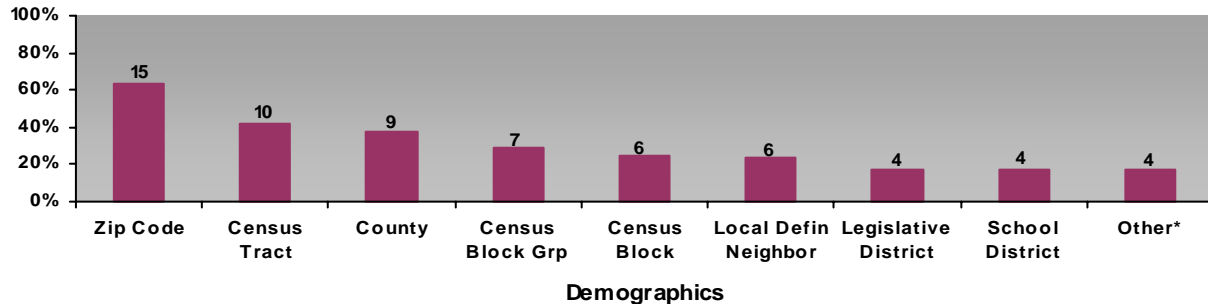
Numerator Rule	Rule Defined	Total # Project Areas	Numerator Rule	Rule Defined	Total # Project Areas
Rule of 0			Rule of 6		
	1	1		0-6	1
Rule of 3			Rule of 10		
	0-2	0			1
	1-2	2			
	0-3	0	Total using a rule		
	1-3	0			19
	Total	2	Other		
Rule of 5					5
	0-5	4	No Rule	N/A	1
	1-5	4		Total	1
	1-4	5			
	0-4	1			
	Total	14	TOTAL RESPONDENTS		
			25		

Project areas that indicated use of a confidentiality rule (24) were asked to indicate the geographic levels the rule was applied. Fifteen (63%) of the project areas applied their rule at the zip code level, 10 (42%) at the census tract level, and 7 (29%) at the census block group level

(Figure 9). Of those using a numerator rule, 11 were integrated STD/HIV programs and 13 were STD only programs.

Figure 9: GGDC survey, 2004-2005; Geographic level numerator rule applied (N=25*)

* Project areas could choose multiple responses. The data below includes all responses and does not equal the number of project areas [N]



Guidelines

Three (3) of the 31 STD project areas that use GIS did not complete any portion of the confidentiality section of the survey. Of the 28 (90%) project areas that responded to the confidentiality questions, 23 (82%) indicated confidentiality of GIS data was addressed informally and 5 (18%) addressed it in written guidelines. The use of a numerator rule to protect the confidentiality of GIS-based data was referenced by 8 (50%) project areas; one (1) indicated the use of a denominator rule.

Discussion

The majority of STD project areas responding to this survey use GIS and geocoding for the purpose of mapping, spatial analyses and intervention targeting. Such maps add visual detail unavailable prior to GIS use. As project areas become more versed in the additional capabilities of spatial analyses, techniques such as clustering, spatial descriptive statistics and modeling will become more common. These techniques will add to the analytical toolbox for epidemiologists when responding to programmatic and/or community data requests, data mining procedures and research activities.

Mapping is performed for both aggregate and point level data. As expected, release of point level data was more restrictive, inclusive of only state and local health departments and legislators, whereas aggregated maps had a much broader dissemination including universities, AIDS service organizations, student inquiries, etc. More restrictive distribution of point level data is perhaps indicative of best faith efforts by STD programs to ensure data confidentiality. STD programs are also making determinations for map distribution based on the level of map detail, as aggregate data is twice as likely to be disseminated via email as point level maps. However, it is worth noting that nearly forty-three percent of respondents that create point level maps (9 of 21) indicated dissemination of such maps via email. This survey did not collect information related to project area security levels related to email systems. Therefore, risk level related to email distribution of point level data is unclear.

A large number of project areas indicated spatial analyses of disease distribution is performed (89%); however, specific project area interpretation and/or definition of spatial analyses and/or intervention targeting were not collected. It is likely that spatial analysis is being understood as

primarily the geographical visualization of disease counts and/or rates using techniques such as choropleth and/or thematic mapping. Spatial analysis techniques, such as use of spatial descriptive statistics, Bayesian methods, clustering and spatial modeling are probably used by a much smaller subset of STD programs.

Given that spatial epidemiology is a relatively new field, courses and/or training opportunities are somewhat limited. Affordable and readily available software and training would assist with some of the issues identified in this survey. For example, the reasons why twenty-one STD programs do not currently use GIS are largely related to lack of training, insufficient staff and budgetary constraints. Plus, one quarter of these programs indicated that additional information related to GIS functionality is desired. The availability of grantor-provided training would assist programs grappling with these issues. In addition, the availability of GIS software licenses, similar to the Centers for Disease Control and Prevention (CDC) SAS Licensing Agreements, would allow programs greater access to GIS software for analysis, visualization and reporting (AVR) improvements. The initiation of such training and/or software licensing agreements would serve to ensure availability of adequate training and parallel access to GIS software for all STD programs (note: as stated earlier, half of all programs not currently using GIS indicated they would use GIS if software and training were provided).

Variability of software applications is also important to our understanding of GIS use within STD programs. This survey found that Environmental Systems Research Institute (ESRI) products, i.e. ArcGIS, are the primary software applications used by STD programs (71%). If training and/or licensing agreements were implemented, it would be advantageous to focus on software used by the majority of programs. Given that CDC has indicated ESRI will comprise the GIS backbone for the National Electronic Disease Surveillance System (NEDSS), the authors compared STD project areas using ArcGIS (22) with NEDSS deployment sites. Of the 19 current NEDSS sites (Danos - 2006 Public Health Information Network conference), 11 were among the respondents to the GIS software question and 82% (9 of 11) are ArcGIS users. This percentage is higher than the 71% that reported ArcGIS use in the survey.

It is not surprising that StreetMap is the most common geocoding software used by STD programs, given that it is an extension for ArcGIS. The second most common geocoding software is from the Centrus Suite of applications (i.e. GeoStan, Group1 Software). The CDC has announced that GeoStan will be the underlying geocoder to be used with the NEDSS PAM Platform (NPP), which is the platform on which the STD PAM will reside. Although program areas will be responsible for the costs of geocoding through the NPP, the agreement between CDC and Group1 Software is a more cost effective approach to geocoding morbidity than site-specific, stand-alone licenses. Plus, the financial burden associated with a geocoder will be lessened as the costs will likely be incurred by multiple programs whose PAMs are part of the NPP.

The advent of GIS and geocoding use within STD programs has exacerbated data confidentiality issues, as the release of point-level data represents increased risk of inadvertent disclosure. Hence, the implementation of appropriate controls for confidentiality and protection of data is essential to maintain the trust and support of the public (Elliott and Wartenburg). The identification of specific points, however, is dependent on a person's knowledge, experience,

scale/distance, physical abilities (vision/hearing), etc. Regardless of these factors, in the absence of reasonable guidance and/or methods for handling such data, many program areas are excluding small-scale data from reports, presentations and data releases. This may negatively impact effective program evaluation as well as epidemiologic research, as researchers need this level of data detail if this field is to progress (Elliott and Wartenburg). In short, GIS technology has outpaced STD data confidentiality standards of practice. And, most statutes that govern data confidentiality and/or sharing likely preceded GIS development (DRAFT - Joint Task Forces document – Oregon).

Numerous data confidentiality reference documents have been produced at the federal level; however, the majority lack adequate guidance related to GIS such as appropriate use of small geographic boundaries, incorporation of population level/denominator data, use of scales/distance, etc. Plus, these documents are located in numerous places, making collective and comprehensive use of such information extremely difficult. To our best knowledge, the Department of Criminal Justice has developed the most comprehensive GIS guidance documentation (Privacy in the Information Age: A guide for Sharing Crime Maps and Spatial Data). Other GIS confidentiality documents exist; however, few of these resources make reference to STDs or other communicable diseases.

Several STD project areas indicated formal guidelines related to GIS were in development. However, at the time of this survey, few STD programs appear to have incorporated GIS into their data confidentiality documentation, and 82% are addressing such issues on an informal basis. Those areas that are developing their own guidance are probably doing so independently which could result in erratic data confidentiality protection. This issue will continue to affect many federal, state, and local governments as attempts to use GIS as a tool for improving policy and decision-making practices continues to expand (DRAFT - Joint Task Forces document – Oregon). Comprehensive data confidentiality documentation and/or a webpage dedicated to this topic would likely be a much sought after tool for STD programs, and would likely be used by a much larger audience.

In addition to GIS usage, this survey documented the variability of numerator rules among project areas to further discussion and understanding related to data confidentiality practices. As expected, use of numerator rules among STD programs varied widely, from the use of ten as the numerator of choice to no rule at all. Within the confines of a specific Rule of X, the explanation of the rule was defined in multiple fashions. For example, the Rule of Five is used by over half of all STD programs that responded to the question; however, the rule is defined and employed in four distinct ways. In other words, the Rule of Five has different implications and data release standards based on individual site protocol. Such variance in numerator rules adds an array of complexity when attempts are made to analyze data at regional or national levels. Delcher et al provide insight into the complexity and variation of STD numerator rule analyses through research that documented over 15 distinct data release procedures within a single national STD dataset.

The continuing shift toward more stringent restrictions on use of personal health data is certainly adding to the data confidentiality dilemma. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 and the subsequent Privacy Rule of 2003 are prime examples. These

advances in personal health data use restrictions should serve to strengthen the need for clear, concise data confidentiality guidance for surveillance purposes.

There are several limitations associated with this survey. Firstly, there may be inherent bias in that the survey data excludes some project areas. Although attempts were made to elicit complete participation, all project areas did not complete the survey. Plus, as alluded to earlier, two project areas were excluded due to minimal information. Secondly, knowledge of GIS terminology among survey respondents is unknown with respect to questions such as spatial analysis, etc. However, via the initial email solicitation, the GIS Workgroup did request STD Project Directors to consider survey completion to be conducted by the most applicable person with knowledge of mapping capacity and confidentiality issues. The third limitation relates to the ability of respondents to stop the survey and return at a later date. This was included in the design as a feature to encourage survey completion. However, some data were incomplete and it is unclear from the data if respondents stopped the survey purposefully at that point or if they intended to return for completion which never occurred.

In summary, many STD programs are using GIS to enhance STD surveillance efforts. However, widespread use of GIS by STD programs heightens the need to examine as well as address the implications of using GIS. STD programs that currently are not using GIS could benefit from increased awareness of the utility of GIS, training in basic geocoding and GIS programming and analysis, improved access to GIS software, and collaboration with other STD or public health programs to share expertise. Even programs currently using GIS could benefit from improved access to GIS software (such as through licensing agreements) and increased training in the more complex functions of GIS technology. Given the heterogeneous approach to data confidentiality demonstrated by this survey, all STD programs could benefit from guidance on how to optimize use of spatial data while also protecting confidentiality. As stated by Clarke et al:

[GIS] is not simply the next widget to come into play. [It] can be seen as a new approach to science, one with a history and heritage, a finite and well researched suite of methods and techniques, and a research agenda of its own. It does not neatly fit into the health scientist's toolbox. It requires rethinking and reorganizing the way that data are collected, used, and displayed. It requires expense, training and a climb up a learning curve...

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