

PROTOCOL FOR DATA REQUESTS

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PROTOCOL FOR DATA REQUESTS

EFFECTIVE DATE: **November 1, 2004**

PURPOSE

To screen and assign data requests to Bureau of TB Control (BTBC) epidemiologists and data analysts.

POLICY

All data requests will be sent to a designated Surveillance epidemiologist who will consult with the Surveillance director or deputy director to evaluate each request. They will then determine whether the request requires data analysis or can be responded to with already published data. Requests requiring data analysis will be evaluated to estimate the type and amount of work needed, and to assign the requests to BTBC epidemiologists as described below.

ELEMENTS OF THE PROTOCOL

1.0 Data Request Coordination

A Surveillance epidemiologist will coordinate all data requests, with guidance from the Surveillance director and deputy director. All data requests from outside of the Bureau, from BTBC staff, or received by BTBC staff from outside individuals will be sent to the designated Surveillance epidemiologist. Requests from Epidemiology Office staff should be sent to the Epidemiology Office director. Requests should not be made to other Epidemiology or Surveillance staff, as this unnecessarily increases staff workload and makes it impossible to track requests.

2.0 Evaluation of the Requests

The designated Surveillance epidemiologist, in consultation with the Surveillance director or deputy director will review the requests and determine the amount of effort and staffing required. Requests will be prioritized based on requestor and need.

2.1 If all or most of the information requested can be found in the annual BTBC Information Summary, a copy of the report or specific pages will be sent to the requestor. All requests will be evaluated for the potential to be responded to with data already analyzed from monthly, quarterly, or annual reports. The Surveillance director's assistant will mail or fax the documents as instructed. Note that all Information Summary reports from 2000 on are on the NYC DOHMH website (<http://www.nyc.gov/html/doh/html/tb/tb-ar.html>). Requestors should be referred to the website for general requests before BTBC staff start analysis. If requestors do not find what they want, they should re-send the request.

2.2 Other requests will be evaluated to determine the amount of effort and type of staffing needed to complete the request. A request may sound simple but be time consuming for programmers. Requests that require analysis from the live registry will be carefully reviewed prior to approval.

2.3 Requests which require significant time and effort will be prioritized by the Surveillance director, based on staff workload and other priorities.

2.4 Requests which constitute the analysis for research papers will not be performed.

- 2.5 If a request is complex and potentially time consuming, it may need to be discussed with the Bureau director; such requests will be performed in order of priority.
 - 2.6 The requests will then be assigned to staff based on the person asking for the data, the use of the data, the database to be used, the complexity of the programming needs, and the workload of the staff involved.
 - 2.7 Data requests for the current year data will not be performed for persons outside the BTBC – except for the Commissioner of health or the Mayor. BTBC staff should use monthly and quarterly reports for current year’s data. Outside individuals should be referred to the MMWR for the current year’s case count.
 - 2.8 For complex requests, the staff assigned to perform the analysis (epidemiologist or computer specialist) may need to discuss the request with the requestor to clarify the exact needs. Data requestors may be unclear about their data needs and may ask for more data than they really need or is available.
- 3.0 Staff Assignments**
- 3.1 The senior computer specialist will perform complex programming requests.
 - 3.2 Requests from the Bureau director will go directly from the director to the central office epidemiologist or research scientist, who will work with the computer programmer, if complex programming is needed.
 - 3.3 Requests from BTBC Surveillance, Medical Affairs, and networks will be assigned to the Surveillance research scientist/data analyst (particularly for moderately complex analysis), the Surveillance epidemiologist, or an Office of Epidemiology epidemiologist/research scientist, if necessary.
 - 3.4 Requests related to the Office of Epidemiology studies will be completed by epidemiologists from that office, unless complex programming is required from the live TB registry. In such cases, assistance from the computer specialist may be needed.
 - 3.5 The Surveillance epidemiologist will run all monthly and quarterly reports and data analysis for annual reports.
 - 3.6 The RVCT coordinator will fulfill data requests concerning TIMS data.
- 4.0 Request Specification**
- The requestor should specify the following for all data requests (except for those requesting published data):
- 1) name and affiliation of requestor,
 - 2) purpose of request,
 - 3) data needed,
 - 4) justification for all requested data, and
 - 5) date desired for completed request.
- Note that the date desired will not necessarily be adhered to by Surveillance but will serve as a guide for prioritization and will need to be realistic. Requests can be made via email.

5.0 Request Performance

- 5.1** A spreadsheet of data requests will be maintained by the Office of Surveillance to keep track of the requests, amount and complexity of work, staff assigned, date requested, due date, and progress.
- 5.2** The epidemiologist completing the data request should use a clear and concise format to present the data. Data analysis results are best presented by using Excel tables or figures. SAS tables are only appropriate to send to other epidemiologists. Results should match the Information Summary, if the data is from the frozen file. For data coming from the live registry, specify that these may not match the annual report.
- 5.3** Results should be reviewed by the Surveillance director or deputy director for accuracy before sending to requestor. The output of complex requests should be reviewed by the Surveillance director or deputy director, Epidemiology director, or Bureau director prior to release.
- 5.4** If the data will be published elsewhere or presented at a scientific meeting, the following citation should be provided in the cover letter: “New York City Department of Health and Mental Hygiene, Bureau of Tuberculosis Control, unpublished data, year.”
- 5.5** All records of requests should be kept under a file name related to the request. Files should include request, cover letter, analysis programs and results. Avoid using numbers as file names, as these do not give helpful hints for locating requests. However, include the request number, as indicated in the spreadsheet, in all files related to that request.

6.0 Special Circumstances

- 6.1** *Frequent requestors*
Some information is requested every year; they should be fulfilled using the usual timeline, if possible.
- 6.2** *Journalists*
Refer them to the Office of Public Affairs.
- 6.3** *DOHMH Public Affairs*
They do not have to submit a formal written request. However, these requests should be discussed with the Bureau director.
- 6.4** *NYS DOH*
They are generally interested in RVCT data. Refer these to the RVCT coordinator.
- 6.5** *Office of Community Relations and Mayor’s Office*
These requests have to be responded to rapidly and discussed with Bureau director.

7.0 Confidentiality

- 7.1** No individual data will be given to persons outside of the BTBC unless the project has DOHMH IRB approval for TB data. IRB approval to receive other types of data does not cover TB data. Even with IRB approval, it is rare that identifiable data will be provided to persons outside BTBC.
- 7.2** If a table contains cells with <5 counts, these counts should be suppressed and replaced by “<5”.

Approved by: (1) <u>Fabienne Laraque, MD, MPH</u>	<u>12/9/04</u>
(2) <u>Sonal Munsiff, MD</u>	<u>12/9/04</u>
(3) <u>Cindy Driver, RN, MPH</u>	<u>12/9/04</u>
Print Name	Date

Reviewed :	Date:	8/30/04	12/01/04		
	Name/Signature	Sonal Munsiff	Sonal Munsiff		
Revised:	Date: (mm-yy)	Created Feb 2004	August 2004	10/04/04	
	Signature:	F. Laraque	F. Laraque	F. Laraque	

APPENDICES

- 1.0 Data Request Form**
- 2.0 Request Results Form Letter**



**New York City Department and Mental Hygiene
Bureau of Tuberculosis Control**

Request Number: _____

Date Received: _____

DATA REQUEST FORM

REQUESTOR INFORMATION

Last name	First name	Initials	
Organization/affiliation	Department	Position/Title	
Address	City	State	Zip code
Telephone number	Fax number	E-mail address	

DATA REQUESTED

Purpose of Request:

Goal of Project (if applicable):

Justification for Requested Data:

Data Needed (Make this as specific as possible; Use additional space as needed): _____

Type of Data Requested

Electronic Database _____ Line Listing _____ Aggregate Tables _____

Desired Date of Completion: _____

Is IRB approval needed: Yes _____ No _____

IRB approval received from your institution: Yes _____ No _____ N/A _____

IRB approval received from NYC DOHMH: Yes _____ No _____ N/A _____

If not applicable, why _____

Office use only

Reviewed by:	_____	_____
	Print Name	Signature
Date:	_____	
Approved by:	_____	_____
	Print Name	Signature
Date:	_____	

Disclaimer

Any data with any identifier will need IRB review except under very limited circumstances. Non-identifiable data may also need IRB approval prior to release and this will have to be decided on a case-by-case basis.

2.0 Data Results Form Letter

Date

Name
Address of Requestor

Dear ...:

In response to your request of (enter date), I am providing you information on (enter type of data requested). As we discussed, (enter limitations—for example, we are unable to provide you data on race/ethnicity because the cell numbers are too small in individual zip codes to share with you and still maintain patient confidentiality). Please note that it is our policy not to provide data if the numbers are too small (<5 per category or cell).

If you use these data in a paper or database, the preferred citation is: New York City Department of Health and Mental Hygiene, Bureau of Tuberculosis Control, unpublished data. Should you have any questions about these data, please call me at (212) .

Sincerely,

BTBC staff name
Title