

THE WTCHR ENROLLMENT SUMMARY

January 31, 2005

This report summarizes the enrollment characteristics of all 71,609* people who registered with the World Trade Center Health Registry (WTCHR). Enrollment interviews occurred between September 5, 2003 and November 20, 2005. Criteria for inclusion in the WTCHR include:

• People who were living south of Canal Street on September 11, 2001

• People who were in a building, on the street, or in transit south of Chambers Street on September 11, 2001

• People involved in the rescue, recovery, clean-up and other disaster-related activities at the WTC site and/or WTC Recovery Operations on Staten Island any time between September 11, 2001 and June 30, 2002

• Children enrolled in schools (pre-K through 12th grade) or day care centers south of Canal Street on September 11, 2001

• Staff employed or volunteering at schools (pre-K through 12th grade) or day care centers south of Canal Street on September 11, 2001

** Interviews with next-of-kin of people who died after September 11, 2001 and who were eligible for the Registry (N=164) will be included in a later report; final enrollment numbers may be revised further pending internal verification of data.*

Information on the following pages includes a review of the Registry's purpose, information on how enrollees can update their contact information, and summaries of the residence, demographics, eligibility, and key eligibility subgroups reported by enrollees.

The New York City Department of Health and Mental Hygiene (NYC DOHMH), along with the Agency for Toxic Substances and Disease Registry (ATSDR), extends its appreciation to all individuals who enrolled in the Registry, as well as to the members of the WTCHR Community Advisory Board and the Scientific Advisory Committee for their ongoing support during data collection.

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PURPOSE OF THE WTC HEALTH REGISTRY

Health registries have been set up to monitor the health of populations for a variety of reasons, including disasters like the Three Mile Island Registry nuclear reactor disaster of 1979 and the Oklahoma City bombing of 1995, and exposure to hazardous substances monitored by the National Exposure Registry. Registries are valuable tools that allow health professionals to track and investigate illness and recovery resulting from disasters, and help create guidelines that can save lives and reduce injuries in future disaster settings. Health registries create a roster of people that can be utilized over time:

- # As a service to affected people to answer questions about their health
- # To inform enrollees and the general public about new advances in treatment for any illnesses associated with exposure to a particular event
- # As an aid to research that allows health professionals to identify trends in illness and recovery, and better understand how exposures affect people's health

The WTCHR is a comprehensive and confidential health survey of those most directly exposed to the events of September 11, 2001. Enrollment was voluntary. Respondents answered a 30-minute telephone or in-person baseline interview about where they were on September 11, 2001, their experiences, and the status of their health. Respondents' data will allow health professionals to compare the health of those most exposed to the events of September 11, 2001 with the health of the general population.

Findings from the WTCHR will be shared with the public so that people can make informed decisions about their health. Doctors and medical providers will also be informed of new health findings. The NYC DOHMH will also work with health professionals who are conducting more specific studies about particular groups of people who were affected by September 11, 2001.

While aggregate data will be reviewed by the NYC DOHMH and other institutions, **personal data is kept strictly confidential**. Names and identifying information of enrollees are protected by a Federal Certificate of Confidentiality (CoC), which is issued by the Centers for Disease Control and Prevention (CDC) to protect this information from forced disclosure. Among other protections, the CoC allows the NYC DOHMH to refuse to disclose identifying information on research participants in any and all civil, criminal, administrative, legislative, or other proceeding, whether at the federal, state, or local level. Further information about the CoC may be found at: <http://grants1.nih.gov/grants/policy/coc/>

An important aspect of the WTCHR is the ability to conduct in-depth studies among specific subgroups of enrollees. The NYC DOHMH will contact registrants for follow-up and other studies they may be eligible for. An overwhelming majority of enrollees:

- # Gave consent to receive information from the NYC DOHMH about other WTC-related health studies (N=65,518; 91%)
- # Gave consent to receive general health information from the NYC DOHMH (N=67,376; 94%)

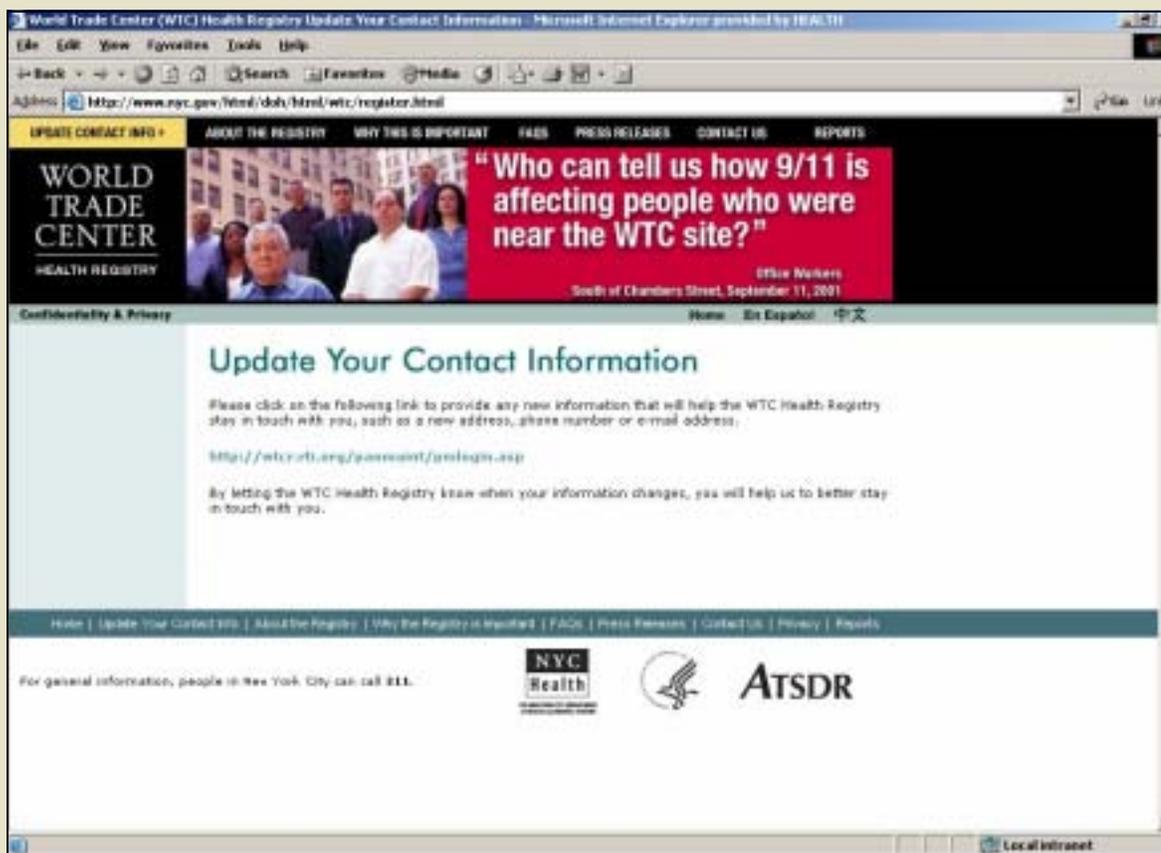


MAINTAINING AN UPDATED REGISTRY

The WTCHR is a partnership between the NYC DOHMH, ATSDR and Registry enrollees. After the baseline interview, the NYC DOHMH will contact enrollees periodically to verify contact information (e.g. address, telephone and e-mail information), conduct WTCHR follow-up interviews, send general health information, and notify enrollees of other health studies for which they might be eligible. The Registry's website helps enrollees update their contact information through a web page designed to accept any new information that will help the WTCHR stay in touch with enrollees, such as a new address, telephone number or e-mail address.

WTCHR enrollees who wish to update their contact information can visit <http://wtcregistry.org> and select the "Update Contact Info" link at the top of the homepage. Follow instructions on this page to link to the WTCHR Locator Information and Contact Update site. If you are updating your information for the first time, click on the "New User" link (see Figure 1 below). Follow instructions to create a password and update your contact information and then press "submit" to send your updates to the Registry. If you did not enroll in the WTCHR, you may still sign up to receive emails about registry activities by visiting <http://nyc.gov/html/doh>.

Figure 1. Web Page for Updating Contact Information



FINAL ENROLLMENT SUMMARY

Information on the following pages includes summaries of the residence, demographics, eligibility and key eligibility subgroups reported by enrollees.

INFORMATION ON ENROLLEES' PLACE OF RESIDENCE

Figure 2 is a map that shows the final number of people enrolled in the WTCHR by their state of residence on 9/11/01. Figure 3 is a table that shows the specific number of enrollees by state. All 50 states are represented in the WTCHR.

Figure 2. National Map of Enrollees by State

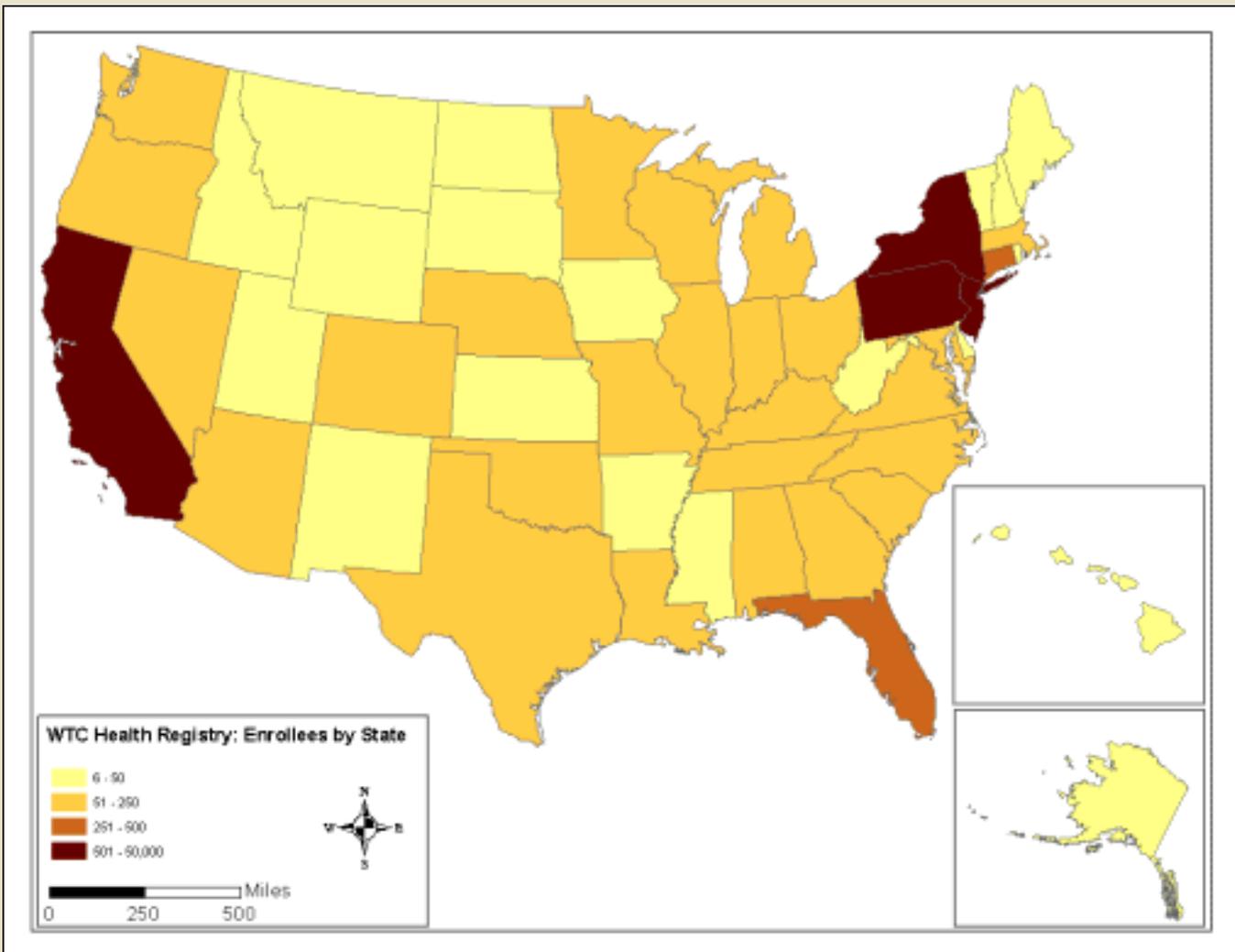


Figure 3. WTCHR Enrollees by State

State	Number Enrolled	State	Number Enrolled
ALABAMA	114	NEBRASKA	63
ALASKA	<25*	NEVADA	64
ARIZONA	61	NEW HAMPSHIRE	30
ARKANSAS	34	NEW JERSEY	7,305
CALIFORNIA	638	NEW MEXICO	<25
COLORADO	129	NEW YORK	56,783
CONNECTICUT	481	NORTH CAROLINA	239
DELAWARE	<25	NORTH DAKOTA	<25
DISTRICT OF COLUMBIA	<25	OHIO	219
FLORIDA	342	OKLAHOMA	80
GEORGIA	171	OREGON	75
HAWAII	<25	PENNSYLVANIA	667
IDAHO	<25	RHODE ISLAND	34
ILLINOIS	167	SOUTH CAROLINA	71
INDIANA	171	SOUTH DAKOTA	<25
IOWA	38	TENNESSEE	100
KANSAS	48	TEXAS	191
KENTUCKY	55	UTAH	<25
LOUISIANA	68	VERMONT	26
MAINE	28	VIRGINIA	172
MARYLAND	117	WASHINGTON	191
MASSACHUSETTS	237	WEST VIRGINIA	35
MICHIGAN	113	WISCONSIN	63
MINNESOTA	129	WYOMING	<25
MISSISSIPPI	46	Other**	1,564
MISSOURI	193	Total:	71,609
MONTANA	<25		

* To protect the confidentiality of enrollees, states with less than 25 enrollees are reported as "<25".

** Includes Puerto Rico, Canada, Mexico, and US Military Base Personnel.

*** Includes enrollees who provided inadequate address information.

Figure 4 is a map of enrollees in the New York City area by their home zip code on September 11, 2001. The WTCHR has 46,088 enrollees from New York City with all five boroughs represented.

- # 21,147 lived in Manhattan on September 11, 2001
- # 9,630 in Brooklyn
- # 7,820 in Queens
- # 4,164 on Staten Island
- # 3,327 in the Bronx

Figure 4. New York City Map of Enrollees

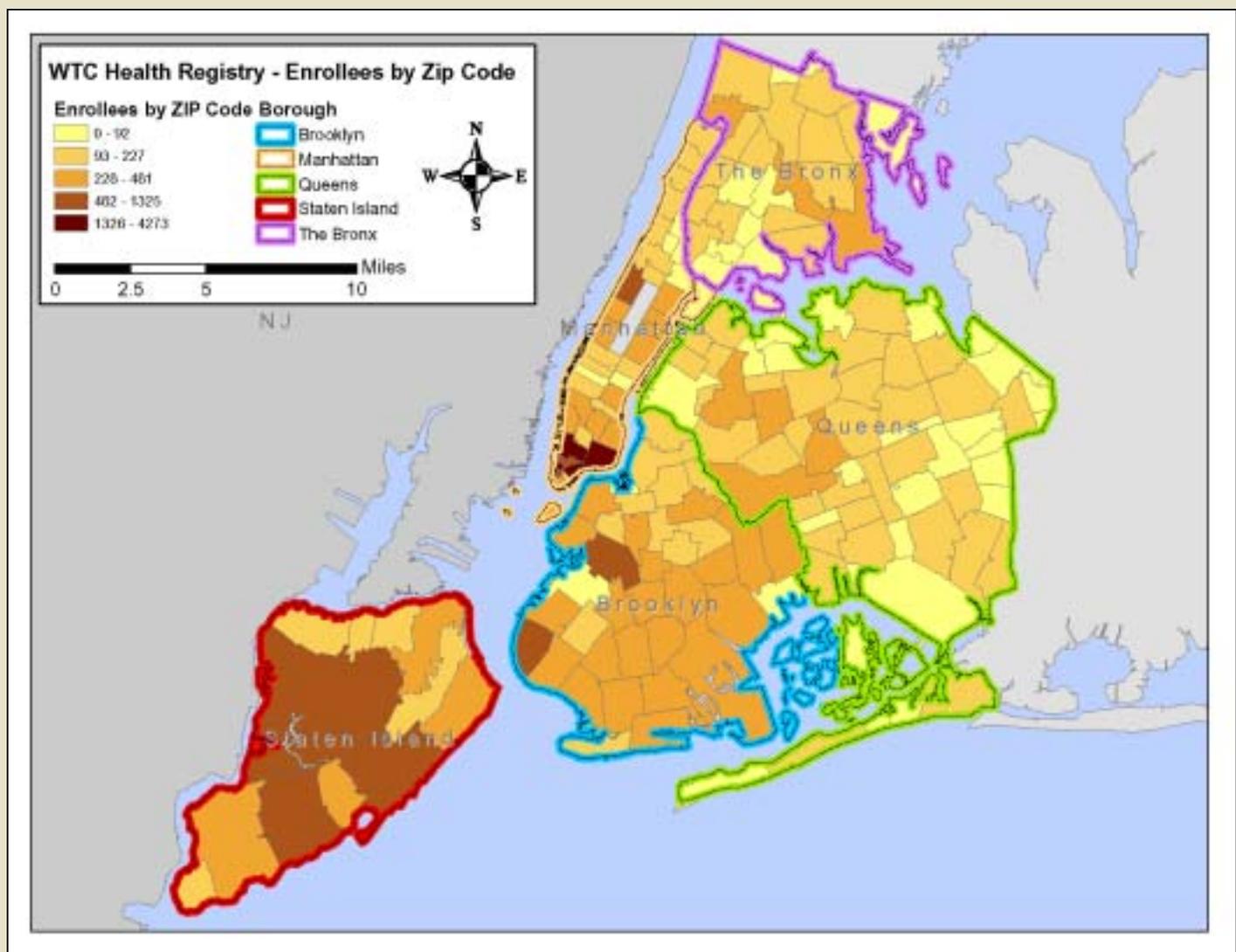
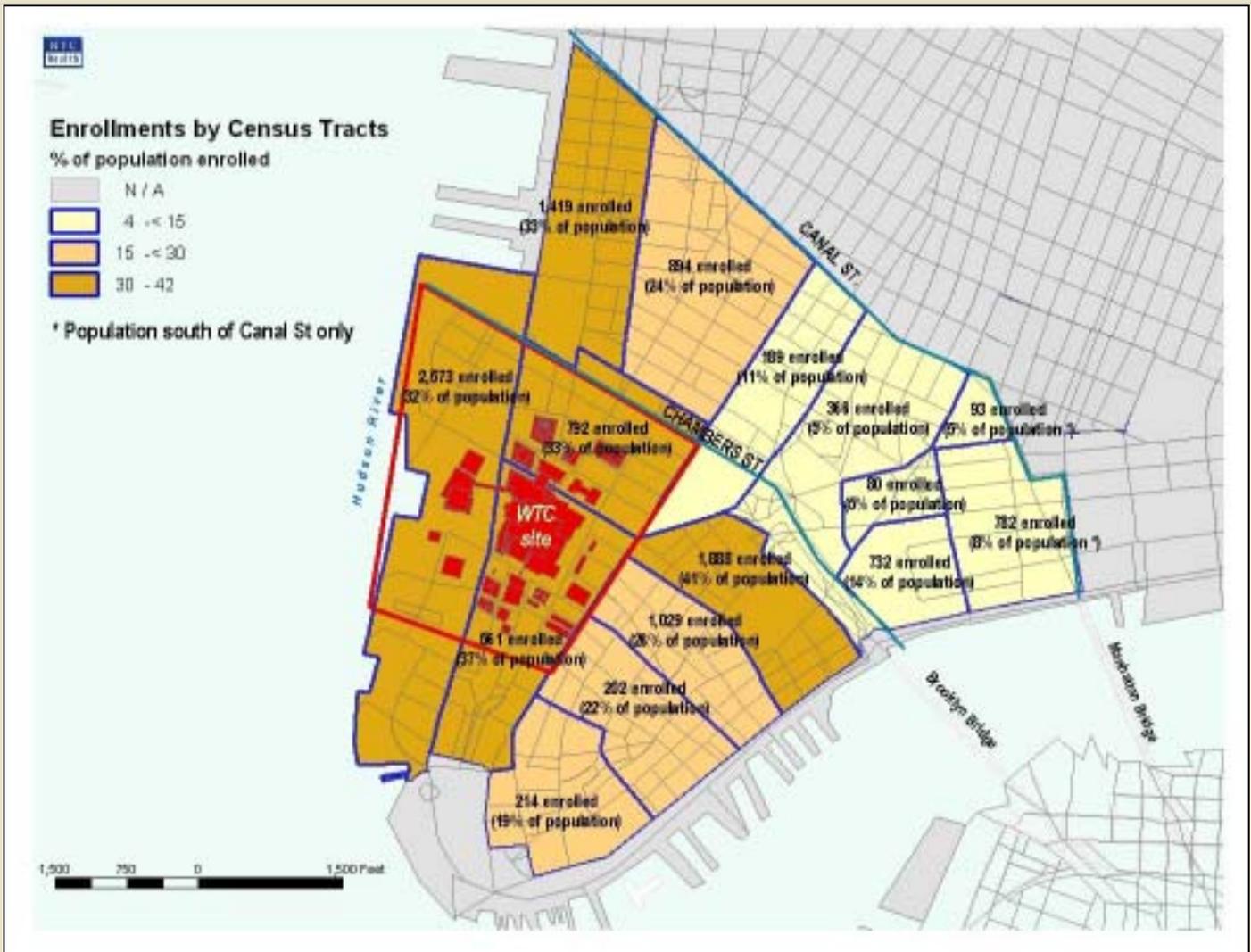


Figure 5 is a map of enrollees living near the WTC on September 11, 2001, with a reported address below Canal Street.

The WTCHR enrolled 14,725 residents who reported living below Canal Street on September 11, 2001, representing 25% of the 58,562 individuals living below Canal Street at the time, according to the 2000 US Census. Coverage is highest among residents who lived closest to the WTC site.

Figure 5. Lower Manhattan Map of Enrollees*



* Among the 14,725 residents with addresses below Canal Street, 11,814 provided complete addresses for mapping.

DEMOGRAPHIC CHARACTERISTICS OF ENROLLEES

Figure 6 provides information on demographic characteristics of 71,607 enrollees in the WTCHR*. Among enrollees, 60% are male and 40% are female. There are a total of 3,123 enrollees who were under the age of 18 on September 11, 2001.

The majority of enrollees report their race as white, non-Hispanic (63%), followed by Hispanic (13%), black, non-Hispanic (12%), and Asian (8%). Most enrollees reported that their highest level of education was some college or more (72%). Among enrollees reporting income, 70% reported a total household income of \$35,000 or more in 2002.

Figure 6. Demographics of Enrollees

	White, non-Hispanic		Black, non-Hispanic		Hispanic		Asian**		Multiracial***		Other****		Total
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	
Total	29,555	15,465	3,569	4,916	5,321	4,306	2,785	2,644	699	723	950	674	71,607*
Age Group on 9/11													
<18	751	714	113	137	302	309	292	307	70	82	24	22	3,123
18-24	1,184	1,186	121	243	343	361	178	178	41	68	49	39	3,991
25-44	15,961	7,019	1,875	2,437	3,085	2,153	1,189	1,054	345	299	466	278	36,161
45-64	10,490	5,623	1,345	1,888	1,434	1,278	745	695	216	239	344	244	24,541
65+	906	729	68	115	96	135	259	274	19	17	27	37	2,682
Unknown	263	194	47	96	61	70	122	136	8	18	40	54	1,109
Education													
< High School	1,369	811	405	270	1,022	690	614	746	86	89	34	22	6,158
HS Diploma/GED	5,717	2,160	953	1,052	1,443	928	324	310	130	77	88	55	13,237
Some college	7,141	2,856	1,074	1,598	1,538	1,331	349	309	198	195	141	93	16,823
College Graduate	9,482	5,474	798	1,369	952	969	860	800	175	231	160	132	21,402
Post-Graduate	5,748	4,105	322	593	318	367	587	421	108	125	103	81	12,878
Unknown	98	59	17	34	48	21	51	58	2	6	424	291	1,109
Household Income													
<\$35,000	2,318	2,558	781	1,476	1,543	1,705	917	1,021	122	175	64	84	12,764
\$35,000 to <\$50,000	2,402	1,854	623	1,206	835	819	227	259	84	146	55	59	8,569
\$50,000 to <\$75,000	5,576	2,810	853	970	1,113	673	389	309	133	136	79	57	13,098
\$75,000 to <\$100,000	6,253	2,115	523	475	772	358	339	218	128	71	72	34	11,358
\$100,000+	10,056	4,113	510	370	684	377	536	360	172	121	80	20	17,399
Unknown	2,950	2,015	279	419	374	374	377	477	60	74	600	420	8,419

* Total equals 71,607 because gender is missing for 2 enrollees.

** Asian includes Native Hawaiians and Pacific Islanders.

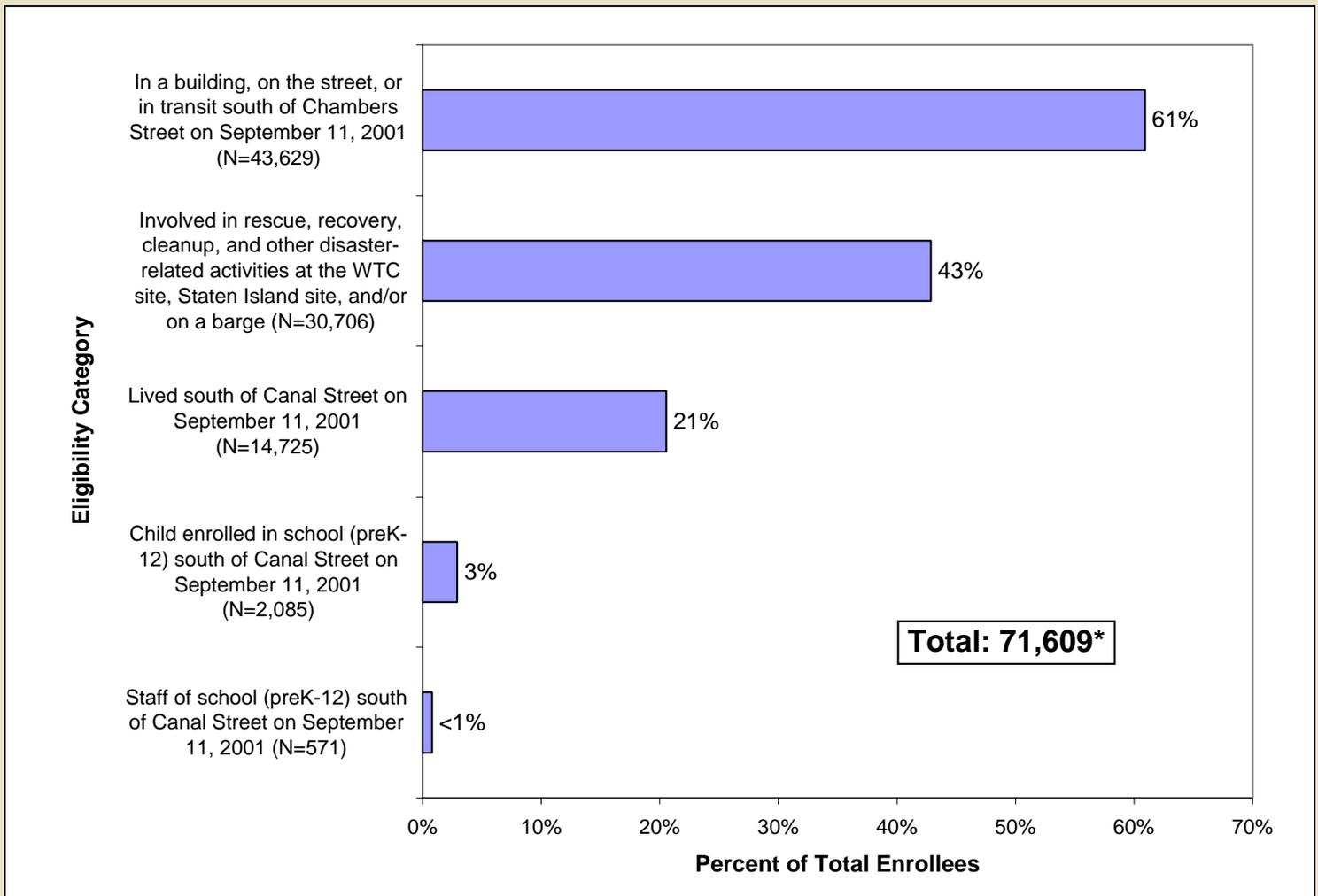
*** Multiracial includes respondents who indicate more than one race.

**** Other includes American Indians, Alaskan Natives, and those who did not report race or ethnicity.

INFORMATION ON EXPOSURE GROUPS BY ELIGIBILITY

Figure 7 shows the distribution of enrollees by eligibility group. The WTCHR includes 43,629 completed interviews from individuals who were in a building, on the street, or in transit south of Chambers Street on September 11, 2001; a total of 30,706 from those involved in rescue, recovery, cleanup or other disaster related activities; 14,725 from those living south of Canal Street on September 11, 2001; 2,085 from students enrolled in pre-K through 12th grade south of Canal Street on September 11, 2001; and 571 from staff of those schools.

Figure 7. Enrollees by Eligibility Groups



*Approximately 25% of enrollees were in more than one exposure category; the sum of the percentages is thus greater than 100%.

Due to the nature of the WTC disaster and related events, approximately 25% of enrollees met the criteria for more than one group (e.g. a rescue worker who also lived south of Canal Street on September 11, 2001). Figure 8 is a table that combines five broad criteria for eligibility into mutually exclusive groups. Each row contains checkmarks that indicate the combination of exposures and the total number of completed interviews for those exposures. Using the third row as an example, 7,640 enrollees indicated they were in a building, on the street, or in transit south of Chambers Street on September 11, 2001 and involved in rescue, recovery, cleanup or other disaster-related activities.

Figure 8. Enrollees by Mutually Exclusive Eligibility Groups

In a building, on street, or in transit south of Chambers Street on 9/11/01	Involved in rescue, recovery, cleanup and other disaster-related activities at the WTC site, Staten Island site, and/or on a barge	Lived south of Canal Street on 9/11/01	Child enrolled in school (preK-12) south of Canal Street on 9/11/01*	Staff of school (preK-12) south of Canal Street on 9/11/01	Number of Completed Interviews	Percent
D					26,327	36.76%
	D				21,739	30.36%
D	D				7,640	10.67%
D		D			6,866	9.59%
		D			5,150	7.19%
D		D	D		960	1.34%
D	D	D			797	1.11%
D			D		642	0.90%
	D	D			434	0.61%
		D	D		351	0.49%
D				D	238	0.33%
			D		132	0.18%
D		D		D	98	0.14%
				D	83	0.12%
		D		D	56	0.08%
D	D			D	50	0.07%
	D			D	33	0.05%
D	D	D		D	<25**	<0.03%
	D	D		D	<25**	<0.03%
43,629	30,706	14,725	2,085	571	71,609***	100.00%

* 40 school students reported they worked as rescue, recovery, or cleanup workers. After in-depth review of these cases it was determined that they did not fit this second criteria. The rescue, recovery, cleanup worker eligibility category was therefore deleted from those files.

** To protect the confidentiality of enrollees, categories with less than 25 enrollees are reported as “<25”.

*** All completed interviews. Totals for “Number of Completed Interviews” are mutually exclusive.



INFORMATION ON KEY ELIGIBILITY SUBGROUPS

This table shows some of the key subgroups represented in the Registry and provides information on the estimated total size of their population. This information is used to determine coverage, or how many people have enrolled out of the total estimated population.

Figure 9. Enrollees by Key Eligibility Subgroups

Key Exposure Group	Completed WTCHR Interviews	Estimated Size of Population	Coverage
Rescue, recovery, cleanup and other disaster-related workers	30,706	60,000 [±]	51%
New York City Fire Department (FDNY), including EMT and EMS *	3,202	14,500	22%
New York City Police Department (NYPD) *	3,767	5,000	75%
New York City Department of Sanitation *	2,122	3,000	71%
Occupants of Damaged and Destroyed Buildings on September 11, 2001**	10,091	35,000 [±]	29%
Occupants of WTC North and South Towers ***	4,242	14,000	30%
Residents living south of Chambers Street on September 11, 2001 ****	7,093	22,000	32%
Children enrolled in school south of Canal Street on September 11, 2001	2,085	14,000	15%
Total	49,975	131,000	38%

* Subgroup of all rescue, recovery, cleanup and other disaster-related workers.

** Damaged and destroyed buildings are from FEMA's WTC Building Performance Study: <http://www.fema.gov/library/wtcstudy.shtm>

*** Subgroup of occupants of damaged and destroyed buildings.

**** Subgroup of all residents living below Canal Street on September 11, 2001.

± This is a provisional estimate of the population. Work is being done to derive the most accurate estimate from as many sources as possible.

SUMMARY

The WTCHR was initiated by the NYC DOHMH and ATSDR to determine the impact on health resulting from the World Trade Center attacks on September 11, 2001. This comprehensive registry includes 71,609 enrollees who, based on the Registry's eligibility criteria, are among the most highly affected and exposed individuals to the disaster. Coverage of particular exposure groups such as tower occupants, uniformed service officers (e.g. FDNY, NYPD, NYC Department of Sanitation), and Lower Manhattan residents is high.

The NYC DOHMH and ATSDR are fully committed to honoring WTCHR enrollees' desire to know more about their health. Over 91% of enrollees consented to receive information about other health studies, and 94% consented to receive general health information. The NYC DOHMH will contact enrollees periodically to conduct WTCHR follow-up interviews, inform them of WTCHR reports and publications, notify enrollees of other WTC-related studies, and send them general health information.

The best way for enrollees to support scientific understanding of the health effects of September 11, 2001 is to remain involved in the WTCHR and to keep their contact information up-to-date. The NYC DOHMH has designed a web-based system at <http://wtcregistry.org> for this purpose.

Now that data collection has concluded, the WTCHR has moved into the analysis phase. Priority areas of analysis include the effects of the WTC disaster on respiratory health and mental health. Data will be analyzed from both the baseline interview and follow-up surveys to distinguish between short term and long term health issues. Another area of concentration is preparing an infrastructure for supporting collaboration with health professionals and researchers, **while protecting individual confidentiality**. Identifying information on enrollees will continue to be protected by the Registry's Federal Certificate of Confidentiality. Finally, it is anticipated that future Data Snapshots will focus on findings from published reports relevant to WTCHR enrollees.

If you would like to contact the NYC DOHMH or the WTCHR, you can do so through the WTCHR website (<http://wtcregistry.org>), the NYCDOH website (<http://www.nyc.gov/html/doh>), or by calling 311, New York City's phone number for government information and non-emergency services.

