



Overview of young Survivors: WTC Environmental Health Center

Joan Reibman, MD

Professor of Medicine and Environmental Medicine, NYU Langone Medical
Center

Medical Director, H+H WTC Environmental Health Center

Goals of the talk

- Brief description of the community of those exposed at a young age in the NYC Disaster Area
- WTC Environmental Health Center: Survivor Center of Excellence in the WTC Health Program
- Our experience with recruitment of those exposed at a young age
- What we know about the population exposed at a young age in the WTC EHC
- Gaps in our knowledge about those exposed at a young age
- Thoughts for recruitment of a cohort of those exposed at a young age

Disclosures

- Founder and Medical Director of the H+H WTC Environmental Health Center
- Pulmonologist
 - Asthma
 - Impact of pollutants on mucosal immune response in the airway
 - Clinical studies in asthma – ALA ACRC

WTC towers sat in the midst of a dense residential and working community with many schools



BMCC

Stuyvesant HS

What is the area of exposure for Survivors?

Red Cross Health Impacts Program – 14th street

NYC Disaster area: used for WTC Health Program (includes Brooklyn)

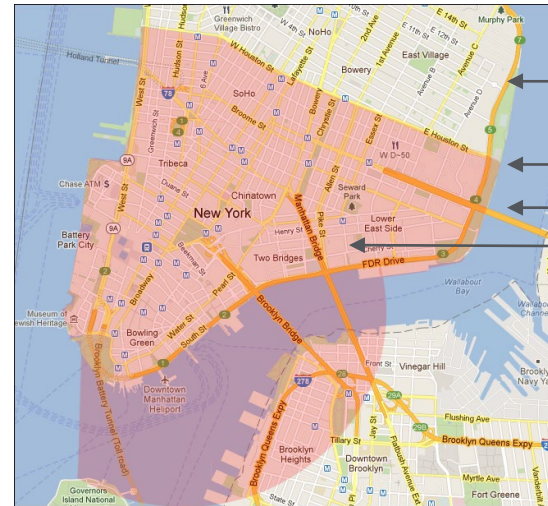
NYC DOH Health Registry – Canal/Chambers St

410,000 exposed south of Chambers St. or residence/school south of Canal (Murphy et al. 2007, Farfel et al. 2008)

300,000 local workers/commuters - ? \leq 21 years old

57,000 residents south of Canal Street (30% assumed to be parents) (Daniels et al. 2022)

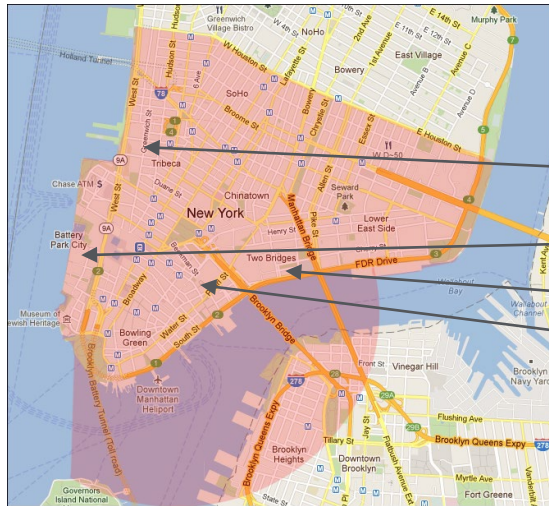
15,000 students/staff south of Canal (Nursery/daycare, elementary, intermediate, HS Not College. (Murphy et al. 2007)



Red Cross Health Impacts program
WTC Health Program (Houston St)
WTC Health Registry (Canal St)
(Chambers St)

Diverse residential housing

- West side: upper and middle income housing – evacuated
- East side: – middle and lower income including public housing – not evacuated, clean up offered 1 year after event



Independence Plaza

Battery Park City

Smith Houses

Southbridge

Battery Park City



Chinatown



Alfred E Smith Houses

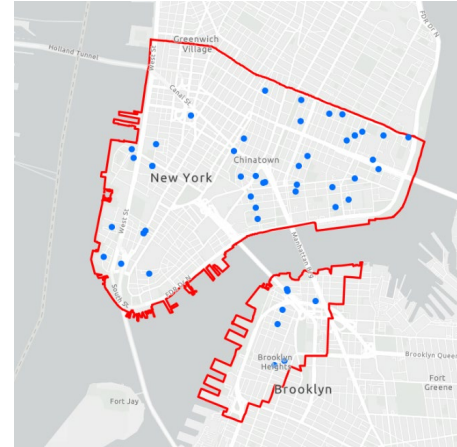


Southbridge Towers



Diverse student population

- Over 50 schools in the WTC Health Program Disaster area
- Children of local residents were not yet attending school (non-student residents)
- Children of local residents attended local schools (student residents)
- Children of residents attended distant schools
- Students of schools in the area were from distant residences (non-resident students)



Geolocations of elementary, middle, and high schools in the disaster on 9/11 are represented in blue (Courtesy of Rebecca Florsheim).

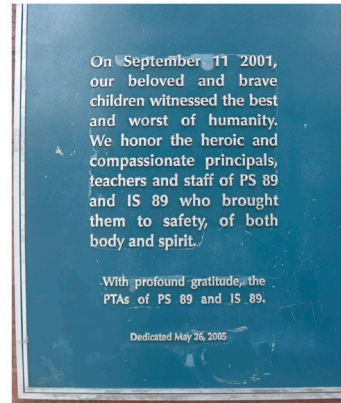
Elementary/middle schools

Some schools inside the WTC Disaster area

- P.S. 234 Greenwich St.
- P.S. 89 201 Warren St
- IS 289 Warren St
- P.S. 150 28-42 Trinity Place
- P.S. 1 Alfred E Smith School Henry Street
- P.S. 124 on Division St (Chinatown)
- M.S. 131 Hester St (Sun Yat Sen)

Outside of the WTC Disaster area

- P.S. 41
- P.S. 3



A plaque on the PS 89 school building. (Photo by Lee Williams.)



P.S. 234 windows faced the Twin Towers

M.S. 131



Secondary Schools

- Stuyvesant High School (West St)
- Murry Bergtraum High School (near Brooklyn Bridge)
Evacuated by police and students told to run
- High School of Economics and Finance (100 Trinity Place, just south of the towers)
- High School of Leadership and Public Services (90 Trinity Place)
Evacuated to Battery Park, Staten Island Ferry across the Hudson River to Curtis High School on Staten Island. Bused home later in the evening



Definition of those exposed at a young age?

- UN/WHO
 - Children < 18
 - Young People
 - Adolescents 10-19
 - Youth 15 – 24
- ILO, Commonwealth (20016) youth as a transition stage from childhood to adulthood – 10 or 15 – 30
- NYC DOH WTC Health Registry (Daniels et al. 20220) < 18
- **CDC-NIOSH RFI - \leq age 21**

Complexity of those exposed at a young age (EYA)

- Age of exposure
- Type/severity of exposures
- Race/ethnicity
- Socioeconomics
- School level/type
- Baseline health

What is the WTC EHC experience with those exposed at a young age?

Creation of the WTC Environmental Health Center

- Study of respiratory health of local residents started in 2001 - collaboration with NYS DOH and community members (Reibman et al. 2005, Lin et al. 2005)
- Bellevue Hospital – 2002 community collaborative treatment program
- WTC Environmental Health Center
 - 2005 American Red Cross Liberty Disaster Relief Fund
 - 2006 funding from City of New York
 - 2008 federal funding (CDC-NIOSH)
 - Contract 2011 - as the Survivor Center of Excellence under the **WTC Health Program** - James Zadroga 9/11 Health and Compensation Act

WTC Environmental Health Center – Center of Excellence for Survivors (community members)

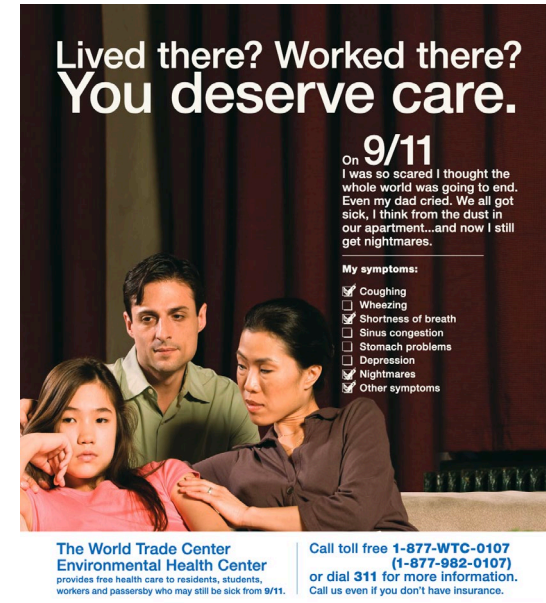
- Very significant differences compared to the Responder Programs/WTC Health Registry programs
 1. Began as a community collaborative-multidisciplinary program with a focus on treatment as well as surveillance of community members with WTC –related conditions
 2. Self-referred population for those with symptoms– not a sampled population of those with and without symptoms
 3. Enrollment in the WTC EHC **requires** the presence of a “certified” condition, not a screening program for those without illness
 4. The WTC Health Program does NOT provide “no cost” treatment to Survivors, but is the final payor after coordination of benefits to support no out of pocket costs for certified conditions. Patients do not get paid work time off for monitoring visits.

Services available for those exposed at a young age in the WTC EHC from the start

- Pediatric services incorporated once funding from NY City was obtained
 - General Pediatrician(s)
 - Pediatric Pulmonologist
 - Specialist in Developmental Medicine
 - Environmental Pediatrician
 - Child Psychologist(s)

Outreach for pediatric population in the WTC EHC

- Meetings with local pediatricians
- PTA meetings
- Tenant meetings
- Local meetings/local fairs and events
- Community collaborators
- Advertisements
 - Radio, TV, local newspapers, subway
 - “Lived there, worked there, you deserve care”



Lived there? Worked there?
You deserve care.

On **9/11**
I was so scared I thought the whole world was going to end. Even my dad cried. We all got sick, I think from the dust in our apartment...and now I still get nightmares.

My symptoms:

- Coughing
- Wheezing
- Shortness of breath
- Sinus congestion
- Stomach problems
- Depression
- Nightmares
- Other symptoms

The World Trade Center Environmental Health Center
provides free health care to residents, students, workers and passersby who may still be sick from 9/11.

Call toll free **1-877-WTC-0107**
(1-877-982-0107)
or dial **311** for more information.
Call us even if you don't have insurance.

Response

- Despite our outreach and resources, we had minimal enrollment in the program

- Potential reasons for low enrollment:

Didn't know about program

Children not sick

Children had care covered by insurance – less need

Pediatricians felt that the illnesses were normal/common childhood illnesses (asthma)

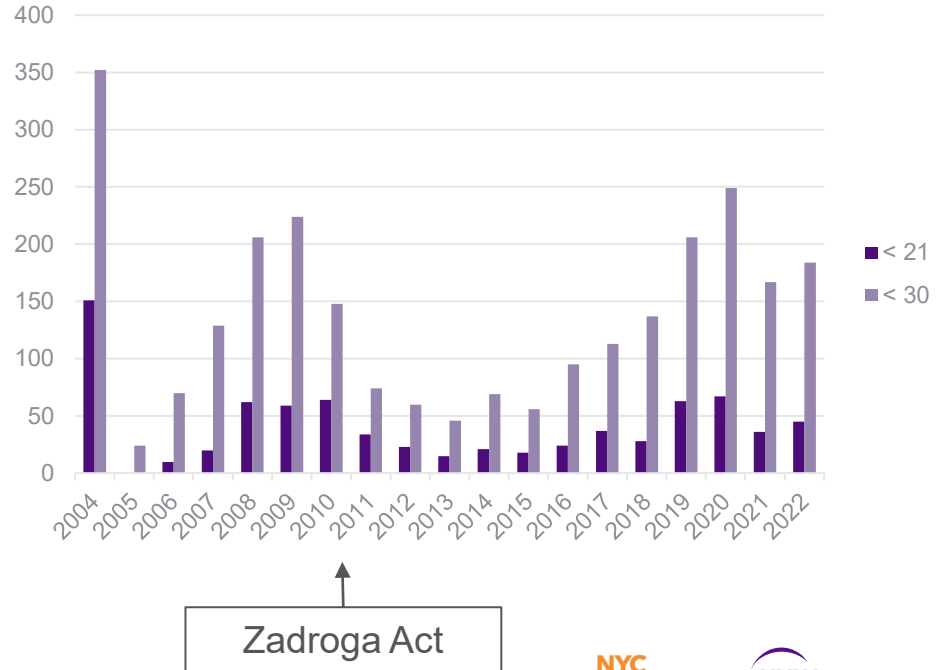
Fear/guilt on part of parents

Early findings in WTC EHC pediatric patients

- Trasande et al. 2013 reported on 148 patients with a focus on pulmonary and cardiometabolic findings in the WTC EHC
- Led to funding for further study in ~ 400 children and controls identified in the WTC Health Registry
- Elevated serum dioxin, furan, perfluoroalkyls substances (PFAS) in WTC children compared to controls. These associations associated with lipid and cardiovascular outcomes
 - Koshy et al. 2017
 - Trasande et al. 2018
 - Kahn et al. 2018
 - Tyre et al. 2018
 - Gaylord et al. 2019

Enrollment in the WTC EHC of those exposed at a young age

- Currently no individuals < 20 in the program-
- Parental consent (influence) no longer required
- Waves of enrollment for initial visits in the WTC EHC over time
- < 21 and ≤ 30 show similar patterns



Demographic characteristics of children and youth in the WTC EHC

- 15,145 patients with initial visits in the WTC EHC as of 12/2022
- 2292 (15%) patients ≤ 30 on 9/11/2001
- 638 (4%) patients < 21 on 9/11/2001
- Equal distribution of men and women

Age on 9/11/2001		<21	≤ 30
n		580*	1968
Sex, n (%)			
	F	301 (52)	999 (51)
	M	279 (48)	969 (49)
Race/ethnicity, n (%)			
	White	192 (45)	724 (39)
	Hispanic	95 (22)	588 (31)
	Asian	93 (22)	300 (16)
	Black/African American	48 (11)	269 (14)
	Native American	1 (0.2)	1 (0.1)
BMI, median [IQR]		23 [20, 27]	26 [22, 30]

*data missing for some patients

Age distribution of those ≤ 30 on 9/11 in the WTC EHC

- Most of those exposed at a young age who were enrolled in the WTC EHC were in the older group

Age on 9/11	≤ 30
Median age (IQR)	24.0 [19, 27]
5 year span, n (%)	
<5	95 (5)
(5, 10]	88 (5)
(10, 15]	117 (6)
(15, 20]	280 (14)
(20, 25]	525 (27)
(25, 30]	863 (44)

Exposure characteristics of those exposed at a young age in the WTC EHC

- Many, but less than 50% reported having been in the dust cloud on 9/11/2001
- Most were residents/students in the < 21 group – more local workers in the < 30 group
- Most were never smokers

Age on 9/11/2001		<21	≤ 30
n		449	1968
Dust Cloud(%)	No	258 (58)	1034 (53)
	Yes	188 (42)	919 (47)
Exposure category, n (%)			
	Local Worker	41 (9)	805 (42)
	Resident	226 (51)	568 (29)
	Student	138 (31)	262 (14)
	Clean-up worker	5 (1)	166 (9)
	Other	34 (8)	139 (7)
Smoking status(%)			
	Never (≤1 p-y)	397 (90)	1590 (82)
	Former smoker	18 (4)	200 (10)
	Current smoker	24 (6)	139 (7)

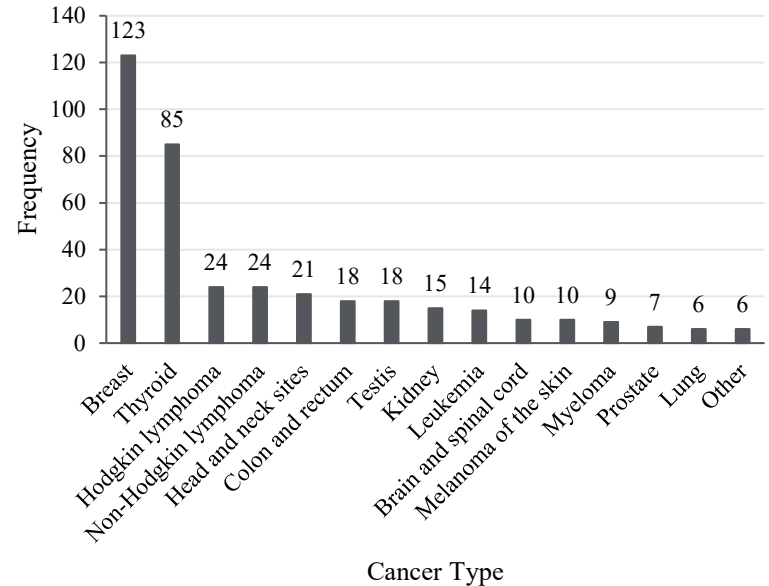
Certifications of those with WTC exposure at a young age

- Most physical certifications for obstructive airway disease (OAD) and upper airway in both age cut-offs
- Increasing % of cancer certifications in ≤ 30 group
- Fewer mental health certifications for PTSD than we see in the adult group

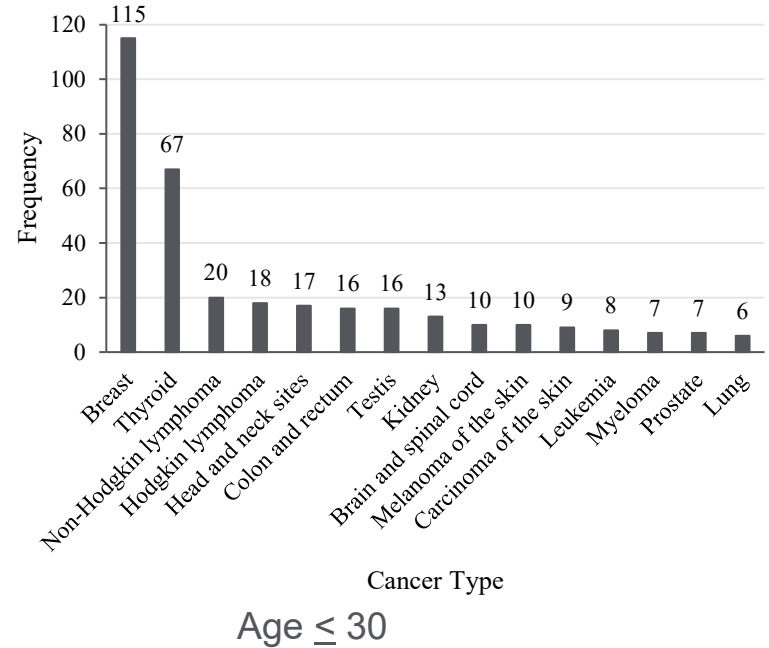
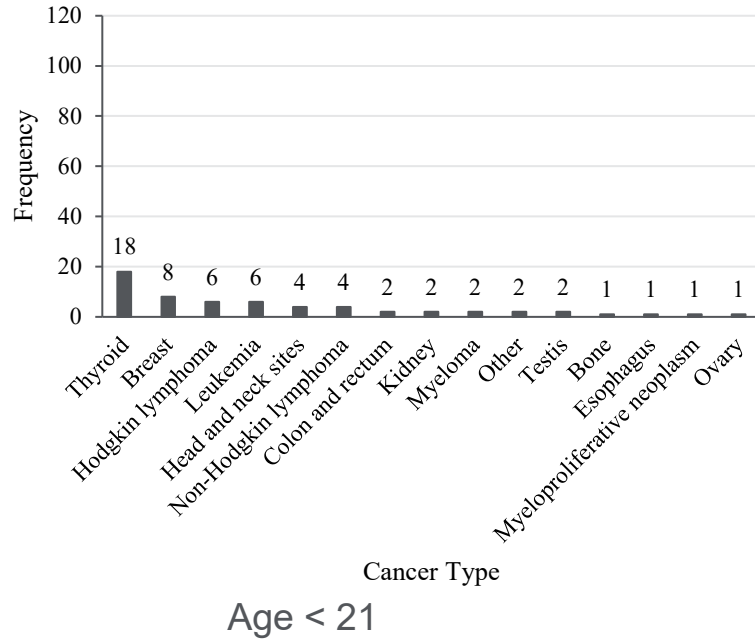
Age on 9/11		< 21	≤ 30
Physical certifications, number of certifications (% of total certifications)			
	OAD	205 (30)	912 (19)
	Upper airway	210 (28)	1140 (24)
	GERD	65 (9)	660 (14)
	ILD	9 (1)	9 (0.10)
	Sarcoidosis	1 (0.1)	43 (0.9)
	Cancer	56 (7)	794 (17)
Mental health number of certifications (% of total certifications)			
	PTSD	75 (10)	442 (9)
	Anxiety	60 (8)	225 (5)
	Depression	43 (6)	243 (5)
	Adjustment disorder	27 (4)	198 (4)
	Substance Abuse	7 (.9)	63 (1)

Top 15 Cancer certifications* in those exposed at a young age (as of 12/2022)

- Breast cancer most common cancer in those ≤ 30 , followed by thyroid, Hodgkin's lymphoma and non-Hodgkin's lymphoma
- Rare cancers include breast cancer in men, mesothelioma
- Florsheim et al. 2022

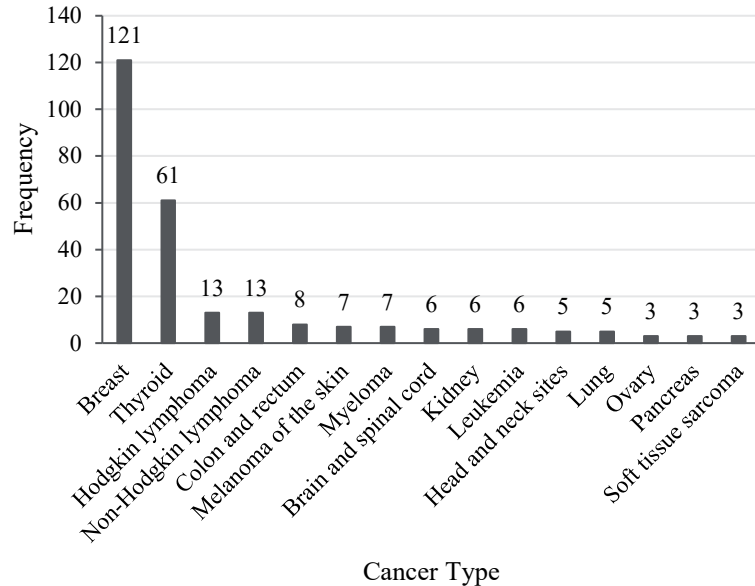


Top 15 cancer certifications* in those exposed at < 21 or ≤ 30

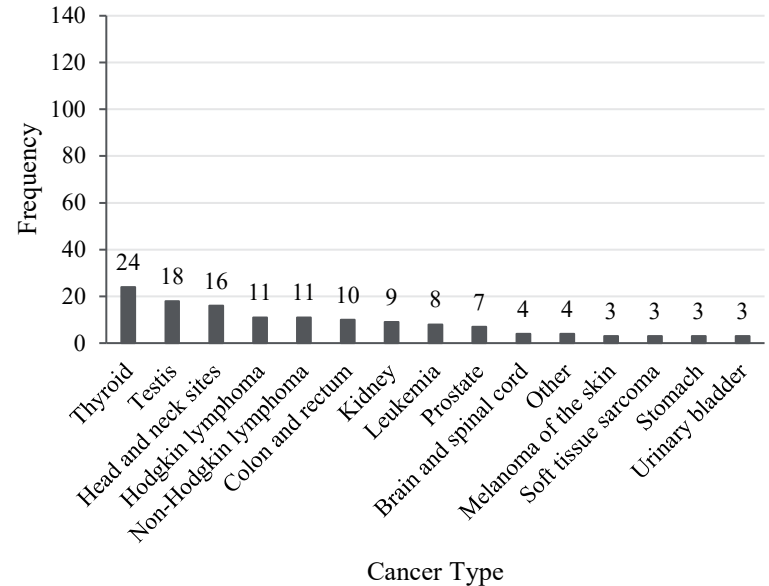


*non melanoma skin cancers excluded

Differences in cancer certifications in those exposed at ≤ 30 by sex distribution*



Women



Men

*non melanoma skin cancers excluded

Knowledge gaps about WTC exposure health effects in those exposed at a young age

- Mental health – how does their experience of a traumatic event incorporate itself into personality and behavior
- Cognitive/developmental health
- Reproductive health/endocrine disruption
- Cardiovascular
- Cancer- types and behaviors

Approaches to examining knowledge gaps

- Is the sample size of study (cohort) appropriate for the outcome of interest? Each of these outcomes may require different size population for study
- Timing of exposure in the lifespan may influence
- race/ethnicity and other demographic characteristics
- Vulnerable populations
- Control population is critical

Our experience in the WTC EHC and recommendations for recruitment

- Difficult population to recruit by standard means
- Age group now focused on family/job/education. May not be interested in “looking back.”
- Need new recruitment techniques – social media, digital studies, remote consents
- Need recruitment/motivation incentives
- One size will not fit all
 - Health benefits (won’t affect whole group)
 - Altruistic/social consciousness - environmental studies
 - Social networking (jobs/economic)
 - Social connectiveness
 - Fear –may/may not be motivating factor

Thank you

Funding

- CDC/NIOSH contracts 200-2017-93327 and 200-2017-93427 for the Center of Excellence at WTC EHC Clinical and Data Center
- NIH/NCI grant 5P30CA016087
- NIH/NCI grant 1P50CA225450

Thanks

H+H/NYU

Yuyan Wang MS

Yongzhao Shao PhD

Nedim Durmus MD

Alan Arslan MD

Qiao Zhang MS

Yian Zhang PhD

Rebecca Florsheim

Sultan Pehlivan MD

Stephanie Tuminello MS

Mengling Liu PhS

Maria Elena Fernandez Beros PhD

Guy Frazier

Michele Hyde

Sharon Abbott

Ramazan Alptekin MD

Muhammed Yilmaz MD

Sefa Keserci MD

Community organizations
WTC EHC Steering Committee

Addendum – Community based participatory research

Why perform community based participatory research

- Goal is to achieve Health equity
- Definition of health equity:
 - CDC: State in which everyone has a fair and just opportunity to attain their highest level of health.
 - WHO: Equity is the absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality (e.g. sex, gender, ethnicity, disability, or sexual orientation).
- Attaining health equity requires the inclusion of affected stake-holders – appropriate community

Community based participatory research - CBPR

- Concept around for > 25 years
- Enormous literature on CBPR
- <https://www.youtube.com/watch?v=RD2EAI0sHD0>

What is community based-participatory research

- A collaborative approach that equitably involves all partners in the research process and recognizes the unique strengths that each brings. It begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities (Kellogg foundation)
- Active involvement of community members, organizational representatives, and researchers in all aspects of the research process. Partners contribute their expertise to enhance understanding of a given phenomenon and to integrate the knowledge gained with action to benefit the community involved. (Isreal et al. Annual rev of Public Health 1998)

Definition of Community-based participatory research

- *Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.*
- CBPR involves:
- Co-learning and reciprocal transfer of expertise, by all research partners, with particular emphasis on the issues that can be studied with CBPR methods.
- Shared decision making power.
- Mutual ownership of the processes and products of the research enterprise

Principles of CBPR

- 1) acknowledging communities as "unities of identity"
- 2) build on existing community strengths and resources
- 3) facilitate partnerships that are equitable, collaborative, empowering, and address social inequalities,
- 4) commit to co-learning and capacity building
- 5) balance knowledge generation and intervention to ensure mutual benefits for partners,
- 6) focus on local issues of public concern,
- 7) utilize a cyclical and repeatable process,
- 8) deliver results and knowledge to all partners, and
- 9) establish sustainable, long-term partnerships with communities.

(Isreal et al. Annual rev of Public Health 1998)

James Zadroga 9/11 Health and Compensation Act and the WTC Health Program is a result of community advocacy/CBPR

- WTC Health Program developed from of community-based advocacy
- Responders – advocacy of unions, local politicians and occupational clinics in academic centers working together to create a program to fit needs for surveillance and eventually treatment

WTC Survivor programs

- Survivor Centers of Excellence (initiated with the WTC Environmental Health Center)- advocacy of numerous ad hoc organizations and academic/public hospital system to identify adverse health effects and create a program for treatment and surveillance

Community organizations involved in the creation of the WTC Survivor program

- (incomplete list):
 - 9/11 Environmental Action
 - Beyond Ground Zero Network – coalition of organizations
 - Asian American Legal Defense and Education Fund
 - National Mobilization against Sweatshops
 - Chinese Staff and Worker Association
 - Commission on the Public's Health System
 - Urban Jstic Center's Community Development Project
 - Local community Boards (CB1, CB3)
 - Tenant's organizations

WTC health programs epitomize community-based collaborations

- WTC Health programs epitomize community based collaborations
- Ongoing community participatory project (steering committees)
- Funding for the development of a young person's cohort is the result of years of community advocacy
- Successful development of a young person's cohort will require continued community involvement

Challenges in using CBPR for the young person's cohort

Who is the community that needs to be involved

- Not one community
 - Diverse age, race/ethnicity, education, socioeconomic class
 - Diverse cultures
 - Geographically diverse

How to motivate the community to become involved?

- Initial motivation was fear – fear of illness
- What will motivate this new community?

Additional questions to address for CBPR for the youth cohort

- How will these relationships be maintained and sustained?
- How much involvement is wanted by this community?
- Which components of the research will communities want to be involved in (study question, study design, data analysis, data presentation)?
- Desire for involvement may change as individual community member's lives change
- How is the relationship modified as information becomes available and needs change?
- How to balance rigour with voice/representation (example NYC DOHMH).
- How do you reimburse community members for time and effort for involvement in CBPR?

CBPR and young people's cohort

- CBPR will be necessary for construction of a successful young people's cohort
- Input can be used to further understand the heterogeneity of the cohort, tools to recruit a cohort, and concerns of the heterogeneous young people community
- Many questions/challenges associated with a CBPR project will need to be addressed
- Approaches/questions, and methods to address these questions may change over time
- The continued involvement and motivation and support for the involvement of various “community” members will promote a successful formation of a cohort.

Thank you