

**Older Adults' Perceptions of Emergency Preparedness Expectations and  
Recommendations for Patients and Families**

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## **Abstract**

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Hurricanes, floods, and their impact on health outcomes have received increased attention over the years. The impact of hurricanes and subsequent flooding on chronic disease management, health care utilization, and mortality has been a major theme of such health research, with additional focus on older adults, who are most often adversely affected. Health care providers have developed robust expectations and recommendations of how community-dwelling patients and their families or informal caregivers can prepare themselves and remain resilient in the face of emergencies, but it is unclear what patients and caregivers understand about those expectations and whether patients and caregivers perceive them as applicable to their own situations. At the same time, certain communities have geographic and social vulnerability factors that make the community inherently less resilient, or able to recover from an emergency like a hurricane. This study is a mixed methods analysis of a) the extent to which patients and caregivers in socially or geographically vulnerable communities are prepared for emergencies, and b) their perceptions of health care providers' recommendations and expectations regarding patient and family member/caregiver emergency preparedness.

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## **Chapter 1. Introduction**

The historic and catastrophic hurricane season of 2017 (Centers for Disease Control and Prevention, 2017), coupled with the five-year anniversary of Superstorm Sandy in New York, has renewed interest in the health of communities in advance of, and in response to, extreme weather events such as hurricanes (Dhillon, 2017). Socially and geographically vulnerable communities like East Harlem, Coney Island, and the Rockaways in New York City, which suffered severe and long-lasting impacts from Superstorm Sandy, house many older adults with significantly worse rates of chronic disease than the general population. Older adults in these communities are therefore at greater risk for adverse health outcomes should another hurricane or flood emergency strike these areas.

Current health status and health decisions are known indicators of emergency planning and evacuation decision making. After Hurricane Katrina, researchers on disaster planning and risk communication in vulnerable communities found that relationships with elders and “obligations to the elderly” were negative indicators for likelihood to evacuate. Evacuation decisions driven by these relationship and obligational factors were described as chain reactions that influenced the decisions of many other people in a community (Eisenman, et al. 2007).

Meanwhile, during emergency events, health system professionals generally expect community-dwelling patients and families to plan and implement their own emergency procedures, separate from any formal health system preparedness measures undertaken by institutional health care settings, or primary care (Toner et al., 2017). What is unclear is whether older adults are aware of this expectation, and whether they consider management of their chronic condition an integral part of their emergency preparedness plans.

Despite significant research into the possible connections between chronic conditions and emergency preparedness, over many years, focused on different locations, and in response to different disasters around the United States, researchers arrive at similar conclusions, exemplified by this comment from a 2005 editorial from *Preventing Chronic Disease*, published, shortly after Hurricane Katrina:

*“Unfortunately, the problems of vulnerable populations who are at risk for adverse health outcomes when routine health care services are disrupted remain inadequately studied or addressed.”* (Mensah, et al. 2005)

This study sought to identify attitudes and perceptions of emergency preparedness steps for chronically-ill, community dwelling older adults. To evaluate general emergency preparedness, the researcher fielded a short questionnaire adapted from a study by Ko, Strine, and Allweiss (2014), of the relationship of general emergency preparedness to chronic disease diagnosis using the Behavioral Risk Factor Surveillance Survey, an annual survey of health-related risk behaviors, chronic conditions, and access to health services (CDC, 2017). To elicit attitudes and perceptions of chronic disease management in emergency preparedness planning, the researcher fielded focus groups with residents of demographically divergent communities in New York City, using a moderated discussion guide composed of questions to elicit the older adults’ perceptions of health care providers’ recommendations and expectations of patients’ and families/caregivers’ emergency preparedness behaviors.

### **Research Question**

To what extent are older adults with chronic conditions or their caregivers prepared for emergencies, and what are the attitudes and perceptions of such individual about the health system’s recommendations and expectations for chronic disease management and emergency preparedness of patients and their families?

## **Chapter 2: Literature Review**

### **Introduction**

Chapter 2 presents the rationale behind this study, exploring connections between community resilience due to social and/or geographic vulnerability, health impacts of emergency events, such as storms and floods, special considerations for older adults in emergencies, research and data trends vis a vis older adults and emergency preparedness, and systems for predicting emergency preparedness needs of vulnerable populations.

Both patients and their caregivers have been shown to be unprepared or underprepared for dealing with such emergencies and the challenging recovery period afterward (Al rousan, 2014). Just as formal health institutions (like hospitals and nursing homes) need to prepare for surges in patient volume and demand for care during and after emergencies, health care providers recommend that community dwelling patients and caregivers should be prepared for the risks that emergencies will pose to themselves and their loved ones, and plan for their needs during the recovery period (Toner, et al., 2017; Williams, 2017). This study attempts to better understand and compare the extent of patients' and caregivers' preparedness and elicit their perspectives on preparation recommendations made to them by health care providers.

### **Health Disparities, Demographics, and Social Vulnerability**

New York City's neighborhoods vary significantly based on the age distribution, the chronic disease burden, and social vulnerability. For example, residents of communities like East Harlem, where 13% of residents are age 65 or older, are at significantly more risk for stroke due to hypertension than their neighbors. Hospitalization rates due to stroke in East Harlem were 401 per 100,000 in 2015, a much higher rate than the rest of Manhattan (New York county), at 319 per 100,000, and almost triple the rate of the more economically advantaged communities of Greenwich Village and SoHo, also in Manhattan, at 140 per 100,000 (King, 2015). In addition

to the stark contrast on chronic disease indicators like hypertension, East Harlem has much shorter life expectancy than other parts of New York City, with an average of 76 years, more than 8 years less than Greenwich Village and SoHo residents. (King, 2015). These health disparities contribute to the combined social vulnerability of communities that make them less resilient, or able to recover from emergencies.

#### *Social Vulnerability and Storm Vulnerability*

Social vulnerability is an index measure used to evaluate a community's resilience to external stress, like disasters (natural or man-made) and outbreaks or epidemics. Increased community resilience is correlated with reduced social vulnerability and suggests decreased potential for human suffering and harm (CDC, 2014). The critical indicators of social vulnerability are all factors considered to be social determinants of health: socioeconomic, housing and transportation, household composition, and race/ethnicity/language spoken. A community's social vulnerability is influenced by its storm vulnerability, flood risk and the potential health outcomes of those events. Taken together with health disparities and geographic vulnerability, these factors may compound risks to certain populations, due to hazard exposures, evacuation or inadequate housing, power and utility outages or shortages, and secondary hazards like contaminated water and homes, among others (Lane, et al. 2013).

Nearly half of all American adults reported one or more chronic disease as of the year 2012, and a quarter of all Americans reported two-or-more chronic conditions (Centers for Disease Control and Prevention, 2017). Among older adults, the number of Americans with multiple chronic conditions jumps to seventy-five percent, or 3 of every 4 people. (Centers for Disease Control and Prevention, 2015).

For example, when Superstorm Sandy made landfall, the tidal surge caused widespread flooding and damage to the electrical grid. Many New York City communities endured weeks of



blackout conditions. The power outages affected thousands of residents around New York City in high rise apartment buildings, such as New York City Housing Authority (NYCHA) Projects. Many residents were without heat, electricity, and running water for months (Goldman, L., 2014; New York City Department of City Planning, 2017). A lack of electrical power can be devastating for the management of a chronic condition. For example, a patient with diabetes who is insulin dependent needs ongoing access to refrigeration to store medication. Prolonged power outages are dangerous for the safe management of a chronic condition that affects up to 11% of all New York City adults. Of the 11% of New Yorkers who report having diabetes, nearly 28% are age 65 and older (New York City Department of Health and Mental Hygiene, 2016). At the same time, some types of housing, such as multi-unit dwellings, are negative indicators for emergency preparedness (Murti, et al., 2013), and are the most common type of housing structure in urban public housing systems like NYCHA.

### **Health Impacts from Floods and Storm Events**

The four major storms of the United States' 2017 hurricane season (Hurricanes Harvey, Irma, Nate, and Maria) are likely to have continuing catastrophic impacts on the health systems of the affected areas and, by extension, the health of individuals in the affected communities. Research regarding the impact of hurricane and flood events on health is plentiful and increasingly available given the increasing frequency of hurricanes and other extreme weather events affecting coastal communities. Because of the widespread and long-lasting impacts of flooding during Hurricanes Rita and Katrina in the early 2000s, and Superstorm Sandy's tidal surge in 2012, there have been several significant contributions to literature on health systems after storms in general and injury and impacts of on individuals. In a systematic review of human health after flood and storm disasters, Saulnier, Brolin Ribacke, and von Schreeb (2017) described differences between post-flood and post-storm presenting conditions, and identified

diabetes and diabetes related complications, cardiovascular disease, and nutrition related outcomes as most prevalent of the non-communicable diseases exacerbated whether directly by storm or flood exposures or by what was described as “worsened management of chronic illness” due to the storms (p.576).

Alderman, et al.’s (2012) review of floods and human health reiterated the CDC’s advice that disasters, like exposures to storms or floods, can worsen chronic disease and increase vulnerability for poor outcomes. Saulnier, et al.’s (2017) findings regarding the worsened management of conditions in Alderman’s earlier synthesis of the literature, where continuity of care was threatened most by a person’s inability self-manage their condition due to the living conditions brought on by a storm or flood’s impact (Alderman, 2012).

#### *Special Considerations for Older Adults*

Older adults, being more socially vulnerable, and being in generally worse health, were both disproportionately and adversely affected by hurricanes, floods and similar emergency events in recent years. In hurricanes Rita and Katrina, and in Superstorm Sandy, most of the victims were older adults. During Hurricanes Rita and Katrina, 200,000 people with chronic disease needs had to be evacuated, and due to the duration of the evacuation, nearly all lacked access to medication to self-manage their conditions effectively (Aldrich, 2008). Also, during Katrina, 75% of those who died were over 60 years old (Al rousan, 2014), despite older adults making up only 15% of the total population of New Orleans (Aldrich, 2008). In New York City during Sandy, 31 of the 44 deaths reported were individuals 55 and over (Goldman, 2014). Aldrich and Benson’s (2008) research on the 1995 Midwestern heatwave also pointed to the disproportionate effect of extreme weather on older adults—in Chicago, where 465 people died from heat related conditions, the median age of victims was 75.

Clearly there are indicators for risk of poor outcomes for older adults with chronic conditions during hurricanes and storms, but less clear is the ability of older adults to prepare for such events. Much of the research on proactive emergency preparedness regarding management of chronic disease in emergencies is based in health care institutions and clinical providers as the locus of care.

### **Older Adults' Preparedness for Emergencies: Trends and Data Sources**

In an overview on the Federal Emergency Management Agency (FEMA) website, the division of Individual and Community Preparedness has asserted that “fifty-four percent of U.S. population does not believe their community will experience a natural disaster” (U.S. Department of Homeland Security, 2017, n.d.). These numbers are not broken down by FEMA by age group, but many researchers have attempted to get at the level of emergency preparedness by age, using data collected from either the BRFSS optional general preparedness module, or the Health and Retirement Study to get at an understanding of older adults' emergency preparedness levels (McGuire, 2007; Ablah, 2009; Bethel, 2013; Strine, 2013; Al rousan, 2014).

There are several drawbacks to using the BRFSS data. The survey is conducted by telephone, and older data sets going back to 2006 through 2010 were limited to landline phones only, as a result, individuals who don't have their own phones, and “cord-cutters” – people who have cellular phones only – are left out of the respondent pool. BRFSS survey fielding has only implemented inclusion of mobile phones to the respondent pool since the 2012 fielding (Centers for Disease Control and Prevention, 2014). Furthermore, the general preparedness module is optional, so there are some years when no states field those questions. The last year any state fielded the general preparedness module was 2012, with only Alabama and Montana reporting (Centers for Disease Control and Prevention, 2014). Lastly, because BRFSS data are self-reported rather than observed, recall bias may affect validity of responses.

The analysis of the BRFSS data still identified important trends to help better understand predictors of preparedness and a person's likelihood to evacuate during an emergency that could be useful in conducting new research. Ablah and Kelley (2009) found that inability to afford medical care in the past year was a strong predictor for being unprepared for an emergency. Their research defined "prepared" as responding positively to 5 of 6 questions regarding objective emergency preparedness (e.g. do you have a flashlight and batteries). Ablah and Kelley also found females and Hispanics to be less likely to be prepared.

Like Ablah and Kelley (2009), Bethel, et al.'s (2013) analysis of BRFSS data across 8 states discovered race/ethnicity disparities in emergency preparedness. Specifically, Bethel et al found that racial/ethnic minorities were less likely to have adequate stockpiles of medication, and among Spanish speaking Hispanic households, less likely to have evacuation plans.

McGuire, et al, utilized BRFSS to study the extent to which older adults were reliant on others for daily assistance and determine what implications there would be for evacuations. Their research suggests that BRFSS data could be used as reasonable baseline data for mapping emergency response during events like hurricanes by helping responders understand localized community needs (McGuire, 2007).

Strine, et al, (2013) used BRFSS data to cross-tabulate emergency preparedness with quality of life measures, suggesting impaired quality of life as a proxy measure for social vulnerability that could be used to develop registries of individuals who will need assistance with emergency preparedness and response (Strine, 2013).

Ko, et al. (2014) was the only study to look specifically at household preparedness and chronic disease interaction, to determine if presence of chronic disease had any impact on preparedness. The study produced mixed results, with evidence of more preparedness around medication preparedness for some chronic conditions (diabetes, asthma) and no perceptible

difference in medication preparedness for individuals with cardiovascular conditions. Overall, however, Ko, et al.'s analysis did not find any significant difference in the level of preparedness between individuals with chronic disease and those without chronic disease (Ko, 2014).

The Health and Retirement Study data, used by Al-rousan et al (2014), cross-tabulated specific indicators of functional status and disability among older adults alongside awareness of and enrollment in community emergency preparedness resources and programs. Of note in Al rousan's research was prevalence data of using electricity dependent medical devices, which was 15% across the entire study (Al rousan, 2014). This number is much higher than the national prevalence based on analysis of the U.S. Department of Health and Human Service (HHS)'s emPower Map 2.0, which notes the Medicare claims data based prevalence of electricity dependent medical equipment at 2,528,230 of the roughly 53 million total Medicare beneficiaries, for a prevalence rate of 4.77% (U.S. Department of Health and Human Services, 2016).

### **Systems for Identifying and Mitigating Community Preparedness Risks for Older Adults**

While there are several sophisticated GIS-based assessments communities can use to develop emergency preparedness plans, such as HHS's emPower Map 2.0, and CDC's Community Assessment for Public Health Emergency Response (National Center for Environmental Health, 2016), lower tech assessment options, like analysis of a limited set of BRFSS data, could be a useful tool for communities to use to identify older adults who may require additional assistance during emergencies, as a reactive measure, or remediation of their emergency preparedness as a proactive measure to build community resilience.

Community based organizations in New York City's aging network are already accustomed to collecting certain health indicator measures regarding the older adult populations they serve, through a risk-oriented survey tool designed to help the New York City Department

for the Aging, and other aging network service providers collect and utilize information to provide evidence-based programming for their seniors (Vladeck, 2010). Use of easy to understand and implement tools for the identification and support of at-risk older adults could be extended to include assessment for emergency preparedness and vulnerability during emergencies.

### **Research Processes**

Predictors of older adults' emergency preparedness were analyzed and reported in the studies discussed here using quantitative descriptive statistics and multivariate analysis of BRFSS or HRS data (McGuire, 2007; Ablah, 2009; Strine, 2013; Al rousan, 2014). This replicates aspects of Ko, et al.'s analysis of the question subset of the BRFSS general preparedness module, with analysis alongside BRFSS questions on chronic disease diagnosis (Ko, 2014). The Ko, et al. study, which sought to identify relationships between chronic conditions and overall preparedness, was not limited to older adults.

### **Conclusion**

Hurricanes and other extreme storm and flooding events can have catastrophic impacts on communities, but particularly on older adults. Exacerbation of chronic conditions is a major adverse health outcome for older adults with chronic disease after hurricanes. The rate of growth of population of older adults, moving faster than rate for younger generations of potential caregivers, raises concerns about the ongoing care of individuals with chronic disease. For geographically and socially vulnerable communities susceptible to severe damage during hurricane events, community emergency preparedness and resiliency plans should take individuals' capacity for chronic disease management during emergencies into account when constructing emergency preparedness and response plans.

## **Chapter 3. Research Design & Methodology**

### **Introduction**

The purpose of this study was to better understand attitudes and perceptions of emergency preparedness among chronically ill community-dwelling older adults living in socially vulnerable communities. The researcher conducted focus groups and a short survey with two groups of older adults with self-reported chronic disease, or who had experience as a caregiver to someone else with a chronic condition. The purpose of the focus groups was to surface themes in both personal attitudes and perceptions of others' attitudes regarding health care providers' recommendations and expectations regarding emergency preparedness of patients and their families.

### **Research Criteria**

Participants for the study were older adults (aged 65 and over) with either self-reported chronic conditions, such as cardiovascular disease, diabetes, or asthma; or individuals who act as caregivers to a family member or friend with a chronic condition. Participants in the study were recruited from researcher-identified communities with social vulnerability or geographic vulnerability factors.

The researcher identified two sites to convene focus groups via convenience sampling. One site was a senior center that conducts health and wellness programming with a group of seniors with self-reported chronic health conditions who routinely attend the senior center's health care supportive activities and volunteer as peer health navigators in the community. The senior center is located in a socially vulnerable community with low geographic flood risk on the Williamsburg/Bushwick border in north-west Brooklyn, New York. The senior center is co-located with a New York City Housing Authority public housing complex and has a large

population of Hispanic/Latino senior center members. The center is run by a community-based organization.

The second focus group took place in a less socially vulnerable, but high geographic flood risk community in Howard Beach, Queens, New York. The participants of this group were older adults from the Howard Beach community who primarily reside in private homes, who do not routinely attend formal health and wellness programs at any senior-serving organization; and are socially tightly connected.

The Social Vulnerability Index (SVI) is a group of measures of resilience factors that are indicative of a community's ability to recover, from an emergency event. Factors measured on the SVI are socioeconomic status, household composition and disability, minority status and language, and housing and transportation. SVI is measured at the census tract level, and high SVI percentile ranks are equated with more vulnerability. The SVI ranks of census tracts in the Williamsburg/Bushwick study area ranged between 42<sup>nd</sup> and 99<sup>th</sup> percentile. SVI in Howard Beach ranged between 20<sup>th</sup> and 52<sup>nd</sup> percentile, putting parts of each community in the highest and lowest quartile of SVI. In this project, geographic vulnerability factors are defined as being within a known high-risk flood zone, such as coastal areas of New York City Flood zones range from high risk, zone 1, to low risk, zone 6. Howard Beach is in the highest risk area, zone 1, and the section of Williamsburg/Bushwick in this project's study area are largely in zones 5, 6, or unzoned<sup>1</sup>.

Inclusion in the study sample was limited to adults aged 65 and older with their own chronic condition or who act as a caregiver to someone with a chronic condition. Chronic disease places older adults at the highest risk of adverse outcomes due to floods, storms, or

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<sup>1</sup> See Appendix A1, A2 for examples of maps of social vulnerability, and A3 for the New York City flood zone map.



power outages. Research by Aldrich (2008), Al-rousan (2014), and Goldman (2014) demonstrated the extent to which older adults' health is negatively affected by storms, floods, and related complications. These events are known to exacerbate chronic conditions and increase vulnerability to poor health outcomes (Alderman, 2012; Saulnier, et al, 2017). This study's focus is on high risk populations and therefore not focused on emergency preparedness among the general population. Individuals under age 65 will be excluded from the study, as will residents who live outside of socially vulnerable or geographically vulnerable communities; developmentally disabled and/or cognitively impaired older adults are also excluded from the study.

### **Instruments**

This mixed methods study used two instruments: a short quantitative survey of general household preparedness, and a qualitative focus group moderator's guide. The survey questions were selected from the Behavioral Risk Factor Surveillance System (BRFSS) general preparedness module. The seven general preparedness questions on the survey instrument were previously used in an analysis of BRFSS survey results among individuals reporting chronic conditions by Ko, Strine, and Allweiss (2014)<sup>2</sup>. The previously validated BRFSS survey questions were not tested or re-validated prior to being fielded with study participants. The BRFSS questions on preparedness have been previously tested and the data they produce are widely researched. As with all BRFSS instruments and data, the questions are within the public domain and available for use without seeking permission (CDC, 2015).

The focus group moderator's guide featured six detailed discussion questions intended to elicit older adults' perceptions of emergency preparedness with relation to the management of chronic disease. The questions for the guide were developed from a checklist of health care

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<sup>2</sup> See Appendix B1

providers' and health care sector staff's recommendations and expectations of patients and caregivers during emergencies, developed and discussed in Toner, et al., 2017.<sup>3</sup> The Toner, et al. checklist covers specific suggestions for preparation and management of serious chronic illness in the event of a disaster or emergency. Topics on the checklist include, but are not limited to: medication stockpiles, preparatory actions regarding life-sustaining equipment, in addition to general preparedness measures similar to those covered in the BRFSS general preparedness module (water, food, flashlight, radio, batteries, etc...).

### **Recruitment**

Focus group participants were recruited via convenience sampling of older adults who were members of a senior center or caregivers to members of a senior center. In Williamsburg/Bushwick, Brooklyn, NY, all of the members of the focus group were also peer health navigators—volunteers who act as health mentors to other chronically ill persons in their community. The Howard Beach, NY, focus group participants were recruited from Howard Beach community residents who were members of the same social circle.

For both groups, an informational flyer describing the research study objectives, the date and location of the focus groups, and an offer of a modest participation incentive was distributed to potential participants, two to three weeks in advance of the focus group meetings.

### **Data Collection**

Focus groups met at two sites: a senior center in Williamsburg/Bushwick, and a public library in Howard Beach, Queens. Research conducted with members of the senior center in Williamsburg, Brooklyn, required additional approvals from the community-based organization (CBO) that operates the center. A research proposal consisting of the literature review in Chapter 2 and the methods discussed here in Chapter 3, along with an administrative form and copies of

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<sup>3</sup> See Appendix B2.

the researcher's certification for research with human subjects was submitted to, and approved by, the CBO's research committee. No such research proposal was required to secure permissions for the site used to conduct the Howard Beach focus group, but the researcher did complete a community resource application in order to secure free access to the community room at the library. The application required a brief explanation of the research project and documentation of any disclosures, as well as the anticipated community benefit.

As a participation incentive and to thank study respondents for their time, participants were offered a small gift pack upon completion of the focus group. The gift pack included: a 30-hour duration water resistant LED mini-flashlight, extra batteries (three AAA) for the flashlight, and several pieces of information material about emergency preparedness from Ready New York, a program of the New York City Office of Emergency Management. The informational material included personal emergency plan pocket cards, a full size *My Emergency Plan* booklet, information on hurricanes in New York City, and emergency preparedness information for homeowners. Ready New York materials were made available in English and Spanish.

Focus group sessions were recorded using a Zoom H4nSP Digital Voice Recorder. Oral consent<sup>4</sup> was requested from focus group participants and any dissenters were asked to leave the group. Upon hearing no dissenters, the focus group sessions commenced. The researcher formally introduced herself and the project and met the participants. At both sites, focus group participants were already acquainted with one another, and participants introductions were brief. Where opinions and expressions are attributed to specific participants, names have been changed.

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<sup>4</sup> See Appendix C2

### **Survey and Focus Group Fielding**

The survey questions were fielded on a paper form (available in English or bi-lingual English/Spanish) by the researcher to participants of the groups, in the same encounter as the focus group. Survey response forms were collected at the completion of the session.

Both focus groups were moderated in-person by the researcher, using the six-question discussion guide. The Howard Beach group was conducted in English. The Williamsburg/Bushwick group was conducted bilingually in English and Spanish. The researcher both moderated and translated bi-directionally throughout the discussion between participants.

After the oral consent request<sup>5</sup> was read, the researcher recorded the discussion group in addition to taking written notes.

### **Assumptions**

The first assumption was that individuals with chronic conditions were more likely to be emergency prepared. Ablah, Konda, and Kelly (2009) found that medical conditions like diabetes, cardiovascular disease, history of falls, and use of special equipment were positive predictors of preparedness. The second assumption is that general emergency preparedness as measured by the survey will not impact attitudes or perceptions regarding management of chronic conditions in emergencies; prior research by Ko, Strine, and Allweiss (2014) found irregularity across conditions in the relationship between preparedness and disease management perceptions, suggesting that the relationship is not generalizable and therefore cannot be assumed.

### **Limitations**

A limitation of this study is its ability to be generalized across all populations due to the specific characteristics of the study populations' location, mix of chronic disease burden, and social vulnerability factors, and limited participant pool. A second limitation is self-reporting

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<sup>5</sup> See Appendix C2

bias, where a participant may adjust responses for social desirability (Althubaiti, 2016). A third limitation is recall bias, since participants are likely to associate discussions of current state or anticipated behavior with past experiences and recollection (Eisenman, 2007; Althubaiti, 2016.; 2016; Toner, et al., 2017).

## Chapter 4. Results

### Participant Demographics

Overall, survey and focus group participants (N=16) were equally split between men and women. A majority of participants identified race as white and were evenly split between Hispanic and Non-Hispanic ethnicity. Several (18.8%) preferred not to report race.

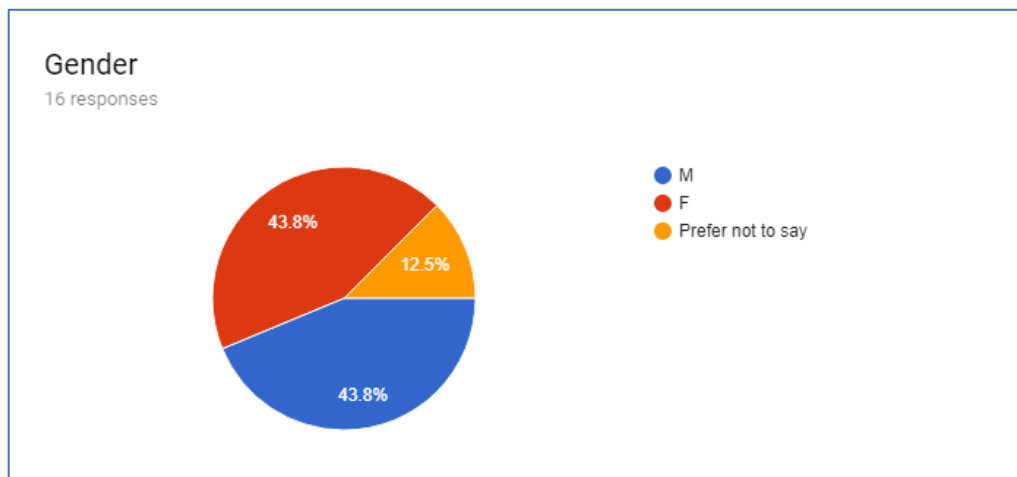


Figure 1. Gender

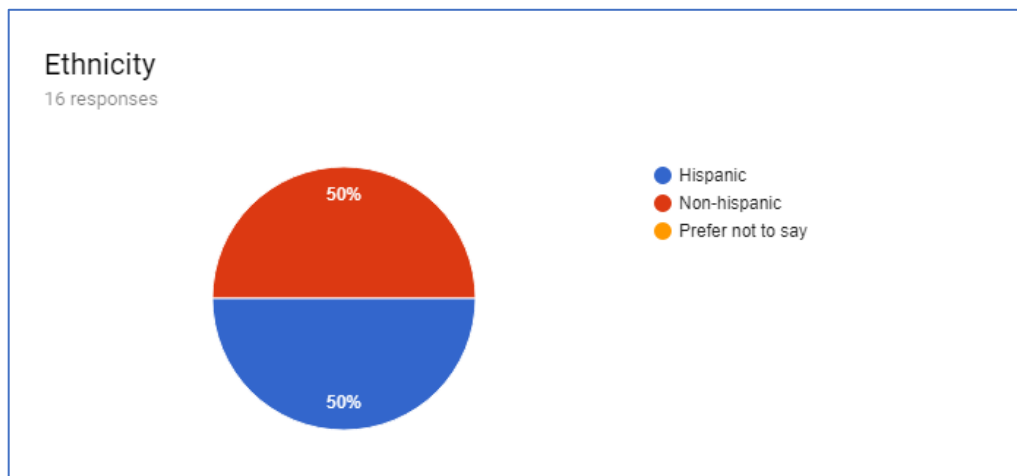


Figure 2. Ethnicity

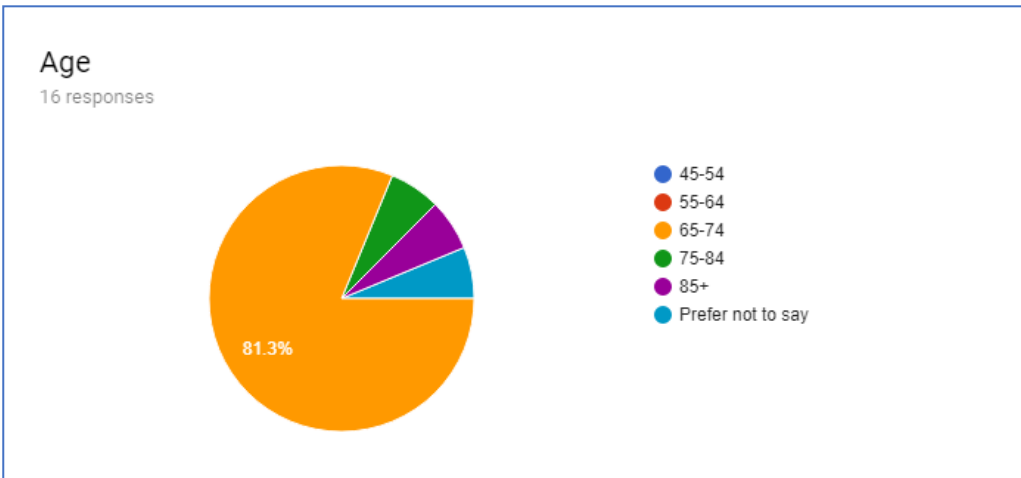


Figure 3. Age

Participants were primarily older adults between 65 and 74 years old ( $n=13$ ); were primarily retired ( $n=12$ ); 1 was employed, 3 identified as homemakers. Occupations of retirees and employed participants were reported as an assortment of skilled-labor and blue-collar occupations—custodian, building maintainers, mechanics, police officer, truck-driver, as well as civil service and education affiliated occupations: school bus drivers, bus matrons, school secretaries, and teachers.

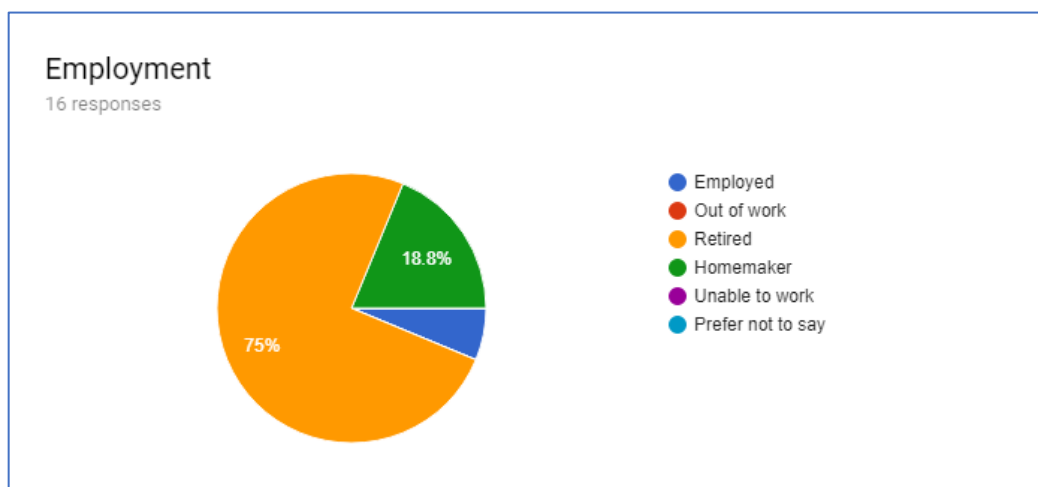


Figure 4. Employment

56.3% of respondents reported they lived alone v. 43.8% who did not live alone, and 56.3% reported they were a caregiver, 37.5% reported they were not a caregiver, and one preferred not to say.

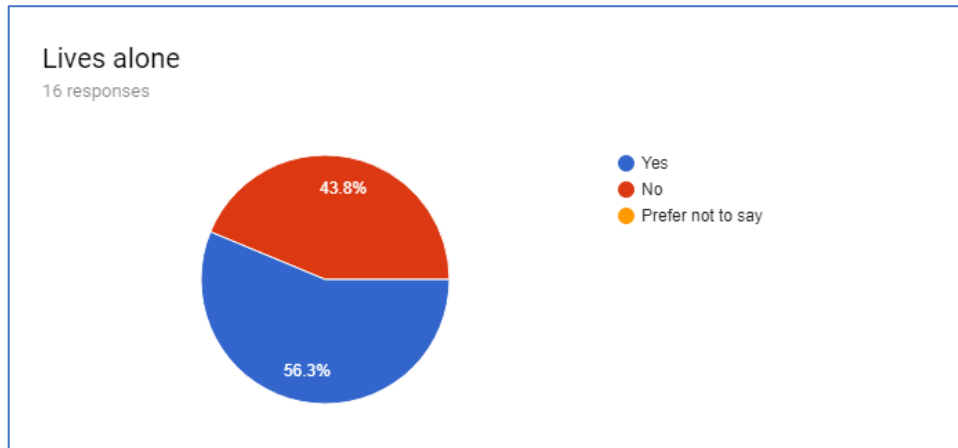


Figure 5. Lives Alone

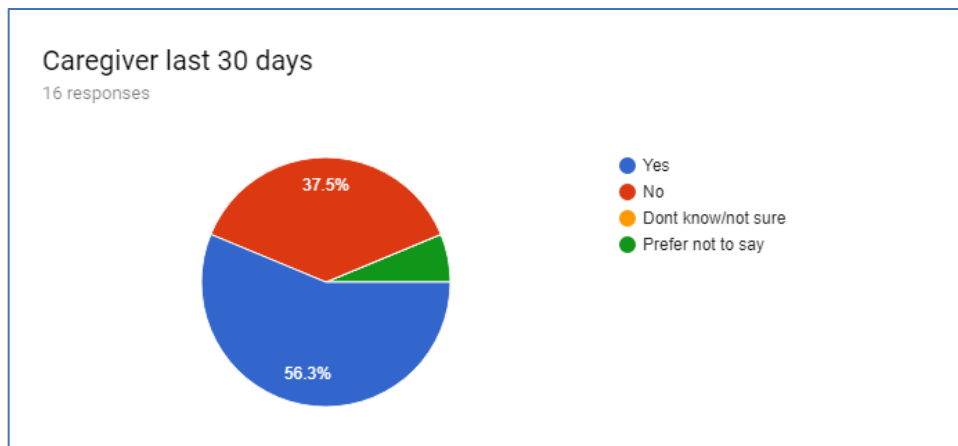


Figure 6. Caregiving Status

### Emergency Preparedness Survey Responses

Fifteen of sixteen participants completed the survey, and surveys were analyzed for overall emergency preparedness. The criteria for emergency prepared in this study replicates the criteria established by Ablah and Kelley's 2009 study, "Factors Predicting Individual



Preparedness: A Multistate Analysis of 2006 BRFSS Data,” in which a participant was considered prepared if five of six of the BRFSS general preparedness module questions were answered in the affirmative (Ablah and Kelley, 2009, p. 319). Questions included in the rating criteria were: 3-day supply of 1) water, 2) food, 3) medication (if needed); have a 4) flashlight and batteries, 5) radio and batteries, and 6) written emergency plan. The same six questions in the Ablah and Kelley study were also used in the Ko, Strine, and Allweiss (2014) study.

Per the Ablah and Kelley (2009) criteria, 68.75% (n=11) of all respondents in the study were prepared, 25% (n=4) were not prepared, and 6.25% (one respondent) did not reply to the preparedness questions. Not-prepared respondents were equally distributed across groups.

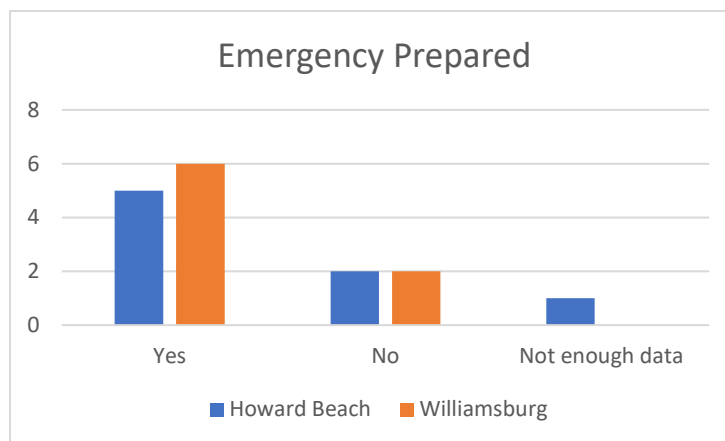


Figure 7. Overall Emergency Preparedness

Of the respondents who were not emergency prepared, did not have a written evacuation plan was the most common response (n=4), followed by did not have a 3-day supply of water (n=3), did not have a 3-day supply of food (n=1), and did not have a flashlight and batteries (n=1).

Overall, slightly more women than men (n=2, vs. n=1) were rated as not emergency prepared. Women who were not prepared were distributed equally across groups.

56.3% of respondents identified as caregivers. Respondents who identified as caregivers rated positively for emergency preparedness slightly more frequently than those who did not identify as caregivers; two respondents did not reply to the caregiver question.

An independent t-test demonstrates the distribution of caregivers to non-caregivers and preparedness

N=14 (2 abstained)	Caregiver N=8	Non-caregiver N=6
Prepared	6	4
Not-prepared	2	2

Figure 8. Caregiving and Emergency Preparedness

Four main areas of variance regarding emergency preparedness emerged between groups. Slightly fewer Howard Beach participants reported having 3 days of water while slightly fewer Williamsburg respondents reported having 3 days of food.

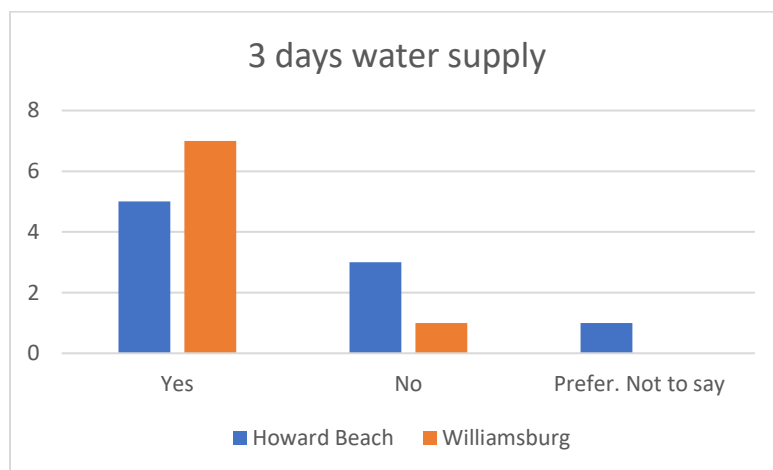


Figure 9. Water Supplies

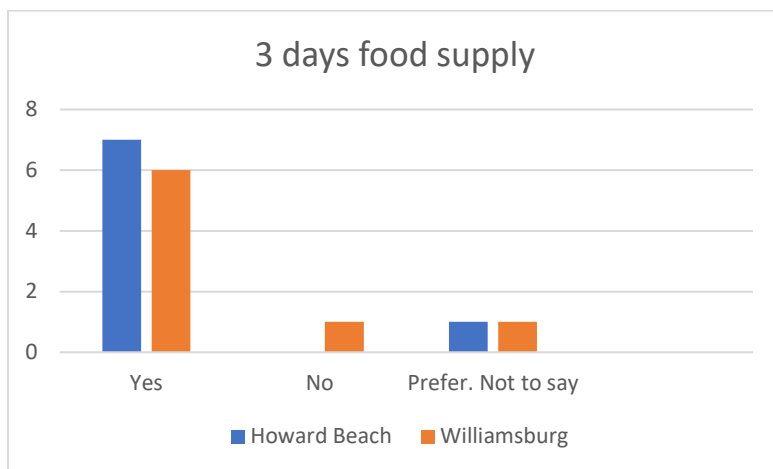


Figure 10. Food Supplies

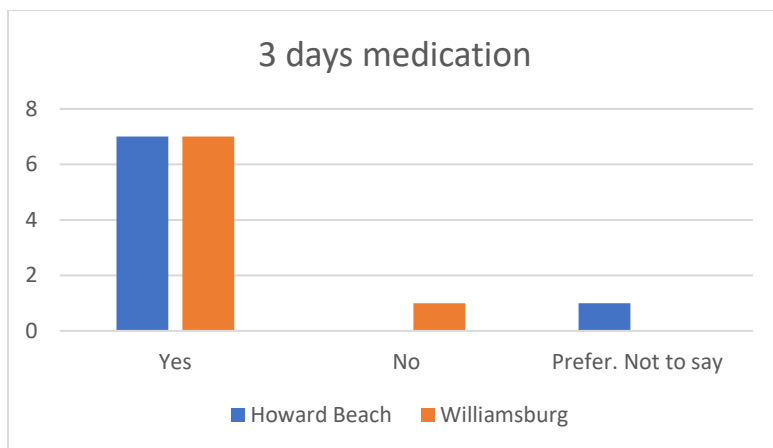


Figure 11. Medication Stockpile

Major differences between groups were identified in evacuation planning. Overall, less than half of respondents had a written evacuation plan, but as a group, Howard beach respondents were much less likely to have one. Howard beach respondents were also slightly less likely to evacuate if mandatory. In Williamsburg/Bushwick, 62.5% of respondents reported having a written evacuation plan, 37.5% did not have a written plan; and 87% would evacuate if mandatory. In Howard Beach 1 respondent (12.5%) reported having a written evacuation plan, 1 abstained, and the remaining 6 respondents (75%) reported they did not have a written evacuation plan. 5 respondents (62.5%) reported they would evacuate if mandatory, 1 abstained, and 2 (25%) reported they would not evacuate.

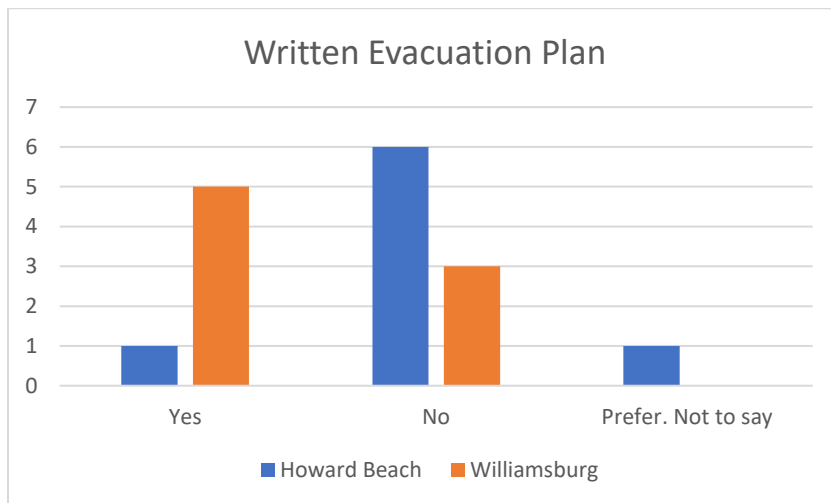


Figure 12. Evacuation Plan

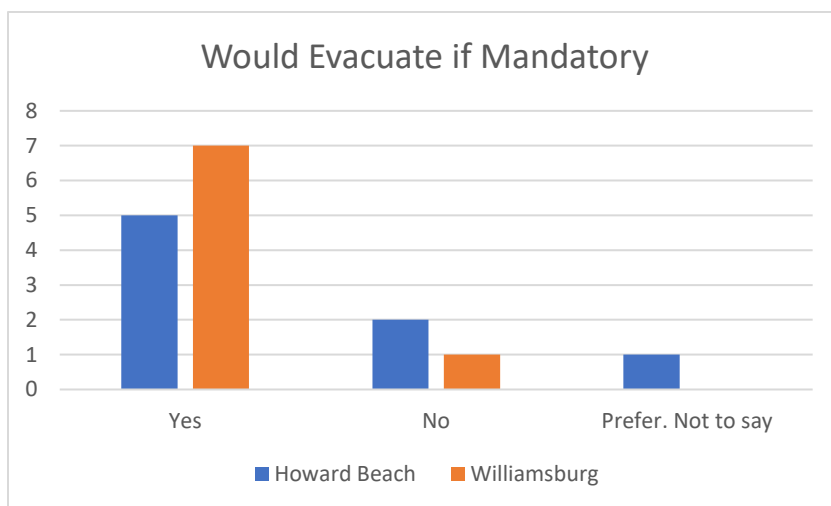


Figure 13. Evacuation Intent

### Focus group results

Focus group participants were engaged in a moderated discussion led by the researcher, using a moderator's guide. Over the course of the discussion, respondents were prompted to:

- Suggest what they thought should be on a health care provider's emergency preparedness checklist for persons with chronic conditions and their families/caregivers
- Project what they thought would be on a health care provider's emergency preparedness checklist for persons with chronic conditions and their families/caregivers

- React to the items on the checklist after hearing them from the researcher

### *Shoulds and Woulds*

The primary theme surfaced in discussions of what should or would be on the health care provider's checklist was medication. A majority of participants suggested having a stockpile of medications should be and would be on the health care provider checklist. Several participants in both groups also noted the importance of *knowing* how to get needed medications, as well as knowing how and where to store medication safely as important factors for preparedness, and maintaining a list of their medications with dose, purpose, and prescribing doctor with them at all times.

A participant in the Williamsburg/Bushwick group, Jose\* (name has been changed) suggested that patients and their caregivers “need to know how what foods to eat to help manage their condition in case they do not have their medication, or they run out of medication,” and discussed how diet is important for some patients to help control conditions like diabetes or kidney disease in the absence of medication. Other participants in the Williamsburg group agreed with Jose.

### *Checklist Reactions and Perceptions*

In general, participants in both groups agreed with many of the suggestions on the checklist, such as having medication stockpiles, the idea of a registry for medically vulnerable individuals, and knowing the emergency plans of any home care providers. Many of these concepts were described as good ideas and “common sense.” That said, concern and discord emerged in two distinct areas: medication access and access to alternate power sources for life-sustaining equipment.

### *Knowing How to Refill Medications*

On medication access, and the recommendation that “Patients and their families who depend on life-sustaining medications should maintain a maximal supply of medication at all

times and know how to refill medications in an emergency,” members of the Howard Beach group showed discord and concern with this suggestion. While one group member, Charlie, asserted:

“most people have 90-day medication” [stockpiles and that] “medication shouldn’t be an issue.”

About half of the group pushed back on this opinion and noted some prescriptions for chronic conditions are frequently monitored and not refillable or “must be renewed every 30-days”. Says Margaret:

“what if you are on some 30-day medication, but not close enough to get a refill, or what if you are at the end of the run?”

Further probing on refilling medication surfaced concerns about pharmacists or insurers being unwilling to dispense medication or approve an advance refill in the event of an emergency. Three members of the Howard Beach group suggested that prior poor experience with health insurance and pharmacies regarding medication and prescription refills would prevent them from attempting to access advance refills or dispensing of medication in an emergency event.

Members of the Williamsburg/Bushwick group were similarly concerned with refilling medication as the Howard Beach group but added affordability of medications and possible lack of insurance as an additional complicating factor in maintaining a medication stockpile and accessing advance medication in an emergency.

#### *Life sustaining equipment and access to adequate emergency power sources*

Significant concern arose in response to the checklist item “All patients and their families who depend on life-sustaining electrical devices at home should have access to adequate emergency power sources, such as batteries or an emergency generator.”

While both the Williamsburg and Howard Beach group participants agreed that this is a good idea in theory, there were differences in their perceptions of its applicability. Discussion of alternate power sources focused on the concept of access to an emergency generator, with Williamsburg/Bushwick group members noting housing structure as a major barrier to access to an emergency generator. Williamsburg/Bushwick group member Manuel noted,

“if you live in [public] housing, or any kind of apartment building, you can’t have your own generator! You can’t have them inside, there’s nowhere safe to put it, and you can’t store the fuel. If there’s an emergency generator its gotta be the building’s.”

Williamsburg/Bushwick group members agreed with Manuel’s assessment.

In the Howard Beach group, the discussion of generators focused on personal access and affordability. Said Howard Beach group member Jimmy:

“Most people can’t afford generators. Even if you can afford it, they’re hard to get. During [Superstorm] Sandy we got ours from Maryland because someone drove it up here for us. But then once you have them you gotta be able to get the fuel, too. What saved us was we had the two boats, so we siphoned the fuel from the boats for the generators [because of the gas shortage].”

Group member Dean added

“another thing with the generators is you need to know how to operate and maintain them. Not everyone knows how.”

### *Additional Findings*

Over the course of the focus group discussion, participants referred to the following factors that inform their decision to evacuate: in the Williamsburg group, needing to care for family members and friends was a major driver for the person who reported they would not evacuate. In Howard Beach, nearly all the participants said perceptions of trustworthiness of the

information used to make the evacuation order was important, and the opinions, previous experience, and preferences for evacuation of community elders who had survived prior emergencies were significant decision drivers.



## **Chapter 5. Discussion**

### ***Introduction***

The preceding chapter reported the data and analysis of this study of older adults' perceptions of emergency preparedness recommendations for patients and caregivers. In chapter a summary of the study with discussion of findings, practice implications and recommendations for future policy and research will be presented along with conclusions. The practice implications and recommendations aim to further the health care sector's understanding of patient and family perceptions and potential ability to carry out recommended and expected behaviors during emergencies. A synthesis of the perceived concerns of older adults regarding recommendations for patients and caregivers is intended to inform future communication between health care providers and patients about the patient's ability to self-manage their condition during an emergency.

### ***Summary of the Study***

The purpose of this study was to understand how patients with chronic conditions or their caregivers would perceive health care providers' recommendations and expectations regarding patient and family preparation for and condition management during emergencies. The study was developed to specifically elicit patient and caregiver perspectives and identify where those perceptions or perspectives diverged from recommendations, as well as whether there were differences in perceptions or perspectives based on social vulnerability or geographic vulnerability factors.

The Behavioral Risk Factor Surveillance Survey, an annual survey of health-related risk behaviors, chronic conditions, and access to health services, has an optional module on emergency preparedness. Prior studies of the BRFSS data for emergency preparedness and chronic disease in the population have demonstrated chronic conditions as predictors of preparedness, as well as disparities in emergency preparedness across race, ethnicity, and socio-

economic factors (Ablah and Kelley (2009); McGuire (2007); Strine, et al., (2014)). In this mixed-methods study, a modified survey of BRFSS emergency preparedness questions was fielded, and focus groups conducted using a moderated discussion guide to elicit perspectives and reactions to Toner, et al.'s checklist of recommendations and expectations for patients and families during emergencies.

The study included 16 respondents, 8 per community of focus, which included a section of the Williamsburg/Bushwick neighborhood in Northwest Brooklyn, and a section of the Howard Beach neighborhood in Southeast Queens, both in New York City. Respondents were recruited via convenience sampling from a) a group of Williamsburg/Bushwick senior center members who were active participants in a health and wellness volunteering program, and b) a social circle of Howard Beach residents acquainted with the researcher.

Quantitative questions addressed in this research were: a) to what extent are members of these groups emergency prepared; b) to what extent does preparedness vary between these groups. Survey results found little variation in general levels of preparedness between groups, with only 2 participants in the Williamsburg/Bushwick group rated as not prepared, and the remainder rated as prepared, with the exception of one respondent in the Howard Beach group who did not complete the survey.

Qualitative questions addressed in this research were: what are the attitudes and perceptions of older adults about the health system's recommendations and expectations for chronic disease management and emergency preparedness of patients and their families, and how do they differ? The primary novel findings in the study emerged from these qualitative questions, discussed in focus groups. Participants in both groups demonstrated concern regarding a) access to refills of medication in an emergency; and b) access to alternate power sources, such as emergency generators. Major points of disparity were found in access to alternate power sources.

### ***Discussion of the Findings***

#### ***Advance access to medication.***

Among focus group participants in both groups, none expressed specific knowledge of how to access refills in advance of an emergency, and few showed any confidence or inclination to attempt accessing refills of medication in advance of an emergency. In the Howard Beach group especially, participants cited previous poor experiences with health care providers and insurers as deterrents from attempting to access medication in advance of an oncoming emergency. Multiple respondents in the Howard Beach group agreed with the declaration by one participant, Mary, “I wouldn’t even bother.”

In the Williamsburg/Bushwick group, one participant suggested, and others agreed, that a possible gap or delay in medication should always be anticipated, not just during an emergency, and individuals need to be prepared to know how to control their condition in the event of the absence of medication.

The expectation that medication will be difficult to access or unavailable during an emergency is not unusual, or unexpected, and is consistent with earlier research regarding the morbidity and mortality outcomes of evacuees during previous emergencies like Hurricane Katrina (Aldrich, 2008). What was surprising, however, was the reticence that participants expressed about attempting to access advance dispensing of medications or refills with their pharmacists or health insurers. In this instance, participant’s prior poor experience with the health care system has a negative impact on the individual’s perceptions of self-advocacy and agency to pursue needed medication.

#### ***Access to alternate power sources.***

The discussion of alternate power sources focused on the topic of emergency generators and access to them, revealing a significant disparity of access and gap in the recommendations for patients and their families. Members of both the Williamsburg/Bushwick group and Howard

Beach group agreed that access to an emergency generator would be beneficial, but Williamsburg/Bushwick participants were quick to point out housing type as a barrier to access to a generator. The Williamsburg/Bushwick community is much more densely populated with multiple-family housing and high-rise apartment buildings. Building and public health and safety codes prevent the operation and storage of generators and fuel indoors, and few individual apartments have outdoor space sufficiently large enough for the safe operation of a generator. In the Williamsburg/Bushwick group and surrounding community, independent decision making regarding personal access to an alternate power source is curtailed by barriers stemming from the housing type and the surrounding built environment. Having access to emergency power becomes a communal decision to be taken up with multiple residents of a building in order to operate a generator safely. This is vastly different than the concerns of participants in the Howard Beach group, where participants were more likely to live in single-family, privately owned homes (as indicated by Howard Beach's community profile). In the Howard Beach group, discussion regarding alternate power source access focused on personal availability of generators and access to fuel. Howard Beach residents were not bound by structural barriers of housing type in their personal decision making regarding alternate power sources.

This disparity in independent decision making between these two communities suggests that the blanket recommendation that "All patients and their families who depend on life-sustaining electrical devices at home should have access to adequate emergency power sources, such as batteries or an emergency generator" does not sufficiently consider housing differentiation in the urban environment. The suggestion to have access to "adequate emergency power sources, such as a generator," inadvertently privileges individuals who live in private, single family homes who have either adequate outdoor space to safely operate a generator, or who live in a building or community with the means to offer communal emergency power

resources. The current recommendation does not adequately account for the many areas of the urban environment that feature multiple unit housing and high-density housing and the safety restrictions on personal generators.

#### *Additional findings on evacuation planning*

A minority of participants described reluctance to evacuate if mandated, citing the need to care for an elder family member or friend, or the experience of an elder in prior emergencies influencing their personal decision to evacuate. These findings were consistent with earlier research by Eisenman (2017), which cites “obligations to elders” as a major driver of evacuation decision making.

#### *Policy and Research Implications*

This study’s objective was to understand the extent to which older adults with chronic conditions or their caregivers were prepared for emergencies, and to learn how what their perceptions were regarding health care providers’ recommendations and expectations regarding emergency preparedness, and whether there would be any place-based variation between those perceptions based between communities with different social vulnerability and geographic vulnerability profiles.

*Policies on Medication.* As discussed above, all participants indicated reticence in approaching health care providers to advance dispensing of medication during an emergency because of an expectation that their request would go unfulfilled. The anticipated frustration of dealing with the health care system is enough to potentially deter participants from seeking care in advance of an emergency. This finding suggests health care providers, pharmacies, and health insurers need to be proactive about developing and communicating to patients, families, and the public their protocols for dispensing medication in an emergency.

*Policies on alternate power sources.* Structural disparities in access to alternate power sources such as generators should be addressed by health care providers. Blanket

recommendations to have “adequate emergency power sources” are insufficient in communities where so many of the public live in high-density housing and are unlikely to have physical access and ability to operate a generator. Insurers and health care providers could emulate work being done by the Centers for Medicare and Medicaid Services; eMPower 2.0 Map project (CMS, 2016) which uses claims data for electricity dependent medical equipment to forecast areas where emergency power would be needed. Health care providers could also independently run registries of their patients using electronic medical records to identify which patients are likely to live in high-density housing and need access to alternate power sources in an emergency. Such individuals could then be targeted for proactive emergency preparedness planning interventions.

Additional methods for the identification of at-risk individuals in high-density housing could be through registries developed by community-based organizations, such as senior centers, to assist with risk education and preparedness interventions on the behalf of, or in concert with health care providers.

### ***Further Research***

Although this study’s small sample size and convenience sampling method limits the generalizability of the survey findings around emergency preparedness, the qualitative findings seems ripe for further research.

Additional emergency preparedness research could focus on the relationship between poor patient/consumer experience and patient activation and emergency preparedness behaviors. Alternatively, in future emergencies, post-event qualitative interviewing could prompt respondents to respond to what role, if any did prior experience with the health system or health insurance system play in decision making.

Another line of inquiry for urban health planning and emergency management could be an audit of emergency preparedness recommendations for applicability across the continuum of community residents. Such a study could ask whether preparedness recommendations are made equitably and are sufficiently differentiated to be useful for all community members.

### ***Conclusion***

This study's intent was to examine the older adults' perspective on health care providers' recommendations and expectations regarding patients' and caregivers' disease management behaviors during emergencies. First, the findings suggest that for maximal applicability, emergency preparedness recommendations to patients and caregivers need to take into consideration the influence of the previous experience with the health care system itself on patient and caregiver behavior; enhanced education of patients, caregivers, and the public on emergency protocols (such as procurement of emergency medications) may mitigate the effects of those negative experiences. Second, the findings suggest that recommendations and instructions are inadequately differentiated for differences in the housing type and other built environment and socio-economic factors around access to alternate power, and that health care providers should revise their recommendations for enhanced applicability to the continuum of patients and families.

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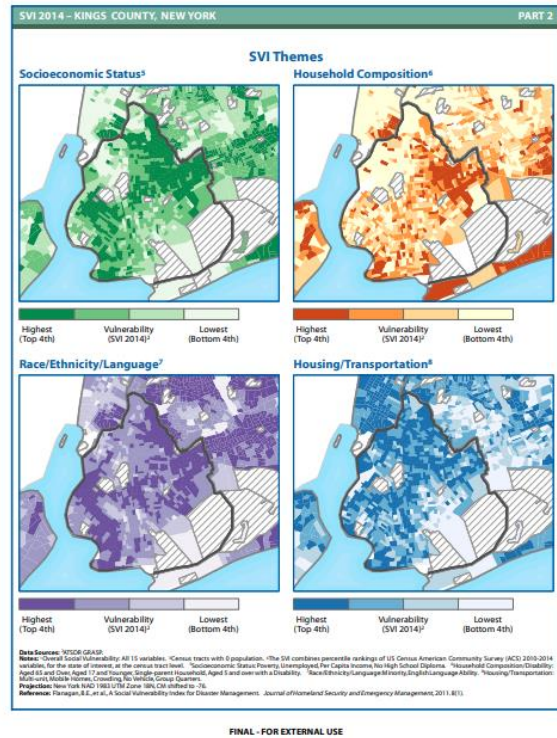
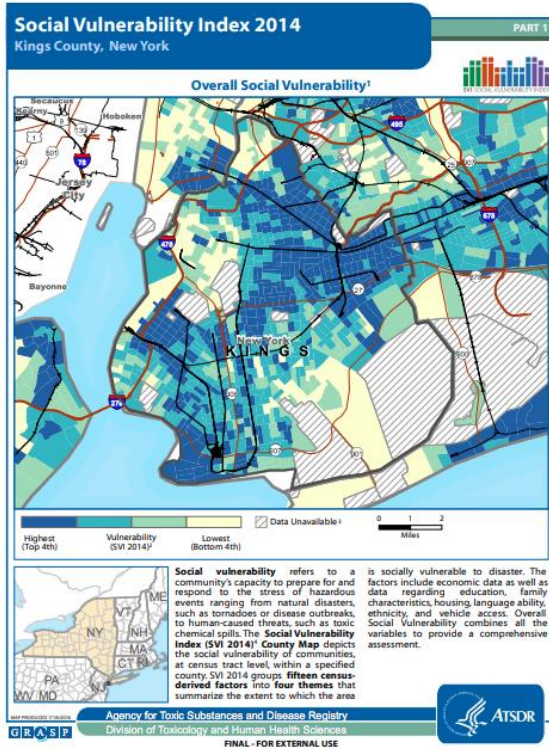


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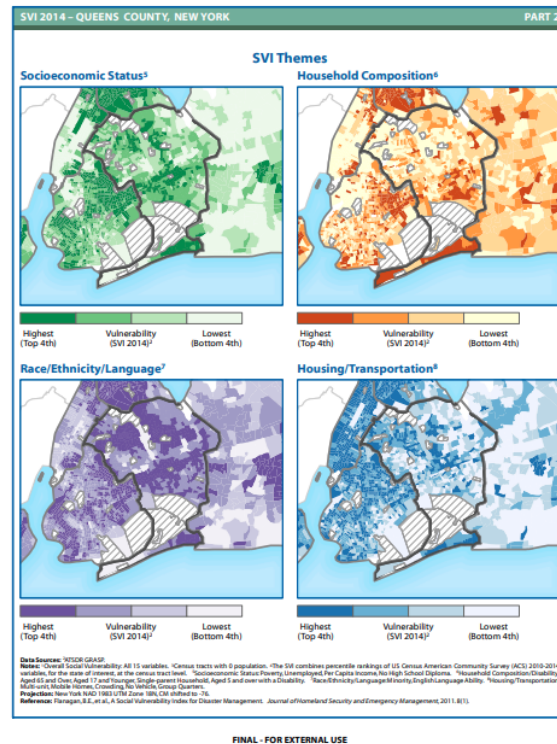
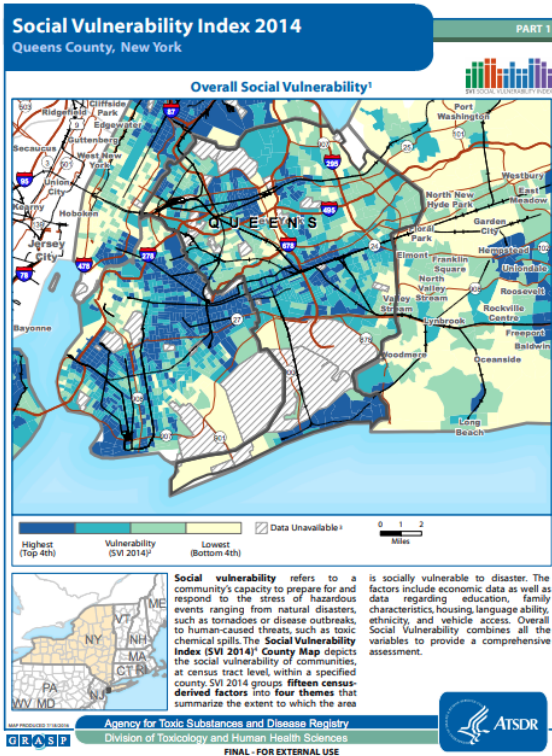
## Appendix A1

### Kings County SVI map



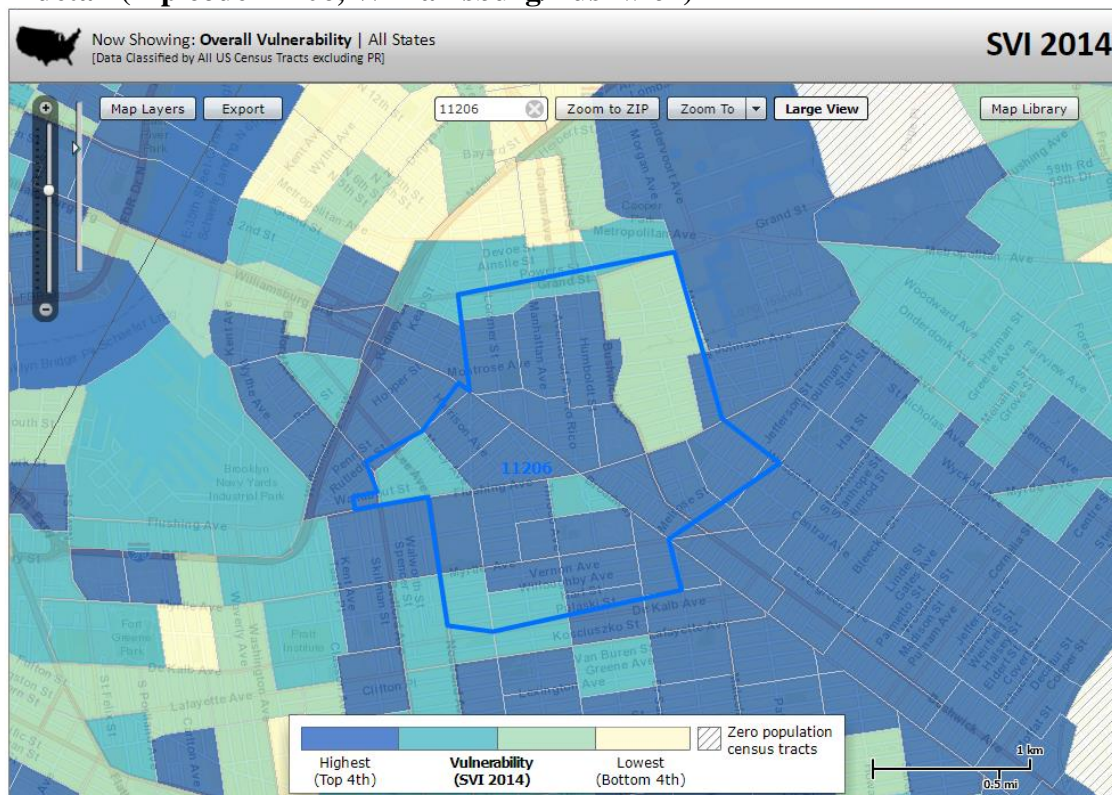
## Appendix A2

### Queens County SVI map

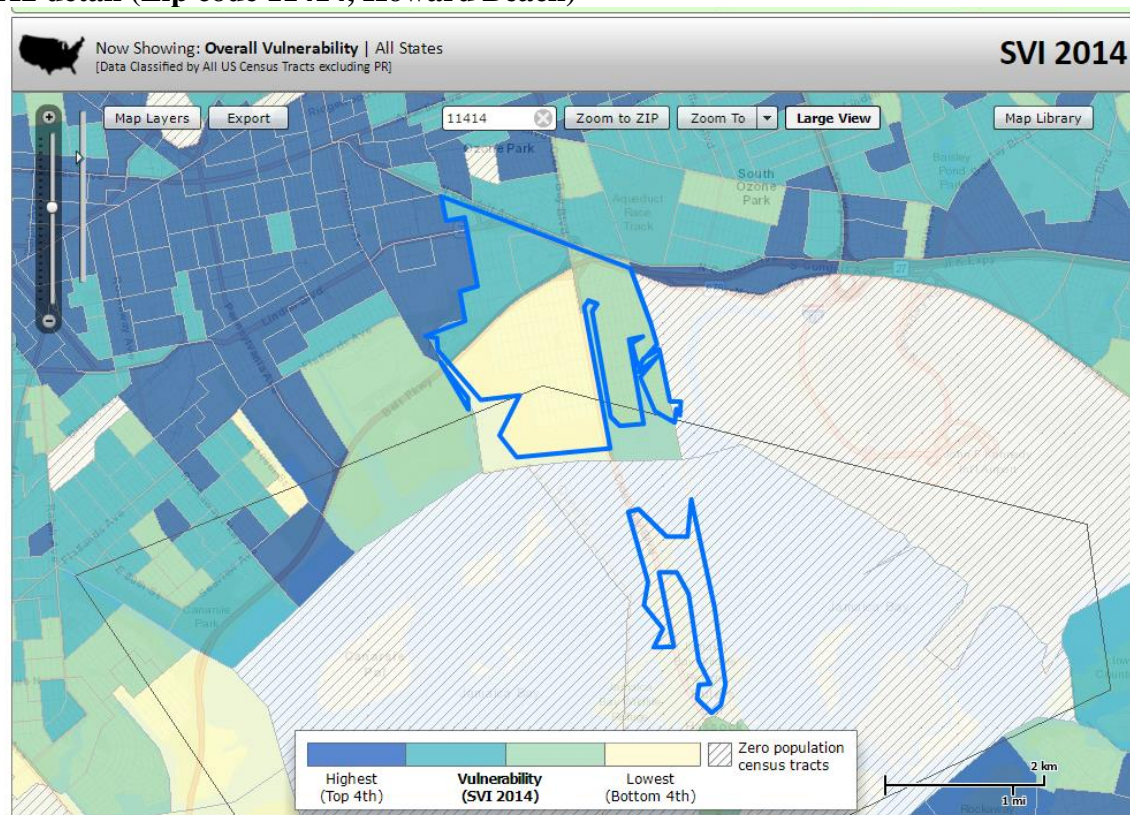




## Appendix A1 detail (Zip code 11206, Williamsburg/Bushwick)



## Appendix A2 detail (Zip code 11414, Howard Beach)





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## Appendix B1

### Emergency Preparedness Survey

#### Demographic Questions *Preguntas demográficas*

<b>Age/Edad</b>	45-54	55-64	65-74	75-84	85+	Prefer not to say/ <i>Prefiero no decirlo</i>
<b>Gender/Género</b>	M	F				Prefer not to say/ <i>Prefiero no decirlo</i>
<b>Employment/ Empleo</b>	Employed <i>empleado</i>	Out of Work <i>desempleado</i>	Retired <i>retirado</i>	Homemaker <i>ama de casa</i>	Unable to work <i>Incapaz de trabajar</i>	Prefer not to say/ <i>Prefiero no decirlo</i>
<b>Occupation/Former occupation if retired</b> <i>Ocupación anterior si está jubilada/si se retiró</i>						Prefer not to say/ <i>Prefiero no decirlo</i>
<b>Race</b> <i>Raza</i>	White <i>Blanco/a</i>	Black or African American <i>Negro/a o afroamericano/a</i>	American Indian or Alaska Native/ <i>Indio/a americano/a o nativo/a de Alaska</i>	Asian <i>Asiático/a</i>	Native Hawaiian or Other Pacific Islander <i>Nativo/a de Hawai o de otras Islas del Pacífico</i>	Prefer not to say/ <i>Prefiero no decirlo</i>
<b>Ethnicity</b> <i>etnicidad</i>	Hispanic	Non-Hispanic				Prefer not to say/ <i>Prefiero no decirlo</i>
<b>Lives alone</b> <i>vive solo</i>	Yes	No				Prefer not to say/ <i>Prefiero no decirlo</i>
<b>During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?</b> <i>Durante los últimos 30 días, ¿brindó atención o asistencia regular a un amigo o miembro de la familia que tiene un problema de salud o discapacidad?</i>			Yes	No	Don't Know/not sure	Prefer not to say/ <i>Prefiero no decirlo</i>

**Appendix B1 (continued)**  
**Emergency Preparedness Survey for**  
**Chronic Disease Management During Emergencies**

		YES SI	NO NO		DON'T KNOW NO SE	REFUSED PREFIERO NO DECIRLO
1	Does your household have a 3-day supply of water for everyone who lives there? A 3-day supply of water is 1 gallon of water per person per day  <i>¿En su hogar hay un abastecimiento de agua para 3 días para cada persona que vive ahí? Un abastecimiento de agua para 3 días equivale a 1 galón por persona por día.</i>	1.1	1.2		1.4	1.5
2	Does your household have a 3-day supply of non-perishable food for everyone who lives there? By non-perishable we mean food that that does not require refrigeration or cooking.  <i>¿En su hogar hay un abastecimiento de alimentos no perecederos para 3 días para cada persona que vive ahí? Los alimentos no perecederos son aquellos que no necesitan refrigeración ni necesitan cocinarse.</i>	2.1	2.2		2.4	2.5
3	Does your household have a 3-day supply of prescription medication for each person who takes prescription medicines? (This question includes a response for households in which no one requires prescription medication)  <i>¿En su hogar hay un abastecimiento de medicamentos de venta con receta para 3 días para cada persona que necesite esos medicamentos?</i>	3.1	3.2	NO ONE IN HOUSEHOLD REQUIRES PRESCRIPTI ON MEDICINE  NADIE EN CASA NECESITA MEDICAMEN TOS DE VENTA CON RECETA 3.3.	3.4	3.5
4	Does your household have a working battery-operated radio and working batteries for your use if the electricity is out?  <i>¿En su hogar tiene un radio de baterías o baterías en buen funcionamiento que pueda utilizar si hay una interrupción en el suministro de electricidad?</i>	4.1	4.2		4.4	4.5
5	Does your household have a working flashlight and working batteries for your use if the electricity is out?  <i>¿En su hogar tiene una lámpara de mano y baterías que funcionen que pueda utilizar si hay una interrupción en el suministro de electricidad?</i>	5.1	5.2		5.4	5.5
6	Does your household have a written evacuation plan for how you will leave your home in case of a large scale disaster or emergency that requires evacuation?  <i>¿En su hogar tiene un plan de evacuación en caso de que ocurra un desastre, un plan escrito sobre cómo salir de la casa en caso de que suceda un desastre o emergencia a gran escala que requiera evacuación?</i>	6.1	6.2		6.4	6.5
7	If public authorities announced a mandatory evacuation from your community due to a large-scale disaster or emergency, would you evacuate  <i>Si las autoridades públicas anuncian una orden de evacuación para su comunidad debido a un desastre o emergencia a gran escala, ¿usted evacuaría su comunidad?</i>	7.1	7.2		7.4	7.5

Survey adapted from 2010 and 2007 Behavioral Risk Factor Surveillance System Questionnaires  
Centers for Disease Control and Prevention

## Appendix B2

### Moderator Questions for Focus Groups

MODERATOR: Read oral consent document to group and note assent.

MODERATOR: In a recent study about how the health care sector can prepare for and respond to disasters, health care providers like doctors and nurses at hospitals and in primary care offices, and staff from organizations like home care agencies, nursing homes, community-based organization made recommendations on how members of the public should prepare for emergencies.

Researchers from Johns Hopkins listened to the health care sector staff and made a list of recommendations on the basics of preparedness, e.g. having several days of water, food, cash, and medicine, evacuation plans, and ways to contact loved ones; and specific measures of preparedness for people with serious chronic illness.

The research study presented a checklist I'd like to share some of recommendations on the checklist with you, and hear your reactions, opinions, or suggestions. These discussion questions are adapted from Toner, et al., 2017 checklist.

Before I go through the list with you,

1. What are some things you think **SHOULD** be on the list, and
2. What are some things that you think **WILL** be on the list?

Now that you've given me your opinion of what **SHOULD** be on the list and what you think **WILL** be on the list, I'm going to read to you some of the recommendations. I'd like you to tell me what you think of them.

- **Patients and their families who depend on life-sustaining medications should maintain a maximal supply of medications at all times and know how to refill medications in an emergency.** They should
  - ask about the pharmacy's emergency plan and where to go if the usual pharmacy is closed.
  - If there is warning of an impending disaster, such as a hurricane, they should request advance dispensing of essential medications.
  - They should maintain a hard-copy list of all medications in case their pharmacy or medical records are not accessible.
  - For medications that require refrigeration, patients and their families should have backup plans to keep medications cold during prolonged power outages.
- **All patients and their families who depend on life-sustaining home care should be familiar with the emergency plans of their home care providers.**



- Know the plan for each home care provider.
- Know how to remain in contact with the providers in an emergency.
- Have a backup plan if their provider is not able to reach them.
- **All patients and their families who depend on life-sustaining electrical devices at home should have access to adequate emergency power sources, such as batteries or an emergency generator.**
- **Patients and their families who depend on life-sustaining supplies at home (eg, peritoneal dialysis solution, oxygen, or intravenous medications) should ensure they have at least several days' worth of supplies at all times**
  - Know how to get resupplied in an emergency
  - Know what to do if re-supplies do not arrive.
- **Patients and their families who depend on life-sustaining equipment at home should know what to do in case of evacuation and how the equipment can be moved.**
- **Some jurisdictions (towns, cities, counties) have registries of medically vulnerable individuals; ask home care providers, utilities, police and fire departments, and public health or emergency management agencies about the registries.**
- **Dialysis patients (either peritoneal or hemodialysis) should know what alternative dietary guidelines to follow in case dialysis is delayed.**
- **Patients and their families who require complicated or uncommon treatments (eg, cancer chemotherapy) should have copies of their medical records and treatment plan with them if they are evacuated and need to seek care somewhere else.**

3. What do you think of these recommendations?
  - a. Are any of the recommendations surprising?
  - b. Are there any suggestions they have made that you think would be difficult to follow? If so, why?

Now I'd like to ask you to tell me in more detail your thoughts on two specific recommendations

- **Some jurisdictions have compiled registries of medically vulnerable individuals; patients and their families should inquire about such registries with their home care providers, utilities, police and fire departments, and public health or emergency management agencies.**
- **Patients and their families who require complicated or uncommon ongoing treatments (eg, cancer chemotherapy) should maintain copies of their medical records and treatment protocols or regimens with them if they are evacuated or if they need to seek alternative sites of care.**

4. What did you think of the recommendation for joining a registry of medically vulnerable individuals? Do you think that is a feasible solution for you? How about for others in your community?
5. What about having copies of complicated treatments or regimens in case a patient is evacuated? Do you think that would be feasible to do? What are some challenges or opportunities around that?

We're almost at the end of our time together, but do you have

6. Any final thoughts on managing your own or someone else's chronic illness through an emergency?

## Appendix C1

### Informational Material for Participants

#### Researcher Seeks Seniors' Opinions on Emergency Preparedness and Managing their Health in Emergencies

Health care providers like hospitals, clinics, home care agencies, rehab centers and long-term care facilities work together to serve patients and their families during emergencies. Recently, researchers from Johns Hopkins interviewed health care providers from the New York City area about how they respond to emergencies. Based on these interviews, the researchers produced a list of health care providers' recommendations and expectations for how patients with chronic conditions and their family members who help them should prepare for emergencies.

For this project, a graduate student researcher from the Murphy Institute at CUNY is recruiting discussion group participants to discuss the list and hear reactions and opinions about the recommendations and expectations. Participants will be offered a small incentive and refreshments in compensation for their time.

Participants for the focus group should be:

- Adult age 65 or older;
- Manage a chronic condition\* for themselves;

OR

- Help a family member (or friend) manage a chronic condition (e.g. help with medication, food preparation, mobility, other activities)

OR

- Have experience helping someone else manage a chronic condition (does not have to be current)

\*Chronic conditions include, but are not limited to: hypertension (blood pressure), diabetes, cardiovascular disease, asthma, arthritis, mobility limitations, and risk for falls, among others.

Participants will not be asked for any specific condition information in the discussion group. The purpose of the discussion group is to understand reactions, opinions, and suggestions for opportunities or barriers/challenges regarding health care providers recommendations and expectations.

Discussion group date and time: 60 minutes, date TBD, but to take place *before* April 17.

About the researcher:

Kristina Ramos-Callan is in her final semester of the Urban Studies program at the Murphy Institute of the City University of New York. Her research is on emergency preparedness among older adults in New York City, in geographically and socially vulnerable communities. She can be reached for questions about the research project via email at [kristina.ramos-callan@spsmail.cuny.edu](mailto:kristina.ramos-callan@spsmail.cuny.edu) or by phone at 917-579-0053.

## Appendix C2

### Oral Consent Script

I am Kristina Ramos-Callan, a graduate student from Urban Studies master's degree program of The Murphy Institute, School of Professional Studies, at the City University of New York.

For my graduate thesis/capstone research, I am conducting a study on older adults' perceptions of emergency preparedness recommendations for patients and families. The research will help me understand what patients and families think about health care providers expectations and recommendations for emergency preparedness steps.

Participants in the study will learn about general household preparedness for emergencies and ways that people with chronic conditions can prepare to self-manage during emergencies. As a thank you for their time, participants will receive printed information on emergency preparedness prepared by the New York City Department of Emergency Management. Participants will also receive a small gift of nominal value, such as a small flashlight.

Lessons learned from this research will be shared with academic researchers, and potentially shared with health care providers, senior service providers, and other health policy professionals to guide work moving forward about emergency preparedness for patients and families.

Your voluntary participation in today's focus group should take about 60 minutes. If you do not wish to participate, you may stop at any time. The discussion will be audio-recorded to help with note-taking. I will assign a pseudonym to participants and your name will not appear in the final report. There are minimal risks associated with this focus group. By taking part in this focus group, you agree to participate and to be audio-recorded.

During the focus group I cannot guarantee confidentiality because we are having a group discussion. I will not be able to guarantee confidentiality because we will be discussing information as a group. If there is anything you feel you do not want shared in or outside of this group, please do not share it during this focus group.

Copies of this letter are available if you would like one for your records. Please let me know and I will give you a paper copy. If you have any questions about this research, please contact me at [kristina.ramos-callan@spsmail.cuny.edu](mailto:kristina.ramos-callan@spsmail.cuny.edu), or 917-579-0053.