# Institute for Public Health Innovation

Identifying Critical Access Rural Counties in MD, NC, VA, and WV for Multiple Sclerosis Education and Care Interventions

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### **Executive Summary**

Institute for Public Health Innovation (IPHI) and Bristol Myers Squibb Foundation (BMSF) have partnered together to improve health care services and capacity for people living with multiple sclerosis (MS) in rural areas of Maryland, North Carolina, Virginia, and West Virginia.

Residents in rural areas face many challenges when accessing health care and specialty care services. These barriers are particularly challenging for people most impacted by MS and other neurodegenerative diseases. This project will address these challenges through

- community engagement
- 2 increased access to trained health care providers
- 3 comprehensive navigation tools

Rural areas face unique challenges like long geographical distances to services and limited specialty care providers. Additionally, there are a variety of demographics that lead to poor health outcomes such as limited job opportunities and a sedentary lifestyle. This report considers rural data such as smoking and excess death rates to help determine areas most at risk for poor health outcomes. Our research also assessed MS-related demographics to further pinpoint highrisk areas such as percent of female residents and adult disability rates.

There are numerous federal definitions used to outline the rural areas of the United States. Each of these definitions has varying levels of effectiveness and relevance to this report. After comparison, we determined The Centers for Medicare and Medicaid (CMS) rurality definition is most relevant to the project goals. This definition includes detailed county information and data on a variety of rural factors from collaborating sources like clinician shortage areas and medically underserved populations, data shared by the Heath Resources and Services Administration (HRSA).

Ultimately, we selected 32 counties from the four states (Appendix A) as the target area for intervention. Each county is in a rural area with some access to medical care and at least one nearby association with larger, comprehensive care systems. This approach can be leveraged to build on the strengths of existing community networks and layer in additive interventions to more effectively identify and support both the physical and social needs of people living with MS.

### Introduction

The Institute for Public Health Innovation (IPHI) has partnered with Bristol Myers Squibb Foundation (BMSF) to improve specialty care access, delivery, and utilization for 5,000 people living with multiple sclerosis (MS) in rural areas of Maryland, North Carolina, Virginia, and West Virginia over the next three years.

These goals will be met by convening people most impacted by MS, improving healthcare capacity, building community connections, bringing health screening to meet people where they are, and network mapping to address resource disparities.

The key indicators for this project include

- expanded patient engagement and social services
- improved patient retention
- improved patient outcomes and quality of life

#### Purpose

This report discusses the various competing rural definitions used at the federal level and determines the definition most relevant to this project. We look at rural health challenges and intersect these with notable risk-factors for MS and common demographics of the MS population. Finally, we use this data to identify the counties most at risk for MS prevalence and thus most important to target for intervention.

### Background

Up to 20% of people in the United States (US) are estimated to live in rural areas. However, depending on the definition used to make this estimate those numbers can fall anywhere between 6.9 million people (roughly 2%) to over 75.5 million people (roughly 23%) (Long et al, 2021). This vast discrepancy is the result of diverse working definitions used to determine the rural population. Several federal agencies have outlined unique definitions of rurality based on a variety of geographic and population density considerations.

As IPHI develops interventions for people living in rural areas impacted by multiple sclerosis and other neurodegenerative diseases it is important to use a consistent and relevant definition of rurality across our service area. Further, we aim to create a specific list of measures and community features that should be considered to effectively target counties most at risk for intervention.

### **Rural Health Risk Factors**

Rural residents are faced with a multitude of barriers when it comes to achieving healthy outcomes. The Agency for Healthcare and Research Quality (AHRQ) lists rural healthcare access and the limited number of specialists as a primary rural health priority in addition to affordability (NHQDR, 2021). Rural residents are markedly disadvantaged when it comes to accessing quality primary and specialized healthcare services (RHI, 2021). While one-fifth of the US population lives in rural areas, only one-tenth of clinicians practice there (Cyr et al., 2019).

The average physician-to-patient ratio in rural areas is 39.8 per 100,000 versus 53.3 in urban areas (Doescher et al., 2009), an important difference when you consider lower mortality rates are associated with an increase of just 10 physicians per 100,000 people (Basu et al., 2019). The need for more quality healthcare providers in rural areas is further evidenced by the fact that almost all HRSA designated healthcare shortage areas are in rural counties. This trend is seen across all types of providers so it's not surprising that specialty healthcare providers are even more scarce and that this lack of access creates profound disparities (Nanni et al., 2016).

Rural residents also face geographic barriers which result in delayed care. More than 5% of rural residents report experiencing a delay in obtaining medical care due to transportation needs (Barton et al., 2021). Considering the US landscape is 86% rural (HRSA, 2021), geography and transportation play a significant role in healthcare accessibility.

There are a variety of other factors that lead to health disparities amongst rural populations including lower socioeconomic status, limited job opportunities, and sedentary, leisure lifestyles (RHI, 2019). Rural residents are also less likely to be insured and have lower rates of private insurance coverage (CDC, 2017).

When reviewing age-adjusted excess death rates, rural areas consistently have significantly higher rates of potentially excess death for the five leading causes of death: heart disease, cancer, unintentional injury, chronic lower respiratory distress, and stroke. (Moy, 2017). In West Virginia, heart disease mortality is 19% higher than the national average (WVDHHR, 2018). Further, amongst rural populations, the majority of Black or American Indian/Alaskan Natives have higher rates of premature death (Henning et al., 2009). Overall low-income, rural, and minority populations are more likely to die from disease (Nanni, 2016).

Socioeconomic status, race, and geography are predominant determinants of health leading to health equity ramifications. These factors are recognized in the West Virginia Rural Health Report which states for "All citizens to receive equal access to healthcare services without culture, distance, language, finance, or terrain being barriers" (WVDHHR, 2018).

Our project to improve specialty care access for people living in rural areas with MS will enhance the existing community and health structures to improve outcomes in rural settings and address health disparities for the MS and ND populations across Virginia, West Virginia, North Carolina, and Maryland. As we assess the level of risk for each rural county in our target area, we will look at healthcare clinician shortage areas, medically underserved areas, rates of age-adjusted premature death, poverty, healthy lifestyle choices, and rates of uninsured and underinsured residents to isolate those most primed for intervention. For example, the Appalachia region, which includes all four of our target states, has a significantly higher mortality rate at 372.3 deaths per 100,000 to 280.5 deaths per 100,000 in non-Appalachian regions (RHI, 2021).

### **Multiple Sclerosis Risk Factors**

People living with MS and other ND and caregivers, or people most impacted (PMI), have unique, ongoing needs that require advanced support and specialized healthcare. Although there are no cures for ND, early diagnosis and access to disease-modifying treatments are essential to ease symptoms and potentially slow the progress of disease. For PMI by MS these early interventions are also crucial to limiting rates of disability. This is a critical consideration of our work as MS is the leading cause of non-traumatic disability amongst middle-aged adults (Dimitrov et al., 2014).

Globally, an estimated 35.9/100,000 people have MS. In the US, estimates are as high as one million. This is significantly higher than earlier estimates of 250,00 to 350,000 (Mitchell et al., 2019). The increase seems to be the result of improved awareness, earlier diagnosis, and increased healthcare access as there is no definitive evidence to suggest that MS incidence is on the rise (Walton et al., 2020).

We aim to expand on these gains by bringing effective and lasting interventions to communities exhibiting factors which place them most at risk for MS. Alongside the rural health risk factors previously identified we look to apply population data relevant to the specific risk factors for MS.

Geography not only plays a role in reducing healthcare access it also plays a role in MS prevalence as instances of MS diagnosis increase in populations further north of the equator. This latitude gradient factor continues to play a significant role in the prevalence of MS however, studies are proving that this is not as steep as once thought (Noonan et al., 2010). Instead, Vitamin D exposure may play a role (NMSS).



Gender also plays a significant role in MS-risk as it is three times more common in females. Current data suggests about 74% of diagnoses are female and about 26% male in the US.

Most people are diagnosed with MS between the ages of 20 and 50, with 32 being the average age of diagnosis (Noonan et al., 2010). There is an increased awareness of pediatric MS and proper treatment, but the incidence is still rare (Brenton et al., 2020).

MS occurs in all racial groups though Caucasians of Northern European ancestry have the highest rates. As a result of improved diagnostic practices and awareness the rate of MS among African Americans is rising however, showing that the prevalence of MS may be more consistent across some racial groups than previously thought (Noonan et al., 2010).

Although it is not directly inherited there is some evidence to suggest that genetics play a role. A person has a 2-3% higher chance of developing MS if they have a direct relative with the diagnosis (Patsopoulos, 2018).

There are also a variety of other characteristics of people living with MS to consider

- Obesity, particularly for females in childhood or adolescence appears to be a factor contributing to the development of MS in adulthood and the progression of the disease (Gianfancesco & Barcellos, 2016)
- People living with MS have higher rates of unemployment due to disability ranging from 32% to 80% of the MS population (Strober, 2020)
- Women who smoke are 1.6 times more likely to develop MS and often experience a more severe form of the disease or rapid progression (NMSS)
- People living with MS are at a higher risk of developing a mood or psychiatric disorder such as bipolar and schizophrenia. One-third to one-half of people living with MS will experience a major depressive episode in their lifetime. One-third of the MS population have anxiety disorders (Chwastiak et al., 2007)
- Studies have also shown that people living with MS have an increased rate of clinician visits for five years prior to diagnosis (Mayor, 2017)

There are already concerns about the increasing demands for rural physicians in general and the slow growth of rural health care practitioners. Only 11% of the clinician workforce practices in rural areas and this number is expected to decrease further as physicians retire (Jaret, 2020). This shortage particularly affects MS populations as shown by the need for increased clinical visits prior to diagnosis and the lack of physician training on MS-specific risks, symptoms, and treatments. Individuals with MS have reported that the lack of MS-specific training often leaves them as the physician trainer. During IPHI's recent ND Congress, a person living with MS spoke about using her appointment times to educate providers on her specific type of MS, symptoms, and treatments (Ruiz et al., 2022). People living with MS report a higher satisfaction of care when they are treated by an MS specialty neurologist and are more likely to be offered disease-modifying therapies. The neurologist workforce is expected to increase by approximately 1% by 2025 and 12% by 2035. Based on the increase of neurodegenerative disease incidence however, these increases may not et al., 2018). Although people living with MS benefit the most when they receive care from MS specialist neurologists, these practitioners account for only 4% of the neurological clinician workforce. Of that small number of MS specialist neurologists, only 6% of those specialists practice in rural areas. By 2025 there is an expected increase of 17% MS specialists across the US, about 69 skilled physicians.

At these rates, the increasing number of rural specialists will still not increase total capacity for MS patients (Halpern et al., 2018). The number of MS specialists in rural areas will remain extremely limited, exacerbating the current reality of primary care physicians attempting to treat MS patients without having knowledge of the disease or its treatments. In these settings, rural patients often end up relying on the use of safety net clinics and intermittent emergency room care. Alternative solutions are critical to addressing this gap in care. According to FSG and BMSF Breaking the Barriers to Specialty Care briefs, some of these include building the capacity of primary care physicians, telemedicine, and coordinated specialist networks (Nanni et al., 2016).

To support the needs of veterans living with MS and improve provider training and clinical care, the Veterans Health Administration (VHA) created MS Centers of Excellence. This effort includes 29 regional programs and 49 MS support networks. It is designed to ensure veterans have access to quality care throughout various regions of the US. Additionally, the VHA uses a unified program of education to support all people impacted by MS including providers, patients, and caregivers (Cameron et al., 2020). The distribution of these centers gives insight into rural access and opportunities to increase clinical support and training. The consortium of Multiple Sclerosis Centers (CMSC) compiles lists of providers skilled at delivering quality MS care as well as more comprehensive providers.

The locations of these facilities are one element we will assess from our MS specific data to inform the selection of our target counties. Additionally, we will consider population data to further define the scope of this program. Rural counties with a higher population of the most common age group for diagnosis (25-34) and a high percentage of ethnically diverse females for example will be targeted to increase the impact of education and screening events.



### **Rural Definitions Analysis**

#### **Definition 1**

The United States Census Bureau defines rural census tracts as anything not urban. The census bureau has over 70,000 census tracts that fall under three categories. These categories are defined by Rural Health Information Hub

- An Urbanized Area (UA) has an urban nucleus of 50,000 or more people. Individual cities with a population of 50,000 may or may not be contained in these UAs. UAs have a core (one or more contiguous census block groups or BGs) with a total land area less than two square miles and a population density of 1,000 persons per square mile. They may contain adjoining territory with, at least, 500 persons per square mile and encompass a population of at least 50,000 people
- An Urban Cluster (UC) also has a core as identified above with a total land area of less than two square miles and a population density of 1,000 persons per square mile. They may contain adjoining territory with, at minimum, 500 persons per square mile and encompass a population of at least 2,500 but less than 50,000 persons
- A rural area consists of all territory, population, and housing units located outside of UAs and UCs (RHI, 2022)

Although the census bureau has a vast, detailed, and consistent rural definition, it tends to overcount the rural population at 19.3% of the US population. Further, it does not follow city or county boundaries and often, the Census mistakenly defines suburban areas as rural (Long, 2021). This definition is particularly challenging for our model therefore as suburban areas typically see greater access to specialty services and would not share the same needs of PMI by MS living in rural areas.

#### **Definition 2**

The Office of Management and Budget (OMB) defines rural as counties outside of designated metro and micro counties. Metro counties have a population of over 50,000 people and micro counties have a population of 10,000-49,999 people. Rural counties in this definition include approximately 15% of the US population (HRSA, 2021).

Notably, many rural health researchers define both nonmetropolitan and micropolitan areas as rural. The OMB describes these areas as:

Metropolitan statistical areas, or metro areas are central or core counties with one or more urbanized areas and outlying counties that are economically tied to the core counties as measured by work commuting. Outlying counties are included in a metropolitan statistical area if 25 percent of workers living in the county commute to the central counties or if 25 percent of employment in the county consists of workers coming out from the central counties

- the so-called "reverse" commuting pattern (RHI, 2022)

Nonmetropolitan (nonmetro) counties are outside the boundaries of metro areas and are further subdivided into two types

Micropolitan statistical areas, or micro areas, are any nonmetro county with an urban cluster of at least 10,000 persons. It is further defined as the central county of a micro area. Like metro areas, outlying counties are included if commuting to the central county is 25 percent or higher or 25 percent of employment in the outlying county are commuters from the central county

Noncore counties all lack an urban core (RHI, 2022)

The OMB's definition uses county lines and is commonly used as a starting point for outlining rural areas. However, the OMB's rural definition tends to undercount the rural population. Further, this definition often misidentifies some rural areas as metro. As a result, the OMB created Urban Influence Codes to further compartmentalize nonmetro counties into ten categories by size of the largest city and proximity to metro and micropolitan areas. This categorization breaks down county data into smaller residential groups (USDA, 2019)

#### **Definition 3**

The US Department of Agriculture has further enhanced the Census and the OMB definitions by creating a subset of rural and nonrural constructs. The Rural-Urban Commuting Area (RUCA) codes were created with the Economic Research Service (ERS) and the Federal Office of Rural Health Policy (FORHP). This strategic model is particularly adept at finding rural areas within metro counties. This definition captures about 19.7% of the US population (RHI, 2022). This model is often preferred by national health agencies due to its in-depth analysis of population density, urbanization, and daily commuting. Additionally, it can assess data based on zip codes or census tracts (USDA, 2019).

Although the RUCA codes are detailed and offer a varied perspective of rural counties, they are less useful in factoring distance to services or finding low-density populations (Long, 2021). Additionally, they do not use county boundaries to compare healthcare services.

#### Maryland

**North Carolina** 

Virginia

West Virginia

Graphs (select links to view) demonstrating the differences between RUCA, Census, and OMB

#### **Definition 4**

The Health Resources and Services Administration (HRSA) and the Federal Office of Rural Health Policy (FORHP) use the Census and the OMB rural definitions along with RUCA codes to create their agency-specific definitions. Further, HRSA attempted to overcome the limitations of the RUCA codes by coding the census tract with added rural parameters to include

- all non-metro counties
- all metro census tracts with RUCA codes 4-10
- large area metro census tracts of at least 400 sq. miles in areas with population density of 35 or less per sq. mile with RUCA codes 2-3
- all outlying metro counties without a UA (HRSA, 2021)

#### **Definition 5**

The Centers for Medicare and Medicaid Services (CMS) defines rural as all territories, population, and housing units found outside of UAs and UCs per the OMB's guidelines. Further, the CMS enhances county-level data with the USDA-ERS RUCA codes (Farley, 2022). CMS places a focus on HRSA Health Clinician Shortage Areas defined as "an area, population, or facility experiencing a shortage of healthcare services" (HRSA, 2021). This is particularly helpful to our engagement model as we focus on addressing health provider shortages in rural areas.

There are also limitations to the CMS model. Most notably are concerns that the shortage areas may not use sufficient data to find the most underserved populations. Further, when compared to others, CMS data finds a smaller discrepancy in rural/urban disparities (Long, 2021). The number of CMS rural health areas and health shortage areas vary significantly. For instance, Maryland has five CMS rural counties and 27 HRSA health clinician shortage areas. West Virginia has 34 CMS rural county designations and 50 HRSA shortage areas (HRSA, 2021). The varying level of access and sheer numbers of rural counties require a strategic selection process.

To achieve our project goals, we seek to improve specialty rural care and enhance healthcare outreach rather than assemble a healthcare network. Therefore, the target counties will need to have some access to primary health care facilities and ideally some level of coordination with a larger, comprehensive health network. These parameters will ensure collaborative opportunities to improve healthcare provision, increase MS and ND screenings, and supply follow-up care.

Federal Agency	Defining Terms	Pros	Cons
Census	<ul> <li>Urban Areas/Clusters (2500- 50,000 or more)</li> <li>Rural</li> </ul>	· Vast · Detailed · Consistent	<ul> <li>Tends to overcount</li> <li>No city / county boundaries Often counts suburban as rural</li> </ul>
ОМВ	<ul> <li>Metro, Micropolitan, Noncore County, Nonmetro</li> </ul>	<ul> <li>More layers to describe outlying metropolitan areas</li> <li>Divided by counties and zip codes</li> </ul>	<ul> <li>Some rural areas are inappropriately excluded</li> <li>Created Urban Influence Codes to address this exclusion</li> </ul>
USDA-ERS	· Rural Urban Commuting Area (RUCA)	<ul> <li>Population density data</li> <li>Assesses urbanization and daily commuting</li> <li>Identifies rural areas within metro areas</li> </ul>	<ul> <li>Less useful when factoring distances to services</li> <li>Still misclassifies areas within counties</li> <li>Unable to use county boundaries</li> </ul>
HRSA/FORHP	· Census + OMB + RUCA Codes + Additional RUCA codes	<ul> <li>Can identify rural tracts in urban counties</li> <li>Inclusive and flexible</li> <li>Includes outlying metropolitan statis- tical area counties with no urbanized area population</li> </ul>	<ul> <li>Eligibility guidelines for many health grants and access</li> <li>Has known flaws when naming rural areas</li> </ul>
CMS	• Urban, Urban Clusters, Rural	<ul> <li>Focus on clinician shortage areas</li> <li>Adept at predicting long term financial stability of an area</li> </ul>	<ul> <li>Shortage areas may not use sufficient data to define underserved populations</li> <li>Calculates a smaller discrepancy in rural/ urban disparities</li> </ul>

# Findings

As IPHI builds an engagement model to improve specialty care access, delivery, and utilization for rural residents living with MS it is imperative we use a consistent, federal definition of rurality that allows us to access and compare relevant data. The varied federal rural definitions create dynamic rural borders which can lead to inconsistencies in analyzing community needs.

In addition to a consistent rural definition, our model relies on detailed selection criteria for the targeted rural areas. This is to ensure we can effectively identify rural areas at the intersection of highest risk for rural health challenges and MS specific challenges to target for intervention.

After assessing the commonly employed federal definitions IPHI believes our project, "Increasing Access to Specialty Care for Rural Populations Impacted by multiple sclerosis in NC, VA, WV, and MD" best aligns with the CMS rural county definition. The CMS rural definition encompasses a variety of federal parameters and includes the Census' UAs and UCs as well as the USDA-Economic Research Services, Rural-Urban Commuting Area codes. Finally, it encompasses HRSA's data on healthcare provider shortage areas, which is a particularly relevant data set when analyzing access to health care services.

The MS population risk factors we considered in our assessment include rates of disability, unemployment, age-adjusted mortality, gender, and rates of smoking. Rural health risk factors we considered include uninsured population rates, broadband access, and factors contributing to delayed care.

We also considered the minimum health care access points in each county. To support our ability to enhance services and improve delivery of specialty care, we identified areas with access to a comprehensive facility within 50 miles or access to an extension clinic associated with a broader comprehensive care system. The following tables list healthcare facilities that play a significant role in coordinating care and responding to patient needs in the target counties.

State	Comprehensive Clinics
Maryland	· John Hopkins Center of Excellence Baltimore & Extension Clinics
North Carolina	<ul> <li>North Carolina VA Center of Excellence Support Program – Salisbury NC (Rowan County)</li> <li>North Carolina VA Center of Excellence Regional Program – Durham NC (Durham County)</li> <li>UNC Caldwell Clinic (Caldwell County)</li> <li>Consortium of Multiple Sclerosis Centers (Forsyth County)</li> </ul>
Virginia	<ul> <li>Consortium of Multiple Sclerosis Centers (Albemarle County)</li> <li>Consortium of Multiple Sclerosis Centers (Roanoke County)</li> <li>National Multiple Sclerosis Center Comprehensive/Partner Facilities (Nottaway County)</li> </ul>
West Virginia	<ul> <li>Consortium of Multiple Sclerosis Centers (Albemarle County)</li> <li>Consortium of Multiple Sclerosis Centers (Roanoke County)</li> <li>National Multiple Sclerosis Center Comprehensive/Partner Facilities (Nottaway County)</li> </ul>

This multidimensional approach informed our selection of high-risk rural areas for intervention and helped us garner a firm understanding of the needs of PMI in those areas (Appendix B).

# Appendix A

State	Counties
Maryland	· Caroline County · Garrett County
North Carolina	<ul> <li>Caswell County</li> <li>Duplin County</li> <li>Greene County</li> <li>Jones County</li> <li>Lenoir County</li> <li>Montgomery County</li> <li>Surry County</li> <li>Wilkes County</li> </ul>
Virginia	<ul> <li>Brunswick County</li> <li>Buckingham County</li> <li>Charlotte County</li> <li>Cumberland County</li> <li>Danville County</li> <li>Henry County</li> <li>Henry County</li> <li>Louisa County</li> <li>Lunenburg County</li> <li>Martinsville County</li> <li>Nottoway County</li> <li>Orange County</li> <li>Patrick County</li> <li>Prince Edward County</li> </ul>
West Virginia	<ul> <li>Fayette County</li> <li>Marion County</li> <li>McDowell County</li> <li>Mercer County</li> <li>Monroe County</li> <li>Preston County</li> <li>Preston County</li> <li>Raleigh County</li> <li>Summers County</li> <li>Wetzel County</li> <li>Wyoming County</li> </ul>

# Appendix B

Example of criteria considered to inform the selection of target counties based on MS risk.

Pop: Not Employed (%)         41 no 20           2015-2019         26 to 20           Pop: Bitability (%)         26 to 20           2015-2019         26 to 20           Pop: Households With No Broadband (%)         17 to 20           2013-2019         17 to 20           Pop: Uninsured, Est.         9 to 100           Pop: Age Adjusted Montality Rate (per 100,000), Est.         849 to 20	00%
Pop: Disability (%) 2015-2019 25 to 10 Pop: Households With No Broadband (%) 2013-2019 17 to 10 2013-2019 9 10 100 Pop: Uninsured, Est. 9 to 100 Pop: Age Adjusted Mortality Rate (per 100,000), Est. 2017-2019	00%
Pop: Households With No Broadband (%) 2015-2019 Pop: Uninsured, Est. (%) 2039 Pop: Age Adjusted Mortality Rate (per 190,000), Est. 2017-2019	
Pop: Uninsured, Est. 9 to 100 (%) 2019 Pop: Age Adjusted Mortality Rate (per 100.000), Est. 2017-2019	00%
Pop: Age Actusted Mortality Rate (per 100.000), Est. 2017-2019	0%6
Darrow & all Alex Male & Alexandre	1813
Pog: Acuts Milo Nave Delayed/ Not Sought Care Due to Cost, Est. (%) 2017	8%
Pop: Adults Who Smoke, Est. (%) 2018	8%
States	
Courties	
ZCTA6	
Geographical Area Primary Care HPSAs Single County Population Group	
Medically Underserved MIGA Areas/Populations MIDP (MUA/P) Governor Designated	
Pop: Uninsured at 138%-400% FPL (%) 2015-20	19
<50%	
55 - 62%	
66 - 70%	
76-80%	
-50%	
Selected ZCTA6	



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