URBAN INSTITUTE

Leveraging Partnerships and Data to Improve Rural Health and Well-Being

A Guidebook for Rural Practitioners

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Contents

Rural communities face many health challenges, often related to structural barriers such as limited access to health care. Targeted services and programs can improve rural health and well-being but require strong partnerships and committed funding. Good data can help identify problems and track how well new programs are working. This guidebook provides ideas and examples for rural stakeholders and communities who want to improve rural health and well-being by building partnerships, implementing innovative service models, and leveraging data.

Who is this guidebook for?

Three groups may find this guidebook useful for exploring program models, partnerships, and data to improve rural health and well-being:

- **Rural community and economic development specialists** who work on improving local economies and social well-being. They may finance or build housing or support systems delivering water, sewer, or broadband internet services to communities. They may also finance and assist local businesses and community spaces like schools and libraries and may want to learn how to focus more on health.
- **Rural health services professionals** who help prevent health problems and address urgent health needs. These medical experts may be looking for different partners and models to work closely with other community stakeholder groups and actors to address health needs.
- **Funders focused on improving rural health** who may want to learn about promising health models and partnerships that they could potentially invest in to help meet their funding goals.

What is addressed in this guidebook?

Readers will find information, guidance, and recommended resources about the following topics:

- making a general case about rural health needs to policymakers and funders, including the challenges and opportunities in meeting these needs
- identifying potential local partners for improving rural health and well-being
- considering service models for rural programs or communities
- measuring progress to understand if programs are achieving desired goals
- finding and using the best data to identify problems and track outcomes

Making the Case for Pursuing Rural Health Initiatives

Why should policymakers and funders focus on rural health and well-being?

Rural communities in the United States face unique health challenges that require attention and resources. Americans in rural areas are more likely to die from heart disease, cancer, unintentional injury, chronic respiratory disease, and stroke than people in more urban areas.[1] Diabetes is 17 percent more prevalent in rural areas than urban ones and cigarette smoking is also more common.[2] Children and teenagers in rural areas are at higher risk for injuries and unintentional death related to injuries than those living in urban areas.[3] People living in rural counties are also more likely to not have health insurance compared to people living in urban counties (Terlizzi and Cohen 2022).

Regionally, some rural areas of the country experience worse health conditions and outcomes than others and may need tailored supports to promote health and well-being. Rural people in the southern US, particularly people of color, have the highest rates of illness and death in the country (Miller and Vassan 2021). People in the rural Appalachian region experience higher rates of obesity, drug use and overdoses, and smoking.[4] This region also has fewer health care providers, including primary care, mental health, and dental providers. In several counties along the US border with Mexico, tuberculosis rates are higher than the national average.[5] People living in the four states bordering Mexico—Arizona, California, New Mexico, and Texas—are less likely to have health insurance than people in other states.[6]

Certain rural populations face unique health challenges and may need expanded access to health services and additional investments to support their well-being. For example, farmworkers face many hazards while working, such as exposure to chemicals, extreme heat, and extreme weather conditions.[7] Many are also often immigrants who do not qualify to receive health insurance. American Indian and Alaska Native people live 5.5 years less than the average US resident.[8] They are also more likely than the average US resident to die from liver disease, diabetes, unintentional injuries, homicide, and suicide. Experiencing deep poverty across generations can also contribute to poor health in every area, regardless of other population characteristics.[9]

What structural barriers require innovative approaches to improving rural health?

Structural issues affect the health of many rural people and communities, in some cases leading to worse health outcomes than those of urban or suburban people. Innovative approaches and

partnerships are key to addressing these geographic disparities and expanding rural health access and opportunity.

Many rural health service providers struggle to stay open, which can decrease physical access to health services in rural communities. Between 2005 and 2019, 150 rural hospitals closed across the country (Center for Healthcare Quality and Payment Reform 2023). In 2020, an additional 18 rural hospitals closed and many more are at risk of closing today. One consequence is fewer facilities to help people during and after they give birth (McMorrow, Benatar, and Fisher 2021). Rural health facilities often serve fewer patients than urban ones, but many costs of providing services are the same. Facilities close when they cost more to run than the money they bring in. Additional government funds during the COVID-19 pandemic helped many rural hospitals stay open, but many are in trouble again today.[10]

Many rural people are also not well-connected to existing health services. Physical facilities can be a long distance from where people live, and some people in rural areas lack adequate or reliable transportation.[11] Telehealth connections—medical appointments that happen over the internet instead of in person—are helpful but not always appropriate. They can also be difficult for residents that do not have access to high-speed broadband internet or reliable cellular service. More than one in five rural people do not have broadband coverage.[12] Broadband is even more limited on tribal lands. Even when people have access to health services, the services may not be offered in the right language or in a way that builds trust and respects cultural differences.[13]

Finally, launching new rural health initiatives requires data, partners, and funders. It can be difficult to access quality data on rural individual and community health needs. It can also be challenging to understand promising models, select potential partners, and identify and access funding options. Proving that a program is working to improve health outcomes for rural people and communities can be difficult, too. We hope this guidebook helps address many of these challenges. Box 1 provides further resources to support case making for rural health policy and program innovations.

BOX 1

Resources that Can Help Make the Case for Rural Health

The below resources provide information about rural health that can help practitioners make the case to policymakers and investors for the need for rural health program innovations and expansions.

Centers for Disease Control and Prevention

https://www.cdc.gov

The Centers for Disease Control and Prevention (CDC) provides relevant statistics to better understand and communicate the current state of health in rural America.

Healthy People 2030

https://health.gov/healthypeople

Healthy People 2030 has 10-year, data-driven public health objectives with tools to track progress. Objectives address numerous health conditions, health behaviors, populations, settings, and social determinants of health. Each of these objectives contains relevant data and evidence-based resources.

National Rural Health Association

https://www.ruralhealth.us

The National Rural Health Association is a nonprofit membership organization comprised of individuals and organizations with an interest in rural health. The website has an "Advocacy" page that contains information on policies impacting rural health.

Rural Health Information Hub

http://www.ruralhealthinfo.org

The Rural Health Information Hub contains many health-related resources focused on rural areas, including toolkits, program models, health statistics, government- and foundation-funding resources, and data.

Identifying Partners

Partnerships can be essential to the efficacy of programs or organizations, as one organization may not have all of the capacity and skills needed to address the health needs of their rural communities. Partnerships can be organized formally through paid contracts or other legal agreements, such as memoranda of understanding, that spell out the roles, responsibilities, and resources committed to the initiative by each partner. Or partners may sign agreements to share data with one another in a secure way. Partnerships can also be voluntary and informal, such as coalitions or referral networks that agree to support one another's work toward a common goal by sharing information, providing physical spaces for meetings and health services provisions, and referring clients.

Identifying and forming partnerships takes time and effort. Below are some common health service providers and other types of partners that rural community and economic development specialists and funders can consider engaging.

What types of health service providers make good partners?

Private and public health care providers can be valuable partners. These providers may include hospitals, federally qualified health centers, and school-based health centers.

- **Public or private hospitals**. Public hospitals are owned by the government and are not-for-profit. Private hospitals may be for-profit or nonprofit. If hospitals are nonprofit, they do not have to pay taxes to the government but in exchange must provide additional benefits to their communities, such as an emergency room open to all regardless of ability to pay. Funding for hospital services comes from patients or their health insurance. Hospitals may have less flexibility in their programming than other health care providers, but often help train new medical staff and conduct community outreach.
- **Federally qualified health centers**. Federally qualified health centers meet community health needs through outpatient clinics—meaning they do not admit patients to stay overnight. They have a special designation from the federal government that qualifies them for reimbursement under Medicare and Medicaid. Federally qualified health centers must meet specific criteria:
  - » provide comprehensive care regardless of a patient's ability to pay
  - » employ teams with diverse skills to meet patient needs
  - » coordinate medical care and other services that facilitate access to care
  - » collaborate with other providers and programs, such as behavioral health agencies, local hospitals, and local colleges and universities, to improve access to care and community resources

  Federally qualified health centers may do outreach and provide education.

- **School-based health centers**. School-based health centers are comprehensive primary care facilities located within or on the grounds of a school. These are different from existing school clinics that meet urgent needs of students that emerge during the school day. School-based health centers may provide physical, mental, and dental health care. School-based health centers may serve students and their families and even the whole community.
- **Community health worker (CHW) programs.** Community health worker programs, also known as *promotores* and *promotoras de salud* in Spanish-speaking communities, mobilize community health workers: trusted individuals that help connect community members to available medical and social services. Common types of assistance include translation and interpretation services and providing culturally appropriate health education. Community health workers usually have similar cultural identities and life experiences as those in the communities they work in. This helps them connect with communities that are harder for traditional health services to reach.
- **Area health education centers.** An area health education center's purpose is to develop and enhance education and training networks within communities, academic institutions, and community-based organizations.

Which other partners can help advance rural health and well-being?

Health service providers are not the only partners to work with. Many organizations are involved in rural health equity and can offer a diverse range of supports and resources. Organizations focused on food access, housing access, and transportation provide important supports that can affect health outcomes. School districts and local governments may also be effective partners and can help increase the scope of a program's impact.

Researchers focused on learning and evaluation, who may be based at research centers and universities, can also be partners, as can funders that support rural health initiatives, including Medicare and Medicaid, state governments, and the federal government. Box 2 provides links to additional resources on finding local partners and building effective partnerships.

BOX 2

Resources Related to Finding Partners and Building Effective Partnerships

The below resources provide helpful advice on finding partners:

Area Health Education Centers Directory Report
US Health Resources and Services Administration
https://data.hrsa.gov/data/reports/datagrid?gridName=AHECDirectoryReport
This directory allows users to look up area health education centers by state and find contact information for program directors.

Community Health Worker Resources
Centers for Disease Control and Prevention
https://www.cdc.gov/chronicdisease/center/community-health-worker-resources.html
This federal agency resource page about community health workers includes resources on policies and program implementation and evaluationacross the country, including a focus on specific health needs, such as diabetes, asthma, and infectious disease.

Engaging Your Community: A Toolkit for Partnership, Collaboration, and Action (pdf)
John Snow, Inc.
https://publications.jsi.com/JSIInternet/Inc/Common/_download_pub.cfm?id=14333&lid=3
This resource, developed for the US Department of Health and Human Services, Office of Adolescent Health, provides tools and resources for building strategic health partnerships, creating effective outreach strategies, and establishing clear communication between partners.

Find a Health Center
US Health Resources and Services Administration
https://findahealthcenter.hrsa.gov/
This tool helps users to find nearby health centers they can partner with.

Guide for Rural Health Care Collaboration and Coordination (pdf)
US Health Resources and Services Administration
https://www.hrsa.gov/sites/default/files/hrsa/rural-health/resources/hrsa-rural-collaboration-guide.pdf
This guide highlights why rural health care collaboration and coordination is important, lists key considerations, and provides examples.

MHP Salud
https://mhpsalud.org/our-programs/promotoras-de-salud/
This national nonprofit is dedicated to strengthening underserved communities by improving access to health care and social services and provides additional information on *promotoras de salud* and the important role of these community health workers in Hispanic communities.

National AHEC Organization
https://www.nationalahec.org/
This organization helps its 300+ Area Health Education Center members enhance access to quality health care by improving the supply and distribution of healthcare professionals via strategic partnerships with academic programs, communities, and professional organizations. It provides an additional information on the work of AHECs, news from members, and hosts events and conferences.

Rural Health Information Hub Resource Directory
https://www.ruralhealthinfo.org/resources/types/directory
This directory provides a national list of hospitals as well as some resources for individual states and tribes. It is updated every January.

School-Based Health Alliance
https://www.sbh4all.org/resources/
This national nonprofit works to improve the health of children and youth by advancing and advocating

for school-based health care provided by more than 2,500 programs across the country. Its resource page includes information on COVID-19, telehealth, vaccines, and school-based health center toolkits.

School-Based Health Centers, in Social Determinants of Health in Rural Communities Toolkit
Rural Health Information Hub
https://www.ruralhealthinfo.org/toolkits/sdoh/2/healthcare-settings/school-based-health-centers
This toolkit section provides additional information on school-based health centers, examples, and resources.

Choosing Service Models

What types of service models are working for rural communities?

A variety of service models exist for meeting rural health needs, including providing on-site services, bringing services closer to work and home, referral networks, and technical assistance. Many rural health services providers and partners have adapted and mobilized these models to meet rural health needs across the country. We provide examples below of each model, and highlight practitioners who are blending these approaches to comprehensively meet the needs of their target populations.

Providing On-Site Services

Improving physical access to health services in the community is a good starting point for communities with existing health facilities or with other buildings where health services could be added. Transportation can be a challenge in rural areas, and colocated services can reduce barriers to accessing necessary supports for individuals and families. Colocated services are based in the same physical space, allowing individuals to access different types of services, resources, and providers all in one visit.

The Sapling Center[14] at Kentucky River Community Care is a community mental health center that offers a safe and supportive environment for teenagers with free services and support for rural youth experiencing housing instability. By colocating resources and providers, the center lowers barriers to access for teens by creating one place where they can receive the different supports they may need. The Sapling Center has a case manager, housing navigator, and therapist on site. Additionally, the center offers drop-in hours from 12 p.m. to 8 p.m., which provides access to individual counseling, group therapy, life skills training, youth groups, and arts and crafts to support the transition into adulthood. The center also provides food, computer labs, lending libraries, games, and workshops on topics such as cooking, careers, job skills, and health. Resources at the center include showers, washers and dryers, a kitchen, food boxes, hygiene boxes, and cleaning supplies. Through the Youth Homeless Demonstration Project, the Sapling Center can add youth to a voucher list. Through the Supportive Services Only program, youth can receive a stipend to assist with food and transportation. Transition Age Youth Individual Placement and Support (TAY IPS) provides youth with career exploration and job support.

Adding health services in public buildings that potential patients already visit can also be beneficial. The state of Arkansas has a grant program for schools to create school-based health centers. In 2010, the Arkansas state legislature passed a bill through the Arkansas Department of Education, in partnership with the Arkansas Department of Health, to provide grant funding for school-based health centers throughout the state. The state funding is competitive and schools need to demonstrate the need for a school-based health center in their community. The state has three specific goals for this

funding: (1) improve attendance, (2) increase early and periodic screening, diagnosis, and treatment, particularly for people receiving Medicaid, and 3) ensure that center hours and provider staffing is adequate to meet patient needs.

Services that respect local culture are necessary to ensure that different groups of people feel comfortable seeking health care when they need it. One Community Health,[15] located in Hood River, Oregon, is a nonprofit, federally qualified community and migrant health center which provides medical, dental, behavioral, and preventive health services. One Community Health includes a Native American-centered health and wellness team comprised of Indigenous team members. This team ensures that the local indigenous communities receive culturally appropriate health care services.

Bringing Services Closer to Home or Work

The Community health worker (CHW) model is implemented in rural communities across the country. CHWs are trusted community members who bring important medical information and connections to their community. Rural Health Projects Inc.,[16] a community-based nonprofit, provides a series of activities and programs to improve the health of rural residents in northwest Oklahoma. The HOME (Health Outreach to Marshallese in Enid) program is intended to provide culturally appropriate patient services navigation and health education, such as how to manage diabetes and other chronic health conditions, to the Marshallese population in Enid, Oklahoma. Initially, the program struggled to reach and build trust with the local Marshallese population. Rural Health Projects Inc. decided to transition HOME to a community health worker model. They provided resources to train CHWs and subsequently saw an increase in trust and participation in the programming thanks to the efforts of the CHWs.

The Native American–centered health and wellness team at One Community Health in Hood River, Oregon, has two mobile health care clinics used to minimize barriers to receiving health care, such as transportation and childcare. One mobile unit works to reach 32 different tribes along the Columbia River George, particularly during the salmon fishing season in the summer, by providing connections to resources, health education, health insurance enrollment, primary and behavioral health services via telehealth, chronic disease screening, basic medical care, oral health, and distribution of health, food, hygiene and clothing supplies. The other mobile unit has a full exam room and small lab and rotates between schools and workplaces providing bilingual services in Spanish and English, including assistance enrolling in health insurance.

Referral Networks

Referral networks are groups of health care providers and organizations who send each other patients. If one health care organization does not provide the specific care someone needs, that organization can refer the patient to a different place where they can receive that care. Referral networks can help address unmet needs but may not alleviate some barriers to care, such as transportation.

The ability to make referrals to other referral network members online appears to be working for rural communities across the country. In Minnesota, Winona Health created a community intervention that is based upon online referrals.[17] Through a community health needs assessment and community listening sessions, Winona Health established the Winona Wellbeing Collaborative in 2016. The collaborative focused on addressing siloed agencies through a community hub model. The hub model includes three steps: (1) find at-risk individuals and determine risks, (2) treat each identified risk with individual care, (3) measure outcomes for each identified risk. Individuals are identified through referral partners, and referrals are made through an online portal that centralizes referrals. Since 2016, there have been 292 participants referred through the hub model (American Hospital Association 2022).

In the Appalachian Highlands of Virginia and Tennessee, Ballad Health joined Unite Us to create a coordinated care network.[18] Unite Us is a national technology company that uses its software to create coordinated care networks. With the Unite Us software, a patient's specific social needs can be noted in their record when seen by Ballad Health or a network partner. If a referral is made, organizations receiving the referral are notified, and partners then update patient progress in the patient's records.

Technical Assistance

Technical assistance provides targeted support to address a certain organizational need or problem, and can be a model to improve the quality of care that patients receive. The California Maternal Quality Care Collaborative develops toolkits to improve quality of care.[19] These research-based toolkits focus on preventable death and complications for mothers and infants. The collaborative launched large-scale outreach initiatives to implement the evidence-based care described in their toolkits. From 2017 to 2019 they had three rounds of cohorts as a part of the Supporting Vaginal Birth Quality Collaboratives,[20] which provided hospitals with technical assistance in implementing quality improvements, such using real time data for feedback, participating in learning groups, and launching public education campaigns.[21]

Health Care Workforce Development

The lack of adequate providers in many rural areas poses challenges for both patients and health care organizations. Models that support providers who are trained to work with rural populations may help fill gaps in health care access and equity in rural communities. The University of Wisconsin-Madison Department of Obstetrics and Gynecology offers a rural residency track.[22] This program was created in response to the growing shortage of physicians in rural areas and includes increased training for medical residents on rural health disparities. Through partnerships with rural Wisconsin hospitals, medical residents are trained in specialty care for women who live in rural areas.

Box 3 highlights blended approaches to meeting rural health needs: a community-wide initiative by the Menominee Nation in Wisconsin to address intergenerational health disparities and an initiative by

Kearny County Hospital in Kansas focused on maternal health, birth outcomes, and supporting refugee and immigrant populations.

BOX 3

Two Blended Approaches to Meeting Rural Health Needs

Spotlight: Menominee Nation, Menominee County, Wisconsin

Menominee Nation created a community-wide adverse childhood experiences (ACEs) intervention to address intergenerational trauma, socioeconomic decline, and significant community health disparities.[23] In 2010, Menominee Tribal Clinic and Menominee Indian School District created a community engagement workgroup. The workgroup includes 41 departments of tribal government and the county department of human services, school district, and college. The group's purpose is to create strategies to address ACEs and intergenerational trauma in the community. Additionally, the Menominee Tribe joined a statewide pilot project, Fostering Futures.[24] This initiative integrates trauma-informed principles into county-based welfare agencies and state agencies.

Through the community engagement workgroup and Fostering Futures, the focus on trauma across partner agencies and organizations led to changes in trauma-informed care in schools, clinics, and the broader community. Menominee Tribal Clinic created a trauma-informed care team and started the Pediatric Integrated Care Collaborative to integrate medical and behavioral health departments and screen children and their families for trauma. In 2021, 7,034 appointments were made with the Menominee Tribal Clinic's Behavioral Health Services, up from 3,145 appointments in 2014. Menominee Indian School District created a student health center that offers behavioral health services with a counselor and a social worker. The schools have seen an increase in graduation rates, a decrease in teen pregnancy, a decrease in substance use rates, and an increase in post-secondary education enrollment. Finally, there were community campaigns to spread awareness of ACEs and there are quarterly trauma trainings at the community resource center that are open to anyone.

Spotlight: Kearny County Hospital, Lakin, Kansas

Since 2011, over 200 hospital-based labor and delivery units have closed across rural America (Topchik et al., 2023). In that timeframe, Kansas lost 13 obstetric units—only three other states lost more. Kearny County Hospital is a rural hospital located in Lakin, Kansas, working to improve maternal health services. Many people giving birth in the region have high rates of gestational diabetes and are diagnosed with type 2 diabetes after giving birth. Kearny County Hospital has taken a multifaceted approach to addressing health disparities and birth outcomes. The hospital focused on the following:

- **Expanding services**: Kearny County Hospital expanded services by increasing access to in-person and virtual prenatal care.
- **Reaching more patients**: The hospital partnered with the largest employer in the county to connect employees to care. It also established relationships with local refugee communities through targeted programming.

- **Training the workforce**: Workforce training included providing education about health care needs during pregnancy and after birth to family medicine providers, as well as partnering with foundations and universities to increase training and quality of care.

All these activities resulted in an increased volume of births and a reduction of births of babies that were large for their gestational age, which are indicators of better maternal and infant health. These activities also resulted in an increase in breastfeeding initiation (Centers for Medicare and Medicaid Services, 2019).

Kearny County Hospital is also expanding the care-coordination services it provides to refugee and immigrant populations, specifically the Somali population.[25] The Care Coordination team has expanded their activities to include in-home visits, checking in on acute care hospital patients, and visits with emergency room patients who do not have emergency-level medical needs. Additionally, the Care Coordination team now includes a social worker. These actions have reduced the number of people going to the emergency room when care is better suited for a clinic.

Who funds rural health services and programs?

A variety of organizations provide funding to rural health services and programs beyond private health insurance companies.

- **Public insurance programs**. Public insurance is provided by the government for low-income individuals or families, people aged 65 and older, and other populations based on eligibility, such as children and veterans. Public insurance includes Medicaid, Medicare, the Children's Health Insurance Program, and the Civilian Health and Medical Program of the Department of Veterans Affairs.[26] The Pennsylvania Rural Health Model,[27] a model intended to test if paying hospitals a fixed amount upfront results in increased access to high-quality care and improved health outcomes, is funded by the Centers for Medicare & Medicaid Services. Programs such as the Sapling Center and the school-based health centers in Arkansas receive reimbursements for services from Medicaid.
- **Federal and state grants**. The US Human Resources and Services Administration's Federal Office of Rural Health Policy and the US Department of Housing and Urban Development provide grants to support rural health services. For example, the Sapling Center receives funding from the Youth Homelessness Demonstration Project and Supportive Services Only program.[28] Arkansas helps finance the buildout of new school-based health centers, such as turning classroom spaces into medical examination rooms.
- **Community development financial institutions (CDFIs)**. Primary Care Development Corporation, a CDFI, provides loans, training, resources, and technical assistance for health care providers in under-resourced communities.[29] Fahe, another CDFI, is involved in the construction and management of several opioid recovery centers across Kentucky, including securing funding for four new recovery centers.[30]

To help rural hospitals and clinics remain open, the National Rural Health Resource Center, a nonprofit organization, funds the Rural Healthcare Provider Transition Project.[31] This project helps rural hospitals and certified rural health clinics prepare to shift from traditional fee-for-service models to a value-based care model (Berenson, Upadhyay, Delbanco, and Murray, 2016). Fee-for-service means that providers are reimbursed based on the *quantity* of services provided, while value-based care models focus on the *quality* of care provided. Value-based care payments can be structured in a few ways, such as charging a fixed price for an appointment no matter how many providers see the patient.[32]

Measuring Progress

What can I track to see if my program is working?

There are many ways to measure if a service program is working in order to see if improvements are needed to reach program goals. Progress can be tracked through program outputs and program outcomes. Outputs are the actions or activities used to meet the goals of the program, while outcomes are the transformative goals of the program.

Program Outputs

One way to measure is to count and compare program outputs. Measures of program outputs show who a program is reaching and how it is reaching them. For example, counting the number of people served by a program shows how many people are reached. This can be compared to how many people the program planned to serve. Understanding additional characteristics of people who use a program—such as the income, race and ethnicity, gender, or age of participants—can indicate whether any populations that the program was hoping to reach are missing or participating at lower levels than expected. This could show where outreach is needed to increase the number of program participants or to reach different groups.

Program Outcomes

Another way to track progress is by looking at program outcomes. These outcomes show that a program is achieving unique goals compared to having no program at all. For example, a program goal might include providing more economical services or reducing hospital visits for non-emergency needs. For a workforce development program, a goal may be to increase the number of licensed medical-services providers by a certain number or percentage. These outcomes are important to track, even though they may not tell the whole story of how a program benefits participants.

Individual Health Outcomes

Some programs will want to track individual health outcomes. Individual health outcomes have to do with someone's health status changing over time. For example, Mariposa Community Health Center,[33] a federally qualified health center along the US-Mexico border, has a successful diabetes-education program that measures blood glucose levels as an individual health outcome for program participants. If a program is not improving health outcomes for participants, this means some aspect of the program is not working as expected. Additional education, services, partnerships, or funding may be needed to improve individual health outcomes.

Community Health Outcomes

In addition to tracking individual health outcomes, some programs may focus on community health outcomes. Community health outcomes can be tracked in a number of ways. For example, a community may have high rates of a certain health condition. Measuring the number of new diagnoses over time can be used to understand whether community-level changes are occurring with the help of a program. Other programs may focus on reducing health differences among various groups in the community, perhaps between groups of different races and ethnicities or groups of different income levels. For these programs, measuring changes over time in the health of one group in the community compared to another group will be important. If changes are not noticeable over time, the program may not be working as intended.

Finding the Right Data

Data is crucial in understanding current community conditions, identifying what services and programs could help improve individual and community health, and tracking progress to see if a program is working. Before selecting which data to use, users should consider what type of data they need and how they want to use the data, such as to identify community health needs or tracking individual health outcomes. Users should also be aware of the strengths and limitations of different data sources. To use available data, organizations will need to have in-house data capacity or to seek assistance from partners, such as a university, community college, or research organization with data-analysis expertise. Box 4 provides a helpful checklist for ensuring high-quality data analysis; each area is discussed in further detail below.

BOX 4

Checklist for Identifying and Using Appropriate Data

Here is a checklist to use prior to accessing, collecting, or analyzing rural data to make sure data are the highest quality and can be used properly.

- **Capacity**: There is sufficient in-house data capacity or an identified partner with data analysis expertise.
- **Source**: Data come from a trustworthy source, are recent, and are available in a format that matches the data capacity of those doing the work.
- **Use**: Data are appropriate to use, representing the desired level of geography, unit of analysis, and measures.
- **Quality**: Data source has good coverage for rural places, meaning it is consistently available at the desired level of geography, is relatively complete, and has a small margin of error.
- **Type**: The type of data—whether collected from individuals, collected from a survey sample, or synthetized—is appropriate for the desired use, and any biases or limitations are taken into account in analysis and reporting.
- **Original research:** If appropriate, high-quality data are not readily available, the data user considers alternatives such as data-sharing agreements with other data owners or collecting original data using methods within the data capacity of those doing the work.

Where can I find relevant data, and what capacities do I need to use them?

This section provides an overview of the most commonly accessible health datasets as well as information on the ease of use for each source and suggestions to help users make the best use of data. This guidebook focuses on existing data that are publicly available nationally or are commonly available from local governments or health service providers. To ensure the guide is useful to a wide range of audiences in rural places, we only include datasets that are available at least at the county level. This allows users to find information specific to their community. We also do not include datasets that are no longer updated or have not been updated in the past five years. This ensures users are making informed decisions based on the most current information available. Each dataset is summarized below, while table 1 provides additional details on the types of measures available and how easy each is to use according to three categories of user data capacity.

- **Beginner**: A data tool is available for user to enter information on the geography or topic of interest. Data and visualizations, such as charts or maps, are automatically generated. Basic understanding of data is needed for interpreting the results.
- **Intermediate**: Data are cleaned and aggregated to common geographies in Excel or other formats available for download. Data are intended for use with statistical analysis software and users can retrieve the information of interest through simple data manipulation. Basic familiarity with Excel or common statistical software is required.
- **Advanced**: Data are only available at the level of an individual person or an individual record, such as a medical visit. Users need to conduct data quality checks and cleaning before more advanced analysis, such as associating individual people or records with an identifier to generate program-level or community-level data.

TABLE 1

National Data Sources for Health-Related Data Available at the County Level or Smaller

Dataset	Measures	Data source	Level of geography	Type of data	Data capacity
PLACES: Local Data for Better Help	For adults aged 18 or older: health outcomes (e.g. arthritis), prevention (e.g. current lack of health insurance), health risk behaviors (e.g. binge drinking), disabilities (e.g. hearing disability), and health status (e.g. mental health not good for 14 days or longer).	Centers for Disease Control and Prevention	county, place, census tract, ZCTA	synthesized	▪ beginner: interactive online map ▪ intermediate: download data and filter by level of geography and measures
US Small-Area Life Expectancy Project Estimates	Estimates of life expectancy at birth for most census tracts in the United States for the period 2010–2015.	Centers for Disease Control and Prevention	census tract	synthesized	▪ intermediate: download data and select census tracts
Area Health Resources Files	More than 60 measures spanning health care professions, health facilities, population characteristics, economics, health professions training, hospital utilization, hospital expenditures, and environment.	Health Resources Services Administration	county	varies based on measure	▪ intermediate: download data and filter by level of geography
Environmental Justice Index	Index of cumulative impacts of environmental injustice on health using 36 measures split into three groups: social vulnerability (e.g. lack of health insurance), environmental burden (e.g. air quality), health vulnerability (e.g. high estimated prevalence of asthma).	Agency for Toxic Substances and Disease Registry	census tract	varies based on measure	▪ beginner: interactive online map ▪ intermediate: download data and filter by measures
Climate and Economic Justice Screening Tool (CEJST)	Over 34 indicators of community burden across eight climate, environment, and socioeconomic categories: climate change, energy, health, housing, legacy pollution, transportation, water and wastewater, and workforce development.	White House Council on Environmental Quality	census tract	varies based on measure	▪ beginner: interactive online map ▪ intermediate: download data and filter by measures
County Health Ranking and Roadmaps	Ranking of counties on more than 30 measures of health outcomes and health factors, categorized into length of life, quality of life, health behaviors, clinical care, social and economic factors and physical environment. Some measures are also disaggregated by race and ethnicity.	University of Wisconsin Population Health Institute	county	varies based on measure	▪ beginner: online search to generate graphs and data snapshots at the county level ▪ intermediate: download data and filter by measures

Dataset	Measures	Data source	Level of geography	Type of data	Data capacity
Reenvisioning Rural America	Peer groups of rural census tracts using 50 measures within seven types of community assets: built capital, cultural capital, financial capital, human capital, natural capital, political capital, and social capital.	Urban Institute	census tract	varies based on measure	▪ beginner: interactive online map and charts ▪ intermediate: download data and filter by peer group and measures

Source: Urban Institute data scan.

Health Status

Health and health status data provide the most direct way for communities to understand community health needs, understand the causes and consequences of health disparities, and make decisions related to improving health status. We have scanned two datasets available at the national level for understanding health status, the CDC PLACES data, and the US Small Area Life Expectancy Project.

- **PLACES**.[34] These data provide information around health status and health behaviors and are available for counties, places (incorporated and census-designated places), census tracts, and ZIP Code Tabulation Areas across the United States. Since these data are estimated through advanced statistical modelling, the data can help identify community health issues but are not intended for tracking progress over time. These data are accessible to users with beginner to intermediate data capacity.
- **US Small-Area Life Expectancy Project**.[35] This dataset provides estimates of life expectancy at birth—the average number of years a person can expect to live—for most of the census tracts in the United States for the period of 2010–2015. These data are accessible to users with intermediate data capacity.

Health Facilities and Professionals

Information about health resources, such as health professionals and facilities, can serve as a valuable resource for identifying partners to deliver health services and designing programs to increase health workforce and investments.

- **Area Health Resources Files**.[36] These files include data on health care professions, health facilities, population characteristics, economics, health professions training, hospital utilization, hospital expenditures, and environment at the county, state, and national levels. These files also include county designations based on Rural Urban Continuum Codes for identifying rural counties. These data are accessible to users with intermediate data capacity.

Environmental Risks Related to Health

Environmental exposures and risks can affect human health, either directly by exposing people to harmful toxins, pollutants, or conditions, or indirectly by disrupting life-sustaining ecosystems. These risks are often compounded by preexisting health and socioeconomic conditions of communities. Understanding the different aspects of potential environmental risks can help identify causes and potential strategies for addressing community health issues related to the environment.

- **Environmental Justice Index**.[37] This index ranks the cumulative impacts of environmental injustice on health for every census tract across the country. These data are accessible to users with beginner to intermediate data capacity.

- **Climate and Economic Justice Screening Tool**.[38] This is an interactive data tool featuring a map of communities experiencing environmental and economic disadvantage. Communities are considered "disadvantaged" if they are in a census tract that is (1) at or above a threshold for one or more environmental, climate, or other burdens, and (2) at or above a threshold for an associated socioeconomic burden. Thresholds vary by indicator and data type. The interactive map allows users to visualize "disadvantaged" tracts and examine environmental, climate, and socioeconomic burden data for each location. These data are accessible to users with beginner to intermediate data capacity.

Social Determinants of Health

Nonmedical factors, such as where people live, learn, play, and work affect many aspects of health, functioning, and quality-of-life outcomes and risks. These social determinant factors are rooted in economic, social, and political systems and can lead to health inequities. Promoting rural health equity requires identifying and addressing the inequities in the many social determinants of health.

- **County Health Rankings**.[39] This tool rates counties on health outcomes (length and quality of life) and health factors (determinants of health) based on a conceptual model of population health. These data are accessible to users with beginner to intermediate data capacity.
- **Reenvisioning Rural America**.[40] This is a data tool that provides information on community assets based on the seven types of capital in the community capitals framework (Beaulieu 2020): built, cultural, financial, human, natural, political and social. Data are available for all rural census tracts, defined as rural-urban commuting areas 4 through 10 generated by the US Department of Agriculture. These data are accessible to users with beginner to intermediate data capacity.

Other Government Sources

Beyond standardized national-level data sources, there is a wealth of state, local and system-level data that can be further analyzed at the community level, which users may find relevant to identifying health needs and developing programs to meet these needs. Below we provide some ideas for additional data from these sources:

- **Vital records**: Many state and county health departments publish, or make available upon request, the birth and death records for understanding health-related death and birth information.
- **Discharge data**: Many state and county health departments publish, or make available upon request, hospital discharge data for understanding the prevalence of and trends related to certain health conditions.
- **Program administration data**: By law and program requirement, state and county departments publish program records around some key social determinants of health, including homelessness and food insecurity. For example, there is information on individuals experiencing homelessness through states' homeless management information systems and information on individuals

receiving food and cash assistance through state and local Supplemental Nutrition Assistance Program and Temporary Assistance for Needy Families data.

- **Safe drinking water information system data**: State public health departments compile information on public water systems, including basic information on each water system and violations and enforcement information around compliance of water regulations. The data is available through the Safe Drinking Water Information System Federal Reporting Services, managed by the Environmental Protection Agency.
- **Wastewater facilities compliance and enforcement data**: State, local, and tribal environmental agencies compile information on wastewater system compliance and enforcement records. The Environmental Protection Agency publishes the data on permits, violations of environmental regulations, and enforcement actions through the Enforcement and Compliance History Online system.
- **Superfund Enterprise Management System**: The Environmental Protection Agency manages this system, which allows users to search and retrieve records on hazardous waste sites within or near their community in order to understand the health and environmental threats posed by hazardous waste sites and contamination.

Other Private Data Sources to Consider

Some private source can also be useful for health-related programming and sometimes can be obtained through purchase or a data sharing agreement. For example, by partnering with local hospitals and insurance providers, users might be able to aggregate medical claims data to understand the prevalence and trends of specific health conditions or behaviors, such as nonessential ER visits, avoidable utilizations, and preterm births. Hospital spending data can also be a good source, if available, for measuring the effectiveness of programs aimed at improving specific health-related issues.

How do I determine the best data to use for my purposes?

Extracting meaningful insights from data requires a thoughtful understanding of the intended use case for the data. Some common considerations include the right level of geography for extracting and compiling the data and the types of measures that are most relevant for making a case, defining a problem, or measuring progress toward goals. For instance, when the objective is to decide how to allocate resources to support individuals and families, knowing the number of individuals affected by a health condition becomes priority. Alternatively, if the intent is to understand a health condition's prevalence within a community, the priority might be understanding the percentage or rate of prevalence within the geography of interest or how the prevalence compares with other communities. This section goes in more detail on how to center use case when considering the level of analysis and types of measures to choose for rural communities.

Level of Geography

One important consideration for health data analysis relates to geographic scale and unit of analysis. This choice will be driven by the use case and the intended audience. Small geographies, such as census tracts—geographic zones created by the US Census Bureau that each contain around 8,000 people—can provide more granular and precise information about health-related issues within one or more rural communities than larger geographies such as counties or states (Scally, Burnstein, and Gerken 2020). Smaller geographies can also be aggregated to create customized measures for a specific service area, say a group of counties spanning three states that create a single service region. Despite their importance for some use cases, data for smaller geographies can be harder to find and can have data quality issues. These are discussed in more detail below.

In cases where a dataset is not available at the desired level of geography, or the geography available does not align well with the analysis of interest, users can translate available data to the desired geography with crosswalks. A common example is creating crosswalks between ZIP codes and other Census Bureau geographies using tools provided by the US Department of Housing and Urban Development[41] Users can also interpret estimates at a larger geography within other local contexts. For example, county-wide data can be applied to a small town within the county if users provide additional context about why measures might be the same, higher, or lower in the town compared to the county. Important comparisons may include demographic and economic characteristics of the people living in the town versus the county as a whole.

Unit of Analysis

The unit of analysis matters for data selection and analysis, whether that is individuals, households, a health services provider, one or more specific rural communities, or some other unit. For example, if the goal is to identify specific individuals to recruit for a new health-focused program, having some data available on individuals and their characteristics will be important. Data users should keep in mind that an individual's health data is subject to data privacy and security standards set by the Health Insurance Portability and Accountability Act, also known as HIPAA.[42] If the data use case centers around a specific health services provider, such as a hospital or federally qualified health center, the data user might prefer to work with individual records aggregated to that provider. This could be useful to understand, for example, how health services costs vary between providers based on patient health conditions and treatments.

Types of Measures

In addition to defining the geography and unit of analysis, users need to clearly define the most suitable type of measures for the use case. This helps guide how data are selected, how data are analyzed, and how outcomes are described. Different types of measures help answer questions such as "how many?" "what percentage/rate?" and "how much compared to others?" Two types of measures are described below.

- Counts and percentages: If the intended use is to prioritize distribution of resources within a community, counts and percentages are straightforward and useful. For example, many of the datasets discussed above provide counts and percentages about the prevalence of health statuses, the size of the health services workforce, the number of water or waste water system violations, and other measures that highlight the extent of health challenges and opportunities within a particular place or population .
- Ranking or comparison: A ranking method tells how a community compares to other communities and can help set targets for progress. Of the datasets discussed above, the County Health Rankings and the Environmental Justice Index are good examples of these types of measures, allowing users to compare one place (e.g. a county) using an aggregated measure.

An additional step related to rural communities is to choose a comparison group when appropriate. While comparing a rural community to all communities nationally can be useful in understanding the broader landscape, such comparison might not be as effective for setting a benchmark or targeting progress in rural places. Due to underlying economic and social conditions, health challenges and solutions can look very different in urban versus rural areas. To address this reality, the Reenvisioning Rural America typology presented above created peer groups out of rural census tracts only, and compared these census tracts to their peers and to the rural average rather than a national average.

How do I make sure I am using the best type of and highest quality data?

It is important to understand the quality of data before diving into analysis and interpreting the results. This is even more true for rural areas with smaller populations and less density. This is because rural data are harder and more expensive to collect and more likely to be missing (Scally, Burnstein, and Gerken 2020). Before analyzing the data, understanding how data are collected can help data users determine the best ways to address any errors or bias that could affect the accuracy of the results. In this section, we discuss potential pitfalls with rural data quality and common types of health data and how they are collected. We suggest how to use these types of data in rural contexts. We also share the results of our data quality analysis for some of the data sources described above. For an expanded discussion about rural data quality challenges across a number of specific data sources not covered in this guidebook, including census data sources such as the American Community Survey, please see *In Search of "Good" Rural Data* by Scally, Burnstein and Gerken (2020).

Potential Pitfalls

Even with the best available data sources for rural communities, there are several potential pitfalls to look for in the data before interpreting results. This section describes common checks to conduct.

DATA ARE INCOMPLETE

Depending on how data are collected, some measures in a dataset may be incomplete, particularly for rural people and places. Data could be missing if they were not entered by the individual supplying the data or they were omitted or transformed for privacy reasons. Individuals may skip some fields when filling out forms or records. If the data are at the individual level from an administrative record system, users should aggregate them to the desired level of geography while being cautious about any potential missingness that is not reported as well as any bias that could affect the results. An example would be providing a clear warning if, say, 20 percent of individuals in the database did not report their income but income is a key measure for analysis.

For most publicly available survey data sources, guardrails are in place to protect the privacy of users so that individuals cannot be easily identifiable through the data. Although there are some emerging techniques for releasing more granular-level data without potentially leading to identification of individuals—such as techniques to add noise to confidential data without changing the population level summary—for geographies or units of reporting that have small populations, data are often omitted, or are simply not released (Bowen, Narayanan, and Scally 2021). When this is the case for the community of interest, users could seek data that is aggregated at a larger geography (e.g., a county instead of a census tract) or larger population group (e.g., all people of color instead of by smaller groups by specific race and ethnicity). Collecting additional data, discussed below, may help fill in gaps, too.

DATA HAVE ERRORS

Margin of error (MOE) is useful information that is provided in many survey data sources. Since survey responses are usually collected from a sample of the population, and different samples sometimes generate different results, MOE helps show the possible variation of the estimate if the same questions were answered by a slightly different group of people. The MOE allows a value from a sample to be interpreted as a range for a broader population. For example, an estimate of the number of people in a community with heart disease might be 11 percent with a MOE of 2 percent, meaning the range of people with heart disease within the target population is between 9 and 13 percent. With this information, data users can infer that the estimate and the actual population value differ by no more than the value of the MOE (e.g. +/- 2 percent) with reasonable certainty, known as a confidence level. Confidence levels are calculated statistically, and generally allow the user to be 90 to 99 percent confident that the actual population value falls within the MOE range.

Data users should always check MOE when the information is available. In rural places with smaller populations, sometimes the MOE can be larger than the estimates. In such cases, users are advised to combine estimates across geographies using statistical methods to reduce the MOE and make the range of true estimates smaller for interpretation. MOE can also vary by geography within the same dataset; in this case, additional statistical testing will be needed when making comparisons across different geographies.

Administrative Records

Administrative records contain information that is collected on every individual who interacts with a system or cases that have been processed. This could be a dataset of all patients who have been screened for a certain type of risky health behavior such as smoking, or a dataset of all water-system violations reported to the EPA. The benefit of using this type of data for rural communities is the relative completeness of information and the small amount of error compared to surveys that depend on robust response rates, because the data contain information on every individual or case that is reported.

One limitation of data from administrative records is the data only include information on the population that interacts with the administrative system or the cases that are reported. For example, medical claims data only captures information on patients who seek care from a health services provider for their health issues. People who may face health challenges but do not seek care will not be included in medical claims data. This limitation can be a potential source of bias when analyzing and interpreting data from administrative records.

Survey Data

Survey data is collected from a selected sample of the population. Common publicly available health data sources, such as the American Community Survey by the US Census Bureau, are designed to be representative of the population of interest. Surveys can be expensive and time-consuming to collect from smaller population areas in a way that yields a high enough response rate needed to reduce the MOE (Martinez-Mesa et al. 2014). Some rural populations, such as Native communities, also have legitimate concerns about participating in data collection because many past data-collection efforts have left them out or caused harm (Scally, Burnstein, and Gerken 2020). These limitations are especially important to acknowledge when interpreting survey data on rural communities.

Synthesized Data

Another popular type of data is synthesized data through statistical modeling, such as imputing (or calculating) health-related measures for geographies that are smaller than an area for which the data collected or reported can generate reliable population estimates. For example, to understand the prevalence of obesity for adults at the census tract level, the CDC PLACES data team developed an advanced statistical model based on a state-level survey, the Behavioral Risk Factor Surveillance System, to identify key factors that are associated with obesity, such as age, sex, and education. Based on how each factor was estimated to affect adult obesity, the team estimated the obesity rate in census tracts with distinct population characteristics around those factors.

This type of synthetic data has great potential in identifying health conditions in areas that are smaller than an area in which data were originally collected to represent, with considerably lower cost than a survey. But users should be aware of the potential inaccuracies generated through the process, both from

the model estimates and in the base data used to produce the estimates. Users of this type of data should read the methodology carefully before using and analyzing the data, and note the margin of error when interpreting the results. Because these data are modeled, they are not appropriate for tracking changes over time.

Results of Data Quality Tests

The Urban team downloaded and analyzed six of the nationally available datasets discussed above in order to gain additional insights into their quality and usefulness in rural contexts. We also chose six nonmetropolitan counties to analyze and test for data quality. We selected these for their diversity of health concerns, demographics, and geographic location: Doddridge County, West Virginia; Navajo County, Arizona; Claiborne County, Mississippi; Val Verde County, Texas; Hill County, Montana; and Southeast Fairbanks Census Area, Alaska.

Most datasets do not provide MOE information. Of the two that do—PLACES and US Small-Area Life Expectancy—the PLACES data have a larger MOE than the life expectancy data in terms of percentages in the test counties. For both datasets, however, the MOE falls within a range of 2 to 5 percent.

Based on our assessment of dataset quality, including across key topics, we found some differences and tradeoffs.

- **Health status**: PLACES data has the least missingness and covers a wide range of topics. US Small-Area Life Expectancy Project provides life expectancy data but is more likely to be missing for rural census tracts.
- **Health facilities and professionals**: Area Health Resources Files provide comprehensive and complete measures on health facilities, health professionals, utilization, and expenditures for rural counties.
- **Environmental risk**: Although the Area Health Resources Files also include some measures around environment conditions, the Environmental Justice Index provides more measures on environmental burden, built environment, and social vulnerability at the census tract level, with decent completeness for rural areas.

To test similar measures across datasets, we tested three different topics that appeared in more than one dataset: mental health, high blood pressure, and air quality.

- **Mental health**: Measures are available in both PLACES and Environmental Justice Index data. The Environmental Justice Index used PLACES as a source but included an additional calculation on the relative prevalence of poor mental health (measured as poor mental health reported for at least 14 days among adults 18 and older), with census tracts scoring in the highest third of all national tracts rated as having "high prevalence." The Environmental Justice Index might be less useful for rural tracts because of the national comparison methodology that includes urban areas. Both datasets

are fairly complete among our test counties, with PLACES missing one tract in Texas and Environmental Justice Index missing for Alaska.

- **High blood pressure**: Measures are available in both available in PLACES and Environmental Justice Index data, and the Environmental Justice Index used PLACES as a source but did additional calculation on the relative prevalence compared to all national tracts. Environmental Justice Index might be less useful for rural tracts because of the national comparison methodology that includes urban areas.
- **Air quality**: The measure of "Percent Good Air Quality Days" from the Area Health Resources Files is missing for five out of six test counties. The measure of "Mean annual percent of days with daily 24-hour average PM2.5 concentrations over the National Ambient Air Quality Standard" from Environmental Justice Index is missing for Southeast Fairbanks Census Area. Due to the high level of missingness, further comparison was not feasible.

How can I fill information gaps when data is not readily available?

Despite the wealth of publicly available data sources that include health data, there can still be instances where data is not available. There all some alternatives for filling the data-needs gap, although they tend to take more coordination and effort among multiple partners. Once successfully implemented, however, they can provide valuable insights into community health that may not be available from other data sources.

Sharing Data

Data sharing requires cross-sector collaboration to efficiently exchange information across partners to address the health and social needs of people and to reduce inequities. Data sharing is also complicated and challenging to successfully execute. It requires cultivating a high level of trust and buy-in among all relevant partners, a clear understanding of the value of data, and effective and secure protocols for transferring information. Successful sharing can result in new data insights: for example, state-level integrated data systems that link administrative records across multiple health and human services, or local partners working together to share information for improved services (Box 5).

BOX 5

Sharing Data on Housing, Health, and Criminal Justice System Involvement in Bozeman, Montana

The Housing First Village pilot program brought together partners from housing, faith-based communities, higher education, local government, criminal justice, health care, and philanthropy. The goal was to provide high-quality tiny homes and supportive services to tenants in order to improve tenants' mental health, physical health, and self-sufficiency. The program wanted to identify priority tenants as individuals who frequently used emergency shelters, hospital emergency rooms, and jails. To do this, a data-sharing agreement was set up between the Human Resource Development Council of District IX, a nonprofit housing and homeless service provider; the local nonprofit hospital Bozeman Health; and the Gallatin

County Detention Center to share data around individuals using these services. The data were used to create a priority list of prospective tenants for the tiny homes in the Housing First Village. The hospital provided outreach support to prospective tenants to protect the privacy of the individuals using emergency room services.

Source: Scally, Gold, Oliver, and Salerno 2020

Collecting Your Own Data

Despite the wealth of public and private data sources, some critical information on community health needs is not represented in the available data. In addition, data sources with incomplete or error-prone data for rural areas with smaller populations may not reflect local-level realities if taken at face value. Although time consuming and expensive, direct data collection can be ideal for understanding the health-related challenges rural communities face in order to identify the best solutions.

Data can be collected in a number of ways, including surveys, interviews, focus groups, and community data interactives. Data collection requires training in these data-collection approaches to ensure data are collected in a manner that reflects the full population of interest and does not bias the results. For example, researchers gathering interview or focus-group data should not ask leading questions that presume the direction of the answer (e.g., asking "do you agree" instead of using more neutral language). Additionally, surveys should obtain responses from a representative group of the full population, taking into account issues around access, such as internet availability and quality, when fielding an online survey. Analyzing collected data requires an intermediate to advanced data capacity, including training in narrative or statistical analysis.

A key principle to consider for any type of direct data collection is to engage community members throughout the process, known as community-engaged methods. Rather than viewing the residents and program recipients as research subjects, community engagement instead acknowledges that community members are experts on their own communities and empowers them to generate their own knowledge and make decisions. Community-engaged research ensures greater trust and respect among researchers, direct service providers, and the people and organizations that share specific interests around a certain geography, topic, or issue (Balls-Berry and Acosta-Pérez 2017). This type of data collection mobilizes community power and resources and can generate authentic local knowledge and partnerships that lead to lasting and meaningful practices, programs, and policies. Box 6 provides additional resources on understanding and collecting quality data on rural communities.

BOX 6

Additional Resources on Generating and Using Quality Rural Data

The Urban Institute has produced several resources on collecting and using quality data through national research and initiatives around local data and community engagement.

Authentic Community Engagement
Urban Institute, 2023
https://www.urban.org/research/publication/authentic-community-engagement
This fact sheet provides tools, examples, and guiding questions for government agencies, researchers, and other decisionmakers to engage communities in a meaningful and robust way.

Community-Engaged Surveys: From Research Design to Analysis and Dissemination
Urban Institute, 2021
https://www.urban.org/research/publication/community-engaged-surveys-research-design-analysis-and-dissemination
This toolkit provides methods for gathering and documenting community input; four key phases for engaging communities in survey work; and best practices.

Collection of Example Data-Sharing Agreements: Labor + Human Services
Urban Institute and National Neighborhood Indicators Partnership, 2018
https://www.neighborhoodindicators.org/library/catalog/collection-example-data-sharing-agreements-labor-human-services
This website provides examples of data sharing agreements between state agencies, regional planning commissions, nonprofit organizations, and data intermediaries.

In Search of "Good" Rural Data
Urban Institute, 2020
https://www.urban.org/research/publication/search-good-rural-data
This report explores the systemic and logistical challenges to improving data accuracy for rural communities, provides examples of the relative strengths and weaknesses of key datasets around on rural economic development, and provides recommendations for policymakers, practitioners, and researchers to improve data quality for rural communities.

NNIP's Resource Guide to Data Governance and Security
National Neighborhood Indicators Partnership, 2018
https://www.neighborhoodindicators.org/library/catalog/nnips-resource-guide-data-governance-and-security
This guide offers resources on data governance, protecting privacy and human subjects, data security plans, and a data life cycle. The guide can help any organization that utilizes secondary data sources.

Appendix A

How we developed this guidebook

To identify promising practices in rural health, we scanned across topics such as schools; housing, including housing quality, rural homelessness, aging in place, and partnerships with housing providers; birth-related health care; rural health systems and hospitals; insurance; and specific populations such as immigrants, refugees, tribal communities, and youth. We particularly looked for examples in rural counties experiencing persistent poverty, as well as geographic and program diversity. Based on this promising practices scan, we selected programs that were particularly aligned with our research questions to include in interviews, but there was limited information online. Interviews included questions about the motivation behind the program, data used to identify needs, outcomes measured, partnerships, and funding sources. The interview findings were synthesized with the promising practices scan to inform this guidebook.

We reviewed a total of 12 common and publicly available health related datasets for completeness, geographic level, measures included, data collection method, and other data features related to rural area, such as suppressions to protect privacy. In addition, we downloaded and analyzed six datasets for additional insights on their quality and usefulness in rural contexts at a national level as well in select counties that we chose based on their diverse preexisting health concerns, demographics, and geographic location. The counties we selected are Doddridge County, WV; Navajo County, AZ; Claiborne County, MS; Val Verde County, TX; Hill County, MT; and Southeast Fairbanks Census Area, AK.

Notes

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