Tips on Finding Data and Writing a Community Description for Harm Reduction Organizations

Overview: Many grants require applicants to describe the community they serve. Below are suggested starting points, reliable data sources, and tips for writing a compelling narrative. for harm reduction organizations and syringe service programs (SSPs).

Types of data

- A catchment area is the geographic area your program will serve. You may define your catchment area
 by where your program offers syringe services, where clients live/stay (e.g., data you collect on client zip
 code or county of residence), or a combination of both. For many organizations this may be an overview
 of your agency's neighborhood. For larger applicants or applicants with multiple locations, consider
 describing the range of areas served or describing the areas separately. Describe features of the area,
 including the towns or cities served, their urban classification(s), and any relevant overlap with other
 nearby jurisdictions
- **Demographics** are statistical descriptors of a given population or groups within it. Common demographics usually included are race/ethnicity, tribal affiliation(s), main languages spoken, sex, gender, sexual orientation, age, housing status, and some socioeconomic indicators, like poverty level. The most important demographic indicators to include about your catchment area may be different than those listed above based on history, geography, available reliable data, or other factors. Often you can choose to describe the demographics of your clientele (based on data you collect), the demographics or the general population (based on publicly available data), or a combination.
- Describing the need for harm reduction services is to showcase the gap between current conditions and
 desired outcomes. In this section, applicants can provide context about their catchment area. This
 section should include a description of service gaps, health disparities, and incidence of poor health
 indicators influenced by social determinants of health (SDOH). The Office of Disease Prevention and
 Health Promotion has a short information page on SDOHs. SDOHs can have major implications on health
 outcomes. They can also interact and build upon each other. Social determinants of health include:
 - o Economic stability: employment, income, debt
 - o Neighborhood and physical environment: housing, transportation, safety, walkability
 - o Education: Literacy, language, early childhood
 - o Community and social context: social integration, support systems, discrimination
 - o Health care system: Health coverage, provider availability, quality of care

Sources for official data from federal, state, or counties

Governmental data sources:

- The <u>U.S. Census</u> and the <u>American Community Survey</u> are great places to start for demographic and SDOH data. Data topics include race and ethnicity, income and poverty, housing, health, employment, and education. With both you can use the filters to pull data for certain geographies, like the counties or zip codes in your catchment area.
- CDC is the most comprehensive and accessible source of data related to public health outcomes. The National Center for HIV, Viral Hepatitis, STD, and TB Prevention has recently developed a searchable and customizable atlas that displays charts and graphs on multiple outcomes. Complete Steps 1 and 2, then select a jurisdiction from the drop-down menu. Detailed data is also available for specific conditions, including hepatitis C, HIV, and opioid overdose.

- Hepatitis C: State-level tables through 2019 are available <u>here</u> and a summary surveillance report in PDF format can be found <u>here</u>.
- HIV: CDC's 2019 HIV surveillance report available here. The National HIV Behavioral Surveillance (NHBS) collects data in 23 cities. The survey runs on a three-year cycle, year 1 focuses on gay, bisexual, and other men who have sex with men, year 2 on people who inject drugs (PWID), and year 3 on people at increased risk for heterosexually-acquired HIV. The last PWID cycle was in 2018. Reports with the data can be found here.
- Opioid overdose: State level data can be found here and here. The National Vital Statistics System provides provisional drug overdose death counts. The data can be downloaded, or viewed online. Viewed online you can see 5-year trends for national and state data, and 1-year trends for county data. WISQARS is another good data dashboard that offers overdose related data visualizations.
- **SAMHSA** has a variety of data about health disparities, it can be difficult to parse through. We recommend starting at the landing page for existing reports.
 - SAMHSA conducts an annual <u>National Survey on Drug Use and Health (NSDUH)</u>. They publish <u>mostly state level data</u>, but not county or local. Of interest, there is a report on racial/ethnic differences in substance use, substance use disorders, and substance use treatment utilization that can be found here.
 - o SAMHSA conducts an annual <u>National Mental Health Services Survey (N-MHSS)</u> that includes some state or regional level data, the <u>most recent report is from 2020</u>. One table of interest is on page 247 and shows the number of clients with co-occurring mental health and substance use disorders as a portion of the total number of clients treated in a hospital, with the column on the far right showing the overall portion of the population in that jurisdiction.
- Most state and local public health departments also publish data about rates of HCV, HIV, and opioid
 overdose, although some states may have less recent data. Try searching Google for "opioid data
 dashboard [your state/jurisdiction]".
 - o Find your <u>local health department website here</u>.
 - O County Health Ratings compiles and compares county health data across the US. Go to the home page and scroll down to "How healthy is your community?" and enter your state, county, or ZIP code to access local data plus compare it to your overall state/US and see the trend (e.g., are cases going up or down). Relevant measures include drug overdose deaths ("select a measure" button, go to "additional measures" > "health behaviors" > "drug overdose deaths"); as well as info on HIV, STIs, and SDOHs.

Nongovernmental data sources

amfAR has an Opioid and Health Indicator Dashboard that pulls from various sources. It includes unique indicators, like distance to nearest syringe service program, as well as indicators related to HIV, HCV, STIs, and now COVID-19. Start by selecting your state or preferred variable from the dropdown menus on the left-hand side of the page.

- <u>Kaiser Family Foundation (KFF)</u> has a <u>state level data dashboard</u> that draws from a variety of sources, including Census data, to provide key SDOH and demographic data including <u>health care coverage</u>, HIV/AIDS, and mental health and substance use.
- Housing-specific data resources:
 - o The <u>National Alliance to End Homelessness</u> utilizes data from the annual Point in Time Count to visualize state level data on homelessness.
 - <u>Eviction Lab</u> at Princeton University makes national eviction data publicly available. Eviction data
 is available for different neighborhoods, cities, and states across the US. The site provides
 compiled reports as well as maps and other visualizations.
- <u>Prison Policy Initiative</u>: The Prison Policy Initiative includes information about mass incarceration by state. It is a research and advocacy center that features data sets and publications on incarceration across the US.
- <u>Feeding America</u>: This site features information on food insecurity in the US and includes <u>local reports</u> from food banks, <u>county level data on food insecurity</u>, and <u>reports on food insecurity by demographic</u> groups.

Other compilations of data sources:

- The American Medical Association compiled <u>a list of state reports</u> (news and data) related to the overdose crisis in this issue brief, starting on page 6.
- In 2019, the HHS Interdepartmental Health Equity Collaborative released a <u>large</u>, <u>comprehensive list of federal datasets</u> that address health disparities, with data from many government departments including environment, labor, transportation, veterans affairs, and more.

General data utilization tips

- Cite your data: It is best practices for all data to be cited, but often an application may not require a certain format. There are two main ways to cite data: endnotes and hyperlinks. For endnotes, you will need to select "References" from the toolbar and "Insert Endnote". We suggest citing data sources using APA format. SAMHSA will likely not be checking for precise accuracy here, so an easier way than manually writing them is to use Citation Machine. We also think applicants can use simple parentheticals, with the name of the source organization (e.g., CDC, SAMHSA), where in the text the information came from (page #) and a link to the source itself included at the end of a sentence. For example you might say, The CDC recommends involving participants in all aspects of an SSP program (CDC, 2020, p. 7) While this approach is not acceptable for academic writing, an application is usually less formal.
- **Use comparison data**: While the application is requesting information specifically about the population you will be serving, it is sometimes helpful to include information about the overall community so the readers can evaluate the distinction. For example, if you describe the race/ethnicity of your participants, you could showcase difference from the general population, e.g.: "40% of our SSP participants have a tribal affiliation, while only 10% of the general population in this catchment area has a tribal affiliation".
- Check the denominator: It is always important to remember where our counts or percentages come from. The denominator is the total number of individuals who are relevant to being counted for a certain metric. Sometimes the denominator will be the number of people who took the survey and sometimes you'll need to calculate a different number for the denominator based on the data you collected. For example, if you are interested in providing data that explain the % of your population that has ever shared syringes, the numerator would be the number of people that report having ever shared syringes in their lifetime and the denominator would be the number of people who have ever injected a

drug who responded to the survey. However, if you are interested I knowing the number of people who have shared syringes in the last year, the numerator would include those individuals that have injected a drug in the last year AND have shared syringes, and the denominator would include those people who have a injected drug in the last year.

- **Describe missing data**: If data are missing, applicants may want to describe the context. Why might this data not be collected? For example, if you have anecdotal information about gender identity that is not reflected in official or organizational quantitative data,
 - o If the data that are missing are integral to the statement of need, you can leverage research findings as an opportunity to connect the dots. For example, if your jurisdiction does not report general statistics on healthcare utilization of PWUD, you may describe the context for why that is and then utilize existing research about healthcare utilization patterns by PWUD.

Tips for utilizing organizational current and/or historical service data:

- Applicants can utilize service data to describe the population of focus for this project. Generally, this
 means leveraging quantitative, unduplicated demographic data collected within a given time frame
 (usually a calendar year, but could be some other period that makes sense to the applicant) to
 characterize program participants. Suggestions for data to utilize are:
 - Aggregate demographic information for unduplicated contacts for all services that collect this
 information (e.g. applicants may have a breakdown of race/ethnicity for case management and
 testing participants but not SSP participants, so you could combine data for those services).
 Common demographic data programs may have on hand include gender, age, race/ethnicity,
 and housing status. Make sure you provide detailed definitions of the subset that the data
 represents.
 - Some programs may also utilize data they have from surveys or intake forms. Common survey data that would be relevant for this section include: healthcare access and utilization (e.g. proportion of clients who have a primary care provider, proportion that are insured, and frequency of emergency room visits), HCV/HIV status, and socioeconomic factors (e.g. income).
 - o Number and percent of participants enrolled in or referred to various harm reduction focused services (e.g. MOUD), with demographic data as available
 - o Proportional results of infectious disease screenings (e.g. number and % positive HCV, HIV, STI tests), with demographic data as available
 - o Some programs may include information on risk factors, including syringe sharing and overdose experiences. This may fit best in the "need for harm reduction services" section.

Still have a question?

If after reviewing this document, you have further questions about sources you can reach out to the Supporting Harm Reduction Programs (SHaRP) team at the University of Washington, we're part of the <u>National Harm</u> Reduction Technical Assistance Center

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