Needs Assessment Meeting Summary for May 9, 2024

Summary

The themes and supporting documentation presented below are a synthesis of input received during three activities conducted during day two of the Hawaii Title V Needs Assessment meeting, held on May 9, 2024. The following is a brief description of the activities:

Activity 1: Mad Libs. Participants were divided into groups and given part of a quote. They were asked to fill in the blanks. Each theme below is illustrated with one of these quotes. The sections written by participants are underlined and in bold.

Activity 2: What Needs to Be Stated or Re-stated? Participants were divided into groups and asked to write down three ideas that need to be stated, restated, or affirmed. These ideas and reflections are responses to quantitative data discussions, held on day one of the meeting.

Activity 3: Guiding Principles for Community Engagement. Participants were divided into groups and asked to reflect on three questions: A. What should be the guiding principles for engaging those with lived experience? B. What lessons have you learned from your prior efforts to engage community? C. How might we hold ourselves accountable to those we engage?

Synthesis

When handled correctly, data may be used to tell a story, elevate unheard voices, create meaningful momentum, and improve population health.

Theme 1: Tell a story

“The core advantage of data is that it tells you something about the world that you **misunderstood, you care about, live in, can give visibility to, and learn from**.”

While data does not tell the whole story, it can be used for storytelling purposes, but we must be thoughtful about our approach. We can diversify our data sources, work with our staff and partners to advise on data publications and focus on short and simple presentations of available data.

* Data does not tell the whole story
* Set up data collection for culturally meaningful data dissemination
* How can various sources of data be used to tell a more comprehensive story
* Stories
* Value of stories
* Sort and analyze the data based on the need
* Be thoughtful of how data is presented
* Data sharing simplicity is needed
* Need for short, simple prioritized summarized data-for policy makers, advocacy, politicians, program planners
* Work with other Epi in DOH to review/advise on data publications
* Data without a story are just numbers

Theme 2: Elevate voices

“Data are just summaries of thousands of stories; tell a few of those stories to help **uplift unheard voices to empower and improve health**.”

We must focus on reaching unheard voices by speaking directly with communities and using both quantitative and qualitative data for storytelling. Specifically, we need to collect additional data including postpartum care data, EHR data, sexual health data, mental health data, maternal mortality data, substance use data, process indicator data. We need to reach vulnerable populations including Micronesians, Pacific Islanders, migrants, NHOPI and Asian populations, and youth. We also need to reach populations on all islands.

* Reaching unheard voices
* We need to work more collaboratively with community
* Qualitative data, community integration
* More focus groups to obtain more data in rural areas
* Qualitative data is more important than quantitative
* The need to do a deeper dive where data is scant to make the stories and voices of marginalized heard
* Reaching unheard voices
* Qualitative data is needed for the story
* Quantitative data is not the only data
* Qualitative and quantitative data
* The voices of our priority populations need to be heard from the beginning to the end of the NA process
* Speak/learn directly to the community members (program clients, WIC clients, homeless, etc.) to learn their needs and priorities and what programs would need and like
* Create structures to have ongoing community advisory groups when we can learn/get feedback to our program development
* Claim/EHR data from all HPS and HCOS
* Postpartum care with women’s experiences
* Sexual health info needs to be collected among adults, adolescents, and children
* Bring awareness to mental health issues to the public
* Maternal mortality specifics
* Houseless
* Post partum
* Substance use
* Migrant-COFA, PI
* Process indicators
* Comparison to U.S./National is not meaningful
* Intake data
* Pacific islanders are missing from the data
* Need data from hard-to-reach minority populations
* Vulnerable populations must be heard
* Need representation of Micronesian populations
* Need to have more data on NHOPI and Asians
* Need to hear voices of youth and families
* Data from youth? How?
* When Maui is listed in the data, is it Maui County or just Maui Island? Maui includes Molokai and Lanai
* Oahu breakdown by areas/zip codes

Theme 3: Create Meaningful Momentum

“We are surrounded by data but starved for **meaningful momentum**.”

We must remember to lead with purpose. What are we going to do with our data? Collecting data for data collection’s sake is a waste of resources, so what actions can we or should we take based on what we learn?

* Lead with purpose. Collecting data for the sake of collecting data has little value
* Next steps, after data is collected
* We need to act on data
* Data can be a call to action
* Data without action is pointless
* Collecting data for the sake of collecting data is a waste of resources
* How much, what kind of information is needed to mobilize needed change?
* Data informed v. analysis paralysis
* Sometimes not all data needs to be collected
* What are we going to do next? What are the action steps?
* There is a lot of data, research, and voices out there. Let us utilize them

Theme 4: Improve Health

“Data is a tool for **enhancing growth for yourself, you peers, and the work that you to improve health**.”

Data are limited, but we must make sure we integrate equity and social determinants of health into everything.

* The data is limited, but how can we use it to inform our needs?
* Many health indicators are improving
* Integrate equity into everything
* Social determinants of health, health equity data

Guiding Principles

* Be thoughtful about the words/language you use (e.g., using acronyms and/or words/phrases that are not understandable to the public)
* Hear all voices
* Follow-up with community
* Be careful about raising expectations
* All ideas/perspectives are honored
* Community Engagement
  + Lead with respect
  + Be aware of conscientious about stigmas attached to the topic
* Be flexible to “meet” where they are at (e.g., time, location, mode/method, etc.)
* Empowerment
* Translation services: meeting them where they are at.
* Community member advocacy support (advocacy training)
* Empowerment- provide info and resources, when able to
* Involve community members at all stages, including interpretation and analysis
* Speak and learn directly from community members, when developing and planning program ongoing engagement
* Reimbursement of participants (strategy incentives)
* Be clear about the/your purpose, intention, objectives, etc. and how the information will be used (do not waste their time)
* Act on what we hear

Conclusions & Lessons Learned

* Establish partnerships early
* Maintain partnerships/give back (not transactional)
* Collaborate, DON’T duplicate
  + Search for existing orgs/community leaders
  + Community-led/recognize their needs
* Language access
* Meeting them where they are at (ex: technology)
* Adequate compensation for participants and community
* Make sure results are valuable to the community
* Empowering/Uplift voices in the community

Accountability

* Compensation (knowledge is not free)
* Honoring community values in the process
  + Signing/written docs versus verbal agreements
  + Collective versus individual
* Define what we mean by community segment of population: ethnicity, rural areas, beneficiaries of Title V. If we know who they are, we know who to engage with, - then this helps with how we engage
* Do we value what we practice? Show face in front of community. Are we valuing what community health workers (CHW) are doing, especially with the health system
  + Creation of CHW Association, compensation, training boots on ground on Maui, you take care of the community
* Co-creation/Co-collaboration of:
  + Process goal/outcomes
  + Ownership
  + Dissemination
* Engaging with community health workers (CHW) and other key informants. Keep in mind safety and support being accountable with community
  + Family resources- CHW -not just talk
* Clear, mutual understanding of expectations between community and “US” (Us = Title V and partners)
* Networking solutions reporting back, checking back, circling back
* Share partnerships as a collaborative process with the community and department (Title V)
* Process and outcomes valuable for community
* Language access
* Coordination of those in community, and those going into community
* Partnership that is truly meaningful; early thought
* Give incentives that are appropriate, relevant, and specific
* Community Centered (on all aspects) (their context)
* Avoid silos
* Transparency- What are the goals? How will the data be used?
* Collect data that is meaningful to the community
* Transparency with what we are collecting, why we are collecting, and how it gets reported back
* Role of your agency (example Hawaii’s Department of Health) acknowledges transparency

However, we must acknowledge the human side of analytics and potential misinterpretations of data, and always lead with empathy, integrity, kindness, listening, and humility

Theme 5: Acknowledge Biases

“The human side of analytics is the biggest **variable**.”

Human biases, judgement, experiences, etc. influence the way data are collected, perceived, defined, and interpreted. Thus, all data are flawed by limitations of those collecting and that must be acknowledged.

There are many ways to collect and interpret data, rather than one right way. Data is also received differently by various audiences, and that should be considered.

* Sometimes it is necessary for an objective POV (external) outside the program, to ask questions
* Perceptions of questions asked/analyze data
* Perceptions of question
* Definitions and interpretation
* Address and acknowledge flaws in data
* These are not all the data
* This is not the only way to look at this data
* Many ways to interpret data
* Consider the audience and how it may be received or interpreted
* What you don’t know

Theme 6: Avoid Data Manipulation

“Data is information, and information is **stories, powerful, and potential action but can be manipulated**.”

We must be careful about the way data are presented, especially concerning disparities. **An absence of data does not mean that no disparities are present.** We must disaggregate and use trend data in a nuanced way, to ensure appropriate representation of communities.

* More clarity on disparity data
* Disparities exist
* Disparity conversation
* Even if the data being analyzed shows there are no disparities present, it doesn’t mean they do not exist
* Absence of data does not mean something is not true
* “No disparities” does not mean there truly are not any disparities, especially within groups
* Recognizing disparities
* No disparities do not equal “no data available to assess disparities”
* Continue working toward data standardization to identify disparities
* Poor, insufficient used interpretation of existing data, e.g., “no disparities”, need representation of communities and specific issues
* Even within a demographic group, there are more nuanced subgroups with vastly different lived experiences
* Better disaggregation
* Misrepresentation of data
* Need to correctly manipulate the data
* Disaggregate CYSHCN data
* Categories/disaggregation
* Disaggregating data to reflect the HI population
* Trend over time may not reflect current trend
* Trend over time
* Distinguishing long term overall trend vs. short term trend
* HHDW is great, but very insufficient for Title V NA

Theme 6: Leading with Empathy, Integrity, Kindness, Listening, and Humility

“**EMPATHETIC, integrity, kindness, listening, and humility** are a prerequisite to solving many problems that humankind faces.”

A thoughtful, strengths-based, community-centered, and context-focused approach is preferred.

* Strengths-based approaches-to view the people of Hawaii and this place as an asset
* Be thoughtful of how data is presented
* Context is kind
* Nothing for us, without us”

Guiding Principles

* Clearly understanding the limitations of data
* Keep an open mind. Do not let your opinions or bias influence your interactions or interpretations.
* Remember that behind every data point, there is a human being
* Do not be extractive, make it a partnership
* Follow through on what you say: be transparent
* Report back
* Go in with mouth closed, ears open
* Be present and focused, active participation
* Wait: be aware “Why am I talking”. Give space to others
* Get feedback, continuous engagement
* Strengths-based perspective-capturing positive efforts
* Remember that for you, you are doing a job for the individual, sharing personal details of their life.
* Educate yourself about group/community before approaching them (be considerate and respectful when approaching them)
* Create a safe space
* Be trustworthy
* Build trust and relations
* Be open to diversity of experiences
* Follow best practices in ethics etc. (No ulterior motive, abusing data, Do IRB etc.)

Lessons Learned

* Strength based approach
* Self-reflection
* Consider trauma
* Build Trust
* Have Competent facilitators

Accountability

* Data can be stolen. Stories can be stolen/misrepresentation
* Reciprocity- Building rapport
* Build trust-keep in mind start to finish, with emphasis on finish and follow through

Facilitators context specific flexible competent