DRAFT FOR DISCUSSION: High level outline for PHAB Framework for Modern Public Health Data

May 29, 2022

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Brief Update on Survey Modernization

March 2022

Background

The Oregon Legislature's Modernization funding for the 2019-2021 biennium included funding to update the adult (BRFSS) and youth (OHT/SHS) survey systems to address these challenges and gather better data for specific communities. The Office of the State Public Health Director (OSPHD) directed Program Design and Evaluation Services (PDES) [1] to lead this project, and the Oregon Public Health Division (OPHD) Science and Epidemiology Council (SEC) provided scientific oversight.

The need and approach for modernizing Oregon's population wide surveys came in several ways including our previous work with communities in various projects, work with African American, Pacific Islander, Alaska Native and other communities, academics, and practice partners. Our approach was informed by the literature and over 30 key informant interviews with local community-based organizations.

The Behavioral Risk Factor Surveillance System (BRFSS) is a telephone survey to collect state-specific data from individual adults on preventive health practices and risk behaviors that are linked to chronic diseases, injuries, and preventable infectious diseases in the adult population. The BRFSS is partially funded by the Centers for Disease Control (CDC). Health departments are dependent on BRFSS data for a variety of purposes, such as targeting services, securing funding, and measuring progress toward public health objectives.

The BRFSS has problems of equity, data quality, and sustainability: (1) the BRFSS is increasingly not representative of all Oregonians, especially for BIPOC communities[2], (2) there are growing concerns about the validity of BRFSS data given the lack of context and sensitivity of many questions, and (3) the BRFSS is expensive to conduct -- BRFSS costs close to $1 million annually and the last racial and ethnic oversample cost over $500 per completed survey and was still not representative of certain major racial and ethnic groups (e.g., Pacific Islanders).

Oregon's Student Health Survey (SHS) is a collaborative effort with the Oregon Department of Education to improve the health and well-being of all Oregon students. The SHS is a comprehensive, school-based, anonymous, and voluntary health survey of 6th, 8th and 11th graders that provides key data for OPHD and ODE for program planning and policy efforts. Prior

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[1] PDES is an interagency applied public health research and evaluation unit, within OPHD and Multnomah County Health Department, and currently coordinates the BRFSS and school-based youth surveys for OPHD.

[2] BRFSS implementation methods (random phone call) exclude communities who are generally mistrustful of government. BFRSS questions are often seen by communities as invasive and lacking the contextual questions to make them meaningful.

to 2020, student health data was collected through the Oregon Healthy Teens Survey, the Student Wellness Survey, and the Youth Risk Behavior Survey.

Survey Modernization Efforts: 2019-2021 Biennium

Rather than investing in an expensive and limited use racial oversample that would only update the content of the surveys, PDES decided to take an approach that examined the root design and implementation of the surveys. PDES invested in two complementary approaches: 1) piloting innovative statewide survey methods that incorporated the most recent scientific advances and (2) collaborating with Oregon tribes and BIPOC and communities to collect, analyze, and contextualize culturally specific survey data. Oregon is among one of the few states to engage communities in modernizing our public health data surveys. We are sharing this information about extensive collaboration with communities in the design of public health surveys to offer a model for how such collaborations can be valuable and feasible in public health systems.

The work included:

1) Collaborating with and funding the Coalition of Communities of Color and the Northwest Portland Area Indian Health Board to form and facilitate community-specific data project teams for the Latinx, Black/African American/African Immigrant & Refugee, and American Indian/Alaskan Native communities. Each team included 5-6 members including community researchers and leadership from community-based organizations (CBOs). They used community-identified priorities to guide the analysis, interpretation, and contextualization of BRFSS (4-year aggregate 2015-2018), and OHT (2019) data. Some partners also led community-driven data collection on topics and methods of their choice. Their critique and recommendations are summarized in two reports: Engaging Communities in Public Health Survey Modernization and NPAIHB Survey Mod Report to OHA FINAL MARCH 2022.

1) Funding Pacific Islander researchers, community organizers, individuals, and CBOs to conduct community-led data collection and build capacity within Pacific Islander communities around research and data. The Pacific Islander community is particularly under-represented on statewide surveys. Using a community-led research model, a Pacific Islander core team of researchers worked with PDES and sought guidance from various advisory groups including the Oregon Pacific Islander Coalition. The Pacific Islander-led core team identified priorities for this project, co-designed the data collection methods that would work best with their communities, and developed a community health assessment tool. They analyzed both the qualitative and quantitative data using a participatory approach (ref) with a broader team of Community Research Workers. The core team co-wrote the final report, which includes results and recommendations in the report: PI HEAL Report 2021.

Detailed results and recommendations can be found in each of the reports. Taken together, the overall results from these community collaborations and the statewide BRFSS pilot of innovative methods highlight that OPHD needs to revamp its community health data collection systems.

Ongoing Survey Modernization Efforts: 2021-2023 Biennium

The results and lessons learned from the initial survey modernization efforts have led to the following ongoing work this biennium:

- Disseminating the survey modernization results to the Oregon Public Health Advisory Board, Oregon Public Health Division and survey leadership, state health programs, community partners, and federal government.

- Facilitating discussions with the Oregon BRFSS leadership about developing the infrastructure and processes to engage communities in designing statewide, locally funded adult surveys (e.g., state BRFSS).

- Establishing and engaging a youth-led, diverse, statewide Youth Data Council to improve the 2022 Student Health Survey, with support from community partners. The Youth Data Council will receive training; make recommendations to improve the survey process, content, messaging, and reporting (e.g., interactive data dashboard); and explore other data sources to provide context and actionable data.

- Coordinating with the Epidemiology and Laboratory Capacity (ELC) funded work examining the broader impact of COVID-19. For that project, OPHD has $1 million to fund BIPOC community researchers and public health leaders to lead the development of a state data system for tracking a broader set of measures (e.g., social determinants of health, mental health) in a culturally responsive way to be prepared for future pandemics and to inform the statewide health improvement plan. Such a system might use existing data sources, as well as include primary data collection.

Key Lessons Learned for Future Efforts

Working with community-based individuals, leaders and researchers on modernization taught us several lessons that are important for OPHD to considers as it moves forward in further engaging communities in modernization efforts:

- Collaborate with community partners through all phases of the data life cycle. This is essential for improving the representativeness and validity of our data systems and reporting.
- Fund community partners directly and sufficiently for their time and expertise. This includes compensation for adult and youth partners.
- Build budgets and timelines to allow sufficient staff time and resources for relationship building and maintenance. Account for staff time for such activities as facilitating continuous communication among partners, organizing meetings, disseminating materials.

- Communicate regularly and be transparent with community partners (e.g., share datasets, budgets, internal decision-making processes, legal responsibilities).
- Share power with community partners at every possible step. (e.g., share datasets and budgets, cede project review for participant compensation to community research partners.)
- Be flexible, willing to recognize mistakes and change course.
- Avoid overburdening community partners.
- Build organization-wide commitment and infrastructure to support staff and programs to advance equity and undo structural racism reflected in data systems by collaborating with community partners through all phases of the data life cycle. Examples of needed infrastructure include:
    - Training, technical assistance, and ongoing coaching for staff (e.g., conflict resolution, power dynamics, data sovereignty and data justice, decolonizing research, and data, and facilitating difficult conversations) to support program and staff commitment to community engagement.
    - Agency-wide infrastructure for sustained partnerships with the communities to engage in all phases of the data life cycle from design through collection, analysis, and dissemination (e.g., funding, contracts, relationships).
    - Agency-wide assessment and coordination of community engagement activities around data (e.g., how many youth councils/advisory groups are there?).
    - Clear vision for the outcome of data equity efforts.
        - Articulation of the public health system's future state for data infrastructure that centers communities in all phases of the data lifecycle.
        - Universal understanding of public health data systems now, and where communities are asking public health data to go, with the understanding that some public health surveys will need to continue but have opportunities to improve.
    - Communication
        - Clear guidance on channels of communication within OPHD and with community partners.
        - Campaign or structures to communicate and coordinate all OPHD community equity activities and to align with related OHA activities.
        - Plan to disseminate knowledge and activities, including roles of communities and OPHD, and strategies for clear, consistent, and effective messaging
    - IT support for software and platforms for collaborating across agencies and with communities. (e.g., Google Docs works for many partners but not state staff, not all parties can use Zoom before IT approval at Multnomah County level).

A Possible Model of Modernized Community Health Data System

In contemplating a model for a modernized community health data system, it is important to consider the system as not a group of individual surveys (e.g., BRFSS, SHS), but as a diverse and integrated set of data sources that inform one another, such as:

- Community-led data collection systems for specific-community data and reporting of those data. In this approach, communities identify priorities and play a lead role in design, data collection, analysis, and contextualization of results.
- State data systems for population-based statewide estimates and reporting that include a sustainable, coordinated system for authentic community engagement to ensure the communities are represented in the surveys and questions are culturally appropriate. For example, a state BRFSS could provide statewide estimates and improve on the CDC BRFSS methods based on community input, the BRFSS statewide pilot, and scientific research. Including minimal community led standards for reporting race, ethnicity, language, disability, sexual orientation, and gender identity (REALD & SOGI).
- Federally funded population-based surveys required for federal reporting (e.g., CDC BRFSS) and useful for supplementing local data systems (e.g., Household Pulse Survey). While OPHD does not have the power to change these systems, they can provide recommendations to our federal funders and their advisors.
- Local complementary surveys (e.g., panel surveys, Facebook surveys) that are quick to implement and less expensive, but not necessarily representative of all adults in Oregon.

The Student Health Survey – Update for Community Partners

The 2022 Student Health Survey focuses on equity

The 2022 Student Health Survey (SHS) is different from previous youth surveys. Community feedback supports and intensifies the need for the Oregon Public Health Division (OPHD) and the Oregon Department of Education (ODE) to focus on equity. Equity is a right, not a privilege, for all Oregon Youth. Oregon Health Authority (OHA) defines health equity as "…when all people can reach their full health potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, age, gender, gender identity, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances. Achieving health equity requires the ongoing collaboration of all regions and sectors of the state, including tribal governments to address: The equitable distribution or redistribution of resources and power and recognizing, reconciling, and rectifying historical and contemporary injustices."[1]

Not only should OHA services be equitable but our methods for collecting and disseminating data should reflect equity as well. To be truly equitable, the Student Health Survey needs more than the revision of a few questions. It needs community and youth engagement from design through the communication of results. It needs fundamentally different and contextualized questions that meet the needs of health programs and communities. It needs structures within OPHD that support community engagement and leadership. To be fully equitable, the SHS needs OPHD to change the way that it works. This requires organizational change which can be challenging and will require sustained effort and leadership.

This update summarizes the collaborative work of Program Design and Evaluation Services (PDES)[2] with community organizations to bring more equity to the design and content of SHS and efforts to shift the way that OPHD engages community.

Community perspective sheds light on the path

OHA's goal is to eliminate health disparities by 2030. What does that mean? Some groups of people experience persistent differences in health and health care that stem from broader systemic inequities, such as unequal distribution of social, political, economic, and environmental resources which result from racism and discrimination. Our goal is to ensure that everyone has the same opportunities to be healthy.

Beginning in the spring of 2019, the OHA Public Health Director's Office began collaborating with the Oregon Pacific Islander Coalition (OPIC), the Coalition of Communities of Color (CCC), and the Northwest Portland Area Indian Health Board (NPAIHB) to modernize Oregon's population health surveys. These community organizations provided a deep community-centered critique of the purpose, design, and implementation of the surveys and developed a set of actionable recommendations for OHA for authentically engaging with communities through all phases of the data life cycle from design through analysis and dissemination.

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[1] https://www.oregon.gov/oha/oei/pages/health-equity-committee.aspx

[2] https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/programdesignandevaluationservices/pages/index.aspx

PDES collaborated with CCC and the NPAIHB to form and facilitate community-specific data project teams for the Latinx, Black/African American/African Immigrant & Refugee, and American Indian/Alaskan Native communities. Project teams used community-identified priorities to guide the analysis, interpretation, and contextualization of student youth data. Some partners also led community-driven data collection on topics and methods of their choice.

OPIC and PDES worked together to build capacity among Pacific Islander researchers, community organizers, individuals, and community-based organizations (CBOs) to conduct community-led data collection and research. A Pacific Islander core team of researchers worked with PDES and sought guidance from various advisory groups including OPIC. The Pacific Islander-led core team identified priorities for this project, co-designed the data collection methods that would work best with their communities, and developed a community health assessment tool. They analyzed both the qualitative and quantitative data using a participatory approach[3] with a broader team of Community Research Workers.

In addition to providing key recommendations on the content of the SHS, OPIC, CCC and NPAIHB gave recommendations on including community at every step of the process of creating data from survey design through dissemination. PDES operationalized these recommendations by standing up a Youth Data Council (YDC) to give input (and ultimately collaborative decision making) into the design, content, and dissemination of the SHS. The community partners have given ongoing feedback on the formation and support of the YDC. Community partners also met with the SHS Advisory Committee in November and December 2021 to discuss their findings and recommendations. This launched the process of modernizing the SHS.

Community partners worked with PDES to write comprehensive reports describing their findings and recommendations. You can learn more about this work and read the final reports here.

These same community organizations have been instrumental in disseminating the findings from the community-led data projects. Community partners have collaborated with PDES in presenting the findings in multiple venues including (but not limited to) the Public Health Advisory Board (PHAB)[4] and OPHD Science and Epidemiology Council.

The recommendations from the community were eye-opening.

We heard that the way many of the survey questions are asked and reported does not help and, in fact, causes harm to Oregon youth. The main criticisms of the survey are:

- Tribal and Indigenous youth, youth of color, non-binary identifying youth, and non-heterosexual youth, have historically been under-represented, marginalized and lack visibility and a voice in the survey.
- Survey questions do not provide communities with enough information, context and understanding of systemic barriers such as racism, and discrimination faced by Oregon youth.

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[3] Pankaj V. et.al. "Participatory Analysis" 2011 accessed at https://www.innonet.org/media/innovation_network-participatory_analysis.pdf on 5/13/22

[4] A recording of the presentations is available at: https://www.youtube.com/watch?v=LEQN7kCy7rk (survey discussion starts at the 52.50 minute mark and is about 90 minutes in length).

- Survey questions should focus on youth’s strength and resilience, rather than negative outcomes that reinforce blame on individuals.
- Survey questions should focus on systems and environments in which youth make choices rather than entirely on decontextualized individual behaviors which have the effect of blaming youth rather than addressing the systemic causes.
- The design of surveys should include youth voice and youth as decision makers in the process.
- Survey questions do not provide enough contextual data to result in meaningfully actionable analysis.

What is Survey Modernization?

Survey Modernization simply means that we’re working to make the survey better. For everyone. We’re taking community recommendations on how to improve the survey and putting them into practice. We are working to reimagine the survey questions and capture data that is more relevant to youth’s lives to help provide the support they need to succeed.

Goals and priorities for the 2022 SHS

Based on the recommendations from community and input of the YDC, we created an action plan for revising the SHS. Primary among our goals were to (1) revisit the purpose of the SHS to ensure that it aligns with our equity focus, (2) stand up a youth data council to provide input and guidance on the content, (3) create criteria for prioritizing survey questions (detailed on the following page) and (4) make the survey more accessible by reducing the number of questions.

SHS Content Work Group Membership

An SHS Content Work Group met regularly throughout 2022 to develop the 2022 SHS questions. Group members consisted of the following representatives from the Oregon Health Authority (OHA), Health Services Division (HSD), and the Oregon Department of Education (ODE):

Oregon Health Authority

Tom Jeanne, Deputy State Epidemiologist
Renee Boyd, Program Design and Evaluation Services
Victoria Buelow, Health Promotion and Chronic Disease Prevention
Meghan Crane, Injury and Violence Prevention
Sarah Knipper, Adolescent and School Health
Alexis Phillips, Adolescent and School Health
Kristen Rohde, Program Design and Evaluation Services
Dagan Wright, Injury and Violence Prevention

Health Services Division

Shanda Hochstetler, Child and Family Program
Roxann Jones, Problem Gambling
Michael (My'kee) Martinez, Tribal Alcohol, Tobacco and Other Drugs Prevention Specialist
Fran Pearson, Child and Family Program

Oregon Department of Education

Grace Bullock, Senior Mental Health Officer, Office of the Director
Josh Rew, Psychometrics and Validity, Department of Accountability
Renee Roman Nose, Native American Student Success Coordinator, Office of Indian Education

How were questions selected?

The SHS Content Work Group prioritized questions based on the following criteria:

- **Accountability**: Is OHA or ODE accountable for providing the information? Does it support a legislative concept or policy related to youth health or education? Does it address an emerging issue?
- **Health Equity and Social Justice**: Does it align with Healthier Together Oregon (HTO) or Student Success Act (SSA) priorities related to institutional bias, adversity, trauma and toxic stress, or economic or social determinants of health (housing, food security, etc.)?
- **Systems-focused:** Does it address the context or environment in which students live? Is it culturally appropriate?

SHS Content Prioritization Guide

Purpose: The Prioritization Guide will be used as part of a transparent process to identify the critical topic areas and questions for inclusion in the Student Health Survey.

	Equity-focused	**Individual vs. System-focused (Tribal, Community, Youth Priority)**	**Public Health or Education Priority**
Healthier Together Oregon (HTO) Value	Equity and Social Justice	Strengths-based Empowerment Authentic community input	Accountability
Goal	• Advances health equity • Aligns with HTO State Health Improvement Plan (SHIP) priorities to address: ✓ Institutional bias ✓ Adversity, trauma and toxic stress ✓ Behavioral health (including mental health and substance use) ✓ Economic drivers of health/social determinants of health (including issues related to housing, living wage, food security and transportation) ✓ Access to equitable preventive health care	• Culturally appropriate • Age appropriate • Aligns with HTO/SHIP/SSA priority populations ✓ Black, Indigenous, people of color, American Indian/Alaska Native people (BIPOC-AI/AN), and emerging bilinguals ✓ People with low incomes navigating poverty, hunger, homelessness or foster care ✓ People who identify as lesbian, gay, bisexual, transgender, queer and questioning (LBGTQ2SIA+) ✓ People with disabilities ✓ People living in rural areas of the state	• Addresses current or emerging issues critical to support policy or required for funding • Supports legislative policy related to youth health or education • Required for: ✓ CDC grant ✓ Student Success Act (SSA) ✓ Every Student Succeeds Act (ESSSA) or other federal education law ✓ Drug-free Communities (DFC) ✓ Community Assessments ✓ Other

Accomplishments

The PDES SHS and YDC Coordinators worked with the SHS Content Work Group to operationalize the recommendations of the culturally specific project teams facilitated by OPIC, CCC, and NPAIHB. While some recommendations were implemented or operationalized this year, others will require continued effort over the long term.

Accomplishments for this year include:

- Launching the initial YDC to center student voice in the survey as a direct result of community feedback
- Revisiting the purpose and goals of the SHS
- Creating criteria and guidance for prioritizing questions
- Minimizing the burden on youth, and shifting away from blame, by shortening all the questionnaires
    - Removing questions. Examples of questions removed include:
        - Excluding four REALD disability questions (3 new; 1 old) based on YDC feedback
        - Removing all the ACEs questions
    - Finding other sources for data rather than asking youth, for example:
        - Using ODE poverty data rather than asking free/reduced lunch status
        - Using school rather than asking youth
- Including the Everyday Discrimination Scale (short version)
- Increasing the number of REALD categories
- Revising gender identity and sexual health questions to less hetero and cis centric by:
    - Including community-specific gender identities (Two Spirit, Pacific Islander specific gender identities)
    - Asking about “sexual contact” rather than “sex” or “sexual intercourse”
- Making questions more inclusive and less blaming by including answer categories “I prefer not to answer” and “I don’t know what this question is asking”
- Enabling more contextual data by including several open-ended questions such as:
    - What helps you feel healthier, happier, and safer?
    - What is causing you to miss school?
    - What made it hard for you to get your physical health care needs met?
    - What made it hard for you to get your emotional or mental health care needs met?
- Working with YDC to revision and revise the Positive Youth Development questions to be trauma-informed, conceptually integrated, and focused on root causes
- Launching an SHS Data Portal to provide online access to 2020 SHS state- and county-level data for data users

In addition to shortening the survey, the SHS Content Work Group also worked to:

- Ensure that questions provide meaningful context to the challenges our youth face
- Transition from deficits-based questions that focus on the individual to more strengths-based questions that address systemic issues

There’s a lot more work to do moving forward. We’ve divided the work into short-term and long-term goals.

Short-term Goals

- Reimagine the SHS website to make the results more accessible and engaging to the general public.
- Increase the scope of the YDC membership to include youth who are diverse in terms of race and ethnicity, geography, disabilities, gender identity, sexual orientation, and lived experiences to include different perspectives on the survey.

Long-term Goals

- Expand the inclusion of youth voice via the YDC to include collaborative decision making.
- Continue collaborating with community (including youth) to enhance the value of the data through contextualization and making it more relevant to community needs.
- Continue discussions with federal funders to revise questions that are required for reporting, so they are more focused on systemic barriers and are more culturally appropriate and strengths-based.
- Explore different methodologies or data sources to complement the SHS data and reduce burden on youth.
- Continue conversations on culturally appropriate metrics (e.g., Body Mass Index (BMI) – see Ongoing Improvements below).

This work will involve ongoing discussion, thought and work involving many different partners with different needs. We plan on achieving these goals within the next five years to make the survey more equitable.

The Youth Data Council (YDC) brings students to the table

In March 2022, the first YDC was formed consisting of a small group of Oregon youth attending public school. Community partners helped recruit members for this initial cohort. Due to the limited timeframe for the work of this initial YDC cohort (March to May 2022), they focused on:

- Establishing relationships amongst themselves and shaping how the group would work
- Selecting and refining the design of the SHS Logo
- High-level review of survey content and recommendations with specific focus on questions related to:
    - Disabilities
    - Mental health
    - Gender identity
    - Sexual orientation
    - Racial & ethnic identity
    - Food security

Future YDC cohorts will consist of youth from a broad range of race, cultures, abilities, gender identities, sexual orientations, geography and lived experiences (houselessness, poverty, hunger, etc.). The YDC will convene throughout the school year and will focus on:

- Making the survey more reflective of youth voice and topics of importance related to their health and well-being.
- Developing communications for a variety of audiences (youth, parents, school administrators, local community/general public).
- Making the data on the website more user-friendly and visually appealing to a general audience.

You can learn more about the YDC here.

Ongoing Challenges to Address

The crux of all improvements in our survey systems is having sustainable relationships with community partners. Building and cultivating relationships with partners takes time and resources. Historical structure of OPHD has not considered the importance of supporting community relationship building and sustenance by providing the appropriate level of staffing and resources internally and the mechanisms of funding for appropriate levels of compensation for community partners. This creates a reality in which time, money and resources are typically in short supply in public health, with survey modernization needs colliding with grant and project deadlines and budget constraints.

Other challenges include:

- Constraints on capacity and increased workloads for everyone (community partners, YDC members, OHA and ODE staff).
- The need to balance the desire for collaborating with community partners while being respectful of their time and being able to meet project and task-specific deadlines.
- Lack of a mechanism for compensating community for their time and expertise. The current OPHD contract mechanisms are not sustainable, equitable or accessible, and preference well established and larger CBOs.
- A divisive political climate that often discourages honest, open, and often painful discussions about complex, personal issues such as race, gender identity and sexual orientation and a lack of training for OPHD staff on how to support having those difficult conversations.

Though there are many challenges to this work, PDES is working with OPHD leadership to begin building these infrastructures. Proposed funding for the next biennium includes funding for more community engagement, training, and technical assistance. OPHD leadership is looking into how to support division-wide community engagement.

Ongoing Conversations & Improvements

Clearly, some questions on the survey are problematic in that they are not respectful of diverse cultures (i.e., BMI questions), are insensitive to trauma and privacy needs (i.e., gun access questions), and downplay experiences of racism (i.e., bullying questions). Unfortunately, and despite their inherent flaws, these questions cannot be changed at this time. Some of the questions, such as those on bullying, are required for Maternal Child Health Grant Title V block grant reporting. At our encouragement, programs are beginning discussions with federal grant funders about how these questions are harmful, fail to serve youth, and perpetuate systems of oppression with the hope that funders will allow Oregon to adapt these questions to better serve the needs of youth, communities and OPHD programs.

Other questions, such as BMI, require more ongoing conversations within the SHS Content Work Group about the relative value of such questions. For example, BMI calculations are derived from height and weight questions. While BMI is used to estimate the percentage of the population who fall into different weight categories and is used in public health as a measure of obesity in the population, it fails to consider differences in frames and body types that are more typical of different racial and ethnic groups. The challenge for programs is that, while it is a flawed metric, it is the only measure that programs have track population obesity. Discussions and exploration of alternative measures with community will continue.

Final thoughts

OHA’s goal to eliminate health disparities by 2030 is our north star that guides the work we do. This involves change on a magnitude that we have not seen previously. The COVID-19 pandemic shed light on the disparities that have been deeply rooted in our systems and society as a whole for centuries.

Rebuilding the Student Health Survey to be equitable is more than revising the content, it is about changing the process for how it is built. It is about engaging communities start to finish and that entails changing the organization of OPHD and OHA to support community engagement. Organizational change is a long and difficult task.

While we are proud of the accomplishments made over the past couple of years, we acknowledge that there’s much still to do to make the survey more relevant and useful for everyone. It will take time and involve a lot of hard work and difficult discussions. And, despite our best efforts, we will make mistakes. We will appreciate being called out when needed, apologize for any mistakes made and unintended consequences, and continue moving forward. We are committed to making Oregon a better place for everyone. We’ll learn, grow, and work together to make sure we better serve all Oregon youth.

Modernization of Public Health Survey Systems:

Behavioral Risk Factor Surveillance System (BRFSS)

December 20, 2022

Oregon Health Authority

Overview of Today's Presentation

- What is the BRFSS?
- Impact of survey modernization project
- Questions and discussion

What is the BRFSS?

Behavioral Risk Factor Surveillance System (BRFSS) is…

- Sponsored by the Centers for Disease Control & Prevention
- Telephone survey (cell and landline) of adults in Oregon
- Part of national survey
- Range of topics: risk and protective factors, prevention/screening, health outcomes, demographics

Oregon BRFSS Design

CDC Grant-funded Survey
(AKA Core Survey)

Required for CDC grant
- n=5,000
- Must follow CDC protocols
  - ✓ All CDC core questions
  - ✓ Random Digit Dialing (RDD) for landline and cell phone interviews

Grant funding does <u>not</u> cover all core survey costs

Data used for:
- National estimates
- State estimates (annual, county, RE)
- County Health Rankings

Program-funded Survey
(AKA State Survey)

More focused on programmatic needs
- n=3,200 or 4,000
- Increase sample size for low prevalence indicators/those asked of subgroups

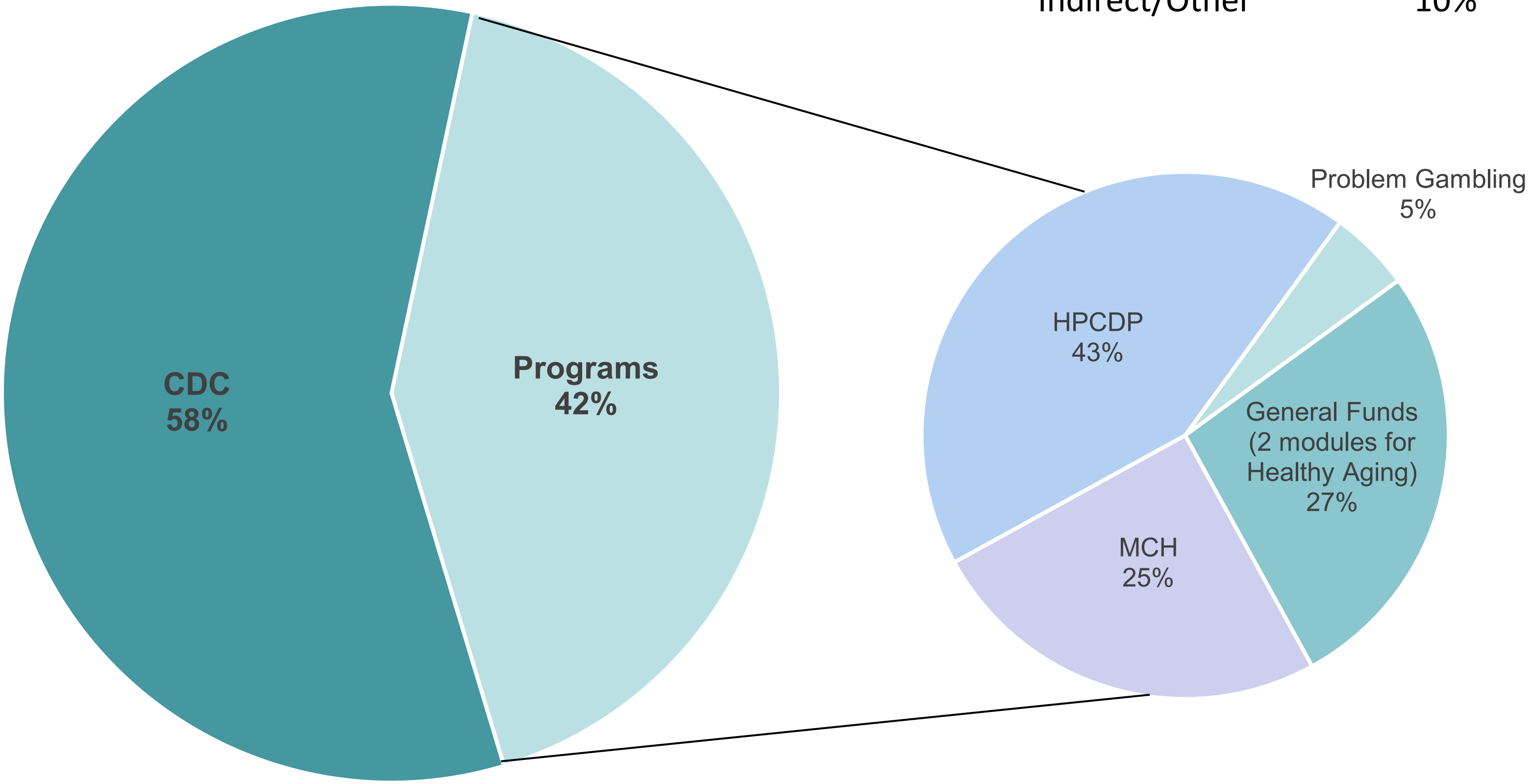
Program funding:
- Covers cost for State survey *and*
- CDC funding deficit for Core survey

Data augments sample sizes for state, county, and race/ethnicity estimates

Oregon BRFSS Funding

2023 Costs: $915,000

Contractual	61%
Personnel	29%
Indirect/Other	10%



Challenges with BRFSS

- Lack of community engagement
- Concerns about representativeness and validity of data
  - Response rates
  - Community reach
- Survey length
- Expensive
- Changing needs

Impact of survey modernization project

Collaboration with communities

Identification of innovative statistical & survey methods

Solutions

Impact

- Community Collaboration
  - ✓ Deep critique of fundamentals of survey design and implementation
  - ✓ Survey can be more equitable
- Innovative Methods – BRFSS Pilot in 2020
  - ✓ Census methodology (ABS push to web)
  - ✓ Proof of concept – it works! Response rate can be improved
- Developing new model of survey systems

Draft initial framework for state adult survey system

- **Federally funded population-based surveys** to monitor core public health measures (e.g., Core BRFSS, Pulse Survey)
- **State BRFSS** that improves on Core BRFSS methods based on community recommendations, BRFSS pilot, and scientific research
- **Community-led data collection models** for specific community needs and priorities
- **Complementary surveys** that are quick to implement and less expensive (e.g., panel surveys, Facebook surveys)
- **Other existing data sources**

Community-led data collection models

- With Epidemiology and Laboratory Capacity (ELC) grant, we are planning to provide $1 million to BIPOC communities to develop community-led data systems:
    - To assess broader impact of pandemics using the State Health Improvement Plan framework (e.g., effects on economic well being & behavioral health)
    - Hope is these data systems will provide information on community strengths and vulnerabilities, so we can consider equity effects of our potential responses
    - One goal is for these data systems to inform SHIP
- Priority-setting will be done by community representatives

Questions and Discussion

Questions?

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Thank You!

RACIAL EQUITY DATA ROAD MAP

DATA AS A TOOL TOWARDS ENDING STRUCTURAL RACISM

Racial equity means being aware of and taking into account past and current inequities, and providing all people, especially those who are most impacted by racism, the support needed to thrive.

1. Looking at health issues with a focus on the impact of racism

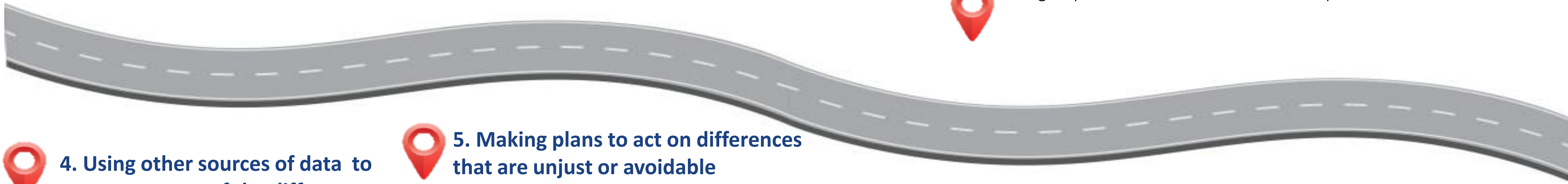
Describes why issues should be looked at with a racial equity lens and introduces a tool for programs to use in their work.

2. Determining if program is ready to use data to address racism

Encourages programs to use a self-assessment to better understand which systems are in place to support racial equity work using data.

3. Understanding what the data say about differences in health outcomes by race and ethnicity

Describes why it is important to look at data in smaller units such as race, ethnicity, or zip code and gives suggestions on how to do this. Provides guidance on comparing data across sub-groups to see whether there are inequities.



4. Using other sources of data to uncover causes of the differences

Provides suggestions on how to describe data with historical and structural context, with a focus on engaging the community.

5. Making plans to act on differences that are unjust or avoidable

Introduces tools to support the process of identifying the most striking inequities and creating a plan to address them.

6. Presenting data in ways that help people make sense of the numbers

Outlines important questions and things to consider in designing materials used to communicate data to key stakeholders.

7. Moving from data to action

Describes how to plan, put in place, and monitor the impact of interventions to address inequities.

For more information, contact: RESPIT@state.ma.us

COMMONWEALTH OF MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH

Racial Equity Data Road Map:

Data as a Tool Towards Ending Structural Racism

Table of Contents

Acknowledgements

This report was prepared by members of the **R**acial **E**quity **S**trategic **P**athway **I**mplementation **T**eam (RESPIT): Stefanie Albert, Elizabeth Beatriz, Antonia Blinn, Lindsay Kephart, Kira Landauer, Susan Manning, Sabrina Selk, Christine Silva, Katie Stetler, Sarah L. Stone, Mahsa Yazdy, and Megan Young. Review and feedback on the Road Map were provided by Melanie Jetter, Emma Posner, Kate Hamdan, and Heather Catledge.

Special thanks go to: Craig Andrade, Alison Mehlman, Beatriz Acevedo, Emily Lu, Tim Nielsen, Ryan Walker, and Hafsatou Diop.

Suggested Citation: Massachusetts Department of Public Health. Racial Equity Data Road Map. Boston, MA; <Insert Release Date>. To obtain additional copies of this report, please contact: Massachusetts Department of Public Health, Bureau of Family Health and Nutrition - 250 Washington Street, 5th Floor Boston, MA 02108. Email: RESPIT@state.ma.us.

Executive Summary

> "We are concerned about the constant use of federal funds to support this most notorious expression of segregation. Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death. I see no alternative to direct action and creative nonviolence to raise the conscience of the nation."
>
> -Dr. Martin Luther King Jr. speaking on the segregation of hospitals at the 2nd National Convention of the Medical Committee for Human Rights, Chicago, Illinois. March 25, 1966

Our Mission: The Massachusetts Department of Public Health (MDPH) works to ensure that all residents of the Commonwealth achieve their best health by eliminating disparities, addressing the social determinants of health and using data-driven practice. We have prepared this document that outlines ideas, suggestions, and best practices for using data to help us close gaps in health outcomes by race and ethnicity.

Why incorporate a racial equity frame in our data?: It has been fifty years since Dr. King spoke to the unacceptable inequities in health outcomes by race that result from a system of segregated health care. While progress has been made to integrate the health care system, the gap in health outcomes between people of color and white people remains. In some cases, the gap has even widened as advances in medicine increase the overall potential for health; at the same time, too little has been done to address historical structural racism that plays out in people's lives and communities. By examining the role that data can have in perpetuating and failing to address inequities in health, we are performing an act of what Dr. King calls "creative nonviolence," to explicitly acknowledge and specifically use racialized data. By racialized data we mean looking at data for racial inequities in ways that reflect the social constructs of race – a system of power and privilege with historical and modern day impacts and consequences. This supports efforts to disrupt the status quo; face racial inequities head on; and inform data-to-action approaches that can be used to test new ideas that may finally lead to all people having the opportunity to reach their full potential for health and wellbeing.

The Racial Equity Data Road Map: The Racial Equity Data Road Map is not a toolkit or one-size-fits all approach. Instead, it is a living document that outlines a number of steps for using data that have been piloted and tested within MDPH as one part of our journey towards achieving racial equity. As such, while the sections are presented in a way that is hopefully easy to follow, there is no set order in which they should be followed. Instead, users of the Road Map can move through the document at the pace and in the manner that makes the most sense for the program or issue being addressed, taking into consideration funding requirements, approval processes, and decision-making structures as needed. The Road Map is divided into the following seven sections:

Section 1. Looking at health issues with a focus on the impact of racism
Describes why issues should be looked at with a racial equity lens and introduces a tool for programs to use in their work.

Section 2. Determining if program is ready to use data to address racism
Encourages programs to use a self-assessment to better understand which systems are in place to support racial equity work using data.

Section 3. Understanding what the data say about differences in health outcomes by race and ethnicity
Describes why it is important to look at data in smaller units such as race, ethnicity, or zip code and gives suggestions on how to do this. Provides guidance on comparing data across sub-groups to see whether there are inequities.

Section 4. Using other sources of data to uncover causes of the differences

Provides suggestions on how to describe data with historical and structural context, with a focus on engaging the community.

Section 5. Making plans to act on differences that are unjust or avoidable

Introduces tools to support the process of identifying the most striking inequities and creating a plan to address them.

Section 6. Presenting data in ways that help people make sense of the numbers

Outlines important questions and things to consider in designing materials used to communicate data to key stakeholders.

Section 7. Moving from data to action

Describes how to plan, put in place, and monitor the impact of interventions to address inequities.

Conclusion: The Road Map is a summary of tools and strategies that help bring together both the intellectual (the head) and emotional (the heart) assets that are necessary to address the ongoing health inequities we face as a Commonwealth. While this document was originally crafted to meet the needs of epidemiologists and data analysts, it is hoped that anyone interested in using data to inform action can use this Road Map to inform their practice. Because no one has yet achieved the goal of fully realizing racial equity there will be a continuing need to refine and build upon what is written here as the practice of using data to inform our racial equity practice evolves. If there are mistakes, corrections or new knowledge that can improve this document, please let us know by emailing us at RESPIT@state.ma.us.

Introduction

Background

The Massachusetts Department of Public Health (MDPH) is dedicated to ensuring optimal health of all residents of the Commonwealth by eliminating disparities, addressing the social determinants of health, and using data-driven practice. According to the United Health Foundation America's Health Rankings, Massachusetts is consistently one of the healthiest states in the nation. However, lost in that achievement is the existence of **health inequities**, specifically racial inequities. MDPH is dedicated to understanding the root causes of inequities seen in communities across Massachusetts and taking action to eliminate them. We have prepared the following document that outlines ideas, suggestions, and best practices for using data to help us close gaps in health outcomes by race and ethnicity.

To achieve this goal, MDPH is addressing **structural** and **institutional racism** and the way systems and policies advantage certain groups and disadvantage others. An explicit focus on racism allows for the development of frameworks, tools, and resources that can be applied to racial inequities that impact health outcomes. This also provides the opportunity to better understand how racism influences public health so that actionable strategies and solutions can be identified.

Importance

It has been fifty years since Dr. Martin Luther King Jr. spoke to the unacceptable racial inequities in health outcomes perpetuated by a system of segregated health care. While significant progress has been made to integrate the health care system, the gap in health outcomes between **people of color** and white people has not been eliminated. In some cases, the gap has even widened as new technologies increase the overall potential for health; at the same time too little has been done to address the history of structural racism that endures in the lives of our people and communities. By examining the role that data can have in perpetuating and failing to address health inequities, we are performing an act of what Dr. King calls "creative nonviolence," to explicitly and specifically use **racialized**

data to: disrupt the status quo; face racial inequities head on; and inform data-to-action approaches that can be used to test new ideas that may finally lead to all people having the opportunity to reach their full potential for health and wellbeing.

Road Map Purpose and Overview

Improving programs' capacity to collect and use data to promote **racial equity** has been identified as a priority need through the Racial Equity Movement at MDPH. This need inspired the development of this Road Map to improve the use of data to inform racial equity work in MDPH-funded programs and initiatives so that services are delivered in a more equitable way, optimizing health and well-being for all residents of the Commonwealth. Improving the use of data to inform racial equity work includes: collecting and analyzing data, collaborating with communities, framing program data in the context of historical and current policies, and identifying system factors that impact the health of communities. Additionally, it includes asking questions and using tools to aid in root cause analyses, identifying and designing solutions, and developing strategies to address inequities.

The vision for the Road Map is to improve the use of data to inform **racial equity work** in MDPH-funded programs to achieve equitable health outcomes across the Commonwealth.

The Road Map provides a suggested methodology for programs to assess their progress in addressing racial inequities in service delivery and health outcomes. This is not a rigid process that must be followed step by step. Rather, it is a collection of guiding questions, tools, and resources that can be customized to best suit the needs of programs with different levels of capacity in data analysis, quality improvement, and racial equity reframing techniques. There are multiple entry points to the Road Map so programs may start at different places.

The Road Map is a collection of guiding questions, tools, and resources that can be customized to best suit the needs of programs, not a prescriptive checklist.

Overview of Sections

The Road Map is organized into seven sections. The purpose of each section is outlined below.

Road Map Section	Purpose
1. **Looking at health issues with a focus on the impact of racism**	Describes why issues should be looked at with a racial equity lens and introduces a tool for programs to use in their work.
2. **Determining if program is ready to use data to address racism**	Encourages programs to use a self-assessment to better understand which systems are in place to support racial equity work using data.
3. **Understanding what the data say about differences in health outcomes by race and ethnicity**	Describes why it is important to look at data in smaller units such as race, ethnicity, or zip code and gives suggestions on how to do this. Provides guidance on comparing data across sub-groups to see whether there are inequities.
4. **Using other sources of data to uncover causes of the differences**	Provides suggestions on how to describe data with historical and structural context, with a focus on engaging the community.
5. **Making plans to act on differences that are unjust or avoidable**	Introduces tools to support the process of identifying the most striking inequities and creating a plan to address them.
6. **Presenting data in ways that help people make sense of the numbers**	Outlines important questions and things to consider in designing materials used to communicate data to key stakeholders.
7. **Moving from data to action**	Describes how to plan, put in place, and monitor the impact of interventions to address inequities.

Foundational Terms/Phrases

A detailed Racial Equity Glossary of Terms can be found at the end of the document. Throughout the document key terms are bolded and linked to the Glossary. Below are explanations of common terms used in the Road Map that are important to be grounded in from the beginning:

- ***Racial equity work*** includes activities or programs that create and reinforce policies, attitudes, and actions for equitable power, access, opportunities, treatment, and outcomes for all people, regardless of race or ethnicity. The goal is to eliminate inequities between people of different races and ethnicities, and to increase success for all groups.[1, 2]
- Using a ***racial equity lens*** means explicitly considering race, ethnicity, and racism in analyzing issues, looking for solutions, and defining success.[3]
- ***Data for racial equity work*** will vary based on the question the program wants to answer or the issue it wants to address. Common individual-level demographic variables that are often helpful in understanding how racism impacts health outcomes include, but are not limited to, race and ethnicity, language, place of birth, and zip code.
- ***Contextualizing data*** means providing a narrative that describes the data and the root causes of inequities in the context of historical and current systems of oppression (e.g., racism, sexism). This must be done by engaging community partners and stakeholders in understanding and interpreting the data, and/or looking at quantitative data on individual and community experience.
- ***Center in the margins*** is to shift the starting point from a majority group's perspective, which is the usual approach, to that of the marginalized group or groups.

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[1] Boston Public Health Commission, Racial Justice and Health Equity Initiative Professional Development Series Glossary

[2] Government Alliance on Race and Equity, http://www.racialequityalliance.org/about/our-approach/benefits/

[3] Annie E. Casey Foundation, http://www.aecf.org/m/resourcedoc/grantcraft-GrantMakingWithRacialEquityLens-2007.pdf

- ***Health disparities*** are differences between the health of one population and another in measures of who gets disease, who has disease, who dies from disease, and other adverse health conditions.
- ***Health inequities*** are differences in health status and mortality rates across population groups that are systemic, avoidable, unfair, and unjust. These differences are rooted in social and economic injustice, and are attributable to social, economic and environmental conditions in which people live, work, and play.
- ***Racialized data*** are stratified in ways that acknowledge the groups of people who have been assigned a race by society (racialized) to perpetuate and support systems of privilege and oppression, such as distinctions by race/ethnicity, language, and place of birth. Moving beyond racialized data to using data for racial equity is part of the journey described throughout this Road Map.
- ***People of color*** is a term that is used to reference the way that groups have been racialized in the United States to privilege certain groups as 'white' based on the countries from where their families immigrated. People of color is a term that has been used in many different ways across time. In this text, it is being used as a way to express the dichotomies that exists based on designation of a person as white or non-white. It is not to be used to broadly classify all non-white populations, or dismiss the varied history of discriminatory and violent policies against specific non-white groups.

Section 1: Looking at health issues with a focus on the impact of racism

In public health, health outcomes are traditionally examined by select demographic characteristics, including race and ethnicity, to highlight disparities in outcomes. It is less common for disparities to be framed as inequities and rarer yet to identify historical and current policy and systems factors that contribute to these inequities. Reframing how your program views health outcomes can help you understand how and why the existing disparities are unfair, unjust, and preventable. Reframing can encourage you to think carefully about the most effective ways to address racial inequities that focus on underlying structural factors. The reframe described below provides a framework to interpret data using a **racial equity lens**.[4]

The way messages are framed can result in substantial differences in how data are interpreted and what potential solutions are considered.

The way messages are framed can result in substantial differences in how data are interpreted and what potential solutions are considered. The Racial Equity Reframing Tool (Figure 1.1) is one way to explicitly describe traditional approaches, and then challenge the underlying assumptions and expectations of those approaches. This exercise often exposes unspoken, pervasive assumptions that underlie how we think about our work. By surfacing these assumptions and making them explicit, your program can question whether they are helping to address inequities or if they might, in fact, be reinforcing inequities.

The Racial Equity Reframing Tool uses five questions, or framing elements, that can be discussed using qualitative data, needs assessment findings, and input from community stakeholders.

1. What is the problem?
2. What is the cause? (What/who is responsible?)
3. What is the solution?

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[4] Framing the Dialogue on Race and Ethnicity to Advance Health Equity: Proceedings of a Workshop. National Academies Press.

4. What action is needed?
5. What values are highlighted?

Figure 1.1: *Racial Equity Reframing Tool*

Framing Element	Traditional Approach	Racial Equity Approach
1. What is the problem?	This is often the problem as defined long ago and reinforced by education and access campaigns over years of programming and funding cycles.	Where is the injustice? Are subgroups affected differently? Are specific groups bearing a greater burden? What is the inequity of interest?
2. What is the cause? ***What/who is responsible?***	Individual behaviors/actions are often identified as the root cause of the problem.	Think through the Social Determinants of Health (SDoH—built environment, social environment, employment, education, housing and violence) as they pertain to the problem defined above. What are the root causes? Think bigger and more broadly about policies, and opportunities within the healthcare or social service systems. Think about the individual level, interpersonal level, organizational level, community level, and public policy levels. This may need to be done collaboratively with stakeholders.
3. What is the solution?	When the cause of the problem is deemed a result of individual action, the solutions developed are likely to be individual-level interventions.	How do you address the root causes identified above? What can be done about internal policies (e.g. program and agency policies)? What is the link between SDoH and larger policies (e.g., government, health system)? This can and should be multifaceted.
4. What action is needed?	Traditional approaches often center on individual-level education or clinical intervention and likely guide you to engage only the same stakeholders, use the same language, and/or	Now that you have solutions, what gets you there? Consider creative strategies. Where do you fit in this? Are you engaging partners from other agencies? Are you engaging the right partners? The community? Are you using racial

	analyze the same data as you have previously.	justice language in your approach to partners? What processes are needed for engaging those partners?
5. What values are highlighted?	Given the problem and solution, what do you know to be true? Traditional approaches often highlight personal responsibility, individual choice, etc.	Given the newly defined problem and solutions, what is now known to be true? The Racial Equity Approach often highlights equity, fairness, shared responsibility, etc.

Figure 1.2 represents an example from a diabetes program of how a racial equity reframe was used to reimagine how they approach their prevention efforts.

Figure 1.2: *Racial Equity Reframing Example – Diabetes*[5]

Framing Element	Traditional Approach	Racial Equity Approach
1. What is the problem?	High rates of diabetes	Persistent racial inequities in diabetes rates for low-income Caribbean Latino seniors. They are healthy in the Islands and they get sick when they come here.
2. What is the cause? ***What/who is responsible?***	Poor nutrition, lack of exercise, overweight/obesity *Individuals*	Food deserts, income inequity, and racial redlining in transit lead to social isolation and lack of community support; zoning for green space, etc. in communities of color; disinvestment in communities of color; residential segregation *Businesses, policy makers, multiple institutions and unfair systems*
3. What is the solution?	Improve nutrition, increase physical activity	Food security in all communities; economic investment in low-income communities and communities of color; accessible and affordable healthy foods in all communities (particularly communities of color)
4. What action is needed?	Nutrition education classes, exercise classes	Food access policies that target roots of inequities; economic policies that invest in communities of color; partnerships across sectors and with community residents

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[5] Adapted from Terry Keleher, The Applied Research Center (ARC)

5. What values are highlighted?	Individualism; personal responsibility; choice; individual freedom	Equity; justice; fairness; shared responsibility

As this example highlights, when a different frame is used, very different messages about the causes of the problem and very different approaches to address this issue arise. In the diabetes example, a traditional approach would lead to solutions addressing access to health care and education about healthy food and exercise choices. Applying a racial equity reframe, the impact of structural issues on an individual's ability to make healthy choices point towards policy, systems, and environmental solutions.

Section 1 Reflection

As you apply your racial equity reframe, check-in with your team about what you have learned from this exercise.

- What surprises you?
- What assumptions did you have that were challenged?
- How does this inform your future thinking and planning?
- Do you have established relationships with the communities you serve? How would their voice change the reframe exercise?
- How can you take your initial reframe and bring it to other stakeholders?

This is an opportunity to think differently about the work and to pursue new ways of imagining solutions. This is an exercise you can do multiple times, with multiple audiences, over time and continue to learn and grow your analytic capacity for applying a racial equity reframe. At any point in your journey you can return to this step to consciously question the assumptions that are informing your work.

Practicing using an equity lens to reframe health topics supports a growth mindset as we confront the fact that many of our assumptions are dependent on a system that was built to maintain and sustain inequities. It is only through challenging our current way of thinking that we will be able to make transformational change.

Section 2: Determining if program is ready to use data to address racism

Purpose

For the purpose of this Road Map, program data readiness is defined as having the knowledge, resources, and capacity to collect and use data to promote **racial equity**. As your program uses this Road Map, you may engage with data in new and unfamiliar ways. After applying a Racial Equity Reframe, your program is encouraged to complete a self-assessment using the Racial Equity Program Data Readiness Assessment (found in the Appendix) to determine whether or not basic data systems are in place to support data-driven **racial equity work**.

The Racial Equity Program Data Readiness Assessment will help your program to:

1. Understand standards that support engagement in data-driven racial equity work.
2. Assess its ability to collect and use data to promote racial equity.
3. Identify gaps in knowledge, resources, and capacity related to data readiness.
4. Use tools and strategies to build capacity for data-driven racial equity work.

There are five Data Readiness Standards used to assess your program's readiness to engage in and support data-driven racial equity work. Your program should strive to achieve the following:

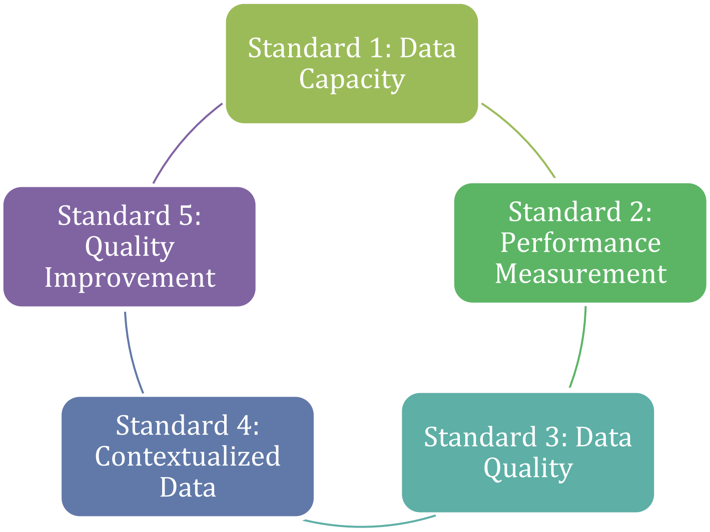
- **Data Capacity**: Program has dedicated staff that can analyze data to be used in program monitoring and decision making with a racial equity lens.
- **Performance Measurement**: Program reports on performance measures in real time to identify areas of improvement with a racial equity lens.
- **Data Quality**: Program collects and reports individual level data to inform racial equity work according to MDPH standards.
- **Contextualized Data**: Program contextualizes data using a structural framework to understand and improve equity in outcomes in their program.

- **Quality Improvement**: Continuous quality improvement is thoroughly integrated in the program and a quality improvement team effectively uses improvement methods to address identified inequities.

In order to make progress on each of the five Program Data Readiness Standards, it is critical to involve community stakeholders at every step of the process, particularly in the interpretation of data, analysis of root causes of inequities, and design of effective, data-informed solutions (see Section 4).

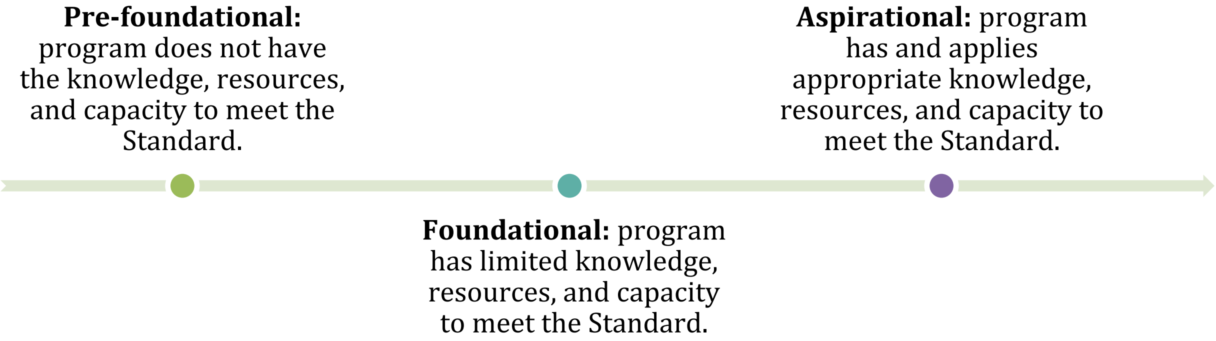
In addition, buy-in from leadership or decision-makers is critical for ensuring resources to support infrastructure for collecting high quality data, ensuring availability of analytic expertise, and dedicating staff time to contextualizing data and making community-informed decisions about how the data can inform improvements in program outcomes. If leadership or decision-makers are not yet invested, components of this work can be implemented and used to demonstrate the value of using data to promote racial equity.

Figure 2.1: *Program Data Readiness Standards*



Program Data Readiness Standards exist on a continuum with three Phases: Pre-foundational, Foundational, and Aspirational. Your program will fall somewhere on the continuum for each Standard; this depends upon your program's access to data and analytic support.

Figure 2.2: *Continuum of Data Readiness Standards*



Pre-foundational: program does not have the knowledge, resources, and capacity to meet the Standard.

Foundational: program has limited knowledge, resources, and capacity to meet the Standard.

Aspirational: program has and applies appropriate knowledge, resources, and capacity to meet the Standard.

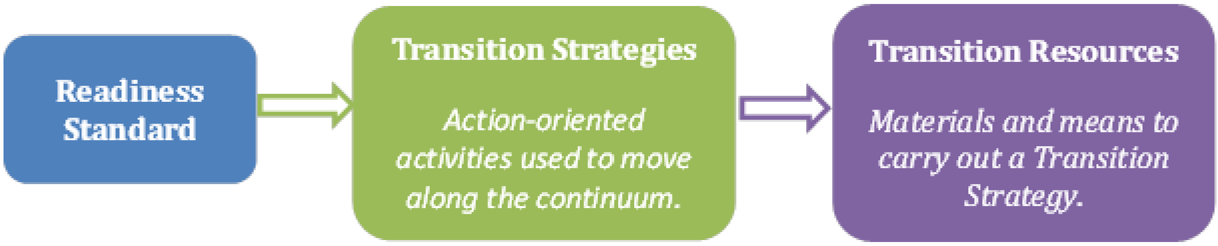
Programs at the Pre-foundational phase should build program capacity, knowledge, and resources in the five Program Data Readiness Standards as they use the Road Map. For programs that are at the Foundational phase, this assessment will provide tools to continue building readiness to maximize efficiency and effectiveness while they use the Road Map.

Programs do not need to reach the Aspirational Phase for each Standard in order to use the Road Map.

Your program is encouraged to assess where you fall on the continuum for each Standard. ***Programs do not need to reach the Aspirational Phase for each Program Data Readiness Standard in order to use the Road Map.*** The strategies and methodology presented in the assessment are intended to guide your program in building capacity, resources, and knowledge as you use the Road Map.

Each Program Data Readiness Standard is associated with Transition Strategies. Transition Strategies are action-oriented activities that can be used to move along the continuum towards the Aspirational Phase for that Readiness Standard. Transition Strategies correspond with Transition Resources, which are materials and means a program may apply to carry out the Transition Strategy.

Figure 2.3: *Program Readiness Transition Strategies and Transition Resources*



Guidelines for Use

A program self-assessment should be conducted for each of the five Data Readiness Standards. The self-assessment is designed to specifically assess data capacity to support data-driven **racial equity work.** There are other tools, such as the Racial Justice Self-Assessment checklist developed by the MDPH Bureau of Community Health and Prevention, that focus more broadly beyond data that can help programs identify concrete actions and steps they can take to better incorporate a racial justice lens in their work. It is recommended that the Data Readiness Assessment be completed with a team including leadership, managers, supervisors, programmatic staff, epidemiologists, and other staff who support your program.

1. To determine your readiness level for a given standard, review Transition Strategies in the Racial Equity Program Data Readiness Assessment (see Appendix).
2. Read each Transition Strategy from left to right, starting with the Pre-foundational Phase column. Review the Pre-foundational Phase Characteristics for each Transition Strategy. Think of practices your program engages in that fit those characteristics.
3. If your program meets all of the Characteristics for the Pre-foundational Phase, move one column to the right, to the Foundational Phase. Repeat the same process for the Aspirational Phase.

4. If your program does not meet all the Characteristics of a Transition Strategy then your program is currently in that Phase of that Readiness Standard.
    a. Once you have identified the Phase your program is in, consider developing goals to move your program along the continuum towards the Aspirational Phase. Transition Resources can help you in this process.
    b. Repeat this process for all Transition Strategies.
5. If you find your program is lacking readiness through this self-assessment, you may need to engage in capacity-, knowledge-, and/or resource-building to fill any major gaps and to increase program data readiness. You can then return to the self-assessment to reassess your readiness status.
6. If you find your program is at least in the Foundational Phase, continue to bolster your program's data readiness capabilities while moving through the Road Map.

Important Notes

- Transition Strategy Characteristics of a 'lower' Phase carry across all Phases, even if not stated explicitly (e.g., characteristics of the Pre-foundational Phase are also characteristics of the Aspirational Phase of that Transition Strategy).
- This is not intended to be a 'one size fits all' tool; some Transition Strategies and Transition Resources may not be applicable to your program or may need to be adapted to your program context.
- The Transition Resources are suggestions, not mandatory.
- Your program may be Pre-foundational for one Transition Strategy and Foundational for another in the same Program Data Readiness Standard. This is expected; this self-assessment will allow you to identify gaps in knowledge, resources, and capacity to facilitate goal-setting to increase program data readiness.

Section 2 Reflection

Now that you have completed the Racial Equity Program Data Readiness Assessment, debrief as a group and discuss program strengths and areas where racial equity work is "in progress" or has not been started.

- What are the current strengths? In which areas has racial equity work been strong?
- Identify where program Standards are “Foundational.” What are the transition strategies that will bring the program to “Aspirational”?
- What areas are “Pre-foundational”? Do they cluster in one particular Readiness Standard? What are the barriers to transitioning to “Foundational”?

Section 3: Understanding what the data say about differences in health outcomes by race and ethnicity

After your program completes the Racial Equity Program Data Readiness Assessment, you are ready to begin looking at your data. Many programs collect individual-level data on the participants or clients they serve. From these data, prevalence estimates and rates are often calculated and presented in aggregate, meaning all data are grouped together to provide a summary measure (e.g., the prevalence of diabetes in Massachusetts). Alternately, data can be disaggregated (or stratified), meaning they are broken down and analyzed in smaller units (e.g., race, ethnicity, or zip code), rather than presented as an overall rate.

Disaggregate Data and Racial Equity

While aggregate data show overall health outcomes, disaggregated data can show how health outcomes can be different between racial and ethnic groups or specific communities. This gets at health disparities—the differences between the health of populations in who gets disease, who has disease, who dies from disease, and other adverse health conditions.

Disaggregating data is important to identify racial and ethnic **health inequities** – differences that are unjust and avoidable – that can then be addressed through changes to policy, practice, and programs. For example, the prevalence of diabetes among Asian women in Norfolk County (disaggregate) may be much higher than the overall prevalence of diabetes in Massachusetts (aggregate). The disaggregated data highlight this health inequity so that future policy and practice can address it.

How to Disaggregate Data

Using **data for racial equity** begins with determining if and how different races and/or ethnicities experience health outcomes differently. Steps in disaggregating data include:

- Engaging with community members. Community members can assist in identifying which racial/ethnic subgroups are most prevalent in the geographic area and which health outcomes are most salient. Involving community members may also provide additional insight into intersectional issues such as race/ethnicity, language access, and immigration status.

- Identifying sources of race and ethnicity data available to your program. Sources may include surveys or program intake/assessment forms. Consider how these data were collected—are measures self-reported or do they come from another data source such as the individual's medical record?
- Determining which health-related outcome(s) to disaggregate. Health-related outcomes can include measures of disease or death, health behaviors, health-related social needs, and program-specific measures (e.g., use of services). For example, outcomes to consider in regard to inequities in tobacco control might include: smoking-related cancer mortalities, use of tobacco in the past 30 days, rates of successful attempts of tobacco cessation, age of first tobacco use, access to tobacco retailors, referrals to tobacco cessation programs, and completed referrals for tobacco cessation programs.
- Breaking down race and ethnicity into as fine categories as data allow. If a program can look at health outcomes by ethnicity (e.g., Chinese, Filipino, Vietnamese), the analysis will provide more detailed and specific information about a particular community as compared to grouping all ethnicities together (e.g., Asian).
- Respecting self-identification. If there are multiple sources of data on race and ethnicity, prioritize self-reported data.[6]

Data Quality Challenges and Limitations

As you look at your program data, you may identify opportunities for improving the completeness and accuracy of the data.

Missing Data

- Use substitute (proxy) measures. If your program does not have race and ethnicity data, there are indirect or proxy measures that can be analyzed such as country of

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[6] Chin M. H. (2015). Using patient race, ethnicity, and language data to achieve health equity. Journal of general internal medicine, 30(6), 703–705. doi:10.1007/s11606-015-3245-2 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4441661/

origin, language, income, education, or zip code. With any use of proxy variables, more context and interpretation will be needed to properly frame the message and limitations of those data should be acknowledged (e.g., if using zip code as a proxy, frame within context of residential segregation). When using this approach, be clear about the possibility of confounding (a distortion of the association between racial groups and an outcome that occurs when racial groups differ with respect to other factors that influence the outcome), as racial/ethnic inequities may become evident when the data are disaggregated by other variables (e.g., income or education).

- Consider the reason why data are missing. Frequently, data are missing because systems do not support the collection of race/ethnicity data, even when there is a regulatory requirement. This may be due to the lack of understanding of the importance of collecting this information, a lack of capacity to use MDPH standards (see accompanying *Racial Equity Data Road Map Attachments* document), discomfort with talking about or acknowledging race/ethnicity, and assumptions that asking about race/ethnicity makes communities of color uncomfortable. Consider how these missing data could potentially distort your analysis and/or interpretation.
- Engage in a quality improvement project to improve data quality, if more than 20% of data are missing. Then you can use Plan-Do-Study-Act cycles or other quality improvement methods to address missing data. See Section 7 for additional quality improvement ideas.

Suppression rules

- When the number of people within a group is small, there is a risk that presenting the data within small categories or populations may identify the individuals and comprise the confidentiality of the data; therefore, MDPH has outlined confidentiality procedures under which individual level or aggregate level data can be disclosed (MDPH's confidentiality procedures, see procedure 7).
- Data suppression is when selected information is removed or hidden when there is concern that small numbers may identify individuals. Data suppression should be

considered when data are being presented 1) by geographic areas smaller than state level, or 2) by more than one covariate (e.g., year, race, gender).

Data Collection

- Consider the terminology used. Be aware that terminology may vary based on the sources of data or how the data were collected over time. There may have been changes in definitions or data collection practices . For example, some programs may use Latino, Hispanic, Spanish, or Latinx interchangeably.
- Consider how race data are collected. Are participants able to identify as more than one race? It is important to explicitly document these data considerations as they provide context during your analysis.

Data Use

- Collapse data using recommended standards. If collapsing race or ethnicity data is necessary to create population estimates, MDPH recommends using the race and ethnicity categories developed as a collaborative post-censal (US ACS Survey estimates) population estimate between the University of Massachusetts Donahue Institute and the MDPH Bureau of Environmental Health.[7] The preferred method is breaking down race and ethnicity into as fine categories as data allow.
- Be explicit when using maternal race/ethnicity as a proxy for infant race/ethnicity.

Assessing for Inequities

Now that the data have been disaggregated by race and ethnicity (or a proxy variable), the next step is to assess for inequities by subgroup.

Even with small numbers, patterns or striking differences can stand out and should be investigated further.

1. Use proportions (ratios in which the numerator is a subset of the denominator) or rates (frequency of events during a certain time period divided by the number of

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[7] Strate, S., Renski, H., Peake, T., Murphy, J.J., Zaldonis, P. (2016). Small area population estimates for 2011 through 2020. [White Paper]. Population Estimates Program, Economic and Public Policy Research, University of Massachusetts Donahue Institute.

people at risk for the event during that time period) instead of raw numbers alone to account for differences in the sizes of the population subgroups. This allows for valid comparisons of health events between population groups and better assessment of risk.

2. Compare the results across population sub-groups and decide whether meaningful differences exist. It is not necessary for there to be a statistically significant difference. When comparing differences across small groups, the sizes of the populations compared are often not large enough for a difference to be considered statistically significant even if a meaningful difference does exist. Even with small numbers, patterns or noticeable differences can stand out and should be investigated further. In some cases small numbers may signal a concern, especially if no cases are expected.

Example

This example demonstrates the importance of using rates when comparing health events:

> During 2016, there were 2,715 low birth weight (LBW, weighing <2500 grams) infants born to White, non-Hispanic mothers in Massachusetts. During the same year, there were 801 LBW births to Black, non-Hispanic mothers. Given these two data points, you might conclude that LBW births are more of an issue for White mothers than Black mothers. However, there were 42,448 births to White mothers and only 7,095 births to Black mothers in Massachusetts during 2016. Therefore, only 6.4% of infants of White mothers were LBW compared with 11.3% of infants of Black mothers. By comparing proportions instead of the actual numbers it becomes clear that Black mothers have a higher likelihood of delivering a LBW infant than White mothers in Massachusetts.

Below are resources with further information about measuring health inequities:

- A framework for measuring health inequity
- A three-stage approach to measuring health inequalities and inequities

- Defining and measuring disparities, inequities, and inequalities in the Healthy People initiative

To truly assess for inequities, rather than just the magnitude or burden of health disparities on certain subpopulations, it is critical to connect the disparities to social and structural determinants of health.

The results of the disaggregation and analysis will be in the form of either an informal or formal data brief dependent upon program needs and deadlines. To really understand the problem, you will need to conduct root cause analyses (Section 4) and consider groundwater approaches (Section 5). The data brief can then be shared with key stakeholders as part of community engagement and contextualizing data, as described in the next section. This is the first step towards developing an Equity Spotlight (Section 6).

Section 3 Reflection

Now that you have examined your disaggregated data and determined if and how different races and/or ethnicities experience health outcomes differently, reflect on the following with your team:

- Are you comfortable with the completeness and quality of your data, or is additional work needed in this area?
- Did you identify disparities among racial groups in the health outcomes you are examining?
- Which stakeholders will you engage to assist in interpreting the data and planning your next steps?

Check in with your team to determine if you are ready to begin incorporating contextual data to shape the narrative in a way that considers historical and current policies and system factors that impact the health of communities.

Section 4: Using other sources of data to uncover causes of the differences

Having disaggregated and analyzed the data to better identify and understand inequities, your program can now contextualize **racial equity** data. Part of **contextualizing data** is describing the problem and using supplemental information gathered from the community. This can be in the form of qualitative and quantitative data.

Contextualizing data is a cyclical and iterative process.

Contextualizing data for equity is the critical process of providing a narrative to describe racially explicit data that addresses both historical and current systems of oppression (e.g., racism, sexism). The purpose of contextualizing data is to frame data in ways that allow it to be interpreted and understood in the larger context of historical and structural factors at play within communities, rather than focusing on individuals.[8] This allows programs to design solutions that directly address structural factors. Without this process, data often become race neutral or race silent.

A case study from the MDPH Welcome Family home visiting program is provided at the end of this section, to demonstrate what contextualizing data can look like in practice.

Identifying the Population/Community of Interest

The first step of contextualizing data is to identify the population/community that will be centered in the work. Previously, this was referred to as focusing on the "target" population. The population/community should be described as specifically as possible. To **center to the margins**[9] is to shift the focus from the advantaged group's perspective,

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[8] "How can we avoid "blaming the victim" when we present information on poor outcomes for different racial, ethnic, language or immigrant groups in our community?" Center for Assessment and Policy Development, 2013

[9] Ford, C. and Airhihenbuwa, C. "Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis." *Am J Public Health* 2010 April; 100 (Suppl 1): S30-35 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2837428/

which is the traditional approach, to that of the marginalized group or groups. The position of "outsiders within"[10] is valuable in facilitating this process. For example, a program might initially define its population as young Hispanic mothers who live in a specific city. Once the primary population has been identified, the program should push itself to further define the centered population, with questions such as:

- Should languages spoken be considered?
- Would sexual orientation or gender identity expression influence the interpretation of the population of interest?
- How might socioeconomic status influence or inform the understanding of the data?
- What other factors raised by our community members or specific to our work would inform our understanding of the data?

To center to the margins is to shift the focus from the advantaged group's perspective, which is the usual approach, to that of the marginalized group or groups.

While not all programs will have data to answer each of these questions, it is still an important programmatic discussion to consider these and other factors that the community may identify as necessary.

Contextualizing Data with Communities/People with Lived Experience

Once the population has been specifically and carefully defined, it is crucial to engage or re-engage with the community/population that is being centered. This is essential for framing program data in the context of historical and current policies and identifying system factors that impact the health of communities, in order to understand and interpret the data. Ensuring the inclusion of community expertise, feedback, participation and decision making are critical elements to using a racial equity approach to data use and interpretation. Without this element, our programs and practices are likely to fail, or worse, to further reinforce existing inadequate and inequitable power structures. It is also

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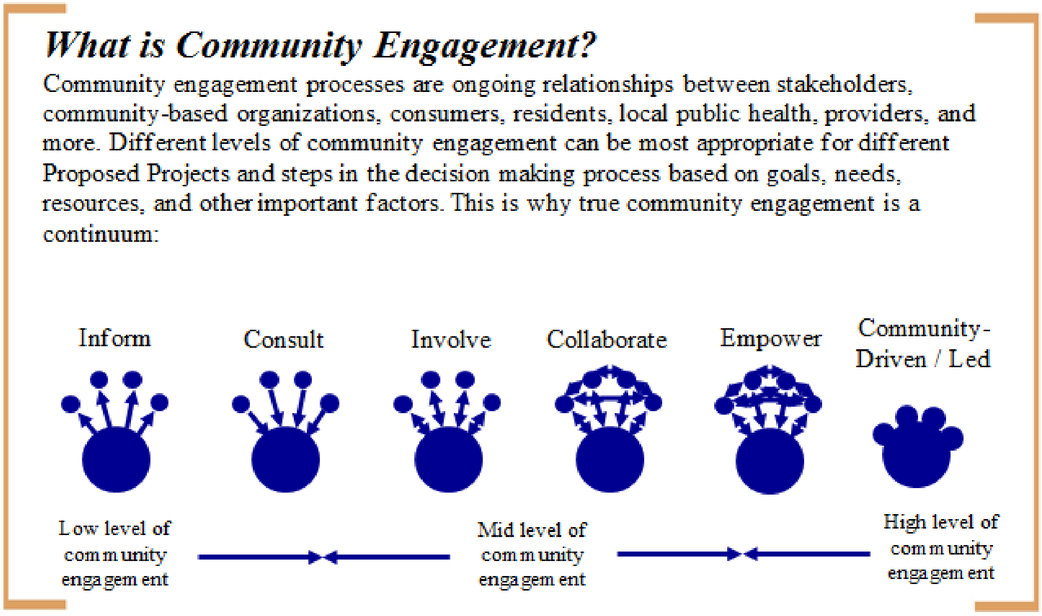
[10] Ford, C. and Airhihenbuwa, C. "Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis." Am J Public Health 2010 April; 100 (Suppl 1): S30-35
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2837428/

important to recognize the ways in which the program has engaged with the community in the past. The program may need to reflect on ways to mend this relationship, restore trust, and ensure respectful engagement of community members including compensation for time and expertise.

Community engagement methods could include stakeholder interviews, focus groups, or surveys. However, it should always include welcoming members of the community to work with the program and to be key decision makers. Centering populations requires a higher level of engagement. To help you assess your current level of community engagement, you can refer to the Community Engagement Guidelines for Community Health Planning.

Figure 4.1: *Community engagement processes*



What is Community Engagement?

Community engagement processes are ongoing relationships between stakeholders, community-based organizations, consumers, residents, local public health, providers, and more. Different levels of community engagement can be most appropriate for different Proposed Projects and steps in the decision making process based on goals, needs, resources, and other important factors. This is why true community engagement is a continuum:

The centering approach leads to the understanding that not all words used in professional settings are appropriate or respectful to the communities centered. It will therefore be critical to familiarize yourself with respectful language as part of this process.[11] There are many tools that outline appropriate terms to use and not to use. There are both external

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[11] Ford, C. and Airhihenbuwa, C. "Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis." Am J Public Health 2010 April; 100 (Suppl 1): S30-35 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2837428/ Accessed on 12/09/19

resources such as the Progressive's Style Guide[12] as well as internal MDPH materials such as the Bureau of Community Health and Prevention's Office of Statistics and Evaluation Health Equity Working Group Style Guides. The Style Guides are being developed in concert with MDPH data standards.

Quantitative Tools for Contextualizing Community Level and Structural Factors

There are numerous measurement tools that can assist data analysts with context at the local and community level, including:

- Life Course metrics developed by the Association of Maternal and Child Health Programs (AMCHP) in partnership with state health departments (such as adverse childhood experiences, concentrated disadvantage, and residential racial segregation)
- America's Health Rankings (such as Community & Environment indicator)
- The Index of Concentrations at the Extremes
- The Child Opportunity Index
- Maps of racial segregation

Internal to MDPH, the Population Health Information Tool (PHIT) and Community Reports outline the social determinants of health for each community of the Commonwealth, with explicit call outs to structural and historical inequities. This short video introduces the concept of the social determinants of health and provides an introduction to the PHIT Community Reports. Environmental Public Health Tracking (EPHT) is the ongoing collection, integration, analysis, and interpretation of data about environmental hazards and health effects potentially related to environmental exposures. Massachusetts EPHT data are available on an interactive web portal.

There are also individual level measures that are likely not part of your program measures but could still add valuable context to how you understand and interpret your data. For

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[12] The Sum Of Us, "A Progressive's Style Guide"

example, perceived experiences of discrimination (individual level) including the Everyday Discrimination Scale.

These types of structural analyses can help you think critically about whether your program will be able to effectively meet the needs of everyone in the community, which is important for future prioritization work (described in Section 5), and what structures or systems may be limiting your program's ability to reach its potential.

Structural analyses can help you think critically about what structures or systems may be limiting your ability to reach your program's potential.

Additional Tools for Contextualizing Data

Environmental scans and root cause analysis are two additional tools that can be useful in contextualizing data. Consider using these tools when engaging with the community/population to be centered.

Environmental Scan

Environmental scanning is the gathering and monitoring of information about a program's internal and external environment. One popular method of environmental scanning is conducting a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis. Strengths and weaknesses are internal to your program/organization—things that you have some control over and may be able to change. Examples include who is on the team, the population being served, programming and services provided, and location of services. These factors determine the decisions a program makes.

Environmental scans should also examine factors external to the program, such as competition, economics, technology, legal issues, and social/demographic factors. During this process, bright spots, evidence informed strategies, community needs and positive deviance can be identified and reviewed.

Outcomes of the environmental scan at the program or organizational level should be used for monitoring the success of implementation:

- Quantity—how much did we do?
- Quality—how well did we do it?
- Is anyone better off?

Root Cause Analysis

A root cause analysis is a systematic process that helps to identify causes associated with a problem of interest and to think about the "why" behind the problem.

One tool recently used by the MDPH Bureau of Community Health and Prevention is the Narrative Equity Analysis Tool (NEAT), a process to get to root causes to identify and describe structural drivers of inequities. There are three steps in the NEAT process:

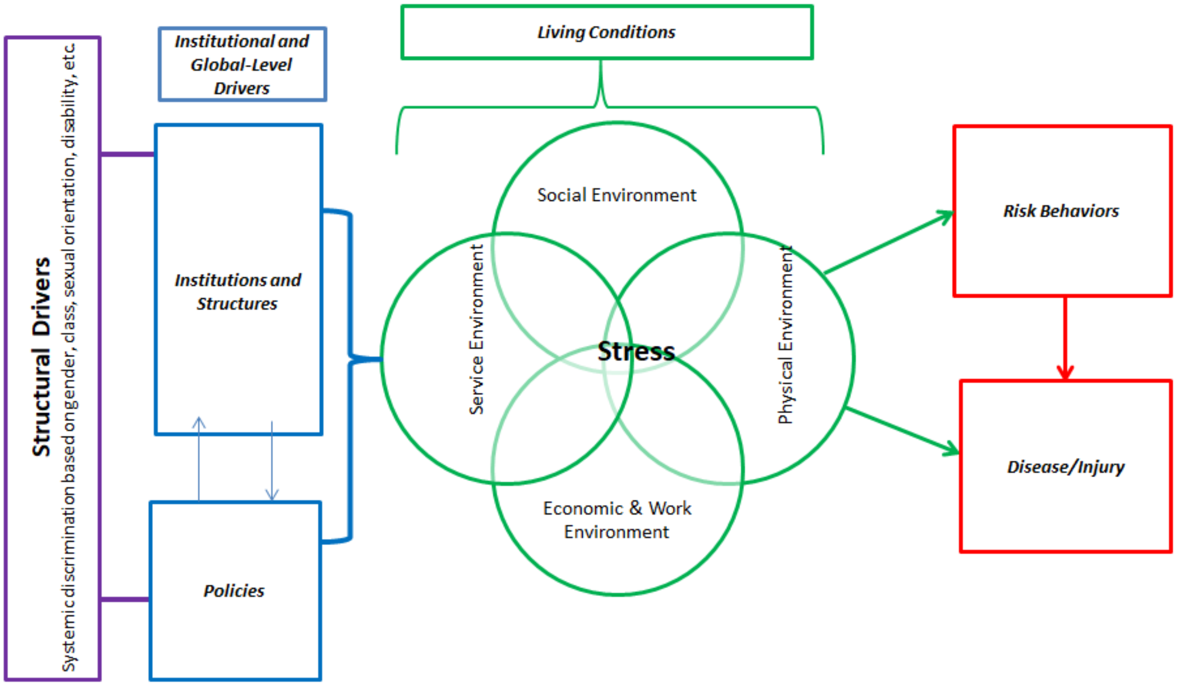
1. Identify a health risk behavior or health outcome from your program, and inequities in that behavior/outcome
2. Fill out the NEAT diagram for the specific inequity
3. Use the diagram to contextualize and frame the risk behavior or outcome

Figure 4.2: *Narrative Equity Analysis Tool Diagram (NEAT)*

Narrative Equity Analysis Tool Diagram

(Adapted from Bay Area Regional Health Inequities Initiative)

Work “backwards” to trace the issue “upstream” and fill in each corresponding box the unique social, economic, and environmental conditions, institutional and systems-level drivers, and structural drivers experienced by this population that led to the health/behavior inequity identified.



A worksheet with questions is also available to guide a team through completion of the NEAT. An example of using the worksheet when completing the NEAT tool can be found in the *Attachments.*

There are a number of other tools that can be used to help in understand the underlying reason for identified inequities, including:

a. 5 Whys
b. Fishbone Diagram
c. Cause and Effect Diagram Adding Cards (CEDAC)
d. Pareto Charts

Information about these tools can also be obtained by emailing PMQI@mass.gov.

Figure 4.3: *Example of contextualizing data during the State Health Assessment/State Health Improvement Plan reframing*

Before: Identifying disparities by subgroups is useful for planning interventions and targeting policies aimed at improving access for members of those subgroups. More than one-third of Black non-Hispanic adults (35.6%) were obese compared to Hispanic (28.9%), and White non-Hispanics (22.7%).

After: The conditions in which people live, learn, work, and play do not offer all citizens of the Commonwealth equal opportunity to modify their behavior. For example, a history of policies rooted in structural racism has resulted in environments with inequitable access to healthy foods, safe spaces for physical activity, walkable communities, quality education, housing, employment, and health care services. The health implications of these structural inequities are evident in the fact that Black and Hispanic residents of the Commonwealth are consistently and disproportionately impacted by obesity and its related conditions. For example, more than one-third of Black non-Hispanic adults (35.6%) were obese compared to Hispanic (28.9%), and White non-Hispanics (22.7%).

NOTE: This example not only provides data, but also explicitly names and provides details about the structural factors that play into differences in outcomes.

Case Study: Welcome Family

Welcome Family is an MDPH-funded program that offers a universal one-time nurse home visit to families with newborns in five Massachusetts communities. With support from MDPH, the five local Welcome Family home visiting programs set out to analyze their performance measure data by race/ethnicity, identify inequities, and take action to eliminate those inequities.

> **The problem:** One of the programs identified, based on analysis of their performance measure data stratified by race and ethnicity, that they had a lower home visit completion rate with Hispanic clients compared to non-Hispanic clients.
>
> **Root cause analysis**: As a team, the program conducted the 5 Whys exercise to identify potential causes of this problem. They focused on systems and structures

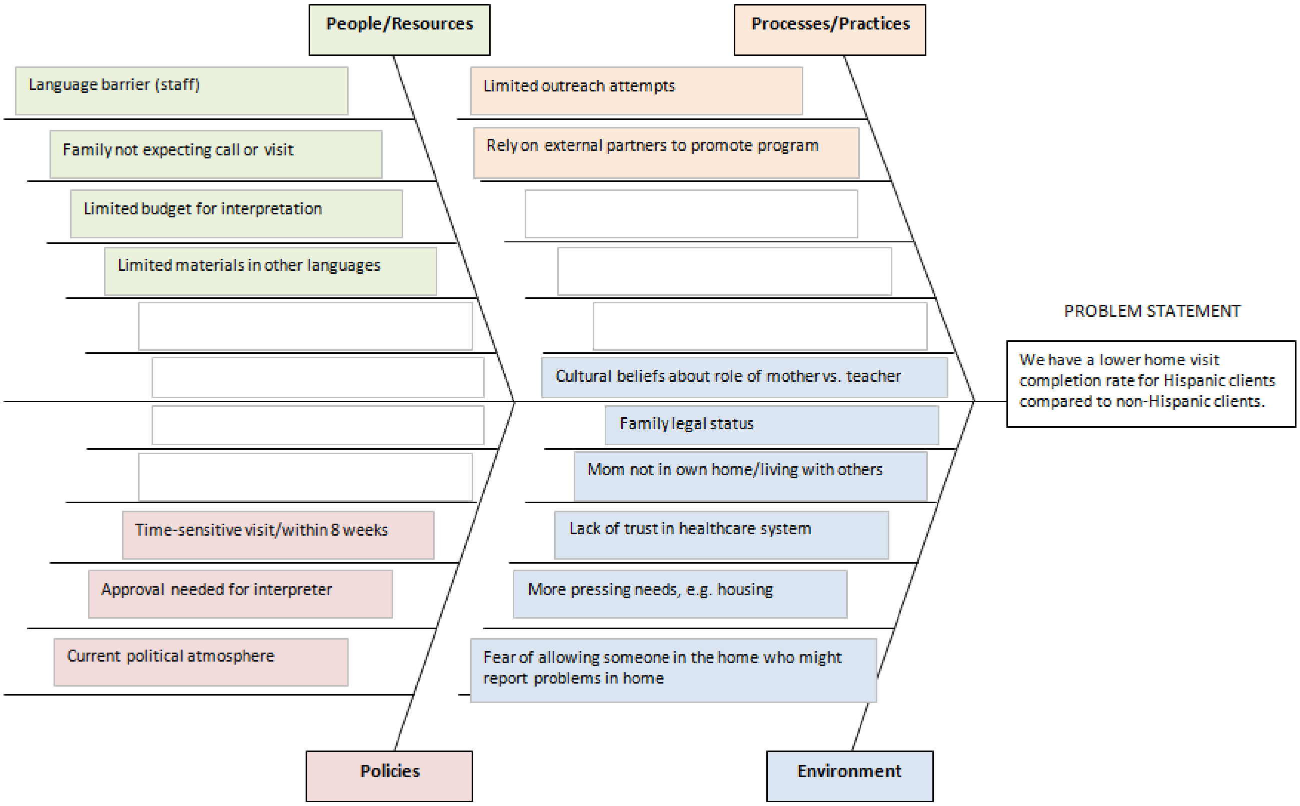
(e.g. history, cultural beliefs, and staff language capacity) rather than individual behavior as the contributors to a lower home visit completion rate.

Community engagement: The program then met with staff from four different community-based agencies who work with this population (including a grassroots organization, non-profit society, medical center, and local child development program). They shared the ideas they had brainstormed during the 5 Whys exercise, and sought additional input/feedback on the root causes of the identified problem, asking questions such as:

- What other data are needed to understand the causes of the inequity?
- What other context about the community, such as needs and assets, can you provide to help understand the causes of the inequity?
- How are historical or current systems of oppression (e.g. racism, sexism) contributing to the inequity?

Fishbone diagram: After meeting with community partners, the program then developed a fishbone diagram using their problem statement and identified root causes. A copy of their fishbone diagram can be found in Figure 4.4 below.

Figure 4.4: *Fishbone Diagram- Developed by the Welcome Family Home Visiting Program*



Section 4 Reflection

As you complete this section, check in with your team to consider whether your identified disparity is actually an inequity (unjust, unfair and preventable). This will allow you to start the process of designing solutions to address the inequity. You may need to go back and further stratify your data, rethink your analysis, or even do a deeper dive of your reframe based on the information that comes up during your contextualizing of the data. This is a normal part of the racial equity journey!

Section 5: Making plans to act on differences that are unjust or avoidable

Now that you have identified the population/community, defined the inequities, and framed the program data in the context of historical and current policies and practices, it is time to prioritize which inequity your program will address first and plot current program initiatives and strategies related to addressing that inequity.

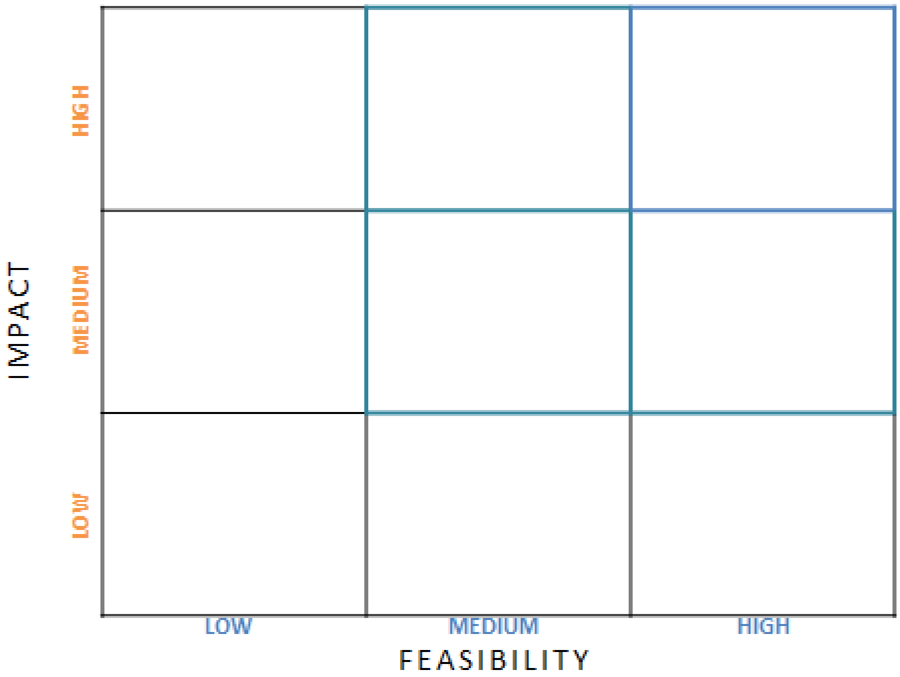
Step 1: Prioritize the inequity you will address.

If more than one inequity has been identified in the preceding sections, you will want to prioritize which to focus on first. A recommended approach for prioritizing is using the Health Equity Feasibility Grid (Figure 5.1) to plot each inequity. *Note: if only one inequity is identified, move to Step 2 below.*

- First, think through the feasibility of addressing the inequity by considering practical supports (e.g. funding, internal capacity, partnerships, etc.) and constraints (e.g. timing of funding, political will, etc.). Is the feasibility of addressing the inequity low, medium, or high?
- Next, consider the potential impact of addressing the inequity. If the inequity is reduced or eliminated, what impact will that have on the community impacted? Is the impact low, medium, or high?
- Finally, review where the inequities fall on the grid. Which one will the team address first? The team may decide to start with the inequity that is most feasible, or where there is a simple solution. With time and practice, however, the team should begin to address more challenging inequities as well.

CAUTION: The Health Equity Feasibility Grid can be used to plot the feasibility/impact of any initiatives or projects, even those unrelated to inequities. This is why it is critical to first identify the inequities and then plot them separately from other issues your program may be addressing.

Figure 5.1: *Health Equity Feasibility Grid*



Step 2: Plot current and potential program initiatives/strategies.

After you choose the specific inequity to address first, move to plotting current and potential program initiatives and strategies related to addressing that inequity.

- First, using the matrix below (Figure 5.2), consider whether the current program initiatives and strategies use a downstream (direct or clinical services), upstream (policies or environment), or interconnected systems (**groundwater**[13]) approach. At the same time, consider the degree or severity of the inequity. Are current strategies addressing the larger system and how many people are the strategies impacting? Plot each initiative/strategy in the appropriate location in the matrix.

The *groundwater* is a metaphor for structural racism developed by the Racial Equity Institute. It demonstrates that racial inequity looks the same across multiple systems, such as health care, education, law enforcement, and child welfare.

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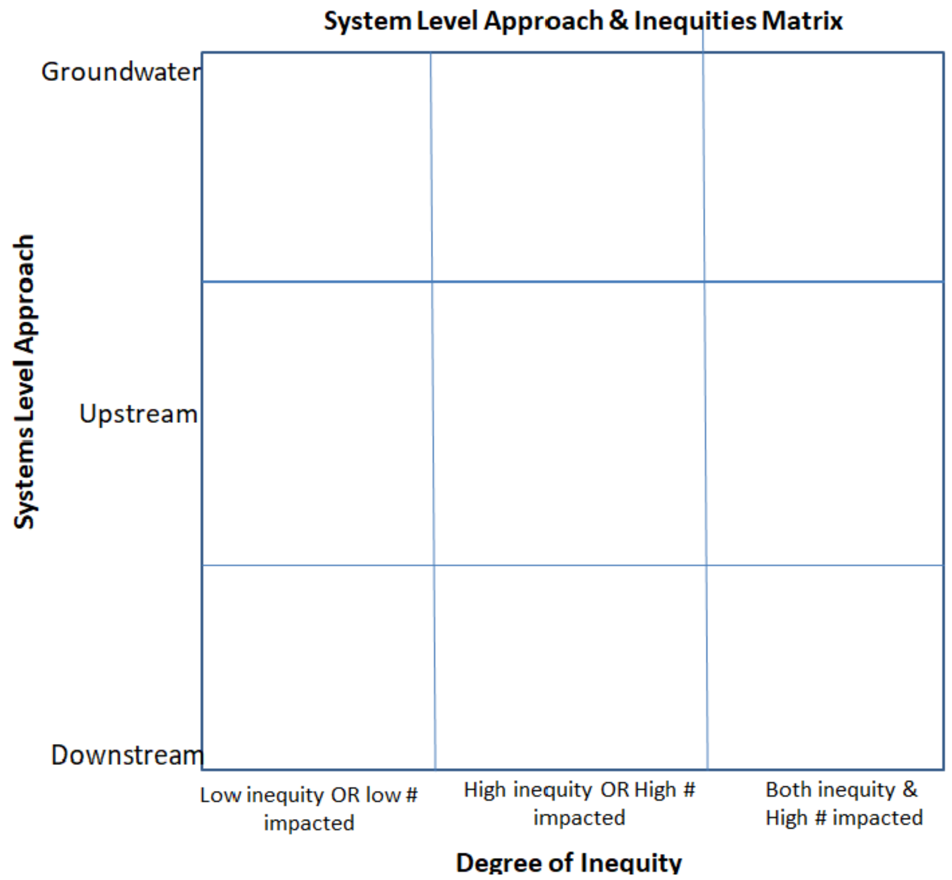
[13] The Groundwater Approach, Racial Equity Institute

- Next, engage stakeholders and community members to come up with additional ideas and strategies together to address the inequity. While it is likely the team may have an understanding of the program and its structure, it is critical to include the voice of those who are receiving services or with lived experience/expertise. They will have insight into barriers and conditions impacting outcomes.

Figure 5.2: *Plotting Current and Proposed Program Initiatives and Strategies*



As solutions are being designed, continually revisit these guiding questions:

- What inequity is this strategy (i.e., activity or program) trying to address?
- Who will benefit from this strategy?
- Who could be harmed by this strategy? What will you do to avoid this?
- Who influences how this activity or program is put into place? Who else should provide input or influence this activity or program?

- Who decides how the activity or program is put into place?

It may seem as if there is an obvious change or solution to address the inequity. However, it is important to maintain a critical racial equity lens and to challenge assumptions when easy fixes are identified. Think about both using a groundwater approach and focusing on the social determinants of health to plan new strategies and interventions. Challenge yourself to think about ways to push your strategies towards more upstream and multi-system approaches. Refer to the *Attachments* for a graphic depiction of this concept. Remember the analysis ***is*** the tool for helping to identify the most appropriate action to address the inequity.

Section 5 Reflection

As you complete this section, check-in with your team about whether you are ready to move on to effectively communicating the root causes of the inequity and proposed solutions. Have you done enough to understand that the solutions considered are informed by the community? Did you share ideas about upstream and multi-system approaches to addressing the problem? The solutions you have developed are crucial for success. Do not hesitate to go back to a previous step if you do not feel that you have the information or solutions you need to proceed.

An equity lens helps to remind us that our biggest impact is when we can address system issues with upstream and groundwater efforts.

Section 6: Presenting data in ways that help people make sense of the numbers

An Equity Spotlight is a communication tool highlighting and framing the inequity.

Now that racial inequities have been identified (Section 3), contextualized (Section 4), and prioritized (Section 5), the findings and strategies should be communicated to stakeholders. Developing an "Equity Spotlight" (i.e., a communication tool highlighting and framing the inequity such as a factsheet, presentation, website, etc.) can be a useful way to share information. It can also help build buy-in and deepen understanding of racial equity. This section outlines six steps with important questions and considerations in designing an Equity Spotlight.

Step 1: Determine the goal of the Equity Spotlight.

One goal of the Equity Spotlight is to share your health inequity and the program's commitment to address it. It should be clear ***why*** these data are being highlighted.

- Is the goal to increase people's awareness of the inequity? (This is likely only appropriate if you are engaging with people outside the community being affected. The community experiences the inequity every day.)
- Is the intention to contextualize an issue and frame it from a systems perspective that addresses root causes?
- Is the goal to highlight opportunities for intervention?
- Are the data intended to demonstrate how current programs do not adequately support certain communities?

Maybe it is all of the above. It is important to be clear on the goal of the Equity Spotlight in order to narrow the scope of the communication and determine key messages.

Step 2: Determine the audience.

The next step is determining who will access and use the product.

Figure 6.1: *Examples of Audiences*

Key Stakeholders	Example Members
MDPH program staff	Program managers, Bureau leadership, Support staff, Field staff
Staff of the program whose data were analyzed	Dentist at the community health center, community health worker (CHW) working directly with clients
Vendor	Local implementing agencies, contracted agencies, community based agencies
Funder	Centers for Disease Control and Prevention (CDC), Health Resources & Services Administration (HRSA), private foundations
Community residents	Families, youth, children and youth with special health needs, people with lived experience
Participant receiving services from the program	Young parents, students with disabilities
Legislature/policy makers	State legislators and their staff, municipal government partners

The identities and lived experiences of the audience will influence the best way to communicate with them. It is important to consider and explicitly address factors such as:

- Race
- Ethnicity
- Gender identity expression
- Age
- Preferred language
- Literacy level
- Culture
- Religion
- Sexual orientation
- Ability
- Lived experience with the issue

Step 3: Identify 2-3 key takeaway messages for the audience.

What exactly should a reader know after reading the Equity Spotlight? What is the story being told? Generally, Equity Spotlights address the following three questions:

1. **What is the inequity?** Describe the inequity. Why is it important? What is the magnitude of the inequity? What data point(s) are being used to demonstrate it?
2. **Why does this inequity exist?** Referring back to your efforts to contextualize the data, explain why this inequity occurs. When using a racial equity lens, it is essential a structural analysis be used to

understand and frame the inequity (rather than describing individual-level risk factors or behaviors).

3. **What can be done about it?** Inequities are by definition preventable. Communicating what could and needs to change (and, as appropriate, the potential role of the audience) can serve as a call to action.

If there are many narratives and data points to share, reflect on the goal of the Equity Spotlight and determine what information is essential. A critical part of this process is engaging with key stakeholders and those most impacted by the inequity to refine and prioritize the key takeaway messages.

Now that you have determined your takeaway messages, ask yourself:

- Do these messages tell a story that is compelling and actionable?
- Do these messages support the goal of the Equity Spotlight?
- Are the messages appropriate for the audience?
- Do these messages inadvertently blame the individual or population experiencing the inequity? Can the message be used to reinforce harmful stereotypes about the population experiencing the inequities?
- Do these messages emphasize that the inequity is preventable?

Step 4: Design your Equity Spotlight.

After the key messages have been determined, consider the rest of the content of the Equity Spotlight. Depending on the audience, some background information will be needed. This includes: information about the health issue/topic area, **racial equity**, **structural racism**, and the terminology used in the Equity Spotlight.

Key Components to Include

- Key takeaway message(s)
- Key definitions (especially around defining equity, necessary technical terms, and any acronyms used)
- Data highlighting inequity – provide a hook or compelling statistic
- Clear, understandable graphics
- Information related to the program that is necessary for the audience to know (e.g., population served, eligibility criteria)
- Framing that recognizes the structural and systemic drivers of the inequity
- Next steps, solutions, and/or opportunities for intervention

There may not be one best format to reach the desired audience. Consider multiple formats.

An Equity Spotlight can come in many different formats, with different lengths, types of visuals, and delivery methods. Consider the advantages and trade-offs of different formats for the audience and the goal of the Equity Spotlight. Some common formats to consider are: infographics, one page fact sheets, longer reports, webpages, peer-reviewed manuscripts, oral presentations, and facilitated workshops.

Also consider the best way to present the information. How much and what part of the messaging should be text or visual (e.g. charts, diagrams, frameworks)? What information best supports the primary message? Additional information can be helpful to frame the message, but it can also be distracting, so use sparingly.

Step 5: Put the Equity Spotlight together.

Once you have all the key components and know the best format to reach your audience, you can create your product. Below are some additional tips to consider when creating your Equity Spotlight.

- Consider accessibility for people with disabilities.

- Use plain language. There are a variety of tools and checklists that can assist from before you start writing, to formatting and visual clarity as well as testing and revising the product.
- Pay attention to the literacy level of your document. It is recommended to create materials at no higher than an 8th grade reading level.
- Does your product need to be translated, and into which languages? Refer to the MDPH Language Access Plan for guidance.
- Remember that visuals can be more powerful than words.
    - Epi Info™, developed by CDC, is public domain software for public health that allows data collection, analysis and visualization, including mapping.
    - Free tools to make engaging presentations, infographics and other visual content include Visme and Piktochart.
    - The Racial Equity Resource Guide also has resources on infographics.
    - The Depict Data Studio website has a useful "chart chooser" to help create appropriate graphics.

Step 6: Pilot the Equity Spotlight.

Once you have created the Equity Spotlight, it is now time to pilot it with internal and external stakeholders. Share the Equity Spotlight with other internal program staff for initial feedback on messaging and images. Gather staff input and incorporate feedback.

Then pilot the Equity Spotlight with key members of the intended audience for feedback on messaging and images. Incorporate feedback into your Equity Spotlight.

Questions to consider when piloting your Equity Spotlight include:

- Are all the terms clear and easy to understand?
- What is the takeaway message?
- What is being said about the population affected by the inequity?
- Is there anything missing? Is there more you would like to know?

Section 6 Reflection

The Equity Spotlight is an important tool to share information with key stakeholders, deepen understanding of racial equity, and build buy-in for moving from data to action. Make sure the story being told reflects your earlier efforts to frame the data in the context of broader historical and structural factors and prioritize upstream and multi-system (groundwater) strategies to addressing the problem. This is an opportunity to make a clear and compelling call to action to address the impact of structural racism on the identified inequity.

Section 7: Moving from data to action

After you have identified the inequity that your program will address, selected potential strategies, and crafted an Equity Spotlight to present the data in a way that helps people make sense of the numbers, it is time to implement interventions and assess their effectiveness at addressing the inequity. Interventions should be evidence-based or informed, tailored to the population most affected by the inequity, and designed to address the root causes of the inequity. Ideally, plans for measuring the effectiveness of interventions are designed in alignment with the implementation plan to allow for real-time assessment and timely modifications to improve health outcomes. Community stakeholders should be engaged throughout the implementation and evaluation process.

Planning and Implementing Interventions

When planning interventions, consider those that have been previously tested and shown to be effective through formal evaluation or community experience. There are a number of sources of information on existing evidence-based public health interventions, including:

- CDC's Community Guide, a collection of evidence-based findings of the Community Preventive Services Task Force that can help organizations select interventions to improve health and prevent disease.
- MCH Evidence, a resource for maternal and child health (MCH) programs to develop evidence-based action plans and strategies to improve MCH outcomes.
- Real World Examples from the Finding Answers: Disparities Research for Change project, a collection of innovative projects across the country that designed and implemented interventions to reduce quality of care disparities in cardiovascular disease, diabetes, and depression.

It is important to consider factors that might influence the success of an intervention in a specific community, including the likelihood it can be put into place, cultural environment, resource availability, and political will.[14] The work you have done with community

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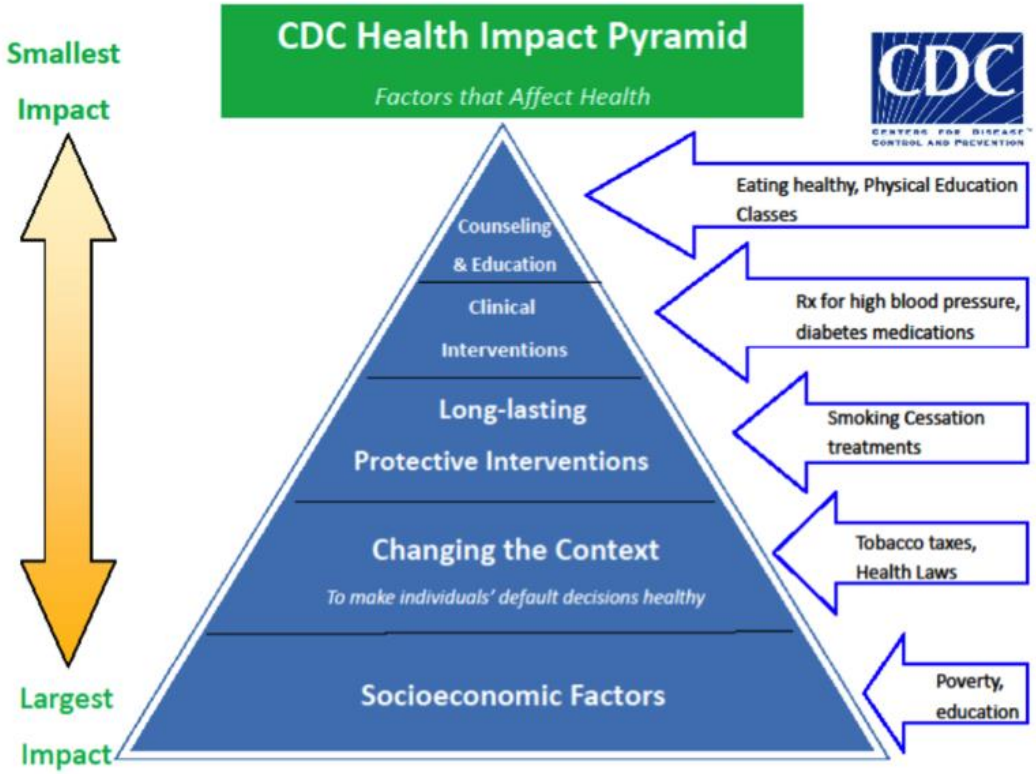
[14] CDC. Selecting Effective Interventions

stakeholders in Section 4 using other sources of data to uncover causes of the observed inequity can be used to adapt the intervention to match your community's context, needs and goals.

There are multiple approaches to implement interventions that can impact health outcomes at various levels. The CDC Health Impact Pyramid (Figure 7.1) describes the impact of public health interventions at different levels and provides a framework to improve health outcomes. At the base of the pyramid are efforts that address social determinants of health (e.g., poverty) with the greatest potential to improve population health. The upstream and multi-system strategies discussed in Section 5 impact this level. As you move up the pyramid, interventions require more individual effort (e.g., healthy eating) and tend to have smaller population impact. Since the causes of racial inequities are complex, effective interventions should address multiple levels of the pyramid.

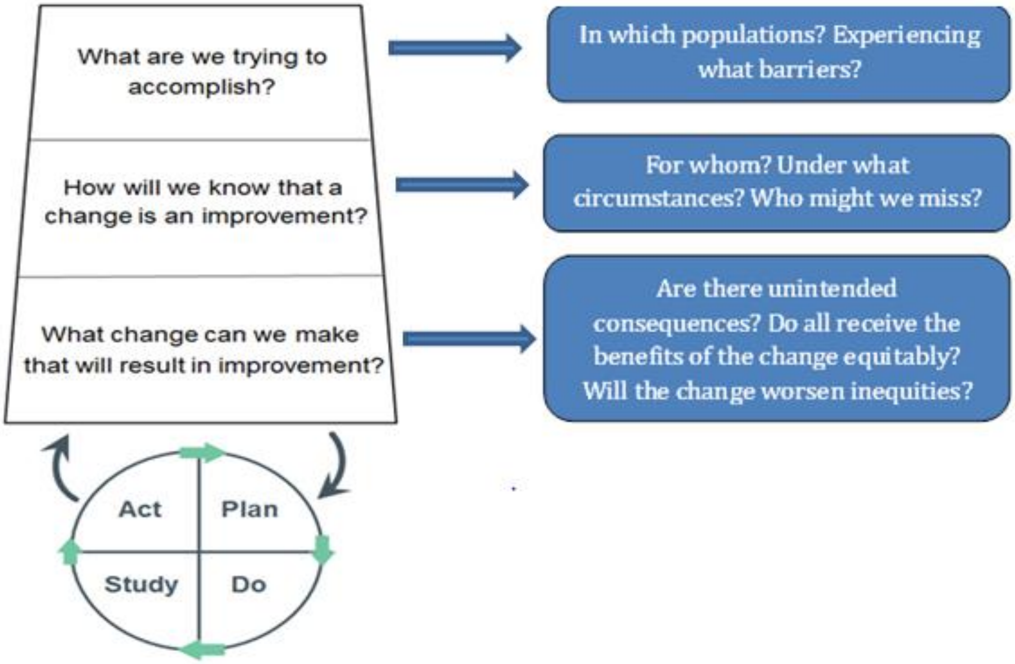
Figure 7.1: *CDC Health Impact Pyramid*



Developing and Assessing the Effectiveness of Interventions

If your interventions focus on higher levels of the pyramid – for example, individual counseling or education about healthy eating and exercise – then conducting rapid cycle tests of change is a good approach to measuring their impact. A frequently used model is the Institute for Healthcare Improvement's Model for Improvement. The Model for Improvement consists of two parts: a series of three core questions followed by a Plan, Do, Study, Act (PDSA) cycle. PDSA is a proven method to make successful improvements. It is a problem solving model used for improving a process or carrying out a change in a series of small steps. A description of the PDSA model with equity framing is described briefly below. When applying a racial equity lens to the Model for Improvement, consider additional questions to the three core questions, such as those shown in Figure 7.2. Once you have answered these questions, you are ready to develop an aim statement.

Figure 7.2: *Equity-Adapted Model for Improvement*



Source: Adapted from the Institute for Healthcare Improvement, Associates in Process Improvement

Setting an aim statement

In quality improvement work, one of the first steps in the change process is writing an aim statement that summarizes what your program or team hopes to achieve over a specific amount of time including the magnitude of change or reduction in inequity to be achieved.

The National Institute for Children's Health Quality (NICHQ) has developed guidance on writing aim statements.[15] First, consider the following:

- What concrete goals do you want to achieve?
- Who will benefit from this improvement? Whose interests are served?
- What will be done? Is it supported by evidence or experience?
- Where will the change occur?
- When will it start and stop?
- What are the boundaries of the processes? What is in, what is out?

With the answers in mind, develop an aim statement. Answer "what," "for whom," "by when," and "how much," then put it all together into a full statement.

It is important that your aim statement be SMART (specific, measurable, attainable, realistic, and time-bound). However, to ensure that the improvement activity is conducted equitably, consider adding two additional components, I=Inclusive and E=Equitable to develop a **SMARTIE** aim statement.[16]

Inclusive – It brings traditionally marginalized people, particularly those most impacted, into processes, activities, and decision- and policy-making in a way that shares power.
Equitable – It includes an element of fairness or justice that seeks to address systemic injustice, inequity, or oppression.

Here is an example of a SMART aim statement improved to a SMARTIE aim statement:

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[15] NICHQ, QI Tips: A Formula for Developing a Great Aim Statement
[16] The Management Center, SMARTIE Goals Worksheet, http://www.managementcenter.org/resources/smartie-goals-worksheet/ Accessed on 12/09/2019

Table 7.1: *Developing SMARTIE aims from SMART aims*

SMART Aim Statement	SMARTIE Aim Statement
Improve enrollment in the program from 50% to 65% by December 20, 2022.	Improve enrollment in the program from 50% to 65% with at least a 10% increase among people of color, who are often lost to follow up, by December 20, 2022.
By 12/31/22, we will increase the home visit completion rate by 3%.	By 12/31/22, we will increase the home visit completion rate for Hispanic caregivers by 3% so that services are distributed more equitably across races and ethnicities.

Plan Do Study Act (PDSA) Cycles

Once you have developed your SMARTIE aim statement, begin the PDSA cycle.

1. In the ***Plan*** stage of the PDSA cycle you can make predictions about the expected result, including whether the intervention will benefit populations equitably. You should also determine how the effect of the change should be measured, and how you will assess whether there are unintended consequences for certain groups of people. Once again, it is critical to engage the populations that are most affected by the problem in the Plan stage to ensure that the change strategies you are testing are acceptable and relevant to the community.

2. Testing the change occurs during the ***Do*** stage. This is when the planned test is carried out and any problems and observations are documented. Measurement is an important part of implementing and testing change and is necessary for monitoring whether the strategy that is put in place is achieving the desired aim. Data should be collected on a series of measures[17] including:
    - Process measures – are the steps in the process performing as intended?
    - Outcome measures – how is the intervention affecting the outcome of interest?
    - Balancing measures – are there unintended effects on other parts of the system?

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[17] Institute for Healthcare Improvement, “Science of Improvement: Establishing Measures”

Be intentional about selecting process measures that allow you to monitor whether the intervention is being implemented equitably to all populations served. PDSA cycles do not require overhauling data collection methods or processes and programs do not need a formal data system to be able to conduct PDSAs.

3. In the ***Study*** stage, analyze the data collected during the Do stage and consider the following:
    - Did the observed inequities improve or worsen?
    - If improved, by how much? Do all populations benefit equitably?
    - Is the objective for improvement met? Is it met among all populations?
    - Were barriers experienced more among some populations compared to others?

4. In the ***Act*** stage, review the results of your PDSA cycle and determine if it led to the intended results. Based on these results, decide whether you will Adapt, Adopt or Abandon the strategy being tested:
    a. **Adapt:** If the inequity did not improve, reflect on why and further refine or plan another test cycle.
    b. **Abandon:** Based on your analysis you might decide to start from scratch and plan a new test cycle altogether. Since the problem is unresolved, you would then move back to the Plan stage to consider new options for implementation. At this point it is crucial to re-engage the community to identify alternative solutions to test.
    c. **Adopt:** If the inequity improves, you should determine if the improvement is adequate and should be sustained.

As you learn from your results you may need to refine or change your aim statement, your change strategy and/or your measures. You might conduct multiple cycles of PDSAs that are linked together[18] and build upon one another (called "ramp cycles").

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[18] Institute for Healthcare Improvement, "Science of Improvement: Linking Tests of Change"

Each step of the PDSA cycle should be documented so that you have a record of the result and can share what you learned with other stakeholders. Consider using a PDSA presentation template or worksheet for presenting the components of the PDSA. An example of a completed worksheet can be found in the *Attachments*.

Assessing Systems Change

If your change strategies include policy and systems changes that are more focused at the base of the health impact pyramid, “implementation science” may have more tools to assist you in assessing the effectiveness of the interventions. Implementation science provides a framework for translating evidence-based/informed practices into programs and policies that impact health outcomes. For more information about implementation science, visit the National Implementation Research Network’s Active Implementation Hub – a free, online learning environment for use by any stakeholder involved in active implementation and scaling up of programs and innovations. The goal is to increase the knowledge and improve the performance of people engaged in actively implementing any program or practice.

Assessing the impact of systems change interventions is complex and can be challenging, and a detailed overview of systems change evaluations is beyond the scope of this Road Map. The Tamarack Institute is an excellent resource for information and guidance on designing, planning and evaluating systems change.

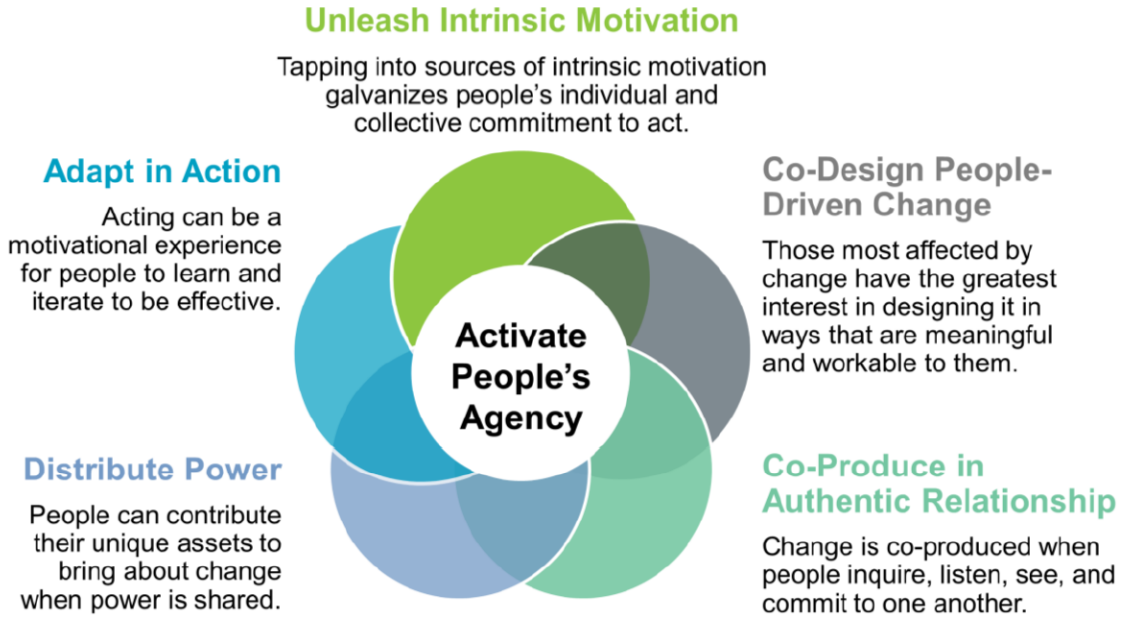
Change Management

Change can be hard, and there are resources to help teams move through change in a productive way.

- Learn more about change management and overcoming resistance to change on the ASQ website.
- The IHI Psychology of Change Framework (Figure 7.3) may help in understanding the underlying psychology of change and using its power to impact quality improvement efforts and achieve breakthrough results, sustainably, and at scale.

- Another tool is Palmer's Change Model, which is flexible and can be used throughout a change process. It applies strategic thinking to influence others and facilitates commitment and behavior change through team dialogue and action.

Figure 7.3: *IHI Psychology of Change Framework*



Section 7 Reflection

Now that you have selected your change strategy based on analysis of the data and community input, developed your implementation plan, and determined how you will monitor the effectiveness of your intervention, consider the following questions:

- What can be done to increase the chances of success?
- Whose support is needed for this change strategy?
- What results will show that this innovation is working?
- How long will it take for those results to appear?
- How might you amplify – or help people see – these results sooner?
- What barriers do you foresee in sustaining the effort? How might those be overcome?

Conclusion

We hope that the collection of guiding questions, tools, and resources offered here will help you to take concrete steps to better identify, understand, and act to address racial inequities in program implementation and health outcomes. Key steps covered in this Road Map have included:

- Looking at health issues with a focus on the impact of racism
- Determining if a program is ready to use data to address racism
- Understanding what the data say about differences in health outcomes by race and ethnicity
- Using other sources of data to uncover causes of the differences
- Making plans to act on differences that are unjust or avoidable
- Presenting data in ways that help people make sense of the numbers
- Moving from data to action

Using this Road Map will support MDPH programs to authentically engage the community; frame data in the broader historical and structural contexts that impact health; communicate that inequities are unfair, unjust and preventable; and design solutions that address the root causes of these issues.

The Road Map is intended to be used in a flexible way that best meets the needs of programs based on their unique goals, structures, and capacity in data analysis and quality improvement. It is also a living document that will be updated based on feedback from its users. Because no one has achieved the goal of fully realizing racial equity, there will be a need to continually refine and build upon this Road Map as the practice of using data to inform our racial equity efforts evolves. If there are mistakes, corrections or new knowledge that can improve this document, please let us know by emailing us at RESPIT@state.ma.us.

Thank you for your commitment to eliminating institutional and structural racism to ensure optimal health of all Massachusetts residents.

Racial Equity Glossary

- ***Center in the margins*** is to shift the starting point from a majority group's perspective, which is the usual approach, to that of the marginalized group(s).

- ***Contextualizing data*** means providing a narrative that describes the data and the root causes of inequities in the context of historical and current systems of oppression (e.g. racism, sexism). This must be done by engaging community partners and stakeholders in understanding and interpreting the data, and/or looking at quantitative data on individual and community experience.

- ***Data for racial equity work*** will vary based on the question the program wants to answer or the issue it wants to address. Common individual-level demographic variables that are helpful in understanding how racism impacts health outcomes include, but are not limited to, race and ethnicity, language, nativity, and zip code.

- ***Groundwater approach*** refers to the applied practice of the groundwater metaphor, which is designed to help practitioners internalize the reality that we live in a racially structured society, and that *that* is what causes racial inequity. The metaphor is based on three observations: 1) racial inequity looks the same across systems, 2) socio-economic difference does not explain the racial inequity; and 3) inequities are caused by systems, regardless of people’s culture or behavior.

- ***Health disparities*** are differences between the health of populations in measures of who gets disease, who has disease, who dies from disease, and other adverse health conditions.

- ***Health equity*** is the opportunity for everyone to attain his or her full health potential. No one is disadvantaged from achieving this potential because of his or her social position (e.g., class, socioeconomic status) or socially assigned circumstance (e.g., race, gender, ethnicity, religion, sexual orientation, geography).

- ***Health inequities*** are differences in health status and mortality rates across population groups that are systemic, avoidable, unfair, and unjust. These differences are rooted social and economic injustice, and are attributable to social, economic and environmental conditions in which people live, work, and play.

- ***Implicit bias***, also known as unconscious or hidden bias, is a negative association that people unknowingly hold. It is often expressed automatically, without conscious awareness.[19]

- ***Institutional racism*** is the discriminatory treatment, unfair policies and practices, and inequitable opportunities and impacts within organizations and institutions, based on race.

- ***Internalized racism*** is the set of private beliefs, prejudices, and ideas that individuals have about the superiority of Whites and the inferiority of people of color. Among people of color, it manifests as internalized racial oppression. Among Whites, it manifests as internalized racial superiority.

- ***Interpersonal racism*** is the expression of racism between individuals. These are interactions occurring between individuals that often take place in the form of harassing, racial slurs, or telling of racial jokes.

- ***People of color*** is a term that is used to reference the way that groups have been racialized in the United States to privilege certain groups as 'white' based on the countries where their families immigrated from. People of color is a term that has been used in many different ways across time. In this text, it is being used as a way to express the dichotomies that exists based on designation of a person as white or non-white. It is not to be used to broadly classify all non-white populations, or

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[19] State of the Science Implicit Bias Review 2013, Cheryl Staats, Kirwan Institute, The Ohio State University.

dismiss the varied history of discriminatory and violent policies against specific non-white groups.

- ***Racial equity*** means acknowledging and accounting for past and current inequities, and providing all people, particularly those most impacted by racial inequities, the infrastructure needed to thrive. People, including people of color, are owners, planners, and decision-makers in the systems that govern their lives. Everyone benefits from a more just, equitable system.

- ***Racial equity lens*** means explicitly considering race, ethnicity, and racism in analyzing issues, looking for solutions and defining success.[20]

- ***Racial equity work*** includes activities or programs that create and reinforce policies, attitudes, and actions for equitable power, access, opportunities, treatment and outcomes for all people, regardless of race. The goal is to eliminate inequities between people of different races and ethnicities, and to increase the success for all groups.[21, 22]

- ***Racialize*** refers to the act or process of imbuing a racial characteristic to something (or someone).[23]

- ***Racialized data*** are stratified in ways that acknowledge the groups of people who have been assigned a race by society (racialized) to perpetuate and support systems of privilege and oppression, such as distinctions by race/ethnicity, language, and place of birth. Moving beyond racialized data to using data for racial equity is part of the journey described throughout this Road Map.

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[20] GrantCraft, Grantmaking with a Racial Equity Lens, http://www.aecf.org/m/resourcedoc/grantcraft-GrantMakingWithRacialEquityLens-2007.pdf

[21] Boston Public Health Commission, Racial Justice and Health Equity Initiative Professional Development Series Glossary.

[22] Government Alliance on Race and Equity, http://www.racialequityalliance.org/about/our-approach/benefits/

- ***Structural racism*** is racial bias across institutions and society over time. It is the cumulative and compounded effects of an array of factors such as public policies, institutional practices, cultural representations, and other norms that work in various, often reinforcing, ways to perpetuate racial inequity.

Appendix: Racial Equity Program Readiness Assessment

Standard 1 – Data Capacity

Phase	***Pre-foundational***	***Foundational***	***Aspirational***
Definition	Program does not have capacity or support to analyze data.	Program has access to staff who can analyze racial equity data.	Program has dedicated staff that can analyze data to be used in program monitoring and decision making with a racial equity lens.
Transition Strategy	**Characteristics of Transition Strategies, by Phase**		
Ensure data access & use	Program does not have access or use data to inform program processes and decision-making.	Program uses data to inform program processes and decision-making.	Program uses data to ensure that strategies and policies it implements or supports are created with a racial equity lens.
Analyze data for racial equity	Program routinely analyzes aggregate race and ethnicity data.	Program routinely disaggregates and analyzes data by race and ethnicity.	Contextual language that is explicit about structural racism is routinely included in data dissemination products.
Analytic staff provides support to translate data findings	Program does not have analytic staff to support data analysis.	Program has analytic staff to analyze and interpret data.	Analytic staff incorporate a racial equity lens into all aspects of data analysis, program monitoring, and decision making.
Dedicate time to explore racial inequities using data	Program does not dedicate time to explore racial inequities using data.	Racial inequities are explored using data but no formal structures, processes, or dedicated time is in place to do so.	Exploring racial inequities using data is included in analytic staff job description; staff receives supervisor support to explore racial inequities using data.

Transition Resources

- Robert Wood Johnson - A New Way to Talk about Social Determinants of Health
- Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health
- Conducting a Health Equity Data Analysis

Self-Assessment: Where are you?

Standard 2 – Performance Measurement

Phase	***Pre-foundational***	***Foundational***	***Aspirational***
Definition	Program does not have performance measures (PMs).	Program has PMs, but they are not timely and are not useful tools to identify areas of improvement.	Program reports on PMs in real time to identify areas of improvement with a racial equity lens.
Transition Strategy	**Characteristics of Transition Strategies, by Phase**		
Align performance measures with program goals	Program does not have PMs, or program has PMs but they are not informed by program goals.	Program staff understands how to align PMs with program goals; PMs reflect program goals.	PMs are aligned with program goals; PMs identify areas for improvement related to program objectives; PMs explicitly address racial equity.
Ensure performance measures are SMARTIE	Program does not have PMs.	Program has PMs but they are not SMARTIE (specific, measurable, achievable, realistic, time-bound, inclusive, and equitable).	PMs are easily understood by and communicated to staff and stakeholders; PMs are SMARTIE.
Set appropriate objectives for performance measures	Program does not have objectives for PMs, or objectives are inappropriate or misaligned with PMs and program goals.	Program staff understands how to set appropriate objectives for PMs; objectives are aligned with PMs and program goals.	Objectives are appropriate, aligned with corresponding racial equity PMs and program goals; staff know how to interpret objectives to inform improvement efforts.
Report on data in a timely manner and more than annually	Program does not have the capacity to report on data in a timely manner; program has no formal structures or processes to allow for timely data reporting.	A formal structure and process for data reporting is established; data are only reported on annually; program has limited capacity for data reporting.	Program has capacity to collect and report racial equity PM data; PMs are within scope of data accessible to program; program reports on data more than annually.

Transition Resources

- Examples of MDPH Programmatic Strategic Plans: MA Cancer Control Plan 2017-2021; MA Asthma Action Plan 2015-2020
- SMARTIE Goals Worksheet

Self-Assessment: Where are you?

Standard 3 – Program Collects High Quality Data to Inform Racial Equity Work

Phase	***Pre-foundational***	***Foundational***	***Aspirational***
Definition	Program does not collect individual level data to inform racial equity work.	Program has some individual level data to inform racial equity work that is not currently aligned with MDPH standards.	Program collects and reports individual level data to inform racial equity work according to MDPH standards.
Transition Strategy	**Characteristics of Transition Strategies, by Phase**		
Train staff in how to collect high quality data in a sensitive way	Staff have not been trained recently in how and the importance of collecting data to inform racial equity work.	Some staff have been trained recently in how and the importance of collecting data to inform racial equity work.	Regular trainings and coaching are in place for all staff on how and the importance of collecting data to inform racial equity work.
Track missing data	Program does not regularly assess missing data.	Program has implemented focused strategies to reduce missing data.	Program has CQI process in place to reduce the amount of missing data.

Transition Resources

- Institute for Healthcare Improvement (IHI) Psychology of Change Framework
- Understanding and Managing Organizational Change: Implications for Public Health Management (article)
- Alliance for Innovation on Maternal Health (AIM): Reduction of Peripartum Racial/Ethnic Disparities Bundle - Complete Resource Listing
- IHI Run Chart Tool (online resources)

Self-Assessment: Where are you?

Standard 4 – Program Contextualizes Data to Inform Racial Equity Work

Phase	*Pre-foundational*	*Foundational*	*Aspirational*
Definition	Program is not aware of what contextual data they need or where and how to access contextual data.	Program is aware of where and how to access contextual data, but has not used them to understand and address racial equity in their work.	Program contextualizes data using an upstream, structural framework to understand and improve outcomes in their program.
Transition Strategy	**Characteristics of Transition Strategies, by Phase**		
Train staff	Program staff have attended racial equity training.	Program staff have not received additional training to contextualize data using an upstream, structural framework to understand and improve program outcomes.	Program staff receive ongoing training to continue contextualizing data using an upstream, structural framework to understand and improve program outcomes.
Define the context	Program is not aware of what contextual data are helpful to understand and address racial equity in their work.	Program is aware of what contextual data are helpful to understand and address racial equity in their work, but has not contextualized their data.	Program continuously assesses contextualizing data to understand and address racial equity in their work.
Identify quantitative and qualitative data sources	Program is not aware of quantitative or qualitative data sources available.	Program is aware of quantitative or qualitative data sources available.	Program uses quantitative and qualitative data sources to understand and address racial equity in their work.
Engage community stakeholders	Program does not engage community stakeholders.	Program collaborates with community stakeholders in some aspects of program implementation or monitoring (e.g. advisory boards, needs assessments)	Program collaborates with community stakeholders to understand and address racial equity in their work.

Transition Resources

- MDPH-hosted activities (Contact BFHN Racial Equity Coordinator for more information)
  - Two day racial equity training
  - Racial equity labs
  - Affinity groups
  - Brown bag lunches
  - Racial Equity 4th Floor Library
- Racial Justice Self-Assessment Checklist (developed by MDPH)
- Community Health Needs Assessment
- Creating Healing Organizations
- Promoting Family Engagement and Involvement
- Voices for Racial Justice: Authentic Community Engagement Seattle Inclusive Outreach and Public Engagement Guide

Self-Assessment: Where are you?

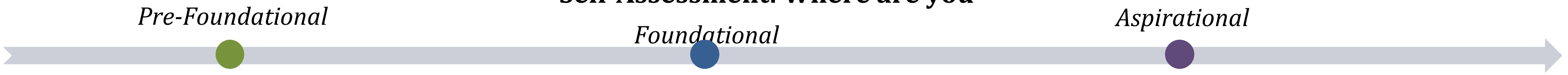
Standard 5 – Program Implements a Continuous Quality Improvement (CQI) Process

Phase	***Pre-foundational***	***Foundational***	***Aspirational***
Definition	Program has no continuous quality improvement (CQI) process.	Program has informal or ad hoc CQI process.	CQI is thoroughly integrated in the program and a CQI team effectively uses improvement methods to address identified challenges.
Transition Strategy	**Characteristics of Transition Strategies, by Phase**		
Train staff	Staff has not received formal training in CQI.	Staff is trained to identify and implement CQI activities.	Program implements train-the-trainer and/or staff pursues ongoing training, professional development, and cultural changes for CQI practices.
Implement a CQI structure and process	Program does not have a CQI process or structure; program does not have the capacity or identified resources and knowledge to do so.	Program has a documented CQI process.	Program has an established CQI structure and formal CQI process that aligns with the program's key strategic goals.

Transition Resources

- MDPH-hosted Lean Six Sigma training (contact Office of Performance Management and Quality Improvement for more information)
- National Institute for Children's Health Quality (NICHQ) online trainings: QI 101 and QI 102
- Population Health Improvement Partners trainings and tools
- IHI Resources and Trainings
- IHI Forming a CQI Team

Self-Assessment: Where are you



> “Let us realize that the arc of the moral universe is long but it bends toward justice.”
>
> -Dr. Martin Luther King Jr.

Data for Equity: Creating an Antiracist, Intersectional Approach to Data in a Local Health Department

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ABSTRACT

Objective: To develop recommendations to embed equity into data work at a local health department and a framework for antiracist data praxis.

Design: A working group comprised staff from across the agency whose positions involved data collection, analysis, interpretation, or communication met during April-July 2018 to identify and discuss successes and challenges experienced by staff and to generate recommendations for achieving equitable data practices.

Setting: Local health department in New York City.

Results: The recommendations encompassed 6 themes: strengthening analytic skills, communication and interpretation, data collection and aggregation, community engagement, infrastructure and capacity building, and leadership and innovation. Specific projects are underway or have been completed.

Conclusions: Improving equity in data requires changes to data processes and commitment to racial and intersectional justice and process change at all levels of the organization and across job functions. We developed a collaborative model for how a local health department can reform data work to embed an equity lens. This framework serves as a model for jurisdictions to build upon in their own efforts to promote equitable health outcomes and become antiracist organizations.

KEY WORDS: data disaggregation, health equity, racism, social determinants of health

Public health agencies make thousands of decisions each year based on data. Although the most thoughtful courses of action are rooted in high-quality, well-collected data, even the best evidence-based decisions can perpetuate harm if equity has not been considered in all aspects of the data collection, analysis, interpretation, and dissemination. Which questions are asked and deemed important and to whom, and how these questions are framed determine what data are collected and analyzed, ultimately influencing the myriad ways in which those data are interpreted and communicated, and the many stakeholders that use them.[1,2] When equity is not considered in these processes, the resulting data can reinforce structural and institutional racism and other systems of oppression.[3]

As the field of public health in the United States begins to confront racism and other systems of oppression by more directly acknowledging and addressing their roles in shaping the health of individuals and their communities,[4] data are often sidelined in reform efforts, despite their centrality in public health practice. This is likely because data, particularly quantitative data, are viewed by many as objective and not susceptible to the biases of the oppressive interpersonal, institutional, and structural systems that influence us all.[5] However, data are influenced by the point of view of the people creating, collecting, and interpreting them, and are therefore replete with subjectivity.

More specifically, data are a social construct, made for and by people, and the ways that data are collected and used in public health practice is an act of power

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The authors thank the members of the 2018 Data for Equity working group for their groundbreaking contributions that led to the creation of these recommendations. They also thank Meghana Ammula, Elise Omaits, and Charisma Hooda served as HRTP interns who supported implementation of these projects.

This work was performed in the course of routine activities at the NYC Department of Health and Mental Hygiene.

The authors declare no conflicts of interest.

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DOI: 10.1097/PHH.0000000000001579

with profound consequences.[6] Data can be used to perpetuate myths that disparities in health outcomes might be caused by some underlying biological differences between races.[7] Data can designate some groups as healthier and making the 'right' choices, while suggesting that other groups cannot or will not make healthy choices and are suffering health consequences as a result. For example, presenting obesity rates by racialized group does not take into consideration structurally racist factors, such as how residential segregation differentially distributes affordable fresh food[8] or how inequities in the labor market create racial pay gaps.[9] In addition, the absence of data collection of certain groups renders them invisible.[10] For example, some races/ethnicities are not represented in data collection at all, or are ultimately grouped heterogeneously for analysis and presentation. Similarly, people who experience oppression due to the societal enforcement of a binary understanding of gender identity and gender expression have historically been invisible in data.[11]

To be a truly antiracist and intersectional public health agency and effectively eliminate health disparities requires recognition of the subjectivity of data and of the power of data to dictate and reinforce narratives, accompanied by intentional reform of data practices. Although the public health community has made strides in foregrounding racial equity in public health rhetoric,[12] fewer resources are available that address how to actually incorporate equity principles in the collection, analysis, and reporting of data that influence public health decisions.

In 2015, the New York City Department of Health and Mental Hygiene ("Health Department') launched Race to Justice (https://www1.nyc.gov/site/doh/health/health-topics/race-to-justice.page), an internal reform effort to embed racial equity and social justice within the agency through organizational alignment and capacity building (short-term outcomes) designed to produce changes in policies, practices, and norms (intermediate outcomes), and ultimately lead to measurable reductions in health inequities (community-level impact). This work began on the premise that an organization that reflects equity in its organizational identity and culture will realize equity for the communities it serves. To achieve this reform, 4 work groups were established as part of the first phase (Finance, Workforce, Community Engagement, and Communications). The work groups were charged with examining these domains to put forward recommendations to advance equity. This initial phase of work did not include a work group around data; however, as the initiative progressed, it became evident that the agency needed a work group to examine and innovate data practices related to equity. It was impossible to grow staff's capacity to do equitable data work and to consistently track progress toward racial equity and social justice goals without an intentional, focused effort. This led to the creation of Data for Equity in 2018, the first institutionally recognized and centralized effort to develop an approach to support agency staff that work with data to apply an intersectional, antiracist equity lens to their work. This included identifying resource needs around social justice and racial and gender equity-informed data analysis and communications, identifying initial guidance for staff working with data, and developing recommendations for leadership on the types of tools and trainings that should be offered.

This article describes (1) the process and resulting Data for Equity recommendations developed in 2018, and (2) the initial progress toward implementing some of the recommended actions. We also describe our framework for antiracist data praxis. The hope is that other jurisdictions can use these recommendations to guide their own efforts to address structural racism in data.

Methods

Planning and development of Data for Equity were led by staff members from the Division of Epidemiology and the Center for Health Equity. Implementation planning was supported as part of an agency pilot to use the Government Alliance on Race and Equity (GARE) Racial Equity Toolkit in project planning.[13]

The first step was to create a working group comprising staff from across the agency who worked with data. We envisioned this broadly to include staff who touch data during collection and analysis and those not traditionally considered "data people" like those who communicate about (eg, external affairs) or make policy decisions based on data (Figure). Deputy commissioners (aka, division leaders/leadership) were asked to nominate 1 to 2 people from their division to serve on this working group. Before convening the first meeting, members of the planning team conducted in-depth/semistructured interviews with each division's representatives to assess their baseline needs and competencies around equity and data and to understand each division's approach to and needs around equity in data.

The working group comprised 24 members from 12 divisions and met 3 times during April-July 2018 to identify and discuss successes and challenges experienced by staff and to generate recommendations for the agency. The first meeting focused on discussing what objectives/goals, resources, and institutional support would be necessary for the Health Department to collect, analyze, and disseminate data using an equity framework. During the second meeting,

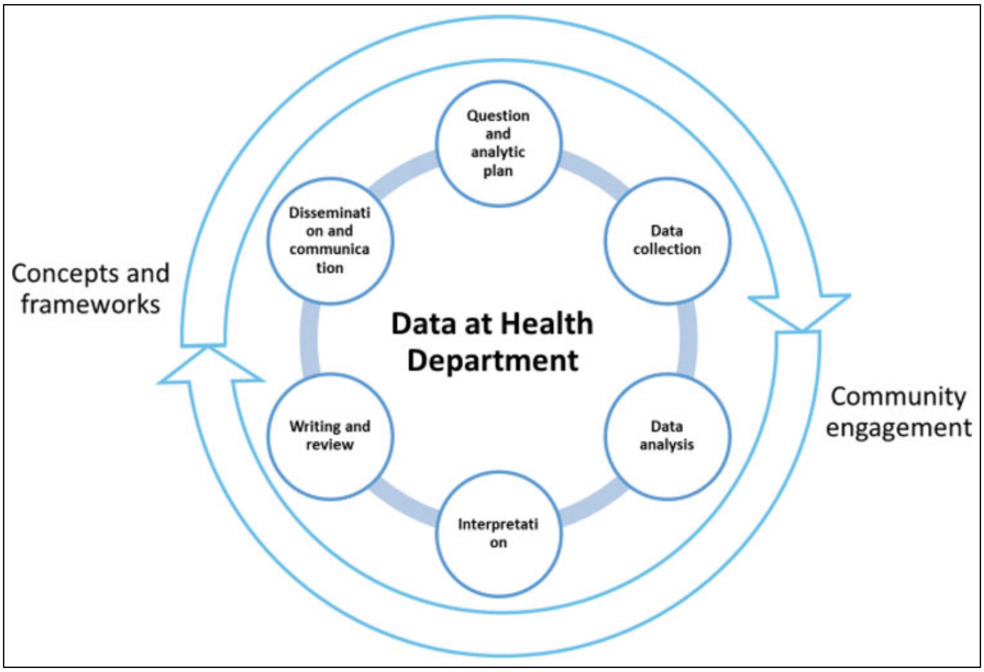

FIGURE Touch Points for Working With Data Envisioned by Data for Equity

representatives from each division presented on successes and challenges with bringing an equity perspective to data work that they had recorded in their individual divisions. Recurring themes included a lack of tools and trainings that help connect data to the Agency's Race to Justice Initiative, a lack of framework and infrastructure for community participation and engagement in data work, the absence of qualitative data expertise and work, and discomfort with not having best practices for making data collection and analysis processes more equitable (eg, more inclusive sampling frameworks, tools to analyze groups of small size, demonstrating validity and reliability of qualitative work in historically quantitative settings). During the third meeting, the group focused on developing recommendations, prioritizing each one based on perceived need, urgency, and feasibility. Final recommendations were approved for implementation by the Commissioner of Health in March 2019.

Results

Recommendations

The final Data for Equity recommendations encompassed 6 themes: strengthening analytic skills, communication and interpretation, data collection and aggregation, community engagement, infrastructure and capacity building, and leadership and innovation. Specific recommendations in each of the 6 areas described later are shown in Table 1.

1. Data collection and aggregation: expand use of existing data and enhance Health Department data collection.

This recommendation focuses on expanding the Health Department's ability to collect and use data with an equity lens. Specifically, the actions included in this recommendation will help ensure improved data collection by holding vendors accountable for including antiracist principles in their work, strengthening data collection for hard-to-reach or marginalized populations and about the social determinants of health, and by creating consistent standards for data disaggregation and demographic data collection. Collectively, these recommendations help ensure that the Health Department collects data that are more reflective of NYC populations, and that analyses using these data are collected using categories that align more meaningfully with how people identify themselves.

2. Strengthening analytic skills: strengthen skills of Health Department staff to incorporate equity into their analytic work.

Encompassed within this recommendation are projects to strengthen staff analytic skills, including social epidemiology and mixed-methods training, and development of a guidance document that formalizes equity conventions for Health Department analyses. This recommendation also includes developing performance metrics to ensure that analysts and their managers routinely include equity principles in all

TABLE 1

Data for Equity Recommendations, NYC Department of Health and Mental Hygiene, 2019

Data collection and aggregation. Expand use of existing data and enhance Health Department data collection
Create agencywide protocols for using data disaggregation consistently during collection, analysis, and reporting of subgroup data, including recommendations to address sparse numbers in current Health Department data collection.
Develop agencywide, standardized list of questions for collecting data on demographics, for example, race/ethnicity/nationality/sexual orientation and gender identity (SOGI); provide internal guidance on using these standards.
Regularly conduct survey on social determinants of health.
Add additional populations to existing Health Department surveys, including persons in long-term care, people involved in the criminal justice system, and students.
Conduct focused data collection for certain populations, focusing on those who have been historically marginalized or are hard to describe using traditional surveillance methodologies (eg, older adults, justice involved, transgender, or gender nonconforming people).
Develop language to include in the scopes of work of vendors who collect data on behalf of Health Department to ensure alignment with Health Department principles of racial equity and social justice.
Strengthening analytic skills: strengthen skills of Health Department staff to incorporate equity into their analytic work
Create a guidance document for analysts including equity conventions process questions to provoke thought and reflection.
Develop and provide regular and ongoing Data for Equity/social epidemiology training for all Health Department analysts, including training in qualitative analysis and mixed methods.
Develop tasks and standards for analysts that ensure that analyses routinely incorporate social determinants of health/social epidemiology/social justice in all phases of their work. Similarly, develop tasks and standards (the agency's performance management tool) for managers that ensure that they support and empower analysts to conduct these analyses.
Data communication, interpretation, and dissemination. Improve how the Health Department communicates and disseminates data findings
Create an equity-focused data communications guide, including guidance on how to message and visualize disparities without perpetuating racism and oppression and how to incorporate historical and contemporary context into data findings.
Create a writing workshop focused on integrating health equity into data products, including guidance on plain language.
Publish special reports on the health of historically marginalized populations that clearly explain the history of marginalization and its effects on health (eg, Latino Health Report).
Community engagement: integrate New Yorkers into Health Department data collection, analysis, communication, and dissemination
Partner with Race to Justice Community Engagement Work group (CEWG) to adapt the community engagement framework for Health Department data work.
Develop and provide training for all analysts on the community engagement framework.
Provide training in community-based participatory action research.
Develop process to incorporate non-Health Department partners in research, including institutional review board process and human subjects training.
Create an external advisory panel, including persons with lived experience, to review and guide Health Department data products and publications.
Infrastructure and capacity building: build infrastructure and capacity for data and skills and knowledge sharing across the Health Department
Conduct equity skills survey and create a list of content experts across the agency.
Create a SharePort site [the agency's intranet page] for Data for Equity to provide a central repository of training materials and resources.
Create position for dedicated Equity Epidemiologist. Ideally, create a dedicated social epidemiology unit. This person/unit will manage this portfolio of work and provide technical assistance to the agency.
Provide additional resources to the Public Health Library to fund better access to peer-reviewed journals in related fields (ie, social science, geography, urban planning, economics, etc) and fund a position to help staff conduct comprehensive literature reviews incorporating different disciplines.
Work within existing infrastructure and working groups for Health Department data (eg, Data Task Force, Epi Grand Rounds, National Public Health Week) to share best practices and challenges in developing data-focused equity skills.
Leadership and innovation: provide leadership and innovation in using data with an equity framework
Establish permanent Data for Equity working group at Health Department to hold agency accountable for these recommendations.
Hold a hackathon/competition to reimagine how Health Department visualizes data with an equity lens.
Share results of Health Department's Data for Equity initiative through peer-reviewed publications, Health Department reports, and presentations at meetings.
Use the Health Data for NYC (HD4NYC) initiative to conduct innovative research on selected topics related to health equity.

aspects of their work. Work on these recommended products is in progress.

3. Data communication, interpretation, and dissemination: improve how the Health Department communicates and disseminates data findings.

This recommendation focuses on improving communication around data, including creating an equity-focused communications guide, developing a writing workshop to train staff to integrate equity into data products, and publishing special reports on the health of historically marginalized populations. These recommendations will help the Health Department communicate more equitably by training staff how to better visualize and message about disparities without perpetuating racism and oppression.

4. Community engagement: integrate New Yorkers into Health Department data collection, analysis, communication, and dissemination.

Centering the experience and knowledge of NYC's many communities into the Health Department's data work is a key tenet of Data for Equity recommendations. This recommendation includes adapting the agency's community engagement framework (https://www1.nyc.gov/site/doh/health/health-topics/race-to-justice.page) to data work, developing training for analysts on this framework as well as on community-based participatory action research, developing a process to incorporate non-Health Department partners in research, including institutional review board process and human subjects training, and creating an external advisory panel, including persons with lived experience, to review and guide Health Department data products and publications. Work on these recommended products has not yet begun.

5. Infrastructure and capacity building: build infrastructure and capacity for data and skills and knowledge sharing across the Health Department.
6. Leadership and innovation: provide leadership and innovation in using data with an equity framework.

These latter 2 recommendations support actions to build capacity and institutionalize this work within the Health Department as well as to provide leadership in the field and share these products externally. Recommended actions include assessing the agency's baseline capacity to incorporate equity into data-related work, creating a platform via the agency's internal Web site and internal working groups to share information and resources, creating permanent staff positions to support the work, resourcing the public health library, making a permanent work group structure, enhancing academic collaborations, and sharing of Data for Equity products externally.

Completed projects

Since finalization of the recommendations, work on several specific projects has been advanced by individual staff and program efforts. Brief, high-level summaries of some successful projects are provided later to highlight initial efforts toward achieving the recommended actions.

Data disaggregation guidance

During the summer of 2019, we conducted 5 focus groups of approximately 5 to 11 staff and reviewed current data disaggregation practices for 28 Health Department data sets to create agency-wide protocols for improving data disaggregation by consistently using more inclusive and collaborative methods during collection, analysis, and reporting of subgroup data, including recommendations to address sparse numbers in current Health Department data collection (including considerations for privacy and confidentiality). The product was a guidance document currently available internally for analysts.

Standardized questions on gender identity

A working group was established to develop guidance for standardizing the collection, analysis, and reporting of gender-related data in the agency and for improving inclusivity in these processes. A draft guidance document was shared with stakeholders for feedback in early 2020; however, implementation was delayed because of the COVID-19 pandemic.

Equity in data technical assistance

The COVID-19 pandemic demonstrated the need to develop more consistent, affirming demographic data collection practices across the agency. We provided a range of technical assistance during the COVID-19 response on documents related to equitably collecting and reporting demographic data. This included revising demographic data collection for the Citywide Immunization Registry, compiling best practices for collection of race/ethnicity, sex assigned at birth and gender identity, ability, nativity, language, and criminal-legal system involvement.

Social determinants of health survey

In 2017, using special one-time funding, the Health Department conducted a unique population-based survey focused on describing the social determinants of health in NYC.[14] The recommendations included making this a routine surveillance tool for ongoing monitoring of social determinants of health (eg, material hardship, health care access, discrimination, community involvement and social support, housing) and their relationships with health indicators. The survey was subsequently resourced to be repeated in 2020 and early 2022 and is planned approximately biannually moving forward.

Reports on the health of historically marginalized populations

In late 2021, the Health Department published reports on the health of Asians and Pacific Islanders and Indigenous Peoples of the Americas living in NYC.[15,16] Both reports were developed in collaboration with community partners who helped identify and prioritize metrics of interest to their communities. Data in the report on the health of Asians are disaggregated by as many as 13 ancestry groups, allowing for a more nuanced description of the health of API NYC residents. These reports happened alongside the data disaggregation project described previously, demonstrating the learnings as an agency as these principles were turned into practice.

All-staff survey

In late 2019, we conducted an all-staff survey to assess staff data-related equity skills agencywide, to provide information to create thoughtful and targeted tools and trainings, and to serve as a baseline upon which to evaluate the impact of future training efforts. The survey included questions to assess proficiency in applying equity principles when working with data throughout the complete data lifecycle. Results from the survey were shared with agency leadership in mid-2021.

Data for Equity work group

Data for Equity was officially made part of the agency Race to Justice infrastructure in early 2020. Because of the COVID-19 pandemic, reestablishment of the agencywide working group was delayed, although the planning team continued to respond to ad hoc requests and plan for the resumption of the working group. Through a blinded agencywide recruitment process, new work group members were identified, and the working group was launched in late 2021; in 2022, the working group will continue progress toward implementing the 2018 guidelines.

Health Data for NYC (HD4NYC)

Health Data for NYC was launched in 2019 with funding from the Robert Wood Johnson Foundation to bring together Health Department and academic investigators to conduct unique policy-relevant research to promote health equity (https://www.nyam.org/hd4nyc/). This program has increased the agency's ability to conduct and disseminate equity-focused research, as well as enhanced data sharing with community and academic partners.

Discussion

Given the paramount role of data in defining public health resource and policy decisions, addressing systematic oppression in how data are collected, analyzed, and shared must be an explicit part of intersectional and antiracist public health practice.[17] Through a focused and collaborative process, we successfully established Data for Equity as an initial set of recommendations to guide equity in the data practices at the New York City Health Department. As momentum gathers nationally for this kind of transformative work in public health[18-20] and data science more broadly,[21-23] this agenda is a starting place that other health departments or organizations can use to assess the need for institutional reform, and serves as a model for thinking about how to build equity-focused data infrastructure.

A major lesson from this work is that embedding equity in data is not just about changing data processes, it is also about embedding guiding equity principles around racial and intersectional justice, combined with process change at all levels of the organization and across job functions. High-level leadership commitment is particularly essential to ensure that equity is embedded into actual planning and execution of analyses, report compiling, and other uses of data whether it be internal dissemination, program or resource allocation decisions, or publications. At the staff level, conventional practice is often simply to make changes to how data are collected or analyzed (eg, changes in demographic data collection), and staff who work with data (encompassing a range of titles and roles including analyst, epidemiologist, program evaluator, etc) are not often encouraged to think more broadly about how these changes contribute to antiracist public health practice. Conversely, staff who work directly with community members or who manage programs and may have a strong grounding in equity principles are often not included in data processes. Our recommendations recognize the multiple ways in which data are touched at all levels, including both the "typical" data work of public health (eg, collection and analysis) and areas less often considered when thinking about data (eg, a community's role and agency in data work), and attempt to create equitable and systematic processes that ensure that staff across all worksites and positions have the necessary resources and support to include equity in their practice.

Addressing racist practices in data work is often secondary to more public facing reforms. This results, at least in part, from the supposed neutrality of data, which itself is tied tightly to educational systems deeply rooted in White supremacy that privilege specific kinds of knowledge and credentialing.[24] These systems create false and inequitable hierarchies between people who identify or are identified as "data people" and those who are not. Although a range of people contribute labor to produce data (eg, survey respondents, community engagement staff, administrators), it is uncommon for "nondata" contributions to be valued equitably and very common for much of the labor of people who work closely with the community to be erased or taken for granted. These omissions are often justified by seemingly neutral certification and training requirements (such as educational degrees) that are structurally less accessible for groups with fewer resources. Also, like in medical training, public health students must undergo training that perpetuates racist narratives to complete their requirements.[25] Addressing these omissions and dismantling these hierarchies must be part of embedding equity in data practices within an institution.

The process of creating Data for Equity led to the identification of a series of ways of working that should be upheld in data-related activities (Table 2). These principles include developing structures and practices that build and nurture internal leaders by elevating the talent and honoring and supporting the leadership of Black, Indigenous, People of Color (BIPOC) individuals. In addition, by using the principles of consensus decision making and respect for others' points of view and lived experiences, this work has set a model for equitable work practices that will have a tangible impact on how the agency addresses and corrects inequities.

There have been many challenges to successfully accomplishing this work that can serve as lessons for other jurisdictions interested in planning similar initiatives. First, resources to implement the recommended actions, particularly the allocation of adequate staff time to learn and subsequently change data practices, have not always been available. Overt allocation of staff efforts in job descriptions and performance management tracking systems is needed. Second, decisions about what to prioritize have shifted with emerging public health crises and changing government administrations. Specifically, while the COVID-19 pandemic has made more apparent the impetus for this work, the allocation of staff to the emergency response has substantially slowed progress. Third, this work has also moved slowly because of the thought and extensive intraagency engagement required to do it and the longer time lines for implementation of more equitable processes. Fourth, as a large city agency with more than 6000 employees, we have observed immense variation among organizational units and data systems, making it difficult to develop systematic processes. Finally, even in jurisdictions such as New York, where the political context allows for this type of programming and discourse, the need for sufficient resources to adequately implement it remains a challenge that stymies advocacy of equitable practices and reform of structures and systems of oppression.

In the aftermath of the murder of George Floyd, widespread protests against racism, and the stark racial gaps in COVID-19 outcomes, the NYC Racial Justice Commission was formed to reckon with the ways that racism is embedded in City structures.[34] As part of the Health Department's overall commitment to be publicly accountable for eliminating racism, in October 2021, Data for Equity was codified in the New York City Board of Health resolution declaring racism a public health crisis.[35] At this time of heightened racial justice reckoning and increasing acknowledgment of such on behalf of all sectors in society, public health data hold immense power to shape narratives and make the invisible visible, which is a necessary step toward dismantling racism and oppression.

Data for Equity has helped establish clear expectations and a collaborative model for how a local health department can reform data work to address the structures and systems that lead to the collection and analysis of biased data. In addition, equity in data is an essential foundation of the national conversation and initiatives toward data modernization.[36] This framework serves as a useful model for other jurisdictions to build upon in their own efforts to promote equitable health outcomes and become antiracist organizations.

Implications for Policy & Practice

- To be a truly antiracist and intersectional public health agency and effectively eliminate health disparities requires recognition of the subjectivity of data and the power of data to dictate and reinforce narratives, accompanied by intentional reform of data practices.
- Addressing systematic oppression in how data are collected, analyzed, and shared must be an explicit part of intersectional and antiracist public health practice. Equity in data is also an essential foundation of the national conversation and initiatives toward data modernization.

TABLE 2

Principles for Working With Data in an Equitable Manner

Principle	Rationale	Challenges	Example of How Data for Equity Implemented/Plans to Implement
Reframe "best practices" as "better practices."	• Recognizing that practices shift and change over time as we learn and unlearn. • People and communities grow and change and language shifts to include new ideas and identities. Categories and terminology will need to be continually evaluated and updated regularly to accommodate these changes.	• Not a one-time effort. • Changing systems (eg, survey instruments, IT) can be resource intensive and expensive. • Resistance to changing the status quo. • Requires a commitment to continuous evolution.	• Data for Equity created COVID-19 demographic data guidance that collapsed race and ethnicity into 1 category and added an ancestry category in acknowledgment of the well-documented limitations of OMB 1997 racial and ethnic group standards.[26]
Embed data reform within institutional reform and personal reform.	• Each person's own lived experience and own position changes how we name and interpret oppression.[27] The process of acknowledging our biases and need for growth is ongoing at the individual and institutional levels.	• Resistance to changing the status quo. • Changes in government administrations can make it challenging to maintain institutional support over longer time periods.	• We explicitly embedded values in our charter, recruitment materials, and ways of working agreements. • Embedded Data for Equity working group in the agency's overall racial and reform initiative, Race to Justice.
Present all data in a historical, political, and experiential context to understand any patterns illuminated by using this language.	• Data are never collected outside of a context. For example, race/ethnicity categories not only add a sociopolitical lens to the data being collected but also reflect histories of privilege, racist social structures, and racist policies.	• Space constraints in manuscripts and presentations and desire for succinct summaries. • Speed often takes precedence over the time needed to include appropriate context. • Learning to predict what narratives are going to be made from the data you create and share.	• Health Department added context to the COVID-19 data page.[28] • Naming histories of colonialism, slavery, and disinvestment in public facing documents, such as the 2019 Community Health Profiles[29] and neighborhood reports.[30]
Collect and analyze data intersectionally.	Truly inclusive data are intersectional. The impact of racism on people of color cannot be fully understood unless we understand the specific impact on women of color and transgender, gender nonconforming, and nonbinary persons as well as people with disabilities, and so forth.[31,32]	• Prohibitive costs associated with collecting samples large enough to describe small groups without compromising privacy. • "Representative" sampling is based on existing population measures that overlook many groups. • Methods to create more inclusive samples (eg, prospective sampling) are often considered biased. • Groups experiencing systemic oppression are often pitted against each other for notice and resources, creating the false notion that only 1 aspect of a person is important to collect (eg, advocating for race/ethnicity data over gender or sexuality data).	• Conducted focus groups on how the agency deals with smaller groups. • Issued guidance on data disaggregation. • Obtained positions for building out qualitative data infrastructure. • Advocated for more comprehensive and inclusive demographic data collection in every system.

(*continues*)

TABLE 2

Principles for Working With Data in an Equitable Manner (*Continued*)

Principle	Rationale	Challenges	Example of How Data for Equity Implemented/Plans to Implement
Value people's lived experience and treat as data rather than anecdote.	• Lived experience is required for meaning and understanding.[33] Identities captured in demographic data are social constructs that reflect complex and ever-evolving hierarchical power structures. Data collection instruments with poorly or broadly defined demographic categories often do not match people's lived experience, making it hard to accurately identify inequities with quantitative data.	• Overemphasis on data standardization across times, across places, and across institutions. • Lived experience difficult to categorize and it often disrupts hegemonic, normative ideas of how health is produced.	• Obtained positions for building out qualitative data infrastructure. • COVID-19 data standardization guidance recommended self-report as the standard for demographic data. • Began to collect data about experiences, not just identity. For example, asking questions about experiences of discrimination in health surveys instead of assuming demographic data represents a uniform exposure.
Be transparent and consultative in methods across the data life cycle.	• Methodologic decisions (eg, reliability estimates) are largely inaccessible to people whose data are being analyzed. For example, decisions about how to aggregate small groups within a data set happen long after the data have been collected. This ends up creating categories that do not reflect lived experience accurately.	• People who make analytic decisions about data are often not the people whose lived experience is represented in the data. • Although very important for communities, conversations about data processes can be dense and inaccessible.	• Data disaggregation protocols recommend engaging with people who are represented in the data at every step along the data life cycle.
Always interrogate who is missing from data, why they are missing, and what that means for the analysis and dissemination.	• When key populations are left out of data collection, it is rare that their absence is noted except for line in a limitations section. These absences have a compounding and inequitable effect. • Data are often described as representing the whole population, rather than the people who could be most easily counted. The needs of people who have been left out of the sampling frame have also been left out.	• It can be costly to do outreach to groups who do not easily respond to our existing strategies. • There are no existing sampling frameworks to recruit people who are invisible to routine surveillance, making it difficult to assess representativeness. • Establishing trust is difficult—many groups have cultural, social, or historical reasons to avoid surveillance.	• COVID-19 data standardization process began with assessing missingness of demographic data across data systems.

- Although the public health community has made strides in foregrounding racial equity in public health rhetoric, fewer resources are available that address how to incorporate equity principles in the collection, analysis, and reporting of data that influence public health decisions. We created a framework to guide embedding equity in data practices at the New York City Health Department. Other health departments can use this model to design similar institutional reform initiatives.
- In addition to staff training and reforms to data collection and analysis, high-level leadership commitment is essential to ensure that equity is embedded into actual planning and execution of analyses, report compiling, and other uses of data whether it be internal dissemination, program or resource allocation decisions, or publications.

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Summary of Survey Modernization Community Specific Reports

The Survey Modernization community-specific reports in 2019-2021 was a review of existing data to identify how representative that data was, how it could be improved, and identify community priorities for improvement in collection and interpretation. In working across four groups, differences in data requested and interpretation highlighted the needs for greater engagement with different culturally specific communities. Each group developed their own report, though the Latino and Black groups worked together on their report, resulting in three reports.

This focused on two specific survey tools: the Behavioral Risk Factor Surveillance System (BRFSS) and the Oregon Healthy Teens/ Student Health Survey (OHT/ SHS) for youth of high school age. Data generated from these two surveys are used for targeting services, securing grant funding, addressing emergent health issues, informing legislation and measuring progress toward public health objectives.

The BRFSS is part of a national survey that is defined and partially funded from the Centers of Disease Control and Prevention (CDC). Multiple public health programs have funding contingent on using the BRFSS; some state and county programs also use the information in applying for funding for federal and other funders. The state carries out the survey annually, with a racial and ethnic oversample conducted every few years as an attempt to gather sufficient participation from communities of color and tribal communities. Currently the survey has several challenges, including insufficient representation of communities of color and tribal communities, a high cost to implement, lack of estimates for smaller geographic areas, and a long length averaging over 24 minutes. Further, there are concerns about representativeness and lack of community engagement in survey design, analysis, interpretation of results and dissemination of findings.

Those challenges were the impetus to develop these reports with these four communities. OHA/ PHD hoped to develop better information and provide the following:

- Understanding and interpreting BRFSS and OHT/SHS survey data;
- Identifying strengths, gaps and limitations of BRFSS and OHT/ SHS data and methods;
- Facilitating community-led data collection on identified gaps in the data; and
- Developing recommendations toward sustainability of these tools.

Below is a summary on each of the reports (1) American Indian/ Alaska Natives; (2) Black and Latinx communities; (3) Pacific Islander communities.

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1 – American Indian/ Alaska Natives.

Summary for “Oregon Tribal Survey Modernization Project: Northwest Portland Area Indian Health Board Northwest Tribal Epidemiology Center (NPAIHB), Final Report to Oregon Health

Authority." July 2021. Report available here:
https://www.oregon.gov/oha/PH/ABOUT/TASKFORCE/Pages/Community-Reports.aspx.

Overview of project: Review survey data from the Oregon Behavioral Risk Factor Surveillance System (BRFSS) and Oregon Healthy Teens (OHT) to highlight priority analyses, identify knowledge gaps and generate topics and methods to provide additional context to the results for AI/AN communities in Oregon.

Methods: This project conducted a critical examination of Tribal BRFSS survey methods and supplemental data. Five participants were recruited to work with four staff of the Tribal Epi Center, drawing from a call for participation to all Oregon Tribes.

Note that the data analyzed is different than what we see at the state, since the Tribal Epi Center manages the BRFSS and other surveys for Tribal members and urban Indians in Oregon. The Tribal Epi Center owns this data.

This group identified the following challenges:

- **Defining AI/AN**: It's challenging to accurately identify race for AI/AN people. Mischaracterization of race happens for 10-60% of AI/AN individuals; those people are generally mischaracterized as white. This workgroup felt strongly that the primary role of improving BRFSS and OHT data for AI/AN communities should be to better inform and serve Oregon tribes, rather than increasing accuracy for researchers.
- **BRFSS methods:** When these surveys are conducted by OHA, there is insufficient outreach and trust, resulting in poor engagement with AI/AN communities.
- **Tribal use of BRFSS data:** This data has primarily been useful at the county level, but difficult to aggregate across counties for Tribal use. The data is commonly used by counties in applying for funding; this could be a conflict with Tribal agreements for data. This team suggests that OHA would be better served by increasing funding for known needs rather than improving surveys.
- **Lack of meaningful context:** Resulting data lacks useful context that would inform action. This group identified focusing on not just negative or behavioral factors for the youth survey, but also protective factors, including involvement in cultural/ Tribal activities.
- **Invest in tribal specific BRFSS surveys:** NPAIHB and NWTEC presently support tribes to conduct specific BRSS surveys that allow Tribes to have full ownership of the data, ask questions relevant to their tribe and community and reach tribal members effectively and efficiently. Tribes have invested in the staff and infrastructure for past surveys and resulting data has provided relevant and actionable information about the needs of Tribal members.
- **Data use and literature review:** Data on tribal members can be taken out of context when interpreted and reported by entities outside of a Tribe. This review identified two specific types of misinterpretations: (1) insufficient context in data on student absenteeism, since it did not include factors that may increase absenteeism and the cultural norms that may affect absenteeism; (2) poor analysis through the "best race"

methodology used by OHA, which can diminish the appearance of health disparities and hide burdens by multi-racial respondents.

This group made the following recommendations to OHA (much of this is a direct quotation from the report

- Data needs to be actionable:
    - Work with Tribes, UIHP and NWTEC to convene future discussions with stakeholders to better understand data priorities and the need for locally actionable, tribal-specific data
    - Incorporate non-western approaches to health and health care in surveys.
- Survey methods
    - Partner with tribes and tribal/ urban AI/ AN organization to increase BRFSS participation and educate community members on BRFSS/ OHT
    - Include questions on protective factors, particularly involvement in tribal and community activities.
- Tribal and AI/AN community engagement
    - Support Oregon tribes in conducting tribal BRFSS surveys'
    - Protect tribal data and sovereignty with data access requirements, tracking posting and publishing of data analyses and reports, ensure transparency and oversight by tribal and AI/AN communities.

2: Black and Latinx Communities

"Engaging communities in the modernization of a public health survey system" Prepared by Dr. Kusuma Madamala, Tim Holbert from Oregon Health Authority; Dr. Andres Lopez and Dr. Mira Mohsini from Coalition of Communities of Color. June 2021. Report available here: https://www.oregon.gov/oha/PH/ABOUT/TASKFORCE/Pages/Community-Reports.aspx

Overview of project: This specific project assembled two 4-5 person culturally specific project teams through a series of interview. These teams comprised research and practice-based partners with lived experience from two groups: the African American, African Immigrant and Refugee community and Latinx communities. This process was co-facilitated by the Coalition of Communities of Color. The two teams met separately throughout the process then convened for the lats two meetings, agreeing to report their work together because of the overlap between areas of interest (mental/ behavioral health and health care access) and the limitations on gathering and community engagement from COVID.

Findings: Both teams share the concern that both survey tools reproduced the assumptions, norms and methodologies of white dominant culture, and thus created further harm by misrepresenting racial and ethnic populations. Observations and critiques beyond this were in six themes

1. Lack of meaningful context: Survey results lacked the necessary context to make results meaningful and appropriately actionable. Team members often reported that the survey questions failed to consider social and cultural conditions and thereby compromised data quality.
2. Intersectionality: Project teams were adamant that it is essential that individuals are complex and live and have identities within multiple overlapping and often politized and/or socially charged structural conditions that shape their everyday experiences. Minimally data needs to be disaggregated by race, ethnicity, income, age, primary language and country of birth.
3. Actionable data: Questions need to be worded so that they produce data that accurately leads to direct action meaningful to the community.
4. Sample size and response rate: Teams were very concerned about the low response rate among BIPOC community members. BRFSS telephone survey methods call landlines and administer surveys in English, biasing survey results toward older white people. Teams recommended engaging community members in question development and administration of survey to their own community. They also asked that the "small numbers" (i.e., an insufficient sample size for representative data) not limit sharing data with communities, since that can create distrust. Further, they urged restraint on creating comparison tables across demographics.
5. Integration of other data sources: project teams requested access to data from other collection systems to provide more context for BRFSS and OHT/ SHS data, including vaccination data (from the Alert IIIS) and free and reduced lunch data from Oregon Department of education.
6. Translation and health literacy: Project team members were concerned that Spanish speaking Oregonians might not understand questions due to translation. They were also concerned about formal and complex language and recommended translation to "plan language" meaning words at a sixth grade reading level. The group suggested an external advisory group specifically for translation.

Other lessons learned:

- Community engagement is critical for scientific integrity for the data. Without it, the validity of the data is questioned, and it limits the relevancy, generalizability and use of the data.
- Accountability: These surveys track individual behavior. But individual behavior is influenced and can be determined by the context of an individual. Without context, this data is not actionable. And without knowing the systems that are affecting behavior, public health agencies cannot be held accountable for public health improvement, the systems they uphold and the public they serve.
- Building trust through equitable partnership and data practices: OHA staff learned much about needed practices to help build trust with community partners. These practices supported the partnership:
- Avoid future harm caused by the following:

    - a lack of qualitative research, individual behavior questions without social context that shift responsibility for wellbeing onto the individual, and lack of questions in the BRFSS about behavioral and medical care beyond mainstream western medical sources.

Recommendations and next steps:

- Build in time and resources necessary for relationship development between governmental public health and community partners in data
- Continue long-term sustained, compensated community-led data collection
- Conduct a minimal BRFSS – explore lessons from the CA Helath Interview Survey (CHIS)
- Integrate community leadership in survey development, administration, analysis and use
- Continue data project teams and ensure team members are made up of folks who share experiences of those being "researched." Let those teams shape the next steps of survey modernization work
- Establish a survey translation advisory committee
- Demonstrate transparency in how BRFSS and OHT data is used by OHA and by others
- Engage and defer to community-based organizations and /or regional health equity coalitions in survey administration
- Re-engage the health equity researchers of Oregon (HERO) group
- Investigate county health rankings and BIPOC data hubs as possible conceptual frameworks for data collection
- Call upon OHA as a grant recipient to advocate for changes in the national framework for BRFSS and other national health survey administration to achieve greater flexibility from federal requirements.

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3. Pacific Islander Community

"This is the Way We Rise: Pacific Islander Data Modernization in Oregon 2021" was written by the Oregon Pacific Islander Coalition, with contributions from multiple Pacific Islander leaders, researchers, community organizations, language experts, and Program Design and Evaluation Services survey modernization staff. A complete list of contributors can be found on page 6 of the report. The report and data are owned by the Oregon Pacific Islander Coalition.

Report here: https://www.oregon.gov/oha/PH/ABOUT/TASKFORCE/Pages/Community-Reports.aspx

Overview of project: The Pacific Islander Data Modernization (PIDM) was led by Pacific Islander community organization leaders and researchers brought together by the Oregon Pacific Islander Coalition (OPIC) with the support of state and county staff. Due to the lack of reliable disaggregated data regarding the health and wellness of Pacific Islanders in Oregon, leaders decided to build upon recommendations and lessons learned from Multnomah County's Pacific Islander Data Project (PIDP). The remarkable work of PIDM led to the development of the

Pacific Islander Health, Equity, and Liberation (PI HEAL) Assessment which was used as the primary data collection tool that honors Pacific Islander ways of knowing and being.

Methods:

The Oregon Pacific Islander Coalition required the Oregon Health Authority's Public Health Division to enter into a data sovereignty agreement to outline aspects such as power structures, ensure Pacific Islanders served as research, engagement, and language experts, provide proper compensation for all participants involved from start to finish, and establish data ownership and usage.

A core research ream was responsible for the overall project development and management, including community engagement, leading data collection and analysis, and providing community based participatory research training and support.

Seven Pacific Islander led community-based organizations served as high-level advisors, hosted data workshops and assisted with outreach.

Ten community research workers co-developed and co-facilitated data workshops and assisted with data analysis.

Seven data workshops were virtually hosted in order to collect meaningful qualitative data to contextualize the PI HEAL Assessment, as well as uplift data and research capacities within our Pacific Islander community. During the workshops, participants were asked to complete the survey and then gathered in small groups to discuss their feedback regarding their survey responses and their experience with the survey. Participants were each compensated $75.

The PI HEAL Assessment was provided in ʻŌlelo Hawaiʻi, Pohnpeian, Tongan, and English. 136 Pacific Islander members responses to the PI HEAL Assessment.

Responses to the PI HEAL Assessment were analyzed using IBM SPSS. The data workshops were recorded by notetakers and Zoom recording. The community research workers and core research team conducted thematic coding and co-developed diagrams to highlight narratives connected to the overall health and wellbeing of our Pacific Islander community.

Challenges:

- **Lack of disaggregated data collection and representation:** In health data systems, Pacific Islanders tend to be categorized under the larger umbrella term of Asian Pacific Islander despite the different nationalities and cultures. According to the 2010 census, Pacific Islander population was the fastest growing racial or ethnic group in the United States (US), while the 2019 US Census' American Community Survey indicate that Oregon is one of ten states in the US with the largest Pacific Islander populations including Hawaii, California, Washington, Texas, Utah, Florida, Nevada, New York, and Arizona.

- **BRFSS**: The BRFSS does not provide reliable data for our Pacific Islander communities. During an attempt to conduct an oversample, the BRFSS was only able to collect responses from 106 Pacific Islanders during a three-year period.

Recommendations:

- Map PI HEAL Assessment community health factors to the State Health Improvement Plan to leverage existing resources and being immediately addressing the health needs raised in this work.
- Have the Oregon Health Authority's Public Health Division and Pacific Islander leaders enter a project evaluation period to assess the effectiveness of the community-led research model, including Data Sovereignty Agreement and design the next phase of this critical body of work.
- Continue to celebrate, uplift and invest in the vast brilliance of the people of Oceania.