**Health Equity Concepts – Community Assessment for Palliative Care Programs**

**Activity Guide**

A Self-Directed Learning Activity

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**I. Introduction to Health Equity Concepts – Community Assessment for Palliative Care Programs**

CAPC recognizes the longstanding gaps in health care equity as it pertains to palliative care in the United States. Therefore, we have made the commitment to disseminate strategies that address inequities in access to quality palliative care. Health equity in both palliative care and larger health care is an urgent priority. This presents an opportunity for palliative care professionals to engage stakeholders in a process to reduce health disparities for people living with serious illness and their family caregivers. Achieving heath equity is a process, not just one action. It begins with understanding the unique aspects of the community in which programs deliver palliative care, including the people who live and work in the community and the organizations, services, and associations that represent the community. Palliative care programs should collaborate with these entities to delineate their needs and design services responsive to their communities. This activity—*Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs*—guides the learner through important concepts, tools, and processes to operationalize health equity into existing program and new program design.

**A. Description**

Palliative care is a human right and a necessity in the continuum of high-quality serious illness care. Structural racism has led to health disparities for many underserved and marginalized groups including but not limited to, Black/African American individuals, Indigenous populations, individuals of color, individuals of Hispanic or Latino background, individuals who identify as LGBTQ+, individuals with serious mental illnesses, individuals experiencing substance use disorders, individuals experiencing homelessness and poverty, individuals who are migrants or have refugee status, as well as persons with cognitive impairments and physical, developmental, and intellectual disabilities. The COVID-19 pandemic more clearly exposed and exacerbated health inequities within these groups. Although palliative care is grounded in quality care accessible for individuals with serious illness, it has not been immune to structural racism and health inequities. The goal of this learning activity is to promote an understanding of foundational principles of health equity and how they pertain to the care of individuals with serious illness. Specifically, the aim is to facilitate the process for a palliative care program to reflect all aspects of a community, ensuring all individuals have equitable access to quality palliative care that is responsive to their unique needs and circumstances.

Achieving health equity is not one intervention, rather it is the commitment to a process. In this activity, palliative care programs (both in the community and the hospital) perform ground level work towards health equity. First, learners will review the foundational principles of health equity. Second, learners will review their palliative program design to examine whether it reflects the community where it is located. Third, learners will explore the characteristics of the community and its assets in which their program exists. Finally, learners will consider how their palliative care program and its services could be tailored to meet the specific needs of the community.

Four questions form the basis of this *Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs* Activity:

1. Who is currently receiving your program’s palliative care services, and who in your community is not receiving palliative care services?
2. How were your populations targeted for the program; by the priorities of referrers, by financial stakeholders, by the preference of the palliative care team, or through a needs assessment process?
3. What are the common serious illnesses, diagnoses, conditions, or unmet needs of the community the program serves, and how is the palliative care team collaborating with local agencies and community-based organizations to address them?
4. How does the palliative care program assess, identify, and collaborate with agencies and organizations within the community it serves to address common serious illnesses or conditions or gaps in care?

**B. Purpose and Goals of the Learning Activity**

*Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs* is a guide to provide a foundation for health equity. It is based upon the best resources and references available at the time of publication and adapts a community assessment process to reflect the work of palliative care teams. This community assessment process may be familiar to some disciplines (e.g., nursing, public health, social work) as it is a required part of course work. It should also be familiar as part of the process of program design. This community assessment learning activity uses both *community mapping* and *asset mapping*. In this activity, *community mapping* is defined as the use of technology (internet) to identify, analyze, understand, resolve, disseminate community issues to deliberately work on social issues such as health and education. *Asset Mapping* is a process that identifies existing assets that can be brought to bear to support patients and families, providing community leaders with information to make strategic decisions in creating health equity. Therefore, concepts, processes, and principles have been built upon the work of established health entities described below in the *References and Resources* section.

At the end of the activity, the learner will have the concepts to foster more inclusive palliative care, the tools to examine the demographics in the communities they serve to reduce inequities to palliative care services within their programs, and the data to inform a strategic plan for more inclusive, culturally responsive, palliative care.

**C. Learning Activity Flow**

This learning activity opens with core concepts and progresses to action strategies for palliative care teams.

First, we begin with the fundamental concept that palliative care is a human right and health equity is a human right, therefore equitable access to high quality palliative care is also a human right.

Second, we describe key concepts—*health equity*, *health disparities, health inequality,* and *health inequities and social determinants of health*—and offer various definitions by well-established entities.

Third, we present key data sources that enable palliative care programs to map and learn about their communities, and to garner demographic data—i.e. *community mapping*. This allows you to analyze the demographics of your community and compare them to your program.

Fourth, we provide guidance to learners on key data and resources to map the resources of the community, to better serve under-represented populations through service partnerships and collaborations—i.e. *asset mapping*. This allows you to strategize and consider potential partners and collaborators.

Fifth, we offer a planning process to palliative care programs to create a strategic plan toward health equity within your sphere of influence and ways to consider priority setting.

**D. Learning Outcomes**

*Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs* is a self-directed, self-paced, learning activity to examine a palliative care program’s design through the lens of equity.

Upon completion of *Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs*, the aim is for learners to be able to:

* Articulate palliative care as a human and health right
* Define the concepts *health equity*, *health disparities, health inequality,* and *health inequities.*
* Describe the responsibility of the field of palliative care, palliative care professionals, and palliative care programs to achieve health
* Discuss the concept of *social determinants of health* and how its essential elements pertain to palliative care delivery
* Use community mapping to examine the demographics of the community a palliative care program serves, by using publicly available data to discover underserved or unrepresented populations who do not have access to quality palliative care
* Use publicly available data to map community assets and resources to inform community partnerships
* Explain the need for palliative care programs to collaborate and partner with communities to work towards health equity
* Use the information gleaned from the activity to develop a strategic plan for palliative care health equity within your community

**E. References and Resources**

Much of the literature documenting inequities in palliative care was published after 2015. As of publication, there are no resources or guides on community mapping specific to palliative care. Therefore, this learning activity translates community mapping and asset mapping resources from trustworthy entities to the palliative care context. These entities include:

* World Health Organization (WHO)
* United States Department of Health and Human Services (HHS)
	+ Office of Minority Health (OMH)
	+ Office of Disease Prevention and Health Promotion (ODPHP)
	+ Centers for Medicare and Medicaid Services (CMS)
	+ Centers for Disease Control and Prevention (CDC)
* National Academies of Sciences, Engineering and Medicine (NASEM)
	+ National Academy of Medicine (formerly Institute of Medicine [IOM])
* Kaiser Family Foundation
* Robert Wood Johnson Foundation (RWJF)

**F. Learning Activity Participation**

*Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs* is appropriate for either an individual palliative care professional or a palliative team, whether a community- or hospital-based palliative care program. This process can be used to develop a new palliative care program, or to reduce health disparities for an established program.

**G. Estimated Time for Completion**

*Health Equity Concepts – Community Assessment for Palliative Care Programs Assessment* requires approximately 2-4 hours for review of learning concepts and completion of the corresponding activities. For maximal effectiveness in retaining concepts, the activity is best done in blocks of times over the course of days or weeks (not months). This activity does not offer continuing education awards.

**H. Questions About Content**

Learners are invited to participate in CAPC’s [Virtual Office Hours (VOHs)](https://www.capc.org/events/virtual-office-hours/) to ask follow-up questions on the specific topics covered in *Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs.* VOHs are led by seasoned faculty who can guide you through strategic planning for health equity. Helpful VOHs include:

* Planning for Community-Based Care: Getting Started
* Hospices Providing Palliative Care
* Home-Based Palliative Care
* Building and Sustaining Your Hospital Palliative Care Program
* Palliative Care in the Long-Term Care Setting

To discuss this activity with palliative care colleagues, join a virtual peer-to-peer conversation in **“**[Palliative Care for Underserved/Vulnerable Patients](https://3.basecamp.com/3415480/join/GmmFMTKcSbM9/accesses/new)” CAPC member online forum on [Basecamp](https://3.basecamp.com/3415480/join/GmmFMTKcSbM9/accesses/new).

**II. Pre-Activity Reflection Questions**

Just as with any change process, a health equity initiative starts with a self-assessment. The proceeding questions are a starting point for understanding health equity as you begin this activity.

These questions in this exercise are not intended to be a research assignment, but rather an opportunity to reflect on your own and your organization’s baseline understanding of health equity and its work towards a process to achieve health equity.

***Write the answers to the questions below and keep them while you complete this activity.***

* + 1. What is your understanding of health equity?
		2. Have you worked towards equity, diversity, and inclusion within your palliative care team?
		3. Does your palliative care program have a strategy for integration of equity into program development?
		4. Does your palliative care program have a strategy for achieving equitable patient care?
		5. Have you considered any barriers to health equity in your palliative care program?
		6. Does your organization or your palliative care program currently require staff to receive training about the principles of health equity?
		7. Does your organization’s mission statement include a statement on health equity? If your palliative care program has a separate mission statement, does it include health equity?
		8. What current mechanisms exist in your palliative care program to collect and manage data that are relevant to health equity which may include diagnoses, ethnicity, race, zip code served, primary language?
		9. In creating your program, was there any type of community assessment performed (i.e., information about the demographics and characteristics of the communities you do and do not serve)?
		10. If yes, how have you adjusted your program to meet those needs?

***Review your responses and consider the following reflection questions.***

* + - 1. Are there some questions for which you don’t have an answer?
			2. Do the questions raise any new thoughts, ideas, or observations for you?

**III. Grounding Principles**

Health equity and community mapping in palliative care is grounded by the [*National Consensus Project for Quality Palliative Care (NCP) Clinical Practice Guidelines*](https://www.nationalcoalitionhpc.org/ncp/) Domain 6: Cultural Aspects of Care, Guideline 6.1.11: “The IDT performs a community assessment to identify underserved populations in need of palliative care” (National Consensus Project for Quality Palliative Care, 2018).

Current data reveals that hospice and palliative care have not adequately addressed social determinants of care or health equity. A review of the recent literature from 2017 to the present offers numerous articles and studies that demonstrate health inequities in palliative care including lack of diversity among patients served, differences in the care patients receive and in the services they receive. The following list is by no means an exhaustive list but is meant to offer a baseline of the evidence of the extent of health disparities in the palliative care setting.

**Selected Literature Review**

Bailey, Z. D., Krieger, N., Agénor, M., Graves, J., Linos, N., & Bassett, M. T. (2017). Structural racism and health inequities in the USA: Evidence and interventions. *The Lancet*, *389*(10077), 1453–1463. [https://doi.org/10.1016/S0140-6736(17)30569-X](https://doi.org/10.1016/S0140-6736%2817%2930569-X)

Barnes, C., Mueller, K., Fawcett, L., & Wagner, B. (2020). Living and dying in a disparate health care system: Rationale and strategies for cultural humility in palliative and hospice care physical therapy. *Rehabilitation Oncology*, *38*(1), 30–38. <https://doi.org/10.1097/01.REO.0000000000000199>

Barrett, N. J., Hasan, M., Bethea, K., & Johnson, K. S. (2020). The fierce urgency of now: Addressing racial and ethnic disparities in serious illness care. *North Carolina Medical Journal*, *81*(4), 254–256. <https://doi.org/10.18043/ncm.81.4.254>

Bazargan, M., & Bazargan-Hejazi, S. (2021). Disparities in palliative and hospice care and completion of advance care planning and directives among non-Hispanic Blacks: A scoping review of recent literature. *American Journal of Hospice and Palliative Medicine®*, *38*(6), 688–718. <https://doi.org/10.1177/1049909120966585>

Bona, K., & Wolfe, J. (2017). Disparities in pediatric palliative care: An opportunity to strive for equity. *Pediatrics*, *140*(4), e20171662. <https://doi.org/10.1542/peds.2017-1662>

Brown, C. E., Curtis, J. R., & Doll, K. M. (2022). A race-conscious approach toward research on racial inequities in palliative care. *Journal of Pain and Symptom Management*, *63*(5), e465–e471. <https://doi.org/10.1016/j.jpainsymman.2021.11.012>

Brown, C. E., Engelberg, R. A., Sharma, R., Downey, L., Fausto, J. A., Sibley, J., Lober, W., Khandelwal, N., Loggers, E. T., & Curtis, J. R. (2018). Race/ethnicity, socioeconomic status, and healthcare intensity at the end of life. *Journal of Palliative Medicine*, *21*(9), 1308–1316. <https://doi.org/10.1089/jpm.2018.0011>

Butler, S. M. (2020). Four COVID-19 lessons for achieving health equity. *JAMA*, *324*(22), 2245. <https://doi.org/10.1001/jama.2020.23553>

Chidiac, C., El Zakhem, A., Osman, H., & Yamout, R. (2021). Recommendations to improve palliative care provision for marginalized populations: Summary of a roundtable discussion. *Journal of Palliative Medicine*, *24*(8), 1132–1138. <https://doi.org/10.1089/jpm.2020.0548>

Foley, R. N., Sexton, D. J., Drawz, P., Ishani, A., & Reule, S. (2018). Race, ethnicity, and end-of-life care in dialysis patients in the United States. *Journal of the American Society of Nephrology*, *29*(9), 2387–2399. <https://doi.org/10.1681/ASN.2017121297>

Frydman, J. L., Berkalieva, A., Liu, B., Scarborough, B. M., Mazumdar, M., & Smith, C. B. (2022). Telemedicine utilization in the ambulatory palliative care setting: Are there disparities? *Journal of Pain and Symptom Management*, *63*(3), 423–429. <https://doi.org/10.1016/j.jpainsymman.2021.09.019>

Gardner, D. S., Doherty, M., Bates, G., Koplow, A., & Johnson, S. (2018). Racial and ethnic disparities in palliative care: A systematic scoping review. *Families in Society: The Journal of Contemporary Social Services*, *99*(4), 301–316. <https://doi.org/10.1177/1044389418809083>

Griggs, J. J. (2020). Disparities in palliative care in patients with cancer. *Journal of Clinical Oncology*, *38*(9), 974–979. <https://doi.org/10.1200/JCO.19.02108>

Grindrod, A. (2020). Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life. *Progress in Palliative Care*, *28*(2), 94–100. <https://doi.org/10.1080/09699260.2019.1705539>

Huff, C. (2019). Bringing palliative care to underserved rural communities. *Health Affairs*, *38*(12), 1971–1975. <https://doi.org/10.1377/hlthaff.2019.01470>

Johnson, K. S. (2013). Racial and ethnic disparities in palliative care. *Journal of Palliative Medicine*, *16*(11), 1329–1334. <https://doi.org/10.1089/jpm.2013.9468>

Johnson, T., Walton, S., Levine, S., Fister, E., Baron, A., & O’Mahony, S. (2020). Racial and ethnic disparity in palliative care and hospice use. *The American Journal of Managed Care*, *26*(2), e36–e40. <https://doi.org/10.37765/ajmc.2020.42399>

Jones, K. F., Laury, E., Sanders, J. J., Starr, L. T., Rosa, W. E., Booker, S. Q., Wachterman, M., Jones, C. A., Hickman, S., Merlin, J. S., & Meghani, S. H. (2022). Top ten tips palliative care clinicians should know about delivering antiracist care to Black Americans. *Journal of Palliative Medicine*, *25*(3), 479–487. <https://doi.org/10.1089/jpm.2021.0502>

Jones, T., Luth, E. A., Lin, S.-Y., & Brody, A. A. (2021). Advance care planning, palliative care, and end-of-life care interventions for racial and ethnic underrepresented groups: A systematic review. *Journal of Pain and Symptom Management*, *62*(3), e248–e260. <https://doi.org/10.1016/j.jpainsymman.2021.04.025>

Khan, M. Z., Khan, M. U., & Munir, M. B. (2021). Trends and disparities in palliative care encounters in acute heart failure admissions; Insight from national inpatient sample. *Cardiovascular Revascularization Medicine*, *23*, 52–56. <https://doi.org/10.1016/j.carrev.2020.08.024>

Lee, K. T., George, M., Lowry, S., & Ashing, K. T. (2021). A review and considerations on palliative care improvements for African Americans with cancer. *American Journal of Hospice and Palliative Medicine®*, *38*(6), 671–677. <https://doi.org/10.1177/1049909120930205>

National Consensus Project for Quality Palliative Care. (2018). *Clinical Practice Guidelines for Quality Palliative Care* (4th ed.). National Coalition for Hospice and Palliative Care. <https://www.nationalcoalitionhpc.org/ncp/>

National Hospice and Palliative Care Organization. (2021). *2021 Edition: Hospice Facts and Figures*. <http://www.nhpco.org/factsfigures>

Nelson, K. E., Wright, R., Fisher, M., Koirala, B., Roberts, B., Sloan, D. H., Wu, D. S., & Davidson, P. M. (2021). a call to action to address disparities in palliative care access: A conceptual framework for individualizing care needs. *Journal of Palliative Medicine*, *24*(2), 177–180. <https://doi.org/10.1089/jpm.2020.0435>

Nelson, K. E., Wright, R., Peeler, A., Brockie, T., & Davidson, P. M. (2021). Sociodemographic disparities in access to hospice and palliative care: An integrative review. *American Journal of Hospice and Palliative Medicine®*, *38*(11), 1378–1390. <https://doi.org/10.1177/1049909120985419>

Ornstein, K. A., Roth, D. L., Huang, J., Levitan, E. B., Rhodes, J. D., Fabius, C. D., Safford, M. M., & Sheehan, O. C. (2020). Evaluation of racial disparities in hospice use and end-of-life treatment intensity in the REGARDS cohort. *JAMA Network Open*, *3*(8), e2014639. <https://doi.org/10.1001/jamanetworkopen.2020.14639>

Patel, M. I., Lopez, A. M., Blackstock, W., Reeder-Hayes, K., Moushey, E. A., Phillips, J., & Tap, W. (2020). Cancer disparities and health equity: A policy statement from the American Society of Clinical Oncology. *Journal of Clinical Oncology*, *38*(29), 3439–3448. <https://doi.org/10.1200/JCO.20.00642>

Prince, H., Kortes-Miller, K., Stajduhar, K., & Marshall, D. (2022). Public health palliative care, equity-oriented care, and structural vulnerability. In J. Abel & A. Kellehear (Eds.), *Oxford textbook of public health palliative care* (pp. 197–208). Oxford University Press.

Quest, T. E., Periyakoil, V. S., Quill, T. E., & Casarett, D. (2021). Racial equity in palliative care. *Journal of Pain and Symptom Management*, *61*(3), 435–437. <https://doi.org/10.1016/j.jpainsymman.2020.12.005>

Rizzuto, J., & Aldridge, M. D. (2018). Racial disparities in hospice outcomes: A race or hospice-level effect? *Journal of the American Geriatrics Society*, *66*(2), 407–413. <https://doi.org/10.1111/jgs.15228>

Rosenberg, A. R., Bona, K., Coker, T., Feudtner, C., Houston, K., Ibrahim, A., Macauley, R., Wolfe, J., & Hays, R. (2019). Pediatric palliative care in the multicultural context: Findings from a workshop conference. *Journal of Pain and Symptom Management*, *57*(4), 846-855.e2. <https://doi.org/10.1016/j.jpainsymman.2019.01.005>

Sedhom, R., Nudotor, R., Freund, K. M., Smith, T. J., Cooper, L. A., Owczarzak, J. T., & Johnston, F. M. (2021). Can community health workers increase palliative care use for African American patients? A pilot study. *JCO Oncology Practice*, *17*(2), e158–e167. <https://doi.org/10.1200/OP.20.00574>

Sprik, P., & Gentile, D. (2020). Cultural humility: A way to reduce LGBTQ health disparities at the end of life. *American Journal of Hospice and Palliative Medicine®*, *37*(6), 404–408. <https://doi.org/10.1177/1049909119880548>

Stajduhar, K. I., Mollison, A., Giesbrecht, M., McNeil, R., Pauly, B., Reimer-Kirkham, S., Dosani, N., Wallace, B., Showler, G., Meagher, C., Kvakic, K., Gleave, D., Teal, T., Rose, C., Showler, C., & Rounds, K. (2019). “Just too busy living in the moment and surviving”: Barriers to accessing health care for structurally vulnerable populations at end-of-life. *BMC Palliative Care*, *18*(1), 11. <https://doi.org/10.1186/s12904-019-0396-7>

Umaretiya, P. J., Wolfe, J., & Bona, K. (2022). Naming the problem: A structural racism framework to examine disparities in palliative care. *Journal of Pain and Symptom Management*, *63*(5), e461–e463. <https://doi.org/10.1016/j.jpainsymman.2021.07.035>

Wen, Y., Jiang, C., Koncicki, H. M., Horowitz, C. R., Cooper, R. S., Saha, A., Coca, S. G., Nadkarni, G. N., & Chan, L. (2019). Trends and racial disparities of palliative care use among hospitalized patients with ESKD on dialysis. *Journal of the American Society of Nephrology*, *30*(9), 1687–1696. <https://doi.org/10.1681/ASN.2018121256>

Williams, D. R., Lawrence, J. A., & Davis, B. A. (2019). Racism and health: Evidence and needed research. *Annual Review of Public Health*, *40*(1), 105–125. <https://doi.org/10.1146/annurev-publhealth-040218-043750>

**IV. Palliative Care: From Human Right to Health Equity**

**A. Palliative Care as a Human Right**

Palliative care teams attend to the myriad needs (physical, psychological, social, cultural, and spiritual) of a person who is coping with serious illness. Palliative care is part of good health care, and all individuals who need it—no matter their age, diagnosis, culture, race, ethnicity, living conditions, or financial status—deserve quality palliative care.

**The World Health Organization (WHO) recognizes palliative care as a basic human right to health.**

“Palliative care needs to be provided in accordance with the principles of universal health coverage. All people, irrespective of income, disease type or age, should have access to a nationally-determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups” (WHO, 2020).

***REFLECTION QUESTIONS***

1. Why is the concept of palliative care as a health and human right important to seeking health equity?
2. How does the concept of palliative care as a health and human right change the perspective of care delivery?
3. How does the concept of palliative care as a health and human right change your commitment to your community?

|  |
| --- |
| **From Theory to Practice**If palliative care is a human right, what do you think are the implications for delivery of palliative care in the community?*Answers should include the following concepts:*Means palliative should be available to all individuals Equitable access for all individualsHealth policy should include palliative careInsurance to include palliative careMeans health infrastructure needs to be builtMore commitment to a communityHealth consumers need to understand the value of palliative care to accept palliative care |

**Section Reference**

World Health Organization. (2020, August 5). *Palliative care*. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

**B. From Human Right to Health Equity**

The philosophy that everyone deserves good health care for all promotes health equity (Artiga & Hinton, 2018). However, health equity is not one action, but a process and a guiding principle. After decades of advocacy, health equity has become a national priority in US health care. The Robert Wood Johnson Foundation put forth the following definition linking health equity to human rights: “Health equity is the ethical and human rights principle that motivates people to eliminate disparities in health and in the determinants of health that adversely affect excluded or marginalized groups” (Braveman et al., 2018).

Your palliative care program’s role in achieving health equity is based on good health care for all. To achieve that, it is important to consider the differences in the following definitions.

**Definitions**

**Health equity: “**Health equity is attainment of the highest level of health and healthy lives for all people. Achieving health equity requires valuing everyone equally, with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities” (Office of Disease Prevention and Health Promotion, n.d.).

**Health disparities: “**Preventable differences in the burden of disease, injury, violence, or opportunities to achieve

optimal health that are experienced by socially disadvantaged populations” (Centers for Disease Control and Prevention, 2020). Health disparities are the particular, preventable, differences in health outcomes based on social, economic, demographic, environmental, and geographic determinants. These include racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; gender expression or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion (i.e., structural racism; (Centers for Disease Control and Prevention, 2020).

**Health inequalities:** Health inequalities are the particular, preventable, differences in health outcomes based on health disparities. Health inequalities is a term sometimes used interchangeably with the term health disparities. It is more often used in the scientific and economic literature to refer to summary measures of population health associated with individual- or group-specific attributes (e.g., income, education, or race/ethnicity; Truman et al., 2011, p. 3).

**Health inequities: “**Health inequities are a subset of health inequalities that are modifiable, associated with social disadvantage, and considered ethically unfair” (Truman et al., 2011, p. 3).

In the context of palliative care, equity means:

1. *Who* receives palliative care services
2. *How* the palliative care team’s services are aligned with the unique needs of its patients

One way to measure this is using high-quality health care domains outlined by the Institute of Medicine (now known as the National Academy of Medicine [NAM]). In 2001, NAM outlined six domains of health care quality in its report [*Crossing the Quality Chasm: A New Health System for the 21st Century*](https://www.nap.edu/read/10027/chapter/1). This report codified equity as a necessary characteristic of high-quality care. The following table reviews the six NAM domains of high-quality health care, and crosswalks them to national palliative care quality standards of the NCP (National Consensus Project for Quality Palliative Care, 2018).

| **Domain** | **NAM Definition** | **Applicability to High-Quality Palliative Care**  |
| --- | --- | --- |
| **Safe** | Avoiding harm to patients from the care that is intended to help them. | Palliative care delivery is based on the patient’s goals of care and weighs the benefits and burdens of interventions according to the unique needs of the patient. Consideration is given to historical aspects of safe care and trust in the health system.  |
| **Effective** | Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively). | High-quality palliative care is delivered based on the evidence and research for specific populations and conditions. Palliative care assures all patients receive and have access to the standard of care for diagnosis and within treatment. Palliative care helps patients, family caregivers, and treating clinicians weigh the benefits and burdens on disease treatments.  |
| **Patient-Centered** | Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions. | The foundational principle of palliative care is to align care delivery with patients’ goals and values. Palliative care is patient-centered and family-focused with the understanding different populations may have different values about health, wellness, illness, dying, and death.  |
| **Timely** | Reducing waits and sometimes harmful delays for both those who receive and those who give care. | When appropriately resourced and integrated, palliative care delivery is based on the acuity of need and the priorities of the patient and family caregivers in their chosen community and site of care. It is responsive to patients’ changing needs over time. |
| **Efficient** | Avoiding waste, including waste of equipment, supplies, ideas, and energy. | Palliative care is delivered to patients with complex need and supports patients and family caregivers to clarify care goals and improve quality of life – which results in appropriate and efficient alignment of health care resources to care needs. |
| **Equitable** | Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status. | Palliative care is based on needs of all populations and individualized with regards to ethnicity, culture, age, gender (identity and expression), geography, and socioeconomic status.  |

**Table References**

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. National Academies Press. <http://www.ncbi.nlm.nih.gov/books/NBK222274/>

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). National Coalition for Hospice and Palliative Care. <https://www.nationalcoalitionhpc.org/ncp/>

***REFLECTION QUESTIONS***

Consider your answers to these questions, keeping in mind your responses to the pre-activity reflection questions:

1. How will or how does your program reach out to all eligible patients?
2. How will or how do you ensure your patients are treated equitably?
3. How will or how do you strive to develop a diverse and inclusive team?

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| **From Theory to Practice – Current Status of Health Equity in Your Program**Think about the National Academy of Medicine definition of equitable care (below). 1. What will or what does your program do to achieve equitable care? 2. In addition to what you’ll *do,* consider how you’ll measure your activities.

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| **Quality Domain** | **NAM Definition** | **NCP Strategy** | **Your Program Strategy** |
| **Equitable** | Providing care that does not vary in quality because of personal characteristics such as gender (identity or expression), ethnicity, geographic location, and socioeconomic status | Palliative care is based on needs of all populations and individualized with regards to ethnicity, culture, age, gender (identity and expression), geography, and socioeconomic status. |  |

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**Section References**

Artiga, S., & Hinton, E. (2018). *Beyond health care: The role of social determinants in promoting health and health equity*. Kaiser Family Foundation. <https://www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>

Braveman, P., Arkin, E., Orleans, T., Proctor, D., Acker, J., & Plough, A. (2018). What is health equity? *Behavioral Science & Policy*, *4*(1), 1–14. <https://doi.org/10.1353/bsp.2018.0000>

Centers for Disease Control and Prevention – Division of Community Health. (2013). *A practitioner’s guide for advancing health equity: Community strategies for preventing chronic disease*. US Department of Health and Human Services. <https://www.cdc.gov/nccdphp/dch/pdf/HealthEquityGuide.pdf>

Corburn, J. (2017). Urban place and health equity: Critical issues and practices. *International Journal of Environmental Research and Public Health*, *14*(2), 117. <https://doi.org/10.3390/ijerph14020117>

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. National Academies Press. <http://www.ncbi.nlm.nih.gov/books/NBK222274/>

National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in Action: Pathways to Health Equity*. National Academies Press. <https://doi.org/10.17226/24624>

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). National Coalition for Hospice and Palliative Care. <https://www.nationalcoalitionhpc.org/ncp/>

Office of Disease Prevention and Health Promotion. (n.d.). *Social determinants of health | Healthy People 2020*. Retrieved July 11, 2022, from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health/objectives>

Truman, B. I., Smith, K. C., Roy, K., Chen, Z., Moonesinghe, R., Zhu, J., Crawford, C. G., & Zaza, S. (2011). Rationale for regular reporting on health disparities and inequalities – United States. *MMWR*, *60*(Supplement), 3-10. <https://www.cdc.gov/mmwr/pdf/other/su6001.pdf>

U.S. Department of Health and Human Services. *Health Equity and Health Disparities Environmental Scan.* Rockville, MD: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Health, Office of Disease Prevention and Health Promotion; 2022. <https://health.gov/sites/default/files/2022-04/HP2030-HealthEquityEnvironmentalScan.pdf>

Centers for Disease Control and Prevention. (2020). *Division of Adolescent and School Health – Health disparities.* https://www.cdc.gov/healthyyouth/disparities/index.htm

U.S. Department of Health and Human Services, Office of Minority Health, National Partnership for Action. National Partnership to End Health Disparities – Toolkit for Community Action. (2011). <https://lucascountyhealth.com/wp-content/uploads/2016/07/NPA_Toolkit-for-Community-Action.pdf>

**C. Responsibility of Palliative Care Professionals**

The *NCP Clinical Practice Guidelines* articulate the need to identify marginalized, underserved, and underrepresented populations to assure equitable access to palliative care for all individuals. **Equity is a tenet of our field’s quality standards.**

In light of the data on inequity, *to do nothing means that we are complicit in continuing the structures that perpetuate health disparities among patients with serious illness.* Instead, we call on palliative care professionals to be part of the solution, and to continuously strengthen their practices and program structures to promote equity among the team, patients, and the community.

According to Stajduhar et al. (2019), “Current palliative care models must be re-envisioned to reach out and meet people where they reside. At the systems level, greater support for developing partnerships between medically-based palliative care professionals and community-based social service providers would serve to enhance access to and reduce barriers to quality palliative care” (p. 11).

What are the benefits of focusing on health equity?

* Establishment of trust and creation of a network within the community
* Identification of critical palliative care issues for patients in your community
* Prioritization of palliative care issues on the community’s health agenda
* Improvement of palliative care quality
* Expansion of palliative care services
* Enrichment of public awareness and positive regard of palliative care service
* Establishment of palliative care benchmarks for health equity

**Community Assessment as the First Step:**

The first step toward health equity is to understand the community you serve. The process of a community assessment includes mapping the medical and social determinants of health in your community, and identifying resources and community partners who can address gaps in care for patients with serious illness. Of note, some health care organizations that receive federal funding require an annual community assessment. Check to see if this is true for your organization.

***REFLECTION QUESTION***

Respond to the following question based on what you know about your program and your pre-activity reflection questions, but without starting an assessment.

* + 1. How do your palliative care program’s mission and vision statements address health equity? If they do *not* reflect equity, how will you address this?

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| **From Theory to Practice – Application of Health Equity Terms to Your Community****Health equity:** Is there equitable access to palliative care in your community?**Health disparities:** Are there patient groups with serious illnesses who experiencing disparity in access to quality palliative care in your community?**Health inequalities:** Does your program or organization have outcomes or measures that lead you to believe there are health inequalities in palliative care?**Health inequities:** What health inequities exist in the current population of patients or the communities you serve? |

**Section References**

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). National Coalition for Hospice and Palliative Care. <https://www.nationalcoalitionhpc.org/ncp/>

Stajduhar, K. I., Mollison, A., Giesbrecht, M., McNeil, R., Pauly, B., Reimer-Kirkham, S., Dosani, N., Wallace, B., Showler, G., Meagher, C., Kvakic, K., Gleave, D., Teal, T., Rose, C., Showler, C., & Rounds, K. (2019). “Just too busy living in the moment and surviving”: Barriers to accessing health care for structurally vulnerable populations at end-of-life. *BMC Palliative Care*, *18*(1), 11. <https://doi.org/10.1186/s12904-019-0396-7>

**V. Understanding the Community to Promote Health Equity**

Because palliative care is a collaborative interprofessional practice, a palliative care program can use these same skills of effective teamwork to create partnerships with the community.

The National Academies of Science, Engineering, and Medicine (NASEM) offer a guide to health equity that is useful for palliative care programs. It is based on an understanding that there are multiple approaches to making health equity a shared vision and value through community-based solutions. Per NASEM (2017), successful health equity initiatives often have three features that palliative care programs can integrate into their overall strategy:

1. A shared sense of urgency to address health equity specific to palliative care, and a commitment to involve the community when designing solutions
2. A clearly articulated shared purpose and set of values around equity for the palliative care organization, program, team and individual palliative care professionals
3. A trusted and respected champion to guide the process, who is committed to the addressing the effects of social determinants of health and to applying this concept to palliative care

The following sections will build upon an understanding of health care as a human right, and the principles that underpin health equity, to create a sense of necessity and urgency in working towards health equity. The first step to developing a health equity strategy for the palliative care team is to understand the characteristics of the community—and the key to this process is listening to community-identified needs, rather than telling the community what it needs.

**Section Reference**

National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in action: Pathways to health equity*. National Academies Press. <https://doi.org/10.17226/24624>

**VI. Foundation to Understanding a Community: Social Determinants of Health**

*Community* is defined here as a unified body or configuration of individuals, families, or groups linked by social ties or relations, values, common perspectives, interests, or geography. Often a community represents both the people living in a place and the place itself (NASEM, 2017).

For the purposes of palliative care, *community* includes individuals living in a particular area, sharing a similar ethnicity, race, religious affiliation or sexual identity, or having a similar diagnosis. All communities will have different needs and experiences with serious illness, and the responsibility of the palliative care programs is to assure that each group has equitable access to palliative care that accounts for its different characteristics. A one size fits all palliative care approach will not work, as demonstrated by the lack of diversity in the palliative care literature.

The term *social determinants of health* (SDoH) refers to the non-medical aspects of one’s life that affect health, wellness, illness, and death. The goal of SDoH is to move beyond a biomedical model of health care and acknowledge the complexity of an individual or community as being a constellation of physical, emotional, psychological, spiritual, cultural, and social beings—similar to the many domains of palliative care. The concept of social determinants is *not* intended to perpetuate assumptions or stereotypes about populations, but rather to acknowledge that individuals are multi-faceted; the consideration of SDoH promotes an understanding of the human condition.

Each community is unique and encompasses unique SDoH. In one community, there may be a high rate of poverty and homelessness meaning that individuals cannot afford health care or the transportation to access it. A palliative care program could then plan to work with a local clinic on a central bus line and create a process for affordable medications to manage palliative care issues. Another community may lack a pharmacy or grocery stores, making it difficult for patients to fill prescriptions or eat healthy food.

Palliative care teams cannot make assumptions about the communities they serve. To understand a community, teams must learn about the opportunities and barriers to health and well-being, including health care access, use of quality health services, and the SDoH (Singh et al., 2017).

**Section References**

National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in action: Pathways to health equity*. National Academies Press. <https://doi.org/10.17226/24624>

Singh, G., Daus, G., Allender, M., Ramey, C., Martin, E., Perry, C., Reyes, A., & Vedamuthu, I. (2017). Social determinants of health in the United States: Addressing major health inequality trends for the nation, 1935-2016. *International Journal of MCH and AIDS (IJMA)*, *6*(2), 139–164. <https://doi.org/10.21106/ijma.236>

**A. Definitions and Models of Social Determinants of Health**

Many organizations have considered social determinants of health (SDoH); however, there is no consensus on its definition. Each definition below is put forth by a major health care organization of influence, and each highlights different principles.

The World Health Organization states that the SDoH are the wider set of forces and systems shaping the conditions of daily life in which people are:

1. **Born**
2. **Grow**
3. **Work**
4. **Live**
5. **Age**

These forces and systems include economic policies and systems, development agendas, social norms, social policies, and political systems. This model emphasizes how social determinants influence health equity, well-being, and quality of life while dealing with a serious or life-limiting illness (WHO, n.d.).

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| **From Theory to Practice – Application of the WHO Model**In the WHO model, the palliative care program considers the communities they serve and do not serve, and where potential patients live, work, and age.How would your program use these 5 indicators to inform palliative care planning or program development? |

The Centers for Disease Control and Prevention (CDC) describes five broad SDoH within a population:

1. **Biology and genetics** *(e.g., sex and age)*
2. **Individual behavior** *(e.g., alcohol use, injection drug use [needles], unprotected sex, and smoking)*
3. **Social environment** *(e.g., discrimination, income, and gender)*
4. **Physical environment** (*e.g., where a person lives or crowded living conditions)*
5. **Health services** (*e.g., health insurance status and access to quality health care)*

This model of determinants emphasizes the individual with serious illness more than the community itself. Biology and genetics and individual behavior influence the types of serious illnesses an individual or population may develop. The physical environment may exacerbate or alleviate suffering from a serious illness, health services may affect how an illness is assessed and managed, and the social environment may influence how the individual or population manages or copes with the serious illness (CDC, 2010).

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| **From Theory to Practice – Application of the CDC Model**In the CDC model, the palliative care program considers the diversity of the patients they do and do not serve, including individuals who may vary by: gender, gender identity and expression and age; populations at risk (e.g., individuals with liver disease, HIV, pulmonary diseases); race; socioeconomic status and location; dwellings (e.g., homelessness, group homes, prisons); and those uninsured or underinsured. How would your program use these 5 categories to make a plan for more equitable palliative care services? |

Healthy People 2020 (Office of Disease Prevention and Promotion, n.d.) defines SDoH using a “place-based” framework:

SDoH are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. This includes five key areas:

1. **Economic Stability**
2. **Education**
3. **Social and Community Context**
4. **Health and Health Care**
5. **Neighborhood and Built Environment**

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| **From Theory to Practice – Application of the Healthy People Model**In the Healthy People model, the palliative care program considers the patients they serve and may not be serving in terms of financial stability and immigration status, education, religion, location of housing, and neighborhoods.How would your program use these 5 conditions to create a more inclusive palliative care program and services? |

The National Academies of Sciences, Engineering, and Medicine (NASEM, 2017) offers another view of SDoH related to health equity which focuses on 8 characteristics:

1. **Physical Safety**
2. **Social Environment**
3. **Transportation**
4. **Education**
5. **Employment**
6. **Health Systems and Services**
7. **Housing**
8. **Income and Wealth**

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| **From Theory to Practice – Application of the NASEM Model**In the NASEM model, the palliative care program considers the resources and stability within the community where patients live.How would your program use these 8 characteristics to collaborate with the community to create palliative care services that meets the needs of the community? |

***REFLECTION QUESTIONS***

1. How has your program considered the SDoH in the care for your patients?
2. Which model of SDoH best suits your community and its needs?

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| **From Theory to Practice – Social Determinants of Health**Which definition of SDoH resonates the most for you in terms of palliative care, and why? |

**Section References**

Centers for Disease Control and Prevention. (2010). *Establishing a holistic framework to reduce inequities in HIV, viral hepatitis, STDs, and tuberculosis in the United States: An NCHHSTP white paper on social determinants of health, 2010*. US Department of Health and Human Services. <https://doi.org/10.1037/e584282012-001>

National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in action: Pathways to health equity*. National Academies Press. <https://doi.org/10.17226/24624>

Office of Disease Prevention and Health Promotion. (n.d.). *Social determinants of health | Healthy People 2020*. Retrieved July 11, 2022, from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health/objectives>

World Health Organization. (n.d.). *Social determinants of health*. Retrieved July 11, 2022, from <https://www.who.int/health-topics/social-determinants-of-health>

**B. Social Determinants of Health within Palliative Care**

The [National Consensus Project for Quality Palliative Care Clinical Practice Guidelines (4th Edition)](https://www.nationalcoalitionhpc.org/ncp/) delineates the domains of palliative care: physical, psychological, cultural, social, and spiritual. Although social determinants of health are emphasized throughout the NCP Guidelines, two domains specifically address this:

Domain 4: Social Aspects of Care states: “*Social determinants of health, hereafter encompassed in the term “social factors,” have a strong and sometimes overriding influence on patients with a serious illness. Palliative care addresses environmental and social factors that affect patient and family functioning and quality of life” (Guideline 4).*

Domain 6: Cultural Aspects further address the responsibilities of the team: “*The IDT delivers care that respects patient and family cultural beliefs, values, traditional practices, language, and communication preferences and builds upon the unique strengths of the patient and family. Members of the IDT work to increase awareness of their own biases and seek opportunities to learn about the provision of culturally sensitive care. The care team ensures that its environment, policies, procedures, and practices are culturally respectful” (Guideline 6.1).*

There is no gold standard tool for health care organizations to identify the social determinants of health for the communities they serve. However, viewing a community through the lens of SDoH allows for a more comprehensive awareness of the needs and perspectives of its patients. LaForge and colleagues (2018) state that understanding SDoH:

1. Improves health care teams' ability to understand the “upstream” factors impacting their patients' health and ability to act on care recommendations;
2. Informs clinical care decisions; and
3. Identifies patients in need of referral to community resources to address identified needs.

Identifying SDoH could also inform the funding and provision of community resources. The Centers for Medicare and Medicaid Services (CMS) is testing a 10-item screening tool to identify patient needs in 5 different domains that can be addressed through community services (housing instability, food insecurity, transportation difficulties, utility assistance needs, and interpersonal safety; Billioux et al., 2017).

The bottom line: High-quality palliative care delivery reflects the context of the community in which the individual with serious illness lives and works – or the social determinants.

***REFLECTION QUESTIONS***

1. What do you perceive to be the SDoH that most often cause lack of access to quality palliative care in your community?
2. How does your program account for an individual’s SDoH in a clinical encounter?

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| **From Theory to Practice – Case Example**Martin is a 45-year-old man with a history of serious mental illness and a new diagnosis of advanced colon cancer. He lives in a group home where there are 10 other people supported by the group home director and social worker. He is insured by the state Medicaid plan because he has been unable to work due to his mental illness. His community social worker, who supports his PCP, has referred Martin to your palliative care program. Your palliative care clinic coordinator calls the group home to schedule an appointment with the group home director. The group home is an hour away from the clinic and Martin doesn’t trust people or like to be in crowds. Martin misses the first appointment. Which social determinants are the *most important in considering in how you will assist* Martin in traveling to the palliative care clinic?Check the categories below:[ ]  Identity, culture, ethnicity[ ]  Religious practice and spirituality[ ]  Family/Social Support [ ]  Employment/Occupation [ ]  Financial Security[ ]  Access to food[ ]  Access to medications and healthcare [ ]  Education and health literacy [ ]  Environmental [ ]  Housing [ ]  Medical/Insurance [ ]  Transportation *Case Example:* Beh is 65-year-old woman who was born in Thailand who has advanced heart failure and obesity. Over the years, Beh worked at multiple jobs to support her family. Beh lives alone in public housing and has health care assistance from the state. Beh has been referred to your home-based palliative care program by the cardiologist. The palliative nurse does a home visit and finds Beh eating many prepared and processed foods and not taking her prescribed medications. Which social determinants are the *most important to creating a successful palliative care plan* related to managing her heart failure?Check the categories below:[ ]  Identity, culture, ethnicity – to understand how she views illness[ ]  Religious practice and spirituality[ ]  Family/Social Support – to determine if she has support[ ]  Employment/Occupation [ ]  Financial security – to understand if she had the ability to pay for treatment and medications and transportation. [ ]  Access to food – to assist with nutritional planning[ ]  Access to medications and healthcare – to help with treatments[ ]  Education and health literacy – to determine her understanding of her illness[ ]  Environmental[ ]  Housing[ ]  Medical/Insurance – to understand what is covered by her insurance[ ]  Transportation – to determine how she will travel to appointments*Answers:* Martin’s most important social determinants in this situation are: * Family/Social Support – to be able to cope with his condition
* Financial Security – to be able to pay for treatment and medications
* Education and health literacy – to be able to understand his condition and possible treatments
* Environmental – to be able to have a therapeutic environment to cope with his condition
* Housing – to be able to have a safe place so as to focus on treatment
* Medical/Insurance – to pay for treatments and medications and home nursing
* Transportation – to be able to travel to appointments

Beh’s most important social determinants in this situation are:* Identity, culture, ethnicity – to understand how she views illness
* Family/Social Support – to determine if she has support
* Financial security – to understand if she had the ability to pay for treatment and medications and transportation.
* Access to food – to assist with nutritional planning
* Access to medications and healthcare – to help with treatments
* Education and health literacy – to determine her understanding of her illness
* Medical/Insurance – to understand what is covered by her insurance
* Transportation – to determine how she will travel to appointments
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**Section References**

Billioux, A., Verlander, K., Anthony, S., & Alley, D. (2017). *Standardized screening for health-related social needs in clinical settings: The accountable health communities screening tool*. National Academy of Medicine. <https://nam.edu/standardized-screening-for-health-related-social-needs-in-clinical-settings-the-accountable-health-communities-screening-tool/>

LaForge, K., Gold, R., Cottrell, E., Bunce, A. E., Proser, M., Hollombe, C., Dambrun, K., Cohen, D. J., & Clark, K. D. (2018). How 6 organizations developed tools and processes for social determinants of health screening in primary care: An overview. *Journal of Ambulatory Care Management*, *41*(1), 2–14. <https://doi.org/10.1097/JAC.0000000000000221>

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). National Coalition for Hospice and Palliative Care. <https://www.nationalcoalitionhpc.org/ncp/>

**C. Initial Demographic Lens into Social Determinants of Health in Your Community**

To begin examining and understanding the particular social determinants of your state and county, it is important to look at nationally curated data. Currently no free, publicly available, federal data sets offer information on many of the SDoH that are important in the context of palliative care. However, in this exercise we will focus on the Centers for Disease Control and Prevention, which provides free data on uninsured status, households living below the federal poverty level, population living in a rural area, and urbanization level. Use the steps below to explore the social determinants in your area.

**Exercise:**

*Go to Centers for Disease Control and Prevention –* [*NCHHTP AtlasPlus*](https://www.cdc.gov/nchhstp/atlas/)

* STEP 1: Select button for ‘Social Determinants of Health.’
* STEP 2: Select ‘How you would like the data presented—in a chart, maps, and tables’. You may want to start with tables. You will be connected to a CDC website with 4 boxes.
* STEP 3: Under ‘Indicator’ you have a choice between ‘Disease’ and ‘Social Determinants of Health,’ choose ‘Social Determinants of Health.’
* STEP 4: When ‘Social Determinants of Health’ is chosen, 6 check boxes appear underneath. Choose these two: Uninsured and Households living below the federal poverty level. If you choose ‘Population living in a rural area’—you can only choose that.
* STEP 5: Press NEXT button on the bottom right.
* STEP 6: Select National, State or County, follow the drop-down to select your state.
* STEP 7: Press NEXT button on the bottom right.
* STEP 8: It will then ask about a data range (in years)—click that square.
* STEP 9: Press NEXT to generate your data. Review the information and note that you can also save the results of your search.

***REFLECTION QUESTIONS***

1. Were you surprised by the numbers of uninsured persons, population over 25, or households living below the federal poverty level in your community?
2. How does this information inform your thoughts on the health care and palliative care services needed in your area?

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| **From Theory to Practice – Using the Data to Examine Your Program**Compare the Atlas Plus data to your program. In your quick assessment and review of the website data, consider the following:1. What populations are being well-served by your palliative care program?
2. Which populations need to be better served by your palliative care program?
3. How will you advocate for these improvements?
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**Section References**

Centers for Disease Control and Prevention. (2021, October 27). *NCHHSTP AtlasPlus*. <https://www.cdc.gov/nchhstp/atlas/index.htm>

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). National Coalition for Hospice and Palliative Care. <https://www.nationalcoalitionhpc.org/ncp/>

**VII. Social Determinants of Health and Palliative Care Community Mapping**

In the previous section, SDoH were defined as well as a process of examining demographics. This section now uses that data to perform community mapping.

Community mapping is the use of technology to identify, analyze, understand, and disseminate community issues to deliberately work on social issues such as education and health. Community mapping—sometimes referred to as environmental scanning—uses spatial data to analyze community issues and assets, and to develop strategies for change around a particular topic like health or health equity (Solar & Irwin, 2010). Although community mapping is often used in other sectors like business, marketing, education, and overall health, it has not been commonly used in palliative care. Yet, the use of community mapping is essential for promoting equity within palliative care—it changes the lens to help palliative care teams better understand their patients’ lived experiences within their community.

Ideally, this process is driven by the community or by underrepresented groups (i.e., a group of community members collect the data), which can spur innovation and action (Corburn, 2017).

The community mapping process identifies the characteristics or gaps that dictate a community’s ability to support people with serious illness and assists palliative care programs to meet patient and family needs. The information gleaned from the process assists an organization align resources and policies to ensure quality care, and promotes the creation of partnerships with mutual goals, strategies, and expected outcomes. It also supports the creation of a strategic plan to improve the alignment, coordination, and delivery of services.

The process of community mapping includes identifying the demographics of a community as well as the social determinants of health. If the goal is to develop equitable community-based palliative care, community mapping provides an understanding of the unique aspects of a community in terms of chronic illness, access to care, and population demographics. Insight into a community’s existing partnerships and programs, resource allocations and policies, and priorities and assets can help evaluate its ability to care for individuals with serious illness and their families. Community mapping can reveal new information to palliative care programs about marginalized, underserved, and underrepresented populations—and about potential service partners. When combined with this community information, resource maps can provide a comprehensive picture of a community’s infrastructure to support comprehensive palliative care.

The five ways community mapping within palliative care can be beneficial are:

1. Determine the baseline level of palliative care penetration within populations, communities, or neighborhoods
2. Evaluate strategies and interventions to align and coordinate community resources to improve care of individuals with serious illness (i.e., clinical provider organizations and social service organizations)
3. Identify populations with serious illness who are not yet being served by palliative care
4. Identify new partners to deliver palliative care within a community
5. Develop new policies and legislation to better meet goals and objectives (Enterprise Center at Salem State University, 2016)

Using these aims, you will be able to measures and evaluate outcomes of wider coordination and collaboration of stakeholders to improving care of individuals with serious illness and health equity initiatives

***REFLECTION QUESTIONS***

* + 1. What communities (by geography, demographics or population health) have you previously mapped to develop your palliative care program’s health equity strategy?
		2. If you have not previously performed some sort of community mapping, what communities do you observe that you would need to map to develop your palliative care program’s health equity strategy?
		3. What communities do you need to map to help your program consider health equity?

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| **From Theory to Practice – Using Community Mapping to Create Priorities**Consider the 5 benefits of community mapping for your program. Which two benefits are the highest priority for your program? |

**Section References**

Corburn, J. (2017). Urban place and health equity: Critical issues and practices. *International Journal of Environmental Research and Public Health*, *14*(2), 117. <https://doi.org/10.3390/ijerph14020117>

Enterprise Center at Salem State University. (2016, August 30). *Community Mapping*. <https://enterprisectr.org/blog/community-mapping/>

Solar, O., & Irwin, A. (2010). *A conceptual framework for action on the social determinants of health. Social determinants of health discussion paper 2 (policy and practice).* World Health Organization. <http://apps.who.int/iris/bitstream/handle/10665/44489/9789241500852_eng.pdf>

**VIII. Community Mapping: Understanding the Demographics of Your Community**

Understanding the demographics of your palliative care population of where you provide services is essential to delivering effective, high-quality care. Your perceptions may differ depending on whether you live in the community in which your patients live and work.

If you are part of a cancer center, hospital, or health system, you may already have access to some data about patient demographics, patient access, or patient diversity. You may also have data from state departments of health. However, it is also important to map local census data as well as other social determinants of health such as employment data, poverty levels, insurance coverage data, and the like to better understand the community you serve.

Using the categories set forth by the U.S. Census Bureau, fill in your quick guesstimates of 1) the demographics of the patients you serve within the community you serve, 2) your palliative care staff, and 3) your organization.

**Exercise 1: Perceptions of the Demographics of Your Palliative Care Program and the Community You Serve**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Overall numbers of individuals** | **Percent****American Indian or Alaska Native** | **Percent****Asian** | **Percent****Black or African American** | **Percent****Hispanic/****Latino** | **Percent** **Native Hawaiian or Other Pacific Islander** | **Percent****White** |
| Service Area/Region |  |  |  |  |  |  |  |
| Patients Your Palliative Program Serves |  |  |  |  |  |  |  |

**Exercise 2: Realities of the Demographics of Your Palliative Care Program and the Community You Serve**

Use the following data sources to look up the actual demographics in your area:

1. By zip codes – [UnitedStatesZipCodes.org](https://www.unitedstateszipcodes.org/)
2. For overall state demographics – [World Population Review](https://worldpopulationreview.com/states/states-by-race)
3. **Note: Save the information by a snapshot of the webpage or saving as a PDF**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Overall numbers of individuals** | **Percent****American Indian or Alaska Native** | **Percent****Asian** | **Percent****Black or African American** | **Percent****Hispanic/****Latino** | **Percent** **Native Hawaiian or Other Pacific Islander** | **Percent****White** |
| Service Area/Region |  |  |  |  |  |  |  |
| Patients Your Palliative Program Serves |  |  |  |  |  |  |  |

***REFLECTION QUESTIONS***

* + 1. Are the demographics of your community and region what you expected?
		2. How does this change the perspective of whether your program is reaching out to all populations, and what communities you may need to foster relationships with (e.g., faith-based entities, community centers, or social service providers)?

**Exercise 3: Examining the Demographics of the Communities You Serve**

Staff diversity is important as well. Although most of the literature focuses only on physicians, there seem to be indications that racial concordance or the shared culture between a palliative care professional and a patient affects patient satisfaction, clinician-patient communication, partnership building, and collaboration for all disciplines (Shen et al., 2018; Takeshita et al, 2020). Examples include an Indigenous clinician and an Indigenous patient, a Latina clinician with a Latina patient, or a Black clinician with a Black patient.

Match the demographic data of your community or the community your program serves to your palliative staffing data, which includes your palliative care team and leadership.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Overall numbers of individuals** | **Percent****American Indian or Alaska Native** | **Percent****Asian** | **Percent****Black or African American** | **Percent****Hispanic/****Latino** | **Percent** **Native Hawaiian or Other Pacific Islander** | **Percent****White** |
| Service Area/Region |  |  |  |  |  |  |  |
| Patients Your Palliative Program Serves |  |  |  |  |  |  |  |
| Palliative Care Team  |  |  |  |  |  |  |  |
| Palliative Care Leadership |  |  |  |  |  |  |  |

***REFLECTION QUESTIONS***

1. Was the data a surprise? Or did the data confirm your hypothesis about your community or the community you serve?
2. What is the explanation for whether your program demographics match or do not match the demographics of the community you serve?

|  |
| --- |
| **From Theory to Practice – Mapping Perception of Demographics to Reality of Demographic to the Community You Serve**How do your community demographics match the demographics of your organization and your program?How does this data inform your thinking about next steps? |

**Exercise 3A (Optional): Taking the Data a Step Further to Examine the Demographics of Your Organization or Health System’s Staff**

Obtain the demographic data from your palliative program data and your team.

|  | **Overall numbers of individuals** | **Percent****American Indian or Alaska Native** | **Percent****Asian** | **Percent****Black or African American** | **Percent****Hispanic/****Latino** | **Percent** **Native Hawaiian or Other Pacific Islander** | **Percent****White** |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Service Area/Region |  |  |  |  |  |  |  |
| Parent Organization  |  |  |  |  |  |  |  |
| Governing Body/Board of the Organization (Board of Directors, Board of Trustees, Advisory Board)  |  |  |  |  |  |  |  |
| Executive Leadership Staff of the Organization (CEO, CFO, COO, CMO, CNO, Directors, Managers, Administrative Staff) |  |  |  |  |  |  |  |
| Clinical Palliative Care Staff (RNs, APRNs, MDs, DOs, PAs, SWs, Chaplains, Nursing/Medical Assistants, Pharmacists, PTs, OTs, SLPs, Art Therapists, Child Life Specialists)  |  |  |  |  |  |  |  |
| Other clinical staff  |  |  |  |  |  |  |  |
| Non-Clinical Staff (Financial Service, Billing) |  |  |  |  |  |  |  |
| Volunteers |  |  |  |  |  |  |  |

|  |
| --- |
| **From Theory to Practice – Applying Equity to Your Team Composition**What do the demographics of your workforce indicate to you about your team and your organization’s commitment to provide equitable care? Why should the staff reflect the populations you serve? Why does staff diversity matter? |

**Exercise 4: Use Additional Databases to Get More Information About Your State and Community**

There is no single website that provides all demographic data for your community. Different databases offer specific facts and figures that, taken together, give a more comprehensive understanding the characteristics of patients you serve or aim to serve. Below are two federal websites you can use to better understand the demographics, health, income, and poverty levels within your community.

Knowing what you know about social determinants of health, consider what information would help you ensure that you are meeting the needs of your community:

1. Are the people who need your services the people that your program is focused on reaching?
2. Are there populations with specific conditions or diseases who need palliative care services, but are not represented among the patients you serve?

**Database 1: The United States Census Bureau**

Go to the [*United States Census Bureau*](https://data.census.gov/cedsci/map?q=United%20States&tid=PEPPOP2019.PEPANNRES&mode=thematic&vintage=2019&cid=POP)



*Select your state to get the following information:*

1. People and Population
2. Race and Ethnicity
3. Families and Living Arrangements
4. Health
5. Education
6. Business and Economy
7. Employment
8. Housing
9. Income and Poverty

*Dig deeper to get county-level data for the area your serve.*

**Database 2:** [**Health Equity Tracker**](https://healthequitytracker.org/exploredata)

1. Click the button that says Investigate Data
2. Examine data categories including COVID-19, COPD, Diabetes, Poverty, and Uninsured Individuals by city, county, and state
3. Note that the tracker provides the information broken down by race and ethnicity

**Database 3:** [**Racial Equity Index**](https://nationalequityatlas.org/research#reindex)

The new Racial Equity Index—available for all geographies in the Atlas—allows you to track how well your community is doing on a set of nine equity indicators compared with other communities (and over time). The index summarizes an inclusion score (which measures racial disparities on nine indicators) and a prosperity score (which measures overall performance levels on those same indicators) and can be further broken down into its components to help you identify the most important challenges and areas of progress to develop targeted equity strategies. You can also examine the prosperity score for each of six major racial/ethnic groups. Here is how to access the index:

* + 1. Go to the [Racial Equity Index](https://nationalequityatlas.org/research#reindex) in the Research section of the National Equity Atlas
		2. Go to [Racial Equity Index: Summary](https://nationalequityatlas.org/research/racial_equity_index/index#/)
		3. Choose your geography type (Nation, State, Region, City)
		4. Choose your geography from the dropdown menu
		5. Explore the data
		6. Go back to [Racial Equity Index](http://nationalequityatlas.org/research#reindex) to examine the Prosperity scores for the Black, Latinx, Native American, Asian or Pacific Islander, Mixed/other race, and White Populations.

Another free, reliable map is: [Kaiser Family Foundation Map - Population Distribution by Race/Ethnicity](https://www.kff.org/other/state-indicator/distribution-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D)

You can look at this map to get more information about your state demographics overall.

***REFLECTION QUESTION***

1. How has this information shaped your perspective on your palliative care program and its goal for increased health equity?

|  |
| --- |
| **From Theory to Practice – Applying Findings to Future Initiatives**From the review of the US Census Bureau information and the Health Equity Tracker, which health initiatives could you focus on to move equity in palliative care forward? |

**Section References**

Shen, M. J., Peterson, E. B., Costas-Muñiz, R., Hernandez, M. H., Jewell, S. T., Matsoukas, K., & Bylund, C. L. (2018). The effects of race and racial concordance on patient-physician communication: A systematic review of the literature. *Journal of Racial and Ethnic Health Disparities*, *5*(1), 117–140. <https://doi.org/10.1007/s40615-017-0350-4>

Takeshita, J., Wang, S., Loren, A. W., Mitra, N., Shults, J., Shin, D. B., & Sawinski, D. L. (2020). Association of racial/ethnic and gender concordance between patients and physicians with patient experience ratings. *JAMA Network Open*, *3*(11), e2024583. <https://doi.org/10.1001/jamanetworkopen.2020.24583>

**IX. Asset Mapping: Coordinating Efforts to Meet the Needs of Your Community**

**Asset mapping is information about the strengths and resources of a community to help uncover solutions to address a to a need or concern.**

Asset mapping is a process that identifies existing assets that can be brought to bear to support patients and families, providing community leaders with information to make strategic decisions. It helps map a community in terms of its wealth of resources in people, things, services, talents, space, and materials (Dorfman, 1998).

Assets can be used as starting points for coordinating or consolidating efforts around a particular issue or service (WHO, n.d.).

**What are assets in a community?**

**What do they bring to the effort to achieve health equity?**

**Examples of assets include the following:**

|  |  |  |
| --- | --- | --- |
| **Local Government** | **Organizations** | **Health Organizations** |
| * Federal Agencies
* Community health organizations such as hospitals or clinical centers
* State health departments and other state agencies
* Local government health agencies and other local government agencies
* Networks such as interagency councils
* Libraries
* Recreational and Community Centers
 | * Civic organizations
* Community interest groups or cultural centers
* News media
* Volunteer organizations
* Professional organizations or foundations
* Private organizations
* Local businesses
* Educators and academic institutions
* Designated Senior Centers
* Sports clubs
 | * Voluntary health organizations
* Health Care Providers which may include:
	+ Federally Qualified Health Centers (FQHCs)
	+ Primary Care Providers (PCPs)
	+ Home Health Agencies
	+ Hospice Agencies
	+ Clinics or Office based Practices
	+ Skilled Nursing Facilities/Nursing Facilities
	+ Assisted Living
	+ Hospitals
	+ Health systems
 |

**Asset Considerations**

Geographic considerations and state laws related to palliative care (i.e., a mandate for palliative care access for Medicaid beneficiaries, or state advance care planning requirements) may affect community mapping and are of key importance for palliative care teams. There are local, state, regional and national differences based on the community and its assets/resources. **For up-to-date information about legislation relevant to palliative care in your state, refer to the** [**Yale Palliative Care GPS**](https://palliativecarelawandpolicy.yale.edu/) **(co-developed with CAPC), as well as the** [**State Palliative Care Forum**](https://3.basecamp.com/3415480/join/sVxSpzwnBcEB/accesses/new) **and** [**CAPC’s State Policy page**](https://www.capc.org/toolkits/palliative-care-state-policy/)**.**

Examples of state mandates for 2 rural programs:

* Consider a rural program situated in South Carolina where overall the population lives at a lower socioeconomic status, but there is no state mandate for palliative care, and there is low access to community-based palliative care with little reimbursement for it.
* Consider a program in rural California where the overall population lives at a higher socioeconomic status, there is a state-funded mandate for palliative care services, and there is more access to community-based palliative care with optimal reimbursement for it.

***REFLECTION QUESTIONS***

1. What types of entities have your palliative care program considered to be assets?
2. What are new types of entities could you consider as assets?

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **From Theory to Practice – Asset Mapping**Exercise: Fill in the grid with the with organization, association, and individual assets in your community that could be helpful to ensure palliative care is serving patients that reflect the range of demographics in your community, and that respond to the social determinants you’ve identified.

|  |  |  |
| --- | --- | --- |
| **Organizations** | **Associations** | **Individuals** |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

***Now consider each organization you listed and the type of asset(s) it brings.***

|  |  |
| --- | --- |
| **Organizations** | **Type of asset(s) they bring:** ***Vision, Membership, Funding, Shared Knowledge, Influence, Structure, Human Resources, Buildings*** |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |

***Now consider each association you listed and the type of asset(s) it brings.***

|  |  |
| --- | --- |
| **Association** | **Type of asset(s) they bring:** ***Leadership, Funding, Services, Influence, Power, Staff time, Knowledge and Expertise, Capacity for Change*** |
|  |  |
|  |  |
|  |  |
|  |  |

***Now consider each individual you listed and what asset(s) that individual brings.***

|  |  |
| --- | --- |
| **Individual** | **Type of asset(s) they bring:** ***Talent, Passion, Time, Skills, Experience, Knowledge*** |
|  |  |
|  |  |
|  |  |
|  |  |

 |

**Section References**

Burns, J. C., Paul, D. P., & Paz, S. R. (2012). *Participatory asset mapping: A community research lab toolkit*. <https://communityscience.com/wp-content/uploads/2021/04/AssetMappingToolkit.pdf>

Dorfman, D. (1998). *Mapping community assets workbook*. Northwest Regional Educational Laboratory. <https://eric.ed.gov/?id=ED426499>

World Health Organization. (n.d.). *Asset mapping*. Retrieved July 11, 2022, from <https://extranet.who.int/agefriendlyworld/afp/asset-mapping/>

**X. Integrating Community Mapping Data and Asset Mapping into Strategic Action for Equitable Palliative Care Delivery**

Solving a public health problem like health equity extends beyond the reach, resources, and mandate of any single agency, organization, or program. Partnerships and collaborations are essential because they can effect long-term change (Centers for Disease Control and Prevention – Division of Community Health, 2013).

Using a partnership approach helps your program:

* Provide responsive and appropriate service delivery to a community.
* Ensure that service delivery is informed and guided by community interests, expertise, and needs.
* Increase use (and therefore impact) of palliative care services by engaging individuals and groups in the community in the design and quality improvement of services.
* Create a team and organizational culture that leads to more responsive, efficient, and effective service delivery and accountability to the community; and
* Empower members of the community to be active participants in health.

**A. Strategic Planning to Achieve Health Equity**

Palliative care programs should consider creating a strategic plan for health equity.

This includes the following steps (adapted from Association for Community Health Improvement, 2017):

1. Forming a palliative care equity advisory committee that reflect diversity and inclusion
2. Creating your mission and vision of health equity for individuals with serious illness
3. Creating a strategic plan for health equity for individuals with serious illness
4. Collect and analyze your data from community mapping to guide decision making about individuals with serious illness
5. Making some hypotheses about the communities your serve and the community, based on your community mapping
6. Prioritizing your patient populations and their needs about having a serious illness
7. Reflecting and strategizing where your program will be most effective for individuals with serious illness
8. Identifying and engaging stakeholders in the community based on your asset mapping information
9. Creating community partnerships and collaborations to better care for all individuals with serious illness
10. Mutually developing and implementing strategies with those partners and collaborators
11. Evaluating your progress on palliative care health equity and iterating your plan over time

The organizational planning and priority-setting process is a clearly defined approach taken to define the goals and objectives of a population health improvement initiative—both within an organization/team, and across organizations or groups that will collaborate (National Quality Forum, 2016).

**B. Developing an Equity Strategic Plan**

Throughout this learning activity, you’ve gathered more information about your community and the necessary information to create a strategy. Now it is time to make a plan to ensure your palliative care program meets the needs of your community.

**Step 1: Review the data you’ve collected and consider where to focus your team’s efforts.**

Consider the Social Determinants of Health in Your Community

1. *Are there populations that make up a high percentage of the community that have been overlooked in palliative care delivery?*
2. *Are there conditions/illnesses that have been overlooked in care provision?*

**Step 2: Consider your assets.**

Consider the Asset Mapping of Your Community

1. *What are the key community resources that you have identified?*
2. *How valuable are they to your organization, palliative care progr*am, and patients and families?

**Step 3: Consider your priorities or areas of focus**

Consider palliative care for a specific population, disease, or condition with unmet needs:

1. *Where do you start and how do you prioritize?*

Remember: Successful elements of health equity initiatives include:

1. A shared sense of urgency to address health equity specific to palliative care, and the need for solutions to involve the community
2. A clearly developed and shared purpose and set of values within an organization, system, program, or individual for health equity in palliative care
3. A trusted and respected champion to guide the process, who is committed to the addressing the effects of social determinants of health and to applying this concept to palliative care

Consider your program resources, priorities, and your asset map to design a plan for partnerships and collaboration.

Working with the successful elements of planning put forth by NASEM (2017).

1. Who are community entities, partners, or collaborators that you will partner with to consider the following:
	* 1. Given what you now know, what are the most urgent unmet needs of your patients with serious illness and their family caregivers?
		2. Which are these shared identified gaps?
		3. Which needs are most urgent?
		4. Which—if addressed—would have the most impact on the well-being of patients and families?
2. Who are key stakeholders?
3. What is your program/team’s capacity to undertake health equity initiatives?
4. Are there any changes that can be quickly and easily achieved?

**Use the following grid to document and prioritize potential action items.**

|  |  |
| --- | --- |
| **Unmet Needs Among Patients with Serious Illness** | **Interventions for the Seriously Ill Population** |
| * Problem and its urgency
 | * Feasibility
 |
| * Potential impact of an intervention to address the problem
 | * Possible collaborators within the community
 |
| * Resources necessary
 |  |

**Once you have listed the issues, you can then consider the need to feasibility as depicted below.**

*Adapted from National Association of County and City Health Officials, 2010.*

**Step 4: Resources, Partnerships and Collaborations**

*Stakeholder Engagement*

1. The United States is in the midst of an essential national dialogue on health equity—and this creates pressure for policymakers and health care leaders to act. Your organizational leadership may already be supporting health equity efforts or may be newly receptive to supporting such efforts.

**Engage your stakeholders** to understand whether there is alignment between their priorities and your program’s equity strategic plan—and whether that alignment can translate into support for your initiative. Use the [CAPC Stakeholder Interview Outline](https://www.capc.org/documents/913/) to identify stakeholders and elicit their priorities.

*Partnership Development*

When assessing the need and opportunity to partner with another team or organization, be aware of the factors that contribute to successful partnerships. Which collaborations or partnerships are possible?

Then create a plan that is it clearly defined to all stakeholders. Consider the following implementation process:

* A shared vision
* Agreement on mission, goals, and outcomes
* A clearly defined plan
* Mutual trust, respect, and commitment
* Identified strengths and assets
* Clear and accessible communication
* The ability to evolve, using feedback from all partners
* Processes based on input and agreement of all partners

**Step 5: Evaluating and Reevaluating Your Health Equity Plan**

You will need to monitor and track your process

1. How will you know whether things are working?
2. How and what will be measured?
3. *What metrics will you use?*

The community demographics may change, the organizations or resources may change. Or some strategies may fail.

You will need to evaluate and reevaluate your work using a quality improvement process.

Quality improvement occurs through the process of planning, implementation, analyzation, and action.

**One model is the PDSA or Plan, Do, Study, Act (Association for Community Health Improvement, 2017).**

**C. Health Equity Resources**

**National Academies of Sciences, Engineering and Medicine**

| **Resource** | **Focus** |
| --- | --- |
| National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in action: Pathways to health equity*. National Academies Press. <https://doi.org/10.17226/24624>  | This resource offers examples of community-based health equity initiatives based on the principle that health equity is crucial for the well-being and vibrancy of communities. Health is a product of multiple determinants. Social, economic, environmental, and structural factors and their unequal distribution matter more than health care in shaping health disparities. Health inequities are in large part a result of poverty, structural racism, and discrimination. Initiatives must be community-based, support public and private policy, and engage multisector partners.  |
| National Academies of Sciences, Engineering, and Medicine. (2018). *Achieving rural health equity and well-being: Proceedings of a workshop*. National Academies Press. <https://doi.org/10.17226/24967>  | This report offers rural-base examples of initiatives to improve community well-being within the intersection challenges of racism, structural inequities, and poverty in the context of rural geographic regions. Who do not fare as well as urban areas and need rural focused initiatives. The workshop included a focus on rural communities, social determinants of health (e.g., jobs, economy, education, transportation, affordable housing), and access to and quality of health care services. It offers some promising and constructive actions that rural communities facing these enormous challenges are taking to equitably improveresidents’ health and well-being including:* Inequities based on race and ethnicity overlap with and intensify
* Inequities based on geography.
 |
| National Academies of Sciences, Engineering, and Medicine. (2019). *Improving access to and equity of care for people with serious illness: Proceedings of a workshop*. National Academies Press. <https://doi.org/10.17226/25530>  | This resource offers strategies for health equity specifically for individuals with serious illness including:* Designing and implementing programs to address inequity
* Improving workforce training and education
* Developing partnerships, including nontraditional health care workers
* Pursuing potential policy initiatives and future research
 |
| National Academies of Sciences, Engineering, and Medicine. (2021). *The future of nursing 2020-2030: Charting a path to achieve health equity*. National Academies Press. <https://doi.org/10.17226/25982>  | This report delineates the major role for the nursing profession to engage in the complex work of aligning public health, health care, social services, and public policies to eliminate health disparities and achieve health equity. Achieved through interprofessional collaboration and current resources, resources for working in partnership with communities and addressing social determinants of health are offered. Recommendations include:* Focusing on the health and well-being of a nation
* Lifting barriers to nurses and others to promote health
* Designing better payment models
* Improving education in social determinants of health
* Using the public health model
* Fostering leadership and advocacy
 |

**Department of Health and Human Services, Office of Minority Health**

|  |  |
| --- | --- |
| **Resource** | **Focus** |
| Office of Minority Health. (2013). *National standards for culturally and linguistically appropriate services in health and health care: A blueprint for advancing and sustaining CLAS policy and practice*. US Department of Health and Human Services. <https://thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedCLASStandardsBlueprint.pdf>  | This resource offers the National Standards for Culturally and Linguistically Appropriate Services (CLAS). Topics pertain to the standards and include: * Culture
* Health
* Health and Health Care Organizations
* Individuals and Groups
* Statement of Intent
* Clarity and Action
* Standards of Equal Importance
* Principal Standard and Three Enhanced Themes
* New Standards: Organizational Governance and Leadership
 |

***REFLECTION QUESTIONS***

1. What is the perception of care of people with serious illness in the communities your serve?
2. How does the language change from community to community?
3. How will you empower your team members to participate in a health equity strategy?

|  |
| --- |
| **From Theory to Practice – Moving to Action**What type of a dashboard can you create for your palliative care team to measure health equity with respect to patients, families, and your team members? |

**Section References**

Association for Community Health Improvement. (2017). *Community health assessment toolkit*. American Hospital Association. <https://www.healthycommunities.org/resources/community-health-assessment-toolkit>

Centers for Disease Control and Prevention – Division of Community Health. (2013). *A practitioner’s guide for advancing health equity: Community strategies for preventing chronic disease*. US Department of Health and Human Services. <https://www.cdc.gov/nccdphp/dch/pdf/HealthEquityGuide.pdf>

National Academies of Sciences, Engineering, and Medicine. (2017). *Communities in action: Pathways to health equity*. National Academies Press. <https://doi.org/10.17226/24624>

National Association of County and City Health Officials. (2010). *Guide to prioritization techniques*. <https://www.naccho.org/uploads/downloadable-resources/Gudie-to-Prioritization-Techniques.pdf>

National Quality Forum. (2016). *Improving population health by working with communities: Action guide 3.0*. <https://www.qualityforum.org/Publications/2016/08/Improving_Population_Health_by_Working_with_Communities__Action_Guide_3_0.aspx>

**XI. Summary**

Remember, achieving health equity is a long-term commitment to a set of principles. As such, It is a process—not just an action—and one that requires intention.

Advancing health equity within palliative care means (Clarke et al., 2014):

1. Equity must be part of the palliative care program’s culture, mission, and vision.
2. Equity must be a cross-cutting quality indicator within the palliative care program.
3. To be successful, the palliative program must engage and collaborate with the community.
4. Ask why a proposed intervention will improve the status quo.
5. Implementing, evaluating, adjusting, and sustaining interventions are important for long-term success.

**Section Reference**

Clarke, A. R., Vargas, O. L., Goddu, A. P., McCullough, K. W., DeMeester, R., Cook, S. C., El-Shamaa, M., & Chin, M. H. (2014). *A roadmap to reduce racial and ethnic disparities in health care* (Finding answers: Disparities research for change). Robert Wood Johnson Foundation. <https://www.solvingdisparities.org/tools/roadmap>

**XII. Next Steps**

**Here is a review of the actions you have taken and what to do next.**

| **Goals of This Activity** | **Steps Taken Thus Far** | **Next Steps in Program Planning** |
| --- | --- | --- |
| Articulate palliative care as a human and health right. | Learned about the World Health Organization (WHO) statement about health equity. | * Integrate those concepts into your palliative care program mission, vision, and care delivery model.
 |
| Define the concepts *health equity*, *health disparities, health inequality,* and *health inequities.* | Learned definitions of health equity, health disparities, health inequities and health inequalities. | * Work with your team to make sure everyone understands these concepts.
* Consider how these terms apply to the populations you serve.
 |
| Describe the responsibility of the field of palliative care, palliative care professionals, and palliative care programs to achieve health equity for individuals with serious illness. | Learned about the necessity for palliative care teams to take action to promote equity.  | * Work with your team to determine where your program will take action.
 |
| Discuss the concept of *social determinants of health* and its essential elements pertaining to palliative care delivery. | Learned about the concept of social determinants of health and the various definitions and models. | * Work with your team to make sure everyone understands these concepts.
* Consider which definition your program will adopt.
 |
| Use community mapping to examine the demographics of the community a palliative care program serves by using publicly available data to discover underserved or unrepresented populations who do not have access to quality palliative care. | Learned about free, national websites that are available to understand your community. Learned how to compare your palliative care program services to the demographics of your community.  | * Set up a team to review the data gleaned from this review.
* Examine the data more deeply to understand populations that are marginalized, underserved or underrepresented in palliative care access in your community.
 |
| Use publicly available data to map community assets and resources to inform community partnerships. | Learned about free, national websites available to determine assets in your community. | * Perform a deep review of your community in terms of association, organizations, community agencies, community service providers, etc. to consider alliances.
 |
| Explain the need for palliative care programs to collaborate and partner with communities to work towards health equity. | Learned about the process and types of potential partners and collaborators within communities. | * Set up a team to consider potential partners and collaborators.
 |
| Use the information gleaned from the activity to develop a strategic plan for palliative care health equity within your community. | Learned about helpful resources and the process for how to create a strategic plan for health equity based on community mapping and asset mapping. | * Set up a team to work to create a strategic plan for health equity.
 |

**XIII. Evaluation**

CAPC appreciates your dedication to equity in palliative care. To assure the quality and utility of *Health Equity Concepts* ***–*** *Community Assessment for Palliative Care Programs,* please [COMPLETE THE EVALUATION](https://www.getfeedback.com/r/LHakRppB/) to give us feedback about your learning experience with this type of activity.

**XIV. Additional Palliative Care Resources on Health Equity, Social Determinants of Health, Community Mapping, and Community Partnerships**

**CAPC Resources**

CAPC blogs on Health Equity <https://www.capc.org/blog/health-equity/>

Center to Advance Palliative Care. (2019). Mapping community palliative care: A snapshot. <https://www.capc.org/mapping-community-palliative-care/>

Curseen, K. (2020, May 21). *Managing implicit bias and its effect on health care disparities* [CAPC Master Clinician Series]. Center to Advance Palliative Care. <https://www.capc.org/events/case-reviews/managing-implicit-bias-and-its-effect-health-care-disparities/>

Ferrell, B., Fratkin, M., Kang, T., Newman, S., Stevens, D. W., & Twohig, J. S. (2020, September 29). *The leader’s role: Forging new paths for racial and health equity* [Webinar]. Center to Advance Palliative Care. <https://www.capc.org/events/recorded-webinars/the-leaders-role-forging-new-paths-for-racial-and-health-equity>

Koomson, P., Winawer-Wetzel, S., Morris, J., Bowman, B., Twohig, J. S., Esch, & A. E. (2021, June 3). *The leader’s role: Advancing diversity, equity, and inclusion (DEI) opportunities in palliative care programs* [Webinar]*.* Center to Advance Palliative Care. <https://www.capc.org/events/recorded-webinars/the-leaders-role-advancing-diversity-equity-and-inclusion-dei-opportunities-in-palliative-care-programs/>

Patneaude, A. (2021, May 18). *Embracing cultural humility in palliative care* [Webinar]. Center to Advance Palliative Care. <https://www.capc.org/events/recorded-webinars/embracing-cultural-humility-in-palliative-care/>

Sprager, L, Maciel, S., & Colfelt, B. (2016, April 27). *OASIS: A replicable model to support communities of color in accessing and utilizing palliative care* [Webinar]. Center to Advance Palliative Care. <https://www.capc.org/events/recorded-webinars/oasis-replicable-model-support-communities-color-accessing-and-utilizing-palliative-care/>

**Other Helpful Resources and Tools**

American Academy of Family Physicians. (n.d.). *The EveryONE ProjectTM*. <https://www.aafp.org/family-physician/patient-care/the-everyone-project/toolkit.html>

Bennett, N. M., Brown, M. T., Green, T., Hall, L. L., & Winkler, A. M. (2016). *Social determinants of health: Improve health outcomes beyond the clinic walls*. American Medical Association. <https://edhub.ama-assn.org/steps-forward/module/2702762>

Health Research & Educational Trust. (2017). *A playbook for fostering hospital-community partnerships to build a Culture of Health*. American Hospital Association. <https://www.aha.org/system/files/hpoe/Reports-HPOE/2017/A-playbook-for-fostering-hospitalcommunity-partnerships.pdf>

Institute for Diversity and Health Equity. (2020). *Health equity snapshot: A toolkit for action*. Institute for Diversity and Health Equity. <https://www.aha.org/toolkitsmethodology/2020-12-14-health-equity-snapshot-toolkit-action>

**Continue the Conversation by joining the “**[**Palliative Care for Underserved/Vulnerable Patients**](https://3.basecamp.com/3415480/join/GmmFMTKcSbM9/accesses/new)**” CAPC** **online forum. You will need a Basecamp account, which is free for participants of the group.**

**Participate in CAPC’s** [**Virtual Office Hours (VOH)**](https://www.capc.org/events/virtual-office-hours/)**, listed below, to ask follow-up questions on the specific topics covered in *Health Equity Concepts – Community Assessment for Palliative Care Programs.***

|  |
| --- |
| Achieving Health Equity and Reducing Implicit Bias in Palliative Care |
| Billing for Community-Based Palliative Care |
| Building and Sustaining Your Hospital Palliative Care Program |
| Business Planning for Palliative Care Programs |
| Home-Based Palliative Care: Program Design and Program Expansion |
| Hospices Providing Palliative Care |
| How Free Standing Home Health and Hospice Agencies Can Deliver Palliative Care in the Community |
| Improving Team Effectiveness and Resilience |
| Inpatient Billing and Coding |
| Making the Case for Palliative Care: Demonstrating Value through Measurement |
| Managing Through the COVID-19 Crisis/Open Topics (PUBLIC) |
| Marketing to Increase Referrals |
| Palliative Care in Long-Term Care Settings |
| Pediatric Palliative Care |
| Planning for Community-Based Care: Getting Started |
| Role of the Social Worker on the Interdisciplinary Team |
| Specialty Palliative Care in the Clinic |
| The Role of Spiritual Care on the Palliative Care Team |
| The Role of the Nurse on the Palliative Care Team |
| Wellness Debriefings: Open Talk about the Challenges of Our Work |

