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**The HAP Foundation Conducts Research Study on
Black Americans' Experience with Serious Illness Care in Chicago**
Research collaborators include NORC at the University of Chicago and Arreola Research

The HAP Foundation and NORC at the University of Chicago have completed a joint research project to understand the knowledge, attitudes, and experiences of Black Americans around serious illness care in Chicago. Through a community-based participatory research design, narratives from Black individuals living in Chicago were captured by focus groups and in-depth interviews. [“Community-Based Study: Prioritizing Dignity and Respect in End-of-Life Care for Black Chicagoans”](#) is being distributed widely to health care providers and the community to encourage conversations and create change in behavioral patterns during end-of-life care.

“Our intention of this qualitative research study is to share the findings with the community to hopefully improve access to care and quality services for those near the end of life,” said Joseph Matty, President of The HAP Foundation. “Engaging with NORC at the University of Chicago has allowed The HAP Foundation to work with leading research specialists to identify behavioral patterns for increased quality of care for individuals.”

“This study reveals the knowledge, beliefs, and attitudes surrounding hospice and palliative care among Black Chicagoans and the findings showing disparities in the utilization of palliative care and hospice services between Black Americans and their White counterparts,” said Jocelyn Wilder, Senior Research Scientist at NORC. “Our research underscores the importance of culturally responsive approaches in health care delivery and the need for collaborative efforts to bridge gaps in access to palliative care and hospice services.”

Key findings include:

- Knowledge of palliative and hospice care varied among participants.
- Access to hospice and palliative care is perceived as lacking.
- Racism and failure to account for cultural differences exacerbated challenges for patients with serious illness and their caregivers.



Kandis Draw, Senior Community Health Associate at The HAP Foundation, recommended this concept for research based on her personal experiences as well as her community health work in the Chatham and Englewood neighborhoods of Chicago. [In August 2022](#), the collaborative research work began with NORC, Arreola Research and The HAP Foundation all contributing to the study design and implementation. In collaboration, the team conducted four focus groups and several key informant interviews, where stories, quotes and thoughts were provided. The report provides a thematic overview of the information collected.

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About The HAP Foundation:

The HAP Foundation is an independent nonprofit that provides education, advocacy, workforce development, and research on hospice, palliative care, and grief for all ages. With four decades rooted in direct patient care, it currently focuses on educating communities and professionals on hospice and palliative care; engaging in community-based research to better understand and impact disparities in hospice, palliative care, and grief support; increasing the Community Health Worker workforce to strengthen and share serious illness resources and education in the community; and advancing policies that assist individuals and families during end of life. Also, The HAP Foundation offers association management and consulting services. www.thehapfoundation.org

About NORC at the University of Chicago

NORC at the University of Chicago conducts research and analysis that decision-makers trust. As a nonpartisan research organization and a pioneer in measuring and understanding the world, we have studied almost every aspect of the human experience and every major news event for more than eight decades. Today, we partner with government, corporate, and nonprofit clients around the world to provide the objectivity and expertise necessary to inform the critical decisions facing society.

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