

# HAYSTACK PROJECT

## The Voices of Rare & Ultra Rare



**HEAT**

Health Equity in Access to Treatment

*Haystack Project works every day on solving for a health system not designed to fully consider the lived experience of rare and ultra-rare patients. As Covid-19 cast a spotlight on the profound impact that race and racial inequities have on health outcomes, Haystack's participating advocacy organizations asked for support in illuminating and addressing the needs of non-white patients in their communities.*

### ***Health Equity in Access to Treatment (HEAT)***

*Haystack is seeking support to launch the Health Equity in Access to Treatment (HEAT) program.*

**Self-Assessment.** The HEAT program will help organizations undertake a self-assessment of (i) the demographics of the patients they reach, and (ii) how they reach them.

**Advisory Panel.** The HEAT program will set up an Advisory Panel to aid the next level of patient engagement. We are pleased to announce Black Women's Health Initiative's (BWHI's) commitment, and we have additional invitations outstanding.

**Outreach and Messaging.** The Advisory Panel will review 5-10 groups' self-assessment to guide/refine their messaging and outreach. The HEAT program's aim is to increase the diversity of each patient group's reach so that advocacy efforts better address the needs of ALL patients living with the condition and their caregivers.

**Divergence in Patient Journeys.** Once patient organizations are reaching a more representative and diverse set of patients, the HEAT program will conduct a patient journey assessment. A series of patient journey interviews, guided by a literature search and Advisory Panel support, will be completed to assess

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divergence in the lived experiences among patients. For larger patient populations, a patient experience survey may be useful to guide interviews and participant selection. The focus will include the journey to diagnosis, finding providers (including specialists), comorbidities, disease trajectory, and accessing treatment options.

### *HEAT will:*

- 🔥 pilot a series of patient journey interviews with 3-5 participating groups to start;
- 🔥 extract, extrapolate, and present data and findings, including gap assessment;
- 🔥 identify key learnings and review/revise advocacy priorities to incorporate findings;
- 🔥 devise strategies to ensure and maintain representativeness and inclusiveness in advocacy efforts;
- 🔥 teach participating groups outside the pilot series how to conduct similar interviews within their communities, through interactive development of interview guides;
- 🔥 observe interviews with another 3-5 participating groups, provide feedback on interviews and guidance on data extraction, extrapolation, and assessments.



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*In this way, the HEAT program aims to create a “best practices” guide for our patient advocacy organizations (i) to evaluate their organization’s inclusiveness and representativeness, (ii) address gaps, and (iii) incorporate lived experience of ALL patients into their advocacy.*

*Haystack and the HEAT program will enable each of our 70+ advocacy organizations to leverage their learnings to proactively drive initiatives toward reducing racial inequities in access to treatment and health outcomes.*

*Haystack Project acknowledges in particular four principles in the American Medical Association’s policy on “Racism as a Public Health Threat” that center us in this work:*

- 🔥 Recognize the false conflation of race with inherent biological or genetic traits leads to inadequate examination of true underlying disease risk factors, which exacerbate existing health inequities.
- 🔥 Encourage characterizing race as a social construct, rather than an inherent biological trait.
- 🔥 Recognize that when race is described as a risk factor, it is more likely to be a proxy for influences including structural racism than a proxy for genetics.
- 🔥 Collaborate with appropriate stakeholders and content experts to develop recommendations on how to interpret or improve clinical algorithms that currently include race-based correction factor