

# Experts by experience: Paving a pathway to engage under-represented oncology patients in the research ecosystem

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## BACKGROUND

Limited engagement of under-resourced and historically underrepresented populations in research exacerbates existing disparities in health outcomes and deepens mistrust of systems, research, and researchers. As a result, research prioritization and methodology lack this group's unique perspective and dissemination efforts never reach this population or fail in their translation—preventing participants from understanding the importance and/or relevance of the results.

## PROJECT DESIGN

To bridge this gap, we surveyed (via email) a diverse network of patients served by PAF with a history of access and affordability challenges. Our purpose was to capture baseline data about patients' experiences, attitudes, skills and barriers to participating in the research ecosystem.

## DEMOGRAPHICS (N = 940)

|  |                      |
|--|----------------------|
|  | 77% Female           |
|  | 33% BIPOC            |
|  | 9% Non-heterosexual  |
|  | 30% Age <55 years    |
|  | 31% Disabled         |
|  | 66% Income <\$48,000 |
|  | 62% < 4-year degree  |

### Cancer Types

|             |
|-------------|
| 54% Breast  |
| 19% Myeloma |
| 6% Prostate |
| 5% Lung     |

## KEY FINDINGS

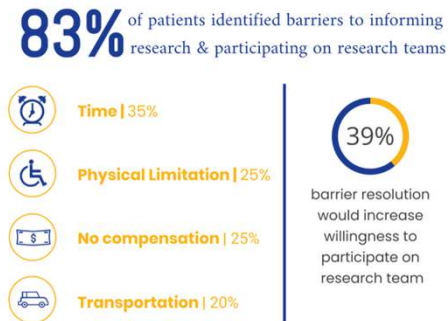
### Research Experience



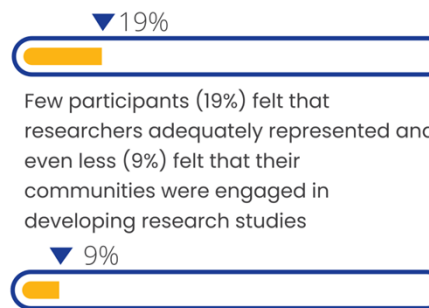
### Research Knowledge & Skills



### Research Barriers



### Research Representation



## RECOMMENDATIONS

There is a visible difference between 'including' patients as research participants versus 'engaging' patients in research design at the developmental stage. Under-represented patients want to **meaningfully contribute** to research impacting their communities.

Representation matters – patients want researchers to **reflect themselves and their communities**.

**Effective communication** and engagement is critical. This includes skill building, addressing barriers to participation, cultural concerns.

Positioning oncology **patients as experts** and honoring their input, strengthens the trust and relationship building required to diversify the research ecosystem.

## NEXT STEPS

We are currently utilizing our findings to provide approaches and tools for researchers to better engage oncology patient populations in their research teams, as an equal member, with valuable and viable insights.

## CONTACT

Visit <https://www.patientinsightinstitute.org/> to see more patient insights and our learning communities or contact [Kathleen.Gallagher@patientadvocate.org](mailto:Kathleen.Gallagher@patientadvocate.org) to partner with us on future patient-informed research and engagement projects. Chronically ill patients with social and financial needs can check out PAF's resources at [www.patientadvocate.org](http://www.patientadvocate.org)