

Co-Design Priorities for Primary Care Dementia Decision Support for African American Families

Early Findings

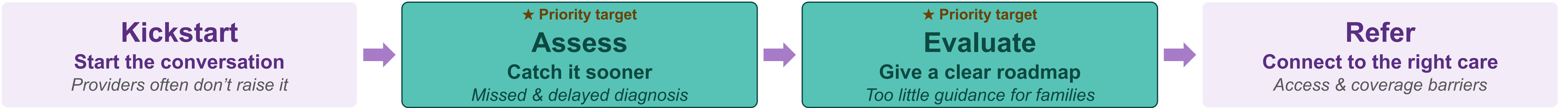
P#-###

Kalisha Bonds Johnson¹, Dawnita Brown², Gaea Daniel¹, Karah Alexander¹, Lauren Parker³, Abraham A. Brody⁴, Carolyn Clevenger¹, Theodore Johnson II⁵
¹ Nell Hodgson Woodruff School of Nursing, Emory University ² Binti Circle ³ Bloomberg School of Public Health, Johns Hopkins University ⁴ Rory Meyers College of Nursing, NYU ⁵ School of Medicine, Emory University

Primary care is missing early dementia in African American families and sending them home with no roadmap.

Co-design with 10 care partners points to the two fixes that matter most: earlier diagnosis and a clear family roadmap.

The KAER Journey — where African American families get stuck



10 themes mapped across KAER (GSA Toolkit). ★ Priority targets identified through co-design; secondary targets: fragmented care and care-partner inclusion.

What we did

Virtual focus groups with current and former African American dementia care partners (4 groups; N=10).
Plus, dementia/healthcare experts (n=3) and community liaisons (n=2).
Directed content analysis, organized within and across KAER domains.

What families told us

Dismissed early concerns and perceived bias when raising brain-health worries.
Missed or delayed diagnosis and fragmented, uncoordinated care.
Too little education about what to expect.
Excluded from care decisions.

What we'll build next

A culturally relevant primary care intervention that standardizes:
1) when and how brain-health concerns get raised,
2) assessment and diagnostic steps with real follow-up, and
3) a practical family roadmap that names the decision-maker and tailors referrals.

Visit the D.E.C.I.D.E. Research Lab

Kalisha Bonds Johnson, PhD, PMHNP-BC
Emory University · decideresearch.com
kalisha.bonds@emory.edu