# Vascular Dementia Inequalities for Lambeth’s Black Communities

In October 2020, we held an online event with [**South London and Maudsley Trust**](https://www.slam.nhs.uk/our-services/service-finder-details?CODE=SU0462) (SLaM) and[**Black Thrive**](https://www.blackthrive.org.uk/) for local people to explore the inequalities linked to [**vascular dementia**](https://www.nhs.uk/conditions/vascular-dementia) experienced by Lambeth’s Black communities.

The inequalities

SLaM has identified that local people of African and Caribbean heritage:

* risk developing the disease up to 10 years earlier than other people
* are diagnosed at a later stage compared with other people
* may encounter cultural bias in the diagnostic tools which could delay their diagnosis further.

# The event

## Aims

The event aimed to offer an initial conversation with some of Lambeth’s Black community members to:

* get a sense of awareness levels about these inequalities
* start to investigate the reasons for the pattern of late diagnoses
* provide information about the healthy living support that can help to prevent and delay the disease, and explore how accessible and effective these initiatives are for local Black communities
* identify some ideas for responding to these challenges.

## Programme

Watch the presentation from Grant Malyn, Dementia Clinical Nurse Specialist at SLaM, explaining what vascular dementia is and how they discovered the inequalities:

[Watch the video here](https://healthwatchlambeth.sharepoint.com/%3Av%3A/g/Eer_sz_gGv1Lp9ZyNpkaPd8BeONQD68hbOgE2T-4xT2Bmg?e=OuanNe)

Watch the presentation from David Truswell, Executive Director of [**the Dementia Alliance for Culture and Ethnicity**](https://www.demace.com) about some of the wider implications for people living with dementia from BAME communities:

[Watch the video here](https://healthwatchlambeth.sharepoint.com/%3Av%3A/g/EYalE3mhdrFOlJ2jm-aHKL0BJwhUauUwUT5VE-wSp8gVog?e=u48VoR)

### Community drama performance

The event also included a live play about a Caribbean family’s different responses to a family member experiencing memory problems and confusion. The play, commissioned by Healthwatch, was developed and performed by local community members and directed by [Tony Cealy](http://www.tonycealy.com).

# What we learned

Over 50 people attended the event and around 30 people were involved in the drama project. Through these activities we learned:

### Awareness levels

Most participants knew something about vascular dementia but few were aware of the associated inequalities faced by people of African and Caribbean heritage.

### Reasons for late diagnosis

* Participants felt that a trusted relationship with GPs is critical, as GPs provide the main referral route to the Memory Service for an assessment, particularly:
* Continuity of care is important to spot changes in patient memory or behaviour, as well as knowledge of family history
* Some participant experiences of GPs who were slow or even reluctant to make a referral may point to unconscious bias and the need for better training
* Patients should feel empowered to ask for and receive appropriate care and have a share in related decisions
* There should be better signposting from GPs to patient information about the range of preventative support available.
* Grouping the memory service with other mental health services (either through shared physical location or branding) may create a barrier for some members of the Black community because of the wider mistrust of mental health provision linked to related systemic inequalities.
* Through the play, performers highlighted that memory loss and behaviour change is often viewed as a natural part of the ageing process and care for people living with dementia may be seen as a family responsibility.

### Access to preventative healthy living support

* Participants recognised the importance of maintaining their mental health and general wellbeing to help manage stress levels and support lower blood pressure.
* The impact of structural racism on stress levels and other long-term health conditions within the Black community must be acknowledged when exploring solutions.
* A wide range of concerns and ideas about diet were shared, including:
	+ Food poverty and the inter-connectedness of wider socio-economic inequalities
	+ The value of food-growing projects to help people develop healthy eating habits
	+ The role of neighbourhood planning for example in limiting the number of fast-food outlets and increasing and sustaining food-growing spaces
	+ The need for better nutritional information including for supplements such as vitamin D and healthy versions of traditional recipes.

###  Ideas for action

Participants suggested:

* More community awareness-raising about the inequalities, including:
	+ opportunities for local people to become involved
	+ information about comparative studies on vascular dementia in Africa and the Caribbean, to help people understand how widespread the disease is
	+ more information on the links between vascular dementia and other conditions such as heart disease and diabetes
* Support existing healthy eating and food-growing initiatives to become more joined-up, sustainable, and inter-generational.
* Invite community members to co-produce healthy versions of traditional recipes with nutritionists
* Develop a healthy living campaign targeting black men.

# Next steps

We will:

* Share these insights with the [**Lambeth Dementia Action Alliance**](https://www.dementiaaction.org.uk/local_alliances/30863_lambeth_dementia_action_alliance)and other health and care practitioners
* Organise a community information session about local healthy living support
* Explore ideas for further community awareness-raising.