

Inclusivity in stroke self-management support: co-designing resources to improve self-management by Black African and Caribbean communities living with stroke in England

The 'ISMASS' project

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No conflict of interest

ISMASS study conducted by university researchers and public contributors (experts-by-experience)

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NIHR | National Institute for
Health and Care Research



Why this study?

- Black people are:
 - **twice as likely** to have a stroke than White people
 - more likely to experience stroke **much younger**
 - at higher risk of > one stroke
- Those living with sickle cell are at higher risk of stroke in childhood and adulthood
- Ethnically minoritized communities have **more severe outcomes** and **higher levels of unmet need** post-stroke

Why this study?

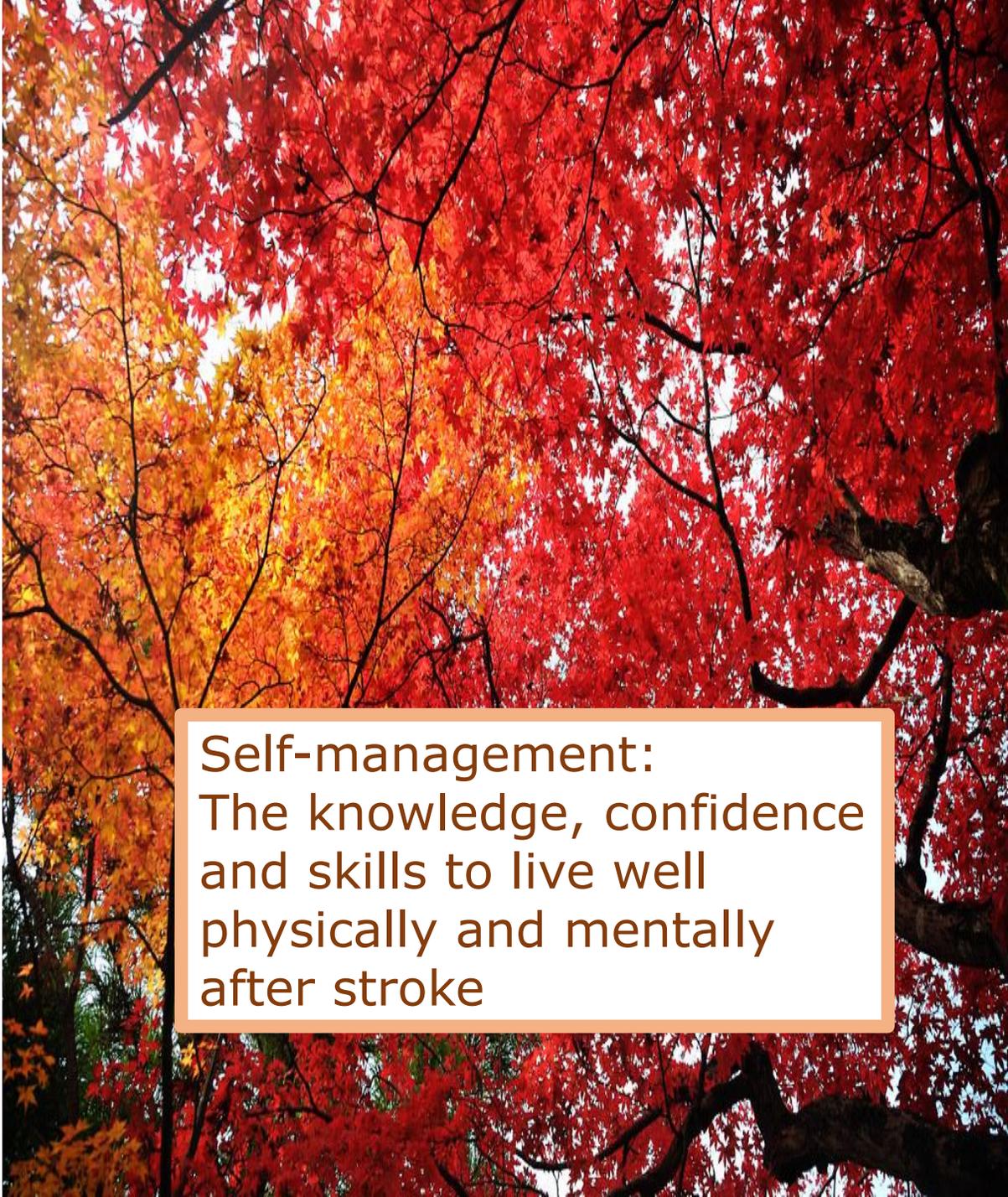
- Black people report **lower satisfaction** in relationships with healthcare providers than White patients due to poor communication and lack of shared decision-making and partnership (Goff et al., 2020)
- Stigma, fear and mistrust **inhibit help-seeking** amongst Black Caribbean people living with long-term health conditions (Shafiq et al., 2020)

Multiple factors are contributing to the health inequalities facing Black people living with stroke in England

Some are historic, systemic and structural

ISMASS aims

- Better understand the experiences and needs of Black people living with stroke and how they can be supported
- Co-design two resources to enhance self-management amongst Black people living with stroke
- Reduce inequalities associated with stroke facing this population



Self-management:
The knowledge, confidence
and skills to live well
physically and mentally
after stroke

What are the experiences of stroke amongst Black people?

- Qualitative study
- 20 participants
- Recruited through local and national organisations
- University and trained community researchers conducted interview
- Reflexive Thematic Analysis (Braun and Clarke 2019)

Age	30 – 39	2
	40-49	2
	50-59	7
	60-69	6
	70-79	2
	>80	1
	Age at first stroke	0-9
30-39		3
40-49		5
50-59		7
60-69		3
>80		1
Gender	Female	10
	Male	10
Self-Reported Ethnicity	Black British	2
	Caribbean	3
	Congolese	2
	English/ Jamaican heritage	1
	Ghanaian	1
	Indian/Jamaican	1
	Jamaican British	1
	Nigerian	7
	Ugandan	1
	Zimbabwean	1
Work Status	In work	5
	Unemployed	1
	Retired	5
	Not working due to acquired disability	9

Overall experiences

Low awareness

- stroke risk
- symptoms
- co-morbidities

Delays in seeking care

I would ask him [the doctor] "what's the cause of this stroke?"
Later they told me it was due to high cholesterol and irregular heartbeats
- Nigerian woman, 55 years old

I woke up and noticed that my left arm was very heavy and numb and I called my sister... And she's like, "You probably slept on your arm. So don't worry"
- Ghanaian woman, 62 years old

Sometimes they're like 'oh, your face falls' or like, there's slurred speech, and there's this, that and the other... loss of mobility and stuff.
I didn't really have that
- Black British/Caribbean woman, 37 years old



Experiences with healthcare providers

- Not feeling heard
- Discrimination and stereotyping
- Context of weak trust



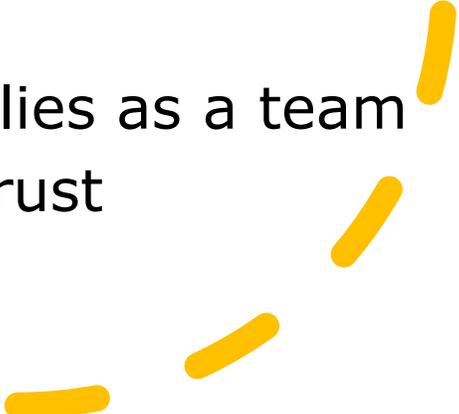
If people do come in [to hospital] because they know something is wrong but you're not being believed, then it defeats the purpose...

As a Black woman, the way I get treated compared to other people is very, very different...

Knowing that I can't get angry if I don't receive good care because I'm going to be labelled as an aggressive or Angry Black Woman... it's just so unfair that we have to navigate that daily - 33 year old Nigerian woman

ISMASS co-design 'EBCD'

Co-design of two short films to tackle specific, inter-linked contributors to inequalities:

- ❖ Film 1 for Black communities:
 - raising awareness of increased stroke risk and symptoms
 - challenging stigma
 - sharing 'what helps' and motivating
 - ❖ Film 2 for Healthcare staff:
 - highlighting patients' needs: feeling heard and safe, staff working with families as a team
 - explaining historic mistrust
 - prompting reflection
- 

(30 Secs)

Setting the scene:

 **Stroke affects Black communities differently**

Stroke occurs twice as often in black communities

It affects individuals on average 5 years younger

Younger black stroke survivors face unique changes

 **Lack of knowledge about stroke**

"I didn't know about it until it happened to me"

"I didn't know sickle cell & dehydration were a risk factor."

"I didn't know that when you have stroke, you can have another"

"I was not taking my medication on time, I think that's it"

(60 Secs)

The reality of stroke:

 **Life adjustments**

"It's almost like having to learn how to deal with your emotions completely 'cause it's almost like it's a complete new journey."

"You might have been doing something before and you might need to...relearn or change your career path completely."

 **Not feeling heard**

"It's almost like having to learn how to deal with your emotions completely 'cause it's almost like it's a complete new journey."

Lack of emotional support

"It's almost like having to learn how to deal with your emotions completely 'cause it's almost like it's a complete new journey."

 **Supporting carers**

The carer is so crucial...for their healing, for their moving forward, for them getting their confidence.

 **Impact on all relationships**

Family relationships and friendships are all impacted

 **Social isolation**

"It was good to know in my local community there is somebody who's going through something similar."

(90 Secs)

What helps:

 **Talking about stroke**

"...share the burden....it might be slightly taboo, but it's crucial to speak and share"

"It was good to know that in my local community there was somebody going through something similar"

"My kids were in school getting support,they had family workers ..."

 **Adapting as a family**

"My family always pushed me to get things checked out and that has been a big motivating factor."

"There was a charity... it involved how to talk to your children about having a stroke"

 **How we cope**

It's been a hard journey but it's not impossible

"...redefining your life, your role in society, in the family, in the workplace"

"things can improve in different ways you didn't expect"

"It boils down to building confidence & hope"

 **Seeking help for emotional aspects**

"...how to deal with your emotion, the changes around you, the impact that it has on your family"

"In the process of counselling, I asked questions on how to get back to my life. And they gave me strategies to cope"

 **Talking to healthcare professionals**

"I went to see my GP... and I asked her, what do I do? I want my life back... And she just opened a huge door for me"

"they assisted me to get back to myself"

"the confidence to ask lis what we need to give people"

What do people need to know?

FAST is good, but be aware of unusual symptoms.

What do people need to know?

It's a hard journey but you are not alone

What do people need to know?

Use your right to complain (about poor services) if needs be

What do people need to know?

Trust yourself & be persistent to get yourself heard by healthcare professionals.

What do people need to know?

Attitudes are changing in the black community, we need to talk about stroke.

What do people need to know?

Getting peer support helps normalise things and stops you feeling alone

Film 1
'Storyboarding'



RESEARCH

Open Access



Do I belong here? The lived experience of navigating health services as a Black person living with stroke in England

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**"It's hard but not impossible":
Black people's experiences of living with stroke**
https://youtu.be/WsAri6DxYxA?si=oeWHyCULIn_oJTUK

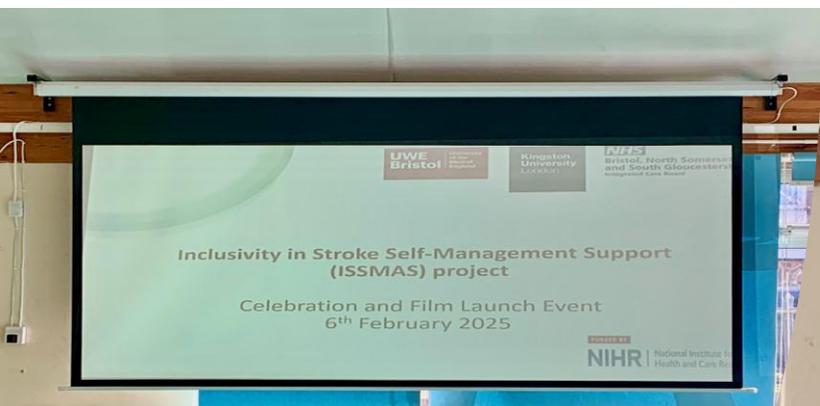


**"People remember how you make them feel":
Black people living with stroke and their experiences of healthcare services**
<https://youtu.be/U5kxoXQZSdc>



Dissemination of ISMASS films - pathways to impact

Initial 'Celebration' event
Bristol, February 2025



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The importance of co-designing
resources to improve self-management
by Black African and Afro-Caribbean
communities living with stroke

Emmanuel and Sarah Okino, UK



[Charlene] The three elements I would say of a good recovery are,





532
2
1
60
584
252







ISMMASS:

