IMPROVE Kidney care: Perspectives from people with CKD and risk factors for CKD on access to and experience of nephrology services

Presenting Author: Rebekah Cheung Judge *(1)*
Roseline Agyekum (1), Anjolaoluwa Awe (1), Muhammad Bojang (1), Kate Bramham (1), Nadine Fontaine-Palmer (2), Stephanie Hanson (2), Imani Henry Bailey (2), Lina Johansson (3), Adam Kamenetzky (2), Ritika Haresh Karamchandani (2), Jordanna Nunes (1), Shone Surendran (1), Nupur Yogarajah (2)

Background

- Prevalence of and outcomes from Chronic Kidney Disease (CKD) are inequitable across race, gender, age & socioeconomic status [1,2]
- Inaccessibility of nephrology services contributes to differential outcomes, with people who present late (< 90 days between first contact with nephrology services and initiation of renal replacement therapy) suffering worse outcomes.
- We conducted a **culturally-tailored qualitative insights study to better understand the factors that influence access to and experience of healthcare services for minoritised & marginalised people with CKD and at risk of CKD i**n South East London, UK.

Known inequalities in kidney care in the UK:

Appointments:

- People who are young, from ethnic minority backgrounds, or who experience deprivation are less likely to be able to attend appointments [1]

Dialysis:

- People who are **South Asian or Black are 3-5 times more likely to start dialysis** than people from White backgrounds [2]
- People from **socially disadvantaged** backgrounds are **more likely to start dialysis** [2]

Transplant

- People from **South Asian, Black and socially disadvantaged backgrounds are less likely to receive a transplant** [2]

Methods

A culturally-tailored, qualitative insights study was conducted as a **cross-sector collaboration** between

- nephrology services and
- an expert, antiracist, activist community-based research and social justice organisation (Mabadiliko Community Interest Company (CIC))

Selection & recruitment

Purposive selection to represent wider cohort.
Use of culturally-tailored communication & consent to recruit people

1. with risk factors for CKD or early-stage CKD
2. who presented late to nephrology services

→

Semi-structured interviews

- co-designed with people with lived experience
- conducted by Mabadiliko CIC

→

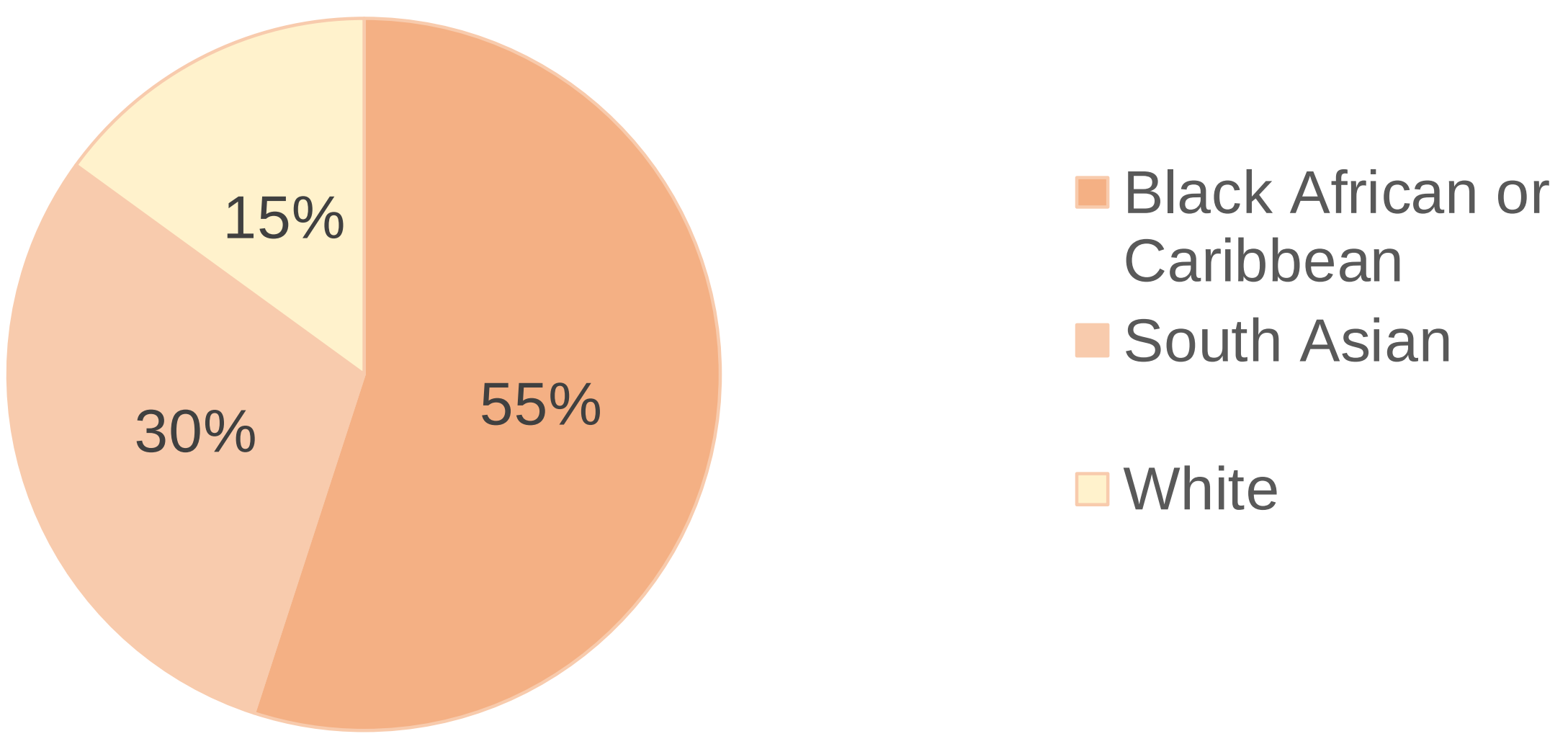
Thematic Analysis

- Inductive and deductive thematic analyses, and framework analysis (using the COM-B model and Behavioural Change Wheel) by Mabadiliko CIC
- Review and refinement of themes in co-productive sessions with nine participants.

Results

20 interviews

- 65% (n=13) <65 years of age
- 55% (n=11) of participants were Black African or Caribbean, 30% (n=6) White and 15% South Asian (n=3)
- 50% (n=10) were female



Late presentation is destabilising with little compensatory support

"it's like a shock...and there's nobody to talk to, they've not sent anybody to follow up; to say, how are you feeling, it's going to be all right. I never got that" (Participant 14)

Individual & community factors

- Varying levels of health literacy with challenges in understanding and managing CKD
- Insufficient accessible, culturally-congruent information and support about CKD – leading to difficulties with self-management and engagement in care
- Peer and community support important and desired

Relationships with HCPs & health services

- Relationships with HCPs & services varied
- While there were instances of positive, empathetic care, many people had experiences of disrespect, dismissal of concerns & discrimination
- Continuity of care was important to positive experiences

Impact of wider system & societal influences

- Difficulty accessing timely, quality care
- Difficulty navigating complex healthcare services
- Experiences of discrimination in healthcare settings
- Financial & logistical burdens of treatment

"I feel fobbed off...they're listening, but they're not hearing. it's like it's whatever they're telling you is for their own convenience. It's not because of what you're worried about." (Participant 4)

Discussion

This study captures the experiences of people at different stages of their journey with CKD, in accessing and engaging with nephrology services. Participants faced a complex array of challenges, highlighting opportunities for interventions at societal, system, service, interpersonal, community and individual levels. Key opportunities include:

- developing **culturally-appropriate, community-developed educational resources**
- **addressing power imbalances in healthcare interactions**
- **building trust** with communities who have faced / do face discrimination from healthcare institutions and within healthcare interactions
- **addressing systemic barriers to accessing care** - both immediate issues of service accessibility, as well as broader societal factors such as systemic racism.

Author affiliations:
1.King's College London, UK
2.Mabadiliko CIC, London, UK
3.Imperial College London, UK

For more information or collaborations please contact: Rebekah Cheung Judge at rebekah.judge@nhs.net

Abstract No: **WCN24-AB-136**

References:
1. London Kidney Network Health Equity Audit 2022
2. Kidney Health Inequalities in the UK, KRUK 2019