Heart Valve Disease Insight Study Summary – February 2022

Project background: Cardiovascular disease, including heart valve disease (HVD), significantly impacts the quality of life of patients, increasing their mortality risk, and contributes to NHS burden. A range of HVD treatment options are available to patients, including drug therapies and trans aortic valve implementation (TAVI), a minimally invasive surgical procedure.
Across South East London, there is a risk of missed opportunity for early HVD diagnosis and intervention. Phil Maccarthy, consultant cardiologist at King's College Hospital, explored data and uncovered significant inequalities in TAVI take up, particularly related to ethnicity. He found that the white populations had up to 8 times more TAVI interventions than black communities. Something needed to be done to understand why, and to address issues to improve TAVI uptake for black communities. The South London Cardiac Operational Delivery Network (ODN) commissioned Mabadiliko to deliver a study to understand perceptions of HVD and TAVI in Black African and Caribbean communities in South East London.

Primary research questions

- What is the understanding of and attitudes towards valve disease and treatment options?
- How can we improve trust and engagement with health services?
- How can we improve TAVI take up through culturally sensitive clinician communications?

Target audience - Black African and Caribbean communities over the age of 50, within South East London.

Key contributors

- Dr. Nadine Fontaine-Palmer, Hillna Fontaine, Natalia Le Gal (Mabadiliko CIC).
- Kate Jones Andrea Marlow, and Bethan O'Donnell (South London Cardiac ODN and Office of Specialised Services),
- Valued South East London study participants.

Summary of approach

- Study designed based on the **Theoretical Framework of Acceptability** *Sekhon et. al 2017*. The model seeks to understand the acceptability of an intervention (e.g. TAVI) in terms of:
  - ***Affective attitude*** *– How the participant feels about the intervention.*
  - ***Burden -*** *The perceived amount of effort that is required to participate in the intervention.*
  - ***Ethicality*** *- The extent to which the intervention has good fit with an individual's value system.*
  - ***Intervention coherence*** *- The extent to which the participant understands how the intervention works.*
  - ***Opportunity costs*** *- The extent to which benefits, profits or values must be given up to engage in the intervention.*
  - ***Perceived effectiveness –*** *Perception of whether the intervention is likely to achieve it's purpose*
  - ***Self-efficacy*** *- The individual's confidence they can do what they need to do to participate in the intervention.*

Data collection

- **Quantitative survey:** Demographic questions plus approx. 20 TFA based questions (86 responses).
- **Qualitative interviews and focus groups:** Semi-structured exploring key insights from quantitative data and identifying service improvements (45 participants).

Selected themes and insights

- **Barrier**: Complex health pathways reduce trust.
- **Barrier**: Impact of historical and current racialised health inequality on general trust in healthcare system.
- **Enabler**: Opportunity to improve take up through community collaboration in service provision.
- **Enabler**: Relatively high levels of trust in health service for HVD support (compared to other conditions).
- **Enabler**: Trust with individual HCP can significantly mitigate wider system mistrust.
- **Enabler**: Beneficial role of HVD education in decision-making.

Affective Attitude

- **Enabler**: Limited impact of religion/ cultural values on TAVI take-up.

Ethicality

- **Barrier**: Ethnicity not sensitively considered during diagnosis/ treatment discussions with HCPs.
- **Enabler**: High acceptability of mobile units for HVD screening (including community pharmacy).

Opportunity Cost

Burden

- **Barrier**: Perceived HVD 'catastrophe' decreases likelihood of sharing with friends/ family for fear of being a burden.
- **Enabler**: Relatively lower levels of stigma attached to HVD (except for in those experiencing other stigmatised conditions e.g. obesity).

Intervention Coherence

- **Enabler**: Critical role of advice from people with lived experience of HVD in decision-making.

Perceived Effectiveness

- **Enabler**: Interest in alternative treatments to support conventional treatment of HVD.
- **Enabler**: High acceptance of TAVI as a HVD treatment option following discussion.

Self-Efficacy

- **Enabler**: Feeling of being active agent in one's own health and having autonomy in decision making.
- **Enabler**: Role of women in driving family health behaviours.

I'm always surprised that the level that they're at with heart technology, and the things that they can do, just so quickly…

My chemist is down the bottom of my road, turn left here and we have good relationship amazing. A lot of things that I will go for GP for, I will call my chemist. I got his number on speed dial.

And I guess I'm always balancing the implements of my faith of my values that come from my faith versus my values that come from my scientific background, and I'm quite comfortable balancing those things out.

And sometimes I think we need to sort of pull up on ourselves and sort of look and search more within ourselves. There are so much fact finders and stuff, we can find out about our rights within the NHS. But sometimes we just don't think it's important.

It's not that people don't want to get fixed, it's probably because most of our hearts are broken already and need fixing .

Can we just say it out loud …racism? Can we just say it, no one's gonna fall down and drop dead if we just say it. But they don't want to deal with that bit. So they focus on all their tactical bits. There's a lot that we're living with. You know, and they don't know that and you don't have that opportunity to say and what they don't realise is the stuff that is not hurting me that I'm living with is probably the reason why I got that pain while I'm here.

I just like to have options [about treatment and tests].

Selected recommendations

- Develop NHS-led culturally sensitive HVD written and video-based communications for use at point of diagnosis.
- Empower and enable community-led HVD support.
- Increase availability of mobile units for HVD screening.
- Primary care outreach into communities outside moments of crises.
- Increase awareness of and access to patient feedback mechanisms.
- Cultural Sensitivity training for HCPs.
- Embed treatment options and autonomy during treatment discussions into face to face diagnosis
- Create space for lifestyle impacts and alternative treatments.