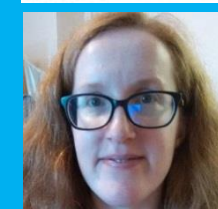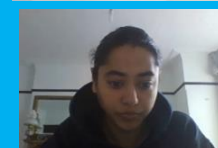# Community Voices: Stories for Change

Capturing the impact of COVID 19 on BAME communities & frontline staff in North West London

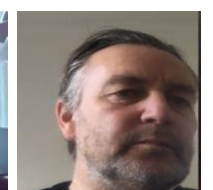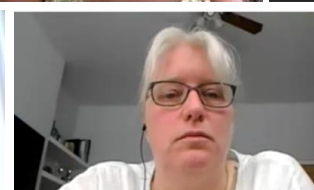Meerat Kaur (NIHR ARC Northwest London)
Janet Wildman

@kaumee   @jwildman1   @CommVoicesNWL
#Commvoicesnwl
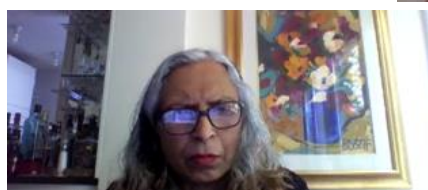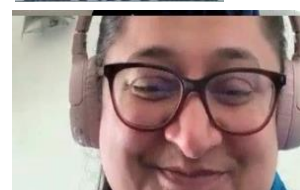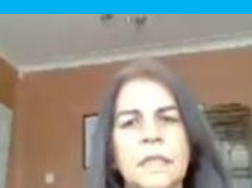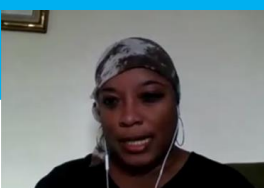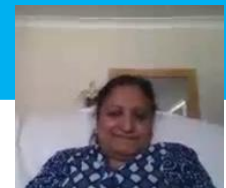
Background

- Increased inequalities in life expectancy, and an increasing percentage of people's life spent in ill health since the 2010 (Marmot et al, 2020; Stevenson and Rao, 2014)

- Worsening outcomes for Black and Minority Ethnic (BME) and people with disabilities (Marmot et al, 2010; Marmot et al , 2020)

- Increased risk of COVID-19 for BME communities (Pareek, 2020; Khunti, 2020)

BME People in Health and Care Research

- Under-representation of people from BME backgrounds in health and care research (Treweek et al 2020; Prinjha et al 2020; Dawson et al 2018)

- Including potentially in COVID-19 related studies (Treweek et al 2020;

- How can we change this narrative?

Engaging diverse people: the evidence

- **Factors to consider:**

"**who**... **research results** must **apply to**, whether there are important **cultural factors** to consider, whether the **focus** of the research... [or] the **proposed design and conduct** of the research will make it harder for some groups to take part."

(NIHR INCLUDE project findings in Treweek et al 2020)

- **Some factors enable engagement:**

Co-working with community partners;

linguistic competency;

cultural competency and awareness;

and reflexivity, power and acknowledgement. (Prinjha et al, 2020)

Our approach

"Community Voices hears **what matters to people**, it gathers the stories of our communities, **in their own words** and **through their preferred formats**"

Ontological and Epistemological Foundations

- Purpose of research: To challenge oppression rather than assess how it can work better

- "an end to the separation of academic and popular knowledge... replaced by the **activist researcher** who **produces knowledge to change social conditions**, which can never be separate from the "people"."[4] (Andrews, 2010)

- Sources of data therefore also vary:

"[stories] are not separate from theory; they make up theory and are, therefore, real and legitimate sources of data and ways of being." (Brayboy, 2006)

Community Voices

- A collective of individuals who volunteer their time and skills

- Networks and relationships based on trust and shared purpose

- People connected to communities most at risk
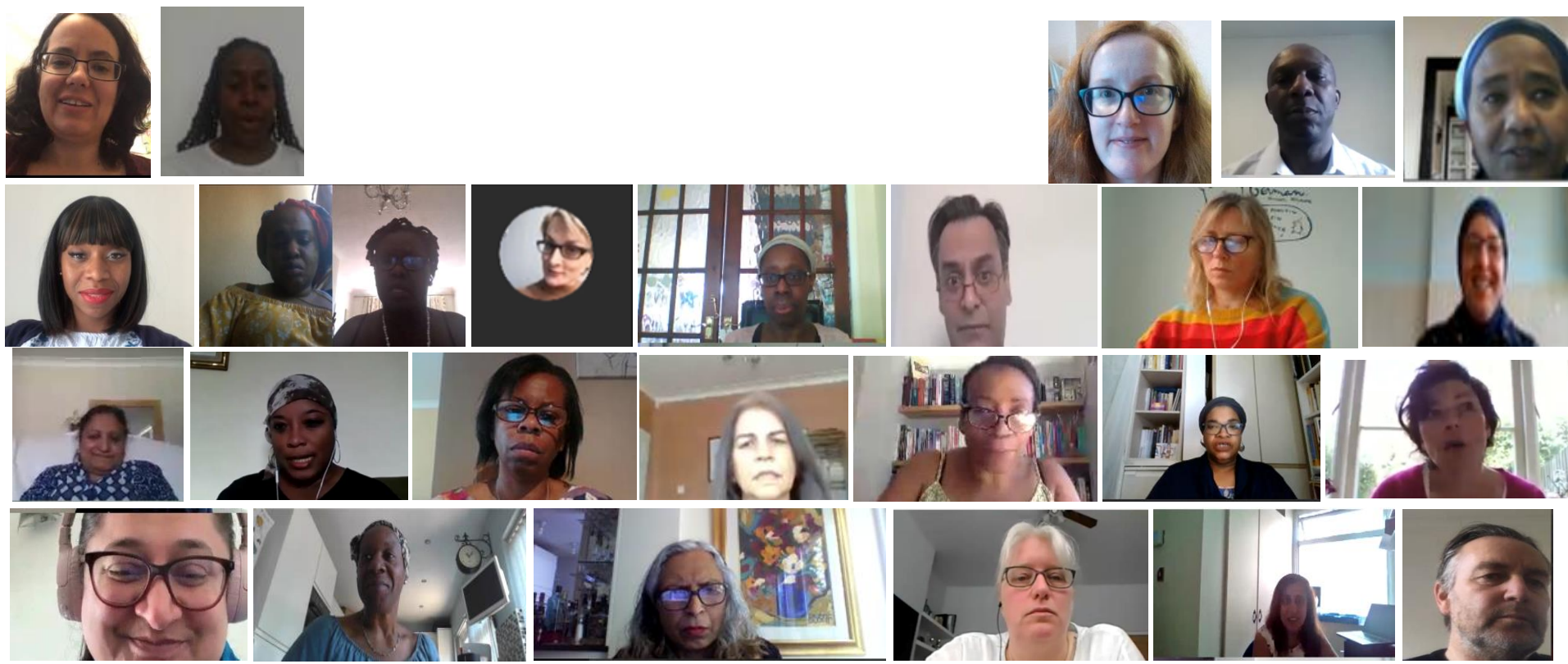
Community-based Participatory Approach

- People who form the collective bring their own local, personal and professional networks

- They are already in the communities we hear from

- We use asset based principles

Rapidly feeding back findings

- Rapid but rigorous qualitative analysis

- Fed back to the collective and our communities

- Highlights who we still need to hear from & issues we may not fully understand

- Informs further data collection

Rapid analysis template:

Source	Written source 4		
Questions	What is being said	Key themes	Illustrative quotes
Relevant experiences or concerns that should be noted	Relationships are crucial	Importance of relationships	"Recommending a more personal touch, this is proving to be a great pathway in to trust."
	Need to reflect on security concerns when contacting service users, and ensure you have safe words etc. so they know it is really you that is calling	Facilitating communication	
How are you coping?	Difficult but also a level of resilience in the organisation because of the resources they have	Organisational resources necessary to cope;	
	Impact on her mental health and wellbeing because of everything her clients are going through	Transferred trauma	"Sometimes it is hard to manage the over whelming pain that people we are supporting, tha dealing with during this time, I find that I am unable to just shut off from some of our servic they have such high priority needs and I am always trying to support them..."
	Has daughter to support her	Coping mechanisms	
	Managing and coping as an organisation and as individuals within the organisation requires resources		

Phase 1: Understanding experiences

- Almost 50 stories collected in 8 weeks

- New people joining the collective regularly

- Expanding explorations of what matters to specific parts of the population

- Growing interest among communities and organisations

Community Voices: Stories for Change

Emerging findings: June 2020
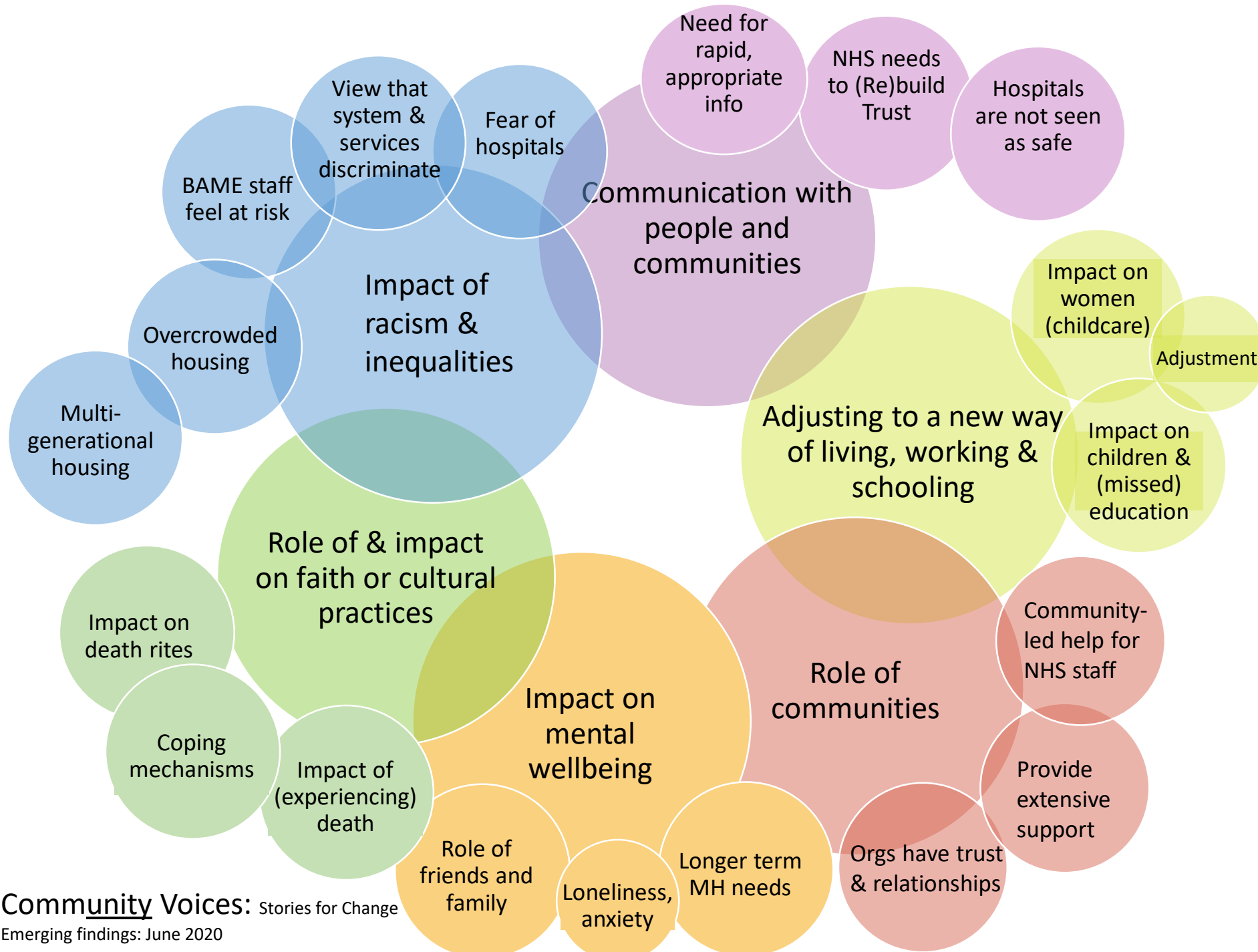
Phase 2: Collective Action

- How we work together to change dominant narratives

- Influence commissioning and funding community-based solutions to tackle health inequalities

- Optimise collaboration across organisations and geographies to tackle health inequalities

- Key workstreams – mental health and bereavement, research and analysis, digital inclusion

Our Ask

- Join Community Voices and share your skills, knowledge, experience

- Help us learn from collective action that has led to improvements for communities

- Initiate opportunities to explore this approach in your work and practice

- Share lessons of successful large-scale change with people from under-served communities within and outside of health and care

References

1. Marmot M, Allen J, Boyce T, Goldblatt P, Morrison J. *Health Equity in England*.; 2020.

2. Stevenson J, Rao M. *Explaining Levels of Wellbeing in Black and Minority Ethnic Populations in England*.; 2014. http://hdl.handle.net/10552/3867.

3. Marmot M, Allen J, Goldblatt P, et al. *Fair Society, Healthy Lives: The Marmot Review*.; 2010. doi:10.1016/j.puhe.2012.05.014

4. Pareek M, Bangash MN, Pareek N, et al. Ethnicity and COVID-19: an urgent public health research priority. *Lancet*. 2020;6736(20):2019-2020. doi:10.1016/S0140-6736(20)30922-3

5. Khunti K, Singh AK, Pareek M, Hanif W. Is ethnicity linked to incidence or outcomes of covid-19? *BMJ*. 2020;369(April):14-15. doi:10.1136/bmj.m1548

6. Treweek S, Forouhi NG, Narayan KMV, Khunti K. COVID-19 and ethnicity: who will research results apply to? *Lancet*. 2020;395(10242):1955-1957. doi:10.1016/S0140-6736(20)31380-5

7. Prinjha S, Miah N, Ali E, Farmer A. Including "seldom heard" views in research: Opportunities, challenges and recommendations from focus groups with British South Asian people with type 2 diabetes. *BMC Med Res Methodol*. 2020;20(1):1-11. doi:10.1186/s12874-020-01045-4

8. Dawson S, Campbell SM, Giles SJ, Morris RL, Cheraghi-Sohi S. Black and minority ethnic group involvement in health and social care research: A systematic review. *Heal Expect*. 2018;21(1):3-22. doi:10.1111/hex.12597

9. Andrews KN. Back to Black: Black Radicalism and the Supplementary School Movement. 2010.

10. Brayboy BMJ. Toward a Tribal Critical Race Theory in Education. *Urban Rev*. 2006;37(5):425-447. doi:10.1007/s11256-005-0018-y