MEDICAL SCEPTICISM

November 2020

TSIP

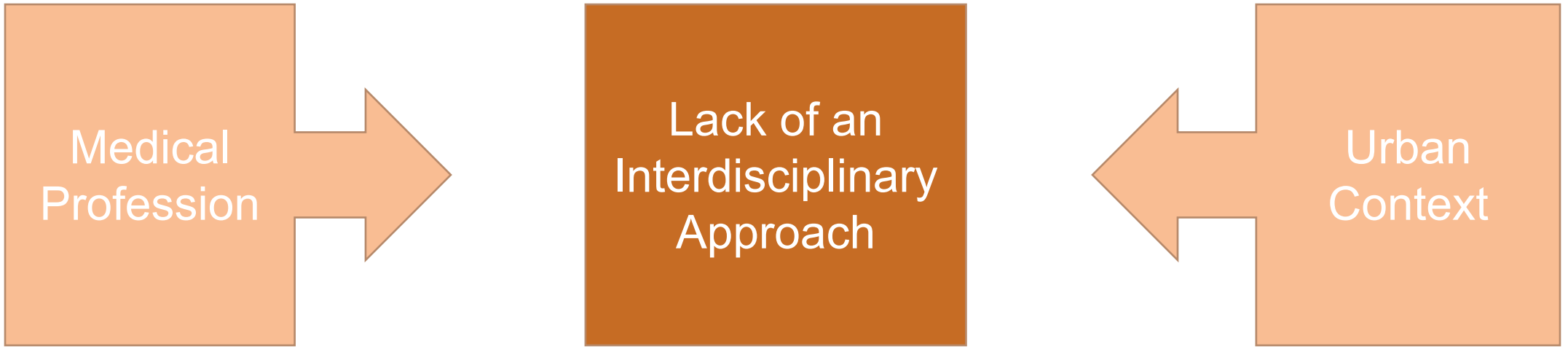
Why are we talking about medical scepticism?

‘In the UK at present, with the mounting impact COVID-19 has had disproportionally on BAME communities, huge distrust is now evident among black communities on UK shores which warrants further enquiry.’

A recent UK study has found that **Black, Asian and minority ethnic people are nearly three times more likely to reject a COVID-19 vaccine** for themselves and their children compared to white people.

A report published this year titled "Black People, Racism and Human Rights" by UK Parliament Human Rights Committee cited a ClearView Research study that found **over 60% of Black people in the UK do not believe their health is as equally protected by the NHS compared to white people.**

THE INTELLECTUAL GAP



INITIAL RESEARCH QUESTIONS

1. Why has medical scepticism taken hold in South London urban locales?
2. To what extent has institutional disconnect led to this?
3. How can health care systems allay distrust?
4. What are the repercussions for individuals of these communities with MLTCs ?

WHY HAS MEDICAL SCEPTICISM TAKEN HOLD IN SOUTH LONDON URBAN AREAS?

Weariness of the government, the police and of health professionals due to:

- Disproportionate impact that illnesses have had on the Black and ethnic minority communities

- **Historical racism**
  - the 1980's 'Sus' laws involving stop and search
  - morally and ethically questionable research and experimentation on black people

- Communities have been over-researched and developed '**research fatigue**'

This has led to the formation of **resistant and defensive identities**.

RACE AND HEALTH INEQUALITIES

Public Health statistics 2018:

- black men have higher reported rates of psychotic disorder than men in other ethnic groups
- available data suggest lower levels of reported ‘wellbeing’ among most minority ethnic groups than the White population
- cancer burden by site of the cancer varies between ethnic groups (e.g. prostate cancer makes up over 40% of Black men’s cancer compared with around 15% among Chinese men and 25% among all men)
- there are large differences in infant mortality by ethnicity. Rates are highest among Pakistani, Black Caribbean and Black African groups
- the National Child Measurement Programme indicates that among children most minority ethnic groups have higher levels of overweight or obesity at age 10-11 than the White majority. Those in Black groups have the highest levels.

‘In this way, BAME communities are often viewed and analysed from a dominant positionality of the, often, white, middle-class researcher who has career development in sight’

TO WHAT EXTENT HAS INSTITUTIONAL DISCONNECT LED TO THIS?

‘Institutions will have the rhetoric to commit when it comes to equality but when it comes to practical implementation **the continual inequitable urban landscape** begs to differ.’

How can health care systems allay distrust?

‘Health care providers and systems should **utilise urban social brokerage**: negotiating, facilitation and translation.’

WHAT ARE THE REPERCUSSIONS FOR INDIVIDUALS OF THESE COMMUNITIES WITH MLTCS ?

‘Some commentators suggest that due to the distrust of healthcare systems found amongst black communities, inadequate health provision becomes a self-fulfilling prophecy as **health care is delayed, treatment regimens are not adhered to and there is an avoidance of seeking care.’**

More research is needed to explore these questions and address medical scepticism in minority communities....

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PROBLEMS WITH TRADITIONAL RESEARCH METHODS

Traditional research methods can often only exacerbate the mistrust and scepticism existing within minority communities:

“Professional researchers” can at times approach communities from dominant epistemological and methodological paradigms and apply established academic terms, conventions and standards to evaluate and dismiss alternative ones. This leads to **distrust of research processes in contexts where there is already cynicism and scepticism.’**

‘Given the sensitivities of the field and the increasing medical scepticism that has been seen across the urban locale, it is imperative that a review of our frameworks is conducted before embarking on any sensitive research in BAME communities.’

A NEW FRAMEWORK

RESEARCH CONSIDERATIONS

- Triangulation of data
- Sampling strategy in research-weary and hard to reach communities
  - ‘respondent-driven sampling which uses four initially identified persons who then recruit a number of additional persons to fill out questionnaires’
- Research validity
  - ‘high validity can be attained via interviews as participants are able to talk about something in detail and depth’

FURTHER RESEARCH AIMS/PREDICTED OUTCOMES

Help understand the dynamics and nuances

Explain the disconnect

Help adapt and develop a more integrated approach

Inform a new strategy

FOCUS FOR FURTHER RESEARCH...

1. Exploration of the presumed **'medicalisation'** of communities and how this transpires in the urban landscape about 'health counter public spheres'.
2. A **narrative analysis** which will allow us to hear the profound stories under the radar across the South London urban locale which have informed medical scepticism. These **'hidden transcripts'**, though possibly deemed 'inferior' by some researchers, can provide a valuable means of knowledge-production.

COMMUNITY RESEARCH MODEL

Moving from exploitative extraction to genuine collaboration…

‘In the spirit of dialogue and thematic investigation all should contribute ideas and analysis should be facilitated via community reflection, rather than *extracting* data and knowledge from a community. **Local knowledge** should not be disregarded or deemed ‘inferior’. collaborative knowledge building between both practitioners and communities needs to be facilitated.’

RESEARCH METHOD AND RATIONALE

Sample: Diverse BAME communities across Lambeth and Southwark; a range of 30 interviews, as that provides a good working number of interviews at which one could expect to reach theoretical saturation, especially when using a semi-structured interview method.

Focus groups and semi-structured 1:1 interviews: conducted by community researchers. The CR team is well-placed to build rapport and occupy the cultural interface required for this field of enquiry due to their cultural competence and positionality.

Unlike traditional approaches in which communities are viewed from a dominant positionality by external researchers, our community researcher-led approach will deliver a democratic process: community members will be partners around the table in a dialogical format, having their concerns fed into the research. This promotes an equitable co-learning and collaborative research environment.

EXAMPLE OF CR TEAM UNIQUE SKILLSET

Objective:

Identifying prospective research interview participants.

Skills:

Distrust is absent in the case of the CR team. Due to the **positionality and accessibility** of the CR team, we do not envisage any methodological challenges to identifying the population of interest, mapping their subjective perceptions, or understanding their concerns.

LINES OF ENQUIRY

1. What has been the significance and history of counter public knowledge in South London? How did it develop?

2. How did health counter public spheres arise in Lambeth and Southwark?

3. Why have individuals opted out, or felt the need to opt-out, from mainstream discourses around health?

4. Has there been a 'sanitisation' and 'medicalisation' of specific communities, more so than white majorities?

4. What has been the experience of the community with health services? Why has there historically been distrust in these communities?

5. Going forward, what can be done to allay distrust and build a better relationship with public health and delivery of health services?

6. Are there grounds for fresh and novel health outreach and harm-reduction across these communities?

QUESTIONS AND NEXT STEPS

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