East London Pandemic Recovery Priority Setting Partnership For Ethnic Minority Communities

- An IDEAL participatory approach?

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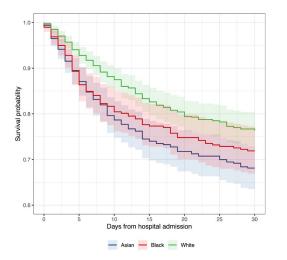
# **A Need For Change**

#### Open access

Original research

BMJ Open Ethnicity and outcomes in patients hospitalised with COVID-19 infection in East London: an observational cohort study

Vanessa J Apea, <sup>1,2</sup> Yize I Wan <sup>3,4</sup> Rageshri Dhairyawan, <sup>1,2</sup> Zudin A Puthucheary, <sup>3,4</sup> Rupert M Pearse, <sup>3,4</sup> Chloe M Orkin, <sup>1,2</sup> John R Prowle<sup>3,4</sup>



#### We needed...

- A deeper understanding and a community informed response
  - Bottom-up approach
  - Community centred approach
  - Intersectional lens to inclusion
  - Embed principles of citizenship
  - Shared power
  - Cultural humility





### **James Lind Alliance**

- A methodology to find out what health and care research is important to:
  - People affected by a condition
  - Carers / relatives
  - Clinicians / health and social care professionals
- Priority Setting Partnerships

#### • Key principles:

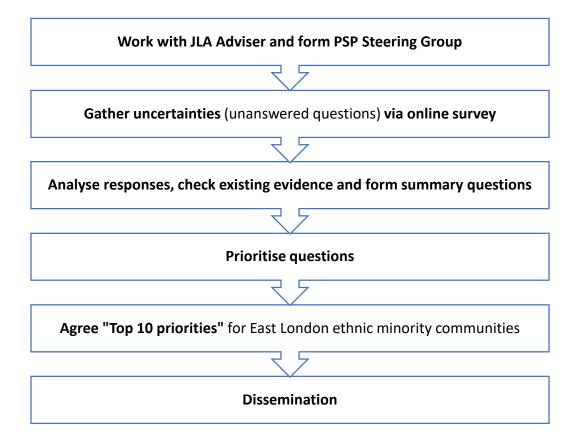
- Transparency
- Balanced inclusion
- Equality of voice
- Using the existing evidence base

Over 100 PSPs so far including in:

Health Conditions	Dermatology:	Funded by:
Asthma • Cvstic Fibrosis • Diabetes Type 1 & 2 • Multiple Scierosis Stroke • Parkinson's	Acne • Cellulitis • Eczema • Hyperhidrosis • Lichen Sclerosus • Psoriasis • Vitiligo	Charities Royal Colleges Clinical groups Universities Grant
Mental Health:		applications
Mental Health in Children and	Health Settings:	
Young People • Bipolar • Schizophrenia • Digital Technologies in Mental Health	Emergency Medicine • Intensive Care Patient Safety in Primary Care • Safe Care for Adults with Complex Health	
Care Professions	Needs • Anaesthesia	
Occupational Therapy • Adult Social Work • Physiotherapy • Community Nursing		

Finer S, Robb P, Cowan K, Daly A, Shah K, Farmer A. Setting the top 10 research priorities to improve the health of people with Type 2 diabetes: a Diabetes UK-James Lind Alliance Priority Setting Partnership. Diabet Med. 2018 Jul;35(7):862-870.







# **Adapting the James Lind Alliance Way**

- Adapting but retaining the JLA ethos
  - Shorter timeframe less than 18 months
  - Beyond health research
  - Focus on interventions and priorities
  - Focuses on a geographic location and ethnic groups, rather than an area of health/care







#### **Investigating the DEterminants of COVID-19 outcomes Across East London**

- The scope of the East London Pandemic PSP for Ethnic Minority Communities\* should focus on the following:
  - 1. To **explore the structural drivers of health inequalities** through the lived experiences of East London ethnic minority communities\* in the domains of, but not limited to, health, education, housing, household dynamics, poverty, and employment in the context of the COVID-19 pandemic
  - 2. To **explore the impact of COVID-19 pandemic on the health and wellbeing** of East London ethnic minority communities\* with a focus on physical and mental health, community involvement, nutrition, health seeking behavior and access to healthcare
  - 3. To provide recommendations for tangible solutions to help inform national and local responses to the COVID-19 pandemic and better support ethnic minority communities\*

\*communities that are represented by our steering group including: Black African, Black Caribbean, Somali, South Asian, Bangladeshi



#### EAST LONDON PANDEMIC RECOVERY PRIORITIES



Do you live in Tower Hamlets, Newham or Waltham Forest?

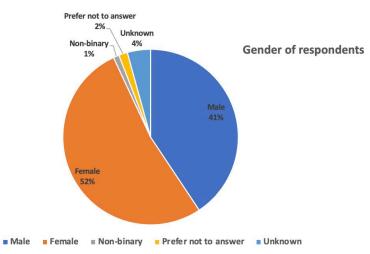
Do you identify as Black African, Black Caribbean, Somali, South Asian or Bangladeshi?

Help us shape the recovery in East London!



#### **First Survey**

• 187 respondents by Sept 2021





# **Early Insights**

- Beyond BAME
- Invest in creating and building relationships with partners
- Language is key
- Provide a plurality of options for engagement
- Embrace change continually evolve approach as needed and guided
- Transparency

#### **1.**Community impact

High rates of illness and death, loss of friends and family, financial impact, job loss, difficult GP access, isolation, institutional racism

#### 2. What has helped?

Online communication, faith groups, family and friends, food banks and employment services, volunteering, community organisations, government data and reliable publications

#### 3. What was missing?

Government reassurance, financial support, support in enforcing public health requirements, mental health support, communication from schools, face to face medical/dental care

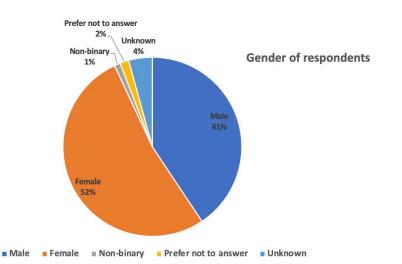
#### 4. Next actions?

Better access to GP and dental care, financial and employment support, cheaper and faster internet access, flexible working patterns, more language support, better representation, continued public health campaigns

# **First Survey**

Prioritisation Survey

• 187 respondents by Sept 2021



- Dec 2022
- Residents and wider stakeholders
- 191 online responses
- 52 paper responses
- 2 focus groups
  - 9 Somali women
  - 4 Black African carers



### **The Questions**

А	More Long Covid community-based support/management
В	Community based social worker clinics/support centres
С	Expansion of current community-based organisations
D	Drop in youth spaces dedicated to mental wellbeing
E	Enhanced community-based support by health visitors
F	Trauma informed individual and group counselling
G	Increased provision of group talking therapies for adults
н	Community mental health support for young people
Ī	Migrant support packages (info/phone credit/clothing/vouchers) – for both new migrants and established migrants

ſ	School based mental health support schemes
к	Emergency accommodation schemes
L	Upgraded food banks and clothes banks
м	Community based after school clubs
Ν	General health education scheme via Whatsapp - people to subscribe to receive regular health updates
0	Social support spaces – 24 hour advice and support – face to face/telephone. Spaces to provide signposting to relevant services
Р	Community support for housing insecurity - homeless/sofa-surfing/pending eviction
Q	More Long Covid community education
R	Supplementary universal credit schemes
S	Community kitchens for prepared meals/cooking lessons/nutrition advice
т	Enhanced school breakfast schemes

U	Map of local social activities
V	Education (health, housing, legal etc) programmes delivered in faith-based organisations
W	Community based day centres (face to face provision)
х	Social meeting hubs
Y	Family support voucher schemes – Food
Z	Refreshed community housing advice and support provided by community organisations

# **Final Workshop: Composition**





- 20 participants
  - 11 female 9 male
  - 8 solely community residents
  - 7 community residents and involved in the voluntary sector
  - 3 Barts rep
  - 1 Waltham Forest Rep
  - 1 academic
  - 5 South Asian 3 Black Caribbean 10 Black African

# **Final Workshop: Top 10 Priorities**



- **1** Expansion of current community-based organisations
- **2** Education programmes delivered in faith-based organisations
- **3** Social support spaces 24 hour advice and support
- **4** Drop in youth spaces dedicated to mental wellbeing
- 5 Migrant support packages
- **6** Community mental health support for young people
- 7 Community based day centres (face to face provision)
- 8 Trauma informed individual and group counselling
- 9 Emergency accommodation schemes
- **10** Community support for housing insecurity



### **Final Workshop: Visual Minutes**





Please share any comments, reflections or observations that you have about any of the priorities in this 1-10 list.

#### RESPONSES

I agree with the priorities.

It was really hard deciding which things were more important than others to go in the top ten. After lengthy group discussions some of the things that weren't in the top 10 were moved there.

It's great that our voices heard during this work shop. Everyone participated in the comments. They were useful. I will definitely participate such work shops in the future.

Every one's views were catered for

A lot of these are being done by community organisations but not funded by the local authorities which is not a good place for them to be Most people would rather interact with someone who has been through the same as themselves, so peer led initiatives are the way to go.



Here are the next ten priorities from the workshop which were not in the Top 10 (but will still be published) Please share any comments, reflections or observations that you have about any of the priorities in this list of numbers 11 - 20

11Communitybased social worker clinics/support centres - 12Increased provision of group talking therapies for adults - 13Family support voucher schemes –Food - 14School based mental health support schemes. - 15Communitybased after school clubs - 16Refreshed community housing advice and support provided by community organisations - 17Supplementary universal credit schemes - 18Social meeting hubs - 19Community kitchens for prepared meals/cooking lessons/nutrition advice - 20More Long Covid community-based support/management

#### RESPONSES

Voucher and supplementary UC schemes. I would have liked these to be higher, because it put the power and choice in peoples hands

I thought that family support vouchers should have been placed in the top 10 but after the whole group discussion and a vote it was decided not to put it in there.

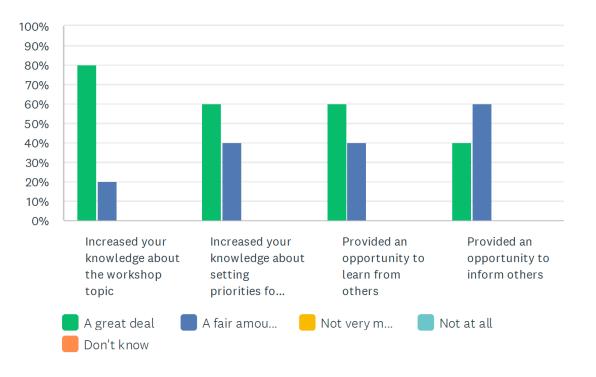
Everyone had the chance to discuss during the work shop. Our voices heard. I will participate such work shops in the future.

#### Well deserved

The family vouchers and top up Universal credit should be higher. People are really struggling to pay bills and buy food, it's become an either or, which can result in bad choices, depression and further debt. Prevention is better than cure.



# To what extent has your attendance at the workshop achieved the following?





Is there anything else you would like to tell us about the workshop?(For example what went well, what didn't go so well, or what could have been different.)

#### RESPONSES

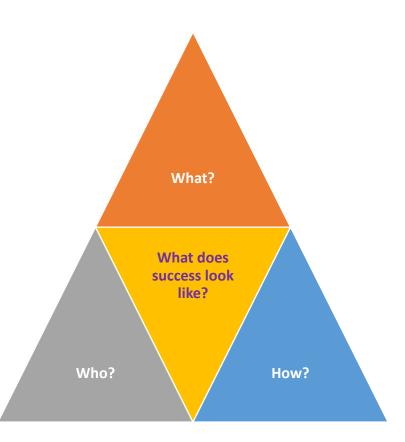
I enjoyed meeting and talking to new people and see some of my old friends

The discussion went well some times we had different opinions on the same topic.

They thought of everything even encouraged us to take time ours if needed. I am now really interested to see the outcomes.

#### SHÂRE REEARCH FOR HEALTH EQUITY

### **Dissemination**









### Acknowledgements

- East London communities in all their diversity
- Professor Chloe Orkin
- JLA Suzannah Kinsella
- Dr Miski Osman
- PSP members
- Team SHARE:
  - Professor Jane Anderson
  - Sadna Ullah
  - Dr Rageshri Dhairyawan
  - Dr John Thornhill
  - Dr Simon Tiberi

