



Coronavirus Intersectionalities

We are exploring the pandemic experiences of people with a long term condition or disability from ethnic minority groups, with a focus on health and social care.

Participatory research for complex interventions: Involving undocumented and recent migrants

Prof Carol Rivas c.rivas@ucl.ac.uk

Social Research Institute UCL London

<https://cicada-study.org.uk/>

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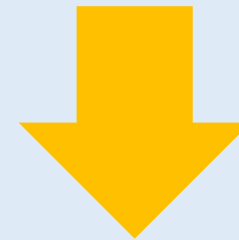
The CICADA-ME Study aims

Coronavirus Intersectionalities: Chronic Conditions And Disabilities And Migrant/Ethnic Minoritisation

Aim

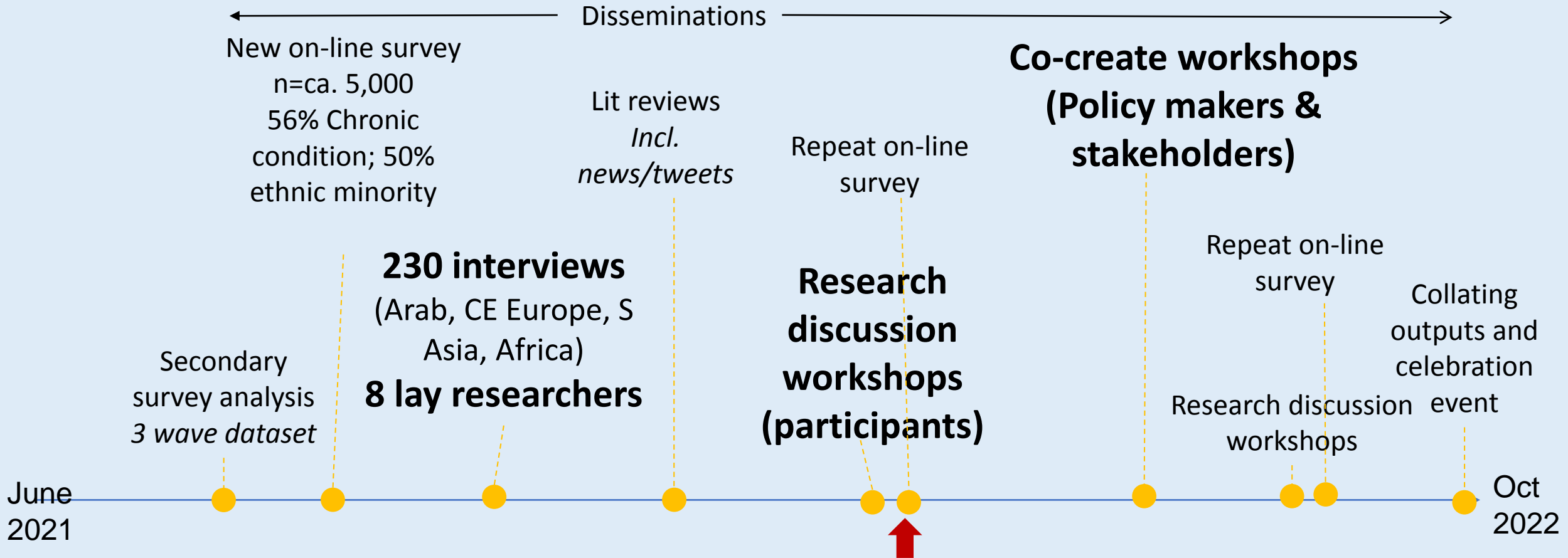
To improve understanding of pandemic-related issues faced by ethnic minoritised groups with chronic conditions (including long COVID) in daily living, mental & physical health

- **Impact of discrimination**
- **How to provide better services**
- **Coping strategies, strengths & solutions**
- **How health behaviour is impacted by sources of information & effect on vaccine uptake**

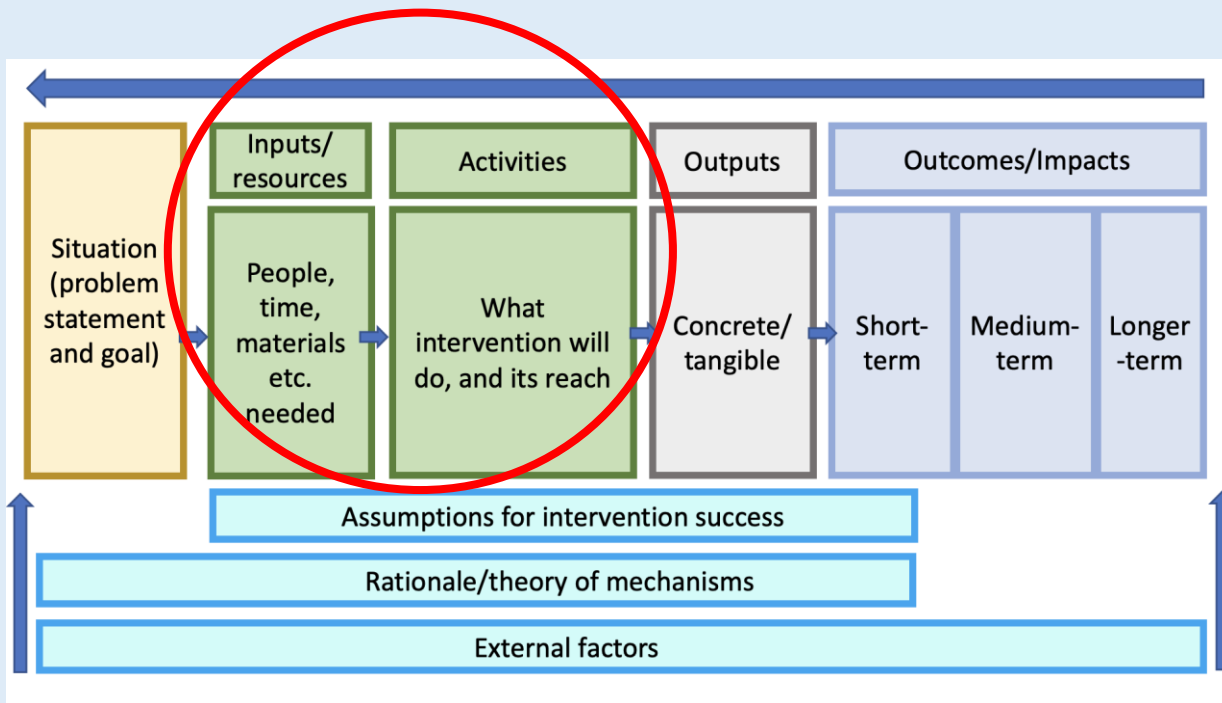


Informing person-centred guidelines
Making recommendations (including digital)
Designing interventions for health & social care policy & practice

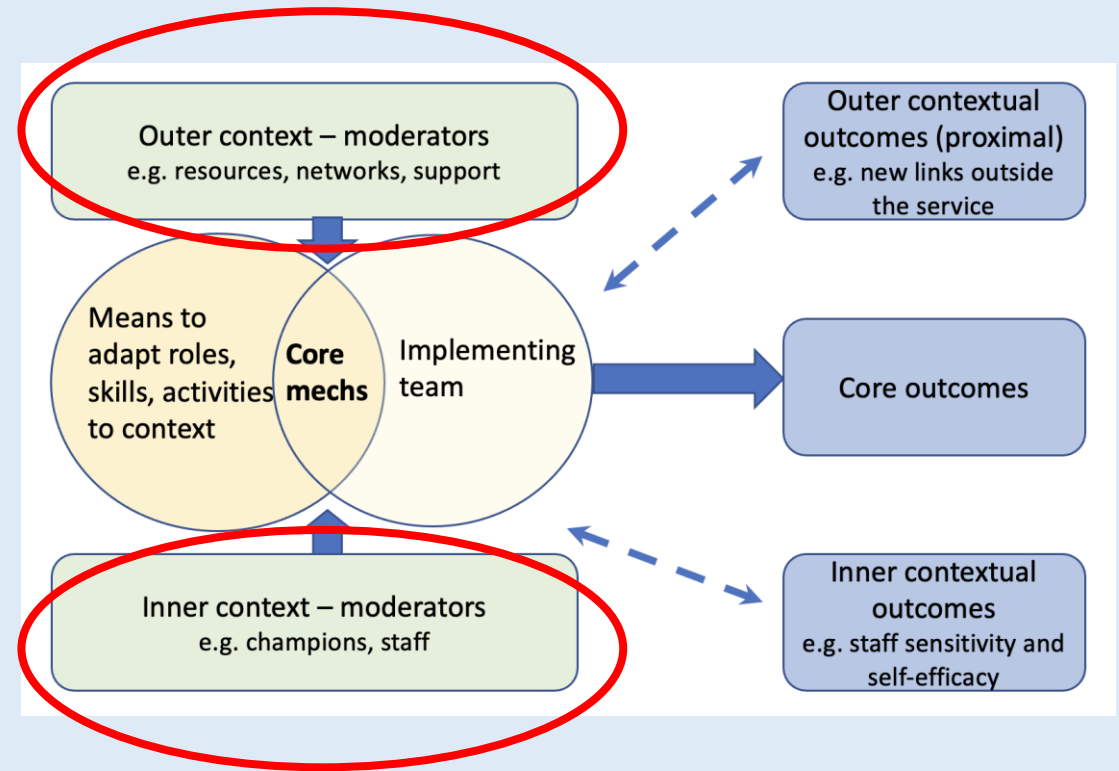
Our approach and progress to date



Logic models for complex interventions



Conventional



More person-centred

Mills, T., Lawton, R. & Sheard, L. Advancing complexity science in healthcare research: the logic of logic models. *BMC Med Res Methodol* **19**, 55 (2019). <https://doi.org/10.1186/s12874-019-0701-4>

Lay co-researchers

True co-researching rare (carrying out the same tasks) - mostly limited to quite distinct tasks (sometimes due to bureaucracy).

- Eg. “the co-researcher was not involved in recruiting participants or the interviews... She was involved in developing the interview guides,added clarity to the questions avoiding jargon”

Marks, S., Mathie, E., Smiddy, J. *et al.* Reflections and experiences of a co-researcher involved in a renal research study. *Res Involv Engagem* 4, 36 (2018).



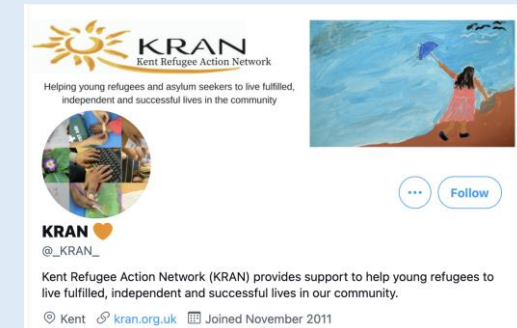
Case Study 3.1

In a study to increase participation of BAME communities in health and social care research (BAME Workshop, 2016) a lay member representing the local Bangladeshi community in Leicester initially contacted the Bangladesh Youth and Cultural Shomiti (BYCS), a community and cultural centre, and explained the purpose of the focus group, and also invited key figures from the community.

This was initially accepted by the committee. The ten invitations were hand-delivered to BYCS by key persons from the Bangladeshi community to attend and contribute to the focus group. They felt better represented and more confident to participate.

11 co-researchers attended the training session – **remuneration plus certificate** – for 4 the main training recorded

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Workshops with our 200+ interviewees to see what has changed



"As a community we share stories...I'm sorry but I don't trust at the end of the day all this pharmaceutical industry ...Its just business"



"Social media was a saviour"

"We organised online cooking sessions... I used traditional remedies... it helped me going"



"Nobody is in touch, they're not checking...I'm getting worse and worse.....is somebody paying attention?"



"It was difficult but I learnt to book online...It was stressful because I'm not good at new technology"

Futures-based co-design workshops

NEW WORLD AFTER THE PANDEMIC

JUST AS THE PANDEMIC CREATED NEW BEHAVIOURS (face masks, home testing kits, hand washing, social distancing, working from home etc.) COMMUNITIES CREATED THEIR OWN BEHAVIOURS:

WORKSHOP PROCESS:

STEP 1: UNDERSTAND WHAT THESE ARE

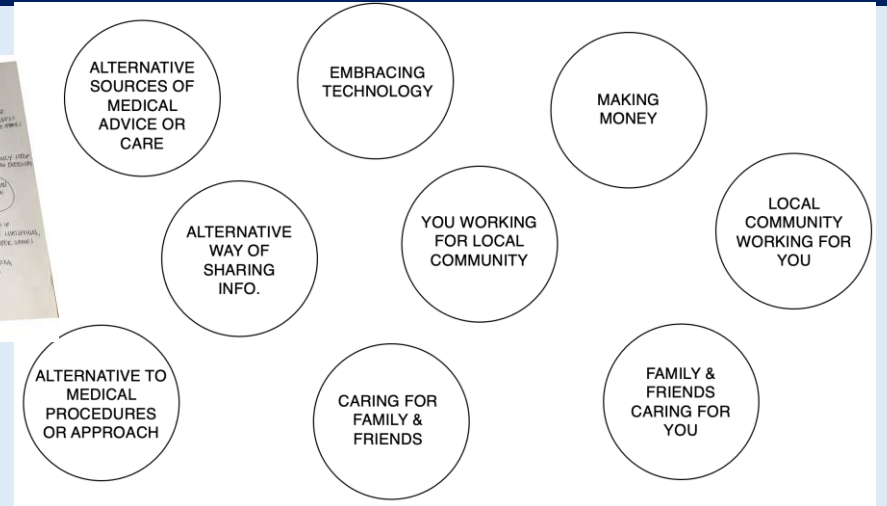
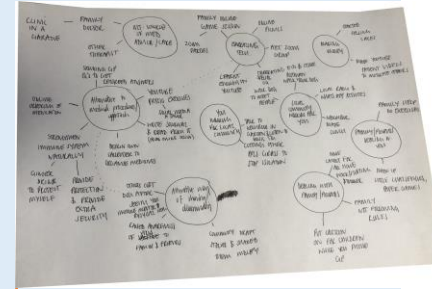
What does this tell us about what is important to these groups?

When this group has access to the same or fewer resources, how have they coped?

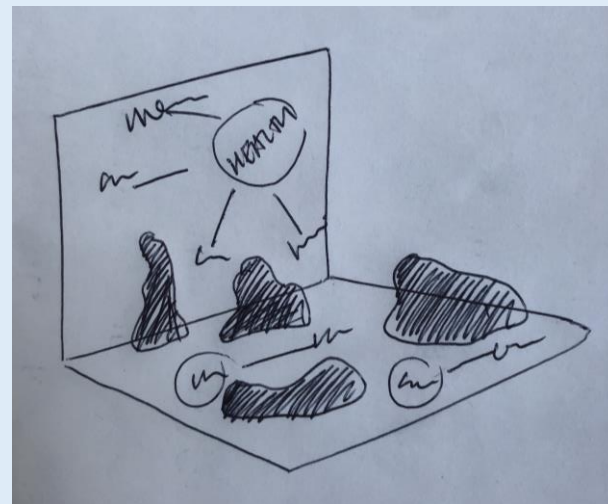
What can we learn from what we've been through to support communities going forward?

STEP 2: DOCUMENT THESE

STEP 3: CELEBRATE THEM



PLAYFULNESS



- INSTRUCTIONS**
1. Read situation and discuss what's going on.
 2. Model the situation
 3. Discuss issues and challenges
 4. Discuss the unique behaviours or strategies they draw on to cope
 5. "Post pandemic world"
 - If we know this now, what would we have done differently
 - How do we share this
 - What can we learn from this?

Conclusions

- Our analysis so far has shown that :
 - common categorisations of people (e.g. as being from particular ethnic or disability groups) over-homogenise experiences, and
 - social determinants of health both cut across these categories and vary within them,
- Therefore a flexible person-centred approach to intervention design and delivery is needed.
- Once core mechanisms are determined, the flexibility required by contextual moderators should be developed from insights from those ‘on the ground’ – e.g. patients and staff.
- These insights should encompass the broader identities and social contexts of people beyond health care encounters (not just ‘patient-centred’)
- Translating these insights into complex interventions requires participatory deliberation and negotiation between stakeholders, with a focus on the can-do and will-benefit.
- We are using different participatory methods to serve different functions – so carefully thought out, not fashionably applied, and to encourage undocumented/recent migrants:
 - lay researchers for reach,
 - workshops to develop understandings across and within communities, and
 - non-staff-based co-design to develop outputs for impact.