



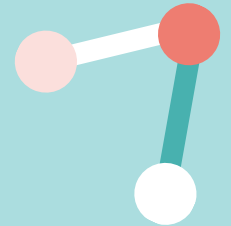
Reaching Out

Addressing barriers to participation in research

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Introduction



Since mid-2020, NIHR partners in the south east of England - Clinical Research Network (CRN), Research Design Service (RDS), and Applied Research Collaboration (ARC) have been building relationships with organisations from the Black ethnic group and the Asian ethnic group across Kent, Surrey and Sussex.

In June 2021, funding from NIHR Centre for Engagement and Dissemination (CED) supported a 'Reaching Out' event that brought together these groups across Kent, Surrey and Sussex to explore the barriers to minority group participation in research and to consider what could be done to address these through partnership.

Initial areas of interest

Community groups, leaders and individuals and community development professionals

Experience, if any, of
participating or getting
involved in
health/social care
research?

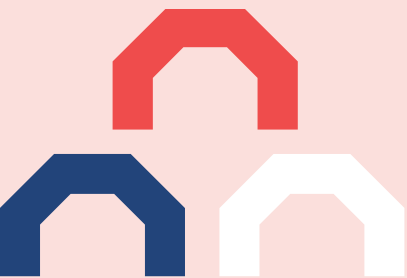
Researchers

Experience, if any, of
people from ethnic
minority groups getting
involved/participating
in research ?

What are the
challenges/barriers
and opportunities to
developing an ongoing
partnership?

What might be the
benefits and outcomes
of working together in
partnership?

What should be the
purpose, aims and
activities of an ongoing
partnership?



Findings

What are the barriers and how are these experienced by researchers and those researched?

Experience of ethnic minority community connectors and development leaders of 'being researched'

Powerlessness of the researched

- self-interested researchers and lack of benefit to communities.
- feelings of distrust towards researchers
- not feeling understood; inappropriate generalisations

Problematic framing of ethnic minority people

- deficit model of research leading to stereotyping and stigmatisation
- lack of ownership of research
- desire for more acknowledgement and use of skills and experience in research

Transactional relationships

- ‘zooming in and out’ by researchers
- disconnect and unequal relationships
- desire for partnership and mutual benefit

Findings

What are the barriers and how are these experienced by researchers and those researched?

Experience of ethnic minority community connectors and development leaders of 'being researched'

Research fatigue

- lack of positive impact and feedback

Treatment of community connectors

- not valued or remunerated despite high cost
- no ongoing relationship due to transactional behaviour
- lack of resources available

Importance of cultural competence and representation

- call for researcher training around issues surrounding minority groups
- perceived lack of will to engage with racism
- experiences of cultural insensitivity, bias and stereotyping
- researchers not representative of communities they are working with

Findings

What are the barriers and how are these experienced by researchers and those researched?

Experience of researchers of ethnic minority people; often mirroring communities' experiences and concerns

Working beyond the library

-mixed stance: some recognising benefits of ongoing relationships but others having faith in their own expertise on communities'

Role of community connectors/partners

-little/no funding available for this

-challenging to find the 'right' partners and the 'right' researcher to engage with them

Low recruitment of people from ethnic minorities in clinical

Getting buy-in and cultural competence

Findings

What should engagement and partnership look like in the future?

Researchers being responsive to community needs

Earlier and ongoing involvement and relationships

- developing relationships prior to start of research projects
- enable groups to have input and shape research ideas earlier
- developed trust

Asset based research

- move away from deficit-based research
- consider amplifying voices and capacity building in communities opportunities

Sharing skills and experience

- desire for mutual learning and active participation
- creation of buddying systems



Findings

What should engagement and partnership look like in the future?

Researchers being responsive to community needs

Authentic and equal partnerships

- build genuine partnerships with researchers/co-production
- shared vision of meaningful research

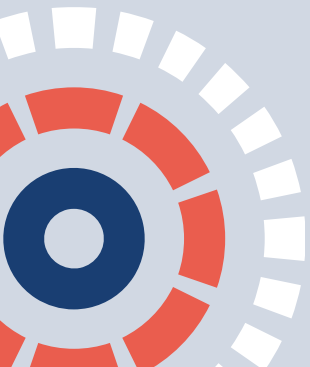
Representation

- more ownership over research



Possible next steps*

- Develop an engagement charter
- Assessing engagement
- Training for researchers
- Training in research for community organisations
- Buddying for researchers
- Match making service
- Advising on research plans
- Develop the Forum into a true partnership between researchers and Community
- Reach out further



*Each of these steps would need to be explored and scoped further.

A new era for partnership working with minority groups in KSS: The Forum

Reaching Out demonstrated a demand, from both communities and researchers, to establish a sustainable regional Forum with a view to increasing the involvement and participation of minority communities in research, co-led by ethnic minority groups and NIHR organisations. Resourced by further funding from NIHR CED, NIHR partners and communities will co-design the forum through a series of workshops.

The Reaching Out event identified three models for the Forum:

- 1. A 'reactive' model: researchers accessing the Forum for feedback on research, and gain access to increase involvement and participation in research**
- 2. An 'active' model: the Forum members play a role in influencing the research priorities of researchers in the region, co-developing proposals, training/mentoring/buddying**
- 3. A hybrid model of both approaches**

