

Under representation in research

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Why we need to talk about under representation in research

Professionals in research

From Royal College of Physicians' survey report, 2020:
"Research for all? An analysis of clinical participation in research"



13%

Respondents from BAME backgrounds are 13% less likely to report being formally employed in research roles



12%

Women are 12% less likely to participate in clinical research than men, despite over a third (35%) of women saying they want to become involved in research



18%

Physicians working in rural hospitals are 18% less likely to participate in clinical research than those in cities, although 40% of them say they do want to become involved in research

Why we need to talk about under representation in research

Public participation in research

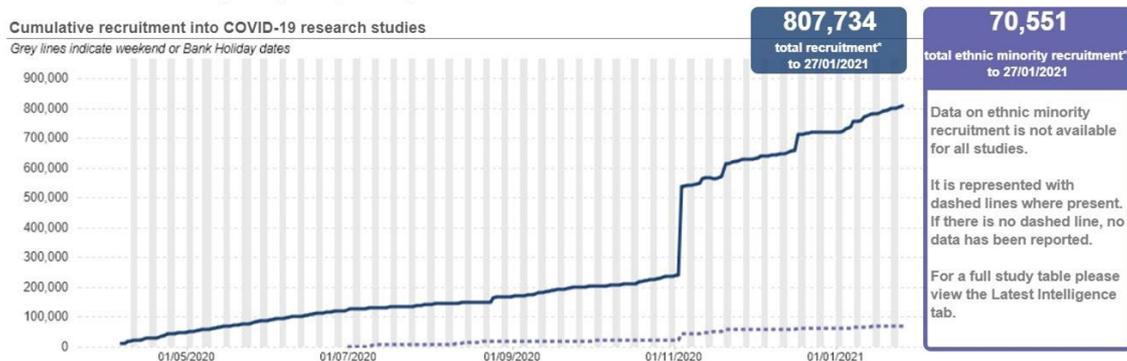
Recruitment to COVID 19 research

Latest intelligence on COVID-19 research supported by NIHR CRN over time

Data collection for latest intelligence reports began on 6 April

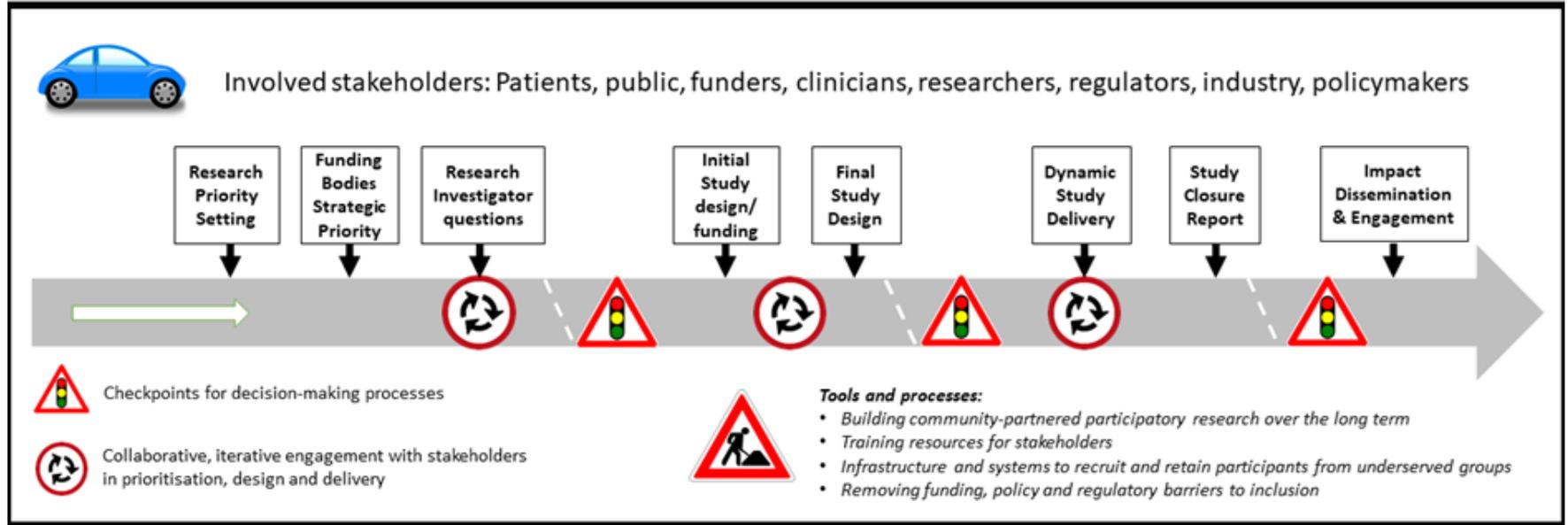
Cumulative recruitment into COVID-19 research studies

Grey lines indicate weekend or Bank Holiday dates

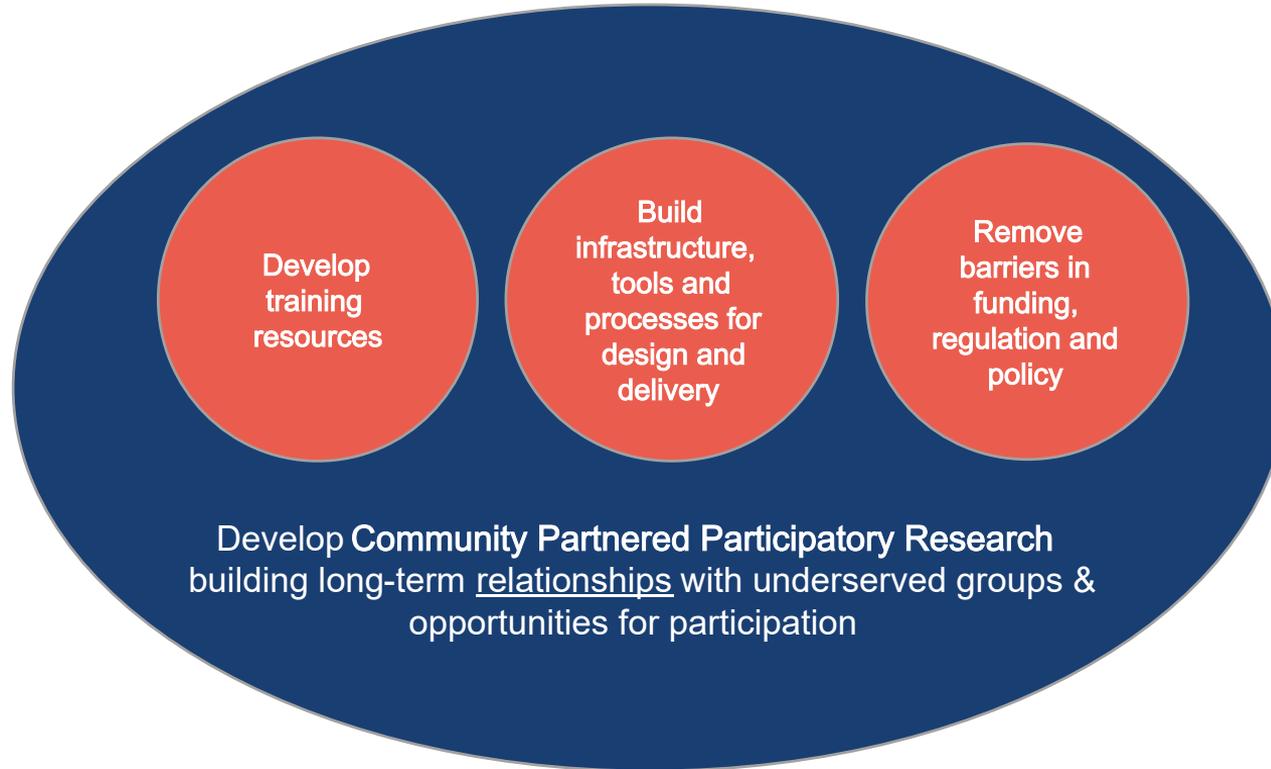


Data from NIHR Open Data Platform, 27 January 2021

The INCLUDE Framework for developing guidelines to improve inclusivity in clinical studies



INCLUDE's core objectives



Setting research priorities and engaging health professionals

Multimillion investment in new research projects to investigate higher COVID-19 risk among certain ethnic groups

Published: 29/07/2020 Read Time: 10 minutes Print



Six new projects to improve our understanding of the links between COVID-19 and ethnicity have been funded by the NIHR and UK Research and Innovation (UKRI).

These projects will seek to explain and mitigate the disproportionate death rate from COVID-19 among people from Black, Asian and minority ethnic (BAME) backgrounds, including BAME health and social care workers.

Welcome Medicine 2021



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Equality, Diversity And Inclusion In Health And Social Care Research

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Enrolment options

Translating Patient and Public Information

- Translating patient information sheets is a research cost that isn't usually centrally funded or delivered; exception made due to pandemic
- CRNCC coordinated translations to date: ~100 documents transcribed from 18 UPH studies
- Languages: Polish, Bengali, Urdu, Punjabi, French, Portugese, Welsh
- Translation of patient information will be an identifiable research cost from 2021/22 (NETSCC)

“COVID and Me” and vaccine research registry materials



Working with others to make a difference

People from Black, Asian and Minority Ethnic backgrounds and the elderly encouraged to participate in vital COVID-19 vaccine studies

Published: 13/10/2020 Read Time: 5 minutes Print



Researchers today have called on more volunteers from Black, Asian and Minority Ethnic backgrounds and the over 65s to participate in vital COVID-19 clinical studies to ensure that any vaccines developed will work for as many people as possible.

Ethnic minorities are currently underrepresented in vaccine clinical trials taking place across the UK, with only 11,000 volunteers from Asian and British Asian backgrounds while 1,200 are Black, African, Caribbean or Black British.

Minister for Equalities Kemi Badenoch, who is volunteering for Covid-19 vaccine trials being conducted by US biotechnology company Novavax at Guy's and St Thomas' NHS Foundation Trust, London, said:

"The UK is leading the world in the search for a Covid-19 vaccine. At home, we have to ensure every community trusts a future vaccine to be safe and that it works across the entire population.

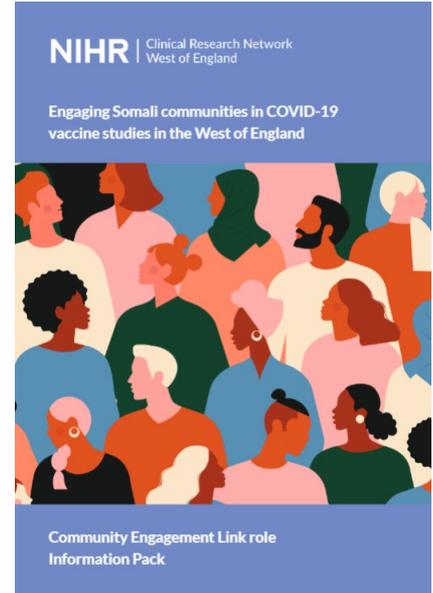
"But with less than half a per cent of people on the NHS Vaccine Registry from a Black background, we have a lot more work to do.

"That is why I am urging more people from the ethnic minority backgrounds to join me in signing up to the NHS Vaccine Registry and taking part in a trial. Together we can be part of the national effort to end this pandemic for good."



Initiatives across the country

- **Community Engagement Link roles** funded to coordinate and facilitate outreach work (West of England)
- **Community panels** established to advise on recruitment to vaccine and other UPH trials (Yorkshire and Humber; West Midlands)
- **Surveyed over 4000 people** to understand views around vaccine trials (West Midlands)
- **Bethnal Green library as vaccine trial location** - visible, accessible and attractive to diverse communities (North Thames)
- **Local radio activity** to reach key audiences - advertising as well as interviews / Q&A with local researchers (Greater Manchester; Wessex)
- **Early Contact and Engagement programme** to include specific discussions around study planning and set up (Yorkshire and Humber)
- Collaborating and sharing resources from **Centre for BME Health** (East Midlands)



Delivering research where it can benefit those who need it most

Chronic obstructive pulmonary disease Highlight Notice

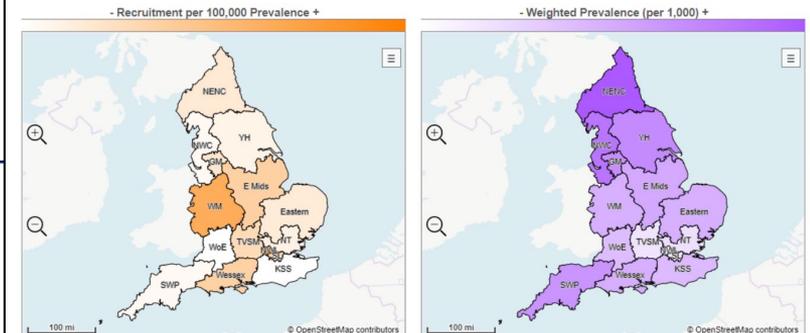
Published: 14/10/2020 Read Time: 7 minutes Version: Version 1.0 - October 2020 [Print this document](#)

Summary

- The Research for Patient Benefit (RfPB) programme is inviting proposals from eligible individuals and research teams for collaborative research projects to better understand and manage the health and social care consequences of Chronic Obstructive Pulmonary disease (COPD). We are particularly interested in populations in the North East of England (NE) where there is a high disease burden and which has been historically underserved by research activity.

Analysis of COPD Prevalence and Research Activity in ALL

NIHR | National Institute for Health Research



Where are the highest proportions of people with COPD being recruited into COPD studies?

Local Network	Recruitment	Prevalence	Recruitment per 100,000 Prevalence
North West London	2,033	24,496	8,299.3
West Midlands	4,348	117,284	5,412.6
East Midlands	2,926	95,014	3,079.5
Wessex	1,757	58,145	3,021.8
South London	1,258	44,523	2,825.5
Thames Valley and South Midlands	829	34,091	2,431.7
Greater Manchester	1,251	73,917	1,692.4
North East and North Cumbria	1,371	88,691	1,545.8
Eastern	1,110	77,333	1,454.4
North Thames	818	83,418	980.6
Yorkshire and Humber	1,205	136,395	890.0
North West Coast	597	107,103	557.4
South West Peninsula	274	51,736	529.6
West of England	83	42,843	193.7
Kent, Surrey and Sussex	140	85,607	163.5
England Total	21,999	1,119,576	1,964.9

Where is COPD most prevalent?

Local Network	Prevalence	General Population	Weighted Prevalence (per 1,000)
North East and North Cumbria	88,691	3,086,379	28.7
North West Coast	107,103	4,187,282	25.6
Yorkshire and Humber	136,395	5,858,143	23.1
Greater Manchester	73,917	3,252,533	22.7
South West Peninsula	51,736	2,354,579	22.0
East Midlands	95,014	4,812,818	19.7
Wessex	58,145	3,033,463	19.2
West Midlands	117,284	6,185,101	19.0
Eastern	77,333	4,085,704	18.9
Kent, Surrey and Sussex	85,607	4,814,220	17.8
West of England	42,843	2,444,032	17.5
North Thames	83,418	6,888,898	13.6
Thames Valley and South Midlands	34,091	2,594,123	13.1
South London	44,523	3,618,023	12.3
North West London	24,496	2,429,144	10.1
England Total	1,119,576	58,906,242	19.0



Thank you

