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## Scaling up our Impact: From Asthma to Respiratory Research & Innovation

Chairs: Professor Chris Griffiths and Professor Laura Bond

## FROM PARENT TO CLEAN AIR ADVOCATE

A Quest for Clean Air, Respiritory Health and Maternal Health Equity



BLACKPEARL CONSULTING GROUP

GLOBAL BLACK MATERNAL HEALTH
GLOAMAMA AWARDS

FOUNDER AND CEO
AGNES AGYEPONG



I am a South London born and raised mother of three who wants to make a positive impact on her family and her community in a sustainable way.





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Founder and CEO, Global Black Maternal Health



Agnes Agyepong is the founder and CEO of Global Black Maternal Health, an organisation committed to placing research and agency back into the hands of Black communities as leaders and

change agents in their own health narratives.





#### INTERNATIONAL JOURNAL OF RESEARCH METHODOLOGY Nurse Researcher







**RCNi** 

'There Is Already Disparity In Black Maternal Health -Pollution Is Making It Worse'

> Black mothers and their children are disproportionately impacted by pollution





#### **World Health** Organization

COVID-19

Global literature on coronavirus disease

Why bias is key to stopping institutional and structural racism in healthcare and research: The way we engage with marginalised communities, our research and our colleagues has to be reassessed Agyepong, Agnes.

### GRAZIA





# Beyonce BeyGOOD Foundation recognises Blackpearl Consulting Group

One of ten organisations selected by Beyonce across UK and Europe as part of her Renaissance World Tour

## Why Does Air Pollution Matter?

"He has symptoms of asthma and I have no way of knowing if this has been caused by my intake of pollution while pregnant...I'm concerned air pollution will make it worse".

"...will my baby develop asthma like his brother due to environmental factors of where we live?" "There was an incident in the media where a Black little girl lost her life due to air pollution"

"My son had a viral wheeze which turned into suspected asthma for which he now takes daily medication". "I've seen news stories of children that have died from pollution elsewhere in London and worry that it could happen to myself or my children".





Bell Ribeiro-Addy MP 🏶 · 15/06/2023 Thank you @global\_bmh for putting on the first annual Black Child Clean Air Conference today.

Black mothers overwhelmingly live in areas with higher concentrations of air pollution.

Cleaning up toxic air is a matter of environmental & social justice #CleanAirDay2023











Gary Fuller @DrGaryFuller · 15/06/2023 We rarely face up to the injustices at the heart of our #AirPollution problems.

Wonderful to get along to the @global\_bmh panel discussion and launch of the Black Child Clean Air Report for #CleanAirDay



## The way forward

what needs to change in the wider system and what we should be fighting for.



## **Community Engagement**

How does the sector currently engage with minoritised communities?

- Collaborate
- Communicate
- Amplify
- Awareness



Government Targets

How are can we set out air quality targets that are developed with the community and policy makers?



**Funding** 

Equitable funding for grassroots groups in research and implentation

## 2nd Annual Black Child Clean Air Conference

20th June 2024
House of Commons, London

## Thank you for listening!

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www.blackchildcleanair.com



## Next steps for respiratory health services in England

Asthma UK Centre for Applied Research 10th Annual Scientific Meeting 23 April 2024

Presented by:

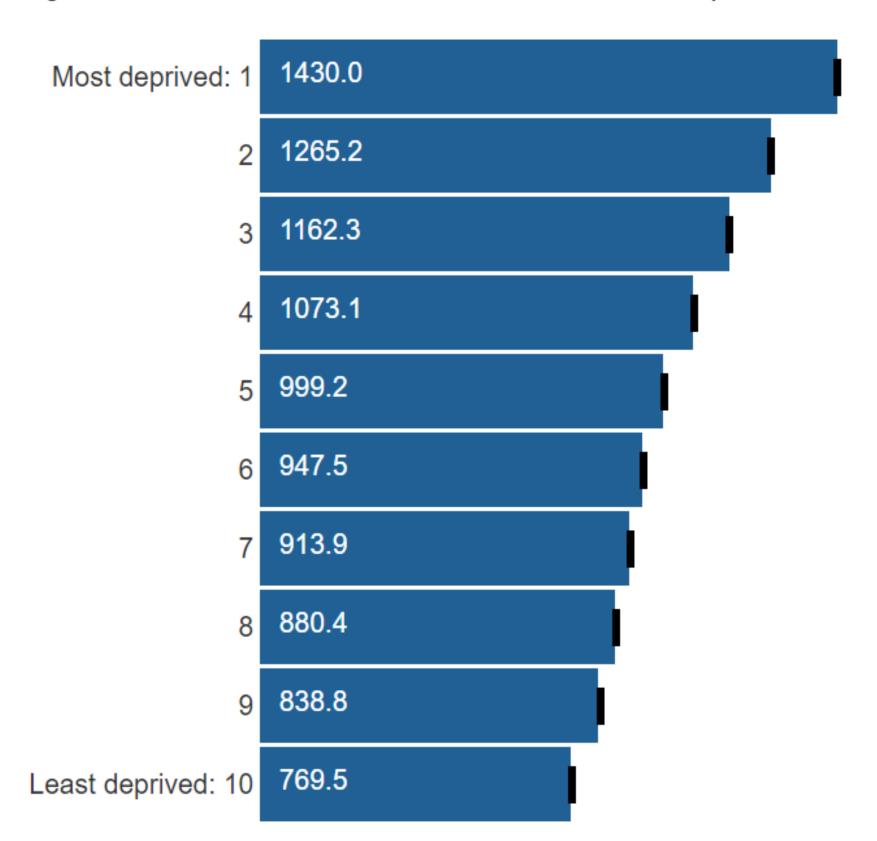
Jonathan Fuld, National Clinical Director for Respiratory Disease

### Why is respiratory a national priority?

- Chronic lung diseases have the most-stark health inequalities, with dramatically different morbidity and mortality outcomes depending on level of deprivation, ethnicity and geography
- Chronic respiratory symptoms are distressing and shrink peoples' lives, leading to inactivity and isolation at all ages and stages of life
- People do not recognise the severity of the problems that they have, often do not seek support and are not always well-served by existing services
- Crises caused by respiratory diseases are a leading cause of hospital utilisation in wintertime; unplanned attendances, admissions and bed days

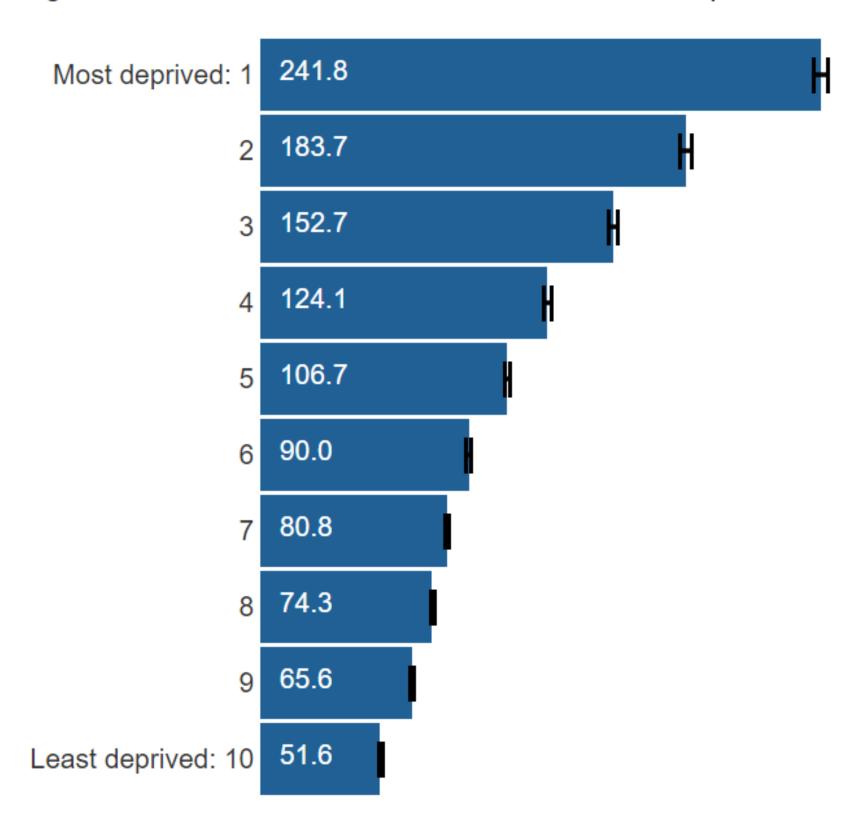
## ONS analysis found the largest differences by deprivation were observed for mortality involving respiratory conditions

All Cause Mortality by Index of Multiple Deprivation Decile (All People)
Age-standardised rate and 95% confidence limits per 100,000 person years



Chronic Obstructive Pulmonary Disease by Index of Multiple Deprivation Decile (All People)

Age-standardised rate and 95% confidence limits per 100,000 person years

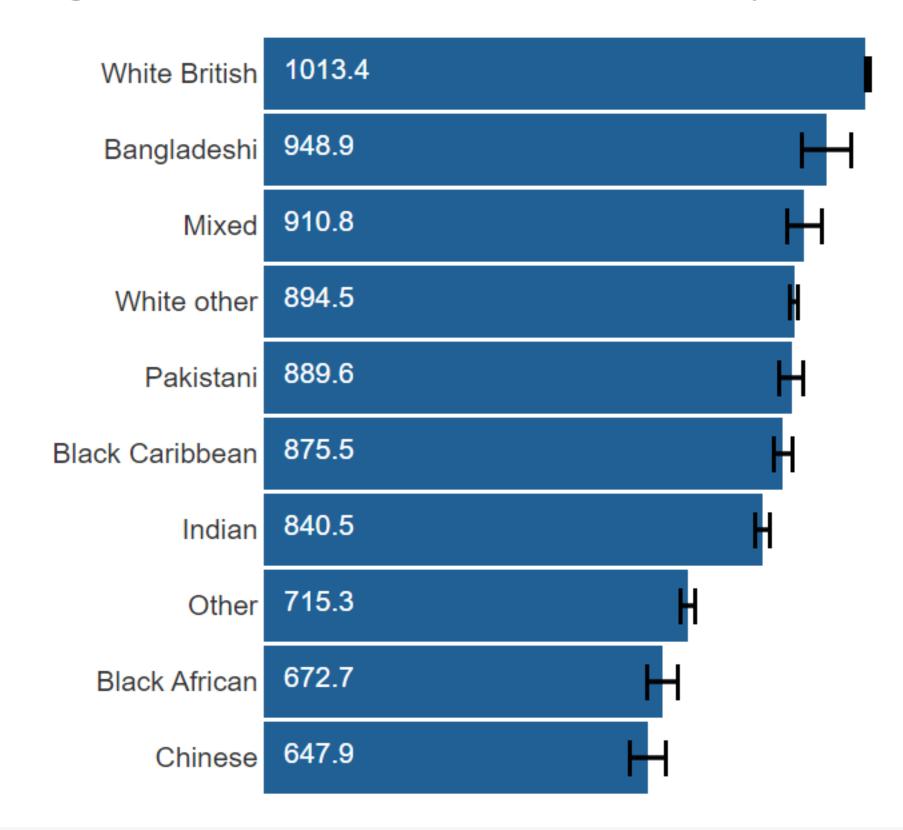


https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/bulletins/inequalitiesinmortalityinvolvingcommonphysic alhealthconditionsengland/21march2021to31january2023

## Together with significant differences in asthma outcomes amongst females from different ethnic groups

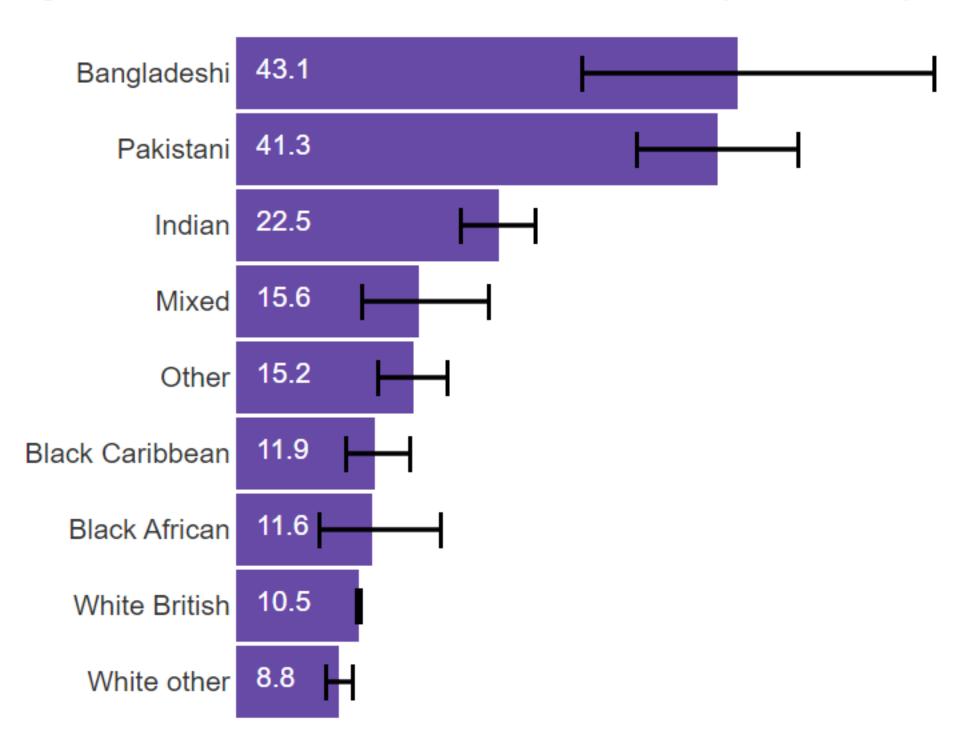
#### All Cause Mortality by Ethnic Group (All People)

Age-standardised rate and 95% confidence limits per 100,000 person years

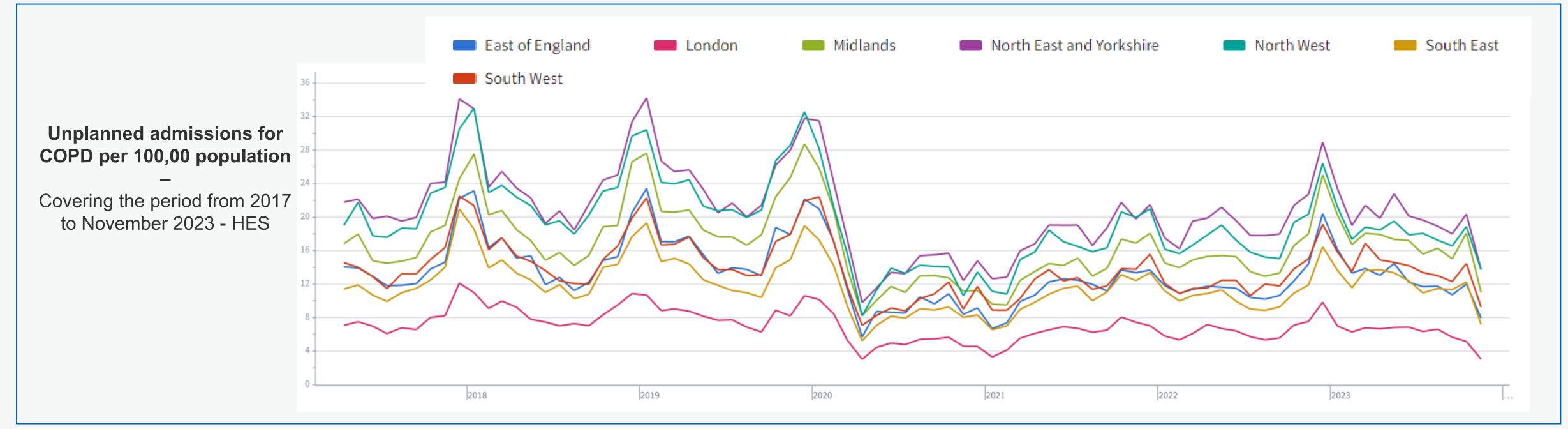


#### **Asthma by Ethnic Group (Female)**

Age-standardised rate and 95% confidence limits per 100,000 person years



## Outcomes, along with unplanned admissions, also vary by geography

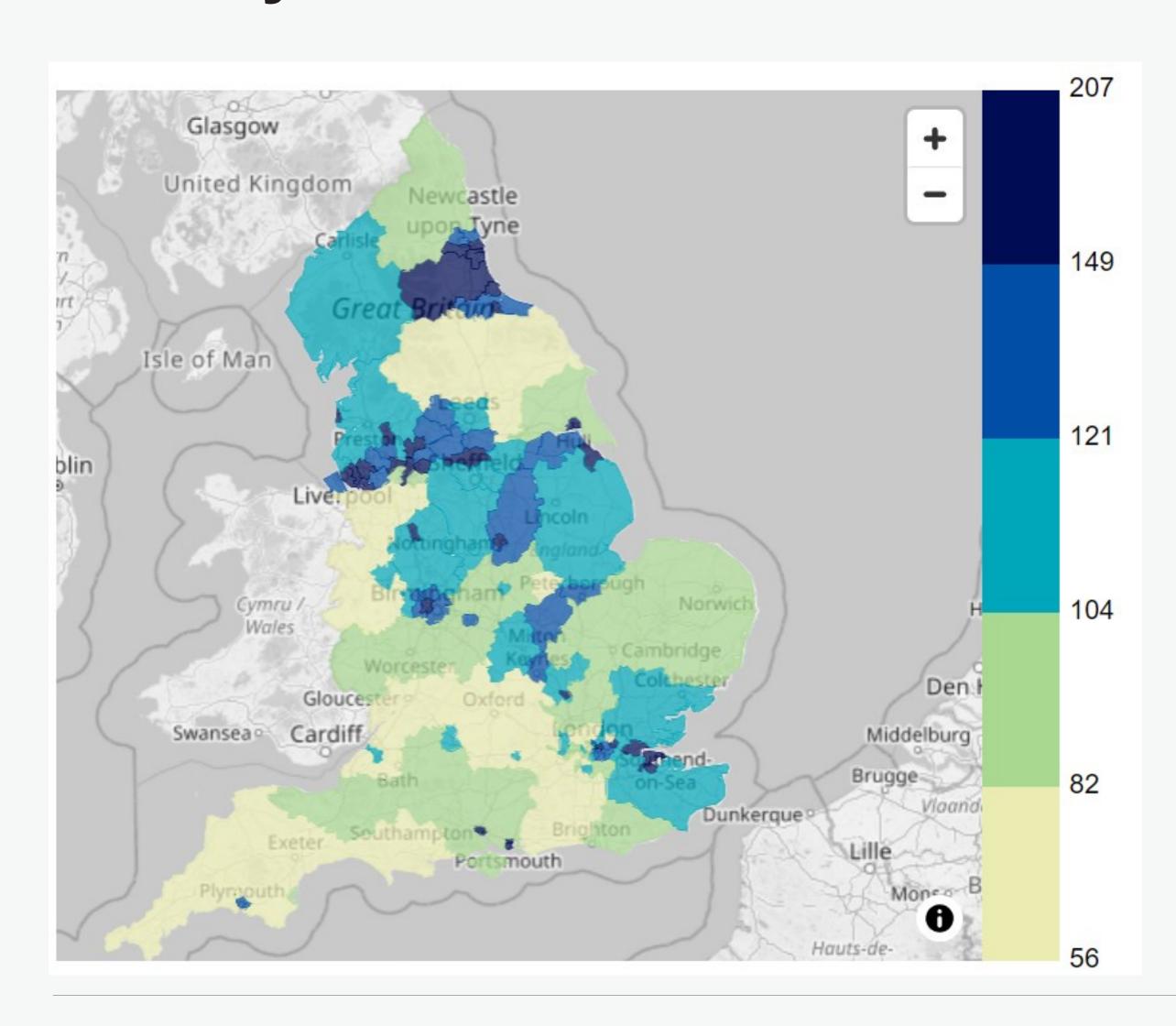


Area ▲ ▼	Count ▲ ▼	Value ▲▼		95% Lower Cl	95% Upper Cl
England	59,475	106.9		106.1	107.8
North West region	9,714	135.0	H	132.3	137.7
North East region	3,547	127.7	H	123.5	131.9
Yorkshire and the Humber region	6,435	118.3	Н	115.5	121.3
West Midlands region	6,825	114.4	Н	111.7	117.2
East Midlands region	5,222	105.0	H	102.2	107.9
East of England region	6,496	95.8	H	93.5	98.2
London region	5,406	95.5	H	92.9	98.1
South East region	9,467	94.9	H	93.0	96.8
South West region	6,363	92.0	Н	89.8	94.3

Mortality rate from respiratory disease, all ages (Persons, 1 year range) 2022 Directly standardised rate – per 100,000

Source: Office for Health Improvement and Disparities (based on Office for National Statistics source data)

## Poor outcomes exist, sometimes in small pockets, across the country



### Age-standardised mortality rates for deaths from COPD March 2022 to January 2023

By Upper Tier Local Authority (All People)
Age-standardised rate and 95% confidence limits per 100,000 person
years
ONS

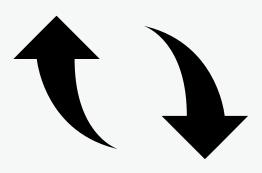
It is for this reason that COPD is one of the five priority **areas** within the **Core20plus5** programme

### What we should all be working towards

People living with lung disease should have the best possible outcomes irrespective of deprivation, locality and ethnicity across key measurable domains:



Symptoms and wellbeing are optimised



Increasing healthy life expectancy and reducing the risk of mortality



Reducing hospital bed occupancy and admissions

## The key first step is a diagnosis

Early and accurate recognition of the causes of the symptoms that people face enables access to key evidence-based interventions

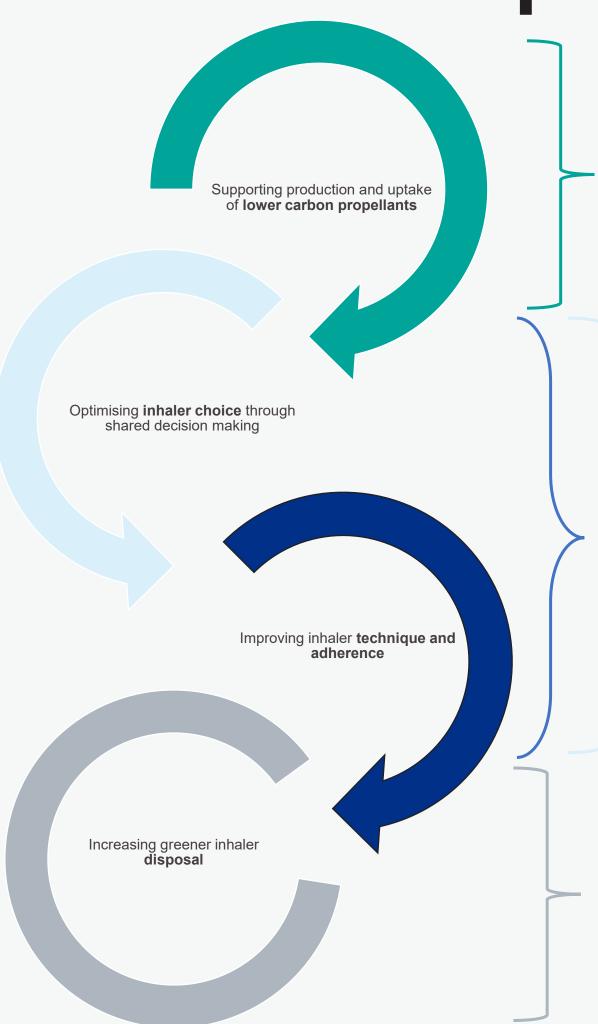
There are examples from across the country where systems, with the support of respiratory clinical networks and the national team in NHS England, have been able to restore and increase the provision of diagnostic testing in the community.



## Irrespective of deprivation or ethnicity, interventions improve outcomes

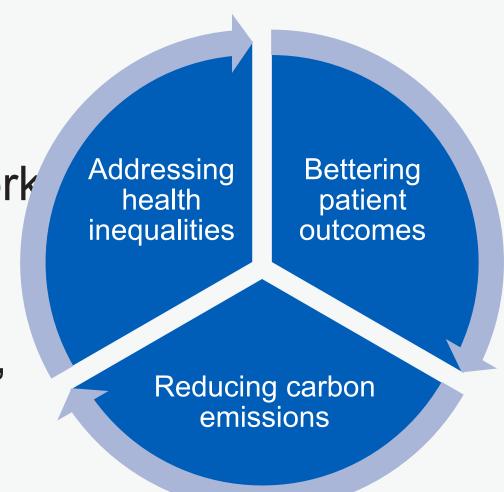
- Tobacco dependency treatment is effective and improves outcomes across conditions and circumstances
- People with chronic lung diseases should be supported to keep well and prevent deterioration through measures such as vaccination and supported self-management
- Across all care settings there are high-value and evidence-based interventions that are
  effective irrespective of the deprivation or ethnicity of the individual for example optimal
  inhaler therapy and lung volume reduction, antifibrotic treatments for interstitial lung diseases
  and biologics for severe asthma.
- Pulmonary rehabilitation can transform lives across a range of chronic respiratory conditions

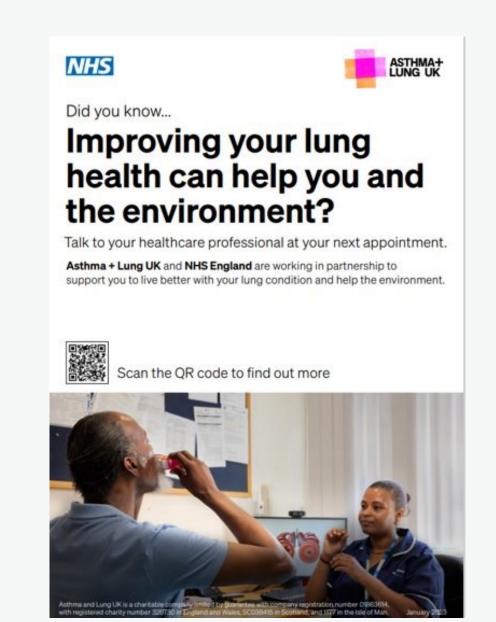
## We are working to optimise inhaler therapy, address health inequalities and reduce carbon emissions



Focus to date on excessive SABA use and poor asthma control

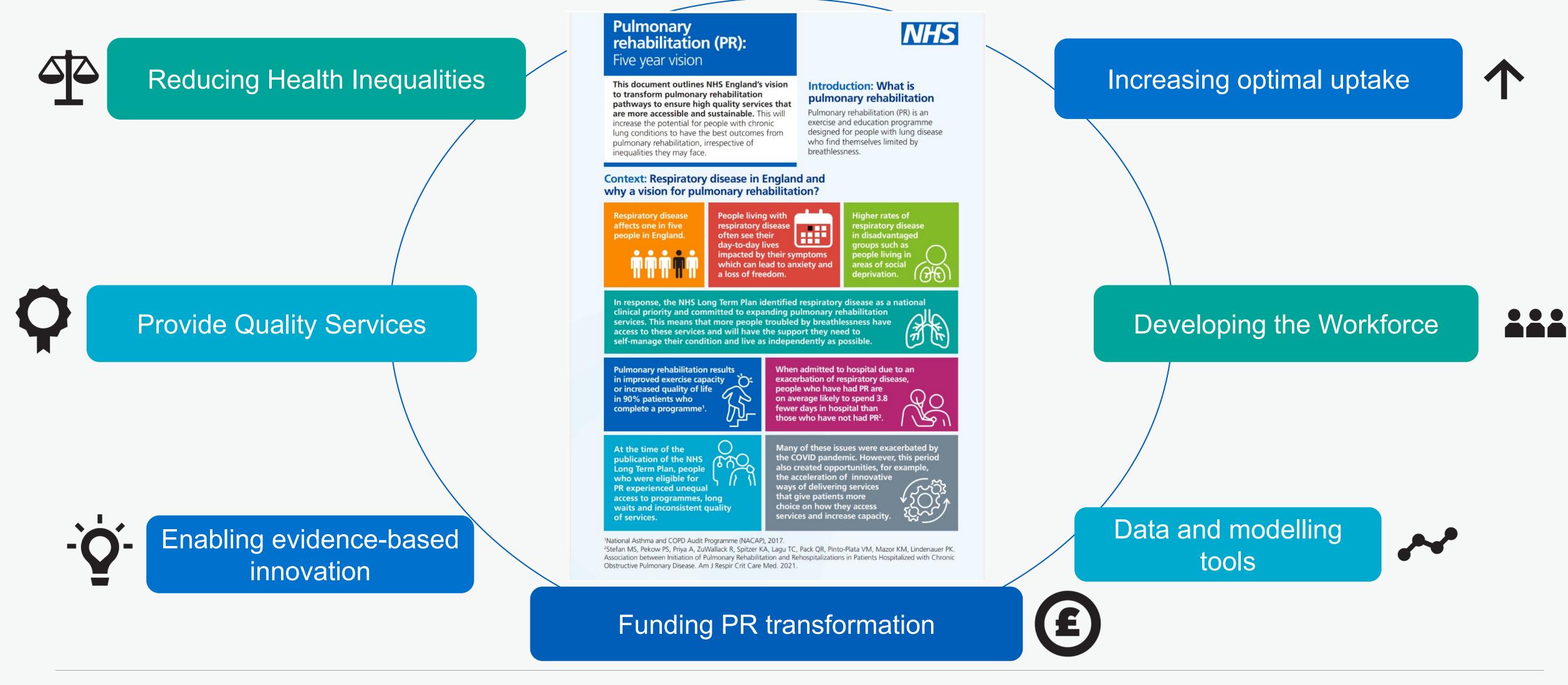
- Incentives Pharmacy quality scheme (PQS) and Quality Outcomes Framework (QOF)
- Patient communications via A+LUK
- Healthcare-focused resources (training, webinars, case studies)
- NICE patient decision aid





Forthcoming refreshed NICE / BTS / SIGN asthma guideline provides opportunity for focus on **asthma reviews** 

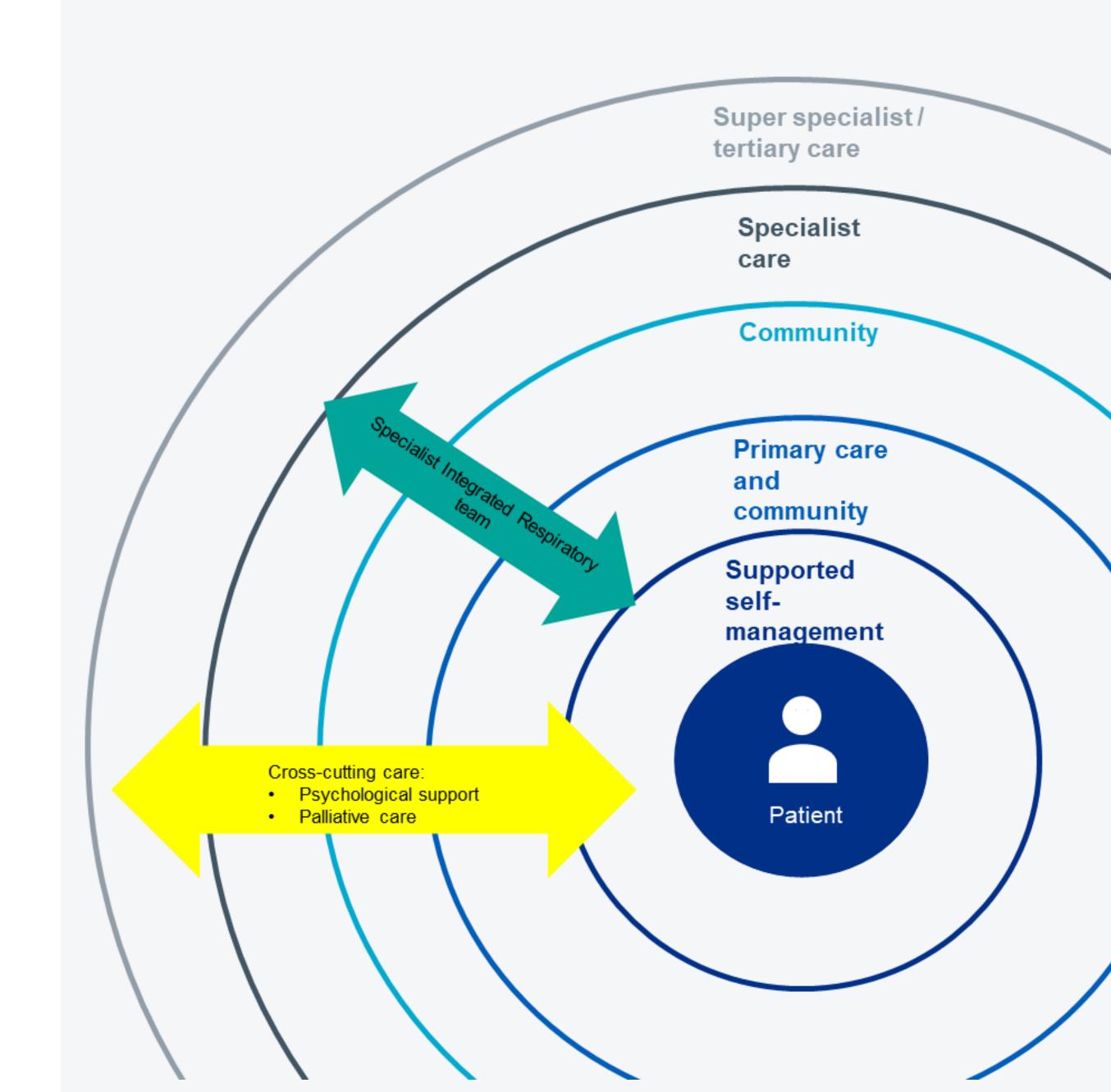
## We have developed a vision that sets out the areas of focus for Pulmonary Rehabilitation transformation



## Integrated respiratory care

NHS England is focusing on supporting systems to increase access to those key interventions that can help people better manage their conditions.

Delivered at scale, these have the potential to improve quality of life, reduce hospitalisations and improve healthy life expectancy



### Comprehensive winter support measures

#### Delivering operational resilience

support primary care to ensure proactive identification and management of people with complex needs and long-term conditions

- 1. Identification of those at high risk
- 2. Optimise care for winter
- 3. Strengthened support for those in crises in winter

- 1. Define exacerbations events (course of oral steroids and COPD diagnosis) as well as admissions
- 2. Specialist review to optimise health and deliver high value interventions
- 3. Provide 7 day community assessment of those at risk of admission and deterioration linked to hospital and community pathways

## Next steps for specialist respiratory services

National responsibility

System responsibility

Commissioning responsibility for severe asthma, ILD, complex home ventilation, cystic fibrosis

Delegation over future years

Commissioning responsibility for severe asthma, ILD, complex home ventilation, cystic fibrosis

Service specifications, policies and costs of high-cost drugs (NICE or NHS England)

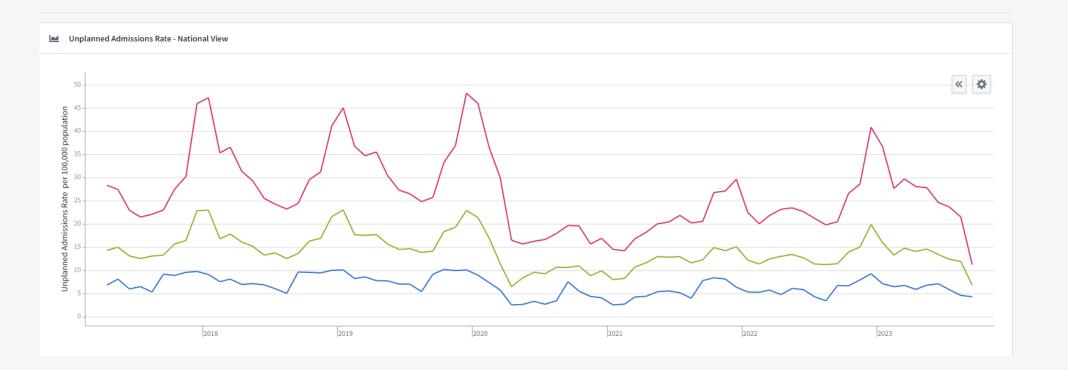
The opportunity here is to transform services and outcomes:

- Timely and equitable access to high quality care as close to home wherever possible
- Embedding specialist expertise and care within ICB based integrated care pathways
- An increased number of networked specialist centres widening access to high value treatments
- ICB and regional respiratory network support for pathways and services

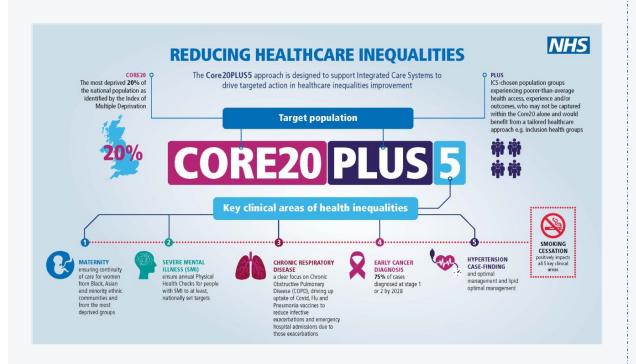
## Areas of focus and enablers

NHS England has a focus on three key areas that are crucial to the successful implementation of each of the specific interventions and approaches.

#### Access to good quality data and analytics

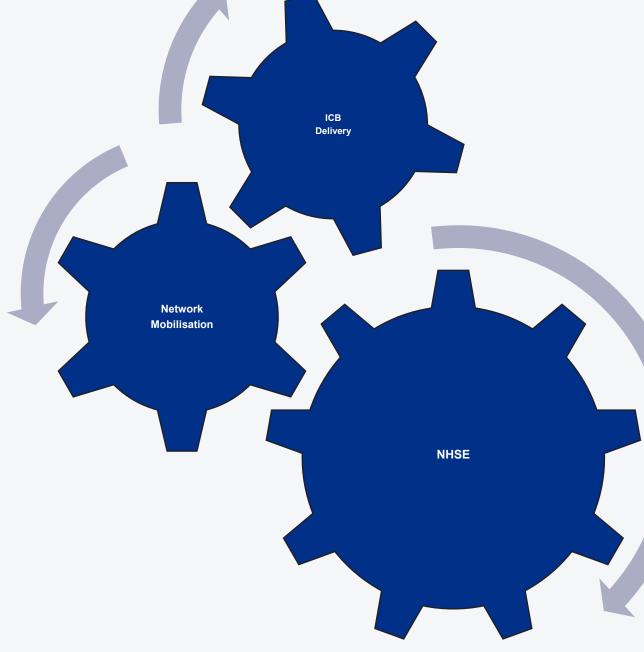


### **NICE EVA**



Addressing health inequalities

#### Respiratory clinical networks



### Developing a national respiratory data strategy



#### Vision:

A clear, ambitious and achievable national respiratory data strategy that is clear on developing and expanding the range of respiratory metrics, tools and resources. It should also drive improvements in respiratory data collection and linkage.



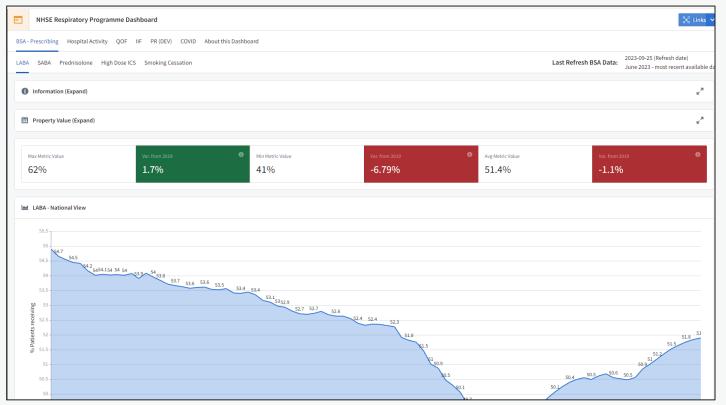
The data should tell the story of the situation of care for people with lung problems: what is needed to improve care and **reduce health inequalities**, how we are doing and what impacts we are having.



A key focus continues to be on ensuring more data is made available to all regions and systems, ensuring there is consistency of data, definitions, and metrics to enable meaningful comparison and the ability to monitor progress, primarily through our national respiratory dashboard.

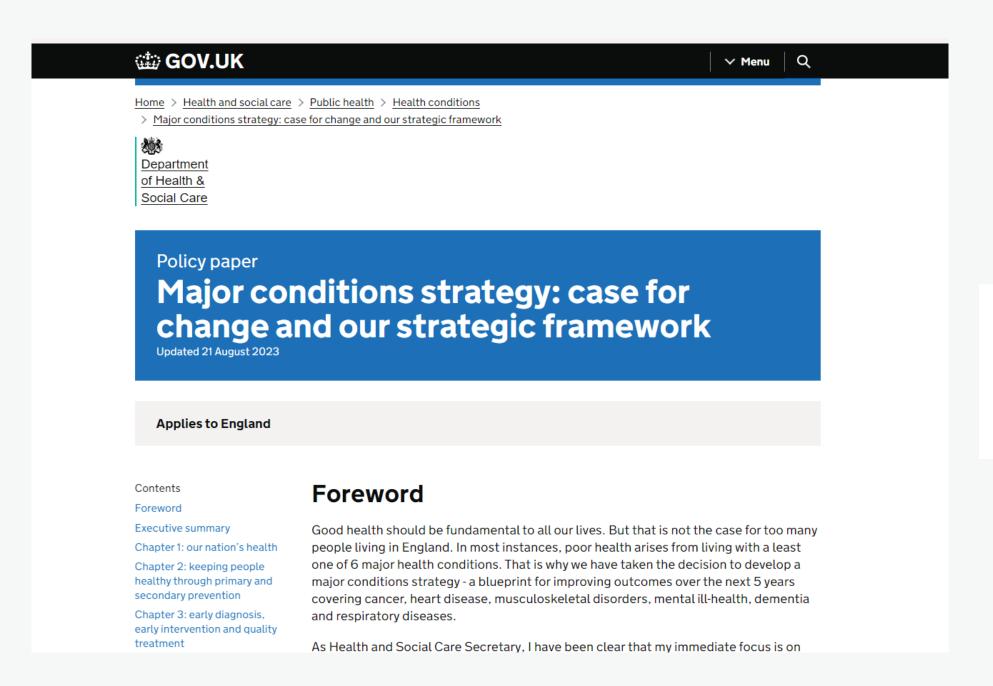


We have been focusing on developing data to enable robust insights into programme delivery and progress.





## Further opportunities and working with partners



















Royal College
of Physicians

National Respiratory Audit
Programme (NRAP) Programme (NRAP)





### Thank You



in company/nhsengland



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# Priority setting as a coalition and progress to date

### Sarah MacFadyen

Vice-chair, Taskforce for Lung Health and Head of Policy, Asthma+Lung UK



### **Today**

- Where the Taskforce came from
- What we've achieved so far
- Where we're going next



#### Who we are



































































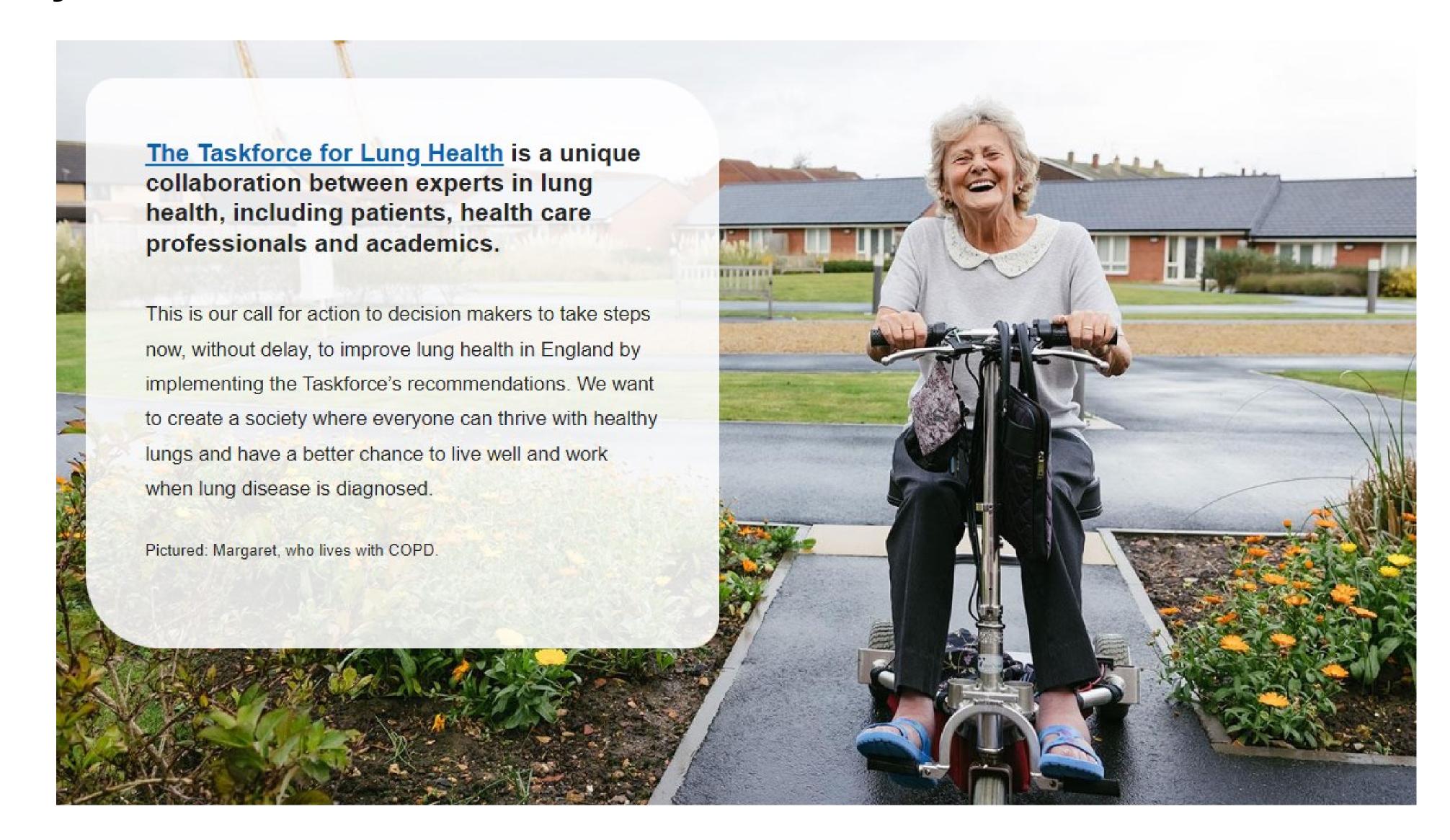








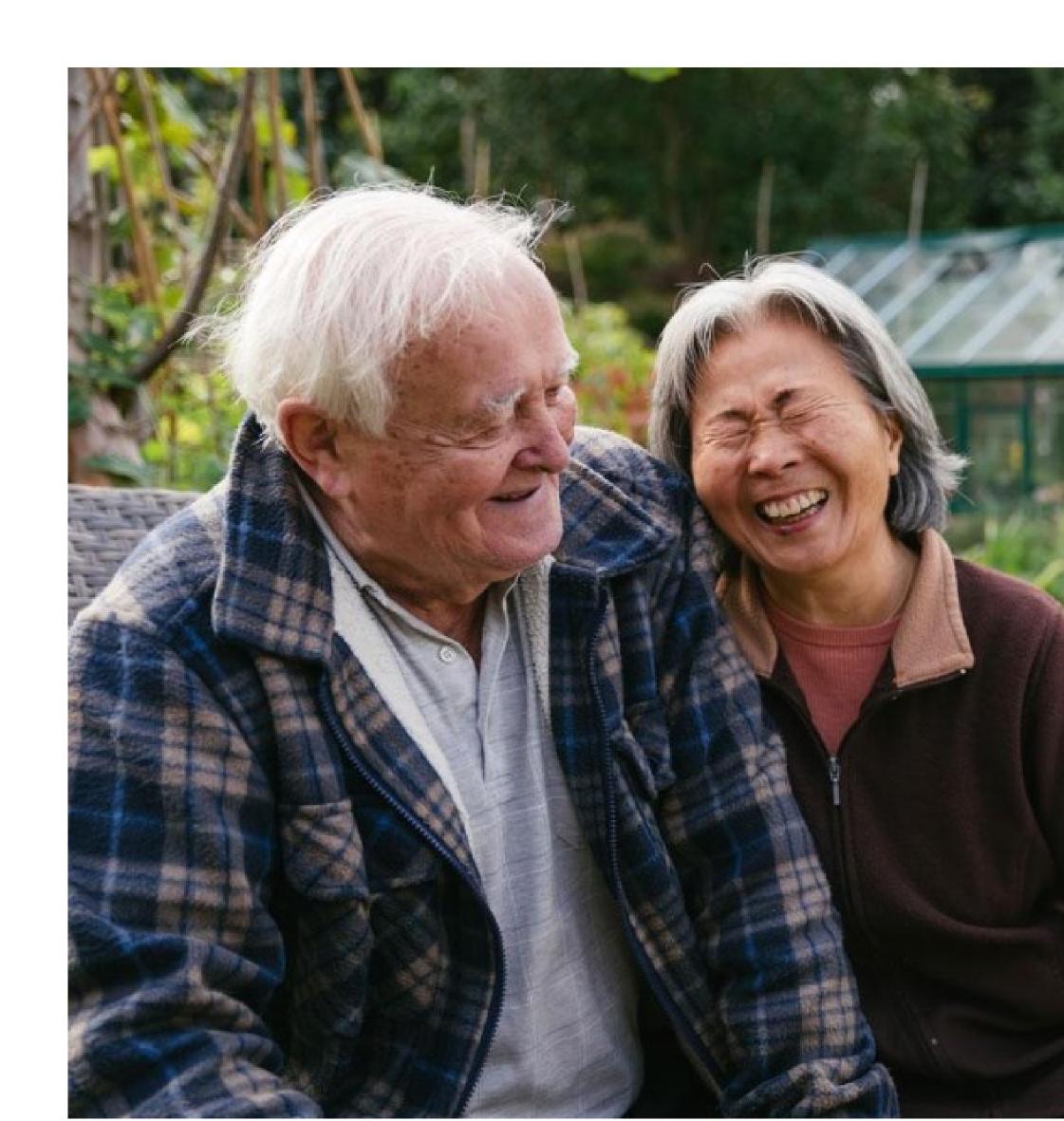
#### **History of the Taskforce**







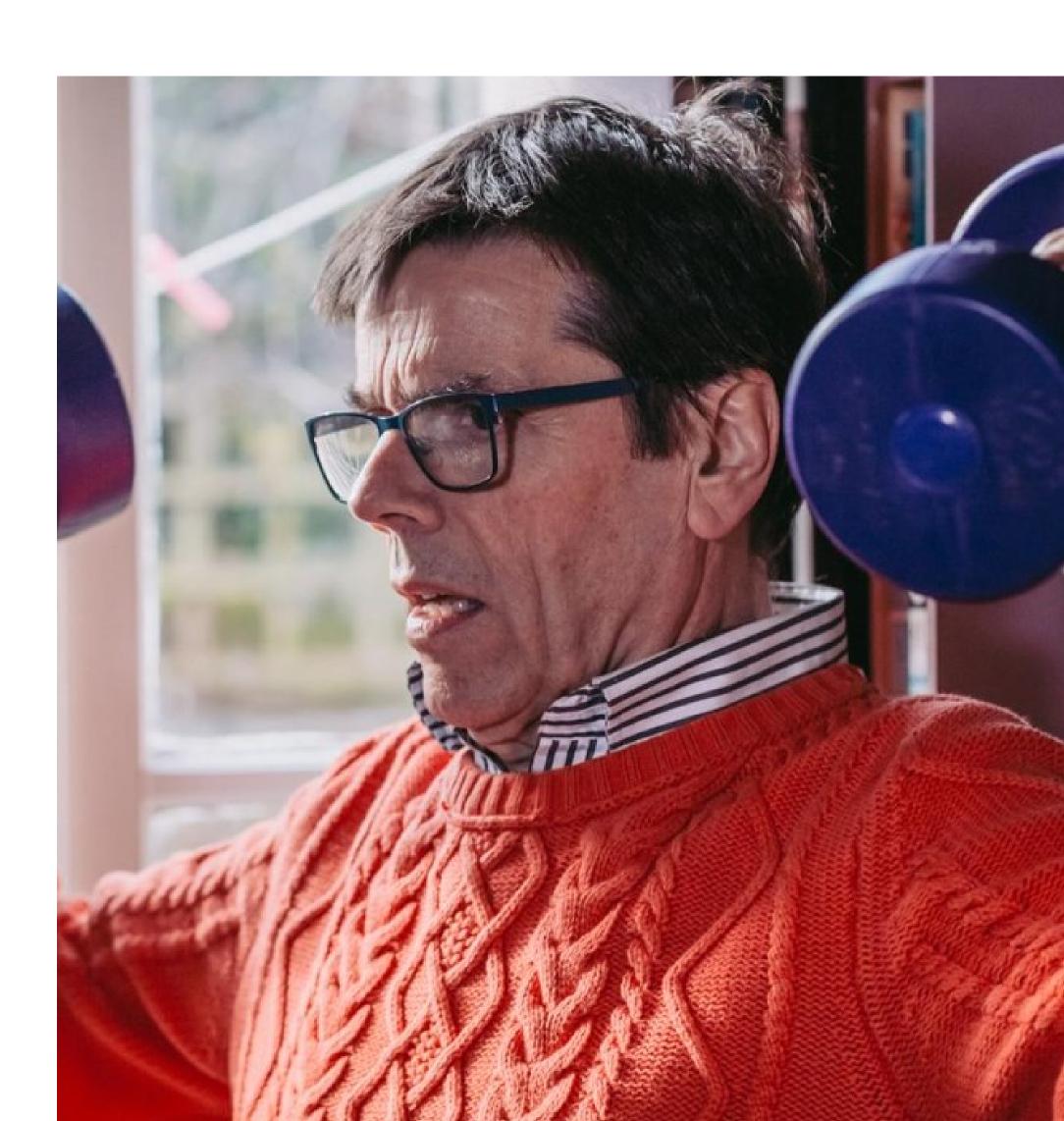
- Engaged with all 42 ICSs
- Established the national lung health data tracker
- Commissioned new research on patient pathways and prevalence
- Executed a public-facing breathlessness campaign in Birmingham







- NHS Adult Breathlessness
   Pathway
- Revised Asthma Guidelines
- Expanded Access to antifibrotics
- Accelerated Access to Biologics
- Targeted Lung Health Checks
- Expanding access to pulmonary rehab and support at home









- Diagnosis breathlessness pathway and equitable access to testing
- Treatments improving access to vaccinations and approved treatments
- Workforce promoting workforce integration and lobbying for adequate staffing across respiratory



- Join the Taskforce
- Become a funding partner
- Lobby the new government with us

### Get in touch: smacfadyen@asthmaandlung.org.uk







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### Scaling up our Impact: From Asthma to Respiratory Research & Innovation Panel discussion

#### Chairs:







Professor Laura Bond



Agnes Agyepong Global Black Maternal Health

#### Panellists:



Dr Jonathan Fuld **National Clinical** Director for Respiratory Disease



Sarah MacFadyen Taskforce for Lung Health and Asthma + Lung UK



Professor Fernando Martinez University of Arizona