Members educational session
“Data to measure inequality”

Thursday 3rd March 2022

Good morning

The session is due to start at 10:00

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Members educational session
“Data to measure inequality”

Thursday 3rd March 2022

10:00 – 11:00

Chris Carrigan, Expert Data Adviser

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Areas to cover

- What do we mean by equality data?
- What are the legal requirements?
- What data is available to monitor equality, and where is it?
- Where can I find out more?

- Plus, anything you want to ask……

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A legal duty – Equalities Act 2010

The Equalities Act 2010 and protected characteristics	**Data recorded in the routine datasets, such as for cancer**
age;	▪ Yes
sex;	▪ Yes
sexual orientation.	▪ Yes
gender reassignment;	▪ No
disability;	▪ No. Only in community services, HIV/AIDS, IAPT and mental health
marriage and civil partnership;	▪ Yes. In admitted patient care data (and mental health data)
pregnancy and maternity;	▪ NO, but held in maternity datasets
race;	▪ NO, but ethnicity is well recorded
religion or belief;	▪ NO

A legal duty – Health and Social Care Act 2012

- The Health and Social Care Act 2012
  - introduced the first specific legal duties on health inequalities, including duties on the Secretary of State
  - All staff undertaking NHS and public health functions on behalf of the Secretary of State are responsible for ensuring compliance with these duties. A breach of these requirements could result in a judicial review
  - Health data is essential to identify and quantify health inequalities, including planning health policy, evaluating the impact of policy, and tracking changes over time

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A practical duty

- “An Equality Impact Assessment is an essential part of identifying and assessing relevant evidence on the proposed new initiatives to improve cancer services, helping the NHS meet its duties in relation to equality legislation and regulations”

- Equality Impact Assessment, England Cancer Strategy (2015-2020)

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Other dimensions of equality

- Deprivation (Rich vs. poor)

  "Those in the most deprived communities are 30% more likely to have high blood pressure, which is the biggest single risk factor for heart attack and stroke"

- Geography

  "Overall, health outcomes are more favourable in rural areas than urban areas; the most recent statistics show that life expectancy is higher, infant mortality rate lower and potential years of life lost from common causes of premature death lower in rural areas than in urban areas."

- Education

  "People who are well educated experience better health as reflected in the high levels of self-reported health and low levels of morbidity, mortality, and disability"

- Language

  "People who cannot speak English well are more likely to be in poor health"

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A more detailed look at one of the dimensions - ethnicity

Ethnicity data in health records

ETHNIC CATEGORY e

The 16+1 ethnic data categories defined in the 2001 census is the national mandatory standard for the collection and analysis of ethnicity.

Format / Length

an2

Description

ETHNIC CATEGORY e is the same as attribute ETHNIC CATEGORY CODE 2001 a.

The 16+1 ethnic data categories defined in the 2001 census is the national mandatory standard for the collection and analysis of ethnicity.

The national code must be transmitted as the first character in the 2 character field. The second character is optional for use locally. It must, however, be able to be grouped consistently with the 16 main categories.

National code Z should be used where the PERSON c has been given the opportunity to state their ETHNIC CATEGORY c but chose not to. Default code 99 should be used where the PERSON c's ETHNIC CATEGORY c is not known.

NHS NHS Data Model and Dictionary

- This is the NHS Data Dictionary
- It shows that the definition is driven from the UK census
- These definitions will apply across the UK

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How is ethnicity defined in the data?

White

A	British
B	Irish
C	Any other White background

Mixed

D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other mixed background

Asian or Asian British

H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background

Black or Black British

M	Caribbean
N	African
P	Any other Black background

Other Ethnic Groups

R	Chinese
S	Any other ethnic group
Z	Not stated

Ethnic Category Code is the classification used for the 2001 UK Census

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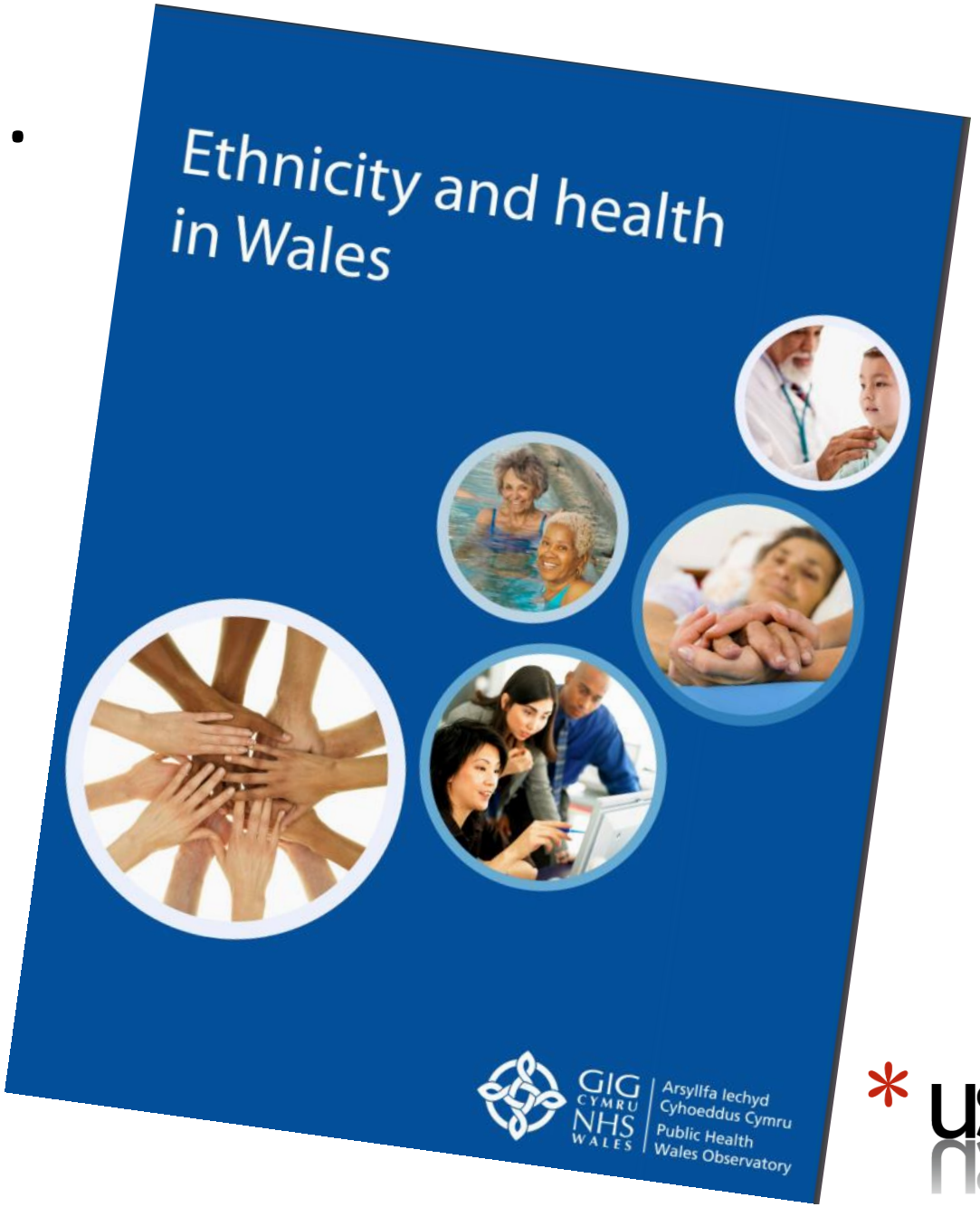
Population data…..



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Indicator	Period	England	East Midlands region	Derby	Derbyshire	Leicester	Leicestershire	Lincolnshire	Northamptonshire	Nottingham	Nottinghamshire	Rutland
Records with valid ethnicity code	2018/19	86.1	81.9	94.1	77.7	96.3	98.9	84.2	41.1	75.2	96.0	97.3
White ethnic group: % of population	2011	85.4	89.3	80.3	97.5	50.5	91.4	97.6	91.5	71.5	95.5	97.1
Mixed/Multiple ethnic group: % of population	2011	2.25	1.90	2.91	0.92	3.51	1.31	0.87	2.05	6.63	1.36	1.04
Asian or Asian British ethnic group: % of population	2011	7.8	6.5	12.5	1.1	37.1	6.3	1.0	3.7	13.1	2.2	1.0
Black or Black British ethnic group: % of population	2011	3.5	1.8	2.9	0.4	6.2	0.6	0.4	2.4	7.3	0.6	0.7
Other ethnic group: % of population	2011	1.0	0.6	1.3	0.1	2.6	0.4	0.2	0.4	1.5	0.3	0.2
Supporting information - % population from ethnic minorities (Female)	2016	13.8	10.6	16.1	3.7	50.3	8.3	3.4	8.8	23.8	4.4	1.8*
Supporting information - % population from ethnic minorities (Male)	2016	13.3	9.8	17.2	2.3	46.9	7.1	2.3	7.8	24.6	3.7	*
Supporting information - % population from ethnic minorities (Persons)	2016	13.6	10.2	16.7	3.1	48.6	7.8	2.9	8.3	24.2	4.0	0.9*
Black and Minority Ethnic (BME) Population	2011	14.6	10.7*	19.7	2.5	49.5	8.6	2.4	8.5	28.5	4.5	2.9
Percentage of population whose ethnicity is not 'White UK'	2011	20.2	14.6*	24.7	4.2	54.9	11.1	7.0	14.3	34.6	7.4	5.7
Percentage of deliveries to mothers from Black and Minority Ethnic (BME) groups	2018/19	20.3	13.5	21.4	3.8	55.2	13.3	2.3	12.2	29.1	6.3	5.0

Ethnicity at the population level (national and local) is easily available

When is ethnicity data recorded about patients?

- On your GP Record
  - When you register with your GP *
- On your hospital record
  - Each A&E Attendance
  - Every Outpatient appointment
  - Every hospital admission
  - Some specialist treatments (sometimes via linkages)
  - During maternity and birth

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How complete is ethnicity data – GP Records?

- On your GP Record
  - "Ethnicity recording within primary care computerised medical record (CMR) systems is suboptimal, exacerbated by tangled taxonomies within current coding systems"

    Ethnicity recording in primary care computerised medical record systems: an ontological approach

    https://informatics.bmj.com/content/23/4/799

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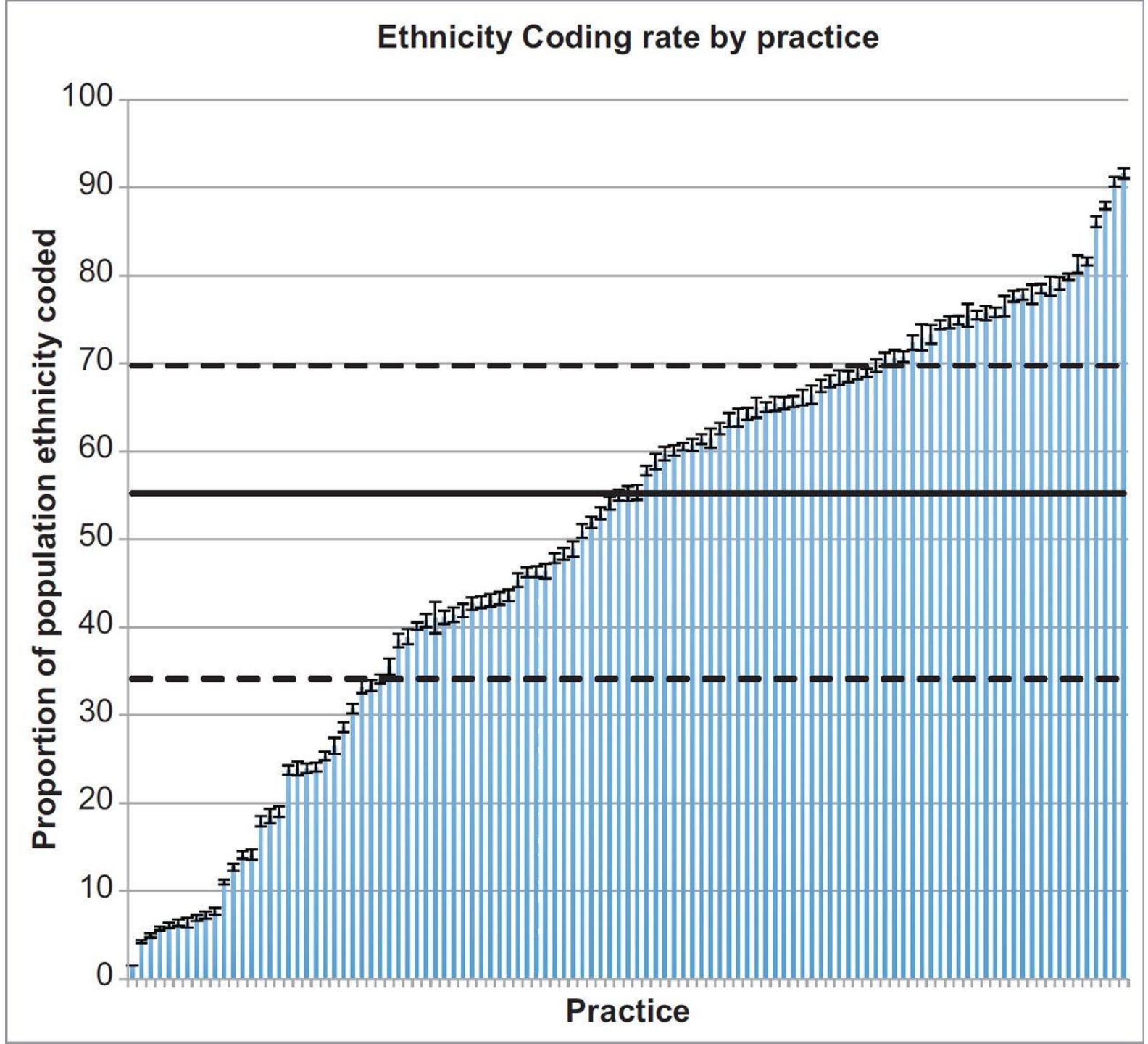
Ethnicity Coding rate by practice
Proportion of population ethnicity coded
100
90
80
70
60
50
40
30
20
10
0
Practice

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How complete is ethnicity data – Hospitals?

- On your hospital record
  - Each A&E Attendance
  - Every Outpatient appointment
  - Every hospital admission
  - Some specialist treatments (sometimes via linkages)

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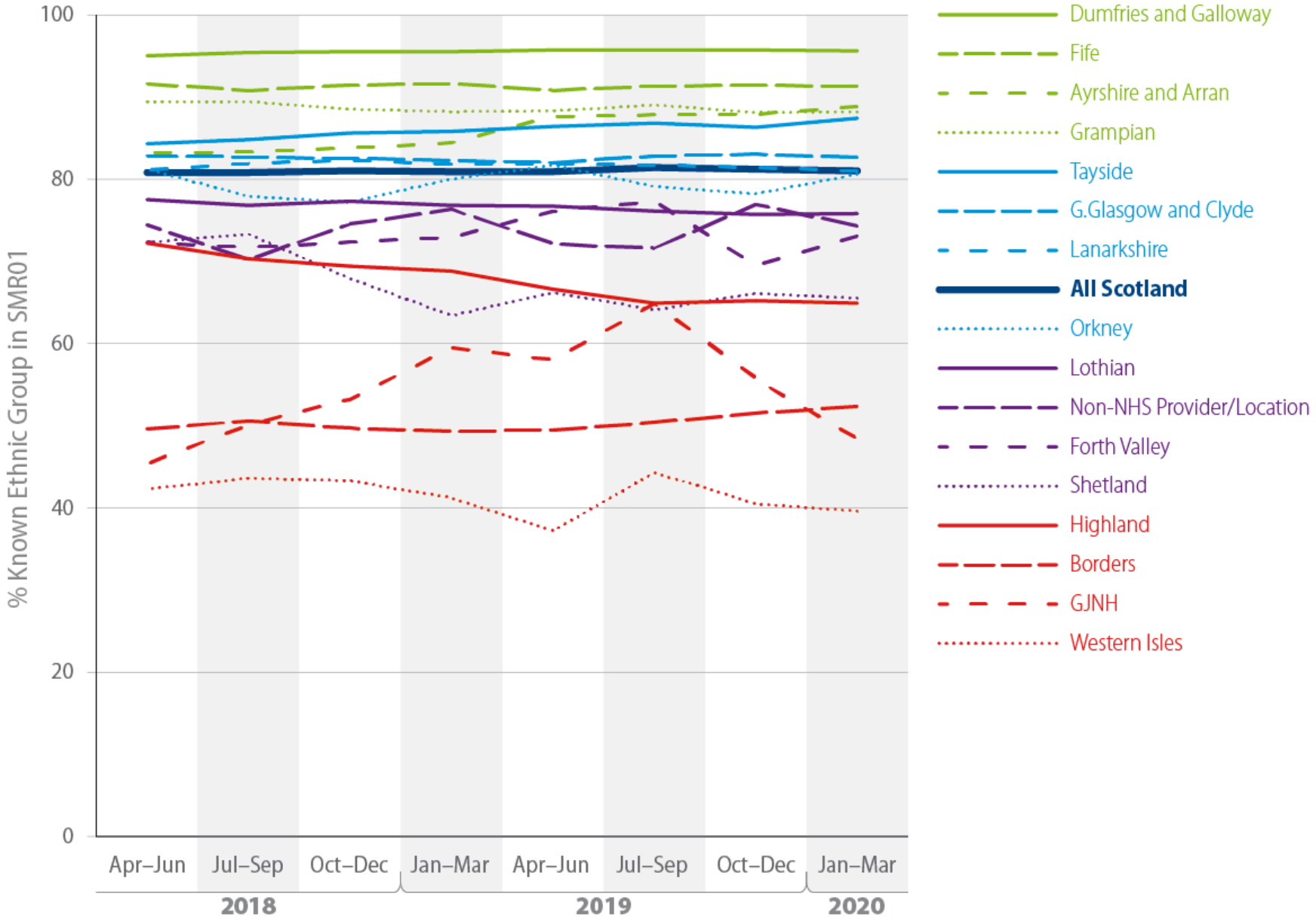
Percentage of acute inpatient and day case records with a known ethnic group
by NHS Board of treatment and quarter: quarters ending June 2018–March 2020



Hospital-recorded ethnicity (Scotland)

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Quality of hospitals ethnicity data - England

October 2020, National comparisons. Error rate in recording of ethnicity data, for admitted patients, outpatients, A&E attendances, and an overall summary

Summary of error rates - overall & regions				
Row Labels	Sum of APC error rate	Sum of OP error rate	Sum of A&E error rate	Sum of Overall ethnicity error rate
INDEPENDENT SECTOR	11.2%	18.3%	28.2%	19.5%
NHS ENGLAND EAST OF ENGLAND (EAST)	5.5%	6.7%	10.1%	7.0%
NHS ENGLAND LONDON	4.0%	6.5%	5.9%	6.1%
NHS ENGLAND MIDLANDS (CENTRAL MIDLANDS)	2.4%	5.7%	8.4%	5.6%
NHS ENGLAND MIDLANDS (NORTH MIDLANDS)	6.3%	8.1%	7.2%	7.8%
NHS ENGLAND MIDLANDS (WEST MIDLANDS)	5.3%	5.9%	4.8%	5.7%
NHS ENGLAND NORTH EAST AND YORKSHIRE (CUMBRIA AND NORTH EAST)	2.3%	5.7%	4.8%	5.1%
NHS ENGLAND NORTH EAST AND YORKSHIRE (YORKSHIRE AND HUMBER)	4.2%	4.1%	5.7%	4.3%
NHS ENGLAND NORTH WEST (CHESHIRE AND MERSEYSIDE)	1.0%	3.4%	6.6%	3.5%
NHS ENGLAND NORTH WEST (GREATER MANCHESTER)	2.7%	4.1%	5.0%	4.1%
NHS ENGLAND NORTH WEST (LANCASHIRE AND SOUTH CUMBRIA)	1.4%	2.2%	2.5%	2.1%
NHS ENGLAND SOUTH EAST (HAMPSHIRE, ISLE OF WIGHT AND THAMES VALLEY)	1.8%	5.0%	6.8%	4.8%
NHS ENGLAND SOUTH EAST (KENT, SURREY AND SUSSEX)	1.6%	4.0%	7.1%	4.1%
NHS ENGLAND SOUTH WEST (SOUTH WEST NORTH)	11.5%	7.0%	4.6%	7.4%
NHS ENGLAND SOUTH WEST (SOUTH WEST SOUTH)	2.3%	3.7%	7.0%	4.0%
Grand Total	**4.1%**	**6.1%**	**7.8%**	**6.1%**

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Quality in hospitals ethnicity data - Yorkshire

October 2020, Yorkshire and Humber Trusts. Error rate in recording of ethnicity data, for admitted patients, outpatients, A&E attendances, and an overall summary

Summary of error rates - Y&H and provider					
Row Labels	Sum of APC error rate	Sum of OP error rate	Sum of A&E error rate	Sum of Overall ethnicity error rate	Rank of overall error rate
NHS ENGLAND NORTH EAST AND YORKSHIRE (YORKSHIRE AND HUMBER)	**4.2%**	**4.1%**	**5.7%**	**4.3%**	
AIREDALE NHS FOUNDATION TRUST	12.3%	0.0%	5.6%	3.4%	8
BARNSLEY HOSPITAL NHS FOUNDATION TRUST	1.7%	3.6%	2.9%	3.2%	7
BRADFORD DISTRICT CARE NHS FOUNDATION TRUST	1.7%	4.6%	#DIV/0!	4.4%	14
BRADFORD TEACHING HOSPITALS NHS FOUNDATION TRUST	0.5%	1.1%	0.7%	0.9%	4
CALDERDALE AND HUDDERSFIELD NHS FOUNDATION TRUST	0.2%	0.6%	1.3%	0.7%	3
DONCASTER AND BASSETLAW TEACHING HOSPITALS NHS FOUNDATION TRUST	2.9%	4.7%	3.7%	4.2%	13
HARROGATE AND DISTRICT NHS FOUNDATION TRUST	5.2%	5.2%	5.0%	5.2%	15
HULL UNIVERSITY TEACHING HOSPITALS NHS TRUST	4.2%	6.8%	5.5%	6.3%	17
HUMBER TEACHING NHS FOUNDATION TRUST	1.0%	15.4%	64.2%	37.8%	20
LEEDS AND YORK PARTNERSHIP NHS FOUNDATION TRUST	3.4%	4.1%	#DIV/0!	4.1%	11
LEEDS COMMUNITY HEALTHCARE NHS TRUST	#DIV/0!	4.0%	#DIV/0!	4.0%	10
LEEDS TEACHING HOSPITALS NHS TRUST	3.0%	7.2%	2.9%	6.2%	16
MID YORKSHIRE HOSPITALS NHS TRUST	7.5%	10.6%	0.1%	7.9%	18
NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST	0.0%	0.0%	0.0%	0.0%	1
ONE MEDICAL GROUP LIMITED	#DIV/0!	#DIV/0!	55.3%	55.3%	21
ROTHERHAM DONCASTER AND SOUTH HUMBER NHS FOUNDATION TRUST	1.7%	#DIV/0!	#DIV/0!	1.7%	6
SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST	0.0%	0.0%	0.0%	0.0%	1
SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	2.8%	3.6%	2.7%	3.4%	9
SOUTH WEST YORKSHIRE PARTNERSHIP NHS FOUNDATION TRUST	0.5%	13.9%	#DIV/0!	13.6%	19
THE ROTHERHAM NHS FOUNDATION TRUST	0.2%	2.1%	0.2%	1.4%	5
YORK TEACHING HOSPITAL NHS FOUNDATION TRUST	13.4%	0.0%	27.5%	4.1%	12
Grand Total	**4.2%**	**4.1%**	**5.7%**	**4.3%**	

Genomics England data

- Genomics England 100K programme cancer arm
- Reported ethnicity in 77% of cases

Ethnicity Group	In GEL	National
Asian.or.Asian.British	3.67%	7.51%
Black.or.Black.British	3.56%	3.33%
Mixed	0.92%	2.18%
Other.Ethnic.Groups	1.86%	1.01%
White	89.99%	85.97%

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What does the data actually tell us?

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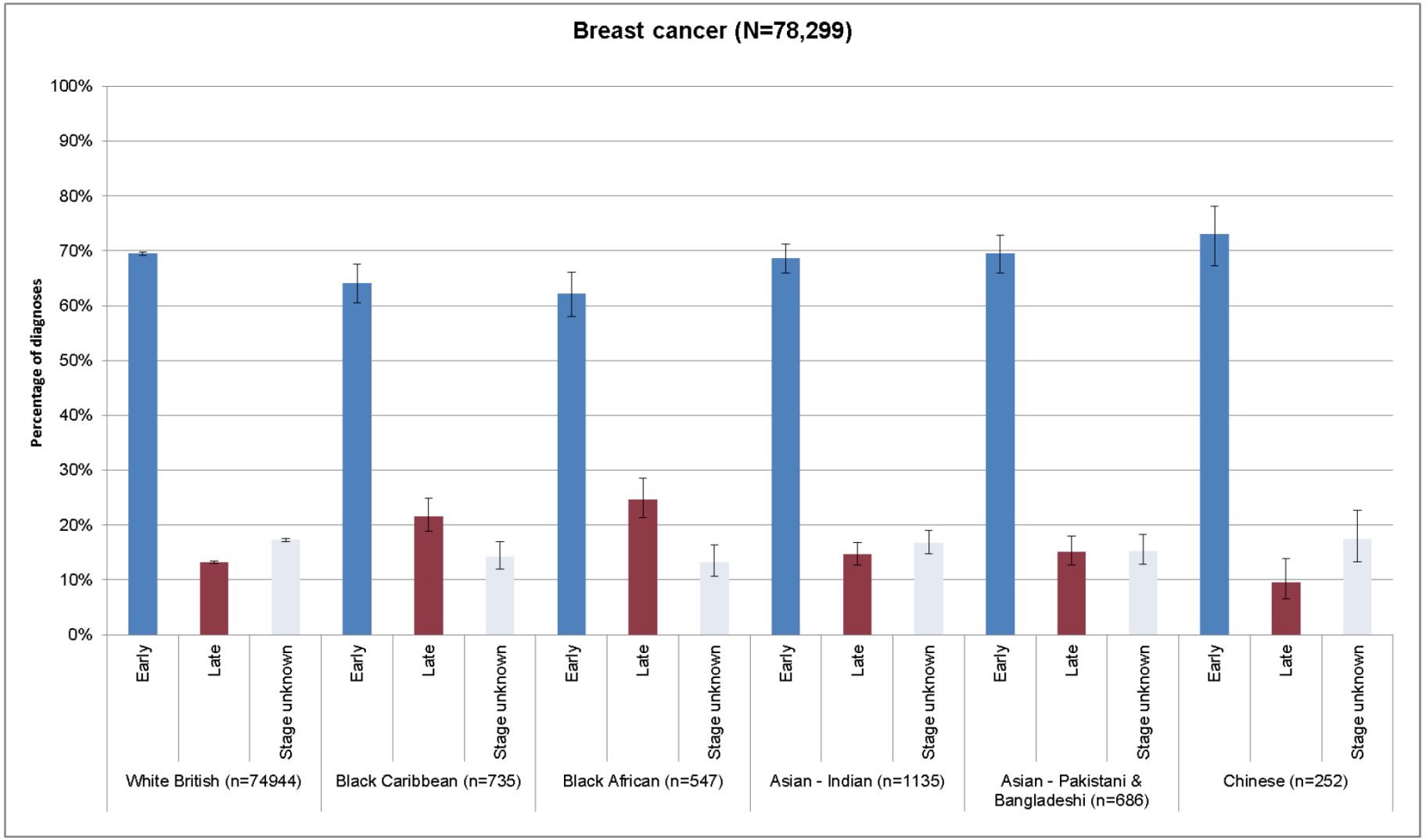
Variation by stage at diagnosis – breast cancer



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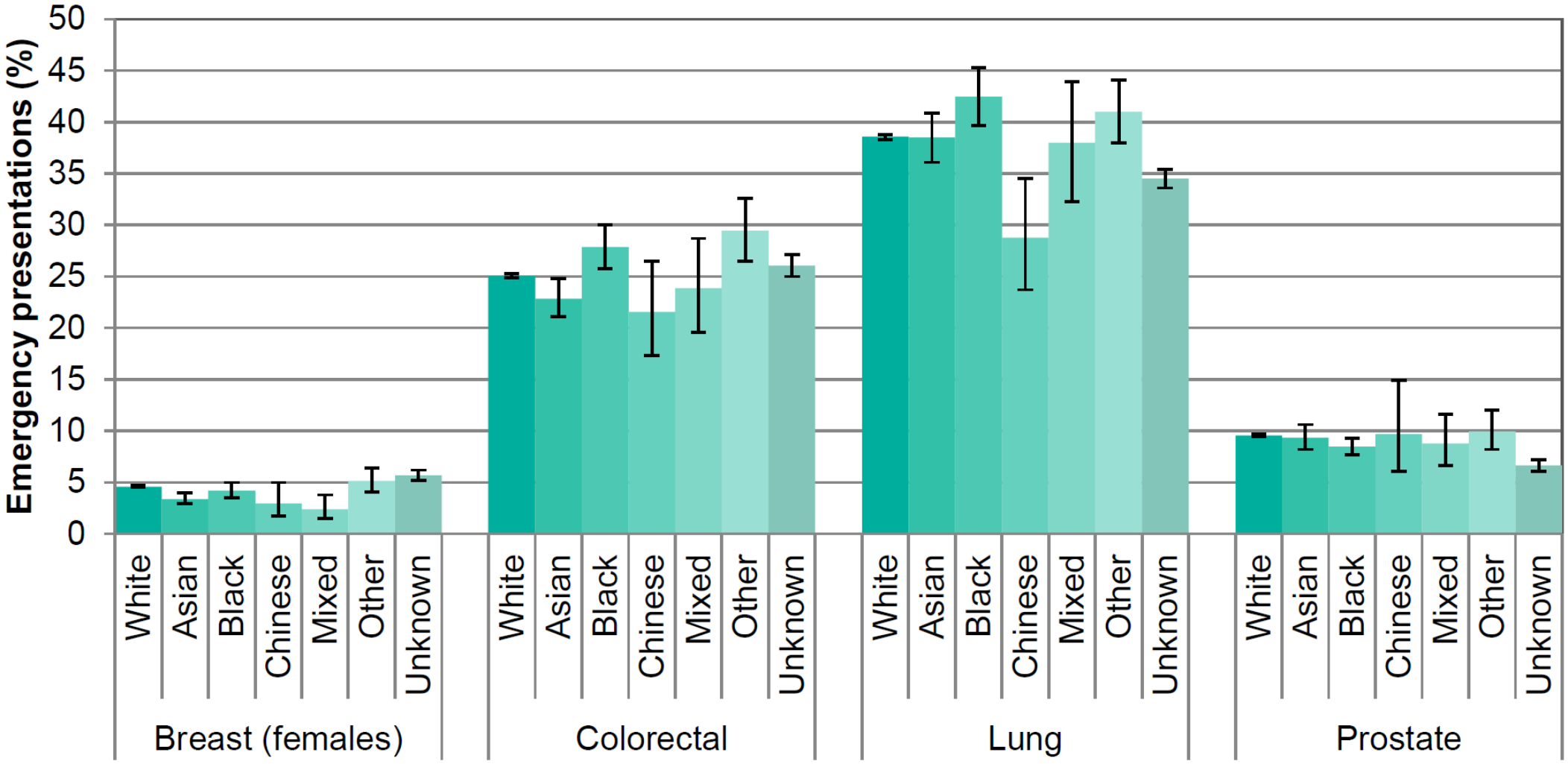
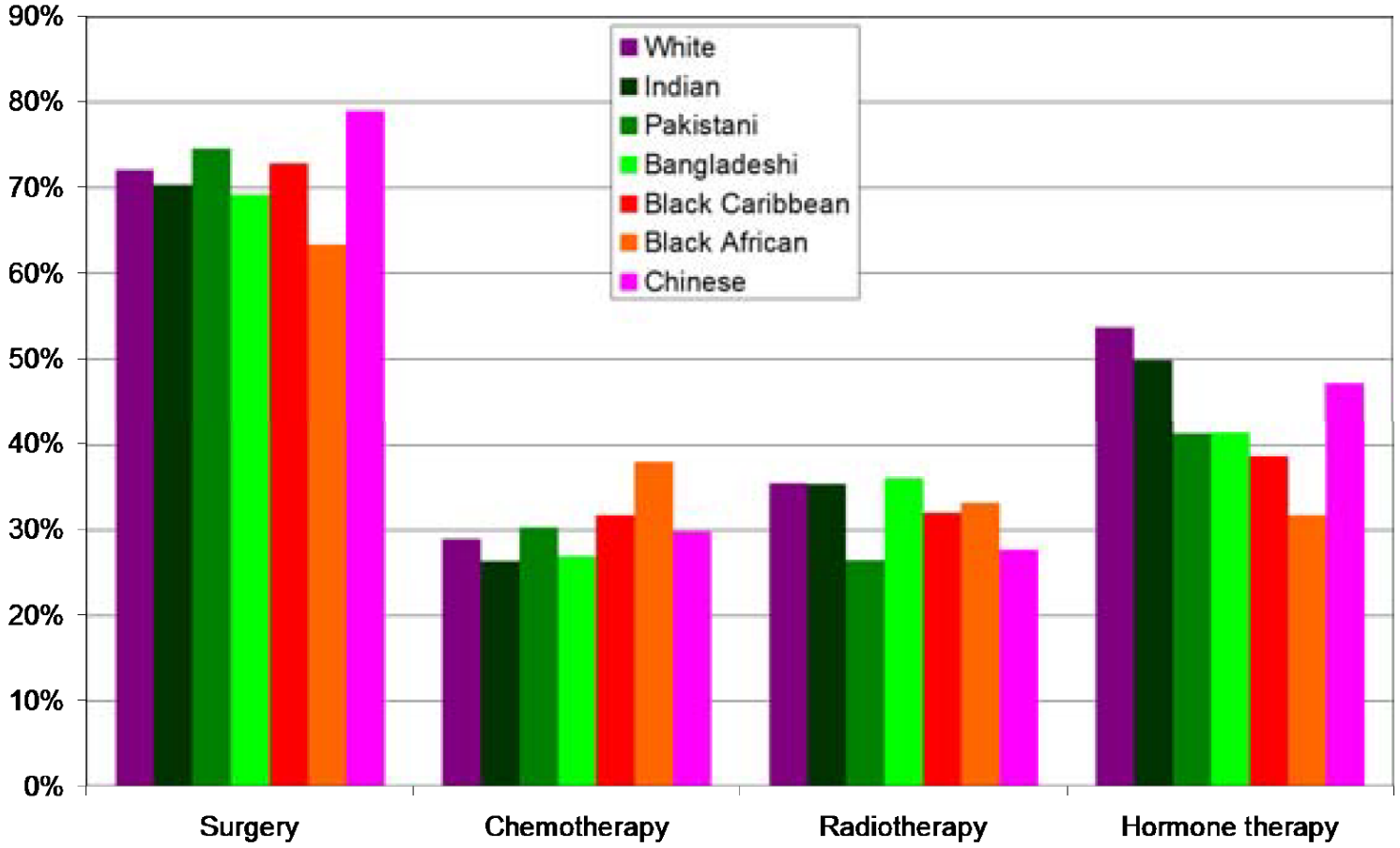
Variation in Emergency Presentations



Variation by treatment (2009*)

Figure 2: Proportion of breast cancer patients receiving cancer surgery, chemotherapy, radiotherapy and hormone therapy by ethnic group. Adjusted for age, socioeconomic deprivation and stage of disease



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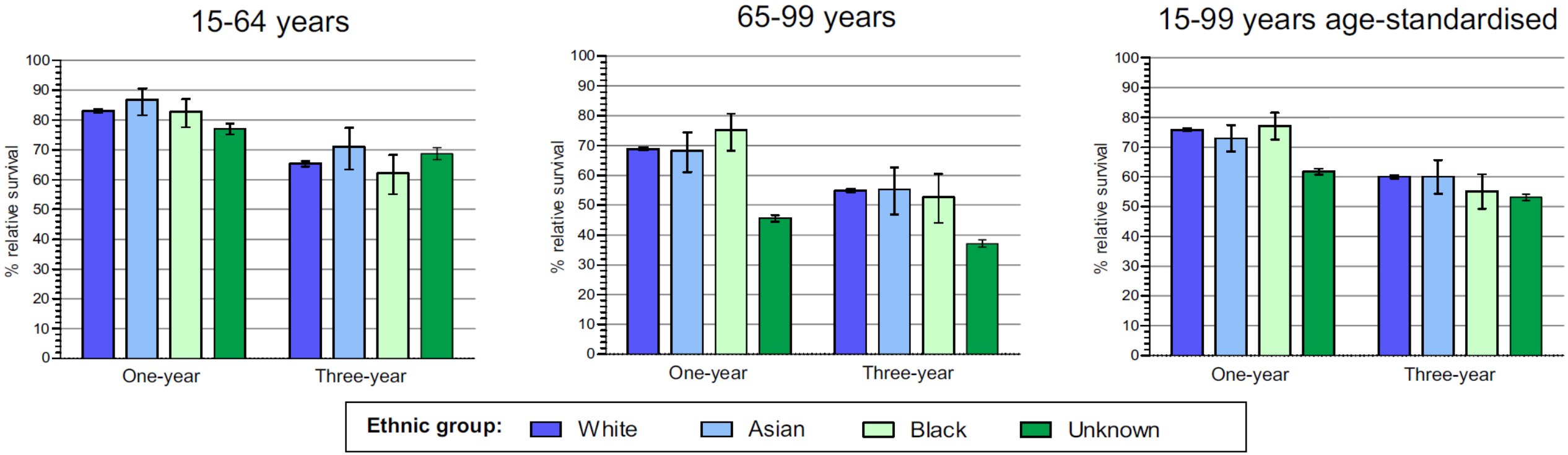
Colorectal survival by major ethnic group (2009*)



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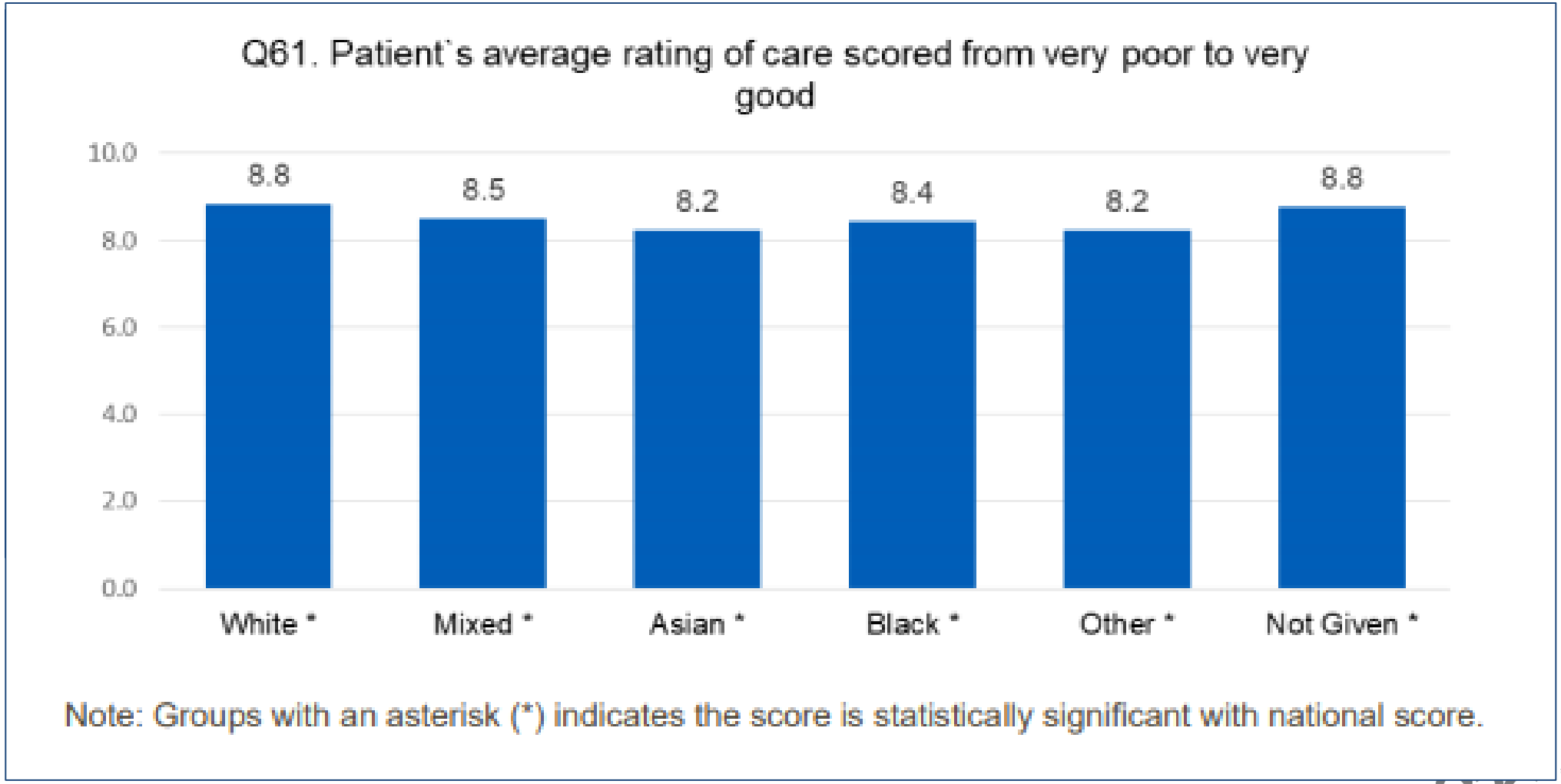
Patient experience – National Cancer Patient Experience Survey (2019)



MY data

Combining data to identify ethnic COVID-19 inequalities

31 January 2022

Just a few weeks into the first COVID-19 wave in the UK, reports identified a higher risk of deaths among ethnic minorities. The creation of the Public Health Research Database (PHRD) – a combination of GP and hospital medical information and 2011 Census records - confirmed these, and allowed evidence-driven policy changes to be to protect the most vulnerable members of our community.

Medical records do not regularly hold information on ethnicity, religion, socioeconomic status and many other factors that influence health outcomes. Without this information, research studies either cannot include these factors or must rely on data at a population level, comparing different regions for instance.

The Data and Connectivity programme jointly led by Health Data Research UK was created to connect UK health data to support and accelerate research on COVID-19. This programme supported the creation of the Public Health Research Database (PHRD) – a combination of GP and hospital medical information and 2011 Census records. The database includes 29 million anonymised records of adults in England and it is the first time that administrative and health data have been combined.

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Data in the understanding of Covid-19

- Analyses highlight issues of data quality, completeness and representativeness
  - OpenSAFELY study: 26% health records lacked ethnicity category

White	10,866,411 (62.9)
Mixed	169,697 (1.0)
South Asian	1,022,130 (5.9)
Black	339,909 (2.0)
Other	320,132 (1.9)
Missing	4,560,113 (26.4)

Source: Williamson, E.J., Walker, A.J., Bhaskaran, K. *et al.* Factors associated with COVID-19-related death using OpenSAFELY. *Nature* **584,** 430–436 (2020).

OpenSAFELY is a new secure analytics platform for electronic health records in the NHS, created to deliver urgent results during the global COVID-19 emergency. It is now successfully delivering analyses across more than 24 million patients' full pseudonymised primary care NHS records, with more to follow shortly.

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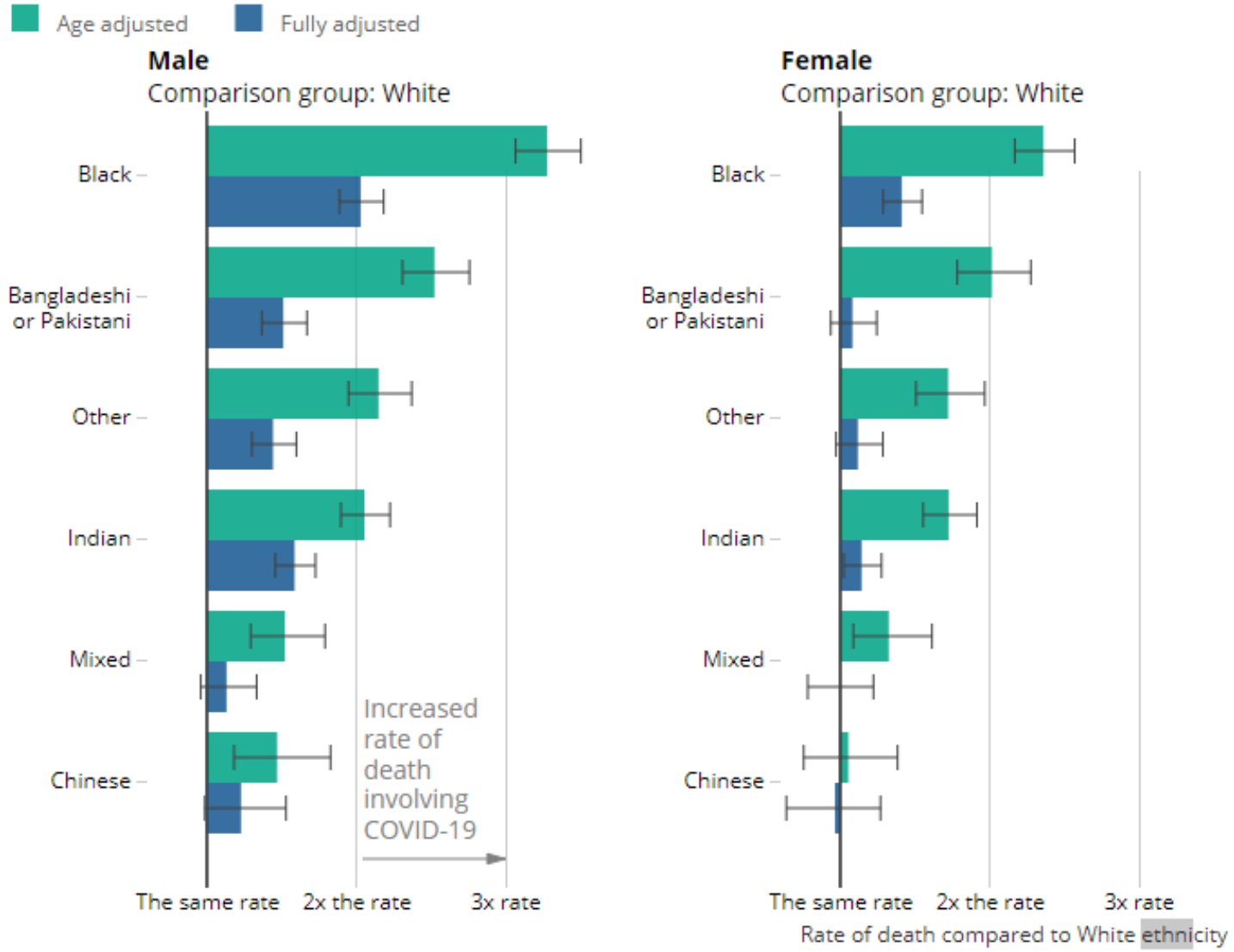
Rate of COVID-19 death by ethnic group and sex relative to the White population, England and Wales, 2 March to 15 May 2020



"Ethnic group is not recorded on the death certificate; to enable us to undertake these analyses, death registrations up to 29 May 2020 have been linked to the 2011 Census, which allowed us to ascertain the self-reported ethnicity of the deceased and other demographic factors."

Take away points

- There are a wide range of dimensions of “equality”
- Data exists to monitor most of these, but much isn’t complete, and much of the datasets are not linked
- We have lots of published analysis of equality in diagnosis, care, outcomes and experience
- COVID data-regulations allowed much more to happen
- We should always think about whether a piece of analysis/research could cover more of the equality dimensions

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Questions?