APPENDIX B

NHS
Leicester, Leicestershire and Rutland

LeDeR Annual Report 2021/22

Learning from Deaths of people with a Learning Disability and autistic people: review programme

NHS Leicester, Leicestershire and Rutland is the operating name of
Leicester, Leicestershire and Rutland Integrated Care Board

Improving outcomes – Primary Care

- Read the **weekly e-newsletter that is sent to all GP practices**, it now includes a Learning Disability section, with all the key information
- **Designate a Clinical Lead GP for Learning Disabilities in every Practice. S**upport and advice for this person is available from ICB Clinical Leads for LD
  - Dr Graham Johnson graham.johnson2@nhs.net and
  - Dr Archana Anandaram a.anandaram@nhs.net
- Ensure individuals are included on the **LD QOF Register*** this is the gatekeeper to being invited to LD AHC, awareness of reasonable adjustments, safeguarding and referrals to secondary care.
- **Instigate RESPECT forms** when the person is well enough to ensure their wishes are heard, in primary healthcare. People with a LD, their family and carers should be supported to understand about RESPECT forms and they differ from a DNACPR.
- Use of **regular appropriate MCA Assessment**
- Promote **hospital passports** for people with LD and to promote at consultation/LD AHC*
- Please increase knowledge and awareness of the **"Adult not brought to appointment;Y2de1**" (Was not brought) read code and safeguarding policy, especially for GP Receptionist teams. https://vimeo.com/392944939

*Use the support of our Primary Care Liaison Nurse Team lpt.pcln@nhs.net

We are working on

- **Wheelchair scales**; once we have them we'll update the GP Annual Health Check and LD Newsletter with guidance on accessing them.
- Improving and simplifying the AHC template
- **Clarifying the blood letting pathway**, designating a Co-Ordinator and will share this with you also.

Improving outcomes – Secondary Care

- Effective planning, identification, and consideration for people at the end of their life through timely commencement of **End of Life care pathway**
- **Communicate with and remind Care Providers** they are welcome to support people with a learning disability in hospital and advocate for them
- Review process of **community follow up after discharge**. E.g. CLDT discharge coordinator in LPT could feed into LPT long term plan
- Establish and communicate as early as possible, the **funding** required when someone with an LD goes into hospital
- Establish early dialogue with **family and carers** so their needs are taken into account when giving information
- Use of **regular appropriate MCA Assessment**
- Promote use of **Hospital Passport**
- **SALT to consider leading a REFLUX campaign** for people with LD in partnership with LeDeR team. Contact us at llrlederadmin@nhs.net
- Where a hospital has been informed that a person has a LD, this is to be communicated to other staff early. Any information about the person/resources to also be circulated amongst staff supporting the patient at admission.
- **Inform Acute Liaison Nurses** immediately of any hospital admission of a person with LD and give ALN contact details for family and carers.
- Pursue wider training for other staff around supporting a patient with LD in an acute setting, so the ALNs are not pressurised with the support required to be provided.

Improving outcomes – Community Care

- **Support people to live where they choose**, and enable them to make decisions in a timely manner. *Funding should not be a barrier.*
- Ensure that **all care providers have access to current, wider learning disability services** and know who to contact.
- **Ensure all care providers clearly understand when a RESPECT form is to be instigated** by all everyone including people with a learning disability, family, carers, health and social care staff
- Use of **regular appropriate MCA Assessment**
- Promote training and education around the u**se of tools to help staff recognise the deteriorating patient**.
- Ensure care providers are **appropriately risk assessed and safeguarding** is assured
- Ensure that when sourcing residential care placements that an individual's **culture, language, preferences and communication needs** are take into account.
    - Put steps into place to **ensure that these needs can be met at all times** by the identified care provider.

LeDeR aims

- To support improvements in the quality of health and social care service delivery for people with learning disabilities and people with autism
- To help reduce premature mortality and health inequalities for people with learning disabilities and people with autism

Two types of review

- Focused (expected 35%) automatically for
- Autism-only
- Ethnic minority
- MH restrictions in last 5 years of life
- If family request
- Allocated locally if a priority area in LLR

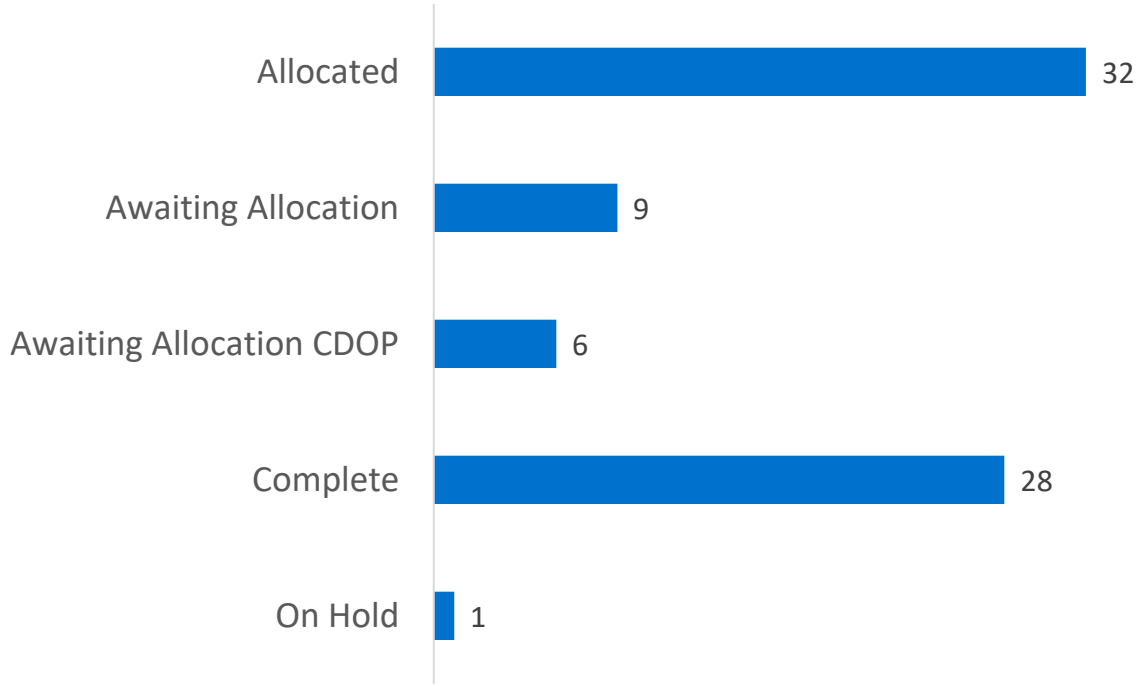
- Initial all other cases

Programme progress

This year we…

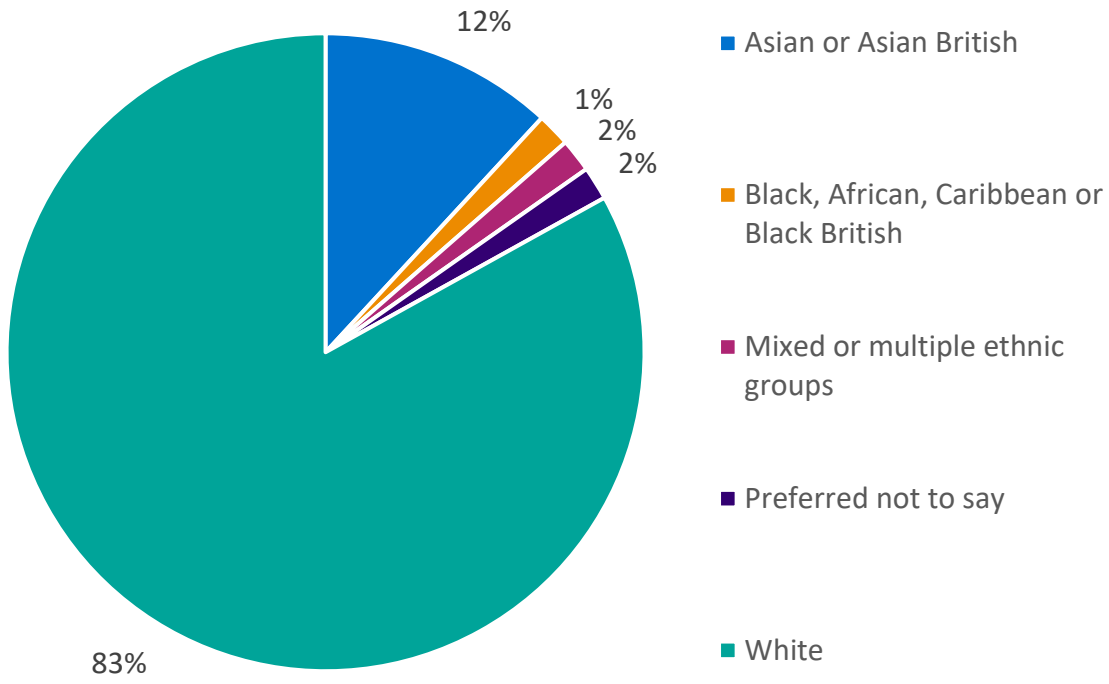
- Received 77 referrals of death
- Completed 65 reviews
- Appointed a new team, with some permanent roles
- Set up governance panels to agree actions from learning
- Refreshed our Steering Group

Case status at year end

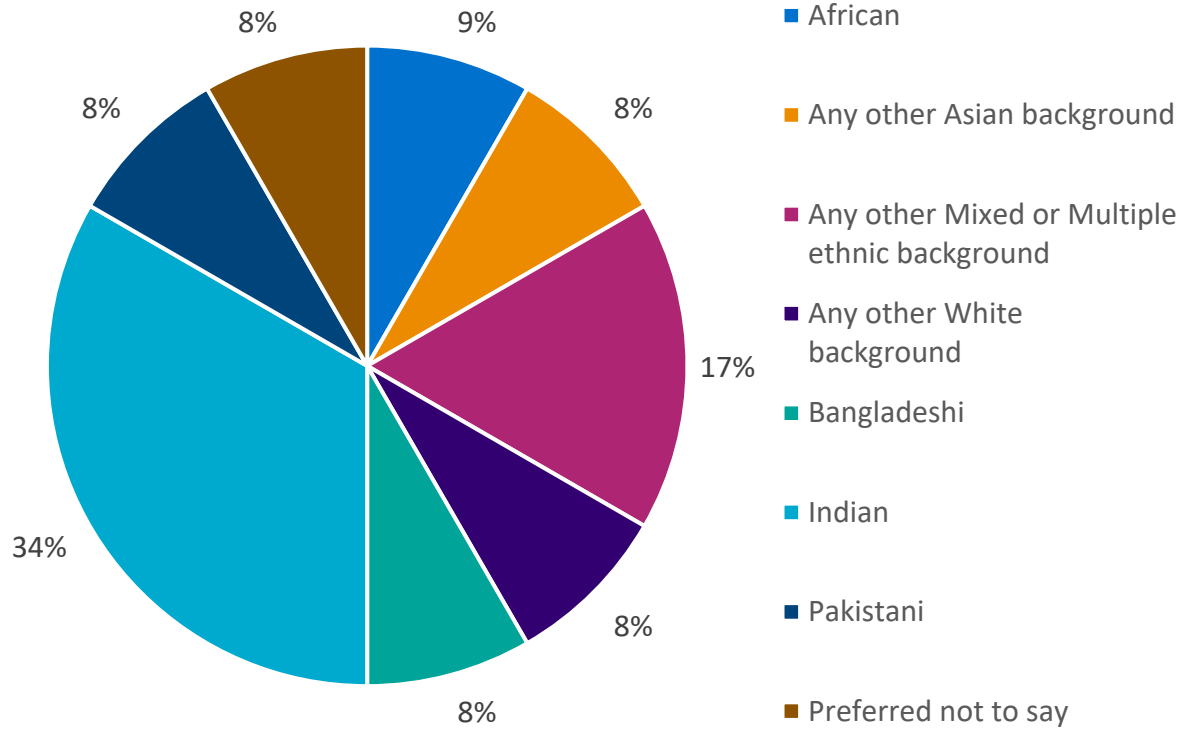


Cases completed in year - ethnicity

Ethnic Group



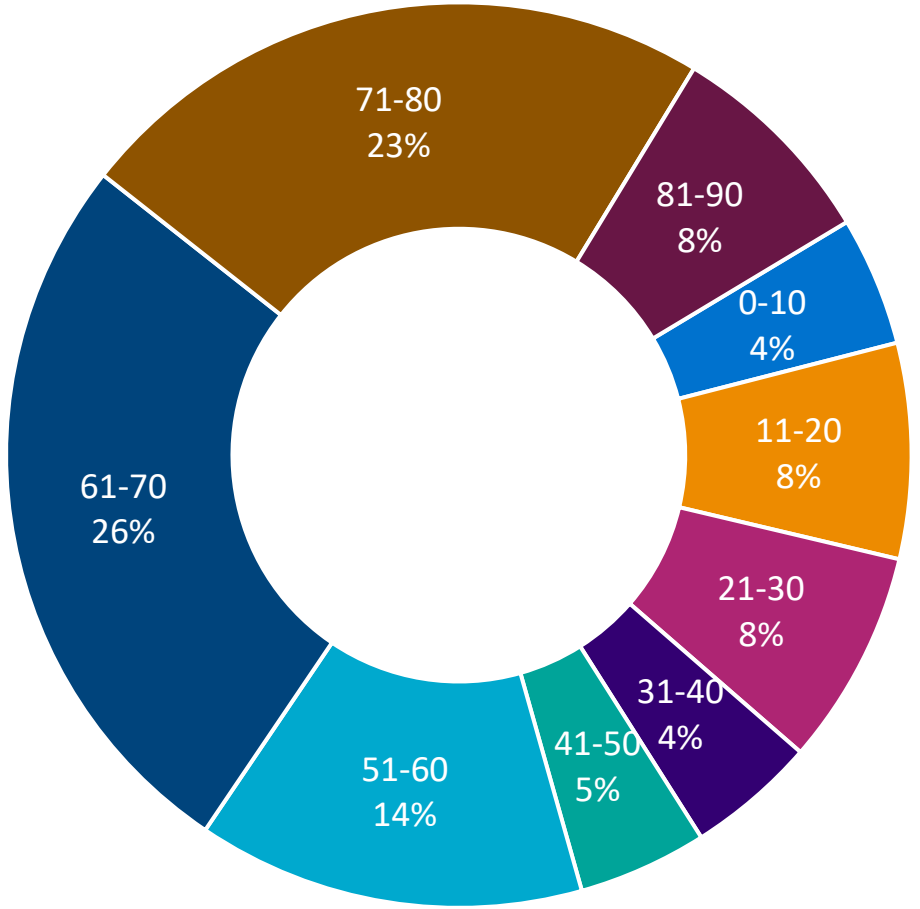
Ethnic Minority



Cases completed in year – age groups

- The majority of people died aged 61 or older (57%) and more than half of those were over 70
- 14% were 51-60
- Among the younger age groups (Under 51) 11-20 and 21-30 each comprised 8%

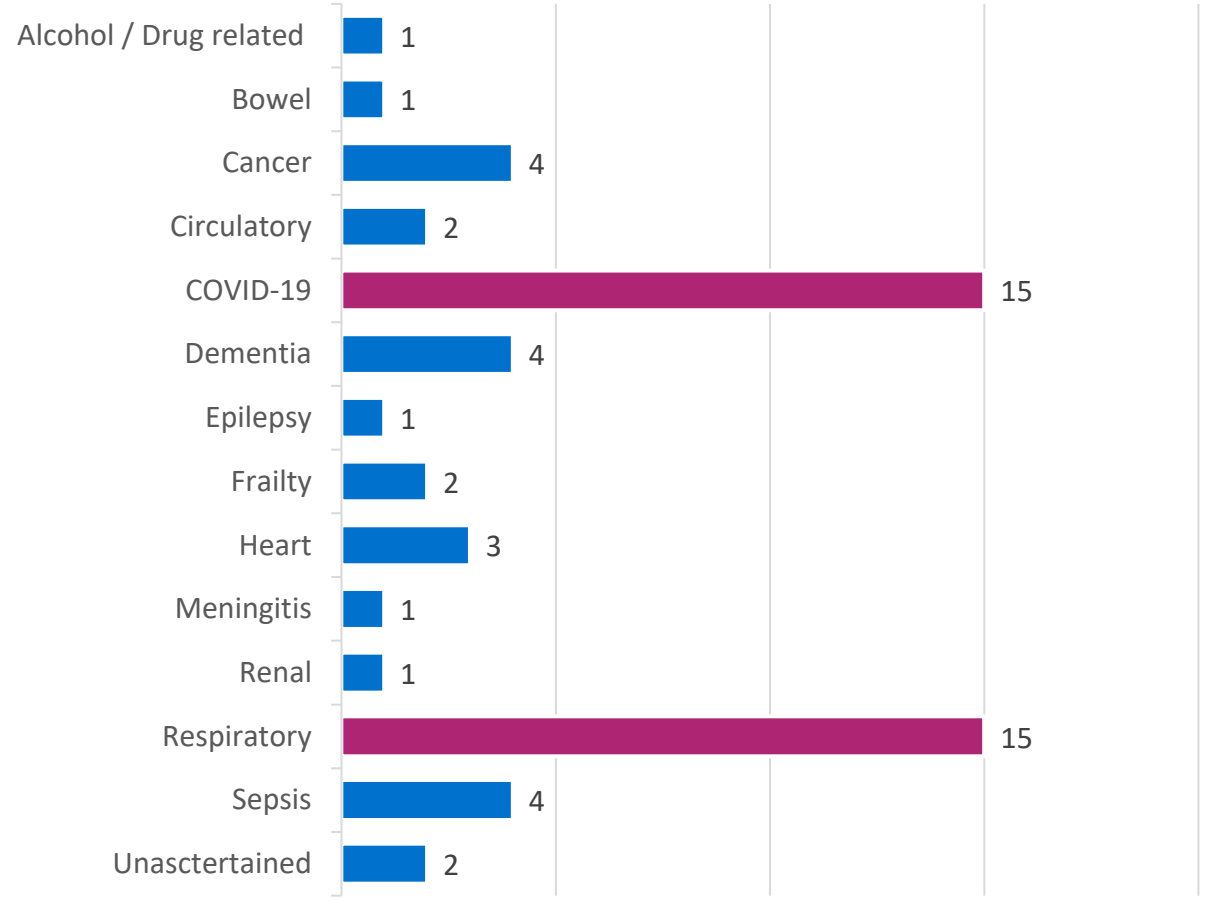
- Median age at death nationally was 62
- **In LLR, it was 64 for adults**
- **Children with life-limiting conditions now transitioning into adulthood**
- In the previous 2 years, it was 59



Causes of death

54% of all deaths were from 2 causes

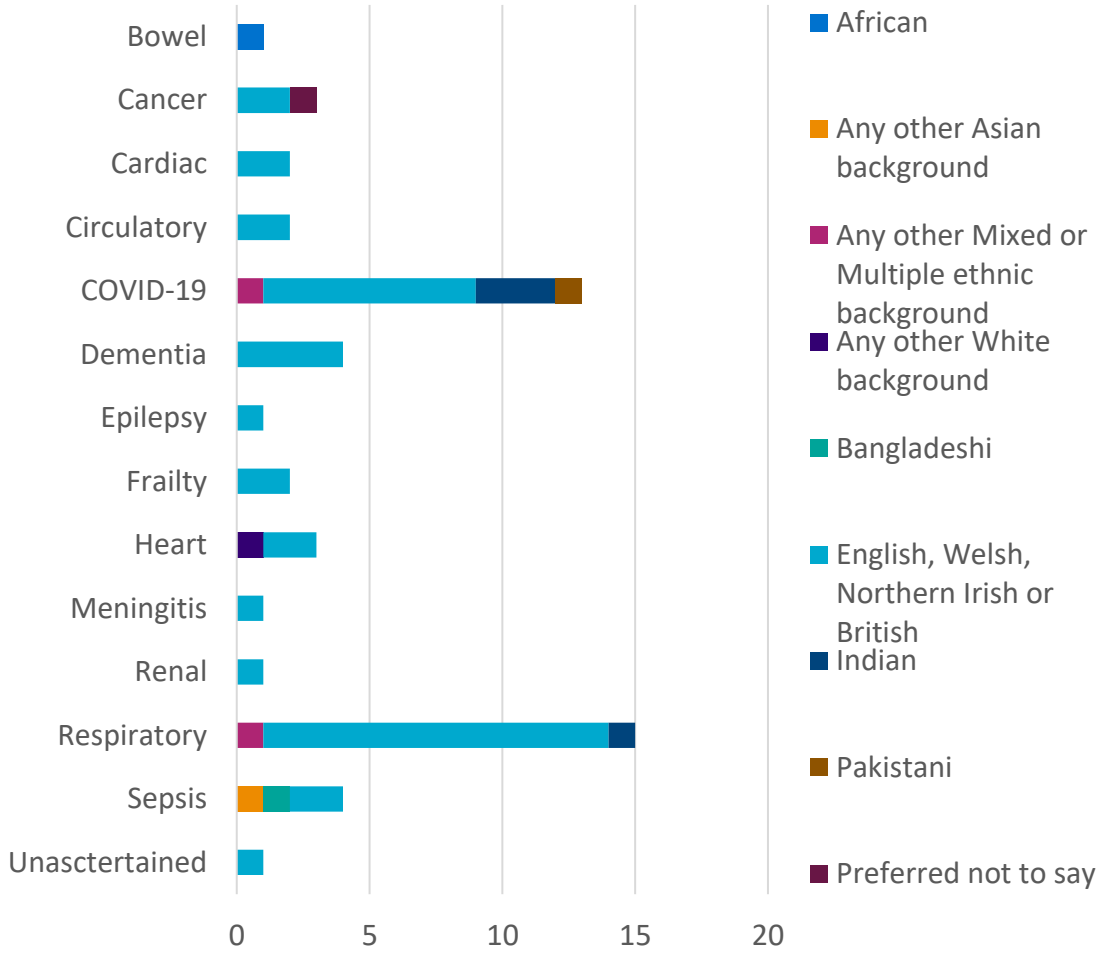
- COVID-19 (15 deaths)
- Respiratory illness (15 deaths) including
  - Aspiration Pneumonia*
  - Respiratory Failure
  - Pneumonia
  - Bronchiectasis
  - Community Acquired Pneumonia
  - Lower Respiratory Tract Infection



Cause of death by Ethnicity

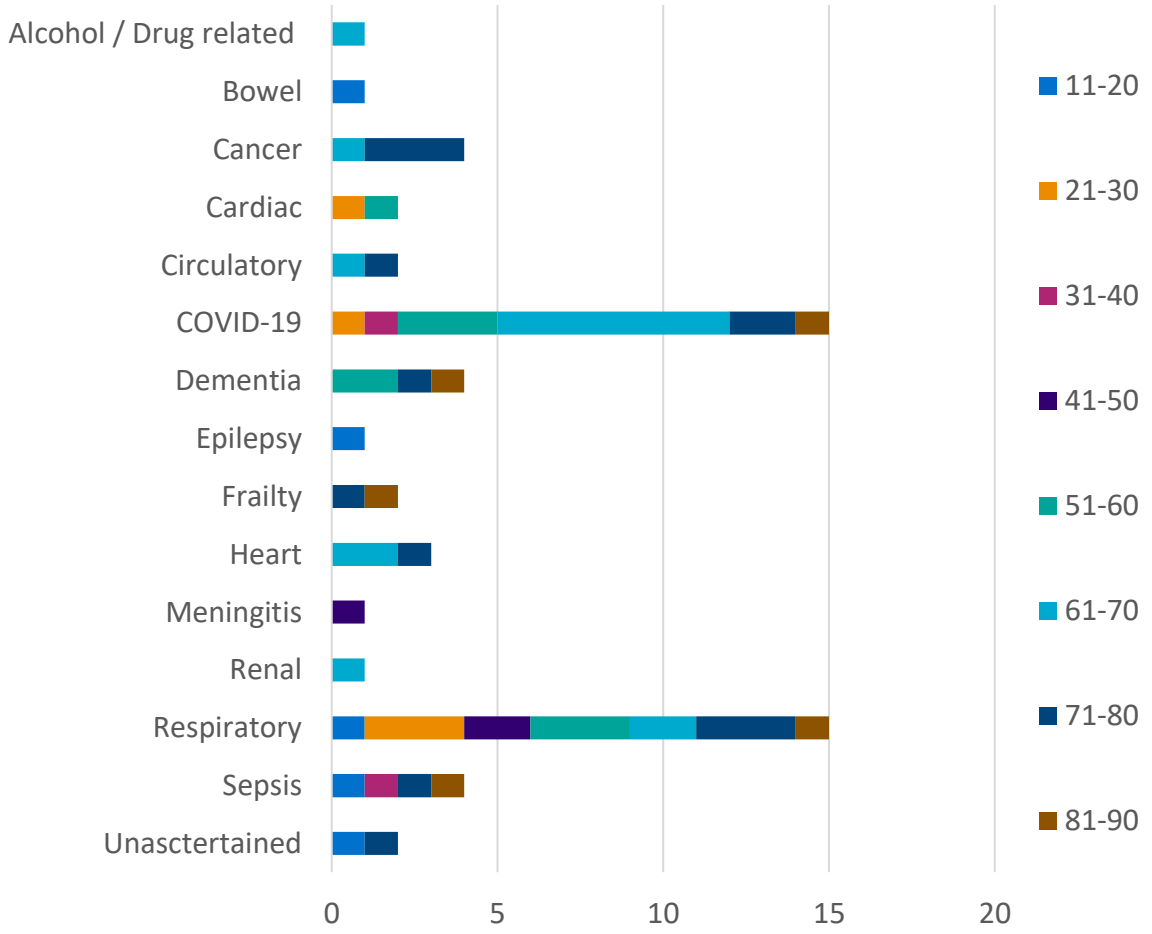
Ethnicity	All Deaths	COVID-19 Deaths
Asian or Asian British	12%	31%
Black, African, Caribbean, or Black British	2%	<1%
Mixed or Multiple Ethnic Groups	2%	<1%
White	83%	69%
No ethnicity recorded	1%	0%

- COVID-19 disproportionately affected Asian or Asian British people
- Respiratory deaths were proportionate across ethnic groups



Cause of death by age group

- COVID-19 caused more deaths in the 61-70s than any other group; this is what we would expect
  - Vaccination data was required only for ‘focused’ reviews
- Respiratory deaths occurred relatively evenly across age groups in comparison



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