

\* use MY data  
use MY data



**Uncharted territory –  
using patient data to tackle COVID-19**

**challenges from a patient's perspective**

*aka Paul Charlton*

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## Patient data citation

**81,176 covid 19 patients in research**

**"This work uses data provided by patients and collected by the NHS as part of their care and support"**



21 March 2020 Email to Covid 19 Researcher

*Clearer Thinking* <https://www.clearer-thinking.co.uk>

*is the home for the work of Dr. Suzanne Shale, independent  
medical ethics consultant and researcher*

Dr Suzanne Shale: Clearer Thinking

links to selected policy, guidance and research about ethical aspects of responding to covid 19

*All my work is, at its heart, about what makes it possible for us to trust each other, to trust professionals, to trust institutions, and to rebuild trust when trust has broken down.*

The Nuffield Council on Bioethics (UK) policy briefing emphasises

*“People should be treated as moral equals, worthy of respect. While individuals may be asked to make sacrifices for the public good, the respect due to individuals should never be forgotten”*

*“Solidarity is crucial ...at the individual level in the way we all respond to the outbreak in day-to-day life.”*

2:10 AM · May 8, 2020 · Twitter Web App  
Georgina P @queenofswords6

*A&E night shift, talking with colleagues. The clapping, we know it's well-meant. But it was moving at first, now meaningless when so many are apologising for government failures that have led to our colleagues' deaths.*

*We are not heroes.*

*We are unprotected workers, being killed.*

Jamie Jenkins @statsjamie  
7:30 PM · May 8, 2020

*My reason for putting numbers together is to assist the public understanding. No financial incentive but its important to communicate what the numbers show.*

*I've been concerned with the quality of the charts presented each day at the daily briefing which are cluttered and confusing*

May 10, 2020·Twitter Media Studio -

*The government's daily briefings on #Covid\_19 are "not trustworthy communication of statistics" says Professor Sir David Spiegelhalter from the University of Cambridge*

<https://twitter.com/bbcpolitics/status/1259409480347004928?s=21>



# Coronavirus (COVID-19) in the UK

Last updated on Saturday 23 May 2020 at 4:14pm

## Total number of lab-confirmed UK cases

**257,154**

Includes tests carried out by commercial partners which are not included in the 4 National totals

## Daily number of lab-confirmed UK cases

**2,959**

Number of additional cases on Saturday 23 May 2020

## Total number of COVID-19 associated UK deaths

**36,675**

Deaths of people who have had a positive test result confirmed by a Public Health or NHS laboratory

## Daily number of COVID-19 associated UK deaths

**282**

Number of additional deaths on Saturday 23 May 2020

COVID-19 associated deaths

**Total number by nation**

# 65,030

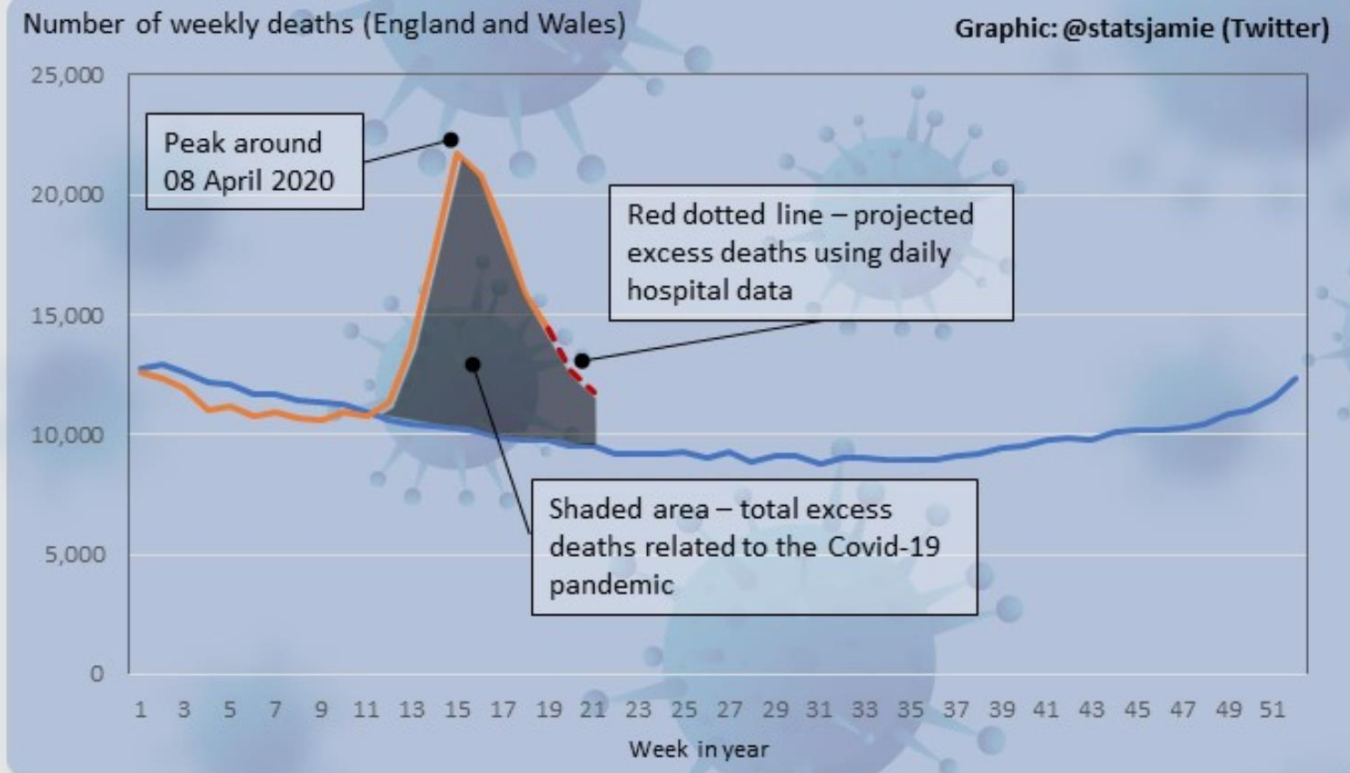
Number of excess deaths  
since the Covid-19  
pandemic hit the UK

### What are excess deaths?

In any given week you expect a level of deaths as sadly each and every day individuals die. Excess deaths are the number of deaths over and above the average for the time of the year.

The blue line on the chart shows the average number of deaths per week in any given week of the year, averaged over the period 2015 to 2019. The orange line shows the total deaths in England and Wales in each week of 2020.

Up to the **22 May 2020**, estimate 65,030 excess deaths (above average) related to the Covid-19 pandemic in the UK. Excess deaths down for the sixth week in a row up to 22 May 2020, peaking around 08 April 2020



Source: ONS / NHS England / Public Health Wales

Created: 23 May 2020

Background vector created by Harryarts - www.freepik.com



Devi Sridhar

12 May Guardian article

Professor & Chair of Global Public Health Univ Edinburgh

@devisridhar

*The decision in early March to shift from **containing** to **mitigating** the virus was disastrous .....*

*By the time the government introduced a lockdown, the number of coronavirus cases had already increased exponentially, making prolonged quarantine necessary.*

*Let the virus rip....  
Learning Disability 21 May*

*“People should be treated as moral equals”*

*In 2018/19 at least 41% of people with a learning disability who died, died as a result of a respiratory condition.*

***Let the virus rip....Learning Disability***  
***18 May Prof Chris Hatton @chrishattoncedr***

***people with learning disabilities***

***54 dying every week 2016-2019***

**Estimates:**

**Vs**

***58.4 COVID-19 related deaths***  
***70.3 people non-COVID attributed causes.***

***Let the virus rip....Learning Disability***  
***18 May Prof Chris Hatton @chrishattoncedr***

***Mortality***

***8 Weeks March-April 2020***

***NHS in Hospital: 468***

***All Cause Expected: 432***

***All Cause Actual: 1030***

***Excess: 598 (220.4% mortality increase)***

***people with learning disabilities were 4-5 times more likely to die a COVID-19 related death in hospital than you would expect***

Carole Cadwalladr  
Guardian & Observer writer

May 23 @carolecadwalla

*The real story is the huge transfer of government assets to private companies ... under cover of a pandemic. We have no insight into these contracts which did not go to tender....*

*Including a massive transfer of our most private, intimate NHS data. The privatisation of essential state functions is happening in real time in almost complete darkness*

Open Letter to Matt Hancock May 18, 2020

Anouk Ruhaak

Mozilla Fellow working with AlgorithmWatch, researching data trusts / data governance models

***Commenting on***

***...a datastore that aggregates COVID-19 health data. Microsoft, Google, Palantir, Faculty and Amazon will assist in the development of the datastore and the processing of the data.***



Open Letter to Matt Hancock May 18, 2020

Anouk Ruhaak

Mozilla Fellow working with Algorithm Watch, researching data trusts / data governance models

***before the NHS continues its plans, we urge you to provide the public with more information and take appropriate measures to reduce risk of data sharing and keep the aggregated data under democratic control***

The Nuffield Council on Bioethics (UK) policy briefing emphasises

*“Solidarity is also important at international level: emergencies such as the COVID-19 pandemic illustrate very clearly how inter-connected and interdependent nation states are.”*

## Fight the Hunger Pandemic



© REUTERS/Rupak De Chowdhuri



93,976 have donated so far! Let's get to 100,000

They say a picture is worth a thousand words -- but this one left me speechless.

A hungry mother in India, baby in her arms, **bursts into tears after queuing for food -- only for it to run out before she could get any.**

Now the UN is warning the world is on the brink of a famine of 'biblical proportions' with a **QUARTER OF A BILLION people, like this young mum, staring starvation in the face!**