

Thread by @dgurdasani1 on Thread Reader App – Thread Reader App

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Deepti Gurdasani

19h, 35 tweets, 11 min read

Ok, time to do a thread on long COVID. Long COVID is a *real* multi-system syndrome that occurs in those infected (far more common than in uninfected controls)- predominantly impacting the young. Let's do a deep delve into this syndrome that some in JCVI are in denial about! 🧵

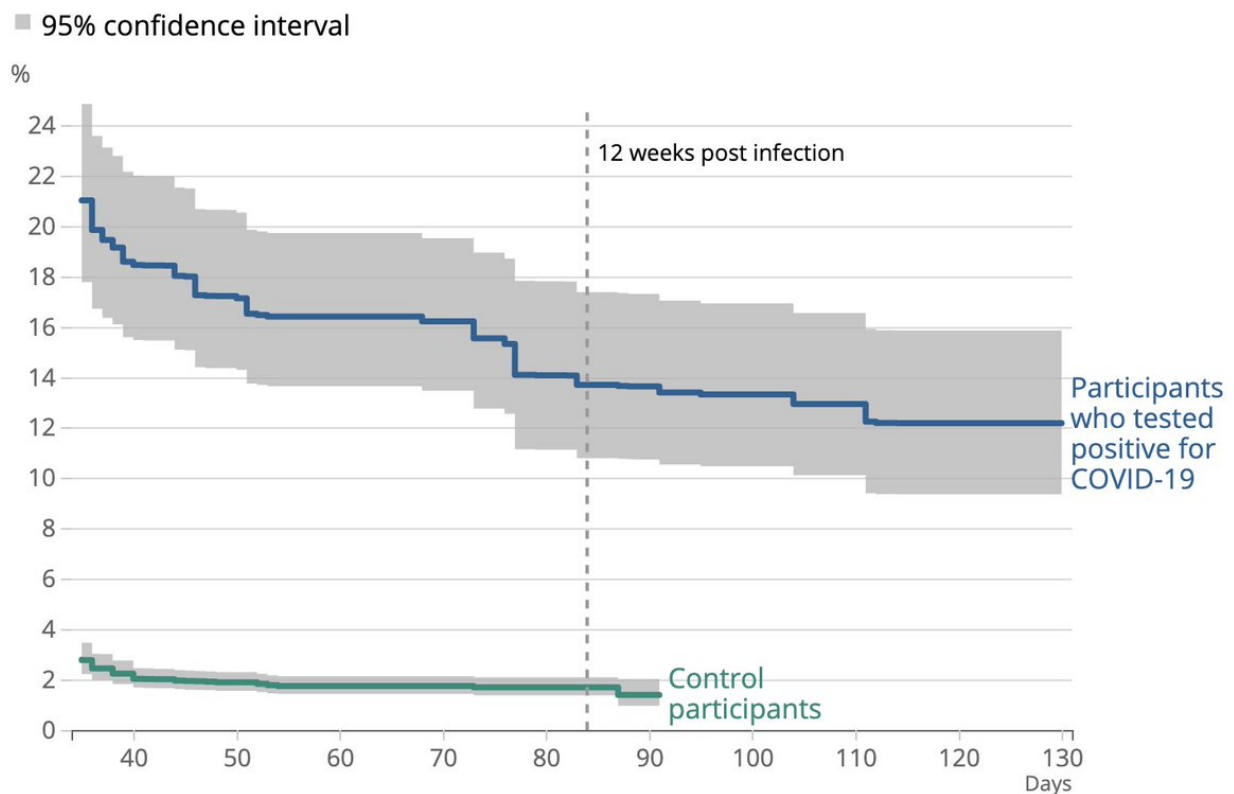
Some stats first - there are several studies that now put the overall incidence of long COVID as between 10-50% of those infected, depending on symptoms studied & cohorts studied. Let's look at some of these.

First, ONS data & REACT-1 data- these are some of the most robust data on long COVID. Why?

- They include infections based on PCR tests through random nationally representative surveys of thousands of people
- ONS data was based on 313,216 samples, REACT-1 on 508,707 people

The ONS data compares symptoms post-infection among those infected with control groups of those confirmed not to have infection. Persisting symptoms were *8x* more common among those testing positive with PCRs compared to those who were negative.

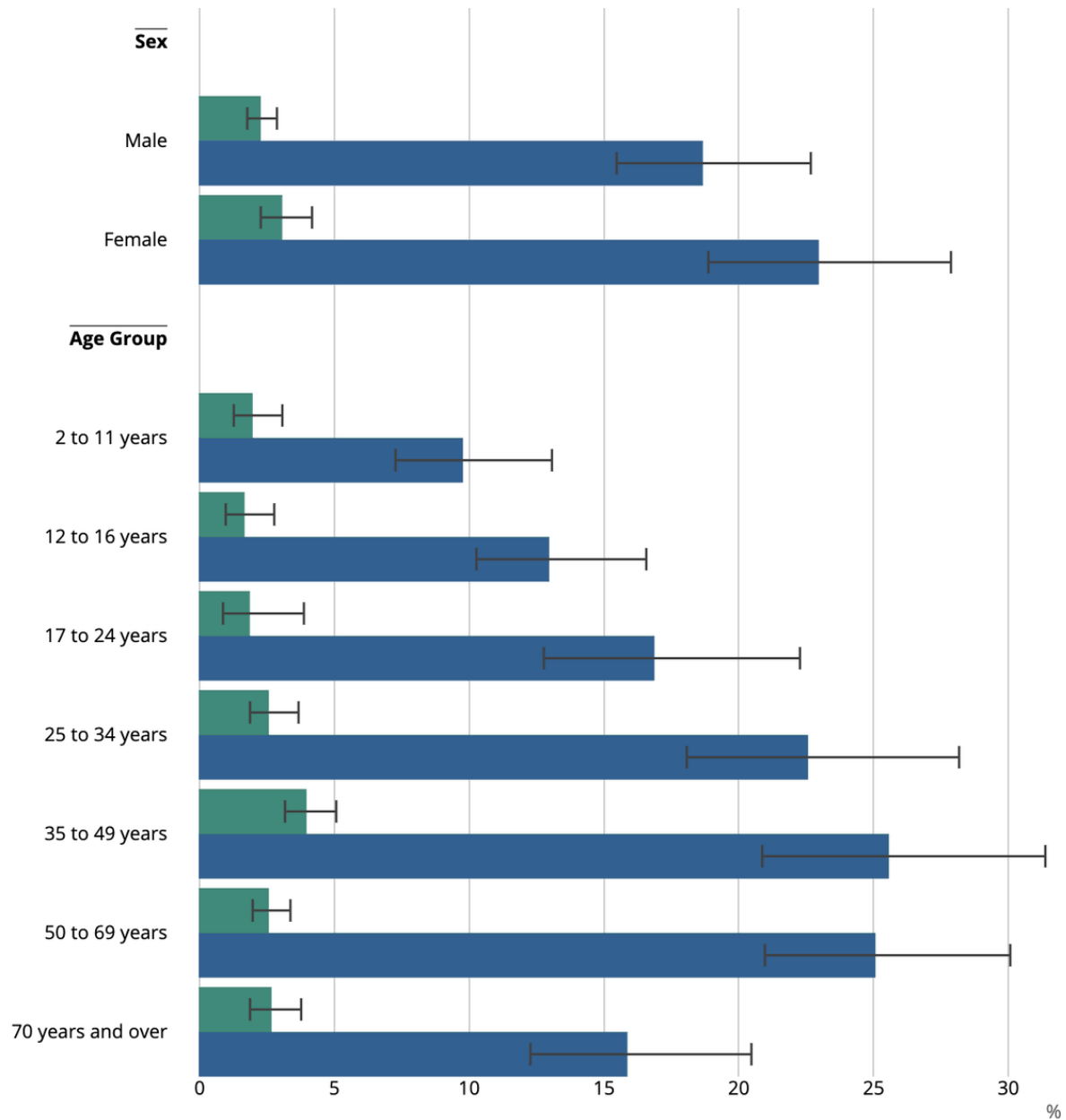
Percentage of study participants reporting any symptom with time from assumed date of infection (participants who tested positive for COVID-19) or time from equivalent date (control participants), UK: 26 April 2020 to 6 March 2021



This strongly challenges the rhetoric by some about 'floating numerators' & that this is 'background symptoms' in the population. The ONS survey showed very clearly that 13.7% of those infected (1 in 8) developed long-term symptoms > 12 wks compared to <2% controls

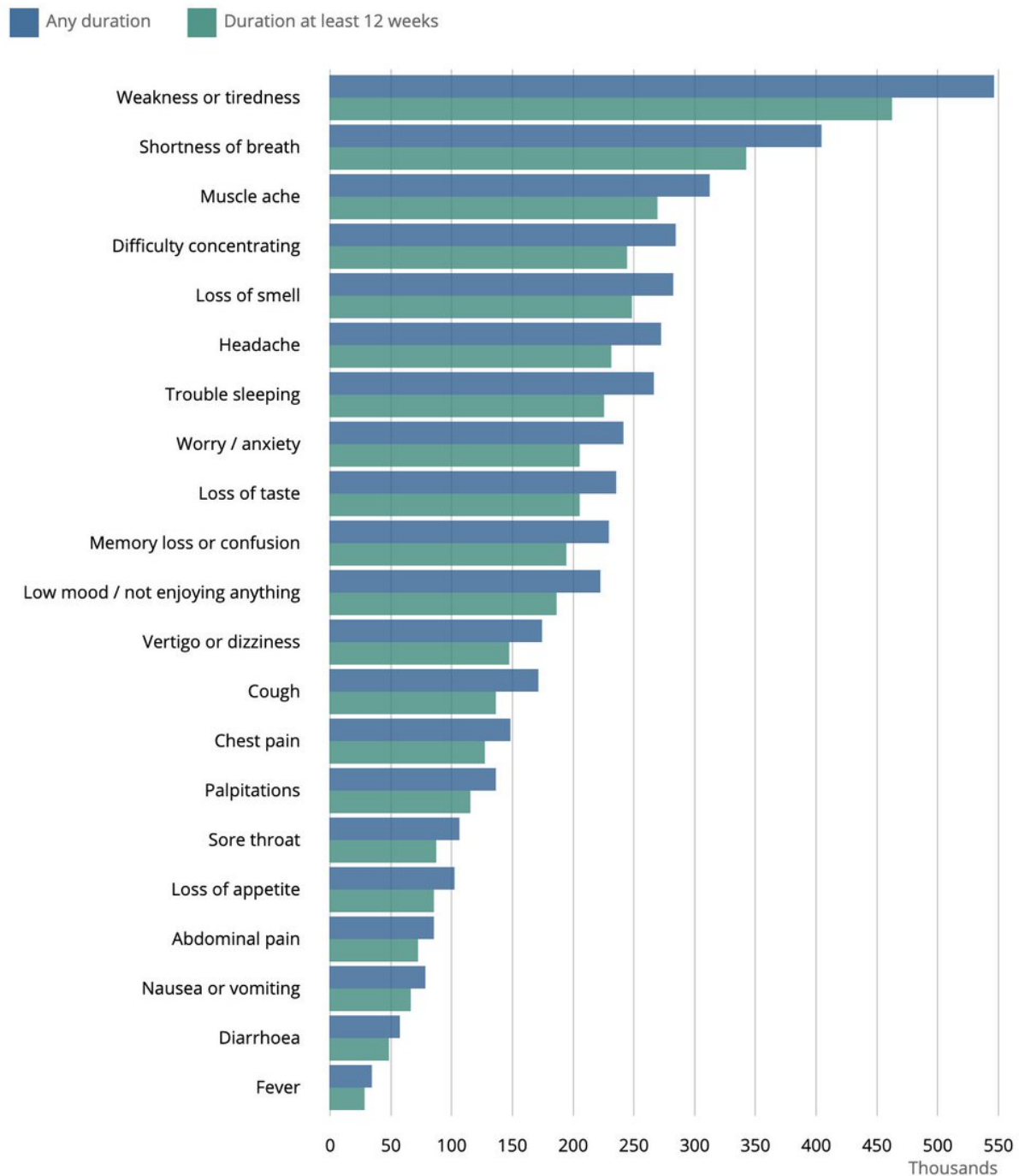
- Among a sample of over 20,000 study participants who tested positive for COVID-19 between 26 April 2020 and 6 March 2021, 13.7% continued to experience symptoms for at least 12 weeks. This was eight times higher than in a control group of participants who are unlikely to have had COVID-19, suggesting that the prevalence of ongoing symptoms following coronavirus infection is higher than in the general population.

'But it doesn't affect old people'... it absolutely does! The majority of those affected are <50 yrs. And it affects children. Between 10-13% of children have symptoms for 5 wks or more, and 7-8% of children had symptoms for *12 wks or more* compared with <2% of controls.



'But it's just mild symptoms that don't matter, and most people only have 1 symptom'
 Unfortunately, there's a plethora of symptoms, and many of them are very common, so many people present with a combination of symptoms. The ONS only examined 21- there are 100s of symptoms.

Number of people with self-reported long COVID by symptom, UK, 2 May 2021



This means the ONS estimate may be underestimating the prevalence of long COVID considerably. Also these symptoms are not mild. Of the ~1 million people affected, 2/3rds said it impacted their day to day activity. And 400,000 have had persistent symptoms for more than a year.

Figure 1: Since March 2021, there has been a marked increase in the number of people with self-reported long COVID of at least a year in duration

Number of people with self-reported long COVID by duration, UK, 6 March 2021 and 2 May 2021



These 400,000 sadly include 9000 children who have been affected for more than a year. This isn't a mild syndrome, or a short one for thousands of our young- who've been impacted due to policies where they were forced to go into unsafe environments without adequate mitigation.

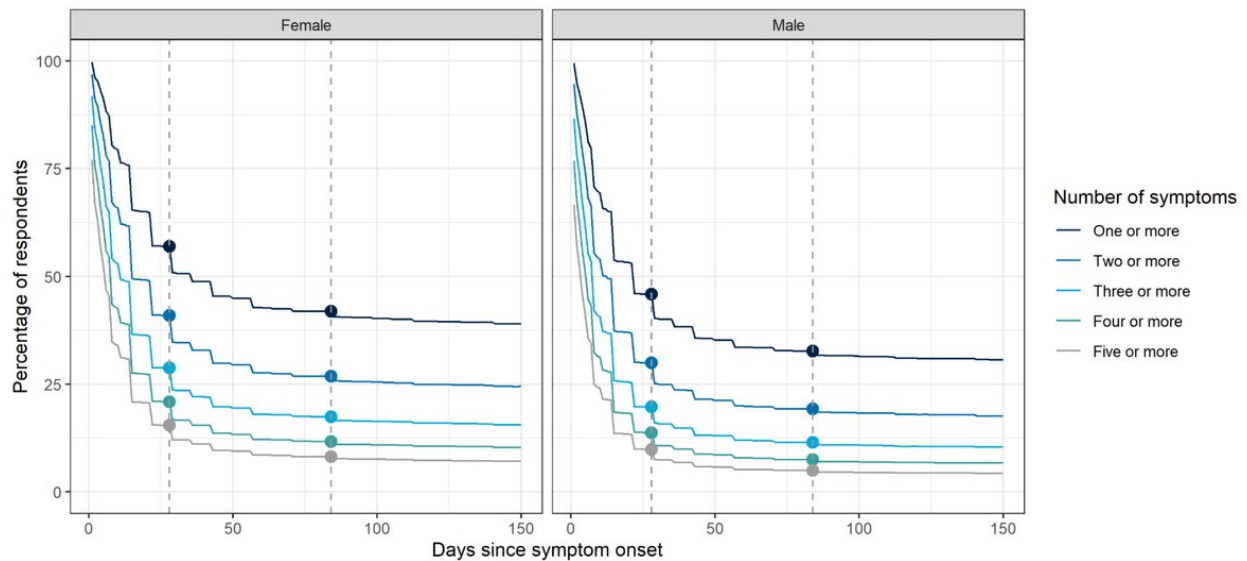
So what does the REACT-1 study, which examined more than half a million people show? This study is limited to ≥ 18 yr olds in England. This examined 29 symptoms, and showed 1 in 3 people with COVID-19 had symptoms lasting more than 12 weeks. This included young adults.

Table 1. Numbers and proportions of participants who reported one or more symptoms (from a list of 29 surveyed symptoms) of COVID-19 at i) time of symptom onset, ii) 4 weeks post symptom onset, and iii) 12 weeks post symptom onset, among the 76,155 symptomatic participants for whom we have 12 weeks' follow-up and complete data.

Category		Symptomatic at infection	4 weeks after initial symptom onset		12 weeks after initial symptom onset	
			Number symptomatic	Percentage symptomatic	Number symptomatic	Percentage symptomatic
All participants	-	76155	39737	52.2 [51.8-52.5]	28713	37.7 [37.4-38.0]
Sex	Women	43654	24812	56.8 [56.4-57.3]	18109	41.5 [41.0-41.9]
	Men	32500	14924	45.9 [45.4-46.5]	10604	32.6 [32.1-33.1]
Age group	18-24	5085	2133	41.9 [40.6-43.3]	1534	30.2 [28.9-31.4]
	25-34	12245	5325	43.5 [42.6-44.4]	3784	30.9 [30.1-31.7]
	35-44	15992	7646	47.8 [47.0-48.6]	5232	32.7 [32.0-33.4]
	45-54	17548	9490	54.1 [53.3-54.8]	6858	39.1 [38.4-39.8]
	55-64	15148	8787	58.0 [57.2-58.8]	6461	42.7 [41.9-43.4]
	65-74	7811	4823	61.7 [60.7-62.8]	3615	46.3 [45.2-47.4]
	74+	2326	1533	65.9 [64.0-67.8]	1229	52.8 [50.8-54.9]

For most affected, this wasn't a single symptom. It was a combination of many symptoms. e.g. 20% of those infected reported 3 or more symptoms and 17% reported 4 or more

symptoms at 12 weeks. Note that there isn't much drop off in prevalence of symptoms after 12 wks



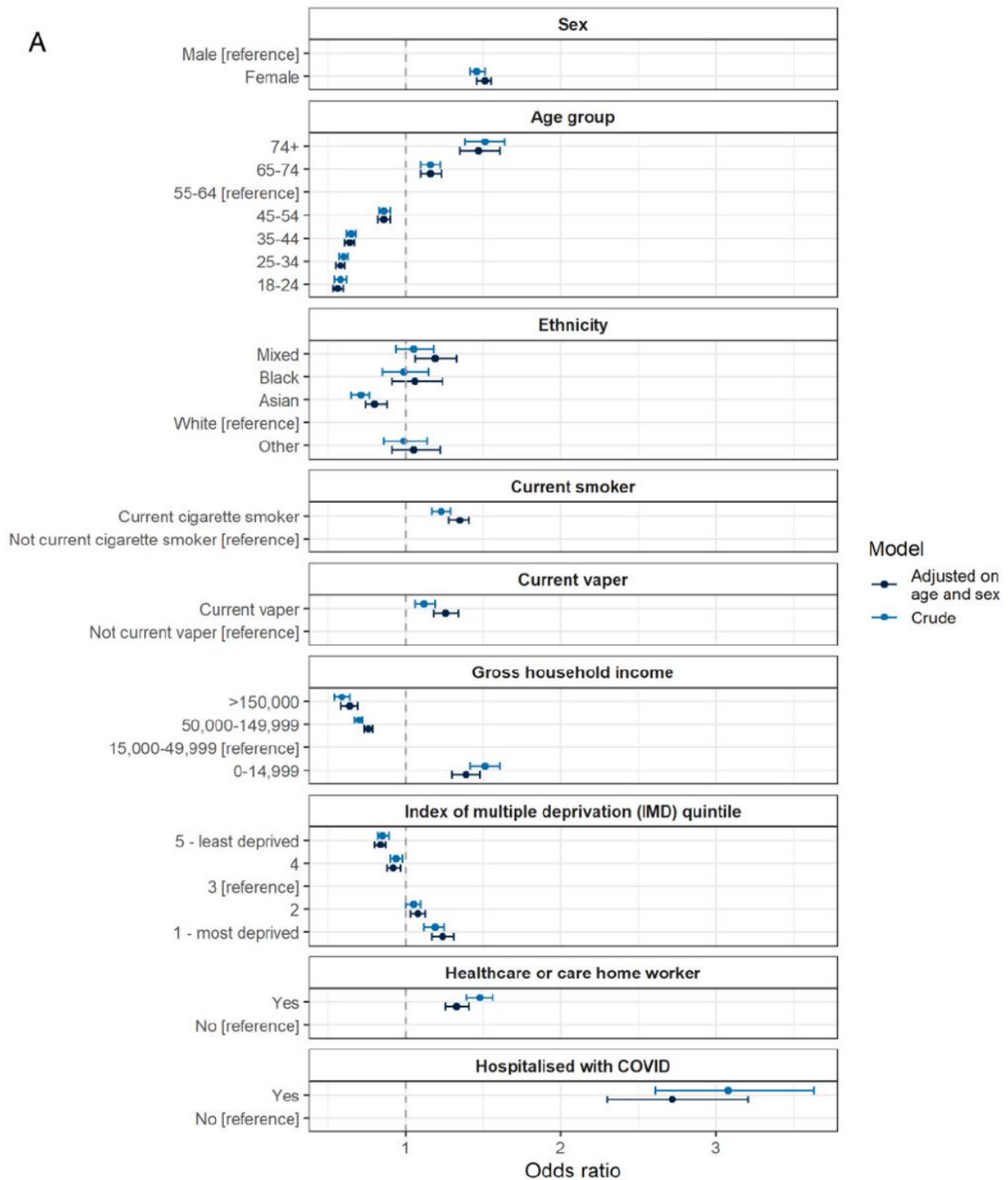
So if symptoms persist for 12 weeks as they do in 1 in 3 people as per the REACT-1 study, they tend to persist for much longer (up to 22 weeks or more). Also 1/3rd of those with one symptom persisting said it impacted their day to day lives- that's just above 10% of cases.

Almost a third of people with at least one symptom lasting 12 weeks or more (8,771/28,713 [30.5%]) reported having had severe COVID-19 symptoms (“significant effect on my daily life”) at the time of their illness, giving a weighted prevalence overall of people with persistent

Risk factors that increased risk included being a woman, increasing age, smoking, and low income, deprivation, and severe acute infection requiring hospitalisation.

That this is a disease that affects disadvantaged & women more might explain why many are happy to dismiss it.

A



B

Another study from Norway showed persistent symptoms at six months were even more common, where over half had persistent symptoms at 6 months (including children). These were people self-isolating at home so not severe illness needing hospitalisation.

Characteristic	All	0–15 years	16–30 years	31–45 years	46–60 years	Over 60 years
	% (n/N)	% (n)	% (n)	% (n)	% (n)	% (n)
	N=247	N=16	N=61	N=58	N=67	N=45
Age, median (IQR)	43 (27–55)	8 (6–12)	24(22–27)	37 (34–41)	53 (49–55)	67 (63–73)
Female gender	53% (131/247)	56% (9)	54% (33)	52% (30)	52% (35)	53% (24)
Status at 6 months						
Any symptoms	55% (136/247)	13% (2)*	52% (32)	59% (34)	61% (41)	60% (27)
Fever	2% (4/247)	0% (0)	0% (0)	5% (3)	1% (1)	0% (0)
Cough	6% (15/247)	0% (0)	0% (0)	9% (5)	4% (3)	16% (7)
Dyspnea	15% (38/247)	0% (0)	13% (8)	17% (10)	18% (12)	18% (8)
Palpitations	6% (15/247)	0% (0)	3% (2)	7% (4)	9% (6)	7% (3)
Stomach upset	6% (15/247)	6% (1)	5% (3)	7% (4)	6% (4)	7% (3)
Disturbed taste/smell	27% (67/247)	13% (2)	28% (17)	34% (20)	28% (19)	20% (9)
Fatigue	30% (69/231)	- ^a	21% (13)	31% (18)	33% (22)	36% (16)
Concentration problems	19% (44/231)	- ^a	13% (8)	19% (11)	21% (14)	24% (11)
Memory problems	18% (42/231)	- ^a	11% (7)	16% (9)	22% (15)	24% (11)
Sleep problems	5% (13/247)	0% (0)	5% (3)	7% (4)	4% (3)	7% (3)
Headache	11% (28/247)	0% (0)	11% (7)	14% (8)	9% (6)	16% (7)
Dizziness	10% (24/247)	0% (0)	7% (4)	10% (6)	10% (7)	16% (7)
Tingling in fingers	4% (9/247)	0% (0)	0% (0)	2% (1)	4% (3)	11% (5)

Long COVID in a prospective cohort of home-isolated patients - Nature Medicine Analysis of a prospectively enrolled cohort of patients with SARS-CoV-2 infections in Bergen, Norway, reveals a high proportion of patients who experienced long COVID symptoms at 6 months, despite bei... <https://www.nature.com/articles/s41591-021-01433-3>

So, to summarise, long COVID is common - even in young people with mild infection - who don't have to go into hospital. And it also affects children, and is usually multiple symptoms, that in many affect day to day lives. Let's look at other data now.

The cognitive symptoms (brain fog, memory loss, difficulty concentrating, sleep disturbances) tend to become prominent later in long COVID, & also last longer. These are worrying also because there are now studies showing the virus affects the brain, even in younger people.

I've summarised some of the evidence here. There is strong evidence now that even those with mild infection can have long-term structural brain changes, including thinning of grey matter in specific brain areas related to smell, taste, memory & emotion

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| <https://twitter.com/dgurdasani1/status/1406726553690595332?s=20>

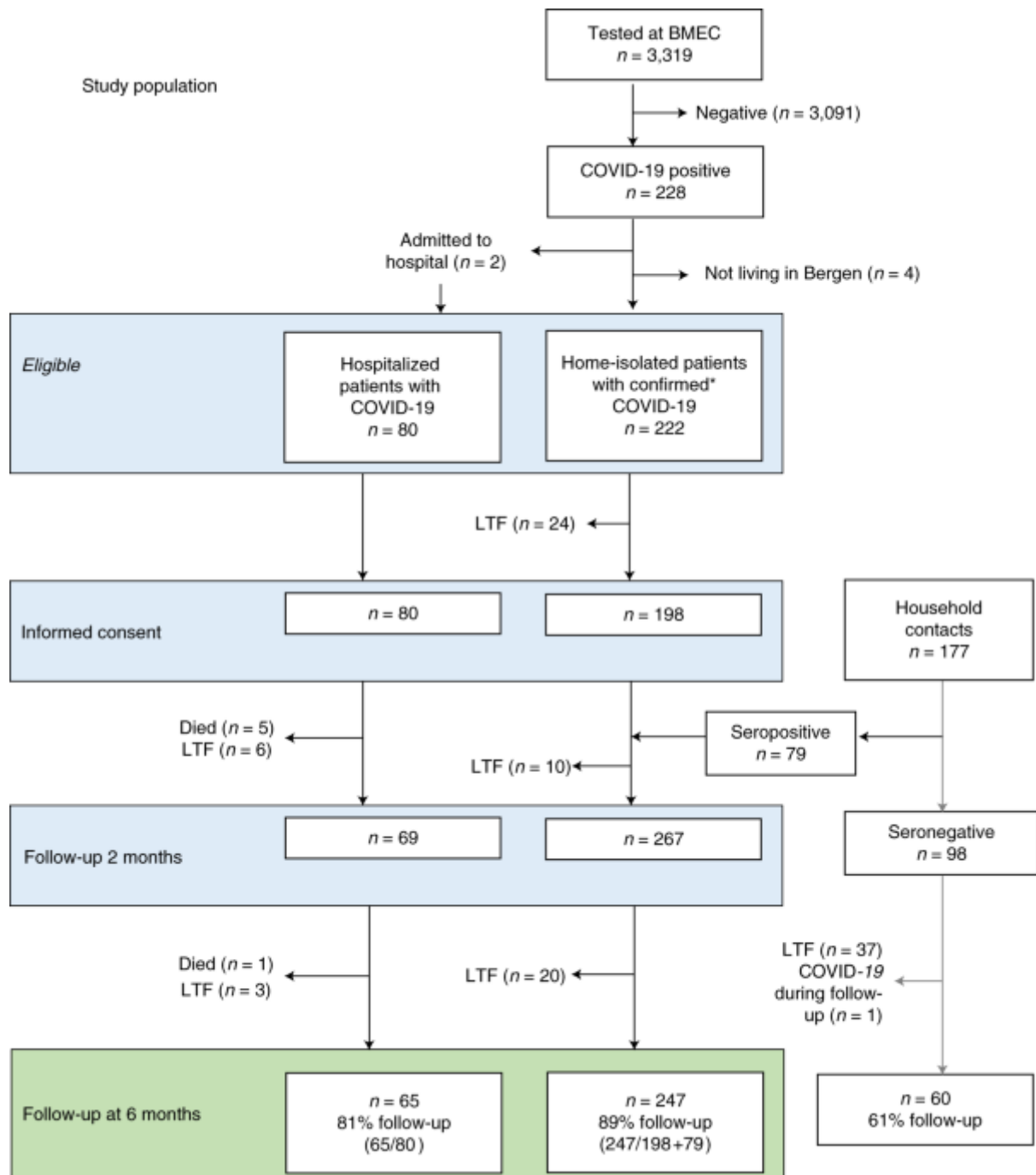
Neuro-psychiatric disease is common post-COVID even among those not hospitalised with severe infection. COVID-19 also appears to be associated with increased risk of strokes, and other neurological conditions at 6 months post infection:

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| <https://twitter.com/dgurdasani1/status/1379721348285673472?s=20>

What else do we know about what COVID-19 does to our immune system?

There's good evidence now that acute infection with COVID-19 leads to a plethora of auto-antibodies against many tissues in our body. We don't know the impact of these fully yet.



Diverse functional autoantibodies in patients with COVID-19 - Nature Rapid extracellular antigen profiling of a cohort of 194 individuals infected with SARS-CoV-2 uncovers diverse autoantibody responses that affect COVID-19 disease severity, progression and clinical an... <https://www.nature.com/articles/s41586-021-03631-y>

We also know that acute infection has impact on many organ systems in those affected with severe infection, including among young people. A recent study of >70,000 hospitalised patients showed that *half* had at least one organ system affected- lung/kidney/heart/brain/gut

The risk of organ dysfunction was 38·9% in those aged 19–49 years - clearly impacting a very high proportion of young people as well.

Characterisation of in-hospital complications associated with COVID-19 using the ISARIC WHO Clinical Characterisation Protocol UK: a prospective,

multicentre cohort study Complications and worse functional outcomes in patients admitted to hospital with COVID-19 are high, even in young, previously healthy individuals. Acute complications are associated

ed with reduced abil... [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00799-6/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00799-6/fulltext)

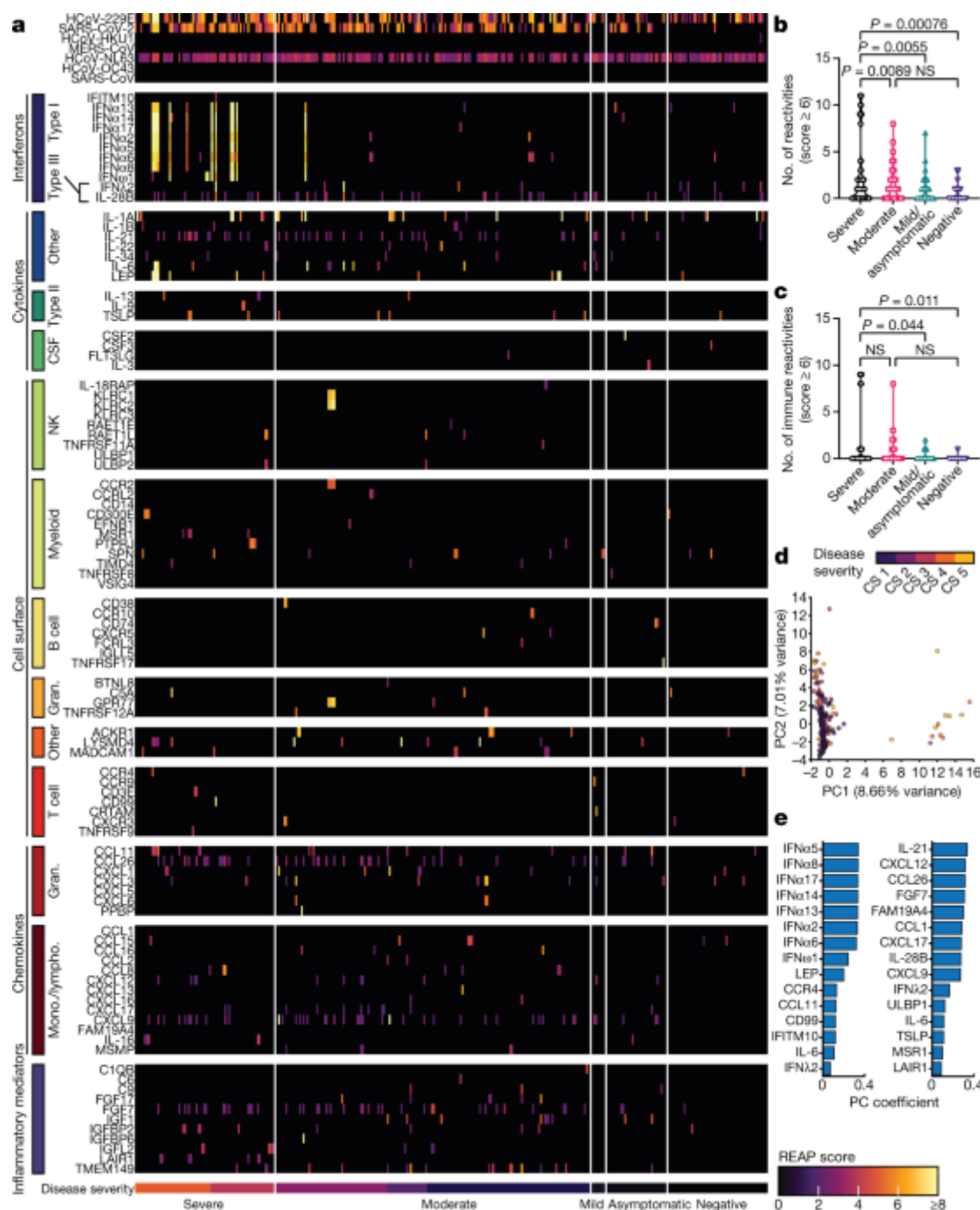
Another large study among those hospitalised in England showed that 1 in 3 were re-admitted after discharge, and 1 in 10 died within 5-6 months. This was 4-8 times higher than in the control hospitalised group studied - matched on many factors.

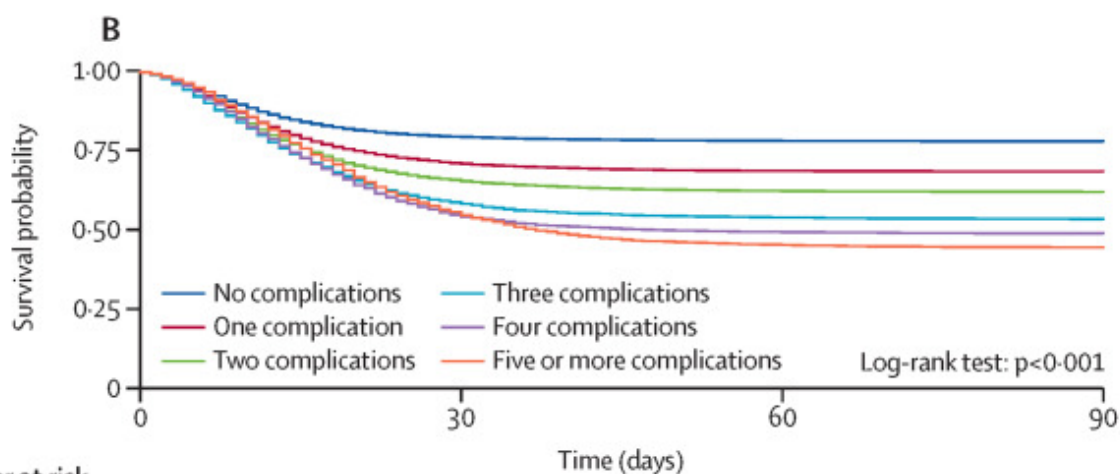
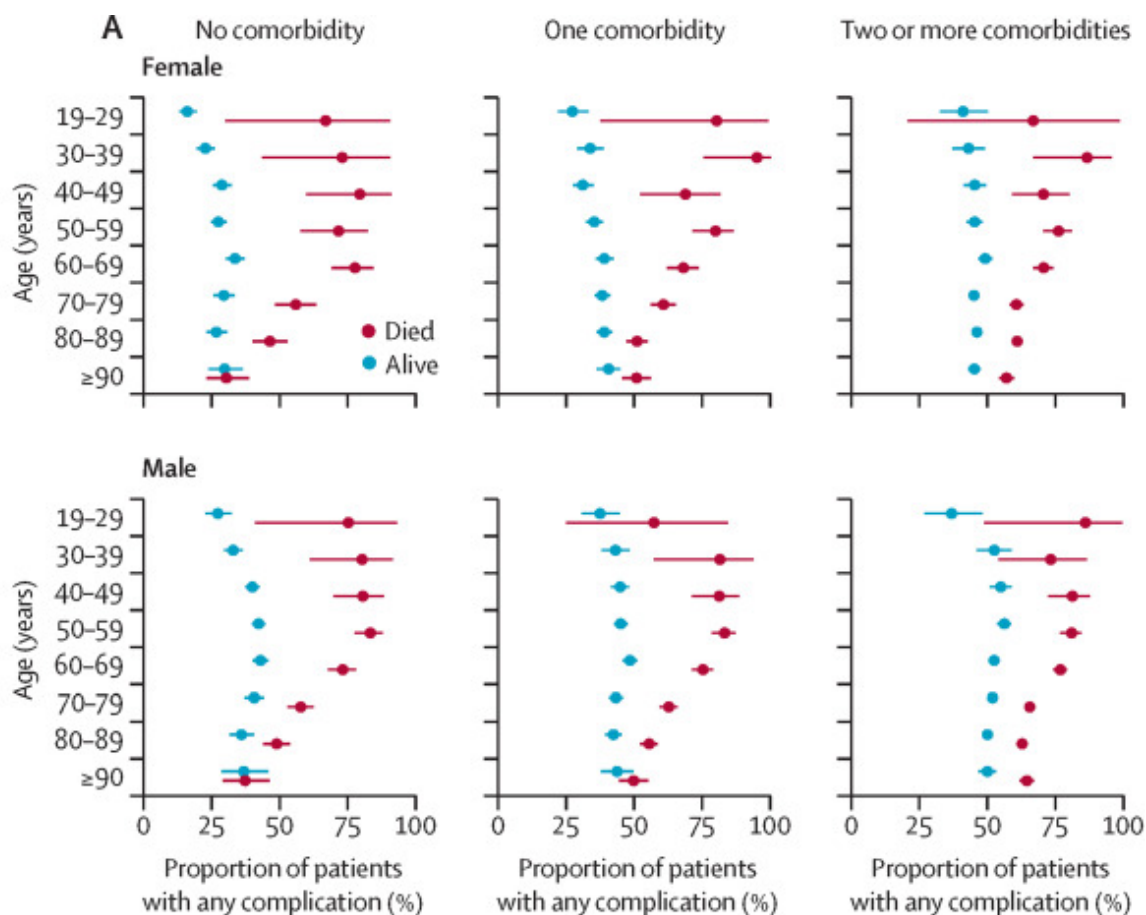
Post-covid syndrome in individuals admitted to hospital with covid-19:

retrospective cohort study Objective To quantify rates of organ specific dysfunction in individuals with covid-19 after discharge from hospital compared with a matched control group from the general population. Design Retrospe...

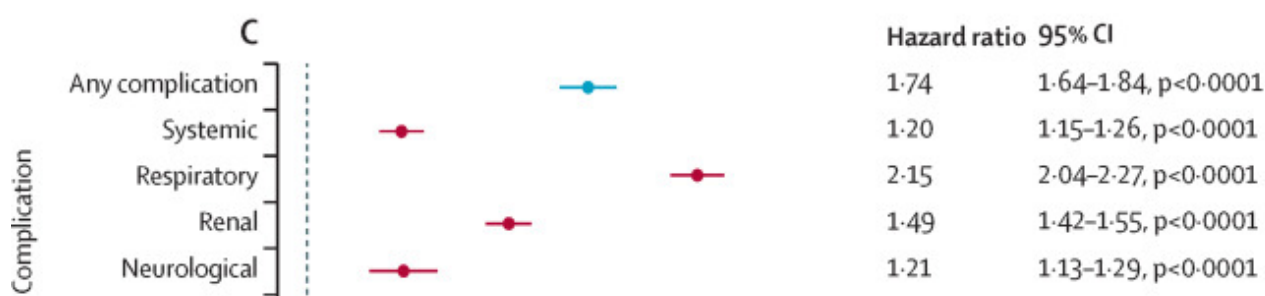
<https://www.bmj.com/content/372/bmj.n693>

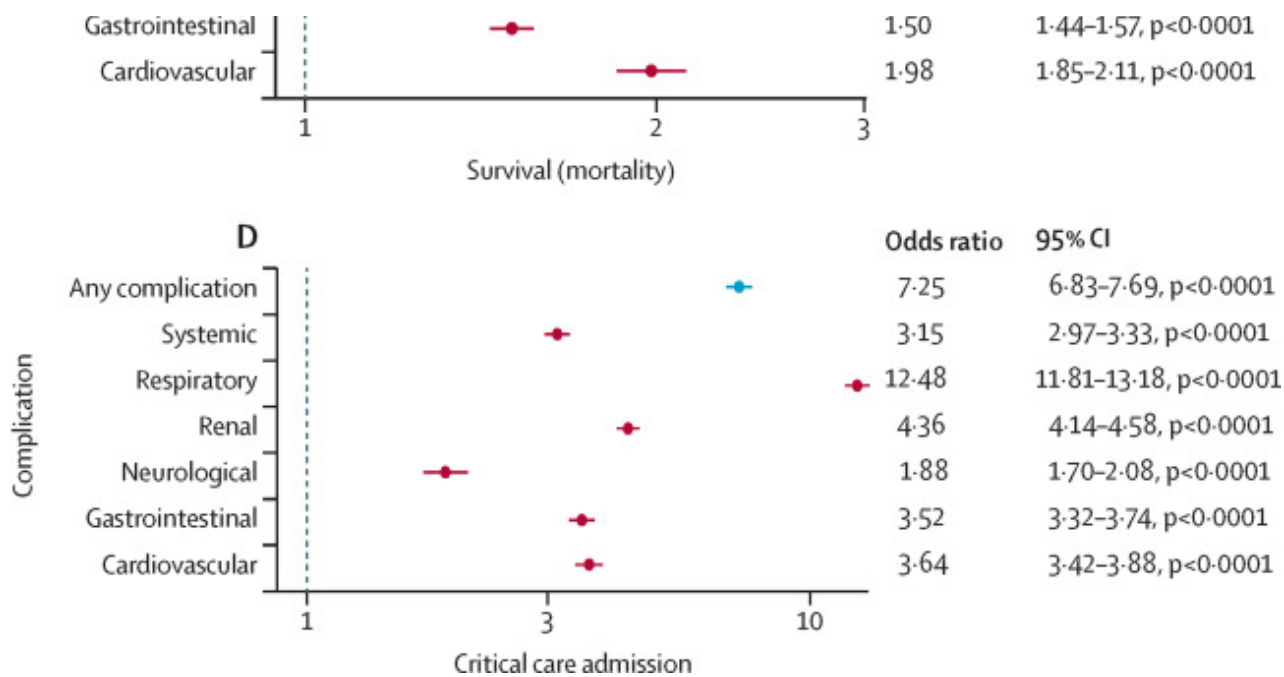
Organ disfunction was common, and far more prevalent in those hospitalised with COVID-19 than in the control group. And more associated with COVID-19 in under 70s





Number at risk					
No complications	33560	26419	25954	25894	
One complication	17988	12746	12288	12253	
Two complications	10018	6570	6223	6191	
Three complications	5432	3183	2924	2897	
Four complications	2872	1571	1415	1401	
Five or more complications	3494	1947	1583	1550	





compared to over 70s.



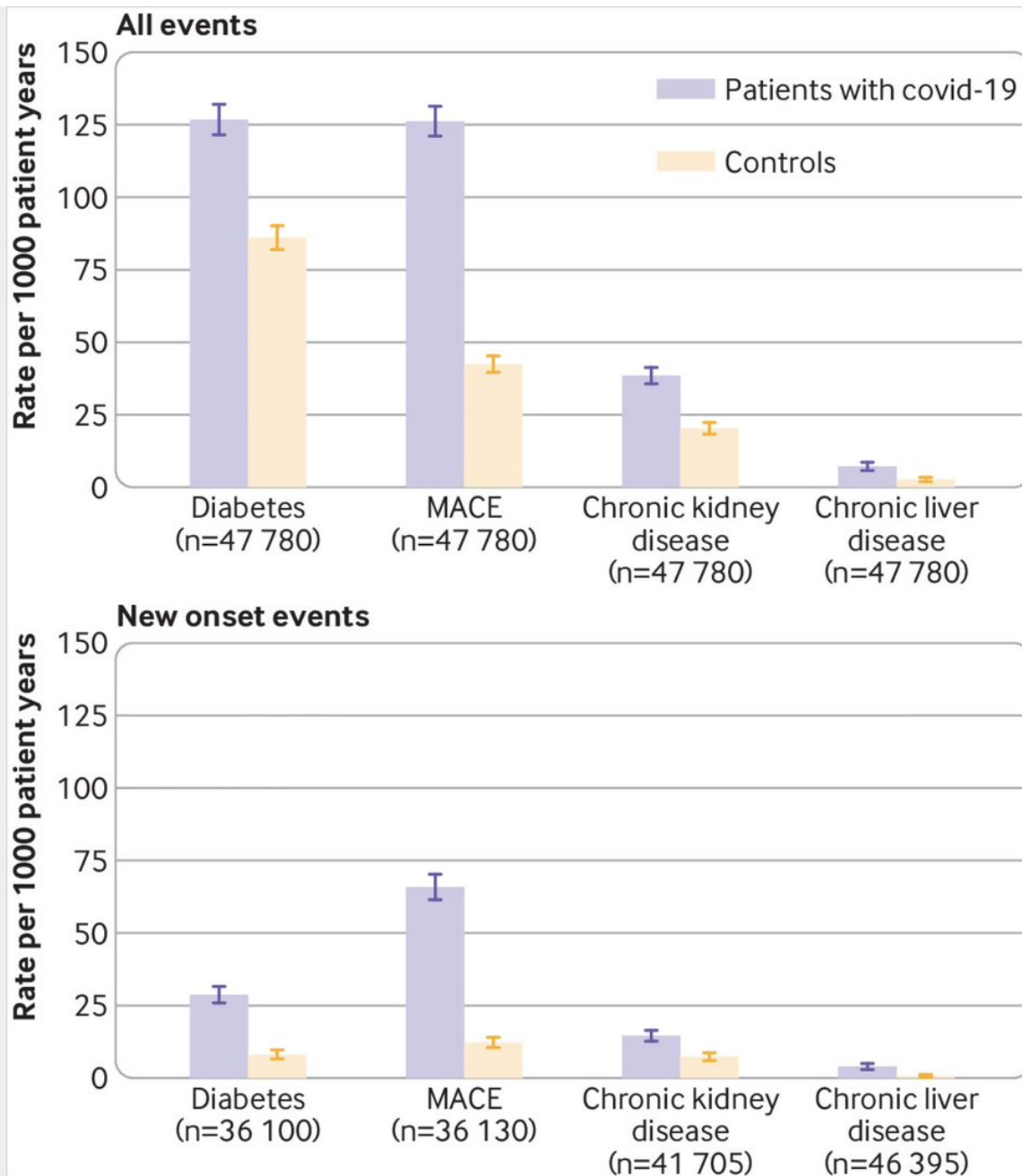


Fig 2

Rates of multi-organ dysfunction comparing individuals with covid-19 in England discharged from hospital by 31 August 2020 with matched controls. Outcomes calculated from hospital admissions to 31 August 2020, and primary care records and

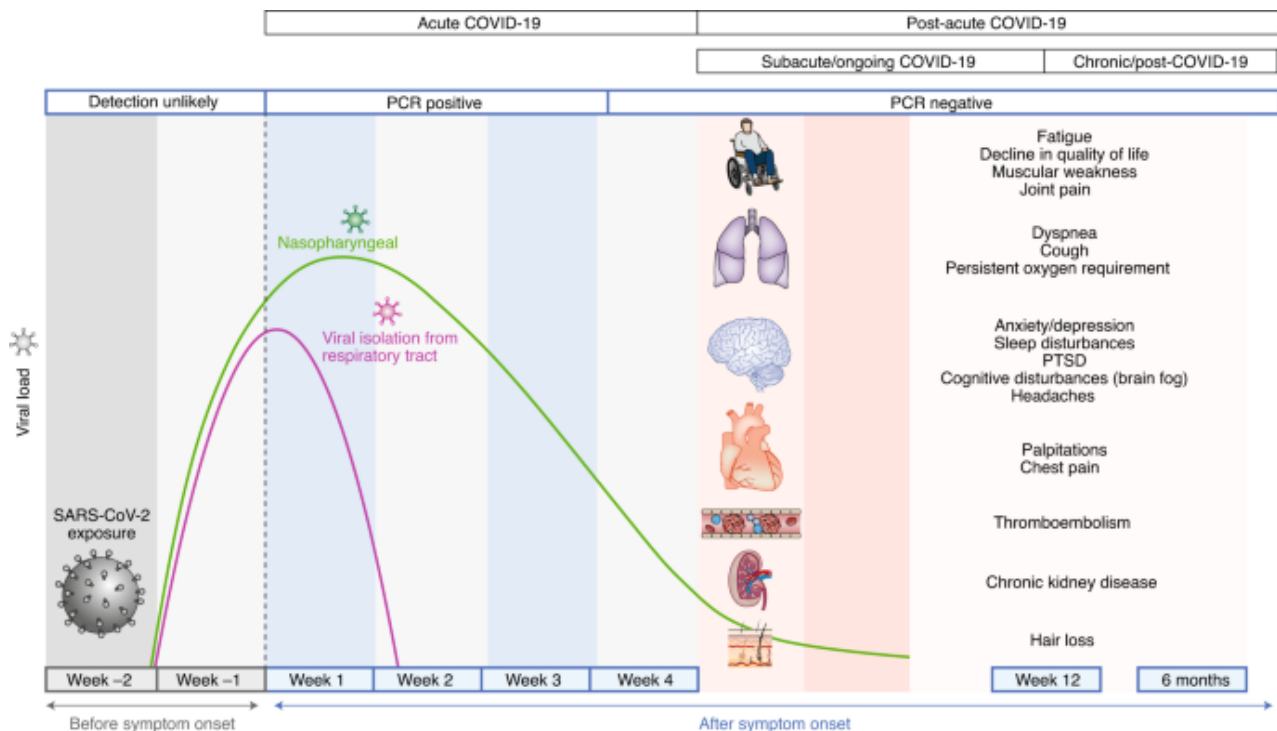
There are also many studies that suggest SARS-CoV-2 impacts our immune system- including T cell ageing & dysregulation of immune responses following infection. There is also evidence of virus persistence in some tissues. I'm not an immunologist- pl follow [@fitterhappierAJ](#) on this

I hope this will go a way to convince those who still aren't that long COVID is a biologically complex syndrome, that is common, and concerning. It impacts young people, and is often quite functionally severe and debilitating. So let's not minimise this.

yes, we don't fully understand the underlying pathology yet, and this will take time, but all indications are that it is serious - even in children. And very likely affects multiple organ systems, with long-term impacts even on young people.

So there is uncertainty- but this uncertainty doesn't mean we can ignore these very real risks - when all signs are pointing in a very worrying direction. We *must* adopt the precautionary principle & protect our young from this multi-system chronic disease.

There is scientific consensus that this is not just a respiratory disease, but a multi-system one. Here's really good review from Nature medicine on this. So let's not follow ideology. Let's follow the current evidence. All of which is gravely concerning.



Post-acute COVID-19 syndrome - Nature Medicine A comprehensive review of the current literature on post-acute COVID-19, also referred to as long COVID, its pathophysiology and its organ-specific sequelae highlights the need for multidisciplinary f... <https://www.nature.com/articles/s41591-021-01283-z>

Choosing to expose children to infection rather than vaccinate them, when millions across the world have been safely vaccinated is negligent, and harmful. We are exposing children to a multi-system chronic illness we don't understand & don't know how to treat.

If you are one of the scientists who made this choice, please be honest that this is ideology, and not science. Because the evidence tells us to be very very cautious about exposing children to infection, & that the benefits of vaccines far outweigh harms.

To put this into perspective, if we vaccinate 1 million 12-17 year olds, we could see 30-40 MILD cases of myocarditis. In this same 1 million, through vaccination we AVOID: 8,000 cases of COVID-19, 200 hospitalizations, 50 ICU stays & 1 death. The benefits far outweigh the risks. <https://t.co/zFVPkZVBmY>

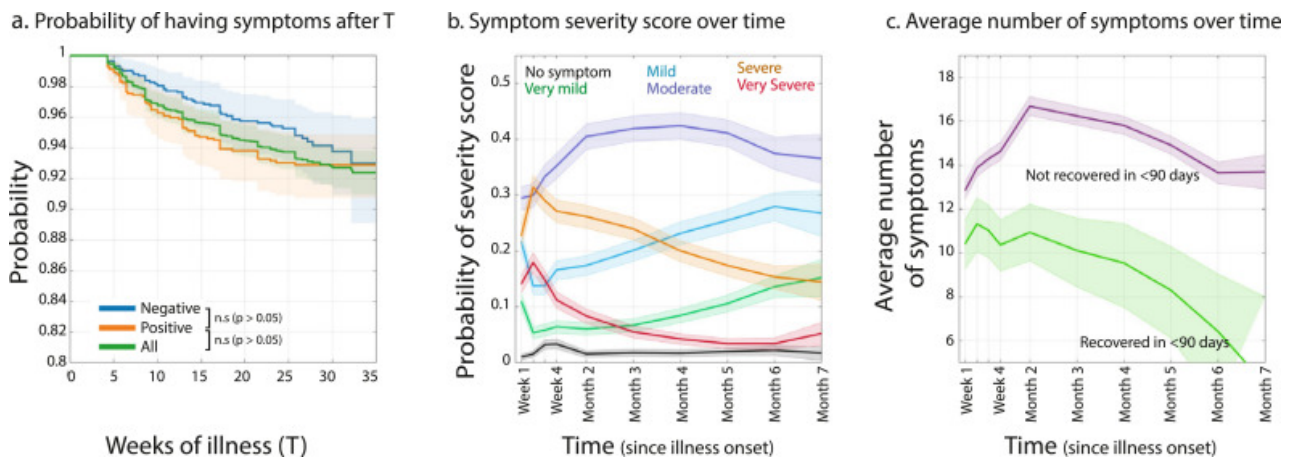
— Rochelle Walensky, MD, MPH (@CDCDirector) June 24, 2021

And pl follow @Daltmann10 @VirusesImmunity @kamleshkhunti @Dr2NisreenAlwan @trishgreenhalgh for accurate information on this.

I partly wrote this thread so anyone could use it to counter false narratives & unevidenced critique from long COVID deniers. Please feel free to link it to anyone who suggests there isn't strong evidence for long COVID. They can then engage on facts.

Sorry, earlier tweet should have read 'but it doesn't affect *young* people', Yes it does!

Also, want to add that there's amazing patient-led work in this area which looked at 74 symptoms of long COVID, and consistent with many other studies showed that neuro-cognitive symptoms tend to increase and persist over time, which is deeply concerning.



Characterizing long COVID in an international cohort: 7 months of symptoms and their impact Patients with Long COVID report prolonged, multisystem involvement and significant disability. By seven months, many patients have not yet recovered (mainly from systemic and neurological/cognitive sy...

[https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00299-6/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext)

This work was led by [@AthenaAkrami](#) and Hannah Davis. Please do follow her, and the many groups who have educated us about this through their lived experience including [@LongCovidKids](#)

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