



Planning for Recovery: Long Covid Supporting Children with Disabilities: Lessons From the Pandemic

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Post acute infection syndrome

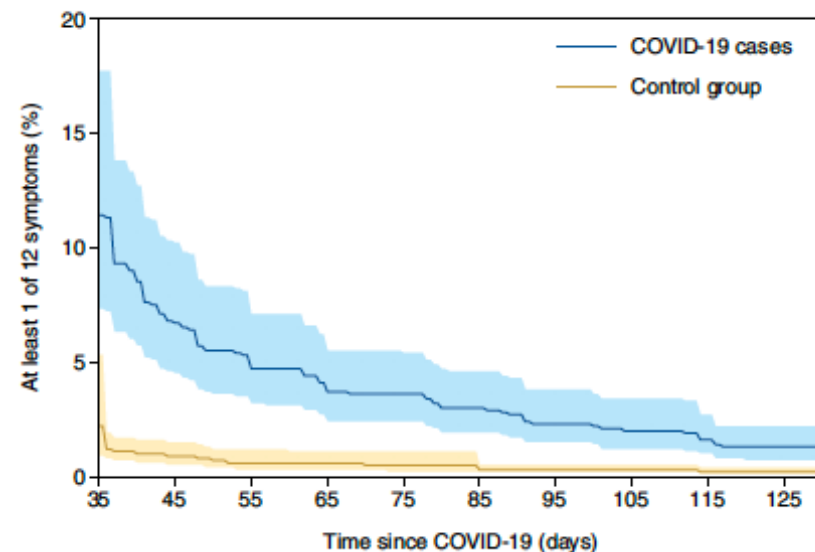
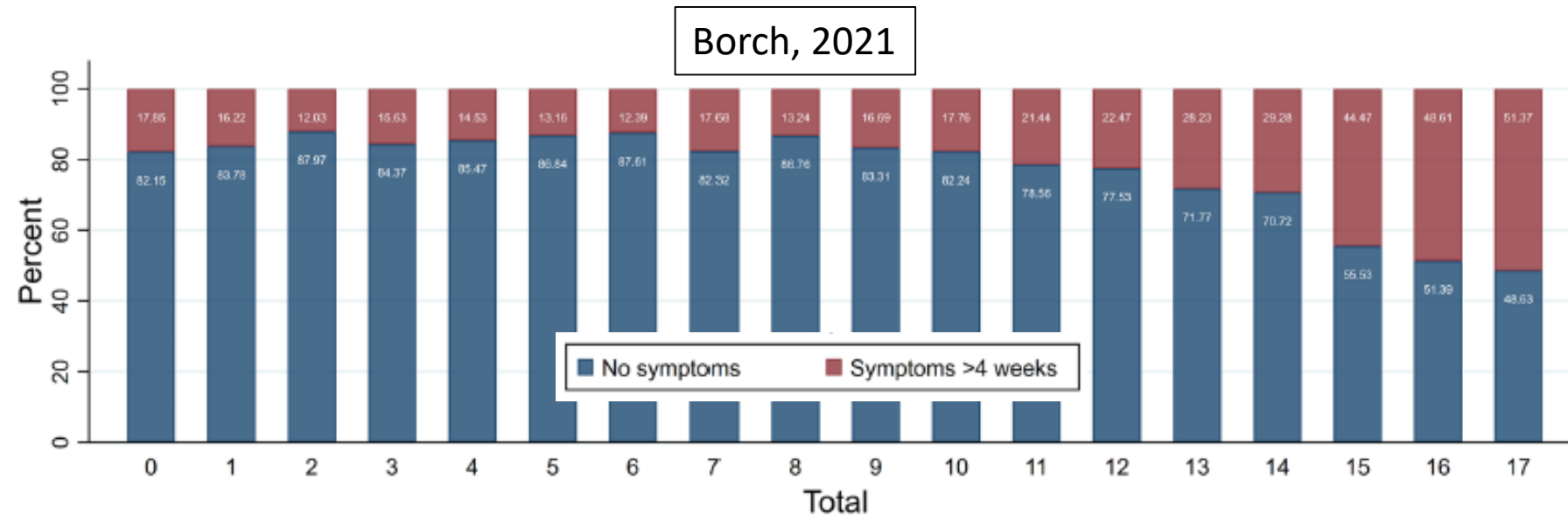
- PASC ("long COVID"):
 - Umbrella term to describe chronic outcomes of SARS-CoV2 infection
 - Total morbidity could be comparable to acute infection
- Several subsets:
 - Post-ICU syndrome; organ specific damage (lung, clotting)
 - Unexplained exertional intolerance, fatigue, headache, myalgia
 - Cognitive and sensory disturbance
 - "unmasking" other conditions → POTS, Guillain Barre
- Multiple infections have historically been associated with post-acute infection syndromes
 - Ebola, Chickungunya, EBV, Polio, Lyme

Clinical case definitions:

- World Health Organization²⁰⁴: Post-COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, and cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.
- US Centers for Disease Control and Prevention²⁰⁵: Post-COVID conditions are a wide range of new, returning, or ongoing health problems people can experience four or more weeks after first being infected with the virus that causes COVID-19. Even people who did not have COVID-19 symptoms in the days or weeks after they were infected can have post-COVID conditions. These conditions can present as different types and combinations of health problems for different lengths of time.
- UK National Institute for Health and Care Excellence²⁰⁶: (1) Ongoing symptomatic COVID-19 for people who still have symptoms between 4 and 12 weeks after the start of acute symptoms; and (2) post-COVID-19 syndrome for people who still have symptoms for more than 12 weeks after the start of acute symptoms. The guideline also makes recommendations for clinical investigations of patients presenting with new or ongoing symptoms 4 weeks or later after acute infection.

Burden of illness

- Prevalence varies greatly with studies and with symptoms reported
- 6-46% reported at least 1 symptom greater than 4 weeks outside of infection
- Most often in adolescence



Choutka 2022

	All participants		
	Tested positive for SARS-CoV-2 (n=3065)	Tested negative for SARS-CoV-2 (n=3739)	p value*
No reported symptoms	1027 (33.5%)	1746 (46.7%)	<0.0001
1 symptom	671 (21.9%)	1019 (27.3%)	..
2 symptoms	439 (14.3%)	371 (9.9%)	..
3 symptoms	300 (9.8%)	228 (6.1%)	..
4 symptoms	217 (7.1%)	137 (3.7%)	..
≥5 symptoms	411 (13.4%)	238 (6.4%)	..

Stephenson, 2022

Common Symptoms

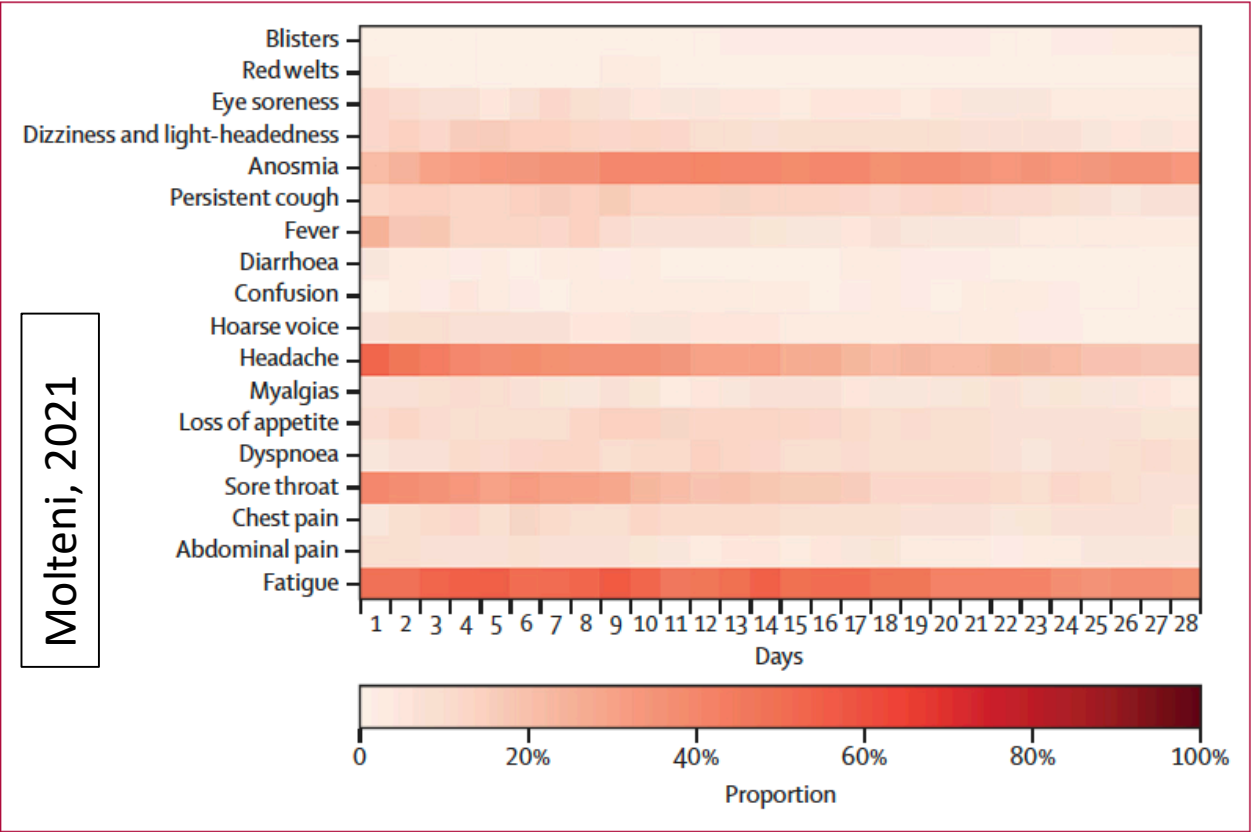


Figure 4: Heat maps showing symptom duration in school-aged children (age 5-17 years) testing positive for SARS-CoV-2 in whom at least one symptom persisted for at least 28 days
n=77. Colour bar provides a percentage comparison. Data refers to children with symptom onset between Sept 1, 2020, and Jan 24, 2021.

- Common symptoms are widespread across many systems.

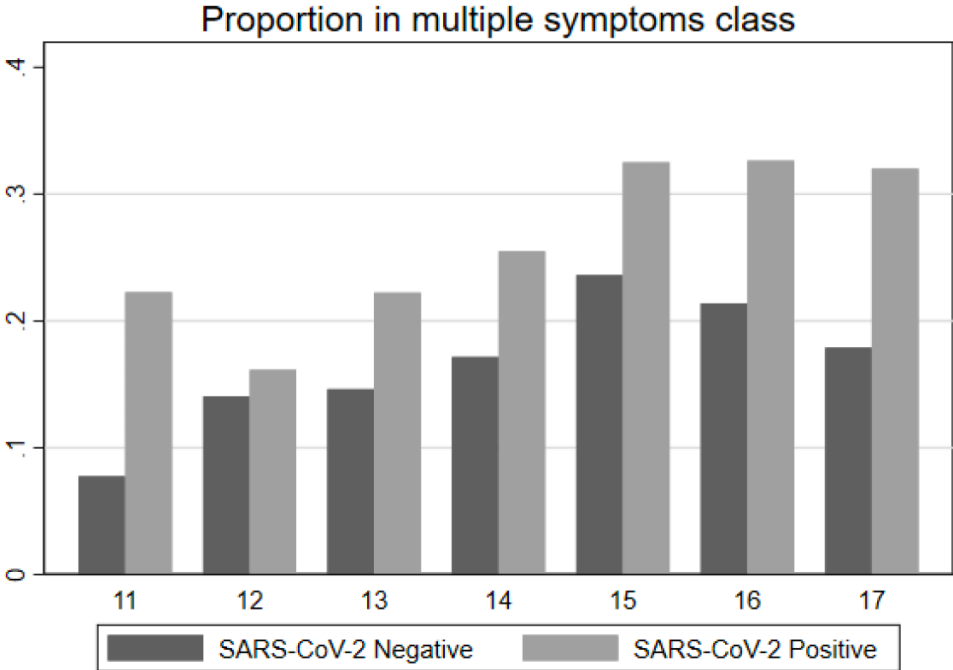
Specific symptoms	+	-	
Fever	50 (1.6%)	55 (1.5%)	0.59
Chills	269 (8.8%)	192 (5.1%)	<0.0001
Persistent cough	98 (3.2%)	98 (2.6%)	0.16
Tiredness	1196 (39.0%)	911 (24.4%)	<0.0001
Shortness of breath	717 (23.4%)	388 (10.4%)	<0.0001
Loss of smell	414 (13.5%)	51 (1.4%)	<0.0001
Unusually hoarse voice	56 (1.8%)	46 (1.2%)	0.044
Unusual chest pain	216 (7.0%)	129 (3.5%)	<0.0001
Unusual abdominal pain	119 (3.9%)	107 (2.9%)	0.019
Diarrhoea	92 (3.0%)	80 (2.1%)	0.024
Headaches	710 (23.2%)	530 (14.2%)	<0.0001
Confusion, disorientation, or drowsiness	198 (6.5%)	123 (3.3%)	<0.0001
Unusual eye-soreness	182 (5.9%)	134 (3.6%)	<0.0001
Skipping meals	296 (9.7%)	275 (7.4%)	0.0007
Dizziness or light-headedness	419 (13.7%)	314 (8.4%)	<0.0001
Sore throat	291 (9.5%)	281 (7.5%)	0.0034
Unusually strong muscle pains	165 (5.4%)	83 (2.2%)	<0.0001
Earache or ringing in ears	191 (6.2%)	165 (4.4%)	0.0008
Raised welts on skin or swelling	48 (1.6%)	32 (0.9%)	0.0069
Red or purple sores or blisters on feet	35 (1.1%)	40 (1.1%)	0.78
Other	335 (10.9%)	590 (15.8%)	<0.0001

Stephenson, 2022



Common Symptoms

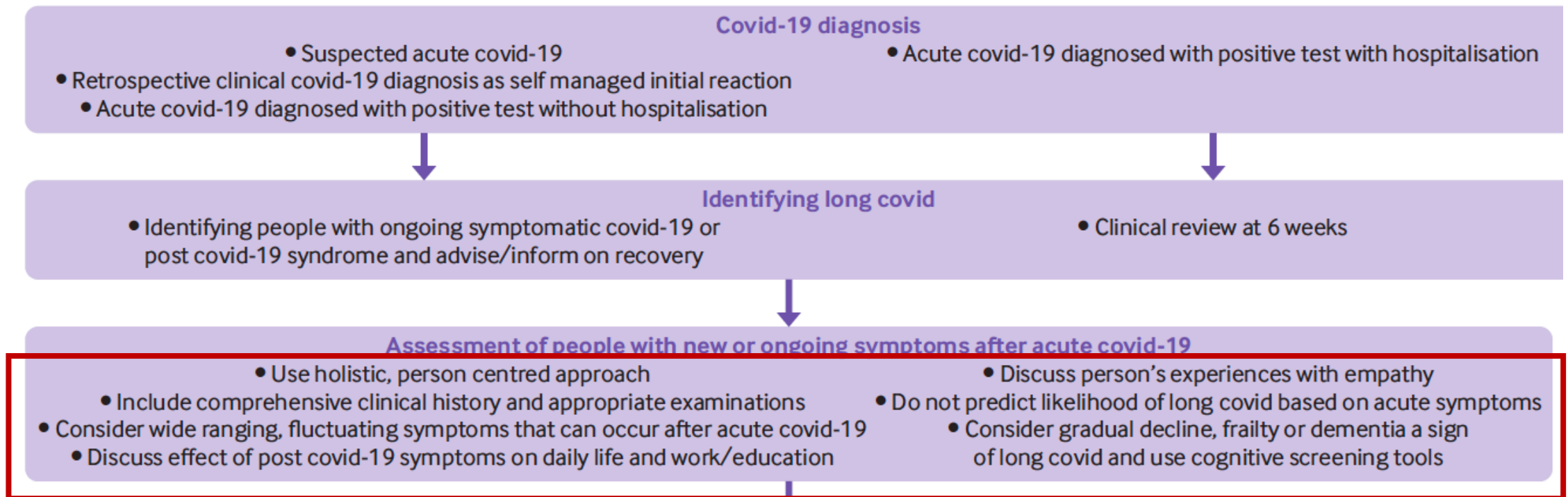
- All patients then stratified to “few” or “multiple” symptoms
 - Probability of having “multiple” symptoms:
 - 30% SARS-CoV2+
 - 19% SARS-CoV2-
 - RR for “multiple” symptoms 1.52
- For both + or – patients; those with multiple symptoms had worse mental health and wellbeing scores
 - Older, female, poorer baseline physical and mental health



		SARS-CoV-2 test Negatives (N=3,739)		SARS-CoV-2 test Positives (N=3,065)	
		Class 1 %	Class 2 %	Class 1 %	Class 2 %
All		80.7	19.3	70.4	29.6
Baseline					
Sex	Male	88.5	11.5	82.4	17.6
	Female	79.0	21.0	65.9	34.1
Age (years)					
	11-14	86.5	13.5	78.2	21.8
	15-17	79.5	20.5	67.7	32.3
Previous physical health					
	Very poor/poor	55.6	44.4	60.6	39.4
	OK	73.5	26.5	63.0	37.0
	Good/v Good	85.8	14.2	74.8	25.2
Previous mental health					
	Very poor/poor	61.9	38.1	48.0	52.0
	OK	75.9	24.1	64.3	35.7
	Good/v Good	88.8	11.2	79.2	20.8

Identification, investigation, management

- Risk factors for severe acute COVID infection is not the same for “long COVID”
 - Female, older teenager, previously “healthy”
- Part of the initial treatment is recognition and empathy with patients.





Identification, investigation, management

Symptom	Lab testing	Radiographic Studies	Consultation
Fever	CBC, CMP, ESR, Crp, UA	CXR	
Cough, shortness of breath, chest pain		CXR, (PFT)	Respiratory
Diarrhea	Fecal calprotectin, fecal WBC	(Endoscopy)	Gastroenterology
Headaches, brain fog		(Brain MRI)	Neurology, psychiatry
Orthostasis	CMP, iron studies, TSH	ECHO, EKG	
MSK pains	Vitamin D, Iron studies	Ultrasound, radiograph, MRI	Rheumatology
Sleep disturbance		(Sleep study)	Sleep medicine

Investigations and referral

- Refer urgently to relevant service if symptoms could be life threatening
 - Offer tailored tests and investigations to determine exact cause
 - If other (non-covid) diagnosis is suspected, offer investigations in line with guidance
 - Offer blood tests
 - Offer tests depending on individual needs (exercise tolerance test, blood pressure and heart rate recordings, chest radiograph, etc)
 - Consider referral (urgently if required) for people with psychiatric symptoms
 - After ruling out life threatening conditions consider referral to multidisciplinary assessment service from 4 weeks after start of acute covid-19

Identification, investigation, management

- Symptom based
 - NSAIDs, breathing treatments, melatonin, migraine medication
- Function based
 - School attendance
 - Physical and occupational therapy
 - Empathy (with expectation)

Planning care

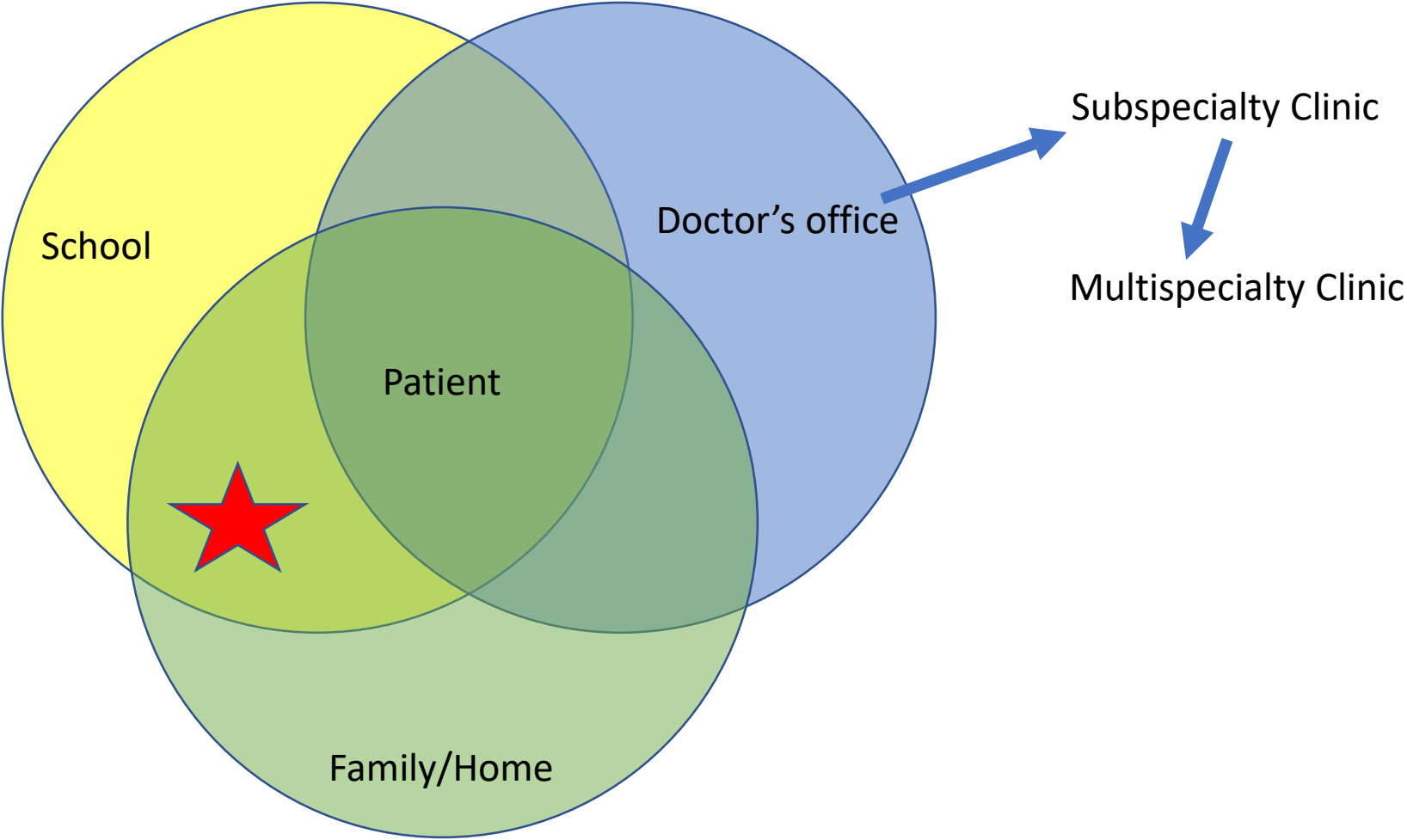
- After assessment, use shared decision making to discuss and agree with person what support and rehabilitation they need including advice on self management and support/referral to agreed clinical pathway
- When discussing appropriate level of support:
 - Think about overall impact of symptoms on life
 - Look at overall trajectory of symptoms including fluctuations

Management

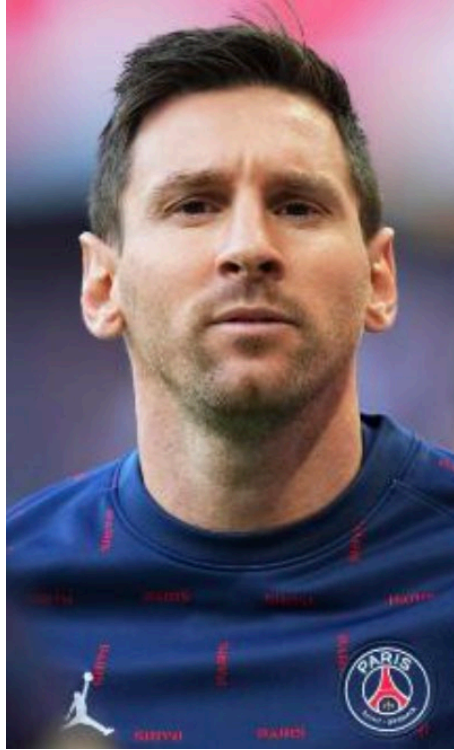
- **Self management and supported self management**
 - Give advice and information on self management
 - Explain that it is unknown if over-the-counter vitamins and supplements are helpful
 - Support people in discussing returning to work/education
- **Multidisciplinary rehabilitation**
 - Assess physical, psychological and psychiatric aspects of rehabilitation
 - Work with person to develop rehabilitation and manage plan
 - Encourage people to monitor progress
- **Support for older people and children**
 - Consider additional support and referral for specialist advice



Identification, investigation, management





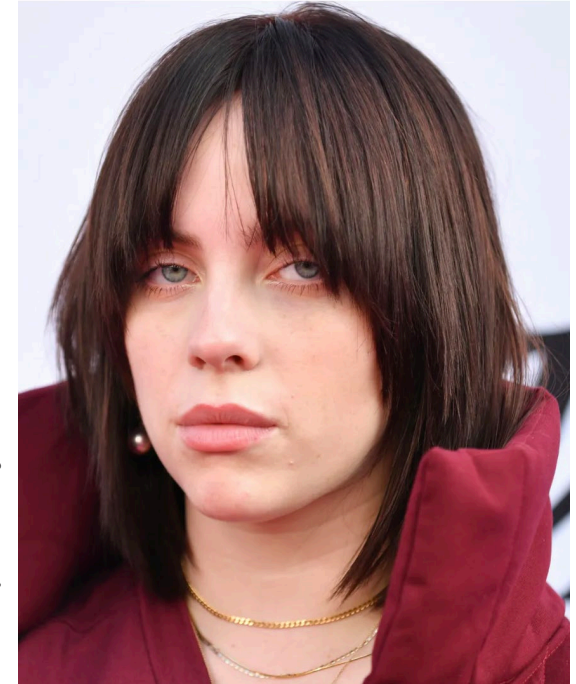
Famous Faces



"It left me with after effects. It left me with after effects in my lungs. I came back and it was like a month and a half without even being able to run because my lungs were affected," Messi said Monday.

During an appearance on an episode of *The Howard Stern Show* on Monday, the pop star opened up about her experience with breakthrough COVID in August. "It was bad. I mean, I didn't die, and I wasn't gonna die, but that does not take away from how miserable it was. It was terrible," Eilish told **Stern**. "I still have side effects. I was sick for, like, two months almost."

One of those side effects is a persistent cough, but she assured fans that she's "fine now" thanks to being vaccinated. "I think if I weren't vaccinated, I would have, like, died, because it was bad," she explained. "When I say it was bad, I more just mean that it felt horrible. But really, in the scheme of COVID, it was not bad. You know what I mean? When you're sick, you feel cking horrible." She added that the vaccine is cking amazing" and it kept her brother, **Finneas**, "from getting [COVID-19], it saved my parents from getting it, saved my friends from getting it."



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