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## Covid-19: How Europe is approaching long covid

**Chris Baraniuk** looks at the range of responses to long covid around the continent

Chris Baraniuk *freelance journalist*

Maarte Preller leads a Facebook group for patients with long covid in Austria. It has nearly 1500 members so far. In September, Preller, and others like her across Europe, established a new network of patient associations, formed partly through social media websites, called Long Covid Europe. The group is demanding better research and treatment for the tangle of ongoing symptoms that afflict many people who have had covid-19.

A patchwork of small studies has given some indication of what long covid on the continent is like. In a study of 130 cases, 40% of patients reported “persistent fatigue” 60 days after their first symptoms, while 30% reported breathlessness. Another, of 143 patients in Italy, revealed 55% had three or more symptoms 60 days after they were discharged from hospital.<sup>1</sup>

A preprint posted in January 2022 of an ongoing study of 70 000 Norwegian patients listed altered smell or taste, poor memory, fatigue, and shortness of breath as common symptoms in the country’s first wave (in early 2021), while those infected from autumn 2021 onwards tended to mention muscle and joint pain more. The data suggest that symptoms were experienced for 11-12 months after infection in the first wave and for one to two months in the second.<sup>2</sup>

A World Health Organization policy brief published earlier this year found that surveillance of long covid was not happening routinely in European countries.<sup>1</sup> There are few specialist clinics for the condition—access to such a service largely depends on where you live—and in many countries action seems to be limited to guidance and monitoring.

### The many faces of action

In the UK, there are more than 80 NHS run long covid clinics. Long covid services were highlighted as part of £6.6bn in new funding announced in March 2021 for the ongoing NHS response to the pandemic.<sup>3</sup> Separately, the Scottish government has announced £10m in funding for local health boards to help patients who have long term symptoms.

In the European Union, specialist long covid clinics are reported to be operating in Belgium, France, Germany, and Spain, among others, but these rarely cater for more than a small part of the population.

In Italy, no government funded clinics for long covid have yet been established, according to Danilo Buonsenso at Gemelli University Hospital in Rome, although some hospitals have day clinics for following up patients who had been admitted to hospital during the acute stage of covid-19. A few of the day clinics include patients who have no history

of hospital admission for covid-19, however, “the waiting list is incredibly high,” Buonsenso adds.

In May 2021, the Italian government allocated around €28m for 2021 and €24m for 2022, to the “respiratory care” of covid-19 patients who had been admitted to hospital.<sup>4</sup> In July, Italy’s National Institute of Health (ISS) published a report on interim indications on long covid management,<sup>5</sup> which refers to the need for specialist “post-covid clinics” as well as facilities linked to general practice and hospitals.

The French National Authority for Health (HAS) published official guidelines for the follow-up of long covid patients in February 2021, stating that most can be followed up through primary care.

This echoes an initiative in Belgium. Ann Li, Long Covid Europe’s representative for Belgium, told *The BMJ* in late 2021 that there was a primary care initiative from Belgium’s National Institute for Health and Disability Insurance, ordered by the minister of health. “Some specialists, assurance companies, and professional associations from [the primary healthcare sector] are part of the initiative. The tool should be ready by the end of this year and should make it easier for our primary care workers to plan rehabilitation for long haulers. It will include a financial compensation plan for patients who visit psychologists, dieticians, or physiotherapists.” The tool is now expected to launch in the spring of 2022, Li added later.

In Spain, two doctors recently received a grant of €1.8m from the Spanish government to open a clinic for long covid patients. One of the pair, César Fernández-de-las-Peñas, a physical therapist at Rey Juan Carlos University, told *The BMJ* that the clinic would be “the first post-covid healthcare unit in Spain” when it opens, possibly as soon as March 2022. They also received €1m funding for long covid research.

In Norway last summer, the then health minister, Bent Høie, asked hospitals to establish outpatient clinics for people with long covid. There are now four in total, one for each health region in the country. A spokesman for Norway’s health directorate told *The BMJ* that there is a “national action plan” focusing on providing information about the condition for patients. “We have also developed guidance for healthcare workers on how to detect and treat people having post-covid symptoms,” the spokesman says. They added, however, that the actual treatment delivered will depend on the clinic in question and that it is down to individual doctors to recommend a plan for each patient.

In neighbouring Sweden, Judith Bruchfeld, physician at Karolinska University Hospital, who leads a

research project on long covid, helped the National Board of Health and Welfare to implement guidelines for follow-up. But support for care or further research has been unforthcoming. “Long covid is new and complex, and resources are needed,” says Bruchfeld, adding that only seven out of 21 regions were able to run a long covid clinic.

Estonia is also providing guidance to healthcare workers. Heidi Alasepp, deputy secretary general on health at Estonia’s ministry of social affairs, says, “Guidance and training has been given to GPs and specialists to raise awareness and provide advice on how to deal with long covid.” There’s no plan for specialist clinics, but the ministry has launched a covid-19 patient follow-up study that will cover a 12 month period.

#### WHO definition

WHO set a clinical case definition in October 2020<sup>6</sup> and added “post covid-19 condition” to the International Classification of Diseases codes used to “document or flag conditions that occur in the context of covid-19. In particular, the need for disambiguation between acute disease, late effects, or lengthy course led to the neutral formulation ‘post-covid.’”<sup>7</sup> The WHO Regional Office for Europe did not respond to a BMJ request for comment.

Post covid-19 condition occurs in people with a history of probable or confirmed SARS-CoV-2 infection, usually three months from the onset of covid-19 with symptoms that last for at least two months that 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.

#### Research gap

Carmen Scheibenbogen, professor of immunology at Charité University in Berlin, says she currently has two or three patient enquiries for every appointment available at her clinic.

“We need to put more effort into research,” she says. “In Germany, at least, we don’t have much funding at the moment for these post-covid syndromes.” The German Ministry of Education and Research has allocated €6.5m to 10 projects investigating the condition. The French government’s budget for long covid research is €2.2m, according to France24.<sup>8</sup> In contrast, the UK has allocated nearly £20m in funding to research the condition.

Dominique Salmon-Ceron, an infectious disease researcher at the Hôtel-Dieu Hospital in Paris, told France24 in June that she had applied for funding four times in the past year, only to be declined by the health ministry.

In May, the European Commission said it would accelerate research into long covid and seek to develop treatments as part of its covid-19 therapeutics plan.<sup>9</sup> But no further details or specific funding has been revealed. A spokeswoman for the European Medicines Agency told *The BMJ* that “none of the treatments that are currently under the EMA’s evaluation are intended for long covid.”

Long Covid Europe’s representatives say they want to see more patient focused research, and longer term follow-up to ensure that clinics have had a positive impact on patients, among other things. There is also a need for improved services for children with long covid, they say.

Bigger and more coordinated treatment trials could, in theory, help to enable that. Mark Toshner, lecturer in translational respiratory research at the University of Cambridge, who is involved in a UK

trial of long covid treatments,<sup>10</sup> says Europe—and the rest of the world—will be missing a trick if experiments with existing drugs or therapies as treatments for long covid aren’t wrapped into formalised, international trials. He points out that thousands of patients need to be enrolled in studies like this to achieve useful results.

As Nina Langeland, professor of infectious diseases at the University of Bergen in Norway, put it, when it comes to long covid, “we’re all lagging behind, that’s my worry.”

I have read and understood BMJ policy on declaration of interests and have no relevant interests to declare.

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