



¹ Patient author, UK

² Long Covid SOS, Nottingham, UK

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The vacuum of information about covid's prevalence puts me at risk—bring back better data collection

The UK's new government should commit to public health, starting with better data collection on the prevalence of covid in the community, writes **Janet Gunter**

Janet Gunter^{1,2}

A few weeks ago, my partner tested positive for covid-19 for the first time. I've never recovered after being infected by covid during the first wave of the pandemic, so this is a big deal for us. The prospect of reinfection and a worsening of my symptoms is deeply troubling, and I spent weeks quarantining and apprehensively waiting to see if I would catch covid again. It's maddening to know that all of this, including my partner's infection, could have been avoided if we'd only had access to better data on the prevalence of covid.

We already lead a very covid-cautious life because I do not want to get worse with another infection. I've had debilitating long covid symptoms since I first became ill in 2020: extreme fatigue, frequent crashes that leave me bed-bound, pain, cognitive impairment, and disrupted sleep are everyday experiences for me. I live a shadow of my former life, unable to travel much, socialise, or work more than part time.

My partner goes to the office one or two days a week, masking in common spaces, and using a personal air filter at her desk. We mask indoors in public and avoid crowded spaces. Previously, we've used data to help us make decisions about how to go about our lives: when we knew the prevalence of covid was high, we'd avoid any extra activity that might expose us to infection.

We got caught out this summer because of a vacuum of information about covid prevalence in England. Before, we could count on data from the Office for National Statistics (ONS) and crowdsourced data by the ZOE app. Both were defunded by the previous government.^{1 2}

The ONS Covid Infection Survey was one of the few "world-beating" initiatives of the government during covid.^{3 4} Experts praised it for setting the gold standard, by going out into the community and testing. Currently, the government shares infection data collected almost exclusively at hospitals, and this does not tell us much about covid's spread in the community. Unlike many countries, England doesn't even collect wastewater data.⁵

Now my partner and I rely on Christina Pagel's Substack and Scottish wastewater data to judge how much of a risk covid poses.^{6 7} But it simply isn't enough. We had believed that summer infections had peaked in early July, but, anecdotally, it seemed to be everywhere in August, including Olympic changing rooms.⁸

My partner and I took risks that we absolutely would not have taken with better prevalence data, and the consequence was bringing covid into our house.

The ability to quarantine is a privilege, but that didn't stop it being extremely difficult for us and very stressful for me, as I wanted to avoid reinfection at all costs. I did manage to avoid it, but all of our efforts to avoid each other and masking took a toll on my physical and mental health.

My partner had to take a week off work; multiplying that at a national scale, and with multiple infections, can give us an idea of how covid is still damaging productivity. The *Economist's* Economist Impact estimated that long covid will cost the UK economy roughly 0.5% of GDP in 2024.⁹ With better prevalence data, employers could prevent covid's spread by encouraging people to work from home during waves of infection, redoubling efforts to ventilate workplaces, and postponing crowded events.

But beyond productivity, covid continues to kill and disable people. Our new parliamentary undersecretary of state for public health and prevention, MP Andrew Gwynne, knows this firsthand. He has long covid and said in May in Parliament "I have managed to control my long covid for the best part of two years, but this week has been a very bad week for me; I was in bed for all of today, and I have only come in to give this speech."¹⁰ His words are a reminder of the ongoing, but often invisible, burden of the disease.

The free circulation of a virus that leaves people with these debilitating symptoms, and the failure to monitor it with surveillance systems, is an ongoing public health disaster. The previous government placed all responsibility for preventing covid on the individual but refused to give us the tools to limit our own personal risk. We need this government to bring back a commitment to public health, starting with better data collection on covid prevalence in the community so that we can save lives, prevent disability, and maintain economic productivity. The moment demands courage and care.

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