

Coronavirus highlights why the Genetic Information Nondiscrimination Act is ripe for overhaul

[Palantir] has been hired and has assigned 45 staff to a project “designed to predict surges in NHS demand during the coronavirus crisis.” For this, Palantir is being paid £1. Yes, about one dollar and 26 cents. The project is costing the company about £88,000 (\$111,000) a week, estimates the New Statesman, so how are they intending to turn a profit? Well, according to [CNBC](#) :

The NHS health records that Palantir has access to can include a patient’s name, age, address, health conditions, treatments and medicines, allergies, tests, scans, X-Ray results, whether a patient smokes or drinks, and hospital admission and discharge information.

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All too often, and perhaps particularly under crisis conditions, the temptations of novelty and the attractions of magic tech bullets eclipse sensible questions such as: What is this for? Who benefits? Is this what society needs?

The Genetic Information Nondiscrimination Act of 2008 ([GINA](#)) is overdue for an update, which might provide an opportunity to cover more than just genetic data. GINA took more than a decade of legislative effort — the first such bill was introduced in [1995](#) — until it was passed [almost unanimously](#), though there have since been [efforts](#) to weaken it. It will likely be even harder to draft legislation to ensure that all data are deployed not for profit or policing, but in the service of public health and social justice. This discussion needs to happen now.

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