Actions coordinated by patients on social media risk breaching impartial research protocols and unblinding clinical trials (see Nature 563, 312–315; 2018). Clarification is therefore needed on the trade-offs between ethics and knowledge gains in shifting testing standards. Otherwise, drug companies could be tempted to exploit this methodological gap to make candidate treatments look better in tests.

Take the PatientsLikeMe web-based personalized health network, which aims to help people to find new treatments, connect with others and take action to improve their outcomes (see https://www.patientslikeme.com). In an event involving people with motor neuron disease (amyotrophic lateral sclerosis, or ALS), we found that use of the network resulted in a potentially disruptive confluence of interests that could not be resolved safely with alternative test designs (N. Tempini and D. Teira Econ. Soc. http://doi.org/czrw; 2019). Patients who inadvertently unblind trials online could weaken testing standards and so open up the market to inferior drugs. And allowing unblinding initiatives to proliferate spontaneously could provide opportunities for the unscrupulous to manipulate or even sabotage experiments.

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