

# Response to commentaries on sharing online clinical notes with patients: implications for nocebo effects and health equity

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I am grateful for the variety of feedback. Three themes struck me: first, commentators recognised the value of open notes but underlined the importance of exploring unintended consequences of the innovation particularly for already disadvantaged populations; second, they suggested nocebo effects might arise via additional routes not identified in my paper; third, they signalled the need for further empirical and ethical exploration of nocebo effects.

Exploring all three issues and offering a commentary that was equal parts intriguing and perturbing, Chang and Torous proposed nocebo effects and other harms might be ubiquitous in the digital health space.<sup>1</sup> For example, they hypothesised that the preoccupation with checking health tracking data including adverse readings or outcomes available via downloadable apps and wearable devices might induce nocebo effects. This supposition is worthy of further scrutiny. Chang and Torous also highlighted the lack of research into potentially disparate effects of digital health innovations on different populations. Their point is well-taken. Similar to limitations with research in placebo studies, researchers need to work harder to learn more about the uptake, use and impact of digital health innovations among diverse populations.

Kharko and Hägglund<sup>2</sup> proposed patients with medically unexplained symptoms (MUS) may also be at risk of nocebo effects since they are more likely to distrust clinicians, and are vulnerable to communication breakdowns in appointments. Indeed, physician surveys suggest people with MUS may be at increased risk of placebo-prescribing,<sup>3 4</sup> and in this journal I previously suggested open notes might be a vehicle that reduces deceptive practices.<sup>5</sup> As Kharko and Hägglund

argue, access offers potential opportunities for increased transparency in communication and enhanced mutual understanding between patients and doctors. Clearly, more work is needed to explore how patients with MUS experience open notes.

Hutchins, Stone and Hall also picked up on the need for research among diverse populations.<sup>6</sup> To better appreciate why open notes might influence nocebo effects, they stressed the importance of exploring the social history of racism and its enduring impact on Black and Latinx patients in the USA. Although discussed in the paper, they doubled down on the problem, and like Chang and Torous focused on the digital divide—the barriers to getting online and reading clinical records in the first place. In the USA, the electronic health record (EHR) was originally designed for billing purposes and as Hutchins, Stone and Hall argue, to be equitable open notes will require more than patients being merely ‘grafted’ into the existing EHR ecosystem.

As all of these contributors variously emphasise, questions relating to justice and equitable care with respect to open notes must be addressed. In response, and to illustrate, it may be useful to run with one such problem that has also received negligible attention: the intersection of health data privacy, internet use and patient record access.<sup>7</sup> Specific privacy concerns arise with respect to how patients might use internet search engines to supplement understanding of their records. In the most recent survey by the Pew Internet and American Life Project—conducted in 2013—80% of internet users—or 93 million Americans—used the web to search for health information—figures that are undoubtedly higher today, and open notes likely encourages more sleuthing.<sup>8</sup> As patients, we might grasp some information in our records, but lacking medical expertise (or social capital in the form of family or friends who are doctors), many of us may be led to copy and paste our own clinical data

or information into search engines to make greater sense of it. Informaticians differentiate between data (raw alphanumeric values), information (the interpretation of data) and knowledge (what we currently know): these distinctions apply to clinical records. Since Google is not the Encyclopedia Britannica this exposes users to privacy vulnerabilities. In the USA, internet searches operate beyond the 1996 Health Insurance Portability and Accountability Act (HIPAA) which created national standards in the USA to protect patients’ health information from being shared by ‘covered entities’—that is providers—to other third parties. In the epoch of the internet, HIPAA lacks teeth, but it is the most disadvantaged patients—including low-income patients, and Black and Latinx patients—who are at greater risk from what Shoshana Zuboff terms ‘surveillance capitalism’<sup>9</sup>—the selling of personal data from these searches including to medical health insurance companies,<sup>10</sup> and direct to consumer drug and health app advertising.

Without greater digital literacy and, at the very least, adequate tools embedded into clinical portals aimed at augmenting patients’ understanding, patients may be at increased risk of significant privacy fissures. This leakage could ultimately deepen health disparities via biases in healthcare risk algorithms, the peddling of misinformation and targeted advertising.<sup>7</sup> Oversight of these issues to date might, in part, reflect the hyperspecialised interests of researchers exploring open notes,<sup>11</sup> or as Ruha Benjamin warns owed to lack of diversity among personnel within digital fields.<sup>7</sup>

When it comes to the prevalence of nocebo effects, like Chang and Torous, McMillan and Davidge suggested the situation may be worse than I presented.<sup>12</sup> They argued clinicians often downplay side effects of medications during appointments or use records to ‘safety-net’—telling patients to seek treatment if certain ‘red flag’ negative symptoms arise. Both routes seem plausible, and evidence already suggests discrepancies between what clinicians discuss and what they document in records can strain patient trust.<sup>13–15</sup> When it comes to mitigating nocebo effects, however, McMillan and Davidge questioned the evidence base and the ethicality of Leibowitz et al.’s strategy of reframing information to present it as evidence that the ‘treatment is working’. Again, these concerns are fair and warrant more bioethics scrutiny. Furthermore, surveys might usefully explore patients’ views about the ethicality of various

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nocebo-mitigating strategies. With regard to the acceptability of any such stratagems, as I emphasised, co-production of research and potential solutions with patients and clinicians will be necessary.

McMillan and Davidge criticised authorised concealment as a potentially harmful means of minimising nocebo effects. The intention behind the suggestion of tooltips was to build on the authorised concealment literature relating only to disclosure of side effects that might induce nocebo effects, not of other serious side effects, as they inferred. Arguably, my paper should have done a better job of clarifying this. But it is worth noting, the same problem arises if, as they also emphasised, doctors are indeed reluctant to discuss medication side effects in person.

Annoni raised a basic concern: nocebo studies are a nascent area of research.<sup>16</sup> Although this issue was caveated at the outset of my paper, it cannot be glossed. There is a real need for further empirical, and in tandem, deeper bioethical exploration of nocebo effects. Constructively pointing the way forward, he made the original suggestion that clinical records housed in EHRs could be used to investigate the prevalence of nocebo effects. Whether patient informed consent is required for such secondary health use is unclear, and Annoni did not discuss the medico-legal maelstrom of the EU's General Data Protection Regulation or HIPAA, for example, to explore research permissions in this space. To circle back, Chang and Torous proposed an additional

method which might also supplement further study of nocebo effects: the use of passive and active data collection from smartphones to record patients' real-time feedback on their treatment. Again, however, privacy assurances, access to digital devices and digital literacy strategies such as Digital Navigators (as they note) will need to be in place to ensure such methodologies do not deepen disparities in data collection, and ultimately, our understanding of these unwanted effects.

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