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Covid-19 vaccine apps should deliver more to patients



Pharmaceutical manufacturers and the US Centers for Disease Control and Prevention rely on mobile phone apps and adverse event reporting websites as the primary means of active surveillance from patients for COVID-19 vaccines.¹ However, digital tools for side-effect surveillance emphasise data collection over providing user feedback, and public misperceptions might influence what is reported and the causal attributions. Preliminary evidence shows that traditional fact-checking approaches to side-effect misinformation can backfire by establishing unsound causal connections; when submitted to health authorities, plausible reports of biological harm might be dismissed if they are tinged with misperceptions.² Therefore, addressing how misinformation and distrust of medical authorities could negatively affect the adoption of COVID-19 vaccine apps is necessary.

Especially among marginalised populations distrustful of the pharmaceutical industry or the rushed approval process, the availability of multiple COVID-19 vaccines might restore a sense of autonomy. Many of the public are hesitant about taking the vaccines, anticipating information on allergic reactions. The public seek opportunities to aid informed choices between vaccines (eg, some vaccines have fewer additives, appealing to vegetarians or the religiously observant). Choosing between vaccines can be an expression of identity. In turn, the expression of identity restores a sense of agency. Compared with the traditional fact checking approach, these choices are more amenable to public health messaging.³

Currently, COVID-19 vaccine adoption mirrors tech gadget launches, complete with influencers and queues of people awaiting their turn eagerly. Beyond early adopters of COVID-19 vaccines, attention must be paid to communities where medical system distrust has bred over centuries of colonialism and racism or has been encouraged by political partisanship. Concerns over vaccine hesitancy online have disproportionately focused on the most extreme claims on social media. But exposure to alarmist screeds cannot be simply undone through fact checking.⁴ Instead, scientists and journalists studying viral misinformation suggest audience segmentation.⁵ Misinformation becomes indelible when vaccine-amenable and anti-vaccination

clusters interact.⁶ Once these impressions are formed they are exceptionally hard to change.⁷ Vaccine-related apps and social media campaigns can help retain audiences by attending to emotional and informational needs, thereby preventing exposure to online spaces in which extremist views are pervasive.

Beyond vaccination benefits, to effectively engage vaccine-hesitant audiences, we suggest that attention should be paid to the linked concepts of safety and autonomy. Dramatic side-effect reports in news and social media reinforce preconceived distrust.⁸ Intense societal pressure and legal requirements to be vaccinated can yield a sense of powerlessness, with the feeling that autonomy has been infringed. The hours during which vaccination side-effects develop are a priming experience to seek additional information, prompting online investigation and questioning to family and friends. A reflexive online search of symptoms offers access to conspiracy-laden networks. The psychology of conspiracy theories suggests that people are more receptive to them when anxious and feeling powerless.⁹ Our experience has shown that professional dismissal of technically minor side-effects is interpreted as an absence of compassion, driving patients to online communities to seek empathy.¹⁰

Mobile apps that provide information on inoculation choices and direct patient feedback could increase the adoption of the technology and make crucial data on side-effects more generalisable. In a bid to increase adverse event surveillance of COVID-19 vaccines, in the USA, an interesting experiment is underway with the hybrid web app and text message platform, V-safe After Vaccination Health Checker. The app conducts daily and weekly surveys on how patients feel following COVID-19 vaccination. Styled as health check-ins, the app is a departure from traditional pharmacovigilance, in which the importance of voluntary reporting is poorly defined.¹¹ However, our experience across 13 countries in North America, Europe, and Africa shows that mobile apps for adverse event reporting have few downloads and submissions.^{10,12} Apps focus on collecting information, whereas patients expect to receive information. The resulting value proposition for voluntary patient reporting of adverse events is based largely on altruism.¹⁰ In many countries, the evolving

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governmental COVID-19 apps are siloed by national and local public health roles: outbreak information, contact tracing, vaccine appointment scheduling, and adverse event reporting. Too often, digital tools take valuable information and give patients little in return.

The reach of digital tools has limits. In the USA, for example, African Americans aged 55 years or older with low incomes have low rates of digital access and self-efficacy to assess vaccine-related misinformation.¹³ We have a concern that sole reliance on app-based voluntary reporting will differentially lower the participation of marginalised groups. Providing information back to patients might improve the value proposition and uptake,¹³ but it does not solve fundamental problems.

While clinicians and pharmacists are overwhelmed, informal self-care suggestions will be promulgated in social media by influencers without medical expertise. Instead, digital public health technologies can provide caregivers with vetted information that is easily sharable, including for individuals tending to older and marginalised populations. These caregivers are the trusted, de-centralised, empathetic voices that patients listen to. There are risks for missed serious side-effects, delayed professional care, and questionable advice. However, during this pandemic there is no alternative. In environments where official distrust is pervasive, digital health tools can leverage the credibility of informal information structures. Cultivating credibility will require digital health designers to pay closer attention to what vaccine-hesitant patients are truly feeling.

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