

# Sharing online clinical notes with patients: implications for nocebo effects and health equity

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## ABSTRACT

Patients in around 20 countries worldwide are now offered online access to at least some of their medical records. Access includes test results, medication lists, referral information, and/or the very words written by clinicians (so-called 'open notes'). In this paper, I discuss the possibility of one unintended negative consequence of patient access to their clinical notes—the potential to increase 'nocebo effects'. A growing body of research shows that nocebo effects arise by engaging perceptual and cognitive processes that influence negative expectancies, and as a consequence, adverse health effects. Studies show that increased awareness about the side effects of medications, the framing of information and the socioemotional context of care can increase the risk of nocebo effects. Connecting research into the nocebo effect with open notes provides preliminary support for the hypothesis that patient access to clinical notes might be a forum for facilitating unwanted nocebo effects. Furthermore, current findings indicate that we might expect to see systematic differences in how nocebo effects are experienced among different patient populations. The ethical implications of the tension between transparency and the potential for harm are discussed, with an emphasis on what open notes might mean for justice and equity in clinical care for a range of already marginalised patient populations. I argue that to resolve these challenges does not thereby justify 'closed notes', and conclude with suggestions for how health systems and clinicians might adapt to this innovation to reduce the risk of potential nocebo effects arising via this novel route.

## INTRODUCTION

From November 2022 patients in England who sign up for an online health service, such as the National Health Service app, will soon be able to access their primary care health record, including free text consultation entries written by their general practitioners.<sup>1</sup> England follows a number of other countries in offering patients ready opportunity to read what their doctors record on computers.<sup>2</sup> For example, starting in 2012, patients in Uppsala in Sweden were invited to read their records, and currently most patients in the Nordic countries are offered access to their online clinical records.<sup>3</sup> Similarly, in the USA, experiments with what are now widely known as 'open notes' began more than a decade ago.<sup>4</sup> By 2021, 55 million people were able to review their clinicians' notes electronically through secure, internet patient portals, and in April 2021, new federal rules mandated, with few permitted exemptions, that all patients be offered rapid access to their full electronic record without charge.<sup>5</sup> Currently, in around 20 countries—including Australia, Canada, England, Estonia, the Nordic countries and the

USA—patients are offered rapid, online access to at least some of their electronic health record (EHR). However, the most extensive research into the practice is in Sweden and the USA, where the innovation has been widely implemented for around a decade.

When patients obtain access to their clinical notes, the obvious bears stating—communication between clinicians and patients is no longer restricted to dialogue arising in real time during face-to-face visits or consultations. With open notes, patients now have 24/7 access to the very words written about their health, and their clinical encounter, by physicians and other health professionals. As a consequence, depending on both the content and the tone of the words that clinicians write, it is increasingly acknowledged that access has the potential to enhance or diminish the quality of patient–clinician relations.<sup>6,7</sup>

Connecting patients' experiences with open notes with research in placebo studies, it has been proposed that patient access might generate both genuinely positive and genuinely adverse health effects by engaging perceptual and cognitive processes that elicit placebo and nocebo effects.<sup>8,9</sup> Expanding on this research, I describe why health professionals, including clinicians and medical ethicists, patients and researchers in the field of placebo studies, should be especially interested in open notes. While acknowledging the potential for open notes to facilitate placebo effects, this paper prioritises the concern that physicians should 'first, do no harm'. Therefore, the focus of this paper is specifically on the potential for patient access to influence adverse health outcomes via nocebo effects.

The paper begins by outlining the burgeoning area of research into nocebo effects. Next, building on previous work, I describe the potential ways in which open notes might elicit nocebo effects.<sup>8,9</sup> In particular, I draw on evidence that accessing detailed information about side effects of treatments might increase patient awareness and anticipation about these effects which may thereby increase unwanted nocebo effects. Studies also suggest that the socioemotional valence of the words that clinicians use may also influence negative expectancies, engendering nocebo effects. Connecting this with research into open notes provides preliminary support for the hypothesis that access might be a forum for facilitating nocebo effects. Open notes may therefore invite a new instantiation of a well-recognised ethical dilemma between balancing respect for honesty and transparency in patient care with the possibility of harm from nocebo effects. Furthermore, current findings suggest that we might expect to see systematic differences in how nocebo effects are experienced among different patient populations. The



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ethical implications of these unintended consequences for patient care will be discussed, and solutions for how to resolve these new challenges will be offered.

### Evidence for nocebo effects in clinical encounters

Nocebo effects are often characterised as the ‘evil twin’ of placebo effects. While placebo effects are understood to be the genuinely salubrious result of patients’ positive expectations about an intervention or prognosis that might also be influenced by positive perceptions about the competence and warmth of clinicians, the nocebo effect is thought to be elicited by negative expectancies, giving rise to adverse health effects.<sup>10</sup> Compared with research into placebo effects, comparatively fewer studies have explored nocebo effects. Notwithstanding, a growing body of empirical work demonstrates that disclosure of clinician information, as well as the manner of such disclosures, might negatively influence patients’ expectancies about treatments, giving rise to nocebo effects and adverse health outcomes.<sup>10–12</sup>

Indeed, nocebo effects have recently made the news leading to heightened interest in the phenomenon.<sup>13</sup> In highly publicised studies, researchers reported that up to two-thirds of side effects of COVID-19 vaccines—such as headaches, fatigue and malaise—may be attributed to the ‘nocebo effect’.<sup>14 15</sup> Beyond COVID-19 vaccines, a wide variety of studies have observed negative responses in placebo arms of clinical trials for a wide range of medical conditions, including irritable bowel syndrome,<sup>16</sup> fibromyalgia,<sup>17</sup> migraines,<sup>18</sup> neurological conditions<sup>19</sup> and pain.<sup>20</sup> In 2018, in a rapid review of 20 systematic reviews of 1271 randomised clinical trials reporting nocebo effects, Howick *et al* reported that adverse events in trial placebo groups were 49%, with a 5% median rate of dropouts due to these adverse events.<sup>21</sup> Furthermore, they argued that adverse events were unlikely to be entirely attributable to natural history, cautioning that nocebo effects might contribute to reported adverse events.

Other experimental studies support the idea that nocebo effect may be more common in clinical settings than previously thought. In his book *Placebo Effects: Understanding the Mechanisms of Health and Disease*, Italian physiologist and neuroscientist Fabrizio Benedetti reviewed studies whereby patients undergoing cancer chemotherapy begin to experience nausea and vomiting just prior to receiving treatment, sometimes when they smell the odours of the clinic.<sup>22</sup> Like the famous study of Pavlov’s dog which learnt to associate the ringing of a bell with food and later salivated when the bell rang but no food arrived, patients appeared to be ‘conditioned’ to expect to feel ill, associating the clinic environment with the adverse effects of chemotherapy. Other studies support the hypothesis that negative expectancies can arise through verbal suggestion. In an experimental study, Lang *et al* found that warning or even sympathising with patients about painful or undesirable experiences following an intervention increased self-reported pain and anxiety, compared with patients who were not offered any negative disclosures about the intervention.<sup>23</sup> In a study of beta-blockers for cardiac disease and hypertension, disclosing to patients that treatment side effects might include erectile dysfunction led to twice the rate of this reported problem among forewarned participants compared with those not informed.<sup>24</sup> In another experimental study of patients with asthma, Jaén and Dalton allocated patients to one of two groups.<sup>25</sup> One group was informed that an odour would elicit asthmatic symptoms (the nocebo effect condition), the other was informed it would alleviate asthmatic symptoms. All participants were then exposed to the odour for 15 min. Participants in the nocebo effect condition who anticipated more negative outcomes reported more sensations of constriction of the lungs,

hyperventilation and panic compared with those in the positive anticipation group. Measuring physiological symptoms revealed participants in the nocebo group showed significantly higher inflammatory responses in the lungs, after exposure to the odour.

Not only the health information disclosed to patients, but the choice of words used and the socioemotional delivery of care, might also influence negative expectancies, giving rise to adverse outcomes. For example, Varelmann *et al* studied how the manner in which a local anaesthetic injection prior to surgery was described influenced the pain patients experienced following the injection.<sup>26</sup> One group was furnished with a negative suggestion: namely, ‘You will feel a big bee sting; this is the worst part’; the other group was advised ‘We are going to give you a local anaesthetic that will numb the area, and you will be comfortable during the procedure’. Patients in the negative suggestion group experienced significantly higher pain scores than when more supportive words were communicated. Varelmann *et al* concluded that ‘using gentler, more reassuring words improves the subjective experience during invasive procedures’. Benedetti *et al* investigated what would happen when morphine administration was interrupted during postoperative pain.<sup>27</sup> One group received information that morphine administration was interrupted; in the other group, morphine was interrupted surreptitiously. With the understanding that morphine administration was interrupted, patients experienced more intense pain with more than double the number of patients requesting further pain medication compared with those who were uninformed about the interruption. Locher *et al* have also proposed that psychotherapy may also be a forum where nocebo effects might arise if clinicians inadvertently embed subtle negative suggestions about treatments, symptoms, or prognoses, or if trust is strained.<sup>28</sup>

In summary, research into nocebo effects shows adverse outcomes can arise as a result of various components of clinician communication.<sup>29 30</sup> Disclosures about possible medication side effects, and non-intentional, negative verbal and/or non-verbal aspects of clinician communication may elicit negative expectancies among patients leading to nocebo effects.<sup>31</sup> Indeed, in light of growing acknowledgement nocebo effects can induce unwanted health outcomes, and might even lead to non-adherence to medications, several recent Delphi polls and consensus studies conducted among experts in placebo studies have recommended clinicians should be educated about and strive to minimise nocebo effects in clinical contexts.<sup>32 33</sup>

## HEALTH DISPARITIES

### Background

The question about whether disparities in patient health outcomes can be driven by placebo and nocebo effects has also received increasing attention in placebo studies. At the outset, it is important to note that health disparities reflect multiple, often interconnected factors. These factors include environmental, economic and social determinants, along with the accessibility of healthcare, and the variable quality of care delivered by providers. With regard to the latter consideration, a substantial body of research shows that a range of factors including patient race/ethnicity,<sup>34 35</sup> income level,<sup>36 37</sup> age,<sup>38 39</sup> gender,<sup>40 41</sup> body weight<sup>42 43</sup> and medical diagnoses,<sup>44 45</sup> including psychiatric health diagnoses,<sup>46 47</sup> may systematically, though unintentionally, influence clinician behaviour<sup>48</sup> including patterns of referral and diagnostic decisions, and the quality of support and communication delivered to patients. The quality of communication matters in medicine. In 2014, a systematic review of 13 randomised clinical trials found that patient–doctor relationships had a small yet

significant effect on objective measures of healthcare outcomes.<sup>49</sup> In 2017, another meta-analysis of 47 studies found that greater trust in clinicians was strongly associated with healthcare satisfaction and patient-rated medical outcomes.<sup>50</sup>

Since the quality of patient–clinician relations can differ among patients, researchers argue we might thereby expect to see an uneven distribution of placebo and/or nocebo effects.<sup>51 52</sup> For example, some patients may receive more detailed information about their side effects or receive fewer expressions of support, thereby facilitating more negative expectancies and increased risk of nocebo effects. Beyond these concerns including the clinician's own training and best efforts, it is important to emphasise aspects of communication also vary according to medical specialties.<sup>53</sup> Some clinicians spend more time with patients than others which may influence clinical notes and subsequent nocebo effects. In addition, some patients are more likely to receive one specialty care over another which may further lead to different individual outcomes related to nocebo effects.

With these considerations in mind, before we explore the literature connecting placebo/nocebo effects and health disparities, it is valuable to review the variety of ways in which quality of communication can differ among different patient populations.

### Evidence of inequalities in patient–clinician communication

It is now well documented that patient race/ethnicity can significantly affect the quality of healthcare that one receives, even in clinic interactions.<sup>54 55</sup> For example, in 2000, a highly cited US study by public health researchers Michelle Van Ryn and Jane Burke found doctors' opinions of patients were correlated with patients' race.<sup>56</sup> Surveying nearly 200 physicians' views after around 850 patient encounters at eight hospitals in New York State, Van Ryn and Burke discovered doctors rated African American patients more negatively than white patients on a number of dimensions including likelihood of adherence to medical advice, intelligence and feelings of affiliation—the latter ranked by agreement with the statement 'This patient is the kind of person I could see myself being friends with'. There is also evidence that such biases might negatively affect the quality of communication. In 2018, a systematic review of 40 studies concluded that racial concordance—sharing the same race or ethnicity with one's physician—was 'clearly associated with better communication'.<sup>57</sup> For example, in 2003, in a study of over 250 patients with the same racial background as their primary care doctor experienced visits that were around 2.2 min longer than people in other pairings.<sup>58</sup> Patients in race-congruent visits also gave more positive ratings of their doctor and reported higher levels of satisfaction with their care. In 2020, these findings were supported in review of nearly 120 000 patient experience surveys completed between 2014 and 2017 at outpatient centres at the University of Pennsylvania Health System: patients in racially concordant visits not only rated their doctor more highly, they were more likely to recommend their doctor to others.<sup>58</sup>

Prejudice against persons who are overweight can also arise in clinic visits. In one US study, as patients' body mass index increased, physicians' desire to help them decreased.<sup>59</sup> Another survey of primary care doctors found that more than 50% viewed heavier patients as 'awkward', 'non-compliant' and 'ugly', with around one-third viewing such persons as 'lazy' and 'sloppy'.<sup>60</sup> In 2014, in a survey of nearly 5000 medical students drawn from 49 American medical schools, two-thirds explicitly embraced discriminatory views, and one in every six medical students agreed with the statement 'I don't like fat people very much'.<sup>42</sup> Research suggests such prejudice may indeed undermine the quality of visits. In 2005, a videotaped study of primary

care appointments investigators found doctors spent considerably less time educating heavier patients about their health.<sup>61</sup> In 2006 in the USA, a survey of women who were obese and overweight found nearly 7 in 10 experienced stigmatising comments at least once from a doctor with 50% reporting inappropriate comments on multiple occasions.<sup>43</sup>

Persons with psychiatric diagnoses are also vulnerable to breakdowns in patient–clinician interactions, and cross-cultural survey research reveals psychiatrists' attitudes may be just as discriminatory as those of the general public.<sup>62–65</sup> A study conducted at the Institute of Psychiatry, King's College London research concluded that 'People with mental illness often report encountering negative attitudes among mental health staff about their prognosis, associated in part with 'physician bias'.<sup>66</sup> In 2013, an extensive review of surveys found that medical professionals 'generally had a negative attitude' towards patients with addiction disorders, and as a result tend to 'make shorter visits, show less empathy and have diminished personal engagement' when caring for them.<sup>67</sup>

Communication in clinic visits is also a two-way process, and complicating matters further, audio-recorded studies suggest some patient groups may be more likely to be passive in clinical encounters.<sup>68–70</sup> For example, in 2006 in the USA, in an analysis of dialogue between patients with lung cancer and their doctors, black patients received less medical information compared with white patients but were less active in soliciting advice.<sup>68</sup> The reasons are not fully understood, though some investigators have hypothesised that patients from racial or ethnic minorities may be more vulnerable to anxiety or anticipated prejudice in visits, leading to less involvement.<sup>71</sup> Misperceiving passivity as indicative of disinterest or disengagement might prompt a detrimental downward spiral whereby medics mirror patients' responses.<sup>72</sup> In 2007, Street *et al* studied more than 200 interactions drawn from visits at 10 outpatient clinics and concluded, 'reciprocity and mutual influence' between patients and doctors played a strong role influencing the tone, and the ebb and flow of dialogue.<sup>73</sup> Investigators found that doctors assumed patient-friendly communication styles with those they considered more actively engaged, better communicators or patients whom they believed would better adhere to treatments, and were 'more contentious with contentious patients'. Studies also show perceived relative status might influence patient behaviours, with some patients reporting more reticence during appointments than those on higher salaries. In 2009, a survey published in the *British Journal of Cancer* showed that less wealthy patients were more embarrassed and less confident to talk about their symptoms compared with patients on a higher income.<sup>74</sup> In 2006, in a study of patients with breast cancer, those with a low income or fewer years of formal education asked fewer questions compared with their peers.<sup>70</sup> Again, this study found that doctors tended to reciprocate by providing an average 153 utterances of biomedical information with lower-income patients compared with 228 among richer patients. Better educated patients also fared better, receiving an average of 207 nuggets of health information compared with 165 among those with fewer years of formal education.

### Health disparities and placebo/nocebo effects

Bridging evidence about communication disparities in care, a range of conceptual and empirical papers drawing predominantly on data conducted in the USA recently proposed that some patient populations may be both less susceptible to placebo effects, and/or more at risk of experiencing nocebo effects during patient–clinician encounters.<sup>51 52 75 76</sup> For example,



in this journal in 2018, drawing on evidence of inequalities in clinical encounters relating to race/ethnicity, income and health diagnoses, Friesen and Blease proposed that differences in expressions of clinician warmth and empathy, and perceived support might diminish experienced placebo effects among these patients.<sup>51</sup> This line of reasoning presents a novel research hypothesis which suggests communication breakdowns in clinic visits, which disrupt trust or lead to diminished patient trust in clinicians, may induce higher levels of nocebo effects. Extending this perspective, in 2021, Yetman *et al* argued that, because expectation in the clinical setting is strongly influenced by clinician attitude, affect and communication style, differences in quality of care in the clinical setting for black patients and other patients of colour, including inferior patient–clinician communication, mistrust and anticipated/perceived discrimination, might also yield increased nocebo effects.<sup>52</sup>

Although an overshadowed research agenda for many years, experimental studies in the USA have begun to explore the connection between health disparities and placebo/nocebo effects, and patient–doctor interactions. For example, in 2020, Okusogu *et al* investigated placebo effects in healthy participants and participants with chronic pain with a diagnosis of temporomandibular disorder, who self-identified as either black or white.<sup>75</sup> Investigators found participants who identified as white reported greater relief expectations and placebo effects when compared with their black counterparts. In secondary analyses, racial concordance between the experiment and the participant induced greater placebo hypoalgesia in patients with temporomandibular disorder. In another experiment, Letzen *et al* also found that, when presented with an ambiguous verbal suggestion—namely, that, ‘the substance would either increase pain sensation, decrease it, or leave it unchanged’—compared with non-Hispanic white participants, non-Hispanic black participants experienced lower rates of placebo effects following administration of a placebo.<sup>76</sup> Although their study did not explore causal explanations, Letzen *et al* noted a legacy of anticipated/perceived discrimination and provider mistrust, exacerbated by historical abuses in the US healthcare system, might have augmented nocebo effects leading to a trajectory of higher pain ratings among black participants. In 2019, in a qualitative systematic review of 34 studies investigating the effects of clinician behaviour and placebo/nocebo effects, Daniali and Flaten concluded that positive and supportive non-verbal behaviours (eg, smiling, strong tone of voice, more eye contact) contributed to lower reported pain and higher placebo effects, and negative non-verbal behaviours (ie, no smiling, monotonous tone of voice, no eye contact) contributed to higher reported pain and higher levels of nocebo effects.<sup>77</sup>

## PRELIMINARY EVIDENCE THAT OPEN NOTES MIGHT GENERATE NOCEBO EFFECTS

Considering what is known about mechanisms of placebo and nocebo effects, it is reasonable to postulate that open notes might present a novel platform for eliciting both placebo and nocebo effects under specified conditions. Specifically, with respect to nocebo effects, Blease *et al* hypothesised that patients might experience nocebo effects if: ‘Clinical notes convey negative expectations about the success of the treatment, including potential negative side effects’.<sup>8</sup> In light of research into nocebo effects, we might tentatively extend this prediction to encompass negative tone or reduced signals of support in clinical notes as potentially disrupting or jeopardising trust between patients and clinicians incurring greater patient fears, uneasiness or anxiety

which may increase negative expectancies, and in turn engenders nocebo effects.

Connecting placebo studies with open notes, a variety of patient surveys and analyses of visit note documentation offer preliminary evidence that nocebo effects might indeed be more likely to arise when patients read their clinical notes, and moreover, that nocebo effects might be unevenly distributed. Below, I argue patient access could augment experienced nocebo effects via two routes: first, by facilitating greater understanding about the adverse side effects of their medications and treatments; and second, via negative wording or framing of health information expressed by clinicians in documentation which diminishes trust, leading to heightened patient anxieties and fears which might thereby augment negative expectancies, giving rise to nocebo effects.

## Greater understanding about adverse effects of treatments

Analysing the largest US survey conducted to date into patients’ experiences with open notes (22% response rate;  $n=22\,947$ ),<sup>78</sup> DesRoches *et al* explored the views of patients who were prescribed or taking medications ( $n=19\,411$ ) and who had read at least one visit note during the previous year.<sup>79</sup> They found 45% of patients reported better understanding about possible adverse effects of medications with 32% reporting access prompted them to seek more information about their medications, and 4% saying they were more worried about their medications after reading their notes.<sup>79</sup> Subsequent, secondary analyses revealed some patient groups experienced greater understanding about medication side effects. For example, excluding patients younger than 65 years and those answering the survey as care partners ( $n=7688$  respondents). DesRoches *et al* found patients with two or more conditions were significantly more likely than those with fewer conditions to report that reading notes helped them to understand the possible side effects of their medications (52.3% with more than 2 conditions vs 47.6% with 1–2 conditions vs 43.5% with 0 conditions).<sup>80</sup>

Survey evidence also indicates patients with mental illness diagnoses might also gain enhanced understanding about negative effects of medications after accessing their clinical notes. Blease *et al* undertook another secondary analysis of the data, using patients’ diagnostic codes, and found significant differences in patients’ experiences: 50% of persons with serious mental illnesses—defined as including major depression, bipolar disorders and schizophrenia disorders—reported better understanding of adverse effects of medications after accessing their notes compared with 47% of patients with other mental health diagnoses, and 45% of patients without mental health diagnoses.<sup>81</sup> In addition, although the difference is small, all patients with mental health diagnoses were significantly more likely than patients without mental health diagnoses (5% vs 3%) to report feeling more worried about their medications as a result of reading their notes. This work supports the findings of an earlier pilot study at an outpatient psychiatric centre by Peck *et al* which found that 82% ( $n=37$ ) of patients reported a better understanding of the potential side effects of their medications.<sup>82</sup>

## Negative wording in documentation

Open notes might also be a forum that induces negative expectancies via the words used by clinicians. As noted, the hypothesised causal link arises via notes containing stigmatising language which are read and interpreted as such by patients accessing them. In turn, patients may form negative expectations about some aspects of their future therapeutic path: such negative expectations may translate into significant nocebo effects. A

range of evidence suggests that after reading their documentation, at least some patients question clinician competence, believe clinicians are less supportive or empathic or perceive negative clinician judgment about their health condition. For example, Fernández *et al* found that 11% (n=2411) of patients who accessed their notes in the three-centred US study felt judged or offended by what they read, which included errors and surprises, and forms of labelling and disrespectful language.<sup>83</sup> Survey participants' comments included: 'I wasn't offended. It was actually betrayal. I felt that the MD had painted a much different picture than what they had written in my chart.' 'Offended may be too strong, but I was put off by a description of a discussion that I felt did not adequately represent my point of view.' Some patients' comments related to labelling including about their weight; for example: 'Note said I wasn't doing everything I could to lose weight which was untrue and very upsetting to see my Dr thought of me like that,' 'I was described as obese. Perhaps that is true according to some chart...I was quite taken aback and embarrassed by that description.' Patients who (a) described their race as 'other', (b) rated their health as fair/poor, (c) reported being unable to work, or (d) reported having read four or more notes were more likely than their counterparts to feel judged or offended by what they read.

In qualitative studies in mental health settings, some patients report strained trust in clinicians after accessing their clinical notes.<sup>6,7</sup> Exploring patients' experiences with their social work notes, O'Neill *et al* reported that some survey participants felt more negative after reading their documentation; for example: 'The therapist only said supportive things to me but the note seemed judgmental in a negative way. After reading it, I felt badly, like she didn't like me as much as I had thought,' 'I felt disempowered.'<sup>7</sup> Again, in a study by Cromer *et al* of patient access to mental health notes, mistakes, errors, or surprises were particular sources of strain and doubts about clinician competence; for example: 'I'm...giving up a lot of time...I would like you to take it seriously too, not just spit something out on paper and not proofread it.'<sup>6</sup>

Other recent studies have explored objective linguistic features of documentation and found stigmatising language tends to be more common in visit note summaries written about some patient populations. Beach *et al* found examined stigmatising linguistic features such as the use of quotations (eg, 'patient had a 'reaction' to the medication'), judgment words (eg, 'patient insists', 'patient claims') or the use of what they referred to as 'evidentials' (phrasing in which patients' symptoms or experiences are reported as hearsay, for example, 'the patient reports that the headache started yesterday' as opposed to 'headache').<sup>84</sup> In their sample of 9251 notes written by 165 physicians, they found notes written about black patients were significantly more likely to contain at least one quotation, judgement word or use of an evidential. Similarly, to examine clinicians' use of negative descriptors (eg, 'non-compliant', 'uncooperative', 'non-adherent'), Sun *et al* analysed a sample of 40 113 history and physical notes of 18 459 patients in an urban medical centre.<sup>85</sup> After controlling for sociodemographic and health characteristics, they found that compared with white patients, documentation of black patients had 2.54 times the odds of having at least one negative descriptor.

Another extensive study by Himmelstein *et al* used natural language processing to explore the use of stigmatising language in 48 651 admission notes written about 29 783 unique patients by 1932 clinicians at an urban academic medical centre.<sup>86</sup> Drawing on language guidelines established by a variety of medical taskforces including the Association of Diabetes Care

and Education Specialists, the American Diabetes Association and the National Institute on Drug Abuse, they examined the notes for stock words including, but not limited to, variants of the following terms: 'Abuse', 'Combative', 'Failure', 'Non-adherent', 'Refused', 'User'. Contextual examples of visit notes included: 'Patient failed to show up to endocrine follow-up', 'He is a habitual cocaine user', 'Patient has numerous psychiatric diagnoses including malingering'. Across all visit note summaries, Himmelstein *et al* reported 2.5% of notes contained stigmatising language, with diagnosis-specific stigmatising language more common among patients with diabetes (6.9%), substance use disorders (3.4%) or chronic pain (0.7%). Compared with non-Hispanic white patients, clinical notes about non-Hispanic black patients had 0.67% greater odds of containing stigmatising language.

It is important to note that surveys into open notes are restricted to a limited number of health centres, and it is not understood whether participants who responded were more enthusiastic or more cynical about experiences with access. Sample sizes for patients from minority backgrounds, older patients and persons with mental health diagnoses were small. In addition, linguistic analysis of documentation does not offer conclusive evidence about patients' experiences with open notes. Notwithstanding these limitations, existing data offer important preliminary evidence about the potential, not just for biases to be transmitted in notes, but for health disparities to arise with this new communication tool. Although it is not known whether patients' enhanced understanding about treatment side effects or negative or stigmatising wording in their notes facilitates negative expectancies, the data present important initial findings that are worthy of further empirical research, and which may be cause for concern.

## ETHICAL IMPLICATIONS

Open notes offer patients unprecedented transparency to their healthcare. Encouragingly, a growing body of research in countries where the practice is advanced demonstrates that the majority of patients who access their notes derive multiple benefits including greater understanding about their treatments, better recall about treatment plans, greater engagement in their care, and enhanced understanding about the rationale for prescribed treatments and interventions.<sup>78 79 81 87–89</sup> However, as this paper has argued, there may also be unintended negative consequences associated with this change of practice, including the potential to increase nocebo effects.<sup>90</sup> Indeed, among placebo studies researchers, it is acknowledged that nocebo effects invite an ethical dilemma with respect to transparency in care: namely, how clinicians might ethically navigate the Scylla and Charybdis of truthfulness, that is, being fully open and honest in disclosures about potential negative treatment effects and non-maleficence, that is, preventing harmful nocebo effects that may result from such disclosures.<sup>29 31 91 92</sup>

Access is further complicated by evidence that patients who might be more vulnerable to communication breakdowns in clinic visits tend to experience greater benefits with open notes. Indeed, it has been argued that open notes may function as a workaround, allowing patients greater time to fully understand and engage with their health information.<sup>93</sup> Studies show that on average, during face-to-face visits, patients fail to recall around half of the health information communicated to them.<sup>94</sup> This figure is likely higher among persons who are anxious, distracted, more passive in interactions, persons who have too much information to remember, and/or those with compromised

short-term memory.<sup>93 95</sup> Perhaps, then, it is not surprising that in large-scale patient surveys, reported benefits are significantly more commonly reported among patients from traditionally marginalised groups. For example, Walker *et al* found that around two out of three patients reported greater understanding about their treatment after access, and these benefits were most often reported by persons who were less educated, older, non-white or Hispanic, and individuals who usually did not speak English at home.<sup>78</sup> Similarly, in a survey by Bell *et al* involving over 10 000 patients and their families who had experience of open notes, compared with white patients, Asian, black and Hispanic/Latino patients were significantly more likely to report better understanding of the reasons for tests and referrals, remembering to keep appointments and remembering to take their medications<sup>96</sup> (p10). Worthy of further study, but outside the remit of this paper, is the question about whether enhanced understanding about treatment rationale, cues of competence and empathy might augment placebo effects, especially among these populations.

In summary, most patients who access their notes might experience advantages, but they might also be more vulnerable to nocebo effects, via enhanced understanding about side effects of medications. However, because already marginalised patients derive more benefits from access, they might also thereby experience greater risk of nocebo effects. As we have seen, this problem might potentially be further exacerbated by negative descriptors in notes that especially affect documentation written about minorities and persons with stigmatised health conditions. While this latter claim is a working hypothesis, should patients experience greater exposure to stigmatising language in notes which, crucially, they recognise as stigmatising, and which thereby facilitates formation of negative expectations about some aspect of their treatment, such patients may be at increased risk of significant nocebo effects. In short, an additional unintended ethical dilemma might arise with the potential for injustice in the distribution of nocebo effects with open notes.

Addressing the first dilemma about transparency and increased understanding about medication side effects, the possibility of increased nocebo effects should not be used to justify hiding or refusing to offer patients access to clinical notes. Instead, how disclosures about side effects are framed might help to mitigate potential nocebo effects while also keeping patients fully informed about their health. Innovative research points to a promising way forward. Drawing on a variety of studies on disclosures on side effects of treatments for pain,<sup>97</sup> hypertension<sup>98</sup> and allergies,<sup>99</sup> Leibowitz *et al* argue that patients who were informed that side effects were a sign that the treatment is working were less anxious about side effects, rating them as less intense and less threatening.<sup>100</sup> In this way, changing patients' mindsets might be considered an important, evidence-based strategy to enhance tolerance for side effects without compromising transparency. Potentially, clinicians could routinely learn to adopt this approach in disclosures during face-to-face or telemedicine visits to encourage positive mindsets and better prepare patients for what they might read in notes about possible treatment side effects. However, whether this approach fully mitigates nocebo effects should be fully explored; recall, for example, the study by Lang *et al* which reported that contrary to common belief, warning or sympathising using negative language may also make patients feel worse.<sup>23</sup> Therefore, further research is required to explore the full potential of mindset changes to neutralise nocebo effects.

Ideally, it would also be valuable to incorporate such mindset prompts into notes, but this might be cumbersome for already

overworked and burnt out clinicians. And this brings us to another point: in the era of open notes, the functionality of EHRs is evolving. The purpose is not merely to serve as an aide memoire or communication tool only for clinicians, nor only as a billing device, as in the USA, but also (whether clinicians acknowledge it or not) to function as a communication tool between clinicians, patients and their caregivers. Acknowledging this novel functionality, the aim should be to preserve accuracy in the clinical record while also enhancing patient understanding about their own health.<sup>101</sup> Therefore, patients and health systems might usefully explore structural adaptations to eHealth portals to automatically populate health information that furnishes patients with understandable advice about their medications and side effects, framed in such a way as to minimise nocebo effects. Relatedly, embedding clever design techniques such as the use of tooltips—boxes of information that pop out when selected by the user—health portals could offer patients the option to read more about side effects if they choose to do so. Such information boxes might come with a forewarning that clicking to reveal medication side effects could prompt patients to experience negative treatment effects. This approach could thereby facilitate a form of 'authorised concealment',<sup>30 31</sup> whereupon patients decide in an informed way whether they want access to information, even if it leads to the potential for harm. This approach might be most suitable if rephrasing or reframing of disclosures is found not to be successful in overcoming nocebo effects.<sup>23</sup> Rather than hiding notes, however, the decision lies with the patient about whether to risk these adverse effects. To support such advances, initiatives should involve health portal and EHR co-design with patients,<sup>102</sup> health psychologists and clinicians, to help reduce documentation burdens while optimising content and health outcomes.

Addressing the second dilemma about the potential for unequal distribution of nocebo effects will require clinicians to be more mindful about the words they use in their documentation.<sup>83</sup> Clinicians might benefit from training in how to write notes that patients will read, including in how to avoid stigmatising phrases or linguistic constructions especially when documenting the health of persons from already disadvantaged patient populations or people with stigmatised conditions. A promising web-based course among mental health clinicians at the Veterans Health Affairs in the USA suggests that it may be possible to enhance confidence with clinical note writing and to encourage use of positive and supportive language in documentation.<sup>103</sup> Further curricular advances in clinical curricula, and ongoing medical education, may help clinicians to modify or eliminate potentially stigmatising medical vernacular. While it remains to be seen, it may be that training to overcome biases in clinical notes might be more effective than current anti-bias training aimed at reducing discrimination in face-to-face encounters.<sup>104</sup> Potentially, clinicians may have more opportunities to reflect on, and to edit their documentation, than they do to neutralise or to overcome discriminatory biases in pressurised visits.

A final consideration is the digital divide in healthcare. This refers to the gap between those who have access to digital technology and those who do not. Lack of access to digital devices, broadband or reduced health literacy can influence who uses and benefits from technologies, and digital inclusion is now regarded as a social determinant of health.<sup>105 106</sup> Studies in the USA show that the likelihood of receiving an access code to activate health portals is significantly lower for black Hispanic patients, older persons and those with a lower income, and might, in part, be driven by provider biases.<sup>107</sup> If, owing to digital divides, patients who do not access their notes thereby forego exposure to potential nocebo effects, this might be considered as helpfully benefiting these patients. However, as previously underscored, such patients will also lose out if they fail to avail of the multiple advantages conferred by access, including



patient safety.<sup>87 108</sup> Therefore, I strongly caution that the risk of nocebo effects should not be used to justify a laissez-faire approach toward closing the digital divide in healthcare, nor to opportunities to removing harmful negative biases that may already be embedded and transmitted in clinical documentation.

## CONCLUSIONS

Words matter in medical interactions, and a growing body of research shows that nocebo effects are ubiquitous in healthcare. Offering patients convenient, rapid, online access to their health records might present a novel route to harness these unwanted effects. Building on the preliminary evidence offered in this paper, further experimental research is now required to explore whether open notes influence nocebo effects. This research is especially warranted because patients will now be able to review their notes recurrently, at any time of their choosing, facilitating—as survey evidence shows—a much more robust understanding about possible side effects of medications. Moreover, while medical ethicists writing about nocebo effects have often focused on the ethical dilemma of balancing harms with transparency, the more overshadowed ethical concern is with potential injustices arising in the distribution of nocebo effects. As evidenced in this article, patient surveys and clinical note analyses offer robust yet worrying evidence of systemic differences in the language used in documentation. To nocebo-proof open notes, it will be imperative for clinicians to become more attentive about the words they use, and for eHealth designers and health organisations to become imaginative and proactive in how they innovate tools that meet the multiple demands of maximising patient understanding, reducing clinician workflow pressures and minimising the potential for harms to patients. The hope is that this article signals the importance of starting that discussion and maps the way forward.

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