Overdosing on Health Information Technology: Notes from the American Dystopia Joseph White Ph.D.

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The 2006 Carnet de Santé de la France included four chapters on "L'informatique et la santé," especially the proposed dossier médical personnel (DMP). In the 2009 Carnet, Professor de Kervasdoué summarized that at the time, "il nous avait semblé que le dossier médical personnel... ne pourrait jamais voir le jour pour des raisons conceptuelles, financières, techniques, épistémologiques, politiques, notamment." He wondered why "personne n'ait écouté les arguments qui nous paraissaient aussi logiques que vérifiables" and why and how "se fait-il qu'à l'instar des rats, puis des enfants, du joueur de flute de Hamelin, des hommes et des femmes responsables suivent la musique charmeuse des vendeurs d'illusion et perdent, au moins un instant, tout sens critique?"¹

The simplest answer would be that information technology is a powerful drug. It is attractive, addictive, and socially approved. Abstinence or even caution about its use is viewed with scorn: skeptics are seen as rejecting progress and mired in the past. If you want to be one of the "cool kids" you need to be a user. The sellers can earn a great deal of money, and it is all legal. In fact, in some cases the law requires that you use it – as in the United States, where hospitals and medical practices are required to both adopt and demonstrate "meaningful use" of electronic records and will have their payments from government health insurance programs reduced if they do not.²

It appears, however, that the drug, or the music, is much more attractive to health care system managers, health systems researchers, and political leaders than it is to patients, physicians, and nurses. French implementation of the DMP

¹ Jean de Kervasdoué ed., *Carnet de Santé de la France 2009*, Dunod, La Mutualité Française, p. 3

² For one short explanation see <u>https://www.usfhealthonline.com/resources/healthcare/electronic-medical-</u> <u>records-mandate/</u> It is part of a university's efforts to recruit students to pay for degrees in health informatics.

at the time of the earlier *Carnets* failed because neither doctors nor the general public followed the piper. The DMP was re-launched in 2010 and "re-relaunched" in the French Health Act published in January of 2016, with various changes such as being renamed as the Dossier Médicale Partagé and giving patients more control of access to the record. By September of 2019, over seven million people had a DMP in France, about a fifth of physicians were adding information to their patients' DMPs and almost half occasionally consulted a DMP for information.³ On the one hand this is progress for advocates of the DMP; on the other hand it is nowhere close to the integration of information technology into practice that was the dream fifteen years ago.

Yet the dream lives on. The National Health Strategy 2022, enacted as law in 2019, declared that, "Switching to a digital health system is a chance to improve the quality of the service patients receive. The use of digital tools leaves more time for treating patients, improves appropriateness and quality of care and may contribute to long-term control over healthcare expenditure."⁴ Policy-makers hope that other digital records from the SNDS (Système Nationale des Donnés de la Santé) will aid development of artificial intelligence (IA) projects to improve care and save money.⁵

These goals are central to the theme of this volume, but the theory about effects is not supported by the evidence. This topic would be hard to cover in a whole book, because there are so many different claims and hopes about different ways in which information technology might make health care a better value for the money spent. I will try to give a brief introduction, however, to why the policy ambitions so widely proclaimed by eminent scholars and policy-makers, ranging

³ Brigette Séroussi and Jacques Bouaud, "Update on the DMP, the French Nationally Shared Medical Record: Did We Make It?" *Studies in Health Technology and Informatics* 2020; 270: 698-702 and same authors, "The (Re)-Relaunching of the DMP, the French Shared Medical Record: New Features to Improve Uptake and Use," *Studies in Health Technology and Informatics* 2018; 247: 256-260.

⁴ Ministère des Solidarités et de la Santé, "National Health Strategy 2018-2022: Summary, p 9. At <u>https://www.gouvernement.fr/sites/default/files/locale/piece-jointe/2018/10/france-national-health-strategy-2018-2022.pdf</u>

⁵ Claudia Graeve, "e-Health in France: Spotlight on the National Healthcare Digitalization strategy" March 24, 2020 on *Health Advances Blog*. At <u>https://healthadvancesblog.com/2020/03/24/e-health-in-france/</u>

from the OECD to the Government of France to many parts of the U.S. government and health services research community, are either hopeless or foolish. The digitization of health care information has many merits but should be used carefully and only for limited purposes.

I will give examples below, but first I should distinguish among terms.

* I will call the full range of efforts to improve health care by putting data in electronic form and then analyzing or sharing it "*Informatique de la Santé*" (*IS*).

* Records of treatments, tests, diagnoses and evaluations by medical professionals about individual patients will be called "*Dossiers Médicaux Électroniques (DME)*. These can be held in various formats by various people and organizations.

* In many sources, what I am calling DME are instead called "*Dossiers de Santé Électroniques" (DSE).* There is no standard distinction, so I will suggest one. Except when quoting others, I will use DSE for data sets that include not just information about work done by the medical industry, but also other information that might affect a patient's health – variables such as poverty, whether housing is adequate, and family situation. Many policy-makers believe that kind of data is needed to help physicians anticipate problems with treatment, and to develop policy innovations to improve health. Most applications, however, are DME.⁶

* *L'intelligence artificielle (IA)* refers to data analysis performed by computers for two purposes. One is as part of diagnosis for an individual patient, such as interpreting a CT scan. This may be the output of a process, as with a CT scan report, or involve informing caregivers of guidelines about treatments: a form of *Aide à la Décision Clinique (ADC,* in English sources, "Clinical Decision Support). The other is analysis of very large datasets in order to develop algorithms that can then be used to diagnose or choose treatments for individual patients. I make a rough distinction between research in which human beings do statistical manipulations of the data, or *L'Analyse des Données, (AD)* and analyses performed

⁶ Most but not all sources in English use "Electronic Health Records" or "EHRs" for what are really DME. We will translate those as DSE because I cannot pretend others have used my distinction.

by the computer with much less choice by human statisticians, so *Apprentissage Automatique (AA,* in English sources, "Machine Learning").

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The dominant "problem" with digitization in almost all countries, according to advocates, is that it has not been implemented widely or deeply enough: to follow our analogy, it's a lack of adherence to the prescribed treatment. In fact, as in England or the Netherlands, efforts have collapsed after (by any standards other than those of the United States), massive waste of money.⁷ In the United States now there are lots of people who think the drug is not used enough. But there is also a great deal of concern about side-effects and overdoses from the most common form of the drug: Electronic Medical Records. DME (Jean, I don't know whether abbreviations of a plural should in French have an "s" added at the end or not; please standardize as you wish) are supposed to be the platform both to improve how care is coordinated and do new research about treatments. Yet instead of seductive flute music, the air is filled with cries for help and screams of pain, especially from physicians.

The United States is the country in which DME and IS have been integrated most thoroughly into delivery of health care. Rather than providing more time for treating patients, DME in the U.S. have taken time away from patient care. In some cases, such as limiting medication errors, ADC may have helped; but it also has created some new errors and we have very little evidence that the improvements were worth the cost. On the whole we know that implementation of DMEs in U.S. hospitals and medical practices has been very expensive, and if there is any proof of savings I have not seen it.

Here are some main themes of U.S. experience.

⁷ On the NHS, see "NHS IT system one of 'worst fiascos ever', say MPs. BBC News September 18, 2013. <u>https://www.bbc.com/news/uk-politics-24130684</u> For a non-academic view of Dutch developments, see Thomas Kostera and Cinthia Brisëno, "E-Health in the Netherlands: Lessons Learned," at <u>https://blog.der-digitale-patient.de/en/e-health-in-the-netherlands/</u>

* "An Unholy Mess" that enables fraud. In a major investigation, *Kaiser Health News* and *Fortune* magazine described the massive investment in "turning medical charts into electronic records" as "an unholy mess," more like, "death by a thousand clicks" than a new era of better care.⁸ Physicians and nurses spend an immense amount of time entering data into the record, "clicking" in response to prompt after prompt, to fill boxes within templates that are supposed to standardize and thereby improve documentation. The study concluded the clearest outcome of the investment was that the systems were being used to maximize questionable billing, a "new era of health care fraud."⁹ This fraud is indicated by "a relatively new documentation problem with potentially far-reaching consequences": errors of "commission" in which the record includes events that did not occur.¹⁰ A doctoral dissertation comparing French and American nursing in hospitals emphasized that because U.S. nurses are judged by what is documented, "these policies push nurses to do a number of things, many of which are deceptive; to chart things they may not have done."¹¹

* **Extra time.** The vast majority of studies find that, contrary to the hopes of the National Health Strategy 2022, the DME does not save time. In one study, internists reported that the DME takes an extra 48 minutes of time each day compared to manual systems.¹² Another found that physicians were spending as much time on "desktop medicine" – working on their computers – as with patients

⁸ Fred Schulte and Erika Fry, "Death By a Thousand Clicks: Where Electronic Health Records Went Wrong." *Fortune* and *Kaiser Health News*, March 18, 2019. At <u>https://khn.org/news/death-by-a-thousand-clicks/</u>

⁹ Fred Schulte and Erika Fry, "Electronic Health Records Creating a 'New Era' of Health Care Fraud," *Fortune* and *Kaiser Health News*, December 22, 2019, at <u>https://khn.org/news/electronic-health-records-creating-a-new-era-of-health-care-fraud-officials-say/</u>

¹⁰ Saul J. Weiner, Shiyuan Wang, Brendan Kelly, Gunjan Sharma and Alan Schwartz. "How accurate is the medical record? A comparison of the physician's note with a concealed audio recording in unannounced standardized patient encounters." *Journal of the American Medical Informatics Association (JAMIA)* 27(5), 2020.

¹¹ Lucie Michel, *Dans la boite noire d'un fardau infirmier: Analyse compare du travail administrative hospitalier en France et aux États-Unis.* Thèse de Doctorat de L'Université Pierre et Marie Curie, 2017. P. 168.

¹² Thomas H. Payne et al., "Report of the AMIA EHR-2020 Task Force on the status and future direction of EHRs." *JAMIA* 22(5), 2015, p. 1103.

in the office for a visit.¹³ A third found that physicians were spending 27% of their time on direct patient care and 49% on DMEs and deskwork; that included spending 37% of their time while in the examination room with patients on DMEs and deskwork.¹⁴ Even Barack Obama, who enthusiastically endorsed the policies that forced and partially paid for American doctors and hospitals to enter the shining future of IS, bemoaned the fact that, "there are still just mountains of paperwork... and the doctors still have to input stuff, and the nurses are spending all their time on this administrative work."¹⁵

* **Burnout.** DME are believed to be a primary cause of an "epidemic of burnout," with clinicians either performing worse, cutting down their work effort, or leaving the profession. The National Academy of Medicine issued a major report about burnout;¹⁶ it has been called a "public health crisis" by leading health care executives,¹⁷ and has generated a burgeoning literature (over 5,000 citations in PubMed for "physician burnout" alone on the day I wrote this). It has even led to a new health policy slogan: replacing the "triple aim" of "enhancing patient experience, improving population health, and reducing costs," with calls for a "quadruple aim" that includes "improving the work life of health care providers."¹⁸ Even the medical informatics profession's main organization declares that, when implementation issues were projected in 2009, "the degree of clinician burnout and

¹³ Ming Tai-Seale et al., "Electronic Health Record Logs Indicate That Physicians Split Time Evenly Between Seeing Patients and Desktop Medicine." *Health Affairs* 36(4), 2017.

¹⁴ Christine Sinsky et al. "Allocation of Physician Time in Ambulatory Practice: A Time and Motion Study of Four Specialties." *Annals of Internal Medicine* 165(11), 2016, pp. 753-760.

¹⁵ Jeff Stein, "Transcript: President Obama talks to Vox about Obamacare's future Vox (January 6,2017), at <u>https://www.vox.com/policy-and-politics/2017/1/6/14193334/obama-vox-interview-transcript</u>

¹⁶ National Academy of Medicine, Consensus Study Report, *Taking Action Against Clinician Burnout: A Systems Approach to Professional Well-Being*. October, 2019, at <u>https://www.nap.edu/catalog/25521/taking-action-against-clinician-burnout-a-systems-approach-to-professional</u>

¹⁷ John Noseworthy et al, "Physician Burnout is a Public Health Crisis: A Message To Our Fellow Health Care CEOs," Health Affairs blog March 28, 2017 at <u>https://www.healthaffairs.org/do/10.1377/hblog20170328.059397/full/</u>

¹⁸ Thomas Bodenheimer and Christine Sinsky, "From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider." The Annals of Family Medcine 12(6), 2014 pp. 573-576.

its contributing factors, such as increased documentation requirements, were significantly underestimated."¹⁹

In Abraham Verghese's words, "My young colleague slumping in the chair in my office survived the student years, then three years of internship and residency and is now a full-time practitioner and teacher. The despair I hear comes from being the highest-paid clerical worker in the hospital."²⁰ Daniele Ofri wrote that, "the EMR has had a massive impact, as medical care has devolved into data-entry drudgery. While the EMR can streamline workflow and make life easier for some specialists, for generalists it has skyrocketed the workload."²¹ Curtis Kommer reported that data about effects of DMEs on quality of patient care was mixed, and he found some functions useful. Yet, he added, "repetitively typing EHR notes on my patient interactions is, for me, a soul-sapping exercise in data-entry; reviewing the novella-length EHR notes of other clinicians has become a tiring and cynical hunt for meaningful observations, interpretations, or conclusions."²²

The DME is not the only cause of burnout but, as one study summarized the situation, "lack of control over workload, an excessive amount of time spent on the EHR at home, and a high proportion of work not requiring physician-level skills likely contribute substantially."²³ Physicians may stay late on days they are in clinic to finish feeding the record. They may see fewer patients in a day in order to leave time for the paperwork – as one study put it, "what's actually happening is

¹⁹ Justin B. Staren et al., "A retrospective look at the predictions and recommendations from the 2009 AMIA policy meeting: did we see EHR-related clinician burnout coming?" *JAMIA* 28(5), 2021, p. 948.

²⁰ Abraham Verghese, "How Tech Can Turn Doctors Into Clerical Workers," New York Times Magazine (May 18, 2018) at <u>https://www.nytimes.com/interactive/2018/05/16/magazine/health-issue-what-we-lose-with-data-driven-medicine.html</u>

²¹ Danielle Ofri, "The EMR has changed the doctor-patient duet into a ménage à trois." *STAT News*, (Oct 31, 2019) at https://www.statnews.com/2019/10/31/emr-changed-doctor-patient-duet-into-menage-a-trois/

²² Curtis G. Kommer, "Good Documentation." JAMA 2018; 320(9); 875-876.

²³ Ross W. Hilliard, Jacqueline Haskell, and Rebekah L. Gardner. "Are specific elements of electronic health record use associated with clinician burnout more than others?" *JAMIA* 27(9), 2020, p. 1407. See also H. C. Eschenroeder Jr. et al., "Associations of physician burnout with organizational electronic health record support and after hours charting." *JAMIA* 28(5), 2021, 960-966. John Adler Milstein et al, "Electronic health records and burnout: Time spent on the electronic health record after hours and message volume associated with exhaustion but not with cynicism among primary care clinicians." JAMIA 27(4), 2020, 531-538. Philip J. Kroth et al., "Association of Electronic Health Record Design and Use Factors With Clinician Stress and Burnout," *JAMA Network Open* 2019; 2(8).

people fractionally quite, so that they can manage the in-basket."²⁴ Or they may feed the record in the evenings or on weekends at home – the former is now called "*pajama time*." Those stresses are joined by frustration about getting information from the record.²⁵

* "The Demise of the Useful Medical Note." The original purpose of a physician's notes was to document to herself, for her own memory and reflection, what she needed to know about the patient. In a team setting, like a hospital, the note then would report to other members of the team what the physician (or other clinician) thought they needed to know. A note might report some test results, but a good note was a narrative that told the story of the patient's illness.

Now the physician is entering dozens or hundreds of clicks about topics that have been standardized either for purposes of billing ("we did this so you should pay us for it"), or "quality assurance" ("I asked if the patient feels safe at home, and I told them smoking is bad for them, which shows I'm providing quality care"), or to make the record something that can be used by everybody in the system (for "interoperability" and "integration"). The record is organized as templates, each to be filled in because it might be relevant in some situations and the record is supposed to be comprehensive and integrated. "The resulting documentation," a task force of the American Medical Informatics Association reported, "has limited relevance to the visit being documented... purely coded templates neither distinguish informational wheat from chaff, nor capture the subtle details of each patient's unique circumstances. Further, coded templates impede effective clinician

 ²⁴ Ellis C. Dillon et al., "Frontline Perspectives on Physician Burnout and Strategies to Improve Well-Being: Interviews with Physicians and Health System Leaders." *Journal of General Internal Medicine* 35(1), 2020: 261-267.
²⁵ Lichtner V and Baysari M. "Electronic display of a patient treatment over time: a perspective on clinicians' burnout." *BMJ Health and Care Informatics* 2021: 28, at <u>https://informatics.bmj.com/content/28/1/e100281</u>

communication."²⁶ As one observer summarizes, "the note as a means of communicating how the patient is doing has all but been destroyed."²⁷

Much of this "note bloat" is because physicians, required to provide "complete" documentation but with limited time to enter it, "copy and paste" language from previous reports into the boxes. This is very helpful for physicians entering the data: "clinicians in the top quartile of copy and paste use were significantly less likely to report burnout." Unfortunately, "copy and paste often leads to longer, less useful notes and potentially dangerous errors or miscommunication" – and is "independently associated with increased stress and burnout" among physicians who have to read the notes, "suggesting that a decrease in burnout for the note writer may be offset by an increase in the note reader."²⁸

It should be obvious that increased communication of unhelpful information is not progress.

* Less human contact between physicians and patients, or physicians and other caregivers. In practice, the DME competes with the patient for the physician's attention. A doctor who is looking at the computer screen and clicking boxes is not paying attention to the patient, and the patient knows it. The physician is paying more attention to the icon that represents the patient on the screen – to the "*iPatient*," in Abraham Verghese's term, rather than the patient.²⁹

"There is nothing more frustrating to a patient than talking to their doctor, wanting advice, and that provider is typing away and looking at a computer screen instead of the patient," commented Lloyd Minor, Dean of the Stanford University School of Medicine. The physician is equally frustrated because she has to be

²⁶ Thomas H. Payne et al, "Report of the AMIA HER-2020 Task Force on the status and future direction of EHRs." *JAMIA* 22(5), 2015, 1103.

²⁷ Paul E. Sax, "Electronic Medical Records and the Demise of the Useful Medical Note," *NEJM Journal Watch* blog, November 16, 2014, at <u>https://blogs.jwatch.org/hiv-id-observations/index.php/electronic-medical-records-and-the-demise-of-the-useful-medical-note/2014/11/16/</u>

²⁸ Ross W. Hilliard, Jacqueline Haskell, and Rebekah L. Gardner, "Are specific elements of electronic health record use associated with clinician burnout more than others?" *JAMIA* 27(9), 2020, 1409.

²⁹ Abraham Verhese, "Culture Shock – Patient as Icon, Icon as Patient." *New England Journal of Medicine* 2008; 359: 2748-2751.

"thinking about the mechanics of the documentation, rather than the implications of the symptoms and findings."³⁰ These and other pathologies of the DME are why, in Atul Gawande's words, "doctors hate their computers."³¹ They also are part of a broader transformation of medicine, in which physicians, like the residents Verghese described, are trained to evaluate the patient based on test results and reports rather than from touching and talking. There are even concerns about processes that seem efficient and helpful, such as radiologists reviewing scans and posting notes on the DME. The problem, as Robert Wachter explains, is that if physicians just see a result and do not talk with the radiologist, they do not learn from the radiologist, there is no consultation about interpretation, and the radiologist becomes part of a production line, not a team – something very different from the common rhetoric about integration.³² Similar concerns have been observed on American hospital wards, with physicians and nurses all focused on the computer screens and much less personal communication.³³

* Mixed Results and Quite Limited Benefits from ADC. One benefit expected from DMEs is that they would reduce some errors and speed communication. Various indicators are monitored in the hospital and can trigger alerts, so the attending clinicians notice a problem earlier. The DME should be especially helpful for medication decisions. The DME can be used to submit a prescription directly to a pharmacy (with the patient's preferred pharmacy being in the record). Typing in prescriptions must reduce the errors from physicians' famously poor handwriting. It also enables ADC, in which the computer compares a specific prescription to other information in the record in order to alert the physician or pharmacist to possible errors, such as prescribing a drug that will interact poorly with another drug. In

³⁰ Quoted in a story on PBS News Hour (American public television), July 21, 2017, at <u>https://www.pbs.org/newshour/health/doctors-think-electronic-health-records-hurting-relationships-patients</u>

 ³¹ Atul Gawande, "The Upgrade: Why doctors hate their computers." *The New Yorker*, November 12, 2018, pp. 62-73. Gawande's article may be the most insightful overview of the problem.

³² Robert Wachter, *The Digital Doctor: Hope, Hype and Harm at the Dawn of Medicine's Computer Age*. New York: McGraw-Hill Education, 2017. Chapter 6.

³³ See Lucie Michel, op.cit.

the policy analysts' ideal world, it could also inform the doctor that an equivalent drug is cheaper, either for the insurer or the patient or both.

In an even more ideal world, the computer could analyze data either entered directly from tests that are in electronic form (such as lab results, monitoring of respiration and circulatory symptoms such as blood pressure and heart rate) or entered manually by clinicians, and use algorithms to make a diagnosis that the physician would have missed. This is most plausible for well-bounded tasks such as interpreting a CT-scan, in which the data is all of the same type and reliability and the algorithm can be "trained" or "learn" on huge databases. It is much less likely to work if the DME is supposed to bring together a wide range of data from different sources, especially since necessary data is far more likely to be missing or unreliable compared to the task of analyzing a specific test, no matter how technically sophisticated the test may be.

Reviewing experience with ADC is far beyond the scope of this paper, but a few points seem clear. First, IS *has* reduced some errors in prescribing medication. Yet a portion of that improvement has been offset by new kinds of errors. When a physician's handwriting was unclear, the pharmacist might ask what she meant; if something is mistyped, the problem is not as obvious. Moreover, the templates for ordering medicines can give so many choices that it is easy to check the wrong box.³⁴ Second, the positive net reduction in prescribing errors does not seem to be matched by an equivalent reduction in harm.³⁵ This should not be a surprise since at least some errors should have normally been caught by pharmacists or others involved in the process after the original prescribing. Third, there are too many alerts, physicians often disagree with them, and the result is that over time they

³⁴ For a good illustration, see Part 3 of Wachter, *The Digital Doctor*.

³⁵ JI Westbrook et al, "Changes in medication administration error rates associated with the introduction of electronic medication systems in hospitals: a multisite controlled before and after study." *BMJ Health & Care Informatics* 2020; 27 at <u>https://informatics.bmj.com/content/27/3/e100170</u> Peter J. Gates et al., "How effective are electronic medication systems in reducing medication error rates and associated harm among hospital inpatients? A systematic review and meta-analysis." JAMIA 28(1), 2021, 167-177.

may be ignored, with physicians being more likely to pay attention if the pharmacist raises an issue.³⁶

The evidence for improvement in other areas, such as during hospital care, is very weak. One fundamental problem is that as a safety measure, ADC relies mainly on alerting clinicians about possible problems. Anyone who programs alerts will worry far more about failing to identify a possible problem than about overstating concerns. There also is substantial uncertainty about many medical situations. For both reasons, the number of alerts far exceeds the number that physicians and nurses find identify real problems. There might be 100 alerts each day for a patient in the ICU; overwhelmed by "alert fatigue," doctors or nurses either ignore or turn off the alerts.³⁷

The deepest dream of IS believers is that the DME will be used to diagnose conditions that a physician team would not and to recommend appropriate treatments. There are very few examples of this occurring, and the obstacles are daunting. ADC is a form of clinical guideline, or "cookbook medicine," and physician distrust of that form of care is deep and in many cases quite justified. The examples of guidelines being adopted by eminent groups and broadly rejected by patients and doctors are legion. Readers might just consider their national version of the controversy over when mammography should be reimbursed.³⁸ But if the guidelines are generated by "deep learning" (AA), the human users do not even know the logic behind the recommendation. As one report states, "it is vitally important to be able to trust the source and to understand what is behind the recommendations that the system offers." The authors recommend a "trust and

³⁶ Trinkley, KE et al. "Clinician preferences for computerized clinical decision support for medications in primary care: a focus group study." *BMJ Health & Care Informatics* 2019; 26 at

https://informatics.bmj.com/content/26/1/e000015. Mustafa I. Hussain, Tera L. Reynolds, and Kai Zheng. "Medication safety alert fatigue may be reduced via interaction design and clinical role tailoring: a systematic review." *JAMIA* 26(10), 2019, 1141-1149.

³⁷ Many of the sources cited above identify the problem; for an official U.S. Government description, see https://psnet.ahrq.gov/primer/alert-fatigue

³⁸ For example see Nikola Biller-Andorno and Peter Jûni, "Abolish Mammography Screening Programs? A View from the Swiss Medical Board." *NEJM* 370:21, May 22, 2014.

value checklist for clinicians" that seems virtually impossible to meet.³⁹ ADC generated by AA asks clinicians and patients to trust a "black box."

This might be fine if the methods of AA were agreed to be reliable, but they are not. "Input data may be incomplete, inaccurate, biased, out of date, not structured, or not defined in a way that the system is expecting." The population on which it was developed may be very different from the population to which the guideline is supposed to be applied.⁴⁰ It turns out to be particularly difficult to replicate many findings. "Pointing out these lapses has become its own subgenre of medical research."⁴¹ With narrow exceptions mentioned above – basically analysis of specific tests in radiology, ophthalmology, dermatology and pathology – people basically should not trust AA. It is hard to imagine that the data will get much better given the burdens of collecting and organizing it, or that physicians and patients would let it guide practice even if it somewhat improved.⁴²

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There are at least four common responses to such evidence.

One is to insist all these problems are temporary and there will be technical fixes. For example, templates will not be necessary because Natural Language Processing would allow extraction of the material the system needs from narrative medical notes. Such arguments leave out logical questions such as how the system designers will make sure physicians put that information in the narrative notes, or why NLP will suddenly be able to cope with the massive complexity of medical care. Nevertheless, versions of this reaction are the norm. There must be thousands of evaluations, including some of the most prominent that I have cited, which identify

 ³⁹ Christina Silcox, Susan Dentzer, and David W. Bates. "AI-Enabled Clinical Decision Support Software: A 'Trust and Value Checklist' for Clinicians." *NEJM Catalyst Innovations in Care Delivery* 1(6), November-December 2020.
⁴⁰ Ibid.

⁴¹ Casey Ross, "Machine learning is booming in medicine. It's also facing a credibility crisis." STAT News, June 2, 2021, at https://www.statnews.com/2021/06/02/machine-learning-ai-methodology-research-flaws/

⁴² A particularly good overview is Kun-Hsing Yu, Andrew L. Beam and Isaac S. Kohane, "Artificial Intelligence in Healthcare." *Nature Biomedical Engineering* Vol. 2 (October, 2018): 719-731.

the problems but insist they will somehow be solved. They do not provide evidence of the necessary path of progress.

The second would be to try to untangle medical care from IS. There are good reasons to reduce reliance on IS. But there are also many ways in which IS is simply logical. It makes no sense to have a machine that conducts a test in pixels, analyzes it electronically, is able to send the result to another machine, and then not do that. It is easier to put a lot of information in electronic form, even if the benefits have been overstated. Some form of DME is and should be here to stay.

The third response would be that the U.S. is unique. Because of the political weakness of physicians, DME has been implemented far more thoroughly in America. But the U.S. DME becomes overloaded because of the ambitions of our system regulators and the immense complexity of medical billing. This argument has a lot of truth. For example, one study found that clinical notes using the same EPIC DME were "nearly 4 times longer on average" in U.S hospitals than in hospitals in Melbourne and Singapore; in these other hospitals the note "tends to be far briefer, containing only essential clinical documentation; it omits much of the compliance and reimbursement documentation that commonly bloats the American clinical note."⁴³

Certainly using the DME for billing makes it a lot more complicated than it would be if it were designed solely for physicians and nurses to exchange information they consider important. David Blumenthal, one of the leading American advocates of health system reform by "paying for value" or performance and integrating care through the DME (or even a DSE), who led the Obama administration's efforts to spread such records through the healthcare system, insists that the problem is fee-for-service payment for care.⁴⁴ His analysis is not

⁴⁴ David Blumenthal, "The Electronic Health Record Problem," Commonwealth Fund blog, December 13, 2018, at <u>https://www.commonwealthfund.org/blog/2018/electronic-health-record-</u>problem#:~:text=David%20Blumenthal.-

⁴³ N. Lance Downing, David W. Bates, and Christopher A. Longhurst. "Physician Burnout in the Electronic Health Record Era: Are We Ignoring the Real Cause?" *Annals of Internal Medicine* 2018 Jul 3; 169(1): 50-51.

President%2C%20The%20Commonwealth&text=They%20say%20they%20spend%20too,pasted%20to%20meet%20documentation%20requirements.

helpful for two reasons. First, the alternative "value-based payment" requires extensive documentation to meet demands to demonstrate "quality." The Medicare rules to document quality in re-invent activity-based payment with a different name. So does performance measurement in any other country. Second, much of the expectations about how DMEs would improve value in other countries make similar assumptions. The whole theory of integration is that every provider will be able to see all the information on a given patient, and that one record will serve all. That has to be a huge and complex database.

The fourth response is to say that the delivery system must change to fit the DME (or DSE, in the context of desires to pay hospitals for "population health" that depends on more than the services hospitals provide). At one level this would make doctors and nurses cogs in the algorithm created by the DME, which seems a very bad idea. But there can be more marginal adjustments. The dominant idea, in the U.S., is to create "medical scribes": new employees who observe the clinical encounter and fill in much of the DME so the doctor can pay attention to the patient.

There is good evidence, though mostly from small studies, that scribes have a positive effect on both the quality of the record and the physician/patient interaction. Most studies that report some reduction in burnout include "an intervention to expand the care team to primarily add clerical support by medical assistants/scribes."⁴⁵ Scribes seem to be good for physicians without much harming patient care.⁴⁶ It is hard to see, however, how creating a new employee for (at a minimum) every primary care physician is going to increase efficiency. In fact, it is hard to see how the supply of competent scribes can meet the need. They are often recent college graduates who are taking a year or two off between college and (they hope) medical school. Many are paid poorly by third-party contractors but see the job as an investment in their futures. The third-party contractor charges much

⁴⁵ J. Kelly et al., "The burden of the digital environment: a systematic review on organization-directed workplace interventions to mitigate physician burnout." *JAMIA* 28(5), 2021, 988.

⁴⁶ Pranita Mishra, Jacqueline C. Kiang, and Richard W. Grant. "Association of Medical Scribes in Primary Care With Physician Workflow and Patient Experience." *JAMA Internal Medicine* 2018, Nov 1; 178(11): 1467-1472.

more to the hospital, in part because of the costs of training and continually replacing the scribes.⁴⁷ This can be a high-quality workforce but could not possibly be expanded to serve more than a small portion of physicians.

The fifth response is proposed by hardly anyone, but I'll suggest it below. It follows from a different diagnosis of the "problem" with DME, DSE, and all the rest of the alphabet soup.

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Advocacy that assumes IS will have major benefits for medical care ignores two basic questions that should be asked about any policy idea.

First, what is the ratio of costs and benefits? The classic example of why a nationwide DME is a good idea is that it would enable someone who is traveling within the country and gets sick to have their record accessed in another city by a new clinician. That's nice. But it assumes that the information on that record will be helpful. In many cases it will not. A test that was done a month ago provides a baseline, but its results may have changes (which is why I'm sick now). The right question is whether the benefits from the relatively rare cases where information helps treat someone who is not near their regular medical providers approach the costs of feeding and maintaining a nationwide, comprehensive medical record. There is a good chance they do not.

The second question is what functions that might be served by a DME are most likely to be successful. Consider the idea of creating DSEs instead. Getting accurate medical data from within the medical system is hard enough; creating reliable social and other data must be much harder and more expensive. And, once you have it, what do you do with it? Will the health care system improve a person's

⁴⁷ Joan S. Ash et al., "Safe use of the EHR by medical scribes: a qualitative study." JAMIA 28(2), 2021, 294-302. Three of my college students who graduated in 2021 took jobs as scribes – all hoping to then go to medical school. There are also international scribes, such as physicians in India, as described by Gawande op. cit. Presumably they will work for longer, but that is a terrible idea for other reasons: Indians should suffer because our DMEs are a mess?

home situation? Will anyone else? With what budget? Why were they not doing that before?

The issue of what functions to pursue is especially relevant to research. What health services and medical researchers think is necessary could not possibly be created. For example, from an official U.S. government document: "individual data points need to be captured seamlessly, completely, accurately, consistently and in a standardized format... that allows for harmonization across different organizations and also to be available for reuse for future research inquiries." It must integrate "data collected outside of the care delivery process that may affect health outcomes—such as social determinants of health, patient-generated health data, and environmental exposures." Since the average patient and provider "may lack clear incentives to participate in or encourage participation in research," the IT system should provide "educational materials regarding research participation" and tell people the results of the research.⁴⁸ I assume the U.S. Army also wants drones that can distinguish friends from foes so only kill who it should want to kill. They will not get the technology they want, either.

The research ambitions for the IS are simply out of line. It is very hard to imagine actionable results from the most ambitious research on both medical and social data. And if the goal is to treat patients, much less complex datasets will do. In the United States, with tens of millions of patients in the data of organizations like Kaiser-Permanente and United Healthcare, no further integration is required. Moreover, if we want information about medical treatment for specific groups of problems – such as cardiac or neurologic or oncologic – physicians specializing in those fields should have the data they think is most important, both for treatment and research, rather than have to fill in and wade through a wide range of less relevant data. Comprehensiveness is the enemy of relevance.

⁴⁸ Office of the National Coordinator for Health Information Technology, "National Health IT Priorities for Research: A Policy and Development Agenda," January 15, 2020. At <u>https://www.healthit.gov/sites/default/files/page/2020-01/PolicyandDevelopmentAgenda.pdf</u> Later they say that, "effective communication will support efficient and patient-centered consent and security procedures." The naiveté would be charming if it didn't lead to such expensive and burdensome ambitions.

There is a third question: how does information, and how do information systems, shape the performance of organizations?

The biggest hallucination in the dream of saving health care through IS is the faith that more information makes things better. Some of the most eminent student of organization have taught us otherwise.

"Information is sometimes ignored at our own peril," Herbert Simon wrote in the final addition of *Administrative Behavior*, "but we are more often guilty of the opposite error – of supposing that all would be well 'if we just had more information."" He added that, "there is no magic in comprehensiveness. The mere existence of a mass of data is not a sufficient reason for collecting it into a single, comprehensive information system."⁴⁹

Perhaps the most important purpose of the division of labor within organizations is to make it possible for people to operate with limited knowledge. In Aaron Wildavsky's explanation, "looked at in the large, organizations exist to suppress data... The vary structure of organization – the units, the levels, the hisearchy – is designed to reduce data to manageable and manipulable proportions." The creation of computers and management information systems meant that, "more data are produced because it is possible. The quota of data enhancement is overfulfilled. But the task of data reduction becomes harder all the time. The chance that collectible data will be missed goes down, but the probability that they will be lost or misinterpreted goes up."⁵⁰

To Simon, one of the fundamental challenges for organizations was "attention management." Attention was "the scarce resource" and in order to conserve it the "totality of decision processes" must "be factored in such a way as to *minimize the interdependence of the components*"⁵¹ (his emphasis). Hopes for IS in healthcare

⁴⁹ Herbert A. Simon, Administrative Behavior: A Study of Decision-Making Processes in Administrative Organizations, 4th ed. New York: The Free Press, 1997. Quotes pages 225, 242.

⁵⁰ Aaron Wildavsky, "Foreword," to Mari Malvey, *Simple Systems, Complex Environments: Hospital Financial Information Systems* Beverly Hills: SAGE Publications, 1983. Quotes pages 7, 8.

⁵¹ Simon op. cit., p. 241.

essentially assume that digitization can fundamentally change the challenges of organization. *Everything will all be considered together, at once*.

Analyzing what now might be called "primitive" hospital Management Information Systems forty years ago, Mari Malvey noted that, "MIS have, for the most part, performed adequately at lower levels of the organization, processing large volumes of data with purposefulness, as long as singularity of objectives and clarity of calculation exist." I would say a good example is the "information system" within a medical device. But, "the information system designed to serve everyone ends up serving few, since it is impossible to maximize every goal simultaneously."⁵² In his 2018 investigation of "why doctors hate their computers," Atul Gawande found the same pattern, both in the history of Management Information Systems and experience with DMEs, The pattern, he explained, is that, "people initially embraced new programs and new capabilities with joy, then came to depend upon them, then found themselves subject to systems that controlled their lives." A program that serves more people and functions, "naturally requires tighter regulation. Software systems govern how we interact as groups" and are "unavoidably bureaucratic in nature."⁵³

Any doctor or nurse feeling forced to click and click and paste is likely to agree. The DME regulates clinicians. It structures their time. Nurses are evaluated by the completeness and timing of entries. Physicians can be rewarded or sanctioned for the "quality" they document (or do not).

If we believe that medical care should involve considering everything all at once then that cannot be done by any organization of human beings. The dream of what health informatics will accomplish can only mean that all care will be determined by algorithms. Only the algorithm can even pretend to pay attention to everything. But it will do so very badly, because the data will never be good enough and the raw material of the machine – patients – vary too much.

⁵² Malvey op. cit., p. 141.

⁵³ Gawande op. cit., p. 65.

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This essay is a desperate plea for more moderate ambition.

I have described health informatics (IS) as a drug. Sometimes its advocates sound like they are using powerful psychedelics. They assume a beautiful vision is true. One OECD chapter, for example, reported that, "countries that develop EHR systems that combine or virtually link together data to capture patients' health care histories have the potential to realise and unprecedented advancement in health care quality, efficiency and performance and in the discovery and evaluation of preventive care and treatments, including precision medicine."⁵⁴

This cannot happen, so will not.

Digitisation in health care can be useful in many ways. Nobody should expect big savings or health improvements from giving patients access to some of their test results and other medical data, but it would be appreciated by some. When a patient has a hospital stay, it should be possible for his ambulatory care doctor to download test results and clinical notes from the hospital. But that does not require that everything be on one massive database. Notes should not be designed for the system; they should be what the physician writing the note thinks is important. Most of the measures used for quality measurement are weak or misleading, so doctors should not be forced to enter them. If there is reason to worry that a medication should not be given to a patient, the pharmacist should get the prompt, and then decide if the physician should be contacted. IA should be developed carefully and tested rigorously to improve evaluation of some test results.

If it is viewed as the key to improving health care, however, health informatics will do more harm than good.

⁵⁴ Luke Slawomirski and Jillian Oderkirk, "Digital technology: Making better use of health data." Chapter 6 in OECD, New Health Technologies: Managing Access, Value, and Sustainability." (Paris: OCDE, 2017).