

The Inverse Data Law: Market Imperatives, Data, and Quality in AI Supported Care

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Abstract. Over the last decade, the explosion of “Big Data” and its fusion with AI has led many to believe that the development and integration of AI systems in healthcare will usher in a transformative revolution that democratises access to high quality healthcare and collectively improve patient outcomes. However, the nature of market forces in the evolving data economy, has started to show evidence that the opposite is more likely to be true. This paper argues that there is a poorly understood “Inverse Data Law” that will exacerbate the widening health divide between affluent and marginalised communities because: (1) data used to train AI systems favour individuals that are already engaged with healthcare, who have the lowest burden of disease, but the highest purchasing power; and (2) data used to drive market decisions around investment in AI health technology favours tools that increase the commodification of healthcare through over-testing, over-diagnosis, and the acute and episodic management of disease, over tools that support the patient to prevent disease. This dangerous combination is more likely to cripple efforts towards preventative medicine, as data collection and utilisation tends to be inversely proportional to the needs of the patients served – the inverse data law. The paper concludes by introducing important methodological considerations in the design and evaluation of AI systems to promote systems improvement for marginalised users.

Keywords. Big data, artificial intelligence, health equity, digital divide, data bias

1. Introduction

In 1971, Julian Tudor Hart, a British General Practitioner, famously proclaimed the inverse care law – the notion that “the availability of good medical care tends to vary inversely with the need for it in the population served” [1]. Tudor Hart critically identified that when medical care was exposed to market forces, inequity ensued, as those who *needed* healthcare the most (the disadvantaged), tended to receive it the least [1,2]. It was purported that the confluence of artificial intelligence (AI), machine learning (ML), Internet of Things (IoT), patient-generated health data (PGHD), and patient-centred eHealth and mHealth applications would signal the end of the inverse care law, by democratising access to high quality, cost-effective healthcare and supporting the goal of universal health coverage (UHC) [3,4]. However, while some individuals have benefited from the digitisation of healthcare, it has become increasingly clear that there

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exists a digital divide – those who are less likely to successfully engage with healthcare online (e.g., elderly, disabled, those with poorer education, and the culturally and linguistically diverse (CALD) groups), tend to experience the greatest burden of disease [5]. Some have suggested that the evolving “digital-first” model to global health systems has given rise to a “digital inverse care law”; the evidence of which is best captured by the management of the COVID-19 pandemic response, which highlighted how those who lacked the capacity for digital engagement, were more likely to have more severe symptoms, several comorbidities, less support, and a higher mortality rate [6,7].

While many researchers have started to examine the socio-technical, ethical, and moral questions that arise from the nature of interaction with digital health systems [8]; this paper identifies a lesser-known pervasive “*inverse data law*” that emerges as a by-product of the digital inverse care law, which is likely to significantly exacerbate the health divide between the affluent and marginalised communities. The inverse data law argues that in the presence of market forces, data collection and data utilisation in AI-supported care, tends to be inversely proportional to the needs of the patients served. The paper suggests that one approach to minimise the impact of the inverse data law, is to develop new methodologies around the design and evaluation of AI-based health technologies that are more robust at catering to the needs of diverse marginalised users.

2. Data Collection and Representational Biases in AI Health Technologies

ML algorithms are perceived to be immensely powerful because they are predicated on a fundamental assumption that embedded within large data distributions exists a set of computationally acquirable relationships that can disentangle the factors of variation that map X inputs to Y outputs, when framed as an optimisation problem. While this approach to computation has stimulated several healthcare innovations across screening, diagnostic, and therapeutic pathways [9,10], it has also raised serious concerns around its potential to amplify pre-existing biases within datasets, given that the main objective of the algorithms are to maximise signals that reinforce their distributions [11–13].

Bias manifests in elusive ways and is not a feature that can be eliminated by “Big Data”, as it is highly influenced by the interrelationships between the nature of representation and engagement in existing healthcare services, and by the broader socio-organisational constructs that contribute to the widening of health disparities when the complexity of an individual is reduced into a function of a group for data classification purposes (e.g., ‘Hispanic’, ‘Asian’, or ‘Black’) [14]. It is for this reason that researchers that audit large datasets and/or their AI implementations, tend to consistently return the same disappointing results – underdiagnosis or misdiagnosis along the lines of race/ethnicity, sex, age, and insurance type, as was observed in a recent audit of the largest publicly available radiology datasets for chest X-ray predictions [15].

In certain disease contexts, these representational biases are implicit to the nature of the disease distribution itself. For example, even though rare diseases affect more than 300 million individuals globally [16], each condition is characterised as low prevalence, affecting fewer than one in 2,000 people. Often, these diseases manifest with complex heterogeneity, overlapping phenotypes, numerous clinical subtypes, and unknown molecular mechanisms [17]. This characterisation is the antithesis of the big data context that medical AI success traditionally thrives on [18]. There is a concern that an over-reliance on such systems over time may alter clinical interaction and shift more human

resources towards episodic care, making underrepresented users with complex needs who demand continuous care ever-more marginalised.

3. AI Supported Care When Data Utilisation is Influenced by Market Forces

Recently, there has been an explosion in companies that offer digital health services across the continuum of prevention, detection, and management of disease that promises to improve health outcomes. However, in a concerning analysis by Cohen et. al. [19], it was revealed that companies in the United States of America (U.S.) that prioritised the acute and episodic management of disease, received significantly more investment than those that were singularly concerned with the prevention of disease. This is despite the fact that preventable chronic health conditions are responsible for at least two-thirds of health-related deaths in the U.S., and disproportionately affects those from disadvantaged backgrounds [20]. These trends suggest that market forces that dictate the dissemination of health technology are typically uninterested in health equity and the needs of the disadvantaged and/or vulnerable populations, as decisions that drive investment revolve around the maximisation of profit [21].

This raises important considerations when the downstream effects of the inverse data law are examined in the context of marginalised citizens receiving AI-supported care that is developed in the presence of market forces. Marginalised individuals participate the least with healthcare (inverse care law), participate even less with digital health services (digital inverse care law), are the least represented by the datasets used in AI development (inverse data law), are the most susceptible to chronic diseases, and are the most disadvantaged when it comes to accessing adequate care. When the key driver of emerging health technology development is consumerism, important ethical questions around how commercial vendors intend to meet the needs of marginalised citizens arise, particularly as promoting behaviours that prevent the need for healthcare is less likely to be endorsed, if there is little alignment with profitability. One potentiality is that vendors may advocate for prevention through over-testing, irrespective of the clinical evidence around its use [22]. It is unsurprising then, that Google's longitudinal "Project Baseline Health Study" (PBHS), aims to monitor maximal longitudinal health data through frequent testing. While its stated objective is to advance biomedical knowledge discovery and "open science" [23], how this fits into Google's commercial health interests and how it impacts health delivery is yet to be seen.

4. Methodological Considerations to Improve AI Health Technologies

The purpose of the Inverse Data Law is to provide a conceptual lens to view potential trends that may arise when developing emerging AI-based healthcare technologies in a market driven system. This section introduces a preliminary discussion around how design and evaluation methodologies may be developed for an era of AI-supported healthcare that aims to benefit marginalised users, while limiting its potential for harm.

Through the product design and development phase, incorporating user-centred design (UCD) principles to capture the needs of diverse user groups could result in systems that better address the concerns of marginalised citizens. However, there remains questions around how to best approach UCD in an era of agile development and disruptive innovation. For instance, given that a consumer's expectation of technology

tends to be constrained by the imaginative boundary of their familiarity with *existing* technologies, is it better for an innovator to engage participants as participatory co-designers for the purpose of ideation, or should the designer attempt disruptive innovation independently and engage participants *after* the design process to evaluate patient acceptability with an iterative view towards design? Furthermore, determining the best way to stratify participants into groups during UCD can be a challenge, particularly as generic group-based definitions tend to fail to capture the heterogeneity of individuals. For example, if one aimed to develop an AI-based intervention to improve colorectal cancer screening amongst under-screened CALD participants, it is likely that demographic differences would yield different technological demands, such that one design choice may benefit one individual at the expense of another within the same group.

Through the evaluation phase, one approach to improve the safety of AI systems, could be to have an independent authority audit and certify AI-based health systems, prior to and during system use, establishing operational constraints on who can consume the technology, based on system evaluation performances. This requires researchers and clinicians to agree upon and develop an evaluation standard for AI health technologies that appropriately considers the nuances of AI system development across: (1) data distributions used through system development, (2) the nature of the technical architecture of the models and their possible constraints, (3) the socio-technical considerations around their use, and (4) the clinical utility of the systems in practice. A possible starting point for such a framework, could be the recently published medical algorithmic audit by Liu and colleagues [24]. This framework, however, requires further development to provide explicit evaluation tools around how to approach different data types, datasets, model architectures, and application contexts, which have different ramifications for evaluation that need to be carefully examined. For instance, generative large language models (LLMs) [25] that have a capacity to (a) authoritatively “hallucinate” misinformation, (b) produce different outputs at each time step, and (c) that may not be privy to the nuances of language across CALD groups; are likely to have different evaluation parameters when compared to a discriminative model used as part of an image processing pipeline.

5. Conclusion and Future Work

This paper argues that there is a lesser-known inverse data law; the view that in the presence of market forces, data collection and data utilisation in AI-supported care, tends to be inversely proportional to the needs of the patients served. It shows how biases in datasets used to train AI systems are not features that can simply be eliminated, as bias emerges out of the contextual human interactions that drives data formation. Disadvantaged patients are the least likely to be represented in the data that underpins AI system development. When this is met with market forces that drive a profit-first strategy, there is a risk that: (a) biases are exacerbated, (b) episodic care becomes valued over long-term care, (c) over-testing becomes preferred over preventative care, (d) support for chronic and rare disease sufferers reduces; and the ones that pay the price, are the ones who need care the most. To curtail the likelihood of such an eventuality, the paper introduces methodological considerations across the design, development, and evaluation phases of AI systems, which will form the basis of our ongoing work.

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