Making Visible the Expertise of Data Workers in AI-Driven Healthcare

A Call to Action

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Abstract

Data constitute a crucial resource in healthcare systems increasingly reliant on digital technologies powered by artificial intelligence (AI). However, before these technologies can be used, they need to be 'trained' on large datasets assembled by individuals often working from home utilising their expertise to ensure that technologies work as they are designed to. Amidst recent enthusiasm for the adoption of AI in healthcare, little attention has been paid to the expertise and plight of these data workers. As I argue in this position piece, researchers have an important role to play in analysing and bringing to public attention the expertise possessed by those who curate content needed to power AI in healthcare and the affective demands and potential harms they face in undertaking this work. I discuss recent efforts to address the working conditions of data workers in general and suggest that the International Labour Organization could help develop standards, policies and programs to protect these individuals. As I conclude, making visible the expertise of data workers in healthcare will assist to both improve their lives and increase public awareness of the fact that AI would not exist without their contributions.

Keywords

Digital Health, Data Work, Artificial Intelligence, Affective Expertise, Emotional Economy.

Introduction

Healthcare is undergoing profound change as new technologies incorporating artificial intelligence (AI) trained on large blocks of data are rapidly finding application in domains such as health surveillance, disease tracking, point-of-care diagnostic testing, genomic sequencing, and personalised medicine, to name a few (Ahmed and Jeon 2021; Khan, Khan and Khan 2023; Zeng, Cao and Neill 2021). The COVID-19 pandemic has served to heighten expectations for the use of digital technologies in healthcare, with AI playing a critical role in related responses including techniques of modelling, virtual screening, and vaccine development (Arshadi et al. 2020; Bagabir et al. 2022; Dolgin 2023; Petersen 2024).

Yet, despite the rapid integration of AI into healthcare, researchers to date have paid little attention to the plight of those who toil behind the scenes in their own homes or other non-public settings to help make health technologies operate safely, efficiently and seamlessly. Before data can be used, they first need to be harvested, aggregated, and evaluated as to their utility and safety and this requires the experience, knowledge, labour, and judgements of the many people who undertake the invisible emotion-based data work that is needed for technologies to operate as they are designed to (Bossen et al. 2019). As Bossen et al. note, while there is a growing literature on data work *outside* healthcare, there has been little research on data work *in* healthcare. Yet, this form of work is of critical importance to everyone today who relies on digital technologies to fulfil their healthcare needs, including AI-generated scans, medical records systems, and point-of-care testing. Following Bossen et al., data work may encompass '*any human activity related to creating, collecting, managing, curating, analysing, interpreting, and communicat[ing] data*' (2019, 2, emphasis in original). In healthcare (and more generally), this activity may entail observations, experiments (for example, clinical trials), medical records, or computations (see Borgman 2015).

While some healthcare-related data work is undertaken in public settings and is thus visible to some extent, for example that performed by medical scribes who assist in documenting doctors' encounters with patients, by healthcare professionals who record patients' details and medical histories in clinical settings, and by patients themselves who create and engage with data in institutions of healthcare and places outside the clinic via wearable or portal devices (for

example, self-tracking devices) or other tools, the increase in the use of AI has meant that a growing proportion of data work is undertaken outside the clinic. This work tends to be performed by poorly paid workers who toil in their own homes or other non-public settings interpreting, sorting, contextualising and 'cleaning' data to make it useable or reusable (Fiske, Prainsack and Buyx 2019). Because those undertaking this data work are 'out of sight, out of mind' (Gruszka and Böhm 2022)—that is, invisible—they have been described as 'ghost workers' (Gray and Suri 2019). This work is often highly skilled and may comprise activities undertaken by content moderators of social media (for example, tagging and screening material to ensure that it does not cause harm) as well as tasks that are unique to healthcare such as scanning and sorting medical images; it also entails distinct demands, pressures and interdependencies.

In this Position Piece, I argue for the importance of making visible the expertise of these workers and the emotional demands and potential harms they may endure in undertaking their work. Making evident this expertise, I propose, requires researchers to adopt a broader analytic lens to consider the expertise that individuals bring to and develop while undertaking their work—an expertise that is not generally considered part of 'healthcare' *because* it is invisible, as well as the pressures and burdens that data workers may endure in the process. While data itself is an increasingly valued commodity—being often described as 'the new oil'— this value can only be realised through the exercise of human ingenuity and labour.

Data workers undertake tasks such as distinguishing between images to ensure that AI can generate representations of people or certain phenomena, editing chunks of text to ensure the effectiveness, efficiency and safety of technologies, and helping professionals keep abreast of new developments in their fields, among other applications (see, for example, Dave, Athaluri and Singh 2023). While AI promises precision, accuracy and timeliness in interventions, its use poses medical, ethical and legal concerns, including the production of biased and harmful results, infringement of copyright laws, and lack of transparency; for example, regarding the credibility of sources (Dave, Athaluri and Singh 2023). Yet those who work on the data to ensure its quality and safety tend to be employed on a precarious, piecemeal basis and face many challenges in undertaking their work. Data workers are often subject to technological surveillance and may suffer a financial penalty or denied further work if they fail to meet ascribed targets of work performance (Gray and Suri 2019, 67–93; see also Casilli 2019).

These workers tend to live in poorer communities far from where the products of their labours are 'consumed', without any social and/or emotional support. In the Philippines, one of the largest destinations for outsourced digital work, more than two million people perform this type of 'crowdwork' (Tan and Cabato 2023). Given

that these individuals mostly work behind the scenes and are thus invisible it may be difficult for researchers working in relatively privileged parts of the world and far from the locations of work to fully appreciate the skills they possess, and the day-to-day struggles and the exploitations and abuses they may endure. Many if not most are subject to some degree of algorithmic management and auditing (ratings or 'reputation scores')—described as 'inadvertent algorithmic cruelty' (Meyer 2014); moreover, they may be penalised by deductions of pay for not meeting ascribed targets set by their employers (Lee 2018; Parent-Rocheleau and Parker 2022). They tend to 'suffer in silence' and, if they complain, they may be excluded from further work (Gray and Suri 2019, 70–1, 80–4). Their pain is reinforced by the relative lack of public attention to their plight compared with social media moderators who have been the subject of recent news coverage, academic research and activism (for example, Safe to Learn 2022; Parent and McQue 2023).

Generative AI and growing automation

In healthcare, the demands are extensive and likely to vastly expand following the advent of generative AI tools such as ChatGPT, Perplexity (both launched in 2022) and Google's Gemini (previously Bard, launched 2023) that require enormous quantities of data to operate effectively, efficiently and safely. According to many commentators, the demand for 'real-time' data used for rapid decision-making, for example, in point-of-care testing, precision medicine, and emergency care delivery will soar in coming years, especially with a growing population of senior citizens, which will increase demand for more and larger data centres and related infrastructure (Adams 2022). This will require more data to be manually annotated ('labelled' or 'tagged') which may involve a vast network of actors since data are widespread and its value and useability needs to be evaluated. For example, medical images from protected health information used by radiologists need to be annotated in line with the technical standard for digital storage and transmission (DICOM Standards Committee 2023) and for each reading task, and scans need to be chosen and tagged from those available at each point of time depending on a defined set of parameters and anatomical coverage (Chaki and Dey 2020, 1214–15). Currently, much of this work is undertaken by medical practitioners, and teams of experts from data science and software development (2020, 1218). But as the demand for quality data surges in tandem with the rapid advance of AI, the work of data annotation is being outsourced, with companies offering specialised services in fields such as radiology, clinical decision-making and research, patient safety and regulatory compliance, and 'sentiment analysis' (for improving patient experience) (see, for example, Abramov 2024; iMerit 2023).

The process of annotation itself is increasingly automated. Datasets of value to healthcare may comprise images, text, and videos which need to be annotated

(e.g., by assigning a label to an entire image such as a tumour in medical imaging, using 'bounding boxes' (rectangular labels) to specify the boundaries and location of an object, or dividing an imaging into segments that belong to different objects or classes), to make it understandable and useable by computer models (AI machine learning) so that they can recognise patterns, shapes and objects by offering them examples to 'learn' from (Aljabri et al. 2022). As recently reported in *Nature Medicine*, brain surgeons can now use AI and new imaging techniques to diagnose tumours as accurately as and faster than pathologists, enabling the samples of patients to be analysed within minutes while they are still in the operating theatre rather than having to wait for tissue to be analysed in a laboratory as has occurred in the past (Hollon et al. 2020). Such applications of AI call for high-quality data if models are to be accurate and reliable, since there is much at stake; namely, people's lives and their quality of life.

As a 'Beginner's Guide' (Alvi 2024) to data annotation explains, the trend in AI-driven healthcare has been to develop well-annotated datasets that encompass a wide range of scenarios and variations which is time-consuming and calls on a combination of human skills and technologies, especially where objects may be occluded or only partially visible, or where lighting conditions affect the quality of the image. The goal, the guide notes, is to be able to

> train models to understand differences between objects, recognize objects in different contexts, and make reliable predictions or decisions based on visual inputs. Inaccuracies or inconsistencies in data annotation can lead to misinterpretations by the model, reducing its effectiveness and reliability in real-world applications.

As the guide states, annotating data involves 'a degree of subjectivity, especially in tasks requiring the identification of nuanced or abstract features within an image', and hence it is inevitable that different interpretations of images will result in inconsistencies in the data. This can affect the training of the model, which is especially challenging across vast volumes of data where clear guidelines and quality control measures are needed to maintain the accuracy of annotation (Alvi 2024).

Despite the increasingly critical role played by data workers in AI-driven healthcare, and the skills required to undertake the numerous tasks described above, commentary and prediction about future digital technologies continues to focus mainly on *physical* infrastructure, especially its adequacy in the light of the burgeoning pools of data, and how data should be stored, shared and securely managed in the different settings in which it is generated and used. The Big Tech companies that dominate the internet have a vested interest in increasing the capacity of this infrastructure to enable the advance of AI, but thus far have

displayed little interest in exposing the sources of their data and the affective demands placed on those who work behind the scenes to add value to their products. The latter aspect is where ideas from the sociology of emotions, building on the seminal contributions of Hochschild (1983), I believe, prove useful.

The emotional demands and harms of healthcare data work

In her classic study of flight attendants, Hochschild (1983) distinguishes 'emotion work' or 'emotion management', involving the thoughtful presentation of one's feelings to others, from 'emotional labour', where one is paid to display certain emotions as 'part of the job'. Hochschild's research addresses the then-expanding service economy where a certain presentation of the self, namely 'service with a smile', was increasingly valued. The advance of the digital economy and digital platforms, however, has increased the varieties of emotion work and the potential for related harm—posing considerable challenges for its regulation. Data work is highly diverse and traverses different industries, and is both location-bound (for example, professional services requiring an onsite presence) and of global reach (for example, professional services work such as consulting, design, and legal work that can be done remotely, as well as micro-tasking such as data entry and surveys)—making it difficult to define the scope of practice and regulating practices to protect workers (World Economic Forum 2020). Because data workers often work alone at home, and there exists no formal mechanism for reporting on their working conditions, we know relatively little about their day-to-day lives and affective experiences, let alone the longer-term harms they may suffer from repeated exposure to content involving depictions of disturbing material, and other emotional harms resulting from the conditions of their work such as physical isolation and lack of psychological and social support.

However, the plight of data workers in general and the emotional demands and harms they endure has recently come under increased scrutiny through a series of highly publicised lawsuits against Big Tech companies, including Microsoft, TikTok, Google and Meta, alleging that they receive inadequate psychological support for jobs that required them to view videos and photos of content involving beheadings, child abuse, rape, torture, bestiality, murders, and suicides, with some suffering PTSD (for example, Do Couto 2022; Elliott 2023; Levin 2017). Exposure to this content may cause high levels psychological distress (Glavin and Schieman 2022). Since healthcare-related data work covers content spanning a vast array of sources, *including* social media, it may involve subjection to similar content. Information gleaned from online information about companies offering AI training services indicates that the tasks likely to be performed by these workers include: medical coding (for example, assigning standardised codes such as the

International Classification of Diseases) to medical procedures, diagnoses and medications; identifying and tagging specific entities such as symptoms, diseases, medications, procedures and anatomical features within medical texts; annotating images such as X-rays, MMR images and CT scans to identify regions of interest, identify abnormalities, or perform segmentation tasks; and labelling specific elements within electronic health records, such as laboratory results, allergies and medication lists (for example, Narayan 2023).

Content may contain visual images of malignant tumours or videos of gruesome acts or of death or dying people. As the website of a content annotation company (Annotation Box 2024) explains, medical content moderation involves 'removing any harmful online content that may negatively impact one's mental health'. It continues:

> The healthcare sector operates on the cornerstone principle that precision saves lives. Every piece of user-generated content, be it detailed patient data, enlightening health articles, informative videos, or even candid discussions on mental health, must pass through the scrutiny of moderation. This commitment to accuracy extends its reach into the healthcare social media moderation sector.

As noted on the website, 'Healthcare is not a monolithic entity but a rich tapestry of varied platforms and services, including telehealth portals, patient-centric forums and medical journals, and 'each facet has its unique set of content moderation requirements', which calls for content moderation 'fusing human expertise with AI-driven precision' (Annotation Box 2024).

A growing movement for change

In response to growing concerns about the demands and harms posed by content moderation, some groups of workers have begun to organise collectively to unionise, which will hopefully encourage technology companies to improve their working conditions and bring prominence to their plight. For example, in May 2023, it was reported that 150 workers whose labour underpins the AI systems of TikTok, ChatGPT and Facebook met in Nairobi and 'pledged to establish the first American Content Moderators Union, in a move that could have significant consequences for the businesses of some of the world's biggest tech companies' (Perrigo 2023). Some workers have also sought legal redress for the emotional harms they have suffered. A group of 184 Facebook moderators who brought a lawsuit against Facebook described their work as 'torture', with one individual saying that 'content moderation is like "soldiers" taking a bullet for Facebook users, with workers watching harmful content showing killing, suicide, and sexual assault and making

sure it is taken down' (Associated Press 2023). In 2023, it was reported that moderators from 'several African countries' had brought a lawsuit of $1.6 billion against Facebook's parent company Meta and its outsourcing firm, Sama, 'alleging poor working conditions, including insufficient mental health support and low pay', with Kenya agreeing to mediate the case (Musambi 2023). (For other cases involving TikTok and Facebook see Allyn 2022; Dwoskin 2022).

These cases have done much to bring prominence to the previously hidden plight of data workers and may represent the beginnings of a new transnational movement committed to advancing their rights. But, as noted, thus far the focus has been on the major platforms rather than the smaller platforms and the many varieties of data work undertaken in healthcare. While the signs of addressing the concerns of data workers in general are promising, there are major hurdles to overcome, including the power of Big Tech and the many internet-reliant companies, organisations and individuals that have a vested interest in maintaining their exploitative work practices. I suggest that acknowledging and using news and other media to make visible the dimensions of and harms associated with undertaking data work for the health and safety of data workers and the critical role they play in contemporary healthcare should be an important part of any collective action to advance workers' interests.

International bodies such as the International Labour Organization (ILO), of which there are 187 member states, also have an important role to play here. The ILO brings together governments, businesses, and workers to establish labour standards and develop policies and programmes to advance the interests of workers internationally, and could provide a focal point for concerted action to protect the health and safety of data workers. Thus far the ILO has tended to target issues such as radiation protection, the risks of occupational cancer, asbestos, air and noise pollution, and chemicals, and work sectors such as agriculture, mining, dock work, rather than the harms associated with data work. However, it is encouraging to see the Organization recently acknowledging the potential harms resulting from the content moderation required to power AI systems (see International Labour Organization 2024). I suggest the ILO should focus more resolutely on the harms that data workers may experience in using their unique expertise—expertise that is critical for the operation of the AI used in a growing number of healthcare domains.

Conclusions

Relations of care are undergoing profound change as AI-enabled technologies and systems are integrated into healthcare systems and services and supporting expertise becomes progressively distributed. More and more, care has been

migrating to homes and mobile devices, a trend that has accelerated with COVID-19 and greater use of telemedicine and remote monitoring (Dorsey 2021). This platformisation of healthcare—whereby the infrastructure, economic processes and governmental frameworks of digital platforms, and related reorganisation of cultural practices and imaginations (Poell, Nieborg, and van Dijck 2019) shape the content and practices of healthcare—has accorded Big Tech extraordinary powers and created new categories of exploited labour. The exploitation of this labour is facilitated by its dispersal to many sites, effecting a new form of divide-and-rule, whereby workers never see the wider context within which they work, and are compelled to compete against each other and have few opportunities to work collectively with others to press their demands.

Making visible data workers' emotional contributions to the delivery of healthcare and the harms that they may endure in the process may not immediately lead to measures that address their exploitation and improve their working conditions, but it will help to make visible the fact that their lives are deeply entwined with others, including the many patients and families who ultimately benefit from the products of their labours.

Authorship statement

Alan Petersen is wholly responsible for the conception and authorship of this article.

Ethics statement

This article does not draw on primary data. The author is responsible for any misrepresentations or errors in content.

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