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# The future of translational medical humanities: bridging the data/narrative divide

Kirsten Ostherr

**Correspondence to**  
Professor Kirsten Ostherr,  
Medical Humanities Research  
Institute, Rice University,  
Houston, TX 77005, USA;  
kostherr@rice.edu

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## ABSTRACT

This essay argues that emerging forms of translational work in the field of medical humanities offer valuable methods for engaging with communities outside of academic settings. The first section of the essay provides a synthetic overview of definitions and critical engagements with the concept of ‘translation’ in the context of medical humanities, a field that, in the wake of the COVID pandemic, can serve as an exemplar for other fields of the humanities. The second section explains the ‘data/narrative’ divide in medicine and health to demonstrate the need for new translational methodologies that can address this nexus of concern, particularly in collaboration with constituencies outside of academic settings. The third section maps out the sites and infrastructures where digital medical humanities is poised to make significant translational interventions. The final section of the essay considers data privacy and health ecology as conceptual frameworks that are necessary for bridging the data/narrative divide. Examples are drawn from the ‘Translational Humanities for Public Health’ website, which aggregates projects worldwide to demonstrate these emerging methodologies.

## INTRODUCTION

The successes and failures of global responses to the pandemic have shown that societies worldwide have much to learn about how the protection of health intersects with social relationships, creative forms of expression, digital technologies, ecological transformations, and community responses to government surveillance and control. While many early responses to the pandemic prioritised scientific and technological solutions to the human problems that arose in the wake of COVID-19, the persistent need to care for the human condition in its vulnerability and resilience sparked the emergence of a wide range of humanities-based methods for translating scholarly research into projects that directly intervened in the global crisis. The concept of translation in the biomedical context is often understood as a process of ‘turn[ing] observations in the laboratory, clinic, and community into diagnostics, therapeutics, medical procedures, and behavioral changes that improve people’s health’ (Rutter 2023). This model posits a linear, hierarchical understanding of scientific discovery leading to patient care, which can be challenged and expanded by considering contributions from the humanities. This paper will examine a set of medical humanities responses to the pandemic, arguing that they can be productively understood as translational interventions

that offer new ways of thinking about the methods and domains of the field, illuminate the future of medical humanities<sup>1</sup> and help us prepare for the next global crisis.

The utility of a concept such as ‘translational medical humanities’ lies in the possibility it raises of intervening in the spaces of harm illuminated by the pandemic, while simultaneously expanding the global impact of those interventions. For a field that is predominantly rooted in academic medical centres and institutions of higher education, what would it mean to do this work further afield, in technology start-ups or policy think tanks or community-based organisations? New methods and skills are needed to reach these settings and interlocutors, as is a new posture of explicit willingness to risk the methodological uncertainties of direct intervention into the sites of ‘problems’ that the medical humanities aim to address. This essay will argue that emerging forms of translational work offer valuable contributions that should be integrated into pedagogical and research methods, within medical humanities and other fields of the humanities that aim to engage directly with communities outside of academic settings. The first section of the essay will provide a synthetic overview of critical engagements with the concept of ‘translation’ in the context of medical humanities, a field that, in the wake of the COVID-19 pandemic, can serve as an exemplar for other fields of the humanities. The second section will explain the ‘data/narrative’ divide in medicine and health to demonstrate the need for new translational methodologies that can address this nexus of concern, particularly in collaboration with constituencies outside of academic settings. The third section will map out the sites and infrastructures where digital medical humanities is poised to make significant translational interventions. The final section of the essay will consider data privacy and health ecology as conceptual frameworks that are necessary for bridging the data/narrative divide.

Throughout the essay, examples of translational medical humanities projects are presented to demonstrate the concepts being discussed. These examples are drawn from projects worldwide that were identified by a team of researchers and collected in an online database called Translational Humanities for Public Health (Ostherr *et al.* 2021). That site aggregates approximately 150 projects from over 20 countries that collectively demonstrate the range of insights that medical humanities can contribute to policy responses to emerging infectious diseases (EIDs) and other future crises. The examples discussed in this essay can be further explored through the Translational Humanities



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for Public Health website, where links to the original project websites and other related projects can be found. Through a discussion of humanities-based projects that aimed to intervene in and ‘improve people’s health’ during the pandemic, this article will show how the humanities already contribute to the objectives of biomedical translation, and how the conceptual framework of ‘translation’ can help clarify the contributions of medical humanities to patients and communities. As translational scientist Christopher Austin explains, the history of biomedical translation ‘is rooted in the immediate medical needs of patients, not in science’ (Austin 2021). By considering translation from the perspective of projects that emerged in direct response to the needs of communities during the SARS-CoV-2 crisis, this essay makes the case that the future of translational medical humanities is already taking shape, and would benefit from making explicit where and how the field can productively extend and diverge from biomedical translation.

### Why translational medical humanities?

The National Center for Advancing Translational Sciences at the US National Institutes of Health (NIH) defines translation as ‘the scientific process by which observations in the laboratory, clinic and community are turned into interventions that improve the health of individuals and the public - from diagnostics and therapeutics to medical procedures and behavioral changes’ (National Center for Advancing Translational Sciences 2020). A fundamental premise of this paper is that the definition of translational science would be strengthened if it embraced the medical humanities, and the humanities would be strengthened if they embraced translational methods. If the NIH views translational science as a means to develop ‘interventions that improve the health of individuals and the public’, then many of the humanities projects developed during the pandemic demonstrate that the humanities offer unique and critically important insights, observations, and methods that can improve the human condition and help alleviate suffering. For this reason, I argue that the concept of ‘translational humanities’ should be understood as a method for improving health, both by expanding the definition of ‘health’, and by balancing out the technological and biomedical responses to the crisis.

In the early months of the COVID-19 outbreak, scientists and engineers scrambled to develop tools that could aid in the global pandemic response. Do-it-yourself ventilator fabrication labs and data visualisation dashboards sprang up to provide technological solutions to the crisis (Budd *et al.* 2020; Jacobs 2020). These interventions were guided by an understanding of ‘health’ as survival, with mortality as the primary metric. At the same time, humanities scholars worked to expand this understanding of health, moving beyond physiological measurements to address human experiences such as the harms of social isolation and the impact of racism. Some humanities scholars created websites featuring crowd-sourced syllabi and bibliographies to help ‘teach the virus’ as Anne Fausto-Sterling tweeted, encouraging faculty to adapt their courses to address the pandemic (@Fausto\_Sterling, 12 March 2020). Researchers in a wide range of humanities fields initiated public-facing projects that brought their expertise to bear on the global calamity as it unfolded (Altschuler and Maddock Dillon 2021). Yet, the emergency responses in the STEM fields and the humanities rarely intersected, and instead, many governments defaulted to a narrow biotechnical response as outbreaks flared around the world. As the pandemic deepened, it became evident that the human experiences of fear, suffering, loneliness, loss and grief needed a different kind of

intervention. The COVID-19 crisis made tragically clear what research in the field of medical humanities had long shown: that technology alone will never accomplish the uniquely human endeavour of vanquishing illness and restoring health.

In a recent article synthesising the power of the concept of ‘translation’ for bridging cultural, medical, and biocultural perspectives and methods, Arnaldi *et al.* argue, ‘a translational medical humanities framework has the potential to cross-fertilize notions and experiences of biological and socio-cultural contagion in an interdisciplinary way, thus impacting, and by extension changing, not just the scholarly landscape of medical humanities but also medical knowledge, practice, and policy themselves’ (Arnaldi, Engebretsen, and Forsdick 2022). This argument aligns with that of health disparities researchers who see translational work as paradigm-shifting in its linkage with transformational and transdisciplinary work that extends the ‘bench to bedside’ metaphor of translational science to include an outreach and dissemination component, thereby modelling ‘bench to bedside to curbside’ (Dankwa-Mullan *et al.* 2010). Importantly, this approach to translational research is ‘bidirectional and cyclical, not linear; it occurs along a continuum from discovery to development to delivery and back to development and discovery’ (Dankwa-Mullan *et al.* 2010). While many biomedical research models functionally enact a linear approach to research dissemination, translational medicine gestures towards the central role of community, as in the European Society of Translational Medicine’s definition of translation as an ‘interdisciplinary branch of the biomedical field supported by three main pillars: benchside, bedside and community’ (Cohrs *et al.* 2015). Yet, the ‘community’ piece of this feedback loop often remains vague. The role of community perspectives comes into view more clearly when approaches that account for human experience explicitly become part of the methodology (Smith *et al.* 2023).

For example, ‘Jefferson COVID Stories’ (Snyderman 2021) is a story-telling project open to all members of the healthcare community at Thomas Jefferson Hospital in Philadelphia, Pennsylvania, USA to help them cope with the trauma of caring for so many patients who died from COVID-19. The medical student who co-led the project observed, ‘While it may not have been clinically measurable, the impact of this project was palpable, in the power of the words received through the myriad heartfelt responses displayed on our site’. In a very real sense that is difficult to measure in quantitative terms, these clinicians ‘believe[d] this ‘intervention’ improved the ‘health’ -- the wellbeing -- of the community at this time’ (Safian 2021). Notably, this site emphasises stories to the exclusion of quantitative data, yet the contrast is palpable as a structuring absence for a project that emerged from and is thoroughly imbued with the sensibilities of a data-driven, quantitative sphere of work. For instance, the opening to the site’s story collection on ‘Racism in Healthcare’, observes, ‘Amid a pandemic due to a viral pathogen, racism represents another chronic, progressive disease in our country’ (Racism in Healthcare 2021). By prefacing the raw, emotional and deeply personal stories that follow with this distinctly clinical tone, this hospital-based story-telling project highlights the inadequacy of medicalisation epistemologies for human processing or functioning in the existentially overwhelming context of COVID-19.

The iterative model of translational science is consistent with recent efforts to reframe the linear and hierarchical model of expert knowledge transfer to a more collaborative translational model of knowledge co-creation with communities (Engebretsen, Fraas Henrichsen, and Ødemark 2020). Building on calls to advance the ‘public humanities’ in American life (NEH n.d.; Krebs 2019; Fisher n.d), this essay argues that translational

humanities is the next generation of public humanities, as it maps the pathways from studying the humanities to mobilising the resulting knowledge and methods for use in the field. Several publications have employed the term ‘translational humanities’ to describe concepts akin to ‘public humanities’, often with a narrower focus on literary or linguistic translation (Lubar 2014; Maienschein *et al.* 2008; Robinson 2017; Rumsey 2013), while others have argued for a consideration of translation as a more expansive and critical approach to ‘knowledge transfer’ (Engbretsen, Sandset, and Ødemark 2017; Greenhalgh and Wieringa 2011). The ‘Translating Illness’ project at Oxford University, UK pursues some of these goals by exploring through a seminar and podcast series the question, ‘How will a nuanced understanding of translation help us advance in literary and linguistic studies as well as in clinical research?’ (Arnaldi 2021). This work is part of a broader movement to show how translation and multilingualism can lead to a more inclusive and trust-driven public health policy in the UK context (Blumczynski and Wilson 2023). The linkages illuminated across linguistic, cultural and biomedical translation show the synergies that already exist between medical humanities and public health policy. This essay extends these intersections and the scholarship on translational humanities by incorporating a new emphasis on bridging the data/narrative divide.

A fundamental premise of this essay is that the COVID-19 pandemic presented new and convincing evidence of the need for a stronger, more visible presence of the humanities in governmental and technological responses to global crises. This premise stems, in part, from the fact that the humanities take as their mandate the work of understanding and interpreting the human experience. While an existential reckoning took hold early in the pandemic, prompting a widespread embrace of the humanities as a realm where questions of meaning could be explored (Worthen 2021), this perspective was not reflected in the policy response to the public health emergency. Instead, throughout the COVID crisis, the predominant governmental method for understanding, interpreting and communicating the pandemic was the production of data-driven visualisations that erased human narratives of suffering. To address the harms made invisible in this representational paradigm, scholars in the humanities developed translational methods for working with and through data-driven frameworks, while also expressing critiques of this logic of accounting for health through mortality statistics. The pandemic brought humanist narrative logics into direct confrontation with data-driven epistemologies. Reflection on the translational interventions of biomedicine and the humanities during the pandemic makes clear that researchers in these fields must learn to bridge data with narratives to explain and anticipate the human experience of global crisis. Moreover, the pandemic showed scientists and humanists alike the challenge of translating their findings into forms of representation that are comprehensible and persuasive to individuals and organisations in positions of decision-making authority related to health. Examples of projects that attempt to bridge these divides will help illuminate the sites of translational medical humanities intervention.

### Bridging the data/narrative divide

Medical humanities researchers are positioned to develop translational methods informed by the lessons of the pandemic that can bridge quantitative and qualitative descriptions of the human condition on a planetary scale, and help build future preparedness from our reflections on the events that have occurred since the first cases of SARS-CoV-2 were detected in Wuhan, China.

Although it may seem paradoxical, a primary and timely aim of a robust translational medical humanities should be to reimagine the very digital technologies that are widely criticised as a primary source of dehumanisation in healthcare (Bailey 2011). While some aspects of the pandemic ‘digital turn’ decreased disparities, for example, by providing more inclusive access to people with disabilities (Pearce *et al.* 2022), massive governmental investments in digital contact-tracing technologies and unproven telehealth tools further increased health inequities in many sectors of society (Colizza *et al.* 2021; Kahn 2020). Data gathering through such digital devices was widely pursued as a method for ensuring the legitimacy of policy decisions, yet, gaps in the data caused widespread mistrust among a range of communities, due to incompleteness of data collection in marginalised communities (Ostherr 2022) and conspiracy theories about data suppression or fabrication (Brennen *et al.* 2020; Calleja *et al.* 2021; Hannah 2021; Shelton 2020). Unilateral policy-making by governments during COVID-19 led to ‘non-compliance with measures at a minimum and larger-scale demonstrations or conflict at a maximum, as seen in France (Marseille), Italy, Spain, the UK and the US during this crisis’, and the countries with the highest COVID-19-related fatality rates early in the pandemic (Brazil, Chile, Colombia, Italy, Mexico and the USA) were those where governments ‘enjoy[ed] lower degrees of trust’ (Organization for Economic Co-Operation and Development 2020). The issue of public trust in government COVID-19 policies and the data practices on which they were based presents an important opportunity for medical humanities to expand its methods and engage with the discursive construction of ‘health’ in its dynamic relationship to information—and misinformation—technologies.

Digital medical humanities (Ostherr 2019a; Ostherr 2019b) can intervene in the redesigning of digital health tools and infrastructures, and the pandemic showed us that this translational work is needed on a comprehensive scale, from data-collection to devices, electronic health record (EHR) systems, and patient portals. As the networks through which communities connect, are surveilled, and access services and care, and as the sites where representations of demographic ground-truth are sought by healthcare policymakers, digital sociotechnical systems directly impact human care and may alleviate or exacerbate suffering. COVID-19 made clear that humanists can provide valuable policy contributions by critically engaging with data—and data visualisations—as sources of information, and as central sites of ambiguity and uncertainty in public health and medicine (Bowe, Simmons, and Mattern 2020). Building on a central observation of medical humanities—that healthcare is filled with uncertainty and ambiguity (Baruch 2013)—a translational extension of this insight into the digital realm might entail design of new interfaces, visualisations and data logics that integrate humanist perspectives. Precisely because the data-driven approach to the pandemic erased narratives of human suffering, health data technologies should be among the primary focal points where translational medical humanities intervenes to develop novel infrastructures and prevent further harm before the next EID outbreak occurs.

If the pandemic has shown that infrastructures of care and harm play a powerful role in shaping our health outcomes, and these infrastructures are increasingly digital, where and how should medical humanities intervene? Legacies of inequitable infrastructure resourcing are evident throughout the built environments of homes and hospitals, they are embedded in our physical bodies, and they define our digital networks (Benjamin 2019; Broussard 2023). The pandemic has illuminated the importance of considering how infrastructures encode societal

values as we evaluate the consequences of unequal access to resources. As a group of public health researchers emphatically declared in an eponymously titled article published early in the COVID-19 pandemic, ‘Broadband Internet Access Is a Social Determinant of Health!’ (Benda *et al.* 2020). The use of an exclamation point in the article title signals the authors’ frustration with the slow acknowledgement, on the part of policy-makers, of the harms that can be embedded within the pretence of neutrality about where to invest, and not invest, in technology infrastructures such as broadband internet. The digital divide during quarantine impacted online schooling, the ability to work from home, and the very possibility of avoiding exposures in public spaces. These privileged forms of protective isolation were dependent on access to high-speed internet for streaming meetings, classes or telehealth appointments, and were further dependent on the physical labour and risk endured by workers at warehouses and delivery services. This point highlights the need to extend the range of medical humanities methodologies to engage more extensively with digital media studies (Ostherr 2019b), and fill the critical scholarly gap that exists between infrastructure analysis focused on digital surveillance, commerce and entertainment on the one hand (Parks and Starosielski 2015; Plantin and Punathambekar 2019), and telehealth, EHRs and genomics on the other (Rampton, Böhmer, and Winkler 2022). The key point is that the same core infrastructures enable all of these activities, and therefore these medical technologies should be further studied through the lenses of both critical digital/data studies and medical humanities (Lupton 2018; Lupton 2020; Mouldrem, Smith, and McClelland 2023). Building on this work, new methodologies should be developed with the explicit aim of enabling direct translational engagement at the site of data creation and representation.

Translational medical humanities projects can bridge the data/narrative divide by combining creative forms of data visualisation with personal or historical accounts that provide contextual specificity and aesthetic or affective signifiers. For example, ‘Stop AAPI Hate’, a crowdsourced website that documents anti-Asian American and Pacific Islander (AAPI) attacks and was launched and curated by a scholar in Asian-American Studies at San Francisco State University, has been used to raise awareness and resources to prevent further acts of violence against members of the AAPI community in the USA (Jeung 2021a). The site is crowdsourced, allows hate incidents to be documented in 16 different languages, and collects details on dates, sites and types of violence, as well as demographic data about the victims such as gender, race, ethnicity and age. Importantly, the site also encourages its users to submit their narratives, emphasising, ‘We can shine a light on what is happening in our communities because you, along with so many others across the country, are willing to share your story with us’ (Jeung 2021b).

‘Stop AAPI Hate’ is an independent project that is included in the online collection ‘Translational Humanities for Public Health’. The projects on this site can be described—in public health emergency terms—as ‘non-pharmaceutical interventions’ (NPIs), but their methods extend far beyond those typically considered to fall under the NPI rubric. NPIs in the context of COVID-19 included policies such as ‘cancelling public events, imposing restrictions on private gatherings and closing schools and workplaces’ (Askitas, Tatsiramos, and Verheyden 2021). In contrast, the interventions collected in ‘Translational Humanities for Public Health’, following the discussion of expanded conceptions of biomedical translation above, aim not only to reduce transmission of disease, but also to improve the lives of the intended recipients of the intervention, through creative,

connective and equity-oriented methods. In addition, many existing analyses of NPIs prioritise outcome measures that are more limited in their definitions of health than a humanities definition might be. For example, NPIs have been studied for their effects on ‘the COVID-19 case growth rate, death growth rate, Intensive Care Unit (ICU) admission, and reproduction number’ (Iezadi *et al.* 2021), whereas many translational medical humanities projects are oriented towards human flourishing, connection to sustaining cultural traditions and imaginative approaches to envisioning a better future.

By providing a database of translational projects and descriptions of the methods employed in each, ‘Translational Humanities for Public Health’ presents a set of techniques for using digital tools to integrate humanities methods into the fields of health and medicine, thereby advancing work in the emergent field of ‘digital health humanities’ (Ewing and Randall 2019; Ostherr 2019a). Moreover, the site builds on digital humanities scholarship that argues, ‘the design of infrastructure, when it engages critically with existing thought about power, represents a form of scholarly argumentation’ (Guldi 2020). The project’s digital infrastructure argues that public-facing health humanities work is a form of translation that can demonstrably improve public health, and the range of projects point to additional sites and infrastructures where translational humanities methods might be productively deployed.

### The sites and infrastructures of digital translation

While the humanities are associated more strongly with qualitative than quantitative contributions to health and medicine, the dominance of data logics in contemporary sites of care requires an expansion of medical humanities methodologies. The work of critical data studies should become more central to medical humanities not only because datafication is ubiquitous and can play a significant role in both health and illness, but also because ‘data-driven’ decision-making has become the dominant paradigm in medicine and public health, a trend which accelerated radically during the pandemic. A minor amount of attention has been paid recently within healthcare to the ways that data algorithms and digital technologies (hardware, eg, pulse oximeters) can encode racism, reproduce racial and gender health disparities, and harm people with disabilities (McFarling 2022; Moran-Thomas 2021; Rabin 2020). The field of medical humanities should use this as an opportunity to push that research and dialogue much further within medical settings and engineering design curriculum.

In addition, medical humanities should lead the way in developing new methodologies for creating and interpreting ‘data-driven narratives’ in healthcare, building on efforts to use natural language processing (NLP) to do ‘distant reading’ of EHR data sets (Ostherr 2020). Narrative analysis has been established as a critically important component of medical care, and functions as the most dominant medical humanities method, in the form of ‘narrative medicine’ (Charon 2008). The COVID-19 pandemic exposed the limits of our current methods by showing the diverse contexts in which more robust frameworks for integrating narrative into clinical care, nursing, end-of-life care, rehabilitation and beyond could provide needed support for caregivers and patients alike (DaGupta 2020). The field of medical humanities should build on the wealth of scholarship in ‘narrative medicine’, broadly understood, and build up its tools for engaging with data, both in the form of quantitative methods that need humanist contextual analysis, and in the form of constructive critical engagement with the dominant

epistemology in medicine, namely ‘data-driven  $x$ ’. This would require skilled participation in the development, testing and deployment of computational tools, such as NLP, sentiment analysis, and other forms of interpretation at scale that are capable of moving beyond topic modelling and thematic clustering. Here, medical humanities should collaborate with technology developers and computer scientists.

An article by a physician describing her own loss of a family member during the pandemic reflected on the inadequacy of the electronic medical record (EMR) system to capture in any meaningful way the end of a person’s life, and raised the need for computational systems that do more to preserve the humanity of patients. In a discussion of the circumstances of her grandmother’s passing, the physician author identified with the doctors, drowning in data all day long as they cared for patients who were isolated from loved ones and even from their professional caregivers who were cloaked in anonymising personal protective equipment (PPE). In that setting, when a patient dies, a doctor must perform the act of writing the ‘deceased note’ amidst the endless data entry in the EMR, the digital chart where narratives are reduced to decontextualised data. This is especially true when physicians are pressed for time, and, ‘In March 2020, there was little time for ‘unnecessary’ documentation when health care workers were pushed beyond the brink of burnout’ (Pasricha 2022). Yet, the author recognises that including even a small personal detail can be integral to healing for patients, loved ones and professional caregivers. She notes, ‘It’s turned out that the process of learning something unexpected about patients brings the medical team as much joy as it brings our patients’ (Pasricha 2022). This perspective highlights the urgency of bridging the data/narrative divide as a key process in the development of translational medical humanities, a practice that transcends academic methods and intervenes directly in crises of human care.

One of the purposes of this intervention is to argue for the importance of contextualised data, and for the necessity of understanding narrative in context, not in artificially clustered chunks that quickly become meaningless when analysed by algorithms as strings of text. Another purpose is to underscore the elements of patient experience that are not captured in quantitative data, and can only be gleaned from narrative, including the emotional, affective and sensorial dimensions of illness experience, across time and space. This is especially important in the realm of digital/virtual health technologies which rely on presumptions of ‘universal’ or ‘generic’ users, deploy a binary logic of emotion, and are guided by sentiment analysis to categorise mood and other affects. One potential approach could be to work with software developers on new methods for designing health technologies that are better able to incorporate the sensorial, emotional, and cultural aspects of illness experience and healing. These facets of patients’ humanity are, at present, quite rigidly excluded from software and device design practices. Consider the need for better, more nuanced and intersectional approaches to understanding factors such as ‘stress’ as it relates to inflammation, healing and chronic illness, for example. Medicine has barely begun to recognise the role of institutional structures and systems in producing ongoing, daily stress for black Americans, for trans people, for members of marginalised and oppressed communities broadly. If we could imagine a (privacy protecting, see below) wellness app that is deeply sensitive to the intersections of race, sex and class, as well as diverse models of identity and subjectivity, that goes beyond the ‘individual user’ model, for example, this could potentially lead to new forms of diagnosis and care that move beyond narrow biomedical constructs,

and could be of real value to patients and caregivers. This will not happen without translational humanities researchers and artists being involved in the development of these technologies.

### Data privacy and health ecology

The issue of data privacy is a major structural and regulatory concern, and links up with the ecological approach that is needed to provide a cohesive frame for bridging the data/narrative divide around health, when ‘health’ is understood as an encompassing term that extends spatially and temporally beyond clinical settings and measurements (Atkinson, Foley, and Parr 2015). In the climate of hostility towards women and reproductive health in America, period and fertility tracking apps that incorporate geospatial data have been revealed to exploit users’ sensitive personal health information by selling it to third parties (Torchinsky 2022). The risk that this type of spatial surveillance will be used as a form of policing in a post-Roe America is high. While scholarship on the harms of these kinds of privacy infringements is important, there is a real need for well-informed participation of medical humanities researchers in translating that scholarship into proposals for viable solutions, in the form of state, federal and international policies. These debates need humanities contributions that can bring in data feminism and antiracism and can build on the movement within critical data studies to decolonise privacy, noting the different and unequal ways that socioeconomic status can further exploit or shield specific groups of users from harm (Arora 2019; Benjamin 2019; Criado-Perez 2019; D’Ignazio and Klein 2020).

Debates about data privacy connect to the environment and the ecological model of health, while also emphasising a linkage with planetary health that is essential to the future of medical humanities (Lewis 2021). This linkage should be pursued in several ways. First, in simple terms, data tracking happens almost everywhere we go, certainly everywhere there is a cellular signal that can track the location of our phones. In this sense, a spatial component of the analysis is needed, especially as the data that feed into risk modelling tools used within clinical settings are often mined from activities that occur outside of clinical settings (and beyond the reach of regulations such as the Health Insurance Portability and Accountability Act of 1996, or HIPAA, in the USA). For this analysis, scholarship linking social and cultural geography with medical humanities provides a compelling starting point (Atkinson *et al.* 2015). Second, the infrastructures and physical components of our data-collecting devices harm the environment, through excessive energy use in manufacturing hardware, maintaining the functioning of server farms, mining of precious metals needed for semiconductors, processing waste, and so on. These harms, too, are not distributed evenly on a global scale, and harm most the ‘Global South’ where there is highest worker and ecological exploitation, amid the lowest use of digital devices and networks (Thompson 2021). Here, environmental humanities offers a wealth of scholarship, starting with the eponymous journal in that field (Rose *et al.* 2012).

Another layer of ecological thought and method should be brought further into medical humanities scholarship, and that is where the term ‘exposome’ comes in. This term was coined by epidemiologist Christopher Wild in 2005 and defined as encompassing ‘life-course environmental exposures (including lifestyle factors), from the prenatal period onwards’ (Wild 2005: 1848). Wild developed the concept of the ‘exposome’ to call for greater research investment in the environmental side of the ‘gene:environment equation’ in cancer epidemiology. Part of the impetus was to draw attention to the role of variables beyond the level of

genetics that play a far more influential role in health outcomes (this is the long-standing assertion of research in social and behavioural health as well). This basic gesture, to move beyond the biomedical framing and ever outward to gain a fuller understanding of the factors in health and disease, is consistent with long-standing principles in medical humanities, and is needed to help us better understand complex syndromes such as long COVID, and specific vulnerabilities to future EIDs. The term ‘exposome’ also usefully signals that our daily exposures to structures of health datafication have consequences for our well-being, it gestures towards critical research on environmental racism and the consequences of unequal exposure to surveillance and harm, and highlights that exposures to data pollution are so ubiquitous that they should be considered as determinants of health (Browne 2015).

By integrating the concept of the digital health exposome into medical humanities, researchers can further expand the domains of ‘health’ considered by the field, engaging with the ecological and the Indigenous, ‘One Health’, as well as ‘more-than-human digital health’ (Lewis *et al.* 2018; Lupton 2022; McClymont *et al.* 2022). One potential direction that this approach could lead is into the realm of ‘green healing spaces’, both the idea of changing the built environment to incorporate more healing elements such as living plants, quiet, soothing sounds instead of beeping, dim, soft lights instead of fluorescence, outdoor spaces, art and so on. A WHO report published in 2019 documented thousands of studies showing that the arts played a major role in the ‘prevention of ill health, promotion of health, and management and treatment of illness across the lifespan’ (Fancourt and Finn 2019). Numerous arts in health projects on the Translational Humanities for Public Health site reinforce this point.

Another direction for ecological scholarship translating across the data-narrative divide in medical humanities could be towards the ‘digital detox’, that is, the purposeful creation of environments that are disconnected from the data grid (Tactical Tech 2021). This latter may be especially helpful in the realms of privacy, security, mental health and well-being, but an overhaul of the typical American hospital/rehab environment in this direction would also likely result in more human-to-human contact, sensitivity to qualitative rather than quantitative measures, and movement away from the fragmentation of data documentation practices that currently prevail in US medicine (Engineer, Ida, and Sternberg 2020). Moreover, a data framework informed by Indigenous practices, such as those proposed in ‘Making Kin with the Machines’ (Lewis *et al.* 2018), would also suggest a more integrative view of the place of data-driven practices within complex networks of care, including the terrestrial ecologies of healing spaces. Finally, data pollution and environmental destruction continuously threaten to undermine our daily existence, and for this reason alone, they should be factored into defining the purpose and greatest impact that the field of medical humanities can offer. These terms offer a shared terrain of concern across many fields of research and practice, and a generative meeting space for multidisciplinary collaboration.

## CONCLUSION

To fully enact a translational model of care that improves the lives of patients and decreases social inequalities, medical humanities must develop new methods for working with four distinct constituencies: communities, policymakers, technology developers and technology companies. The adaptation of biomedical translational methods discussed throughout this essay would enable medical humanities to develop strategies for

translational work that take seriously the view of co-creation of knowledge with local communities, which requires collaborative definition of research priorities, methods and participants. As noted, some translational medical humanities projects have already begun to work with policymakers, at hyper-local levels (eg, hospital and health system administrators), local levels (city and state governments), and nationally, enabling research findings to influence changes in social and healthcare systems. As discussed in relation to the challenges of bridging the data/narrative divide, one of the most pressing but also least developed fields of translational medical humanities is that which entails working with technology developers. One major objective in this domain would be to integrate human-centred and patient-focused design into the creation of software and devices, and to prioritise development of tools that advance equity and address the most pressing problems for patients. A final domain of translational work that requires significant development involves working with corporations involved in healthcare ecosystems. This site of engagement presents perhaps the most difficult challenge of translating critiques of the business of healthcare into research questions of relevance to companies whose interests balance financial priorities with the necessary altruism of caring for others.

While the field of medical humanities already engages with some of these constituencies, a robust translational agenda would require new methodologies for research and teaching that extend across disciplinary boundaries beyond the humanities and medicine. This bridging is needed to ensure that future generations of students, researchers and healthcare professionals carry these new translational approaches into their domains of practice. Ultimately, this will require a reimagining of some sectors of the academy itself, for example, by integrating collaborative, participatory learning with community partners into the core learning outcomes of medical and other humanities programmes. Doing this would build public engagement into the infrastructures of learning, and, if extended to the requirements of computer science programs, for example, would ensure that programmers learnt some core principles of medical humanities alongside learning how to create the next generation of digital health technologies. Students and researchers might be required to learn new approaches to scholarly and scientific communication, drawn from creative writing and digital story-telling; integration of engineering practices, drawn from human-centred design and applied ethics; and novel approaches to addressing health disparities in the private sector, drawn from business ethics. All of these translational efforts would integrate humanities perspectives into adjacent fields, while also integrating the core concerns of a broad range of stakeholders that will likely challenge some core perspectives in the medical humanities, leading, if successful, to new, transdisciplinary approaches.

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#### ORCID iD

Kirsten Ostherr <http://orcid.org/0000-0002-6425-9527>

#### NOTE

1. While fully cognizant of current debates about the terminology of 'medical' versus 'health' humanities (Jones *et al.* 2017), this essay chooses to use 'medical humanities' to clarify the argument for extending the paradigm of biomedical translational science from 'medical' settings into broader 'health' domains and community settings. This choice of terminology allows the essay to trace out pathways of interventions that move through medical and health settings, while noting that the boundaries between these realms at times perform important work.

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