



The Social Life of Health Data

Health Records and Knowledge
Production in Ghana

Edited by
Alena Thiel
Samuel Aniegye Ntewusu

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Developing an Interdisciplinary Reading of Ghanaian Health Data Histories: An Introduction

Samuel Aniegye Ntewusu and Alena Thiel

1.1 INTRODUCTION

Health data is indispensable for the routine operation, monitoring, and planning of interventions in public health systems. Within population data ecosystems at large, administrative health registers are often among the most sophisticated systems, as the “ability to measure and monitor the health of populations” in terms of epidemiology, demography, and biostatistics is a prerequisite for public health decision-making (AbouZahr & Boerma, 2005). Ghana’s health information system in particular has attracted intensive foreign donor attention, fuelling investments in infrastructure and capacity. These investments, however, are

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often made without much critical interrogation of the proliferation of multiple (and at times competing) infrastructures, platforms, and standards (Erikson, 2012), or their far-reaching impacts on Ghanaians' lives—for example, as seen across the globe in the restrictions in mobility accompanying the drive for real-time monitoring of the Covid-19 pandemic (Ntewusu, 2020; Thiel & Agyekum, 2023). The present volume was inspired by a collection of researchers interested in various aspects of Ghana's health system, and by the observation that practices of recording health in Ghana's colonial past and the country's present-day health system have remained understudied. The present volume seeks to address this gap by detailing from multiple disciplinary angles the procedures through which Ghanaian health professionals organise knowledge about health, and how these practices are both conditioned by larger societal developments while at the same time “retroactively” (Desrosières, 2015) impacting Ghanaian society.

Zooming in from different disciplinary angles, we position health-related knowledge practices—whether oral, written, or digital—as central to the maintenance of colonial and contemporary power relations. We also show that the forces of standardisation at various moments of Ghana's history have co-opted plural medical practice in diverse ways, e.g. in the capture of oral traditional knowledge by colonial medical officers for the treatment of tropical diseases, or in the professionalisation of traditional medical practice through the mobilisation of quantitative forms of evidence. Hence, the case studies in this volume paint a complex picture of how standardisation and medical pluralism interact in practice.

Where the literature has presented the diversity of health data production in Ghana and other developing countries, it generally foregrounded the issue of access to basic health care in the context of low penetration of health services. For example, studies on telecommunication and health care have covered the remote provision of midwifery, advice services, and verbal autopsies (Al Dahdah et al., 2015; Duclos, 2015). Information Systems research on the other hand has given intensive attention to the genealogy, setup, and operation of Health Information Management Systems (Gyaase & Bright, 2019; Miscione & Staring, 2009; Sæbø et al., 2011); the digital labour required to populate such registers (Siyam et al., 2021); the participation of private sector innovations (Burchardt & Umlauf, 2023); and other forms of non-clinical institutions in the datafication of health (Feldman et al., 2018; Ruckenstein & Schüll, 2017). However, little attention has been paid to registration practices and

“the ways that data technology enables or constrains human experience” (Ruckenstein & Schüll, 2017, p. 271). This is highly problematic, as “[p]opulations do not simply exist as objects of knowledge, but are products of data practices” and “particular technologies of counting and modelling” (Hoeyer et al., 2019, pp. 462, 466). For this reason, our argument departs from recent studies of health information systems that have predominantly focused on management practices. Instead, we seek to contribute to the field our observations around the social dimensions of health data practices. Scholars who have adopted critical social science approaches have certainly advanced the debate around international efforts to impose global health standards (e.g. as explored by Patterson, 2018; Prince, 2014) and the particular role of metricisation therein (Adam, 2016). Biruk’s *Cooking Data: Culture and Politics in an African Research World* (2018) particularly serves as an inspiration for detailing in a thick, qualitative manner both the global interconnections and local situatedness of data practices in a single country case, in this case Malawi. We take inspiration from Biruk when zooming in on the case of Ghana to describe at proximity the expert knowledges, materialities, and implications of health data collection across historical periods and shifting socio-political alignments. In distinction to Biruk, we go beyond the level of global health research and instead open our investigation to the micro-processes in the Ghanaian health data system at large, along with specific attention to its infrastructural arrangements, and the convergence of several materialities, or types of registers, participating in the constitution of composite health realities.

Before elaborating the critical advancements made by the contributors to this volume, we deem it necessary to clarify how we conceptualise the multiple knowledge practices that accompany the varying interventions in health that are presented in this volume.

1.2 HEALTH DATA, KNOWLEDGE, INFORMATION: DEFINING THE CONCEPTS

The arguments presented in this volume differentiate between the terms health information, health data, knowledge production, and registration practices. Hence a word regarding definition is in order. Specifically, when we talk about information, we follow Harold Garfinkel’s socio-logical theory of information (Garfinkel, 2008). Here, information is

characterised, first, by its actual, rather than merely conceptual properties (Rawls, 2008, pp. 45, 46). It must, in other words, be transformable and able to be “stored, owned, lost and found” (Rawls, 2008, p. 46). Different from knowledge, which is widely shared, information is distributed unevenly across populations and must therefore be allowed a degree of incompleteness, ambiguity, and even “ignorance” (Rawls, 2008: 46). Garfinkel’s theory is particularly relevant to our present argument, as it draws our attention to the social nature of information. To be intelligible, information manifests itself as a clear order of symbols, signals, and messages by “those actors who are engaged in a situation together and committed to a shared practice (...) There is no information without an order generated by actors orienting towards rules—or constitutive practices—that they use to produce that order” (Rawls, 2008, p. 47).

Similar to information, data too is profoundly relational in its nature. If information is only meaningful in the context of agreed upon orders, the concept of data points us to “the raw material produced by abstracting the world into categories, measures and other representational forms—numbers, characters, symbols, images, sounds, electromagnetic waves, bits—that constitute the building blocks from which information and knowledge are created” (Kitchin, 2014, p. 1). To describe the nature of data, Kitchin (2014, pp. 4–9) differentiates between data’s form (text, images, etc.), organisation (structured, semi-structured, unstructured), and kind (indexical, attribute data, metadata), among other dimensions. For our purposes, it suffices to understand data production as a social activity geared towards some form of value generation, e.g. with the aim to further abstraction, reproducibility, efficiency, and rationalisation, but possibly also political values such as those tied to the process of territorialisation.

Data practices, then, signify the combined practices involved in the production of data for various types of intervention. This includes the “selecting, formatting, editing, storing, cleaning,” but also the “standardisation, and classification, as well as the development of methods for retrieval, analysis, visualization, and quality control” of data (Ruppert & Scheel, 2021, pp. 30, 31). Data practices hinge on diverse assemblages of material technologies, as well as methods, expertise, and forms of organisation. At the same time, they entail distinct logics, struggles, and contestations, but also hopes, trust, and claims to legitimacy, truth, and validity (Ruppert & Scheel, 2019, p. 234). This is relevant as, oftentimes, data practices support the logic of testing, which

has become a critical practice to know unknowns, identify risks, and orient actions at a time when often interpretations of the evidence base rather than the political imaginary of a better world generate legitimacy for policy decisions. Sometimes, however, experimenting, testing, and measuring produce disorienting results that do nothing to resolve a situation. (Beisel et al., 2018, p. 109)

We concur with these authors' analysis that testing represents an effort "to make the world more predictable," while also silencing the limits of the test. "[A]s a technique of knowing, it limits itself to comparing a current situation to a standard that was established in advance," while necessarily hiding this assumption to achieve universal applicability (Beisel et al., 2018, p. 109).

Positing health information, knowledge, and data as fundamentally social phenomena that performatively hide their world-making impact requires us to explore them in light of their specific contexts of production. Here, the focus on the work of health registration, or the writing of health, provides us with a useful conceptual avenue. Specifically, we follow anthropologist Susan Reynolds Whyte (2011, pp. 34, 30), who notes that writing is an "integral part of healthcare" that "opens relational possibilities for those who write and those who are written." At the heart of this is the production of "data and treatises that abstract and objectify that knowledge" as it is written into material form, transmitted, and disseminated, while also creating "a more lasting artefact, a medical record that is both a history and a time line into the future" (ibid., p. 36). Whyte's argument not least points us to the authority of written knowledge over other forms of knowing—which is an observation that is central to our case studies as well—and its "capacity to mediate such relations" of power between government and communities while engaging with multiple publics in the "therapeutic marketplace" (Whyte, 2014).

In this edited volume, we propose using the term health registration in a broad fashion, as any measure to contain, in a systematic manner, data on patients and health-related events. Health registration "unfolds on a number of different scales and registers, including data-driven medical research and public health infrastructures, clinical health care, and self-care practices" (Ruckenstein & Schüll, 2017, p. 216; cf. Feldman et al., 2018). Health registration practices, as Sund et al. (2014) have shown, further differ widely in coverage (varying from a total registration to

a population sample and from national to regional or local coverage); modes of data collection (such as data collected for various reasons, from economic and administrative purposes to more strict epidemiological purposes); methodology (e.g., registration by the health services or by interviews with patients or population groups); and temporal dimensions (with data being collected continuously or repeatedly with some time intervals). Additionally, we here refer to historically varying types of data and explicitly seek to foreground the material and techno-political shifts that accompany and embed health registration practices at various moment in Ghanaian history. In so doing, we seek to shed particular light on the intersection of materialities of knowledge, the standardisation of health data, and plural medical practice.

1.3 BETWEEN STANDARD AND PRACTICE: MEDICAL PLURALISM IN INTERDISCIPLINARY PERSPECTIVE

Central to our argument is the contributors' common observation that practices of recording health seek to impose (often implicit) standards. Among these forces of standardisation, Erikson (2012, p. 368) has identified the central role of the global health business, along with its administrative structures and technological means of collecting increasing amounts of data. Besides this central vector, the contributors to this book expand our view of the forces of standardisation, foregrounding, among other vectors, an early interest in global health during colonial times (see Tasin, Chapter 2 in this volume). Health standards further originate from international best practices in disease control and prevention, such as standard case definitions and data standards in health reporting. Upon their translation into Ghanaian contexts, these standards encounter plural medical practices, knowledges, and relations of care. Medical pluralism here is understood as the coexistence of multiple conceptions of health and healing, as well as the recognition of their embeddedness within specific socio-technical settings. The chapters in this volume reject the notion that Ghanaian medical professionals blindly submit to globally circulating registration tools and formats. Instead, they illustrate these experts' attunement to, and translation and localisation of standards into the Ghanaian realities. The contributions to this volume present arguments about how different assemblages of health registration—that is, forms of measurement and testing, oral and written practices of retaining information, and the arrangements of data infrastructures, personnel,

and expert knowledges at the core of these registration practices—are mobilised and adapted to diverse ends.

In the interest of attuning to the plurality of actors, infrastructures, and practices of health registration, we train an interdisciplinary lens onto the question of how Ghana has generated an apparatus for capturing knowledge about health since colonial times, and how these processes have come to intersect with other clinical and societal transformations, such as the development of ideas of global health, or the ongoing digitalisation of health interventions. Our argument joins perspectives from history, medical anthropology, public health, as well as anthropology, to investigate the layered nature of knowledge infrastructures in Ghana's health domain. The value of such an interdisciplinary approach to knowledge practices is that it probes, from different analytical entry points, into the phenomenon of health registration, and hence allows us to connect its "living" "material," and "technical" elements (Duclos, 2015). Yet, interdisciplinarity also implies "a variety of boundary transgressions," requiring us to transcend deeply internalised "rules, subjectivities and knowledge corpuses" (Barry and Born 2014, p. 1). Despite their varying perspectives, the chapters in this volume align not only through their focus on a common country case, but crucially also through the common goal of providing thick empirical contextualisations of the observed knowledge practices.

We bring together analyses of oral, written, and digital forms of inscription to present a more encompassing account of how experts and professionals—ranging from colonial health officers to contemporary medical practitioners, health policy planners, CSOs, and patient organisations—have established an apparatus for data collection regarding health, throughout Ghana's history. Our first analytical angle is rooted in the historical method. The book's commitment to present the genealogies of health registration taps into well-established descriptions of the key trends in the historical transformations in public health provision. Prince (2014) describes the shifts from early attempts of colonial administrations to improve public health to the post-Independence, developmentalist vision of government-controlled universal healthcare access, and more recently, the rise of private, nongovernmental, and humanitarian service provision following the structural adjustment period in the 1980s. Health care and health data "in colonial Africa was intimately tied to a repressive, coercive, and violent system of power and knowledge, which reached deep into