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# Materiality, Health Informatics and the Limits of Knowledge Production

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**Abstract.** Contemporary societies increasingly rely on complex and sophisticated information systems for a wide variety of tasks and, ultimately, knowledge about the world in which we live. Those systems are central to the kinds of problems our systems and sub-systems face such as health and medical diagnosis, treatment and care. While health information systems represent a continuously expanding field of knowledge production, we suggest that they carry forward significant limitations, particularly in their claims to represent human beings as living creatures and in their capacity to critically reflect on the social, cultural and political origins of many forms of data ‘representation’. In this paper we take these ideas and explore them in relation to the way we see healthcare information systems currently functioning. We offer some examples from our own experience in healthcare settings to illustrate how unexamined ideas about individuals, groups and social categories of people continue to influence health information systems and practices as well as their resulting knowledge production. We suggest some ideas for better understanding how and why this still happens and look to a future where the reflexivity of healthcare administration, the healthcare professions and the information sciences might better engage with these issues. There is no denying the role of health informatics in contemporary healthcare systems but their capacity to represent people in those datascares has a long way to go if the categories they use to describe and analyse human beings are to produce meaningful knowledge about the social world and not simply to replicate past ideologies of those same categories.

**Keywords:** knowledge production · health informatics · critical analysis · materiality

## 1 Introduction

In this paper we argue that while the conceptual distinction data-information-knowledge (and wisdom) [1] is ubiquitous in the information sciences, it remains, poorly understood and actualized in some informatics sub-fields, and in particular in health informatics. We then consider how the political economy of new technology can be taken for granted or unexamined in ways which serve to naturalise the ‘inevitability’

of technological innovations [2]. We show how the teleological orientation of the health sciences, as a seemingly dominant secular mythology of progress and virtue is in actuality compromised by the carrying forward of some questionable intellectual constructions (including concepts, ideas and ideologies) and the failure to integrate other emergent information science constructions that are prevalent outside of health informatics.

We go on to explore number of specific examples of a problematic aspect of health informatics as a site of skewed knowledge(s) about human beings as individuals and as social beings as well as loci of illness and disease. These examples demonstrate the persistence of deeply ideological social constructions reproduced through the: taxonomies of database structures applied in health informatics (with an absence of sustained critical inquiry on the same); highly reductive nature of what passes for patient information in many of these systems and: data exclusions that can occur in establishing and maintaining such systems.

Leaving aside important questions of political and organizational motivations in the particular, we focus primarily on the structuration of data inputs to information systems and especially health information systems with their materialist consequences for knowledge production, in general, utilizing case studies such as the 'hot spotting' of vulnerable groups. Taxonomic structures and classificatory systems about human beings are deeply implicated in the support and reproduction of historical social hierarchies and inequalities, by creating the illusion of 'objective scientific' (that is, empirical and therefore by implication or assertion ideological neutral) discussions of social divisions such as class, socio-economic status, 'race' and the like [3, 4]. We discuss some examples of why and how this happens as well as the ways in which this limits (and delimits) the boundaries of scientific practice in the health informatics domain. The central relationship between theory and practice is also key aspect of this discussion. The issue of not asking certain types of questions or failing to analyze particular kinds of data we leave for a later discussion.

Lastly, we propose that to make claims to the production of scientific knowledge, including medical scientific knowledge, requires that practitioners meet certain standards of practice in their work. We question whether a technical domain making claims to scientific status and scientific knowledge production should exhibit a greater reflexivity in relation to its implications and application to social issues than is currently exhibited in health informatics. Disciplinary integrity requires a science to do more than simply produce the established knowledge architectures and to inquire more actively on the inclusions and exclusions practiced within the sub-disciplines that the discipline supports. The information sciences have shown significant activity in this area as their methods and theories have expanded in recent decades but, we maintain, this remains a poorly developed aspect of health informatics which remain largely subordinate to, particularly, medicine as the dominant knowledge production and authorizing paradigm in the health sciences generally.

## 2 Informatics as Social Scientific Practice

The pervasiveness of information systems and their role in complex scientific and social policy and practice often begs the question of how they are constituted and used in relation to their objects of study. This is especially relevant in the context of the collection of data and information *about* human beings where the study of humans is, usually by omission, assumed to be as developed as those which are applied to the collection of physical phenomena.

Information systems are designed and developed to collect, structure and analyze data and information to produce domain-specific knowledge, through the application of sets of formal methods and processes including ontologies, classificatory schemata and information taxonomies [5]. Their essential purpose is not simply or solely the neutral collection of administrative or research data but rather the production of knowledge (that is actionable, meaningful data and information) [6] about some aspect of the world.

Information systems are designed to produce a relatively discrete epistemic domain which informs their audience about some selective aspects of the human and/or natural worlds (meaning philosophical ontology not information ontology in this context). Yet many such systems default to the collection aspect, some to the analysis aspect, and a far lesser proportion to the explicit production of knowledge, in spite of claims to the contrary.

These collection processes range widely from project briefs and business cases on through to interoperability criteria and data sharing protocols. This is a continuously expanding field because the technology, its applications and its users are all in a seemingly un-ending state of development, production and innovation. Growth and diversification are central features of the information sciences in the digital information age [7]. Recent developments have led to the ‘big data’ construct in which the growth in data is characterized by volume, variety, velocity, veracity, variability and value [8, 9]. The big data construct currently emphasizes the process or processes associated with the acquisition of data, rarely exposing information structures themselves or the processes associated with the collection or classification of such data. This acts we argue, to create what Bourdieu calls an *illusio* [4], that is an implicit belief in the value of the data collection process, and at the same time, to hide (through the creation of ‘doxa’ or taken for granted-ness)[4] the socially influenced development of the methods themselves: including how data and information are collected; how terms and terminologies are defined; the choice to include or exclude particular information; which individuals, groups or populations are included or excluded in any given collection; and even how data are ‘cleaned’ [10-14].

Key to any collection process are the decisions made to exclude or include certain kinds of data. This can be seen in some cases, as a mechanism through which there is an acceptance or rejection of the *prima facie* legitimacy of certain kinds of information. Even the generic claim in the research and information sciences to be collecting ‘raw’ data can be seen as highly problematic and contestable. As Gitelman argues in the aptly titled *Raw Data is an Oxymoron* [14, p. 3], “Data need to be imagined *as* data, to exist and function as such, and the imagination of data entails an interpretive base”. All data

collection processes are predicated on specific disciplinary and institutional reasoning and constraints, including two of the most common - cost (How much can we afford to collect? Whom can we afford to include in the collection) and belief (What data are important to collect?). This is usually represented as an objective, rationalistic process that produces data uncontaminated by the collectors' and their commission institutions practices and beliefs. Yet such processes necessitate an explicit or implicit rationale for the inclusion and exclusion of certain data or information from the initial development of design through to the final analysis processes.

The other side of this equation, as noted above, is the large amounts of data and information that are not collected at all. No information system, or its producers, is so naïve as to suggest they collect everything. The capacity to collect data is finite even if the potential data domain or sub-domain is seemingly infinite. Exclusions are necessary and even data collected via remote or mediated technical systems automatically exclude the majority of the available information, as information systems are themselves finite [15] and as indeed are human perceptual and analytical capacities [16]. The point here is not that *some* data or information will need to be excluded, but that the way in which this exclusion is consistent with the historical and persistent exclusion of minority groups, including women, in research studies [17, 18] and from big data environments, such as national censuses, all the way down to the level of the inclusion or exclusion of specific “non-human” participants [19, 20] and the researchers themselves [19].

The largely unproblematic illusion that big data does or will somehow by-pass this social, systematic and systemic flaw by the sheer amount of data collected, remains a dominant feature of its value, and virtue, claims. Big data analysis relies on the same systems that systematically exclude certain types of data or individuals, for example census data, where definitions of ethnicity, have been shaped, accepted or rejected according to the power relations within and across countries at any given point in time [21-23]. In this sense, the production of data can be understood as a form of practice, in the Bourdesian sense, that is a dialectic between the social structures and systems within which data are generated and collected and the human and organizational agency which determines what should be deemed data, and which data are worthy of capturing and preserving [24, 25].

Many data collection systems have been limited by the state of technology available at any specific point in time, this is understandable. But more problematic has been the tendency to ignore aspects of the wider ontological domain in order to validate existing technologies. This can have the effect of constraining epistemic frameworks to what can be physically captured and analyzed. Thus broad physical and social science questions can be delimited by the physical and conceptual tools currently available. In this sense, technical systems (in both the ontological and epistemological sense) can constrain or narrow the growth of knowledge because the investment in their explanatory power requires that their very real limitations are minimized in discourse about them [26].

### 3 Problematizing Health Informatics

Health information systems tend to support two major knowledge production domains. The first is clinical practice and its associated sub-domains including pathology, pharmacology, radiography and so on. The second is characterized by the administrative data required by funders, including governments and insurers, usually central to administrative practices such as financial reporting and, in association with classification systems, some data about patients (often summary demographics) and their conditions utilizing the International Classification of Disease and a variety of related taxonomies [27].

However, it is reasonable to suggest that *patients* are not the primary focus of either of these systems and that this might be one reason why the reform of patient information systems, including the development of electronic health records and portable patient records, have proven so problematic in practice. On one side, clinicians may feel that they 'own' their data systems and the information in them while on the other, funders and regulators feel that they own their side of the informatics equation [28: see both article and correspondence]. Since neither party sees *patient* information as especially central, the idea of divesting any aspect of that ownership (and its attendant organizational authority) is viewed poorly by both parties.

In health informatics this problem is compounded by a number of factors. Health informatics focuses on the applied aspects of clinical and administrative information work, at times shying away from the theoretical as though tacitly accepting the idea that knowledge production does not necessarily, implicitly or explicitly, involve theory [29]. As a result, such work can be presented as though the researchers have or take no position on the social and political issues that any health system produces and reproduces in its work [30, 31].

At the same time, health systems take social categories to be as materially real and concrete as the categories used for biological and physiological phenomena, pathological indicators, diagnoses and so on. In other words, there is a deep commitment to the materiality of data that supports existing knowledge structures and ideological positions on the nature of knowledge and its importance in the clinical and administrative aspects of health systems and health informatics.

This commitment to counting and collecting is partly a result of the deeply social role of medicine and nursing since their development as central activities in healthcare, mostly developing in the nineteenth century during the emergence of the modern territorial nation state [32, 33]. Public health systems and health insurance schemes were built in part to support the concept of the nation as a healthy body and this conceptualization of the nation as a singular entity, containing a structured arrangement of multiples, emerged at the same time as scientific racism and eugenics, producing an interlinking of these concepts that persist down to the present day [34, 35]. The result can be a blurring of the significance of the embodiment of difference between the cytokine count in a biopsy as an indicator of the presence of cancer or the formal and informal use of socio-historical categories of "personhood", and the status of such persons, and the lived experience of the individuals involved [36].

## 4 Missing the Meaningful: Place, Space and the Current Limits of Health Informatics

If, as argued here, health information systems tend to be controlled by the dominant medical perspective then it seems fair to suggest that the knowledge such systems can (be permitted to) produce is likely to be ‘approved of’, that is accepted as doxa, by medicine. Thus there is already a central aspect to the way in which health information systems are involved in a process of co-production. They legitimate and reinforce the kind of data, information and knowledge that medicine as a discipline finds acceptable. Knowledge that falls outside of these established and often conservative parameters is much less likely to impinge on this dominant paradigm [37].

There is already an awareness that the focus of many health information systems is not about people as individual human beings. Indeed as Simpson and Novak have observed even Electronic Health Records (EHRs) collect comparatively little data about the broader social and economic context of patient’s lives, much of which would be relevant to their potential illnesses, treatment and possible cure [38].

The micro focus of clinical medicine is poor at integrating the broader social epidemiological context of patients’ lives that often impacts directly on their health status. The recent work of Jeffrey Brenner in Camden, New Jersey is an example of how complex systems can collect patient data, such as address, and fail to use it in any clinically meaningful way. Brenner, an emergency department doctor, spent his evenings developing a spreadsheet of his department’s ‘superutilizers’. He was able to show very quickly that a very high proportion of people with chronic health conditions, low incomes and limited health insurance were all co-located in one public housing building in Camden. Their emergency department visits were far above the average, costing the health system itself considerable amounts of money and leading to a cycle of ill-health for the patients who always sought treatment late in their acute episodes. As a result of identifying this single, ubiquitous fact – the patients’ address – he was able to target local interventions which limited or even prevented the need for and use of expensive emergency services and which have resulted in significant reductions in utilization [39] and improvements in morbidity.<sup>1</sup>

While the idea that location is important to health has most recently been packaged around the idea of ‘hot spotting’, it is well known and understood across many disciplines, including medicine, public health and geography. John Snow’s famous 1854 cholera map is, in effect, an exercise in medical and public health ‘hot spotting’ [40]. Yet what the hot spotting study (and the media coverage and funding attention it has attracted) shows is that while the general importance of location may be understood, and locational data routinely and systematically collected from patients, the analysis and application of even the most basic quotidian data was dependent not on information systems but on curious and committed individuals who went beyond the information system as it stood.

The failure to integrate and act on broader contextual information about a patient’s (or class of patients) social environment is clearly still an issue for health systems and

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<sup>1</sup> see <http://www.rwjf.org/en/about-rwjf/newsroom/features-and-articles/Brenner11.html>

many of the health professions. Even those health professionals who have the opportunity observe the lived environments of patients such as occupational therapists and community geriatricians, have a limited capacity to collect and apply social information to the bigger picture. The information systems used for acute care systems and community health systems, for example, do not always interact well or even at all. Data collected about medical errors (including errors of omission where patients do not obtain the care required in a timely and appropriate fashion) do not routinely include fields for patients' identity or language spoken. The various emphases of these information silo systems are only rarely what could be called a 'system' in the usual formal sense of the idea. Rather, the complex historical development of such systems, often disconnected and serving the very different needs of very different users, can have little at all to do with lived experience of patients.

One final aspect emerges in the information science domain from this lack of understanding of and capacity to apply locational or place inference in the clinical and administrative domains. The many sciences that currently work with locational information and analysis as central to their activities all emerged at about the same time as medical informatics. They are all largely a result of advances in computational information science that took place during and shortly after the Second World War. The combination of computational science, aerial surveillance and navigational telemetry required for military rockets to travel from one place to another all developed in the same window as medical informatics.

The potential knowledge development associated with the spatial and locational aspects of health that could have occurred did not take emerge, and health and medical geography remain entirely marginal to work conducted in mainstream healthcare and health information systems. Despite these silos the development of geographic information science, including both theory and computer-software approaches, emerged in the 1960's and has gained momentum in recent years as digital technologies have developed and expanded. Goodchild felt that the field had developed sufficiently well to warrant the term 'geographical information *science*' which took the field beyond the hardware-software computer system nexus to one of specific types of knowledge production [41]. In the last decade or so, the emergence of 'virtual earth' software environments such as Google Earth have made the integration of spatial coordinates, of varying levels of precision, a much more viable possibility that at any time previously. Soon we are likely to see the expansion of the concept of 'place-based' knowledge in a variety of sciences and yet the question remains as to what extent this will be reflected in healthcare where place has, for so long, had no place [42].

In the previous sections we have alluded to the way in which the processes of collecting, categorizing and utilizing data is directly influenced by the limits within, placed on, and utilized by, the field of health informatics. One of the issues with current knowledge production is the way in which the field has recently emerged from the basic forms of linking up and bundling together of a variety of clinical and administrative information systems within medicine and healthcare management [43]. Yet, the very definition of the broader (not just medicine) field of health informatics often defaults to a form of medical informatics due to dominance clinically, and more specifically medically, trained personnel in health information management in this field [44, 45].



The convergence of medicine and information technology has a long history of problematic results with many systems experiencing failures in both the development and implementation phases with a variety of clinical and other consequences [46, 47].

An example of how health informatics can lag behind external developments can be seen in the (to date) limited incorporation of the dimension (and theory) of space within health information systems in particular and health information analysis more generally. Geographic information science and technology have developed rapidly since their emergence in the 1960's. Many sciences make active use of GIS and related software and methods in their work as can be seen from archaeology and anthropology to climate science [48].

The material world that scientific practices aim to understand and explain is multi-dimensional including three-dimensional (x, y, z) space, temporality (t) and scalar issues as a fifth dimension as can be seen with any map or time series map [49]. The two-dimensional file requires a huge range of reductionist processes to make that material world conform to traditional information architectures but this process of reducing or even deleting complexity to fit current technologies means that some changes in the field are passing some disciplines by. Indeed, we would argue, reduction *as* representation is integral to much of what passes for knowledge production across a variety of disciplines.

In the health information sciences the spatial dimension is a fringe area of interest. Many health information systems do not collect useful spatial data or index patient information in analytically useful ways. The developments of spatial sciences are poorly incorporated into health informatics and yet health information systems are increasingly extending outside their traditional domain of the acute care hospital, through the emergence of tele-health, m-health and e-health. These new fields reflect the controlled extension of health informatics via the acceptance and incorporation of certain, selective, aspects of rapidly developing technologies associated with increasing bandwidths, mobile devices and remotely accessible database environments via the cloud. Most of these technologies are highly enabled spatially (e.g. GPS, RFID etc) and many uses have been found in other industries for these spatial capabilities. The potential of space and place factors are on the rise in health informatics but that the a-spatial construction of health informatics around the hospital environment means that the incorporation of spatial thinking is remains limited.

## **5 The Power of Taxonomies and Categories in Knowledge Production**

The creation and collection of data, information and knowledge occurs, as we have previously discussed, through the use of material and conceptual technologies. One such technology is the use of taxonomies and categories. Bowker and Star have argued that taxonomic systems can have a deep and abiding influence on how we produce accepted knowledge about the world and that the values we attach to concepts constructed and represented through such taxonomic processes [5]. The application of taxonomic processes to human beings can have both a reductive and productive aspect, in

that self-definition can be deeply influenced by the social definitions that are supported by the purportedly objective taxonomies of the sciences.

Classification is clearly part of how humans function cognitively as human beings. But classification also has its own consequences in that, especially since the 19th century, the elision between scientific and social taxonomies has become difficult to separate and people have become used to, and some would argue indoctrinated in, accepting the authority of science being applied to complex social phenomena without clearly distinguishing between the social and scientific domains [50, 51]. The pervasive nature of classification systems and taxonomies often possess an implicit moral hierarchy (poor health behaviours, bad lifestyle decisions, low health literacy, non-compliance) add scientific weight to socially ordered systems of surveillance and control [52, 53].

Hacking offers an explanatory process for how this knowledge production process operates [54]. First, specific processes permit the production of certain kinds of knowledge through ‘engines of knowledge’ which are, in order: count; quantify; norm; correlate; medicalize; biologize; geneticize; normalize; bureaucratize; and resist. The last of these is perhaps more indicative of efforts at countervailing knowledge production but, we would suggest, relies on the individual’s capacity to recognize the application and power of these other engines in shaping not only how individuals are taught to think as individuals and as social creatures but also their ability to shape and delimit our environments, in Bourdieu’s terms, their habitus [55]. To identify a ‘false consciousness’ that requires resistance an individual or group needs to have an awareness that these are generated engines of knowledge and not objective data, information and knowledge about the material world.

Systems such as the International Classification of Diseases (ICD) [27] and the Diagnostic and Statistical Manual of Mental Disorders (DSM) [56] are two of the more highly recognised classificatory systems in use in the health sciences generally. Both of these experience considerable internal contestation and debate but this is often unclear to external observers who are used to accepting knowledge taxonomies as ‘given’ [57-59]. The power of a successful classification process and taxonomic edifice can be seen in its unquestioned acceptance outside of the field of its production. This power has, as Hacking observed, the ability to produce new types of people, as well as to shape the way in which such people are permitted to exist. There is a strongly normative dimension to the taxonomic process because it is a powerful form of knowledge production that has, once authorized, the capacity to reproduce, defend and extend itself.

Perhaps more important than this is the capacity for such systems to delimit the scope of further developments in their fields and to regulate and even police the boundaries of knowledge production. Hacking’s first engine – that of counting, as we have shown, is neither automatic nor neutral, and the progression of data through subsequent engines, and their conversion from packets of ‘facts’, through contextualized information and actionable knowledge, to the point where they ‘warrants’ bureaucratization reflect wider social and power relations, and cannot be seen simply as a neutral or positive process of information gathering. By omission or commission, the transformation of data in health as in every other sector, has real and significant implications for those whom the data is meant ultimately, to represent.

## 6 Digital Materiality and the Production of Knowledge

One of the central identifying aspects of contemporary health informatics practice is the gradual expansion of digitally collected data within system that were historically wedded to the written document. Resistance to digitization has been strong in some parts of healthcare and data control is a central aspect of the shift to digitization in medical practice.

Patient safety information can be seen as another example of how information systems can be compromised by disciplinary politics and utilised to protect the interests of practitioners at the expense of those they were established to assist. The introduction of systems designed to collect information about mistakes, errors and failures in health systems has long been in development [60]. Even now, many of these systems are problematic because the definitions of harmful practice and harmful outcomes are still largely administered by those within the healthcare system and public involvement, while increasing, remains limited [61]. While they may encourage reporting, studies have found that small scale direct record review – rather than large scale reporting – is more accurate in identifying major errors [62]. In addition, as previously mentioned, many of these systems take a technical perspective that minimizes the collection of data about the patient as a person and instead defaults to an emphasis on the collection of information about ‘critical incidents’ and the application of an associated terminology of risk. These systems can inadvertently minimize the materiality of the patient (and the clinicians) to whom errors occur and increase, preferentially, the nature and location of the ‘incident’ in a terminology that defines these events as failures of abstracted and over-arching systems rather than as the direct experiences of humans, and of particular groups.

This inward focus on the collection, classification and review of errors rather than of patients has led to a situation where ever more sophisticated technological systems continue to be based on simplistic conceptual schemata. By not including elements such as ethnicity or disability, these taxonomies ignore the social patterning of errors, which the scant evidence that is available shows, most closely resemble the social determinants of health [63, 64].

In part then we can see how the ‘realness’ or materiality of information is a strategic device in the activities where information systems are situated. The data is both ‘raw’ and ‘real’ – this validates the information system and the processes as well as the actual outcomes and their applications. The information experts position themselves as objective because this is a central strategy for professional legitimacy in the modern state and economy – professionals produce legitimate and authorizing knowledge. Consequently, it is a strategic process to ensure that the data supports the power of the system within which it is implemented and that it does not provide power, either by accident or purposively, to those outside of that system.

### 6.1 Making the Immaterial Real

The process of digitally producing, instantiating and regulating database taxonomies, categories and fields that rely on social constructs for their deployment has the effect

of reifying these constructs. That is the process itself tends to make ephemeral phenomena that are stored in binary coding as real as the events the data claims to capture. In some cases, as we have seen with patient safety information systems, this process can make the data more real to the system than the person to whom the event happened. This has the effect of reducing the individual to the status of data and even, in some cases, less than the data, because so much of their materiality is left out of these digital systems. The reductive processes of classification and data capture leave so little of the individual left digitally speaking that their physical existence can easily be seen as less than that of the system in which their delimited details are held, in essence the digital ghost in these digital machines.

Even the claims made for digitizing individual genetic code still potentially reduce us to the quantified, numericised versions of the biological reality of genes and the bodies that those genes 'inhabit' [65]. Thus, except in the most deterministic sense possible, those representations are not us or ourselves but an instrumental and even preferable form of 'us'. Current debates and legal cases about data sharing, with or without consent [66], in a variety of jurisdictions make this point very clearly – individuals don't own data about or from about themselves because political and economic systems have priority-making claims to both a higher moral purpose (usually couched as potential future benefits – teleology and transcendence in the one ambit claim) and to the benevolent representation of all of us over any single one of us who might choose to object [67].

Health care systems also make claims to expertise and that expertise supports their authority to act in various ways, often without the possibility of an engaged or informed (or any) response from those whose data is collected, categorised and indexed within these information systems. If we consider that expertise is at least partly informational (medical knowledge, risk knowledge, how the system works, available choices and the lack of them) then it is clear that healthcare information systems primarily support the existing power and authority of health care providers. Information is representational and, as noted above, refined and practiced forms of representation, however problematic on close inspection, can acquire a social life of their own. The equation of expertise authorizing specific systems of representation is an instrument of power in its own right. This links health information systems to Foucault's key concepts of governmentality and biopower through the regulatory frameworks and self-regulation that 'expertise' manufactures and which experts manage [68, 69]. In other words, health information systems are a central enactment of this regulatory process which discursively enables self-regulation by manufacturing the limited number of legitimate categories a person and their identity can be permitted to have within such information systems.

Foucault also discussed very early in his writing the importance of space as an avenue for governmentality including the shifting role of the hospital and its organisation of space [70]. Elden has taken this idea and developed it in relation to the concept of *territory*. He suggests that territory need not be physical but instead can be entirely conceptual so long as it is understood as existing in the minds of those who believe in its existence [71]. This can be seen in the nature of maps representing different claims to the same physical space, expressed as territory. In this sense, the hospital can be seen as a territorial space claimed by medical and nursing personnel on the one side and

political, managerial and administrative personnel on the other. The development of the hospital as a physical architecture of knowledge can be seen not only in Foucault's analysis but in the geographical work of Livingstone [72].

Based on this construction we can begin to think of health information systems as virtual spaces, even territories, of governmentality. The obsession with governments in tracking all forms of electronic communication in their efforts to ensure a 'secure' state illustrates how easily an information domain becomes an exercise in total governance through the constitution of a digital territory or set of territories.

## **7 Informational Biopolitics**

Biomedical informatics has been an 'emerging field' for decades [73]. The concept of biopolitics has a history going back at least to the 1920s and the work of Rudolf Kjellén, with some suggestion that it can be effectively situated in the work of Schopenhauer, Nietzsche and Bergson [74]. Its current formulation emerged mainly from Michel Foucault's work in the mid-1970s [75]. Illich's *Medical Nemesis* emerged at about the same time indicating that philosophy and sociology were beginning to take a serious interest in knowledge production within medicine in particular [37]. Even McKeown's somewhat older argument about the role played by medicine in human health improvements can be seen as sitting within a cultural discussion about what claims can be made by a discipline to self-represent and actively promote its contribution to societal improvements and the knowledge that supports those claims [76, 77].

More recently the notion of 'incidentalomas' has entered the health environment. The term refers to tumors located incidentally through the application of highly detailed scanning technologies. This is part of a broader field of incidental findings understood to exist in medical research and practice, one which research projects have had to accommodate by including provisions for them in various clinical screening activities and the like [78, 79]. The procedures identify these 'incidental' tumors while looking for other, suspected, diagnostic features. These tumors often have no clinical symptoms or suspicious characteristics and, as a consequence, there is a growing awareness that new technologies identify phenomena not currently implicated in the pathology of an existing or suspected disease state. Acting surgically on some of these, such as aneurisms, can be almost or even as risky as the potential clinical threat that their presence might lead to at some future point. Advances in scientific and medical technologies, invariably information-based, can produce their own clinical sequelae. They are assumed to be risks because they are imaged as such and our systems and people have been conditioned to act on observable risks even when the consequences are distant in time and potential effect.

## **8 Social Hegemony and Information**

Information theory is generally accepted as having social and political implications in most if not all of its implementational aspects [80]. There is therefore an understanding that information systems produce particular types of knowledge that are then acted on

in specific ways, both good and bad, in societal contexts. Even if the knowledge produced through information science were entirely 'objective', the uses to which that knowledge is often put cannot be seen in the same light. Discussions about data security and access rights are one aspect of this discussion but representational issues are another under-explored aspect of the information sciences.

Information collection about society and the groups and individuals who constitute society benefited enormously from the development of demography and statistics. The kind of conceptual and taxonomic abstraction required to understand complex social processes only began to take on our 'modern' idea of a scientific activity in the Victorian era. It was then that statistical surveys of the people within nation states began to gain momentum. Prior to this a major difficulty had been to actually map the state cartographically but now with statistical survey instruments, the whole population could be 'captured' as data even in contexts where the definition of what a population actually is have not been resolved [31]. This required the development of categories and implicitly social taxonomic systems to analyze the information in those categories.

The problem with these categories is that they move beyond mere representation to *become* the populations they are used to represent in information systems that cannot by their very nature cope with the complexity of individual human beings. Hacking's people-producing processes also find any kind of nuanced difference difficult to deal with and the categories represented by field names in databases take on a normative character of their own [11]. There is, across the many disciplines that produce these kinds of knowledge, a cultural dimension that reflects the specific preferences and imbedded understandings of how data is collected, what information is produced and analyzed, and lastly the acceptable representations of those knowledge production processes [81].

Information collection has moved far beyond this analogical and descriptive approach to a digitally enabled environment in which there are claims that it will be possible to understand the whole of the material world [2]. One of those claims is that 'data' will ultimately explain both 'society' in the abstract sense and also the actual societies in which we live.

Allied to this is a level of digital surveillance never previously possible and which operates across the entire field of human engagements from government and commerce, through to data collection about individuals' behaviors, habits and beliefs. Marketing and managerial practice are data-informed and those same practices are being gradually incorporated into healthcare including medical practice and health administration. In all these activities there is a claim that 'patients' and 'consumers' (yet again abstract categories claiming to represent real people) will benefit both directly and indirectly from this information collection and analysis. The language of risk, quality, value and choice is pervasive as a rationale for continuous change even in systems where we may not have, as citizen consumers, indicated any specific dissatisfaction with the status quo. Consequently, discourses of risk and quality are employed as strategies for systemic change by corporations and governments whose intention is change regardless of consumer and citizen opinion. The manufacture of informational concepts, which risk and quality have become regardless of their historical origins, makes them instruments for the manipulation of systems claimed to be representative and collaborative. Being

able to reposition the meaning of terms and use those same terms as justifications for policy changes within societies makes them highly useful as political strategies. Coole has discussed how these processes work in relation to the shift in aged care policy and political discourse. The increase in data capture *about* older people may contribute very little to the betterment *of* older people [82].

## 9 Conclusion

In this paper we have sought to explore in a brief and general way in this paper is how information systems are instruments of biopolitical practice and that they influence the social environment by legitimizing some aspects of our material reality and de-legitimizing or even deleting other possibilities for human identity. The nature of information, its collection, analysis and representation within society is not an abstract and objective process but a deeply politically engaged activity. Indeed, the various knowledge claims associated with information including 'raw' data, data objectivity and analytical neutrality as being an ideological representation and a claim for authority which has significant social effects.

As a result, we suggest, information systems and their associated practices which purport to be doing 'objectivity work', are engaged in an often a-theoretical form of political practice. The failure to acknowledge or understand the way data is constituted and becomes information within and across a variety of scientific and social scientific sub-cultures is an epistemic failure in its own right. To make claims about producing legitimate knowledge requires of the producer an informed understanding of what knowledge is, how it is produced and where it comes from. The deeper history of the conceptual primitives apparent in health informatics and the information sciences more broadly need to be subject to scrutiny of this type. The moralizing discourse so prevalent in healthcare and health policy (the selfish 'bed blocking' elderly, the lazy obese, the uncaring mothers, the willful smokers, the ungrateful disabled etc) is so assuredly political in its conception and deployment that there is a risk of intellectual dishonesty in ignoring these links.

The information sciences need to be critically informed and engaged. Some already are, including library science and geographic information science. There needs to be a move from a utilitarian viewpoint which claims to be driven by practical aims serving practical outcomes to a more nuanced inquiry on its own practices, underpinnings and assumptions. The nature of health information science must engage with the power of its political positioning and the influence it has on knowledge and understanding once it is produced and acted on as evidential and true.

## References

1. Rowley, J.: The Wisdom Hierarchy: Representations Of the DIKW Hierarchy. *Journal of Information Science* 33, 163-180 (2007)
2. Breen, M.: Information Does Not Equal Knowledge: Theorizing the Political Economy of Virtuality. *Journal of Computer-Mediated Communication* 3(3) (1997)

3. Bourdieu, P.: *Distinction: A Social Critique Of the Judgement of Taste*. Harvard University Press (1984)
4. Bourdieu, P., Wacquant, L.J.: *An Invitation to Reflexive Sociology*. University of Chicago Press, Chicago (1992)
5. Bowker, G., Starr, S.: *Sorting Things Out: Classification and Its Consequences*. MIT Press, New Baskerville (2000)
6. Bhatt, G.D.: Knowledge Management in Organizations: Examining the Interaction between Technologies, Techniques, and People. *Journal of Knowledge Management* 5, 68-75 (2001)
7. Negroponte, N.: *Being Digital*. Hodder and Stoughton, London, UK (1995)
8. Ahalt, S.C.: *Data Science and the NCDS: Putting North Carolina First in Data through the National Consortium for Data Science*. Presentation at the University of North Carolina, Chapel Hill (2013)
9. Bellini, P., di Claudio, M., Nesi, P., Rauch, N.: Tassonomy and Review of Big Data Solutions Navigation. In: Akerkar, R. (ed.) *Big Data Computing*, pp. 57-101. CRC Press, Boca Raton, FL (2013)
10. Nagel, T.: *The View from Nowhere*. Oxford University Press, Oxford (1989)
11. Haraway, D.: *Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective*. *Feminist Studies* 14, 575-599 (1988)
12. Galison, P., Daston, L.: *Objectivity*. Zone Books, London (2008)
13. Boyd, D., Crawford, K.: *Critical Questions for Big Data*. *Information, Communication & Society* 15, 662-679 (2012)
14. Gitelman, L.: *Raw Data Is an Oxymoron*. MIT Press, Cambridge, MA (2013)
15. Gleick, J.: *The Information: A History*. Fourth Estate, London (2011)
16. Duncan, S., Barrett, L.F.: *Affect is a Form of Cognition: A Neurobiological Analysis*. *Cognition and Emotion* 21, 1184-1211 (2007)
17. *Nature: Putting Gender on the Agenda*. *Nature* 465, 665 (2010)
18. Cherubini, A., Oristrell, J., Pla, X., Ruggiero, C., Ferretti, R., Diestre, G., ... Lesauskaite, V.: *The Persistent Exclusion of Older Patients from Ongoing Clinical Trials Regarding Heart Failure*. *Archives of Internal Medicine* 171, 550-556 (2011)
19. Guthrie, R.V.: *Even the Rat Was White: A Historical View of Psychology*. Pearson Education, Upper Saddle River, NJ (2004)
20. Beery, A.K., Zucker, I.: *Sex Bias in Neuroscience and Biomedical Research*. *Neuroscience & Biobehavioral Reviews* 35, 565-572 (2011)
21. Saperstein, A.: *Capturing Complexity in the United States: Which Aspects of Race Matter and When?* *Ethnic and Racial Studies* 35, 1484-1502 (2011)
22. Simon, P.: *Collecting Ethnic Statistics in Europe: A Review*. *Ethnic and Racial Studies* 35, 1366-1391 (2011)
23. Simon, P., Piché, V.: *Accounting for Ethnic and Racial Diversity: The Challenge of Enumeration*. *Ethnic and Racial Studies* 35, 1357-1365 (2011)
24. Bourdieu, P.: *Outline of a Theory of Practice*. Cambridge University Press, Cambridge (1977)
25. Bourdieu, P.: *The Logic of Practice*. Stanford University Press, Stanford, CA (1990)
26. Bourdieu, P.: *Is a Disinterested Act Possible?* In: Bourdieu, P. *Practical Reason: On the Theory of Action*, pp. 75-91. Stanford University Press, Stanford (1998)
27. Centers for Disease Control and Prevention: *International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM)*. Centers for Disease Control and Prevention, Hyattsville, MD (2014) <http://www.cdc.gov/nchs/icd/icd10cm.htm>
28. Blumenthal, D., Tavenner, M.: *The "Meaningful Use" Regulation for Electronic Health Records*. *New England Journal of Medicine* 363, 501-504 (2010)



29. Barnes, B.: *Scientific Knowledge and Sociological Theory*. Routledge, London (2013)
30. Anderson, W.: Teaching 'Race' at Medical School Social Scientists on the Margin. *Social Studies of Science* 38, 785-800 (2008)
31. Krieger, N.: Who and What Is a "Population"? Historical Debates, Current Controversies, and Implications for Understanding "Population Health" and Rectifying Health Inequities. *Milbank Quarterly* 90, 634-681 (2012)
32. Carroll, P.E.: Medical Police and the History of Public Health. *Medical History* 46, 461-494 (2002)
33. Elden, S.: *The Birth of Territory*. University of Chicago Press, Chicago (2013)
34. Anderson, Z.: One 'Body/Nation': Pathology and Cultural Citizenship in Australia. *Cultural Studies Review* 15, 110-129 (2009)
35. Weiss, K.M., Long, J.C.: Non-Darwinian Estimation: My Ancestors, My Genes' Ancestors. *Genome Research* 19, 703-710 (2009)
36. Skloot, R., Turpin, B.: *The Immortal Life of Henrietta Lacks*. Crown Publishers, New York (2010)
37. Illich, I.: *Medical Nemesis: The Expropriation of Health*. Random House, New York (1976)
38. Simpson, C.L., Novak, L.L.: Place Matters: The Problems and Possibilities of Spatial Data in Electronic Health Records. In: *AMIA Annual Symposium Proceedings 2013*, pp. 1303-1311. American Medical Informatics Association (2013)
39. Gawande, A.: The Hot Spotters: Can We Lower Medical Costs by Giving the Neediest Patients Better Care? *The New Yorker*, 40-51 (2011, January 24)
40. Snow, J.: *On the Mode of Communication of Cholera*. John Churchill, London (1855)
41. Goodchild, M.F.: Geographical Information Science. *International Journal of Geographical Information Systems* 6, 31-45 (1992)
42. Fisher, T.: Place-Based Knowledge in the Digital Age. *ArcNews* 34(3), 1-6 (2012)
43. Vest, J.R., Gamm, L.D.: Health Information Exchange: Persistent Challenges and New Strategies. *Journal of the American Medical Informatics Association* 17, 288-294 (2010)
44. Flynn, R.: Clinical Governance and Governmentality. *Health, Risk and Society* 4, 155-173 (2002)
45. Flynn, R.: *Structures of Control in Health Management*. Routledge, London (2012)
46. Joint Commission on Accreditation of Healthcare Organizations (JCAHO): Safely Implementing Health Information and Converging Technologies. *Sentinel Event Alert* 42, 1-4 (2008)
47. Goodman, K.W., Berner, E.S., Dente, M.A., Kaplan, B., Koppel, R., Rucker, D., ... Winkelstein, P.: Challenges in Ethics, Safety, Best Practices, and Oversight Regarding HIT Vendors, their Customers, and Patients: A Report of an AMIA Special Task Force. *Journal of the American Medical Informatics Association* 18(1), 77-81 (2011)
48. Kosiba, S., Bauer, A.M.: Mapping the Political Landscape: Toward a GIS Analysis of Environmental and Social Difference. *Journal of Archaeological Method and Theory* 20, 61-101 (2013)
49. Goodchild, M.F.: Twenty Years of Progress: GIScience in 2010. *Journal of Spatial Information Science* 1, 3-20 (2014)
50. Cohn, B.S.: *Colonialism and Its Forms Of Knowledge: The British in India*. Princeton University Press, Princeton, NJ (1996)
51. Richards, T.: *The Imperial Archive: Knowledge and the Fantasy of Empire*. Verso, London (1993)
52. Mayes, C., Thompson, D.B.: Is Nutritional Advocacy Morally Indigestible? A Critical Analysis of the Scientific and Ethical Implications of 'Healthy' Food Choice Discourse in Liberal Societies. *Public Health Ethics* 7, 158-169 (2014)

53. Bacon, L., Aphramor, L.: Weight Science: Evaluating the Evidence for a Paradigm Shift. *Nutrition Journal* 10, 9 (2011)
54. Hacking, I.: Kinds of People: Moving Targets. In: *Proceedings of the British Academy* 151, pp. 285-318. British Academy (2007)
55. Swartz, D.: *Culture and Power: The Sociology of Pierre Bourdieu*. University of Chicago Press (2012)
56. American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. American Psychiatric Publishing, Washington, DC (2013)
57. Cooper, R.: What is Wrong with the DSM? *Historical Psychiatry* 15, 5-25 (2004)
58. Sadler, J.Z., Fulford, B.: Should Patients and Their Families Contribute to the DSM-V Process? *Psychiatric Services* 55(2), 133-138 (2004)
59. James, J.: Health Policy Brief: Transitioning to ICD-10. *Health Affairs* (2014, March 20)
60. Beckmann, U., West, L., Groombridge, G., Baldwin, I., Hart, G.K., Clayton, D.G., ... Runciman, W.B.: The Australian Incident Monitoring Study in Intensive Care: AIMS-ICU. The Development and Evaluation of an Incident Reporting System in Intensive Care. *Anaesthesia and Intensive Care* 24, 314-319 (1996)
61. Vincent, C., Coulter, A.: Patient Safety: What About the Patient? *Quality and Safety in Health Care* 11, 76-80 (2002)
62. Sari, A.B.-A., Sheldon, T.A., Cracknell, A., Turnbull, A.: Sensitivity of Routine System for Reporting Patient Safety Incidents in an NHS Hospital: Retrospective Patient Case Note Review. *BMJ* 334, 79 (2007)
63. Davis, P., Lay-Yee, R., Dyall, L., Briant, R., Sporle, A., Brunt, D., Scott, A.: Quality of Hospital Care For Maori Patients in New Zealand: Retrospective Cross-Sectional Assessment. *The Lancet* 367, 1920-1925 (2006)
64. Lawthers, A.G., Pransky, G.S., Peterson, L.E., Himmelstein, J.H.: Rethinking Quality in the Context of Persons with Disability. *International Journal for Quality in Health Care* 15, 287-299 (2003)
65. Barnes, B., Dupré, J.: *Genomes and What to Make of Them*. University of Chicago Press (2009)
66. Boyd, D., Crawford, K.: Critical Questions for Big Data: Provocations for a Cultural, Technological, and Scholarly Phenomenon. *Information, Communication & Society* 15, 662-679 (2012)
67. Rouvroy, A.: *Human Genes and Neoliberal Governance: A Foucauldian Critique*. Routledge (2007)
68. Foucault, M.: *The Birth of the Clinic: An Archeology of Medical Perception*. Vintage, New York (1975)
69. Foucault, M.: *The Birth of Biopolitics: Lectures at the Collège de France, 1978-1979*. Picador, New York, NY (2010)
70. Foucault, M.: *Security, Territory, Population: Lectures at the Collège de France, 1977-1978*. Burchell, G. (trans.). Palgrave Macmillan, Basingstoke (2008)
71. Elden, S.: Plague, Panopticon, Police. *Surveillance & Society* 1, 240-253 (2002)
72. Livingstone, D.N.: *Putting Science in Its Place: Geographies of Scientific Knowledge*. University of Chicago Press, Chicago (2010)
73. Bernstam, E.V., Smith, J.W., Johnson, T.R.: What Is Biomedical Informatics? *Journal of Biomedical Informatics* 43, 104-110 (2010)
74. Lemke, T., Casper, M.J., Moore, L.J.: *Biopolitics: An Advanced Introduction*. NYU Press, New York (2011)
75. Foucault, M.: *Society Must Be Defended: Lectures at the Collège de France, 1975-1976*. Ewald, F. (trans.). Macmillan, London (2003)

76. McKeown, T.: *The Role of Medicine: Dream, Mirage or Nemesis*. Nuffield Provincials Hospital Trust, London (1976)
77. Colgrove, J.: *The McKeown Thesis: A Historical Controversy and Its Enduring Influence*. *American Journal of Public Health* 92, 725-729 (2002)
78. Ballantyne, C.: *To Know or Not to Know*. *Nature Medicine* 14, 797-797 (2008)
79. Wolf, S.M., Paradise, J., Caga-anan, C.: *The Law of Incidental Findings in Human Subjects Research: Establishing Researchers' Duties*. *Journal of Law, Medicine & Ethics* 36(2), 361-383 (2008)
80. Laudon, K., Laudon, J.: *Management Information Systems: International Edition*, 11th edn. Pearson Higher Education, New Jersey (2009)
81. Knorr Cetina, K.: *Epistemic Cultures: How the Sciences Make Knowledge*. Harvard University Press, Cambridge, MA (1999)
82. Coole, D.: *Reconstructing the Elderly: A Critical Analysis of Pensions and Population Policies in an Era of Demographic Ageing*. *Contemporary Political Theory* 11, 41-67 (2012)