Big Data in Healthcare – Defining the Digital Persona through User Contexts from the Micro to the Macro
Contribution of the IMIA Organizational and Social Issues WG

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Summary

Objectives: While big data offers enormous potential for improving healthcare delivery, many of the existing claims concerning big data in healthcare are based on anecdotal reports and theoretical vision papers, rather than scientific evidence based on empirical research. Historically, the implementation of health information technology has resulted in unintended consequences at the individual, organizational and social levels, but these unintended consequences of collecting data have remained unaddressed in the literature on big data. The objective of this paper is to provide insights into big data from the perspective of people, social and organizational considerations.

Method: We draw upon the concept of persona to define the digital persona as the intersection of data, tasks and context for different user groups. We then describe how the digital persona can serve as a framework to understanding sociotechnical considerations of big data implementation. We then discuss the digital persona in the context of micro, meso and macro user groups across the 3 Vs of big data.

Results: We provide insights into the potential benefits and challenges of applying big data approaches to healthcare as well as how to position these approaches to achieve health system objectives such as patient safety or patient-engaged care delivery. We also provide a framework for defining the digital persona at a micro, meso and macro level to help understand the user contexts of big data solutions.

Conclusion: While big data provides great potential for improving healthcare delivery, it is essential that we consider the individual, social and organizational contexts of data use when implementing big data solutions.

Keywords

Big data, organizational and social issues, context, digital persona, patient-engaged healthcare delivery

Introduction

The field of biomedical informatics continues to undergo phenomenal changes that offer hope for enhancing healthcare delivery. The Health 2.0 and Web 2.0 social media paradigms offer the chance for patients to become more active participants in their own care delivery, and these paradigms have shown promise in improving patient health outcomes [1, 2]. Mobile health (m-health), which enables the delivery of healthcare through applications delivered via mobile devices, is another approach that offers potential for bringing about meaningful healthcare change. M-health is even being referred to as the "biggest technology breakthrough of our time" [3]. M-health technologies have the potential to change every aspect of the healthcare environment, while delivering better outcomes and substantially lowering costs and at the same time collecting data about healthcare consumers' health status. For consumers, m-Health offers the promise of improved convenience, engagement and personalization [3]. The increasing use of social media and m-health technologies as well as the large amount of data being captured and produced via these applications, have contributed to what is now being called the "big data" movement. Broadly speaking, big data refers to the science behind the collection of data and its analysis such that organizations can meet their objectives. Big

data has been described as the 'future of healthcare' because it may generate better evidence for health care delivery, improve data quality and access, and help drive social media to promote better communication between patients, providers and communities [4]. We posit that the combination of big data and social media can enhance our ability to collect and filter raw data that can be reanalysed to deduce relevant information at the micro level to improve patient outcomes and to facilitate research and knowledge discovery at the healthcare system or population health levels. Personalized medicine is an emerging example of this model. Through a combination of advances in genomics research, the availability of data from electronic health record systems, and the e-patient movement leveraging social networks, big data can be used to inform individual patients about their health status and regional health authorities about health status, and trends of patient populations in their service areas [5].

While big data has emerged as an area of great interest, our perception is that much of the current research in this area has focused on technical algorithms, tools, or speculative potential of what big data can achieve. Few studies have addressed the social or organizational implications of big data and how big data may affect workflows and other care delivery activities. As an emerging phenomenon, many publications on big data in healthcare describe its potential, with little

scientific evidence or few frameworks to clearly guide big data scientific inquiry [6].

In studying big data we can look at what we have learned through the various paradigms of health information technology (HIT) implementations. If history has taught us anything it is that technology-based healthcare saviours are often anything but that. Though the role of HIT in reengineering the healthcare system has been well discussed [7, 8] and the benefits to improved processes and patient safety have been demonstrated, there is still much room for HIT outcomes-based research to demonstrate its value. HIT has also brought with it issues such as human computer interaction, technology-induced errors (e-iatrogenesis) and workaround issues [9, 10], which have the potential to grow as innovations continue to be introduced into healthcare at rapid rates.

The evidence based on big data is similar to other emerging technologies such as Web 2.0 or m-health in that the literature consists of anecdotal reports and theoretical vision papers rather than sound evidence based on empirical research [3]. To address this important issue we believe that there is a fundamental need to understand the healthcare systems we are trying to change in order to be able to position our interventions (such as the collection of big data for analysis) to achieve positive change while minimizing unintended outcomes [11]. The 1999 IOM report 'To Err is Human: Building a Safer Health System' raised awareness of the number of medical errors that occur on an annual basis [12]. The 2001 IOM report 'Crossing the Quality Chasm' identified how healthcare systems are not designed to support integrated, collaborative and patient-centered care delivery [8]. Yet more than a decade later we still struggle with issues such as patient safety, human computer interaction, and systems integration, showing that complexities in healthcare require multifaceted approaches. for problem solving.

Viewing big data and analytics as a 'savior' of healthcare delivery -- without acknowledging the sociotechnical and organizational requirements to transform data to information, information to knowledge, and knowledge to practice -- will result in a costly data tsunami at best and in the unintended consequences of poor practice and ethically questionable privacy encroachments at worst. Given that big data is an emerging phenomenon in medical informatics this is an ideal opportunity to look at it from social and organizational perspectives.

The goals of the IMIA Organizational and Social Issues (OSI) Working Group are to investigate and evaluate socio-technical, organizational, social, ethical, and individual behavioural issues surrounding the introduction and use of information and communication technologies (ICTs) in order to identify strategies to support the systems and workflow analysis, product design, and implementation of ICTs [13]. We recognize that there are multiple ways that big data can be discussed from an OSI perspective. The expertise and research background of the current WG membership is on sociotechnical studies of HIT implementation and therefore it is through that lens that we review big data in healthcare. In no way do we suggest that other OSI perspectives of big data such as governance issues around security, trust, information exchanges or patient profiling are any less important; rather, they are not an explicit focus of our WG at this time. However, implementation research is timely and necessary. Two recent review articles on organizational aspects of HIT have emphasized the importance and need for research on organizational issues surrounding HIT implementation while noting that implementation has not received adequate research attention [14, 15]. Others have stated that the most important need of HIT evaluation is studies and reports on implementation and context [16].

In this paper we address that need and provide an OSI-based framework for studying big data in healthcare. First, we introduce the digital persona as being the intersection of data, tasks and context for different user groups. Second, we describe how this persona can serve as a framework to understanding sociotechnical considerations of HIT, and more specifically, big data implementation. Third, we extend the framework to describe the 3V's of big data in the context of micro, meso and macro user groups. We conclude with a discussion of our findings and implications for HIT research.

The Digital Persona - The Sweet Spot of Contexts, Tasks and Users

Data drives all healthcare activities and many such activities are information management tasks [17]. Figure 1 shows the cycle of data generation and application in biomedical informatics. As shown in Figure 1, for data to be effective, it must fit into the 'sweet spot' of the intersection of context, task and users. We call that intersection the digital persona. A persona refers to a representation of a group of target users of technology [18,19].

How data will influence the digital persona will vary by user group and the processes being done with the data. Only a select amount of the vast healthcare data available is relevant and valuable for any given user-task-context combination (see Figure 1). The strategy of carefully filtering and delivering data to facilitate the requirements of the user, the task, and the context is one approach to inform the design and development of technology to support healthcare delivery. Thus, the success of big data for enhancing the digital persona hinges on the flexibility and suitability of the tools and approaches we develop to accommodate different combinations of users, tasks, and contexts.

The importance of users and tasks in the System Development Life Cycle was noted more than a decade ago [20]. However, context as another critical factor in system design and development, especially within the domain of healthcare, has recently gained prominence [21]. Kushniruk and Turner [22] argued that the complex and dynamic nature of healthcare necessitates the consideration of context (in addition to task and user) in health information system development to ensure that resultant systems do not compromise patient safety. They also provided examples of contextual factors that could potentially play a role in performance (e.g. physical environment, urgency, uncertainty, time-sensitivity, collaborative work) [22]. Other contextual factors at the implementation level include individual and group coordination of data usage, and coordinating processes with technology [23].
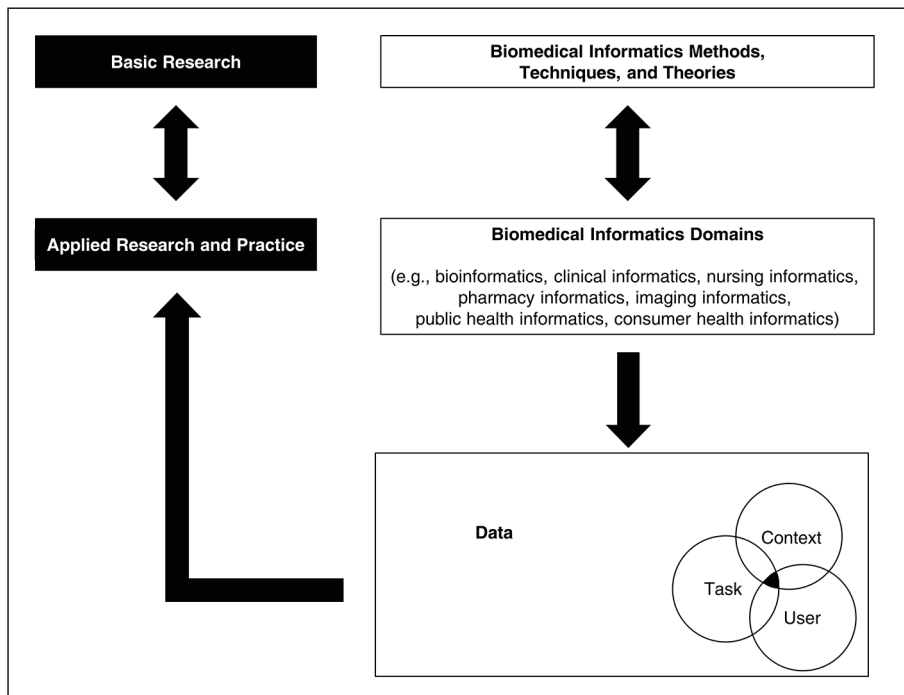
Fig. 1 Cycle of data generation and application in biomedical informatics (adapted from [17])

An essential first task is defining the digital persona for different user groups (i.e., micro, meso and macro) across the spectrum of healthcare delivery. Each user group is a unique context and we need to understand how increased data and applications from the data will affect people and processes within each context. A shortcoming on research of organizational and social perspectives of the digital persona is that we often use abstraction to mask the underlying messy nature of how people interact with healthcare technology or data while conducting processes (e.g., improving their health and wellness) [24]. Novak and colleagues have raised awareness about the difference between the ideal or abstract description (the ostensive dimension) of how HIT should be used and how it is actually used in real clinical settings (the performance dimension) [25]. The gap is defined by the specific contexts where HIT is used, and failure to account for the ostensive-performance gap leads to unintended consequences such as communication, coordination and patient safety issues [25, 26]. A particular need they highlight is a better understanding of the intersection of organizational routines and technology [25].

Research and perspectives on big data in healthcare is very much at the ostensive (i.e., ideal or abstract) stage. Although publications about big data are increasing in number the role of big data in healthcare has not been looked at from the perspective of social and organizational issues. We see a danger in big data approaches in that its analysis may lead to a reductionist perspective of a situation, which raises the question of whether analyzing data of complex human behaviour such as healthcare delivery is by itself an adequate way of understanding the underlying human behaviour.

To better position big data in healthcare we need to understand the contexts of how it is applied in healthcare delivery in order to incorporate the performance dimension into big data analytics. We believe that studying big data from the perspective of the digital persona (i.e., user, task, context) can help us mitigate the potential "data deluge", and provide insights on performance aspects and thereby better position big data approaches and tools to support healthcare delivery.

A Framework for Defining the Digital Persona of Big Data in Healthcare

No framework exists that describes big data in the context of organizational and social perspectives. As we described in Figure 1, the intersection of data with a task, context and user is what defines the digital persona. Figure 2 expands upon Figure 1 by looking at the digital persona from the perspective of the three Vs of big data: velocity, volume and variety, and in the context of micro, meso and macro user groups.

Velocity

Many processes that used to be done manually have moved to automated approaches, which has greatly increased the speed by which data becomes available for analysis and interventions to improve outcomes. At the micro level, the ability to collect data in a timely manner from a number of different sources (e.g., EMRs, patient smartphone apps) has led to an increase in disease registries. While registries are still in the early stage, they offer great potential for supporting patient-centered self-management of chronic illness [27] and for designing therapeutic plans customized to individual patients [28]. In Canada, diabetes registry programs have enhanced the ability to identify diabetes patients and to enable known patients to meet treatment goals [29]. This has resulted in reduced wait times to see specialists and increased productivity in clinics. Other micro-level benefits to patients from big data analytics are the option for targeted medicine, more accurate diagnoses, and safer interventions. Gene sequencing and the use of genetic data in diagnosis and treatment will play a central role in the future of personalized medicine. Pharmacogenomics (the prescription of drugs based on genomic profiles of individual patients) is a prime example of this trend, e.g., [30-32]. Big data approaches have also been used to develop clinical decision support tools for neonatal intensive care to provide proactive management for care delivery of premature babies [33].
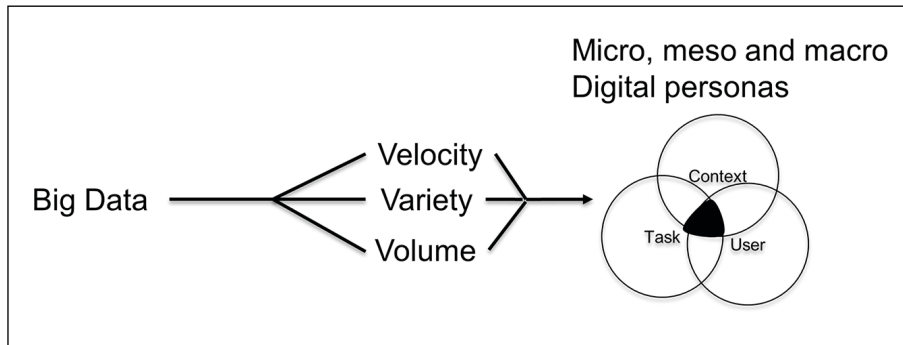
Fig. 2 Framework for defining micro, meso and macro digital personas in the context of the 3Vs of big data

At the meso level, patient satisfaction surveys have been organized for a long time but were historically done manually, which prevented timely analysis of the data to bring about process change. A more recent work involving big data has focused on the use of electronic patient satisfaction data to allow timely data analysis and management of any problems [34]. Faster access to data also enables hospitals to develop and implement quality improvement initiatives that constantly monitor outcomes to ensure that organizational targets are met [35]. Hospitals have also taken advantage of the velocity of data collected in electronic health records that were originally intended to document care and repurposed it to identify system-related inefficiencies and quality issues. In mining electronic health record data researchers were able to identify possible sources of adverse events. Health professionals found this information useful in examining healthcare organizational practices and informing quality improvement activities at the unit level and have used this information to initiate quality improvement activities aimed at reducing error rates [36].

At the macro level, faster access to data has had a great impact on the identification and management of disease outbreaks as well as on enabling population health initiatives to be targeted to specific areas based upon analysis of the population [37]. The ability to collect and combine multiple organizational datasets in a timely manner has also drastically reduced the time needed for analysis of population data [37, 38].

Volume

From a volume perspective, healthcare data is no longer restricted to corporate entities such as EHRs or EMRs. The evolution of social media, personal health records, and health management applications that operate on mobile devices (e.g., Smartphones, Smart watches, wearable technologies) can provide timely access to multiple data points that are increasingly interconnected. However, this potential does bring about challenges such as the construction of mechanisms capable of coping with the sheer volume of continuously generated micro-blog messages in real time, and the sparsity of relevant information, which requires effective filtering techniques. Although a plethora of applications exist for collecting data, a challenge is how to integrate the apps to enable them to be used in a meaningful manner [39]. Another issue is the small size of typical microblog messages (140 characters in the example of Twitter), which imposes practical limits for algorithms that attempt to infer the semantic context of each message post. One potential way to increase the accuracy of determining relevant context would be to analyze *message series* rather than individual messages. Another approach would be to combine textual processing of microblogs with *social network analysis* [40]. However, both approaches will add complexity to the analytical algorithms and thus decrease its overall performance and ability to cope with high volume data feeds. This performance hit may not be detrimental for other applications in population health that deal with more targeted data sets, e.g., monitoring addictive behaviour, prescription drug abuse, spread of communicable diseases, etc. Analytical algorithms for these applications select data based on an original set of confirmed or suspected cases and their social networks [41].

Another micro level benefit of volume is the ability for patients to exchange information, share experiences, and connect to other patients to improve patient experiences [42]. However, there is a difference between collecting data, having access to data, and knowing how it should be used to improve healthcare. Though tools like Dr. Google and PatientsLikeMe® provide connectivity for patients, simply providing patients with access to data in inappropriate contexts is at best unhelpful and at worst could introduce patient safety issues. Furthermore, patients have not always found it beneficial to have increased access to data, at times experiencing overload from the information and opinions that they receive through support groups, receiving incorrect data that is irrelevant or meaningless because it is not context specific, and finding the lack of physical connection to be a disempowering aspect even as access to data has increased [42].

At the meso level, crowdsourcing and other tools to capture data can support teamwork and provide the means of brainstorming to support distributed collaboration [43-44]. Also at the meso-level the increasingly pervasive use of advanced information and communication technology provides an increasingly large volume of meta data that can be used for analytics and process improvement. Hospitals, for example, may use RFID-based location tracking of personnel, patients, and equipment. The vast volume of data generated by such tracking systems can be utilized for smart, real-time adaptations to patient flows and clinical pathways, e.g., in emergency departments [45]. Moreover, many clinical information systems such as EMR and CPOE systems capture a large amount of meta data about their use, e.g., for auditing purposes. Analyzing such meta data may indeed allow us to detect human computer interaction problems (e.g., user confusion, individual training needs), shrinking safety margins (for example, due

to deteriorating data quality) and other technology-related safety concerns before any adverse event occurs [46]. Following this trend, future clinical information systems may be equipped with components akin to black box flight recorders used to diagnose safety problems in avionics.

From a population health perspective, the automated analysis of social media such as Twitter and Facebook has shown promises in detecting the outbreak and in monitoring the spread of infectious diseases [47, 48]. Another promising application of social network analytics at the macro level is in targeted health prevention and promotion initiatives, e.g., in promoting sexual health to gay men [49]. However, online media and the Internet also pose new health risks by themselves, Internet addiction being one of them [50]. Automated analyses of social network usage data can be used to diagnose such issues and potentially related mental health problems such as depression and schizophrenia. Many of these applications in population health are privacy-sensitive and thus require effective assurances that guarantee that no individually identifiable information is disclosed to unauthorized parties [51].

Variety

The variety of big data that is available can allow us to tailor solutions to unique contexts, particularly at the micro (i.e., patient) level. One aspect of the current trend toward patient engagement is an increased use of patient-reported outcomes (PROs) that record how patients – rather than providers – rate their treatment outcomes, health, and quality of life. A related aspect of this trend is the growing consumer interest in uploading patient-generated health information such as exercise and nutrition data to electronic health records (EHRs). Since 2009, the National Health Service (NHS) has been collecting patient-reported outcome measures on four surgical procedures (groin hernia operations, hip replacements, knee replacements, varicose vein operations) performed on patients treated in English facilities [38]. In this approach, patients complete a pre-operative questionnaire given by the provider

and a post-operative questionnaire three or six months after the procedure. NHS plans to collect PROs for additional procedures in the future [52]. Similarly, in the United States, the Food and Drug Administration (FDA) outlined in 2009 how it evaluates instruments that pharmaceutical and medical device manufacturers use in clinical trials to collect PROs in support of approved product labeling claims [53]. The FDA considers PRO data as an expression of patients' view of the usefulness of the treatment under investigation. FDA's guidance does not address other uses of PROs, such as for post-marketing claims. Inclusion of patient-reported information in EHRs is a high priority for the US Office of the National Coordinator for HIT [54]. The federally funded US Patient-Centered Outcomes Research Institute will receive approximately US$3.5 billion through 2019 to fund research and develop research methodologies that answer questions of interest to patients [55].

PRO development has been growing steadily over the past several years in both the public and private sectors. The Patient Reported Outcomes Measurement Information System (PROMIS), sponsored by the US National Institutes of Health to measure PROs in clinical settings, is used by providers in several European countries, Brazil, Australia, China, Japan, and others [56]. The patient network PatientsLikeMe® offers researchers access to its community of 200,000+ members for patient feedback through its Open Research Exchange [57]. This heightened interest comes as researchers acknowledge the need to include PROs in comparative effectiveness research within oncology [58] and recommend PRO use in treatment of conditions such as asthma [59].

Critics suggest that patient-reported outcomes reflect patient satisfaction with the healthcare experience rather than treatment efficacy, but published research indicates patient satisfaction is positively correlated with macro level guideline-based clinical practice [60]. In addition, PROs reflect patients' assessment of communications with providers rather than non-care-related factors such as parking and clinic environment [61]. However, the integration of PROs into provider-based EHRs presents challenges, including: [54, 62, 63]

- Lack of time for providers to review and manage PROs and patient-generated information submitted for inclusion in the EHR
- Increased exposure to malpractice claims if patient-generated information is inaccurate
- Data security risks arising from the submission of PROs over patient-maintained mobile devices
- Ability of US providers to meet proposed requirements for PRO use in Stage 3 of meaningful use under the Medicare and Medicaid Electronic Health Record Incentive Program
- Provider concerns about sharing control over EHRs with patients

Conclusion

In this paper we have presented a framework of the digital persona to discuss the 3 Vs of big data across micro, meso and macro user groups. Sociotechnical perspectives of the implementation of big data approaches are necessary because we cannot simply use big data from a reductionist approach but rather we need to understand the performance aspects of what we are reducing through data analytics. Winograd and Flores stated that creating new tools also creates new connections and conversations [62]. These connections and conversations help define the digital persona of how HIT is adopted and used. To date implementing HIT has been a challenge in that we have struggled to identify the new connections and conversations that emerge from HIT and as a result we ended up with unintended consequences both positive and negative [10, 63-64].

Industries outside healthcare have benefited from big data implementation. For example, UPS has benefited from big data by establishing predictive analytics for truck maintenance in its fleet [65] while IBM has developed applications for predicting landslides and other natural disasters [66]. However, there are two clear differences between these examples and the challenges that exist within the healthcare system. One is that big data applications in manufacturing or

supply chains are not necessarily solving new problems but rather looking at ways to make existing processes (i.e., machine maintenance) more efficient. In contrast, many of the processes that would benefit from big data analytics are still evolving. For example, patient engagement at the micro level and team-based collaborative care delivery at the meso level are largely immature processes. Therefore, we need to ensure research is done to shape these processes to best leverage big data solutions while minimizing negative unintended consequences. The second difference is that organizations such as Walmart and UPS are able to leverage big data analytics by abstracting the underlying complexity of their business processes in order to achieve efficiency. The digital persona in healthcare offers complex challenges in that processes such as discharge or handover are often defined by a high degree of interrelatedness and independent but parallel activities that make these processes inherently complex [67]. Abstracting complex processes without considering the underlying complexity of the processes will lead to unintended consequences [67].

Data alone will not transform healthcare systems into sustainable systems or resolve healthcare delivery problems and, in fact, will likely make things worse. Big data and the approaches for collecting (i.e., crowdsourcing) and analyzing (i.e., predictive analytics) data is very much in a tool-centric state. We suggest that a needed area of research is on the digital persona and on how big data *can* bring about change. Rather than focusing all analytics on data we need to define and begin to incorporate people and context analytics to understand how big data impacts the digital persona in different user contexts. For example, from a volume perspective more data is not necessarily the answer but rather we need frameworks that provide insight on how to enable it to provide meaningful support for healthcare delivery. It could be argued that many of the information management issues that currently plague healthcare are delivery or presentation problems rather than a lack of data.

Some people have suggested that a fourth V of big data, variability, is also necessary. However, we believe that *value* may be a

more appropriate fourth V. Regardless of how much research we conduct, or approaches we develop to deal with issues of volume or velocity of big data, it will only make a difference if the big data analysis provides value at the micro, meso and macro user levels. We need to ensure that we do not simply collect data for the sake of collecting data but rather to create knowledge and innovations that will lead to improved healthcare for individual and patient populations. Focusing big data analytics on providing value for different user groups will help ensure that the big data research we do is firmly grounded in the digital persona of health data consumers.

Figure 3 provides the OSI perspective on big data in healthcare as described in this paper. Data affects the digital persona at micro, meso and macro contexts of use. Ideally, we would define big data analytics to provide insight on OSI issues such as sociotechnical considerations of big data tools and applications, patient-centered care delivery and governance for organizational data sharing and use. This insight would be used to develop improved processes and applications for the different contexts of use that would produce new data and the cycle would go around again.

At each individual context we need to understand how increased data and applications from the data will impact people and processes. For example, at the micro level we need to consider the front-line patients and providers. We need to ensure that the burden of data collection does not overwhelm front line care providers who are already under stress. As patients and other

allied or non-traditional healthcare providers (i.e., alternative medicine) become more involved in care delivery we will need to ensure appropriate processes are in place to best support these new ways of care delivery. At the meso level we need to understand how the micro processes are integrated at the organizational level and how individual provider workflows integrate to provide collaborative care delivery. Inter-organizational governance and data sharing is also part of the meso level. The macro level focuses on high-level contexts such as the Institute of Medicine or World Health Organization. While these organizations frequently provide strategies for patient safety, systems integration and chronic disease management, these efforts need to be integrated with the underlying micro and meso processes that provide the front-line care delivery. At the macro level we also need to ensure that medical informatics and medical education programs continue to evolve to provide the appropriate skill sets to support the changing landscape of healthcare delivery needs.

Although we have focused our discussion on sociotechnical aspects of big data implementation we fully acknowledge that a key OSI issue is a need for understanding and development of big data governance. In the same way as big data will create new process issues it will also create new governance issues. However, we first need to understand the details of what is being governed. Focusing exclusively on governance issues without understanding the people and process interactions that will necessitate the governance is putting the cart before the horse.
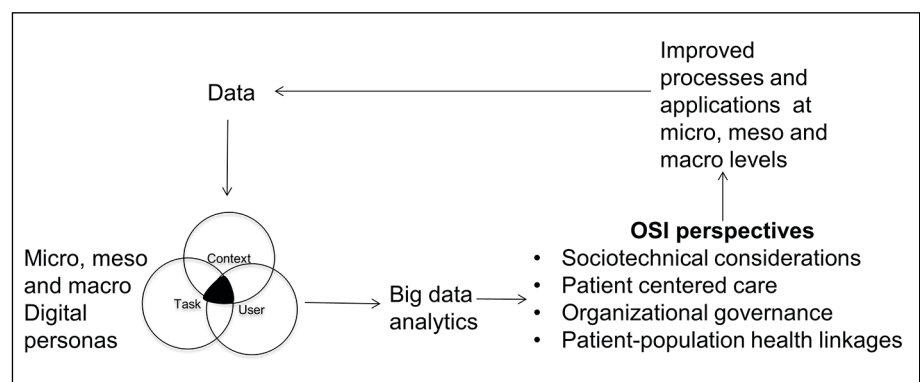

Fig. 3 Organizational and social issue (OSI) perspective on big data by defining the digital persona through micro, meso and macro contexts

Big data offer enormous potential for improving healthcare delivery by providing data to support real-time processes. However, we need to ensure we heed the lessons learned from past HIT implementations in which we automated processes without an appropriate development of the digital persona, resulting in various types of unintended consequences including organizational and social consequences. The insight and framework presented in this paper provide perspectives on developing the digital persona through micro, meso and macro contexts of use.

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